Co-produced Engagement with All Age Carers in Norfolk and Waveney

Summary of Approach and Main Findings

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Contents

1: Background and Context

In the summer of 2021, Carers Voice started the process of engaging Carers in the design of a survey, with a view to informing the development of an All Age Carers Strategy for Norfolk and Waveney. This work was supported by Norfolk County Council and included co-producing the survey with Carers and other key stakeholders. The decision to place co-production at the centre of this work helped to increase the relevance of the survey and enabled Carers to directly impact the actions and recommendations. By April 2022, co-production had contributed to a high response rate, with more than 445 Carers completing the survey and 50 participants taking part in focus groups and interviews. Based upon this, it seems reasonable to suggest that the approach has overcome some of the challenges associated with survey fatigue.

The previous Carers Strategy for Norfolk and Waveney ran until 2017, although discussions to update and refresh this preceded the launch of the survey, in November 2021. Groups involved in these discussions included the Locality Carers Involvement Groups for Norfolk and Waveney, the Carers Voice Partnership Board, and the Health and Wellbeing Board for Norfolk and Waveney. This level of early engagement meant that the survey was able to hit the ground running upon launch, reaching out to a range of Carers Groups and networks. Despite this, the survey needed to find more creative ways to engage Hidden Carers, and to achieve this, the use of co-production was extended to include more generalist groups and services.

In addition to this survey, other research projects aimed at Carers are carried out on an annual basis. These include the Survey of Adult Carers in England (Department of Health and Social Care) and the State of Caring Survey (Carers UK). This report can be used to add value to these surveys by providing more local context, which has been strengthened by the use of open-ended questions and focus groups. Collectively, these surveys provide the opportunity to develop a set of local indicators, which can be used to identify trends and to monitor a Carers Strategy. The recent projects undertaken by Caring Together, which focussed on Young Carers and Parent Carers, should be taken into account when establishing these indicators.

The focus on co-production meant that the process of developing and implementing the survey was extended over a four-month period. The potential downsides of having a less controlled timeframe were outweighed by the benefits of extending reach to underrepresented groups, which helped to improve the quality of the findings. The longer timeframe also enabled focus groups and interviews to start identifying emerging trends linked to the pandemic and cost of living.

To facilitate reach to a wide group of Carers, Carers Voice worked in partnership with grassroots providers including smaller community and voluntary groups. Support from these organisations included promotion of the survey and discussion of its themes within meetings. Carers Voice also worked with community development organisations and Healthwatch Norfolk to facilitate workshops and to provide reach to a wider network of services. In addition, telephone calls were arranged for those people who were unable to attend workshops. All of this helped to ensure the broadest level of engagement in the available timeframe.

The more iterative approach associated with co-production has helped to identify links between the Carers survey and other emerging work, such as the implementation of an Integrated Care System for Norfolk and Waveney, and the design of skills and employment services by local councils using the UK Government's Community Renewal Fund. This type of strategic alignment will be further supported by linking the accountability for this work to multi-stakeholder bodies such as the Carers Voice Partnership Board and the Health and Wellbeing Board for Norfolk and Waveney.

2: Methodology and Co-production

The methodology used in this work comprised three substantive phases, which are underpinned by a commitment to co-production. This approach aims to move beyond short term engagement with a view to empowering Carers to develop an All Age Carers Strategy in partnership with other stakeholders. These phases are summarised below. Combined, they can be credited with helping to achieve a large number of engaged responses to the survey, which is demonstrated by a high completion rate for all questions. There were also a large number of comments made using the survey's open text boxes, and a good rate of sign up to focus groups, with the majority of participants opting to join follow-up sessions.

Phase one: working with Carers to design and test the survey including checking the appropriateness of questions and language. These groups included Norfolk Young Carers Forum, Locality Carers Involvement Groups, Family Voice Norfolk, Autism Engagement Group, West Norfolk Carers, Carers Matter Norfolk, and Young Carers Matter Norfolk. Work was also carried out to raise the profile of the survey in order to achieve widespread publicity and promotion at the point of launch. This phase started in summer 2021 and was completed by November 2021.

Phase two: launch and promotion of the survey and circulation across various platforms including social media. Additional promotion was achieved using press releases, with the survey featuring in a number of local titles including the Eastern Daily Press. Carers Voice also provided interviews and information to local broadcast media including BBC Radio Norfolk and Future Radio. All of these organisations were encouraged to include the survey link in their social media. In addition, Carers Voice emailed the survey to their 1500 members and to 80 Carers Groups across Norfolk and Waveney. The survey was also sent to over 200 County and District Councillors, all local FE colleges and universities, and a wide range of voluntary organisations and networks. It was also circulated by officers at Norfolk County Council and sent directly to Young Carers, Young Adult Carers and Sensory Support Groups. The survey was also available in easy read and hard copy formats, and printed versions were provided in community venues such as local churches and information hubs. The survey was directly promoted to 20 minority groups with specific outreach undertaken to support this, whilst participation from Young Carers and Young Adult Carers was encouraged by introducing the survey as a discussion topic in group meetings. This phase of work was able to build on the preparatory work at phase one, which meant the survey enjoyed a high level of recognition ahead of its launch. This also helped to achieve a snowballing effect, and this ongoing momentum was a key reason for keeping the survey open for an extended period, which took place over four months up to 31 March 2022.

During this same phase, focus groups were extensively advertised by Carers Groups and other partners. These provided participants with the opportunity to give more detailed contributions and / or to raise any themes not covered in the survey. In total, 10 focus groups took place with four of these linked to specialist themes covering mental health, dementia, long term care planning, and General Practice and Community Nurses. These focus groups asked participants to think about a) what's working well, b) what could be working better, and c) what more can we do. These initial focus groups took place over a two-month period and were completed at the end of January 2022. They were supplemented by a series of semi-structured interviews, which were conducted with 10 people who were unable to attend the online sessions.

Phase three: ensuring continuous feedback to participants, which was facilitated by an extra focus group and interviews. These provided updates on survey findings and helped to identify possible solutions. These sessions directly informed the themes and ideas set out in section 4 of this report. Participants from the focus groups and interviews will continue to be updated on next steps, with a number of them expressing an interest in supporting the development and monitoring of an All Age Carers Strategy. This opportunity to stay involved will be widely promoted using Carers Groups and local networks.

Using a combination of survey, focus groups and interviews means that the themes and recommendations in this report are drawn from both quantitative and qualitative data. Following feedback from Carers, the survey itself also embedded some qualitative elements by encouraging extra comments. In total 15 of the 21 questions included open text boxes, which received a total of 2055 responses. Removing the 3 questions that only allowed for open ended responses still results in an extra 1075 comments, with 5 questions each receiving 100 or more additional comments. These high engagement questions were:

- Please tell us why the person or people you care for need your help and support? (192 extra comments).
- Please tell us if you have any support needs yourself? (133 extra comments).
- Have you had a Carer's Assessment (100 extra comments).
- As a Carer, where have you been able to find help or support for yourself? (134 extra comments).
- Have you found it easy or difficult to get the support you need as a Carer? (115 extra comments).

Piloting the survey with Carers also helped to achieve a high degree of relevance with very few people choosing to bypass questions. The lowest number of skipped responses for a single question was 2, and the highest number was 51, although the majority of skipped responses were in the range of 2-19. This means that on average, less than 5% of respondents skipped any single question, suggesting that the survey held people's attention from start to finish. Along with the high number of extra comments, this demonstrates how co-production can enhance the effectiveness of research methodologies. Other benefits from co-production include:

- Raising awareness of the survey and forming connections between Carers.
- Increasing the profile of Carers Groups and the value they provide.
- Creating shared spaces for Carers and services to exchange ideas.
- Providing wider context by testing and validating key themes.
- Reducing consultation fatigue by encouraging wider ownership of the survey and its findings.
- Developing new partnerships and raising awareness of specific groups, such as Young Carers.
- Extending knowledge of accreditation schemes such as Carers Friendly Tick and Disability Confident.
- Providing time and space to understand the impact of emerging themes, such as the cost of living crisis.
- Adding momentum to existing work, such as Carers Passports and Carers Ambassadors.
- Providing a blueprint for how Carers can engage with strategic bodies and vice versa.
- Raising the profile of Carers amongst generalist services, such as employability support.
- Establishing indicators to add value and local context to national survey work.
- Providing Carers with more time and space to tell their story.
- Articulating the value of caring within the context of public sector budgets.

3: Recommendations

The following recommendations have been drawn from the survey findings and the extra context provided by focus groups and interviews. These recommendations are overarching and are designed to provide a strategic framework for supporting the development and implementation of an All Age Carers Strategy. The action plan for this strategy will be more operational in nature but there should be a clear and recognised interdependency between the actions and recommendations, which will help to create a single monitoring framework. Both the action plan and monitoring framework can be drawn from the ideas set out in table 4.2 and used to support the flow of information between Locality Groups, the Carers Voice Partnership Board, the Integrated Care Partnership and the Health and Wellbeing Board for Norfolk and Waveney.

Recommendations	Detail
Recommendation 1: To establish a task and finish co-production group to develop an All Age Carers Strategy underpinned by an action plan. Monitoring of the strategy to be overseen by the Carers Voice Partnership Board, which will be informed by experiences of Carers Locality Groups, and report to the Integrated Care Partnership and the Health and Wellbeing Board for Norfolk and Waveney.	The action plan will build upon the solutions identified in table 4.2. Along with the strategy, it should include a realistic timeframe and monitoring framework. The plan should identify any resource implications, and where necessary, suggest ways of overcoming these, such as improved alignment and/ or leverage of external funds. The action plan and strategy should be co-produced and create links to the roll out of an Integrated Care System for Norfolk and Waveney.
Recommendation 2: To use the findings from the survey and focus groups to develop a set of indicators showing demand and supply of key services and support to Carers. To use these indicators to add value to other datasets including regional and national Carers surveys.	To use indicators to facilitate join-up across services, and wherever practicable, to share these with other services and strategy groups. To include indicators that can be used to show the impact of external factors, such as the effects of rising cost of living and the longer-term impact of the pandemic. These indicators should help to monitor demand for community support and other key services such as benefit and debt advice, and mental health services. A Carers Panel could be used to inform and update indicators at agreed intervals.

Recommendation 3: To identify workstreams for extra research and analysis and to invite partners to align their resources and pool budgets, with a view to improving services for Carers.	To link workstreams to those parts of the action plan and strategy that require more in-depth research and resources. To support Carers and services to use the findings from this work to test new ways of working. To convene a multi-stakeholder funders' group to share findings and to identify opportunities to support programme development.
Recommendation 4: From the perspective of both Carers and services, to understand the equilibrium between support offered by family and community infrastructure, and the support made available by professional services.	Survey and focus group work shows the high level of support provided by family and community infrastructure and the impact this can have on other areas of life, such as friendships, education, work, and the mental health of both the Carer and cared for. Working with Carers and services to identify the amount of support provided by each, and to agree what a fair, realistic, and balanced arrangement should look like will support prevention by helping to inform the commissioning of future services by redressing the balance, recognising the value of community infrastructure, and attributing resources accordingly. Working with the principles and commitment to Carers in the Carers Charter particularly regarding the identification and support of Young Carers and Young Adult Carers in education. Establishing a set of shared value measurements for the work undertaken by primary and secondary Carers will support this.
Recommendation 5: To build upon co-production to complement existing work, and to maintain conversations with wider stakeholders including generalist services, funders and commissioners.	To widen impact by promoting the strategy to generalist services and to add momentum to existing co-production, including Carer-led small grant panels and the development of a Carers Passport. To further embed co-production by supporting Carers to monitor the strategy and to capture the value they place on community networks. To support other services to involve Carers in their delivery and commissioning plans by developing a Carers Engagement Toolkit.

4: Key Themes

This section includes quantitative data collected from focus groups. These comprised 6 generalist focus groups open to Carers and 4 specialist focus groups aimed at both Carers and service providers. The four specialist themes covered were dementia, long term care planning, mental health, and General Practice and Community Nurses. Table 4.1 shows the main comments and themes from these focus groups, which gave Carers and services the opportunity to add context to survey responses and to quality check the research analysis. They also allowed more space to explore issues that were not directly referenced in the survey and / or to build upon comments made in open text boxes. Although they were supported by different facilitators, the generalist and specialist focus groups used a similar structure, which asked Carers to draw upon their own experiences to identify what works well and what needs to improve. These workshops were carried out between December 2021 and January 2022 and were supplemented by interviews with 10 participants who were unable to attend the online sessions. Typically, these interviews lasted up to one hour and used the same semi-structured question frame as focus groups. Findings from interviews have been included as part of the comments and themes from the focus groups. Two follow-up sessions took place in February and March 2022 to review main themes and to identify possible solutions. These sessions were framed around four main groupings based upon the comments made at previous focus groups. These solutions are shown in table 4.2, providing the basis for an initial action plan to underpin, and help drive, the overarching strategic recommendations made in section 3. In total, 50 people took part in focus groups and interviews.

4.1: Findings from Generalist Focus Groups

Themes	Notes
Theme 1: The importance of getting the care right for the cared for.	• When this doesn't happen, it can have an impact on the wider family, with less time available for friendships and other support networks. As a result of this, both the Carer and cared for can experience increased anxieties and worsening mental health. • The education and access to employment for Young Carers and Young Adult Carers can be impacted by the levels of support. • Putting in place the right care package at the outset can be especially critical in some areas, such as dementia support. • Delayed or inappropriate levels of support can also impact on household finances, with the Carer having to reduce hours or give up work to compensate for a lack of professional support. Economic factors, such as rising cost of living, are likely to worsen these impacts.

Theme 2: Accessing support and knowing what’s available.	• Making an application for support can take a long time and it can be difficult to understand the processes involved and eligibility criteria. • Meanwhile, reassessments for support can feel too narrow rather than based upon the needs of the whole person or the experience of the Carer. • The language used by support services doesn’t always resonate with Carers including Hidden Carers. • Once identified, services can be hard to navigate and there is still a need for human contact, as well as online services. • All of this can leave Carers feeling unsupported and outside of a system that isn’t working for them or their cared for.
Theme 3: Continuity of support and fragmentation of services.	• A lack of resources and contingency planning can impact on service continuity, which is compounded by Carers having to navigate fragmented services. • Carers can also be left feeling unsupported during periods of staff absence, and when key services are restructured, such as GP mergers. • There is a need to improve information and coordination during discharge from hospital and fully involve Carers in discharge plans. • The experience of GP surgeries is mixed, with Carers expressing some positive and negative experiences. • These differing experiences can include knowledge and availability of mental health support, the accessibility of online services, the likelihood of seeing a named GP, and the experience of ordering prescriptions. • The impact of the pandemic has been especially harsh on some groups, including people with dementia. Understanding this will help to shape continuity plans for Carers and their support networks.

Theme 4: Communication between services and departments.	• Professionals including health practitioners are often praised for doing the best they can against a backdrop of limited resources and rising demand. • This results in Carers having to repeat information during appointments and handovers. • In response to these problems, Carers have to develop workarounds including having to understand professional language. • These workarounds become harder for Carers who are struggling with their own health, who do not have the confidence to ask questions, who may be Young Carers, Young Adult Carers or whose expertise remains unacknowledged. • During focus groups, some good practice examples were cited of specific services, such as a hospital department or GP surgery. Sharing best practice would help to address inconsistencies.
Theme 5: The Role of Carers Groups and other community networks.	• These groups and networks can provide Carers with companionship and a listening ear, providing Carers with much needed time for themselves. This can be especially valuable in the absence of respite care. • Throughout the pandemic, some of these groups were able to continue using zoom, and focus groups helped to connect them to potential new members. • Amongst professional services there can be an assumption that Carers continue to cope, and these types of groups can help Carers to articulate when that isn’t the case. • Voluntary sector support was recognised for helping to keep people connected during the pandemic. Groups referenced in this way were Carers Voice and Carers Matter Norfolk.

Theme 6: Identification and raising awareness of Carers and capturing their value	• Public awareness campaigns can support prevention by asking people how they would cope if they had caring responsibilities. • Such campaigns can also help to raise awareness amongst Hidden Carers and their support networks, such as community groups and Young Carers and Young Adult Carers and their networks. • Services should use language that will be recognised by Carers and Hidden Carers of all ages which can be supported by Carer awareness training. • This awareness can be extended to other services using the Carers Friendly Tick and Disability Confident schemes. • Capturing the value and savings made by Carers will help to inform commissioning and make clearer the breadth of support that is provided by Carers.
Theme 7: Involving Carers and long-term care planning.	• Carers want to be more involved, and this should be by design and not accident. • The language used by some services including GP surgeries can feel exclusive. • It is not always clear who Carers should talk to about contingency planning, in particular, parents who are caring for their children. • There is a lack of focus on long-term care planning and the resources needed to replace Carers. Attaching a list of Carers tasks to a care plan might help to start this conversation. • Despite feeling as if they have to take on the role of the professional, the experience of Carers isn’t always acknowledged at critical points.
Crosscutting theme: Mental health support for Carers and cared for.	• Access to mental health support is cross cutting, which was raised frequently when discussing other themes. It is also an area of support that has become more needed, with many Carers becoming increasingly isolated during the pandemic. • GP surgeries are often the first point of contact for mental health support, however there can be inconsistencies with some GPs having more specialist knowledge. • The lack of availability of respite care can have a direct impact on the mental health of both Carer and cared for. • The lack of support, long waiting times, and fragmentation of support in mental health services, all serve to increase the anxieties felt by Carers. • Whilst waiting for professional support, community networks can provide a vital role although it should be acknowledged that some of this support was interrupted by the pandemic.

4.2: Ideas from Solutions Workshop

Theme	Example Solutions
Raise awareness of Carers and their value.	• Development of an All Age Carers Strategy. • Introduction of a Carers Passport and introduction of Carers lead in key services, helping to raise awareness of the passport and Carers Strategy. • Work with the Integrated Care Board and across the Integrated Care System to ensure Carers are fully involved in discharge plans. • Demonstrate the value provided by Carers including savings made to public purse. • Develop a public awareness campaign to help people prepare for their future caring roles.
Improve access to information and services including single point of contact.	• Provide information in different formats. • Recognise GP surgeries as first point of contact and understand how community infrastructure can support this role. • Increase the knowledge of Carers amongst more general advice services such as employment support. • Explore opportunities for services to bring together their publicity and promotional activities.
Provide support for Carers Groups and share learning of their experiences.	• Research the support needs of these groups and the scope for small grants to assist with basic needs, such as meeting space. • Support these groups to share grassroots experiences with commissioners and grant making bodies. • Enable these groups to provide representation to relevant partnerships and networks including those linked to an All Age Carers Strategy. • Offer training and facilitation support to these groups.
Reach out to Hidden Carers.	• Raise awareness amongst generalist services, which might already be supporting Hidden Carers at community projects, such as food banks and job clubs. • Encourage services to pool their marketing budgets and to use language that will resonate with the wider public. • Utilise GP surgeries as a first point of contact and strengthen links between surgeries and community infrastructure, such as Carers Ambassadors. • Strengthen links to community assets such as libraries and village shops.

5: Appendix: Survey Findings

The findings are based upon responses from 445 Carers. The survey was open between November 2021 and March 2022, with the majority of responses made in the first two months. Responses gained in the second half of this period were often from specific groups as a result of targeted outreach, such as Young Carers. The survey comprised 21 questions, with 5 of these linked to characteristics covering age, gender, sexual orientation, ethnic origin, and location. On the last of these, respondents were asked to provide the first part of their postcode. In most cases, these postcode areas could be mapped against district councils, however, in some cases these areas straddled more than one local authority, and where this happened, responses were divided proportionately.

5.1: Profile of Respondents

5.1.1: Please tell us your age and the age of the person or people you are caring for.

Answer Choice	Carer	Cared for
15 years or under	75	71
16-25 years	12	58
26-45 years	58	83
46-64 years	172	93
65-84 years	114	118
85 years or over	7	81
Prefer not to say	6	6
Total	444	510

Notes:

- 444 / 445 people responded to this question.
- The number of respondents under the cared for column exceeds 445 as some people care for more than one person.
- 16.9% of respondents were from Carers aged 15 or younger. Engagement of people aged 16-25 will be enhanced as part of the task and finish work and during design of the monitoring framework for the All Age Carers Strategy.
- 38.7% of respondents were aged 46-64.
- 27.3% of Carers were aged over 65, which can be linked to concerns about contingency planning (see section 3.2).

5.1.2: Please tell us your gender and the gender of the person / people you care for.

Answer Choice	Carer	Cared for
Female	322	243
Male	101	247
Trans Woman	0	2
Trans Man	2	3
Non-Binary	3	0
Other	1	0
Do not know	2	0
Prefer not to say	11	7

Notes:

- 442 / 445 people responded to this question.
- The number of responses under the ‘cared for’ column totals 502, as this includes respondents who care for more than one person.
- Almost three quarters of Carers who responded to the survey were female (72.9%) compared to 22.9% male.

5.1.3: What is your sexual orientation?

Answer Choice	Number of responses
Heterosexual	307
Gay or Lesbian	11
Bisexual	23
Other	6
Do not know	7
Prefer not to say	76
Total	428

Notes:

- 428 / 445 respondents answered this question.
- 17.8% of respondents preferred not to answer.

5.1.4: How would you describe your ethnic origin?

Answer Choice	Number of responses
White British, English, Welsh, Scottish, Northern Irish or British	399
White Irish	1
White Gypsy or Irish Traveller	0
Any other white background	7
White and Black Caribbean	2
White and Black African	0
White and Asian	1
Any other mixed or multiple ethnic background	4
Indian	2
Pakistani	0
Bangladeshi	0
Chinese	0
Any other Asian background	0
Black African	2
Black Caribbean	0
Any other Black, African or Caribbean background	0
Arab	1
Any other ethnic group	4
Prefer not to say	17
Total	439

Notes:

- 439 / 445 people responded to this question.
- 90.9% of respondents described themselves as White British, English, Welsh, Scottish, Northern Irish or British.
- 3.9% of respondents preferred not to answer.

5.1.5: What is the first half of your postcode?
(postcode areas have been mapped against district boundaries, shown below)

Answer Choice	Number of responses
Great Yarmouth and Waveney	104
Norwich	70
Breckland	61
King's Lynn and West Norfolk	54
North Norfolk	48
South Norfolk	46
Broadland	43
Total	426

Notes:

- A small number of responses have not been included in this table as it was not possible to map their postcodes to areas in Norfolk or Waveney.
- Respondents were drawn from 47 postal areas, which suggests the survey was well promoted.
- A high number of responses were received from Great Yarmouth, which were supported by community organisations in the area, such as Young Carers Groups.
- Exploring the link between response levels and community infrastructure is a potential theme for extra research, which can be considered as part of strategy development.

5.2: Main Questions

5.2.1: How many people do you care for?

Answer Choice	Number of responses
1 person	329
2 people	74
3 people	24
4 people	9
5 people	6
Total	442

Notes including links to themes and recommendations in section 3 and 4:

- A total of 113 people, or 25.6% of respondents, are looking after more than 1 person.
- This provides some level of insight into the multiple needs being supported by Carers and makes the case for services to operate at a whole family level.
- As such, responses to this question have helped to inform theme 1, the importance of getting care right for the cared for, theme 3, the need to improve continuity of support and reduce fragmentation of services, and theme 6, raising awareness and capturing the value of Carers. There is also a clear link to recommendation 4, to understand the balance of support that is provided by Carers and services.

5.2.2: How many hours a week on average do you spend caring?

Answer Choice	Number of responses
Up to 10 hours	62
Up to 20 hours	49
Up to 30 hours	47
Up to 40 hours	40
Up to 50 hours	24
More than 50 hours	208
Other	8
Total	438

Notes including links to themes and recommendations in section 3 and 4:

- Almost half of respondents (47.5%) provide more than 50 hours of care per week, and some of this will result from the number of respondents caring for more than 1 person (25.6%).
- Extra research in this area might cover how many Carers have been able to make planned adjustments to their working or family life, and this could be included as part of the indicators set out in recommendation 2, section 3.
- In addition, responses to this question have helped to inform theme 1, the importance of getting the care right for the cared for, theme 5, the role of Carers Groups in providing Carers with time for themselves in the absence of respite care, and theme 6, demonstrating the value of Carers and raising awareness amongst employers and other organisations using the Carers Friendly Tick and Disability Confident schemes.

5.2.3: Please tell us why the person / people you care for need(s) your help and support.

Answer Choice	Number of responses
Autism	92
Dementia	111
End of life	17
Frailty	90
Learning Disability	76
Mental Health	156
Physical Disability	195
Sensory Impairment	61
Addiction	8
Other	86

Notes including links to themes and recommendations in section 3 and 4:

- 442 / 445 people responded to this question, with 35.3% of people cared for requiring support with their mental health.
- 192 people used the open-ended text box to provide additional information about the health and personal care needs of the person they care for. These responses help to demonstrate the complexity of support that is often provided by Carers, in addition to the number of hours shown in table 5.2.2.
- Based upon the types of support provided and the likelihood of Carers needing to interact with multiple services, responses to this question have helped to inform theme 1, the importance of getting the care right for the person being cared for, theme 3, the need to improve continuity of support and reduce fragmentation of services, theme 4, the importance of good communication between services and departments, and theme 7, the need to involve Carers in long term care planning.
- There is also a strong link to the cross-cutting theme of mental health support for both Carers and the cared for, in particular, where there is an absence of respite care and / or a lack of join up between other health services.

5.2.4: Please tell us if you have any support needs yourself.

Answer Choice	Number of responses
Autism	14
Dementia	4
End of life	2
Frailty	5
Learning Disability	14
Mental Health	102
Physical Disability	63
Sensory Impairment	17
Addiction	3
Other	56
None	196

Notes including links to themes and recommendations in section 3 and 4:

- 402 / 445 people responded to this question, with 133 providing more information on their health needs using the open text box. This additional information reinforced the need for services to join-up and to provide a whole family approach.
- A quarter of Carers who responded to the survey required support with their own mental health, and 15.7% responded that they have a physical disability, which should probably be taken as a minimum figure when read in conjunction with the extra comments.
- The support needs of Carers in this survey have helped to inform theme 1, the importance of getting the care right for the cared for, and the likely impact on mental and physical health when this doesn't happen, theme 3, the need to reduce the fragmentation of services to provide a more joined-up and a whole family approach, theme 4, the need to acknowledge the experience of Carers, and theme 7, the need to involve Carers in long term care planning.

5.2.5: Have you had a Carer’s Assessment?

Answer Choice	Number of responses
Yes	144
No	215
Not sure	87
Total	446

Notes including links to themes and recommendations in section 3 and 4:

- Nearly 50% of Carers taking part in this survey had not received a Carer’s Assessment.
- A further 20% were unsure if they had received an assessment, meaning that the number of respondents without an assessment could be as high as 70%.
- Against this backdrop, it is perhaps not surprising that a quarter of Carers who responded to this survey had their own mental health support needs.
- Responses to this question have helped to inform theme 2, the need to make it easier to access and find out about support, theme 4, improved communication between services to raise awareness of Carer’s Assessments, theme 5, the value of community infrastructure in enabling Carers to share experiences with other Carers, theme 7, the need to involve Carers in long term planning, and the cross cutting theme of mental health, where a lack of support and waiting times can increase anxieties felt by Carers.

5.2.6: As a Carer, where have you been able to find help and support for yourself?

Answer Choice	Number of responses
Doctor / health service	85
Social services	57
Family and / or friends	193
Carers Matter Norfolk	137
Other Carer group / organisation	93
Charities / community group	58
Education provider	18
Religious group	22
Other	27
I have not been able to find the help and support I need	87
I do not need any support or services	28

Notes including links to themes and recommendations in section 3 and 4:

- When measured against the number of Carers who provide more than 50 hours of care per week (Q5.2.1) and who support multiple needs (5.2.3), it is perhaps to be expected that only 6.4% of respondents do not require any support services.
- A total of 438 / 445 respondents answered this question with a large number (134) providing more information using the open text box. These extra responses reinforced the importance of family and friends and the voluntary sector including national charities such as Dementia UK and the Alzheimer's Society. There were also comments linked to lack of support during periods of staff absence, and uncertainty around where to turn for help.
- Responses to question 3.2.4 showed that 48.8% of respondents did not have any support needs, which is much higher than the 6.4% of people in this question who said they didn't have any need for support or services. This difference is probably best explained by the framing of the questions, with the answer choices in 5.2.4 focussing on medical conditions, whereas the options in this question cover more informal support such as charities and community groups. Although these are broader categories, they can be linked to wider determinants of health.
- An additional line of enquiry for future research would be to ask how many people have approached their doctor or health service in the first instance when looking for support, which links to recommendation 3. In addition to this, the high number of people shown to be receiving support from family and friends confirms the importance of community networks (theme 5) along with the need to capture their value (theme 6 and recommendation 4).

5.2.7: Have you found it easy or difficult to get the support you need as a Carer?

Answer Choice	Number of responses
I have found it very easy	22
I have found it quite easy	31
I have found it neither easy nor difficult	109
I have found it quite difficult	125
I have found it very difficult	118
I do not need any support or services	24

Notes including links to themes and recommendations in section 3 and 4:

- 429 / 445 people responded to this question with 115 providing extra information using the open text boxes, where key themes included difficulties finding and then navigating support and waiting times.
- Only 5.6% of respondents say that they don’t need any support or services, which is close to the number who answered the same in question 5.2.6 and is again likely to result from the volume and complexity of tasks undertaken by Carers in this survey.
- 56.6% of respondents attach some level of difficulty to finding the support they need as a Carer, with 27.5% finding it very difficult. In comparison, only 12.4% of respondents have found it quite easy or very easy to find the support they need.
- Responses to this question have helped to inform theme 2, access to support and knowing what’s available. This is linked to the cross-cutting theme suggesting that anxieties linked to mental health are worsened when access to support is delayed. According to Carers focus groups, the introduction of a Carers Passport and service map is seen as partial solution to the difficulties of finding support as it enables identification and recognition of Carer knowledge. These themes are covered in more detail in section 4.2.

5.2.8: Please tell us how important the following are to you?

Answer Choice	Extremely important	Very important	Somewhat important	Not so important	Not at all important
Time for yourself / time away from caring role.	207	110	94	26	7
Support with your physical health	98	115	112	66	42
Support with your mental health	138	127	103	43	17
Someone to talk to	161	145	76	37	17
Advice on benefits and finance	96	96	98	68	53
Planning including for an emergency and future	144	131	95	36	26
More information about the services available to Carers.	129	119	93	49	32
Practical support including home adaptions and technology	88	121	86	70	50
Knowing the person(s) you care for is safe and receiving the support they need.	323	87	16	3	6

Notes including links to themes and recommendations in section 3 and 4:

- 444 / 445 people responded to this question with 83 people providing extra information using the open text boxes. These comments help to draw attention to the importance of contingency planning, the time spent by Carers having to join-up services, the difficulties of knowing what services are available, and the potential benefits of appropriate respite.
- The ranking of answers is below. This is based upon combining the extremely, very and somewhat important categories to demonstrate the amount of importance attached to each answer choice. Percentages have been calculated using the total number of people who responded to each answer choice.
  - Knowing the person(s) you care for is safe and receiving the support they need: 97.9%
  - Time for yourself / time away from caring role: 92.6%
  - Someone to talk to: 87.6%
  - Planning including for an emergency and the future: 85.6%
  - Support with your mental health: 84.4%
  - More information about the services available to Carers: 80.1%
  - Support with your physical health: 75.1%
  - Practical support including home adaptions and technology: 71.1%
  - Advice on benefits and finances: 70.6%
- The level of importance attached to each category adds to the picture of Carers managing a high volume of care needs and multiple support.
- Answers from this question have helped to inform most of the themes set out in section 4.1 including theme 1, the importance of getting the care right for the cared for, theme 3, supporting continuity of support and reducing the fragmentation of services, and theme 5, the role of Carers Groups and other community networks, which can be linked to the answer choice of having someone to talk to.
- The high number of people attaching importance to mental health support reinforces this as a cross cutting theme. There is also the opportunity to include the number of people who require advice on benefits and finances within the monitoring framework for an All Age Carers Strategy (recommendation 2). This would allow services to reflect the need of Carers in their responses to rising cost of living.

5.2.9: Have you been involved in the planning and development of care for the person / people you look after?

Answer Choice	Number of responses
Yes	196
No	83
Not aware of a plan being created	156

Notes including links to themes and recommendations in section 3 and 4:

- 435 / 445 people responded to this question, with 88 providing more information using the open text boxes, where comments suggested a need for more information about care planning including when and how to ask for one, and what they should contain.
- More than a third of people responding to this question were not aware of a plan being created for the person they care for, with less than half confirming that they had been involved in the planning and development of care. For more context, these answers should be read in conjunction with responses to 5.2.8 covering the high number of Carers attaching some level of importance to planning for future and emergency, having more information about services available to Carers, and practical support including technology and home adaptions.
- Responses to this question have helped to inform theme 7, involving Carers and long-term care planning, and link to the ideas in section 4.2 around working with the Integrated Care Board and across the Integrated Care System to fully involve Carers in hospital discharge plans. There are also clear links to the principle and practice of co-production as set out in recommendation 5.

5.2.10: During this planning and development of care, did you feel that you were:

Answer Choice	Yes	No
Listened to	163	52
Respected	166	48
Valued	141	68

Notes including links to themes and recommendations in section 3 and 4:

- 394 / 445 people responded to this question. Apart from the open-ended question in 3.2.16, this represents the lowest response rate, which is likely to have resulted from the number of people not involved / unaware of care planning (54.9% in question 5.2.9).
- 57 people provided more information using the open text box, which included examples of involvement by both design and accident, and some examples of Carers not being recognised / assumed to be coping.
- Of those who had been involved in care planning, 75.8% felt that they had been listened to, 77.6% felt respected, and 67.5% felt valued. This indicates that when involved, more than two thirds of Carers are satisfied with their experience of care planning. However, these numbers need to be read alongside the numbers of people who haven’t been involved in, or who are unaware of, care planning.
- Responses to this question and question 5.2.9 have helped to inform theme 4, communication between services and departments, with opportunities to raise awareness of care planning at different touch points, theme 7, the need to involve Carers in long term care planning, recommendation 4, to understand the equilibrium between support provided by Carers and services, and recommendation 5, to build upon and embed co-production.

5.2.11: Please tell us how your caring role has changed any of the following.

Answer Choice	Very positive change	Some positive change	No change	Some negative change	Very negative change	Not applicable
Your physical health	11	46	126	185	56	7
Your mental health	16	35	65	198	113	7
Your financial circumstances	9	16	147	119	88	46
Time for yourself	22	31	49	148	180	5
Your day to day life	23	35	64	171	138	5
Your relationships	19	38	119	141	100	18
Your employment	7	12	103	57	83	158
Your education	6	25	136	42	26	185

Notes including links to themes and recommendations in section 3 and 4:

- 439 / 445 people responded to this question with 64 providing more information in the open text box. Comments gave more detail on reasons for leaving work or education, and the effects of this on household finances and being able to meet the cost of care.
- The ranking of answers is below, and this is based upon the number of people who indicated that caring had resulted in some negative change or a very negative change. Percentages have been calculated using the total number of people who responded to each answer choice.
    - Time for yourself: 75.4%
    - Mental health: 71.7%
    - Day to day life: 70.9%
    - Physical health: 55.9%
    - Relationships: 55.4%
    - Financial circumstances: 48.7%
    - Employment: 33.3%
    - Education: 16.2%
- The high number of people stating some level of negative impact on time for yourself, day to day life, and relationships has helped to inform theme 5, which acknowledges the important role played by Carers Groups and other community networks.
- The number of extra comments in the open text box suggests that the impact on Carers and their employment might be greater than the 33.3% stated above. This links to theme 6, raising awareness of Carers and in particular, amongst employability services using the Carers Friendly Tick and Disability Confident schemes. There is also the option to consider education and employment as areas for further research as set out in recommendation 3.
- The impact of caring on Carers mental health confirms this as a cross cutting theme.

5.2.12: Are you currently in paid employment / self-employment / education / voluntary work / retired?

Answer Choice	Number of responses
Full time paid employment	48
Part time paid employment	66
Full time self-employment	9
Part time self-employment	12
Education	79
Voluntary work	29
Retired	115
Unable to work as a result of caring responsibilities	89
Not currently in paid employment / education / voluntary work	48

Notes including links to themes and recommendations in section 3 and 4:

- 435 / 445 people responded to this question with 80 providing more information in the open text box. Comments were similar to those provided in 5.2.11 covering the reasons for giving up work, the flexibility or otherwise of employers, the options for online work or training, and the value of volunteering.
- In total, a fifth of respondents (20.5%) stated they were unable to work because of their caring responsibilities, and as part of the proposed monitoring framework for an All Age Carers Strategy, it would be helpful to develop an indicator to monitor this alongside any changes to household finances. Monitoring such trends will help to engage providers of employment services, which can often include wrap around support in money and debt.
- The impact of not being able to work or having to reduce hours should be factored into the development of value measurements for caring, which is included in theme 6 and recommendation 4. There is also the potential to compare the survey findings to wider labour market data and join-up with the Local Enterprise Partnership and others which will help to support this (recommendation 5).

5.2.13: How do you prefer to make contact with people and services?

Answer Choice	Number of responses
Telephone	219
Email	276
Post	90
In-person	176
Online	142
Other	22

Notes including links to themes and recommendations in section 3 and 4:

- 426 / 445 people responded to this question, with 22 providing more information in the open text box, where other options included use of text for people who are deaf, and in-person use of sign language.
- That just over 50% of people prefer to make contact using the telephone might reflect the personal and complex nature of enquiries. This could also mirror how services are provided, with a number of health enquiries still having to be conducted over the telephone.
- There is also the potential for responses to be split according to age groups, which might explain the relatively high number of people preferring to correspond using post. This might be driven by the fact that 27% of all survey respondents are aged 65 or over.
- Despite the increased use of online technologies during the pandemic, 41.3% of respondents still prefer to communicate in person, which reinforces the importance of human contact and should be considered when developing awareness tools, such as service maps and Carers Passports.
- These findings should also be captured when taking forward co-production and reflected in the proposed engagement toolkit, as set out in recommendation 5.

5.2.14: How did you find out about this survey?

There were no answer prompts to this question. A total of 399 respondents provided information in an open text box. This was one of the last questions, which suggests the survey managed to avoid response fatigue. In total, there were 18 different responses, which confirms the importance of including different types of communication in co-production and engagement toolkits. In no particular order, the 18 responses were:

Response
Email
Charity and community groups
Facebook
Carers Groups and peer support networks
Workplace
Radio
Press
NHS including hospitals
Friends
School / college
Councillors / council services
Norfolk Residents panel
Post
Websites
Word of mouth
Twitter
Support workers
Newsletters

5.2.15: What is your relationship to the person(s) you care for?

Answer choice	Number of responses
I am their parent	116
I am their sibling	50
I am their spouse / partner	162
I am their son / daughter	142
I am their grandparent	5
Other family member	17
I am their friend / neighbour	14
Other	8

Notes including links to themes and recommendations in section 3 and 4:

- 440 / 445 people responded to this question. The number of individual responses exceeds this number, which reflects the fact that some respondents care for more than 1 person.
- More than a quarter or respondents (26.4%) are a parent caring for their son or daughter. In particular, this should be considered when reviewing responses to question 5.2.5 (Carer's Assessments), and 5.2.9 and 5.2.10 (involvement in care planning).
- The high number of Parent Carers has helped to inform the main themes of this report including the need to involve Carers in long term planning, for services to support conversations around contingency, and to adopt practical measures such as attaching a list of Carers tasks to care plans. Understanding the concerns of specific groups of Parent Carers is an area for extra research as set out in recommendation 3.
- Responses to this question also help to highlight how caring can impact on wider family life and preparing people for this could be taken forward in awareness raising campaigns as covered in theme 6 and recommendation 4.

5.2.16: Please use this space if you would like to tell us more about any concerns you have as a Carer for the future, any changes that would improve services, and any further comments.

There were no prompts to this question. A total of 146 respondents provided information in an open text box. When read collectively, the responses show a need to improve access to services. The list below has been formed by grouping key phrases and themes. However, this is not an exact science, and some level of interpretation was needed to align similar looking references. Despite this, some clear themes emerged linked to concerns about contingency planning in the absence of the Carer (25.3% of responses), household finances including the cost of care (11.8% of responses), and the availability of appropriate care and fragmentation of support (10.4% of responses). All of the areas listed below have informed the development of the themes and recommendations in this report, including theme 2, accessing support and knowing what is available, theme 3, the need to improve continuity of support and reduce fragmentation, theme 6, raising awareness of Carers including amongst employment and money and debt wrap around services, theme 7, involving Carers in long term care planning, and the cross cutting theme of the importance of mental health support.

Comments and themes ranked according to number of references made:
The need for contingency plans and concerns about coping in the future.
Impact of caring on household finances and the high cost of care.
The lack of appropriate care and fragmentation of support
The need to recognise and value Carers.
The impact of caring on employment.
The impact of caring on relationships and lack of respite care.
The importance of human contact to help navigate services.
The impact on health including mental health.
Making information more accessible including for users of British Sign Language.