



# Sussex Carers Partnership CCG Engagement Report (December 2020 – March 2021)

**The Carers Centre for Brighton and Hove**

**Care for the Carers (East Sussex)**

**Carers Support West Sussex**

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# Contents

	<b>PAGE</b>
<b><u>Contents</u></b>	2
<b><u>Executive Summary</u></b>	3
• Introduction and Aims	3
• The Project	3
• The Project Aims	3
• The Report	3
• Stage 1 and 2 Findings	4
• Stage 3 Findings	5
• Summary of Main Conclusions	5
• Differences Over the Year	5
<b><u>Methodology</u></b>	6
<b><u>Equalities Monitoring</u></b>	8
<b><u>Results</u></b>	11
• Stage 1	11
• Stage 2	13
• Stage 3	14
<b><u>Theme 1: Carers and Coronavirus: Planning for Recovery</u></b>	14
<b><u>Theme 2: Exploring Carer’s Experiences of Navigating Healthcare Systems</u></b>	21
<b><u>Theme 3: Making Carers Visible</u></b>	27
<b><u>Evaluation: Discussion Workshops</u></b>	33
<b><u>Stage 4: The Webinar</u></b>	33
<b><u>Conclusions</u></b>	34
<b><u>Recommendations</u></b>	36

# Executive Summary

## INTRODUCTION AND AIMS

This work has been commissioned by the Sussex CCGs and forms a part of their legal requirement to involve patients, carers and the public in their commissioning of health services.

The project outlined in this introduction has been delivered by the Sussex Carers Partnership which comprises:

- The Carers Centre for Brighton and Hove (CCBH)
- Carers Support West Sussex (CSWS)
- Care for the Carers (East Sussex) (CFTC)

## THE PROJECT

Looking at healthcare during the Covid-19 pandemic and into the future, this project seeks carers views on their experience of healthcare thus far and, importantly, “what action can be taken to ensure people get the care they need, in a way that suits them.”

The project seeks to hear not only from carers who regularly engage in discussion and debate but also from those we may not hear from frequently.

## THE PROJECT AIMS

- Seek the views of carers across Sussex regarding the challenges they have faced when accessing healthcare including being recognised as carers.
- Establish if there are issues which may relate to a particular community or area of Sussex and differences compared to other areas and communities.
- Identify the priorities for carers re healthcare services especially relating to Covid-19 and the vaccination programme.

## THE REPORT

The main body of the report details the methodology used and response total, Equalities Monitoring, the results by method and conclusions and recommendations for the CCG and the Sussex Carers Partnership.

The main results are laid out in 3 themes and detailed question by question with survey and workshop research shown together.

Some results in the main report will be shown in graphical form with anecdotal evidence from carers included where they add to the understanding of a particular point.

The research comprises 4 stages.

1. Stage one was work that had already been completed by the three organisations comprising the Sussex Carers Partnership, which occurred during Summer 2020.
2. Stage two was a detailed comparison of the stage one findings to establish common themes and issues that related to only one organisations cohort.
3. Stage three was extensive additional research conducted jointly to further understanding, establish the current view following lockdowns due to Covid-19 and gain carers views as to priorities moving forward.
4. Stage four involves feedback of findings by providing a webinar session with representatives of the CCG, NHS and carers organisations present. A question and answer session is also included in the webinar.

## STAGE 1 AND 2 FINDINGS

Stage 1 work ran from early 2020 and completed in the summer of 2020. It was not part of a joint project and therefore research was conducted on differing themes and used different methodology. Overall, the research raised a number of general issues for carers which could also be seen in the wider population as a result of the pandemic, such as access to food and medicine shopping, doctor's/hospital appointments and feelings of stress and worry.

Some key issues that were also identified were frequently also seen in the stage 3 research.

More extensive issues are shown in the results section for Stage 1 and 2, but the common themes were as follows:

- Recognition of being a carer is key to access services but the term is not always well received or understood by carers, and identification is only one aspect. Being involved by health and social care, and carers' expertise being valued, are also key.
- Confused communication about services and messaging around shielding and accessing of key resources.
- Importance of peer support/forums/apps to stay connected and need for a variety of support options at the right time (these were mentioned as being positively provided by the three carer support organisations). The independence of the carer and the person they care for being maintained was an issue, especially in the context of some services being less available during the pandemic. Deterioration of some people being cared for was noticeable.
- Navigating healthcare and support services is difficult and time consuming. Carers say they are fighting the system instead of the system supporting them.
- Digital inclusion has become key but is not available to all – greater support is needed, and often physical meet ups are preferred.
- Loneliness and isolation (plus lack of understanding from public and family).
- Finance issues especially regarding the low rate and limitations of Carers Allowance – described as “an insult”.

The following issues were identified by one or two of the organisations comprising the Sussex Carers Partnership, but not all. This may be due to differences in demographic make-up across Sussex, availability and access to services differing from urban to rural areas and/or simply that different research was undertaken in Stage 1.

- Greater choice and control to maintain a balanced life is needed including not only respite but training for carers – CSWS
- Improved social opportunities for Young Carers are needed – CSWS
- Increased support for carers at each stage of the caring journey – CSWS
- Respite services were cut or unavailable but desperately needed – CCBH and CSWS
- Importance of promoting a whole family approach (where possible) – CSWS
- Benefits and financial guidance – CSWS
- Information provided in a way that reaches out empathetically to communities that are less heard from – CSWS
- Covid-19 impact and communication of vaccine rollout and messaging – CCBH
- Working carers often feel they are penalised by employers – CSWS
- Carers not receiving timely information – CFTC
- New carers felt especially vulnerable – CFTC
- Access to PPE – CFTC
- Access to basic services such as food and medicine were problematic during Spring 2020 and in a minority of cases were ongoing for a considerable time – CCBH

## STAGE 3 FINDINGS

Stage 3 comprised an expansion of knowledge based on issues identified in stages 1 and 2. This was designed to lead to a greater understanding of what, if anything, had changed since Spring 2020 and the ongoing issues carers are facing. This revolved around further research in 3 key areas:

1. “Carers and Coronavirus: Planning for Recovery.”
2. “Caring Doesn’t Come with a ‘How To’ Manual: Exploring Carer’s Experiences of Navigating Healthcare Systems.”
3. “The Invisible Army: Making Carers Visible.”

The research was undertaken through three discussion workshops and an online survey (telephone surveys were carried out with a minimum of five non-digitally engaged carers for each organisation).

## SUMMARY OF MAIN CONCLUSIONS

- Communication between carers and healthcare providers is seen as inconsistent and leads to highly variable outcomes. This was already an issue for carers, but has been exacerbated by the pandemic.
- The negative impact of caring on mental health (including loneliness and isolation) is one of the single biggest issues expressed by carers.
- Identification of carers and recognition of carers’ expertise by healthcare services is generally seen as haphazard or poor.
- Delayed/cancelled appointments and services due to the pandemic are still a concern.
- Back up for carers and respite is critical.
- Uncertainty about when/how carers will access the Covid-19 vaccine and concerns about the reasoning behind those they care for being vaccinated earlier than carers.
- Covid-19 messaging from NHS and Government is ranked highest in terms of carers’ levels of trust, but this is not universal.

## DIFFERENCES OVER THE YEAR

Access to services both health and food is now less of an issue than in Spring 2020, though cancelled and delayed appointments for non Covid-19 healthcare are still frequently raised.

The biggest difference appears to be a more significant deterioration in carers’ mental health following the second and third lockdowns.

Vaccination communication and rollout has now become key. The who, when, where and how of the rollout were all questions that carers were/are seeking answers to. This must be a continuing priority as the vaccination programme appears to be a regular annual event similar to Flu vaccinations.



# Methodology

**Stage 1:** Completed research from Summer 2020 to be examined in preparation for stage 2 deep review.

**Stage 2:** Examine the Covid-19 and healthcare-related reporting from research that had already been carried out in Summer 2020, to look for corresponding themes and recommendations across the Sussex Carers Partnership members.

**Stage 3:** Conduct additional research with co-production of solutions by carers. Research took the form of a survey electronically distributed but also rolled out to a minimum of five non digitally engaged carers from each organisation via individual phone contact.

Stage 3 also included three Discussion Workshops, each taking one of three main themes from the survey and allowing for in-depth discussion. One of the workshops was conducted during an early evening, to allow working carers or others who could not participate during the day to attend.

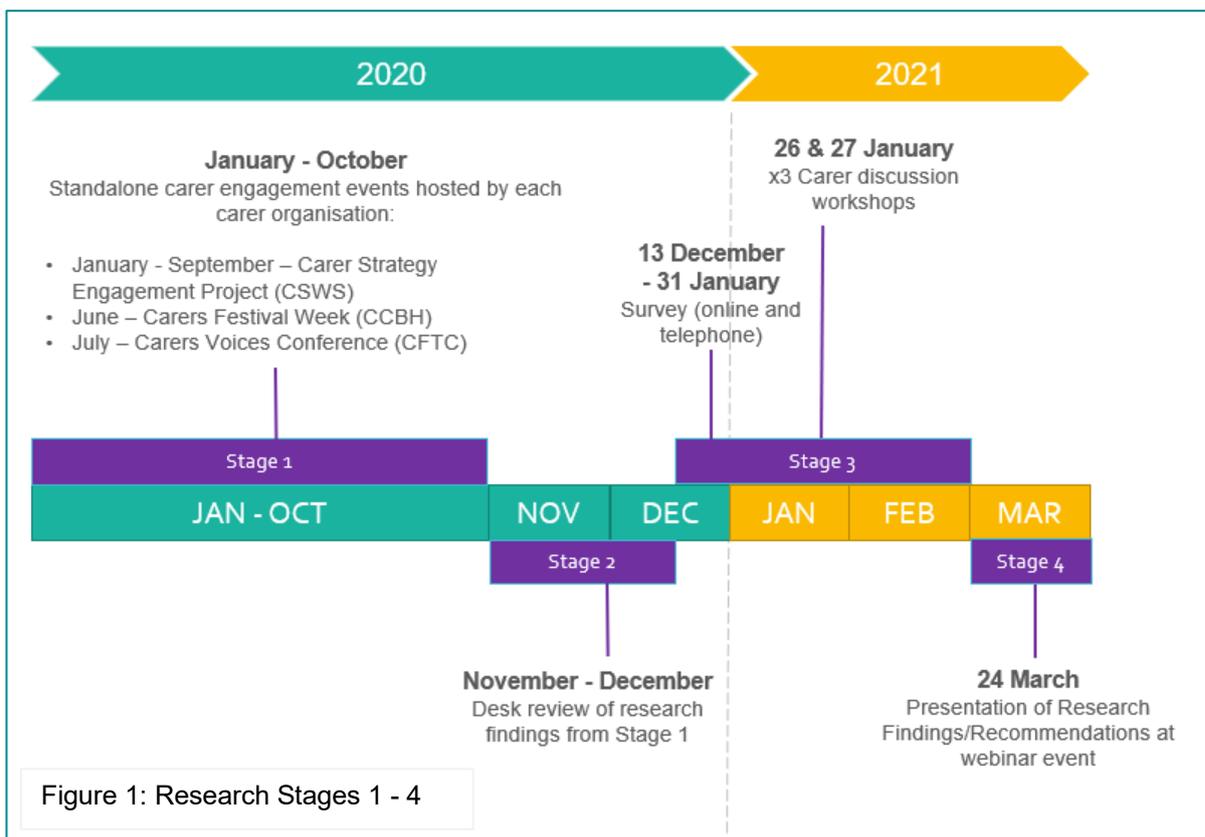
The themes researched were:

- “Carers and Coronavirus: Planning for Recovery.”
- “Caring Doesn’t Come with a ‘How To’ Manual: Exploring Carer’s Experiences of Navigating Healthcare Systems.”
- “The Invisible Army: Making Carers Visible.”

These three themes made up the complete survey.

Stage 3 includes this report.

**Stage 4:** Following completion of this report for the CCGs, a webinar will be held to provide feedback on the results and to allow a panel of guests from the CCG and NHS to answer carer’s questions about the recommendations made.



## SURVEY

Experience has shown that shorter surveys taking between 5 to 10 minutes to complete attract a great number of responses. Therefore, the survey questions were kept to a minimum (18 questions) while maintaining maximum insight.

The survey attracted 118 responses.

- Questions were simple in design to avoid confusion.
- Mixture of suggested answers for questions with tick boxes and open comments enabled.
- Open and closed question approach allowed for the collection of statistical evidence alongside more valuable anecdotal quotes from carers regarding their experiences and hopes.
- Disadvantage of such an approach noted in only receiving results about services we listed, whereas responses could have been very wide ranging. Explanations were provided where necessary.

In total, the explanatory email and survey link was emailed to the entire digitally engaged cohort of the Sussex Carers Partnership. This reach is tens of thousands of carers (est. 40,000+).

Additionally, newsletters and regular publications ran coverage of the survey and workshops for any carers that might be digitally excluded or less likely to engage digitally or were not already engaged with the Sussex Carers Partnership organisations' communications channels.

The focus groups were planned for the last week of January 2021 to ensure Christmas and New Year did not impact on responses.

The survey remained open from mid-December 2020 until 31 January 2021. Carers survey responses were anonymous though a contact section was included to allow invites to the webinar to be made.

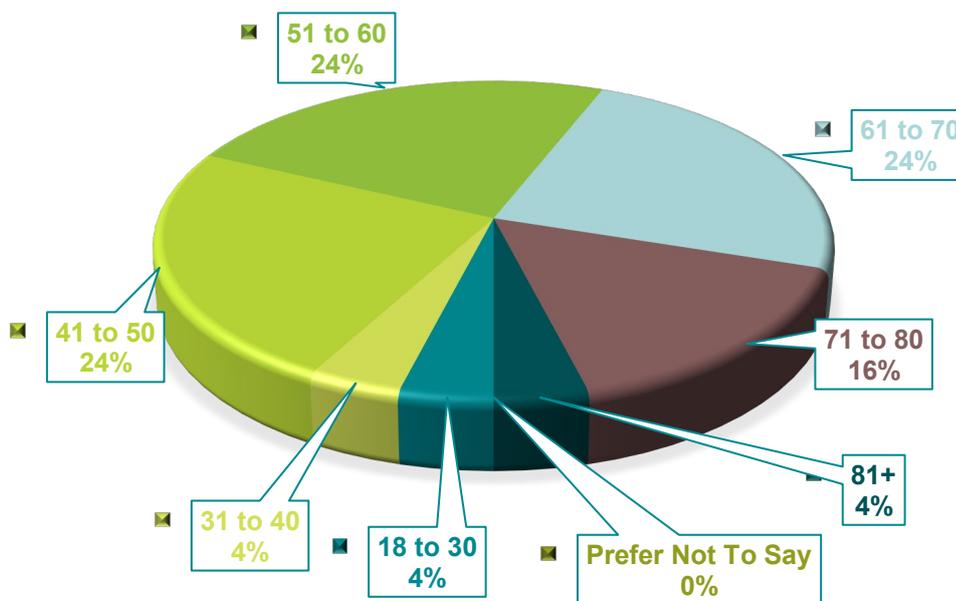


# Equalities Monitoring

In tackling exclusion and inequality, and understanding the experience of different groups, there was a need to ask for personal details, such as age, gender, ethnicity, and sexual orientation.

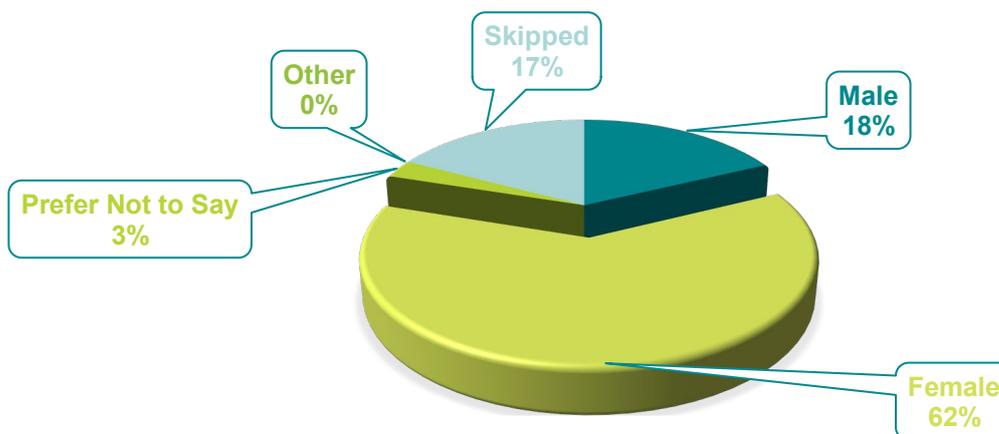
Data presented below has been combined from the Survey (online and telephone) and the Discussion Workshops.

**FIGURE 2: AGE BY PERCENTAGE (%)**



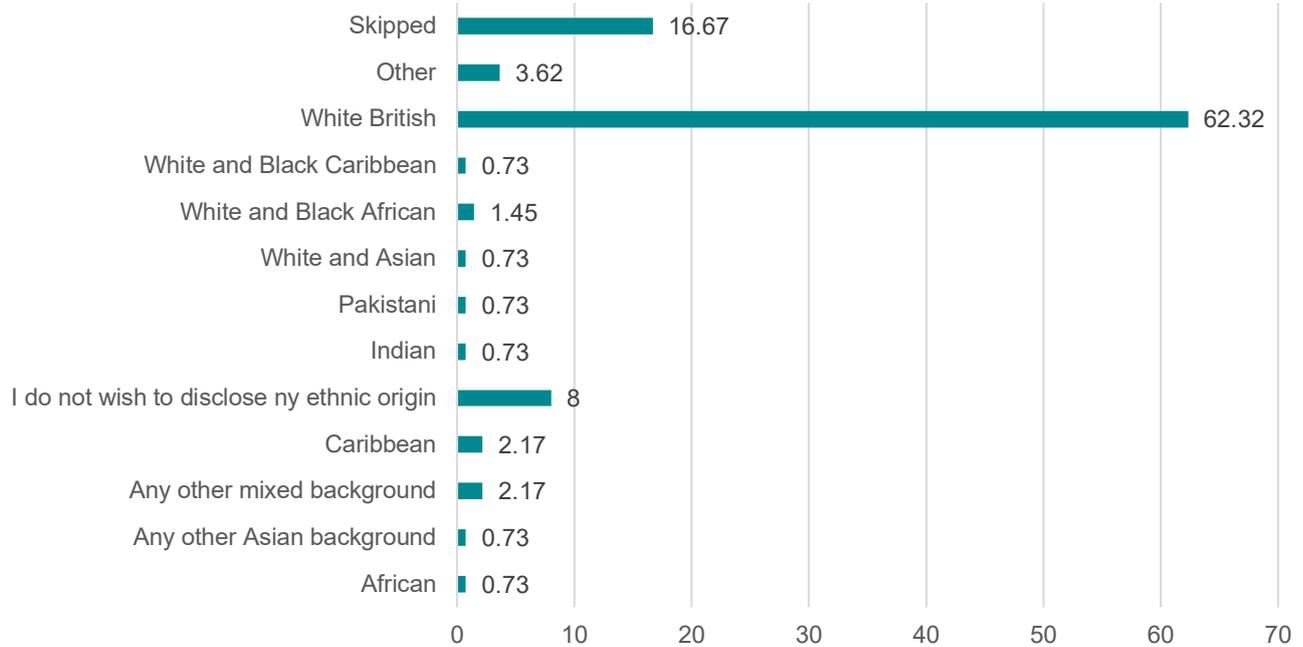
- There was a wide and relatively even spread of ages represented, with 41 to 80 years of age dominating (88%).

**FIGURE 3: GENDER BY PERCENTAGE (%)**



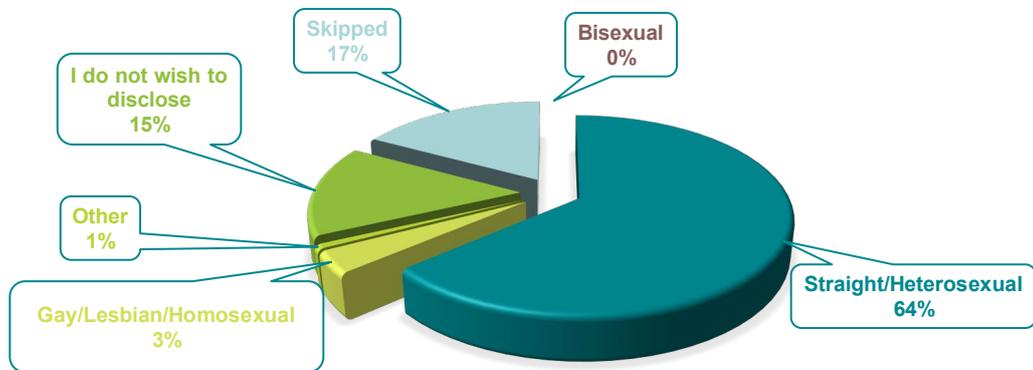
- The majority (62%) identified as Female.

**FIGURE 4: ETHNICITY BY PERCENTAGE (%)**



- Overwhelmingly, respondents were White British (62%), 17% skipped this question, 8% did not wish to disclose ethnic origin, 5% were 'other', and the remaining 8% were BAME (Black, Asian or Minority Ethnic).

**FIGURE 5: SEXUAL ORIENTATION BY PERCENTAGE (%)**



- The responses to this question perhaps indicate that there is a lack of trust in disclosing sexual orientation, with 32% either skipping or not wishing to disclose.

## DISCUSSION WORKSHOP RESPONSES

Carer Organisation	No. of Carers	Percentage (%)
CC (Brighton & Hove)	10	45
CFTC (East Sussex)	5	23
CSWS (West Sussex)	7	32

Workshop	Total Carers Attending	Percentage (%) of Total
Group 1	5	23
Group 2	9	41
Group 3	8	36

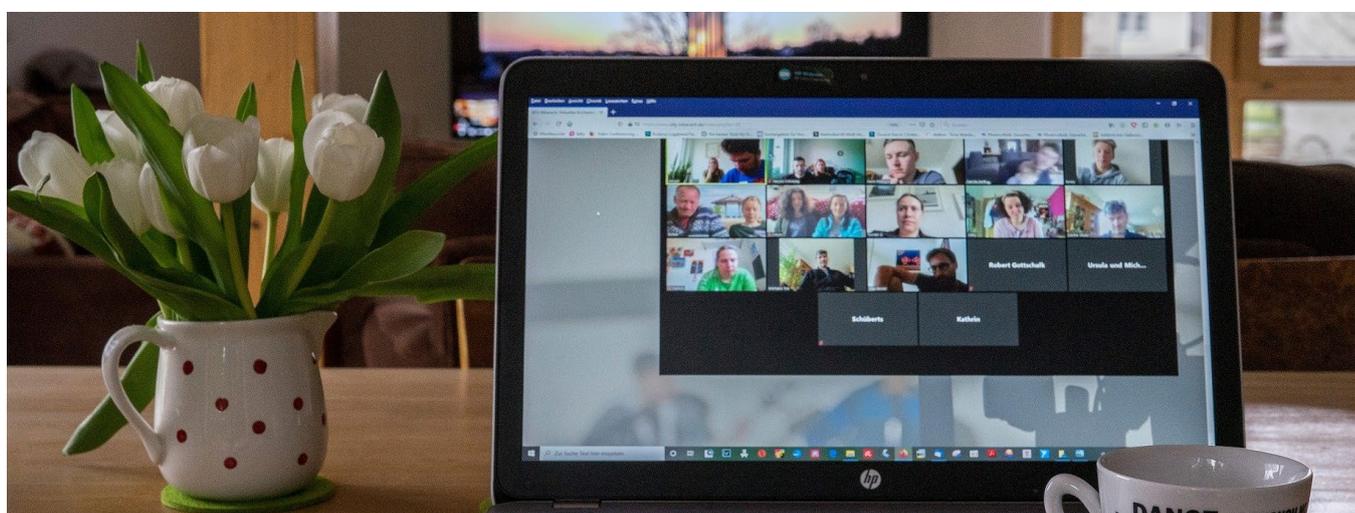
## SURVEY RESPONSES

Carer Organisation	No. of Carers	Percentage (%)
CC (Brighton & Hove)	30	31.3
CFTC (East Sussex)	31	32.3
CSWS (West Sussex)	35	36.5

## GEOGRAPHICAL INFORMATION

As can be seen, there was an even spread of responses either by survey or by attendance at workshops, from across the three regions. Detail of exact location behind individual responses is not available therefore it is impossible to know if carers from one area are all responding in a consistent way and how this differs compared to other areas.

Stage 1 research does provide some geographical information since it was conducted independently by the three organisations comprising the Sussex Carers Partnership. This was examined as part of Stage 2 and the main commonalities and differences can be found on page 10-11 of this report and key points on page 2-3 of the Executive Summary.



# Results

## STAGE 1: CARER ENGAGEMENT ACROSS SUSSEX

The research already conducted and disseminated, by the members of the Sussex Carers Partnership during 2020 was not completed in partnership.

A brief overview is provided. Reports are available from the respective organisations.

Work was completed separately and comprised the following:

### **Care for the Carers (East Sussex)**

Annual Carers Voices Conference, with 97 participants, comprised of:

- online keynote speeches (212 views)
- live online Q&A session with carer organisations (14 carers participated)
- opportunities for carers to 'visit' the online marketplace (51 page views and providers viewed 100 times), and online consultation workshops on the hot topics for carers (6 workshops arranged, 5 completed with 6-10 participants each)
- also took the consultation workshop themes out for discussion with carers groups taking place throughout the month, obtained carer's views through one-to-one telephone discussions and invited carers to send written feedback.

### **Carers Support West Sussex**

Carer Strategy Engagement project, comprised of:

- stakeholder survey (online 169 respondents)
- carer engagement survey (both online and postal totaling 1000 respondents)
- 5 focus groups over two time periods (Feb/Mar 2020 and Sept 20) with a total of 34 attendees.

### **The Carers Centre for Brighton and Hove**

The Carers Centre for Brighton and Hove conducted a survey into digital engagement following the Carers Festival week and this was run concurrently with a survey examining the challenges of Covid-19 for carers.

- 2-part survey initially promoted online via SurveyMonkey and generated 49 responses from a sample of approx. 1200.
- Paper copies were not distributed as the first part of the survey was aimed at carers who had provided an email address and therefore had some digital resource.

## STAGE 2: REVIEW OF STAGE 1 RESEARCH

Stage 2 involved examining the key points from each of the stage 1 reports to determine common themes, and to establish where commonality did not exist.

Stage 2 was conducted during December 2020 and the themes arrived at fed directly into the creation of the discussion workshops and survey which formed Stage 3.

The Stage 2 "deep dive" also included relevant comments and quotations from carers. For brevity, these have not been included here and only the main points are shown.

## **Common Key Points surrounding carer challenges (not only pandemic related):**

- Recognition of being a carer is key to access services but the term is not always well received or understood by carers, and identification is only one aspect
- Being involved by health and social care, and carers' expertise being valued, are also key
- Confused communication about services and messaging around shielding and accessing of key resources
- Importance of peer support/forums/apps to stay connected and need for a variety of support options at the right time (these were mentioned as being positively provided by the three carer support organisations)
- The independence of the carer and the person they care for being maintained was an issue, especially in the context of some services being less available during the pandemic.
- Counselling/Meditation were regarded as useful to support carers with their wellbeing
- Carers say they are fighting the system instead of the system supporting them
- Navigating healthcare and support services is difficult and time consuming. Independent advocacy support is seen as necessary
- Inconsistency of services, both where the carer is known and where they are not identified as a carer (and possibly do not identify themselves as a carer)
- Digital inclusion has become key but is not available to all – greater support is needed and often physical meet ups are preferred
- Support must be inclusive, accessible and appropriate for all carers
- Difficulties accessing services increased due to pandemic
- Loneliness and isolation (plus lack of understanding from public and family)
- Deterioration seen in people with care and support needs, due to lockdown
- Finance issues, especially regarding the low rate and limitations of Carers Allowance – described as “an insult”

## **Points relating to one or two organisations research but not all**

This does not indicate that these items are unimportant to some carers. The findings are based on different themes, differing demographic groups and services available.

- Greater choice and control to maintain a balanced life is needed including not only respite but training for carers – CSWS
- Improved social opportunities for Young Carers are needed – CSWS
- Increased support for carers at each stage of the caring journey – CSWS
- Respite services were cut or unavailable but desperately needed – CCBH and CSWS
- Importance of promoting a whole family approach (where possible) – CSWS
- Benefits and financial guidance – CSWS
- Information provided in a way that reaches out empathetically to communities that are less heard from – CSWS
- Covid-19 impact and communication of vaccine rollout and messaging – CCBH
- Working carers often feel they are penalised by employers – CSWS
- Carers not receiving timely information – CFTC
- Barriers to access – including carers not understanding eligibility, cost concerns, communication and stigma – CFTC
- Concern over care home provision following economic impact of pandemic – CFTC
- Feelings of guilt when negative emotions surface – CFTC
- New carers felt especially vulnerable – CFTC
- Access to PPE – CFTC
- Lack of recognition as a carer when the person cared for is in a care home setting – CSWS
- The need for advocacy for carers – CSWS
- CSWS reported that 84% of respondents required no training to get online and only 3% requiring training for at a novice level. This is the opposite of findings from CFTC and CCBH
- Service responses can be slow when support is sought – CCBH
- Access to basic services such as food and medicine were problematic during Spring 2020 and in a minority of cases were ongoing for a considerable time – CCBH

## STAGE 3: SURVEY AND DISCUSSION WORKSHOPS

### The Survey

The survey contained 18 questions with 13 relating to: Covid-19, healthcare system challenges and visibility of carers. The final 5 were demographic information already shown above.

### The Discussion Workshops

The 3 workshops contained many of the same questions as the survey with three main themes:

- Group 1: Carers and Coronavirus: Planning for Recovery
  - 5 carers attended from 9 booked
- Group 2: Caring Doesn't Come with a 'How To' Manual: Exploring Carer's Experiences of Navigating Healthcare Systems.
  - 9 carers attended from 14 booked
- Group 3: The Invisible Army: Making carers visible
  - 8 carers attended from 17 booked

For ease of comparison, the results and analysis below are split into these three themes with survey and workshop results detailed in the same section. Most comments by carers touched on multiple issues, therefore there are lot of instances of a comment relating to two or more of the themes.

The workshops closely but not exactly followed the questioning from the survey, therefore there are instances where a question asked in one was not directly asked in the other.



# Theme 1

## Carers and Coronavirus: Planning for Recovery

Survey Questions 1 - 4 dealt with this theme. There were also four questions in the Workshop, however there was a slight difference in the questions.

For brevity, key points and a selection of carers quotations are shared.

**QUESTION 1** was the same for the survey (answered by 107 respondents) and the poll conducted with carers in Group 1 (answered by 5 respondents).

Q1) What issues, if any, are you facing as a carer now in relation to health services and the pandemic, compared to in Spring 2020? (Please select ALL that apply). As a carer, I am facing:	SURVEY		WORKSHOP POLL	
	Response Percent	Response Total	Response Percent	Response Total
delayed and/or cancelled health care appointments 	64.49%	69	60%	3
concerns around accessing Personal Protection Equipment (also known as PPE) 	4.67%	5	0%	0
concerns about my mental health and/or wellbeing 	65.42%	70	80%	4
issues in receiving medication and/or equipment deliveries 	15.89%	17	20%	1
issues getting online to access health services (i.e. virtual GP appointments, online prescriptions) 	22.43%	24	40%	2
confusion around public messaging and information about COVID-19 	38.32%	41	20%	1

We can see that the two sets of data are very similar. The survey has a far larger sample size so statistically has a higher validity in terms of the percentages.

The survey had also been running for several weeks before the focus groups, which may have had a bearing on results, such as the reduction in percentage of carers highlighting confusing messaging as an issue.

Initial viewing shows us that the most significant issues currently facing carers in relation to this question are around their mental health and health care appointments being delayed or cancelled. The focus group expanded on these points.

### Takeaways themes for Question 1 were:

- Mental health issues arising due to lockdowns and services being reduced so normal respite activities are not available, therefore increasing the demands on carers.
- GP surgeries not accommodating carers and providing a consistent service.
- Covid-19 restrictions, such as “bubbling”, resulting in some carers becoming isolated from family/friend support
- Cessation of clubs and activities leading to a decline in physical health for the people being cared for
- Reliance on technology to provide solutions due to activities ceasing not being suitable for all

Themes from Q1	Carer Quotes	Notes
Mental health issues due to lockdowns and services being reduced so normal respite activities are not available.	<p><i>“Thank you very much for this meeting and I think the impact of mental health is very profound because you are in the same boat as everyone, but you have the same care role that you normally have which is stressful enough normally and especially now. Then you have the fact that you can’t see friends you are used to going to see to talk about it.”</i></p> <p><i>“It helped when you are trying to be cheerful with the person you care for but really deep down, you’re screaming inside!”</i></p> <p><i>“I felt I had conquered all these problems and I was planning for myself and what due to my age, I would need to plan to get other support in for them for when I cannot be there. Then Covid-19 hit, and my daughter is distressed due to people dying and my son is out of work (after 19 years). He has masses of energy and I don’t know how we will ever get him back into work with so many other people out of work now. This situation has suddenly hit me after I felt I had done so well and I panic now.”</i></p> <p><i>“I think carers’ patience is suffering now – where do we go to let it all out. I don’t want to go to the Doctor’s!”</i></p>	<ul style="list-style-type: none"> <li>• Support from voluntary sector organisations was seen as important and highly beneficial in combatting mental health/wellbeing issues: e.g. <i>“Care for the Carers have been particularly good, always having monthly meetings so there was a place to talk.”</i></li> <li>• It was noted that not only carers being impacted, but generally the population were under pressure as well, and this also led to increased suicides.</li> <li>• Another carer echoed the idea that mental health is being severely impacted due to lockdown restrictions and the pandemic economic effect, but carers must continue to remain resilient not only for themselves but also those around them.</li> <li>• One carer praised the Citizens Advice Bureau for help with getting unemployment benefits and also a worker at the JobCentre Plus because they actually listened to the problem that her son wanted to work, not go on courses, and they seemed to understand the problem.</li> <li>• One carer stated that her spirits had been raised and she could have some hope following the phone call.</li> <li>• Carer felt she must keep herself going for the sake of everyone else including her husband who is normally very resilient.</li> </ul>
GP surgeries not accommodating carers and providing a consistent service.		<ul style="list-style-type: none"> <li>• This issue highlighted that the carer’s surgery had amalgamated with others and where there were some issues regarding appointments and seeing GP/doctor prior to the pandemic, these have increased, though recently there has been a slight improvement.</li> </ul>
Covid-19 restrictions, such as “bubbling”, resulting in some carers becoming isolated from family/friend support	<p><i>“Summer meant myself and my brother could visit but the November lockdown resulted in me becoming the support bubble as I live on my own. This means I cannot bubble with anyone else such as friends who I rely on. I am now not supported by being in a bubble with friends and my brother can’t go round to my parents as he is not part of their bubble.”</i></p>	<ul style="list-style-type: none"> <li>• Due to caring role, not being able to connect with other friends or family for social support was noted as impacting on carer wellbeing.</li> </ul>
Cessation of clubs and activities leading to a decline in physical health for the people being cared for	<p><i>“The person I care for has Alzheimer’s and I am the carer but I don’t live with her. Before lockdown there were still lots of clubs. Since they have stopped, there has been a noticeable decline in her condition.”</i></p> <p><i>“She [the person I care for] won’t exercise now either, in summer she would walk but not even chair exercise is ok now.”</i></p>	<ul style="list-style-type: none"> <li>• Carers felt there was a negative impact on the person/s they care for because of the suspended day services in the local area.</li> </ul>

<p>Reliance on technology to provide solutions due to activities ceasing not suitable for all</p>	<p><i>“The pandemic also brought out that my father is clinically extremely vulnerable but had hospital appointments. It has made him realise how vulnerable life is which in some ways is good but also while we have moved to having virtual meetings and it is brilliant, there is an assumption that people will have equipment and skills to use it which is often not the case. My mum has no idea how to use tools like Zoom. My dad does know how to use computers, but this means he has to be relied upon for my mum and she doesn’t engage in that way anyway. She is old fashioned and wants to use a phone.”</i></p> <p><i>“I agree with what has been said. I am dealing with a person with a stroke and vascular dementia. Crossroads used to visit every week. We now have no support at all and I feel like I am on my own. I do a Zoom meeting with The Carers Centre (Brighton and Hove) each week which is very helpful, but we are all in the same boat.”</i></p>	<ul style="list-style-type: none"> <li>• Consensus amongst group about some people not having the skills, or preference, to utilise technology to access support service (i.e. carer groups). However, those who had, have found it to be helpful.</li> </ul>
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**QUESTION 2** was an open comment answer, which asked carers if they were any other issues they would like to share that they were facing now in relation to health services and the pandemic, compared to in Spring 2020. It received 67 survey responses and was the same as the second question discussed in the Workshop.

The themes already touched on in Question 1 and later specifically asked about in other questions, were repeated and built upon.

There was a mixture of positive and negative comments and a selection of comments shared in the table reflect the views expressed as many comments contained significant detail and multiple themes. Therefore, comments may have been separated into different themes where multiple issues were mentioned.

**Takeaways themes for Question 2 were:**

- No respite/day care
- Loneliness / Stress of caring / Mental Health
- Shielding and loss of regular monitoring by GP/Hospital
- Recognition of carers – consent and understanding by healthcare services
- Vaccinations (Covid-19 and Flu)
- Communication with health services and inconsistency of service
- Impact of reduced services usually relied upon
- Communication and messaging (Government/NHS)
- Hospital discharge
- Fear of attending hospital

Loss of income and stress of home schooling alongside caring were also other issues mentioned.

Themes from Q2	Carer Quotes
Respite	<p>““Lack of support of respite.”, “Respite.”, “No respite – day centre closed.”</p>
Loneliness / Stress of caring / Mental Health	<p>“Loneliness!”</p> <p>“I'm finding that I feel more invisible now than I did last year. Understandably, the whole situation has meant less contact for everyone but there is a degree of feeling more isolated and, oddly, lonely on occasion, even though my wife is next door with her PA.”</p> <p>“I am left feeling isolated. Now my mental health is a problem as I am grieving before I have lost him and fighting to give him quality of life for the rest of his life.”</p> <p>“Mental health - depression or at least anxiety but I don't want to go and get a diagnosis.”</p>
Shielding and loss of regular monitoring by GP/Hospital	<p>“My husband needs blood tests for the hospital every couple of months. His mobility's decreased, sometimes he's able to get out, often not. He asked to have the blood tests done at the G.P practice, which is nearby, but reception said he couldn't. This has meant he's not had bloods done. The hospital is contacting the practice to request the G.P practice to do the bloods.”</p> <p>“The person I am caring for (my mum) is afraid to see me because my husband still goes out to work in a busy workplace”.</p>
Recognition of carers - consent and understanding by healthcare services	<p>“When taking my partner who I care for to local hospital, I am not allowed to be with him as he has difficulties explaining himself as he has a very bad memory, sometimes he is so much pain he cannot explain himself and I have to either wait outside the hospital or go home till he contacts me to collect him, this has happened 3 times so far since August 2020.”</p> <p>“On a recent hospital appointment, I was told to attend alone and asked if he could 'wait outside!' (With a very anxious autistic adult son - that was not going to happen).”</p> <p>“When my partner goes to health appointments, I've not been allowed in to accompany him - which means we're missing out on key information as my partner can't remember or understand the information the health people have given him. I understand they need to manage the risks of COVID but it's so frustrating to be left out.”</p> <p>“Lack of understanding as to how my role has increased due to raised anxiety for the person I care for.”</p>
Vaccinations (Covid-19 and Flu)	<p>“Lack of info re vaccination and whether or not my husband will get it soon as he is very high risk and not going out has caused his health to get worse (pressure sore) The doctor is unaware of this and when I tried to mention it, she said that my husband had to let them know, which he won't. Also will I be eligible for the vaccine soon? As his sole carer I would end up giving Covid-19 to him if I caught it as due to his level of care, I am unable to isolate from him.”</p> <p>“Also flu jabs - He's 75. Previously the surgery has contacted him for flu jabs but he's always declined (apart from once). This year he said he would have the flu jab, but the surgery didn't contact him. He did contact the surgery a few weeks ago, but they've not got back to him.”</p> <p>“Things have improved but now the issues are about vaccination. Which one do we get and why? When? How do I get my mother there?”</p>
Communication with health services and inconsistency of service	<p><u>Survey Comments:</u></p> <p>“Really upset that GP Surgery STILL seems unsure about the disability status of the person I care for although has been registered with them since birth. Repeatedly have to evidence his diagnosis, flag his entitlements. They are CLUELESS. Also impacts on my status as a CARER.”</p> <p>“My GP doesn't seem to support or understand the medical condition I am dealing with. How can you influence your GP to support rather than hinder care without causing further problems? Is there an independent complaint process that can allow you to remain anonymous?”</p>

	<p><i>"Lock down has been a time of extreme anxiety due to personal health care issues but my GP has her on a priority list and this care has been exemplary."</i></p> <p><u>Workshop Comments:</u></p> <p><i>"My mum's GP practice has improved. Easier to get through and their understanding such as giving dual appointments for both parents. Phone memory assessment went well and the practice seems to have improved.</i>  <i>In first few weeks of the pandemic, I contacted GP due to panic attacks as people were not socially distancing. Even receptionist was brilliant. GP called back and were very good. The health service has stepped up."</i></p> <p><i>"I feel my surgery has gone downhill. I'm very fit despite age. I phoned them about a problem and was 40<sup>th</sup> in the queue. When I spoke to reception, they asked how long I had had the problem and I told them a couple of days and they said oh well you must be alright then. That was the end of the conversation! I have not called back! They seem to go round in circles. Ours used to be brilliant."</i></p> <p><i>"I am dealing with an end of life situation and the surgery is impossible to get through to. You have to complete an online form to get an appointment which is unnecessary, and the form should be shorter. I also need blood tests every two months and cannot go to the polyclinic now so have to go to the hospital on the bus which is worrying. You're not meant to fill in forms for other people as well but I have to do this for the person I care for. Also, surgeries seem to be getting so big now as they are merging. This means you don't see the same doctor, so they know nothing about you."</i></p>
Impact of reduced services usually relied upon	<p><i>"Getting medication during covid has been a challenge. I'm a Clinically Extreme Vulnerable (CEV) person but also a carer for my wife who has mental health and mobility issues. Luckily NHS Responders has been a lifeline."</i></p>
Communication and messaging (Government/NHS)	<p><i>"There has been very little consideration given to carers who are also in the "clinically extremely vulnerable" category! The assumption is always that they (the vulnerable person) are the "cared for" rather than the carer themselves! Letters are sent out saying stay at home, don't go food shopping, avoid chemists etc. but what if you are supposed to be caring for someone who couldn't cope/survive without the carer doing those things?"</i></p> <p><i>"The messaging is at the root of a lot of my problems. Tiers and everything are so confusing. Now we have vaccines being rolled out but what about carers? Are we not providing a critical service? We appear at the moment to be being left behind again which is shameful. I already have a tough time with my mental health because I'm looking after a bed ridden person who has started to have memory issues which I suspect is the beginning of dementia. My own health has started to suffer and I can't even get out for an hour to look at the shops because of tier 4 restrictions."</i></p> <p><i>"Lockdown is so confusing this time. I don't know if I should go out, stay in, attend any appointments. I have had the first vaccination and have not been told that the 2nd is delayed but I keep seeing on the news that it is being delayed by 12 weeks. What is going on?"</i></p>
Hospital discharge	<p><u>Workshop comment:</u></p> <p><i>"My daughter has just been discharged from hospital simply because they are overloaded, rather than her health issues being resolved. She will just have to live with pain for a couple of years before it escalates enough to meet the threshold for priority treatment. For my own respiratory condition, my follow up appointments have been very delayed, so I am very short of breath and it's not being treated."</i></p>
Fear of attending hospital	<p><u>Workshop comment:</u></p> <p><i>"Following an accident, I had to take the person I care for to hospital. My grandson decided it was safer to go to Haywards Heath. We are scared of going to hospital."</i></p>

**QUESTION 3** was answered by a total of 107 respondents. The discussion Workshop Question 3 was different to the survey\*, but responses covered a very similar theme, therefore Q4, which was the same as Q3 (barriers to vaccination) in the survey, was not asked during the Workshop.

Q3: What main barrier, if any, might you face in accessing the COVID-19 vaccine when it becomes available? Please select ONE answer only OR provide your own answer.	SURVEY	
	Response Percent	Response Total
Eligibility and priority as a carer for vaccination		35.51% 38
Associated cost, if any		0.00% 0
Lack of information about the effectiveness or success rate of the vaccination		2.80% 3
Choice as to which vaccination can be administered, if more than one is offered		0.00% 0
Concerns about the possible side effects or risks, if any		14.95% 16
Availability and/or flexibility of appointments for vaccination		4.67% 5
Location of where the vaccination is administered (i.e. local GP surgery, hospital)		12.15% 13
Lack of replacement care available for the person I care for		5.61% 6
Other (please state):		24.30% 26

Many of the comments under “other” echoed the tick box issues. “None” or “I have already had the vaccination” were also mentioned several times.

**Takeaways themes for Question 3 were:**

- Carers’ preference for having the vaccine at the same time as the person they care for.
- Inconsistency of information about priority for vaccine (i.e. age related or underlying health issues etc.).
- Concern about side effects especially long term not found during testing and regarding effect on allergies and illnesses.
- Concern at being in a room with people waiting for the vaccination.
- Identification as carer.
- Travel to be vaccinated.

\*Workshop 1 – Question 3: The NHS has asked us to give them specific recommendations about how they can improve their response to carers, whether that’s through GPs, hospitals, or pharmacies. What practical actions can health services take to best meet your needs as a carer during the pandemic recovery period in 2021 and beyond?

Themes from Q3	Carer Quotes
Preference for having the vaccine at the same time as the cared for.	<p><u>Survey Comment:</u>  <i>"Have had to wheel 3 people to be vaccinated, my 91-year-old parents and my Parkinson's suffering 76 year' old husband - am official carer for all of them - Could my vaccination not have been done at the same time as I remain the weakest link for all 3 having to shop for food, medications etc."</i></p> <p><u>Workshop Comment:</u>  <i>"Cared for people are having the vaccine but the carers are not being prioritised and we are looking after people who are extremely vulnerable."</i></p>
Inconsistency of information about priority for vaccine (i.e. age related or underlying health issues etc.).	<i>"Have received the vaccination along with the person I care for at home this week. Was confusion from a G.P. at the practice I attend whether I should be given the vaccine. I was told that there was a strict protocol who was to receive it. But when I received another phone call from the nurses giving the vaccine, I was told that as my mum's main carer I would automatically receive one at the same time. So, the first person didn't have the right information which caused me stress for a day."</i>
Concern about side effects especially long term not found during testing and regarding effect on allergies and illnesses.	This was an issue referenced by one carer.
Concern at being in a room with people waiting for the vaccination.	<i>"I took one of the people I care for who is over 90 to have their vaccine. I was in a room with over 30 people. How can that be safe? I was being asked to put my health at risk so that my Mother could have the vaccine."</i>
Identification as carer.	<i>"How are we being identified as a carer by our GP practice? It seems like a postcode lottery as to who gets the vaccine and when. My parents practice did the over 75's 3 weeks ago."</i>
Travel to be vaccinated.	<i>"In Hove, most people have been told to go to Portslade which seems to be outsourcing. Brighton Centre is opening but it is for people within a 60mile radius which would include Croydon."</i>

**QUESTION 4** was specific to the survey and was answered by 106 respondents.

Q4) Thinking about your most trusted sources of information about the COVID-19 vaccine, please rank the following in order (1 being most trusted):	
	Total Score**
NHS website	726
Gov.uk website	668
Direct call or letter/email from GP/District Nurse/Health professional	605
GP text messages	586
County Council email updates	445
News media	357
Facebook/Twitter	217
Word of mouth	212
**Score is a weighted calculation. Items ranked first are valued higher than the following ranks, the score is a sum of all weighted rank counts.	

It should be noted that while the Government website ranked second overall, there were several comments which explicitly referenced the Government as being untrustworthy due to U-turns on decisions and "lies".

Other information outlets mentioned as being trusted are:

- Carers organisations
- Independent SAGE
- Word of mouth when the person works directly with a vaccination team or Public Health England.

# Theme 2

## Caring Doesn't Come with a 'How To' Manual: Exploring Carer's Experiences of Navigating Healthcare Systems

This theme encompassed questions 5 – 9 in the Survey and started by examining whether carers felt they were valued for their knowledge and care expertise of the person they care for.

**QUESTION 5** was the same for the survey (answered by 104 respondents) and the poll conducted with carers in Workshop 2 (answered by 8 respondents).

Q5) We've heard from carers that they don't feel valued as expert partners by healthcare staff. As a carer, do you feel valued by healthcare staff as an expert partner? Please select ONE of the following:	SURVEY		WORKSHOP POLL
	Response Percent	Response Total	Response Percent
Yes, all/most of the time 	20.19%	21	50%
Sometimes 	55.77%	58	50%
No, not at all 	24.04%	25	0%
Don't know	0%	0	0%

It is immediately apparent that there is an issue here, with carers often feeling as though they are discounted when the health needs of their cared for are examined.

It is significant that almost 25% of carers surveyed via the online survey felt they were never valued for their knowledge. Whereas the main difference for the carers polled in the workshop was that they generally had a more favourable view than those completing the survey. No one at the workshop answered that they never felt valued.

### **Workshop Discussion - Q5:**

The survey did not have a comments section; however, the workshop was able to expand on the answers and shows that the responses are tempered by inconsistent healthcare provision.

*"It depends on which part of the health service you talk about. My GP has been exceptional. Really sensitive to our needs and those of my cared for person. They value my input and the hospital (Royal Sussex County) have been very positive. Less positive have been the people who are specifically there to help the person I provide care for.. Assessment services, MH services, Millview – they have been appalling."*

A second carer outlined that being listened to by services is fundamental.

*"We had really good access to MH services (St Marys). They are very appreciative of us as carers. Listening to what the carer says is key and being sensitive to the carers needs as well as the cared for."*

Another carer outlined how even a single person in an organisation can completely alter the carer's experience (in this case, positively).

*"My experience previously was with Dorset mental health services. It was atrocious, the person I provide care for was discharged without diagnosis and therefore without the medication they need. Oakleaf seem really good. One person there managed to engage with the person I care for, for 25 minutes by starting the conversation saying, "You don't want to be fixed do you?" This recognised that the person is a human and personalised the contact, even I learnt something new."*

**QUESTION 6** was the same for the survey (answered by 104 respondents) and the poll conducted with carers in Workshop 2 (answered by 8 respondents).

Q6) Please rank from 1 to 4, the practical steps healthcare staff* could/do take to make you feel valued as a carer? (1 being most important and 4 being least important) *i.e. any staff you may come into contact with at your GP practice, hospital, urgent and emergency care, community health care, mental health or learning disability services, to name a few.	SURVEY	
	Total Score(1)	Overall Rank
Trained to proactively involve carers as part of the care and planning process	288	1
Routinely and consistently ask questions about who is providing care, in order to identify carers	277	2
Signposting or referring carers for timely information, support and guidance	207	3
Being better informed about consent, confidentiality and sharing of information with carers	207	4
(1) Score is a weighted calculation. Items ranked first are valued higher than the following ranks, the score is a sum of all weighted rank counts.		

It is evident from the scoring that carers prize being identified as carers and involved in the care provision by the use of effective and consistent questioning to enable carer identification, and listening to the answers. This was also evident in the second Discussion Workshop.

### **Workshop Discussion - Q6**

This was the second question asked in Discussion Workshop 2. The workshop did not present options and ask carers to rank them. Instead, it was open for discussion and below are some key points raised:

Carers reported that little actions and behaviours which demonstrate that the carer has been recognised and valued can have a huge positive impact. Some carers were quite emotional about the positive impact that small behaviours can make.

*“It’s small things that you don’t have to ask or fight for.”*

An example was when arranging an appointment with the GP, they are automatically given a double appointment as the GP surgery understand the needs.”

*“Being listened to but also being asked without you having to do so and then having to push for answers or information. It shows that healthcare see that you can help them.”*

Some carers feel they are excluded until there is a crisis.

*“I was not involved at all until after the assessment was completed and then the services realised that they couldn’t understand the information they were being given. Then they turned to me as their “saviour” despite having previously blocked me.”*

Getting the whole picture of the cared for person’s needs is crucial

*“Parkinson’s nurses are very good at including the carer. It can actually be upsetting for the person being cared for but it may be the only way to get to the true situation. If the true situation isn’t known, the treatment may be skewed or not given at all.”*

Empathy being shown is as important as good treatment for some carers

*“It’s all about the people. I’ve seen about 6 different services in the last week with the person I provide care for and it’s noticeable the difference in empathy from person to person. As a carer you need them to show they care even if what they can do is actually very little. Sometimes you can see they are not listening; they might be looking at their watch. We know the services are very busy! We have good access to healthcare but not all the healthcare professionals are good.”*

**QUESTION 7** was answered by 101 survey respondents, who were able to select as many options as they felt were relevant.

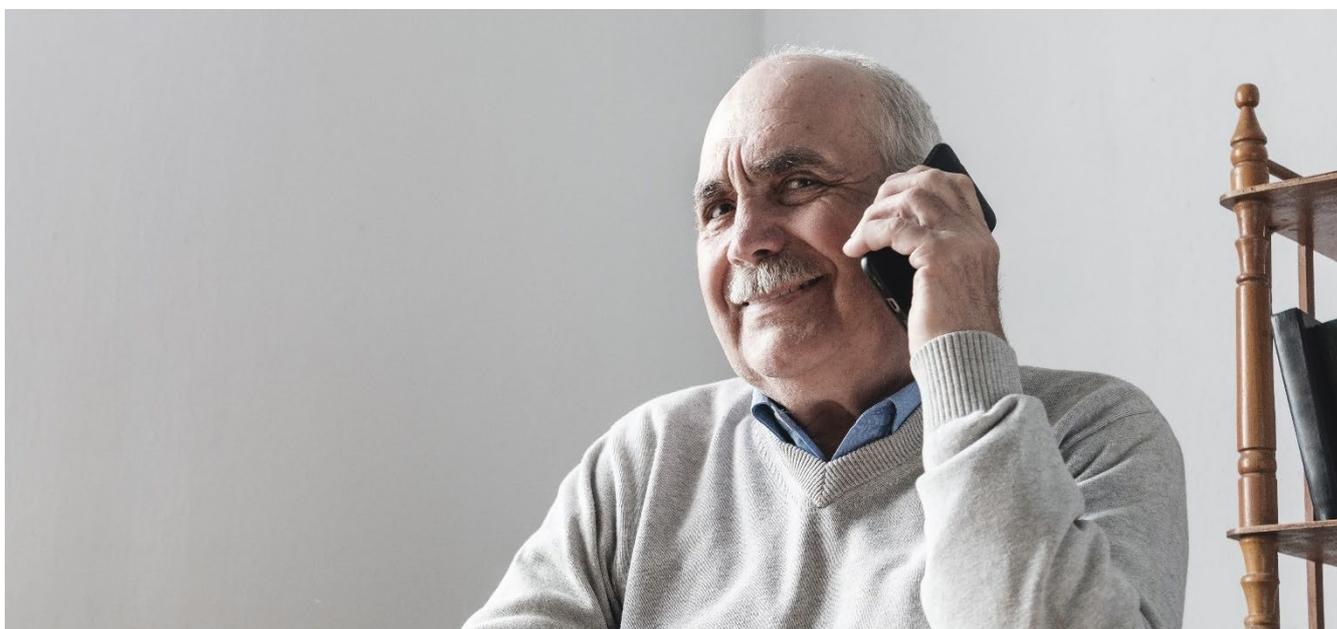
Q7) We’ve heard from carers that finding the right information at the right time in their caring journey can be a challenge. What information has been, or would have been, most helpful to you during your caring journey? Please select all that apply.		SURVEY	
		Response Percent	Response Total
Information on the diagnosis and/or treatment plan for the person I care for.		63.37%	64
Information on the support available to me as a carer.		75.25%	76
Information on how to manage the care and/or medical needs of the person I care for.		67.33%	68

Clearly, all information is deemed helpful, with a small emphasis on information relating to their own support options. This is consistent with the strong call for respite and mental health support seen in Q1 and 2 of the first theme.

**Workshop Discussion – Q7**

A poll was conducted with the same question as above. The poll only allowed one option to be chosen, therefore delivered slightly different results but the overall effect is consistent in that all the options were important.

Information on the diagnosis and/or treatment plan for the person I care for	0%
Information on the support available to me as a carer	0%
Information on how to manage the care and/or medical needs of the person I care for	0%
All of these	88%
Don’t know	13%



**QUESTION 8** was answered by 103 survey respondents.

Q8) Who would it be most helpful to receive information from about the support available to you as a carer? Please select ONE of the following:	SURVEY	
	Response Percent	Response Total
GPs		17.48% 18
GP surgery staff		7.77% 8
Pharmacy staff		0.00% 0
Hospital staff		3.88% 4
Carer support organisations		33.01% 34
Other voluntary organisations		0.97% 1
All of these		36.89% 38

### **Workshop Discussion – Q8**

The same question was asked and the polling mechanism only allowed one answer to be chosen which is the same as the survey question. The results from both polls, showed that there are two main groups from whom information is sought and relied upon though generally information coming from any of the groups listed is welcome.

It is interesting to note that GPs and Carer support organisations were highly ranked (relatively) but surgery staff, pharmacy, hospital staff and other voluntary organisations were not singled out as being most useful sources of information (other than they are included in the “All” category).

GPs	13%
GP surgery staff	0%
Pharmacy staff	0%
Hospital staff	0%
Carer support organisations	13%
Other voluntary organisations	0%
All of these	75%
Don't know	0%

**QUESTION 9** was answered by 102 survey respondents.

Q9) How helpful was the timing of when you received information you needed to support you in your caring role? Please select ONE of the following:	SURVEY	
	Response Percent	Response Total
I've received information at the right time to meet my needs		25.49% 26
I haven't received enough information to support me in my caring role		60.78% 62
I received too much information at the point of diagnosis and then nothing since then		13.73% 14

## Workshop Discussion – Q9

The workshop again asked the same question, and the results were consistent with the survey with the exception that no one indicated they had received too much information at the point of diagnosis (but one carer commented exactly this point). 25% of those polled chose to say they did not know, which was not an option in the survey.

I've received information at the right time to meet my needs	25%
I haven't received enough information to support me in my caring role	50%
I received too much information at the point of diagnosis and then nothing since then	0%
Don't know	25%

Key Responses for Q9	Carer Quotes
1) The term carer needs to be explained as a legal term to access services which in no way diminishes the persons status as a parent, partner, etc.	<i>"The way the carer question is phrased is so important. My gut reaction was no, I'm not a carer, I'm his mum! The question needs to be asked in such a way that it does not negate my primary identity as his mother. It needs to be a conversation to help me to understand that I'm a carer, and what doors that label might open for me, not just a tick box or a closed question. There needs to be sensitivity."</i>
2) Information is often provided at the start of a carers journey but needs to be updated and disseminated rather than relying on the carer to check websites or call for updates.	<i>"I got a lot of information at the start, during the first year and The Carers Centre (Brighton &amp; Hove) sent a lot of stuff but then it stops. I haven't been contacted once by services during the pandemic. I know about and go to some of the meetings that The Carers Centre have run but often these don't fit in around work."</i>
3) Services need to be trained and clear on what constitutes care and when they can include carers in conversations.	<i>"The person I care for is an adult and until they signed a document basically signing away their life, no one would acknowledge me as their carer."</i>

### Takeaways themes for Question 9 were:

- Carers are given information at the point of diagnosis (or recognition of them as a carer via completing an assessment) but this is insufficient in half the respondents view and follow up information is lacking or must be sought out.
- Carers can be resistant to the term "Carer" and the use of this term needs to be explained in such a way that the person does not feel they are diminished.
- Healthcare staff need to be trained to identify and deal with carers in a way that is accurate, sensitive and empathetic.

## **Workshop Discussion – Theme 2**

In the second Discussion Workshop, there was an additional question not asked in the survey.

**Question: What needs to change to help you to access the information you need at the right time and to navigate services more easily?**

Carers in Discussion Workshop two provided some key changes:

1. The term “Carer” needs explaining at outset, why it is used and what it means.
2. Information such as leaflets on being a carer are often in GP surgeries. Can they be elsewhere?
3. Every time a record is opened at a GP, maybe a box could pop up to remind the GP/staff to check if the person has a care role. Carers need to be asked more than once if they are in a caring role.
4. Re point 1, phrasing of the carer identification question is important. Rather than saying “Are you a carer?”, it needs to be more like, “Do you find yourself in a caring role?”, or “Are you looking after someone who couldn’t manage without your help?”. This would retain a person’s identity as a parent, partner etc. but also open the door to access services that being a “carer” provides.
5. A roadmap of services that lets you know who is responsible for acting on a request. Carers were unsure if they had to follow up referrals or if this was the job of the GP, nurse, Occupational Therapist etc. It was felt that there were a lot of times that the “problem” was passed onto someone else and for carers it is especially difficult at the moment to get hold of people as so many people are not at their usual contact numbers.
6. The way that information is received (and where it is found). There were no direct comments about preferences re online, physical, etc. however, one carer stated they had given up looking for help due to the “Signposting merry-go-round”. Information needs to be available at the place the carer expects it to be or the signposting needs to be minimal.



# Theme 3

## The Invisible Army: Making Carers Visible

Discussion Workshop three started with a question that wasn't included in the survey.

**Question: Carers often don't identify as carers early in their caring journey, and therefore don't realise that carer support is available to them. If this was your experience, what could health staff have said to you to help you identify as a carer and access support sooner?**

One carer's response highlighted that the person they care for had mental health issues starting in childhood and that:

*"Because of that, I don't know when I stopped being their mum and became their carer!"*

They also felt that this made it very difficult for healthcare services to identify a point where them being a carer could be raised.

Another point that was made was that carers often do not know what being a carer will involve, especially when the care demands will increase over time. This means that they are not thinking about being a carer so healthcare staff must help them to identify as such. If this does not happen, this can lead to them being "left behind" as services for the person they care for take priority.

A key element is the initial recognition that a person has a caring role, and this being flagged on medical records. One carer described contacting her GP to check she was registered as a carer at the surgery, after four years of the GP being fully aware she was a carer, and found that she was not on the GP's Carers Register. This carer also described the help available as a "DIY kit" and that *"I just don't know what questions to ask to get help."*

Other responses to this question referenced that in some other countries, there is more of a financial incentive to identify carers and for carers themselves to identify, such as a monthly activity allowance.

GP practices and schools appear to be inconsistent in recognising carers.

*"A busy practice in Hove looked at me like an alien when I tried to inform them that I am a carer."*

A suggestion made via email after the focus group was that a tick-box on applications for school, college and university would be a way of identifying carers especially young carers. This could be expanded to include GP surgery applications, pharmacy, and dental practices etc. However, it was also noted that this needs to be accompanied by carer awareness training and appropriate language being used, to overcome the barriers to identification covered above.

### **Key takeaway point:**

- In none of the examples given, was there a proactive approach by healthcare to identify carers and explain the term or support available.

Within the third Discussion Workshop, the facilitator asked a supplemental question.

**Question: What could have been asked that would have helped to identify the care situation?**

The following are quotations in response to the question:

1. Talk about what it means to be a carer at school.
2. Language has to be used that doesn't remove the identity of a "parent" because you are a "carer". It's not one or the other.
3. Use the word carer (if that is the word that must be used legally) and explain it opens doorways because of its legal definition.
4. Distinguish between paid carers and unpaid carers.
5. Sometimes the person you are caring for doesn't remember you as their wife/husband/partner etc. so it is useful to be the "carer" to them. That works for my husband but there is nothing there to help me feeling alone and uncertain. My husband stopped engaging with services which meant I was left at home climbing the walls.
6. Never thought of myself as a carer until my father died and then a new caring role forced an outward look. It was good to see CarersUK had percentages of things that carers do and it wasn't just personal care (30%) but things like help with finance etc.
7. Put the definition "Do you help someone who can't do without that help?" on a poster in the libraries, GP surgeries and other public places.

**Key takeaway point:**

- The language used and the term, "carer", throw up barriers. People do not always understand why the term is used, and an awareness of this needs to be brought to the dialogue by healthcare professionals, in order to increase the likelihood of carers being identified.

**QUESTION 10** was answered by 100 survey respondents and

Q10) Does your GP know you are a carer? Please select ONE of the following	SURVEY		WORKSHOP POLL
	Response Percent	Response Total	Response Percent
Yes	73.00%	73	57%
No	11.00%	11	14%
Don't know	16.00%	16	29%

Clearly the aim here is for 100% of carers to be responding that their GP knows they are a carer. Any reasoning as to why this is not the case is speculation though logic suggests that a consistent questioning approach by GPs would lead to a higher percentage responding "Yes".

**QUESTION 11** was answered by 71 respondents and was an open comment question and responses highlighted the inconsistencies in the way GP practices are seen by carers.

Q11) If yes, how has that impacted on how your GP surgery accommodates your needs?	SURVEY	
	Response Percent	Response Total
	100%	71

Responses have been organised and split into four sections:

- |                                    |            |
|------------------------------------|------------|
| 1. Positive difference             | 29 answers |
| 2. No difference/negative          | 25 answers |
| 3. Some positive and some negative | 14         |
| 4. Unable to determine             | 3          |

Example comments for sections:

#### Positive difference:

*"It is highlighted on both our records that I am a carer. So any problems come straight to me. I am told that I can ring at any time for advice."*

*"Refers to me in the first instance but is good at consulting my Mother (who I care for) also, so she doesn't feel left out or 'the poor old dear in the corner'. Making appointments later in the day as we don't do mornings."*

*"GP is aware that mental health, overweight and back pain issues are closely related to caring role. He seems to go out of his way to try and help and be supportive."*

#### No difference/negative:

*"Sometimes I have to remind them that I know more than them about my husband's condition and sometimes, although I am always polite, they seem to resent this."*

*"They provide NO RECOGNITION/NO SUPPORT. Multiple times I have had to remind them. They have received STACKS of relevant paperwork both physically and electronically. Multiple forms filled in and at best we get 'we add a note to your record' DON'T just ADD a note. MAKE IT A MAJOR CATEGORY please because it absolutely dominates and dictates our entire lives."*

*"It makes no difference- they don't accommodate my needs as a carer, I've had dreadful experiences of our GP surgery."*

#### Some positive and some negative:

*"Some flexibility with appointments - finally not offering them at school run times in the morning or afternoon...next issue is when they over-run and/or me having to explain that I cannot take a 2pm appointment because then I can't be ready to pick up my cared for at 2.30pm given appointment time and journey time never mind a delay...by the time I actually get to an appointment I need a double appointment because the list is too long but the mantra still seems to be '1 thing per appt'".*

*"They have been very good - eventually! Allow me to book appointments, sit in and hear what needs to be done regarding treatment but I find the receptionists the most off-putting part. They believe they rule the roost and hate for their authority to be challenged but I'm not telling them all my private business."*

## **Workshop Discussion – Q11**

The workshop attendees echoed the survey findings. Experiences were either described as very good or problematic.

*“I couldn’t get appointments due to the booking system and where I lived meant I needed notice to be able to travel. The receptionists were always “off” with me. I had to ask to speak to the head receptionist before anything changed. Not being flexible with appts is very frustrating when you are caring for someone. It felt as if they saw me as someone who just expected everything to fall into their lap.”*

*“I had the opposite experience with my GP, they were very good. Then they left and it became worse. I had seen how it could function but it’s not that way now.”*

Key takeaway points for Q11:

- As with other areas of this research, we can see the importance of being recognised/registered as a carer and accepted as such by healthcare services, which can have a huge impact on their lives.
- The impact of being known as a carer by GP practices is inconsistent, with a range of positive and negative impacts noted. Receptionists were generally viewed less favorably than GPs.

**QUESTION 12** followed on from Question 10 and was answered by 25 survey respondents.

Q12) If no, what are the barriers to your GP knowing you are a carer?	SURVEY	
	Response Percent	Response Total
	100%	25

This question was also open comment question and elicited a range of replies. It was not directly asked in the workshop, however some comments relate to this, so have been included.

Key Responses for Q12	Carer Quotes
1) Provision of ID/System issues	<p><i>“I moved home to become a carer and cannot provide the required ID to join a surgery in this area. I cannot get my ID updated due to Caring duties.”</i></p> <p><i>“The person I help and I are in different surgeries but they will not or cannot communicate with each other. Can computers not do that?”</i></p>
2) Too many staff at the practice with inefficiency in recording details	<p><i>“Too many doctors in the practice, many locum doctors, information not recorded clearly or shared effectively.”</i></p> <p><i>“Lots of part time GPs who do not know our history and therefore don’t bring an awareness that I’m a carer to our consultations. It doesn’t seem to be flagged on our medical notes that I’m a carer.”</i></p> <p><i>“Previous doctor did know, but judging by his replacement, the information was not passed on.”</i></p>
3) Assumption that this will happen automatically/Waiting to be asked/ Lack of drive to register carers.	<p><i>“I am assuming that my GP knows that I am a carer because I am registered at my surgery.”</i></p> <p><i>“I have not been asked.”</i></p> <p><i>“When I told them, I was caring for someone I wasn’t asked who for. There was no curiosity at all.”</i></p>

**QUESTION 13** was answered by 93 survey respondents and was also asked in the third Discussion Workshop.

Q13) What is the main barrier to you being visible within the health system as a carer? Please select ONE of the following:	SURVEY		WORKSHOP POLL
	Response Percent	Response Total	Response Percent
Healthcare staff don't ever talk to me about being a carer or talk to me about my needs as a carer.	34.41%	32	57%
Healthcare staff didn't talk to me about being a carer until I had already been caring for some time.	15.05%	14	0%
Healthcare staff didn't use the right language to help me to understand that I'm a carer.	5.38%	5	0%
Healthcare staff are too busy focusing on the treatment/support/care of the person I care for to consider my needs as a carer or consider my role within the care plan.	27.96%	26	43%
Other (please specify):	17.20%	16	0%

There were an additional 16 comments in the survey which helped to identify specific issues. A selection of these are detailed below.

### **Question 13 – Additional Survey Responses**

*“The times when my role as a carer has been made difficult were when my father was in hospital. I often wasn't kept sufficiently informed, and often had to repeat myself to different doctors, nurses, specialists, but I think that this is symptomatic of poor communication, bad management (at high levels), and overworked staff that exists in hospitals.”*

*“Healthcare workers don't consider that I know the person very well and never contact me.”*

*“NOTHING Forthcoming from the GP practice or healthcare system. We are Utterly INVISIBLE. Nobody wants to know. Unpaid. Unimportant. The toll emotionally, financially, mentally is massive both for myself as a Carer and the person I care for.”*

*“As I ticked above, the main problem is resources, especially time. I'm sure all the Drs and nurses are lovely and given time to stop and chat, it would be like one of those TV shows where they leave work to check up on a patient who has left the hospital. The reality is nothing like that, so expecting them to do more than diagnose and treat is like wishing to find the gold at the end of the rainbow.”*

One carer provided very detailed comments which highlight that carers can often face a multitude of barriers to being visible, not a single issue.

A selection of this carer's points are summarised into three points here to demonstrate the depth of feeling around these issues. Quotes where possible are included and some detail has been removed for confidentiality.

Point 1: Caring can be an evolving situation leading to dealing with multiple agencies which can in turn lead to a loss of self-worth coupled with fear, anger, loss of hope and exhaustion.

*“I have been a carer now for 20 years. (I physically nursed my parents until they died ) Looking back over that time I see the initial years of the Mental Health issues were the worst, dominated by isolation, fear and confusion. As with any job you need skills, with skills come confidence and self-worth, which I lost at the beginning and made me invisible.”*

Point 2: Promises made look great on a poster or presentation but this carer believes that when the promise is not delivered, the result crushes the carer's spirit.

*"It's impossible, as there are so many different problems carers are facing in their situation and sometimes just knowing that there is a person at the end of the phone who will listen and signpost is the best that can be done but promising above delivery is crushing. I often look at the leaflets and posters in the surgery and know from experience that they cannot be expected to deliver what you actually need in that present moment."*

Point 3: Self-help, group help, peer support and experts attending groups can all give carers confidence to challenge when they feel they are marginalised or invisible to healthcare.

*"There was a Tuesday Evening meet that I started to attend. Lecturers from providers and experts and personal support with navigating the MH services. This interpersonal support until 2016 was invaluable and meeting other carers of those with mental health issues. This gave me confidence to ask for stuff I felt was appropriate and challenge the professionals."*

### **Workshop Discussion – Theme 3**

#### **Question: What practical steps needs to happen to make carers more visible within the health system?**

This question was separate from the survey and elicited the following key points.

- The person I care for told the Doctor that I was caring for them and this created a clear agreement re sharing data. If this is a legal facility that is required, the GP needs to make it clear.
- Carer Awareness training and Carer Champions at surgeries. Receptionists tend to be more of a barrier than the GPs.
- Need to speak to you about how your caring role is affecting your health especially at the present time. Empathy is needed, even if they can't do anything.
- This applies to hospitals as well – see beyond "I'm too busy" and let's help each other.
- Identifying carers carries no financial incentive for GPs hence it is not a priority for all. Investment is required.
- Have a tick-box on any application forms for school, college and University so that carers do not fall through the gaps. It's especially easy for young carers to remain unidentified.

# Evaluation: Discussion Workshops

Following the workshops, evaluation was completed by 12 carers.

The sessions were all positively received, with them receiving high ratings for being enjoyable, well facilitated and a good opportunity for experiences to be listened to.

Additional feedback mostly related to the sessions being a good space and opportunity to discuss issues even for those who do not normally enjoy online events.

Some extra points were raised.

1. Several carers noted how everyone has different experiences of caring and it is valuable to share these.
2. Some health conditions appear to have better defined healthcare structures.
3. The sessions could have been longer was one view.
4. There are still significant gaps between what carers need in terms of support from healthcare systems and what is available.

## Stage 4: The Webinar

1. At a webinar hosted on March 24, the research findings were strongly endorsed by the carers and professionals present, with the following areas of the findings generating significant discussion:

- **Navigating Healthcare Systems:** The necessity for a clear roadmap of services and referral pathways was endorsed. Lack of clarity can lead to significant health inequalities and should be viewed via a "diversity lens" to ensure equal and accessible services for all. This is connected with the need for consistent communication not only in terms of Covid-19 messaging but also within healthcare services generally.
- **The Challenges of Identifying Carers:** Identification is not enough. It must always lead to the offer of support appropriate for the individual even if that support is initially rejected. See point 3 below also.
- **The Use of the Term "Carer":** The wide range of meaning this term may have and also the challenge of a single term being applicable for all, across all communities, was explored. Discussion highlighted that the term should include anyone who is undertaking caring responsibilities, and the impact on the carer should be a prime consideration, rather than assumptions being made about a carer's experience based on the number of hours spent caring each week.
- **Mandatory Training and Systems:** Training and systems to enable healthcare staff to proactively identify where a care role may exist was strongly endorsed. This needs to include: understanding the challenges for carers, upskilling practitioners to facilitate carers identifying as carers and accessing support, and not "leaving the carers to get on with it". Awareness of support available locally is critical and carer-friendly adaptations can often be small and simple things such as flexible appointments at GP surgeries, but should also include respite options. Awareness of the impact on carers mental health and wellbeing and support available must also form a part of the training.

2. From the recommendations, there was other debate centred around the possible methods that could ensure that proactive discussions about caring and what it means take place consistently across health settings. Discussions must be in an appropriate and timely manner with the potential carer. There was significant debate about the idea of introducing financial incentives for healthcare providers to identify carers. There was agreement generally that this should not be necessary but may be a way to ensure increased carer identification and referral by healthcare practitioners, given the mixed practice currently experienced by carers.

3. Many of the findings are not new. Work which may go some way to address them is already underway such as NHS England's GP Quality Markers, but carers' experience suggests that these are not consistently being implemented. Findings and recommendations should add to and reinforce existing initiatives and not seek to create new work unless necessary as this is likely to lead to confusion.

4. A strong commitment was given by the panel to take forward the findings and examine how to implement the recommendations as a mandate for change. Change was agreed as necessary and requires the co-production of solutions with NHS, CCG, Carer organisations and carers.

View a recording of the webinar highlights [HERE](#).

## Conclusions

1. **Inconsistent Communication:** Communication between carers and healthcare providers is seen as inconsistent and leads to highly variable outcomes. Some are described as "brilliant" at identifying carers, including carers in discussions about the care being provided/to be provided and demonstrating that their knowledge of the person they help is of value and leads to an improved service. This is not a universal view unfortunately and many carers felt that the service provided from one healthcare setting to another and even within the same GP Practice, Trust etc. was more dependent on the individual you interacted with rather than a standard that applied to all.
2. **Impact on Carer Mental Health:** The negative impact of caring on mental health (including loneliness and isolation) is one of the single biggest issues expressed by carers during the research (80% of respondents in the workshops cited this). Previous research has frequently shown this to be an issue for carers, as their normal way of living has to change to accommodate the care they provide. Another factor to consider is that there is a stigma attached to mental health that is not found to the same level regarding physical health. For some communities, this is even more prevalent. The pandemic has exacerbated mental health issues towards crisis levels for some carers.
3. **Poor Carer Identification:** Identification of carers and recognition of carers' expertise by healthcare services is generally seen as haphazard or poor. It is felt that this has had a profoundly negative effect during the pandemic, with carers not being prioritised for vaccination, multiple journeys having to be made in the case of carers who help more than one person, and a lack of joined up thinking relating to carers and the person they are caring for.
4. **Term 'Carer' Not Understood:** The pandemic has highlighted the issues in conclusion 3 above. Carers were frequently unsure if they were listed as a carer at their GP practice. Covid-19 vaccination information, (i.e. when, where, how and for whom) is of huge importance to carers. There is also an issue around the use of the term "carer" for some. It is understood by some respondents to be simply a legal term that allows access to services and therefore is accepted/tolerated. For others, it is a degradation of their human relationship with the person they help. This was most strongly espoused by those with a close familial relationship such as parent/child or partners.

5. **Delayed/Cancelled Access to Healthcare Services:** The ability to access healthcare services, especially with regards to delayed or cancelled appointments and services, compared to Spring 2020, is still a major concern for carers. Carers frequently cited services being cut and the loss of regular checks and monitoring as causes for concern. This issue affected both the person being cared for and the carer in many cases. More than 60% of carers responded that this was an issue for them across both the survey and workshops.
6. **Concerns Around Carer Contingency:** Back up for carers and respite is critical. Back up plans are available to carers, however, already limited respite options have reduced further during the pandemic. This is a long-standing issue which has been raised by carers many times previously. The pandemic has raised the need for respite to critical levels and is particularly acute with those who have been shielding and/or are isolated from support by Covid-19 restrictions.
7. **Difficulty Navigating Healthcare Services:** Carers successfully navigating services is difficult without a proactive approach from healthcare providers. Carers frequently cite it being a “struggle” or a “fight” to access the care or support that they or the person they care for need. Main services and options, and the routes to them, need to be clear and obvious, not only for carers and people they care for but also for other healthcare professionals.
8. **Confusing Messaging About Covid-19:** Covid-19 messaging from NHS and Government is ranked highest in terms of trust but this is not universal. This messaging is around the actions society and individuals should take to keep themselves and the people they care for safe. It includes messages about shielding, access to healthcare services (Covid-19 and general), vaccinations and the prevalence of the virus in particular areas of society.



# Recommendations

The following recommendations are derived directly from the conclusions and from suggestions made by carers within the research.

The main intention is that they will be considered and where agreed, actioned by the Sussex CCG.

- 1. Incentives to Identify Carers:** Explore the introduction of incentives for health services to identify and ensure that carers are registered, views are sought, and all necessary consents are obtained to allow seamless interaction between healthcare service, the person with care and support needs and their carer. Healthcare services are in a privileged position with regards to identifying and supporting carers and by extension the person that is receiving the care. Financial incentives for healthcare providers to identify carers and refer them for support could add weight to the good practice guidance already recommended by NHS England (e.g. Supporting carers in General Practice: a framework of quality markers). Inclusion of carers within GP Practices' Patient Participation Groups is also recommended.
- 2. Introduction of Mandatory Carer Awareness:** Introduce mandatory carer awareness training for all healthcare staff, including identification, the use of the term, "carer", and referral for carer support. Evidence that healthcare staff are able to question appropriately to identify carers, understand how to work with the carers' own knowledge and experience and are aware of the support services available is a minimum standard. Local carer organisations should be involved in the utilisation of existing training resources and the development of new resources, to ensure that accurate messaging regarding local support provision is incorporated. Due to the significant staff numbers working within healthcare services across Sussex, it would be practical to have a blended learning approach with a mix of e-learning and face-to-face delivery available, dependent on local commissioning.
- 3. Centralised Carer Records:** Introduce a mandatory centralised record of carers. Medical records held, whether Sussex-wide or at a more local level must have a requirement for a prominent "Carer" field to be completed, even if this is to record that the person is not a carer or in the case of a patient record, that no carer is involved. 'Unknown' should not be an option and completion should be monitored. Since many existing records will not have this information, healthcare staff routinely enquiring about caring, having regular dialogues with potential carers to support carer identification and access to carer support and completing the mandatory field will be needed.
- 4. Reduce Negative Impact of Caring on Mental Health:** Prioritise responses to the negative impact of caring on mental health, as this is a previously known issue which has been significantly exacerbated by the pandemic and lockdowns. Healthcare services need to respond with an awareness that an individual has a caring role and be proactive in discussing issues and impacts and referring to appropriate support. Similarly, to item 2 above, mental health awareness training should be mandatory for all healthcare staff, and relevant support services and resilience-building workshops should be commissioned where they are not already available.
- 5. Regular and Consistent Messaging:** Ensure regular and consistent messaging to carers regarding the Covid-19 vaccination programme and the continuation of non-Covid-19 services. Trusted sources (NHS, GP, Government) must ensure that carers are not overlooked as they previously appear to have been. If as looks likely, vaccination is to become an annual event, careful consideration should be given to carers and the people they help being vaccinated at the same time. This is achievable where accurate records of carer and the person they help are kept. This also provides benefits due to efficiencies for the NHS and also the carer, ensuring there are no barriers which will prevent the carers continuing to provide care.
- 6. Road Map for Services and Support:** Produce a clear, concise and accessible road map of major services and options for carer support. This can be provided to all known carers as well as new carers identified either by healthcare providers, carer support organisations, carers assessment workers or other agencies in a position to offer this information such as schools and libraries.

# SUSSEX CARERS PARTNERSHIP



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