

# Survey of Adult Carers 2021/22

## Main Findings



## VERSION CONTROL

Confidentiality
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## SUMMARY

Derbyshire conducted the mandatory Survey of Adult Carers in England in Autumn 2021. NHS Digital published the verified results for England in summer 2022. This report summarises the findings for Derbyshire in comparison with CIFPA (similar local authorities), East Midlands and England. Due to the Covid-19 pandemic councils could opt out of running the SACE 2020/21. The majority of English councils, including Derbyshire, opted out. The SACE 2021/22 replaces the survey that would have run in 2020/21.

### Demographics

12,046 active carers are registered with Derbyshire Carers Association. In line with NHS Digital methodology 950 randomly selected carers were sent the survey; 420 responses were received. This response rate of 44.2% is greater than the national response rate of 32.5%.

Derbyshire is similar to England in that most carers are female and aged between 55 and 64 years. Only 10% of all carers who responded are employed full-time and nearly 70% of carers have their own health conditions. Many care for multiple people and children. 47% of carers spend more than 100 hours a week caring; this is higher than the England average.

Physical disability (49.1%) is the most prevalent condition in the people cared for, followed by dementia (42.3%) and then a long-standing illness (41.8%). Those with dementia have increased since 2018/19 (39%) and is a greater proportion than England. Note that the cared for person can have multiple conditions.

### ASCOFS

#### 1D Carer reported quality of life

This is declining nationally over time. However, Derbyshire with a score of 6.7 out of 12 is significantly lower than England (7.3).

#### 1I2 The proportion of carers who reported they had as much social contact as they would like

This has declined 10% since the previous SACE 2018/19, to 19.3%; it is significantly lower than the England average of 28%.

#### 3B Overall satisfaction with social services

Though this decreased slightly since the previous survey, at 41.3% it is higher than England (36.3%), though not significantly.

#### 3C The proportion of carers who report they had been included or consulted in discussion about the person they care for

This indicator, possibly impacted by the Covid-19 pandemic, saw a decline of over 12% since the previous survey (74.1%). 61.5% of carers felt they had been included or consulted compared with England's proportion of 64.7%.

#### 3D2 The proportion of carers who find it easy to find information about services/support

62.4% of Derbyshire carers, who responded, found it easy to find information. This is a decrease from 71% in 2018/19, but slightly higher than the 2021/22 rate for England (57.7%).

### Key findings

Carers report the top five effects of caring are tiredness, stress, depression, disturbed sleep and irritation.

Of the carers who responded, 99% receive support and advice from Derbyshire County Council or other support groups. 3.4%, of those who responded also received training for carers and 1.4% also received support to continue employment.

The Covid-19 pandemic affected carer's wellbeing, health and relationships most.

25% of respondents who completed free text boxes expressed appreciation. However, 50% felt the support received was not adequate for their needs. Access to and ability to navigate the internet and websites was an issue for many carers.

The majority of carers were retired (57.2%) or not in paid work (21.5%). This is noteworthy as most are now below the state retirement age. 19.3% stated they were not in employment because of their caring responsibilities. 44.5% have some level of financial difficulty caused by their caring role.

## Conclusion

The eligible population for the survey is smaller than the number of carers registered with the Derbyshire Carers Association meaning the survey may not be fully representative of Derbyshire's carer population.

The demographic of the carers has changed, with the majority now in the working age category. Caring responsibilities impact the ability to work, with associated impacts on household finances and carer wellbeing.

Derbyshire residents are caring for more people with dementia and carers themselves suffer more mental illness than in comparator areas. Further ways to support those with these conditions should be explored.

Like comparator areas Derbyshire's quality of life score has declined. However, Derbyshire has declined significantly more, the reasons behind this decline need to be understood.

Where carers have praised the support received, this should be reviewed to inform good practice and "what works well".

Two key communication issues were raised throughout the survey:

1. Access and ability to navigate the internet. Given the crucial part the internet plays in everyday life, it is important that those carers who struggle in this respect are not disadvantaged through digital exclusion.
2. Difficulties carers had in obtaining a response from the health and care system which included phone messages not being returned and the unavailability of social workers, GPs and medical services.

Carers cite the importance of being able to access the 'right support', feeling someone cares, knowing how to understand and navigate the health and social care system as factors which would improve their daily lives.

*An easy read infographic summarising this report is included in appendix 2, and will be one of the methods used to inform the public of the SACE 2021/22 findings.*

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# 1 INTRODUCTION

## 1.1 Context

All local authorities with adult social care responsibilities (which includes Derbyshire County Council, or DCC) must carry out a carers' survey (Personal Social Services: Survey of Adult Carers in England or SACE) every 2 years. Managed centrally by NHS Digital, the results are included in official statistics reports and help inform policy decisions both nationally and locally. The latest national survey was conducted in autumn 2021. The survey was due to be conducted in the Autumn of 2020, owing to the Covid-19 pandemic this was postponed to Autumn 2021. The next survey will be conducted in Autumn 2023.

The survey was developed to learn more about the extent to which services received by carers help them in their caring role, to understand more about life outside caring, and also about carers' perception of the services provided to the person they care for. It asks questions about carers' quality of life and the impact that services have on this and collects information on the general health and wellbeing of carers. The data are used to inform a number of Adult Social Care Outcomes Framework (ASCOF) performance measures.

The current population of Derbyshire is 794,600 (2021 Census), 12,046 are actively registered with Derbyshire Carers Association, as of October 2022. The 2011 census indicated there were 92,634 carers living in Derbyshire, the number of carers recorded in the 2021 census has not yet been published<sup>1</sup>. These figures indicate that carers represent a sizable proportion of the local population. The eligible population of carers on Derbyshire County Council's (DCC's) case management system, Mosaic, numbered 2,204 at the time of the data extraction for the SACE 2021-22. These are carers who had received support from DCC in the previous 12 months (September 2020 – September 2021).

## 1.2 The Carer Act 2014 Definitions and Responsibilities

The Care Act 2014 definition of a carer is an adult who provides or intends to provide care for another adult but is not contracted to provide the care or providing the care as formal voluntary work. The term 'cared for' is used to describe the person that the carer supports. Local authorities are required under the Care Act 2014 to assess the support needs of carers of cared for people living in the area where the cared for person is ordinarily resident; this is known as the carers' assessment. In Derbyshire, those carers who are eligible are given a support plan detailing how their needs will be met and may be awarded a Personal Budget of up to £300 per annum.

The Personal Budget is awarded as payment for forms of support designed to meet the identified need. This might include help with household chores (for example, money to purchase a new vacuum cleaner or washing machine), equipment to help the carer maintain social contact (such as a laptop or mobile phone), or access to an activity or club that means the carer is able to care for themselves better (such as gym membership).

Since April 2017, the vast majority of these carers' assessments in Derbyshire have been undertaken by Derbyshire Carers Association (DCA) under contract to DCC. After 12 months, the carer is entitled to a new assessment of their needs and a further Personal Budget. DCA also runs a number of activities and forms of support for carers including emergency planning, support groups, telephone befriending and signposting to other services.

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<sup>1</sup> Expected release 19<sup>th</sup> Jan 2023

## 1.3 The Carer Role

Carers do not automatically think of themselves as such. Often a relative, friend or neighbour, many carers believe they are simply supporting someone who needs their help. The word 'carer' itself is also commonly associated with home care workers or staff in residential homes who provide paid support as a care worker, which adds to the relative reluctance of individuals to adopt the term 'carer' to describe their own role.

Another reason that it is hard for people to think of themselves as a carer is the fact that the carer role can be assumed gradually, with responsibilities increasing sometimes unnoticed by others. Eventually, some carers can find themselves supporting the cared for person full time (and at times 24/7).

Although potentially rewarding, the carer role can also be complex and demanding; it can cover a range of tasks from assisting with medication and meals to personal care (showering, bathing, toileting). Inevitably, a carer's health can be compromised as a result, particularly as their own health and wellbeing often takes second place to that of the cared for person.

## 1.4 Covid-19 Pandemic

On the 23rd March 2020 the UK population was instructed to stay indoors (lockdown) to prevent the spread of the Covid-19 virus. Most workplaces were closed, with only essential services operating. Members of the population who were classed as vulnerable due to health conditions were instructed to isolate (shielding), with arrangements made for deliveries of food, medical supplies and other essential items. The lockdown restrictions eased in the summer of 2020 but were then reinstated nationally twice more (with additional localised restrictions) until the final removal of restrictions on 19<sup>th</sup> July 2021.

The Covid-19 pandemic and associated lockdowns had significant impact on the carer population of Derbyshire as many support networks, respite centres and groups ceased to function during that time period. Where carers supported someone outside of their home, they felt unable to continue the support if they or the cared for person was classed as vulnerable. If they cared for a vulnerable person within the home, the entire household was obliged to isolate completely also. The SACE 2021 – 22 survey asked additional questions about the impact of Covid-19 and DCC added an extra question to gain further understanding of the impact on carers' lives.



## 2 METHODOLOGY

The SACE methodology is determined by the guidance document issued by NHS Digital which ensures a uniform approach across all local authorities. This also means that there can be a large degree of confidence in the reliability of the SACE results and also in the ability to generalise the findings to the broader population of carers in Derbyshire. Being a paper survey, the SACE 2021-22 was distributed in two 'waves' in October 2021 to a sample of 950 carers selected at random from the DCC database of carers who had received support in the previous 12 months.

The Carers' Survey contained 35 questions, including questions about the impact of Covid-19. The data for this report were extracted from NHS Digital, a number of questions were removed due to a risk of data being identifiable. The rest of the survey covered demographic information including age, gender and ethnicity, and a range of detailed questions to provide insight into the caring experience. The full survey can be viewed online.

Responses collected for the carers survey are also used to populate five of the measures within the Adult Social Care Outcomes Framework (ASCOF), these are:

- 1D: Carer-reported quality of life (Q7-12).
- 1I2: The proportion of carers who reported that they had as much social contact as they would like (Q11).
- 3B: Overall satisfaction of carers with social services (Q4).
- 3C: The proportion of carers who report they have been included or consulted in discussions about the person they care for (Q18).
- 3D2: The proportion of carers who find it easy to find information about support (Q16).

For full details and a copy of the questionnaire visit the [NHS Digital website](#)

In addition to the data extracted from NHS Digital results, DCC's Public Health Knowledge and Intelligence Team undertook thematic analysis of the comments input by survey respondents into "free text boxes". Where relevant to a question a summary of this analysis is included below.

## 3 RESULTS

During October and November 2021, a survey was sent to a random sample of 950 Derbyshire carers. During November, reminders were sent out to those who had not responded. In total, 420 completed questionnaires were returned, representing a response rate of 44.2%.

### 3.1 Demographics of Carer and Cared for Person

#### 3.1.1 Age of carers

Of the 950 carers sent a survey, age was recorded for 914. When grouped the majority of carers (59.3%) were aged 18 – 64 years. Derbyshire had a lower percentage (39.6%) of 65+ years old carers compared to England, East Midlands and CIPFA, figure 1. Further breakdown of the age groups by gender within Derbyshire can be seen in figure 2. Two thirds of the respondents were female (69.5%). Carers within age groups under 84 years were more likely to be female, whereas carers over the age of 85+ years were more likely to be male. The largest percentage of carers were female and in the 55 to 64 years age group (18.1%).

Figure 1: Age of carers, grouped by 18 – 64 years and 65 years +

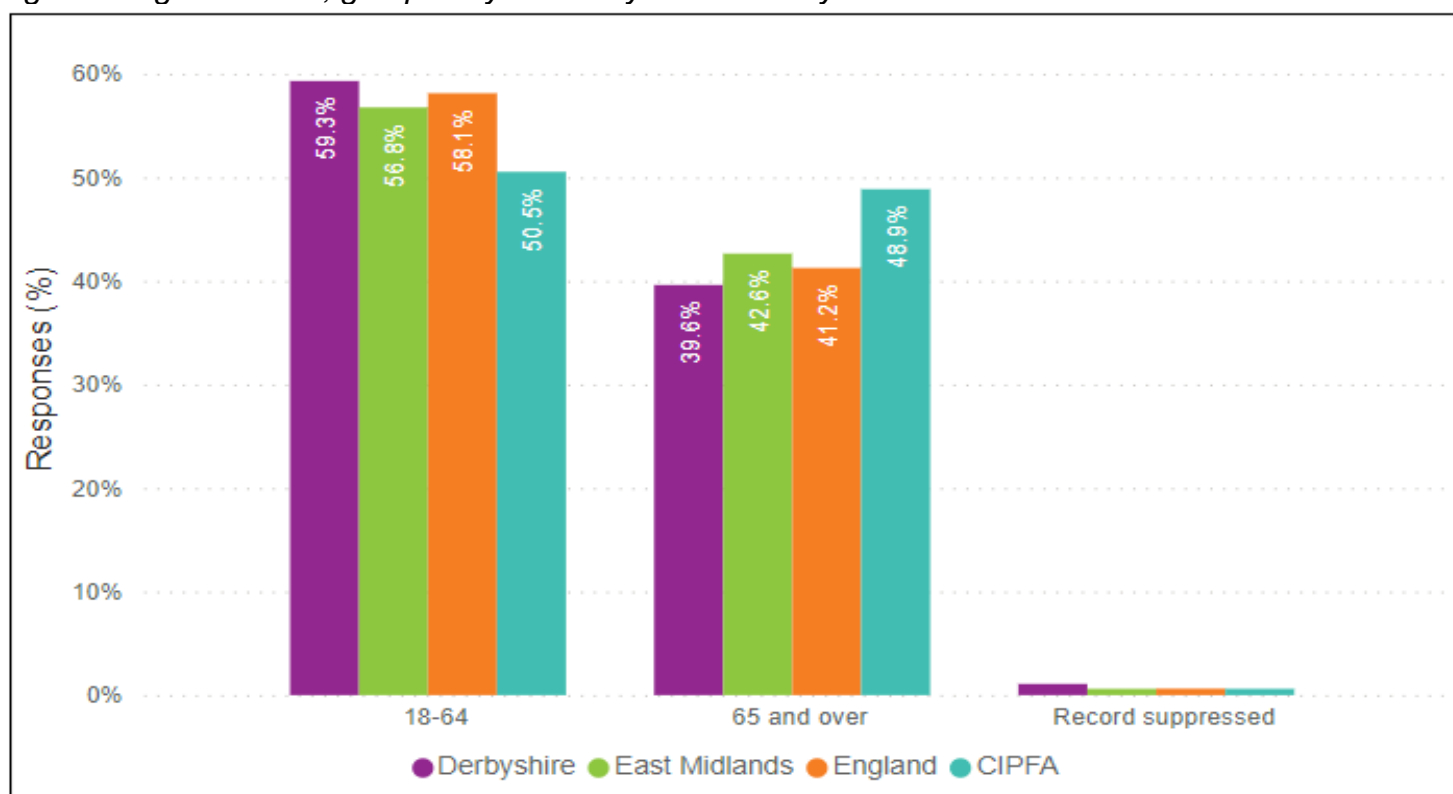
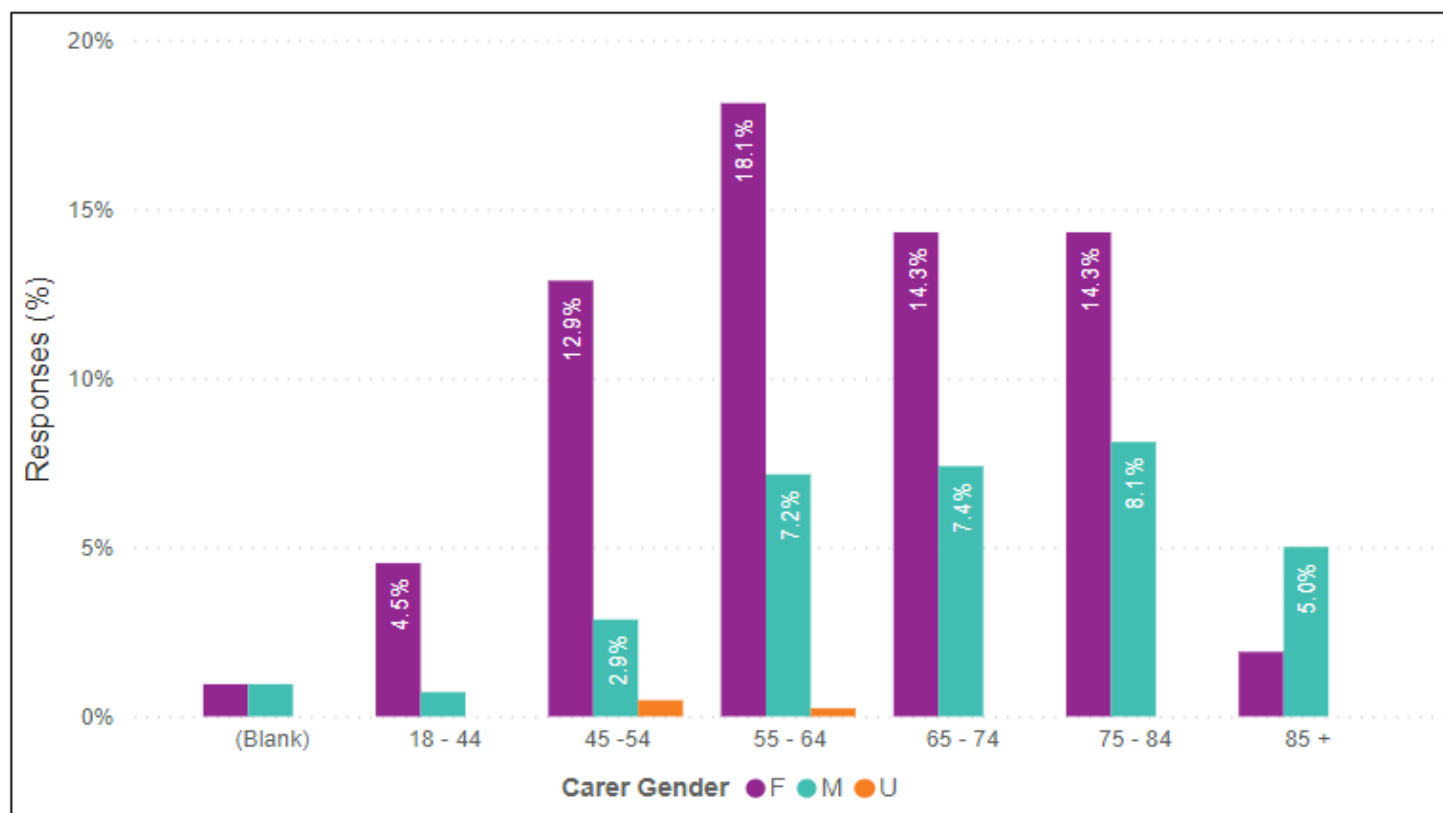


Figure 2: Derbyshire age of carers by gender

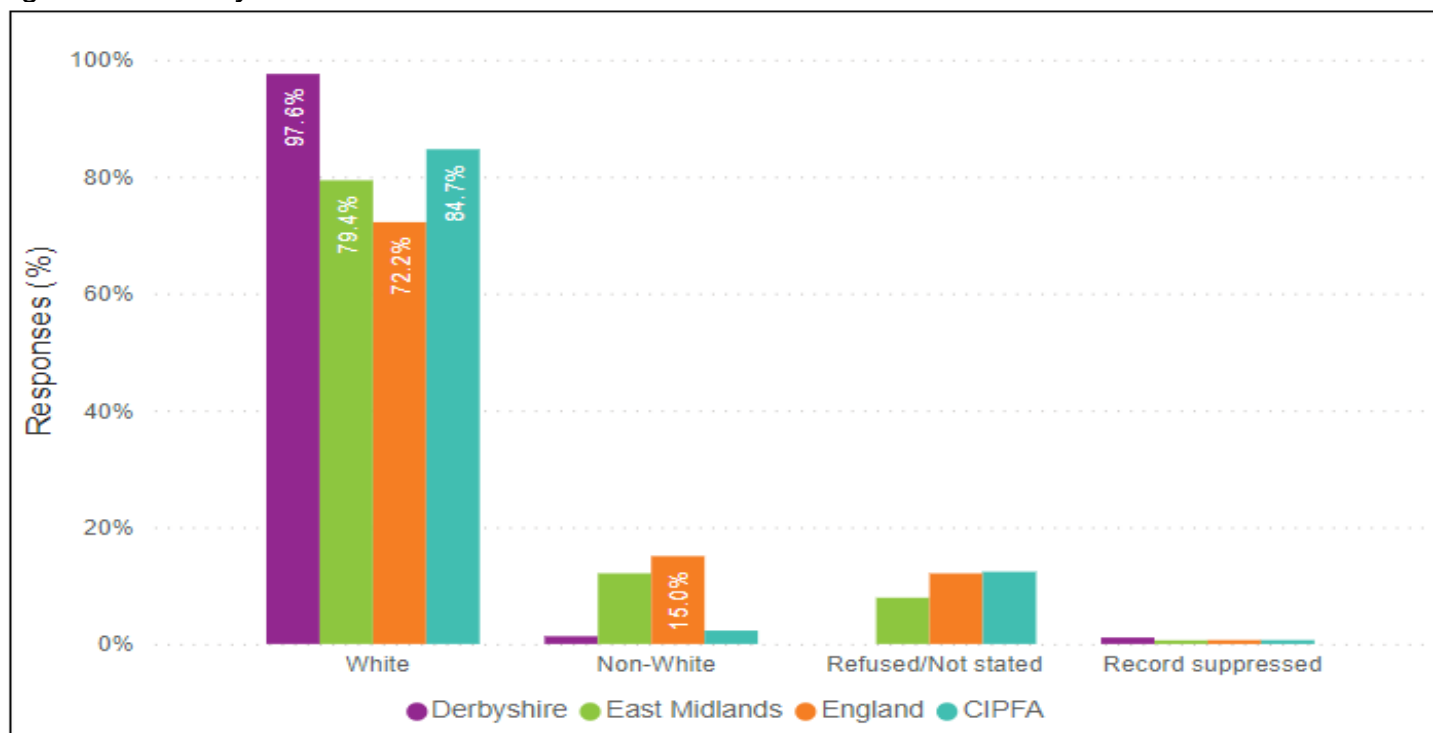


F = female, M = male, U = undefined

### 3.1.2 Ethnicity of carers

The results show that the majority of the respondents were of a white ethnic background (97.6%), this is higher than the comparators.

Figure 3: Ethnicity of carers



### 3.1.3 Age of person cared for

Of the 420 responses received, 419 provided the age of the person they cared for. When grouped the majority of the cared for people were over 65 years old (64.7%), figure 4. This is similar to the figure for England, East Midlands and CIPFA comparators. Within Derbyshire the highest percentage of cared for people are women aged 85 years and older (16.4%), as shown in figure 5.

Figure 4: How old is the person you care for?

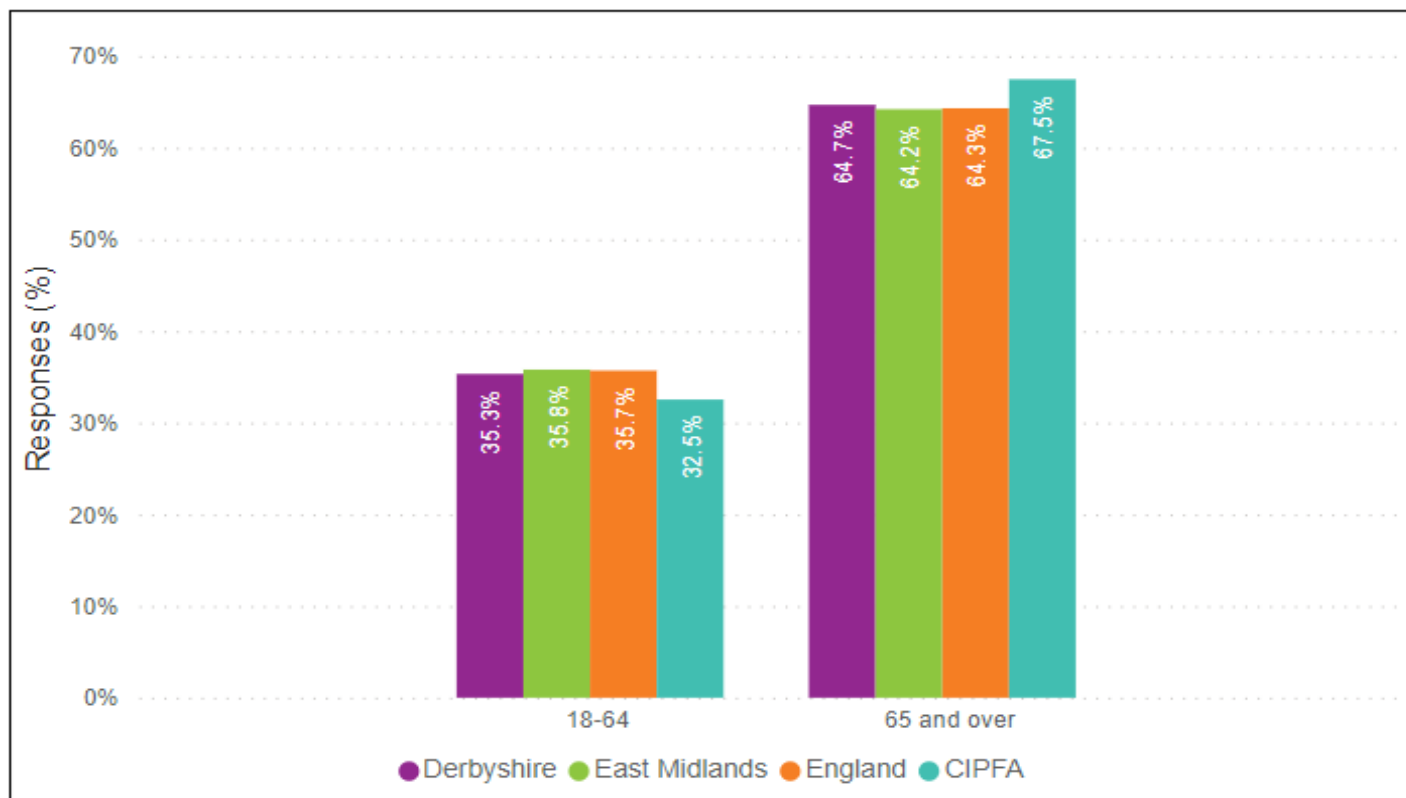
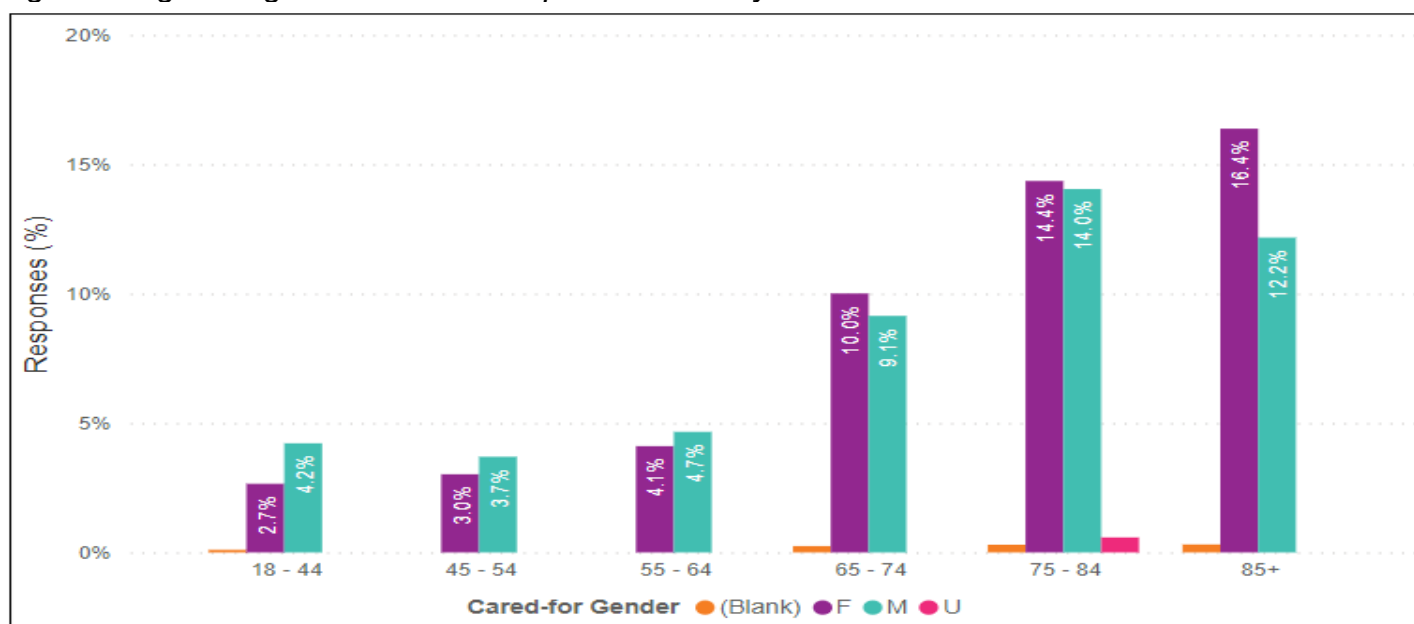


Figure 5: Age and gender of cared for person in Derbyshire

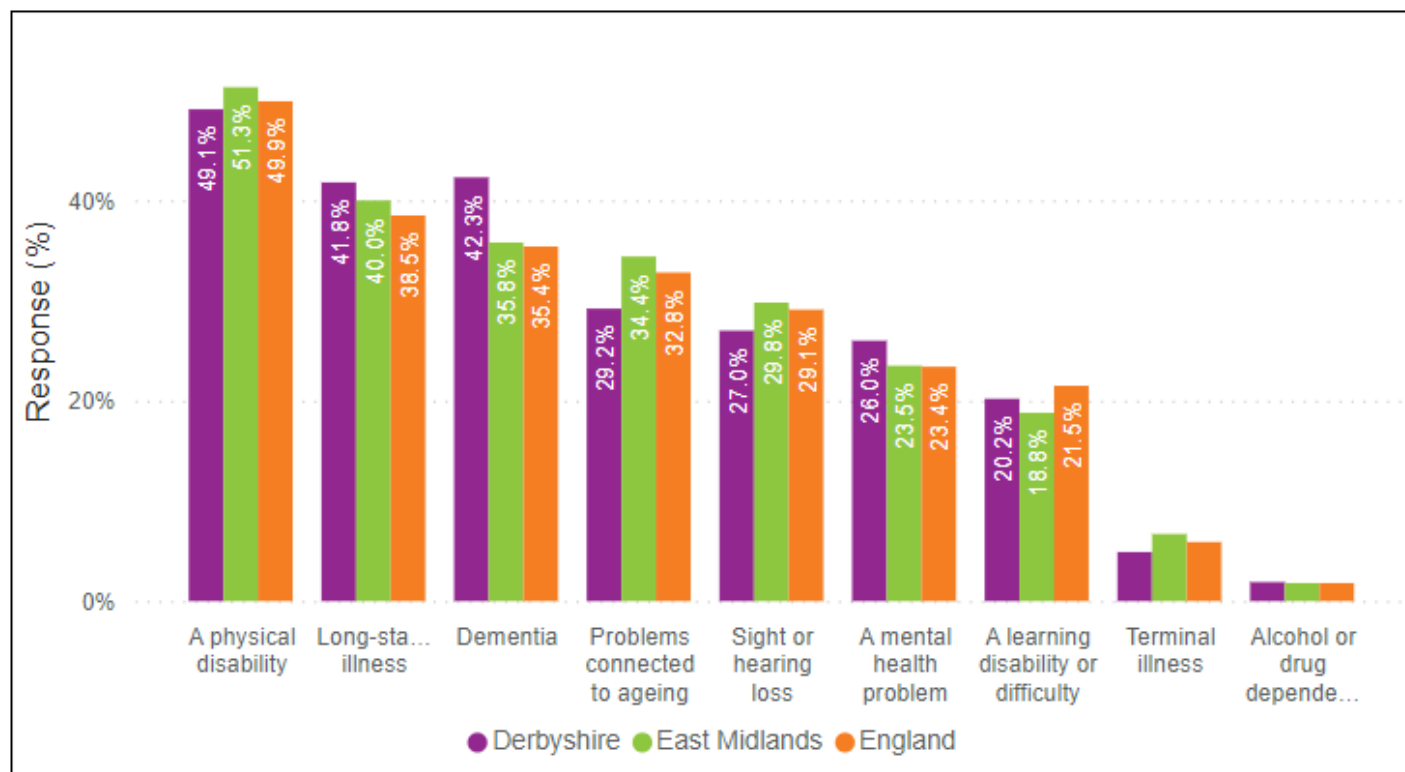


F = female, M = male, U = undefined

### 3.1.4 Support needs of the cared for person

The needs of those being cared for are likely to be many and complex. Survey respondents reported that the most prevalent conditions of the cared for were physical disability (49.1%), long standing illness (41.8%) and dementia (42.3%), figure 6. Dementia conditions were reported as a greater proportion in Derbyshire than in the comparator areas of England and the East Midlands.

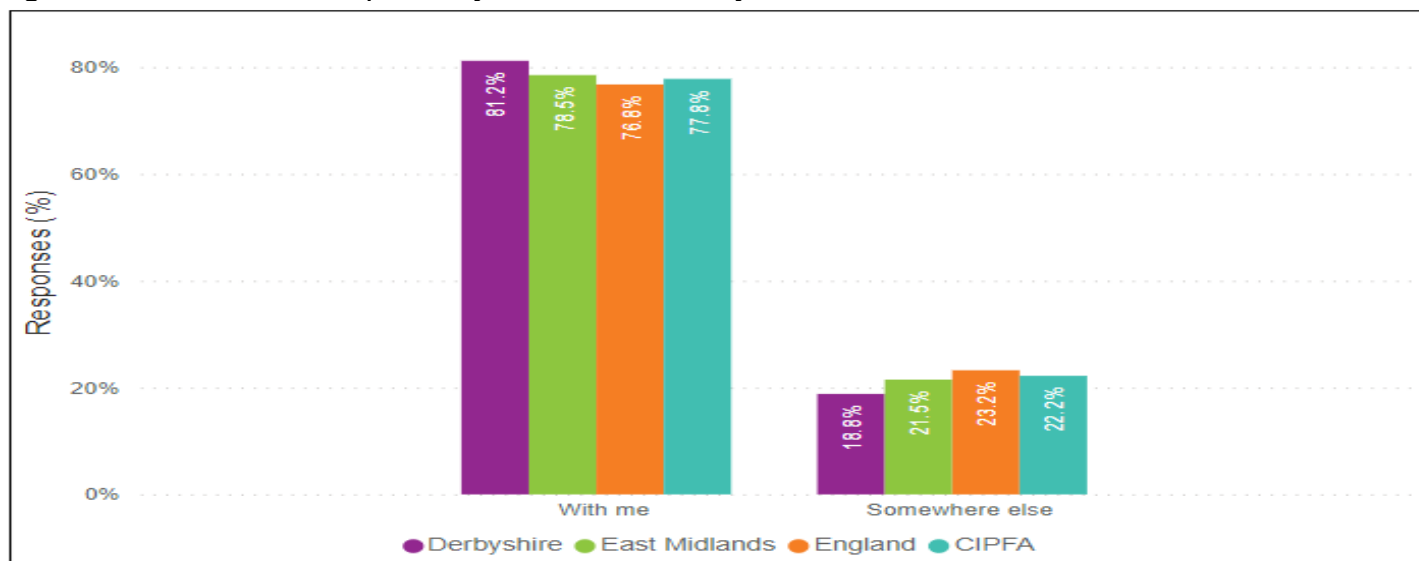
Figure 6: Support needs of the cared-for person



### 3.1.5 Where does the person you care for live?

Figure 7 shows that the majority of Derbyshire carers live with the person that they care for (81.2%). This is similar to the comparators.

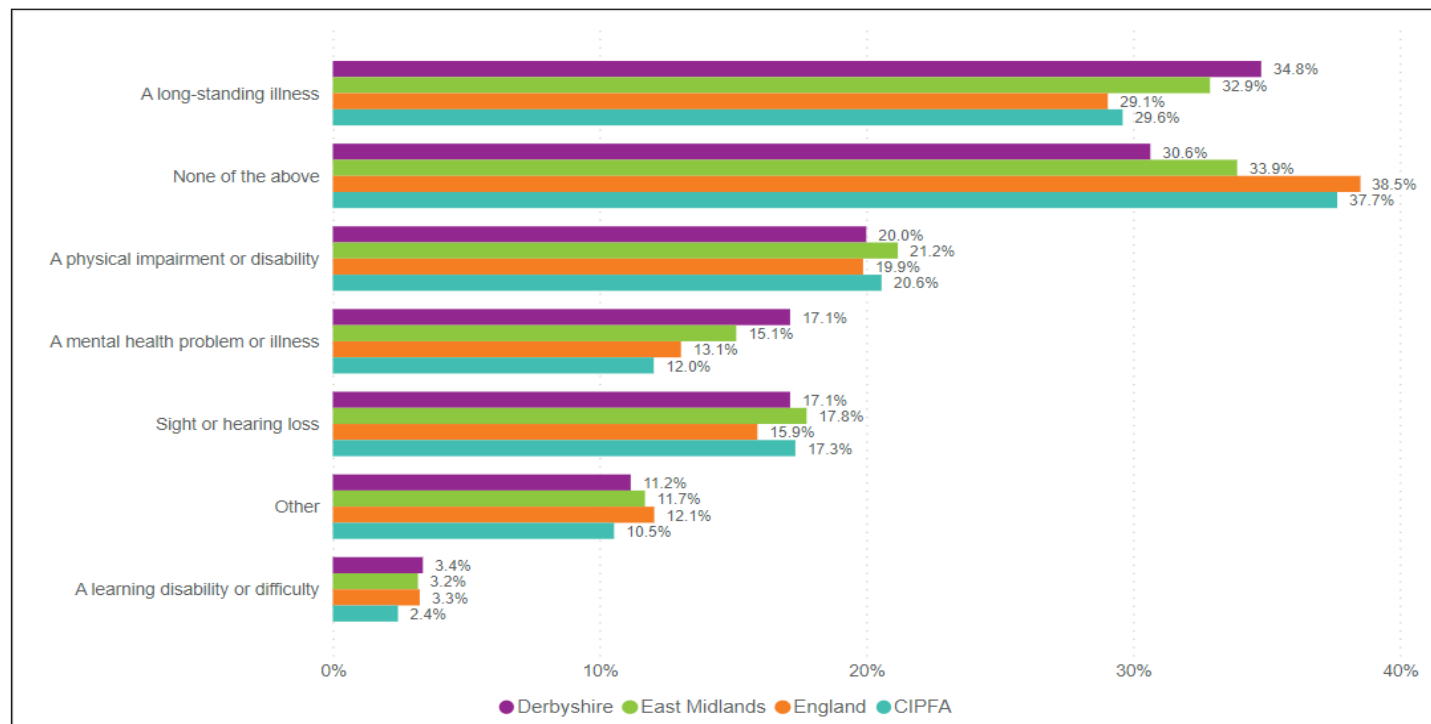
Figure 7: Where does the person you care for usually live?



### 3.1.6 Carer health issues

As well as dealing with the health issues of the person they care for, carers may also have their own health problems. Figure 8 shows the health conditions that carers self-reported. One third (34.8%) reported a long standing illness, higher than the comparators and 17.1% said they had a mental health problem, again higher than the comparators.

Figure 8: Do you have any of the following?



It is worth noting that carers may also be caring for more than one person - which is not recorded in the survey – as well as children. 12.3% of the Derbyshire carers who responded to the survey also have parental responsibility for children.

Carers could ask for help in completing the form, though this could influence the results, few (5.4%) Derbyshire carers needed help, less than the comparators, England (8.9%)



## 3.2 Adult Social Care Outcomes Framework (ASCOF)

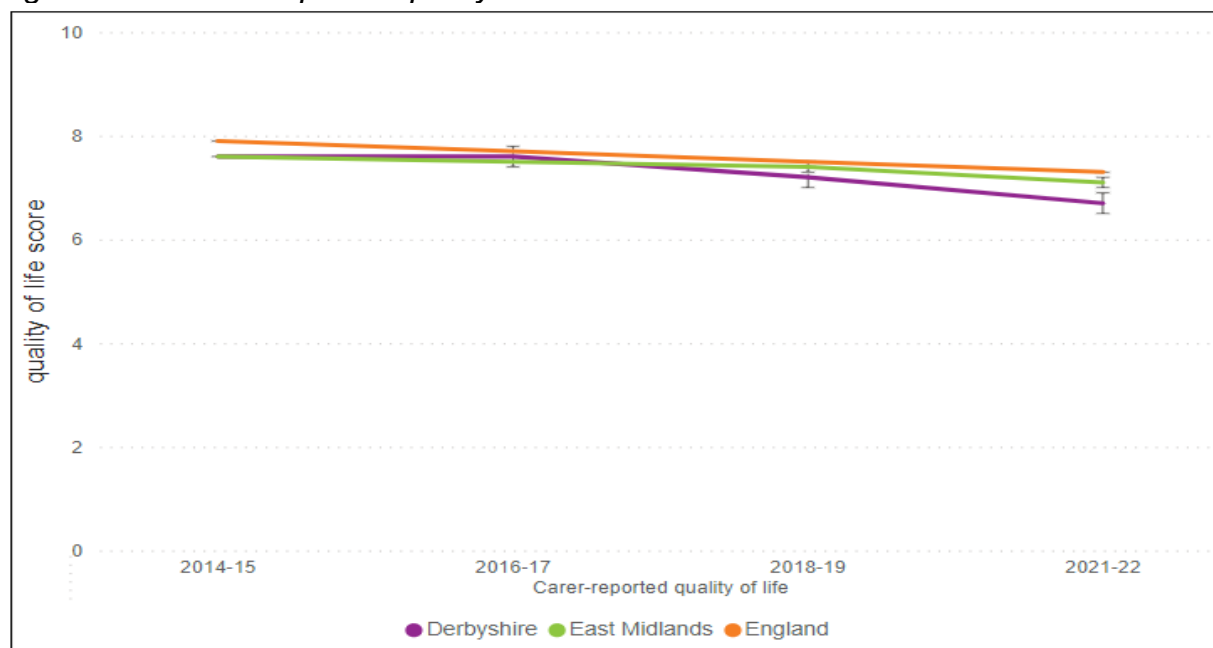
The Adult Social Care Outcomes Framework (ASCOF) measures how well care and support services achieve the outcomes that matter most to people. The measures are grouped into five domains which are typically reviewed in terms of movement over time. Below is an overview of the five ASCOFs calculated from the Survey of Adult Carers in England. (A table containing ASCOF figures can be found in the appendix).

### 3.2.1 1D Carer reported Quality of Life Score

Quality of life in carers is measured by the responses to 6 individual questions in the survey relating to overall quality of life. They cover occupation, control, personal care, safety, social participation and encouragement and support. The carer reported quality of life score is ASCOF measure 1D; the average score for Derbyshire in 2021/22 was 6.7, this was significantly lower in comparison to the average for England (7.3), and East Midlands (7.1), figure 9. The scores for the comparators are also declining over time.

It is important to remember that all the health impacts and questions relating to quality of life are self-reported and highlights the wide variety in the experience of carers. However, Derbyshire carers report more mental health conditions than the comparators which could impact on the quality of life score.

Figure 9: 1D Carer reported quality of life score

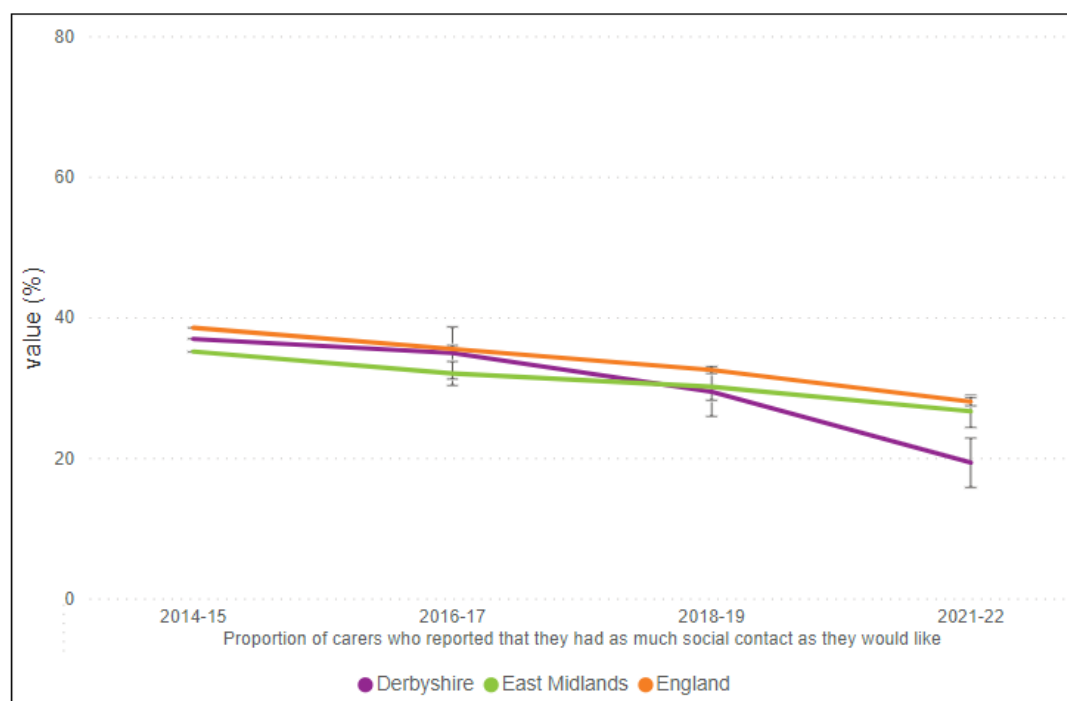


### 3.2.2 112 The proportion of carers who reported that they had as much social contact as they would like

410 out of 420 carers answered this question. 19.3% felt that they had as much social contact as they would like. This was a decrease of 10.1% from SACE 2018/19 result (29.4%). This figure should be considered with reference to the restrictions and concerns raised by the Covid-19 pandemic, particularly around vulnerable people being asked to shield and families protecting their relatives.

Derbyshire has a significantly lower proportion of carers reporting that they had enough social contact compared to the average for England (28%) and East Midlands (26.6%), figure 10.

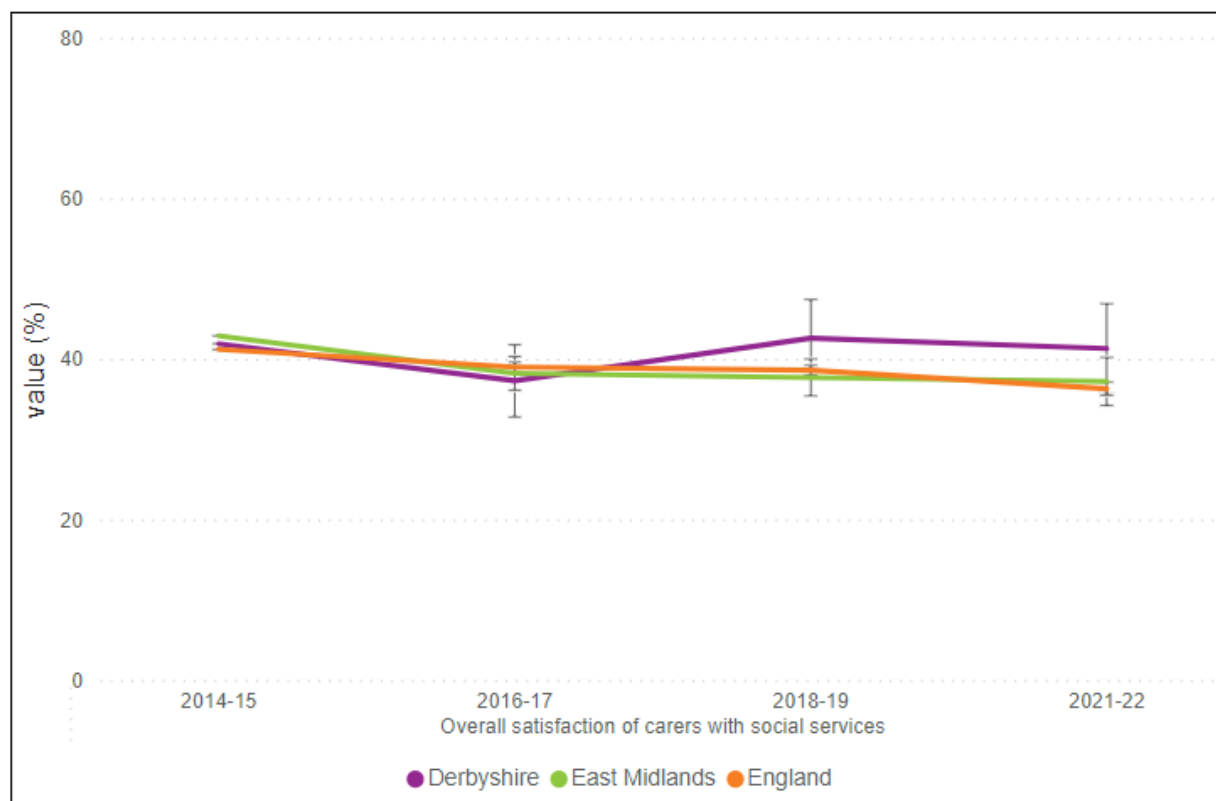
Figure 10: 112 Carers who had as much social contact as they would like



### 3.2.3 3B Overall satisfaction of carers with social services

Of the 265 out of 420 carers who responded to this question, 41.3% felt satisfied with social services. This was a slight decrease from 2018/19 (42.6%). However, it was higher, though not significantly, than the England (36.3%) and East Midlands (37.2%) satisfaction percentage, figure 11.

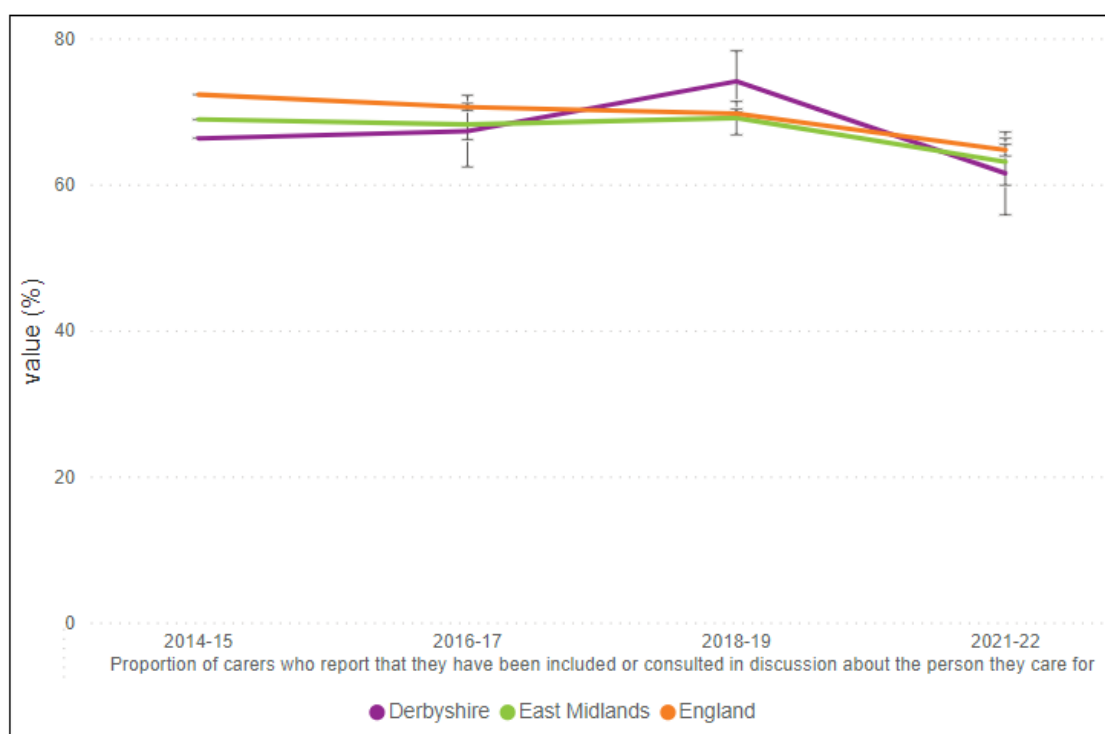
Figure 11: 3B Overall satisfaction of carers with social services



### 3.2.4 3C The proportion of carers who report that they had been included or consulted in discussion about the person they care for

Of the 250 out of 420 carers who answered this question 61.5% felt that they had been included or consulted in discussions about the person they care for. This was a large decrease from 2018/19 (74.1%), and again could be explained by services shutting down due to the Covid-19 pandemic. However, this means that nearly 40% of carers currently do not feel included or consulted. The average for Derbyshire was lower, though not significantly, compared to the average for England (64.7%), figure 12.

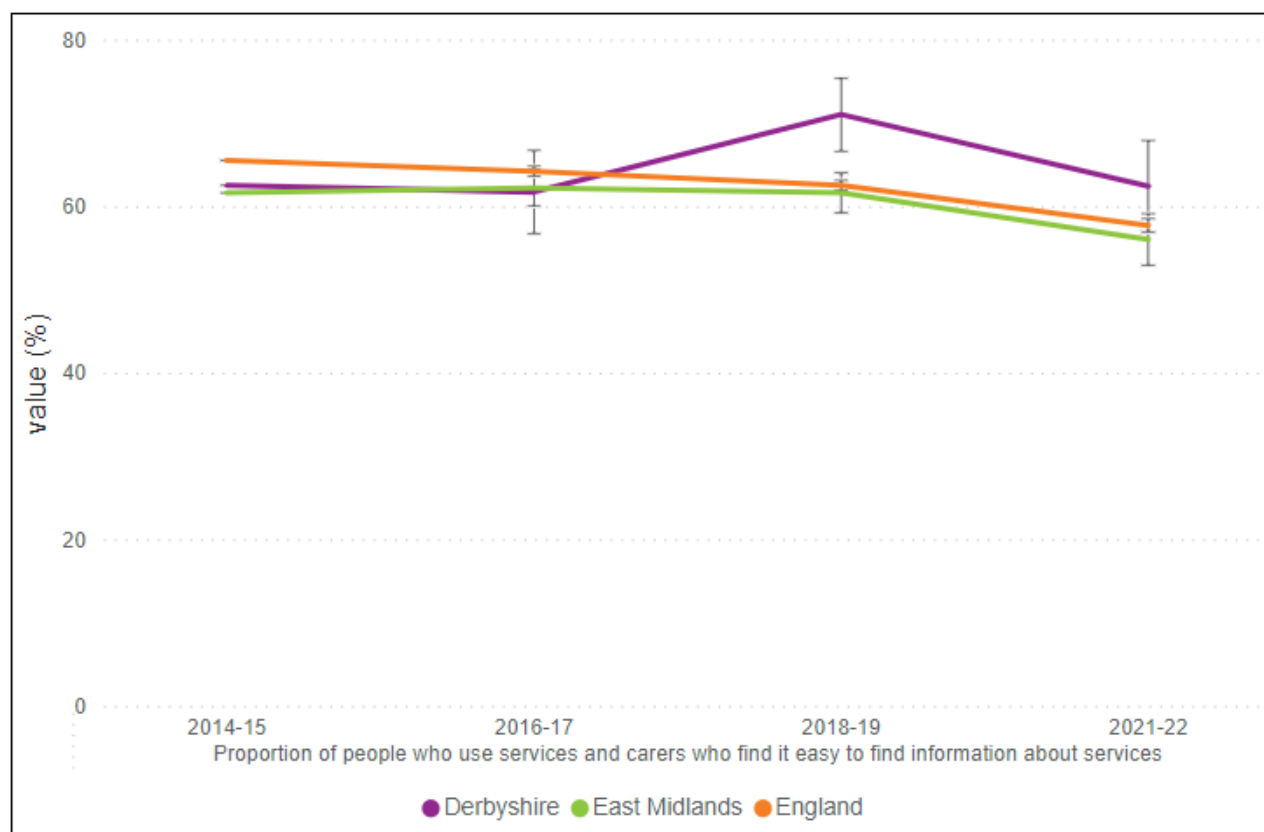
*Figure 12: 3C Carers who report being included or consulted in discussion about the person they care for*



### 3.2.5 3D2 The proportion of carers who find it easy to find information about services/support

265 of the 420 carers had tried to find information or advice. Of these, 62.4% found it easy to find information about services/support. This was a decrease from 2018/19 (71%). However, the Derbyshire percentage was higher, but not significantly, when compared to the average for England (57.7%), figure 13

Figure 13: Proportion of carers who find it easy to find information about services/support



### 3.3 Caring role and Impact

Caring for others has a significant impact on the carer's life, this section describes that impact.

#### 3.3.1 Tasks completed for the cared for person

The type of support provided by carers can vary greatly, from giving medicines to providing physical and emotional support. Figure 14 shows the types of support/activities that respondents usually provide for the person they care for. Carers reported “*Other practical help*” as the most prevalent support undertaken, this includes tasks such as preparing meals, doing the shopping, housework and liaising with health services. There were high rates across the majority of activities/support, highlighting that carers are likely to provide support in multiple areas

Figure 14: Over the last 12 months, what kind of things did you usually do for the person you cared for?



Derbyshire carers were also given the option to elaborate further on the support they provided. 16% of carers took this opportunity and responses were analysed into 5 themes, table 1, which further describe the complex and relentless role of the carer.



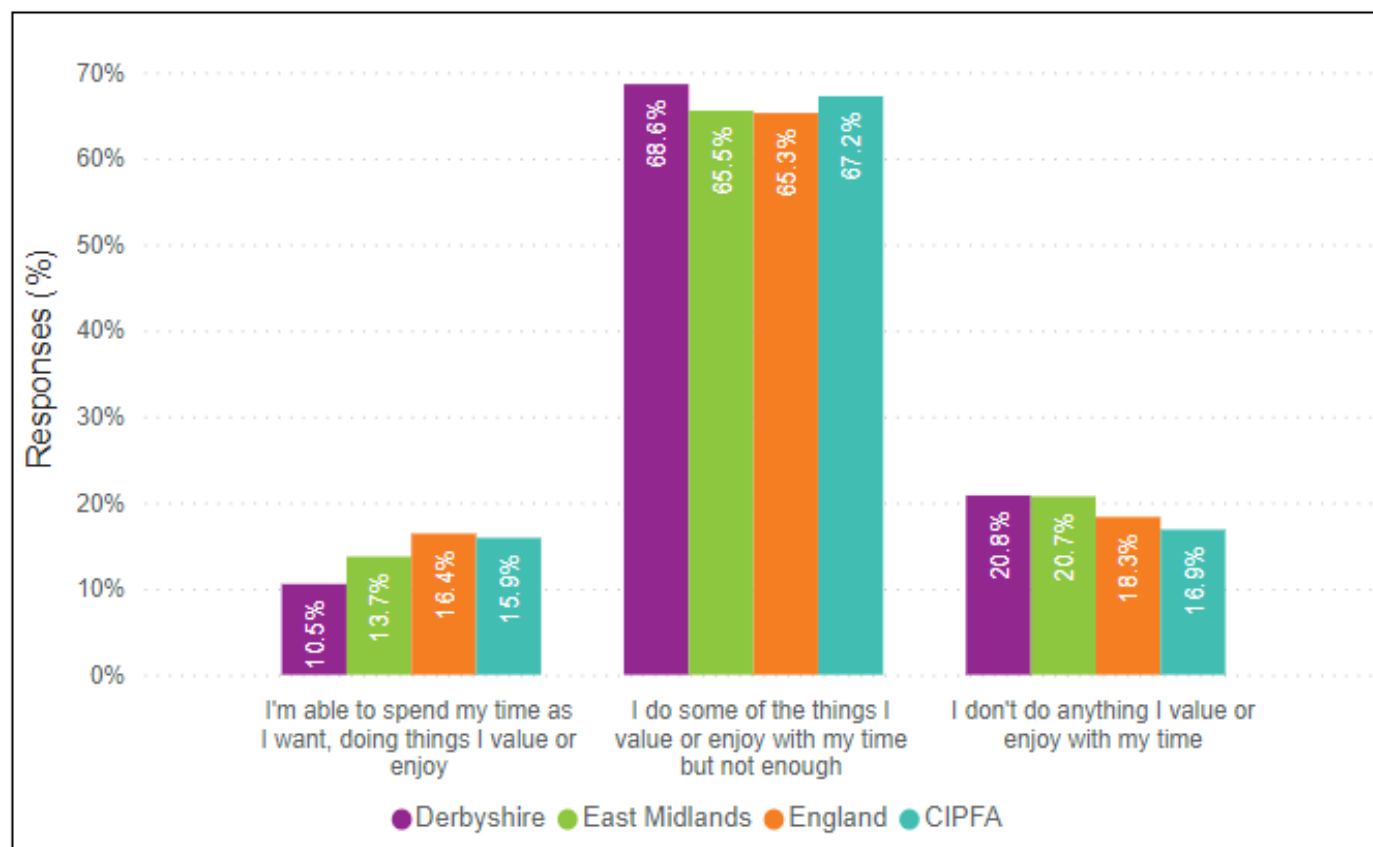
*Table 1: Support provided by carers for cared for person themes*

Theme	Quote
Constant support	<i>"I do everything 7 days, 24 hours" "Everything to do with his daily life"</i>
Physical health and support	<i>"Clinical needs including tracheostomy care, peg feed care, suction to keep airway clear, oxygen support, ventilator support, physiotherapy"</i>
Positively influencing mental wellbeing	<i>"Being strong emotionally not showing fear" "Making sure our friends visit him".</i>
Support with daily activities	<i>"Reminding to wash, clean teeth, get haircut, cut nails, change bedding, needs support when gets tremors, unable to work safely" "Anything technical e.g. using TV appliances (microwave)"</i>
Tracking their health	<i>"Monitor health, e.g., regular frequent blood pressure &amp; pulse. Liaise with medical professionals e.g., side effects of medication. Changing convene catheter".</i>

### 3.3.2 How carers spend their time

Carers were asked how they spent their time and whether they have enough time to do the things they value and enjoy. Figure 15 shows that only 10.5% of carers were able to spend their time as they want, to do the things they enjoy and value. This is less than the value for England (16.4%). Over 20% of carers said they do not find the time to do anything they enjoy or value, this is similar to the carers across the East Midlands region.

Figure 15: Which of the following statements best describes how you spend your time?



### 3.3.3 How much control carers felt they had over their daily life

The majority of carers (66.3%) responded that they have some but not enough control over their daily lives. However, 19.9% said they had no control of their daily life, this was higher than the comparators, figure 16. Only 13.8% responded that they had as much control over their daily life as they wanted, this is lower than the comparators.

It is also worth noting that 56.6% of carers felt they were neglecting themselves or sometimes felt they did not have the time to look after themselves (figure 17), this is higher than the comparators.

Similarly, most carers (80.7%) did not feel they had enough or any social contact, figure 18. Again, this was more than the comparator areas.

Figure 16: Control over daily life

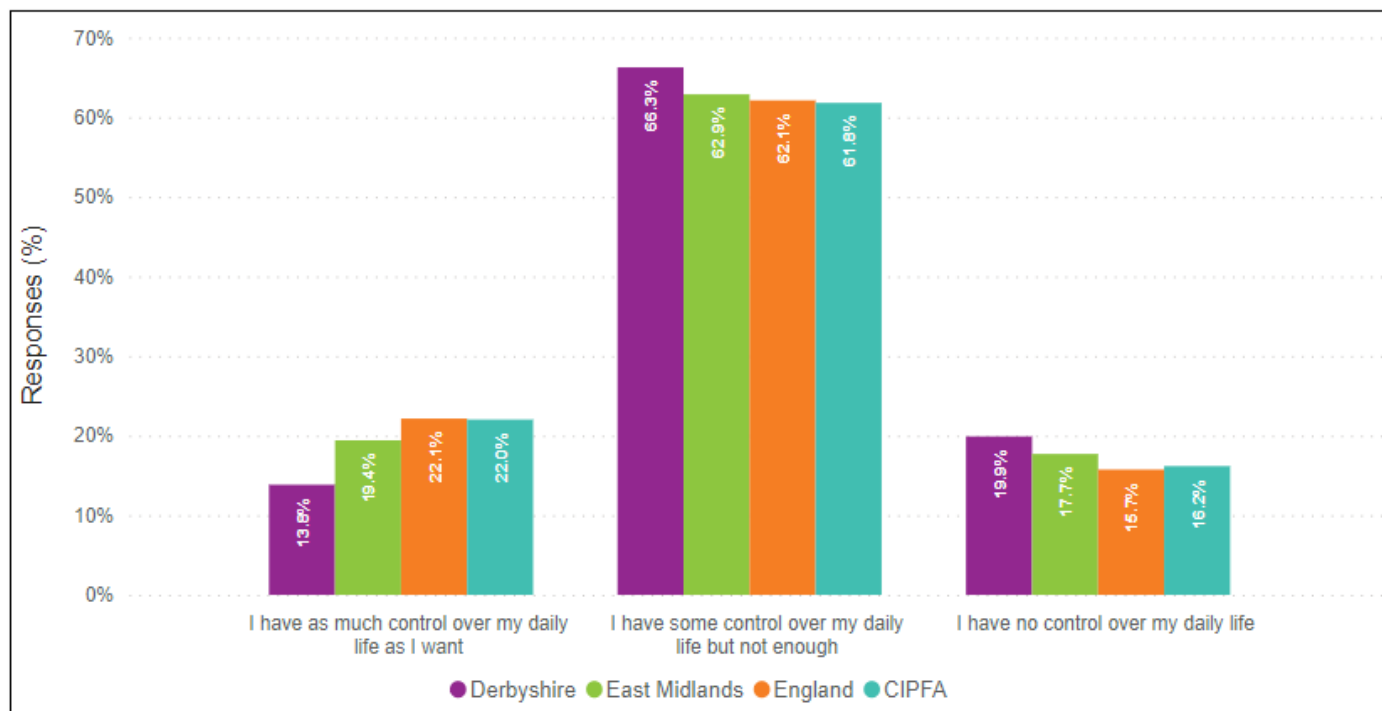


Figure 17: Thinking about how much time you have to look after yourself

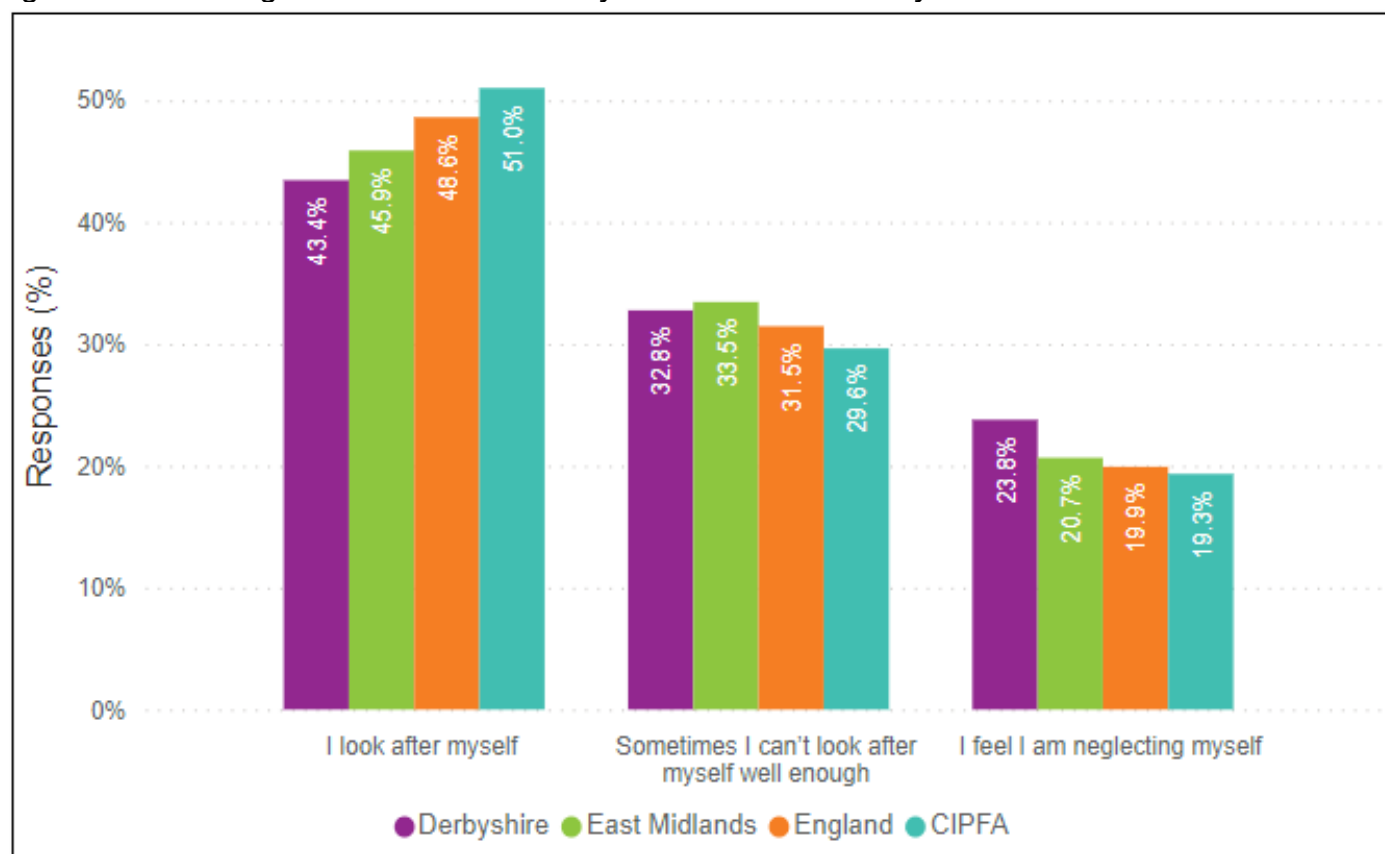
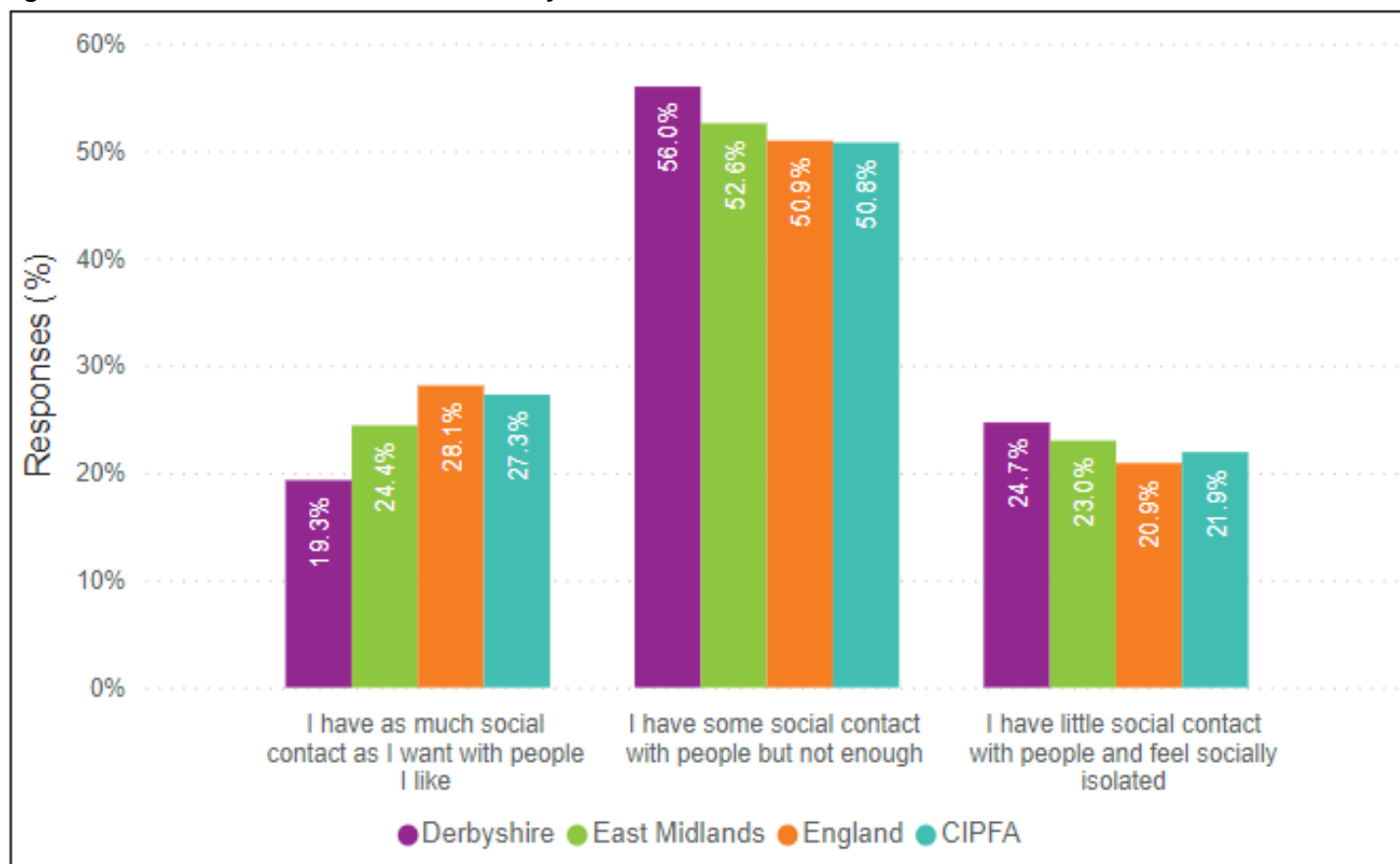


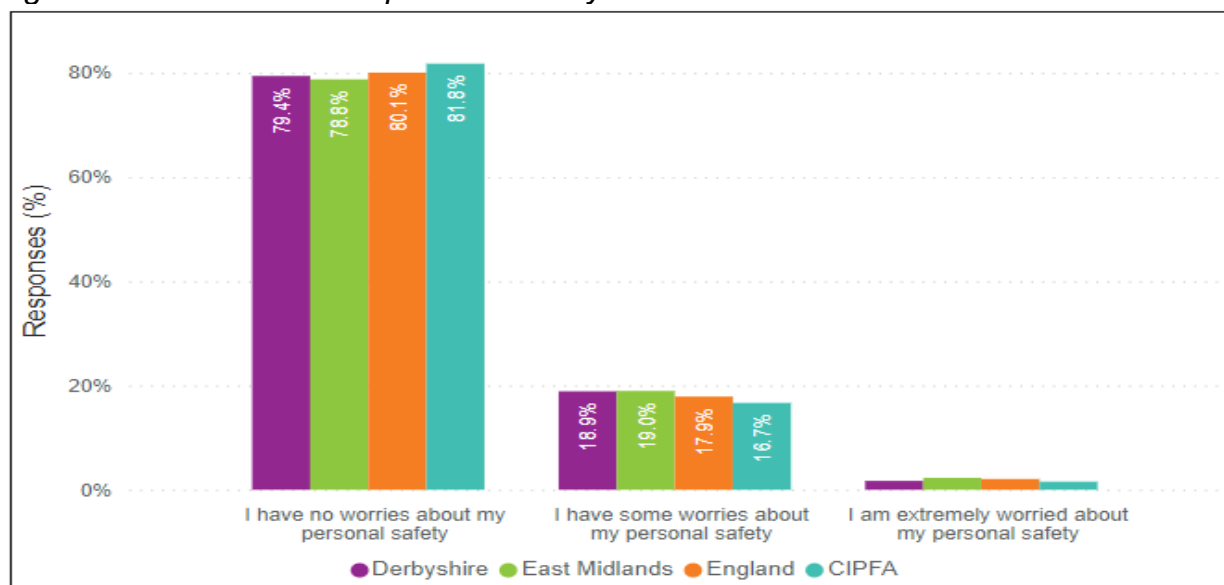
Figure 18: How much social contact do you have?



### 3.3.4 Carers Personal Safety

When asked about their personal safety, the majority had no concerns, however a percentage (18.9%) had some worries and 1.7% were extremely worried, figure 19. In total 21 safeguarding concerns were followed up by the Commissioning Manager (Carers & Advocacy).

Figure 19: Concerns about personal safety



### 3.3.5 Impact that Caring has on the Carer

Figure 20 illustrates the impact that caring has on the carer, with many carers selecting multiple responses. The chart shows that Derbyshire carers are suffering more from the impacts of caring than carers across England, the East Midlands and the CIPFA, particularly with reference to disturbed sleep and feeling tired; stress, irritableness & depression; and physical strain such as back ache.

Over a fifth of carers (22.3%) have been caring for someone for over 20 years, however the majority (57.8%) having been caring for more than one year but less than 10 years, figure 21.

Figure 20: Impact of caring

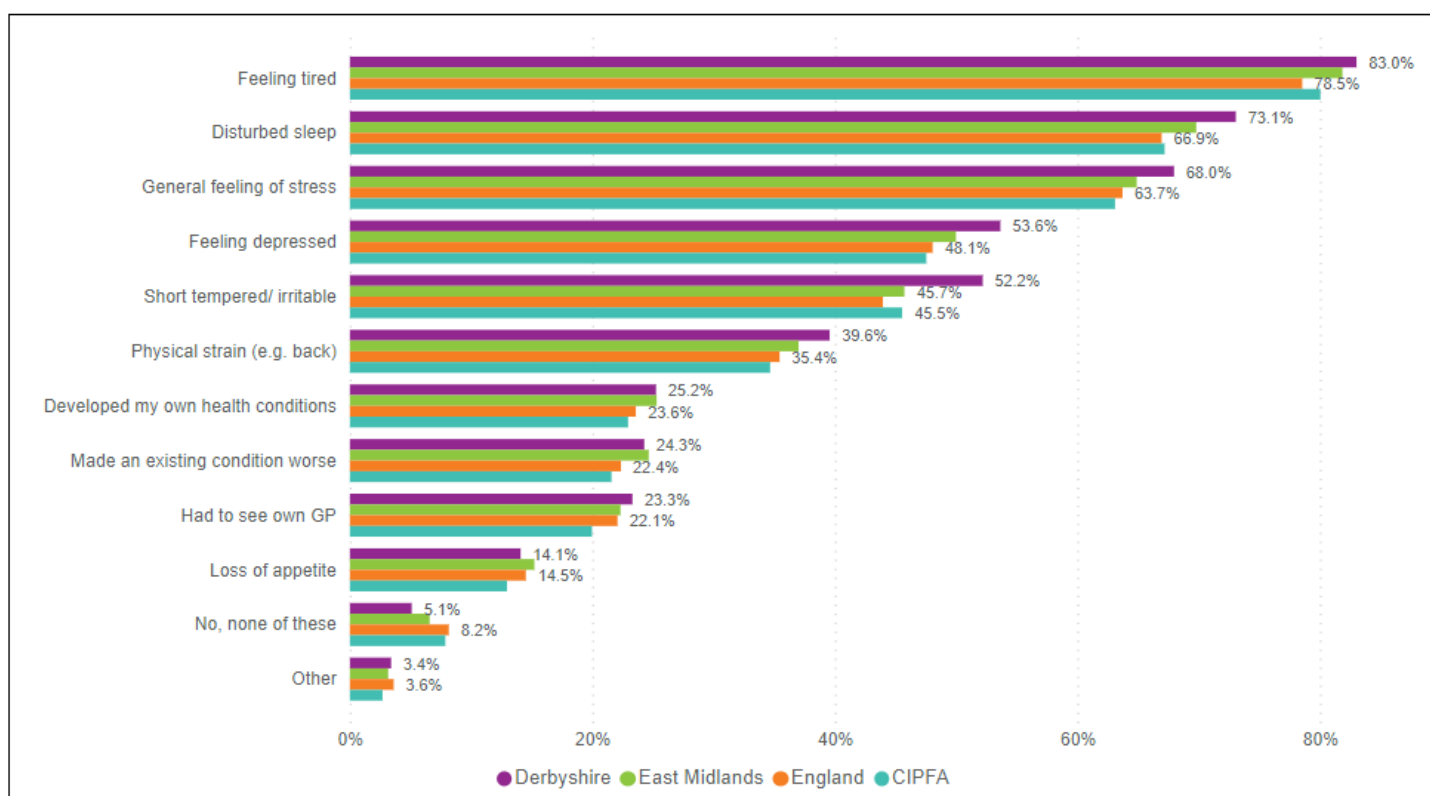
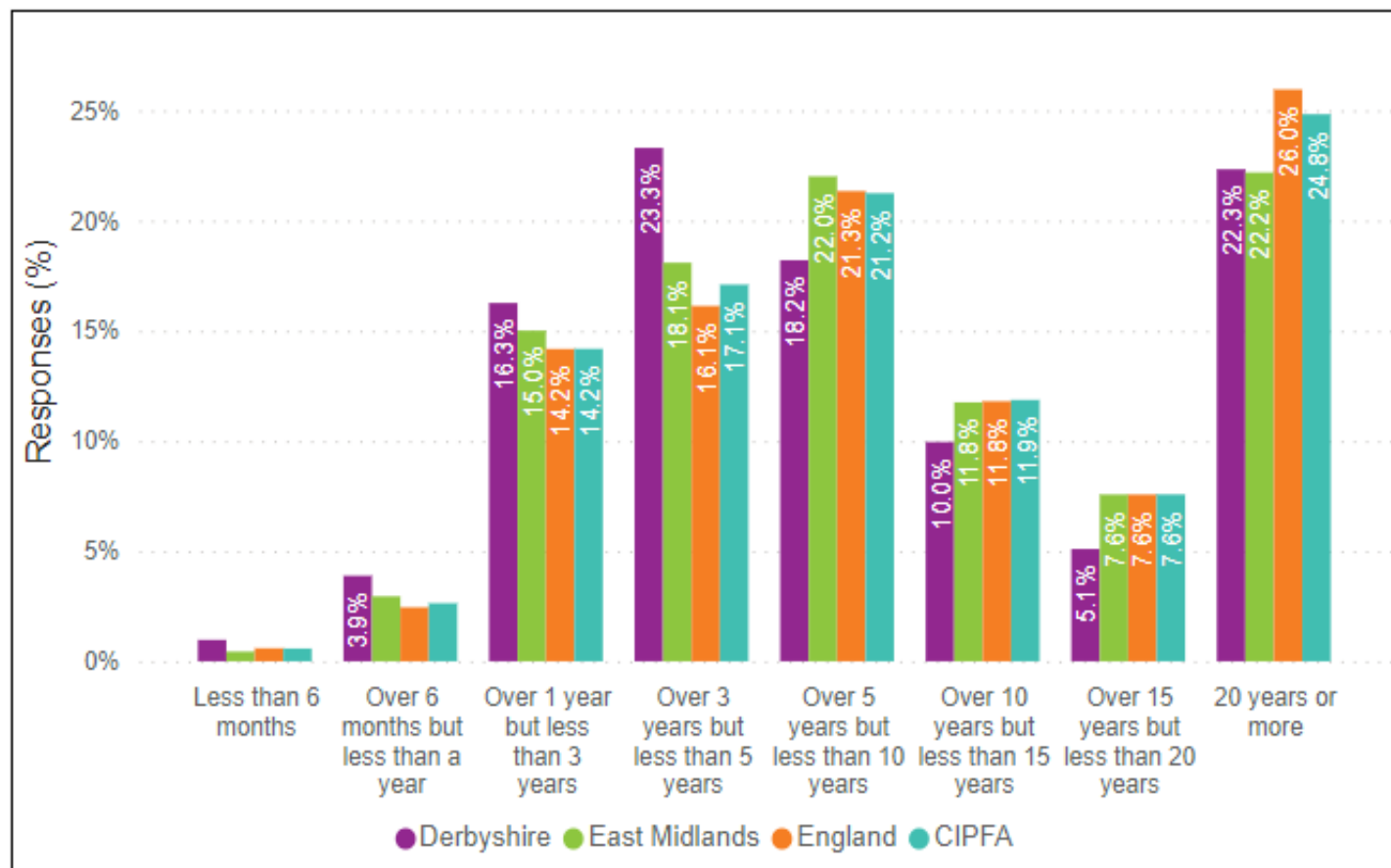


Figure 21: Length of time caring

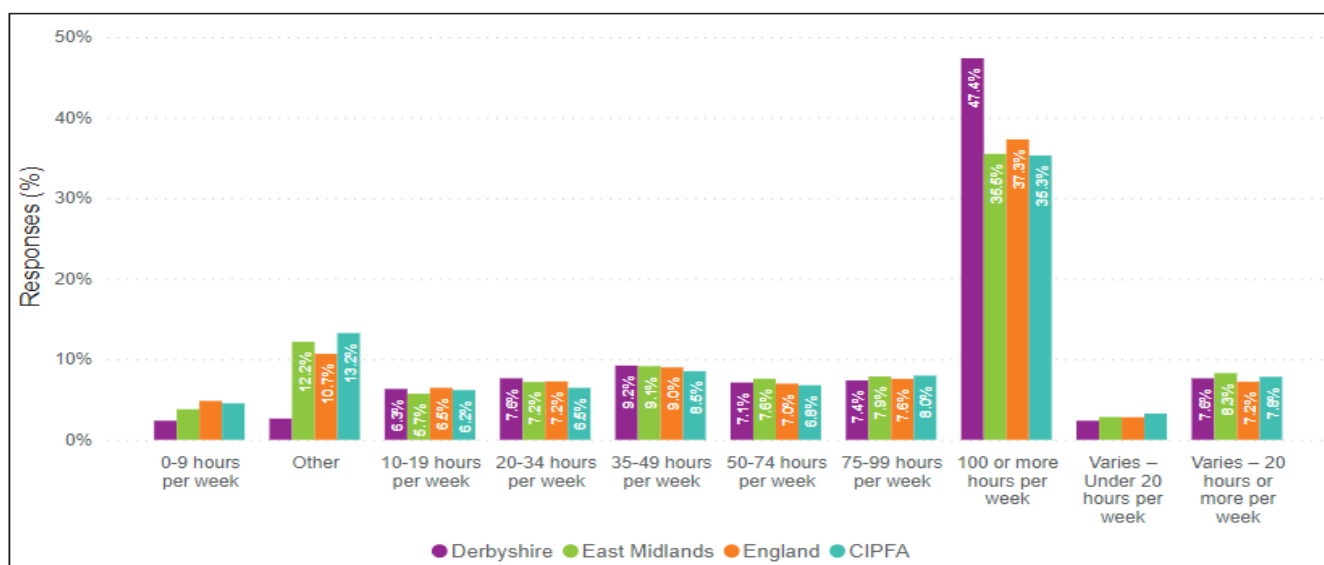


### 3.4 Work Life Balance

#### 3.4.1 Time spent caring per week

47.4% of Derbyshire respondents spend 100 or more hours per week on their caring duties. This is a larger proportion than in comparator areas, as illustrated in figure 22.

Figure 22: Hours per week spent caring





### 3.4.2 Employment Status

Figure 23 shows that the majority of carers were retired (57.2%). This was similar for comparators. Figure 24 shows that the majority of carers were not in paid employment for other reasons, such as being retired (54.8%). Again, similar to the comparators.

Figure 23: In addition to your caring role, please tell us which of the following applies to you?

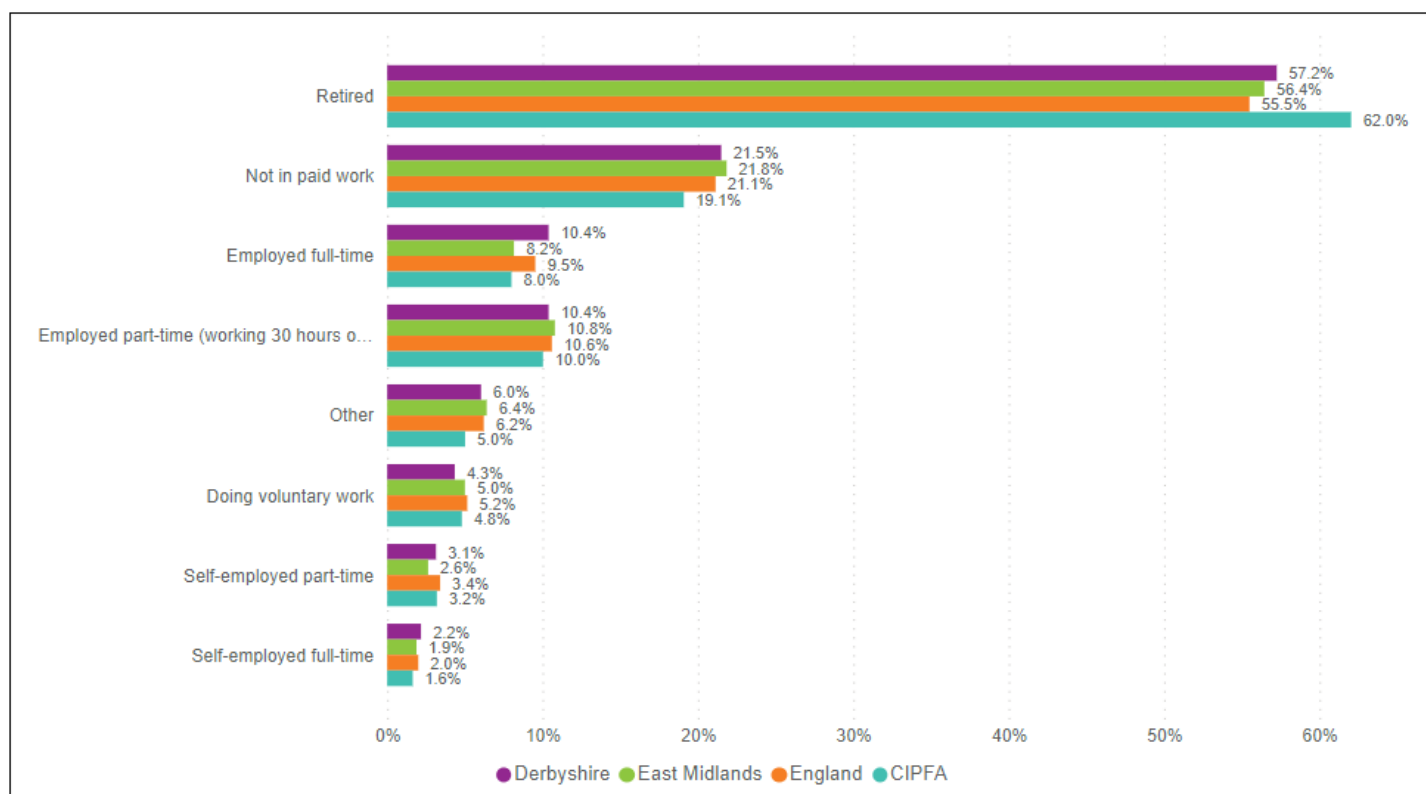
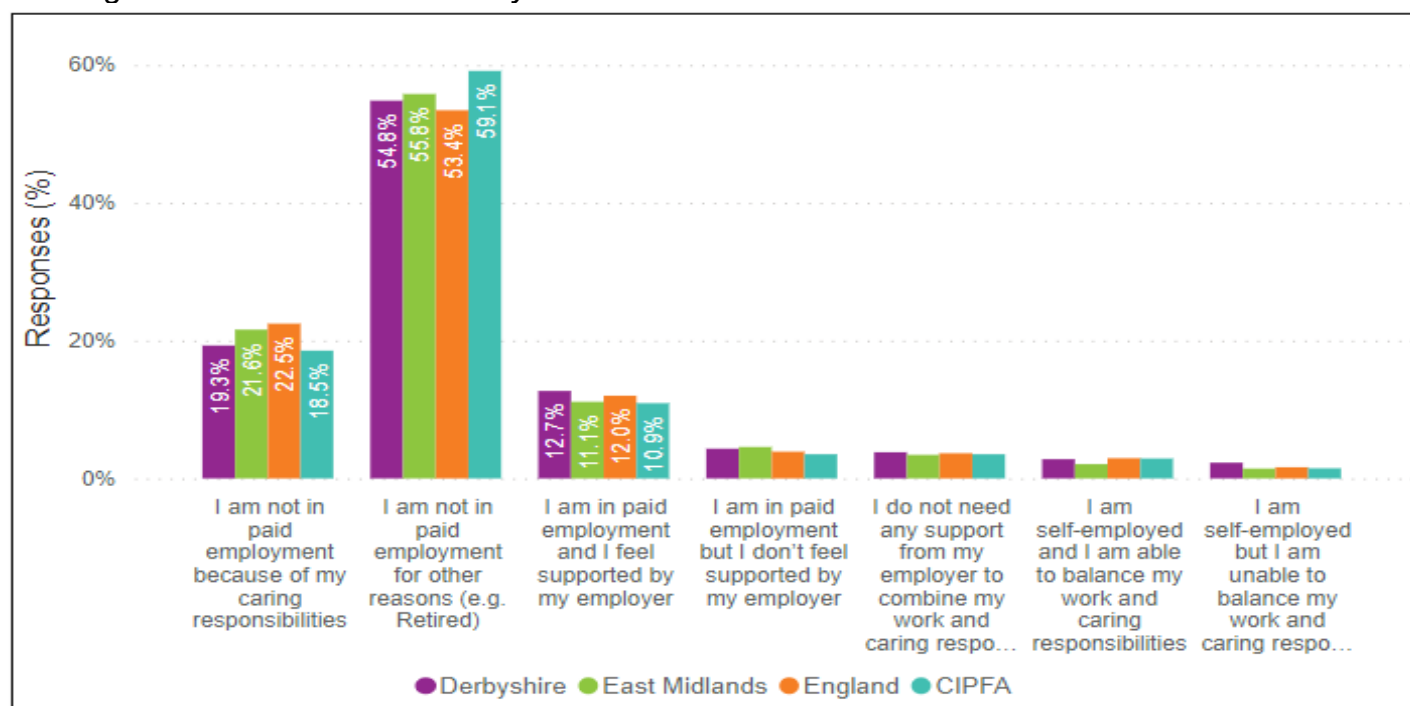


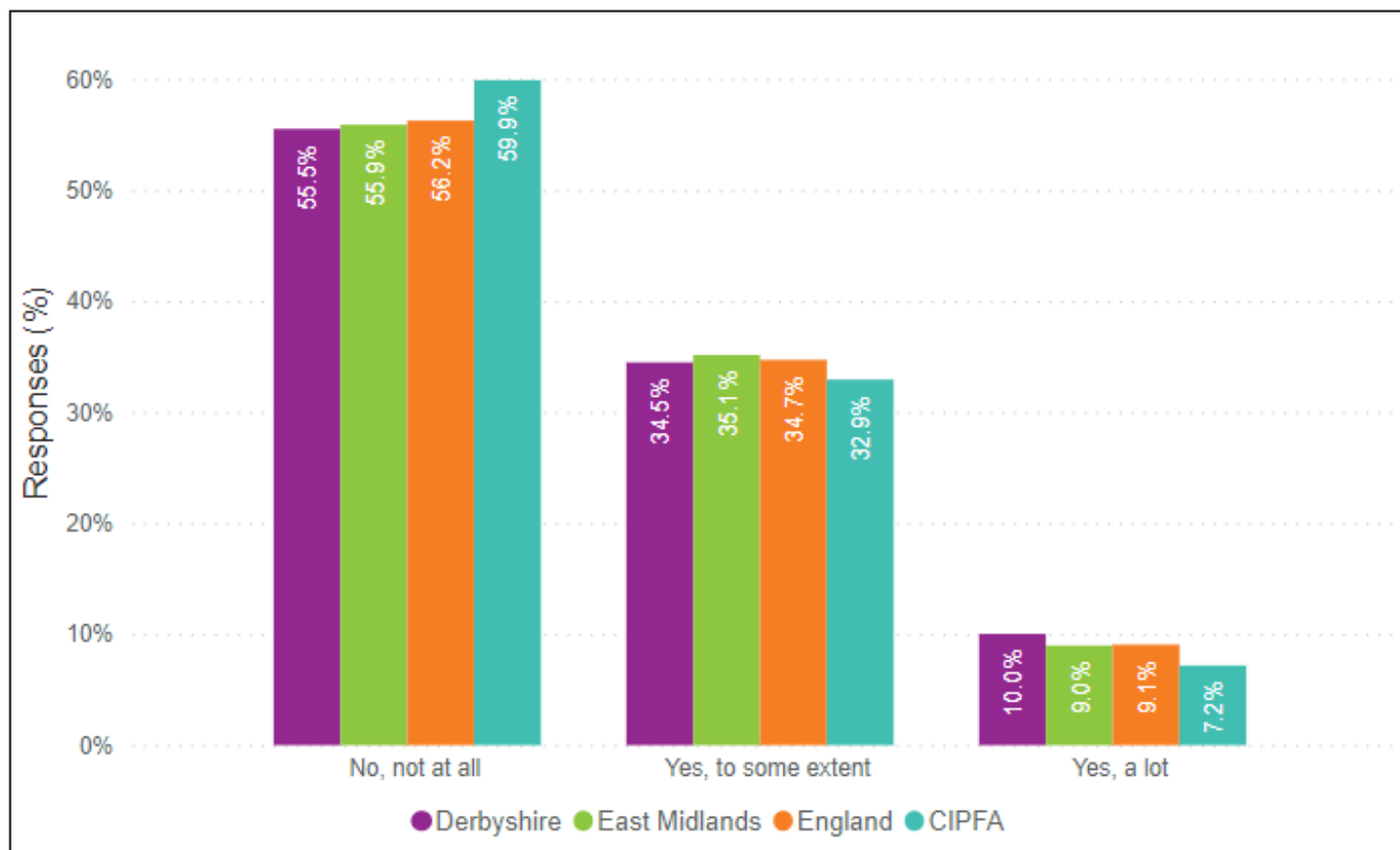
Figure 24: Thinking about combining your paid work and caring responsibilities, which are the following statements best describes your current situation



### 3.4.3 Has caring caused you any financial difficulties

Figure 25 shows that for the majority of Derbyshire carers, caring has not caused them any financial difficulties (55.5%). This is similar to the comparators. However, it is still of concern both for Derbyshire and nationally, that nearly half had answered that caring had caused financial difficulties, either 'to some extent' or 'a lot'.

Figure 25: In the past 12 months has caring caused you any financial difficulties?

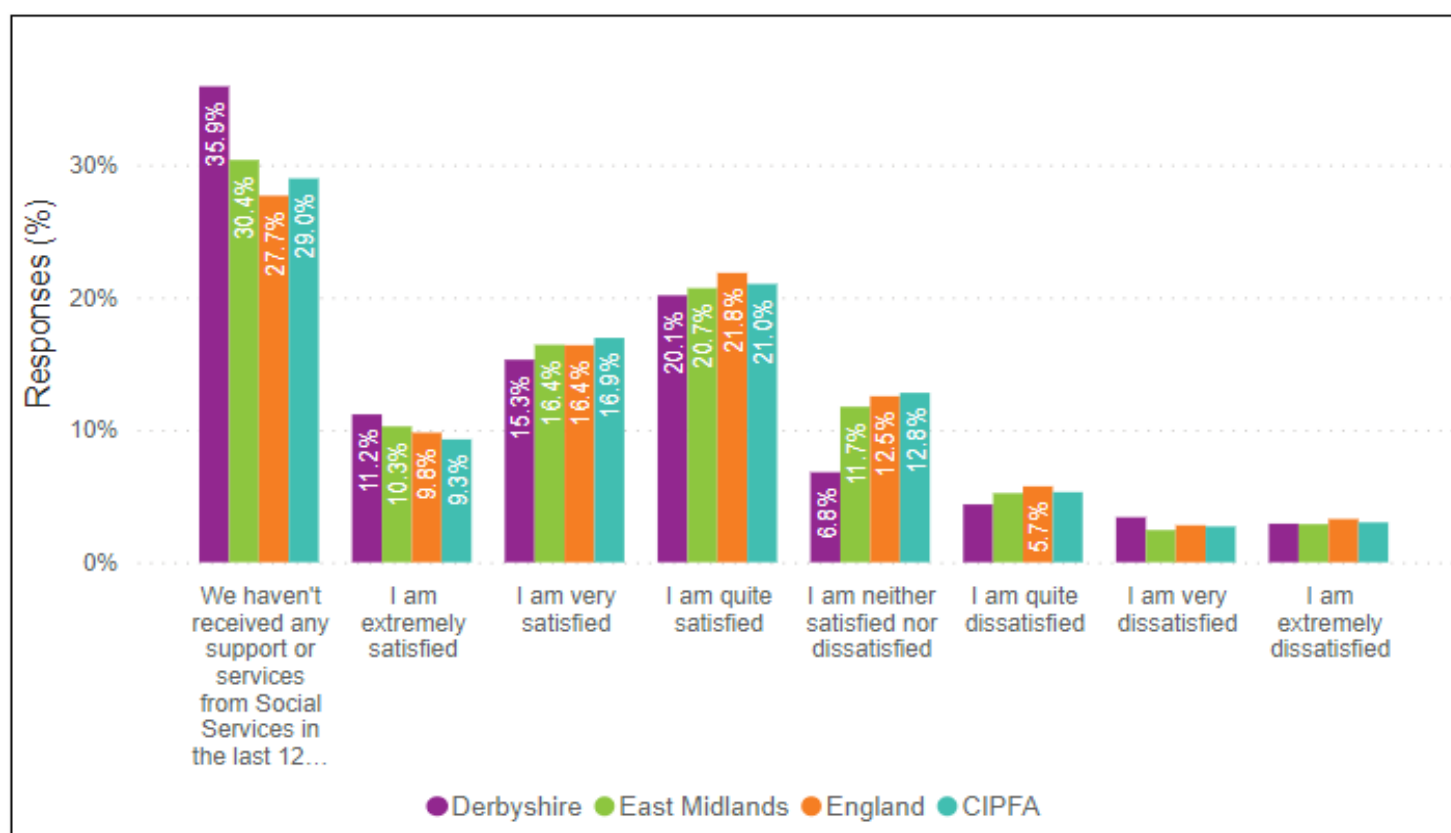


## 3.5 Services

### 3.5.1 Satisfaction with services

This question is used to provide data to the ASCOF indicator 3B “Overall satisfaction of carers with social services”, measured by combining individuals that have selected “I am extremely satisfied” or “I am very satisfied”, and excluding those who have not received any support from social services. Figure 26 shows the satisfaction for the support and services received from Social Services in the last 12 months. 35.9% have not received any support or services in the last 12 months - a larger percentage than the comparators. Again this could reflect the impact of the Covid-19 pandemic.

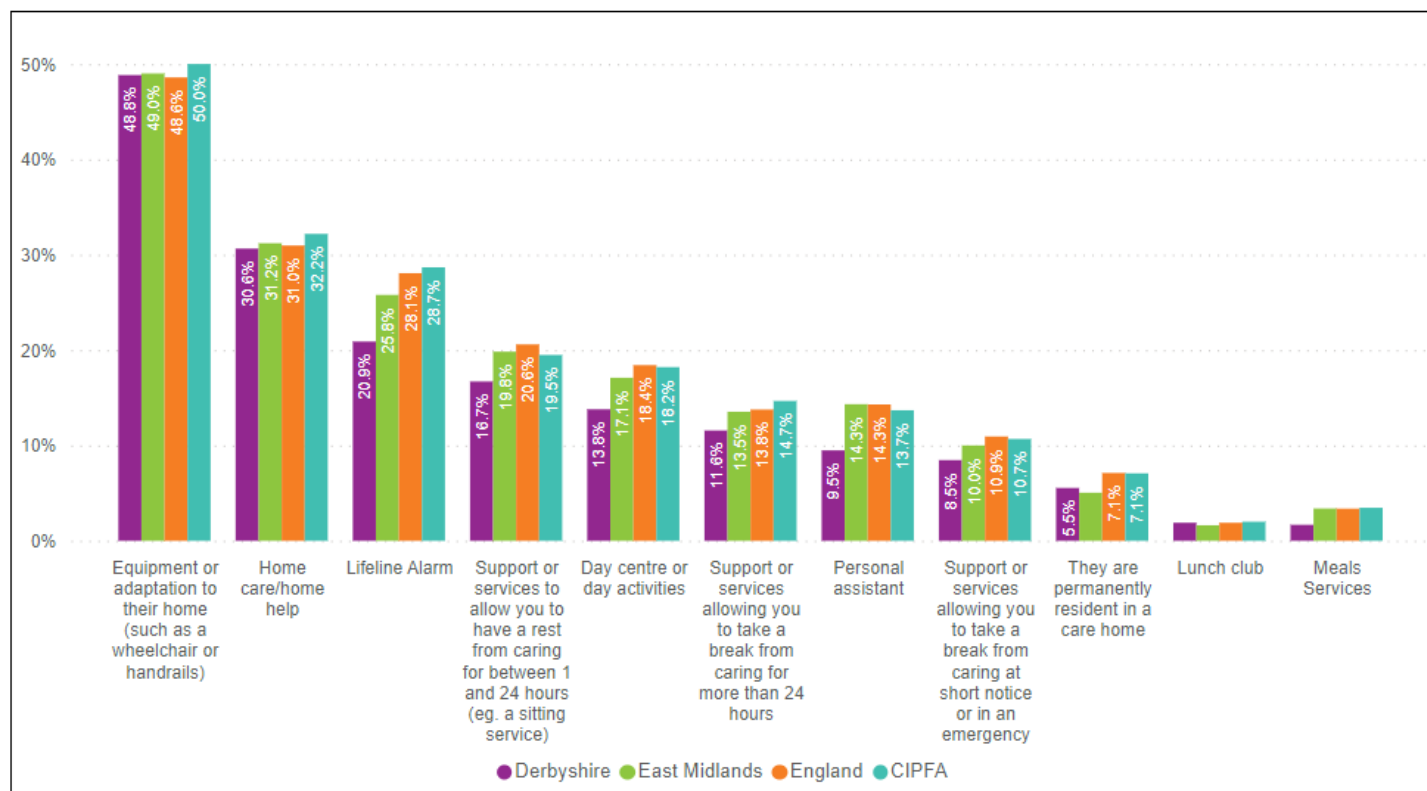
*Figure 26: Satisfaction with support and services received from Social Services in the last 12 months*



### 3.5.2 Support or services received by carer in the last 12 months

Carers were asked what support services the person they cared for had received from voluntary organisations, private agencies or Social Services. The most popular services used were “Equipment or adaptation to their home” (48.8%) and “Home care/home help” (30.6%), figure 30.

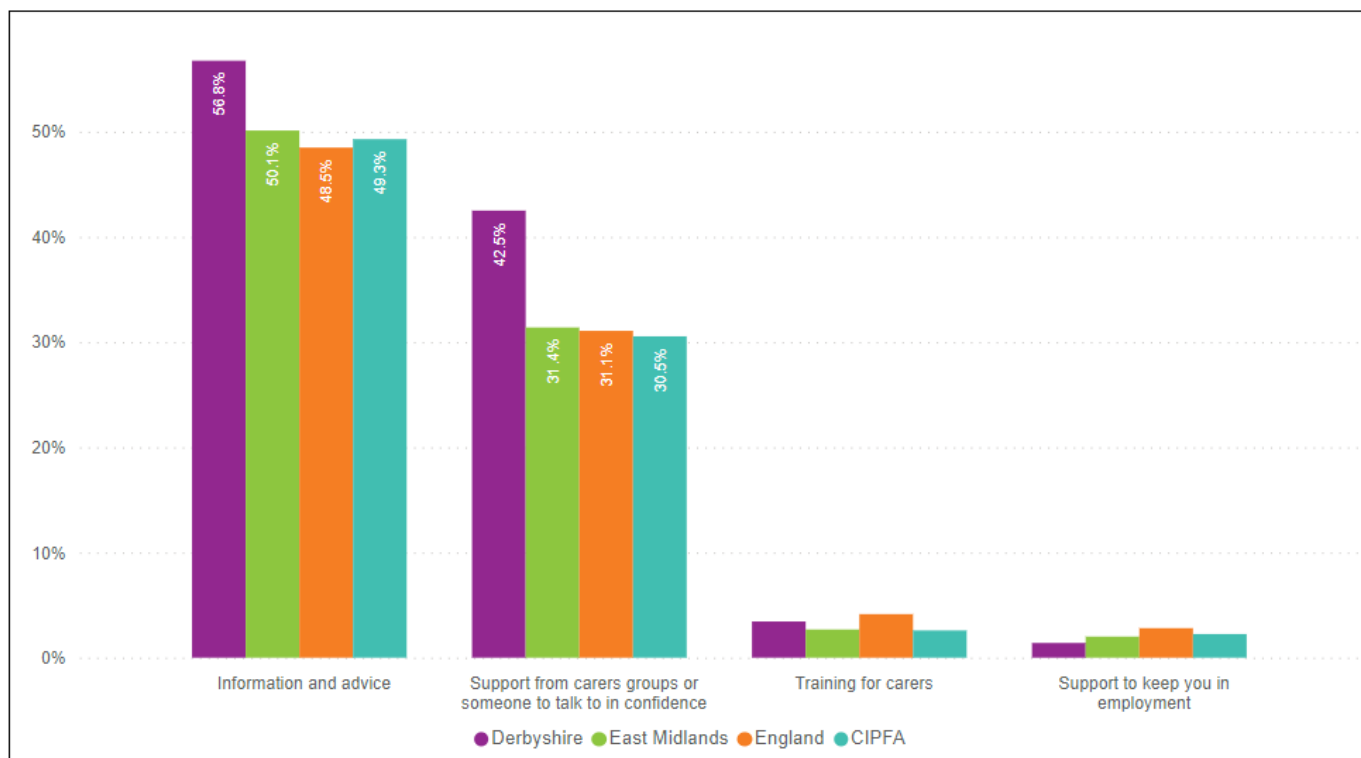
Figure 27: Has the person you care for used any of the support or services listed below in the last 12 months.



### 3.5.3 Support and Services used by carers

Carers were asked which services and support (provided by voluntary organisations, private agencies or Social Services) they themselves had used in the previous 12 months. The responses are shown in figure 28. The services accessed most by carers were “Information and advice” (56.8%) and “support from carers groups” (42.5%).

*Figure 28: Have you used any of the services listed below, to help you as a carer, over the last 12 months?*



### 3.5.4 Information and Advice on Services

Carers were asked how easy they found it to find information and advice about support, services or benefits. Though 34.2% carers had not tried to find any information or advice, 41.1% found it very easy or fairly easy, which is higher than the comparators, figure 29. Carers were also given the option to describe how finding information and advice could be improved. 127 carers responded in a free text box, these comments were analysed into 7 themes, outlined in table 2. The responses to the themes were a mixture of positive and negative, sometimes praising DCC, or suggesting improvements, other times complaining.

Figure 29: How easy is it to find information and advice?

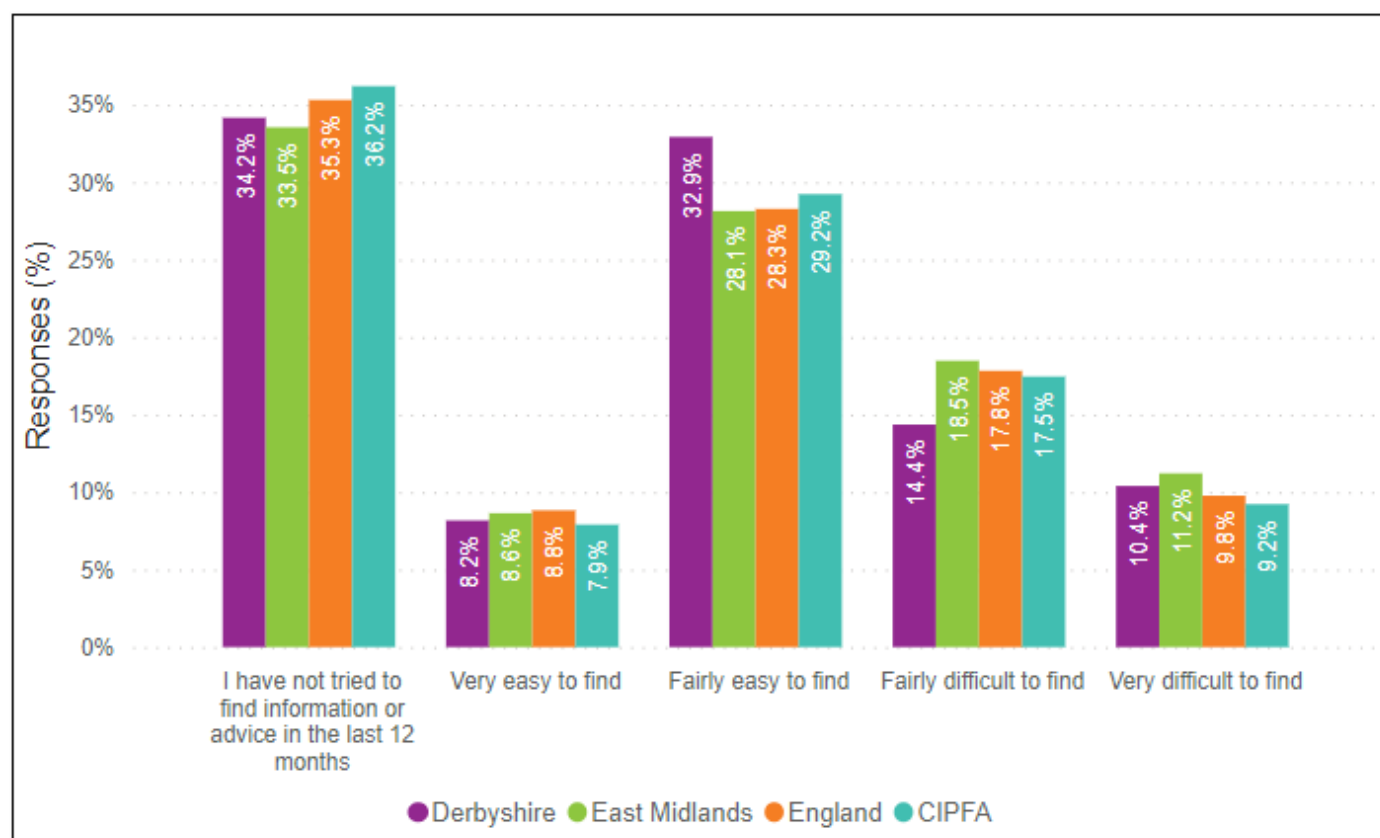


Table 2: Themes associated with finding information and advice

Theme	Quote
Contact and engagement	"I get contacted which is very helpful" "Send me leaflets or call me now and again"
Lack of access and preferred method of access	"Everything seems to revolve around the internet what about us that don't have a computer?" "[cared-for-person] had a social worker who was never available - and who never returned my telephone calls, I only rang her about 3 times, so I just got on with it!"
Lack of time and external pressures/complexity	"There are various issues I need information on, but daily tasks have taken over".
Not knowing where to look	"I am not sure how to set about it" -"Most carers haven't planned to become carers, so the situation evolves, and you don't know what help is available to you or what help you need".



Quality and relevance of information	<i>Derbyshire Carers very helpful and supportive. Occupational therapist excellent contact with. Adult social services have been very good not used much up to date but helpful as to journey ahead in caring for my mother".</i>
Referral	<i>"Impossible to get any information ref services for people with a learning disability, despite emailing all levels of adult care".</i>
Signposting	<i>The problem I have found is that there is a lot of help out there but to find what is best for my mum or me that is when it is a minefield" "Create an easily accessible directory of carers, day centres, sitting services etc and any other groups available for care respite local to my area to alleviate the stress of having to contact individual agencies which would enable me to tailor them to my/my husband's individual needs".</i>

### 3.5.5 How helpful has the information and advice you have received been?

Figure 30 shows that although over a third (33.9%) of Derbyshire carers did not try to find information and advice, those that did found it very helpful (21.1%) or quite helpful (35.9%). This is higher than for the comparators. As with the question above carers were given the option to further expand on this question in a free text box. 61 out of 420 carers took this opportunity, and the responses were analysed into 7 themes, table 3. Again, some of the comments were positive, some negative and some suggested improvements. It is also worth noting that these themes only represent the opinions of 14.5% of the respondents.

Figure 30: How helpful as the advice been

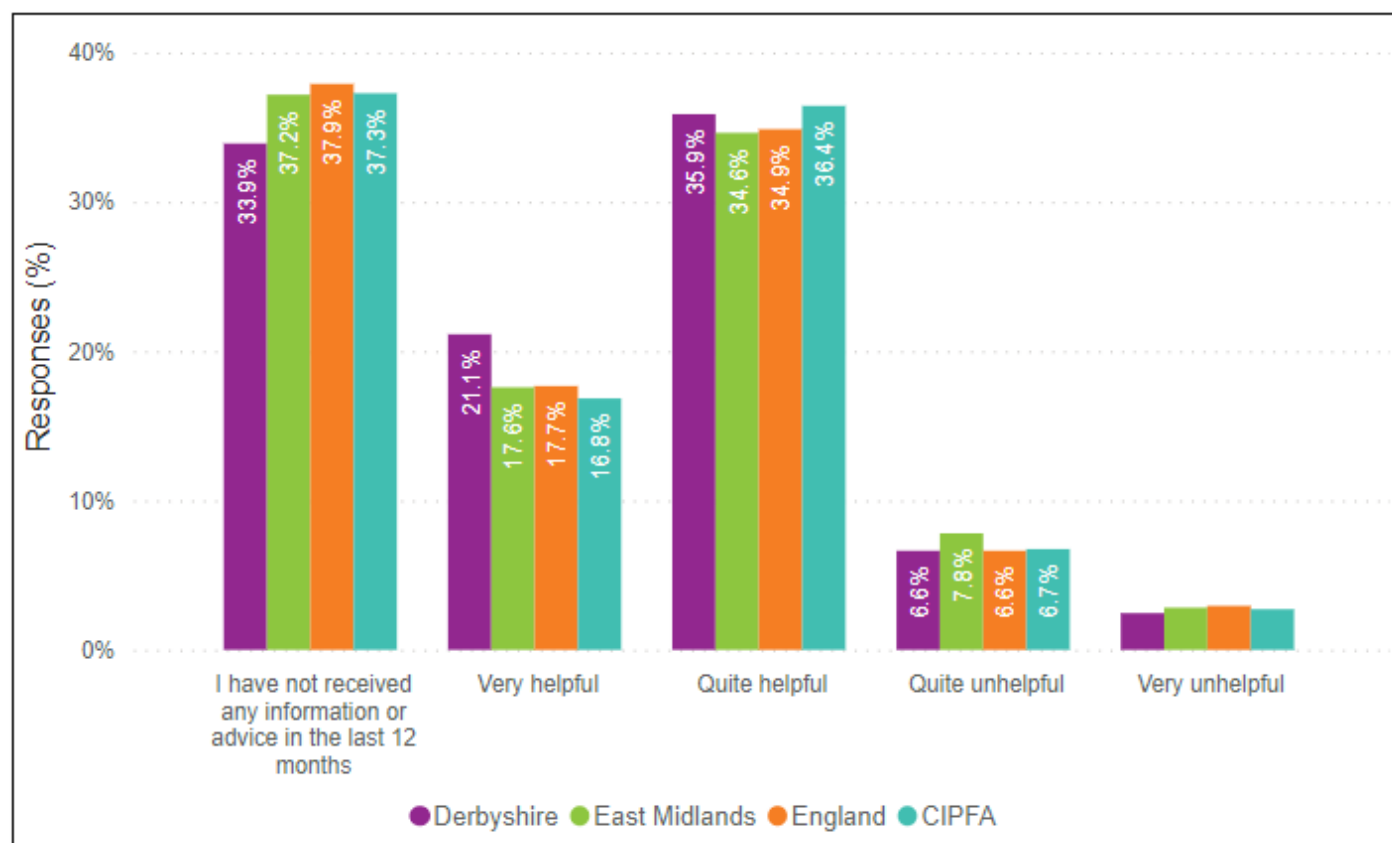


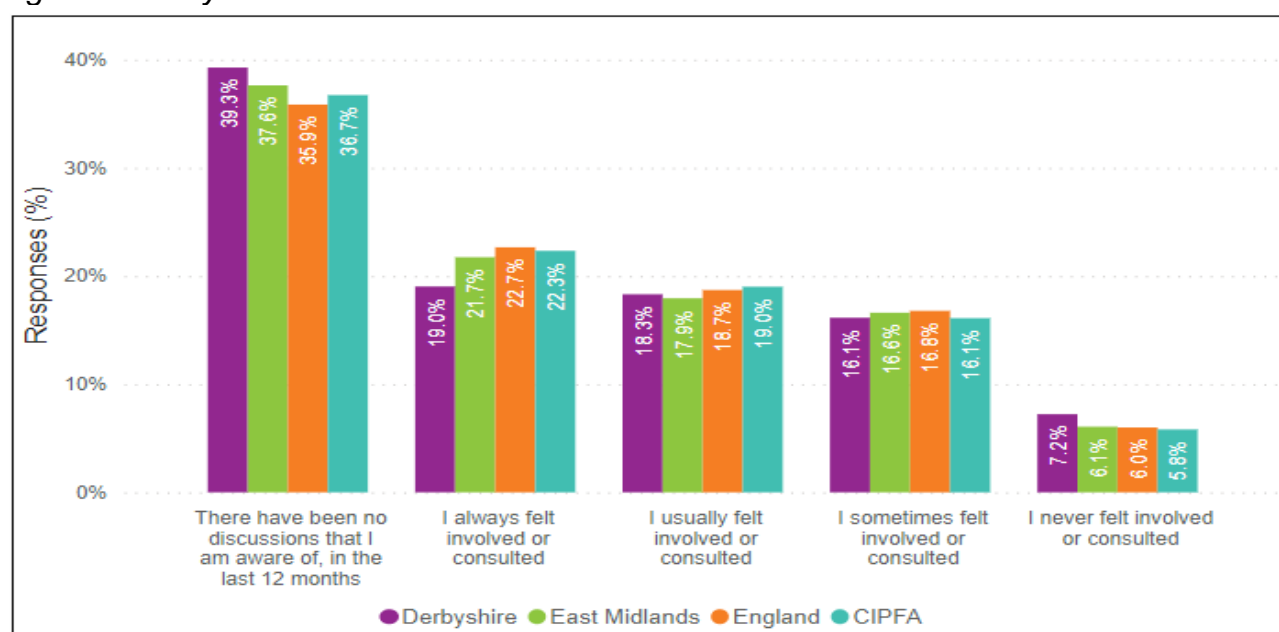
Table 3: Helpfulness of advice themes

Themes	Quote
Information & support not specific to individual	<i>"Didn't really address or understand my concerns".</i>
No response or action from social worker/GP/DCC	<i>"In avenues of help and advice goes as follows: I make phone call: - they answer; we chat, discuss problems, have sign of relief which is short lived no action follows". "Asked social services for options on independent living nothing received".</i>
No support or support stopped	<i>"I haven't had any help nobody has called to help". "There is nothing like there was for adults with learning difficulties".</i>
Pathways to find information or support	<i>"You get constantly side-lined and no one communicates". "A clear route map with identifiable individuals and their roles"</i>
Received support but not used, usable, or accessible	<i>"Leaflets/emails of virtual events etc. lovely but never at a time I can access due to also having to work". "Just not the time to read".</i>
Respite	<i>"I feel I need a break and respite" "The pressure on carers has been immense with daytime respite not available and residential respite not available for almost 2 yrs".</i>
Praise	<i>"The carers information is brilliant I have my carers card which is brilliant also I have a contact number and the ladies always respond".</i>

### 3.5.6 Do you feel you have been involved and consulted?

Figure 31 shows that more than a third (39.3%) of all respondents were not aware of any discussion of their case? In the last 12 months, this is a considerable increase from the SACE 2018/19 results, where 28% were unaware of discussions. Derbyshire also appears not to be consulting or involving as much as the comparator regions, again this is a reversal from the SACE 2018/19 results, where 31% always felt consulted or involved compared with 19% in 2021/22. However, this could have been a result of the Covid-19 pandemic when many services were restricted.

Figure 31: Do you feel involved and consulted?



### 3.5.7 Additional Information about your experiences

At the end of the survey respondents were given the opportunity to comment further on experiences. 46.2% (194 out of 420) of the respondents took this opportunity to comment and their responses were analysed into 8 main themes. One of the themes “support received is not adequate for needs” was further divided into 4 sub themes. Table 4 lists the themes and gives example quotes. The number in brackets after the theme shows the number of times the theme was coded.

*Table 4: Other experience and comments themes*

Theme	Quote
Accessing information (24)	<p><i>“Access to information is insufficient for elderly people unless they are internet savvy and many aren’t, unless they have family members who are, such as my brother and I.”</i></p> <p><i>“I just think that more information about the help available could be given as early as possible in a proper package for the NHS and various charities”.</i></p>
Appreciation (56)	<p><i>“As a family we have been pleased with the care we have received throughout this long and debilitating period.”</i></p> <p><i>“I had an assessment, then I was offered emotional support from Derbyshire Carers which was a great help.”</i></p>
Cutting of services and funding (9)	<p><i>“The government are withdrawing the £20 universal credit uplift. This will cause more financial strain for people (including me). Prices of food and fuel are rising. I am unable to work due to my caring responsibilities, £67 a week carers allowance for 24 hours, 7 days a week care is an insult. Unpaid carers save the government, and local councils, millions of pounds every year. We are the forgotten members of society. We should be paid at least the minimum wage (instead of £0.40 an hour)!!!”.</i></p>
Deterioration of health (36)	<p><i>“If I have any concerns at all it would be regarding my own physical fitness in the future and subsequently becoming unable to look after my wife as I am able to do at the moment. I am considering requesting a cleaning service, as at [age] years old I am feeling unable to keep the house up to the standard my wife once achieved.”</i></p>
Direct impact of Covid-19 (28)	<p><i>“The pandemic restrictions have been detrimental to my mental wellbeing as I have not been able to have contact and outings with my children and grandchildren that I would usually have. This has made it more difficult to cope with caring for my husband”.</i></p>
Loneliness (13)	<p><i>“Sometimes a chat with the care service would help most things as it is someone you can chat about all your worries and fears to”</i></p> <p><i>“With dementia you feel quite isolated. People do not understand it and often stand back not knowing what to do. This happens with family members and others”.</i></p>
Quality of life (54)	<p><i>“So, I have no life, no chance of work and I am solely responsible for all aspects of my daughter’s life…… Carers are never cared for.”</i></p>
Respite (16)	<p><i>“The help I feel I need most is respite to help as and when the pressure gets too great. To be able to de-stress”.</i></p>
Support received is not adequate for needs (96)	Sub-divided below

Financial (24)	<i>"the two local authorities just argued over who would pay for care and did not really want to help. We are facing a new PIP review next year. He will not suddenly be cured of autism and the stress of these reviews is cruel and unnecessary."</i>
Forgotten (24)	<i>To be brutally honest this form and my answers are a complete waste of time. Normally I don't bother filling in forms, but I feel so frustrated it helps to get things off my chest. I know it's a waste of time, nothing ever happens and nobody cares".</i>
Medical (19)	<i>Not only has it been impossible to get a face-to-face appointment, but she has also had to wait several weeks for a telephone appointment, which on a few occasions has been cancelled on the day. (refers to GP)</i>
Social worker and social care (41)	<i>"There has been times when they have not come and many times they are late" "Our social worker left over a year ago no replacement as yet" "Having to phone a central telephone number using an answer phone. Call is then transferred to local district nurse or social workers. Often they do not get back to me"</i>

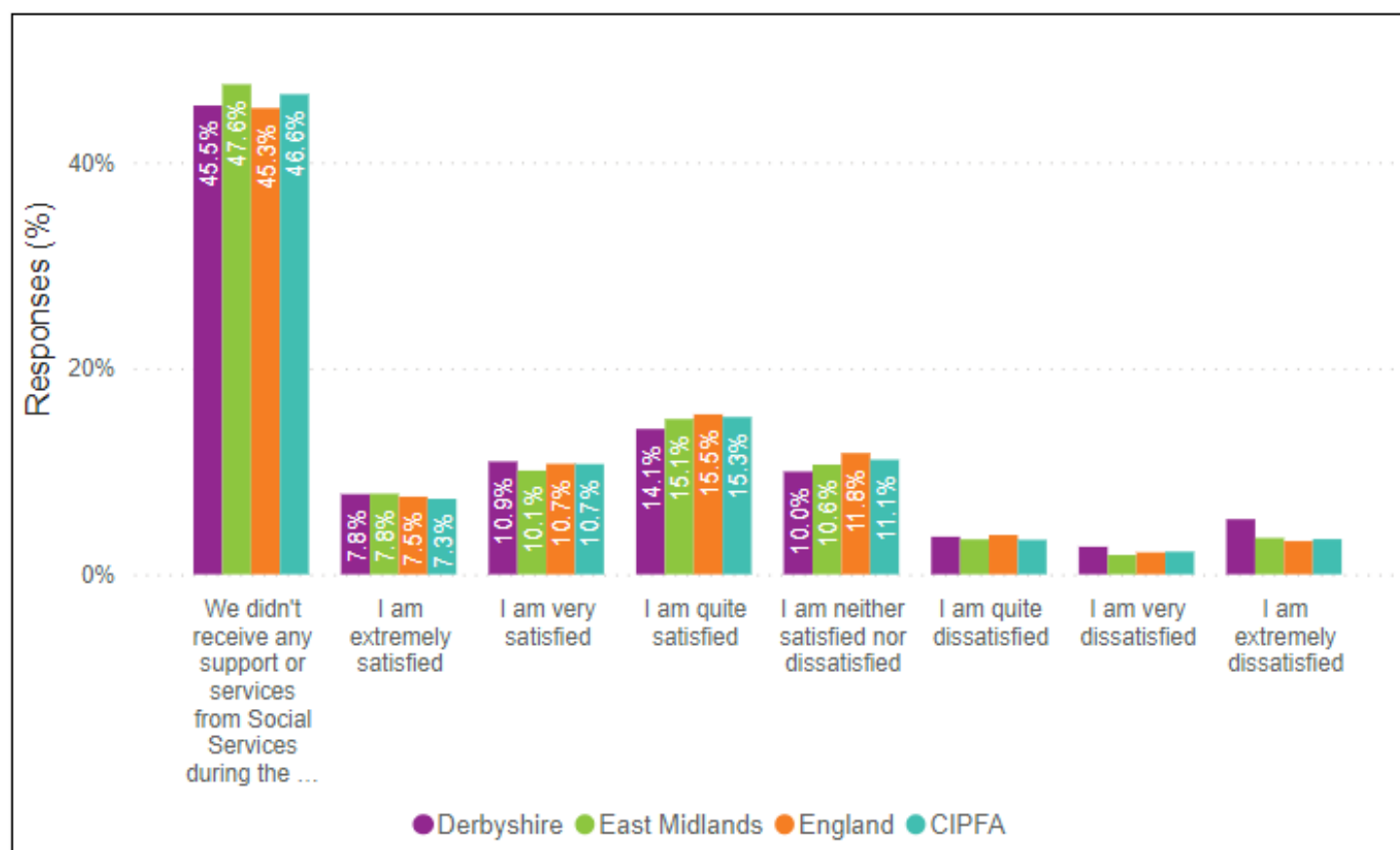
## 3.6 Effects of the Covid-19 Pandemic

The SACE 2021/22 surveys were sent out in Autumn 2021, this was following the end of Covid-19 restrictions and lockdowns. However, Covid-19 was still prevalent in the population and many people who were surveyed had been categorised as vulnerable and told to isolate, so understandably were still fearful of mixing with the general population. The survey also asked about the previous 12 months which would have included lockdown periods. NHS Digital included four specific extra questions about the Covid-19 pandemic period and DCC also asked an additional question about the areas of the carer's life that had been impacted by the pandemic.

### 3.6.1 During the Covid-19 pandemic how satisfied or dissatisfied were you with social services?

Similar to the comparators, over 45% of the respondents stated that they did not receive any support from social services during the pandemic. Satisfaction and dissatisfaction figures are also similar to the comparators.

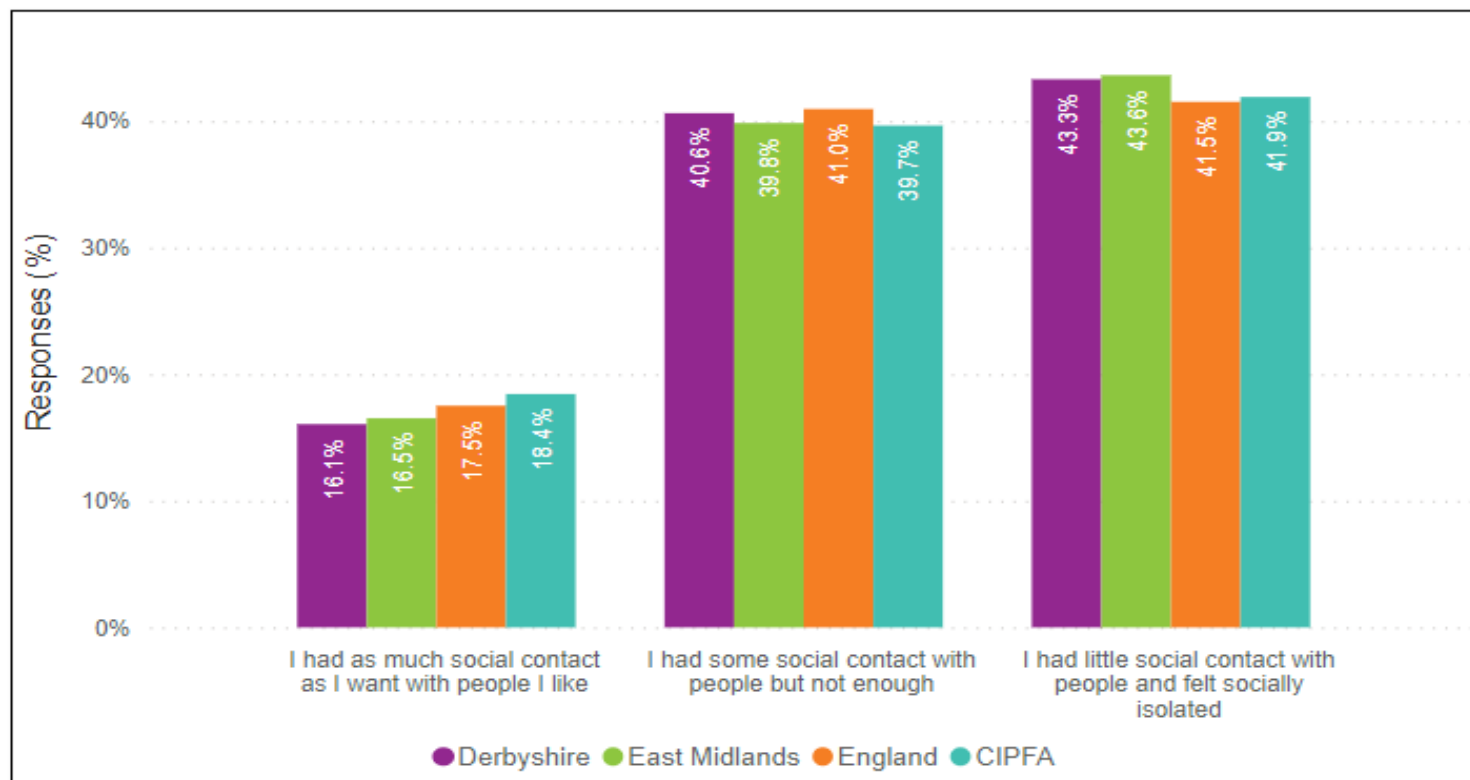
Figure 32: Satisfaction with social services during the Covid-19 pandemic



### 3.6.2 During the Covid-19 pandemic did you have as much social contact as you liked.

Again, the results from Derbyshire were similar to the comparators with over 43% stating that they had no social contact during the pandemic and felt socially isolated.

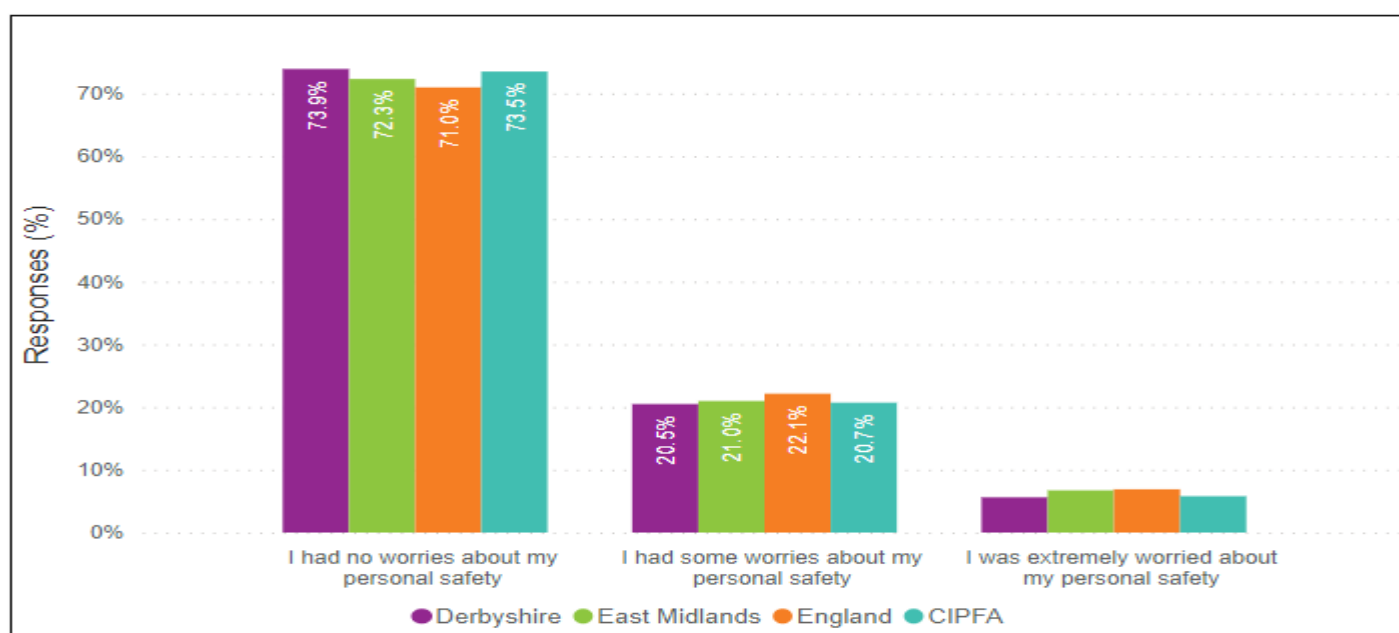
Figure 33: Social contact during the Covid-19 pandemic



### 3.6.3 During the pandemic did you feel safe?

This question asked about the carer's feelings of personal safety during the pandemic. Further explanation in the question text indicated the question was about fear of abuse, being attacked or other physical harm, not fear of contracting coronavirus. Figure 34 shows that the results in Derbyshire were similar to comparators with only 5.6% of people extremely worried about their personal safety. As with the question in section 3.3.4 above, where this box was ticked DCC followed up on concerns.

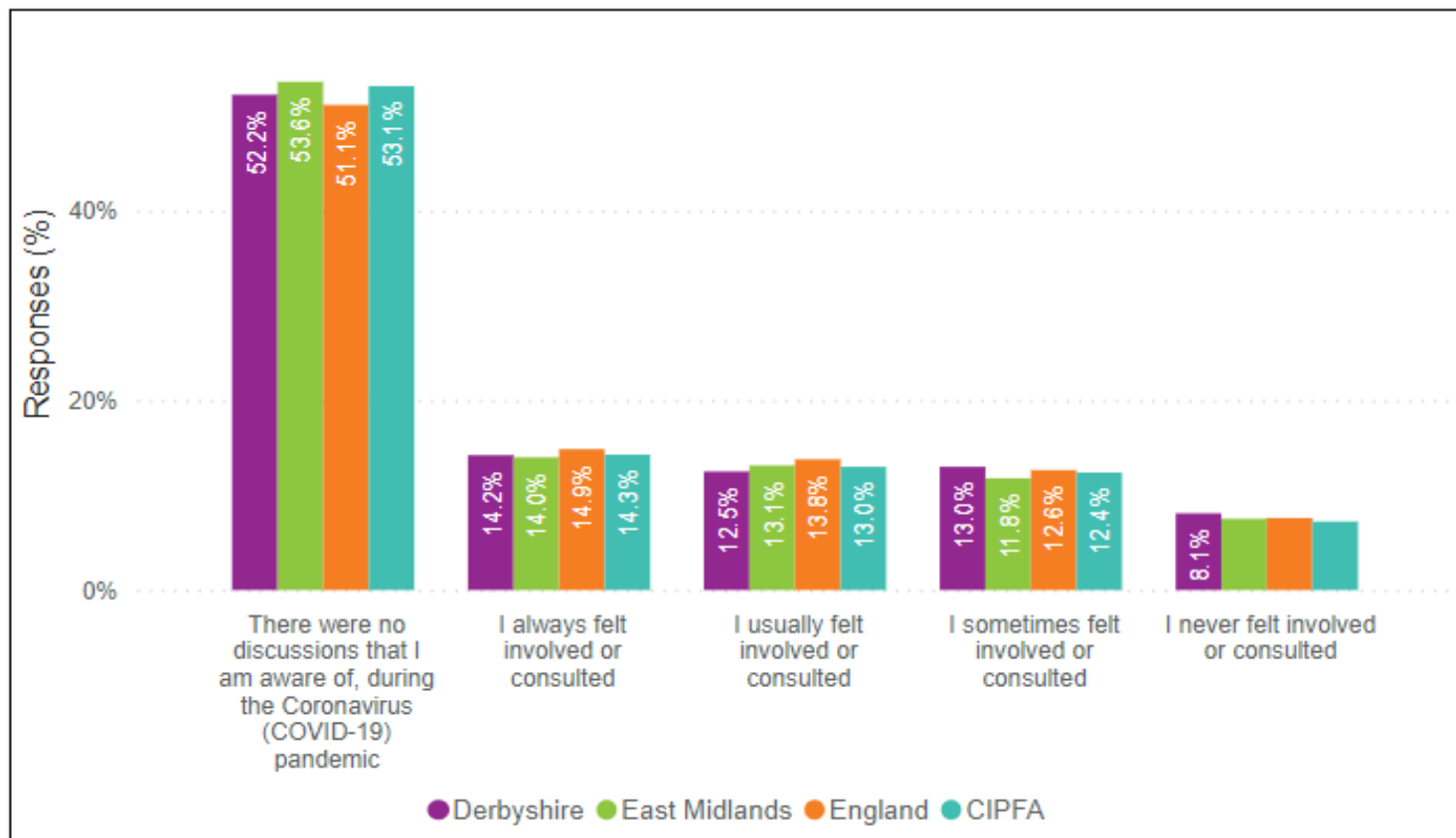
Figure 34: During the pandemic, did you feel safe?



### 3.6.4 During the pandemic did you feel involved or consulted?

This question asked respondents to consider whether they were involved or consulted in discussions about support and services provided to the person they cared for, during the pandemic. The results in figure 35 show the Derbyshire respondents were similar to the comparators with 14.2% always feeling involved and consulted and 52.2% being unaware of any discussions during the pandemic per

Figure 35: During the pandemic, did you feel involved or consulted?



### 3.6.5 Areas of life affected by the pandemic

This question was an additional one added by Derbyshire County Council and asked which areas of life were affected by the Covid-19 pandemic. All 420 respondents answered this question as shown in table 5. Respondents could select more than one area and were also given the option to complete a free text box, further expanding on how their life had been affected, see table 6. From the defined options the most frequently selected were related to relationships (33.8%), health (46.4%) and wellbeing (52.1%), with education being selected least (0.5%), though this probably reflects on the age of the carers, who are predominately older and less likely to be studying. 34 out of 420 (8.1%) opted to further elaborate on the effect of the pandemic on their lives, these comments were analysed into 6 themes as shown in table 6.



Table 5: Areas of life affected by the pandemic

Q34 Response Options (Multiple Responses Allowed)	Number of Respondents Who Selected an Option	Percentage of Respondents Who Selected an Option
My education	2	0.5%
Other	24	5.7%
My work	36	8.6%
My finance	64	15.2%
No areas	72	17.1%
My access to essentials	108	25.7%
My caring relationships	127	30.2%
My relationships	142	33.8%
My health	195	46.4%
My wellbeing	219	52.1%
<b>Number of Unique Respondents to Q34</b>	<b>420</b>	<b>100.0%</b>

Table 6: Themes associated with the impact of the pandemic on carers' lives

Theme	Quote
Access to formal care	"Unable to contact doctor for help with changing medication to liquid form"
All aspects of life affected	"It has really affected all aspects of life to some extent" "Everything is affected"
Covid-19 restrictions and shielding	"Unable to see any family who provide emotional support, feeling isolated" "Couldn't get any help to get food and couldn't go and fetch it as my daughter had covid and we couldn't get home delivery when needed"
Food	"...dad not living with me but carers coming in to do food" "I would have loved to be offered someone to bring my groceries of food"
Mental Wellbeing	"I feel worried that I will give covid to my vulnerable husband" "As I have been unable to take my son on holiday there has been a lot of stress"
Social contact and support networks	"Unable to see any family who provide emotional support, feeling isolated" "...also they recommended a support group with people dealing with similar issues. This has helped me more than anything talking to people who really understand because the issues are the same, friends + family try to help but sometimes make things worse".



## 4 MAIN FINDINGS

This section summarises the main findings of the report, broken down into the relevant sections.

### 4.1 Demography

- Derbyshire now has a higher proportion of carers aged 18 – 64 years, compared with the previous SACE 2018/19. This is the same for England and the age distribution of carers has now changed, with a larger percentage under 65 years.
- The majority of Derbyshire carers are white, female and in the age group 55 – 64 years.
- Over two thirds of the cared for persons are over 65 years age, similar to England. A larger proportion of these are women over the age of 85 years.
- In terms of support needs of the person cared for, the most common was 'physical disability (49.1%) followed by dementia (42.3%) and a long standing illness (41.8%). Those with dementia is greater than England and has increased from 39% in the SACE 2018/19 results.
- Most carers live with the person they are caring for.
- Carers themselves also have health issues. Over a third of Derbyshire carers have a long standing illness, this is more than the England percentage. Derbyshire carers also have more mental illness than England and the other comparators.

### 4.2 ASCOFS

#### 4.2.1 Carer reported quality of life

This was 6.7 compared to 7.3 for England, and it has dropped in line with the national trend having been 7.2 in the SACE 2018/19 survey. However, Derbyshire has declined significantly more.

#### 4.2.2 Social contact

Less than 20% (19.3%) of carers felt they had as much social contact as they would like, this has fallen again from 29.4% in 2018/19, in line with national trend. The value for England is 28%, so Derbyshire carers are reporting significantly much less social contact. The influence of the Covid-19 pandemic and shielding need to be considered against this result.

#### 4.2.3 Satisfaction

Satisfaction with social services has decreased slightly, to 41.3% (though higher than England at 36.3%) from 42.6%. The confidence intervals still overlap with England and with the previous result, indicating it is not significantly different.

#### 4.2.4 Included or consulted

61.5% of carers felt included or consulted in discussions about the person they care for, a decrease from 2018/19 (74.1%) and lower than the average for England (64.7 %) but not significantly so.

#### 4.2.5 Information

The percentage of carers who find it easy to find information about services and/or support was 62.4%, a decrease from 2018/19 (71%). However, the Derbyshire average was higher, but not significantly, when compared to the average for England (57.7%).

### 4.3 Caring role and Impacts

- 20.8% of carers do not do anything they value or enjoy with their time and 23.8% feel they are neglecting themselves.
- The top five health impacts are feeling tired (83%), disturbed sleep (73.1%), general feeling of stress (68%), feeling depressed (53.6%) and being short tempered/irritable (52.2%). Derbyshire figures were higher than England.
- The majority of carers (57.8%) had spent more than 1 year but less than 10 years caring. Over a fifth (22.3%) of carers had spent over 20 years caring for someone.
- 47.4% of carers spend 100 hours a week or more caring, this is far greater than the comparator areas; England (37.3%), East Midlands (35.5%) and CIPFA (35.3%).
- The top five areas in which carers provide support are practical help (92.8%), keeping an eye on him/her (91.4%), helping deal with care services (86.6%), help with paperwork (85.6%) and giving emotional support (83.5%). This is similar to the England results.
- Analysis of the comments in the additional free text boxes into themes found
  - 25% of those who completed the comment box expressed appreciation.
  - 50% felt that the support they received was not adequate for their needs, with issues around contacting medical services, accessing social care, and feeling unsupported and isolated.
  - Access to and ability to navigate the internet and website was an issue for many carers

### 4.4 Work Life Balance

- The majority of carers were retired (57.2%) or not in paid work (21.5%). This is noteworthy as most are now below the state retirement age.
- 19.3% stated they were not in employment because of their caring responsibilities.
- 44.5% have some level of financial difficulty caused by their caring role.

### 4.5 Impact of the Covid-19 pandemic

The responses to the NHS Digital extra questions around social contact, involvement, and consultations with discussion of the cared for persons support, satisfaction with social services

and feeling safe during the pandemic period were similar for Derbyshire, England, East Midlands and CIPFA. These reflected the results in the main questions about the previous 12 months.

The response to a further question by DCC indicated that carers felt their wellbeing had been impacted by the pandemic, along with health and relationships.

Many mentioned that during the pandemic day care services were closed so they had no respite from caring and their cared for person also lacked the social contact previously received.

## 5 CONCLUSION

The following points have been drawn out from the findings of this report and have also had input from the commissioning manager for carers and advocacy:

- The eligible population for this survey was only 2,204 people (known to the Council and received carer's service within the last 12 months) whereas we know there are 92,634 carers in Derbyshire (Census 2011) and 12,046 active carers are registered with the commissioned carer's service from Derbyshire Carers Association (DCA). Therefore, this survey may not be representative.
- This report shows the age demographic of carers has changed and they are now predominantly in the working age category. Caring responsibilities compromise the ability to work with associated impacts on household finances and the carer's wellbeing. This impact should be further explored as it not only affects the economy of Derbyshire as members of a qualified/trained population are unavailable for work, it also means carers are likely to suffer financial hardship, become more dependent on welfare benefits and impacts adversely on identity and wellbeing.
- Derbyshire residents are caring for more people with dementia than comparator areas and are suffering from more mental health illness than comparators. Ways to support the carers with their own health should be addressed as well as support for those caring for people living with Dementia.
- Like England and the comparator areas, Derbyshire's quality of life score has decreased. This could be partially influenced by the Covid-19 pandemic; however, the Derbyshire score has declined more and the reasons behind this decline need to be understood.
- Where Derbyshire carers have praised the support and services they received it would be useful to review this to inform further good practice and "what works well".
- Comparatively Derbyshire carers found it easier to find information and that the information was helpful. However, there is still a proportion who had not attempted to find information or found it not relevant. Access to relevant, reliable and up to date information, in a variety of formats, is vital to providing carers with the information they need, when they need it.
- Two key communication issues were raised throughout the survey. The first centres around access and ability to navigate the internet. Given the crucial part the internet plays in everyday life, it is important that those carers who struggle in this respect are not disadvantaged through digital exclusion. The second communication issue was around the difficulties carers had in obtaining a response from the health and care system which included phone messages not being returned and the unavailability of social workers, GPs and medical services. Carers cite the importance of being able to access the 'right support', feeling someone cares, knowing how to understand and navigate the health and social care system as factors which would improve their daily lives.

## 6 APPENDIX 1 – ASCOF TABLES

### 1D Carer reported quality of life score

Area	2014/15	2016/17	2018/19	2021/22
Derbyshire	7.60	7.60	7.20	6.70
East Midlands	7.60	7.50	7.40	7.10
England	7.90	7.70	7.50	7.30

### 1I2 Percentage of people who used the services who reported they had as much social contact as they would like

Area	2014/15	2016/17	2018/19	2021/22
Derbyshire	36.9	34.9	29.4	19.3
East Midlands	35.1	32.0	30.1	26.6
England	38.5	35.5	32.5	28.0

### 3B Overall satisfaction with social services (%)

Area	2014/15	2016/17	2018/19	2021/22
Derbyshire	41.9	37.3	42.6	41.3
East Midlands	42.9	38.2	37.7	37.2
England	41.2	39.0	38.6	36.3

### 3C Percentage of carers who report that they had been included or consulted in discussion about the person they care for

Area	2014/15	2016/17	2018/19	2021/22
Derbyshire	66.3	67.3	74.1	61.5
East Midlands	68.9	68.2	69.1	63.1
England	72.3	70.6	69.7	64.7

### 3D2 Percentage of carers who find it easy to find information about support and services

Area	2014/15	2016/17	2018/19	2021/22
Derbyshire	62.5	61.7	71.0	62.4
East Midlands	61.6	62.2	61.6	56.0
England	65.5	64.2	62.5	57.7

## 7 APPENDIX 2 – INFOGRAPHIC

### Carers in Derbyshire 2021/22

This infographic gives a summary of the Survey of Adult Carers in England carried out by all councils with social services responsibilities, focusing on the results for Derbyshire. It is for carers and staff.

#### Who are the carers that responded to the survey?



Youngest: 21yrs male, cares for grandfather



Most are women. Majority aged 55 – 64 years. Caring for partners, children and parents



Oldest: 94yrs male, cares for wife

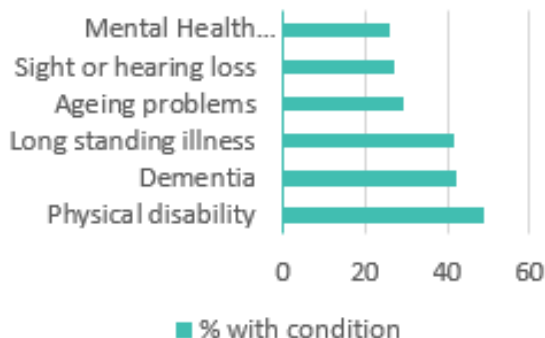
Nearly 70% of carers have their own health issues

Only 10% of carers are employed full time

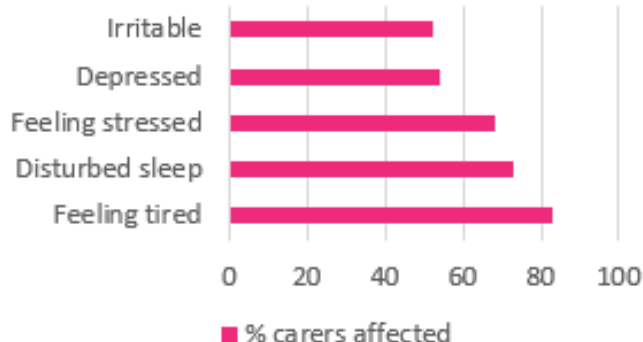
More than 25% of carers have cared for 15 years or more

47% of Derbyshire carers spend more than 100 hours a week caring

#### Who are they caring for? Conditions of cared for person



#### How are carers affected?



#### What support do carers receive?



#### What did carers tell us?

As a family we have been pleased with the care we have received throughout this long and debilitating period.

Everything seems to revolve around the internet, what about us that don't have a computer?

You get constantly side-lined and no one communicates.

I feel I need a break and respite.

Derbyshire carers very helpful and supportive.

With dementia you feel quite isolated.

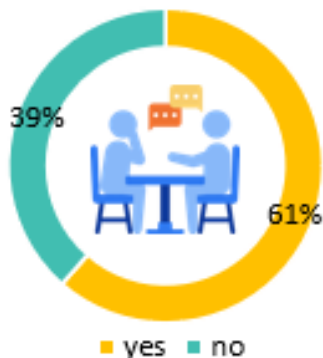
#### What are we doing?

- Carer feedback through the survey has provided invaluable information which will inform the update of the Derbyshire Carers Strategy.
- The survey provides strong, local evidence which will influence future Council policies, to make sure carers are effectively supported

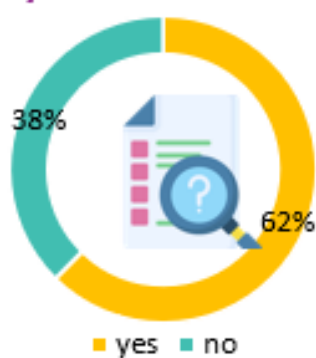
# Carers in Derbyshire 2021/22

This infographic gives a summary of the Survey of Adult Carers in England carried out by all councils with social services responsibilities, focusing on the results for Derbyshire. It is for carers and staff.

## Included in discussion



## Easy to find information

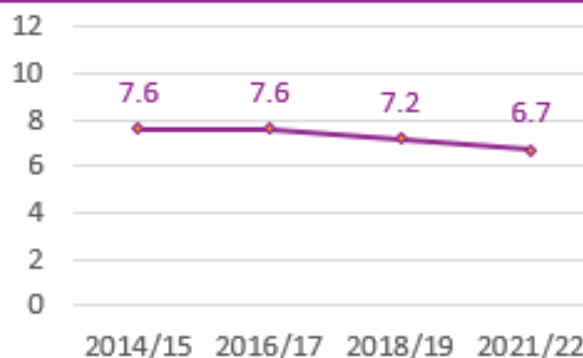


**12,046** active registered carers with Derbyshire Carers Association

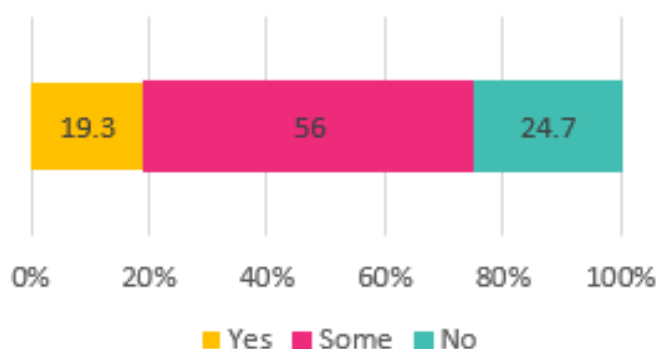
**950** randomly selected carers were sent survey through the post. **420** responded (44.2%)

## Quality of life score

This is based on a combination of different questions, scored out of 12 and is declining in line with the national trend.



## As much social contact as wanted?



## Satisfied with social services

**41%**



## 3 Biggest Impacts of COVID-19 Pandemic on Carers.

Wellbeing



Health



Relationships



For any further information please contact  
[kit@derbyshire.gov.uk](mailto:kit@derbyshire.gov.uk)



Public Health Knowledge & Intelligence Team