



Public Health  
England

Protecting and improving the nation's health

# **Caring as a social determinant of health**

## **Findings from a rapid review of reviews and analysis of the GP Patient Survey**

Technical document annex

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Public Health England  
Wellington House  
133-155 Waterloo Road  
London SE1 8UG  
Tel: 020 7654 8000

[www.gov.uk/phe](http://www.gov.uk/phe)

Twitter: [@PHE\\_uk](https://twitter.com/PHE_uk)

Facebook: [www.facebook.com/PublicHealthEngland](https://www.facebook.com/PublicHealthEngland)

Prepared by Gemma Spiers, Jennifer Liddle, Daniel Stow, Claire Welsh, Orla Whitehead, Patience Kunonga, Fiona Beyer, Dawn Craig, Sheena Ramsay, Barbara Hanratty, Population Health Sciences Institute, Newcastle University.



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## Executive summary

Unpaid carers provide critical support for people with health and social care needs. The majority of recipients of unpaid care are older parents or spouses and partners and changes in the make-up of our population indicate that the number of dependent older people in the UK will increase by 113% by 2051.<sup>1</sup> Supporting those who provide unpaid care to older people is therefore hugely important, and evidence is needed on how best to do this. The support provided by carers is often physically and emotionally demanding, with consequences for carers' own health and wellbeing.

In this work, PHE commissioned Newcastle University to a) explore the consequences of being an unpaid carer of older people, and b) identify evidence about how best to support this group of carers. To address these aims, a rapid review of existing evidence reviews (an 'umbrella review') was conducted, alongside analysis of data on carers (for any population) from the NHS England GP Patient Survey.

This work was undertaken during 2019 to 2020, prior to the COVID-19 pandemic. Therefore the work does not take into account the impact of COVID-19 on both the number of people providing unpaid care, the consequences of providing this care or mechanisms to support carers during COVID-19. This is recognised as a limitation of the work, however, many of the findings in relation to the impact of caring on the physical and mental health of carers will remain relevant in this context.

### Key findings

#### Carers experience poor physical and mental health, but also have unmet care needs themselves

The evidence available suggests that the consequences of caring for older people are not significantly different to the consequences of caring for other populations. The rapid review evidence indicates that carers of older people experience poor mental health, including anxiety and depression, alongside 'carer burden'<sup>1</sup>, stress and poor quality of life. This aligns with findings from previous research about the impact of providing unpaid care (for any population) on mental health.

The rapid review identified very little evidence about the physical health of carers of older people. However, the findings from the GP Patient Survey analysis of carers for

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<sup>1</sup> The term 'carer burden' is the term used by the published studies included in this rapid review and it is used in this report specifically in reference to those studies' findings.

any population, including those caring for older people, showed that carers are at increased risk of illness, and specifically musculoskeletal conditions, cardiovascular disease, generalised cognitive deterioration and function, and poor sleep.

Evidence about the extent to which the health of carers differs from non-carers is limited. Taking into account age and other sociodemographic factors (see table 2.3), carers are 16% more likely than non-carers to live with 2 or more long-term health conditions. Among carers living with 2 or more long-term conditions, arthritis and high blood pressure are the most common conditions. Limited evidence (one review) from the rapid review of reviews indicates that mental health outcomes may be worse for carers compared to the general population. Overall, this evidence suggests that carers have their own complex health needs that are likely to be exacerbated by the demands of caring. Yet carers also report that they feel their general, mental health and long-term health care needs are not being met. This is supported by the observation that carers are less likely than non-carers to report using 5 or more medicines (polypharmacy), despite being more likely to live with multiple health conditions. This may suggest that carers struggle to access adequate services and support.

### Different groups of carers may have different support needs

The rapid review of reviews suggests that younger carers, and carers with poor social and financial support, may experience higher 'carer burden' when caring for older people. Support that is specifically targeted at reducing the emotional, physical and social hardships associated with caring may be particularly beneficial for these groups. Findings from the analysis of survey data also indicate that older carers, and carers living in the most disadvantaged areas, are providing the most care (in terms of the number of hours per week). More time spent caring may place carers who are older or living in disadvantaged areas, at greater risk of poor health or delays in meeting their own needs. Support that enables access to services to meet carers' own health needs and reduces the risk of exacerbating existing poor health as a result of caring, may be helpful for these groups of carers.

### There is a lack of clear and robust evidence about how best to support people caring for older populations, and gaps in evidence on key outcomes

The overall quality of the evidence about caring for older people was poor (with some exceptions), and the rapid review of reviews identifies key gaps in what is known. Clear, quantified estimates of the impact on mental health and 'burden' is needed to improve the quality of evidence. There was also a lack of evidence about the impact of caring for older people on physical health, social relationships and financial wellbeing. This points to a need for robust, high quality systematic reviews of these important, but overlooked, outcomes. Evidence is also needed to ascertain how best to support those

caring for older people. Carefully designed interventions with clear pathways to impact (for example physical therapy to improve back pain) and robust evaluation are needed.

## Considerations

Caring places demands on carers that affect their physical and mental health. Based on this work, 5 key considerations are offered for supporting carers:

- support for those caring for older people should aim to lessen the impact on their mental health, with targeted specialist support for depression, anxiety and stress when needed
- measures to prevent poor physical health that arise as a consequence of caring (for example injuries, back pain, high blood pressure) are an important part of supporting those caring for other people
- carers often have their own long-term conditions and disability, which should be addressed as part of any support package
- support is needed to reduce the perceived emotional, physical and social hardships associated with caring and improve quality of life for carers; contact with other carers may help to achieve this
- some groups of carers are at greater risk of poor health, and of experiencing the adverse consequences of caring – these groups may benefit from additional support

This work has also identified key gaps in evidence about the impact of caring for older people. To address these gaps, it is suggested that organisations involved in planning or commissioning research consider:

- a high quality comprehensive systematic review to identify the impact of caring for older people on physical health and social and financial wellbeing outcomes
- a high quality systematic review or primary research study to assess and identify the prevalence and severity of specific illnesses experienced by carers of older people, with comparisons to the general population
- robust evaluations of promising interventions for carers of older people, with clearly established pathways to impact on appropriate outcomes
- a national mapping of existing practice to gain a clear picture of what support and interventions are in place and develop a shareable resource of emerging and established good practice

## Conclusions

This work contributes to mounting evidence that unpaid caring should be considered a social determinant of health. Carers experience poor physical and mental health, struggle to access services and are at risk of financial hardship. More robust evidence

is needed to identify if there are unique consequences for those people caring for older adults and how best to support them.

# Glossary

Term used in this report	Definition
Carer	Any person providing unpaid care to family members, friends or partners who have an illness, disability or frailty and require support. In this report, the term carers refers to adult carers of any age and ethnicity, and does not include those aged <18 years of age.
Caregiver/carer burden	<p>In this report, we refer to caregiver or carer burden as an outcome reported by systematic reviews that were included in the rapid review of reviews. Typically, systematic reviews did not offer a clear definition of what constituted the outcome caregiver/carer burden, nor did they specify how the studies within the review defined it.</p> <p>We acknowledge that caregiver/carer burden is an ambiguous and potentially contentious, term. This criticism is also noted by others.<sup>2</sup> For the purposes of this report, we interpret caregiver/carer burden using the broad definition offered by Ge (2018): the perceived emotional, physical and social hardships associated with caregiving.<sup>3</sup> However it is important to acknowledge that the operationalisation of caregiver/carer burden may have differed between reviews and the studies included within them.</p> <p>We use inverted commas ('carer burden' or 'burden') throughout this report where the term is used to reflect the terminology used in the literature that we are reporting or synthesising.</p>
Chi Square ( $X^2$ )	A statistical test of the relationship between 2 categorical variables
Multimorbidity/multiple long-term conditions	In this report, we use these terms to refer to the presence of 2 or more long-term health conditions. <sup>4</sup>
Older people	There is no single definition of what constitutes an older person. In this report, we use this term to refer to those aged 60 years and over. However, for the purpose of the rapid review of reviews reported here, an age threshold was not used to define older people as many systematic reviews did not report this. Instead, reviews were included if they reported evidence about carers of older people, or carers of populations likely to include older people (for example people with dementia). The reader is referred to the methods section in Part 2 of this report for further detail.



Polypharmacy	In this report, we use this term to refer to the use 5 or more medicines.
Rapid synthesis/review	An approach that streamlines systematic review methods, in particular the selection and synthesis of studies, to produce a timely overview of evidence.
Review of reviews	A method of synthesising evidence from existing systematic reviews to produce an overview of what is known in response to a pre-specified question (also known as an umbrella review).
Role strain	<p>In this report, we refer to role strain as an outcome reported by systematic reviews that were included in our rapid review of reviews. However, the systematic reviews that report role strain did not define this term.</p> <p>For the purposes of this report, we interpret role strain as the difficulties associated with a particular role or responsibility.<sup>5</sup> However, it is important to acknowledge that the operationalisation of role strain may have differed between reviews and the studies included within them.</p> <p>We use inverted commas ('role strain') throughout this report where the term is used to reflect the terminology used in the literature that we are reporting or synthesising.</p>
Study weights/ weighted methods	A statistical method to adjust data so that a study sample more closely matches the population from which it is drawn. <sup>6</sup>
Systematic review	A method of identifying, pooling and summarising evidence on a given topic. Each stage of a systematic review is conducted in a way to minimise bias and thus achieve a robust and impartial summary of evidence.
Umbrella review	A method of synthesising evidence from existing systematic reviews to produce an overview of what is known in response to a pre-specified question (also known as a review of reviews).

## Introduction and overview

There are approximately 5.8 million people in England and Wales providing unpaid care to ill and disabled family members, friends or partners. A typical carer is female, with those in their 50s and 60s most likely to be providing care.<sup>8</sup> Approximately 400,000 carers in the UK are aged over 85 years,<sup>9</sup> and the population of carers aged over 65 years is expected to increase to 1.8 million by 2030.<sup>10</sup> Care recipients are a diverse group, but the majority are older parents or spouses and partners.<sup>8</sup> Whilst the amount of care provided varies, around 14% of carers are providing 50 hours or more of unpaid care a week.<sup>8</sup> The economic contribution of this unpaid care is estimated to be up to £132 billion per year.<sup>11</sup>

Against a backdrop of increasing demand for social care, reduced state provision and an unstable private care market,<sup>12-15</sup> the role and contribution of carers to health and social care in England is critical.<sup>16</sup> Maintaining the mental and physical health and wellbeing of carers is therefore essential. Yet premature death, higher levels of disease and neglect of their own health care needs are known to be common amongst carers.<sup>10</sup> They are also twice as likely as non-carers to experience poor physical and mental health, with these outcomes exacerbated by social isolation, poor information and support, and financial stress.<sup>17</sup> Older carers are a particularly high-risk group: they are more likely to be living with long-term conditions and disability.<sup>10</sup>

The recent publication of National Institute for Health and Care Excellence (NICE) guidelines for supporting carers signals the high priority this issue has in health and social care policy.<sup>18</sup> A focus on carers of older populations is especially important. Those aged 85 years and over are in the fastest growing age group in the UK, and this population is expected to double to 3.2 million by 2041.<sup>19</sup> The growth in numbers of people aged over 85 will most likely translate to a growth in care needs. Indeed, estimates indicate that the number of dependent older people in the UK will increase by 113% by 2051.<sup>20</sup> Supporting carers of older populations should, therefore, be a priority for the UK.

The study presented here addresses 2 key questions relating to carers of older populations. First, what are the consequences of being an unpaid carer of older people? Second, how can this group of carers best be supported?

A rapid review of existing reviews (an ‘umbrella review’), and analysis of data on carers (for any population) from NHS England’s GP Patient Survey are the main components of this work. In addition, a set of resources is provided to support future research and practice: a profile of data sources on caring; local examples for health and social care commissioning leads; and a set of considerations for future research and practice.

### Structure of this technical document

This document includes the methodology, methods, results in tables, Prisma, search terms and summary of papers.

The findings and key messages can be found in the Main report document. The main report and key messages are structured in 4 parts.

# Appendices

Appendix A: Methods for the rapid review of reviews Search strategy as applied to MEDLINE

Appendix B: Rapid Review Tables

Appendix C: Summary of systematic reviews about dementia carers

Appendix D: Questions posed for exploration in the analysis of the GP Patient Survey

Appendix E: methods and tables for the analysis of the GP Patient Survey

Appendix F: Data sources about carers

## Appendix A: Methods for rapid review

Search strategy as applied to MEDLINE

Database(s): Ovid MEDLINE(R) 1946 to January Week 2 2020; Searched 21 January

#	Searches	Results
1	meta-analysis.pt.	109635
2	meta-analysis/ or systematic review/ or meta-analysis as topic/ or "meta analysis (topic)"/ or "systematic review (topic)"/ or exp technology assessment, biomedical/	205585
3	((systematic* adj3 (review* or overview* or analys*)) or (methodologic* adj3 (review* or overview* or analys*))).ti,ab,kf,kw.	150031
4	((((quantitative or narrative) adj3 (review* or overview* or synthes*)) or (research adj3 (integrati* or overview*))).ti,ab,kf,kw.	17348
5	((integrative adj3 (review* or overview*)) or (collaborative adj3 (review* or overview*)) or (pool* adj3 analy*)).ti,ab,kf,kw.	20727
6	(data synthes* or data extraction* or data abstraction*).ti,ab,kf,kw.	20899
7	(handsearch* or hand search*).ti,ab,kf,kw.	7850
8	(mantel haenszel or peto or der simonian or dersimonian or fixed effect* or latin square*).ti,ab,kf,kw.	21652
9	(met analy* or metanaly* or technology assessment* or HTA or HTAs or technology overview* or technology appraisal*).ti,ab,kf,kw.	7271
10	(meta regression* or metaregression*).ti,ab,kf,kw.	6630
11	(meta-analy* or metaanaly* or systematic review* or biomedical technology assessment* or bio-medical technology assessment*).mp,hw.	235567
12	(medline or cochrane or pubmed or medlars or embase or cinahl).ti,ab,hw.	166667
13	(cochrane or (health adj2 technology assessment) or evidence report).jw.	18482
14	(comparative adj3 (efficacy or effectiveness)).ti,ab,kf,kw.	10523

15	(outcomes research or relative effectiveness).ti,ab,kf,kw.	7615
16	((indirect or indirect treatment or mixed-treatment) adj comparison*).ti,ab,kf,kw.	1649
17	((meta-narrative or meta-ethnograph* or mixed method* or critical or thematic or realist or framework) adj3 (review* or synthes*)).ti,ab,kf,kw.	20949
18	or/1-17	395639
19	((carer* or caregiver* or caring or care partner* or "family care" or "spousal care" or "unpaid care" or "informal care") adj5 (older or senior* or elder* or dement* or alzheimer*)).ti,ab.	9395
20	18 and 19	613

**Table 1.1. Review criteria**

<b>INCLUSION CRITERIA</b>	
<b>SYNTHESIS 1: CONSEQUENCES OF CARING</b>	<b>SYNTHESIS 2: INTERVENTIONS FOR CARERS</b>
<b>POPULATION</b>	<p>Carers (for example unpaid, family, 'informal') of older adults. No age criteria for care recipients is specified, but must be, or likely to include, older populations (for example people with dementia).</p> <p>Carers include people of all ages, male and female.</p>

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	<p>Care recipients (that is older adults) include male and female, with any medical diagnosis, impairment, disability, or frailty, and no limits to ethnicity.</p> <p>Setting – Care provided in the community, hospital, care home.</p>	
<b>INTERVENTION</b>	Not applicable	<p>Any carer intervention that is targeted only on the carer (that is not a joint carer and care recipient intervention) and which aims to improve carers' health, wellbeing and/or access to services.</p> <p>Any or no comparator, including usual care</p>
<b>COMPARATOR</b>	No comparator, or non-carers	
<b>OUTCOME</b>	<p>Health status, quality of life, well-being, incident ill-health, admission to hospital, financial wellbeing, poverty, measured changes in material circumstances, social relationships including loneliness, isolation, social support, social networks.</p>	
<b>STUDY DESIGN</b>	<p>Systematic reviews (those that meet 3 of 5 DARE criteria). Publication dates 2000-2019. If more recently published systematic reviews include evidence that is also in earlier reviews, the most recent reviews will be prioritised to avoid duplication.</p>	
	<p>English language publications</p>	

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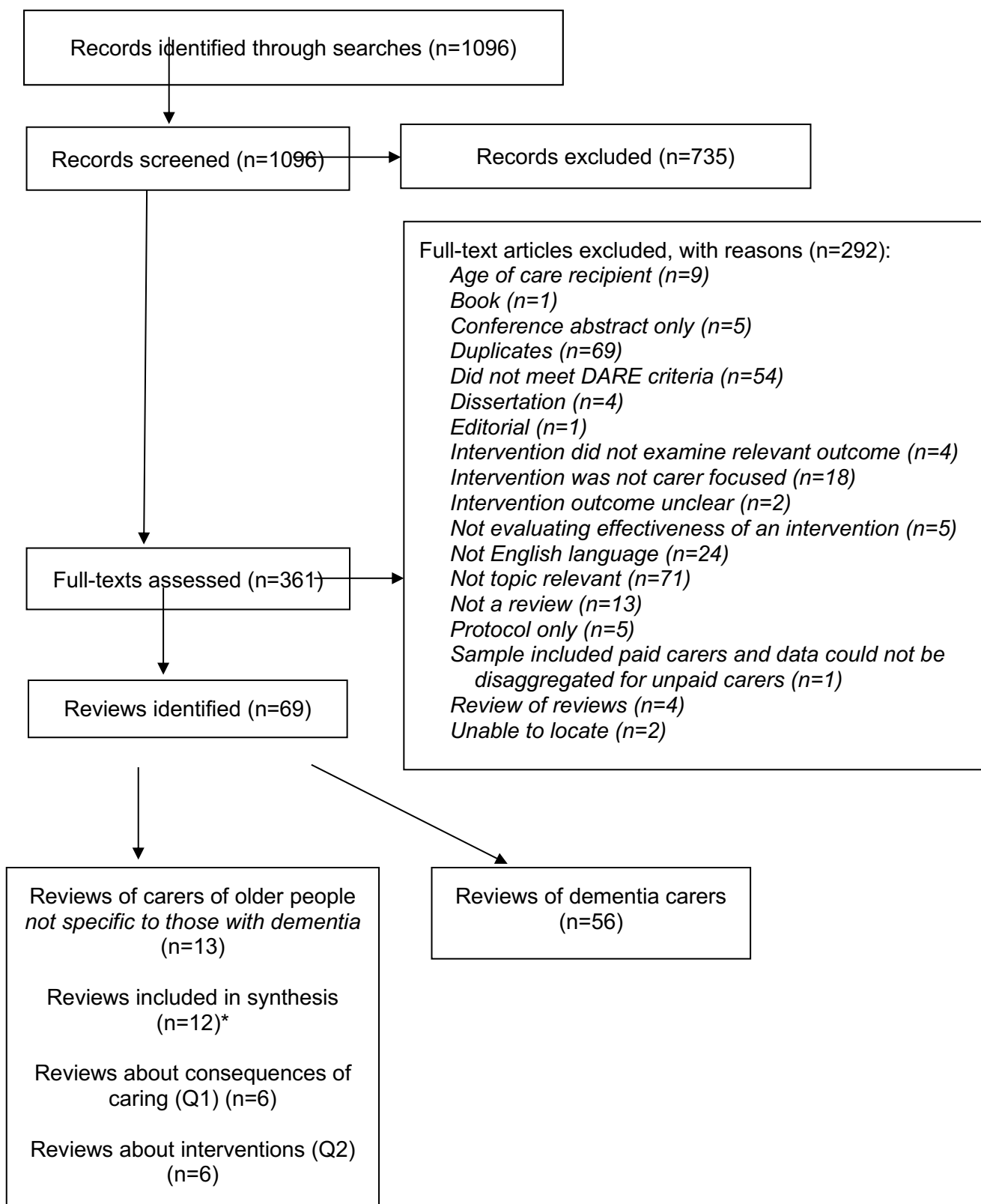
**Table 1.2. Abbreviated risk of bias criteria, adapted from the ROBIS tool<sup>25</sup>**

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1. Can searches be considered exhaustive and thus prone to minimal bias?
  2. Are review criteria clear, and thus prone to minimal selection bias?
  3. Is the quality assessment incorporated into the synthesis to prioritise more robust evidence, or considered in relation to the conclusions drawn?
  4. Is the synthesis transparent and clear: sufficient study details are reported; synthesised evidence is referenced appropriately?
  5. Do review findings and synthesis avoid emphasising results based only on statistical significance?
-



**Figure 1.1. PRISMA flowchart of study selection**



\*One review intended to focus on generic older populations, but all but one included studies were specifically for those with dementia. This review was therefore excluded from this synthesis.

**Table 1.3. Number of included systematic reviews by population and focus of review**

<b>Total number of reviews: 69</b>		
	<b>Older people</b>	<b>People with dementia or Alzheimer’s Disease</b>
<b>Systematic reviews about the consequences of caring</b>	7	9
<b>Systematic reviews about carer interventions</b>	7	49
<b>Number of unique reviews</b>	<b><u>13 unique reviews</u></b> (one review reported both consequences and interventions)	<b><u>56 unique reviews</u></b> (2 reviews report both consequences and interventions)
<b>Total reviews included in this synthesis</b>	12*	

\*One of the 13 reviews intended to focus on generic older populations, but all but one included studies were specifically for those with dementia. This review was therefore excluded from this synthesis.

## Appendix B. Data summary tables for the rapid review of reviews

**Table 1.4. Overview of systematic reviews reporting evidence about the consequences of caring**

Study	Date	Number of studies in review	Data range of included studies	Population (care recipient)	Type of consequence/impact reported	Do studies within the review compare presence/level of impact with non-carer samples?	Does the review identify evidence about impact for specific carer sub-groups relating to age, sex, socioeconomic status and geographical location?	Synthesis	Indicative risk of bias
Amer <sup>35</sup>	2019	19	1990-2017	Older people	'Caregiver burden', quality of life, perceived difficulty assisting recipient	No	No	Narrative	HIGH
Bom <sup>36</sup>	2019	15	2009-2017	Older people	Mental health, physical health	Yes, controls matched for caregiver health	Sex, SES, location (European region)	Narrative	HIGH
Ge <sup>2</sup>	2017	7	1999-2014	Older people with cancer	'Caregiver burden' prevalence and severity	No	Sex, SES, age	Narrative	MODERATE
Jansen <sup>37</sup>	2018	14	1994-2016	Older cancer survivors	Prevalence and predictors of 'caregiver burden', depression, anxiety, self-esteem, distress, communication issues, stress and QoL	Yes, general population	Sex, SES	Narrative	HIGH
Namasiv ayam <sup>38</sup>	2018	4	2002-2017	Older people	'Caregiver burden' associated with feeding difficulties	No	No	Narrative	HIGH
Ringer <sup>40</sup>	2017	9	1997-2012	Older people with frailty	'Caregiver burden', negative reactions to caregiving	Unclear	No	Narrative	MODERATE

**Table 1.5. Summary of evidence by review risk of bias**

Study	Type of consequence/impact reported					Evidence about which groups may be at greater risk
	Health (physical and mental)	Social	Finance	Quality of life	Other	
<i>Evidence from reviews with a moderate risk of bias</i>						
Ge <sup>2</sup>	<p><b>'BURDEN' (PREVALENCE)</b> Across 3 studies, the proportion of carers reporting levels of 'carer burden' varied from 37% to 100%.</p> <p><b>'BURDEN' (SEVERITY)</b> The percentage of carers who reported high 'burden' ranged from 1% to greater than 35% (across 4 studies).</p>	NA	NA	NA	NA	<p><b>SEX</b> Limited evidence of an association between sex of carer (male) and higher 'carer burden'.</p> <p><b>AGE</b> Younger carer age was associated with higher 'carer burden'.</p> <p><b>SES</b> Limited evidence that lack of social support and insufficient financial support were factors contributing to higher 'carer burden'.</p>
Ringer <sup>40</sup>	<p><b>'BURDEN', DEPRESSION, ANXIETY</b> Carers of frail older adults experienced 'burden', depression and anxiety, but it was not possible to quantify this from included studies. Evidence from one included study indicated that the 'burden' experienced by carers of frail older people was less than that</p>	NA	NA	NA	NA	None

of carers of those with cancer, diabetes and dementia.						
<i>Evidence from reviews with a high risk of bias</i>						
Amer <sup>35</sup>	<p>DEPRESSION (SEVERITY) Evidence about the level of depression experienced by carers differed across studies; levels were judged to be both mild to moderate, and severe, although it is not clear how these were defined.</p> <p>'BURDEN' (SEVERITY) 'Carer burden' was judged to be low to moderate, although it is not clear how these are defined.</p>	NA	NA	Carers' quality of life was lower compared to national levels.	Limited findings suggest an association between carers' perceived difficulty in assisting care recipients and differences in cultural values.	None
Bom <sup>36</sup>	<p>DEPRESSION (PREVALENCE) Caring was associated with higher prevalence of depressive feelings and lower mental health scores.</p> <p>PHYSICAL HEALTH There was mixed evidence about impact on physical health; review authors suggest this reflects different outcome measures.</p>	NA	NA	NA	NA	SEX Impact of caring on health is greater for females and those married.
Jansen <sup>37</sup>	<p>DISTRESS AND ANXIETY (SEVERITY) There was limited evidence showing greater distress and anxiety in carers of older cancer</p>			Limited evidence shows an association between lower quality of life and carers of older	There was limited evidence that carers reported difficulties in	SEX One study reported that being a female carer was a predictor for 'burden' while another study found that being a male spousal

	<p>survivors compared to the general population.</p> <p><b>SELF-ESTEEM</b> There was limited evidence that caring was associated with a high self-esteem.</p> <p><b>DEPRESSION</b> Evidence of impact on depression was reported to be varied (although full details are not reported). Authors suggest that this was due to the variety of instruments used to measure the outcome.</p> <p><b>'BURDEN' (PREVALENCE)</b> Limited evidence indicated 40% of carers experienced high 'carer burden'.</p> <p><b>STRESS (SEVERITY)</b> Limited evidence that carers experience higher levels of stress than the UK general adult population</p>				<p>cancer survivors compared with the general population</p>	<p>talking to the care recipients about their illness, suggesting communication issues</p>	<p>carer was a risk factor for 'burden'.</p>
Namasivayam <sup>38</sup>	<p><b>'BURDEN' (SEVERITY)</b> Dysphagia in older care recipients is associated with increased 'carer burden'.</p>	NA	NA	NA	NA		None

**Table 1.6. Overview of systematic reviews reporting evidence about carer interventions**

Number							Synthesis	Indicative risk of bias
Domingues <sup>88</sup>	2018	4	2013-2016	Older people with mild cognitive impairment	Cognitive, multicomponent	'Burden', quality of life, anxiety, mood	Narrative	HIGH
Guay <sup>89</sup>	2017	12	2000-2015	Older people	Internet-based interventions, including education, self-help therapeutic, and human-supported therapeutic.	Depression, anxiety, stress, 'strain', 'burden', physical burden, self-perceived health, quality of life	Narrative	HIGH
Lopez-Hartman <sup>90</sup>	2012	10	2002-2009	Older people	Individual and group psychosocial support	Depression, 'burden', stress, 'role strain', coping, knowledge, social support, anxiety, economic burden.	Narrative	HIGH
Mason <sup>91</sup>	2007	22	1085-2003	Older people	Respite	Satisfaction, 'burden'	Both	LOW
Murfield <sup>92</sup>	2019	4	2013-2018	Older people	Mindfulness + stress reduction, yoga and meditation.	Self-compassion, 'other health' outcomes	Narrative	MODERATE
Shaw <sup>93</sup>	2009	104	2005-2009	Older people	Respite	'Burden', depression, anxiety, morale, anger, hostility, caregiving relationship	Both	LOW

**Table 1.7. Summary of evidence by review risk of bias**

Study	Interventions for carers of older people	
	Findings	Sub-group analysis
	<i>Evidence from reviews with a low risk of bias</i>	
Shaw 2009 <sup>93</sup>	Pooled analyses indicated respite care had no effect on ‘carer burden’ and anxiety, and little effect on carer depression. Some evidence indicated that respite was associated with worse carer quality of life, although the review authors note there were potential sources of bias in these studies. Other evidence indicated respite may improve the carer-recipient relationship. Home help-based respite may improve carers’ morale.	None reported.
Mason 2007 <sup>91</sup>	There was no consistent evidence to indicate respite care was beneficial to carers. Pooled analysis indicated no effect on ‘carer burden’, and a small improvement in depression, although authors note a methodological flaw which undermines the reliability of this finding. However, satisfaction levels were generally high for all types of respite compared to usual care.	<i>Although the authors report findings from one study about outcomes for sub-groups, it is not clear if this refers to the carer or recipient. Other sub-group findings reported relate to likelihood of the carer ‘institutionalising’ the care recipient.</i>
	<i>Evidence from reviews with a moderate risk of bias</i>	
Murfield 2009 <sup>92</sup>	There was limited evidence (1 study) that a mindfulness stress reduction intervention may improve carer depression and anxiety but not other outcomes. There was limited evidence (1 study) that a yoga + meditation based intervention improved carer self-compassion and quality of life.	None reported.
	<i>Evidence from reviews with a high risk of bias</i>	
Domingues 2018 <sup>88a</sup>	There was limited and mixed evidence for a cognitive intervention and a multicomponent intervention.	None reported.
Guay 2017 <sup>89</sup>	There was no consistent evidence to indicate web-based education interventions were beneficial to carers, and mixed evidence for therapy interventions.	None reported.
Lopez-Hartman 2012 <sup>90</sup>	There was inconsistent evidence about whether individual and group psychosocial support interventions are beneficial for carers, with improvements to some outcomes but not others.	One study reported that carers sharing a household with care recipients may benefit more from an individual psychosocial support group compared to those living apart.

<sup>a</sup>Other interventions were reported in this review but did not target only the carer and were primarily oriented towards supporting the care recipient.



**Table 1.8. Reviews reporting outcomes by intervention classification**

OUTCOME	INTERVENTION TYPE				
	Respite	Psychosocial	Cognitive	Education	Multicomponent
'Burden'	Shaw 2009	Lopez-Hartman 2012	Domingues 2018	Guay 2017	Domingues 2018
	Mason 2007	Guay 2017			
Depression/mood	Shaw 2009	Lopez-Hartman 2012 Guay 2017	Domingues 2018	Guay 2017	Domingues 2018
Anxiety	Shaw 2009	Lopez-Hartman 2012 Guay 2017	-	-	-
Stress, wellbeing, quality of life, 'role strain', morale, self-compassion	Shaw 2009	Lopez-Hartman 2012 Murfield 2019	-	Guay 2017	
Health, physical burden, 'other' health	-	Guay 2017	-	-	-
Anger, hostility	Shaw 2009	-	-	-	-
Knowledge	-	Lopez-Hartman 2012 Guay 2017	-	-	-
	-	Lopez-Hartman 2012 Guay 2017	-	-	-
Coping	-	Lopez-Hartman 2012 Guay 2017	-	-	-
Relationships	Shaw 2009	-	-	-	-
Satisfaction	Mason 2007	-	-	-	-
Economic burden	-	Lopez-Hartman 2012	-	-	-

## Appendix C: Systematic reviews about dementia carers

This appendix provides summary details of the 56 systematic reviews (9 about the consequences of caring,<sup>26-34</sup> and 49 about interventions<sup>26,30,41-87</sup>) and 3 reviews of reviews ('umbrella reviews'), identified about dementia carers.

### Summary of existing review of reviews on the consequences of caring for dementia specific populations

Searches identified one review of reviews that reported evidence about the consequences of caring for people with dementia. This review reported evidence from 4 studies that being a carer for a person with dementia increased risk of psychological stress and physical ill-health.<sup>95</sup>

### Summary of existing reviews of reviews on carer interventions for dementia specific populations

Searches identified 3 reviews of reviews of dementia carer interventions, published between 2015 and 2017.<sup>94-96</sup> The Gilhooly review found evidence that psychosocial, psychoeducational, therapy, social support groups and multicomponent interventions improved carer psychological wellbeing, coping and knowledge.<sup>95</sup> The Hui in het Veld review reported evidence that professional self-management interventions improved carer stress and social outcomes.<sup>96</sup> Information interventions improved carer knowledge, but not competence and decision making. There was less evidence about the benefits of interventions to promote carer coping and memory change. Finally, the Dickinson review concluded that multicomponent interventions are beneficial to carers' psychological health, and are most effective when incorporating education and therapy.<sup>94</sup>

**Appendix C Table 1. Overview of systematic reviews reporting evidence about the consequences of caring (dementia care recipients)**

Study	Date published	Number of studies in review	Data range of included studies	Population (care recipient)	Type of consequence/impact reported	Do studies within the review compare presence/level of impact with non-carer samples?	Does the review identify evidence about impact for specific carer sub-groups relating to age, sex, socioeconomic status and geographical location?	Syntheses	Indicative risk of bias
Allen	2017	151	1996-2015	People with dementia	Psychobiological markers of stress	Yes, where relevant	None	Narrative	HIGH
Chiao	2015	21	2003-2012	People with dementia	'Burden'	Not reported	SES, sex	Narrative	HIGH
Cooper	2007	33	1988-2005	People with dementia	Anxiety prevalence	Yes, where relevant	Age, diagnosis, sex	Narrative	LOW
Farina	2017	41		People with dementia	Quality of life, health, emotional wellbeing, relationships	Not reported	Sex, SES	Narrative	MODERATE
Gao	2019	35	1999-2018	People with dementia	Sleep	Yes	None	Meta-analysis	HIGH
Kaddour	2019	10	1995-2015	People with dementia	Anxiety prevalence	No	None	Meta-analysis	LOW
Ma	2018	18	1990-2015	People with dementia and Alzheimer's	Depression, mood	Yes	Sex (as moderator analysis)	Meta-analysis	MODERATE
Sallim	2015	17	2001-2015	People with Alzheimer's	Prevalence of depression, anxiety, use of psychotropic drugs	No	Sex, sex of recipient.	Both	HIGH
Schoenmakers	2010	14	1998-2005	People with dementia	Depression	Yes, where relevant	Age, sex	Both	MODERATE

**Appendix C Table 2. Overview of systematic reviews reporting evidence about carer interventions (dementia care recipients)**

Number						Outcome	Synthesis	Indicative risk of bias
Abrahams	2018	22	2015-2018	People with dementia	Multicomponent	'Burden', depression, health and social support	Meta-analysis	HIGH
Acton	2001	24	1985-1999	People with dementia	Support groups, education, psychoeducation, counselling, respite care, and multicomponent	'Burden'	Meta-analysis	HIGH
Akarsu	2019	13	2003-2015	People with dementia, minority ethnic communities	Psychological therapies, educational, multicomponent	Depression	Meta-analysis	MODERATE
Allen	2017	151	1996-2015	People with dementia	Yoga, medication, CBT, respite, coping, support	Psychobiological markers of stress	Narrative	HIGH
Brodaty	2003	30	1985-2001	People with dementia	Psychosocial	Distress, 'burden', knowledge, mood	Meta-analysis	HIGH
Bunn	2016	33	2001-2012	People with dementia	Admiral Nurses, psychosocial, educational, multicomponent, information, support, case management.	'Burden', depression, mood, social support, wellbeing, knowledge, health, satisfaction	Narrative	HIGH

Chien	2011	30	1998-2009	People with dementia	Support groups	Psychological well-being, Depression, 'burden', and social outcomes.	Meta-analysis	MODERATE
Collins	2019	12	2010-2016	People with dementia	Mindfulness- and acceptance-based interventions Social support (befriending and peer support, family support, social network interventions, support groups, remote interventions using the internet or telephone)	Depression, 'burden'	Meta-analysis	MODERATE
Dam	2016	39	1987-2014	People with dementia	Technology-based interventions	Social support, wellbeing	Narrative	HIGH
Deeken	2019	33		People with dementia	Online training	'Burden', depression	Meta-analysis	MODERATE
Egan	2017	8	1995-2015	People with dementia	Psycho-educational skill building, psychotherapy-counselling, multicomponent, technology-based interventions.	Mental health, 'burden', quality of life, coping, knowledge, self-efficacy.	Narrative	HIGH
Elvish	2012	20	2005-2011	People with dementia	Psychoeducational (technology and group delivered)	Carer wellbeing	Narrative	HIGH
Frias	2019	20	2005-2016	People with dementia	Sleep intervention	Anxiety, depression, insomnia, 'burden', quality of life, self-efficacy	Narrative	MODERATE
Gao	2019	35	1999-2018	People with dementia	CBT	Sleep quality and duration	Meta-analysis	HIGH
Hopkinson	2019	25	1996-2017	People with dementia		Depression, stress, anxiety	Meta-analysis	LOW

Hopwood	2018	40	1995-2018	People with dementia	Internet-based interventions, including: contact with health or social care providers, peer interaction, provision of information, decision support, and psychological support	Depression, anxiety, 'burden'	Narrative	HIGH
Jackson	2016	17	1998-2015	People with dementia	Telephone, psychoeducation, psychotherapy, support, multicomponent; delivered by telephone, internet or both	'Burden', distress, depression, anxiety, social support, suicidality, self-efficacy, quality of life, health, reactions to problem behaviour, coping, life satisfaction	Narrative	HIGH
Jones	2012	12	1991-2010	People with dementia	Pharmacological, psychosocial, service delivery	Cost effectiveness	Narrative	HIGH
Kaddour	2018	12	1999-2016	People with dementia	CBT	Anxiety, depression, 'burden', distress	Meta-analysis	LOW
Kor	2018	5	2010-2015	People with dementia	Mindfulness intervention	Stress, 'burden', anxiety and depression	Meta-analysis	LOW
Lee	2019	26	2005-2017	People with dementia, AD or MCI	Multicomponent interventions, CBT, mindfulness, psychoeducation, social support, case management and cognitive rehabilitation therapy.	Depressive symptoms	Meta-analysis	MODERATE
Lee	2004	3	1989-2003	People with dementia	Respite care	'Burden'	Narrative	LOW

(SEE UPDATED REVIEW Maayan 2014)									
Lee	2020	26	2007-2017	People with dementia	Multicomponent, cognitive behavioural therapy, complementary alternative medicine therapy, psychoeducation, social support, case management, cognitive rehabilitation therapy	Health related quality of life	Meta-analysis	MODERATE	
Liew	2019	33	2005-2014	People with dementia	Multicomponent	Depression	Meta-analysis	MODERATE	
Lins	2014	12	1999-2008	People with dementia	Telephone counselling	Depressive symptoms, 'caregiver burden', distress, anxiety, quality of life, self-efficacy, satisfaction.	Both	LOW	
Liu	2017	7	2010-2017	People with dementia	Mindfulness	Depression, stress, mental health related quality of life	Meta-analysis	MODERATE	
Liu	2018	5	2010-2016 (NOTE: 4 studies are the same as those included in Liu 2017)	People with dementia	Mindfulness	Depression, anxiety, 'burden', coping	Meta-analysis	LOW	
Lucero	2019	12	1995-2015	People with dementia	Information & communication technologies	Service use, anxiety,	Narrative	MODERATE	

						depression, 'burden', wellbeing, stress, self-efficacy, positive affect, negative affect, confidence, social isolation		
Maayan (See Lee 2004)	2014	4	1989-2003	People with dementia	Respite care	'Burden', psychological stress and health, and quality of life	Meta-analysis	LOW
McKechnie	2014	14	2003-2011	People with dementia	Computer delivered psychosocial interventions	'Burden', stress, depression, anxiety, positive aspects of caring, self-efficacy, social support, physical aspects.	Narrative	LOW
Moore	2019	11	2009-2015	People with dementia	Education	Depression, knowledge, 'burden'	Both	HIGH
Muller	2017	5	2004-2015	People with dementia	Psychosocial	Depression, 'burden', feeling of guilt, emotional distress, overload, interactions with staff, stress, placement	Narrative	MODERATE



						adaptation, role overload, role captivity.		
Orgeta	2014	4	1997-2011	People with dementia	Physical activity	'Burden'	Narrative	MODERATE
Parker	2018	40	2000-2005	People with dementia	Psychoeducational, support, multicomponent, other interventions	Depression, health, wellbeing, self-efficacy, 'burden'.	Both	MODERATE
Petriwskyj	2016	3		People with dementia	Resilience building interventions	Resilience, self-efficacy, locus of control, perceived 'burden', psychological wellbeing, strength, coping, positive adjustment, resourcefulness	Narrative	MODERATE
Piersol	2017	43	2008-2013	People with dementia and Alzheimer's	Multicomponent psychoeducational, communication skills training, mindfulness based training, professionally led support groups, cognitive reframing	Quality of life (QOL), confidence, self-efficacy, reduce 'burden', anxiety, depression, stress, skill	Narrative	LOW
Pinquart	2006	127	1989-2005	People with dementia	Psychoeducational, CBT, counselling, general support, respite, multicomponent interventions	'Burden', depression, subjective well-being	Meta-analysis	LOW
Pusey	2001	30	1985-1999	People with dementia	Psychosocial	Wellbeing, 'burden', stress,	Narrative	MODERATE

						psychological morbidity, coping, stress, anger, depression, 'strain'		
Schoenmakers	2010	26	1980-2006	People with dementia	Psychosocial, case management, respite	Depression, 'burden'	Narrative	MODERATE
						Depression. Other outcomes were reported in the included studies but these were not synthesised in the review (anxiety, coping, self-efficacy, stress, 'CG strain/gain', quality of life, anger).		
Scott	2016	4	2000-2013	People with dementia	Technology-based (that is not face to face) CBT	quality of life, anger).	Meta-analysis	MODERATE
						Mental health, 'burden', depression, anxiety, stress, 'strain'		
Selwood	2007	62	1988-2003	People with dementia	Psychological		Narrative	HIGH
Smith	2014	4	2002-2008	People with dementia	Befriending, mentoring and peer support	Depression	Narrative	HIGH
						'Burden', depression, general health		
Teahan	2020	22	2007-2015	People with dementia	Psychosocial interventions		Meta-analysis	LOW

Thompson	2007	44	1982-2003	People with dementia	Information and support	Depression, 'burden', self-efficacy	Meta-analysis	LOW
Waller	2017	34	1995-2016	People with dementia	Computer and telephone delivered interventions including psycho-education, peer support, skills training and health assessments	Wellbeing, depression, mental health	Narrative	MODERATE
Weinbrecht	2016	33	2005-2014	People with dementia	Knowledge, skills training, emotional support, practical support	Depression	Meta-analysis	LOW
Williams	2019	34	2001-2017	People with dementia	Multicomponent, education/skills, support/counselling, physical activity	'Burden'	Both	LOW
Wu	2018	19	2002-2016	People with dementia	Behavioural management techniques, psychological and social support, education, case management, coping strategies, cognitive behavioural therapy	'Burden', depression, distress, self-efficacy, quality of life, wellbeing, health.	Narrative	HIGH
Zhao	2019	6	2005-2015	People with dementia	Web-based	Depression	Meta-analysis	MODERATE

# Appendix D: Questions posed for exploration in the analysis of the GP Patient Survey

Note: In the timeframe available, it was not possible to address all these questions, and in consultation with the advisory group, questions about carers' health were prioritised.

GP Patient Survey Data – Overarching areas of interest:

- Are the health needs of carers being met?
- Are there sub-sections of the population of carers who experience inequalities in health and access to health care services?

Other questions to explore (dataset variable question number in brackets)

## 1. Descriptive questions

Demographic Questions

- What is the proportion of carers (and numbers) by age bands 45 to 54 and up by 10 year bands? (Q55)
- What is the proportion of carers by gender? (Q54)
- What is the proportion of carers by ethnicity? (Q56)
- Proportion of carers by geographical regions (London, North West etc)
- % of carers by what they are doing at present (by all identified in Q57), full time paid work, etc.
- % of carers providing care by hours a week (Q59)
- % of carers who are deaf people using sign language (Q60)
- What proportion of persons attending GP appointments were carers?

Analytical questions

2.0 Compared to the general population aged 45 to 54 and upwards, completing the survey:

- How satisfied are carers 45 to 54 and upwards with the general practice appointment times that are available to them? (Q8)
- When was the carer's last general practice appointment? (Q23)
- What proportion of carers have been successful in getting an NHS dental appointment (Q51)
- Has the carer experienced any of the following over the last 12 months? (Q32)
  - Problems with physical mobility
  - 2 or more falls that need attention
  - Feeling isolated from others
  - None of these

### 3.0 Carers only

- Is there a difference in hours of care provided by age/gender/ethnicity?
- What proportion of carers are working full time/part time/unemployed/retired and what ages/gender/ethnicity are these carers? (Q57 & 59)
- How does hours of care provided relate to the carer's paid work/current occupation? (Q57)

#### 3.1 Inequalities:

- Is there a difference in provision of caring related to socio-economic status? (e.g. using postcode and indices of deprivation)
- For higher and lower socio-economic groups, how many hours of care are being provided each week?

#### 3.2 Mental Health

- What proportion of carers feel that their mental health needs are recognised and understood in their general practice, by age/gender/ethnicity?(Q27)
- Are health needs of carers being met by age/gender/ethnicity? (Q30)

#### 3.3 Multiple long-term conditions (multimorbidity)

- What proportion of carers (by age, gender, ethnicity, SES) have ONE identified health conditions? (Q34)
- What proportion of carers have 2 or more health conditions (multi-morbidity) by age, gender, ethnicity)? (Q33 and Q35)
- What are the top 3 health conditions affecting carers? (Q35)
- What proportion of carers are receiving enough support to manage their conditions (tick in 'yes, definitely' box) (Q38)
- What proportion of carers have in the last 12 months had an unexpected stay in hospital because of their condition (Q39)?
- What % of carers take 5 or more medications on a regular basis? (Q33)

#### 3.4 Dental Health

- What proportion of carers by age/gender/ethnicity have been successful in getting an NHS dental appointment (Q51)?
- Is there a relationship between amount of caring that is done and having not tried to get a dental appointment in the last 2 years because carers haven't had time to visit a dentist (Q53)?

#### 3.5 Smoking habits

What are the smoking habits of carers by age, gender, ethnicity? (Q61)

## Appendix E: GP Patient Survey methods and tables

This section describes the methods used for the analysis of GP Patient survey.

The data source

The GP Patient Survey is an annual population based postal survey of adults aged 16 and over, run by Ipsos MORI on behalf of NHS England. The study population comprises a random sample of patients registered with each English GP surgery, provided they have been continuously registered for at least 6 months. The survey focuses on patient experiences of accessing primary care and dental services, but also contains a short section about respondents' health and employment. The results reported here were extracted from the 2019 survey data release. Full details of the GP Patient Survey methodology are reported elsewhere.<sup>97</sup> As the survey does not contain data about care recipients, the analysis reported here is not specific to carers of older people.

### Study variables

Carers were identified using responses to question 59 of the survey, which asks 'Do you look after, or give any help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill health / disability, or problems related to old age?', to which respondents could choose one from the following options; 'No', 'Yes, 1 to 9 hours a week', 'Yes, 10 to 19 hours a week', 'Yes, 20 to 34 hours a week', 'Yes, 35 to 49 hours a week' or 'Yes, 50 or more hours a week'. This variable was used in 2 ways: as an ordinal variable using the original categories (with the 1 to 9 hours category as the referent and excluding non-carers), or as a binary variable describing any amount of caring versus none. All analyses were restricted to participants aged 45 years and over. Deprivation status was measured using the index of multiple deprivation (IMD). Office of National Statistics (ONS)-calculated IMD ranks were converted to tertiles, with tertile 1 being the least deprived and tertile 3, the most deprived.

### Study weights

Weighted methods were used throughout the analysis to ensure that the results reflect the views of the general population. The weights supplied with the data were created using a model-based approach, accounting for local factors (such as deprivation, crime levels, ethnicity, marital status, overcrowding in households, household tenure and employment status) as well as individual sociodemographic characteristics. For further

information on how the weights were created, please see the GP Patient Survey technical annex.<sup>97</sup>

## Statistical analysis

Respondent characteristics were analysed across caring groups and presented using counts and percentages. Comparisons between groups were assessed using chi square ( $\chi^2$ ) tests.

Logistic and ordinal logistic regression models were used to assess the associations of age, sex, ethnicity and deprivation (tertiles) on caring as a binary or ordinal variable, where ordinal models were run using the caring subset and logistic models were run on the full data. Similarly, the associations of age, sex, deprivation and ethnicity on multimorbidity status (2 or more conditions of those reported in Q35 excluding autism and learning difficulties) and polypharmacy (taking 5 or more medications regularly) were modelled in logistic regression models. The outcomes of multimorbidity (multiple long-term conditions) and polypharmacy were selected for this analysis in consultation with the commissioners of this report.

Weighted models were created using the Survey package,<sup>98</sup> in R software version 3.5.1 (R Core team, Vienna, Austria).

**Table 2.1. Characteristics of respondents to the 2019 GP Practice Survey by carer status. Numbers are the weighted totals, percentages are based on column totals, p-values are results of  $\chi^2$  tests of independence between categories**

	Not a carer	Carer	P-value
<b>GP practice location</b>			<0.001
East Midlands	28669 (9%)	8108 (9%)	
Eastern	36314 (11%)	10430 (12%)	
London	44512 (14%)	10512 (12%)	
North East	16079 (5%)	4690 (5%)	
North West	43064 (13%)	12379 (14%)	
South East	54669 (17%)	15306 (17%)	
South West	34642 (11%)	10109 (11%)	
Wales	92 (<1%)	20 (<1%)	
West Midlands	33984 (11%)	9855 (11%)	
Yorkshire & Humber	31577 (10%)	9181 (10%)	
<b>Q8.* GP appointment time satisfaction</b>			<0.001
No	90355 (31%)	29109 (35%)	
Yes	200369 (69%)	53008 (65%)	
<b>Q23. Attended GP appointment</b>			<0.001
Past 3 months	177584 (57%)	50548 (57%)	
3-6 months	58042 (18%)	16478 (19%)	
6-12 months	40812 (13%)	11615 (13%)	
12 + months	34041 (11%)	9121 (10%)	
Not attended since registered	3692 (1%)	642 (1%)	
<b>Q27. Mental health needs met</b>			<0.001
No	12114 (11%)	4378 (13%)	
Yes	102084 (89%)	29695 (87%)	



		<b>Not a carer</b>	<b>Carer</b>	<b>P-value</b>
<b>Q30. Needs met</b>				<0.001
	No	11337 (4%)	3788 (4%)	
	Yes	288375 (96%)	81703 (96%)	
<b>Q32. Health problems over the past 12 months</b>				
<b>Physical mobility</b>				<0.001
	No	260320 (83%)	74037 (84%)	
	Yes	53346 (17%)	13943 (16%)	
<b>Falls</b>				<0.001
	No	303961 (97%)	86099 (98%)	
	Yes	9706 (3%)	1881 (2%)	
<b>Isolation</b>				<0.001
	No	297679 (95%)	83014 (94%)	
	Yes	15987 (5%)	4966 (6%)	
<b>Q33. Polypharmacy (use of 5+ medicines)</b>				<0.001
	No	227929 (71%)	66928 (74%)	
	Yes	92502 (29%)	22937 (26%)	
<b>Q34. Long Term condition</b>				<0.001
	No	100462 (33%)	27566 (32%)	
	Yes	207016 (67%)	59001 (68%)	
<b>Q38. Long term health needs met</b>				<0.001
	No	24313 (18%)	8078 (20%)	

		<b>Not a carer</b>	<b>Carer</b>	<b>P-value</b>
	Yes	109437 (82%)	31458 (80%)	
<b>Q39. Unexpected hospital stay in past 12 months</b>				<0.001
	No	178734 (89%)	52684 (92%)	
	Yes	21624 (11%)	4696 (8%)	
<b>Q51. Dental appointment</b>				<0.001
	No	7930 (5%)	2754 (5%)	
	Yes	163459 (95%)	50112 (95%)	
<b>Q54. Sex</b>				<0.001
	Male	167271 (52%)	39883 (40%)	
	Female	155429 (48%)	59472 (60%)	
<b>Q55. Age</b>				<0.001
	45-54	103172 (32%)	29839 (33%)	
	55-64	86885 (27%)	31073 (34%)	
	65-74	74010 (23%)	18668 (21%)	
	75-84	42503 (13%)	8809 (10%)	
	85+	17123 (5%)	2221 (2%)	
<b>Q56. Ethnic Group</b>				<0.001
	White	286949 (89%)	82556 (92%)	

	<b>Not a carer</b>	<b>Carer</b>	<b>P-value</b>
Asian	17964 (6%)	4022 (4%)	
Black	9117 (3%)	1768 (2%)	
Mixed	2616 (1%)	708 (1%)	
Other	4871 (2%)	920 (1%)	
<b>Q57. Employment</b>			<0.001
Other	7986 (3%)	3193 (4%)	
Full-time education	430 (<1%)	91 (<1%)	
Full-time paid work	113110 (36%)	29153 (34%)	
Fully retired	121383 (38%)	27716 (32%)	
Looking after family/home	8895 (3%)	7188 (8%)	
Part-time Paid work	37919 (12%)	14484 (17%)	
Permanently sick or disabled	16841 (5%)	2694 (3%)	
Unemployed	8986 (3%)	1960 (2%)	
<b>Q60. Deaf or Sign Language User</b>			<0.001
No	321017 (>99%)	89666 (>99%)	
Yes	1242 (<1%)	273 (<1%)	
<b>Q61. Smoking habits</b>			<0.001
Never	169360 (53%)	49399 (55%)	
Former	113865 (35%)	30365 (34%)	
Occasional	15407 (5%)	4191 (4%)	
Regular	23554 (7%)	6203 (7%)	

See <https://gp-patient.co.uk/practices-search> for the precise wording of questions and possible responses. Percentages are calculated column-wise and may not sum to exactly 100 due to rounding.

\*Q8, etc: This refers to Question 8 of the GP Patient Survey

**Table 2.2. Factors associated with caring: Regression models**

Ordinal and logistic regression models of caring as a binary (any or none) or ordinal (levels of caring in hours per week) variable

		Logistic model (any versus no caring)		Ordinal model <sup>b</sup>
		Coefficient (95% CI) <sup>a</sup>	P-value	Coefficient (95% CI) <sup>a</sup>
<b>Age (years)</b>	45 to 54	1 (REF)		1 (REF)
	55 to 64	1.22 (1.19-1.25)	<0.01	1.10 (1.06-1.15)
	65 to 74	0.84 (0.82-0.86)	<0.01	1.56 (1.50-1.63)
	75 to 84	0.68 (0.66-0.70)	<0.01	2.76 (2.63-2.90)
	85+	0.41 (0.39-0.43)	<0.01	4.96 (4.51-5.46)
<b>Gender</b>	Female	1 (REF)		1 (REF)
	Male	0.72 (0.71-0.73)	<0.01	0.89 (0.87-0.92)
<b>Ethnic group</b>	White	1 (REF)		1 (REF)
	Asian	0.76 (0.73-0.79)	<0.01	1.38 (1.30-1.48)
	Black	0.65 (0.61-0.69)	<0.01	0.90 (0.81-1.00)
	Mixed	0.88 (0.79-0.98)	0.02	1.03 (0.86-1.24)
	Other	0.66 (0.60-0.71)	<0.01	1.63 (1.44-1.83)
<b>Deprivation tertile</b>	1 (Least deprived)	1 (REF)		1 (REF)
	2	0.97 (0.95-0.99)	<0.01	1.37 (1.32-1.41)
	3 (Most deprived)	0.89 (0.89-0.93)	<0.01	2.36 (2.27-2.45)

<sup>a</sup>Confidence Interval; <sup>b</sup>Number of hours of care given per week across 5 categories: 1-9 hours was the reference category

**Table 2.3. Caring and multiple long-term conditions: Logistic regression model**

Logistic regression of multiple (2 or more) long-term conditions as a binary dependent variable

		<b>Coefficient (95% CI)</b>	<b>P-value</b>
<b>Carer</b>	No	1 (REF)	
	Yes	1.16 (1.14-1.18)	<0.001
<b>Age (years)</b>	45 to 54	1 (REF)	
	55 to 64	1.92 (1.14-1.18)	<0.001
	65 to 74	3.54 (3.46-3.62)	<0.001
	75 to 84	5.88 (5.74-6.03)	<0.001
	85+	8.88 (8.56-9.20)	<0.001
<b>Gender</b>	Female	1 (REF)	
	Male	1.08 (1.07-1.10)	<0.001
<b>Ethnic group</b>	White	1 (REF)	
	Asian	0.93 (0.90-0.97)	<0.001
	Black	0.80 (0.76-0.84)	<0.001
	Mixed	1.08 (0.97-1.21)	0.14
	Other	0.88 (0.82-0.95)	<0.001
<b>Deprivation tertile</b>	1 (Least deprived)	1 (REF)	
	2	1.25 (1.22-1.27)	<0.001
	3 (Most deprived)	1.83 (1.79-1.86)	<0.001

**Table 2.4. Caring and polypharmacy: Logistic regression model**

Logistic regression model of polypharmacy (5 or more medications) among respondents to the 2019 GP Patient Survey

		<b>Coefficient (95% CI)</b>	<b>P-value</b>
<b>Carer status</b>	No	1 (REF)	
	Yes	0.98 (0.96-1.00)	0.04
<b>Age (years)</b>	45 to 54	1 (REF)	
	55 to 64	1.89 (1.84-1.94)	<0.001
	65 to 74	3.60 (3.51-3.69)	<0.001
	75 to 84	7.29 (7.10-7.49)	<0.001
	85+	10.76 (10.36-11.18)	<0.001
<b>Gender</b>	Female	1 (REF)	
	Male	1.13 (1.12-1.15)	<0.001
<b>Ethnic group</b>	White	1 (REF)	
	Asian	1.26 (1.21-1.31)	<0.001
	Black	0.86 (0.81-0.91)	<0.001

	Mixed	1.05 (0.93-1.19)	0.45
	Other	1.27 (1.18-1.37)	<0.001
<b>Deprivation tertile</b>	1 (Least deprived)		
	2	1.33 (1.31-1.36)	<0.001
	3 (Most deprived)	2.24 (2.20-2.29)	<0.001

## Appendix F: Data sources about carers

This section presents a profile of data sources about carers.

### Profiles of data sources

Table 4.1 presents a summary of data sources in the UK that include data about carers. Three sources are UK wide, and 5 are specific to the English population. Most data sources are those that are routinely collected from national administrative surveys, and are free to download from NHS Digital or the UK data service.

**Table 4.1. Profile of data sources on caring**

<b>DATA SOURCE</b>	<b>Type of data set</b>	<b>Years</b>	<b>Sample size</b>	<b>Population</b>	<b>Topics covered</b>	<b>Access</b>
Personal Social Services Survey of Adult Carers  ENGLAND	Routine, every other year	2009-2019	Varies by year; most recent year, 136,095 surveyed via local authorities.	Carers aged 18+ caring for those aged 18+	<ul style="list-style-type: none"> <li>• Provision of care</li> <li>• Socio-demographics of carers</li> <li>• Services used by carers</li> <li>• Impact of services on ability to provide care</li> <li>• ASCOF outcomes include quality of life, social contact, satisfaction with services, being included in discussions with recipient, ease of finding information and support.</li> </ul>	Free, data downloadable from NHS Digital.
Survey of Carers in Households  ENGLAND	One-off cohort	2009-2010	2400	Carers aged 16+	<ul style="list-style-type: none"> <li>• Provision of care</li> <li>• Socio-demographics of carers and care recipients</li> <li>• Impact of caring</li> <li>• Services used by carers</li> </ul>	Free, data downloadable from NHS Digital.

2011 Census UK	Routine	2011	Census	Carers of any age caring for someone of any age	<ul style="list-style-type: none"> <li>• Provision of care</li> <li>• Socio-demographics of carers</li> </ul>	Free, data downloadable from the Office for National Statistics.
GP Patient Survey ENGLAND	Routine, yearly	2007-2019	750,000	Random sample of primary care patients.	<ul style="list-style-type: none"> <li>• Provision of care</li> <li>• Socio-demographics of carers and care recipients</li> <li>• Use and satisfaction with services</li> <li>• Impact of caring on employment, quality of life, health.</li> </ul>	<a href="http://www.gp-patient.co.uk">www.gp-patient.co.uk</a>
Understanding Society UK	Longitudinal cohort study, with refreshed samples at intervals.	2009-2019	Varies each wave.	Carers aged 16+	<ul style="list-style-type: none"> <li>• Provision of care</li> <li>• Socio-demographics of carers and care recipients</li> <li>• Impact of caring on employment, wealth, health and wellbeing.</li> </ul>	Three levels of access depending data required. Free, application to UK Data Service required to obtain licence for use.
English Longitudinal Study of Ageing ENGLAND	Longitudinal cohort study, with refreshed samples at intervals.	1998-2017	Varies each wave.	Carers aged 50+	<ul style="list-style-type: none"> <li>• Provision of care</li> <li>• Socio-demographics of carers</li> </ul>	Free, available from UK Data Service, but requires application.
Family Resources Survey UK	Routine, yearly	2010-2019	Varies each year.	Carers aged 16+	<ul style="list-style-type: none"> <li>• Provision of care</li> <li>• Socio-demographics of carers and care recipients</li> <li>• Employment of carers.</li> </ul>	Free, downloadable from the Office for National Statistics
Health Survey for England	Routine, yearly	2011-2018	Varies each year,	Carers aged 16+	<ul style="list-style-type: none"> <li>• Provision of care</li> </ul>	Free, downloadable from NHS Digital.



ENGLAND			but 8178 participants in 2018 survey.		<ul style="list-style-type: none"> <li>• Socio-demographics of carers and care recipients</li> <li>• Data on informal caring from 2011.</li> <li>• Perceived impact of caring on health, mood, sleep and employment.</li> </ul>	
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