



Technical note accompanying the model: 'Socioeconomic Costs and Benefits of Unpaid Carers'

Produced for NHS England



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1. Introduction

The context of unpaid caring in the UK

'A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support' (Carers Trust)

The United Kingdom is experiencing rapid growth in the number of paid and unpaid carers, catering to the needs of an aging population profile and (until recently) increasing life expectancies. Data from the 2018 GP Survey puts the total number of carers in England at around 7.3 million. The very large contribution these carers make in the economy is broadly recognised in health and social care research, and was estimated by the Office for National Statistics to be worth £57 billion in 2017.¹ Despite this, high-level decision-making and service commissioning have often not integrated the socioeconomic costs and benefits of dependence on unpaid carers.¹ Extensive research by Carers UK has highlighted the personal and societal cost levied on carers, particularly around issues such as mental and physical health, and career opportunities.²

Research has shown that integrating the impact of a health or social care intervention on the unpaid carer population can affect which option emerges as optimal.ⁱⁱ However, with growing national dependence on the unpaid carer population and extreme budgetary pressures on health and social care commissioning bodies, there is increasing interest in better understanding and quantifying the relative merits of providing support services directly aimed at carers.

NEF Consulting were commissioned by NHS England to undertake the second phase of a project begun in 2017 aimed at better understanding the economic case for support to carers. This work involves the development of a cost-benefit model that can be populated with local data by ICSs/STPs to enable costed, evidence-based business cases for intelligent, locally targeted carer support. To our knowledge, the full range of costs and benefits associated with unpaid care has not been aggregated nor systematically estimated at a population level, and this model and technical note represents a first attempt to do so.

¹ Unpaid carers provide social care worth £57 billion. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10> [accessed 17/05/2019]

² <https://www.carersuk.org/for-professionals/policy/policy-library>

Project overview

Scoping phase

Facilitated by the NHS project team, NEF Consulting conducted a scoping phase involving:

- Review of the initial first qualitative study conducted in 2017, wider literature, research, and data.
- Scoping interviews with members of three ICSs/STPs and Carers UK.

From this scoping work we distilled a wide range of potential model data sources and parameters. The most notable data sources, which underpin the model's primary functions, are the 2017 and 2018 GP Survey, and the 2017 HSE Survey. In processing this data we were assisted by the GP Survey team. During scoping we also established a broad categorisation of the types of intervention which tend to be targeted at carers:

1. Working with employers to help them understand and support carers in their organisations.
2. Carer support groups.
3. Respite services.
4. Carer training programmes.

Also important, but treated differently, is the process of identifying and reaching out to carers.

This categorisation will later inform the intervention-testing component of the model. We have also refined and simplified the outcomes framework established in the scoping study to make it suitable for conversion into a credible economic model.

Identifying outcomes

The outcomes in Table 1 were distilled from the logic models designed in Phase One of this project, the scoping interviews, and the literature reviews conducted.

2. The structure of the modelling

Baseline and interventions modelling approaches

The modelling work in this project addressed two questions about the carer population:

- What are the direct and indirect costs of providing unpaid care (both to carers and to different stakeholders) across the outcomes identified above?
- What scale of value could be achieved across stakeholders if carers were better supported to improve across these outcomes?

Table 1: Outcomes identified.

Stakeholder	Outcome
Carer	Mental health-related wellbeing
	Social relationships-related wellbeing
	Employment/job – related wellbeing (double counting with two outcomes above was accounted for)
	Physical health
	Income (salary/benefits)
State (NHS)	Mental health care costs (carer)
	Physical health care costs (carer)
	Physical health care costs (cared-for)
State (Local authorities)	Costs of (avoidable) residential care (cared-for)
State (undefined)	Cost of professional care worker
Cared-for person	Mental health-related wellbeing
	Physical health-related wellbeing
	Costs of (avoidable) residential care

The model approaches these questions through the ‘baseline approach’ and ‘interventions modelling’:

- The baseline approach offers an understanding of the scale of costs associated with different stakeholders in the provision of unpaid care, by comparing carers’ outcomes, and their implications for public services and benefits, with the non-carer population. Most of these are calculated by comparing carer and non-carer outcomes in the GP Survey, but some involve a different approach. For a full explanation of the approach taken for each outcome, see Table 4.
- The interventions modelling offers an understanding of how different sources of support can affect different stakeholder outcomes. It takes the figures developed in the baseline approach, and calculates the value of improving carer and ‘person with care needs’ (PWCN) outcomes across stakeholders. In addition to the baseline approach, the interventions modelling also draws on assumptions developed from the literature around the four main types of intervention (respite care, working with employers, carer support groups, and carer training groups), and from data input by users. See the section titled *Interventions Modelling Approach* for an explanation of the assumptions used.

Key assumptions

Population assumptions

Data sources: Both models are based on population data from the following sources:

- ONS 2017 mid-year population estimates³;
- GP Survey 2018 data on the number and age of people reporting providing care;
- A study by LSE that projects the growth of the carer population between 2015 and 2025.ⁱⁱⁱ

The **baseline approach** offers an estimate of the value of carers for 2020, and the **interventions modelling** uses 2020 as its first year. To estimate the size of the carer population in 2020 and beyond we began with an estimate of the size of an STP, disaggregated by age group. We calculated each group as a proportion of the entire STP population, and then scaled up each group by a value derived from the aforementioned LSE study. We then applied the proportion of each age group that identified themselves as carers in the GP Survey (2018) to the scaled-up STP size. The results for a fictional STP are shown in **Table 2** below. Users can either use these generic results or input more accurate data for their STP.

Table 2: Example of population scaling calculations.

Age group	STP population size (2019)	STP population size scaled to 2020	Carer proportion (from 2018 GP Survey)	Projected STP carer population 2020
under 16	241,482	x	x	x
aged 16 to 24	137,500	138,325	0.079	10,861
aged 25 to 34	172,271	173,304	0.095	16,512
aged 35 to 44	160,839	161,804	0.133	21,482
aged 45 to 54	176,091	177,147	0.223	39,423
aged 55 to 64	146,686	147,566	0.262	38,646
aged 65 to 74	124,741	125,489	0.200	25,112
aged 75 to 84	72,260	72,694	0.168	12,191
aged 85 and over	30,692	30,876	0.111	3,418
Total	1,262,561			167,645

Another key population assumption in both models is that **each carer only cares for one person**. This is relevant in outcomes experienced by persons with care needs – both in terms of their own wellbeing, and in terms of their use of State services. Data from the Health

³ These were the most up-to-date estimates available at the time of writing

Survey for England 2017 reports that only 3% of respondents (19% of carers) cared for two or more people. The model does account for the reverse situation, where one PWCN has multiple carers, in the sense that it scales by number of hours providing care. However, the model does not account for any interaction effects, e.g. if two carers are caring for a PWCN at the same time, nor if interventions play out differently for a PWCN with multiple carers versus PWCN with only one. As benefits accruing to the PWCN make up a very small proportion of total benefits in our model baseline, this assumption should not have a major impact. One of our interventions, skills training for carers, is highly sensitive to the value of the outcome for the person with care needs, and as such should be treated with additional caution.

3. The baseline approach – what it tells us

Results

‘The baseline’ tab reports upper and lower estimates for costs and savings accruing to different stakeholders for the outcomes identified and for the specified population. The upper/lower estimates are usually based on upper and lower proxy values (see ‘Proxy valuations’ section of the report) but in a few cases where it was not appropriate to use variable proxy values, this range was instead created by developing different modelling approaches (see Table 4). These results are all in 2020 values.

Where do savings accrue from the work of unpaid carers?

The vast majority of the savings from the work of unpaid carers accrue to the State. This estimate is based on the assumption that if unpaid carers were not providing care, then the State would have to step in and provide professional homecare. We crudely estimate that the state currently pays 74% of professional homecare costs (see Table 4) – compared to 56% of residential care costs. According to our estimate, these savings could range between **£54bn** and **£86 billion** annually, although this would very much depend on the level of State care that would be provided in lieu of the unpaid carer (our model has assumed a like-for-like replacement in terms of hours). There are two key uncertainties in this calculation:

- We do not know precisely how many hours of care are provided as survey respondents only provide bands, e.g. 1-9 hours per week, and the upper band is simply 50+ hours per week leaving considerable uncertainty.
- There is a question as to whether the cost of homecare in our calculation should be the current actual hourly price (used for the lower estimate) or the recommended price (used for the upper estimate) which is higher due, arguably, to price suppression.

There are also savings to the State from unpaid carers supporting people to stay in their homes longer and therefore avoiding the need for residential care, which is more expensive for both the PWCN and the state.

Where do costs accrue from the work of unpaid carers?

Despite saving the State large sums by providing unpaid care, providing unpaid care comes at a heavy cost. Some of these costs are **costs to the State**, which come from carers being unable to stay in employment due to heavy caring responsibilities, leading to a loss of potential tax income and an increase in out-of-work benefits. Together, these costs could amount to between **£172-251m** per year within one STP. This does not exclude the wider impact on the economy of losing people from the paid work force, which also has implications for the State but has not been modelled in this project.

We have modelled substantial **costs to the NHS** of the work of unpaid carers, the majority of which come from providing services in response to the poorer mental and physical health outcomes experienced by carers. We estimate that these are in the range of an additional **£8.4-£12.8m** per year for an STP. The final cost to the NHS modelled here is the cost of additional use of emergency services by carers. This is not intended to reflect that persons with care needs have higher need for emergency services than those without care needs, who presumably have better health. It reflects research by Carers UK, where carers reported using emergency services because they did not know what else to do, and who felt that some of this use could have been prevented had they been better supported. The cost of these unnecessary uses of emergency services, we estimate, could range between **£817,500 and £34,000,000** within an STP. This broad range reflects different approaches to calculating the use of emergency services, due to a lack of data on how a carer's use differs to a non-carer. See Table 4 for more detail.

The model also allows us to consider costs that accrue to **carers** as a result of the care they provide. The **direct costs** are based around the loss of income from lower employment levels than the non-carer population, which we estimate to be worth **£252m** a year across an STP. The **indirect costs** come from the loss of the wellbeing benefits of being in employment, and the poorer mental and physical health that carers experience compared to the non-carer population. These indirect costs could total between **£109-£153m** for carers across an STP. The costs for England are shown in Table 3.

Table 3: Estimates of costs and benefits relating to unpaid carers for England, 2020 prices (Model Version 3, May 2019)

	Outcome	Lower		Upper	
		Savings	Costs	Savings	Costs
Savings on paid care	Saving on professional homecare	£54,155,894,506		£86,235,720,137	
	Savings to the state on avoided residential care	£380,603,968		£2,698,883,082	
Savings to the PWCN	Savings on avoided residential (PWCN)	£805,157,611		£3,240,900,261	
Costs to the exchequer	Cost to the state in lost tax income		£3,002,951,697		£5,807,893,058
	Cost to the state in welfare payments		£4,556,655,662		£5,237,036,257
Costs to the NHS	Cost to the NHS in mental health care (carer)		£70,625,881		£264,561,348
	Cost to the NHS in physical health care (carer)		£297,562,745		£297,562,745
	Cost to NHS of extra use of emergency services		£36,013,953		£1,499,224,343
Direct costs to the carer	Costs of lost income/salary		£11,106,811,550		£11,106,811,550
Indirect costs to the carer	Costs of lost mental health		£2,105,784,099		£8,560,019,330
	Costs of lost social wellbeing		£307,887,040		£861,837,485
	Costs of lost physical health (QALY approach)		£2,370,478,241		£3,108,756,849
	TOTALS	£55,341,656,086	£23,854,770,868	£92,175,503,480	£36,743,702,965
	TOTAL PER CARER	£7,494	£3,230	£12,481	£4,975

Limitations

The major limitation of the baseline model at present is the lack of outcomes for persons with care needs (PWCN), only reflected in savings on avoided residential care. However, the baseline approach is designed to measure costs/savings that are accrued due to differences between the carer and non-carer populations, and there is not an appropriate population on which to base a similar approach for persons with care needs. The ideal match would be data comparing outcomes for people with paid vs unpaid carers but, if this research exists, we have not been able to find it.

Proxy valuations

The values in Table 4 below were used in both the baseline and interventions modelling approaches. All proxies are reported here in 2020 prices. Proxy values from earlier years were uprated to 2018 using the Bank of England inflation calculator, and then uprated again to 2020 using Bank of England forecasts (1.8% for 2018-19 and 2.3% for 2019-20^{iv}). These can be updated in the tool as non-forecast rates become available. If readers have any questions regarding specific parameters in the model which are not addressed or adequately explained in Table 4, please contact the authors.

Table 4: Financial proxies used for each outcome

Outcome	Baseline approach	Proxy approach	Proxy sources
Improved carer mental health (specifically anxiety and depression)	Comparison between carer and non-carer responses to the question on anxiety and depression in the 2017 GP survey	<p>Lower: QALY approach</p> <p>We have taken £20,000 as the lower proxy value for one QALY. We have then calculated the difference in the anxiety and depression component of the QALY score (anxiety and depression is one of five outcomes making up a QALY) between the carer and the general population.¹</p> <p>Upper: HACT social value bank “Relief from depression/anxiety (adult)”²</p>	<p>QALY approach</p> <p>¹The range of £20,000 - £30,000 has been used by the UK’s National Institute for Health and Care Excellence (NICE) for some time. In some circumstances an upper value of £50,000 is applied to spending decisions affecting the final 24 months of life.</p> <p>²HACT Social Value Calculator (2019 edition). Available at: https://www.hact.org.uk/value-calculator</p>
Improved carer physical health (specifically pain and discomfort)	Comparison between carer and non-carer responses to the question on pain and discomfort in the 2017 GP survey	<p>QALY approach</p> <p>We have taken £30,000 as the upper proxy value for one QALY, and £20,000 as the lower proxy value. This range reflects the range suggested by NICE. We have then calculated the difference in the pain and discomfort component of the QALY score (pain and discomfort is one of five outcomes making up a QALY) between the carer and the general population.</p>	<p>QALY approach</p> <p>The range of £20,000 - £30,000 has been used by the UK’s National Institute for Health and Care Excellence (NICE) for some time. In some circumstances an upper value of £50,000 is applied to spending decisions affecting the final 24 months of life.</p>
Increased carer social connectedness	We compared carers and non-carers’ responses to the question “Have you experienced any of the following over the last 12 months?...Feeling isolated from	<p>Lower: this proxy is developed through ONS data from the Family Spending Survey (2018)¹. We have added together average household weekly spend on the following activities that are usually social in</p>	<p>¹Figure 2 from ONS 2018 Family Spending Survey. Accessed here: https://www.ons.gov.uk/peoplepopulationandcommunity/personala</p>

	<p>others". The data was disaggregated by age group.</p> <p>For each age group, we applied the proxy value to the carer population size to estimate overall value of social connectedness, and then compared it to the value that they would achieve if their rate of full-time employment matched the non-carer population. This gap is considered a direct cost to the carer.</p>	<p>nature: sports admissions, subscriptions, leisure class fees and equipment hire (£6.60); cinema, theatre and museums etc (£3.10); alcoholic drinks away from home (£8); restaurant and café meals (full value is £18.60 but we have taken 50% assuming that lunches at work take up a proportion of this, leaving £9.30); mobile phone account (£7.90).</p> <p><i>Upper:</i> wellbeing valuation approach². The combined value of "talks to neighbours frequently" and "member of a social group". This proxy differentiates according to age (18-24, 25-44, 45+).</p>	<p>ndhouseholdfinances/expenditure/bulletins/familyspendingintheuk/financialyearending2018#household-spending-in-fye-2018-was-the-highest-since-fye-2005</p> <p>²HACT Social Value Calculator (2019 edition). Available at: https://www.hact.org.uk/value-calculator</p>
Protected income (carer)	<p>We compared the full-time employment rate for carers and non-carers in the GP Survey to calculate the value of income lost to carers who are not in work. For each age group, we applied the proxy value to the carer population size to estimate overall earnings for carers, and then compared it to what carers' earnings would be if their rate of full-time employment matched the non-carer population. This gap is considered a direct cost to the carer.</p>	<p><i>Lower and upper:</i> this proxy calculates carers' income by subtracting income tax and National Insurance contributions from median income¹ by age group. The data for carer age breakdown (GP Survey) and income (ASHE) do not use the same age groupings. The GP Survey age groups each overlap two ONS groups, of which we took an unweighted average to estimate the GP Survey group income. It also includes a small reduction (5%) for the average time that a person spends unemployed each year, based on the long-term unemployment rate. Since this proxy is the most accurate calculation that can be made, we have not calculated separate upper and lower values.</p>	<p>¹Income data is from Annual Survey of Hours and Earnings, Office for National Statistics, 2018 (provisional) Table 6.7a. Accessed here: https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/earningsandworkinghours/datasets/agegroupshetable6</p>
Wellbeing benefit of staying in work (carer)	<p>We compared the full- and part-time employment rate for carers and non-carers in the GP Survey to calculate the difference in their employment rates. For each age group, we applied the proxy value for each type of</p>	<p>The proxies for this are separated according to full- and part-time work, according to data from the GP Survey. The proxy uses a wellbeing valuation approach¹, and since it is difficult to find a</p>	<p>¹HACT Social Value Calculator (2018). This approach measures the value of moving into employment (from unemployment).</p>

	work to the number of carers reporting it. We then compared this to the wellbeing value that carers would achieve if their rate of full- and part-time employment matched the non-carer population. This is considered an indirect cost to the carer.	reasonable market-value alternative, we have not used upper and lower proxy values.	
NHS			
NHS: less mental health care needed for carers	We compared the proportion of carers and non-carers who responded 'Yes' to the following GP Survey question: "Which, if any, of the following long-term conditions do you have?...A mental health condition." We applied this rate (11%) to the entire carer population, and used the upper and lower proxy values to estimate the cost to the NHS of their mental health outcomes. We then applied the response rate from the non-carer population (8.6%) to the size of the carer population and used the upper and lower proxy values to estimate the additional cost to the NHS from carers' worse mental health outcomes.	<i>Lower:</i> This proxy was based on a real costs approach, using ONS data from the UK Health Accounts (2017) ¹ on the annual Government spend per head on healthcare. Kings Fund reported that 11% of Government expenditure on health is on mental health ² , and we have therefore taken 11% of the total expenditure per head. <i>Upper:</i> Kings Fund (2008) ³ estimates that the NHS spent £2.92bn on depression and anxiety in 2007 treating 3.52m patients. This put an average cost/patient at £974.43 (2007 prices).	¹ ONS UK Health Accounts 2017, accessed here: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/ukhealthaccounts/2017#total-current-healthcare-expenditure-in-the-uk ² Kings Fund, https://www.kingsfund.org.uk/projects/verdict/has-government-put-mental-health-equal-footing-physical-health ³ See Table 14 https://www.kingsfund.org.uk/sites/default/files/Paying-the-Price-the-cost-of-mental-health-care-England-2026-McCrone-Dhanasiri-Patel-Knapp-Lawton-Smith-Kings-Fund-May-2008_0.pdf
NHS: less physical health care	Comparison between carer and non-carer responses to the question on pain and discomfort in the 2017 GP survey	This proxy was based on a real costs approach, using ONS data from the UK Health Accounts (2017) on the annual Government spend per head on healthcare. We have deducted 11% from this	¹ ONS UK Health Accounts 2017, accessed here: https://www.ons.gov.uk/peoplepopulationandcommunity/healthand

needed for carers		value, which is the amount spent on mental healthcare ² .	socialcare/healthcaresystem/bulletins/ukhealthaccounts/2017#total-current-healthcare-expenditure-in-the-uk ² Kings Fund, https://www.kingsfund.org.uk/projects/verdict/has-government-put-mental-health-equal-footing-physical-health
NHS: less urgent care for person with care needs	<p>As we were using the same proxy costs for this outcome, we developed upper and lower estimates by calculating the baseline in two ways.</p> <p><i>Lower:</i> this was based on a difference between carer and non-carer responses to a question in the GP Survey asking what they did last time they could not get the appointment they wanted with their GP. One of the responses was “went to A&E,” with 37% of carers reporting this compared to 35% of non-carers. This gave us a non-carer: carer ratio of 1.06 – for every visit by a non-carer to A&E, carers made 1.06. We applied this ratio to the national/head A&E visits (0.35) and ambulance attendances (0.1) to estimate uses/carers. Multiplying this by the proxy values, we calculated a difference in the value of emergency services used by carers and non-carers (a difference of £5), which we applied to the total carer population, assuming that they each care for one person.</p>	This proxy was based on a real costs approach, using unit costs per ambulance use ¹ and per A&E visit ² . Since the unit costs are reported by the NHS, we developed upper and lower approaches to the valuation by applying these costs in different ways (see ‘baseline approach’).	¹ Cost of an ambulance where the patient is seen, treated and conveyed to hospital. NHS Reference Costs 2017/18, accessed here (Table 6) https://improvement.nhs.uk/documents/1972/1_-_Reference_costs_201718.pdf ² NHS Reference Costs, 2017-18. Accessed here (Table 2): https://improvement.nhs.uk/documents/1972/1_-_Reference_costs_201718.pdf

	<p><i>Upper:</i> this was based on a proxy population for people with care needs. After examining the data available on A&E attendances, we selected the over 75s population as this proxy population. The data provided the total number of A&E visits and ambulance attendances by age. We grouped this data into over 75s and under 75s, and calculated a /head rate of use using ONS population estimates for 2017. We then applied the proxy values to these rates, giving a /head cost of emergency services for the populations we designated as proxies for carers and non-carers (a difference of £179/head). This value was applied to the entire carer population, assuming that they all care for one person.</p>		
Social services			
Less residential care for person with care needs	See Appendix	To calculate an estimate for the annual cost of residential care, we took an unweighted average of the annual cost of four types of residential care listed in the PSSRU 2018: private (old people); care home for adults requiring long-term mental health support; adults requiring learning disability support; adults requiring physical support. We then deducted 44% from this annual average to account for those who self-fund residential care ² .	<p>¹ PSSRU 2018, Tables 1.2, 2.2, 4.3.1, and 5.2.</p> <p>² National Audit Office report: https://www.nao.org.uk/wp-content/uploads/2018/07/Adult-social-care-at-a-glance.pdf; See page 16.</p>
State saving on paid care	We calculated an annual number of hours spent caring from weekly data provided in the GP Survey (an upper and lower value based on the ranges given in the GP Survey	<p>This proxy was based on two costs estimated for the unit cost of the cost to councils of an hour of home care.</p> <p><i>Lower:</i> research by the Kings Fund found that local</p>	<p>¹ See Section 7, 'Expenditure', https://www.kingsfund.org.uk/publications/social-care-360/expenditure</p>

	responses), and then multiplied these by the upper and lower proxy values for an hour of in-home care. We have not divided this cost between state and PWCN, but under the current social care funding system, a proportion of this would be paid for by the PWCN.	authorities were paying, on average, £16.04/hour for externally provided home care in 2017/18 ¹ . <i>Upper:</i> the United Kingdom Home Care Association has reported that a minimum price for home care for 2019 should be £18.93, to allow full compliance with National Minimum Wage changes and ensuring sustainable delivery of services ² .	² https://www.ukhca.co.uk/downloads.aspx?ID=434
Exchequer			
Tax income retained from carers' employment	We compared the full-time employment rate for carers and non-carers in the GP Survey, applied this rate to the overall carer population, and applied the upper/lower proxy values to estimate the tax revenue lost due to carers' lower levels of employment. This difference is considered a cost to the Exchequer.	<i>Lower:</i> this proxy calculates income tax and National Insurance contributions from median income ¹ by age group. The data for carer age breakdown (GP Survey) and income (ASHE) do not use the same age groupings. The GP Survey age groups each overlap two ONS groups, of which we took an unweighted average to estimate the GP Survey group income. There is a small income reduction (5%) for the average time that a person spends unemployed each year, based on the long-term UK unemployment rate. From this estimated income, tax contributions are calculated; income tax at 2019 rate (20% after a personal allowance of £12,500), and National Insurance at the 2019 rate (12% on weekly earnings above £162). <i>Upper:</i> The upper estimate integrates the tax multiplier effect of having an additional member of the workforce, these are based on the Government's own calculator for the value of moving citizens into employment. This affect approximately doubles the value of each new employed individual, but is arguably the more credible approach. ²	¹ Income data is from Annual Survey of Hours and Earnings, Office for National Statistics, 2018 (provisional) Table 6.7a. Accessed here: https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/earningsandworkinghours/datasets/agegroupshetable6 ² https://www.gov.uk/government/publications/movement-into-employment-return-on-investment-tool

Avoiding increase in out of work benefits	<p>As in the outcome above, this approach is underlain by the differing rate of full-time employment for carers and non-carers reported in the GP Survey. We based this approach on the assumption that unemployed carers are eligible for both Carers' Allowance and Jobseekers Allowance.</p> <p>For each age group (based on JSA rates), we applied the cost of a year of both Carers Allowance and JSA to the population of carers in full-time work, and compared this cost to the lower cost to the Exchequer if carers had the employment rate of non-carers. This is considered a direct cost to the Exchequer.</p>	<p>This proxy reflects the value of savings to the state on avoided out of work benefits that would be provided to carers who cannot stay in employment due to their caring responsibilities.</p> <p><i>Lower:</i> For simplicity and to take a conservative approach, we have only included two out of work/low income benefits: Job Seeker's Allowance and Carer's Allowance. We have applied the weekly rates for both to calculate an annual value, with the JSA rate being variable by age (under 25 and over 25) and applied to the correct proportion of the carer population.</p> <p><i>Upper:</i> it is likely that carers would become eligible for further benefits after becoming unemployed. Owing to the complexity in the application of this, we have assumed a value of a further 10% for under 24s, and 15% for over 24s (this difference being a reflection of their eligibility for higher benefits).</p>	<p>2019 rates for Jobseekers Allowance and Carers Allowance accessed here: https://www.gov.uk/government/publications/benefit-and-pension-rates-2019-to-2020/proposed-benefit-and-pension-rates-2019-to-2020</p>
Cost of increased benefits payments	This only applies to interventions	<p>This proxy reflects the cost to the State of carers claiming benefit entitlements that they are currently unaware of.</p> <p><i>Lower:</i> this proxy reflects the annual value of Carers Allowance.¹</p> <p><i>Upper:</i> this proxy reflects the combined annual value of Carers Allowance and PIP/Attendance Allowance. It assumes that some people with care needs are also underclaiming their benefits.</p>	¹ All rates used are 2019 rates, updated for inflation.
Person with care needs			
Avoidable move into	See Appendix	It is generally more expensive to a person with care needs (PWCN) for them to move into a residential	https://www.kingsfund.org.uk/sites/default/files/2018-12/Key-

residential care		<p>care home. In residential care the PWCN typically pays 44% of costs.² We made a crude estimate of the proportion of professional homecare costs paid by the PWCN of 26%. This was derived from two sources: an estimate of the total expenditure of self-funders in 2014/15 by the UKHCA, and data reported by NICE in 2013/14 on the total investment by local authorities on homecare. We also needed an estimate of the number of people entering residential care each year, this was taken from the Local Government Association's online data portal, with the latest data available from 2013/14 (around 6.5 people per 1,000 over 65s). Finally we needed an estimate of the proportion of entries to residential care which are a result of 'carer breakdown'. Data on this was scarce, we found an estimate from the Policy Studies Institute from the year 2000 of 20%. A study by Oxford Brookes University and Hertfordshire County Council in 2010 estimated it at 17% (we could only find this value cited in another council document – the link provided is to this source). We have used the 17% value.</p>	<p>challenges-facing-the-adult-social-care-sector-in-England.pdf</p> <p>https://www.nice.org.uk/guidance/ng21/resources/costing-statement-488862829</p> <p>https://lginform.local.gov.uk/</p> <p>http://www.psi.org.uk/publications/archivepdfs/Elderly/TAB8.pdf</p> <p>https://www.hertfordshire.gov.uk/media-library/documents/about-the-council/data-and-information/hertfordshire-carers-strategy-2015.pdf</p>
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4. Interventions modelling approach

The interventions modelling approach calculates potential costs/benefits to stakeholders of four types of intervention identified through the scoping interviews and literature review: respite care, skills training for carers, peer support groups for carers, and working with employers to become more accommodating of carers and help them stay in work. Through secondary research, we developed assumptions about the scale of impacts that these interventions could have across the outcomes identified and modelled the value of these changes over (up to) five years. The interventions take the value from the baseline approach, and apply an increase in outcome (%) for the first year (2020) and subsequent years. The impact range should always be understood relative to the baseline year.

Interventions and outcomes

Based on our review of the literature surrounding interventions with carers, we identified the following key outcomes associated with each intervention:

Table 5: Outcomes linked with each intervention typology

		Working with employers	Support groups	Skills training	Respite care (not included)
Carers	Wellbeing benefit of employment (includes components of mental health)	x			
	Income retained	x			
	Improved mental health		x	x	x
	Increased social connectedness		x		x
	Improved physical health				x
Exchequer	Cost: carers taking up benefit entitlement		x		
	Tax income retained	x			x
	Avoided cost: out of work benefit payments	x			x
NHS	Less mental health care needed: carers		x		
	Less urgent care needed: cared for person			x	
	PWCN sustained out of residential care			x	x
Cared for person	Receives higher quality care leading to improved mental and physical health			x	
	PWCN sustained out of residential care		x		x

For each outcome, we developed assumptions around the scope of the intervention's impact (how much can an intervention like this be expected to impact an outcome?), whether value was created or displaced, and the rate at which value created would drop off over time. Each intervention is explained below.

Evidencing the impact of interventions

Working with employers

Impact range: 0.16% - 0.48%.

The outcomes for this intervention all depend on the intervention's potential to help more carers stay in work. Brimblecombe et al (2018)^v modelled a government scheme to incentivise employers to promote flexible working amongst carers. They modelled the impact over 5 years, and estimated that such a scheme could keep an additional 60,000 (2.4%) of extra-resident working age carers in employment between 2015 and 2020, with no further increase in subsequent years. We have applied this increase evenly over five years, giving an annual rate of **0.48%**, which we used as the upper end of the impact range. For the lower impact rate, we discounted this value on the basis of the following considerations:

- A government incentive would likely have more impact than a non-statutory intervention that we assume. We have assumed a deduction of 50% from the original value.
- The source excludes co-resident carers since many are aged 65 and over and most of them provide intensive care (20 or more hours per week) which would be unlikely to be compatible with employment. We exclude over 65s through our age-stratified population data, but do not automatically exclude co-resident carers. We therefore propose a deduction of a further 33% to account for carers who provide a high level of care that would be difficult to combine with work (GP Survey data showed 33% of carers caring 20+ hour/week).

We have assumed that, without statutory changes, the impact scope for this intervention will be low and therefore advise using the lower impact value of **0.16%**. However, it may be useful to consider that even without statutory changes, an intervention could contribute to a wider culture change which will have longer-term impacts beyond this study.

Displacement is not relevant for the outcomes for carers, but does matter for Exchequer outcomes since, were a carer no longer in employment, someone else would likely take that job, contribute tax revenue and stop claiming out-of-work benefits. A working paper from the Department for Work and Pensions (2010) states that demand-side programmes (e.g. employer incentive schemes) should be considered to have a fairly large displacement effect, and that cost-benefit analyses of similar programmes should estimate that around 45% of the value is displaced^{vi}. We have adjusted the value created by the intervention to reflect this.

Support groups

Non-completion of support group and training interventions. Studies of these type of interventions noted a rate of non-completion by participants. We have looked at the non-completion rate from two studies (Yeandle & Wigfield 2011 – 41%, Chu et al 2010 – 30%), as well as Livingston et al (2014) who reported that 25% completed less than five out of eight training sessions. While people may accrue partial benefits from partial attendance, the model assumes that carers stop attending because either their caring responsibilities end, or

they do not find the programme useful. Therefore, if participants do not complete the course they are assumed to gain no benefits. We have selected the upper end, 41%, since this was by far the largest study and we considered the more reliable.

Improved carer mental health, impact range: 4.3% - 5.6%.

In a study of the effects of support groups on carers' experiences of depression, Chu et al (2011) found a significant improvement in carers' level of depression. The intervention lasted 12 weeks, after which carers showed a reduction of 2.73 units on the 64-point Beck Depression Inventory II from a pre-intervention baseline, which rose to a reduction of 3.63 units at one-month follow-up^{vii}, the equivalent of a 4.3% and 5.6% improvement. We have taken these two values as the lower and upper estimates for the impact range.

Displacement is not relevant for this outcome.

Carers' increased social connectedness, impact range: 1.7% - 4.3%. As with other outcomes, the evidence reviewed was somewhat mixed. Some individual studies found no effect on social connectedness, for example a study of a telephone support group for dementia carers^{viii}. Others did, and supportive evidence was also found in meta analyses (e.g. Chien et al, 2011^{ix}). We found evidence for the scale of impact in a study of a 12-session telephone support group for carers of frail older adults in the US. Those who were caring for a parent showed an increase in social support, measured using the Medical Outcomes Study (MOS) Social Support Survey (SSS), of 4.3%, compared to the control group. However, there was no significant effect found for spouse caregivers, and we account for this variation in setting the lower end of the impact range. Adult children make up 40% of UK carers, compared to 26% of spouse and 34% who care for someone else (Carers UK, 2015)^x.⁴ Therefore, we reduced the upper impact value by 60% to assume that **only** adult children were impacted. This provides a lower impact estimate of 1.7%.

Displacement is not relevant for this outcome.

Increased Exchequer cost of more carers taking up benefits allowance, impact range: 5.5% - 11%. Several programme evaluations suggest that support groups were an effective way for carers to learn about their benefit entitlements as carers. In Yeandle and Wigfield's 2011 evaluation of a national carer programme, 'Caring with Confidence'^{xi}, 11% of participants who took part in the evaluation reported claiming additional benefits as a result of what they had learned in the programme. We have taken this as the upper end of the impact range, and have taken 50% of this for the lower end on the assumption that support groups are likely to be good sources of information on benefit entitlement but may not provide the same support to claim these benefits as a training programme. Therefore, we estimate a lower value of 5.5%.

Displacement is not relevant for this outcome.

⁴ This estimate comes from data in the 2011 Census. It is plausible that the balance has since shifted.

Less mental health care needed for carers (NHS cost saving). The above two outcomes, indicating an improvement in carers' mental health and wellbeing, indicate a cost saving to the NHS from a reduced need for mental health care for carers. However, while the link is obvious, the literature around interventions do not assess the link between support groups and mental health service use. Therefore, we did not value this outcome here.

Skills training for carers

Improved carer mental health, impact range: 4.1% - 4.5%.

In our literature review, we found substantial evidence that skills-training programmes lead to improved mental health for carers, providing them with information, support, and skills to better cope with their caring responsibilities. A study of a programme training the carers of stroke patients (Kalra et al, 2004)^{xii} found that carers who received more thorough training had significantly improved mental health (measured on the Hospital Anxiety and Depression Scale) compared to those who received only the conventional approach on patient discharge. The training cohort had showed a statistically significant improvement of 4.5% compared to the control group across anxiety and depression, and we have applied this as the upper limit of the impact range. Another study^{xiii} (using the same measurement scale) looking at the effectiveness of a manual-based coping strategy compared to treatment as usual in reducing depression and anxiety for dementia carers found that a significant difference of 4.1% between the intervention and control groups, which we have applied as the lower limit of the impact range.

Displacement is not relevant for this outcome.

Improved carer social connectedness, impact range: 0.86% - 2.15%.

Yeandle and Wigfield (2011) found evidence that, if carer training is delivered in a group setting, many carers will also experience positive social benefits. They asked carers to respond to the following: "Taking part has made me feel less socially isolated in the long-term" (70% agree/strongly agree); "I met carers I have stayed in touch with" (50% agree/strongly agree); and "I miss the friendship involved in the programme" (73% agree/strongly agree). However, many of the training interventions reported by other studies were delivered 1:1 by a medical practitioner, with no opportunity for meeting other carers. Therefore, we have included this as a user-defined outcome: when inputting the details of a training intervention, users indicate whether or not the proposed training is delivered in a group setting and the outcome is only included *if they indicate yes*.

We have used the same impact rationale for this outcome as for support groups, but have taken 50% of the values estimated there on the assumption that, while in a support group the primary goal is to connect carers with others with similar experiences, this will be secondary in a skills training programme. Therefore we have estimated an impact range of between 0.86% and 2.15%.

Displacement is not relevant for this outcome.

Less urgent care for person with care needs, impact range: 16% - 32%.

A survey by Carers UK found that 32% of carers whose family member/friend had had an emergency admission to hospital in the previous year felt this could have been avoided had they been better supported as a carer^{xiv}. Although this data is specific to emergency admissions to hospital, not just trips where there was no admission, we have assumed that this figure is indicative of the maximum amount of all A&E visits that could have been avoided if carers were better supported through training. We have taken this as the upper limit of the range and have reduced it by 50% to estimate a lower impact value of 16%.

Displacement is not relevant for this outcome.

Improved mental and physical health for person with care needs, impact range: 4.5% - 6.8%; and 3.75% - 5%.

This outcome assumes that, if a carer has better training in how to deliver care, the physical and mental health of the cared for person will improve, although it should be noted that *how* this happens, and its extent, will depend on the type of care needs. At present, the model is not sensitive to this variation. Unlike other outcomes, there is no baseline value upon which to base an increase so we have taken a slightly different approach, modelling an annual estimate of 3.75% of the potential value.

Kalra et al's study of training for carers of stroke patients (2004) also measured outcomes for the person with care needs. Using the Hospital Anxiety and Depression Score, the study found that a year after the intervention, those whose carers had received better training were showing an improvement of 6.8% (anxiety) and 4.5% (depression) compared to the control group. We have taken these as the upper and lower bounds for improved mental health.

The same study also used the EuroQol visual analogue scale (where respondents report their perceived health status with a score from 0, worst health, to 100, best health) to test for changes in people's physical health as a result of their carer's training. They found a 5% difference between the intervention group and the control group, which we have taken as the upper limit. While we assume that all people with carers could benefit from improved mental health, it is not clear that benefits of physical health would be as broadly applied, for example with particular types of mental health conditions or palliative care. One in four carers in the UK are health carers (Carers UK)^{xv}, so we have reduced the upper value by 25% to account for those carers where care responsibilities are not focussed on physical medical care, giving a lower impact estimate of 3.75%.

Displacement is not relevant for this outcome.

Respite care

The evidence base around the benefits of provision of respite care can be contradictory and challenging to navigate. In qualitative terms carers have described the pivotal role respite can play in managing a situation, developing resilience, and improving mental health.^{xvi} However, across the body of literature there have been mixed results, some studies showing

no measurable effects in outcomes, others showing effects across a range of outcomes.^{xvii} Given the qualitative evidence provided by carers on the value of respite services (also referred to as ‘day services’) we have selected a set of outcomes for which there is strongest scientific evidence. Our selected outcome set does not include outcomes experienced by the person with care needs as the evidence base is generally weaker.

Improved mental well-being for the carer on the day respite is received.

Evidence from Lui et al. (2018) suggests that cortisol levels in carers return to ‘normal’ levels seen in the general population on the day respite is received.^{xviii} Elevated cortisol levels are broadly associated with higher levels of stress and anxiety. Our approach to this was to remove all well-being losses experienced by carers (in comparison with the general population) on each day respite is received.

Displacement is not relevant for this outcome.

Reduced social isolation in carers.

Studies have shown the social-wellbeing benefits of day centres, allowing carers to socialise both at the centre, and while taking a break from their care duties. On this outcome, one study reported a sustained 13% reduction in reported social isolation in users of day centres however, this involved intensive use of the service.^{xix} For the purposes of this study we have assumed that carers’ social wellbeing returns to normal levels on days they receive respite care but have not assumed that this benefit goes beyond the time spent in respite.

Displacement is not relevant for this outcome.

Improved sustainability of employment for carers.

Studies have shown that respite care can reduce the burden on carers in employment and sustain carers in work.^{xx} One study suggested that attendance at day centres reduced the conflict between work and care by around 11% compared to a control group.^{xxi} Another study suggested that the burden of caregiving for employed carers reduced by around 50% as a result of day centre attendance.^{xxii} However, both of these studies analysed interventions involving intensive use of day centres (as opposed to occasional use of respite services). We have assumed a linear relationship between the number of days attended and the impact on the employment sustainability outcome.

Displacement is not relevant for the carer for this outcome, but it is relevant for the state.

Reduced likelihood of carer breakdown, and hence avoidable residential care

The technical approach taken to this outcome is addressed in some detail in the Appendix. There is relatively strong evidence that respite care reduces the ‘role overload’ carers can experience^{xxiii} and can lead to carer breakdown. Our estimate for the impact of respite care on this outcome is from Mossello et al. (2008). The authors reported an 18% reduction on the Caregiver Burden Inventory (CBI) after 2 months using respite services.^{xxiv} However, these respite services were intensive, involving use of the service 4.5 days per week (on average).

We have assumed that benefits accrue with a linear proportional relationship to frequency of use.

Displacement is not relevant for this outcome.

Issues valuing respite care

Having completed our literature review and model development process for the respite care intervention we held two key concerns:

1. That the evidence base on the longitudinal impact of respite care was contradictory and inadequate, with many recent reviews citing out-dated studies, but few new studies shedding new light.
2. That we could not capture the complex benefits users identify with respite care in qualitative research. Benefits are typically highly individual-specific, and some of the most commonly cited benefits (such as regaining control over personal lives) are extremely difficult to monetise.^{xxv}

Given the above, we have not included a respite care component of the model at this time. Further research is urgently required to gain a more comprehensive understanding of the benefits of respite care. Once available, this research can be used to operationalise this component of the model.

Variable modelling period and estimates for impact drop-off

Due to the paucity of data around the impacts of interventions in the medium-term (as discussed in ‘caveats’), estimating the benefit period for interventions is challenging. Therefore, we use this section to explain clearly the assumptions that we have made in modelling each outcome over time (up to five years).

- We assume that for the duration of an intervention, full benefits (100%) are accrued. All interventions are assumed to last at least a year, and users can enter the length of their intervention in the ‘Intervention valuation’ tab, and the model will update accordingly.
- After the intervention ends, a drop-off rate is introduced. This is based on assumptions that have been developed through a mixture of data and trying to ensure internal consistency (i.e. that they make sense within the logic of the model). The details of these assumptions can be found in Table 6 below.
- Some outcomes are limited to the duration of the caring relationship (we have assumed 4 years, an estimate from the US^{xxvi}) – these are those where the mechanism for the outcome relies on the carer still providing that care. This also relies on the assumption that all carers in the intervention cohort will be at the start of their caring relationship which is unlikely to be true. However, for some outcomes we believe that benefits could continue after the caring responsibilities have ended, for example

employment outcomes, due to the challenges carers (especially older carers) would face in getting back into work after their caring ended.

Table 6: Rationale for chosen drop-off rates

Intervention	Stakeholder/ outcome	Drop-off rationale
Working with employers	Carer and Exchequer / Carer supported to stay in work, tax income from carers, avoided out of work benefits payments to carers	In our calculation of the overall impact, we have assumed it is spread evenly across the five years modelled in the source. As noted in the source, there would be no further change after Year 5.
Carer skills training	Carer mental health	We assume that 100% of the impact is retained for the duration of intervention. Drawing on data from Livingston et al (2014) who recorded that carers were still experiencing statistically significant reduced HADS-T scores 24 months after a training intervention, we assume that full value is retained for 2 years after the intervention. The outcome here assumes that carers' mental health has improved because they have the skills and knowledge to cope better with their responsibilities, and therefore we assume that this will sustain beyond 2 years post intervention, but have included an annual reduction of 50%.
	NHS: Reduced urgent care needs	The mechanism for this outcome is more confidence and better provision of care at home. Therefore we have assumed the same drop-off as the outcome 'Better quality of care'. This outcome also relies on the caring relationship continuing, and so again benefits end after Year 4.
	Better quality of care: person with care needs better mental health outcomes	We assume that 100% of the impact is retained for the duration of intervention. CwC evaluation reported the 32% of carers thought the training had improved the standard of care they give, rising to 33% at 6 months. Perceptions that the pwc's quality of life improved as a result of the training also rose, from 21% to 26% at 6 months. This suggests that for the year following intervention, the improvements sustain, and we have assumed that after this there is a relatively small annual drop-off of 15%. After Year 4, we assume that the caring responsibilities have ended and the person with care needs no longer receives the benefit from the carer's acquired skills.

Carer support groups	Exchequer: cost of carers taking up benefits entitlement	We assume that carers will learn about their entitlement within the first three months of the programme and will backdate their application three months therefore receiving the full value for Year 1. They will continue to receive the benefit for the duration of their caring relationship. Based on evidence from the US, we assume this relationship to last, on average, 4 years. After Year 4, we assume that the caring responsibilities have ended and the carer no longer receives the benefit.
	Carer social connectedness	We assume that carers will receive 100% of the value of social connectedness for the duration of the intervention. After this, we assume that the drop-off rate will be fairly small: Caring with Confidence 6 month evaluation found that the proportion of carers reporting having met people they will stay in touch with, and feeling less isolated, fell in the 6 months after completion of the course from 57% to 50% (13% decrease), and 74% to 71% (4% decrease). We have assumed that this would mean a decrease over a year of 26% and 8%, and we have used the mid-point of 17% as the annual drop-off.
	Carer mental health	We assume that 100% of the impact is retained for the duration of intervention. Drawing on data from Livingston et al (2014) who recorded that carers were still experiencing statistically significant reduced HADS-T scores 24 months after a training intervention, we assume that full value is retained for 2 years after the intervention. Although it is logical to assume that they will, we have no data to prove that benefits will continue and therefore we assume that they drop to zero.
	Carer social connectedness	We assume that 100% of the impact is retained for the duration of intervention. We assume that a support group setting will foster stronger relationships than a skills training one (such as CwC) where relationships are not the main focus, and therefore we have reduced by drop-off estimated for the same outcome in 'Carer skills' by 25%, meaning an annual decrease of 12.75%.
	Exchequer: cost of carers taking up benefits entitlement	We assume that carers will learn about their entitlement within the first three months of the programme and will backdate their application three months therefore receiving the full value for Year 1. They will continue to receive the benefit for the duration of their caring relationship. Based on evidence from the US, we assume this relationship to last, on average, 4 years. After Year 4, we assume that caring responsibilities have ended and the carer no longer receives the benefit.

Limitations

There are several important limitations to our approach. We have tried to address these limitations by presenting a clear and transparent approach to the assumptions in our model, and they should be born in mind when interpreting results:

- From the literature, we see that intervention impacts will not be uniform, and rather have different impacts in different contexts. In a systematic review that investigated the impact of caregiving, Schoenmakers, Buntinx, & Delepeleire (2010) found that rates of depression are higher among those who provide care for people with dementia than among caregivers of people with other chronic illnesses. This is also reflected in the shape of the academic literature on interventions; studies often focus on the impact of an intervention on a particular *type* of carer. However, at this stage the model is not sensitive to such variations; instead it addresses change on the level of broad populations and therefore users should be cautious in interpreting results and not using the tool to calculate exact costs/savings for small scale interventions; i.e. we do not recommend use of this model for decisions at scales lower than a county or CCG. We would expect the targeted number of individuals for a given intervention to at least be in the hundreds, ideally thousands.
- The quality of data on interventions supporting carers is not high. Several meta analyses and systematic reviews in the literature noted that the overall quality of evidence they examined was low (Van de Pitte et al, 2016^{xxvii}; Thompson et al, 2007^{xxviii}; Yesufu-Udechuku et al, 2015^{xxix}). Therefore, while we have tried to ensure consistency in terms of the scale of impacts that this model rests on, results should be interpreted cautiously;
- The results reported by studies assessing interventions with carers are also very mixed – for every study that finds a significant effect, there is another study that fails to find one. There are several plausible reasons for this: the very specific nature of interventions, variation in the quality of their delivery, and the specific profile of the carer cohort that they engage.

Appendix A: Approach to carer breakdown

Carer breakdown and avoidable admission to residential care

One aim often cited for providing support to unpaid carers is to prevent carer breakdown⁵ as a result of ‘role overload’ experienced by carers.⁶ A key question, and potential source of value in the cost-benefit equation, is whether unpaid care by family and friends is a direct substitute for professional care from a care provider. There is evidence to suggest that some persons with care needs, kept out of residential care by their unpaid carer, would have to be transferred to residential care if the state takes over. This issue is implicit in many studies, but is not well researched.⁷ The primary evidence is data captured on reasons for admission to care homes. This is not widely available, and to our knowledge is not systematically collected. In the following section we build a logic chain for the calculation of the value generated from unpaid carers preventing residential care admission. This is based on the available data and knowledge, and we recognise significant limitation. *What follows should be treated with caution!*

According to the document ‘*Community care statistics, social services activity, England – 2015-16*’ when an individual goes for an assessment with social services there are three main outcomes possible:

- Move into residential/nursing care
- **Support in the community**
- **Short-term support**

First, we want to know what proportion of these requests for support had a carer.

From sheet STS002a we can estimate that, for those for whom needs were identified, 29.2% of those who were allocated **short-term support** had a carer. The total number of people newly awarded support, that this applies to, was around 38,000 in 2015-16.

From sheet LTS001b we can estimate that, of those awarded long-term **support in the community**, 44% already had a carer. The total number of people newly awarded support in this classification would be around 58,000 (using data from sheet STS001).

⁵ Guberman, N., Keefe, J., Fancey, P., & Barylak, L. (2007). ‘Not another form!’: lessons for implementing carer assessment in health and social service agencies. *Health & Social Care in the Community*, 15(6), 577–587. <https://doi.org/10.1111/j.1365-2524.2007.00718.x>

⁶ Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M.-A. P., Townsend, A., & Greene, R. (2003). Adult day service use and reductions in caregiving hours: effects on stress and psychological well-being for dementia caregivers. *International Journal of Geriatric Psychiatry*, 18(1), 55–62. <https://doi.org/10.1002/gps.772>

⁷ Pickard, S., & Glendinning, C. (2001). Caring for a relative with dementia: The perceptions of carers and CPNs. *Quality in Ageing and Older Adults*, 2(4), 3–11. <https://doi.org/10.1108/14717794200100024>

Let us take all of the above as examples of 'carer breakdown', i.e. these people had carers, but the carers could not cope and needed support.

The sum of carer breakdowns in 2015-16 using the above logic was around 96,000 in the year.

In addition to this, we know there were a number of carer breakdowns which resulted in admission to residential care of some form. Based on data on the admissions to residential care (estimated at 6.5 per 1,000 over 65 year-olds), and based on a proportion attributable to carer breakdown of 17% (see main Technical Note), around 11,000 admissions to residential care were due to carer breakdown.

On this basis, the total carer breakdowns in the year was around 107,000. Around 10% of those were individuals who had to move into residential care as a result, i.e. the state could not replace the role of the carer through equivalent community/short-term support.

Is this credible?

As a reference point, Carers UK, in their 2014 report *Carers at breaking point*, reported that 1 in 9 of their respondents had experienced a situation where the state had to step in to cover for them. We do not know if this breakdown was temporary or permanent.

The population of carers in England, according to our analysis of GP Survey data, is around 7.386 million. This would imply 821,000 instances of *temporary* carer breakdown (we do not know the number that became permanent) based on the Carers UK data. Much higher than our figure for permanent carer breakdown of 107,000. However, the 7.386 million figure contains a large number of 'off-the-radar' carers, who are not interacted with by any public or private services and were not included in Carers UK's analysis (and *on average* probably experience lesser care burden). For example, the number of carers reporting providing more than 9 hours per week of care is estimated at around 3.3 million, this would imply 369,000 instances of temporary carer breakdown at the Carers UK rate. However, it is not reasonable to assume that only those providing large amounts of care are liable to carer breakdown.

From this data, we conclude that it is reasonable that there might be 107,000 carer breakdowns resulting in a need for state intervention each year. Although in reality the drivers will be complex, and carer breakdown may only be one factor.

How many people are being kept out of residential care by unpaid carers?

In order to better capture to carer population liable to breakdown we have calculated the proportion of carers reporting problems with anxiety or depression (2018 GP Survey). This acts as a proxy for the intensity of care demanded by the individual. This might alternatively be calculated from data on the severity of health conditions of the person with care needs.

16.2% of carers report moderate, severe, or extreme anxiety or depression

4.3% of carers report severe or extreme anxiety or depression.

These form our upper and lower bounds, and we assume, as discussed above, that 10% of cared for individuals will move to residential care if transferred to state responsibility.

As such, **crudely**, the outcome incidence of individuals being kept out of residential care by their unpaid carer is:

Lower estimate: 0.43%

Upper estimate: 1.62%

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