



The  
Strategy  
Unit.

# The Economics of Caring: a scoping review

NHS England

November 2017



Midlands and Lancashire  
Commissioning Support Unit

# Document control

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<b>Document Title</b>	The Economics of Caring: a scoping review
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<b>Date</b>	2 <sup>nd</sup> November 2017

# Main findings from the review

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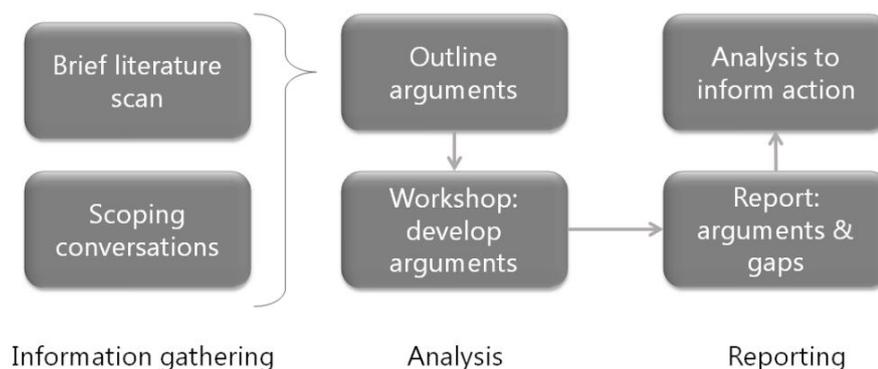
This report is the final output from a project commissioned by NHS England (NHSE) from [The Strategy Unit](#) and [ICF](#), which aimed to:

1. Set out the main arguments from an economic perspective for supporting carers;
2. Assess – in broad terms – the existing evidence base for these arguments; and,
3. Recommend, by combining aims 1 and 2, areas where further analytical effort would bring greater clarity and weight to the arguments for supporting carers.

The project was therefore a scoping study, tasked with clarifying the topic and focusing future analytical attention. To meet these aims, the study team:

- Undertook a rapid review of the literature (annexed to this report);
- Consulted with stakeholders to this topic;
- Developed a set of outline arguments; and,
- Tested and refined these arguments in a stakeholder workshop (a summary of which is also annexed).

This process is summarised in the Figure to the right, which also shows the function of this report: to summarise the main arguments and make proposals to address gaps in the current analytical / evidence base.



It is important to note the limitations on this work following from the above. The nature and scale of the project implies a general need for caution and modesty. It is beyond the bounds of this scoping review to have full sight of all extant literature on what is a complex set of topics. The evidence available to the study was derived solely from conversations with stakeholders, the literature scan and workshop. No pretence is therefore made at comprehensiveness; points of detail will be missing; and our aim is to guide thinking in broad terms, rather than attempt a definitive and detailed view.

What follows summarises the main findings from the work. It is set out under three main arguments (see aim 1) which, from an economic perspective (i.e. leaving aside other material considerations) provide a case for supporting carers.

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These arguments are:

1. If we provide effective support to carers, then the carer's health status will improve: they may require less health and social care.
2. If we provide effective advice to carers and employers, then the carer will be more able to remain in work.
3. If we provide effective support to carers, then the person with care needs will be better supported: they may require less health and social care.

Each is considered in turn below - summarised on a single page - as a logic model with commentary as to the main mechanisms (or 'active ingredients') that show the means of transmission from intervention<sup>1</sup> to economic effect. Readers wanting substantiating detail / a description of the process used to derive the three arguments are kindly referred to the Annexes.

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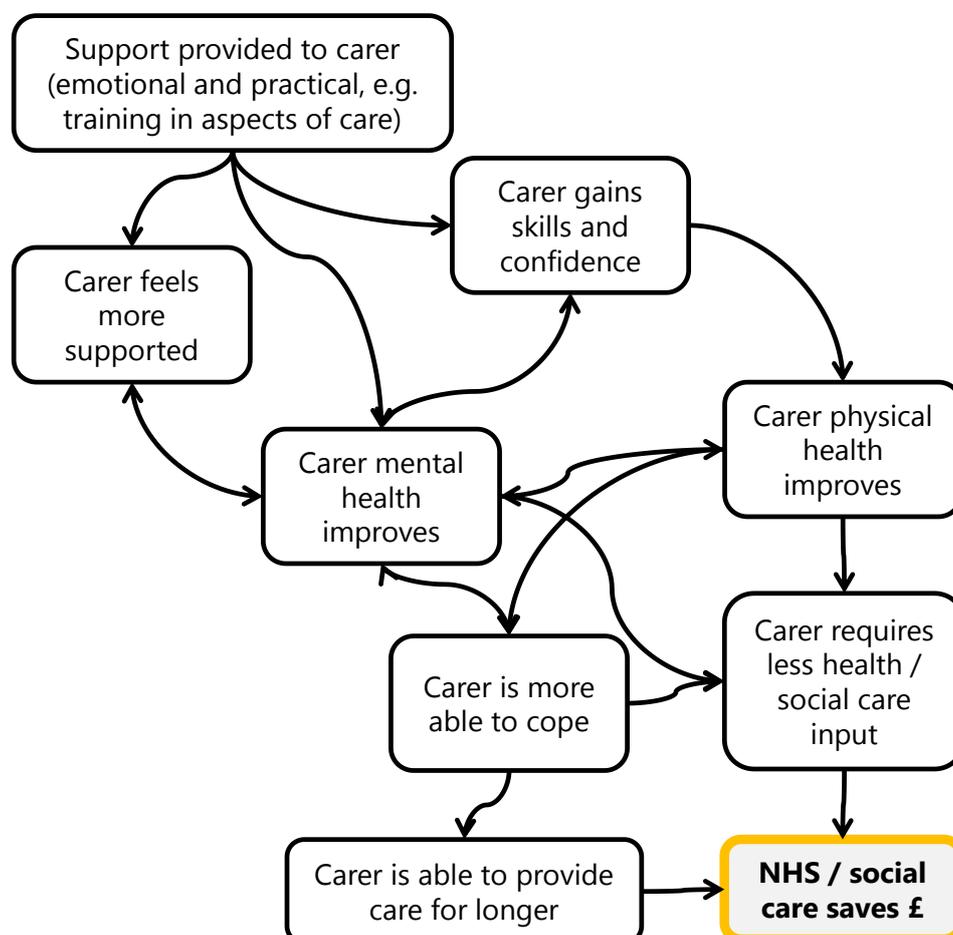
<sup>1</sup> The project was not a review of effective interventions: links between cause and effect shown in the logic models are hypothesised (albeit hypotheses based on expert opinion / evidence from the literature scan). Readers wanting information on likely effectiveness are referred to the recent meta-review: Thomas S, Dalton J, Harden M, Eastwood A, Parker G. *Updated meta-review of evidence on support for carers*. Health Serv Deliv Res 2017;5(12)

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**ARGUMENT 1: If we provide effective support to carers, then the carer's health status will improve: they may require less health and social care**

This argument is summarised in the logic model below. There are three points of note:

- Within the model, the mental health of the carer is a pivotal mechanism. There are multiple suggested links (uni- and bi- directional) between this and their: physical health; ability to cope; ability to provide good quality care; and their use of health and social care services (positive effects assuming that caring responsibilities are not excessive). This suggests that improving carers' mental health would reap wider gains;
- The main economic benefits in this model (shown in the white box) derive from a reduction and / or delay in the carer's use of health and social care services. It is not shown within the model, but this would also incorporate changes in the nature of service use – with a healthier / more able to cope carer accessing services on a more planned basis than a carer falling in and out of crisis. This would work differently for different 'types' of carer: notably for young carers the ability to pursue education / training / employment would be the main benefit; and,
- There are very strong overlaps between this and Argument 3, which focuses more on benefits to the person with care needs (described further below).

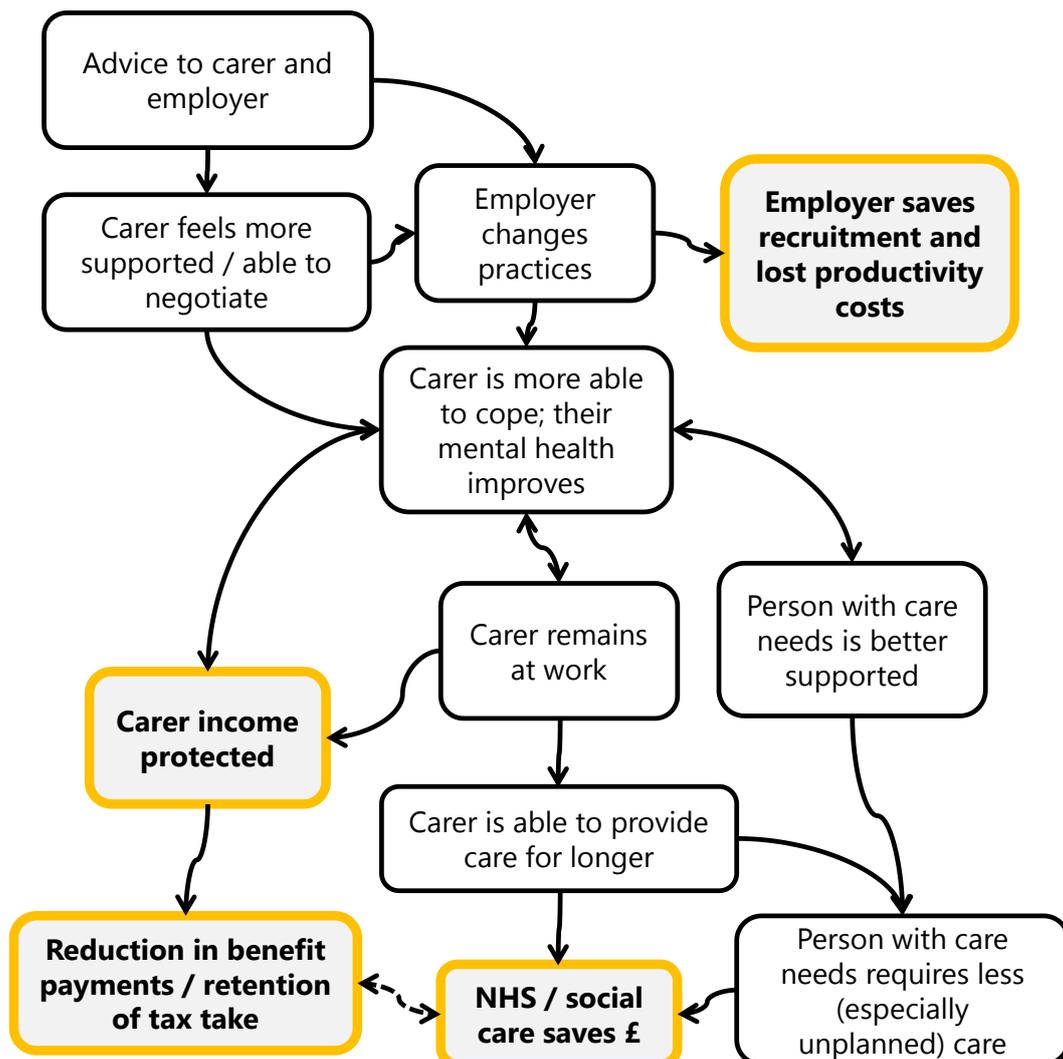


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**ARGUMENT 2: If we provide effective advice to carers and employers, then the carer will be more able to remain in work**

This argument is summarised in the model below. It suggests that:

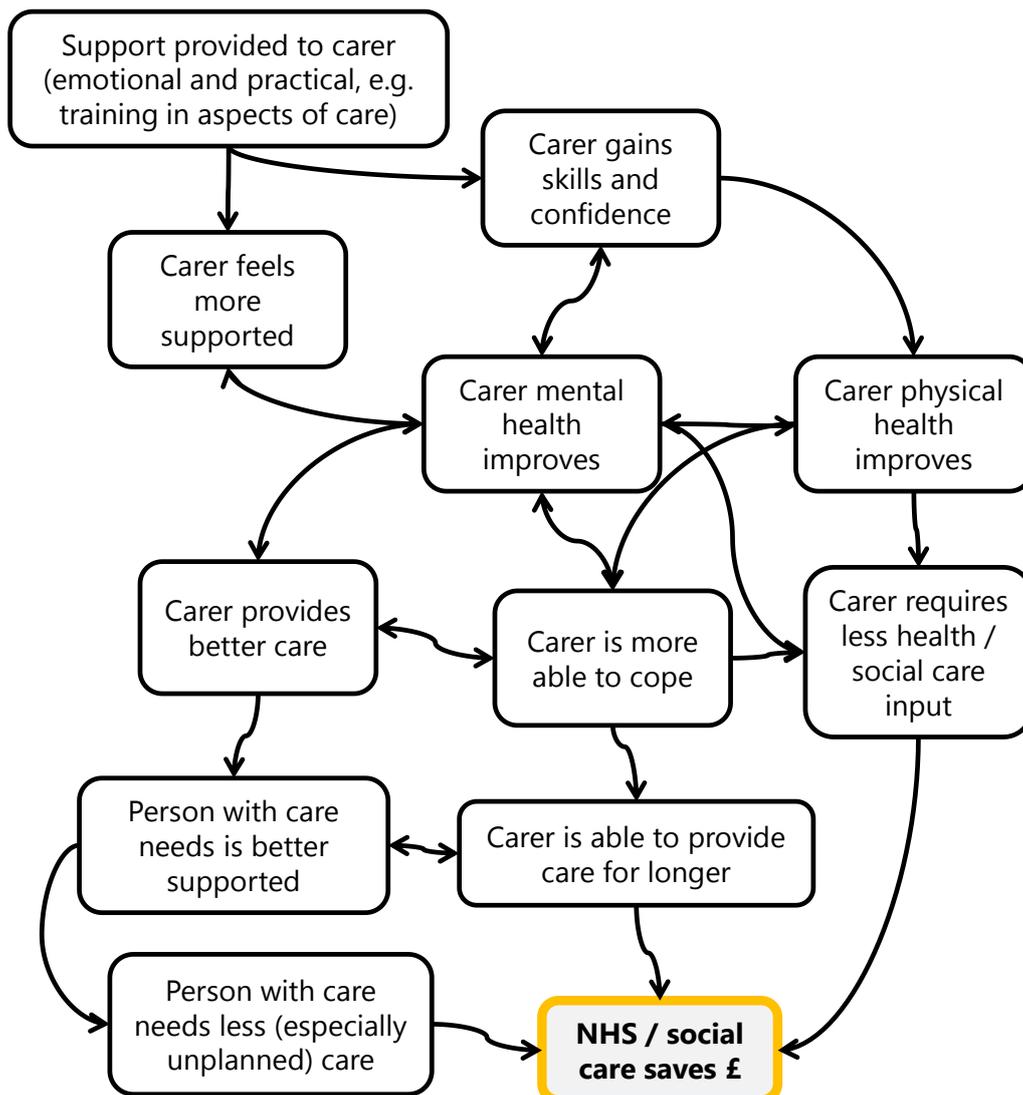
- Relative to Argument 1, there are more means by which economic benefits might follow;
- These benefits are also distributed both over time (some are fairly immediate, others come later) and by stakeholder (employers gain, individuals gain, the state / public services gain);
- As for Argument 1, the main mechanism by which this argument seems to work is carers' ability to cope / their mental health. In turn, this is affected by the extent to which they feel supported and their employer changes practice. As with Argument 2, the mechanisms and sources of benefit would be different for young carers – especially if relating to participation in education / training rather than (just) the labour market; and,
- The main way in which health and social care services are expected to benefit is through reduced use of (especially unplanned) services by the person being cared for.



**ARGUMENT 3: If we provide effective support to carers, then the person with care needs will be better supported: they may require less health and social care**

The logic model for this argument shows that:

- This is an elaboration of Argument 1; it illustrates the 'double benefit' of supporting carers;
- This is also shown in the way in which this support might lead to economic impacts in that this derives from reductions in health and social care use by both the carer and person being cared for. One question for subsequent analysis might be about the relative weight of these relationships: does economic benefit result mainly from one or the other? As with Arguments 1 and 2, the mechanisms and sources of benefit for young carers are most likely to be education / training / labour market related; and,
- Again, the mental health of the carer appears to be a fundamental mechanism within the model. The extent to which the carer feels resilient and able to cope affects much of the rest of the model: if this does not change remaining benefits do not flow.



# Next steps for analysis; moving into action

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This project set out with three aims:

1. Set out the main arguments from an economic perspective for supporting carers;
2. Assess – in broad terms – the existing evidence base for these arguments; and,
3. Recommend, by combining aims 1 and 2, areas where further analytical effort would bring greater clarity and weight to the arguments for supporting carers.

At a headline level, the project has shown that it is possible to define a broad but clear set of arguments for supporting carers from an economic perspective.

Moreover, and accepting the limitations of the evidence available to the study, these arguments seem generally well supported by available evidence (see Annexes). Notwithstanding this, there is a general need for tighter and greater quantification of the types of benefits under consideration here. But – at a headline level - there are no 'gaping holes' to fill.

The recommendations in this section concentrate almost exclusively on national level action. This is on the assumption / in the knowledge that local systems lack analytical capacity and that 'doing it once' nationally, but then helping the process of translation into local action (primary, it is suggested here, through specific products) will be more effective than trying to spur local analytical action.

In approaching this, the initial task for the analytical agenda (aim 3) is one of refinement. It is to go a level of detail below the headline arguments and to look at more specific instances where analysis would add to the case for local action: both by 'type' of carer and by type of support.

Therefore, to provide a conceptual bridge between the three headline arguments and an analytical programme that NHSE and its partners can pursue, our main recommendations are to:

**1: Use a matrix approach to see how each Argument applies to different 'types' of carer – and where gaps in current evidence are**

In approaching this task, we recommend the use of the matrix below (or some variant of it). In essence, it:

- Takes a very broad typology of carer 'types'. In this case the typology uses a simple lifecourse approach; experts in the field may have more refined categories (for example, an alternative / complimentary approach would be to use conditions, such as dementia / cancer - or situations such as end of life). One important consideration here would be to resist over-differentiation by asking whether currently available datasets support any typology used (e.g. main demographic factors generally would be, less easily observable factors would not);
- Asks (on an a priori basis) how applicable each of the three Arguments is to each category of carer; and then,

- Asks for an assessment of the evidence base in each area. 'Evidence' in this case would be assessed by both relevance (focused on economic effects) and rigour (privileging quantification / monetisation of costs and benefits).

Carer 'type'	Argument 1		Argument 2		Argument 3	
	Applicability	Evidence	Applicability	Evidence	Applicability	Evidence
Young						
Working age						
Retirement age						
Older						

Completing a matrix like this would therefore help to show where the economic arguments apply especially strongly and where the extant evidence is especially lacking. This would build on the wide-ranging review undertaken of the caring literature by Mary Larkin at the Open University (in press) and the recent NIHR funded meta review<sup>2</sup> footnoted on page 2. It would help focus down on the costs and benefits around interventions for particular issues faced by carers.

The matrix below is completed for illustrative purposes, highlighting areas of mismatch between the assessed relevance of the argument and the evidence to support it:

Carer 'type'	Argument 1		Argument 2		Argument 3	
	Applicability	Evidence	Applicability	Evidence	Applicability	Evidence
Young	✓	✓	✓✓✓	✓	✓✓	✓
Working age	✓		✓✓✓	✓✓✓	✓✓	
Retirement age	✓✓	✓	✓	✓	✓✓	✓✓✓
Older	✓✓✓	✓			✓✓✓	✓

Where these areas of mismatch are shown, then this provides a framework – a level of detail down from our three headline arguments - within which an analytical agenda can be advanced.

The exact ways in which this agenda might be developed in practice would depend upon the mismatch revealed. So, taking the example in the table above of young carers and evidence relating to education / training benefits (Argument 2), this could be investigated in further detail in terms of: existing literature (what is effective in supporting young carers to remain in education?); the design of effective interventions found (what do these interventions 'contain'? What do they cost? What effects are typically seen?); case studies of implementation (how are they implemented

<sup>2</sup> Here it is worth noting that, as a meta-review, this study will have excluded (potentially many) studies that might be relevant to the topic but failed their test of methodological rigour.

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in practice?); and modelling (if they were done in Area x, or at Scale y, what might the costs and benefits be?). Even this short example shows how analytical effort could then have a practical effect, spurring local areas / agencies to take action.

Following on from this recommendation, the study also suggested a need to:

## **2: Focus on improvements in carer mental health as a fundamental mechanism**

The ability of carers to 'cope' and resilience to changes in their situation was a recurrent theme in the Arguments. This is not to neglect physical health as a topic (evidence presented in Annex 2 shows that carers' physical wellbeing is typically worse than that of the background population), but it is to suggest that interventions designed to achieve economic impacts will most likely have to do so via gains in mental health.

The recent meta-review on effective interventions (referenced elsewhere) highlighted several proven means of improving carers' mental wellbeing and ability to cope. This could be extended – most likely through additional primary research – to examine whether these changes subsequently 'cash out' in economic terms in the ways suggested in this review. So, for example, do interventions to improve carers' mental health then lead to a reduction in the use of unplanned care by the person being cared for?

## **3: Scale and demonstrate ways in which the NHS could take immediate action to generate economic benefit**

Two areas of focus suggest themselves here:

### **Young and working age carers**

Map out the notion of 'unproductive care' that came through the workshop. Here the question was about the ways services arrange themselves without regard to wider economic effects.

So, for example, if a working age carer has to attend multiple appointments with the person they are caring for, then there is an opportunity cost to them (of working time) which has consequent economic impacts (maybe to them as individuals; maybe to employers). For young carers the same will be true, with the opportunity cost perhaps being education related. While possible remedies for this problem (the provision of care closer to home; moving follow-up appointments from secondary to primary care settings; greater use of remote care, etc) are an accepted part of the policy mix, the wider potential benefits of such approaches - beyond 'better use of NHS resources' – are not well articulated or measured.

Taking the above example (of the working age carer attending multiple, uncoordinated appointments) and mapping it out – perhaps using case studies or an expert panel of working age carers – would help to scale / expose this opportunity cost and suggest possible ways in which the configuration of care could contribute to economic efficiency.

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To move this from analysis to practical action, this could be developed into a product for Sustainability and Transformation Partnerships (STPs) / Accountable Care Systems (ACSs) and others with a broader remit and a need to engage across a broader public service agenda. Such a product could help STPs / ACSs in their interactions with local authorities and Local Enterprise Partnerships – showing how supporting changes in health and social care services could achieve wider goals relating to economic development.

### **Older carers**

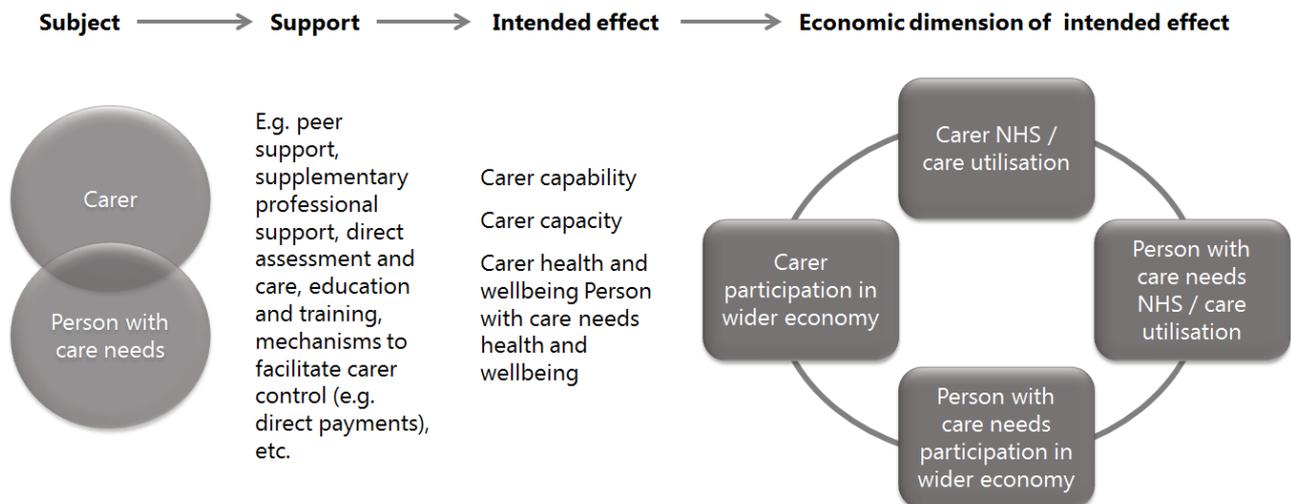
Carer mental health was a vital mechanism within the Arguments; so too was carer skills and confidence. The logic models produced for this study, allied to the costs involved, suggest that concentrating on care at the end of life would produce positive economic impacts.

There is much the NHS could do (and most likely is doing) to transfer skills from staff to carers – so that they know how to spot specific problems, what to do under specific circumstances, how to perform particular tests / techniques (etc).

NHSE could therefore act to codify this and stimulate the transfer of good practice – again by thinking about products for more local parts of the system (such as STPs). This could include literature reviews of effectiveness; collection of case study examples; 'How to...' guides; Return on Investment calculators, etc.

# Annex 1: Description of the workshop

The project began with the development of an initial framework (below), which was used to map



out the main areas of expected economic effect:

This framework took a broad view of the costs and benefits involved: not focusing narrowly on costs and benefits to health and social care services, but including effects on the wider economy, to individuals, to other public services, etc.

The initial framework was elaborated through the literature scan and conversations with stakeholders. To maximise clarity – and to provide some outline propositions for the workshop - the study team set out the information gathered as a series of ‘If x, then y and so z’ type arguments.

Following refinement at the workshop, three main arguments were produced (right) and subsequently refined by the study team.

Feedback from the workshop was very strong in two main respects:

1. There was a high degree of consensus on these arguments. With some refinement (discussed further below), participants believed these arguments to be true and did not suggest other significant / missing arguments. This is a useful finding in itself: it significantly narrows the analytical territory;

*If we provide effective support to carers, then:*

1. The carer’s health status will improve: they may require less health and social care
2. The carer will have more time: they may be able to work / study / volunteer
3. The person with care needs will be better supported: they may require less health and social care

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2. There was however a sense that these arguments as they stood were expressed at too high a level of abstraction to guide analytical action. Here, participants saw a need develop them to the next level of detail.

On this second point, one animating concern was the need to understand the subtleties in what is meant by a being a 'carer'. Participants noted that the same term applies to such radically different situations as to offer little analytical purchase, in that 'carer' could mean:

- An older person caring for a spouse for a limited time at the end of life;
- A parent caring for a child with a disability;
- A younger person caring for a parent;
- A middle-aged person caring for an ageing parent and / or young children;
- And so on - and with further demographic and socio-economic differentiation, for example of location (urban / rural), ethnicity, class and gender; and with an acceptance that each of the above situations would change over time.

Yet fully embracing this subtlety would be fatal to the analytical enterprise. To usefully guide service / policy responses, analysis must be undertaken at some level of generality. Therefore, to meet the aims of this study, there was a need to find a means of embracing some of the subtlety implied by the above, while retaining the ability to categorise and generalise sufficiently that analysis can proceed. We used the three headline arguments (above) as a framework to find these means. Using the workshop, we tested each argument and took them down to the next level of detail.

## **Workshop summary**

The workshop was structured according to the main arguments set out above. Below we present a summary of the main points arising from the discussions, adding further detail to that presented in the main body of the report.

### **ARGUMENT 1: If we provide effective support to carers, then the carer's health status will improve: they may require less health and social care**

An important theme emerging from the discussion of the first argument was the extent to which caring can affect carers' health status. Participants noted that there are carers for whom caring positively impacts their health status; for example, if they see their caring making a difference. Yet, in general, participants noted that effects were typically negative.

It was argued that there is a 'tipping point', which will be different for all carers, when factors combine to make a caring situation unsustainable. As well as support to prevent this, when it

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occurs this is the stage where support is most needed. However, in order to understand what support will be effective at reducing use of health and social care, more evidence is required about the health status of carers and how this compares between different groups of carers and between them and non-carers.

Participants identified that there were both physical and mental health implications of caring, and that the two were linked. One of the main themes emerging from discussions was the significance of stress as a factor leading to short- and long- term mental and physical health outcomes.

Participants identified how these can lead to otherwise avoidable costs for health and social care services. For instance, as well as the care needs associated with poor mental health, an older carer can have an increased risk of stroke as a result of stress caused by caring responsibilities; with an associated risk of their requiring acute care services.

Participants then formulated various ways in which improving the carer's health status, and therefore reducing their stress, could help them (and in turn the person they cared for) require less health and social care. For example:

- Enhanced support enables carers to feel empowered, and, as a result, carers are better able to cope or know how to get appropriate help and care for themselves. This means that carers can make appropriate choices for the person they are caring for;
- In turn, carers make better use of primary care services for both themselves and the person they are caring for. This results in the prevention, reduction or delay of ill health and/or improvements in health and wellbeing (physical, mental and emotional); and that
- This has further implications, for example, reducing the chance of a breakdown in care because the carer is healthy for longer (reducing 'replacement' care costs).

Following on from this, participants agreed that a typology of carers would help to understand both the health outcomes and the risk implications of different types of caring. This was especially important around the issue of hidden or unidentified carers, who may experience negative health consequences from caring but are not aware of the link to these responsibilities. Further, better evidence around which interventions work, for whom, is also important (i.e. early prevention support compared to specific intervention programmes). Evidence gaps in emerging areas were identified, in the potential of telecare and digital aids, as well as the need for better evaluations of current interventions.

**ARGUMENT 2: If we provide effective support to carers, then the carer will have more time: they may be able to work / study / volunteer**

Participants identified a number of ways in which making more time for carers away from caring would be beneficial. One of the main ideas centred on carers being able to achieve their potential;

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carers may be able to take opportunities they may not otherwise have had a chance to because of their caring responsibilities. This was identified as having a number of consequences, for example:

- A reduction in social isolation and exclusion, which has positive health and wellbeing outcomes for the carer and therefore a potential reduction in use of health and social care resources;
- A reduction in benefit payments, if the carer chooses to or can engage in paid employment. Linked to this is an increase in (household) disposable income, which will then be put back into the (local) economy; and,
- A reduction in the difficulties a carer may face with re-entering employment if they had to stop or work part-time previously. Staying in work will also prevent the need for re-training (as there will no longer be a substantial gap in employment).

Participants concluded that both being able to make current or future economic contributions and having disposable income may reduce stress (addressing the issues identified above in Argument 1) and in turn help carers provide more efficient, quality care in the time they are still caring.

There were also some concerns raised about the assumptions underpinning the argument. Firstly, participants agreed that the argument should be extended to include carers who will either choose to or be obliged to spend any (more) free time contributing to other caring responsibilities (for example caring for other family members including familial childcare, or volunteering in a caring role). This created further discussion around the use of the term "will" in the argument and the assumption that carers would choose to use free time away from caring. Secondly, participants believed that whilst understanding and quantifying the opportunity cost of caring on work, education and even volunteering could be possible, doing the same for behaviours that did not have tangible economic benefits but did bring wellbeing outcomes (for example, reading a book) may be more difficult.

Participants recognised the need for a comparison of interventions that could support healthy choices for free time, and provide suitable, cost-effective ways to generate this free time. They identified two main ways to achieve this: comparing the costs of full replacement care to the costs of more simple time-saving measures such as organising services (for example, GP appointments) around the carer's schedule; and, involving carers or ex-carers in the design of support services.

Again, participants argued that having a typology of carers was important: for instance, a carer who had retired from paid employment would have very different priorities to a younger carer of a child with complex needs. Further, understanding the lifecycle or lifecourse of a carer was seen to be important in discerning the longitudinal economic consequences of caring choices and obligations (e.g. the long-term economic consequences for young carers missing out on education).

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### **ARGUMENT 3: If we provide effective support to carers, then the person with care needs will be better supported: they may require less health and social care**

One of the main themes that emerged from the discussion of this argument was the high costs of care 'breaking down'. Participants reflected on the earlier discussion of the significance of the carers' health and wellbeing, and their 'tipping point', and suggested:

- Supporting carers will lead to them being better able to cope, and carers will therefore provide better and more efficient care;
- When there is no breakdown in care, the person with care needs will have continued support;
- As a result, acute and unplanned services, as well as replacement care, do not need to be utilised;
- Therefore, less costly health and social care resource is required.

Participants reflected on and supported the suggestion that a healthy carer leads to a healthy caring situation. Being able to sustain the carer in their role, by providing them with training, information and guidance to make effective decisions, will reduce the stress on the person with care needs and help the carer to provide and sustain better care. This is particularly important given the person with care needs is likely to have a close relationship to the person that is caring for them, and thus they are highly sensitive to their health and wellbeing status.

Participants discussed the importance of 'whole-family' care planning and approaches for interventions; support plans for everyone who is affected by the caring situation may mean less health and social care is required as everyone is better supported. Participants also mentioned the importance of respecting the autonomy of people with care needs, as well as the specific requirements and status of their condition (for example, linked to terminal illnesses, long-term support or rarity of condition) alongside carers' views.

The discussion also identified the need for evidence on how current support is funded, as very little economic analysis appears to have been conducted in this area. Participants considered how the funding of community and other scheme, for example activity groups most often provided by the third sector, may fill the gap of more expensive health and social care services, whilst also providing relief for the carer.

#### **Final reflections from the workshop**

The final session of the workshop asked participants to identify the key assumptions, evidence and thinking that was missing from the discussion of the three arguments. The following summarises their reflections, presented as four themes:

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1. Clarify the argument: By unpicking the argument, and providing evidence for assumptions, it will become easier to understand cost savings and benefits. The phrase “if we provide effective support” should be refined by answering the following questions:

- Does the ‘we’ consist of just the health and social care sector?
  - Are they working together, in parallel or separately?
  - Are health, social care and the Voluntary, Community and Social Enterprise Sector working together? Doing so means they may be more effective at improving the satisfaction of the carer and person being cared for.
- What is ‘effective’ provision?
  - Effective may be read as ways to reduce costs but then it’s no longer about achieving the most appropriate care.
  - Good care is not always cheaper and ‘cheaper’ isn’t a synonym for better since it does not necessarily mean a more effective use of resources.
  - Participants therefore suggested rephrasing the argument to “if we work with carers as expert care partners”, “if we work with carers to deliver personalised support”, or “if we work with carers using a whole-family approach”.

2. Collate a variety of evidence: There is useful data available, such as GP data, which can form an evidence base necessary for a longitudinal analysis, which in turn can convince stakeholders of the economic arguments for why support should be enhanced. There were examples given of how an economic case for investment has been made successfully using available evidence and by embedding new referral mechanisms for carer support that themselves generate new data about the scale of caring, carers needs and the outcomes from support (Surrey). Collecting qualitative evidence is also important; the lived experience of a carer will help to identify both the negatives and positives about caring, and what really makes a difference to their lives. This can inform a quantitative analysis that explores the economic consequences linked to these factors. Any analysis must be taken at both a national and local level.

3. Reflect on the moral case: Understanding what is fair and reasonable for carers to undertake is essential for building an economic case for enhancing support. Starting with the question “do carers want to give care at all?” will enhance the arguments.

4. Focus on ‘unproductive’ care: Delivering effective and cost-effective care is dependent on reducing the amount of unproductive caring that results from a lack of knowledge, training and skills (for example, unpaid carers can be trained to undertake tasks either in the home or in hospital). It is also important to consider the time spent trying to help those who refuse support, as the challenges of their caring responsibilities are extremely different to those receptive to care. A

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major source of unproductive care can also be lack of coordination by services provided to the cared for by statutory sector, services which require the attendance or participation of the carer. Multiple disconnected appointments on different days as opposed to 'one-stop shop' arrangements can have a major detrimental effect.

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## Annex 2: Results of the literature scan

This short literature scan was used to gather background material to inform the workshop and the main body of this report. It is reproduced here in full.

### Introduction

There has been a steady increase in the number of unpaid carers in the UK over recent years, from 8.2 million in 2011 to 9 million in 2014<sup>3</sup> (Age UK, 2017). Given the pressures of an ageing population, the demand for carers is likely to continue increasing. A short, non-systematic, review of literature (n = 16<sup>4</sup>) relating to the economics of caring was conducted to inform workshop participants of the arguments for enhancing carer support. The review identifies three central arguments for why providing enhanced support to carers makes economic sense:

- Supporting carers helps to deliver better and more effective unpaid care, thus reducing or delaying the use of NHS and social care services.
- Supporting carers helps to reduce the resource burdens placed on the carer and the person with caring needs.
- Supporting carers helps to reduce the opportunity cost of caring, caused by productivity losses associated with caring responsibilities.

### Unpaid carers are the focus of this review

This review defines carers as people who provide care to others in need of assistance or support (Deloitte Access Economics, 2015), although their duties and obligations vary depending on whether they are an unpaid carer or care worker. Care workers are paid by the state or a private provider, to provide care. As care workers are likely to be health and social care professionals, they will have (specialised) medical expertise. In contrast, unpaid carers are 'free' and often do not have any training for their role (ibid.). This review is focused on support for unpaid carers, and therefore, any use of the term 'carers' is in reference to this group only.

The caring responsibilities of unpaid carers vary considerably, and are in part decided by their relationship to the person with caring needs as well as the reasons why care were required. The

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<sup>3</sup> These figures are likely to disguise the number of people who assume caring responsibilities but do not identify or record themselves as an unpaid carer.

<sup>4</sup> This figure only takes into account the main sources identified in the review. Additional contextual policy documents (e.g. The NHS Five Year Forward View) and updates to studies or articles (e.g. the annual Carers UK 'State of Caring' survey) were also examined and are referred to in this review. A full list of cited references is available at the end of this document.

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2009/10 Survey of Carers in Households (NHS Information Centre, 2010) found that carers are most likely to look after close family members such as a parent (33%), a spouse or partner (26%) or a child (13%). Only 9% of respondents were looking after friends and neighbours. Over half of respondents stated physical disability (58%) as the reason why care was required – other common reasons included a long standing illness (37%) or a sight or hearing loss (20%).

The significant variation in caring responsibilities of unpaid carers makes it difficult to calculate the 'value' of unpaid carers, but it is clear that there is increasing recognition that carers are valuable. Indeed, carers are described as making a "critical and underappreciated contribution not only to loved ones, neighbours and friends, but to the very sustainability of the NHS itself" (NHS England, 2014 cited in Bunyan and Woodall, 2017).

Supporting carers helps to deliver better and more effective unpaid care, thus reducing or delaying the use of NHS and social care services

Providing support to carers can improve the quality of care they deliver, in turn reducing or delaying the use of state-funded NHS and social care services. Improving support to unpaid carers can also help to sustain carers in their role, by reducing their own use of NHS and social care services.

## **The value of unpaid care**

Unpaid carers can help to reduce pressures on formal health and social care services. An estimated £132 billion a year is saved by the state due to unpaid care for disabled, seriously-ill or older loved ones in the UK (Buckner and Yeandle, 2015). This value is especially remarkable given that it is almost equal to the total annual cost of all state-funded health spending in the UK (£134.1 billion in the year 2014-2015)<sup>5</sup> (ibid.).

The value of carers has increased over time, and, as a result of the increasing numbers of carers and costs of replacement care, is projected to continue (Buckner and Yeandle, 2011).<sup>6</sup> Estimates by Netten *et al.* (cited in Pickard, 2004) suggested that in 1990, the cost to the carer was £31.42 per week, compared to £29.98 to society. Taking into account inflation, this increased to £47.13 and £44.97 per week respectively, in 2006 (Pickard, 2004).

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<sup>5</sup> As Casey (2011) warns, measuring economy-wide costs of caring is problematic. It requires looking at what it would cost to replace unpaid care inputs with paid care inputs (though this necessitates the assumption the state would provide care in the absence of unpaid carers) or as the income/working and leisure-time forgone as a result of time devoted to caring (which necessitates assumptions about the value of work and leisure for people).

<sup>6</sup> The costs of replacement care have increased from £14 per hour to £18 per hour which is an increase of 24% (Buckner and Yeandle, 2011)

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In supporting carers in their role, there is a potential equivalent reduction in the use of NHS and state-funded health and social care services and state-funded resources. For example, with every £1.00 invested in carers, there is a potential equivalent reduction of £5.90 in costs for local authorities (for producing a care intervention) (Local Government UK, 2015). This implies that unpaid care is cost-effective for the state, especially if it reduces or delays the use of more acute health and social care services, though the concept of cost-effectiveness should factor in hidden public or private costs (Casey, 2011). Supporting carers to continue delivery of this care is key to maintaining a balanced use of state-funded resources. This is of particular economic importance given that many people now have longer-term conditions (because of improved medical care) and because many people are living longer.

## **Support for carers, to provide better and more effective care, will help reduce or delay the use of NHS and social care services**

The Five Year Forward View notes that unpaid carers are often 'experts by experience' and that the personalised care they provide can be more effective (NHS England, 2014). Empowering carers to deliver better and more effective care can help the people they care for to be more independent in their healthcare choices, and less reliant on formal health and social care services. In turn, this reduces or delays the use of additional healthcare and social care services and resources because carers and those they care for will feel more confident about when to access services they need (HM Government, 2010).

Investment in support for unpaid carers can also create opportunities for technological innovation. Telehealth or telecare (i.e. the remote provision of health care through mobile technology) can support people with long-term conditions to maintain or regain their independence and confidence, and so reduce their dependence on carers. In turn, carers are able to provide better and more effective care and to have the opportunity to reduce other resource burdens or participate in the labour market.

## **Support for the carer's health and wellbeing may help reduce or delay their use of NHS and social care services**

Unpaid care not only has impact on the health of the person they are caring for, but also has an impact on the carer's own health and their ability to sustain their role as a carer (Department of Health, 2014). Providing advice and support can help carers to improve their health and wellbeing which in turn will help to reduce or delay the carer's own use of NHS and social care services.

It is well-recognised that carers often neglect their own health and wellbeing as a result of their caring responsibilities (Carers UK, 2015; Marie Curie, 2015; Buckner and Yeandle, 2011; HM Government, 2010). Unpaid carers are twice as likely to have poorer physical and mental health

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compared to non-carers (Office for National Statistics, 2013 cited in Marie Curie, 2015). For example, carers of people who are approaching the end of their life consistently report 'intense, conflicting, negative and/or difficult emotions' (Marie Curie, 2015); and 55% of 4,572 carers in the UK report that their caring role has contributed to depression (Carers UK, 2015) and loneliness. A similar picture is seen at a regional level; in this instance, the 2015-2018 Carers' Strategy for the City of London (City of London Corporation, 2015) highlights that 4 in 10 carers who provide more than 20 hours of unpaid care a week report being in 'not good' health<sup>7</sup>, and this increases to 6 in 10 carers who are aged 65 and over.

Carers may also already have existing health issues which can worsen as a result of their caring responsibilities. For example, 65% of 639 carers over the age of 60 reported having long-term health problems or a disability themselves (The Princess Royal Trust for Carers, 2011 cited in Marie Curie, 2015). The 2013 GP patient survey (cited in Bunyan and Woodall, 2017) showed that carers report experiencing high blood pressure, back problems, depression and higher levels of arthritis compared to non-carers. Often, the health issues faced by carers are long-term, and can persist even after the carer gives up their caring responsibilities (Mayhew, 2012).

## **Supporting carers helps to reduce the resource burdens placed on the carer and the person with caring needs**

Unpaid care can create 'resource burdens' for the carer because of the financial and time constraints they may face. This can make it challenging for them to be able to carry out their caring responsibilities, and can have indirect effects in the form of poorer health and future employment outcomes (Mayhew, 2012).

### **The hidden costs of caring**

Caring causes a financial burden on both the carer and the person they are caring for. This is often accompanied by a steep drop in income if carers have to reduce their participation in the labour market. Carers can incur direct 'living' costs of caring such as extra heating hospital parking, transport costs and the costs vary considerably by the types of care that is required (Marie Curie, 2015). For example, people who have been diagnosed with cancer face an estimated additional living cost of £540 per month whereas for people with neurological conditions can spend an average of almost £200 a week on costs related to their disability (Macmillan Cancer Support and Extra Cost Commission estimates, cited in Marie Curie, 2015).

Though the cost of unpaid care varies depending on the type of illness and the family's needs and situation, the financial strain can have other, related consequences. In this instance, the financial

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<sup>7</sup> Health reported as 'not good' includes carers who declared their health to also be 'fair', 'bad' and 'very bad'.

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burden of caring for someone also has health implications. For example, according to 6,149 carers interviewed as part of the annual 'State of Caring' report (Carers UK, 2016), 73% state they are struggling to make ends meet and that worrying about their finances is affecting their health. This can result in further financial difficulties, for example, if a carer is unable to return to work once their caring responsibilities are over. This in turn can also create public expenditure costs, for example, costs to the NHS incurred by carers getting treatment (as explored in Section 0) or costs arising from increased social security benefits (Marie Curie, 2015).

### **The personal cost of caring**

Caring comes with a high personal cost for many carers, particularly in terms of the time burden of caring. Research shows that carers are worried about the negative impact their caring role has on both their relationship with the person they care for as well as their relationships with other friends and family (Carers UK, 2015). Due to the nature and structure of unpaid care, carers have to trade time with their family and friends (including time spent caring for other family members and friends), leisure time and time on other social activities with time caring (Beesley, 2006).

This can have further consequences, for example, the failure to have a 'healthy lifestyle' and feeling alone or trapped, which can have related consequences for the economic status of carers. Indeed, Carers Week research (Carers Week, 2016) shows that, when carers are supported by their community, they face far fewer barriers to having a life outside of their caring role. This includes engaging in paid work or education; carers who are not supported by their communities are more than twice as likely to never be able to balance work with care (35% compared with 15%) and education with care (47% compared with 23%).<sup>8</sup>

### **Inequalities in caring**

Caring can also exacerbate existing resource demands among certain groups of carers. For example, rural carers may face particular issues around social exclusion, and this may make it even more difficult for them to have a life outside of their caring role (HM Government, 2010). Further, though the evidence is inconclusive as to whether the wealth and economic status of a person has an impact on the likelihood of providing unpaid care (Beesley, 2006), it has been argued that those from a less 'advantageous' background are more likely to provide unpaid care (Young *et al.*, 2015 as cited in Beesley, 2006). This can lead to their reduced participation in the labour market, which can create opportunity cost burdens for the carer.

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<sup>8</sup> The research for this report was carried out as part of Carers UK annual State of Caring survey (2016)

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## **Supporting carers helps to reduce the opportunity cost of caring, caused by productivity losses associated with caring responsibilities**

Whilst unpaid carers are not paid for providing care, unpaid care is not completely 'free'. Carers may have to forfeit time they spend on paid work<sup>9</sup> because of their caring responsibilities, and, as such, unpaid care can be valued as the opportunity cost associated with the loss of economic resources such as labour, taxes and pension contributions (Deloitte Access Economics, 2015; Casey, 2011).

Supporting carers to remain in work could therefore benefit not only individuals and families, but also employers, businesses and the wider economy by, among other things regaining output currently lost to caring; reducing the loss of talent; increasing business productivity; additional potential gains in tax revenues and NI contributions and; additional benefits to government revenues (Carers in Employment Task and Finish Group, 2013).

### **The participation of carers in the labour market**

Carers can struggle to balance and engage in both work and care responsibilities, and a high proportion of carers appear to give up work to care. The London School of Economics estimates that there are approximately 315,000 working age carers who have left work and remain completely out of employment (Pickard, 2012 cited in Carers in Employment Task and Finish Group, 2013).

Already, the public expenditure costs of carers who feel unable to continue working are an estimated £1.3 billion per year<sup>10</sup> (ibid.) but the number of carers who reduce their participation in the labour market, partially or completely, is expected to rise as a result of the ageing population and the subsequent increase in need for carers (Carers in Employment Task and Finish Group, 2013). Employers thus face the real risk losing talented people in whom they have invested time and money (Casey, 2011), particularly as the age at which people are most likely to have developed the skills employers need is also the same as the peak age for caring i.e. 45 – 64 (Carers in Employment Task and Finish Group, 2013).

Casey (2011) notes that in an economy with less than full employment, this may have minimal impact as replacement full-time or part-time workers can be hired to maintain productivity.

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<sup>9</sup> Carers may disrupt their participation in the labour market in multiple ways including: leaving work completely, switching to part-time work, increased absenteeism from work, and even interruptions to a working day because of 'crises' or caring responsibilities such as hospital visits (Casey, 2011).

<sup>10</sup> This is based on the costs of Carer's Allowance payments and lost tax revenues. Note, this is likely an underestimation of the true cost, which would need to take into account carers' reliance on other benefits and the lost revenue through carers' tax and pension contributions.

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Nevertheless, it can also be argued that carers who forfeit their participation in the labour market because of their caring responsibilities affect the labour supply on a larger scale, causing the productivity capacity of whole economy to diminish. Employers can also incur substantial additional costs in recruiting replacement staff or training other existing employees (Carers in Employment Task and Finish Group, 2013).

Carers also face financial stresses as a result of their reduced or lack of participation in the labour market. For example, though less defined, unemployment can impact carers' health and wellbeing. Having to forfeit participation in the labour market can therefore lead to associated costs for health and social care services (Carers in Employment Task and Finish Group, 2013).

Carers may also require support to re-enter the labour market. Carers attempting to fully rejoin the labour market may find it difficult to do so as a result of their gap in employment, which may have caused (or appeared to cause) a loss of skills and experience. This issue is compounded by health and financial issues. Carers who combine childcare with looking after older or disabled loved ones, i.e. 'sandwich' or 'dual' carers, are particularly at risk because such care can, theoretically, last many years (Mayhew, 2012). For example, almost 30% of respondents to Carers UK's State of Caring (Carers UK, 2011 cited in Carers in Employment Task and Finish Group, 2013) spent over ten years out of work as a result of caring. This has financial implications for both the carer and the state; if the carer does not gain a source of income, they may then become reliant on job allowance benefits, housing benefits and council tax support. There is an additional risk of lost potential in the workplace if skilled workers have to operate at a lower skill level to get better flexibility or local employment to enable them to care at the same time as working; this can also lead to lost productivity (ibid.).

If, however, carers were better supported, it is likely they would be able to continue investing their time in work, and this could unlock significant economic gains for carers. For example, greater support for carers could enable them to increase their skill levels; enable them to balance work and care; access financial products, benefits entitlements and advice on paying for care; and, help with finding employment (Mayhew, 2012). Furthermore, there are also economic gains for the employer. A survey carried out by Carers in Employment Task and Finish Group (2013) highlighted that that employers who have policies in place to support carers see improved service delivery, cost savings and increased productivity. However, only one in every five medium-sized employers responding to the survey had formal companywide policies in place.

Improved support services could also help carers stay or get back to work and contribute to the growth of the care and support service sector. In this instance, over a third of carers responding to

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the 2013 State of Caring survey<sup>11</sup> said they gave up work or reduced their hours because caring services were inadequate or expensive (Carers UK, 2013). Investment in the paid caring sector could also help retain the labour workforce, and create considerable demand and therefore benefit the wider economy.

### **Female participation in the labour market**

Caring is deeply gendered, and this can make it disproportionately more difficult for women to be economically active (Beesley, 2006).

Whilst 82% of the adult social care workforce in the UK is female, women only represent 46% of all economically active individuals in England (Skills for Care, 2015 cited in Elias *et al.*, 2016). Women are also four times more likely than men to give up paid work to do unpaid care work (Carers UK, 2012). As Beesley (2006) notes, it is not clear whether the lower levels of economic activity among women are the result of caring responsibilities, or whether the greater 'availability' of females out of the labour market contributes to the higher caring prevalence among women.<sup>12</sup> It is likely however, that it is a combination of the two factors which therefore means that female carers are more likely to require support to both get back into work, and also to be compensated for the amount of time spent on unpaid care (particularly in the case of the 'double burden' of carrying out both paid and unpaid care).

### **Young carers**

The opportunity costs of caring may be higher for young carers<sup>13</sup> compared to other unpaid carers, because they have never participated in the labour market and caring restricts their future employment potential. In this instance, as many as 27% of all secondary school-aged young carers and 13% of all primary school-aged young carers experience some problems relating to academic progress and attainment, and/or social interactions in school (Dearden and Becker, 2004 cited in Hounsell, 2013). These figures may well be higher given that young carers are also 1.5 times more likely than their peers to have a special education need or disability, and therefore may require care themselves (Hounsell, 2013). Educational disruption, underachievement and the failure to reach educational potential can make it more difficult for young carers to engage with the labour market later on in life. This in turn can create further issues, such as requiring financial support (Deloitte

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<sup>11</sup> The survey was administered to over 3000 carers.

<sup>12</sup> ONS data from the Labour Force Survey (cited in Beesley, 2006) highlights that 23 per cent of those who are economically inactive because they are 'looking after family or home' do not want a job compared to 7 per cent who did want a job but had not sought one. This suggests that although a caring role may have impact on workforce participation, there are also other factors, such as personal choice and how work is valued.

<sup>13</sup> Young carers are defined here as carers under the age of 18, who provide ongoing care and support to a family member.

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Access Economics, 2015) or health issues caused by worrying about employment prospects (Carers Week, 2016)<sup>14</sup>.

Young carers are also at risk of falling into a cycle of inequality. Higher levels of education appear to reduce the probability of caring (for those living outside the household of the care recipient) (Machin and McShane 2001, cited in Beesley 2006) but, as shown below, young carers are likely to have disrupted education experiences which may make it difficult for them to 'escape' caring responsibilities. Enhancing carer support for younger carers can improve their job prospects and further educational opportunities, and enable them to choose better skilled occupations.

## **Conclusion**

This short review has identified three interlinked arguments for enhancing the support currently made available to unpaid carers, and prioritising caring for carers.

Though difficult to calculate, the value of unpaid care is significant and supporting carers will help to deliver better and more effective unpaid care will take pressures of funded health and social care services. This is of particular economic importance given that many people now have longer-term conditions (because of improved medical care) and because many people are living longer. Support to carers also helps to negate any use of NHS or social care services they will require as a consequence of the physical and psychological stresses of their caring responsibilities.

Enhancing support to carers also helps to reduce other 'hidden' costs on personal finances and time. In particular, increased support can help carers to manage financial challenges which result from the extra expenditure on caring. This is significant as carers often have to reduce their participation in the labour market as they may find it difficult to find working opportunities that can fit around their caring responsibilities or re-enter the labour market. This leads to 'knock-on' effects for employers, businesses and the wider economy.

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<sup>14</sup> And see <https://professionals.carers.org/young-adult-carer-mental-health> for further information on the mental health issues that can result for young carers.

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