

Unpaid Care in England: Future Patterns and Potential Support Strategies

Nicola Brimblecombe, Jose-Luis Fernandez, Martin Knapp, Amritpal Rehill and Raphael Wittenberg

ESHCRU at LSE, based in the Personal Social Services Research Unit

September 2018



The Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science is a leading social care research centre. Since its establishment in 1974 at the University of Kent, PSSRU has had considerable impact on national social care and mental health policy and practice in the UK and in a number of other countries.

PSSRU contact information

Personal Social Services Research Unit
London School of Economics and Political Science
Houghton Street
London
WC2A 2AE

Email: pssru@lse.ac.uk

Tel: +44 (0)20 7955 6238

Website: www.lse.ac.uk/pssru

This is independent research commissioned and funded by the UK NIHR Policy Research Programme (Policy Research Unit in the Economics of Health and Social Care Systems: Ref 103/0001). ESHCRU is a joint collaboration between the University of York, London School of Economics and Political Science, and University of Kent. The views expressed are those of the authors and not necessarily those of the NHS, the National Institute for Health Research, the Department of Health and Social Care or its arm's length bodies or other UK government departments.

© London School of Economics and Political Science, 2018

Executive Summary

This report summarises the methodology, results and implications of a study with two overarching objectives:

- to develop an analytical framework for the policy analysis of unpaid care;
- to model the implications of alternative patterns of unpaid care provision over the next 20 years, and estimate the impact of alternative policy interventions for supporting unpaid carers (hereafter carers).

Methods

We used a two-pronged approach for this study of the economics of caring, combining a review of existing international evidence with quantitative modelling of unpaid care demand and supply, and of the impact of a small number of possible policy reforms aimed at supporting carers.

We used two linked projections models. For the demand side, we used our existing PSSRU long-term care projections model. It produces projections of the overall numbers of disabled older people, the numbers receiving unpaid care and/or formal services, and public and private expenditure on long-term care for older people. For the supply side, we developed a new model for the present study to project the numbers of adults providing unpaid care to older people, with a detailed breakdown by the characteristics of the carer.

Numbers of unpaid carers

The current size of the pool of carers in England appears to differ depending on the perspective (care-recipient or carer) used to quantify it. Analysis of Health Survey for England data for 2011 to 2014, when applied to the 2015 England population by age and gender, imply that there are 5.0 million adults providing unpaid care for older people, and 2.1 million older people receiving unpaid care from their family or friends.

Some 3.6 million of the 5.0 million carers of older people provide less than 10 hours of care per week, 645,000 provide care for 10 to 19 hours per week, 520,000 for 20 to 49 hours per week and 300,000 for 50 or more hours per week. The last group comprises 250,000 providers of co-resident care (including 185 spouse carers) and 50,000 providers of extra-resident care.

There are some 680,000 spouse carers, of whom 345,000 are female. Approximately 590,000 (87%) of them are aged 65 or over. Almost half of them (48%) provide care for 20 hours or more per week.

There are some 400,000 other co-resident carers, of whom the vast majority, 375,000 (93%) are aged under 65, and over half (52%) are in employment; 170,000 of them are female and 230,000 are male. Around 160,000 (40%) of them provide 20 or more hours of care per week.

There are 2.7 million extra-resident carers of their parents, i.e. caring for one or more parents or parents-in-law. They account for more than half of all carers of an older person; 1.6 million of them are female and 1.1 million male. 2.4 million (90%) of these extra-resident carers of parents are aged under 65, and 1.8 million (67%) are in employment. Around 300,000 (11%) provide care for 20 or more hours per week.

There are 1.25 million extra-resident carers of an older person other than a parent: 750,000 of them are female and 500,000 are male. 825,000 (two-thirds) of these extra-resident carers of people other than their parents are aged under 65, and 500,000 (41%) of them are in employment. Only around 40,000 of them (5%) provide care for 20 or more hours per week.

Projections of numbers of unpaid carers

To keep pace with demographic pressures, the number of older people receiving unpaid care would need to rise from 2.1 million in 2015 to 2.65 million in 2025 (a rise of 27%) and to over 3.4 million in 2035 (a rise of 63% from 2015). This is based on an assumption that the proportion of older people with care needs remains constant by age and gender.

To keep pace with this projected rise in the number of older people needing care, while maintaining the current ratio of carers to care-recipients, the number of carers of older people would need to rise from 5.0 million in 2015 to 6.4 million in 2025 (a rise of 27%) and to 8.1 million in 2035 (a rise of 63%). These projections assume that the number of older people receiving formal services, which has been falling in recent years, not only ceases to fall but actually rises in line with demographic pressures.

We project that the total number of carers of older people in England will rise from 5.0 million in 2015 to 5.8 million in 2035. This projection is sensitive to an assumption that the proportion of adults by age and gender providing unpaid care to an older person remains constant. On this basis there would be a shortfall in 2035 of 2.3 million unpaid carers.

We expect that within the overall total the number of extra-resident carers of working age in employment to rise from 2.32 million in 2015 to 2.41 million in 2035. As a proportion of all carers, this is a fall from 46% to 41% because the number of older carers (aged 65 and over) will grow faster than the number of younger carers.

These projections of future numbers of older people needing care and of unpaid carers of older people are, it should be stressed, on reference case assumptions that the proportions needing and providing care remain unchanged through to 2035. While this reference case is valuable for studying the impact of alternative assumptions, this does not mean that it is necessarily the most likely outcome. In particular, it is possible but by no means certain that, as the number of older people needing care rises rapidly, the

proportion of people providing unpaid care to an older person will rise and the shortfall in 2035 will prove lower than 2.3 million unpaid carers. There is clearly scope for debate about this.

Supporting unpaid carers

There are four main types of interventions for carers:

- services aimed at the care-recipient (benefits in kind);
- services aimed directly at the carer;
- work conditions;
- cash benefits.

Our review covered evidence regarding the impact of interventions on employment; health, wellbeing and quality of life; income, wealth and poverty; and changes in supply of unpaid care. However, it was only for impacts on carers' employment status that we could identify evidence that was sufficiently robust and quantifiable to use in our modelling analysis. We have therefore focussed on policy measures to increase employment rates among carers.

We have identified three policy measures (statutory care leave, flexible working arrangements and formal care) which evidence suggests would increase employment rates among carers.

Overall, the employment-generating effects of the interventions considered were relatively limited, in particular for two of the schemes investigated.

The evidence suggests that statutory care leave can potentially both increase (or maintain) provision of unpaid care and increase (maintain) employment, possibly in conjunction with other interventions at a certain level of care need. We estimate that statutory care leave would raise the number of extra-resident working age carers who are in employment by around 187,000 (7.9%) in 2020 with no further increase in subsequent years. There would likely be costs to employers and to government both in its capacity as an employer and in its potential role in promoting the scheme.

Flexible working has also been found to be effective in improving employment outcomes for carers. Carers in the UK already have legal rights to request flexible working, but issues such as lack of awareness and a reluctance to request it mean that further gains in employment outcomes could be achieved by increasing take-up. Flexible working would raise the number of extra-resident working age carers who are in employment by around 60,000 (2.4%) in 2020 with no further increase in subsequent years. Again there would be costs to employers and to government.

Formal care has been found to increase supply of low-intensity unpaid care and to decrease higher-intensity caring that is less compatible with employment. For maximising employment, home care/personal assistant (PA) support or day care for the person with care needs is the most effective intervention for those caring for 10 hours or more per week. This would raise the number of extra-resident working age carers who are in employment by around 58,000 (2.4%) in 2020, increasing to 69,000 additional such carers in employment in 2025, and then falling to 65,000 in 2035. If the extra home care-recipients received care packages similar to those currently supported jointly by local authority and unpaid care, the total additional cost of the scheme is estimated to amount to almost £1.8 billion.

Analysis caveats

The following analysis caveats ought to be noted:

- The review identified only a limited amount of evidence suitable for the quantitative modelling. In particular, the analysis could not produce suitable evidence to model a possible substitution effect between formal services and unpaid care.
- The analysis included non-UK evidence, some of it of limited applicability to the English context due to important cultural and legal differences between countries.
- We have conducted sensitivity analyses on some of our important assumptions in order to assess the degree of uncertainty of the estimates. Our base case projections are particularly sensitive to assumptions that disability rates among older people will remain constant by age and gender and that rates of providing unpaid care to older people will also remain constant by age and gender.
- We have not worked out the implementation processes that would be required to operationalise the three policy strategies modelled. These are likely to be complex and will require careful consideration.

Unpaid Care in England: Future Patterns and Potential Support Strategies

CONTENTS

LIST OF TABLES	1
LIST OF FIGURES	1
INTRODUCTION	2
ANALYSIS FRAMEWORK	6
Evidence review	6
Projections of patterns of unpaid care demand and supply	8
Analysis scope	9
FUTURE DRIVERS OF UNPAID CARE SUPPLY	10
Distribution of carers in England	10
Projections of future numbers of carers and older care-recipients	14
MODELLING ALTERNATIVE STRATEGIES FOR SUPPORTING UNPAID CARERS	19
Supporting unpaid carers: review of international evidence	19
Modelling the impact of selected unpaid care support schemes	39
POLICY IMPLICATIONS	52
The care gap challenge	52
Policy strategies for meeting the challenge	52
Analysis caveats	54
REFERENCES	56

LIST OF TABLES

Table 1:	Estimated numbers of unpaid carers of older people in England (2015), by carer characteristics	11
Table 2:	Estimated distribution of unpaid carers of older people in England (2015) by key characteristics including intensity of unpaid care support	12
Table 3:	Assistive technology and telecare	29
Table 4:	Services directly aimed at carer	31
Table 5:	Numbers of additional recipients of home care, of employed unpaid carers of older people and associated costs for formal care scenario (England 2015)	50
Table 6:	Projected number of carers of older people by category and scenario (2015–35)	51

LIST OF FIGURES

Figure 1:	Analytical framework	4
Figure 2:	Distribution of unpaid carers of older people by key characteristics (England, 2015)	13
Figure 3:	Distribution of carer characteristics for carers of older people providing over 10 hours of care per week (England, 2015)	14
Figure 4:	Projected demand for and supply of unpaid care for older people	17
Figure 5:	Numbers of carers of older people by employment outcome (2015–2035): base case	18
Figure 6:	Illustration of employment effect in Pavalko and Henderson	40
Figure 7:	Distribution of extra-resident carers of older people (aged 16–64) by employment status and modelling scenario (2015)	46
Figure 9:	Numbers of carers of older people by employment outcome (2015–2035): care leave for all scenario	47
Figure 8:	Numbers of carers of older people by employment outcome (2015–2035): care leave for women scenario	47
Figure 11:	Numbers of carers of older people by employment outcome (2015–2035): formal care scenario	48
Figure 10:	Numbers of carers of older people by employment outcome (2015–2035): flexible working scenario	48

INTRODUCTION

Unpaid or informal carers (hereafter 'carers') provide the bulk of the support given to people with social care needs in England. The 2011 Population Census indicated that over 10% of adults in England provided unpaid care to a family member, relative or friend. Although the highest prevalence of unpaid caring is found for females aged 50 to 64 years, this key activity involves adults from all groups in society, as well as some children.

Whether or not somebody decides to provide unpaid care has a number of important implications.

- **For the person with care needs**, it affects the nature and overall amount of support received (formal and informal), and therefore potentially affects to what extent their needs are met, and hence influences their health and wellbeing. The availability of unpaid care affects what formal care services are offered and used, and consequently the private and public costs of delivery. Some formal services, such as care home or inpatient admissions, are expensive and rarely the preferred locus of support for the cared-for person.
- **For carers**, the decision to provide unpaid care might affect the extent and nature of their participation in the labour force, the conditions and characteristics of any employment, including any associated entitlements (including benefits such as occupational health services and health insurance), their post-retirement income and their health and wellbeing.
- **At a macroeconomic level**, changes in the prevalence of unpaid care will have important repercussions for levels of state social care expenditure and thus for the financial sustainability of the formal care system, and for economic growth through possible effects on overall labour force participation and productivity.

Each of these potential effects is complex in nature, and will vary depending on the characteristics of the cared-for person, including their needs and assets (personal and economic), and the circumstances of the potential carer.

Given these potential effects, the state has a strong incentive to implement policies which support carers in ways that maintain their wellbeing and that help them take part in paid employment while continuing to provide appropriate support for people with health and social care needs.

This report summarises the methodology, results and implications of a study with two overarching objectives:

- to develop an analytical framework for the policy analysis of unpaid care;
- to model the implications of alternative patterns of unpaid care provision over the next 20 years, and estimate the impact of alternative policy interventions for supporting carers.

Understanding likely future OverallTaxpatterns of unpaid care, the implications of such patterns for the state and for individuals, and the suitability of alternative policy measures is particularly complex because of the range of individual, community and contextual factors involved in decisions to provide unpaid care and that mediate their impacts on different parts of society. Our analysis has considered as wide a range as possible of drivers and consequences of unpaid care for different groups in society.

Our overall analytical framework is summarised in Figure 1. In the context of the relationships highlighted in Figure 1, the study emphasised the study of the following questions:

What factors affect unpaid care provision?

We investigated the relationship between key population characteristics and present and future supply levels of unpaid care by different groups in society and for different groups of people with health and social care needs. The analysis focussed in particular on key individual-level factors such as age, gender, household structure, relational propinquity, and educational and vocational qualifications and skills. Other 'environmental' factors such as macroeconomic performance were considered, but insufficient evidence was identified to incorporate them into the quantitative analysis.

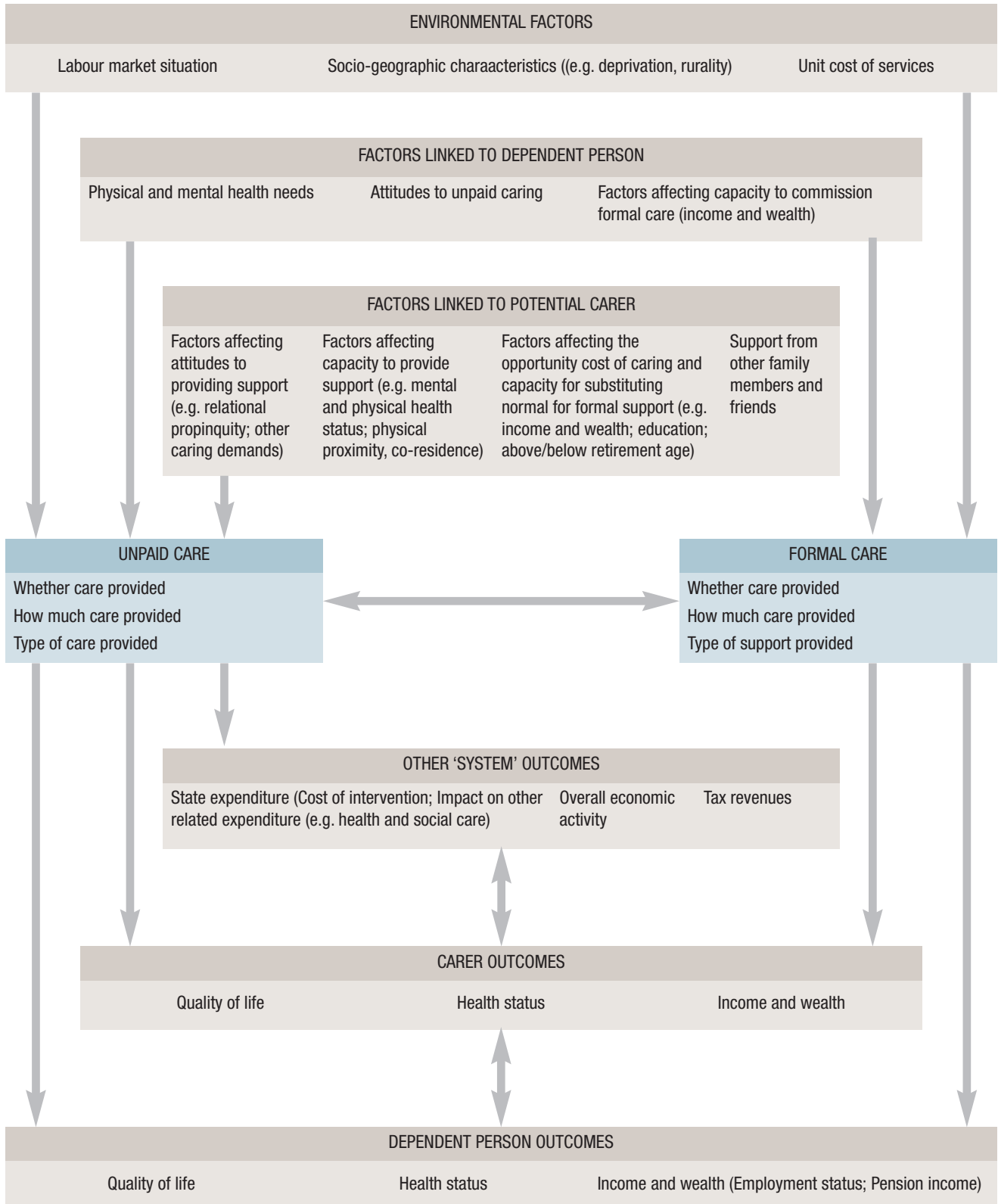
What are the implications of changes in the supply of unpaid care for individuals and the state?

As noted above, the decision to provide unpaid care has important implications for cared-for people, carers and the state. Within the limitations of existing evidence, we explored the following three questions:

What is the impact of providing unpaid care on carers' labour force participation, and on the nature of their employment? How do these effects vary for different groups of carers (e.g. by demographic and socioeconomic characteristics), with different characteristics of the cared-for person (e.g. type and intensity of need, assets, relational propinquity between cared-for person and carer) and with different macro-environmental factors (e.g. unemployment rates, social capital)? Two important aspects of this question are the impact of unpaid care provision on (a) a carer's income and wealth post-retirement and their own future needs for state financial support; and (b) the impact of different carers' employment outcomes on economic growth.

What is the impact of providing unpaid care on carers' own current and future health and care needs? Caring can have both positive and negative consequences for a carer's own health and wellbeing. These health and wellbeing consequences could affect carers' own needs for state-funded and other health or social care, both now and in later years, with associated public and private costs. Overall, the limited amount of evidence available meant that the analysis has concentrated on the quality of life effects

Figure 1: Analytical framework



of unpaid caring, and specifically on interventions for improving carers' quality of life, as noted below.

What is the relationship between paid and unpaid care provision for different people with social care needs, and in different socioeconomic groups? We have explored the international evidence to understand the nature of the relationship between unpaid and formal care use.

What is the effectiveness (and cost-effectiveness) of different interventions to support carers?

A number of interventions have been employed in the UK and elsewhere to support unpaid carers, including payment of cash benefits, provision of information and advice, formal services for the cared-for person (such as home care), services directly targeted at meeting carers' own needs (such as psychosocial approaches and relaxation techniques, and including formal assessment of those needs), and flexible working environments to enable carers to combine caring with paid employment. These various interventions could require expenditure from, or have cost impacts on a range of public and private budgets.

We reviewed the international evidence on the effectiveness and cost-effectiveness of interventions to support carers, and the policies behind them. We focussed particularly on evidence about the impact of such interventions on the health and wellbeing of carers, patterns of carer employment, and costs across all budgets (of which there was very limited evidence).

ANALYSIS FRAMEWORK

Given the limited timeframe for the study, our aim was to provide an initial scoping exercise of the issues highlighted above. We used a two-pronged approach, combining a review of existing international evidence with quantitative modelling of unpaid care demand, supply and the impact of a small number of possible policy reforms aimed at supporting unpaid carers.

EVIDENCE REVIEW

We carried out a rapid review of the literature, including relevant grey literature, particularly reports from government bodies, third sector organisations and think tanks. We also built on existing work, including research by PSSRU colleagues at LSE.

The emphasis of the analysis was to use existing, published evidence. A limited amount of new quantitative analyses using Health Survey for England (HSE) and British Household Panel Survey (BHPS) data were carried out. Additionally, we contacted international experts in the unpaid care field to discuss our findings. The final prioritisation of interventions was agreed with policy customers at Department of Health (DH).

The literature review focussed on identifying international evidence of interventions and policies aimed at supporting unpaid carers. In doing so, the aim was also to identify any evidence that might be useful for modelling the key relationships in Figure 1, such as the nature of the substitution between formal and unpaid care, or the impact of different levels of care intensity on carer outcomes, with particular emphasis on patterns of carer employment and carer health and wellbeing. Where possible, we explored cost and cost-effectiveness implications of unpaid care interventions. In addition, the review considered evidence on the effect of interventions on propensity to provide unpaid care.

An initial overview of the literature showed that there are four main types of interventions for carers:

- services aimed at the care-recipient (benefits in kind);
- services aimed directly at the carer;
- work conditions;
- cash benefits.

In general, the research on services aimed at the care-recipient, work conditions and cash benefits considers impact on employment and to some extent propensity to supply unpaid care; this is particularly the case for research on cash benefits. The research on services aimed directly at the carer explores, in the main, health and wellbeing outcomes, in particular mental health. The evidence for some interventions in

the review are only relevant to working age carers (e.g. work conditions). Others evidence is potentially relevant to a broader range of unpaid carers, including those above the state pension age as well as under it (e.g. services aimed directly at the carer). Yet other interventions may be relevant to older carers as well as working age carers such as services aimed at the care-recipient. However these have mainly been studied in relation to working age carers.

This list covers a broad range of topics and the literature is very extensive, in particular for interventions aimed directly at carers. We sought to maximise breadth and depth within the time constraints of the review. We therefore began with recent key reviews: Parker and colleagues' (2010) international meta-review of systematic reviews 2000-2009 of interventions to support unpaid carers, and Victor's (2009) review of 107 UK studies 1990-2009 'offering some measurement of intervention outcomes for carers'. We also drew on an unpublished scoping literature review by Pickard and Perkins (2011) on the role of formal services in supporting carers' employment and Pickard's earlier (2004) review of support for unpaid carers for the Audit Commission, which used mainly UK but also international literature from 1990 to 2003. Using relevant search terms and key databases (Academic Search Complete; ASSIA; HMIC; Pubmed; Google Scholar; MODEM toolkit; SCOPUS; Social Care Online, Web of Science), this was then supplemented with key, more recent, systematic reviews as needed, except for formal services for care-recipients, work conditions and cash benefits, where we could find no systematic reviews or meta-reviews. For the latter, we utilised reports and key recent academic papers, again retrieved from key databases (listed above).

OECD, WHO and EU synthesis reports also form part of the evidence base, including the comprehensive OECD report by Colombo (2011), the 2016 WHO Report on Ageing and Health (WHO 2016) and the recent ESPN 35-country synthesis report on the impact of national policies on carers employment and wellbeing (Bouget *et al.* 2016). In addition, we included evidence from UK government reports, policy documents and impact assessments, as well as reports from key voluntary sector organisations such as Carers UK and Eurocarers. We consulted experts in the field, including academics in the UK, Finland and the US, policy experts from SCIE and the ILO, experts from Carers UK and Eurocarers. We drew on their advice and suggested references and reviews, in particular from the team at Diak in Finland who are carrying out similar work for the Finnish government.

We also built on relevant expertise and publications from within PSSRU. Relevant intervention areas in which we have experience are: the relationship between formal services and carers' employment, assistive technology (AT) and dementia. Much of the interventions literature focuses on carers of people with dementia and, in particular, we use evidence from the MODEM toolkit, a database of over 1400 research studies on interventions for people living with dementia and their carers, which also has evidence summaries, and the recent PIRU review by Knapp *et al.* (2016) on technology for people with dementia and their carers. Furthermore, we looked at key publications from

other academic research units working in this field, including evaluations by Yeandle and colleagues on DH initiatives for carers such as the National Carers' Strategy Demonstrator Sites programme and the Caring with Confidence programme.

Our review looked at outcomes for carers only. Some of the interventions will have positive (or perhaps negative) outcomes and associated costs for care-recipients as well, but this was beyond the scope of this review. Additionally, there is other effective support for carers such as an informal care and support network that does not fall under the remit of 'interventions' in this review.

It should be noted that the policy and practice environments around unpaid care and long-term care can change rapidly. Since many of these papers and reviews were written, there have been marked changes in carer support availability and policy. In England, there has been reduced availability and changes in eligibility criteria for formal care and reduced funding for many voluntary sector support organisations. Conversely, recent legislation has brought in and extended the right for carers to request flexible working, and new legal duties on local authorities to provide support to meet carers' needs, explicitly including through provision of services to the care-recipient. These recent developments have not to our knowledge been evaluated.

PROJECTIONS OF PATTERNS OF UNPAID CARE DEMAND AND SUPPLY

The projection modelling builds on previous macro-simulation models built in PSSRU, and used for instance for the MAP2030 study (although the underlying models have continued to be developed and updated in subsequent projects). We were also able to build on learning from current work in our dementia projects, although the present study of course needed to look at a wider set of needs.

Specifically, we used two linked projections models for the study of the economics of caring. For the demand side, we used our existing long-term care projections model, developed over many years with DH funding and regularly updated as part of our core work in PSSRU. It produces projections of the overall numbers of disabled older people, the numbers receiving unpaid care and/or formal services, and public and private expenditure on long-term care for older people.

For the supply side, we developed a new model for the present study to project the numbers of adults providing unpaid care to older people, with a detailed breakdown by the characteristics of the carer (see tables below).

The two models draw substantially on our analyses of data from the HSE, conducted as part of a study of care for older people in the community funded by the Nuffield Foundation. From 2011 onwards, HSE has included a module of questions on the care needs of older people in the community and their receipt of and payments for care and a module of questions on provision by adults of unpaid care. (These modules were in fact developed in previous PSSRU research.)

Our analysis used these two models to model alternative scenarios regarding patterns of unpaid care in England over the next 20 years. The modelling explored:

Alternative assumptions about the supply of unpaid care from different groups in society and in support of people with different types and intensities of social care needs.

The long-term consequences of the hypothetical implementation of a small number of policy measures identified in the review seen to be particularly promising in the English context.

Given the limited amount of economic evidence on unpaid care, it was especially important to examine lessons and evaluations from beyond England. However, we ensured that we restricted our attention to interventions, policies and research findings that are relevant to and interpretable within the English context.

ANALYSIS SCOPE

Geographical scope

All of our modelling focusses on England, even though – as just noted - our review examined international evidence. This broad international scope was particularly pertinent when exploring alternative models of support for carers, as restricting the review to English experience would have missed important policy initiatives and interventions, for instance regarding the support received by carers in the workplace. We acknowledge, however, that one must be cautious in interpreting non-English experiences and evidence for the English context.

Range of carers considered

Our modelling concentrated on carers of older people, because the relevant simulation models already in place cover this user group, and extending the models to try to cover carers of younger adults or children with social care needs was not feasible within the time available. However, the literature review considered evidence from all carer groups, in order not to miss transferable evidence between groups.

Range of policy influences considered

The availability of formal care plays a key role in determining present and future “need” for unpaid care support. Formal care availability will itself depend on a wide range of factors, including factors specific to the care system (e.g. government social care policy) and to the broader socio-economic environment (e.g. GDP growth). Given the limited time available for the project, the analysis had to concentrate in exploring the impact of a small number of factors associated with unpaid care supply, and could not test the impact of changes in broader influences, such as changes in migration patterns and economic growth.

FUTURE DRIVERS OF UNPAID CARE SUPPLY

The influences of the various drivers of unpaid care supply are likely to change in the future because of a number of demographic, social and economic changes already evident, including changes in longevity, population age structure, family size, employment patterns (especially of females), employment-related incentives and the availability of formal care. It is therefore important to understand the extent to which socio-demographic changes, for instance, are likely to impact on the number of potential carers and the consequences of such changes on the economy and the wellbeing of people with health and social care needs and of carers themselves.

In this section we summarise the results of our modelling analysis examining likely patterns of demand for and supply of carers in England over the next 20 years.

DISTRIBUTION OF CARERS IN ENGLAND

The implications for the public purse of different patterns of unpaid care provision will depend on the circumstances of users and carers. Whereas maintaining carers in employment might raise overall tax revenues and contribute to overall GDP growth, for instance, it might generate costs in terms of additional need for formal care support for the cared-for person which, subject to needs and means-testing eligibility criteria, might fall on the state.

It is therefore important, when thinking about future supply of unpaid care, to draw a detailed picture of the characteristics of the main groups of unpaid carers in society.

Numbers of carers

The size of the pool of unpaid carers in England appears to differ depending on the perspective (care-recipient or carer) used to quantify it. The findings of the analyses of HSE data for 2011 to 2014, when applied to the 2015 England population by age and gender, imply that they are 5.0 million adults providing unpaid care for older people, and 2.1 million older people receiving unpaid care from their family or friends. The difference arises partly because some older people receive unpaid care from more than one carer, and some carers support more than one older person. The average number of carers reported by each older person receiving unpaid care is almost 1.6. The average number of cared-for older people reported by each carer of older people is 1.22. This suggests that, nationally, for each 100 older care-recipients there could be expected to be around 130 unpaid carers ($100 \times 1.58/1.22$).

The ratio of 5.0 million adults providing unpaid care to 2.1 million older people receiving unpaid care is much larger than the expected 1.3 noted above (a factor of almost 2.4). It seems that there are many cases where someone reports providing care for an older person but the older person does not report receiving unpaid care. This point does not apply to spouse care but to other caring relationships.

Characteristics of carers of older people

Table 1 and Table 2 provide estimated numbers of carers in England in 2015 by the following key characteristics:

- Age
- Gender
- Living arrangements
- Educational attainment
- Relationship between carer and person being cared for (whether the user is the carer's spouse, parent, or other)
- Employment status
- Intensity of unpaid care provided (less than 10 hours per week, between 10 and 20 hours, and more than 20 hours).

Table 1: Estimated numbers of unpaid carers of older people in England (2015), by carer characteristics

Carer characteristics			Number of carers				
Age	Education	Employed	Spouse carer	Other co-resident carer	Extra-resident carer of parent(s)	Extra-resident carer of other(s)	Total
16 to 64	Low	Yes	18,400	85,800	653,400	146,100	903,700
16 to 64	High	Yes	18,000	122,400	1,151,600	367,100	1,659,100
16 to 64	Low	No	36,100	114,900	306,000	211,400	668,400
16 to 64	High	No	19,100	50,700	303,400	98,100	471,300
65+	Low	All	444,200	21,400	152,100	275,700	893,500
65+	High	All	144,300	5,900	122,600	153,200	426,000
Total	All	All	680,100	401,200	2,689,100	1,251,600	5,021,900

Table 2: Estimated distribution of unpaid carers of older people in England (2015) by key characteristics including intensity of unpaid care support

Number of hours of support	Males (000s)				Females (000s)				Total (000s)
	<10	10 to <20	20+	50+	<10	10 to <20	20+	50+	
Spouse carers, 16–64	11	5	5	4	29	12	30	18	92
Spouse carers, 65+	105	54	155	92	100	38	137	69	589
Other co-resident carers, 16–64	114	37	65	21	59	21	79	37	374
Other co-resident carers, 65+	4	3	9	6	5	1	6	4	27
Extra resident carers of parent, employed	619	84	33	4	802	163	104	17	1,805
Extra resident carers of parent, not employed, 16–64	145	26	31	2	247	70	90	16	609
Extra resident carers of parent, 65+	124	23	12	0	70	20	26	4	275
Extra resident carers of others, employed, 16–64	177	10	2	0	296	19	9	0	513
Extra resident carers of others, not employed, 16–64	115	11	5	2	150	15	13	3	309
Extra resident carers of others, 65+	162	11	5	3	226	21	5	0	429
Total	1,576	264	322	134	1,984	380	499	168	5,022

The numbers in Table 2 are also used to elaborate Figure 2 and Figure 3, which focusses exclusively on the characteristics of carers providing in excess of 10 hours per week of care. For the sake of simplicity, not all possible permutations of the above characteristics are included in Figure 2. Instead, certain groups of limited size are combined into ‘aggregated’ groups. For instance, spouse carers are split by age, gender and level of support, but not by employment status.

The figure shows that by far the two most prevalent groups of unpaid carers are made up of women and men in employment and providing less than 10 hours of support per week.

Some 3.6 million of the 5.0 million carers of older people provide less than 10 hours of care per week, 645,000 provide care for 10 to 19 hours per week, 520,000 for 20 to 49 hours per week and 300,000 for 50 or more hours per week. The last group comprises 250,000 providers of co-resident care (including 185,000 spouse carers) and 50,000 providers of extra-resident care.

There are some 680,000 spouse carers, of whom 345,000 are female and 335,000 male. Not surprisingly, 590,000 (87%) of them are themselves aged 65 or over. Almost half of them (48%) provide care for 20 hours or more per week.

There are some 400,000 other co-resident carers, of whom the vast majority, 375,000 (93%) are aged under 65 and over half (52%) are in employment. 170,000 of them are female and 230,000 are male. Around 160,000 (40%) of them provide 20 or more hours of care per week.

There are 2.7 million extra-resident carers of their parents, that is caring for one or more parents or parents-in-law. They account for more than half of all carers of an older person. 1.6 million of them are female and 1.1 million are male. 2.4 million (90%) of them are aged under 65 and some 1.8 million (two-thirds of the total) are in employment. Around 300,000 (11%) provide care for 20 or more hours per week.

There are 1.25 million extra-resident carers of an older person other than a parent. 750,000 of them are female and 500,000 are male. 825,000 (two-thirds) of them are aged under 65 and some 500,000 (41%) of them are in employment. Only around 40,000 of them (5%) provide care for 20 or more hours per week.

Figure 2: Distribution of unpaid carers of older people by key characteristics (England, 2015)

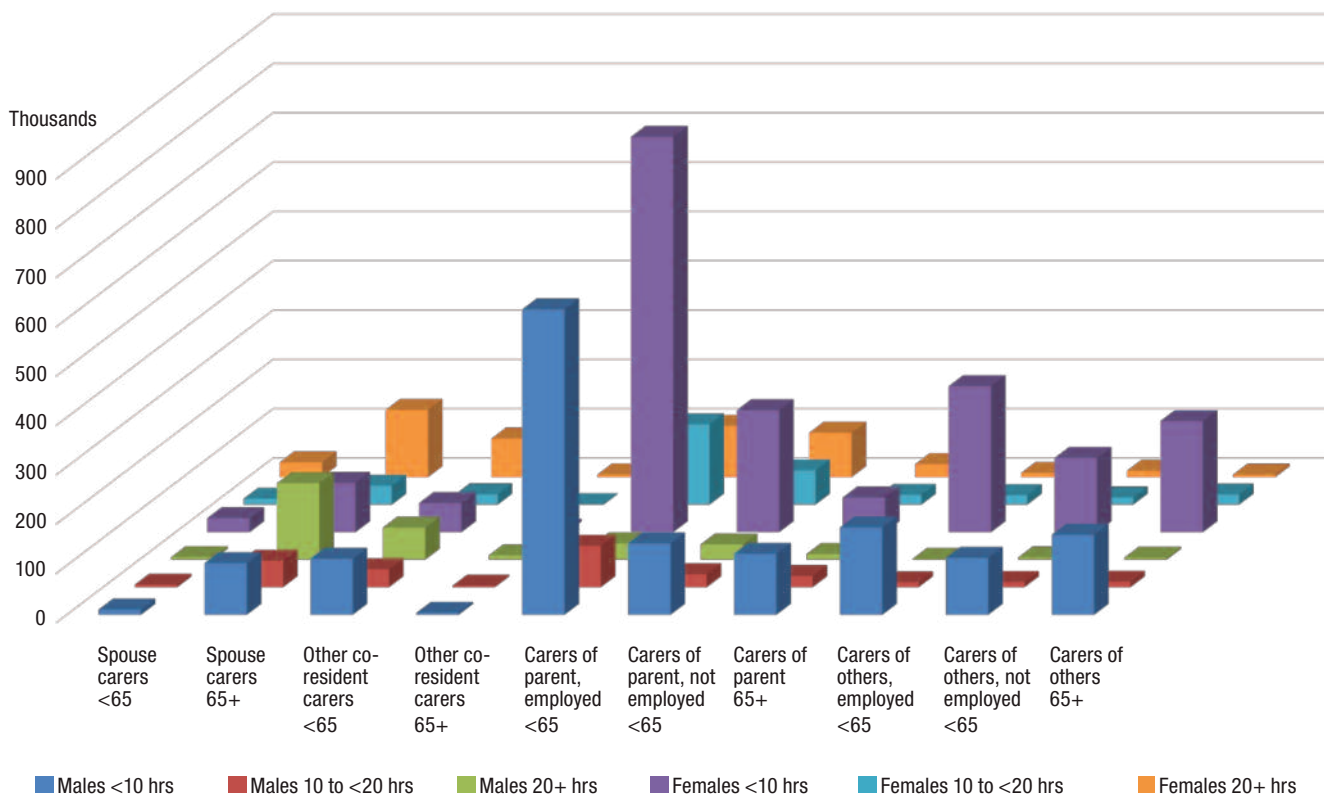
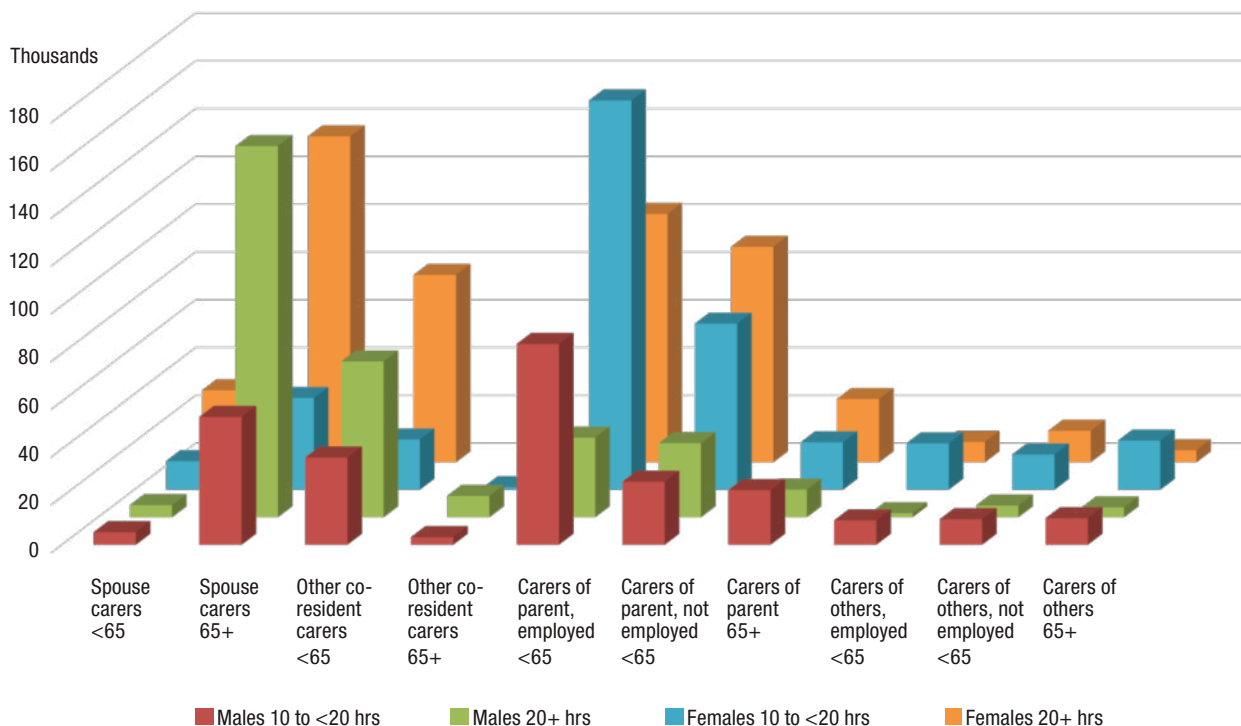


Figure 3: Distribution of carer characteristics for carers of older people providing over 10 hours of care per week (England, 2015)



PROJECTIONS OF FUTURE NUMBERS OF CARERS AND OLDER CARE-RECIPIENTS

Our projection modelling shows that, in order to keep pace with demographic pressures, the number of older people receiving unpaid care would need to rise from 2.1 million in 2015 to 2.65 million in 2025 (a rise of 27%) and to over 3.4 million in 2035 (a rise of 63% from 2015). These projections are on the basis that the number of older people (by age, gender and marital status) rises in line with the 2014-based ONS principal population projections, that disability rates by age and gender remain constant and that the balance of care is unchanged, i.e. that there is no change in the proportion of older people with a given level of need who receive unpaid care and who receive formal services. The number aged 85 and over receiving unpaid care is projected to more than double between 2015 and 2035, rising from 26% of all older recipients of unpaid care in 2015 to around 34% in 2035.

Sensitivity analyses which we have conducted in previous studies (e.g. Wittenberg and Hu 2015) found that these projections are sensitive to use of ONS high and low life-expectancy variant population projections but not to the use of their variant migration population projections. The projections are inevitably sensitive to variant assumptions about changes in disability rates by age and gender. Our assumption of unchanged disability rates may be optimistic (see Jagger *et al.*) if rising life expectancy comprises

additional years with disability as well as extra years without disability; but it seems a plausible base case in the context of this study. They are also sensitive to reductions in the proportion of care (relative to need) supplied by unpaid carers. Whether the projected level of demand can be met clearly depends on the future supply of unpaid care.

The number of carers of older people would need to rise from 5.0 million in 2015 to 6.4 million in 2025 (a rise of 27%) and to 8.1 million in 2035 (a rise of 63%) to keep pace with the projected rise in the number of older people needing care and maintain the current reported ratio of carers to care-recipients. This is on the basis that the number of older people receiving formal services, which has been falling in recent years, not only ceases to fall but actually rises in line with demographic pressures.

Our projection modelling of the supply side shows that the number of unpaid carers of older people will, on certain assumptions, rise from 5.0 million in 2015 to 5.5 million in 2025 (a rise of 9%) and to over 5.85 million in 2035 (a rise of 16% from 2015). The key assumption is that the proportion of adults by age and gender providing unpaid care to an older person remains constant. On this basis the numbers of carers of older people will rise at only one quarter of the rate of increase in the number of older people needing care. In 2025 there is a projected shortfall of 0.9 million carers and in 2035 of 2.3 million carers. If formal services do not rise to keep pace with demographic pressures the shortfalls would be even greater. If, for example, the number of older users of publicly funded care was 10% below the level required to meet demographic pressures from 2020 onward and half of this shortfall was met by increased unpaid care, the projected shortfall in the number of carers would be around 2.35 million in 2035.

This projection of number of carers is not sensitive to use of the ONS high and low life-expectancy variant population projections. It appears to be sensitive to use of the ONS variant migration population projections, but whether in practice future migrants are as likely to provide unpaid care as others may be doubtful, since their parents may not also immigrate to England.

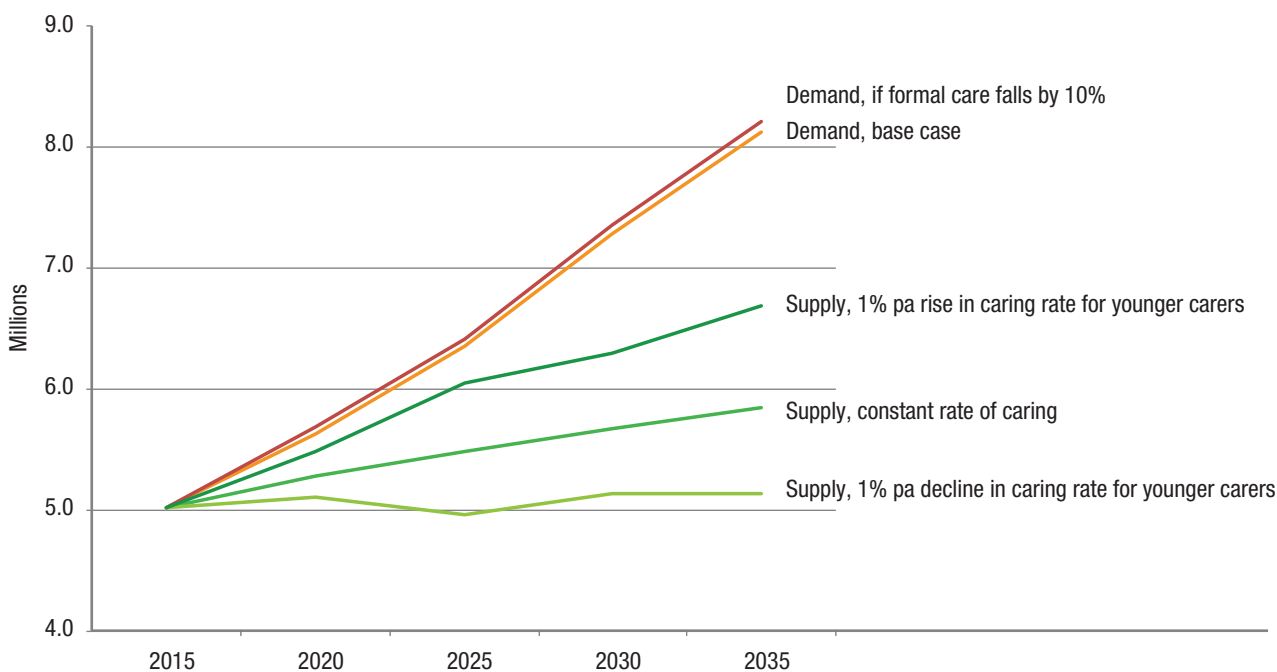
The projection is inevitably sensitive to the assumption that the proportion of adults by age and gender providing unpaid care to an older person remains constant. It is entirely possible but by no means certain that, as the number of older people needing care rises, the proportion of people providing unpaid care to an older person will rise and the shortfall in 2035 will prove lower than 2.3 million unpaid carers. If the proportion rose by 1% per year for adults of working age but remained constant for older people, the number of unpaid carers of an older person would reach 6.7 million in 2035. This would be an increase of one third between 2015 and 2035, around twice the projected increase if rates of care provision remained constant. If, however, the proportion fell by 1% per year for adults of working age (16 to 64) but remained constant for older people, for example, the number of unpaid carers of an older person would reach only 5.1 million rather than 5.8 million in 2035.

A range of factors could influence the proportion of adults by age and gender who provide unpaid care. These could include, as discussed above: the health state of the carer and their capability to provide care, geography (living reasonably close to the family member requiring care), competing responsibilities (child care as well as employment), closeness of family relationships, attitudes/beliefs about responsibility to provide care, availability of alternatives (formal care), and availability of support for carers.

An arguably surprising finding of our analysis of HSE data is that an increase in employment rates in middle age would likely not have a significant effect on the future numbers of carers. While men in employment are less likely to provide care than men not in employment, women in employment, who might also be expected to be less likely to provide care than those not in employment, are actually more likely to provide care than those not in employment. It should be noted that the 'not in employment' category includes not just those who are unemployed but also those who are economically inactive due to child care responsibilities, poor health etc. It seems possible that child care responsibilities are the reason why women not in employment are less likely to provide unpaid care than women in employment. Colombo (2011) also suggested that staying at work can also help carers to cope with increased expenditures and a reduction in their disposable income (see review section below).

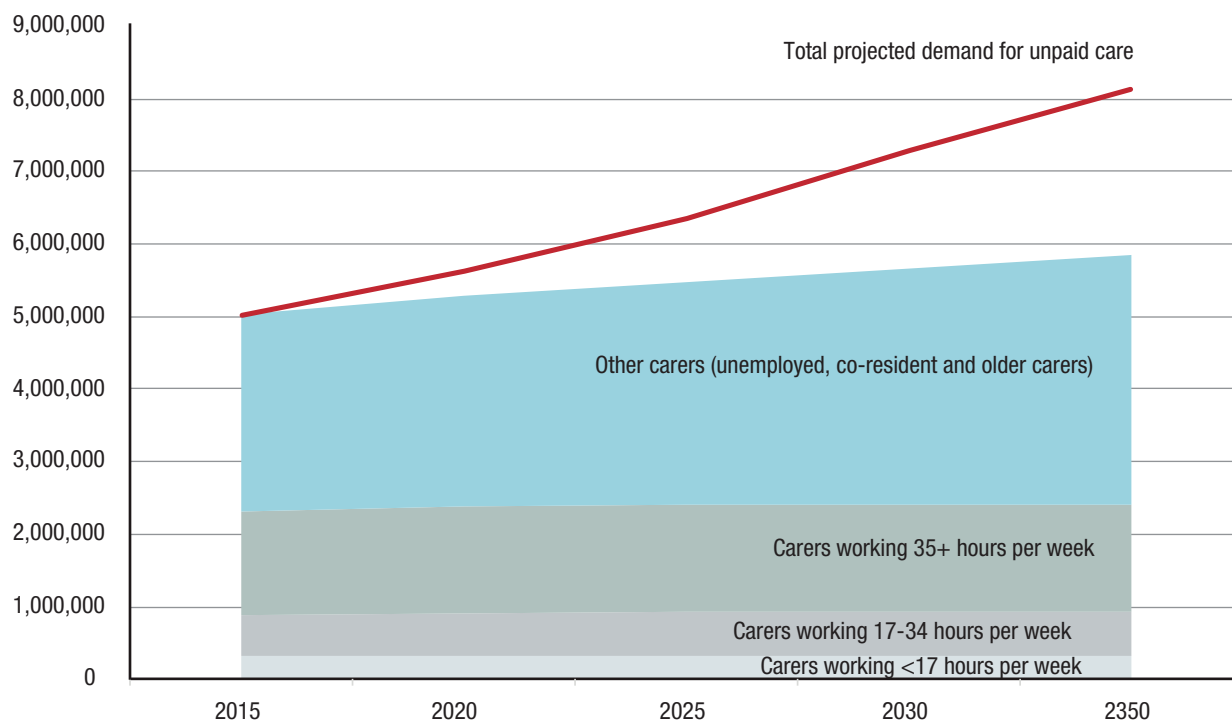
The projection based on constant rates of providing unpaid care by age and gender may be pessimistic for a more general reason: because an increasing number of people in future have an older relative who needs care from them, more of them may be willing to provide care. It is possible to directly observe actual supply of unpaid care, not latent supply (willingness to provide). It is likely that a considerable proportion of the adult population who are not currently carers would be able and willing to supply unpaid care if and when they have a close relative requiring it. Alternatively, the assumption of constant rates of unpaid care provision could be too optimistic if the combination of increasing female labour force participation and the raising of statutory pension age mean that despite any willingness to provide care, fewer working age family members are able to provide care in the future. There is clearly scope for debate about the proportion of adults who will provide unpaid care for older people in the future.

Figure 4: Projected demand for and supply of unpaid care for older people



The projected demand for and supply of unpaid carer for older people in England for the period 2015 to 2035 is shown in Figure 4. It illustrates how sensitive the projection of future supply is to the assumption that propensity to provide care remains constant. As explained above, the projection of future demand is sensitive to the assumption that disability rates in old age remain constant. On an optimistic set of assumptions, disability rates in old age could fall and propensity to provide care in working age rise such that there will be little or no care gap; but on a pessimistic set of assumptions, disability rates in old age could rise and propensity to provide care in working age fall such that there will be a very large care gap.

Figure 5: Numbers of carers of older people by employment outcome (2015–2035): base case



Changes in the demand and supply of carers by employment status under the base case are indicated in Figure 5. The focus is on extra-resident carers of working age, since this is the group most likely to be affected by policies to help carers to combine caring and employment. In terms of employment status, we expect the number of extra-resident carers of working age in employment to rise from 2.32 million in 2015 to 2.41 million in 2035, an increase of 3.8% over the two decades (Figure 3). This is a fall from 46.2% of all carers of older people in 2015 to 41.2% on them in 2035. The main reason for this decline in the proportion of carers expected to be in the category of interest (extra-resident, of working age and in employment) is that the number of older carers (aged 65 and over) is projected to rise far faster (by almost 50%) over the 20-year period than the number of younger carers (by under 5%). Within the total of 2.32 million over 60% work 35 or more hours per week, with this proportion projected to rise marginally over the two decades.¹

1. By definition, demand and supply of unpaid care in Figure 4 are in equilibrium in 2015. It is important to note that this does not imply that we assume that the situation in 2015 represents a hypothetical long-term optimum equilibrium. The diagram is meant to represent the difference between demand for and supply of unpaid care in the future, assuming that 2015 patterns of demand and propensity to supply care were to continue in the future.

MODELLING ALTERNATIVE STRATEGIES FOR SUPPORTING UNPAID CARERS

SUPPORTING UNPAID CARERS: REVIEW OF INTERNATIONAL EVIDENCE

The outcomes under study are: carers' employment (labour force participation, working hours); and carers' health and wellbeing (mental and physical health, quality of life, wellbeing). Where there are data available we review potential costs to the state and to employers. There is extensive research on the consequences of caring in these domains, and to a much more limited extent the associated costs or cost implications.

Employment

There is extensive evidence that caring responsibilities are associated with leaving employment, having difficulties returning to employment, reduction in hours and other effects on work such as taking on less senior roles or disruptions and absenteeism (e.g. Colombo 2011; DH 2014; Bauer and Sousa-Poza 2015; Nazroo 2015). The relationship may be bidirectional (e.g. Mentzakis *et al.* 2009; Michaud *et al.* 2010) although other research does not show this directionality (Van Houtven *et al.* 2013).

Employment rate

Unpaid carers are less likely to be in paid employment (e.g. Carmichael and Charles 2003; Viitanen 2005; Bolin *et al.* 2008a, 2008b; Carmichael *et al.* 2010; Lilly *et al.* 2010; Colombo 2011; Casey 2011; King and Pickard 2013; Pickard *et al.* 2013; Van Houtven *et al.* 2013; DH 2014; DWP 2014; Nguyen and Connelly 2014; Pickard *et al.* 2015; Scheil-Adlung 2015; Aldridge and Hughes 2016; Bauer and Sousa-Poza 2015; Nazroo 2015; Glendinning 2016).

For example, King and Pickard (2013) found that for women, becoming an unpaid carer for 10 hours or more a week means significantly lower odds of being employed one wave later than non-carers (0.51, 95% CI 0.30–0.87). The DWP (2014) report Fuller Working Lives found that 12% of economically inactive people aged between 50 and the state pension age are caring for a sick, disabled or elderly person for 20 or more hours per week, compared to only 3% of workers overall. Similarly, analysis by Age UK and Carers UK (2016) found that caring is responsible for someone caring for 20–34 hours per week being only 61.1% as likely to be in employment as someone who has no-caring responsibilities. Pickard and colleagues (2013) found that 315,000 adults below state pension age left work to care in one year. The DH 2014 Care Act Impact Assessment, using data from the Survey of Carers in Households 2009/10 found that, among working age carers, 26% felt caring had affected their ability to stay in employment, and of these, 39% had left work altogether, 32% had reduced their employment hours and 18% had agreed flexible employment arrangements. Data from

Australia also indicate that carers have on average nearly three years shorter working career than non-carers (Colombo 2011). A survey carried out for Carers UK in 2013 suggested that over 2 million people have given up work at some point to provide unpaid care (Carers UK 2013).

There are difficulties with re-entering employment after caring finishes. For example, Spiess and Schneider (2003) identify an asymmetric response in which providing unpaid care reduces labour force participation, but stopping or reducing provision results in no return to the labour market. The same result was found by Carmichael *et al.* (2008), Glendinning *et al.* (2009), Michaud *et al.* (2010) and Van Houvten *et al.* (2013). The longer a carer is out of paid work, the harder it is for them to return to it (Hirst 2005; Buckner and Yeandle 2005).

Intensity of care hours is a significant factor in whether carers remain or are in employment (e.g. Carmichael and Charles 2003; Heitmueller 2007; Glendinning *et al.* 2008; Carmichael, Charles and Hulme 2010; King and Pickard 2013; Carmichael 2011; Aldridge and Hughes 2016). In their review, Lilly *et al.* (2007) conclude that intense care is inherently related to lower labour force participation; similar results are reported by, among others, Pickard and Perkins (2011) and Bauer and Sousa-Poza (2015) in their reviews. Numerous UK government and EU reports come to the same conclusion (e.g. Colombo 2011; Rodriguez 2013; DWP 2014; Hoff 2015; Nazroo 2015; Bouget *et al.* 2016; Glendinning 2016).

For example, Colombo (2011) found that the greater the number of hours of care provided, the more likely carers are to give up paid employment. Increasing hours of care by 1% resulted in carers being more likely to stop working by 10%. The impact of care on labour force participation appears only when individuals provide a high intensity of care: according to Colombo, at least 20 hours per week. King and Pickard (2013) identify the threshold at which carers are at higher risk of leaving employment as providing care for ten or more hours a week. Some other studies have also identified thresholds of 20 or more hours a week (in part because the data they used did not differentiate under 20 hours a week) (e.g. Heitmueller 2007, Lilly *et al.* 2010), whereas others have identified even lower thresholds (Age UK and Carers UK 2016). Caring hours are associated with both level of disability and co-residency, so it is unsurprising that researchers have found co-residential care has a significant impact on employment whereas extra-residential care generally does not (e.g. Heitmueller 2007; Heitmueller *et al.* 2010; Michaud *et al.* 2010; Casado-Marin *et al.* 2011; Colombo 2011; Nguyen and Connelly 2014; Carmichael *et al.* 2010).

Of note is that becoming an unpaid carer for <10 hours a week is associated with significantly higher odds of being employed one wave later than non-carers (for women the odds are 2.29, 95% CI 1.05–5.01), something also found by Carmichael and Charles (1998) for carers providing care under the 20 hour/week threshold. Colombo (2011) suggests that, at lower intensities, it is easier to combine work and care because such carers are providing care to less disabled individuals or as a complement to a

primary carer, giving them more flexibility. Furthermore, staying at work can also help carers to cope with increased expenditures and a reduction in their disposable income. However, as disability increases, and/or care hours increase, carers tend to leave the labour market (Pickard and Perkins 2011).

Work hours

There is evidence that carers are more likely to work fewer hours than non-carers (Lilly *et al.* 2007; Bolin *et al.* 2008a, 2008b; Leigh 2010, Casey 2011; Kotsadam 2011; Meng 2012; Van Houtven *et al.* 2013), although it is still the case that carers, particularly those caring for ten or more hours a week are more likely to leave employment than to reduce their hours (Colombo 2011; Age UK and Carers UK 2016). For example, Bolin *et al.* (2008a) find that working time for carers is reduced by -0.26 compared to non-carers. Kotsadam (2011) finds that carers in Europe have 2% to 3% lower working hours compared to non-carers. Johnson and Lo Sasso (2006) find that providing care reduces the working hours of middle-aged women by 41% on average. Carers work on average 2 hours less per week than non-carers and they tend to be over-represented in part-time work (Colombo 2011). A survey carried out for Carers UK in 2013 suggested that 3 million have reduced their working hours to provide unpaid care (Carers UK 2013).

Reducing working hours is, like leaving employment, related to intensity of caring (Carmichael and Charles 2003; Casado-Marin *et al.* 2011; Heitmueller 2007; Spiess and Schneider 2003; Glendinning *et al.* 2009). For example, Age UK and Carers UK found that women who continue in paid employment after starting to provide unpaid care for at least 10 hours a week are more likely to reduce their working hours, compared to women who do not take on caring responsibilities, although overall both men and women age 50 or above providing 10 hours or more of care are more likely to leave paid employment altogether than to reduce their hours. Colombo (2011) found that the effect on working hours is twice as high for high-intensity caring compared to medium-intensity (10-19 hours/week). Hours of work are sensitive to a change in hours of care: a 1% increase in hours of care translates, on average, into slightly more than 1% decrease in hours of work (Colombo 2011). The impact of caring does not lead to reduced work hours in cases of low caring responsibilities. Provision of care also has other effects on work including disruption, missing hours or days of work and sickness absence (see e.g. Schneider *et al.* 2011; Ugreninov 2013; Nazroo 2015; Bauer and Sousa-Poza 2015).

The effect of caregiving on employment and work hours appears to differ between men and women. Several studies have found that effects of caring on employment are greater for women (e.g. Carmichael and Charles 2003; Heitmueller 2007; Michaud 2006; Heitmueller 2010; Carmichael *et al.* 2010; Van Houten *et al.* 2012; Viitanen 2010; King and Pickard 2013). Several studies suggest that carers in lower socio-economic groups are more likely to leave work (e.g. Colombo 2011). Recent analysis by Age UK on carers aged over 50 found that the higher the occupational group the smaller the

reduction in number of hours in paid employment as a result of becoming a carer (Age UK and Carers UK 2016). In part, this may be because those from lower socio-economic groups are proportionally more likely to provide higher-intensity care (Colombo 2011) and/or less likely to be able to work flexibly (Age UK 2012).

Health and wellbeing

Although some research finds a positive effect of caring on health and wellbeing (e.g. Evandrou and Glaser 2003; Young *et al.* 2008), especially when it is done voluntarily, is of short duration, and can be carried out alongside other productive roles (Hinterlong 2006), there is substantial research that shows that provision of unpaid care is associated with poorer mental and physical health and quality of life (see e.g. Beesley 2006; Bauer and Sousa-Poza 2015; Nazroo 2015; Hoff 2015), particularly at higher intensities. There is also evidence that psychological and physical health and employment consequences continue once caring has ended (e.g. Larkin 2009).

Several meta-analyses find a negative association between caring and psychological ill-health, mainly depression, anxiety and poorer wellbeing, including stress and burden (e.g. Schulz *et al.* 1990, 1995; Pinquart and Sörensen 2003a, 2003b, 2006; Savage and Bailey 2004; Cooper *et al.* 2007). Carers' surveys find worse self-reported mental health: for example, Carers UK (2012) found that 87% of carers report an impact on their mental health. An OECD report found prevalence of mental health problems among carers to be 20% higher than among non-carers (Colombo *et al.* 2011). Coe and Van Houtven (2009) found that carers have more depressive symptoms than non-carers. Lamura and colleagues (2008) identified a range of mental health problems associated with caring, including anxiety, guilt, insecurity, depression, stress, panic attacks.

There is much less research on the impact of caring on physical health. The available evidence shows, however, that caring is associated with poorer physical health. This may be due to the often physically demanding nature of caring; neglect of the carer's own health and health-promoting behaviours; increased stress and poorer psychological health associated with caring. Meta-studies and reviews show that carers have worse physical health than non-carers (e.g. Schulz *et al.* 1995; Vitaliano *et al.* (2003); Pinquart and Sörensen 2007; Legg *et al.* 2013; Social Protection Committee 2014). The aforementioned Carers UK 2012 survey found that 83% of carers report an impact on their physical health. Psychological and physical health is particularly affected for carers of people with dementia (e.g. Bauld *et al.* 2000; Pinquart and Sörensen 2003a; Black and Almeida 2004; Cooper *et al.* 2007; Pinquart and Sörensen 2007; Leggett *et al.* 2010; Schoenmakers *et al.* 2010).

Intensity of caring, and relatedly co-residence, is significantly associated with poorer health (e.g. Pinquart and Sörensen 2003a, Coe and Van Houtven 2009; Glendinning and Bell 2008; Schultz and Sherwood 2008; Mentzakis *et al.* 2009; Legg *et al.* 2013, ONS 2013; Ugreninov 2013). The DH's Care Act impact assessment found that around

half (52%) of carers said that their health had been affected because of the care they provide; this was 39% of those caring for less than 20 hours a week and 66% of those caring for 20 or more hours. Working carers with intensive care responsibilities are two to three times more likely than their non-caring counterparts to be in poor health (Buckner and Yeandle 2011). Glendinning *et al.* (2009) found that risks of adverse effects on carers' health and wellbeing increase with the level and intensity of care provided, and with levels of other competing responsibilities, such as paid work and childcare. Lamura and colleagues (2008) reached a similar conclusion. In the UK, poor mental health is already evident at a caring intensity of 10–19 hours/week, but the impact is greater at 20+ hours a week. At that level it is associated, on average, with a 20% higher prevalence of mental health problems. Lower-intensity caring does not always lead to a higher prevalence of mental health problems than among non-carers (Colombo 2011). Physical and mental health problems were associated more with co-residential caring, for example increasing the odds of self-reported depression by 68% compared to 34% for extra-residential care (Rodriguez *et al.* 2013). Furthermore, Coe and Van Houtven (2009) found that duration of care provision has a significant effect specifically on the physical health of the carer.

Reviews of the literature show stronger adverse effects on mental health for women than for men (e.g. Bauer and Sousa-Poza 2015), although this may be in part because women tend to provide more intense care. Physical health problems are seen more often in (older) male carers (Pinquart and Sörensen 2007).

Costs

There are costs to the state, employers and individuals of reduced labour force participation and poorer health, particularly for intensive carers. Individual costs accumulate from reduced income over the lifecourse (Colombo *et al.* 2011; Keating 2014) with implications for pensions and savings (Evandrou and Glaser 2003; Keating 2014). For employers, there are costs associated with recruitment and non-retention, absenteeism, and reduced productivity (Mazanec *et al.* 2011; Ugreninov 2013; Keating 2014).

For society, costs result from lower tax revenues and lower social security contributions, increased welfare benefits and lost productivity and contribution to GDP (e.g. Social Protection Committee 2014; Carers UK 2010). There are some data on level of costs. Hoff (2015), for example, reports that the aggregate cost of providing eldercare in lost productivity to US businesses is estimated to exceed \$17 billion per year. In Germany, the annual costs of not reconciling employment and care is estimated at €14,200 per employee, or €18.94 billion per year overall (Schneider *et al.* 2011).

In the UK, public expenditure costs of carers leaving employment are estimated at £1.3 billion a year, based on the costs of Carer's Allowance and lost tax revenues on forgone incomes alone (Pickard *et al.* 2013). Working from this analysis, Age UK estimated the additional output from carers being able to work could therefore be up to £5.3 billion

per annum (Age UK 2012). For a sample of carers of people with advanced cancer, Mazanec *et al.* (2011) found a 22% reduction in productivity. This was associated with greater number of care hours, higher cancer stage, marital status, anxiety status, as well as burden related to financial problems. Casey (2011) estimated that the total loss of output in the UK is approximately 0.8% of GDP. This is on the assumption that carers entering the labour market would be paid a relatively low wage and does not account for reduced hours as a result of caring. It is likely that there are greater health care costs associated with carers' poorer mental health and physical health. However, we could find appropriate estimates for the direct costs of health care services attributable to providing unpaid carer.

Services for the care-recipient

Employment

Although some research finds no relationship (Bullock *et al.* 2003; US study) or a negative relationship (Covinsky *et al.* 2001; US study), the vast majority of research shows a positive relationship between use of formal services by the care-recipient and carers' employment outcomes and thus the potential to reduce individual, employer and societal costs of negative employment outcomes. This is the case using within-country studies (e.g. Doty *et al.* 1998 and Scharlach 2007 in the US; Pickard *et al.* 2015 in England). These studies find that the provision of formal care support for the person cared for is associated with a higher probability of being in employment, particularly for women. This is particularly so for those providing unpaid care above the threshold of ten or more hours a week. That a greater effect is seen for people providing care at higher intensity is perhaps not unsurprising in the context of the relationship between higher-intensity caring and negative employment outcomes. Modelling of German data finds that benefits in kind have small positive effects on labour supply. A 1% increase of benefits in kind leads to an increase in labour force participation of 0.02%. The effects are larger for women (0.03%) and at higher care levels (0.07%) (Geyer and Korfhage 2015). Pickard and colleagues find a positive association between carers' employment and receipt of paid services in England. Specifically, women who provide unpaid care for ten or more hours a week have significantly higher odds (OR 1.57, CI 1.34–1.85) of being in employment if the person they care for receives at least one formal paid service compared with if they receive no services, as do men (1.69, CI 1.34–2.12) (Pickard *et al.* 2015). On specific services, the odds ratios are: home care (women 1.64; men 1.69); personal assistant (women 1.74; men 2.45); day care (women 1.26; men non-significant); meals-on-wheels or equivalent (women 2.85; men ns) (Pickard *et al.* 2015).

Quantitative findings on formal care services are backed up by qualitative studies which show that carers feel that provision of services for the care-recipient is important in enabling them to remain in employment and the lack of them is a barrier to being in employment (Milne *et al.* 2014; Yeandle *et al.* 2007; Carers UK 2016; Arksey and Glendinning 2008). The importance of social care for the care-recipient in supporting

carers' employment has been recognised in carers' strategies and legislation, most recently in the 2014 Care Act (HMG 2014).

Several cross-country comparisons have shown that countries with extensive provision of formal home care services tend to have higher levels of employment among those 'at risk' of caring compared to those with less extensive provision of formal home care services (e.g. Lundsgaard 2005). Using European Community Household Panel data, Viitanen (2007) found that raising government expenditure on formal services for older people to the EU average (or the EU average excluding Denmark as an outlier) if it was below that average would increase labour force participation rates among women aged 45–59 by between 9 and 13 percentage points. Comparing the cost of doing so to the average tax revenue per person, Viitanen concluded that such a policy would be potentially cost-effective. Two other studies – one by Heger (2014) using data from the Survey for Health, Aging and Retirement in Europe (SHARE), and one by Lamura *et al.* (2008) as part of the European Commission's 2006 EUROFAMCARE multi-country study – found increased labour force participation to be associated with formal care services. Haberkern (2015), also using SHARE data, found similar results looking at filial carers but much more so for daughters, concluding that 'in general, caregiving by sons is hardly influenced by social care policies' (Haberkern 2015). A recent synthesis of reports from country experts on the impact of policies from 35 European countries found that a model of generous in-kind benefits to dependent people to be particularly effective in improving the work-life balance of women providing unpaid care (Bouget *et al.* 2016).

Although most studies look at services for the care-recipient and labour force participation rates, a similar effect is found for working hours in EU countries (e.g. Rodriguez 2013; Viitanen 2010) and OECD countries (e.g. Colombo 2011). Geyer and Korfhage found that a 1% increase of benefits in kind leads to an increase in average working hours of 0.06%. Again this effect was greater for women (0.10%) and at higher caring intensity (0.21%).

Much of the literature on services and employment does not differentiate type of service. However, the type of services that appear to be most effective in supporting carers employment are home care, personal assistants, day care and meals-on-wheels or their equivalent (Pickard *et al.* 2015). These types of services are provided during the working day and so can enable carers to be in paid employment. They are also services which provide Activity of Daily Living (ADL) – or personal care. This type of care is most 'time-bound' (Hassink and van den Berg 2011), i.e. it has to be done at a particular time, unlike many IADL tasks such as shopping, cleaning or paperwork, and is thus least compatible with employment. Personal care is also most strongly associated with higher care hours and therefore these types of services are likely to be of most benefit to higher-intensity carers, the group who are most at risk of leaving employment. Pickard and colleagues (2015) further found that 'short breaks' (respite) are effective in supporting carers' employment only if in combination with other services.

Health and wellbeing

There is much less research on the effect of services in supporting carers' health and wellbeing, with the exception of short breaks (respite). There is some evidence from Davies and Fernandez (2000) that day care and home care can be effective in reducing the negative psychological effects of caring, particularly for higher-intensity carers, but little more recent research. The research on short breaks and carer health is extensive and includes many high-quality studies and systematic reviews. In the main these studies focus on mental health and wellbeing outcomes rather than physical health. Victor's (2009) review of 107 UK studies is typical in concluding that although carers generally showed satisfaction with breaks, and perceive benefits to their emotional wellbeing, there is little robust quantitative evidence of improvements to emotional wellbeing, and in fact several studies show negative effects on carers' emotional wellbeing. The meta-review by Parker and colleagues (2010) similarly concluded that there is no evidence for the impact of respite care on physical or mental health, with a suggestion from some reviews that it has negative impact on measures of carers' wellbeing or quality of life (e.g. Shaw 2009). A more recent Cochrane review of four studies concluded again that current evidence does not demonstrate any benefits or adverse effects from the use of respite care for people with dementia or their carers (Maayan *et al.* 2014). Colombo further adds that both duration and frequency of respite breaks are relevant when assessing the importance for the carer and the care-recipient but again concludes that although carers highly value such services, this does not systematically translate into better mental health outcomes for carers. Both reviews of cost-effectiveness identified in the Parker 2010 meta-review find no evidence of cost-effectiveness for respite care (Mason 2007; Shaw 2009), both using the same studies.

Yeandle *et al.* (2012) conducted an evaluation of the DH National Carers' Strategy Demonstrator Sites programme which included twelve 'breaks' sites which ran over 18 months. Total expenditure was £9,527,613 with 5,655 carers supported; a cost of on average £1,685 per carer although there was wide local variation. Almost half of the carers felt that accessing the service had enabled them to have more time for themselves. Carers' perceptions of how their health and wellbeing were affected showed positive outcomes. Analysis comparing carers who said they had not received a break with all other respondents completing the four-month follow-up questionnaire showed that carers who had not received a break were more likely than those who had done so to show a significant deterioration in their wellbeing scores. However, the proportion of carers who showed 'poor wellbeing', as measured by these questions, was higher after than before the service was received.

The absence of an observable relationship may of course mean there is not one to observe. It may also be - as several reviews suggest - that results may reflect the lack of high-quality research in this area rather than an actual lack of benefit (e.g. Maayan *et al.* 2015; Parker *et al.* 2010). Equally, as short breaks are by definition services provided for a short length of time they may only be sufficient to provide temporary relief rather than any substantive improvements before returning to an often very demanding caring

situation and same intensity of care hours, a key factor in poorer mental health. This is particularly the case in situations where the care-recipient's health is worsening over time and care hours are increasing (e.g. Yeandle *et al.* 2012).

Propensity to provide unpaid care

There is a potential trade-off between the supply of unpaid care and labour supply which may imply a conflict between policies promoting full employment and policies that rely on family carers to support care in the community (Carmichael and Charles 2010). As outlined above, formal care services are associated with better employment outcomes for working carers, especially those providing care for ten or more hours a week, and thus have the potential to reduce the individual, state and employer costs associated with negative employment outcomes.

On provision of care, there is a significant body of research on the relationship between provision of formal and unpaid care. Certainly formal care provision has an effect on the provision of unpaid care but there is debate over the nature of the relationship (for example substitutive or complementary, 'crowding in' or 'crowding out') and amount or ratio of the relationship. The nature and quantity of the relationship may depend on care need and the carer's circumstances. For example, some literature suggests that the effect depends on level of disability (Bonsang 2009) and related type of care, for example domestic or IADL-need care versus personal or ADL-need care (Bolin *et al.* 2008; Van Houtven and Norton 2004; Hassink and van den Berg 2015). There are gender differences in the substitution effect. Provision of formal home care services is related to a lower likelihood of receiving care from daughters but not sons the probability of receiving care from sons is not lower in countries with high service provision Haberkern (2015). There are also differences by education/income level (Zigante *et al.* 2014).

There is some evidence that availability of formal care services encourages the supply of unpaid care (Casey 2011), at least at the lower unpaid care intensity level (e.g. Schaffer 2015; Zigante *et al.* 2014). This may be because of reduction in the need for residential care brought about by a combination of formal care and unpaid care (e.g. Schaffer 2015), because lower-intensity caring has a less detrimental effect on the health and wellbeing of carers and/or it is more compatible with other activities in particular paid employment so is more sustainable, manageable or indeed attractive. Research using the implementation of free personal care for people aged 65 and over in Scotland as a natural experiment and data from the British Household Panel Survey shows that the policy increased overall probability of supplying unpaid care by 3 to 5 percentage points. Within that, there is a higher probability of entering care at lower intensity levels, a lower probability at the sort of higher intensities associated with poorer employment outcomes. Not only did unpaid care participation increase, but individuals who were supplying unpaid care before the policy change did not reduce their hours. The two types of care appear to act as complements. Zigante and colleagues (2014), analysing data from the 2001 and 2011 English Censuses, found that formal care has a positive

effect at low levels of caring whereas at the high level care (20+ hrs per week) the relation is the opposite and formal care has a negative effect.

On specific services, Victor (2007) concluded from her review of UK studies that in some cases 'short breaks' services sustain a caring situation, whilst in others it is a step on a fairly inevitable journey towards permanent residential care.

Assistive technology

Our review looked at two broad types of assistive technology. The first is directed at the care-recipient and thus can be seen as a service for the care-recipient that may also support the carer. We looked at the evidence on technology that acts as memory aids; provides safety or security; and/or enables more independent living. The second type is technology that is aimed directly at the carer such as training or support. Interventions that appear to be potentially most effective for either carers' employment or their health and wellbeing are summarised in Table 3. There is also arguably a third type of technology that supports working carers: technology that can support flexible working, such as working from home.

For AT aimed at care-recipients, there is some evidence for self-reported better balance of work and care (e.g. (Mahoney *et al.* 2008; Beale *et al.* 2009; Chiatti *et al.* 2011)), but no difference in carer productivity or morale (Mahoney *et al.* 2008). Several reports conclude that assistive technologies may contribute to a better reconciliation of paid work and family care if such technologies are part of a broader package of services and support for the care-recipient and/or are integrated in care networks (e.g. Yeandle 2014; Hoff 2015). The DH is currently funding two-year pilots looking at the use of telecare in supporting carers' employment (HMG 2015).

There are rather more studies on the health and wellbeing of carers. Overall there is some evidence for improved health and wellbeing of carers, again particularly if part of a broader package of services and support. At the same time, there are also some negative aspects of telecare for carers' wellbeing identified. The systematic review by Davies and colleagues (2013) concluded that many evaluations are of weak methodological quality. However, the evidence tentatively indicated that telecare exerts a positive effect on carer stress and strain. They found no evidence to indicate benefits on burden or quality of life. Carretero and colleagues (2015), in their review of evaluations of technology interventions, found qualitative and quantitative evidence for improved psychological health for carers. They concluded that there may be associated cost savings for health and social care systems, although there are few studies that look into this. A review by Knapp and colleagues (2016) on technology to manage the global costs of dementia identified both positive and negative aspects of assistive technology for carers for people with dementia. Several studies have reported better, mainly qualitative, health and wellbeing outcomes, in particular less stress, for technology aimed directly at the care-recipient (e.g. Beale *et al.* 2009; Chiatti *et al.* 2011; Holthe 2004; Mahoney *et al.* 2008; Pleace 2011; Jarrow and Yeandle 2009),

although some of these are very small-scale studies (Table 3). Effective interventions may vary by care need but include various memory, safety and security and independent living technology aids. There is also evidence for a reduction in carers stress and depression for telecare aimed directly at carers (e.g. reviews by Bensink *et al.* 2006, Powell *et al.* 2008; studies by Marziali and Garcia 2011; Finkel *et al.* 2007) (Table 3). Again type of AT intervention that is most effective may vary by care need but includes psychological support, training and education.

Table 3: Assistive technology and telecare

Intervention	Effect	Care need (if specified)
AT for care-recipient (e.g. memory aids; safety/monitoring; independent living)		
Telecare Scotland (various different projects)	Enabled some carers to participate in paid employment (self-reported) and reduce self-reported stress (Beale <i>et al.</i> 2009; Jarro and Yeandle 2009)	Predominantly dementia
ICTs for independent living	Self-reported better ability to balance care and employment, fewer health problems (Chiatti <i>et al.</i> 2011)	
Selection of night and day calendar, automatic lamp, item locator, medicine reminder, picture phone, remote day planner	Trend towards a significant reduction in self-reported stress seen between baseline and 3-week follow-up, and baseline and 3-month follow-up (Holthe 2004)	Dementia
Motion sensors (two schemes)	Perceived better balance of work and care but no significant quantitative difference in carer productivity or morale (Mahoney <i>et al.</i> 2008). Less stress as measured by a significant increase in carers' self-reported ability to make activities pleasant for the care-recipient and themselves in the intervention groups compared with the control (Mahoney <i>et al.</i> 2008)	Adult with one health or safety concern who resided alone during the workday; carer in paid employment
Services that enable older people to remain at home (e.g. telecare, alarm, mobile warden services)	Improved wellbeing of carers (Pleace 2011)	
Two or three pieces of equipment from a selection of memory, safety/monitoring, independent living devices	Self-report recall before-and-after introduction of the telecare; statistically significant reduction in stress for 8 of the 13 items relating to stress measured (Woolham 2005)	
Sensors: bed monitor, gait monitor, impact fall detector, stove sensor	In a before-and-after evaluation that assessed strain using the carer strain index, there was a significant reduction in carer strain between baseline and 4 months (Alwan <i>et al.</i> 2006)	
MP3 players with individualised musical content for care-recipient	Before and after study, no control, outcome: decreased psychological distress for family carers, offered some 'respite' (Lewis <i>et al.</i> 2015)	Dementia
AT for carer e.g. training; education; psychosocial support		
Stress reduction interventions delivered through technology	Appears to reduce improve mental health-related outcomes for carers compared to text based chat. Text based chat group (comparison) showed significant improvement in self-efficacy. (Marziali and Garcia 2011)	Dementia
E-care technology-based psychoeducational intervention	Decreased carer burden and depression (Finkel <i>et al.</i> 2007)	Dementia

The evidence is inconclusive on effect of telecare on provision of unpaid care, i.e. on the amount of time carers spend on caring. In one evaluation, the majority of carers reported that the telecare intervention (monitoring) had improved how they spent their time, freeing up time for themselves (Kinney *et al.* 2004). Others research found that telecare had decreased time spent caring for a minority (14%), however, an equal proportion (13%) said that it had increased the time that they spent caring, and 73% of participants said that the amount of time spent caring remained 'about the same' (Beale *et al.* 2009; Jarrold and Yeandle 2009). A further evaluation that examined change in time spent caring did not find a statistically significant reduction (Mahoney *et al.* 2008).

Services directly for carers

There is a very extensive international literature on interventions aimed directly at carers. The research covers a range of interventions for people in a range of caring situations and caring for people with differing care needs. Despite the extensiveness of the literature, previous reviews comment on the need for more methodologically robust, rigorous research in this area, particularly for some types of interventions (e.g. Parker *et al.* 2010). Evidence on cost-effectiveness was highlighted as a particular weakness: there are very few such evaluations, insufficient data collected to be able to estimate cost-effectiveness through modelling, and/or methods used to collect these data are not robust.

Nevertheless, there is evidence of some effective and potentially effective interventions to support carers. Evaluations of these interventions, and indeed the interventions themselves, focus almost exclusively on health as an outcome, in the main mental health and wellbeing. Reviews and reports conclude that the interventions that appear to be most effective and, where there is evidence, also cost-effective are psychological therapy, training and education interventions, and support groups (e.g. Victor 2009; Parker 2010; Pickard 2004; Heslin 2016; Colombo 2011; WHO 2015; Nai-Ching *et al.* 2015; Chien 2011).

Specific examples of the strongest evidence for effective interventions are in Table 4. Interventions are aimed at carers of people with different care needs. Within the scope of our review (carers of older people) the majority of studies evaluate interventions aimed at carers of people with dementia; the next largest group is carers of people who have had a stroke and carers of people with cancer/at end-of-life. Some of the interventions combine more than one type, for example training and psychological support. In addition, there is some qualitative evidence of interventions to support carers. For example, Yeandle and Wigfield (2011), in their evaluation of the Caring with Confidence training programme for carers, found improved self-reported health or wellbeing after the programme and six months later. The budget for the three-year programme was £15.2m, with a relatively high cost per filled carer place. There are other types of interventions that appear to be effective. For example, there is 'tentative' evidence from a recent review of the effectiveness of meditation-based techniques for carers of people with dementia (Hurley 2014).

We could find no effect on propensity to provide care of any of these types of intervention. This is not the aim of either the intervention or the research that evaluates it.

Table 4: Services directly aimed at carer

Intervention	Outcomes	Care need (if specified)
Psychological/psychosocial/psychoeducational		
STrategies for RelaTives (START) programme (psychological therapy)	Effective and cost-effective at reducing depression and anxiety (Livingston et al. 2014)	Dementia
Computer-mediated psychosocial intervention	Reduced depression, anxiety, burden and stress (McKechnie 2014)	Dementia
Telephone counselling	Reduced depression (Lins 2014)	Dementia
Cognitive behavioural therapy (CBT)	Reduces depression, anxiety, burden and stress (Vernooij-Dassen 2011)	Dementia
Couples-based psychosocial interventions	Reduces psychological and physical distress (Regan 2012)	Cancer
Psychosocial intervention based on problem-solving and communication skills	Improves quality of life (Waldron 2013)	Cancer
Group interventions; CR/carers dyad interventions; one-to-one interventions	Positive effects on carer quality of life, burden of patient's symptoms and carer burden (Harding 2011)	Cancer/ palliative care
CBT and psychoeducational interventions	Improved psychological health (including anxiety), quality of life (Nai-Ching 2015)	Cancer/ palliative care
Interventions comprising psychoeducation, skills training, and/or counselling	Positive effect on quality of life and burden but not depression (Northouse 2010)	Cancer
Education/training (often with support)		
Training in nursing and personal care techniques and providing 'problem-solving partnerships' and support	Positive effects on quality of life and wellbeing (Brereton 2007)	Stroke
Education interventions	Improved mental health (using SF-36) (Lee et al. 2007)	Stroke
Training in management of stroke patients	Reduced anxiety and depression; improved quality of life, reduced burden (Kalra et al 2004); evidence of cost-effectiveness	Stroke
Educational interventions aimed at teaching skills	Reduces burden (Jensen 2015)	Dementia
Support groups		
Support groups	Reduces depression and burden (Chien review 2011)	Dementia
Videoconferencing	Improved carers wellbeing (Dam et al. 2016)	Dementia
Other		
Meditation-based interventions	Reduced depression (Hurley 2014)	Dementia

Work conditions

Our review looked at two types of work conditions indicated as being potentially effective in the literature: flexible working practices and statutory paid care leave. Unsurprisingly this research looks mainly at employment outcomes and/or propensity to provide care rather than health outcomes, with some exceptions.

Flexible working

Flexible working might include, for example, flexi-time, working from home or some form of annualised hours. It might also include reduced hours or part-time work. However, some part-time jobs, particularly lower paid ones, do not necessarily have flexible work conditions per se.

There is evidence that flexible work conditions enable better reconciliation of work and care and lower chance of not being in employment. For example, EU experts conclude that the work-life balance of working carers is better in countries with various part-time work arrangements and flexible working time, and suggest that they offer good solutions to balance care obligations and work (Bouget *et al.* 2016). Flexible working helps accommodate caring responsibilities and limits the consequences of providing care on employment (Da Roit and Naldini 2010; Colombo 2011). Arksey and Glendinning (2008) found that flexible working hours were critical to the successful combination of work and caregiving. Similar findings were reported in a small-scale study by Arksey and colleagues (2005), a report by the Social Protection Committee on long-term care (Social Protection Committee 2015) and recent evidence reviews for Foresight (Hoff 2015; Nazroo 2015). Flexible working increases the chances of remaining in employment or extends the employment trajectory (e.g. Pavalko and Henderson 2006; Arskey and Moree 2008; HSISC 2010; Mooney and Statham 2002; Age UK 2012). Flexible working hours lower the chances of reduced hours of work for carers in Australia and the UK (Bouget *et al.* 2016). There is also some evidence that flexible working mediates the mental and physical effects on the health of carers, with the effect larger for women (Earle and Heymann 2011).

There are also positive outcomes for employers in terms of improved retention, productivity, good employee relations and concomitant lower costs (Schneider *et al.* 2011; Carers UK 2014; Hoff 2015). Hamblin and Hoff (2011) found that working carers employed by a publicly recognised 'best practice employer' are reluctant to leave their jobs there, even at the expense of better earnings or career prospects elsewhere.

However, there is also some evidence that flexible work conditions do not increase probability of remaining in employment. For example, Henz found that job flexibility has little effect for women leaving the labour market (Henz 2006). Working carers, particularly those caring for ten or more hours a week, are more likely to leave employment than to reduce their hours (Colombo 2011; Age UK and Carers UK 2016). It is likely that flexible working practices are not the only factor. The ability to work flexibly depends on household income, the structure of the labour market with respect to opportunities for

part-time work (Bouget *et al.* 2016) and intensity of care need (Rodriguez *et al.* 2013; Milne 2014). For higher-intensity care hours, or as care hours increase beyond risk thresholds, flexible working may not be sufficient to enable reconciliation of work and care (e.g. Pickard *et al.* 2015). In part, this is because higher-intensity of care hours reflects greater care needs which tend to be personal care needs. These are less time-flexible and therefore less compatible with even reduced or flexible work conditions (Hassink and van den Berg 2011). Flexible working arrangements alone may not be sufficient to enable higher-intensity carers to work and care, and a combination of work conditions and other interventions may be needed (e.g. DWP 2014; Colombo 2011; Arksey and Corden 2009; Hoff 2015; Mooney and Stratham 2002).

In the UK since 2007, carers have had the right to request flexible working; this was extended to all employees with 26 weeks' service or more in 2014. There are still some issues. Part-time working has financial consequences for carers through lower income and lower pension contributions (Arksey *et al.* 2005; Evandrou and Glaser 2003). Lack of awareness of rights is also a factor. Recent research evidence suggests that few carers are aware of their right to request flexible working (HSISC 2010). Data from the 2009/10 Survey of Carers in Households shows that only 27% of carers in full-time employment and 24% of those in part-time employment were aware of their rights to request flexible working. There are concerns about requesting flexible working. Some carers are reluctant to reveal their carer status to employers or to take advantage of flexible working arrangements, for fear of being thought of as a 'weak' employee (e.g. Arksey 2005). Carers have concerns that their employer would disadvantage them if they were to request flexible working. This was particularly true of people working in sectors such as manufacturing, where there is a perception that they would be perceived as 'difficult' and could end up losing their job (Age UK and Carers UK 2016).

Care leave

The literature on care leave is less extensive and Glendinning (2016) argues that multiple reasons for work and care decisions mean it is not possible to assess the impact of lack of care leave on caregiving or labour market participation. Carers may, for various reasons, be reluctant to stop paid work altogether; rather they want to achieve an on-going balance between caring and employment (e.g. Arksey *et al.* 2005). However, there is some evidence that care leave has a positive effect on employment, particularly in combination with flexible working practices (e.g. Pavalko and Henderson 2006; Colombo 2011; Skira 2015; Bouget 2016).

In the US, Pavalko and Henderson found that carers who had access to unpaid family leave were more likely to remain employed than carers who did not have this benefit (odds ratio 3.74). Also using US data, Skira (2015) found that unpaid care leave was associated with a 44% increase in the proportion of women in full-time employment in the years subsequent to the take-up of the unpaid leave. For part-time employment, this was 27%. Skira found similar increases in women's full- and part-time employment rates for paid care leave as unpaid care leave, although take-up was higher for the former.

However, there are substantial differences in work conditions between the US and other countries. The US is the only advanced economy in the world that does not guarantee its workers any paid annual leave with the result that paid average annual leave is among the lowest in the world, with some employers offering no paid leave at all (World Bank 2017). Internationally, many carers use annual leave, when available, for caring responsibilities as this is more likely to be paid even when care leave exists (Colombo *et al.* 2011; Ikeda 2017). Working hours in the US are also among the longest in the world's advanced economies (World Bank 2017). In Japan, Ikeda suggests that the system of Family Care Leave (93 days long-term leave to be taken in up to three blocks plus five days per year short-term leave to be taken in half or whole days) helped unpaid carers stay in employment particularly in conjunction with the other provisions for carers in Japan since 2016 including rights to flexibility at work. However, when caring responsibilities were prolonged, care leave was less effective (Ikeda 2017). Other research also shows that care leave alone may be insufficient where care demands are intense and sustained over a long period of time (Arksey 2003; Hill *et al.* 2008) and at higher levels of need, unpaid care may be insufficient on its own to meet care needs (Colombo *et al.* 2011). What certainly seems to be the case is that under the current system in the UK where care leave is unpaid, or paid at the employer's discretion, this is a major disincentive to taking it, as in many cases carers are unable to afford a period of unpaid leave (Mooney *et al.* 2002; Arksey *et al.* 2005; Colombo 2011).

The Joint Social Protection Committee-European Commission report on adequate social protection for long-term care needs in an ageing society (Social Protection Committee 2015) suggests that care leave and flexible work arrangements help carers address the balance between workplace obligations and caring responsibilities, and so can induce the supply of both, although it argues, this should be in the context of other intervention measures. There is limited evidence available on effect on supply. The US study from Skira (2015) described above shows that unpaid care leave generates small increases in intensive care provision compared to baseline (between 1.6 and 1.8 percentage points). Paid leave generates larger increases with the more generous scheme modelled generating the greatest increases. The corresponding figures are 2.3 and 3.3 percentage point increase for scheme 1 and 3.4 and 5.7 percentage points for scheme 2.² However, as also described above, work conditions in the US are very different from other OECD countries.

2. Scheme 1, loosely scheme loosely based on Germany's Cash Allowance for Care scheme extrapolated to a two-year period: \$6,600 to women who intensively care for mothers with ADL needs or a memory problem and \$13,200 to women who intensively care for mothers who cannot be left alone.

Scheme 2 based on the recently suspended US CLASS Act: \$18,250 to women who intensively care for mothers with ADL needs or a memory problem and \$36,500 to women who intensively care for mothers who cannot be left alone

In the absence of statutory rights to care leave (as in England currently) there is significant variation between employment sector with care leave most often used in the public sector and/or in larger companies (Colombo 2011). Even in the presence of statutory paid leave, carers may be reluctant to request it for similar reasons to those suggested above for the reluctance to request flexible working. For example, there is also some evidence of a reluctance to take care leave because of perceived impact on career (Colombo 2011). An additional issue can be that care leave is not flexible enough to support carers in their caring situations nor the care needs of the person they care for. There are a variety of different care leave arrangements in Europe, Canada, Australia and Japan among others that address the issues of lack of statutory provision; not paid except at employer's discretion; and lack of flexibility (see Box 1 for some European examples).

BOX 1: CARE LEAVE ARRANGEMENTS IN EUROPEAN COUNTRIES

Eligibility criteria

Eligibility criteria for carer's leave can be divided into four main categories: (a) age of the cared-for person; (b) dependency assessment; (c) social insurance contributions period; (d) employment status of the carer.

Dependency of the cared-for person. Two main categories of dependency assessment are used. Many countries use disability scales, ranging from full health to severe disability. When such measurement tools do not exist, the assessment is based on a medical examination and a medical certificate, depending on a doctor's decision. Many countries provide specific carer's leave when an individual is providing end-of-life support.

Carer's social insurance contributions period and/or her current employment relationship e.g. minimum length of service; self-employed are sometimes excluded, sometimes not.

Payment arrangements

Many countries provide both paid and unpaid leave

One method is based on a proportion of previous earnings, subject to various ceiling conditions. The percentage generally varies between 70 and 80% but can be 100% for some countries for short-term leave

A few countries apply a flat rate amount

In some countries, the amount provided during certain types of leave is calculated on the basis of sickness benefits (e.g. In Denmark it is 1.5 times the sickness benefit). The upper limit depends on previous earnings, on a legally established threshold which can be linked to inflation, or on the amount of other (most often sickness) benefits.

In Austria, the rate of care leave benefits is income-related and approximately equal to the rate of unemployment benefits.

Duration

There are three main trends: (a) countries providing both short-term and long-term leave; (b) countries providing only short-term leave and (c) leave schemes of unspecified (reasonable) duration.

Short-term leave varies from a couple of days to a 3–4 weeks. Short-term leave is often tailored to taking care of a sick person over a short period of time (whatever the sickness-related reason) and/or to enable the arrangement of formal care services.

Long-term leave can vary from a month to several months or even more than a year and is specifically meant to allow the carer to provide care for a dependent person.

Often the duration varies considerably according to the age group of the dependent person: leave provisions for carers of dependent children are usually better developed than those concerning other age groups

In the third type of carer's leave provisions, duration is not specified (as is currently the case in UK where duration is left up to a negotiation with the employer and is intended for emergencies)

The Netherlands has short-term leave, long-term leave and emergency care leave provisions (the latter is unspecified duration)

Flexibility of leave

Arrangements can consist in taking some days or hours off over a couple of months or splitting the leave into weeks and/or months.

For instance, in Italy carers are entitled to take three working days per month, on a piecemeal hourly basis.

In the Netherlands, carers can take up to a maximum of six weeks (six times the weekly working hours) a year and this can be spread over the year.

“Crédit temps” in Belgium: full or partial reduction in working time up to a maximum of one to five years (one year Full Time Equivalent (FTE)) usually in blocks. Two types: one for age 55 plus (as a pre-retirement option). Minimum service requirement of 2 to 5 years depending on scheme, monthly allowance of €481.02 to €641.37 gross pro rata.

Social security rights

In most countries, leave provisions generally allow the carer to continue building up social security rights

Cash benefits

There are two main policy approaches: (i) carer's allowances, which are provided directly to the carer if she or he applies for it, subject to eligibility criteria, as is the current system in the UK; (ii) a care allowance to a person with care needs who may buy in services of carers from the labour market, or who can use it to remunerate a relative who becomes the carer.

Cash-for-care benefits increase the likelihood, or apparent likelihood, of providing care (e.g. Glendinning 2003; Colombo 2011; Haberkern 2015; Skira 2015; Bouget 2016; Glendinning 2016). Skira (2015), using US data, found that a carer allowance of \$18,250 to women who intensively care for mothers with ADL needs or a memory problem and \$36,500 to women who intensively care for mothers who cannot be left alone increases the proportion providing care by 7.4 for the former and 13.6 percentage points for the latter. This is a higher increase than the same amount paid as care leave. In further analysis to explore this, Skira concludes that this is because women do not have to leave work to receive the carer allowance.

Other research suggests that the higher the amount the state spends on such payments, the higher the likelihood of providing care (Haberkern 2015; Bouget 2016), which may partly explain the greater increase in propensity to provide care seen with the greater payments in Skira's study, although care needs also differed between the payment groups. The effect is greater for women and for those with lower income relative to level of cash benefit (Haberkern 2015; Bouget 2016). As men still earn more compared to women throughout Europe, this is often the same thing and may in large part explain the higher incentive of cash-for-care for women compare to men (Haberkern 2015). Low cash benefits do not appear to have a substantial effect on provision of unpaid care, except for specific segments of the labour market with unskilled workers, low pay and undeclared work (e.g. Bouget 2016).

Higher levels can alleviate poverty for families, particularly in combination with part-time employment or part-time care leave as they provide some compensation for reduced income (Bouget 2016). However, they can also increase or maintain gender inequality and low income, as even in the most generous countries payment for care involves fairly low wage (e.g. Bouget 2016; Colombo 2011). Higher levels also act as a disincentive to work, again particularly for women, and so have negative effects on female labour force participation (e.g. Haberkern 2015; Skira 2015). Skira (2015) found that rates of women's non-employment increased from 59.5% at baseline to 62.2% under the carer allowance model, with corresponding decreases in full-time employment, and to a lesser extent part-time employment. There is thus a trade-off. If the level is high enough to reduce risk of poverty, it tends to act as a disincentive to work, particularly for those with relatively low (household) income relative to allowance level and/or low earning power, who may be those with most difficulties entering the labour market. By increasing non-labour income through cash benefits, the marginal utility of an extra hour of working decreases, thus acting as a negative labour supply

incentive (Geyer and Korfhage 2015). When allowances are low or very low, EU experts consider that they do not have any impact on carer's employment, except for poor families where even low allowances could have a disincentive effect on the employment of carers (Bouget *et al.* 2016). Looking at German data, Geyer and Korfhage (2015) found that a 1% increase in benefits in cash decreases working hours by 0.46% and LFP by 0.17%. For women this is a decrease of 0.60% and 0.19% respectively, and for those caring for higher intensity there is a decrease of 0.71% and 0.25% respectively.

In some instances, the policy as well as the level act as a disincentive to work because the eligibility criteria limit combination with formal paid employment, or more than minimal formal employment, as is the case in the UK (Glendinning 2016). In addition to creating disincentives to take up formal employment, cash benefits or allowances discourage carers from working additional hours. Some carers may forgo opportunities to increase their working hours and earnings, in order to stay within the CA earnings limit. Others report being unable to do overtime because of the risk of exceeding the earnings limit (Arksey *et al.* 2005; Fry *et al.* 2011; DWP 2014). Means-tested allowances such as those in Australia and the UK generate incentives to reduce hours of work for carers (Colombo 2011). The employment effect of cash benefits depends not only on level and eligibility criteria but also on the structure of the labour market, especially the availability of part-time and flexible working hours and, as noted before, the carer's (family) income (Bouget *et al.* 2016). There will clearly be a difference in effect of cash benefits for carers of working age and non-working age. Furthermore, providing financial incentives for carers might be a helpful strategy especially for low-intensity, low-skilled care, but it might be more problematic as care needs increase (Colombo 2011; Bonsang 2009).

In the UK under the current system, the relatively low weekly earnings limit and the eligibility conditions result in disincentives to work, whilst the level does not protect against poverty nor increase propensity to provide unpaid care (e.g. Arksey 2005; Glendinning 2016). The care allowance system in the UK also results in significant uncompensated earnings lost by those who reduce from full- to part-time work (Glendinning 2016). The UK Carers Allowance also has a very steep income taper, discounts other benefits and pension³, and is taxed. Perhaps because of this it has very low take-up (Fry *et al.* 2011). One of the benefits of the UK Carers Allowance is that it protects carers' state pension and national insurance rights. Box 2 shows examples of cash benefit policies in other European countries.

3. www.gov.uk/carers-allowance/effect-on-other-benefits

BOX 2: EXAMPLES OF CASH BENEFITS FOR CARERS

Sweden

The attendance allowance is granted directly to the care-recipient, to be used to pay a family member. Eligibility is usually based on the assessed level of dependency or time spent in caregiving, reflected in terms of weekly hours of help needed.

Amount: The salary amounts to the same as a home help employed by the municipality in their own services.

Spain

There are cash benefits targeted at care-recipients to pay a carer who can be a professional or a family member. These benefits depend on the dependency assessment of the person cared for. This allowance aims to compensate the unpaid carer for their work and the costs of care in the family setting. At-home care must be provided by family members and only in exceptional circumstances by non-family members.

Amount: In 2015, the amount varied between EUR 153 and EUR 387.64 per month, depending on degree of dependency and economic capacity. There is a possibility for non-professional carers to make voluntary Social Security contributions (until 2012 contributions were paid by Social Security).

Slovenia

The benefit granted to a person with a disability to hire a home care assistant depends on the dependency assessment. In order to be eligible the home care assistant has to either live with the cared-for person or be her/his relative. She/he has the right to work part-time. It can only be a person who is unemployed, or who left the labour market or shifted to part-time employment, in order to become a home care assistant.

Amount: Partial payment for lost income amounting to EUR 734.15 per month (in 2016 and 2017), or a proportional share thereof, if working part time. The municipality pays (deducts) social security contributions from this amount, so that the home care assistant receives only the net amount. The person with disabilities and the persons obliged by law to care for him/her (usually the spouse/partner and/or grown up children) have to refund, according to their ability to pay, (a part of) the home care assistant's gross payment to the municipality.

Finland

Municipal informal care support is a combination of in-kind and cash benefits. Municipal informal care support demands a contract between the municipality and the carer. The informal care benefit also includes access to municipal services (such as washing,

medical care, meals-on-wheels etc.) to make the care at home possible. Informal carers get remuneration, accrue their pensions, are insured and get days off. A carer doing demanding care work gets three days off per month. Since 2011, families have been able to hire another family member or a friend to be the substitute carer.

Amount: The amount of support is linked to the intensity of the care needed. The minimum is EUR 387.49 a month. The support is taxable income. If the carer is unable to work due to heavy care obligations, the minimum amount is EUR 774.98 a month. This higher amount is envisioned for shorter periods, e.g. while discharging patients from hospital or during terminal care. The average amount was EUR 440,30 in 2012/13.

Ireland

Carer's Benefit is a payment made to insured people who leave the workforce to care for a person(s) in need of full-time care. This may be claimed as a single continuous period or in any number of separate periods up to a total of 104 weeks for each person being cared for. The conditions for eligibility for Carer's Benefit stipulate that the carer must be aged at least 16 and under 66 years. In addition, since it is an insurance-based benefit the carer must have been employed for at least eight weeks in the previous 26-week period for a minimum of 16 hours a week or 32 hours a fortnight and have made at least 39 weeks of social insurance contributions in the relevant tax year. She or he must also have (had) to give up work to become a full-time carer. The second and far more widely-used provision is the Carer's Allowance. Like the Carer's Benefit this is received on a weekly basis provided one meets the conditions. Unlike the Carer's Benefit it is means-tested.

Amount: Carer's Benefit is EUR 205 a week and Carer's Allowance is EUR 204 a week if the carer is under 66 years and caring for one person (it is EUR 307.50/EUR 306 if caring for two people). For carers aged over 66 years, the respective weekly rates for the Allowance are EUR 242 and EUR 363. Those in receipt of Carer's Benefit and Carer's Allowance can build up credits for social insurance contribution.

United States of America

In many states there are Medicaid Home and Community-Based waiver payments which a care-recipient can use to pay a non-spousal family member for personal care.⁴ Additionally, the Department of Veterans Affairs has a programme to support carers of post-9/11 Veterans. This programme pays a monthly stipend directly to eligible carers (Van Houtven et al. 2017).

4. www.abcdnj.org/publications/community-based-services/supporting-family-caregiving-via-the-federal-waiver

Combinations

Many reviews and reports conclude that a combination or multiple choice of interventions may be most effective in supporting carers and helping to meet the diverse needs of carers and people with care needs. UK and EU 35-country synthesis reports on reconciling work and care conclude that improving work-life balance for carers requires co-ordinated measures across multiple policy domains and for both disabled people and carers. Good work-life balance (and wellbeing) cannot be achieved by carers' benefits alone and additionally need formal care services, flexible working and poverty alleviation measures (Glendinning 2016; Bouget *et al.* 2016). Similarly, Eurocarers (2009) citing Himmelweit (2008) argue that carers need support combining paid employment and care in terms of cash, time and services.

The DWP Fuller Working Lives report (2014) suggests a range of actions is needed to help more carers stay in employment: support services; income protection; flexible working practices; plus innovation in areas such as assistive technology. An EU report on the indirect costs of LTC argues that the three factors most important to the reconciliation of care and employment are availability of formal care for the person cared for; policies supporting unpaid carers in combining work and care such as flexible working; and care intensity (Rodriguez *et al.* 2013). Yeandle and Buckner (2007) say that three key elements have been identified as important in facilitating continued employment: workplace support for carers; effective provision of health and social care; and 'other local infrastructure' such as access to information. An OECD report on providing and paying for long-term care concludes that both financial support and services are needed to support carers (Colombo 2011). Finally, in his evidence review on volunteering, providing unpaid care and paid employment in later life for the Foresight report, Future of an Ageing Population (2016), Nazroo (2015, p15) argues that 'without sufficient flexible sources of formal care, flexible work places and the support of other informal carers, those taking on informal caring responsibilities are likely to face some degree of withdrawal from paid work'.

MODELLING THE IMPACT OF SELECTED UNPAID CARE SUPPORT SCHEMES

Modelling strategy and assumptions

Based on the results of the literature review, four schemes have been identified for further analysis:

- Statutory care leave
- Arrangements for flexible working
- Additional home care support
- Carer wellbeing support scheme: the START study

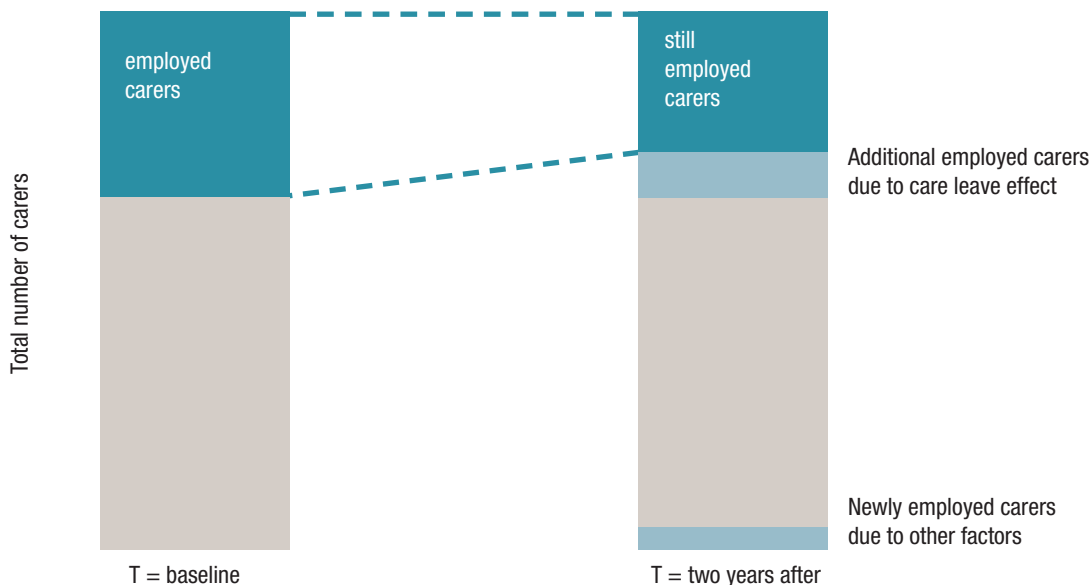
Statutory care leave

The evidence suggests that statutory care leave can potentially both increase (or maintain) provision of unpaid care and increase (maintain) employment, possibly in conjunction with other interventions at a certain level of care need.

There is very little quantitative evidence on the potential effect size of care leave. We have based our modelling of care leave on the findings by Pavalko and Henderson, who found that carers who had access to unpaid family leave were more likely to remain employed than caregivers who did not (odds ratio 3.74). Care hours were assumed to remain the same.

Some limitations to the applicability of the evidence in Pavalko and Henderson to the present review need to be noted. Their data are from the US, and date from 2006, and there exist important differences between general work leave practices in the UK and US. The care leave scheme examined in their paper is not paid, whereas much of the UK and EU research points to the need for care leave to be paid in order to be effective. (However, there is no research that we can find on size of effect of paid care leave in the UK or EU.) Additionally, there are no specific figures on effect of care leave on unpaid care supply.

Figure 6: Illustration of employment effect in Pavalko and Henderson



Our modelling focusses on the increase in the number of unpaid carers in employment after two years. Pavalko and Henderson's evidence refers specifically to:

- Women carers in the US
- Women who were employed and were not doing care work at the start of the time interval considered
- Women were defined as doing care work if they were caring for someone inside the home or if they were caring for some- one outside the home for six or more hours per week.

Our modelling scenario was based on the following approach:

- We used BHPS data to estimate the proportion of carers in employment who would remain in employment two years later. It is estimated that 77% of employed carers remain in employment after two years.
- We calculated the increase in the proportion of employed carers who would be associated with an increase in the odds ratio (OR) of 3 (instead of 3.74 as quoted in the paper). This is equivalent to a 14% increase in the likelihood of employment.⁵
- In the first instance, we assumed that the estimated proportional increase applies only to female carers (as this is the group the estimates in the paper were based on). A second scenario assumes that the effects would apply equally to men.
- No assumptions were made about any unpaid care supply effects due to the lack of appropriate evidence.
- There does not seem to be evidence of significant changes in levels of informal care, and so we could assume unpaid care remains constant, and as a result formal care also to remain constant.

In line with the scheme in Pavalko and Henderson, we assumed care leave would be unpaid. However, as noted above, some evidence suggests that paid care leave would be more effective. There are a range of policies in Europe on paid care leave. Most have level of disability as one of the eligibility criteria (plus other eligibility criteria). Further details are provided in the review section above.

Flexible working

Flexible working has also been found to be effective in improving employment outcomes for carers. Carers in the UK already have legal rights to request flexible working, but issues such as lack of awareness and a reluctance to request it mean that further gains in employment outcomes could be achieved by increasing take-up.

5. This estimate is comparable, if slightly below the modelled effect of two-year care leave programmes on the employment of daughters caring for their mothers reported in Skira (2015), which ranged from 16% for unpaid leave to 20% and 25% for paid care leave. It was calculated by applying the odds-ratio of 3 to the estimate of 77% of carers in employment after two years.

In our analysis we attempt to model a scenario in which government implements a scheme to incentivise employers to promote flexible working amongst carers.

- The Survey of Carers in Households 2009/10 found that awareness of the right to request flexible working from an employer was 19% among all carers, 27% among carers in full-time employment and 24% of those in part-time employment.
- In Carers UK's State of Caring 2013 survey, 21% said they had given up work because of issues around getting flexible hours or a lack of understanding from their employer.
- In Carers UK State of Caring 2016, of those who gave up work, retired early or reduced working hours, 16% said that the leave available from work was insufficient to be able to manage caring alongside work and 18% were unable to negotiate suitable working hours.

The flexible working scheme modelling assumptions were based on the following evidence:

- Carers UK survey indicates that 1 in 5 of carers reported that they have given up work because of lack of flexibility. Because carers might be referring to past events, we assume in the analysis a smaller 1 in 7 ratio.
- Flexible working is likely to be most effective for medium and low levels of caregiving. We therefore assume that the effect applies to carers providing less than 20 hours per week of support.
- We further assume that the scheme would only apply to carers of working age and not in work.
- We take into account the impact of lack of awareness: we assume the information and incentive campaign would double awareness to 50%, and that this mediates the effect on the 1 in 7 ratio mentioned above.
- As in the care leave modelling example, and in line with the limited amount of evidence available, we assume that flexible working does not impact significantly on levels of unpaid care, and thus would not affect levels of formal care provision either.

Formal care services for care-recipient

Formal care has been found to increase supply of low-intensity unpaid care supply, and to decrease the higher-intensity caring that is less compatible with employment.

For maximising employment, home care/PA (or day care) for the person with care needs is the most effective intervention for those caring for 10 hours or more a week. There is a greater effect for women (and more women are affected).

There are some data quantifying the effect of (increasing) formal care on employment:

- Women who provide unpaid care for ten or more hours a week have significantly higher odds (OR=1.57, CI 1.34–1.85) of being in employment if the person they care for receives at least one formal paid service compared with if they receive no services as do men (1.69, CI 1.34– 2.12) (Pickard *et al.* 2015).
- On specific services the odds ratios are: home care (women 1.64; men 1.69); personal assistant (women 1.74; men 2.45); day care (women 1.26; men non-significant); meals-on-wheels or equivalent (women 2.85; men non-significant) (Pickard *et al.* 2015).
- A 1% increase of benefits in kind in Germany leads to an increase in labour force participation of 0.02%. The effects are larger for women (0.03%) and at higher care levels (0.07%) (Geyer and Korfhage 2015).
- Viitanen (2007) used European Community Household Panel data to argue that increasing government expenditure on formal services for older people to the EU average (or the EU average excluding Denmark as an outlier) if it was below that average would increase labour force participation rates among 45 to 59-year-old women by between 9 and 13 percentage points.

We concentrate in our modelling on the UK evidence from Pickard *et al.* (2015).

However, the estimates in Pickard *et al.* reflect associations rather than causal effects. We should therefore interpret cautiously the estimated effects, because of the possible endogeneity between the allocation of formal care and the employment status of the carer (i.e. the carers' employment might itself be the reason for the allocation of formal care services, and providing services to carers not currently employed would not necessarily incentivise them to work).

We therefore assume a smaller positive effect of formal support on employment status, with an OR of 1.2 instead of the 1.6 in the paper. In line with the analysis in Pickard *et al.* (2015), we assume the effect only applies to unpaid carers providing more than 10 hours of support per week. The scheme is therefore assumed to target only such carers. Also, the scheme is assumed not to increase support for carers looking after older people who received local authority social care support, as it was assumed that such support would already include some support for the carer, in line with current social care eligibility criteria.

As noted above, some of the evidence identified in the review suggests that formal support could increase unpaid care supply. In particular, Schaffer (2011) found that the introduction of the policy of free personal care in Scotland to those aged 65 and older led to increases in the probability of providing unpaid care amongst the population of over 45s by 3 to 5 percentage points.

We have decided not to include the results of the effects identified in Schaffer (2015), due to the very large size of the increases in supply that they implied when applied to the simulation model, and the lack of clear rationale for the nature of the resulting effects.

Interventions for improving health and wellbeing of carers

There are several possible candidate interventions for improving the health and wellbeing of carers. We suggest the STRategies for RelaTives (START) programme (Livingston *et al.* 2014), which is an example of an effective and cost-effective psychological therapy for carers of people with dementia.

The START intervention aims to reduce depression and anxiety in family carers of people with dementia. Each carer receives an 8-week programme of individual psychological therapy sessions delivered by trained, supervised psychology graduates. Sessions include information on: what dementia is and how it affects people; carer stress, how to recognise it and techniques for managing it; how to manage difficult behaviour; how to access support that is available for people with dementia and family carers; and maintaining skills learned and planning for the future. Carers receive a manual and relaxation CD so they can practice techniques learned in the sessions at home.

START was evaluated in a randomised controlled trial in which 260 family carers took part, receiving either the START intervention or usual support. The evaluation found that the START programme helped reduce anxiety and depression in people caring for a family member with dementia to an extent that was considered to be clinically significant. The scores were improved in both the short term (8 months after the study started) (Livingston *et al.* 2013), and in the longer term (24 months after the study started) (Livingston *et al.* 2014). Indeed, carers who only got the usual kind of support were four times more likely to have clinically significant depression than carers who got the additional coping intervention (START) by 8 months, and seven times more likely by 24 months. Carers who received the START coping strategy also had significantly better health-related quality of life by 24 months than carers who got usual support. In-depth interviews revealed that carers expressed very positive views about the intervention (Sommerlad *et al.* 2014).

In addition to those effects on carers, the evaluation looked at effects on people with dementia. Over the 24-month period, no differences – either negative or positive – were found in dementia severity, neuropsychiatric symptoms or quality of life between people whose carers had received START and those whose carers had received usual support.

The economic evaluation examined cost-effectiveness by looking at the health and quality of life effects for both carers and people with dementia, and by measuring costs of health and social care services used by both groups (including the cost of delivering START itself). In the short term (over 8 months), the cost of START was offset by

reductions in use of other services by carers. Overall, there was no statistically significant difference in costs between the two groups of carers. Combined with the positive outcome findings, START was clearly cost-effective (Knapp *et al.* 2013).

In the longer term (over 24 months), the costs of services used by carers were slightly but not statistically significantly higher in the START group, and the costs of services used by people with dementia were slightly but not statistically significantly lower in the START group. Considering costs associated with service use by both carers and people with dementia, START is clearly cost-effective when looking at carer outcomes, and has a very high probability of being cost-effective when looking at outcomes for people with dementia (by reference to NICE thresholds, for example).

Key findings from the modelling of schemes

As indicated above, none of the carer support schemes explored could be associated with changes in levels of unpaid care supply. Given that unpaid care levels remained unchanged, we assumed that formal care use would also remain unchanged from the base case scenario, unless this change in formal care was itself the scheme being modelled.

We concentrate on the impact of the policy scenarios on employment rates among working age (16 to 64) carers providing extra-resident care (for their parents or other relatives or friends aged 65 and over). We focus on carers of working age since we expect that the impact on older carers would be much lower and our estimates of it less reliable. We do not consider co-resident carers since not only are most of them aged 65 and over but most of them provide intensive care (20 or more hours per week) which would be unlikely to be compatible with employment. We focus on impacts on employment and not on caring since, as indicated above, we have not found any evidence that the policies would yield impacts on prevalence of caring or intensity of caring. In the absence of an impact on caring we would not expect an impact on receipt of formal care services (except where the policy is explicitly to increase formal care).

Figure 7 summarises the distribution of employment status for extra-resident carers aged 16 to 64, and therefore with the greatest chances of being employed. Increases in the proportion of carers employed are indicated in the graph by reductions in the height of the red bar (the fourth bar from the left in each cluster), which identifies carers who are not employed, relative to the base case. The figure shows that although some improvements in employment status are associated with each of the three schemes modelled, they tend to be small, in particular for the work flexibility and formal care options.

These results are further illustrated in Figure 8 to Figure 11, which compare the estimated levels of demand for unpaid carers against the expected supply, by carers' employment status, and for the period 2015 to 2035. As well as being used to

generate these figures, the projections have been presented in table 6. Overall, the lack of unpaid care supply effects and the relatively moderate employment effects mean that the future projections of unpaid care supply under the three schemes and the base case are very similar.

The care leave scenario would raise the number of extra-resident working age female carers who are in employment by around 186,000 (7.8%) in 2020 with no further increase in subsequent years. The additional numbers of employed carers would increase more substantially, by approximately 309,000 (13.0%), if the evidence which relates to female carers is applied equally to men and women.

The flexible working scenario would raise the number of extra-resident working age carers who are in employment by around 60,000 (2.5%) in 2020 with no further increase in subsequent years.

The formal care scenario would raise the number of extra-resident working age carers who are in employment by around 63,000 (2.6%) in 2020, and by similar amounts up to 2035.

Figure 7: Distribution of extra-resident carers of older people (aged 16–64) by employment status and modelling scenario (2015)

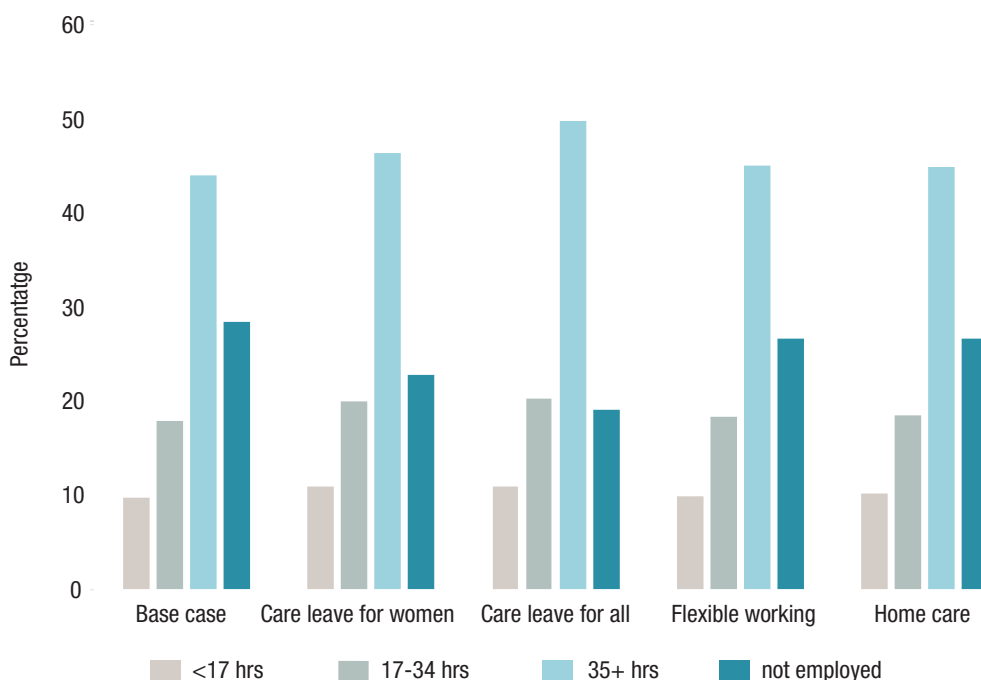


Figure 8: Numbers of carers of older people by employment outcome (2015–2035): care leave for women scenario

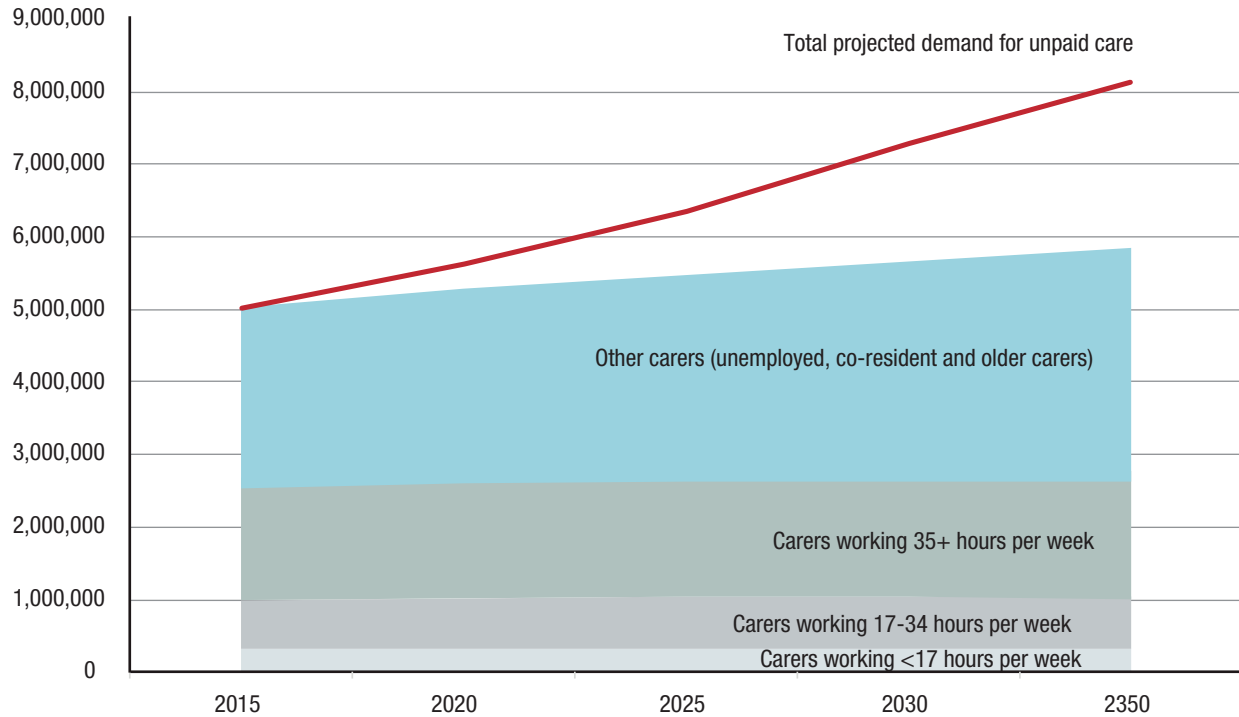


Figure 9: Numbers of carers of older people by employment outcome (2015–2035): care leave for all scenario

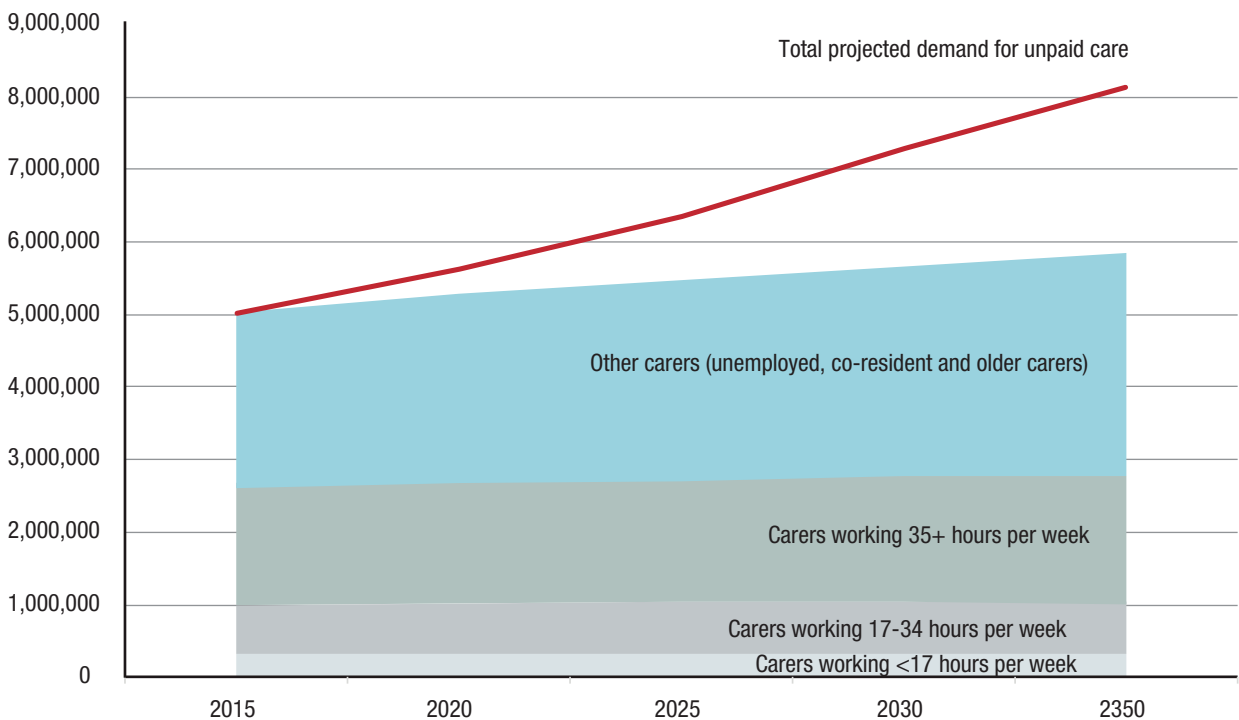


Figure 10: Numbers of carers of older people by employment outcome (2015–2035): flexible working scenario

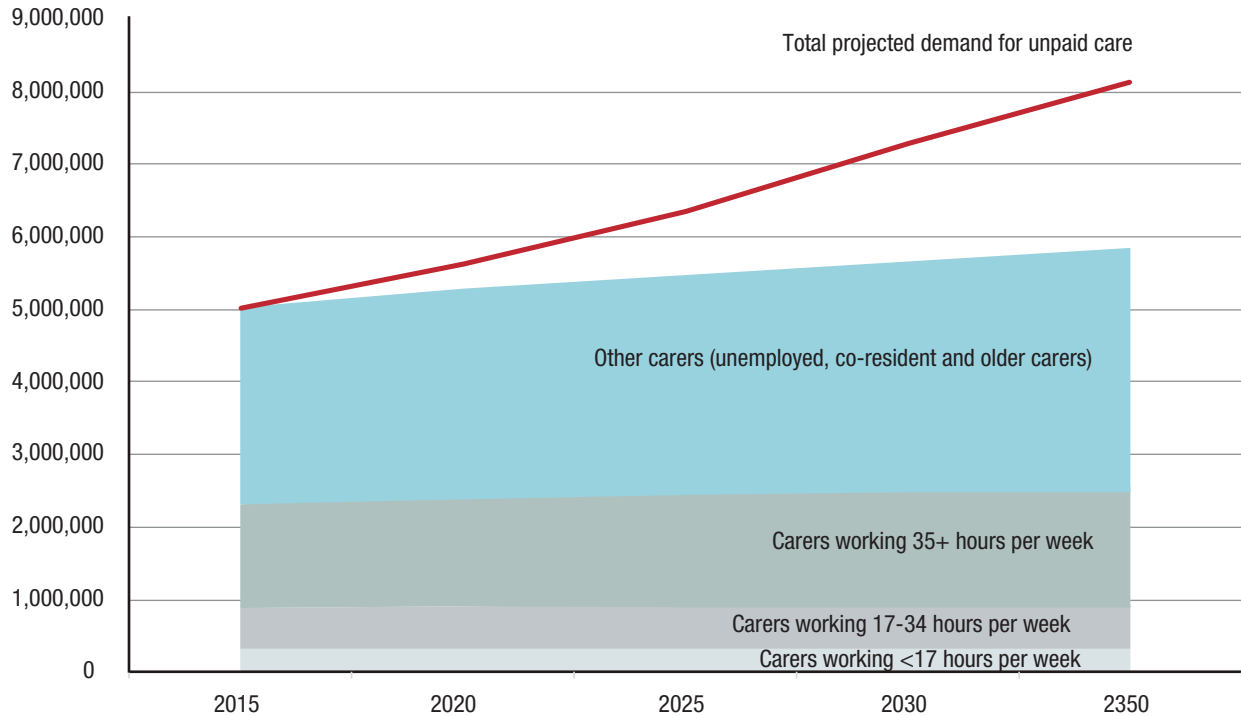
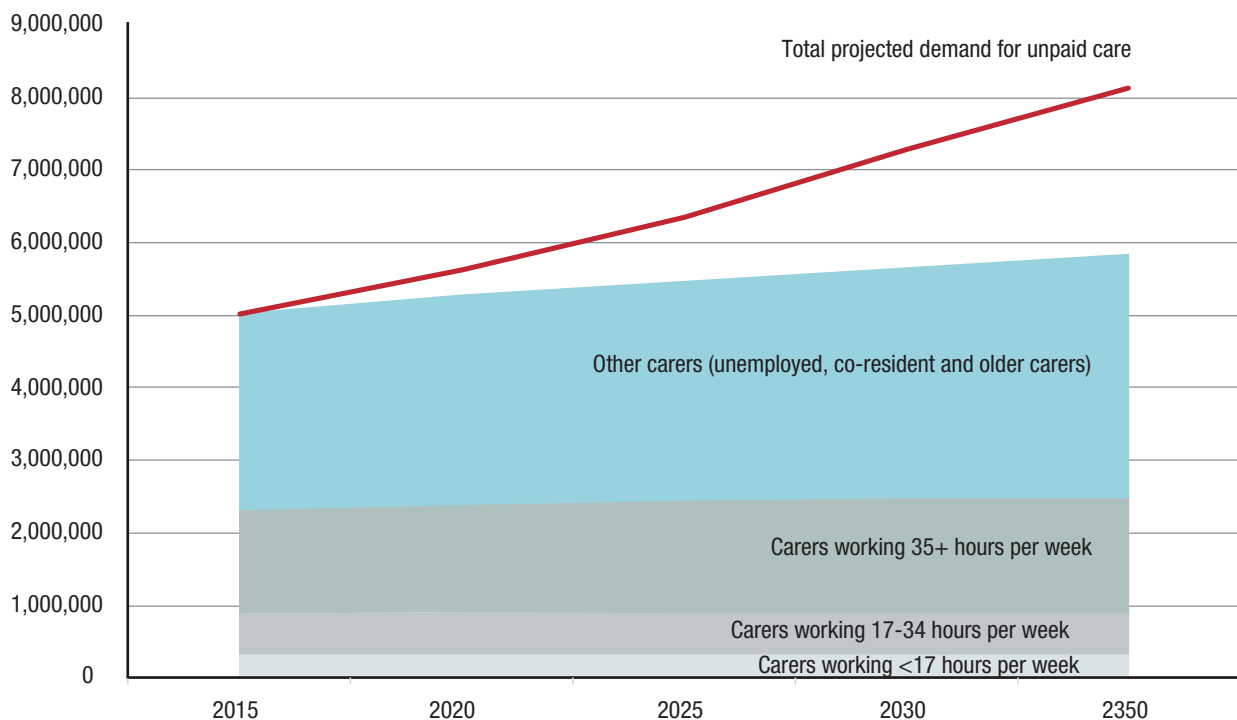


Figure 11: Numbers of carers of older people by employment outcome (2015–2035): formal care scenario



Costs of formal care scenario

The flexible working and care leave scenarios do not imply direct costs for government at the individual unpaid carer level except in its capacity as an employer of public sector staff.⁶ In contrast, the home care scenario assumes that the state would provide care resources for some carers looking after older dependent people without formal support. It is therefore important to attempt to cost the additional expenditure that government would need to incur in order to fund such increase in formal care levels.

Costing the formal care scenario requires assumptions to be made about:

- The levels of support provided to recipients of the scheme
- Whether the scheme would be means-tested
- The targeting of the scheme on particular carers, and in particular whether in addition to target carers providing at least 10 hours of support, it would be restricted to employed carers

The positive effect on carers employment of formal care in Pickard *et al.* (2015), which underpins the home care scenario modelling, is expressed in terms of 'having' versus 'not having' formal support, rather than in terms of particular levels of formal care. We assume in the costing analysis that the support provided to recipients of the scheme would be similar to the support given to dependent older people with unpaid carers by the social care system.

These levels of support are calculated on the basis of data from the English Longitudinal Study of Ageing (ELSA) waves 6 and 7, stratifying carers by the levels of care they provide. Unfortunately, we did not have sufficient evidence for our model to differentiate carers in terms of the needs of the person being looked after, and so it was not possible to estimate care packages also on the basis of care needs of the dependent person.

We calculate two sets of results depending on whether the scheme is assumed to be means-tested or not. In the means-tested versions of the results, we have assumed that 2 in 3 of care-recipients would not meet the current means-test, and that those individuals that did would contribute one-eighth of care costs. In line with the findings outlined in previous sections, all calculations assume a ratio of 1.3 carers for each person being cared for, and a unit cost for home care of £15 per hour.

Table 5 summarises the results (number of supported users, employed carers, and costs) associated with the different sets of assumptions tested. In the most generous of scenarios, which includes all carers providing at least 10 hours per week of care and

6. It is important to note that these scenarios are not cost free. Costs might for instance be incurred by employers who encourage a greater proportion of their workforce to benefit from flexible arrangements and/or care leave, and Government might need to invest resources on information campaigns and/or incentives for employers in order to increase take-up of flexible working and care leave.

Table 5: Numbers of additional recipients of home care, of employed unpaid carers of older people and associated costs for formal care scenario (England 2015)

	Unpaid care intensity		Total	
	10 to 20 hours	Over 20 hours	Not means-tested	Means-tested
Targeted on carers providing 10+ hours per week				
Extra users receiving formal care	181,000	98,000	279,000	81,000
Extra carers in employment	37,000	20,000	58,000	17,000
Hours per week of home care	6	12		
Extra yearly home care hours	58,353,000	60,750,000	119,103,000	34,738,000
Extra yearly care costs (£m)	875	911	1,786	521
Targeted on employed carers				
Extra users receiving formal care	28,000	15,000	43,000	13,000
Extra carers in employment	37,000	20,000	57,000	17,000
Hours per week of home care	6	12		
Extra yearly home care hours	9,019,000	9,263,000	18,282,000	5,332,000
Extra yearly care costs (£m)	135	139	274	80

not receiving formal support, 279,000 additional dependent older people would receive formal support, a figure that drops to 81,000 if eligibility to the scheme was subject to current means-testing eligibility criteria.⁷ Approximately 58,000 and 17,000 extra carers would gain employment, respectively. The total additional cost of the scheme would amount to almost £1.8 billion if no means-test was applied, and to £520 million if means-tested.

Table 5 shows that the costs of the scheme would vary significantly depending on which only carers that gained employment would be targeted. Under this scenario, the cost of the scheme would be reduced to £274 million and £80 million, depending on whether the scheme was means-tested. The number of additional recipients of care would fall to 43,000 and 13,000, respectively. The number of additional employed carers would not change. In terms of employment outcomes, restricting the scheme to carers who gain employment would therefore appear much more cost-effective. However, the analysis has not been able to include estimates for other important outcomes, such as likely differences in quality of life for users and carers, and impact on GDP of differences in the use of formal care providers linked to differences in the numbers of people receiving formal home care support.

7. Although means-testing the benefit reduces very significantly its scope, not doing so would be problematic from an equity point of view unless similar additional support was to be provided to dependent older people with similar needs and without informal support.

Table 6: Projected number of carers of older people by category and scenario (2015–35)

Category	Scenario	2015	2020	2025	2030	2035
Carers working <17 hours per week	BASE CASE	314	323	326	324	324
	Paid leave for women	353	362	364	363	363
	Paid leave for men and women	355	364	368	367	366
	Flexible working	322	331	333	332	332
	Formal services	327	337	340	339	338
Carers working 17–34 hours per week	BASE CASE	580	595	600	599	599
	Paid leave for women	646	663	668	667	667
	Paid leave for men and women	655	673	678	677	677
	Flexible working	594	610	616	614	613
	Formal services	596	614	620	618	617
Carers working 35+ hours per week	BASE CASE	1424	1464	1476	1476	1482
	Paid leave for women	1502	1544	1556	1555	1561
	Paid leave for men and women	1610	1654	1668	1667	1674
	Flexible working	1458	1499	1513	1512	1518
	Formal services	1454	1496	1511	1510	1515
Other carers (unemployed, co-resident and older carers)	BASE CASE	2704	2901	3077	3272	3435
	Paid leave for women	2521	2714	2891	3086	3249
	Paid leave for men and women	2402	2592	2765	2960	3123
	Flexible working	2648	2843	3017	3213	3377
	Formal services	2645	2836	3008	3204	3370
Total projected supply of unpaid care	BASE CASE	5022	5283	5479	5671	5840
	Paid leave for women	5022	5283	5479	5671	5840
	Paid leave for men and women	5022	5283	5479	5671	5840
	Flexible working	5022	5283	5479	5671	5840
	Formal services	5022	5283	5479	5671	5840
Total projected demand for unpaid care	All scenarios	5,020	5,627	6,351	7,285	8,125

POLICY IMPLICATIONS

THE CARE GAP CHALLENGE

One of the key aims of our analysis has been to quantify the extent to which the likely future supply of unpaid carers will keep pace with expected increases in demand for such care. Overall, the results suggest that over the next 20 years a significant gap will emerge between the numbers of unpaid carers and levels of demand for care.

- Our projection modelling of the supply side shows that the number of unpaid carers of older people will, on our base case assumptions, rise from 5.0 million in 2015 to 5.5 million in 2025 (a rise of 9%) and to over 5.85 million in 2035 (a rise of 16% from 2015). The key assumption is that the proportion of adults by age and gender providing unpaid care to an older person remains constant. The projection is inevitably highly sensitive to this assumption.
- The numbers of carers of older people will rise, on our base case assumptions, at only one quarter of the rate of increase in the number of older people needing care. In 2025 there is a projected shortfall of 0.9 million carers and in 2035 of 2.3 million carers. If formal services do not rise to keep pace with demographic pressures the shortfalls would be even greater.
- A range of factors could influence the proportion of adults by age and gender who provide unpaid care. These could include: the health state of the carer and her capability to provide care, competing responsibilities (child care as well as employment), closeness of family relationships, geographical distance between family members, attitudes/beliefs about responsibility to provide care, availability of formal care and availability of support for carers. The projection based on constant rates of providing unpaid care by age and gender may be pessimistic: as an increasing number of people in future have an older relative who needs care from them more of them may be willing to provide care. It is likely that a considerable proportion of the adult population who are not currently carers would supply unpaid care if and when they have a close relative requiring it. In contrast, changes in the state pension age and increases in female workforce participation could reduce future propensity to provide unpaid care in the population.

POLICY STRATEGIES FOR MEETING THE CHALLENGE

The key policy challenge is to design and implement evidence-based, cost-effective, affordable policy measures which either reduce the care gap by incentivising increased supply of unpaid care without reducing employment or increase employment rates among carers without reducing their provision of care. There is a lack of robust evidence on effective policy measures to incentivise increased supply of unpaid care. We have therefore focussed on policy measures to increase employment rates among

carers. If more carers who are not currently in employment (or actively seeking employment) enter the labour market, this will increase employment, output and government revenues. The additional revenues could be used to fund more formal care.

We have identified three policy measures (statutory care leave, flexible working arrangements and formal care) which evidence suggests would if adopted increase employment rates among carers. In estimating their impacts we have concentrated on employment rates among working age (16 to 64) carers providing extra-resident care. We expect that the impact on older carers and co-resident carers would be substantially lower, since the former are less likely to seek employment and the latter mostly provide intensive care (20 hours or more per week) which is unlikely to be compatible with employment.

Overall, the employment-generating effects of the interventions considered was relatively limited, in particular for two of the schemes investigated.

- The evidence suggests that statutory care leave can potentially both increase (or maintain) provision of unpaid care and increase (maintain) employment, possibly in conjunction with other interventions at a certain level of care need. While we assumed care leave would be unpaid, some evidence suggests that paid care leave would be more effective. Statutory care leave would, we estimate, raise the number of extra-resident working age carers who are in employment by around 187,000 (7.9%) in 2020 with no further increase in subsequent years. There would likely be costs to employers and to government both in its capacity as an employer and in its potential role in promoting the scheme.
- Flexible working has also been found to be effective in improving employment outcomes for carers. Carers in the UK already have legal rights to request flexible working, but issues such as lack of awareness and a reluctance to request it mean that further gains in employment outcomes could be achieved by increasing take-up. Flexible working would raise the number of extra-resident working age carers who are in employment by around 60,000 (2.4%) in 2020 with no further increase in subsequent years. There would again likely be costs to employers and to government both in its capacity as an employer and in its potential role in promoting the scheme.
- Formal care has been found to increase supply of low-intensity unpaid care and to decrease higher-intensity caring that is less compatible with employment. For maximising employment, home care/PA (or day care) for the person with care needs is the most effective intervention for those caring for 10 hours or more per week. This would raise the number of extra-resident working age carers who are in employment by around 58,000 (2.4%) in 2020 increasing to 69,000 additional such carers in employment in 2025 and 2030 and then falling to 65,000 in 2035. If the extra home care recipients received care packages similar to those currently supported jointly by local authority and unpaid care, the total additional cost of the scheme is estimated to amount to almost £1.8 billion.

ANALYSIS CAVEATS

It is important to note the following limitations of the methods and evidence used in the analysis.

- The review identified a **limited amount of evidence** suitable for the quantitative models. In particular, the analysis could not find suitable evidence to model a possible substitution effect between formal services and unpaid care. In part, the absence of evidence responded to the fact that no signs of such effect were identified in some studies that looked for it. We do not feel, however, that there is sufficiently clear evidence to state that no reductions in unpaid care could be expected if formal care services were to expand significantly, for some carers at least, other things being constant.
- **Non-UK evidence.** The limited nature of the available evidence means that we have had to use non-UK sources, of limited applicability to the English context due to important cultural and legal differences between countries.
- **Lack of evidence about variations in effects across individuals:** many of the analyses identified in the literature did not explore the differences in the effects between subgroups of carers and/or dependent people. However, it is likely that the cost-effectiveness of interventions to support unpaid carers will not be homogeneous.
- We used data from two major surveys of the household population, the HSE and the BHPS. The data on provision and receipt of unpaid care depends not only on the definitions of caring in the survey questions but also on how they are understood by those interviewed. There is a large difference between the number of older people reporting receipt of unpaid care (2.1 million) and the number of people reporting provision of care to an older person (5.0 million). It seems that there are many cases where someone reports providing care for an older person but the older person does not report receiving unpaid care. This suggests a **considerable degree of subjectivity** about whether people regard themselves as receiving or providing unpaid care.
- **Uncertainty of estimates.** There is inevitable uncertainty about some of the assumptions in our projections of future demand for and supply of unpaid care for older people. We have for this reason conducted sensitivity analyses on some of our important assumptions. Our base case projections are particularly sensitive to assumptions that disability rates among older people will remain constant by age and gender and that rates of providing unpaid care to older people will also remain constant by age and gender. We suggest that the latter assumption may be pessimistic.

- In the absence of appropriate evidence in the literature, we were unable to explore the full range of consequences on costs and outcomes of different patterns of unpaid care. There is a need to investigate the nature of the trade-offs between formal vs. unpaid care, and their impact on society overall. In particular, we need a better understanding of a number of things.
- The impact of alternative balances between unpaid or formal care on GDP growth, and how this relationship might vary with broader macroeconomic factors, such as employment rates. Costs of carers leaving employment (which is only those providing care for 10 hours per week) have been estimated to be at least £1.3 billion a year.
- We also need a better understanding of the longitudinal effects of some of the caring decisions, and in particular the lifetime consequences on carers' wellbeing and socio-economic status of different caring choices, and of different support schemes.
- We set out to cover these questions in the study, but could not due to a lack of robust quantitative evidence. Dynamic simulation techniques could be used in the future to investigate the lifetime effects of unpaid caring on carers, the person with care needs, and the care system.
- The analysis has not worked out the detail of the implementation processes that would be required by the three policy strategies evaluated. The implementation of the formal care scenario would in particular involve significant implementation challenges, in terms for instance of the choice of agency and mechanisms for assessing eligibility to support. It is likely that eligibility assessment would require a processes for monitoring caring hours and the work status of carers. The nature of the interaction between these eligibility criteria and existing needs and financial criteria for social care should be considered carefully.

REFERENCES

- Age UK. (2012). Estimation of the Financial Impact of Leaving Work due to Caring Responsibilities. London: Age UK.
- Acton, G.J., and Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: a meta-analysis, *Research in Nursing and Health*, 24, 349–360.
- Age UK., and Carers UK. (2016). *Walking the Tightrope*. London: Age UK.
- Age UK (2015). *Caring into Later Life*. London: Age UK. Retrieved from www.ageuk.org.uk/Documents/EN-GB/For-professionals/Policy/care-and-support/caring_into_later_life.pdf?dtrk=true
- Aldridge, H., and Hughes, C. (2016). *Informal Carers and Poverty in the UK*, London: New Policy Institute.
- Alwan M., Mack D., Dalal S., Kell S.W., Turner B., and Felder R. (2006). Impact of Monitoring Technology in Home Health Outcome Pilot. Proceedings of the 1st Distributed Diagnosis and Home Healthcare (D2H2) Conference. Arlington, Virginia, USA, April 2–4.
- Anderson, W. L., and Wiener, J. M. (2015). The impact of assistive technologies on formal and informal home care. *Gerontologist*, 55(3), 422–433.
- Arber, S., and Ginn, J. (1995). Gender differences in informal caring. *Health and Social Care in the Community*, 3(1), 19–31.
- Arksey, H. (2002). Combining informal care and work: Supporting carers in the workplace. *Health and Social Care in the Community*, 10(3), 151–161.
- Arksey, H., and Glendinning, C. (2008). Combining work and care: Carers' decision-making in the context of competing policy pressures. *Social Policy and Administration*, 42(1), 1–18.
- Arksey, H., Kemp, P., Glendinning, C., Kotchetkova, I., and Tozer, R. (2005). *Carers' Aspirations and Decisions Around Work and Retirement*. London: Department for Work and Pensions. Retrieved from www.york.ac.uk/inst/spru/pubs/pdf/rrep290.pdf
- Aspinall, A. (2011). A weight off my mind: exploring the impact and potential benefits of telecare for unpaid carers in Scotland. *Journal of Assistive Technologies*, 5(1), 43–44.
- Audit Commission. (2013). *Social Care for Older People*. London: Audit Commission. Retrieved from www.audit-commission.gov.uk/wp-content/uploads/2013/06/Social-care-briefing-v-FINAL-16-July-2013.pdf
- Bauer, J., and Sousa-Poza, A. (2015). Impacts of Informal Caregiving on Caregiver Employment, Health, and Family, Discussion Paper No. 8851. Bonn: Institute for the Study of Labor.
- Beale S., Sanderson D., and Kruger J. (2009) Evaluation of the Telecare Development Programme: Final Report. Edinburgh, Scotland: Scottish Government.
- Beard, J. R., Officer, A. M., and Cassels, A. K. (2016). The world report on ageing and health. *Gerontologist*, 56, S163–S166.

- Beesley, L. (2006). *Informal Care in England*. London: King's Fund. Retrieved from www.kingsfund.org.uk/sites/files/kf/informal-care-england-wanless-background-paper-lucinda-beesley2006.pdf
- Bensink M., Hailey D., and Wootton R. (2006). A systematic review of successes and failures in home telehealth: preliminary results. *Journal of Telemedicine and Telecare*, 12, 8–16.
- Bernard, M., and Phillips, J. E. (2007). Working carers of older adults. *Community, Work and Family*, 10(2), 139–160.
- Bolin, K., Lindgren, B., and Lundborg, P. (2008a). Informal and formal care among single-living elderly in Europe. *Health Economics* 17(3), 393–409.
- Bolin, K., Lindgren, B., and Lundborg, P. (2008b). Your next of kin or your own career? Caring and working among the 50+ of Europe. *Journal of Health Economics* 27(3), 718–738.
- Bonsang, E. (2009). Does informal care from children to their elderly parents substitute for formal care in Europe? *Journal of Health Economics*, 28(1), 143–154.
- Bouget, D., Spasova, S., and Vanhercke, B. (2016). *Work-life Balance Measures for Persons of Working Age with Dependent Relatives in Europe A study of National Policies*. Brussels: European Commission.
- Brereton, L., Carroll, C., and Barnston, S. (2007). Interventions for adult family carers of people who have had a stroke: a systematic review. *Clinical Rehabilitation*, 21(10), 867–884.
- Brodaty, H., Green, A., and Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51(5), 657–664.
- Brown, S., Farrell, L., and Harris, M. N. (2008). *Modelling the Incidence of Self-Employment: Individual and Employment Type Heterogeneity*. Sheffield Economic Research Paper Series SERP Number: 2008010. Sheffield: University of Sheffield.
- Buckner, L., and Yeandle, S. (2011). *Valuing Carers 2011 Calculating the value of carers' support*. London: Carers UK.
- Burrows, A., and Gannon, K. (2013). An evaluation of health and well-being checks for unpaid carers. *Journal of Integrated Care*, 21(3), 148–156.
- Carers UK, HM Government, and Employers for Carers. (2013). *Supporting Working Carers: The Benefits to Families, Business and the Economy: Final Report of the Carers in Employment Task and Finish Group*. London: Carers UK. Retrieved from www.gov.uk/government/uploads/system/uploads/attachment_data/file/232303/Supporting_Working_Carers_Final_Report_accessible_.pdf
- Carers UK. (2012). *Valuing Carers – Calculating the Value of Unpaid Care*. London: Carers UK, 1–13. Retrieved from <http://circle.leeds.ac.uk/files/2012/09/valuing-carers.pdf>
- Carers UK. (2013). *The State of Caring 2013*.
- Carers UK. (2014). *Facts about Carers: Policy Briefing*. London: Carers UK.
- Carers UK. (2015). *State of Caring 2015*. London: Carers UK. Retrieved from www.carersuk.org/professionals/policy/policy-library/state-of-caring-2015

- Carers UK. (2016). State of Caring 2016. London: Carers UK. Retrieved from www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016
- Carmichael, F., and Charles, S. (2003). The opportunity costs of informal care: Does gender matter? *Journal of Health Economics* 22(5), 781–803.
- Carmichael, F. (2011). Informal Care in the UK: Constraints on Choice. Unpublished paper.
- Carmichael, F., and Charles, S. (2003). The opportunity costs of informal care: Does gender matter? *Journal of Health Economics*, 22(5), 781–803.
- Carmichael, F., Charles, S., and Hulme, C. (2010). Who will care? Employment participation and willingness to supply informal care. *Journal of Health Economics*, 29(1), 182–190.
- Carmichael, F., Hulme, C., Sheppard, S., and Connell, G. (2008). Work-life imbalance: Informal care and paid employment in the UK. *Feminist Economics* 14(2): 3–35.
- Carretero, S., Stewart, J., and Centeno, C. (2015). Information and communication technologies for informal carers and paid assistants: benefits from micro-, meso-, and macro-levels. *European Journal of Ageing*, 12(2), 163–173.
- Casado-marín, D., Gracia Gomez, P., and Lopez Nicolas, A. (2011). Informal care and labour force participation among middle-aged women in Spain. *SERIEs* 2(1), 1–29.
- Casey, B. (2011). The Value and Costs of Informal care. Unpublished paper.
- Charlesworth, G., Burnell, K., Crellin, N. *et al.* (2016). Peer support and reminiscence therapy for people with dementia and their family carers: a factorial pragmatic randomised trial. *Journal of Neurology, Neurosurgery & Psychiatry*. 87(11), 1218–1228..
- Chiatti, C., Fry, G., Hanson, E., Magnusson, L., Socci, M., Stuckler, A., Szeman, Z., Widehn, N., Barbabella, F., and Lamura, G. (2011). Final Report Containing Case-by-case Detailed Description and Analysis of Selected 12 Good Practices. Vienna: European Centre for Social Welfare Policy and Research.. http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/D4.3_FinalreportAnalysisof12goodpractices.pdf
- Chien, LY., Chu, H., Guo, JL., Liao, YM., Chang, LI., Chen, CH., et al. (2011). Caregiver support groups in patients with dementia: a meta-analysis. *International Journal of Geriatric Psychiatry*, 26, 1089–1098.
- Chien, W-T., and Norman, I. (2016). The effectiveness and active ingredients of mutual support groups for family caregivers of people with psychotic disorders: A literature review. *International Journal of Nursing Studies*, 46(12), 1604–1623.
- Citizens Advice Bureau (2015). The Role of Carers Allowance in Supporting Unpaid Care. London: Citizens Advice Bureau.
- Coe, N. and Van Houtven, C. (2009). Caring for mom and neglecting yourself? The health effects of caring for an elderly parent. *Health Economics*, 18(9), 991–1010.
- House of Commons Work and Pensions Committee. (2008). House of Commons Work and Pensions Committee Valuing and Supporting Carers. London: The Stationery Office Limited.

- Colombo, F., Llana-Nozal, A., Mercier, J., and Tjadens, F. (2011c). *Help Wanted? Providing and Paying for Long-Term Care*. Paris: OECD Health Policy Studies.
- Courtin, E., Jemai, N., and Mossialos, E. (2014). Mapping support policies for informal carers across the European Union. *Health Policy*, 118(1), 84–94.
- Daly, M. (2016). *ESPN Thematic Report on Work-Life Balance Measures for Persons of Working Age with Dependent Relatives: Ireland*. Brussels: European Commission.
- Dam, A., de Vugt, M., Klinkenberg, I., Verhey, F., van Boxtel, M. (2015) A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise?, *Maturitas*, 85, 117–130.
- Davies, A., Rixon, L., and Newman, S. (2013). Systematic review of the effects of telecare provided for a person with social care needs on outcomes for their informal carers. *Health and Social Care in the Community*, 21(6), 582–597.
- De Boer, M. E., Hertogh, C. M., Droes, R. M., Riphagen II, Jonker, C., and Eefsting, J. A. (2007). Suffering from dementia – the patient’s perspective: a review of the literature. *International Psychogeriatrics*, 19(6), 1021–1039.
- Department of Health (2014). *The Care Act - Reforming How People Pay for their Care and Support (Report) (Vol. Factsheet)*. London: Department of Health.
- Department of Health. (2014). *UK: Care Act Impact Assessment (IA) Summary: Intervention and Options Summary: Analysis and Evidence Policy Option 1*. London: Department of Health.
- Doty, P., Jackson, M. E., and Crown, W. (1998). The impact of female caregivers’ employment status on patterns of formal and informal eldercare. *The Gerontologist*, 38(3), 331–341.
- Drinkwater, S. (2011). Informal caring and labour market outcomes informal caring and labour market outcomes within England and Wales. *Regional Studies*, 49(2), 273–286.
- Dujardin, C., Farfan-Portet, M.-I., Mitchell, R., Popham, F., Thomas, I., and Lorant, V. (2011). Does country influence the health burden of informal care? An international comparison between Belgium and Great Britain. *Social Science and Medicine*, 73(8), 1123–1132.
- DWP (2014) *Fuller Working Lives*. London: DWP.
- DWP (2014). *Household Finances of Carer’s Allowance Recipients*. London: DWP.
- Earle, A., and Heymann, J. (2011). Protecting the health of employees caring for family members with special health care needs. *Social Science and Medicine*, 73(1), 68–78.
- Eldred, C., and Sykes, C. (2008). Psychosocial interventions for carers of survivors of stroke: A systematic review of interventions based on psychological principles and theoretical frameworks. *British Journal of Health Psychology*, 13(3), 563–581.
- Ettelt, S., Mays, N., and Nolte, E. (2013). Policy-research linkage: What we have learned from providing a rapid response facility for international healthcare comparisons to the department of health in England. *Evidence and Policy*, 9(2), 245–254.

- Etters, L., Goodall, D. and Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20(8), 423–428.
- Eurocarers. (2009). Carers in Europe. Retrieved from www.eurocarers.org/userfiles/file/Factsheet2009_pages1to6.pdf
- Eurofound. (2015). Working and Caring: Reconciliation Measures in Times of Demographic Change. Luxembourg: Publications Office of the European Union.
- Evandrou, M., and Glaser, K. (2003). Combining work and family life – the pension penalty of caring. *Ageing and Society*, 23(5), 583–601.
- Finkel, S., Czaja, S.J., Schulz, R., Martinovich, Z., Harris, C., and Pezzuto, D. (2007). Impact of passive in-home health status monitoring technology in home health: Outcome pilot1 e-care: A telecommunications technology intervention for family caregivers of dementia patients. *American Journal of Geriatric Psychiatry*, 15, 443–448.
- Geyer, J., and Korfhage, T. (2015). Long-term care insurance and carers' labor supply – a structural model. *Health Economics*, 24, 1178–1191.
- Glendinning, C. (2016). ESPN Thematic Report on Work – Life Balance Measures for Persons of Working Age with Dependent Relatives. Brussels: European Commission.
- Glendinning, C., and Bell, D. (2008). Rethinking Social Care and Support: What can England learn from other countries. York: Joseph Rowntree Foundation. Retrieved from www.jrf.org.uk/sites/files/jrf/2335.pdf
- Glendinning, C., Tjadens, F., Arksey, H., Morée, M., Moran, N., and Nies, H. (2009). Care Provision within Families and its Socio-economic Impact on Care Providers. York: Social Policy Research Unit, University of York.
- Haberkern, K., Schmid, T., and Szydlik, M. (2015). Gender differences in intergenerational care in European welfare states. *Ageing and Society*, 35(2), 298–320.
- Hanson, E., and Magnusson, L. (2016). Piloting Information and Communication Technology based services to reach out and support working carers. Eurocarers Workshop, 3–4 March. Brussels: Eurocarers.
- Harding, R., and Higginson, I. J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17(1), 63–74.
- Harding, R., List, S., Epiphaniou, E., and Jones, H. (2011). How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 26(1), 7–22.
- Hassink, W. H. J., and Van den Berg, B. (2011). Time-bound opportunity costs of informal care: Consequences for access to professional care, caregiver support, and labour supply estimates. *Social Science and Medicine*, 73(10), 1508–1516.
- Havighurst, R. J., and Albrecht, R. E. (1980). *Older People*. New York: Longmans, Green and Co. Retrieved from <https://books.google.com/books?id=3TvuncFKULYC&pgis=1>

- Heger, D. (2014). *Work and Well-Being of Informal Caregivers in Europe*. Germany: Leibniz Institute for Economic Research.
- Hegewisch, A., and Gornick, J. C. (2011). The impact of work-family policies on women's employment: a review of research from OECD countries. *Community, Work and Family*, 14(2), 119–138.
- Heitmueller, A., and Inglis, K. (2007). The earnings of informal care: Wage differentials and opportunity costs. *Journal of Health Economics*, 26(4), 821–841.
- Heitmueller, A. (2007). The chicken or the egg? Endogeneity in labour market participation of informal carers in England. *Journal of Health Economics*, 26(3), 536–559.
- HM Government (2014). *Care Act 2014 Explanatory Notes (Report)*. London: The Stationery Office. Retrieved from www.legislation.gov.uk/ukpga/2014/23/notes/contents
- HM Government. (2014). *Care Act 2014 (c.23) [Web Page]*. Retrieved from www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm
- HM Government (2015) *Supporting Carers to Stay in Paid Employment*. London: The Stationery Office. Retrieved from www.gov.uk/government/news/supporting-carers-to-stay-in-paid-employment
- Heslin, M., Forster, A., Healey, A., and Patel, A. (2016). A systematic review of the economic evidence for interventions for family carers of stroke patients. *Clinical Rehabilitation*, 30(2), 119–133.
- Himmleweit, S., and Land, H. (2011). *Reducing Gender Inequalities to Create a Sustainable Care System*. York: Joseph Rowntree Foundation.
- Hirsch, D., Phung, V., and Manful, E. (2011). *Poverty, Ethnicity and Caring*. York: Joseph Rowntree Foundation. Retrieved from www.jrf.org.uk/sites/files/jrf/poverty-ethnicity-caring-full.pdf
- Hirst, M. (2005). Carer distress: A prospective, population-based study. *Social Science and Medicine*, 61(3), 697–708.
- Hoff, A. (2015). *Current and future challenges of family care in the UK Future of an ageing population: evidence review family care in the UK. Future of an Ageing Population: Evidence Review*. London: Government Office for Science. Retrieved from www.gov.uk/government/publications/future-of-ageing-volunteering-informal-care-and-paid-work-in-later-life
- Hoffmann, F., and Rodrigues, R. (2010). *Informal Carers: Who Takes Care of Them?* Vienna: European Centre for Social Welfare Policy and Research.
- Holthe, T. (2004). *Enabling Technologies for People with Dementia: National Report on Results from Norway*. Tonsberg: The Norwegian Centre for Dementia Research. Available at: www.enableproject.org/download/Enable%20-%20National%20Report%20-%20Norway.pdf.
- Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. *The Gerontologist*, 25(6), 612–617.
- HSISC, (2010). *Survey of Carers in Households 2009/10*. London: The Health and Social Care Information Centre.

- Hudson, P. L., Remedios, C., and Thomas, K. (2010). A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliative Care*, 9, 17.
- Hurley, R.V.C, Patterson, T.G., and Cooley S.J. (2014). Meditation-based interventions for family caregivers of people with dementia: a review of the empirical literature. *Aging and Mental Health*, 18(3), 281–288.
- Hutton, S. (1999). *The Employment of Those Undertaking Informal Care: A Longitudinal Analysis*. Brussels: Social Policy Research Institute.
- Jarrold, K., and Yeandle. S. (2009) *A Weight Off My Mind: Exploring the Impact and Potential Benefits of Telecare for Unpaid Carers in Scotland*. Carers UK. Glasgow: Scottish Joint Improvement Team.
- Jensen, M., Agbata, I.N., Canavan, M., and McCarthy, G. Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: systematic review and meta-analysis of randomised controlled trials. *International Journal of Geriatric Psychiatry*, 30, 130–143.
- Johansson, L. (2016). *ESPN Thematic Report on Work-life Balance Measures for Persons of Working Age with Dependent Relatives: Sweden*. Brussels: European Commission.
- Johnson, C. L., and Catalano, D. J. (1983). A longitudinal study of family supports to impaired elderly. *The Gerontologist*, 23(6), 612–618.
- Johnson, R. and Lo Sasso, A. (2006). The impact of elder care on women's labor supply. *Inquiry*, 43, 195–210.
- Kalra, L., Evans, A., Perez, I., Melbourn, A., Patel, A., Knapp, M., and Donaldson, N. (2004). Training carers of stroke patients: randomised controlled trial. *British Medical Journal*, 328(7448), 1099.
- King, D., and Pickard, L. (2013). When is a carer's employment at risk? Longitudinal analysis of unpaid care and employment in midlife in England. *Health and Social Care in the Community*, 21(3), 303–314.
- Kinney J.M., Kart C.S., Murdoch L.D. and Conley C.J. (2004) Striving to provide safety assistance for families of elders: the SAFE House project. *Dementia: The International Journal of Social Research and Practice*, 3, 351–370.
- Knapp, M., Barlow, J., Comas-Herrera, A., Damant, J., Freddolino, P., Hamblin, K., Hu, B., Lorenz, K., Perkins, M.A., Rehill, A., Wittenberg, R., and Woolham, J. (2016). *The Case for Investment in Technology to Manage the Global Costs of Dementia*. London: Personal Social Services Research Unit.
- Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., Cooper, C., and Livingston, G. (2013) Cost effectiveness of a manual based coping strategy programme in promoting mental health of family carers of people with dementia (the START (STrategies for RelaTives) study): a pragmatic randomized controlled trial. *British Medical Journal*, 347, f6342.
- Kosloski, K., and Montgomery, R. J. V. (1994). Investigating patterns of service use by families providing care for dependent elders. *Journal of Aging and Health*, 6, 17–37.

- Kotsadam, A. (2011). Does informal eldercare impede women's employment? The case of European welfare states. *Feminist Economics*, 17(2), 121–144.
- Kvist, J. (2016). *ESPN Thematic Report on Work-life Balance Measures for Persons of Working Age with Dependent Relatives: Denmark*. Brussels: European Commission.
- Lamura, G., Mnich, E., Nolan, M., Wojszel, B., Krevers, B., Mestheneos, L., Dohner, H., and EUROFAMCARE Group. (2008). Family carers' experiences using support services in Europe: empirical evidence from the EUROFAMCARE Study. *The Gerontologist*, 48(6), 752–771.
- Lee, J., Soeken, K., and Picot, S.J. (2007). A meta-analysis of interventions for informal stroke caregivers. *Western Journal of Nursing Research*, 29,(3), 344–356.
- Lee, Y. and Tang, F. (2015). More caregiving, less working: Caregiving roles and gender difference. *Journal of Applied Gerontology*, 34(4), 465–483.
- Legg, L., Weir, C. J., Langhorne, P., Smith, L. N., and Stott, D. J. (2013). Is informal care giving independently associated with poor health? A population-based study. *Journal of Epidemiology and Community Health*, 67(1), 95–97.
- Leigh, A. (2010). Informal care and labor market participation. *Labour Economics*, 17(1), 140–149.
- Lewis, V., Bauer, M., Winbolt, M., Chenco, C., and Hanley, F. (2015). A study of the effectiveness of MP3 players to support family carers of people living with dementia at home. *International Psychogeriatrics*, 27, 471–479.
- Lilly, M. B., Laporte, A., and Coyte, P. C. (2010). Do they care too much to work? The influence of caregiving intensity on the labour force participation of unpaid caregivers in Canada. *Journal of Health Economics*, 29(6), 895–903.
- Lilly, M., Laporte, A. and Coyte, P. C. (2007). Labor market work and home care's unpaid caregivers: A systematic review of labor force participation rates, predictors of labor market withdrawal, and hours of work. *Milbank Quarterly*, 95(4), 641–690.
- Lins, S., Hayder-Beichel, D., Rücker, G., Motschall, E., Antes, G., Meyer, G., and Langer, G. (2014). Efficacy and experiences of telephone counselling for informal carers of people with dementia. *Cochrane Databases Systematic Reviews*, 1(9).
- Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E.L., and Cooper, C. (2013). Clinical effectiveness of a manual based coping strategy programme (START, STRategies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomized controlled trial. *British Medical Journal*, 347, f6276.
- Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Romeo, R., Livingston, D., Mummery, C., Walker, Z., Hoe, J. and Cooper, C. (2014) Long-term clinical and costeffectiveness of START (STRategies for RelaTives) psychological intervention for family carers and the effects on cost of care for people with dementia: a randomised controlled trial. *Lancet Psychiatry*, 1(7), 537–548.
- Lloyd, B. T., and Stirling, C. (2011). Ambiguous gain: uncertain benefits of service use for dementia carers. *Sociology of Health and Illness*, 33(6), 899–913.
- Lundsgaard, J. (2005). *Consumer Direction and Choice in Long-Term Care for Older Persons*. Paris: OECD Health Working Papers.

- Maayan, N., Soares-Weiser, K., and Lee, H. (2014) Respite Care for People with Dementia and their Carers. *Cochrane Databases Systematic Reviews*, 16(1).
- Mahoney, D.M., Mutschler, P.H., Tarlow, B., and Liss, E. (2008) Real world implementation lessons and outcomes from the Worker Interactive Networking (WIN) project: workplace- based online caregiver support and remote monitoring of elders at home. *Telemedicine Journal and E-Health*, 14(3), 224–234.
- Marziali, E., and Garcia, L. J. (2011). Dementia caregivers' responses to two internet-based intervention programs. *American Journal of Alzheimer's Disease and Other Dementias*, 26, 36–43.
- Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., Drummond, M., and Glendinning, C. (2007), A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers, *Health Technology Assessment*, 11(15), 1–157.
- Mazanec, S. R., Daly, B. J., Douglas, S. L., and Lipson, A. R. (2011). Work productivity and health of informal caregivers of persons with advanced cancer. *Research in Nursing and Health*, 34(6), 483–95.
- Mckechnie, V., Barker, C., and Stott, J. (2014). Effectiveness of computer-mediated interventions for informal carers of people with dementia—a systematic review. *International Psychogeriatrics*, 26(10), 1619–1637.
- Meng, A. (2012). Informal home care and labor force participation of household members. *Empirical Economics*, 44(2), 959–979.
- Mentzakis, E., McNamee, P., and Ryan, M. (2009). Who cares and how much: Exploring the determinants of co-residential informal care. *Review of Economics of the Household*, 7(3), 283–303.
- Michaud, P. C., Heitmueller, A., and Nazarov, Z. (2010). A dynamic analysis of informal care and employment in England. *Labour Economics*, 17(3), 455–465.
- Milne, A., Brigden, C., Palmer, A., and Konta, E. (2014). The intersection of employment and care: evidence from a UK case study. *European Journal of Social Work*, 16(5), 651–670.
- MODEM toolkit <https://toolkit.modem-dementia.org.uk>
- Mooney, A., and Statham, J. (2002). *The Pivot Generation: Informal Care and Work after Fifty*. Generic, Bristol: The Policy Press.
- Nai-Ching, C., Demiris, G., Lewis, F. M., Walker, A. J., and Langer, S. L. (2015). Behavioral and educational interventions to support family caregivers in end-of-life care: A systematic review. *American Journal of Hospice and Palliative Medicine*, 33(9), 894-908.
- Nazroo, J. (2015) *Volunteering, Providing Informal Care and Paid Employment in Later Life: Role Occupancy and Implications for Well-being*. London: Government Office for Science.
- Nguyen, H. T., and Connelly, L. B. (2014). The effect of unpaid caregiving intensity on labour force participation: results from a multinomial endogenous treatment model. *Social, Science and Medicine*, 100, 115–122.

- Northouse, L. L., Katapodi, M., Song, L., Zhang, L., and Mood, D. W. (2010). Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA: A Cancer Journal for Clinicians*, 60(5), 317–339.
- Novi, C. Di, Jacobs, R., Migheli, M., and York, C. (2013). *The Quality of Life of Female Informal Caregivers: From Scandinavia to the Mediterranean Sea (Report)*. York: Centre for Health Economics University of York.
- Oliver, M., and Barnes, C. (2012). *The New Politics of Disablement*. Basingstoke: Palgrave Macmillan.
- Parker, G., Arksey, H., and Harden, M. (2010). *Meta-review of International Evidence on Interventions to Support Carers*. York: Social Policy Research Unit. Retrieved from www.york.ac.uk/inst/spru/research/pdf/CarersLit.pdf
- Pavalko, E. K. and Henderson, K. A. (2006). Combining care work and paid work: Do workplace policies make a difference? *Research on Aging*, 28(3), 359–374.
- Phillips, J., Bernard, M., and Chittenden, M. (2002). *Juggling Work and Care. The Experiences of Working Carers of Older Adults*. Bristol: Policy Press.
- Pickard, L. (2004). *The Effectiveness and Cost-effectiveness of Support and Services to Informal Carers of Older People. A Review of the Literature*. London: Audit Commission.
- Pickard, L., and Perkins, M. (2011). *Scoping study literature review*. Unpublished paper.
- Pickard, L., Brimblecombe, N., King, D., and Knapp, M. (2013). *Can we Save the Government 1.3 billion a Year by Supporting Unpaid Carers in Employment?* London: NIHR SSCR.
- Pickard, L., King, D., Brimblecombe, N., and Knapp, M. (2015). The effectiveness of paid services in supporting unpaid carers' employment in England. *Journal of Social Policy*, 44(3), 567–590.
- Pinquart M., and Sorensen S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging*, 18, 250–267.
- Pinquart, M. and Sörensén, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 61(1), 33–45.
- Pinquart, M. and Sörensén, S. (2007). Correlates of physical health of informal caregivers: A metaanalysis. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 62(2), 126–137.
- Pleace, N. (2011). *The Costs and Benefits of Preventative Support Services for Older People*. York: University of York.
- Pusey, H., and Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging and Mental Health*, 5(2), 107–119.
- Regan, TW., Lambert, SD., Girgis, A., Kelly, B., Kayser, K., and Turner, J. (2012). Do couple-based interventions make a difference for couples affected by cancer? A systematic review. *BMC Cancer*, 12, 279.

- Riedel, M., and Kraus, M. (2011). Informal Care Provision in Europe: Regulation and Profile of Providers. ENEPRI research report n.96. Brussels: European Network of Economic Policy Research Institutes. Retrieved from [www.ancien-longtermcare.eu/sites/default/files/RR No 96 _ANCIEN_ Regulation and Profile of Providers of Informal Care.pdf](http://www.ancien-longtermcare.eu/sites/default/files/RR%20No%2096_ANCIEN_Regulation%20and%20Profile%20of%20Providers%20of%20Informal%20Care.pdf)
- Rodrigues, R., Schulmann, K., Schmidt, A., and Kalavrezou, N. (2013). The Indirect Costs of Long-term Care. Brussels: European Commission.
- Schaffer, S. K. (2015). The effect of free personal care for the elderly on informal caregiving. *Health Economics*, 24(S1), 104–117.
- Scharlach, A. E., Gustavson, K., and Dal Santo, T. S. (2007). Assistance received by employed caregivers and their care recipients: who helps care recipients when caregivers work full time? *The Gerontologist*, 47(6), 752–762.
- Scheil-Adlung, X. (2015). Long-term Care Protection for Older Persons: A Review of Coverage Deficits in 46 Countries. Geneva: International Labour Organization.
- Schmidt, A., Chiatti, C., Fry, G., Hanson, E., Magnusson, L., Stückler, A., Szeman, Z., Barbabella, F., Hoffmann, F., and Lamura, G. (2011). Analysis and Mapping of 52 ICT-based Initiatives for Caregivers. Vienna: European Centre for Social Welfare Policy and Research.
- Schneider, H., Heinze, J. and Hering, D. (2011) Betriebliche Folgekosten Mangelnder Vereinbarkeit von Beruf und Pflege [Company-based Follow-up Costs of Lacking Reconciliation of Employment and Eldercare]. Berlin: Steinbeis University. Available at: www.carersatwork.tu-dortmund.de/download/Expertise_final.pdf
- Schoenmakers, B., Buntinx, F., and DeLepeleire, J. (2010) Supporting the dementia family caregiver: the effect of home care intervention on general well-being. *Aging and Mental Health*, 14, 44–56.
- Schulz, R., and Beach, S. (1999). Caregiving as a risk factor for mortality. *Journal of the American Medical Association*, 282(23), 2215–2219.
- Schulz, R., O'Brien, A. T., Bookwala, J., and Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist*, 35(6), 771–791.
- Skira, M. M. (2015). Dynamic wage and employment effects of elder parent care, *International Economic Review*, 56(1), 63–93.
- Social Protection Committee. (2014). Adequate social protection for long-term care needs in an ageing society. Report jointly prepared by the Social Protection Committee and the European Commission services. Brussels: Council of the European Union. Retrieved from <http://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=7724>
- Sommerlad, A., Manela, M., Cooper, C., Rapaport, P., and Livingston, G. (2014). START (STRAtegies for RelaTives) coping strategy for family carers of adults with dementia: qualitative study of participants' views about the intervention. *BMJ Open*, 4, e005273.
- Spieß, C. K., and Schneider, U. (2003). Interactions between care-giving and paid work hours among European midlife women, 1994 to 1996. *Ageing and Society*, 23(1), 41–68.
- Stacey, R., and Malley, J. (2014). Carers' quality of life and experiences of adult social care support in England. *Health and Social Care in the Community*, 22, 375–385.

- Stansfeld, S., Smuk, M., Onwumere, J., Clark, C., Pike, C., Mcmanus, S., Harris, J., and Bebbington, P. (2014). Stressors and common mental disorder in informal carers – an analysis of the English Adult Psychiatric Morbidity Survey 2007. *Social Science and Medicine*, 120, 190–198.
- Stokes, P. (2013). *The Gender Gap in Unpaid Care Provision: Is There an Impact on Health and Economic Position?* London: Office for National Statistics. Retrieved from www.ons.gov.uk/people/populationandcommunity/healthandsocialcare/healthandwellbeing/articles/fullstorythegendergapinunpaidcareprovisionisthereanimpactonhealthandeconomicposition/2013-05-16
- Stoltzfus, J. C. (2011). Logistic regression: a brief primer. *Academic Emergency Medicine*, 18(10), 1099–1104.
- Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopex, M., Woods, R. T., and Orrell, M. (2003). Whose quality of life is it anyway? The validity and reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) scale. *Alzheimer Disease and Associated Disorders*, 17(4), 201–208.
- Ugreninov, E. (2013). Offspring in squeeze: Health and sick leave absence among middle-aged informal caregivers. *Journal of Population Ageing*, 6(4), 323–338.
- Van Houtven, C. H., Coe, N. B., and Skira, M. M. (2013). The effect of informal care on work and wages. *Journal of Health Economics*, 32(1), 240–252.
- Van Houtven, C.H., Smith, V., Stechuchak, K., Shepherd-Banigan, M., Hastings, S.N., Maciejewski, M., Wieland, G., Olsen, M., Miller, K.E.M., Kabat, M., Henius, J., Campbell-Kotler, M., and Oddone, E.Z. (2017). Comprehensive support for family caregivers of post-9/11 veterans: impact on veteran health care utilization and costs. *Medical Care Research and Review*, published online.
- Vernooij-Dassen, M., Draskovic, I., McCleery, J., and Downs, M. (2011). Cognitive reframing for carers of people with dementia. *Cochrane Databases Systematic Reviews*, 9(11).
- Vickerstaff, S., Loretto, W., Milne, A., Alden, E., Billings, J., and White, P. (2009). *Employment Support for Carers*. London: Department for Work and Pensions.
- Victor, E. (2009). *A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence*. Essex: The Princess Royal Trust for Carers. Retrieved from <http://static.carers.org/files/systematic-review-15-jan-3840.pdf>
- Viitanen, T. (2010). Informal eldercare across Europe: Estimates from the European Community Household Panel. *Economic Analysis and Policy*, 40(2), 149–178.
- Viitanen, T. (2007) *Informal and Formal Care in Europe Discussion Paper No. 2648*. Sheffield: University of Sheffield and IZA.
- Vitaliano, P. P., Zhang, J. and Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129(6), 946–972.
- Vlachantoni, A., Evandrou, M., Falkingham, J., and Robards, J. (2013). Informal care, health and mortality. *Maturitas*, 74(2), 114–118.
- Waldron, E.A., Janke, E.A., Bechtel, C.F., Ramirez, M., and Cohen, A. (2013.) A systematic review of psychosocial interventions to improve cancer caregiver quality of life. *Psychooncology*, 22, 1200–1207.
- WHO. (2015.) *World Report on Ageing and Health*. Geneva: WHO.

- Wittenberg, R., and Hu, B. (2015). Projections of Demand for and Costs of Social Care for Older People and Younger Adults in England, 2015 to 2035. London: Personal Social Services Research Unit.
- Woolham, J. (2005). The Safe at Home Project: Using Technology to Help People with Dementia Remain Living in their Own Homes in Northampton. London: Hawker.
- World Bank. (2017). Labor Market Regulation. Available at: www.doingbusiness.org/data/exploretopics/labor-market-regulation#rigidityHours
- Yeandle, S. (2014). Frail Older People and their Networks of Support: How does Telecare Fit In? Leeds: Centre for International Research on Care, Labour and Equalities.
- Yeandle, S., Bennett, C., Buckner, L., Fry, G., and Price, C. (2007). Managing Caring and Employment. Leeds: University of Leeds. Retrieved from [www.northerntrust.hscni.net/pdf/Managing_Caring_and_Employment\(1\).pdf](http://www.northerntrust.hscni.net/pdf/Managing_Caring_and_Employment(1).pdf)
- Yeandle, S., Bennett, C., Buckner, L., Shipton, L., and Suokas, A. (2006). Who cares wins: The social and business benefits of supporting working carers. Sheffield: Centre for Social Inclusion, Sheffield Hallam University.
- Yeandle, S., and Buckner, L. (2007). Carers, Employment and Services: Time for a New Social Contract? London: Carers UK.
- Yeandle, S., and Wigfield, A. (2011). Training and Supporting Carers: The National Evaluation of the Caring with Confidence Programme. Leeds: University of Leeds
- Yeandle, S., and Wigfield, A. (2011). New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites Programme. Leeds: Centre for International Research on Care, Labour and Equalities. Retrieved from www.sociology.leeds.ac.uk/circle/circle-projects/national-carers-strategy-demonstrator-sites.php
- Young, H., and Grundy, E. (2008). Longitudinal perspectives on caregiving, employment history and marital status in midlife in England and Wales. *Health and Social Care in the Community*, 16(4), 388–399.