

This is a repository copy of *Financial advice for funding later life care: A scoping review of evidence from England*.

White Rose Research Online URL for this paper:
<https://eprints.whiterose.ac.uk/138007/>

Version: Published Version

Article:

Heavey, Emily Elizabeth Louise orcid.org/0000-0003-0920-7705, Baxter, Catherine Rachel orcid.org/0000-0002-3094-9546 and Birks, Yvonne Frances orcid.org/0000-0002-4235-5307 (2019) *Financial advice for funding later life care: A scoping review of evidence from England*. *Journal of Long-Term Care*. pp. 51-65.

10.21953/lse.1ey61d7r28cg

Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND) licence. This licence only allows you to download this work and share it with others as long as you credit the authors, but you can't change the article in any way or use it commercially. More information and the full terms of the licence here: <https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



JOURNAL OF
LONG-TERM CARE



INTERNATIONAL
LONG TERM CARE
POLICY NETWORK



© University of Huddersfield and University of York, 2019

Open access through CC BY-NC-ND licence

DOI: 10.21953/lse.1ey61d7r28cg

Article received 15 January 2018, accepted 27 October 2018 and published 21 February 2019

Suggested citation:

Heavey, E., Baxter, K., & Birks, Y. (2019). Financial advice for funding later life care: A scoping review of evidence from England. *Journal of Long-Term Care*, February, 51–65. doi:10.21953/lse.1ey61d7r28cg

The **Journal of Long-Term Care** is an international, multi- and interdisciplinary, peer-reviewed, online journal established as a focus for advancing the research evidence base for all aspects of long-term care for adults. It is managed by the International Long-Term Care Policy Network at the London School of Economics and Political Science and has received funding from the National Institute for Health Research School for Social Care Research.

The Journal's range includes empirical papers and theoretical discussions relevant to policy and practice, and methodological papers about improving methods in social care research.

The editorial board welcomes submissions of high quality, original articles that fit with the Journal's remit. We will consider articles that are also relevant to the care of children and younger people where there is clear relevance for adult care (e.g. concerning issues of families or transitions into adult care). There is no fee for submitting or publishing articles, which will be made available with open access on the journal's website to encourage maximum impact for all work.

Correspondence and enquiries should be addressed to the managing editor at: Journal.of.Long-Term.Care@lse.ac.uk. Further information is available on the journal website, <https://www.ilpnetwork.org/journal/>

Executive Editor: Dr Jose-Luis Fernandez, London School of Economics and Political Science

Managing Editor: Dr Michael Clark, London School of Economics and Political Science

Assistant Editor: Dr Juliette Malley, London School of Economics and Political Science

Editorial Officer: Nick Brawn

Editorial Board

Professor David Abbott, University of Bristol

Professor Jennifer Beecham, University of Kent

Dr Blanche Le Bihan, École des hautes études en santé publique

Professor Yvonne Birks, University of York

Professor John Campbell, University of Michigan

Professor David Challis, University of Manchester

Dr Barbara Da Roit, Universiteit van Amsterdam & Università Ca' Foscari Venezia

Professor Julien Forder, University of Kent

Professor Courtney Van Houtven, Duke University

Professor Naoki Ikegami, Keio University in Tokyo

Dr Lennarth Johansson, Karolinska Institutet

Professor Martin Knapp, London School of Economics and Political Science

Dr Giovanni Lamura, Istituto Nazionale di Riposo e Cura per Anziani

Professor Jill Manthorpe, King's College London

Anji Mehta, London School of Economics and Political Science

Professor Marthe Nyssens, Université catholique de Louvain

Professor Heinz Rothgang, University of Bremen

Professor Ulrike Schneider, Vienna University of Economics and Business Administration

Professor Gerdt Sundström, Jönköping University

Professor Gerald Wistow, London School of Economics and Political Science

Raphael Wittenberg, London School of Economics and Political Science

Financial advice for funding later life care: A scoping review of evidence from England

Emily Heavey, Kate Baxter and Yvonne Birks

Abstract

Context: Ageing populations across the world make the provision of long-term care a global challenge. A growing number of people in England are faced with paying for later life social care costs, but do little to plan for these costs in advance. Recent legislation in the form of the Care Act 2014 gave local authorities new responsibilities to provide information on how people can access independent financial advice on matters relating to care needs.

Objectives: This scoping review aimed to identify existing evidence about people's engagement with financial advice in relation to paying for later life care in England.

Methods: Electronic and manual searching identified seventeen papers reporting empirical evidence on the topic, published between 2002 and 2017.

Findings: We found evidence of low numbers accessing regulated financial advice. Barriers included limited consumer awareness, preferences for other sources of advice such as friends and family, and poor signposting and referrals by local authorities. Most papers indicated that financial advice would be useful in helping people to plan for care costs. Robust research evidence on this topic is limited, with

particular gaps in evidence about stakeholders' experiences of the barriers to, and usefulness of, financial advice about paying for long-term care in later life.

Limitations: The paper does not include a formal quality assessment of the included research papers. Our interpretation of study findings was hindered by lack of methodological transparency in some papers and lack of studies focusing specifically on the topic of financial planning for long-term care.

Implications: An improved evidence base could assist financial advisers specialising in this area and local authorities that are now obliged to signpost people to such advice. With better evidence they would be better placed to explain to members of the public the financial and non-financial implications of obtaining financial advice about care costs. It might also enable those organisations to overcome barriers and facilitate access to appropriate advice.

Keywords: self-funders, financial advice, later life care, paying for care, older people, scoping review, Care Act 2014

Acknowledgements and disclaimers

This paper reports on independent research funded by the NIHR School for Social Care Research. It forms part of the project 'Independent financial advice about funding social care in later life – a project exploring evidence and practice'. The views expressed in this presentation are those of the authors and not necessarily those of the NIHR SSCR, the National Institute for Health Research or the Department of Health and Social Care.

E. Heavey¹ (✉), K. Baxter², Y. Birks²

¹ Department of Behavioural and Social Sciences, University of Huddersfield

² Social Policy Research Unit, University of York

Dr Emily Heavey, Lecturer, School of Human and Health Sciences, University of Huddersfield, Queensgate, Huddersfield, HD1 3DH, UK. Email: e.e.heavey@hud.ac.uk

Introduction

An ageing population, rising care costs, and an ‘intergenerational savings gap’ represent global challenges to ensuring the provision of later life social care (Franklin & Hochlaf, 2017; Robertson et al., 2014). In the last 50 years, countries including France, Germany, Japan, Korea and the Netherlands have introduced statutory long-term care insurance (LTCI), while Australia, Ireland, the United Kingdom (UK) and the United States (US) offer differing levels of needs- and means-tested government support. A private insurance market also exists in some countries.

The context for long-term, or social, care in England is unusual. The provision of healthcare free at the point of use for everyone is relatively generous when compared with some other countries. Yet state pensions are less generous than many other countries (Franklin & Hochlaf, 2017) and social care is ‘heavily means-tested’ (Robertson et al., 2014, p. 11), with assessments of individuals’ finances taking into account savings, assets, and income. The exception is the individual’s home, which is excluded from the assessment if the individual remains living there (i.e. receives domiciliary/home care) or if their partner or certain other family members remain living there when the individual enters residential care. Social care support is also needs-tested. Thus, only those whose social care needs are assessed as being *above* a defined threshold and whose financial means are *below* a certain threshold qualify for state support. Those not entitled to state support, known as ‘self-funders’, must meet the costs of their care needs themselves. As the population ages and with central government financial austerity limiting the resources of local authorities (who are responsible for organising local care systems within national frameworks of policy and legislation), the number of self-funders in England looks set to rise (ADASS, 2018; Baxter & Glendinning, 2014; Humphries, 2013; Humphries et al., 2016).

The Care Act 2014 introduced new responsibilities for local authorities in England to provide information and advice to enable people to plan for and access appropriate care. These responsibilities extend to self-funders, a group who can struggle to navigate the services and find the information needed to get appropriate care, and who particularly struggle to engage effectively with local authorities (Baxter et al., 2017; Henwood, 2014; Henwood & Hudson, 2008; Wright, 2003). The Care Act specifically recognises the need for ‘independent financial advice on matters relevant to the meeting of needs for care and support’ (Care Act, 2014, section 4). Since April 2015, local authorities have been required to provide information on how people can access such advice.

Planning for future care costs

Planning for one’s future care costs appears to be a low priority internationally. In their survey of individuals in the UK, US, France, Singapore, and Hong Kong, Franklin and Hochlaf (2017) found variation in how many saved and how much they saved. However, in all countries, saving for retirement in general and care costs specifically were low priorities. The Health Survey for England is an annual national survey examining the health and lifestyles of adults in England aged 30+. The most recent survey to report on the issue of financial planning found that around 50% of participants had not thought about how they would pay for care (Sal, 2015). Older people (75+) were most likely to report having taken no action to plan for future care costs. Another recent survey found that 23% of over-45s in England had considered care options and discussed the implications (including financial implications) with family, but only 6% had financial plans in place to meet care costs (Partnership, 2016).

There are barriers to this financial planning that relate to deeply held anxieties about money, ageing, and care. Studies from across the UK have found that people fear the spiralling expenses of care costs and being unable to pay for care – or running out of money while paying for it – even *with* careful planning (Blood et al., 2015; Ward et al, 2012; Wright, 2002). Such anxieties may translate into a reluctance to save or otherwise plan for this eventuality (Croucher & Rhodes, 2006), or ‘paralyse’ people into inaction (Price et al., 2014). This is by no means unique to the UK; the wide literature on loss aversion demonstrates that such inaction is a common reaction to the fear of losing something the individual values (Kahneman and Tversky, 1984; Kahneman et al., 1991). Moreover, anxiety about *care itself* can deter people from planning for its costs. Qualitative research carried out by Price and colleagues (2014) found that older couples in England were comfortable planning for retirement and funeral costs, but the fear of living in a state of dependency deterred them from thinking about care. Money spent on care was seen as money wasted, as people expressed a preference for death over a life with care. Similar aversion to receiving paid care has been found in US contexts (Girling & Morgan, 2014; Peters & Pinkston, 2002), including a particular aversion to imagining an ageing, dependent self that is at odds with the American ideal (DaDalt et al., 2016; San Antonio & Rubinstein, 2004). Such aversions also speak to the broader concept of ‘discounting the future’ in favour of the present, particularly when that future is neither desirable nor certain (Broome, 2004; Lawless et al., 2013). Indeed, in this sense, choosing not to plan for care costs can be a calculated risk: ‘[d]eath is inevitable, but going into residential care is not’ (Price et al., 2014, p. 407).

The unique context of the English care system raises specific barriers to planning. Relatively generous health-care spending may prompt the assumption that social care spending by the state will be equally generous (Robertson et

al., 2014). The public's struggle to understand and accept the financial implications of the social care funding system was illustrated by reactions to a Conservative Party manifesto pledge in the 2017 general election campaign. The pledge to include people's properties in their financial assessments for domiciliary care was widely denounced as a 'dementia tax', and eventually withdrawn (Asthana & Elgot, 2017; Dispatches, 2017; Walters, 2017). Widespread lack of understanding of social care funding is not new. Twenty years ago, Parker and Clarke (1997, 1998) found little planning for care costs, with adults in a wide age range mistakenly believing their care would be paid for by the state, and feeling let down on learning this was not necessarily the case. Another study suggested an expectation among people aged 50+ that the government should pay for care, and limited knowledge of respondents' own responsibilities (Deeming & Keen, 2002). More recently, the National Audit Office (2011) found that 69% of self-funders felt ill-informed about the financial implications of long-term care, while Ipsos Mori (2011, p. 10) reported 'a perception gap between expectations and reality' about care funding and reluctance among the public to take responsibility for financial planning for future care.

Today, care costs can still come as a shock (Baxter, et al., 2017; Tanner et al., 2017), and the fairness of a welfare policy based on personal financial assets remains controversial (Overton & Fox O'Mahoney, 2017). Recent studies do suggest some increase in awareness of the care funding system, perhaps due to increased media attention since the Care Act (Partnership, 2016). The Health Survey for England found that around half of adults understood that state contribution to social care costs was means-tested (Sal, 2015). However, as that survey also demonstrated, this awareness does not guarantee behaviour change in relation to planning for care. Indeed, acute awareness of the fluctuating political climate and uncertainty about future care funding legislation also deter planning for future care costs (Partnership, 2016).

The role of the financial sector

There are a number of financial products that may be used to pay for later life care costs (Chartered Insurance Institute, 2011). **Equity release** involves borrowing against the value of one's home, with the money repaid through the sale of the home when the homeowner moves or dies. Because the loan must be repaid upon moving home, including moving into a care home, this type of product can be used to pay for domiciliary care but not residential care.

Immediate needs annuities are a type of insurance purchased when care is needed; in return for an upfront lump sum, calculated according to the buyer's age and health-related factors, the purchaser receives a fixed annual payment towards care costs until death. **Pre-funded long-term care insurance (LTCI)** involves the buyer paying premiums before care is needed. The availability of and markets for

such products vary between countries. For example, in addition to the mandatory LTCI scheme, France has a relatively large private LTCI market, with government incentives for participating, while in the US private LTCI has a low take-up (Robertson et al., 2014).

In the UK, financial products to pay for care have struggled to find a foothold. LTCI is no longer available to purchase, the UK market having collapsed for reasons including a lack of consumer demand and insurers' uncertainty around issues like consumer longevity and the availability of informal care (Chartered Insurance Institute, 2011; Lloyd, 2011a). Immediate needs annuities are available, but poorly understood by the general public (Partnership, 2016), and only an estimated 7% of self-funders entering a care home obtain terms for such products (Just, 2017a). Low engagement with such products among UK consumers has been attributed to low awareness; cost and complexity; uncertainty over their usefulness and cost-effectiveness; and distrust of the financial services sector (Baxter & Glendinning, 2014; Chartered Insurance Institute, 2011; Lloyd, 2011a; 2011b; Lunt & Blundell, 2000; Parker & Clarke, 1997, 1998; Resolution Foundation, 2008; Terry & Gibson, 2012).

Regulated financial advice is a prerequisite for buying certain financial products in the UK; reluctance to get such advice has been identified as a further possible barrier to accessing products to pay for care (Lloyd, 2011a, 2011b). Yet there is strong support for the role of financial advice in helping people to understand, plan for, and meet the costs of later life care (e.g. APPLG, 2012; Burstow, 2013; Chartered Insurance Institute, 2011; Featherstone & Whitham, 2010; Hudson & Henwood, 2009; Partnership, 2016). The Care Act implies an increased role for the financial sector, stating that local authorities in England are obliged to enable access to independent financial advice. Since the Care Act was passed there has been a 25% increase in membership of the Society of Later Life Advisers (SOLLA), a body that offers accreditation to financial advisers specialising in the needs of older people (Partnership, 2016). Recently published guidance on the Act emphasises the importance of financial advice as 'fundamental to enabling people to make well-informed choices about how they pay for their care' and offers further information on local authorities' obligations (Care Act guidance, 2018, section 3).

It is important to note here the different interpretations of the term 'independent financial advice'. Within the UK financial sector, independent financial advisers (IFAs) are advisers who are regulated by the Financial Conduct Authority (FCA) and have access to the whole market; that is, they are not restricted to offering advice about particular products or companies. The Care Act does not specify that local authorities must enable access to IFAs; in the context of the Act, 'independent financial advice' is defined as advice provided by a person who is independent of the local authority (Care Act, 2014, part 1, section 4; Care Act

guidance, 2018, section 3). This could include advice offered by a restricted or independent regulated financial adviser, or by voluntary organisations and other bodies not regulated by the FCA. Literature from outside the financial sector often uses the terms 'regulated financial adviser', 'independent financial adviser' and 'financial adviser' interchangeably; in reporting the results of this review, we use the terms as they were used in the studies reviewed.

Methods

The aim of this scoping review was to establish what is currently known about engagement with financial advice in the context of paying for later life care in England.

We undertook electronic searches for published research and grey literature in the following databases: Applied Social Science Index & Abstracts (ASSIA); Health Management Information Centre (HMIC); Scopus; Social Care Online; Social Policy & Practice; Social Sciences Citation Index; Social Services Abstracts. These were supplemented with manual searches. As our aim was to identify the range and scope of available evidence, we did not formally assess quality. We searched for evidence around the provision of financial advice for funding later life care from the perspective of members of the public and professional stakeholders, and for evidence on advice received at any life stage (e.g. retirement, point of care needs). Figure 1 gives an example search strategy. The search was restricted to items published after 1997 (to coincide with the government appointment of the Royal Commission on Long-term Care to examine the options for a sustainable system of funding of long-term care for older people in the UK). The research was designed to address the unique context in England, therefore we included research that referred to England only, and to England plus one or more other UK nation. Table 1 gives full inclusion and exclusion criteria.

The initial search produced 6380 articles. After de-duplication, the remaining 6296 records were subject to an initial screen of relevance by title, date and language. 6021 references were excluded. The abstracts and, where necessary, full texts of the remaining 275 items were read and further exclusions made as detailed in figure 2. Relevant literature reviews were read at this stage and any articles in those reviews that met the inclusion criteria but were not captured in our initial search were included as additional articles; the literature reviews themselves were excluded. The references in the final papers were also searched for new inclusions.¹

The final set of 17 references included one peer-reviewed article and 16 reports. All included sources are described in detail in table 2.

These papers were re-read and all text discussing empirical data about financial advice about paying for later life care was extracted into an excel spreadsheet. Following iterative coding, this data was refined into three themes relating to: the extent to which advice is accessed, barriers to accessing it, and perceptions of its usefulness.

Figure 1. Example search strategy

Search strategy used for Social Policy & Practice, via Ovid

- 1 ("long term care" or "long-term care" or LTC or LTCI or "nursing home care" or "long-term service*" or "long term service*") adj2 (agree* or behavior* or behaviour* or choice* or choos* or chosen or consensus or decid* or decision* or expect* or future* or influenc* or intend* or intention* or option* or plan*).ti,ab,de. (420)
- 2 ("long term care" or "long-term care" or LTC or LTCI or "nursing home care" or "long-term service*") adj2 (annuities or annuity or consumer* or economic* or fee or fees or financ* or insurance* or payment* or purchas* or pay or pays or paying or paid or paying).ti,ab,de. (889)
- 3 ("care fees plan*" or "care fees advic*" or "care fees advis*" or "care annuity" or "care annuities" or "deferred payment*" or "deferred care plan*" or "disability-links annuit*" or "disability links annuit*" or "equity release" or "immediate needs annuit*" or "immediate needs insurance*" or "property disregard" or "specialist care advis*" or "specialist care advic*" or "self-insurance" or "self insurance").ti,ab,de. (200)
- 4 ((advice or advise* or advising or assist* or guidance or guide* or guiding or inform or informs or informing or decision* or decid*) adj2 (capital or cost or costs or costed or costing or financ* or fiscal or funding or income or invest or invests or investing or investment* or money or pay or pays or payment* or paying or paid or saving* or wealth)).ti,ab,de. (3209)
- 5 (LTC or "long term care" or "long-term care" or "elderly care" or "nursing care" or "care home*" or "residential care" or "residential home*" or "nursing home*").ti,ab,de. (23635)
- 6 4 and 5 (177)
- 7 1 or 2 or 3 or 6 (1476)
- 8 limit 7 to yr="1997 -Current" (935)

1 One of the included papers (Carr-West & Thraves, 2011, p. 12) refers to research by Oliver Wyman on the number of self-funders receiving independent financial advice, but does not provide a reference. In searching for the original research, we found multiple other sources that use the same figures, none of which provide a complete reference (e.g. Chartered Insurance Institute, 2011, p. 33; Miller et al., 2013, p. 20; Private HealthCare UK, 2010). The Chartered Insurance Institute links the figure to Partnership,

which led us to one additional inclusion of more recent work by Just (formerly Partnership), but we were unable to trace an original research paper for the Wyman research.

Table 1. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Published on or after 01 January 1997	Published before 01 January 1997; unpublished theses; conference abstracts
Research focus on England	No research focus on England
English language	Not English language
Includes empirical research	Contains no empirical research, for example: <ul style="list-style-type: none"> • Commentaries, discussions • Policy documents • Guidance documents, recommendations • Theoretical works • Literature reviews
Evidence relating to public engagement with financial advice about paying for care in later life	No evidence relating to public engagement with financial advice about paying for care in later life. This included articles about: <ul style="list-style-type: none"> • Financial advice in a context other than later life care, including financial advice about retirement but not care, and financial advice about disability outside a later life context • Later life care without a focus on financial advice, including articles about attitudes to paying for care and non-financial advice about care (e.g. advice about care options or local authority benefits) • Financial products only, including the development of financial products for funding later life care • Financial advice about paying for care does not form part of the evidence base (i.e. evidence is collected on another topic and financial advice is discussed in a speculative or explanatory context)

Figure 2. Flowchart of screening process

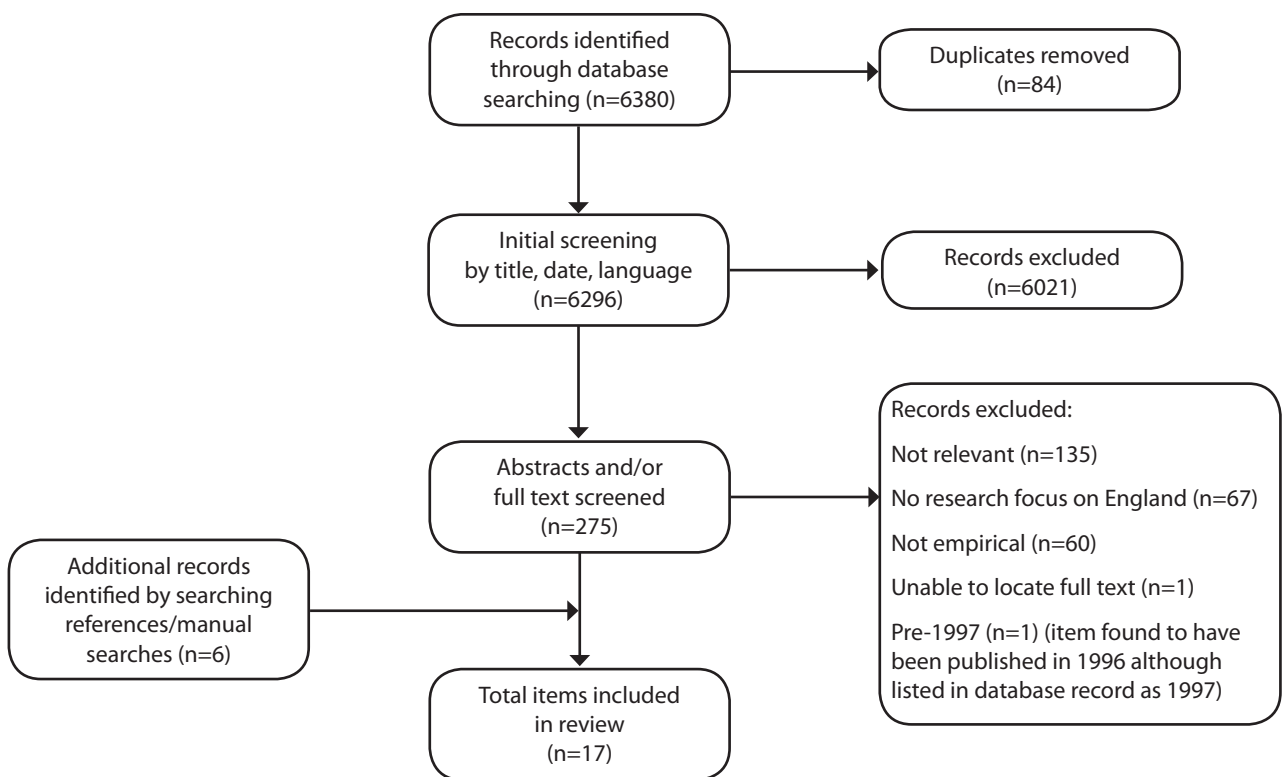


Table 2. Summary of included references

Reference	Reference type	Overall study aim	Design of empirical work
Arksey, H., Corden, A., Glendinning, C., & Hirst, M. (2006). <i>Minding the money: Carers and the management of financial assets in later life</i> . Report of a scoping study. York: Social Policy Research Unit, University of York. [Qualitative research component only.]	Report; research funded by Institute of Actuaries.	To explore perceptions of the prevalence of resource and asset management by friends and relatives; the circumstances which may trigger such arrangements; sources of information and advice about best practice currently available; and key questions that a larger study might address.	Semi-structured interviews with 12 representatives and practitioners from key stakeholders representing the legal, voluntary, statutory pensions and private financial services sectors. UK countries not specified.
Bushnell, J., & Kaye, A. (2017). <i>Caring about the Care Act: A Freedom of Information research briefing</i> . London: Independent Age.	Report by Independent Age (third sector).	To examine key aspects of the Care Act 2014 and local authorities' performance, policies and practice in relation to market shaping, deferred payments, and care home top-up fees.	Freedom of Information requests to top tier authorities in England with social services responsibilities (n=152).
Carr-West, J., & Thraves, L. (2011). <i>Independent ageing: Council support for care self-funders</i> . London: Local Government Information Unit and Partnership.	Report by Local Government Information Unit (membership organisation and think tank).	To assess local authority support for older people making decisions about choosing and paying for care.	Survey of chief executives, leaders, finance directors, adult services directors and cabinet portfolio holders in all 174 upper tier authorities in England and Wales.
Carr-West, J., & Thraves, L. (2013). <i>Independent ageing 2013: Council support for care self-funders</i> . London, Local Government Information Unit and Partnership.	Report by Local Government Information Unit (membership organisation and think tank).	To update the findings from Carr-West and Thraves (2011) and provide a state of the nation picture of council support for self-funders.	Survey of council information sources; qualitative interviews with adult services departments. Participant numbers and UK countries not specified.
Commission For Social Care Inspection (2007). <i>A fair contract with older people? A special study of people's experiences when finding a care home</i> . London: Commission for Social Care Inspection.	Report by the Commission for Social Care Inspection (public body).	To examine whether older people, carers and their families get the information, advice and support needed at every stage of their move into a care home and whether they get clear and unambiguous contracts and agreements about what the care home will provide and who pays for what.	Interviews with 36 older people who had recently moved or were moving into a care home and their carers, 33 care home managers and care home workers, 28 social workers (care managers) and 13 commissioners. 110 'thematic' inspections of care homes; focused inspection work in 396 planned inspections of care homes; online survey completed by 188 relatives and carers of older people who had moved into care homes or were considering doing so; mystery-shopping exercise with all 150 councils with social services responsibilities. All work undertaken in England.
Croucher, K., & Rhodes, P. (2006). <i>Testing consumer views on paying for long-term care</i> . York: Joseph Rowntree Foundation.	Report; research funded by the Joseph Rowntree Foundation (third sector).	To test the viability and acceptability of policy options for paying for care, via testing public attitudes.	Eight focus groups with adults in England and Scotland aged 26-90 (total n=59).
Fox O'Mahony, L., & Overton, L. (2014). Financial Advice, Differentiated Consumers, and the Regulation of Equity-release Transactions. <i>Journal of Law and Society</i> , 41(3), 446–469.	Peer-reviewed journal article; research funded by the Leverhulme Trust.	To explore the role of financial advice within the factors that shape equity-release decision making.	Semi-structured in-depth interviews with 70 equity-release consumers in England and Scotland.

Table 2 (continued)

Reference	Reference type	Overall study aim	Design of empirical work
Henwood, M. (2010). <i>Journeys without maps: The decisions and destinations of people who self fund</i> . In <i>People who pay for care: quantitative and qualitative analysis of self-funders in the social care market</i> . London: Putting People First Social Care Consortium, pp. 42-83.	Report commissioned by the Putting People First Consortium and the Commission for Social Care Inspection (public bodies).	To track the journeys undertaken by self-funders, to explore their decisions and the consequences, and to understand the nature and sources of advice and information to which they had access.	Face to face interviews with key providers of social care services; 30 face to face or telephone interviews with self-funders or carers/family members of self-funders in England.
Henwood, M., & Hudson, B. (2009). <i>Navigating the parallel universe: Information and advice for people who self-fund</i> . London: Association of Directors of Adult Social Services.	Report commissioned by Putting People First Consortium (public body), the Social Care Institute for Excellence (third sector), and the Joseph Rowntree Foundation (third sector).	To explore the approach of key national organisations and charities involved in the provision of information and advice across the area of social care and support, and examine whether and how such information addresses the needs of people who are self-funding.	An online questionnaire returned by 16 key national (UK) organisations and charities that operate helplines or make information available to the public; semi-structured interviews with 8 of the respondents.
Ipsos MORI (2012). <i>Caring for our future engagement: analysis of responses</i> . London: Department of Health.	Report commissioned by the Department of Health.	To identify immediate and longer-term priorities for reforming the care and support system.	Views from those in the care and support community, voluntary sector, service users and carers from across the UK (n=565) collected by online feedback forms, feedback forms and reports/minutes from stakeholder-run events, comments and chat logs on a website, other response formats sent by organisations or individuals (e.g. letters).
Just (2017b). <i>We need to talk about care: Care report 2017</i> . Surrey: Just. [Most recent update of ongoing research.]	Report by Just Group plc (regulated financial services provider).	None stated.	Interviews with advisers, powers of attorney, and adults aged 40+ in England (n=11,870).
Local Government Association (2015). <i>Care Act implementation: Results of local authority stocktake 4</i> .	Report by Local Government Association (membership organisation).	To inform local, regional and national preparations and to ensure councils have the support and resources they need for implementation.	Email survey of all 152 local authorities in England.
Passingham, A., Holloway, J., & Bottery, S. (2013). <i>Care home top-up fees: The secret subsidy</i> . London: Independent Age.	Report by Independent Age (third sector).	To shed some light on the grey area of 'top-up' fees for care homes.	Data and case studies from the Independent Age Advice Service; Freedom of Information request to all 152 local authorities in England; survey of care homes in England.
Qa Research (2016). <i>Information and advice since the Care Act: How are councils performing?</i> London: Independent Age.	Report commissioned by Independent Age (third sector).	To determine whether English local authority websites are providing accurate and up-to-date information and advice on social care that complies with their new duties under the Care Act.	Review of all English local authority websites; website testing by people aged 70+; mystery shopping exercise with 151 local authorities in England.
Sal, N. (2015). <i>Health survey for England 2014. Chapter 7: Planning for future care</i> . Leeds: The Health and Social Care Information Centre.	Report commissioned by the Health and Social Care Information Centre (public body).	To assess people's awareness and understanding of how social care is funded, and whether people have taken any steps to plan for their own future care needs. (Chapter in a large national study.)	Structured interviews with 1276 adults aged 30+ living in their own homes in England.

Table 2 (continued)

Reference	Reference type	Overall study aim	Design of empirical work
SOLLA & ABI (2013). <i>Financial advice and long term care. In Pensions and Insurance Working Group, Developing products for social care.</i> London: Association of British Insurers, pp. 36-40.	Report by Society of Later Life Advisers (not for profit organisation) and Association of British Insurers (trade association).	None stated.	Questionnaire emailed to members of the Society of Later Life Advisers (UK locations not specified). 105 responses.
Wright, F. (2002). <i>Asset stripping: Local authorities and older homeowners paying for a care home place.</i> Bristol: The Policy Press.	Report; research funded by The Nuffield Foundation (third sector).	To identify, explore and understand the significant issues that arise when older homeowners enter residential care and nursing home care.	National postal survey of senior finance officers in English and Welsh social services departments and 28 structured telephone interviews with responding finance officers; case studies in five English local authority areas consisting: 20 qualitative interviews with social services department staff; 28 structured interviews with independent sector care home providers; 28 semi-structured interviews with recently-admitted care home residents; 28 semi-structured interviews with relatives of care home residents.

Results

There is little empirical research evidence about the public's engagement with financial advice to plan for later life care costs, and less still on regulated financial advice. Of the sources included in the final review, financial advice was rarely the main focus, and in some it was mentioned only briefly. Reports often included only minimal empirical evidence and methods were not always transparent. However, we did find evidence around access to financial advice for later life care, barriers to it, and perceptions of its usefulness.

To what extent is financial advice accessed to plan for later life care costs?

There was limited evidence on how many people access regulated financial advice about funding later life care. It was clear that access was low, both before care needs arise and when care is arranged, but people do seek financial advice from alternative, unregulated sources.

Two studies drew attention to low engagement with financial advice in advance of care needs. The Health Survey for England asked adults aged 30+ to state which they had undertaken from a list of actions 'that might contribute to paying for [their] own future care' (Sal, 2015, p. 14). The actions included consultation with a financial adviser, although the study does not specify whether that consultation was undertaken *in order* to discuss paying for future care, or whether future care was actually discussed. The number of people who had taken this action was low across all age groups, including the age group most likely to need later life care. Those aged 55–64 were most likely to have

consulted a financial adviser (18% compared to 7% of those aged 75+). If these consultations were undertaken for reasons other than discussing care costs, then that topic may not have been raised. This was a finding of Fox O'Mahoney and Overton (2014), who conducted qualitative research with people who had received regulated financial advice for the purpose of equity release outside a care context. They found that when equity was released for a financial need or crisis, the effects on future entitlement to benefits relating to social care did not feature prominently in discussions with financial advisers.

Access to financial advice also appears to be low among people already paying for care. Carr-West and Thraves (2011) point to unreferenced research by Oliver Wyman, indicating that 26% (14,000) of self-funders surveyed had received independent financial advice about funding care. Only half of those had received that advice from an adviser with care-specific qualifications. In a qualitative study on self-funders' care decisions and destinations (Henwood, 2010), none of the self-funders interviewed had received independent financial advice; carers were slightly more informed about financial matters, but had little or no engagement with independent financial advisers. Wright's (2002) study of homeowners entering residential care mentioned financial advisers briefly in the context of other findings but highlighted that their services were rarely accessed: 'some' relatives of self-funding care home residents had sought financial advice from 'miscellaneous sources', including financial advisers, a friend, or a bank manager (Wright, 2002, p. 28). Arksey et al. (2006) noted that a move to a care home can prompt older people and their relatives to seek financial advice, but did not specify the source(s) of this advice.

Several studies drew attention to the role of third party organisations such as local authorities and charities in signposting or referring people to financial advice services, including regulated financial advisers and financial helplines (Bushnell & Kaye, 2017; Carr-West and Thraves, 2013; Commission for Social Care Inspection, 2007; Local Government Association, 2015; Passingham et al., 2013; Qa Research, 2016). Henwood and Hudson (2009), for example, found national organisations and charities involved in the provision of advice about health and social care were aware of the importance of financial advice to self-funders; some were cautious about giving such advice themselves, instead directing people to find their own financial adviser or signposting them elsewhere. However, most of these reports do not provide evidence about whether such suggestions were followed. We explore signposting and referrals in the next section.

There was evidence that people used non-regulated sources of financial advice and/or sources that were not independent of the local authority when planning or paying for care. Relatives and friends were a common source of financial management and advice (Arksey et al., 2006; Henwood, 2010; Wright, 2002). In turn, relatives were unlikely to seek regulated financial advice, instead turning to sources such as the media (Henwood, 2010) or care providers (Wright, 2002). Arksey et al. (2006) also noted that when isolated older people relied on particular taxi firms or house maintenance services, they sometimes turned to these services for suggestions about financial management. Local authorities themselves were another source of financial information and advice. A quarter of the relatives interviewed by Wright (2002) consulted a care manager or social worker. Henwood (2010) noted that some carers got financial information (as opposed to advice) from the council during their financial assessment. Nearly three quarters of local authorities surveyed by Carr-West and Thraves (2013) reported offering 'documentary financial information and advice' at the point of care or assessment (73%) or earlier (72%), and the Commission for Social Care Inspection (2007) found evidence of council finance departments providing information to prospective care home residents. In the survey of 16 national organisations and charities involved in the provision of advice about health and social care, seven offered financial advice (Henwood and Hudson, 2009).

What are the barriers to accessing financial advice in the context of funding later life care?

Reasons why people did not access independent or regulated financial advice for funding later life care were explored by a number of studies. These included preferences for other (non-professional) sources of advice and inadequate opportunities for independent or regulated advice, including a lack of signposting or referrals.

While we found very little evidence capturing people's views of financial advisers themselves, there was some

indication that they were often not the preferred source of advice. The previous section outlined various alternative sources of financial advice and some studies suggested a consumer preference for these sources. Arksey et al. (2006, p. 44) found that when family provided other types of support to an older person, arrangements in which they also managed the older person's finances 'evolved naturally in response to perceived needs and reflected expectations and norms shared between family members'. When such arrangements were satisfactory, other options for financial advice and support were not considered. More recently, only 12% of adults in England surveyed by Just (2017b) said they would seek advice from a professional financial adviser if they needed to enter residential care; their preferred sources of advice included voluntary organisations, their local authority, and friends and family.

More general public mistrust of the financial services sector and individuals working in it is one possible reason for such preferences. Among the focus groups they conducted about paying for long-term care, Croucher and Rhodes (2006, p. 7) found 'enormous mistrust of any private sector financial 'packages' or 'products''. Ipsos Mori (2012) also found mistrust of the financial sector; people felt it did not 'belong' with the social care sector, preferring to turn to the voluntary sector or community groups. Evidence on the views of financial advisers themselves supported this finding. While only 6% of SOLLA members surveyed thought that people did not *want* professional advice, 55% agreed or strongly agreed that mistrust of the financial services industry was a barrier to people accessing financial advice for long term care costs (SOLLA and ABI, 2013). Moreover, 67% agreed or strongly agreed that people thought they could not afford such advice, and 82% that people did not want to think about needing care in the future.

In research that predates the Care Act, there was evidence of a lack of *opportunity* to access regulated financial advice. Forty-eight per cent of SOLLA members felt that a lack of qualified advisers acted as a barrier to people accessing financial advice about care costs, while 80% felt that lack of consumer awareness was a barrier (SOLLA & ABI, 2013). The latter finding supports earlier evidence by Henwood (2010) that carers dealing with self-funders' financial matters were not generally aware of the possibility of accessing independent financial advice to help plan paying for care costs. Absent or inadequate signposting and referrals to such advice were also identified as a barrier to access. In this context, 'signposting' is when an organisation or professional suggests that a member of the public approach and make use of another organisation or professional, and provides the necessary details for them to do so. 'Referral' is a more direct action, whereby the first organisation or professional directly facilitates that contact. Passingham et al. (2013) found 75% of English local authorities responding to their survey did not signpost people to independent advice, including financial advice, before they signed contracts agreeing to top up

a relative's care fees. The authors also noted lack of signposting to independent financial advice as a concern raised by members of the public who contacted the Independent Age advice service. Carr-West and Thraves (2013) found a large increase, since their 2011 report, in local councils referring self-funders to various services offering independent financial advice. However, despite the increase, less than half of councils (47%) referred self-funders to 'a firm or panel of regulated, independent financial advisers' at or following an assessment of needs or finances, and only 17% made such referrals before an assessment. SOLLA members also identified the need for direct referrals by local authorities, as well as care providers, health professionals, and voluntary organisations (SOLLA & ABI, 2013).

More recent research, scrutinising the extent to which local authorities were fulfilling their Care Act responsibilities since implementation, suggests that these barriers are beginning to fall. One survey, completed by all authorities in May 2015, found that 80% said they had established arrangements to support access to independent financial advice (Local Government Association, 2015). However, the nature of those arrangements was not reported. In a review of local authority websites that assessed and ranked the strength of information provision in eight key areas, the provision of information on paying for care and independent financial advice was ranked fifth (Qa Research, 2016). The authors suggest that examples of strong performance included directing people to a third-party organisation such as SOLLA; poor performance included absent or limited information about independent financial advice, a lack of signposting, or signposting to specific financial advisers (as opposed to an organisation like SOLLA). Finally, a Freedom of Information request by Independent Age suggests a reversal of the findings reported by Passingham et al. (2013), with 77% of responding local authorities stating that they referred people to financial advice regarding third party top-ups (Bushnell & Kaye 2017). The report also pointed to the use of third-party organisations such as the Care Advice Line, which offers a referral system to specialist financial advisers.

It is important to note that any figures on local authority signposting or referrals to financial advisers necessarily only apply to self-funders who have been in contact with those authorities. Many self-funders never contact the local authority and Carr-West and Thraves (2011, 2013) draw attention to this issue as a barrier in itself to facilitating financial advice.

How useful is financial advice about funding later life care?

There was a strong suggestion in the literature that financial advice about funding later life care would be beneficial. However, there was very limited *evidence* on specific outcomes of financial advice (regulated or otherwise). Where evidence about usefulness was presented, it tended

to be about the *perceived* benefit among the public and other stakeholders.

Most sources stated that people could benefit from financial advice about funding later life care, with some emphasising the importance of financial advisers being independent, regulated, and/or specialists in later life needs (Arksey et al., 2006; Carr-West & Thraves 2011; 2013; Henwood, 2010; Henwood & Hudson, 2009). Suggested benefits included keeping self-funders financially independent for longer (Carr-West & Thraves, 2011, 2013), preventing poor financial decisions, and assuaging feelings of powerlessness and uncertainty (Henwood, 2010; Henwood & Hudson, 2009). Arksey et al. (2006) also point to the need for carers and family members to receive financial advice, to prevent risky decisions about an older person's finances.

Despite distrust of the financial sector, some members of the public also seem to perceive financial advisers as helpful. Ipsos Mori (2012) found evidence that people felt the sector did have a role to play in care planning, through providing independent financial advice and raising awareness of the need to plan for future costs. While a minority of people surveyed by Just (2017b) said they would contact a professional financial adviser themselves when planning care, more than half (54%) said they would find it helpful to be referred to one when they approached their local authority about care options. Only 10% said they would not contact the recommended adviser.

Several studies pointed to the inadequacy of financial advice offered by those outside the financial sector. Arksey et al. (2006) noted the problems that can arise from having family members and neighbours manage and advise on an older person's finances. These included the older person feeling beholden to following that advice against their own preferences in order to preserve the relationship, a loss of independence and control, and vulnerability to financial abuse. They also note that friends and family risked 'wrong doing' based on their own lack of understanding of the rules around gifting and inheritance tax. Henwood and Hudson (2009) reported that while the national organisations and charities they interviewed felt very confident in giving advice in various areas, nearly 40% identified financial issues as an area in which they were weakest. The Commission for Social Care Inspection (2007) found that 64% of self-funders thought that written information offered by the local council did not clearly explain care costs, and Carr-West and Thraves (2011) found that much of the financial advice offered by councils at the point of needing care was insufficiently tailored to self-funders' needs. Wright (2002) reported that most self-funders who approached local authorities for advice were dissatisfied, and that the financial advice offered by care providers was inadequate and potentially biased.

Finally, Fox O'Mahoney and Overton (2014) demonstrated the 'pitfalls' of omitting discussion of future care needs when consumers engage with the financial services

sector for non-care related reasons. Years after the purchase of equity release, a small number of their respondents were finding the product detrimental to plans for financing care, which suggests that advice on such issues would have been useful. However, the authors noted that when their participants' financial advisers *did* bring up future care costs, this advice could sometimes be ignored, possibly due to the purchasers' inability to foresee future care needs. Thus, their study implies that the usefulness of financial advice for funding care in later life may be limited by consumers' own vision of what the future holds.

Discussion

We identified 17 papers that included empirical research relating to financial advice about later life care in England, although none took the topic as their primary focus. The studies demonstrated that people rarely accessed regulated financial advice in order to plan for possible future care needs or to inform decisions about paying for current care needs. Barriers to access included personal preferences for other sources of advice, mistrust of the financial sector, and absent or inadequate signposting and referrals, although the latter may be improving since the implementation of the Care Act. It is important to note that the majority of papers were published before the implementation of the Care Act, and local authority signposting may continue to improve. The studies we reviewed suggest that financial advice would help people in planning for care costs, with some providing evidence that the public perceive such advice as useful and would welcome the opportunity to access it. Some of these findings echo wider research on the financial sector in a non-care context, and research on later life social care outside the context of financial advice. For example, we found that mistrust of the financial sector acts as a barrier to people accessing it in the context of planning for care costs. This reflects findings that more general mistrust is a deterrent to seeking financial advice in other contexts (Moss, 2015), and findings that older people are more likely to seek financial advice from public and voluntary organisations with which they have long-standing relationships (Hean et al., 2012).

The key and overarching gap identified in the literature is the lack of up-to-date evidence specifically focused on financial advice about funding later life care. While conclusions might be drawn from research focused solely on experiences of the social care system or solely on experiences of the financial sector, such conclusions can only be speculative. There are two particularly crucial gaps in the evidence.

First, more evidence is needed on the outcomes and the usefulness or otherwise of financial advice in the context of paying for care in England. Relevant stakeholders include members of the public seeking or receiving later life care; regulated financial advisers, particularly those offering specialist later life advice; and signposting/referral organisations. Research taking a specific focus on financial advice

for funding later life care might use the stakeholder perspective to answer a number of questions. For example, we know little about whether members of the public who have taken (regulated) financial advice about paying for care have benefited from it, financially or otherwise. Research in a US context has suggested benefits to receiving financial advice include a perception of greater control (Peters & Pinkston, 2002; Stum, 2006) and improved coping in carer populations (DaDalt et al, 2016). However, we do not know how applicable such non-financial benefits may be to consumers in England. Moreover, there is evidence to suggest that financial advice in a non-care context can have *detrimental* effects on consumers, particularly when those consumers lack understanding about finances and are not well placed to distinguish good advice from bad (Fox O'Mahoney & Overton, 2014; Inderst & Ottavani, 2012). Determining whether such effects are experienced by people accessing financial advice to pay for care costs should be a high priority. Robust evidence in this area would be of use to members of the public considering seeking financial advice. If presented and disseminated in an appropriate and accessible way, it would enable them to understand both the purpose and the potential pitfalls of taking such advice. It would also be beneficial to organisations encouraging people to consider financial advice, including organisations that cannot offer the advice themselves but wish to signpost or refer to it.

The second significant gap is the lack of evidence around the circumstances in which financial advice about paying for care costs is accessed, including what stakeholders experience as barriers to access. A better understanding is needed of the extent to which these barriers overlap with factors that discourage people from seeking financial advice in a non-care context. Which factors are more or less important in a care setting? Are there additional factors unique to the care context? For example, Moss (2015) suggests that financial advice can be seen as a route to purchasing a product rather than a means of planning for future risk; given the lack of products designed to pay for care in England, this may be a particularly pertinent barrier in a care context. In a US context, there is evidence that financial planning for future care costs is seen to violate cultural norms around familial provision of care (San Antonio & Rubinstein, 2004) and that people consider the matter too private to discuss with professionals (Stum, 2000; 2001). Yet there is no evidence on whether such factors act as barriers to seeking financial advice in the cultural context of England. Despite improvements in signposting, it will also be helpful to understand what factors might continue to deter local authorities and other organisations from signposting or referring to financial advice, and what those organisations understand to constitute good signposting and referrals. One study implied that referral to a specific firm of regulated financial advisers is good practice (Carr-West and Thaves, 2011, 2013), while another cited such specificity as poor practice (Qa Research, 2016). Conversely, evidence is also

needed on how barriers are overcome. For example, family relationships can be crucial in helping self-funders find care (Tanner et al., 2017), and might be similarly central in helping them to find financial advice about care. Research in a US context has suggested that people are more likely to seek help from a financial planner to pay for care if they already have a relationship with that person (DaDalt et al., 2016); the importance or otherwise of such pre-existing professional relationships should be explored in the context of England. Taken together, such evidence could benefit financial advisers and organisations responsible for signposting and referrals. It could raise awareness of the specific facilitators and barriers faced by people who may benefit from financial advice about paying for care, and inform strategies to reach those members of the public.

Limitations of our study

We did not undertake a formal quality assessment of studies and treated all evidence equally. However, the lack of methodological transparency in some studies would have made quality judgements challenging and may be taken as a wider indication of low quality. Moreover, for the purposes of this review, the aims and foci of the included studies represented a limitation. None of the studies focused specifically on financial advice about funding later life care, and some only briefly touched on the topic. These limitations made interpreting findings in the light of our chosen topic difficult in two ways.

First, financial advice and financial advisers were sometimes discussed in fairly general terms, with no explanation of what an author meant by 'financial adviser' or by 'independent financial advice'. As mentioned previously, these terms can be interpreted in different ways and it was frequently unclear exactly what type of advice or adviser was being discussed. Indeed, in one case, 'financial advisers' were grouped together with other sources of information under the label 'miscellaneous sources' (Wright, 2002), which further complicated the interpretation of the evidence about financial advisers. Second, it was often difficult to determine to what extent a study's claims about financial advice were grounded in evidence, and to what extent they were the authors' suggestions. This was particularly the case when papers discussed the barriers and usefulness of financial advice. Likewise, as discussed in the findings of this review, several studies presented financial advice as being useful in helping people plan for future care costs, without offering evidence of specific ways in which it has been useful to people. This necessarily weakens the evidence base presented and strengthens our call for further evidence.

Conclusion

This review adds to knowledge about engagement with financial advice about later life care costs in England by

identifying and synthesising the current literature, and highlighting the substantial gaps. Despite the case for financial advice about funding later life care being promoted before the Care Act (e.g. APPLG, 2012; Burstow, 2013; Chartered Insurance Institute, 2011; Featherstone & Whitham, 2010; Hudson & Henwood, 2009) and the subsequent responsibilities enshrined in it, research in this area is extremely limited. More evidence is needed on the specific conditions that prompt people to use financial advice and the barriers to doing so, as well as the outcomes of getting advice. We recommend that such evidence should come from collecting the perspectives of a variety of relevant stakeholders. These diverse groups would also benefit from the analysis and dissemination of such evidence to improve practice with regard to signposting and referrals, accessing and offering good financial planning advice for long-term care in later life.

References

- ADASS (Association of Directors of Adult Social Services) (2018). *ADASS Budget Survey 2018*. Available at <https://www.adass.org.uk/media/6434/adass-budget-survey-report-2018.pdf> (accessed 12 June 2018).
- APPLGG (All Party Parliamentary Local Government Group) (2012). *Care now and for the future: An inquiry into adult social care*. London: Local Government Information Unit. Available at <https://www.lgiu.org.uk/wp-content/uploads/2012/07/Care-now-and-for-the-future-an-inquiry-into-adult-social-care.pdf> (accessed 20 December 2017).
- Arksey, H., Corden, A., Glendinning, C., & Hirst, M. (2006). *Minding the money: Carers and the management of financial assets in later life. Report of a scoping study*. York: Social Policy Research Unit, University of York. Available at <https://www.york.ac.uk/inst/spru/pubs/pdf/IOA.pdf> (accessed 20 December 2017).
- Asthana, A., & Elgot, J. (2017). Theresa May ditches manifesto plan with 'dementia tax' U-turn. *The Guardian*, 22 May. Available at <https://www.theguardian.com/society/2017/may/22/theresa-may-u-turn-on-dementia-tax-cap-social-care-conservative-manifesto> (accessed 20 December 2017).
- Baxter, K., & Glendinning, C. (2014). *People who fund their own social care: Scoping review*. London: NIHR School for Social Care Research. Available at <https://pure.york.ac.uk/portal/files/33313357/sscrSelfFundSR11.pdf> (accessed 20 December 2017).
- Baxter, K., Heavey, E., & Birks, Y. (2017). *Older self-funders and their information needs*. London: NIHR School for Social Care Research. Available at <http://eprints.whiterose.ac.uk/119213/1/RF62.pdf> (accessed 20 December 2017).
- Blood, I., Copeman, I., & Pannell, J. (2015). *The anatomy of resilience: Helps and hindrances as we age. A review*

- of the literature. Cardiff: Social Services Improvement Agency. Available at https://socialcare.wales/cms_assets/file-uploads/19a-The-Anatomy-of-Resilience-helps-and-hindrances-as-we-age.pdf (accessed 20 December 2017).
- Burstow, P. (2013). *Delivering Dilnot: Paying for elderly care*. London: CentreForum. Available at <https://www.bl.uk/collection-items/delivering-dilnot-paying-for-elderly-care> (accessed 20 December 2017).
- Bushnell, J., & Kaye, A. (2017). *Caring about the Care Act: A Freedom of Information research briefing*. London: Independent Age. Available at https://www.independentage.org/sites/default/files/2017-11/Caring_about_the_Care_Act_A_Freedom_of_Information_Research_Briefing.pdf (accessed 21 December 2017).
- Broome, J. (2004). *Weighing Lives*. Oxford: Oxford University Press.
- Care Act 2014, Chapter 23. Available at http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf (accessed 20 December 2017).
- Care Act statutory guidance: Care and support statutory guidance (updated 12 February 2018). London: Department of Health & Social Care. Available at <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#chapter-3> (accessed 15 May 2018).
- Carr-West, J., & Thraves, L. (2011). *Independent ageing: Council support for care self-funders*. London: Local Government Information Unit. Available at <https://www.lgiu.org.uk/wp-content/uploads/2012/04/Independent-Ageing.pdf> (accessed 20 December 2017).
- Carr-West, J., & Thraves, L. (2013). *Independent ageing 2013: Council support for care self-funders*. London, Local Government Information Unit. Available at <https://www.lgiu.org.uk/wp-content/uploads/2013/07/Independent-Ageing-2013.pdf> (accessed 20 December 2017).
- Chartered Insurance Institute (2011). *Who cares? The implications of a new partnership to fund long-term care*. London: The Chartered Insurance Institute. Available at http://www.cii.co.uk/media/852939/CII_Special_Report_on_Long_Term_Care_Final_Web_Version.pdf (accessed 20 December 2017).
- Commission For Social Care Inspection (2007). *A fair contract with older people? A special study of people's experiences when finding a care home*. London: Commission for Social Care Inspection. Available at <http://www.housingcare.org/downloads/kbase/2946.pdf> (accessed 20 December 2017).
- Croucher, K., & Rhodes, P. (2006). *Testing consumer views on paying for long-term care*. York: Joseph Rowntree Foundation. Available at <https://www.jrf.org.uk/report/testing-consumer-views-paying-long-term-care> (accessed 20 December 2017).
- DaDalt, O., Burstein, A., Kramer, B., D'Ambrosio, L.A., & Coughlin, J.F. (2016). Dementia and financial incapacity: A caregiver study. *Working with Older People*, 20(2), 66–75.
- Deeming, C., & Keen, J. (2002). Paying for old age: Can people on lower incomes afford domiciliary care costs? *Social Policy and Administration*, 36(5), 465–481.
- Dispatches: How to avoid the dementia tax*, 2017 (TV programme). Channel 4. 20 November.
- Featherstone, H., & Whitham, L. (2010). *Careless: Funding long-term care for the elderly*. London: Policy Exchange. Available at <https://www.policyexchange.org.uk/wp-content/uploads/2016/09/careless-jul-10.pdf> (accessed 20 December 2017).
- Fox O'Mahony, L., & Overton, L. (2014). Financial advice, differentiated consumers, and the regulation of equity-release transactions. *Journal of Law and Society*, 41(3), 446–469.
- Franklin, B., & Hochlaf, D. (2017). *The Global Savings Gap*. London: International Longevity Centre – UK. Available at <https://ilcuk.org.uk/the-global-savings-gap> (accessed 16 May 2018).
- Girling, L.M., & Morgan, L.A. (2014). Older women discuss planning for future care needs: An explanatory framework. *Journal of Aging and Health*, 26(5), 724–749.
- Hean, S., Fenge, L.A., Worswick, L., Wilkinson, C., & Fearnley, S. (2012). Intersectoral interagency partnerships to promote financial capability in older people. *Journal of Interprofessional Care*, 26(5), 419–421.
- Henwood, M. (2010). *Journeys without maps: The decisions and destinations of people who self fund*. In *People who pay for care: quantitative and qualitative analysis of self-funders in the social care market*. London: Putting People First Social Care Consortium, pp.42–83 Available at https://ipc.brookes.ac.uk/publications/People_who_pay_for_care_-_report_12_1_11_final.pdf (accessed 20 December 2017).
- Henwood, M. (2014). Self-funders: The road from perdition? In C. Needham & J. Glasby, (Eds.), *Debates in Personalisation* (pp. 75–83). Bristol: Policy Press.
- Henwood, M., & Hudson, B. (2008). *Lost to the system? The impact of fair access to care*. London: Commission for Social Care Inspection. Available at <http://www.melaniehenwood.com/perch/resources/cscifacslottothesystem.pdf> (accessed 20 December 2017).
- Henwood, M., & Hudson, B. (2009). *Navigating the parallel universe: Information and advice for people who self-fund*. London: Association of Directors of Adult Social Services. Available at https://www.thinklocalactpersonal.org.uk/_assets/Resources/Personalisation/Localmilestones/IAA_for_people_who_fund_their_own_Social_Care_2009.pdf (accessed 20 December 2017).
- Hudson, B., & Henwood, M. (2009). *A Parallel Universe? People who fund their own care and support: a review of the literature*. London: Association of Directors of Adult Social Services. Available at https://www.thinklocalactpersonal.org.uk/_assets/Resources/Personalisation/Localmilestones/IAA_for_people_who_

- fund_their_own_Social_Care_2009.pdf (accessed 20 December 2017).
- Humphries, R. (2013). *Paying for social care: Beyond Dilnot*. London: The King's Fund. Available at https://www.kingsfund.org.uk/sites/default/files/field/field_publication_summary/social-care-funding-paper-may13.pdf (accessed 20 December 2017).
- Humphries, R., Thorlby, R., Holder, H., Hall, P., & Charles, A. (2016). *Social care for older people: Home truths*. London: The King's Fund and Nuffield Trust. Available at <https://www.nuffieldtrust.org.uk/files/2017-01/social-care-older-people-web-final.pdf> (accessed 20 December 2017).
- Inderst, R., & Ottavani, M. (2012). Financial advice. *Journal of Economic Literature*, 50(2), 494–512.
- Ipsos MORI (2011). *Public opinion research on social care funding: A literature review on behalf of the Commission on the Funding of Care and Support*. London: Ipsos MORI. Available at www.dilnotcommission.dh.gov.uk/files/2011/03/MORI.pdf (accessed 20 December 2017).
- Ipsos MORI (2012). *Caring for our future engagement: analysis of responses*. London: Department of Health. Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136456/2900021-Ipsos-MORI-Caring-for-our-future-engagement-analysis-of-responses.pdf (accessed 20 December 2017).
- Just (2017a). *Care funding: Some statistics around long term care*. Surrey: Just. Available at <http://www.justadviser.com/documents/statistics-around-long-term-care-1312736.pdf> (accessed 08 January 2018).
- Just (2017b). *We need to talk about care: Care report 2017*. Surrey: Just. Available at http://www.justgroupplc.co.uk/~/_/media/Files/J/JRMS-IR/news-doc/we-need-to-talk-about-care-report-2017.pdf (accessed 21 December 2017).
- Kahneman, D., Knetsch, J.L., & Thaler, R.H. (1991). Anomalies: The endowment effect, loss aversion, and status quo bias. *Journal of Economic Perspectives*, 5(1), 193–206.
- Kahneman, D., & Tversky, A. (1984). Choices, values, and frames. *American Psychologist*, 39(4), 341–350.
- Lawless, L., Drichoutis, A.C., & Nayga, R.M. (2013). Time preferences and health behaviour: a review. *Agricultural and Food Economics*, 1(17).
- Lloyd, J. (2011a). *Gone for good? Pre-funded insurance for long-term care*. London: The Strategic Society Centre. Available at <http://strategicsociety.org.uk/wp-content/uploads/2013/01/Gone-for-Good-Pre-funded-insurance-for-long-term-care.pdf> (accessed 20 December 2017).
- Lloyd, J. (2011b). *Immediate Needs Annuities: Their role in funding care*. London: The Strategic Society Centre. Available at <http://strategicsociety.org.uk/wp-content/uploads/2013/01/Immediate-Needs-Annuities-Their-role-in-funding-care.pdf> (accessed 20 December 2017).
- Local Government Association (2015). *Care Act implementation: Results of local authority stocktake 4* (accessed 20 December 2017 at <https://www.local.gov.uk/sites/default/files/documents/results-local-authority-c-d5f.pdf> but not online at time of publication).
- Lunt, P., & Blundell, J. (2000). Public understanding of financial risk: The challenges to regulation. In P. Taylor-Gooby (Ed.), *Risk, Trust and Welfare* (pp. 114–130). London: Macmillan.
- Miller, C., Bunnin, A., & Rayner, V. (2013). *Older people who self-fund their social care: A guide for health and wellbeing boards and commissioners*. London: OPM. Available at <https://www.scie-socialcareonline.org.uk/older-people-who-self-fund-their-social-care-a-guide-for-health-and-wellbeing-boards-and-commissioners/r/a11G000002W3mMIAS> (accessed 20 December 2017).
- Moss, J.G.R. (2015). *Personal financial planning advice: Barriers to access*. (Unpublished PhD thesis). Birmingham: University of Birmingham.
- National Audit Office (2011). *Report by the Comptroller and Auditor General: Oversight of user choice and provider competition in care markets*. London: The Stationery Office. Available at <https://www.nao.org.uk/wp-content/uploads/2011/09/10121458.pdf> (accessed 20 December 2017).
- Overton, L., & Fox O'Mahoney, L. (2017). Understanding attitudes to paying for care amongst equity release consumers: Citizenship, solidarity and the 'hardworking homeowner'. *Journal of Social Policy*, 46(1), 49–67.
- Parker, G., & Clarke, H. (1997). *Attitudes and behaviour towards financial planning for care in old age*. Leicester: University of Leicester and Nuffield Community Care Studies Unit.
- Parker, G., & Clarke, H. (1998). Paying for long term care in the UK: Policy, theory and evidence. In P. Taylor-Gooby (Ed.), *Choice and Public Policy* (pp. 24–41). Basingstoke: Macmillan.
- Partnership (2016). *Care report 2016: 5th care index*. London: Partnership. Accessed 20 December 2017 at <http://www.justadviser.com/documents/partnership/care-report-2016-ltc-4288.pdf> (at the time of publication the original report is unavailable online, but has been reported on here: <https://thecareruk.com/care-fees-planning-majority-of-over-45s-agree-council-referral-to-adisvers-would-be-helpful>).
- Passingham, A., Holloway, J., & Bottery, S. (2013). *Care home top-up fees: The secret subsidy*. London: Independent Age. Available at <http://whereisthecare.co.uk/wp-content/uploads/2016/01/Independent-Age-Top-Up-Fees.pdf> (accessed 20 December 2017).
- Peters, C.M., & Pinkston, E.M. (2002). Controllers and noncontrollers: A typology of older Americans and their caregivers' approaches to managing the private funding of long-term care. *Qualitative Health Research*, 12(9), 1161–1183.

- Price, D., Bisdeem, D., Daly, T., Livsey, L., & Higgs, P. (2014). Financial planning for social care in later life: The 'shadow' of fourth age dependency. *Ageing & Society*, 34(3), 388–410.
- Private HealthCare UK (2010). Over 50s drastically underestimate the cost of long term care. Available at <https://www.privatehealth.co.uk/news/over-50s-dramatically-under-estimate-cost-long-term-care-85003/> (accessed 20 December 2017).
- Qa Research (2016). *Information and advice since the Care Act: How are councils performing?* London: Independent Age. Available at <https://www.independentage.org/sites/default/files/2016-05/Care%20Act%20Information%20and%20Advice%20Research%20Report.pdf> (accessed 20 December 2017).
- Resolution Foundation (2008). *Facilitating increases in long-term care funding: A discussion paper*. Available at <http://www.resolutionfoundation.org/app/uploads/2014/08/Facilitating-Increases-in-Long-Term-Care-Funding-discussion-paper.pdf> (accessed 20 December 2017).
- Robertson, R., Gregory, S., & Jabbal, J. (2014). *The social care and health systems of nine countries*. London: The King's Fund. Available at <https://www.kingsfund.org.uk/sites/default/files/media/commission-background-paper-social-care-health-system-other-countries.pdf> (accessed 14 May 2018).
- Sal, N. (2015). *Health survey for England 2014. Chapter 7: Planning for future care*. Leeds: The Health and Social Care Information Centre. Available, with tables of figures, at <https://digital.nhs.uk/catalogue/PUB19295> (accessed 20 December 2017).
- San Antonio, P.M., & Rubinstein, R.L. (2004). Long-term care planning as a cultural system. *Journal of Aging & Social Policy*, 16(2), 35–48.
- SOLLA and ABI (2013). *Financial advice and long term care*. In Pensions and Insurance Working Group, *Developing products for social care* (pp. 36–40). London: Association of British Insurers. Available at <https://www.abi.org.uk/globalassets/sitecore/files/documents/publications/public/2014/social-care/developing-products-for-social-care-report.pdf> (accessed 8 January 2018).
- Stum, M.S. (2000). Later life financial security: Examining the meaning attributed to goals when coping with long term care. *Journal of Financial Counseling and Planning*, 11(1), 25–39.
- Stum, M.S. (2001). Financing long-term care: Examining decision outcomes and systemic influences from the perspective of family members. *Journal of Family and Economic Issues*, 22(1), 25–53.
- Stum, M.S. (2006). Financing long term care: Risk management intentions and behaviors of couples. *Journal of Financial Counseling and Planning*, 17(2), 79–89.
- Tanner, D., Ward, L., & Ray, M. (2017). 'Paying our own way': Application of the capability approach to explore older people's experiences of self-funding social care. *Critical Social Policy*. Advance online publication. <https://doi.org/10.1177/0261018317724344>.
- Terry, R., & Gibson, R. (2012). Affording help at home. *Journal of Care Services Management*, 6(1), 26–34.
- Walters, S. (2017). The Dementia tax backlash: Tories' lead slips by 5% after manifesto pledge to make more elderly pay for care. *Daily Mail*, 20 May. Available at <http://www.dailymail.co.uk/news/article-4525918/Tories-lead-slips-5-care-manifesto-pledge.html> (accessed 20 December 2017).
- Ward, L., Barnes, M., & Gahagan, B. (2012). *Well-being in old age: Findings from participatory research*. Brighton: University of Brighton and Age Concern, Brighton, Hove and Portslade. Available at http://eprints.brighton.ac.uk/10631/1/Well_being_in_old_age_findings_from_participatory_research_full_report.pdf (accessed 20 December 2017).
- Wright, F. (2002). *Asset stripping: Local authorities and older homeowners paying for a care home place*. Bristol: The Policy Press.
- Wright, F. (2003). Discrimination against self-funding residents in long-term residential care in England. *Ageing & Society*, 23(5), 603–624.



<https://journal.ilpnetwork.org>

ISSN 2516-9122