Unmet social care needs among older people in England: determinants, costs and outcomes

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A thesis submitted in partial fulfilment
of the requirements for the degree of
Doctor of Philosophy

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February 2024

Abstract

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Background. Unmet social care needs are an important problem for England's ageing population. This PhD study aimed to address research gaps relating to the determinants, consequences and costs of unmet need among older people living in private households in England.

Methods. A literature review was carried out to identify the determinants of unmet need, care receipt and source of care. Data from the English Longitudinal Study of Ageing (ELSA) was analysed to assess the determinants of unmet need and the association between unmet need and the progression of frailty over the following two years. Economic modelling was done using a decision tree connected to a Markov cohort model to assess the potential costs and benefits of shortening waiting lists for home care.

Results. The review included ten studies, which all used ELSA data. The data analysis found that living alone was a risk factor for unmet need, except in the wealthiest quartile. Local authority deprivation was positively associated with unmet need. Unmet need had a borderline significant association with lower odds of worsening frailty over the following two years. The economic model showed that shortening waiting lists for home care by six months would lead to an increase in life years, social care-related quality of life and informal carers' earnings, as well as to a reduction in NHS and private costs. However, it would also lead to increased personal social services costs and public sector costs.

Conclusion. This PhD study calls for more research on the consequences of unmet need. Further research would require data with detailed information on older people's difficulties with activities of daily living and information on whether those without help think they would need or want help.

Acknowledgments

I would like to thank my supervisors Dr. Sarah Barnes, Dr. Gurleen Popli and Dr. Chloe Thomas for all their invaluable guidance and feedback. I am immensely grateful to them for their constant reliability and for the care taken in supervising this PhD study.

I would also like to thank Prof. Helen Weatherly at the University of York for her useful and generous advice in relation to my economic modelling work. I am deeply grateful to the many people who provided advice in relation to this project. In particular, I would like to thank the public advisory group of older people and informal carers; the health and social care professionals and academics working outside the University of Sheffield who gifted me with their time and advice; the many members of staff in the Wellcome Trust Doctoral Training Centre in Public Health Economics and Decision Science, and more widely at the University of Sheffield, for providing precious advice for this project. I would also like to thank the other students in the Division of Population Health for sharing this PhD adventure and for being such great colleagues.

Finally, I would like to thank my whole very extended family and all my friends for all their support. In particular, I would like to thank my late grandmother Annamaria, for sharing her passion for numbers and social issues; my great-uncle Silvio for supporting me through my undergraduate degree, which opened up many opportunities for me; my mother, for always cheering for me and for helping me in so many ways; Andrea, for the constant support and positivity.

This research was supported by the University of Sheffield and the Wellcome Trust (108903/B/15/Z).

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Acronyms

ASCOT	Adult Social Care Outcomes Toolkit
BHPS	British Household Panel Survey
CES-D	Center for Epidemiological Studies Depression Scale
CI	Confidence interval (or credible interval in relation to the economic model results)
DAG	Directed Acyclic Graph
DHSC	Department of Health and Social Care
ELSA	English Longitudinal Study of Ageing
EU	European Union
IADL	Instrumental activity of daily living
ICER	Incremental cost-effectiveness ratio
IDAOPI	Income Deprivation Affecting Older People Index
IMD	Index of Multiple Deprivation
LA	Local authority
N	Number
NA	Not applicable
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OECD	Organisation for Economic Co-operation and Development
OLS	Ordinary least squares
ONS	Office for National Statistics
OR	Odds ratio
PADL	Personal activity of daily living
PSA	Probabilistic sensitivity analysis
PSS	Personal Social Services
PSS ASCS	Personal Social Services Adult Social Care Survey
PSS SACE	Personal Social Services Survey of Adult Carers in England
QALY	Quality-adjusted life year
SC-QALY	Social care quality-adjusted life year
SCRQoL	Social care-related quality of life
SD	Standard deviation
SE	Standard error
WHO	World Health Organization

Chapter 1. Introduction

The UK's population is ageing due to increased life expectancy and declining fertility [1]. 19% of the UK population was aged 65 and over in 2019; this percentage is projected to rise to 24% in 2043 [2]. For some older people, their right to a life with dignity is only possible with care and support from others [3]. The Universal Declaration of Human Rights [4] states that "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including […] necessary social services" (Article 25).

However, in England, local authority (LA)-funded social care is affected by a lack of funding and staff shortages [5]. Only those with high levels of need [6] and the "lowest" economic means ([7], p. 7) can have access to LA-funded care. In 2018/19, only 401,000 older people out of 1.4 million were successful in their request for care to LAs [8]. Moreover, difficulties to contact social services have been reported [9] and there have been long waiting lists to have an assessment of social care needs and for care to start after an assessment [5]. There have also been cases when social services could not provide the care that was initially agreed with the council because of a lack of capacity [9]. Problems of poor service quality and unreliability have been identified [9], especially with publicly funded services but also with services that people pay privately for [5]. For example, people have reported: visits that are too short [9]; changes in carers and times of visits without warning [9]; carers coming at inappropriate times (e.g., 5 pm to go to bed) [5, 9].

People with no access to publicly funded care or receiving inadequate publicly or privately funded care may not be able to rely on family and friends or they may feel guilty asking for help [10]. Moreover, people may not be able to afford private care or they may ration their care to save money for the future, when their needs may worsen [11]. Therefore, there are various circumstances which may lead to unmet need for care and support.

1.1. Definitions

1.1.1. Social and long-term care

Long-term care refers to services for people who "can no longer perform everyday activities on their own" ([12], para. 1). Long-term care includes social care and some forms of health care [13], for example nursing services.

Adult social care has not been defined in English legislation [14]; the Care Act 2014 mostly uses the term "care and support" ([15], p. i). The Department of Health & Social Care (DHSC)

2020 statutory guidance on care and support , which is based on the Care Act 2014, defines care and support as: “The mixture of practical, financial and emotional support for adults who need extra help to manage their lives and be independent” ([16], p. 404). Adult social care “includes a broad range of non-medical services” ([17], p. 4), including support with personal care (help with activities such as washing and dressing), practical help (assistance with tasks such as cooking, cleaning and grocery shopping); it “can also extend to a range of so-called *non-traditional services*” ([18], p. 2) such as courses or sport activities [18]. This research mostly focuses on personal care and practical support and uses the term social care to include formal and informal care.

Formal care can be publicly or privately funded, whereas informal care is unpaid [19] personal care and practical help given by family, friends [11], and neighbours [20].

“Home care” is used in this research to refer to personal care and practical support [21] provided at home by formal (public or private) services.

This study only focuses on care provision for people living in “private households”. This means that it does not focus on people in care homes. Care homes can be residential homes or nursing homes, i.e., homes that always have one or more qualified nurses on duty for the provision of nursing care [22]. “Residential care” is “long-term care provided in a care home” ([23], para. 2), so it refers to both residential homes and nursing homes [23].

1.1.2. Functional limitations, disability, impairment and frailty

Recipients of long-term care have functional limitations; these include limitations in “activities of daily living” ([24], p. 3), limitations in “general mobility” tasks ([24], p. 3) and “symptoms of chronic conditions” ([24], p. 3).

Activities of daily living can be classified into two categories: firstly, “personal activities of daily living” ([25], p. 1) (PADLs), which are sometimes called “basic activities of daily living” ([26], p. 1009) and abbreviated as “ADL” ([26], p. 1009); the PADL term is used in the present research. PADLs are “those skills required to manage one’s basic physical needs” ([27], para. 10). Questions on PADLs are included in the questionnaires of the English Longitudinal Study of Ageing (ELSA), which has studied people aged 50 and older living in private households in England, using surveys, since 2002 [28]. (The ELSA dataset is used for data analysis in this PhD study and is described more in detail in section 4.2.1.1). More specifically, six PADLs included in ELSA questionnaires are: “dressing, including putting on shoes and socks”, "walking across a room", "bathing or showering", "eating", including cutting up food, "getting in or out of bed", and "using the toilet, including getting up or down" ([29], p. 94). PADL limitations are addressed by personal care.

Secondly, "instrumental activities of daily living (IADLs)" ([27], para. 10) are "more complex activities that are related to the ability to live independently in the community" ([27], para. 10). IADLs would require practical help beyond personal care. The eight IADLs included in the ELSA questionnaires are: "using a map to figure out how to get around in a strange place", "recognising when you are in physical danger", "preparing a hot meal", "shopping for groceries", "doing work around the house or garden", "taking medications", "making telephone calls", and "managing money, such as paying bills and keeping track of expenses" ([29], p. 94).

Examples of general mobility tasks from the ELSA questionnaires are: "walking 100 yards", "climbing one flight of stairs without resting", "stooping, kneeling, or crouching", "lifting or carrying weights over 10 pounds", and "picking up a 5p coin from a table" ([29], p. 93).

Examples of symptoms of chronic conditions are problems with eyesight, hearing or balance [24].

In the present work, impairment refers to "problems in body function or alterations in body structure" ([30], p. 20). Disability includes "impairments, activity limitations and participation restrictions" ([31], para. 1) and is the "complex interrelationship between impairment, individual response to impairment, and the social environment" ([32], p. 7). Examples of what is included in the social environment are the built environment, technology, relationships, attitudes, support and services [33].

There are many definitions of frailty, but generally it can be defined as an increased vulnerability to stressors [34], which raises the risk of impairment, care home admission and death [35]. Some definitions of frailty include psychological and social factors in addition to physical ones [36]. Data analysis in the present work uses a frailty index that considers the presence or absence of many different potential health deficits. Section 4.2.1.4.4 presents previous literature about frailty indexes and describes the frailty index used in data analysis in chapter 4. A slightly different index is used in data analysis in chapter 5, as described in section 5.2.3.

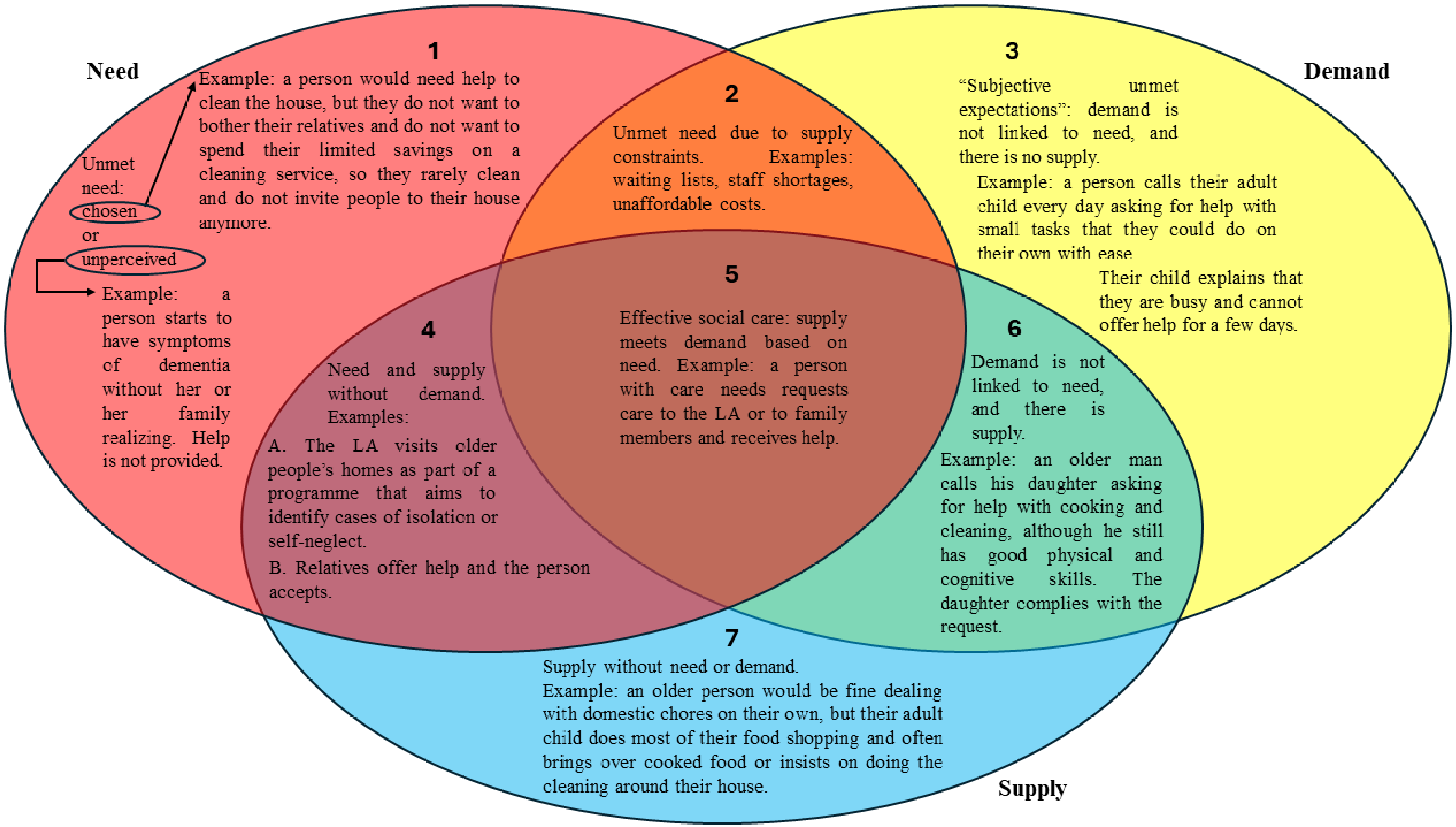
1.1.3. Unmet need for personal care or practical support

Unmet social care need has been defined differently in different studies. One study defined unmet need based on whether help was provided and if so, whether the person with care needs thought that it met their needs all the time (as opposed to usually, sometimes, or hardly ever) [37]. Another study defined unmet need based on target hours for five care need levels; where unmet need was the difference between the hours of care provided and the target amount [38]. Other unmet need definitions are outlined in section 3.3.2.

Kröger [39] distinguishes between unmet needs with PADLs, unmet needs with IADLs and unmet social and emotional needs. This work mostly focuses on unmet need for personal care and practical support rather than on social and emotional needs. However, when unmet need is defined based on people's perceptions of whether the help they receive for PADLs or IADLs or mobility tasks meets their needs, they may also refer in their answers to socio-emotional aspects.

Rodriguez Santana et al. [40] have published a conceptual framework that focuses on need, demand and supply in health care, which they use to define different kinds of unmet need (unperceived, chosen, or driven by supply constraints) and to clarify that subjective perceptions of unmet need do not necessarily correspond to unmet need as judged by professionals. The present work adapted their framework to the social care context. This is represented graphically in Figure 1.

Rodriguez Santana et al. [40] define need for health care as "the capacity to benefit from health care" (p. 3). Similarly, need for social care can be defined as the capacity to benefit from social care. The present work defines social care demand as the set of requests for help to either informal sources such as family or friends or to formal sources such as the local authority or private providers. Social care supply, in turn, is defined as the provision of social care, from informal or formal sources. Utilisation of social care occurs when a person receives social care.



1

Unmet need: chosen or unperceived

Example: a person would need help to clean the house, but they do not want to bother their relatives and do not want to spend their limited savings on a cleaning service, so they rarely clean and do not invite people to their house anymore.

Example: a person starts to have symptoms of dementia without her or her family realizing. Help is not provided.

2

Unmet need due to supply constraints. Examples: waiting lists, staff shortages, unaffordable costs.

3

“Subjective unmet expectations”: demand is not linked to need, and there is no supply.

Example: a person calls their adult child every day asking for help with small tasks that they could do on their own with ease.

Their child explains that they are busy and cannot offer help for a few days.

4

Need and supply without demand. Examples:

A. The LA visits older people’s homes as part of a programme that aims to identify cases of isolation or self-neglect.

B. Relatives offer help and the person accepts.

5

Effective social care: supply meets demand based on need. Example: a person with care needs requests care to the LA or to family members and receives help.

6

Demand is not linked to need, and there is supply.

Example: an older man calls his daughter asking for help with cooking and cleaning, although he still has good physical and cognitive skills. The daughter complies with the request.

7

Supply without need or demand.

Example: an older person would be fine dealing with domestic chores on their own, but their adult child does most of their food shopping and often brings over cooked food or insists on doing the cleaning around their house.

Figure 1. Conceptual framework of social care need, demand and supply. Adapted from Rodriguez Santana et al. [40].

Abbreviations: LA: local authority.

Figure notes. The phrase “subjective unmet expectations” is from Rodriguez Santana et al. [40], p. 4.

Figure 1 shows that if there is need but no demand, this means that there is either unperceived unmet need or chosen unmet need (see area 1 in Figure 1). There can also be demand for care without need (i.e., no capacity to benefit from the care that is requested). Demand without need and with no supply would correspond to “subjective unmet expectations” ([40], p. 4) but not to unmet need (see area 3 of Figure 1). Demand without need that results in supply of care would correspond to utilisation of inappropriate care (this would be area 6 in Figure 1).

When there is need and demand but no supply, unmet need would arise from issues such as waiting lists, staff shortages or unaffordable costs (see area 2 of Figure 1). A scenario that is important in social care but not always relevant to health care is the provision of care that is appropriate in response to a specific need, but is insufficient in quantity: for example, an insufficient number of hours of home care. This means that the same person could be experiencing both the provision of effective care and unmet need due to supply constraints, so it could be in both area 2 and 5 of Figure 1 at the same time. In relation to this, it is worth highlighting that a different conceptual framework of unmet need, produced by Kröger [39], distinguishes between unmet need with some care available and unmet need without any care. If a person had unmet need with no care at all, and if this was due to supply constraints, they would only be in area 2 of Figure 1.

The conceptual framework adapted from Rodriguez Santana et al. [40] is useful to reflect on how some people may not perceive a social care need, while in fact they might benefit from help, while on the other hand, self-reports of unmet social care need may not necessarily be supported by professionals making social care needs assessments.

Data analysis in the present work uses definitions of unmet need that have been constructed based on the ELSA dataset, so these definitions should not be considered as generalisable to other contexts. The definitions partly rely on people’s perceptions of met or unmet need and partly on the presence of difficulties with activities of daily living and the availability of help. They are presented in sections 4.2.1.3, 4.3.2 and 5.2.1.

This PhD study uses unmet need, unmet care need and unmet social care need as interchangeable terms.

1.1.4. Inequalities and inequity

The term inequalities refers to variations between groups of people, as defined by relevant determinants such as age, wealth, or area of residence [41]. Using the term inequalities implies that no moral judgement has been made on “whether observed differences are fair” ([41], p. 2). In contrast, the term inequity is used to refer to a difference that has been judged as unjust [41].

1.2. Research question, aims and objectives

Research question: What are the determinants, costs and outcomes associated with unmet need for personal care or practical support among older people living in private households in England?

Aims: To add to the existing evidence base on the determinants of unmet need among older people with functional limitations living in private households in England; to assess whether unmet need is a determinant of increased frailty; to analyse the costs and benefits of reducing unmet need by shortening waiting lists for home care for older people in England. This research aims to produce evidence that could be used in economic models and in health and social care policies focused on older people with limitations in activities of daily living.

Objectives

1. To understand the social care pathways operating in England for older people with functional limitations. This informs quantitative data analyses, the economic model, and the interpretation of results.

2. To incorporate the views of stakeholders (older people, informal carers, academics and health and social care professionals) by involving them in discussions about research choices and findings. This informs quantitative data analyses, the economic model, and the interpretation of results.

3. To review studies on the determinants of social care receipt, unmet need and source of care (including informal care and publicly or privately funded care) among older people living in private households in England. This informs additional investigation into the determinants of unmet need and the interpretation of results.

4. To add to the evidence base on the determinants of unmet need in England by conducting quantitative data analysis that incorporates new elements and provides new insight. This informs the selection of possible confounders for the data analysis assessing whether unmet need is a determinant of increased frailty. It also informs decisions on population subgroups of relevance for the economic model.

5. To investigate, using quantitative analysis, whether unmet need for care is a determinant of increased frailty and whether having falls and the number of depressive symptoms are mediators between unmet need and increased frailty. This enables consideration as to whether increased frailty, depressive symptoms and falls should be included in the economic model.

6. To develop an economic model that assesses the costs and benefits of reducing unmet care need by shortening waiting lists for home care.

The next section provides a rationale for pursuing these objectives.

1.3. Rationale for this research

This research focuses on both the determinants and the outcomes of unmet need. Understanding the determinants of unmet need is important to support policy makers, local authorities and charities to identify targets for new interventions and to tailor their efforts towards groups most at risk. Moreover, investigating inequalities in the receipt of care and support can help advocacy efforts by organisations, such as Age UK, to make unmet social care need a political priority. The reason for this is that while unmet social care need is a problem in itself, it is even more concerning if it is associated with specific characteristics such as gender or socioeconomic status: the International Covenant on Economic, Social and Cultural Rights, ratified by the UK in 1976 [42], states not only that everyone has a right to “an adequate standard of living” (article 11, [43]), but also that rights have to be guaranteed “without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status” (article 2, [43]).

Investigating the outcomes of unmet care need is important because unmet need can also be a problem from an economic perspective. For example, it could lead to health deterioration that leads to additional health care utilisation or to a care home admission. Limited budgets have been an important reason for unmet need in England. Therefore, assessing whether unmet need may cause increasing costs due to adverse outcomes would enable better decision-making in a context of scarce resources and may provide an economic argument for increasing the resources allocated to social care. However, research on the adverse consequences of unmet need has been limited within the English context. A review of studies that focused on these consequences [39] included only one UK study [11], which assessed the link between unmet need and wellbeing.

There are many potential consequences of unmet care need on the health status of a person with functional limitations [39]. This research assesses whether unmet need is linked to the progression of frailty over the following two years. This outcome was selected because frailty is associated with various adverse outcomes, as mentioned in section 1.1.2. A more detailed rationale for looking at the association between unmet need and the progression of frailty is presented in section 5.1.

Among various social care interventions that can reduce unmet need, shortening waiting lists for home care is an important one: a stakeholder consultation looking into research priorities for home care for older people identified “timely engagement with homecare” as one of the main priorities ([44], p.e5656). Economic modelling is best placed to assess the costs and benefits of shortening waiting lists because it can make transparent assumptions where evidence is lacking and can test the effects of changing these assumptions. It can also combine evidence from different sources. Section 6.1 provides a more detailed rationale of why an economic model of shortening waiting lists may be needed.

The literature on the determinants of unmet care need and its adverse outcomes has so far remained mostly unlinked from economic modelling methodologies. For example, Kröger’s book [39] on older people’s unmet needs extensively focuses on inequalities and adverse consequences, but never mentions economic modelling. Some economic models have included unmet need but have remained unlinked from the literature reviewed in Kröger’s book [39], as is outlined in section 6.4. Making this link is important to evaluate possible health and wellbeing outcomes, costs and any impacts on inequalities of interventions that aim to reduce unmet care need.

This research focuses on the English context. England was chosen rather than the UK because social care in Scotland, Wales and Northern Ireland is under the responsibility of the devolved legislatures and administrations for these three UK countries [45]. This has resulted in four social care systems with considerable differences [46].

This rationale is explained more in detail in the following chapters. The next section provides an overview of the thesis structure.

1.4. Thesis structure

Chapter 1 has outlined the problem of unmet care need, relevant definitions, aims and objectives, and has provided a brief rationale for the whole thesis.

Chapter 2 sets the research in context by reviewing existing social care pathways (as per objective 1) and explaining how stakeholders were involved (note that incorporating their views corresponds to objective 2). Chapter 2 also includes information about the ethical approval obtained for this research project.

Chapter 3 presents a literature review on the determinants of social care receipt, unmet care need and source of care among older people living in private households in England (which addresses objective 3).

Chapter 4 addresses objective 4 and describes two data analyses on the determinants of unmet need. The main analysis, presented in section 4.2, includes both people with and without help in the sample. The second analysis, presented in section 4.3, is restricted to people with help and examines different sources of care as determinants of unmet need. Both data analyses are discussed in section 4.4.

Chapter 5 describes data analysis on whether unmet need is associated with worsening frailty over the following two years and whether having any falls and the number of depressive symptoms are mediators in this relationship. This addresses objective 5.

Chapter 6 presents an economic model which assesses the costs and benefits of shortening waiting lists for home care. This addresses objective 6.

Each chapter from 2 to 6 has sub-sections that include an introduction or rationale for the work presented within the chapter, methods, results, and a discussion. Chapter 7 presents a final discussion, which summarises the original contribution made in this PhD study and includes further reflections that relate to all chapters together.

Chapter 2. Setting the research in context: care pathways and stakeholder input.

This chapter describes the involvement of older people, informal carers, academics and health and social care professionals, and presents a review of social care pathways in England after the Care Act 2014 [15]. Both the input from stakeholders and the review were important to set the research in context. This chapter also details the ethical approval obtained for this PhD study.

2.1. Ethical approval.

The PhD project was approved by the University of Sheffield Ethics Committee on 26/10/2021 (reference number: 042507). An amendment was approved on 18/10/2022. The approved ethics application outlined data management procedures and explained how stakeholders would be involved. See Appendix 2A for the ethics application (including the amendment), Appendix 2B for the data management plan (which was attached to the ethics application), and Appendix 2C for the ethics approval letter. Regarding data management, this project abided to the conditions of the End User Licence and Special Licence for the ELSA data as agreed with the UK Data Service.

The sections below provide more details on how stakeholders were involved. This is followed by a review of care pathways.

2.2. Involvement of older people, informal carers and professionals

2.2.1. Patient and public involvement– the public advisory group

A public advisory group of older people and informal carers from different areas of England was set up. The aim of the group was to provide advice on research choices as well as on interpretation of results, giving more depth and context to the quantitative data sources utilised for the study.

The opportunity to be part of the public advisory group was advertised by email to people registered in a database of the University of Sheffield, who had been recruited through a variety of networks, including the People in Research platform [47]. Seven people responded and then took part in some or all meetings. One person became uncontactable after the first meeting, two people joined later but were regularly engaged with the project since joining, and four people were involved throughout the study.

Meetings took place on Google Meet and were audio recorded through Google Meet (after switching videos off first as per the School of Health and Related Research Information Governance Policy).

INVOLVE guidance was followed in relation to the involvement of older people and carers [48]. For example, they were provided with feedback on their recommendations through email updates and presentations and were offered payment in line with the rates suggested by the National Institute for Health and Care Research (NIHR).

Table 1 provides a chronological summary of how the public advisory group was involved.

Table 1. Chronological summary of the involvement of the public advisory group.

Month & year and N of people	**Purpose of meeting / email contact plus any comments.**
January 2021 5 people	In the first meeting, initial research ideas were presented, and feedback was sought on potential directions of research. An idea was presented, to study the determinants of unmet need, defined in terms of frequency of support. The public advisory group criticised this definition of unmet need and emphasised that each person has unique care needs. Considering their advice, as well as some limitations regarding the information available in ELSA in relation to the frequency of support, the idea was dropped.
March 2021 5 people responded.	The group was emailed to give advice on whether the data analysis should focus on the effect of unmet need on physical health or mental health. Replies from the group members were mixed but highlighted that mental health influences physical health, and vice versa. Considering this, depressive symptoms were included as a mediating variable between unmet need and increase in frailty.
August 2021	An update was sent to the group by email on progress made up to that point.
February and March 2022 5 people	Meetings with the group members were held to discuss the potential inclusion of variables relating to aids and adaptations in the data analysis on the determinants of unmet need. Section 4.4.4 provides more details on this. After this, a pdf summary of the feedback provided and an update on the research decision taken by the PhD study author on this was sent to the group in April. One person joined for the first time.
December 2022 6 people	A meeting with the group was held as part of conceptual modelling for the economic model (section 6.2.1 explains this further). One person joined for the first time.
March 2023 6 people	A meeting was held with the group to present the data analysis results. The feedback from the group was that the language was too complex, and they disagreed with some results (for example, the result that no association was found between LA expenditure and unmet care need).
June 2023 6 people	Another meeting was held about the data analysis results to address feedback from the previous meeting. This time, the presentation had been considerably simplified and emphasised the limitations of the ELSA dataset. The presentation also highlighted that results should in no way be considered as a challenge to the lived experiences of people with care needs and their carers.
August 2023 4 people responded.	Due to scheduling issues, a meeting could not be held. A presentation of the economic modelling results was sent by email to the public advisory group and the group members were asked to provide feedback by email.

Table notes. Abbreviations: ELSA: English Longitudinal Study of Ageing; N: number.

2.2.2. Involvement of other advisors

Academics and social and health care professionals were also involved in the research as advisors. Because of their busy schedules, they were involved in one-to-one meetings as these were easier to organise and had the advantage that more questions could be asked to each advisor. They helped with research decisions and with the interpretation of results. Academics and health and social care professionals were initially not offered payment, but after a request was made for this from a stakeholder’s employer, an amendment was made to the ethics application in order to offer them the same payment given to older people and carers. Some advisors accepted the thank-you payment while others refused it.

2.3. Review – Social care pathways for older people with functional limitations living in private households in England and for their carers

2.3.1. Introduction

This review aims to outline social care pathways as set out in official government guidance and policies since the Care Act 2014. It highlights key points for an economic evaluation of the costs and benefits of shortening waiting lists for LA-funded home care. Moreover, having a clear picture of the policy context helped with the choice of variables to be included in quantitative data analysis and with the interpretation of results.

The first objective is to describe current access criteria for LA-funded care and support, which includes home care. This is useful to inform the quantitative data analyses on the determinants of unmet need and to understand who would be included in the population of the economic model.

The second objective is to outline any publicly funded services available to those that do not have access to LA-funded home care. This provides context for the quantitative data analysis, and it is useful to understand what would be available to people on a waiting list for LA-funded home care and to think about the economic model boundaries.

The third objective is to highlight essential requirements for the whole national context versus criteria allowed to vary locally. Considering local variations can inform the inclusion of geographical determinants in quantitative data analysis and can help to think about how an economic model for the English context could be adapted to local contexts.

The fourth objective is to outline publicly funded support for informal carers. This is useful to be aware of interventions other than home care when thinking about the economic model's boundaries.

The next sections present the review methods, findings, and a discussion.

2.3.2. Review methods

A review protocol was developed, which stated that the intervention of interest was publicly funded social care, including information and advice, personal care, domestic help, equipment and adaptations, so-called "non-traditional services" ([18], p. 2) such as courses or sport activities, and services for carers. See Appendix 2D for more details.

Inclusion criteria determined that the review would include information found on the national government website www.gov.uk, including the DHSC 2020 statutory guidance on care and support [16], and information from NICE guidelines on the website www.nice.org. Examples of resources that were excluded were: reports by charities or academics; resources focusing on care pathways for specific conditions; reports on the quality of services provided in practice, or geographical variations in practice (rather than variations allowed by official guidance and policies).

The search strategy followed published recommendations on systematic searches of websites and other online sources [49]. Based on these recommendations, the first step was to select which websites to search. The two websites mentioned above were selected. Search keywords on www.gov.uk included "Care Act 2014", "older people", "disability equipment", "disability benefits". The website www.nice.org was searched using the keyword "older people", filtering for guidance only. A systematic record was made of how each website was searched (see Appendix 2E, Table 46). Preliminary screening was done within websites based on titles and headings (see Appendix 2E, Table 47). Then, the full text of potentially relevant items was checked for further examination.

For data extraction and narrative synthesis, the protocol recommended prioritising the DHSC 2020 statutory guidance on care and support, which aimed to support local authorities in the implementation of the Care Act 2014. It was prioritised for its comprehensiveness as well as its reader-friendly language, as opposed to extracting information directly from the Care Act 2014 and related regulations. For topics not covered by the statutory guidance (standards relating to home care and eligibility criteria relating to specific benefits, i.e., the Disabled

Facilities Grant, Attendance Allowance, Carers’ Allowance, Carers’ Credit) information was extracted from other pages within www.gov.uk and from NICE guidelines.

As per protocol, the narrative synthesis prioritised key information for developing the structure of an economic model that would focus on access to LA-funded care.

2.3.3. Review findings

Nine sources were identified which had relevant information for the review [15, 16, 21, 50-55]: the Care Act 2014, the DHSC 2020 care and support statutory guidance, three NICE guidelines focused on older people (one about home care, one about falls and one about “independence and mental wellbeing” ([51], p. 8)), and four pages from the UK government website, which covered aspects not dealt with under the other documents. Fourteen sources were excluded after being checked full-text, see list with exclusion reasons in Appendix 2F.

The next sections summarise the care pathways identified based on the included sources.

2.3.3.1 Overview of care pathways

Figure 2 gives an overview of social care pathways.

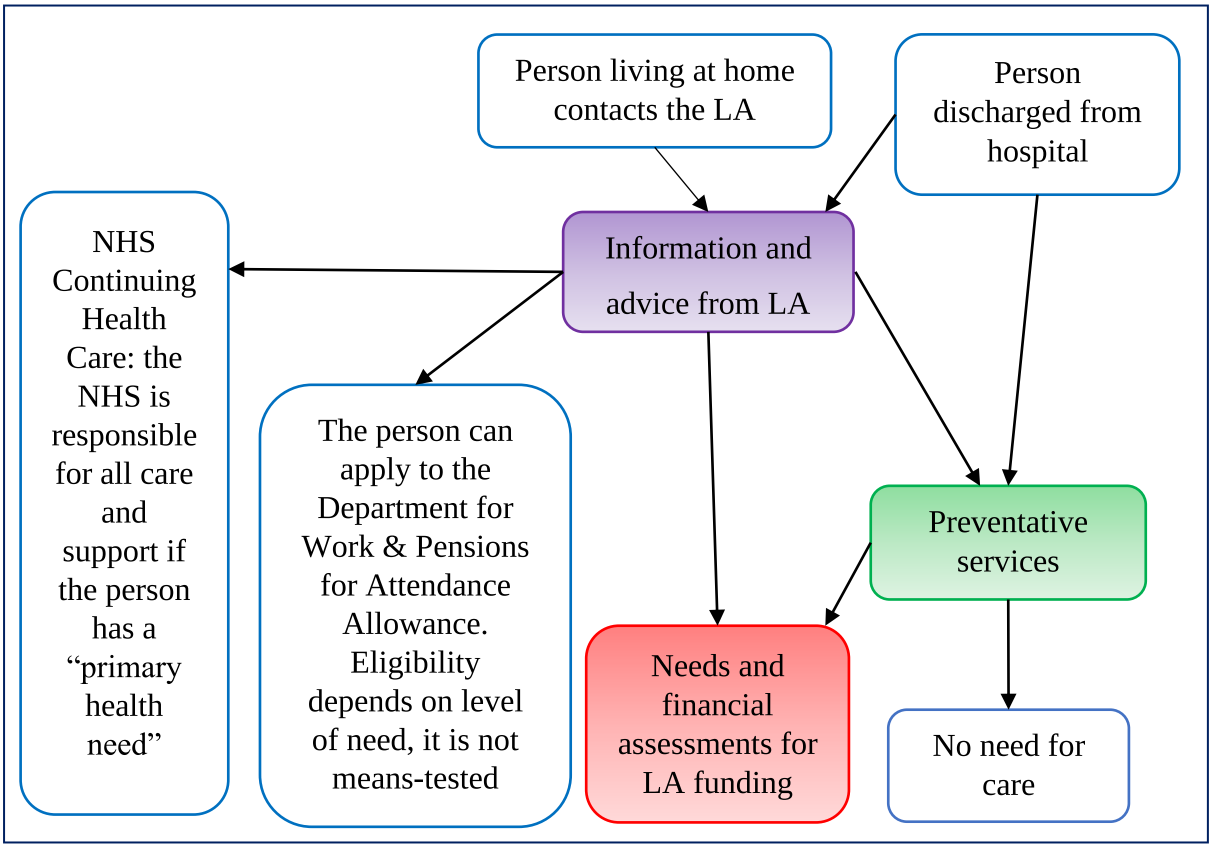


Figure 2. Overview of social care pathways relating to publicly funded services.
The figure colours are used to visually connect this figure to the other figures on care pathways: the green colour indicates preventative services, so it is used in Figure 3, which is about these services. The red colour indicates the needs and financial assessments for LA funding, so it is used in Figure 4, which is about these assessments. The purple colour is used for information and advice from the LA; it is also used in Figure 4.

According to the DHSC 2020 statutory guidance, information and advice should be received from the first contact a person makes with the LA regarding care and support [16]. Subjects to be covered include: what care and support is available and how it can be accessed, reducing care needs or delaying their progression, social isolation, housing options, handyman services, home adaptations, welfare benefits, support from family and friends [16]. The DHSC 2020 statutory guidance emphasises that LAs have to give information and advice to everyone, regardless of whether they may be eligible for LA-funded care [16].

After information and advice, people can be directed towards preventative interventions or to a formal care and support assessment, which decides whether the person is entitled to LA-funded care [16].

Separately from the eligibility assessments for LA support, the person can apply to the Department for Work & Pensions for Attendance Allowance [52]. This is financial help for people over state pension age with a physical or mental impairment severe enough that they need someone to help look after them [52]. It is not means-tested [52].

Alternatively to LA-funded care, a person may receive NHS Continuing Health Care. This is an arrangement where the NHS takes charge of all care and support needs [16]. It is for people that are judged to have a “primary health need” due to complex healthcare needs or due to the type or quantity of needs ([16], p. 243).

After hospital discharge, a person might receive intermediate care, which helps people recover and prevent readmission, so it comes under preventative services [16]. An example of intermediate care is reablement, which is carried out at home, mainly with social care professionals, to regain skills and capabilities and support independent living [16]. After that, the person may need to be assessed for longer term LA-funded support.

2.3.3.2 Preventative services

Figure 3 gives an overview of preventative services.

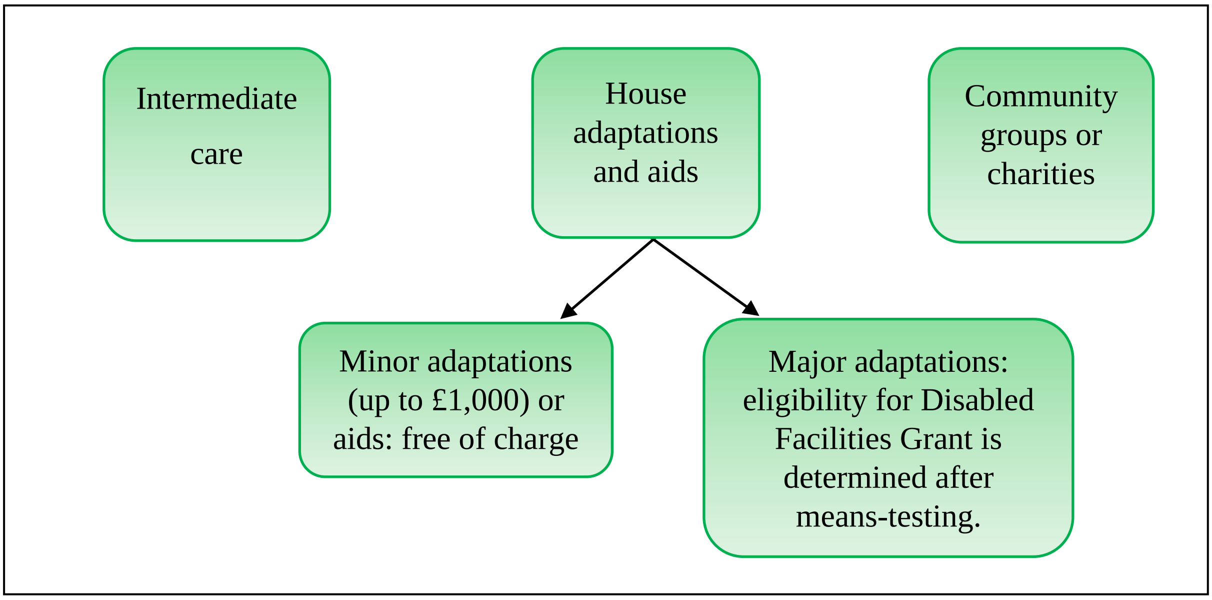


Figure 3. Preventative services.
The green colour indicates preventative services; it is also used in Figure 2, so it is used to link together the two figures.

LAs have responsibility for providing preventative services to all adults, regardless of any needs they may have. Intermediate care, including reablement, has to be given without charging for up to six weeks [16].

House adaptations and aids can promote independence. Aids and minor adaptations (not costing more than £1,000) must be given free of charge [16]. For expensive adaptations, for example installing a stairlift, a Disabled Facilities Grant is available from the local council based on means-testing [55].

Official guidance recognises that community groups or charities can play an important role to promote wellbeing and to prevent social isolation. Indeed, the NICE guidance on home care recommends considering the involvement of the voluntary sector and community organisations to support the person's wellbeing [21]. Other NICE guidance considers that older people with a disability related to age and carers are at higher risk of deterioration in their "independence and mental wellbeing" ([51], p. 8). Therefore, NICE recommends that they should be encouraged to engage in activities that interest them, including group activities and one-to-one befriending opportunities, and should be encouraged to volunteer [51]. The DHSC 2020 guidance states that the assessment of care and support needs is an opportunity to signpost people to any relevant community support groups [16]. Moreover, care and support planning must consider support available in the community [16].

2.3.3.3 Eligibility assessments and personal budgets

Figure 4 shows the pathways from having formal assessments to either receiving LA-funded care or simply receiving further information and advice.

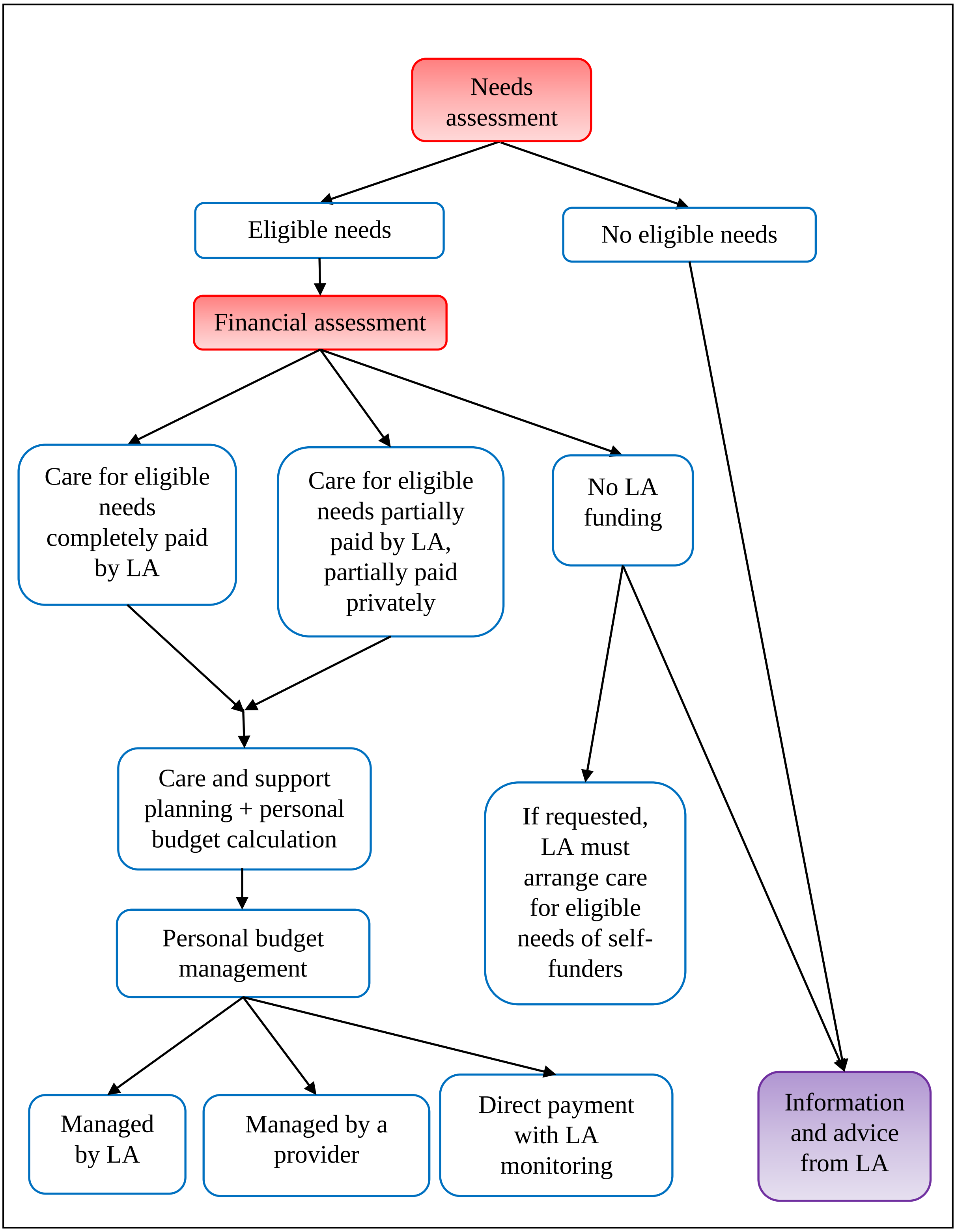


Figure 4. Eligibility assessments for LA funding and management of personal budgets. The figure colours are used to link the figure above to Figure 2. The red colour is used for the needs and financial assessments, and it is also used in Figure 2. The purple colour is used for information and advice from the LA, and it is also used in Figure 2.

2.3.3.3.1. Needs assessment

A needs assessment must not be influenced by the financial situation of a person or by any support provided by a carer [16]. A financial assessment would only be done after the need eligibility determination [16]. The carer must only be considered when planning care and support following the needs and financial assessments [16].

At the national level, there is a minimum level of care and support needs eligible for LA support [16]. An LA can also meet needs lower than this threshold [16]. The minimum threshold is that the person is unable to achieve at least two outcomes, with an impact on their wellbeing, out a list of outcomes that include for example: "maintaining personal hygiene" ([16], p. 84); "developing and maintaining family or other personal relationships" ([16], p. 84).

An adult is considered unable to accomplish an outcome if they cannot do it on their own, or doing it without help causes "significant pain, distress or anxiety" ([16], p. 82), or endangers health or safety, or takes a long time [16]. Wellbeing includes for example personal dignity and control over daily life [16].

2.3.3.3.2. Financial assessment

A means-test determines whether a person has a right to care free of charge [16]. When undertaking a financial assessment, the LA must consider both income and capital [16]. Income includes "pensions, benefits or earnings" and capital includes "cash savings and investments, land", "property" and "business assets" ([56], para. 3). For people living in private households, the value of their home is ignored [16].

Capital is assessed using an upper and lower limit. A person with capital above the upper threshold has to pay the whole cost of care and support [16]. Capital between the lower and upper threshold is considered able to produce income, so the person has to contribute to care and support costs [16]. Capital below the lower threshold is not considered when calculating whether the person should pay any charges [16]. The DHSC 2020 Care and Support Statutory Guidance mentions that the upper limit corresponds to £23,250, the lower limit to £14,250 [16]. However, for adults living in private households, these limits are "simply minimums" ([16], p. 111). Therefore, local authorities can adopt higher capital limits [16] to reduce the number of people that face charges.

Regarding income, charges are limited by a national minimum income guarantee; people can be left with more than this minimum, depending on local authorities' decisions [16].

If requested, the LA has to organise care and support to address the eligible needs of people that finance their own care and live in private households [16].

2.3.3.3.3. Care and support planning

For people that are eligible for LA-funded or arranged care, the care and support plan should “put people in control of their care” ([16], p. 139). The LA does not have to take on any care and support duties performed by an informal carer if the informal carer wants to do so [16].

2.3.3.3.4. Personal budgets

The DHSC 2020 statutory guidance explains that a personal budget is the money allocated to the care and support plan and it includes any amount that the LA must pay as well as the amount that the adult must pay themselves (if any, based on their financial assessment) [16]. People can choose to let the LA or a provider manage the personal budget, or can choose to receive a payment from the LA to “buy their own care and support” ([16], p. 7); this is called a “direct payment” ([16], p.6). Usage should be monitored by the LA [16].

2.3.3.4 Home care

Home care or other services that may result from care and support planning would be paid for through a personal budget managed by the LA or a provider, or with a direct payment. NICE guidance states all the following points relating to home care: it must be person-centred, rather than a “one size fits all” service ([21], p. 13). It needs to focus not just on practical support, but also on wellbeing [21]. Home care should address people’s priorities; people should decide whether they want to have a flexible home care package, so that home care focuses on what is needed each time and is used for a variety of tasks [21]. Home care should provide support beyond personal care, for example, with cleaning tasks [21]. “Continuity of care” ([21], p. 13), where the person has the same home care workers, should be a priority [21]. Home care visits need to be long enough for completing the work without compromising quality or the dignity of the person [21].

2.3.3.5 Informal carer’s support

The care pathways for informal carer’s support are not represented in the figures above. Eligibility for support would be decided with a carer’s assessment conducted by the LA [16]. Eligibility of carers does not depend on the eligibility of the cared-for person [16]. Carer eligibility depends on the impact of their caring role on their physical or mental health, their wellbeing, and specific outcomes such as engaging in work [16]. Some support can be provided through activities where carers participate, for example, a meditation course. Additionally, care and support can be given to the cared-for person, so that the carer can have some time off [16]. In the latter case, the LA must not charge a carer, but may charge the cared-for person [16]. Moreover, those that care for a minimum of 35 hours a week and fulfil other conditions, including earnings below a certain amount, are entitled to a weekly Carer's Allowance [53]. Carers under state pension age who look after someone for at least 20 hours a week are entitled to Carer's Credit, which allows to fill gaps in the National insurance record [54]. This record is used to calculate a state pension [54].

2.4. Discussion

The review outlined access criteria for LA-funded care for people living in private households. The review focused on official guidance and policies, while stakeholder input and other reports [5, 57] were useful to better understand how policy implementation partly differs from official guidance. Both the review and stakeholder input inform the economic model on waiting lists for home care in chapter 6 and quantitative data analysis in chapter 4 on the determinants of unmet care need. The following paragraphs summarise how the review and stakeholder input informed both pieces of work.

The review mentioned multiple services available to those who do not have access to LA-funded care; these include universal access services (information and advice, intermediate care, aids and minor house adaptations), as well as care or benefits that are provided based on evaluations that are separate from the LA needs and financial assessment (Attendance Allowance, the NHS Continuing Health Care, the Disabled Facilities Grants). Moreover, the review highlighted that the role of community groups or charities is recognised in official guidance and policies. The review also briefly mentioned services and benefits available to informal carers. This information is useful to clarify the boundaries of the economic model in chapter 6, which explicitly excludes people recently discharged from hospital, people funded by the NHS Continuing Healthcare, and any interventions other than home care. The review also explained how the availability of informal carers is considered by the council in care and support planning. This is useful to interpret some findings in chapter 3 on the relationship between formal and informal care.

The review also defined the role of home care. The emphasis of NICE guidance on how care should be flexible and person-centred, based on what is needed, highlights that home care provision is an intervention that should directly address unmet need for personal care and practical support. However, stakeholder input highlighted that home care in practice has many limitations and the literature mentioned that home care in practice is often limited to personal care in England [58]. In considering how the reality partly differs from official guidance, the economic model in chapter 6 considers that home care is commonly limited to personal care and it includes the possibility that LA-funded home care may not meet needs.

The review section on personal budgets and direct payments is useful to better understand the home care intervention in the economic model in chapter 6. It makes clear that improving access to home care would include not only home care provision by the LA, but also direct payments to people arranging their own care or LA-funded personal budgets managed by private providers. Furthermore, home care may be arranged by the LA but funded privately. All of this informs the definition of different sources of care in the data analysis in section 4.3.

The review highlighted that LAs can protect more people from charges than those who are protected from charges under the Care Act 2014; LAs can also meet more needs than those eligible under the same act. This informs quantitative analysis in chapter 4, which includes LA-level determinants following the consideration that local authorities' policies and services may be important determinants of unmet need. Although the economic model in chapter 6 does not include local area variation, findings from this review are useful to consider how this variation could be incorporated in further modelling work.

The review focused on social care pathways in the post-Care Act 2014 context. A social care reform is planned from October 2025 [59], which will modify some of these pathways. The present work does not focus on this, but section 7.5 briefly mentions the key changes expected from the reform and provides recommendations for further research in the new context.

The next chapter presents a literature review on the determinants of social care receipt, unmet care need and source of care. The review is not limited to the post-Care Act 2014 context, while data analysis in chapters 4 and 5 and the economic model in chapter 6 focus on this context.

Chapter 3. Review of the determinants of unmet care need, care receipt and source of care

3.1. Introduction

As mentioned in section 1.3, identifying the determinants of unmet need can help to identify targets for new interventions and to tailor social care interventions towards groups most at risk. Kröger [39] published an international review on the determinants of unmet need. This included two England-based studies [11, 60] but did not include other relevant studies conducted in the English context. Therefore, a more comprehensive review focused on England is required.

The present review focuses not only on unmet need but also on care receipt. Unmet need has been defined based on an absence of care by some authors [19, 60, 61], while other authors have examined the determinants of receiving care without attempting to define unmet need [19, 62]. This review focuses on both kinds of studies to provide a comprehensive picture of the literature.

In addition to investigating the determinants of unmet need and of care receipt, understanding what sources of care people rely on is also important. Some groups of people may be more likely to rely on informal carers, who, in turn, can have adverse consequences from caring for many hours. For example, a study in the UK found that providing more than 20 hours of informal care per week had a negative effect on mental health [63]. Therefore, a distinction has to be made between care received from informal carers and care received from privately or publicly funded sources.

The first objective of this literature review is to assess the determinants of unmet need and of care receipt. Relevant outcomes include receipt of any care versus no care receipt, the amount or frequency of care received, or a subjective assessment of whether the care received is sufficient.

The second objective of this review is to investigate the determinants of care receipt from specific sources, for example, informal or formal care, children or spouses, or publicly or privately funded care. For this second objective, relevant studies can focus either only on people receiving care or on anyone in need. For example, if a study focuses on the determinants of receiving informal care, compared to not receiving it, no receipt could mean no care at all or care from other sources.

This review aims to highlight key findings from previous studies and identify any gaps for further research. The review is also used to produce a list of variables to consider for inclusion in further analyses on the determinants of unmet need, care receipt or source of care.

3.2. Review methods

Inclusion and exclusion criteria are presented in Table 2. For more details, see the review protocol in Appendix 3A.

Table 2. Inclusion and exclusion criteria.

Population	Included studies on older people (as defined in the studies) living in private households and with functional limitations (as defined in the studies). Excluded studies that only focused on specific conditions (e.g., dementia).
Determinants	Included all determinants reported in the studies. Examples: gender, age, level of care need, wealth, education, occupational class, characteristics of LA where a person lives.
Outcomes	Met or unmet need, as defined in the studies; receipt or no receipt of care, as defined in the studies; receipt or no receipt of an adequate amount of care, as defined in the studies; amount of care received. Care receipt from a specific source (e.g., publicly funded, privately funded, informal).
Study design	Included quantitative studies that used multivariable data analysis. Included individual-level studies and multi-level studies and excluded ecological studies.
Context	Included studies conducted in England, before any Covid-19 restrictions were put in place.
Publication date	Included studies published from 2010 onwards.

Three databases were searched between January and March 2021: Social Care Online, Embase via Ovid and Econlit via Ovid. These databases cover social care, biomedical and economic literature, respectively. Search terms were tailored to the specific databases, and included keywords related to older people, informal care, adult social care, long term care and unmet need. Geographic filters were used to narrow the search down as far as possible, i.e., to the United Kingdom (Social Care Online and Embase) or to Europe (Econlit). A date limit from 2010 was included. The systematic search strategies and exact search dates are outlined in Appendix 3B.

Bibliographic details of retrieved studies were stored in EndNote 20. After removing duplicate records, titles and abstracts were screened. This was followed by full-text screening of articles that looked relevant based on title and abstract. Data extraction was performed in Microsoft Excel (version 2304). Data extraction focused on the key characteristics of included studies, the determinants assessed, whether there were significant associations and the direction of these associations. Quality assessment of the included studies was done with a slightly modified version of the Joanna-Briggs case-control studies critical appraisal tool [64]. Although not all included studies were case-control studies, slightly adapting the questions retained the usefulness of the tool to reflect on the methodological quality of all included studies. Adaptations to the critical appraisal tool are presented in Appendix 3D.1. After data extraction and quality assessment, a narrative synthesis was carried out. All steps were performed by one reviewer only (the author of this PhD study).

3.3. Results

3.3.1. Studies identified

Two resources were not among the outputs of the systematic searches and were added manually to the search outputs:

- Read et al. [61] was identified through a pre-print version [65]. Initially, results from the pre-print were included, then, these were updated based on the final publication.
- A Think Local Act Personal Partnership (2012) report was identified when checking a scoping review which was found with the systematic searches (Baxter 2016). See Appendix 3C for exclusion reasons of both the report and the review.

Overall, 439 titles and abstracts were reviewed. 38 publications were reviewed full-text, 27 were excluded full-text (see exclusion reasons in Appendix 3C) and 10 studies reported in 11 publications were included. Figure 5 shows the PRISMA flowchart.

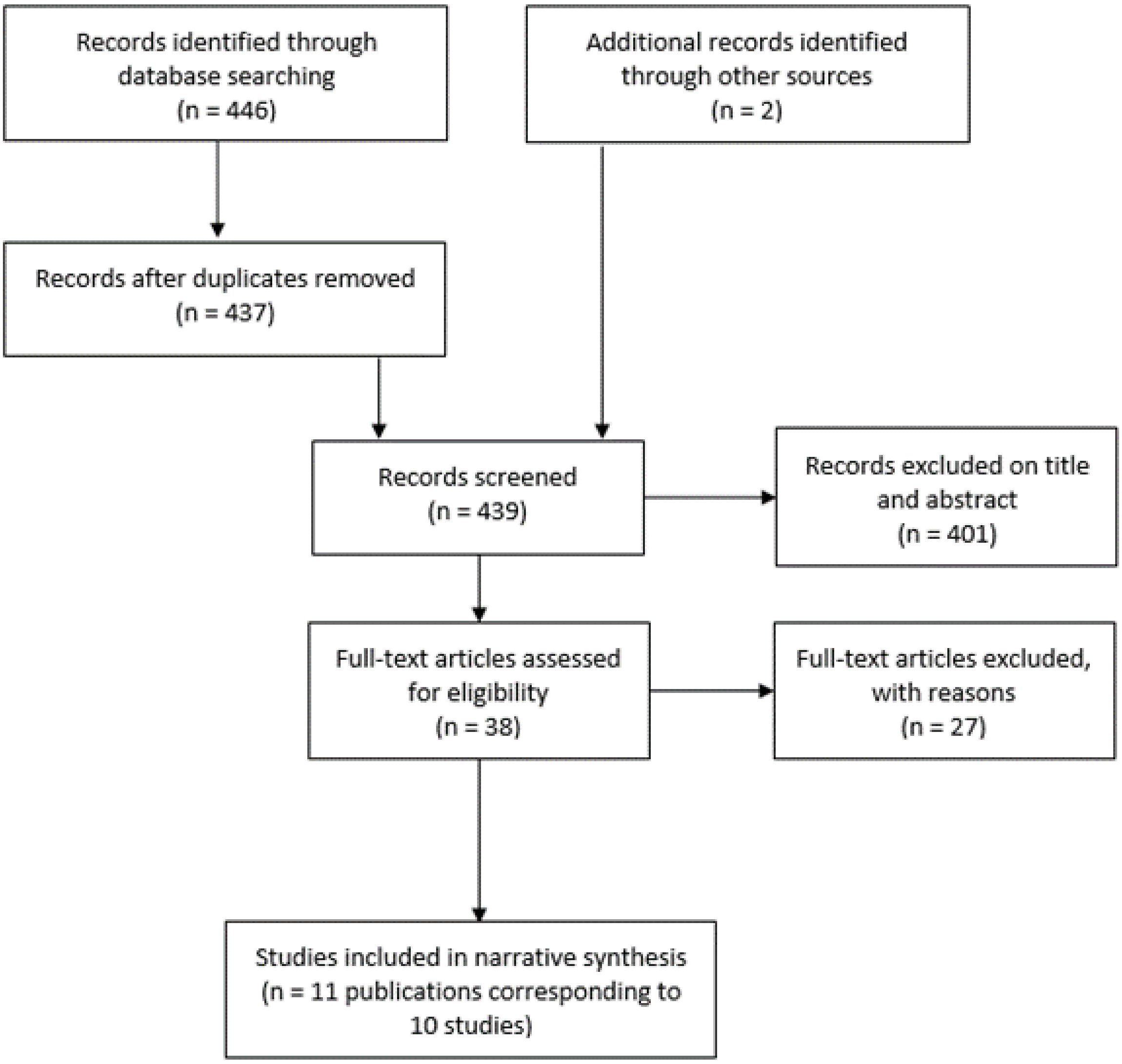


Figure 5. PRISMA flow diagram.
Adapted from: [66]

3.3.2. Characteristics of included studies

All studies were retrospective studies, as they were based on pre-existing datasets. All studies focused on England and used data from ELSA. ELSA data have been collected at two-yearly waves since the first wave in 2002-3. ELSA follows the same participants over time but new participants (called “refreshment samples”) ([67], p. 5) have been added at several waves [67]. ELSA questionnaires present people with a list of PADL, IADL and mobility tasks and ask them if they have any difficulty with each of these tasks. In case of an affirmative answer, questions on help receipt follow on. The studies used data from different waves. Moreover, different studies used different age and difficulties criteria to define their samples. Two studies [37, 68] also used data from other sources to include geographical determinants.

Six studies, reported in seven publications, assessed the determinants of unmet need or care receipt [11, 19, 37, 60-62, 69]. More specifically, four studies reported in five publications focused on unmet need [11, 37, 60, 61, 69], while two studies focused on care receipt vs. no care receipt, without attempting to define "unmet need" [19, 62]. Two publications that looked at unmet need presented the same analysis: one was a grey literature publication [11] and one was a journal publication [69]. For data extraction and the narrative synthesis, only reference to the journal publication is made [69] except for any information contained solely in the other publication [11].[1]

Studies that focused on unmet need defined it in different ways. Three studies considered the difficulties reported by a person and whether help was received specifically for these difficulties [60, 61, 69]. One of these three studies also considered whether the person had a relevant aid or home adaptation [69]. A fourth study [37] focused on receipt of any help and on people's perceptions of this help. See Table 3 for more details on the unmet need definitions.

Of the two studies that looked at care receipt, one study [19] looked at whether care was received for any PADL or IADL difficulties; a second study [62] focused on whether care was received for any mobility, PADL or IADL difficulties. This study also focused on continued absence of care receipt across two consecutive surveys and on offset of care, i.e., care no longer provided in the second interview (two years after the first). Although these studies focused on whether any care was received, data extraction focused on "absence of any care" and so reversed directions of associations accordingly. This was done to make the data extraction tables more consistent: for example, a positive association indicated that a specific determinant was a risk factor for either "unmet need" or "absence of any care".

Six studies [19, 62, 68, 70-72] assessed the determinants of receiving care from a specific source, including: from spouse or partner ([68, 70], children [70, 71] , son, daughter [68], relatives, friends, "children or relatives or friends" [71], any informal source [62, 72], any formal source [62], privately-funded, publicly-funded [62, 68, 72], only informal care from within the same household, only informal care from another household, only formal care, a mix of formal and informal care [19].

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[1] The odds ratios calculated from the multivariable logistic regression were exactly the same in the two publications. The grey literature publication mentioned two additional variables (which were not found to be significant predictors in the multivariable analysis and were not included in the final model): presence of children in the household; income.

One study [19] only included people who received help, so the focus of the analysis was on whether someone received care from one source (or combination of sources) rather than another source. The other five studies focused on whether someone received care from one specific source or not; in these studies, not receiving care from that specific source could mean either receiving care from other sources or not receiving any care.

See Table 3 for the characteristics of included studies on unmet need or care receipt and Table 4 for the characteristics of included studies on receiving care from a specific source. Note that two studies [19, 62] covered both outcomes: care receipt and receiving care from specific sources. Therefore, they are included in both tables.

Table 3. Characteristics of included studies on the determinants of absence of care or unmet need.

Study	Study design and methods	Population	Sample size	Data source	Outcomes
Crawford and Stoye 2017[62]	Retrospective study Analysis 1: cross-sectional Analysis 2, 3 and 4: longitudinal Linear probability models	People aged 65 and over. Moreover, different conditions applied for sample size definition, depending on the analysis: Analysis 1: with at least one limitation in PADLs, IADLs or mobility tasks Analysis 2: interviewed in two consecutive surveys, with at least one limitation in PADLs, IADLs or mobility tasks in second interview, and no difficulties and no care at first interview Analysis 3: interviewed in two consecutive surveys, no care receipt at first interview and with at least one limitation in PADLs, IADLs or mobility tasks in both interviews Analysis 4: interviewed in two consecutive surveys and received care at first interview	Analysis 1: 2,289 Analyses 2, 3, 4: not reported	Analysis 1: ELSA, wave 7 (2014-15) Analyses 2, 3, 4: ELSA, wave 1 (2002-03) to wave 5 (2010-11)	Analysis 1 and 2: absence of any care for PADL, IADL or mobility difficulty[2] Analysis 3: continued absence of care[3] Analysis 4: offset of care, i.e. care no longer provided

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[2] Note that data extraction and narrative synthesis focused on this outcome although the outcome in the original paper was the opposite, i.e., receiving help for any difficulty; directions of association were reversed accordingly.

[3] Note that data extraction and narrative synthesis focused on this outcome although the outcome in the original paper was the opposite, i.e., onset of care; directions of association were reversed accordingly.

Study	Study design and methods	Population	Sample size	Data source	Outcomes
Dunatchik, Icardi and Blake 2019 [69] (and Dunatchik 2016 [11] reporting the same analysis)	Retrospective study, longitudinal (the study focused on 10-year prior predictors of unmet need). Logistic regressions, results presented as odds ratios.	People without PADL limitations at wave 1 (2002-03) and with at least 1 PADL or 2 or more IADL or mobility limitations (disregarding difficulties with stairs) at wave 6 (2012-13), aged 60 and older at wave 6.	749	ELSA, wave 1 (2002-03) for determinants[4]; wave 6 (2012-13) for unmet need.	Unmet need defined as not receiving help and not having an aid or home adaptation for at least one PADL difficulty or at least two non-PADL difficulties.
Iparraguirre 2020a[37]	Retrospective study, longitudinal. Using "two-level and cross-classified panel logistic regressions" ([37], p. 1).	Analysis 1: people with at least one PADL or IADL limitation, aged 65 and over Analysis 2: people with at least one PADL or IADL limitation, aged 65 and over receiving some help	Wave 2: 1,695; wave 3: 1,530; wave 4: 1,762; wave 5: 1,624; wave 6: 1,737	ELSA, waves 2-6 (2004-2005 and 2012-2013) and other datasets for LA-level determinants.	Analysis 1: unmet need defined as not receiving help or help not meeting needs all the time Analysis 2: unmet need defined as help which does not meet needs "all the time" ([37], p. 10)
Read et al. 2022 [61]	Retrospective, cross-sectional study Analysis 1: logit model; beta	People aged 50 and over with at least one limitation in PADLs, IADLs or mobility tasks.	Analysis 1: 12,756	ELSA, data pooled across three waves: waves six (2012/13),	Analysis 1: at least one unmet need, i.e., did not receive help for at least one reported difficulty

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[4] Except for one determinant: becoming widowed between wave 1 and 6.

Study	Study design and methods	Population	Sample size	Data source	Outcomes
	coefficients presented. Analysis 2: “generalised linear model (GLM) with a log link and a gamma distribution” ([61], p. 3)	Additionally, analysis 2 only included people that had at least one unmet need.	Analysis 2: 8,490	seven (2014/15) and eight (2016/17)	Analysis 2: the number of unmet needs, i.e., the number of difficulties without related help.
Solé-Auró and Crimmins 2014 [19]	Retrospective, cross-sectional study Logistic regressions; beta coefficients presented	People aged 50 and over who had at least one limitation in PADLs or IADLs	2,372	ELSA, wave 3 (2006-07)	No receipt of any care for PADLs and IADLs[5]
Vlachantoni 2019[60]	Retrospective, cross-sectional study	People aged 65 and over with at least one PADL, IADL or mobility limitation who did not respond by proxy[6]. [69]	1,223 people with a PADL difficulty; 1,217 people with a	ELSA, wave 7 (2014-15)	The paper focused on 3 outcomes: unmet need for care and support with PADLs; unmet need for support with IADLs;

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[5] Note that data extraction and narrative synthesis focused on this outcome although the outcome in the original paper was the opposite, i.e., receiving help for any PADL or IADL difficulty; directions of association were reversed accordingly.

[6] Proxy respondents are used in ELSA either because the respondent is temporarily in a hospital or nursing home, or because they chose not to engage in a self-interview. Moreover, from wave 4, a proxy interview has also been used if a physical or cognitive impairment prohibited an in-person interview 69. Dunatchik A, Icardi R, Blake M. Predicting unmet need for social care. J Long Term Care [Internet]. 2019 [cited 2021 March 17]:194-205. Available from: https://doi.org/10.31389/jltc.33.

Study	Study design and methods	Population	Sample size	Data source	Outcomes
	Logistic regressions.		IADL difficulty; 2,364 people with a mobility difficulty		unmet need for support with mobility tasks. Unmet need was defined as not receiving any help from any source with at least one reported difficulty in the relevant category (PADLs, IADLs or mobility).

Table 4. Characteristics of included studies on receiving help from a specific source of care.

Study	Study design	Population	Sample size	Data source	Outcomes
Blomgren et al. 2012 [70]	Retrospective, cross-sectional study. Logistic regressions	Older people aged 70 and over with functional limitations, defined as limitations in at least one ADL, IADL or with climbing stairs. The analysis on help from children only included parents. The analysis on help from spouse only included those who lived with a spouse (not only married people but also those with a partner)	Analysis on people living with a spouse: 1,084 Analysis on parents: 1,913	ELSA wave 1 (2002-2003)	Outcome in the analysis only with those who lived with a spouse: receiving care and support from spouse. Outcome in the analysis only with parents: receiving care and support from children.
Crawford and Stoye 2017 [62]	Retrospective study Analysis 1: cross-sectional Analysis 2, 3 and 4: longitudinal Linear probability models	People aged 65 and over who did not fill in an institutional questionnaire. Moreover, different conditions applied for sample size definition, depending on the analysis: Analysis 1A and 1B: limited in at least one PADL, IADL or mobility task. Analysis 2A and 2B: interviewed in two consecutive surveys, limited in at least one PADL, IADL or mobility task in second interview, and no difficulties and no care at first interview. Analysis 3A and 3B: interviewed in two consecutive surveys, no care receipt at first interview and limited in at least one PADL, IADL or mobility task in both interviews.	Analysis 1A and 1B: 2,289 Analyses from 2A to 5B: not reported	Analysis 1: ELSA, wave 7 (2014-15) Analyses from 2A to 5B: ELSA, wave 1 (2002-03) to wave 5 (2010-11)	Analysis 1A: receipt of formal care Analysis 1B: receipt of informal care Analysis 2A: onset of informal care receipt Analysis 2B: onset of formal care receipt Analysis 3A: onset of informal care receipt Analysis 3B: onset of formal care receipt Analysis 4A: onset of privately-funded formal care receipt Analysis 4B: onset of publicly-funded formal care receipt Analysis 5A: offset of informal care receipt Analysis 5B: offset of formal care receipt

Study	Study design	Population	Sample size	Data source	Outcomes
		Analysis 4A and 4B: interviewed in two consecutive surveys, limited in at least one PADL, IADL or mobility task at second interview and no care receipt at first interview; people may or may not have had difficulties when they did the initial interview Analysis 5A and 5B: interviewed in two consecutive surveys and received care at first interview			
Grundy and Read 2012 [71]	Retrospective, longitudinal (determinants from time t-1 and outcomes from time t). Logistic regressions, separate analyses for men and women	People aged 60 and older in 2002-03 with at least a PADL or IADL limitation at wave 2. The analyses on help from children only included parents.	Analyses with overall sample: 781 men, 1,212 women; Analyses only with parents: 646 fathers and 991 mothers.	ELSA, wave 1 for determinants (2002-03) and 2 (2004-05) for receipt of help	Three outcomes in analyses with whole sample: receiving care and support from relatives; receiving care and support from friends; receiving care and support from “children or relatives or friends” (considered all together without making a distinction). Outcome in the analyses only with parents: receiving help from children
Iparraguirre 2020b [68]	Retrospective, longitudinal study (the study focused on the effect of sources of care at time t-1 on sources of care at time t;	People aged 65 and over, with at least one PADL or IADL difficulty for which help questions were asked in ELSA (excluding managing money, as this would be less likely to trigger formal or informal care). Sub-samples varied depending on the outcome. For example, to study the determinants of help from son, only	Wave 2: 1,695, wave 3: 1,530, wave 4: 1,762, wave 5: 1,624, wave 6: 1,737	ELSA, waves 2-6 (2004-2005 and from each successive wave to 2012-2013); Health and Social Care	Five outcomes: care or support from partner, from son, from daughter, LA-funded care or privately funded care

Study	Study design	Population	Sample size	Data source	Outcomes
	where t-1 meant two years earlier). "Dynamic multi-level mixed-effects logistic regression models" ([68], p. 1638).	people with a son and a daughter were included, because there was interest in studying substitution between help from son and daughter.		Information Centre (HSCIC) for LA-expenditure data.	
Solé-Auró and Crimmins 2014 [19]	Retrospective, cross-sectional study. Multinomial logistic regression	People aged 50 and over, with at least one PADL or IADL limitation, who received help	1,600	ELSA, wave 3 (2006-07)	One outcome with four categories: receiving only informal care from people in the same household; receiving only informal care from people in a different household; only formal care; receiving a mix of formal and informal care (the multinomial logistic regression uses the latter category as reference category).
Vlachantoni et al. 2015 [72]	Retrospective, cross-sectional study. Logistic regressions. Two separate analyses were conducted for men and	People aged 65 and over who were core respondents in ELSA reporting difficulty in at least one PADL, IADL or mobility task. Excluded those responding by proxy.	3,395	ELSA, wave 4 (2008-09)	Three outcomes: receipt of informal, publicly or privately funded care

Study	Study design	Population	Sample size	Data source	Outcomes
	women in relation to informal care.				

3.3.3. Determinants assessed in the included studies

Table 5 shows the determinants considered by the included studies in relation to unmet need or any care receipt. The number of studies assessing each determinant varied from only one to all six studies. Age and gender were assessed by all studies. Five studies included having a partner or marital status, while three looked at living alone or at household size. Four studies included children-related variables. All studies included health-related variables, although these differed across the studies. Five studies included socio-economic variables. Only one study included LA-level variables. Only one study looked at interactions between different determinants.

Table 5. Determinants assessed in the included studies on unmet need or any care receipt.

Determinants	[62]	[69]	[37]	[61]	[19]	[60]	N of studies
Socio-demographic variables							
Age	X	X	X	X	X	X	6
Gender	X	X	X	X	X	X	6
Having a partner/marital status	X	X		X	X	X	5
Living with others/household size		X	X			X	3
Having children	X			X			2
Having children in or outside the household		X			X		2
Having siblings	X						1
Social inclusion variables							
How often meets children		X					1
How often talks over the phone with children		X					
Having friends		X					1
Family members understand how one feels		X					1
Health-related variables							
PADL limitations		X	X		X		3
IADL limitations			X		X		2
Limitations (not grouped under above categories but may include/relate to the above)	X			X			2
Cognition test scores		X		X			2
Self-reported health	X					X	2
Long-term illness		X				X	2
Specific diagnoses	X			X			2
Health behaviours		X					1
Quality of life		X					1
Socio-economic variables							
Housing tenure	X	X		X		X	4
Wealth	X	X	X	X			4
Occupational status		X		X		X	3

Determinants	[62]	[69]	[37]	[61]	[19]	[60]	N of studies
Income		X	X				2
Educational qualifications	X	X		X		X	4
Geographical variables							
LA spending on community-based care			X				1
LA share of older people on low-income benefits (IDAOPI (income deprivation affecting older people) score).			X				1
LA type (“London Borough”, “Metropolitan”, “Non-metropolitan”, “Unitary”) ([37], p. 9)			X				1
LA rural/urban classification			X				1
Interactions							
Low memory/time orientation and N of functional limitations				X			1
Dementia and N of functional limitations				X			1

Table notes. Abbreviations: IADL: instrumental activity of daily living; LA: local authority; N: number; PADL: personal activity of daily living.

Table 6 shows the determinants assessed in the included studies in relation to receiving care from a specific source. The determinants were very similar to those examined in relation to unmet need or any care receipt. The number of studies assessing each determinant varied from only one to all six studies. Age was assessed by all studies. Five studies included having a partner or marital status, while three looked at living alone or at household size. Five studies included children-related variables. All studies assessed health-related variables, although these differed across the studies. Five studies included socio-economic variables. Only one study examined LA-level variables.

The main differences compared to the determinants examined in relation to unmet need or any care receipt were the following: among the determinants of source of care, one study examined house adaptations and the use of aids, and three looked at receiving care from another source. Moreover, some studies conducted separate analyses by gender (the other studies included gender as a determinant; all studies considered gender). Finally, no study looked at interactions between different determinants.

Table 6. Determinants reported in the studies on receiving care from a specific source.

Determinants	Study						N of studies
	[70]	[62]	[71]	[68]	[19]	[72]	
Socio-demographic variables							
Age	X	X	X	X	X	X	6
Gender	X	X	Separate analyses by gender	X	X	X	6
Having a partner / marital status	X	X	X		X	X	5
Living with others / household size	X			X		X	3
Having siblings	X						1
Having children / number of children	X	X	X		X	X	5
Having at least a daughter			X				1
Children living in the same or a different household					X	X	2
Social inclusion variables							
Weekly face-to-face contact with relatives			X				1
Weekly face-to-face contact with friends			X				1
Weekly face-to-face contact with children			X				1
Health-related variables							
PADL limitations	X			X	X	X	4
IADL limitations	X			X	X	X	4
Mobility limitations	X	X				X	3
Limitations (not grouped under above categories but may include/relate to the above)		X					1
Cognition test scores	X					X	2
Self-reported health		X	X			X	3
Long-term illness			X			X	2
Diagnoses of specific conditions		X				X	2
Other support							
House adaptations						X	1
Use of aids						X	1
Receiving care from another source	X			X		X	3

Determinants	Study						N of studies
	[70]	[62]	[71]	[68]	[19]	[72]	
Socio-economic variables							
Wealth		X	X	X		X	4
Housing tenure		X	X			X	3
Income				X		X	2
Access to a car						X	1
Educational qualifications	X	X	X				3
Geographical variables							
LA spending for community-based social care			X				1
LA share of older people that received Guarantee Credit (a low-income benefit which is part of Pension Credit [73])			X				1
LA type			X				1
LA rural/urban classification			X				1

Table notes. Abbreviations: IADL : instrumental activity of daily living; LA: local authority; N: number; PADL: personal activity of daily living.

3.3.4. Significance of the assessed determinants and directions of associations – narrative synthesis.

Data extraction tables are presented in Appendix 3E (for studies on unmet need and care receipt) and Appendix 3F (for studies on receiving care from specific sources). A narrative synthesis is presented in the following sections.

3.3.4.1 Demographic variables

Two studies that included age as a continuous variable found that older people had higher odds of unmet need [37, 61]. In the other four studies, which categorised age into age groups, the results were the opposite; in most cases, there were significant associations, and all significant associations indicated lower odds of unmet need or absence of care in the older age groups [19, 60, 62, 69].

Results were mixed in relation to age and receiving care from a specific source of care, but whenever significant, associations were positive between being older and receiving care from informal carers [62, 70-72], formal sources [62, 68] or more than one source [19]. The only exception was care from a partner or spouse, which was either not associated with age [70] or negatively associated with age [68].

Results were mixed in relation to gender and unmet need. Two analyses found no association between unmet need and gender [37, 69]; three other studies found a positive association between being male and unmet need or absence of care [19, 60, 62]. One study found that women had fewer unmet needs, although gender was not related to having at least one unmet need [61]. Only one analysis found higher odds of unmet need among women; this analysis was limited to people receiving help and considered whether they thought that help met needs all the time [37].

Compared to men, women were more likely to receive informal care [62]. One study found that among people with a spouse, women had higher odds of being cared for by a spouse than men [70]. Another study found no association between gender and help from partner [68]. Mothers had higher odds of receiving care from children [70], or at least from daughters [68], than fathers. Compared to men, women had lower odds of having only informal care from people in the same household rather than a mix of formal and informal care [19]. For analyses that focused separately on men and women when assessing the role of other determinants, results are outlined below, when focusing on each of these determinants.

3.3.4.2 Health-related variables

There was a positive association between having a higher number of PADL or IADL limitations [19] or having difficulty with a higher number of activity categories[7] [62] and receiving any care. However, among those receiving help, responding that help did not meet needs all the time was more likely if the person had PADL limitations [37].

Presence of PADL or IADL limitations or a higher number of these limitations mostly meant higher odds of receiving informal care and publicly funded care [68, 70, 72]. Privately funded care was not associated with PADL limitations [72], while it was positively associated with IADL limitations [68, 72].

There was indication that worse self-reported health status was negatively associated with unmet need or positively associated with receiving care [60, 62]. A long-term illness meant lower odds of unmet need [69].

Diagnoses of various health conditions were considered as potential determinants of unmet need and of receiving care from specific sources. In most cases, no association was found [62, 69, 72].

Different studies reported different findings relating to cognitive function or a diagnosis of Alzheimer's disease or dementia as potential determinants of unmet need or care receipt [61, 62, 69]. One study found that the relationship between low cognition or dementia and unmet need changed depending on the number of functional limitations [61]. One study that focused on source of care [72] found that a lower cognitive function was not associated with publicly funded care, but there was a positive association between a diagnosis of dementia and publicly funded care.

3.3.4.3 Household, family, care from other sources, aids and adaptations

Living alone increased the odds of unmet need compared to living with others or in a couple [60, 69], although it was not associated with unmet need for help with IADLs [60]. A bigger household size meant lower odds of unmet need [37]. Being single or unmarried [19, 61, 62],

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[7] Six "activity categories": "mobility (walking 100 yards, walking across a room, climbing a single or multiple flights of stairs, getting into or out of bed, using the toilet), washing (bathing or showering, getting dressed), eating (including cutting up food), housework (shopping for groceries, doing work around the house or garden), taking medication and managing money (managing money, making phone calls)" (62. Crawford R, Stoye G. The prevalence and dynamics of social care receipt London: Institute for Fiscal Studies; 2017 [cited 2021 March 17]. 64]. Available from: https://www.ifs.org.uk/uploads/publications/comms/R125_The%20prevalence%20and%20dynamics%20of%20social%20care%20receipt.pdf.), pp. 9-11

divorced or separated [60, 62] or widowed [62, 69] increased the odds of unmet need or of not receiving any care compared to being married or in a couple.

Results were mixed on whether living with others was negatively associated or not associated with LA-funded care and privately funded care [68, 72]. Being in a couple had a positive association with informal care [62, 72] and a negative association with formal care [62]. Single never married people had higher odds of receiving publicly or privately funded care than people who were married or civil partnered [72].

Results were mixed on whether having children was negatively associated or not associated with unmet need or absence of care [61, 62]. A borderline significant positive association was found between receiving care and having children inside the household [19].

Having children increased the likelihood of informal care [62]. When split by gender, having children [71] or having children inside the household [72] increased the odds of informal care for women, but not for men. Having a daughter increased the odds of care from children for mothers, but not for fathers [71].

In one study, no association was found between unmet need and how often one meets children or speaks over the phone with children or whether someone has friends ten years prior [69]. However, in another study, having face-to-face weekly contact with children two years prior increased the odds of care from children [71].

Regarding associations between formal and informal care, results were mixed. One study found that receiving LA-funded or privately funded help did not affect the odds of care from partner, daughter or son two years later [68]. Instead, receiving care from a partner and from a daughter, but not from a son, decreased the odds of LA-funded help two years later [68]. Care from a partner also reduced the odds of privately funded care two years later [68]. One cross-sectional study found a negative association between privately funded care and informal care [72]. Another cross-sectional study found a negative association between help from spouse and formal care, but no association between help from children and formal care [70].

Focusing on the relationship between care from a son and from a daughter, receiving care from one child reduced the odds of receiving help from the other child two years later [68].

In some analyses, there was a negative association between being in a couple and receiving care from people that are not the spouse or partner (i.e., friends, relatives or children) [71]. In other analyses, no significant association was found [71].

Focusing on the relationship between aids and adaptations and care provision, a few significant associations were found. Men, but not women, with at least a house adaptation had lower odds of informal care [72]. People with at least a house adaptation had higher odds of privately funded care [72].

3.3.4.4 Socio-economic variables

No association was found between income and unmet need [11, 37]. Two studies found no association between income and publicly funded care [68, 72]. One study found no association between income and receipt of informal care or privately funded care [72]. In contrast, another study found that higher income increased the odds of help from partner and of privately funded care, although it did not affect the odds of care from children [68].

Results were mixed for wealth and unmet need. Most analyses found no association between wealth and unmet need or care receipt [37, 62, 69]. One study found that people in a higher wealth quintile (including housing wealth) had fewer unmet needs [61]. One analysis found that the wealthiest quintile had higher probability of continued absence of care in two consecutive waves and higher probability of no care receipt among people with no difficulties in the previous interview [62].

Regarding wealth and informal care, results were mixed, but all significant associations showed that a lower wealth quintile had higher odds of informal care than a wealthier quintile [62, 71, 72]. Three studies found a positive association between wealth and privately funded care [62, 68, 72]. In two studies, no association was found between wealth [72] or non-housing wealth [68] and publicly funded care.

With regards to housing tenure, results were mixed. Two studies found no association with unmet need or care receipt [62, 69]. One study found that home owners had lower odds of at least one unmet need and fewer unmet needs [61]. Another study found that people who rented socially had lower odds of unmet need with PADLs than those who owned the property where they lived [60]. No study found association between housing tenure and informal care sources, publicly or privately funded care [62, 71, 72].

No association was found between occupational status and unmet need in most analyses focusing on this [60, 61, 69].

No association was found between educational qualifications and unmet need or care receipt in the four studies that focused on this [60-62, 69]. Some analyses found no association between educational qualifications and care receipt from informal sources of care [62, 70, 71]. However, a few significant associations indicated that those with higher education had lower odds of receiving care, from either children, relatives or informal care overall [70, 71]. In contrast, women who had achieved A levels or a higher educational qualification had higher odds of receiving care from friends than women with no qualifications [71].

3.3.4.5 LA-level variables

Regarding LA-level determinants, there was one finding with borderline significance (p value above 0.05 but below 0.1), which was, that people in local authorities with higher community-based social care spending had lower odds of unmet need [37]. When the analysis focused only on those receiving help, the inverse association between LA spending and unmet need became significant [37]. Higher LA spending on community-based social care increased the odds of LA-funded care [68].

People in metropolitan or unitary councils had lower odds of unmet need compared to London boroughs [37]. No association was found between rural-urban classification or the share of older people receiving low-income benefits in the local area and unmet need or care receipt from specific sources [37, 68].

3.3.5. Quality of the included studies

All studies were based on ELSA, which records whether there are any difficulties with activities of daily living and mobility tasks with a binary response (yes/no) but it does not focus on the level of difficulty. Therefore, level of care need in these studies was only considered based on the number of difficulties.

Most studies focused on the receipt of any help for reported difficulties, without considering whether help was needed or sufficient. Only one study [37] looked at whether the person thought that help met needs all the time or not.

Studies were based on self-report, which is not the gold standard of measurement for many variables (for example, health diagnoses or wealth), although it is appropriate to measure unmet need, as it is discussed in section 3.4.

As per the review inclusion criteria, all studies used multivariable analysis to adjust for confounding factors. The studies assessed associations rather than providing evidence of causal relations. Five studies [19, 60, 61, 70, 72] were cross-sectional. Therefore, they provided more limited information than longitudinal studies in relation to the sequence of events. See quality assessment tables in Appendix 3D.2 and Appendix 3D.3 for details.

3.4. Discussion

Studies differed in their sample inclusion criteria, in their definition of the outcome of interest, in the determinants considered and in the time period on which they focused. Despite the differences, all studies used data from ELSA and so at least part of their samples overlapped, because the same respondents were interviewed at multiple waves, although some "refreshment samples" ([67], p. 5) were added at wave 3,4,6,7 and 9 [67]. For some determinants, similar results were found across different studies, while in other cases, the different perspectives were useful for gaining a deeper understanding of the determinants of unmet need, care receipt and source of care.

Results were mostly consistent across multiple studies relating to: a negative association between unmet need and an older age group, having a partner, living with others; no association between unmet need and income, occupational status, education; a positive association between wealth and privately funded care.

Studies that focused on age groups, rather than age as a continuous variable, had the advantage that they could capture possible non-linear effects of age [71]; these studies generally found lower odds of unmet need among older age groups [19, 60, 62, 69].

Results on gender and care receipt or unmet need were mixed, with the most common result being a positive association between being male and unmet need or absence of care [19, 60, 62]. Possible reasons for this are discussed in section 4.4, which relates the findings from this review to the results from the data analysis conducted for this PhD study.

Results on wealth and unmet need or absence of care were mixed, with the most frequent result being no association [37, 62, 69]. This result was also found in the only study that focused on people's perceptions of how help met needs [37]. Definitions of wealth varied: in two studies housing wealth was excluded [37, 69], in one study included [61], while one study did not mention how wealth was measured [62]. The different definitions, combined with the other differences between the included studies, could have contributed to the different findings.

This literature review is the first to systematically identify evidence on the determinants of unmet social care need, care receipt and source of care, and to summarise different aspects of the evidence: the characteristics of included studies, the determinants assessed, and any significant results.

Section 3.3.5 mentions that due to limitations of the ELSA data, the included studies only considered the number of difficulties with activities of daily living but not the extent of these difficulties. Kröger [39] mentions that most studies on unmet need focus on the number of functional limitations but not on their extent, however the amount and frequency of help needed are key in the subject of unmet need [39] .

Any definition of unmet need based on pre-specified objective criteria inevitably comes with "one size fits all" categorisations and is not going to capture each person's unique conditions (personal communication with the public advisory group 2021). Section 3.3.5 mentions that most studies focused on the receipt of any help for reported difficulties, without considering whether help was sufficient. This approach has been criticised by Kröger [39] because receiving some support does not guarantee that the person receives sufficient care. Moreover, when studies focused on whether help was received or not for a reported difficulty, they ignored whether people thought they needed help [69]. Therefore, focusing on a person's subjective judgement of unmet care need seems more appropriate and reflects a person-centred approach to care. However, it involves a degree of subjective judgement, which may vary by socioeconomic status [74].

Capturing people's perceptions of how care met needs was possible in the study by Iparraguirre [37] because the ELSA data relies on self-report. In this case, self-report is a strength. However, self-report also comes with limitations in relation to some variables. One study found that for 38% of older people living in private households, IADL self-report was different from performance [75].

This review has identified a number of areas for further research. None of the studies focused on the amount of care received. A study was identified, which examined the determinants of the number of hours of informal care provided within a carer's household in the UK [76]. However, this study was not included in the review for various reasons; for example, it was not limited to older people. It would be important to research whether the number of hours of care received is associated with source of care or wealth. However, ELSA questionnaires do not ask about the exact number of hours provided from each informal carer; they only ask about intervals (e.g., 1-4 hours, 5-9 hours). Intervals cannot be summed across helpers, so it is not possible to know the number of care hours received by anyone with more than one informal carer.

None of the studies focused on ethnicity as a determinant. Most likely, this was due to the small number of people from each different non-white ethnicity. When conducting data analysis for this PhD study, it was initially considered that grouping all white and non-white ethnicities together could get around this. Although this approach has limitations, it could be more informative than completely ignoring ethnicity. However, it was later observed, looking at ELSA data, that the number of non-white people was too limited. Further research using other data sources should examine ethnicity as a determinant of unmet need or source of care.

While the aforementioned research recommendations were not addressed in this PhD study, other research gaps were identified, which were addressed with data analysis in chapter 4. Firstly, the review showed that no study focused on unmet need exclusively after the implementation of the Care Act 2014 began on the 1st of April 2015. Secondly, only one included study [37] focused on a subjective assessment of unmet need. It grouped help that “usually” met needs with “sometimes” and “hardly ever” to define unmet need. No study grouped these categories in a different way. Thirdly, it is surprising that only two studies by the same author [37, 68] considered LA-level determinants, given that local authorities have responsibility for meeting care and support needs [16] and social care services are funded not just from the central government but also through local taxation and user contributions [77]. Fourthly, one study [69] found no association between unmet need and these variables: how often a person meets their children, how often they talk over the phone with their children, whether they have friends, and whether family members understand how one feels. However, no study assessed a determinant which incorporated the frequency of social contacts across a variety of social networks. Fifthly, none of the studies looked at source of care as a determinant of unmet need.

In conclusion, the review systematically identified evidence on the determinants of unmet need, care receipt and source of care. It identified various research gaps, some of which were addressed with data analysis in chapter 4. The review informed the selection of determinants for data analysis in chapter 4: the data analysis included not only new determinants but also key determinants examined in previous studies. The review also informed the sample inclusion criteria and the outcome definition for the data analysis in chapter 4 and helped with the interpretation of results from the data analysis in chapter 4.

Chapter 4. Empirical study: determinants of unmet need for help with activities of daily living

4.1. Rationale

Whilst several recent studies of the determinants of unmet need exist, some important research gaps were identified in the review in chapter 3. Firstly, no study focused on unmet need exclusively after the Care Act 2014 began to be implemented on the 1st of April 2015. Secondly, some potentially important determinants were not assessed in any previous study.

Studying the determinants of unmet care need specifically in the post-Care Act 2014 context is important for various reasons. Compared to the previous Fair Access to Care Services (FACS) guidelines, the Care Act set minimum care eligibility thresholds for the whole of England [78]. Prior to this, minimum thresholds were decided by local authorities [78]. The Care Act also introduced a new emphasis on wellbeing and personalisation, as well as a recognition of the role of informal carers and eligibility criteria for informal carer support [78]. Moreover, there were financial changes over time. Between 2009/10 and 2016/17, social care expenditure per adult living in England decreased by 13.5 per cent on average [79] and the number of social care recipients decreased by more than 400,000 due to limited funding [9]. The financial and policy changes may have impacted on the determinants of unmet need. For example, the reduction in expenditure may have exacerbated wealth inequalities in unmet need, because people with the lowest wealth are those eligible for publicly funded care. Moreover, the establishment of national minimum eligibility thresholds may have impacted on the relationship between LA-level variables and unmet need.

This PhD study assessed the determinants of unmet need in the post-Care Act 2014 context (unmet need was measured in 2016/17) and included some additional determinants not assessed in previous studies. The present work investigated the determinants of unmet need with two different analyses: a main analysis, described in section 4.2, and another analysis focusing on source of care as a determinant of unmet need, presented in section 4.3. Section 4.2.1.4 provides additional details on the determinants included in the main analysis. Table 7 compares them to those included in the only previous study that looked at both individual-level and LA-level determinants [37]. Section 4.3.1 provides a justification for focusing on source of care as a determinant of unmet need and section 4.3.2 mentions the determinants included in the analysis looking at source of care.

In the review in chapter 3, only one included study by Iparraguirre [37] focused on a subjective assessment of unmet need. The present work also focused on this but it defined unmet need in a different way in the analysis in section 4.2 (while the analysis in section 4.3 defined unmet need in the same way as Iparraguirre [37]). More details are given in sections 4.2.1.3 and 4.3.2.

4.2. Main analysis

4.2.1. Data and methods

4.2.1.1 Data

The main dataset used in this study is from ELSA [80], which has been briefly introduced in chapter 1 and chapter 3. The design of the ELSA sample aims to make it representative of people aged 50 and over living in private households in England. The sample is made up of households that took part in the Health Survey for England (HSE), except for a "boost sample" to represent ethnic minorities, which was discarded in ELSA due to budget constraints ([67], p. 5). Households participating in the HSE were contacted for ELSA if there was an adult aged 50 or older in the household who had given consent to be recontacted. Their cohabiting partners were also invited to participate in ELSA, even if they did not fit the age criteria [67].

As mentioned in section 3.3.2, the same people have been interviewed at two-yearly waves, although some were lost to follow-up or died while new participants (called "refreshment samples") ([67], p. 5) were added at several waves [67]. Data collection for the first wave was conducted in 2002-03 [81], when 12,099 people were interviewed [80, 81]. Data collection for the 9th wave was conducted in 2018-19 [81], when 8,736 people were interviewed [80]. After wave 9, there was an interruption to the two-yearly waves and an ELSA Covid-19 Substudy was conducted, which interviewed people at two time points: firstly in June and July 2020 and then in November and December 2020 [82]. After this, data collection for the 10th ELSA wave was conducted between 2021 and 2023 [83], when 7,586 people were interviewed [84]. Only a minority of participants (2,090 people) were interviewed in each of the 10 waves [80, 84].

Proxy interviews were conducted if an eligible respondent could not take part due to a physical or cognitive impairment or was hospitalised or had a temporary care home admission; moreover, proxy interviews were also carried out for people that declined to participate but accepted to have someone else do an interview on their behalf [67].

Most questions were asked by an interviewer, but there was also a self-completion questionnaire which focused on topics such as wellbeing and relationships with friends and family members [29, 67].

All waves included questions about difficulties with activities of daily living, about whether the person received help and how often help met needs. However, these questions referred to a different set of activities, depending on the wave. For example, in waves 1 to 5, the person was asked if they received any help after being asked about difficulties with 10 general mobility tasks and difficulties with activities of daily living (13 activities in waves 1 to 3, 15 activities in waves 4 and 5) [85-89]. From wave 6 to 10, there was no longer a general question asking about any help received for a whole set of possible difficulties. Instead, 13 help questions were asked in relation to 3 general mobility tasks and 10 activities of daily living [29, 90-93].

The specific ELSA waves used for the current analysis are wave 7 (2014/15) and wave 8 (2016/17) [80]. More details on this are provided in section 4.2.1.5.1.

Most ELSA variables were available from the UK Data Service under an End User Licence. Moreover, under a Special Licence, the name of the LA where each respondent lived was obtained. The exception was London, because the ELSA dataset only stated whether the person lived in Inner or Outer London. The LA name was used for data linkage with publicly available datasets with LA characteristics. For Inner and Outer London, an average or weighted average value was calculated based on the relevant local authorities.

Full details on LA-level data sources are provided in Appendix 4A, but the most important datasets are listed below:

- Reference data tables of the Adult Social Care Activity and Finance Report [94] were used to extract data for each LA on: gross current expenditure on community-based long-term care for people aged 65 and over; the percentage of “requests for support received from new clients” aged 65 and over resulting in no care or equipment ([94], worksheet T9).
- A score measuring the quality of social care information provided on each council’s website was extracted from an Independent Age report [95].
- An Office for National Statistics (ONS) dataset on disability-free prevalence [96] was used to calculate the number of people aged 65 and over with disability in each LA.
- ONS population estimates by LA [97].

- Deprivation scores for each LA were calculated based on the English indices of deprivation 2015 datasets [98].

4.2.1.2 Sample

The sample inclusion criteria were: being aged 65 and over in wave 8 (2016/17); having either a PADL limitation (this referred to “bathing or showering”, “dressing”, “walking across a room”, “eating”, “getting in or out of bed” and “using the toilet”) ([29], p. 94) or having at least 2 IADL or mobility limitations in wave 8. IADLs and mobility tasks were those for which help questions were asked and excluded difficulties with stairs, so they referred to: “walking 100 yards”, “shopping for groceries”, “taking medications”, “doing work around the house or garden” and “managing money” ([29], pp. 93-94). Difficulties with climbing stairs without resting were disregarded because they are so common among older people that they do not seem useful to identify people with care needs [69]. The final inclusion criteria were having been interviewed in wave 7 and wave 8 and with available data to define needs as met or unmet.

The 65 and over age threshold was used in a report on social care for older adults based on the Health Survey for England 2018 [99]. Inclusion criteria relating to difficulties at baseline were the same as per one study by Dunatchik et al. [69] included in the review in chapter 3. They excluded people with only one IADL or mobility limitation after consultation with experts, to make the definition of care need relevant to funders and care providers [69]. In contrast, Iparraguirre [37] argued that studies should focus on need per se rather than need as defined by fiscal policy, so anyone with at least a PADL or IADL difficulty should be considered as with care need. The present work considered that excluding people with only one IADL or mobility difficulty made it more likely that no receipt of help indicated unmet need. This is important considering that ELSA does not ask about the level of difficulty with activities or whether people with no care think that they have unmet need.

4.2.1.3 Outcome: unmet care need in wave 8

Unmet need was defined by combining the responses to multiple questions.

Firstly, the ELSA questionnaire included 13 questions which asked whether people had received help from anyone in the previous month in relation to these 13 activities: “walking 100 yards”, “climbing several flights of stairs without resting”, “climbing one flight of stairs without resting”, “dressing, including putting on shoes and socks”, “walking across a room”, “bathing or showering”, “eating, such as cutting up food”, “getting in or out of bed”, “using the toilet, including getting up or down”, “shopping for groceries”, “taking medications”, “doing work around the house or garden”, “managing money, such as paying bills and keeping track of expenses” ([29], pp. 115-117).

If the respondent answered yes in relation to receiving help for any of the activities above, they were asked: “Thinking about all the help [you receive], would you say that the help [you receive]” “meets [your] needs all the time” / “usually meets [your] needs” / “sometimes meets [your] needs” / “hardly ever meets [your] needs” ([29], p. 119).

Unmet need was defined as either no help receipt at all in the previous month or as having received help in the previous month that met needs sometimes or hardly ever. If the respondent stated that help met needs usually or all the time, they were classified as with met need.

A study by Iparraguirre [37], included in chapter 3, focused on a subjective assessment of whether help met needs, grouping help that met needs “usually” together with “sometimes” or “hardly ever”; the present research grouped “usually” with “all the time”. Ideally, each category would have been analysed separately, but this was not possible due to a limited number of people in individual categories. The aim of grouping “usually” with “all the time” rather than with “sometimes” or “hardly ever” was to make safer assumptions of unmet need compared to Iparraguirre [37]. This was consistent with using a higher minimum care need level compared to Iparraguirre [37]. Clearly grouping “usually” with “all the time” led to the issue that “met need” no longer referred to “completely met” needs. However, it seemed important to separate “usually” met needs from other more worrying responses or from not receiving any care.

Some robustness checks were made around the outcome definition, see Appendix 4G.2 for more details. Section 4.2.2.5 presents the summary results from these checks.

4.2.1.4 Determinants

The determinants assessed in relation to unmet need covered the following domains: demographic; household and family; social inclusion; health; use of other care; socio-economic; local authority. Key variables to capture each domain were selected based on the literature review in chapter 3, discussions with stakeholders, theoretical rationales, considerations of data available within the reference data tables for the Adult Social Care Activity and Finance Report for England [94] and within the ELSA dataset. Moreover, correlations between variables were taken into account.

4.2.1.4.1. Demographic domain

Sex and age were included. Age was categorised into these age groups: 65-69, 70-74, 75-79, 80-84, 85+. Age was taken from wave 8.

4.2.1.4.2. Household and family domain

A binary variable was used with two categories: living alone and living with others in wave 7.

Another binary variable was whether there was a child living in close proximity (in the household or maximum 30 minutes away; this was measured by asking the person with care needs how long it would take them to get to where their nearest child lived). This variable was only available from wave 8, although ideally it would have been taken from wave 7 to limit issues of reverse causality: although the present work was interested in whether a child in close proximity reduced the odds of unmet need, it is also possible that unmet care need may lead to a child living in close proximity. If the child proximity variable had been measured in wave 7 and the unmet care need variable in wave 8, the latter possibility would become less likely.

4.2.1.4.3. Social inclusion domain

A social contact index was created using criteria in Bu et al. [100], i.e., based on how often the person met or spoke on the phone with children, relatives and friends. A point was given if the person spoke on the phone at least weekly with children; another point was given if the person met up face-to-face at least weekly with children. The same point scoring applied in relation to relatives and friends. This resulted in a sum score index ranging from 0 to 6, with a higher value corresponding to a higher level of social contact. This actually inverted the scoring in Bu et al. [100], where a higher value indicated fewer social contacts. This was done to make interpretation of results easier.

Robustness checks assessed alternative social contact variables, see Appendix 4G.5 for more details.

An additional determinant was whether the person used the internet. This was included considering that good information and advice can facilitate access to services (LA-funded, privately funded or from charities), both for the person with care needs and for informal carers. Frequency of internet use was categorised into a binary variable to have more people per category. The two categories were: uses the internet at least once in a while; never uses the internet.

4.2.1.4.4. Health domain

The health domain included the number of PADL and IADL limitations, and a frailty index.

A frailty index has been previously used in analyses of ELSA data [101-103] and in other literature [104]. A frailty index corresponds to an understanding of frailty as an accumulation of health deficits, which include diseases, disabilities, symptoms and signs [105]. Therefore, a frailty index incorporates many variables into one. This was appropriate in this analysis, where the number of variables had to be limited in consideration of the limited sample size (see section 4.2.2.1).

A frailty index is calculated by first defining a set of possible deficits and then calculating the proportion of deficits present in each person. For each deficit, a score of 0 is assigned if there is no deficit and a score of 1 if there is a full expression of the deficit [104]. Moreover, some studies have assigned a value between 0 and 1 if there was a partial expression of the deficit [101, 102, 104]. Frailty indexes can include different numbers and types of deficits but are nonetheless comparable across studies [103]: Rockwood et al. [106] showed that a frailty index measured with a number of equally weighted deficits was related to survival and time to care home admission regardless of which deficits were included in the index. More specifically, Rockwood et al. [106] created different indexes using random sampling without replacement of 50% to 75% of a set of possible variables. For survival, they repeated the whole process with two different datasets which included similar, but not exactly the same, variables. One dataset included 40 variables and the other 51. For time to care home admission, they only used the dataset with 40 variables. They observed that worse frailty was associated with worse survival and with a higher risk of care home admission regardless of the random set of deficits that made up the frailty index.

Some conditions apply in order for frailty indexes to be comparable. Firstly, a minimum number of deficits should be included: a 2007 article by Rockwood and Mitnitski [105] mentioned about 40, while more recent literature mentions about 30 [35, 103]. Secondly, variables should relate to health and to age (without becoming universal too early, like presbyopia) [104]. Thirdly, variables must relate to a range of body systems [104]: for example, if all deficits were about cognitive function, the index would be measuring cognition, rather than frailty.

For the present work, a frailty index was designed, which included 43 deficits: ten general mobility limitations, fifteen physical health diagnoses, self-reported general health, any long-standing (and whether limiting) illness, hearing and eyesight, whether often troubled by pain, any mental health problem in the previous two years, any falls in the previous two years, a hip fracture in the previous two years, a joint replacement in the previous two years, two deficits capturing the presence of Alzheimer's or dementia, and seven deficits relating to cognition test scores. The index was constructed based on wave 8 responses. For most deficits, a value of 0 or 1 was assigned, but in some cases, a value between 0 and 1 was given, based on the scoring applied in previous frailty indexes. See Appendix 4B.1 for more details. The sum of scores for all deficits present was then divided by the number of potential deficits and expressed as a percentage, so that the frailty index values ranged between 0% (no deficit) and 100% (all deficits present).

Given that the level of disability is likely to be key in determining care provision, the number of PADL and IADL difficulties in wave 8 were taken out of the frailty index and considered as separate variables.

Considering that some studies included in the literature review in chapter 3 had assessed cognition-related variables as separate determinants (cognition test scores [61, 69] or a diagnosis of Alzheimer's or dementia [61, 62]), some checks were made to make sure that it was appropriate to include these variables within the frailty index: pairwise correlations were checked to make sure that the frailty index excluding cognition-related variables had a positive correlation with cognition-related deficits (see Appendix 4C) and robustness checks were run around the inclusion of cognition-related variables within or separately from the frailty index (see Appendix 4G.3)

See Appendix 4B.1 for all included deficits, how each was scored, and how the frailty index in the present work compared to frailty indexes in previous studies that used ELSA data [101-103].

4.2.1.4.5. Use of other care in wave 8

A new "meal provision" variable was created. A person was classified as having had meals provided if, in the previous month, they had attended a lunch club or a day care centre, or had used "meals on wheels" ([29], p. 137) or a private frozen meals provider, or family, friends or neighbours had brought a meal. The definition of unmet need outlined in section 4.2.1.3 did not consider meal provision. So, if a person had meals provided but received no other help, they would automatically be classified as with unmet need. However, this work hypothesised that meal provision may be an indicator of help being available, and so it may have a negative association with unmet need.

4.2.1.4.6. Socio-economic domain

Net total wealth was included. This corresponded to the “sum of savings, investments, physical wealth and housing wealth after financial debt and mortgage debt has been subtracted” ([107], p. 22). In the ELSA dataset, wealth is at the level of the benefit unit, which corresponds to “a couple or a single person plus any dependent children they may have” ([107], p. 10). The present work calculated an equivalised version of wealth, i.e., wealth adjusted by benefit unit size. See Appendix 4B.2 for details on how this was calculated.

Note that wealth was included rather than income. The literature review in chapter 3 identified mixed findings on the relationship between wealth and unmet need [37, 61, 62, 69], while no significant association was found between income and unmet need [11, 37]. Multiple ELSA studies have included wealth rather than income [103, 108, 109]. Wealth is regarded as particularly important to classify older people’s socio-economic status because “it captures both past and present circumstances” ([110], p. 907) while many older people have “relatively low or absent incomes” ([111], p. 250).

Another socio-economic determinant assessed in the present work was whether people left school after the official school leaving age, which marks the end of compulsory education. This variable was chosen over educational qualifications. This was done for three reasons. Firstly, cultural norms regarding educational qualifications have changed considerably over the years. Secondly, focusing on school leaving age reduced the number of categories to two: leaving after school leaving age or not. So, more people could be included in each category. Thirdly, there was no missing data with leaving age, while there would have been a few missing data with educational qualifications. See Appendix 4B.3 for more details on how the variable was created.

4.2.1.4.7. Local authority domain

Four LA-level variables were included in the model.

One LA-level variable captured gross current expenditure on community long-term care for people aged 65 and over divided by the number of people aged 65 and over with a disability living in the LA. The natural logarithm of this variable was used in order to de-emphasise outliers and reduce variability in the data. Expenditure on community long-term care was calculated by summing spending on home care, direct payments, supported living and “other [community] long term care" in 2016/17 ([94], worksheet T33). Expenditure was in £ thousands (i.e., divided by 1,000). Gross current expenditure also included client contributions [112]. Spending on short-term care was excluded because it was not disaggregated between community and residential care ([94], worksheet T23).

Spending was adjusted by an area cost adjustment factor for personal social services for older people [113] with this formula:

$$\text{Adjusted LA spending} =$$

$$\frac{\text{Gross expenditure on community long term care for people aged } 65+/1000}{\text{Cost adjustment factor}}$$

Incorporating the cost adjustment factor was important to account for geographical differences in wages and other costs faced by local authorities [114].

Adjusted spending was then divided by the number of people aged 65 and over with a disability:

$$\frac{\text{Adjusted LA spending}}{\text{N of people aged } 65+\text{ with a disability}}$$

Having a disability was defined in the data as being "limited in day to day activities because of a health problem lasting a year or more" ([96], para. 8). See Appendix 4A for more details on data sources and data manipulation.

The Income Deprivation Affecting Older People Index (IDAOPI) average score referring to 2015 was also included. This measures the proportion of people aged 60 and over who receive low-income benefits.[8] The IDAOPI score had also been included in a previous study on the determinants of unmet need [37]. It could be an important confounder of the relationship between unmet need and expenditure because the level of social care spending on people aged 65 and over tends to be higher in local authorities with a higher IDAOPI score (i.e., with more deprivation) (see both [116] and correlation plot in Appendix 4D).

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[8] Low-income benefits considered by the IDAOPI score are: "Income Support or income-based Jobseekers Allowance or income-based Employment and Support Allowance" or the Guarantee Credit element of Pension Credit (115. Department for Communities and Local Government. The English Indices of Deprivation 2015: Technical report. 2015 [cited 2021 November 19]. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/464485/English_Indices_of_Deprivation_2015_-_Technical-Report.pdf., p. 33)

Robustness checks assessed the inclusion of alternative expenditure measures and of an alternative deprivation score, see Appendix 4G.7 and Appendix 4G.8 for more details.

Another LA variable was the quality of social care-related information on the council website according to a 2016 Independent Age report [95]. A higher score indicated a better website; the maximum possible score for each LA was 30. See Appendix 4A for more details on the criteria used to assign a score.

Another LA variable was the percentage of “requests for support received from new clients” aged 65 and over in 2016/17 that resulted in no long-term care, no short-term care and no assistive equipment ([94], worksheet T9). This was based on the NHS Digital Short and Long Term Support (SALT) data collection [94]. Requests for support were defined as contacts “being made in relation to the provision of adult social care services, excepting ‘casual contacts’ where no client details are captured” ([117], p. 18). New clients were defined as people who did not receive any long-term support at the time of contact ([117]. The variable included in the present work was the percentage of requests classified as either “universal services/signposted to other services” or “no services provided” ([94], worksheet T9). See Appendix 4A for more details on this variable.

4.2.1.5 Statistical analysis

Descriptive univariate and bivariate statistics were outlined. Then, multivariable models were run.

4.2.1.5.1. Analysis model

Unmet need is a binary variable, so a logistic regression was appropriate. The equation to assess the determinants of unmet need is outlined below.

$$Ln(Pr(UN_{it} = 1)/(1 - Pr(UN_{it} = 1))) = \alpha_0 + \alpha_1 \mathbf{X}_{it} + v_{it} \qquad (1)$$

Where UN_{it} is the binary unmet need of individual i, measured at time t, t =2016-17 (wave 8), α_0 is a constant to be estimated, $\mathbf{X}_{it}$ is the set of determinants of unmet need, α_1 is a vector of parameters to be estimated, and v_{it} the error term. The determinants which are part of $\mathbf{X}_{it}$, including times when the determinants are measured, are outlined below.

$\mathbf{X}_{it} = gender_{i0},\ education_{i0},\ living\ alone_{it-1},\ \ wealth_{it-1},$
$internet\ use_{it-1},\ \ social\ contacts_{it-1}, meal\ provision_{it}, age_{it},$
$having\ a\ child\ in\ close\ proximity_{it}, health\ related\ variables_{it},$

$LA\ expenditure_{it}, LA\ deprivation_{i2015},\ LA\ \%\ of\ new\ requests\ resulting\ in\ no\ care_{it},$
$LA\ quality\ of\ information_{i2015}$

The choice of subscript for each determinant, indicating the time when the determinant is measured, is explained below:

- 0 indicates that these are initial conditions, i.e., the determinants are not expected to change over time for most people.
- $t-1$=2014-15 (wave 7): determinants are measured at a time prior to when unmet need is measured. This is done for two different reasons:
    1. For some determinants (internet use and social contacts), the intention is to limit the issue of confounding by health deterioration over time. For example, it is possible that high internet use may lead to met need due to better information; an extended social network may lead to met need. However, these associations may not be observed by the time a person is in need of care because their internet use or their social contacts may have decreased after their cognitive function or physical health deteriorated. This confounding issue can be limited by measuring these determinants in 2014-15 rather than in 2016-17. The issue would still be present if health deterioration started to have an effect before 2014-15.
    2. For some determinants (living alone, wealth, and social contacts, which fit into this category as well as the previous one) the intention is to limit the issue of reverse causality from unmet need to these characteristics. For example, household size might increase because a relative moves in with the person with care needs in order to provide care; wealth might diminish when it starts to be used to purchase care; contacts with children or other relatives might increase when they start providing care. Therefore, the meeting of needs could influence these characteristics. This reverse causality issue can be limited by measuring these determinants in 2014-15 rather than in 2016-17. The issue would still be present if care provision started to have an effect before 2014-15.
- t (2016/17): this is the time when the following determinants are measured:
    - determinants for which confounding by health deterioration and reverse causality are not an issue or less of an issue (age, LA characteristics), so they can be taken from the same time when unmet need is measured.
    - health related variables, which can measure health deterioration
- Data on some determinants (LA deprivation and quality of information provided by the council) were only available in relation to a specific year (2015), so this year is specified.

4.2.1.5.2. Missing data

When a variable had only a few missing values, the observations with these missing values were dropped.

When the reason for missing data was no response to the entire self-completion questionnaire, the observations were dropped from the analyses. The reason was that previous research found significant differences on multiple characteristics between respondents and non-respondents to the ELSA self-completion questionnaire [118].

For two variables (social contact and internet use), many people had not answered these two questions despite answering the self-completion questionnaire that included these items. In these cases, missing values were replaced with 0 and two dummy variables for missing information were added (one for social contact, one for internet use). This method was chosen to deal with missing data after alternative methods were explored, such as multiple imputation (see Appendix 4E). As results were very similar with all methods, the simplest method was chosen.

4.2.1.5.3. Different domains considered in sequential modelling

Some domains were included in all multivariable models; other domains were considered as optional and only kept in if there was statistical significance. Table 7 shows the domains assessed in sequential modelling. The same table compares the included domains and variables to those included in the only previous study that assessed both LA-level and individual-level determinants of unmet need among older people in England [37].

Table 7. Domains in sequential modelling.

Domain	**Prioritised variables**	**Models**					**Determinants assessed in a study by Iparraguirre [37]**
		1	**2**	**3**	**4 (final)**	**5**	
Demographic	Age and sex	X	X	X	X	X	Age and sex
Household and family	Living alone and having a child in close proximity	X	X	X	X	X	Household size
Social inclusion	Social contact index and internet use		X		X		None
Health	Frailty index including cognition deficits; number of difficulties with PADLs and IADLs	X	X	X	X	X	Number of difficulties with PADLs and IADLs
Use of other care	Meal provision					X	None
Socio-economic	Education beyond school leaving age and equivalised net total wealth	X	X	X	X	X	Equivalised total income and equivalised net total non-housing wealth
LA	LA gross current expenditure on community long-term care per person with disability aged 65+; IDAOPI score; LA website score; % of new requests resulting in no care or equipment.			X	X		LA net current expenditure on community care per resident aged 65+; IDAOPI score; LA type; rural/urban classification.

Table notes. Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; PADLs: personal activities of daily living.

4.2.1.5.4. How a multivariable model with clustered standard errors was selected.

Firstly, for exploration purposes, ordinary least squares (OLS) models were run. Secondly, logit models were run, with standard errors adjusted for LA clustering.

Logit multilevel models were also run and compared to the logit models with clustered standard errors. As the results were very similar (see Appendix 4F), the models with clustered standard errors were chosen, because they made it easier to make comparisons during sequential modelling: the coefficients of different multilevel logit models cannot be compared because the scale changes [119].

Household clustering was not accounted for, however, the three-level model in Appendix 4F suggested that this was not an issue in the models.

4.2.1.5.5. Interactions

Multiple interactions of interest were initially considered. It was decided to prioritise only a couple of interactions, as opposed to trying them all and potentially find a significant one by chance. The interaction between wealth and living alone was prioritised: it was hypothesised that lower wealth might potentially lead to unmet need only if someone lived alone, with no possibility to rely on informal care from a cohabiting person. Similarly, the interaction between wealth and having a child in close proximity was also prioritised. Interaction terms were added one at a time to the final model.

4.2.2. Results

4.2.2.1 Missing data flowchart and final sample size

The sample size was of 992 people, after people with some missing data were excluded from the initial sample of 1255 people who fitted the inclusion criteria. See Figure 6 for the missing data flowchart.

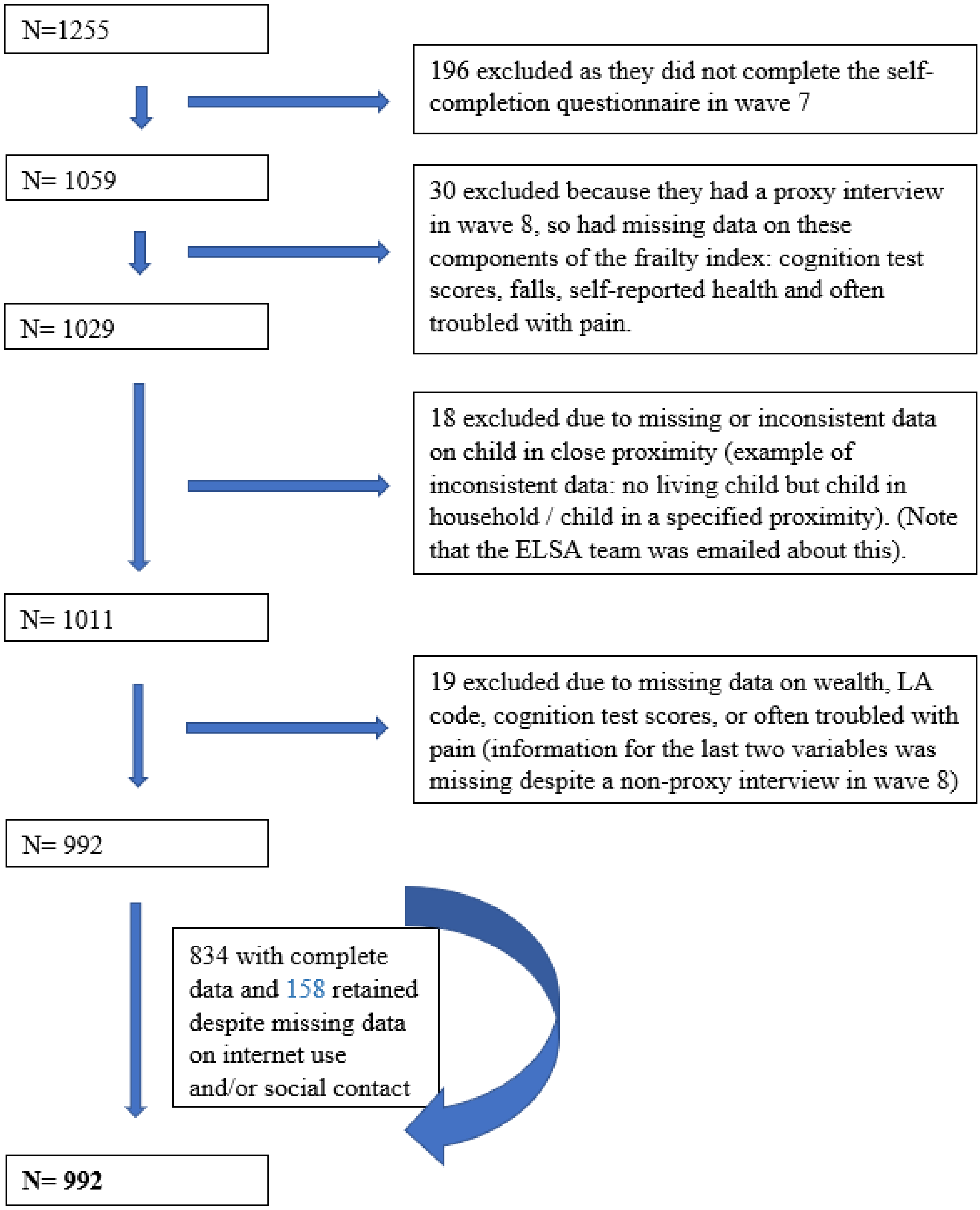


Figure 6. Missing data flowchart.

4.2.2.2 Descriptive statistics

992 people were included in the sample. They belonged to 930 households and they lived in 115 non-London LAs or in inner or outer London (117 areas in total). In England there are 152 local authorities with social care functions [120]. Excluding 33 London authorities, one would expect 119 local authorities outside London, so four non-London LAs were not included in the current dataset.

Of 992 people, 360 (36%) had unmet need. Of these, 312 received no help at all, while 48 reported that help met needs sometimes or hardly ever.

Table 8 presents descriptive statistics for the overall sample and for those with met need and with unmet need. The unmet need group included a higher percentage of people who were in the age groups 65-69 or 70-74, males, living alone, using the internet, or with education beyond school leaving age; it also included a lower percentage of people in the age groups 80-84 or 85+, with a child in close proximity or with meal provision. In the unmet need group, on average, frailty, the number of PADL limitations, the number of IADL limitations and the level of social contact were lower. The proportion of people belonging to each wealth quartile was 0.25 both in the unmet and met need group, where the quartiles had been calculated based on the overall sample of 992 individuals. LA characteristics were similar between the met and unmet need groups.

Table 8. Descriptive statistics stratified by met / unmet need and for the overall sample.

	Met need (N=632)	Unmet need (N=360)	Total (N=992)
Categorical variables	*Proportion (SD)* *[exception: mean (SD) for wealth in the "Total" column]*		
Age 65-69	0.18 (0.39)	0.27 (0.45)	0.22 (0.41)
Age 70-74	0.19 (0.39)	0.28 (0.45)	0.22 (0.41)
Age 75-79	0.19 (0.39)	0.19 (0.39)	0.19 (0.39)
Age 80-84	0.22 (0.41)	0.16 (0.36)	0.19 (0.40)
Age 85+	0.23 (0.42)	0.11 (0.31)	0.19 (0.39)
Male	0.39 (0.49)	0.53 (0.50)	0.44 (0.50)
Living alone in wave 7	0.32 (0.47)	0.36 (0.48)	0.34 (0.47)
Child within 30 minutes in wave 8	0.65 (0.48)	0.62 (0.49)	0.64 (0.48)
Internet use in wave 7	0.48 (0.50)	0.64 (0.48)	0.54 (0.50)
Meal provision in wave 8	0.15 (0.36)	0.10 (0.30)	0.13 (0.34)
Education beyond school leaving age	0.41 (0.49)	0.49 (0.50)	0.44 (0.50)
Wealth in wave 7: quartile 1 (lowest)	0.25 (0.43)	0.25 (0.43)	7,523 (17,734)
Wealth in wave 7: quartile 2	0.25 (0.43)	0.25 (0.43)	107,978 (26,517)
Wealth in wave 7: quartile 3	0.25 (0.43)	0.25 (0.43)	207,474 (35,058)
Wealth in wave 7: quartile 4 (highest)	0.25 (0.43)	0.25 (0.44)	526,086 (557,761)
Numerical variables	*Mean (SD)*		
43-deficits frailty index in wave 8	37.50 (9.81)	29.65 (9.60)	34.65 (10.44)
N of PADL limitations in wave 8	1.74 (1.55)	1.39 (1.07)	1.61 (1.40)
N of IADL limitations in wave 8	2.06 (1.67)	0.80 (1.15)	1.60 (1.62)
Social contact index in wave 7	3.06 (1.65)	2.75 (1.65)	2.94 (1.65)
LA gross spending	0.46 (0.12)	0.47 (0.13)	0.46 (0.12)
LA IDAOPI average score	15.66 (5.37)	16.37 (5.75)	15.92 (5.52)

	Met need **(N=632)**	**Unmet need** **(N=360)**	**Total** **(N=992)**
LA website score	24.33 (3.65)	24.08 (3.88)	24.24 (3.73)
Percentage of new requests to the LA not resulting in care or equipment	51.33 (14.62)	50.89 (14.88)	51.17 (14.71)

Table notes.

Abbreviations: IADL: instrumental activity of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADL: personal activity of daily living; SD: standard deviation.

Wave 7 refers to 2014-15 and wave 8 to 2016-17.

Total N was different for social contact because values refer to available cases: 526 with met need and 331 with unmet need. Total N was different for internet use because values refer to available cases: 597 with met need and 350 with unmet need. Total N was different for meal provision because values refer to available cases: 631 with met need and 360 with unmet need.

The frailty index was measured as percentage.

The social contact index ranged from 0 to 6. A higher value indicated more social contact.

Wealth refers to equivalised net total wealth. Quartiles were calculated based on the final sample of 992 people.

LA gross spending refers to spending on community long-term care (adjusted by an area cost adjustment factor) per older person with a disability, in £ thousands (i.e., divided by 1,000).

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Table 9 shows the pairwise correlation coefficients between individual-level variables. Most determinants were very weakly correlated with unmet care need; the frailty index and the number of IADL limitations were weakly and negatively correlated with unmet need. There was a positive and moderate correlation between the frailty index and the number of IADL limitations. Both variables had a positive and weak correlation with the number of PADL limitations.

Table 9. Pairwise correlations, individual-level variables, based on N=992.

Variables		(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)	(14)	(15)	(16)	(17)	(18)
Unmet need in wave 8	(1)	1.00																	
Age in wave 8	(2)	-0.19	1.00																
Male	(3)	0.13	-0.01	1.00															
Living alone in wave 7	(4)	0.04	0.22	-0.21	1.00														
Child in close proximity in wave 8	(5)	-0.03	-0.05	-0.03	-0.11	1.00													
Social contact in wave 7	(6)	-0.09	-0.03	-0.19	0.07	0.33	1.00												
Using the internet in wave 7	(7)	0.16	-0.32	0.10	-0.17	-0.04	-0.07	1.00											
Missing social contact in wave 7	(8)	-0.12	0.08	-0.04	0.02	0.03		-0.08	1.00										
Missing internet use in wave 7	(9)	-0.06	0.08	0.00	0.04	0.03	0.06		0.22	1.00									
43-deficits frailty index in wave 8	(10)	-0.36	0.11	-0.14	0.10	0.03	0.09	-0.16	0.10	0.07	1.00								
N of PADL limitations in wave 8	(11)	-0.12	-0.06	0.09	0.00	-0.04	0.01	-0.01	0.04	0.02	0.40	1.00							
N of IADL limitations in wave 8	(12)	-0.38	0.14	-0.07	0.08	-0.04	0.02	-0.20	0.12	0.10	0.49	0.37	1.00						
Meal provision in wave 8	(13)	-0.08	0.20	-0.07	0.26	-0.01	0.04	-0.13	0.02	-0.01	0.16	0.10	0.21	1.00					
Education beyond school leaving age	(14)	0.07	-0.05	-0.01	-0.04	-0.16	-0.11	0.32	-0.10	-0.08	-0.13	0.01	-0.06	-0.07	1.00				
Wealth in wave 7: quartile 1 (lowest)	(15)	-0.01	-0.12	-0.05	0.19	0.02	0.05	-0.13	0.08	0.03	0.18	0.03	0.08	0.08	-0.19	1.00			
Wealth in wave 7: quartile 2	(16)	0.00	0.02	0.01	-0.12	0.05	0.04	-0.06	0.02	0.03	0.00	0.03	0.01	0.01	-0.12	-0.33	1.00		
Wealth in wave 7: quartile 3	(17)	0.00	0.04	0.02	-0.03	0.00	-0.05	0.01	-0.01	-0.04	0.00	-0.01	-0.02	-0.05	-0.02	-0.33	-0.33	1.00	
Wealth in wave 7: quartile 4 (highest)	(18)	0.01	0.07	0.02	-0.04	-0.08	-0.04	0.17	-0.09	-0.03	-0.18	-0.05	-0.07	-0.04	0.32	-0.33	-0.33	-0.33	1.00

Legend

Colour	**Value of correlation coefficient**		**Interpretation for the present work**
	Positive coefficient (in green)	**Negative coefficient (in red)**	
🟨	>0 & <0.2	<0 & >-0.2	Very weak
🟨	>=0.2 & <0.4	<=-0.2 & >-0.4	Weak
🟨	>=0.4 & <0.6	<=-0.4 & >-0.6	Moderate
🟧	>=0.6 & <0.8	<=-0.6 & >-0.8	Strong
🟫	>=0.8 & <1	<=-0.8 & >-1	Very strong

Table notes. Abbreviations: IADL: instrumental activity of daily living; N: number; PADL: personal activity of daily living. Wave 7 refers to 2014-15 and wave 8 to 2016-17. Total N was different for social contact (857), internet use (947) and meal provision (991) because values refer to available cases. The social contact index ranged from 0 to 6. A higher value indicated more social contact. The frailty index was measured as a percentage.

4.2.2.3 Sequential modelling

Table 10 shows the results from logit models with the standard errors adjusted by LA clustering.

The most appropriate model was model 4. Note that Table 10 does not show another model which included meal provision and was excluded in a separate comparison, which was based on a lower sample size.

Model 4 showed that people aged 80 or above had lower odds of unmet care need compared to people aged 65 to 69. People who were frailer and with more IADL limitations had lower odds of unmet need. Being male, living alone, and living in a more deprived LA were associated with higher odds of unmet need. Having more social contacts was associated with lower odds of unmet need. Not having answered about social contacts was also associated with lower odds of unmet need.

Table 10. Outcome: unmet need. Odds ratios. Sequential modelling, including the final model (model 4).

	(1) Base model	(2) Base plus social inclusion	(3) Base plus LA variables	(4) Final model: Base plus social inclusion plus LA variables
Age 70-74	0.991	1.018	0.986	1.022
	[0.668,1.470]	[0.684,1.516]	[0.661,1.470]	[0.684,1.528]
Age 75-79	0.728	0.764	0.739	0.782
	[0.470,1.128]	[0.483,1.209]	[0.481,1.134]	[0.500,1.224]
Age 80-84	0.447***	0.481***	0.437***	0.477***
	[0.276,0.722]	[0.291,0.795]	[0.268,0.714]	[0.288,0.790]
Age 85+	0.357***	0.384***	0.369***	0.402***
	[0.230,0.554]	[0.240,0.614]	[0.238,0.571]	[0.253,0.641]
Male	1.706***	1.592***	1.654***	1.530***
	[1.295,2.247]	[1.189,2.131]	[1.260,2.171]	[1.146,2.041]
Living alone in wave 7	2.295***	2.353***	2.258***	2.326***
	[1.595,3.302]	[1.613,3.430]	[1.569,3.251]	[1.595,3.391]
Child within 30 minutes in wave 8	0.916	1.018	0.887	0.997
	[0.631,1.329]	[0.695,1.491]	[0.617,1.277]	[0.690,1.441]
43-deficits frailty index in wave 8	0.945***	0.945***	0.943***	0.944***
	[0.930,0.960]	[0.930,0.960]	[0.928,0.959]	[0.929,0.959]
N of PADL limitations in wave 8	1.063	1.069	1.065	1.072
	[0.908,1.244]	[0.916,1.249]	[0.912,1.244]	[0.919,1.250]
N of IADL limitations in wave 8	0.551***	0.557***	0.536***	0.541***
	[0.460,0.660]	[0.464,0.669]	[0.445,0.646]	[0.448,0.655]
Education beyond school leaving age	1.297	1.202	1.341*	1.236
	[0.939,1.791]	[0.853,1.695]	[0.959,1.873]	[0.870,1.756]
Wealth in wave 7: quartile 2	0.949	0.932	0.944	0.931
	[0.578,1.559]	[0.567,1.531]	[0.573,1.554]	[0.566,1.534]
Wealth in wave 7: quartile 3	0.872	0.828	0.938	0.892
	[0.553,1.375]	[0.524,1.308]	[0.607,1.450]	[0.574,1.384]
Wealth in wave 7: quartile 4 (highest)	0.637	0.601*	0.742	0.702
	[0.372,1.091]	[0.347,1.041]	[0.431,1.278]	[0.401,1.229]

	(1) Base model	(2) Base plus social inclusion	(3) Base plus LA variables	(4) Final model: Base plus social inclusion plus LA variables
Social contact index in wave 7		0.909*		0.901**
		[0.817,1.011]		[0.811,1.000]
Using the internet in wave 7		1.195		1.236
		[0.899,1.587]		[0.932,1.638]
Missing social contact in wave 7		0.436***		0.430***
		[0.239,0.797]		[0.239,0.773]
Missing internet use in wave 7		0.977		0.988
		[0.488,1.957]		[0.495,1.971]
Log of LA gross spending			0.936	1.007
			[0.478,1.833]	[0.523,1.941]
LA IDAOPI average score			1.050***	1.052***
			[1.015,1.087]	[1.016,1.090]
LA website score			0.998	1.000
			[0.951,1.047]	[0.954,1.049]
Percentage of new requests to the LA not resulting in care or equipment			1.001	1.002
			[0.989,1.014]	[0.990,1.015]
N	992	992	992	992

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: IADL: instrumental activity of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; log: natural logarithm; PADL: personal activity of daily living.

Wave 7 refers to 2014-15 and wave 8 to 2016-17.

Reference category for age: 65-69. The frailty index was measured as a percentage.

Wealth refers to equivalised net total wealth. Reference category for wealth: lowest quartile.

The social contact index ranged from 0 to 6. A higher value indicated more social contact. In the social contact index and in the internet use variable, missing values were replaced with 0 (only for people who responded to the self-completion questionnaire; people who did not do so were excluded).

LA gross spending refers to spending on community long-term care (adjusted by an area cost adjustment factor) per older person with a disability, in £ thousands (i.e., divided by 1,000). A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Additional sequential modelling evaluated a model which included meal provision. This sequential modelling was based on N=991 people. Meal provision was not a significant predictor and made no difference to the other coefficients, so the variable was excluded.

4.2.2.4 Interactions

Table 11 compares the final model selected after sequential modelling to other models with interaction terms. Model 2 shows that the term for interaction between living alone and the highest wealth quartile was significant, with a point estimate (0.333) below 1. The odds ratio indicating a positive association between living alone and unmet need was higher among people in the lowest wealth quartile (point estimate: 3.817) than across all wealth quartiles (point estimate: 2.326); both were significant. The association between living alone and unmet need was no longer significant in the highest wealth quartile (point estimate of the odds ratio: 3.817*0.333=1.271).

Moreover, among people living with others, wealth quartiles were not significantly associated with unmet need (point estimate of the odds ratio comparing the highest to the lowest wealth quartile: 1.072). However, among people living alone, the highest wealth quartile was significantly associated with lower odds of unmet need compared to the lowest wealth quartile (point estimate of the odds ratio: 1.072*0.333=0.357).

Table 11. Outcome: unmet need. Odds ratios. Exploring interactions.

	(1) Final	(2) Final + interaction between living alone and wealth	(3) Final + interaction between having a child in close proximity and wealth
Age 70-74	1.022	0.991	1.019
	[0.684,1.528]	[0.664,1.477]	[0.676,1.537]
Age 75-79	0.782	0.789	0.781
	[0.500,1.224]	[0.504,1.235]	[0.505,1.208]
Age 80-84	0.477***	0.462***	0.483***
	[0.288,0.790]	[0.275,0.775]	[0.293,0.796]
Age 85+	0.402***	0.421***	0.415***
	[0.253,0.641]	[0.263,0.673]	[0.260,0.663]
Male	1.530***	1.529***	1.534***
	[1.146,2.041]	[1.148,2.036]	[1.155,2.038]
Social contact index in wave 7	0.901**	0.896**	0.897**
	[0.811,1.000]	[0.805,0.996]	[0.808,0.996]
Using the internet in wave 7	1.236	1.242	1.263
	[0.932,1.638]	[0.933,1.653]	[0.954,1.673]
Missing social contact in wave 7	0.430***	0.424***	0.427***
	[0.239,0.773]	[0.232,0.773]	[0.241,0.759]
Missing internet use in wave 7	0.988	0.944	0.965
	[0.495,1.971]	[0.466,1.911]	[0.493,1.890]
43-deficits frailty index in wave 8	0.944***	0.943***	0.945***
	[0.929,0.959]	[0.928,0.958]	[0.929,0.960]
N of PADL limitations in wave 8	1.072	1.084	1.066
	[0.919,1.250]	[0.926,1.269]	[0.912,1.245]
N of IADL limitations in wave 8	0.541***	0.540***	0.540***
	[0.448,0.655]	[0.446,0.654]	[0.446,0.654]
Education beyond school leaving age	1.236	1.220	1.252
	[0.870,1.756]	[0.858,1.735]	[0.879,1.784]
Log of LA gross spending	1.007	1.005	0.995
	[0.523,1.941]	[0.507,1.991]	[0.519,1.908]
LA IDAOPI average score	1.052***	1.053***	1.052***
	[1.016,1.090]	[1.016,1.092]	[1.016,1.090]
LA website score	1.000	1.001	0.998
	[0.954,1.049]	[0.954,1.050]	[0.952,1.047]
Percentage of new requests to the LA not resulting in care or equipment	1.002	1.002	1.002
	[0.990,1.015]	[0.989,1.015]	[0.990,1.015]
Wealth in wave 7: quartile 2	0.931	1.273	0.542*
	[0.566,1.534]	[0.664,2.441]	[0.266,1.104]
Wealth in wave 7: quartile 3	0.892	1.056	0.860
	[0.574,1.384]	[0.573,1.944]	[0.411,1.800]
Wealth in wave 7: quartile 4 (highest)	0.702	1.072	0.732
	[0.401,1.229]	[0.552,2.081]	[0.313,1.716]

	(1) Final	(2) Final + interaction between living alone and wealth	(3) Final + interaction between having a child in close proximity and wealth
Living alone in wave 7	2.326***	3.817***	2.287***
	[1.595,3.391]	[1.805,8.074]	[1.587,3.295]
Child within 30 minutes in wave 8	0.997	1.033	0.866
	[0.690,1.441]	[0.718,1.486]	[0.404,1.857]
Interaction term: wealth quartile 2 and living alone		0.453	
		[0.151,1.356]	
Interaction term: wealth quartile 3 and living alone		0.784	
		[0.307,2.004]	
Interaction term: wealth quartile 4 (highest) and living alone		0.333**	
		[0.129,0.864]	
Interaction term: wealth quartile 2 and child in close proximity			2.158*
			[0.927,5.025]
Interaction term: wealth quartile 3 and child in close proximity			1.041
			[0.380,2.854]
Interaction term: wealth quartile 4 (highest) and child in close proximity			0.878
			[0.323,2.385]
N	992	992	992

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; log: natural logarithm; PADLs: personal activities of daily living.

Wave 7 refers to 2014-15 and wave 8 to 2016-17.

Reference category for age: 65-69.

The frailty index was measured as a percentage.

The social contact index ranged from 0 to 6. A higher value indicated more social contact. In the social contact index and in the internet use variable, missing values were replaced with 0 (only for people who responded to the self-completion questionnaire; people who did not do so were excluded).

Wealth refers to equivalised net total wealth. Reference category for wealth: lowest quartile.

LA gross spending refers to spending on community long-term care (adjusted by an area cost adjustment factor) per older person with a disability, in £ thousands (i.e., divided by 1,000).

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

4.2.2.5 Robustness checks

Multiple robustness checks are presented in Appendix 4G, which compared the final model selected after sequential modelling (model 4, Table 10) to alternative models. Some results were robust to all changes attempted in these checks: living alone was always positively associated with unmet need, while no association was found in any of the models between unmet need and these determinants: education beyond school leaving age; the quality score of social care information on the LA website; the percentage of new requests to the LA that resulted in no care and no assistive equipment.

In contrast, the association between social contacts and unmet need often changed from significant to borderline significant, and sometimes to non-significant. Additionally, when alternative measures of social contacts were used, no association was found (see Appendix 4G.5 for more details).

A robustness check included ELSA longitudinal weights, which are intended to minimise bias from non-response [118]. For most independent variables, significance and direction of association did not change when weights were used. See Appendix 4G.1 for more details on this.

Robustness checks around the outcome definition indicated that the risk factors for not receiving any help were different to the risk factors for receiving help that did not always meet needs. The results in the final model were considerably influenced by people with no help, which were the great majority of people with unmet need. When definitions of met and unmet need were changed to help receipt and no help receipt, respectively, results were very similar to the final model. In contrast, results changed considerably when people with no help were excluded and unmet care need was only defined based on people's perceptions as help that did not always meet needs. For example, frailty was negatively associated with unmet need in the final model (Table 10, model 4), but it was a borderline significant risk factor for unmet need among people with help. It should be noted that in the robustness analysis that excluded people without help, those with help that met needs sometimes/hardly ever could not be looked at as a separate group due to their limited number; they were grouped with people with help that usually met needs. See Appendix 4G.2 for more details.

Robustness checks showed that cognition test scores should not be excluded from the frailty index, even if this led to the exclusion of additional people from the analysis. Indeed, when these scores were excluded, using the internet had a borderline significant positive association with unmet need; this was a sign of omitted variable bias. See Appendix 4G.3 for more details.

Some robustness checks were made around the child in close proximity variable. When people with no children were put into a separate comparison category from people with children living far away, results changed very little. Little change was also seen when a threshold of one hour was used instead of a threshold of 30 minutes. Unexpectedly, having a child within 15 minutes was a borderline significant risk factor for unmet need. See Appendix 4G.4 for more details.

When equivalised wealth quartiles were replaced by benefit unit (non-equivalised) wealth quartiles and equivalised wealth as a continuous variable, the finding of no association with unmet need was consistent. See Appendix 4G.6 for more details.

When alternative measures of LA expenditure were used, the finding of no association with unmet need was consistent. See Appendix 4G.7 for more details.

When the Index of Multiple Deprivation (IMD) score was used instead of the IDAOPI score, the finding of a positive association with unmet need was consistent. When no LA deprivation score was included, the highest wealth quartile had a borderline significant negative association with unmet need, compared to the lowest wealth quartile. See Appendix 4G.8 for more details.

4.3. Analysis on people with help to assess source of care as a determinant of unmet need.

4.3.1. Justification

None of the included studies in the review in Chapter 3 assessed source of care as a determinant of unmet need. The annual publication of the Adult Social Care User Survey (ASCS) is useful to gain some insight into the views of social care users, but it only focuses on individuals in receipt of "long-term support services provided or commissioned by the council" or the NHS ([121], p. 4). The present analysis aimed to assess whether, among those who received care, specific sources of care were positively or negatively associated with unmet need, looking at: at least some informal care from inside the household, all informal care from outside the household, or no informal care; LA-funded care; care paid with private funds or benefits.

Considering that living alone was a risk factor for unmet need (see model 4, Table 10), it was hypothesised that receiving at least part of the help from an informal carer living in the same household might be associated with lower odds of unmet need compared to receiving all informal care from outside the household. It was also hypothesised that receiving no informal care would be associated with increased odds of unmet need.

4.3.2. Data and methods

This analysis used similar data sources to those used for the analysis described in section 4.2: it used ELSA data from waves 7 and 8 [80] merged with publicly available data about LA characteristics. The distinction was that some LA-level determinants were excluded from the present analysis, so the corresponding datasets were not used. More details are provided below.

The sample inclusion criteria were the same as those described in section 4.2.1.2 plus an additional criterion: being in receipt of help in 2016/17.

The outcome was partly different to the outcome definition outlined in section 4.2.1.3. This was because people with no help were not included, so the "unmet need" group was much smaller. Therefore, people with help that "usually" met needs were classified as with unmet need, together with people for which help only met needs "sometimes" or "hardly ever". The met need group only included people for which help met needs "all the time". This was the same categorisation as in a previous study by Iparraguirre [37].

The determinants for the source of care domain were:

1. Whether the person had:
    a. at least some informal care from a person living in the same household (potentially with some additional informal care from outside the household);
    b. all informal care from outside the household (this implies that the person had no informal care from within the household);
    c. no informal care.
2. Whether the person paid for at least part of the help with own income, savings, benefits, or gifts, or a family member paid for at least part of the help.
3. Whether the person had at least some LA-funded care.

Note that 1, 2 and 3 were not mutually exclusive, while a, b and c were mutually exclusive. In the analysis, at least some informal care from within the household (a) was used as the reference category.

Appendix 4B.4 explains how the two variables corresponding to determinants 2 and 3 above were created, indicating how different questions of the ELSA questionnaire were used.

The other determinants assessed in sequential modelling were the same as those described in section 4.2.1.4 except for these variables, which were excluded: living alone; having a child in close proximity; social contact; using the internet; the quality of social care information on the council website; the percentage of new requests to the council resulting in no care and no assistive equipment. Living alone was excluded because the determinant "at least some informal care from within the household" was prioritised. Social contact was excluded because it was assumed that its main impact would be on the likelihood of receiving help, rather than on how help met needs once help was available. The other variables were excluded because no significant association with unmet need was found in the data analysis described in section 4.2. Additionally, whether one had care during both day and night was added in sequential modelling.

There were two hypotheses about care during both day and night:

1. It could be a mediator of the relationship between source of care and unmet need: for example, some people with informal care in the household may have less unmet need due to receiving day-and-night care.

2. It could be a confounder of the relationship between source of care and unmet need: for example, some people may pay for care because they need care day and night; they might report

more unmet need as it may be more difficult to meet their higher level of need; as a result, it may look as if paying for care is associated with unmet need.

The equation to assess source of care as a determinant of unmet need is outlined below.

$$Ln(Pr(UN_{it} = 1)/(1 - Pr(UN_{it} = 1))) = \gamma_0 + \gamma_1 \mathbf{W}_{it} + u_{it} \qquad (2)$$

Where UN_{it} is the binary unmet need of individual i, measured at time t, t =2016-17 (wave 8), γ_0 is a constant to be estimated, $\mathbf{W}_{it}$ is the set of determinants of unmet need, γ_1 is a vector of parameters to be estimated, and u_{it} the error term. The determinants which were assessed as potentially part of $\mathbf{W}_{it}$, including times when the determinants were measured, are outlined below. Note that some of these were not included in the final model (see section 4.3.3.3 on sequential modelling).

$$\begin{aligned}&\mathbf{W}_{it} = gender_{i0}, education_{i0}, wealth_{it-1}, age_{it},\ health\ related\ variables_{it},\\&help\ day\ and\ night_{it}, informal\ care\ availability\ and\ setting_{it},\\&care\ paid\ with\ private\ funds\ or\ benefits_{it}, LA - funded\ care_{it},\\&LA\ expenditure_{it}\ , LA\ deprivation_{i2015}\end{aligned}$$

Note that wealth was measured at $t - 1$, corresponding to 2014-15 (wave 7).

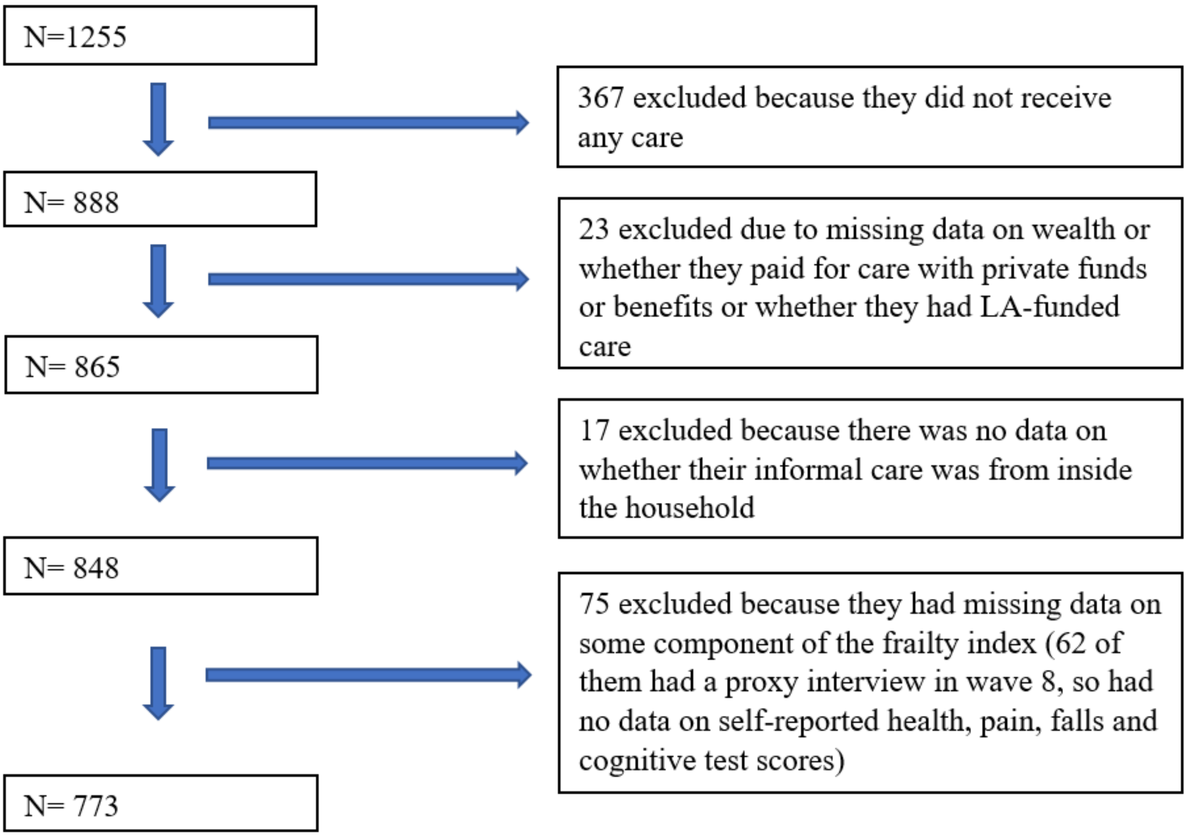
For missing data, the same methods mentioned in section 4.2.1.5.2 were applied. Logistic regressions with clustered standard errors were run.

Interaction was assessed between the informal care categories and paying for at least some care with private funds or benefits. One hypothesis was that not having informal care or having all informal care from outside the household may increase the odds of unmet need only for people who did not pay for care with private funds or benefits. Another hypothesis was that paying for at least some care with private funds or benefits may decrease the odds of unmet need only for people with no informal care or people with all informal care from outside the household. The rationale was that informal care from within the household may be more likely to meet needs and so the presence or absence of care paid with private funds or benefits may make little difference.

4.3.3. Results

4.3.3.1 Missing data flowchart and final sample size

773 people were included in the final model.



367 excluded because they did not receive any care

23 excluded due to missing data on wealth or whether they paid for care with private funds or benefits or whether they had LA-funded care

17 excluded because there was no data on whether their informal care was from inside the household

75 excluded because they had missing data on some component of the frailty index (62 of them had a proxy interview in wave 8, so had no data on self-reported health, pain, falls and cognitive test scores)

Figure 7. Missing data flowchart - analysis on source of care.

4.3.3.2 Descriptive statistics

See Table 12 for the descriptive statistics. The unmet need group had a higher percentage of females, of people with education beyond school leaving age, with help both day and night, with all informal care from outside the household and with care paid with private funds or benefits. The unmet need group also had a lower percentage of people with informal care from within the household. On average, frailty and the number of PADL and IADL limitations were higher in the unmet need group.

Table 12: Descriptive statistics by met/unmet care need and for the overall sample.

	Met need (N=505)	**Unmet need (N=268)**	**Total (N=773)**
Categorical variables	*Proportion (SD)* *[exception: mean (SD) for wealth in the "Total" column]*		
Age 65-69	0.19	0.18	0.18
	(0.39)	(0.39)	(0.39)
Age 70-74	0.18	0.19	0.18
	(0.39)	(0.39)	(0.39)
Age 75-79	0.19	0.18	0.19
	(0.39)	(0.39)	(0.39)
Age 80-84	0.20	0.21	0.20
	(0.40)	(0.41)	(0.40)
Age 85+	0.24	0.24	0.24
	(0.43)	(0.43)	(0.43)
Male	0.42	0.34	0.39
	(0.49)	(0.47)	(0.49)
Education beyond school leaving age	0.38	0.44	0.40
	(0.48)	(0.50)	(0.49)
Wealth in wave 7: quartile 1 (lowest)	0.25	0.26	2,655
	(0.43)	(0.44)	(12,307)
Wealth in wave 7: quartile 2	0.23	0.28	97,558
	(0.42)	(0.45)	(30,207)
Wealth in wave 7: quartile 3	0.28	0.19	193,857
	(0.45)	(0.39)	(33,805)
Wealth in wave 7: quartile 4 (highest)	0.24	0.26	447,746
	(0.43)	(0.44)	(230,346)
Help day and night	0.20	0.26	0.22
	(0.40)	(0.44)	(0.42)
At least some informal care from inside the household	0.58	0.46	0.54
	(0.49)	(0.50)	(0.50)
All informal care from outside the household	0.29	0.43	0.34
	(0.45)	(0.50)	(0.47)
No informal care	0.13	0.12	0.13
	(0.34)	(0.32)	(0.33)
Care paid with private funds or benefits	0.20	0.28	0.23
	(0.40)	(0.45)	(0.42)
LA-funded care	0.10	0.12	0.11
	(0.30)	(0.32)	(0.31)
Numerical variables		*Mean (SD)*	
Frailty index in wave 8	36.99	39.63	37.90
	(10.16)	(9.59)	(10.04)
N of PADL limitations in wave 8	1.58	2.05	1.74
	(1.48)	(1.67)	(1.57)
N of IADL limitations in wave 8	2.06	2.40	2.17
	(1.71)	(1.75)	(1.73)

	Met need (N=505)	**Unmet need (N=268)**	**Total (N=773)**
LA gross spending	0.46	0.47	0.46
	(0.12)	(0.13)	(0.13)
LA IDAOPI score	15.80	16.37	16.00
	(5.52)	(5.68)	(5.58)

Table notes.

Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADLs: personal activities of daily living; SD: standard deviation.

All variables from 2016/17 (wave 8 in ELSA), except from wealth, which was measured in the wave 7 of ELSA, and the IDAOPI score.

The frailty index is based on 43 deficits and is measured as a percentage.

Wealth refers to equivalised net total wealth; wealth quartiles were calculated based on the final sample of 773 people.

Care paid with private funds or benefits refers to: respondent pays out of own income, savings or benefits or gives gifts or the family member pays.

LA gross spending refers to spending on community long-term care (adjusted by an area cost adjustment factor) per older person with a disability, in £ thousands (i.e., divided by 1,000).

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Table 13 shows pairwise correlations between individual-level variables. All correlations between unmet need and the other variables were very weak.

Table 13. Pairwise correlations of individual-level variables based on 773 people.

Variables		(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)	(14)	(15)	(16)	(17)
Unmet need	(1)	1.00																
Age	(2)	0.01	1.00															
Male	(3)	-0.08	0.01	1.00														
43-deficits frailty index	(4)	0.13	-0.01	-0.08	1.00													
N of PADL limitations	(5)	0.15	-0.13	0.11	0.37	1.00												
N of IADL limitations	(6)	0.09	0.11	-0.03	0.37	0.32	1.00											
Education beyond school leaving age	(7)	0.07	-0.02	-0.03	-0.13	0.00	-0.03	1.00										
Wealth: quartile 1 (lowest)	(8)	0.02	-0.14	-0.07	0.15	-0.01	0.01	-0.16	1.00									
Wealth: quartile 2	(9)	0.06	0.01	0.03	0.02	0.06	0.03	-0.15	-0.33	1.00								
Wealth: quartile 3	(10)	-0.10	0.08	0.02	-0.01	0.01	0.04	0.01	-0.33	-0.33	1.00							
Wealth: quartile 4 (highest)	(11)	0.03	0.05	0.02	-0.16	-0.06	-0.08	0.31	-0.33	-0.33	-0.33	1.00						
At least some informal care from someone in household	(12)	-0.12	-0.31	0.15	-0.05	0.06	-0.02	-0.01	-0.14	0.13	0.03	-0.01	1.00					
All informal care from outside the household	(13)	0.14	0.23	-0.15	0.11	-0.01	0.09	-0.05	0.11	-0.08	-0.01	-0.01	-0.77	1.00				
No informal care	(14)	-0.02	0.13	-0.01	-0.08	-0.08	-0.09	0.09	0.06	-0.08	-0.02	0.04	-0.41	-0.27	1.00			
Paying for care with private funds or benefits	(15)	0.09	0.22	-0.04	0.01	-0.02	-0.01	0.14	-0.10	-0.04	-0.06	0.20	-0.32	0.09	0.35	1.00		
LA-funded care	(16)	0.03	0.10	-0.02	0.08	0.14	0.16	0.04	0.03	0.02	-0.05	-0.01	-0.18	0.07	0.17	0.24	1.00	
Help day and night	(17)	0.07	-0.07	0.07	0.23	0.25	0.22	-0.02	-0.09	0.14	0.00	-0.05	0.25	-0.20	-0.10	-0.13	0.06	1.00

Legend

Colour	**Value of correlation coefficient**		**Strength of the correlation**
	Positive coefficient (in green)	**Negative coefficient (in red)**	
░	>0 & <0.2	<0 & >-0.2	Very weak
▒	>=0.2 & <0.4	<=-0.2 & >-0.4	Weak
▓	>=0.4 & <0.6	<=-0.4 & >-0.6	Moderate
█	>=0.6 & <0.8	<=-0.6 & >-0.8	Strong
■	>=0.8 & <1	<=-0.8 & >-1	Very strong

Table notes. Abbreviations: IADLs: instrumental activities of daily living; LA: local authority; N: number; PADLs: personal activities of daily living. Wealth refers to equivalised net total wealth. Quartiles were calculated based on the final sample of 773 people.

4.3.3.3 Sequential modelling

Table 14 shows two models included in sequential modelling. The base model (without local-authority level variables) was the most appropriate one and was selected as the final model. Note that Table 14 does not show an additional model which included help during both day and night and was excluded in a separate comparison, which was based on a lower sample size. The reason for selecting the base model was that none of the additional variables were significant or changed the significance of the other coefficients.

Unmet need had a borderline significant negative association with being male, a borderline significant positive association with being frailer, and a positive association with the number of PADL difficulties. Unmet need also had a positive association with education beyond school leaving age.

People who had informal care only from outside the household had higher odds of unmet need compared to people with at least some informal care from inside the household. Paying for at least part of the care with private funds or benefits had a borderline significant positive association with unmet need. No association was found between receiving care that was at least in part funded by the LA or absence of informal care and unmet need.

Table 14. Outcome: unmet need (help that does not meet needs all the time). Odds ratios. Sequential modelling, including the final model (model 1).

	(1) Base model (Final model)	(2) Base plus LA variables
Age 70-74	1.087	1.070
	[0.681,1.733]	[0.669,1.713]
Age 75-79	1.025	1.012
	[0.639,1.645]	[0.631,1.623]
Age 80-84	1.028	1.027
	[0.633,1.670]	[0.632,1.668]
Age 85+	0.884	0.888
	[0.521,1.498]	[0.527,1.497]
Male	0.743*	0.730*
	[0.536,1.030]	[0.526,1.013]
43-deficits frailty index in wave 8	1.014*	1.014*
	[0.998,1.029]	[0.998,1.029]
N of PADL limitations in wave 8	1.182***	1.190***
	[1.056,1.322]	[1.064,1.332]
N of IADL limitations in wave 8	1.046	1.046
	[0.943,1.160]	[0.945,1.157]
Education beyond school leaving age	1.434**	1.451**
	[1.018,2.022]	[1.026,2.052]
Wealth in wave 7: quartile 2	1.304	1.344
	[0.817,2.081]	[0.849,2.127]
Wealth in wave 7: quartile 3	0.658*	0.688*
	[0.426,1.015]	[0.446,1.060]
Wealth in wave 7: quartile 4	1.005	1.074
	[0.667,1.513]	[0.711,1.624]
Informal care only from outside the household	1.851***	1.832***
	[1.263,2.713]	[1.242,2.701]
No informal care	1.127	1.132
	[0.677,1.877]	[0.681,1.881]
Care paid with private funds or benefits	1.438*	1.447*
	[0.980,2.110]	[0.988,2.120]
LA-funded care	0.781	0.784
	[0.477,1.280]	[0.481,1.277]
Log of LA gross spending		1.688
		[0.780,3.650]
LA IDAOPI score		1.007
		[0.965,1.050]
N	773	773

Table notes

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

All variables from 2016/17 (wave 8) except for wealth, which was measured in wave 7, and the IDAOPI score, measured in 2015.

The reference category for age was 65-69.

The frailty index was measured as a percentage.

Wealth refers to equivalised net total wealth; wealth quartiles were calculated based on the final sample of 773

people. The reference category for wealth was the lowest quartile (quartile 1).
The reference category for all informal care from outside the household and no informal care was “at least some informal care from within the household”.
Care paid with private funds or benefits refers to: respondent pays out of own income, savings or benefits or gives gifts or the family member pays.
Sequential modelling also included models with an additional variable: receiving help during both day and night. This was not significant and did not affect the other variables’ coefficients, so it was excluded.
A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

4.3.3.4 Interactions

Table 15 shows that the term for interaction between having all informal care from outside the household and paying for care with private funds or benefits was borderline significant (point estimate: 0.481). Having all informal care from outside the household had a positive and significant association with unmet need compared to at least some informal care from within the household among people who did not pay for care with private funds or benefits (point estimate of the odds ratio: 2.143). No significant association was found between all informal care from outside the household and unmet need among people who paid for care with private funds or benefits (point estimate of the odds ratio: 2.143*0.481=0.966).

Paying for care with private funds or benefits was positively and significantly associated with unmet need among people with at least some informal care from within the household (point estimate of the odds ratio: 2.075). No association was found between paying for care with private funds or benefits and unmet need among people with only informal care from outside the household (point estimate of the odds ratio :2.075*0.481=0.998).

Table 15. Outcome: unmet need. Odds ratios. Exploring interactions.

	(1) Final	(2) Final + interaction terms
Age 70-74	1.087	1.082
	[0.681,1.733]	[0.676,1.730]
Age 75-79	1.025	1.025
	[0.639,1.645]	[0.634,1.657]
Age 80-84	1.028	0.999
	[0.633,1.670]	[0.617,1.617]
Age 85-90+	0.884	0.883
	[0.521,1.498]	[0.518,1.507]
Male	0.743*	0.752*
	[0.536,1.030]	[0.536,1.053]
Frailty index in wave 8	1.014*	1.014*
	[0.998,1.029]	[0.998,1.030]
N of PADL limitations in wave 8	1.182***	1.183***
	[1.056,1.322]	[1.057,1.322]
N of IADL limitations in wave 8	1.046	1.051
	[0.943,1.160]	[0.947,1.165]
Education > school leaving age	1.434**	1.411*
	[1.018,2.022]	[0.993,2.005]
Wealth in wave 7: quartile 2	1.304	1.334
	[0.817,2.081]	[0.832,2.140]
Wealth in wave 7: quartile 3	0.658*	0.674*
	[0.426,1.015]	[0.435,1.044]
Wealth in wave 7: quartile 4	1.005	1.029
	[0.667,1.513]	[0.684,1.548]
LA-funded care	0.781	0.797
	[0.477,1.280]	[0.495,1.282]
Informal care only from outside the household	1.851***	2.143***
	[1.263,2.713]	[1.418,3.241]
No informal care	1.127	0.983
	[0.677,1.877]	[0.440,2.196]
Care paid with private funds or benefits	1.438*	2.075**
	[0.980,2.110]	[1.099,3.919]
Interaction term: all informal care from outside the household and care paid with private funds or benefits		0.481*
		[0.205,1.130]
Interaction term: no informal care and care paid with private funds or benefits		0.921
		[0.347,2.441]
N	773	773

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

All variables from wave 8 except wealth, which was from wave 7.

The reference category for age was 65-59.

The frailty index is based on 43 deficits and is measured as a percentage.

Wealth refers to equivalised net total wealth; wealth quartiles were calculated based on the final sample of 773

people. The reference category was the lowest quartile (quartile 1).
The reference category for all informal care from outside the household and no informal care was "at least some informal care from within the household".
Care paid with private funds or benefits refers to: respondent pays out of own income, savings or benefits or gives gifts or the family member pays.

4.3.3.5 Robustness checks

A robustness check showed that the positive association between informal care all from outside the household and unmet need was robust when the variables for LA-funded care and care funded with private funds or benefits were replaced with a formal care variable (see Appendix 4G.10).

4.4. Discussion

In the final model of the main analysis including people with and without help (model 4, Table 10), living alone, being male, with lower frailty, with fewer IADL limitations, with less social contact, and living in a more deprived LA were positively associated with unmet need. The same positive association was observed for the age group 65-69, compared to being aged 80 and over.

Robustness checks indicated that most results in model 4 of Table 10 were sensitive to the definition of unmet care need and the sample inclusion criteria. In particular, results changed considerably when people with no help were excluded and unmet care need was defined based on people's perceptions as help that did not always meet needs.

The relationship between some determinants and unmet need changed between model 4 in Table 10, which included people with and without help, and model 1 in Table 14, which excluded people with no help to assess whether different sources of care were determinants of unmet need. In particular, the direction of association for the male and frailty variable was the opposite when the two models were compared. Table 16 summarises the differences between the two models.

Table 16. Comparison of model 4 in Table 10 and model 1 in Table 14.

Differences in methods	**Main analysis: model 4 in Table 10**	**Analysis on source of care: model 1 in Table 14**
Unique sample inclusion criteria	People with and without help	People with help
Definition of unmet need	Either no help or help meeting needs sometimes or hardly ever	Help meets needs usually / sometimes / hardly ever
Definition of met need	Help meets needs usually / all the time	Help meets needs all the time
Sample size	992	773
Unique determinants	Living alone, child in close proximity, social contact, using the internet, LA-level variables	Sources of care
Association of shared determinants with unmet need		
Some older age groups	Negative	No association found
Male	Positive	Negative (borderline sig.)
Higher frailty	Negative	Positive (borderline sig.)
N of PADL limitations	No association found	Positive
N of IADL limitations	Negative	No association found
Education beyond school leaving age	No association found	Positive
Wealth quartiles	No association found. A significant association was found when interaction with living alone was assessed in a separate model.	No association found

Table notes. Abbreviations: sig.: significant. “Unique” means only included in one of the two models, “shared” means included in both models.

Model 1 in Table 14 actually found a borderline significant negative association with the third wealth quartile. This is ignored in the summary table as it was not reflected in the results for the second or fourth quartile and so seemed an arbitrary result.

Section 4.4.1 discusses the findings relating to the individual-level determinants, with the exception of source of care, while section 4.4.2 focuses on LA-level determinants. The results relating to the source of care variables are discussed in section 4.4.3. Section 4.4.4 provides some further discussion relevant to all determinants.

4.4.1. Individual-level determinants (excluding source of care)

Focusing on the main analysis that included both people with and without help (final model: model 4, Table 10), living alone was the only determinant that was consistently associated with unmet need regardless of any changes to the analysis made in robustness checks. This positive association was also observed in the literature review in chapter 3 [60, 69]. However, the present study, which was the first to assess the interaction between living alone and wealth, found that the association between living alone and unmet need did not hold among people in the highest wealth quartile. This finding should be interpreted with caution due to the limited number of people included in the analysis (there were 122 people living alone in the lowest wealth quartile, 60 in the second lowest wealth quartile, 77 in the second highest and 75 in the highest). However, the finding suggests that high wealth enables people to purchase care that counteracts the lack of informal help from within the household. In support of this interpretation, the review in chapter 3 identified a positive association between wealth and privately funded care [62, 68, 72]. Moreover, being in the lowest wealth quartile was associated with increased odds of unmet need compared to the highest quartile only among people living alone. This suggests that for people with low wealth, informal care provided by people living in the same household compensates for the limited resources available to buy privately funded care and fills any care gaps left by LA-funded care. The compensatory role of informal care in relation to low wealth is supported by some studies in chapter 3, which found that people in a lower wealth quintile had higher odds of informal care than those in a wealthier quintile [62, 71, 72].

In the main analysis including both people with and without help (final model: model 4, Table 10), another result that was robust to all model changes was that no association was found between unmet need and education beyond school leaving age. This is consistent with the results from the review in chapter 3 where no association was found between unmet need and educational qualifications [60-62, 69]. However, in the analysis restricted to people with help to assess source of care as a determinant of unmet need (model 1, Table 14), education beyond school leaving age was positively associated with unmet need. It may be that source of care was an omitted confounder in all the other analyses. The correlation plot in Table 13 shows a very weak positive correlation between education beyond school leaving age and care paid with private funds or benefits, LA-funded care and absence of informal care. This may have confounded results in other analyses.

In the main analysis that included both people with and without help (final model: model 4, Table 10), no significant association was found between having children living within 30 minutes and unmet need. No study included in chapter 3 considered whether the older person had a child living within 30 minutes. One included study found a borderline significant positive association between having a child inside the household and receiving help [19]. A second study found that having children was positively associated with care receipt [62], while a third study found no association between having a child and unmet need, defined as not having help with a difficulty, or with the number of unmet needs [61].

Further research should assess the interaction between age and children living in close proximity: it may be that having children nearby has an effect on unmet need after a certain age, when help from a spouse or friends may become less likely, as they would also be older. In England, children were the most common providers of informal care for older people aged 75 and over in 2018 [1]. However, for people aged 65-74, spouses or partners were the most common informal care providers in 2018 [1].

Further research should also consider whether there are other relatives or friends living nearby, rather than only children, or generally focus on the wider social network around a person. This recommendation is supported by the finding that the social contact variable, which considered not only children, but also other relatives and friends, had a significant inverse association with unmet need in the final model (Table 10, model 4).

In addition to spouses, other relatives, friends and neighbours, it is possible that formal care fills the care gaps that may occur when no children live nearby: in England, the percentage of older people receiving formal care was higher among those without children (12%) than among those with children (7%) in 2016/17 [1].

In the main analysis including both people with and without help (model 4, Table 10), being aged 65 to 69 was associated with increased odds of unmet need compared to being aged 80 and over. In the analysis that only included people with help to assess source of care as a determinant of unmet need (model 1, Table 14), no association was found between age group and unmet need. Studies included in chapter 3 also found that younger age groups had higher odds of unmet need [19, 60, 62, 69]. It is possible that younger people may be more reluctant to admit they have difficulties and to ask for help (personal communication with the public advisory group). An alternative explanation is that the association with age may be confounded by how much difficulty people had with activities of daily living: the analysis included the number of limitations, but not the extent of these limitations.

In the main analysis including both people with and without help (model 4, Table 10), being frailer was associated with reduced odds of unmet need. However, in the analysis that focused only on people with help to assess source of care as a determinant of unmet need (model 1, Table 14), being frailer had a borderline significant positive association with unmet need. The same result for frailty was observed in a robustness check in Appendix 4G.2 which excluded people with no help (model 5, Table 87). This would suggest that people who are less frail may be less likely to receive care, perhaps because they may be more likely to manage to get by without it. However, once care is provided, it may be more difficult to meet needs for people who are frailer.

Results on the relationship between the number of PADL limitations and unmet need changed depending on the analysis. Comparing the results in Table 10 (model 4), Table 14 (model 1) and Table 87 (models 4 and 5, run as robustness checks), it appears that when help that "usually" met needs was classified as unmet care need together with help that "sometimes" or "hardly ever" met needs, a positive significant association was found between the number of PADL limitations and unmet need, regardless of whether people without help were included or excluded. Therefore, it seems that it is more difficult for help to meet needs "all the time" for people with more PADL limitations. A previous study found that among those receiving help, responding that help met needs usually/sometimes/hardly ever as opposed to all the time was more likely if the person had PADL limitations [37].

In the main analysis including both people with and without help, being male was positively associated with unmet need (model 4, Table 10). This result appeared in some studies included in the literature review in chapter 3 [19, 60, 62]. Some studies also found a negative association between being male and receiving informal care [62, 68, 70, 72]. However, the data analysis focused on source of care (Table 14, model 1), which excluded people with no help, found a borderline significant negative association between being male and unmet need. Similarly, in chapter 3, the only analysis that found lower odds of unmet need among men was limited to people with help and focused on whether help always met needs [37]. In the robustness checks in Table 87, the model which excluded people with no help (model 5) was the only one where the odds ratio was in the direction of a negative association between being male and unmet need, although it was not significant. Therefore, results from both the literature review and from the data analysis suggest that men were less likely to receive help, but once help was received, they were not at increased risk of unmet need.

Men's lower likelihood of care receipt may have been influenced by residual confounding by the level of impairment: it may be that women are more impaired than men. Although the analyses adjusted for the number of activity difficulties, the extent of the difficulties could not be included because this information is not available in ELSA, so the adjustment would have been limited. In support of this possible interpretation, an American study found that among people with limitations with PADLs, IADLs and mobility tasks, women had a greater disability (this was measured based on the level of difficulty reported in relation to different PADLs, IADLs and mobility tasks) [122].

Another possible reason for men's lower likelihood of care receipt is social networks: in England, in 2012/13, more men than women had contact with children less than once a month, contact with other relatives less than once a month, contact with friends less than once a month [123]. This could be linked to less informal care provision and less information about available services. The present data analysis adjusted for social contacts, but the social contact variable had limitations (see Appendix 4G.5 for more details on this).

Alternatively, the help-seeking behaviour may be different between men and women. One UK study found that men had lower primary care consultation rates than women, although the gap was narrower in the 58-and-over age group [124].

Alternative explanations are connected to a "gender-based division of labor" ([125], p. 111) in the household [70]: it may be that men's reporting of difficulties with domestic tasks tends to only occur when no one is available to do these tasks, and men may be less likely to report receipt of help because tasks performed by wives are taken for granted rather than being perceived as "help". This may explain the finding in one study that among people with a spouse, women had higher odds of reporting that they received help from a spouse than men [70].

Therefore, to summarise, possible reasons behind being male appearing as risk factor for not receiving care are residual confounding by the level of disability, social networks, help-seeking behaviour and different perceptions of what is "help" when it comes to domestic tasks.

4.4.2. The local authority domain

In the analysis including both people with and without help, the final model (Table 10, model 4) found that a higher IDAOPI score (i.e., higher deprivation) was associated with higher odds of unmet need. The finding held after adjusting for expenditure, so even if the level of expenditure differed between more and less deprived LAs, this was not the reason for this result. The Census 2021 found that provision of informal care in England was more common in the most deprived areas compared to the least deprived areas (deprivation referred to the Index of Multiple Deprivation (IMD)) [126]. This may be due to the higher prevalence of disability in more deprived areas: Appendix 4D shows a strong correlation between the IDAOPI score and the percentage of people with disability in an LA. It is possible that there may be more people meeting both the means-testing and the disability criteria for LA-funded care in more deprived LAs, and they may also have more complex problems, and so, it might become more difficult for councils to meet needs. Moreover, deprivation among older people may affect the number of self-funders; areas with fewer self-funders are at higher risk of having providers decide that it is financially unsustainable to operate, especially if they have to face below-cost commissioning from the LA [127]. One study in chapter 3 [68] found no association between the LA percentage of older people that received Guarantee Credit (a low-income benefit which is part of Pension Credit [73]) and the receipt of help from a partner, son, daughter, or LA-funded or privately funded help. However, the analysis focused on the pre-Care Act context. Further research should assess the association between the LA IDAOPI score and different sources of care in the post-Care Act context. Geographical inequalities in unmet care need relating to LA deprivation should be explored further to identify the reasons behind this and possible changes that may address this.

Model 4 in Table 10 did not find a significant association between LA expenditure and unmet need. In contrast, a study included in chapter 3 [37] found a borderline significant and inverse association between LA expenditure and unmet need. The same study found no association between the IDAOPI score and unmet need [37]. There were various differences between the two sets of results. Iparraguirre [37] focused on the pre-Care Act context and used a different measure of expenditure from the present work: LA net (rather than gross) current expenditure on community care for people aged 65 and over divided by the number of residents aged 65 and over (rather than by the number of people with a disability aged 65 and over). A robustness check for the present work included net rather than gross expenditure but no association was found with unmet need (see Appendix 4G.7). Moreover, various other determinants differed between the two analyses (see Table 7 for a comparison). In particular, Iparraguirre [37] did not include frailty in its model, so a robustness check for the present work excluded frailty (see Appendix 4G.9). The finding of no association between expenditure and unmet need held in this robustness check.

No association was found between unmet need and the LA percentage of new requests for support that resulted in no care or equipment. This percentage could potentially capture the strictness or generosity of the local application of national minimum standards. However, the percentage would also be affected by the kind of requests received. Moreover, informal care or privately funded care would often fill the care gap left by the LA.

No association was found between unmet need and the quality of information on the LA website. Although a lack of good information and advice does not seem to directly impact on unmet need, it is still likely to impact on the stress of arranging care, and on people with care needs and informal carers who may miss out on available support.

4.4.3. The source of care domain

Model 1 in Table 14 showed that having all informal care from outside the household was associated with higher odds of unmet care need compared to having at least some informal care from within the household. This finding informed the choice of subgroups in the economic model, as it is described in chapter 6.

Paying for care with private funds or benefits had a borderline significant association with higher odds of unmet need. This finding may be explained by various factors. Firstly, people who pay for their own care may ration their care to save money [11]. A qualitative study conducted in England in 2015/16 found that full self-funders were often worried about the financial sustainability of paying for care in the future. Additionally, concerns around inheritance also contributed to care choices [128]. Another interpretation could be that people who have unmet need resort to paying privately for at least some of their care. However, this additional care would not lead to met need.

Having at least some care funded by the local authority and having no informal care were not found to be significantly associated with unmet need. There were only 83 people with LA-funded care and 98 people without informal care. So, the analysis may have lacked the statistical power to detect any significant differences, and these results should be interpreted with caution.

The positive association between paying for care with private funds or benefits and unmet need changed from borderline significant across the whole sample to significant in the subgroup with informal care from within the household. This finding may be affected by residual confounding linked to the level of disability, because it may be that people with both privately funded care and informal care from within the household have a higher level of difficulties with activities of daily living.

These interactions were of interest but were not assessed because there were only 83 people with LA-funded care:

- Interaction between having at least some care funded by the LA and having at least some care funded with private funds or benefits. A qualitative study found that people who self-funded their care without any LA funding had difficulties navigating the care market and arranging care [128]. Although the DHSC 2020 statutory guidance states that information and advice from councils should also be provided to full self-funders [16], the aforementioned qualitative study found that councils provided very limited advice and support with decision-making for full self-funders [128].
- Interactions between having at least some care funded by the LA and informal care categories.

These interactions could be explored in further research. Moreover, considering that ELSA records how much money is paid for care, further research could look into whether lower or higher spending from private funds or benefits is associated with unmet care need.

The receipt of disability benefits such as Attendance Allowance is recorded in ELSA but it was excluded from the model. Future research could investigate the interaction between paying for care and receipt of benefits. Further research could also look into whether the receipt of benefits is associated with higher disability, or with lower economic means, even if benefits are not linked to means-testing, or with higher awareness of one’s rights and available services.

There were concerns around the validity of the LA-funding variable: it was observed that 37% of people classified with “LA-funded care” had equivalised non-housing wealth above £23,250, which is the threshold that enables the LA to not provide funding for the care of a person living in their own home, based on the Care Act 2014 (see Appendix 4H). This was surprising; it might be that the LA calculates non-housing wealth in a different way compared to ELSA. Because of these concerns, a robustness check replaced the LA funding and private funding variables with a “formal care” variable. This showed that the positive association between informal care all from outside the household and unmet need was robust.

Different classifications of source of care should be considered in future work using ELSA data. ELSA asked whether the LA managed money for care and whether it arranged care. People responding affirmatively were not automatically classified as LA-funded in the present work because full self-funders can also ask the LA to arrange their care and manage their money. However, in practice these cases are rare, so it is likely that the vast majority of people answering affirmatively had some LA funding (personal communication with an advisor).

A small percentage of people said they did not pay for care but then selected the response "Sometimes give them money or gifts for the help they give" ([29], p. 134). They were classified in the present work as paying for care. However, it is likely that these responses were referring to money given as gifts to informal carers, so future work should consider classifying them as not paying for care. Future data collections should consider making a clearer distinction between gifts and payments.

Further research could look beyond the source of funding for the individual and consider whether formal providers are government-run or private for-profit or third sector (private and non-profit) providers. A study on social care providers in Scotland (on many different kinds of services, residential and non, and covering all ages) found that government-run and third sector providers were more likely to have high quality ratings than for-profit providers, which were more likely to have adequate quality ratings. For-profit providers were also more likely to receive complaints [129].

4.4.4. Further discussion

One strength of the present work is that it used lagged variables to limit issues such as reverse causality or confounding by health deterioration, as explained in section 4.2.1.5.1. Although causality cannot be established with the methods used, lagging variables helps with the interpretation of findings. For example, the analysis found a positive association between living alone in wave 7 and unmet need in wave 8, and a negative association between more social contacts in wave 7 and unmet need in wave 8. The living alone and social contacts variables were lagged because the hypothesis was that these impacted on unmet need. The use of lagged variables makes it less likely that it was care provision that affected living arrangements or social contacts. Although reverse causality is still possible if care provision started to have an effect before wave 7, the use of lagged variables makes reverse causality less likely. Moreover, lagging the internet use variable reduced the risk that the reason for finding no association with unmet need was health deterioration, which may have prevented people from using the internet by the time care was provided.

Another strength of this work is that the analysis was informed by discussions with stakeholders. In particular, data on aids and adaptations were not included in the analysis after discussing this with the advisory group of older people and carers. They pointed out that it was problematic to lump different aids and adaptations together when studying how they relate to care provision. Some aids or adaptations may reduce the need for a carer (for example, a walking stick or a personal alarm), but others would only be used with a carer present (for example, a hoist). Moreover, ELSA does not ask questions on some relevant aids or home adaptations (for example, a wet room with level-access and non-slippery shower floor). Additionally, it does not have questions on the quality of aids or adaptations (e.g., if they are of the right size or height). Finally, ELSA does not ask whether the respondent thinks they have the aids and adaptations they need.

Some limitations in this analysis relate to limitations in the ELSA datasets, and so have already been outlined in section 3.4. In particular, the level of care need was only captured by the number of difficulties. Considering this, the present analysis included adjustment for the frailty index, which included multiple health and cognitive components. However, there may be some residual confounding in the analysis relating to the level of cognitive or physical difficulties. For further investigation into the determinants of unmet care need, more detailed information would be needed, including information about the level of difficulty when people respond affirmatively about having difficulty with an activity, and information about whether people without help would need or want help. This would prevent researchers from wrongly classifying under the “unmet need” label people who may be fine performing activities independently despite some difficulty. Finally, it would be useful to have information about whether the person thinks they have the aids and adaptations they need, and whether they have received professional advice on this subject. This would help to more accurately classify people as with met or unmet needs, by taking into account not only their perceptions of the help they receive, but also their perceptions regarding aids and adaptations, and whether these aids and adaptations are likely to be appropriate or used in an appropriate way thanks to professional advice.

In terms of policy recommendations, it is useful to think back to the conceptual framework adapted from Rodriguez Santana et al. [40] highlighted in section 1.1.3. This enables consideration of whether a policy focuses on need, demand, or supply. For example, policies may focus on reducing need by preventing frailty and disability. Other policies may provide information and advice in order to guide demand towards appropriate services. Moreover, policies could focus on better aligning supply with need, for example by hiring and retaining additional staff. Table 17 assigns the domains and variables assessed in the data analysis to need, demand or supply categories, and makes some examples of related policy levers. The table shows that various domains and variables fall within more than one category, which means that it is not clear whether a significant result was driven by need, demand or supply.

Therefore, it is not straightforward to make policy recommendations. However, the table provides examples of policies that could be considered. In order to recommend a specific policy, further research should be conducted to gain more clarity on the interpretation of the data analysis results.

Table 17. Linking the data analysis results to policies acting on need, demand or supply to reduce unmet need.

Domain and variables	**Link to need (N), demand (D) and supply (S)**				**Examples of policies to reduce unmet need**	
	N	**D**	**S**	**Explanation**	**Policies that could be relevant based on significant associations identified in the data analysis**	**Policies that are not supported by the data analysis results (no significant association found)**
Demographic (age and sex)	X	X	X	N: any associations between age or sex and level of impairment should be taken into account because the level of impairment in the data analysis was only partly controlled for. This was due to limited data availability. D: age and sex may influence how people perceive their own needs and their help-seeking behaviour (section 4.4.1 discusses this). S: family members’ or LA assessors’ perceptions of the person’s needs may be influenced by the sex and age of the person with care needs.	Example of a policy targeting demand: if help-seeking behaviour was a reason behind the negative association between being male and care receipt, awareness campaigns targeting men with impairments around the appropriateness of requesting relevant support to the LA or family members could increase their demand for care.	N/A
Health (frailty, N of difficulties with PADLs and IADLs)	X	X	X	N: the number of limitations with PADLs and IADLs and the level of frailty are used in the analysis to measure (in an imperfect way) the level of care need. D: demand for care may be more likely when there are higher needs, but cognitive limitations may hinder the capacity to ask for care. S: the results showed that higher frailty and more IADL limitations were associated with higher odds of care receipt. Therefore, it seems that these variables could drive the supply of social care.	Example of a policy driving supply: current policies prioritise higher needs when assessing eligibility for LA-funded care. However, the data analysis showed that among people with care, people with more PADL limitations were less likely to report that help met needs all the time. To address this, the LA could increase the number of hours of care for people with a high number of PADL limitations.	N/A

Domain and variables	Link to need (N), demand (D) and supply (S)				Examples of policies to reduce unmet need	
	N	**D**	**S**	**Explanation**	**Policies that could be relevant based on significant associations identified in the data analysis**	**Policies that are not supported by the data analysis results (no significant association found)**
Household and family (living alone, having a child in close proximity)	X	X	X	N & D & S: The household and family domain falls within the supply category in relation to informal care, and within the need and demand categories in relation to formal care.	Example of a policy targeting the supply of informal care: if there was a policy that could reduce the number of people living on their own and could incentivise cohabitations that involved people with impairments, this may reduce unmet need, especially among people with lower wealth. However, the effects of this policy on informal carers would have to be considered.	Example of a policy targeting the supply of informal care: any policy that could incentivise people to live close to their older parents.
Social inclusion (social contact and internet use)		X	X	D: a higher frequency and variety of social contacts or using the internet might help a person to gain awareness of their rights and available services and might encourage them to ask for help. S: a higher frequency and variety of social contacts could mean that there are more people available to help.	Example of a policy targeting demand: the LA could start a programme to identify people who may be in need of care but have not requested it due to their social isolation and lack of awareness. Example of a policy targeting the supply of informal care: promotion of social contacts within each neighbourhood, including intergenerational interactions and involving people with impairments.	Example of a policy targeting demand: encouraging older people to use the internet so that they are better informed about their rights and about services available.

Domain and variables	Link to need (N), demand (D) and supply (S)				Examples of policies to reduce unmet need	
	N	D	S	Explanation	Policies that could be relevant based on significant associations identified in the data analysis	Policies that are not supported by the data analysis results (no significant association found)
Socio-economic (education and wealth)	X	X	X	N: any associations between socio-economic status and level of impairment should be taken into account because the level of impairment in the data analysis was only partly controlled for. This was due to limited data availability. Note for example, in Table 9, the negative correlations between the highest wealth quartile on the one hand and the frailty index, the N of PADL limitations and the N of IADL limitations on the other hand. D: people with higher education may be better able to navigate complex documents to demand care. S: low wealth is a requirement for LA-funded care supply, while high wealth can be used to buy care supply privately.	Example of a policy driving LA-funded care supply: based on the Care Act 2014, low wealth is an eligibility requirement for LA-funded care.	Example of a policy targeting demand: providing support for making care requests to the LA so that people with a low level of education are as likely to apply as people with higher education.
LA-level (expenditure, deprivation, quality of online information, % of new requests resulting in no care or equipment)	X	X	X	N: Table 83 shows that the IDAOPI score had a strong positive correlation with the percentage of older people with a disability in an LA. D: the quality of information on the LA website could influence demand. The percentage of new requests resulting in no care and equipment is affected by the kind of requests that are made. S: LA expenditure determines the level of supply. The percentage of new requests resulting in no care and equipment is affected by supply.	Example of a policy targeting need: a programme that aims to prevent disability in the poorest areas.	Example of a policy targeting demand: improving the LA website so that everyone can easily learn about their rights and services available and apply for care if appropriate.

Domain and variables	Link to need (N), demand (D) and supply (S)				Examples of policies to reduce unmet need	
	N	D	S	Explanation	Policies that could be relevant based on significant associations identified in the data analysis	Policies that are not supported by the data analysis results (no significant association found)
						Example of a policy targeting supply: increasing LA expenditure.
Source of care (informal care availability and setting, care paid with private funds or benefits, LA-funded care)	X	X	X	N: source of care may relate to the level of impairment. For example, having more than one source of care may be more likely at higher levels of impairment. This is relevant in the present work because the level of impairment in the data analysis was only partly controlled for. This was due to limited data availability. D & S: availability of one source of care may affect demand for and supply from another source of care.	Example of a policy driving supply: the LA could pay special attention to the number of hours of care allocated to people with informal care available only from outside the household, taking into account that they may be more likely to have unmet need compared to people with at least some informal care from within the household.	Example of a policy driving supply: allocating more hours of LA-funded care to people without any informal care available.

Table notes. Abbreviations: D: demand; IDAOPI: Income Deprivation Affecting Older People Index; LA: local authority; N: need; S: supply.

4.5. Conclusion

The data analyses in this chapter combined useful elements from the review in chapter 3, such as the sample inclusion criteria and some key determinants, with new determinants, a new unmet need definition and a different context. This provided new insight into the determinants of unmet need.

Risk factors for unmet need were different depending on sample inclusion criteria and the definition of unmet need. Therefore, the availability of data that allow for an appropriate definition of unmet need is key. However, limitations in the available data have been identified.

Living alone was the only risk factor associated with unmet care need across all robustness checks on the final model of the main analysis (model 4, Table 10). Among people with help, receiving all informal care from outside the household was associated with increased odds of unmet need, compared to having at least some informal care from within the household. Therefore, people living alone remained at a disadvantage even if they had informal care from people living elsewhere. However, living alone was not a risk factor among people in the highest wealth quartile. This suggests that with appropriate resources, people living alone would not have to be at a disadvantage. In contrast, it seems that current limited budgets in social care have led to wealth inequities in unmet care need among people living alone. LA deprivation was also found to be positively associated with unmet need. These results indicate that an equity case can be made for addressing unmet social care needs and that consideration of socio-economic inequalities has to be part of policy-making in social care. The next chapter focuses on whether unmet need is associated with increased frailty, which is useful towards a better understanding of whether an economic case can be made for addressing unmet need.

Chapter 5. Empirical study: assessing whether unmet care need was a determinant of progression of frailty

5.1. Rationale

Chapter 1 introduced the economic importance of assessing the possible adverse outcomes linked to unmet care need. The main focus of the data analysis in this chapter is the association between unmet care need and progression of frailty. This outcome was selected because it is linked to various adverse consequences, as mentioned in section 1.1.2.

A previous study focused on the determinants of progression of frailty among people aged 50 and over, using ELSA data [103], but it did not focus specifically on people with limitations in activities of daily living and so it did not include unmet care need among the determinants.

In an economic model that evaluated two UK social care policy interventions (the introduction of “fully tax-deductible social care expenses” ([130], p. 10) and an alternative need eligibility threshold) [130], unmet need increased the probability of transition to a higher care need level; this meant that more weekly hours of care were required. The model’s assumption was based on the opinion of experts; they thought that a long time of unmet need for care would increase people’s frailty and health deterioration [130]. The method for eliciting expert opinion was not clarified in the paper. The present research examines whether the model’s assumption holds when assessed with data analysis.

In contrast to the assumption described in the above paragraph, other papers argue that when people stop doing things for themselves, they are likely to deteriorate [131]: not engaging with activities on a regular basis may lead to functional decline [132]. In support of this hypothesis, a previous longitudinal study on older people in the United States found that receipt of informal care was associated with increased disability among older people [132]. Moreover, a case study in an English local authority using qualitative methods found that delivering too many services prevented people from going out and socialising and undermined their independence [133].

Considering all of the above, the link between unmet care need and progression of frailty is important from an economic point of view and given the uncertainty in the link, it needs further investigation.

5.1.1. Reasons for a potential effect of unmet need on progression of frailty

Unmet need for help could impact chronic disease management due to an inability to have special diets or not taking medications when appropriate [134]. A disease, in turn, leads to "dysfunctions and structural abnormalities in specific body systems: musculoskeletal, cardiovascular, neurological, etc." ([135], p. 4). This, in turn, would lead to functional limitations, including mobility limitations, sight problems and cognitive limitations [135]. Moreover, unmet need for help could also lead to lower mobility and to weight loss (public advisory group 2021). Weight loss could be caused by inability to eat or drink when needed [134]. Weight loss and reduced mobility can accelerate sarcopenia [136, 137], i.e., the loss of "skeletal muscle mass and strength" ([137], p. 1) related to ageing [137]. Sarcopenia, in turn, increases the risk of cardiac disease [138], respiratory disease [139], cognitive impairment [140] and mobility limitations [141].

Unmet care need may also increase social isolation: for some people, their only social contact may be the person who comes in to help; for other people, not having help with activities of daily living may prevent the person from engaging in social contacts (personal communications with stakeholders). Social isolation, in turn, has been found to be associated with cognitive decline among people aged 50 and over in longitudinal studies [142, 143]. Moreover, a systematic review of longitudinal studies found that social isolation was associated with a higher risk of developing coronary heart disease and stroke [144].

Overall, unmet care need would impact on multiple body systems. Therefore, a frailty index, which captures the accumulation of health deficits, as described in section 4.2.1.4.4, seems an appropriate outcome that could capture health deterioration in a comprehensive way. However, no previous study assessing the association between unmet care need and frailty increase was identified.

Section 5.2.3 provides more details on the deficits that were included into the frailty index used in this chapter (there were some differences compared to the index used for the analysis in chapter 4).

This work also assessed whether the number of depressive symptoms was a possible mediator between unmet care need and increased frailty. The other hypothesised mediator was having at least one fall. More details relating to these mediators are provided below.

5.1.2. Possible mediators between unmet need and progression of frailty

Unmet need can increase the risk of fall or self-injury when performing tasks for which assistance would be needed [134] or because of a messy environment (personal communication, public advisory group). One study in the United States that used bivariate analysis found that falls were more common among people with unmet need for help with PADLs or IADLs [145]. The same study also found that having injurious falls was more common among people with unmet need [145]. Injurious falls may reduce mobility at least temporarily; inactivity can accelerate sarcopenia, and in turn, this can lead to a range of adverse consequences, as mentioned in the previous section. Terroso et al. [146] reviewed the literature on the adverse outcomes of falls and identified, among others, hip fractures, functional decline, and morbidity. All of these are included in the frailty index.

Conflicting findings have been reported on a possible link between unmet need or absence of care and depressive symptoms in older people. A study in the United States randomised older people to a waiting list or to receive support, including personal care and domestic help. The study only included people who were considered to be at "moderate risk" ([147], p. 335) of adverse outcomes based on a risk score that considered chronic health conditions, limitations in activities of daily living and other aspects. People considered to be at "high risk" ([147], p. 335) based on the same score were excluded from the trial as they were immediately given services. In this trial, depression in the intervention group decreased significantly compared to the control group [147]. Additionally, some observational studies that used multivariable analysis were conducted in the United States, Spain and China. Only two of these were longitudinal studies [132, 148], while the others were cross-sectional. Both longitudinal studies were from the United States. One found that having received care over the previous year from family or friends did not mediate the relationship between disability and depressive symptoms [148]. The other found that receipt of informal care was associated with increased depressive symptoms among older people [132]. The study authors commented that if a person feels that they are relying too much on family members, this may negatively affect their self-esteem and their sense of control; this may in turn increase depressive symptoms [132]. Among the cross-sectional studies, one was conducted in the United States; it focused on elderly women and found that unmet need for help with IADLs, but not unmet for help with PADLs, was associated with higher psychological distress; this was measured using an index that included anxiety, depression, irritability and cognitive problems [149]. Two cross-sectional studies were conducted in Spain. One found a negative association between depression and unmet care need

[150]; the other one found that the relationship between unmet need and depression depended on the kind of unmet need (relating to daily, weekly or monthly tasks) [151]. Furthermore, a cross-sectional study from China found that unmet need was associated with more depressive symptoms in rural areas but not in urban areas [152]. The different results from all these studies indicate that the relationship between unmet need and depressive symptoms requires further investigation.

A systematic review on the relationship between depressive symptoms and frailty [153] identified a longitudinal study from the United States that found an association between higher depressive symptoms and incident (new-onset) frailty [154]. Moreover, Davies et al. [101] included depressive symptoms in a frailty index constructed using ELSA data. Therefore, based on this evidence, it seems reasonable to hypothesise that the number of depressive symptoms may be associated with progression of frailty.

5.2. Data and methods

5.2.1. Data, sample inclusion criteria and the unmet care need determinant

The data sources were similar to those used for the analyses described in chapter 4: ELSA data merged with publicly available datasets on LA characteristics. Specific ELSA waves for the analysis described in the present chapter were wave 7 (2014/15), wave 8 (2016/17) and wave 9 (2018/19) [80]. The LA-level determinants were partly different in the present analysis so the datasets with LA characteristics differed accordingly. In particular, the present analysis also used a UK government dataset providing the percentage of people living in rural areas in each LA [155]. See Appendix 4A for more details.

Some inclusion criteria in the present analysis were the same as per the analysis in section 4.2: being aged 65 and over in wave 8 (2016/17); having either a PADL limitation or at least 2 IADL or mobility limitations (excluding difficulties with stairs) in wave 8; with available data to define needs as met or unmet in wave 8; with an interview that was not conducted in an institutional setting in wave 8.

An additional inclusion criterion for the analysis in this chapter was that people should have been interviewed in waves 7, 8 and 9. A wave 7 interview was needed because one of the determinants (frequent problems with balance) was only available from wave 7.

In the final models, unmet need was defined as per the analysis in section 4.2, so it referred to either no help receipt at all in the previous month or to help that met needs sometimes or hardly ever (see section 4.2.1.3). Robustness checks used alternative unmet care need definitions (see section 5.3.7 and Appendix 5C.6).

5.2.2. DAG

The directed acyclic graph (DAG) in Figure 8 represents the relationships that were investigated with statistical analysis. The figure shows the expectation that part of the impact of unmet need on progression of frailty was mediated by falls and depressive symptoms. Mediators are coloured in blue. There are a range of covariates as well, which have been accounted for.

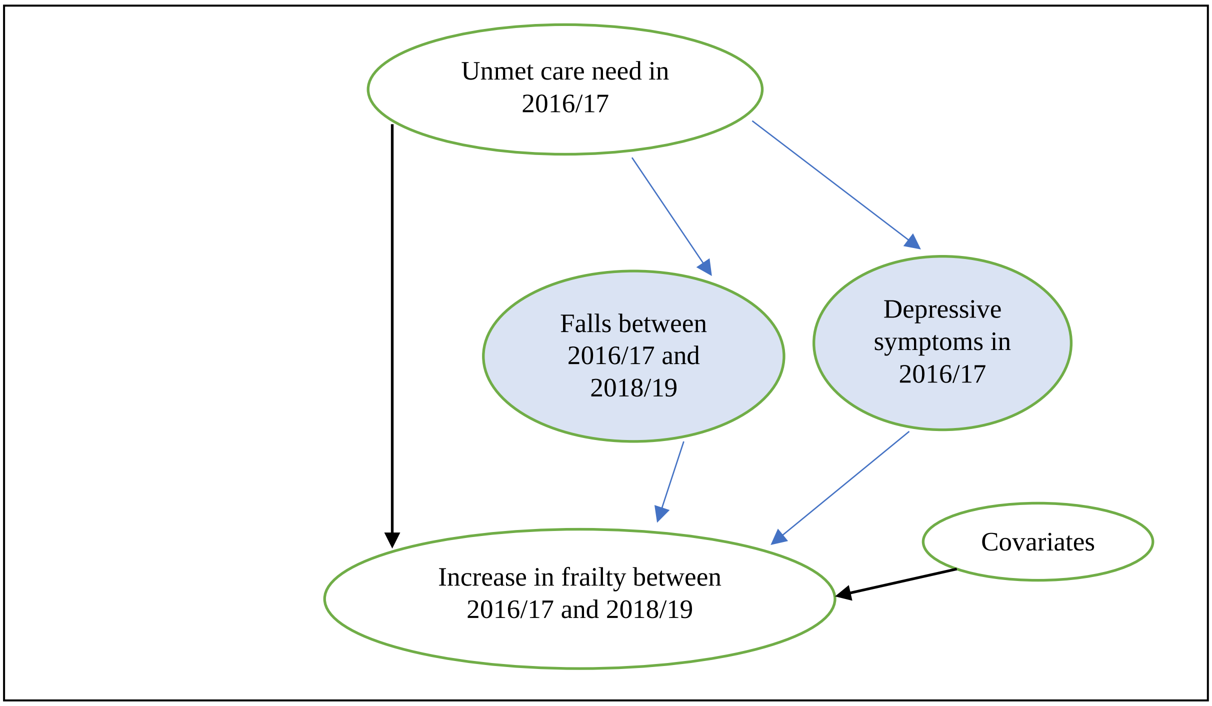


Figure 8. Relationship between unmet need and progression of frailty, including mediators and covariates.

5.2.3. The frailty outcomes

The frailty index used in this chapter's analysis is based on 40 deficits, because it excludes three deficits from the 43-deficits frailty index used in chapter 4 (described in section 4.2.1.4.4 and presented in more detail in Appendix 4B.1). Firstly, having falls was excluded because it was included as a separate mediator variable. Secondly, having had any mental health problem in the previous two years was taken out because the number of depressive symptoms was included as a mediator variable. Thirdly, having had a joint replacement was also excluded, because it might be related to getting to the end of a hospital waiting list rather than to worsening health status.

Figure 8 refers to an increase in frailty. The analyses focused on both a binary outcome "any increase in frailty: yes/no" and a numerical outcome "change in frailty". The binary outcome was the main outcome. The numerical outcome was a secondary outcome. This could capture to what extent frailty may worsen and it could also show any factors associated with improved frailty. However, a focus on change in frailty as a continuous outcome assumes that one unit increase in frailty means the same regardless of the level of baseline frailty. Instead, the frailty index corresponds to ordinal movement, which implies that moving from 10% to 11% does not necessarily mean the same as moving from 15% to 16%. Therefore, it was preferred to focus on the binary outcome as the main outcome.

5.2.4. More details on falls

The analysis focused on the binary variable “Any falls between wave 8 and wave 9”. The analysis did not focus on the number of falls. Section 5.2.7.3 explains the reason for this.

5.2.5. More details on the number of depressive symptoms

The eight-item Centre for Epidemiological Studies Depression scale (CES-D) was used to measure depressive symptoms in wave 8. The eight items enquired about whether the respondent felt as described below for “much of the time during the past week” ([29], p. 428):

- “felt depressed” ([29], p. 428)
- felt “everything” they did “was an effort” ([29], p. 428)
- felt their sleep was “restless” ([29], p. 428)
- was “happy” ([29], p. 428)
- “felt lonely” ([29], p. 428)
- “enjoyed life” ([29], p. 428)
- “felt sad” ([29], p. 428)
- “could not get going” ([29], p. 428)

Each item corresponded to a point of 1 if the answer indicated the presence of a depressive symptom, and to a point of 0 otherwise. The total score ranged from 0 to 8.

The final model focused on the number of depressive symptoms as a numerical variable, while robustness checks focused on a binary variable defined by a cut-off of at least 3 or at least 4 symptoms (see Appendix 5C.3 for more details).

5.2.6. Covariates in the multivariable models

The covariates were selected based on previous publications on the determinants of falls [109], depressive symptoms [156] and progression of frailty [103] as well as considering the following: missing data, a limited sample size (this meant that a low number of categories was preferred for each determinant), results from chapter 4 (for example, based on these, living alone was prioritised over marital status). Appendix 5A compares the determinants included in the present work to the determinants included in previous studies, providing reasons for the differences.

Based on all of the above, these individual-level covariates were included: age groups (same as in chapter 4), gender, living alone in wave 8, the number of PADL limitations in wave 8, the number of IADL limitations in wave 8, frequent problems with balance in wave 7 (this variable was not available for wave 8), current smoker in wave 8, centred baseline frailty in wave 8 (more details on this are provided in section 5.2.7.1), education beyond school leaving age, net total equivalised wealth in wave 8.

Additionally, although none of the previous studies included LA-level determinants, two LA-level variables were included. Firstly, LA deprivation measured with the IDAOPI score was included because it was found to be associated with an increased risk of unmet need in section 4.2. Moreover, area deprivation is an important social determinant of health. For example, in England, in 2018 to 2020, life expectancy for males living in the most deprived areas was 9.7 years shorter compared to males living in the least deprived areas; the difference was 7.9 years for females [157].

Secondly, this work also included the percentage of people living in rural areas in each LA. This was considered worth including because previous research studied the links between rurality and health outcomes but did not have definitive conclusions. Sinclair et al. [158] studied small-area frailty prevalence among older adults in England and found a higher prevalence for urban than for rural areas. The study authors commented that this may be due to urban areas being more deprived than rural areas. A report by the Local Government Association and Public Health England [159] commented that generally, health outcomes are better in rural areas than in urban areas, however, smaller area pockets of deprivation and poor health indicators can be masked by wider area statistics.

5.2.7. Statistical analysis

Regression analysis was used. The use of an instrumental variable approach was initially considered because it would enable the analyst to establish causality. However, it was not straightforward to find a good instrument that would meet the exclusion restrictions, i.e., a variable that would be correlated with unmet need but would not directly influence the outcome of interest, namely progression of frailty. Only one study was identified that used an instrument for unmet need [160]. The study was conducted in China and assessed the relationship between unmet care need and healthy aging (measured considering PADLs, cognition, and involvement in a wide-ranging set of activities) among older people with impairment. It used the old-age dependency ratio (corresponding to “the ratio of the number of people aged 65 or above to that aged 15-64" ([160], p. 5) within each province as the instrument. Data analysis in chapter 4 did not include this variable and so it was unclear if it was associated with unmet need. It was also unclear if it may relate to progression of frailty, falls or depressive symptoms in other ways than through unmet care need.

5.2.7.1 Equations relating to the relationship between unmet need and increased frailty

The equation below shows how the numerical variable "change in frailty" was calculated:

$$\Delta F_t = F_t - F_{t-1} \qquad (3)$$

Where ΔF_t is the change in frailty by time t, i.e., 2018/19 (wave 9), F_t is frailty in 2018/19, F_{t-1} is frailty at time $t-1$, i.e., 2016/17 (wave 8). F_t and F_{t-1} can range from 0 to 100%. ΔF_t can be positive, negative or equal to 0.

The categorised version of ΔF_t is $IncrF_t$, which is a binary variable with two categories, defined as:

- $IncrF_t = 1$ if $(F_t - F_{t-1}) > 0$, indicating increased / worse frailty.
- $IncrF_t = 0$ if $(F_t - F_{t-1}) \leq 0$, indicating no increase in frailty.

When the outcome of the regression is increased frailty or change in frailty, two main issues arise. The first issue is regression to the mean, i.e., "the tendency of change scores to be negatively related to baseline values" ([161], p. 80). "Regression to the mean is an inevitable consequence of a time sequence of measurements needing to stay in some viable range" ([161], p. 80). Therefore, in most cases, regression to the mean is an "artifactual" rather than a real phenomenon ([161], p. 80). Considering this, one would want to adjust for baseline values. However, in adjusting for baseline values, the second issue arises, i.e., correlation of frailty baseline values with the error term, because these values are used to calculate the outcome variable.

One way to deal with both of these issues is to use conditional change models, which use demeaning: the mean baseline value is subtracted from each baseline value, thus obtaining a centred frailty variable. Conditional change models tend to reduce the issue of regression to the mean [161] and eliminate the issue of correlation between baseline frailty and the error term. Moreover, they usually output lower standard errors [161]. The present work uses conditional change models when the outcomes are change in frailty and worse frailty. Baseline frailty was checked for outliers with visual inspection of a histogram before centring the variable, as outliers would cause bias, but no outliers were identified.

Equation (4) represents the hypothesised relationship between unmet need and increased frailty and is a conditional change model. It is estimated as a logit model because the outcome variable is binary. Note that this equation is linked to a mediator model; details on the mediator model are given in section 5.2.7.2. Also, note that for simplicity the subscript indicating the individual is supressed.

$$Ln(Pr(IncrF_t = 1)/(1 - Pr(IncrF_t = 1))) =$$

$$\beta_0 + \beta_1 UN_{t-1} + \beta_2 FA_t + \beta_3 DE_{t-1} + \beta_4 \mathbf{Z_{t-1}} + \beta_5 (F_{t-1} - \bar{F}_{t-1}) + \varepsilon_t \quad (4)$$

Where Ln is a natural logarithm, Pr a probability, β_0 is a constant to be estimated; UN_{t-1} is the unmet need in 2016/17; FA_t is a binary variable indicating whether the person had any falls, as measured in 2018/19, which refers to falls occurring between 2016/17 and 2018/19; DE_{t-1} is the number of depressive symptoms in 2016/17; this variable was taken from 2016/17 because it was assumed that unmet need for care would have an immediate effect on depressive symptoms, while it would take time for depressive symptoms to have an effect on frailty change. $\boldsymbol{Z_{t-1}}$ is the set of covariates from 2016/17; $\bar{F}_{t-1}$ is the sample average frailty in 2016/17, and so $F_{t-1} - \bar{F}_{t-1}$ is demeaned baseline frailty (another term to indicate this is centred baseline frailty); $\beta_1, \beta_2, \beta_3$ and β_5 are parameters, and β_4 a vector of parameters, to be estimated; ε_t is the error term.

5.2.7.2 Equations relating to the relationship between unmet need and mediators

The equations relating to the association of unmet need with mediators are below.

For falls (binary variable), the equation refers to a logit model.

$$Ln(Pr(FA_t = 1)/(1 - Pr(FA_t = 1))) =$$

$$\omega_0 + \omega_1 UN_{t-1} + \omega_2 \mathbf{Z_{t-1}} + \omega_3 (F_{t-1} - \bar{F}_{t-1}) + v_t \quad (5)$$

Where $\mathbf{Z_{t-1}}$ is the same set of covariates included in the main equation (4); ω_0 is a constant to be estimated; ω_1 and ω_3 are parameters, and ω_2 a vector of parameters, to be estimated; v_t is the error term.

For depressive symptoms, the equation refers to an ordinary least squares model:

$$DE_{t-1} = \delta_0 + \delta_1 UN_{t-1} + \delta_2 \mathbf{Z_{t-1}} + \delta_3 (F_{t-1} - \bar{F}_{t-1}) + q_{t-1} \quad (6)$$

Where $\mathbf{Z}_{t-1}$ is the same set of covariates included in the main equation (4); δ_0 is a constant to be estimated; $\delta_1$and δ_3 are parameters, and δ_2 a vector of parameters, to be estimated; q_{t-1} is the error term.

Note that to establish mediation, the following conditions must be fulfilled: firstly, unmet need must affect the mediator (falls or depressive symptoms) in equations (5) or (6); secondly, unmet need must affect progression of frailty in equation (4) before the mediator is inserted into the regression; and third, the mediator must affect progression of frailty in equation (4) [162]. If these conditions all hold in the predicted direction, then the degree of association between unmet need and progression of frailty must decrease when regression (4) incorporates the mediators [162]. Complete mediation holds if unmet need is no longer associated with worse frailty when the mediator variable is controlled for; if unmet need is still associated with worse frailty, the mediation is partial [163].

5.2.7.3 Choice of model type

For the outcome worse frailty (binary variable), a logistic regression was run. For the outcome change in frailty (numerical variable), a linear regression was run.

For the outcome “any falls between wave 8 and wave 9” (binary variable), a logistic regression was run. It was considered whether it might be better to use a double-hurdle model, because this would assess not only the determinants of having at least one fall, but also the determinants of the number of falls among those with at least one fall. More specifically, the double-hurdle model would produce two separate sets of coefficients through simultaneous estimation of two equations, allowing for correlation between the error terms across the two equations. Despite its potential usefulness, it was noted that a double-hurdle model did not seem appropriate in the present work for two reasons:

- Focusing on the number of falls among those with at least one fall was expected to yield limited information because of the low variation in the number of falls: descriptive analysis showed that 56% of the included sample had no falls, 34% had between one and three falls, and only 10% (n=77) had more than 3 falls.
- A double-hurdle model would have been particularly useful if there had been an expectation that there were different predictors for having at least one fall and for the number of falls among people with at least one fall. However, no evidence was identified in support of this expectation. Moreover, the present work focused on a

mediation model, which requires consistency of determinants across the different equations.

Nonetheless, an attempt was made to run a double-hurdle model. However, the model did not achieve convergence. Lack of convergence was likely due to low variation among those with positive falls, with some extreme values.[9] Considering all of this, it was decided to limit the analysis to a logistic regression focused on the binary outcome “any falls”.

The number of depressive symptoms was a count variable ranging from 0 to 8. Both a linear regression and a Poisson regression were run with this outcome. Results were similar, so the simpler model (linear regression) was chosen as the final model. See Appendix 5B for the results of the Poisson regression.

5.2.7.4 Interactions

Considering the possible limitations of the variable “unmet need”, interaction was explored between unmet need and living alone. It was hypothesised that for people living alone, it may be more likely that no care receipt was connected to a lack of available help rather than to a lack of need.

Interaction between unmet need and baseline frailty was not explored because the conditional change model with demeaned baseline frailty does not allow for this, as it focuses on the association between unmet need and worse frailty at the mean of baseline frailty [161].

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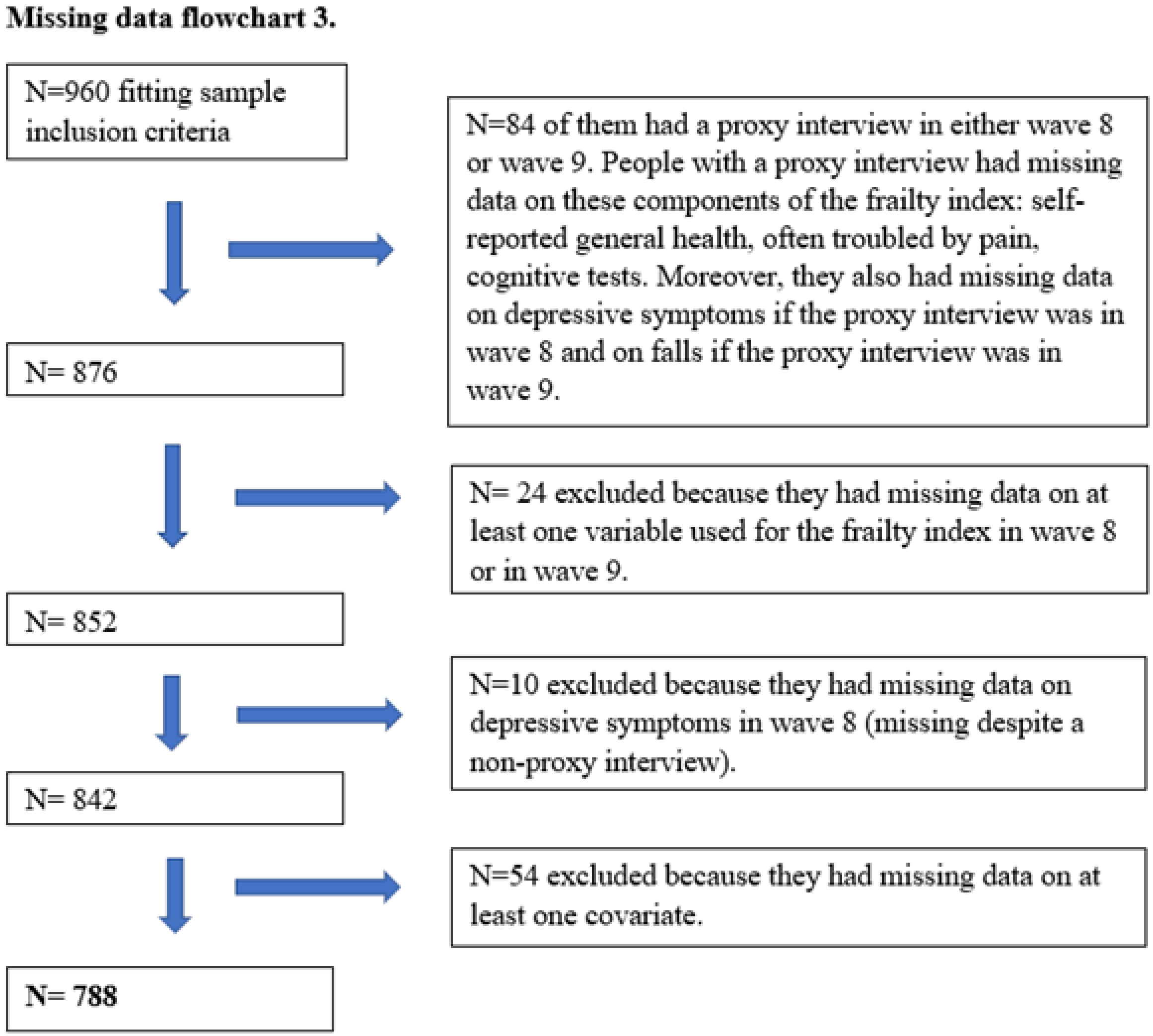
[9] The exact values and the number of people reporting these are not mentioned here due to statistical disclosure concerns.

5.3. Results

5.3.1. Missing data flowchart and final sample size



Missing data flowchart 3.

N=960 fitting sample inclusion criteria

N=84 of them had a proxy interview in either wave 8 or wave 9. People with a proxy interview had missing data on these components of the frailty index: self-reported general health, often troubled by pain, cognitive tests. Moreover, they also had missing data on depressive symptoms if the proxy interview was in wave 8 and on falls if the proxy interview was in wave 9.

N= 876

N= 24 excluded because they had missing data on at least one variable used for the frailty index in wave 8 or in wave 9.

N= 852

N=10 excluded because they had missing data on depressive symptoms in wave 8 (missing despite a non-proxy interview).

N= 842

N=54 excluded because they had missing data on at least one covariate.

N= 788

Figure 9. Missing data flowchart.

5.3.2. Descriptive statistics

56% of people did not experience falls over the two years between wave 8 and 9. The 90th percentile was 3 falls, the 95th percentile was 6 falls. Figure 10 shows a histogram of the number of depressive symptoms, based on the final sample of 788 people. The variance (4.60) of the depressive symptoms variable was bigger than the mean (2.30) so there was some overdispersion compared to a Poisson distribution, where the mean is equal to the variance.

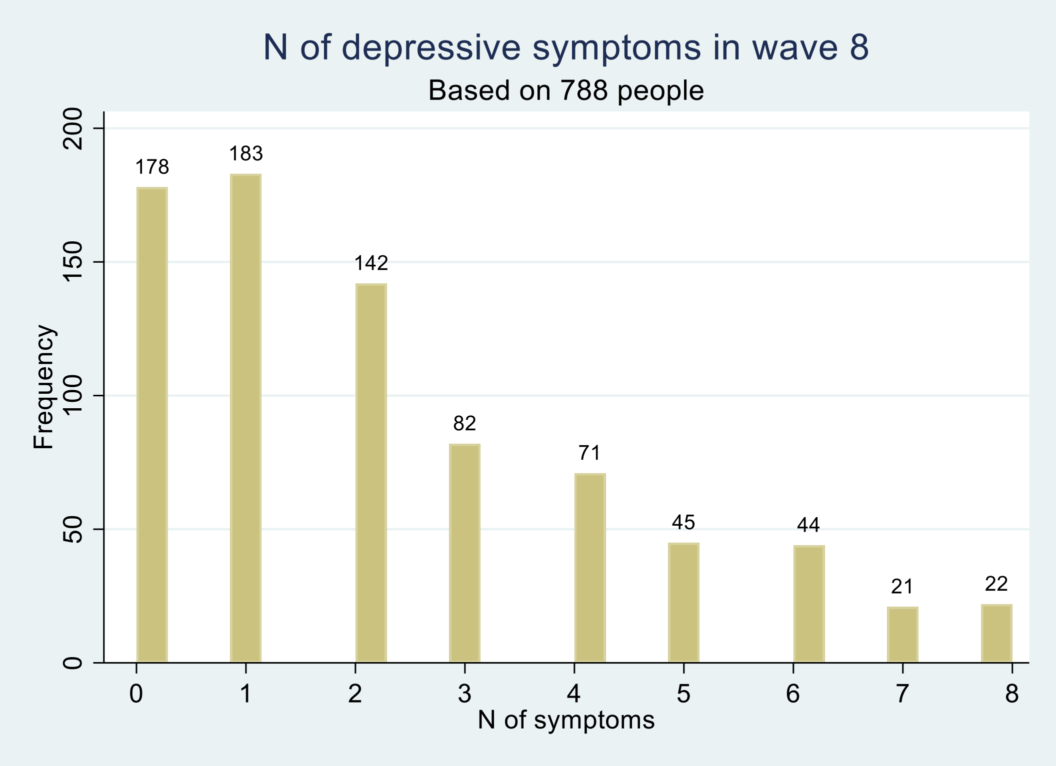


Figure 10. Histogram of the number of depressive symptoms in wave 8.
Figure notes. Abbreviations: N: number.

Figure 11 shows the histogram for change in frailty, based on 788 people. When the outcome was positive, this indicated that there had been an increase in frailty between wave 8 and wave 9. When the outcome was negative, this indicated that frailty had decreased between wave 8 and wave 9.

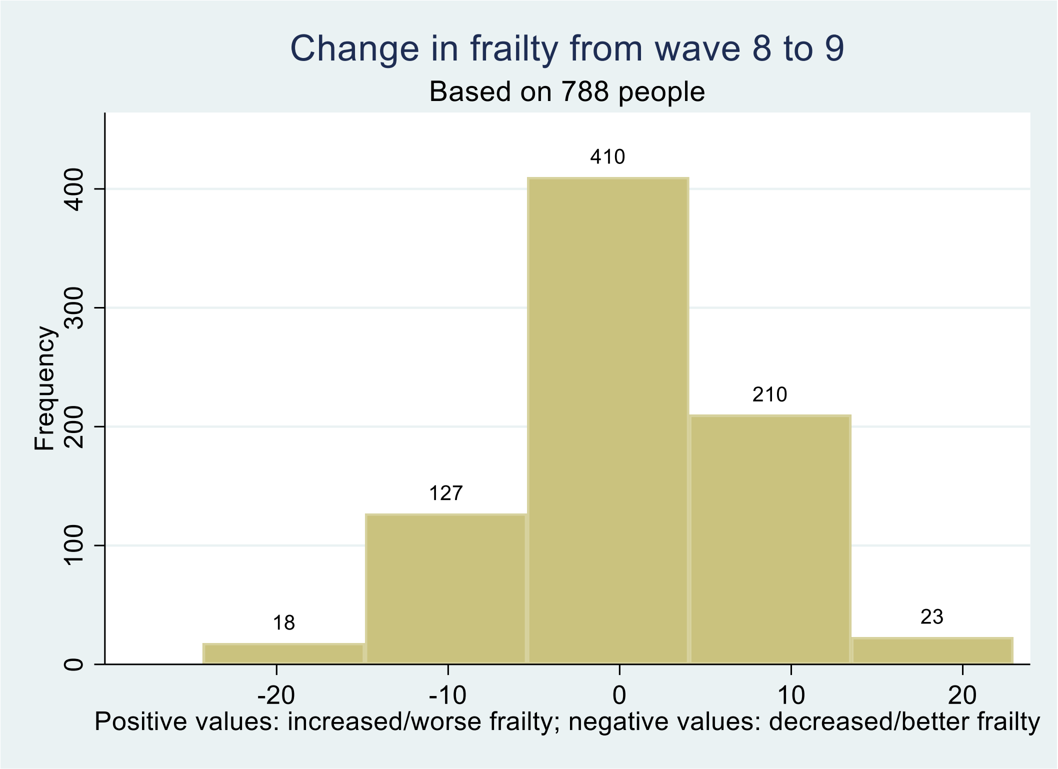


Figure 11. Histogram: change in frailty.

Change is measured in percentage points. Values were grouped into 5 bins to avoid statistical disclosure (based on a threshold value of 10 as per Griffiths et al. [164]).

Table 18 presents the descriptive statistics grouped by people who experienced an increase in frailty between 2016/17 and 2018/19 (417 people) and those who did not (371 people). Unmet need was less common among people who experienced an increase in frailty by 5 percentage points. Among those who experienced increased frailty, the percentage of people aged 65-69 was lower by 13 percentage points, the percentage of males was higher by 9 percentage points, and the percentage of people with at least a fall was higher by 14 percentage points. Baseline frailty was lower by 3 percentage points among those who experienced an increase in frailty.

Table 18. Descriptive statistics by worse or not worse frailty between wave 8 and 9 and for overall sample.

	Same or better (decreased) frailty (N=371)	**Worse (increased) frailty (N=417)**	**Total (N=788)**
Categorical variables	*Proportion (SD)* *[exception: mean (SD) for wealth in the "Total" column]*		
Unmet need in wave 8	0.44 (0.50)	0.39 (0.49)	0.41 (0.49)
Age 65-69	0.33 (0.47)	0.20 (0.40)	0.26 (0.44)
Age 70-74	0.19 (0.39)	0.23 (0.42)	0.21 (0.41)
Age 75-79	0.19 (0.39)	0.19 (0.39)	0.19 (0.39)
Age 80-84	0.16 (0.36)	0.19 (0.39)	0.17 (0.38)
Age 85+	0.14 (0.34)	0.19 (0.39)	0.16 (0.37)
Male	0.35 (0.48)	0.44 (0.50)	0.40 (0.49)
Living alone in wave 8	0.37 (0.48)	0.36 (0.48)	0.36 (0.48)
Frequent problems with balance in wave 7	0.21 (0.41)	0.24 (0.43)	0.22 (0.42)
Current smoker in wave 8	0.09 (0.29)	0.07 (0.25)	0.08 (0.27)
Any falls between wave 8 and wave 9	0.36 (0.48)	0.50 (0.50)	0.44 (0.50)
Education beyond school leaving age	0.45 (0.50)	0.43 (0.50)	0.44 (0.50)
Wealth in wave 8: quartile 1 (lowest)	0.26 (0.44)	0.24 (0.43)	7,906 (13,941)
Wealth in wave 8: quartile 2	0.25 (0.43)	0.25 (0.44)	116,635 (30,041)
Wealth in wave 8: quartile 3	0.23 (0.42)	0.26 (0.44)	227,650 (41,719)
Wealth in wave 8: quartile 4 (highest)	0.26 (0.44)	0.24 (0.43)	577,243 (453,879)
Numerical variables	*Mean (SD)*		
N of PADL limitations in wave 8	1.60 (1.37)	1.44 (1.23)	1.52 (1.30)
N of IADL limitations in wave 8	1.27 (1.35)	1.48 (1.56)	1.38 (1.47)
N of depressive symptoms in wave 8	2.36 (2.19)	2.24 (2.10)	2.30 (2.14)
Change in the 40-deficits frailty index between wave 8 and 9	-5.07	5.52	0.54

	Same or better (decreased) frailty (N=371)	**Worse (increased) frailty (N=417)**	**Total (N=788)**
	(4.43)	(4.38)	(6.88)
40-deficits frailty index in wave 8	36.04	33.10	34.48
	(10.54)	(10.64)	(10.69)
40-deficits frailty index in wave 9	30.97	38.62	35.02
	(10.88)	(10.86)	(11.51)
LA IDAOPI average score	16.41	15.68	16.02
	(5.89)	(5.28)	(5.59)
% of people in rural areas	32.40	33.16	32.80
	(27.13)	(26.34)	(26.70)

Table notes.
Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADLs: personal activities of daily living; SD: standard deviation.
Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.
Frequent problems with balance refer to: always/very often/often has "problems with balance when walking on level surface" ([80], variable name).
The frailty index was measured as a percentage.
Wealth refers to equivalised net total wealth. Quartiles were calculated based on the final sample of 788 people.
A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Table 19 presents a correlation plot for individual-level variables. Most correlations were weak or very weak. There were two exceptions: a moderate positive correlation between the 40-deficits frailty index in wave 8 and the number of IADL limitations in wave 8; a strong positive correlation between the numerical variable measuring frailty change and the binary variable for increased frailty. Unmet care need had a very weak negative correlation with the number of depressive symptoms, with falls and increased frailty over the following two years. Unmet need had a weak negative correlation with baseline frailty. Baseline frailty had a very weak negative correlation with increased frailty.

Table 19. Correlation plot of individual-level variables based on 788 people.

Variables		(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)	(14)	(15)	(16)	(17)	(18)
Unmet need in wave 8	(1)	1.00																	
N of depressive symptoms in wave 8	(2)	-0.05	1.00																
Any falls between wave 8 and wave 9	(3)	-0.05	0.11	1.00															
Increased frailty index in w9 compared to w8	(4)	-0.05	-0.03	0.14	1.00														
Change in frailty index between w8 and w9	(5)	-0.05	-0.06	0.17	0.77	1.00													
Age	(6)	-0.14	-0.04	0.09	0.10	0.13	1.00												
Male	(7)	0.15	-0.17	-0.03	0.10	0.09	-0.05	1.00											
Living alone in wave 8	(8)	0.03	0.18	0.10	-0.01	-0.03	0.23	-0.20	1.00										
N of PADL limitations in wave 8	(9)	-0.12	0.15	0.08	-0.06	-0.08	-0.12	0.01	0.01	1.00									
N of IADL limitations in wave 8	(10)	-0.34	0.20	0.08	0.07	0.03	0.11	-0.15	0.08	0.30	1.00								
40-deficits frailty index in wave 8	(11)	-0.31	0.31	0.13	-0.14	-0.20	0.07	-0.22	0.11	0.37	0.43	1.00							
Frequent problems with balance in wave 7	(12)	-0.11	0.14	0.11	0.03	0.01	0.08	-0.09	0.07	0.21	0.24	0.31	1.00						
Current smoker in wave 8	(13)	-0.04	0.07	-0.01	-0.04	-0.04	-0.14	0.07	-0.02	0.08	0.03	0.10	0.04	1.00					
Education > school leaving age	(14)	0.05	-0.06	0.00	-0.03	0.01	0.02	0.00	-0.03	0.01	-0.06	-0.17	-0.05	-0.05	1.00				
Wealth quartile 1 (lowest)	(15)	0.00	0.16	0.05	-0.01	-0.05	-0.13	-0.02	0.19	0.06	0.06	0.19	0.03	0.21	-0.16	1.00			
Wealth quartile 2	(16)	-0.05	0.04	-0.07	0.01	0.04	0.04	0.01	-0.12	0.00	0.06	0.06	0.05	-0.02	-0.14	-0.33	1.00		
Wealth quartile 3	(17)	0.01	-0.02	0.00	0.03	0.04	0.04	0.03	-0.06	0.01	-0.03	0.01	-0.03	-0.08	-0.04	-0.33	-0.33	1.00	
Wealth quartile 4 (highest)	(18)	0.04	-0.18	0.02	-0.03	-0.04	0.05	-0.03	-0.01	-0.07	-0.09	-0.26	-0.04	-0.11	0.33	-0.33	-0.33	-0.33	1.00

Wave 7 refers to 2014-15, w8 (wave 8) to 2016-17, w9 (wave 9) to 2018-19. For change in frailty, a positive value indicated an increase.

IADLs: instrumental activities of daily living; PADLs: personal activities of daily living.

Legend

Colour	**Value of correlation coefficient**		**Strength of corr.**
	Positive coefficient	**Negative coefficient**	
▨	>0 & <0.2	<0 & >-0.2	Very weak
▨	>=0.2 & <0.4	<=-0.2 & >-0.4	Weak
▨	>=0.4 & <0.6	<=-0.4 & >-0.6	Moderate
▨	>=0.6 & <0.8	<=-0.6 & >-0.8	Strong
▨	>=0.8 & <1	<=-0.8 & >-1	Very strong

Corr.: correlation.
Frequent problems with balance refer to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).

Wealth refers to equivalised net total wealth. Quartiles were calculated based on final sample of 788 people.

5.3.3. Multivariable modelling: the relationship between unmet need and the hypothesised mediators

Any falls

Table 20 shows that no association was found between unmet care need and having at least one fall over the following two years. People aged 75 to 79 and 85+ had higher odds of falls compared to the 65-69 age group. Baseline frailty had a borderline significant association with higher odds of falls over the following two years.

The number of depressive symptoms

Table 20 shows that no association was found between unmet care need and the number of depressive symptoms. Being male was associated with a lower number of depressive symptoms. Compared to being aged 65-69, being in the 85+ age group was associated with a lower number of depressive symptoms; being aged 70 to 79 had a borderline significant association with a lower number of depressive symptoms. Living alone, a higher number of IADL limitations and higher baseline frailty were associated with a higher number of depressive symptoms. Compared to the lowest wealth quartile, being in the highest wealth quartile was associated with a lower number of depressive symptoms. The biggest effect size related to wealth; being in the highest wealth quartile was associated with a reduction of 0.8 depressive symptoms on average, compared to the lowest quartile, controlling for the other characteristics included in the model.

Table 20. Relationship between unmet need and the hypothesised mediators

	Outcome: any falls between wave 8 and 9 (odds ratios)	Outcome: N of depressive symptoms in wave 8 (coefficients from OLS model)
Unmet need in wave 8	0.970	0.225
	[0.719,1.307]	[-0.105,0.554]
Age 70-74	1.111	-0.344*
	[0.724,1.703]	[-0.747,0.060]
Age 75-79	1.797***	-0.381*
	[1.179,2.740]	[-0.789,0.027]
Age 80-84	1.194	-0.127
	[0.755,1.888]	[-0.710,0.455]
Age 85+	1.598**	-0.612**
	[1.015,2.517]	[-1.125,-0.099]
Male	1.056	-0.398**
	[0.781,1.428]	[-0.719,-0.077]
Living alone in wave 8	1.293	0.621***
	[0.944,1.772]	[0.298,0.943]
N of PADL limitations in wave 8	1.084	0.053
	[0.956,1.228]	[-0.061,0.167]
N of IADL limitations in wave 8	1.012	0.112**
	[0.890,1.150]	[0.000,0.224]
Centred variable of the 40-deficits frailty index in wave 8	1.016*	0.041***
	[0.997,1.036]	[0.025,0.057]
Frequent problems with balance in wave 7	1.356	0.241
	[0.934,1.970]	[-0.145,0.628]
Current smoker in wave 8	0.914	0.162
	[0.500,1.673]	[-0.366,0.689]
Education beyond school leaving age	1.033	0.114
	[0.730,1.462]	[-0.197,0.424]
Wealth in wave 8: quartile 2	0.691*	-0.116
	[0.452,1.058]	[-0.537,0.305]
Wealth in wave 8: quartile 3	0.876	-0.321
	[0.588,1.306]	[-0.800,0.159]
Wealth in wave 8: quartile 4 (highest)	1.016	-0.756***
	[0.686,1.505]	[-1.227,-0.284]
LA IDAOPI average score	0.995	-0.002
	[0.964,1.027]	[-0.037,0.034]
% of people in rural areas	1.000	0.003
	[0.992,1.007]	[-0.004,0.009]
Constant		2.293***

	Outcome: any falls between wave 8 and 9 (odds ratios)	Outcome: N of depressive symptoms in wave 8 (coefficients from OLS model)
		[1.400,3.187]
N	788	788

Table notes.

Exponentiated coefficients: odds ratios from logistic regression with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; OLS: ordinary least squares; PADLs: personal activities of daily living.

Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.

For the age groups, the reference category was 65-69.

The frailty index was measured as a percentage.

Frequent problems with balance refer to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).

Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

5.3.4. Multivariable modelling: worse frailty

Table 21 shows the outputs from the models with the outcome “worse frailty”. The final and most appropriate model included the unmet need variable, demographic variables, socio-economic variables, LA variables, health variables and mediator variables (model 4).

In the multivariable analysis, unmet care need had a borderline significant association with lower odds of increased frailty over the following two years. Moreover, being frailer at baseline was associated with lower odds of increased frailty two years later. Both results were consistent with the descriptive statistics in Table 18 and Table 19. Note that Table 19 also shows a negative correlation between unmet need and baseline frailty. Therefore, baseline frailty was lower among those with unmet need. However, in multivariable analysis, lower baseline frailty was associated with higher odds of increased frailty, while unmet need was associated with lower odds of increased frailty.

Compared to the age group 65-69, being in an older age group was associated with higher odds of experiencing an increase in frailty over the next two years. Being male had a positive association with increased frailty. Having more IADL limitations and having any falls was associated with higher odds of worse frailty. No association was found between the number of depressive symptoms and increased frailty over the following two years. Compared to the lowest wealth quartile, being in the highest wealth quartile was associated with lower odds of worse frailty. In contrast, LA deprivation was associated with lower odds of worse frailty.

Table 21. Outcome: worse (increased) frailty. Odds ratios. Sequential modelling, including the final model (model 4).

	(1) Base model	(2) Model 2: Base plus LA variables	(3) Model 3: Base plus LA and health variables	(4) Model 4: Base plus LA, health and hypothesised mediator variables
Unmet need in wave 8	0.819	0.826	0.763*	0.763*
	[0.604,1.110]	[0.607,1.123]	[0.556,1.046]	[0.553,1.053]
Age 70-74	1.933***	1.984***	2.149***	2.155***
	[1.255,2.979]	[1.303,3.023]	[1.421,3.250]	[1.420,3.270]
Age 75-79	1.572**	1.576**	1.685**	1.550**
	[1.033,2.392]	[1.035,2.402]	[1.090,2.606]	[1.001,2.403]
Age 80-84	1.966***	1.978***	2.053***	2.035***
	[1.253,3.086]	[1.249,3.132]	[1.276,3.302]	[1.268,3.266]
Age 85+	2.203***	2.169***	2.098***	1.994***
	[1.371,3.538]	[1.341,3.507]	[1.278,3.445]	[1.224,3.251]
Male	1.538***	1.572***	1.480**	1.487**
	[1.148,2.061]	[1.172,2.109]	[1.076,2.035]	[1.052,2.102]
Living alone in wave 8	0.965	0.977	0.989	0.945
	[0.690,1.351]	[0.696,1.373]	[0.708,1.382]	[0.673,1.328]
Education beyond school leaving age	0.929	0.916	0.875	0.869
	[0.679,1.272]	[0.670,1.252]	[0.624,1.226]	[0.605,1.249]
Wealth in wave 8: quartile 2	0.964	0.977	0.849	0.904
	[0.653,1.424]	[0.660,1.445]	[0.572,1.260]	[0.604,1.352]
Wealth in wave 8: quartile 3	1.097	1.021	0.920	0.944
	[0.781,1.541]	[0.719,1.448]	[0.626,1.352]	[0.642,1.387]
Wealth in wave 8: quartile 4 (highest)	0.910	0.792	0.578***	0.573***
	[0.623,1.331]	[0.539,1.164]	[0.392,0.853]	[0.381,0.863]
LA IDAOPI average score		0.957***	0.958**	0.958**
		[0.927,0.988]	[0.925,0.992]	[0.926,0.990]
% of people in rural areas		0.996	0.996	0.996
		[0.989,1.002]	[0.989,1.003]	[0.989,1.002]
N of PADL limitations in wave 8			0.959	0.944
			[0.825,1.115]	[0.805,1.107]
N of IADL limitations in wave 8			1.285***	1.285***
			[1.106,1.492]	[1.101,1.499]
Centred variable of the 40-deficits frailty index in wave 8			0.952***	0.949***

	(1) Base model	(2) Model 2: Base plus LA variables	(3) Model 3: Base plus LA and health variables	(4) Model 4: Base plus LA, health and hypothesised mediator variables
			[0.937,0.968]	[0.933,0.965]
Frequent problems with balance in wave 7			1.394*	1.337
			[0.960,2.025]	[0.914,1.956]
Current smoker in wave 8			0.782	0.795
			[0.483,1.268]	[0.494,1.279]
Any falls between wave 8 and wave 9				1.918***
				[1.431,2.570]
N of depressive symptoms in wave 8				1.008
				[0.934,1.089]
N	788	788	788	788

Table notes.

Exponentiated coefficients from logistic regressions with clustered standard errors; 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADLs: personal activities of daily living.

Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.

For the age groups, the reference category was 65-69.

The frailty index was measured as a percentage.

Frequent problems with balance refers to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).

Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

5.3.5. Multivariable modelling: change in frailty

Table 22 shows the results for the models where change in frailty was the outcome. A negative coefficient indicated that the predictor variable was associated with decreased/better frailty, a positive coefficient indicated that the predictor variable was associated with increased/worse frailty. The final and most appropriate model included the unmet need variable, demographic variables, socio-economic variables, LA variables, health variables and mediator variables (model 4). Unmet need had a significant association with a decrease of 1 percentage point in the frailty index over the following two years, holding the other variables constant. In agreement with the results relating to increased frailty (presented in section 5.3.4), compared to the reference age group 65-69, being in an older age group was associated with increased frailty. Having more IADL limitations and having falls was also associated with increased frailty. Being frailer at baseline was associated with decreased frailty. No association was found between the number of depressive symptoms and change in frailty over the following two years. Compared to the lowest wealth quartile, being in the highest wealth quartile was associated with decreased frailty. Differently from the results relating to increased frailty (presented in section 5.3.4), no association was found between being male or LA deprivation and change in frailty.

Table 22. Outcome: change in frailty (numerical). Sequential modelling, including the final model (model 4).

	(1) Base model	(2) Model 2: Base plus LA variables	(3) Model 3: Base plus LA and health variables	(4) Model 4 (final): Base plus LA, health and hypothesised mediator variables
Unmet need in wave 8	-0.527	-0.531	-1.158**	-1.136**
	[-1.605,0.551]	[-1.604,0.543]	[-2.290,-0.027]	[-2.239,-0.033]
Age 70-74	1.733**	1.766**	1.883***	1.810***
	[0.360,3.107]	[0.403,3.129]	[0.561,3.205]	[0.496,3.124]
Age 75-79	1.717**	1.727**	2.002***	1.617**
	[0.399,3.035]	[0.418,3.037]	[0.735,3.269]	[0.351,2.883]
Age 80-84	1.761**	1.739**	1.781**	1.669**
	[0.264,3.257]	[0.225,3.252]	[0.303,3.260]	[0.231,3.108]
Age 85+	3.561***	3.473***	3.468***	3.152***
	[1.821,5.302]	[1.728,5.218]	[1.769,5.166]	[1.471,4.833]
Male	1.262**	1.325**	0.780	0.736
	[0.242,2.283]	[0.311,2.339]	[-0.234,1.794]	[-0.342,1.814]
Living alone in wave 8	-0.601	-0.558	-0.444	-0.593
	[-1.729,0.528]	[-1.684,0.568]	[-1.471,0.584]	[-1.579,0.392]
Education beyond school leaving age	0.266	0.240	0.017	-0.001
	[-0.727,1.259]	[-0.722,1.202]	[-0.949,0.983]	[-1.004,1.002]
Wealth in wave 8: quartile 2	0.451	0.463	-0.034	0.195
	[-0.867,1.768]	[-0.848,1.775]	[-1.310,1.241]	[-1.062,1.452]
Wealth in wave 8: quartile 3	0.574	0.398	-0.046	0.029
	[-0.707,1.854]	[-0.916,1.713]	[-1.339,1.246]	[-1.274,1.332]
Wealth in wave 8: quartile 4 (highest)	-0.467	-0.847	-2.035***	-2.063***
	[-1.737,0.802]	[-2.134,0.440]	[-3.314,-0.757]	[-3.358,-0.769]
LA IDAOPI average score		-0.131*	-0.101	-0.098
		[-0.263,0.001]	[-0.228,0.027]	[-0.215,0.020]
% of people in rural areas		-0.021	-0.017	-0.017
		[-0.047,0.006]	[-0.043,0.009]	[-0.041,0.008]
N of PADL limitations in wave 8			-0.002	-0.053
			[-0.467,0.463]	[-0.531,0.426]
N of IADL			0.495***	0.490***

	(1) Base model	(2) Model 2: Base plus LA variables	(3) Model 3: Base plus LA and health variables	(4) Model 4 (final): Base plus LA, health and hypothesised mediator variables
limitations in wave 8				
			[0.135,0.855]	[0.135,0.844]
Centred variable of the 40-deficits frailty index in wave 8			-0.193***	-0.202***
			[-0.246,-0.140]	[-0.255,-0.150]
Frequent problems with balance in wave 7			0.915	0.723
			[-0.393,2.223]	[-0.593,2.038]
Current smoker in wave 8			-0.385	-0.324
			[-2.260,1.489]	[-2.137,1.489]
Any falls between wave 8 and wave 9				2.693***
				[1.770,3.615]
N of depressive symptoms in wave 8				-0.025
				[-0.253,0.202]
_cons	-1.374*	1.529	1.042	0.146
	[-2.759,0.010]	[-1.816,4.875]	[-2.175,4.258]	[-3.026,3.317]
N	788	788	788	788

Table notes.

Coefficients from OLS models with clustered standard errors. 95% confidence intervals in brackets.

* p<0.10, ** p<0.05, *** p<0.01

Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADLs: personal activities of daily living.

Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.

For the age groups, the reference category was 65-69.

The frailty index was measured as a percentage.

Frequent problems with balance refer to: always/very often/often has "problems with balance when walking on level surface" ([80], variable name).

Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

5.3.6. Interactions

Table 23, Table 24 and Table 25 show that the term for interaction between living alone and unmet need was not significant for any of the adverse outcomes considered.

Table 23. Outcome: any falls. Odds ratios. Exploring interactions.

	(1) No interaction	(2) Interaction between unmet need and living alone
Unmet need in wave 8	0.970	1.082
	[0.719,1.307]	[0.757,1.546]
Term for interaction between living alone and unmet need		0.754
		[0.390,1.456]
Living alone in wave 8	1.293	1.452*
	[0.944,1.772]	[0.981,2.148]
Age 70-74	1.111	1.115
	[0.724,1.703]	[0.728,1.708]
Age 75-79	1.797***	1.803***
	[1.179,2.740]	[1.179,2.759]
Age 80-84	1.194	1.181
	[0.755,1.888]	[0.750,1.862]
Age 85+	1.598**	1.580**
	[1.015,2.517]	[1.005,2.483]
Male	1.056	1.054
	[0.781,1.428]	[0.779,1.425]
N of PADL limitations in wave 8	1.084	1.084
	[0.956,1.228]	[0.957,1.228]
N of IADL limitations in wave 8	1.012	1.011
	[0.890,1.150]	[0.889,1.151]
Centred variable of the 40-deficits frailty index in wave 8	1.016*	1.017*
	[0.997,1.036]	[0.998,1.036]
Frequent problems with balance in wave 7	1.356	1.374*
	[0.934,1.970]	[0.941,2.005]
Current smoker in wave 8	0.914	0.911
	[0.500,1.673]	[0.499,1.662]
Education beyond school leaving age	1.033	1.025
	[0.730,1.462]	[0.721,1.458]
Wealth in wave 8: quartile 2	0.691*	0.683*
	[0.452,1.058]	[0.449,1.041]
Wealth in wave 8: quartile 3	0.876	0.869
	[0.588,1.306]	[0.584,1.292]
Wealth in wave 8: quartile 4 (highest)	1.016	1.011
	[0.686,1.505]	[0.681,1.501]
LA IDAOPI average score	0.995	0.994
	[0.964,1.027]	[0.963,1.027]
% of people in rural areas	1.000	0.999
	[0.992,1.007]	[0.992,1.007]
N	788	788

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADLs: personal activities of daily living.

Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.
For the age groups, the reference category was 65-69.
The frailty index was measured as a percentage.
Frequent problems with balance refer to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).
Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.
A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Table 24. Outcome: N of depressive symptoms. Exploring interactions.

	(1) No interaction	(2) Interaction between unmet need and living alone
Unmet need in wave 8	0.225	0.021
	[-0.105,0.554]	[-0.412,0.454]
Term for interaction between living alone and unmet need		0.541
		[-0.235,1.318]
Living alone in wave 8	0.621***	0.397*
	[0.298,0.943]	[-0.037,0.831]
Age 70-74	-0.344*	-0.351*
	[-0.747,0.060]	[-0.756,0.054]
Age 75-79	-0.381*	-0.387*
	[-0.789,0.027]	[-0.795,0.021]
Age 80-84	-0.127	-0.109
	[-0.710,0.455]	[-0.671,0.454]
Age 85+	-0.612**	-0.589**
	[-1.125,-0.099]	[-1.092,-0.086]
Male	-0.398**	-0.394**
	[-0.719,-0.077]	[-0.714,-0.074]
N of PADL limitations in wave 8	0.053	0.053
	[-0.061,0.167]	[-0.061,0.166]
N of IADL limitations in wave 8	0.112**	0.113**
	[0.000,0.224]	[0.002,0.224]
Centred variable of the 40-deficits frailty index in wave 8	0.041***	0.040***
	[0.025,0.057]	[0.024,0.056]
Frequent problems with balance in wave 7	0.241	0.219
	[-0.145,0.628]	[-0.168,0.606]
Current smoker in wave 8	0.162	0.168
	[-0.366,0.689]	[-0.362,0.698]
Education beyond school leaving age	0.114	0.128
	[-0.197,0.424]	[-0.184,0.439]
Wealth in wave 8: quartile 2	-0.116	-0.095
	[-0.537,0.305]	[-0.523,0.334]
Wealth in wave 8: quartile 3	-0.321	-0.304
	[-0.800,0.159]	[-0.786,0.177]
Wealth in wave 8: quartile 4 (highest)	-0.756***	-0.746***
	[-1.227,-0.284]	[-1.217,-0.275]
LA IDAOPI average score	-0.002	-0.001
	[-0.037,0.034]	[-0.037,0.035]
% of people in rural areas	0.003	0.003
	[-0.004,0.009]	[-0.004,0.010]
_cons	2.293***	2.329***
	[1.400,3.187]	[1.421,3.238]
N	788	788

Table notes.
Coefficients from OLS models with clustered standard errors. 95% confidence intervals in brackets.

* p<0.10, ** p<0.05, *** p<0.01
Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADLs: personal activities of daily living.
Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.
For the age groups, the reference category was 65-69.
The frailty index was measured as a percentage.
Frequent problems with balance refers to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).
Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.
A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Table 25. Outcome: worse frailty. Odds ratios. Exploring interactions.

	(1) No interaction	(2) Interaction between unmet need and living alone
Unmet need in wave 8	0.763*	0.745
	[0.553,1.053]	[0.511,1.087]
Term for interaction between living alone and unmet need		1.066
		[0.626,1.814]
Living alone in wave 8	0.945	0.921
	[0.673,1.328]	[0.611,1.388]
Age 70-74	2.155***	2.152***
	[1.420,3.270]	[1.418,3.267]
Age 75-79	1.550**	1.549**
	[1.001,2.403]	[1.001,2.396]
Age 80-84	2.035***	2.039***
	[1.268,3.266]	[1.266,3.283]
Age 85+	1.994***	2.000***
	[1.224,3.251]	[1.220,3.278]
Male	1.487**	1.488**
	[1.052,2.102]	[1.053,2.102]
N of PADL limitations in wave 8	0.944	0.944
	[0.805,1.107]	[0.805,1.107]
N of IADL limitations in wave 8	1.285***	1.285***
	[1.101,1.499]	[1.102,1.499]
Centred variable of the 40-deficits frailty index in wave 8	0.949***	0.949***
	[0.933,0.965]	[0.933,0.964]
Frequent problems with balance in wave 7	1.337	1.334
	[0.914,1.956]	[0.914,1.947]
Any falls between wave 8 and wave 9	1.918***	1.920***
	[1.431,2.570]	[1.436,2.567]
N of depressive symptoms in wave 8	1.008	1.008
	[0.934,1.089]	[0.933,1.088]
Current smoker in wave 8	0.795	0.796
	[0.494,1.279]	[0.494,1.280]
Education beyond school leaving age	0.869	0.871
	[0.605,1.249]	[0.605,1.254]
Wealth in wave 8: quartile 2	0.904	0.906
	[0.604,1.352]	[0.607,1.353]
Wealth in wave 8: quartile 3	0.944	0.945
	[0.642,1.387]	[0.644,1.388]
Wealth in wave 8: quartile 4 (highest)	0.573***	0.574***
	[0.381,0.863]	[0.382,0.863]
LA IDAOPI average score	0.958**	0.958**
	[0.926,0.990]	[0.926,0.990]
% of people in rural areas	0.996	0.996
	[0.989,1.002]	[0.989,1.002]
N	788	788

Table notes.
Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * $p<0.10$, ** $p<0.05$, *** $p<0.01$.
Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADLs: personal activities of daily living.
Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.
For the age groups, the reference category was 65-69.
The frailty index was measured as a percentage.
Frequent problems with balance refer to: always/very often/often has "problems with balance when walking on level surface" ([80], variable name).
Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.
A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

5.3.7. Robustness checks

Robustness checks, described in Appendix 5C, showed that the finding of no association between unmet need and falls was consistent across all model changes, which were: including ELSA longitudinal weights to minimise bias arising from non-response [118]; replacing equivalised wealth with benefit unit wealth; excluding people with no PADL difficulties; using alternative definitions of unmet need; restricting the sample to people with help.

The finding of no association between unmet need and the number of depressive symptoms was consistent across the same robustness checks, with two exceptions. Firstly, when unmet need was defined as no help for at least one PADL difficulty, it had a borderline significant positive association with the number of depressive symptoms (see Appendix 5C.6). Secondly, when people with no help were excluded, and unmet need was defined as having help that did not always meet needs, this newly defined unmet need variable was positively and significantly associated with the number of depressive symptoms (see Appendix 5.C.6.A).

In additional robustness checks, logistic regressions were run with the outcomes "at least 3 depressive symptoms" or "at least 4 depressive symptoms" instead of the numerical outcome. The finding of no association with unmet care need was consistent with the final model. See Appendix 5C.3 for more details.

The finding of a borderline significant negative association between unmet need and worse frailty did not hold in the robustness checks. No association was found between unmet need and worse frailty when these model changes were made: excluding baseline frailty from the covariates (see Appendix 5C.1); reducing the sample to observations with an available ELSA longitudinal weight (with and without the inclusion of longitudinal weights to minimise bias arising from non-response; see Appendix 5C.2); replacing equivalised wealth with benefit unit wealth (see Appendix 5C.4); using alternative unmet need definitions and restricting the sample to those with help (see Appendix 5C.6). A significant negative association between unmet need and increased frailty was found when the sample was restricted to people with at least a PADL difficulty (see Appendix 5C.5).

5.4. Discussion

In the final models, unmet need was not a significant determinant of having any falls or the number of depressive symptoms. Moreover, contrary to the relationship hypothesised in Figure 8, unmet need had a borderline significant association with lower odds of worse frailty and was a significant predictor of decreased frailty over the following two years.

Having falls was associated with increased frailty over the following two years, which fitted with the initial hypothesis. However, contrary to expectations, the number of depressive symptoms was not found to be associated with increased frailty.

The negative associations between unmet need and the frailty outcomes were only observed once health variables were included in the multivariable models. One possible interpretation for this is that unmet need did lead to health deterioration, and so the health variables included as covariates may have been themselves outcomes of unmet need, and so they may have been "bad controls" [165]. However, the negative correlations between unmet need and the health-related variables in Table 19 do not support this interpretation.

An alternative explanation for the negative association between unmet need and worse frailty is that, as mentioned in section 5.1, when people stop performing activities of daily living, this can lead to functional decline [132]; this would be captured by some components of the frailty index, for example, mobility limitations.

A third alternative interpretation is that limitations in the definition of unmet need (defined as not receiving any help or receiving help that meets needs sometimes or hardly ever) may be affecting the results. As previously mentioned in sections 3.4 and 4.4, people may have difficulties with activities of daily living but may not need help. The data did not include the level of difficulty with each activity, so this may be an omitted confounder: not receiving help may be associated with a lower level of difficulty with activities of daily living. At the same time, people with a lower level of difficulty may be less likely to see their frailty worsen over the following two years. In support of this interpretation, the number of IADL limitations at baseline was positively associated with worse frailty over the following two years in multivariable models.

The limitations in the definition of unmet need (not having any help or having help that meets needs sometimes or hardly ever) are of particular concern because robustness checks showed that this definition mattered for the results: with alternative definitions, no association was found between unmet need and worse frailty.

Robustness checks assessed whether it made any difference to exclude people with no help, thus limiting the analysis to people with help and defining unmet need exclusively based on people's perceptions. This was important to eliminate the assumption that no help was equal to unmet need. With this change, no association was found between unmet need and worse frailty. However, a positive association between unmet need and the number of depressive symptoms was observed. It is unclear if reverse causality could be playing a role in this finding: it may be that depressive symptoms affect people's perceptions and make them answer more negatively about the help received.

When unmet need was defined as no help for at least one PADL difficulty in robustness checks, it was a borderline significant risk factor for the number of depressive symptoms. Finding a borderline significant association in this model but not in the final model, where unmet need also referred to IADLs, is in agreement with Kröger's argument that adverse consequences are mostly related to unmet need with PADLs [39]. This finding was used to inform the economic model (see chapter 6). However, it should be noted that this definition did not consider people's perceptions. It was not possible to do so because ELSA's questions about how people perceive the help received do not distinguish between PADLs and IADLs. Future data collections should make this distinction, which is important because home care in England is currently mostly limited to personal care [58].

The finding that unmet need was not associated with having any falls over the following two years was consistent across all robustness checks.

Interaction between unmet need and specific conditions was not explored in the present work due to limited numbers. This could be investigated in future work. For example, dementia increases the risk of falls [166]. It may be that among people with dementia, falls are likely to occur regardless of met care needs. However, it may be that met care need can help prevent falls among other subgroups of people without dementia.

Survivor bias and attrition bias were important issues in this analysis. Table 26 shows that there was a higher percentage of losses to follow-up among people with met need compared to people with unmet need. This may be because people with met need had more impairment and frailty and so were more likely to die or to become too ill to respond over the following two years.

As detailed in Appendix 5C.2, longitudinal weights from the ELSA dataset were applied in robustness checks to take account of people that participated in wave 8 but not in wave 9 [118]. While the longitudinal weights make the sample more representative of people living in private households in England since 2008 [118], reweighting does not address bias that would arise if unmet need led to an increased risk of death linked to a frailty increase. Therefore, reweighting the sample does not solve survivorship bias.

Table 26. Met or unmet need in wave 8 and interview status in wave 9.

Met or unmet need in wave 8	**Responded in wave 9**	**Did not respond in wave 9, unknown if alive or dead**	**Total**
Met need in wave 8	585 (67.63%)	280 (32.37%)	865 (100%)
Unmet need in wave 8	375 (83.33%)	75 (16.67%)	450 (100%)
Total	960 (73%)	355 (27%)	1315 (100%)

Table notes. The table includes people who fulfilled these criteria in wave 8: being aged 65 and over, with at least one PADL difficulty or at least two non-PADL difficulties, no institutional interview, and data on the unmet need outcome.

An additional limitation may have been that the two-year follow-up was too short to capture the effect of unmet care need on some of the deficits included within the frailty index. For example, section 5.1.1 mentions that unmet need may be linked to an inappropriate diet. An inappropriate diet would generally be expected to increase the risk of cancer over a longer term (personal communication with stakeholder). However, an inappropriate diet could have a short-term effect on deficits such as high blood pressure, high cholesterol, or diabetes (personal communication with stakeholder).

Another limitation was that social isolation was not included in the analysis due to issues with missing data relating to people who did not fill in the self-completion questionnaire in wave 8. However, stakeholders mentioned that social isolation may be a possible mediator between unmet care need and worsening frailty. Further research could investigate this relationship.

5.4.1. Focusing on the models' covariates

Moving on from the relationship between unmet need, worse frailty, depressive symptoms and falls, the following paragraphs focus on the covariates included in the analyses. Higher frailty at baseline was negatively associated with worse frailty over the following two years and predicted better frailty over the following two years. It is possible that despite demeaning, regression to the mean was still an issue. Moreover, this result may have been influenced by the adjustment for the number of IADL limitations, which had a moderate positive pairwise correlation with baseline frailty and was positively associated with worse frailty in the multivariable analysis.

None of the included determinants were significantly associated with falls, except for some older age groups (a positive association) and baseline frailty (a borderline significant positive association). The finding about the older age groups is in agreement with Gale et al. [109], which examined seventeen possible risk factors for falls among older people, stratifying the analysis by men and women. Gale et al. [109] did not restrict their sample to people with limitations in activities of daily living. They found that only older age was associated with a higher risk of falls in both men and women. Gale et al. [109] did not find an association between frailty and falls, but defined frailty differently from the present work (as the presence of three or more of the following components: "unintentional weight loss, weakness, self-reported exhaustion, slow walking speed and low physical activity" ([109], p. 3; this was based on the Fried phenotype [167]). Gale et al. [109] found that some characteristics were associated with falls only among men or only among women. Further research on the determinants of falls among people with limitations in activities of daily living should stratify the analysis by gender and should assess the interaction between gender and unmet need.

Comparing the current findings on the determinants of depressive symptoms to the findings in the systematic review by Zenebe et al. [156], some were consistent, and others were not. It should be noted that only one study included in Zenebe et al. [156] was from the UK [168] and it was limited to people aged 80 to 90 and living alone.

Being male was associated with a lower number of depressive symptoms in the present work. This finding is consistent with Zenebe et al. [156]. Being in the highest wealth quartile was associated with a lower number of depressive symptoms, compared to the lowest one. This finding is consistent with the finding in Zenebe et al. [156] that poverty and a low income were associated with depression. In the present work, the number of IADL limitations and higher frailty were associated with a higher number of depressive symptoms. This is consistent with the finding in Zenebe et al. [156] that cognitive impairment, presence of physical illness and total dependence for activities of daily living were associated with depression.

In the present work, being aged 65-69 was associated with a higher number of depressive symptoms, compared to some older age groups (although in some cases the association was borderline significant). This finding differs from Zenebe et al. [156], which found that being older than 75 was a risk factor for depression. The presence of limitations with activities of daily living across all age groups in the current sample may explain the difference in findings. Additionally, living alone was associated with more depressive symptoms in the present work. Zenebe et al. [156] reported inconsistent findings across different studies in relation to this.

Regarding the determinants of worse frailty or change in frailty, some findings were consistent and some were not, compared to Niederstrasser et al. [103]. Some inconsistencies were expected as Niedestrasser et al. [103] did not limit their analysis to people with limitations in activities of daily living at baseline and included people aged 50 and over. Moreover, they used a 12-year follow-up, focusing on the association between characteristics in wave 2 (2004/05) and frailty in wave 8 (2016/17).

The present work found that being in an older age group was positively associated with worse frailty. This was consistent with the finding in Niederstrasser et al. [103] that older age in wave 2 (as a numerical variable) was positively associated with higher frailty in wave 8.

This PhD study found that being male was positively associated with worse frailty two years later, while in Niederstrasser et al. [103], it was negatively associated with frailty 12 years later. The difference in results may occur because in the present work, frailty was common at baseline: 80% of people in the included sample were frail, based on a threshold of a score of at least 25% on the frailty index (threshold previously used in Niederstrasser et al. [103]). At baseline, frailty prevalence was higher among women (86%) than men (71%), and the average frailty index score was higher among women than men (36% vs. 32%). Therefore, women's higher risk of frailty development and progression is adjusted for in the analysis when adjusting for baseline frailty, and so it is not captured by the outcome.

The present analysis found that being in the highest equivalised wealth quartile was associated with lower odds of worse frailty, compared to the lowest one. Niederstrasser et al. [103] found that each higher wealth quintile was negatively associated with frailty 12 years later, compared to the lowest quintile. They did not specify whether they used equivalised wealth or benefit unit wealth, but robustness checks in the present work show that this is unlikely to be the reason for the differences in findings (see Appendix 5C.4). It may be that a longer follow-up is needed to more accurately capture the effect of wealth on progression of frailty. One alternative explanation for the different results could be that wealth may have a less important role in relation to progression of frailty after limitations in activities in daily living have developed, and so a significant difference is only observed between the wealthiest and the least wealthy.

No association was found between school leaving age or current smoking and worse frailty two years later in the present work. In contrast, in Niederstrasser et al. [103], having educational qualifications at baseline was associated with lower frailty 12 years later, and being a current or previous smoker was associated with higher frailty 12 years later. Similarly to wealth, it may be that a longer follow-up is needed to capture the effect of these determinants, or it might be that these determinants no longer have a significant role once activities of daily living have developed. Alternatively, the different categories used for these variables could have played a role.

The finding that LA deprivation was associated with lower odds of worse frailty was unexpected. Average baseline frailty was higher in the most deprived quintile (37%) than in the least deprived quintile (33%), therefore, it may be that the higher probability of progression of frailty in more deprived areas was adjusted for when adjusting for baseline frailty rather than being captured by the outcome. Niederstrasser et al. [103] did not include LA-level variables in their analysis.

5.4.2. Researching the determinants of adverse health outcomes among people with disability

Overall, this chapter has highlighted some differences in the determinants of falls, depressive symptoms, and worse frailty, compared to previous analyses on older people. Among other differences with previous analyses, the present work narrowed the included sample to people with difficulties in activities of daily living. Future research should look further into how the determinants of adverse health outcomes may differ in this population compared to the general population of older people.

Some previous research has been identified, which focused on some determinants specific to people with disability. One study [169] used ELSA data to assess the determinants of falls among older adults with severe mobility impairments and found that “external housing modifications” ([169], p. 1), i.e., “widened doorways, ramps, automatic doors, parking and lift” ([169], p. 1) were associated with a lower probability of falls. Moreover, a review of systematic reviews by Mitchell et al. [170] on the socio-environmental factors that impact on the health outcomes of people with impairments identified various barriers and facilitators. Among these, a lack of relevant training for health professionals in relation to the needs of people with impairments; barriers in the physical environment to access the use of facilities for physical activity or preventive healthcare services; difficulties in obtaining equipment or assistive devices; attitudes and social support around exercising in public; communication barriers; transport accessibility to access health services; the potential opportunities offered by telemedicine. However, this was not specific to older people. Mitchell et al. [170] found that there was a lack of reviews on the social, physical or attitudinal factors influencing health outcomes specifically among older people with impairments. Further research on adverse health outcomes among older people with functional limitations should consider determinants that are specific to this population, such as housing adaptations, care receipt or unmet care need, in addition to other determinants that are also relevant to the general population of older people.

5.5. Conclusion

In conclusion, based on a review of studies on the consequences of unmet need [39], this work was the first to assess the association between unmet care need and outcomes other than wellbeing within the English context, and the first to assess the association between unmet care need and the progression of frailty in any context.

The final models found no association between unmet need and depressive symptoms or falls, and a borderline significant association between unmet need and lower odds of worse frailty. Data limitations affected the definition of unmet need and are likely to have impacted on the results. Robustness checks showed that modifications to the definition of unmet need changed whether unmet need had an association with the number of depressive symptoms or worse frailty. This supports the recommendations made in chapter 4 that data collections should include detailed information on the level of difficulty with activities of daily living and on whether people without help would need or want help. This would enable data analyses to use more appropriate definitions of unmet care need.

The next chapter presents an economic model on the costs and benefits of shortening waiting lists for home care. The economic model includes a parameter from a robustness check in Appendix 5C.6 which found that not having help for at least one PADL difficulty had a borderline significant association with higher depressive symptoms. This was included to explore the potential effect of shortening waiting lists on depressive symptoms and related costs. Falls were excluded from the economic model because no association was found with unmet need. The borderline significant finding (model 4, Table 21) that unmet need was negatively associated with worsening frailty was not included in the economic model. Considering the additional complexity that would arise from incorporating this finding in the economic model and linking it to further outcomes connected to frailty, the finding was not included due to concerns with data limitations. Other consequences of unmet need taken from the published literature were included in the economic model, as it is explained in the next chapter.

Chapter 6. Economic model on shortening waiting lists for home care

6.1. Introduction

The present work focuses not only on the determinants and outcomes of unmet care need, but also on its costs, and on the possible outcome improvements and savings that can arise from a reduction of unmet care need. More specifically, it aims to assess the potential costs and benefits of reducing unmet care need by shortening waiting lists for home care (which corresponds to objective 6 of this PhD study, as mentioned in chapter 1).

Section 1.3 mentions that economic modelling can make transparent assumptions in the absence of evidence and can show how results would change if assumptions were modified. Moreover, it can combine evidence from different sources. This makes economic modelling particularly appropriate for evaluating the potential costs and benefits of shortening waiting lists for home care, because no evidence was identified on the effects of reducing these waiting lists within the English context. Moreover, although some evidence was identified on the effects of home care, very limited evidence was available on the consequences of unmet care need in England, as outlined in chapter 5.

There are some England-based economic models relating to home care for older people, but their scope is limited. Three models have made projections of social care demand and supply into the future, comparing different eligibility or funding scenarios or different interventions to support informal carers [171-173]. However, these models did not look at the effects of home care on the health and wellbeing of the person with care needs, so were not relevant for assessing the costs and benefits of reducing waiting lists for home care. They only considered how different policies or interventions would affect public expenditure and private expenditure [171-173] and, in one case, the employment status and working hours of informal carers [173].

A fourth England-based economic model evaluated a “help-at-home scheme” ([174], p. 1) implemented by Age UK for older people living in private households, which included befriending as well as practical help with gardening, shopping and cleaning [174]. However, this model was not relevant to the evaluation of costs and benefits of reducing waiting lists for home care because personal care was not included, although there was assessment and referral for it in the “help-at-home scheme” [174]. A fifth England-based model focused on replacement care to support adult carers’ return to work (not just carers of older people) [175]. This latter model was of limited relevance to assess the costs and benefits of reducing waiting lists of home care for older people because it only focused on informal carers' outcomes, not on the outcomes of people with care needs.

Finally, a cost-effectiveness analysis of home care focused on public expenditure and on psychological well-being measured by GHQ-12 [176]. It was of limited relevance for the present work because it compared older people using home care to older people using other social care services, rather than being on a waiting list. Moreover, it did not use a modelling approach.

Therefore, no England-based economic model has been identified, which focused specifically on home care (with the inclusion of personal care) considering a variety of outcomes, ranging from the health and wellbeing of the person with care needs to the outcomes for informal carers. It is important to conduct economic modelling work that considers the consequences of unmet care need and the positive effects of home care as this may help advocacy efforts by organisations such as Age UK to improve access to home care.

6.1.1. Aims and objectives.

Aim: to assess the costs and benefits of reducing waiting lists for home care among older people eligible for fully LA-funded home care in England. More specifically, in relation to people with care needs: the gains in life years and quality of life; the personal social services costs relating to home care, admissions to care homes (residential and nursing) and depressive symptoms; the NHS costs relating to GP visits, hospitalisations, care home admissions and depressive symptoms; the privately funded costs relating to care home admissions and depressive symptoms. Additionally, the gains in earnings for informal carers.

Objective 1: to build an economic model which evaluates the costs and benefits of reducing waiting lists for home care as delivered in the current English context, limiting the analysis to people eligible for full funding of their home care by the local authority.

Objective 2: to present costs based on different perspectives: personal social services; NHS; public sector (NHS plus personal social services); the private payer; informal carers' earnings.

6.1.2. Background and rationale for focusing on waiting lists for home care

Stakeholders mentioned that care needs and waiting lists for social care assessments and for home care have increased during the COVID-19 pandemic. The May 2022 report by the Association of Directors of Adult Social Services (ADASS) [177] mentioned that 61% of

Directors of Adult Social Services had limited capacity to provide assessments and so could only prioritise people whose life or limbs were at risk or people who were being discharged from hospital. Age UK [5] highlights that older people who are waiting for an assessment in their own homes are deprioritised compared to people discharged from hospital. Moreover, there are also month-long waiting lists between the time of the assessment and the time when the assessment outcome is communicated [5].

ADASS [178] reported that on the 31st of August 2022 there were 245,821 people awaiting a first assessment of their care and support needs. 1 in 3 had been waiting more than 6 months. Additionally, 29,571 people had had an assessment but were waiting for care and support to start or for their first direct payment. Moreover, for 216,271 people receiving a service or direct payment, a review of the care and support plan was overdue by at least 12 months.

6.2. Methods

6.2.1. Conceptual modelling

Conceptual modelling is the first stage of an economic modelling project, which focuses on understanding the problem and developing an appropriate model structure [179]. It requires the involvement of stakeholders and considerations of how the model is linked to decision-making [179].

6.2.1.1 Conceptual modelling methods

The conceptual modelling framework presented in Squires et al. [179] was used as the main point of reference, although it was followed in a simplified way. This framework refers to public health economic models, which face some challenges that the present work also faced: the inclusion of costs and outcomes beyond healthcare, considerations of equity and of complex systems [180].

The conceptual modelling phase focused on (a) making sure that the aims and objectives were relevant in relation to the current context, (b) outlining the model scope and boundaries (by defining the population, intervention, comparator and outcomes), (c) defining the model structure and ensuring that the structure had face validity for stakeholders. Conceptual modelling involved reviewing existing evidence on home care and unmet care need, investigating data sources and talking with stakeholders.

Evidence on the effectiveness of home care interventions and on the consequences of unmet care need was reviewed. Moreover, previous economic models relating to home care and unmet care need were also reviewed. The review of existing literature aimed to identify estimates of the effects of home care and unmet care need, to be included as model parameters; previous model structures; available data sources that could potentially be used in the model.

All evidence on the website of the Economics of Social Care Compendium (ESSENCE) [181] was assessed for inclusion if it was classified under the "Home Care" keyword. Additionally, non-systematic searches led to the identification of a review of economic evaluations in social care [182], a review on the consequences of unmet care need [39], reviews on interventions to support informal carers [183, 184] and other primary studies on home care and unmet need. Relevant primary studies and data sources are mentioned in relation to specific model inputs in section 6.2.4.

Between November 2022 and February 2023, meetings were held with the following stakeholders to discuss the aim, pathways and outcomes of the economic model and the definitions and consequences of unmet care need:

- public advisory group of older people and carers (six people)
- two home care commissioning officers
- two occupational therapists
- one GP
- one person working for an independent living scheme
- one academic with expertise of social care modelling

The model scope and model structure defined during conceptual modelling are described below.

6.2.2. Model scope

The model uses a lifetime horizon.

6.2.2.1 Population

The population of interest has the following characteristics: aged 65 and over; living in private households in England; fitting the need eligibility and means-testing criteria for having home care fully funded by the LA (this was done for simplicity, to avoid inclusion of privately funded home care in the model).

The population is comprised of a cohort of individuals with mean age of 77.5 at the start of the model. Initial mean age is based on people aged 65 and over with at least two PADL difficulties in the ELSA 2016-17 dataset (mean age was 77.2 in the dataset; this was rounded to 77.5 so that annual cycles after the initial 6 months could start at age 78). With each annual cycle, mean age increases by 1. Note that the threshold of at least two PADL difficulties is based on a previous study that argued that need eligibility for LA-funded care in ELSA would be best captured by having at least two PADL limitations [185].

This work excludes:

- People not aware of services (they would not be affected by waiting lists).
- People who do not want home care (they would not be affected by waiting lists). However, the model does include situations where the person starts home care and then cancels it.
- People who are recommended home care as part of a hospital discharge package.
- People who only need home care for a short time (e.g., due to an injury).
- People for whom needs are mitigated while on a waiting list, potentially due to an intervention different from home care.
- People receiving NHS continuing healthcare.
- People receiving palliative care.
- People in sheltered housing / independent living schemes, extra-care housing or care homes (although care home admissions are included in the model for people who enter the model when they are living in a private household).

The model looks separately at three population subgroups, defined by the availability of informal care: 1. People with availability of at least some informal care from within the household; 2. People with informal care that only comes from outside the household; 3. People without informal care. The separation between subgroup 1 and 2 was done based on the data analysis from section 4.3, which showed that informal care only from outside the household was associated with higher odds of unmet need compared to at least some informal care from within the household. Additionally, it was important to separate subgroup 3 from the others because of the key role of informal carers. This role is recognised in the Department of Health & Social Care's statutory guidance, which states that the local authority should consider if there are informal carers willing and able to provide care when making care and support plans [16].

Additional subgroups could have been defined based on the determinants of unmet need identified with data analysis in chapter 4, but the present work did not do so due to limited time. Section 7.4 makes research recommendations relating to this.

The following subgroups were identified as being important in conversations with stakeholders but the present work does not focus on them due to limited time (the availability of relevant data for these subgroups was not explored):

- with and without moderate or severe dementia;
- with and without invisible disabilities, such as deafness, autism, cognitive and mental health issues;
- using a higher or lower number of different medication types;
- with specific health problems, such as chronic alcohol misuse;
- with and without direct payments;
- different ethnicities.

6.2.2.2 Intervention and comparator

- Intervention: provision of home care 6 months earlier than standard care
- Comparator: standard care

Due to funding limitations, home care in England typically focuses on personal care [58], although NICE guidance states that home care should consider needs beyond personal care and use time flexibly according to what is needed [21]. The present model focuses on home care as it is delivered in current practice, i.e., mostly as personal care. Although some parameters from data analysis in chapter 4 referred to a wider range of needs, they were used in the present model based on the assumption that they would also apply to personal care specifically.

This work assesses the potential costs and benefits of reducing the waiting time for home care by 6 months. There is a lack of data on the duration of waiting times, and in practice people may wait more or less than that. When referring to waiting time, time before and after an assessment is included. Due to a lack of data, it is not possible to split the waiting time into time before and after an assessment.

Ideally, in an economic evaluation, waiting time before an LA care needs assessment would be linked to the costs and benefits of all possible interventions that could be recommended at such assessment. However, this work ignores interventions other than home care for simplicity. For example, reablement may be recommended before starting home care, but this is not included in the model.

This work does not directly focus on waiting lists for reviews of care and support plans, although delays in these are indirectly considered in the model as they would affect the extent to which home care meets needs.

6.2.2.3 Outcomes

The outcomes that were included in the model were selected based on the available evidence among many suggested by stakeholders. The relevant evidence is mentioned when describing the model inputs in section 6.2.4.

The included outcomes are:

In relation to people with care needs:

- Number of life years
- Number of life years adjusted by unweighted "social care-related quality of life" ([186], p. iii) (SCRQoL)
- Cost of depressive symptoms (NHS, personal social services (PSS), privately funded)
- NHS cost of GP visits
- NHS cost of hospitalisations
- NHS, PSS, and privately funded cost of a permanent admission to a care home (residential or nursing)
- Total NHS costs
- Total PSS costs
- Total public sector costs (NHS & PSS)
- Total privately funded costs
- Incremental cost-effectiveness ratios (ICERs):
    - incremental public sector (NHS & PSS) cost per additional life year
    - incremental public sector (NHS & PSS) cost per additional life year adjusted by unweighted SCRQoL.

Note that the model did not include "social care quality-adjusted life year[s]" ([186], p. vii) (SC-QALYs) because of a lack of relevant evidence (section 6.2.4.4 explains this and explains what is meant by "unweighted" SCRQoL).

In relation to informal carers:

- Informal carers’ earnings

Note that total privately funded costs exclude informal carers’ earnings; the reason is that all costs are presented per person with care needs, but informal carers’ earnings are presented per carer. Because of this, the ICERs only include public sector costs.

The main outcomes are life years, life years adjusted by unweighted SCRQoL, total costs stratified by funding source, informal carers’ earnings, and the ICERs. Cost components (the cost of GP visits, hospitalisations, care homes, and depressive symptoms) are secondary outcomes.

Due to a lack of evidence, the model did not include the possibility of an increased risk of a temporary admission to a care home. Moreover, potential benefits of home care for informal carers beyond employment earnings (for example, improved quality of life or mental health) were excluded from the model because no relevant evidence was identified.

All the included outcomes are half-cycle corrected to account for events occurring on average halfway through the initial 6-month period. After this initial period, half-cycle correction accounts for events occurring on average halfway through the year (section 6.2.3 presents the model structure and explains that the model uses annual cycles after focusing on the initial 6 months).

6.2.3. Model structure

This section gives an overview of the model structure, then describes the care states and the model pathways.

The model starts with an initial 6-month period which corresponds to a waiting list with standard care and to home care receipt (or home care cancellation) with the intervention. For this initial period, a decision tree was used. The distribution of the population within care states at the end of the decision tree was used as the first row in a cohort Markov model with annual cycles.

A decision tree at the start made it easy to make the waiting list last exactly 6 months. A Markov model was chosen over a decision tree for the long-term modelling because it could easily capture the fact that people may stay in the same care state over many years. Additionally, it could easily show that people could go back to a waiting list and then re-start their journey along the same model pathways. Both the decision tree and the Markov model were built in Microsoft Excel (version 2304).

The model pathways ignore interventions other than home care, such as reablement, aids and adaptations, day care centres, support to carers, or Attendance Allowance.

An assumption behind model pathways is that once people are eligible for home care, their needs do not reduce to a point that they do not need home care (please note that people with short-term needs for home care have been excluded).

6.2.3.1 Care states

In the model, people are classified into care states defined by whether they have no care, informal care, LA-funded home care, or both, and by whether their care needs are met, or unmet. Met and unmet care needs are not defined in a unique way, because the model includes parameters from different studies as well as from data analyses in chapters 4 and 5 of the present work, and different parameters correspond to different definitions. Table 27 includes different definitions of met and unmet care need that were used in the analyses that calculated the model's parameters.

Although care needs would be subjectively defined by each person and could also refer to the social aspect of care, the definitions of care needs used to calculate the parameters for the model mostly refer to help with PADLs. The exception is the definition in the first row of Table 27: this was linked to estimates from chapter 4, which refer to help with PADLs, IADLs or mobility tasks.

Table 27. Definitions of met and unmet need that were used to estimate parameters used in the economic model.

Source	Met need	Unmet care need	Comments
Data analysis using ELSA data described in section 4.3	Stating that help meets needs all the time.	Stating that help meets needs usually / sometimes / hardly ever.	The ELSA questionnaire enquired about this after questions about receiving help with PADLs, IADLs and mobility tasks.
Data analysis using ELSA data described in Appendix 5C.6 (the analysis was a robustness check)	Receiving help for each PADL difficulty.	At least one PADL difficulty without help.	As above.
Xu et al. [187] (United States)	People did not say [see right column].	People said they “could have used more help” (p. 928) with a PADL “or had to wait” (p. 928) to do a PADL task “because they did not have enough help” (p. 928), or they had no help and said they could have used help.	None.
Gaugler et al. [188] (United States, people with dementia)	Caregivers’ report that care recipients had enough help for all / all but one PADL.	At least two unmet PADL needs (unmet need was based on caregivers’ reports that care recipients did not have enough help for PADLs).	This article also used other definitions that were not used in the present model.

6.2.3.2 Model pathways - people with availability of informal care (population subgroups 1 and 2)

Figure 12, Figure 13 and Figure 14 show the model pathways for the subgroups with informal care (the pathways are the same for the subgroup with at least some informal care from within the household and the subgroup with all informal care from outside the household). Figure 12 and Figure 13 show the decision tree used for the first 6 months (Figure 12 refers to standard care and Figure 13 to the intervention). Figure 14 shows the Markov model, which applies to both standard care and the intervention over the following years.

Note that the model assumes that home care never fully replaces informal care. If available, informal care is always provided, at least in part. The literature review from chapter 3 supports this: one study found that having LA-funded home care was not associated with informal care receipt two years later [68].

Figure 12 shows that with standard care, people start in the waiting list states. On the waiting list, they receive only informal care, and do not have privately funded care or free care from the third sector. The rationale behind this assumption is that most people would not be able to pay for private care because a person eligible for full LA funding could have a maximum of £14,250 in savings and would have limited income. Even if they were able to purchase some care, people would be careful about spending their savings on private care, partly because of the awareness that their care needs may worsen in the future [11]. Additionally, it was assumed that free schemes linked to the third sector would generally not offer personal care and would be focused instead on activities such as signposting, befriending, or practical support with domestic tasks such as gardening or food shopping. Indeed, a conceptual distinction has been made between this kind of "help-at-home schemes" by community and voluntary organisations [189] and publicly funded "home care" which mostly consists of personal care [58].

During the initial 6 months, people stay on the waiting list, unless they are admitted to a care home or die. At the end of the 6 months, people transition from the waiting list to the home care states, except for people who move from the waiting list to the cancelled home care states. In practice, home care cancellation would happen because of concerns with inappropriate home care [57]. The model assumes that cancellation occurs a short time after the start of home care, and so this time is ignored in the model.

At the start of the Markov model (Figure 14), people start from the home care states or from the cancelled home care states, unless they have already been admitted to a care home or have already died during the first 6 months.

After having cancelled home care, some people may stay for various annual cycles with only informal care, even if they have unmet care need. In the Markov model, there is also a probability of going back to the waiting list for home care, which in practice could be for reasons such as a change in the availability of informal care or increasing needs. The waiting list after home care cancellation in the Markov model is assumed to last one year for simplicity.

From each care state, both in the decision tree and in the Markov model, a person could be admitted to a care home or die. Notably, a person could also go directly from met needs to a care home. An example of when this could occur in practice is after an acute event.

The model pathways are the same with the intervention and with standard care, but with the intervention, everyone in the decision tree (Figure 13) starts from the home care states or from the cancelled home care states, rather than from the waiting list states. For simplicity, the decision tree does not include the possibility that a person with cancelled home care can go back to the waiting list during the initial six months.

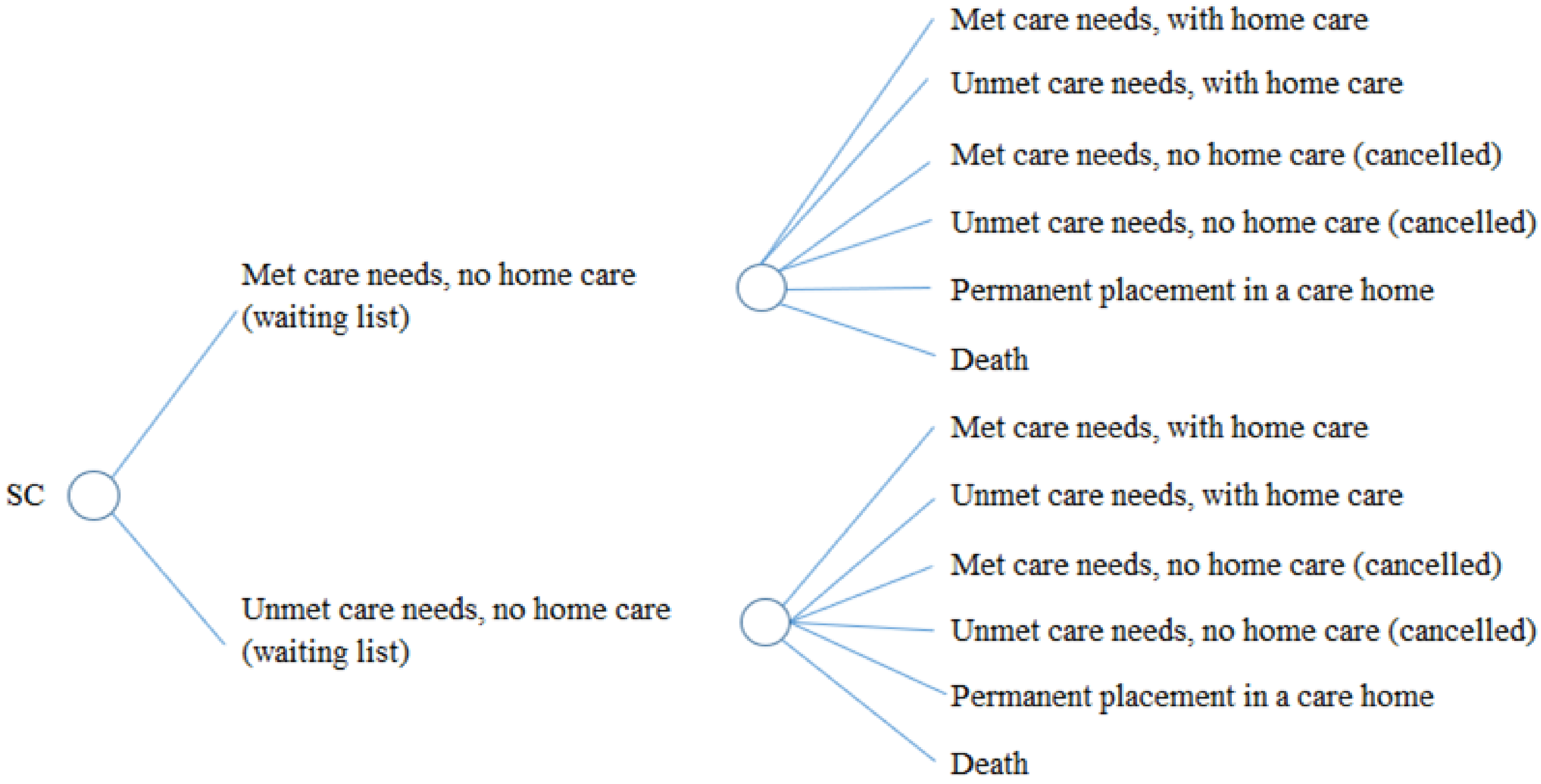


Figure 12. Decision tree, standard care – population subgroups: people with informal care available (subgroup 1: people with at least some informal care from within the household; subgroup 2: people with informal care only from outside the household).
Abbreviations: SC: standard care.
Note that the transitions to a care home or death would occur during the first 6 months, while the transitions to the home care or cancelled home care states would occur at the end of the first 6 months.

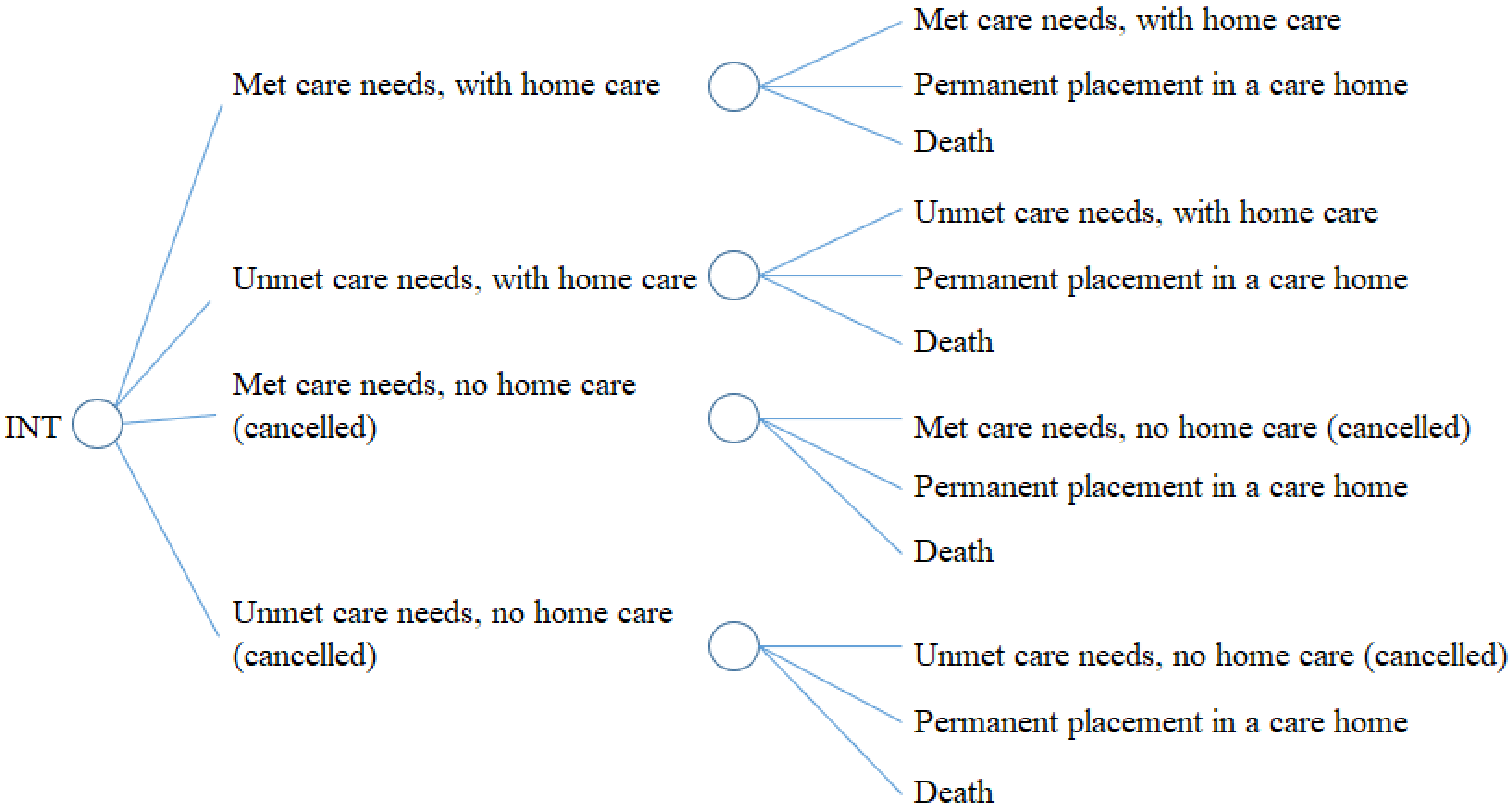


Figure 13. Decision tree, intervention – population subgroups: <u>people with informal care available</u> (subgroup 1: people with at least some informal care from within the household; subgroup 2: people with informal care only from outside the household).
Abbreviations: INT: intervention.

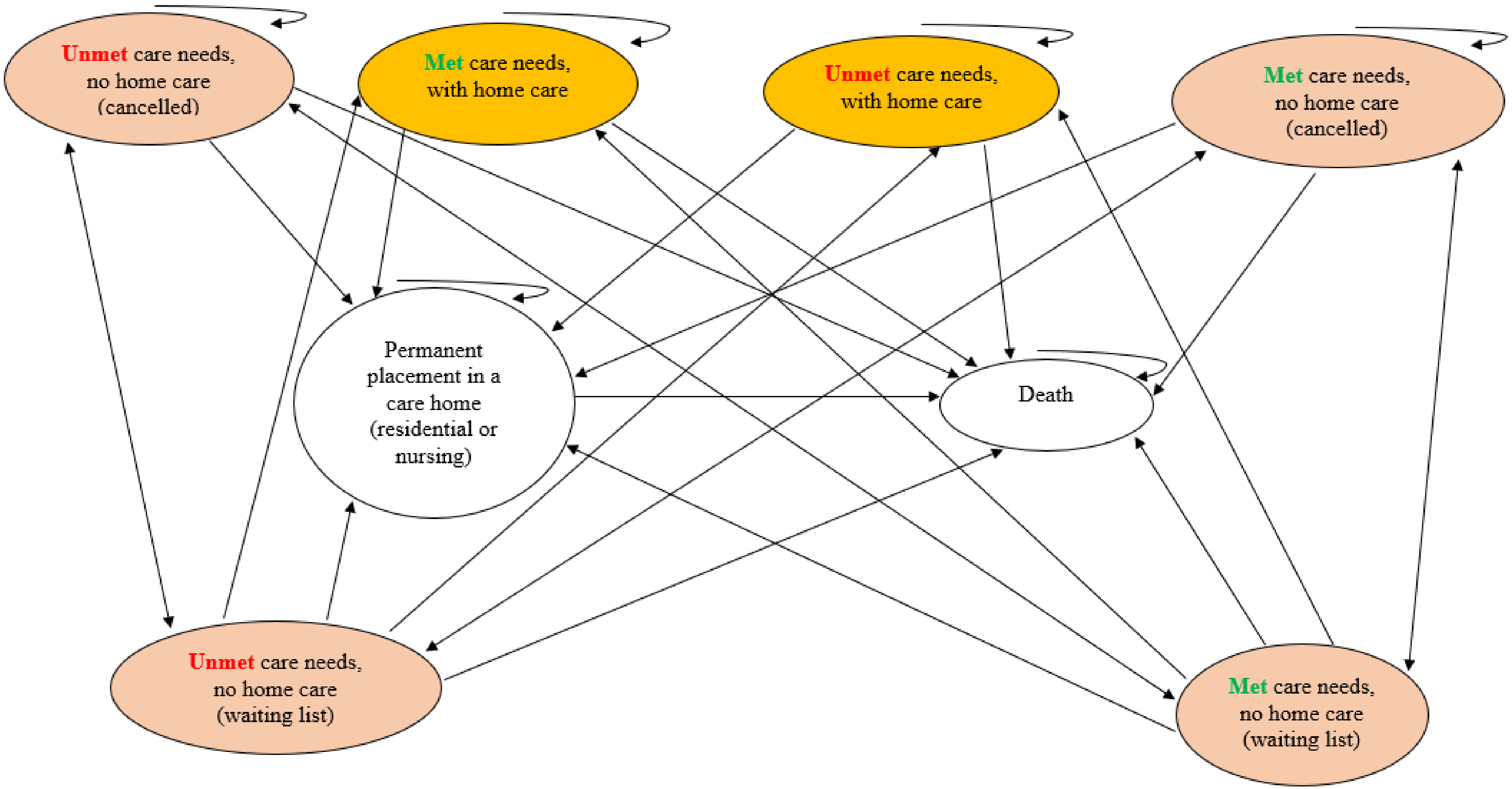


Figure 14. Markov model – population subgroups: <u>people with informal care available</u> (subgroup 1: people with at least some informal care from within the household; subgroup 2: people with informal care only from outside the household).

6.2.3.3 Model pathways - people without availability of informal care (population subgroup 3)

Figure 15 and Figure 16 show the pathways that are modelled for people without informal care. Figure 15 presents the decision tree for the first 6 months and Figure 16 the Markov model for the following years.

With standard care, people start by spending 6 months on a waiting list with unmet care needs, unless they are admitted to a care home or die. People would be on their own while on a waiting list, without using privately paid care or free care from charities. In addition to the reasons mentioned in the previous section, a lack of informal care would often indicate social isolation.

At the end of the 6 months, people transition from the waiting list to the home care states. They do not cancel home care, because they do not have informal care to fall back onto.

At the start of the Markov model, people start from the home care states, unless they have already been admitted to a care home or have already died during the first 6 months.

From each care state, both in the decision tree and in the Markov model, they can transition to a permanent care home admission or to death.

With the intervention, people start from the home care states in the decision tree rather than from the waiting list. After that, the model pathways are the same as with standard care.

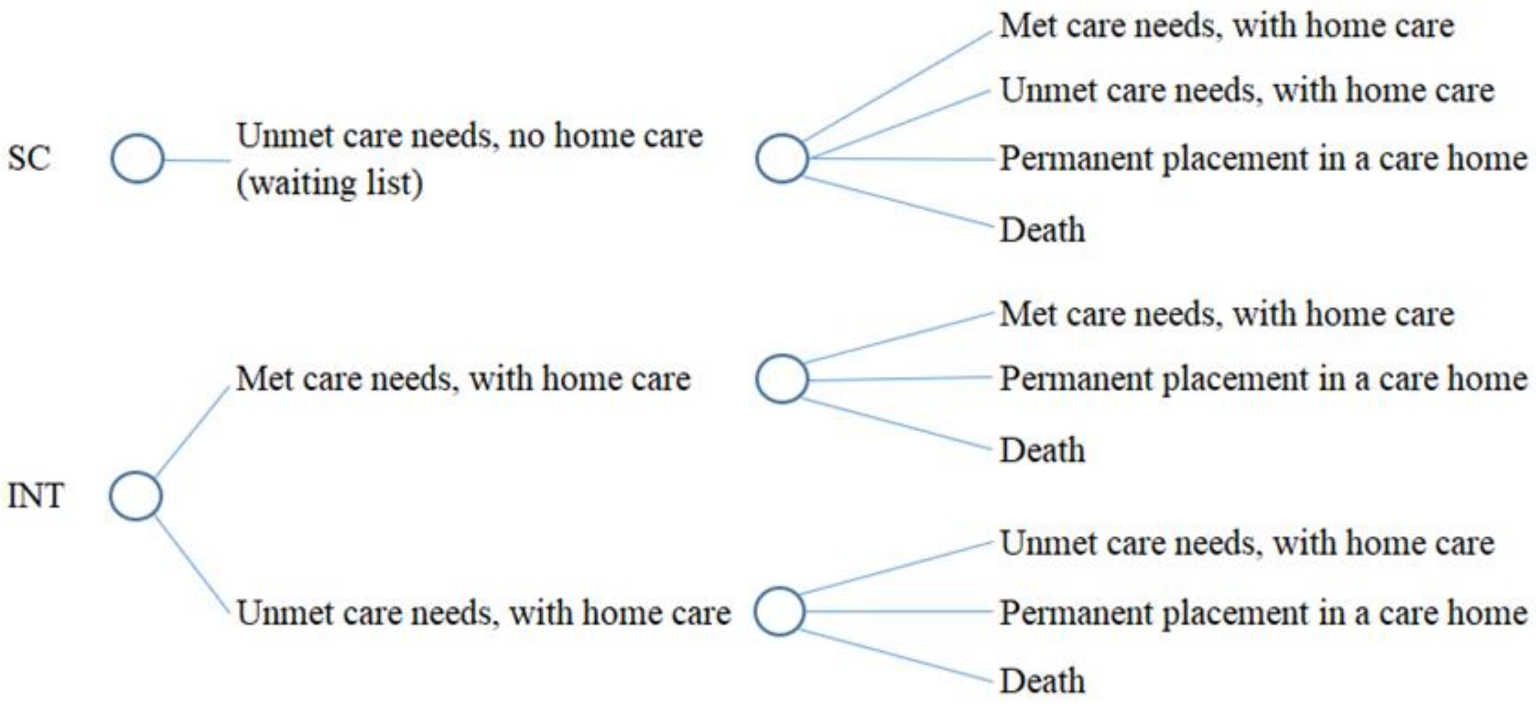


Figure 15. Decision tree – population subgroup 3: <u>people without availability of informal care</u>.
Abbreviations: INT: intervention; SC: standard care.
Note that the transitions to a care home or death would occur during the first 6 months, while the transitions from the waiting list to the home care states would occur at the end of the first 6 months.

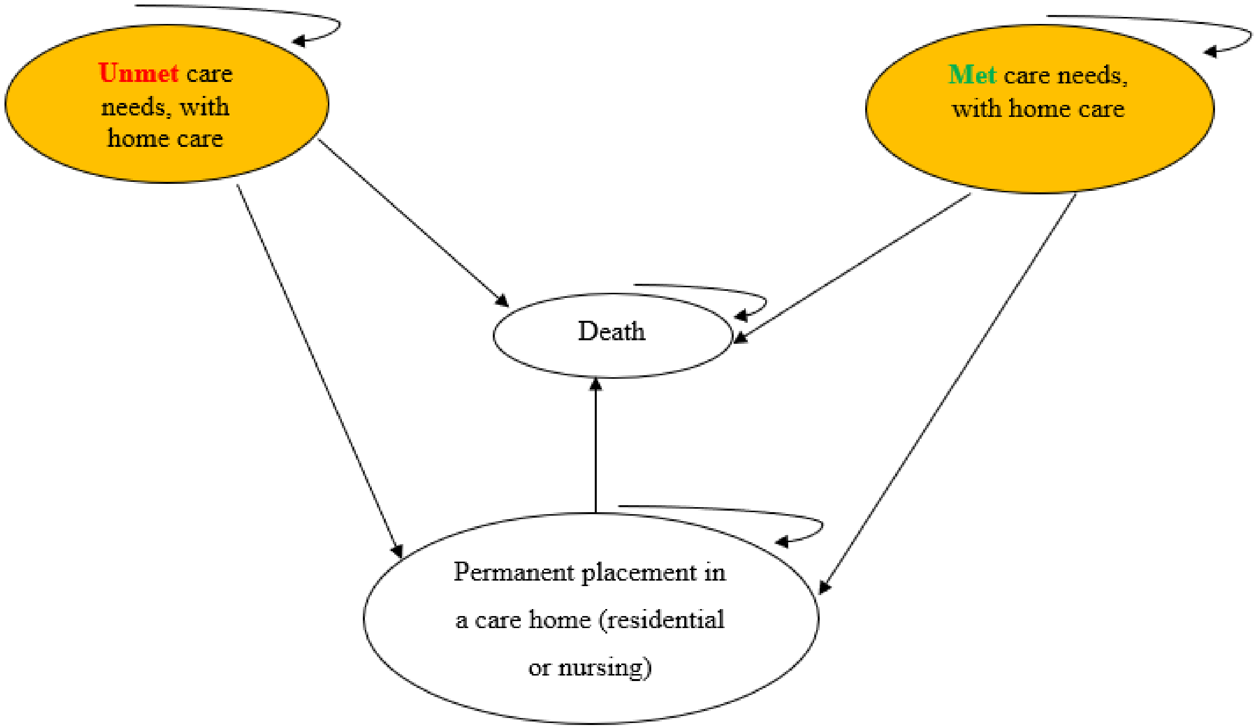


Figure 16. Markov model – population subgroup 3: people without availability of informal care.

6.2.4. Model parameters

6.2.4.1 Population subgroup proportions

The proportions of people belonging to each subgroup are presented in Table 28. These were used to calculate weighted averages of the results across the subgroups.

Table 28. Proportion belonging to each subgroup.

Probability	Mean	95% CI		Source
		Lower limit	**Upper limit**	
P (informal care from within the household)	0.367	0.365	0.369	Data from the Personal Social Services Adult Social Care Survey 2021/22 [190] on 210,190 people aged 65 and over living in private households (excluding those with learning disability).
P (informal care only from outside the household)	0.480	0.478	0.482	
P (no informal care)	0.153	0.152	0.155	

Table notes. Abbreviations: CI: confidence interval; P: probability.

6.2.4.2 Proportions with met needs based on different sources of care

The parameters described in this section are proportions used to partition people into met vs. unmet need states when they are at home, whether on the waiting list, with cancelled home care, or with home care.

Subgroups with informal care (see Figure 12, Figure 13 and Figure 14 for pathways)

The proportion of people with met need if receiving informal care from within the household without home care was 0.696 (95% CI: 0.624 to 0.761). This was based on 184 people aged 65 and over from ELSA wave 8 with at least 2 PADL difficulties, informal care from within the household and no LA-funded care or privately funded care in 2016/17.

The proportions with met need in the presence of LA-funded care and/or informal care only from outside the household were calculated by combining the estimate above with the marginal effect on the probability of met need of LA-funded care (0.052; 95% CI: -0.051 to 0.155) and/or the marginal effect of receiving informal care only from outside the household (-0.134; 95% CI: -0.216 to -0.051). See Table 29 for more details.

The confidence interval of the marginal effect of having LA-funded home care on the probability of met need ranged from negative to positive. Therefore, in some iterations of the probabilistic sensitivity analysis, receiving LA-funded home care decreased the probability of met need compared to having only informal care. This was deemed plausible, considering that there have been reports of inappropriate home care, for example with carers coming at unreliable times [5].

Subgroup: people without informal care (see Figure 15 and Figure 16 for pathways)

The probability of met care need with home care in the absence of informal care was 0.660 (95% CI: 0.601 to 0.719). This was based on a survey of LA-commissioned home care in Warwickshire conducted in July and August 2022 (n=249). In the survey, 66% "strongly agreed or agreed" that the service met the needs of the care user [191]. Despite being a local estimate, it was prioritised over other estimates that were less recent [192] or not specific to home care [190].

When looking at Table 29, note that the probability of met care need with home care and all informal care from outside the household was lower than the probability of met care need with home care and no informal care. Given that the estimates were from different data sources, there was high uncertainty around this, so this was modified in a scenario analysis (see section 6.2.5.2).

Table 29. Marginal effects and proportions with met need relating to different sources of care.

Marginal effect or proportion	Source of care	Mean	95% CI		Source
			Lower limit	Upper limit	
Marginal effect, outcome: met need	LA-funded care vs. no LA-funded care (in the presence of informal care)	0.052	-0.051	0.155	Data analysis linked to chapter 4 (see Appendix 6B.1 for more details)
Marginal effect, outcome: met need	Informal care only from outside the household vs. at least some from within the household	-0.134	-0.216	-0.051	
P (met need)	Informal care within hh, no home care	0.696	0.624	0.761	Descriptive analysis of ELSA data.
	Informal care within hh, with home care	0.748	NA – linked to estimates above.		Combination of estimates in rows above. Note that combining these estimates assumed no interaction between informal care and receipt of LA-funded care.
	Informal care all outside hh, no home care	0.562	NA – linked to estimates above.		
	Informal care all outside hh, with home care	0.614	NA – linked to estimates above.		
	No informal care, no home care	0	NA. It was assumed that no one had met needs.		Model assumption
	No informal care, with home care	0.660	0.601	0.719	A survey in Warwickshire [191]
	Weighted average across the three subgroups at the start of the model with the intervention (used in formulas that include the prevalence of unmet need, see Appendix 6.D.1.B for more details)	0.653	NA – linked to parameters above.		Calculated based on parameters above.

Table notes. Abbreviations: CI: confidence interval; ELSA: English Longitudinal Study of Ageing; hh: household; LA: local authority; NA: not applicable; P: proportion.

6.2.4.3 Transition probabilities

The following paragraphs summarise information about the transition probabilities.

6.2.4.3.1. Probability of transitioning from the waiting list to home care with met and unmet needs

Everyone moves out from the waiting list states after the initial 6 months. Of all individuals who do not cancel home care, the remainder are split into met or unmet need states with home care, using the probabilities in section 6.2.4.2.

6.2.4.3.2. Probability of cancelling home care

It was assumed that the probability of transitioning from a waiting list state to a cancelled home care state was 3% (95% CI: 0.028 to 0.032). This was based on satisfaction data in the Personal Social Services Adult Social Care Survey (PSS ASCS), England 2021-22 [190]. On average, 3% of 23,215 people aged 65 and over living in private households (excluding those with learning disability support) were “extremely or very dissatisfied” ([190], Annex table T2a) with the social care services provided [190]. It was assumed that the percentage that would cancel home care was the same, if informal care was available. Those with cancelled home care are split into met and unmet care need states using the proportions in section 6.2.4.2.

6.2.4.3.3. Probability of going back to the waiting list after a home care cancellation

No data was found on the annual probability of transitioning to the waiting list after cancelling home care. Therefore, it was parameterised as a uniform distribution from 0 to 1.

6.2.4.3.4. Care home admissions in different care states

Gaugler et al. [188] reported that the odds of a long-term admission to a nursing home for people with unmet care need for at least 2 PADL difficulties were 1.77 times the odds of people with no unmet care need for PADL difficulties over 18 months (95% CI: 1.53 to 2.05). This was a study from the United States focusing on people with dementia, so its findings may not be applicable to all older people with limitations in activities of daily living in England. However, this estimate was used in the present model as no other estimate was found. In the model, it was applied to permanent admissions to all care homes (nursing homes and residential care homes).

Considering that the odds ratio referred to an 18-month period, this should have been converted to a risk ratio or hazard ratio before applying it to annual or six-month probabilities. However, this was not possible due to the limited data available in Gaugler et al. [188] and also because the odds ratio had been calculated from a multivariable analysis. The risk ratio and hazard ratio would have been similar to the odds ratio if the percentage of people admitted to nursing homes was small. However, no relevant data on this was presented in Gaugler et al. [188].

Bauer et al. [58] reported an annual probability of care home admission for people with long-term support of 4.89%, based on data from the Health and Social Care Information Centre (HSCIC) [193]. For the decision tree, a 6-month probability was calculated by converting the annual probability into an annual rate and then by converting the annual rate into a 6-month probability. See formula in Appendix 6.D.1.A.

The present work combined the odds ratio and the probabilities above to calculate the annual and six-month probability of permanent care home admission for those with met and unmet needs. The formula used for this calculation is presented in Appendix 6.D.1.B. The estimated probabilities are presented in Table 30.

Table 30. Transition probabilities relating to home care cancellation and care home admission, and related odds ratios.

Odds ratio or probability	Subgroup	Care state	Mean	95% CI		Source
				Lower limit	Upper limit	
P (cancelling home care)	Any with informal care	Any on waiting list	0.030	0.028	0.032	Assumption linked to satisfaction data in the PSS ASCS [190]
P (waiting list for home care)	Any with informal care	Any with cancelled home care	Not available			No evidence
Odds ratio for outcome: care home admission	All	Comparing unmet to met need	1.77	1.53	2.05	Gaugler et al. [188]
Annual P (care home admission)	All	NA. Overall (only used to calculate estimates below)	0.0489	Not available		Bauer et al. [58]
		Met need	0.040	NA – linked to the OR for care home admissions and to the prevalence of unmet need		Calculated using the odds ratio from Gaugler et al. [188], the probability from Bauer et al. [58] and the prevalence of unmet need.
		Unmet need	0.069			
6-month P (care home admission)	All	NA. Overall (only used to calculate estimates below)	0.025	Not available		Calculated by converting the annual probability from Bauer et al. [58] into an annual rate and then converting the annual rate into a 6-month probability.
		Met need	0.020	NA – linked to the OR for care home admissions and to the prevalence of unmet need		Calculated using the odds ratio from Gaugler et al. [188], the probability from Bauer et al. [58] and the prevalence of unmet need.
		Unmet need	0.036			

Table notes. Abbreviations: CI: confidence interval; NA: not applicable; OR: odds ratio; P: probability.

6.2.4.3.5. Mortality in different care states

Gaugler et al. [188] reported that people with unmet care need had 1.37 times the odds of death over 18 months compared to people with met care need (95% CI: 1.08 to 1.74). Unmet need in this study referred to unmet need with at least 2 PADL difficulties. This study focused on people with dementia and living in the United States, but in the absence of more relevant data, it was used in the model.

In the model, the probability of death was linked to average age and was taken from the national life tables for the UK 2017-19 [194]. There were more recent life tables available, referring to 2018-2020 [194], but the 2017-19 tables were prioritised to avoid including mortality relating to the initial phases of the COVID-19 pandemic.

The annual probability of death for each age was calculated as a weighted average across males and females. See Appendix 6.D.1.C for details about the calculation of the weighted average.

The annual probability of death for those with met and unmet need was calculated combining the probability for everyone at the relevant age with the odds ratio from Gaugler et al. [188]. The calculations used a formula presented in Appendix 6.D.1.B. The estimated annual probabilities of death for each average age are presented in Appendix 6.D.1.C.

In the decision tree, a 6-month probability of death was applied. This was estimated based on the annual probability of death at age 77 in the national life tables [194], using the formulas inAppendix 6.D.1.A.

For people in residential care, the annual probability of death varied by age group. It was based on estimates for 2021/22 ([195], table 8). See Table 31 below.

It was assumed that the probability of death after reaching an average age of 101 was 100%. This assumption was made because ONS life tables only provide the annual probability of death for people aged up to 100 [194].

Table 31. Transition probabilities relating to death, and related odds ratios.

Odds ratio or probability	**Care state**	**Mean**	**95% CI**		**Source**
			Lower limit	**Upper limit**	
Odds ratio for mortality outcome	Comparing unmet to met care need	1.37	1.08	1.74	Gaugler et al. [188]
Annual P (death)	Met need	Depends on age	NA – linked to the OR for the mortality outcome and to the prevalence of unmet need		Calculated using the OR from Gaugler et al. [188] as well as the ONS life tables [194] and the prevalence of unmet need.
	Unmet need	Depends on age			
	Care home, aged 75 to 79	0.216	0.210	0.222	ONS [195]
	Care home, aged 80 to 84	0.256	0.251	0.261	
	Care home, aged 85 to 89	0.294	0.289	0.298	
	Care home, aged 90 and over	0.360	0.356	0.365	
6-month P (death) at average age 77.5	NA. Overall (only used to calculate estimates below)	0.016	Not available		Calculated using the annual probability from the ONS life tables [194] and the formula in Appendix 6D.
	Met need	0.015	NA – linked to the OR for the mortality outcome and to the prevalence of unmet need		Calculated using the OR from Gaugler et al. [188] as well as the ONS life tables [194] and the prevalence of unmet need.
	Unmet need	0.020			

Table notes. Abbreviations: CI: confidence interval; NA: not applicable; OR: odds ratio; P: probability.

Combining the proportions in Table 29 and the transition probabilities in Table 30 and Table 31, different transition matrices for the Markov model were calculated for each subgroup and average age. Some examples are provided in Appendix 6C.

6.2.4.4 Social-care related quality of life (SCRQoL) in different care states

The Adult Social Care Outcome Toolkit (ASCOT)

The social-care related quality of life (SCRQoL) estimates used in this model have been obtained through the ASCOT. This instrument includes eight domains: "personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, safety, social participation and involvement, occupation, control over daily life and dignity" ([186], p. iii). Each domain has four levels. For example, for personal cleanliness and comfort, the four levels are: "I feel clean and am able to present myself the way I like"; "I feel adequately clean and presentable"; "I feel less than adequately clean or presentable"; "I don't feel at all clean or presentable" ([186], p. 23).

The ASCOT includes two different components: firstly, a main instrument which provides unweighted measures of SCRQoL and SCRQoL gain connected to services (unweighted means that equal weights are assumed for each domain); secondly, "a set of preference weights" ([186], p. 19), which refer to each SCRQoL level and domain. These weights can be used to calculate a social care QALY (SC-QALY) index, with 0 corresponding to "being dead" ([186], p. XII), 1 corresponding to the "ideal" ([186], p. XII) SCRQoL state, and negative values corresponding to states "worse than 'being dead'" ([186], p. XII).

The main ASCOT instrument (unweighted SCRQoL)

The main instrument captures people's views of their current SCRQoL and "services users' views of their 'expected' SCRQoL in the absence of services" (Netten et al. 2012, p. III). By subtracting the expected SCRQoL from the present SCRQoL, one obtains an indicator of service impact [186].

There is no question measuring dignity in the absence of services, so when focusing on service impact, one can ignore the dignity domain and only focus on seven domains [196].

Individual ASCOT domains are coded from 0 (the worst state) to 3 (ideal state). Therefore, if seven domains are considered, the current and expected SCRQoL score can go from 0 to 21.

In Trukeschitz et al. [196], the current and expected ASCOT scores are measured by summing the scores for each domain and then dividing the sum by the maximum possible score, i.e., 21. Therefore, the current and expected ASCOT score can range from 0 to 1 and the change in SCRQoL can range from -1 to 1, with positive values indicating a gain in quality of life from a service.

Estimates in the present model

In the present model, SCRQoL estimates are not linked to preference weights. This is because the main estimates come from a study that focused on unweighted measurements of SCRQoL [196]. Therefore, the present model does not include SC-QALYs. Instead, it focuses on life years adjusted by unweighted SCRQoL.

Trukeschitz et al. [196] studied people aged 55 and over in 22 LAs in England and reported an average increase of 0.37 in unweighted SCRQoL associated with receiving home care. The study found no evidence that the level of gain in SCRQoL from home care was affected by the presence of informal care. The study did not directly look at met vs. unmet care need but looked at two specific features of home care provision that were used as a proxy for met vs. unmet need in the present model: firstly, whether the person was kept informed about changes in the delivery of the home care service; this increased the gain in SCRQoL by 0.0482 (95% CI: 0.0208 to 0.0756); secondly, whether the care workers normally did what the service user wanted done; this increased the gain in SCRQoL by 0.0455 (95% CI: 0.0200 to 0.0710).

The present model assumed that the SCRQoL gain would be 0.3700 (95% CI: 0.3361 to 0.4039) across the population with home care. Based on the expected proportions with met needs in the model and the overall QoL difference between met and unmet need, the average SCRQoL gain from home care was estimated to be: 0.4025 for people with met needs and 0.3088 for people with unmet need.

The average unweighted SCRQoL was 0.4895 among people with no home care (95% CI: 0.4671 to 0.5119). This corresponded to the expected unweighted SCRQoL in the absence of services among a sample of social care service users with physical or sensory impairment (n=546) in England [197].[10]

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[10] The SCRQoL reported in the study was 10.28 (SD 5.60). In agreement with Trukeschitz et al. 196. Trukeschitz B, Hajji A, Kieninger J, Malley J, Linnosmaa I, Forder J. Investigating factors influencing quality-of-life effects of home care services in Austria, England and Finland: A comparative analysis. J Eur Soc Policy [Internet]. 2021 [cited 2022 March 30]; 31(2):192-208. Available from:

No evidence was found on the quality of life of people without home care and met/unmet needs. Dunatchik et al. [11] found no evidence of an association between unmet care need and wellbeing, based on ELSA data, but their analysis encountered the data limitations of the ELSA datasets outlined in chapters 4 and 5. In the present work, the difference in SCRQoL between those with met need and unmet need in the absence of home care was assumed to be the same as for people with home care.

Based on the values mentioned above, composite values were calculated for each care state in the model. See Table 32 below for these values.

No estimate was found for unweighted SCRQoL in care homes. Many people prefer to stay in their own home [3], so on average, one would expect quality of life to be the highest at home with met needs. At the same time, data from the PSS ASCS survey suggest that quality of life is higher in a care home than at home. Indeed, the PSS ASCS survey for 2021/22 found that the percentage that rated their overall quality of life "good" or "very good" or "so good, it could not be better" ([190], annex table T2a) was lower among people living in private households (49.2%) than among people in care homes (69.6%). These percentages were based on people aged 65 and over, excluding learning disability support ([190], annex table T2a).

Considering all of the above, the model assumed that quality of life in a care home was mid-way between SCRQoL at home with unmet need and SCRQoL at home with met need, so it was assumed to be 0.8452 on average. Given that with home care, a person was more likely to have met than unmet needs, a care home admission reduced quality of life overall. Due to the high uncertainty around this, this was explored further in scenario analysis (see section 6.2.5.2).

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https://dx.doi.org/10.1177/0958928720974189., this score was transformed for the present work dividing it by the maximum possible score across seven domains, i.e., 21. The result of this transformation was 0.490 (SD 0.267)

Table 32. Unweighted SCRQoL for each care state and related estimates.

Care state	Mean	95% CI		Source
		Lower limit	Upper limit	
Gain from home care, overall	0.3700	0.3361	0.4039	Trukeschitz et al. [196]
Marginal effect of “user kept informed about changes” on outcome “gain in SCRQoL from home care”.	0.0482	0.0208	0.0756	
Marginal effect of “Care workers did the things the user wanted done” on outcome “gain in SCRQoL from home care”.	0.0455	0.0200	0.0710	
Gain from home care if needs are met	0.4025	NA – linked to parameters above		Calculated using the parameters from Trukeschitz et al. [196] and the prevalence of unmet need.
Gain from home care if needs are unmet	0.3088			
No home care, overall (only used to calculate estimates below)	0.4895	0.4671	0.5119	Forder et al. [197]
Unmet needs, no home care	0.4283	NA – linked to parameters above		Calculated using the parameter from Forder et al. [197], the parameters from Trukeschitz et al. [196] and the prevalence of unmet need.
Met needs, no home care	0.5220			
Unmet needs, with home care	0.7983			
Met needs, with home care	0.8920			
Care home	0.8452			

Table notes. Abbreviations: CI: confidence interval; NA: not applicable; SCRQoL: social care-related quality of life.

6.2.4.5 Costs

6.2.4.5.1. Using 2021/22 prices

All costs were inflated to 2021/22 prices in the present model. NHS costs from 2014/15 onwards were inflated to 2021/22 prices using the NHS Cost Inflation Index (NHSCII) for pay and prices [198]. NHS costs prior to 2014/15 were firstly inflated to 2014/15 prices using the Hospital & Community Health Services (HCHS) pay and prices index [199]. Private healthcare costs were inflated in the same way as NHS costs.

PSS costs were inflated using the Adult Personal Social Services Pay and Prices (excluding capital) Index for all sectors (adult local authority services and independent sector services considered together) [198].

6.2.4.5.2. Discounting

Costs, life years and SCRQoL were discounted at an annual rate of 3.5%. This was chosen because NICE guidance recommends this rate for costs and effects [200].

6.2.4.5.3. Home care costs

It was assumed that on average people received 12.8 hours of home care per week, based on the Unit Costs of Health and Social Care 2021 [199]. No more recent updates to this information were available in the Unit Costs of Health and Social Care 2022 Manual [198].

The average hourly cost of home care in the base case analysis was £21.43. This corresponded to the 2021-22 Homecare Association's Minimum Price, which was based on the Statutory National Living Wage (wage rate of £8.91 per hour) and referred to the year starting in April 2021 [201].

Based on the estimates above, the average annual cost of home care was £14,313. A 95% CI was calculated around the average cost based on +-20%, so it ranged from £11,451 to £17,176.

A scenario analysis was conducted around the price of home care, see section 6.2.5.2.

Note that for people who cancelled home care, no cost of home care was included for simplicity, based on the assumption that cancellation would occur a short time after the start of home care.

6.2.4.5.4. Care home costs

It was considered that some people would have to self-fund their stay in a care home even if they had their home care fully funded by the LA. This is because when a person moves to a care home, their house may start to be considered as capital that can be used to pay for social care [56].

Jones et al. [198] reported how the mean weekly cost of PSS services provided in a care home varied depending on whether it was a private sector-run nursing home, (£810), a private sector-run residential care home (£725) or a council-run residential care home (£1,138 excluding capital costs relating to buildings and oncosts).[11] The mean weekly NHS cost of nursing services in a private sector-run nursing home was £187.60 [198]. All these costs were specific to people aged 65 and over and in 2021/22 prices.

Jones et al. [198] also reported the cost of external NHS services for people in care homes. The external GP services costs were included in the model under GP costs (see section 6.2.4.5.5). The external nursing services (£8 per week in each type of care home) were not included in the model, because nursing services were not considered for people at home. Therefore, only nursing services provided by a nursing home were included.

The model combined the above estimates into a weighted average of PSS and NHS care home costs. The weights were the percentage of people that were admitted to each type of care home: 52.5% to a nursing home ([202], table 11); 3% to a council-run residential care home [203]; 44.5% to a private sector-run residential care home (calculated based on previous percentages). The calculations resulted in an average annual cost for PSS services of £40,804 and an average annual NHS cost of £5,135.

The cost of PSS services would be a state-funded PSS cost for some people and a privately funded cost for other people, depending on wealth. In the base case analysis, on average, 39.1% of care home residents were full self-funders (95% CI: 36.7% to 41.4%) [202], table 7), 46.65% were fully state-funded,14.25% were partly state-funded and partly self-funded. These percentages were calculated by combining data for England from the ONS [202] with data from the PSS ASCS 2021/22 [190]; see Table 33 for more details.

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[11] £810 and £725 are the mean cost for LA-funded clients. In the present model these costs are also applied to self-funders, although in practice, self-funders pay more on average than what the LA pays for LA-funded clients.198. Jones KC, Weatherly H, Birch S, Castelli A, Chalkley M, Dargan A, et al. Unit Costs of Health and Social Care 2022: Manual: Personal Social Services Research Unit (University of Kent) & Centre for Health Economics (University of York); 2023 [cited 2023 August 2]. 118]. Available from: https://doi.org/10.22024/UniKent%2F01.02.100519.

No data was found on the percentage of care that was privately funded by people who were only partly state-funded. The model assumed that people who were partly state-funded paid for 50% of their PSS services costs privately, while the other 50% was covered by the LA.

Based on the calculations above, the average annual cost of PSS services in a care home (£40,804) was split in the model into £21,753 PSS cost and £19,051 privately funded cost.

There was uncertainty around whether the percentage of full self-funders in the model population could be estimated based on an English average, so this was investigated in scenario analysis (see section 6.2.5.2).

Table 33. Costs of care homes and related parameters.

Parameter	**Mean**	**95% CI**		**Source**
		Lower limit	**Upper limit**	
Probability of being in a private sector nursing home if care home resident	0.525	0.523	0.526	ONS data ([202], table 11)
Probability of being in a private sector residential care home if care home resident	0.445	NA – linked to parameter above and below		Calculated based on parameters above and below.
Probability of being in an LA own-provision residential care home if care home resident	0.030	0.029	0.031	Point estimate: [203]. 95% CI calculated using N from ONS ([202], table 11)
Weekly cost of PSS services (includes both state-funded and privately funded costs) in a private sector nursing home	£810	£648	£972	Point estimate from Jones et al. [198]. 95% CI calculated assuming +-20%. Note that £810 and £725 correspond to the mean cost for LA-funded clients. In the present model these costs are also applied to self-funders, although in practice, self-funders pay more on average than what the LA pays for LA-funded clients.
Weekly cost of PSS services (includes both state-funded and privately funded costs) in a private sector residential care home	£725	£580	£870	
Weekly cost of PSS services (includes both state-funded and privately funded costs) in an LA own-provision residential care home (excludes capital)	£1,138	£910	£1,366	
Weighted average of weekly cost of PSS services (includes both state-funded and privately funded costs) across different kinds of care homes (private sector nursing, private sector residential and LA own-provision residential)	£782	NA – linked to parameters above.		Calculated based on parameters above

Parameter	Mean	95% CI		Source
		Lower limit	Upper limit	
Weighted average of annual cost of PSS services (includes both state-funded and privately funded costs) across different kinds of care homes (private sector nursing, private sector residential and LA own-provision residential)	£40,804	NA – linked to parameter above.		Multiplied the weekly cost above by 52.18 weeks.
Proportion of people in care homes who are full self-funders	0.391	0.367	0.414	[202], table 7. Refers to care homes for older people or providing dementia care
Proportion of people in care homes who are state-funded	0.609	0.586	0.633	[202], table 7. Refers to care homes for older people or providing dementia care.
Proportion of state-funded people in care homes that are fully state-funded	0.751	0.748	0.753	PSS ASCS 2021/22 [190]
Proportion of state-funded people in care homes that are partially state-funded and partially privately funded	0.249	0.247	0.252	PSS ASCS 2021/22 [190]
Annual cost of PSS services in a care home considered as a PSS state-funded cost (based on the % of people who were partly or fully state-funded)	£21,753	NA – linked to parameters above.		Calculated based on parameters above
Annual cost of PSS services in a care home considered as a privately funded cost (based on the % of people who were partly or fully self-funded)	£19,051	NA – linked to parameters above.		Calculated based on parameters above

Parameter	**Mean**	**95% CI**		**Source**
		Lower limit	**Upper limit**	
Weekly NHS cost per person in a nursing home	£188	£150	£225	Point estimate from Jones et al. [198]. 95% CI calculated assuming +-20%.
Weighted average of weekly NHS cost across different kinds of care homes (private sector nursing, private sector residential and LA own-provision residential)	£98	NA – linked to parameters above.		Calculated based on the probabilities of being in different types of care home (see parameters above), the weekly NHS cost per person in a nursing home (see parameter above), and an assumption of no NHS costs in other care homes.
Weighted average of annual NHS cost across different kinds of care homes (private sector nursing, private sector residential and LA own-provision residential)	£5,135	NA – linked to parameter above.		Multiplied the weekly cost above by 52.18 weeks

Table notes. Abbreviations: CI: confidence interval; NA: not applicable.

6.2.4.5.5. Cost of GP visits in different care need states

Forder, Gousia and Saloniki [204] studied the effect of home care on GP visits for people aged 75 and over. They reported that among people using home care, the mean number of GP visits per year was 7.17 (standard deviation: 7.04). Based on their analysis, using home care corresponded to an average decrease in GP visits of 5.5 in a year. This was based on British Household Panel Survey data which referred to 8,895 people aged 75 and over in England from 1991 to 2009. Considering this, the model assumed that on average, there were 12.67 GP visits per year in care states without home care.

Jones et al. [198] reported that the cost of a surgery consultation lasting 9.22 minutes was £38 with “qualification costs” and “excluding direct care staff costs” (p. 66). Therefore, for people with home care, the average cost of GP visits per person per year was £272, while for people without home care, it was £481.

Jones et al. [198] reported that the cost of external GP services in care homes for people aged 65 and over was the same in private sector nursing homes, private sector residential care, and local authority own-provision residential care (£12 per week). Therefore, the average annual cost of GP services for a person in a care home was £626.

See Table 34 for the 95% CIs of these estimates.

Table 34. Cost of GP visits and related parameters.

GP visits	Care state	Mean	95% CI		Source
			Lower limit	Upper limit	
Marginal effect of home care on the N of GP visits	People at home	5.5	Not available		Forder, Gousia and Saloniki [204]
N of GP visits per person per year	Home care	7.17	6.78	7.56	Forder, Gousia and Saloniki [204]
	No home care	12.67	NA – linked to parameters above.		Calculated based on parameters above
Cost of a 9.22-minute GP surgery consultation	All	£38	£30	£46	Point estimate based on Jones et al. [198]. Includes “qualification costs” and excludes “direct care staff costs” (p. 66). 95% CI calculated assuming +-20%
Cost of GP visits per person per year	No home care	£481	NA – linked to parameters above.		Calculated based on parameters above
	Home care	£272			
	In a care home	£626	£501	£751	Point estimate based on Jones et al. [198]. 95% CI calculated assuming +-20%.

Table notes. Abbreviations: CI: confidence interval; N: number; NA: not applicable.

6.2.4.5.6. Cost of hospitalisations in different care states

Xu et al. [187] found that people with unmet care need were 1.14 times more likely to have one or more hospitalisations in a year compared to people with met care need (hazard ratio: 1.14; 95% CI: 1.01 to 1.28). Unmet care need in this study was defined as insufficient PADL help, see Table 27 for more details. This study was conducted in the United States based on data from 1994, 1999 and 2004. The findings may not be applicable to England, but this study was used in the model as no other study was found on this.

Bardsley et al. [205] investigated the number of inpatient admissions among home care users and residents in care homes aged 75 and over, based on data relating to four primary care trusts in England. The study found that the average number of inpatient admissions per person per year was 0.61 in care homes (95% CI: 0.58 to 0.64) and 0.91 among people with home care (95% CI: 0.84 to 0.98).

The estimate relating to home care in Bardsley et al. [205] was combined with the estimate from Xu et al. [187] to calculate the number of hospitalisations among people at home with met and unmet needs. The estimate in Xu et al. [187] referred to having at least a hospitalisation, but for simplicity, the model assumed that it was also applicable to the number of hospitalisations.

The calculation that combined the estimates above used a formula presented in Appendix 6.D.1.B. The calculation showed that on average, people with met need had 0.87 hospitalisations per year and people with unmet need had 0.99 hospitalisations per year.

The cost of a hospitalisation was £4,409 for a non-elective long stay, £5,845 for an elective long stay, £801 for a non-elective short stay [206]. These costs were combined with the proportion of people that had emergency or elective admissions (see Table 36). Based on these calculations, the average cost of one hospitalisation was estimated to be £3,074 for people at home and £3,025 for people in a care home.

Table 35 provides the annual average cost of all hospitalisations per person by care state.

Table 35. Average cost of all hospitalisations per person.

Parameter	**Care state**	**Cost**
Annual cost	Any at home with met needs	£2,673
	Any at home with unmet needs	£3,047
	Care home	£1,845
6-month cost	Any at home with met needs	£1,336
	Any at home with unmet needs	£1,524
3-month cost	Any at home with met needs	£668
	Any at home with unmet needs	£762

Table notes. 3-month and 6-month costs with met and unmet needs for the decision tree were calculated by using the formula in Appendix 6.D.1.B, while 3-month costs in a care home were calculated by simply dividing annual care home costs by 4, so are not reported in the table.

Table 36. Model inputs relating to hospitalisation costs.

Hospitalisations	**Care state**	**Mean**	**95% CI**		**Source**
			Lower limit	**Upper limit**	
Hazard ratio for outcome: at least one hospitalisation	Comparing unmet to met need	1.14	1.01	1.28	Xu et al. [187].
N of hospitalisations per person per year	Across everyone at home (only used to calculate the estimates below)	0.91	0.84	0.98	Bardsley et al. [205]
	Any at home with met need	0.87	NA – linked to other parameters.		Calculated using the hazard ratio from Xu et al. [187], the overall N of hospitalisations from Bardsley et al. [205] and the prevalence of met and unmet need.
	Any at home with unmet need	0.99			
	In a care home	0.61	0.58	0.64	Bardsley et al. [205]
N of hospitalisations per person over 6 months	Any at home with met need	0.43	NA – linked to other parameters.		Same calculation as for annual costs, after dividing the annual N of hospitalisations from Bardsley et al. [205] by two.
	Any at home with unmet need	0.50			
N of hospitalisations per person over 3 months	Any at home with met need	0.22	NA – linked to other parameters.		Same calculation as for annual costs, after dividing the annual N of hospitalisations from Bardsley et al. [205] by four.
	Any at home with unmet need	0.25			
N of elective admissions per person per year	Any at home	0.11	0.09	0.13	Bardsley et al. [205]
N of emergency admissions per person per year	Any at home	0.65	0.61	0.69	
Proportion elective	Any at home	0.14	NA – linked to parameters above.		Calculated based on parameters above from Bardsley et al. [205]

Hospitalisations	Care state	Mean	95% CI		Source
			Lower limit	Upper limit	
Proportion emergency	Any at home	0.86	NA – linked to parameter above to make sure that the proportions add up to 1.		
N of elective admissions per person per year	In a care home	0.07	0.06	0.08	Bardsley et al. [205]
N of emergency admissions per person per year	In a care home	0.47	0.44	0.50	
Proportion elective	In a care home	0.13	NA – linked to parameters above.		Calculated based on parameters above from Bardsley et al. [205]
Proportion emergency	In a care home	0.87	NA – linked to parameter above to make sure that the proportions add up to 1.		
Cost of an elective inpatient	All	£5,845	£4,676	£7,014	Point estimate from the National Schedule of NHS costs 2021-22 [206]. 95% CI calculated assuming +-20%.
Cost of a non-elective long stay	All	£4,409	£3,527	£5,291	
Cost of a non-elective short stay	All	£801	£641	£961	
Cost of one hospitalisation	Any at home	£3,074	NA – linked to other parameters.		Calculated using parameters above on the proportion of hospitalisations that were elective or emergency and their related costs. It was assumed that 50% of emergency admissions were long stay and 50% short stay, as per Bauer et al. [58].
	In a care home	£3,025			

Table notes. Abbreviations: CI: confidence interval; NA: not applicable.

6.2.4.5.7. Cost of high depressive symptoms in different care states

Multivariable analysis linked to chapter 5 showed that unmet care need was associated with an absolute increase of 0.080 in the probability of at least four depressive symptoms on the eight-item CES-D scale. For more details, see Appendix 6B.2.

The probability of having at least four depressive symptoms on the same scale among people with met care needs was 0.380 (95% CI: 0.281 to 0.488). This was estimated with a descriptive analysis of the ELSA dataset, based on 92 people aged 65 and over with at least 2 PADL limitations and help for all PADL difficulties in 2016/17.

The estimates above were combined to output an average probability of high depressive symptoms of 0.460 among people with unmet care need.

The average probability of high depressive symptoms in a care home was 0.45. This was from a study on 248 people aged over 65 admitted within the previous two weeks into a care home in the north-west of England [207]. This study was conducted in 1996-97 and used the 15-item Geriatric Depression Scale (GDS-15) to define depression cases.

Considering that a person was more likely to have met than unmet needs at home, a care home admission increased the prevalence of high depressive symptoms overall.

Annual costs related to depression were extracted from a cost-effectiveness analysis of telehealth for people with depression living in England [208]. This study was about adults, rather than specifically about older people, and it excluded people with dementia, as mentioned in the study protocol [209]. Moreover, it did not mention care homes. Therefore, it may be of limited applicability for the present model, but it was used in the absence of better evidence.

Annual costs of depressive symptoms included the NHS costs of medications, PSS costs, for example for a social worker's intervention, and privately funded costs for "private counselling, psychotherapy, psychiatry and complementary/alternative remedies" ([208], p. 265). Combining these costs with the probabilities above resulted in an average cost per person in each care state, see Table 37.

Table 37. Average annual costs of depressive symptoms per person

Cost type	Care state	Average annual cost per person
NHS	Met care needs	£38.7
	Unmet care needs	£46.8
	Care home	£45.8
PSS	Met care needs	£18.3
	Unmet care needs	£22.1
	Care home	£21.6
Privately funded	Met care needs	£20.9
	Unmet care needs	£25.3
	Care home	£24.7

Table notes. Abbreviations: NHS: National Health Service; PSS: personal social services.

Table 38. **Model inputs relating to the cost of depressive symptoms.**

Depressive symptoms	Care state	Mean	95% CI		Source
			Lower CI	Upper CI	
Marginal effect of not having help for at least one PADL difficulty on the outcome: at least 4 depressive symptoms	Comparing unmet to met needs	0.080	-0.003	0.163	Multivariable analysis linked to chapter 5 (see Appendix 6B.2)
P (high depressive symptoms)	Met needs	0.380	0.281	0.488	ELSA data (92 people aged 65 and over who had at least two PADL difficulties and help for each PADL difficulty in wave 8)
	Unmet needs	0.460	NA – linked to parameters above		Calculated using the two parameters above.
	Care home	0.450	0.388	0.512	Mozley et al. [207]
Annual PSS cost of depression per person in 2012/13 prices	All	£38.0	£12.52	£63.48	Dixon et al. [208]
Annual PSS cost of depression per person in 2021/22 prices	All	£48.0	£15.8	£80.2	Inflation index applied to estimate above
Annual NHS drug cost of depression per person in 2012/13 prices	All	£88.0	£64.48	£111.52	Dixon et al. [208]
Annual NHS drug cost of depression per person in 2021/22 prices	All	£101.8	£74.6	£129.0	Inflation index applied to estimate above
Annual privately funded cost of depression per person in 2012/13 prices	All	£47.54	Not available	Not available	Dixon et al. [208]
Annual privately funded cost of depression per person in 2021/22 prices	All	£55.0	£43.99	£65.98	Inflation index applied to estimate above. 95% CI calculated assuming +-20%

Table notes. Abbreviations: CI: confidence interval; NA: not applicable; P: probability.

6.2.4.5.8. Informal carers’ earnings from current employment

The model included informal carers’ earnings connected to current employment. It did not include retirement income.

Informal carers aged up to 64 and caring for at least ten hours per week had increased odds of being in employment if the people they cared for received home care. More specifically, the odds ratio was 1.2. This estimate was taken from an economic model on interventions to support informal carers in England [173]. They adapted an estimate from Pickard et al. [210], which studied the association between home care and employment among informal carers of working age who cared for at least 10 hours per week in England.

Employment probabilities for different subgroups of informal carers were calculated combining different estimates: the odds ratio mentioned above; the age of carers of older people [211]; the number of hours of caring done by each age group [175]; the employment rate by age group for the general population [212]; the likelihood of employment for a carer compared to the general population based on the hours of caring ([175] based on data from [213]). See Appendix 6.D.1.D for more details on the calculations.

No data was identified on the likelihood of employment after the cared-for person was admitted to a care home or died. In the base case analysis, it was assumed that the probability of employment in these cases was the same as per the general population. Due to uncertainty around this assumption, this was modified in a scenario analysis, see section 6.2.5.2 for more details.

The median gross annual earnings were £27,756 in 2022 [214]. Of this, £12,570 would be taxed at 0% and the rest at 20%, based on tax rates for the year 2021-22 [215]. Therefore, the median net salary in the model was £24,719.

See Table 39 for the average probability of employment in each subgroup of informal carers and for the earnings in each care state.

Table 39. **Annual earnings of informal carers corresponding to different care states, and related parameters.**

Informal carers' earnings and related parameters	**Care state**	**Mean**	**95% CI**		**Source**
			Lower limit	**Upper limit**	
P (being aged 18-24 if a carer of an older person)	All	0.0014	0.0013	0.0016	Personal Social Services Survey of Adult Carers in England (PSS SACE) 2021/22 [211]
P (being aged 25-34 if a carer of an older person)	All	0.0061	0.0058	0.0064	
P (being aged 35-44 if a carer of an older person)	All	0.0237	0.0230	0.0243	
P (being aged 45-54 if a carer of an older person)	All	0.089	0.088	0.091	
P (being aged 55-64 if a carer of an older person)	All	0.220	0.218	0.221	
P (being aged 65+ if a carer of an older person)	All	0.660	0.658	0.662	
P (aged up to 64 if a carer of an older person)	All	0.340	NA – linked to parameter above.		Linked to parameter above
P (employment of main informal carer) if aged up to 64	Caring for 1 to 9 hours, with or without home care	0.674	NA – linked to other parameters.		Appendix 6D explains how these probabilities were calculated.
	Caring for at least 10 hours, without home care	0.474			
	Caring for at least 10 hours, with home care	0.520			
	Care home admission or death of cared-for person	0.721	Not available		Calculated using the employment rates for the general population by age group [212].

Informal carers’ earnings and related parameters	**Care state**	**Mean**	**95% CI**		
			Lower limit	**Upper limit**	**Source**
P (employment of main informal carer) if aged 65 and over	At home, with or without home care, weighted average across all hours of care	0.079	Not available		Appendix 6D explains how this was calculated.
	Care home admission or death of cared-for person	0.111	Not available		Corresponds to the employment rate for the general population aged 65 and over [212].
P (caring for one to nine hours) if aged up to 64	Any at home	0.378	Not available		NICE [175]
P (caring for at least ten hours) if aged up to 64	Any at home	0.622			
Estimated annual median net salary	All	£24,719	£19,775	£29,663	ONS [214] and UK government [215]. 95% CI calculated assuming +-20%.
Earnings per informal carer per year	Home care	£6,146	NA – linked to other parameters.		Calculated using the annual median net salary (see row above), the probabilities of belonging to different carers’ subgroups (defined by age, number of caring hours and receipt of home care) and the employment probabilities for these subgroups.
	No home care	£5,908			
	Care home or death	£7,866			

Table notes. Abbreviations: CI: confidence interval; NA: not applicable; P: probability; PSS SACE: Personal Social Services Survey of Adult Carers in England.

6.2.5. Model analyses

6.2.5.1 Base case analysis

The base case analysis was a probabilistic sensitivity analysis (PSA) rather than a deterministic analysis. PSA includes parameters as distributions rather than as point estimates [216]. PSA repeats the same analysis multiple times. In each iteration, the analysis uses values drawn by random sampling from the parameter distributions. Therefore, multiple sets of results are calculated with multiple PSA runs. This enables the modeller to provide results with credible intervals, rather than as point estimates. Therefore, PSA takes into account the uncertainty in model inputs [216]. Moreover, and most importantly, PSA is used because only using the mean values of parameters could produce incorrect results if input parameters are related in a non-linear way to outputs [217].

Beta distributions were used for probabilities; gamma distributions were used for costs; lognormal distributions were used for odds ratios and for a hazard ratio; normal distributions were used for the number of GP visits and hospitalisations in a year, for unweighted SCRQoL and for marginal effects. A multivariate normal distribution was used for two marginal effects calculated from the same analysis (the marginal effects on met need of LA-funded care and of informal care only from outside the household). Moreover, in the absence of evidence, a uniform distribution from 0 to 1 was used for the probability of going back to the waiting list after cancelling home care. See Appendix 6A for more details on the distributions used for each parameter.

PSA was based on 2,000 iterations. Each iteration produced incremental results for each subgroup and a weighted average of incremental results across the three subgroups based on that iteration's sampling of the proportions in each subgroup. Then, for each outcome, the mean, 2.5th and 97.5th percentile of the incremental results across the 2,000 iterations were calculated; this produced 95% credible intervals of the incremental results for each subgroup and across the subgroups.

6.2.5.2 Scenario analyses

Some scenario analyses were carried out to explore how changes in a specific parameter would affect the results. These analyses are summarised in Table 40 below. Additionally, other scenario analyses investigated structural uncertainty by assuming some long-term effects of the intervention. Each scenario analysis was based on 2,000 iterations.

Table 40. Scenario analyses changing one specific parameter

Parameter affected	Parameter in the base case analysis	Modification in the scenario analysis	Justification
Proportion with met needs among people with home care and all informal care from outside the household	Point estimate: 0.614 (probabilistic sampling based on other parameters)	The proportion was increased to be equal to the proportion with met need among people with home care and no informal care: 0.660 (95% CI: 0.601 to 0.719)	In the base case analysis, the proportion was lower among people with home care and all informal care from outside the household than among people with home care and no informal care. There was uncertainty around the validity of this.
Annual cost of home care	£14,313 (95% CI: £11,451 to £17,176)	The average annual cost of home care was increased to £15,381 (95% CI: £12,304 to £18,457).	The higher cost was a weighted average based on two 2021-22 Homecare Association Minimum Prices per hour: £22.73 based on the Voluntary UK Living Wage (£9.50 per hour) and £25.70 based on the Voluntary London Living Wage (£10.85 per hour) (both from [201]).
SCRQoL in a care home	Point estimate: 0.8452. Probabilistic sampling linked to other parameters.	SCRQoL was lowered to the level of people with home care and unmet needs: 0.7983. Probabilistic sampling linked to other parameters.	The base case analysis assumed that quality of life in a care home was mid-way between SCRQoL at home with unmet need and SCRQoL at home with met need. There was high uncertainty around this.
The proportion of full self-funders in care homes	0.391 (95% CI: 0.367 to 0.414).	The proportion was lowered as per the most deprived decile on the IMD index: 0.187 (95% CI: 0.167 to 0.206) ([202], table 6).	The model only focused on people with home care fully funded by the LA; they may be less likely to fully self-fund in a care home compared to the English average.

Parameter affected	**Parameter in the base case analysis**	**Modification in the scenario analysis**	**Justification**
The probability of employment after a care home admission or death	For people aged up to 64: 0.721. For people aged 65 and over: 0.111. (No probabilistic sampling)	For people aged up to 64, the probability was set equal to people with home care and caring responsibilities of at least 10 hours: 0.520 (probabilistic sampling linked to other parameters). For people aged 65 and over, it was set equal to people caring for someone at home: 0.079 (no probabilistic sampling).	There was uncertainty around the base case analysis assumption that the likelihood of employment after the cared-for person was admitted to a care home or died was the same as per the general population. This may not be valid because any past impacts of caring responsibilities on a person's employment, working hours or career opportunities may have long-lasting consequences.

Scenario analyses investigating structural uncertainty: long-term benefits of the intervention.

Although the model incorporated an increased risk of adverse consequences while in an unmet care need state, the base case analysis did not include any long-term effects of unmet care need (with the exception of permanent care home admissions and deaths), due to a lack of relevant data. However, the intervention may help avoid health deterioration and consequently, generate long-term benefits. Scenario analyses explored the following long-term benefits: one less hour of home care required; two fewer hours of home care required; a 10% reduction in the number of hospitalisations required.

The benefit of one less hour of home care required was applied as follows: in the scenario analysis, it was assumed that people with home care during the first 6 months would require one less hour of home care both at the start and in the long-term, compared to people who had unmet need on the initial 6-month waiting list. This meant that with the intervention, the cost of home care was lower than with standard care, although all the other parameters associated with home care were the same as with standard care. The lower cost was calculated taking into account the percentage of people who would have had unmet need on the waiting list in each subgroup. Therefore, the intervention benefit of a reduced requirement for home care was not applied to people who would have had met need on the waiting list thanks to informal care.

The other long-term benefits (two fewer hours of home care required and a reduction of 10% in the number of hospitalisations) were applied in the same way. The benefits no longer applied once people were admitted to a care home.

A weighted average of the cost of home care and of the number of hospitalisations across people with and without long-term benefits from the intervention produced the estimates in Table 41. The estimates varied by subgroup based on the proportion with unmet care need with standard care at the start of the model.

Table 41. Parameters calculated after assigning long-term benefits to people who avoided unmet care need in the first six months thanks to the intervention

Analysis	**Subgroup**	**Annual cost of home care per person: point estimate**
Base case analysis	Everyone	£14,313
Scenario analysis: one less hour of home care required as a long-term benefit of the intervention.	With standard care	£14,313
	With the intervention:	
	• At least some informal care from within the household	£13,983
	• All informal care from outside the household	£13,835
	• No informal care	£13,195
Scenario analysis: two fewer hours of home care required as a long-term benefit of the intervention.	With standard care	£14,313
	With the intervention:	
	• At least some informal care from within the household	£13,653
	• All informal care from outside the household	£13,358
	• No informal care	£12,077
Analysis	**Subgroup / care state**	**Annual number of hospitalisations per person: point estimate**
Base case analysis	Everyone:	
	○ With met care need	0.87
	○ With unmet care need	0.99
Scenario analysis: a ten per cent reduction in the number of hospitalisations required as a long-term benefit of the intervention.	With standard care:	
	○ With met care need	0.87
	○ With unmet care need	0.99
	With the intervention:	
	• At least some informal care from within the household:	
	○ With met care need	0.84
	○ With unmet care need	0.96
	• All informal care from outside the household:	
	○ With met care need	0.83
	○ With unmet care need	0.95
	No informal care:	
	○ With met care need	0.78
	○ With unmet care need	0.89

Table notes. For the cost of home care, a 95% CI based on +-20% of the point estimate was calculated, and probabilistic sampling was done accordingly. For the N of hospitalisations, probabilistic sampling was linked to other parameters.

6.3. Results

6.3.1. Base case analysis: main outcomes

Table 42 and Table 43 present the results of the base case analysis. Table 42 focuses on the main outcomes and Table 43 on the cost components. The results are provided separately for each subgroup, but a weighted average across the subgroups is also presented. The results are presented per person with care needs, except for informal carers' earnings, which are presented per carer.

Table 42 shows that, when all subgroups were considered together, the intervention resulted in 0.0195 additional life years (95% CI: 0.0085 to 0.0337), compared to standard care. The increase in life years was due to a lower probability of death and of permanent care home admission during the first 6 months. On average, an increase in life years was observed in each subgroup. However, in the subgroups with informal care, the 95% credible interval for incremental life years ranged from negative to positive. The reason was that for these subgroups, the probability of met need with home care was calculated using the marginal effect of LA-funded care on met need; this ranged from negative to positive, although it was positive on average (see section 6.2.4.2). In contrast, in the subgroup with no informal care, the probability of met need with home care was calculated based on a different source (see section 6.2.4.2) and was always higher than the probability of met need without home care. Therefore, the 95% credible interval for incremental life years was all above 0 in this subgroup.

Table 42 also shows that, when all subgroups were considered together, the intervention resulted in 0.3842 additional life years adjusted by unweighted SCRQoL (95% CI: 0.3447 to 0.4242). An increase in life years adjusted by unweighted SCRQoL was observed within each subgroup, with 95% credible intervals all above 0. This increase was driven by earlier home care provision and was observed in all PSA iterations, including those where there was a decrease in life years. The reason was that home care increased quality of life even if needs were unmet.

When all subgroups were considered together, the intervention resulted in an increase of £7,058 in total PSS costs (95% CI: £5,717 to £8,596), a reduction in total NHS costs of £104 (95% CI: -£149 to -£58), and a reduction in private payer costs of £124 (95% CI: -£209 to -£59). Overall, the intervention resulted in an increase in total NHS & PSS costs of £6,954 (95% CI: £5,609 to £8,483) per person with care needs. Section 6.3.2 focuses on how different cost components contributed to increases or savings in total NHS, PSS or private costs. The average incremental NHS and PSS cost per additional life year was £357,404, while the average incremental NHS and PSS cost per additional life year adjusted by SCRQoL was £18,101. Scatterplots in Figure 17 show the relationship between the incremental NHS and PSS cost and incremental life years in different PSA iterations. Scatterplots in Figure 18 show the relationship between the incremental NHS & PSS cost and incremental life years adjusted by unweighted SCRQoL in different PSA iterations.

The intervention also resulted in an increase in informal carer earnings of £90 (95% CI: £58 to £122). This was caused by the increase in the probability of employment linked to home care for carers aged up to 64 caring for at least 10 hours per week. At the same time, the intervention reduced the probability of a permanent care home admission or death during the first six months. This reduction, in turn, lowered the probability of employment for informal carers, because the base case analysis assumed that the likelihood of employment would bounce back to the levels of the general population after a care home admission or death of the cared-for person. However, overall, the increase in the probability of employment linked to home care applied to a bigger proportion of informal carers, and so the intervention led to an increase in earnings.

Average results for each subgroup were similar to the weighted average across all subgroups: in each subgroup, on average, there was an increase in life years, life years adjusted by unweighted SCRQoL, total PSS costs, total NHS & PSS costs, and informal carers' earnings, while there were NHS savings and private savings. Most 95% credible intervals for these subgroup outcomes were all above or all below 0. One exception was the 95% credible interval for incremental life years in subgroups with informal care, already discussed above. Other exceptions were incremental total private costs in the subgroups with informal care and incremental total NHS costs in the subgroup with no informal care. The reasons for these exceptions are explained in the following sections: section 6.3.2, which focuses on the cost components, and section 6.3.3, which focuses on the differences between the subgroups.

Table 42. Base case analysis. Mean results and 95% credible intervals. Main outcomes: life years, life years adjusted by unweighted SCRQoL, and total costs per person with care needs; informal carers' earnings; ICERs. Costs in £.

		Incremental, per person with care needs (excludes informal carers' earnings)						Incremental, per informal carer		
		Life years	**Life years adjusted by unweighted SCRQoL**	**Total PSS cost**	**Total NHS cost**	**Total NHS & PSS cost**	**Total private cost**	**Informal carers' earnings**	**ICER: incremental NHS & PSS cost per additional life year**	**ICER: incremental NHS & PSS cost per additional life year adjusted by unweighted SCRQoL**
Weighted average across subgroups	Mean	0.0195	0.3842	7,058	-103.7	6,954	-124	90	357,404	18,101
	2.5th p	0.0085	0.3447	5,717	-148.7	5,609	-209	58	NA	NA
	97.5th p	0.0337	0.4242	8,596	-58.2	8,483	-59	122	NA	NA
Informal care from within the household	Mean	0.0099	0.3662	6,927	-99.8	6,827	-56	91	692,714	18,641
	2.5th p	-0.0005	0.3261	5,628	-129.8	5,525	-133	60	NA	NA
	97.5th p	0.0226	0.4059	8,455	-70.6	8,341	5	122	NA	NA
Informal care all from outside the household	Mean	0.0108	0.3670	6,929	-99.7	6,830	-62	89	630,064	18,608
	2.5th p	-0.0001	0.3265	5,626	-130.8	5,523	-142	56	NA	NA
	97.5th p	0.0244	0.4070	8,455	-68.2	8,342	2	121	NA	NA
No informal care	Mean	0.0693	0.4808	7,773	-125.4	7,648	-478	NA	110,287	15,908
	2.5th p	0.0440	0.4365	6,189	-265.6	6,040	-677	NA	NA	NA
	97.5th p	0.0970	0.5254	9,606	20.2	9,501	-304	NA	NA	NA

Table notes. Abbreviations: ICER: incremental cost-effectiveness ratio; NHS: National Health Service; p: percentile; PSS: Personal Social Services; SCRQoL: social care-related quality of life. Private costs exclude informal carers' earnings. Colour legend: green = intervention more effective or cheaper; pink=intervention less effective or more expensive.

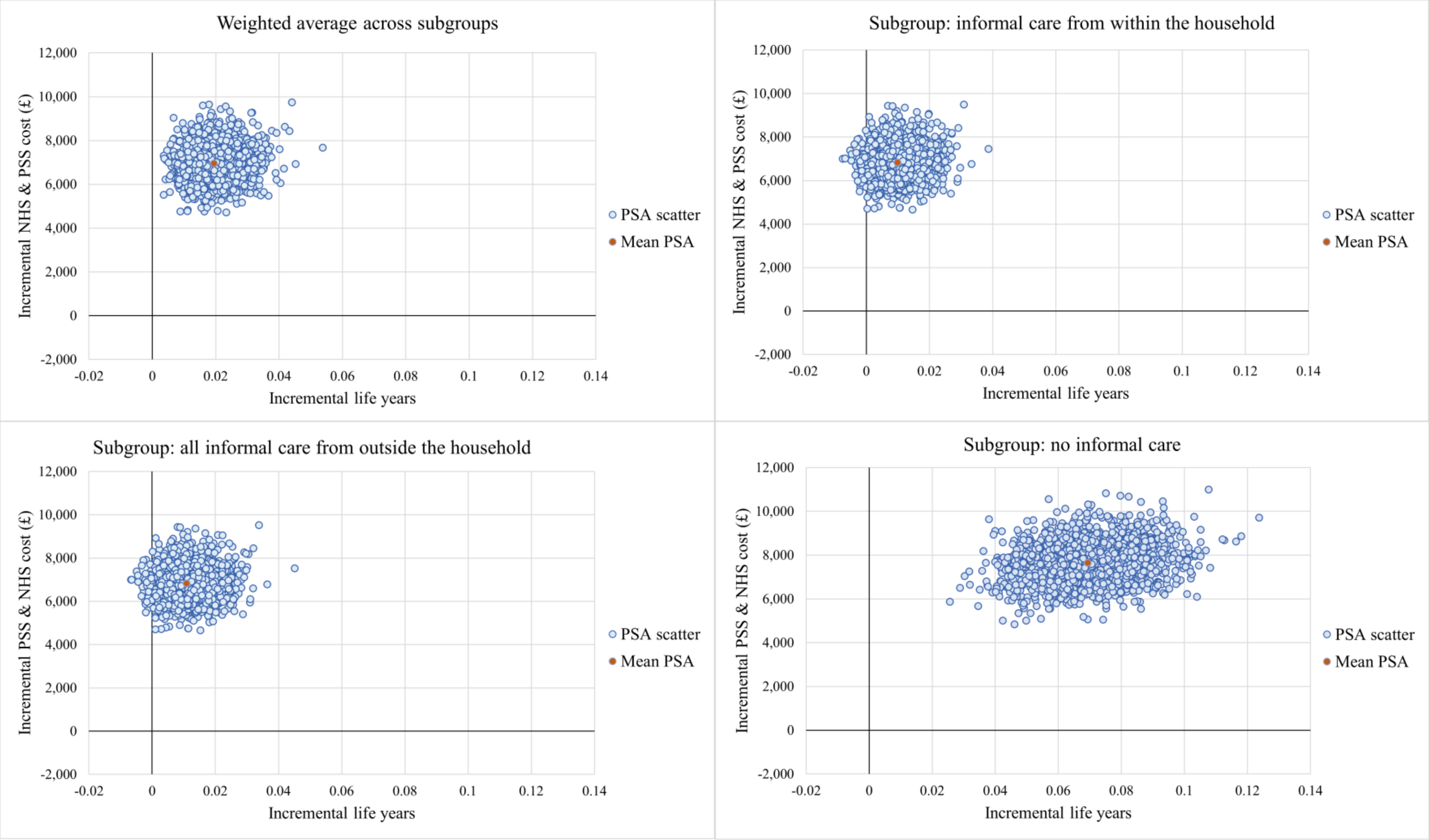

Figure 17. Scatterplots showing the relationship between the incremental NHS & PSS cost and incremental life years in different PSA iterations – weighted average across subgroups and by subgroup.

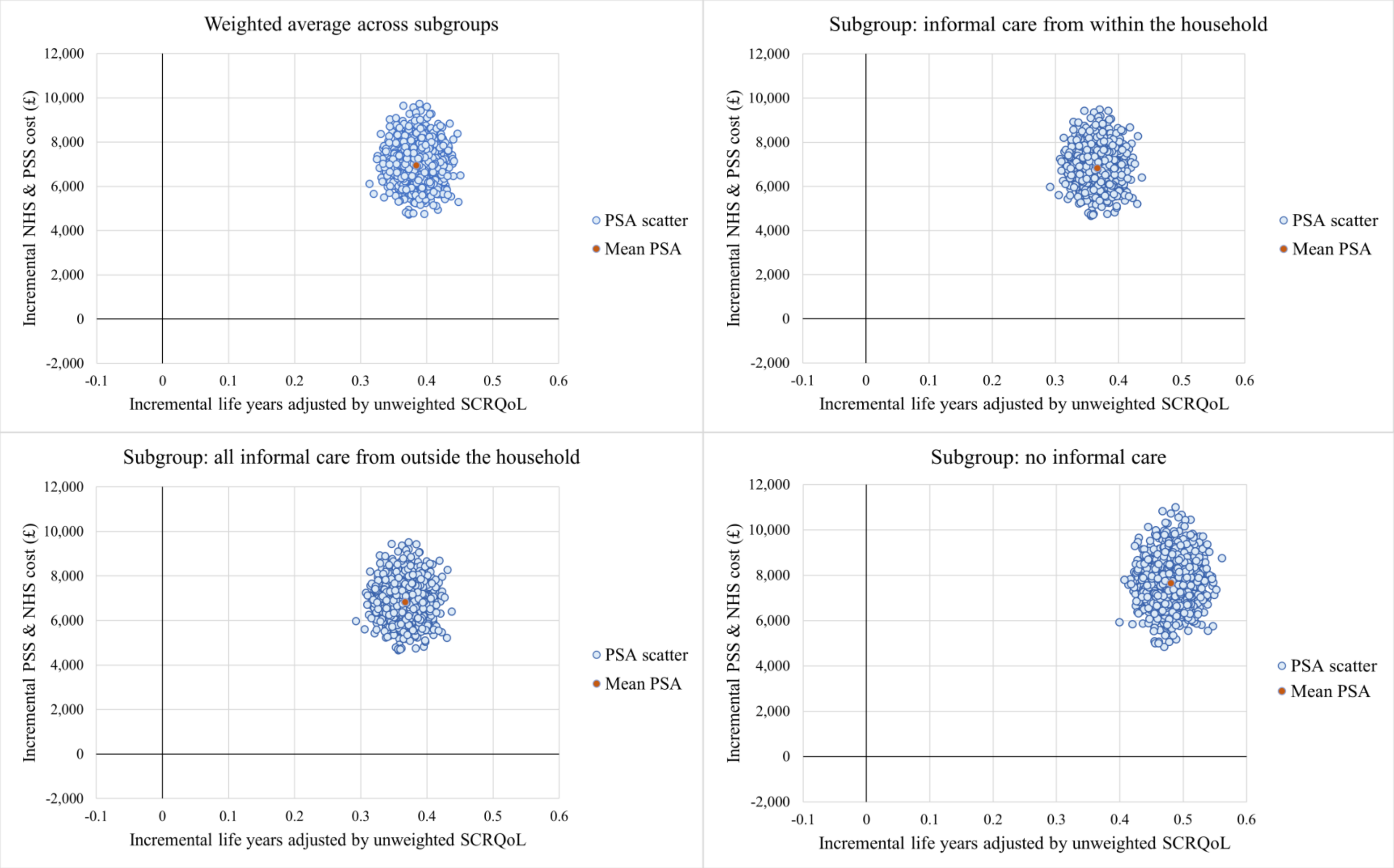

Figure 18. Scatterplots showing the relationship between the incremental NHS & PSS cost and incremental life years adjusted by unweighted SCRQoL in different PSA iterations – weighted average across subgroups and by subgroup.

6.3.2. Base case analysis: cost components

Table 43 shows the incremental differences in cost components. For some, there were contrasting factors behind the increase or decrease associated with the intervention, as it is explained in the following paragraphs.

On average, across all subgroups, the costs of GP visits were lower with the intervention, while the hospitalisation costs were higher. This was due to the following reasons. The intervention decreased the number of GP visits and hospitalisations during the first six months. The intervention also reduced the probability of a permanent care home admission during the initial six months; this reduction decreased GP visit costs but increased hospitalisation costs. This was because the annual cost of GP visits was higher for people in a care home than for people at home, while being in a care home was associated with lower hospitalisation costs compared to being at home. Finally, the intervention decreased the probability of death linked to the initial six months. This pushed towards a cost increase because death meant no costs.

On average, across all subgroups, the intervention led to an increase in the PSS, NHS and privately funded cost of depressive symptoms. This was due to increased survival. Increased survival counteracted two contrasting factors that pushed towards a cost decrease: firstly, the intervention meant a lower probability of high depressive symptoms during the first six months. Secondly, the intervention reduced the probability of a permanent care home admission during the first six months; this reduction pushed towards a decrease in the costs of depressive symptoms.

It may seem counterintuitive that the intervention increased depressive symptoms costs, but it should be considered that the marginal effect of unmet care need on the probability of high depressive symptoms was limited (increasing the probability from 0.38 to 0.46 on average) and the probability of depressive symptoms in a care home (0.45 on average) was only slightly higher than the probability at home (the weighted average across everyone at home at the start of the intervention was 0.41). Instead, death reduced the probability of depressive symptoms to 0. Error-checking was done around the unexpected result of increased depressive symptoms costs, see Appendix 6E for details.

Table 43 shows that the increase in PSS costs was driven by the increase in home care costs, which was bigger than the savings relating to care home admissions. The increase in the PSS cost of depressive symptoms was very small so had little influence.

The NHS savings were driven by the savings related to GP visits and care homes. These counteracted the increase in hospitalisation costs. The increase in the NHS cost of depressive symptoms was very small so had little influence.

The private payer savings were linked to the private care home savings. The increase in the private cost of depressive symptoms was very small.

In PSA iterations where LA-funded home care decreased the probability of met need in the subgroups with informal care, the intervention resulted in increased costs of care homes in these subgroups, and consequently in increased total private payer costs. This explains why the credible interval for incremental total private costs in Table 42 ranged from negative to positive in these subgroups.

Table 43. Base case analysis. Mean results. Cost components in £.

	Incremental, per person with care needs								
	PSS cost of home care	**PSS cost of care homes**	**PSS cost of depressive symptoms**	**NHS cost of GP visits**	**NHS cost of hospitalisations**	**NHS cost of care homes**	**NHS cost of depressive symptoms**	**Private cost of care homes**	**Private cost of depressive symptoms**
Weighted average across subgroups	7,199	-141	0.020	-96.5	26	-33	0.042	-124	0.023
Informal care from within the household	6,991	-64	0.010	-97.6	13	-15	0.021	-56	0.011
Informal care all from outside the household	7,000	-70	0.011	-97.3	14	-17	0.024	-62	0.013
No informal care	8,321	-547	0.070	-91.5	95	-129	0.148	-478	0.081

Table notes. Abbreviations: NHS: National Health Service; PSS: Personal Social Services. Colour legend: green = intervention more effective or cheaper; pink=intervention less effective or more expensive.

6.3.3. Base case analysis: Differences between subgroups

The subgroup with no informal care had the lowest ICERs. Table 42 and Table 43 show that for most other outcomes, the magnitude of the outcomes (whether positive or negative) was the biggest in the subgroup without informal care. In this subgroup, the intervention led to the biggest increase in the probability of met need during the first 6 months, compared to standard care (on average, an increase of 66 percentage points, see section 6.2.4.2). This led to the biggest reduction in the probability of death and care home admissions.

One exception to the above was the savings linked to GP visits, which were the smallest in the subgroup with no informal care. The reason was that this subgroup had the biggest increase in survival, which increased costs, despite also having the biggest reduction in care home admissions. Moreover, the reduction in GP visits was only linked to home care receipt, not to the decrease in unmet need, so the biggest reduction in unmet need did not directly influence GP visit costs. Home care receipt was similar across all subgroups, although it was slightly more likely in the subgroup with no informal care, due to a lack of home care cancellations in this subgroup.

Moreover, the subgroup with no informal care was the only one with a 95% credible interval for incremental total NHS costs that ranged from negative to positive. The reason was that in some PSA iterations, the increase in the cost of hospitalisations was bigger than the savings relating to GP visits and care homes.

The subgroup with informal care from within the household had the highest ICERs. For most outcomes, the magnitude of the outcome (whether positive or negative) was smaller in the subgroup with at least some informal care from within the household than in the subgroup with all informal care from outside the household. In both subgroups, the receipt of home care led to an average increase of 5.2 percentage points in the probability of met need (see section 6.2.4.2). However, the subgroup with informal care from within the household had higher probabilities of met need with both the intervention and standard care; this affected the incremental results. Error-checking was done around the different results between the two subgroups: it was double-checked that if the probability of met need was the same across the two subgroups, both with and without home care, the incremental results were the same for the two subgroups.

Exceptions to the above were the savings linked to GP visits, the total NHS savings, the increase in informal carers' earnings; all of these were bigger in the subgroup with informal care from within the household than in the subgroup with all informal care from outside the household. There were various reasons for this. The reduction in mortality was bigger in the subgroup with all informal care from outside the household; this bigger reduction reduced the savings related to GP visits. This subgroup also had a bigger reduction in care home admissions; this increased the savings related to GP visits. However, overall, savings were lower in this subgroup. Moreover, the bigger reduction in mortality and care home admissions in this subgroup reduced the increase in informal carers' earnings. Finally, total NHS savings were bigger in the subgroup with informal care from within the household because this subgroup had a lower increase in hospitalisation costs and bigger savings relating to GP visits, despite having lower care home savings. Finally, there was also this exception: the decrease in life years corresponding to the 2.5th percentile of the credible interval for incremental life years was bigger in the subgroup with at least some informal care from within the household.

6.3.4. Scenario analyses

Table 44 and Table 45 show how mean results changed in scenario analyses, compared to the base case analysis. Table 44 focuses on the main outcomes, Table 45 on the cost components.

In the first scenario analysis, the probability of met care need with home care and all informal care from outside the household was increased to be equal to the probability of met care need with home care in the absence of informal care. With this change, the ICERs became smaller for the subgroup with all informal care from outside the household; all increases and savings became bigger in this subgroup, with some exceptions: firstly, the increase in informal carers' earnings became smaller. This was because of the increased reduction in the probability of care home admission and death for the cared-for person. Secondly, the savings related to GP visits became smaller because of the increased reduction in the probability of death. Thirdly, the increases in the PSS, NHS and private costs of depressive symptoms became smaller. This was in contrast to the increased reduction in the probability of death, so it was driven by the increased reduction in the probability of depressive symptoms during the first six months and by the increased reduction in care home admissions. The ICERs were still the smallest in the subgroup with no informal care, and the magnitude of the other outcomes was still the biggest in the subgroup with no informal care (with the exception mentioned in section 6.3.3, i.e., savings related to GP visits).

When the cost of home care was increased as per the voluntary UK and London Living Wage rates, the ICERs increased across all subgroups because the intervention was linked to a bigger increase in home care costs and total PSS costs.

When the percentage of full self-funders in care homes was reduced as per the most deprived IMD decile, the intervention was linked to bigger PSS savings relating to care homes and smaller private savings relating to care homes. Consequently, the increase in total PSS costs was smaller and the total private savings were smaller. The ICERs decreased across all subgroups.

When the probability of employment for the informal carer after a care home admission or death was reduced, the intervention was linked to a bigger increase in informal carer's earnings.

When SCRQoL in a care home was lowered to the level of people at home with unmet need, the increase in life years adjusted by unweighted SCRQoL became slightly bigger across all subgroups. The corresponding ICERs became smaller.

Another scenario analysis explored structural uncertainty by applying a long-term benefit from the intervention of one less hour of home care required (see section 6.2.5.2 for details). In this scenario analysis, the increase in home care costs and total PSS costs became smaller, and so, the ICERs decreased across all subgroups. When an intervention benefit of two fewer hours of home care required was assumed, these reductions were even bigger, and in the subgroup with no informal care, the incremental cost of home care and the incremental total PSS cost became negative. The incremental total NHS & PSS cost and the ICERs became negative both when looking at the weighted average across subgroups and in the subgroup with no informal care. The negative ICERs indicated that the intervention would lead to an increase in life years and life years adjusted by unweighted SCRQoL and would also reduce public sector (NHS & PSS) costs.

In another scenario analysis, it was assumed that people with home care during the first 6 months would require 10% fewer hospitalisations in the short- and long-term than people who had unmet need on the initial 6-month waiting list. In this scenario, the intervention led to savings in NHS hospitalisations and to bigger total NHS savings. The ICERs decreased compared to the base case analysis but remained positive.

In a final scenario analysis, it was assumed that people with home care during the first 6 months would require both two fewer hours of home care and 10% fewer hospitalisations (in the short- and long-term) than people who had unmet need on the initial 6-month waiting list. This scenario corresponded to negative ICERs when all subgroups were considered together. Focusing on the subgroup results, reductions in total NHS & PSS costs and the related negative ICERs were observed only in two subgroups: the one with all informal care from outside the household and the one with no informal care.

Table 44. Results from scenario analyses compared to the base case analysis. Mean results. Main outcomes: life years, life years adjusted by unweighted SCRQoL, and total costs per person with care needs; informal carers' earnings per carer; ICERs. Costs in £.

Analysis	Weighted average/subgroup	Incremental, per person with care needs (excludes informal carers' earnings)						Incremental, per carer	ICER: incremental NHS & PSS cost per additional life year	ICER: incremental NHS & PSS cost per additional life year adjusted by unweighted SCRQoL
		Life years	Life years adjusted by unweighted SCRQoL	Total PSS cost	Total NHS cost	Total NHS & PSS cost	Total private cost	Informal carers' earnings		
Base case PSA	WA	0.0195	0.3842	7,058	-103.7	6,954	-124	90	357,404	18,101
	IC from within hh	0.0099	0.3662	6,927	-99.8	6,827	-56	91	692,714	18,641
	IC all from outside hh	0.0108	0.3670	6,929	-99.7	6,830	-62	89	630,064	18,608
	No informal care	0.0693	0.4808	7,773	-125.4	7,648	-478	NA	110,287	15,908
P (met need) with IC all from outside hh + home care was increased to the level of home care + no IC	WA	0.0216	0.3881	7,084	-104.1	6,980	-136	84	323,461	17,986
	IC from within hh	0.0099	0.3662	6,927	-99.8	6,827	-56	91	692,714	18,641
	IC all from outside hh	0.0153	0.3751	6,983	-100.5	6,882	-87	79	451,101	18,349
	No informal care	0.0693	0.4808	7,773	-125.4	7,648	-478	NA	110,287	15,908
Higher cost of home care based on the voluntary UK and London Living Wage rates	WA	0.0195	0.3842	7,568	-103.7	7,465	-124	90	383,630	19,429
	IC from within hh	0.0099	0.3662	7,422	-99.8	7,323	-56	91	742,985	19,994
	IC all from outside hh	0.0108	0.3670	7,425	-99.7	7,326	-62	89	675,826	19,959
	No informal care	0.0693	0.4808	8,364	-125.4	8,238	-478	NA	118,800	17,136
Lower percentage of care home full self-funders, as per the most deprived decile	WA	0.0195	0.3842	7,011	-103.7	6,907	-76	90	354,963	17,977
	IC from within hh	0.0099	0.3662	6,905	-99.8	6,806	-35	91	690,520	18,582
	IC all from outside hh	0.0108	0.3670	6,906	-99.7	6,806	-38	89	627,878	18,543
	No informal care	0.0693	0.4808	7,590	-125.4	7,464	-296	NA	107,638	15,526

		Incremental, per person with care needs (excludes informal carers' earnings)						Incremental, per carer		
Analysis	**Weighted average/subgroup**	**Life years**	**Life years adjusted by unweighted SCRQoL**	**Total PSS cost**	**Total NHS cost**	**Total NHS & PSS cost**	**Total private cost**	**Informal carers' earnings**	**ICER: incremental NHS & PSS cost per additional life year**	**ICER: incremental NHS & PSS cost per additional life year adjusted by unweighted SCRQoL**
Base case PSA	WA	0.0195	0.3842	7,058	-103.7	6,954	-124	90	357,404	18,101
	IC from within hh	0.0099	0.3662	6,927	-99.8	6,827	-56	91	692,714	18,641
	IC all from outside hh	0.0108	0.3670	6,929	-99.7	6,830	-62	89	630,064	18,608
	No informal care	0.0693	0.4808	7,773	-125.4	7,648	-478	NA	110,287	15,908
Lower P (employment) of informal carer after a permanent care home admission or death of the cared-for person	WA	0.0195	0.3842	7,058	-103.7	6,954	-124	119.8	357,404	18,101
	IC from within hh	0.0099	0.3662	6,927	-99.8	6,827	-56	119.5	692,714	18,641
	IC all from outside hh	0.0108	0.3670	6,929	-99.7	6,830	-62	120.0	630,064	18,608
	No informal care	0.0693	0.4808	7,773	-125.4	7,648	-478	NA	110,287	15,908
SCRQoL in a care home lowered to the level of people at home with unmet need	WA	0.0195	0.3845	7,058	-103.7	6,954	-124	90	357,404	18,085
	IC from within hh	0.0099	0.3664	6,927	-99.8	6,827	-56	91	692,714	18,633
	IC all from outside hh	0.0108	0.3672	6,929	-99.7	6,830	-62	89	630,064	18,600
	No informal care	0.0693	0.4821	7,773	-125.4	7,648	-478	NA	110,287	15,865
Long-term benefits of the intervention: one less hour of home care required	WA	0.0195	0.3842	3,492	-103.7	3,388	-124	90	174,142	8,819
	IC from within hh	0.0099	0.3662	4,826	-99.8	4,726	-56	91	479,498	12,903
	IC all from outside hh	0.0108	0.3670	3,538	-99.7	3,438	-62	89	317,171	9,367
	No informal care	0.0693	0.4808	165	-125.4	39	-478	NA	569	82
Long-term benefits of the intervention: two fewer hours of home care required	WA	0.0195	0.3842	55	-103.7	-49	-124	90	-2,502	-127
	IC from within hh	0.0099	0.3662	2,556	-99.8	2,456	-56	91	249,220	6,706
	IC all from outside hh	0.0108	0.3670	510	-99.7	410	-62	89	37,842	1,118
	No informal care	0.0693	0.4808	-7,344	-125.4	-7,470	-478	NA	-107,716	-15,537

Analysis	Weighted average/subgroup	Incremental, per person with care needs (excludes informal carers’ earnings)						Incremental, per carer	ICER: incremental NHS & PSS cost per additional life year	ICER: incremental NHS & PSS cost per additional life year adjusted by unweighted SCRQoL
		Life years	**Life years adjusted by unweighted SCRQoL**	**Total PSS cost**	**Total NHS cost**	**Total NHS & PSS cost**	**Total private cost**	**Informal carers' earnings**		
Base case PSA	WA	0.0195	0.3842	7,058	-103.7	6,954	-124	90	357,404	18,101
	IC from within hh	0.0099	0.3662	6,927	-99.8	6,827	-56	91	692,714	18,641
	IC all from outside hh	0.0108	0.3670	6,929	-99.7	6,830	-62	89	630,064	18,608
	No informal care	0.0693	0.4808	7,773	-125.4	7,648	-478	NA	110,287	15,908
Long-term benefits of the intervention: fewer hospitalisations required	WA	0.0195	0.3842	7,058	-956	6,102	-124	90	313,595	15,882
	IC from within hh	0.0099	0.3662	6,927	-636	6,291	-56	91	638,282	17,176
	IC all from outside hh	0.0108	0.3670	6,929	-861	6,069	-62	89	559,874	16,535
	No informal care	0.0693	0.4808	7,773	-2,019	5,754	-478	NA	82,981	11,969
Long-term benefits of the intervention: two fewer hours of home care + fewer hosp. required	WA	0.0195	0.3842	55	-956	-901	-124	90	-46,311	-2,345
	IC from within hh	0.0099	0.3662	2,556	-636	1,920	-56	91	194,788	5,242
	IC all from outside hh	0.0108	0.3670	510	-861	-351	-62	89	-32,348	-955
	No informal care	0.0693	0.4808	-7,344	-2,019	-9,363	-478	NA	-135,022	-19,476

For table notes, see Table 42. Additional abbreviation note: hosp: hospitalisations.

Table 45. Results from scenario analyses compared to the base case analysis. Mean results. Cost components. Costs in £.

Analysis	Weighted average/subgroup	Incremental cost, per person with care needs, stratified by source of funding and cost component								
		PSS: home care	PSS: care homes	PSS: depr. Symptoms	NHS: GP visits	NHS: hosp.	NHS: care homes	NHS: depr. Symptoms	Private: care homes	Private: depr. Symptoms
Base case PSA	WA	7,199	-141	0.020	-96.5	26	-33	0.042	-124	0.023
	IC from within hh	6,991	-64	0.010	-97.6	13	-15	0.021	-56	0.011
	IC all outside hh	7,000	-70	0.011	-97.3	14	-17	0.024	-62	0.013
	No informal care	8,321	-547	0.070	-91.5	95	-129	0.148	-478	0.081
P (met need) with IC all from outside hh + home care was increased to the level of home care + no IC	WA	7,239	-155	0.019	-96.2	29	-37	0.041	-136	0.022
	IC from within hh	6,991	-64	0.010	-97.6	13	-15	0.021	-56	0.011
	IC all outside hh	7,083	-100	0.010	-96.6	20	-24	0.022	-87	0.012
	No informal care	8,321	-547	0.070	-91.5	95	-129	0.148	-478	0.081
Higher cost of home care based on a competitive labour market wage rate	WA	7,710	-141	0.020	-96.5	26	-33	0.042	-124	0.023
	IC from within hh	7,487	-64	0.010	-97.6	13	-15	0.021	-56	0.011
	IC all outside hh	7,496	-70	0.011	-97.3	14	-17	0.024	-62	0.013
	No informal care	8,911	-547	0.070	-91.5	95	-129	0.148	-478	0.081
Lower percentage of care home full self-funders, as per the most deprived decile	WA	7,199	-189	0.020	-96.5	26	-33	0.042	-76	0.023
	IC from within hh	6,991	-86	0.010	-97.6	13	-15	0.021	-35	0.011
	IC all outside hh	7,000	-94	0.011	-97.3	14	-17	0.024	-38	0.013
	No informal care	8,321	-731	0.070	-91.5	95	-129	0.148	-296	0.081
Lower P (employm.) of inf. carer after a care home admission or death of cared-for person	WA	7,199	-141	0.020	-96.5	26	-33	0.042	-124	0.023
	IC from within hh	6,991	-64	0.010	-97.6	13	-15	0.021	-56	0.011
	IC all outside hh	7,000	-70	0.011	-97.3	14	-17	0.024	-62	0.013
	No informal care	8,321	-547	0.070	-91.5	95	-129	0.148	-478	0.081
Lower SCRQoL in a care home (equal to: at home with unmet need)	WA	7,199	-141	0.020	-96.5	26	-33	0.042	-124	0.023
	IC from within hh	6,991	-64	0.010	-97.6	13	-15	0.021	-56	0.011
	IC all outside hh	7,000	-70	0.011	-97.3	14	-17	0.024	-62	0.013
	No informal care	8,321	-547	0.070	-91.5	95	-129	0.148	-478	0.081

Analysis	**Weighted average/subgroup**	**Incremental cost, per person with care needs, stratified by source of funding and cost component**								
		PSS: home care	**PSS: care homes**	**PSS: depr. Symptoms**	**NHS: GP visits**	**NHS: hosp.**	**NHS: care homes**	**NHS: depr. Symptoms**	**Private: care homes**	**Private: depr. Symptoms**
Base case PSA	WA	7,199	-141	0.020	-96.5	26	-33	0.042	-124	0.023
	IC from within hh	6,991	-64	0.010	-97.6	13	-15	0.021	-56	0.011
	IC all outside hh	7,000	-70	0.011	-97.3	14	-17	0.024	-62	0.013
	No informal care	8,321	-547	0.070	-91.5	95	-129	0.148	-478	0.081
Long-term benefits of the intervention: one less hour of home care required	WA	3,633	-141	0.020	-96.5	26	-33	0.042	-124	0.023
	IC from within hh	4,890	-64	0.010	-97.6	13	-15	0.021	-56	0.011
	IC all outside hh	3,608	-70	0.011	-97.3	14	-17	0.024	-62	0.013
	No informal care	712	-547	0.070	-91.5	95	-129	0.148	-478	0.081
Long-term benefits of the intervention: two fewer hours of home care required	WA	196	-141	0.020	-96.5	26	-33	0.042	-124	0.023
	IC from within hh	2,620	-64	0.010	-97.6	13	-15	0.021	-56	0.011
	IC all outside hh	580	-70	0.011	-97.3	14	-17	0.024	-62	0.013
	No informal care	-6,797	-547	0.070	-91.5	95	-129	0.148	-478	0.081
Long-term benefits of the intervention: fewer hospitalisations required	WA	7,199	-141	0.020	-96.5	-826	-33	0.042	-124	0.023
	IC from within hh	6,991	-64	0.010	-97.6	-524	-15	0.021	-56	0.011
	IC all outside hh	7,000	-70	0.011	-97.3	-747	-17	0.024	-62	0.013
	No informal care	8,321	-547	0.070	-91.5	-1,798	-129	0.148	-478	0.081
Long-term benefits: two fewer hours of home care + fewer hosp. required	WA	196	-141	0.020	-96.5	-826	-33	0.042	-124	0.023
	IC from within hh	2,620	-64	0.010	-97.6	-524	-15	0.021	-56	0.011
	IC all outside hh	580	-70	0.011	-97.3	-747	-17	0.024	-62	0.013
	No informal care	-6,797	-547	0.070	-91.5	-1,798	-129	0.148	-478	0.081

Table notes. Abbreviations: depr: depressive; inf: informal; IC: informal care; NHS: National Health Service; hosp: hospitalisations; PSS: Personal Social Services; WA: weighted average. Colour legend: green = intervention more effective or cheaper; pink=intervention less effective or more expensive.

6.4. Discussion

The base case analysis in the economic model showed that on average, reducing waiting lists would lead to some positive outcomes: an increase in life years, life years adjusted by unweighted SCRQoL and informal carers' earnings, and a reduction in NHS costs and private costs. However, it would also increase PSS costs and public sector (NHS & PSS) costs. When all subgroups were considered together, the ICER based on life years was £357,404, while the ICER based on life years adjusted by unweighted SCRQoL was £18,101. Incorporating SCRQoL is key to account for the benefits of shortening waiting lists beyond reduced mortality, and the present model shows that considering SCRQoL can considerably reduce an ICER. This is important in light of concerns around potentially high ICERs relating to interventions in older people: Huter [218] argues that there is a risk for age discrimination if economic evaluations consider life year gains, because the remaining life expectancy of older people is lower than for younger people.

This work only used unweighted SCRQoL and so could not calculate SC-QALYs. If SC-QALYs had been included, judgements of cost-effectiveness would have faced the issue that there is no accepted cost-effectiveness threshold for social care [200]. A review of social care economic evaluation methods [182] found that some studies including QALYs applied thresholds used for NICE guidelines, i.e., between £20,000 and £30,000, while other studies used a range of hypothetical thresholds. A NICE economic model on replacement care for informal carers [175] used a £20,000 threshold to calculate societal net monetary benefit.

The average results from the present model showed that the subgroup with no informal care would see the biggest gain in life years and quality of life, and the biggest private savings. The biggest increase in public sector costs per person would also be in this subgroup, but this subgroup would have the lowest ICERs. In the subgroups with informal care, unmet care need is not as likely while on a waiting list, so the benefits from the intervention are lower, and the ICERs are higher. Therefore, the higher ICERs are dependent on care duties being shifted to informal carers with longer waiting lists. Because of this, the outcomes for informal carers should also be considered when comparing subgroups.

The model included informal carers' earnings but it did not focus on their quality of life. This was due to a lack of available evidence. A review by Brimblecombe et al. published in 2018 [184] highlighted that there was limited evidence on how home care affected informal carers' wellbeing. According to another review by Victor published in 2009 [219], qualitative evidence suggested a beneficial impact of formal care on informal carers' wellbeing, but there was also evidence that informal carers could experience anxiety and guilt around the person being cared by a formal source. Moreover, there is some workload involved in providing instructions to new carers (personal communication with the public advisory group), which can be burdensome if there is no continuity of care. In the absence of quantitative evidence relevant for the present work, the effect on quality of life of going back to work should be considered, because the model assumes that home care increases the probability of employment. On the one hand, spending time away from caring and increased earnings could increase wellbeing, but on the other hand, it could be stressful for the informal carer to manage both responsibilities from employed work and coordination of care for the cared-for-person. However, being on a waiting list means that there is a demand for home care which is not being met, so it may be assumed that quality of life would improve for the informal carer once home care starts. If this assumption was incorporated into the model, and if the model produced an ICER that took into account the gain in quality of life as well as in earnings for the informal carer, the ICER would be lower than the current ICER, which only incorporates public sector costs and life years adjusted by quality of life of the person with care needs.

It is likely that the model underestimated the increase in informal carers' earnings arising from the intervention, for various reasons. Firstly, the model did not consider how caring would affect working hours. Only the probability of employment was considered. Secondly, the model did not consider how the intervention may affect retirement income. This is an important limitation because 66% of carers of people aged 65 and over are also aged 65 and over [211]. Additionally, the model did not stratify the results by gender and so it did not assess how the increase in earnings may impact on gender equality. This is important because women are more likely than men to provide informal care at an age when they would be expected to be in paid employment [220].

The model focuses on informal carers' earnings, which are linked to the likelihood of being in employment. Apart from this, it does not include the costs of informal carers' time. Future modelling work could use one of the available methods to include these costs. For example, the "replacement cost method" ([221], p. 1863), also called "proxy good method" ([221], p. 1863), values informal carers' time based on the cost of their activities if these were provided from a formal care provider [221, 222]. An alternative is the "opportunity cost method" ([221], p. 1863), which values the costs of opportunities forgone because of informal caregiving, including both opportunities to earn an income and to participate in leisure [221]. There is also the “contingent valuation method” ([222], p. 274), which relies on asking the informal carer how much they would want to be paid for providing an extra hour of informal care or how much they would pay for decreasing caregiving by one hour [222]. These and other methods are described in an article by Koopmanschap et al. [222], which also discusses when some methods may be most appropriate. Moreover, Engel et al. [221] published a systematic review of methods that have been applied to value informal care provided to people with dementia. The NICE social care guidance manual ([200], p. 213) mentions that there is no consensus on which method should be used to value informal care.

The model separated informal carers’ earnings from the total privately funded costs. This separation is artificial because informal carers’ earnings may be used to fund the private costs of a care home or of depressive symptoms incurred by the person with care needs. However, it seemed important to present these earnings per carer and so it seemed appropriate to separate them from the other costs, calculated per person with care needs. Further work should combine everything together to calculate societal costs per person with care needs and should also present an ICER based on societal costs. To do so, an average number of carers per person would have to be included among the model parameters. A focus on societal costs should be in parallel with, rather than replace, a focus on the costs incurred by different sectors or people. This is because economic evaluations of social care interventions should consider whether costs are being shifted from the public sector to informal carers [200]. Moreover, experts have advised that evaluations of social care interventions should include different perspectives in order to be relevant to different decision makers [182].

Due to a lack of data, the base case analysis did not include any long-term effects of unmet care need apart from the possibility of a permanent care home admission and death. However, it is plausible that unmet care need may lead to health deterioration, which in turn may lead to an increase in the number of home care hours and hospitalisations required over the following years, even after care needs are met. Scenario analyses showed that if this was the case and the intervention generated long-term benefits, the increases in public sector costs and the related ICERs would be considerably reduced across all subgroups. The intervention could even lead to a decrease in public sector costs, depending on the extent of the long-term benefits. Long-term reductions in the requirements for home care had the biggest influence on incremental public sector costs.

A scenario analysis considered a higher cost of home care based on a higher wage and showed that higher ICERs and bigger increases in PSS and public sector costs would be observed in this case. This scenario analysis is important because an increase in wages may be necessary to reduce waiting lists: high vacancy rates are an important factor behind waiting lists [223]. Vacancy rates in local authority and independent sector adult social care services have increased from 6.9% in 2020/21 to 10.4% in 2021/22 [224]. High vacancy rates in adult social care are in part connected to high turnover rates. Both are due to various factors, including a low wage, zero-hours contracts and limited opportunities for professional development and career progression [224].

One observational study [225] examined the factors affecting vacancy rates in the social care sector in England, using multivariable analysis. The study found that an increase in the share of staff on a zero-hours contract by one percentage point increased vacancy rates by 0.6 percentage points. The study did not find an association between vacancy rates and wages. The population in this study were social care workers, not just home care workers, and working in home care was one of the independent variables. The study did not focus on the effect of a combination of improved working conditions.

Improving working conditions is an intervention that may not be immediately feasible because home care providers are usually tied in contracts which limit their costs (personal communication with stakeholders). Moreover, improving working conditions may not be sufficient to increase the pool of care workers to the required level. Indeed, the carer role can be difficult for the nature of the job itself, which does not fit into office hours and involves dealing with intimate tasks (personal communication with stakeholders). Furthermore, an increase in vacancy rates has also been observed in the wider UK economy, from 2.2% in February to April 2021 to 4.3% in February to April 2022 [224]).

According to an Independent Age report [226], one in five workers employed in the adult social care sector was born in a country other than the UK. Therefore, immigration policies are another factor to consider for facilitating carer's recruitment, as well as possible technical solutions which may increase productivity. A UK stakeholder consultation looking into research priorities for home care for older people identified the recruitment and retention of workforce as one of the main priorities [44].

The present economic modelling work has various strengths. It has addressed a lack of previous economic models on the costs and benefits of reducing waiting lists for home care among older people in England. It involved professionals and lay stakeholders and developed new conceptual modelling and a new model structure.

Moreover, this model has added to the limited previous economic modelling work that used the concept of unmet care need in relation to the English context. Unmet need was included as an outcome in previous economic modelling work that compared different social care funding and eligibility scenarios in England [38, 227, 228] or the UK [130] (Note that these models did not distinguish between home care and residential care so were not mentioned in the introduction to this chapter). However, only one previous economic model [130] has been identified, where unmet need affected transition probabilities: in a model by Gostoli and Silverman [130], unmet care need affected the probability of developing higher care needs, of being hospitalised and of dying. However, no reference was made in their publication to existing literature on the determinants or adverse consequences of unmet care need. The study authors only mentioned that they had consultations with social care experts, and that these experts suggested that prolonged unmet care need would increase frailty and lead to health deterioration, as mentioned in section 5.1.

Moreover, Gostoli and Silverman [130] did not refer to the concept of a “care state”. The “care state” term is used in the present work to mirror the “health state” term. In health care modelling, time spent in different health states is associated with specific costs and health outcomes [229]. Care states work in the same way but also capture different sources of care and whether needs are met or unmet. This is important in social care, where needs may be met thanks to informal care in the absence of a formal intervention like home care or a day care centre, and needs may be unmet in the presence of a publicly funded intervention due to long-standing funding problems.

The modelling work also has limitations. An important limitation is that no data was identified on the average duration of waiting lists. The model focused on reducing waiting lists by 6 months. Further work would need to evaluate different time reductions. Moreover, the limited evidence available affected the choice of parameters. This is discussed in the next chapter, in section 7.2. [230]

Future modelling work should go beyond people with home care fully funded by the LA and include people who are funded by the NHS Continuing Healthcare and those whose home care is partially funded by the LA and partially privately funded. 48.5% of people aged 65 and over who have “long-term support services provided or commissioned by the council” or the NHS

([121], p. 4) in the community contributed to care and support with private funding in 2021/22 ([190], table T2a, excluding learning disability support).

The current model focused on home care as it is currently delivered in current practice. Further work should focus on how results may change if home care was better at meeting needs. In particular, it would be important to look at how results would change if home care had more of an enabling approach, where home care workers would do things with the person rather than for the person. This would help the person retain their skills over time, which would prevent or delay a later increase in needs; this approach could even reduce care needs over time for some people (personal communication with stakeholders). An enabling approach would be based on additional home care time. Additional time would also help against social isolation. This could have multiple benefits because social isolation has been found to be associated with multiple adverse health outcomes [142-144], as mentioned in section 5.1.1. Therefore, future modelling work should focus on increasing the hours of home care. Limited evidence was identified around the benefits of more hours of home care. Forder et al. [231] studied the marginal effect on SCRQoL of an additional hour of home care among people aged 65 and over. However, the study used new methods applied "as a proof of concept" ([231], p. 979). In the future, it would be important to conduct a study, ideally an RCT, where one group receives the standard number of hours of care and another group receives more hours and adopts an enabling home care approach.

6.4.1. Future unrelated costs in social care economic modelling.

Section 6.3.2 mentions that increased survival had an impact on incremental costs: it reduced the savings in GP visits and the increase in informal carers' earnings, it caused an increase in the cost of depressive symptoms and contributed to an increase in the cost of home care and of hospitalisations. This raises some questions about how the debate on future unrelated costs in health care economic modelling applies to social care modelling. The present section briefly explains what unrelated future costs are and briefly summarises the debate around their inclusion in health care economic modelling. It then makes some considerations that link this debate to social care economic modelling.

Unrelated future costs are health costs that are linked to an intervention through increased survival rather than through the implementation of the intervention, its adverse effects [232] or the condition of interest [233]. NICE recommends the exclusion of future unrelated costs [233], however, there is controversy around this [232].

In favour of their inclusion, it has been argued that these are real costs that imply a use of resources that cannot be spent elsewhere, and so should be taken into account for better decision-making [232]. It has also been argued that they should be included because unrelated future health benefits are included [232]: for example, any QALYs gains would be in part linked to any future medical interventions, and so future healthcare costs should also be included.

On the other hand, there are also arguments against the inclusion of future unrelated costs. Firstly, there are practical unresolved issues around how these would be measured [232]. Secondly, ethical concerns around equity have been raised. Among these, one argument highlights that because of discounting in economic modelling, the inclusion of future unrelated costs would discriminate against the elderly, who have higher healthcare costs than younger people in the near future [218, 232]. Additionally, Kearns [232] highlights that it is unclear whether utilities should be age-adjusted in estimating unrelated health effects, although the use of age-adjusted utilities in economic evaluations is recommended by NICE to reflect how quality of life decreases with age for the general population [233]. A third argument could be made considering that the cost-effectiveness threshold used by NICE represents the ICER of the least cost-effective service already covered by the existing NHS budget [234]. If all current treatments are assumed to be cost-effective, it could be argued that the inclusion of future unrelated costs is not needed because it should not be a problem if people incur the costs (and benefits) of having further treatments because they are alive.

The present economic model included costs over a lifetime horizon. In the base case analysis, costs were linked to the intervention in the long-term through increased survival and through decreased care home admissions. Considering these costs, it seems that the distinction between related and unrelated future costs may be more blurred in social care, for different reasons. Firstly, outcomes may not be specific to a disease, but may be more general, such as all-cause hospitalisations, GP visits or depressive symptoms. Secondly, it may be more common to have scarce evidence about the long-term effects of an intervention. Thirdly, costs associated with increased survival may be directly related to the intervention because the intervention may impact on where survival occurs: at home or in a care home. In the model, a reduction in care home admissions was associated with both cost decreases (in GP visits and depressive symptoms) and with cost increases (in home care and hospitalisations), and with a reduction in informal carers' employment and consequently earnings.

Another discussion point around the inclusion of future unrelated costs in economic models of social care interventions is that if their inclusion may discriminate against older people because they typically have higher healthcare costs in the near future [218, 232] or because utilities may be adjusted by age and by comorbidities [233], this discrimination is expected to become particularly relevant when evaluating social care interventions aimed specifically at older people with disabilities. The use of ASCOT may help against this because utilities are less directly linked to health status than EQ-5D (a measure of health-related quality of life used in health care modelling). ASCOT utilities (corresponding to the SC-QALY index) are more linked to the care and support that may be available, and so the decline linked to age or to the level of impairment may be less steep: EQ-5D focuses on “mobility”, “self-care”, “usual activities”, “pain / discomfort”, and “anxiety / depression” ([235], p. 2), while ASCOT focuses on “personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, safety, social participation and involvement, occupation, control over daily life and dignity” ([186], p. iii).

Finally, focusing on the argument that unrelated future costs could be disregarded if existing treatments are assumed to be cost-effective, this may not hold in social care: the argument is based on the methods used to calculate the cost-effectiveness threshold for health care interventions; these methods were based on the NHS budget [234] rather than on the social care budget.

All of this suggests that further work is needed to explore the issue of future unrelated costs in social care economic modelling, and how it relates to the debate around the inclusion of these costs in health care economic modelling.

6.5. Conclusion

In conclusion, this PhD study has added to limited previous economic modelling work which has focused on unmet care needs. It has created a new model to evaluate the costs and benefits of shortening waiting lists for home care, it has used unmet need to define different care states and has combined literature on the effectiveness of home care with literature on the consequences of unmet care need. It has shown that there would be some positive gains from shortening waiting lists. It has also shown that there would be public sector cost increases. However, these increases would be considerably reduced if shortening waiting lists prevented health deterioration and generated long-term benefits in terms of home care requirements and hospitalisation requirements. The intervention could even lead to a reduction in public sector costs, depending on the extent of the long-term benefits. Therefore, further research is needed on the long-term effects of unmet care need and of timely home care receipt.

Chapter 7. Discussion and conclusion

7.1. Summary of the PhD study and of its original contribution to knowledge

This PhD study set out to assess the determinants of unmet need for personal care and practical support among older people living in private households in England, and to investigate whether unmet care need was a determinant of worsening frailty. It also set out to assess the costs and benefits of reducing unmet need by shortening waiting lists for home care for older people in England. It aimed to make a contribution that could be used in economic models and in health and social care policies focused on older people with limitations in activities of daily living.

The review of the social care pathways in chapter 2 described access criteria for LA-funded care and outlined publicly funded services beyond home care, including services for informal carers. This was important to set the research in context and informed the data analysis and the economic modelling work.

The literature review in chapter 3 was the first to systematically identify and summarise previous studies on the determinants of social care receipt, unmet need and source of care among older people living in private households in England. The determinants of unmet need assessed in previous literature were then discussed with stakeholders and compared to individual-level data available within the ELSA dataset [29, 81] and LA-level data available within publicly available datasets. Based on this, it became clear that some potentially important determinants had not been included in any previous study. These included individual-level determinants: frailty; having a child living in close proximity (previous work had only assessed whether there was any child living within the same household); a social contact index that considered children, other relatives and friends; using the internet; meal provision. Moreover, among people with help, different sources of care (LA-funded, paid with private funds or benefits, or informal care) and receiving help during both day and night had not been assessed as determinants of unmet care need. Furthermore, LA-level characteristics that had not been previously assessed but may impact on unmet need were identified: the percentage of new requests to the council resulting in no care and no assistive equipment; the quality of social care information on the council website. Therefore, data analysis in chapter 4, which aimed to investigate the determinants of unmet care need among older people living in private households in England, assessed the aforementioned variables for the first time, in addition to including other determinants which had already been shown to be important in previous literature (age group, gender, living alone, number of PADL limitations, number of

IADL limitations, education, wealth, LA expenditure, LA deprivation). Moreover, the review in chapter 3 highlighted that no study had assessed the determinants of unmet need specifically after the Care Act 2014 [15] started to be implemented in April 2015 [236], so the data analysis in chapter 4 focused on this context: unmet care need was measured in 2016/17.

In relation to the newly assessed determinants listed above, the following significant results were found in data analysis described in chapter 4: more social contacts were associated with lower odds of unmet care need. The direction of association between frailty and unmet need changed depending on the analysis, suggesting that people with higher frailty were more likely to receive help, but once people had help, higher frailty meant that help was less likely to meet needs all the time. In the analysis that focused on different sources of care, receiving all informal care from outside the household was associated with higher odds of unmet need, compared to at least some informal care from within the household. Care funded with private funds or benefits had a borderline significant positive association with unmet need.

With data analysis described in chapter 4, this PhD study assessed for the first time the interaction between living alone and wealth in relation to unmet need among older people living in private households in England. Previous studies included in the review in chapter 3 had identified living alone as a risk factor for unmet need [60, 69]. However, this PhD study found that living alone was not a risk factor for unmet need in the wealthiest quartile. Moreover, among people living alone, those in the lowest wealth quartile had higher odds of unmet need compared to people in the highest wealth quartile. However, these wealth inequalities in unmet need were not observed among people living with others.

In addition to wealth inequalities among those living alone, another socio-economic inequality identified in data analysis in chapter 4 related to LA deprivation, which was positively associated with unmet need. Moreover, evidence of gender inequalities was identified both with the review in chapter 3 and with data analysis in chapter 4. Both the review and the data analysis showed that different models produced different results relating to the association between being male and unmet need. Based on the similarities and differences across these models, results suggested that men were less likely to receive help, but once help was received, they were not at increased risk of unmet need. Section 4.4 provides possible interpretations for both the finding relating to LA deprivation and the findings relating to gender, concluding that further investigation is needed in both cases.

Data analysis in chapter 5 investigated whether unmet need was associated with subsequent progression of frailty and whether having at least one fall and the number of depressive symptoms were mediators in this relationship. With this analysis, this PhD study was the first to assess whether unmet need was associated with outcomes other than wellbeing within the English context. The analysis found that unmet need had a borderline significant negative association with worsening frailty. This finding may be due to various data limitations. Another reason for the finding may be that perceived unmet care need can have different effects depending on individual situations: although some studies have found an association between unmet need and an increased risk of hospitalisation [187] or death [188], in some cases, having to keep doing things for one self may help against functional decline. The borderline significant negative association was not robust to model changes. In investigating the mediators between unmet need and progression of frailty, this study found no evidence of an association between unmet need and falls. Although no association was found between unmet need and the number of depressive symptoms in the final model (Table 20), an association was observed in robustness checks that used different definitions of unmet need (the association was borderline significant in model 2 in Table 114 and significant in model 2 in Table 117).

Chapter 6 focused on the assessment of the potential costs and benefits of shortening waiting lists for home care among older people in England. Based on the published literature reviewed, this PhD study was the first to carry out an economic model on this topic in the English context. Moreover, the present work has also produced the first England-based economic model which focused specifically on home care considering a variety of outcomes, including life years and SCRQoL for people with care needs and the earnings from employment for informal carers. According to the base case analysis, shortening waiting lists by six months would lead to an increase in life years, life years adjusted by unweighted SCRQoL and informal carers' earnings, as well as to a reduction in NHS costs and private costs, but it would also lead to increased PSS costs and public sector (NHS & PSS) costs. Two ICERs were calculated: one referred to the incremental public sector (NHS & PSS) cost per additional life year, the other to the incremental public sector (NHS & PSS) cost per additional life year adjusted by unweighted SCRQoL. Both ICERs were the lowest in the subgroup with no informal care and the highest in the subgroup with at least some informal care from within the household. Looking at the weighted average across all subgroups, the ICER that took into account SCRQoL was considerably lower (£18,101) than the ICER which only focused on life years (£357,404). This shows the importance of considering SCRQoL in evaluating social care interventions. Scenario analyses showed that the increase in public sector costs could be considerably reduced and even become a saving if shortening waiting lists had long-lasting benefits in terms of the requirements for home care hours and hospitalisations.

Within the English context, this PhD study has connected for the first time economic modelling methodologies to the literature on the determinants and adverse consequences of unmet care need. From the point of view of the determinants of unmet need, this connection is important because economic modelling can stratify outcomes by subgroups and can use different parameters depending on the subgroup. For example, the economic model in the present work has identified that reducing waiting lists would imply different costs and benefits depending on whether people have informal care and whether at least some of this is from inside the household. The connection between the literature on the adverse outcomes of unmet need and economic modelling in social care is also important because it can be used to estimate the costs of unmet need.

The economic model in this PhD study is based on “care states” which incorporate whether the person receives home care, informal care, or both, and whether needs are met or unmet. Including met or unmet need into care states encourages consideration by the economic modeller of how informal care may or may not replace publicly funded social care interventions, and how these interventions may be experienced by the person with care needs. Thanks to this approach, the economic model described in chapter 6 could include a proportion of people with met needs thanks to informal care while on a waiting list for LA-funded home care; once LA-funded home care started, the probability of met care needs increased, but some people still had unmet needs. The economic model then linked met and unmet need to the number of hospitalisations, the level of SCRQoL and the probability of care home admission, death, and high depressive symptoms. A link between unmet need and the probability of hospitalisation or death had already been made in a previous economic model by Gostoli and Silverman [130], which evaluated two UK social care policy interventions (the introduction of “fully tax-deductible social care expenses” ([130], p. 10) and an alternative need eligibility threshold). However, Gostoli and Silverman did not make a distinction between home care and residential care, while this PhD study has applied their approach to a new economic model on waiting lists for home care and has incorporated care home admissions. Moreover, their work did not use the concept of “care state” used in this PhD study.

The discussion sections within the other chapters of this PhD thesis include reflections on the methods and the results, outlining possible interpretations, strengths, limitations, comparisons with previous literature and research recommendations. However, these sections are specific to each chapter. Instead, the current discussion provides additional reflections that relate to all chapters together.

7.2. Availability of data and evidence relating to home care and unmet need

The economic model combines parameters from studies on the effectiveness of home care and from studies on the consequences of unmet care need. Each kind of literature has its own advantages and disadvantages, and given the overall scarcity of evidence, considering both at the same time is a strength of the economic model. Studies on home care directly focus on the intervention of interest but are often complicated by endogeneity problems because non-receipt of home care may be linked to a lack of need for it. For example, people may be able to independently perform activities of daily living despite some difficulties, or informal care may work well for them. Additionally, randomised trials in this field may be difficult to conduct because of ethical concerns. The literature on unmet care need changes the perspective away from the intervention of interest to people's perceptions. This can address endogeneity issues, by making sure that the control group perceives a care need that is not met. However, focusing on unmet care need leaves open questions as to what intervention may be the most appropriate to address it. For example, short-term reablement or a day centre may be more appropriate than home care for some people or should be combined with home care. Therefore, one cannot conclude directly from studies on the adverse consequences of unmet care need that home care should be provided to avoid these adverse outcomes.

Moreover, data collections need to be designed in a way that enables an appropriate definition of unmet care need. ELSA data are limited in relation to this: firstly, if people respond affirmatively about having a difficulty with an activity of daily living, there are no questions enquiring about the level of difficulty. Secondly, people with no help are not asked whether they think they would need or want help. Therefore, the data analyst cannot ensure that the included sample is restricted to people with care needs, and consequently cannot ensure that the "unmet care need" variable is actually capturing unmet need. Robustness checks in chapters 4 and 5 confirmed the importance of these limitations by showing that various results were sensitive to sample inclusion criteria and to the definition of unmet need. Another reason for including the level of difficulty in data collections is that this can address confounding in data analyses by the level of disability.

In both the data analysis and in the economic model, no distinction was made between people with no help and people with help that did not meet needs (the exception to this were some robustness checks and the analysis on source of care, which was limited to people with help). In the data analyses, the reason for not making this distinction was that the sample included a low number of people who responded that help met needs sometimes or hardly ever. In the economic model, the reason was a lack of relevant evidence. Therefore, in the model, people with unmet care need had the same chances of adverse outcomes regardless of whether informal care or home care was available. However, this may not hold in practice: it may be hypothesised that people without any help may face higher risks. In contrast to this hypothesis, Kröger [39] argues that those who receive no support at all generally have lower needs and so are in a less severe situation than people who receive inadequate support. Kröger ([39], p. 527) mentions a study by Freedman and Spillman [237] which found that adverse consequences of unmet care need (such as wetting or soiling clothes, staying inside, or making mistakes with medicine) were more common among those receiving some assistance than among those who had difficulties but did not have assistance. However, their analysis was descriptive and so it is likely that the level of impairment was a confounder. Overall, detailed data and further research are needed to study how any adverse outcomes of unmet need may differ between those with some support available and those who do not have any help available.

The economic model in chapter 6 was affected by the limited England-based research on the adverse outcomes of unmet need and on the effects of home care. Because of this, the model used some parameters referring to people with dementia in the United States, which may be inappropriate. Further individual-level research is needed to assess whether there is a link between home care and unmet care need on the one hand and A&E attendance, hospital admissions, care home admissions and death on the other hand. Research should also focus on the long-term effects of unmet care need, especially looking at whether it leads to increased home care requirements over the following years, as this affected public sector costs the most in the model. Moreover, research is needed on the effect of home care on the SC-QALY index, so that SC-QALYs can be calculated.

Because of limited data availability, some parameters used in the economic model and linked to data analysis described in chapter 4 were about overall care needs rather than specifically

PADL care needs, because ELSA does not differentiate between PADLs and IADLs when asking how help meets needs. However, home care mostly corresponds to personal care in the English context. This supports the recommendation made in chapter 5 around the need for more detailed data that distinguish between PADLs and IADLs when asking about people's perceptions of the help they receive.

Weatherly et al. noted that "there are substantial challenges in developing a decision model […] where data are non-existent or of poor quality" ([182], p. 23). However, Weatherly et al. also considered that

> Economic evaluations are implemented to inform a decision, and decisions are made regardless of the quality of available data. It can be argued, therefore, that it is probably better to use poor data in a quantitative way such as in a decision model and to explore the impact of uncertainty, than not undertake an evaluation. ([182], p. 27)

If additional evidence becomes available, future research should consider a microsimulation model on the potential costs and benefits of shortening waiting lists for home care, which could incorporate additional aspects compared to a Markov cohort model. For example, the model could capture individual variability in impairment, home care hours, and the effects of unmet care need. Moreover, if future research showed that there are long-term effects of unmet care need and that these are increased with a longer time spent with unmet need or with repeated experiences of unmet need, a microsimulation model could "remember" the past experiences of unmet need.

In summary, further research is needed on the consequences of unmet social care need and on the effects of home care. This should be based on appropriate data. The key recommendations from this PhD thesis for future data collection relating to unmet social care need are listed below:

- Include detailed information on the level of difficulty with activities of daily living.
- Ask people without help whether they think they would need or want help.
- Ask whether people think that they have the aids and adaptations they need and enquire whether they have received professional advice relating to this.
- Make a distinction between PADLs and IADLs when asking about people's perceptions around the help they receive or would want to receive.

7.3. Linking the current work to the wider context

This work has focused on unmet needs, but future research should consider using the concept of “care poverty” to refer to a lack of adequate help for people in need of care and support ([39], pp. 5-6). This concept highlights how unmet needs arise from the combination of individual and societal factors. In contrast, according to Kröger [39], the concept of unmet needs directs attention to the individuals rather than to the social and political context.

Moreover, it is important to link research on unmet care needs to research on informal carers and on the social care workforce. The following paragraphs summarise the limited focus of this PhD study on these topics, then move on to highlight that socio-economic and gender inequalities should be considered not only in relation to unmet need but also in relation to informal caregiving and the social care workforce. The text also draws attention to ethnic inequalities within the social care workforce.

This PhD study focuses on informal care when it assesses different sources of care as determinants of unmet need with data analysis in chapter 4. Moreover, the important role of informal care is recognised in the economic model, which divides the population into subgroups based on informal care availability. The model also considers how home care would affect informal carers’ employment and consequently earnings. This PhD study also pays attention to the role of informal carers by focusing on the determinants of receiving care from different sources in the literature review in chapter 3. Nonetheless, the studies included in chapter 3 and data analysis in chapter 4 did not focus on the characteristics of children, partners, family members or friends, although studies did consider whether they were present or how much social contact the older person had with them, or their proximity or gender. However, characteristics such as age, functional limitations [70] or employment [238] can affect caregiving.

The literature review in chapter 3 found mixed results on the relationship between wealth and informal care, but all significant associations showed that a lower wealth quintile had higher odds of informal care than a wealthier quintile [62, 71, 72]. Other research conducted across various European countries also found that people of lower socio-economic status were more likely to use informal care [239]. Reasons that have been reported to explain this include: a need to avoid paying for care, different cultural norms, family members living closer, and a lower pay, which might contribute to a decision to leave work to provide care [239]. One study included in the review in chapter 3 [68] reported a finding which went in the opposite direction to the aforementioned findings: help from a partner was more likely in couples with a higher income. This might be because partners were in better health.

Other research on the socio-economic determinants of informal caregiving has reported findings which reflect the socio-economic determinants of informal care receipt. Research that pooled ELSA data with data from other European countries found that higher wealth was associated with a lower likelihood of providing informal care within the household [240]. Research based on UK data from 1991 to 2018 showed that among those caring for at least 50 hours per week, “semi-routine and routine” occupations were more common than “management and professional” occupations ([220], p.4). Additionally, the Census 2021 found that there was a higher percentage of people providing informal care in the most deprived areas of England compared to the least deprived areas (10.1% vs. 8.1%) [126].

Regarding gender inequalities in informal caregiving, a study included in chapter 3 found that receiving care from a daughter, but not from a son, decreased the odds of receiving help from a partner two years later and the odds of receiving LA-funded care two years later [68]. This would suggest that women take on a more substantial role than men when providing informal care to a parent. Moreover, the Census 2021 found that in England, 10.3% of females were informal carers, versus 7.6% of males [126]. Therefore, gender and socio-economic inequalities in informal caregiving are important issues.

In addition to inequalities in informal caregiving, inequalities affecting formal care workers are another area of concern, as it is briefly explained in the following paragraph. The focus of this PhD study on the social care workforce has been very limited and it can be summarised as follows: the economic model includes a scenario analysis that considers how results would change if there was a higher wage for home care workers. Moreover, the discussion section of chapter 6 mentions how waiting lists for home care appear to be related to working conditions in social care.

82% of workers employed in the adult social care sector in England are women [224]. Moreover, ethnic inequalities in the social care workforce have been identified by an inquiry by the Equality and Human Rights Commission, which examined the experiences of minority ethnic workers in low-paid roles (carers working in care home settings and in private households, healthcare assistants, cleaners, porters and security workers) [241]. The inquiry found that they faced discrimination and mistreatment in their workplaces during the COVID-

19 pandemic. Moreover, zero-hour contracts were more common among ethnic minority workers [241]. Therefore, a relationship between ethnic and socio-economic inequalities was identified.

In addition to inequalities experienced within England, it should be emphasised that “care is also a global issue and, in its manifestation through migrant care work, part of geopolitical inequalities between richer and poorer nations” ([242], p. 558). Section 6.4 mentions that one in five workers employed in the adult social care sector was born in a country other than the UK [226].

Therefore, further academic and policy work should link research on inequalities among people with care needs, informal carers, and professional care workers, and should also consider the impact on other countries of migrant care work.

The following section includes various recommendations on how some findings from this PhD study on the determinants of unmet need and of source of care could be incorporated into further economic modelling work.

7.4. Recommendations for further economic models incorporating unmet care need

Future economic modelling work could incorporate various characteristics of care recipients, their family members, and the local authorities where they live, in order to model different sources of care, met or unmet need and its effects.

The model presented in chapter 6 could be enriched by considering some additional characteristics. It could incorporate the gender of the person with care needs as a factor which may determine informal care allocation: one study included in the review in chapter 3 found that receipt of informal care was more likely for women than for men [62]. Furthermore, based on the review in chapter 3, mothers had higher odds of receiving care from children [70], or at least from daughters [68], than fathers. Moreover, based on the findings from data analysis in chapter 4, section 4.4 argues that men seem less likely to receive help, but once help is received, they do not seem at increased risk of unmet need. As mentioned in section 4.4, further investigation is needed to understand if the lower likelihood of receiving help is related to residual confounding by the level of impairment or to social networks, help-seeking behaviour or different perceptions of what is “help” when it comes to domestic tasks. This further research would enable the incorporation of the gender of care recipients into future economic models.

Future modelling work may have to consider LA deprivation too. Data analysis in section 4.2 found that LA deprivation was a risk factor for unmet need. Section 4.4 mentions that other studies found no association between LA deprivation and unmet need [37] or specific sources of care [68]. Therefore, the finding should be investigated further. If people were less likely to receive LA-funded home care in more deprived LAs, or if home care in these LAs was less likely to meet needs, this could be incorporated in future economic models.

Future models should also consider the wealth of older people with care needs. Section 4.2.1.4.6 explains that for older people, wealth is generally considered more relevant than income in defining their socio-economic status. Economic models could incorporate the findings from studies included in chapter 3 that people with higher wealth were more likely to receive privately funded care [62, 68, 72] and less likely to be supported by informal carers [62, 71, 72] than people with lower wealth. Data analysis in section 4.2 also found that living alone had a statistically significant interaction with wealth in relation to the unmet need outcome. Further data analysis should assess the interaction between wealth and receiving informal care from within the household, from outside the household or no informal care in relation to the unmet need outcome. Then, an economic model could stratify people based on wealth as well as based on the availability of informal care. It could then assess how the costs and benefits of a social care intervention would impact on wealth inequalities, taking informal care availability into account. If the focus is on wealth inequalities, the population in the model would have to be anyone with care needs rather than just people eligible for having home care fully funded by the council as in the economic model in chapter 6. Moreover, the costs and benefits for informal carers would have to be included, and the results should look separately at changes in wealth inequalities in unmet need and in informal caregiving. Furthermore, economic models that incorporate privately funded care could consider how likely this is to meet needs. Data analysis in section 4.3 found a borderline significant positive association between paying for care with private funds or benefits and unmet need. This finding should be investigated further.

Gostoli and Silverman [130] have incorporated multiple characteristics of care recipients and their family members in their agent-based simulation model on UK social care policy interventions. Individuals in their model started with no need for care and progressed to higher care need levels over time based on age, gender, socioeconomic status and any unmet past care need. Moreover, informal care receipt was modelled based on the individual’s family network. Additionally, the receipt of LA-funded care and of privately funded care was also included in the model. In modelling informal caregiving, Gostoli and Silverman [130] mostly focused on the characteristics of informal carers, like the income of family members, the degree of family relationship and geographical distance. The only care recipient characteristic that they linked to informal care receipt was the individual's care need level. Including the care recipient care need level is sensible: some analyses reported in the review in chapter 3 found that a higher number of PADL or IADL limitations was associated with higher odds of receiving informal care [19, 68, 70]. Moreover, data analysis in chapter 4 suggested that higher frailty was positively associated with care receipt. However, Gostoli and Silverman's modelling work does not consider the gender of care recipients, LA deprivation, or how different sources of care may be more or less likely to meet needs. Therefore, further research into these determinants of unmet need could help improve existing and future economic models.

Data analysis in section 4.2 found that more social contacts were associated with lower odds of unmet care need, although this finding was sensitive to model changes. Future research should explore further the link between the amount and type of social contacts and unmet care need. This future work might be able to inform an economic model of interventions to increase social contacts that also includes unmet care need and its effects.

7.5. Recommendations for further work in a changing context

Further data analysis and economic modelling work should be conducted in consideration of the changing English context, as it is outlined in the following paragraphs.

This PhD project started in July 2020 and the data analyses focused on the pre-COVID-19 and pre-Brexit context. Further research would need to focus on the determinants of unmet care need in the English context after the UK left the European Union at the end of 2020 and after the end of the COVID-19 public health emergency, which officially started in January 2020 [243] and ended in May 2023 [244]. Section 6.4 mentions that vacancy rates in social care increased by 3.5 percentage points between 2020/21 and 2021/22 [224]. Among home care providers, reasons for staff leaving during the COVID-19 emergency included burnout and stress, in addition to better pay and working conditions elsewhere [245]. A 2022 qualitative study looking into the effect of Brexit on the social care workforce in Scotland found that managers witnessed a considerable decline in the "number and quality" ([246], p. 6) of job applications, as a consequence of the reduction in EU applicants [246]. Understaffed services are likely to impact on inequalities in unmet care need, for example through longer waiting lists for LA-funded care. Therefore, further research in a more recent context is important, although at the time of writing, data collected after the end of the COVID-19 public health emergency is still likely to be limited.

Further work should also focus on the social care reforms that are planned to be implemented from October 2025. The review of social care pathways in chapter 2 focused on the post-Care Act 2014 context, and the data analysis and the economic model also focused on this context. However, important policy changes are expected from October 2025: a cap on lifetime personal care costs of £86,000 will be introduced; capital thresholds for LA-funded care will be raised to £20,000 (lower limit) and £100,000 (upper limit) [5, 59]. These reforms are expected to cause an increase in the number of people going through LA assessments and receiving LA-funded care. Therefore, concerns have been raised that the reforms may worsen waiting lists [5]. They may also lead to an increase in the number of people partially funded by the LA while being able to afford privately funded care. Future modelling work should focus on these reforms.

7.6. Conclusion

This PhD study has contributed towards a better understanding of the determinants and outcomes of unmet care need among older people living in private households in England. The study has also focused on the costs of unmet need for the NHS, personal social services, and for the private payer. In investigating the determinants of unmet need, it has considered whether an equity case could be made for addressing unmet social care needs. Moreover, taking into account the consequences and costs of unmet need as well as the effects of home care reported in the literature, it has assessed whether an economic case could be made for reducing unmet need by shortening waiting lists for home care.

The study showed that an equity case can be made for addressing unmet social care needs in policymaking because wealth inequalities in unmet need were observed among people living alone and because people living in more deprived LAs had a higher risk of unmet need. However, research on the determinants of unmet need would be strengthened with more detailed information on the level of older people’s difficulties with activities of daily living and information on whether people without help think they need or want help.

The present work has contributed towards an understanding of whether an economic case can be made for reducing unmet need by shortening waiting lists for home care. It has created a new model structure using care states that incorporate different sources of care and whether needs are met or unmet. However, it has encountered issues of limited evidence, especially on the long-term effects of unmet need and on the effect of home care on the SC-QALY index. Further research on these topics is needed in order to gain the most from the link made in this PhD study between the unmet care need literature and economic modelling methodologies.

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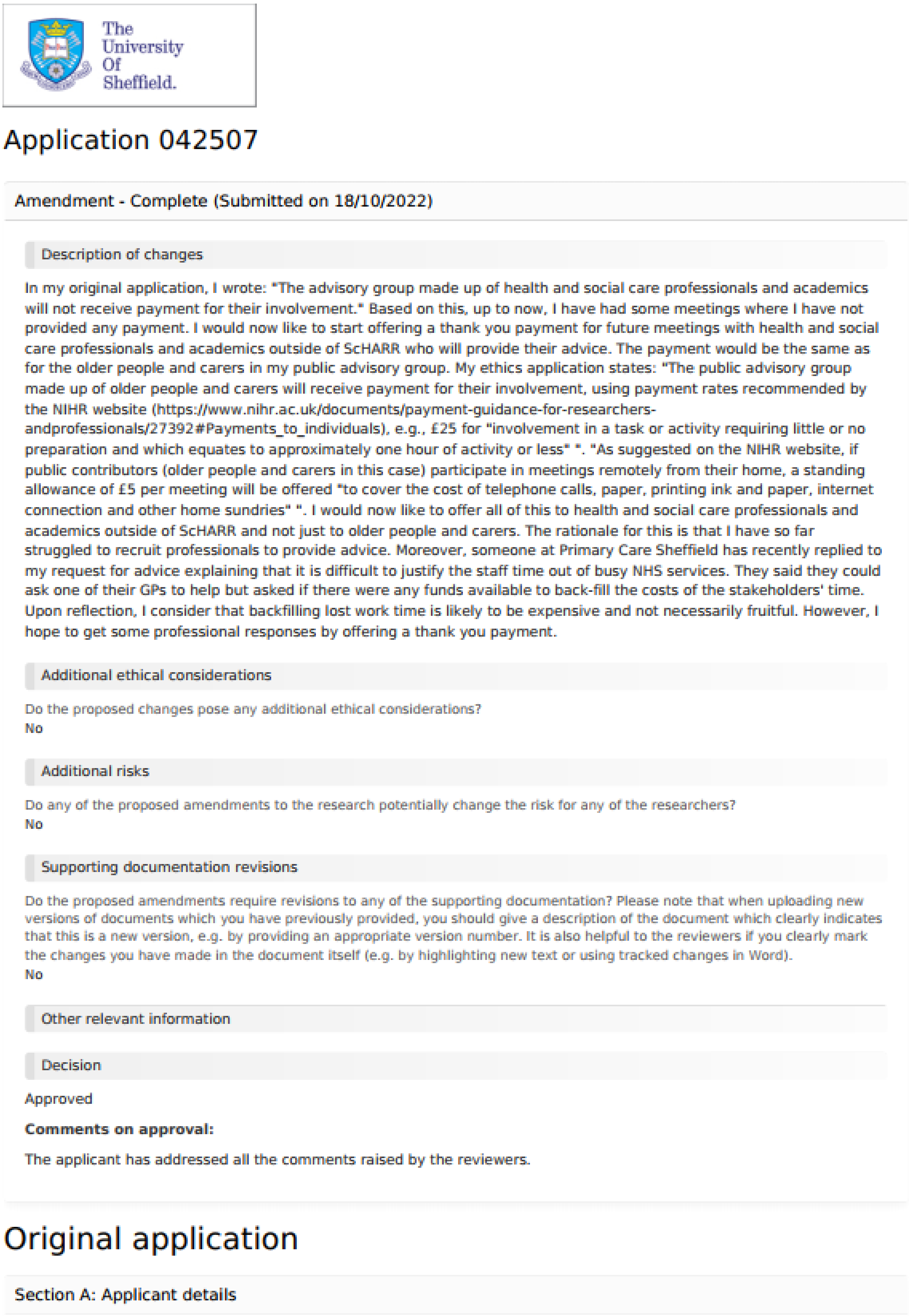
Appendices

Appendices chapter 1

None

Appendices chapter 2

Appendix 2A. Ethics application



The University Of Sheffield.

Application 042507

Amendment - Complete (Submitted on 18/10/2022)

Description of changes

In my original application, I wrote: "The advisory group made up of health and social care professionals and academics will not receive payment for their involvement." Based on this, up to now, I have had some meetings where I have not provided any payment. I would now like to start offering a thank you payment for future meetings with health and social care professionals and academics outside of ScHARR who will provide their advice. The payment would be the same as for the older people and carers in my public advisory group. My ethics application states: "The public advisory group made up of older people and carers will receive payment for their involvement, using payment rates recommended by the NIHR website (https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-andprofessionals/27392#Payments_to_individuals), e.g., £25 for "involvement in a task or activity requiring little or no preparation and which equates to approximately one hour of activity or less" ". "As suggested on the NIHR website, if public contributors (older people and carers in this case) participate in meetings remotely from their home, a standing allowance of £5 per meeting will be offered "to cover the cost of telephone calls, paper, printing ink and paper, internet connection and other home sundries" ". I would now like to offer all of this to health and social care professionals and academics outside of ScHARR and not just to older people and carers. The rationale for this is that I have so far struggled to recruit professionals to provide advice. Moreover, someone at Primary Care Sheffield has recently replied to my request for advice explaining that it is difficult to justify the staff time out of busy NHS services. They said they could ask one of their GPs to help but asked if there were any funds available to back-fill the costs of the stakeholders' time. Upon reflection, I consider that backfilling lost work time is likely to be expensive and not necessarily fruitful. However, I hope to get some professional responses by offering a thank you payment.

Additional ethical considerations

Do the proposed changes pose any additional ethical considerations?
No

Additional risks

Do any of the proposed amendments to the research potentially change the risk for any of the researchers?
No

Supporting documentation revisions

Do the proposed amendments require revisions to any of the supporting documentation? Please note that when uploading new versions of documents which you have previously provided, you should give a description of the document which clearly indicates that this is a new version, e.g. by providing an appropriate version number. It is also helpful to the reviewers if you clearly mark the changes you have made in the document itself (e.g. by highlighting new text or using tracked changes in Word).
No

Other relevant information

Decision

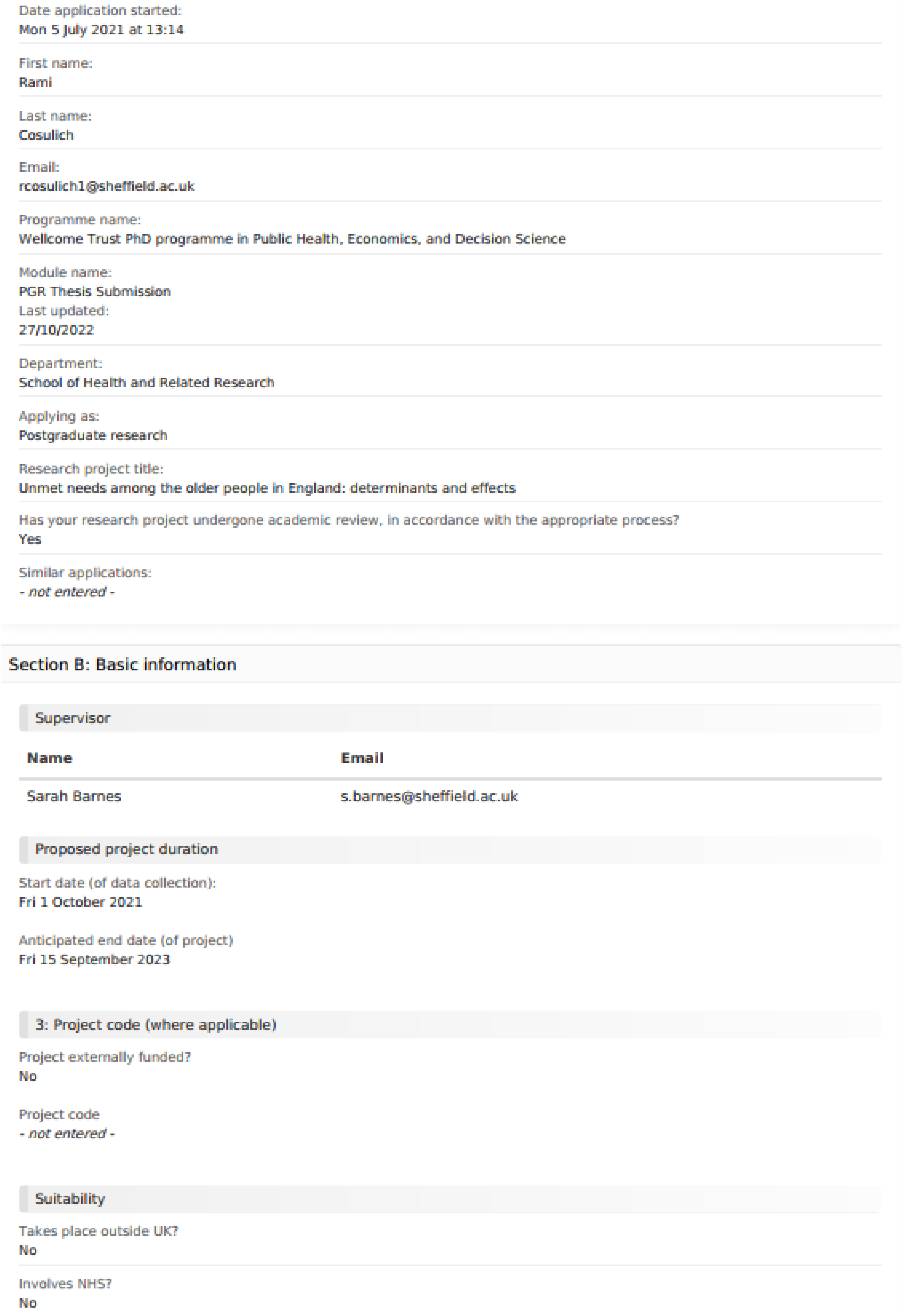
Approved

Comments on approval:

The applicant has addressed all the comments raised by the reviewers.

Original application

Section A: Applicant details



Date application started:
Mon 5 July 2021 at 13:14

First name:
Rami

Last name:
Cosulich

Email:
rcosulich1@sheffield.ac.uk

Programme name:
Wellcome Trust PhD programme in Public Health, Economics, and Decision Science

Module name:
PGR Thesis Submission
Last updated:
27/10/2022

Department:
School of Health and Related Research

Applying as:
Postgraduate research

Research project title:
Unmet needs among the older people in England: determinants and effects

Has your research project undergone academic review, in accordance with the appropriate process?
Yes

Similar applications:
- not entered -

Section B: Basic information

Supervisor

Name	**Email**
Sarah Barnes	s.barnes@sheffield.ac.uk

Proposed project duration

Start date (of data collection):
Fri 1 October 2021

Anticipated end date (of project)
Fri 15 September 2023

3: Project code (where applicable)

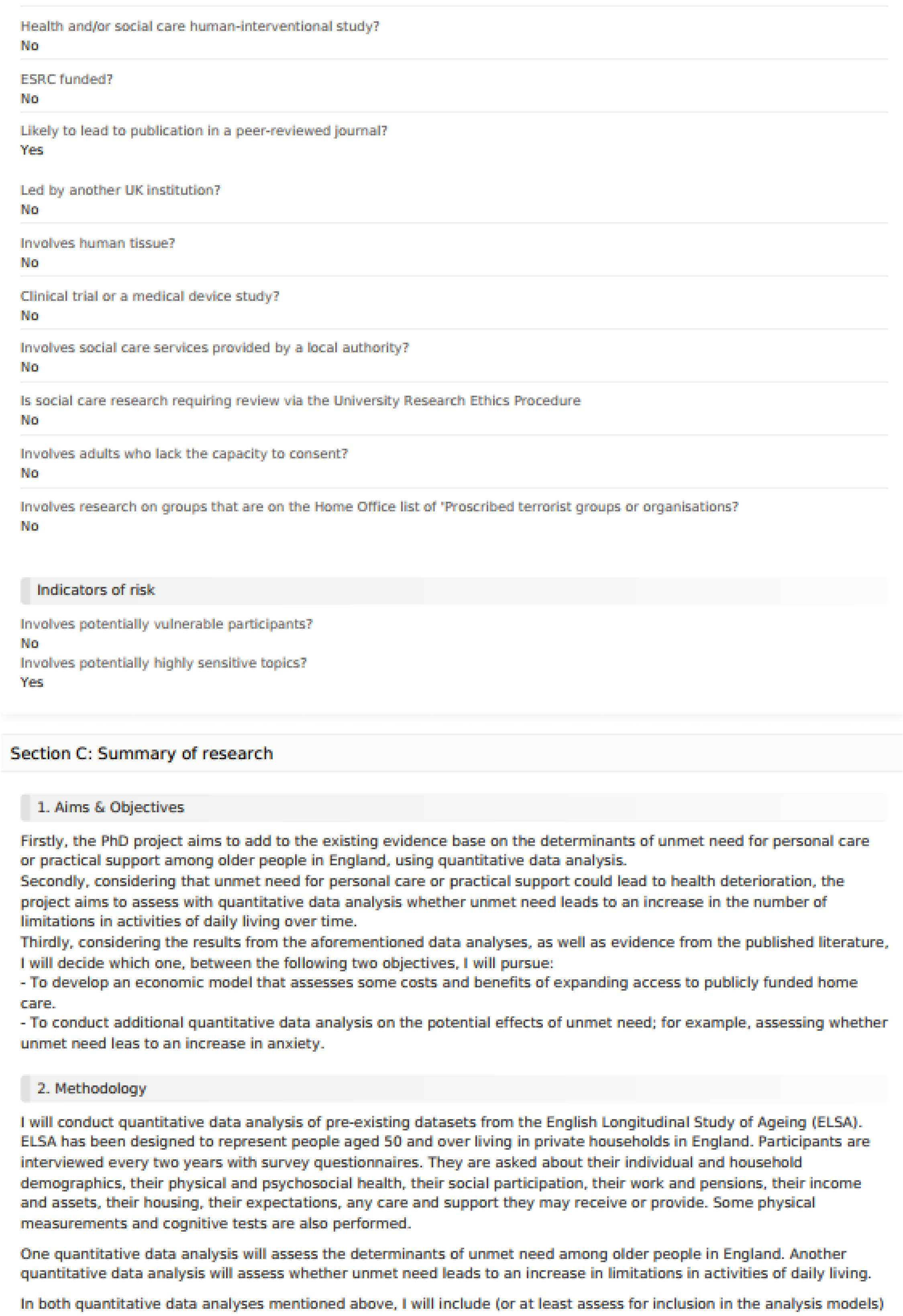
Project externally funded?
No

Project code
- not entered -

Suitability

Takes place outside UK?
No

Involves NHS?
No



Health and/or social care human-interventional study?
No

ESRC funded?
No

Likely to lead to publication in a peer-reviewed journal?
Yes

Led by another UK institution?
No

Involves human tissue?
No

Clinical trial or a medical device study?
No

Involves social care services provided by a local authority?
No

Is social care research requiring review via the University Research Ethics Procedure
No

Involves adults who lack the capacity to consent?
No

Involves research on groups that are on the Home Office list of 'Proscribed terrorist groups or organisations?
No

Indicators of risk

Involves potentially vulnerable participants?
No
Involves potentially highly sensitive topics?
Yes

Section C: Summary of research

1. Aims & Objectives

Firstly, the PhD project aims to add to the existing evidence base on the determinants of unmet need for personal care or practical support among older people in England, using quantitative data analysis.
Secondly, considering that unmet need for personal care or practical support could lead to health deterioration, the project aims to assess with quantitative data analysis whether unmet need leads to an increase in the number of limitations in activities of daily living over time.
Thirdly, considering the results from the aforementioned data analyses, as well as evidence from the published literature, I will decide which one, between the following two objectives, I will pursue:
- To develop an economic model that assesses some costs and benefits of expanding access to publicly funded home care.
- To conduct additional quantitative data analysis on the potential effects of unmet need; for example, assessing whether unmet need leas to an increase in anxiety.

2. Methodology

I will conduct quantitative data analysis of pre-existing datasets from the English Longitudinal Study of Ageing (ELSA). ELSA has been designed to represent people aged 50 and over living in private households in England. Participants are interviewed every two years with survey questionnaires. They are asked about their individual and household demographics, their physical and psychosocial health, their social participation, their work and pensions, their income and assets, their housing, their expectations, any care and support they may receive or provide. Some physical measurements and cognitive tests are also performed.

One quantitative data analysis will assess the determinants of unmet need among older people in England. Another quantitative data analysis will assess whether unmet need leads to an increase in limitations in activities of daily living.

In both quantitative data analyses mentioned above, I will include (or at least assess for inclusion in the analysis models) the following variables from the ELSA datasets: socio-demographic variables (for example, age, gender, ethnicity, marital status, household size), social inclusion variables (for example, frequency of contacts with friends or relatives), health-related variables (for example, number of limitations with activities of daily living, level of cognition, any health diagnoses, self-reported health), variables relating to the receipt of care and support and the use of aids, socio-economic variables (for example, wealth, housing tenure, income, educational qualifications) and geographical variables (for example, type of local authority, Index of Multiple Deprivation quintile, rural/urban classification). In the analysis on whether unmet need leads to an increase in limitations in activities of daily living, I will also include health behaviour variables (for example, relating to smoking, alcohol consumption, physical activity).

I have also asked the UK Data Service to access ELSA data stating the local authority (LA) district where each participant lives, because I plan to link ELSA data to publicly available data on LA characteristics, such as: expenditure on community-based social care for people aged 65 and over for each LA, which is available from the NHS Digital website, divided by the number of people aged 65 and over in each LA, which is available from the ONS website; the quality of information and advice provided by each LA, as judged by an Independent Age 2016 report.

After the quantitative data analyses described above, I will either conduct economic modelling using the results from data analysis and/or published evidence, or further quantitative data analysis on the effects of unmet need, using the same kind of variables mentioned above.

A public advisory group of older people and carers from different areas of England has been set up. If possible, an advisory group of health and social care professionals and academics will also be set up. The aim of these groups is to provide advice on research choices as well as on interpretation and dissemination of results. Members of the advisory groups will provide their advice through group discussions, or if this is not possible, by email or individual call. The group members will not take part in the analysis of the data and will not be part of the research team.

The public advisory group made up of older people and carers will receive payment for their involvement, using payment rates recommended by the NIHR website (https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392#Payments_to_individuals), e.g., £25 for "involvement in a task or activity requiring little or no preparation and which equates to approximately one hour of activity or less".
When payment will be offered, advisory group members will be told that the NIHR Centre for Engagement and Dissemination strongly advises anyone who receives welfare benefits to seek expert, personalised advice before accepting payment for involvement. They will also be told that they have the option to be paid at a lower rate or to volunteer, in consideration of any welfare benefit they may be receiving.

The advisory group made up of health and social care professionals and academics will not receive payment for their involvement.

The decision over whether meetings should be in person at the University of Sheffield or on Google Meet will be made based on the groups' preferences. If a group prefers to meet in person, any travel cost will be reimbursed as soon as possible. Subsistence costs, i.e., costs "for time spent away from home and the costs that need to be met because of this, for example paying for meals, snacks and refreshments" (NIHR website), will also be reimbursed as soon as possible. Any cost of a replacement carer for carers and of a personal assistant/support worker for people with disability will also be covered, as recommended on the NIHR website. Before any travel is planned, participants will be asked what kind of payment proof they can provide for replacement carer costs and personal assistant costs, and a check will be made with university administrators to ensure that reimbursements can be made.
The NIHR website recommends that when people are in receipt of benefits, they must be reimbursed the exact amount, not a rounded up figure, as rounded up amounts are treated as earnings.

As suggested on the NIHR website, if public contributors (older people and carers in this case) participate in meetings remotely from their home, a standing allowance of £5 per meeting will be offered "to cover the cost of telephone calls, paper, printing ink and paper, internet connection and other home sundries". Again, participants will be reminded of the NIHR recommendation for people in receipt of welfare benefits to seek personalised advice before accepting any payment.

3. Personal Safety

Have you completed your departmental risk assessment procedures, if appropriate?

Not applicable

Raises personal safety issues?

Yes

The research area can be emotionally demanding. I will regularly check how I feel emotionally. If I feel the research is affecting me emotionally, I will talk with my supervisors and mentor, I will consider getting involved in the Emotionally Demanding Research Network at The University of Sheffield and I will consider using the University's Counselling Service.

Section D: About the participants

1. Potential Participants

I will only use pre-existing datasets.

2. Recruiting Potential Participants

I will only use pre-existing datasets.

2.1. Advertising methods

Will the study be advertised using the volunteer lists for staff or students maintained by CiCS? No

- *not entered* -

3. Consent

Will informed consent be obtained from the participants? (i.e. the proposed process) No

I will be using pre-existing datasets.

I will not obtain informed consent from the members of the advisory groups. Their eventual contribution to the interpretation of findings will be advisory and form part of a wider interpretation, which will be carried out by myself and my supervisory team. In any reporting of my findings, no individuals from the advisory groups will be identifiable.

4. Payment

Will financial/in kind payments be offered to participants? No

5. Potential Harm to Participants

What is the potential for physical and/or psychological harm/distress to the participants?

I will be using pre-existing datasets.

How will this be managed to ensure appropriate protection and well-being of the participants?

I will be using pre-existing datasets.

6. Potential harm to others who may be affected by the research activities

Which other people, if any, may be affected by the research activities, beyond the participants and the research team?

Older people and carers in the public advisory group may be affected emotionally by their participation in meetings about my research. However, I will try to keep discussions focused on decisions needed for my research rather than asking them about their personal experiences. They may bring up their own experiences but I will not encourage them to go into detail.

What is the potential for harm to these people?

No potential for harm.

How will this be managed to ensure appropriate safeguarding of these people?

Not applicable.

7. Reporting of safeguarding concerns or incidents

What arrangements will be in place for participants, and any other people external to the University who are involved in, or affected by, the research, to enable reporting of incidents or concerns?

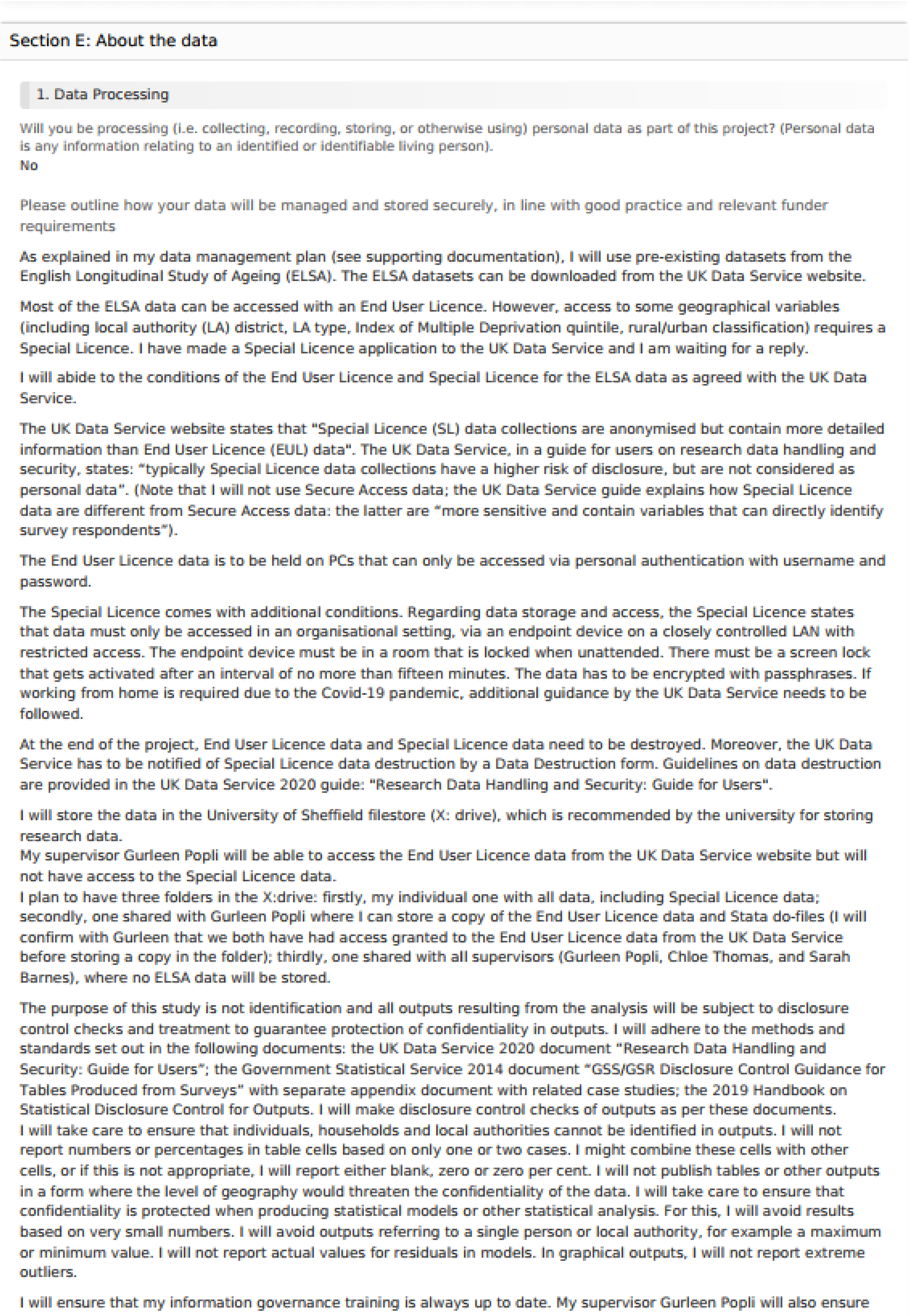
Older people and carers in the public advisory group will be informed that they can report any safeguarding incidents or concerns to the Designated Safeguarding Contact.

Who will be the Designated Safeguarding Contact(s)?

My primary supervisor Sarah Barnes.

How will reported incidents or concerns be handled and escalated?

Sarah Barnes will deal with any initial concerns and escalate appropriately to Mark Strong, Dean (general) should they arise.



Section E: About the data

1. Data Processing

Will you be processing (i.e. collecting, recording, storing, or otherwise using) personal data as part of this project? (Personal data is any information relating to an identified or identifiable living person).
No

Please outline how your data will be managed and stored securely, in line with good practice and relevant funder requirements

As explained in my data management plan (see supporting documentation), I will use pre-existing datasets from the English Longitudinal Study of Ageing (ELSA). The ELSA datasets can be downloaded from the UK Data Service website.

Most of the ELSA data can be accessed with an End User Licence. However, access to some geographical variables (including local authority (LA) district, LA type, Index of Multiple Deprivation quintile, rural/urban classification) requires a Special Licence. I have made a Special Licence application to the UK Data Service and I am waiting for a reply.

I will abide to the conditions of the End User Licence and Special Licence for the ELSA data as agreed with the UK Data Service.

The UK Data Service website states that "Special Licence (SL) data collections are anonymised but contain more detailed information than End User Licence (EUL) data". The UK Data Service, in a guide for users on research data handling and security, states: "typically Special Licence data collections have a higher risk of disclosure, but are not considered as personal data". (Note that I will not use Secure Access data; the UK Data Service guide explains how Special Licence data are different from Secure Access data: the latter are "more sensitive and contain variables that can directly identify survey respondents").

The End User Licence data is to be held on PCs that can only be accessed via personal authentication with username and password.

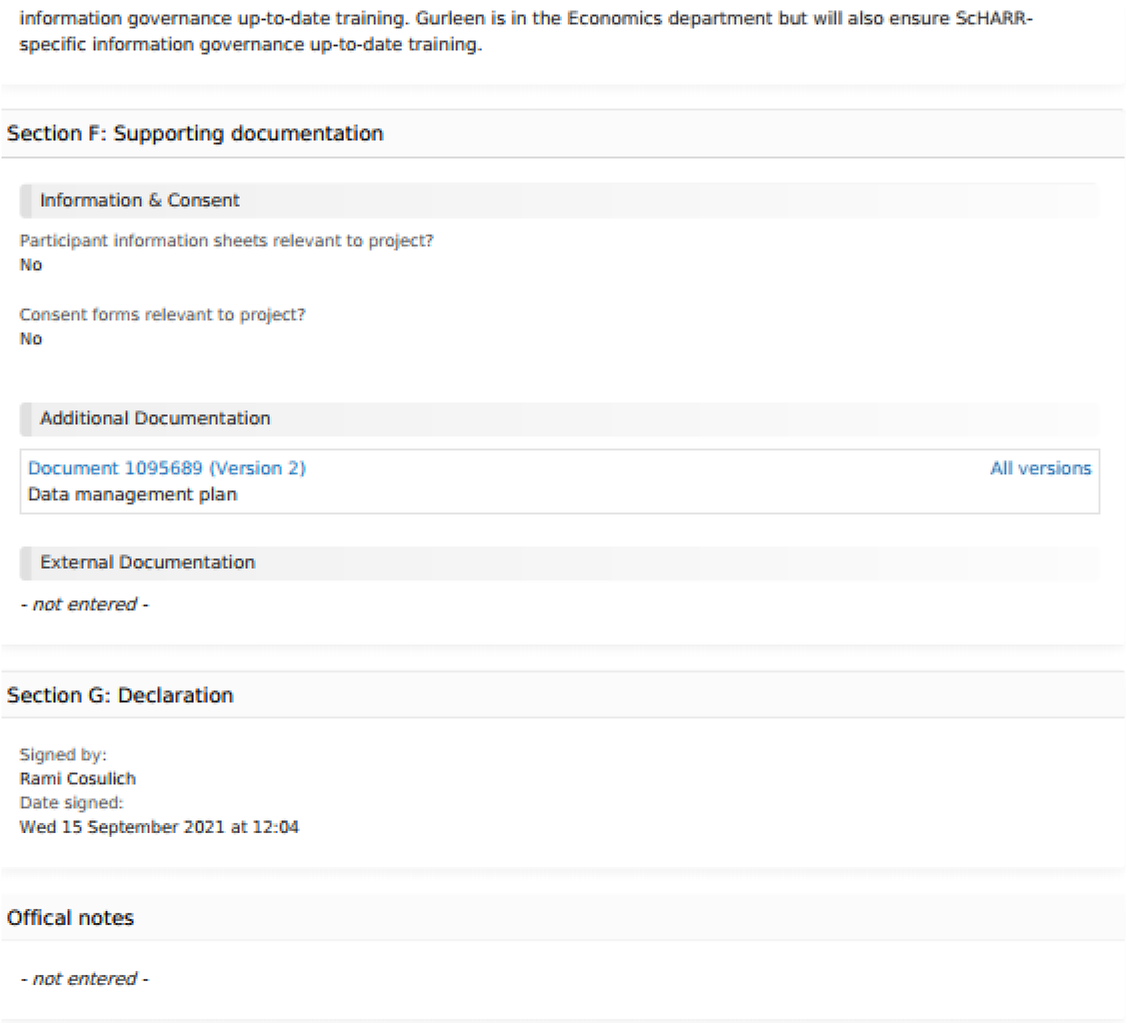
The Special Licence comes with additional conditions. Regarding data storage and access, the Special Licence states that data must only be accessed in an organisational setting, via an endpoint device on a closely controlled LAN with restricted access. The endpoint device must be in a room that is locked when unattended. There must be a screen lock that gets activated after an interval of no more than fifteen minutes. The data has to be encrypted with passphrases. If working from home is required due to the Covid-19 pandemic, additional guidance by the UK Data Service needs to be followed.

At the end of the project, End User Licence data and Special Licence data need to be destroyed. Moreover, the UK Data Service has to be notified of Special Licence data destruction by a Data Destruction form. Guidelines on data destruction are provided in the UK Data Service 2020 guide: "Research Data Handling and Security: Guide for Users".

I will store the data in the University of Sheffield filestore (X: drive), which is recommended by the university for storing research data.
My supervisor Gurleen Popli will be able to access the End User Licence data from the UK Data Service website but will not have access to the Special Licence data.
I plan to have three folders in the X:drive: firstly, my individual one with all data, including Special Licence data; secondly, one shared with Gurleen Popli where I can store a copy of the End User Licence data and Stata do-files (I will confirm with Gurleen that we both have had access granted to the End User Licence data from the UK Data Service before storing a copy in the folder); thirdly, one shared with all supervisors (Gurleen Popli, Chloe Thomas, and Sarah Barnes), where no ELSA data will be stored.

The purpose of this study is not identification and all outputs resulting from the analysis will be subject to disclosure control checks and treatment to guarantee protection of confidentiality in outputs. I will adhere to the methods and standards set out in the following documents: the UK Data Service 2020 document "Research Data Handling and Security: Guide for Users"; the Government Statistical Service 2014 document "GSS/GSR Disclosure Control Guidance for Tables Produced from Surveys" with separate appendix document with related case studies; the 2019 Handbook on Statistical Disclosure Control for Outputs. I will make disclosure control checks of outputs as per these documents.
I will take care to ensure that individuals, households and local authorities cannot be identified in outputs. I will not report numbers or percentages in table cells based on only one or two cases. I might combine these cells with other cells, or if this is not appropriate, I will report either blank, zero or zero per cent. I will not publish tables or other outputs in a form where the level of geography would threaten the confidentiality of the data. I will take care to ensure that confidentiality is protected when producing statistical models or other statistical analysis. For this, I will avoid results based on very small numbers. I will avoid outputs referring to a single person or local authority, for example a maximum or minimum value. I will not report actual values for residuals in models. In graphical outputs, I will not report extreme outliers.

I will ensure that my information governance training is always up to date. My supervisor Gurleen Popli will also ensure



information governance up-to-date training. Gurleen is in the Economics department but will also ensure ScHARR-specific information governance up-to-date training.

Section F: Supporting documentation

Information & Consent

Participant information sheets relevant to project?
No

Consent forms relevant to project?
No

Additional Documentation

Document 1095689 (Version 2) Data management plan	All versions

External Documentation

- not entered -

Section G: Declaration

Signed by:
Rami Cosulich
Date signed:
Wed 15 September 2021 at 12:04

Offical notes

- not entered -

Appendix 2B. Data management plan

DATA MANAGEMENT PLAN

PhD study: Unmet needs among the older people in England: determinants and effects
PhD student: Rami Cosulich

DEFINING YOUR DATA

- **What data will you collect or create during the project?**
- **How will the data be collected or created, and over what time period?**
- **What formats will your digital data be in?**
- **Approximately how much digital data will be generated during the project?**
- **Are you using pre-existing datasets? Give details if possible, including conditions of use**

I will use pre-existing datasets from the English Longitudinal Study of Ageing (ELSA). ELSA has been designed to represent people aged 50 and over living in private households in England. Participants are interviewed every two years with survey questionnaires. Some people have been in the study since 2002, other people ("refreshment samples") have entered the study at a later date.

The ELSA datasets can be downloaded in Stata, SPSS or TAB format from the UK Data Service website. I have already downloaded part of the data in Stata format.

Most of the ELSA data can be accessed with an End User Licence. However, access to some geographical variables (including local authority (LA) district, LA type, Index of Multiple Deprivation quintile, rural/urban classification) requires a Special Licence.

The End User Licence includes various terms and conditions; for example, the data is to be held on PCs that can only be accessed via personal authentication with username and password. Moreover, bibliographic details of any published work using the data must be supplied to the UK Data Service.

The Special Licence comes with additional conditions. Regarding data storage and access, the Special Licence states that data must only be accessed in an organisational setting, via en endpoint device on a closely controlled LAN with restricted access. The endpoint device must be in a room that is locked when unattended. There must be a screen lock that gets activated after an interval of no more than fifteen minutes. The data has to be encrypted with passphrases. If working from home is required due to the Covid-19 pandemic, additional guidance by the UK Data Service needs to be followed.

At the end of the project, End User Licence data and Special Licence data need to be destroyed. Moreover, the UK Data Service has to be notified of Special Licence data destruction by a Data Destruction form. Guidelines on data destruction are provided in the UK Data Service 2020 guide: "Research Data Handling and Security: Guide for Users".

The citation for using ELSA data is:

Banks, J., Batty, GD., Coughlin, K., Dangerfield, P., Marmot, M., Nazroo, J., Oldfield, Z., Steel, N., Steptoe, Wood, M., Zaninotto, P. (2019). English Longitudinal Study of Ageing: Waves 0-9, 1998-2019. [data collection]. 33rd Edition. UK Data Service. SN: 5050, http://doi.org/10.5255/UKDA-SN-5050-20

I also plan to link ELSA data to LA characteristics such as: expenditure on community-based social care for people aged 65 and over for each LA, which is publicly available from the NHS Digital website, divided by the number of people aged 65 and over in each LA, which is publicly available from the ONS website; the quality of information and advice provided by each LA, as judged by a publicly available Independent Age 2016 report.

LOOKING AFTER YOUR DATA

- **How will you make data easier to understand and use? (e.g. creating a README file)**
- **Where will you store digital and physical data during the project?**
- **How will you name and organise your data files?**
- **How will you ensure data is backed up? (e.g. using University research data storage)**
- **How often will you check your backup files? (e.g. on backup, at set intervals)**
- **Will you use extra security precautions for any of your digital or physical data? (e.g. for sensitive and/or personal data)**

I will store the data in the University of Sheffield filestore (X: drive), which is recommended by the university for storing research data.

I have downloaded the End User Licence ELSA data from wave 1 to wave 9. The volume of the folder with these data is 1.14 GB. I will download the Special Licence ELSA data when I get it and I still need to download data relating to LA characteristics from publicly available sources, so I am not sure about volume. Volume should not be an issue because storage space on the X:drive for each research project is up to 10TB.

The organisation of the ELSA dataset folders will be left the same as it was when downloaded from ELSA; for the End User Licence data, the datasets for all waves are all in the same folder; each dataset is named starting with wave_ followed by the wave number, then a brief description of the dataset (e.g. nurse_data). An ELSA Special Licence folder and a folder with datasets from publicly available sources will also be created.

I will use the software Stata MP4, version 16 for Windows. Stata enables me to create do-files to save all my commands with notes, so I can have a clear record of all the data processing that I do. My code will be saved in multiple do-files saved in a master folder containing all the folders mentioned so far. Stata do-files will be named using the following elements in this set order: RC code, w (for wave), wave number, brief description of do-file purpose, date in format yyyy.mm.dd. There will also be a master do-file that sets the order in which other do-files need to run. I will create an archive folder where I will transfer old versions of do-files.

My supervisor Gurleen Popli will be able to access the End User Licence data from the UK Data Service website but will not have access to the Special Licence data.

I plan to have three folders in the X:drive: firstly, my individual one with all data, including Special Licence data; secondly, one shared with Gurleen Popli where I can store a copy of the End User Licence data and Stata do-files (I will confirm with Gurleen that we both have had access granted to the End User Licence data from the UK Data Service before storing a copy in the folder); thirdly, one shared with all supervisors (Gurleen Popli, Chloe Thomas, and Sarah Barnes), where no ELSA data will be stored.

Using the X:drive will ensure that data is backed up because the University standard research storage is backed up to protect against failures and disasters, and enables file recovery as well. The ELSA data is also held by the UK Data Service, while other datasets are publicly available, so backup would also be ensured by this.

I will use extra security precautions for the Special Licence data, as set out in the UK Data Service 2020 guide "Research Data Handling and Security: Guide for Users" and as outlined in the first section of this data management plan.

ARCHIVING YOUR DATA

- **What data will be archived (stored on a long-term basis) at the end of the project?**
- **How long will the data be stored for? (e.g. standard TUoS retention period of 10 years)**
- **Where will the archive be stored? (e.g. subject-specific repository, or ORDA)**
- **Who will archive the data? (e.g. you, or your supervisor)**
- **If you plan to use storage other than a repository, who will be responsible for the data?**

Upon project completion, I will destroy the ELSA data, as outlined in the first section of this data management plan. The publicly available datasets do not need archiving; references to where these datasets can be located will be included in the thesis document.
I can include the Stata do-files commands in the appendix of my thesis document.

SHARING YOUR DATA

- **How will you make your data available outside the research group after the project? (e.g. through data repository, or access on request via data availability statement)**
- **Will you make all of your data available, or are there reasons you can't do this? (e.g. personal data, commercial or legal restrictions, very large datasets)**
- **How might you make more of your data available? (e.g. anonymisation, participant consent, analysed data only)**
- **What licence might you attach to your data to say how it can be reused and shared?**

Not applicable, I will destroy the ELSA data at project completion and the other datasets are publicly available.

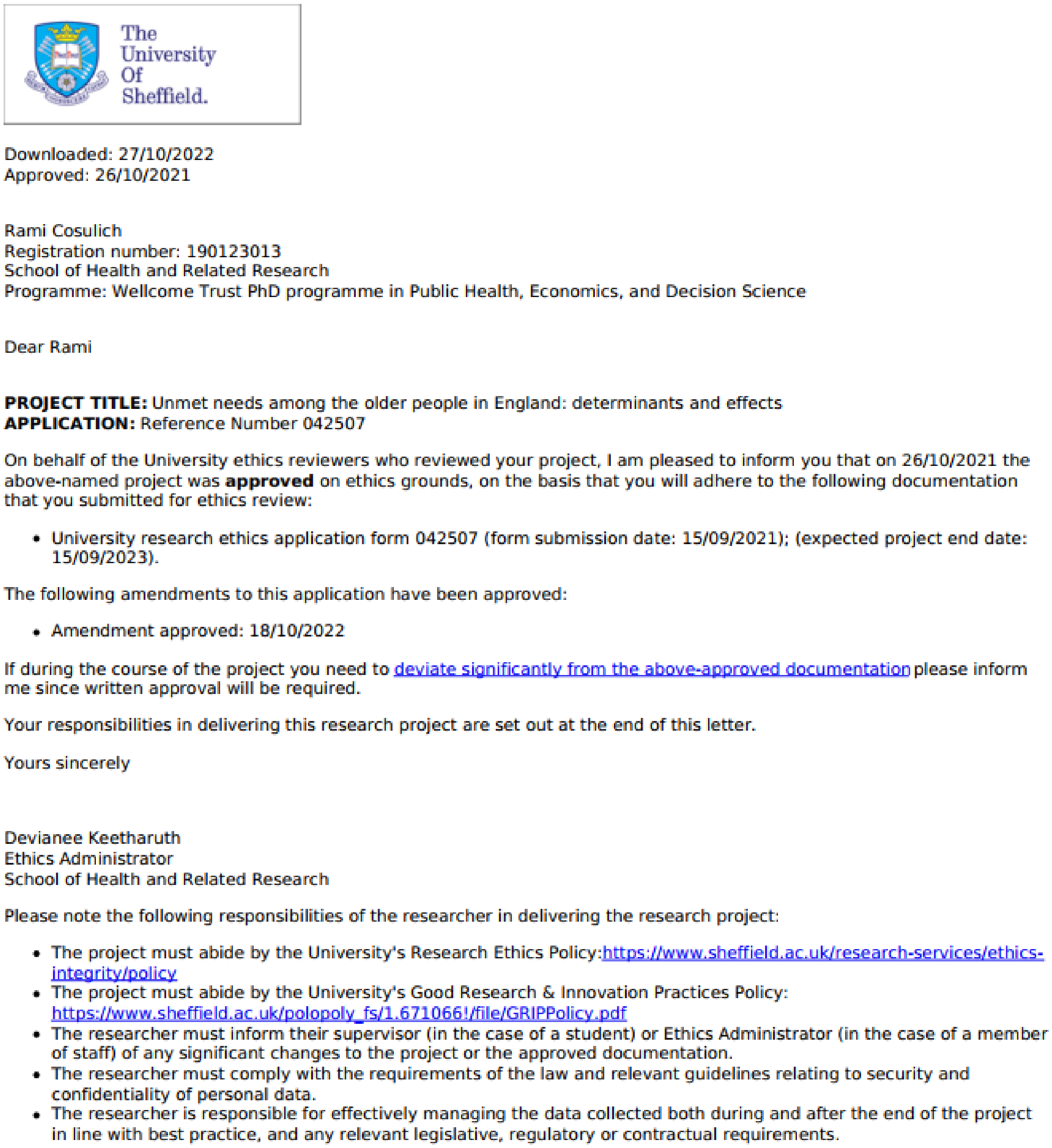
IMPLEMENTING YOUR PLAN

- **Who is responsible for making sure the plan is followed? (e.g. you, your supervisor)**
- **How often will the plan be reviewed and updated? (e.g. if the project changes, yearly)**
- **What actions have you identified from the rest of this plan? (e.g. selecting a repository, requesting University research data storage)**

I am responsible for making sure this plan is followed. I will review this plan yearly and if needed I will update it in agreement with supervisors.

Actions identified from this plan: request standard research storage on the X:drive. I am currently storing the End User Licence ELSA data on the university Google Drive. Although this is fine because the data are not highly sensitive, I was advised at a university webinar on research data management that the X:drive is better.

Appendix 2C. Ethics approval letter



The University Of Sheffield.

Downloaded: 27/10/2022
Approved: 26/10/2021

Rami Cosulich
Registration number: 190123013
School of Health and Related Research
Programme: Wellcome Trust PhD programme in Public Health, Economics, and Decision Science

Dear Rami

PROJECT TITLE: Unmet needs among the older people in England: determinants and effects
APPLICATION: Reference Number 042507

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 26/10/2021 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 042507 (form submission date: 15/09/2021); (expected project end date: 15/09/2023).

The following amendments to this application have been approved:

- Amendment approved: 18/10/2022

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Devianee Keetharuth
Ethics Administrator
School of Health and Related Research

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:https://www.sheffield.ac.uk/research-services/ethics-integrity/policy
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix 2D. Review protocol

Review question

What are the social care pathways for older people with functional limitations living in private households in England? What are the social care pathways for their carers?

Review objectives

To outline the social care pathways for older people with functional limitations living in private households in England, as set out in official government guidance and policies.

To briefly outline the social care pathways for their carers, as set out in official government guidance and policies.

Population

Older people (aged 65 and over) who have limitations in personal activities of daily living or instrumental activities of daily living and are living in their own home, and their carers. Both people with eligible and ineligible needs will be included.

Context

- England
- Care pathways since 1st April 2015 (when implementation of the Care Act 2014 started)

Intervention

Publicly funded social care, defined for this review as including:

- information and advice
- personal care (help with activities such as washing and dressing)
- domestic help (help with tasks such as cooking and cleaning)
- equipment and adaptations
- so-called "*non-traditional services*" ([18], p. 2) such as courses or sport activities
- services for carers

Inclusion criteria

Use the following resources:

- NICE guidelines

- National government website www.gov.uk, including the DHSC care and support statutory guidance

Exclusion criteria

Exclude:

- documents relating to the time period prior to April 2015
- resources other than official guidance and policies, for example reports or studies by charities, academics and think tanks
- guidance relating to Covid-19
- resources focusing on care pathways for specific conditions
- reports or sections of reports focusing on the quality of services provided in practice, such as:
    - surveys or qualitative studies focusing on service quality
    - papers focusing on quality ratings by the Care Quality Commission
    - papers on the impact of budget cuts on service quality
- papers on the number of people receiving services, expenditure, variation between local authorities, trends in funding pressures
- documents or sections of documents focusing on:
    - residential care
    - social care workforce, e.g. training and recruitment
    - a service delivery perspective, e.g. organisational structures, skill-mix or monitoring and evaluation of services
- resources that do not have a national focus, such as information from an LA website
- commentaries, letters, editorials
- papers evaluating the outcomes of interventions, such as randomised clinical trials
- analyses of outcomes or costs

Search strategy

The search strategy will follow published recommendations [49].

Information extraction and synthesis

The Department of Health & Social Care statutory guidance on care and support, which aims to help to implement the Care Act 2014, will be prioritised for its comprehensiveness and accessibility. For topics not covered by the statutory guidance, government websites and NICE guidance will be used. Legislation such as Statutory Instruments and Acts of Parliament will be deprioritised because the Department of Health & Social Care statutory guidance and government websites present information in a more accessible format.

The review will narratively synthesise the most helpful points for a conceptual model which focuses on access to LA-funded care. The review will not aim to be an exhaustive or detailed narrative.

The key points will include:

- universal access and non-universal access services
- access criteria for non-universal services
- essential requirements versus criteria and services allowed to vary locally

Moreover, a brief overview of support for carers and eligibility criteria for carers will be given.

Appendix 2E. Search strategies

Table 46. Recordkeeping of how websites were searched.[12]

Name or resource	Date searched	Date when last accessed (if different)	"Pathway followed, e.g. browsed headings/ searched site" ([49], p. 5)	Notes
Search 1				
www.gov.uk	24.09.2020	16.10.2020	Searched using keyword: disability equipment	
https://www.gov.uk/apply-home-equipment-for-disabled	24.09.2020	16.10.2020	Browsing the section: Related content	Arrived to this link from the search outlined in table row above
https://www.gov.uk/disabled-facilities-grants	24.09.2020	16.10.2020	Browsing	Arrived to this link from browsing related content on link in table row above
Search 2				
www.gov.uk	24.09.2020	16.10.2020	Searched using keyword "disability benefits"	
https://www.gov.uk/financial-help-disabled	24.09.2020	16.10.2020	Browsing	Arrived to this link from the search in gov.uk using keyword "disability benefits"
https://www.gov.uk/financial-help-disabled/disability-and-sickness-benefits	24.09.2020	16.10.2020	Browsing	Arrived to this link from browsing link in table row above
https://www.gov.uk/attendance-allowance, https://www.gov.uk/carers-allowance, https://www.gov.uk/carers-credit	24.09.2020	16.10.2020	Browsing	Arrived to this link from browsing link in table row above
https://www.gov.uk/if-you-become-disabled	24.09.2020	16.10.2020	Browsing	Arrived to this link from the search in gov.uk using keyword "disability benefits"

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[12] Table template adapted from published paper on systematic searching of websites and online resources (49. Stansfield C, Dickson K, Bangpan M. Exploring issues in the conduct of website searching and other online sources for systematic reviews: how can we be systematic? . Syst Rev [Internet]. 2016 [cited 2020 September 20]; 5:191 [9 pages]. Available from: https://doi.org/10.1186/s13643-016-0371-9.)

Name or resource	**Date searched**	**Date when last accessed (if different)**	**“Pathway followed, e.g. browsed headings/ searched site” ([49], p. 5)**	**Notes**
https://www.gov.uk/rights-disabled-person	24.09.2020	16.10.2020	Browsing	Arrived to this link from browsing link in table row above
https://www.gov.uk/disability-premiums	24.09.2020	16.10.2020	Browsing	Arrived to this link from the search in gov.uk using keyword “disability benefits”
Search 3				
Clicked on heading “Disabled People” on www.gov.uk	12.10.2020	19.10.2020	Browsing	
https://www.gov.uk/browse/disabilities	12.10.2020	19.10.2020	Browsing	Arrived to this link from heading “Disabled People” on www.gov.uk
https://www.gov.uk/browse/disabilities/benefits	12.10.2020	19.10.2020	Browsing	Arrived to this link from https://www.gov.uk/browse/disabilities
https://www.gov.uk/browse/disabilities/carers	12.10.2020	19.10.2020	Browsing	Arrived to this link from https://www.gov.uk/browse/disabilities
https://www.gov.uk/browse/disabilities/carers	12.10.2020	19.10.2020	Browsing	Arrived to this link from https://www.gov.uk/browse/disabilities
https://www.gov.uk/day-care-centres	12.10.2020	19.10.2020	Browsing	Arrived to this link from https://www.gov.uk/browse/disabilities/carers
https://www.gov.uk/browse/disabilities/equipment	12.10.2020	19.10.2020	Browsing	Arrived to this link from https://www.gov.uk/browse/disabilities
https://www.gov.uk/mobility-scooters-and-powered-wheelchairs-rules	12.10.2020	19.10.2020	Browsing	Arrived to this link from https://www.gov.uk/browse/disabilities/equipment
https://www.gov.uk/browse/disabilities/rights	12.10.2020	19.10.2020	Browsing	Arrived to this link from https://www.gov.uk/browse/disabilities
Search 4				
www.gov.uk	12.10.2020	19.10.2020	Searched using keyword: Older people	
https://www.gov.uk/universal-credit	12.10.2020	19.10.2020	Browsing	Arrived at this link by searching “older people” on gov.uk

Name or resource	Date searched	Date when last accessed (if different)	"Pathway followed, e.g. browsed headings/ searched site" ([49], p. 5)	Notes
https://www.gov.uk/guidance/housing-for-older-and-disabled-people	12.10.2020	19.10.2020	Browsing	Arrived at this link by searching "older people" on gov.uk
https://www.gov.uk/winter-fuel-payment	12.10.2020	19.10.2020	Browsing	Arrived at this link by searching "older people" on gov.uk
https://www.gov.uk/government/publications/quality-standards-for-care-services-for-older-people	12.10.2020	19.10.2020	Browsing	Arrived at this link by searching "older people" on gov.uk
Search 5				
www.gov.uk	17.09.2020	19.10.2020	Searched using keyword: Care Act 2014	
Search 6				
www.nice.org.uk	13.10.2020	19.10.2020	Search using keyword: older people, filtering for guidance only	

Table 47. Recordkeeping of "initial screening and information management"[13] ([49], p. 6).

Name of resource and search terms if relevant	**Automated exporting in RIS/XML?**	**"If no automated exporting available" ([49], p. 6)**			**Number outputted by search function, if applicable**
		No. of promising search outputs (documents or links)	**Number of search output scanned**	**"Approach to screening, e.g. title, then abstract/full text OR first 100 ranked by relevance" ([49], p. 6)**	
Search 1					
www.gov.uk, searched "disability equipment"	No	One title: • Apply for equipment for your home if you're disabled	20	Title screening of page 1 of search outputs sorted by relevance	I got 28,727 results
https://www.gov.uk/apply-home-equipment-for-disabled	No	One heading: • Disabled Facilities Grants	n/a	Browsing headings	n/a
https://www.gov.uk/disabled-facilities-grants	No	Three headings: • What you'll get • Eligibility • How to apply	n/a	Browsing headings	n/a
Search 2					
www.gov.uk, searched "disability benefits"	No	Four headings: • Financial help if you're disabled • Carer's allowance • What to do if you become disabled • Disability premiums	60	Title screening of search outputs sorted by relevance. Stopped after page 3, where there were no relevant titles	I got 525 results on 27 pages
https://www.gov.uk/financial-help-disabled	No	Four headings: •Disability and sickness benefits • Vehicles and transport • Home and housing • On a low income	n/a	Browsed headings and the brief summaries underneath headings	n/a
https://www.gov.uk/financial-help-disabled/disa	No	Four headings: •Disability allowance for adults	n/a	Browsed headings and the brief summaries underneath headings	n/a

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[13] Table template adapted from published paper on systematic searching of websites and online resources (49. Ibid.)

Name of resource and search terms if relevant	**Automated exporting in RIS/XML?**	**“If no automated exporting available” ([49], p. 6)**			**Number outputted by search function, if applicable**
		No. of promising search outputs (documents or links)	**Number of search output scanned**	**“Approach to screening, e.g. title, then abstract/full text OR first 100 ranked by relevance” ([49], p. 6)**	
bility-and-sickness-benefits		•Personal Independence Payment •Attendance Allowance •Carers – carer’s allowance •Carers – carer’s credit			
https://www.gov.uk/attendance-allowance	No	Two headings: •How it works •Eligibility	n/a	Browsed headings and the brief summaries underneath headings	n/a
https://www.gov.uk/carers-allowance	No	Two headings: •How it works •Eligibility	n/a	Browsed headings and the brief summaries underneath headings	n/a
https://www.gov.uk/carers-credit	No	Three headings: •Overview •What you’ll get •Eligibility	n/a	Browsed headings and the brief summaries underneath headings	n/a
https://www.gov.uk/if-you-become-disabled	No	One heading: •Overview	n/a	Browsed headings and the brief summaries underneath headings	n/a
https://www.gov.uk/rights-disabled-person	No	One heading: •Overview	n/a	Browsed headings and the brief summaries underneath headings	n/a
https://www.gov.uk/disability-premiums	No	Three headings: •Overview •What you’ll get •Eligibility	n/a	Browsed headings and the brief summaries underneath headings	n/a
Search 3					
https://www.gov.uk/browse/disabilities	No	Four headings: • Benefits and financial help • Carers •Disability equipment and transport • Disability rights	n/a	Browsed headings	n/a

Name of resource and search terms if relevant	**Automated exporting in RIS/XML?**	**"If no automated exporting available" ([49], p. 6)**			**Number outputted by search function, if applicable**
		No. of promising search outputs (documents or links)	**Number of search output scanned**	**"Approach to screening, e.g. title, then abstract/full text OR first 100 ranked by relevance" ([49], p. 6)**	
https://www.gov.uk/browse/disabilities/benefits	No	Some relevant heading of links already accessed or topics already covered	n/a	Browsed headings	n/a
https://www.gov.uk/browse/disabilities/carers	No	One heading: • Disability day care centres Other relevant headings of links already accessed or topics already covered	n/a	Browsed headings	n/a
https://www.gov.uk/day-care-centres	No	No relevant headings, only request to enter a postcode	n/a	Looked at	n/a
https://www.gov.uk/browse/disabilities/equipment	No	One heading: • Mobility scooters and powered wheelchairs: the rules Other relevant headings of links already accessed or topics already covered	n/a	Browsed headings	n/a
https://www.gov.uk/mobility-scooters-and-powered-wheelchairs-rules	No	No relevant headings	n/a	Looked at	n/a
https://www.gov.uk/browse/disabilities/rights and https://www.gov.uk/rights-disabled-person	No	No relevant headings or content	n/a	Browsed headings and content	n/a
Search 4					
www.gov.uk, searched	No	Four headings: • Universal Credit	40	Title screening of first two pages, on	76,184 results

Name of resource and search terms if relevant	**Automated exporting in RIS/XML?**	**“If no automated exporting available” ([49], p. 6)**			**Number outputted by search function, if applicable**
		No. of promising search outputs (documents or links)	**Number of search output scanned**	**“Approach to screening, e.g. title, then abstract/full text OR first 100 ranked by relevance” ([49], p. 6)**	
“older people”		•Housing for older and disabled people • Winter Fuel Payment • National service framework: older people		the second page no relevant titles	
https://www.gov.uk/universal-credit	No	One heading: •Eligibility	n/a	Browsed headings and content	n/a
https://www.gov.uk/guidance/housing-for-older-and-disabled-people	No	Five headings: • Introduction • Identifying the housing requirements of older and disabled people • Accessible and adaptable housing • Specialist housing for older people • Inclusive design	n/a	Browsed headings and content	n/a
https://www.gov.uk/winter-fuel-payment	No	Three headings: • Overview • Eligibility • What you’ll get	n/a	Browsed headings and content	n/a
https://www.gov.uk/government/publications/quality-standards-for-care-services-for-older-people	No	No relevant headings or content	n/a	Browsed headings and content	n/a
Search 5					
www.gov.uk, searched “Care Act 2014”	No	Four titles: • Care Act 2014: Care and support statutory guidance	180	Title screening of first nine pages of search outputs sorted by relevance, on the ninth page there	I got 133,367 results on

Name of resource and search terms if relevant	**Automated exporting in RIS/XML?**	**“If no automated exporting available” ([49], p. 6)**			**Number outputted by search function, if applicable**
		No. of promising search outputs (documents or links)	**Number of search output scanned**	**“Approach to screening, e.g. title, then abstract/full text OR first 100 ranked by relevance” ([49], p. 6)**	
		• Care Act 2014 Part 1: factsheets •Hospital discharge service: policy and operating model •Assistive technology: definition, examples and safe use		were no relevant titles.	6669 pages.
Search 6					
www.nice.org.uk, search for “older people”, guidance only	No	Six titles: • Older people: independence and mental wellbeing • Falls in older people: assessing risk and prevention • Older people with social care needs and multiple long-term conditions • Home care: delivering personal care and practical support to older people living in their own homes • Mental wellbeing in over 65s: occupational therapy and physical activity interventions • Transitions between inpatient hospital settings and community or care homes settings for adults with social care needs	60	Title screening of first four pages of search outputs sorted by relevance, on the fourth page there were no relevant titles	I got 240 results

Appendix 2F. Excluded resources that were checked full-text

Resource	Exclusion reason
Medicines and Healthcare products Regulatory Agency (2019). *Assistive technology: definitions and safe use*. [Viewed 12 October 2020]. Available from: https://www.gov.uk/government/publications/assistive-technology-definition-and-safe-use/assistive-technology-definition-and-safe-use	This publication focuses on safety rather than on care pathways
National Institute for Health and Care Excellence (NICE) (2008). *Home care: mental wellbeing in over 65s: occupational therapy and physical activity interventions* [PH16]. [Viewed 12 October 2020]. Available from: https://www.nice.org.uk/guidance/ph16/resources/mental-wellbeing-in-over-65s-occupational-therapy-and-physical-activity-interventions-pdf-1996179900613	This is public health guidance for all older people and it is not limited to those with functional limitations. It was not considered key for the conceptual model
National Institute for Health and Care Excellence (NICE) (2015). *Transition between inpatient hospital settings and community or care home settings for adults with social care needs*. [Viewed 12 October 2020]. Available from: https://www.nice.org.uk/guidance/ng27/resources/transition-between-inpatient-hospital-settings-and-community-or-care-home-settings-for-adults-with-social-care-needs-pdf-1837336935877	The content of this guidance was not deemed necessary for the conceptual model, considering that the Department of Health & Social Care statutory guidance (2020) already covers some key points on intermediate care
National Institute for Health and Care Excellence (NICE) (2015c). *Older people with social care needs and multiple long-term conditions*. NICE guideline [NG22]. [Viewed 12 October 2020]. Available from: https://www.nice.org.uk/guidance/ng22/resources/older-people-with-social-care-needs-and-multiple-longterm-conditions-pdf-1837328537797	Guidance on people with specific conditions was excluded and having multiple long-term conditions was considered a specific condition
UK government. *Care Act 2014 Part 1: factsheets*. [Viewed 24 September 2020]. Available from: https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets	The factsheets summarise information presented in the Department of Health & Social Care statutory guidance, which was prioritised for this review
UK government. *Disability rights*. [Viewed 24 September 2020]. Available from: https://www.gov.uk/rights-disabled-person	Content was not considered key for the conceptual model
UK government. *Disability premiums*. [Viewed 24 September 2020]. Available from: https://www.gov.uk/disability-premiums	Disability premiums are for people under pension credit age

Resource	**Exclusion reason**
UK government. *Financial help if you're disabled – Vehicles and transport.* [Viewed 24 September 2020]. Available from: https://www.gov.uk/financial-help-disabled/vehicles-and-transport	Content was not considered key for the conceptual model
UK government. *Home and housing.* [Viewed 24 September 2020]. Available from: https://www.gov.uk/financial-help-disabled/home-and-housing	Some content refers to support already described based on other sources included in the review, for example the disabled facilities grants. Some content refers to support not considered key for the economic model, for example the disabled band reduction scheme relating to council tax
UK government. *Housing for older and disabled people* [Viewed 24 September 2020]. Available from: https://www.gov.uk/guidance/housing-for-older-and-disabled-people	The resource guides councils in preparing planning policies rather than focusing on care pathways
UK government. *Mobility scooters and powered wheelchairs: the rules.* [Viewed 24 September 2020]. Available from: https://www.gov.uk/mobility-scooters-and-powered-wheelchairs-rules	Not about eligibility criteria. Not relevant for the conceptual model
UK government. *Universal Credit.* [Viewed 24 September 2020]. Available from: https://www.gov.uk/universal-credit	Universal Credit is for people under State Pension age
UK government. *Hospital Discharge Service: Policy and Operating Model.* [Viewed 24 September 2020]. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/912199/Hospital_Discharge_Policy_1.pdf	Information either not relevant or already covered by other sources
UK government. *Winter Fuel Payment.* [Viewed 24 September 2020]. Available from: https://www.gov.uk/winter-fuel-payment	Winter fuel payments were not considered key for the conceptual model

Appendices chapter 3

Appendix 3A. Review protocol

Population

Older people (as defined in the studies) living in private households (i.e., not in care homes) with functional limitations (as defined in the studies). Exclude studies on all ages unless subgroup results are presented for older people. Exclude studies on all older people unless subgroup results are presented for older people with functional limitations. Exclude studies that only focus on specific conditions or specific disabilities. Exclude studies that focus only on carers without looking at older people's characteristics.

Study design

Include quantitative studies that use multivariable data analysis. Include individual-level studies and multi-level studies and exclude ecological studies. Include systematic reviews but exclude literature reviews. Exclude qualitative studies, letters, comments.

Determinants or predictors

All determinants reported in the studies. Examples: gender, age, level of need, wealth, education, occupational class, characteristics of LA of residence.

Outcomes

Met or unmet need, as defined in the studies; receipt or no receipt of care, as defined in the studies; receipt or no receipt of an adequate amount of care, as defined in the studies; amount of care received; care receipt from a specific source (e.g., publicly funded, privately funded, informal). Quality of care will not be an outcome included in the review.

Context

Only studies conducted in England, before any Covid-19 restrictions were put in place, will be included. Studies looking at determinants of care receipt or unmet need within the context of the Covid-19 pandemic will be excluded.

Other inclusion/exclusion criteria.

Only include studies published from 2010 onwards.

Data extraction

Findings will be extracted in tables to show all determinants assessed in the studies, any significant associations and the direction of these associations.

Data synthesis

Findings will be summarised with a narrative synthesis.

Appendix 3B. Search strategies

Appendix 3B.1. Database: Social Care Online

Two online searches were conducted on the database Social Care Online, one with an England filter and one with a United Kingdom filter (unfortunately the database did not enable the use of brackets to specify "(England or United Kingdom)":

Advanced search on 05/03/2021

Subject term: "informal care"

OR subject term: "adult social care"

OR subject term: "long term care"

OR subject term: "unmet need"

AND subject term: "older people"

AND location: "England"

AND publication year: 2010-2021

Results: 245 titles and abstracts

Advanced search on 05/03/2021

Subject term: "informal care"

OR subject term: "adult social care"

OR subject term: "long term care"

OR subject term: "unmet need"

AND subject term: "older people"

AND location: "United Kingdom"

AND publication year: 2010-2021

Results: 138 titles and abstracts

Appendix 3B.2. Database: Embase

The search was conducted via Ovid and saved in the Ovid ScHARR account under the name “0 0 0 0 A unmet need Embase”. The search included the Embase (OVID) UK geographic search filter [247].

Database: Embase <1996 to 2021 Week 04> on 31/01/2021

Search Strategy:

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1 (older people or older person$ or older adult$ or old age or aged people or aged person$ or elderly or senior$ or pensioner$).ti. (76842)

2 help.ti. (28692)

3 "informal care".ti. (398)

4 "unmet need".ti. (1155)

5 "social care".ti. (1379)

6 2 or 3 or 4 or 5 (31607)

7 1 and 6 (383)

8 letter.pt. (876659)

9 editorial.pt. (595118)

10 note.pt. (733699)

11 8 or 9 or 10 (2205476)

12 7 not 11 (347)

13 animal/ (966797)

14 exp animal experiment/ (1852305)

15 nonhuman/ (5109794)

16 (rat or rats or mouse or mice or hamster or hamsters or animal or animals or dog or dogs or cat or cats or bovine or sheep).ti,ab,sh. (4064645)

17 13 or 14 or 15 or 16 (6702413)

18 exp human/ (17664506)

19 human experiment/ (405738)

20 18 or 19 (17665282)

21 17 not (17 and 20) (4502402)

22 12 not 21 (347)

23 conference abstract.pt. (3997077)

24 22 not 23 (313)

25 exp United Kingdom/ (343161)

26 (national health service* or nhs*).ti,ab,in,ad. (364322)

27 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. (42701)

28 (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad. (2629846)

29 (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad. (2097599)

30 (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad. (87623)

31 (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad. (284768)

32 (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad. (39336)

33 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 (3225911)

34 (exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/ or exp "australia and new zealand"/) not (exp united kingdom/ or europe/) (2689661)

35 33 not 34 (3010737)

36 24 and 35 (103)

37 limit 36 to (english language and yr="2010 - Current") (58)

Appendix 3B.3. Database: Econlit

The search was conducted via Ovid and saved in the Ovid ScHARR account under the name “0 0 0 0 A unmet need Econlit”

Database: Econlit <1886 to January 21,2021>

Search Strategy:

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1 (older people or older person$ or older adult$ or old age or aged people or aged person$ or elderly or senior$ or pensioner$).ti. (1829)

2 help.ti. (1969)

3 "informal care".ti. (93)

4 "unmet need".ti. (31)

5 "social care".ti. (67)

6 2 or 3 or 4 or 5 (2160)

7 1 and 6 (19)

8 limit 7 to (yr="2010 - 2021" and english and europe) (5)

Appendix 3C. List of excluded studies

Table 48. Studies excluded based on full-text screening.

N	Study	Exclusion reason
1	Age, U. K. 2018. The failing safety net (Age UK: London).	No relevant study design. This report presents multiple case studies.
2	Age, U. K. 2019. Estimating need in older people: findings for England (Age UK: London).	No relevant study design. This study provides qualitative findings and descriptive statistics but it does not assess associations between potential determinants and unmet need.
3	Age U.K. 2019. Briefing: health and care of older people in England 2019	No relevant study design. Descriptive statistics but no assessment of statistically significant associations.
4	Baxter, K. 2016. Self-funders and social care: findings from a scoping review. *Research, policy and planning*. 31 (3). 179-193.	The review was checked for any relevant references. The review highlighted an evidence gap regarding the characteristics of self-funders and did not mention any study on the determinants of being a self-funder for home care. There was one mention of a report (Think Local Act Personal Partnership 2012) on geographical differences in the percentage of self-funders in home care. This report was assessed separately for inclusion in the present review.
5	Blake, Margaret, Claire Lambert, and Zarina Siganporia. 2017. Unmet need for care: final report: July 2017 (Ipsos MORI: London).	No relevant study design. Qualitative. This paper briefly refers to the quantitative findings in Dunatchik et al. (2016), which was separately assessed for inclusion in the present review.
6	Cameron, Gordon. 2016. Older people's care survey (Family and Childcare Trust: London).	No relevant study design. Descriptive statistics of variation of availability of care by region and by service; qualitative feedback comments from respondents working in local authorities.
7	Christie, Amelia, and Adrian McDowell. 2017. The obstacle course: overcoming the barriers to a better later life (Independent Age: London).	No relevant study design. Literature review and case studies.
8	Clarke, C. S., J. Round, S. Morris, K. Kharicha, J. Ford, J. Manthorpe, S. Iliffe, C. Goodman, and K. Walters. 2017. 'Exploring the relationship between frequent internet use and health and social care resource use in a community-based cohort of older adults: An	No relevant population. This study included people aged 65 and over but it was not restricted to people with functional limitations.

N	Study	Exclusion reason
	observational study in primary care', BMJ Open, 7: e015839.	
9	Dahlberg, L., and K. J. McKee. 2016. 'Living on the Edge: Social exclusion and the receipt of informal care in older people', Journal of Aging Research, 2016: 6373101.	No relevant population. The sample was not restricted to people in need. The outcome in the multivariate analysis with multinomial logistic regression included four categories, i.e. informal care receipt at least four hours a week, assurance-receiver (having someone checking in on the person with care needs), no care receipt despite need, no care receipt without need. The reference category in the multinomial logistic regression was no care receipt without need.
10	Forder, Julien, and Jose-Luis Fernandez. 2010. The impact of a tightening fiscal situation on social care for older people (Personal Social Services Research Unit: Canterbury).	No relevant study aim. The analysis is based on a micro-simulation model and shows how different funding scenarios (demand-led or reduced budget with tightened need eligibility criteria) affect the level of unmet need.
11	Hancock, R. et al. 2013. Long-term care funding in England: an analysis of the costs and distributional effects of potential reforms. PSSRU discussion paper	No relevant study design. This study uses simulation modelling to make projections of costs and distributional effects of alternative long-term care reforms to 2030. Some of the projections are stratified by income quintile for people aged 85 and over. No multivariable analysis is applied. Results for home care recipients are not separated from results for care home residents.
12	Humphries et al. 2016. Social care for older people: home truths. The King's fund and Nuffield Trust.	Section five of this report was checked as potentially relevant to the review. However, the study design was not relevant. Section five provided a brief summary of existing literature and qualitative findings on the impact of reductions in social care spending on older people.
13	International Longevity Centre, U. K., and Holden, D. 2019. Care in places: inequalities in local authority adult social care spending power (International Longevity Centre UK Salvation Army: London).	No relevant study design. This report assesses differences between local authorities and only focuses on local authority-level determinants, it does not focus on individual-level determinants.
14	Iparraguirre, Jose. 2015. How much would it cost to meet the unmet social care needs of older people in England? (Age UK: London).	No relevant study aim. This study does not focus on the determinants of care receipt.
15	Khan, O., Ahmet, A., and Victor, C. 2014. Balancing	No relevant study design. The report presents some qualitative findings on accessing care. Moreover, the

N	Study	Exclusion reason
	caring and earning for British Caribbean, Pakistani and Somali people. Joseph Rowntree Foundation.	report also presents some data on prevalence of caring or intense caring stratified by subgroups; these data are not the result of multivariable analyses and the subgroups are defined by carers' characteristics only (older people's characteristics are not included).
16	Leonard Cheshire Disability. 2016. The state of social care in Great Britain in 2016. Our call for urgent action on social care.	No relevant study design. No multivariable analysis. Descriptive statistics from survey data and qualitative findings are presented. Moreover, survey findings are not about the relevant population. One survey only interviewed adults aged between 18 and 65, the other survey interviewed adults aged 18 and over, but no survey findings specific to older people are presented.
17	NHS Digital. 2020. Personal Social Services Adult Social Care Survey (ASCS): England, 2019-20	No relevant study design. No multivariable analysis.
18	Office for National Statistics. 2018. Demand for adult social care across counties and unitary authorities in England	No relevant study design. Descriptive statistics regarding counties and unitary authorities.
19	Office for National Statistics. 2020. Living longer: implications of childlessness among tomorrow's older population.	No relevant study design. Some data on care receipt are stratified by subgroup, but no results from multivariable analysis are presented.
20	Petrie, K. and Keohane, N. 2018. No easy options. Exploring the options for reforming social care funding and eligibility	No relevant study design. No multivariable analysis. The report compares alternative funding and eligibility social care policies. For each policy option, care payment status is stratified by wealth, income, region and age.
21	Pickard et al. 2012. Mapping the future of family care: receipt of informal care by older people with disabilities in England to 2032	No relevant study design. The percentage of older people in receipt of informal care in wave 1 of ELSA was stratified based on characteristics such as marital status, house ownership and age. However, no multivariable analysis was conducted. Stratification was used to project informal care receipt to 2032 for different subgroups.
22	Pickard, L. 2012. Substitution between formal and informal care: a 'natural experiment' in social policy in Britain between 1985 and 2000. Ageing and Society. 32. 1147-1175	No relevant study design. This study looks at trends over time in residential care and in intense informal care (at least 20 hours per week) for older people provided by their children. Analyses are stratified by age and disability. No multivariable analysis of determinants of care receipt is performed.
23	Public Health England. 2021. Productive healthy ageing profile.	Not a paper. This is a tool with data and links. It includes data for social care indicators broken down at the local, regional and national level.

N	Study	Exclusion reason
24	Quilter-Pinner, Harry, and Dean Hochlaf. 2019. Social care: free at the point of need. The case for free personal care in England (Institute for Public Policy Research: London).	No relevant study aim. This report does not focus on the determinants of unmet need. It focuses on the costs of unmet need and the costs and benefits of providing free personal care for people aged 65 and over.
25	Saloniki et al. 2019. The impact of formal care on informal care for people over 75 in England. PSSRU Discussion Paper 5812. Personal Social Services Research Unit, University of Kent	No relevant population. This study included people aged 75 and above as they would be more likely to be using formal and informal care. However, it did not limit the included sample to people with a need for care, so it was excluded. A minimum level of need to be eligible for formal care, as defined in the Care Act 2014, was used in the study as an instrument to study the effect of formal care on informal care, with an instrumental variable approach.
26	Think Local Act Personal Partnership. 2012. Follow-on study: older people who pay for care	No relevant study design. Case studies of four local authorities were carried out. The study included surveys of care providers and twenty interviews with self-funders in these local authorities. No multivariable analysis on the determinants of privately-paid for care receipt was conducted.
27	Vlachantoni, A., R. Shaw, R. Willis, M. Evandrou, J. Falkingham, and R. Luff. 2011. 'Measuring unmet need for social care amongst older people', Population Trends: 56-72.	No relevant study design. Descriptive statistics without testing for statistically significant associations.

Appendix 3D. Quality assessment of included studies

Appendix 3D.1. The critical appraisal tool

Table 49. Adaptations to the Joanna Briggs case-control studies critical appraisal tool for the current review.

Original case control studies critical appraisal tool	**Modified using unmet need rather than "case" and "control" terms**[14]	**Modified using source of care rather than "case" and "control" terms**[15]
1. "Were the groups comparable other than the presence of disease in cases or the absence of disease in controls?" ([64], appendix 7.2)	1. "Were the groups comparable other than the presence of" [64] unmet need "or the absence of" [64] unmet need?	1. "Were the groups comparable other than the presence" [64] or "the absence of" [64] care receipt from a specific source / care receipt from different sources of care?
2. "Were cases and controls matched appropriately?" ([64], appendix 7.2)	2. Were people with and without unmet need "matched appropriately" [64]?	2. Were people with and without care from a specific source "matched appropriately" [64]? OR: Were people with different sources of care "matched appropriately" [64]?
3. "Were the same criteria used for identification of cases and controls?" ([64], appendix 7.2)	3. "Were the same criteria used for identification of" [64] people with and without unmet need?	3. "Were the same criteria used for identification of" [64] people with and without a specific source of care / with care from different sources?
4. "Was exposure measured in a standard, valid and reliable way?" ([64], appendix 7.2)	4. Were potential determinants "measured in a standard, valid and reliable way" [64]?	4. Were potential determinants "measured in a standard, valid and reliable way" [64]?
5. "Was exposure measured in the same way for cases and controls?" ([64], appendix 7.2)	5. Were potential determinants "measured in the same way" [64] for those with and without unmet need?	5. Were potential "measured in the same way" [64] for those with and without a specific source of care / for people with different sources of care?
6. "Were confounding factors identified?" ([64], appendix 7.2)	6. "Were confounding factors identified?" [64]	6. "Were confounding factors identified?" [64]

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[14] All quotations in the table are from: 64. Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetc R, et al. Chapter 7: Systematic reviews of etiology and risk. 2020 [cited 2021 March 10]. In: JBI Manual for Evidence Synthesis [Internet]. [cited 2021 March 10]. Available from: https://doi.org/10.46658/JBIMES-20-08., appendix 7.2

[15] All quotations in the table are from: 64. Ibid., appendix 7.2

7. “Were strategies to deal with confounding factors stated?” ([64], appendix 7.2)	7. “Were strategies to deal with confounding factors stated?” [64]	7. “Were strategies to deal with confounding factors stated?” [64]
8. “Were outcomes assessed in a standard, valid and reliable way for cases and controls?” ([64], appendix 7.2)	8. Was met or unmet need “assessed in a standard, valid and reliable way” [64] for people with and without unmet need?	8. Was care receipt “assessed in a standard, valid and reliable way” [64] for people with and without a specific source of care / people with different sources of care?
9. “Was the exposure period of interest long enough to be meaningful?” ([64], appendix 7.2)	9. Was the period of exposure to potential determinants “long enough to be meaningful” [64]?	9. Was the period of exposure to potential determinants “long enough to be meaningful” [64]?
10. “Was appropriate statistical analysis used?” ([64], appendix 7.2)	10. “Was appropriate statistical analysis used?” [64]	10. “Was appropriate statistical analysis used?” [64]

Appendix 3D.2. Quality assessment, studies on the determinants of unmet need

Table 50. Quality assessment, questions 1-5 of critical appraisal tool.

Study	Comparable groups	Appropriate matching	Same criteria for identification of both groups	Measurement of determinants	Same determinant measurement in both groups
Crawford and Stoye 2017 [62]	Yes, both from ELSA dataset.	No matching was done	Yes, both from ELSA dataset, same eligibility criteria regarding age, difficulties experienced, and, for some analyses, care receipt in previous wave.	Self-report	Yes, same questions
Dunatchik, Icardi and Blake 2019 [69]	Yes, both from ELSA dataset	No matching was done	Yes, both from ELSA dataset, same eligibility criteria regarding age and difficulties experienced.	Self-report	Yes, same questions
Iparraguirre 2020a [37]	Yes, both from ELSA dataset	No matching was done	Yes, both from ELSA dataset, same eligibility criteria regarding age, difficulties experienced and, in one analysis, care receipt.	Self-report	Yes, same questions
Read et al. 2022 [61]	Yes, both from ELSA dataset	No matching was done	Yes, both from ELSA dataset, same eligibility criteria regarding age and difficulties experienced.	Self-report	Yes, same questions
Solé-Auró and Crimmins 2014 [19]	Yes, both from ELSA dataset	No matching was done	Yes, both from ELSA dataset, same eligibility criteria regarding age and difficulties experienced.	Self-report	Yes, same questions
Vlachantoni 2019 [60]	Although the groups were comparable, the sample may not have been fully representative of the population of interest because the study excluded proxy	No matching was done	Yes, both from ELSA dataset, same eligibility criteria regarding age and difficulties experienced.	Self-report	Yes, same questions

Study	Comparable groups	Appropriate matching	Same criteria for identification of both groups	Measurement of determinants	Same determinant measurement in both groups
	respondents. Although proxy interviews cannot answer all the questions, not having some answers is better than completely failing to represent people who are impaired physically or cognitively (Weir et al. 2011).				

Table 51. Quality assessment, questions 6-7 of critical appraisal tool.

Study	Identification of confounding factors	Dealing with confounding factors
Crawford and Stoye 2017 [62]	Yes	Yes, the study authors mentioned that they used multivariable regressions. However, ELSA only has information on the number of difficulties with activities of daily living or mobility tasks, but it does not have information of the extent of these difficulties. This could have been an omitted confounder. In analyses of onset and offset of care, characteristics were measured 2 years before the measurement of onset or offset of care. This would limit the issue of confounding, although the issue would still be present, if the effect of a confounding factor started more than 2 years prior. Non-response and attrition over time in ELSA could have affected checks for confounding factors; for example, if the poorest were most likely to have unmet need and also the most likely to be lost to follow-up in the survey, the relationship between wealth and unmet need may become less visible.
Dunatchik, Icardi and Blake 2019 [69]	Yes	Yes, the study authors mentioned that they used multivariable regressions. However, ELSA only has information on the number of difficulties with activities of daily living or mobility tasks, but it does not have information of the extent of these difficulties. This could have been an omitted confounder. Most characteristics were measured 10 years before measuring unmet need. This addressed confounding by health deterioration and reverse causality from unmet need to the determinants: e.g. limited wealth could be a cause of activity difficulties and unmet need, but it is unlikely that it would be a consequence of care purchased to meet needs.
Iparraguirre 2020a [37]	Yes	Yes, multivariable analysis. However, ELSA only has information on the number of difficulties with activities of daily living or mobility tasks, but it does not have information of the extent of these difficulties. This could have been an omitted confounder.
Read et al. 2022 [61]	Yes	Yes, multivariable analysis. The study authors did not use the term “multivariable” but the table presenting regression results mentioned one logit model and one GLM model, which made it clear that each set of variables belonged to one multivariable model. However, ELSA only has information on the number of difficulties with activities of daily living or mobility tasks, but it does not have information of the extent of these difficulties. This could have been an omitted confounder.

Study	Identification of confounding factors	Dealing with confounding factors
Solé-Auró and Crimmins 2014 [19]	Yes	Yes, multivariable analysis. The study authors did not mention the term “multivariable” but presented a formula for their regression model which included a vector with regression coefficients and a vector of independent variables, so it was clear that the regression model was a multivariable one. However, ELSA only has information on the number of difficulties with activities of daily living or mobility tasks, but it does not have information of the extent of these difficulties. This could have been an omitted confounder.
Vlachantoni 2019 [60]	Yes	Yes, multivariable analysis. The study author presented logistic regression models after presenting tables with bivariate associations, so it was clear that logistic regression models were multivariable ones. All variables were included in multivariable logistic regressions, regardless of whether there was an association in bivariate analysis. However, the level of care need was only captured by self-reported health status and report of a limiting long-term illness. Therefore, the level of care need may have been an omitted confounder.

Table 52. Quality assessment, questions 8-10 of critical appraisal tool - on outcome assessment, exposure period and statistical analysis.

Study	Outcome assessment	Exposure period to determinants	Appropriate statistical analysis
Crawford and Stoye 2017 [62]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. Some determinants would be fixed over time while others would change over time. In this study, some analyses were cross-sectional. Moreover, the authors did consider that some people would stop having difficulties or develop new difficulties, and that there could be transitions in and out of care, so specific analyses focusing on onset and offset of care over two years were conducted, focusing on old and new difficulties.	Probability linear models. The study authors presented a table with regression results that listed independent variables (not significantly associated variables were mentioned in a note rather than in the table itself). They did not mention whether any variables were initially assessed as potential determinants but discarded before getting to the final models.
Dunatchik, Icardi and Blake 2019 [69]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. Some determinants would be fixed over time while others would change over time. Most characteristics were measured 10 years before measuring unmet need.	Clear explanation of how the multivariable model was selected. To build the model, the study authors tested possible predictors one-by-one to assess the association between each of them taken individually and unmet need, i.e. the unadjusted association. The study authors presented a list of all variables that were tested in an annex. The variables that had an unadjusted significant association with unmet need "were selected and introduced stepwise in blocks in the regression model. This procedure was repeated for each block of variables to obtain a final model which included only variables which showed a significant association with unmet needs" ([69], p. 198). The only variables that were kept regardless of significance were age, gender and household

Study	Outcome assessment	Exposure period to determinants	Appropriate statistical analysis
			composition, long-term illness, educational qualifications, and housing tenure. The six “blocks of variables which were tested in the model” ([69], p. 198) were: socio-demographic characteristics, socio-economic characteristics, health-related characteristics, behaviours, social inclusion and becoming widowed.
Iparraguirre 2020a [37]	Self-report	Length of exposure period not particularly relevant for the present review.	Two-level cross-classified panel logistic regressions. Iparaguirre 2020 considered responses from the same people over time and included time as a level in their econometric model. Iparraguirre 2020a presented a list of variables included in the econometric modelling but did not mention whether there were other variables that had been assessed but not included in the final models.
Read et al. 2022 [61]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. This was a cross-sectional study.	Yes. For at least one difficulty with unmet need (yes/no): logistic regression. For the number of difficulties with unmet need: “a generalized linear model (GLM) with a log link and a gamma distribution” ([61], p. 3). As the study included responses from the same individuals answering at several waves, the study authors accounted for intra-temporal correlations. They also accounted for intra-household correlation, which is important since cohabiting partners were interviewed in ELSA. The study authors mentioned a list of independent variables that were included in the regression models. It was not reported if any other variables had been tested before getting to the final regression models. The study authors only mentioned how they decided on the inclusion of interaction terms.
Solé-Auró and Crimmins 2014 [19]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. This study was cross-sectional.	Yes. Logistic regressions. Solé-Auró and Crimmins 2014 mentioned a list of independent variables and these were included in the descriptive statistics. Most of these were included in the regression models, but some were not

Study	Outcome assessment	Exposure period to determinants	Appropriate statistical analysis
			included [16] and the study authors provided no explanation for why one variable was chosen over the other in the regression model. Other variables were categorised differently in the initial list of independent variables and in the regression model [17] but no explanation was given for this.
Vlachantoni 2019 [60]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. This study was cross-sectional.	Yes. Logistic regressions.

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[16] Number of individuals per household and number of children were not included in the regression model. The regression models only included whether there was at least a child in the same household, or whether there was at least a child living in a different household. Living with a spouse/cohabitant was mentioned in the list of independent variables and in some descriptive statistics but not in the regression model.

[17] Marital status was included in a slightly different form in the list of independent variables (single, married, widowed and separated or divorced), and in the regression model (married: yes/no) but no explanation was given for this. Age was presented as a continuous variable in the descriptive statistics and as a categorised variable in the regression model

Appendix 3D.3. Quality assessment of studies on care receipt from a specific source

Table 53. Quality assessment, questions 1-5 of critical appraisal tool.

Study	Comparable groups	Appropriate matching	Same criteria for identification of both groups	Measurement of exposure	Same exposure measurement in both groups
Blomgren et al. 2012 [70]	Yes, both from the ELSA dataset. Moreover, the analysis on help from children only included parents, which ensured that the groups of people receiving and not receiving help from children were comparable. For the same reason, the analysis on help from spouse only included those who lived with a spouse.	No matching was done	Yes, same eligibility criteria regarding age and difficulties experienced.	Self-report	Yes, same questions
Crawford and Stoye 2017 [62]	Yes, both from the ELSA dataset	No matching was done	Yes, same eligibility criteria regarding age and difficulties experienced; moreover, for the analyses on onset of care, both groups had no care in the previous wave, and for the offset of care, both groups had some care in the previous wave.	Self-report	Yes, same questions
Grundy and Read 2012 [71]	Yes, both from the ELSA dataset. Moreover, the analysis on help from children only included parents, which ensured that the groups of people receiving and not receiving help from children were comparable.	No matching was done	Yes, same eligibility criteria regarding age and difficulties experienced.	Self-report	Yes, same questions
Iparraguirre 2020b [68]	Yes, both from the ELSA dataset. In some analyses, the study only included people who had at least one son, one daughter and a spouse, because the paper the study wanted to examine	No matching was done	Yes, same eligibility criteria regarding age and difficulties experienced.	Self-report	Yes, same questions

Study	Comparable groups	Appropriate matching	Same criteria for identification of both groups	Measurement of exposure	Same exposure measurement in both groups
	the effect of care receipt from one person on care receipt from another person.				
Solé-Auró and Crimmins 2014 [19]	Yes, both from the ELSA dataset. However, this issue with the groups was identified: the outcomes were: only informal care from people in the same household, only informal care from people in a different household, only formal care, and a combination of informal and formal care, but the authors did not mention how they categorised or excluded people who had informal care from a mix of people in the same household and in a different household and no formal care.	No matching was done	Yes, same eligibility criteria regarding age and difficulties experienced.	Self-report	Yes, same questions
Vlachantoni et al. 2015 [72]	Yes, both from the ELSA dataset. However, overall, the sample may not have been fully representative of the population of interest because the study excluded proxy respondents. Although proxy interviews cannot answer all the questions, not having some answers is better than completely failing to represent people who are impaired physically or cognitively (Weir et al. 2011).	No matching was done	Yes, same eligibility criteria regarding age and difficulties experienced.	Self-report	Yes, same questions

Table 54. Quality assessment, questions 6-7 of critical appraisal tool.

Study	Identification of confounding factors	Statement of strategies to deal with confounding factors
Blomgren et al. 2012 [70]	Yes	Yes. Multivariable analysis. However, there was some lack of clarity on how the final multivariable models were built. The study authors listed independent variables and when needed explained why variables were categorised in a specific way, but all the variables they mentioned were included in the final models and it was not clear whether they assessed other variables before getting to the final models.
Crawford and Stoye 2017 [62]	Yes	Yes. Multivariable analysis.
Grundy and Read 2012 [71]	Yes	Yes. Multivariable analysis. Moreover, the study authors focused on unmet need two years after determinants were measured, which limits confounding by health deterioration and reverse causality due to care provision. However, there was some lack of clarity on how the final multivariable models were built. The study authors listed independent variables and when needed explained why variables were categorised in a specific way, but all the variables they mentioned were included in the final models and it was not clear whether they assessed other variables before getting to the final models.
Iparraguirre 2020b [68]	Yes	Yes. Multivariable analysis. Moreover, the study focused on the effect of sources of care at time t-1 on sources of care at time t (where t-1 meant two years earlier). This would have reduced issues of reverse causality. However, there was some lack of clarity on how the final multivariable models were built. The study authors listed independent variables and when needed explained why variables were categorised in a specific way, but all the variables they mentioned were included in the final models and it was not clear whether they assessed other variables without including them in the final models.
Solé-Auró and Crimmins 2014 [19]	Yes	Yes. Multivariable analysis. However, the study authors lacked clarity on how they selected and operationalised variables for their final models. The study authors mentioned a list of independent variables and these were included in the descriptive statistics. Most of these were included in the regression models, but some were not included and the study authors provided no explanation for why one variable was chosen over the other in the regression model. The regression model did not include number of individuals per household and number of children, but it included whether there was at least a child living in the same household, or whether there was at

Study	Identification of confounding factors	Statement of strategies to deal with confounding factors
		least a child living in a different household. Living with a spouse/cohabitant was mentioned in the list of independent variables and in some descriptive statistics but not in the regression model. Other variables were categorised differently in the initial list of independent variables and in the regression model but no explanation was given for this. Marital status was included in a slightly different form in the list of independent variables (single, married, widowed and separated or divorced), and in the regression model (married: yes/no); age was presented as a continuous variable in the descriptive statistics and as a categorised variable in the regression model. No explanation was given for this.
Vlachantoni et al. 2015 [72]	Yes	Yes. Multivariable analysis. The study authors were clear about how the multivariable models were selected. They used “a sequential model-building process, with model fitness being based on log-likelihood ratio tests” ([72], p. 327). They initially planned a model for informal care that made no distinction between men and women but then decided to run separate models for men and women; the decision was based on the literature and on the significance of the gender variable in their initial model. They initially allocated independent variables to seven groups: “demographic”, “socio-economic”, “physical health”, “mental health”, “disability/functional limitations”, “environment/technology”, “receipt of support/use of services” ([72], p. 328). A list of variables in each category was provided in the publication. In each category, variables that were not significantly associated with the outcome were excluded before starting the multivariable analysis. Then the sequential modelling started. “Starting with a base model containing demographic variables, variables from subsequent categories were then added to the model, and those variables which significantly improved the model fit were retained before the next category of variables was added” ([72], p. 328).

Table 55. Quality assessment, questions 8-10 of critical appraisal tool.

Study	Outcome assessment	Exposure period to determinants	Appropriate statistical analysis
Blomgren et al. 2012 [70]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. This was a cross-sectional study.	Yes. Logistic regression, odds ratios presented
Crawford and Stoye 2017 [62]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. Depending on the analysis, cross-sectional study or longitudinal study on the onset or offset of care over two years.	Yes. Linear probability models
Grundy and Read 2012 [71]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. Grundy and Read 2012 was a longitudinal study because it focused on unmet need two years after determinants were measured.	Yes. Logistic regression, odds ratios presented. Moreover, to avoid issues with interaction of various determinants with gender, the study authors conducted separate analyses for men and women in relation to receipt of help from friends, relatives, and "children or relatives or friends".
Iparraguirre 2020b [68]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. Iparraguirre 2020b used dynamic regression models, which treat the parameter as time-	Yes. "Dynamic multi-level cross-classified mixed-effects logistic regression models" ([68], p. 1631). Regression beta coefficients presented.

		varying rather than static, so it was a longitudinal study.	
Solé-Auró and Crimmins 2014 [19]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. This was a cross-sectional study.	Yes. The outcome had four categories and the study authors conducted a multinomial logistic regression. Regression beta coefficients presented.
Vlachantoni et al. 2015 [72]	Self-report	Length of exposure period not particularly relevant for the present review. For this review, it is more relevant when determinants and outcomes were measured. This was a cross-sectional study.	Yes. Logistic regression. Moreover, to avoid issues with interaction of various determinants with gender, Vlachantoni et al. 2015 conducted separate analyses for men and women in relation to informal care but not in relation to privately funded care or state care.

Appendix 3E. Data extraction tables, studies on the determinants of unmet need

This review considered p values between 0.05 and 0.1 as non-significant, regardless of how they were considered in the papers. However, one study [61] had an error in the publication when it came to p values (“* $p < 0.05$, ** $p < 0.05$, *** $p < 0.05$”), so significance was based on the paper’s classification of significant.

Table 56. Determinants of unmet need – age and gender.

	Determinants: variables and categories							
Study, population and outcome	**Age**						**Gender**	
Crawford and Stoye 2017[62]	65-74	75-84	85+				M	F
No care at all	Ref	-	-				+	Ref
No care at all among people with no difficulties in previous interview	Ref	-	-				+	Ref
No care at all among people with difficulties in both interviews	Ref	-	-				+	Ref
Offset of care	Ref	0	0				+	Ref
Dunatchik, Icardi and Blake 2019 [69]	49-54	55-59	60-64	65-69	70-74	75+	M	F
Unmet need	Ref	0	0	0	-	-	0	Ref
Iparraguirre 2020a [37]	CV – older						M	F
No support received, or support did not always meet need	+						0	Ref
Only people receiving support: support did not always met needs	+						-	Ref
Read et al. 2022 [61]	CV – older						M	F
At least one difficulty with unmet need	+						0	Ref
The number of difficulties with unmet need	0						+	Ref
Solé-Auró and Crimmins 2014 [19]	50-64	65-79	80+				M	F
No care at all	+	+	Ref				+	Ref
Vlachantoni 2019 [60]	65-74	75-84	85+				M	F

Unmet need relating to PADL care	+	+	Ref	+	Ref
Unmet need relating to support with IADLs	+	+	Ref	+	Ref
Unmet need relating to mobility tasks	+	+	Ref	+	Ref

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome (exception: for count of needs outcome, the plus sign indicates a higher number of unmet needs); minus sign "-" : lower odds or lower likelihood of outcome (exception: for count of needs outcome, the minus sign indicates fewer unmet needs); CV: continuous variable; F: female; M: male; NA: not applicable; PADL: personal activities of daily living; IADL: instrumental activities of daily living; ref: reference category

Table 57. Determinants of unmet need – PADL, IADL, functional limitations and cognition test scores.

Study, population and outcome	**Determinants: variables and categories**											
	PADL limitations							**IADL limitations**				
Dunatchik, Icardi and Blake 2019[69]	Any PADL limitations (ref: no)											
Unmet need with at least one PADL difficulty or with at least two non-PADL difficulties	+											
Iparraguirre 2020a[37]	Number of PADL limitations							Number of IADL limitations				
	0	1	2	3	4	5	6	0	1	2	3	4
No support received, or support did not always meet need	Ref	+	+	0	+	+	+	ref	-	-	-	-
Only people receiving support: support did not always met needs	NA	Ref	+	+	+	+	+	NA	ref	0	0	-
Solé-Auró and Crimmins 2014[19]	CV - more PADL limitations							CV - more IADL limitations				
No care at all	-							-				

Study, population and outcome	**Functional limitations**					
Crawford and Stoye 2017[62]	Number of activity categories[18] with difficulties					
	1	2	3	4	5	6
No care at all	Ref	-	-	-	-	-
Crawford and Stoye 2017[62]	Number of activity categories[19] with difficulties					
	1	2	3	4+		
No care at all among people with difficulties in both interviews	Ref	-	-	-		
Offset of care	Ref	-	-	-		
Crawford and Stoye 2017[62]	New report of difficulties with					
	Mobility	Washing	Eating	Housework /shopping	Medicine	Money
No care at all, among people with no difficulties in previous interview	0	-	0	-	-	-
No care at all among people with difficulties in both interviews	-	-	0	-	0	-
Crawford and Stoye 2017[62]	No longer difficulties with					
	Mobility	Washing	Eating	Housework /shopping	Medicine	Money
Offset of care	+	+	0	+	0	+
Crawford and Stoye 2017[62]	Higher walking speed (m/s)					
No care at all	+					
No care at all, among people with no difficulties in	0					

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[18] Six activity categories: "mobility (walking 100 yards, walking across a room, climbing a single or multiple flights of stairs, getting into or out of bed, using the toilet), washing (bathing or showering, getting dressed), eating (including cutting up food), housework (shopping for groceries, doing work around the house or garden), taking medication and managing money (managing money, making phone calls)" (62. Crawford R, Stoye G. The prevalence and dynamics of social care receipt London: Institute for Fiscal Studies; 2017 [cited 2021 March 17]. 64]. Available from: https://www.ifs.org.uk/uploads/publications/comms/R125_The%20prevalence%20and%20dynamics%20of%20social%20care%20receipt.pdf.), pp. 9-11.

[19] Same as previous note

previous interview			
No care at all, among people with difficulties in both interviews	0		
Offset of care	Error in publication: coefficient 0.000 but statistically significant		
Read et al. 2022 [61]	CV - more functional limitations[20]		
At least one difficulty with unmet need	+		
The number of difficulties with unmet need	+		
Study, population and outcome	**Cognition (measured through cognitive tests)**		
Dunatchik, Icardi and Blake 2019[69]	Intact cognition	Poor cognitive function - immediate recall	Poor cognitive function - delayed recall
Unmet need	Ref	0	0
Read et al. 2022 [61]	Intact cognition	Low cognition (lowest quartile of a score based on multiple cognitive tests)	
At least one difficulty with unmet need	Ref	Interaction with the number of functional limitations. Among people with the lowest level of functional limitation (1-2 limitations): +. Interaction term: -. Significance among those with more limitations: not reported.	
The number of difficulties with unmet need	Ref	Interaction with the number of functional limitations. Among people with the lowest level of functional limitation (1-2 limitations): +. Interaction term: -. Significance among those with more limitations: not reported.	

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome (exception: for count of needs outcome, the plus sign indicates a higher number of unmet needs); minus sign "-" : lower odds or lower likelihood of outcome (exception: for count of needs outcome, the minus sign indicates fewer unmet needs); CV: continuous variable; F: female; M: male; NA: not applicable; PADL: personal activities of daily living; IADL: instrumental activities of daily living; ref: reference category

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[20] ADLs or general mobility limitations

Table 58. Determinants of unmet need – health and illness; lifestyle and quality of life.

Study, population and outcome	**Determinants: variables and categories**				
	Health and illness				
Crawford and Stoye 2017[62]	Self-reported health				
	Excellent	Very good	Good	Fair	Poor
No care at all	Ref	0	0	0	-
Crawford and Stoye 2017[62]	Self-reported health				
	Excellent/very good	Good	Fair/poor/very bad		
No care at all, people with no difficulties in previous interview	Ref	0	-		
Continued absence of care, people with difficulties in both interviews	Ref	-	-		
Crawford and Stoye 2017[62]	Self-reported health status (categories not specified)				
Offset of care	0				
Vlachantoni 2019[60]	Self-reported health status				
	Good	Fair	Poor	Missing	
Unmet need relating to PADL care	+	+	Ref	0	
Unmet need relating to support with IADLs	+	+	Ref	-	
Unmet need relating to mobility tasks	+	+	Ref	0	
Dunatchik, Icardi and Blake 2019 [69]	Long-standing illness (ref: no)	Eyesight (bad/good)			
Unmet need	-	0			

<table>
<tr><td rowspan="2"><i>Vlachantoni 2019 [60]</i></td><td colspan="4">Long-term illness</td></tr>
<tr><td>No</td><td colspan="2">Yes, not limiting</td><td>Yes, limiting</td></tr>
<tr><td>Unmet need relating to PADL care</td><td>Ref</td><td colspan="2">0</td><td>0</td></tr>
<tr><td>Unmet need relating to support with IADLs</td><td>Ref</td><td colspan="2">0</td><td>0</td></tr>
<tr><td>Unmet need relating to mobility tasks</td><td>Ref</td><td colspan="2">+</td><td>-</td></tr>
<tr><td><i>Crawford and Stoye 2017[62]</i></td><td colspan="4">Ever diagnosed with Alzheimer’s (ref: no diagnosis)</td></tr>
<tr><td>No care at all</td><td colspan="4">-</td></tr>
<tr><td><i>Crawford and Stoye 2017[62]</i></td><td colspan="4">Ever diagnosed with one of the following conditions was assessed as a potential determinant: osteoporosis, Parkinson’s disease, dementia, “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke or high cholesterol” ([62], p. 11)</td></tr>
<tr><td>No care at all</td><td colspan="4">0</td></tr>
<tr><td><i>Crawford and Stoye 2017[62]</i></td><td colspan="2">Ever diagnosed with Alzheimer’s disease</td><td colspan="2">Ever diagnosed with congestive heart failure</td></tr>
<tr><td>No care at all among people with no difficulties at previous interview</td><td colspan="2">-</td><td colspan="2">-</td></tr>
<tr><td><i>Crawford and Stoye 2017[62]</i></td><td colspan="4">Ever diagnosed with one of the following: “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack”, “heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease”, “dementia, osteoporosis or high cholesterol” ([62], p. 58)</td></tr>
<tr><td>No care at all among people with no difficulties at previous interview</td><td colspan="4">0</td></tr>
<tr><td><i>Crawford and Stoye 2017[62]</i></td><td colspan="4">Ever diagnosed with high cholesterol</td></tr>
</table>

Continued absence of care among people with difficulties in both interviews	+	
Crawford and Stoye 2017[62]	Ever being diagnosed with one of the following conditions was assessed as a potential determinant: “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis” ([62], p. 61)	
Continued absence of care among people with difficulties in both interviews	0	
Crawford and Stoye 2017[62]	Ever diagnosed with dementia	
Offset of care	-	
Crawford and Stoye 2017[62]	Ever diagnosed with one of the following conditions: “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease”, “osteoporosis or high cholesterol” ([62], p. 32)	
Offset of care	0	
Crawford and Stoye 2017[62]	New diagnosis with asthma	New diagnosis with Parkinson’s disease
No care at all among people with no difficulties at previous interview	+	+
Crawford and Stoye 2017[62]	New diagnosis with one of the following conditions: “lung disease”, “arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke”, “Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 58)	
No care at all, among people with no	0	

difficulties at previous interview	
Crawford and Stoye 2017[62]	New diagnosis of one of the following conditions was assessed as a potential determinant: “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 61)
No care at all among people with difficulties in both interviews	0
Crawford and Stoye 2017[62]	New diagnosis with heart attack
Offset of care	-
Crawford and Stoye 2017[62]	New diagnosis with one of the following conditions: “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina”, “heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 32)
Offset of care	0
Read et al. 2022 [61]	Diagnosis of dementia or Alzheimer’s disease
At least one difficulty with unmet need	Interaction with the N of functional limitations. People with 1/ 2 limitations: +. Interaction term: -. At higher levels of functional limitations: not reported.
The number of difficulties with unmet need	Interaction with the N of functional limitations. People with 1/ 2 limitations: +. Interaction term: -. People with 7+ functional limitations: -.

Study, population and outcome	**Determinants: variables and categories**		
	Lifestyle and quality of life		
Dunatchik, Icardi and Blake 2019 [69]	Physical activity (no activity, light only, vigorous or moderate)	Ever smoked (ref:no)	Wellbeing/quality of life
Unmet need	0	0	0

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome (exception: for count of needs outcome, the plus sign indicates a higher number of unmet needs); minus sign "-" : lower odds or lower likelihood of outcome (exception: for count of needs outcome, the minus sign indicates fewer unmet needs); CV: continuous variable; F: female; M: male; NA: not applicable; PADL: personal activities of daily living; IADL: instrumental activities of daily living; ref: reference category

Table 59. Determinants of unmet need – having a partner/marital status.

Study, population and outcome	**Determinants: variables and categories**			
	Having a partner/marital status			
Crawford and Stoye 2017[62]	Couple	Always single	Widowed	Separated/divorced
No care at all	Ref	0	0	0
No care at all among people with no difficulties in previous interview	Ref	+	+	+
No care at all among people with difficulties in both interviews	Ref	+	+	+
Offset of care	Ref	0	0	+
Crawford and Stoye 2017[62]	Becoming widowed between interviews		New partner between interviews	
No care at all among people with no difficulties in previous interview	0		0	
Continued absence of care among people with difficulties in both interviews	+		0	
Offset of care	+		0	
Dunatchik, Icardi and Blake 2019[69]	Becoming widowed (ref: no)			
Unmet need	+			
Read et al. 2022 [61]	Having a partner (ref: no)			
At least one difficulty with unmet need	0			
The number of difficulties with unmet need	-			
Solé-Auró and Crimmins 2014[19]	Married (ref: no)			
No care at all	-			
Vlachantoni 2019[60]	Married or civil	Single never married	Separated or divorced	Widowed

	partnered			
Unmet need relating to PADL care	Ref	0	+	0
Unmet need relating to support with IADLs	Ref	0	0	0
Unmet need relating to mobility tasks	Ref	0	0	0
Study, population and outcome	**Living with others/household size**			
Dunatchik, Icardi and Blake 2019 [69]	Lives alone	Lives with others		
Unmet need	+	Ref		
Iparraguirre 2020a[37]	CV - bigger household size			
No support received, or support did not always meet need	-			
Only people receiving support: support did not always met needs	-			
Vlachantoni 2019[60]	Lives alone	Lives in a couple	Other household composition	
Unmet need relating to PADL care	+	Ref	0	
Unmet need relating to support with IADLs	0	Ref	0	
Unmet need relating to mobility tasks	+	Ref	0	

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome (exception: for count of needs outcome, the plus sign indicates a higher number of unmet needs); minus sign "-" : lower odds or lower likelihood of outcome (exception: for count of needs outcome, the minus sign indicates fewer unmet needs); CV: continuous variable; F: female; M: male; NA: not applicable; PADL: personal activities of daily living; IADL: instrumental activities of daily living; ref: reference category

Table 60. Determinants of unmet need – having children, where do they live, contact with children; relationships with friends and family.

Study, population and outcome	**Determinants: variables and categories**		
	Having children, where do they live, contact with children		
Crawford and Stoye 2017[62]	Has children (ref: no)		
No care at all	-		
No care at all among people with no difficulties in previous interview	0		
Continued absence of care among people with difficulties in both interviews	0		
Offset of care	0		
Read et al. 2022 [61]	Has children (ref: no)		
At least one difficulty with unmet need	0		
The number of difficulties with unmet need	0		
Solé-Auró and Crimmins 2014[19]	Children living in the same household (ref: no)		Children in a different household (ref: no)
No care at all	0 (but borderline significant negative association)		0
Dunatchik 2016 [11]	Children in the same household (ref: no)		
Unmet need	0		
Dunatchik, Icardi and Blake 2019[69]	How often meets children – 10 years prior		
	Weekly	monthly	once or less a year
Unmet need	Ref	0	0
Dunatchik, Icardi and Blake 2019[69]	How often talk over the phone with children – 10 years prior		
	Weekly	monthly	once or less a year
Unmet need	Ref	0	0
Study, population and outcome	**Relationships with friends and family**		
Crawford and Stoye 2017[62]	Has siblings (ref: no)		
No care at all	0		
No care at all among people with no difficulties in previous interview	0		
No care at all among people with difficulties in both interviews	0		
Offset of care	0		

Dunatchik, Icardi and Blake 2019 [69]	Has friends (ref: no)	Family members understand how one feels
Unmet need	0	0

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome (exception: for count of needs outcome, the plus sign indicates a higher number of unmet needs); minus sign "-" : lower odds or lower likelihood of outcome (exception: for count of needs outcome, the minus sign indicates fewer unmet needs); CV: continuous variable; F: female; M: male; NA: not applicable; PADL: personal activities of daily living; IADL: instrumental activities of daily living; ref: reference category

Table 61. Determinants of unmet need – housing tenure; wealth.

Study, population and outcome	**Determinants: variables and categories**				
	Housing tenure				
Crawford and Stoye 2017[62]	Homeowner (ref: other tenure)				
No care at all	0				
No care at all, among people with no difficulties in previous interview	0				
No care at all among people with difficulties in both interviews	0				
Offset of care	0				
Dunatchik, Icardi and Blake 2019 [69]	"Own the house" (*[69]* p. 200)	"Buying the house"(*[69]* p. 200)	"Rent" (*[69]* p. 200)	"Rent free" (*[69]* p. 200)	
Unmet need	Ref	0	0	0	
Read et al. 2022 [61]	Own the house or "mortgage or shared-ownership" (Read et al. 2022, p. 3)	"Renting, living rent free or squatting" (Read et al. 2022, p. 3)			
At least one difficulty with unmet need	-	Ref			
The number of difficulties with unmet need	-	Ref			
Vlachantoni 2019[60]	Owner-occupier	Rent socially	Rent privately	Rent-free	Other
Unmet need relating to PADL care	Ref	-	0	0	0
Unmet need relating to support with IADLs	Ref	0	0	0	0
Unmet need relating to mobility tasks	Ref	0	0	0	0

Study, population and outcome	**Determinants: variables and categories**				
	Wealth				
Crawford and Stoye 2017[62]	Least wealthy[21]	Wealth quintile 2	Wealth quintile 3	Wealth quintile 4	Wealthiest
No care at all	0	0	0	0	Ref
No care at all among people with no difficulties in previous interview	-	-	0	-	Ref
No care at all, among people with difficulties in both interviews	-	-	-	-	Ref

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[21] No definition of wealth provided.

Offset of care	0	0	0	0	Ref
Dunatchik, Icardi and Blake 2019 [69]	Non-pension, non-housing wealth				
	Below lower capital limit	Between lower and upper	Above upper and <£50,000	>£50,000	
Unmet need	Ref	0	0	0	
Iparraguirre 2020[a] [37]	Higher benefit unit equivalised[22] net total non-housing wealth[23] - CV				
No support received, or support did not always meet need	0				
Only people receiving support: support did not always met needs	0				
Read et al. 2022 [61]	CV - Higher wealth quintile, based on “non-pension wealth comprising financial, physical and housing wealth net of debt” (p. 3).				
At least one difficulty with unmet need	0				
The number of difficulties with unmet need	-				

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign “+”: higher odds or higher likelihood of outcome (exception: for count of needs outcome, the plus sign indicates a higher number of unmet needs); minus sign “-“ : lower odds or lower likelihood of outcome (exception: for count of needs outcome, the minus sign indicates fewer unmet needs); CV: continuous variable; F: female; M: male; NA: not applicable; PADL: personal activities of daily living; IADL: instrumental activities of daily living; ref: reference category

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[22] A benefit unit is defined as “either a single person or a couple regardless of whether they keep their finances separate or together” (p. 5).

[23] Net total non-housing wealth is “the sum of savings, investments, and physical wealth after financial debt is subtracted” (p. 5).

Table 62. Determinants of unmet need – occupational status and income.

Study, population and outcome	**Determinants: variables and categories**						
	Occupational status and income						
Dunatchik, Icardi and Blake 2019 [69]	In work (ref: no)						
Unmet need	0						
	National statistics socio-economic (NS-SEC) categories						
Read et al. 2022 [61]	Routine and manual	Intermediate	Higher managerial, administrative and professional				
At least one difficulty with unmet need	Ref	0	0				
The number of difficulties with unmet need	Ref	0	0				
	National statistics socio-economic (NS-SEC) categories						
Vlachantoni 2019[60]	Semi-routine and routine	Lower supervisory	Small employer and own account worker	Intermediate	Other	Managerial or professional	Incomplete or no info
Unmet need relating to PADL care	0	0	0	0	0	Ref	0
Unmet need relating to support with IADLs	0	0	0	0	0	Ref	+
Unmet need relating to mobility tasks	0	0	0	0	0	Ref	0
Iparraguirre 2020[a] [37]	Higher benefit-unit equivalised income[24]						

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[24] A benefit unit is defined as "a single person or a couple regardless of whether they keep their finances separate or together" (p. 1635). "Income is the sum of income from employment, self-employment, state benefit, state pension, private pension, assets and other sources" (p. 1635)

No support received, or support did not always meet need	0
Only people receiving support: support did not always met needs	0
Dunatchik 2016 [11]	Income
Unmet need	0

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome (exception: for count of needs outcome, the plus sign indicates a higher number of unmet needs); minus sign "-" : lower odds or lower likelihood of outcome (exception: for count of needs outcome, the minus sign indicates fewer unmet needs); CV: continuous variable; F: female; M: male; NA: not applicable; PADL: personal activities of daily living; IADL: instrumental activities of daily living; ref: reference category

Table 63. Determinants of unmet need – educational qualifications.

Study, population and outcome	**Determinants: variables and categories**		
	Educational qualifications		
Crawford and Stoye 2017[62]	Low education	Mid education	High education
No care at all	0	0	Ref
No care at all among people with no difficulties in previous interview	0	0	Ref
Continued absence of care among people with difficulties in both interviews	0	0	Ref
Offset of care	0	0	Ref
Dunatchik, Icardi and Blake 2019[69]	None	Medium	High
Unmet need	0	0	Ref
Read et al. 2022 [61]	None	Any	
At least one difficulty with unmet need	0	Ref	
The number of difficulties with unmet need	0	Ref	
Vlachantoni 2019[60]	None	Low	High
Unmet need relating to PADL care	0	0	Ref
Unmet need relating to support with IADLs	0	0	Ref
Unmet need relating to mobility tasks	0	0	Ref

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome (exception: for count of needs outcome, the plus sign indicates a higher number of unmet needs); minus sign "-" : lower odds or lower likelihood of outcome (exception: for count of needs outcome, the minus sign indicates fewer unmet needs); CV: continuous variable; F: female; M: male; NA: not applicable; PADL: personal activities of daily living; IADL: instrumental activities of daily living; ref: reference category

Table 64. Determinants of unmet need – LA-level variables.

Study, population and outcome	Determinants: variables and categories					
	LA-level variables					
Iparraguirre 2020[a] [37]	Higher LA spending on community-based social care per resident aged 65 and over[25]		Income deprivation (the share of older people aged 60 and over in receipt of low-income benefits in the local area)			
No support received, or support did not always meet need	- (borderline significant)		0			
Only people receiving support: support did not always met needs	-		0			
	Council type					
Iparraguirre 2020[a] [37]	London Borough		Metropolitan	Non-metropolitan	Unitary	
No support received, or support did not always meet need	Ref		-	0	-	
Only people receiving support: support did not always met needs	Ref		0	0	0	
	Rural/urban					
Iparraguirre 2020a[37]	“Mainly rural” ([37], p. 10)	“Largely rural” ([37], p. 10)	“Urban with significant rural” ([37], p. 10)	“Urban with city and town” ([37], p. 10)	“Urban with minor conurbation” ([37], p. 10)	“Urban with major conurbation” ([37], p. 10)
No support received, or support did not always meet need	Ref	0	0	0	0	0
Only people receiving support:	Ref	0	0	0	0	0

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[25] “Net Current Expenditure on community-based social care services for clients aged 65 or over inflated to 2015-16 prices using the GDP deflator” (p. 5). The services included were: “Home care, Day Care/Day Services, Fairer charging – Community services, Direct Payments, Equipment and adaptations, Meals and Other services to older people” (p. 5). “we divided spending figures in each local area by the total resident population aged 65 or over” (p.5)

support did not always met needs						

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome (exception: for count of needs outcome, the plus sign indicates a higher number of unmet needs); minus sign "-" : lower odds or lower likelihood of outcome (exception: for count of needs outcome, the minus sign indicates fewer unmet needs); CV: continuous variable; F: female; M: male; NA: not applicable; PADL: personal activities of daily living; IADL: instrumental activities of daily living; ref: reference category

Appendix 3F. Data extraction tables, studies on receiving care from a specific source.

This review considered p values between 0.05 and 0.1 as non-significant, regardless of how they were considered in the papers.

Table 65. Determinants of receiving help from a specific source of care – age and gender.

Study, population and outcome	**Determinants: variables and categories**					
	Age				**Gender**	
Blomgren et al. 2012[70]	70-74	75-79	80-84	85+	M	F
People with spouse: help from spouse	Ref	0	0	0	-	Ref
Parents: help from children	Ref	0	0	+	-	Ref
Crawford and Stoye 2017[62]	65-74	75-84	85+		M	F
Informal care	Ref	0	+		-	Ref
Formal care	Ref	+	+		0	Ref
No difficulties in previous interview, onset of informal care[26]	Ref	+	+		-	Ref
No difficulties in previous interview, onset of formal care[27]	Ref	+	0		0	Ref
Difficulties at both interviews, onset of informal care[28]	Ref	+	+		-	Ref
Difficulties at both interviews, onset of formal care[29]	Ref	+	+		-	Ref
Difficulties at one or both interviews, onset of privately-funded care	Ref	+	+		-	Ref
Difficulties at one or both interviews, onset of publicly-funded care	Ref	+	+		0	Ref
Offset of informal care	Ref	0	0		+	Ref
Offset of formal care	Ref	0	0		+	Ref

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[26] Data for this subgroup was extracted from appendix C. The analysis on the determinants of onset of care in the main report included everyone with difficulties at second interview and no care at first interview, regardless of whether they had difficulties at first interview. Appendix C divided the sample into those that had difficulty at first interview and those that did not have difficulty at first interview. The present review extracted results relating to the onset of care from these two sub-samples rather than from the overall sample.

[27] Ibid.

[28] Ibid.

[29] Ibid.

Grundy and Read 2012[71]	CV – older						M	F
Men: help from children / relatives / friends	+						NA	NA
Women: help from children / relatives / friends	+						NA	NA
Men: help from relatives	+						NA	NA
Women: help from relatives	0						NA	NA
Men: help from friends	+						NA	NA
Women: help from friends	+						NA	NA
Fathers: help from children	+						NA	NA
Mothers: help from children	+						NA	NA
Iparraguirre 2020b [68]	CV – older						M	F
Care and support from partner	-						0	Ref
Care and support from son	0						0	Ref
Care and support from daughter	0						-	Ref
LA-funded care and support	+						0	Ref
Privately funded care and support	+						0	Ref
Solé-Auró and Crimmins 2014 (ref category: formal plus informal care)[19]	50-64	65-79	80+				M	F
People receiving help: only informal care from people in the same household	+	+	Ref				+	Ref
People receiving help: only informal care from people in a different household	+	0	Ref				0	Ref
People receiving help: only formal care	0	0	Ref				0	Ref
Vlachantoni et al. 2015[72]	65-69	70-74	75-79	80-84	85-89	90+	M	F
Men: receiving informal care	Ref	+	+	0	0	0	NA	NA
Women: receiving informal care	Ref	0	0	0	0	0	NA	NA

State care	Ref	0	0	0	0	0	0	Ref
Privately funded care care	Ref	0	0	0	0	0	-	Ref

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign “+”: higher odds or higher likelihood of outcome; minus sign “-” : lower odds or lower likelihood of outcome; CV: continuous variable; F: female; M: male; NA: not applicable; ref: reference category

Table 66. Determinants of receiving help from a specific source of care – PADL limitations, IADL limitations and cognition test scores.

Study, population and outcome	**Determinants: variables and categories**								
	Number of PADL limitations					**Number of IADL limitations**			
Blomgren et al. 2012[70]	0		1-2	3-6		0	1	2-3	
People with spouse: help from spouse	Ref		+	+		Ref	+	+	
Parents: help from children	Ref		+	+		Ref	+	+	
Iparraguirre 2020b[68]	1	2	3	4		1	2	3	4
Care and support from partner	Ref	+	+	0		Ref	+	+	+
Care and support from son	Ref	0	0	0		Ref	0	0	0
Care and support from daughter	Ref	0	0	0		Ref	0	0	+
LA-funded care and support	Ref	+	+	+		Ref	0	+	+
Privately funded care and support	Ref	0	0	0		Ref	0	0	+
Solé-Auró and Crimmins 2014[19] (ref category: formal plus informal care)	CV - more PADL limitations					CV - more IADL limitations			
People receiving help: only informal care from people in the same household	-					-			
People receiving help: only informal care from people in a different household	-					-			
People receiving help: only formal care	-					-			
Vlachantoni et al. 2015[72]	0		1	2-3	4-6	0	1	2-4	5-9
Men: receiving informal care	Ref		+	+	+	Ref	+	+	+
Women: receiving informal care	Ref		0	0	0	Ref	+	+	+
State care	Ref		0	+	+	Ref	+	+	+

Privately funded care	Ref	0	0	0	Ref	+	+	+

Crawford and Stoye 2017[62]	Number of activity categories[30] with difficulties					
	1	2	3	4	5	6
Informal care	Ref	+	+	+	+	+
Formal care	Ref	+	+	+	+	+

Crawford and Stoye 2017[62]	Number of activity categories[31] with difficulties at first interview			
	1	2	3	4+
Difficulties at both interviews, onset of informal care	Ref	+	+	+
Difficulties at both interviews, onset of formal care	Ref	+	+	+
Offset of informal care	Ref	-	-	-
Offset of formal care	Ref	-	-	-

Crawford and Stoye 2017[62]	Number of activity categories[32] with difficulties at first interview				
	0	1	2	3	4+
Difficulties at one or both interviews, onset of privately-funded care	Ref	+	+	+	+
Difficulties at one or both interviews, onset of publicly-funded care	Ref	+	+	+	+

Crawford and Stoye 2017[62]	New difficulties with					
	Mobility	Washing	Eating	Housework /shopping	Medicine	Money
No difficulties in previous interview, onset of informal care	0	+	+	+	+	+
No difficulties in previous interview, onset of formal care	0	+	0	+	0	0
Difficulties at both interviews, onset of informal care	+	+	0	+	0	+

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[30] Six activity categories: "mobility (walking 100 yards, walking across a room, climbing a single or multiple flights of stairs, getting into or out of bed, using the toilet), washing (bathing or showering, getting dressed), eating (including cutting up food), housework (shopping for groceries, doing work around the house or garden), taking medication and managing money (managing money, making phone calls)" (62. Crawford R, Stoye G. The prevalence and dynamics of social care receipt London: Institute for Fiscal Studies; 2017 [cited 2021 March 17]. 64]. Available from: https://www.ifs.org.uk/uploads/publications/comms/R125_The%20prevalence%20and%20dynamics%20of%20social%20care%20receipt.pdf.) pp. 9-11.

[31] As note above

[32] As note above

Difficulties at both interviews, onset of formal care	+	+	+	+	0	0
Difficulties at one or both interviews, onset of privately-funded care	+	+	0	+	0	0
Difficulties at one or both interviews, onset of publicly-funded care	+	+	+	+	+	+
Crawford and Stoye 2017[62]	No longer difficulties with					
	Mobility	Washing	Eating	Housework /shopping	Medicine	Money
Offset of informal care	+	+	0	+	0	+
Offset of formal care	+	+	0	+	0	0
Study, population and outcome	**Cognition (measured through cognitive tests)**					
Blomgren et al. 2012[70]	Number of errors in orientation in time					
	0	1+[33]				
People with spouse: help from spouse	Ref	+				
Parents: help from children	Ref	0				
Vlachantoni et al. 2015[72]	Number of errors in orientation in time					
	0	1	2+			
Men: receiving informal care	Ref	0	0			
Women: receiving informal care	Ref	0	+			
State care	Ref	0	0			
Privately funded care	Ref	0	0			

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome; minus sign "-": lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

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[33] Correct answers for month and year; at least one incorrect answer for month or year (they did not include the question on current day because they needed to compare answers between England and Finland and data was slightly different on this)

Table 67. Determinants of receiving help from a specific source of care – mobility.

Study, population and outcome	**Determinants: variables and categories**				
	Mobility problems				
	Problems with stairs				
Blomgren et al. 2012[70]	No problems	Difficulty with climbing one flight of stairs	Difficulty with climbing several flights of stairs		
People with spouse: help from spouse	Ref	+	0		
Parents: help from children	Ref	+	+		
Crawford and Stoye 2017[62]	Walking speed (m/s)				
Informal care	0				
Formal care	-				
No difficulties in previous interview, onset of informal care	0				
No difficulties in previous interview, onset of formal care	0				
Difficulties at both interviews, onset of informal care	0				
Difficulties at both interviews, onset of formal care	Error in publication - Coefficient -0.000 and statistically significant				
Difficulties at one or both interviews, onset of privately-funded care	Error in publication - Coefficient -0.000 and statistically significant				
Difficulties at one or both interviews, onset of publicly-funded care	Error in publication - Coefficient -0.000 and statistically significant				
Offset of informal care	0				
Offset of formal care	+				
	Difficulty walking one quarter of a mile				
Vlachantoni et al. 2015	No difficulty	some difficulty	much difficulty	unable	
Men: receiving informal care	Ref	0	0	0	
Women: receiving informal care	Ref	+	+	+	
State care	Ref	0	0	+	
Privately funded care	Ref	0	0	0	
Vlachantoni et al. 2015[72]	Number of mobility limitations				
	0 to 1	2	3 to 4	5 to 7	8 to 10

Men: receiving informal care	Ref	0	+	+	+
Women: receiving informal care	Ref	+	+	+	+
State care	Ref	0	0	0	0
Privately funded care	Ref	0	0	0	0

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome; minus sign "-": lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

Table 68. Determinants of receiving help from a specific source of care – self-reported health and long-term illness (diagnosis not specified).

<table>
<tr><th rowspan="2">Study, population and outcome</th><th colspan="5">Determinants: variables and categories</th></tr>
<tr><th colspan="5">Self-reported general health and long-term illness</th></tr>
<tr><td rowspan="2"><i>Crawford and Stoye 2017[62]</i></td><td colspan="5">Self-reported health</td></tr>
<tr><td>Excellent</td><td>Very good</td><td>Good</td><td>Fair</td><td>Poor</td></tr>
<tr><td>Informal care</td><td>Ref</td><td>0</td><td>0</td><td>0</td><td>0</td></tr>
<tr><td>Formal care</td><td>Ref</td><td>0</td><td>0</td><td>0</td><td>0</td></tr>
<tr><td></td><td colspan="5">Self-reported health</td></tr>
<tr><td><i>Crawford and Stoye 2017[62]</i></td><td colspan="2">Excellent/very good</td><td>Good</td><td colspan="2">Fair/poor/very bad</td></tr>
<tr><td>No difficulties in previous interview, onset of informal care</td><td colspan="2">Ref</td><td>0</td><td colspan="2">+</td></tr>
<tr><td>No difficulties in previous interview, onset of formal care</td><td colspan="2">Ref</td><td>0</td><td colspan="2">0</td></tr>
<tr><td>Difficulties at both interviews, onset of informal care</td><td colspan="2">Ref</td><td>0</td><td colspan="2">+</td></tr>
<tr><td>Difficulties at both interviews, onset of formal care</td><td colspan="2">Ref</td><td>+</td><td colspan="2">0</td></tr>
<tr><td>Difficulties at one or both interviews, onset of privately-funded care</td><td colspan="2">Ref</td><td>+</td><td colspan="2">0</td></tr>
<tr><td>Difficulties at one or both interviews, onset of publicly-funded care</td><td colspan="2">Ref</td><td>0</td><td colspan="2">0</td></tr>
<tr><td><i>Crawford and Stoye 2017[62]</i></td><td colspan="5">Self-reported health status (categories not reported)</td></tr>
<tr><td>Offset of informal care</td><td colspan="5">0</td></tr>
</table>

Offset of formal care	0	
Grundy and Read 2012 [71]	Poor health (ref: not poor)	Long-term illness (ref: no)
Men: help from children / relatives / friends	+	+
Women: help from children / relatives / friends	+	+
Men: help from relatives	+	0
Women: help from relatives	0	+
Men: help from friends	+	0
Women: help from friends	0	+
Fathers: help from children	0	+
Mothers: help from children	+	+
Vlachantoni et al. 2015[72]	No details on categories for self-reported general health	Limiting long-stand illness (ref: no)
Men: receiving informal care	0	+
Women: receiving informal care	0	0
State care	0	0
Privately funded care	0	+

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome; minus sign "-": lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

Table 69. Ever diagnosed with specific conditions.

Crawford and Stoye 2017[62]	Ever diagnosed with Alzheimer’s	
Informal care	+	
Crawford and Stoye 2017[62]	Ever diagnosed with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke” ([62], p. 11), “Parkinson’s”, “dementia”, “osteoporosis” ([62], p. 12) “or high cholesterol” ([62], p. 11)	
Informal care	0	
Crawford and Stoye 2017[62]	Ever diagnosed with osteoporosis	Ever diagnosed with Parkinson’s
Formal care	+	+
Crawford and Stoye 2017[62]	Ever diagnosed with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke” ([62], p. 11), “Alzheimer’s”, “dementia” ([62], p. 12)“or high cholesterol” ([62], p. 11)	
Formal care	0	
Crawford and Stoye 2017[62]	Ever diagnosed with Alzheimer’s disease	Ever diagnosed with congestive heart failure
No difficulties in previous interview, onset of informal care	+	+
Crawford and Stoye 2017[62]	Ever diagnosed with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack” ([62], p. 58), “heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease” ([62], p. 58), “dementia, osteoporosis or high cholesterol” ([62], p. 58)	
No difficulties in previous interview, onset of informal care	0	
Crawford and Stoye 2017[62]	Ever diagnosed with Parkinson’s disease	Ever diagnosed with Alzheimer’s disease
No difficulties in previous interview, onset of formal care	-	+

Crawford and Stoye 2017[62]	Ever diagnosed with lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke” ([62], p. 58), “dementia, osteoporosis or high cholesterol” ([62], p. 58)			
No difficulties in previous interview, onset of formal care	0			
Crawford and Stoye 2017[62]	Ever diagnosed with arthritis	Ever diagnosed with dementia	Ever diagnosed with angina	Ever diagnosed with high cholesterol
Difficulties at both interviews, onset of informal care	+	+	+	-
Crawford and Stoye 2017[62]	Ever diagnosed with “lung disease, asthma”([62], p. 61), “cancer, psychiatric problems, blood disorders, hypertension” ([62], p. 61), “heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease” ([62], p. 61) or “osteoporosis” ([62], p. 61)			
Difficulties at both interviews, onset of informal care	0			
Crawford and Stoye 2017[62]	Ever diagnosed with psychiatric problems			
Difficulties at both interviews, onset of formal care	+			
Crawford and Stoye 2017[62]	Ever diagnosed with “lung disease, asthma, arthritis, cancer” ([62], p. 61), “blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 61)			
Difficulties at both interviews, onset of formal care	0			
Crawford and Stoye 2017[62]	Ever diagnosed with psychiatric problems		Ever diagnosed with dementia	

<table>
<tr><td>Difficulties at one or both interviews, onset of privately-funded care</td><td>+</td><td>-</td></tr>
<tr><td>*Crawford and Stoye 2017[62]*</td><td colspan="2">Ever diagnosed with “lung disease, asthma, arthritis, cancer” ([62], p. 28), “blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease” ([62], p. 28), “osteoporosis or high cholesterol” ([62], p. 28)</td></tr>
<tr><td>Difficulties at one or both interviews, onset of privately-funded care</td><td colspan="2">0</td></tr>
<tr><td>*Crawford and Stoye 2017[62]*</td><td colspan="2">Ever diagnosed with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 28)</td></tr>
<tr><td>Difficulties at one or both interviews, onset of publicly-funded care</td><td colspan="2">0</td></tr>
<tr><td>*Crawford and Stoye 2017[62]*</td><td colspan="2">Ever diagnosed with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 32)</td></tr>
<tr><td>Offset of informal care</td><td colspan="2">0</td></tr>
<tr><td>*Crawford and Stoye 2017[62]*</td><td colspan="2">Ever diagnosed with high blood pressure</td></tr>
<tr><td>Offset of formal care</td><td colspan="2">-</td></tr>
<tr><td>*Crawford and Stoye 2017[62]*</td><td colspan="2">Ever diagnosed with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders” ([62], p. 32), “angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 32)</td></tr>
<tr><td>Offset of formal care</td><td colspan="2">0</td></tr>
<tr><td>*Vlachantoni et al. 2015[72]*</td><td>Doctor's diagnosis of chronic lung disease (ref: no)</td><td>Doctor's diagnosis of dementia (ref: no)</td></tr>
</table>

Men: receiving informal care	+	0
Women: receiving informal care	0	0
State care	0	+
Privately funded care	0	0
Vlachantoni et al. 2015[72]	The following health conditions were assessed one by one as potential determinants: “self-reported general health, self-reported eyesight, self-reported hearing, self-reported pain, doctor’s diagnosis of arthritis, chronic lung disease, Parkinson’s disease or high blood pressure” ([72], p. 328), “doctor's diagnosis of depression” ([72], p. 328)	
Outcomes as above	0	

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign “+”: higher odds or higher likelihood of outcome; minus sign “-”: lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

Table 70. New diagnoses.

Crawford and Stoye 2017[62]	New diagnosis with asthma	New diagnosis with Parkinson’s disease
No difficulties in previous interview, onset of informal care	-	-
Crawford and Stoye 2017[62]	New diagnosis with “lung disease” ([62], p. 58), “arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke” ([62], p. 58), “Alzheimer’s disease, dementia, osteoporosis or high cholesterol”([62], p. 58)	
No difficulties in previous interview, onset of informal care	0	

Crawford and Stoye 2017[62]	New diagnosis with	New diagnosis with angina	New diagnosis	New diagnosis with stroke	New diagnosis with high

	Alzheimer’s disease		with diabetes		cholesterol
No difficulties in previous interview, onset of formal care	-	-	-	-	-
Crawford and Stoye 2017[62]	New diagnosis with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension” ([62], p. 58), “heart attack, heart failure, heart murmur, heart rhythm” ([62], p. 58), “Parkinson’s disease”, “dementia, osteoporosis” ([62], p. 58)				
No difficulties in previous interview, onset of formal care	0				
Crawford and Stoye 2017[62]	New diagnosis with Alzheimer’s disease				
Difficulties at both interviews, onset of informal care	+				
Crawford and Stoye 2017[62]	New diagnosis with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease” ([62], p. 61), “dementia, osteoporosis or high cholesterol” ([62], p. 61)				
Difficulties at both interviews, onset of informal care	0				
Crawford and Stoye 2017[62]	New diagnosis with arthritis				
Difficulties at both interviews, onset of formal care	-				
Crawford and Stoye 2017[62]	New diagnosis with “lung disease, asthma” ([62], p. 61), “cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 61)				

<table>
<tr><td>Difficulties at both interviews, onset of formal care</td><td colspan="5">0</td></tr>
<tr><td>Crawford and Stoye 2017[62]</td><td>New diagnosis with cancer</td><td>New diagnosis with psychiatric problems</td><td>New diagnosis with heart attack</td><td>New diagnosis with heart murmur</td><td>New diagnosis with high cholesterol</td></tr>
<tr><td>Offset of informal care</td><td>+</td><td>-</td><td>-</td><td>-</td><td>-</td></tr>
<tr><td>Crawford and Stoye 2017[62]</td><td colspan="5">New diagnosis with “lung disease, asthma, arthritis” ([62], p. 32), “blood disorders, hypertension, angina” ([62], p. 32), “heart failure” ([62], p. 32), “heart rhythm” ([62], p. 32), “diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis” ([62], p. 32)</td></tr>
<tr><td>Offset of informal care</td><td colspan="5">0</td></tr>
<tr><td>Crawford and Stoye 2017[62]</td><td colspan="2">New diagnosis with asthma</td><td colspan="2">New diagnosis with Parkinson’s disease</td><td>New diagnosis with irregular heart rhythm</td></tr>
<tr><td>Offset of formal care</td><td colspan="2">+</td><td colspan="2">-</td><td>-</td></tr>
<tr><td>Crawford and Stoye 2017[62]</td><td colspan="5">New diagnosis with “lung disease” ([62], p. 32), “arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur” ([62], p. 32), “diabetes, stroke” ([62], p. 32), “Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 32)</td></tr>
<tr><td>Offset of formal care</td><td colspan="5">0</td></tr>
<tr><td>Crawford and Stoye 2017[62]</td><td colspan="5">New diagnosis with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke, Parkinson’s disease, Alzheimer’s disease, dementia, osteoporosis or high cholesterol” ([62], p. 28)</td></tr>
<tr><td>Difficulties at one or both interviews, onset of privately-funded care</td><td colspan="5">0</td></tr>
<tr><td>Crawford and Stoye 2017[62]</td><td colspan="3">New diagnosis with Parkinson’s disease</td><td colspan="2">New diagnosis with osteoporosis</td></tr>
</table>

Difficulties at one or both interviews, onset of publicly-funded care	-	+
Crawford and Stoye 2017[62]	New diagnosis with “lung disease, asthma, arthritis, cancer, psychiatric problems, blood disorders, hypertension, angina, heart attack, heart failure, heart murmur, heart rhythm, diabetes, stroke” ([62], p. 28), “Alzheimer’s disease, dementia” ([62], p. 28) “or high cholesterol” ([62], p. 28)	
Difficulties at one or both interviews, onset of publicly-funded care	0	

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign “+”: higher odds or higher likelihood of outcome; minus sign “-”: lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

Table 71. Determinants of receiving help from a specific source of care – having a partner/marital status.

Study, population and outcome	**Determinants: variables and categories**			
	Having a partner/marital status			
Crawford and Stoye 2017[62]	Couple	Always single	Widowed	Separated/divorced
Informal care	Ref	0	-	-
Formal care	Ref	+	+	+
No difficulties in previous interview, onset of informal care	Ref	-	-	-
No difficulties in previous interview, onset of formal care	Ref	0	0	0
Difficulties at both interviews, onset of informal care	Ref	-	-	-
Difficulties at both interviews, onset of formal care	Ref	+	+	+
Difficulties at one or both interviews, onset of privately-funded care	Ref	0	+	0
Difficulties at one or both interviews, onset of publicly-funded care	Ref	+	+	+

Offset of informal care	Ref	+	+	+
Offset of formal care	Ref	-	0	0
Crawford and Stoye 2017[62]	Becoming widowed between interviews		New partner between interviews	
No difficulties in previous interview, onset of informal care	0		0	
No difficulties in previous interview, onset of formal care	0		0	
Difficulties at both interviews, onset of informal care	-		0	
Difficulties at both interviews, onset of formal care	+		0	
Difficulties at one or both interviews, onset of privately-funded care	0		0	
Difficulties at one or both interviews, onset of publicly-funded care	+		0	
Offset of informal care	+		0	
Offset of formal care	-		0	
Grundy and Read 2012[71]	Married	never married	divorced/ separated	Widowed
Men: help from children / relatives / friends	Ref	0	0	+
Women: help from children / relatives / friends	Ref	0	+	+
Men: help from relatives	Ref	0	0	+
Women: help from relatives	Ref	0	+	+
Men: help from friends	Ref	+	+	0
Women: help from friends	Ref	0	+	+
Grundy and Read 2012[71]	Married	not married		
Fathers: help from children	Ref	+		
Mothers: help from children	Ref	+		
Solé-Auró and Crimmins 2014 [19] (ref category: formal plus informal care)	Married	not married		
People receiving help: only informal care from people in the same household	+	Ref		
People receiving help: only informal care from people in a different household	-	Ref		

People receiving help: only formal care	0	Ref		
Vlachantoni et al. 2015[72]	having a partner	not having a partner		
Men: receiving informal care	+	Ref		
Vlachantoni et al. 2015[72]	married or civil partnered	single never married	separated or divorced	Widowed
Women: receiving informal care	+	Ref	+	+
State care	-	Ref	0	-
Privately funded care	-	Ref	0	0

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome; minus sign "-": lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

Table 72. Determinants of receiving help from a specific source of care – living with others and household size; having siblings; contact with relatives, friends or children.

Study, population and outcome	**Determinants: variables and categories**				
	Living with others/household size				
Blomgren et al. 2012[70]	Living with a spouse, not with children	Living with a spouse and children	Living with children, not with spouse	Living with someone else	Living alone
Parents: help from children	Ref	+	+	0	+
Blomgren et al. 2012[70]	Living with a spouse, not with children	Living with a spouse and children			
People with spouse: help from spouse	Ref	0			
Iparraguirre 2020b[68]	Household size (two or more people compared to ref category of living alone)				
Care and support from partner	0				

Care and support from son	0	
Care and support from daughter	0	
LA-funded care and support	-	
Privately funded care and support	-	
Vlachantoni et al. 2015[72]	Cohabitation (categories not specified)	Number of household members
Men: receiving informal care	0	0
Women: receiving informal care	0	0
State care	0	0
Privately funded care	0	0
Study, population and outcome	**Determinants: variables and categories**	
	Having siblings; contact with relatives, friends or children	
Crawford and Stoye 2017[62]	Having siblings (ref: no)	
Informal care	0	
Formal care	-	
No difficulties in previous interview, onset of informal care	0	
No difficulties in previous interview, onset of formal care	0	
Difficulties at both interviews, onset of informal care	0	
Difficulties at both interviews, onset of formal care	-	
Difficulties at one or both interviews, onset of privately-funded care	0	
Difficulties at one or both interviews, onset of publicly-funded care	-	
Offset of informal care	0	
Offset of formal care	0	
Grundy and Read 2012[71]	Weekly face-to-face contact (ref: no weekly contact) 2 years prior	
	with relatives	with friends

Men: help from children / relatives / friends	0	0
Women: help from children / relatives / friends	0	0
Men: help from relatives	0	0
Women: help from relatives	+	0
Men: help from friends	0	+
Women: help from friends	0	0
Grundy and Read 2012[71]	Weekly face-to-face contact with child 2 years prior (ref: no weekly contact)	
Fathers: help from children	+	
Mothers: help from children	+	

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome; minus sign "-": lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

Table 73. Determinants of receiving help from a specific source of care – having children, and where do they live.

Study, population and outcome	**Determinants: variables and categories**			
	Having children, and where do they live			
Blomgren et al. 2012[70]	Number of children			
	0	1	2	3+
People with spouse: help from spouse	ref	0	0	0
Blomgren et al. 2012[70]	Number of children			
	1		2	3+
Parents: help from children	Ref		0	+
Crawford and Stoye 2017[62]	Having children (ref: no)			
Informal care	+			
Formal care	0			
No difficulties in previous interview, onset of informal care	0			
No difficulties in previous interview, onset of formal care	-			
Difficulties at both interviews, onset of informal care	0			
Difficulties at both interviews, onset of formal care	0			

Difficulties at one or both interviews, onset of privately-funded care	-				
Difficulties at one or both interviews, onset of publicly-funded care	0				
Offset of informal care	0				
Offset of formal care	0				
Grundy and Read 2012[71]	Number of children				
	0	1	2	3	4+
Men: help from children/relatives/friends	ref	0	0	0	0
Women: help from children/relatives/friends	ref	+	0	+	+
Men: help from relatives	ref	0	0	0	0
Women: help from relatives	ref	0	0	0	0
Men: help from friends	ref	0	0	0	-
Women: help from friends	ref	0	-	-	-
Grundy and Read 2012[71]	Number of children				
	1		2	3	4+
Fathers: help from children	Ref		0	0	0
Mothers: help from children	Ref		0	0	+
Grundy and Read 2012[71]	Having at least a daughter				
	No	Yes			
Fathers: help from children	ref	0			
Mothers: help from children	Ref	+ if weekly contact with child is excluded from the model			
Solé-Auró and Crimmins 2014 [19] (ref category: formal plus informal care)	Children living in the same household		Children living in a different household		
	None	Any	None	Any	
People receiving help: only informal care from people in the same household	Ref	+	Ref	0	
People receiving help: only informal care from people in a different household	Ref	-	Ref	0	
People receiving help: only formal care	ref	0	Ref	-	
Vlachantoni et al. 2015[72]	Children in the household		Children outside the household		
	None	Any	None	Any	
Men: receiving informal care	ref	0	Ref	0	
Women: receiving informal care	ref	+	Ref	0	
State care	ref	0	Ref	0	
Privately funded care	ref	-	Ref	0	

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome; minus sign "-": lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

Table 74. Determinants of receiving help from a specific source of care – adaptations and aids and receiving other care.

Study, population and outcome	**Determinants: variables and categories**			
	Adaptations and aids			
Vlachantoni et al. 2015[72]	House adaptations (ref: no)	Retirement housing (no details)	Use of cane/walking stick (ref: no)	Manual or electric wheelchair (ref: no)
Men: receiving informal care	-	0	+	0
Women: receiving informal care	0	0	0	0
State care	0	0	-	+
Privately funded care	+	0	0	0
Vlachantoni et al. 2015[72]	Personal alarm (ref: no)	Zimmer frame/walker (ref: no)	Buggy/scooter (ref: no)	Elbow crutches (ref: no)
Men: receiving informal care	0	0	0	0
Women: receiving informal care	0	0	0	0
State care	+	0	0	0
Privately funded care	+	0	0	0

Study, population and outcome	**Determinants: variables and categories**				
	Receiving other care				
Blomgren et al. 2012*[70]*	Receiving formal care (ref: no)				
People with spouse: help from spouse	-				
Parents: help from children	0				
Iparraguirre 2020b[68]	Help from partner in (t-1) (ref: no)	Help from son in (t-1) (ref: no)	Help from daughter in (t-1) (ref: no)	LA-funded help in (t-1)	Privately funded help in (t-1)
Care and support from partner	+	0	-	0	0

Care and support from son	0	+	-	0	0
Care and support from daughter	0	-	+	0	0
LA-funded care and support	-	0	-	+	+
Privately funded care and support	-	0	0	+	+

Vlachantoni et al. 2015[72]	Receiving privately funded care (ref: no)	Receiving any other care (ref: no)	Ever used a lunch club or day care centre (ref: no)
Men: receiving informal care	-	0	0
Women: receiving informal care	0 (borderline, p value 0.06)	0	0
State care	not included	0	0
Privately funded care	NA	0	0

Vlachantoni et al. 2015[72]	Has ever used meals-on-wheels (ref: no)	Going to an occupational therapist or physiotherapist (ref: no)	Going to a chiropodist (ref: no)	Engaging in exercise therapy (ref: no)
Men: receiving informal care	0	+	0	0
Women: receiving informal care	0	0	0	-
State care	0	0	0	0
Privately funded care	+	+	+	0

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome; minus sign "-": lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

Table 75. Determinants of receiving help from a specific source of care – wealth and housing tenure.

Study, population and outcome	**Determinants: variables and categories**					
	Wealth					**Housing tenure**
Crawford and Stoye 2017[62]	Lowest wealth	Second lowest	Third	Second highest	Highest wealth	Home owner (ref: no)
Informal care	+	0	0	0	Ref	0
Formal care	-	0	0	0	Ref	0
No difficulties in previous interview, onset of informal care	0	+	+	+	Ref	0
No difficulties in previous interview, onset of formal care	0	0	-	0	Ref	0
Difficulties at both interviews, onset of informal care	+	+	+	+	Ref	0
Difficulties at both interviews, onset of formal care	0	0	0	0	Ref	0
Difficulties at one or both interviews, onset of privately-funded care	-	-	-	0	Ref	0
Difficulties at one or both interviews, onset of publicly-funded care	0	+	+	+	Ref	0
Offset of informal care	0	0	0	0	Ref	0
Offset of formal care	0	0	0	0	Ref	0
	Wealth quintile using “nonpension wealth indicating financial, physical and housing wealth net of debts” ([71], p. 746).					Home owner (ref: no)
Grundy and Read 2012[71]	Lowest wealth	Second lowest	Third	Second highest	Highest wealth	
Men: help from children / relatives / friends	+	0	+	+	Ref	0
Women: help from children / relatives / friends	+	+	0	0	Ref	0
Men: help from relatives	+	0	0	+	Ref	0
Women: help from relatives	0	0	0	0	Ref	0
Men: help from friends	0	0	0	0	Ref	0
Women: help from friends	0	0	0	0	Ref	0

Fathers: help from children	+	+	+	+	Ref	0
Mothers: help from children	+, if weekly contact excl	+, if weekly contact excl	0	0	Ref	0
Iparraguirre 2020b[68]	Higher benefit unit equivalised[34] net total non-housing wealth[35] - CV					
Care and support from partner	0					
Care and support from son	0					
Care and support from daughter	0					
LA-funded care and support	0					
Privately funded care and support	+					
Vlachantoni et al. 2015[72]	Benefit unit equivalised[36] wealth quintile[37]					Housing tenure
	Lowest wealth	Second lowest	Third	Second highest	Highest wealth	
Men: receiving informal care	Ref	0	0	0	0	0
Women: receiving informal care	Ref	0	0	-	0	0
State care	Ref	0	0	0	0	0
Privately funded care	Ref	+	+	+	+	0

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign "+": higher odds or higher likelihood of outcome; minus sign "-": lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

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[34] A benefit unit is defined as "a single person or a couple regardless of whether they keep their finances separate or together" (p. 1635).

[35] Net total non-housing wealth is "the sum of savings, investments and physical wealth after financial debt is subtracted" (p. 1635).

[36] "A benefit unit is defined as a single person or a couple (regardless of whether they keep their finances separate or together)" (p. 342).

[37] Wealth "refers to total non-pension wealth, including net housing wealth (*e.g.* house value) and net non-housing wealth (*e.g.* savings)" (p. 342)

Table 76. Determinants of receiving help from a specific source of care - income, access to a car and education.

Study, population and outcome	Determinants: variables and categories
	Income and access to a car
Iparraguirre 2020b[68]	Higher benefit unit equivalised income[38]
Care and support from partner	+
Care and support from son	0
Care and support from daughter	0
LA-funded care and support	0
Privately funded care and support	+

Vlachantoni et al. 2015[72]	Benefit unit equivalised income[39]	Access to a car (ref: no)
Men: receiving informal care	0	0
Women: receiving informal care	0	0
State care	0	-
Privately funded care	0	0

Study, population and outcome	Determinants: variables and categories
	Educational qualifications

Blomgren et al. 2012[70]	Lower than GCE O-level	At least GCE O-level
People with spouse: help from spouse	0	Ref
Parents: help from children	+	Ref

Grundy and Read 2012[71]	Below GCSE level	GCSE level	At least A levels
Men: help from children / relatives / friends	Ref	0	0
Women: help from children / relatives / friends	Ref	-	0
Men: help from relatives	Ref	0	0
Women: help from relatives	Ref	0	0
Men: help from friends	Ref	0	0
Women: help from friends	Ref	0	+
Fathers: help from children	Ref	0	0
Mothers: help from children	Ref	-	0

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[38] A benefit unit is defined as "a single person or a couple regardless of whether they keep their finances separate or together" (p. 1635). "Income is the sum of income from employment, self-employment, state benefit, state pension, private pension, assets and other sources" (p. 1635)

[39] "A benefit unit is defined as a single person or a couple (regardless of whether they keep their finances separate or together)" (p. 342). "Income includes total income from employment, self-employment, private pensions, state pensions, benefits, assets (*e.g.* interest from savings)" (p. 342)

Crawford and Stoye 2017[62]	Low education	Mid education	High education
Informal care	0	0	Ref
Formal care	0	0	Ref
No difficulties in previous interview, onset of informal care	0	0	Ref
No difficulties in previous interview, onset of formal care	0	0	Ref
Difficulties at both interviews, onset of informal care	0	0	Ref
Difficulties at both interviews, onset of formal care	-	-	Ref
Difficulties at one or both interviews, onset of privately-funded care	-	0	Ref
Difficulties at one or both interviews, onset of publicly-funded care	0	0	Ref
Offset of informal care	0	0	Ref
Offset of formal care	0	0	Ref

Abbreviations and symbols: 0: no statistically significant associations in the multivariable model or variable not included in the multivariable model after being assessed as a potential determinant; plus sign “+”: higher odds or higher likelihood of outcome; minus sign “-”: lower odds or lower likelihood of outcome; CV: continuous variable; NA: not applicable; ref: reference category

Table 77. Determinants of receiving help from a specific source of care – geographical characteristics.

<table>
<tr><th rowspan="2">Study, population and outcome</th><th colspan="4">Determinants: variables and categories</th></tr>
<tr><th colspan="4">Geographical characteristics</th></tr>
<tr><td>Iparraguirre 2020b[68]</td><td colspan="2">Higher LA spending on community-based social care services[40] for people aged 65 and over per capita (spending divided by number of LA residents aged 65 and over)</td><td>Higher rurality, calculated based on “the percentage of residents in mainly and largely rural areas and rural-related hub towns” (p. 1636).</td><td>Higher share of older people receiving a low-income benefit</td></tr>
<tr><td>Care and support from partner</td><td colspan="2">0</td><td>0</td><td>0</td></tr>
<tr><td>Care and support from son</td><td colspan="2">0</td><td>0</td><td>0</td></tr>
<tr><td>Care and support from daughter</td><td colspan="2">0</td><td>0</td><td>0</td></tr>
<tr><td>LA-funded care and support</td><td colspan="2">+</td><td>0</td><td>0</td></tr>
<tr><td>Privately funded care and support</td><td colspan="2">0</td><td>0</td><td>0</td></tr>
<tr><td>Iparraguirre 2020b[68]</td><td>London borough</td><td>Metropolitan borough</td><td>Non-metropolitan council</td><td>Unitary authority</td></tr>
<tr><td>Care and support from partner</td><td>ref</td><td>0</td><td>0</td><td>0</td></tr>
<tr><td>Care and support from son</td><td>ref</td><td>0</td><td>0</td><td>0</td></tr>
<tr><td>Care and support from daughter</td><td>ref</td><td>-</td><td>0</td><td>-</td></tr>
</table>

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[40] Included expenditure for: “home care, day care/day services, fairer charging – community services, direct payments, equipment and adaptations, meals, and other services to older people” (p. 1636), excluding “spending on assessments and referrals” (p. 1636)

LA-funded care and support	ref	0	0	0
Privately funded care and support	ref	0	0	0

Appendices chapter 4 (some also relevant for chapter 5)

Appendix 4A. LA-level variables: data sources and data manipulation

See Table 78. Note that cells highlighted in grey colour indicated that the variables were only used in robustness checks.

Table 78. LA-level variables: data sources and data manipulation.

Variable	**Original unit**	**Unit of analysis**	**Financial year**	**Notes**	**Source**	**Link**	**Date of last access**
LA code	LAs + Inner and Outer London	LAs + Inner and Outer London	NA	NA	ELSA Special Licence dataset	NA	NA
Gross current expenditure on community long-term care for people aged 65 and over, in £ thousands (divided by 1,000)	LA	LAs + Inner and Outer London	2016/17	Spending was summed across different Inner and Outer London LAs	NHS Digital. Adult Social Care Activity and Finance Report, England 2016-17: Reference data tables [94], worksheet 33 [94]	https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/adult-social-care-activity-and-finance-report-england-2016-17	24/05/2022
Gross current expenditure on long-term care (community +	LA	LAs + Inner and	2016/17	Spending was summed across different Inner and Outer London LAs	NHS Digital. Adult Social Care Activity and Finance	https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-	24/05/2022

Variable	Original unit	Unit of analysis	Financial year	Notes	Source	Link	Date of last access
residential) and on short-term care for people aged 65 and over, in £ thousands (divided by 1,000)		Outer London		Spending on long-term care including both community and residential settings was summed to spending on short-term care for a robustness check	Report, England 2016-17: Reference data tables [94], worksheet 33 for long-term care and worksheet 23 for short-term care	activity-and-finance-report/adult-social-care-activity-and-finance-report-england-2016-17	
Net current social care expenditure for people aged 65 and over on: "physical support", "sensory support", "support with memory and cognition", "learning disability support", "mental health support" ([248],	LA	LAs + Inner and Outer London	2016/17	Spending was summed across different Inner and Outer London LAs	Department for Communities and Local Government. Revenue Outturn (RO) 2016-17: Social Care and Public Health (RO3) data for England [248]	https://www.gov.uk/government/statistics/local-authority-revenue-expenditure-and-financing-england-2016-to-2017-individual-local-authority-data-outturn	25/05/2022

Variable	Original unit	Unit of analysis	Financial year	Notes	Source	Link	Date of last access
worksheet “Front Page”), in £ thousands (divided by 1,000)							
Area cost adjustment factor	Area Cost Adjustment areas (corresponding LAs were specified in the document)	LA + Inner and Outer London	2013/14	An area cost adjustment factor relating to 2013/14 rather than 2016/17 was used because a later year cost adjustment factor was not found and it was noted that two 2020 publications also used the 2013/14 cost adjustment factor.[41]	Department for Communities and Local Government [113]	http:/www.local.communities.gov.uk/finance/1314/CalcFFs.pdf https://webarchive.nationalarchives.gov.uk/20140505105851/	25/05/2022
Proportion of people with a disability among people aged 65 and over	The proportion of people without a disability was stratified by gender and age	LA + Inner and Outer London	2013-15 (no proportion was found for	Different estimates of disability-free prevalence were presented, which were based on different methods. Estimates	Office for National Statistics [96, 97]	Source for proportion without a disability: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/disabilityfreeprevalenceratesanddisa	22/05/2022

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[41] Firstly, a publication which focused on expenditure data from 2017/2018 (77. Longo F, Claxton K, Lomas J, et al. Does public long-term care expenditure improve care-related quality of life in England? CHE Research Paper 172: Centre for Health Economics (CHE), University of York; 2020 [cited 2020 November 10]. Available from: https://www.york.ac.uk/che/news/news2020/cheresearchpaper172/., p. 24). Secondly, a 2020 publication from the Local Government Association which focused on expenditure data from 2018/19 but referred to a 2014 area cost adjustment 116. Local Government Association. Explaining Variation in Spending – Adults’ Services for Older People. 2020 [cited 2021 July 20]. Available from: https://www.local.gov.uk/publications/explaining-variation-spending-adults-services-older-people..

Variable	**Original unit**	**Unit of analysis**	**Financial year**	**Notes**	**Source**	**Link**	**Date of last access**
	group for each LA.		2016 or 2017)	from method 1 were chosen. The following was calculated: Weighted average across age groups; weighted average for men and women together; weighted average for inner and outer London. The N of people used as weights were the ONS population estimates from mid-2015. Finally, the % of people with a disability was calculated by subtracting the % of people without a disability from 100.		bilityfreelifeexpectancybymethodsexgeographicalareaandperiod Source for weights (N of people) for weighted averages: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland	
N of people aged 65 and over with a disability	This variable was calculated for the present work for upper tier LAs + inner and outer London	LA + Inner and Outer London	2016, but part of estimate came from 2013-2015	The proportion of people aged 65 and over with a disability in 2013-2015 (see row above in this table) was multiplied by the N of people aged 65 and over in 2016 (see row above)	NA	NA	NA

Variable	**Original unit**	**Unit of analysis**	**Financial year**	**Notes**	**Source**	**Link**	**Date of last access**
IDAOPI average score	Lower tier LAs (LA-level weighted averages based on LSOAs)	Upper tier LAs plus Inner and Outer London	2015	Weighted averages were calculated; the weights were the number of people aged 60 and over in each LA in mid-2015. (60 and over was used because the IDAOPI score refers to people aged 60 and over).	Department for Communities and Local Government. File 10: local authority district summaries [98]. Office for National Statistics [97, 249]	https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015 Matching of lower tier LAs to upper tier LAs based on https://geoportal.statistics.gov.uk/datasets/lower-tier-local-authority-to-upper-tier-local-authority-december-2016-lookup-in-england-and-wales-1/about Source for weights (N of people) for weighted averages: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland	24/05/2022
IMD average score	As above	As above	As above	Weighted averages were calculated; the weights were the number of people in the LA (all ages) in mid-2015	As above	As above	As above

Variable	**Original unit**	**Unit of analysis**	**Financial year**	**Notes**	**Source**	**Link**	**Date of last access**
LA website score	LAs	LAs + Inner and Outer London	2015	Average was calculated for inner and outer London. The Independent Age report assigned scores based on different topic areas, including: information for carers, adult social care, rules that changed after the Care Act, assessments and eligibility criteria, information on "paying for care and independent financial advice" (p.7), types of providers and choice of provider, "how to obtain accessible information and advocacy" (p.7), and "planning and paying for future care" (p.7).	Independent Age [95]	https://www.independentage.org/policy-research/research-reports/information-and-advice-since-care-act-how-are-councils-performing	10/04/2022
% of "requests for support received from new clients" aged 65 and over	LAs	LAs + Inner and Outer London	2016/17	The dataset presented totals; a percentage was calculated for the present work.	NHS Digital. Adult Social Care Activity and Finance Report,	https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-	24/05/2022

Variable	Original unit	Unit of analysis	Financial year	Notes	Source	Link	Date of last access
resulting in no care and no assistive equipment ([94], worksheet T9)				Additional notes in footnote[42]	England 2016-17: Reference Data Tables [94]. Worksheet T9	report/adult-social-care-activity-and-finance-report-england-2016-17	
% living in rural areas (considering Large Market Towns as rural, as per the source file on the government website)	Lower-tier LAs	Upper tier LAs + Inner and Outer London	2001	Weighted averages were calculated for the bigger LAs. The weights were the total population estimates in the same rurality information file; these were based on the 2001 Census. Used in chapter 5 only	UK government. 2001 Local Authority Classification dataset - post April 2009 LA boundaries. [155]	https://www.gov.uk/government/statistics/2001-rural-urban-definition-la-classification-and-other-geographies Matching of lower tier LAs to upper tier LAs based on https://geoportal.statistics.gov.uk/datasets/lower-tier-local-authority-to-upper-tier-local-authority-december-2016-	30/12/2022

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[42] SALT data focus on number of requests rather than number of clients. The SALT guidance specifies: "If multiple requests for support are made within a short period of time for the same client and presenting issue, then only one request should be counted. If subsequent requests relating to a different need are received for that client, then they may be included" (p. 19) into the previous one as long as they are made in the same financial year (117.NHS Digital. Short and Long Term (SALT) data return: 2019-20 guidance. 2020 [cited 2022 May 18]. Available from: [URL no longer available].)

The SALT guidance 117. Ibid. explains that requests can only be classified under one single sequel (response). The first classification which applies has to be selected according to the following order, from first to last: "Short Term Support to Maximise Independence" (p. 7), "Long Term Support", "End of Life", "Ongoing Low Level Support" (which refers to equipment an adaptations) (p. 22), "Short Term Support (Other)", "Universal Services/Signposted to other services", "No services provided" (p. 23).

There were two sequels for which reporting was voluntary, so these were not included in the calculations for the present work: "100% NHS Funded Care" and "No services provided - deceased", referring to people who died before receiving services (The SALT guidance 117. Ibid. Worksheet T9).

Variable	Original unit	Unit of analysis	Financial year	Notes	Source	Link	Date of last access
					Office for National Statistics [249]	lookup-in-england-and-wales-1/about	

Table notes. Abbreviations: LA : local authority.

Appendix 4B. More details about how specific individual-level variables were created

Appendix 4B.1. The frailty index

The present work constructed a frailty index in a similar way to previous studies using ELSA data: Gale et al. [102] included 52 deficits, Niederstrasser et al. [103] 56 deficits and Davies et al. [101] 59 deficits. All three studies included self-reported health conditions, difficulties in activities of daily living and mobility, self-rated health, vision and hearing. Moreover, they all included cognition in addition to physical deficits. Niederstrasser et al. [103] and Davies et al. [101] also included depressive symptoms, whilst Gale et al. [102] did not. Gale et al. [102] and Davies et al. [101] also included falls, fractured hip, joint replaced, pain whilst walking.

Differently from Davies et al. [101] and Niederstrasser et al. [103], and same as Gale et al. [102], the present work did not include depressive symptoms.

Table 79 shows all deficits included in the frailty index for the present work and how each was scored. In the notes section, comments compare each deficit inclusion to Gale et al. [102] and Davies et al. [101].

Table 79. The 43-deficits frailty index constructed using ELSA data.

Type of deficit	**Deficit**	**Scoring**	**Notes**	**N**	**Missing data in initial sample of 1255 people?**
Difficulties with these general mobility tasks (wording from [29], p. 93):	“Walking 100 yards”	Yes=1, no=0	As in Davies et al. [101] and Gale et al. [102]	1	No
	“Sitting for about 2 hours”	Yes=1, no=0	As in [101] and [102]	2	No
	“Getting up from a chair after sitting for long periods”	Yes=1, no=0	As in [101] and [102]	3	No
	“Climbing a single flight of stairs without resting”	Yes=1, no=0	As in [101] and [102]	4	No
	“Climbing several flights of stairs without resting”	Yes=1, no=0	Included in [101]; not included in [102]	5	No
	“Stooping, kneeling, or crouching”	Yes=1, no=0	As in [101] and [102]	6	No
	“Reaching or extending” “arms above shoulder level”	Yes=1, no=0	As in [101] and [102]	7	No
	“Pulling or pushing large objects like a living room chair”	Yes=1, no=0	As in [101] and [102]	8	No
	“Lifting or carrying weights over 10 pounds like a heavy bag of groceries”	Yes=1, no=0	As in [101] and [102]	9	No
	“Picking up a 5p coin from a table”	Yes=1, no=0	As in [101] and [102]	10	No
Physical health diagnoses - doctor has ever diagnosed:	Angina	Yes=1, no=0	As in [101] and [102]	11	No
	A heart attack	Yes=1, no=0	As in [101] and [102]	12	No
	Congestive heart failure	Yes=1, no=0	As in [101] and [102]	13	No
	A heart murmur	Yes=1, no=0	As in [101] and [102]	14	No
	An abnormal heart rhythm	Yes=1, no=0	As in [101] and [102]	15	No
	Diabetes or high blood sugar	Yes=1, no=0	As in [101] and [102]	16	No
	High blood pressure	Yes=1, no=0	As in [101], not included in [102]	17	No
	High cholesterol	Yes=1, no=0	Not included in [101] nor in [102]	18	No
	A stroke	Yes=1, no=0	As in [101] and [102]	19	No

Type of deficit	**Deficit**	**Scoring**	**Notes**	**N**	**Missing data in initial sample of 1255 people?**
	Chronic lung disease	Yes=1, no=0	As in [101] and [102]	20	No
	Asthma	Yes=1, no=0	As in [101] and [102]	21	No
	Arthritis	Yes=1, no=0	As in [101] and [102]	22	No
	Osteoporosis	Yes=1, no=0	As in [101] and [102]	23	No
	Cancer	Yes=1, no=0	As in [101] and [102]	24	No
	Parkinson's disease	Yes=1, no=0	As in [101] and [102]	25	No
Mental health	Has had any "emotional, nervous or psychiatric problem" during the last two years ([29], p. 72)	Yes=1, no=0	As in [101] and [102]	26	No
Cognition-related diagnoses: a doctor has ever diagnosed	Alzheimer's disease	Yes=1, no=0	As in [101] and [102]	27	No
	Dementia	Yes=1, no=0	As in [101] and [102]	28	No
Overall health	Self-reported general health	Excellent=0, very good=0.25, good=0.5, fair=0.75, poor=1.	Scoring as in Searle et al. [104]. Davies et al. [101] considered health reported to be fair or poor as a deficit. Not included in [102].	29	Yes
	Long-standing illness	No illness=0, illness, not limiting=0.50, limiting illness=1	My own scoring. Not included in [101] and [102].	30	No
Hearing and eyesight	Self-reported hearing	Excellent=0, very good=0.25, good=0.5, fair=0.75, poor=1.	Scoring as in [102]. Davies et al. [101] counted fair or poor self-reported hearing as having a deficit.	31	No
	Self-reported eyesight	Excellent=0, very good=0.20, good=0.40, fair=0.60, poor=0.80, spontaneous: registered or	My own scoring, emulating the scoring for self-reported health by Searle et al. [104]. Gale et al. [102] applied a slightly different scoring. Davies et al.	32	No

Type of deficit	**Deficit**	**Scoring**	**Notes**	**N**	**Missing data in initial sample of 1255 people?**
		legally blind=1.	[101] counted fair or poor self-reported eyesight as having a deficit.		
Pain	Often troubled by pain	Yes=1, no=0	Gale et al. [102] focused on: often troubled by severe pain. Not included in [101].	33	Yes
Other	Fallen down in the last two years	Yes=1, no=0	As in [101] and [102]	34	Yes
	Whether has fractured hip over the previous two years	Yes=1, no=0	As in [101] and [102]	35	No
	Ever had any joint replacement	Yes=1, no=0	As in [101] and [102]	36	No
Cognitive function	Cannot answer correct day of month (either incorrect answer or “don’t know”)	Yes=1, no=0	As in [101] and [102]	37	Yes
	Cannot answer correct year (either incorrect answer or “don’t know”)	Yes=1, no=0	As in [101] and [102]	38	Yes
	Cannot answer correct month (either incorrect answer or “don’t know”)	Yes=1, no=0	As in [101] and [102]	39	Yes
	Cannot answer correct day (either incorrect answer or “don’t know”)	Yes=1, no=0	Included in [101] but not in [102]	40	Yes

Type of deficit	Deficit	Scoring	Notes	N	Missing data in initial sample of 1255 people?
	Verbal fluency test: mention as many animals as you can in 60 seconds	Score divided into quartile. Lowest score quartile=1 Second lowest quartile=0.66 Second highest quartile=0.33 Highest score quartile=0. For each chapter, quartiles were defined based on the people included in the main models, so quartiles differed for chapter 4 and chapter 5.	My own scoring. Gale et al. [102] mentioned mapping cognitive function to a deficit, but no details were provided on how cognitive function was measured. With regards to scoring, in Gale et al. [102] the level of cognitive function was divided into quartiles, and scoring was: "1 (lowest scores)=1, 2=0.6, 3=0.3, 4 (highest scores)= 0" (Appendix 1, p. 5) Davies et al. [101] did not include this test.	41	Yes
	Immediate recall of 10 words test	10 words=0 9 words=0.1 8 words=0.2 7 words=0.3 6 words=0.4 5 words=0.5 4 words=0.6 3 words=0.7 2 words=0.8 1 word=0.9 0 words=1	My own scoring. Davies et al. [101] mentioned mapping the immediate recall test results to a 0-1 deficit interval, but they did not provide details on how this was done. Gale et al. [102] mentioned mapping cognitive function to a deficit, but no details were provided on how cognitive function was measured.	42	Yes

Type of deficit	**Deficit**	**Scoring**	**Notes**	**N**	**Missing data in initial sample of 1255 people?**
	Delayed recall of 10 words test	10 words=0 9 words=0.1 8 words=0.2 7 words=0.3 6 words=0.4 5 words=0.5 4 words=0.6 3 words=0.7 2 words=0.8 1 word=0.9 0 words=1	My own scoring. Davies et al. [101] mentioned mapping the delayed recall test results to a 0-1 deficit interval, but they did not provide details on how this was done. Gale et al. [102] mentioned mapping cognitive function to a deficit, but no details were provided on how cognitive function was measured.	43	Yes

Table notes. Abbreviations: p: pence.

Questions relating to the deficits listed in the table are available in the ELSA wave 8 questionnaire [29] within the "health module" (p. 49-114).

Appendix 4B.2. Equivalised wealth

The present work calculated an equivalised version of wealth, i.e., wealth adjusted by benefit unit size. The ELSA dataset does not include an equivalised version of wealth, despite including an equivalised version of income, because there is no internationally agreed equivalence scale of wealth. The Organisation for Economic Co-operation and Development (OECD) [250] writes that there is no consensus on whether scales used for income are appropriate for wealth. According to the OECD, the use of equivalence scales for wealth depends on the goal of the analysis. If wealth is considered as a source of income “that can be used to finance consumption and contribute to economic wellbeing in the household” ([250], p. 169), it might be equivalised in the same way as income [250].

The ELSA dataset includes an OECD equivalence scale used to equivalise income for each person, depending on what benefit unit they belong to. The scale assigns a value of “0.5 to second adults and dependent children aged 14 and over and a weight of 0.3 to children under 14 years of age” ([107], p. 23). The present work calculated an equivalised version of wealth using this scale.

Appendix 4B.3. Education beyond school leaving age.

School leaving age became 14 in 1918, 15 in 1947 and 16 in 1972 [251]. ELSA asks at what age people finished continuous full time education. Using this, and their year of birth to identify the leaving age that applied to them, people were classified as below.

Table 80. Classification of education beyond school leaving age.

Year born	**School leaving age that applied to them**	**Left school later than ‘school leaving age’**	**Left school before or at ‘school leaving age’**
In 1932 or earlier	14	Left school at 15 years old or later	Left school at 14 or earlier
Between 1933 and 1952 (people born after 1952 not in the present study sample)	15	Left school at 16 years old or later	Left school at 15 or earlier

Note that the school leaving age of 16 would have applied to people born in 1957 onwards so it was not applicable to the present study sample of people aged 65 and over in wave 8.

Note that ELSA collapses age to 90 and year of birth accordingly. This would only be an issue for any respondent that had been born in 1905 or earlier, so aged 111/12 or more in wave 8; a school leaving age of 12 should have been applied in that case but this would not be possible due to age collapse.

Appendix 4B.4. LA-funded care and care paid with private funds or benefits: how the variables were generated

The table below explains how the variables “paying for care with private funds or benefits” and “LA-funded care” were generated. Note that each possible answer in the table corresponded to a separate ELSA variable. When the table mentions that an answer was not used, it means that the corresponding variable was not used when coding in Stata.

Table 81. Constructing source of care variables based on the ELSA wave 8 questionnaire [29].

Who was asked the question	**Question code and variable name**	**Question in ELSA**	**Link to the variables:** • **paying for care with private funds or benefits;** • **LA funding.**
People who had a formal care provider or had an informal carer who provided 20 or more hours of care per week	CADP Cadp1, cadp2, cadp3	"Local authorities/council/social services offer different ways of arranging payment for people's care. This card describes some of these ways. Please look at the card and tell me whether either of these apply for the care" received ([29], p. 127). The question included a reminder to only include payments for social care and not to include other payments, for example pension or attendance allowance. The options were: 01. "Direct payments". ([29], p. 127) 02. "Local authority/council/social services manages the money". ([29], p. 127) 03. "Neither of these". ([29], p. 127) (A person could select both 01 and 02 if applicable). ([29], p. 127)	In relation to option 01 (direct payments), the classification was as follows: • *Mentioned* -> classified as with LA-funded care. • *Not mentioned* or *not applicable* -> classified as no LA-funded care if a "not mentioned" or "not applicable" response was also given to other questions used for the LA funding classification (see separate table rows). Answers relating to option 02 were not used for classifying whether people had LA funding. The reason was that some self-funders can have their money managed by the LA. Answers relating to option 03 ("Neither of these") were not used, other answers were prioritised.[43]

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[43] Among those that answered that they had no direct payments and the LA did not manage money under this question, some later mentioned paying for care with a "Direct Payment/ Personal or Individual Budget from the Local Authority/council/ Social Services" (under the CAHPW question) (29. NatCen Social Research. Questionnaire & Data Documentation. Wave 8 – 2016/17. 2018 [cited 2021 February 08]. Available from: https://www.elsa-project.ac.uk/study-documentation., pp. 130-131) or that the "local authority /council /social services" paid for care (under the CAPAD question) (29. Ibid., pp. 131-132). In these cases, people were classified as with LA-funded care.

Who was asked the question	**Question code and variable name**	**Question in ELSA**	**Link to the variables:** - **paying for care with private funds or benefits;** - **LA funding.**
People who had replied that they paid or gave any money to the person who provided help	CAPHW caphwoi, caphwoi2, caphwoi3 caphwdp, caphwdp2, caphwdp3 caphwot caphwot2 caphwot3	Whether the person who helped was paid using money from: 01. “Own personal income, savings, pension or benefit (such as Attendance Allowance)”. ([29], p. 131) 02. “Direct Payment/ Personal or Individual Budget from the Local Authority / council / Social Services”. ([29], p. 131) 03. “From another source”. ([29], p. 131) (Note that if applicable, each question was asked about up to three different helpers; for each helper, the person could choose more than one response) ([29], pp. 130-131)	In relation to option 01, the classification was as follows: - *Mentioned* -> classified as paying for care with private funds or benefits. - *Not mentioned* or *not applicable* -> classified as not paying for care with private funds or benefits if a “not mentioned” or “not applicable” response was also given to other questions used for the “paying with private funds or benefits” classification (see separate table rows). In relation to option 02, the classification was as follows: - *Mentioned* -> classified as with LA-funded care - *Not mentioned* or *not applicable* -> classified as no LA-funded care if a “not mentioned” or “not applicable” response was also given to other questions used for the LA funding classification (see separate table rows) Option 03 was not used.

Who was asked the question	**Question code and variable name**	**Question in ELSA**	**Link to the variables:** - **paying for care with private funds or benefits;** - **LA funding.**
People with a formal care provider or with an informal carer providing 20 or more hours per week	CAPAD Capadla, capadla2, capadla3, capadfm, capadfm2, capadfm3, capadot, capadot2, capadot3, capadno, capadno2, capadno3	Whether, as far as they were aware, anyone else or any organisation paid or gave money to the person who provided help. The respondent was told not to count any benefits such as Carers Allowance or Attendance Allowance. These were the answer options: 01. "Yes, the local authority / council / social services". ([29], p. 131) 02. "Yes, a family member (with their own money)". ([29], p. 131) 03. "Yes, other". ([29], p. 131) 04. "No, nobody else pays". ([29], p. 131) (Note that if applicable, each question was asked about up to three different helpers; for each helper, the person could choose more than one response). ([29], p. 131)	In relation to option 01, the classification was as follows: - *Mentioned* -> classified as with LA-funded care - *Not mentioned* or *not applicable* -> classified as no LA-funded care if a "not mentioned" or "not applicable" response was also given to other questions used for the LA funding classification (see separate table rows) In relation to option 02, the classification was as follows: - *Mentioned* -> classified as paying for care with private funds or benefits. - *Not mentioned* or *not applicable* -> classified as not paying for care with private funds or benefits if a "not mentioned" or "not applicable" response was also given to other questions used for the "paying with private funds or benefits" classification (see separate table rows) Option 03 and option 04 were not used.
If no payment for care	CANOP Canopf, canopf, canopf3, canopg, canopg2, canopg3, canopot, canopot2, canopot3	"You have told me that no payment was made" for the person helping. Why was this? 01. "They provided their help for free / there is no charge for this service". ([29], p. 134) 02. "Sometimes give them money or gifts for the help they give". ([29], p. 134) 03. "Other". ([29], p. 134) (Note that if applicable, each question was asked about up to three different helpers). ([29], p. 134)	Option 01 was not used. In relation to option 02, the classification was as follows: - *Mentioned* -> classified as paying for care with private funds or benefits. - *Not mentioned* or *not applicable* -> classified as not paying for care with private funds or benefits if a "not mentioned" or "not applicable" response was also given to other questions used for the "paying with private funds or benefits" classification (see separate table rows) Option 03 was not used.

Appendix 4C. Correlation plot involving the frailty index

Cognition-related variables were included in the frailty index after some checks were made with a correlation plot (Table 82) as well as making robustness checks on the multivariable analysis model (see Appendix 4G.3).

These checks involved a standardised z score. This was built using methods in Zheng et al. [252]. Three z-scores were generated, one for the summed scores of immediate recall and delayed recall, one for verbal fluency and one for the number of correct answers to the four time-orientation questions (it was decided to do so even if time orientation scores were not normally distributed). These three z-scores were averaged. Then, this average z-score was standardised into its own z-score for ease of interpretation (interpretation could then focus on an increase in the standard deviation of the average z-score).

In Table 82, it was observed that better cognition (as measured by a standardised z score) was very weakly inversely correlated with the 34-deficits frailty index excluding cognition, so cognition deficits would be very weakly positively correlated with the 34-deficits frailty index. Similarly, a diagnosis of dementia or Alzheimer’s had a very weak positive correlation with the 34-deficits frailty index.

Moreover, there was a weak negative correlation between the 34-deficits frailty index and unmet need. At the same time, there was a very weak positive correlation between better cognition (as measured by the standardised z score) and unmet need, so there would be a very weak negative correlation between cognition deficits and unmet need.

Based on all the above observations, it was considered appropriate to incorporate cognition deficits into the frailty index.

Table 82. Pairwise correlations considered when deciding whether to include cognition-related variables in the frailty index; based on 992 people.

Variables		(1)	(2)	(3)	(4)	(5)	(6)	(7)
Unmet need	(1)	1.00						
Frailty including cognition (43 deficits)	(2)	-0.36	1.00					
Frailty excluding cognition (34 deficits)	(3)	-0.32	0.96	1.00				
Cognition standardised z score	(4)	0.20	-0.32	-0.05	1.00			
Dementia or Alzheimer's diagnosis	(5)	-0.11	0.15	0.01	-0.31	1.00		
N of PADL limitations	(6)	-0.12	0.40	0.37	-0.16	0.04	1.00	
N of IADL limitations	(7)	-0.38	0.49	0.38	-0.42	0.28	0.37	1.00

Legend

Colour	**Value of correlation coefficient**		**Interpretation for the present work**
	Positive coefficient (in green)	**Negative coefficient (in red)**	
🟨	>0 & <0.2	<0 & >-0.2	Very weak
🟨	>=0.2 & <0.4	<=-0.2 & >-0.4	Weak
🟨	>=0.4 & <0.6	<=-0.4 & >-0.6	Moderate
🟧	>=0.6 & <0.8	<=-0.6 & >-0.8	Strong
🟫	>=0.8 & <1	<=-0.8 & >-1	Very strong

Table notes. Abbreviations: IADLs: instrumental activities of daily living; N: number; PADLs: personal activities of daily living.

A higher standardised z score indicates better cognition. The terms “cognition-related variables” and “cognition deficits” refer to both cognition test scores and to a diagnosis of Alzheimer’s or dementia.

Appendix 4D. Correlation plot of LA-level variables

Correlation between the LA-level variables was explored before linking them to the ELSA dataset. Some variables had information for 121 LAs (Inner London, outer London and 119 non-London LAs). Other variables only had information for 120 LAs (no data on the Isles of Scilly). The IDAOPI score had a positive correlation with expenditure. The correlation ranged from weak to moderate, depending on the measure of expenditure.

Table 83. Pairwise correlations, LA-level variables: dataset where each LA corresponds to an observation (121 in total); based on publicly available data only, unlinked to ELSA.

Variables		(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
Community LTC gross expenditure per person with a disability aged 65 and over	(1)	1.00										
Community LTC gross expenditure per resident aged 65 and over	(2)	0.95	1.00									
STC and community LTC gross expenditure per person with a disability aged 65 and over	(3)	0.89	0.88	1.00								
Total STC and LTC gross expenditure per person with a disability aged 65 and over	(4)	0.52	0.53	**0.62**	1.00							
LA net spending on support per person with a disability aged 65 and over	(5)	0.48	0.47	0.49	**0.78**	1.00						
IDAOPI score	(6)	0.26	0.47	0.33	0.45	0.29	1.00					
IMD score	(7)	0.10	0.31	0.17	0.39	0.20	0.93	1.00				
Percentage of people aged 65 and over with a disability	(8)	0.03	0.34	0.13	0.15	0.05	**0.72**	**0.72**	1.00			
Percentage of people living in rural areas	(9)	-0.40	-0.50	-0.45	-0.41	-0.25	-0.65	-0.56	-0.47	1.00		
LA website score	(10)	-0.03	-0.06	-0.03	-0.15	-0.08	-0.22	-0.23	-0.10	0.18	1.00	
% of new requests resulting in no care or assistive equipment	(11)	-0.12	-0.13	-0.13	-0.07	0.11	-0.21	-0.20	-0.09	0.18	0.00	1.00

Legend

Colour	**Value of correlation coefficient**		**Strength of the correlation**
	Positive coefficient (in green)	**Negative coefficient (in red)**	
🟨	>0 & <0.2	<0 & >-0.2	Very weak
🟨	>=0.2 & <0.4	<=-0.2 & >-0.4	Weak
🟨	>=0.4 & <0.6	<=-0.4 & >-0.6	Moderate
🟧	>=0.6 & <0.8	<=-0.6 & >-0.8	Strong
🟫	>=0.8 & <1	<=-0.8 & >-1	Very strong

Table notes. Abbreviations: IMD: index of multiple deprivation; IDAOPI: income deprivation affecting older people; LA: local authority; LTC: long-term care; STC: short-term care. The dataset included 119 non-London LAs, plus Inner and Outer London. Some publicly available data were only available for 118 non-London LAs due to missing data on the Isles of Scilly. A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 4E. Different ways of handling missing data

Section 4.2.1.5.2 explains that in the final model, for the social contact and internet use variables, missing values were replaced with 0 and two dummy variables for missing information were added. Robustness checks were carried out where the final model selected with sequential modelling (Table 10, model 4) was re-run using two different methods of dealing with missing data:

- Alternative method 1. An average of the social contact index was calculated based on available data. Missing values for social contact were replaced with this average and a dummy variable for missing information was added. For internet use, replacement with 0 was retained, as this was a categorical variable.
- Alternative method 2. Multiple imputation by chained equations was attempted. An advantage of multiple imputation is that it incorporates the uncertainty involved in missing values. Ten imputations were carried out.

Multivariable imputation in relation to social contact was based on an OLS regression including the following predictors: age, sex, having a spouse or partner, frailty index, education, equivalised net total wealth, currently working, access to a car, the percentage of people in the local authority that lived in rural areas, and unmet need. The selection of covariates included in the regression was in part made based on an article on the determinants of "social detachment" ([253], p. 924) in later life [253]. It should be noted that social detachment in the article was defined differently from social contact in the present work: although it included some relevant variables ("meeting in person a child, family member or friend at least once a week" ([253], p. 924), it also included other additional items, for example membership of religious or cultural groups or sports clubs [253]. The unmet need variable was included given that the present work hypothesised a relationship between social contact and unmet need.

Multivariable imputation in relation to internet use was based on a logit model. The predictors were the same as for social contact, but with these differences: access to a car was omitted and routine or manual occupation was included. The selection of covariates included in the regression was made considering two articles that analysed ELSA data in relation to internet use [254, 255]. Additionally, the percentage of local authority residents living in rural areas was kept considering the differences in average broadband speeds [256].

Results

Sample size was reduced to 983 rather than 992 with multiple imputation: 9 observations had missing data for the routine or manual occupation variable (used to impute internet use).

When missing values of social contact were replaced with an average value, the results were the same as when the missing values were replaced with 0, except for the coefficient of the missing social contact dummy. All other coefficients were the same with these two replacement methods.

The coefficients obtained after multiple imputation were very similar. The significance and direction of association was the same for all the coefficients across the three models; the exception was the level of significance for the missing social contact dummy, which changed based on the replacement method. Table 84 shows the odds ratios relating to social contacts and internet use.

Table 84. Outcome: unmet need. Odds ratios relating to social contact and internet use. Alternative ways of dealing with missing data.

	(1) Replaced missing with 0 for social contact and internet use (final model)	(2) Replaced missing with average for social contact, with 0 for internet use	(3) Replaced missing with imputed values for social contact and internet use
Social contact index in wave 7	0.901*	0.901*	0.906*
	[0.811,1.000]	[0.811,1.000]	[0.809,1.016]
Using the internet in wave 7	1.230	1.230	1.245
	[0.931,1.626]	[0.931,1.626]	[0.932,1.663]
Missing social contact in wave 7	0.430***	0.584**	
	[0.239,0.773]	[0.363,0.941]	
Missing internet use in wave 7	1.046	1.046	
	[0.524,2.085]	[0.524,2.085]	
N	983	983	983

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: N: number. Wave 7 refers to 2014-15.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (see Table 10, model 4). The significance and direction of association for the variables not included in the table above were the same across the three models.

The social contact index ranged from 0 to 6. A higher value indicated more social contact. Replacement with 0 or with an average value only applied to people who filled in a self-completion questionnaire; people who did not do so were excluded.

Appendix 4F. Comparison between a model with clustered standard errors and multilevel models

Table 85 shows that a two-level and a three-level model outputted very similar results to the clustered standard error model, except for some exceptions highlighted in bold: social contact changed from significant to borderline significant; LA deprivation was still significant based on a p<0.05 threshold but no longer significant based on a p<0.01 threshold. Considering these limited differences, the clustered standard error model was chosen as it made it easier to make comparisons during sequential modelling, as explained in the main text.

Random effects methods were chosen over fixed effects methods for the multilevel models. Fixed effects methods were not applicable because they would have eliminated any LA-effect and so were not applicable to study the effect of LA-level variables. However, in random effects models, the assumption is that the explanatory variables are uncorrelated with the unobserved cluster effects. The models included LA characteristics that were hypothesised to be key determinants of unmet need, however, there may have been additional LA characteristics not included in the models that may have been correlated with the other variables. This was a potential weakness of the models.

The bottom of Table 85 shows the estimated variance components, i.e., between-LA variance and between-household variance (the latter below the former). Between-LA variance was borderline significant (*p value < 0.1), between-household variance was not significant.

Table 85. Outcome: unmet need. Odds ratios. Comparing a clustered standard error logit model to multilevel logit models.

	(1) Clustered standard error	(2) Multilevel (2 levels)	(3) Multilevel (3 levels)
Age 70-74	1.022	1.037	1.037
	[0.684,1.528]	[0.651,1.653]	[0.650,1.653]
Age 75-79	0.782	0.723	0.723
	[0.500,1.224]	[0.437,1.197]	[0.437,1.197]
Age 80-84	0.477***	0.435***	0.435***
	[0.288,0.790]	[0.260,0.729]	[0.259,0.728]
Age 85+	0.402***	0.383***	0.383***
	[0.253,0.641]	[0.216,0.679]	[0.216,0.679]
Male	1.530***	1.588***	1.588***
	[1.146,2.041]	[1.131,2.229]	[1.131,2.230]
Living alone in wave 7	2.326***	2.472***	2.472***
	[1.595,3.391]	[1.686,3.625]	[1.686,3.625]
Child within 30 minutes in wave 8	0.997	0.968	0.968
	[0.690,1.441]	[0.677,1.384]	[0.678,1.384]
Social contact index in wave 7	**0.901****	**0.902***	**0.902***
	[0.811,1.000]	[0.807,1.008]	[0.807,1.008]
Using the internet in wave 7	1.236	1.235	1.235
	[0.932,1.638]	[0.856,1.784]	[0.855,1.783]
Missing social contact in wave 7	0.430***	0.410***	0.409***
	[0.239,0.773]	[0.220,0.766]	[0.219,0.765]
Missing internet use in wave 7	0.988	0.909	0.910
	[0.495,1.971]	[0.372,2.221]	[0.372,2.226]
43-deficits frailty index in wave 8	0.944***	0.943***	0.943***
	[0.929,0.959]	[0.924,0.962]	[0.924,0.962]
N of PADL limitations in wave 8	1.072	1.062	1.062
	[0.919,1.250]	[0.921,1.225]	[0.921,1.225]
N of IADL limitations in wave 8	0.541***	0.531***	0.531***
	[0.448,0.655]	[0.451,0.624]	[0.451,0.624]
Education beyond school leaving age	1.236	1.245	1.244
	[0.870,1.756]	[0.867,1.788]	[0.866,1.787]
Wealth in wave 7: quartile 2	0.931	0.951	0.951
	[0.566,1.534]	[0.592,1.527]	[0.592,1.529]
Wealth in wave 7: quartile 3	0.892	0.931	0.931
	[0.574,1.384]	[0.583,1.486]	[0.583,1.486]
Wealth in wave 7: quartile 4 (highest)	0.702	0.732	0.732
	[0.401,1.229]	[0.435,1.234]	[0.434,1.233]
Log of LA gross spending	1.007	1.065	1.060
	[0.523,1.941]	[0.475,2.389]	[0.471,2.384]

	(1) Clustered standard error	(2) Multilevel (2 levels)	(3) Multilevel (3 levels)
LA IDAOPI average score	**1.052*** **	**1.053** **	**1.053** **
	[1.016,1.090]	[1.010,1.097]	[1.010,1.097]
LA website score	1.000	0.998	0.999
	[0.954,1.049]	[0.947,1.053]	[0.947,1.053]
Percentage of new requests to the LA not resulting in care or equipment	1.002	1.003	1.004
	[0.990,1.015]	[0.990,1.017]	[0.990,1.018]
LA percentage of new requests that arose from a hospital discharge			1.001
			[0.980,1.023]
/			
Between-LA variance		1.282*	1.280*
		[0.991,1.658]	[0.990,1.657]
Between-household variance			1
			[1.000,1.000]
N	992	992	992

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Results were highlighted in bold if the significance or direction of association changed across the models.

Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; log: natural logarithm; PADLs: personal activities of daily living.

Wave 7 refers to 2014-15 and wave 8 to 2016-17.

Reference category for age: 65-69.

The frailty index was measured as a percentage.

Wealth refers to equivalised net total wealth. Reference category for wealth: lowest quartile.

The social contact index ranged from 0 to 6. A higher value indicated more social contact. In the social contact index and in the internet use variable, missing values were replaced with 0 (only for people who responded to the self-completion questionnaire; people who did not do so were excluded).

LA gross spending refers to spending on community long-term care (adjusted by an area cost adjustment factor) per older person with a disability, in £ thousands (i.e., divided by 1,000).

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 4G. Robustness checks

Appendix 4G.1. Robustness checks using ELSA longitudinal weights

Robustness checks, but not the final model (model 4, Table 10), included ELSA longitudinal weights. The use of weights in the analysis of survey data minimises bias that arises when certain characteristics, for example socio-economic status or health status, are associated with non-response. More specifically, the longitudinal weights that were used took account of non-response at previous waves since wave 4 and non-response during wave 8. Reweighting makes the sample “as representative as possible” ([118], p. 127) of people aged 50 or more and living in England in 2008/09 (time of wave 4) and who remained to live in private households over the following years [118] (there is no expectation that the sample is representative of people in residential care).

There were two reasons for only including longitudinal weights in robustness checks rather than in the final model. Firstly, this work focused on older people aged 65 and over with a minimum level of difficulties. Ideally it would have used weights calculated specifically for this sub-population, which may have different predictors of non-response. Moreover, weights were only available for Core Members who participated in every biannual interview from wave 4 [118] (Core Members were people who participated in the HSE, fitted the ELSA age criteria and were interviewed for ELSA at their first opportunity [67]). Therefore, the use of weights led to the exclusion of 100 people from the analysis. Considering these two issues, weights were only used in robustness checks.

Results

When weights were used, significance and direction of association did not change for most independent variables. The exceptions are in Table 86.

Table 86. Outcome: unmet need. Odds ratios relating to variables with changed significance in the robustness check around using ELSA longitudinal weights.

	(1)	(2)
	Model without weights, sample size reduced to those with available weight	Model with wave 8 longitudinal weights
Social contact index in wave 7	0.893**	0.904*
	[0.800,0.998]	[0.811,1.009]
Using the internet in wave 7	1.160	1.326*
	[0.858,1.568]	[0.959,1.833]
Missing social contact in wave 7	0.423**	0.357***
	[0.218,0.823]	[0.183,0.695]
	(0.301)	(0.223)
LA IDAOPI average score	1.056***	1.047**
	[1.015,1.098]	[1.007,1.090]
N	892	892

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: N: number; IDAOPI: income deprivation affecting older people. Wave 7 refers to 2014-15.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (see Table 10, model 4). The significance and direction of association for the variables not included in the table above were the same across the two models.

The social contact index ranged from 0 to 6. A higher value indicated more social contact. In the social contact index and in the internet use variable, missing values were replaced with 0 (only for people who responded to the self-completion questionnaire; people who did not do so were excluded).

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 4G.2. Robustness checks on the outcome definition

Some robustness checks were made in relation to the definition of met and unmet need, see models in Table 87. Models 2 and 3 in Table 87 defined unmet care need simply as not having help. Compared to the final model (model 1 in Table 87), the significance and direction of association of the results mostly did not change (a couple of exceptions are highlighted in bold in Table 87). Therefore, people that had help which only met needs sometimes or hardly ever, who were a minority among people with unmet need, had little influence on the results. People with no help, who were the great majority of people classified as with unmet need, influenced the results considerably. The problem with this was that people with no help were not asked if they wanted or needed help, so this raised concern around the unmet need definition.

In an attempt to address the same concern about people with no help, a robustness check was done, where people without PADL difficulties were excluded (model 6). PADL difficulties usually emerge after IADL difficulties [39], so having PADL difficulties could be considered as an indicator of having higher disability. This, in turn, could potentially make it more likely that people without help would need help. Results were very similar between the main model (model 1) and model 6. This may be interpreted as providing some reassurance around defining a lack of help as unmet need, but the same problem with the definition persists, because it is unclear if everyone with PADL difficulties needs help.

Other robustness checks separated help that met needs “all the time” from help that “usually” met needs, grouping the latter with “sometimes” and “hardly ever”, as per Iparraguirre [37] (models 4 and 5). Some results changed with this (model 4), but results changed the most when in addition to this, people with no help were excluded, so that the sample was restricted to those receiving care and unmet need was only defined based on people’s perceptions (model 5). For example, in model 5, the association between frailty and unmet need changed from a significant negative one to a borderline significant positive one. Overall, considering models 1 to 5, it stands out that the risk factors for not receiving any help were different to the risk factors for help that did not always meet needs once people had help. The results in the main model were greatly influenced by people with no help.

Some results in Table 87 were robust to the changes in the definition of unmet need and changes in the sample inclusion criteria: living alone was always positively associated with unmet need, while these determinants had no association with unmet need: being aged 70-74, compared to being aged 65-69; having a child within 30 minutes; education beyond school leaving age; the

LA website score and the percentage of new requests to the LA that resulted in no care or equipment. Instead, most associations observed in the main model were sensitive to changes in the definition of the outcome and included sample. These changed results were in relation to: the age groups 75-79, 80-84, 85+, being male, social contacts, using the internet, the number of PADL limitations, the number of IADL limitations, frailty, wealth, LA deprivation, LA spending.

Table 87. Outcome: unmet need. Odds ratios. Robustness checks on the outcome definition.

	(1) Final model	(2) Unmet need = no help; met need = any help	(3) Excluding people with help that meets needs sometimes/hardly ever; unmet need = no help	(4) Help that usually meets needs classified as unmet need	(5) Help that usually meets needs classified as unmet need; excluding people with no care	(6) Excluding people without PADL difficulties
Age 70-74	1.022	0.814	0.907	1.030	1.161	1.039
	[0.684,1.528]	[0.520,1.274]	[0.572,1.438]	[0.706,1.502]	[0.699,1.927]	[0.666,1.621]
Age 75-79	0.782	0.733	0.803	**0.711***	0.783	0.814
	[0.500,1.224]	[0.467,1.151]	[0.508,1.272]	[0.486,1.039]	[0.465,1.318]	[0.523,1.268]
Age 80-84	0.477***	0.432***	0.442***	**0.714**	**1.008**	0.517**
	[0.288,0.790]	[0.251,0.742]	[0.254,0.769]	[0.475,1.073]	[0.625,1.627]	[0.307,0.871]
Age 85+	0.402***	0.264***	0.284***	0.511***	**0.841**	0.345***
	[0.253,0.641]	[0.161,0.432]	[0.172,0.469]	[0.342,0.764]	[0.488,1.449]	[0.203,0.585]
Male	1.530***	1.709***	1.694***	**1.182**	**0.806**	1.538***
	[1.146,2.041]	[1.251,2.335]	[1.233,2.327]	[0.888,1.573]	[0.566,1.147]	[1.135,2.083]
Living alone in wave 7	2.326***	1.989***	2.179***	1.984***	1.899***	2.525***
	[1.595,3.391]	[1.327,2.981]	[1.435,3.310]	[1.455,2.706]	[1.304,2.765]	[1.640,3.887]
Child within 30 minutes in wave 8	0.997	0.922	0.933	1.046	1.070	0.983
	[0.690,1.441]	[0.598,1.419]	[0.600,1.453]	[0.806,1.357]	[0.762,1.503]	[0.663,1.457]
Social contact index in wave 7	0.901**	**0.887***	0.873**	0.903**	**0.923**	**0.924**
	[0.811,1.000]	[0.781,1.007]	[0.776,0.981]	[0.834,0.978]	[0.825,1.033]	[0.821,1.041]
Using the internet in wave 7	1.236	**1.475****	**1.498****	1.156	0.993	1.184
	[0.932,1.638]	[1.056,2.060]	[1.095,2.051]	[0.900,1.486]	[0.693,1.422]	[0.849,1.653]
Missing social contact in wave 7	0.430***	**0.484****	0.422***	**0.575****	**0.663**	**0.523***
	[0.239,0.773]	[0.259,0.903]	[0.222,0.804]	[0.351,0.942]	[0.351,1.252]	[0.270,1.013]

	(1) Final model	(2) Unmet need = no help; met need = any help	(3) Excluding people with help that meets needs sometimes/hardly ever; unmet need = no help	(4) Help that usually meets needs classified as unmet need	(5) Help that usually meets needs classified as unmet need; excluding people with no care	(6) Excluding people without PADL difficulties
Missing internet use in wave 7	0.988	1.356	1.381	0.717	0.490	0.873
	[0.495,1.971]	[0.578,3.177]	[0.586,3.253]	[0.373,1.378]	[0.204,1.178]	[0.407,1.873]
43-deficits frailty index in wave 8	0.944***	0.941***	0.938***	0.976***	**1.018***	0.941***
	[0.929,0.959]	[0.923,0.960]	[0.920,0.957]	[0.961,0.992]	[0.998,1.038]	[0.924,0.959]
N of PADL limitations in wave 8	1.072	0.908	0.916	**1.189*****	**1.186*****	0.954
	[0.919,1.250]	[0.760,1.085]	[0.772,1.087]	[1.060,1.334]	[1.045,1.346]	[0.800,1.137]
N of IADL limitations in wave 8	0.541***	0.363***	0.366***	0.771***	**0.988**	0.596***
	[0.448,0.655]	[0.291,0.453]	[0.293,0.458]	[0.697,0.852]	[0.888,1.100]	[0.488,0.729]
Education beyond school leaving age	1.236	1.077	1.196	1.191	1.279	1.196
	[0.870,1.756]	[0.694,1.671]	[0.772,1.852]	[0.874,1.622]	[0.897,1.826]	[0.838,1.707]
Wealth in wave 7: quartile 2	0.931	1.197	1.148	1.282	1.256	0.944
	[0.566,1.534]	[0.686,2.088]	[0.644,2.047]	[0.862,1.907]	[0.817,1.931]	[0.543,1.643]
Wealth in wave 7: quartile 3	0.892	1.143	1.103	0.824	**0.657***	0.892
	[0.574,1.384]	[0.720,1.816]	[0.670,1.817]	[0.579,1.172]	[0.422,1.024]	[0.549,1.451]
Wealth in wave 7: quartile 4 (highest)	0.702	0.945	0.864	1.149	1.275	0.786
	[0.401,1.229]	[0.517,1.728]	[0.462,1.617]	[0.774,1.707]	[0.789,2.061]	[0.440,1.404]
Log of LA gross spending	1.007	1.000	1.145	1.454	**1.973***	0.833

	(1) Final model	(2) Unmet need = no help; met need = any help	(3) Excluding people with help that meets needs sometimes/hardly ever; unmet need = no help	(4) Help that usually meets needs classified as unmet need	(5) Help that usually meets needs classified as unmet need; excluding people with no care	(6) Excluding people without PADL difficulties
	[0.523,1.941]	[0.467,2.145]	[0.525,2.497]	[0.865,2.446]	[0.900,4.325]	[0.400,1.735]
LA IDAOPI average score	1.052***	**1.049****	1.063***	**1.018**	**1.003**	**1.049****
	[1.016,1.090]	[1.008,1.093]	[1.022,1.107]	[0.985,1.053]	[0.963,1.045]	[1.011,1.089]
LA website score	1.000	1.007	1.012	0.979	0.963	1.008
	[0.954,1.049]	[0.953,1.064]	[0.958,1.070]	[0.938,1.021]	[0.920,1.008]	[0.959,1.059]
Percentage of new requests to the LA not resulting in care or equipment	1.002	1.000	1.002	0.996	0.992	1.005
	[0.990,1.015]	[0.986,1.015]	[0.988,1.016]	[0.984,1.008]	[0.979,1.005]	[0.993,1.018]
N	992	992	944	992	680	820

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.
Coefficients highlighted in bold indicate that the significance of the association changed compared to the final model.
Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; log: natural logarithm; PADLs: personal activities of daily living.
Wave 7 refers to 2014-15 and wave 8 to 2016-17.
Reference category for age: 65-69.
The frailty index was measured as a percentage.
Wealth refers to equivalised net total wealth. Reference category for wealth: lowest quartile.
The social contact index ranged from 0 to 6. A higher value indicated more social contact. In the social contact index and in the internet use variable, missing values were replaced with 0 (only for people who responded to the self-completion questionnaire; people who did not do so were excluded).
LA gross spending refers to spending on community long-term care (adjusted by an area cost adjustment factor) per older person with a disability, in £ thousands (i.e., divided by 1,000).
A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 4G.3. Robustness checks focused on cognition

Table 88 shows models that were run to test the robustness of results to different ways of handling cognition-related variables. Some models excluded cognition-related variables. This was explored because the inclusion of these variables led to losing 40 people from the analysis (30 of them had a proxy interview, so also had missing data on falls, self-reported health and often troubled by pain, but these variables could also have been excluded together with cognition).

The frailty index in model 2 excluded the cognition test scores variables. In model 3, dementia and Alzheimer's diagnoses were also taken out of the frailty index, in addition to the cognition test scores being taken out. The sample across all models was 992 as per the final model, to enable appropriate comparisons.

In models 4, 5 and 6, cognition test scores and/or dementia and Alzheimer's diagnosis were added to the model separately from the frailty index.

In model 4, a standardised z score calculated based on cognition test scores (see Appendix 4C for details on how it was calculated) was included separately from the frailty index.

In model 5, the standardised z score was calculated differently, because the score of immediate recall and delayed recall were not summed together; the z score for each test was calculated separately. Therefore, four z scores were generated and averaged rather than three. Then, this average z-score was standardised into its own z score.

In model 6, a variable capturing dementia or Alzheimer's diagnosis was added in addition to the standardised cognition z score.

Results

Results across the models were similar, with this exception: when the cognition test scores were excluded from the models, using the internet became a borderline significant risk factor for unmet need. This showed that the inclusion of cognition test scores was important to address confounding. Therefore, it was decided to keep them in the main model.

Table 88 shows that the cognition z score was not significantly associated with unmet need, but the odds ratio was in the direction of a positive association between a better cognition z score and unmet need. Moreover, an Alzheimer's or dementia diagnosis was not significantly associated with unmet need, but the odds ratio was in the direction of a negative association between a diagnosis and unmet need. Both of these results supported the incorporation of the cognition test scores and a dementia or Alzheimer’s diagnosis into the frailty index, because the frailty index was negatively associated with unmet need, indicating that the more the deficits a person had, the lower the odds of unmet need.

Table 88. Outcome: unmet need. Robustness checks on cognition. Odds ratios for the frailty and cognition variables, and for coefficients with changed significance across the models.

	(1) 43-deficits frailty index	(2) 36-deficits frailty index (without cognition test scores)	(3) 34-deficits frailty index (without cognition scores and without dementia or Alzheimer's diagnosis)	(4) 34-deficits frailty index plus standardised average z score of cognition test scores	(5) Same as model 4, but calculation of standardised average z score separated delayed and immediate recall tests	(6) Model 4 plus dementia or Alzheimer's diagnosis
Using the internet in wave 7	1.236	1.294*	1.292*	1.230	1.232	1.241
	[0.932,1.638]	[0.974,1.719]	[0.973,1.716]	[0.911,1.661]	[0.910,1.667]	[0.917,1.679]
Frailty index in wave 8	0.944***	0.955***	0.958***	0.956***	0.956***	0.956***
	[0.929,0.959]	[0.942,0.968]	[0.946,0.970]	[0.944,0.968]	[0.944,0.969]	[0.944,0.968]
Cognition z score in wave 8				1.162	1.154	1.148
				[0.954,1.416]	[0.956,1.393]	[0.934,1.411]
Dementia or Alzheimer's diagnosis in wave 8						0.435
						[0.074,2.568]
N	992	992	992	992	992	992

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (see Table 10, model 4). The significance and direction of association for the variables not included in the table above were the same across the six models.

Abbreviations: N: number. Wave 7 refers to 2014-15 and wave 8 to 2016-17.

A higher cognition z score indicates better cognition.

Appendix 4G.4. Checks on child in close proximity

With model 2 in Table 89, one robustness check was made where the category “no alive children” was split from “children all live further than 30 minutes away”; this was important because children living away could still help financially or by interacting with the council or formal care providers through the internet or the phone. Other robustness checks were made where a child in close proximity was defined as living within 15 minutes or within one hour from the respondent.

Results

Changes made to the child in close proximity variable had little effect on covariates. However, having a child within 15 minutes was a borderline significant risk factor for unmet need. This result was unexpected.

Table 89. Outcome: unmet need. Robustness checks on the child in close proximity variable. Odds ratios relating to said variable and odds ratios with changed significance across the models.

	(1) Final: close proximity defined as 30 minutes	(2) Split no-child-proximity-categories into: 1. child living further than 30 mins away; 2. no children. Reference category: child within 30 minutes.	(3) Close proximity defined as 15 minutes	(4) Close proximity defined as one hour
Social contact index in wave 7	0.901**	0.907*	0.881**	0.899*
	[0.811,1.000]	[0.815,1.009]	[0.793,0.979]	[0.808,1.001]
Child in close proximity	0.997		1.297*	1.017
	[0.690,1.441]		[0.959,1.755]	[0.714,1.449]
All children living further than 30 minutes away in wave 8		0.893		
		[0.582,1.369]		
No alive children in wave 8		1.301		
		[0.823,2.054]		
N	992	992	992	992

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: N: number. Wave 7 refers to 2014-15 and wave 8 to 2016-17.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (Table 10, model 4). The significance and direction of association for the variables not included in the table above were the same across the four models.

Appendix 4G.5. Robustness checks on the social contact variable

The limitations of the social index used in the main analysis [100] should be noted: if person A met up with both children and other relatives every day, they would get 2 points. If person B met up once a week with both children and other relatives, and talked on the phone with friends once a week, they would get 3 points. Arguably, person A might seem to have more social contacts than person B. Overall, it seems that the index captures the variety of social contacts in terms of different network types and modes of contact, rather than the frequency of contacts.

Robustness checks were made where the social contact index was replaced with the indexes in Table 90. Additionally, at least weekly in-person contact with friends was considered on its own, and so was at least weekly in-person contact with relatives other than children. Having friends was also included as an alternative.

Results

Table 91 shows that no significant association was found between unmet need and any of the alternative social contact measures.

Table 90. Social contact indexes used in robustness checks.

	Index similar to Ding et al. [257], but inverted	**Index similar to Shankar et al. [258] but inverted**
Contact with children	At least weekly contact by meeting, phoning, text or email: 3 points. “Once or twice a month”: 2 points. “Once every few months”: 1 point. “Once or twice a year or less”: 0 points. ([257], supplementary material, p. 4)	At least monthly contact (including face-to-face, phone and written): one point.
Contact with other family members	As above	As above
Contact with friends	As above	As above
Being part of different kinds of organisations, considering the church or a religious group as well as the following: 1) “Political party, trade union or environmental groups”; 2) “Tenants groups, resident groups, neighbourhood watch”; 3) “Charitable associations”; 4) “Education, arts or music groups or evening classes”; 5) “Social Clubs”; 6) “Sports clubs, gyms, exercise classes” ([257], supplementary material, p. 4)	Being a member of a church or other religious group: 1 point. Being part of 5 or 6 kinds of non-religious organisations: 3 points. Being part of 3 or 4: 2 points. Being part of 1 or 2: 1 point.	Being part of at least one group or organisation, including religious ones: one point.
Total score	0 to 13 (the higher the more social contact)	0 to 4 (the higher the more social contact)
How the original index was adapted to the present work	Score inverted so that the higher the score the more the social contact. Having a spouse or cohabiting with a partner was ignored so the score range was 0-13 rather than 0-14. Contact by text was included in addition to in-person, by phone and by email.	Score inverted so that the higher the score the more the social contact. Being married or cohabiting with a partner was ignored so the score range was 0-4 rather than 0-5.

Table 91. Outcome: unmet need. Robustness checks on the social contact variable. Odds ratios relating to social contacts.

	(1) Final model (Bu's social contact index inverted, 0-6)	(2) Edited & inverted Ding's social integration index (0-13)	(3) Edited & inverted Shankar's social contact index (0-4)	(4) Face-to-face contact at least weekly with relatives other than children (0-1)	(5) Face-to-face contact at least weekly with friends (0-1)	(6) Any friends (0-1)
Contact /index variable in wave 7	0.901**	0.998	0.989	0.837	0.720	0.937
	[0.811,1.000]	[0.930,1.071]	[0.845,1.158]	[0.605,1.157]	[0.476,1.089]	[0.573,1.533]
Missing data for index/contact in wave 7	0.430***	0.859	0.843	0.595**	0.760	0.521
	[0.239,0.773]	[0.452,1.634]	[0.465,1.526]	[0.378,0.937]	[0.459,1.258]	[0.142,1.913]
N	992	992	992	992	992	992

Table notes. Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

For each index, a higher value indicates more social contact or more social integration, as relevant. For each index/contact variable, missing values were replaced with 0 (only for people who responded to the self-completion questionnaire; people who did not do so were excluded).

Wave 7 refers to 2014-15.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (Table 10, model 4). The significance and direction of association for the variables not included in the table above were the same across the six models.

Appendix 4G.6. Robustness checks on the wealth variable

Table 92 shows the odds ratios for wealth in: the final model (model 1, with equivalised wealth quartiles); model 2, which included benefit unit (non-equivalised) wealth quartiles; model 3, which included equivalised wealth as a continuous variable. Results were very similar across the models: wealth was not a significant determinant of unmet need. The significance and direction of associations did not change for the other independent variables.

Table 92. Outcome: unmet need. Robustness checks on wealth. Odds ratios for the wealth variables.

	(1) Final: quartiles of equivalised total net wealth	(2) Quartiles of non-equivalised total net wealth	(3) Equivalised total net wealth as a continuous variable
Wealth in wave 7: quartile 2	0.931	0.954	
	[0.566,1.534]	[0.588,1.548]	
Wealth in wave 7: quartile 3	0.892	0.873	
	[0.574,1.384]	[0.557,1.369]	
Wealth in wave 7: quartile 4 (highest)	0.702	0.661	
	[0.401,1.229]	[0.393,1.109]	
Equivalised total net wealth in wave 7			1.000
			[1.000,1.000]
N	992	992	992

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: N: number. Wave 7 refers to 2014-15.

The lowest wealth quartile was the reference category in models 1 and 2.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (Table 10, model 4). The significance and direction of association for the variables not included in the table above were the same across the three models.

Appendix 4G.7. Robustness checks on the LA expenditure variable

A first robustness check was done, where both expenditure on short-term care and expenditure on residential long-term care were added to expenditure on community long-term care (expenditure for people aged 65 and over in all cases). The main reason to include short-term care was that it has a preventative role, as it would include reablement and intermediate care, so it has the potential to reduce spending on community long-term care. Moreover, it is directly involved in addressing unmet need in the community, even if for short time periods. Additionally, spending on residential care can also be related to expenditure and unmet need in the community, considering that people may be living in the community because they cannot afford residential care or are on a waiting list for residential care.

A second robustness check was done, where net expenditure replaced gross expenditure. This was done considering that a previous paper on the determinants of unmet need [37] focused on net current expenditure on community-based care.

One benefit of using net expenditure is that it excludes client contributions [112], so it only captures government spending. However, in addition to client contributions, it also subtracts all other sources of income [112, 248]. This would be more of interest for budgeting purposes than for the current work's focus on unmet need. Moreover, the net expenditure data that were identified also carried the disadvantage of not making a distinction between community and residential settings [248].

The net expenditure data specific to people 65 and over that was identified for the present work was social care expenditure on: "physical support", "sensory support", "support with memory and cognition", "learning disability support", and "mental health support" ([248], worksheet "Front Page"). The present work excluded other social care activities which were not disaggregated by age group in the data source. For sources of gross and net expenditure see Appendix 4A.

All expenditure data were specific to people aged 65 and over. The expenditure measures used in robustness checks were handled in the same way as the main expenditure variable: expenditure was divided by an area cost adjustment factor. Moreover, expenditure was divided by the number of people aged 65 and over with a disability in each LA. Finally, the logarithm of expenditure was calculated.

Results

The finding of no association between LA expenditure and unmet need was consistent. The results relating to the other independent variables were very similar with the different expenditure measures. Any changes in significance are shown in Table 93.

Table 93. Outcome: unmet need. Robustness checks on LA expenditure. Odds ratios for expenditure and for variables with changed significance across the models.

	(1) Final: log of LA gross spending on community long-term care	(2) Log of LA gross total spending (includes short-term care, plus community and residential long-term care)	(3) Log of LA net spending on physical support, sensory support, support with memory and cognition, learning disability, and mental health
Social contact index in wave 7	0.901**	0.901*	0.901*
	[0.811,1.000]	[0.811,1.000]	[0.811,1.002]
LA IDAOPI average score	1.052***	1.057***	1.041**
	[1.016,1.090]	[1.018,1.097]	[1.005,1.078]
Log of LA spending	1.007	0.802	1.655
	[0.523,1.941]	[0.227,2.831]	[0.758,3.615]
N	992	992	992

Table notes. Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: log: natural logarithm; N: number; IDAOPI: income deprivation affecting older people. Wave 7 refers to 2014-15.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (Table 10, model 4). The significance and direction of association for the variables not included in the table above were the same across the three models.

Expenditure data: adjusted by area cost factor, per older person with a disability, in £ thousands (i.e., divided by 1,000).

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 4G.8. Robustness checks on the LA deprivation variable

A robustness check was done, where the Index of Multiple Deprivation (IMD) score replaced the IDAOPI score. IMD is not limited to older people; this was relevant to the present work because younger people might provide informal care. ELSA does not record carers' characteristics (unless the carer is a cohabiting partner [67]). Therefore, the level of deprivation in the area where a person lives may act as a proxy for informal carers' socio-economic characteristics.

Results were similar with the IDAOPI score and the IMD score, but the coefficient of expenditure rose with the IMD score (without reaching significance), so the IDAOPI score seemed better at suppressing confounding caused by deprivation in the relationship between expenditure and unmet need.

In an additional robustness check which excluded any LA deprivation score from the model, the highest wealth quartile became a borderline significant protective factor against unmet need, see Table 94.

Table 94. Outcome: unmet need. Robustness checks on LA deprivation. Odds ratios of deprivation scores, expenditure scores and variables with changed significance across the models.

	(1) Final: IDAOPI average score	(2) IMD average score	(3) No deprivation score
Social contact index in wave 7	0.901**	0.903*	0.910*
	[0.811,1.000]	[0.813,1.003]	[0.819,1.010]
Wealth: quartile 4	0.702	0.684	0.595*
	[0.401,1.229]	[0.390,1.198]	[0.342,1.035]
Log of LA gross spending	1.007	1.283	1.456
	[0.523,1.941]	[0.707,2.329]	[0.797,2.661]
LA IDAOPI average score	1.052***		
	[1.016,1.090]		
IMD average score		1.032**	
		[1.004,1.061]	
N	992	992	992

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (Table 10, model 4). The significance and direction of association for the variables not included in the table above were the same across the three models.

Abbreviations: IMD: Index of Multiple Deprivation; log: natural logarithm; N: number; IDAOPI: income deprivation affecting older people.

Wealth refers to equivalised net total wealth. Reference category for wealth: lowest quartile.

The social contact index ranged from 0 to 6. A higher value indicated more social contact. In the social contact index, missing values were replaced with 0 (only for people who responded to the self-completion questionnaire; people who did not do so were excluded).

LA gross spending refers to spending on community long-term care (adjusted by area cost factor) per older person with a disability, in £ thousands (i.e., divided by 1,000).

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 4G.9. Assessing whether not including frailty would make LA spending significant

A check was done, to see if excluding frailty would make LA spending negatively associated with unmet need. This was done because a study by Iparraguirre [37] found that higher LA spending had a negative and borderline significant association with unmet need, but frailty was not included in Iparraguirre's model. The results showed that taking out frailty made little difference to the model; the significance and direction of associations of determinants did not change, except for those shown in Table 95.

Table 95. Outcome: unmet need. Removing frailty. Odds ratios for spending, deprivation, and for variables with changed significance across the models.

	(1) Final model	(2) Frailty index removed
Age 75-79	0.782	0.674*
	[0.500,1.224]	[0.432,1.053]
Frailty index (43 deficits), in wave 8	0.944***	
	[0.929,0.959]	
Log of LA gross spending	1.007	1.086
	[0.523,1.941]	[0.569,2.071]
LA IDAOPI average score	1.052***	1.047**
	[1.016,1.090]	[1.011,1.085]
N	992	992

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Abbreviations: LA: local authority; log: natural logarithm; N: number; IDAOPI: income deprivation affecting older people. Wave 8 refers to 2016-17.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (Table 10, model 4). The significance and direction of association for the variables not included in the table above were the same across the two models.

Reference category for age: 65-69.

The frailty index was measured as a percentage.

LA gross spending refers to spending on community long-term care (adjusted by area cost factor) per older person with a disability, in £ thousands (i.e., divided by 1,000).

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 4G.10. Looking at formal care instead of looking at LA-funded care or care paid with private funds or benefits

Given concerns with the validity of the LA-funding variable (see Appendix 4H), a check was done to see if other results held when the variable "receiving at least some formal care" replaced the two variables: LA funding and care paid with private funds or benefits. The significance and direction of association for the other determinants did not change, except for a wealth quartile shown in Table 96.

Table 96. Outcome: unmet need. Robustness checks on sources of care. Odds ratio for sources of care and for a variable with changed significance across the models.

	(1) Final model	(2) Inserting formal care and taking out LA-funded and funded by private funds or benefits
Wealth in wave 7: quartile 3	0.688*	0.704
	[0.446,1.060]	[0.453,1.093]
Informal care only from outside the household	1.832***	1.827***
	[1.242,2.701]	[1.251,2.668]
No informal care	1.132	1.112
	[0.681,1.881]	[0.661,1.871]
LA-funded care	0.784	
	[0.481,1.277]	
Care paid with private funds or benefits	1.447*	
	[0.988,2.120]	
Receives formal care in wave 8		1.263
		[0.893,1.786]
N	773	773

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model selected after sequential modelling (Table 14, model 1). The significance and direction of association for the variables not included in the table above were the same across the two models.

Abbreviations: LA: local authority; N: number. Wave 7 refers to 2014-15 and wave 8 to 2016-17.

Wealth refers to equivalised net total wealth. Reference category for wealth: lowest quartile. Quartiles were calculated based on the final sample (N=773).

The reference category for informal care only from outside the household and no informal care was at least some informal care from someone in household.

Care financed with private funds or benefits refers to the respondent paying out of own income, savings, or benefits or giving gifts or a family member paying.

Appendix 4H. Validation checks on the variable "LA-funded care".

People living in private households with non-housing wealth above £23,250 would not be eligible for LA-funded care, unless their LA has more generous thresholds compared to the minimum thresholds set in the Care Act 2014 [16]. A check was made to see how many people with and without LA-funded care had non-housing wealth above £23,250. Table 97 shows that 37% of people with LA-funded care had equivalised total net non-housing wealth above £23,250. The present work did not check if the calculation of non-housing wealth in ELSA corresponds to the way councils calculate non-housing wealth. If this was the case, potentially the LA-funded care variable did not accurately capture people with and without LA funding, or the wealth variable may not be accurately capturing information. Because of these concerns, a robustness check was conducted around this in Appendix 4G.10.

Table 97. Total net non-housing wealth and LA-funded care.

At least some LA-funded care in wave 8	Equivalised total net non-housing wealth above £23,250 in wave 8		TOT
	No	Yes	
No	408 (59%)	279 (41%)	687 (100%)
Yes	51 (63%)	30 (37%)	81 (100%)
Total	459 (60%)	309 (40%)	768 (100%)

Appendices chapter 5

Appendix 5A. More details on the selection of covariates

The following publications were used to select the covariates:

- a publication that used ELSA data to study the risk factors for falls by Gale et al. [109]. Table 98 compares the present work to the study by Gale et al. [109].

- a systematic review on the determinants of depression among older people by Zenebe et al. [156]. This included literature from any country. Table 99 compares the present work to the review by Zenebe et al. [156].

- an article that used ELSA data to study the determinants of frailty development and progression by Niederstrasser et al. [103]. Table 100 compares the present work to the study by Niederstrasser et al. [103].

Appendix 5A.1. Covariates selection. Outcome: any falls.

Table 98. Outcome: any falls - comparing the individual-level covariates in the present work to Gale et al. [109].

Items	Gale et al. [109]	The present work	Comments
Population	People aged >=60	See sample inclusion criteria in section 5.2.1; note the minimum level of difficulty with activities of daily living or mobility tasks, as well as age >=65.	-
Stratification	By sex	None	Limited sample size in the present work
Outcome	Any falls over 4 years: yes/no	Any falls over 2 years: yes/no	The period of interest for the present work was between 2016/17 (after the Care Act 2014 started to be implemented) and 2018/19 (before the COVID-19 pandemic)
Predictors	-	Unmet care need	Main focus of the present work
	Stratified by sex	Gender as an independent variable	-
	Age	Age groups	Age groups were preferred in the present work to avoid assumptions about a linear effect of age.
	Marital status	Living alone	Living alone was prioritised in the present work given its importance as a determinant of unmet need (see sections 4.2.2.3 and 4.4.1).
	BMI	-	Issue with missing data
	Smoking status: current, ex or never	Current smoker	A lower number of categories was preferred given the limited sample size in the present work. Current smoker preferred as indicator of current lifestyle
	Alcohol consumption: five categories from “almost every day” to “not at all in past year”.	-	Deprioritised (small sample size requires a limited number of variables)
	Physical activity:	-	Deprioritised (a small sample size requires a limited number of variables). The binary variable

	sedentary, low, moderate, high. This was based on a question on how much physical activity their job entailed and three questions about physical activity in their daily life.		"current smoker" was prioritised as a lifestyle indicator.
	N of diagnosed conditions	Included in frailty index	-
	-	N of PADL difficulties; N of IADL difficulties	Important confounder when studying the relationship between unmet need for care and N of falls
	Frailty (Fried phenotype) (Included weight loss, walking speed, grip strength, exhaustion measured by two CES-D items, low physical activity)	Frailty index used instead (see section 5.2.3 and Appendix 4B.1); none of the components of the Fried phenotype were included.	Missing data issues for weight loss, walking speed, grip strength. The CES-D items were used to measure depressive symptoms in the present work, so they were excluded from the frailty index.
	Depressive symptoms as measured by the 8-item CES-D scale	-	The number of depressive symptoms and having at least one fall were both considered as mediators from unmet need to worse frailty. To avoid over-complication of the mediation model, the DAG did not consider the possible influence of depressive symptoms on falls or vice versa.
	Hearing	Included in the frailty index	-
	Eyesight	Included in the frailty index	-
	Troubled by pain: none / mild / moderate / severe	Often troubled by pain included in the frailty index	-
	Incontinence	-	Not included due to issues with missing data, mostly linked to not

			filling in the self-completion questionnaire
	Balance (full tandem stand test)	Often/very often/always has problems with balance in wave 7	Problems with balance was taken from wave 7 as only available from wave 7
	Lung function	-	Only available from wave 6
	General cognitive function (verbal memory, prospective memory, attention/timed letter cancellation task, executive function/verbal fluency)	Included in the frailty index: cognition deficits relating to time orientation, immediate recall, delayed recall, verbal fluency	Timed letter cancellation task not included as per Zheng et al. [252].
	Household wealth	Equivalised household wealth	See Appendix 4B.2
	-	Education beyond school leaving age	Indicator of socioeconomic status and proxy for many unobservable factors.
	-	LA deprivation score	See section 5.2.6
	-	LA rurality score	See section 5.2.6

Appendix 5A.2. Covariates selection. Outcome: the number of depressive symptoms.

Table 99 compares the determinants identified as strongly associated with depression in the systematic review by Zenebe et al. [156] to the variables included in the present work.

Table 99. Outcome: the number of depressive symptoms – comparing the individual-level covariates in the present work to the determinants in Zenebe et al. [156].

Items	**Zenebe et al.** [156]	**The present work**	**Comments**
Sample inclusion criteria	Old people in a variety of countries	See sample inclusion criteria in section 5.2.1 (including a minimum level of difficulty with activities of daily living or mobility tasks).	-
Outcome	Depression, defined based on different cut-off points on various scales, for example the Geriatric Depression Scale-30 and the Geriatric Mental State Schedule.	N of depressive symptoms.	-
Predictors	-	Unmet care need	Main focus of this work
	Gender	Gender	-
	Age – using a >75 cut-off	Age groups: 65-69, 70-74, 75-79, 80-84, 85+	Age groups as per chapter 4.
	Marital status	-	Living alone was prioritised in the present work given its importance as a determinant of unmet need (see sections 4.2.2.3 and 4.4.1).
	Living alone	Living alone	-
	Cognitive impairment	Included in the frailty index	-
	Physical illness	Included in the frailty index	-

	-	Problems with balance	This was important for falls so also included here
	Dependent totally for the activities of daily living	N of PADL limitations; N of IADL limitations	-
	History of serious life events	-	Other variables were prioritised
	Disturbed sleep	One of the depressive symptoms measured by the 8-item short CES-D scale was about restless sleep.	
	Substance use	-	Other variables were prioritised
	Poor daily physical exercise	-	Deprioritised (a small sample size requires a limited number of variables). The binary variable “current smoker” was prioritised as a lifestyle indicator.
	-	Current smoker	This was important for falls and worse frailty so also included here. Also an indicator of current lifestyle.
	Lack of social support		A social support index ([257], supplementary material) was considered for inclusion but there were missing data issues (some linked to non-completion of self-completion questionnaire)
	Exposure to abuse	-	Other variables were prioritised
	Employment status	-	Other variables were prioritised
	Education	Education beyond school leaving age	-
	Income	Equivalised household wealth	See section 4.2.1.4.6 for why wealth was prioritised over income
	Poverty	Equivalised household wealth and LA-level deprivation	-
	-	LA rurality score	See section 5.2.6

Appendix 5A.3. Covariates selection. Outcome: worse frailty.

Table 100 below compares the study by Niederstrasser et al. [103] to the present work.

Table 100. Outcome: increase in frailty – comparing the individual-level covariates in the present work to the determinants in Niederstrasser et al. [103].

Items	Niederstrasser et al. [103]	The present work	Comments
Sample	People aged 50 and over; one analysis limited to people without frailty at baseline; the other analysis included everyone	See sample inclusion criteria in section in section 5.2.1, including a minimum level of difficulty with activities of daily living or mobility tasks and age >=65.	-
Outcome of interest	• Development of frailty defined as a score >=0.25 on the frailty index (binary variable) • Frailty index in wave 8 (numerical variable)	• Worse/increased frailty index from wave 8 to wave 9 (binary variable) • Change in frailty (numerical variable)	-
Components included in the frailty index	Health conditions, mobility, limitations in activities of daily living, self-reported health, cognitive function, hearing, eyesight, depressive symptoms.	Similar components (more details in section 5.2.3 and Appendix 4B.1), but did not include activities of daily living and depressive symptoms.	Number of limitations in activities of daily living and depressive symptoms excluded from the outcome and considered as determinants..
Predictors	-	Unmet care need	Main focus of this work
	Male	Male	-

	Age (numerical)	Age groups	-
	-	N of PADL and IADL limitations	In Niederstrasser 2019, activity limitations were part of the outcome variable.
	Baseline frailty	Frailty index in wave 8 included – centred variable	See section 5.2.7.1 on conditional change model.
	Pain (none, mild, moderate, severe)	Frequently troubled by pain was included in the frailty index	-
	Lower body strength: time to perform five or ten chair rises.	-	Most recent available measurements from wave 6
	BMI: underweight, normal (ref), overweight, obese	-	Issue with missing data
	Abdominal obesity measured by the waist-hip ratio.	-	Most recent available measurements from wave 6
	-	Any falls: yes/no	Hypothesised as a mediator between unmet need and worse frailty (see DAG).
	-	Problems with balance	This was important in the model on having at least one fall so it was also included here
	Physical activity level: sedentary, mild, moderate, vigorous	Not included	Deprioritised (a small sample size requires a limited number of variables). The binary variable "current smoker" was prioritised as a lifestyle indicator.
	Smoking: current or previous vs. abstinence	Smoking: Current vs. other	A proxy of current lifestyle.
	Social isolation: Shankar's index [258]	Living alone	Social isolation not included due to issues with missing data relating to people who did not fill in the self-completion questionnaire in wave 8. Moreover, Niederstrasser et al. found no association between social isolation and frailty development and progression [103].

	Loneliness	One of the depressive symptoms measured by the 8-item short CES-D scale was about feeling lonely.	-
	-	Depressive symptoms	Depressive symptoms were part of the outcome in Niederstrasser et al. [103]. In the present work, depressive symptoms were hypothesised as a mediator between unmet need and worse frailty (see DAG).
	Total net wealth quintiles	Total net equivalised wealth quartiles	See Appendix 4B.2
	Educational qualifications: any vs. none	Education beyond school leaving age: yes/no	See section 4.2.1.4.6
	-	LA deprivation	See section 5.2.6
	-	LA rurality score	See section 5.2.6

Appendix 5B. Poisson regression for depressive symptoms

As the measure for depressive symptoms was count data, it was assessed whether it followed a Poisson distribution. Although there was overdispersion compared to a Poisson distribution (see section 5.3.2), a Poisson model was run to compare results with the linear regression.

Results were similar to the linear regression. The finding of no association between unmet need and the number of depressive symptoms was consistent. For most other independent variables, the significance and direction of association did not change. One exception is highlighted in bold in Table 101: with the Poisson regression, the number of IADL limitations became a borderline significant risk factor for depressive symptoms rather than a significant one.

Table 101. Outcome: N of depressive symptoms in wave 8. Rate ratios from Poisson model compared to coefficients from OLS model.

	(1) Poisson model, clustered SE, RR	(2) OLS model, clustered SE
Unmet need in wave 8	1.085	0.225
	[0.945,1.245]	[-0.105,0.554]
Age 70-74	0.853*	-0.344*
	[0.716,1.017]	[-0.747,0.060]
Age 75-79	0.857*	-0.381*
	[0.719,1.021]	[-0.789,0.027]
Age 80-84	0.937	-0.127
	[0.737,1.190]	[-0.710,0.455]
Age 85+	0.765**	-0.612**
	[0.610,0.959]	[-1.125,-0.099]
Male	0.827**	-0.398**
	[0.710,0.962]	[-0.719,-0.077]
Living alone in wave 8	1.306***	0.621***
	[1.149,1.485]	[0.298,0.943]
N of PADL limitations in wave 8	1.014	0.053
	[0.973,1.055]	[-0.061,0.167]
N of IADL limitations in wave 8	**1.040***	**0.112****
	[0.998,1.083]	[0.000,0.224]
Centred variable of the 40-deficits frailty index in wave 8	1.019***	0.041***
	[1.012,1.026]	[0.025,0.057]
Frequent problems with balance in wave 7	1.090	0.241
	[0.944,1.259]	[-0.145,0.628]
Current smoker in wave 8	1.071	0.162
	[0.886,1.293]	[-0.366,0.689]
Education beyond school leaving age	1.059	0.114
	[0.928,1.208]	[-0.197,0.424]
Wealth in wave 8: quartile 2	0.973	-0.116
	[0.835,1.134]	[-0.537,0.305]
Wealth in wave 8: quartile 3	0.890	-0.321

	[0.737,1.075]	[-0.800,0.159]
Wealth in wave 8: quartile 4 (highest)	0.690***	-0.756***
	[0.549,0.867]	[-1.227,-0.284]
LA IDAOPI average score	0.999	-0.002
	[0.985,1.014]	[-0.037,0.034]
% of people in rural areas	1.001	0.003
	[0.998,1.004]	[-0.004,0.009]
		2.293***
		[1.400,3.187]
N	788	788

Table notes. Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

Results are highlighted in bold if the significance or direction of association changed across the models.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 20).

Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADLs: personal activities of daily living; RR: rate ratios.

Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.

For the age groups, the reference category was 65-69.

The frailty index was measured as a percentage.

Frequent problems with balance refer to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).

Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 5C. Robustness checks

Appendix 5C.1. Comparing the conditional change model to a model without baseline frailty

A robustness check was carried out, which took out baseline frailty; the equation for this model was:

$$Ln(Pr(IncrF_t = 1)/(1 - Pr(IncrF_t = 1))) =$$

$$\beta_0 + \beta_1 UN_{t-1} + \beta_2 FA_t + \beta_3 DE_{t-1} + \beta_4 \mathbf{Z}_{\boldsymbol{t-1}} + \varepsilon_t \qquad (6)$$

See section 5.2.7.1 for the definition of each equation term.

When baseline frailty was excluded from the model, no association between unmet need and worse frailty was found. This was different from the conditional change model, which found a borderline significant negative association between unmet need and worse frailty. There were also changes in significance for other independent variables. These changes are highlighted in bold in Table 102.

Table 102. Outcome: worse frailty. Comparing the conditional change model to a model without baseline frailty.

	(1) Conditional change model	(2) Model without baseline frailty
Unmet need in wave 8	**0.763***	**0.913**
	[0.553,1.053]	**[0.659,1.266]**
Age 70-74	2.155***	1.971***
	[1.420,3.270]	[1.292,3.007]
Age 75-79	**1.550****	**1.347**
	[1.001,2.403]	**[0.879,2.064]**
Age 80-84	2.035***	1.856***
	[1.268,3.266]	[1.171,2.944]
Age 85+	**1.994*****	**1.769****
	[1.224,3.251]	**[1.096,2.855]**
Male	**1.487****	**1.702*****
	[1.052,2.102]	**[1.234,2.347]**
Living alone in wave 8	0.945	0.941
	[0.673,1.328]	[0.666,1.331]
N of PADL limitations in wave 8	**0.944**	**0.866***
	[0.805,1.107]	**[0.740,1.014]**
N of IADL limitations in wave 8	**1.285*****	**1.172****
	[1.101,1.499]	**[1.028,1.336]**
Centred variable of the 40-deficits frailty index in wave 8	0.949***	
	[0.933,0.965]	
Frequent problems with balance in wave 7	1.337	1.111
	[0.914,1.956]	[0.785,1.571]
Any falls between wave 8 and wave 9	1.918***	1.794***
	[1.431,2.570]	[1.342,2.398]
N of depressive symptoms in wave 8	1.008	0.973
	[0.934,1.089]	[0.901,1.051]
Current smoker in wave 8	0.795	0.725
	[0.494,1.279]	[0.464,1.132]
Education beyond school leaving age	0.869	0.939
	[0.605,1.249]	[0.669,1.318]
Wealth in wave 8: quartile 2	0.904	0.983
	[0.604,1.352]	[0.666,1.450]
Wealth in wave 8: quartile 3	0.944	1.014
	[0.642,1.387]	[0.703,1.463]
Wealth in wave 8: quartile 4 (highest)	**0.573*****	**0.750**
	[0.381,0.863]	**[0.496,1.136]**
LA IDAOPI average score	0.958**	0.954***
	[0.926,0.990]	[0.924,0.984]
% of people in rural areas	0.996	0.995
	[0.989,1.002]	[0.989,1.002]
N	788	788

Table notes. Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.
Results are highlighted in bold if the significance or direction of association changed across the models.
Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people;

LA: local authority; N: number; PADLs: personal activities of daily living.
Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.
For the age groups, the reference category was 65-69.
The frailty index was measured as a percentage.
Frequent problems with balance refer to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).
Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.
A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 5C.2. Including longitudinal weights

Longitudinal weights were used in robustness checks, as per chapter 4. For the present chapter's analysis, longitudinal weights for wave 9 rather than for wave 8 were used.

When wave 9 longitudinal weights were added, the finding of no association between unmet need and falls or depressive symptoms was consistent. No significant association was found between unmet need and worse frailty once the sample was reduced to the observations with an available weight. This was observed both with and without the inclusion of weights in the model.

Moreover, the significance and direction of association did not change for most variables. The exceptions are shown in Table 103, Table 104 and Table 105, together with the odds ratios or coefficients relating to unmet need.

Table 103. Outcome: any falls. Including longitudinal weights. Odds ratios for unmet need and odds ratios with changed significance across the two models.

	(1) Model without weights, sample size reduced to those with available weight	(2) Model with wave 9 longitudinal weights
Unmet need in wave 8	0.983	0.940
	[0.697,1.387]	[0.670,1.320]
Age 75-79	1.911***	1.804**
	[1.222,2.990]	[1.130,2.881]
N of PADL limitations in wave 8	1.143**	1.116
	[1.005,1.300]	[0.970,1.284]
Centred 40-deficits frailty index in wave 8	1.018*	1.022**
	[0.999,1.037]	[1.000,1.045]
N	710	710

Table notes. Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.
The results relate to multivariable models that included all the independent variables included in the final model (see Table 20). However, for the present analysis the covariate baseline frailty was centred based on the sample of N=710 people rather than N=788.
Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number; PADLs: personal activities of daily living.
Wave 7 refers to 2014-15, wave 8 to 2016-17, wave 9 to 2018-19.
The frailty index was measured as a percentage.
Frequent problems with balance refers to: always/very often/often has "problems with balance when walking on level surface" ([80], variable name).
Wealth refers to equivalised net total wealth. Quartiles were calculated based on the final sample of 788 people.
A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Table 104. Outcome: N of depressive symptoms. Including longitudinal weights. Coefficients for unmet need and coefficients with changed significance across the two models.

	(1) Model without weights, sample size reduced to those with available weight	(2) Model with wave 9 longitudinal weights
Unmet need in wave 8	0.191	0.196
	[-0.155,0.536]	[-0.217,0.608]
Age 70-74	-0.394*	-0.557**
	[-0.819,0.030]	[-1.082,-0.032]
Age 75-79	-0.405*	-0.559**
	[-0.851,0.042]	[-1.094,-0.025]
N of PADL limitations in wave 8	0.106*	0.092
	[-0.013,0.225]	[-0.049,0.233]
% of people in rural areas	0.004	0.006*
	[-0.003,0.011]	[-0.001,0.013]
N	710	710

Table notes. Coefficients from OLS models with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 20). However, for the present analysis the covariate baseline frailty was centred based on the sample of N=710 people rather than N=788.

Abbreviations: N: number; PADLs: personal activities of daily living.

Wave 8 refers to 2016-17, wave 9 to 2018-19.

Table 105. Outcome: worse frailty. Including longitudinal weights. Odds ratios for unmet need and odds ratios with changed significance across the two models.

	(1) Model without weights, sample size reduced to those with available weight	(2) Model with wave 9 longitudinal weights
Unmet need in wave 8	0.767	0.742
	[0.548,1.073]	[0.517,1.064]
Male	1.636**	1.647***
	[1.124,2.381]	[1.129,2.401]
LA IDAOPI average score	0.962**	0.967*
	[0.929,0.996]	[0.932,1.004]
N	710	710

Table notes. Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 21, model 4). However, for the present analysis the covariate baseline frailty was centred based on the sample of N=710 people rather than N=788.

Abbreviations: IDAOPI: income deprivation affecting older people. Wave 8 refers to 2016-17, wave 9 to 2018-19.

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 5C.3. High depressive symptoms as binary variable

Previous studies had used the >=3 symptoms cut-off [259] and the >=4 symptoms cut-off [260, 261] to refer to high depressive symptoms, or the >=3 cut-off to refer to the presence of depression [262]. So, the same cut-offs were used in robustness checks. For the binary variables based on these cut-offs, logistic regressions were run.

When the final model with depressive symptoms as a numerical outcome was compared to models with high depressive symptoms as a binary variable, the finding of no association with unmet need was consistent across the models. There was no change in significance or in the direction of significant associations for most other independent variables. The exceptions are shown in Table 106 together with the coefficient or odds ratios relating to unmet need.

Table 106. Robustness checks with binary variables for high depressive symptoms. Only showing coefficients / odds ratios for unmet need and for the variables with changed significance across the models.

	Outcome: N of depressive symptoms (coefficients from OLS model)	Outcome: at least 3 depressive symptoms (odds ratios)	Outcome: at least 4 depressive symptoms (odds ratios)
Unmet need in wave 8	0.225	0.949	1.209
	[-0.105,0.554]	[0.622,1.447]	[0.792,1.846]
Age 70-74	-0.344*	0.868	0.778
	[-0.747,0.060]	[0.557,1.354]	[0.461,1.314]
Age 75-79	-0.381*	0.712	0.769
	[-0.789,0.027]	[0.440,1.152]	[0.459,1.290]
Living alone in wave 8	0.621***	1.605**	1.583**
	[0.298,0.943]	[1.113,2.313]	[1.087,2.305]
N of IADL limitations in wave 8	0.112**	1.155**	1.146*
	[0.000,0.224]	[1.013,1.318]	[0.999,1.314]
Wealth in wave 8: quartile 3	-0.321	0.841	0.609*
	[-0.800,0.159]	[0.546,1.297]	[0.353,1.051]
N	788	788	788

Table notes. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.
The results relate to multivariable models that included all the independent variables included in the final model (see Table 20).
Abbreviations: N: number.
Wave 8 refers to 2016-17.
For the age groups, the reference category was 65-69.
Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

Appendix 5C.4. Benefit unit wealth instead of equivalised wealth

When equivalised wealth was replaced by benefit unit wealth, the finding of no association between unmet need and falls or depressive symptoms was consistent; unmet need no longer had a borderline significant negative association with worse frailty.

For the other independent variables, the significance and the direction of association did not change, with some exceptions. With benefit unit wealth, living alone became a significant risk factor for falls. This and other exceptions are shown in Table 107, Table 108, and Table 109, together with the coefficients or odds ratios relating to unmet need and the wealth quartiles.

Table 107. Outcome: any falls. Robustness checks on wealth. Odds ratios for unmet need, wealth quartiles and variables with changed significance across models.

	(1) Equivalised wealth	(2) Benefit unit wealth
Unmet need in wave 8	0.970	0.973
	[0.719,1.307]	[0.720,1.316]
Age 85+	1.598**	1.527*
	[1.015,2.517]	[0.984,2.368]
Living alone in wave 8	1.293	1.416**
	[0.944,1.772]	[1.028,1.950]
Wealth in wave 8: quartile 2	0.691*	0.734
	[0.452,1.058]	[0.486,1.110]
Wealth in wave 8: quartile 3	0.876	1.090
	[0.588,1.306]	[0.727,1.633]
Wealth in wave 8: quartile 4 (highest)	1.016	1.211
	[0.686,1.505]	[0.769,1.906]
N	788	788

Table notes.
Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01. The results relate to multivariable models that included all the independent variables included in the final model (see Table 20).
Wave 8 refers to 2016-17.

Table 108. Outcome: the number of depressive symptoms. Robustness checks on wealth. Coefficients for unmet need, wealth quartiles and variables with changed significance across models.

	(1) Equivalised wealth	(2) Benefit unit wealth
Unmet need in wave 8	0.225	0.225
	[-0.105,0.554]	[-0.102,0.552]
N of IADL limitations in wave 8	0.112**	0.100*
	[0.000,0.224]	[-0.011,0.212]
Wealth in wave 8: quartile 2	-0.116	-0.006
	[-0.537,0.305]	[-0.453,0.442]
Wealth in wave 8: quartile 3	-0.321	-0.430*
	[-0.800,0.159]	[-0.878,0.017]
Wealth in wave 8: quartile 4 (highest)	-0.756***	-0.619***
	[-1.227,-0.284]	[-1.054,-0.184]
N	788	788

Table notes. Coefficients from OLS models with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 20).

Abbreviations: IADLs: instrumental activities of daily living; N: number.

Wave 8 refers to 2016-17.

For the age groups, the reference category was 65-69.

For wealth, the reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

Table 109. Outcome: worse frailty. Robustness checks on wealth. Odds ratios for unmet need, wealth quartiles and variables with changed significance across models.

	(1) Equivalised wealth	(2) Benefit unit wealth
Unmet need in wave 8	0.763*	0.764
	[0.553,1.053]	[0.554,1.054]
Age 75-79	1.550**	1.543*
	[1.001,2.403]	[0.998,2.387]
Wealth in wave 8: quartile 2	0.904	0.899
	[0.604,1.352]	[0.591,1.368]
Wealth in wave 8: quartile 3	0.944	0.819
	[0.642,1.387]	[0.535,1.252]
Wealth in wave 8: quartile 4 (highest)	0.573***	0.568***
	[0.381,0.863]	[0.372,0.867]
N	788	788

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 21, model 4).

Wave 8 refers to 2016-17.

For wealth, the reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

Appendix 5C.5. Taking out people with no PADL difficulties

It was hypothesised that unmet need may only be associated with adverse outcomes at a higher level of disability. PADL difficulties usually emerge after IADL difficulties [39], so having PADL difficulties could be considered as an indicator of having higher disability. Therefore, in a robustness check, the analysis was restricted to people with PADL difficulties.

In the models restricted to people with at least one PADL difficulty, the coefficient of unmet need remained non-significant in relation to having at least one fall and the number of depressive symptoms. In relation to the increased frailty outcome, the negative association with unmet need changed from borderline significant to significant when the sample was restricted to people with at least one PADL difficulty. This was the opposite of what had been hypothesised. Potentially, among people with more PADL limitations, not receiving help was an even more important indicator of lower impairment, which in turn may be associated with lower odds of worse frailty in the following two years. For the other independent variables, the significance and direction of association mostly did not change. The exceptions are shown in Table 110, Table 111 and Table 112.

Table 110. Outcome: Any falls. Excluding people with no PADL difficulties. Odds ratios for unmet need and for variables with changed significance across models.

	(1) All people	(2) Only people with at least a PADL difficulty
Unmet need in wave 8	0.970	0.982
	[0.719,1.307]	[0.669,1.442]
Age 75-79	1.797***	1.782**
	[1.179,2.740]	[1.121,2.834]
Living alone in wave 8	1.293	1.440**
	[0.944,1.772]	[1.011,2.052]
Frequent problems with balance in wave 7	1.356	1.407*
	[0.934,1.970]	[0.938,2.110]
Wealth in wave 8: quartile 2	0.691*	0.656
	[0.452,1.058]	[0.397,1.084]
Centred variable of the 40-deficits frailty index in wave 8	1.016*	1.016
	[0.997,1.036]	[0.997,1.037]
N	788	658

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 20). However, when only people with at least a PADL difficulty were included, baseline frailty was centred based on the restricted sample of N=658 people rather than based on N=788 people.

Abbreviations: PADLs: personal activities of daily living.

Wave 7 refers to 2014-15, wave 8 to 2016-17.
For the age groups, the reference category was 65-69.
Frequent problems with balance refer to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).

Table 111. Outcome: the number of depressive symptoms. Excluding people with no PADL difficulties. Coefficients for unmet need and for variables with changed significance across models.

	(1) Everyone	(2) Only people with at least one PADL difficulty
Unmet need in wave 8	0.225	0.295
	[-0.105,0.554]	[-0.071,0.661]
Age 75-79	-0.381*	-0.289
	[-0.789,0.027]	[-0.740,0.161]
Age 85+	-0.612**	-0.455
	[-1.125,-0.099]	[-1.067,0.157]
Male	-0.398**	-0.602***
	[-0.719,-0.077]	[-0.948,-0.255]
N of IADL limitations in wave 8	0.112**	0.124*
	[0.000,0.224]	[-0.006,0.255]
Wealth in wave 8: quartile 3	-0.321	-0.430*
	[-0.800,0.159]	[-0.933,0.074]
N	788	658

Table notes.
Coefficients from OLS models with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.
The results relate to multivariable models that included all the independent variables included in the final model (see Table 20). However, when only people with at least a PADL difficulty were included, baseline frailty was centred based on the restricted sample of N=658 people rather than based on N=788 people.
Abbreviations: IADLs: instrumental activities of daily living; N: number; PADLs: personal activities of daily living.
Wave 8 refers to 2016-17.
For the age groups, the reference category was 65-69.
Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

Table 112. Outcome: worse frailty. Excluding people with no PADL difficulties. Odds ratios for unmet need and for variables with changed significance across models.

	(1) Everyone	(2) Only people with at least one PADL difficulty
Unmet need in wave 8	0.763*	0.698**
	[0.553,1.053]	[0.511,0.954]
Age 75-79	1.550**	1.506*
	[1.001,2.403]	[0.925,2.453]
Age 85+	1.994***	1.427
	[1.224,3.251]	[0.869,2.343]
Wealth in wave 8: quartile 4 (highest)	0.573***	0.702*
	[0.381,0.863]	[0.469,1.051]
LA IDAOPI average score	0.958**	0.948***
	[0.926,0.990]	[0.913,0.985]
N	788	658

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 21, model 4). However, when only people with at least a PADL difficulty were included, baseline frailty was centred based on the restricted sample of N=658 people rather than based on N=788 people.

Abbreviations: PADLs: personal activities of daily living.

Wave 8 refers to 2016-17.

For the age groups, the reference category was 65-69.

Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 5C.6. Alternative unmet need definitions

Kröger’s book on care poverty [39] distinguished between personal care poverty (unmet need with PADLs) and practical care poverty (unmet need with IADLs). This distinction seems particularly important in the English context, where, due to a lack of funding, publicly funded home care is in practice often restricted to PADLs [58]. The definition of unmet need in the final models (not receiving any help or responding that help meets needs sometimes or hardly ever) did not make this distinction. The main reason was that ELSA asks for a person’s perceptions about all help received, without making a distinction between PADLs and IADLs.

Three alternative definitions which made this distinction between PADLs and IADLs were used in robustness checks, as detailed below:

- Not receiving help for at least one PADL difficulty (“bathing or showering”, “dressing”, “walking across a room”, “eating”, “getting in or out of bed”, “using the toilet”) ([29], p. 94)
- Not receiving help for walking 100 yards or at least one IADL difficulty (“shopping for groceries”, “taking medications”, “doing work around the house or garden”, “managing money”) ([29], p. 94)
- Not receiving help for at least two PADL difficulties

Differently from the main definition, these three definitions did not take into account the person’s perceptions of help received. The first two definitions were used in a previous study [60]. The third definition, focusing on a lack of help for at least two PADL difficulties, was included considering that eligibility criteria for LA-funded care mention the inability of achieving at least two outcomes, rather than only one.

Table 113 shows that the finding of no association between unmet need and falls was consistent with any of the alternative unmet need definitions. Table 114 shows that no help for at least one PADL difficulty was a borderline significant risk factor for the number of depressive symptoms. Note that in the other models where the outcome was the number of depressive symptoms (including the final model), the coefficient was not significant but was always in the direction of a positive association between unmet need and the number of depressive symptoms.

Table 115 shows that the finding of a borderline significant negative association between unmet need and worse frailty did not hold when alternative unmet need definitions were used: no association was found with these alternative definitions.

Table 113. Outcome: any falls. Alternative unmet need definitions. Odds ratios for unmet need and for variables with changed significance across models.

	(1) Final model: Unmet need defined as receiving no help at all or responding that help only meets needs sometimes or hardly ever	(2) Unmet need defined as no help for at least one PADL difficulty	(3) Unmet need defined as no help for at least two PADL difficulties	(4) Unmet need defined as no help for at least one IADL difficulty or for walking 100 yards
Unmet need in wave 8	0.970	1.288	0.983	0.793
	[0.719,1.307]	[0.856,1.938]	[0.645,1.496]	[0.576,1.092]
Age 85+	1.598**	1.643**	1.609**	1.552*
	[1.015,2.517]	[1.040,2.595]	[1.014,2.555]	[0.986,2.444]
Living alone in wave 8	1.293	1.250	1.291	1.341*
	[0.944,1.772]	[0.910,1.718]	[0.939,1.774]	[0.975,1.846]
N	788	788	788	788

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 20).

Abbreviations: IADLs: instrumental activities of daily living; PADLs: personal activities of daily living.

Wave 8 refers to 2016-17.

For the age groups, the reference category was 65-69.

The frailty index was measured as a percentage.

Table 114. Outcome: Number of depressive symptoms. Alternative unmet need definitions. Coefficients for unmet need and for variables with changed significance across models.

	(1) Final model: unmet need defined as receiving no help at all or responding that help only meets needs sometimes or hardly ever	(2) Unmet need defined as no help for at least one PADL difficulty	(3) Unmet need defined as no help for at least two PADL difficulties	(4) Unmet need defined as no help for at least one IADL difficulty or for walking 100 yards
Unmet need in wave 8	0.225	0.372*	0.228	0.027
	[-0.105,0.554]	[-0.024,0.768]	[-0.272,0.729]	[-0.282,0.336]
Age 70-74	-0.344*	-0.337	-0.356*	-0.343*
	[-0.747,0.060]	[-0.743,0.068]	[-0.761,0.049]	[-0.749,0.063]
Age 75-79	-0.381*	-0.385*	-0.417**	-0.400*
	[-0.789,0.027]	[-0.799,0.029]	[-0.823,-0.012]	[-0.801,0.002]
Age 85+	-0.612**	-0.625**	-0.670***	-0.652**
	[-1.125,-0.099]	[-1.137,-0.113]	[-1.176,-0.165]	[-1.160,-0.144]
N of IADL limitations in wave 8	0.112**	0.128**	0.100*	0.093*
	[0.000,0.224]	[0.017,0.238]	[-0.008,0.208]	[-0.010,0.197]
N	788	788	788	788

Table notes.

Coefficients from OLS models with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 20).

Abbreviations: IADLs: instrumental activities of daily living; N: number; PADLs: personal activities of daily living.

Wave 8 refers to 2016-17.

For the age groups, the reference category was 65-69.

Table 115. Outcome: worse frailty. Alternative unmet need definitions. Odds ratios for unmet need and for variables with changed significance across models.

	(1) Unmet need defined as receiving no help at all or responding that help only meets needs sometimes or hardly ever	(2) Unmet need defined as no help for at least one PADL difficulty	(3) Unmet need defined as no help for at least two PADL difficulties	(4) Unmet need defined as no help for at least one IADL difficulty or for walking 100 yards
Unmet need in wave 8	0.763*	0.970	0.886	0.897
	[0.553,1.053]	[0.677,1.389]	[0.549,1.430]	[0.671,1.199]
LA IDAOPI average score	0.958**	0.956***	0.956***	0.957***
	[0.926,0.990]	[0.925,0.989]	[0.925,0.989]	[0.925,0.989]
N	788	788	788	788

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 21, model 4).

Abbreviations: IADLs: instrumental activities of daily living; PADLs: personal activities of daily living.

Wave 8 refers to 2016-17, wave 9 to 2018-19.

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 5.C.6.A. Restricting the analysis to those with care and defining unmet need as help that does not meet needs all the time.

A robustness check was made, where people without help were excluded, and the analysis was restricted to those with care, so that unmet need was only defined based on their perceptions; unmet need was defined as help that met needs usually/sometimes/hardly ever, as opposed to all the time. Note that "usually" had to be grouped with "all the time" due to limited numbers in the "sometimes" and "hardly ever" categories.

When unmet need was only defined based on people's perceptions, the finding of no association with any falls was consistent with the final model; unmet need had a significant positive association with the number of depressive symptoms. It is not possible to infer causality from the results of the analysis or to understand whether any direction of causality would go from unmet need to depressive symptoms or viceversa. When the model was restricted to people with help, no association was found between help that did not meet needs all the time and worse frailty.

Table 116. Outcome: any falls. Excluding people with no help. Only including odds ratios for unmet need and for variables with changed significance across models.

	(1) Everyone (final model)	(2) Only people with help; unmet need defined as help that does not meet needs all the time
Unmet need in wave 8	0.970	1.040
	[0.719,1.307]	[0.692,1.563]
Age 75-79	1.797***	1.843*
	[1.179,2.740]	[0.965,3.519]
Age 85+	1.598**	1.740*
	[1.015,2.517]	[0.954,3.176]
Centred variable of the 40-deficits frailty index in wave 8	1.016*	1.019
	[0.997,1.036]	[0.994,1.045]
Frequent problems with balance in wave 7	1.356	1.492*
	[0.934,1.970]	[0.973,2.288]
Wealth in wave 8: quartile 2	0.691*	0.673
	[0.452,1.058]	[0.402,1.125]
N	788	505

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 20). However, when people without help were excluded, the covariate baseline frailty was centred based on a sample of N=505 instead of N=788.

Wave 7 refers to 2014-15, wave 8 to 2016-17.

For the age groups, the reference category was 65-69.

Frequent problems with balance refer to: always/very often/often has "problems with balance when walking on level surface" ([80], variable name).

Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

Table 117. Outcome: the number of depressive symptoms. Excluding people with no help. Only including coefficients for unmet need and for variables with changed significance across models.

	(1) Everyone (final model)	(2) Only people with help; unmet need defined as help that does not meet needs all the time
Unmet need in wave 8	0.225	0.340**
	[-0.105,0.554]	[0.023,0.656]
Age 75-79	-0.381*	-0.261
	[-0.789,0.027]	[-0.817,0.296]
Age 85+	-0.612**	-0.474
	[-1.125,-0.099]	[-1.061,0.113]
Male	-0.398**	-0.297*
	[-0.719,-0.077]	[-0.646,0.052]
Living alone in wave 8	0.621***	0.434**
	[0.298,0.943]	[0.024,0.844]
N of IADL limitations in wave 8	0.112**	0.082
	[0.000,0.224]	[-0.028,0.193]
Current smoker in wave 8	0.162	0.563*
	[-0.366,0.689]	[-0.087,1.213]
Wealth in wave 8: quartile 4 (highest)	-0.756***	-0.584*
	[-1.227,-0.284]	[-1.180,0.011]
N	788	505

Table notes.

Coefficients from OLS models with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 20). However, when people without help were excluded, the covariate baseline frailty was centred based on a sample of N=505 instead of N=788.

Abbreviations: IADLs: instrumental activities of daily living; N: number.

Wave 8 refers to 2016-17.

For the age groups, the reference category was 65-69.

Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

Table 118. Outcome: worse frailty. Excluding people with no help. Only including odds ratios for unmet need and for variables with changed significance across models.

	(1) Everyone (final model)	(2) Only people with help; unmet need defined as help that does not meet needs all the time
Unmet need in wave 8	0.763*	0.821
	[0.553,1.053]	[0.534,1.263]
Age 70-74	2.155***	1.993**
	[1.420,3.270]	[1.151,3.450]
Age 75-79	1.550**	0.987
	[1.001,2.403]	[0.525,1.856]
Age 80-84	2.035***	1.451
	[1.268,3.266]	[0.800,2.632]
Male	1.487**	1.304
	[1.052,2.102]	[0.849,2.003]
Frequent problems with balance in wave 7	1.337	1.488*
	[0.914,1.956]	[0.946,2.338]
Wealth in wave 8: quartile 4 (highest)	0.573***	0.613
	[0.381,0.863]	[0.333,1.130]
LA IDAOPI average score	0.958**	0.961*
	[0.926,0.990]	[0.922,1.001]
N	788	505

Table notes.

Exponentiated coefficients: odds ratios from logistic regressions with clustered standard errors. 95% confidence intervals in brackets. * p<0.10, ** p<0.05, *** p<0.01.

The results relate to multivariable models that included all the independent variables included in the final model (see Table 21, model 4). However, when people without help were excluded, the covariate baseline frailty was centred based on a sample of N=505 instead of N=788.

Abbreviations: IADLs: instrumental activities of daily living; IDAOPI: income deprivation affecting older people; LA: local authority; N: number.

Wave 7 refers to 2014-15, wave 8 to 2016-17.

For the age groups, the reference category was 65-69.

The frailty index was measured as a percentage.

Frequent problems with balance refer to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).

Wealth refers to equivalised net total wealth. The reference category was the lowest quartile. Quartiles were calculated based on the final sample of 788 people.

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendices chapter 6

Appendix 6A. Parameters with distributions for PSA

Table 119. Proportion belonging to each subgroup (including distributions for PSA).

			Distribution parameters		
Probability	**Mean**	**Distribution**	**Alpha**	**Beta**	**Source**
P (informal care from within the household)	0.367	Beta	77,050	133,140	Data from the Personal Social Services Adult Social Care Survey 2021/22 [190] on 210,190 people aged 65 and over living in private households (excluding those with learning disability).
P (informal care only from outside the household)	0.480	NA. Probabilistic sampling linked to the parameters above and below to ensure that the overall probability is equal to 1.			
P (no informal care)	0.153	Beta	32,260	177,930	

Table notes. Abbreviations: NA: not applicable; P: probability.

Table 120. Marginal effects and proportions with met need relating to different sources of care (including distributions for PSA).

Marginal effect or proportion	Source of care	Mean	Distribution	Distribution parameters		Source
				Alpha/mean	Beta/SD	
Marginal effect, outcome: met need	LA-funded care vs. no LA-funded care (in the presence of informal care)	0.052	Multivariate normal	0.052	0.052	Data analysis linked to chapter 4 (see Appendix 6B.1 for more details)
Marginal effect, outcome: met need	Informal care only from outside the household vs. at least some from within the household	-0.134	Multivariate normal	-0.134	0.042	
P (met need)	Informal care within hh, no home care	0.696	Beta	128	56	Descriptive analysis of ELSA data.
	Informal care within hh, with home care	0.748	NA - probabilistic sampling linked to estimates above.			Combination of estimates in rows above. Note that combining these estimates assumed no interaction between informal care and receipt of LA-funded care.
	Informal care all outside hh, no home care	0.562	NA - probabilistic sampling linked to estimates above.			
	Informal care all outside hh, with home care	0.614	NA - probabilistic sampling linked to estimates above.			
	No informal care, no home care	0	NA. It was assumed that no one had met needs.			Model assumption
	No informal care, with home care	0.660	Beta	164	85	A survey in Warwickshire [191]
	Weighted average across the three subgroups at the start of the model with the intervention (used in formulas that include the prevalence of unmet need, see Appendix 6.D.1.B for more details)	0.653	NA - probabilistic sampling linked to parameters above.			Calculated based on parameters above.

Table notes. Abbreviations: hh: household; LA: local authority; NA: not applicable; P: proportion; SD: standard deviation. Alpha and beta are used for beta distributions. Mean and SD are used for normal distributions. The SD of the distribution of an estimate is in fact the standard error of the estimate calculated in Appendix 6B.1.

Table 121. Transition probabilities relating to home care cancellation and care home admission, and related odds ratios (including distributions for PSA).

Odds ratio or probability	Subgroup	Care state	Mean	Distribution	Distribution parameters		Source
					Alpha / mean	Beta / SD	
P (cancelling home care)	Any with informal care	Any on waiting list	0.030	Beta	696	22,519	Assumption linked to satisfaction data in the PSS ASCS [190]
P (waiting list for home care)	Any with informal care	Any with cancelled home care	Not available	Uniform, with range 0 to 1	NA	NA	No evidence
Odds ratio for outcome: care home admission	All	Comparing unmet to met need	1.77	Lognormal	0.571	0.075	Gaugler et al. [188]
Annual P (care home admission)	All	NA. Overall (only used to calculate estimates below)	0.0489	Not available			Bauer et al. [58]
		Met need	0.040	NA - probabilistic sampling linked to the OR for care home admissions and to the prevalence of unmet need			Calculated using the odds ratio from Gaugler et al. [188], the probability from Bauer et al. [58] and the prevalence of unmet need.
		Unmet need	0.069				
6-month P (care home admission)	All	NA. Overall (only used to calculate estimates below)	0.025	Not available			Calculated by converting the annual probability from Bauer et al. [58] into an annual rate and then converting the annual rate into a 6-month probability.
		Met need	0.020	NA - probabilistic sampling linked to the OR for care home admissions and to the prevalence of unmet need			Calculated using the odds ratio from Gaugler et al. [188], the probability from Bauer et al. [58] and the prevalence of unmet need.
		Unmet need	0.036				

Table notes. Abbreviations: NA: not applicable; OR: odds ratio; P: probability; SD: standard deviation. Alpha and beta are used for beta distributions. Mean and SD are used for lognormal distributions.

Table 122. Transition probabilities relating to death, and related odds ratios (including distributions for PSA).

Odds ratio or probability	**Care state**	**Mean**	**Distribution**	**Distribution parameters**		**Source**
				Alpha / mean	**Beta / SD**	
Odds ratio for mortality outcome	Comparing unmet to met care need	1.37	Lognormal	0.315	0.122	Gaugler et al. [188]
Annual P (death)	Met need	Depends on age	NA - probabilistic sampling linked to OR for mortality outcome and prevalence of unmet need			Calculated using the OR from Gaugler et al. [188] as well as the ONS life tables [194] and the prevalence of unmet need.
	Unmet need	Depends on age				
	Care home, aged 75 to 79	0.216	Beta	21,606	78,394	ONS [195]
	Care home, aged 80 to 84	0.256	Beta	25,589	74,411	
	Care home, aged 85 to 89	0.294	Beta	29,371	70,629	
	Care home, aged 90 and over	0.360	Beta	36,041	63,959	
6-month P (death) at average age 77.5	NA. Overall (only used to calculate estimates below)	0.016	Not available			Calculated using the annual probability from the ONS life tables [194] and the formula in Appendix 6D.
	Met need	0.015	NA - probabilistic sampling linked to OR for mortality outcome and prevalence of unmet need			Calculated using the OR from Gaugler et al. [188] as well as the ONS life tables [194] and the prevalence of unmet need.
	Unmet need	0.020				

Table notes. Abbreviations: NA: not applicable; OR: odds ratio; P: probability; SD: standard deviation. Alpha and beta are for beta distributions. Mean and SD are for lognormal distributions.

Table 123. Unweighted SCRQoL for each care state and related estimates (including distributions for PSA).

Care state	**Mean**	**Distribution**	**SD (distribution parameter)**	**Source**
Gain from home care, overall	0.3700	Normal	0.0173	Trukeschitz et al. [196]
Marginal effect of "user kept informed about changes" on outcome "gain in SCRQoL from home care".	0.0482	Normal	0.0140	
Marginal effect of "Care workers did the things the user wanted done" on outcome "gain in SCRQoL from home care".	0.0455	Normal	0.0130	
Gain from home care if needs are met	0.4025	NA - probabilistic sampling linked to parameters above		Calculated using the parameters from Trukeschitz et al. [196] and the prevalence of unmet need.
Gain from home care if needs are unmet	0.3088			
No home care, overall (only used to calculate estimates below)	0.4895	Normal	0.0114	Forder et al. [197]
Unmet needs, no home care	0.4283	NA - probabilistic sampling linked to parameters above		Calculated using the parameter from Forder et al. [197], the parameters from Trukeschitz et al. [196] and the prevalence of unmet need.
Met needs, no home care	0.5220			
Unmet needs, with home care	0.7983			
Met needs, with home care	0.8920			
Care home	0.8452			

Table notes. Abbreviations: NA: not applicable; SCRQoL: social care-related quality of life; SD: standard deviation. SD of the distribution of the estimate corresponds to the SE reported in papers.

Table 124. Costs of care homes and related parameters (including distributions for PSA).

Parameter	Mean	Distribution	Distribution parameters		Source
			Alpha or shape	Beta or scale	
Probability of being in a private sector nursing home if care home resident	0.525	Beta	189,265	171,526	ONS data ([202], table 11)
Probability of being in a private sector residential care home if care home resident	0.445	NA. Probabilistic sampling linked to parameter above and below			Calculated based on parameters above and below.
Probability of being in an LA own-provision residential care home if care home resident	0.030	Beta	10,824	349,967	Point estimate: [203]. 95% CI calculated using N from ONS ([202], table 11)
Weekly cost of PSS services (includes both state-funded and privately funded costs) in a private sector nursing home	£810	Gamma	96.04	8.4	Point estimate from Jones et al. [198]. 95% CI calculated assuming +-20%.
Weekly cost of PSS services (includes both state-funded and privately funded costs) in a private sector residential care home	£725	Gamma	96.04	7.5	
Weekly cost of PSS services (includes both state-funded and privately funded costs) in an LA own-provision residential care home (excludes capital)	£1,138	Gamma	96.04	11.8	

Parameter	**Mean**	**Distribution**	**Distribution parameters**		**Source**
			Alpha or shape	**Beta or scale**	
Weighted average of weekly cost of PSS services (includes both state-funded and privately funded costs) across different kinds of care homes (private sector nursing, private sector residential and LA own-provision residential)	£782	NA - probabilistic sampling linked to parameters above.			Calculated based on parameters above
Weighted average of annual cost of PSS services (includes both state-funded and privately funded costs) across different kinds of care homes (private sector nursing, private sector residential and LA own-provision residential)	£40,804	NA - probabilistic sampling linked to above parameter.			Multiplied the weekly cost above by 52.18 weeks.
Proportion of people in care homes who are full self-funders	0.391	Beta	118204	184107	[202], table 7. Refers to care homes for older people or providing dementia care
Proportion of people in care homes who are state-funded	0.609	NA - probabilistic sampling linked to above parameter.			[202], table 7. Refers to care homes for older people or providing dementia care.
Proportion of state-funded people in care homes that are fully state-funded	0.751	Beta	90610	30080	PSS ASCS 2021/22 [190]
Proportion of state-funded people in care homes that are partially state-funded and partially privately funded	0.249	NA - probabilistic sampling linked to above parameter.			PSS ASCS 2021/22 [190]

Parameter	Mean	Distribution	Distribution parameters		Source
			Alpha or shape	Beta or scale	
Annual cost of PSS services in a care home considered as a PSS state-funded cost (based on the % of people who were partly or fully state-funded)	£21,753	NA - probabilistic sampling linked to parameters above.			Calculated based on parameters above
Annual cost of PSS services in a care home considered as a privately funded cost (based on the % of people who were partly or fully self-funded)	£19,051	NA - probabilistic sampling linked to parameters above.			Calculated based on parameters above
Weekly NHS cost per person in a nursing home	£188	Gamma	96.04	1.95	Point estimate from Jones et al. [198]. 95% CI calculated assuming +-20%.
Weighted average of weekly NHS cost across different kinds of care homes (private sector nursing, private sector residential and LA own-provision residential)	£98	NA - probabilistic sampling linked to parameters above.			Calculated based on the probabilities of being in different types of care home (see parameters above), the weekly NHS cost per person in a nursing home (see parameter above), and an assumption of no NHS costs in other care homes.
Weighted average of annual NHS cost across different kinds of care homes (private sector nursing, private sector residential and LA own-provision residential)	£5,135	NA - probabilistic sampling linked to parameter above.			Multiplied the weekly cost above by 52.18 weeks

Table notes. Abbreviations: NA: not applicable. Alpha and beta are for beta distributions, shape and scale for gamma distributions.

Table 125. Cost of GP visits and related parameters (including distributions for PSA).

GP visits	Care state	Mean	Distribution	Distribution parameters		Source
				Mean or shape	SD or scale	
Marginal effect of home care on the N of GP visits	People at home	5.5	Not estimated			Forder, Gousia and Saloniki [204]
N of GP visits per person per year	Home care	7.17	Normal	7.17	0.20	Forder, Gousia and Saloniki [204]
	No home care	12.67	NA - probabilistic sampling linked to parameters above			Calculated based on parameters above
Cost of a 9.22-minute GP surgery consultation	All	£38	Gamma	96.04	0.396	Point estimate based on Jones et al. [198]. Includes "qualification costs" and excludes "direct care staff costs" (p. 66). 95% CI calculated assuming +-20%
Cost of GP visits per person per year	No home care	£481	NA - probabilistic sampling linked to parameters above			Calculated based on parameters above
	Home care	£272				
	In a care home	£626	Gamma	96.04	6.5	Point estimate based on Jones et al. [198]. 95% CI calculated assuming +-20%.

Table notes. Abbreviations: NA: not applicable; SD: standard deviation; SE: standard error. Mean and SD are for normal distributions, shape and scale for gamma distributions. The SD of the distribution of the estimate corresponds to the SE of the estimate.

Table 126. Model inputs relating to hospitalisation costs (including distributions for PSA).

Hospitalisations	Care state	Mean	Distribution	Distribution parameters		Source
				Mean or shape	SD or scale	
Hazard ratio for outcome: at least one hospitalisation	Comparing unmet to met need	1.14	Lognormal	0.131	0.060	Xu et al. [187].
N of hospitalisations per person per year	Across everyone at home (only used to calculate the estimates below)	0.91	Normal	0.91	0.034	Bardsley et al. [205]
	Any at home with met need	0.87	NA - probabilistic sampling linked to other parameters.			Calculated using the hazard ratio from Xu et al. [187], the overall N of hospitalisations from Bardsley et al. [205] and the prevalence of met and unmet need.
	Any at home with unmet need	0.99				
	In a care home	0.61	Normal	0.61	0.016	Bardsley et al. [205]
N of hospitalisations per person over 6 months	Any at home with met need	0.43	NA – probabilistic sampling linked to other parameters.			Same calculation as for annual costs, after dividing the annual N of hospitalisations from Bardsley et al. [205] by two.
	Any at home with unmet need	0.50				
N of hospitalisations per person over 3 months	Any at home with met need	0.22	NA – probabilistic sampling linked to other parameters.			Same calculation as for annual costs, after dividing the annual N of hospitalisations from Bardsley et al. [205] by four.
	Any at home with unmet need	0.25				
N of elective admissions per person per year	Any at home	0.11	Normal	0.11	0.01	Bardsley et al. [205]

Hospitalisations	**Care state**	**Mean**	**Distribution**	**Distribution parameters**		**Source**
				Mean or shape	**SD or scale**	
N of emergency admissions per person per year	Any at home	0.65	Normal	0.65	0.0225	
Proportion elective	Any at home	0.14	NA - probabilistic sampling linked to parameters above.			Calculated based on parameters above from Bardsley et al. [205]
Proportion emergency	Any at home	0.86	NA - probabilistic sampling linked to parameter above to make sure that the proportions add up to 1.			
N of elective admissions per person per year	In a care home	0.07	Normal	0.07	0.0045	Bardsley et al. [205]
N of emergency admissions per person per year	In a care home	0.47	Normal	0.47	0.0128	
Proportion elective	In a care home	0.13	NA - probabilistic sampling linked to parameters above.			Calculated based on parameters above from Bardsley et al. [205]
Proportion emergency	In a care home	0.87	NA - probabilistic sampling linked to parameter above to make sure that the proportions add up to 1.			
Cost of an elective inpatient	All	£5,845	Gamma	96.04	60.86	Point estimate from the National Schedule of NHS costs 2021-22 [206]. 95% CI calculated assuming +-20%.
Cost of a non-elective long stay	All	£4,409	Gamma	96.04	45.91	
Cost of a non-elective short stay	All	£801	Gamma	96.04	8.34	
Cost of one hospitalisation	Any at home	£3,074	NA - probabilistic sampling linked to other parameters.			Calculated using parameters above on the proportion of hospitalisations that were elective or emergency and

Hospitalisations	**Care state**	**Mean**	**Distribution**	**Distribution parameters**		**Source**
				Mean or shape	**SD or scale**	
	In a care home	£3,025				their related costs. It was assumed that 50% of emergency admissions were long stay and 50% short stay, as per Bauer et al. [58].

Table notes. Abbreviations: NA: not applicable; SD: standard deviation; SE: standard error. Mean and SD are for normal and lognormal distributions, shape and scale for gamma distributions. The SD of the distribution of the estimate corresponds to the SE of the estimate.

Table 127. Model inputs relating to the cost of depressive symptoms (including distributions for PSA).

Parameter	**Care state**	**Mean**	**Distribution**	**Distribution parameters**		**Source**
				Alpha, mean or shape	**Beta, SD or scale**	
Marginal effect of not having help for at least one PADL difficulty on the outcome: at least 4 depressive symptoms	Comparing unmet to met needs	0.080	Normal	0.080	0.042	Multivariable analysis linked to chapter 5 (see Appendix 6B.2)
P (high depressive symptoms)	Met needs	0.380	Beta	35	57	ELSA data (92 people aged 65 and over who had at least two PADL difficulties and help for each PADL difficulty in wave 8)
	Unmet needs	0.460	NA - probabilistic sampling linked to parameters above			Calculated using the two parameters above.
	Care home	0.450	Beta	111.6	136.4	Mozley et al. [207]
Annual PSS cost of depression per person in 2012/13 prices	All	£38.0	NA			Dixon et al. [208]
Annual PSS cost of depression per person in 2021/22 prices	All	£48.0	Gamma	8.5	5.6	Inflation index applied to estimate above
Annual NHS drug cost of depression per person in 2012/13 prices	All	£88.0	NA			Dixon et al. [208]
Annual NHS drug cost of depression per person in 2021/22 prices	All	£101.8	Gamma	53.8	1.9	Inflation index applied to estimate above

Parameter	Care state	Mean	Distribution	Distribution parameters		Source
				Alpha, mean or shape	Beta, SD or scale	
Annual privately funded cost of depression per person in 2012/13 prices	All	£47.54	NA			Dixon et al. [208]
Annual privately funded cost of depression per person in 2021/22 prices	All	£55.0	Gamma	96.04	0.573	Inflation index applied to estimate above. 95% CI calculated assuming +-20%

Table notes. Abbreviations: NA: not applicable; P: probability; SD: standard deviation; SE: standard error. Alpha and beta are for beta distributions, mean and SD for normal distributions, shape and scale for gamma distributions. The SD of the distribution of the estimate corresponds to the SE of the estimate.

Table 128. Annual earnings of informal carers corresponding to different care states, and related parameters (including distributions for PSA).

Informal carers' earnings and related parameters	Care state	Mean	Distribution	Distribution parameters		Source
				Alpha or Shape	Beta or Scale	
P (being aged 18-24 if a carer of an older person)	All	0.0014	Beta	300	206,760	Personal Social Services Survey of Adult Carers in England (PSS SACE) 2021/22 [211]
P (being aged 25-34 if a carer of an older person)	All	0.0061	Beta	1,260	205,800	
P (being aged 35-44 if a carer of an older person)	All	0.0237	Beta	4,900	202,160	
P (being aged 45-54 if a carer of an older person)	All	0.089	Beta	18,520	188,540	
P (being aged 55-64 if a carer of an older person)	All	0.220	Beta	45,480	161,580	
P (being aged 65+ if a carer of an older person)	All	0.660	NA. Probabilistic sampling linked to parameters above to make sure probabilities add up to 1.			
P (aged up to 64 if a carer of an older person)	All	0.340	NA. Probabilistic sampling linked to parameter above.			Linked to parameter above
P (employment of main informal carer) if aged up to 64	Caring for 1 to 9 hours, with or without home care	0.674	NA. Probabilistic sampling linked to other parameters.			Appendix 6D explains how these probabilities were calculated.
	Caring for at least 10 hours, without home care	0.474				
	Caring for at least 10 hours, with home care	0.520				

Informal carers' earnings and related parameters	**Care state**	**Mean**	**Distribution**	**Distribution parameters**		**Source**
				Alpha or Shape	**Beta or Scale**	
	Care home admission or death of cared-for person	0.721	Not available			Calculated using the employment rates for the general population by age group [212].
P (employment of main informal carer) if aged 65 and over	At home, with or without home care, weighted average across all hours of care	0.079	Not available			Appendix 6D explains how this was calculated.
	Care home admission or death of cared-for person	0.111	Not available			Corresponds to the employment rate for the general population aged 65 and over [212].
P (caring for one to nine hours) if aged up to 64	Any at home	0.378	Not available			NICE [175]
P (caring for at least ten hours) if aged up to 64	Any at home	0.622				
Estimated annual median net salary	All	£24,719	Gamma	96	257	ONS [214] and UK government [215]. 95% CI calculated assuming +-20%.
Earnings per informal carer per year	Home care	£6,146	NA. Probabilistic sampling linked to other parameters.			Calculated using the annual median net salary (see row above), the probabilities of belonging to different carers' subgroups
	No home care	£5,908				

Informal carers' earnings and related parameters	**Care state**	**Mean**	**Distribution**	**Distribution parameters**		**Source**
				Alpha or Shape	**Beta or Scale**	
	Care home or death	£7,866				(defined by age, number of caring hours and receipt of home care) and the employment probabilities for these subgroups.

Table notes. Abbreviations: NA: not applicable; P: probability; PSS SACE: Personal Social Services Survey of Adult Carers in England. Alpha and beta are for beta distributions, shape and scale. for gamma distributions.

Appendix 6B. Modifications to some analyses in chapters 4 & 5 to calculate parameters for the economic model

The analysis on source of care in section 4.3 was re-run, but mean marginal effects were calculated from the logit model instead of odds ratios. Moreover, the outcome was changed from “unmet need” to “met need”.

For depressive symptoms, robustness checks using alternative definitions of unmet need (see Appendix 5C.6) were re-run with binary outcomes representing “high depressive symptoms”, and calculating mean marginal effects instead of odds ratios.

Note that the population in the data analyses in chapters 4 and 5 was defined by having at least one PADL limitation or at least two non-PADL limitations. This is different from the threshold of at least 2 PADL limitations that was preferred and used whenever possible in the economic model, as mentioned in section 6.2.2.1.

Appendix 6B.1. Analysis on source of care: same as chapter 4, but with outcome “met need” and outputting mean marginal effects from the logit model

Table 129. Outcome: met need. Mean marginal effects from logit model.

	(1) Final model (base)
Age 70-74	-0.018
	[-0.117,0.081]
Age 75-79	-0.005
	[-0.105,0.094]
Age 80-84	-0.006
	[-0.108,0.096]
Age 85-90+	0.026
	[-0.083,0.134]
Male	0.062*
	[-0.006,0.131]
43-deficits frailty index in wave 8	-0.003*
	[-0.006,0.000]
N of PADL limitations in wave 8	-0.035***
	[-0.058,-0.012]
N of IADL limitations in wave 8	-0.009
	[-0.031,0.012]
Education > school leaving age	-0.076**
	[-0.146,-0.005]
Wealth in wave 7: quartile 2	-0.058
	[-0.161,0.044]
Wealth in wave 7: quartile 3	0.084*
	[-0.001,0.169]
Wealth in wave 7: quartile 4	-0.001
	[-0.088,0.086]
Informal care only from outside the household	-0.134***
	[-0.216,-0.051]
No informal care	-0.024
	[-0.129,0.080]
Care paid with private funds or benefits	-0.076*
	[-0.156,0.004]
LA-funded care	0.052
	[-0.051,0.155]
N	773

Table notes.
95% confidence intervals in brackets
* p<0.10, ** p<0.05, *** p<0.01
The reference category for age was 65-69.
The frailty index is based on 43 deficits and is measured as a percentage.
Wealth refers to equivalised net total wealth; wealth quartiles were calculated based on the final sample of 773 people. The reference category for wealth was the lowest quartile (quartile 1).
The reference category for all informal care from outside the household and no informal care was “at least some informal care from within the household”.
Care paid with private funds or benefits refers to: respondent pays out of own income, savings or benefits or gives gifts or the family member pays.

The marginal effect on the probability of met need of having LA-funded care and of having all informal care from outside the household were sampled probabilistically using a multivariate normal distribution. This was based on a variance-covariance matrix that was produced by the multivariable analysis presented above. The matrix is presented below.

Table 130. Variance-covariance matrix for the multivariate normal distribution. Outcome: met need.

	Marginal effect: all informal care from outside the household vs. at least some informal care from within the household	Marginal effect: LA-funded care vs. no LA-funded care
Marginal effect: all informal care from outside the household vs. at least some informal care from within the household	0.0018	
Marginal effect: LA-funded care vs. no LA-funded care	-0.0004	0.0027

Appendix 6B.2. Alternative definitions of unmet care need combined with the outcomes >=3 or at least >=4 depressive symptoms: mean marginal effects

	(1) Outcome: at least 3 depressive symptoms. Unmet need: no help for at least one PADL difficulty	(2) Outcome: at least 4 depressive symptoms. Unmet need: no help for at least one PADL difficulty	(3) Outcome: at least 3 depressive symptoms. Only people with help. Unmet need: help that does not meet needs all the time.	(4) Outcome: at least 4 depressive symptoms. Only people with help. Unmet need: help that does not meet needs all the time
Unmet need	0.069	0.080*	0.083**	0.098***
	[-0.031,0.169]	[-0.003,0.163]	[0.012,0.154]	[0.038,0.158]
Age 70-74	-0.027	-0.041	-0.039	-0.097
	[-0.118,0.065]	[-0.133,0.052]	[-0.168,0.091]	[-0.223,0.028]
Age 75-79	-0.065	-0.046	-0.067	-0.032
	[-0.163,0.034]	[-0.137,0.046]	[-0.209,0.075]	[-0.146,0.083]
Age 80-84	0.017	0.007	0.050	0.052
	[-0.106,0.140]	[-0.109,0.123]	[-0.096,0.195]	[-0.088,0.192]
Age 85+	-0.140**	-0.110**	-0.105	-0.085
	[-0.257,-0.024]	[-0.216,-0.003]	[-0.253,0.043]	[-0.215,0.046]
Male	-0.081**	-0.069**	-0.017	-0.035
	[-0.150,-0.012]	[-0.136,-0.003]	[-0.107,0.073]	[-0.116,0.047]
Living alone in wave 8	0.085**	0.072**	0.041	0.033
	[0.013,0.156]	[0.009,0.135]	[-0.047,0.130]	[-0.041,0.107]
N of PADL limitations in wave 8	-0.003	-0.004	-0.010	0.001
	[-0.035,0.029]	[-0.030,0.022]	[-0.035,0.015]	[-0.023,0.024]
N of IADL limitations in wave 8	0.036***	0.028**	0.029*	0.024*
	[0.009,0.062]	[0.004,0.051]	[-0.001,0.059]	[-0.003,0.052]
Centred variable of the 40-deficits frailty index in wave 8	0.008***	0.005***	0.013***	0.010***
	[0.004,0.012]	[0.002,0.009]	[0.008,0.018]	[0.005,0.014]
Frequent problems with balance in wave 7	0.033	0.026	-0.028	-0.056
	[-0.046,0.113]	[-0.048,0.100]	[-0.124,0.069]	[-0.142,0.031]
Current smoker in wave 8	-0.012	-0.055	0.094	0.025
	[-0.141,0.118]	[-0.159,0.050]	[-0.059,0.247]	[-0.085,0.135]

Education beyond school leaving age	0.027	0.010	0.035	0.013
	[-0.045,0.098]	[-0.055,0.074]	[-0.059,0.129]	[-0.078,0.104]
Wealth in wave 8: quartile 1 (lowest)	0.000	0.000	0.000	0.000
	[0.000,0.000]	[0.000,0.000]	[0.000,0.000]	[0.000,0.000]
Wealth in wave 8: quartile 2	0.019	-0.040	0.037	0.010
	[-0.075,0.112]	[-0.129,0.049]	[-0.077,0.151]	[-0.092,0.113]
Wealth in wave 8: quartile 3	-0.037	-0.093*	-0.021	-0.080
	[-0.129,0.055]	[-0.197,0.010]	[-0.137,0.095]	[-0.203,0.043]
Wealth in wave 8: quartile 4 (highest)	-0.164***	-0.194***	-0.141**	-0.152***
	[-0.258,-0.070]	[-0.280,-0.108]	[-0.264,-0.018]	[-0.267,-0.036]
LA IDAOPI average score	-0.004	-0.002	-0.009**	-0.006
	[-0.011,0.003]	[-0.010,0.005]	[-0.018,-0.001]	[-0.016,0.003]
% of people in rural areas	-0.000	0.000	0.000	0.001
	[-0.002,0.001]	[-0.001,0.002]	[-0.001,0.002]	[-0.001,0.002]
N	788	788	505	505

Table notes.

95% confidence intervals in brackets

* p<0.10, ** p<0.05, *** p<0.01

For the age groups, the reference category was 65-69.

Frequent problems with balance refers to: always/very often/often has “problems with balance when walking on level surface” ([80], variable name).

Wealth refers to equivalised net total wealth. Quartiles were calculated based on the overall sample (n=788). The reference category was the lowest quartile.

The frailty index was measured as a percentage.

A higher IDAOPI score means that there is a higher proportion of people aged 60 and over who experience income deprivation.

Appendix 6C. Transition matrices

This appendix shows the transition matrices for average age 80. Table 131 refers to the subgroup with at least some informal care from inside the household. Table 132 refers to the subgroup with all informal care from outside the household. Table 133 refers to the subgroup without informal care.

Table 131. Transition matrix. Subgroup 1: at least some informal care from inside the household. Mean transition probabilities for average age 80.

From row to column	Unmet care needs, no home care (waiting list)	Met care needs, no home care (waiting list)	Unmet care needs, with home care	Met care needs, with home care	Unmet care needs, no home care (cancelled)	Met care needs, no home care (cancelled)	Long-term placement in a care home (residential or nursing)	Death	Total
Unmet care needs, no home care (waiting list)	0.000	0.000	0.213	0.632	0.009	0.021	0.069	0.055	1.000
Met care needs, no home care (waiting list)	0.000	0.000	0.224	0.664	0.009	0.021	0.040	0.041	1.000
Unmet care needs, with home care	0.000	0.000	0.875	0	0.000	0.000	0.069	0.055	1.000
Met care needs, with home care	0.000	0.000	0.000	0.919	0.000	0.000	0.040	0.041	1.000
Unmet care needs, no home care (cancelled)	0.061	0.139	0.000	0.000	0.675	0.000	0.069	0.055	1.000
Met care needs, no home care (cancelled)	0.061	0.139	0.000	0.000	0.000	0.719	0.040	0.041	1.000
Long-term placement in a care home (residential or nursing)	0.000	0.000	0.000	0.000	0.000	0.000	0.744	0.256	1.000
Death	0.000	0.000	0.000	0.000	0.000	0.000	0.000	1.000	1.000

Table 132. Transition matrix. Mean transition probabilities. Subgroup 1: all informal care from outside the household. Average age: 80.

From row to column	Unmet care needs, no home care (waiting list)	Met care needs, no home care (waiting list)	Unmet care needs, with home care	Met care needs, with home care	Unmet care needs, no home care (cancelled)	Met care needs, no home care (cancelled)	Long-term placement in a care home (residential or nursing)	Death	Total
Unmet care needs, no home care (waiting list)	0.000	0.000	0.326	0.519	0.013	0.017	0.069	0.055	1.000
Met care needs, no home care (waiting list)	0.000	0.000	0.343	0.546	0.013	0.017	0.040	0.041	1.000
Unmet care needs, with home care	0.000	0.000	0.875	0.000	0.000	0.000	0.069	0.055	1.000
Met care needs, with home care	0.000	0.000	0.000	0.919	0.000	0.000	0.040	0.041	1.000
Unmet care needs, no home care (cancelled)	0.088	0.112	0.000	0.000	0.675	0.000	0.069	0.055	1.000
Met care needs, no home care (cancelled)	0.088	0.112	0.000	0.000	0.000	0.719	0.040	0.041	1.000
Long-term placement in a care home (residential or nursing)	0.000	0.000	0.000	0.000	0.000	0.000	0.744	0.256	1.000
Death	0.000	0.000	0.000	0.000	0.000	0.000	0.000	1.000	1.000

Table 133. Transition matrix. Mean transition probabilities for average age: 80. Subgroup 3: no informal care.

From row to column	Unmet care needs, no home care (waiting list)	Unmet care needs, with home care	Met care needs, with home care	Long-term placement in a care home (residential or nursing)	Death	Total
Unmet care needs, no home care (waiting list)	0.000	0.298	0.578	0.069	0.055	1.000
Unmet care needs, with home care	0.000	0.298	0.578	0.069	0.055	1.000
Met care needs, with home care	0.000	0.312	0.606	0.040	0.041	1.000
Long-term placement in a care home (residential or nursing)	0.000	0.000	0.000	0.744	0.256	1.000
Death	0.000	0.000	0.000	0.000	1.000	1.000

Appendix 6D. Model inputs: additional information

Appendix 6.D.1.A. Converting annual probabilities into 6-month probabilities

For care home admissions and for mortality, 6-month probabilities were needed for the short-term model. These were calculated by converting annual probabilities into annual rates and then converting annual rates into 6-month probabilities. These conversions were based on these formulas:

$$r = -\frac{\ln(1-p)}{t}$$

$$p = 1 - \exp(-rt)$$

Where r is the rate and p the probability.

So for example, for care home admissions, the annual probability was 0.0489. Therefore, the annual rate was calculated as follows:

$$r = -\frac{\ln(1-0.0489)}{1} = 0.05014$$

And the 6-month probability was:

$$p = 1 - \exp(-0.05014 * 0.5) = 0.02476$$

The formulas were taken from an article by Gidwani and Russell [263].

Appendix 6.D.1.B. Formula for combining overall probabilities or numbers with odds ratios and hazard ratios.

This appendix describes a formula that was used in relation to care home admissions, mortality and the number of hospitalisations. For these events, an odds ratio or hazard ratio comparing people with unmet needs to people with met needs was available. In addition, an overall probability or number across everyone was available. In order to calculate probabilities or numbers specific to those with met and unmet needs based on these estimates, this formula was used:

Adjusted OR for those with unmet needs = Reported OR ^ (1 - prevalence of unmet need)

Adjusted OR for those with met needs = Reported OR ^ (0 – prevalence of unmet need)

The adjusted OR compared people with unmet or met needs to the overall population.

The prevalence of unmet need was assumed to be 65.3% on average (see Table 29). This was a weighted average across all subgroups at the start of the intervention.

Appendix 6.D.1.C. Mortality of people at home: additional details

The weights used for calculating a weighted average of the probability of death across males and females for each age were the population estimates in England for mid-2021 up to age 90, which were stratified by age and sex [264]. These collapsed together the population estimates for people aged 90 and over. Therefore, from age 90, population estimates were taken from a separate ONS file which was specifically about people aged 90 and over in 2020 [265]. It was assumed that everyone died after reaching an average age of 101.

The average annual probabilities for each age for people at home are presented in Table 134. Probabilistic sampling was linked to the OR from Gaugler et al. [188] and to the prevalence of unmet need.

Table 134. Average annual probability of death at each average age for people at home.

Average age	Overall probability of death	Adjusted OR (unmet need) = Reported OR ^ (1 - Prevalence unmet need)	Adjusted OR (met need) = Reported OR ^ (0 - Prevalence unmet need)	Overall odds of death	Odds of death with unmet need	Odds of death with met need	Prob. of death with unmet need	Prob. of death with met need
78	0.037	1.228	0.897	0.038	0.047	0.034	0.045	0.033
79	0.041	1.228	0.897	0.042	0.052	0.038	0.050	0.037
80	0.045	1.228	0.897	0.048	0.058	0.043	0.055	0.041
81	0.051	1.228	0.897	0.054	0.066	0.048	0.062	0.046
82	0.057	1.228	0.897	0.060	0.074	0.054	0.069	0.051
83	0.065	1.228	0.897	0.069	0.085	0.062	0.078	0.058
84	0.073	1.228	0.897	0.079	0.097	0.070	0.088	0.066
85	0.082	1.228	0.897	0.089	0.109	0.080	0.099	0.074
86	0.093	1.228	0.897	0.102	0.126	0.092	0.112	0.084
87	0.104	1.228	0.897	0.116	0.142	0.104	0.124	0.094
88	0.117	1.228	0.897	0.133	0.163	0.119	0.140	0.106
89	0.131	1.228	0.897	0.150	0.185	0.135	0.156	0.119
90	0.143	1.228	0.897	0.167	0.205	0.150	0.170	0.130
91	0.160	1.228	0.897	0.191	0.234	0.171	0.190	0.146
92	0.177	1.228	0.897	0.215	0.264	0.193	0.209	0.161
93	0.195	1.228	0.897	0.242	0.297	0.217	0.229	0.178
94	0.215	1.228	0.897	0.274	0.337	0.246	0.252	0.197
95	0.238	1.228	0.897	0.313	0.384	0.280	0.278	0.219
96	0.261	1.228	0.897	0.354	0.435	0.317	0.303	0.241
97	0.278	1.228	0.897	0.385	0.473	0.345	0.321	0.257
98	0.302	1.228	0.897	0.433	0.532	0.389	0.347	0.280
99	0.327	1.228	0.897	0.485	0.596	0.435	0.373	0.303
100	0.358	1.228	0.897	0.557	0.684	0.499	0.406	0.333
101	1.000	NA	NA	NA	NA	NA	1.000	1.000

Table notes. See section 6.2.4.3.5 for data sources used in table above.

Appendix 6.D.1.D. Informal carers’ earnings: additional details

Calculations combined the data presented in the tables below. Note that although the pension age in England is 66, the model separated carers aged up to 64 from carers aged 65 and over based on data availability.

Table 135. Employment rate by age group, general population, November 2022 to January 2023 [212].

Age group	Employment rate
18-24	63.1%
25-34	84.8%
35-49	85.4%
50-64	70.9%
65+	11.1%

Table 136. Likelihood of employment compared to the general population, by hours of caring ([175] based on data from [213]) .

Hours of care	Likelihood of employment compared to the general population
1 to 4	0.99
5 to 9	0.89
10 to 19	0.78
20 to 34	0.63
35 to 49	0.58
50 to 60	0.45

Table 137 provides the proportion caring for a specific number of hours within each age group. This was calculated based on data presented by NICE [175]. The hours were grouped for the present work using the same categories used in Table 136.

Table 137. Proportion caring for a specific number of hours by age group.

Hours grouped	Age 18-24	Age 25-49	Age 50-64	Age 65+
1 to 4	0.20	0.18	0.19	0.16
5 to 9	0.20	0.18	0.19	0.16
10 to 19	0.27	0.25	0.26	0.20
20 to 34	0.21	0.18	0.18	0.13
35 to 49	0.09	0.10	0.08	0.13
50 to 60	0.03	0.12	0.10	0.23
TOT	1.00	1.00	1.00	1.00

Combining the information in Table 135 to Table 137, the present work calculated a weighted average of the probability of employment among carers in each age group up to age 64, stratified by whether caring was for one to nine hours or for at least ten hours. The results of this calculation are in Table 138 (the receipt of home care was not yet considered in this table).

Table 138. Probability of employment by age group up to age 64 and by whether caring was for less than 10 hours or at least 10 hours.

Age group	Caring for one to nine hours	Caring for at least ten hours
18-24	59.06%	42.87%
25-49	79.70%	55.26%
50-64	66.30%	46.69%

A weighted average of the probability of employment across everyone aged up to 64 was then calculated, stratified by whether caring was for less than 10 hours or at least 10 hours. The weights corresponded to the percentages in Table 139, which shows how carers were distributed across different age groups.

Table 139. Informal carers of people aged 65 and over: percentage in each age group; calculated based on data from the PSS Survey of Adult Carers in England (SACE) 2021/22 [211].

Age group	Percentage of carers		
	Average	95% CI: lower limit	95% CI: upper limit
18-24	0.14%	0.13%	0.16%
25-34	0.61%	0.58%	0.64%
35-44	2.37%	2.30%	2.43%
45-54	8.94%	8.82%	9.07%
55-64	21.96%	21.79%	22.14%
65+	65.97%	65.77%	66.18%
TOT	100%	NA	NA

Table notes. Abbreviations: CI: confidence interval; NA: not applicable; PSS: personal social services.

Carers' earnings in a care state with home care were calculated as follows:

*Net yearly salary **
*(probability that the carer is aged up to 64 years old**
*(probability of caring for one to nine hours if aged up to 64 * probability of employment if caring for one to nine hours and aged up to 64*
*+ probability of caring for at least 10 hours if aged up to 64 * probability of employment if aged up to 64 and caring for at least 10 hours and having home care)*
*+ probability that the carer is aged 65 and over * probability of employment if aged 65 and over)*

Carers' earnings in the other states were calculated in a similar way.

Appendix 6E. Error-checking relating to the increase in the cost of depressive symptoms.

Deterministic analyses were used for error-checking around the increase in the cost of depressive symptoms linked to the intervention. Firstly, the marginal effect of unmet need on high depressive symptoms was increased from 0.08 to 0.3. Secondly, the probability of depressive symptoms in a care home was increased to 0.9. With both changes, the intervention led to a decrease in the cost of depressive symptoms in each subgroup, on average. Thirdly, the odds ratio linking unmet care need to additional mortality was increased so that the intervention led to a bigger increase in survival. With this change, the increase in the cost of depressive symptoms became bigger.