National Institute for Health and Care Excellence

Final

Supporting Adult Carers

RQA - Identifying carers as defined by the Care Act 2014 (including hidden carers)

NICE guideline NG150

Evidence reviews

January 2020

Final

These evidence reviews were developed by the National Guideline Alliance part of the Royal College of Obstetricians and Gynaecologists

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Identifying carers as defined by the Care Act 2014 (including hidden carers)

Review question

What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?

Introduction

The Care Act 2014 sets out a legal requirement to identify carers in order to ensure that they receive the information and support which will enable them to carry out their caring roles. Qualitative evidence from a number of sources clearly shows that practitioners across health and social care understood the importance of early identification of carers and welcomed a range of processes and procedures to help them better identify carers in order to meet their Care Act requirements. However, notwithstanding good intentions, the early identification of carers is still varied and not all carers identify with the information and images of caring available to them. Equally, not all practitioners across health and social care are fully aware of the implications of the Care Act for carers and their responsibilities with regard to identification.

Many carers will be first identified through the NHS (the 2018 NHS Continuing Health Care Guidance setting out the joint health and social care responsibility to identify carers) but evidence again suggests that their specific needs are not always recognised either initially or at different stages of their carer's journey. There has also been growing awareness that caring can affect the whole family and identification should take account of the full range of family members affected (in particular the often under-identified young or young adult carers in a family, whose access to education, training or employment may be limited by their caring responsibilities).

Summary of the protocol

Please see Table 1 for a summary of the population, phenomenon of interest and context characteristics of this review.

Table 1: Summary of the protocol

Population	• Adult carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs. • Health-/social-care and other practitioners involved in their care.
Phenomenon of interest	• Factors that facilitate or impede the identification of carers, as stipulated by The Care Act 2014, and that are related to: ○ self-identification of carers as carers; and ○ recognition and formal identification of carers by relevant stakeholders (for example, social and healthcare professionals, voluntary organisations, or local authorities). • This might include formal initiatives such as: ○ Triangle of Care by the Carers' Trust ○ NHS England's Carers Tool Kit ○ Employers for Carers ○ Royal College of GPs

	• Association of directors of adult social services in England (ADASS). Carers' views and experiences • Professionals' views
Context	• UK only.
Outcomes	Expected themes from the qualitative evidence might include: • number of routes through which carers can be identified • level of support provided by professional or voluntary sector organisations • level of support provided to professional or voluntary sector organisations • insufficient service information • relevance of the information provided (for example, language used and cultural relevance) • not perceiving oneself as a carer when looking after a relative.

For further details see the review protocol in appendix A.

Included studies

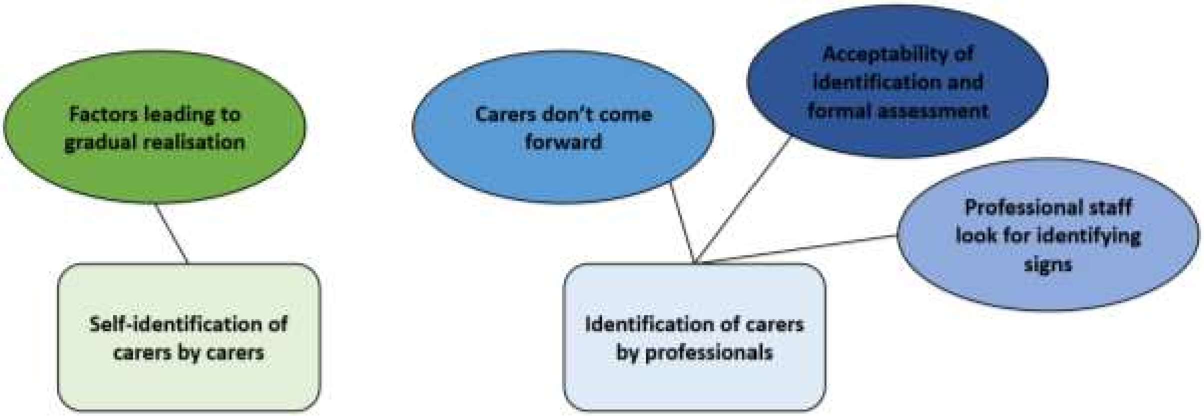
This is a qualitative review with the aim of understanding the factors that facilitate or impede the identification of carers. 3 qualitative studies were identified for this review, 2 peer-reviewed studies (Carduff 2016, Carduff 2014), and 1 non-peer reviewed study (Bennett 2016).

The included studies are summarised in Table 2. They were published between 2014 (Carduff 2014) and 2016 (Bennett 2016, Carduff 2016). Individuals who were interviewed within these studies were caring for people with a mixture of conditions. 1 included study collected data via semi-structured interviews (Carduff 2016), 1 study used focus group techniques (Carduff 2014), and for 1 study data were collected through online and offline surveys, and also written semi-structured questionnaires completed by carers, local carers services, local authorities, local NHS and other charities involved in providing support to carers about how they felt the Care Act was working for carers, a year after implementation (Bennett 2016). Data analysis methods included content analysis and thematic analysis.

All studies were conducted in the UK. Except for 1 study, which recruited carers from all across the UK (Bennett 2016), 2 included studies took place in Scotland (Carduff 2016, Carduff 2014).

As shown in the theme map (**Error! Reference source not found.**), these concepts have b een explored in a number of central themes and subthemes.

Figure 1: Theme map



Excluded studies

Studies not included in this review with reasons for their exclusions are provided in appendix K.

Summary of studies included in the evidence review

A summary of the studies that were included in this review are presented in Table 2.

Table 2: Summary of included qualitative studies

Study and aim of the study	Participants	Methods	Themes
Bennett 2016 **Aim of the study** • The aims of this mixed-methods research were to explore the views of carers about how they felt the Care Act was working for them a year after its implementation in relation to the recognition, formal identification and self-identification of themselves as carers.	N = 624 **Carer** • Age = Range (years): 16 to 85 • Gender (M/F)= 107/329 (reported) **Professionals** • N = Unclear **Person being cared for** • Mixed conditions	• **Recruitment period:** February - April 2016 • **Data collection & analysis methods:** ○ Data were collected through online and offline survey, and also written semi-structured questionnaires completed by carers, local carers services, local authorities, local NHS and other charities. ○ No details are reported about the data analysis.	• What has gone well? - Identifying carers and assessment. • What needs to improve? - Identifying and reaching out to carers.
Carduff 2014 **Aim of the study** • The aims of this qualitative study were to explore the views of carers of people towards the end of life in primary care in relation to the recognition, formal identification and self-identification of their role as carers.	N=15 adult carers **Carer** • Age = N/R • Gender (M/F)= 3/12 **Professionals** • N = 8 **Person being cared for** • people towards the end of life	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through focus group interviews. ○ Data were analysed using a constructionist perspective. ○ Validity of findings was assessed by triangulating the data from 2 other sources (literature review, and stakeholder workshop).	Barriers to carer identification: • Caring as a gradual process: ○ identifying with the term 'carer' ○ changing relationships in the context of caring. • Engulfed by the caring role: ○ managing competing demands. • The role of primary care in legitimising need ○ role ambiguity ○ communication.
Carduff 2016 **Aim of the study** • The aims of this mixed-methods research were to explore the views of carers of people with palliative and supportive care needs in relation to the recognition, a formal identification intervention and self-	N=11 adult carers **Carer** • Age = mean - range (years): 74 - 58 to 86 • Gender (M/F)= 4/7 **Professionals** • N = 8 **Person being cared for** • People with palliative and supportive care needs	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through face-to-face semi-structured interviews guided by a topic guide. ○ Thematic analysis was used to analyse data.	• The acceptability of the formal identification intervention proposed developed to – ○ carers ○ professionals

Study and aim of the study	Participants	Methods	Themes
identification of themselves as carers		○ Validity was ensured by data triangulation (carers and professionals) and by running a stakeholder workshop to discuss the findings amongst those who they related to.	

F: Female; M: Male; N: Number; N/R: not reported

See the full evidence tables in appendix D

Quality assessment of outcomes included in the evidence review

See the evidence profiles in appendix F.

Economic evidence

Included studies

A systematic review of the economic literature was conducted but no economic studies were identified which were applicable to this review question.

Excluded studies

No economic studies were identified which were applicable to this review question.

Summary of studies included in the economic evidence review

No economic studies were identified which were applicable to this review question.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation. Furthermore, only a qualitative review was being undertaken for this question and therefore there was no effectiveness evidence available to inform economic modelling.

Evidence statements

Theme 1: Self-identification by carers as carers – factors leading to the gradual realisation of being a carer.

- **ID1 Noticing that the relationship with the person they care for has changed.** Very low quality evidence from 1 study found that the transition into caring is often a gradual process, however at some point the carer realises that the nature of the relationship with the person they care for has shifted. The person they care for is no longer independent but reliant on them and this may be a big role change or role reversal from before.
- **ID2 The carer's self-perception may be disrupted by the views of the person they care for.** Very low quality evidence from 1 study found that carers may not see themselves as a carer if the person they are supporting does not acknowledge or recognise that they are being cared for.

- **ID3 Noticing that other social relationships have changed.** Low quality evidence from 2 studies found that interactions and relationships with other people including friends, spouses and other relatives may change and decline, as carers have less time to put in to relationships and pursue interests outside of their home and their care role.

- **ID4 Having to make decisions about employment.** Very low quality evidence from 1 study found that the caring role often strains the carer's existing roles - and work status in particular may need to be reconsidered. The carer may receive conflicting messages from different sources about whether to do this, and may also be influenced by the wish to spend time with the person they care for before they die.

Theme 2: Identification of carers by health and social-care professionals – carers don't identify themselves to professionals.

- **ID5 Carers often don't know that they have a right to recognition and support.** Very low quality evidence from 1 study found that carers may be aware of the role and strain they are under, but not aware that recognition and support are available to them if they make themselves known to several professional sources.
- **ID6 General Practitioners say carers don't see them as a contact point for support.** Very low quality evidence from 1 study found that GPs believe that offering support to carers is part of their role, however carers see them as being only for 'medical' queries or problems related to the person they are supporting.

Theme 3: Identification of carers by health and social-care professionals – acceptability of identification and formal assessment.

- **ID7 Carers appreciate being recognised and offered support.** Low quality evidence from 2 studies found that being recognised by a professional and asked about their needs and how they're coping is a relieving experience for carers and makes them feel valued.
- **ID8 Some carers have positive experiences of being formally assessed.** Very low quality evidence from 1 study found that carers appreciate formal carer assessments (and periodical reassessments) when they are done comprehensively and competently. They make carers feel valued, and able to discuss how they're coping and what they need.

Theme 4: Identification of carers by health and social-care professionals – professional staff look for identifying signs.

- **ID9 Professionals want to identify and support carers.** Low quality evidence from 2 studies found that professionals report they want to be able to identify and support carers. They often have informal systems within their services for identifying carers and approaching them to assess their needs. However, they are also open to the establishment of more formal systems.
- **ID10 Shared electronic record systems may be helpful for identifying carers.** Low quality evidence from 1 study found that the eKIS (electronic Key Information Summaries) system is used in Scotland to share information between medical/health and care workers. This can be useful as a source of information about carers, but would require someone to take charge of searching for potential carers in need of support within the notes.
- **ID11 It is challenging to find the opportunity to talk with carers about their roles and needs.** Very low quality evidence from 1 study found that professionals often have lots to cover when meeting the needs of the person receiving care, and find it hard to make time to talk meaningfully with the carer about their needs too. Additionally, it may be hard to have honest conversations with the carer about coping in the presence of the person being supported.

Economic evidence statements

No economic evidence was identified which was applicable to this review question.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

The committee focused their discussion on two main areas – the first was self-identification of carers as carers, and the second was the recognition and formal identification of carers by social and healthcare professionals, voluntary organisations, or local authorities. All the themes were reported qualitatively, and were considered equally important and relevant by the committee for drafting recommendations on carer identification. The committee were interested in producing recommendations that would improve self-identification by carers as well as identification by practitioners.

Additionally, the committee noted that the Care Act 2014 stipulates carers have a right to formal recognition. They therefore prioritised increasing awareness among services and professionals about the statutory requirements as well as drafting recommendations based on the reported evidence.

The quality of the evidence

When assessed using GRADE-CERQual methodology all the evidence statements were found to be either low or very low quality. As a result, the recommendations were drafted partly based on these statements but supplemented by the committee's own expertise, the requirements of the Care Act (2014), and also with reference to related NICE guidelines.

The evidence was consistently downgraded due to poor adequacy as there were only 1 or 2 studies supporting each statement. Several evidence statements were also downgraded due to methodological issues in the included studies, for example, providing little detail on their sampling methods or analytical methods.

There were notable gaps in the evidence base. The lack of evidence into the experiences of people who do not identify as carers (despite providing regular care and support) is detrimental, although arguably it was inevitable as researchers struggle to locate and recruit this group. There was also no evidence identified in this review about the experiences of people who have had the responsibilities of and identification as a carer thrust upon them quite quickly and intensively rather than gradually, or how these experiences might differ and have different impacts on identification.

Most of the evidence about the actions and willingness of professionals to identify carers came from professionals themselves. While they reported positive intentions the committee recognised the limits of these data, which did not include carers' views and experiences of being identified by professionals to verify this.

In the protocol the committee suggested information on formal identification initiatives might be found such as the Triangle of Care by the Carers' Trust, NHS England's Carers Tool Kit and others (see appendix A) however no evidence was identified.

Benefits and harms

The principal benefit of increasing self-identification amongst carers as carers, and the identification of carers by professional services, is that help and support can be sought and delivered. The intention is that more carers will have their needs identified and met and that they will be supported in their caring role. The focus here is on carers who do not recognise they are carers, as opposed to others who may not want to be identified, for whatever reason.

Related to the recommendations for health and social care practitioners

The Care Act (2014) stipulates that all carers have a right to assessment, however the evidence suggested that many carers are not aware of this right and may not identify themselves as carers. The committee strongly agreed it was the role of all health and social care practitioners to make every effort to identify carers and to offer them an assessment, explaining what it is and what the benefits may be. [Care Act 2014, ID5, ID9] Regardless of whether they recognise themselves as carers, evidence from 1 study also suggested that carers often don’t know about the rights they subsequently have to external recognition and support. This resonated with the committee’s experience and as a result they wanted to encourage recognition of this among practitioners although they also agreed it was important to explain that some support may be means tested. They agreed it was similarly important to explain to people that a formal carers assessment was not necessary to access community services. [ID5]

Some carers assume the role gradually as the condition of the person they care for develops incrementally, and so they may not initially see the role and help they provide as ‘being a carer’. Subsequent triggers may prompt them to realise their role has shifted. These include noticing a distinct change in the relationship with the cared for person, a change in their relationships with other people such as friends and relatives, or the need to make decisions about their career or occupation. In discussing this evidence, further supported by their own experience, the committee noted that denial on the part of the person they care for, or a sense of being overwhelmed by competing demands, may also stand as obstacles to identifying that they are a carer. Finally, when the cared for person lives or moves away (for example in supported living) it is possible carers will no longer recognise themselves in that role. Failure to identify or no longer identifying as carers would mean failing to seek support. As a result, the committee drafted recommendations intending to encourage awareness among professionals that some people may not be actively seeking help, or may be surprised when offered it. They also agreed it was important that all health and social care practitioners take an active role in encouraging self-identification among carers [ID1-ID4].

There was no specific evidence about the differing experiences of people who have had the responsibilities of carer thrust upon them rapidly and intensively, rather than gradually, and how this may differ. The committee discussed their experiences of how the onset of a caring role varies from a gradual realisation of being a carer to suddenly undertaking the role. They did not draft recommendations specifically in relation to the latter group as they felt these carers would be more likely to be aware of their newly acquired role.

Included evidence about the role of GPs in this context suggested that although they think they are well placed to provide support to carers, they know that in reality, carers themselves don’t perceive GPs as a source of support. The committee discussed that carers may see the purpose of a GP appointment as solely about discussing health issues relating to the person being supported or treated. The committee also believed that GPs may not be doing enough to prompt and inform carers that discussions about their own needs is an entirely relevant topic. For these reasons they thought it was important to make health and social care practitioners aware that carers may not ask them for support even though it is appropriate for them to do so. [ID6]

Evidence suggested that carers appreciate being recognised, and that professionals want to identify and support them. The committee elaborated on this, saying that not only do carers appreciate being recognised, the fact of their recognition can make an important positive difference in the assessment and planning of support for the cared for person. On this basis the committee reached consensus that having identified carers, practitioners should work with them, treating them as a key member of the team around the cared for person, involving them in decision making and care planning keeping them up to date. It was important to highlight this involvement should be established with the consent of the cared for person. The committee agreed it was most relevant to include this recommendation in a sub section of the guideline about ‘working with and involving carers’.

Also stemming from discussions about the evidence on carers appreciating being recognised, the committee reached consensus that cared-for people themselves are one of the most important sources for identifying carers. They stated from experience that carers may be friends or neighbours as well as spouses or family members, and in some cases there may be more than one carer. Evidence suggested that when people receiving care do not acknowledge it, this may be a barrier to carer’s self-identification and to help address this they recommended asking people directly whether people other than professionals provide them with help or support. [committee consensus, ID2, ID7, ID9]

The committee discussed that some people find themselves in the role of carer following the transfer from hospital of the person for whom they now care. In line with existing NICE guidance and the Care Act 2014 the committee felt that teams transferring people to and from hospital should identify people who will be providing ongoing care and refer them to the relevant services.

There was evidence that routine records about people using services can be used by practitioners and services to also identify carers. The committee suggested that assessments and records should be designed to include details about the person’s carers (with necessary consent) in addition to the important information about the person themselves. [ID10] The committee agreed there were opportunities for identifying carers other than assessments, including GP visits, flu jab appointments and discharge planning meetings. Once identified these carers should have their details recorded (provided they consent) in order to be given the information they have a right to.

Included evidence about frontline practitioners found that practitioners and carers are sometimes reluctant to talk about caring roles in front of the person being supported for fear of upsetting them. This sometimes acted as a barrier to carers and practitioners having necessary conversations and carers being identified or assessed. This resonated with the committee who agreed that carers should be given the opportunity to have confidential conversations about their own needs, separately from the person they are supporting. [ID11]

Many people who have care and support needs also have caring responsibilities. Existing guidelines already stipulate that this should be accounted for in a care and support needs assessment (recommendation 1.3.7 in NICE’s guideline NG86 on people's experience in adult social care services). The committee believed it was important to refer to the existing guidance here, and so adapted this recommendation to make it specific to the carer population.

Related to the recommendations for health and social care organisations

Evidence found that carers are often unaware of their own status, their rights, or where to seek help and information. The committee agreed it is the responsibility of organisations, trusts and practitioners to use all information, awareness and communication mechanisms available to them to disseminate information and awareness to carers. This recommendation is reinforced by the Care Act (2014) which places this onus on organisations and services. In the experience of the committee this would be most successful if relatable language and descriptions were used, so that carers would be more likely to recognise the messages as relevant to them. Each organisation or service would need to think about how best to reach their own target audiences and the committee included a list of ideas for ways this could be done (for example through publicity campaigns, digital communication or the development of partnerships with local community organisations and further education). [ID2, ID5, ID6]

The Care Act (2014) outlines the responsibility of organisations and services to identify and offer support to carers. No evidence was identified about how organisations can best promote this implementation, however the committee drafted 3 recommendations through informal consensus and on the basis of their expertise. They recommended that services and organisations consider nominating a ‘carers champion’ with responsibilities for helping to implement ways to identifying and offering support to carers. They also emphasised that services have an obligation to prioritise the identification of carers within their systems and processes. Finally, they emphasised the need for frontline staff to understand their responsibilities, under the Care Act (2014) in relation to identifying carers. [ID9]

Related to other topics within this guideline

Evidence from this review showed that primary care providers are open to ways to identify carers and then make sure they are offered information and support. The committee drew on these findings to draft a recommendation about nominating carer champions within a primary care setting or primary care network as one example of how to promote and offer services to carers. [ID9, ID10] The recommendation is found in the sub section of the guideline on ‘sharing information with carers’.

Cost effectiveness and resource use

Several of the recommendations contained important considerations for professionals to recognise and to be aware of, or suggested ways to optimise existing practice and better utilise the resources available. The committee considered these recommendations may improve the identification of carers but that they would not have significant cost implications.

Some recommendations may require training or re-training for staff, a re-think of the systems in place or changes in how the workload is distributed. This may have some resource implications but would depend on the current level of practice.

One recommendation suggested primary care providers or primary care networks could nominate a ‘carers champion’ as one means of promoting carers services. Evidence suggests primary care staff already wish to be proactive and try to develop systems to do this. The committee believed that the additional time and resources needed by one carer champion would be offset by freeing up other staff from the task – as a single system under one person would be more efficient and time-effective than several staff splitting it informally between their existing tasks.

The recommendation that organisations should ensure their policies and systems include a formal process for identifying carers is the one most likely to have significant cost implications for organisations, although this would depend to a large extent on current practice, which varies. However, as of 2014, this is mandated by the Care Act (2014) meaning that any necessary expenditure is a regulatory requirement. More recently, in 2019, ‘Supporting carers in general practice: a framework of quality markers’ was published with the aim of improving how general practice can better identify and support carers of all ages. Although the framework is not a mandatory requirement, the committee are aware that the quality markers are beginning to influence practice, which also suggests that the resource impact of this recommendation will further reduce as the quality markers all rolled out more widely, at least in so far as primary health is concerned.

Other factors the committee took into account

Throughout discussions the committee carefully considered the wording of the Care Act (2014) ensuring recommendations were complimentary and did not contradict its provisions.

The committee also considered some of the existing recommendations relating to identifying carers published in other NICE guidelines. These were generally aimed at specific sub-groups, usually with particular health conditions, although some of the recommendations were considered to be generally applicable. Once published the role of the current guideline would be to supersede these ‘non-specific’ recommendations and so the committee discussed what could be learned from them. While doing this the committee considered the wording of the recommendations closely. They also considered the applicability of the recommendations to the general carer population given the specific research and population contexts in which they had each been developed.

References

Bennett 2016

Bennett L. Care Act for carers: one year on. London; 2016: Carers Trust.

Carduff 2014

Carduff E, Finucane A, Kendall M, Jarvis A, Harrison N, Greenacre J, Murray SA. Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. BMC Fam Pract 2014;15:48.

Carduff 2016

Carduff E, Jarvis A, Highet G, Finucane A, Kendall M, Harrison N, Greenacre J, Murray SA. Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: a feasibility study. BMC Fam Pract 2016 11;17:18.

Appendices

Appendix A – Review protocols

Review protocol for review question: What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?

Table 3: Review protocol

Field (based on PRISMA-P)	Content
Review question	What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?
Type of review question	Qualitative
Objective of the review	This review aims to identify the factors facilitating or impeding the identification of carers, whether through self-identification or through health- and social-care professionals. The resulting recommendations are expected to assist local authorities, social care providers, voluntary organisations, healthcare providers, and other relevant stakeholders to implement the requirements of The Care Act 2014 for the identification of carers (including the implementation for strategies for engaging seldom heard groups).
Eligibility criteria – population/disease/condition/issue/domain	Adult carers who provide unpaid care for: • ≥ 1 adult(s); or • ≥ 1 young people aged 16 – 17 years with ongoing needs. Social- and health-care professionals.
Eligibility criteria – phenomenon of interest	Factors that facilitate or impede the identification of carers, as stipulated by The Care Act 2014, and that are related to: • self-identification of carers as carers; and • recognition and formal identification of carers by relevant stakeholders (for example, social and healthcare professionals, voluntary organisations, or local authorities). This might include formal initiatives such as: • Triangle of Care by the Carers' Trust • NHS England's Carers Tool Kit • Employers for Carers

Field (based on PRISMA-P)	Content
	• Royal College of GPs • Association of directors of adult social services in England (ADASS).
Eligibility criteria – comparator(s)/control or reference (gold) standard	N/A
Outcomes and prioritisation	Not relevant to a views and experiences question. Expected themes might include: • number of routes through which carers can be identified • level of support provided by professional or voluntary sector organisations • level of support provided to professional or voluntary sector organisations • insufficient service information • relevance of the information provided (for example, language used and cultural relevance) • not perceiving oneself as a carer when looking after a relative.
Eligibility criteria – study design	Qualitative studies (for example, studies that use interviews, focus groups, or observations)
Other inclusion exclusion criteria	Only studies conducted in the UK will be considered The following settings will be considered: • carers' own homes • social and healthcare settings in which adult carers provide care and support (including neighbourhoods and communities).
Proposed sensitivity/sub-group analysis, or meta-regression	Stratified analysis: • different types of carers based on specific cultural or ethnic groups, age groups, mutual carers • setting: primary or secondary care, and third sector • professional groups
Selection process – duplicate screening/selection/analysis	Dual screening will not be performed for this review question.
Data management (software)	NGA STAR will be used for generating bibliographies and citations, sifting studies, extracting data and for the quality appraisal of the included studies. A GRADE CERQual Microsoft Excel template will be used to record the overall quality of findings from the qualitative evidence. A Microsoft Excel template will also be used to record the findings of questionnaire surveys.

Field (based on PRISMA-P)	Content
Information sources – databases and dates	Sources to be searched: ASSIA, Embase, IBSS, Medline, Medline In-Process, PsycINFO, Sociological Abstracts, Social Services Abstracts, Social Policy and Practice Filters: Qualitative Standard animal/non-English language exclusion Limits: Date – from database inception
Identify if an update	This review question is not an update.
Author contacts	Developer: The National Guideline Alliance
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual 2014
Search strategy – for one database	For details please see appendix F of the guideline
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (evidence tables) or G (economic evidence tables) of the guideline.
Data items – define all variables to be collected	For details please see evidence tables in appendix D (evidence tables) or G (economic evidence tables) of the guideline.
Methods for assessing bias at outcome/study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual 2014 The confidence in the evidence extracted from the included studies will be evaluated for each theme using GRADE CERQual approach: https://www.cerqual.org/
Criteria for quantitative synthesis (where suitable)	For details please see section 6.4 of Developing NICE guidelines: the manual 2014
Methods for analysis – combining studies and exploring (in)consistency	For details please see the methods chapter of the guideline
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual 2014.
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual 2014

Field (based on PRISMA-P)	**Content**
Rationale/context – Current management	For details please see the introduction to the evidence review in the guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by The National Guideline Alliance and chaired by Mr. Phil Taverner in line with section 3 of Developing NICE guidelines: the manual. Staff from the National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods chapter of the guideline.
Sources of funding/support	The National Guideline Alliance is funded by NICE and hosted by The Royal College of Obstetricians and Gynaecologists
Name of sponsor	The National Guideline Alliance is funded by NICE and hosted by The Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds The National Guideline Alliance to develop guidelines for those working in the NHS, public health, and social care in England
PROSPERO registration number	Not registered in PROSPERO

ASSIA: Applied Social Sciences Index and Abstracts; CDSR: Cochrane Database of Systematic Reviews; DARE: Database of Abstracts of Reviews of Effects; IBSS: International Bibliography of the Social Science; GRADE: Grading of Recommendations Assessment, Development and Evaluation; GRADE CERQual: GRADE Confidence in the Evidence from Reviews of Qualitative research; N/A: not applicable; NICE: National Institute for Health and Care Excellence; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; PROSPERO: International prospective register of systematic reviews.

Appendix B – Literature search strategies

Literature search strategies for review question What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?

The search for this topic was last run on 9th January 2019.

Database: Embase, Medline, Medline Ahead of Print and In-Process & Other Non-Indexed Citations – OVID [Multifile]

#	Searches
1	caregiver/ use emez or caregivers/ use mesz, prem or caregivers/ use psyh or caregiver burden/ use psyh or (carer* or caregiv* or care giv*).ti,ab.
2	(functional assessment of care* environment or (face adj (approach* or assessment* or tool*)) or (face recording adj2 measurement system) or face risk profile*).tw.
3	(carer* support need* assessment tool* or csnat).tw.
4	start approach*.tw.
5	(r-outcome* or r outcome* or cisr outcome*).tw.
6	(howru or how ru or ((health confidence or personal wellbeing or personal wellbeing or service integration or selfcare or self care) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*))).tw.
7	((hcs or pws) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*)).tw.
8	(howrthey or howr they or how rthey or how r they or ((carer* wellbeing or carer* well being or carer* confidence) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*))).tw.
9	(howrwe or how rwe or ((work wellbeing or job confidence) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*))).tw.
10	((service integration or better care integration) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*)).tw.
11	((wws or jcs) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*)).tw.
12	(innovation readiness or innovation adoption or ((digital confidence or application rating) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*))).tw.
13	((arq or dcs) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*)).tw.
14	or/2-13

#	Searches
15	needs assessment/ use emez, mesz, prem, psyh or *health care need/ use emez or "health services needs and demand"/ use mesz
16	((carer* or caregiv* or care giv*) adj8 (assess* or selfassess*)).ti.
17	((social or social care) adj assessment).tw.
18	((assess* or selfassess*) adj2 need*).tw.
19	((assess* or selfassess*) adj2 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or subscale* or survey* or test* or tool*)).tw.
20	((carer* or caregiv* or care giv*) adj5 (assess* or selfasses* or (needs adj3 assess*) or risk assess*)).tw.
21	or/15-20
22	1 and (or/14,21)
23	limit 22 to English language
24	limit 23 to yr="2003 -current"
25	needs assessment/ use emez, mesz, prem, psyh or *health care need/ use emez or "health services needs and demand"/ use mesz or ((assess* or selfassess*) adj2 need*).tw.
26	(((identif* or identit* or recogni* or selfidentif* or unidentif*) adj5 (carer* or caregiver* or care giv* or care or caring)) or ((identif* or identit* or recogni* or selfidentif* or unidentif*) adj5 need* adj5 (carer* or caregiver* or care giv* or care or caring)) or carer* pass* or ((early or personal) adj2 identif*) or hidden carer* or signpost*).ti,ab
27	((access* or barrier* or challeng* or difficult* or facilitator* or imped* or strateg* or local authorit* or organi?ation* or practitioner* or professional* or worker*) adj3 (identif* or identit* or recogni* or unidentif* or selfidentif*) adj7 (carer* or caregiver* or care giv* or care or caring)).ti,ab.
28	(question* adj5 (identif* or identit* or recogni* or selfidentif* or unidentif*) adj5 (carer* or caregiver* or care giv* or care or caring)).ti,ab.
29	or/25-29
30	1 and 29
31	limit 30 to English language
32	interviews as topic/ or qualitative research/
33	32 use emez
34	interviews as topic/ or anthropology, cultural/ or focus groups/ or exp tape recording/ or personal narrative/ or narration/ or nursing methodology research/ or observation/ or qualitative research/ or sampling studies/ or cluster analysis/ or videodisc recording/
35	34 use mesz, prem
36	cluster analysis/ or "culture (anthropological)" or interviews/ or narratives/ or observation methods/ or qualitative research/ or tape recorders/
37	36 use psyh
38	(interview* or action research or audiorecord* or ((audio or tape or video*) adj5 record*) or colaizzi* or (constant adj (comparative or comparison)) or content analy* or critical social* or (data adj1 saturat*) or discourse analys?s or emic or ethical enquiry or ethno* or etic or experiences or fieldnote* or (field adj (note* or record* or stud* or research)) or (focus adj4 (group* or sampl*)) or giorgi* or glaser or (grounded adj (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or human science or husserl* or ((life or lived) adj experience*) or maximum variation or merleau or narrat* or ((participant* or nonparticipant*) adj3 observ*) or ((philosophical or social) adj research*) or (pilot testing and survey) or purpos* sampl* or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or

#	Searches
	structured categor* or tape record* or taperecord* or testimon* or (thematic* adj3 analys*) or themes or theoretical sampl* or unstructured categor* or van kaam* or van manen or videorecord* or video record* or videotap* or video tap*).ti,ab.
39	(cross case analys* or eppi approach or metaethno* or meta ethno* or metanarrative* or meta narrative* or meta overview or metaoverview or metastud* or meta stud* or metasummar* or meta summar* or qualitative overview* or ((critical interpretative or evidence or meta or mixed methods or multilevel or multi level or narrative or parallel or realist) adj synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)).ti,ab,hw,pt.
40	or/33,35,37-39
41	"*attitude to health"/ or *consumer/ or *consumer attitude/ or *health care quality/ or *patient attitude/ or *patient compliance/ or *patient preference/ or *patient satisfaction/
42	41 use emez
43	*attitude to health/ or comprehensive health care/ or exp consumer participation/ or exp consumer satisfaction/ or "patient acceptance of health care"/ or patient care management/ or patient centered care/ or exp patient compliance/ or patient satisfaction/ or "quality of health care"/
44	43 use mesz, prem
45	exp client attitudes/ or client satisfaction/ or consumer attitudes/ or exp health attitudes/ or exp consumer attitudes/ or patient satisfaction/ or treatment compliance/
46	45 use psyh
47	((carer* or caregiv* or care giv* or famil* or friend* or mother* or father* or son or daughter*) adj3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or buy in* or choice* or co?operat* or co operat* or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or (perception* not speech perception) or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry)).ti,ab.
48	((consumer or patient) adj2 (focus* or centered or centred)).ti,ab.
49	or/42,44,46-48
50	or/40,49
59	meta-analysis/
60	meta-analysis as topic/ or systematic reviews as topic/
61	“systematic review”/
62	meta-analysis/
63	(meta analy* or metanaly* or metaanaly*).ti,ab.
64	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
65	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
66	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
67	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
68	(search* adj4 literature).ab.
69	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
70	cochrane.jw.
71	((pool* or combined) adj2 (data or trials or studies or results)).ab.
72	or/59-60,63,65-71 use mesz, prem
73	(or/61-64,66-71) use emez

#	Searches
74	meta analysis/ use psyh or or/63-71 use psyh
75	(cross case analys* or eppi approach or metaethno* or meta ethno* or metanarrative* or meta narrative* or meta overview or metaoverview or metastud* or meta stud* or metasummar* or meta summar* or qualitative overview* or ((critical interpretative or evidence or meta or mixed methods or multilevel or multi level or narrative or parallel or realist) adj synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or meta anal* or synthes* or systematic review* or qualitativ*)).ti,ab,hw,pt.
76	or/72-75
77	united kingdom/
78	(national health service* or nhs*).ti,ab,in,ad.
79	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
80	(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,jw,in,ad.
81	(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.
82	(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.
83	(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.
84	(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.
85	or/77-84 use emez
86	exp united kingdom/
87	(national health service* or nhs*).ti,ab,in.
88	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.

#	Searches
89	(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,jw,in.
90	(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.
91	(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.
92	(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.
93	(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.
94	or/86-93
95	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/)
96	94 not 95
97	96 use mesz, prem
98	(national health service* or nhs*).ti,ab,in,cq.
99	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
100	(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,cq.
101	(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

#	Searches
	"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,cq.
102	(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,cq.
103	(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,cq.
104	(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,cq.
105	or/98-104 use psyh
106	or/85,97,105
107	or/24,31 and or/50,76 and 106

Database: Social Policy and Practice, Health Management Information Consortium - OVID

#	Searches
1	(carer* or caregiv* or care giv*).ti,ab.
2	(functional assessment of care* environment or (face adj (approach* or assessment* or tool*)) or (face recording adj2 measurement system) or face risk profile*).tw.
3	(carer* support need* assessment tool* or csnat).tw.
4	start approach*.tw.
5	(r-outcome* or r outcome* or cisr outcome*).tw.
6	(howru or how ru or ((health confidence or personal wellbeing or personal well being or service integration or selfcare or self care) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*))).tw.
7	((hcs or pws) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*)).tw.
8	(howrthey or howr they or how rthey or how r they or ((carer* wellbeing or carer* well being or carer* confidence) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*))).tw.
9	(howrwe or how rwe or ((work wellbeing or job confidence) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*))).tw.
10	((service integration or better care integration) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*)).tw.
11	((wws or jcs) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*)).tw.
12	(innovation readiness or innovation adoption or ((digital confidence or application rating) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*))).tw.
13	((arq or dcs) adj3 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or (self adj (assess* or report*)) or subscale* or survey* or test* or tool*)).tw.
14	or/2-13
15	((carer* or caregiv* or care giv*) adj8 (assess* or selfassess*)).ti.
16	((social or social care) adj assessment).tw.
17	((assess* or selfassess*) adj2 need*).tw.
18	((assess* or selfassess*) adj2 (index or instrument* or interview* or inventor* or item* or measure*1 or questionnaire* or rate* or rating or scale* or score* or screen* or subscale* or survey* or test* or tool*)).tw.
19	((carer* or caregiv* or care giv*) adj5 (assess* or selfasses* or (needs adj3 assess*) or risk assess*)).tw.
20	or/15-19
21	1 and (or/14,20)
22	limit 21 to english language
23	limit 22 to yr="2003 -current"

24	((assess* or selfassess*) adj2 need*).tw.
25	(((identif* or identit* or recogni* or selfidentif* or unidentif*) adj5 (carer* or caregiver* or care giv* or care or caring)) or ((identif* or identit* or recogni* or selfidentif* or unidentif*) adj5 need* adj5 (carer* or caregiver* or care giv* or care or caring)) or carer* pass* or ((early or personal) adj2 identif*) or hidden carer* or signpost*).ti,ab
26	((access* or barrier* or challeng* or difficult* or facilitator* or imped* or strateg* or local authorit* or organi?ation* or practitioner* or professional* or worker*) adj3 (identif* or identit* or recogni* or unidentif* or selfidentif*) adj7 (carer* or caregiver* or care giv* or care or caring)).ti,ab.
27	(question* adj5 (identif* or identit* or recogni* or selfidentif* or unidentif*) adj5 (carer* or caregiver* or care giv* or care or caring)).ti,ab.
28	or/24-27
29	1 and 28
31	limit 29 to english language
32	or/23,31

Database: Social Services Abstracts, Sociological Abstracts, International Bibliography for Social Sciences (IBSS), Applied Social Sciences Index and Abstracts (ASSIA) - Proquest

#	Searches
s1	noft (carer* or caregiv* or “care giv*”)
s2	noft (“functional assessment of care* environment” or (face near/1 (approach* or assessment* or tool*)) or (“face recording” near/2 “measurement system”) or “face risk profile*”)
s3	noft (“carer* support need* assessment tool*” or csnat)
s4	noft (“start approach*”)
s5	noft (“r-outcome*” or “r outcome*” or “cisr outcome*”)
s6	noft (howru or “how ru” or ((“health confidence” or “personal wellbeing” or “personal well being” or “service integration” or selfcare or “self care”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*)))
s7	noft ((hcs or pws) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*))
s8	noft (howrthey or “howr they” or “how rthey” or “how r they” or ((carer* wellbeing or “carer* well being” or “carer* confidence”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*)))
s9	noft (howrwe or “how rwe” or ((“work wellbeing” or “job confidence”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*)))
s10	noft ((“service integration” or “better care integration”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*))
s11	noft ((wws or jcs) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*))

#	Searches
s12	noft (“innovation readiness” or “innovation adoption” or ((“digital confidence” or “application rating”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*)))
s13	noft ((arq or dcs) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*))
s14	s2 or s3 or s4 or s5 or s6 or s7 or s8 or s9 or s10 or s11 or s12 or s13
s15	noft ((carer* or caregiv* or “care giv*”) near/5 (assess* or selfasses* or risk assess*))
s16	noft ((carer* or caregiv* or “care giv*”) near/8 (assess* or selfassess*))
s17	noft ((social or “social care”) near/1 assessment)
s18	noft ((assess* or selfassess*) near/2 need*)
s19	noft ((assess* or selfassess*) near/2 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or subscale* or survey* or test* or tool*))
s20	noft (need* near/3 assess*)
s21	s15 or s16 or s17 or s18 or s19 or s20
s22	s1 and (s14 or s21)
s23	(s1 and (s14 or s21)) limits applied
s24	noft ((assess* or selfassess*) adj2 need*)
s25	noft (((identif* or identit* or recogni* or selfidentif* or unidentif*) near/5 (carer* or caregiver* or “care giv*” or care or caring)) or ((identif* or identit* or recogni* or selfidentif* or unidentif*) near/5 need* near/5 (carer* or caregiver* or “care giv*” or care or caring)) or “carer* pass*” or ((early or personal) near/2 identif*) or “hidden carer*” or signpost*)
s26	noft ((access* or barrier* or challeng* or difficult* or facilitator* or imped* or strateg* or “local authorit*” or organisation* or organization* or practitioner* or professional* or worker*) near/3 (identif* or identit* or recogni* or unidentif* or selfidentif*) near/7 (carer* or caregiver* or “care giv*” or care or caring))
s27	noft (question* near/5 (identif* or identit* or recogni* or selfidentif* or unidentif*) near/5 (carer* or caregiver* or “care giv*” or care or caring))
s28	s24 or s25 or s26 or s27
s29	s1 and s28
s30	s1 and s28 limits applied
s31	noft (interview* or “action research” or audiorecord* or ((audio or tape or video*) near/5 record*) or colaizzi* or (constant near/1 (comparative or comparison)) or content analy* or “critical social*” or (data near/1 saturat*) or “discourse analysis” or “discourse analyses” or emic or “ethical enquiry” or ethno* or etic or experiences or fieldnote* or (field near/1 (note* or record* or stud* or research)) or (focus near/4 (group* or sampl*)) or giorgi* or glaser or (grounded near/1 (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or “human science” or husserl* or ((life or lived) near/1 experience*) or “maximum variation” or merleau or narrat* or ((participant* or nonparticipant*) near/3 observ*) or ((philosophical or social) near/1 research*) or (“pilot testing” and survey) or “purpos* sampl*” or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or “structured categor*” or “tape record*” or taperecord* or testimon* or (thematic* near/3 analys*) or themes or “theoretical sampl*” or “unstructured categor*” or “van kaam*” or “van manen” or videorecord* or “video record*” or videotap* or “video tap*”)
s32	noft (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or

#	Searches
	metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) near/1 synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or “meta anal*” or synthes* or “systematic review*”))
s33	noft ((carer* or caregiv* or “care giv*” or famil* or friend* or mother* or father* or son or daughter*) near/3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or “buy in*” or choice* or cooperat* or “co operat*” or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry))
s34	noft ((consumer or patient) near/2 (focus* or centered or centred))
s35	s31 or s32 or s33 or s34
s36	noft (“meta analy*” or metanaly* or metaanaly*)
s37	noft ((systematic or evidence) near/2 (review* or overview*))
s38	noft (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) near/1 synthes*) or metasynthes*)
s39	s36 or s37 or s38
s40	s35 or s39
s41	(s23 or s30) and s40

Database: CINAHL – EBSCO

1 (mh "caregivers")
2 tx (carer* or caregiv* or “care giv*”)
3 #1 or #2
4 tx (“functional assessment of care* environment” or (face near/1 (approach* or assessment* or tool*)) or (“face recording” near/2 “measurement system”) or “face risk profile*”)
5 tx (“carer* support need* assessment tool*” or csnat)
6 tx “start approach*”
7 tx (“r-outcome*” or ”r outcome*” or “cisr outcome*”)
8 tx (howru or “how ru” or ((“health confidence” or “personal wellbeing” or “personal well being” or “service integration” or selfcare or “self care”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*)))
9 tx ((hcs or pws) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*))
10 tx (howrthey or “howr they” or “how rthey” or “how r they” or ((“carer* wellbeing” or “carer* well being” or “carer* confidence”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*)))
11 tx (howrwe or “how rwe” or ((“work wellbeing” or “job confidence”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*)))

12 tx ((“service integration” or “better care integration”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*))

13 tx ((wws or jcs) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*))

14 tx (“innovation readiness” or “innovation adoption” or ((“digital confidence” or “application rating”) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*)))

15 tx ((arq or dcs) near/3 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or (self near/1 (assess* or report*)) or subscale* or survey* or test* or tool*))

16 #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15

17 (mh "needs assessment") or (mh "health services needs and demand")

18 ti ((carer* or caregiv* or “care giv*”) near/8 (assess* or selfassess*))

19 tx ((social or “social care”) near/1 assessment)

20 tx ((assess* or selfassess*) near/2 need*)

21 tx ((assess* or selfassess*) near/2 (index or instrument* or interview* or inventor* or item* or measure* or questionnaire* or rate* or rating or scale* or score* or screen* or subscale* or survey* or test* or tool*))

22 tx ((carer* or caregiv* or “care giv*”) near/5 (assess* or selfasses* or (needs near/3 assess*) or risk assess*))

23 #17 or #18 or #19 or #20 or #21 or #22

24 #3 and (#16 or #23)

25 limiters - publication year: 2003-2019

26 (mh "needs assessment") or (mh "health services needs and demand")

27 tx (((identif* or identit* or recogni* or selfidentif* or unidentif*) near/5 (carer* or caregiver* or “care giv*” or care or caring)) or ((identif* or identit* or recogni* or selfidentif* or unidentif*) near/5 need* near/5 (carer* or caregiver* or “care giv*” or care or caring)) or “carer* pass*” or ((early or personal) near/2 identif*) or “hidden carer*” or signpost* or ((assess* or selfassess*) near/2 need*))

28 tx ((access* or barrier* or challeng* or difficult* or facilitator* or imped* or strateg* or “local authorit*” or organisation* or organization* or practitioner* or professional* or worker*) near/3 (identif* or identit* or recogni* or unidentif* or selfidentif*) near/7 (carer* or caregiver* or “care giv*” or care or caring))

29 tx (question* near/5 (identif* or identit* or recogni* or selfidentif* or unidentif*) near/5 (carer* or caregiver* or “care giv*” or care or caring))

30 #26 or #27 or #28 or #29

31 #3 and #30

32 #25 or #31

33 (mh "cluster analysis") or (mh "qualitative studies") or (mh "observational methods") or (mh "narratives") or (mh "audiorecording") or (mh "videorecording") or (mh "focus groups") or (mh "anthropology, cultural") or (mh "structured interview") or (mh "unstructured interview") or (mh "semi-structured interview")

34 tx (interview* or “action research” or audiorecord* or ((audio or tape or video*) n5 record*) or colaizzi* or (constant n1 (comparative or comparison)) or “content analy*” or “critical social*” or (data n1 saturat*) or “discourse analysis” or “discourse analyses” or emic or “ethical enquiry” or ethno* or etic or experiences or fieldnote* or (field n1 (note* or record* or stud* or research)) or (focus n4 (group* or sampl*)) or giorgi* or glaser or (grounded n1 (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or “human science” or husserl* or ((life or lived) n1 experience*) or “maximum variation” or merleau or narrat* or ((participant* or nonparticipant*) n1 observ*) or ((philosophical or social) n1 research*) or (“pilot testing” and survey) or “purpos* sampl*” or qualitative* or ricoeur or

semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or structured categor* or ”tape record*” or taperecord* or testimon* or (thematic* n1 analys*) or themes or “theoretical sampl*” or “unstructured categor*” or “van kaam*” or “van manen” or videorecord* or “video record*” or videotap* or “video tap*”)

35 tx (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) n1 synthes*) or metasynthes*) or mw (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)) or tx (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*))

36 (mh "attitude to health") or (mh "consumer participation") or (mh "consumer satisfaction+") or (mh "patient centered care") or (mh "patient compliance") or (mh "quality of health care")

37 tx ((carer* or caregiv* or “care giv*” or famil* or friend* or mother* or father* or son or daughter*) n3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or “buy in*” or choice* or cooperat* or “co operat*” or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or (perception* not “speech perception”) or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry))

38 tx ((consumer or patient) n2 (focus* or centered or centred))

39 #33 or #34 or #35 or #36 or #37 or #38

40 (mh "clinical trials") or (mh "randomized controlled trials") or ab (placebo or randomised or randomized or randomly) or ti (trial)

41 (mh "meta analysis")

42 (mh "systematic review")

43 tx (“meta analy*” or metanaly* or metaanaly*)

44 tx ((systematic* or evidence*) n2 (review* or overview*))

45 tx (“reference list*” or bibliograph* or “hand search*” or “manual search*” or “relevant journals”)

46 tx (“search strategy” or “search criteria” or “systematic search” or “study selection” or “data extraction”)

47 (search* n4 literature)

48 tx (medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit)

49 so cochrane

50 tx ((pool* or combined) n2 (data or trials or studies or results))

51 tx (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) n1 synthes*) or metasynthes*) or mw (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)) or tx (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*))

52 #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51

53 #39 or #40 or #52

54 #32 and #53

Non-database searches

In addition to the above databases, searches were undertaken in a range of websites and other relevant sources:

1. Agency for Healthcare Research and Quality
2. Care Quality Commission
3. Carer Research and Knowledge Exchange Network
4. Carers Trust
5. Carers UK
6. Centre for Mental Health
7. Centre for International Research on Care, Labour and Equalities
8. Department of Health
9. Department for Work and Pensions
10. Directors of Adult Social Services
11. Equality and Human Rights Commission
12. Eurocarers
13. Google UK
14. Health and Social Care Information Centre
15. Health in Wales
16. Healthcare Improvement Scotland
17. Healthcare Quality Improvement Partnership
18. Institute for Public Policy Research
19. Joseph Rowntree Foundation
20. Kings Fund
21. National Audit Office
22. New Policy Institute
23. NHS England
24. NHS Improving Quality
25. Office for National Statistics
26. Research in Practice
27. Royal College of General Practitioners
28. Royal College of Nursing
29. Royal College of Physicians
30. Royal College of Psychiatrists
31. SIGN
32. Turning Point
33. Welsh Government

Health economics

Database: Embase, Medline, Medline Ahead of Print and In-Process & Other Non-Indexed Citations – OVID [Multifile]

#	Searches
1	caregiver/ use emez or caregivers/ use mesz, prem
2	(carer* or caregiv* or care giv*).ti,ab.
3	1 or 2
4	budget/ or exp economic evaluation/ or exp fee/ or funding/ or health economics/ or exp health care cost/
5	4 use emez
6	exp budgets/ or exp "costs and cost analysis"/ or economics, nursing/ or economics, pharmaceutical/ or economics/ or exp economics, hospital/ or exp economics, medical/ or exp "fees and charges"/ or value of life/
7	6 use mesz

#	Searches
8	budget*.ti,ab.
9	cost*.ti.
10	(economic* or pharmaco?economic*).ti.
11	(price* or pricing*).ti,ab.
12	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
13	(financ* or fee or fees).ti,ab.
14	(value adj2 (money or monetary)).ti,ab.
15	or/5,7-14
16	3 and 15

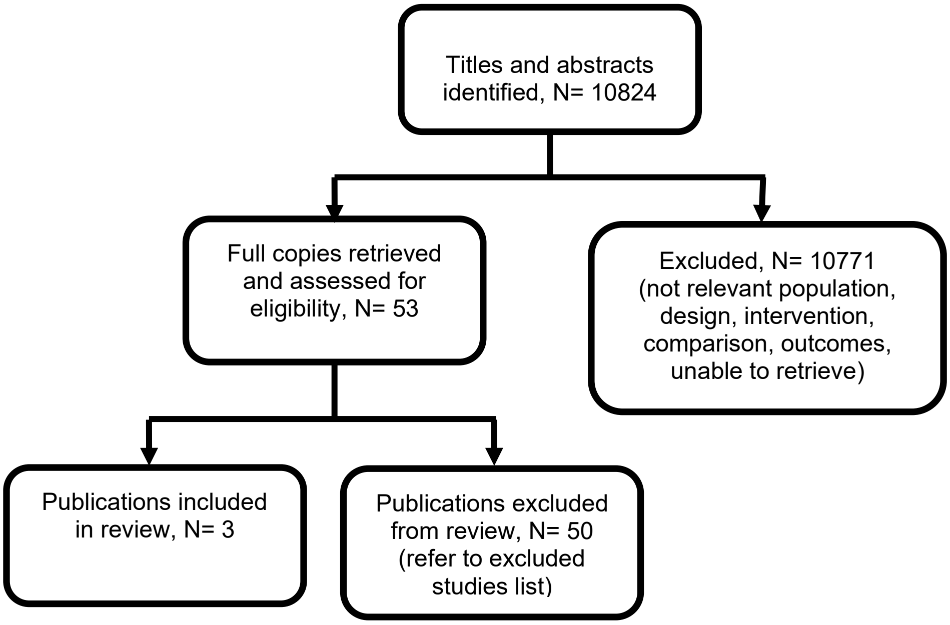
Database: Cochrane Library – Wiley

#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or “care giv*”):ti,ab,kw
3	#1 or #2

Appendix C – Evidence study selection

Study selection for review question What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?

Figure 2: Study selection flow chart



Appendix D – Evidence tables

Evidence tables for review question: What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?

Table 4: Evidence tables

Study details	Participants	Interventions	Methods	Themes and findings	Comments
Full citation Bennett Laura, Care Act for carers: one year on **Ref Id** 818263 **Country/ies where the study was carried out** UK - N/R **Study type** mixed-methods original research (non peer-reviewed) **Aim of the study** The aims of this mixed-methods research were to explore the views of carers about how they felt the Care Act was working for them a year after its implementation in relation to the recognition, formal identification and self-identification of themselves as carers	**Sample size** Carers=unclear (N=624 carers who responded, N=427 carers for which is reported age, N=438 carers for which is reported gender) Health and social care professionals=unclear (N=624 carers who responded, N=427 carers for which is reported age, N=438 carers for which is reported gender) **Characteristics** **Carer** Carer age = Range, years: 16 to 85 Carer gender (M/F)= 107/329 "Relationship to care recipient"= N/R **Person being cared for** Person being cared for (condition)= Unclear (mixed	**Phenomenon of interest (as reported in the study)**: Identifying and reaching out to carers **Phenomenon of interest (according to the protocol)**: Recognition, formal identification and self-identification of carers	**Recruitment strategy**: It is unclear whether the sample was selected purposively or was a self-selected sample. **Data collection & analysis**: Data were collected through online and offline survey, and also written semi-structured questionnaires from carers, local carers services, local authorities, local NHS and other charities involved in providing support to carers about how they felt the Care Act was working for carers, a year after implementation. No further details on data collection are given. No details are reported about the data analysis.	• What has gone well? - Identifying carers and assessment . • What needs to improve? - Identifying and reaching out to carers.	**Limitations (assessed using the CASP Checklist for qualitative research)** • Q1: Was there a clear statement of the aims of the research? – Yes. • Q2: Was a qualitative methodology appropriate? – Yes. • Q3 Was the research design appropriate to address the aims of the research? - unclear: not enough information on the qualitative study design justification. • Q4: Was the recruitment strategy appropriate to the aims of the research? - unclear: not enough information were provided on the methods and rationale of the recruitment approach. • Q5: Were the data collected in a way that addressed the research

Study details	Participants	Interventions	Methods	Themes and findings	Comments
Study dates **Publication date**: 2016 **Data collection**: February - April 2016 **Source of funding** Carers Trust, Pears Foundation, University of Birmingham	conditions, no single specific condition) **Inclusion criteria** N/R **Exclusion criteria** N/R				issue? - unclear: It is unclear whether saturation has been achieved in the analysis of data gathered from the interviews. • Q6: Has the relationship between researcher and participants been adequately considered? - unclear: The role of the authors is unclearly reported (in relation to potential bias/influence during data analysis, data collection, or carers' recruitment). • Q7: Have ethical issues been taken into consideration? – Yes. • Q8: Was the data analysis sufficiently rigorous? - Unclear: no sufficient details on data analysis methods are reported. • Q9: Is there a clear statement of findings? – Yes. • Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) – Yes. **Overall methodological limitations** - Major

Study details	Participants	Interventions	Methods	Themes and findings	Comments
Full citation Carduff, E., Jarvis, A., Highet, G., Finucane, A., Kendall, M., Harrison, N., Greenacre, J., Murray, S. A., Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: a feasibility study, BMC family practice, 17, 18, 2016 **Ref Id** 724931 **Country/ies where the study was carried out** Scotland **Study type** mixed-methods original research (peer-reviewed) **Aim of the study** The aims of this mixed-methods research were to explore the views of carers of people with palliative and supportive care needs in relation to the recognition, a formal identification intervention, and self-identification of themselves as carers	**Sample size** N=11 carers N=8 health and social care professionals **Characteristics** **Carer** Carer age = mean - range (years): 74 - 58 to 86 Carer gender (M/F)= 4/7 "Relationship to care recipient"= parents (n): 0; spouses (n): 8; daughters-sons (n): 1; sibling (n): 2; friends (n): 0; others-N/R (n): 0 **Person being cared for** Person being cared for (condition)= Unclear (no condition specific) **Inclusion criteria** 1) practices in where the carers identification (N=4) were selected and recruited to reflect heterogeneity in practice size and demographics (These practices were thought to be 'carer aware', but that there was room for improvement in terms of identification and support) 2) further details on the recruitment process were not reported	**Phenomenon of interest (as reported in the study)**: Identifying and supporting carers **Phenomenon of interest (according to the protocol)**: Recognition, formal identification and self-identification of carers	**Recruitment strategy**: 4 general practices were recruited. Each practice was recruited purposively to reflect heterogeneity in practice size and demographics. These practices identified a 'carer liaison' person to take the lead in identifying carers. The practice manager and GPs for each practice were approached to discuss how the study would work and consulted them about the intervention before finalising the model. The intervention lasted 12 months in each practice, and aimed to identify, assess and support carers of people with supportive and palliative care needs in primary care. **Data collection & analysis**: Data were collected through semi-structured interviews. The carer interviews were conducted in the carer's own home or by	• The acceptability of the intervention – carers. • The acceptability of the intervention – professionals.	**Limitations (assessed using the CASP Checklist for qualitative research)** • Q1: Was there a clear statement of the aims of the research? – Yes. • Q2: Was a qualitative methodology appropriate? – Yes. • Q3 Was the research design appropriate to address the aims of the research? – Yes. • Q4: Was the recruitment strategy appropriate to the aims of the research? – Yes. • Q5: Were the data collected in a way that addressed the research issue? - Unclear: Theoretical sufficiency/ saturation of data has not been discussed. • Q6: Has the relationship between researcher and participants been adequately considered? – Yes. • Q7: Have ethical issues been taken into consideration? – Yes. • Q8: Was the data analysis sufficiently rigorous? – Yes.

Study details	Participants	Interventions	Methods	Themes and findings	Comments
Study dates **Publication date**: 2016 **Data collection**: N/R **Source of funding** Dimbleby Marie Curie Cancer Care Research Fund (Grant number DCMC-RF-12-06).	**Exclusion criteria** N/R (look at the inclusion criteria)		telephone. All 4 carer liaison interviews were conducted in the GP practices. Telephone interviews were conducted with GPs. All interviews were audio-taped and transcribed. The analysis used the thematic approach. Validity was ensured by data triangulation (carers and professionals) and by running a stakeholder workshop to discuss, formulate and disseminate the key findings with 21 healthcare professionals, academics and carers who would be affected by the findings and the formal identification intervention.		- Q9: Is there a clear statement of findings? – Yes. - Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) – Yes. **Overall methodological limitations** – Minor.
Full citation Carduff, E., Finucane, A., Kendall, M., Jarvis, A., Harrison, N., Greenacre, J., Murray, S. A., Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating	**Sample size** N=15 carers N=8 health and social care professionals **Characteristics** **Carer** Carer age = Range, years: N/R Carer gender (M/F)= 3/12	**Phenomenon of interest (as reported in the study)**: Identifying carers in primary care: barriers and facilitators **Phenomenon of interest (according to the protocol)**: Recognition,	**Recruitment strategy**: A convenience sample of carers were recruited through a local carer organisation (for example by a local carer third sector organisation; from the local hospice; and	- Barriers to carer identification - Caring as a gradual process: Identifying with the term 'carer'	**Limitations (assessed using the CASP Checklist for qualitative research)** - Q1: Was there a clear statement of the aims of the research? – Yes. - Q2: Was a qualitative methodology appropriate? – Yes.

Study details	Participants	Interventions	Methods	Themes and findings	Comments
three data sources, BMC family practice, 15, 48, 2014 **Ref Id** 721175 **Country/ies where the study was carried out** Scotland **Study type** qualitative original research (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore the views of carers of people towards the end of life in primary care in relation to the recognition, formal identification and self-identification of their role as carers **Study dates** **Publication date**: 2016 **Data collection**: N/R **Source of funding** Dimbleby Marie Curie Cancer Care Research Fund (Grant number DCMC-RF-12-06).	"Relationship to care recipient"= parents (n): 0; spouses (n): 8; daughters-sons (n): 7; sibling (n): 0; friends (n): 0; others-N/R (n): 0 **Person being cared for** Person being cared for (condition)= Unclear (no condition specific) **Inclusion criteria** N/R **Exclusion criteria** N/R (look at the inclusion criteria)	formal identification and self-identification of carers	through specialist nurses at the local teaching hospital). Their experiences may have differed from that of carers not in contact with carer agencies. **Data collection & analysis**: Data were collected through 5 focus groups with carers and health professionals to develop an in-depth understanding of identification and support-seeking in the primary care context. All focus group discussions were audio-taped and transcribed. Specific focus was given to the barriers to identification, assessment and support, and to the organisation of services. Analysis of the carer focus groups also considered the caregiving journey, which allowed to reflect on transition points, for example when the carer felt they took on the caregiving role. A	• Barriers to carer identification - Caring as a gradual process: Changing relationships in the context of caring. • Barriers to carer identification - Engulfed by the caring role: Managing competing demands. • Barriers to carer identification - The role of primary care in legitimising need: Role ambiguity. • Barriers to carer identification - The role of primary	• Q3 Was the research design appropriate to address the aims of the research? – Yes. • Q4: Was the recruitment strategy appropriate to the aims of the research? - no: self-selected study sample. • Q5: Were the data collected in a way that addressed the research issue? - unclear: It is unclear whether saturation has been achieved in the analysis of data gathered from the interviews. • Q6: Has the relationship between researcher and participants been adequately considered? – Yes. • Q7: Have ethical issues been taken into consideration? – Yes. • Q8: Was the data analysis sufficiently rigorous? – Yes. • Q9: Is there a clear statement of findings? – Yes. • Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) – Yes.

Study details	Participants	Interventions	Methods	Themes and findings	Comments
			constructionist perspective to analysis of data was adopted, where attention was paid to areas of agreement and disagreement within the groups. Validity of findings was assessed by triangulating the data: findings from the 3 sources were compared, contrasted and corroborated (literature review, stakeholder workshop, and focus group)	care in legitimising need: Communication.	**Overall methodological limitations** – Unclear due to lack of methodological information given.

F: Female; M: Male; N: Number; N/R: not reported

Appendix E – Forest plots

No meta-analysis was undertaken for this review and so there are no forest plots.

Appendix F – GRADE CERQual tables

GRADE tables for review question: What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?

Table 5: Summary of evidence (GRADE-CERQual), ID Theme 1. Self-identification by carers as carers – factors leading to the gradual realisation of being a carer

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
ID1 Noticing that the relationship with the person they care for has changed							
1 (Carduff 2014)	1: focus groups	The transition into caring is often a gradual process, however at some point the carer realises that the nature of the relationship with the person they care for has shifted. The person they care for is no longer independent but reliant on them and this may be a big role change or role reversal from before.	Moderate concerns[1]	Minor concerns	Moderate concerns[3]	Serious concerns[5]	VERY LOW
ID2 The carer's self-perception may be disrupted by the views of the person they care for							
1 (Carduff 2014)	1: focus groups	Carers may not see themselves as a carer if the person they are supporting does not acknowledge or recognise that they are being cared for.	Moderate concerns[1]	Moderate concerns[2]	Moderate concerns[3]	Serious concerns[5]	VERY LOW
ID3 Noticing that other social relationships have changed							
2 (Carduff 2014, Carduff 2016)	1: focus groups, 1: semi-structured interviews	Interactions and relationships with other people including friends, spouses and other relatives may change and decline, as carers have less time to put in to relationships and pursue interests outside of their home and their care role.	Moderate concerns[1]	Minor concerns	Minor concerns	Moderate concerns[4]	LOW
ID4 Having to make decisions about employment							
1 (Carduff 2014)	1: focus groups	The caring role often strains the carer's existing roles - and work status in particular may need to	Moderate concerns[1]	Minor concerns	Minor concerns	Serious concerns[5]	VERY LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		be reconsidered. The carer may receive conflicting messages from different sources about whether to do this, and may also be influenced by the wish to spend time with the person they care for before they die.					

1 Evidence was downgraded because of methodological limitations, as Carduff 2014 had some ambiguity in the reporting of data collection methods
2 Evidence was downgraded for coherence of findings, as there was some divergence in the experiences reported by carers about whether this occurred
3 Evidence was downgraded for applicability, as the findings were only reported by people who care for somebody living with dementia

4 Evidence was downgraded by 1 due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)
5 Evidence was downgraded by 2 due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Part II. Identification of carers by health- and social-care professionals

Table 6: Summary of evidence (GRADE-CERQual), ID Theme 2: Identification of carers by health and social-care professionals – carers don't identify themselves to professionals

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
ID5 Carers often don't know that they have a right to recognition and support							
1 (Bennett 2016)	1: survey questionnaire	Carers may be aware of the role and strain they are under, but not aware that recognition and support are available to them if they make themselves known to several professional sources.	Serious concerns[1]	Moderate concerns[3]	Minor concerns	Serious concerns[4]	VERY LOW
ID6 General Practitioners say carers don't see them as a contact point for support							
1 (Carduff 2014)	1: focus groups	GPs believe that offering support to carers is part of their role, however carers see them as being only for 'medical' queries or problems related to the person they are supporting.	Moderate concerns[2]	Minor concerns	Minor concerns	Serious concerns[4]	VERY LOW

1 Evidence was downgraded because of several methodological limitations in the Bennett 2016 survey, including unclear recruitment strategy, unclear data collection methods and unclear data analysis

2 Evidence was downgraded because of methodological limitations, as Carduff 2014 had some ambiguity in the reporting of data collection methods
3 Evidence was downgraded for coherence of findings, as there was some divergence in the experiences reported by carers about whether this occurred
4 Evidence was downgraded by 2 due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 7: Summary of evidence (GRADE-CERQual), ID Theme 3. Identification of carers by health and social-care professionals – acceptability of identification and formal assessment

Study information		**Description of Theme or Finding**	**CERQUAL Quality Assessment**				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
ID7 Carers appreciate being recognised and offered support							
2 (Bennett 2016, Carduff 2016)	1: survey questionnaire, 1: semi-structured interviews	Being recognised by a professional and asked about their needs and how they're coping is a relieving experience for carers and makes them feel valued.	Moderate concerns[1]	Minor concerns	Minor concerns	Moderate concerns[3]	LOW
ID8 Some carers have positive experiences of being formally assessed							
1 (Bennett 2016)	1: survey questionnaire	Carers appreciate formal carer assessments (and periodical reassessments) when they are done comprehensively and competently. They make carers feel valued, and able to discuss how they're coping and what they need.	Serious concerns[1]	Moderate concerns[2]	Minor concerns	Serious concerns[4]	VERY LOW

1 Evidence was downgraded because of several methodological limitations in the Bennett 2016 survey, including unclear recruitment strategy, unclear data collection methods and unclear data analysis
2 3 Evidence was downgraded for coherence of findings, as there was some divergence in the experiences reported by carers about whether this was the case
3 Evidence was downgraded by 1 due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)
4 Evidence was downgraded by 2 due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 8: Summary of evidence (GRADE-CERQual), ID Theme 4. Identification of carers by health and social-care professionals – professional staff look for identifying signs

Study information		**Description of Theme or Finding**	**CERQUAL Quality Assessment**				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
ID9 Professionals want to identify and support carers							
2 (Carduff 2014, Carduff 2016)	1: focus groups, 1: semi-structured interviews	Professionals report they want to be able to identify and support carers. They often have informal systems within their services for identifying carers and	Moderate concerns[1]	Minor concerns	Minor concerns	Moderate concerns[2]	LOW

Study information		**Description of Theme or Finding**	**CERQUAL Quality Assessment**				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
		approaching them to assess their needs. However they are also open to the establishment of more formal systems.					
ID10 Shared electronic record systems may be helpful for identifying carers							
1 (Carduff 2016)	1: semi-structured interviews	The eKIS (electronic Key Information Summaries) system is used in Scotland to share information between medical/health and care workers. This can be useful as a source of information about carers, but would require someone to take charge of searching for potential carers in need of support within the notes.	Minor concerns	Minor concerns	Minor concerns	Serious concerns[3]	LOW
ID11 It is challenging to find the opportunity to talk with carers about their roles and needs.							
1 (Carduff 2014)	1: focus groups	Professionals often have lots to cover when meeting the needs of the person receiving care, and find it hard to make time to talk meaningfully with the carer about their needs too. Additionally it may be hard to have honest conversations with the carer about coping in the presence of the person being supported.	Moderate concerns[1]	Minor concerns	Minor concerns	Serious concerns[3]	VERY LOW

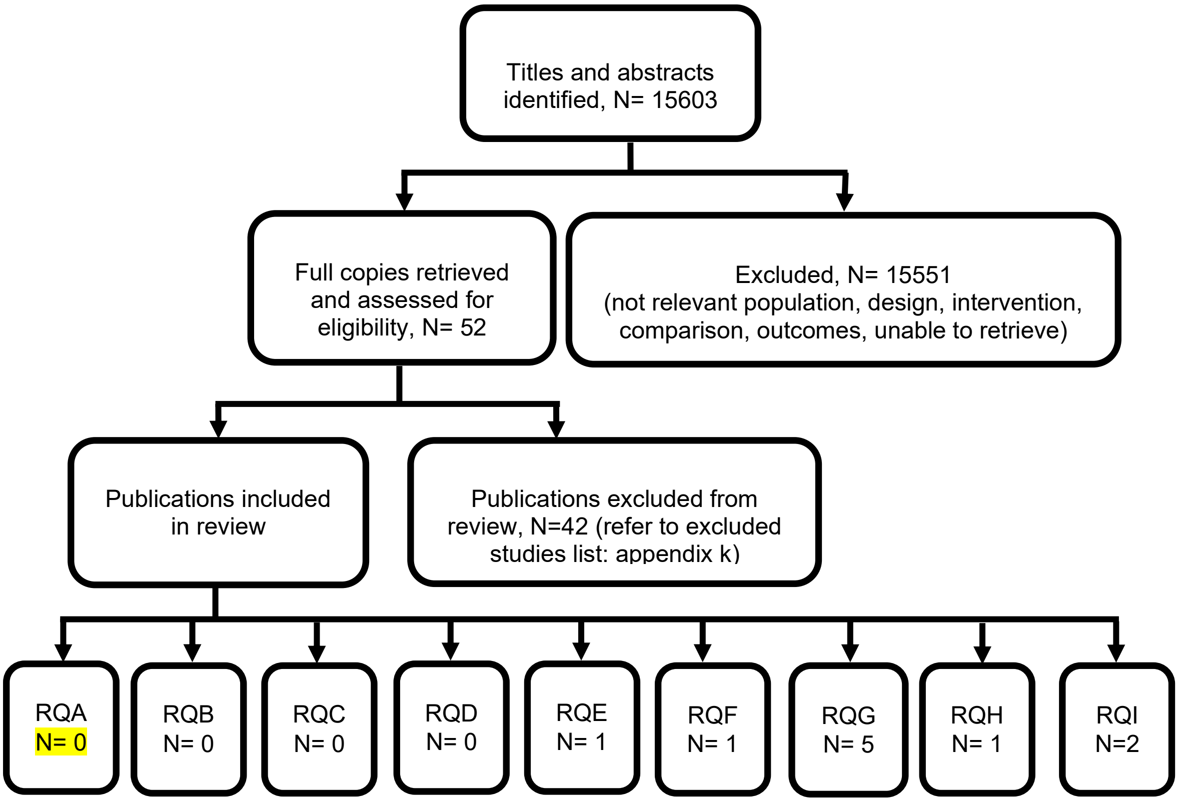
1 Evidence was downgraded because of methodological limitations, as Carduff 2014 had some ambiguity in the reporting of data collection methods
2 Evidence was downgraded by 1 due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)
3 Evidence was downgraded by 2 due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health and social care professionals?

A global economic literature search was undertaken for supporting adult carers. This covered all 9 review questions in this guideline. However, as shown in Figure 3 below no economic evidence was identified which was applicable to this review question.

Figure 3: Study selection flow chart



Appendix H – Economic evidence tables

No evidence was identified that was applicable to this review question

Appendix I – Economic evidence profiles

No evidence was identified that was applicable to this review question.

Appendix J – Economic analysis

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?

Qualitative studies

Table 9: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Argyle, C., Caring for carers: how community nurses can support carers of people with cancer, British journal of community nursing, 21, 180-184, 2016	No qualitative data on phenomenon of interest.
Arksey Hilary, et al.,, Access to health care for carers: barriers and interventions: report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO), 158, 2003	No sufficient qualitative data on adult unpaid carers to allow this study to be included in the analysis.
Barber, M., Siskowski, C., Youth caregivers: unrecognized providers of care, Pediatrics, 121, 873-4, 2008	This publication was an abstract only.
Barnes, A., Am I a carer and do I care? An exploration of the concept of care as applied to osteopathic practice, Medicine, health care, and philosophy, 7, 153-161, 2004	The study was not related to the phenomenon of interest.
Bifulco, Antonia, Jacobs, Catherine, Bunn, Amanda, Thomas, Geraldine, Irving, Karen, The Attachment Style Interview (ASI): A support-based adult assessment tool for adoption and fostering practice, Adoption & Fostering, 32, 33-45, 2008	The study was not related to the phenomenon of interest.
Blumenthal-Barby, J. S., Kostick, K. M., Delgado, E. D., Volk, R. J., Kaplan, H. M., Wilhelms, L. A., McCurdy, S. A., Estep, J. D., Loebe, M., Bruce, C. R., Assessment of patients' and caregivers' informational and decisional needs for left ventricular assist device placement: Implications for informed consent and shared decision-making, Journal of Heart and Lung Transplantation, 34, 1182-1189, 2015	The study was not related to the phenomenon of interest.
Bond, John, Garrow, Graham, Gregson, Barbara A., Bamford, Claire, Buck, Deborah, McNamee, Paul, Wright, Ken, Informal Caregiving for Frail Older People at Home and in Long-Term Care Institutions: Who Are the Key Supporters?, Health & social care in the community, 7, 434-444, 1999	Study was conducted prior to 2004.
Burke, Jay Evan, Brosi, Whitney Edition date, Male relative caregivers: Well-being, service utilization, and service awareness, AAI1461795, 2005	Study was not conducted in the UK.
Burke, T., Galvin, M., Pinto-Grau, M., Lonergan, K., Madden, C., Mays, I., Carney, S., Hardiman, O., Pender, N., Caregivers of patients with	Study was not conducted in the UK.

Study	Reason for Exclusion
amyotrophic lateral sclerosis: investigating quality of life, caregiver burden, service engagement, and patient survival, Journal of Neurology, 264, 898-904, 2017	
Care,, Social Services Inspectorate, Wales, In support of carers: carers engagement overview report, 14, 2017	No sufficient qualitative data on adult unpaid carers to allow this study to be included in the analysis.
Carers, U. K., Carer passport: identifying carers and improving support, 21, 2016	No sufficient qualitative data on adult unpaid carers to allow this study to be included in the analysis.
Cavaye Joyce, Hidden carers, 84p., bibliog., 2006	Full-text article could not be found.
Cavaye, Joyce, Hidden carers (Policy and practice in health and social care number three), 2006	Reference referred to a book.
Cavaye, Joyce, Hidden carers, 84 pp, 2006	This reference was a duplicate.
Creasy, K. R., Lutz, B. J., Young, M. E., Ford, A., Martz, C., The impact of interactions with providers on stroke caregivers' needs, Rehabilitation Nursing, 38, 88-98, 2013	Study was not conducted in the UK.
Demers, L., Fuhrer, M. J., Jutai, J., Lenker, J., Depa, M., De Ruyter, F., A conceptual framework of outcomes for caregivers of assistive technology users, American Journal of Physical Medicine & RehabilitationAm J Phys Med Rehabil, 88, 645-55; quiz 656-8, 691, 2009	The study was not related to the phenomenon of interest.
Freyne, A., Dolan, M., Cooney, C., Carer-rated needs assessment of a cohort of people with dementia, Irish Journal of Psychological Medicine, 27, 72-76, 2010	Study was not conducted in the UK.
Funk, L. M., Allan, D. E., Stajduhar, K. I., Palliative family caregivers' accounts of health care experiences: The importance of security, Palliative and Supportive Care, 7, 435-447, 2009	Study was not conducted in the UK.
Gansler, T., Kepner, J., Willacy, E., Soloe, C., Rupert, D., Jarblum, M., Driscoll, D., Orr, A., Fitzgerald, T., Esparza, A., Evolving information priorities of hematologic cancer survivors, caregivers, and other relatives, Journal of Cancer Education, 25, 302-11, 2010	Study was not conducted in the UK.
Gardiner, C., Ingleton, C., Gott, M., Ryan, T., Exploring the transition from curative care to palliative care: a systematic review of the literature, BMJ supportive & palliative care, 1, 56-63, 2011	Study design was a review: reviews have been excluded. References of included studies have been hand searched.
Garvelink, M. M., Ngangue, P. A., Adekpedjou, R., Diouf, N. T., Goh, L., Blair, L., Legare, F., A Synthesis Of Knowledge About Caregiver Decision Making Finds Gaps In Support For Those Who Care For Aging Loved Ones, Health Affairs, 35, 619-26, 2016	Study was not conducted in the UK.
Gordon, P. C., Valiengo, L. D. C. L., Proenca, I. C. G. F., Kurcgant, D., Jorge, C. L., Castro, L. H., Marchetti, R. L., Comorbid epilepsy and	The study was not related to the phenomenon of interest.

Study	Reason for Exclusion
psychogenic non-epileptic seizures: How well do patients and caregivers distinguish between the two, Seizure, 23, 537-541, 2014	
Häikiö, Liisa, Anttonen, Anneli, Local welfare governance structuring informal carers' dual position, The International Journal of Sociology and Social Policy, 31, 185-196, 2011	Study was not conducted in the UK.
Happell, B., Wilson, K., Platania-Phung, C., Stanton, R., Filling the gaps and finding our way: family carers navigating the healthcare system to access physical health services for the people they care for, Journal of clinical nursing, 26, 1917-1926, 2017	Study was not conducted in the UK.
Henderson, A., Vaz, H., Virdun, C., Identifying and assessing the needs of carers of patients with palliative care needs: an exploratory study, International journal of palliative nursing, 24, 503-509, 2018	Study was not conducted in the UK.
Hobson, E. V., "Just another piece of equipment." the role, identity and experiences of carergivers in motor neurone disease: A qualitative study, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 19 (Supplement 1), 322-323, 2018	This publication was a conference abstract only, which were to be excluded by the protocol.
James, I., Andershed, B., Ternestedt, B. M., The encounter between informal and professional care at the end of life, Qualitative health research, 19, 258-271, 2009	Study was not conducted in the UK.
Keefe, J., Guberman, N., Fancey, P., Barylak, L., Nahmiash, D., Caregivers' aspirations, realities, and expectations: The CARE Tool, Journal of Applied Gerontology, 27, 286-308, 2008	Study was not conducted in the UK.
Li, H., Identifying family care process themes in caring for their hospitalized elders, Applied Nursing Research, 18, 97-101, 2005	Study was not conducted in the UK.
Michael, N., O'Callaghan, C., Clayton, J. M., Exploring the utility of the vignette technique in promoting advance care planning discussions with cancer patients and caregivers, Patient Education and Counseling, 99, 1406-1412, 2016	Study was not conducted in the UK.
Mikolas-Peters, Cynthia Jean, Nursing Home Residents' and Family Caregivers' Strategies in Financing the Costs of Long-Term Care, 2592-A-2593-A	This publication was an dissertation – these were excluded in the protocol.
Mochari-Greenberger, H., Mosca, M., Aggarwal, B., Umann, T. M., Mosca, L., Caregiver status: a simple marker to identify cardiac surgery patients at risk for longer postoperative length of stay, rehospitalization, or death, The Journal of cardiovascular nursing, 29, 12-19, 2014	Study was not conducted in the UK.
Moore, H., Gillespie, A., The caregiving bind: Concealing the demands of informal care can undermine the caregiving identity, Social Science and Medicine, 116, 102-109, 2014	Not the phenomenon of interest: the aims of this mixed-methods study were to explore the views of carers of people with acquired brain injury in relation to 'Caregivers bind' as cause of

Study	Reason for Exclusion
	caregivers' negative identity, and feelings of social recognition.
Moriarty Jo, Manthorpe Jill, Social care practice with carers: what social care support is provided to family carers? What support to family carers want?, 4, 2014	No sufficient qualitative data on adult unpaid carers to allow this study to be included in the analysis.
O'Connor, Deborah L., Self-identifying as a caregiver: Exploring the positioning process, Journal of aging studies, 21, 165-174, 2007	Study was not conducted in the UK.
Orsini, M., Mello, M., Lisieux, D., Passaro, C. P., Leite, M. A. A., Baldez, A. C., Silva, J. G., de Menezes, S. L. S., Porto, F. H., Machado, D., Bastos, V. H., de Freitas, M. R. G., Oliveira, A. B., Quality of life of caregivers and patients with amyotrophic lateral sclerosis, Revista Neurociencias, 20, 2012	Study was not written in English language.
Pereira, H. R., Rebelo Botelho, M. A., Sudden informal caregivers: the lived experience of informal caregivers after an unexpected event, Journal of clinical nursing, 20, 2448-57, 2011	The study was not related to the phenomenon of interest.
Rao, S., Dobie, A., Lincoln, N., Sarnacki, D., Gignac, G., Advance care planning in cancer: Using a novel SOI tool, Journal of Palliative Medicine, 20 (4), A5, 2017	This publication was a conference abstract only, which were to be excluded by the protocol.
Robinson, C. A., Pesut, B., Bottorff, J. L., Supporting rural family palliative caregivers, Journal of family nursing, 18, 467-490, 2012	Study was not conducted in the UK.
Skills For, Care, Carers, Trust, Carers assessments: workforce development opportunities based on carers experiences, 19, 2013	The study was not related to the phenomenon of interest.
Small, N., Brooks, H., Grundy, A., Pedley, R., Gibbons, C., Lovell, K., Bee, P., Understanding experiences of and preferences for service user and carer involvement in physical health care discussions within mental health care planning, BMC Psychiatry, 17 (1) (no pagination), 2017	The study was not related to the phenomenon of interest.
Smeltzer, M., Rugless, F. E., Lee, H. K., Ward, K., Faris, N. R., Ray, M. A., Meadows, M., Jiang, B., Jackson, B., Foust, C., Patel, A., Boateng, N., Kedia, S., Roark, K., Houston-Harris, C., Fehnel, C., Signore, R. S., Fox, R., Robbins, E. T., Li, J., Osarogiagbon, R. U., Prospective evaluation of multidisciplinary lung cancer care: Timeliness, thoroughness, and patient/caregiver perspectives, Journal of Thoracic Oncology, 12 (11 Supplement 1), S1560, 2017	This publication was a conference abstract only, which were to be excluded by the protocol.
Spigelmyer, Pamela C. PhD R. N. C. N. S. C. S. N., Hupcey, Judith E. EdD Crnp Faan, Smith, Carol A. PhD Fnap, Loeb, Susan J. PhD R. N. Fgsa Faan, Kitko, Lisa PhD R. N. Faha, Resistiveness to Care as Experienced by Family Caregivers Providing Care for Someone With Dementia, Journal of Nursing Scholarship, 50, 36-46, 2018	Study was not conducted in the UK.

Study	Reason for Exclusion
Taylor, J., Carers. Why the NHS must look after its hidden workers, Health Service Journal, 119, 18, 2009	This publication contained no qualitative data.
Townsend Jean, Moore Jeanette, Careful thoughts: recognising and supporting older carers in intermediate care, Research Policy and Planning, 24, 39-52, 2006	The study was not related to the phenomenon of interest.
Van Exel, N. J. A., Koopmanschap, M. A., Van Den Berg, B., Brouwer, W. B. F., Van Den Bos, G. A. M., Burden of informal caregiving for stroke patients: Identification of caregivers at risk of adverse health effects, Cerebrovascular Diseases, 19, 11-17, 2005	Study was not conducted in the UK.
Wilcock, A., Crosby, V., Hussain, A., McKeever, T. M., Manderson, C., Farnan, S., Freer, S., Freemantle, A., Littlewood, F., Caswell, G., Seymour, J., Lung cancer diagnosed following an emergency admission: Mixed methods study of the management, outcomes and needs and experiences of patients and carers, Respiratory Medicine, 114, 38-45, 2016	Study did not have sufficient qualitative data on adult unpaid carers to allow this study to be included in the analysis.
Wiles, J., Moeke-Maxwell, T., Williams, L., Black, S., Trussardi, G., Gott, M., Caregivers for people at end of life in advanced age: knowing, doing and negotiating care, Age and ageing, 47, 887-895, 2018	Study was not conducted in the UK.
Willis Paul, Ward Nicki, Fish Julie, Searching for LGBT carers: mapping a research agenda in social work and social care, British Journal of Social Work, 41, 1304-1320, 2011	The study had no sufficient qualitative data on adult unpaid carers to allow this study to be included in the analysis.
Wingham, J., Frost, J., Britten, N., Jolly, K., Greaves, C., Abraham, C., Dalal, H., Needs of caregivers in heart failure management: A qualitative study, Chronic Illness, 11, 304-319, 2015	The study was not related to the phenomenon of interest.

Economic component of the review

A global economic literature search was undertaken for supporting adult carers. This covered all 9 review questions in this guideline. The table below is a list of excluded studies across the entire guideline and studies listed were not necessarily identified for this review question.

Table 10: Excludes studies from the economic component of the review

Study	Reason for Exclusion
Arksey Hilary, et al.,, Review of respite services and short-term breaks for carers for people living with dementia: report for the National Co-ordinating Centre for NHS Service Delivery and Organisation	Study design: This report is a review, and reviews are excluded. References could not be hand-searched as there was no reference list included in the report.
Arts, E. E., Landewe-Cleuren, S. A., Schaper, N. C., Vrijhoef, H. J., The cost-effectiveness of	Population of interest: the study focus is primarily on patients.

Study	Reason for Exclusion
substituting physicians with diabetes nurse specialists: a randomized controlled trial with 2-year follow-up, Journal of advanced nursing, 68, 1224-34, 2012	
Forster, A., Young, J., Chapman, K., Nixon, J., Patel, A., Holloway, I., Mellish, K., Anwar, S., Breen, R., Knapp, M., Murray, J., Farrin, A., Cluster Randomized Controlled Trial: Clinical and Cost-Effectiveness of a System of Longer-Term Stroke Care, Stroke; a journal of cerebral circulation, 46, 2212-2219, 2015	Population of interest: the study focus is primarily on patients.
Forster, A., Young, J., Green, J., Patterson, C., Wanklyn, P., Smith, J., Murray, J., Wild, H., Bogle, S., Lowson, K., Structured re-assessment system at 6 months after a disabling stroke: a randomised controlled trial with resource use and cost study, Age & AgeingAge Ageing, 38, 2009	This cost analysis is focused primarily on patients.
Gardiner, Clare, Brereton, Louise, Frey, Rosemary, Wilkinson-Meyers, Laura, Gott, Merryn, Approaches to capturing the financial cost of family care-giving within a palliative care context: A systematic review, Health & Social Care in the Community, 24, 519-531, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Gitlin LN, Hodgson N, Jutkowitz E, Pizzi L. The cost-effectiveness of a nonpharmacologic intervention for individuals with dementia and family caregivers: the tailored activity program. Am J Geriatr Psychiatry 2010;18(6):510-9.	Economic evaluation conducted in the USA.
Gomes, B., Calanzani, N., Curiale, V., McCrone, P., Higginson, I. J., Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers, Cochrane Database of Systematic Reviews, 2016 (3) (no pagination), 2013	Study design - this review of HE studies has been excluded for this guideline - but its references have been checked for any relevant HE study.
Gomes, Barbara, Calanzani, Natalia, Higginson, Irene J., Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers, JAMA: Journal of the American Medical Association, 311, 1060-1061, 2014	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Heslin, M., Forster, A., Healey, A., Patel, A., A systematic review of the economic evidence for interventions for family carers of stroke patients, Clinical Rehabilitation, 30, 119-33, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE study.
Hoefman, R. J., van Exel, J., Brouwer, W. B., Measuring Care-Related Quality of Life of Caregivers for Use in Economic Evaluations: CarerQol Tariffs for Australia, Germany, Sweden, UK, and US, PharmacoEconomics, 35, 469-478, 2017	No intervention of interest.
Huter, K., Kocot, E., Kissimova-Skarbek, K., Dubas-Jakobczyk, K., Rothgang, H., Economic evaluation of health promotion for older people-methodological problems and challenges, BMC	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.

Study	Reason for Exclusion
Health Services Research, 16 Suppl 5, 328, 2016	
Jones Carys, Edwards Rhiannon Tudor, Hounsome Barry, A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people living with dementia residing in the community, International Psychogeriatrics, 24, 6-18, 2012	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Jones, C., Edwards, R. T., Hounsome, B., Health economics research into supporting carers of people living with dementia: A systematic review of outcome measures, Health and Quality of Life Outcomes, 10 (no pagination), 2012	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Jutkowitz, E., Gitlin, L. N., Pizzi, L. T., Evaluating willingness-to-pay thresholds for dementia caregiving interventions: application to the tailored activity program, Value in Health, 13, 720-5, 2010	Economic evaluation conducted in the USA.
Kenealy, T. W., Parsons, M. J., Rouse, A. P., Doughty, R. N., Sheridan, N. F., Hindmarsh, J. K., Masson, S. C., Rea, H. H., Telecare for diabetes, CHF or COPD: effect on quality of life, hospital use and costs. A randomised controlled trial and qualitative evaluation, PLoS ONE [Electronic Resource], 10, e0116188, 2015	Population of interest: the study focus is primarily on patients.
Kenrik Duru, O., Ettner, S. L., Vassar, S. D., Chodosh, J., Vickrey, B. G., Cost evaluation of a coordinated care management intervention for dementia, American Journal of Managed Care, 15, 521-528, 2009	Population of interest: the study focus is primarily on patients.
Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., Cooper, C., Livingston, G., Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people living with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial (Structured abstract), Bmj, 347, f6342, 2013	Study finding updated by a more recent HE study (Livingston 2014).
Lauret, G. J., Gijsbers, H. J., Hendriks, E. J., Bartelink, M. L., de Bie, R. A., Teijink, J. A., The ClaudicatioNet concept: design of a national integrated care network providing active and healthy aging for patients with intermittent claudication, Vascular Health & Risk Management, 8, 495-503, 2012	Research protocol.
Li, C., Zeliadt, S. B., Hall, I. J., Smith, J. L., Ekwueme, D. U., Moinpour, C. M., Penson, D. F., Thompson, I. M., Keane, T. E., Ramsey, S. D., Burden among partner caregivers of patients diagnosed with localized prostate cancer within 1 year after diagnosis: an economic perspective, Supportive Care in Cancer, 21, 3461-9, 2013	Not the intervention of interest: This study estimates lost productivity and informal caregiving and associated costs among partner caregivers of localized prostate cancer patients within 1 year after diagnosis.
Lopez-Villegas, A., Catalan-Matamoros, D., Robles-Musso, E., Peiro, S., Workload, time and	Not the intervention of interest: aim of this study was to assess the burden borne by and

Study	Reason for Exclusion
costs of the informal carers in patients with tele-monitoring of pacemakers: the PONIENTE study, Clinical Research in Cardiology, 105, 307-313, 2016	the costs to informal carers of patients with remotely monitored pacemakers.
Magnusson, L., Hanson, E., Supporting frail older people and their family carers at home using information and communication technology: cost analysis, Journal of advanced nursing, 51, 645-57, 2005	This cost analysis uses a case study methodology involving 5 families, cost and resource usage are not reported separately for carers and patients.
Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., Drummond, M., Glendinning, C., A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers, Health Technology Assessment (Winchester, England), 11, 1-157, iii, 2007	Study design - this review of HE studies has been excluded for this guideline (but its references have been hand-searched for any relevant HE studies.
Mason, Anne, Weatherly, Helen, Spilsbury, Karen, Golder, Su, Arksey, Hilary, Adamson, Joy, Drummond, Michael, The Effectiveness and Cost-Effectiveness of Respite for Caregivers of Frail Older People, Journal of the American Geriatrics Society, 55, 290-299, 2007	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Menn P, Holle R, Kunz S, Donath C, Lauterberg J, Dementia care in the general practice setting: a cluster randomized trial on the effectiveness and cost impact of three management strategies. Value Health. 2012 Sep-Oct;15(6):851-9	Population of interest: no primary focus on carers.
Morgan, R. O., Bass, D. M., Judge, K. S., Liu, C. F., Wilson, N., Snow, A. L., Pirraglia, P., Garcia-Maldonado, M., Raia, P., Fouladi, N. N., Kunik, M. E., A break-even analysis for dementia care collaboration: Partners in Dementia Care, Journal of General Internal Medicine, 30, 804-9, 2015	Population of interest: the study focus is primarily on patients.
Nichols LO, Chang C, Lummus A, Burns R, Martindale-Adams J, The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. J Am Geriatr Soc. 2008 Mar;56(3):413-20	This economic evaluation was conducted in the USA.
Nichols LO, Martindale-Adams J, Zhu CW, Kaplan EK, Zuber JK, Impact of the REACH II and REACH VA Dementia Caregiver Interventions on Healthcare Costs. J Am Geriatr Soc. 2017 May;65(5):931-936	This economic evaluation was conducted in the USA.
Orgeta, V., Leung, P., Yates, L., Kang, S., Hoare, Z., Henderson, C., Whitaker, C., Burns, A., Knapp, M., Leroi, I., Moniz-Cook, E. D., Pearson, S., Simpson, S., Spector, A., Roberts, S., Russell, I. T., de Waal, H., Woods, R. T., Orrell, M., Individual cognitive stimulation therapy for dementia: a clinical effectiveness and cost-effectiveness pragmatic, multicentre, randomised controlled trial, Health Technology Assessment (Winchester, England), 19, 1-108, 2015	Population of interest: the study focus is primarily on patients.

Study	Reason for Exclusion
Patel, A., Forster, A., Young, J., Nixon, J., Chapman, K., Knapp, M., Mellish, K., Holloway, I., Farrin, A., Cluster randomised trial evaluation of a patient and carer centred system of longer-term stroke care (the LoTS care trial): Economic evaluation, Cerebrovascular Diseases, 35, 584, 2013	Conference abstract.
Pickard, Linda, The effectiveness and cost-effectiveness of support and services to informal carers of older people: a review of the literature prepared for the Audit Commission, 2004	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Quinn, C., Anderson, D., Toms, G., Whitaker, R., Edwards, R. T., Jones, C., Clare, L., Self-management in early-stage dementia: a pilot randomised controlled trial of the efficacy and cost-effectiveness of a self-management group intervention (the SMART study), Trials [Electronic Resource], 15, 74, 2014	Research protocol.
Romeo, R., Knapp, M., Banerjee, S., Morris, J., Baldwin, R., Tarrier, N., Pendleton, N., Horan, M., Burns, A., Treatment and prevention of depression after surgery for hip fracture in older people: cost-effectiveness analysis, Journal of Affective Disorders, 128, 211-9, 2011	Population of interest: no adult carers.
Sandberg, M., Jakobsson, U., Midlov, P., Kristensson, J., Cost-utility analysis of case management for frail older people: effects of a randomised controlled trial, Health Economics Review, 5 (1) (no pagination), 2015	Population of interest: no adult carers.
Schepers, J., Annemans, L., Simoens, S., Hurdles that impede economic evaluations of welfare interventions, Expert Review of Pharmacoeconomics & Outcomes Research, 15, 635-42, 2015	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.
Søgaard R, Sørensen J, Waldorff FB, Eckermann A, Buss DV, Early psychosocial intervention in Alzheimer's disease: cost utility evaluation alongside the Danish Alzheimer's Intervention Study (DAISY). BMJ Open. 2014 Jan 15;4(1):e004105	Population of interest: no primary focus on carers.
Sogaard, R., Sorensen, J., Waldorff, F. B., Eckermann, A., Buss, D. V., Waldemar, G., Private costs almost equal health care costs when intervening in mild Alzheimer's: a cohort study alongside the DAISY trial, BMC Health Services Research, 9, 215, 2009	Study findings updated by a more recent HE study (Søgaard 2014)
Teng, J., Mayo, N. E., Latimer, E., Hanley, J., Wood-Dauphinee, S., Cote, R., Scott, S., Costs and caregiver consequences of early supported discharge for stroke patients, Stroke, 34, 528-36, 2003	Population of interest: the study focus is primarily on patients.
Toseland RW, Smith TL. The impact of a caregiver health education program on health care costs. Research on Social Work Practice 2006;16(1):9–19.	This economic evaluation was conducted in the USA.

Study	Reason for Exclusion
Vicente, C., Sabapathy, S., Formica, L., Maturi, B., Piwko, C., Cost-utility analysis of tocilizumab in the treatment of active systemic juvenile idiopathic arthritis, Value in Health, 16 (3), A225, 2013	Not the intervention of interest: The objective of this HE study is to determine the cost-effectiveness of tocilizumab with or without methotrexate compared to placebo with methotrexate for the treatment of juvenile idiopathic arthritis.
Wilson, E., Thalanany, M., Shepstone, L., Charlesworth, G., Poland, F., Harvey, I., Price, D., Reynolds, S., Mugford, M., Befriending carers of people living with dementia: a cost utility analysis, International Journal of Geriatric Psychiatry, 24, 610-23, 2009	Duplication (Charlesworth 2008).
Wittenberg, E., Prosser, L. A., Disutility of illness for caregivers and families: A systematic review of the literature, Pharmacoeconomics, 31, 489-500, 2013	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.
Wray, L. O., Shulan, M. D., Toseland, R. W., Freeman, K. E., Vasquez, B. E., Gao, J., The effect of telephone support groups on costs of care for veterans with dementia, Gerontologist, 50, 623-31, 2010	Population of interest: no adult carers.

Appendix L – Research recommendations

Research recommendations for review question What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?

No research recommendations were drafted for this review question.

Appendix M – Quotes extracted from the included papers, which support the qualitative review findings

Quotes extracted for review question: What are the barriers and facilitators to (i) self-identification by carers and (ii) identification of carers by health- and social-care professionals?

Bennett 2016

What has gone well? - Identifying carers and assessment: "I have just had an assessment done. I have been my son's carer for the last 27 years unpaid and at this assessment I was asked about my needs. This has never happened before." (Adult carer - 1 year after Carer Act); "I have the right to be asked if I am 'willing and able to continue caring,' has stopped the crucifying assumption I have a duty to care until I drop." (Adult carer - 1 year after the Care Act [2014]); "it is the only time in the year when I am asked about me. That in itself validates he process in my eyes. We discuss me, how I am coping and what's available. ll our other contact with healthcare professionals centres around my husband. Having that opportunity and someone who understands without me explaining has meant something" (Adult carer - 1 year after the Care Act [2014])

What needs to improve? - Identifying and reaching out to carers: "I have no idea, I know for me nothing has changed. I am doing the same exhausting job of caring for my son as I always have." (Adult carer - 1 year after the Care Act [2014]); "...continue to have zero personal support after a mental breakdown."(Adult carer - 1 year after the Care Act [2014]); "Sorry, this is the first time I have heard of this one . . . To be honest, this survey, found by chance on social media, has been the most enlightening experience re caring in the whole year!"(Adult carer - 1 year after the Care Act [2014])

Carduff 2016

The acceptability of the intervention - carers: "I've also found that nobody wants to know your problems – you lose friends, they don't want to come to the house, they don't want to see you, and all the rest of it. Your family itself, it gets very distant" (Adult carer participating in a pilot intervention to identify, assess and support carers of people with supportive and palliative care needs in primary care); "It's always nice if somebody rings you up and says, how are you? I think that would make you feel that you were connected because at the moment I don't" (Adult carer participating in a pilot intervention to identify, assess and support carers of people with supportive and palliative care needs in primary care)

The acceptability of the intervention - professionals: "Key Information Summary, so it's sharing information with the out of hours, but if you start one of those they're asking for relatives and next of kin and carer information, so it's highlighting that sort of information that you need to be providing as well so I guess we're picking up a lot more than we used to and we're certainly thinking about it a lot more" (Health professional, GP); "one of the advantages of continuity of care is that you get to know people and you get to know what's going on in the wider family or at what point you need to step in and say actually, I think you need a bit of a rest and so on" (Health professional, GP); "It's a very, very complex area but I'm so glad you've done this because I think it's really made us think about it and we have discussed at partners' meetings and its thrown up some interesting thoughts on it" (Carer Liaison)

Carduff 2014

Barriers to carer identification - Caring as a gradual process: Identifying with the term 'carer' - "“Where I feel the carer became what was the daughter, the carer part became more relevant, was when she lost that confidence.” (Adult carer - female)

Barriers to carer identification - Caring as a gradual process: Changing relationships in the context of caring - "But I do feel that relationships slide, both with your children, with your husband or your partner, I just think it all just… And I think that, you know, your children and your partner or your husband maybe understand initially but when it's for some years, you know, it begins to bite.” (Adult carer - female)

Barriers to carer identification - Engulfed by the caring role: Managing competing demands - "And so it made me… you know, when you were thinking, maybe I shouldn't be at work, maybe I should leave, and the GP – his GP – you know, was saying “oh, you must keep your work, you can't…” you know, and so they were stressing it and I'd think well, that's fair enough but how do I do this as well?.” (Adult carer - female)

Barriers to carer identification - The role of primary care in legitimising need: Role ambiguity - "“Well, certainly as a GP, I would certainly see it as a very important part of my role to help someone who is a carer with that issue, but I think they would struggle to see it as the GP's role” (Health professional, GP); "But I'm aware that, the same with people when they come to the GP, they think they have to do it with some kind of medical problem, or they at least have to be officially depressed or something” (Health professional, GP)

Barriers to carer identification - The role of primary care in legitimising need: Communication - “You kind of can put paranoia to the patient then because they feel 'what are they talking about?' and… And I've had that with patients before is, you know “what were you talking about? You know how long I've got left” and “you know more than you're letting on” and stuff.” (Health professional, community specialist palliative care nurse)