National Institute for Health and Care Excellence

Final

Supporting Adult Carers

RQC - Assessment of carers as defined by the Care Act 2014

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

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive. All NICE guidance is subject to regular review and may be updated or withdrawn.

Copyright

© NICE 2020. All rights reserved. Subject to Notice of Rights.

ISBN: 978-1-4731-3654-0

Contents

Assessment of carers as defined by the Care Act 2014

Review question

What is the acceptability of different tools or approaches for assessing the needs of carers?

Introduction

Assessment is widely regarded as being the cornerstone of the Care Act 2014, which in turn gives carers new entitlements to support in their own rights and for the first time ‘parity of esteem’ with the person for whom they are providing are. However, the implementation of the Care Act duties poses challenges for commissioners, practitioners and of course carers themselves. The Cross-Government Carers Action Plan 2018-2020 underlines the Government’s intention “*to support carers to provide care as they would wish and to do so in such a way that takes account of their own health and well-being and access to education and employment and life chances*”. But a survey of carers following Care Act implementation by the Carers Trust (2016) found that although 31% of carers felt that their assessment process had been good, a further 34% felt it to be inadequate.

The Care Act permits considerable flexibility to local authorities and their partners in determining how, when and where assessment is carried out (including the possibility of collaboration and integrated assessments with the NHS, a proposal strongly endorsed in the NHS England proposals for Universal Personalised Care and the NHS Long Term Plan). However, there is an ongoing debate as to how assessments can best be outcome focused, have regard to the carer’s well-being and adopt a whole family approach. Section 61 of the Care Act 2014 expects that “*the assessment and eligibility process is one of the most important elements of the care and support system and it should not just be seen as a gateway to care and support but a critical intervention in its own right*”.

Although it is generally agreed that the Care Act provides a framework for more dynamic assessment system and for a new flexibility for carers through the introduction of Personal Budgets and Direct Payments, there is still limited evidence on their use specifically for carers. As Carers UK has noted (2018), over the next 10 years, 20 million people are likely to start caring. With 1.4 million carers over 50 (and with 2.9 million older people with three or more long term conditions) and at least 1,636 young adult carers, carers’ assessments provide both a challenge and an opportunity to use Care Act flexibilities and to consider the effectiveness and acceptability of a range of models of assessment and personalised responses to meet assessed needs (including collaborative models between local authorities and the NHS).

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 (PICO table)

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. • Social care professionals who are responsible for conducting carers' assessments. Also, any other professionals (including from the health or voluntary sectors) to whom responsibility for carrying out an assessment has been delegated by the local authority.
Phenomenon of interest	• Carers' views and experiences of formal carer assessments with any statutory assessment tool or approach will be considered. • Professionals' views of conducting a formal carer assessment with any statutory assessment tool or approach will also be considered.
Context	• UK only
Outcomes	Expected themes from the qualitative evidence might include: • acceptability of and satisfaction with the assessment process (for example a one off meeting or an ongoing conversation) • approach to carer assessments (for example, integrated approach across health and social care, joint or separate assessments, self-assessments) • attitudes towards carers during a carer assessment • carers' participation and wellbeing • experiences and satisfaction in relation to review arrangements. • perceived areas of unmet need following a carer assessment and resulting support plan. • provision of information in advance of and in preparation for a carer's assessment. • suitability of a statutory assessment tool in identifying all areas of need

For full details see the review protocol in appendix A

Included studies

This is a qualitative review with the aim of understanding people's views and lived experiences about the acceptability of statutory carer's assessments. 7 studies were identified for inclusion, 4 qualitative studies (Ewing 2016, Ewing 2018, Regulation and Quality Improvement Authority [RQIA] 2012, and Stock 2011), and 3 cross-sectional on-line surveys including 'qualitative' data gathered using open-ended questions (Carers UK 2016, Carers UK 2017, Carers UK 2018).

The included studies are summarised in Table 2. They were published between 2011 (Stock 2011) and 2018 (Carers UK 2018, and Ewing 2018). 4 studies focussed only on carers' views and experiences of formal carers assessments (Carers UK 2016, Carers UK 2017, Carers UK 2018, and Stock 2011); 1 study focussed only on professionals' views of conducting a formal carer assessment (Ewing 2016); while 2 studies included both carers' and professionals' views and experiences with carers assessments (Ewing 2018, RQIA 2012). In particular they focussed on the following tools or approaches for assessing carers' needs:

- Carer's Support and Needs Assessment Tool (RQIA 2012).
- The Carer Support Needs Assessment Tool (CSNAT) (Ewing 2016, and Ewing 2018).
- Statutory Carer's Assessments since the Care Act 2014 (Carers UK 2016, Carers UK 2017, and Carers UK 2018).

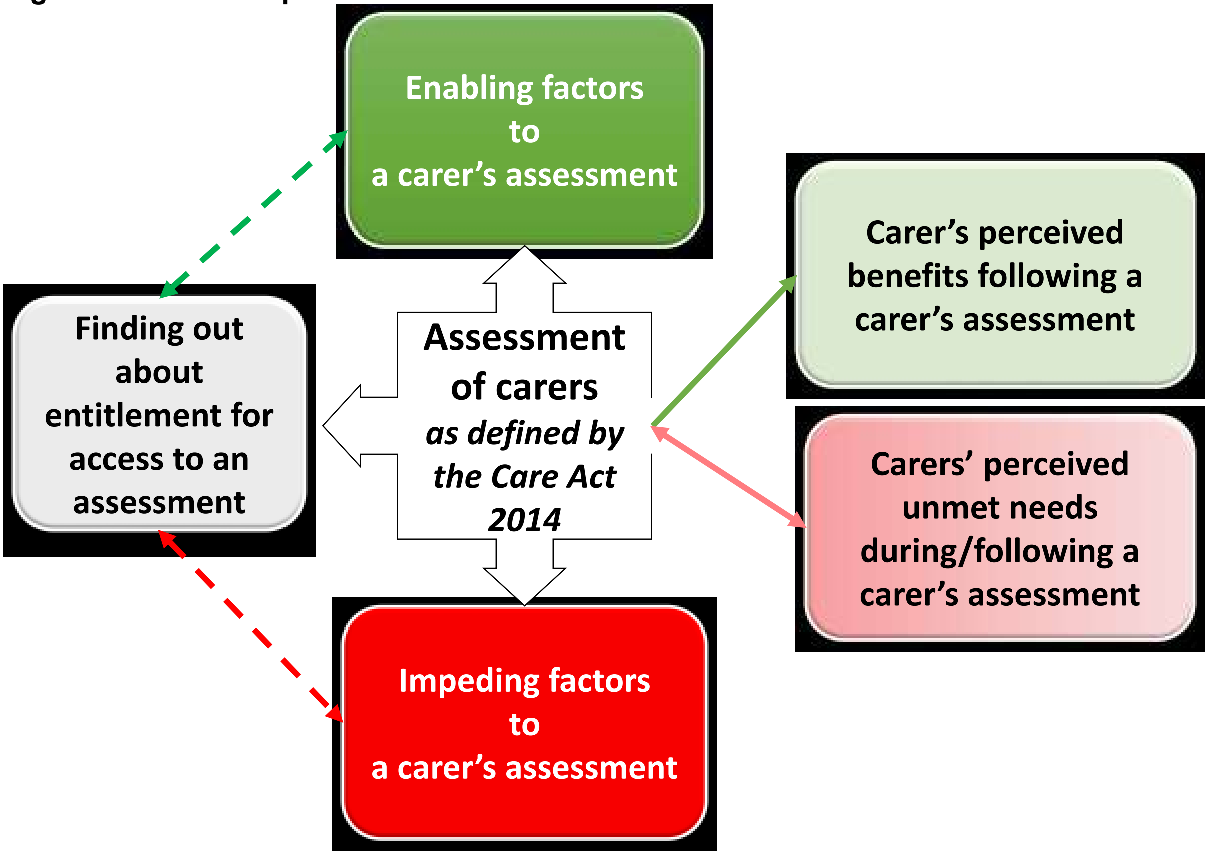
- Carer's Assessments since the Care (Equal Opportunities) Act 2004 (Stock 2011).

3 studies collected data via focus groups (Ewing 2016, Ewing 2018, and RQIA 2012), 3 studies gathered data through free on-line surveys (Carers UK 2016; Carers UK 2017; Carers UK 2018), and 1 study collected data through semi-structured (face-to-face) interviews (Stock 2011). Data analysis methods included content analysis, thematic analysis, and the use of descriptive statistics.

All studies were conducted in the UK, in line with the review protocol. 3 studies recruited carers from all across the UK (Carers UK 2016, Carers UK 2017, and Carers UK 2018), 2 included studies were conducted in England (Ewing 2016, and Ewing 2018), 1 Northern Ireland (RQIA 2012), and 1 in Wales (Stock 2011).

As shown in the theme map (Figure 1), the concepts identified in the included evidence have been 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.

1 **Table 2: Summary of included qualitative studies**

Study and aim of the study	Participants	Methods	Themes
Carers UK 2016 **Aim of the study** • The aim of this mixed -methods policy report was to understand the state of caring in the UK in 2016 by means of a national on-line survey including a large and varying sample of carers	• **Carers**: N= 5,682 • **Professionals**: N/A **Carers** • Age, Range - years (% of the total sample) = ○ 25-34 (4%) ○ 35-44 (12%) ○ 45-54 (30%) ○ 55-64 (33%) ○ 65 and over (20%) • Gender (M/F/LGBT: N) = 1,136/4,432/N/R **Professionals** • N/A **Care recipients** • No specific condition	• **Recruitment period:** March - April 2016 • **Data collection & analysis methods:** ○ Data were collected through a free online survey (that is survey-monkey) "Carers UK State of Caring survey". ○ No details are reported about the data analysis	• Carers' perceived unmet needs during/following a carer's assessment • Carer's perceived benefits following a carer's assessment • Impeding factors to carer's assessment
Carers UK 2017 **Aim of the study** • The aim of this mixed -methods policy report was to understand the state of caring in the UK in 2017 by means of a national on-line survey including a large and varying sample of carers	• **Carers**: N= 6,607 • **Professionals**: N/A **Carers** • Age, Range - years (% of the total sample) = ○ 25-34 (4%) ○ 35-44 (13%) ○ 45-54 (29%) ○ 55-64 (34%) ○ 65 and over (19%) • Gender (M/F/LGBT: N) = 1,321/5,153/198 **Professionals** • N/A **Care recipients** • No specific condition	• **Recruitment period:** March - May 2017 • **Data collection & analysis methods:** ○ Data were collected through a free online survey (that is survey-monkey) "Carers UK State of Caring survey" ○ No details are reported about the data analysis	• Carers' perceived unmet needs during/following a carer's assessment • Carer's perceived benefits following a carer assessment • Impeding factors to carer's assessment
Carers UK 2018 **Aim of the study** • The aim of this mixed -methods policy report was to understand the state of caring in the UK in 2018 by means of a national on-line survey including a	• **Carers**: N= 6,828 • **Professionals**: N/A **Carers** • Age, Range - years (% of the total sample) = ○ 25-34 (4%) ○ 35-44 (12%) ○ 45-54 (27%) ○ 55-64 (35%)	• **Recruitment period:** March - May 2018 • **Data collection & analysis methods:** ○ Data were collected through a free online survey (that is survey-monkey) "Carers UK State of Caring survey"	• Carers' perceived unmet needs during/following a carer's assessment • Carer's perceived benefits following a carer assessment • Impeding factors to carer's assessment

Study and aim of the study	Participants	Methods	Themes
large and varying sample of carers	○ 65 and over (22%) • Gender (M/F/LGBT: N) = 1,365/5,325/204 **Professionals** • N/A **Care recipients** • No specific condition	○ No details are reported about the data analysis	
Ewing 2016 **Aim of the study** • The aim of this qualitative study was to examine practitioner perspectives of carer assessment before-and-after implementation of the CSNAT intervention, in order to identify its impact and mechanisms of action	• **Carers**: N/A • **Professionals**: N = 29 **Carers** • N/A **Professionals** • Age = N/R [Length of time in post ranged from 1 to 12 years] • Gender = N/R **Care recipients** • End of life/Palliative care	• **Recruitment period:** 2010-2011 • **Data collection & analysis methods:** ○ Data were collected through focus group interviews ○ Interview data were analysed using thematic analysis, based on the framework approach	• Enabling factors to a carer's assessment • Impeding factors to carer's assessment
Ewing 2018 **Aim of the study** • The aim of this study was to explore whether and how family carers are currently supported during patient discharge at end of life; to assess perceived benefits, acceptability and feasibility of using the CSNAT approach in the hospital setting to support carers	• **Carers**: N= 22 • **Professionals**: N =40 **Carers** • Age = Range (years): 21 to 80 • Gender (M/F/LGBT: N) = 3/19/0 **Professionals** • N = Unclear **Care recipients** • End of life/Palliative care	• **Recruitment period:** December 2014 - November 2015 • **Data collection & analysis methods:** ○ Data were collected through focus group and (face-to-face) semi-structured interviews ○ Interview data were analysed using thematic analysis, based on the framework approach. Triangulation of study findings was achieved by performing 2 workshops involving both professionals and carers	• Enabling factors to a care's assessment • Impeding factors to carer's assessment • Carer's perceived benefits following a carer assessment
RQIA 2012 **Aim of the study**	• **Carers**: N= 40 • **Professionals**: 65 **Carers**	• **Recruitment period:** 2012 • **Data collection & analysis methods:**	• Finding out about entitlement for access to an assessment

Study and aim of the study	Participants	Methods	Themes
• The aim of this qualitative report was to report presents the findings of Stage 2 of a broader research project (including 1- describing views of carers of their experiences of the Carer's Support and Needs Assessment Tool; and 2 - describing the impact for staff in the implementation and use of the Tool) involving carers of people with different conditions	• Age = N/R • Gender = N/R **Professionals** • Age = N/R • Gender = N/R **Care recipients** • No specific condition	○ Data were collected through focus group interviews ○ No details are reported about the data analysis	• Enabling factors to a care's assessment • Impeding factors to carer's assessment
Stock 2011 **Aim of the study** • The aim of this qualitative study was to explore the experiences of adult carers who have undertaken a carer's needs assessment and explores whether legislation has had a positive effect their caring responsibilities	• **Carers**: N= 6 • **Professionals**: N/A **Carers** • Age = N/R ('working-age') • Gender (M/F/LGBT: N) = 2/4/0 **Professionals** • N/A **Care recipients** • No specific condition (that is end of life, dementia, disability)	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through (face-to-face) semi-structured interviews guided from a topic guide ○ Interview data were analysed using thematic analysis	• Finding out about entitlement for access to an assessment • Enabling factors to a care's assessment • Impeding factors to carer's assessment • Carers' perceived unmet needs during/following a carer's assessment • Carer's perceived benefits following a carer assessment

CSNAT: Carer Support Needs Assessment Tool; F: Female; M: Male; LGBT: Lesbian, Gay, Bisexual, and Transgender; N: Number; N/A: not applicable; N/R: not reported; RQIA: Regulation and Quality Improvement Authority

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 this review did not address a comparison of competing alternatives and only a qualitative review was being undertaken for this question and therefore there was no effectiveness evidence available to inform economic modelling.

Evidence statements

Each evidence statement has an identifying code to ensure ease of reference to the data during presentation and committee discussions. The code is derived from the title of the review and in this case is ‘A’ and then a number. A stands for assessment (of carers as defined by the Care Act 2014).

Finding out about entitlement for access to an assessment

- **A1 Source of information for access to an assessment** There is low quality evidence from 2 studies that many adult carers reported that the common sources of information about entitlement to an assessment came from voluntary sector carers’ organisations, disease-specific charities or information leaflets being available in places such as GP surgeries. Many felt that information about assessments was not always clearly written, understandable or easy to access. Despite having had an assessment some carers still did not understand what entitlement to an assessment meant. Most carers were aware of the information being available online, but they preferred to be given information face-to-face from a professional – as they had no access to the internet and did not know anything about websites.

Impeding factors to a carer’s assessment

- **A2 Obtaining (and waiting for) an assessment** There is low quality evidence from 4 studies that many adult carers reported to have been given an assessment within six months (since they have requested or being offered one), but many others had to wait for an assessment much longer than six months. Those carers waiting six months or more for an assessment reported to be looking after someone at the end of their life or with palliative care needs, and to have requested an assessment (rather than being offered one).
- **A3 Paperwork to obtain a carer’s assessment** There is very low quality evidence from 2 studies that many adult carers felt difficulties in understanding and completing the assessment forms was a major obstacle to their assessment. Some carers who had completed an assessment confirmed that although the process provided valuable emotional support, the assessment form could not be completed without professional help. Some carers felt frustrated by the length of time it took to complete one an assessment.
- **A4 (Negative) Attitudes of health and social care professionals** There is moderate quality evidence from 4 studies that many adult carers felt that the negative attitudes of health and social care professionals involved in the process were a major obstacle to their assessment. Many carers and (hospital) professionals felt that a lack of capacity on the part of professionals could have serious implications for assessment - as carers assessments were not considered part of their usual practice. Other carers and (hospital) professionals reported that certain hospital staff lack skills and awareness in relation to carer issues (for example availability of community support resources).
- **A5 Lack of communication between health and social care services** There is low quality evidence from 2 studies that many adult carers felt that a lack of communication

(and collaboration) between health and social care services involved in the assessment process is a major obstacle to their assessment. Other carers and (hospital) professionals described a purely hospital-based assessment as inadequate; rather, they felt that a two-stage process linking a hospital carer's assessment with follow-up by community staff as essential for ensuring meaningful support for carers during transfer from hospital, often in a crisis situation.

Enabling factors to a carer's assessment

- **A6 Enablers for professionals to implement carers' needs assessment** There is moderate quality evidence from 4 studies that many adult carers and professionals identified several factors which enable professionals to implement carers' needs assessment; training, incorporating carers' assessment into routine care practice, and engaging early with carers as enabling factors. Many professionals involved in carers' assessment felt there is a need for more education and training of staff in person-centred care and greater availability of community resources around carer support. Some professionals made the point that non-mandatory carer assessment training was not taken up by many staff. Many carers and (hospital) professionals agreed the importance of engaging carers as soon as possible with their assessment during the patient's hospital stay, in order to have more time available for discussions (rather than rushing conversations) prior to discharge, and to create an opportunity to 'manage carers' expectations' about their future needs and the amount of available support.

Carers' perceived unmet needs during/following a carer's assessment

- **A7 Focus of assessment more on the needs of the care recipient than on carers' needs** There is low quality evidence from 3 studies that many adult carers reported that their assessment was more focused on the needs of the person they support rather than their own needs as carers. A number of carers said that their assessment had been completed at the same time as the assessment of the care recipient and their needs had not been considered independently or addressed directly.
- **A8 Need to have regular breaks from caring** There is low quality evidence from 4 studies that many adult carers felt their need to have regular breaks from caring was not considered during or following their assessment. Many carers commented on the lack of flexible provision of practical support services after the needs assessment. They said the emphasis was on 'what was available' rather than 'what carers needed' to enable them to improve the overall quality of their lives and their caring role.
- **A9 Need to juggle care with work/education/training** There is low quality evidence from 3 studies that many adult carers did not feel that the support needed to juggle care with work was sufficiently considered during or following their assessment.
- **A10 Need of information or advice** There is low quality evidence from 3 studies that many adult carers reported they received little or no helpful information or advice during their assessment and following. As a result they felt they didn't know how to access support with caring.

Carer's perceived benefits following a carer's assessment

- **A11 Emotional and psychosocial benefits - gaining recognition as a carer** There is low quality evidence from 2 studies that many adult carers reported that the assessment process confirmed their status and identity as carers. Some carers acknowledged the psychosocial and emotional benefits of having a carer's assessment, because of the recognition the assessment process gave them as carers. In particular, they appreciated the exploration of their own needs and feelings, they valued 'being listened to' and the recognition of their work by social services.
- **A12 Practical benefits** There is low quality evidence from 2 studies that many adult carers reported that the assessment process enabled them to address their emotional, practical and psychosocial needs. For instance, some carers felt that support to look after their own mental and physical health was thoroughly considered, other carers felt their

need to have regular breaks from caring was properly addressed through the assessment process.

- **A13 Better awareness of support availability** There is low quality evidence from 2 studies that many adult carers felt that the assessment process provided them with a better awareness of support availability.

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 focussed their discussion mainly on the following five qualitative outcomes (or themes): finding out about entitlement to an assessment (including the source of information about access to an assessment); impeding factors to a carer's assessment (including obtaining - and waiting for - an assessment, paperwork to obtain a carer's assessment, negative attitudes of health and social care professionals, and lack of communication/cooperation between health and social care services); factors enabling access to a carer's assessment (including enablers for professionals to implement carers' needs assessment); carers' perceived unmet needs during/following a carer's assessment (including the focus of assessment on carers' needs, the need to have regular breaks from caring, need to balance care with work/education/training, and the need for information or advice); and carer's perceived benefits following a carer's assessment (including emotional and psychosocial benefits, practical benefits, and better awareness of support availability). All of these themes were reported qualitatively and were considered as important and relevant by the committee, in making recommendations on carers' assessment.

The quality of the evidence

The evidence for the various themes identified in the review ranged from moderate to very low quality, according to GRADE-CERQual. Due to the uncertainty with many of the findings in this review, the committee thought that the evidence should be interpreted with caution when drafting reccomandations.

The quality of the included evidence was mostly downgraded due to adequacy of data, as there was enough data for only a few themes to develop an understanding of the phenomena of interest, either due to insufficient studies (offering poor data) or diversity of carers involved in the studies. For most themes, the overall quality of evidence was also downgraded due to the methodological limitations of the individual studies (relating to recruitment, data collection and analysis). In drafting recommendations, the committee noted that the evidence referred to very specific care settings and carers' circumstances. It was also noted by the committee that the populations of carers in most included studies were mixed (in terms of gender, conditions of people being supported, and geographical setting); so, they agreed that the data from most included studies were applicable across all the UK population of adult carers.

No evidence was found on the views, experiences and preferences of carers and practitioners in relation to the acceptability of integrated community teams, the lead professional approach, and around the whole family approach, so the committee did not make any recommendations relating to these areas. They agreed to recommend further research as regard to whole family approach to carer's assessments as they considered this topic of high priority for research funding. They highlighted that given the Care Act 2014 guidance around combined and integrated assessment and a national drive towards joined up working across the health and social care system the committee considered this a high priority for research funding.

The finding of the review also highlighted certain gaps in evidence, especially as it pertains to the conduct of carer's assessments following the implementation of the Care Act 2014. In particular, no evidence was located about: people's experiences or satisfaction with review arrangements, different approaches to carers' assessments, carers' participation in assessments and the perceived effects of an assessment on carer wellbeing. The committee therefore supplemented the evidence with expert witness testimony supported by their experience and knowledge of what good practice in relation to the conduct of carer's assessment was likely to improve carers' outcomes.

Benefits and harms

Finding out about entitlement for access to an assessment

The committee used the evidence from the review supported by their expertise and knowledge to inform these recommendations. The evidence relating to finding out about entitlement to an assessment showed that information was not always clearly written, understandable or easy to locate. This evidence also demonstrated that even when having received an assessment some carers still did not understand what entitlement to an assessment meant. In addition, the evidence showed that most carers preferred to be given information about assessment face-to-face.. Therefore, the committee noted that there was a gap in between when carers were identified (as carers) and when their assessment happened, a gap that could be filled by informing carers about their statutory right to an assessment, as soon as they were recognised as a carer. Discussing the evidence about entitlement to a carer's assessment, the committee pointed out that some carers did not understand what entitlement to an assessment meant, despite having received an assessment. They therefore recommended that in informing carers about their statutory right to an assessment, professionals must tell carers what exactly a carer's assessment involves and means. The committee also highlighted the importance of health and social care services and professionals cooperating in the process of informing carers about their right to an assessment.

Factors impeding a carer's assessment

Evidence about the factors impeding carer's assessments showed that many carers had to wait for an assessment much longer than six months. Those carers waiting six months or longer for an assessment reported to be looking after a person at the end of life or with palliative care needs. The committee recognised the potentially harmful effects of this, agreeing that the timing of a carer's assessment is critical. They therefore agreed to draft a recommendation on the timing of providing an assessment. They agreed that the timing should be determined by the carer's readiness to participate in an assessment and that the level of urgency should be influenced by the carer's circumstances such as supporting someone at the end of life, level of stress on the carer, and changes to the caring role – including transitions between hospital and home.

The evidence about factors impeding a carer's assessment also demonstrated that many adult carers felt difficulties in understanding and completing the assessment forms, and this represented a major obstacle to their assessment. These data showed also that some carers felt frustrated by the length of time it took to complete an assessment. One suggestion was that carers should be given a copy of the assessment questions in advance, so that they are able to consider and prepare their responses before the assessment. Based on the evidence and their expertise, the committee noted that the process of conducting an assessment should be accessible, proportionate and not onerous. It should also be tailored (or proportionate) to the carers' circumstances and communication needs.

Evidence about factors impeding a carer’s assessment suggested that health and social care professionals often showed negative attitudes, including a lack of capacity or time and the lack of skills and awareness in relation to carer needs and circumstances. The committee agreed that a carer’s assessment should be co-produced, and saw it as the role of the assessor to ensure the carer feels the assessment has been conducted collaboratively.

In line with the Care Act, the committee also highlighted the responsibility of staff to avoid any assumptions about the willingness and the ability of carers to carry out caring tasks. The Care Act (2014) requires that assessments of the cared for person must be ‘carer blind’, meaning that their support needs should be assessed without assumptions about the availability of unpaid care from a friend or family member. The Care Act (2014) also states that carers assessments must include an assessment of how ‘willing’ and how ‘able’ somebody is to provide care. The committee were concerned that assessors might make assumptions about the willingness and ability of potential carers to provide support, and so recommended against this.

The evidence also demonstrated that the lack of communication (and cooperation) between health and social care services and professionals involved in the carers’ assessment process was a major obstacle. Based on their expertise and on this evidence, the committee therefore agreed to recommend that health and social care practitioners conducting or contributing to assessments should work together, sharing information and ensuring all aspects of the carer’s health and wellbeing are covered by the process.

Evidence relating to joint working in this area also showed that a purely hospital-based assessment was felt as “inadequate” and a coordinated approach linking a hospital carer’s assessment with follow-up by community services was felt to be essential. The committee noted that when an assessment of carers’ needs was performed in a hospital setting (whether this assessment was statutory or not) it was relevant and important that such information about carers’ needs fed into the statutory carer’s assessment. They therefore recommended that if a carer’s needs have been identified during a hospital-based assessment these should be communicated to the local authority or a delegated care organisation and that a process should be in place to link a hospital carer’s assessment with the community based statutory assessment. **Factors enabling a carer’s assessment**

The evidence about the barriers and facilitators to obtaining a carers’ assessment demonstrated that there were several factors which could enable professionals to implement carers’ needs assessment; such as, workload and capacity, training and incorporating carers’ assessment into routine care practice. Based on this evidence, the committee agreed to emphasise that health and social care professionals with responsibilities for carrying out or contributing to carers’ assessments should have adequate knowledge and expertise appropriate to their role. Hence, they agreed practitioners tasked with performing assessments should have training and skills in that role and should also have access to advice from specialist colleagues, as necessary.

Carers’ perceived unmet needs during or following a carer’s assessment

The evidence about carers’ perceived unmet needs during or following an assessment demonstrated that assessments were more commonly focused on the needs of the care recipient rather than on carers’ needs. Based on this evidence and the testimonies of two expert witnesses, the committee recommended that an assessment of carers’ needs should be independent but could be linked to the assessment of the care recipient if this is what the care recipient and carer would prefer. Testimony from the expert witnesses also highlighted the importance of conducting carers’ assessments in the context of the wider family and support environment being aware for example, that someone may be caring for more than one person, or may be sharing their care responsibilities with other people. The committee concurred with this and drafted a recommendation accordingly.

Carer’s perceived benefits following a carer’s assessment

The evidence about carer’s perceived benefits of an assessment demonstrated that most often carers acknowledged the psychosocial and emotional benefits of the process, which gave them recognition in their role. The evidence also showed that many carers felt that the assessment process helped to address their practical needs (for example support to look after their own mental and physical health, and support to have regular breaks from their caring responsibilities). Based on this evidence in addition to their expertise, the committee drafted a ‘be aware’ recommendation to highlight the potential therapeutic benefits of conducting a carer’s assessment.

Other related evidence found that following assessments, some carers did not receive the follow up support needed to achieve their desired outcomes. This was perhaps due to the unavailability of carer support resources in the local area, or because the right services aren’t subsequently notified. Since this chimed with their experience, the committee drafted recommendations for action following a carers assessment. They agreed that a clear set of outcomes and actions should be established following assessment and that it is important for carers to be helped to understand those actions and what the next steps will be. They also agreed that assessors should take responsibility to pass on the outcomes of assessments and where appropriate share information with the relevant services for follow up. Finally, if the outcome of an assessment is the development of a carer’s support plan, the committee agreed about the critical importance of ensuring it monitored regularly and updated given that carer’s needs are likely to change over time.

Cost effectiveness and resource use

No existing economic evidence was identified for this review question to assess the acceptability of different tools or approaches for assessing the needs of carers. In the absence of any economic evidence or original analysis, the committee made a qualitative assessment about the cost effectiveness of recommendations relating to this review question.

The committee was of a view that recommendations in relation to the conduct of carers’ assessments are essential in ensuring the success of supporting adult carers and improving their well-being. They also considered that their recommendations are consistent with supporting the statutory rights of carers to a carers’ assessment. The committee did not consider that their recommendations about conducting assessments would require any additional NHS resources over what is necessary to fulfil statutory requirements and therefore they believed their recommendations would be in line with current practice. Information giving is not expensive and the committee considered it would be cost-effective as would facilitate the effective provision of the carers’ assessment, which are judged as important in supporting adult carers. The cost of support that will come in follow-up to an assessment will depend on each case, but assessors should be careful to keep the assessment framed within the feasibility and availability of local resources.

Other factors the committee took into account

The committee heard expert testimony from Bernadette Simpson and John Bangs, respectively senior specialist of a national carer organisation and commissioning manager of a local carer organisation. They heard about assessment of carers, including whole family planning assessments and planning for the caring role. Particularly, an important gap in the evidence was addressed, that related to different approaches to carers’ assessments. The presentation made the case for carers assessments based on consideration of whole family and on integrated approaches, which were being implemented locally. These approaches to conducting carers’ assessment included offering a proactive and joined up approach to needs assessment including a whole family approach that includes the needs of carers and takes into account others in a caring role. It was also discussing how guidance would be needed to foster whole family approaches in doing carers assessments.

In addition to research evidence and expert testimony the committee also took account of Care Act 2014 and associated care and support statutory guidance, and the Children and Families Act 2014 requirements to provide information to carers and to assess the needs of carers in their own right.

References

Carers UK 2016

Carers UK. State of Caring 20176. 2016, London: Carers UK.

Carers UK 2017

Carers UK. State of Caring 2017. 2017, London: Carers UK.

Carers UK 2018

Carers UK. State of Caring 2018. 2018, London: Carers UK.

Ewing 2016

Ewing G, Austin L, Grande G. The role of the Carer Support Needs Assessment Tool in palliative home care: A qualitative study of practitioners' perspectives of its impact and mechanisms of action Palliat Med 2016;30(4):392-400

Ewing 2018

Ewing G, Austin L, Grande G, Gibson D. Who cares for the carers at hospital discharge at the end-of-life? A qualitative study of current practice in discharge planning and the potential value of using the Carer Support Needs Assessment Tool (CSNAT). Palliative Medicine 2018;32(5)

Regulation and Quality Improvement Authority (RQIA) 2012

Review of the Implementation of the Northern Ireland Single Assessment Tool; Stage Two: Carer’s Support and Needs Assessment Tool: Overview Report. Regulation and Quality Improvement Authority (RQIA), August 2012.

Stock 2011

Stock C, Lambert S. Who cares wins? Carers' experiences of assessment since the introduction of the Carers (Equal Opportunities) Act 2004. Research Policy and Planning 2011; 28:173-184

Appendices

Appendix A – Review protocols

Review protocol for review question: What is the acceptability of different tools or approaches for assessing the needs of carers?

Table 3: Review protocol

Field (based on PRISMA-P)	Content
Review question	What is the acceptability of different tools or approaches for assessing the needs of carers?
Type of review question	Qualitative
Objective of the review	The review aims to: • Explore the views, experiences and preferences of carers and practitioners in relation to the conduct of carers' assessments. • Understand the features of a carer's assessment which are perceived to improve carer outcomes. • Identify perceived good practice principles in relation to the conduct of carer's assessment.
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 care professionals who are responsible for conducting carers' assessments. Also any other professionals (including from the health or voluntary sectors) to whom responsibility for carrying out an assessment has been delegated by the local authority.
Eligibility criteria – intervention	Carers' views and experiences of formal carer assessments with any statutory assessment tool or approach will be considered. Professionals' views of conducting a formal carer assessment with any statutory assessment tool or approach will also be considered.
Eligibility criteria – comparator(s)/control or reference (gold) standard	Comparisons will not be relevant to this question.
Outcomes and prioritisation	Expected themes from the qualitative evidence might include:

Field (based on PRISMA-P)	Content
	• Acceptability of and satisfaction with the assessment process (for example a one off meeting or an ongoing conversation) • Approach to carer assessments (for example, integrated approach across health and social care, joint or separate assessments, self-assessments) • Attitudes towards carers during a carer assessment • Carers' participation and wellbeing • Experiences and satisfaction in relation to review arrangements. • Perceived areas of unmet need following a carer assessment and resulting support plan. • Provision of information in advance of and in preparation for a carer's assessment. • Suitability of a statutory assessment tool in identifying all areas of need
Eligibility criteria – study design	• Systematic reviews including qualitative evidence syntheses (that is systematic thematic synthesis, meta-synthesis, and meta-ethnography). • Qualitative studies (including phenomenological studies; ethnographic studies; grounded theory studies; case studies; and action research studies). • Mixed methods studies. • National surveys reporting analyses of qualitative data, including Carers UK Survey, Personal Social Services Survey of Adult Carers, Health and Digital Behaviours Survey 2017 (Teva Pharmaceutical Industries), and Think Local Act Personal (TLAP) Care Act 2014 survey.
Other inclusion exclusion criteria	Additional inclusion criteria • Setting of intervention can be people's own homes and any other health and social care setting (including neighbourhood and community) in which adult carers provide care and support • Only qualitative studies that were conducted in the UK will be considered. • Full-text English-language articles published in or after 2003. Exclusion criteria • Conference abstracts will be excluded as they typically do not provide sufficient information to evaluate risk of bias/quality of study. • Non-English language articles Studies will be prioritised for inclusion if they:

Field (based on PRISMA-P)	**Content**
	• Provide comprehensive data, for example covering a wide section of the review population or cover a wide range of themes • Were published more recently.
Proposed sensitivity/sub-group analysis, or meta-regression	Where data are available, they will be stratified for different groups of carers according to: • Age • Culture and ethnicity • Mutual caring relationships • The setting where the assessment takes place.
Selection process – duplicate screening/selection/analysis	Duplicate 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.
Information sources – databases and dates	Sources to be searched: • ASSIA, CDSR, DARE, Embase, IBSS, Medline, Medline In-Process, PsycINFO, Sociological Abstracts, Social Services Abstracts, Social Policy and Practice Filters: • Systematic review • Qualitative • NICE UK geographic • Standard animal/non-English language exclusion Limits: • Date from 2003
Identify if an update	This review question is not an update.
Author contacts	Developer: The National Guideline Alliance

Field (based on PRISMA-P)	Content
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 G (evidence tables) or H (economic evidence tables) of the guideline.
Data items – define all variables to be collected	For details please see evidence tables in appendix G (evidence tables) or H (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 Surveys would be assessed using the quality checklist for questionnaire surveys (CEBM checklist) listed as the preferred checklist in appendix H of the NICE guideline Manual (2018). 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
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 2014. 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 full guideline.

Field (based on PRISMA-P)	Content
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

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 is the acceptability of different tools or approaches for assessing the needs of carers?

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 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

#	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

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/

#	Searches
7	6 use mesz
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

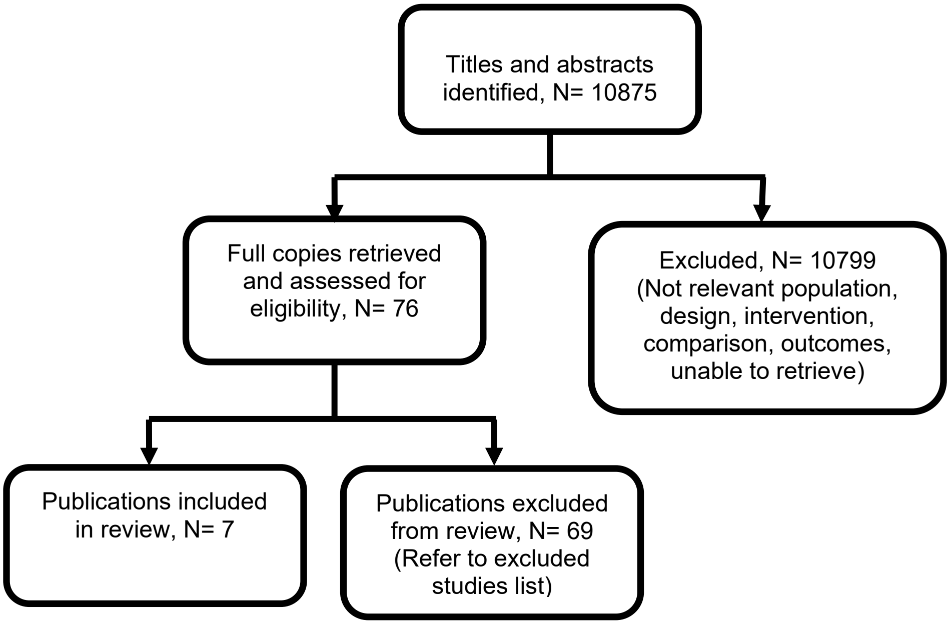
Database: Cochrane Library – Wiley

#	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 is the acceptability of different tools or approaches for assessing the needs of carers?

Figure 2: Study selection flow chart



Appendix D – Evidence tables

Evidence tables for review question: What is the acceptability of different tools or approaches for assessing the needs of carers?

Table 4: Evidence tables

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Full citation Carers, U. K., State of caring 2016, 18, 2016 **Ref Id** 724926 **Country/ies where the study was carried out** UK **Study type** Mixed -methods [Cross-sectional survey including qualitative data] report (not peer-reviewed) **Aim of the study** The aim of this mixed - methods policy report was to understand the state of caring in the UK in 2016 by means of a national on-line survey including a large and varying sample of carers. **Study dates**	**Sample size** • **Carers**: N= 5.682 (78% from England, 9% from Scotland, 8% from Wales and 5% from Northern Ireland) • **Professionals**: N/A **Characteristics** **Carer** • Carer age = Range - years (% of the total sample) = 25-34 (4%), 35-44 (12%), 45-54 (27%), 55-64 (35%), 65 and over (22%) • Carer gender (M/F/LGBT: n) = 1136/4432/N.R. • "Relationship to care recipient"= N/R (35% have been caring 15 years or more, 16% for between 10-14	**Interventions** • **Phenomenon of interest (as reported in the study)**: Carers' experiences of assessment since the Care Act 2014 • **Phenomenon of interest (according to the protocol):** a. Suitability of a statutory assessment tool in identifying all areas of need; b. Perceived	**Details** • **Recruitment strategy**: Online: Self-selected study sample • **Data collection & analysis**: Data were collected through a free online survey "Carers UK State of Caring survey". The survey sample included both current carers and former carers. However, only current carers who completed the survey were included in the data analysis. No details are given about data analysis methods.	**Results** **Survey (quantitative) findings** UK • Barriers to receive an assessment. ENGLAND • Obtaining (and waiting for) an assessment. • Experiences of receiving (and support following) an assessment. ***See appendix M for details about data extracted*** **Qualitative findings** Experiences of Carer's Assessment in the UK Experiences of Carer's Assessment in England • Obtaining an assessment • Waiting for an assessment	**Limitations (assessed using the CASP checklist for qualitative studies)** **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?** - no: not enough information on how carers were recruited. Furthermore the sample was "self-selected", therefore potentially inappropriate to the aims of the research (the selected carers might not be the most appropriate to

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
• **Publication date**: 2016 • **Data collection**: March - April 2016 **Source of funding** N/R	years, 24% for 5-9 years, 23% for 1-4 years and just 3% have been supporting less than one year) **Professionals** • N/A **Care recipient** • Care recipient (condition)= Different conditions (details not reported) **Inclusion criteria** N/R (look at Q4 'recruitment strategy' – details column) **Exclusion criteria** N/R	areas of unmet need following a carer assessment and resulting support plan		• Experiences of receiving an assessment • Support following an assessment ***See appendix M for details about the quotes extracted***	provide access to the type of knowledge sought by the survey) **Q5: Were the data collected in a way that addressed the research issue?** - Yes **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: Unclear description about relationship between researcher and carers during data collection and analysis **Q7: Have ethical issues been taken into consideration?** - Yes **Q8: Was the data analysis sufficiently rigorous?** - Unclear: no 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 (see appendix M for more details on the quotes obtained from the papers)	Comments
					Other information
Full citation Carers, U. K., State of caring 2017, 30, 2017 **Ref Id** 723833 **Country/ies where the study was carried out** UK **Study type** Mixed -methods [Cross-sectional survey including qualitative data] report (not peer-reviewed) **Aim of the study** The aim of this mixed - methods policy report was to understand the state of caring in the UK in 2017 by means of a national on-line survey including a large and varying sample of carers. **Study dates** - **Publication date**: 2017 - **Data collection**: March - May 2017 **Source of funding** N/R	**Sample size** - Carers: N= 6.607 (75% from England, 10% from Scotland, 7% from Wales and 9% from Northern Ireland) - Professionals: N/A **Characteristics** **Carer** - Carer age = Range - years (% of the total sample) = 25-34 (4%), 35-44 (13%), 45-54 (29%), 55-64 (34%), 65 and over (19%) - Carer gender (M/F/LGBT: n) = 1321/5153/198 - "Relationship to care recipient"= N/R (33% have been caring 15 years or more, 15% for between 10-14 years, 23% for 5-9 years, 25% for 1-4 years and just 3% have been supporting less than one year) **Professionals** - N/A	**Interventions** - **Phenomenon of interest (as reported in the study)**: Carers' experiences of assessment since the Care Act 2014 - **Phenomenon of interest (according to the protocol):** a. Suitability of a statutory assessment tool in identifying all areas of need; b. Perceived areas of unmet need following a carer assessment and resulting support plan	**Details** - **Recruitment strategy**: Online: Self-selected study sample - **Data collection & analysis**: Data were collected through a free online survey "Carers UK State of Caring survey". The survey sample included both current carers and former carers. However, only current carers who completed the survey were included in the data analysis. No details are given about data analysis methods.	**Results** **Survey (quantitative) findings** UK - Unmet needs following an assessment. ENGLAND - Obtaining (and waiting for) an assessment. - Experiences of receiving (and support following) an assessment. ***See appendix M for details about data extracted*** **Qualitative findings** Experiences of Carer's Assessment in the UK Experiences of Carer's Assessment in England - Obtaining an assessment - Waiting for an assessment - Experiences of receiving an assessment ***See appendix M for details about the quotes extracted***	**Limitations (assessed using the CASP checklist for qualitative studies)** **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?** - no: please see Carers UK 2016 - **Q5: Were the data collected in a way that addressed the research issue?** - Yes **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: please see Carers UK 2016 **Q7: Have ethical issues been taken into consideration?** - Yes **Q8: Was the data analysis sufficiently rigorous?** -

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
	Care recipient • Care recipient (condition)= Different conditions (details not reported) **Inclusion criteria** N/R (look at the 'recruitment strategy') **Exclusion criteria** N/R				Unclear: please see Carers UK 2016 **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 **Other information**
Full citation Carers UK, State of Caring, 2018 **Ref Id** 963872 **Country/ies where the study was carried out** UK **Study type** Mixed -methods [Cross-sectional survey including qualitative data] report (not peer-reviewed) **Aim of the study** The aim of this mixed -methods policy report was to understand the state of caring in the UK in 2018 by means	**Sample size** • **Carers**: N= 6.828 (75% from England, 8% from Northern Ireland, 9% from Scotland, and 8% from Wales) • **Professionals**: N/A **Characteristics** **Carer** • Carer age = Range - years (% of the total sample) = 25-34 (4%), 35-44 (12%), 45-54 (30%), 55-64 (33%), 65 and over (20%) • Carer gender (M/F/LGBT: n) = 1365/5325/204	**Interventions** • **Phenomenon of interest (as reported in the study): Carers'** experiences of assessment since the Care Act 2014 • **Phenomenon of interest (according to the protocol):** a. Suitability of a statutory assessment	**Details** • **Recruitment strategy**: Online: Self-selected study sample • **Data collection & analysis**: Data were collected through a free online survey "Carers UK State of Caring survey". The survey sample included both current carers and former carers. However, only current carers who completed the survey were included in the data analysis. No details are given about data analysis methods.	**Results** **Survey (quantitative) findings** UK • Unmet needs following an assessment. ENGLAND ○ Obtaining (and waiting for) an assessment. • Experiences of receiving (and support following) an assessment. ***See appendix M for details about data extracted*** **Qualitative findings**	**Limitations (assessed using the CASP checklist for qualitative studies)** **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?** - no: please see Carers UK 2016 **Q5: Were the data collected in a way that**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
of a national on-line survey including a large and varying sample of carers. **Study dates** • **Publication date**: 2018 • **Data collection**: March - May **2018** **Source of funding** N/R	• "Relationship to care recipient"= N/R (33% have been caring 15 years or more, 15% for between 10-14 years, 24% for 5-9 years, 25% for 1-4 years and just 3% have been supporting less than one year) **Professionals** • N/A **Care recipient** • Care recipient (condition)= Different conditions (details not reported) **Inclusion criteria** • N/R (look at the 'recruitment strategy') **Exclusion criteria** • N/R	tool in identifying all areas of need; b. Perceived areas of unmet need following a carer assessment and resulting support plan		Experiences of Carer's Assessment in the UK Experiences of Carer's Assessment in England • Obtaining an assessment • Waiting for an assessment • Experiences of receiving an assessment ***See appendix M for details about the quotes extracted***	**addressed the research issue?** - Yes **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: please see Carers UK 2016 **Q7: Have ethical issues been taken into consideration?** - Yes **Q8: Was the data analysis sufficiently rigorous?** - Unclear: please see Carers UK 2016 **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 **Other information**
Full citation Ewing, G., Austin, L., Grande, G., The role of the Carer Support Needs Assessment Tool in palliative home care: A qualitative	**Sample size** • **Carers**: N/A • **Professionals**: N =29 **Characteristics** **Carer**	**Interventions** • **Phenomenon of interest (as reported in the study)**: Carer Support	**Details** • **Recruitment strategy**: Participants were recruited purposively from 2 care setting: one small hospice at home service (Setting A), and a large	**Results** • Post-implementation: CSNAT for carer-led assessment ○ Visibility of carers' support needs.	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
study of practitioners' perspectives of its impact and mechanisms of action, Palliative Medicine, 30, 392-400, 2016 **Ref Id** 724779 **Country/ies where the study was carried out** England: Manchester **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aim of this qualitative study was to examine practitioner perspectives of carer assessment before-and-after implementation of the Carer Support Needs Assessment Tool (CSNAT) intervention, in order to identify its impact and mechanisms of action **Study dates** - **Publication date**: 2012 - **Data collection**: N/R **Source of funding**	- N/A **Professionals** - Mean (range - years): N/R [Length of time in post ranged from 1 to 12 years] **Care recipient** - Care recipient (condition)= End of life/Palliative care **Inclusion criteria** N/R (look at Q4 'recruitment strategy' – details column – details column) **Exclusion criteria** N/R	Needs Assessment Tool in palliative home care - **Phenomenon of interest (according to the protocol):** a. Perceived areas of unmet need following a carer assessment and resulting support plan; b. Attitudes towards carers during a carer assessment; c. Acceptability of and satisfaction with the assessment process; d. Provision of information in advance of and in preparation	hospice home-care (HHC) organisation with both a hospice at home service and a community-based specialist palliative care. Recruitment was purposive to ensure that participants were from contrasting geographical locations (urban/rural) with different service sizes and staff composition, ensuring contextual diversity. - **Data collection & analysis**: Data were collected through 9 focus group interviews, facilitated by two researchers and carried out pre and post CSNAT implementation. All interviews were audio-taped, and transcribed. A thematic analysis was conducted, based on the framework approach. The analysis process involved two researchers.	○ Legitimacy of support for carers ○ Different types of conversations with carers - Mechanisms of action ○ Creating a space for the separate needs of carers. ○ Providing an opportunity to express needs. ○ Carer prioritised support needs.	**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?** - Unclear: Unclear description about relationship between researcher and carers during data collection and analysis **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 (see appendix M for more details on the quotes obtained from the papers)	Comments
The pilot work was funded by the Phillip Poole-Wilson Seed Corn Fund, the BUPA Foundation (Grant reference number 22094791). The feasibility study was supported by a grant from Dimbleby Cancer Care Research Fund.		for a carers assessment.			**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 **Other information**

Full citation
Ewing, G., Austin, L., Jones, D., Grande, G., Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach, Palliative Medicine, 32, 939-949, 2018
Ref Id
956499
Country/ies where the study was carried out
England (Manchester)
Study type
	Sample size
	• **Carers**: N=22 (21 bereaved, 1 current carer)
	• **Professionals**: N=40
	Characteristics
	Carer
	• Carer age = Range (years): 21-80
	• Carer gender (M/F/LGBT: n) = 3/19/0
	• "Relationship to care recipient"= parents (n): 2; spouses (n): 1; daughters-sons (n): 3; sibling (n): 0; other/undisclosed (n): 0
	Professionals
	• N=29 Hospital-based
		Interventions
		• **Phenomenon of interest (as reported in the study)**: The Carer Support Needs Assessment Tool (CSNAT) Approach for the carers at hospital discharge at the end of life
		• **Phenomenon of interest (according to the protocol):** a. Perceived areas of
			Details
			• **Recruitment strategy**: Participants were recruited purposively from three National Health Service (NHS) Trusts in England. Carers were recruited by in these sites to guarantee a diverse population in terms of social deprivation, ethnicity and urban/rural areas. Practitioners were purposively sampled from teams involved in discharge of patients with a palliative condition to home (specialist palliative care, complex discharge, community Macmillan and district nursing teams) aiming for broad representation of different healthcare professionals (HCPs).
				Results
				• utility of The CSNAT Approach for hospital discharge
				  ○ Legitimising support for carers themselves.
				  ○ Visibility of support needs.
				  ○ Assisting communication of support needs.
				  ○ Facilitating discussion with carers of caregiving at EOL and support at home.
				• fit of The CSNAT Approach within a hospital context
				  ○ Organisational factors
				  ○ Responsibility for the process of carer assessment.
				  ○ Time and workload capacity.
					Limitations (assessed using the CASP checklist for qualitative studies)
					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

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Qualitative study (peer-reviewed) **Aim of the study** The aim of this study was to explore whether and how family carers are currently supported during patient discharge at the end of life; to assess perceived benefits, acceptability and feasibility of using The Carer Support Needs Assessment Tool (CSNAT) Approach in the hospital setting to support carers **Study dates** - **Publication date**: 2012 - **Data collection**: N/R **Source of funding** The study was funded by a Marie Curie Project Award – reference no. MCCC-RP-14-A17071. The work was supported by NIHR CLAHRC Greater Manchester.	- N=11 Community-based **Care recipient** - Care recipient (condition)= End of life/Palliative care **Inclusion criteria** N/R (look at Q4 'recruitment strategy' – details column) **Exclusion criteria** N/R	unmet need following a carer assessment and resulting support plan; b. Attitudes towards carers during a carer assessment; c. Acceptability of and satisfaction with the assessment process; d. Provision of information in advance of and in preparation for a carers assessment.	- **Data collection & analysis**: a. Professionals - Data were collected through 8 focus group interviews lasting 35–105 min, facilitated by two researchers and guided from a topic guide including 4 broad elements: 1) current assessment processes leading up to patient discharge including involvement of carers; 2) exploration of carer-related concerns surrounding discharge; 3) initial views of the CSNAT and its person-centred approach and; 4) when/how The CSNAT Approach may be used at discharge to improve carer support. b. Carers - Data were collected through (face-to-face) open interviews guided from a topic guide including 2 broad elements: 1) exploration of carer's experience of the discharge process; 2) Carers' views about the CSNAT. All interviews were audio-taped, and transcribed. A thematic analysis was conducted, based on the	○ Skills and training ○ Incorporating The CSNAT Approach into routine practice ○ Earlier engagement with carers. ○ A two-stage process of assessment ○ CSNAT as a carer-held record.	**Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: Unclear description about relationship between researcher and carers during data collection and analysis **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 **Overall methodological limitations** - Minor **Other information**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
			framework approach. The analysis process involved two researchers. Triangulation of study findings was achieved by performing 2 workshops involving both health care professionals and carers.		

Full citation
Regulation, Quality Improvement, Authority, Review of the implementation of the Northern Ireland single assessment tool: stage two: carer's support and needs assessment tool: overview report, 61p., 2012
Ref Id
705303
Country/ies where the study was carried out
UK: Northern Ireland
Study type
Qualitative study (no peer-reviewed)
Aim of the study
The aims of this qualitative report were to report presents the findings of Stage 2
	Sample size
	• **Carers**: N= 40
	• **Professionals**: N = 65
	Characteristics
	Carer
	• Carer age = N/R
	• Carer gender (M/F: n) = N/R
	• "Relationship to care recipient"= N/R
	Professionals
	• N/R
	Care recipient
	• Care recipient (condition)= Different conditions (details not reported)
	Inclusion criteria
	N/R (look at the 'recruitment strategy')
	Exclusion criteria
	N/R
		Interventions
		• **Phenomenon of interest (as reported in the study)**: [Northern Ireland] Carer's Support and Needs Assessment Tool (which is a component of the Northern Ireland Single Assessment Tool within the Older People's Programme of Care)
		• **Phenomenon of interest (according to the**
			Details
			• **Recruitment strategy**: All participants were from the five trust areas in which was implemented this research. Professionals recruited were staff members who work in the older people's programme of care. These staff members had experience of completing carer's support and needs assessments with carers. Recruited carers were all receiving services from the older people's programme of care. It is unclear whether the recruitment process was purposive or not.
			• **Data collection & analysis**: Data were collected through 10 focus group interviews (n=5 for cares and n=5 for HCP). Health care professionals' (HCP) focus groups were
				Results
				• Focus Group Interviews with Trust Staff
				  ○ Training
				  ○ Carer's Support and Needs Assessment Tool
				  ○ Engagement with Carers
				• Focus Group Interviews with Carers
				  ○ Carer Information
				  ○ Experience of the Carer's Support and Needs Assessment Tool
				  ○ Information about a carer's assessment
				  ○ Services to address carers' health and wellbeing
					Limitations (assessed using the CASP checklist for qualitative studies)
					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 on how carers/professionals were selected/recruited
					Q5: Were the data collected in a way that addressed the research

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
(including 1- describing views of carers of their experiences of the Carer's Support and Needs Assessment Tool; and 2 - describing the impact for staff in the implementation and use of the Tool) in carers of people with different conditions. **Study dates** - **Publication date**: 2012 - **Data collection:** 2012 **Source of funding** Department of Health, Social Services and Public Safety (DHSSPS) - Northern Ireland		**protocol):** a. **Attitudes** towards carers during a carer assessment; b. Acceptability of and satisfaction with the assessment process	guided from a topic guide including 3 broad elements: 1) Training in the use of the Carer's Support and Needs Assessment tool; 2) The use of the Carer's Support and Needs Assessment Tool; and 3) Engagement with carers. HCP focus groups were guided from a topic guide including 3 broad elements: 1) the types of carer information provided to them by the trust; 2) their experience of the completion of Carer's Support and Needs Assessment Tool; and 3) carers' services offered to them in relation to supporting their health and wellbeing. No details on data analysis were reported		**issue?** - no: no details on data collection methods are reported, furthermore theoretical sufficiency/ saturation of data has not been discussed **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: Unclear description about relationship between researcher and carers during data collection and analysis **Q7: Have ethical issues been taken into consideration?** - Yes **Q8: Was the data analysis sufficiently rigorous?** - Unclear: no 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 **Other information**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Full citation Stock Christine, Lambert Susan, Who cares wins? Carers' experiences of assessment since the introduction of the Carers (Equal Opportunities) Act 2004, Research Policy and Planning, 28, 173-184, 2011 **Ref Id** 717943 **Country/ies where the study was carried out** Wales: Swansea **Study type** Qualitative study (peer-reviewed) **Aim of the study** The aim of this qualitative study was to explore the experiences of adult carers who have undertaken a carer's needs assessment and explore whether legislation has had a positive effect in supporting their caring role **Study dates**	**Sample size** • **Carers**: N= 6 • **Professionals**: N/A **Characteristics** **Carer** • Carer age = N/R ('working-age') • Carer gender (M/F/LGBT: n) = N=2/4/0 • "Relationship to care recipient"= parents (n): 2; spouses (n): 1; daughters-sons (n): 3; sibling (n): 0; other/undisclosed (n): 0 **Professionals** • N/A **Care recipient** • Care recipient (condition)= Different conditions (including end of life, dementia, disability) **Inclusion criteria** Carers had to have undertaken a carer's assessment in the previous six months and to be of working age. **Exclusion criteria**	**Interventions** • **Phenomenon of interest (as reported in the study)**: Carers' experiences of **assessment** since the Carers (Equal Opportunities) Act 2004 • **Phenomenon of interest (according to the protocol):** Carers' **views** and experiences of formal carer assessments	**Details** • **Recruitment strategy**: Participants were recruited purposively from voluntary sector carer organisations in three local authority areas. The sampling approach was aimed to recruit carers who would have in-depth, recent experience relevant to the aims of the study. • **Data collection & analysis**: Data were collected through (face-to-face) interviews using open ended questions guided from a topic guide including 5 broad elements: 1) Availability of clear, published eligibility criteria and ease of access to an assessment; 2) Provision of information to carers; 3) Whether the assessment focussed on the desired outcomes of the carer; 4) Identification of gaps in services and actions taken in partnership with carers to address these; and 5) Awareness of and signposting to the multiple agencies involved in supporting caregivers and	**Results** • Finding out about entitlement to an assessment; • Gaining recognition as a carer; • Partnership working with service professionals; • Carers' awareness of support availability; • Did the assessment meet carers' desired outcomes? • Carers' unmet needs in relation to education, work and leisure.	**Limitations (assessed using the CASP checklist for qualitative studies)** **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?** - Unclear: Unclear description about relationship between researcher and carers during data collection and analysis

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
- **Publication date**: 2012 - **Data collection**: N/R **Source of funding** N/R	N/R (look at the inclusion criteria)		recipients. All interviews were audio-taped, and transcribed. Interview data were analysed using thematic analysis.		**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 **Overall methodological limitations** - minor **Other information**

CSNAT: the Carer Support Needs Assessment Tool; F: Female; M: Male; LGBT: Lesbian, Gay, Bisexual, and Transgender; N: Number; N/A: not applicable; N/R: not reported; RQIA: Regulation and Quality Improvement Authority

Appendix E – Forest plots

Forest plots for review question: What is the acceptability of different tools or approaches for assessing the needs of carers?

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 is the acceptability of different tools or approaches for assessing the needs of carers?

Table 5: Summary of evidence (GRADE-CERQual), ID Theme 1. Finding out about entitlement to a carer's 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**
Source of information for access to an assessment							
2 (RQIA 2012; Stock 2011)	1: Focus group 1: Semi-structured interviews	Many adult carers reported that the common sources of information about entitlement to an assessment came from voluntary sector carers' organisations, disease-specific charities or information leaflets being available in places such as GP surgeries. Many felt that information about assessments was not always clearly written, understandable or easy to access. Despite having had an assessment some carers still did not understand what entitlement to an assessment meant. Most carers were aware of the information being available online, but they preferred to be given information face-to-face from a professional – as they had no access to the internet and did not know anything about websites.	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW

1 Evidence was downgraded due to moderate methodological limitations (Both papers reported unclear detail about the relationship between researcher and carers during data collection and analysis, furthermore theoretical sufficiency/ saturation of data has not been discussed in both researches)
2 Evidence was downgraded due to substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering thin data)

Table 6: **Summary of evidence (GRADE-CERQual), ID Theme 2. Impeding factors to a carer's 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
Obtaining (and waiting for) an assessment							
4 (Carers UK 2016; Carers UK 2017; Carers UK 2018; Stock 2011)	3: Online survey 1: Semi-structured interviews	Many adult carers reported to have been given an assessment within six months (since they have requested or being offered one), but many others had to wait for an assessment much longer than six months. Those carers waiting six months or more for an assessment reported to be looking after someone at the end of their life or with palliative care needs, and to have requested an assessment (rather than being offered one)	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Minor concerns[2]	LOW
Paperwork to obtain a carer's assessment							
2 (RQIA 2012; Stock 2011)	1: Focus group 1: Semi-structured interviews	Many adult carers felt difficulties in understanding and completing the assessment forms was a major obstacle to their assessment. Some carers who had completed an assessment confirmed that although the process provided valuable emotional support, the assessment form could not be completed without professional help. Some carers felt frustrated by	Serious concerns[3]	No or very minor concerns	No or very minor concerns	Serious concerns[4]	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
		the length of time it took to complete one an assessment.					
(Negative) Attitudes of health and social care professionals							
4 (RQIA 2012; Ewing 2016; Ewing 2018; Stock 2011)	3: Focus group 1: Semi-structured interviews	Many adult carers felt that the negative attitudes of health and social care professionals involved in the process were a major obstacle to their assessment. Many carers and (hospital) professionals felt that a lack of capacity on the part of professionals could have serious implications for assessment - as carers assessments were not considered part of their usual practice. Other carers and (hospital) professionals reported that certain hospital staff lack skills and awareness in relation to carer issues (for example availability of community support resources).	Moderate concerns[5]	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE
Lack of communication between health and social care services							
2 (Stock 2011; Ewing 2018)	1: Focus group 1: Semi-structured interviews	Many adult carers expressed the lack of communication (and collaboration) between health and social care services involved in the assessment process a major obstacle to their assessment. Many carers highlighted how the lack of communication between health and social care services (even when their needs were identified)	Minor concerns[6]	No or very minor concerns	No or very minor concerns	Serious concerns[4]	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
		could be an important issue, as they were not been told of their right to a carers' assessment. Other carers and (hospital) professionals described as insufficient a hospital-based assessment alone; rather, they felt that a two-stage process linking hospital carer assessment with follow-up by community staff as essential, to ensure meaningful support for carers at discharge from the hospital (in a transition, often in a crisis situation).					

1 Evidence was downgraded due to major methodological limitations (Carers UK 2016; Carers UK 2017; Carers UK 2018: not enough information on how carers were recruited. Furthermore, the sample was "self-selected", therefore potentially inappropriate to the aims of the research (the selected carers could not be the most appropriate to provide access to the type of knowledge sought by the survey. Additionally, no details were provided on data collection and analysis methods)
2 Evidence was downgraded due to minor concerns with the adequacy of data, as only 4 studies supported the review's findings (offering unclear data)
3 Evidence was downgraded due to substantial methodological limitations (RQIA 2012: no details on the recruitment strategy, data collection and analysis methods, and whether saturation was achieved in terms of data collection or data analysis; Stock 2011: Unclear description about relationship between researcher and carers during data collection and analysis, additionally, theoretical sufficiency/ saturation of data has not been discussed)
4 Evidence was downgraded due to substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering thin data)
5 Evidence was downgraded due to potential methodological limitations (Stock 2011: Unclear description about relationship between researcher and carers during data collection and analysis, additionally, theoretical sufficiency/ saturation of data has not been discussed; RQIA 2012: no details on the recruitment strategy, data collection and analysis methods, and whether saturation was achieved in terms of data collection or data analysis; Ewing 2016 and Ewing 2018: theoretical sufficiency/ saturation of data has not been discussed)
6 Evidence was downgraded due to minor methodological limitations (Stock 2011: Unclear description about relationship between researcher and carers during data collection and analysis, additionally, theoretical sufficiency/ saturation of data has not been discussed; Ewing 2018: theoretical sufficiency/ saturation of data has not been discussed)

Table 7: Summary of evidence (GRADE-CERQual), ID Theme 3. Enabling factors to a carer's 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
Enablers for professionals to implement carers' needs assessment							
4 (Ewing 2016;	3: Focus group	Many adult carers and professionals identified	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

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
Ewing 2018; RQIA 2012; Stock 2011)	1: Semi-structured interviews	several factors which enable professionals to implement carers' needs assessment; training, incorporating carers' assessment into routine care practice, and engaging early with carers as factors Many professionals involved in carers' assessment felt the is a need for more education and training of staff in person-centred care and greater availability of community resources around carer support. Some professionals made the point that non-mandatory carer assessment training was not taken up by many staff. Many carers and (hospital) professionals agreed the importance of engaging carers as soon as possible with their assessment during the patient's hospital stay, in order to have more time available for discussions (rather than rushing conversations) prior to discharge, and to create an opportunity to 'manage carers' expectations' about their future needs and the amount of available support					

1 Evidence was downgraded due to potential methodological limitations (Stock 2011: Unclear description about relationship between researcher and carers during data collection and analysis, additionally, theoretical sufficiency/ saturation of data has not been discussed; RQIA 2012: no details on the recruitment strategy, data collection and *analysis methods, and whether saturation was achieved in terms of data collection or data analysis; Ewing 2016 and Ewing 2018: theoretical sufficiency/ saturation of data has not been discussed)*

Table 8: Summary of evidence (GRADE-CERQual), ID Theme 5. Carers' perceived unmet needs during/following a carer's 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**
Focus of assessment more on the needs of the care recipient person than on carers' needs.							
3 (Carers UK 2017; Carers UK 2018; Stock 2011)	2: Online survey 1: Semi-structured interviews	Many adult carers reported that their assessment was more focused on the needs of the person they support rather than their own needs as carers. A number of carers said that their assessment had been completed at the same time as the assessment of the care recipient and their needs had not been considered independently or addressed directly.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Minor concerns[2]	LOW
Need to have regular breaks from caring							
4 (Carers UK 2016; Carers UK 2017; Carers UK 2018; Stock 2011)	3: Online survey 1: Semi-structured interviews	Many adult carers felt their need to have regular breaks from caring was not considered during or following their assessment. Many carers commented on the lack of flexible provision of practical support services after the needs assessment. They said the emphasis was on 'what was available' rather than 'what carers needed' to enable them to improve the overall quality of their lives and their caring role.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Minor concerns[3]	LOW
Need to juggle care with work/education/training							

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
3 (Carers UK 2016; Carers UK 2018; Stock 2011)	2: Online survey 1: Semi-structured interviews	Many adult carers did not feel that the support needed to juggle care with work was sufficiently considered during or following their assessment.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Minor concerns[2]	LOW
Need of information or advice							
3 (Carers UK 2016; Carers UK 2017; Stock 2011)	2: Online survey 1: Semi-structured interviews	Many adult carers reported they received little or no helpful information or advice during their assessment and following. As a result they felt they didn't know how to access support with caring.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Minor concerns[2]	LOW

1 Evidence was downgraded by 1due to serious methodological limitations in many studies that contributed to the review findings (Carers UK 2016; Carers UK 2017; Carers UK 2018: not enough information on how carers were recruited. Furthermore, the sample was "self-selected", therefore potentially appropriate to the aims of the research (they selected carers could not be the most appropriate to provide access to the type of knowledge sought by the survey. Additionally, no details were provided on data collection and analysis methods)

2 Evidence was downgraded due to minor concerns with the adequacy of data, as only 3 studies supported the review's findings (offering unclear data)

3 Evidence was downgraded due to minor concerns with the adequacy of data, as only 4 studies supported the review's findings (offering unclear data)

Table 9: Summary of evidence (GRADE-CERQual), ID Theme 6. Carer's perceived benefits following a carer's 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
Emotional and psychosocial benefits - gaining recognition as a carer							
2 (Ewing 2018; Stock 2011)	1: Focus group 1: Semi-structured interviews	Many adult carers reported that the assessment process confirmed their status and identity as carers. Some carers acknowledged the psychosocial and emotional benefits of having a carer's assessment, because of the recognition the assessment process gave them as carers. In particular, they appreciated	Minor concerns[1]	No or very minor concerns	No or very 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**
		the exploration of their own needs and feelings, they valued 'being listened to' and the recognition of their work by social services.					
Practical benefits							
2 (Ewing 2018; Stock 2011)	1: Focus group 1: Semi-structured interviews	Many adult carers reported that the assessment process enabled them to address their emotional, practical and psychosocial needs. For instance, some carers felt that support to look after their own mental and physical health was thoroughly considered, other carers felt their need to have regular breaks from caring was properly addressed through the assessment process.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Moderate concerns[2]	LOW
Better awareness of support availability							
2 (Ewing 2018; Stock 2011)	1: Focus group 1: Semi-structured interviews	Many adult carers felt that the assessment process provided them with a better awareness of support availability	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Moderate concerns[2]	LOW

1 Evidence was downgraded due to minor methodological limitations (Stock 2011: Unclear description about relationship between researcher and carers during data collection and analysis, additionally, theoretical sufficiency/ saturation of data has not been discussed; Ewing 2018: theoretical sufficiency/ saturation of data has not been discussed)

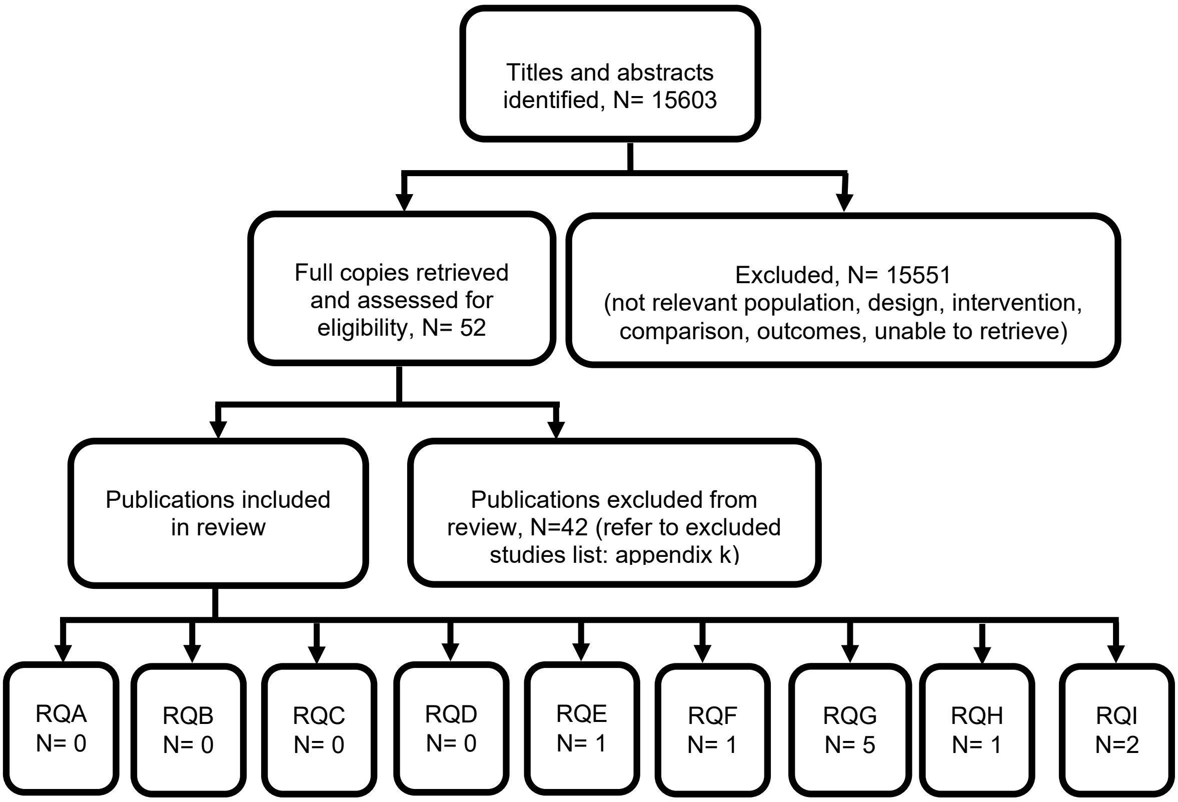
2 Evidence was downgraded due to substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering thin data)

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What is the acceptability of different tools or approaches for assessing the needs of carers?

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

Economic evidence study selection for review question: What is the acceptability of different tools or approaches for assessing the needs of carers?

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

Appendix I – Economic evidence profiles

Economic evidence study selection for review question: What is the acceptability of different tools or approaches for assessing the needs of carers?

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

Appendix J – Economic analysis

Economic evidence study selection for review question: What is the acceptability of different tools or approaches for assessing the needs of carers?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: What is the acceptability of different tools or approaches for assessing the needs of carers?

Qualitative studies

Table 10: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Andrews Nick, Driffield Deborah, Poole Vicky, All together now: a collaborative and relationship-centred approach to improving assessment and care management with older people in Swansea, Quality in Ageing, 10, 12-23, 2009	No concept phenomenon of interest: no assessment of carers' needs.
Aoun, S. M., Deas, K., Kristjanson, L. J., Kissane, D. W., Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool, Palliative & supportive care, 15, 32-43, 2017	No UK evidence.
Bakker, C., Millenaar, J., het Need, Y. D. projectteam, Care needs and experiences of relatively young people (< 65 years) with dementia and their relatives, Huisarts en Wetenschap, 57, 633-635, 2014	Article in Dutch.
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	No UK evidence.
Boland, J. W., Reigada, C., Yorke, J., Hart, S. P., Bajwah, S., Ross, J., Wells, A., Papadopoulos, A., Currow, D. C., Grande, G., Macleod, U., Johnson, M. J., The Adaptation, Face, and Content Validation of a Needs Assessment Tool: Progressive Disease for People with Interestitial Lung Disease, Journal of Palliative Medicine, 19, 549-555, 2016	No qualitative data.
Brown, S. A., Mnemonics for assessing and addressing spiritual care needs of the caregiver, Southern Medical Journal, 108, 67, 2015	Not a qualitative study design.
Cameron I, D., et al.,, Assessing and helping carers of older people, British Medical Journal, 24, 630-633, 2011	No qualitative data on adult unpaid carers.
Carers, U. K., State of caring 2014, 2014	This report does not include qualitative data on cares' assessment.
Carers, U. K., State of caring 2015, 2015	This report does not include qualitative data on cares' assessment.
Carers, U. K., The state of caring 2013, 8, 2013	This report does not include qualitative data on cares' assessment.
Centre For Mental, Health, Supporting carers: mental health carers' assessments in policy and practice	No qualitative data.
Charlesworth, G. M., Tzimoula, X. M., Newman, S. P., Carers Assessment of Difficulties Index (CADI): psychometric	No concept/ phenomenon of interest: no assessment of carers' needs.

Study	Reason for Exclusion
properties for use with carers of people with dementia, Aging & mental health, 11, 218-25, 2007	
Chow, T. W., Pio, F. J., Rockwood, K., An international needs assessment of caregivers for frontotemporal dementia, Canadian Journal of Neurological Sciences, 38, 753-7, 2011	No UK evidence.
Clay Dan, et al.,, The lives of young carers in England: qualitative report to DfE, 135, 2016	No qualitative data.
Coleman, E. A., Ground, K. L., Maul, A., The Family Caregiver Activation in Transitions (FCAT) Tool: A New Measure of Family Caregiver Self-Efficacy, Joint Commission journal on quality and patient safety / Joint Commission Resources, 41, 502-507, 2015	No UK evidence.
Deshields, T. L., Applebaum, A. J., The time is now: assessing and addressing the needs of cancer caregivers, Cancer, 121, 1344-6, 2015	Not a qualitative study design.
Diffin, J., Ewing, G., Harvey, G., Grande, G., Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: a qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention, BMC Palliative Care, 17, 129, 2018	No phenomenon of interest: this paper does not focus on the acceptability of different tools or approaches for assessing the needs of carers.
Diffin, J., Ewing, G., Harvey, G., Grande, G., The Influence of Context and Practitioner Attitudes on Implementation of Person-Centered Assessment and Support for Family Carers Within Palliative Care, Worldviews on evidence-based nursing, 15, 377-385, 2018	No phenomenon of interest.
Diffin, Janet, Ewing, Gail, Grande, Gunn, Facilitating successful implementation of the carer support needs assessment tool (CSNAT) intervention within palliative care, BMJ supportive & palliative care, 6, 391, 2016	No study design.
Diffin, Janet, Ewing, Gail, Grande, Gunn, The influence of organisational context and practitioner attitudes on implementation of the carer support needs assessment tool (CSNAT) intervention, BMJ supportive & palliative care, 6, 391, 2016	No study design.
Ewing, G., Brundle, C., Payne, S., Grande, G., The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: A validation study, Journal of Pain and Symptom Management, 46, 395-405, 2013	No qualitative data
Ewing, Gail, Grande, Gunn, Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study, Palliative Medicine, 27, 244-56, 2013	This paper aims to identify carer needs and then it describes how the findings were used to create a carer assessment tool. Neither of these could be classed as describing experiences of assessments.
Feinberg, Lynn, Caregiver Assessment, Journal of Social Work Education, 44, 39-41, 2008	No UK evidence.
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	No UK evidence.
Gamiz Rebecca, Tsegai Abenet, Carer's assessment and outcomes focused approaches to working with carers: a joint project between Midlothian Council Community Care team and VOCAL, Midlothian Carers Centre, 83, 2013	No concept phenomenon of interest: no assessment of carers' needs.

Study	Reason for Exclusion
Guberman Nancy, et al.,, Impacts on practitioners of using research-based carer assessment tools: experiences from the UK, Canada and Sweden, with insights from Australia, Health and Social Care in the Community, 11, 345-355, 2003	No study design.
Haigh, Rachel, Treasure, Janet, Investigating the needs of carers in the area of eating disorders: Development of the Carers' Needs Assessment Measure (CaNAM), European Eating Disorders Review, 11, 125-141, 2003	No qualitative data - This article doesn't seem to provide qualitative data about participants' experiences of using the measure.
Hamity, C., Jackson, A., Peralta, L., Bellows, J., Perceptions and Experience of Patients, Staff, and Clinicians with Social Needs Assessment, The Permanente journal, 22, 2018	No UK evidence.
Hanson, Elizabeth, Magnusson, Lennart, Nolan, Janet, Swedish experiences of a negotiated approach to carer assessment: The Carers Outcome Agreement Tool, Journal of Research in Nursing, 13, 391-407, 2008	No UK evidence.
Hein, A., Steen, E. E., Thiel, A., Hulsken-Giesler, M., Wist, T., Helmer, A., Frenken, T., Isken, M., Schulze, G. C., Remmers, H., Working with a domestic assessment system to estimate the need of support and care of elderly and disabled persons: results from field studies, Informatics for health & social care, 39, 210-31, 2014	No UK evidence.
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	No UK evidence.
Hughes, Jennifer C., Banerjee, Tanvi, Goodman, Garrett, Lawhorne, Larry, A Preliminary Qualitative Analysis on the Feasibility of Using Gaming Technology in Caregiver Assessment, Journal of Technology in Human Services, 35, 183-198, 2017	No UK evidence.
Janlov, A. C., Hallberg, I. R., Petersson, K., Family members' experience of participation in the needs of assessment when their older next of kin becomes in need of public home help: a qualitative interview study, International Journal of Nursing StudiesInt J Nurs Stud, 43, 1033-46, 2006	No UK evidence.
Levine, C., Supporting family caregivers: the hospital nurse's assessment of family caregiver needs, American Journal of Nursing, 111, 47-51, 2011	No UK evidence.
McCormack, B., The usability of the Northern Ireland single assessment tool for the health and social care of older people	Unavailable.
Noonan, M. C., Wingham, J., Taylor, R. S., 'Who Cares?' the experiences of caregivers of adults living with heart failure, chronic obstructive pulmonary disease and coronary artery disease: A mixed methods systematic review, BMJ Open, 8 (7) (no pagination), 2018	No phenomenon of interest.
Nottinghamshire County, Council, Co-produced carers assessment and support plan	No concept phenomenon of interest: no assessment of carers' needs.
Oliver, D. R., Demiris, G., Fleming, D. A., Edison, K., A needs assessment study for the Missouri Tele-hospice Project, Amia .., Annual Symposium Proceedings/AMIA Symposium., 959, 2003	No UK evidence.

Study	Reason for Exclusion
Pantlin Richard, Online tools within a needs assessment process	No qualitative data.
Pitt, Vern, Help at hand for the hidden carers (carers' assessments), Community Care. No, 16, 1868	Unavailable.
Reigada, C., Papadopoulos, A., Boland, J. W., Yorke, J., Ross, J., Currow, D. C., Hart, S., Bajwah, S., Grande, G., Wells, A., Johnson, M. J., Implementation of the Needs Assessment Tool for patients with interestitial lung disease (NAT:ILD): Facilitators and barriers, Thorax, 72, 1049-1051, 2017	No unpaid carers.
Seddon, D., Robinson, C. A., Carers of older people with dementia: assessment and the Carers Act, Health & social care in the community, 9, 151-158, 2001	Before 2003.
Shamsaei, F., Kermanshahi, S. M. K., Vanaki, Z., Hajizadeh, E., Holtforth, M. G., Cheragi, F., Health status assessment tool for the family member caregiver of patients with bipolar disorder: Development and psychometric testing, Asian Journal of Psychiatry, 6, 222-227, 2013	No UK evidence.
Skills For, Care, Carers, Trust, Carers assessments: workforce development opportunities based on carers experiences, 19, 2013	General focus on carers support with no specific focusing on providing practical support for carers.
Smithgall Cheryl, Yang Duck-Hye, Weiner Dana, Unmet mental health service needs in kinship care: the importance of assessing and supporting caregivers, Journal of Family Social Work, 16, 463-479, 2013	No UK evidence.
Smith-Hoban, D., Hook, S. S. V., Rutkowski, A., A congenital muscular dystrophy quality of life and caregiver assessment survey, Neuromuscular Disorders, 20, 564-565, 2010	No UK evidence.
Social Care Institute For, Excellence, Care Act: assessment and eligibility: process map	No qualitative data.
Social Care Institute For, Excellence, Care Act: assessment and eligibility: supported self-assessment	No qualitative data.
Social Care Institute For, Excellence, Fluctuating needs in assessment and eligibility for the Care Act 2014	No qualitative data.
Sterba, K. R., Zapka, J., LaPelle, N., Garris, T. K., Buchanan, A., Scallion, M., Day, T., Development of a survivorship needs assessment planning tool for head and neck cancer survivors and their caregivers: a preliminary study, Journal of cancer survivorship : research and practice, 11, 822-832, 2017	No UK evidence.
Tatangelo, G., McCabe, M., Macleod, A., You, E., "I just don't focus on my needs." The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study, International journal of nursing studies, 77, 8-14, 2018	No UK evidence.
Tebb Susan S, Berg-Weger Maria, Rubio Doris McGartland, The Caregiver Well-Being Scale: developing a short-form rapid assessment instrument, Health and Social Work, 38, 222-230, 2013	No qualitative data.
Thibodeau, M. A., Geller, J., Iyar, M., Development of self-report scales measuring collaborative vs. directive support: Assessing beliefs and behaviors in carers of adults with eating disorders, Eating Behaviors, 23, 156-161, 2016	No UK evidence.

Study	Reason for Exclusion
University Of, Stirling, et al.,, Food for thought: food based training, assessment and intervention tools for carers of looked after young people	No concept phenomenon of interest: no assessment of carers' needs.
Van Rysewyk, S., The integration of emotion and reason in caregiver pain assessment, Journal of Pain, 11, 804-805, 2010	No UK evidence.
Walters, K., Iliffe, S., Tai, S. S., Orrell, M., Assessing needs from patient, carer and professional perspectives: The Camberwell assessment of need for elderly people in primary care, Age and Ageing, 29, 505-510, 2000	Before 2003.
Wancata, J., Friedrich, F., Unger, A., Jahn, R., Development of a clinical version of the Carers' Needs Assessment for Schizophrenia, Neuropsychiatrie, 1-6, 2017	No UK evidence.
Wancata, J., Krautgartner, M., Berner, J., Scumaci, S., Freidl, M., Alexandrowicz, R., Rittmannsberger, H., The "Carers' needs assessment for Schizophrenia". An instrument to assess the needs of relatives supporting schizophrenia patients, Social psychiatry and psychiatric epidemiology, 41, 221-229, 2006	No UK evidence.
Wancata, Johannes, Krautgartner, Monika, Berner, Julia, Alexandrowicz, Rainer, Unger, Anne, Kaiser, Gerda, Marquart, Barbara, Weiss, Maria, The Carers' Needs Assessment for Dementia (CNA-D): Development, validity and reliability, International Psychogeriatrics, 17, 393-406, 2005	No UK evidence.
Watts Lynelle, Hodgson David, Assessing the needs of carers of people with mental illness: lessons from a collaborative study, Practice: Social Work in Action, 28, 235-252, 2016	No UK evidence.
Webber Sarah Helen, Wright Chloe, Balancing need: the relationship between carers' assessment and needs assessment	Not enough qualitative data.
Williams Val, Robinson Carol, In their own right: Carers Act and carers of people with learning difficulties	Book.
Win, K. T., Nang, S. Z., Min, A., Community-based assessment of dengue-related knowledge among caregivers, Dengue Bulletin, 28, 189-195, 2004	No UK evidence.
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	This study sets out to try and identify the needs of carers in a particular situation (heart patients). It does not examine experiences of having a carer's assessment.
Wiseman, J. T., Fernandes-Taylor, S., Barnes, M. L., Tomsejova, A., Saunders, R. S., Kent, K. C., Conceptualizing smartphone use in outpatient wound assessment: patients' and caregivers' willingness to use technology, Journal of Surgical Research, 198, 245-51, 2015	No UK evidence.
Wong, R. K., Franssen, E., Szumacher, E., Connolly, R., Evans, M., Page, B., Chow, E., Hayter, C., Harth, T., Andersson, L., Pope, J., Danjoux, C., What do patients living with advanced cancer and their carers want to know? - a needs assessment, Supportive Care in Cancer, 10, 408-15, 2002	Before 2003.
Young, M. E., Lutz, B. J., Creasy, K. R., Cox, K. J., Martz, C., A comprehensive assessment of family caregivers of stroke survivors during inpatient rehabilitation, Disability & Rehabilitation, 36, 1892-902, 2014	No UK evidence.

Study	Reason for Exclusion
Zarit, S. H., Femia, E. E., Kim, K., Whitlatch, C. J., The structure of risk factors and outcomes for family caregivers: implications for assessment and treatment, Aging & mental health, 14, 220-31, 2010	No UK evidence.
Zhong, M., Evans, A., Peppard, R., Velakoulis, D., Validity and reliability of the PDCB: a tool for the assessment of caregiver burden in Parkinson's disease, International PsychogeriatricsInt Psychogeriatr, 25, 2013	No UK evidence.

Economic studies

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 11: 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 substituting physicians with diabetes nurse specialists: a randomized controlled trial with 2-year follow-up, Journal of advanced nursing, 68, 1224-34, 2012	Population of interest: the study focus is primarily on care recipients.
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 care recipients.
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 care recipients.
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	Study design - this review of HE studies has been excluded for this guideline - but its

Study	Reason for Exclusion
illness and their caregivers, Cochrane Database of Systematic Reviews, 2016 (3) (no pagination), 2013	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 Health Services Research, 16 Suppl 5, 328, 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.
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 care recipients.
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 care recipients.
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	Study finding updated by a more recent HE study (Livingston 2014).

Study	Reason for Exclusion
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	
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 localised prostate cancer patients within 1 year after diagnosis.
Lopez-Villegas, A., Catalan-Matamoros, D., Robles-Musso, E., Peiro, S., Workload, time and costs of the informal carers in patients with tele-monitoring of pacemakers: the PONIENTE study, Clinical Research in Cardiology, 105, 307-313, 2016	Not the intervention of interest: aim of this study was to assess the burden borne by and the costs to informal carers of people 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 care recipients.
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 care recipients.

Study	**Reason for Exclusion**
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 care recipients.
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.

Study	Reason for Exclusion
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.
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 is the acceptability of different tools or approaches for assessing the needs of carers?

Why this is important

The review on carers' assessments found no evidence about the whole family approach, which is promoted in the Care Act 2014 as an effective means of identifying opportunities to support carers and address needs arising from their caring role. The committee heard from expert witnesses about the crucial importance of a whole family approach and perceived benefits where it has been implemented in practice. However with no research evidence about the outcomes of this approach to assessment or about the perceived acceptability, the committee agreed about the importance of recommending future research on this question.

Research recommendation in question format: What is the effectiveness, cost-effectiveness and acceptability of the whole family approach to carers' assessments?

Research question	**What is the effectiveness, cost-effectiveness and acceptability of the whole family approach to carers' assessments?**
Importance to people or the population	Within the context of formal assessments, carers describe having their own needs overlooked. Carers' assessments are often conducted at the same time as assessments of the cared-for person with little or no regard for their own needs as carers. Assessments can also overlook the needs of the wider family or the fact that a person with care and support needs might also have caring responsibilities. The result is that needs are not identified and support is not offered, affecting the quality of life and physical and psychological well-being of the carer and cared-for person. The impact is also felt at a wider level as a crisis or break down in caring is likely to result in unplanned health contacts including hospital admissions.
Relevance to NICE guidance	NICE guidance provides advice on effective, good value health and social care including care and support for adult carers, which is tailored to their needs and preferences.
Relevance to NHS/ social care	The Care Act (2014) places a statutory duty on local authorities to assess the needs of carers in their own right. The Care Act also requires local authorities to adopt a whole system, whole-family approach, considering the impact of the care needs of an adult (which includes carers) on their family and social support network. Although the expert witness testimony was supportive of this approach, the systematic review did not locate any published evidence to support it. Development of an evidence base about the effectiveness, cost-effectiveness and acceptability of taking this whole-family approach to carers' assessments will provide a clearer understanding of the associated outcomes and the preferences of carers and practitioners about how assessments should be conducted.
National priorities	The Care Act (2014) places a statutory duty on local authorities to assess the needs of carers in their own right and in doing so requires local authorities to adopt a whole-family approach. Determining the effectiveness of this approach and the acceptability of Care Act compliant assessments will contribute towards this objective.
Current evidence base	There is currently no published evidence about the effectiveness, cost-effectiveness or acceptability of a whole family approach to carers' assessments.
Equalities	N/A

N/A: not applicable

Criterion	**Explanation**
Population	• Adults 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.
Intervention	• Whole family approaches to needs assessments
Comparator	• Practice as usual
Outcomes	• carer health and social care related quality of life • carer mental health • health care contacts • carer satisfaction/ experience Expected themes from the qualitative component: • acceptability of and satisfaction with the whole family approach to assessment • carers' participation in the assessment • attitudes towards carers during the assessment • provision of information in advance of and in preparation for a carer's assessment • suitability of the whole family approach to assessment as a means of identifying all areas of need • perceived areas of unmet need following a carer assessment and resulting support plan • experiences and satisfaction in relation to review arrangements
Study design	• integrated qualitative methods alongside an RCT • economic evaluation
Timeframe	• two years from randomisation

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

Carers UK 2016

UK

- Barriers to receive an assessment. Across the UK, 31% of carers responding to Carers UK survey reported having an assessment of the impact of their caring role on them in the previous year (2015 – 2016). Of these carers:
  - 29% of carers (almost one-third) who reported having an assessment in the past year had to wait six months or longer for it.
  - 22% of carers (almost one-quarter) had to request an assessment for themselves over the last year instead of having one offered to them, as the law requires.
  - Unmet needs following an assessment. Of carers who received an assessment in the past year:
  - 68% (almost two-thirds) felt their need to have regular breaks from caring was either not considered or not thoroughly considered
  - 35% (over one-third) felt that support to look after their own health was thoroughly considered
  - 21% (1 in 5) reported they received little or no helpful information or advice, and felt they didn’t know where to go for support with caring

ENGLAND

- Obtaining (and waiting for) an assessment. Across England, 50% of carers responding to Carers UK survey reported having an assessment of the impact of their caring role on them in the previous year (2015 – 2016). Of these carers:
  - 50% (almost half) received an assessment within 6 months, but nearly 29% (almost one-third) waited for more than 6 months or are still waiting 6 months later
  - 39% of carers (over one-third) looking after someone at the end of their life had to wait six months or more for an assessment.
  - There was a difference in the timeliness of assessments depending on whether a carer requested an assessment or was offered one (Of those carers who requested a carer’s assessment, 34% have waited or have been waiting for more than 6 months; of those carers who were offered an assessment, 25% have waited or have been waiting for more than 6 months.
- Experiences of receiving (and support following) an assessment. Of carers who received an assessment in the past year:
  - 74% working age carers (3 in 4) did not feel that the support needed to juggle care with work was sufficiently considered.
  - The area which most carers found was not properly considered as part of the assessment or the support received was the support needed to juggle care with training or education (data not reported)
  - 67% (almost two-thirds) felt their need to have regular breaks from caring was either not considered or not thoroughly considered
  - 64% (over one-third) felt that support to look after their own mental and physical health was thoroughly considered.
  - 47% (almost 1 in 2) of carers say that it is struggle for them to afford the cost of care whilst 8% of carers pay for care because the person they support cannot afford it.
  - 21% (1 in 5) reported they received little or no helpful information or advice, and felt they didn’t know where to go for support with caring

Qualitative findings

"I requested a carer's assessment and council refused it, said I did not have a right to one as I was supporting child not an adult!" (Carer supporting a person without a specific condition – Carers UK 2016); "I had to wait almost a year to get an assessment" (Carer supporting a person without a specific condition – Carers UK 2016); " I had to fight for a social worker but got an assessment immediately and finally got some support although it's still not at the correct level". (Carer supporting a person without a specific condition – Carers UK 2016); "Waiting a year has made the situation much more difficult and my need for help considerably greater. I definitely feel the length of time waiting has had a detrimental effect on my mental health". (Carer supporting a person without a specific condition – Carers UK 2016); "The assessment is just a piece of paper and I have no help". (Carer supporting a person without a specific condition – Carers UK 2016); "Lots of good ideas but no support is really available and if you cannot get care for the disabled person none of it can happen – no funds" (Carer supporting a person without a specific condition – Carers UK 2016); "All assessment areas were considered by my assessor but due to cuts there was no support they could practically offer me. I was listened to but there was no positive outcome". (Carer supporting a person without a specific condition – Carers UK 2016); "I was told I was lucky to be able to work at all, that I should ask my employers (who are very tolerant already) to schedule me in a way that enables time with my partner. I stressed this absolutely would not meet our needs and was immediately rejected for any help around the house". (Carer supporting a person without a specific condition – Carers UK 2016)

Carers UK 2017

Survey (quantitative) findings

UK

- Unmet needs following an assessment. Across the UK, 65% of carers responding to Carers UK survey reported having an assessment of the impact of their caring role on them in the previous year (2016 – 2017). Of these carers:
    - 68% (almost two-thirds) felt their need to have regular breaks from caring was either not considered or not thoroughly considered
    - 45% (fewer than half) said that their ability and willingness to provide care was thoroughly considered and reflected in the support they receive
    - 34% (over one-third) felt that support to look after their own health was thoroughly considered and reflected in the assessment process and subsequent consideration
    - 21% (1 in 5) reported they received little or no helpful information or advice, and felt they didn't know where to go for support with caring

ENGLAND

- Obtaining (and waiting for) an assessment. Across England, 68% of carers responding to Carers UK survey reported having an assessment of the impact of their caring role on them in the previous year (2016 – 2017). Of these carers:
    - 81% received an assessment within 6 months, but 25% (almost 1 in 4) waited for more than 6 months or are still waiting 6 months later (improvement on last year)
    - 25% of carers (1 in 4) looking after someone at the end of their life had to wait six months or more for an assessment. (improvement on last year)
- Experiences of receiving (and support following) an assessment. Of carers who received an assessment in the past year:
    - 67% (almost two-thirds) felt their need to have regular breaks from caring was either not considered or not thoroughly considered

  - 65% (over one-third) felt that support to look after their own mental and physical health was thoroughly considered.

Qualitative findings

"As a parent carer of disabled children my local authority says I'm not entitled to an assessment". (Carer supporting a person without a specific condition – Carers UK 2017); "I don't feel the assessment considered me as a person...I felt it was more about making sure I could carry on caring". (Carer supporting a person without a specific condition – Carers UK 2017); "No support was offered or report on the meeting supplied. It would have been nice to have a reference letter of what to do should I become ill or should there be an emergency that requires the patient to be looked after by someone else at short notice". (Carer supporting a person without a specific condition – Carers UK 2017); "When my daughter was under 18 I was told there was no point in having an assessment as there 'isn't any funding attached'. I have recently had an adult carer's assessment in preparation for 'transition'. It was over a month ago and I still haven't had formal response but been told I would be better off organising respite myself". (Carer supporting a person without a specific condition – Carers UK 2017); "I found that all the right questions were asked but ultimately when it came down to it there just isn't enough funding to implement anything that would help to any great extent". (Carer supporting a person without a specific condition – Carers UK 2017); "Support I'd been offered in previous years was now not available despite my caring increasing due to cuts". (Carer supporting a person without a specific condition – Carers UK 2017)

Carers UK 2018

Survey (quantitative) findings

UK

- Unmet needs following an assessment. Across the UK, 66% (almost two-thirds) of carers responding to Carers UK survey reported having an assessment of the impact of their caring role on them in the previous year (2017 – 2018). Of these carers:
  - (% not reported) Many felt that their Carer's Assessment had been completed at the same time as the assessment of the cared for person and that their needs had not been considered independently or addressed directly.
  - (% not reported) Others reported that they hadn't heard of a Carer's Assessment.

ENGLAND

- Obtaining (and waiting for) an assessment. Across England, 67% of carers responding to Carers UK survey reported having an assessment of the impact of their caring role on them in the previous year (2017 – 2018). Of these carers:
  - 82% received an assessment within 6 months, but nearly 18% waited for more than 6 months or are still waiting 6 months later (improvement on last year)
  - 24% of carers (almost one-quarter) looking after someone at the end of their life had to wait six months or more for an assessment.(no improvement)
- Experiences of receiving (and support following) an assessment. Of carers who received an assessment in the past year:
  - 43% said their ability and willingness to provide care was thoroughly considered and reflected in the support they receive
  - 42% working age carers did not feel that the support needed to juggle care with work was sufficiently considered.
  - 33% (almost two-thirds) felt their need to have regular breaks from caring was either not considered or not thoroughly considered

Qualitative findings

"I received funding for a local gym which has been a lifesaver for me". (Carer supporting a person without a specific condition – Carers UK 2018); "The assessment was quite thorough. But what it lacked was the possibility of hands-on support for the carers, especially in time of crisis". (Carer supporting a person without a specific condition – Carers UK 2018); "I asked for a Carer's Assessment and they said they would do a joint one, but they only cared about and asked about my daughter". (Carer supporting a person without a specific condition – Carers UK 2018)

Ewing 2016

- "And quite often in that kind of situation it is "oh I don't know what I want", you know, they can't focus, but the CSNAT allows them to focus on that because it is asking them specific questions" (Carer supporting a person at the end of life – CSNAT); "had had a look at our carer assessment form and he noted really that he needed extra support really around knowing what's going to happen at the end, and symptom management" (Carer supporting a person at the end of life – CSNAT)
- "But I think what this does, it puts it in the minds of the carers that they are allowed to have needs and that it's okay to ask for help because we've made that introduction" (Carer supporting a person at the end of life – CSNAT);
- "I think because they were centring their care on dad and they couldn't think past that. So all your questions [on the CSNAT] brought it all out in the open and they all talked to each other with me" (Carer supporting a person at the end of life – CSNAT); "I've used it sometimes as a way of saying to a patient, 'look this is what he does for you; he does all your medication, he does all of this, he does your washing, and the only thing he's not doing is having a bit of time to himself in the day" (Carer supporting a person at the end of life – CSNAT)
- "I let him have a look at it himself, I didn't read it out to him, because I think he needed to do that. And he did, he filled it all in and I did get stuff from that so it, it was very useful" (Carer supporting a person at the end of life – CSNAT); "I think you do just pick up on when it's the right time to go through it with them […] and when it's the right time to say, 'look, this is for you and I want you to look through this when it's a bit quieter and I will phone you next week" (Carer supporting a person at the end of life – CSNAT)
- "She didn't seem to identify many concerns at all. Well no concerns in fact. So I left the CSNAT with her and asked her if she would post it back to me, and she was very happy to do that. When I received the CSNAT back in the post I was quite surprised at the amount of information that was on it, and the areas that had been identified". (Carer supporting a person at the end of life – CSNAT)
- "my assessments can be a bit long and long winded. I think sometimes I'm guilty of giving people too much information all at once. So what I've tried to do on a subsequent assessment was to do the CSNAT first before I told them anything about the service". (Carer supporting a person at the end of life – CSNAT)

Ewing 2018

- "because we've got nothing at all in place and also I am aware that there are quite a few things on here that we don't do very well". (Professional – CSNAT, hospital-based carers' assessment during discharge planning); "They should be asking all these questions, you know, to the carers". (Carer – CSNAT, hospital-based carers' assessment during discharge planning); "I think all those are something that need dealing with, don't they". (Carer – CSNAT, hospital-based carers' assessment during discharge planning)
- "'[it] gives the carer permission to think about themselves". (Carer – CSNAT, hospital-based carers' assessment during discharge planning); "relatives feel that they need the permission to say, do you know what, I can't do this and I need help". (Professional – CSNAT, hospital-based carers' assessment during discharge planning).

- “because you’re completely at sea, you’ve no idea, you’re going home with your family member with their bag of drugs and if somebody said, ‘what kind of help do you need?’ you wouldn’t know, you need to have … in a situation like that you’ve got to have prompts and suggestions, would you need help with this, would you need …and that’s perfect”. (Carer – CSNAT, hospital-based carers’ assessment during discharge planning)
- “… sometimes you don’t know what to ask and you can’t remember. Whereas if you’ve got something written down that you can go back to, you can make notes or you can gather your thoughts”. (Carer – CSNAT, hospital-based carers’ assessment during discharge planning)
- “You could actually hand it to them and say, ‘I want you to look at this, and the next time we come back, we’re going to talk about it’. Because sometimes you haven’t got, like, time to spend going slowly through something. But if they’ve had a chance to just have a quick look, to look at it when they were quiet, and think, right, I just need that. And then the next time the nurse comes, you can say, ‘Have you had a look at that, and what did you think?’ And then it just, sort of, like, opens things up”. (Professional – CSNAT, hospital-based carers’ assessment during discharge planning)
- “I don’t think it’s the time to do that. I honestly don’t. They don’t have time to do the drug rounds let alone anything else”. (Professional – CSNAT, hospital-based carers’ assessment during discharge planning)
- “Nurses are running round like blue-arsed what’s-its, so you don’t want to ask them either. So you end up with this, ‘It’ll be alright, It’ll be alright’. And you don’t ask because you know everyone’s so busy. So you need to have something built in”. (Carer – CSNAT, hospital-based carers’ assessment during discharge planning)
- “‘it’s about the information, it’s about what’s out there. And if you don’t know what’s happening, you can be talking about home, and people have this lovely rosy view, but the practicalities are very different”. (Professional – CSNAT, hospital-based carers’ assessment during discharge planning)
- “… to actually pick up any carer concerns, and then if discharge was then an option I think and kind of refer back to that. So it’s almost like a two part thing, it’s assessing the concerns but then checking out those concerns in relation to proposed discharge”. (Professional – CSNAT, hospital-based carers’ assessment during discharge planning)
- “‘because until she was home we hadn’t realised we’d have a problem at night. […] we thought she’d go to bed and she’d be able to go to the toilet like she always could before and she couldn’t”. (Carer – CSNAT, hospital-based carers’ assessment during discharge planning); “… maybe even a couple of days later, because until they’re actually at home they don’t”. (Professional – CSNAT, hospital-based carers’ assessment during discharge planning).

RQIA 2012

“…this information would all have been mixed up with everything else given to me from the trust staff”. (Carer supporting a person without a specific condition - [Northern Ireland] Carer’s Support and Needs Assessment Tool); “…not a form that you would want to complete on your own as it needs the professional support to help address/think through some of the issues… ”. (Carer supporting a person without a specific condition - [Northern Ireland] Carer’s Support and Needs Assessment Tool); “…took about two days to complete. I wanted a sleep over arrangement and was told I had to complete a carer‟s assessment. The outcome was no sleep over. I had to appeal the panel decision and found the assessment was a waste of time…”. (Carer supporting a person without a specific condition - [Northern Ireland] Carer’s Support and Needs Assessment Tool); “had asked for the assessment form which was sent to the home. Her mother who had Alzheimer‟s had misplaced the form and it was found many months later but in the meantime no one had made contact to chase it up”. (Carer supporting a person without a specific condition - [Northern Ireland] Carer’s Support and Needs Assessment Tool); "…so many forms that you got lost in what you are doing. Not always explained that this is for you as the carer…". (Carer supporting a person without a specific condition - [Northern Ireland] Carer's Support and Needs Assessment Tool)

Stock 2011

- "Carers Wales sent me a booklet, it was confusing really, lots and lots of information and I still didn't really know where to go, it was a bit too much. I wasn't aware I could have my own assessment until six weeks ago and I've been officially registered as a carer for six years". (Carers' experiences of assessment since the Care Act 2004); "I've looked after dad for five years and it wasn't until now that I found out I could have an assessment myself, it was the Carers' Centre who told me". (Carers' experiences of assessment since the Care Act 2004)
- "It's the way you slide into it. I'd have humorous arguments with the Carers' Centre saying 'I'm not a regular and substantial carer, no, I'm not a carer". (Carers' experiences of assessment since the Care Act 2004); "Well, first of all he's my dad, he always will be, and he doesn't want to be like he is. It's very difficult but I don't complain. I try and cope the best I can without bothering people". (Carers' experiences of assessment since the Care Act 2004); "What I wasn't expecting … was how amazing, how wonderful it was just speaking to somebody for two hours about me, and how it was affecting me". (Carers' experiences of assessment since the Care Act 2004)
- "I have grave doubts about the social worker that came to see me. She seemed to resent having to give me the assessment, it was as if she thought she had more important things to do, and I shouldn't be wasting her time". (Carers' experiences of assessment since the Care Act 2004)
- "It's so stressful babysitting my father twenty four hours a day, seven days a week … if I don't get a break soon I don't know what will happen. Some of his friends from church call in and will sit with him for me to pop out. I need more time to be able to do little things like going to the dentist and the doctor's by myself, taking my father with me is very difficult. I hope he'll get on with the sitters they send". (Carers' experiences of assessment since the Care Act 2004); "The outcome of the assessment was, when the staffing situation allowed there might be sitters". (Carers' experiences of assessment since the Care Act 2004); "It was me having assistance for [daughter] really. I plan to go to work when she leaves school. Carers have got to put her on the bus to day services and then be here, to work around my schedule. We've started to introduce carers now in the mornings with [daughter]. It's worked really well. I am confident that everything is going to work out". (Carers' experiences of assessment since the Care Act 2004)
- "But there was never, there was no suggestion of sort of, I mean I know there's issues with time, but with going back to my mother and in a nice way saying 'Well, you know, I really think it would be worth your while going to day-care for an extra day, now I know it might be a bit of a burden to your daughter to take you but you know £10 a week [for her mother to pay for a taxi to attend day care rather than relying on her daughter to take her] isn't a lot and we'll find someone else that can share it'. There was no possibility of negotiation which was what I would, that's what I would have liked most". (Carers' experiences of assessment since the Care Act 2004)

Appendix N: Expert witness testimonial

Table 12: Expert witness testimonial for review question: What is the acceptability of different tools or approaches for assessing the needs of carers? John Bangs

Section A: Completed by the developer	
Name:	John Bangs
Role:	Commissioning Manager (Carers strategy)
Institution/Organisation (where applicable): **Contact information:**	Surrey County Council Penrhyn Road, Kingston Upon Thames, Surrey KT1 2DW
Guideline title:	Carers: provision of support for adult carers
Guideline Committee:	Guideline Committee meeting 12
Subject of expert testimony:	Assessment of carers, including whole family planning assessments and planning for the caring role.
Evidence gaps or uncertainties:	*What is the acceptability of different tools or approaches for assessing the needs of carers?*

The objective of the review question was to identify perceived good practice principles in relation to the conduct of carers' assessments and understand the features of a carers' assessment which people perceive to improve outcomes through exploring the views, preferences and lived experiences of carers and practitioners.

Following a systematic search of published literature and screening against agreed criteria, a total of seven papers have been included in this research review, including three national surveys reporting qualitative data. The included papers provide evidence for the committee about: perceived areas of unmet need following an assessment, attitudes towards carers during assessments and satisfaction with the carers' assessment process. They also provide a small amount of evidence about the provision of information in advance of carers' assessments and the suitability of statutory assessment tools as a means of identifying all areas of need.

The results of the review also highlighted certain gaps in evidence, especially as it pertains to the conduct of carers assessments following the implementation of the Care Act 2014. In particular no evidence was located about: people's experiences or satisfaction with review arrangements, different approaches to carers' assessments, carers' participation in assessments and the perceived effects of an assessment on carer wellbeing.

In light of these gaps in evidence, the Committee agreed to try and supplement the data by inviting an expert witness. Committee members are looking for the witness to present evidence which plugs the highlighted gaps and which reflects on the acceptability of assessment tools which are Care Act compliant. It is important that the recommendations they draft are based on evidence which is as relevant and up to date as possible and reflects current policy and practice in this area. It is also important that the committee considers evidence about the views and experiences of carers experiencing assessments as well as practitioners conducting them.

In summary, evidence on the following aspects of support for adult carers would enable the committee to develop recommendations and add weight to the results of the systematic review:

- The acceptability of different tools or approaches for assessing the needs of carers – from the point of view of carers experiencing assessments and practitioners conducting them.
- Data would ideally provide evidence on the following themes:
- Provision of information in advance of and in preparation for carers assessments
- The suitability of statutory assessment tools in identifying all areas of need

- Experiences and satisfaction in relation to review arrangements.
- Perceived advantages and disadvantages of different approaches to carers assessments (for example, integrated approach across health and social care, joint or separate assessments, self-assessments)
- Carers' participation in the assessment process
- The effects of an assessment on carer wellbeing.

The expert witness has been identified for his specific expertise in local solutions to carers assessments under the Care Act 2014.

Section B: Completed by the expert

Development of a Legal Right to a Carers Assessment

Pre 1996 some councils undertook carers assessments as good practice. This was introduced into law through three private members bills. Rights for adult carers, parent carers and young carers were re-enforced and strengthened via the Care Act 2014 and Children and Families Act 2014. This included:

- Carers of adults being entitled to an assessment on the appearance of need (Care Act)
- Young Carers and Parent Carers also being entitled to assessments under children's legislation
- National Eligibility Criteria for adult carers (Care Act)
- Identifying young carers and protect them having to undertake excessive or inappropriate care (Statutory Guidance for both sets of legislation)
- Carers Assessments for young carers in Transition to adult hood (Care Act)

Both the Care Act and the amended Section 17 of the Children Act contain mirrored statutory obligations also requiring:

- Provision of information and advice to carers whether or not they have eligible needs
- A whole family approach to assessment; identifying where there are children and young people in the household
- Reaching into communities to provide preventative support to carers
- A duty placed on the NHS to cooperate with local authorities:

Who Can Undertake Carers Assessments?

Section 79 of the Care Act 2014 allows local authorities to delegate undertaking of carers assessments'. Such delegation does not absolve the local authority of its legal responsibilities. The Care Act 2014 is clear that anything done (or not done) by the third party in carrying out the function, is to be treated as if it has been done (or not done) by the local authority itself.

The form of adult and carers assessments is a matter for local discretion but there is a fair degree of direction as to the necessary content. Local authorities have to collect sufficient to make eligibility decisions and follow national statutory guidance. This should enable an evaluation of the sustainability of the caring role and the carer's ability to have a life outside of caring. A good carers assessments should take account of the carers abilities and aspirations as well as what they may be struggling with.

Councils use a range of databases and assessment tools and therefore notion of having a standard tool was quickly discounted during preparations for implementation of the Care Act. In a recent ADASS survey of local authorities with 47 respondents (Published December 2018) included a question about who undertakes carers assessments; When asked about how they conduct carers assessments respondents said:

- 63% all statutory carers assessments are conducted in house.
- 20% contract out assessments including eligibility decisions an
- 22% take advice from the contracted organisation but make eligibility decisions themselves.

Next Steps

- As yet there is no comparative data as to the efficacy of each approach. Contracting with carers organisations may have the advantage of ensuring carer friendly, carer aware staff undertake these. It may be less clear how these are tied together with assessments of the person who is looked after in order to take a whole family view.

- ADASS has been commissioned by the Department of Health and Social Care to undertake a sector led improvement programme concerning Care Act implementation and it is expected that a new guide or toolkit to aid quality improvement will be developed relating to whole family approaches and carers assessments. Underpinning the development of this, will be a commitment to approaching care assessments on a whole family basis. It is expected that this will include circumstances where health and social care develop joint assessment and care planning arrangements (Identified as a priority in the NHS Long Term Plan). It is hoped that Guidelines developed by NICE will help support this approach.

References to other work or publications to support your testimony' (if applicable):

In order to help support implementation of the Care Act the Department of Health Commissioned a guide "The Care Act and Whole Family Approaches"
https://www.local.gov.uk/sites/default/files/documents/care-act-and-whole-family-6e1.pdf

Table 13: Expert witness testimonial for review question: What is the acceptability of different tools or approaches for assessing the needs of carers? Bernadette Simpson

Section A: Developer to complete

Name:	Bernadette Simpson
Role:	Senior specialist (workforce and carers), Personalised Care Group
Institution/Organisation (where applicable): **Contact information:**	Strategy and Innovation Directorate, NHS England Skipton House 80 London Road London SE1 6LH
Guideline title:	Carers: provision of support for adult carers
Guideline Committee:	Guideline Committee meeting 12
Subject of expert testimony:	Assessment of carers, including whole family planning assessments and planning for the caring role.
Evidence gaps or uncertainties:	*What is the acceptability of different tools or approaches for assessing the needs of carers?*

The objective of the review question was to identify perceived good practice principles in relation to the conduct of carers' assessments and understand the features of a carers' assessment which people perceive to improve outcomes through exploring the views, preferences and lived experiences of carers and practitioners.

Following a systematic search of published literature and screening against agreed criteria, a total of seven papers have been included in this research review, including three national surveys reporting qualitative data. The included papers provide evidence for the committee about: perceived areas of unmet need following an assessment, attitudes towards carers during assessments and satisfaction with the carers' assessment process. They also provide a small amount of evidence about the provision of information in advance of carers' assessments and the suitability of statutory assessment tools as a means of identifying all areas of need.

The results of the review also highlighted certain gaps in evidence, especially as it pertains to the conduct of carers assessments following the implementation of the Care Act 2014. In particular no evidence was located about: people's experiences or satisfaction with review arrangements, different approaches to carers' assessments, carers' participation in assessments and the perceived effects of an assessment on carer wellbeing.

In light of these gaps in evidence, the Committee agreed to try and supplement the data by inviting an expert witness. Committee members are looking for the witness to present evidence which plugs the highlighted gaps and which reflects on the acceptability of assessment tools which are Care Act compliant. It is important that the recommendations they draft are based on evidence which is as relevant and up to date as possible and reflects current policy and practice in this area. It is also important that the committee considers evidence about the views and experiences of carers experiencing assessments as well as practitioners conducting them.

In summary, evidence on the following aspects of support for adult carers would enable the committee to develop recommendations and add weight to the results of the systematic review:

- The acceptability of different tools or approaches for assessing the needs of carers – from the point of view of carers experiencing assessments and practitioners conducting them.

Data would ideally provide evidence on the following themes:

- Provision of information in advance of and in preparation for carers assessments
- The suitability of statutory assessment tools in identifying all areas of need
- Experiences and satisfaction in relation to review arrangements.
- Perceived advantages and disadvantages of different approaches to carers assessments (for example, integrated approach across health and social care, joint or separate assessments, self-assessments)
- Carers' participation in the assessment process
- The effects of an assessment on carer wellbeing.

Section B: Expert to complete

Under the Care Act 2014 Local Authorities are encouraged to take a whole family approach to assessment and must consider the impact of the care needs of an adult on their family or others in their support network and including children. I was the principle author of guidance on whole family approaches https://www.local.gov.uk/sites/default/files/documents/care-act-and-whole-family-6e1.pdf and believe that promoting this approach is critical to the identification and assessment of carers needs and then ensuring that care and support plans work for everyone. This requires a cultural shift away from thinking just about an individual to thinking about people in the context in which they live and being alert to considering the impact of any event on other family members and close network. By looking at the whole picture of a person's life carers will be identified, their expertise and views considered, and it will help recognise what's important as part of a family unit as well as individually, enabling the development of plans that build on the collective strengths of the family and their support network. Assessments of the person and their carers can where appropriate be made at the same time but there should always be the option for people including carers to have separate assessments. Whatever method is used its important that the assessments are aligned to inform the care planning process and that carers are asked about the degree to which the carer/family are willing and able to contribute towards meeting the outcomes the person wants to achieve.

I am now working for NHS England personalised care programme. The NHS Long Term Plan https://www.england.nhs.uk/long-term-plan/ includes the importance of personalised care and NHS England has produced details of how we will deliver this through a programme entitled Universal Personalised Care https://www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model

We are working with a number of exemplar sites three of which will focus particularly on integrated approaches which will include offering a proactive and joined up approach to needs assessment including a whole family approach that includes the needs of carers.

Unlike local authorities the NHS does not have a specific duty to assess carers although it does a duty to cooperate under the Care Act which should include the identification and assessment of carers. Continuing Health Care guidance makes clear the responsibilities to look at the carers' role, provide respite breaks, contingency plans, and ensure a referral pathway to carer assessment. It is sometimes reported that carers are missing out in relation to assessment and support when the person they care for has their needs met primarily by the NHS. The integration work we are involved with will consider how we ensure that carers get equal access to assessment and support.

Carers often do not identify with the title 'carer' so by utilising a whole family approach there is greater potential to identify people with caring responsibilities (including children) and ensure they have their needs assessed. Utilising more person centred approaches and starting with questions such as “what does a good life look like for you and your family and how can we work together to achieve it?” (as suggested in Care Act guidance) can provide a better way to engage with people and help provide families with choice and control over the support they may need.

References to other work or publications to support your testimony’ (if applicable):

None