National Institute for Health and Care Excellence

Draft for consultation

Supporting Adult Carers

RQB - providing information and advice about caring to carers in the UK

NICE guideline tbc

Evidence reviews

August 2019

Draft for Consultation

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

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Providing information and advice about caring to carers in the UK

Review question

What are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordinating care, or self-care - has been (and is) currently provided in the UK?

Introduction

Successive surveys of carers and their priorities demonstrate the importance of high quality and relevant information and advice not only at the onset but throughout their caring journeys. The Government's Action Plan for Carers 2018-2010 underlines the importance of high quality information and advice, but noted with concern that 3,000 out of 6,000 carers responding to their call for evidence considered that they did not have the information and advice necessary for their caring roles.

The Care Act 2014 introduced a new statutory duty for local authorities to establish and maintain information and advice services relating to care and support for all people in their areas. The Care Act guidance emphasises the importance of personalised care and support and recognises the crucial role of high-quality information and advice to enable carers to make informed decisions not only about their own support but also about the optimal care for their family member or friend.

However, information and advice for carers are not always of sufficient quality and relevant to their particular situations. There is some encouraging evidence of new initiatives, such as Carers UK's digital resource and the Carers Passport to ensure that information is shared, updated and instantly available when needed. However, a number of challenges can arise, with carers needing information from multiple sources. There is an ongoing debate about how best to integrate information and advice around health and social care and, in some instances financial and housing issues. Some carers have also argued that insufficient attention is paid to the distinct and sometimes different needs of carers and the person they support and that information and advice should take account of the needs of all family members and adopt a 'whole family approach'.

Summary of the protocol

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

Table 1: Summary of the protocol

Population	• Adult carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs. • 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	• Adult carers who have received some form of information and/or advice (including signposting) about caring from UK health- or social care services (including the emergency services) or

	relevant third-sector/voluntary organisations (including non-UK third-sector organisations)
Context	• UK only
Outcomes	Expected themes from the qualitative evidence might include: • accessibility, availability, and/or accuracy of information and services • content (for example quality, volume, jargon) • timeliness (when information is provided) • source (for example person, group, impersonal) or type (face-to-face, leaflet, email) of information • relevance/usefulness • apparent/perceived benefits, effectiveness or negative consequences of the information received.

For further details see the review protocol in appendix A.

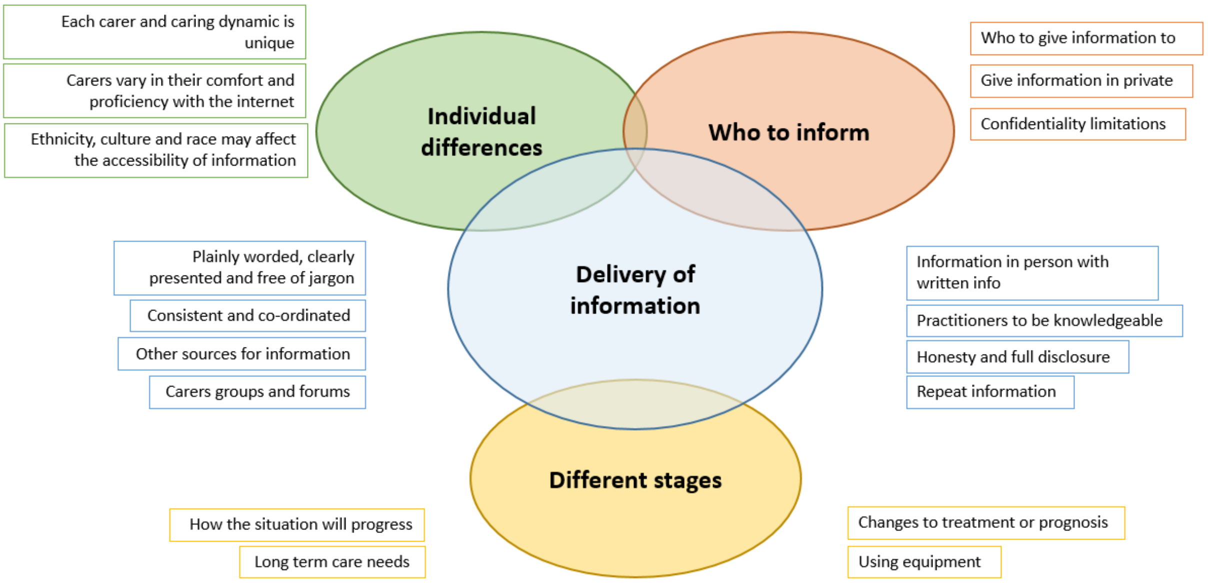
Included studies

This was a qualitative review with the aim of understanding how information and advice is provided to adult carers and how it can be improved.19 studies were identified for inclusion, published between 2003 and 2018. Out of these, 12 studies used qualitative interview methods only (Abley 2013, Aldred 2005, Bajwah 2013, Beaver 2007, CSSIW 2017, Garrett 2005, Harding 2004, Hughes 2005, McIlfatrick 2017, McKechnie 2014, Smith 2003, Woolham 2018). 1 study was a survey only with qualitative response components (Alsaeed 2018). 6 studies used a mix of different qualitative methods such as a survey, interviews and focus groups combined (Moriarty 2015, Newbronner 2011, Pinfold 2005, Powell 2010, Wingham 2015, Wright 2005).

The included studies are summarised in Table 2. 6 studies collected data from carers and professionals, while 13 colleceted data from carers only. 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.

As shown in the theme map (Figure 1) the concepts identified in the included evidence review fell into 4 overlapping themes.

Figure 1: Theme map



Excluded studies

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

Summary of studies included in the evidence review

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

Table 2: Summary of included qualitative studies

Study and aim of the study	Participants	Methods	Themes
Abley 2013 **Aim of the study** To explore the views of people with cognitive impairment and their carers on what constitutes high-quality communication and information provision when undergoing assessment in memory clinics.	**Sample:** 26 carers **Person being cared for:** Cognitive impairment **Characteristics:** M/F: 6/20 Spouses: 50%, Other: 50%	**Recruitment period:** September 2009 - March 2010 **Data collection:** Semi-structured interviews. **Analysis methods:** Thematic analysis using constant comparison.	• Carers want information delivered to them in person, supplemented with written information to take away. • All information whether written or verbal should be plainly worded, clearly presented and free of jargon. • Carers value honesty and full disclosure. • Carers need information to be repeated to them. • There are several sensitive considerations to account for when deciding who to give information to. • Information for carers should acknowledge how the situation will progress, and will often require follow-ups.
Aldred 2005 **Aim of the study** To explore the impact of heart failure on the lives of older people and their informal carers.	**Sample:** 10 carers **Person being cared for:** Older people with advanced heart failure. **Characteristics:** M/F = 4/6	**Recruitment period:** 2001 - 2002 **Data collection:** Semi-structured interviews. **Analysis methods:** Thematic analysis.	• When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. • Carers value honesty and full disclosure.
Alsaeed 2018 **Aim of the study** To explore carers' experience of home enteral feeding for medicine administration, the strategies they develop, and their suggestions for improving medicine administration; we relate these to the principles of medicines optimization.	**Sample:** 42 carers (family or paid) **Person being cared for:** People who use home enteral feeding for medicine administration **Characteristics:** Age range = 18-69 Parent: 2; Grandparent: 1; Son/daughter: 31; Sibling: 2;	**Recruitment period:** N/R **Data collection:** Survey. **Analysis methods:** Thematic analysis.	• Carers need clear information related to using equipment for long-term care.

Study and aim of the study	Participants	Methods	Themes
	Partner/spouse: 5; Non-family member: 2		
Bajwah 2013 **Aim of the study** To explore understanding of the disease, preferences regarding end-of-life planning, and views on communication and coordination of care in people with Progressive Idiopathic Fibrotic Interstitial Lung Disease.	**Sample:** 4 carers 6 health professionals **Person being cared for:** End-stage fibrotic interstitial lung disease **Characteristics:** Carers: M/F: 1/3 Age range: 41-63 Spouses: 3; Child: 1.	**Recruitment period:** December 2010 - March 2011 **Data collection:** Semi-structured interviews. **Analysis methods:** Thematic analysis.	• Carers want information delivered to them in person, supplemented with written information to take away. • When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. • Carers value honesty and full disclosure. • Carers turn to other sources for information when needed.
Beaver 2007 **Aim of the study** To examine the information needs and sources of information for informal carers of women treated for breast cancer in the acute cancer setting.	**Sample:** 50 carers **Person being cared for:** Women who had been treated for breast cancer and were attending hospital outpatient clinics **Characteristics:** M/F: 37/13 Relationship: husbands/partners (n):37; daughters (n):9; mothers (n):2; sisters (n):2.	**Recruitment period:** N/R **Data collection:** Semi-structured interviews. **Analysis methods:** Thematic analysis.	• Carers value honesty and full disclosure. • Carers turn to other sources for information when needed. • There are several sensitive considerations to account for when deciding who to give information to.
Care, Social Services Inspectorate, Wales (CSSIW) 2017 **Aim of the study** To enquire amongst Welsh carers and relevant professionals whether (a) Carers receive the support they need, (b) Carers know their rights and understand the support that is available to them, (c) Carers are equal partners and feel supported and valued for the care they give, and (c) The vision for support for carers recognises their economic contribution and is clear about the intended outcomes.	**Sample:** Approximately 400 carers **Person being cared for:** Any adults with social care needs	**Recruitment period:** N/R **Data collection:** Interviews (did not specify the type of interview) **Analysis methods:** Collected data was considered and written up by the researcher.	• All information whether written or verbal should be plainly worded, clearly presented and free of jargon. • Carers groups and forums are another valued source of information and support. • Carers vary in their comfort and proficiency with the internet.

Study and aim of the study	Participants	Methods	Themes
Garrett 2005 **Aim of the study** To discover the perceived information needs of stroke patients and carers at 2, 20 and 90 days post stroke.	**Sample:** 16 carers and stroke patients **Person being cared for:** Primary diagnosis of stroke **Characteristics:** Mostly spouses	**Recruitment period:** N/R **Data collection:** Interview (did not specify the type of interview). **Analysis methods:** Thematic analysis.	• Carers want information delivered to them in person, supplemented with written information to take away. • All information whether written or verbal should be plainly worded, clearly presented and free of jargon. • Carers need information to be repeated to them. • Carers need information about long term care needs beyond the specific condition.
Harding 2004 **Aim of the study** To evaluate, in terms of processes and outcomes for carers, a short-term group intervention for informal carers of people using a home palliative care service.	**Sample:** 24 carers **Person being cared for:** Users of a palliative care service **Characteristics:** M/F(%): 31/69 Relationship (%): wife/partner=34%, husband/partner=29%, daughter=14%, parent=11%, son=4%, sibling=1%. other family=3%, friend=3%, ex-partner=1%.	**Recruitment period:** N/R **Data collection:** Semi-structured interviews. **Analysis methods:** Content analysis.	• Carers groups and forums are another valued source of information and support.
Hughes 2005 **Aim of the study** To understand people's experiences and to generate ideas for developing practice and policy in MND health, social and palliative care.	**Sample:** 5 carers 15 professionals **Person being cared for:** People living with MND **Characteristics:** <u>Carers:</u> M/F: 1/4 <u>Professionals:</u> M/F: 2/13	**Recruitment period:** N/R **Data collection:** Semi-structured interviews. **Analysis methods:** Thematic analysis.	• Information should be consistent and co-ordinated between different services. • Carers turn to other sources for information when needed. • Each carer and caring dynamic is unique. • Information for carers should acknowledge how the situation will progress, and will often require follow-ups.
McIlfatrick 2017 **Aim of the study** To identify modifiable psychosocial factors associated with caregiver burden and to evaluate the support needs of caregivers when caring for people living with advanced heart failure at the end of life.	**Sample:** 30 carers (20 current caregivers, and 10 bereaved former caregivers) **Person being cared for** Caregivers of people with heart failure **Characteristics** Age of interviewees: N/R Current caregivers M/F: 5/15	**Recruitment period:** April 2014 to June 2016 **Data collection:** Semi-structured interviews **Analysis methods:** Thematic analysis	• Carers value honesty and full disclosure. • Each carer and caring dynamic is unique. • Information for carers should acknowledge how the situation will progress, and will often require follow-ups.

Study and aim of the study	Participants	Methods	Themes
	Previous caregivers M/F: N/R.		
McKechnie 2014 **Aim of the study** To examine the impact of a UK-based online support forum for carers of people living with dementia.	**Sample:** 8 carers **Person being cared for:** Dementia **Characteristics:** M/F: 2/6 Mean age (range): 61 (43-84)	**Recruitment period:** July 2012 – April 2013 **Data collection:** Semi-structured interviews. **Analysis methods:** Thematic analysis.	• Carers groups and forums are another valued source of information and support. • Carers vary in their comfort and proficiency with the internet.
Moriarty 2015 **Aim of the study** To describe different ways of working with family carers in adult social care departments and to collect the views of a range of stakeholders about the advantages and disadvantages of the approaches that were identified.	**Sample:** 24 family carers 38 workers **Person being cared for:** Not specified **Characteristics:** Not reported	**Recruitment period:** 2011-2012 **Data collection:** Mixed qualitative methods. **Analysis methods:** Thematic analysis	• Carers vary in their comfort and proficiency with the internet. • Ethnicity, culture and race may affect the accessibility of information.
Newbronner 2011 **Aim of the study** To provide evidence to inform good practice in personal budget processes for people with mental health issues and older people.	**Sample:** 23 carers 40 practitioners and managers **Person being cared for:** People with mental health issues and older people **Characteristics:** Mental health carer M/F: 3/6 Age: N=1 25-39; N=7 40-64, N=1 65-74 Older person carer: M/F: 2/8; Age: N=4, no answer; 2, 25-39; N=3, 40-64; N=9, 65-74. Older person & mental health carer: M/F: 0/4 Age: N=2, 40-64; N=1, 65-74 N= 1, 75 or over. Details of practitioners not provided.	**Recruitment period:** N/R **Data collection:** Mixed qualitative methods. **Analysis methods:** Themetic analysis.	• Carers want information delivered to them in person, supplemented with written information to take away. • All information whether written or verbal should be plainly worded, clearly presented and free of jargon. • When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. • Carers need information to be repeated to them. • Information should be consistent and co-ordinated between different services.
Pinfold 2005 **Aim of the study**	**Sample:** 12 carers 17 professionals	**Recruitment period:** August 2003 - June 2004	• All information whether written or verbal should be plainly worded, clearly

Study and aim of the study	Participants	Methods	Themes
The study had 4 main aims, all in relation to information sharing between mental health professionals and carers of people with mental health problems.	**Person being cared for:** Mental health and cognitive conditions **Characteristics:** Professionals working in mental health and ageing N= 5 (M/F: 2/3) Professionals working in adult mental health services N=9 (M/F:4/5) Carers for people with severe mental illness N=7 (M/F:0/7) Carers supporting people living with dementia N=5 (M/F: 2/3) Carer support workers N=3 (M/F: 0/3)	**Data collection:** Mixed qualitative methods. **Analysis methods:** Thematic analysis	presented and free of jargon. • When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. • Carers need information to be repeated to them. • Information should be consistent and co-ordinated between different services. • Carers groups and forums are another valued source of information and support. • Each carer and caring dynamic is unique. • Ethnicity, culture and race may affect the accessibility of information. • There are several sensitive considerations to account for when deciding who to give information to. • Carers sometimes feel it would be best to get information in private. • Carers and professionals need to work together to find a way to work with confidentiality limitations. • Carers need to be informed of any changes to treatment or prognosis.
Powell 2010 **Aim of the study** To investigate the perspectives of carers of people living with dementia about new networked technologies – including carers views of networked information and communication technologies, whether and how they use them, the possible benefits and disadvantages, and the barriers and facilitators to future implementation.	**Sample:** 34 carers **Person being cared for:** People living with dementia **Characteristics:** M/F: 12/22 Age:20–29= 1; 30–39 =3; 40–49= 7; 50–59= 9; 60–69= 7; 70–79= 5; 80–89=1; 90–99 =1	**Recruitment period:** N/R **Data collection:** Mixed qualitative methods. **Analysis methods:** Grounded method for analysing qualitative data	• Carers vary in their comfort and proficiency with the internet.
Smith 2003 **Aim of the study** To report the number and type of problems experienced by informal	**Sample:** 184 carers **Person being cared for:**	**Recruitment period:** 1999-2000 **Data collection:** Structured interviews	• Information should be consistent and co-ordinated between different services.

Study and aim of the study	Participants	Methods	Themes
carers when managing medication for older people, and to relate these to measures of coping and health.	Older people whose carer manages their medication. **Characteristics:** Sex % (M/F): 39/61 Mean age (range): 65 (30-91)	**Analysis methods:** Thematic analysis.	- Carers need to be informed of any changes to treatment or prognosis.
Wingham 2015 **Aim of the study** To undertake a qualitative assessment of the needs of HF caregivers to inform an evidence-based self-help intervention aimed at heart failure patients and caregivers.	**Sample:** 26 caregivers **Person being cared for:** Heart failure **Characteristics:** Caregiver participants in interviews: M/F: 6/16 Mean age (range): 67 (39–84) Caregiver participants in the focus groups: M/F: 1/3 Mean age (range): 62 (42–72)	**Recruitment period:** N/R **Data collection:** Mixed qualitative methods. **Analysis methods:** Thematic analysis.	- Information should be consistent and co-ordinated between different services. - Carers turn to other sources for information when needed. - Carers need information about long term care needs beyond the specific condition. - Carers need clear information related to using equipment for long-term care.
Woolham 2018 **Aim of the study** To examine the impact of a personal budget – either in the form of a direct payment or managed personal budget – on the role of unpaid carers of older budget holders.	**Sample:** Interviews: 31 carers. Survey: 1500 carers **Person being cared for:** Not explicitly stated, but various conditions **Characteristics**: Carers of DP users M/F:13/33 Mean age: 59.2 years Carers of MPB users M/F:66/128 Mean age: 63.9 years	**Recruitment period:** N/R **Data collection:** Mixed qualitative methods. **Analysis methods:** Framework analysis.	- Carers want information delivered to them in person, supplemented with written information to take away. - Information should be consistent and co-ordinated between different services.
Wright 2005 **Aim of the study** The research concentrated on specific difficulties that, according to the Health Survey for England, are commonly experienced with ageing.	**Sample:** 12 carers 40 health, social care and housing professionals 60 care home managers **Person being cared for:** Not reported **Characteristics:** Not reported	**Recruitment period:** April 2004 - March 2005 **Data collection:** Mixed qualitative methods. **Analysis methods:** Not reported.	- When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. - Carers turn to other sources for information when needed. Carers groups and forums are another valued source of information and support. - Each carer and caring dynamic is unique.

Study and aim of the study	Participants	Methods	Themes
			• Carers vary in their comfort and proficiency with the internet.

CSNAT: the Carer Support Needs Assessment Tool; DP: Direct Payment; F: Female; LGBT: Lesbian, Gay, Bisexual, and Transgender; M: Male; MND: Motor Neurone Disease; MPD: Managed Personal Budget; N: Number; N/A: not applicable; N/R: not reported; SD: Standard Deviation.

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

Theme 1: Delivery of information

IA1: Carers want information delivered to them in person, supplemented with written information to take away. Moderate quality evidence from 5 studies found that carers find face-to-face information most helpful as it allows the chance to ask for clarifications. However accompanying it with written information gave them something helpful to refer back to at a later point.

IA2: All information whether written or verbal should be plainly worded, clearly presented and free of jargon. Moderate quality evidence from 5 studies found that carers need bite-sized chunks of information delivered in plain English. Pictures or visual aids (diagrams, scans, videos) are especially helpful when receiving information both verbally and in written or digital form. Different formats should be available for people with visual impairments.

IA3: When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. High quality evidence from 5 studies found that while the support carers provide is essential, they often feel like practitioners don't have time for them or see explaining things to them as a burden. Carers are aware that practitioners are busy which can make them reserved about asking for the information they need. Professionals should spend sufficient time with carers and be proactive about ensuring they have the information they need.

IA4: Carers value honesty and full disclosure. High quality evidence from 5 studies found that professionals sometimes try and protect carers by softening difficult or upsetting facts. However carers normally want as much information as possible to enable them to plan and prepare. Carers report that the worst thing is being unclear or finding something out late.

IA5: Carers need information to be repeated to them. High quality evidence from 4 studies found that information is often both technically complex and also emotionally strenuous - making it doubly hard to process. Carers will often need to receive the same information several times or to have the provision of information staggered over several conversations. These needs are heightened among carers with memory impairments.

IA6: Information should be consistent and co-ordinated between different services. High quality evidence from 6 studies found that carers often receive information from several sources at the same time. It is important that professionals and services are in contact with each other and give carers coherent information.

IA7: Carers turn to other sources for information when needed. Moderate quality evidence from 5 studies found that carers often turn to sources like the internet or to friends and neighbours when they need further information. Sometimes this information may not be as reliable – which emphasises the need for clear information to come from professional sources.

IA8: Carers groups and forums are another valued source of information and support. Moderate quality evidence from 5 studies found that carers group meetings or online forums are valued by carers. They are used as sources of information as well as for support and as a place to share experiences or concerns.

Theme 2: Individual differences

IA9: Each carer and caring dynamic is unique. Moderate quality evidence from 4 studies found that carers vary in their information preferences and in how able they are to comprehend information. Mobility and accessibility differences need to be accommodated. The nature of each carer's relationship with the person they are supporting may also vary greatly. Professionals must be considerate, flexible and accommodating in how they deliver information.

IA10: Carers vary in their comfort and proficiency with the internet. Moderate quality evidence from 5 studies found that the internet can be a useful source of information, assistance and connection for many carers. However not all carers have access to the internet and some feel suspicious about the sharing of private information. Also online information can be misleading, hard to read, and hard to find at a stressful time.

IA11: Ethnicity, culture and race may affect the accessibility of information. Moderate quality evidence from 2 studies found that language can create a barrier to accessing information for carers whose first language is not English. Even if written information is available in their own or preferred language, some carers may miss out on the benefits of a verbal explanation. Differences in terminology and cultural understanding of illness may also act as barriers.

Theme 3: Who to inform

IA12: There are several sensitive considerations to account for when deciding who to give information to. Moderate quality evidence from 3 studies found that carers want to be viewed as part of the team, but can find it hard to obtain information if the person being supported is not well informed or is unable to attend conversations with professionals. At the same time care should be taken to ensure the person being supported is enabled to participate in such conversations. Their capacity needs to be considered, and so too do their wishes around confidentiality. Finally, the quality of relationships between people being supported and their relatives can vary and this can be another complicating factor related to information sharing.

IA13: Carers sometimes feel it would be best to get information in private. Low quality evidence from 1 study found that carers suggested some information might best be given in private away from the cared-for person to avoid distressing them and to protect their dignity.

IA14: Carers and professionals need to work together to find a way to work with confidentiality limitations. Low quality evidence from 1 study found that carers are generally respectful of consent and confidentiality in relation to information sharing. However they need certain information in order to be effective carers. They want professionals to explain how information sharing is restricted by the principles of 'patient confidentiality' and to work with them to find ways that they can get as much necessary information as possible while respecting those limits. This is particularly important when the carer is supporting someone experiencing memory less or certain psychiatric conditions (for example paranoia, eating disorders).

Theme 4: Different stages

IA15: Information for carers should acknowledge how the situation will progress, and will often require follow-ups. Moderate quality evidence from 3 studies found that carers' information needs will develop and change as the situation evolves, for example through diagnosis, transfer between hospital and home, disease progression, long-term care or end of life. Information should advise carers how the situation is likely to progress, prepare them to spot signs of change and highlight that they will benefit from new information in future.

IA16: Carers need information about long term care needs beyond the specific condition. Low quality evidence from 2 studies found that carers are given information about the long term development of the specific condition but are not informed or prepared to deal with other long term effects such as depression, sexual needs, recovery of speech etc.

IA17: Carers need to be informed of any changes to treatment or prognosis. Moderate quality evidence from 2 studies found that changes are sometimes made to medication or to prognosis without carers being told. They find this stressful and confusing and don't know whether they need to change the support they provide.

IA18: Carers need clear information related to using equipment for long-term care. Low quality evidence from 2 studies found that carers often feel under confident with equipment they are given to use (defibrillators, enteral tubes). Training is needed, and may need regular follow-up. Clear written instruction should include a troubleshooting page.

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 on information for carers in 2 subcategories – the first related to the information carers should be given, and the second related to how this information should best be delivered.

Under both subcategories the committee believed that the most critical outcome with regards to information was to ensure that the carer's and the person they care for's statutory rights are met. The Care Act 2014 sets out the information that carers have right to receive from services. The Equalities Act 2010 sets out the obligations that services have to make information accessible. The committee drafted strong recommendations about these areas in order to remind services and professionals about their obligations relating to information. The person being cared for also has rights to confidentiality in parallel with the carers rights, and so recommendations relating to information was also discussed to ensure respect for this.

Once statutory obligations were met, the other important outcomes were to make sure that professionals and services gave carers the information they need to be effective in their role and to be able to continue, including to look after their own well-being, and to making sure that it is delivered in a way that they can comprehend and retain, and can access again when needed.

The quality of the evidence

After appraisal using GRADE CERQual methodology most of the evidence statements were assessed as moderate or high quality overall. In terms of adequacy almost all of the evidence statements were backed up by findings from at least 3 separate studies, and the data tended to be rich with detailed quotations or author descriptions or both.

The carer populations who were subjects within the studies provided care for people living with a broad cross-section of different needs including dementia, mental health difficulties, heart failure and palliative care. This meant the general applicability of the evidence base to the scope's target population could be considered high. However it was noted by the committee that the evidence base was somewhat dominated by carers of people in later life and mostly spouses. The evidence came from studies that had been conducted exclusively in the UK and so were highly applicable to the context that the guidelines will apply to, although the committee noted that some regional variances are still likely.

There were moderate methodological concerns about some of the studies underlying a small number of evidence statements because a few key papers had not been clear about their methodological processes. In these cases the study's recruitment strategies, ethical considerations, and the nature of relationship between the researcher and the participant were the areas most likely to be unclearly reported. For many of the papers the participants for qualitative study also tended to be recruited quite opportunistic rather than purposively sampled.

The overall quality of evidence was assessed as low in a few domains. The evidence statements on the topic of privacy and confidentiality were low primarily because they were based on evidence from only 1 study – however the committee proceed to draft a recommendation on this topic because the statements were also reinforced by another guideline (CG138). Evidence statements about carers' ongoing information needs for care in the long term were also assessed as low quality, however a recommendation was drafted because moderate quality evidence on this topic had also been identified in another review question within this guideline [PS7].

Benefits and harms

What information carers should receive

The Care Act 2014 outlines that local authorities must provide carers with the information they need. The committee felt it was important to open with a recommendation reiterating this. They also recongised that health and social care practitioners are often in the best position to relay this information because they usually have most contact with carers. This is in line with the Care Act 2014 which urges authorities, services and individual practitioners to work together and ensure carers are given all the support they need.

Next the committee reviewed the wording of the Care Act 2014 and related guidance as well as several existing NICE guidelines (GC42, NG97, CG142, NG11, GC159) and supported by their own expertise, they developed a list of examples of the services and areas of information/advice that carers should be made aware of. The list was intended be applicable to all carers, regardless of the specific condition or needs of the person they care for. Evidence from the review [IA12] suggested that carers want to be recognised as a valued member of the 'care team' for the person they are supporting. The evidence found that keeping carers informed and 'in the loop' was as an important way to do this, and the committee's experience resonated with the finding. On the other hand evidence from the review [IA12, IA14] also highlighted that the extent of provision of information to carers may be limited due to issues around confidentiality and the privacy of the person they care for. As well as confidentiality, the committee agreed that sharing of information had to take account of the wishes and mental capacity of the cared for person, in line with the existing NICE guideline on decision making and mental capacity (CG138).

How information should be delivered to carers

Evidence from the review found that carers' information needs change over time and as circumstances change or the condition of the cared-for person develops [IA15-17]. In the committee's experience information may be made available at some stages like diagnosis or during times of crisis but can dwindle or become obsolete as the carer continues to provide care into the longer term. The committee therefore agreed to draft a recommendation about the timely provision of information.

According to the evidence carers may find complex or emotionally difficult information hard to remember [IA5], and both carers and practitioners reported that information may need to be repeated more than once, or given in increments that are reiterated over time. Evidence also highlighted several other aspects of formatting and delivery that would make carers more able to retain and use information that they were given. The committee were compelled by the strength of the evidence and the applicability of these points, which lead them to draft recommendations about tailoring information and delivering it in the clearest way possible [IA1-3, IA5-6]. Evidence also suggested several reasons related to equality that may mean carers need to have information tailored to their individual needs. Factors like language, technological literacy, and accessibility were highlighted within the evidence [IA9-11]. The committee felt that equality of accessibility was particularly important.

Evidence highlighted how a practitioner's manner can affect the carer when information is being given [IA3]. The committee agreed that practitioners who take their time and exude confidence are more likely to make carers comfortable to ask questions or seek important clarifications. The evidence also suggested carers prefer it when practitioners are tactful about emotionally difficult topics but also don't withhold important information [IA4].

Aside from service providers and practitioners, other important sources of information for carers were highlighted in the evidence. Carers forums were a source highlighted within the evidence statements [IA7-8]. Additionally, evidence from the review about identifying carers (RQA) suggested that primary care services might consider a 'carers champion' within their service with responsibility for identifying carers and making sure they have the necessary information.

Cost effectiveness and resource use

Whilst there are opportunity costs associated with information provision the recommendations are not especially expensive to implement. Therefore, the committee considered the provision of information would be cost-effective by allowing carers to better access existing services and advice.

The committee considered that current practice with respect to information provision varies across providers, and so the resource implications and financial impact of these recommendations is likely to vary by area to some extent. In some areas, additional training and review of current information provision may be required. However, because information provision is statutory and relatively inexpensive, the committee felt the recommendations would not introduce any major financial implications beyond what should already be current practice.

Other factors the committee took into account

Throughout discussions the committee was careful considered the wording of the Care Act (2014) ensuring recommendations were complimentary of its requirements to provide information to carers.

The committee also considered some of the existing recommendations relating to identifying carers published in other NICE guidelines. Some guidelines such as GC42, NG97, CG142, NG11, GC159 were reviewed for the types of information they provide. Some of these guidelines were aimed at specific sub-groups, usually with particular health conditions, although some of the recommendations were considered to be generally applicable. Once published the role of the current guideline would be to supersede these ‘non-specific’ recommendations and so the committee discussed what could be learned from them. While doing this the committee considered the wording of the recommendations closely. They also considered the applicability of the recommendations to the general carer population given the specific research and population contexts in which they had each been developed.

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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 are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordinating care, or self-care - has been (and is) currently provided in the UK?
Type of review question	Systematic qualitative review
Objective of the review	The objective of this review is to determine how information and advice provided to adult carers about caring, and the services available to them, has been provided, and how it can be improved.
Eligibility criteria – population/disease/condition/issue/domain	• UK adult carers who have provided, or are providing, unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs and who have received information and advice about caring. • Relevant social-/health- care and other practitioners involved in providing care.
Eligibility criteria – intervention	• Adult carers must have received some form of information and/or advice (including signposting) about caring from UK health- or social care services (including the emergency services) or relevant third-sector/voluntary organisations (including non-UK third-sector organisations).
Eligibility criteria – comparator(s)/control or reference (gold) standard	Not applicable
Expected themes	Themes will be identified from the literature, but expected themes are: • Accessibility, availability, and/or accuracy of information and services • Content (for example quality, volume, jargon) • Timeliness (when information is provided) • Source (for example person, group, impersonal) or type (face-to-face, leaflet, email) of information

Field (based on PRISMA-P)	**Content**
	- Relevance/usefulness - Apparent/perceived benefits, effectiveness or negative consequences of the information received
Eligibility criteria – study design	- Systematic reviews including a qualitative evidence synthesis (such as 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 or international surveys, 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* - Full-text English-language articles published in or after 2003 - Only UK studies will be included *Exclusion criteria* - Conference abstracts will be excluded as they typically do not provide sufficient information to evaluate risk of bias/quality of study. - Non- articles A step-wise approach to the included evidence will be used if required: although only studies published in or after 2003 will be initially included, subsequent modifications to the inclusion criteria may be warranted, subject to ratification by the GC, if the volume of studies to examine is very high. For example, studies may be restricted to those conducted in the UK or a more recent date of publication may be used. If changes to the initial inclusion criteria are deemed necessary, reasons for these will be explicitly noted in the methods section of the guideline.
Proposed sensitivity/sub-group analysis, or meta-regression	Not applicable
Selection process – duplicate screening/selection/analysis	Duplicate screening will be performed using STAR - minimum sample size is 10% of the total for <1000 titles and abstracts, and 5% of the total for ≥1000 titles and abstracts. All discrepancies are discussed and resolved

Field (based on PRISMA-P)	**Content**
	between 2 screeners. Any disputes will be resolved in discussion with the Senior Systematic Reviewer. Data extraction will be supervised by a senior reviewer. Draft excluded studies and evidence tables will be discussed with the Topic Advisor, prior to circulation to the Topic Group for their comments. Resolution of disputes will be by discussion between the senior reviewer, Topic Advisor and Chair.
Data management (software)	NGA STAR software will be used for generating bibliographies and citations, study sifting, data extraction and recording quality assessment of 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	Not an update
Author contacts	Developer: The National Guideline Alliance
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual 2014.
Search strategy – for one database	For details please see appendix F of the guideline.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix G (evidence tables) or H (economic evidence tables) of the guideline.

Field (based on PRISMA-P)	**Content**
Data items – define all variables to be collected	For details please see evidence tables in appendix G (eviidence tables) or H (economic evidence tables) of the guideline.
Methods for assessing bias at outcome/study level	GRADE-CERQual will be used to assess the overall quality of a theme (across studies). The following checklists will be used to evaluate the risk of bias of individual studies • Boynton & Greenhalgh checklist for cross-sectional surveys and survey questionnaire studies • Newcastle-Ottawa Scale for studies examining associations between variables (this does not include variables relevant to clinical diagnosis and prognosis). • CASP Qualitative Checklist for individual qualitative studies
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	Meta synthesis will be used to elucidate any themes or patterns revealed across the included qualitative or mixed methods studies relevant to establishing the acceptability of an intervention. GRADE-CERQual will be used to assess the quality of evidence for a theme across studies.
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual 2014. If sufficient relevant RCT evidence is available, publication bias will be explored using RevMan5 software to examine funnel plots.
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.
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.

Field (based on PRISMA-P)	Content
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 are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordinating care, or self-care – has been (and is) currently provided in the UK?

The search for this topic was last run on 7th November 2017.

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
2	(carer* or caregiv* or care giv*).ti,ab.
3	1 or 2
4	exp *cognitive therapy/ or (counseling.hw. and exp *counseling/) or *friend/ or *friendship/ or *group dynamics/ or *group process/ or *group therapy/ or *hotline/ or *mindfulness/ or *peer group/ or *problem solving/ or *psychotherapy/ or *reality therapy/ or *relaxation training/ or *self-help/ or *social adaption/ or *social network/ or *social support/ or exp *support group/
5	*advance care planning/ or *bereavement/ or *case management/ or *crisis intervention/ or *friends/ or *group process/ or *group therapy/ or *human relation/ or exp *peer group/ or *social network/ or *support group/ or *terminal care/
6	4 or 5
7	6 use emez
8	exp counseling/ or cognitive behavioral therapy/ or mindfulness/ or patient centered care/ or problem solving/ or psychotherapy*.sh. or exp psychotherapy, group/ or reality therapy/ or relaxation therapy/ or social support/
9	bereavement/ or case management/ or crisis intervention/ or education, nonprofessional/ or friends/ or group processes/ or hotlines/ or interpersonal relations/ or palliative care/ or exp peer group/ or professional family relations/ or exp psychotherapy, group/ or self-help groups/ or exp social networking/ or terminal care/
10	8 or 9
11	10 use mesz, prem
12	case management/ or client centered therapy/ or exp cognitive behavior therapy/ or exp counselling/ or exp group psychotherapy/ or mindfulness/ or exp problem solving/ or psychotherapy/ or reality therapy/ or exp relaxation therapy/ or social support/
13	advocacy/ or bereavement/ or crisis intervention services/ or crisis intervention/ or “death and dying”/ or friendship/ or group dynamics/ or group counseling/ or hot line services/ or interpersonal relationships/ or outreach programs/ or palliative care/ or peer counseling/ or peer evaluation/ or peer relations/ or peers/ or exp peer relations/ or exp social networks/ or self help techniques/ or social networks/ or social group work/ or support groups/ or terminally ill patients/
14	12 or 13
15	14 use psyh

#	Searches
16	*internet/ or *computer/ or *computer network/ or *internet/ or *online system/ or exp *computer assisted therapy/ or *social media/ or *social network/ or exp *telecommunication/
17	16 use emez
18	computers/ or computer assisted instruction/ or computer communication networks/ or exp internet/ or online systems/ or o social media/ or exp social networking/ or therapy, computer assisted/ or telecommunications/ or telemedicine/
19	18 use mesz, prem
20	computer assisted instruction/ or computer assisted therapy/ or computers/ or exp computer mediated communication/ or exp online therapy/ or exp internet/ or exp social media/ or exp social networks/ or telecommunications media/ or telemedicine/
21	20 use psyh
22	or/17,19,21
23	(((psychological* or psychosocial or psychotherapeutic) adj2 (intervention* or program* or support* or therap* or treat*)) or brief intervention* or psychotherap*).ti,ab.
24	(((behaviour* or behavior*) adj2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) adj3 (intervention* or manag* or program* or therap* or treat*)) or cognitiv* behav*).ti,ab.
25	counsel*.ti,ab.
26	(((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj based) or ((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) adj (intervention or program* or therap* or psychotherap*)) or elearning or e learning).ti,ab.
27	(case manag* or ((person centred or replacement) adj (care or therap*))).ti,ab.
28	((communit* or social) adj2 support*).ti,ab.
29	((intervention* or therap* or program* or workshop*) adj7 (caregiver* or care giver* or carer*) adj7 (burden or distress* or stress*)).ti,ab.
30	or/7,11,15,22-29
31	(befriend* or be* friend* or buddy or buddies or ((community or lay or paid or support) adj (person or worker*))).ti,ab.
32	((peer* or voluntary or volunteer*) adj3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)).ti,ab.
33	((peer* or support* or voluntary or volunteer*) adj2 group*).ti,ab.
34	((peer* or support* or voluntary or volunteer*) adj3 (intervention* or program* or rehab* or therap* or service* or skill*)).ti,ab.
35	((peer* adj3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or expert patient* or mutual aid).ti,ab. or (peer* adj3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)).ti,ab.
36	((bereav* or death or dying or end of life or grief* or ((palliative or terminal) adj care)) adj3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or anticipatory grief).ti,ab.
37	(((communit* or family or social) adj (network* or support*)) or group conferencing or individualis?ed support).ti,ab.

#	Searches
38	(((carer* or caregiv* or care giv*) adj2 (mentor* or support*)) or (unpaid adj3 support*) or mentoring scheme*).ti,ab.
39	((carer* or caregiv* or care giv*) adj3 (communication or integrat* or relations or relationship*) adj3 (famil* or practitioner* or professional* or worker*)) or (famil* adj3 (intervention* or program*)).ti,ab.
40	(psychoeducat* or psycho educat*).ti,ab.
41	((emotion* adj (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) adj (adapt* or reintegrat* or support*))).ti,ab.
42	((dyadic or loneliness or psychosocial* or psycho social*) adj2 (assist* or intervention* or program* or support* or therap* or treat*)).ti,ab.
43	((emotion* or one to one or transition*) adj support*).ti,ab.
44	(lay adj (led or run)).ti,ab.
45	((crisis or crises or emergenc*) adj3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)).ti,ab.
46	((coping or resilien* or well being or wellbeing) adj2 (intervention* or program* or therap* or skill* or strateg* or workshop*)).ti,ab.
47	(advocate or advocacy or ((support* adj3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* adj (service* or system)))).ti,ab.
48	((network* or peer*) adj2 (discuss* or exchang* or interact* or meeting*)).ti,ab.
49	(carer* network* or support group*).ti,ab.
50	or/31-49
51	(helpline or help line or ((phone* or telephone*) adj3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) adj2 (assist* or based or driven or led or mediat*))).ti,ab.
52	(helpseek* or ((search* or seek*) adj3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))).ti,ab.
53	(information adj (needs or provision or support)).ti,ab.
54	(selfhelp or self help or selfmanag* or self manag* or self support or selfsupport).ti,ab.
55	or/51-54
56	*education/ or *health education/ or *education program/ or *first aid/
57	56 use emez
58	caregiver/ed or education/ or first aid/ or exp health education/
59	58 use mesz, prem
60	client education/ or education/ or educational programs/ or health education/
61	60 use psyh
62	(((carer* or caregiv* or care giv*) adj5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) adj3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) adj3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) adj care) or rescue breath*)) or first aid or personali* train* or resourcefulness train* or (skill* adj2 (build* or coach* or educat* or learn* or train))).ti,ab.
63	(psychoeducat* or psycho educat*).ti,ab,hw.
64	(((medication or pain) adj2 manag*) or pain control program* or ((educat* or train*) adj5 (handling or movement))).ti,ab.
65	or/57,59,61-64

#	Searches
66	exercise*.hw. or exp *physical activity/ or *"physical education"/ or exp *sports/
67	66 use emez
68	exp exercise/ or physical exertion/ or exp "physical education and training"/ or exp sports/
69	68 use mesz, prem
70	exercise/ or exp physical activity/ or "physical education"/ or exp sports/
71	70 use psyh
72	(aerobic train* or exercis* or gym* or jog* or (physical adj (activit* or fit)) or resistance train* or sport* or strength train* or (swim* not rat*) or walk* or weight lift* or (leisure adj2 (activit* or intervention* or program* or therap*)) or leisure based).ti,ab.
73	or/67,69,71-72
74	exp *employment/ or exp *return to work/ or *supported employment/ or *vocational education/ or *vocational rehabilitation/ or *work/ or *work resumption/ or (employment and rehabilitation).hw.
75	74 use emez
76	employment/ or employment, supported/ or rehabilitation, vocational/ or return to work/ or unemployment/ or vocational education/ or work/ or workplace/ or (employment/ and rh.fs.)
77	76 use mesz, prem
78	employment status/ or exp vocational rehabilitation/ or reemployment/ or (employment and rehabilitation).hw. or vocational education/ or work adjustment training/
79	78 use psyh
80	*child welfare/ or *financial management/ or *social care/ or *social security/ or *social welfare/ or “social work/
81	80 use emez
82	“aid to families with dependent children”/ or child welfare/ or financing, government/ or government programs/ or public assistance/ or social security/ or social welfare/ or social work/
83	82 use mesz
84	government programs/ or social security/ or child welfare/ or "welfare services (government)"/ or community welfare services/ or exp social case services/ or social services/ or social security/
85	84 use psyh
86	(((employ* or job* or reemploy* or vocation* or work*) adj3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or carer* lead or flexible working or individuali* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*)).ti,ab.
87	((individual placement adj2 support) or ips model).ti,ab.
88	((permitted or voluntary or rehab*) adj3 work*).ti,ab.
89	((psychosocial or psycho social or social) adj2 rehab*).ti,ab.
90	rehabilitation counsel*.ti,ab.
91	((prevocat* or vocat*) adj3 (advice* or advis* or assist* or casework* or case work* or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)).ti,ab.
92	(volunteering or (work adj2 placement*)).ti,ab.

#	Searches
93	(((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
94	(return adj to* adj (education or study or training or work*)).ti,ab.
95	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
96	(signpost* or sign post*).ti,ab.
97	or/75,77,79,81,83,85-96
98	*day care/ or *respite care/
99	98 use emez
100	day care, medical/ or respite care/
101	100 use mesz, prem
102	adult day care/ use psyh or day care centers/ use psyh or respite care/ use psyh
103	(day care or daycare or day therap* or daytherap* or home help or short break or ((carer* or caregiv* or care giv*) adj3 support*)).ti,ab.
104	(((crisis or volunteer) adj support) or holiday* or homehelp* or home help* or housekeep* or house keep* or meal support or personal assistant or respite or ((activity or fund* or short) adj2 break*) or signpost*).ti,ab.
105	or/99,101-104
106	*assistive technology/ or *occupational therapy/ or *telehealth/ or *telemedicine/ or *telemetry/ or *telemonitoring/
107	106 use emez
108	assistive technology/ or occupational therapy/ or self-help devices/ or telemedicine/ or telemetry/ or telemonitoring/
109	108 use mesz, prem
110	assistive technology/ or occupational therapy/ or telemedicine/ or telemetry/
111	110 use psyh
112	((assistive adj2 (platform* or technolog*)) or interactive health communication).ti,ab.
113	(simulated presence or social robot* or telecare or telehealth or telematic* or telemonitor*).ti,ab.
114	(gps track* or location technology).ti,ab.
115	occupational therap*.ti,ab.
116	or/107,109,111-115
117	exp acupuncture/ use emez or exp alternative medicine/ use emez or biofeedback/ or massage/ use emez or meditation/ use emez or acupressure/ use mesz, prem or massage/ use mesz, prem or acupuncture/ use mesz, prem or exp complementary therapies/ use mesz, prem or exp mind body therapies/ use mesz, prem or exp alternative medicine/ use psyh or biofeedback/ use psyh or massage/ use psyh or mind body therapy/ use psyh
118	(chinese medicine or medicine, chinese traditional or (moxibustion or electroacupuncture)).sh,id. or ((alternative or complementary) adj2 (medicine* or therap*)).ti,ab,sh. or (acu point* or acupoint* or acupressur* or acupunctur* or (ching adj2 lo) or cizhen or dianzhen or electroacupunctur* or (jing adj2 luo) or jingluo or massag* or needle therap* or zhenjiu or zhenci).tw.
119	meditation.sh. or meditat*.ti,ab.
120	(acceptance adj2 commitment therap*).ti,ab.

#	Searches
121	dyadic intervention*.ti,ab.
122	(reminiscence adj (group* or therap*)).ti,ab.
123	self disclosure/ use emez,mesz,psyh or ((emotional or self) adj disclosure).ti,ab.
124	art/ or art therapy/ or music/ or music therapy/ or singing/ or painting/ use emez or singing/ use emez, mesz, prem or paintings/ use mesz, prem
125	124 use emez,mesz
126	art/ or art education/ or art therapy/ or "painting (art)"/ or music/ or music education/ or music therapy/ or singing/
127	126 use psyh
128	(art or cafe or cafes or gallery or music or sing or singing).ti,ab.
129	or/117-123,125,127-128
130	30,50,55,65,73,97,105,116,129
131	3 and 130
132	interviews as topic/ or qualitative research/
133	132 use emez
134	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/
135	134 use mesz, prem
136	cluster analysis/ or "culture (anthropological)" or interviews/ or narratives/ or observation methods/ or qualitative research/ or tape recorders/
137	136 use psyh
138	(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 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.
139	(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.
140	or/133,135,137-139
141	"*attitude to health"/ or *consumer/ or *consumer attitude/ or *health care quality/ or *patient attitude/ or *patient compliance/ or *patient preference/ or *patient satisfaction/
142	141 use emez
143	*attitude to health/ or comprehensive health care/ or exp consumer participation/ or exp consumer satisfaction/ or "patient acceptance of health care"/ or patient care

#	Searches
	management/ or patient centered care/ or exp patient compliance/ or patient satisfaction/ or "quality of health care"/
144	143 use mesz, prem
145	exp client attitudes/ or client satisfaction/ or consumer attitudes/ or exp health attitudes/ or exp consumer attitudes/ or patient satisfaction/ or treatment compliance/
146	145 use psyh
147	((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.
148	((consumer or patient) adj2 (focus* or centered or centred)).ti,ab.
149	or/142,144,146-148
150	or/140,149
151	clinical trials as topic.sh. or (controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or (placebo or randomi#ed or randomly).ab. or trial.ti.
152	151 use mesz, prem
153	(controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or drug therapy.fs. or (groups or placebo or randomi#ed or randomly or trial).ab.
154	153 use mesz, prem
155	crossover procedure/ or double blind procedure/ or randomized controlled trial/ or single blind procedure/ or (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab.
156	155 use emez
157	(assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab. use psyh
158	or/152,154,156-157
159	meta-analysis/
160	meta-analysis as topic/ or systematic reviews as topic/
161	“systematic review”/
162	meta-analysis/
163	(meta analy* or metanaly* or metaanaly*).ti,ab.
164	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
165	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
166	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
167	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
168	(search* adj4 literature).ab.
169	(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.
170	cochrane.jw.
171	((pool* or combined) adj2 (data or trials or studies or results)).ab.
172	or/159-160,163,165-171 use mesz, prem
173	(or/161-164,166-171) use emez
174	meta analysis/ use psyh or or/163-171 use psyh

#	Searches
175	(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.
176	or/172-175
177	or/158,176
178	exp case control study/ or cohort analysis/ or cross-sectional study/ or follow up/ or longitudinal study/ or observational study/ or prospective study/ or retrospective study/
179	178 use emez
180	exp case control studies/ or exp cohort studies/ or cross-sectional studies/ or epidemiologic studies/
181	180 use mesz, prem
182	(cohort analysis or followup studies or longitudinal studies or prospective studies or retrospective studies).sh,id. or (followup study or longitudinal study or prospective study or retrospective study).md.
183	182 use psyh
184	((epidemiologic* or observational) adj (study or studies)).ti,ab.
185	(cohort*1 or cross section* or crosssection* or followup* or follow up* or followed or longitudinal* or prospective* or retrospective*).ti,ab.
186	(case adj2 (control or series or stud*)).ti,ab.
187	(nonequivalent control group or posttesting or pretesting or pretest posttest design or pretest posttest control group design or quasi experimental methods or quasi experimental study or time series or time series analysis).sh.
188	(((nonequivalent or non equivalent) adj3 control*) or posttest* or post test* or pre test* or pretest* or quasi experiment* or quasiexperiment* or timeseries or time series).tw.
189	or/179,181,183-188
190	177 or 189
191	190
192	united kingdom/
193	(national health service* or nhs*).ti,ab,in,ad.
194	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
195	(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.
196	(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

#	Searches
	(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.
197	(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.
198	(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.
199	(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.
200	or/192-199 use emez
201	exp united kingdom/
202	(national health service* or nhs*).ti,ab,in.
203	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
204	(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.
205	(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.

#	Searches
206	(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.
207	(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.
208	(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.
209	or/201-208
210	(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/)
211	209 not 210
212	211 use mesz, prem
213	(national health service* or nhs*).ti,ab,in,cq.
214	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
215	(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.
216	(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,cq.
217	(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.
218	(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.
219	(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.
220	or/213-219 use psyh
221	or/200,212,220

#	Searches
222	150 and 221
223	131 and or/177,222

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

#	Searches
1	(carer* or caregiv* or care giv*).ti,ab.
2	(((psychological* or psychosocial or psychotherapeutic) adj2 (intervention* or program* or support* or therap* or treat*)) or brief intervention* or psychotherap*).ti,ab.
3	(((behaviour* or behavior*) adj2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) adj3 (intervention* or manag* or program* or therap* or treat*)) or cognitiv* behav*).ti,ab.
4	counsel*.ti,ab.
5	(((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj based) or ((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) adj (intervention or program* or therap* or psychotherap*)) or elearning or e learning).ti,ab.
6	(case manag* or ((person centred or replacement) adj (care or therap*))).ti,ab.
7	((communit* or social) adj2 support*).ti,ab.
8	((intervention* or therap* or program* or workshop*) adj7 (caregiver* or care giver* or carer*) adj7 (burden or distress* or stress*)).ti,ab.
9	or/2-8
10	(befriend* or be* friend* or buddy or buddies or ((community or lay or paid or support) adj (person or worker*))).ti,ab.
11	((peer* or voluntary or volunteer*) adj3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)).ti,ab.
12	((peer* or support* or voluntary or volunteer*) adj2 group*).ti,ab.
13	((peer* or support* or voluntary or volunteer*) adj3 (intervention* or program* or rehab* or therap* or service* or skill*)).ti,ab. or ((peer* adj3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or expert patient* or mutual aid).ti,ab.
14	((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief").ti,ab.
15	(peer* adj3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)).ti,ab.
16	(((communit* or family or social) adj (network* or support*)) or group conferencing or individualis?ed support).ti,ab.
17	(((carer* or caregiv* or care giv*) adj2 (mentor* or support*)) or (unpaid adj3 support*) or mentoring scheme*).ti,ab.
18	((carer* or caregiv* or care giv*) adj3 (communication or integrat* or relations or relationship*) adj3 (famil* or practitioner* or professional* or worker*)) or (famil* adj3 (intervention* or program*)).ti,ab.
19	(psychoeducat* or psycho educat*).ti,ab.

#	Searches
20	((emotion* adj (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) adj (adapt* or reintegrat* or support*))).ti,ab.
21	((dyadic or loneliness or psychosocial* or psycho social*) adj2 (assist* or intervention* or program* or support* or therap* or treat*)).ti,ab.
22	((emotion* or one to one or transition*) adj support*).ti,ab.
23	(lay adj (led or run)).ti,ab.
24	((crisis or crises or emergenc*) adj3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)).ti,ab.
25	((coping or resilien* or well being or wellbeing) adj2 (intervention* or program* or therap* or skill* or strateg* or workshop*)).ti,ab.
26	(advocate or advocacy or ((support* adj3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* adj (service* or system)))).ti,ab.
27	((network* or peer*) adj2 (discuss* or exchang* or interact* or meeting*)).ti,ab.
28	(carer* network* or support group*).ti,ab.
29	or/10-28
30	(helpline or help line or ((phone* or telephone*) adj3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) adj2 (assist* or based or driven or led or mediat*))).ti,ab.
31	(helpseek* or ((search* or seek*) adj3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))).ti,ab.
32	(information adj (needs or provision or support)).ti,ab.
33	(selfhelp or self help or selfmanag* or self manag* or self support or selfsupport).ti,ab.
34	or/30-33
35	(((carer* or caregiv* or care giv*) adj5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) adj3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) adj3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) adj care) or rescue breath*)) or first aid or personali* train* or resourcefulness train* or (skill* adj2 (build* or coach* or educat* or learn* or train))).ti,ab.
36	(psychoeducat* or psycho educat*).ti,ab,hw.
37	(((medication or pain) adj2 manag*) or pain control program* or ((educat* or train*) adj5 (handling or movement))).ti,ab.
38	or/35-37
39	(aerobic train* or exercis* or gym* or jog* or (physical adj (activit* or fit)) or resistance train* or sport* or strength train* or (swim* not rat*) or walk* or weight lift* or (leisure adj2 (activit* or intervention* or program* or therap*)) or leisure based).ti,ab.
40	39
41	(((employ* or job* or reemploy* or vocation* or work*) adj3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or carer* lead or flexible working or individuali* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*)).ti,ab.
42	((individual placement adj2 support) or ips model).ti,ab.
43	((permitted or voluntary or rehab*) adj3 work*).ti,ab.

#	Searches
44	((psychosocial or psycho social or social) adj2 rehab*).ti,ab.
45	rehabilitation counsel*.ti,ab.
46	((prevocat* or vocat*) adj3 (advice* or advis* or assist* or casework* or case work* or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)).ti,ab.
47	(volunteering or (work adj2 placement*)).ti,ab.
48	(((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
49	(return adj to* adj (education or study or training or work*)).ti,ab.
50	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
51	(signpost* or sign post*).ti,ab.
52	or/41-51
53	(day care or daycare or day therap* or daytherap* or home help or short break or ((carer* or caregiv* or care giv*) adj3 support*)).ti,ab.
54	(((crisis or volunteer) adj support) or holiday* or homehelp* or home help* or housekeep* or house keep* or meal support or personal assistant or respite or ((activity or fund* or short) adj2 break*) or signpost*).ti,ab.
55	or/53-54
56	((assistive adj2 (platform* or technolog*)) or interactive health communication).ti,ab.
57	(simulated presence or social robot* or telecare or telehealth or telematic* or telemonitor*).ti,ab.
58	(gps track* or location technology).ti,ab.
59	occupational therap*.ti,ab.
60	or/56-59
61	(chinese medicine or medicine, chinese traditional or (moxibustion or electroacupuncture)).sh,id. or ((alternative or complementary) adj2 (medicine* or therap*)).ti,ab,sh. or (acu point* or acupoint* or acupressur* or acupunctur* or (ching adj2 lo) or cizhen or dianzhen or electroacupunctur* or (jing adj2 luo) or jingluo or massag* or needle therap* or zhenjiu or zhenci).tw.
62	meditation.sh. or meditat*.ti,ab.
63	(acceptance adj2 commitment therap*).ti,ab.
64	dyadic intervention*.ti,ab.
65	(reminiscence adj (group* or therap*)).ti,ab.
66	self disclosure/ use emez,mesz,psyh or ((emotional or self) adj disclosure).ti,ab.
67	or/61-66
68	(art or cafe or cafes or gallery or music or sing or singing).ti,ab.
69	68
70	or/9, 29, 34, 38, 40, 52, 55, 60, 67, 69
71	1 and 70

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 (psychotherap*)
S3	noft (((psychological* or psychosocial or psychotherapeutic) near/2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*)
S4	noft (((behaviour* or behavior*) near/2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) near/3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”)
S5	noft (“case manag*” or counsel* or ((“person centred” or replacement) near/1 (care or therap*)))
S6	noft (((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) near/1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”)
S7	noft ((“person centred” or replacement) near/1 (care or therap*))
S8	noft ((communit* or social) near/2 support*)
S9	noft ((intervention* or therap* or program* or workshop*) near/7 (caregiver* or “care giver*” or carer*) near/7 (burden or distress* or stress*))
S10	S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9
S11	noft (befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) near/1 (person or worker*)))
S12	noft ((peer* or voluntary or volunteer*) near/3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*))
S13	noft ((peer* or support* or voluntary or volunteer*) near/2 group*)
S14	noft ((peer* or support* or voluntary or volunteer*) near/3 (intervention* or program* or rehab* or therap* or service* or skill*))
S15	noft (((peer* near/3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* near/3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)))
S16	noft ((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief")
S17	noft (((communit* or family or social) near/1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”)
S18	noft (((carer* or caregiv* or “care giv*”) near/2 (mentor* or support*)) or (unpaid near/3 support*) or “mentoring scheme*”)
S19	noft (((carer* or caregiv* or “care giv*”) near/3 (communication or integrat* or relations or relationship*) near/3 (practitioner* or professional* or worker*)) or (famil* near/3(intervention* or program*)))
S20	noft (psychoeducat* or “psycho educat*”)
S21	noft ((emotion* near/1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) near/1 (adapt* or reintegrat* or support*)))
S22	noft ((dyadic or loneliness or psychosocial* or “psycho social*”) near/2 (assist* or intervention* or program* or support* or therap* or treat*))

#	Searches
S23	noft ((emotion* or “one to one” or transition*) near/1 support*)
S24	noft (lay near/1 (led or run))
S25	noft ((crisis or crises or emergenc*) near/3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*))
S26	noft ((coping or resilien* or “well being” or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop*))
S27	noft (advocate or advocacy or ((support* near/3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* near/1 (service* or system))))
S28	noft ((network* or peer*) near/2 (discuss* or exchang* or interact* or meeting*))
S29	noft (carer* network* or “support group*”)
S30	S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 or S29
S31	noft (helpline or “help line” or ((phone* or telephone*) near/3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) near/2 (assist* or based or driven or led or mediat*)))
S32	noft (helpseek* or ((search* or seek*) near/3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*)))
S33	noft (information near/1 (needs or provision or support))
S34	noft (selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport)
S35	S31 or S32 or S33 or S34
S36	noft (((carer* or caregiv* or “care giv*”) near/5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) near/3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) near/3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) near/1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* near/2 (build* or coach* or educat* or learn* or train)))
S37	noft (psychoeducat* or “psycho educat*”) ti,ab,hw.
S38	noft (((medication or pain) near/2 manag*) or “pain control program*” or ((educat* or train*) near/5 (handling or movement)))
S39	S36 or S37 or S38
S40	noft (“aerobic train*” or exercis* or gym* or jog* or (physical near/1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure near/2 (activit* or intervention* or program* or therap*)) or “leisure based”)
S41	S40
S42	noft (((employ* or job* or reemploy* or vocation* or work*) near/3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* near/2 employ*) or (work near/2 coach*))
S43	noft ((“individual placement” near/2 support) or “ips model”)
S44	noft ((permitted or voluntary or rehab*) near/3 work*)
S45	noft ((psychosocial or “psycho social” or social) near/2 rehab*)
S46	noft (“rehabilitation counsel*”)

#	Searches
S47	noft ((prevocat* or vocat*) near/3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*))
S48	noft (volunteering or (work near/2 placement*))
S49	noft (((carer* or “care giv*” or caregiv*) near/3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”)
S50	noft (return near/1 to* near/1 (education or study or training or work*))
S51	noft (“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) near/3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) near/7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) near/7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)))
S52	noft (signpost* or “sign post*”)
S53	S42 or S43 or S44 or S45 or S46 or S47 or S48 or S49 or S50 or S51 or S52
S54	noft (“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) near/3 support*))
S55	noft (((crisis or volunteer) near/1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) near/2 break*) or signpost*)
S56	S54 or S55
S57	noft ((assistive near/2 (platform* or technolog*)) or “interactive health communication”)
S58	noft (“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*)
S59	noft (“gps track*” or “location technology”)
S60	noft “occupational therap*”
S61	S57 or S58 or S59 or S60
S62	noft ((alternative or complementary) near/2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching near/2 lo) or cizhen or dianzhen or electroacupunctur* or (jing near/2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci)
S63	noft (meditat*)
S64	noft (acceptance near/2 “commitment therap*”)
S65	noft (“dyadic intervention*”)
S66	noft (reminiscence near/1 (group* or therap*))
S67	noft ((emotional or self) near/1 disclosure)
S68	S62 or S63 or S64 or S65 or S66 or S67
S69	noft (art or cafe or cafes or gallery or music or sing or singing)
S70	S69
S71	s10 or s30 or s35 or s39 or s41 or s53 or s56 or s61 or s68 or s70
S72	S1 and S71
S73	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

#	Searches
	(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*”)
S74	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*).mp. or (qualitative* and (metaanal* or “meta anal*” or synthes* or “systematic review*”))
S75	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))
S76	noft ((consumer or patient) near/2 (focus* or centered or centred))
S77	S73 or S74 or S75 or S76
S78	noft (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) near/1 blind*) or factorial* or placebo* or random* or volunteer*)
S79	S78
S80	noft (“meta analy*” or metanaly* or metaanaly*)
S81	noft ((systematic or evidence) near/2 (review* or overview*))
S82	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*)
S83	S80 or S81 or S82
S84	noft ((epidemiologic* or observational) near/1 (study or studies))
S85	noft (cohort* or “cross section*” or crosssection* or followup* or “follow up*” or followed or longitudinal* or prospective* or retrospective*)
S86	noft (case near/2 (control or series or stud*))
S87	noft (((nonequivalent or non equivalent) near/3 control*) or posttest* or “post test*” or “pre test*” or pretest* or “quasi experiment*” or quasiexperiment* or timeseries or “time series”)
S88	S84 or S85 or S86 or S87
S89	S77 or s79 or S83
S90	S72 and S89

Database: CINAHL – Ebsco

1 (mh "caregivers")
2 tx (carer* or caregiv* or “care giv*”)
3 #1 or #2
4 (mh "counseling+")
5 (mh "psychotherapy, group+")
6 (mh "cognitive therapy+")
7 (mh "mindfulness")
8 (mh "patient centered care")
9 (mh "problem solving")
10 (mh "reality therapy")
11 (mh "simple relaxation therapy (iowa nic)")
12 (mh "social support (iowa noc)") or (mh "support, psychosocial")
13 tx (psychotherap*)
14 (mh "case management")
15 (mh "crisis intervention")
16 (mh "crisis intervention (iowa nic)")
17 (mh "education, nonprofessional")
18 (mh "social networks")
19 (mh "group processes")
20 (mh "interpersonal relations")
21 (mh "professional-family relations")
22 (mh "support groups")
23 (mh "peer group")
24 (mh "psychotherapy, group")
25 (mh "social networking+")
26 (mh "computers and computerization")
27 (mh "computer assisted instruction")
28 (mh "computer communication networks")
29 (mh "online systems")
30 (mh "social media+")
31 (mh "therapy, computer assisted")
32 (mh "telecommunications")
33 (mh "telemedicine")
34 (mh "internet+")
35 (mh "social networking+")
36 tx (((psychological* or psychosocial or psychotherapeutic) n2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*)
37 tx (((behaviour* or behavior*) n2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) n3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”)
38 tx (“case manag*” or counsel* or ((“person centred” or replacement) n1 (care or therap*)))
39 (((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) n1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) n3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) n1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”)
40 tx ((“person centred” or replacement) n1 (care or therap*))
41 tx ((communit* or social) n2 support*)
42 tx ((intervention* or therap* or program* or workshop*) n7 (caregiver* or “care giver*” or carer*) n7 (burden or distress* or stress*))

43 #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42
44 tx (befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) n1 (person or worker*)))
45 tx ((peer* or voluntary or volunteer*) n3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*))
46 tx ((peer* or support* or voluntary or volunteer*) n2 group*)
47 tx ((peer* or support* or voluntary or volunteer*) n3 (intervention* or program* or rehab* or therap* or service* or skill*))
48 tx (((peer* n3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* n3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)))
49 tx ((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) n1 care))
near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief")
50 tx (((communit* or family or social) n1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”)
51 tx (((carer* or caregiv* or “care giv*”) n2 (mentor* or support*)) or (unpaid n3 support*) or “mentoring scheme*”)
52 tx (((carer* or caregiv* or “care giv*”) n3 (communication or integrat* or relations or relationship*) n3 (practitioner* or professional* or worker*)) or (famil* n3(intervention* or program*)))
53 tx (psychoeducat* or “psycho educat*”)
54 tx ((emotion* n1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) n1 (adapt* or reintegrat* or support*)))
55 tx ((dyadic or loneliness or psychosocial* or “psycho social*”) n2 (assist* or intervention* or program* or support* or therap* or treat*))
56 tx ((emotion* or “one to one” or transition*) n1 support*)
57 tx (lay n1 (led or run))
58 tx ((crisis or crises or emergenc*) n3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*))
59 tx ((coping or resilien* or “well being” or wellbeing) n2 (intervention* or program* or therap* or skill* or strateg* or workshop*))
60 tx (advocate or advocacy or ((support* n3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* n1 (service* or system))))
61 tx ((network* or peer*) n2 (discuss* or exchang* or interact* or meeting*))
62 tx (carer* network* or “support group*”)
63 #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
64 tx (helpline or “help line” or ((phone* or telephone*) n3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) n2 (assist* or based or driven or led or mediat*)))
65 tx (helpseek* or ((search* or seek*) n3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*)))
66 tx (information n1 (needs or provision or support))
67 tx (selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport)
68 #64 or #65 or #66 or #67
69 (mh "education")
70 (mh "health education")

71 (mh "first aid") or (mh "first aid (iowa nic)")
72 tx (((carer* or caregiv* or “care giv*”) n5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) n3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) n3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) n1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* n2 (build* or coach* or educat* or learn* or train)))
73 tx (psychoeducat* or “psycho educat*”) ti,ab,hw.
74 tx (((medication or pain) n2 manag*) or “pain control program*” or ((educat* or train*) n5 (handling or movement)))
75 #69 or #70 or #71 or #72 or #73 or #74
76 (mh "exertion")
77 (mh "exercise+")
78 (mh "physical education and training+")
79 (mh "sports+")
80 tx (“aerobic train*” or exercis* or gym* or jog* or (physical n1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure n2 (activit* or intervention* or program* or therap*)) or “leisure based”)
81 #76 or #77 or #78 or #79 or #80
82 (mh "employment")
83 (mh "employment, supported")
84 (mh "rehabilitation, vocational")
85 (mh "job re-entry")
86 (mh "unemployment")
87 (mh "vocational education")
88 (mh "work")
89 (mh "work environment")
90 (MH "Dependent Families")
91 (mh "child welfare")
92 (mh "financing, government")
93 (mh "government programs")
94 (mh "public assistance")
95 (mh "social welfare")
96 (MH "Economic and Social Security")
97 (mh "social work")
98 tx (((employ* or job* or reemploy* or vocation* or work*) n3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* n2 employ*) or (work n2 coach*))
99 tx ((“individual placement” n2 support) or “ips model”)
100 tx ((permitted or voluntary or rehab*) n3 work*)
101 tx ((psychosocial or “psycho social” or social) n2 rehab*)
102 tx “rehabilitation counsel*”
103 tx ((prevocat* or vocat*) n3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*))
104 tx (volunteering or (work n2 placement*))
105 tx (((carer* or “care giv*” or caregiv*) n3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”)
106 tx (return n1 to* n1 (education or study or training or work*))
107 tx (“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or

lodging* or money or “working rights”) n3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) n7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) n7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)))
108 tx (signpost* or “sign post*”)
109 #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108
110 (mh "day care")
111 (mh "respite care") or (mh "respite care (iowa nic)")
112 tx (“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) n3 support*))
113 tx (((crisis or volunteer) n1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) n2 break*) or signpost*)
114 #110 or #111 or #112 or #113
115 (mh "assistive technology")
116 (mh "occupational therapy")
117 (mh "assistive technology devices+")
118 (mh "telemedicine")
119 (mh "telemetry")
120 (mh "telenursing")
121 tx ((assistive n2 (platform* or technolog*)) or “interactive health communication”)
122 tx (“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*)
123 tx (“gps track*” or “location technology”)
124 tx “occupational therap*”
125 #115 or #116 or #117 or #118 or #119 or #120 or #121 or #122 or #123 or #124
126 (mh "acupressure")
127 (mh "massage")
128 (mh "acupuncture")
129 (mh "alternative therapies+")
130 (mh "mind body techniques+")
131 (mh "medicine, chinese traditional")
132 (mh "moxibustion")
133 tx ((alternative or complementary) n2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching n2 lo) or cizhen or dianzhen or electroacupunctur* or (jing n2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci)
134 (mh "meditation") or (mh "meditation (iowa nic)") or tx (meditate*)
135 tx (acceptance n2 “commitment therap*”)
136 tx “dyadic intervention*”
137 tx (reminiscence n1 (group* or therap*))
138 tx ((emotional or self) n1 disclosure)
139 (mh "self disclosure")
140 (mh "art")
141 (mh "music")
142 (mh "singing")
143 (mh "paint")
144 (mh "art therapy")
145 (mh "singing")
146 tx (art or cafe or cafes or gallery or music or sing or singing)
147 #126 or #127 or #128 or #129 or #130 or #131 or #132 or #133 or #134 or #135 or #136 or #137 or #138 or #139 or #140 or #141 or #142 or #143 or #144 or #145 or #146

148 #3 and (#43 or #63 or #68 or #75 or #81 or #109 or #114 or #125 or #147)

149 (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")

150 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*”)

151 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*))

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

153 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))

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

155 #149 or #150 or #151 or #152 or #153 or #154

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

157 (mh "meta analysis")

158 (mh "systematic review")

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

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

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

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

163 (search* n4 literature)

164 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)

165 so cochrane

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

167 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*))
168 #157 or #158 or #159 or #160 or #161 or #162 or #163 or #164 or #165 or #166 or #167
169 #155 or #156 or #168
170 #148 and #169

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
4	mesh descriptor: [counseling] explode all trees
5	mesh descriptor: [psychotherapy, group] explode all trees
6	mesh descriptor: [cognitive behavioral therapy] this term only
7	mesh descriptor: [mindfulness] this term only
8	mesh descriptor: [patient centered care] this term only
9	mesh descriptor: [problem solving] this term only
10	mesh descriptor: [reality therapy] this term only
11	mesh descriptor: [relaxation therapy] this term only
12	mesh descriptor: [social support] this term only
13	(psychotherap*):ti,ab,kw
14	(mesh descriptor: [case management] this term only
15	mesh descriptor: [crisis intervention] this term only
16	mesh descriptor: [education, nonprofessional] this term only
17	mesh descriptor: [friends] this term only
18	mesh descriptor: [group processes] this term only
19	mesh descriptor: [hotlines] this term only
20	mesh descriptor: [interpersonal relations] this term only
21	mesh descriptor: [professional family relations] this term only
22	mesh descriptor: [self-help groups] this term only
23	mesh descriptor: [peer group] explode all trees
24	mesh descriptor: [psychotherapy, group] explode all trees
25	mesh descriptor: [social networking] explode all trees
26	mesh descriptor: [computers] this term only
27	mesh descriptor: [computer assisted instruction] this term only
28	mesh descriptor: [computer communication networks] this term only
29	mesh descriptor: [online systems] this term only
30	mesh descriptor: [social media] this term only
31	mesh descriptor: [therapy, computer assisted] this term only
32	mesh descriptor: [telecommunications] this term only
33	mesh descriptor: [telemedicine] this term only
34	mesh descriptor: [internet] explode all trees
35	mesh descriptor: [social networking] explode all trees
36	(((psychological* or psychosocial or psychotherapeutic) near/2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*):ti,ab,kw
37	(((behaviour* or behavior*) near/2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) near/3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”):ti,ab,kw
38	(“case manag*” or counsel* or ((“person centred” or replacement) near/1 (care or therap*))):ti,ab,kw

39	(((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) near/1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”):ti,ab,kw
40	((“person centred” or replacement) near/1 (care or therap*)):ti,ab,kw
41	((communit* or social) near/2 support*):ti,ab,kw
42	((intervention* or therap* or program* or workshop*) near/7 (caregiver* or “care giver*” or carer*) near/7 (burden or distress* or stress*)):ti,ab,kw
43	#4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42
44	(befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) near/1 (person or worker*))):ti,ab,kw
45	((peer* or voluntary or volunteer*) near/3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)):ti,ab,kw
46	((peer* or support* or voluntary or volunteer*) near/2 group*):ti,ab,kw
47	((peer* or support* or voluntary or volunteer*) near/3 (intervention* or program* or rehab* or therap* or service* or skill*)):ti,ab,kw
48	(((peer* near/3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* near/3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*))):ti,ab,kw
49	((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief"):ti,ab,kw
50	(((communit* or family or social) near/1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”):ti,ab,kw
51	(((carer* or caregiv* or “care giv*”) near/2 (mentor* or support*)) or (unpaid near/3 support*) or “mentoring scheme*”):ti,ab,kw
52	(((carer* or caregiv* or “care giv*”) near/3 (communication or integrat* or relations or relationship*) near/3 (practitioner* or professional* or worker*)) or (famil* near/3(intervention* or program*))):ti,ab,kw
53	(psychoeducat* or “psycho educat*”):ti,ab,kw
54	((emotion* near/1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) near/1 (adapt* or reintegrat* or support*))):ti,ab,kw
55	((dyadic or loneliness or psychosocial* or “psycho social*”) near/2 (assist* or intervention* or program* or support* or therap* or treat*)) :ti,ab,kw
56	((emotion* or “one to one” or transition*) near/1 support*):ti,ab,kw
57	(lay near/1 (led or run)):ti,ab,kw
58	((crisis or crises or emergenc*) near/3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)):ti,ab,kw
59	((coping or resilien* or “well being” or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop*)):ti,ab,kw

60	(advocate or advocacy or ((support* near/3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* near/1 (service* or system)))):ti,ab,kw
61	((network* or peer*) near/2 (discuss* or exchang* or interact* or meeting*)):ti,ab,kw
62	(carer* network* or “support group*”):ti,ab,kw
63	#44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
64	(helpline or “help line” or ((phone* or telephone*) near/3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) near/2 (assist* or based or driven or led or mediat*))):ti,ab,kw
65	(helpseek* or ((search* or seek*) near/3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))):ti,ab,kw
66	(information near/1 (needs or provision or support)):ti,ab,kw
67	(selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport) :ti,ab,kw
68	#64 or #65 or #66 or #67
69	mesh descriptor: [education] this term only
70	mesh descriptor: [health education] explode all trees
71	mesh descriptor: [first aid] this term only
72	(((carer* or caregiv* or “care giv*”) near/5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) near/3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) near/3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) near/1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* near/2 (build* or coach* or educat* or learn* or train))):ti,ab,kw
73	(psychoeducat* or “psycho educat*”) ti,ab,hw.
74	(((medication or pain) near/2 manag*) or “pain control program*” or ((educat* or train*) near/5 (handling or movement))):ti,ab,kw
75	#69 or #70 or #71 or #72 or #73 or #74
76	mesh descriptor: [physical exertion] this term only
77	mesh descriptor: [exercise] explode all trees
78	mesh descriptor: [physical education and training] explode all trees
79	mesh descriptor: [sports] explode all trees
80	(“aerobic train*” or exercis* or gym* or jog* or (physical near/1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure near/2 (activit* or intervention* or program* or therap*)) or “leisure based”):ti,ab,kw
81	#76 or #77 or #78 or #79 or #80
82	mesh descriptor: [employment] this term only
83	mesh descriptor: [employment, supported] this term only
84	mesh descriptor: [rehabilitation, vocational] this term only
85	mesh descriptor: [return to work] this term only
86	mesh descriptor: [unemployment] this term only
87	mesh descriptor: [vocational education] this term only
88	mesh descriptor: [work] this term only
89	mesh descriptor: [workplace] this term only
90	mesh descriptor: [aid to families with dependent children] this term only

91	mesh descriptor: [child welfare] this term only
92	mesh descriptor: [financing, government] this term only
93	mesh descriptor: [government programs] this term only
94	mesh descriptor: [public assistance] this term only
95	mesh descriptor: [social security] this term only
96	mesh descriptor: [social welfare] this term only
97	mesh descriptor: [social work] this term only
98	(((employ* or job* or reemploy* or vocation* or work*) near/3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* near/2 employ*) or (work near/2 coach*)):ti,ab,kw
99	((“individual placement” near/2 support) or “ips model”) :ti,ab,kw
100	((permitted or voluntary or rehab*) near/3 work*):ti,ab,kw
101	((psychosocial or “psycho social” or social) near/2 rehab*):ti,ab,kw
102	“rehabilitation counsel*”:ti,ab,kw
103	((prevocat* or vocat*) near/3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)):ti,ab,kw
104	(volunteering or (work near/2 placement*)):ti,ab,kw
105	(((carer* or “care giv*” or caregiv*) near/3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”) :ti,ab,kw
106	(return near/1 to* near/1 (education or study or training or work*)):ti,ab,kw
107	(“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) near/3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) near/7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) near/7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))):ti,ab,kw
108	(signpost* or “sign post*”):ti,ab,kw
109	#82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108
110	mesh descriptor: [day care, medical] this term only
111	mesh descriptor: [respite care] this term only
112	(“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) near/3 support*)):ti,ab,kw
113	(((crisis or volunteer) near/1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) near/2 break*) or signpost*):ti,ab,kw
114	#110 or #111 or #112 or #113
115	mesh descriptor: [assistive technology] this term only
116	mesh descriptor: [occupational therapy] this term only
117	mesh descriptor: [self-help devices] this term only
118	mesh descriptor: [telemedicine] this term only
119	mesh descriptor: [telemetry] this term only

120	mesh descriptor: [telemonitoring] this term only
121	((assistive near/2 (platform* or technolog*)) or “interactive health communication”):ti,ab,kw
122	(“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*):ti,ab,kw
123	(“gps track*” or “location technology”):ti,ab,kw
124	“occupational therap*”:ti,ab,kw
125	#115 or #116 or #117 or #118 or #119 or #120 or #121 or #122 or #123 or #124
126	mesh descriptor: [acupressure] this term only
127	mesh descriptor: [massage] this term only
128	mesh descriptor: [acupuncture] this term only
129	mesh descriptor: [complementary therapies] explode all trees
130	mesh descriptor: [mind body therapies] explode all trees
131	mesh descriptor: [medicine, chinese traditional] this term only
132	mesh descriptor: [moxibustion] this term only
133	((alternative or complementary) near/2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching near/2 lo) or cizhen or dianzhen or electroacupunctur* or (jing near/2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci) :ti,ab,kw
134	meditation.sh. or meditat*:ti,ab,kw
135	(acceptance near/2 “commitment therap*”):ti,ab,kw
136	“dyadic intervention*”:ti,ab,kw
137	(reminiscence near/1 (group* or therap*)):ti,ab,kw
138	((emotional or self) near/1 disclosure):ti,ab,kw
139	mesh descriptor: [self disclosure] this term only
140	mesh descriptor: [art] this term only
141	mesh descriptor: [music] this term only
142	mesh descriptor: [singing] this term only
143	mesh descriptor: [painting] this term only
144	mesh descriptor: [art therapy] this term only
145	mesh descriptor: [singing therapy] this term only
146	(art or cafe or cafes or gallery or music or sing or singing):ti,ab,kw
147	#126 or #127 or #128 or #129 or #130 or #131 or #132 or #133 or #134 or #135 or #136 or #137 or #138 or #139 or #140 or #141 or #142 or #143 or #144 or #145 or #146
148	#3 and (#43 or #63 or #68 or #75 or #81 or #109 or #114 or #125 or #147)

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/
7	6 use mesz
8	budget*.ti,ab.
9	cost*.ti.
10	(economic* or pharmaco?economic*).ti.
11	(price* or pricing*).ti,ab.

#	**Searches**
12	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
13	(financ* or fee or fees).ti,ab.
14	(value adj2 (money or monetary)).ti,ab.
15	or/5,7-14
16	3 and 15

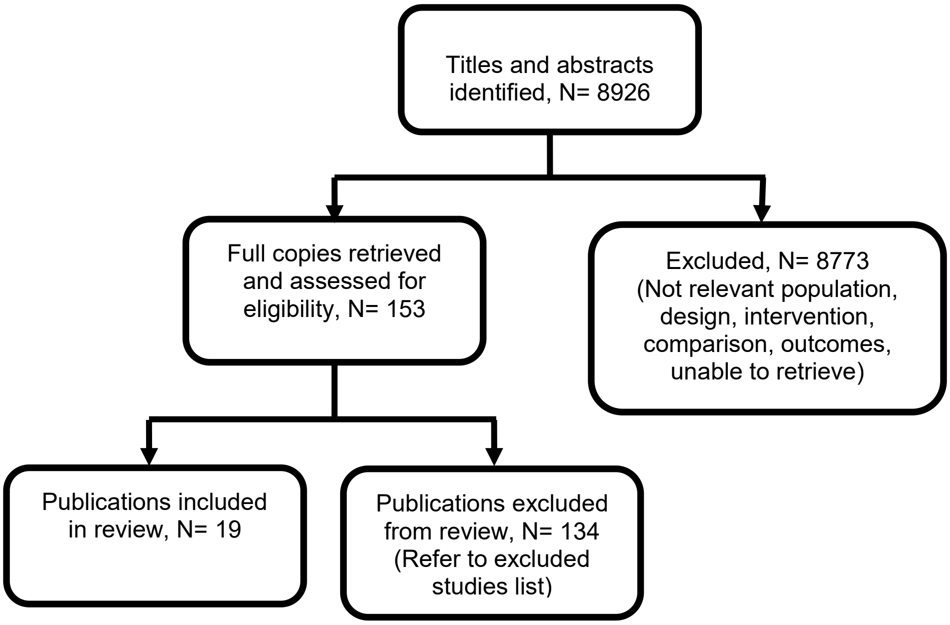
Database: Cochrane Library – Wiley

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

Appendix C – Evidence study selection

Study selection for review question: What are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordinating care, or self-care - has been (and is) currently provided in the UK?

Figure 2: Study selection flow chart



Appendix D – Evidence tables

Evidence tables for review question: What are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordinating care, or self-care - has been (and is) currently provided in the UK?

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 Abley, C., Manthorpe, J., Bond, J., Keady, J., Samsi, K., Campbell, S., Watts, S., Robinson, L., Patients' and carers' views on communication and information provision when undergoing assessments in memory services, Journal of Health Services & Research Policy, 18, 167-73, 2013 **Ref Id** 722263 **Country/ies where the study was carried out** UK	**Sample size** 26 carers **Person being cared for** People with cognitive impairment (13 with confirmed living with dementia) **Characteristics** M/F: 6/20 Spouses: 50%, Other: 50% **Inclusion criteria** People living with dementia and their carers were recruited both retrospectively, a dementia diagnosis disclosed within the	**Phenomenon of interest to the paper** The views of people with cognitive impairments and carers on what constitutes high-quality communication and information provision. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has	**Recruitment Details** Participants were recruited from memory clinics, subject to the inclusion and exclusion criteria. Recruitment continued until data saturation was reached. **Collection Details** Interviews took place in the participants' homes in accordance with the topic guide. The audio files were transcribed and summarised. The summaries were subsequently sent to the participants and any clarifications were discussed over the phone. **Analysis Details** Thematic analysis using constant comparison. Potential	**Themes** • Carers want information delivered to them in person, supplemented with written information to take away. • All information whether written or verbal should be plainly worded, clearly presented and free of jargon. • Carers value honesty and full disclosure. • Carers need information to be repeated to them. • There are several sensitive considerations to account for when deciding who to give information to. • Information for carers should acknowledge how the situation will progress, and will often require follow-ups.	**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.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Study type Semi-structured interviews **Aim of the study** To explore the views of people with cognitive impairments and their carers on what constitutes high-quality communication and information provision when undergoing assessment in memory clinics **Date of data collection** September 2009 to March 2010 **Source of funding** Funded by The National Institute for Health Research's Service Delivery and Organisation Programme	previous 3 months, and prospectively, participants attending a memory clinic for assessment who had not yet received a diagnosis **Exclusion criteria** People who weren't able to consent and their carers were excluded, as assessed by a short pro forma.	been provided, and how it can be improved	themes were discussed and agreed upon by the team.	**Findings** • Being kept informed. • Being told outcomes of the assessment. • What do patient and carer find helpful.	**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 - the researcher was unrelated to the service, but this may not have been clear. **Q7: Have ethical issues been taken into consideration?** Unclear - there is considerations of consent, but no mention of any ehtics board approval. **Q8: Was the data analysis sufficiently rigorous?** Yes. **Q9: Is there a clear statement of findings?** Yes.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes - samples from across the UK. **Overall methodological limitations** Minor.
Full citation Aldred, H., Gott, M., Gariballa, S., Advanced heart failure: impact on older patients and informal carers, Journal of advanced nursing, 49, 116-24, 2005 **Ref Id** 778396 **Country/ies where the study was carried out** UK **Study type**	**Sample size** 10 carers **Person being cared for** Older people with advanced heart failure. **Characteristics** M/F = 4/6 **Inclusion criteria** Cared-for people must be over 60 years of age, had NYHA (New York Heart Association classification) stage II–IV disease, have no evidence of cognitive	**Phenomenon of interest to the paper** The interview covered the following key issues: understanding of condition; impact of condition on everyday life; information needs; attitudes towards service provision; key worries and concerns at the present time and for the future.	**Recruitment Details** The sample was purposive, and potential participants were approached by the research nurse managing the project and invited to participate in an interview. They were also asked to nominate an informal carer to participate with them. **Collection Details** Interviews were carried out with the care-receiver and nominated carer together. All were audiotaped, lasted between 30 and 60 minutes, and conducted in the participants' own homes.	**Themes** • When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. • Carers value honesty and full disclosure. **Findings** • Professional support. • Concerns for the future.	**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.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Semi-structured interview **Aim of the study** To explore the impact of heart failure on the lives of older people and their informal carers . **Date of data collection** 2001–2002 **Source of funding** NS	impairment and be able to complete the study materials in English. **Exclusion criteria** NS	**Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	**Analysis Details** Interviews were transcribed and anonymised, then thematically analysed by a team.		**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?** Yes. **Q6: Has the relationship between researcher and participants been adequately considered?** Unclear. **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.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes. **Overall methodological limitations** Minor.
Full citation Alsaeed, D., Furniss, D., Blandford, A., Smith, F., Orlu, M., Carers' experiences of home enteral feeding: A survey exploring medicines administration challenges and strategies, Journal of Clinical Pharmacy and Therapeutics., 2018 **Ref Id** 819792 **Country/ies where the study was carried out** UK	**Sample size** 42 carers (family or paid) **Person being cared for** Users of home enteral feeding for medicine administration **Characteristics** Age range = 18-69 Parent: 2, Grandparent: 1, Son/daughter: 31, Sibling: 2, Partner/spouse: 5, Non-family member: 2 **Inclusion criteria**	**Phenomenon of interest to the paper** How well-informed carers practice is **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	**Recruitment Details** The survey was promoted nationally through the PINNT (Patients On Intravenous & Nasogastric Nutrition Therapy) website, PINNT quarterly magazine and social media outlets such as Twitter. The incentive of entering a prize draw was offered to participants who completed the questionnaire. **Collection Details** The survey was open online for 2 months. The estimated time to complete the survey was an hour. **Analysis Details** Qualitative responses were extracted from the survey and	**Themes** • Carers need clear information related to using equipment for long-term care. **Findings** • Suggestions to make enteral tube use easier for carers.	**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 - although face-to-face interview may have allowed for more exploration of topics that arose.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Study type Survey **Aim of the study** To explore carers' experience of home enteral feeding for medicine administration, the strategies they develop, and their suggestions for improving medicine administration; we relate these to the principles of medicines optimization. **Date of data collection** NS **Source of funding** The Learning about carer errors and resilience strategies (CARE-ERRS) research was supported by a University College London—Grand Challenges of Human Wellbeing small grant	Carers aged 18 years or over, family or paid, of a person who needed assistance with enteral tube feeding and medicines administration. **Exclusion criteria** NS		analysed thematically, initially by lead author and then discussed with the team.		**Q4: Was the recruitment strategy appropriate to the aims of the research?** Unclear - online survey relied on technology use, which may exclude many relevant carers. **Q5: Were the data collected in a way that addressed the research issue?** Yes - appropriate questions were asked. **Q6: Has the relationship between researcher and participants been adequately considered?** Yes - anonymous online surveys make this less of an issue. **Q7: Have ethical issues been taken into consideration?** Yes - ethical approval, consent and anonymisation are all covered.

Study details	**Participants**	**Interventions**	**Methods**	**Themes and Findings (see appendix M for more details on the quotes obtained from the papers)**	**Comments**
and CHI+MED, which is a programme grant supported by the UK Engineering and Physical Sciences Research Council.					**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** Moderate.
Full citation Bajwah, S., Koffman, J., Higginson, I. J., Ross, J. R., Wells, A. U., Birring, S. S., Riley, J., 'I wish I knew more ...' the end-of-life planning and information needs for end-stage fibrotic interstitial lung disease: views of patients, carers and	**Sample size** 4 carers 6 health professionals **Person being cared for** End-stage fibrotic interstitial lung disease **Characteristics** Carers: M/F: 1/3	**Phenomenon of interest to the paper** (1) patients' and carers' understanding of their disease (specifically in areas surrounding prognosis), (2) patients' and carers'	**Recruitment Details** Participants were recruited from ILD (interstitial lung disease) clinics. Sampling was used to recruit a diverse participant group (in terms of age, co-morbidities, clinics and care. **Collection Details** Participants were interviewed alone, on "loose" accordance to the topic guide. Interviews	**Themes** • Carers want information delivered to them in person, supplemented with written information to take away. • When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns.	**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.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
health professionals, BMJ supportive & palliative care, 3, 84-90, 2013 **Ref Id** 722220 **Country/ies where the study was carried out** UK **Study type** Semi-structured interviews **Aim of the study** To explore understanding of the disease, preferences regarding end-of-life planning, and views on communication and coordination of care in people with Progressive Idiopathic Fibrotic Interstitial Lung Disease (PIF-ILD) **Date of data collection**	Age range: 41-63 N= 3 Spouses,N= 1 Child Professionals: ILD (interstitial lung disease) physiotherapist (n):1; ILD clinical nurse specialist (n):1; ILD consultant (n):1 community palliative care clinical nurse specialist (n):1; palliative care consultant (n): 1 general practitioner(n): 1. **Inclusion criteria** Patients who fulfilled the following inclusion criteria: a diagnosis of non-specific interstitial pneumonia, Idiopathic pulmonary fibrosis and idiopathic interstitial pneumonia, as classified by the American Thoracic Society/European Respiratory Society criteria, with a percentage-predicted	preferences regarding end-of-life planning and (3) patients', carers' and health professionals' views on communication and coordination of care. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	were recorded and subsequently transcribed and anonymised. **Analysis Details** Each line was coded and themes were confirmed by 3 of the researchers.	• Carers value honesty and full disclosure. • Carers turn to other sources for information when needed. Findings • End-of-life information needs. • Sources of information.	**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 - although only a small number. **Q5: Were the data collected in a way that addressed the research issue?** No - only a small number of carers and one of each type of professional. **Q6: Has the relationship between researcher and participants been adequately considered?** Unclear - not discussed. **Q7: Have ethical issues been taken into consideration?** Yes - ethics board approval, although little

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
December 2010 to March 2011 **Source of funding** Funded primarily by a Biomedical Research Unit grant from the Royal Brompton Hospital, and partly by the Royal Marsden and Royal Brompton Palliative Care Research Fund	transfer factor <40%, and an ability to understand and speak English fluently. **Exclusion criteria** Those under 18 years of age with cognitive impairment, or those unable to provide informed consent, were excluded.				other considerations detailed or stated. **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)** Unclear - UK based, but a small group and from only 1 area. **Overall methodological limitations** Moderate.
Full citation Beaver, Kinta, Witham, Gary, Information needs of the informal carers of women treated for breast cancer, European Journal of	**Sample size** 50 carers **Person being cared for** Women who had been treated for breast	**Phenomenon of interest to the paper** The information needs, and the sources of information, for informal carers	**Recruitment Details** Women at a regional cancer centre in the North West of England were approached for consent to a researcher contacting their primary carer. **Collection Details**	**Themes** • Carers value honesty and full disclosure. • Carers turn to other sources for information when needed.	**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
Oncology Nursing, 11, 16-25, 2007 **Ref Id** 714580 **Country/ies where the study was carried out** UK **Study type** Semi-structured interviews **Aim of the study** To examine the information needs and sources of information for informal carers of women treated for breast cancer in the acute cancer setting. **Date of data collection** NS **Source of funding** NS	cancer and were attending hospital outpatient clinics. **Characteristics** M/F: 37/13 Mean age (range): 53 (20-70) Relationship: husbands/partners (n):37; daughters (n):9; mothers (n):2; sisters (n):2 **Inclusion criteria** Cared-for people were required to have had a known diagnosis of breast cancer, had undergone treatment for the disease and could identify a primary informal carer who was fully aware of their diagnosis. **Exclusion criteria** Patients in the initial stages of diagnosis (<3 months) were excluded as it was considered to be too intrusive to	of women with breast cancer. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	Face-to-face semi-structured interviews were conducted in the carers' homes. **Analysis Details** Qualitative data initially coded according to the 9 domains of the 'Information Needs Questionnaire' which had formed the basis of the topic guide, and then within each question was coded to identify particular phenomena of interest.	• There are several sensitive considerations to account for when deciding who to give information to. **Findings** • Cure (other sources) • Spread of disease (what to expect). • Treatment and side effects.	**Q2: Was a qualitative methodology appropriate?** Yes - although quite a mixed approach was used. **Q3 Was the research design appropriate to address the aims of the research?** Unclear - seemingly a very deductive approach that did not leave much room for new ideas to emerge from the data. **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 - deductive approach seemed potentially limiting. **Q6: Has the relationship between researcher and participants been adequately considered?**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
	approach individuals at this particularly stressful time.				Unclear - not considered. **Q7: Have ethical issues been taken into consideration?** Yes - ethical approval, consent, and considerate of patient distress at a sensitive time. **Q8: Was the data analysis sufficiently rigorous?** Unclear - they describe working from the 'Information Needs Questionnaire' and drawing out phenomena of interest as the basis of coding, but don't specify what these were or where they came from. **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 - although limited to only 1 local centre.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					Overall methodological limitations Major.
Full citation Care and Social Services Inspectorate, Wales, In support of carers: carers engagement overview report, 14, 2017 **Ref Id** 723835 **Country/ies where the study was carried out** UK **Study type** Interviews (did not specify the type of interview) **Aim of the study** To enquire amongst Welsh carers and relevant professionals whether (a) Carers receive the support they need, (b) Carers	**Sample size** Approximately 400 carers **Person being cared for** Any adults with social care needs **Characteristics** NS **Inclusion criteria** NS **Exclusion criteria** NS	**Phenomenon of interest to the paper** How effective is the council in providing information advice, assistance and assessment and support planning to carers? **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved Accessibility, availability,	**Recruitment Details** Carers attended events that had been organised locally to support carers. **Collection Details** Carers were interviewed at the events, and some in telephone calls, to hear about their experience **Analysis Details** Collected data was considered and written up by the researcher.	**Themes** • All information whether written or verbal should be plainly worded, clearly presented and free of jargon. • Carers groups and forums are another valued source of information and support. • Carers vary in their comfort and proficiency with the internet. **Findings** • Providing information	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** No. **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 - those who are most informed already would be the most likely to be contactable by the researchers.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
know their rights and understand the support that is available to them, (c) Carers are equal partners and feel supported and valued for the care they give, and (c) The vision for support for carers recognises their economic contribution and is clear about the intended outcomes. **Date of data collection** NS **Source of funding** Care and Social Services Inspectorate Wales (CSSIW)		and/or accuracy of information and services. Source (for example person, group, impersonal) or type (face-to-face, leaflet, email) of information.			**Q5: Were the data collected in a way that addressed the research issue?** Unclear. Data collection not clearly reported. **Q6: Has the relationship between researcher and participants been adequately considered?** Unclear. Details about the researcher or their relationship to participants not discussed. **Q7: Have ethical issues been taken into consideration?** No. Ethics or ethical approval not discussed. **Q8: Was the data analysis sufficiently rigorous?** No - No coherent methodology. **Q9: Is there a clear statement of findings?** No.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Unclear - a large number included, but proportion that is rural/urban is unclear as is how well it may be applicable to other parts of the UK. **Overall methodological limitations** Major.
Full citation Garrett, D., Cowdell, F., Information needs of patients and carers following stroke, Nursing older people, 17, 14-6, 2005 **Ref Id** 715530 **Country/ies where the study was carried out** UK **Study type**	**Sample size** 16 carers and stroke patients **Person being cared for** Primary diagnosis of stroke **Characteristics** Mostly spouses **Inclusion criteria** The patient should have had a stroke and that this was the primary reason for	**Phenomenon of interest to the paper** Participants' experiences of receiving information and their perceived needs in terms of what information they needed, at what time and in what format **Phenomenon of interest**	**Recruitment Details** Unclear exactly how participants were approached or identified. There were 3 groups - the 2-day participants were those who had been admitted to an acute stroke unit. The 20-day participants had been previously admitted and had begun the rehabilitation phase in hospital or secondary care environments. The 90-day participants were either in hospital or had been discharged to home. **Collection Details**	**Themes** • Carers want information delivered to them in person, supplemented with written information to take away. • All information whether written or verbal should be plainly worded, clearly presented and free of jargon. • Carers need information to be repeated to them. • Carers need information about long term care needs beyond the specific condition.	**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?**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Unspecified interview **Aim of the study** To discover the perceived information needs of stroke patients and carers at 2, 20 and 90 days post stroke. **Date of data collection** NS **Source of funding** NS	their current episode of healthcare **Exclusion criteria** Patients or carers with aphasia, or a mini-mental state examination score below 17	**according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	Interviews were conducted in a location of the participants' choice, using open-ended questions related to information needs. They were conducted by a researcher who was not a regular member of the stroke team. After interviews with 16 patients and carers it was felt that saturation had been reached. **Analysis Details** Data was transcribed and analysed for themes. A process of constant comparison was used for data analysis in which initial data were coded and categorised and subsequent incoming data were compared and the developing codes and categories were assessed for 'fit'.	**Findings** • Processing information • Formats • Long term	Yes. **Q4: Was the recruitment strategy appropriate to the aims of the research?** Unclear - the details of how participants were recruited is not given. **Q5: Were the data collected in a way that addressed the research issue?** Unclear - the nature of the questions/topics asked about is not specified. **Q6: Has the relationship between researcher and participants been adequately considered?** No - no discussion, and although some steps were taken it seems the interviewer was a member of the team, likely to cause some bias. **Q7: Have ethical issues been taken into consideration?** Unclear. Approval by an ethics board, but no further

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					discussions, for example of distress that may be caused by interviewing participants at a traumatic time. **Q8: Was the data analysis sufficiently rigorous?** Unclear - little detail on how themes were theorised or developed. **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 - although only draws from 1 area/centre. **Overall methodological limitations** Major.
Full citation Harding, Richard, Higginson, Irene J, Leam, Celia,	**Sample size** 24 carers (in qualitative component)	**Phenomenon of interest to the paper**	**Recruitment Details** Eligible carers were referred to the study.	**Themes** • Carers groups and forums are another valued source of information and support.	**Limitations (assessed using the CASP checklist for qualitative studies)**

Study details	**Participants**	**Interventions**	**Methods**	**Themes and Findings (see appendix M for more details on the quotes obtained from the papers)**	**Comments**
Donaldson, Nora, Pearce, Alison, George, Rob, Robinson, Vicky, Taylor, Liz, Evaluation of a short-term group intervention for informal carers of patients attending a home palliative care service, Journal of Pain and Symptom Management, 27, 396-408, 2004 **Ref Id** 977053 **Country/ies where the study was carried out** UK **Study type** Semi-structured interviews **Aim of the study** To evaluate, in terms of processes and outcomes for carers, a short-term group intervention for	**Person being cared for** Users of a palliative care service **Characteristics** [characteristics for overall study population] M/F(%): 31/69 Median age (range): 59 (26-88) Relationship (%): wife/partner=34%, husband/partner=29%, daughter=14%, parent=11%, son=4%, sibling=1%. other family=3%, friend=3%, ex-partner=1%. **Inclusion criteria** Adult, informal unpaid carers of patients attending 1 of 2 home palliative care services in London. Also fluent in English, and with a staff prognostication that the patient would be alive for a minimum of 3 weeks. **Exclusion criteria**	The primary unmet needs among this population - namely, psychological support/anxiety reduction, information giving, and enhancement of short-term coping. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	**Collection Details** Qualitative data on the processes and experiences of participants were collected using a semi-structured schedule. Interviews were audio recorded and transcribed verbatim. Evaluation staff were not involved in recruitment or intervention delivery. **Analysis Details** Interview data was analysed using a content analysis matrix of principal categories. Data was analysed using the software NVivo. There was independent peer review of categorisation.	**Findings** • Group Processes	**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 - evaluate experiences of the intervention **Q4: Was the recruitment strategy appropriate to the aims of the research?** Unclear. It is clear how they were identified but not how they were approached, or how many agreed. **Q5: Were the data collected in a way that addressed the research issue?** Yes.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
informal carers of people using a home palliative care service. **Date of data collection** NS **Source of funding** Funded by NHS Executive Research and Development London Region	NS				**Q6: Has the relationship between researcher and participants been adequately considered?** Unclear. **Q7: Have ethical issues been taken into consideration?** Unclear. Ethical approval was granted by the local Research Ethics Committee. Other aspects of ethics/consent not discussed. **Q8: Was the data analysis sufficiently rigorous?** Yes. Evaluation staff were not involved in recruitment or intervention delivery. **Q9: Is there a clear statement of findings?** Yes. Although no quotations given to back up the stated findings. **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					Yes. In a UK context. **Overall methodological limitations** Moderate.
Full citation Hughes, R. A., Sinha, A., Higginson, I., Down, K., Leigh, P. N., Living with motor neurone disease: Lives, experiences of services and suggestions for change, Health and Social Care in the Community, 13, 64-74, 2005 **Ref Id** 820945 **Country/ies where the study was carried out** UK **Study type** Semi-structured interviews	**Sample size** 5 carers 15 professionals **Person being cared for** People living with MND **Characteristics** Carers: M/F: 1/4 Age: 30-39=1, ≥70=4 Professionals: M/F: 2/13 Age: 20-29=3, 30-39=3, 40-49=7, 50-59=2 Service setting: hospital=8, community=4, social service=3 Length of service (years): <5=5, 5-9=6, ≥10=4	**Phenomenon of interest to the paper** The experiences of people living with MND, its impact, experiences of services, and suggestions for service changes. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	**Recruitment Details** People with MND and their families were identified through a MND centre hospital register, and posted an invitation to participate. Similarly, letters were sent to professionals in contact with the MND centre. **Collection Details** Semistructured interviews were conducted by the researcher in the carers' homes and in professionals' offices. **Analysis Details** The research team read over the transcripts and discussed themes. Coding as a mix of deductive based on literature and inductuve from the data. Findings from different participant groups were then brought together where suitable.	**Themes** • Information should be consistent and co-ordinated between different services. • Carers turn to other sources for information when needed. • Each carer and caring dynamic is unique. • Information for carers should acknowledge how the situation will progress, and will often require follow-ups. **Findings** • Experiences of services.	**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 - although likely some participant bias.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Aim of the study To understand people's experiences and to generate ideas for developing practice and policy in MND health, social and palliative care. **Date of data collection** NS **Source of funding** Support from Joseph Rowntree Foundation, the Guy's and St Thomas' Charitable Foundation, the Motor Neurone Disease Association and the Tim Perkins Trust.	**Inclusion criteria** Families and professionals of people with MND **Exclusion criteria** People were not invited for interview if they had impaired mental health status, were involved in other research or did not have a good command of English.				**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. **Q7: Have ethical issues been taken into consideration?** Yes. **Q8: Was the data analysis sufficiently rigorous?** Yes. **Q9: Is there a clear statement of findings?** Yes. **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** Yes.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					Overall methodological limitations Minor.
Full citation McIlfatrick, S., Doherty, L. C., Murphy, M., Dixon, L., Donnelly, P., McDonald, K., Fitzsimons, D., 'The importance of planning for the future': Burden and unmet needs of caregivers' in advanced heart failure: A mixed methods study, Palliative Medicine., 01, 2017 **Ref Id** 821480 **Country/ies where the study was carried out** England and Ireland **Study type**	**Sample size** 30 carers **Person being cared for** Caregivers of people with heart failure (HF) **Characteristics** Age of interviewees: N/R Current caregivers M/F: 5/15 Previous caregivers M/F: N/R **Inclusion criteria** Current caregiver: Aged 18 years or older; Able and willing to provide informed consent; Current informal caregiver as nominated by the patient'	**Phenomenon of interest to the paper** The burden and support needs when caring for someone with advanced heart failure at the end of life. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	**Recruitment Details** "Patients with advanced HF and their caregivers who met study inclusion criteria (Table 1) were recruited from 3 specialised secondary care centres across the United Kingdom (*N*= 2) and Ireland (*N*= 1). Where available, databases were screened by clinical teams in the secondary care centres to identify potential patients meeting the inclusion criteria'…. Access to the caregivers was negotiated through the patient; therefore, patients interested in taking part were posted a study pack for themselves and their informal caregiver and both individuals were asked to return their completed questionnaire to the research team in stamped addressed envelopes provided. As an additional recruitment strategy to increased sample size, patients meeting the inclusion criteria were identified by clinical teams in participating	**Themes** • Carers value honesty and full disclosure. • Each carer and caring dynamic is unique. • Information for carers should acknowledge how the situation will progress, and will often require follow-ups. **Findings** • Information on HF prognostication and palliative care. • Knowledge on what to expect at the end of life.	**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 (note paper reports this as a mixed methods study). **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**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Qualitative - postal survey with and interviews **Aim of the study** To identify modifiable psychosocial factors associated with caregiver burden and to evaluate the support needs of caregivers when caring for people living with advanced heart failure at the end of life. **Date of data collection** April 2014 to June 2016 **Source of funding** Funded by the Health Research Board and the All Ireland Institute for Hospice and Palliative Care (AIIHPC) through its Palliative Care Research Network (PCRN)	Bereaved caregiver: Bereaved informal caregiver **Exclusion criteria** Current caregiver • Less than 18 years • Formal caregivers (an individual associated with a formal service system, whether a paid worker or volunteer) Bereaved caregiver Bereaved in the previous 6 months or more than 5 years previously.		sites during hospital stays." (p.883) **Collection Details** Phase 1 Survey data collected via Patient Health Questionnaire-9 (PHQ-9), Generalised Anxiety Disorder-7 (GAD-7), Minnesota Living with Heart Failure Questionnaire (MLHFQ) and Multidimensional Scale of Perceived Social Support (MSPSS) questionnaires. Patients also completed the Self-Care of Heart Failure Index (SCHFI) and Survey of Illness Beliefs (SIBHF). Caregivers completed the Zarit Burden Interview (ZBI), Preparedness for Caregiving Scale and Carer Support Needs Assessment Tool (CSNAT). Phase 2 - semi-structured, face-to-face interviews conducted by research team. Interview schedule were based on previous research and preliminary findings from phase 1. Interviews were conducted in the caregivers' home (N= 21) or a place of their choosing (N=		**addressed the research issue?** Yes. **Q6: Has the relationship between researcher and participants been adequately considered?** Unclear - not reported. **Q7: Have ethical issues been taken into consideration?** Unclear. Approved by an ethics board but no other discussion. **Q8: Was the data analysis sufficiently rigorous?** Yes. **Q9: Is there a clear statement of. findings?** Yes. **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** Yes.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
			9), and 1 patient attended part of an interview. **Analysis Details** Qualitative interviews were digitally recorded, and then transcribed verbatim and supplementary field notes were used to document contextual data. A thematic analysis was conducted.		**Overall methodological limitations** Moderate.
Full citation McKechnie, Vicky, Barker, Chris, Stott, Josh, The Effectiveness of an Internet Support Forum for Carers of People With Dementia: A Pre-Post Cohort Study, Journal of medical Internet research, 16, 2014 **Ref Id** 783676 **Country/ies where the study was carried out** UK	**Sample size** 128 completed survey at baseline 119 eligible participants 8 final sample interviewed **Person being cared for** People living with dementia **Characteristics** Sex (M/F): 2/6 Age in years (range 43-84), mean (61yrs) **Inclusion criteria** 'Inclusion criteria were that participants had to	**Phenomenon of interest to the paper** To examine the outcome of online mutual support for carers of people living with dementia, or to understand more about how carers find online mutual support to be helpful. **Phenomenon of interest according to the protocol**	**Recruitment Details** "New users of the forum were invited to take part in the research through an advertisement on the home page, from which they could access the consent form and survey. An email was also sent to forum users to inform them of the research. At baseline, participants indicated if they would like to take part in an optional interview about their experiences of using the forum. Interview participants were selected according to inclusion criteria and represented a range of different users, in terms of their sex, age, person they were caring for, and length of time they had been caring." (page 4)	**Themes** • Carers groups and forums are another valued source of information and support. • Carers vary in their comfort and proficiency with the internet. **Findings** • New Learning.	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** Yes, objective stated. **Q2: Was a qualitative methodology appropriate?** Yes. **Q3 Was the research design appropriate to address 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 type Semi-structured interviews. **Aim of the study** To examine the impact of a UK-based online support forum for carers of people with dementia. **Date of data collection** It is assumed that interview data was collected after the 1st survey (between July 25, 2012 and January 9, 2013) and 2nd survey (12 weeks post completion of first survey). **Source of funding** Not reported	be (1) a new user on their first visit to the forum, (2) an informal carer for a relative or friend with dementia (ie, unpaid), (3) involved in a significant amount of the care of this person, (4) older than 18 years, and (5) fluent in English. Additionally, participants were eligible for the qualitative interview if (1) they indicated at baseline that they were interested in being interviewed, (2) they completed the survey at 12 weeks, and (3) they visited the forum at least 6 times over the 12-week study period.' (page 3) **Exclusion criteria** Not reported	How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	**Collection Details** "The interview schedule was developed with reference to the literature on peer support, and with input from the forum's manager and the charity's head of evaluation.The manager and volunteer moderators provided feedback during the development of the interview schedule. Seven interviews were conducted by telephone and 1 was face-to-face. The interviews lasted approximately 40 minutes." (page 5) **Analysis Details** 'Semi-structured interviews were transcribed verbatim, with all identifiable data removed to preserve anonymity. They were analyzed using thematic analysis [22], taking an inductive, data-driven approach. Interview transcripts were repeatedly reviewed to become familiar with the data and to ensure that information was represented accurately. During this process, an initial list of ideas was generated. These were grouped into codes and then brought together into		**Q4: Was the recruitment strategy appropriate to the aims of the research?** Yes, individuals were sampled from the larger group involved in the quantitative arm of the study. **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?** No, but report points to the fact that the first author, who conducted the interviews and led the analysis, was a white, middle-class, female clinical psychology doctoral student in her twenties. She had no direct experience of caring for a friend or family member living with dementia, but had seen the impact of the caring role on other people and was aware of the

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
			meaningful themes, which were then checked against initial codes and the overall dataset, and amended in some instances. Finally, themes were organised into overarching domains. Credibility checks [21, 23] involved a third party examining sections of analyzed interview transcripts and providing feedback on codes, themes, and domains. Respondent validation [20] was used as a further credibility check. Each interviewed participant was emailed a summary of the themes generated from their interview and asked to complete a feedback form. 7 of the 8 interview participants responded to this, either by completing the form or simply by replying to the email, and said that they felt that the list of themes was a good summary of their interview.' (page 6).		challenges and stress that this role can bring. The other 2 authors were white, male clinical psychologists, who were generally favorably disposed toward mutual and peer support. All authors attempted to bracket their preconceptions during the analysis. **Q7: Have ethical issues been taken into consideration?** Unclear. Approved by an ethics board but no other discussion. **Q8: Was the data analysis sufficiently rigorous?** Yes. **Q9: Is there a clear statement of findings?** Yes. **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** Yes.

Study details	**Participants**	**Interventions**	**Methods**	**Themes and Findings (see appendix M for more details on the quotes obtained from the papers)**	**Comments**
					Overall methodological limitations Minor.
Full citation Moriarty, Jo, Manthorpe, Jill, Cornes, Michelle, Reaching out or missing out: Approaches to outreach with family carers in social care organisations, Health & social care in the community, 23, 42-50, 2015 **Ref Id** 725412 **Country/ies where the study was carried out** England **Study type** Qualitative **Aim of the study**	**Sample size** 24 family carers 38 workers whose job description included a specific remit to support family carers **Person being cared for** Not specified **Characteristics** Not reported **Inclusion criteria** Funders, carers' workers, representatives of voluntary organisations and family carers based in 4 contrasting localities **Exclusion criteria** NS	**Phenomenon of interest to the paper** The significant differences between information provision and outreach. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	**Recruitment Details** 'Four different adult social care departments in England were requested to take part in the study. They were selected on the basis of maximum variation sampling in which there is a deliberate intention to include phenomena that differ widely from one another (for example geographical location, and population size and composition). This approach helps to identify whether there are central themes that cut across participants, organisations or localities (Patton 2002).(p.44) **Collection Details** Interview sample was sourced through contacting commissioners and representatives of voluntary organisations with a carer remit. 'It was a specific requirement of ethical approval that carers' workers and carers were not to be approached	**Themes** • Carers vary in their comfort and proficiency with the internet. • Ethnicity, culture and race may affect the accessibility of information. **Findings** • Identifying and informing carers. • Hidden carers and the role of specialist outreach.	**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**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
To describe different ways of working with family carers in adult social care departments and to collect the views of a range of stakeholders about the advantages and disadvantages of the approaches that were identified. **Date of data collection** Main data collection in 2012, some interviews in 2011 **Source of funding** NIHR School for Social Care Research			directly by the research team to minimise any pressure that they might feel to participate.' (p.44). 'Face-to-face semi-structured interviews combined exploratory and hypothesis-testing approaches (Kvale & Brinkmann 2009) and were informed by existing research and emerging policy debates' (p.44). The survey was emailed to all directors of Adult Services departments in England, with a request to send the survey to the Carers Lead or other individual responsible for their policy on carers. Respondents were given various response options such as replying by email or post or being involved in a phone interview. **Analysis Details** 'Interview data and responses to open-ended survey questions were analysed using the software NVivo 10 using a process of applied thematic analysis (Guest 2012). Thematic		**addressed the research issue?** Yes. **Q6: Has the relationship between researcher and participants been adequately considered?** Unclear. Not discussed, although there is no direct power relationship. **Q7: Have ethical issues been taken into consideration?** Yes. Board approval and some ethical considerations discussed. **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)**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
			analysis focuses on identifying and describing both implicit and explicit ideas within the data to generate themes. These themes were partly driven by the literature (for example outreach location) and partly driven by the data (for example outreach work with other professionals). Numeric data from the study were entered into the software SPSS. By comparing the different types of data (survey and interview data), data across different informants (survey respondents, commissioners, carers, carers' workers and voluntary organisations) against existing research on outreach, we aimed to achieve methodological, data and theoretical triangulation (Seale 1999)' (p.45).		Yes. **Overall methodological limitations** Minor.
Full citation Newbronner, Liz, et al.,, Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their	**Sample size** 69 PB holders and carers, of which, carer population broken down as follows: Mental health carer (n):9; older person carer (n):10; Older	**Phenomenon of interest to the paper** To get an up-to-date understanding of which LA areas and/or organisations	**Recruitment Details** Drawing on the policy and research literature, and national interviews with 10 representatives from key national organisations (including the department of health, the National Mental Health Development Unit,	**Themes** • Carers want information delivered to them in person, supplemented with written information to take away. • All information whether written or verbal should be plainly worded, clearly	**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**
carers (Adults' services report 40), 2011 **Ref Id** 717523 **Country/ies where the study was carried out** England **Study type** Qualitative - interviews and focus groups **Aim of the study** To provide evidence to inform good practice in personal budget processes for people with mental health problems and older people. **Date of data collection** During the period of personal budgets being implemented across the country. No	person & mental health carer (n):4; Practitioners and managers (n):40. **Person being cared for** People with mental health issues and older people **Characteristics** Mental health carer M/F = 3/6 Age: N=1 25-39; N=7 40-64, N=1 65-74 Older person carer M/F =2/8; Age: N=4, no answer; N=2, 25-39; N=3, 40-64; N=9, 65-74. Older person & mental health carer M/F N=0/4; Age: N=2, 40-64; N=1, 65-74 N= 1, 75 or over. Details of practitioners not provided. **Inclusion criteria** Not explicit, but families, carers and professionals.	were considered to demonstrate good practice in relation to PBs for older people, people with mental health problems and their carers. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	Carers UK, MIND and Age UK) 5 case study LAs sites were drawn up, representing diversity in terms of types of councils, and different geographical, demographic and socioeconomic characteristics. PB leads in these sites were the main point of contact for setting up and implementing the research with staff, PB holders and carers. Prior to this, focus groups were held in each LA with practitioners including social workers/care managers and community psychiatric nurses to explore their views on culture change, systems and processes, support for people to manage their PB and staff training and support. (p.20). Interviews were also held with staff and/or managers from 12 local provider organisations. **Collection Details** Data collection in each site involved: • individual telephone or face-to-face interviews with PB holders and carers • focus groups with PB holders and carers	presented and free of jargon. • When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. • Carers need information to be repeated to them. • Information should be consistent and co-ordinated between different services. **Findings** • Deciding on a personal budget. • External organisations.	**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?** Yes. **Q6: Has the relationship between researcher and participants been adequately considered?** No. **Q7: Have ethical issues been taken into consideration?**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
specific dates provided. **Source of funding** Not specified.	**Exclusion criteria** Not stated		• interviews (either face-to-face or by telephone) and small group discussions about assessment, brokerage and support planning arrangements with officers having lead responsibility for implementing *Putting people first*, andwith practitioners and staff from social services and local support organisations. In the 5 LAs, a letter and information sheet was sent to all PB holders and carers inviting them to take part in the research. Individuals who were interested were asked to return a consent form to the research team in a pre-paid envelope, or ring a Freephone number to complete the form by telephone. PB holders and carers were offered the option of taking part either through interviews or a focus group. **Analysis Details** 'All the interviews and discussions were recorded and transcribed using detailed notes and quotes. The data was then analysed thematically and illustrated		Unclear. Approved by an ethics board but no other discussion. **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.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
			using 'personal stories' from PB holders and carers, and 'positive practice examples'. (p.4).		
Full citation Pinfold Vanessa, et al.,, Positive and inclusive?: effective ways for professionals to involve carers in information sharing, 202p., 2005 **Ref Id** 715226 **Country/ies where the study was carried out** England **Study type** Mixed qualitative methods **Aim of the study** 'The study had four main aims, all in relation to information sharing between	**Sample size** 12 carers 17 professionals **Person being cared for** Mental health conditions **Characteristics** Professionals working in mental health and ageing N= 5 (M/F: 2/3) Professionals working in adult mental health services N=9 (M/F:4/5) Carers for people with severe mental illness N=7 (M/F:0/7) Carers supporting people living with dementia N=5 (M/F: 2/3) Carer support workers N=3 (M/F: 0/3)	**Phenomenon of interest to the paper** The sharing of relevant and important information between mental health professionals and carers is seen as a key component of supporting carers and for improving the recovery outcomes for service users. This report presents results of a national study addressing effective ways for professionals to involve carers in information sharing with a	**Recruitment Details** The policy and literature review, group discussions with groups who had been reached less successfully through the survey; and the 2 multidisciplinary workshop events held to assess the impact of policies for carers on the ground are not a part of the data extracted in this table. Review focus is: • national surveys to review information sharing practices with 5 different stakeholder groups: service users (N=168); young carers (N=29); adult carers (N=496); professionals (N=212); carer support workers (N=93) • in-depth interviews (N=34) with stakeholders to identify good practice experiences **Collection Details** In-depth interviews with stakeholders to identify good	**Themes** • All information whether written or verbal should be plainly worded, clearly presented and free of jargon. • When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. • Carers need information to be repeated to them. • Information should be consistent and co-ordinated between different services. • Carers groups and forums are another valued source of information and support. • Each carer and caring dynamic is unique. • Ethnicity, culture and race may affect the accessibility of information.	**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: 'The rationale for carrying out a multi-method grounded study, where each stage in the research process built upon the preceding research activity, was based upon the complex nature of the research subject, with limited previous research

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
mental health professionals and carers of people with mental health problems: 1. To identify examples of good practice for information sharing with carers. 2. To identify the contrasting perspectives of 3 stakeholder groups – carers, service users and professionals – on priorities in information sharing. 3. To identify differences between the views of carers of adults of working age and carers of older people with mental health problems. 4. To develop synthesised model(s) of good practice, which are widely applicable and appropriate for multi-disciplinary use'. (p.33)	**Inclusion criteria** Carers and professionals **Exclusion criteria** Not explicitly stated	focus on good practice examples. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	practice experiences (N=:29 carers & professionals, N=5 service users) The research team recruited individuals using a quota sampling procedure. It was important to interview stakeholders from different groups (service user, professional, carer support worlers, carer) but also to be mindful of the different contexts that people worked or lived in relating to geographical location, ethnic background, gender, age, length of experience in role and mental health specialism. The in-depth interviews were conducted as telephone interviews, except for 5 interviews that were carried out face-to-face at the request of the individual participant. To supplement the survey and in-depth interviews, the project team ran group discussions in a mosque and a day centre in Southern England to identify points of good practice. **Analysis Details**	• There are several sensitive considerations to account for when deciding who to give information to. • Carers sometimes feel it would be best to get information in private. • Carers and professionals need to work together to find a way to work with confidentiality limitations. • Carers need to be informed of any changes to treatment or prognosis. **Findings** • Effective ways for professionals to involve carers in information sharing. • Strategies - professionals in adult services. • Principles: carers for older adults. • Strategies - professionals working with older people.	in this area, necessitating data collection to be derived from a range of different stakeholders in an exploratory manner'.(p.35) **Q4: Was the recruitment strategy appropriate to the aims of the research?** Yes, but the survey was less successful at identifying carers of people with living dementia, carers from BME communities and service users. To supplement the survey and in-depth interviews, the project team ran group discussions to identify points of good practice (p.44). **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?** No.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Date of data collection August 2003 - June 2004 **Source of funding** National Coordinating Centre for the Service Delivery and Organisation NCCSDO			The analysis seemed to use thematic analysis: 'In this section the analysis of the interviews is presented thematically' (p. 109) 'The interviews were analysed manually. The applied analysis procedure was systematic and rigorous, following well defined principles of qualitative analysis (Silverman, 2001). Two members of the research team led the process under supervision from a third member of the team'(p.44). Data synthesis relied on triangulation of results. An 'expert panel' and 'virtual network', provided support and assistance, commenting on survey questions and interview schedules and shaped the final report through an extensive consultation process.		**Q7: Have ethical issues been taken into consideration?** Unclear. Approved by an ethics board but no other discussion. **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.
Full citation Powell, John, et al., New networked technologies and	**Sample size** 34 carers	**Phenomenon of interest to the paper**	**Recruitment Details** 'Most participants were recruited with the help of community psychiatric nurses	**Themes** • Carers vary in their comfort and proficiency with the internet.	**Limitations (assessed using the CASP checklist for qualitative studies)**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
carers of people with dementia: an interview study, Ageing and Society, 2010 **Ref Id** 718280 **Country/ies where the study was carried out** England **Study type** Qualitative **Aim of the study** To investigate the perspectives of carers of people living with dementia about new networked technologies – including carers views of networked information and communication technologies, whether and how they use them, the possible benefits and disadvantages, and the barriers and	**Person being cared for** Living with dementia **Characteristics** male/female: 12/22 Age:20–29= 1; 30–39 =3; 40–49= 7; 50–59= 9; 60–69= 7; 70–79= 5; 80–89=1; 90–99 =1 **Inclusion criteria** Not stated **Exclusion criteria** Not stated	To gain insight into the experiences and attitudes of a diverse sample of carers towards new networked assistive technologies and if they would consider using them increasingly in the future. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	employed by NHS community mental health teams and of the group leaders of user and carer voluntary organisations. Others came forward having seen flyers, after hearing an introductory talk, or having seen adverts circulated by email or on the internet (on either the university website or on users' organisation websites). Once potential participants had been identified, we purposively selected respondents who covered the diversity of the area's population.' (p. 1075). **Collection Details** Most interviews took place in the participant's homes and were audio-recorded and transcribed with written informed consent. A group discussion was held with 9 informal carers after preliminary analysis of the interview data. **Analysis Details** 'The transcripts were analysed using the framework approach (Ritchie and Spencer 1993). This is a grounded method for	**Findings** • Current and future use of networked technologies. • Access to online information.	**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?** Yes. **Q6: Has the relationship between researcher and participants been adequately considered?** No.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
facilitators to future implementation. **Date of data collection** N/R **Source of funding** The UK Department of Health Policy Research Programme, through the Information and Communication Technology Research Initiative (ICTRI)			analysing qualitative data. (p.1076).		**Q7: Have ethical issues been taken into consideration?** Unclear. Approved by an ethics board but no other discussion. **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.
Full citation Smith, Felicity, Denham, Michael, Francis, Sally-Anne, Graffy, Jonathan, Gray, Nicola, A multi-	**Sample size** 184 carers **Person being cared for**	**Phenomenon of interest to the paper** The number and type of problems experienced by	**Recruitment Details** 10 pharmacies were randomly selected at each of 4 study sites accross the UK and used to screen and recruit potential volunteer participants.	**Themes** • Information should be consistent and co-ordinated between different services.	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?**

Study details	**Participants**	**Interventions**	**Methods**	**Themes and Findings (see appendix M for more details on the quotes obtained from the papers)**	**Comments**
centre survey among informal carers who manage medication for older care recipients: problems experienced and development of services, Health and Social Care in the Community, 11, 138-145, 2003 **Ref Id** 820366 **Country/ies where the study was carried out** UK **Study type** Structured interviews **Aim of the study** To report the number and type of problems experienced by informal carers when managing medication for older people, and to relate these to measures of coping and health.	Older people whose carer manages their medication. **Characteristics** Sex % (M/F): 39/61 Mean age (range): 65 (30-91) **Inclusion criteria** People aged over 18 years collecting a prescription on behalf of someone else aged over 60 years and unpaid in their caring role. **Exclusion criteria** The recruitment procedure meant that carers of people who received their medication through a pharmacy delivery service would be excluded.	informal carers when managing medication for older people. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	**Collection Details** Participants were interviewed in their homes by a team of trained interviewers. The interviewers obtained consent and then worked from a structured interview schedule and audio-recorded the discussions. **Analysis Details** The responses to the open questions were identified in the transcripts and collated. Issues raised were grouped into themes and a coding frame was devised by discussion between 3 members of the research team.	• Carers need to be informed of any changes to treatment or prognosis. **Findings** • Making clinical judgements.	Yes. **Q2: Was a qualitative methodology appropriate?** Yes. **Q3 Was the research design appropriate to address the aims of the research?** Yes - mixed methods survey including a qualitative component. Had a high number of participants which meant a high saturation of data. **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?** Yes - although some of the nuance of the findings may have got lost in the high saturation. **Q6: Has the relationship between researcher and**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Date of data collection 1999 – 2000 **Source of funding** Wellcome trust.					**participants been adequately considered?** Yes - care to make sure the interviewers were local people, spoke their languages etc. **Q7: Have ethical issues been taken into consideration?** Yes. **Q8: Was the data analysis sufficiently rigorous?** Unclear - lots of qualitative data, its unclear what they ommited to report. **Q9: Is there a clear statement of findings?** Yes, although not all findings they sought to investigate were clearly reported on. **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** Yes - covered 4 regions.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					Overall methodological limitations Moderate.
Full citation 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 **Ref Id** 822576 **Country/ies where the study was carried out** England **Study type** Qualitative **Aim of the study** To undertake a qualitative assessment of the needs of HF caregivers to inform	**Sample size** 26 carers **Person being cared for** Heart failure **Characteristics** Demographics of caregiver participants in the individual interviews M/F: 6/16 Mean age (range): 67 (39–84) Demographics of caregiver participants in the focus groups M/F: 1/3 Mean age (range): 62 (42–72) **Inclusion criteria** Inclusion criteria not specifically stated, but research defined carer as ‘anyone who cares,	**Phenomenon of interest to the paper** Research to inform the development of an intervention for carers as part of the Rehabilitation Enablement in Chronic Heart Failure (REACH-HF) research programme. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided,	**Recruitment Details** Caregivers were contacted by community-based cardiac nurses or the cardiac rehabilitation team in 3 geographical areas reflecting the diversity of the United Kingdom population, including Cornwall, Birmingham and Leicester. The clinical team checked that the person with HF and their caregiver were both still alive prior to contact and sent the caregiver a participant information sheet, a questionnaire and a letter inviting them to take part in the research. Caregivers from a support group for people with an implantable cardiac device were also invited to take part (p.307). Some potential participants were also contacted through advertising by the National Cardiomyopathy Association. A questionnaire, collecting demographic, socio-economic and contact details was sent to potential participants with a	**Themes** • Information should be consistent and co-ordinated between different services. • Carers turn to other sources for information when needed. • Carers need information about long term care needs beyond the specific condition. • Carers need clear information related to using equipment for long-term care. **Findings** • Understanding and managing medicines. • Living with a cardiac device. • Supporting depression management.	**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?**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
an evidence-based self-help intervention aimed at heart failure patients and caregivers. **Date of data collection** Not stated **Source of funding** National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-1210-12004).	unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support...and people with at least 6 months' experience of being caregivers' (p.306). **Exclusion criteria** Not stated	and how it can be improved	stamped addressed envelope. The research team selected a purposive sample through maximal variation techniques to develop the sampling frame. **Collection Details** 'Participants were given the choice of a location that did not conflict with their caregiving responsibilities. 'Twenty-two participants took part in individual interviews, 21 were in the caregiver's home and one was in the research unit at a general hospital...Sixteen interviews took place in Cornwall, four in Birmingham and two in Leicester.(p.307). Focus group consisted of four caregivers. One caregiver became ill and could not stay. 3 caregivers were accompanied by the person they cared for. These people sat together in a separate social group during the focus group but were not included in the research'. (p.308). **Analysis Details** The audio-recordings from the interviews and focus group		Yes. **Q6: Has the relationship between researcher and participants been adequately considered?** Researchers 'reflected on their own performance and influence on the interview; how the caregiver responded to the questions and initial thoughts about the main points arising from the interview'.(p.307) **Q7: Have ethical issues been taken into consideration?** Unclear. Approved by an ethics board but no other discussion. **Q8: Was the data analysis sufficiently rigorous?** Yes. 'The audio-recordings from the interviews and focus group were transcribed verbatim by an experienced transcriber, checked for accuracy by DT and JW, and anonymised. Data were managed using computer

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
			were transcribed verbatim, checked for accuracy by 2 researchers and anonymised. Data were managed with computer software Nvivo 10 and analysed according to different themes.		software Nvivo 10 and thematically analysed. The researchers conducted a six-step process which involved familiarisation oneself with the data, generating initial codes, searching for themes, reviewing the themes, defining and naming the themes, and producing the report.' (p.308) **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** Moderate.
Full citation Woolham, John, Steils, Nicole, Daly, Guy, Ritters, Katrina, The impact of personal budgets on unpaid carers of older	**Sample size** Interviews: 31 carers. Survey: 1500 carers	**Phenomenon of interest to the paper** The impact of D Ps and MPBs on carers of older people.	**Recruitment Details** Carers of older DP and MPB users were randomly selected from 3 local authority sites. The 3 sites were opportunistically selected and a postal survey was sent to 1500 randomly	**Themes** • Carers want information delivered to them in person, supplemented with written information to take away.	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
people, Journal of Social Work, 18, 119-141, 2018. **Ref Id** 819665 **Country/ies where the study was carried out** England **Study type** Mixed qualitative methods **Aim of the study** To examine the impact of a personal budget – either in the form of a direct payment or managed personal budget – on the role of unpaid carers of older budget holders. **Date of data collection** Not reported	Carers of DP users: Sent survey N=153, Response N=53 Carers of MPB: Sent survey N=1347, Response N=240 **Person being cared for** Not explicitly stated, but various conditions **Characteristics** Carers of DP users Mean age: 59.2 years M/F:13/33 Carers of MPB users Mean age: 63.9 years M/F:66/128 **Inclusion criteria** 'Eligibility criteria were that carers should be caring for someone aged 75 or older who lived in their own home (or with the carer) or in sheltered housing, and that they should be paying for	**Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	selected carers. Interview participants were randomly selected from a larger, self-selecting group who had given their contact details on the survey questionnaire after an invitation to take part in a follow-up interview. **Collection Details** Collection details of survey not provided. Interviews used a semi-structured questionnaire and were conducted either in the carer's home or by telephone, and a postal survey sent to carers. **Analysis Details** Survey data were analysed using SPSS (version 22) statistical software. Interviews were digitally recorded and fully transcribed and entered into NVivo computer software. 'Framework analysis (Ritchie & Spencer, 1994) was used to code and inductively analyse the data (Hodkinson, 2008) to identify underlying themes.' (p.122).	• Information should be consistent and co-ordinated between different services. **Findings** • Needs for information.	Yes, stated as the main objective. **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, but with the caveat that not all local authorities were able to identify the required number of carers of DP users, either because the information was not collected or because the information systems were not able to properly identify such carers. Demographic information was also not fully available. Minority ethnic groups were under-represented.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Source of funding School for Social Care Research	care services though a DP or MPB.’ (p.122). **Exclusion criteria** Carers who had been formally allocated a PB to spend on behalf of the person they were caring for.				**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?** Not reported. **Q7: Have ethical issues been taken into consideration?** Unclear. Approved by an ethics board but no other discussion. **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)**

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					Yes. **Overall methodological limitations** Minor.
Full citation Wright, Fay, McCreadie, Claudine, Tinker, Anthea, Institute of Gerontology, King's College London, Improving the provision of information about assistive technology for older people, 2005 **Ref Id** 715199 **Country/ies where the study was carried out** England **Study type** Mixed qualitative methods	**Sample size** 12 carers 40 health, social care and housing professionals 60 care home managers **Person being cared for** Not reported. **Characteristics** Not reported. **Inclusion criteria** Not explicitly reported. **Exclusion criteria** Not reported.	**Phenomenon of interest to the paper** The results of research about the provision of information about assistive technology. **Phenomenon of interest according to the protocol** How information and advice given to adult carers about caring and the services available has been provided, and how it can be improved	**Recruitment Details** Not reported **Collection Details** • In-depth interviews with 40 key professionals in health, social care and housing • 3 focus group discussions with 28 people aged 75 and over, and 2 focus groups with 12 carers to explore their experiences of obtaining information about assistive technology and their ideas for improving the situation. • A postal questionnaire to a stratified national sample of 131 care home managers (response rate of 45%). • **Analysis Details** Not reported	**Themes** • When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns. • Carers turn to other sources for information when needed. Carers groups and forums are another valued source of information and support. • Each carer and caring dynamic is unique. • Carers vary in their comfort and proficiency with the internet. **Findings** • Sources of information. • Identifying needs for assistive technology.	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** No. **Q2: Was a qualitative methodology appropriate?** Yes. **Q3 Was the research design appropriate to address the aims of the research?** Unclear as not reported. **Q4: Was the recruitment strategy appropriate to the aims of the research?** Not reported.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
Aim of the study The research concentrated on specific difficulties that, according to the Health Survey for England, are commonly experienced with ageing. **Date of data collection** April 2004 - March 2005 **Source of funding** Helen Hamlyn Foundation					**Q5: Were the data collected in a way that addressed the research issue?** Unclear. Collection methods not reported. **Q6: Has the relationship between researcher and participants been adequately considered?** No. **Q7: Have ethical issues been taken into consideration?** No. **Q8: Was the data analysis sufficiently rigorous?** Not 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.

Study details	Participants	Interventions	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Comments
					Overall methodological limitations Major.

BME: Black and Minority ethnic; CASP: Critical Appraisal Skills Programme; CSNAT: the Carer Support Needs Assessment Tool; DP: Direct Payment; F: Female; HF: Heart Failure; ILD: interstitial lung disease; LA: local authority; LGBT: Lesbian, Gay, Bisexual, and Transgender; M: Male; MND: Motor Neurone Disease; MPB: Managed Personal Budget; N: Number; NA: not applicable; NS: not stated; PB: Personal Budget; SD: standard deviation; SPSS: Statistical Package for the Social Sciences;

Appendix E – Forest plots

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

Appendix F – GRADE CERQual tables

GRADE CERQual tables for review question: What are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordinating care, or self-care - has been (and is) currently provided in the UK?

Table 5: Summary of evidence (GRADE-CERQual), Theme 1. Delivery of information

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**
IA1: Carers want information delivered to them in person, supplemented with written information to take away.							
5 (Abley 2013, Bajwah 2013, Garrett 2005, Newbronner 2011, Woolham 2018)	3 semi-structured interviews, 1 unspecified interviews, 1 mixed qualitative methods	Carers find face-to-face information most helpful as it allows the chance to ask for clarifications. However accompanying it with written information gave them something helpful to refer back to at a later point.	Minor concerns	Moderate concerns[1]	Minor concerns	Minor concerns	MODERATE
IA2: All information whether written or verbal should be plainly worded, clearly presented and free of jargon.							
5 (Abley 2013, CSSIW 2017, Garrett 2006, Newbronner 2011, Pinfold 2005)	1 semi-structured interviews, 2 unspecified interviews, 2 mixed qualitative methods	Carers need bite-sized chunks of information delivered in plain English. Pictures or visual aids (diagrams, scans, videos) are especially helpful when receiving information both verbally and in written or digital form. Different formats should be available for people with visual impairments.	Moderate concerns[2]	Minor concerns	Minor concerns	Minor concerns	MODERATE
IA3: When being given information carers need practitioners to be knowledgeable, take time and listen to their questions and concerns.							
5 (Aldred 2005, Bajwah 2013, Newbronner 2011, Pinfold	2 semi-structured interviews, 3 mixed	While the support carers provide is essential, they often feel like practitioners don't have time for them or see explaining things to them	Minor concerns	Minor concerns	Minor concerns	Minor concerns	HIGH

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
2005, Wright 2006)	qualitative methods	as a burden. Carers are aware that practitioners are busy which can make them reserved about asking for the information they need. Professionals should spend sufficient time with carers and be proactive about ensuring they have the information they need.					
IA4: Carers value honesty and full disclosure.							
5 (Abley 2013, Aldred 2005, Bajwah 2013, Beaver 2006, McIlfatrick 2018)	4 semi-structured interviews, 1 mixed qualitative methods	Professionals sometimes try and protect carers by softening difficult or upsetting facts. However carers normally want as much information as possible to enable them to plan and prepare. Carers report that the worst thing is being unclear or finding something out late.	Minor concerns	Minor concerns	Minor concerns	Minor concerns	HIGH
IA5: Carers need information to be repeated to them.							
4 (Abley 2013, Garrett 2005, Newbronner 2011, Pinfold 2005)	1 semi-structured interviews, 1 unspecified interviews, 2 mixed qualitative methods	Information is often both technically complex and also emotionally strenuous - making it doubly hard to process. Carers will often need to receive the same information several times or to have the provision of information staggered over several conversations. These needs are heightened among carers with memory impairments.	Minor concerns	Minor concerns	Minor concerns	Minor concerns	HIGH

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**
IA6: Information should be consistent and co-ordinated between different services.							
6 (Hughes 2005, Newbronner 2011, Pinfold 2005, Smith 2003, Wingham 2015, Woolham 2018)	2 semi-structured interviews, 1 survey, 3 mixed qualitative methods	Carers often receive information from several sources at the same time. It is important that professionals and services are in contact with each other and give carers coherent information.	Minor concerns	Minor concerns	Minor concerns	Minor concerns	HIGH
IA7: Carers turn to other sources for information when needed.							
5 (Bajwah 2013, Beaver 2006, Hughes 2005, Wingham 2015, Wright 2006)	3 semi-structured interviews, 2 mixed qualitative methods	Carers often turn to sources like the internet or to friends and neighbours when they need further information. Sometimes this information may not be as reliable – which emphasises the need for clear information to come from professional sources.	Moderate concerns[3]	Minor concerns	Minor concerns	Minor concerns	MODERATE
IA8: Carers groups and forums are another valued source of information and support.							
5 (CSSIW 2017, Harding 2004, McKechnie 2014, Pinfold 2005, Wright 2006)	2 semi-structured interviews, 1 unspecified interviews, 2 mixed qualitative methods	Carers group meetings or online forums are valued by carers. They are used as sources of information as well as for support and as a place to share experiences or concerns.	Moderate concerns[4]	Minor concerns	Minor concerns	Minor concerns	MODERATE

1 Evidence was downgraded for coherence of findings, as there was some divergence in carers' accounts of the ways that they preferred information to be shared.

2 Evidence was downgraded for methodological limitations, as two of the contributing studies (CSSIW 2017 and Garrett 2006) were rated by CASP as having major methodological limitations.

3 Evidence was downgraded for methodological limitations, as two of the contributing studies (Beaver 2006 and Wright 2006) were rated by CASP as having major methodological limitations.
4 Evidence was downgraded for methodological limitations, as two of the contributing studies (CSSIW 2017 and Wright 2006) were rated by CASP as having major methodological limitations.

Table 6: Summary of evidence (GRADE-CERQual), Theme 2. Individual differences

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**
IA9: Each carer and caring dynamic is unique.							
4 (Hughes 2005, McIlfatrick 2017, Pinfold 2005, Wright 2006)	1 semi-structured interviews, 3 mixed qualitative methods	Carers vary in their information preferences and in how able they are to comprehend information. Mobility and accessibility differences need to be accommodated. The nature of each carers' relationship with the person they are supporting may also vary greatly. Professionals must be considerate, flexible and accommodating in how they deliver information.	Minor concerns	Moderate concerns[1]	Minor concerns	Minor concerns	MODERATE
IA10: Carers vary in their comfort and proficiency with the internet.							
5 (CSSIW 2017, McKechnie 2014, Moriarty 2015, Powell 2010, Wright 2006)	1 semi-structured interviews, 1 unspecified interviews, 3 mixed qualitative methods	The internet can be a useful source of information, assistance and connection for many carers. However not all carers have access to the internet and some feel suspicious about the sharing of private information. Also online information can be misleading, hard to read, and hard to find at a stressful time.	Moderate concerns[2]	Minor concerns	Minor concerns	Minor concerns	MODERATE
IA11: Ethnicity, culture and race may affect the accessibility of information							

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
2 (Moriarty 2015, Pinfold 2005)	2 mixed qualitative methods	Language can create a barrier to accessing information for carers whose first language is not English. Even if written information is available in their own or preferred language, some carers may miss out on the benefits of a verbal explanation. Differences in terminology and cultural understanding of illness may also act as barriers.	Minor concerns	Minor concerns	Minor concerns	Moderate concerns[3]	MODERATE

1 Evidence was downgraded for coherence of findings, as there was some divergence in the challenges carers described and the accounts of the exact ways that they prefer information to be shared.

2 Evidence was downgraded for methodological limitations, as two of the contributing studies (CSSIW 2017 and Wright 2006) were rated by CASP as having major methodological limitations.

3 The evidence was downgraded by 1 due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)

Table 7: Summary of evidence (GRADE-CERQual), Theme 3. Who to inform

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
IA12: There are several sensitive considerations to account for when deciding who to give information to.							
3 (Abley 2013, Beaver 2006, Pinfold 2005)	2 semi-structured interviews, 1 mixed qualitative methods	Carers want to be viewed as part of the team, but can find it hard to obtain information if the person being supported is not well informed or is unable to attend conversations with professionals. At the same time care should be taken to ensure the person being supported is enabled to participate in such conversations. Their capacity needs to be considered, and	Minor concerns	Moderate concerns[1]	Minor concerns	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
		so too do their wishes around confidentiality. Finally, the quality of relationships between people being supported and their relatives can vary and this can be another complicating factor related to information sharing.					
IA13: Carers sometimes feel it would be best to get information in private.							
1 (Pinfold 2005)	1 mixed qualitative methods	Carers suggested some information might best be given in private away from the cared-for person to avoid distressing them and to protect their dignity.	Minor concerns	Minor concerns	Minor concerns	Serious concerns[2]	LOW
IA14: Carers and professionals need to work together to find a way to work with confidentiality limitations.							
1 (Pinfold 2005)	1 mixed qualitative methods	Carers are generally respectful of consent and confidentiality in relation to information sharing. However they need certain information in order to be effective carers. They want professionals to explain how information sharing is restricted by the principles of 'patient confidentiality' and to work with them to find ways that they can get as much necessary information as possible while respecting those limits. This is particularly important when the carer is supporting someone experiencing	Minor concerns	Minor concerns	Minor concerns	Serious 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
		memory less or certain psychiatric conditions (for example paranoia, eating disorders).					

1 Evidence was downgraded for coherence of findings, as there was some divergence the specific situations in which the various carers were discussing information needs.

2 The evidence was downgraded by 2 due to adequacy of data, as only 1 study supported the review's findings (offering very thin data)

Table 8: Summary of evidence (GRADE-CERQual), Theme 4. Different stages

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
IA15: Information for carers should acknowledge how the situation will progress, and will often require follow-ups.							
3 (Abley 2013, Hughes 2005, McIlfatrick 2017)	2 semi-structured interviews, 1 mixed qualitative methods	Carers' information needs will develop and change as the situation evolves, for example through diagnosis, transfer between hospital and home, disease progression, long-term care or end of life. Information should advise carers how the situation is likely to progress, prepare them to spot signs of change and highlight that they will benefit from new information in future.	Minor concerns	Moderate concerns[1]	Minor concerns	Minor concerns	MODERATE
IA16: Carers need information about long term care needs beyond the specific condition.							
2 (Garrett 2007, Wingham 2015)	1 unspecified interviews, 1 mixed qualitative methods	Carers are given information about the long term development of the specific condition but are not informed or prepared to deal with other long term effects such as depression, sexual needs, recovery of speech etc.	Moderate concerns[2]	Minor concerns	Minor concerns	Moderate concerns[3]	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
IA17: Carers need to be informed of any changes to treatment or prognosis.							
2 (Smith 2003, Pinfold 2005)	1 semi-structured interviews, 1 unspecified interviews, 1 mixed qualitative methods	Changes are sometimes made to medication or to prognosis without carers being told. They find this stressful and confusing and don't know whether they need to change the support they provide.	Minor concerns	Minor concerns	Minor concerns	Moderate concerns[3]	MODERATE
IA18: Carers need clear information related to using equipment for long-term care.							
2 (Alsaeed 2018, Wingham 2015)	1 survey, 1 mixed qualitative methods	Carers often feel under confident with equipment they are given to use (defibrillators, enteral tubes). Training is needed, and may need regular follow-up. Clear written instruction should include a troubleshooting page.	Moderate concerns[4]	Moderate concerns[5]	Minor concerns	Moderate concerns[3]	LOW

1 Evidence was downgraded for coherence of findings, as there was some divergence in the experiences and time periods at which different studies were asking carers about their information needs.

2 Evidence was downgraded for methodological limitations, as 1 of the contributing studies (Garrett 2007) was rated by CASP as having major methodological limitations.

3 The evidence was downgraded by 1 due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)

4 Evidence was downgraded for methodological limitations, as all of the contributing studies (Alsaeed 2018, Wingham 2015) were rated by CASP as having moderate methodological limitations.

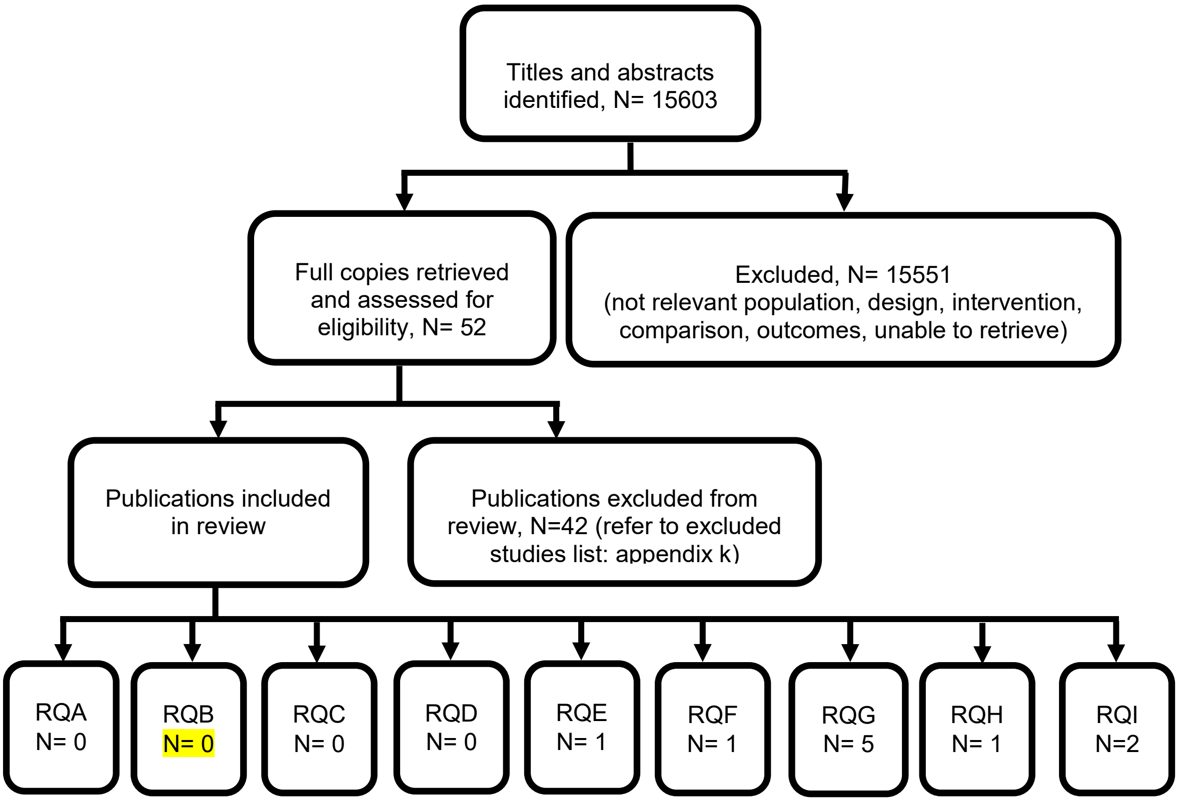
5 Evidence was downgraded for coherence of findings, as there was some divergence in the types of information discussed relating to equipment and occasions when it might be needed.

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordination care, or self-care – has been (and is) currently provided in the UK?

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

Figure 3: Study selection flow chart



Appendix H – Economic evidence tables

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

Appendix I – Economic evidence profiles

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

Appendix J – Economic analysis

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: What are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordinating care, or self-care - has been (and is) currently provided in the UK?

Qualitative studies

Table 9: Excluded qualitative studies and reasons for their exclusion

Study	Reason for Exclusion
Adult social care : scoping report	Law Commission Scoping report - not research
Andersson, S., Magnusson, L., Hanson, E., The use of information and communication technologies to support working carers of older people - a qualitative secondary analysis, International journal of older people nursing, 11, 32-43, 2016	Non-UK study
Andersson, Stefan, Erlingsson, Christen, Magnusson, Lennart, Hanson, Elizabeth, Information and communication technology-mediated support for working carers of older family members: an integrative literature review, International Journal of Care and Caring, 1, 247-273, 2017	Review covering studies outside our scope. Excluded but 2 contained two relevant references.
Anonymous,, Help for caregivers, American family physician, 83, 1322, 2011	Non-UK carer information leaflet
Arksey Hilary, Glendinning Caroline, Choice in the context of informal care-giving, Health and Social Care in the Community, 15, 165-175, 2007	A review of studies that did not meet the inclusion criteria.
Au, A., Lai, M. K., Lau, K. M., Pan, P. C., Lam, L., Thompson, L., Gallagher-Thompson, D., Social support and well-being in dementia family caregivers: the mediating role of self-efficacy, Aging & mental health, 13, 761-8, 2009	This was a non-UK study.
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 written in Dutch
Bar-Tal, Y., Barnoy, S., Zisser, B., Whose informational needs are considered? A comparison between cancer patients and their spouses' perceptions of their own and their partners' knowledge and informational needs, Social Science & Medicine, 60, 1459-65, 2005	This was a non-UK study.
Beech, Roger, Ong, Bie Nio, Jones, Sue, Edwards, Vicky, Delivering person-centred holistic care for older people, Quality in Ageing and Older Adults, 18, 157-167, 2017	No qualitative data relating to ways of sharing information or improving information sharing
Bellon, Michelle, Sando, Sandi, Crocker, Ruth, Farnden, Jennifer, Duras, Melissa, Information, connection and giving back: peer support outcomes for families following acquired brain injury in South Australia, Health & social care in the community, 25, 204-214, 2017	This was a non-UK study.
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	This was a non-UK study.

Study	Reason for Exclusion
consent and shared decision-making, Journal of Heart and Lung Transplantation, 34, 1182-1189, 2015	
Blusi, Madeleine, Asplund, Kenneth, Jong, Mats, Older family carers in rural areas: Experiences from using caregiver support services based on Information and Communication Technology (ICT), European Journal of Ageing, 10, 191-199, 2013	This was a non-UK study.
Bowes Alison, Macintosh Sherry, Andrews June, Baseline assessment of current information provision to people with dementia and their carers, 36p., 2009	A quantitative survey. Focus groups were only used to form the questions, and data is not provided.
Boyle Geraldine, 'She's usually quicker than the calculator': financial management and decision-making in couples living with dementia, Health and Social Care in the Community, 21, 554-562, 2013	Not about information and advice
Braithwaite, M., Philip, J., Tranberg, H., Finlayson, F., Gold, M., Kotsimbos, T., Wilson, J., End of life care in CF: patients, families and staff experiences and unmet needs, Journal of Cystic Fibrosis, 10, 253-7, 2011	This was a non-UK study.
Broady, Timothy R., Saich, Freya, Hinton, Tom, Caring for a family member or friend with dementia at the end of life: A scoping review and implications for palliative care practice, Palliative Medicine, 32, 643-656, 2018	Review covering studies outside our scope. No relevant references contained within.
Bronson, M., Toye, C., Providing information for family carers of hospital patients experiencing dementia, Dementia (London, England), 14, 267-272, 2015	This was a non-UK study.
Browne, Graeme, Hemsley, Martin, Housing and living with a mental illness: Exploring carers' views, International Journal of Mental Health Nursing, 19, 22-29, 2010	This was a non-UK study.
Buchanan Robert J, Huang Chunfeng, Crudden Adele, Use of the internet by informal caregivers assisting people with multiple sclerosis, Journal of Technology in Human Services, 30, 72-93, 2012	This was a non-UK study.
Bull, M. J., Boaz, L., Sjostedt, J. M., Family Caregivers' Knowledge of Delirium and Preferred Modalities for Receipt of Information, Journal of Applied Gerontology, 35, 744-58, 2016	This was a non-UK study.
Campbell, S. H., Carey, M., Sanson-Fisher, R., Barker, D., Turner, D., Taylor-Brown, J., Hall, A., Measuring the unmet supportive care needs of cancer support persons: the development of the support person's unmet needs survey--short form, European journal of cancer care, 23, 255-62, 2014	This was a non-UK study.
Canning, A. H. M., O'Reilly, S. A., Wressell, L. R. S., Cannon, D., Walker, J., A survey exploring the provision of carers' support in medium and high secure services in England and Wales, Journal of Forensic Psychiatry and Psychology, 20, 868-885, 2009	No qualitative data relating to ways of sharing information or improving information sharing
Care Act first-phase reforms	Not empirical research
Carers, U. K., Caring homes: how the Carers Strategy can make housing suitable for carers	Not about views and experiences of carers or practitioners
Carers, U. K., Choice or chore?: carers' experiences of direct payments, 10p., 2008	No qualitative data relating to ways of sharing information or improving information sharing

Study	Reason for Exclusion
Carr, Sarah, Robbins, Diana, Social Care Institute for Excellence, Scie Social Policy Research, Evaluation,, The implementation of individual budget schemes in adult social care, 27 pp, 2009	Not research on views and experiences about information and advice about caring
Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., Neville, A. J., The supportive care needs of family members of men with advanced prostate cancer, Canadian Oncology Nursing Journal, 20, 166-76, 2010	This was a non-UK study.
Caswell, Glenys, Seymour, Jane, Crosby, Vincent, Freer, Sarah, Freemantle, Alison, Wilcock, Andrew, INFORMATION PROVISION AND THE WIDER EXPERIENCE OF CARE: A QUALITATIVE STUDY OF PATIENTS DIAGNOSED WITH LUNG CANCER FOLLOWING EMERGENCY ADMISSION AND THEIR CARERS, BMJ supportive & palliative care, 4, 2014	Full text is the abstract. Reference is a poster presentation.
Chen, S. C., Chiou, S. C., Yu, C. J., Lee, Y. H., Liao, W. Y., Hsieh, P. Y., Jhang, S. Y., Lai, Y. H., The unmet supportive care needs-what advanced lung cancer patients' caregivers need and related factors, Supportive Care in Cancer, 24, 2999-3009, 2016	This was a non-UK study.
Chen, S. C., Lai, Y. H., Liao, C. T., Huang, B. S., Lin, C. Y., Fan, K. H., Chang, J. T., Unmet supportive care needs and characteristics of family caregivers of patients with oral cancer after surgery, Psycho-Oncology, 23, 569-77, 2014	This was a non-UK study.
Cho, J., Noh, H. I., Ha, M. H., Kang, S. N., Choi, J. Y., Chang, Y. J., What kind of cancer information do Internet users need?, Supportive Care in Cancer, 19, 1465-9, 2011	This was a non-UK study.
Clay Dan, et al.,, The lives of young carers in England: qualitative report to DfE, 135, 2016	About young carers under 18
Cleary, M., Freeman, A., Hunt, G. E., Walter, G., What patients and carers want to know: An exploration of information and resource needs in adult mental health services, Australian and New Zealand Journal of Psychiatry, 39, 507-513, 2005	This was a non-UK study.
Coffey, Nathan T. M. P. H., Cassese, James M. S., Cai, Xinsheng PhD, Garfinkel, Steven PhD, Patel, Drasti M. P. H., Jones, Rebecca M. P. H., Shaewitz, Dahlia M. A., Weinstein, Ali A. PhD, Identifying and Understanding the Health Information Experiences and Preferences of Caregivers of Individuals With Either Traumatic Brain Injury, Spinal Cord Injury, or Burn Injury: A Qualitative Investigation, Journal of medical Internet research, 19, 2017	This was a non-UK study.
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	This was a non-UK study.
Cook, A. M., Pierce, L. L., Hicks, B., Steiner, V., Self-care needs of caregivers dealing with stroke, Journal of Neuroscience Nursing, 38, 31-6, 2006	This was a non-UK study.
Cox, R., Skouteris, H., Fuller-Tyszkiewicz, M., Jones, A. D., Gallant, D., Omerogullari, S., Miller, R., Hardy, L. L., Descriptive study of carers' support, encouragement and modelling of healthy lifestyle behaviours in residential out-of-	This was a non-UK study.

Study	Reason for Exclusion
home care, Australian & New Zealand Journal of Public Health, 39, 588-92, 2015	
Creasy, K. R., Lutz, B. J., Young, M. E., Ford, A., Martz, C., The impact of interactions with providers on stroke caregivers' needs, Rehabilitation Nursing, 38, 88-98, 2013	This was a non-UK study.
DaDalt, Olivia, Burstein, Arielle, Kramer, Birgit, D'Ambrosio, Lisa A., Coughlin, Joseph F., Dementia and financial incapacity: a caregiver study, Working With Older People, 20, 66-75, 2016	This was a non-UK study.
Dall'Armi, L., Simpson, G. K., Forstner, D., Simpson, T., Roydhouse, J. K., White, K. J., The information needs of patients with head and neck cancer and their caregivers: a short report of instrument development and testing, Applied Nursing Research, 26, 40-4, 2013	This was a non-UK study.
Dawson, Suzanne, Gerace, Adam, Muir-Cochrane, Eimear, O'Kane, Deb, Henderson, Julie, Lawn, Sharon, Fuller, Jeffrey, Carers' experiences of accessing and navigating mental health care for older people in a rural area in Australia, Aging & mental health, 21, 216-223, 2017	This was a non-UK study.
Debska, G., Pasek, M., Wojtyna, E., Does anybody support the supporters? Social support in the cancer patient-caregiver dyad, Family Medicine and Primary Care Review, 19, 110-113, 2017	This was a non-UK study.
Docherty Andrea, et al.,, Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review, Palliative Medicine, 22, 153-171, 2008	Systematic review excluded as most studies did not meet protocol. Relevant references screened separately.
Down, Keren, Higginson, Irene, Hughes, Rhidian A., Leigh, P. Nigel, Sinha, Anu, Living with motor neurone disease: lives, experiences of services and suggestions for change, Health & social care in the community, 13, 64-74, 2005	Duplication of Hughes 2005 which is included.
Eames, S., Hoffmann, T., Worrall, L., Read, S., Stroke patients' and carers' perception of barriers to accessing stroke information, Topics in Stroke Rehabilitation, 17, 69-78, 2010	This was a non-UK study.
Eames, Sally, Hoffmann, Tammy, Worrall, Linda, Read, Stephen, Delivery styles and formats for different stroke information topics: Patient and carer preferences, Patient Education and Counseling, 84, e18-e23, 2011	This was a non-UK study.
Edmonds, P., Vivat, B., Burman, R., Silber, E., Higginson, I. J., 'Fighting for everything': service experiences of people severely affected by multiple sclerosis, Multiple Sclerosis, 13, 660-7, 2007	No qualitative data relating to ways of sharing information or improving information sharing
Edwards, Megan, Distance caregivers of people with Alzheimer's disease and related dementia: A phenomenological study, The British Journal of Occupational Therapy, 77, 174-180, 2014	This was a non-UK study.
El-Jawahri, A., Traeger, L., Shin, J. A., Knight, H., Mirabeau-Beale, K., Fishbein, J., Vandusen, H. H., Jackson, V. A., Volandes, A. E., Temel, J. S., Qualitative Study of Patients' and Caregivers' Perceptions and Information Preferences about Hospice, Journal of Palliative Medicine, 20, 759-766, 2017	This was a non-UK study.

Study	Reason for Exclusion
Exley, Catherine, Field, David, Jones, Linda, Stokes, Tim, Palliative care in the community for cancer and end-stage cardiorespiratory disease: the views of patients, lay-carers and health care professionals, Palliative medicine, 19, 76-83, 2005	No qualitative data relating to ways of sharing information or improving information sharing to carers
Feinstein, Rebecca T., Pollack, Harold A., "We don't have a plan. We should be working on a plan.": Obstacles to caregiver transition planning for individuals with Fragile X Syndrome, Social Service Review, 90, 464-514, 2016	This was a non-UK study.
Firbank, O. E., Connecting the voices of users, caregivers and providers on service quality: A study of home-care services, International Journal of Health Care Quality Assurance, 25, 403-420, 2012	This was a non-UK study.
Funk, L. M., Allan, D. E., Stajduhar, K. I., Palliative family caregivers' accounts of fetime experiences: The importance of security, Palliative and Supportive Care, 7, 435-447, 2009	This was a non-UK study.
Gansler, T., Kepner, J., Willacy, E., Soloe, C., Rupert, D., Jarblum, M., Driscoll, D., Orr, A., Fitzgerald, T., Esparza, A., Evolving information priorities of hematologic cancer survivors, caregivers, and other relatives, Journal of Cancer Education, 25, 302-11, 2010	This was a non-UK study.
Garvelink, M. M., Ngangue, P. A., Adekpedjou, R., Diouf, N. T., Goh, L., Blair, L., Legare, F., A Synthesis Of Knowledge About Caregiver Decision Making Finds Gaps In Support For Those Who Care For Aging Loved Ones, Health Affairs, 35, 619-26, 2016	This was a non-UK study.
Gibson, Grant, Dickinson, Claire, Brittain, Katie, Robinson, Louise, The everyday use of assistive technology by people with dementia and their family carers: a qualitative study, BMC Geriatrics, 15, 89, 2015	No qualitative data relating to ways of sharing information or improving information sharing
Given, B. A., Sherwood, P., Given, C. W., Support for caregivers of cancer patients: transition after active treatment, Cancer Epidemiology, Biomarkers & Prevention, 20, 2015-21, 2011	This was a non-UK study.
Great Britain Parliament. House of Commons. Committee of Public Accounts, Improving services and support for people with dementia: sixth report of session 2007-08: report, together with formal minutes, oral and written evidence	Not research about views and experiences on information and advice about caring
Halkett, G. K., Lobb, E. A., Oldham, L., Nowak, A. K., The information and support needs of patients diagnosed with High Grade Glioma, Patient Education & Counseling, 79, 112-9, 2010	This was a non-UK study.
Halm, M. A., Specific needs, concerns, strategies and advice of caregivers after coronary artery bypass surgery, Heart & Lung, 45, 416-22, 2016	This was a non-UK study.
Hazen, R. J., Lazar, A., Gennari, J. H., Assessing patient and caregiver needs and challenges in information and symptom management: a study of primary brain tumors, Amia .., Annual Symposium proceedings. AMIA Symposium. 2016, 1804-1813, 2016	This was a non-UK study.
Heckel, L., Fennell, K. M., Reynolds, J., Osborne, R. H., Chirgwin, J., Botti, M., Ashley, D. M., Livingston, P. M., Unmet needs and depression among carers of people newly diagnosed with cancer, European Journal of Cancer, 51, 2049-57, 2015	This was a non-UK study.

Study	Reason for Exclusion
Jarrold, Yeandle, A weight off my mind: Exploring the impact and potential benefits of telecare for unpaid carers in Scotland, 2009	No qualitative data relating to ways of sharing information or improving information sharing
Kelsey, S. G., Laditka, S. B., Laditka, J. N., Caregiver perspectives on transitions to assisted living and memory care, American Journal of Alzheimer's Disease and other Dementias, 25, 255-264, 2010	This was a non-UK study.
Kessler, David, Peters, Tim J, Lee, Liz, Parr, Susie, Social class and access to specialist palliative care services, Palliative medicine, 19, 105-110, 2005	No qualitative data relating to ways of sharing information or improving information sharing
King, R. B., Semik, P. E., Stroke caregiving: difficult times, resource use, and needs during the first 2 years, Journal of Gerontological NursingJ Gerontol Nurs, 32, 2006	This was a non-UK study.
Longacre, M. L., Galloway, T. J., Parvanta, C. F., Fang, C. Y., Medical Communication-related Informational Need and Resource Preferences Among Family Caregivers for Head and Neck Cancer Patients, Journal of cancer education : the official journal of the American Association for Cancer Education, 30, 786-791, 2015	This was a non-UK study.
McHugh, J., Wherton, J., Prendergast, D., Lawlor, B., Identifying opportunities for supporting caregivers of persons with dementia through information and communication technology, Gerontechnology, 10, 220-230, 2012	This was a non-UK study.
Merckaert, I., Libert, Y., Lieutenant, F., Moucheux, A., Farvacques, C., Slachmuylder, J. L., Razavi, D., Desire for formal psychological support among caregivers of patients with cancer: prevalence and implications for screening their needs, Psycho-Oncology, 22, 1389-95, 2013	This was a non-UK study.
Moriarty Jo, Manthorpe Jill, Social care practice with carers: what social care support is provided to family carers? What support to family carers want?, 4, 2014	No qualitative data relating to ways of sharing information or improving information sharing.
Mosher, C. E., Champion, V. L., Hanna, N., Jalal, S. I., Fakiris, A. J., Birdas, T. J., Okereke, I. C., Kesler, K. A., Einhorn, L. H., Given, B. A., Monahan, P. O., Ostroff, J. S., Support service use and interest in support services among distressed family caregivers of lung cancer patients, Psycho-Oncology, 22, 1549-56, 2013	This was a non-UK study.
N. G. Guat Tin, Support for family caregivers: what do service providers say about accessibility, availability and affordability of services?, Health and Social Care in the Community, 16, 590-598, 2009	This was a non-UK study.
National Development Team For, Inclusion, Spotlight on a carer's journey: exploring what works in supporting carers through the Care Act, 20, 2016	Not research - this is a guide
Nikoletti, S., Kristjanson, L. J., Tataryn, D., McPhee, I., Burt, L., Information needs and coping styles of primary family caregivers of women following breast cancer surgery, Oncology nursing forum, 30, 987-96, 2003	This was a non-UK study.
O'Connell, B., Baker, L., Prosser, A., The educational needs of caregivers of stroke survivors in acute and community settings, The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses, 35, 21-28, 2003	This was a non-UK study.

Study	Reason for Exclusion
Osse, B. H. P., Vernooij-Dassen, M. J. F. J., Schade, E., Grol, R. P. T. M., Problems experienced by the informal caregivers of cancer patients and their needs for support, Cancer Nursing, 29, 378-388, 2006	This was a non-UK study.
Outram, Sue, Harris, Gillian, Kelly, Brian, Bylund, Carma L., Cohen, Martin, Landa, Yulia, Levin, Tomer, Sandhu, Harsimrat, Vamos, Marina, Loughland, Carmel, 'We didn't have a clue': Family caregivers' experiences of the communication of a diagnosis of schizophrenia, The International journal of social psychiatry, 61, 10, 2015	This was a non-UK study.
Parveen, S., Blakey, H., Oyebode, J. R., Evaluation of a carers' information programme culturally adapted for South Asian families, International Journal of Geriatric Psychiatry., 2017	No qualitative data relating to ways of sharing information or improving information sharing
Petty, M., Supporting Caregivers in Caring: Empowered to Disempowered and Back Again, Creative Nursing, 21, 69-74, 2015	This was a non-UK study.
Philip, J., Gold, M., Brand, C., Miller, B., Douglass, J., Sundararajan, V., Facilitating change and adaptation: the experiences of current and bereaved carers of patients with severe chronic obstructive pulmonary disease, Journal of Palliative Medicine, 17, 421-7, 2014	This was a non-UK study.
Pieper, B., Sieggreen, M., Freeland, B., Kulwicki, P., Frattaroli, M., Sidor, D., Palleschi, M. T., Burns, J., Bednarski, D., Garretson, B., Discharge information needs of patients after surgery, Journal of Wound, Ostomy, & Continence Nursing, 33, 281-9; quiz 290-1, 2006	This was a non-UK study.
Pierce, L. L., Gordon, M., Steiner, V., Families dealing with stroke desire information about self-care needs, Rehabilitation Nursing Journal, 29, 14-7, 2004	This was a non-UK study.
Piil, K., Juhler, M., Jakobsen, J., Jarden, M., Daily Life Experiences of Patients With a High-Grade Glioma and Their Caregivers: A Longitudinal Exploration of Rehabilitation and Supportive Care Needs, Journal of Neuroscience Nursing, 47, 271-84, 2015	This was a non-UK study.
Rand, Stacey, Malley, Juliette, Carers' quality of life and experiences of adult social care support in England, Health & social care in the community, 22, 375-385, 2014	No qualitative data relating to ways of sharing information or improving information sharing
Reblin, M., Cloyes, K. G., Carpenter, J., Berry, P. H., Clayton, M. F., Ellington, L., Social support needs: discordance between home hospice nurses and former family caregivers, Palliative & supportive care, 13, 465-472, 2015	This was a non-UK study.
Robben, S., Van kempen, J., Heinen, M., Zuidema, S., Olde rikkert, M., Schers, H., Melis, R., Preferences for receiving information among frail older adults and their informal caregivers: A qualitative study, Family Practice, 29, 742-747, 2012	This was a non-UK study.
Rowe, F. J., Walker, M., Rockliffe, J., Pollock, A., Noonan, C., Howard, C., Glendinning, R., Feechan, R., Currie, J., Care provision for poststroke visual impairment, Journal of Stroke and Cerebrovascular Diseases, 24, 1131-1144, 2015	Not about views and experiences of carers and practitioners regarding information and advice
Rupert, Douglas J., Gard Read, Jennifer, Amoozegar, Jacqueline B., Moultrie, Rebecca R., Taylor, Olivia M., O'Donoghue, Amie C., Sullivan, Helen W., Peer-Generated Health Information: The Role of Online Communities in	This was a non-UK study.

Study	Reason for Exclusion
Patient and Caregiver Health Decisions, Journal of health communication, 21, 1187-1197, 2016	
Salin, S., Astedt-Kurki, P., Women's views of caring for family members: use of respite care, Journal of gerontological nursing, 33, 37-45, 2007	This was a non-UK study.
Salin, S., Kaunonen, M., Astedt-Kurki, P., Informal carers of older family members: how they manage and what support they receive from respite care, Journal of clinical nursing, 18, 492-501, 2009	This was a non-UK study.
Schook, Romane Milia, Linssen, Cilia, Schramel, Franz M. N. H., Festen, Jan, Lammers, Ernst, Smit, Egbert F., Postmus, Pieter E., Westerman, Marjan J., Why Do Patients and Caregivers Seek Answers From the Internet and Online Lung Specialists? A Qualitative Study, Journal of medical Internet research, 16, 2014	This was a non-UK study.
Sekelja, N., Butow, P. N., Tattersall, M. H. N., Bereaved cancer carers' experience of and preference for palliative care, Supportive Care in Cancer, 18, 1219-1228, 2010	This was a non-UK study.
Self, R., Rigby, A., Leggett, C., Paxton, R., Clinical decision support tool: A rational needs-based approach to making clinical decisions, Journal of Mental Health, 17, 33-48, 2008	Not about info and advice
Shiba, K., Kondo, N., Kondo, K., Informal and Formal Social Support and Caregiver Burden: The AGES Caregiver Survey, Journal of epidemiology, 26, 622-628, 2016	This was a non-UK study.
Skills For, Care, There for carers: the workforce development needs of carer support workers	Not in PICO
Smith, J., Forster, A., Young, J., Cochrane Group for information provision after, stroke, Cochrane review: information provision for stroke patients and their caregivers, Clinical rehabilitation, 23, 195-206, 2009	UK studies do not fit eligibility criteria
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	This was a non-UK study.
Social Care Institute For, Excellence, Personal budgets briefing: learning from the experiences of people with mental health problems and their carers, 6p., 2011	No qualitative data relating to ways of sharing information or improving information sharing
Social work practice with carers	Not a systematic review
Squire, L., Glover, J., Corp, J., Haroun, R., Kuzan, D., Gielen, V., Impact of HF on HRQoL in patients and their caregivers in England: Results from the ASSESS study, British Journal of Cardiology, 24, 30-34, 2017	Not a qualitative study
Stajduhar, K. I., Martin, W. L., Barwich, D., Fyles, G., Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home, Cancer Nursing, 31, 77-85, 2008	This was a non-UK study.
State of caring 2017	No qualitative data relating to ways of sharing information or improving information sharing
Steiner, V., Pierce, L. L., Salvador, D., Information Needs of Family Caregivers of People With Dementia, Rehabilitation nursing : the official journal of the Association of Rehabilitation Nurses, 41, 162-169, 2016	This was a non-UK study.

Study	Reason for Exclusion
Strang, V. R., Koop, P. M., Dupuis-Blanchard, S., Nordstrom, M., Thompson, B., Family caregivers and transition to long-term care, Clinical Nursing Research, 15, 27-45, 2006	This was a non-UK study.
Takagi, Emiko, Davey, Adam, Wagner, Donna, A National Profile of Caregivers for the Oldest-Old, Journal of Comparative Family Studies, 44, 473-490, 2013	This was a non-UK study.
Taylor, L. A., Bahreman, N., Hayat, M. J., Hoey, F., Rajasekaran, G., Segev, D. L., Living kidney donors and their family caregivers: developing an evidence-based educational and social support website, Progress in Transplantation, 22, 119-28, 2012	This was a non-UK study.
Teixeira, M., Pinto, J., Caregivers' knowledge and skills: which reality?, Studies in health technology and informatics, 146, 835-836, 2009	This was a non-UK study.
Tieu, Lina M. P. H., Sarkar, Urmimala M. D. M. P. H., Schillinger, Dean M. D., Ralston, James D. M. D. M. P. H., Ratanawongsa, Neda M. D. M. H. S., Pasick, Rena DrPH, Lyles, Courtney R. PhD, Barriers and Facilitators to Online Portal Use Among Patients and Caregivers in a Safety Net Health Care System: A Qualitative Study, Journal of medical Internet research, 17, 2015	This was a non-UK study.
Tjia, J., Ellington, L., Clayton, M. F., Lemay, C., Reblin, M., Managing Medications During Home Hospice Cancer Care: The Needs of Family Caregivers, Journal of Pain & Symptom Management, 50, 630-41, 2015	This was a non-UK study.
Togher, F. J., O'Cathain, A., Phung, V. H., Turner, J., Siriwardena, A. N., Reassurance as a key outcome valued by emergency ambulance service users: a qualitative interview study, Health expectations : an international journal of public participation in health care and health policy, 18, 2951-2961, 2015	Spouses were interviewed but it is not specified whether they were carers.
Torp Steffen, et al.,, A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway, Health and Social Care in the Community, 16, 75-85, 2008	This was a non-UK study.
Ugalde, Anna, Mathers, Susan, Hennessy, Anderson Nicole, Hudson, Peter, Orellana, Liliana, Gluyas, Cathy, A self-care, problem-solving and mindfulness intervention for informal caregivers of people with motor neurone disease: A pilot study, Palliative Medicine, 32, 726-732, 2018	This was a non-UK study.
Vaingankar, J. A., Chong, S. A., Abdin, E., Picco, L., Shafie, S., Seow, E., Pang, S., Sagayadevan, V., Chua, B. Y., Chua, H. C., Subramaniam, M., Psychiatric morbidity and its correlates among informal caregivers of older adults, Comprehensive Psychiatry, 68, 178-185, 2016	This was a non-UK study.
van der Roest, H. G., Meiland, F. J., Jonker, C., Droes, R. M., User evaluation of the DEMentia-specific Digital Interactive Social Chart (DEM-DISC). A pilot study among informal carers on its impact, user friendliness and, usefulness, Aging & mental health, 14, 461-70, 2010	This was a non-UK study.
Van Duijn, E., Giltay, E. J., Zitman, F. G., Roos, R. A. C., Van Der Mast, R. C., Measurement of psychopathology in huntington's disease: The critical role of caregivers, Journal of Nervous and Mental Disease, 198, 329-333, 2010	This was a non-UK study.

Study	Reason for Exclusion
Verhaeghe, S., Defloor, T., Van Zuuren, F., Duijnstee, M., Grypdonck, M., The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature, Journal of clinical nursing, 14, 501-9, 2005	Not limited to only UK studies
Vernooij-Dassen M. J. F, J., et al.,, Information for dementia patients and their caregivers: what information does a memory clinic pass on, and to whom?, Aging and Mental Health, 7, 34-38, 2003	This was a non-UK study.
Wakui, T., Agree, E. M., Saito, T., Kai, I., Disaster Preparedness Among Older Japanese Adults With Long-Term Care Needs and Their Family Caregivers, Disaster medicine and public health preparedness, 11, 31-38, 2017	This was a non-UK study.
Walder, A. E., et al.,, Caregivers' experience of risk in dementia: the LASER-AD study, Aging and Mental Health, 10, 532-538, 2006	Not a qualitative study
Waldrop, Deborah P., Meeker, Mary Ann, Kerr, Christopher, Skretny, Judith, Tangeman, John, Milch, Robert, The Nature and Timing of Family-Provider Communication in Late-Stage Cancer: A Qualitative Study of Caregivers' Experiences, Journal of Pain and Symptom Management, 43, 182-194, 2012	This was a non-UK study.
Warchol-Biedermann, K., Mojs, E., Gregersen, R., Maibom, K., Millan-Calenti, J. C., Maseda, A., What causes grief in dementia caregivers?, Archives of Gerontology & Geriatrics, 59, 462-7, 2014	This was a non-UK study.
Waters John, Third national personal budget survey: experiences of personal budget holders and carers across adult social care and health, 84, 2014	Not a qualitative study
Weaver, F. M., Perloff, L., Waters, T., Patients' and caregivers' transition from hospital to home: needs and recommendations, Home health care services quarterly, 17, 27-48, 1998	This was a non-UK study.
Werner, N. E., Stanislawski, B., Marx, K. A., Watkins, D. C., Kobayashi, M., Kales, H., Gitlin, L. N., Getting what they need when they need it. Identifying barriers to information needs of family caregivers to manage dementia-related behavioral symptoms, Applied clinical informatics, 8, 191-205, 2017	This was a non-UK study.
Whittier, S., Scharlach, A. E., Dal Santo, T. S., Availability of caregiver support services: implications for implementation of the National Family Caregiver Support Program, Journal of aging & social policy, 17, 45-62, 2005	This was a non-UK study.
Wilcock, A., Crosby, V., Hussain, A., McKeever, T. M., Manderson, C., Farnan, S., Freer, S., Freemantle, A., Littlewood, F., Caswell, G., Seymour, J., Lung cancer diagnosed following an emergency admission: Mixed methods study of the management, outcomes and needs and experiences of patients and carers, Respiratory Medicine, 114, 38-45, 2016	Not about information and advice about caring
Wilks, S. E., Croom, B., Perceived stress and resilience in Alzheimer's disease caregivers: testing moderation and mediation models of social support, Aging & mental health, 12, 357-65, 2008	This was a non-UK study.
Williams Val, Robinson Carol, In their own right: Carers Act and carers of people with learning difficulties	Book

Study	Reason for Exclusion
Williamson, S. S., Gorman, P. N., Jimison, H. B., A mobile/web app for long distance caregivers of older adults: functional requirements and design implications from a user centered design process, Amia .., Annual Symposium proceedings / AMIA Symposium. AMIA Symposium. 2014, 1960-1969, 2014	This was a non-UK study.
Wilson, L. S., Pillay, D., Kelly, B. D., Casey, P., Mental health professionals and information sharing: carer perspectives, Irish Journal of Medical Science, 184, 781-90, 2015	This was a non-UK study.
Wong, Alison G. PhD, Ki, Ppudah M. A., Maharaj, Artie M. A., Brow n, Edna PhD, Davis, Cindy M. S. W. PhD, Apolinsky, Felice Lcsw, Social Support Sources, Types, and Generativity: A Focus Group Study of Cancer Survivors and Their Caregivers, Social Work in Health Care, 53, 214, 2014	This was a non-UK study.
Yeh, L. L., Hwu, H. G., Chen, C. H., Wu, A. C. C., Factors related to perceived needs of primary caregivers of patients with schizophrenia, Journal of the Formosan Medical Association, 107, 644-652, 2008	This was a non-UK study.
Zelenikova, R., Ren, D., Schulz, R., Given, B., Sherwood, P. R., Symptoms as the main predictors of caregivers' perception of the suffering of patients with primary malignant brain tumors, Cancer Nursing, 39, 97-105, 2016	This was a non-UK study.
Zhang, S., Edwards, H., Yates, P., Li, C., Guo, Q., Self-efficacy partially mediates between social support and health-related quality of life in family caregivers for dementia patients in Shanghai, Dementia & Geriatric Cognitive Disorders, 37, 34-44, 2014	This was a non-UK study.

Economic component of the review

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

Table 10: Excludies studies from the health 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 patients.
Forster, A., Young, J., Chapman, K., Nixon, J., Patel, A., Holloway, I., Mellish, K., Anwar, S., Breen, R., Knapp, M., Murray, J., Farrin, A., Cluster Randomized Controlled Trial: Clinical and Cost-Effectiveness of a System of Longer-Term Stroke Care, Stroke; a journal of cerebral circulation, 46, 2212-2219, 2015	Population of interest: the study focus is primarily on patients.

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

Study	Reason for Exclusion
measures, Health and Quality of Life Outcomes, 10 (no pagination), 2012	searched for any relevant HE studies.
Jutkowitz, E., Gitlin, L. N., Pizzi, L. T., Evaluating willingness-to-pay thresholds for dementia caregiving interventions: application to the tailored activity program, Value in Health, 13, 720-5, 2010	Economic evaluation conducted in the USA.
Kenealy, T. W., Parsons, M. J., Rouse, A. P., Doughty, R. N., Sheridan, N. F., Hindmarsh, J. K., Masson, S. C., Rea, H. H., Telecare for diabetes, CHF or COPD: effect on quality of life, hospital use and costs. A randomised controlled trial and qualitative evaluation, PLoS ONE [Electronic Resource], 10, e0116188, 2015	Population of interest: the study focus is primarily on patients.
Kenrik Duru, O., Ettner, S. L., Vassar, S. D., Chodosh, J., Vickrey, B. G., Cost evaluation of a coordinated care management intervention for dementia, American Journal of Managed Care, 15, 521-528, 2009	Population of interest: the study focus is primarily on patients.
Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., Cooper, C., Livingston, G., Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people living with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial (Structured abstract), Bmj, 347, f6342, 2013	Study finding updated by a more recent HE study (Livingston 2014).
Lauret, G. J., Gijsbers, H. J., Hendriks, E. J., Bartelink, M. L., de Bie, R. A., Teijink, J. A., The ClaudicatioNet concept: design of a national integrated care network providing active and healthy aging for patients with intermittent claudication, Vascular Health & Risk Management, 8, 495-503, 2012	Research protocol.
Li, C., Zeliadt, S. B., Hall, I. J., Smith, J. L., Ekwueme, D. U., Moinpour, C. M., Penson, D. F., Thompson, I. M., Keane, T. E., Ramsey, S. D., Burden among partner caregivers of patients diagnosed with localized prostate cancer within 1 year after diagnosis: an economic perspective, Supportive Care in Cancer, 21, 3461-9, 2013	Not the intervention of interest: This study estimates lost productivity and informal caregiving and associated costs among partner caregivers of localized prostate cancer patients within 1 year after diagnosis.
Lopez-Villegas, A., Catalan-Matamoros, D., Robles-Musso, E., Peiro, S., Workload, time and 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 patients with remotely monitored pacemakers.
Magnusson, L., Hanson, E., Supporting frail older people and their family carers at home using information and communication technology: cost analysis, Journal of advanced nursing, 51, 645-57, 2005	This cost analysis uses a case study methodology involving 5 families, cost and resource usage are not reported separately for carers and patients.
Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., Drummond, M., Glendinning, C., A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers, Health	Study design - this review of HE studies has been excluded for this guideline (but its references have been hand-

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

Study	Reason for Exclusion
Romeo, R., Knapp, M., Banerjee, S., Morris, J., Baldwin, R., Tarrier, N., Pendleton, N., Horan, M., Burns, A., Treatment and prevention of depression after surgery for hip fracture in older people: cost-effectiveness analysis, Journal of Affective Disorders, 128, 211-9, 2011	Population of interest: no adult carers.
Sandberg, M., Jakobsson, U., Midlov, P., Kristensson, J., Cost-utility analysis of case management for frail older people: effects of a randomised controlled trial, Health Economics Review, 5 (1) (no pagination), 2015	Population of interest: no adult carers.
Schepers, J., Annemans, L., Simoens, S., Hurdles that impede economic evaluations of welfare interventions, Expert Review of Pharmacoeconomics & Outcomes Research, 15, 635-42, 2015	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.
Søgaard R, Sørensen J, Waldorff FB, Eckermann A, Buss DV, Early psychosocial intervention in Alzheimer's disease: cost utility evaluation alongside the Danish Alzheimer's Intervention Study (DAISY). BMJ Open. 2014 Jan 15;4(1):e004105	Population of interest: no primary focus on carers.
Sogaard, R., Sorensen, J., Waldorff, F. B., Eckermann, A., Buss, D. V., Waldemar, G., Private costs almost equal health care costs when intervening in mild Alzheimer's: a cohort study alongside the DAISY trial, BMC Health Services Research, 9, 215, 2009	Study findings updated by a more recent HE study (Søgaard 2014)
Teng, J., Mayo, N. E., Latimer, E., Hanley, J., Wood-Dauphinee, S., Cote, R., Scott, S., Costs and caregiver consequences of early supported discharge for stroke patients, Stroke, 34, 528-36, 2003	Population of interest: the study focus is primarily on patients.
Toseland RW, Smith TL. The impact of a caregiver health education program on health care costs. Research on Social Work Practice 2006;16(1):9–19.	This economic evaluation was conducted in the USA.
Vicente, C., Sabapathy, S., Formica, L., Maturi, B., Piwko, C., Cost-utility analysis of tocilizumab in the treatment of active systemic juvenile idiopathic arthritis, Value in Health, 16 (3), A225, 2013	Not the intervention of interest: The objective of this HE study is to determine the cost-effectiveness of tocilizumab with or without methotrexate compared to placebo with methotrexate for the treatment of juvenile idiopathic arthritis.
Wilson, E., Thalanany, M., Shepstone, L., Charlesworth, G., Poland, F., Harvey, I., Price, D., Reynolds, S., Mugford, M., Befriending carers of people living with dementia: a cost utility analysis, International Journal of Geriatric Psychiatry, 24, 610-23, 2009	Duplication (Charlesworth 2008).
Wittenberg, E., Prosser, L. A., Disutility of illness for caregivers and families: A systematic review of the literature, Pharmacoeconomics, 31, 489-500, 2013	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.
Wray, L. O., Shulan, M. D., Toseland, R. W., Freeman, K. E., Vasquez, B. E., Gao, J., The effect of telephone support groups on costs of care for veterans with dementia, Gerontologist, 50, 623-31, 2010	Population of interest: no adult carers.

Appendix L – Research recommendations

Research recommendations for review question: What are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordinating care, or self-care - has been (and is) currently provided in the UK?

No research recommendations were drafted for this review question.

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

Quotes extracted for review question: What are the views and experiences of adult carers, and of healthcare and related practitioners, regarding how information and advice about caring – including personal budgeting, legal issues, housing, planning and coordinating care, or self-care - has been (and is) currently provided in the UK?

Abley 2013

Being kept informed:

“He (GP) referred me to the memory loss clinic, when they were taking tests and what have you. Then it went on from there and I thought I’d go in and do a couple of weeks and then I’ll go, but it wasn’t like that. It took a long time.” (S3; P8) “You had better see this letter which I don’t like at all! That’s what I am supposed to be like at the moment, but some of those things are what (daughter) told them and they’re not quite accurate . . . I didn’t think I was as bad as that … Apparently I am half mad, half forgotten myself. I haven’t really . . . I do lose my words, but I always have done . . . ‘‘Euthymic in mood’’, I don’t know what it means” (S3; P3) “He asked mum would she like anybody else to have a copy of the letter and . . . it was really, did they want me to have a letter and mum couldn’t quite grasp that, so he had a try a couple of times . . . but she couldn’t quite work it out, what he was trying to say to her, but I mean she did say ‘‘yes’’ in the end . . . we got there eventually” (S2; C11) “I think the doctor in the hospital shown me the scan, and he said this is interesting. He said the right side of your brain has got a blockage and the blood is not going through. Do you understand that and it’s affecting the left side?” (S1; P4) “Quite disturbed because I can’t find anything more about it . . . I said I needed to speak to somebody, can you advise me where to go and she said well you are coming on the 17th, but that was two possibly three weeks ago, so I don’t know. I’m probably asking for the moon” (S2; P1).

Being told outcomes of the assessment: “It’s just not having a name! I just want a name you know what I mean? I just want to know why these things are happening to him and hopefully it’s not anything like Alzheimer’s and stuff. I just know, because he’s not pretending. I mean he’s not that sort, you know.” (S3; C5).

What do patients and carers find helpful: “knowing everything was better than not knowing’ and that this helped them to ‘plan and be aware of things that may happen” (S1; C6). “Well everything’s there (in the file) really. It’s quite a good folder that. I found it very good because it’s a decent size print . . . I found it very helpful.” (S1; C6)

Aldred 2005

Professional support: “No, because he doesn’t have the time. As he said, he would love to be able to do it with all his patients, but he just hasn’t got time, which they haven’t.”

Concerns for the future: “Reg: I’d like to know…whether it’s going to be a long job or a short job, you know.”

Alsaeed 2018

Suggestions to make enteral tube use easier for carers: “Have a good proactive and friendly enteral team -approachable and able to offer holistic practical advice to parents – without prejudice! We haven’t got that in our area anymore and it makes me more aware how much better it was years ago! I have 10 y of tube feeding experience -and have no one to call on for help! Terrifying and you just have to hope everything goes OK” (Carer 27)

Bajwah 2013

End-of-life information needs: “Empowering the patient with information about what their disease is (...) eh … what’s likely to happen and the treatment so you’re involving them very early on so they have a good understanding of the whole … (...) package of what’s wrong with them. I think that is the single most import thing that we can do (...) eh to help them to understand.” (ILD consultant). “I think sometimes the delivery is wrong (...) which could be a problem. Um what you don’t want to do is completely say ‘you’re going to die’ what you want to do is give them some hope …” (ILD CNS). “I think that the healthcare professionals involved tend to … (...) tell patients verbally a lot of information, but that’s not the same as having written information that they can take away, digest and share with their family … they’ll go and look it up on the internet and read lots of horror stories perhaps (...) and I think what we should be better at is providing our own … written information” (ILD consultant). “People often um have (1) um (4) you know attend clinics where there’s decisions taken about their management um but (2) maybe not um enough thought and enough time is given to giving them (1) information really about things.” (Palliative Care consultant).

Sources of information: “Myself and my husband got on the internet and found out ‘well actually life spans 5 years,’ she had no idea, no one’s even told her that (...) so we go ‘how do we tell her this’ (...) so actually the actual breaking the news was myself …” (Jane).

Beaver 2006

Cure: “I know breast cancer’s different to other cancers but I looked after my grandad who had cancer and had chemo, I knew what to expect.” (ID 12; daughter) “At the end of the day I want to know the prognosis, whether it’s good, bad or (pause), you get mixed signals from everyone. Obviously no-one can give you a guarantee but it would be beneficial for a carer in my opinion to have some idea, however bleak it is, even if it’s hedged with lots of what if’s or maybe’s and all that sort of thing. To have some idea what the prognosis is. If it’s good then obviously everyone’s overjoyed, if it’s not good then you can start preparing yourself ready to get the added strength to be able to give to somebody else. It’s not knowing, the prognosis is not spelt out to you.” (ID 2; husband)

Spread of disease: “They don’t take the family as a whole, the person that’s there at the time gets it. It’s hard to get all the information, we get what we can and share whatever we get.” (ID 19; daughter)

Treatment and side effects: “We’ve talked about it, we’ve talked about the fact that she’s now on this drug and she doesn’t know which one she’s on; she’s on this trial. I go with her to the hospital but nobody speaks to me.” (ID 43; sister) “I feel I still don’t know quite what the situation is actually, more to do with the removal of the lymph nodes. [name of patient] was told to avoid having her arm used for blood pressure etcetera and I think the GP didn’t see it as that serious.. so actually what is the effect of removal of the lymph nodes?” (ID 21; husband)

CSSIW 2017

[no participants quotes presented]

Garrett 2005

Processing information: "You don't realise the full implications and afterwards you think 'what did he mean"

Formats: "Drawings, pictures and scans definitely help the overview"

Long term: "I was glad to see him go back because he had been crying all the time"

Harding 2004

[no participants quotes presented]

Hughes 2005

Experiences of services: "I mean, if you're coming in blind and you have no idea, you know, where, where do you start? I mean, I was phoning up the – to start with – I was phoning up the town hall, you don't even know where to start as to who to phone up. Um, we were just sort of like plopped in, I didn't know where to get any help from at all." (Wife of man with MND, in her thirties, whose husband had been diagnosed for 8 months) "I don't know if you could present it [information] in any better way because you've either got the person who wants to throw themselves into it, find out as much information as possible, or the ostriches like me who just want to bury their heads in the sand. So, I mean, you've got to decide what sort of person you're dealing with really before you give them the information. So is this person the sort of person that could take the facts and reality, or is it best that we protect them perhaps?" (Wife of man with MND, in her thirties, whose husband had been diagnosed for 8 months)

McIlfatrick 2017

Information on HF prognostication and palliative care: "the heart attack happened and then a few days after that we were given a booklet, … He'd been released from hospital, we'd been told he'd heart failure and that was it." (ID 1122 current caregiver) "Nobody said, 'Your mother has progressive heart failure and is going to die'. I think consultants need to be honest, stop being afraid, if your loved one is dying, then say it." (ID 04 bereaved caregiver)

Knowledge on what to expect at the end of life: "said Is that a sign? Is he just going to get cold? We don't know what you are supposed to do." (ID 1034 current caregiver) "I am probably burying my head in the sand, I suppose. If I don't know, is it going to give him longer? Well, it is not really. It is just me, scared to know, probably more than anything." (ID 1138 current caregiver)

McKechnie 2014

[no participants quotes presented]

Moriarty 2015

Identifying and informing carers: "INTERVIEWER: If you wanted more information, would you look on the local authority website? RESPONDENT: I wouldn't now, because [daughter's] all right. It's when she's not all right that I need somebody. INTERVIEWER: Where would you look if you wanted information? RESPONDENT: I don't know. I just wouldn't think of it. I think I'm in too much of a state [then] to even use the computer to be honest." (Wilma, Carer 22)

Hidden carers and the role of specialist outreach: "trying to get [this carer] to understand the terminologies that are being used . . . is really difficult on the phone. Hence [I am] going to . . . take . . . leaflets that have information about the diagnosis that [her husband] has . . . I think I need to go and do a home visit and sit down and do a face-to-face and get her to understand a little bit." (Ifrah, Worker 20)

Newbronner 2011

[no participants quotes presented]

Pinfold 2005

Effective ways for professionals to involve carers in information sharing: “You felt like you were the dirt under their shoe.” (carer 1) “Unless the patient specifically states that they don’t want the carer involved then confidentiality shouldn’t exist. But by the same token the patient can’t expect the carer to care if they use this confidentiality term.” (Carer 14) “The professionals see all things as confidential so I always gain consent – even when information is not confidential it is the professionals who are deciding what information is shared not the service user. Lots of service users are encouraged not to share information with anyone.” (Carer 12) “The hurdle of conflict of interests between the patient and carer.” (Carer 17) “There’s always the two-way side of things. If it’s obtaining information I would test the water with regard to risk. I would hold back and find out whether they already know a bit of information. They may know information that helps to put the picture together. … I would have to ascertain what was hearsay.” (ASW/CPA manager) “Because of the nature of this illness many sufferers will live at home with their parents – we need to know exactly when our daughter is coming home – not two hours before when my husband is supposed to be at a conference and I am elsewhere………. if the carer is a carer and the sufferer is coming back to live with the carer then there is a need for basic information.” (Carer 11) “Eating disorder sufferers have a tendency to lie and distort the truth regarding food, it’s just the illness. If we had a diet plan we can see what she needs to eat and not necessary what she wants to eat.” (Carer 11) “I think there are times when you really want to tell relatives about the patient’s behaviour. Sometimes you have to say ‘I can’t let you go home unless I tell them this.” (Psychiatrist) “Ask right at the beginning. If the professional spends a bit of time with carers to explain CPA, confidentiality and all of that without the patient being there. To explain to the user and patient about consent forms. Very few users and carers know about consent forms.” (carer support worker) “Carers are actually the ones dealing with the person – they need to know what medication, side effects of this medication, how to deal with treatment and what the future holds. If you are the carer you need to know all of these key things - if you don’t you could do more harm then good.” (Carer 14) “Black carers also find it difficult to understand the information which they are given.” (Carer 12)

Strategies - professionals in adult services: “The direction I’m coming from is to share information. This concerns other disabilities too – cancer. The charade when partners don’t want each other to know. I get into a mess. I feel trapped. Therefore I think it’s better to start from information sharing, ideally in front of both parties. It’s tricky when you can’t do that.” (GP) “Build trust between everyone involved. It’s important to give carers information to enable, empower and support their relatives, and for carers to feel part of the team.” (carer support worker)

Principles - carers for older adults: “You know a lot of carers are old. Some are in their late eighties - they can’t cope with finding out all this information for themselves.” (Carer 6) “The core issue for the old or young is they still want to feel in control as much as possible. Sharing information can potentially threaten that. Professional carer partnerships can be very threatening if they are managed in a way that takes away patient choice and autonomy. But for people with psychotic/paranoid illness you are immediately in trouble.” (Psychiatrist) “I think that it is easier to talk and ask questions regarding my mother when she actually isn’t there. For example in the early stages when my mother was very much alert I didn’t want to ask questions like what will be the outcome of this disease be or that would have upset her.” (Carer 7) “Workshops between professionals, carers and service users around the issues involved in information sharing.” (Carer 9) “Explain clearly, repeat over and over, carers are older themselves and likely to forget.” (carer support worker)

Powell 2010

Access to online information: “I haven’t used the internet to get information or anything like that… because sometimes the more information you get, the more… anxieties and worries you get, whereas the less you know … I think you sort of cushion yourself. I dread to find out what … you know … I'm frightened to find out anything new, anything that will show me how hard things will get or can get. I don't think I want to know just yet."

Smith 2003

Making clinical judgements: "Sometimes, when you read side-effects and things like that, a lot of drugs will say, 'If you have breathing difficulties, consult your GP' and so on. Well, yes, she does have breathing difficulties, but if the GP has prescribed them, then I have to assure her that he knows all about your breathing difficulties or he wouldn't have given you them." (131) "You take the prescription in, you get the medication, you get it home, you open it up, and then you find something is different and, OK, I can phone up, but if I wasn't here, and she gets it home and it's something different É Until she sees me sheÕs worried about it: 'Should I take it? What if it makes me ill?' and the thought of that would do her far more harm than perhaps the medication would." (119)

Wingham 2015

Understanding and managing medicines: "I write out a checklist, so I know what tablets I've got to put in (pill box). . . if put like a chart in your manual as to what tablets have to be taken when." (P19)

Living with a cardiac device: "I think I put my head in the sand a bit when he first had the ICD. . ..because they were all talking about the shocks. And I thought I don't know what to do; what shall I do if he has a shock?" (P15)

Supporting depression management: "One weekend, he said, 'Oh, I can't stand this any longer. They've got to do something else.' He started talking about finishing it. And then we went to the doctors and he was put on anti-depressants, and it's helped." (P4)

Woolham 2018

Needs for information: "Direct Payments, which is what my mother has, was confusing at first, as in the explanation and what exactly it could be used for, when and how it would be paid – it's offered under enormous stress (for the family) and so the info (information) is difficult to digest. Far too many 'experts' with a hand in the pie, in my opinion – lots of facets picked up by different people, honestly, it's a nightmare!" (Survey respondent)

Wright 2006

[no participants quotes presented]