LA TROBE UNIVERSITY

AACQA literature review: Choice and quality in community care

Final report

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Executive summary

Introduction

The purpose of this literature review is to inform the development of a Consumer Experience Report (CER) for home-based and community-based aged care services, similar to the one recently introduced by the Australian Aged Care Quality Agency (AACQA) in residential aged care.

The scope of this consultancy work is a rapid review of available literature and expert opinion to assist in identifying:

1. Key drivers of choice, in terms of expectations of the characteristics sought by consumers and potential customers when looking for a home- or community-based aged care service.
2. Key domains that capture consumer perceptions and, or experience, of the quality of services and care in home- or community-based aged care.

Methods

Our approach was to conduct **two** literature reviews for the project, one on key drivers of choice (Q1) and the other on key domains that capture consumer perceptions or experience of quality of services and care (Q2).

Our methodology was a rapid evidence review. To meet the requirements of the project as efficiently as possible, we planned to:

- Conduct a review that is systematic and methodologically justifiable and that relies on specificity (rather than sensitivity) to deliver outputs within a short time frame.
- Use La Trobe library expertise to assist with developing our search strategies.
- Use the Covidence software package to assist with managing the literature identified.
- Limit searches to literature published in the last 10 years (since 2007), from countries with comparable systems of aged care.

For both reviews, we systematically searched Medline and EMBASE databases and supplemented these searches with hand-searches in; CINAHL, Scopus, PsychINFO, and Web of Science; Government reports; and other grey literature. Hand-searches did not attempt to identify and download all potentially relevant articles, but focused on identifying articles likely to be relevant to the research questions. A combination of Medline searching and hand-searching has been recommended following studies comparing their results,[1] despite the limitation that hand-searches are not replicable in the way that full systematic searches are.

Search terms for searching in all databases included combinations of terms designed to elicit home-based or community-based aged care and choice or quality.

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[1] Langham, J., Thompson, E., & Rowan, K. (1999). Identification of Randomized Controlled Trials from the emergency medicine literature: Comparison of hand searching versus MEDLINE searching. *Annals of Emergency Medicine, 34*, 25-34.

Results

The search strategy for Q1 led to the following:

- Identified articles: 205 from Medline/EMBASE + 18 from CINAHL + 11 from the grey literature
- Title and Abstract screening: 221 articles + 11 from grey literature
- Full Text screening: 44 articles/reports
- Included studies: 21 articles/reports.

The search strategy for Q2 led to the following:

- Identified articles: 167 from Medline/EMBASE + 22 from CINAHL + 4 from the grey literature
- Title and Abstract screening: 166 articles + 4 from grey literature
- Full Text screening: 40 articles/reports
- Included studies: 19 articles/reports.

Findings

The themes identified by this literature review fall into two broad categories: how consumers choose to spend their budgets; and what consumers value in their packaged home- and community-based services. It was not possible to differentiate between home-based and community-based services, as they were inextricably linked.

While some older consumers feel free to use their packages in non-traditional or imaginative ways, most consumers still choose traditional home care, personal support services, or equipment within an aged care package or similar services. The drivers underlying this choice are likely to be consumers' needs or unmet needs in the areas of personal support with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), as well as a relatively high degree of familiarity with these service types. Though recognised as important, social needs and respite needs appear to take second place in the context of having a limited budget.

The top 8 themes identified by the literature reviews are:

1. ***Control*** – Most consumers want to actively participate in the decision-making for their care services, and have the freedom to choose services based on their physical and mental needs. The drivers underlying this choice are likely to be consumers' needs or unmet needs in the areas of personal support with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), as well as a relatively high degree of familiarity with these service types. Consumers also value as little bureaucracy and red tape as possible
2. ***Interpersonal interaction*** – Consumers want to receive services from someone they know, and enough continuity to build rapport and a genuine relationship. In many cases, consumers' only regular social contact with their carer, and thus it is carers should show respect, sensitivity and kindness, as well as being competent.
3. ***Flexibility*** - Consumers want the delivery of their care to be flexible, in terms of choice of service provider, choice of daily activities, people employed to assist, and adjustment over time according to their changing physical and mental needs. They also want the capacity to include family members in the package and to "save" funds for a special purpose.
4. ***Local residence*** – Consumers want to be able to receive high quality care locally or at home, and not have to move away from their friends and family. This is particularly an issue for Indigenous consumers and those living in remote areas.
5. ***Affordability*** – Consumers want their services to be affordable and subsidised where possible.

6. ***Administrative and financial literacy*** – Consumers would benefit from information on and assistance in understanding their care service entitlements, and receiving support with the financial planning and management of their services.
7. ***Safety*** – Consumers want to feel protected in their homes and local communities, and to know that both general and emergency assistance is readily available.
8. ***Timeliness of service care provision*** – Consumers prefer to receive information, their care entitlements and services in a timely manner.

Introduction

The purpose of this literature review is to inform the development of a Consumer Experience Report (CER) for home-based and community-based aged care services, similar to the one recently introduced by the Australian Aged Care Quality Agency (AACQA) in residential aged care.

The scope of this consultancy work is a rapid review of available literature and expert opinion to assist in identifying:

- Key drivers of choice, in terms of expectations of the characteristics sought by consumers and potential customers when looking for a home- or community-based aged care service.
- Key domains that capture consumer perceptions and, or experience, of the quality of services and care in home- or community-based aged care.

The current report sets out the methods and results for both literature reviews. Features of this review include:

- Inclusion of Australian and international academic and grey literature from 2007-2017.
- A focus on countries with systems of providing consumer directed home- and community-based care to older people that are broadly alike that operating in Australia.

The researchers were asked to identify the top 8 themes in each category.

The main project deliverables include:

- A teleconference and an initial report on progress due by 31 January 2018. (This was delivered in the form of an interim report.)
- A final report addressing the drivers, domains, and themes to be completed by 28 February 2018.

La Trobe University submitted a tender on 11 December 2017, and were successful in securing the contract for this work.

Project team

The project team was led by Professor Yvonne Wells, Australian Institute for Primary Care & Ageing (AIPCA), located within the School of Nursing and Midwifery at La Trobe. She had the main responsibility for managing the project and communicating with AACQA.

The reference group (Professor Richard Gray and Associate Professor Deirdre Fetherstonhaugh) responded to major reports to ensure that key issues were identified by the literature review.

Stav Hillel, La Trobe library, provided support and expertise in designing the literature search strategy.

The team of research assistants was led by Dr Nikk Hunter, who had experience in using Covidence. The other research assistants were post-graduate students in the School of Nursing and Midwifery, with various levels of experience in literature review.

Methods

Our methodology is a rapid evidence review. To meet the requirements of the project as efficiently as possible, we planned to:

- Conduct a review that is systematic and methodologically justifiable and that relies on specificity (rather than sensitivity) to deliver outputs within a short time frame.
- Use La Trobe library expertise to assist with developing our search strategies.
- Use the Covidence software package to assist with managing the literature identified.

Our approach is to conduct **two** literature reviews for the project, one on key drivers of choice and the other on key domains that capture consumer perceptions or experience of quality of services and care. Where possible, we intended to divide results into home-based care and community-based care services at the analysis stage and to highlight any research that focuses on consumer-directed care or personal budgets. We conceptualised home-based and community-based care as follows:

- Home-based care covers personal care services (bathing, dressing) and domestic assistance.
- Community-based care covers assistance with services that are not home-based, such as assistance with shopping and banking, and centre-based day care and respite.
- Respite services for carers is also be included (home-based and centre-based only), but not services that focus specifically on carers only (e.g., educational services, counselling).

Although the questions posed by this review were divided into results relevant for home-based aged-care and community-based aged care separately, we combined these service types in conducting our literature reviews. This is because in Australian and overseas literature, as anticipated, the division between home-based and community-based aged care services was not clear.

In Australia, prior to the introduction of the Commonwealth Home Support Programme and Home Care Packages, support was provided to older people living at home through the Home and Community Care (HACC) Program and packaged care services that did not clearly differentiate between home-based and community-based services. The same providers could deliver one or a combination of these, and consumers' perceptions of quality could apply to the whole array of services they received. Further, the term "community care" is often used to cover both home-based and community-based services, and as a term to contrast with residential care. In the UK, services are divided into health care and social care: social care includes all the services that we would normally think of as home-based or community-based, except for home nursing. In the US, the concept of long-term care is used to cover services provided in both residential care and home/community settings.

Project plan: Rapid review

This project was a rapid review, rather than a thorough exploration of the literature. A rapid review is not a full systematic review, but strategic decision-making in the planning phase sets out parameters that limit the review to project what is manageable within set timelines.

A commonly-used strategy to limit the scope of literature reviews is to examine only peer-reviewed literature. In this case, we believed that this would reduce the scope of the review too far, and that the grey literature should also be scanned. Similarly, while many rapid reviews rely only on quantitative studies, we also included qualitative research, because of the nature of the research questions—studies of perceptions and experiences may rely on qualitative methodologies. Observations from qualitative studies individually have limited generalisability or transferability. However, when many qualitative studies have similar results, more confidence can be placed in their transferability.

The review is constrained by:

a. The databases searched.
b. The extent of the additional "grey" literature searched. We planned to search only for major reports readily available on-line (i.e., government reports or major evaluation reports identified using a search engine such as Google).

Project plan: Search strategy

The questions posed for this literature review do not lend themselves to a systematic review framework. Nevertheless, the following table sets out a Population / Intervention / Comparison / Outcomes (PICO) framework for the review questions. A PICO framework is helpful in identifying the search terms to be used and inclusion and exclusion criteria. The PICOs for the current project were:

QUESTION	POPULATION	INTERVENTION / EXPOSURE	COMPARISON	OUTCOMES
QUESTION 1	People aged 65+ years (50+ if Indigenous)	Experience of making choices in seeking a home-based or community-based aged care service	Not applicable	Drivers of choice in services
QUESTION 2	People aged 65+ years (50+ if Indigenous)	Experience of receiving home-based or community-based aged care services	Not applicable	Perceptions of quality of services

The study protocol was not registered due to time constraints.

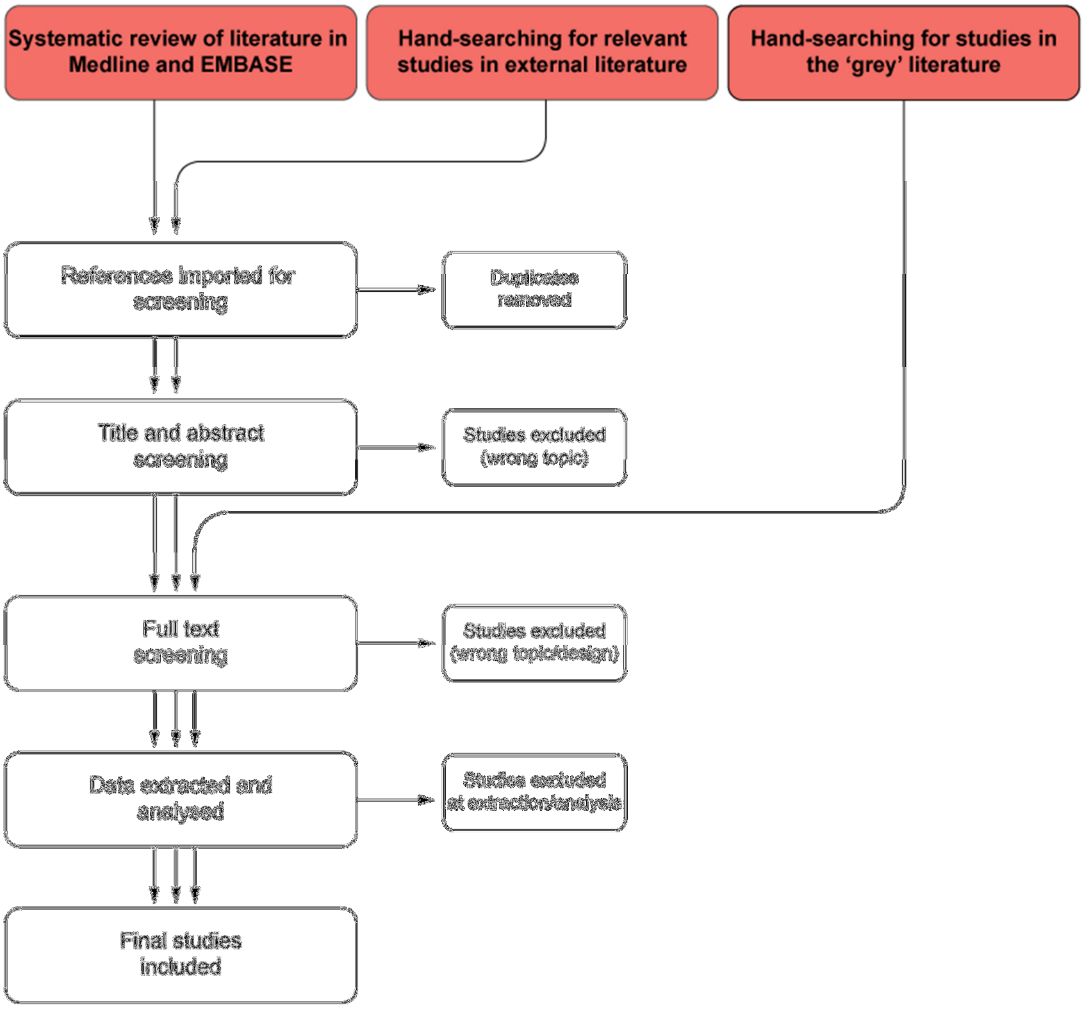
Our original intention was to include Medline and CINAHL as sources of literature, supplemented by grey literature. However, we found that:

1. The literature from Medline by itself did not identify sufficient studies relevant to the research question, and failed to identify articles that had been opportunistically identified by the research team in other databases.
2. The systematic literature search in CINAHL identified too many studies. Further, CINAHL limited transfer to EndNote to 10 articles at a time. Including references from CINAHL was not a good use of staff time in the context of completing a rapid review.

Our compromise solution to this dilemma was to supplement Medline with EMBASE (to identify any relevant European literature) and to rely on limited hand-searching of articles across several databases (CINAHL, Scopus, PsychINFO, Web of Science) using key search terms related to community- and home-based services that use personal budgets with older people. This hand-searching was non-systematic, which limits the replicability of the search.

Results were illustrated using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram. The diagram depicts the flow of information through the different phases of a systematic review. It maps out the number of records identified, included and excluded, and the reasons for exclusions. Our strategy may be represented thus:

PRISMA diagram (search plan)



Process for managing the systematic literature review

The process used to manage the systematic literature search in Medline and EMBASE was as follows:

- Library staff assisted with running the searches and uploading them to Covidence (via EndNote).
- Two team members independently screened titles and abstracts against the inclusion criteria.
- Disagreements were resolved by a third staff member.
- Articles that passed this stage were retrieved for full text screening.
- Two team members independently conducted full text screening and disagreements were resolved by a third member.
- Team members extracted the data. Further studies were excluded at this stage if they did not address the research question (suggested by a team member and checked by the project lead).

- Team members conducted a risk of bias assessment, using the Joanna Briggs Initiative (JBI) Critical Appraisal Tool appropriate to the study design (Appendices 1-7). For this review, most articles were assessed using the Critical Appraisal Checklist for Analytical Cross-Sectional Studies.[2]
- The project lead organised the resulting literature and compiled reports, with feedback from other members of the project team and the reference group.

Search terms for Q1

The search terms specifically focused on research on aged care services that involved personal budgets. The argument behind this decision was that the term “drivers” of choice implies choices made within constraints.

Ovid Technologies, Inc. Email Service------------------------------Search for: limit 5 to (english language and yr="2007 - 2017" and ("middle aged (45 plus years)" or "all aged (65 and over)" or "aged (80 and over)"))

Database: Ovid MEDLINE Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present> Search Strategy:

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1. ('home based aged care' or 'home based aged service' or 'home care package' or 'home service package' or 'care package home' or 'service package home' or 'aged Home care package' or 'home aged care package' or 'aged home service package' or 'home aged service package' or 'aged care package at home' or 'aged service package at home' or 'home health care service' or 'home health care' or 'home aged care service' or 'home aged care' or 'health care service at home' or 'health care at home' or 'aged care service at home' or 'aged care at home' or 'community based aged care' or 'community based aged service' or 'community care package' or 'community service package' or 'aged community care package' or 'community aged care package' or 'aged community service package' or 'community aged service package' or 'community health care service' or 'community health care' or 'community aged care service' or 'community aged care' or 'consumer directed care' or 'individual budget* or 'personal budget*' or 'personal assistance budget*' or 'cash payment* for care' or 'home care service voucher*' or 'consumer directed personal assistance service*' or 'cash counselling' or 'individual budget*' or 'home care package* program*' or 'self directed support').mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (3647)
2. (driver* or factor* or caus* or determinant* or motiv* or 'driver* of choice' or 'driver* of option*' or 'driver* of select*' or 'driver* of choos*' or 'factor* of choice' or 'factor* of option*' or 'factor* of select*' or 'factor* of choos*' or 'cause* of choice' or 'cause* of option*' or 'cause* of select*' or 'cause* of choos*' or 'determinant* of choice' or 'determinant* of option*' or 'determinant* of select*' or 'determinant* of choos*' or 'motiv* of choice' or 'motiv* of option*' or 'motiv* of select*' or 'motiv* of choos*' or 'motiv* for choice' or 'motiv* for option*' or 'motiv* for select*' or 'motiv* for choos*').mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (6808129)
3. Home Care Services/ or Health Services for the Aged/ (45793)
4. 1 and 3 (1686)
5. 2 and 4 (319)
6. limit 5 to (english language and yr="2007 - 2017" and ("middle aged (45 plus years)" or "all aged (65 and over)" or "aged (80 and over)")) (89)

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[2] Available from: http://joannabriggs.org/research/critical-appraisal-tools.html

Inclusion criteria specified in Covidence were:

- About drivers of choice in home-based or community-based aged care services (social care services in UK; long-term services and supports in the US)
- Settings in which choice is relevant (packaged care or home care packages [in Australia] / consumer directed care or CDC / personal budgets / cash for care)
- In English
- From countries with comparable systems of aged care
- Participants (consumers) aged 50 or over
- Published between 2007 and 2017
- Quantitative or qualitative

Exclusion criteria were:

- Drivers of choice in residential care facilities / nursing homes
- Drivers of choice in retirement villages
- Not in English
- From countries with under-developed systems of community/home-based aged care
- Participants are "young" (most aged 64 years or younger)
- Choices made by family members (not the older person themselves)

Search terms for Q2

The search terms for our review specifically focused on identifying what elderly consumers value in terms of how their care services (home- or community-based) settings are provided.

Ovid Technologies, Inc. Email Service------------------------------Search for: limit 5 to (english language and yr="2007 - 2017" and ("middle aged (45 plus years)" or "all aged (65 and over)" or "aged (80 and over)"))Results: 73

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present> Search Strategy:

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1. ('home based aged care' or 'home based aged service' or 'home care package' or 'home service package' or 'care package home' or 'service package home' or 'aged Home care package' or 'home aged care package' or 'aged home service package' or 'home aged service package' or 'aged care package at home' or 'aged service package at home' or 'home health care service' or 'home health care' or 'home aged care service' or 'home aged care' or 'health care service at home' or 'health care at home' or 'aged care service at home' or 'aged care at home' or 'community based aged care' or 'community based aged service' or 'community care package' or 'community service package' or 'aged community care package' or 'community aged care package' or 'aged community service package' or 'community aged service package' or 'community health care service' or 'community health care' or 'community aged care service' or 'community aged care').mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (3682)
2. Home Care Services/ or Health Services for the Aged/ (48473)
3. 1 and 2 (1739)

4. (quality or standard or excellence or value or worth or 'perception* of quality' or 'perceive* of quality' or 'attitude* of quality' or 'impression* of quality' or 'understand* of quality' or 'evaluat* of quality' or 'perception* of excellence' or 'perceive* of excellence' or 'attitude* of excellence' or 'impression* of excellence' or 'understand* of excellence' or 'evaluat* of excellence' or 'perception* of value' or 'perceive* of value' or 'attitude* of value' or 'impression* of value' or 'understand* of value' or 'evaluat* of value' or 'perception* of worth' or 'perceive* of worth' or 'attitude* of worth' or 'impression* of worth' or 'understand* of worth' or 'evaluat* of worth').mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2734398)
5. 3 and 4 (412)
6. limit 5 to (english language and yr="2007 - 2017" and ("middle aged (45 plus years)" or "all aged (65 and over)" or "aged (80 and over)")) (73)

Inclusion criteria specified in Covidence were:

- About perceptions of quality in home-based or community-based aged care services (social care services in UK; long-term services and supports in the US)
- Settings in which choice is relevant (packaged care or home care packages / consumer directed care or CDC / personal budgets / cash for care / cash and counselling)
- In English
- From countries with comparable systems of aged care
- Participants (consumers) aged 50 or over
- Published between 2007 and 2017
- Quantitative or qualitative

Exclusion criteria were:

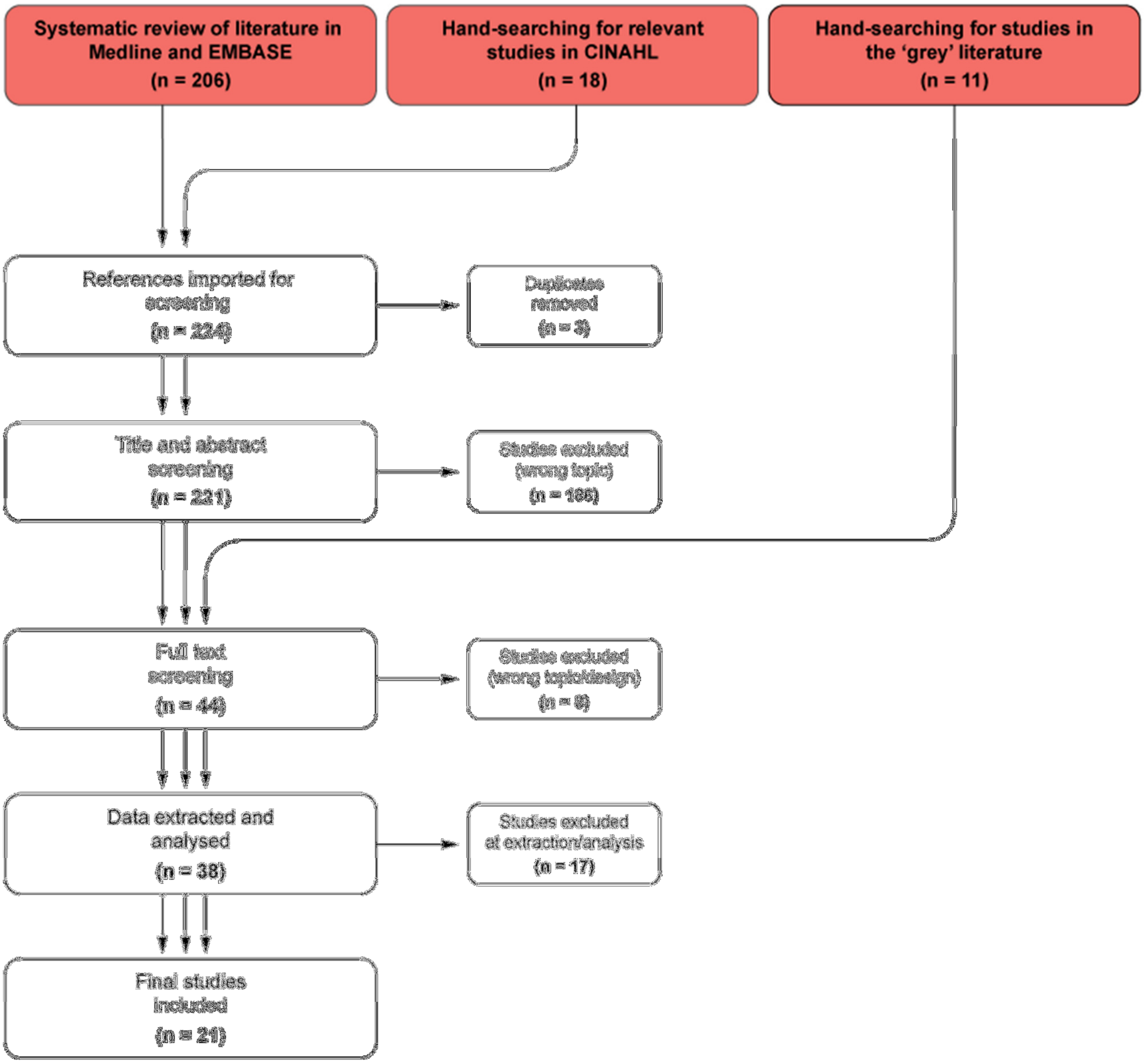
- Perceptions of quality in residential care facilities / nursing homes / retirement villages
- Perceptions of quality of care delivered by hospitals or GPs
- Not in English
- From countries with under-developed systems of community/home-based aged care
- Participants are "young" (most aged 64 years or younger)
- Perceptions of family members (not the older person themselves)

Results

The search strategy for Q1 led to the following:

- Identified articles: 205 from Medline/EMBASE + 18 from hand-searching other databases + 11 from the grey literature
- Title and Abstract screening: 221 articles + 11 from grey literature
- Full Text screening: 44 articles/reports
- Included studies: 21 articles/reports (4 from the systematic review of Medline and EMBASE, 12 from hand-searching other databases, including CINAHL, and 12 from hand-searching the grey literature).

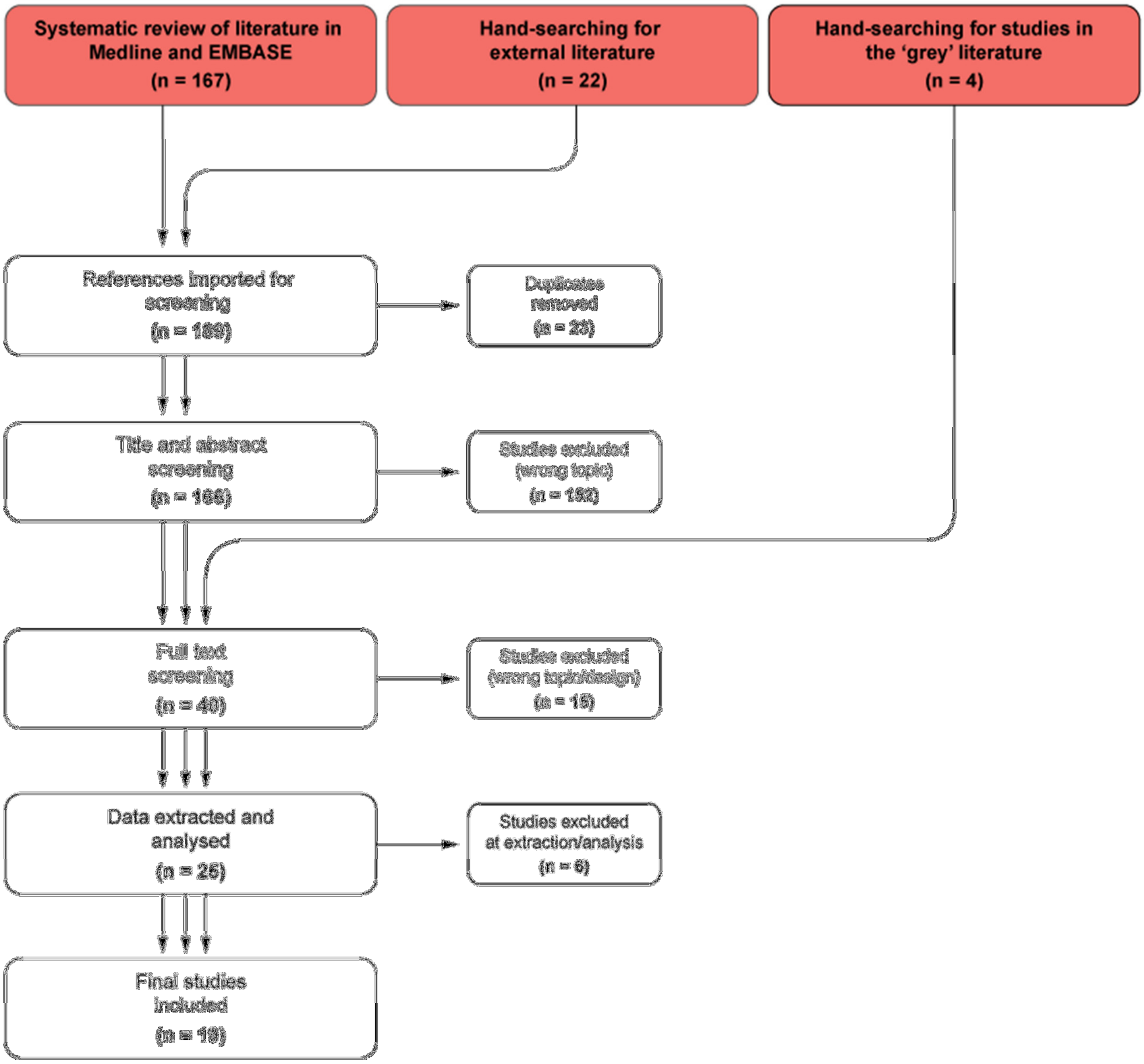
PRISMA diagram for Q1



The search strategy for Q2 led to the following:

- Identified articles: 167 from Medline/EMBASE + 22 from hand-searching other databases + 4 from the grey literature
- Title and Abstract screening: 166 articles + 4 from grey literature
- Full Text screening: 40 articles/reports
- Included studies: 19 articles/reports (2 from the systematic review of Medline and EMBASE, 12 from hand-searching other databases, including CINAHL, and 4 from hand-searching the grey literature).

PRISMA diagram for Q2



Where previous reviews of the same topic have been published and are identified in a review, the usual strategy is to include the reviews, assuming they have identified all previous studies, and any extra literature published since the most recent review. The current search identified several relevant reviews of the literature:

- Low et al. (2011), which includes literature published from 1994 to 2009 and aims to evaluate the outcomes of case managed, integrated or consumer-directed home and community care services for older people.
- Age UK (2013). No details about the date range are provided in their report, but the chapter summarises research findings on what older people expect from their care and support, and their purchasing habits.
- Ottman et al. (2013), which features literature published from 1992 to 2011 and focuses on user preferences for and satisfaction with services associated with a CDC approach.
- Zamfir (2013), which includes literature published from 1995 to 2012 and explores effectiveness of personalisation through personal budgets and self-directed support.
- Manthorpe et al. (2014), which includes literature published up to 2012 and focuses on the evidence base: to inform efforts to reduce red tape for people choosing their own social care and support; about leadership and training to support changes to ‘self-directed support’; and the use of specific transitional funding to ease the implementation process.

None of these previous reviews has quite the same focus as the current review. Hence, the strategy undertaken in the current review was to:

- Scan reference lists of the previous reviews were scanned for titles of articles or reports that might directly inform the current review.
- Rely on previous reviews to have identified and described the literature published previously and to have summarised it accurately.
- Focus on locating articles and reports missing from the reviews and/or published since 2012.

The 21 studies from Q1 and the 19 studies from Q2 are presented in six tables below, by question (Q1 or Q2) and by source: (a) systematic literature review, (b) hand-searching other literature, and (c) hand-searching grey literature.

Q1: Summary tables of included studies 1: Systematic literature search

Author (date)	Sample	Design	Measures	Results
Davitt & Kaye (2010) USA	Age: Medicare Beneficiaries 65 years and older Gender: Male and Female Analyses of home health care use of 2,437 users, before and after introduction of an Interim Payment System (IPS). Medicare Current Beneficiary Survey (MCBS), 1998.	MCBS Sample is a stratified multistage area probability design Secondary data analysis.	Race Health status Activities of Daily Living (ADLs) Other predisposing and enabling control variables were: ▪ patient age ▪ number of caregivers ▪ years of education ▪ gender ▪ Medicaid eligibility ▪ Census region ▪ Rural residence ▪ Marital status ▪ Supplemental insurance coverage	Between 1996 and 1998 the total number of health users in the fee for service decreased significantly -12%. Total visits decreased by 38%. Home health care experienced the greatest decreases during 1996-1998 post the 1997 Balanced Budget Act (BBA). Skilled nursing facility (SNF) care days per user also decreased -19.49%, P<.05 while SNF stays increased 26% p<.01 The number of White users decreased (18%, $\square^2$ = 4.3, p = .038), whereas those with other racial backgrounds increased (69%, $\square^2$= 6.6, p = .01). This study suggests that Medicare beneficiaries above the poverty line, but with limited financial and social resources, may have difficulty obtaining needed home health care if they cannot afford to purchase it privately.
Kaambwa et al. (2015) Australia	117 study participants 87 Consumers 30 Informal Carers Mean age of consumers 80 years The mean age of informal carers 74 years 86% of informal carers lived with their spouse English-speaking Cognitively intact	Survey (face-to-face) Cohort study Discrete Choice Experiment (DCE) approach Comparison on Quality of life with Australian norms	Demographics Quality of life: EQ-5D (EuroQoL) Adult Social Care Outcomes Toolkit (ASCOT) Quality of life; Older People's Quality of Life (OPQoL) Consumer Experience Scale (CES) Importance to Community Aged Care Services (CACS) consumers and informal (family) carers of CACS consumers of 6 features of consumer directed care (CDC)	All study participants preferred a CDC approach that provided: ▪ Flexibility to save unused funds from a CACS package for future use ▪ Flexible support workers in terms of changing activities within their CACS care plan ▪ Choice of support workers providing day-to day CACS Consumers desire personal choices; they do not wish to be constricted by agencies, activities, or set care workers. Individuals want to be able to choose services from multiple service providers. Clients prefer regular scheduled contact with service

Author (date)	Sample	Design	Measures	Results
			▪ Choice of service provider(s) ▪ Budget Management ▪ Saving unused/unspent funds ▪ Choice of support/care worker(s) ▪ Support worker flexibility ▪ Level of contact with service coordinator	coordinators. Notably, most consumers (87%) and half of the informal carers had not heard of CDC. Consumers and informal caregivers felt that community aged care packages contribute substantially to a consumer's QoL but decisions about the type of services in the care package should be jointly made by the service provider (preferably a service coordinator) and the consumer and/or their informal carer. Some consumers preferred to delegate decision-making capacity to the provider. This preference was more common among those with fewer academic qualifications. Most participants said consumers should not be restricted to services covered within their budget and should be able to purchase additional services if they have the funds.
Low et al. (2011) Australia	Older persons (N=55) Carers (N=37) *Inclusion criteria* Aged 65 years and older; the ability to provide informed consent or carer providing proxy consent; approval by ACAT as eligible for Australian home-based care packages (CACP, EACH or EACH-D); and ability of participant or carer to complete interviews in English	Cross-sectional, longitudinal Data from: Community care for the Elderly: Needs and Service Use Study (CENSUS): on recipients of home care packages in Illawarra/Shoalhaven region of NSW	*Sociodemographic*: age, gender, marital status, language spoken at home, previous occupation and education for both participants and carers. *Care needs*: **Care Needs Assessment Package (V2)**. Needs in eight domains of functioning (mobility, health, nutrition, self-care and toileting, mental health, social behaviour/community living, life skills/opportunities, and maintaining the home), coded as not identified, met or unmet. Carer needs identified with 11-item scale. *Care services:* Number and hours of the participants' current formal services (provided by government or private agencies). Hours of informal care. *Satisfaction with care*: modified 22-	Over the 12-month study, 30/55 participants were offered a package, 18 were not offered a home care package, one participant died and six were admitted to a nursing home before receipt of a package. Factors associated with being offered a home care package were being female and higher baseline QOL but not needs, unmet needs, neuropsychological symptoms, cognitive status or carer burden. Between carers of participants who were or were not offered a package, there were no demographic differences, including gender or whether the carer was co-resident with the participant. Receiving a home care package did not affect the participants' level of needs, unmet care needs, or QOL over time but was associated with decreased carer burden.

Author (date)	Sample	Design	Measures	Results
			item questionnaire devised for carers of stroke patients (range 0–88). Carers also rated satisfaction. Cognitive status: Rated by nurse on the Global Deterioration Scale (GDS) *Quality of life*: 13-item Quality of Life in Alzheimer's Disease. Symptoms: Carers rated participants on the 12-item **Neuropsychiatric Inventory**. Carer Burden: **Zarit Burden Interview**.	
Ottmann et al. (2013) Australia	To systematically establish an evidence base of user preferences for and satisfaction with services associated with consumer-directed care programmes for older people ▪ Review includes literature published from January 1992 to August 2011. ▪ **N=277** references identified. Of these **N=17** met selection criteria and were reviewed.	Literature review	The identified studies are categorized based on the global CDC scheme of interest: Consumer-Directed Personal Assistance Services (CDPAS; US); Cash for Counselling (US) and Individual Budgets (UK).	*Consumer-Directed Personal Assistance Services (CDPAS)* Users report no difference between CDC and agency-directed care on measures of satisfaction with services, unmet needs and perceived safety and security in the home. *Cash for Counselling* This scheme refers to programs in the US states of Arkansas, New Jersey and Florida, which succeeded CDPAS programs. The programs were designed to provide counselling assistance to support decision making, planning and fund management and targeted people living with disabilities including elderly people. Participants indicated preferences for greater participation in their care and related decisions, whereas others expressed satisfaction with their existing agency-directed services. Age variations were an important determinant of interest in Cash-for-Care schemes. Also, people with a more substantial support budget (>US$3000) were more interested in the self-direction option. Greater support and training with administrative and accounting tasks was associated with older people's

Author (date)	Sample	Design	Measures	Results
				interest in CDC in these programmes. *Individual budgets* This program is the most recent generation of consumer-directed social care models in the UK. Offers flexible roles in self-assessment, self-definition of needs and desired outcomes; and increased opportunities for users to decide how they want those outcomes to be achieved. Survey findings indicated that those people participating in the Individual Budgets program reported better service satisfaction outcomes and sense of control over their lives than those using agency-directed care. However, many older people did not want the additional responsibility of planning and managing their own support and managing the risk associated with directly employing support staff. The review calls for the development of consumer-directed care programmes offering a broad range of options that allow for personalization and greater control over services without necessarily transferring the responsibility for administrative responsibilities to service users. Review findings suggest that consumer-directed care approaches have the potential to empower older people.

Q1: Summary tables of included studies 2: Hand-searching, other databases

Author (date)	Sample	Design	Measures	Results
Day et al. (2017) Australia	5 older people. 81 to 91 years.	Qualitative study. One service provider of home care packages (HCP) in regional New South Wales. In-depth interviews (face-to-face) just before CDC was introduced in the service.	NA Used palm card phrases with words (as set out below) and participants could answer positive or negative emotion words for each phrase word: The following questions guided analysis of the data: 1. What is the consumer saying about this moment in their experience? 2. What really matters to this consumer? 3. What is the consumer saying could change and how? 4. What opportunities were expressed for use of technology?	The four emergent themes were: seeking quality and reciprocity in carer relationships; patchworking services; the waiting game; and technology with utility. Respondents had concerns about whether they would like the carer, if the carer would like them, or whether the carer would appreciate their personal goals to maintain their preferences. Participants preferred carers who were accommodating, proactive and adaptable to their changing circumstances and needs. All participants sought good relationships with their care coordinator, and they wanted frequent contact with them. Patchworking services: There were limitations in the nature and range of support offered by service providers. Participants compensated by acquiring other supports outside the system. The waiting game: Participants could wait excessive lengths of time for the home care package (HCP). This created problems with the continuity of care and support. Technology with utility: Older participants were using a range of digital technologies to meet communication, security and safety needs. However, participants did not use technology for communication with HCP. This represents an opportunity for improvement.
Gill et al. (2017) Australia	N= 25 consumers (15 female); aged 51- 80+ N= 18 staff (17 female); all < 61yrs N= 14 carers (10 female); all > 50yrs	Qualitative phase of mixed methods, sequential study Semi-structured interviews with professionals, carers and consumers;	NA The study aimed to identify the shared issues and challenges being experienced by staff, their clients and informal carers, with the introduction of Consumer Directed Care (CDC).	Four key themes emerged: 1. Culture. Existing organizational culture may affect consumer activity by way of: (formal) carer changes and associated lack of rapport between carer and consumer; lack of flexibility on part of organization in terms of adjusting services according to changing needs 2. Change: Role change on part of consumer was welcome in its autonomy but not supported with

Author (date)	Sample	Design	Measures	Results
				sufficient, relevant, service specific information. Financial literacy also relevant here 3. Systems: Operational systems often precluded optimal, desired access to services- location of services and frequency of visits not sufficient for some. Third party contracting and associated poor quality staff in context of poor engagement with third party agency. In conjunction with potential additional costs from over prescriptive service agreements. 4 resources: Adequate allocation of appropriate resources (staff etc.) to services to ensure full individualization with associated rapport between consumer and carer.
Harrison et al. (2014) Australia	55 community-dwelling older adults and carers >65 years. Cross-sectional data from the Community care for the Elderly: Needs and Service Use Study (CENSUS)	Quantitative study (Cross-sectional study). Government-subsidised community care services. Interviews	For Needs: 76 items from Care Needs Assessment Package (Version-2). Needs were measured in eight domains of functioning. Coded as not identified, met or unmet. For Expectation of care of the pending packages of community care services Participants were asked to describe the three most important things they expected to achieve with the help of the package.	Approximately 20% of needs were unmet. Life skills/opportunities and mental health had comparatively high proportions of unmet needs. Self-care/toileting had the lowest proportion (13%) of unmet needs of the 8 domains. **EXPECTATIONS OF CARE** The most common expectations were for domestic support (64%), personal care (33%), transport (22%) and shopping (15%). Assistance with life skills/opportunity, mental health, and social behaviour/community living were not mentioned by any participants. Participants who held an expectation of domestic support had higher unmet needs for maintaining the home than those who did not. Those who held an expectation of personal care had higher unmet needs for self-care. Those who held expectations of transport, socialisation or shopping did not differ on unmet needs from those who did not. Participants holding an expectation of respite had higher unmet mobility, social and life skill needs than others

Author (date)	Sample	Design	Measures	Results
				along with lower, and received four times as much informal help.
Low et al. (2011) Australia	Search Yield 34,816 articles 163 Full text articles	Systematic Review from 1994 –May 2009 35 papers included in the review	Inclusion Criteria for article review ▪ In English ▪ Evaluating the delivery of case managed, integrated or Consumer Directed Care (CDC) ▪ Sample: Community dwelling with majority or sample 65+years 4. Dementia diagnosis excluded	Different models of home and community care have differing outcomes depending on their focus. Randomized controlled trials showed -Case management improves function and appropriate use of medications, increases the use of community services and reduces nursing home admission Non Randomized controlled trials showed that integrated care increases service use, but randomized trials reported that integrated care does not improve clinical outcomes. CDC – appears to increase satisfaction with care and community service use, but has little effect on clinical outcomes Ultimately rather than asking which model is the best for improving outcomes, we should be asking how to combine the successful features of all three models to maximize outcomes.
Manthorpe et al. (2014) Scotland	Search of Social care on line 564 items containing Personal budgets 332 Items containing IBs 398 containing SDS (many duplicates)	Scoping Literature review Exploratory approach	Themes: Barriers to and facilitators of implementing SDS	Discussion on Self-directed support (SDS) being an innovation rather than the mainstream Little evidence regarding how to sustain the changes and demands of SDS, highlighted the importance to have user and peer support as well as professional and managerial leadership to promote change. Policy makers have a lack of understanding of SDS needs. National in addition to local attention may be required Leadership is a necessity for major change Research in this area should be utilized by policy makers.
McCaffrey et al. (2015) Australia	Older people and informal carers recruited separately through providers Older people 65+ years Carers: 18+years	Discrete choice experiment (DCE) Qualitative semi-structured interviews	Aim: Determine what features (attributes) of consumer-directed (CDC), home based support services are important to older people and their informal carers	Eight themes initially identified 1. Information and knowledge 2. Choice and control 3. Self-managed continuum 4. Effective co-ordination

Author (date)	Sample	Design	Measures	Results
	Sample Size: 17 Older people receiving home based support services 10 informal carers from 5 providers in South Aust. and NSW 2/3 participants women Approximately half of the older people had experience with CDC services Informal carers all had experience with CDC			5. Effective communication 6. Responsiveness and flexibility 7. Continuity 8. Planning Six salient service features characterizing consumer preferences for the provision of home-based support services models were identified: 1. Choice of provider 2. Choice of support worker 3. Flexibility in care activities provided 4. Contact with the service coordinator 5. Managing the budget 6. Saving unspent funds The desired level of self-management varies, with some individuals preferring provider-management, some desiring complete autonomy, and others in-between. Older Australians appear to have similar drivers and concerns regarding consumer-directed, home-based services to their UK counterparts.
Moran et al. (2013) UK	Older persons (n= 263), a subset of the sample population used in the RCT (n=959). In some cases, interviews were conducted with a proxy. Interview w/ older person (n=188) Interview w/ proxy (n=75) *Sample demographics* Mean age 81 66% women 5% ethnic minority	Secondary analysis of RCT Semi-structured face-to-face interviews, collected 6 months after a randomized controlled trial (Glendinning et al., 2008).	12-item version of the General Health Questionnaire (GHQ-12), used to assess psychological wellbeing A single quality of life question using a seven-point scale Adult Social Care Outcome Toolkit (ASCOT), used to assess impacts of social care interventions on an individual's quality of life Self-perceived health The interviews aimed to explore older people's experiences of planning how to use their IB.	In both the IB group and the comparison group, the value of the support received by an older person was consistently less than that received by a younger disabled person with similar activities of daily living (ADL) restrictions. The majority of older people (53%) used their IB to purchase conventional mainstream services (including home care, meals, equipment and adaptations, accommodation, short breaks and transport) and personal assistance (41%). 15% of older people spent part of their IB on leisure activities. The IB group had higher scores on the GHQ-12 and worse self-rated health than the comparison group, but better

Author (date)	Sample	Design	Measures	Results
				ASCOT scores. *Qualitative outcomes* Older people were more likely to report plans based on personal care and domestic support and less likely to report any wider plans, including leisure and recreational activities. The lower levels of IBs awarded to older people typically restricted their ability to use the IB on anything other than personal care and domestic support. Support was most needed by those who had chosen to take the IB as a cash direct payment (DP) and typically involved identifying the costs of various services or support options, recruiting staff, writing the support plan, and allocating the budget. Experiences of help received with support planning were overwhelmingly positive. The possibility of directly employing staff (personal assistants) through an IB led to anxiety as this was anticipated to carry more responsibility and. Plans for using IBs included: using their IB to purchase small pieces of equipment, including rails to aid mobility; bathroom adaptations to make personal care easier; personal alarm systems; adapted footwear; and a special chair; transport costs to enable the older person to continue to attend church; money to maintain hobbies and attend related courses; support to attend community activities; and money to purchase a computer and broadband router to enable the older person to retain independence through, for example, shopping via the internet. Some participants planned to use the IB to pay someone to accompany them on outings; others indicated they would rather spend time with family or friends and be able to compensate them financially for their assistance Contingency planning was considered important to a small proportion (e.g. purchasing agency care when personal assistant takes holidays).

Author (date)	Sample	Design	Measures	Results
				Older people also reported anxieties about the management and administration of the budget. The possibility of directly employing staff (personal assistants) through an IB also led to anxiety as this was anticipated to carry more responsibility and risk for the user. Anxiety about relationships with directly employed care workers could break down, resulting in (potentially unfair) dismissals, threats of legal action, and older people possibly being left temporarily without care.
Norrie et al. (2014) UK	N= 7 "older people" and carers in receipt of personal budgets in one LA in London	Qualitative structured interviews	Research questions: 1. What are experiences of service users of assessment process 2. Whether service users wanted full control over budgets 3. Whether personal budgets make a difference to quality of life for consumers	Consumers valued: 1. clarity of information regarding available services 2. flexibility in control of funds (LA or consumer of both) as well as deposition of funds
Rabiee et al. (2008) UK	14 participants; 18-85 yrs 9 service users 5 proxies 2 were "older people"	Qualitative semi-structured interviews, 2-3 months after first being offered an individual budget (IB)	Previous support arrangements Experience of (self-)assessment and support planning (Anticipated) impacts of IBs	6 interviewees had previously received DPs 6 previously had personal assistants visiting on a regular basis. While some were reasonably happy with these arrangements, other complained about the lack of flexibility and consistency, and unreliability. DPs were also criticized for being restrictive, as participants believed they could be used to pay for personal care only, and no other support needs. In planning how to use their IBs, interviewees' first priority was generally personal assistance, through directly employed personal assistants, agency staff, or paying family/informal carers. They also planned to spend their IBs on: • Transport to be more involved in their communities, • Equipment such as tele-care equipment

Author (date)	Sample	Design	Measures	Results
				- Short periods of respite care at times that suited users and their families Other things that mattered to them that would not have been funded under previous support arrangements. All interviewees thought that the most important aspect of IBs was that they offered more choice and control. Some interviewees admitted that they were not clear about what an IB was. Freedom to employ one's own carer was appreciated by interviewees in all groups, but the significance of this varied according to individual circumstances. Many interviewees talked about how using the IB had already enhanced their sense of identity and self-esteem.
Rabiee & Glendenning (2014) UK	18 participants: 15 women aged 65-98; care delivery between 6wks and 5 yrs	Qualitative multiphase project -- article reports on one phase Semi-structured interviews Jan 2011- Dec 2012	Measured difference between "ideal" and reality with regards to consumer choice in Personal Budgets Factors that contribute to satisfaction with PBs and consequent quality of life	Only two of the 18 interviewees seemed to have any knowledge of the budget allocated to them. Most interviewees reported being satisfied with the agency they received support from. This did not mean that they had been able to use an agency of their choice. Almost all said the agency had been allocated to them. Many felt they would not have been able to make a choice because they had no knowledge of the home care market or were too ill at the time to make a choice. Some had changed their (formal) carer. However, most who were not satisfied with the car workers put up with them because they did not want to make a fuss. Typically, tasks included in support plans were related to personal care. There were reports of low-level choices over some tasks specified in the care plan. That were discussed with the care workers on a day-to-day basis. Most interviewees were reluctant to ask their care workers to do any extra tasks for them. Most service users wanted more choice and flexibility over how to use their budget, and in choice and flexibility over timing and duration of visits. The gap between the ideal of user choice and control and

Author (date)	Sample	Design	Measures	Results
				the reality of practice continues to be significant.
Woolham et al. (2017) UK	N= 339 respondents 75+ yrs living in non-assisted community settings	Retrospective, comparative design Postal questionnaire across three English local areas 2012-13 Cross comparison between consumers on direct payment plans and those with managed PBs	EQ-5D-3L (health status) Sheldon–Cohen Perceived Stress Scale Adult Social Care Outcomes Toolkit (ASCOT: social care-related quality of life)	No statistically significant difference in outcomes between direct payment and managed personal budget users. Direct payment users appreciated the control conferred by budget ownership, but in practice for many it did not translate into improved living arrangements. It also found no statistically significant difference in outcomes between direct payment and managed personal budget users. Both groups of respondents greatly valued budget ownership but referred to lack of funds to support activities aside from direct personal care Necessary dependence of 75+ consumers potentially reduced effectiveness of PBs considering reduced capacity to manipulate services independently
Zamfir (2013) UK	68 documents reviewed	International literature review of quant, qual and grey literature data 1995-2012	NA	Broad themes extracted from literature were: 1. enhancement of wellbeing 2. financial management 3. personal involvement in managing care 4. enhancing personal and health outcomes Some evidence that recipients of PBs experience poorer wellbeing than others may indicate the additional complexity required to manage personal finances. Personal and health outcomes are minimally improved for those on PBs when compared with younger adults. The review also found, however, some evidence that personal budgets could improve older people’s outcomes, but only if the budget amount is sufficient and the right level and type of support are available.

Q1: Summary tables of included studies 3: Hand-searching, grey literature

Author (date)	Sample	Design	Measures	Results
Age UK (2013) UK	NA (years not stated)	Review of evidence within ‘manual’; (Chapter 2)	Guide for social service providers Chapter 2 summarises research findings. *Aim:* To highlight what older people want from their care and support To identify what works (in terms of various services) To demonstrate how the voluntary sector can support the local authority to achieve outcomes.	Some older people welcome the option of a direct payment. Many do not, but they still want choice and control over the help they receive: who, what, where, when and how. This often has less to do with a choice between providers and more to do with a choice about how support is delivered by the chosen provider. What older people value is: ▪ Support from a named person, from assessment through to support plan implementation – and beyond to ensure that it remains appropriate ▪ As little bureaucracy as possible ▪ Flexibility, continuity and on-going relationships with care providers ▪ To get out and about, with support if necessary, and to be involved in social and community activities ▪ Help to put creative support arrangements in place, but also traditional services: day services and activities, help with housework and gardening ▪ The same types of help, especially to plan care and support and to put it in place, regardless of how it is being funded. Access to a budget does not ensure choice or personalisation. Many self funders exercise little real choice and often achieve poor outcomes. Often people have little understanding of what is available and what is possible. People with care and support needs require: ▪ Good, accessible information and advice, as early as possible in their care journey, with the option of face-to-face contact) ▪ Access to advocacy, especially for people with dementia and others who may have difficulty in representing their needs ▪ Person-centred support that starts with the needs,

Author (date)	Sample	Design	Measures	Results
				capabilities and preferences of the individual, not with service-based solutions or categorisation of need - Help to understand what is possible within the care system and what support is available within their local community - Assistance to plan care and support, put it in place; and review its continued effectiveness and appropriateness as needs and circumstances change. Choice is meaningless without diversity. People need to know what is available and the options should be realistic for them. Resource allocation systems should generate indicative budgets that are adequate to meet assessed need – where they fall short, budgets must be increased.
Hatton & Waters (2011) UK	1,114 PB holders responded to survey; 61% female 26% aged 16-44 31% aged 45-64 43% aged 65+	Programme evaluation Implementation of POET Survey (Personal Budget Outcome Evaluation Tool) 10 local authorities across UK Online and paper formats	Survey focus: Factors associated with positive outcomes for PB holders and carers	Overall, personal budget holders reported positive experiences of the impact of personal budgets (PBs) on their lives, although experiences of the personal budget process were varied. Carers were highly positive about the impact of PBs on the lives of the PB holder, themselves as carers and other family members, but were more negative about all aspects of the personal budget process and the stress and worry for them associated with PBs for the person they were caring for. Older people were more likely than other groups to have a PB managed by the council, and were more likely than other groups to not know how their PB was managed. 77% of respondents reported that they had been told the costs of their support The single most commonly issue in the survey was a lack of clarity, often regarding how money could or couldn’t be used. Substantial majorities of people reported PBs having a positive impact on all seven aspects of people’s

Author (date)	Sample	Design	Measures	Results
				lives. Key findings Positive outcomes fostered by: 1. Timely assessment and allocation of funds 2. Clarity of information, documents etc. 3. Flexibility in fund use 4. Availability of local services
KPMG (2012) Australia	Profile of participants (administrative data) Surveys 124 CDC participants and 126 standard packaged care recipients. Interviews	Programme evaluation evaluating 700 CDC packages approved in November 2010 Review of the literature Paper-based surveys to all CDC participants and packaged care and respite comparison groups Semi-structured interviews	Evaluation foci: 1. evaluate departmental implementation of programme and operationalization of CDC by service providers 2. evaluate impacts and benefits of the CDC on participants and carers 3. to determine cost of initiative and value for money of initiative and value for money 4. identify barriers to success and key achievements, key lessons to inform future roll-out Research questions: 1. To what extent was CDC person-centred, and how did it increase choice and control for participants and their carers? 2. To what extent did CDC enhance community-based	Top types of supports accessed by CDC participants depended on the level of the package. For low care, these were domestic assistance, assistance with activities of daily living, and social support. For High care packages, these priorities were the same, but in a different order. For dementia packages, they were activities of daily living, domestic assistance, and nursing care. Reasons for participating in the CDC pilot were: 1. more choice in service selection 2. more choice of providers 3. more control over care planning 4. recommended by care provider 5. not satisfied with previous community care Most CDC participants and carers were satisfied with their level of choice and options in relation to supports, though there some participants expressed dissatisfaction For the most part, people chose the same types of services as those available under standard packaged care, and they exercised choice and control over how the services were delivered (mostly around flexible service delivery and continuity of support workers). Many participants also used part of the package funding for

Author (date)	Sample	Design	Measures	Results
			care for participants and their carers?	‘no-traditional’ supports, goods and services, such as holidays, gym membership, television subscriptions, continence products and petrol.
Newbronner et al. (2014) UK	69 participants (48 female) PB recipients and carers	Programme evaluation Aim: to examine personal budgets processes and practices from people with mental health problems and older people by investigating the front-line experience of service users and their carers Case study methods: focus groups and interview data Five Local Authorities- rural and urban	Research foci: 1. moving to a personal budget 2. assessment and resource allocation 3. support planning and setting up services 4. managing personal budgets	PB holders and carers emphasised the importance of clear and understandable information about what a PB is, how it can be used and what is involved in holding one. However, time spent discussing PBs with their social worker, community psychiatric nurse or support provider organisation helped them most. Decisions about how to manage the PB can have a powerful knock-on effect on the ways in which people can exercise choice and control. A significant proportion of older PB holders were very clear about what they wanted in their support plan and felt that this was respected. Older PB holders were much more likely to use their PB to pay for regular personal care or help with getting out and about. A significant proportion were employing personal assistants, usually with help from a provider. A few PB holders employed family members or friends as personal assistants. In most sites, domestic tasks such as cleaning and gardening could be funded by a PB without a problem, but a few PB holders and carers said that they had needed to negotiate in order to spend part of their PB on these services. Transport, especially the use of taxis, was another area of expenditure that PB holders often felt unsure about. This was particularly the case for older PB holders who sometimes viewed taxis as a luxury rather than a necessity. Older PB holders and their carers were using their PBs to fund a variety of supports and services including residential respite, day services and warden call systems. In addition, some quite creative support arrangements had also been put in place. Several PB holders were using

Author (date)	Sample	Design	Measures	Results
				their funds to have a short break with their family rather than going into residential respite care. Although this had worked well, some carers felt 'guilty' that they were benefiting indirectly from the PB. One of the most important factors in helping PB holders to make the most of their PB was clarity about what their PB could be spent on. Older PB holders and carers tended to be cautious and some almost felt they needed 'permission' to spend their PB on certain things. Key findings: 1. awareness of PB existence and options within them 2. creative use of funds encouraged 3. available services appropriate for current needs with ready modification as needs change 4. control over fund account and divestment options 5. ability to relinquish control of funds as function declines
Simons et al., (2016) Australia	45 participants (10 interviewed twice) 28 women 17 men	Programme evaluation /Action research Structured interviews with consumers and/or carers	Study foci: How well consumers understood the elements of CDC How well consumers understood new case management arrangements under BSL model How consumers felt about the information provided them What changes they experienced to services delivered and activities Attitudes to acceptance of new budget arrangements	While some interviewees clearly understood from an early stage the main elements of CDC, such as the way funding is allocated, responsibility for budget management, the opportunity to organise activities and Home Support services for themselves and the possible impact on the scope of services or activities they could afford within their individual budget, others did not. About half of the 45 interviewees said they were still confused about the term 'consumer directed care'. About half of the interviewees said that they decided on their autonomy level collaboratively with the case manager: As consumers' understanding of the individualised

Author (date)	Sample	Design	Measures	Results
			The introduction of monthly financial statements	budget and opportunities for choice and control over their services increased, many began to take the initiative in spending their funds in line with the health and wellbeing goals outlined in their Plan. Many consumers appreciated the flexibility to coordinate their own services, including being able to organise them quickly in response to an urgent need, or to ask care attendants to undertake tasks as needed, rather than a fixed set of tasks for each visit. Having a say gave many consumers a sense of independence and confidence in their own ability. Some consumers had accumulated funds for the future in anticipation of increasing needs as their physical or medical conditions changed. BSL clients had been able to attend activities subsidised through the Social Inclusion Programme (SIP). With the introduction of fee for service as a result of IBs, only half of those interviewed who had attended SIP activities said that they would probably continue to attend. Only one consumer said they would cut back on personal care or domestic services to attend. Most participants expressed: 1. need for more flexibility in coordinating care programmes 2. a greater sense of independence

Q2: Summary tables of included studies 1: Systematic literature search

Author (date)	Sample	Design	Measures	Results
Bulamu et al. (2017)	*Study population:* 65 years or older, male or female	Self-Reported quality of life using the EuroQoL five dimensions, five-level version, and the older	Descriptive statistical data was used to examine the relationship between QoL, mode of service delivery, and other	Quality of life for patients receiving CDC and PDC was similar;

Author (date)	Sample	Design	Measures	Results
Australia	Current recipients of Community aged care services (CACS), either Consumer Directed Care (CDC) or provider directed care(PDC) recruited from five organisations providing CACS in South Australia and New South Wales *Sample size:* n=139 older adults living in the community and in receipt of CACS, n= 81 receiving CDC n= 58 recipients were receiving PDC services	people-specific capability index (ICECAP-O) instruments.	sociodemographic characteristics The EuroQoL is a five dimensions self-completed questionnaire (EQ-5D-5L) that is a generic measure of health status The ICECAP-O measures different attributes of capabilities across 5 key attributes 1. Attachment (love and friendship) 2. Security (thinking about the future without concern) 3. Role (doing things to feel valued) 4. Enjoyment (pleasure) 5 Control (independence)	QoL and ICECAP measures (ICECAP-O: CDC mean 0.74 [SD 0.17], PDC mean 0.78 [SD 0.17] EuroQoLfive dimensions five-level version: CDC mean 0.46 [SD 0.33], PDC mean 0.49 [SD0.27]). Generally, individuals receiving CDC reported higher levels of capability in the control and independence dimension for the ICECAP-O relative to those receiving PDC. Multivariate regression analysis showed that living alone was associated with higher quality of life (P=0.01) and higher levels of capability (P=0.02). No discernible difference in QoL however CDC recipients valued greater support from family and friends to assist interpretation of services, and reported higher levels of control and independence with "choice" and "control" being important when assessing the quality of the care
Doyle et al. (2012) **Australia**	*Study population:* Older People (not defined), living in South East Queensland Prolonged engagement with participants (strength of study) Self-reflective process by the researcher enabled transparency of the process	*Design:* Qualitative – Heidegger's interpretive hermeneutical phenomenological approach Snowball sampling *Procedure:* Analysis of in-depth interviews conducted with	*Research Question:* "How do older people in receipt of community aged care packages, perceive the impact of the care provided, on the older person, including their independence, autonomy, and personal fulfilment?	Experiences of consumers enabled them to assess the quality of their care on the presence of the following 1. Independence (being able to make active choices on an everyday level) 2. Older persons should be provided with opportunities to make choices and decisions within the context of their own care e.g. the time of day for a carer visit 3. Interpersonal interactions are important in quality care

Author (date)	Sample	Design	Measures	Results
		12 older people receiving care at the level of a Community Aged Care Package (CACP) who participated in the study In-depth recorded and transcribed interviews with 11 participants (one participant did not agree to an in-depth interview but a narrative only) Identification of sub themes which were ultimately grouped into larger categories		4. The same carer, promoting person centred and continuity of care is important for the consumer Meanings of care experiences can significantly alter the older person's lived experiences and personal identity. Four primary themes identified: 1. "My life is still my own" 2. "People are the most important thing to me" 3. "Doing battle" and "Who's in charge here?" 4. "How I would like things to be"

Q2: Summary tables of included studies 2: Hand-searching, other databases

Author (date)	Sample	Design	Measures	Results
Gethin-Jones (2012a) **UK**	*Study population:* Service users of home care delivery from one English local authority, >65 years. **Intervention group** (20 participants) received the outcome-focused care. **Comparison group** (20 participants) received the traditional form of delivery (''task-focused'' model). Outcome-focused care is established by an agreement on appropriate outcomes that can be measured by the social worker and the service user, rather than a purely tasked-focused approach based on physical care. This model allows the individual the flexibility to bank time which could be used to meet their desired outcomes.	*Design:* Quantitative study (longitudinal study with two cohort groups). *Data collection:* Questionnaires (face to face).	Two validated questionnaires: (i) Measure Yourself Medical Outcomes Profile (MYMOP); (ii) and Measure Yourself Concerns and Wellbeing (MYCAW). Some additional questions were added to measure the level of social isolation and satisfaction with the paid care provided.	The ability to establish a relationship with participants' carers was very important; this was facilitated by the extra contact time provided by the outcome-focus care model. This (extra contact time) in turn allows improving their personal well-being, perceived as a measure of quality of care. There was a greater improvement in subjective well-being in the group receiving outcome-focused care, when compared with the comparison group receiving the traditional task-focused model.
Gethin-Jones (2012b) **UK**	*Study population:* 20 service users, >65 years. **The intervention group** (10 participants) received the outcome-focused care. **The comparison group** (10 participants) received the traditional form of delivery (''task-focused'' model).	*Design:* Qualitative study Outcomes and well-being part 2: a comparative longitudinal study of two Service users of home care delivery from one English local authority. *Data collection:*	The purpose of the interviews was to examine why the participants felt change had happened in the case of outcome-focused care and why change had not happened with the traditional model of time/task provision.	Participants from the outcome-focused care group considered the following important: The ability to establish a relationship with the homecare workers providing the care. The need to target more flexible and consistent care packages to them. *Additional measures in perceiving quality:* The need for consistency in care delivery to enable a focal relationship to develop between the professional carer and

Author (date)	Sample	Design	Measures	Results
		Two semi-structured interviews; one interview at the start of the intervention and one at the six-month stage.		the service user. Flexibility in care delivery to allow for a wider completion of tasks. Prioritizing the delivery of outcome-focused care to the most socially isolated.
Grigorovich (2016) **Canada**	*Study population:* Women who to self-identified as lesbian or bisexual, ≥55 years. Service users receiving publicly funded home care in Ontario, Canada. *Sample size:* 16 participants. No comparison group.	*Design:* Qualitative study *Data collection:* Semi-structured interviews.	*Research question:* How do older lesbian and bisexual women who receive home care services define 'quality of care'?	Participants considered that quality was enabled when providers: ▪ Were attentive and responsive to their needs demonstrated appropriate competencies (technical and emotional) and actively enabled recipients 'comfort. Providers should show attentiveness by learning how users wanted the care to be provided according to their situation. This also included that providers should be responsive to their feedback ▪ Let users involved in decision-making and allowed them to direct the care. This ensured that care provision met their needs and enabled their autonomy through active participation. ▪ Were aware of their feelings of vulnerability and to take responsibility for establishing a comfortable caring environment by acting in a respective and affirmative manner.
Grimmer et al. (2015) **Australia**	*Study population:* Community dwelling residents in South Australia, purposive recruitment. Individuals aged 65+ years. *Sample size:* N=23 (14 individuals, and 9 with a companion)	*Procedure:* Two purposively sampled community dwelling resident groups aged 65+ years, were recruited for individual or focus groups *Data collection:* Semi structured, audio recorded and transcribed Interviews	*Research question:* What is the perspective of their own and others ageing in place and functional decline?	No specific articulation of measures of quality but general discussion of what is desirable including: Quality services needed to be: ▪ "Targeted, timely, affordable and self-directed" ▪ Flexible according to changing functional and cognitive needs of consumer ▪ Adequately subsidized to enhance affordability

Author (date)	Sample	Design	Measures	Results
Kwak et al. (2017) **South Korea**	*Study population:* Elderly individuals in receipt of welfare benefits (N=123 in home care recipients) *Sample size:* 246 participants	*Design:* Cross-sectional study *Data collection:* Survey design with structured interviews	This study examined care satisfaction in a nursing home and at home among low-income elders in South Korea: - Quality of Services - Quality of caregivers	Quality measured on two levels: Quality of Services: - Service information - Contact availability Quality of caregivers: - Reliability - Professionalism - Sensitivity - Respectfulness - Friendliness - Safeguard
McGrath et al. (2006) **Australia**	*Study population:* Older Aboriginal adults (n = 10), carers (n = 19), Aboriginal healthcare workers (n = 11), healthcare workers (n = 30) and interpreters (n = 2).	Cross sectional Design *Data collection* Open-ended, qualitative interviews *Procedure* Taped interviews conducted in four geographical areas in the NT. Research questions focused on: What palliative care services are provided, and are they meeting the clients' needs? How can services be modified to deliver a culturally appropriate, innovative and exemplary model?	To investigate the potential need for respite in Indigenous communities. Study undertaken to inform development of an innovative model for Indigenous palliative care.	Quantity and quality of the availability of respite centres seen as a perception of quality. Identified lack of resources *Perceptions of quality* Participants described a serious lack of services for Indigenous people, either community-based or inpatient, and emphasised the serious need for respite. For many the necessity to leave home and community is a problem. Many Aboriginal people do not want to leave home and travel a distance to the metropolitan area because they do not have the opportunity to return at will. An important cultural concern about relocating for many Indigenous people is that they have never previously left their community; and do not want to be relocated away from their carers. The lack of local respite creates hardship, especially for elderly people, as they do not want to leave the comfort and

Author (date)	Sample	Design	Measures	Results
		What strategies are needed to develop and apply the model developed?		familiarity of their own family and community. The establishment of respite centres is a positive objective that needs action. However, in consideration of the hardship caused by having to relocate to the metropolitan area for respite services, the suggestions are for respite centres to be built close to where people live, especially those in rural and remote locations. It is also suggested that funding could be used to help other families in the same community to provide respite to avoid relocation. Outstations could be a convenient and attractive location.
Moran et al. (2012) **UK**	*Study population:* Older persons receiving individual budgets *Sample size:* N= 263 (IB group= 142; 44 with proxy, Non IB group 121; 31 with proxy)	*Design:* RCT of IB and non-IB recipients, with follow up after 6mths. (non-IB recipients were offered IB at 6mths) Semi-structured interviews 6mths after randomization exploring: General health Social care outcomes Self-perceived health Thematic analysis of interview data	Older people's experience of cash-for-care schemes: evidence from the English Individual Budget pilot projects. Exploring: - General Health - Social Care Outcomes - Self–perceived Health	Quality was viewed as: - Assistance with financial literacy and subsequent planning of various services to best suit current needs - Feeling heard by service providers or case managers - Assistance with administrative requirements - Familiarity with care providers, consistent carers within the home - Sufficiently funded to allow fulsome access to necessary services
O'Rourke (2016) **UK**	*Study population:* Recipients of individual budgets *Sample size:* 8 participants Interview data	*Design:* Narrative study with in depth narrative interviews	Perspectives of consumers to assess the relationship between participants' individual experiences of self and personalised services.	Services are perceived as high quality if the consumer feels they can preserve their sense of self within the structure of provided care
Ottman et al.	17 references included in review;	*Design:*	Measuring how the current	Perceptions of quality include:

Author (date)	Sample	Design	Measures	Results
(2013) **Australia**	quant and qual papers	Systematic review exploring Older Peoples experiences with CDC and considering implications for model development	evaluation of CDC translates into practice To establish an evidence base of user preferences for satisfaction with services associated with CDC programs for older people	1. Flexibility in service delivery according to changing health requirements 2. Ability to increase or decrease agency involvement in care design as desired by older person 3. Ability to collaborate in service design with agencies
Rioux et al. (2011) **France**	*Study population:* 103 participants, ranging from age 72-86 years of age, living at home in Central France. The communities were chosen because all have had similar development over the past 40 years and are currently similar in composition and urban form. The participants were a mix of people who grew old in the villages and newcomers who have retired from larger cities	*Design:* Qualitative *Data collection:* Purpose developed questionnaire	Residential Satisfaction	Residential satisfaction of elderly persons living in their own dwellings, and identifying demographic and psychological variables related to this residential satisfaction. Measures showed that older people's residential satisfaction corresponded to four-dimensional structures corresponding to distinct ecological areas: 1. Local area satisfaction 2. Satisfaction with accessibility to services in the local area 3. Satisfaction with relationships with neighbours 4. Home satisfaction Satisfaction with each component was related to different predictors, supporting the idea that older people hold complex views of their homes and neighbourhoods.
Snell et al. (2011) **Australia**	*Study population:* Home medicines review (HMR) setting patients. *Sample size:* 8 men 12 women Participants were purposively recruited from different urban and regional areas in Australia.	*Design:* Qualitative study using in depth interviews. HMR was a program aimed at improving patient health and well-being and involved the collaboration between the general practitioner, pharmacist, and patient in reviewing use of medicines.	Patients were asked to describe the factors that they believed were essential for a quality HMR. Service quality had three dimensions: 1. interpersonal 2. technical 3. administrative Interpersonal included trust, rapport, respect and	Emotional Intelligence (EI) and health competence influenced patients' perceptions of service quality. Intervention initiatives aimed at increasing patient awareness and education of their health conditions could also improve service quality perceptions and adherence behavior. Female respondents were more EI than their male counterparts. Higher numbers of females indicated that they had good relations with other people, while males mentioned difficulties interacting with people.

Author (date)	Sample	Design	Measures	Results
	Age ranged from 44 to 90 years, majority of respondents (15) were 65 years or over.	*Inclusion criteria* 1. English speaking with a previous HMR within 3 months of the interview date. *Data collection:* The majority (19) of interviews were conducted within the patient home. Average time of interview 50 minutes.	communication. Technical quality based on judged on perceived knowledge, credentials and perceived experience. Administrative issues had two core themes: timeliness and collaborative support.	*Key findings:* Consumer perceptions of their health and emotional state could influence 1. their assessment of the quality of provider services. 2. their overall perceptions of the service quality.
Smith-Carrier et al. (2017) **Canada**	*Study population:* Patients accessing Home-based primary care (HBPC). Above 65 years. *Sample size:* 26 individuals	*Design:* Qualitative study using in-depth patient interviews *Data collection:* A face-to-face interview to explore experiences and perspectives of participants receiving home-based primary care.	There were open-ended questions such as can you tell me about your experiences receiving HBPC?, What is it about receiving HBPC care that you dis/like?, etc	Participants wanted to receive a patient-centred care. Participants considered that this type of service was an essential service because most of them were unable to go alone outside. They preferred using this type of service because the health care provider gave them more time and attention at home. This was better instead of being waiting long time in the hospital, where there was a higher risk of exposures to contagious diseases. HBPC was a fundamentally necessary service. Despite the intrusions into personal space and lack of privacy. The HBPC team was the only source of social support for some participants living isolated and without adequate social interactions. *Key findings:* 1. Participants preferred HPBC over the standard office-based care because HPBC served frail homebound older adults, ensuring that patients receive appropriate primary, home and community care. 2. HPBC promoted better care base on patients' preferences and needs at home, where majority of participants felt most comfortable.

Author (date)	Sample	Design	Measures	Results
Van Hoof et al. (2011) **Netherlands**	*Study population:* Older community dwelling individuals. *Sample size:* 18 individuals	*Design:* Qualitative interpretive approach. *Data collection:* Semi-structured interviews with recipients of ambient technology.	Evaluating implementation of 'ambient' in home technology: 1. needs and motives of users. 2. solutions offered by introduction of ambient technology.	*Key findings:* 1. Increased sense of safety in own home after instillation of technology 2. Increased sense of safety enhanced wellbeing and desire to remain in own home. 3. Perception that assistance is readily available.

Q2: Summary tables of included studies 3: Hand-searching, grey literature

Author (date)	Sample	Design	Measures	Results
Australia Government Department of Health (2018) **Australia**	*Study population:* A total of 215 consumers (Home Care Package participants) and 300 service providers. 21% aged <70 17% aged 70 – 74 21% aged 75 – 79 40% aged 80+ 71% female 29% male 35% were from New South Wales and 33% Queensland. 44% income < $30,000 16% income 30,001 – 75,000 5% income > 75,000 50% Level 2 Package 30% Level 4 Package 13 % Level 3 Package 3% Aboriginal or Torres Strait Islander. 5% culturally and linguistically diverse.	*Data collection:* Survey The department commissioned independent agency AMR to conduct research among home care package clients and service providers in August and September 2017.	*Aim:* To measure experiences and perceptions since the increasing Choice in Home Care reforms were introduced on 27 February 2017. Among home care package providers, the aim was to measure levels of satisfaction with changes introduced in February 2017.	Four in five participants indicated high satisfaction with: the services they received (85%); the services matching these expectations (86%); and their general standard and suitability (over 80%) of the aged care services. The most valued service was domestic support (41%), followed by the personal support received mainly by older and higher-level clients (12%). Domestic support was more likely to be most valued in Victoria (52%), transport in NSW (12%), and social support in Queensland (12%). 68% agreed that the reforms would make moving to a new provider easier. Very few (7%) were contemplating changing providers. Main reasons were a lack of satisfaction with the quality of services (50%) and provider staff who delivered the services (46%). Satisfaction with services received (85%) and the staff administering them (75%) were the major reasons cited by those not wanting to change provider. Those receiving higher-level packages (3 or 4) were significantly more likely to mention their positive views of the staff providing their services (86%). Regional residents were significantly more likely to feel there were no other providers in their area that could service their needs (26%). Participants agreed that the provider they selected had been available (83%) and appropriate to their needs (76%). They were less likely to be dissatisfied with the cost or the service provider's ability to cater to their background. There was broad satisfaction with funding allocation, with 65% indicating satisfaction and only one in four (24%) being dissatisfied. Women (75%), those in regional areas (76%), and those whose services started before February 27th (76%) were somewhat more likely to indicate satisfaction. Close to half of participants recorded using the My Aged

Author (date)	Sample	Design	Measures	Results
				Care Contact Centre (a printed brochure/booklet and/or information provided by a service provider), and around 80% were satisfied with the information received from the My Aged Care Contact Centre. The wait time for a package was usually seen as satisfactory (74%). A majority (65%) indicated satisfaction with the amount of time they had to decide which provider would deliver the services. A majority felt that each of the prompted outcomes of My Aged Care had been achieved at least 'fairly well', with the highest agreement that it 'assists people to arrange aged care assessments' (70%) and the lowest that it 'provides accurate information on fees and charges' (54%). The Net Promoter Score for My Aged Care, was +30, which indicates a high level of satisfaction. *Key findings:* High satisfaction with: 1. the services they receive. 2. the services matching these expectations. 3. the suitability of the services. 4. the information received from the My Aged Care Contact Centre. 5. Majority considered satisfactory: 6. the waiting time before they were assigned a package. 7. the amount of time they had to decide about which provider would deliver the services. 8. the funding allocation for home care packages.
Hatton & Waters (2011) **UK**	*Study population:* Personal budget holders responded to survey *Sample size:* 1114 individuals	Programme evaluation Implementation of POET Survey (Personal Budget Outcome Evaluation Tool) 10 local authorities across	*Survey focus:* Factors associated with positive outcomes for PB holders and carers	Overall, personal budget holders reported positive experiences of the impact of personal budgets (PBs) on their lives, although experiences of the personal budget process were varied. Older people were more likely than other groups to have a PB managed by the council, and were more likely than

Author (date)	Sample	Design	Measures	Results
	26% aged 16-44 31% aged 45-64 43% aged 65+ 61% women	UK Online and paper formats		other groups to not know how their PB was managed. 77% of respondents reported that they had been told the costs of their support. The single most commonly issue in the survey was a lack of clarity, often regarding how money could or couldn't be used. Substantial majorities of people reported PBs having a positive impact on all seven aspects of people's lives. Positive outcomes were: 1. Timely assessment and allocation of funds 2. Clarity of information, documents etc. 3. Flexibility in fund use 4. Availability of local services
KPMG (2012) **Australia**	*Study population:* Consumer directed care (CDC) participants and standard packaged care recipients. *Sample size:* n=124 (CDC group) n=126 (packaged care group)	*Design:* Programme evaluation evaluating 700 CDC packages approved in November 2010 *Data collection:* Paper-based surveys to all CDC participants and packaged care and respite comparison groups Semi-structured interviews	*Evaluation foci:* 1. evaluate departmental implementation of programme and operationalization of CDC by service providers 2. evaluate impacts and benefits of the CDC on participants and carers 3 to determine cost of initiative and value for money of initiative and value for money 4 identify barriers to success and key achievements, key lessons to inform future roll-out *Research questions:* 1. To what extent was CDC person-centred, and how did it increase choice and control for participants and their carers? 2. To what extent did CDC enhance	Top types of supports accessed by CDC participants depended on the level of the package. For low care, these were domestic assistance, assistance with activities of daily living, and social support. For High care packages, these priorities were the same, but in a different order. For dementia packages, they were activities of daily living, domestic assistance, and nursing care. Reasons for participating in the CDC pilot were: 1. more choice in service selection 2. more choice of providers 3. more control over care planning 4. recommended by care provider 5. not satisfied with previous community care Most CDC participants and carers were satisfied with their level of choice and options in relation to supports, though there some participants expressed dissatisfaction

Author (date)	Sample	Design	Measures	Results
			community-based care for participants and their carers?	
Simons et al. (2016) **Australia**	*Study population:* Recipients of a consumer directed care package. *Sample size:* 45 participants (10 interviewed twice) n=28 (women) n=17 (men)	Programme evaluation /Action research *Data collection:* Structured interviews with consumers and/or carers	*Study foci:* How well consumers understood the elements of CDC How well consumers understood new case management arrangements under BSL model How consumers felt about the information provided them What changes they experienced to services delivered and activities Attitudes to acceptance of new budget arrangements The introduction of monthly financial statements	While some interviewees clearly understood from an early stage the main elements of CDC, such as the way funding is allocated, responsibility for budget management, the opportunity to organise activities and home support services for themselves and the possible impact on the scope of services or activities they could afford within their individual budget, others did not. About half of the 45 interviewees said they were still confused about the term 'consumer directed care'. About half the interviewees said they decided on their autonomy level in collaboration with their case manager: As consumers' understanding of the individualised budget increased, many began to take the initiative in spending their funds in line with health and wellbeing goals outlined in their Plan. Many consumers appreciated the flexibility to coordinate their own services, including being able to organise them quickly in response to an urgent need, or to ask care attendants to undertake tasks as needed, rather than a fixed set of tasks for each visit. Having a say gave many consumers a sense of independence and confidence in their own ability. Most participants expressed: 1. need for more flexibility in coordinating care programmes 2. a greater sense of independence

Findings

This section of the report integrates findings from both questions.

Somewhat unexpectedly, much of the literature identified by the systematic review of Medline and EMBASE had only marginal relevance to the research question. In contrast, articles and reports identified through hand searches tended to be more relevant.

The 33 studies and reports included in this review were conducted in six countries (Australia, Canada, Korea, The Netherlands, France, the UK, and the US). Most of these studies were qualitative.

A substantial proportion of the identified literature was Australian. This contrasts with our usual experience in conducting literature reviews, given the large research output on most topics from the US and UK. This raises the issue of whether this result was an artefact caused by attentional bias in hand-searching. It is possible that some bias was caused by reliance on terms used in Australia (e.g., consumer-directed care and packaged care). However, the research team made genuine efforts to identify all similar terms used in the UK and the US (such as individual budgets and cash for care), and employed these terms in their searches. Inspection of the tables above shows that five of the six studies identified through searches of Medline and EMBASE were Australian.

Determinants of choice within a CDC model

The services that consumers choose

Rabiee et al.'s (2008) study indicated that interviewees' priority was generally to secure personal assistance, through directly employed personal assistants, agency staff, or paying family carers. They also intended to spend their individual budgets (IBs) on transport that would enable them to be more involved in their communities, equipment (to support, for example, use of tele-health), short periods of respite care, and other things that mattered to them that would not have been funded under previous support arrangements.

A later study identified, not surprisingly, that unmet need shaped consumers' expectations about the provision of packages in the future. Moran et al. (2013) showed that most older people in the UK used their individual budgets (IBs) to purchase conventional mainstream services and personal assistance. Some (15%) spent part of the IB on leisure activities. Moran et al. (2013) also found that plans for using IBs included: using their IB to purchase small pieces of equipment, including rails to aid mobility; bathroom adaptations to make personal care easier; personal alarm systems; adapted footwear; and a special chair; transport costs to enable the older person to continue to attend church; money to maintain hobbies and attend related courses; support to attend community activities; and money to purchase a computer and broadband router to enable the older person to retain independence through, for example, shopping via the internet. Some participants planned to use the IB to pay someone to accompany them on outings; others indicated they would rather spend such times with family or friends and be able to compensate them financially for their assistance. Contingency planning was considered important to a small proportion (e.g. purchasing agency care when personal assistant takes holidays). The drivers of these choices were not identified.

Again, Newbronner et al.'s study (2014) on personal budgets (PBs) in the UK found that older PB holders were most likely to use their PB to pay for regular personal care or help with getting out and about. A significant proportion were employing personal assistants, usually with the help of a support provider organisation. A few PB holders employed family members or friends as personal assistants. Newbronner's study emphasised the importance of clear and understandable information about what a PB is, how it can be used, and what is involved in holding one. Time spend discussion PBs with staff was critically important.

Similarly, in the CDC pilot in Australia, most participants chose the same types of services as those available under standard packaged care and they exercised choice and control over how the services were delivered and who provided them. However, others spent at least part of their package on 'non-traditional' supports such as holidays and gym memberships. Similar results were reported in Simons' (2016) study of packages in BSL, which found that most respondents prioritised personal care or domestic services over a social support program.

Consumer perspectives on managing CDC

Problems are caused when consumers had to wait excessive lengths of time to access their package, when payments were delayed, and when there were restrictions about what individual budgets can be spent on. In the UK, the low levels of funding in individual budgets (IBs) awarded to older people in comparison to younger ones with disabilities typically restrict people's ability to use the IB on anything other than personal care and domestic support. One US study suggested that when services are capitated by cost, potential beneficiaries with limited financial and social resources may opt out, and may have difficulty organising needed support.

Older people report anxieties about the management and administration of the budget, while the possibility of directly employing staff carries responsibility and risk for the consumer. Many clients and carers are not aware of terms such as consumer-directed care or felt confused by them. However, clients and carers felt that CDC contributes substantially to consumers' quality of life. Many interviewees in various studies talked about how using an individual budget had enhanced their sense of identity and self-esteem.

Glendinning's (2008) review identified three distinct groups of participants in the UK Individual Budgets scheme: passive participants who wanted their care to remain the same; anxious and stressed uses who perceived some benefits in the model but regarded the administrative responsibilities as burdensome, and those who embraced the program, who tended to have accounting or social care management experience.

The KPMG (2012) report found reasons for participating in the Australian CDC initiative included anticipating that the new service would provide more choice in service selection, more choice of providers, and more control over care planning. In addition, some consumers were recommended to participate by their service provider, and a final group were not satisfied with arrangements in their previous community care provision.

Moran et al. (2013) found that, in contrast to the assumptions of care managers that older people would struggle to manage their own budgets or support arrangements, some older people could see lots of potential advantages to IBs, primarily greater opportunities for choice and control, compensating family and friends for the help they provided, respite, and improved wellbeing and social participation. Some participants who had their package in place reported benefits of IBs. There were also examples of people getting used to the administration, with it becoming less daunting over time, especially as support was generally freely available to IB users to manage their payroll and paperwork. Those older people with the IB in place reported that help from family members was necessary, both during the support planning stage and in managing the budget to realise the benefits of IBs.

Quality of caregivers

Relationship with the carers

A common observation across the studies is that consumers' familiarity with care providers, and having consistent carers within the home, may help consumers feel comfortable receiving services from them, as it allows consumers to establish an ongoing relationship (Moran et al., 2012). According to Gethin-Jones (2012a), the use of the outcome-focus care model instead of a task-focus model facilitates extra contact time between the participants and formal caregivers, and demonstrates improvements in participants' well-being. Participants of Doyle et al.'s (2012) qualitative study also emphasized that ongoing continuity of care from the same carer is a key component of service quality.

Skills and competencies of carers

Preferred characteristics of carers were described in several studies. One study sample expressed the view that carers should be reliable, professional, sensitive, respectful and friendly, and safe (Kwak et al., 2017). Carers should also be responsive to participants' needs and demonstrate appropriate competencies, including technical and emotional support (Grigorovich, 2016). In addition, caregivers should be able to undertake tasks as required, rather than following a fixed task list for each visit (Simons et al., 2016). Finally, consumers have expressed a lack of financial literacy, and require caregiver support with financial planning of their care services (Moran et al., 2012).

Quality of services

Flexible services according to the needs of consumers

Consumers expressed the need for availability of flexible and consistent care packages, covering a wide range of needs (Gethin-Jones, 2012b: Hatton & Waters, 2011; Moran, 2013). This includes flexibility in care delivery according to clients' changing functional and cognitive health needs (Grimmer et al., 2015). Services should be targeted, timely, affordable, and self-directed (Grimmer et al., 2015; Ottman et al., 2013). Thus, it is important that services are suitable and accord with participants' needs (Australia Government Department of Health, 2017).

Services are judged as providing good quality if consumers feel that they can preserve their 'sense of self' within the structure of the care services (O'Rourke, 2016). This gives consumers a sense of independence and confidence in their own ability to control their care (Simons et al., 2016).

Participation in care

Consumers prefer services where they can be involved in the decision-making regarding their care. This involvement includes the flexibility to organise and coordinate their own services as required, either independently or in collaboration with a carer (Simons et al., 2016); and to participate in selection of the wide range of options available to them (KPMG 2012; Ottman, 2013). Participation in the decision-making process ensures that care provision meets their needs and enables their autonomy (Grigorovich, 2016). The feeling of being heard by service providers or case managers was considered important by many participants (KPMG, 2012; Moran et al., 2012).

Service information and funding allocations

Consumers prefer information about care services that is clear, easy to follow, and readily accessible to them (Australia Government Department of Health, 2018: Kwak et al., 2017). In one qualitative study targeting participants receiving consumer-directed care, it was found that many individuals did not fully understand the term or its framework (Simons et al., 2012).

Information considered important by consumers includes contact availability (Kwak et al., 2017), accessibility (Rioux et al., 2011) and availability of services (Hatton & Waters, 2011). Consumers also express the view that there should be clarity regarding how care budgets may be used (Hatton & Waters, 2011), and that their entitlements should be sufficiently funded to allow complete access to necessary services (Australia Government Department of Health, 2017; Moran et al., 2012).

Cultural issues

In the study by McGrath et al. (2006), participants described a serious lack of services for Indigenous people, either community-based or inpatient, and emphasised the serious need for local respite close to family. The lack of local respite creates hardship for older Indigenous people, as many have never left their local communities.

Caring and social support

A comfortable, caring environment is considered an important quality by consumers. Sometimes services provided by either home-based or community-based aged care services were the only source of social support for some participants, who were isolated and without adequate social interactions (Smith-Carrier, 2017). Consumers express their need to feel safe (Van Hoof et al., 2011) and comfortable with care services (McGrath et al., 2006), and to know that assistance is readily available to them, both in emergency and more generally (Van Hoof et al., 2011).

Top eight themes

The themes identified by this literature review relating to choice and quality in home- and community-based aged care are set out below:

1. ***Control*** – Most consumers want to actively participate in the decision-making for their care services, and have the freedom to choose services based on their physical and mental needs. The drivers underlying this choice are likely to be consumers' needs or unmet needs in the areas of personal support with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), as well as a relatively high degree of familiarity with these service types.
2. ***Local residence*** – Consumers want to be able to receive high quality care locally or at home, and not have to move away from their friends and family. This is particularly an issue for Indigenous consumers and those living in remote areas.
3. ***Interpersonal interaction*** – Consumers want supportive interpersonal interactions with their carers over the longer term. In many cases, consumers' only regular social contact with their carer, and thus it is carers should show respect, sensitivity and kindness.
4. ***Flexibility*** - Consumers want the delivery of their care to be flexible, in terms of choice of service provider, choice of daily activities, people employed to assist, and adjustment over time according to their changing physical and mental needs.
5. ***Affordability*** – Consumers want their services to be affordable and subsidised where possible.
6. ***Administrative and financial literacy*** – Consumers would benefit from assistance in understanding their care service entitlements, and receiving support with the financial planning and management of their services.
7. ***Safety*** – Consumers want to feel protected in their homes and local communities, and to know that both general and emergency assistance is readily available.
8. ***Timeliness of service care provisions*** – Consumers prefer to receive their care entitlements and services in a timely manner.

Risk of bias

Risk of bias assessments completed as part of the current project (see Appendices) indicate that:

- Of the quantitative studies reviewed, most were strong in terms of measuring the "exposure" (i.e., the program or intervention) in a reliable way and using reliable outcome measures and statistical analysis. However, only about one-half of the studies clearly described the inclusion criteria for participation in the study, and relatively few used objective measures or strategies for dealing with confounding factors.
- Of the qualitative studies identified, all used methods and data that were congruent. However, no studies addressed the influence of the researcher on the research and only one study included a statement locating the researcher culturally or theoretically.
- All the systematic reviews achieved high scores on all criteria, apart from assessment of publication bias.

In general, the studies varied a great deal in the risk of bias detected as part of this review. The identified systematic reviews were of higher quality than individual studies.

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Appendix 1: Risk of bias assessment criteria

To ensure replicability and validity in our findings, each article included in the systematic reviews underwent a risk of bias assessment following data extraction. For qualitative and systematic review articles, we used the Joanna Briggs critical appraisal criteria (http://joannabriggs.org/research/critical-appraisal-tools.html). For quantitative studies, we used a modified form of the Joanna Briggs checklist, which combined criteria used to assess cohort, randomized controlled trial and cross-sectional analysis studies.

In general, all articles were deemed satisfactory for inclusion in the systematic review. Articles excluded at the data extraction phase did not fit the scope and/or the inclusion criteria of the research question (e.g., age range).

Quantitative studies

1. Were the criteria for sample inclusion clearly defined?
2. Were the study subjects and the setting described in detail?
3. Was the exposure measured in reliable way?
4. Were objective, standard criteria used for measurement of the condition?
5. Were confounding factors identified?
6. Were strategies to deal with confounding factors stated?
7. Were the outcomes measured in a valid and reliable way?
8. Was appropriate statistical analysis used?

Qualitative studies

1. Is there congruity between the stated philosophical perspective and the research methodology?
2. Is there congruity between the research methodology and the research question or objectives?
3. Is there congruity between the research methodology and the methods used to collect data?
4. Is there congruity between the research methodology and the representation and analysis of data?
5. Is there congruity between the research methodology and the interpretation of results?
6. Is there a statement locating the researcher culturally or theoretically?
7. Is the influence of the researcher on the research, and vice- versa, addressed?
8. Are participants, and their voices, adequately represented?
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Systematic reviews

1. Is the review question clearly and explicitly stated?
2. Were the inclusion criteria appropriate for the review question?
3. Was the search strategy appropriate?
4. Were the sources and resources used to search for studies adequate?
5. Were the criteria for appraising studies appropriate?
6. Was critical appraisal conducted by two or more reviewers independently?
7. Were there methods to minimize errors in data extraction?
8. Were the methods used to combine studies appropriate?
9. Was the likelihood of publication bias assessed?
10. Were recommendations for policy and/or practice supported by the reported data?
11. Were the specific directives for new research appropriate?

Appendix 2: Risk of bias assessment summary – Q1 quantitative studies

			Inclusion criteria clearly defined?	Subjects/setting described in detail?	Exposure measured in reliable way?	Objective, standard criteria for measures?	Confounding factors identified?	Strategies for confounding factors?	Reliable outcome measures?	Appropriate statistical analysis?	INCLUDE	EXCLUDE
Peer-review	Davitt	2010	U	U	+	NA	+	+	+	+	✓	
	Jones	2012	+	+	+	+	+	+	+	+	✓	
	Kaambwa	2015	NA	NA	+	NA	+	+	+	+	✓	
	Kirby and Lau	2010	+	+	+	+	+	+	+	+	✓	
	Low	2011	+	+	+	+	U	U	+	+	✓	
	Mery	2016	NA	NA	+	NA	-	U	+	+	✓	
Hand-search	Harrison	2014	+	+	+	+	+	-	+	+	✓	
	James	2010	NA	+	+	+	NA	NA	+	+	✓	
	McCaffery	2015	+	+	+	+	+	+	+	+	✓	
	Moran	2013	+	+	+	+	+	+	+	+	✓	
	Woolham	2017	-	+	+	U	-	-	+	+	✓	
	Davitt	2010	U	U	+	NA	+	+	+	+	✓	
	Jones	2012	+	+	+	+	+	+	+	+	✓	

+ Satifactory - Unsatisfactory U: Unclear NA: Not applicable

Appendix 3: Risk of bias assessment summary – Q1 qualitative studies

			Congruity between perspective and method	Congruity between method and question	Congruity between method and methods	Congruity between method and data	Congruity between method and data interpretation	Statement locating researcher culturally/theoretically?	Influence between researcher/research addressed?	Participants adequately represented?	Ethical research, evidence of ethical approval?	Conclusions flow from data analysis/interpretation?	INCLUDE	EXCLUDE
Hand search	Byrne	2010	+	+	+	+	+	-	-	+	+	+	✓	
	Day	2017	+	+	+	+	+	-	-	U	+	+	✓	
	Gill	2017	+	+	+	+	+	+	-	+	+	+	✓	
	Norrie	2014	NA	+	+	+	+	-	-	+	+	+	✓	
	Rabiee	2008	NA	+	+	+	+	NA	-	+	+	+	✓	
	Rabiee	2014	-	+	+	+	+	-	-	+	+	+	✓	
Grey literature	Age UK	2013	-	+	+	+	NA	NA	NA	+	NA	NA	✓	
	Alzheimer's Australia	2011	NA	+	+	+	NA	NA	NA	+	NA	NA	✓	
	Hatton	2011	NA	+	+	+	NA	NA	NA	+	NA	NA	✓	
	KPMG	2012	NA	+	+	+	NA	NA	NA	+	NA	NA	✓	
	Newbonner	2014	NA	-	-	+	+	NA	NA	+	NA	NA	✓	
	Simons	2016	NA	+	+	+	+	NA	NA	+	NA	+	✓	
	Teshuva	2007	NA	+	+	+	+	NA	NA	+	NA	+	✓	

+ Satisfactory - Unsatisfactory U: Unclear NA: Not applicable

Appendix 4: Risk of bias assessment summary – Q1 systematic reviews

			Review question clearly and explicitly stated?	Inclusion criteria appropriate for the review question?	Search strategy appropriate?	Sources/resources used to search for studies adequate?	Appropriate criteria for appraising studies?	Critical appraisal conducted by 2+ reviewers?	Methods to minimize errors in data extraction?	Appropriate methods to combine studies?	Assessment of publication bias?	Recommendations for policy/practice supported?	Appropriate directives for new research?	INCLUDE	EXCLUDE
Peer-review	Ottmann	2013	+	+	+	+	+	+	+	U	-	+	+	✓	
Hand-search	Low	2011	+	+	+	+	+	+	+	+	+	+	+	✓	
	Manthorpe	2014	+	+	+	+	+	+	+	NA	U	+	+	✓	
	Zamfir	2013	+	+	+	+	+	U	+	+	U	+	+	✓	

+ Satisfactory - Unsatisfactory U: Unclear NA: Not applicable

Appendix 5: Risk of bias assessment summary – Q2 quantitative studies

			Inclusion criteria clearly defined?	Subjects/setting described in detail?	Exposure measured in reliable way?	Objective, standard criteria for measures?	Confounding factors identified?	Strategies for confounding factors?	Reliable outcome measures?	Appropriate statistical analysis?	INCLUDE	EXCLUDE
Peer-review	Bulamu	2017	NA	+	+	NA	NA	NA	+	+	✓	
Hand-search	Gethin-Jones	2012a	NA	+	+	NA	+	U	+	+	✓	
	Kajonius	2016	+	+	+	U	U	U	+	+	✓	
	Kwak	2017	+	+	+	+	U	U	+	+	✓	
	McGrath	2006	U	+	+	+	-	-	+	+	✓	
	Moran	2012	U	+	+	+	-	-	+	+	✓	

+ Satisfactory - Unsatisfactory U: Unclear NA: Not applicable

Appendix 6: Risk of bias assessment summary – Q2 qualitative studies

			Congruity between perspective and method	Congruity between method and question	Congruity between method and methods	Congruity between method and data	Congruity between method and data interpretation	Statement locating researcher culturally/theoretically?	Influence between researcher/research addressed?	Participants adequately represented?	Ethical research, evidence of ethical approval?	Conclusions flow from data analysis/interpretation?	INCLUDE	EXCLUDE
Peer review	Doyle	2012	+	+	+	+	+	+	+	+	+	+	✓	
Hand-search	Gethin-Jones	2012b	+	+	+	+	+	-	-	+	+	+	✓	
	Grigorovich	2015	+	+	+	+	+	-	-	+	+	+	✓	
	Grimmer	2015	-	+	+	+	+	-	-	+	+	+	✓	
	O'Rourke	2016	+	+	+	+	+	+	U	+	+	+	✓	
	Smith-Carrier	2017	+	+	+	+	+	-	-	+	+	+	✓	
	Snell	2011	+	+	+	+	+	+	+	+	+	+	✓	
	van Hoof	2011	+	+	+	+	+	-	-	+	+	+	✓	
Grey literature	Department of Health	2018	NA	+	+	+	+	NA	U	+	+	+	✓	
	Hatton	2011	NA	+	+	+	NA	NA	NA	+	NA	NA	✓	
	KPMG	2012	NA	+	+	+	NA	NA	NA	+	NA	NA	✓	
	Simons	2016	NA	+	+	+	+	NA	NA	+	NA	+	✓	

+ Satisfactory - Unsatisfactory U: Unclear NA: Not applicable

Appendix 7: Risk of bias assessment summary – Q2 systematic reviews

			Review question clearly and explicitly stated?	Inclusion criteria appropriate for the review question?	Search strategy appropriate?	Sources/resources used to search for studies adequate?	Appropriate criteria for appraising studies?	Critical appraisal conducted by 2+ reviewers?	Methods to minimize errors in data extraction?	Appropriate methods to combine studies?	Assessment of publication bias?	Recommendations for policy/practice supported?	Appropriate directives for new research?	INCLUDE	EXCLUDE
Hand-search	Ottmann	2013	+	+	+	+	+	+	+	U	-	+	+	✓	

+ Satisfactory - Unsatisfactory U: Unclear NA: Not applicable