

REVIEW ARTICLE

Choice and quality in home-based and community-based aged care: insights from two rapid evidence reviews

Nicholas J. R. Hunter* , Yvonne Wells , Samantha J. Clune, Beatriz P. Ayala Quintanilla and Erica Johnstone

College of Science, Health and Engineering, La Trobe University, Bundoora, Victoria, Australia

*Corresponding author. Email: n.hunter@latrobe.edu.au

(Accepted 10 July 2019; first published online 13 December 2019)

Abstract

As consumer-directed care programmes become increasingly common in aged care provision, there is a heightened requirement for literature summarising the experience and perspectives of recipients. We conducted rapid evidence reviews on two components of consumer experience of home- and community-based aged care: (a) drivers of choice when looking for a service (Question 1 (Q1)); and (b) perceptions of quality of services (Question 2 (Q2)). We systematically searched MEDLINE and EMBASE databases, and conducted manual (non-systematic) searches of primary and grey literature (e.g. government reports) across CINAHL, Scopus, PsychINFO, and Web of Science, Trove and OpenGrey databases. Articles deemed eligible after abstract/full-text screening subsequently underwent risk-of-bias assessment to ensure their quality. The final included studies (Q1: N = 21; Q2: N = 19) comprised both quantitative and qualitative articles, which highlighted that consumer choices of services are driven by a combination of: desire for flexibility in service provision; optimising mobility; need for personal assistance, security and safety, interaction, and social/leisure activities; and to target and address previously unmet needs. Similarly, consumer perspectives of quality include control and autonomy, interpersonal interactions, flexibility of choice, and safety and affordability. Our reviews suggest that future model development should take into account consumers' freedom to choose services in a flexible manner, and the value they place on interpersonal relationships and social interaction.

Keywords: consumer-directed care; home-based care; community-based care; personal budgets; aged care; ageing in place; individual budgets

Introduction

In the past few decades, models of aged care provision have attempted to increase consumer control, allowing consumers to choose services according to their needs and preferences, and offering them greater involvement in decision-making about how financial resources are spent. Such schemes are often collectively referred to as

‘consumer-directed care’ (CDC) or ‘individual budgets’ (IB), and view the consumer as capable of making informed choices and handling their service provisions. A number of international models have been implemented, including Consumer Directed Personal Assistance Programs and ‘Cash and Counselling’ schemes introduced in the United States of America (USA) during the 1990s (Heumann, 2003); personal budget models in the United Kingdom (UK) (Age UK, 2013); and the CDC scheme in Australia first piloted in 2010 (Department of Health and Ageing, 2012; Cash *et al.*, 2017). In the majority of these schemes, responsibilities are placed on the consumer, in conjunction with staff, to plan what services will be provided, who will provide the services and when they will be provided.

Given the advent of schemes with emphasis on consumer choice, it is increasingly important to consider the collective experience of recipients, and to identify the qualities of service packages that are most important to them. A systematic review by Ottmann *et al.* (2013) suggested that CDC-based services should offer a broad enough range of options to accommodate the wide range of needs and preferences of recipients. Another recent systematic review by Cash *et al.* (2017) highlighted the need for research into relationships between CDC recipients, carers and providers. However, a review of the key drivers of choice for consumers when choosing service providers and types, and their perceptions of quality in these services, has not been undertaken.

This paper documents the outcomes of two rapid evidence reviews that sought to understand the experience of consumers participating in CDC schemes. It was not our intention to provide a comprehensive overview of CDC policies, which might include more detailed analyses across political, economic and social contexts (*see Foster et al.*, 2005, San Antonio *et al.*, 2009; Ottmann *et al.*, 2013). Rather, our reviews focus explicitly on addressing two questions to inform assessment of consumer experience within CDC schemes:

- (1) What are the drivers of choice, in terms of expectations of the characteristics sought by consumers when looking for a home- or community-based aged care service?
- (2) What are consumers’ perceptions, or experience, of the quality of services and care in home- or community-based aged care?

We begin by introducing the context and search strategies for each rapid review. We then detail the results of both search strategies and identify common themes. Finally, we discuss the key outcomes and implications arising from both reviews, and draw conclusions on the consumer experience.

Method

Our two rapid reviews were conducted to compile studies investigating consumer experience of home- and community-based care services, and to consider implications for the development of future policy. Whilst rapid evidence reviews aim for rigour and systematic methods, it must be borne in mind that they may be more susceptible to bias than other types of reviews (Grant and Booth, 2009). This is an inevitable by-product of the speed with which they are produced. To control

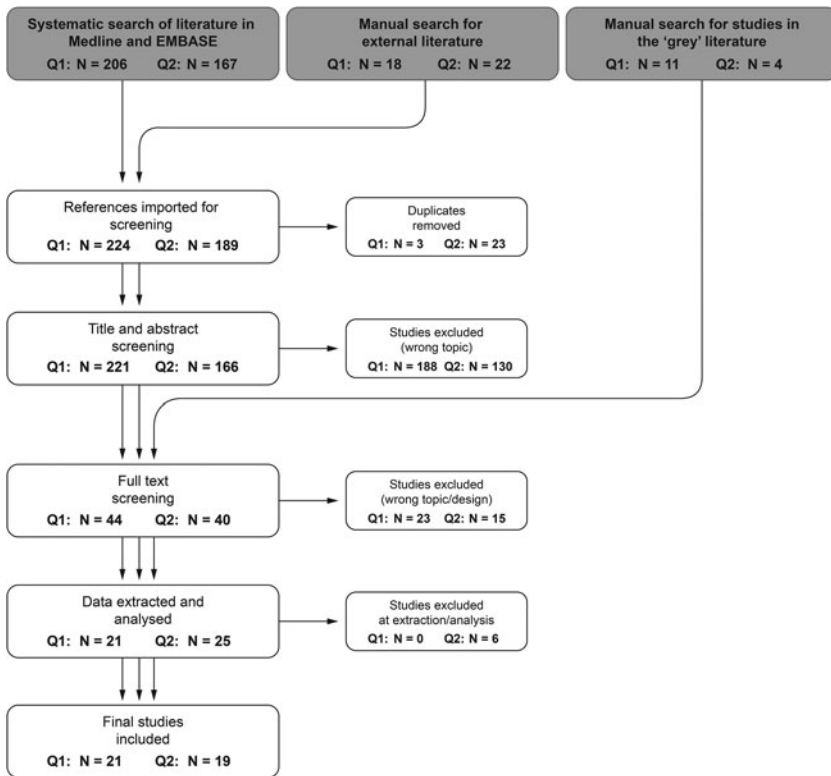


Figure 1. Overview of the literature screening and extraction process for both reviews.

Notes: Q1: Question 1. Q2: Question 2.

for this possibility, we have presented our workflow (see Figure 1) and the search terms (see Table S1 in the online supplementary material) that elicited this review's data.

We also included qualitative research in our searches, as studies involving perceptions and experiences may rely on use of such methodologies as exploratory techniques. We conceptualised home-based and community-based care as follows:

- 'Home-based care' covers personal care services (e.g. bathing, dressing), home adaptations (e.g. handrails, lift access), equipment procurement and maintenance, and domestic assistance.
- 'Community-based care' covers assistance with all services that are not based in the home (e.g. shopping and banking) and centre-based day care and respite.

Respite services for carers were also included in our search strategies, but not services that focus on carers only (e.g. educational services, counselling).

Search strategies

The workflow for both search strategies is presented in [Figure 1](#). In both cases, we systematically searched MEDLINE and EMBASE databases (for search strategies, see Table S8 in the online supplementary material). In addition to their wealth of literature, these databases were chosen as they support Medical Subject Headings indexing, which allowed us to capture relevant articles that were not explicitly linked to the search terms. For Question 1 (Q1), search terms specifically focused on research on aged care services where ‘choice’ in how resources are allocated is an essential component of the service. Our search strategy made use of the range of terminologies that collectively refer to CDC (see Table S1 in the online supplementary material). For Question 2 (Q2), search terms focused on identifying what older consumers value in terms of how their care services (home- or community-based) are provided.

In response to any limitations of our search terms in capturing appropriate literature, we performed additional manual (non-systematic) searches of primary literature across CINAHL, Scopus, PsychINFO and Web of Science. To expand the scope of the review further, we also searched the grey literature (*e.g.* government and evaluation reports) using Opengrey, APO, Trove and Google (regions set to Australia, New Zealand, UK, USA and Canada). In both cases, search terms included ‘consumer-directed care’, ‘cash for care’, ‘personal budgets’, ‘individual budgets’, ‘cash for counselling’, ‘self-directed care’, ‘self-directed support’, ‘ageing in place’ and ‘direct payments’. Limiters included ‘older persons’, ‘elderly’, ‘aged’ and ‘older people’ and were connected to search terms by the Boolean operator ‘AND’. Truncations and wildcards were used where appropriate. All searches took place between March and April 2018.

Inclusion and exclusion criteria

For both reviews, studies were included if they: (a) were written in English; (b) were published between 2007 and 2017, thus containing the most up-to-date knowledge; (c) reported data from countries with well-developed aged care frameworks and health-care systems; (d) included participants aged 50 and over (45 years for indigenous participants); and (e) focused on drivers of choice (Q1) or perceptions of quality (Q2) in home- or community-based aged care services where consumer choice is relevant (*e.g.* CDC, personal budget schemes). Studies were excluded in both cases if they reported: (a) drivers of choice (Q1) or perceptions of quality (Q2) in residential aged care facilities or retirement villages; (b) experiences of parties other than the consumer (*e.g.* family members, care-givers); and (c) data from countries with emerging (and thus non-comparable) systems of home- and community-based aged care.

Screening, extraction and evaluation process

Literature screening and extraction was undertaken by a team of four research assistants (RAs). Title/abstract and full text screenings for the systematic search were undertaken independently by two RAs using the Covidence software package (<https://www.covidence.org>). All studies that met the inclusion criteria and

scope of the review proceeded to the data extraction stage. A third RA was appointed to screen studies where consensus on eligibility was not met. All RAs participated in conducting manual searches and compiling studies that met the inclusion criteria. Once duplicates were removed, eligible studies underwent full-text screening, from which all studies fitting the scope of the review proceeded to data extraction.

For extraction of both qualitative and quantitative studies, RAs used a modified version of Cochrane's data collection form (<https://dplp.cochrane.org/data-extraction-forms>). To ensure replicability and validity in our findings, each article included in the rapid reviews underwent a risk of bias assessment following data extraction. For qualitative and systematic review articles, we used the Joanna Briggs critical appraisal criteria (Table 1; <http://joannabriggs.org/research/critical-appraisal-tools.html>). For quantitative studies, we used a modified form of the Joanna Briggs critical appraisal checklist that combined evaluation criteria across cohort, randomised controlled trial and cross-sectional analysis studies. Risk of bias assessments were undertaken by the RAs, and a member of the research team with expertise in the field. Table 1 summarises evaluation criteria used to assess each of the study types. Any publications that did not satisfy the evaluation criteria, or were deemed to not meet the study scope and criteria, were excluded at the extraction stage. Included studies that satisfied the critical appraisal checklist were then presented before the wider research group, from which key themes were identified.

Results

Summary of included studies

The search strategy for Q1 identified a total of 235 articles (MEDLINE/EMBASE: 206; CINAHL: 18; grey literature: 11). From this initial data-set 214 articles were excluded at screening and extraction rounds, leaving 21 articles for data extraction and risk of bias assessment (MEDLINE/EMBASE: 4; CINAHL: 12; grey literature: 5). The search strategy for Q2 identified 193 articles (MEDLINE/EMBASE: 167; CINAHL: 22; grey literature: 4). From this data-set we excluded 174 articles at the screening and extraction rounds, leaving a total of 19 articles for data extraction and risk of bias assessment (MEDLINE/EMBASE: 2; CINAHL: 13; grey literature: 4). Two studies were identified in both Q1 and Q2 search strategies (Moran *et al.*, 2013; Ottmann *et al.*, 2013).

Over half of the 40 studies and reports included in the reviews were qualitative (22 studies; Table 2) and conducted in one of seven countries (Australia, Canada, Korea, The Netherlands, France, the UK and the USA), with a substantial proportion of the identified literature being Australian. Tables 3–8 summarise data extracted from included studies for Q1 and Q2. Risk of bias assessments associated with these studies are available as supporting material (see Tables S2–S7 in the online supplementary material). The extracted studies for Q1 and Q2 were found to have minimal bias, with some minor observations: (a) it was often unclear in quantitative studies how confounding factors were identified and addressed; and (b) a number of qualitative studies did not address any influence between the researcher and the topic addressed (see Tables S2–S7 in the online supplementary material).

Table 1. Evaluation criteria for assessing quantitative and qualitative primary articles, and systematic reviews

	Include (+)	Exclude (-)	Unclear (U)	N/A
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 a 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 <i>vice versa</i> , 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?			

Table 1. (Continued.)

	Include (+)	Exclude (-)	Unclear (U)	N/A
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 minimise 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?				

Note: N/A: not available.

Services that consumers choose (Q1)

The studies included in Q1 revealed that choices in CDC and IB schemes are driven by several key factors, including needs for security and personal assistance (Day *et al.*, 2017), desire for autonomy (Woolham *et al.*, 2017), extent of mobility (Newbronner *et al.*, 2011; Age UK, 2013; Moran *et al.*, 2013; Harrison *et al.*, 2014), social/leisure needs (Age UK, 2013; Harrison *et al.*, 2014; Manthorpe *et al.*, 2015), valuing flexibility (Low *et al.*, 2011; Norrie *et al.*, 2014; Kaambwa *et al.*, 2015; McCaffrey *et al.*, 2015) and addressing unmet needs (Rabiee *et al.*, 2008).

A study by Rabiee *et al.* (2008) indicated that interviewees' priority was generally to secure personal assistance, through directly employed personal assistants, agency staff or paying family carers. Consumers also intended to spend their IBs on: transport to 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.

Moran *et al.* (2013) identified unmet needs as shaping consumers' expectations about the provision of packages in the future. This study showed that older people in the UK used their IBs to purchase conventional mainstream services and personal assistance. Some (15 per cent) spent part of the IB on leisure activities. Recipients' plans for using their IBs included: purchasing small pieces of equipment, including rails to aid mobility, bathroom adaptations to make personal care easier, personal alarm systems, adapted footwear and specialised chairs; paying for transport to enable the older person to continue to attend church; allocating

Table 2. Summary of quantitative, qualitative and systematic review articles in the included studies

	Quantitative	Qualitative	Reviews
Q1:			
Peer review	3		1
Hand search	4	5	3
Grey literature		5	
Q2:			
Peer review	1	1	
Hand search	5	7	1
Grey literature		4	

Note: Some studies appear in both Question 1 (Q1) and Question 2 (Q2) reviews.

money to maintain hobbies and attend related courses; acquiring support to attend community activities; and earmarking money to purchase a computer and broadband router to enable the older person to retain independence (*e.g.* through online shopping). Some participants planned to use their 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 by a small proportion (*e.g.* for purchasing agency care when their personal assistant took holidays). The drivers of these choices were not identified.

Similarly, the study by Newbronner *et al.* (2011) on personal budgets (PBs) in the UK found that older persons were most likely to use their PB to pay for regular personal care or help with getting out and about. A significant proportion employed personal assistants, usually with the help of a support provider organisation. A few PB holders employed family members or friends as personal assistants. The study by Newbronner *et al.* (2011) 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 spent discussing PBs with staff was critically important.

In the CDC pilot in Australia, most participants chose the same types of services as those available under standard packaged care but 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 the study by Simons *et al.* (2016) of Brotherhood of St Laurence clients, which found that most respondents prioritised personal care or domestic services over a social support programme.

Consumer perspectives on CDCs and IBs

The literature also highlighted several issues pertaining to the administration of CDC and IB/PB initiatives, which may have considerable impact on consumers'

Table 3. Data summary for studies in Q1, collected using a manual search.

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Day et al. (2017)	Australia	Explore experiences and perceptions of older people using home care package services.	5 older people.	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.	81 - 91 years.	N/A	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?	Four themes identified: seeking quality and reciprocity in carer relationships; patchworking services; the waiting game; and technology with utility. Carer relationships: Respondents had concerns about whether they would like their carers, if carers would like them, or if carers would appreciate their care preferences. Participants preferred carers who were accommodating, proactive and adaptable to their changing circumstances and needs. All participants sought good relationships with care coordinators, and wanted frequent contact. 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 often wait a long time for their home care package, creating problems with care continuity and support.

Table 3. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Gill et al. (2017)	Australia	Identify challenges affecting staff, their clients and carers, with the introduction of Consumer Directed Care (CDC).	N= 25 consumers N= 18 staff N= 14 carers	Qualitative phase of mixed methods, sequential study Semi-structured interviews with professionals, carers and consumers;	Consumers: 51-80+ years Staff: >61 years Carers: >50 years	Consumers: 15 (60%) female Staff: 17 (94%) female Carers: 10 (71%) female	Derivation of themes through iterative inductive process.	Technology with utility: Older participants were using a range of digital technologies to meet communication, security and safety needs. Four themes identified: 1. Culture. Existing organizational culture may affect consumer activity by way of: (formal) lack of rapport between carer and consumer; lack of organizational flexibility with adjusting services according to changing consumer needs 2. Change: Role change on part of consumer was welcome in its autonomy but not supported with 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. 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	Investigate relationships between clinically assessed care needs and expectations of care of older people and carers	55 community-dwelling older adults and carers	Quantitative study (Cross-sectional study). Government-subsidised community care services. Interviews	Older people: 80.7 years (mean) Carers: 64.6 years (mean)	Older people: 36 (66%) female Carers: 27 (73%) female	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. 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, and received four times as much informal help.
------------------------	-----------	--	---	---	--	--	--	---

Table 3. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Low et al. (2011)	Australia	Evaluate outcomes of case managed, integrated or consumer directed (home and community) care for older persons	Search Yield 34,816 articles 163 Full text articles	Systematic Review from 1994 –May 2009 35 papers included in the review	N/A	N/A	Inclusion Criteria for article review 1. In English 2. Evaluating the delivery of case managed, integrated or Consumer Directed Care (CDC) 3. 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.
Manthorpe et al. (2015)	Scotland	Investigate and review literature on the outcomes of self-directed support to inform evaluation of the scheme in 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	N/A	N/A	Themes: Barriers to and facilitators of implementing self-directed support (SDS)	Little evidence regarding how to sustain the changes and demands of SDS; it is important 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 attention may be required.

McCaffrey et al. (2015)	Australia	Determine features of consumer-directed, home-based support services most important to users and carers	17 older people 10 informal carers	Discrete choice experiment (DCE) Qualitative semi-structured interviews	Older people: 72-90+ years Carers: 51-90 years	Older people: 11 (64%) female Carers: 7 (70%) female	Aim: Determine what features (attributes) of consumer-directed (CDC), home based support services are important to older people and their informal carers	Leadership is a necessity for major change. Research in this area should be utilized by policy makers.
<p>Eight themes identified:</p> <ol style="list-style-type: none"> 1. Information and knowledge 2. Choice and control 3. Self-managed continuum 4. Effective co-ordination 5. Effective communication 6. Responsiveness and flexibility 7. Continuity 8. Planning 								
<p>Six service features characterizing consumer preferences for the provision of home-based support services models identified:</p> <ol style="list-style-type: none"> 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 								
<p>The desired level of self-management varies, with some individuals preferring provider-management, some desiring complete autonomy, and others in-between.</p>								

Table 3. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Moran et al. (2013)	UK	Investigate impact and outcomes for older people engaging in Individual Budget (IB) pilot scheme	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)	Secondary analysis of RCT Semi-structured face-to-face interviews, collected 6 months after a randomized controlled trial (Glendinning et al., 2008).	81 years (mean)	174 (66%) female	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 Interviews aimed to explore older people's experiences of planning how to use IBs.	Value of support received by older persons was consistently less than that received by a younger disabled person with similar activities of daily living (ADL) restrictions. 53% of older people used IBs to purchase conventional mainstream services (e.g. home care, meals) and personal assistance (41%). 15% spent part of IBs on leisure activities. IB group scored higher on GHQ-12 and had worse self-rated health than the comparison group, but better ASCOT scores. <i>Qualitative outcomes</i> Older people more likely to report plans based on personal care and domestic support and less likely to report wider plans (e.g. leisure activities). Older people granted lower value IBs had restricted ability for care services. Plans for using IBs included: purchasing small pieces of equipment (e.g. mobility rails); house adaptations; personal alarm systems; adapted footwear; transport costs; money to maintain hobbies and attend related courses;

								<p>support to attend community activities; money to purchase a computers and broadband routers. Contingency planning was considered important to a small proportion (e.g. purchasing agency care when personal assistant takes holidays).</p> <p>Some older people reported anxieties about the management and administration of the budget, particularly with respect to directly employing staff (i.e. personal assistants).</p>
Norrie et al. (2014)	UK	Investigate consumer experiences with introduced individual personal budget scheme for older people in local authority	N=7 older people and carers in receipt of personal budgets	Qualitative structured interviews	N/A	N/A	<p>Research questions:</p> <ol style="list-style-type: none"> 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 	<p>Consumers valued:</p> <ol style="list-style-type: none"> 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	Investigate experiences and outcomes of early individual budget (IB) users	N=14; (9 service users; 5 proxies)	Qualitative semi-structured interviews, 2-3 months after first being offered IBs	18-85 yrs	N/A	<p>Previous support arrangements</p> <p>Experience of (self-) assessment and support planning</p> <p>(Anticipated) impacts of IBs</p>	<p>Six interviewees had received direct payments. Most had personal assistants visiting on a regular basis. Some interviewees complained about the lack of flexibility, consistency, and unreliability of these arrangements. Direct payments were considered restrictive.</p>

Table 3. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
								<p>A key priority for interviewees receiving direct payments was to plan personal assistance. Other purchases included transport, care equipment and respite care.</p> <p>Interviewees considered the most important aspect of IBs was choice and control. IBs had also enhanced their sense of identity and self-esteem. Some were unsure about what an IB was.</p>
Rabiee & Glendenning (2014)	UK	Report experiences and satisfaction of older people using council-managed personal budgets (PBs) to fund home care services	18 participants Care delivery between 6wks and 5 yrs	Qualitative multiphase project – article reports on one phase Semi-structured interviews Jan 2011- Dec 2012	65- 98 years	15 (83%) women	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	<p>Most interviewees were satisfied with agency services, but many did not know the details of their allocated budget. Many felt they had improper knowledge of home care markets to make informed choices. Many wanted more choice and flexibility over how to use budgets.</p> <p>Some had changed their (formal) carer. However, most who were not satisfied with care workers put up with them because they did not want to “make a fuss”.</p> <p>Interviewees expressed reluctance to ask for additional tasks from care workers.</p>

Woolham et al. (2017)	UK	Compares outcomes of older direct payment users and recipients of personal budgets (PB)	339 respondents 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	Direct payment: 84.3 years (mean) Managed PB: 85.8 years (mean)	Direct payment: 633 (71.7%) female Managed PB: 705 (72.4%) female	EQ-5D-3L (health status) Sheldon-Cohen Perceived Stress Scale Adult Social Care Outcomes Toolkit (ASCOT: social care-related quality of life)	No difference in outcomes between direct payment and 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.
Zamfir (2013)	UK	Investigate and review effectiveness of personalisation through personal budgets for older people in England	68 documents reviewed	International literature review of quant, qual and grey literature data 1995-2012	N/A	N/A	N/A	Broad themes extracted from literature: 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. Some evidence that PBs could improve outcomes of older people, but only if amount is sufficient and adequate support is available.

Table 4. Data summary for studies in Q1, collected using a manual search of grey literature.

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Age UK (2013)	UK	<p>Highlight what older people want from their care and support</p> <p>Identify what works (in terms of various services)</p> <p>Demonstrate how the voluntary sector can support the local authority to achieve outcomes.</p>	N/A (years not stated)	Review of evidence within 'manual'; (Chapter 2)	N/A	N/A	<p>Guide for social service providers</p> <p>Chapter 2 summarises research findings.</p>	<p>Older people want choice and control with care services and how they are delivered. Key values older people identify are: (i) support from named personnel; (ii) minimal bureaucracy; (iii) strong care provider relationships; (iv) social and community involvement; (v) assistance with creative support arrangements; and (vi) the same types of help.</p> <p>People with care and support needs require accessible information and advice, access to person-centred support, help with understanding care possibilities, and assistance with planning.</p>
Hatton & Waters (2011)	UK	Survey personal budget holders and family carers of people holding personal budgets on their experiences.	1,114 PB holders responded to survey;	<p>Programme evaluation</p> <p>Implementation of POET Survey (Personal Budget Outcome Evaluation Tool)</p> <p>10 local authorities across UK</p> <p>Online and paper formats</p>	<p>26% aged 16-44</p> <p>31% aged 45-64</p> <p>43% aged 65+</p>	61% female	Survey focus: Factors associated with positive outcomes for PB holders and carers	<p>PB holders and carers reported positive overall experiences, although experiences related to processes were varied.</p> <p>Older people were more likely than other groups (e.g. young adults) to have their PBs managed by third parties (e.g. councils), and were more likely than other groups to not know it was managed.</p> <p>Most respondents expressed lack of clarity with their PBs, particularly with acceptable purchases.</p>

								Positive outcomes fostered by:
								<ol style="list-style-type: none"> 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	Determine to what extent CDC is 'person-centred', and how it increases choice and control for participants, and enhances community-based care.	124 CDC participants and 126 standard packaged care recipients.	Programme evaluation evaluating 700 CDC packages approved in November 2010 Paper-based surveys to all CDC participants and packaged care and respite comparison groups Semi-structured interviews	N/A	N/A	<p>Evaluation foci:</p> <ol style="list-style-type: none"> 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 	<p>Key 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.</p> <p>Reasons for participating in the CDC pilot were:</p> <ol style="list-style-type: none"> 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 <p>Most CDC participants and carers satisfied with their level of choice and options.</p>

Table 4. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
								Participants typically chose the same services as those falling under standard packaged care, and exercised choice and control over services delivery. However, many participants also used funds for 'non-traditional' supports, goods and services (e.g. holidays, gym memberships, television subscriptions).
Newbronner et al. (2011)	UK	Examine personal budgets (PB) processes and practices from people with mental health problems and older people by investigating the front-line experience of service users and their carers	69 personal budget recipients and carers	Programme evaluation Case study methods: focus groups and interview data Five Local Authorities- rural and urban	N/A	48 (69%) female	Research foci: 1. Moving to a personal budget 2. Assessment and resource allocation 3. Support planning and setting up services 4. Managing personal budgets	<p>PB holders and carers require clear definitions of PBs, how they can be used, what services can be funded, and consumer responsibilities.</p> <p>Many older PB holders were confident about what they wanted in their support plan. Many felt their choices were respected.</p> <p>Older PB holders often use their PB to pay for regular personal care (e.g. personal assistants).</p> <p>Some areas of expenditure are unclear, and PB holders have trouble differentiating luxuries from necessities.</p> <p>A variety of supports and services were funded by PB holders: residential respite, day services, warden call systems.</p> <p>Key findings:</p>

								<ol style="list-style-type: none"> 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	Evaluate consumer's experience of BSL Home Care Package and their adjustment to the new model of service delivery under the Consumer Directed Care (CDC) framework.	45 participants	Programme evaluation /Action research Structured interviews with consumers and/or carers	N/A	28 (62%) female	<p><i>Study foci:</i></p> <p>How well consumers understood the elements of CDC</p> <p>How well consumers understood new case management arrangements under BSL model</p> <p>How consumers felt about the information provided them</p> <p>What changes they experienced to services delivered and activities</p> <p>Attitudes to acceptance of new budget arrangements</p> <p>The introduction of monthly financial statements</p>	<p>Many participants confused about CDC terminology, required guidance from case managers.</p> <p>Participants appreciated flexibility to coordinate their own services, particularly with respect to meeting urgent needs.</p> <p>Participants also felt a sense of independence, and confidence in their own ability to coordinate their care. Freedom in choosing services considered important.</p>

Table 5. Data summary for studies in Q1, collected using a systematic search.

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Davitt & Kaye (2010)	USA	Analyse historical policy changes related to use of home health care	Medicare Beneficiaries 65 years and older, all genders Analyses of home health care use of 2,437 users, before and after Interim Payment System (IPS).rollout Medicare Current Beneficiary Survey (MCBS), 1998.	MCBS Sample is a stratified multistage area probability design Secondary data analysis.	N/A	N/A	Race Health status Activities of Daily Living (ADLs) Other predisposing and enabling control variables were: <ul style="list-style-type: none">• 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%. Skilled nursing facility (SNF) care days per user decreased, while SNF stays increased 26%. The number of White users decreased, whereas those with other racial backgrounds increased. Study suggests that Medicare beneficiaries above the poverty line, but with limited resources, may have difficulty addressing home health care needs if unable to purchase private care.
Kaambwa et al. (2015)	Australia	Investigate features of CDC most important to Australian consumers and informal carers of consumers and identify factors that may influence clients' preferences for particular attributes.	117 study participants (87 consumers; 30 informal carers) 86% of informal carers lived with their spouse	Survey (face-to-face) Cohort study Discrete Choice Experiment (DCE) approach Comparison on Quality of life with Australian norms	Consumers: 80 years (mean) Carers: 74 years (mean)	Consumers: 75% (female) Carers: 53% (female)	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: <ul style="list-style-type: none">• 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

							<ul style="list-style-type: none"> • 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 	<p>be restricted by agencies, activities, or set care workers. Consumers also want to be able to choose services from multiple service providers.</p> <p>Consumers and informal caregivers felt that community aged care packages contribute to a consumer's QoL. Decisions about service types included in the care package should be jointly made by the service provider and the consumer and/or their informal carer. In some cases, consumers delegated decision-making to the provider.</p> <p>Most participants said consumers should be able to purchase additional services not covered in standard packages, if appropriate funds are available.</p>
Low et al. (2015)	Australia	Investigate factors associated with waiting times for home care packages and outcomes for care recipients (and non-recipients) and carers.	Older persons (N=55) Carers (N=37)	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	Consumers (package): 81.0 years (mean) Consumers (no package): 80.3 years (mean) Carers (package): 66.0 years (mean) Carers (no	Consumers (package): 24 (80%) female Consumers (no package): 12 (48%) female Carers (package): 14 (63.6%) female Carers (no	<p><i>Sociodemographic:</i> age, gender, marital status, language spoken at home, previous occupation and education for both participants and carers.</p> <p><i>Care needs: Care Needs Assessment Package (V2).</i> 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),</p>	<p>54% of participants were offered a package; 33% were not offered a home care package.</p> <p>Factors associated with being offered a home care package: gender, high baseline QOL; but not needs, unmet needs, neuropsychological symptoms, cognitive status and carer burden.</p> <p>Receiving home care package did not affect the participants' level of needs, unmet care needs, or QOL.</p>

Table 5. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
					package): 62.7 years (mean)	package): 13 (86.7%) female	coded as not identified, met or unmet. Carer needs identified with 11-item scale. <i>Care services</i> : Number and hours of the participants' current formal services (provided by government or private agencies). Hours of informal care. <i>Satisfaction with care</i> : modified 22-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) <i>Quality of life</i> : 13-item Quality of Life in Alzheimer's Disease. Symptoms: Carers rated participants on the 12-item Neuropsychiatric Inventory .	Receiving home care package was associated with decreased carer burden.
Ottmann et al. (2013)	Australia	Review and establish 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	N/A	N/A	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).	<i>Consumer-Directed Personal Assistance Services (CDPAS)</i> No difference between CDC and agency-directed care with respect to service satisfaction, unmet needs and safety/ security. <i>Cash for Counselling</i> Some consumers wanted greater participation in decision-making processes. Others expressed satisfaction

with existing agency-directed services.

Individual budgets

Consumers reported better service satisfaction outcomes and sense of control than those using agency-directed care. Many older people did not want additional planning and management responsibilities (e.g. employing support staff).

Review findings suggest that consumer-directed care approaches have the potential to empower older people.

Table 6. Data summary for studies in Q2, collected using a manual search.

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Gethin-Jones (2012a)	UK	Examine whether altering the delivery of care to an outcome-focused model would improve participant well-being	40 service users of home care delivery from one English local authority	Quantitative study (longitudinal study with two cohort groups). Questionnaires (face to face).	76.4 years (mean).	22 (55%) females	Two validated questionnaires: (i) Measure Yourself Medical Outcomes Profile (MYMOP); (ii) and Measure Yourself Concerns and Wellbeing (MYCAW). Additional questions added to measure social isolation and satisfaction with paid care.	Participants considered relationships with their carers as very important. The outcome-focus care model provided extra contact time with carers, which increased personal wellbeing. Group receiving outcome-focused care showed greater improvement in subjective well-being compared with comparison group.
Gethin-Jones (2012b)	UK	Investigate why outcome focussed care was associated with increased participant well-being (Gethin-Jones 2012a)	20 service users of home care delivery from one English local authority	Qualitative study Two semi-structured interviews; one interview at the start of the intervention and one at the six-month stage.	76 years (mean)	13 (65%) females	The purpose of the interviews was to examine why the participants felt change had happened in the case of outcome-focused care and also why change had not happened with the traditional model of time/task provision.	Participants considered the following important: <ul style="list-style-type: none"> • The ability to establish relationships with the homecare workers providing care. • The need to target more flexible/consistent care packages to them. <p>Additional measures in perceiving quality:</p> <ul style="list-style-type: none"> • Consistency in care delivery. • Flexibility in care delivery. • Prioritizing delivery of care to socially isolated consumers.

Grigorovich (2016)	Canada	Understand how older lesbian and bisexual women who receive home care services define 'quality of care'	16 women who to self-identified as lesbian or bisexual, ≥55 years. Service users receiving publicly funded home care in Ontario, Canada.	Qualitative study comprising semi-structured interviews.	64 years (mean)	N/A		<p>Participants discussed the following provider qualities:</p> <ul style="list-style-type: none"> • Attentive and responsive to client needs • Involved clients in decision-making and allowed them to direct their care. • Were aware of users' feelings of vulnerability and could take responsibility for establishing comfortable caring environments.
Grimmer et al. (2015)	Australia	Investigate older people's experiences and perspectives for planning and experiencing aging-in-place.	23 community dwelling residents in South Australia. 14 individuals, and 9 with a companion	Semi structured, audio recorded and transcribed interviews	Individuals aged 65+ years.	24 (57% female)		<p>General discussion of desirable service qualities included:</p> <ul style="list-style-type: none"> • "Targeted, timely, affordable and self-directed" • Flexible according to changing functional and cognitive needs of consumer • Adequately subsidized to enhance affordability
Kwak et al. (2017)	South Korea	Examine care satisfaction in nursing homes and at home among South Korean	246 elderly individuals in receipt of welfare benefits (N=123 in	Cross-sectional study. Survey design with structured interviews	Homecare: 45.5% >85 years	Homecare: 82 (66.7%) female	This study examined care satisfaction in a nursing home and at home among low-income elders in South Korea:	<p>Quality measured on two levels: <i>Quality of Services:</i></p> <ul style="list-style-type: none"> • Service information • Contact availability

Table 6. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
		low-income elders	home care recipients)				<ul style="list-style-type: none"> • Quality of Services • Quality of caregivers 	<p><i>Quality of caregivers:</i></p> <ul style="list-style-type: none"> • Reliability • Professionalism • Sensitivity • Respectfulness • Friendliness • Safeguarding
McGrath et al. (2006)	Australia	Investigate the potential need for respite in Indigenous communities. Study undertaken to inform development of an innovative model for Indigenous palliative care.	Older Aboriginal adults (n = 10), carers (n = 19), Aboriginal healthcare workers (n = 11), healthcare workers (n = 30) and interpreters (n = 2).	Cross sectional Design Open-ended, qualitative interviews	N/A	N/A		<p>Quantity and quality of the availability of respite centres seen as a perception of quality.</p> <p>Identified lack of resources <i>Perceptions of quality</i></p> <p>Participants described a serious lack of services for Indigenous people, either community-based or inpatient, and emphasised needs for respite.</p> <p>Many Indigenous people do not want to leave their homes to access services. Many have never left their community, and don't want to be relocated away from carers.</p> <p>Participants suggested respite centres in rural and remote locations, and support for families within the community to provide local respite.</p>

Moran et al. (2013)	UK	Investigate impact and outcomes for older people engaging in Individual Budget pilot scheme	263 Older persons receiving individual budgets IB group= 142; 44 with proxy, Non IB group 121; 31 with proxy	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	81 years (mean)	174 (66%) female	Older people's experience of cash-for-care schemes: evidence from the English Individual Budget pilot projects. Exploring: <ul style="list-style-type: none"> • General Health • Social Care Outcomes • Self-perceived Health 	Quality viewed as: <ul style="list-style-type: none"> • 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	Understanding the relationship between older people's experience of 'self' and their personalised care services	8 recipients of individual budgets	Narrative study with in depth narrative interviews	N/A	N/A	Perspectives of consumers to assess the relationship between participants' individual experiences of self and personalised services.	Services perceived as 'quality' if the consumer feels they are able to preserve their sense of self within the structure of provided care
Ottman et al. (2013)	Australia	To establish an evidence base of user preferences for satisfaction with services associated with CDC programs for older people	17 references included in review; quant and qual papers	Systematic review exploring Older Peoples experiences with CDC and considering implications for model development	N/A	N/A	Measuring how the current evaluation of CDC translates into practice	Perceptions of quality include: <ul style="list-style-type: none"> • Flexibility in service delivery according to changing health requirements • Ability to increase or decrease agency involvement in care design as desired by older person

Table 6. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
								<ul style="list-style-type: none"> Ability to collaborate in service design with agencies
Rioux et al. (2011)	France	Investigate residential satisfaction in elderly persons ageing in place; and identify demographic and psychological variables related to this residential satisfaction	103 participants living at home in Central France.	Qualitative study using a purpose developed questionnaire	79.8 years (mean)	64 (62%) female	Residential Satisfaction	<p>Older people's overall residential satisfaction corresponded to:</p> <ol style="list-style-type: none"> Local area satisfaction; Their satisfaction with accessibility to services; Satisfaction with relationships with neighbours Home satisfaction
Smith-Carrier et al. (2017)	Canada	Explore experiences of patients accessing home-based primary care (HBPC) delivered by interprofessional teams	26 patients accessing HBPC	Qualitative study using in-depth patient interviews	>65 years.	N/A	Open-ended questions (e.g. 'Can you tell me about your experiences receiving HBPC?'; 'What is it about receiving HBPC care that you dis/like?')	<p>Most participants wanted to receive a patient-centred care. Participants considered that HBPC was essential because most were unable to go outside alone.</p> <p>Participants preferred using HBPC because health care providers gave them more time and attention.</p> <p>HPBC promoted better care base on patients' preferences and needs at home, where majority of participants felt most comfortable.</p>

Snell et al. (2011)	Australia	Investigate relationship between patients' perceptions of emotional intelligence (EI), health competence, service quality, and adherence behaviour to a government initiated well-being enhancement program (Home Medicines Review)	20 participants	Qualitative study using in depth interviews	44-90 years, majority of respondents (15) >65 years	12 (60%) female	<p>Patients were asked to describe the factors that they believed were essential for a quality HMR.</p> <p>Service quality had three dimensions:</p> <ol style="list-style-type: none"> 1. interpersonal 2. technical 3. administrative <p>Interpersonal included trust, rapport, respect and communication.</p> <p>Technical quality based on judged on perceived knowledge, credentials and perceived experience.</p> <p>Administrative issues had two core themes: timeliness and collaborative support.</p>	<p>Patients' perceptions of service quality influenced by emotional intelligences and health competence.</p> <p>Female respondents more emotionally intelligent than males. Males mentioned difficulties interacting with people.</p> <ol style="list-style-type: none"> 1. Consumers' assessment of service quality could be influenced by their own health and emotional states.
Van Hoof et al. (2011)	Netherlands	Investigate needs related of older people ageing-in-place and receiving ambient intelligence technologies	18 older community dwelling individuals.	Qualitative interpretive approach. Semi-structured interviews with recipients of ambient technology.	79.2 years (mean)	14 (88%) female	<p>Evaluating implementation of 'ambient' in home technology:</p> <ol style="list-style-type: none"> 1. Needs and motives of users. 2. Solutions offered by introduction of ambient technology. 	<p>Participants felt and increased sense of safety in own home after installation of technology.</p> <p>Participants' increased sense of safety enhanced wellbeing and their desire to remain in their homes.</p>

Table 7. Data summary for studies in Q2, collected using a manual search of grey literature.

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Australia Government Department of Health (2018)	Australia	Measure experiences and perceptions of My Aged Care scheme, following the introduction of an 'Increasing Choice in Home Care' reform.	215 consumers (Home Care Package participants) and 300 service providers.	Survey	<70 years: 21% 70-74 years: 17% 75-79 years: 21% >80 years: 40%	153 (71%) female	Survey measured satisfaction with My Aged Care scheme, within the context of the implemented Increasing Choice reforms.	<p>Most participants indicated satisfaction with: the services they received (85%); services matching their personal expectations (86%); and the general standard and suitability of the services (> 80%).</p> <p>Most consumers did not want to change providers. Of the few consumers contemplating changing their providers (7%), the main reasons were lack of satisfaction with service quality and staff delivering services.</p> <p>Most consumers (65%) indicated satisfaction with the amount of time they had for decision-making on provider choices.</p>
Hatton & Waters (2011)	UK	Survey personal budget holders and family carers of people holding personal budgets on their experiences.	1,114 PB holders responded to survey;	Programme evaluation Implementation of POET Survey (Personal Budget Outcome Evaluation Tool) 10 local authorities across UK Online and paper formats	26% aged 16-44 31% aged 45-64 43% aged 65+	61% female	Survey focus: Factors associated with positive outcomes for PB holders and carers	<p>PB holders and carers reported positive overall experiences, although experiences related to processes were varied.</p> <p>Older people were more likely than other groups (e.g. young adults) to have their PBs managed by third parties (e.g. councils), and were more likely than other groups to not know it was managed.</p> <p>Most respondents expressed lack of clarity with their PBs, particularly with acceptable purchases.</p>

								Positive outcomes fostered by:
								<ol style="list-style-type: none"> 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	Determine to what extent CDC is 'person-centred', and how it increases choice and control for participants, and enhances community-based care.	124 CDC participants and 126 standard packaged care recipients.	Programme evaluation evaluating 700 CDC packages approved in November 2010 Paper-based surveys to all CDC participants and packaged care and respite comparison groups Semi-structured interviews	N/A	N/A	Evaluation foci:	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:
							<ol style="list-style-type: none"> 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 	<ol style="list-style-type: none"> 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 <p>The majority of CDC participants and carers were satisfied with their level of choice and options in relation to supports, though some participants expressed dissatisfaction</p>

Table 7. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Simons et al., (2016)	Australia	Evaluate consumer's experience of BSL Home Care Package and their adjustment to the new model of service delivery under the Consumer Directed Care framework.	45 participants	Programme evaluation /Action research Structured interviews with consumers and/or carers	N/A	28 (62%) female	<p><i>Study foci:</i></p> <p>How well consumers understood the elements of CDC</p> <p>How well consumers understood new case management arrangements under BSL model</p> <p>How consumers felt about the information provided them</p> <p>What changes they experienced to services delivered and activities</p> <p>Attitudes to acceptance of new budget arrangements</p> <p>The introduction of monthly financial statements</p>	<p>Many participants confused about CDC terminology, required guidance from case managers.</p> <p>Participants appreciated flexibility to coordinate their own services, particularly with respect to meeting urgent needs.</p> <p>Participants also felt a sense of independence, and confidence in their own ability to coordinate their care. Freedom in choosing services considered important.</p>

Table 8. Data summary for studies in Q2, collected using a systematic search.

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
Bulamu et al. (2017)	Australia	Investigate relationships between quality of life for older adults receiving community aged care services in Australia under CDC compared with those receiving traditional provider-directed care (PDC)	CDC participants: n=81 PDC participants: n=58	Self-Reported quality of life using the EuroQoL five dimensions, five-level version, and the older people-specific capability index (ICECAP-O) instruments.	CDC participants: 81.22 years (mean) PDC participants: 82.41 years (mean)	CDC participants: 50 (62%) female PDC participants: 35 (60%) female	Descriptive statistical data was used to examine the relationship between quality of life (QoL), mode of service delivery, and other sociodemographic characteristics The EuroQoL is a five dimensions self-completed questionnaire (EQ-5D-5L) that is a generic measure of health status	CDC participants reported higher levels of capability compared to PDC participants. Living alone was associated with higher QoL and higher levels of capability.
Doyle et al. (2012)	Australia	Explore older person's experience of care within Australian community-based aged care service settings	11 older people living in South East Queensland	Qualitative – Heidegger's interpretive hermeneutical phenomenological approach, with snowball sampling Analysis of in-depth interviews conducted with 12 older people receiving care at the level of a Community Aged Care Package (CACP) who participated in the study	N/A	N/A	In-depth recorded and transcribed interviews Identification of sub themes which were ultimately grouped into larger categories	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

Table 8. (Continued.)

Author (date)	Country	Aims	Sample	Design	Age	Gender	Measures	Results
								<p>4. The same carer is important for the consumer</p> <p>Meanings of care experiences can significantly alter older people's lived experiences and personal identity. Four themes identified:</p> <ol style="list-style-type: none"> 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"

choices (Manthorpe *et al.*, 2015; Gill *et al.*, 2017). In many cases, recipients expressed a need for clear information and guidance on how to use and manage their budgets (Hatton and Waters, 2011; Zamfir, 2013; Norrie *et al.*, 2014; Rabiee and Glendinning, 2014; Gill *et al.*, 2017). Many clients and carers were not aware of terms such as ‘consumer-directed care’ or felt confused by them (Simons *et al.*, 2016). Older people reported anxieties about the management and administration of the budget, given the possibility of directly employing staff carries responsibility and risk for the consumer (Moran *et al.*, 2013; Zamfir, 2013; Gill *et al.*, 2017). However, Moran *et al.* (2013) also described examples of people getting used to such administrative tasks and finding them less daunting over time, especially as support was generally freely available to help IB users manage their payroll and paperwork.

Dissatisfaction is also experienced when consumers have to wait excessive lengths of time to access their package, when payments are delayed or when restrictions apply to what IBs can be spent on (Day *et al.*, 2017). In the UK, low levels of funding in IBs awarded to older people in comparison to younger ones with disabilities typically restrict older people’s ability to use the IB on anything other than personal care and domestic support (Moran *et al.*, 2013).

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 could see many 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.

Consumer-perceived quality of services (Q2)

Our analysis of research identified in response to Q2 identified themes in consumer perceptions of quality in home- and community-based services, outlined below.

Relationships with paid carers

A common observation was that consistency in allocation of formal carers and consumers’ familiarity with them help older people feel comfortable receiving services from carers, as it promotes establishing an ongoing relationship (Moran *et al.*, 2013). According to Gethin-Jones (2012a), use of an outcome-focused care model instead of a task-focused model facilitates extra contact time between participants and formal care-givers, and can lead to improvements in participants’ wellbeing. Participants of Doyle’s (2012) qualitative study also emphasised 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). Finally, given consumers’ lack of financial literacy, they require support from carers with financial management of their care services (Moran *et al.*, 2013).

Flexible services according to the needs of consumers

Consumers expressed the need for flexible and consistent care packages, covering a wide range of needs (Hatton and Waters, 2011; Gethin-Jones, 2012b; Moran *et al.*, 2013). This includes flexibility in care delivery according to clients' changing functional and cognitive health needs (Grimmer *et al.*, 2015). In addition, carers should be able to undertake tasks as required, rather than following a fixed task list for each visit (Simons *et al.*, 2016). Services should be targeted, timely, affordable and self-directed (Ottmann *et al.*, 2013; Grimmer *et al.*, 2015). Thus, it is important that services are suitable and accord with participants' needs if consumers feel that they are able to 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 co-ordinate their own services as required, either independently or in collaboration with a carer (Simons *et al.*, 2016; Bulamu *et al.*, 2017); and to participate in selection from the range of options available to them (KPMG, 2012; Ottmann *et al.*, 2013). Participation in the decision-making process ensures that care provision meets their needs and facilitates autonomy (Grigorovich, 2016; Bulamu *et al.*, 2017). Many consumers value highly being heard by service providers or case managers (KPMG, 2012; Moran *et al.*, 2013).

Service information and funding allocations

Consumers prefer information about care services that is clear, easy to follow and readily accessible (Kwak *et al.*, 2017; Australia Government Department of Health, 2018). However, many consumers do not recognise or fully understand the term 'consumer-directed care' (Simons *et al.*, 2016).

Information considered important by consumers includes contact availability (Kwak *et al.*, 2017), accessibility (Rioux and Werner, 2011) and availability of services (Hatton and Waters, 2011). Consumers also express the view that there should be clarity regarding how care budgets may be used (Hatton and Waters, 2011), and believe their entitlements should be sufficiently generous to allow unrestricted access to necessary services (Moran *et al.*, 2013; Australia Government Department of Health, 2018).

Issues with Indigenous populations

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

Caring and social support

A sense of being cared for is considered an important quality by consumers. Sometimes services are the only source of social support for participants who are

isolated and lack adequate social interaction (Smith-Carrier *et al.*, 2017). Consumers express their need to feel safe and comfortable with care services and to know that assistance is readily available to them, both in emergencies and more generally (McGrath *et al.*, 2006; van Hoof *et al.*, 2011).

Discussion

Key themes

The themes identified in both reviews, relating to drivers of choice and perceptions of quality in home- and community-based aged care, can be summarised as follows.

- *Control*: Most consumers want to participate actively in the decision-making for their care services, and value freedom to choose services based on their physical and mental needs.
- *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.
- *Interpersonal interaction*: Consumers want supportive interpersonal interactions with their carers over the longer term. In many cases, consumers' only regular social contact is with their formal carer, and thus carers should show respect, sensitivity and kindness.
- *Flexibility*: Consumers want the delivery of their care to be flexible, in terms of both their choice of daily activities, and adjustment over time according to their changing physical and mental needs.
- *Affordability*: Consumers want their services to be affordable and subsidised where possible.
- *Administrative and financial literacy*: Consumers benefit from assistance in understanding their care service entitlements and receiving support with the financial planning and management of their services.
- *Safety*: Consumers want to feel protected in their homes and local communities, and to know that both general and emergency assistance is readily available.
- *Timeliness of service care provisions*: Consumers prefer to receive their care entitlements and services in a timely manner.

Several implications for future model development are apparent, some of which considered in conjunction illustrate tensions between consumers' needs and service providers' obligations. For example, CDC packages need to allow for consumers' service preferences to change with time, as shifts in their functional and cognitive abilities will influence their care needs. However, there is also evidence that consumers want to build and sustain trusting relationships with their carers over the long term, which would require such services to be provided over long periods with reasonable consistency. An ideal model, therefore, would strike a balance between allowing consumers to reconfigure their care packages, but also allow services, in particular those involving carers, to be stable over the long term. Providing more

basic, user-friendly documentation on CDC packages and more opportunities to discuss them might allow consumers to understand better their rights and allowances under CDC schemes, and the implications of their decisions.

Limitations

The most important limitation in our rapid review methodology was its design. Due to the paucity of data captured by our search strategies, we chose to combine our findings with manual searching methods in primary and grey literature databases. These manual searches were non-systematic, which limits the replicability of the search and potentially introduces bias to the results.

The significant proportion of Australian literature identified across our reviews contrasted with our expectations, given large research outputs from the USA and UK. It is possible that this result was an artefact caused by attentional bias in our manual searches or by over-reliance on terms used in Australia (e.g. ‘consumer-directed care’ and ‘packaged care’), despite the research team’s efforts to identify and specify the wider range of terms used in the UK, the USA and elsewhere (see the Appendix in the online supplementary material).

Conclusion

We conducted rapid evidence reviews of consumers’ drivers of choice when looking for a home- or community-based aged care service, and their perceptions of the quality of these services. Results from peer-reviewed and grey literature suggest that consumer choices of services are driven by a combination of the following: the desire for flexibility in service provision; the extent of mobility; the need for security, personal assistance, interaction and social/leisure activities; and to target and address previously unmet needs. Consumer perspectives of quality include control and autonomy, interpersonal interactions, flexibility of choice, and safety and affordability. Both reviews highlighted the consumer’s need for personal/social interaction and community involvement, and for participating in the planning and decision-making on how to manage their budgets. These factors are critical to the further development of consumer-directed initiatives in home- and community-based aged care and to the wellbeing of service recipients.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S0144686X19001065>

Financial support. This work was supported by the Australian Aged Care Quality Agency (reference number AACQA CERHC-01). Additional support was provided by La Trobe University Library.

Conflict of interest. The authors declare no conflicts of interest.

References

- Age UK (2013) *Making Managed Personal Budgets Work for Older People*. London: Age UK.
- Australia Government Department of Health (2018) *Home Care Package Research Report*. Canberra: AMR.
- Bulamu N, Kaambwa B, Gill L, Cameron I, McKechnie S, Fiebig J, Grady R and Ratcliffe J (2017) Impact of consumer-directed care on quality of life in the community aged care sector. *Geriatrics and Gerontology International* 17, 1399–1405.

- Cash T, Moyle W and O'Dwyer S (2017) Relationships in consumer-directed care: an integrative literature review. *Australasian Journal on Ageing* 36, 193–204.
- Day J, Taylor ACT, Summons P, Van Der Riet P, Hunter S, Maguire J, Dilworth S, Bellchambers H, Jeong S and Haydon G (2017) Home care packages: insights into the experiences of older people leading up to the introduction of consumer directed care in Australia. *Australian Journal of Primary Health* 23, 162–169.
- Department of Health and Ageing (2012) *Aged Care Packages in the Community 2010–11: A Statistical Overview*. Canberra: Australian Institute of Health and Welfare.
- Davitt JK and Kaye LW (2010) Racial/ethnic disparities in access to medicare home health care: the disparate impact of policy. *Journal of Gerontological Social Work* 53, 591–612.
- Doyle S (2012) 'Being-in-the-world-of-care': the lived experiences of older people receiving community aged care packages in Queensland. *Health Care for Women International* 33, 905–921.
- Foster L, Brown R, Phillips B and Carlson BL (2005) Easing the burden of caregiving: the impact of consumer direction on primary informal caregivers in Arkansas. *The Gerontologist* 45, 474–485.
- Gethin-Jones S (2012a) Outcomes and well-being part 1: a comparative longitudinal study of two models of homecare delivery and their impact upon the older person self-reported subjective well-being. *Working with Older People* 16, 22–30.
- Gethin-Jones S (2012b) Outcomes and well-being part 2: a comparative longitudinal study of two models of homecare delivery and their impact upon the older person self-reported subjective well-being. A qualitative follow up study paper. *Working with Older People* 16, 52–60.
- Gill L, McCaffrey N, Cameron ID, Ratcliffe J, Kaambwa B, Corlis M, Fiebig J and Gresham M (2017) Consumer Directed Care in Australia: early perceptions and experiences of staff, clients and carers. *Health & Social Care in the Community* 25, 478–491.
- Glendinning C (2008) Increasing choice and control for older and disabled people: a critical review of new developments in England. *Social Policy & Administration* 42, 451–469.
- Grant MJ and Booth A (2009) A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal* 26, 91–108.
- Grigorovich A (2016) The meaning of quality of care in home care settings: older lesbian and bisexual women's perspectives. *Scandinavian Journal of Caring Sciences* 30, 108–116.
- Grimmer K, Kay D, Foot J and Pastakia K (2015) Consumer views about aging-in-place. *Clinical Interventions in Aging* 10, 1803–1811.
- Harrison F, Low LF, Barnett A, Gresham M and Brodaty H (2014) What do clients expect of community care and what are their needs? The Community care for the Elderly: Needs and Service Use Study (CENSUS). *Australasian Journal on Ageing* 33, 208–213.
- Hatton C and Waters J (2011) *The National Personal Budget Survey*. Lancaster, UK: Lancaster University.
- Heumann J (2003) *Consumer-directed Personal Care Services for Older People in the US*. Washington, DC: AARP Public Policy Institute.
- Kaambwa B, Lancsar E, McCaffrey N, Chen G, Gill L, Cameron ID, Crotty M and Ratcliffe J (2015) Investigating consumers' and informal carers' views and preferences for consumer directed care: a discrete choice experiment. *Social Science & Medicine* 140, 81–94.
- KPMG (2012) *Evaluation of the Consumer-directed Care Initiative – Final Report*. Melbourne: KPMG.
- Kwak C, Lee E and Kim H (2017) Factors related to satisfaction with long-term care services among low-income Korean elderly adults: a national cross-sectional survey. *Archives of Gerontology and Geriatrics* 69, 97–104.
- Low L-F, Fletcher J, Gresham M and Brodaty H (2015) Community care for the Elderly: Needs and Service Use Study (CENSUS): who receives home care packages and what are the outcomes? *Australasian Journal on Ageing* 34, E1–E8.
- Low L-F, Yap M and Brodaty H (2011) A systematic review of different models of home and community care services for older persons. *BMC Health Services Research* 11, 93.
- Manthorpe J, Martineau S, Ridley J, Cornes M, Rosengard A and Hunter S (2015) Embarking on self-directed support in Scotland: a focused scoping review of the literature. *European Journal of Social Work* 18, 36–50.
- McCaffrey N, Gill L, Kaambwa B, Cameron ID, Patterson J, Crotty M and Ratcliffe J (2015) Important features of home-based support services for older Australians and their informal carers. *Health & Social Care in the Community* 23, 654–664.

- McGrath P, Patton MA, McGrath Z, Olgivie K, Rayner R and Holewa H (2006) 'It's very difficult to get respite out here at the moment': Australian findings on end-of-life care for Indigenous people. *Health & Social Care in the Community* **14**, 147–155.
- Moran N, Glendinning C, Wilberforce M, Stevens M, Netten A, Jones K, Manthorpe J, Knapp M, Fernández JL, Challis D and Jacobs S (2013) Older people's experiences of cash-for-care schemes: evidence from the English Individual Budget pilot projects. *Ageing & Society* **33**, 826–851.
- Newbrunner L, Chamberlain R, Bosanquet K, Bartlett C, Sass B and Glendinning C (2011) *Keeping Personal Budgets Personal: Learning from the Experiences of Older People, People with Mental Health Problems and Their Carers*. London: Social Care Institute for Excellence.
- Norrie C, Weinstein J, Jones R, Hood R and Bhanbro S (2014) Early experiences in extending personal budgets in one local authority. *Working with Older People* **18**, 176–185.
- O'Rourke G (2016) Older people, personalisation and self: an alternative to the consumerist paradigm in social care. *Ageing & Society* **36**, 1008–1030.
- Ottmann G, Allen J and Feldman P (2013) A systematic narrative review of consumer-directed care for older people: implications for model development. *Health & Social Care in the Community* **21**, 563–581.
- Rabiee P and Glendinning C (2014) Choice and control for older people using home care services: how far have council-managed personal budgets helped? *Quality in Ageing and Older Adults* **15**, 210–219.
- Rabiee P, Moran N and Glendinning C (2008) Individual budgets: lessons from early users' experiences. *British Journal of Social Work* **39**, 918–935.
- Rioux L and Werner C (2011) Residential satisfaction among aging people living in place. *Journal of Environmental Psychology* **31**, 158–169.
- San Antonio P, Simon-Rusinowitz L, Loughlin D, Eckert JK, Mahoney KJ and Ruben KAD (2009) Lessons from the Arkansas Cash and Counseling Program: how the experiences of diverse older consumers and their caregivers address family policy concerns. *Journal of Aging & Social Policy* **22**, 1–17.
- Simons B, Kimberley H and McColl Jones N (2016) *Adjusting to Consumer Directed Care: The Experience of Brotherhood of St Laurence Community Aged Care Service Users*. Melbourne: Brotherhood of St Laurence.
- Smith-Carrier T, Sinha SK, Nowaczynski M, Akhtar S, Seddon G and Pham TNT (2017) It 'makes you feel more like a person than a patient': patients' experiences receiving home-based primary care (HBPC) in Ontario, Canada. *Health & Social Care in the Community* **25**, 723–733.
- Snell L and White L (2011) A sociocognitive approach to service quality and adherence amongst elderly patients: A pilot study. *Health Marketing Quarterly* **28**, 99–115.
- van Hoof J, Kort HSM, Rutten PGS and Duijnste MSH (2011) Ageing-in-place with the use of ambient intelligence technology: perspectives of older users. *International Journal of Medical Informatics* **80**, 310–331.
- Woolham J, Daly G, Sparks T, Ritters K and Steils N (2017) Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment. *Ageing & Society* **37**, 961–984.
- Zamfir M (2013) Personalisation through personal budgets: its effectiveness for older adults in social care services. Findings from an English-based literature review. *Research, Policy and Planning* **30**, 77–89.

Cite this article: Hunter NJR, Wells Y, Clune SJ, Ayala Quintanilla BP, Johnstone E (2021). Choice and quality in home-based and community-based aged care: insights from two rapid evidence reviews. *Ageing & Society* **41**, 875–916. <https://doi.org/10.1017/S0144686X19001065>