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What features of ‘consumer-directed’ home-based support services are important to older Australians and their informal carers – development of attributes for a discrete choice experiment

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ABSTRACT

In Australia, newly initiated, publicly subsidised ‘Home Care Packages’ designed to assist older people (≥65 years of age) live in their own home must now be offered on a ‘consumer-directed care’ (CDC) basis by service providers. However, CDC models have largely developed in the absence of evidence on users’ views and preferences. The aim of this study was to determine what features (attributes) of consumer-directed home-based support services are important to older people and their informal carers to inform the design of a discrete choice experiment (DCE). Semi-structured, face-to-face interviews were conducted December 2012-November 2013 with 17 older people receiving home-based support services and 10 informal carers from 5 providers located in South Australia and New South Wales. Salient service characteristics important to participants were determined using thematic and constant comparative analysis and formulated into attributes and attribute levels for presentation within a DCE. Initially eight broad themes were identified: information and knowledge, choice and control, self-managed continuum, effective co-ordination, effective communication, responsiveness and flexibility, continuity, and planning. Attributes were formulated for the DCE by combining overlapping themes such as effective communication and co-ordination, and the self-managed continuum and planning into single attributes. Six salient service features that characterise consumer preferences for the provision of home-based support service models were identified: choice of provider, choice of support worker, flexibility in care activities provided, contact with the service coordinator, managing the budget and saving unspent funds. Best practice indicates that qualitative research with individuals who represent the population of interest should guide attribute selection for a DCE and this is the first study to employ such methods in aged care service provision. Further development of services could incorporate methods of consumer engagement such as DCEs which facilitate the identification and quantification of users' views and preferences on alternative models of delivery.

KEY WORDS Consumer directed care, preferences, older people

BULLET POINTS

What is known about this topic

- Little is known about users' views and preferences for consumer-directed care.
- Discrete choice experiment (DCE) methodology offers a promising approach for eliciting the preferences of older people in health and social care.
- Few reported studies adequately describe attribute development from qualitative data to inform DCE design.

What this paper adds

- Information, choice and control, effective co-ordination and communication, responsiveness and flexibility, continuity, and planning are important service characteristics for users.
- The design of a DCE can facilitate health and social care policy by incorporating potential future service delivery model options not yet available such as full budgetary control and self-management.

INTRODUCTION

‘Consumer-directed care’ (CDC) is being embraced within Australia as a means of promoting autonomy and choice in the delivery of health and social services (Commonwealth of Australia 2012; National Health and Hospitals Reform Commission June 2009). From August 2013, publicly funded ‘Home Care Packages’ designed to assist older people (persons ≥65 years of age) remain living at home for as long as possible (hereon in termed ‘home-based support’) must be offered on a CDC basis by service providers (Commonwealth of Australia 2000; Commonwealth of Australia 2012). Whilst there is no universally accepted definition of CDC, the distinguishing feature concerns service recipients or their representatives having ‘control’ over allocated funds, so they can be used preferentially to meet the individual’s needs. Unlike similar schemes in countries such as England where direct payments can be made to older people so they can self-manage funds and purchase their own care directly (Department of Health 2010), in Australia the service provider is the fund-holder and in principle expends the budget as directed by each individual. The latter model may reduce the burden of CDC for older people as responsibility for budgeting arrangements and the management of funds remains with the service provider (Glendinning C 2008; Ottman *et al* 2009). However, service models have largely developed in the absence of evidence on users’ views and substantial consumer research into CDC within the Australian context is lacking (Ottman *et al* 2009). Very few studies have sought the preferences of older people and their informal carers on what basic features should make up a consumer-directed approach to home-based support services.

Increasingly, discrete choice experiment methodology (DCE) is being employed to elicit preferences for health and social care programmes to inform policy (de Bekker-Grob *et al* 2012). DCE methodology is designed to establish the relative importance or value of individual characteristics or features (attributes) of a product, programme or service upon the total benefit acquired from the purchase and/or consumption of the product, programme or service (Ryan M *et al* 2008). DCEs are underpinned by a psychological model relating the probability of choosing one characteristic in preference to other characteristics to the total benefit associated with each product, programme or service (Ratcliffe *et al* 2012). In a DCE study participants are asked to choose between hypothetical alternatives described using attributes and associated levels (Ryan *et al* 2001) (see example in Table 1).

Historically, expert opinion, literature reviews, outcome measurement tools, surveys, group discussions and interviews have been used to derive attributes for DCEs (Coast *et al* 2012). Ideally, attribute selection should be guided by qualitative research such as thematic analysis of interviews (see Methods) or focus groups with individuals who represent the population of interest (Lancsar and Louviere 2008; Coast *et al* 2012; Stevens and Palfreyman 2012). Such person-centred approaches promote appropriate language, relevancy, and responsiveness, and ensure that the attributes are developed according to purpose (Stevens and Palfreyman 2012). DCE studies based on qualitative research methodologies offer a way of systematically engaging users to determine the most important attributes of consumer-directed home-based support services from their perspective. Furthermore, these studies enable exploration of trade-offs between attributes, evaluation of the relative value of each attribute and preferences for alternative service models (Ryan M *et al* 2008). However, despite being widely acknowledged as a valuable tool for informing targeted service delivery (Ryan 2004; Ryan M *et al* 2008), DCEs specifically designed for, and conducted with, older people remain relatively rare compared with general adult samples (Ratcliffe J *et al* 2012).

The main objective of this study was to determine what features (attributes) of consumer-directed home-based support services are important to users and their informal carers to inform the design of a DCE. The process by which the attributes and levels were formulated is also described to aid development of future DCEs of health and aged care services.

METHODS

Ethical approval for the study (including the consent procedure) was granted by Flinders University Social & Behavioural and the University of Sydney Human Research Ethics Committees, and five aged care service providers (Helping Hand, South Australia (SA); ACH, SA; Resthaven Incorporated, SA; Catholic Community Services, New South Wales (NSW); HammondCare, NSW). Older people and informal carers were recruited through the providers. Study information packs (letter of introduction, information leaflet and consent form) were distributed to potential participants by staff members. Volunteers contacted the researchers (NM, LG) directly if they wished to participate. Older people were eligible if they were: aged ≥65 years; receiving home-based support (provided on a non-/CDC basis); English-speaking; able to understand the information given; and could provide informed consent. Informal carers were eligible if they were: aged ≥18 years; giving regular, ongoing assistance to an older person receiving home-based support services without payment for the care given (other than pension or benefit); English-speaking; able to understand the information given; and could provide informed consent. The absolute sample size was determined by the analysis and the interviews were halted when new, dominant issues no longer emerged from the interviews and sufficient data were obtained to adequately describe the attributes and attribute levels (Coast *et al* 2012).

Consenting participants meeting the eligibility criteria took part in a recorded interview in their home. Written consent was obtained by the interviewers (NM, LG) and a copy was mailed to the participant. Views on the key features of home-based support services important to older people and their informal carers were sought through semi-structured, face to face interviews as this was recently recommended as the preferred approach to attribute development (Coast *et al* 2012). Face-to-face interviews were chosen given the: frail nature of the target population; personal nature of choice and control issues; opportunity to respond to visual cues, probe, clarify individual responses and pursue deeper meanings where appropriate; and ability of open-ended and structured, detailed questions to provide rich data (Bowling 2004). A topic guide was developed from a review of the literature to assist consistent data collection by the two interviewers (see supporting material). Both researchers have experience interviewing older people and are allied health professionals (McCaffrey N and Currow DC 2010; Gill *et al* 2011). As the key feature of a CDC approach concerns users having ‘control’, questions focused on participants’ views and preferences for choice and control. Initially, general questions about the individual’s needs and existing support services were used as an introduction to the topic. Open-ended questions then explored choice and control in the home setting, including the impact of choice and control (or lack of) on the individual. The participants’ views about their current service, how services could be improved, and means of participating in service planning were also explored. Post-interview the researchers made field notes regarding observations, feelings and impressions and iteratively reviewed the interview process to promote self-reflection and rigour whereby the researcher questions personal assumptions, actions and interpretations during the research process (Whittemore *et al* 2001; Finlay 2002; Hansen 2006).

Socio-demographic data were analysed using descriptive analysis. The transcribed interviews were analysed in QSR International's NVivo® version 10, 2012 (Doncaster, Australia) using thematic analysis involving: (i) open coding, where data are initially analysed using line-by-line coding; (ii) axial coding, where data are categorised and linked; and (iii) selective coding, where overarching themes are established and linked together (McCann and Clark 2003; Braun and Clarke 2006; Brod *et al* 2009). Interview transcripts were iteratively reviewed and emerging themes were identified using constant comparative analyses where successive interview data are compared with previous data. The two researchers cross analysed their first interviews and codes were amended following discussion, enhancing the rigour of the research process.

Major themes were reviewed to determine salient service characteristics important to participants with particular emphasis on what features might cause individuals to choose between service models. Service characteristics were subsequently developed into draft attributes and attribute levels which were identified according to the principals of good practice for DCEs including: their ability to be traded with one another; plausibility; and realisable in practice (Ryan M *et al* 2008; Ratcliffe J *et al*

2012). Final attributes and levels were produced following an iterative process comprising consultation with members of the research team and the project steering committee to clarify meaning and understanding.

FINDINGS

Interviews (lasting on average 61 minutes) were conducted December 2012-November 2013 with 17 older people and 10 informal carers as data saturation was reached by this stage, i.e. new, major themes no longer emerged and elicitation of the attributes and levels was sufficient. Participant characteristics are summarised in Table 2. Two-thirds of participants were female and 60% of the older people lived alone. About half of the older people interviewed, and virtually all of the informal carers, had experience of CDC services.

Following initial analysis of the interviews, eight broad service characteristics emerged: information and knowledge, choice and control, self-managed continuum, effective co-ordination, effective communication, responsiveness and flexibility, continuity, and planning. Views on features of consumer-directed home-based support services important to older people and informal carers were similar. Therefore, the analysis is presented for both groups together.

Service characteristics

Information & knowledge

Participants repeatedly raised concerns about timely, accessible information on home-based support services;

> [Information] is very fragmented. There's no comprehensive information as I see it and I see it as a nurse as well as a patient.
> (Female, 80 years, older person)

> …information at different times because as I've gone along, there's been different things that I've needed at different times…it probably would be helpful if some time during the year somebody just came out and said, "Look, this is where we're at. Don't forget you've got these other options."
> (Female, 63 years, informal carer)

Participants talked about the challenges of making decisions about service possibilities without adequate information and highlighted the burden of acquiring and maintaining relevant knowledge;

> The other thing is carers get paid differently depending on when they actually provide the service so I didn't want to be bothered with budgeting for that because I'm thinking, "Do I really want to look at awards and start doing that whole thing?"
> (Female, 63 years, informal carer)

> If someone who's not aware of what goes on in the community and how these packages work, you'd be very vulnerable.....just be blind and have to go with the flow.....knowledge is very important.
> (Female, 57 years, informal carer)

Finally, the coordinator was seen a vital source of accessible information;

> I think the coordinator, a good coordinator, and they vary, is worth their weight in gold because the person hasn't the knowledge.
> (Female, 80 years, older person)

Choice & control

Participants wanted to influence: which services were provided; when they were provided; who provided services; the volume of services; and the day-to-day activities support workers performed. Participants desired: more services; broader coverage, eg home maintenance, meals, lawn mowing, social outings; and greater flexibility in timing of service delivery. Furthermore, some participants wished family members, friends and previously used privately funded specialist providers could supply services;

> And they [the provider] said "That's fine if you want to do that. It's just that it will come out of our balance"…I want this same person coming back on a regular basis, every couple of months he'll just come back for an hour or so.

> (Female, 69 years, informal carer)

Typically, participants felt they had some choice and control over aspects of their service provision irrespective of the model of service delivery. For example, even those receiving a more traditional provider-managed service felt they had some influence over the timing of services, which support workers provided the services and how often they received specific services. However, overall, services appeared menu-driven, even for those receiving consumer-directed care;

> They have their list of what they do and that sort of suited us.
> (Female, 80 years, older person)

The thought of having no choice or control over services was associated with ill-being and feelings of powerlessness, and elicited some strong reactions;

> Well, truthfully, I think I'd take my own life.
> (Female, 82 years, older person)

Conversely, participants felt having some choice and control was extremely positive and promoted well-being;

> I think life would be a lot easier. I think you'd feel in yourself, you'd feel boosted.
> (Female, 82 years, older person)

For some participants their choice of service provider was restricted by geography or availability of services, despite their preferences;

> At the moment, there are no places available in the area which I live.
> (Female, 85 years, older person)
>
> It was all teed up with the paperwork and everything for me to get [the preferred provider organisation] and then they found out they couldn't come to the area.
> (Female, 78 years, older person)

Self-managed continuum

Participants' views varied on the degree of desired self-management of services, possibly influenced by: individuals' personalities; experience with services; expectations; life experience; socio-economic status; capabilities; support network; and knowledge and information. For example, some individuals, particularly those who are sicker, may not be capable of (or may not wish to) manage their services and may need assistance recognising their needs and navigating the system to meet those needs;

> I've lived on my own for 34 years, 35 years and I've done all those things. I don't want to do them now at 85. I would far rather give the providers a percentage of the money.
> (Female, 85 years, older person)
>
> But even before that for a long time I wasn't well enough to even think of how to organise different services, I simply was not well enough.
> (Female, 80 years, older person)
>
> If you're in control of the money, you would also have to have insurance for your people that you employed and a whole lot of malarkey. And if you didn't get on with them, you'd have to find somebody else. Now there'd be a lot of people who couldn't cope with it. I would prefer now, not to cope with it.
> (Female, 85 years, older person)

Some individuals sought complete autonomy whereas others welcomed provider-managed services;

> But other than that I think that if it's going to be consumer directed it has to be really consumer directed…I don't expect them to take responsibility. I think that's the case where money needs to be passed over to us.
> (Female, 69 years, informal carer)
>
> Someone said to me did I want to go on it [consumer directed care] with mum and I said 'no'. It's because I've got – because I know what I've got… no, I don't want to change it…I don't want to be thinking all the time about what I want.
> (Female, 69 years, informal carer)

For some participants service sub-contracting created challenges to self-management with third party providers requiring service provider authorization before making changes to service provision. This incurred a cost to the client for the time taken to approve service changes;

> They'll say, "oh no we've got to speak to [the coordinator]." So I said "stop doing that because you're taking money out of my budget"....I have to pay for her [the coordinator] input, her phone calls, her letters, her everything.
> (Female, 51 years, informal carer)

Effective co-ordination

Participants repeatedly stressed the pivotal role of the coordinator in providing quality home-based support services, particularly in the absence of an identified primary informal carer. Effective coordination of services played an extremely important role in satisfying individuals' needs;

> But the key to it is the coordination; the coordinator can make or break how you perceive the whole system.
> (Female, 69 years, informal carer)

Characteristics of 'good' coordinators expressed by participants included listening skills, flexibility, and responsiveness;

> She listens well. She responds quickly. She's very flexible and very caring.
> (Female, 85 years, older person)

There were numerous examples of coordinators acting proactively and suggesting services that could meet the clients' needs, although the effectiveness of the coordinator varied by the individual;

> [Coordinator 1] and [Coordinator 2] had a good understanding of me and let me be a person with their rather compassionate approach to their work…whereas I didn't feel that with that other one at all…she didn't form any communication rapport at all.
> (Female, 80 years, older person)

Service recipients may need assistance recognising their needs and navigating services to meet those needs. The coordinator has the knowledge, experience and training to help identify individual needs and ways these needs might best be met.

Effective communication

There were many examples of effective, regular communication between participants and coordinators facilitating adaptation of services over time as the individuals' needs changed;

> …you know like, when he [husband] was in hospital, [the coordinator] is on the phone straight away, "now do you need so and so, do you need, we can get somebody to pick you up and take you shopping" and she's making suggestions.
> (Female, 78 years, older person)

However, miscommunication caused anxiety and stress;

> He was being objectionable. But I sort of spoke to him, and as I said to him 'you've got to understand the worry here.'
> (Male, 73 years, informal carer)
>
> Now the first thing that girl did when I started saying something "I don't have the time", and that's not what I want to hear, right? … I don't want to hear there's no money in the package, I want you to say "okay, you've got a problem, let's work with it and see what we can do".
> (Male, 73 years, informal carer)

Responsiveness & flexibility

Participants desired a flexible and responsive service. Problems were caused by lack of flexibility in roles and timing of services. For example, some support workers were limited to performance of specific tasks. According to participants, support workers displayed different levels of responsiveness to variations in day-to-day tasks; some support workers performed daily tasks rigidly and would not deviate from the proscribed services, whereas others were more flexible;

> She does anything that I would ask…she leaves me to choose and that’s an important thing, just choosing if we’re going to go out, or clean up the backroom, or do something but she does everything that I request.
> (Female, 82 years, older person)

Participants were sometimes frustrated by the limitations placed on desired day-to-day tasks by occupational health and safety regulations;

> See they do the cleaning, because of health and safety, they’re not allowed to move anything, so therefore nothing gets, like my lounge suite, doesn’t get moved.
> (Female, 78 years, older person)

Others with experience of consumer-directed care felt the consumer-directed approach promoted flexibility in meeting individual's needs;

> One of the things they did for us, and this is consumer driven care…they allowed us to buy a GPS because there's no way he could read a map…and he has to have transport.
> (Female, 69 years, informal carer)

However, in general, participants had inadequate information & experience on which to make decisions about other service possibilities and were reliant upon the coordinators.

Continuity

Another vital issue for participants was continuity of care. Participants highlighted the importance of their relationship with support workers and coordinators and the value of consistency;

> I would trust [the support worker] completely. She's been coming long enough and she’s had to do some awful things for me sometimes and although I just wish she wasn’t always going off at the present moment I think she’s a very fine lady in her own right. But with other people it takes a while to get to know them and I've been around the traps long enough to know what can happen with that.
> (Female, 80 years, older person)

Changes in care workers or the hours of service caused participants stress and anxiety, whereas consistency promoted quality service delivery;

> …they get to know what you like and you get to know how they work.
> (Female, 78 years, older person)

> you get up, and you think ‘I've got to tell someone all over again’.
> (Female, 80 years, older person)

> Normally you became accustomed to the people who serve you and the people who serve you became accustomed to you. There is an inter-function between those two groups of people. So you - the older person came in contact with new faces and it takes a time to understand each other.
> (Male, 81 years, older person).

Planning

Participants valued the ability to accrue and carry over funds from one year to the next. Reported benefits of having a notional budget included the ability to prioritise and plan for the future;

> I think, actually, allocating people a set amount is a good idea…Most people I think can manage knowing how much they’ve got quarterly. You might have a big, as you say, go away for a week and then not go out for another three weeks or three months or whatever, you know.
> (Female, 63 years, informal carer)

> …that's how I had the $3,600 [accruing funds]…for the respite
> (Female, 69 years, informal carer)

However, a common problem reported by participants was difficulty understanding the regular financial information sent to them by the service provider.

Attributes and attribute levels

The initial draft attributes and attribute levels considered for inclusion in the DCE and their corresponding themes are presented in the supporting material. The first iteration was drafted and revised by authors NM, BK and JR. The second iteration was circulated amongst the project steering committee members and the attributes were refined based on member feedback. Duplicate attributes were removed and the remaining attributes were rationalised according to importance, plausibility, tradability, and realisability in practice. For example, effective communication and co-ordination, and the self-managed continuum and planning were combined into single attributes. Figure 1 summarises the final attributes and their corresponding themes.

The final six attributes were:

1. Choice of provider: services can be provided by a single provider, multiple providers or multiple providers plus others
2. Choice of support worker: all support workers (including family members), some, or none of the support workers can be chosen by the individual
3. Flexibility in care activities provided: the support worker is able to change any, some, or none of the activities on the community aged care plan as directed by the individual
4. Contact with the service co-ordinator: high, medium or low face-to-face contact
5. Managing the budget: the budget is managed by the individual, informal carer or service provider
6. Saving unspent funds: all, half, or none of the unused funds can be saved

A fuller description of the attributes and levels is provided in the supporting material. The attributes will be utilised to generate hypothetical scenarios for a DCE for the quantification of user preferences for alternative models of home-based support service delivery. The results of the DCE will inform the development of CDC service delivery across the partner organisations.

DISCUSSION

This article has described the principal features of consumer-directed home-based support services valued by older people and their informal carers based on in-depth qualitative interviews to inform the design of a DCE. Six key service attributes were identified: choice of provider; choice of support worker; flexibility in care activities provided; contact with the service co-ordinator; managing the budget; and saving unspent funds. Whilst the findings support the continued development of a consumer-directed approach for Australians aged ≥65 years, the desired level of self-management varies, with some individuals preferring provider-management, some desiring complete autonomy and others in-between. Effectively, the CDC model currently legislated by the Australian federal government (Commonwealth of Australia 2000; Commonwealth of Australia 2012) does not enable services to be completely self-managed as funds are not made directly available to individuals and there are some restrictions on how the budget can be spent (Commonwealth of Australia 2012), limiting choice and control. The design of a DCE can be used to elicit preferences for possible future service delivery policy options not yet available in practice such as self-management.

This is the first study to employ qualitative research methods to inform the design of a DCE to evaluate the relative value of features of consumer-directed home-based service models for older people. A recent systematic narrative review of UK and USA-based studies reporting on older peoples' and informal carers' preferences for, and satisfaction with, CDC services highlighted the wide range of views on participation corresponding with the self-managed continuum (Ottmann *et al* 2013). Other similar reported themes in the systematic review included greater continuity of care, coordination, education and accessible information, flexibility, management of funds and control of employing support workers. Generally, the study participants' views and preferences appear consistent with those reported in other countries despite differences in the administrative, socio-political and legislative contexts. However, *individual* preferences vary widely possibly influenced by individuals' personalities, experience, expectations, capabilities, and support networks. Consequently, identifying individuals' preferences and tailoring services accordingly is essential in meeting their needs. DCE methodology can be used to investigate whether there are systematic differences in preferences according to individual characteristics, facilitating the identification of subgroups to whom services can be specifically tailored.

A wide range of users' views were captured from individuals receiving non-/consumer-directed services. However, few participants were from culturally and linguistically diverse or indigenous backgrounds and the views of people with dementia were minimally represented. Additionally, distilling the large body of rich interview data into the six most important attributes was a challenging but necessary task for informing the DCE and minimising the cognitive burden of the DCE study for older people.

Qualitative research methods are the recommended approach for developing attributes and attribute levels for a DCE and this is the first study in aged care service provision to apply such an approach. Few reported studies in health and social care apply or adequately describe attribute development using qualitative methods. This paper adds to this limited body of literature (Ryan *et al* 2001; Coast and Horrocks 2007; Ke *et al* 2013) and is the first step towards further development of the consumer-directed service model. The next step is to administer the DCE questionnaire to a sample of older people and informal carers to assess the relative importance of the attributes and the trade offs participants are willing to make between attributes. Subsequently, data from the DCE will inform delivery of CDC services with evaluation across the partner organisations.

CONCLUSION

This is the first study to employ recommended, qualitative research methods to develop attributes for a DCE in aged care service provision. Based on users' views, a DCE of consumer-directed home-based support service models should include the following attributes: choice of provider; choice of support worker; flexibility in care activities provided; contact with the service co-ordinator; managing the budget; and saving unspent funds. Such a study would enable quantification of user preferences for alternative models of service delivery informing further development of consumer-directed home-based support service models.

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REFERENCES

Bowling A 2004. *Chapter 11 Data collection methods in quantitative research; questionnaires, interviews and their response rates*. *Research methods in health: investigating health and health services.* Maidenhead, Berkshire: Open University Press.

Braun V, Clarke V (2006) Using thematic analysis in psychology. Qualitative Research in Psychology 3: 77.

Brod M, Tesler LE, Christensen TL (2009) Qualitative research and content validity: developing best practices based on science and experience. Qual Life Res 18: 1263-78.

Coast J, Al-Janabi H, Sutton EJ, Horrocks SA, Vosper AJ, Swancutt DR, Flynn TN (2012) Using qualitative methods for attribute development for discrete choice experiments: issues and recommendations. Health Economics 21: 730-741.

Coast J, Horrocks S (2007) Developing attributes and levels for discrete choice experiments using qualitative methods. J Health Serv Res Policy 12: 25-30.

Commonwealth of Australia (2000) Aged Care Act 1997. Canberra: Ausinfo

Commonwealth of Australia 2012. Living longer. Living better. Canberra: Department of Health and Ageing.

Couzner L CM, Walker R, Ratcliffe J (2013) Examining older patient preferences for quality of care in postacute transition care and day rehabilitation programs. Health 5: 730-41.

de Bekker-Grob EW, Ryan M, Gerard K (2012) Discrete choice experiments in health economics: a review of the literature. Health Economics 21: 145-72

Department of Health (2010) Putting people first: personal budgets for older people - making it happen. Department of Health: London

Finlay L (2002) "Outing" the researcher: the provenance, process, and practice of reflexivity. Qualitative Health Research 12: 531-545.

Gill L, White L, Cameron ID (2011) Interaction in community-based aged healthcare: Perceptions of people with dementia. Dementia 10: 539-554.

Glendinning C CD, Fernandez J, Jacobs S, Jones K, Knapp M, Manthorpe J, Moran N, Netten A, Stevens M, Wilberforce M (2008) Evaluation of the Individual Budgets Pilot Programme: Final Report. Social Policy Research Unit, University of York: York

Hansen EC 2006. *Research design and rigour*. *Successful qualitative health research: a practical introduction.* Crows Nest, New South Wales, Australia: Allen & Unwin.

Ke KM, Mackichan F, Sandy JR, Ness AR, Hollingworth W (2013) Parents' perspectives on centralized cleft services for children: the development of a DCE questionnaire. Oral Diseases 19: 185-192.

Lancsar E, Louviere J (2008) Conducting discrete choice experiments to inform healthcare decision making: a user's guide. PharmacoEconomics 26: 661-77.

McCaffrey N, Currow DC (2010) Psychometric development of a single-item end-of-life patient-reported outcome (EOLPRO): the first piece of the puzzle. Palliative Medicine, 24: s58.

McCann TV, Clark E (2003) Grounded theory in nursing research: Part 1--Methodology. Nurse Res 11: 7-18.

National Health and Hospitals Reform Commission (June 2009) A Healthier Future For All Australians: Final Report of the National Health and Hospitals Reform Commission.

Ottman G, Allen J, Feldman P (2009) Self-directed community aged care for people with complex needs: a literature review. Available:

http://www.pc.gov.au/__data/assets/pdf_file/0012/108201/subdr561-attachment1.pdf.

Ottmann G, Allen J, 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.

Ratcliffe J, Laver K, Couzner L, Crotty M 2012. Health economics and geriatrics: challenges and opportunities. In: ATWOOD, C. (ed.) Geriatrics. Rijeka, Croatia: InTech.

Ratcliffe J, Flynn T, Terlich F, Stevens K, Brazier J, Sawyer M (2012) Developing adolescent-specific health state values for economic evaluation: an application of profile case best-worst scaling to the Child Health Utility 9D. PharmacoEconomics 30: 713-27.

Ryan M (2004) Discrete choice experiments in health care. BMJ 328: 360-361.

Ryan M, Gerard K, Amaya-Amaya M (2008) Using discrete choice experiments to value health and health care. Springer: Dordrecht

Ryan M, Bate A, Eastmond CJ, Ludbrook A (2001) Use of discrete choice experiments to elicit preferences. Qual Health Care 10: i55-60.

Stevens K, Palfreyman S (2012) The Use of Qualitative Methods in Developing the Descriptive Systems of Preference-Based Measures of Health-Related Quality of Life for Use in Economic Evaluation. Value in Health 15: 991-998.

Whittemore R, Chase SK, Mandle CL (2001) Validity in qualitative research. Qual Health Res 11: 522-37.

SUPPORTING MATERIAL

- Interview topic guide
- Candidate attributes

Table 1 Example of hypothetical alternatives in a choice task (Couzner L 2013)

Attribute	Program A	Program B
Patient & family involvement in the decision to move from hospital to the next destination	None	Shared
How your medical history is transferred between the health care professionals who are caring for you	Full electronic record	A written record
Intensity of rehabilitation programme	Twice weekly therapy	Daily therapy
How you will get information about your health and treatment whilst receiving care	Senior doctor and specialist aged care nurse with follow up and summary	Social worker and junior doctor
Duration of rehabilitation therapy provided	Decided by team	Until you think you are well

Table 2 Participant characteristics

Characteristic		**Older people** **(N=17)**	**Informal carers** **(N=10)**
Gender, n	Female/ Male	11/6	7/3
Age (years), n	51-60	-	2
	61-70	-	6
	71-80	6	1
	81-90	10	1
	>90	1	-
Usual language spoken at home, n	English	16	10
	Other	1	-
Living arrangements, n	Alone	10	1
	Partner	6	6
	Family	1	3
Primary carer identified, n	Yes	9	N/A
	No	8	
Highest education level achieved, n	Up to year 9	9	1
	Years 10-12	1	4
	Completed university or TAFE	4	4
	Postgraduate	3	1
Current homed-based support service, n	HACC[a]	2	-
	CACP[a]	4	-
	EACH[a]	1	-
	CDC[a]	9	9[b]
	Don't know	1	1

HACC = Home and Community Care; CACP = Community Aged Care Package; EACH Extended Aged Care at Home; CDC = consumer-directed care; [a] descriptions of these services can be found at http://www.myagedcare.gov.au/ ; [b] 6 CDC & 3 CDC dementia

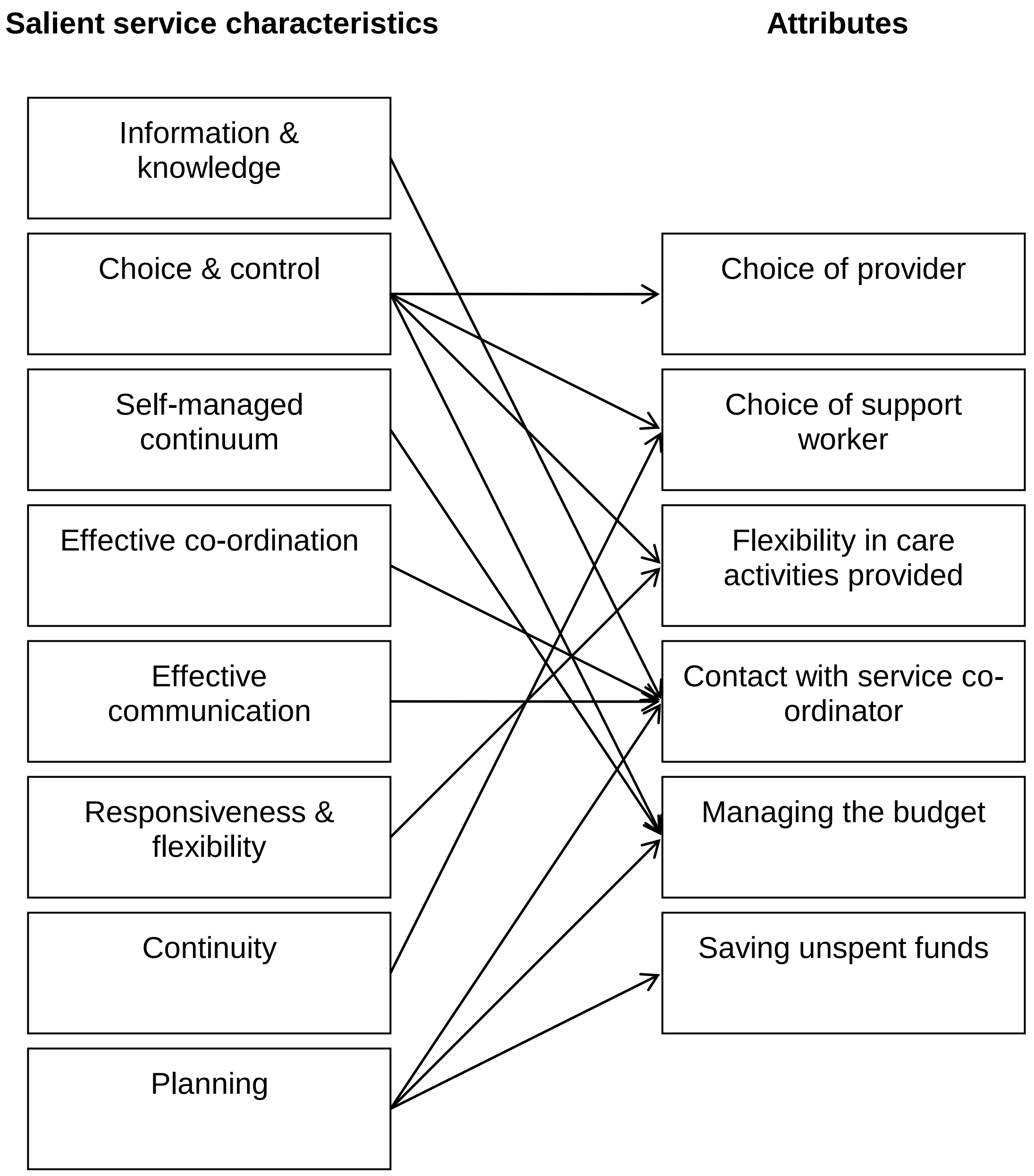
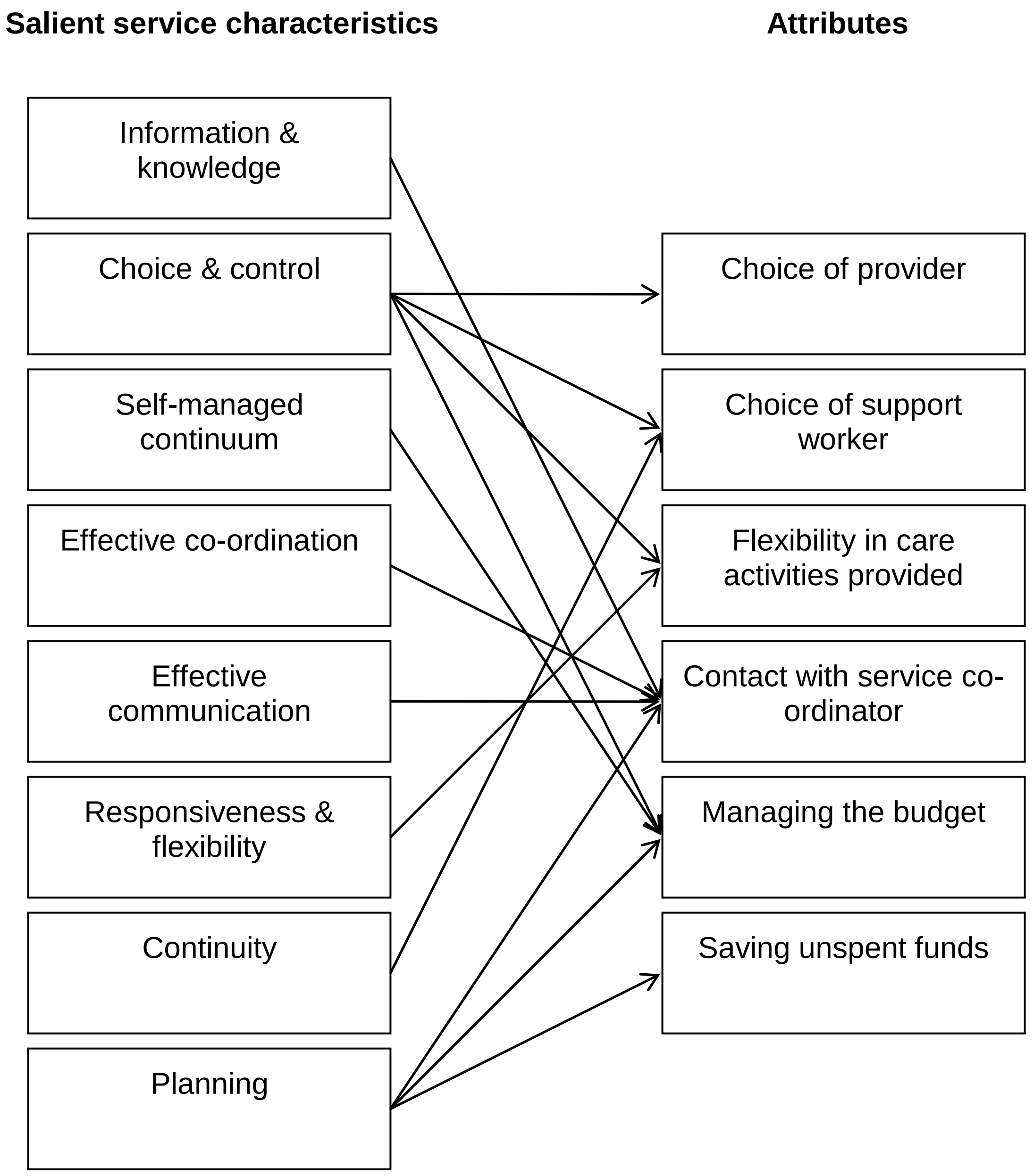

Salient service characteristics
Attributes
Information & knowledge
Choice & control
Self-managed continuum
Effective co-ordination
Effective communication
Responsiveness & flexibility
Continuity
Planning
Choice of provider
Choice of support worker
Flexibility in care activities provided
Contact with service co-ordinator
Managing the budget
Saving unspent funds

Figure 1

Figure Legends

Figure 1 Development of attributes from service characteristics


Salient service characteristics
Attributes
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Choice of support worker
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INTERVIEW TOPIC GUIDE

- What help do you need so that you can stay at home?
- What help do you get?
- What else would you like?
- What would it look like?
- What information have you been given about the services available?
- What choices have you been offered? What did they look like?
- How did you feel about the choices you were offered?
- Is there anything you would like to be different? What would it look like?
- How do you feel if you are able to choose the kind of services you need?
- How do you feel if you have no choice?
- What affect does this have on you?
- What can you decide about the services you get?
- What can’t you decide about the services you get?
- What would you like to be able to control about your services?
- Is there anything you would like to be different? What would it look like?
- How do you feel if you are able to control the services you get?
- How do you feel if you have no control?
- What affect does this have on you?
- Thinking now about flexibility, what would a flexible service look like?
- How would you like to be involved in the planning of your services?
- Describe how that might happen? What would it look like?
- If you could wave a magic wand and create the perfect service, what would it look like?
- Is there anything you would like to add?

CANDIDATE ATTRIBUTES

Iteration 1

Administration of funds (self-managed continuum)

(i) 100% self-managed

(ii) 80% self-managed & 20% provider managed

(iii) 100% provider-managed

OR

Management of funds (self-managed continuum)

(i) You will administer the funds

(ii) You and the provider will administer the funds

(iii) The provider will administer the funds

Choice of services (choice & control, responsiveness & flexibility)

(i) You can spend the funds as you see fit to meet your needs

(ii) You need provider approval before spending any funds to meet your needs

(iii) You can spend the funds on a list of specified services to meet your needs

Planning services (planning)

(i) You can accumulate funds on a monthly and yearly basis

(ii) You can accumulate funds monthly but not yearly

(iii) You cannot accumulate funds

Coordination of services (effective coordination)

(i) You will coordinate the services you need

(ii) You and the coordinator will organise the services you need

(iii) The coordinator will organise the services you need

Accessible information (information & knowledge)

(i) You would like to know where to find the information you need

(ii) You would like the coordinator to find the information you need

(iii) You would like the government to provide you with the information you need

Effective communication (effective communication)

(i) You would like regular face-to-face contact with the provider

(ii) You would like regular telephone contact with the provider

(iii) You will contact the provider when needed

Service delivery (choice & control, continuity)

(i) You want the same support worker(s) all (100%?) of the time

(ii) You want the same support worker(s) most (80%?) of the time

(iii) You are willing to have different support workers

Day-to-day activities (choice & control, flexibility & responsiveness)

(i) You will decide what the support worker should do each time they visit

(ii) The support worker will do some set tasks and some tasks you decide each time they visit

(iii) You want the support worker to do set tasks only

Iteration 2

Administration of funds for your care package (self-managed continuum)

(i) You will be able to administer the funds for your care package yourself

(ii) You and the provider will jointly administer the funds for your care package

(iii) The provider will administer the funds for your care package

Choice of services (choice & control, responsiveness & flexibility)

(i) You will be able to spend the funds as you see fit to meet your needs

(ii) You will need provider approval before spending any funds to meet your needs

(iii) You will be able to spend the funds from a menu of services specified by your care provider to meet your needs

Services included in your care package (choice & control)

(i) You will be able to spend your care package on personal assistance to meet your daily needs at home including e.g. bathing, dressing, showering, preparing meals, home help and gardening

(ii) You will be able to spend your care package on personal assistance to meet your daily needs e.g. bathing, dressing, showering, preparing meals, home help and gardening plus transport to help you attend health care appointments and attend social activities

(iii) You will be able to spend your care package on personal assistance to meet your daily needs plus transport to help you attend health care appointments and attend social activities and rehabilitation support e.g. to help you achieve greater mobility and independence

Planning services (planning)

(i) You will be able to bank any unused funds from your care package for future use on a monthly and yearly basis

(ii) You will be able to bank any unused funds from your care package for future use monthly but not yearly

(iii) You will not be able to accumulate any funds which you do not use

Organisation of services (effective coordination)

(i) You will be responsible for coordinating the services you need

(ii) You and the coordinator will jointly organise the services you need

(iii) The coordinator will organise the services you need on your behalf

Composition of services (choice & control, continuity)

(i) You will have the option to employ people you know (including family members) to provide care for you as part of your care package

(ii) You will not have the option to employ people you know (including family members) to provide care for you as part of your care package

Effective communication (effective communication)

(iii) You will have regular face-to-face contact with your aged care package co-ordinator

(iv) You will have regular telephone contact with your aged care package co-ordinator

(v) You will not have regular contact with your aged care package co-ordinator but you will be able to contact them by telephone when needed

Continuity in care delivery (continuity)

(i) You will have the same support worker(s) visiting you all of the time

(ii) You will have the same support worker(s) visiting you for some of the time

(iii) You will have different support workers visiting you for most of the time

Day-to-day care activities (choice & control, responsiveness & flexibility)

(i) You will decide what care activities the support worker should do each time they visit

(ii) The support worker will perform some pre-set care activities and some tasks you decide each time they visit

(iii) The support worker will perform pre-set care activities only

Iteration 3 – final attributes

Choice of provider (choice & control)

(i) Single service provider: You are able to choose from a menu of services your service provider is able to deliver

(ii) Multiple service providers: You are able to choose from a menu of services your service provider is able to deliver and you are able to choose additional services from other service providers

(iii) Multiple service providers and other individuals including family members: You are able to choose services from any service provider and you are free to use other people e.g. family members, friends or neighbours to provide support to you

Choice of support worker (choice & control, continuity)

(i) Choose all your support workers: You are able to choose all the workers that provide your day to day services, including family members and friends

(ii) Choose some support workers: You are able to choose some of the workers that provide your day to day services

(iii) Not able to choose support worker to employ: You are not able to choose any of the workers that provide your day to day services

Flexibility in care activities provided (choice & control, responsiveness & flexibility)

(i) Fully flexible: Your support worker is fully flexible and able to change any of the activities on your community aged care plan (e.g. cleaning, shopping, meal preparation and gardening) as directed by you.

(ii) Partly flexible: Your support worker is partly flexible and able to change some of the activities on your community aged care plan as directed by you.

(iii) Inflexible: Your support worker is inflexible and unable to change any of the activities on your community aged care plan

Contact with the service co-ordinator (information & knowledge, effective co-ordination, effective communication, planning)

(i) High contact: You have regular monthly face to face contact with your service co-ordinator plus you are able to contact your co-ordinator in person or by telephone whenever an issue arises that you would like to discuss

(ii) Medium contact: You have face to face contact with your service co-ordinator every three months plus you are able to contact your co-ordinator in person or by telephone whenever an issue arises that you would like to discuss

(iii) Low contact: You have face to face contact with your service co-ordinator every six months plus you are able to contact your co-ordinator in person or by telephone whenever an issue arises that you would like to discuss

Managing the budget (choice & control, self-managed continuum, planning)

(i) Held by the individual: You are responsible for managing the budget for the services received

(ii) Held by an informal carer: Your informal carer is responsible for managing the budget for the services received

(iii) Held by the service provider: Your service provider is responsible for managing the budget for the services received

Saving unspent funds (planning)

(i) Save all unused funds: You are able to save all of the unused funds from your community aged care package for future use

(ii) Save half of unused funds: You are able to save half of all unused funds from your community aged care package for future use

(iii) Not able to save unused funds: You are not able to save any unused funds from your community aged care package for future use