DRAFT PROJECT EVALUATION REPORT

Dementia and Aged Care Services Fund (DACS)

Organisation	COTA Australia Ltd
Project Name:	Increasing Consumer Self-management in Home Care
Grant Activity Name	Grant Opportunity 3: Developments that support innovation in aged care
Grant Activity ID	4-4Z7LS6S

ACTIVITY DETAILS					
Activity Start Date	01 July 2017	**Activity End Date**	30 June 2019	**Total Activity Funding (GST Exclusive)**	$1,192,350
Objective *Refer Item A.2 of the Standard Funding Agreement Schedule*	Increase flexibility in the delivery of home care services for consumers, increase consumer awareness of their choice in the care that they receive, develop information on the most appropriate means to share information on consumer choice with special needs groups, develop tools or models that enable the department to assess awareness of consumer choice in the delivery of aged care services, and support the role for consumers in informing continuous quality improvement within aged care services.				
Activity Details	This project proposes a model for the innovative delivery of home care services to clients and will develop initial consumer and provider				

Refer Item B.3 of the Standard Funding Agreement Schedule	toolkits that identify the tasks and competencies associated with different levels of self-management. The project will evaluate the requirements, benefits and challenges of this approach by investigating the activities involved in self-management, the personal competencies that consumers and/or their representatives need to maximise consumer choice and flexibility, ways of increasing consumer capacity to undertake the tasks associated with self-management, and the safeguards needed to achieve positive outcomes where consumers self-manage. The project will also assess how competing aims can best be managed so that consumers are supported to be engaged in continuous improvement and use the maximum amount of their packages in supports and services, while providers remain financially viable when consumers pay minimum fees.

1. Executive Summary

A review of aged care sector literature, scoping surveys and a series of sector consultations revealed that most existing models of home care self-management did not go far enough in offering consumers genuine choice, control or autonomy over the day-to-day functions of their home care package. To address this gap, this project aimed to develop, test and evaluate the efficacy and outcomes of a well-defined model of consumer self-management in home care packages, and to deliver resources for others to implement with confidence.

Project partners included home care packages providers, consumers, carers, and a range of specialised external collaborators. The project adopted a co-designed, multi-phase, action research methodology to ensure the final result was inclusive of the varied experiences of all major stakeholders, and provided a foundation for robust and evidence-based research to occur.

An environment of considerable sector change was present during the implementation period of the self-management project. Government-led reforms required our project partners to adapt and refine their systems and practices to meet the changed environment in which they operated.

Key findings illustrated statistically significant benefits for consumer and carer participants on a range of measures. Qualitative results equally endorsed self-management as a way for consumers to remain engaged, interested and active participants in their own care. Providers' views on the implementation of self-management could be themed into eight factors that contributed to building a successful organisation that supports participants to self-manage.

Recommendations for extensive roll-out of key project resources to older Australians, peak bodies, Government departments and related ancillary organisations is the next step in promoting the values and benefits of consumer directed home care packages. Currently, self-management is not a predominant feature of most home care providers. Decisive action is required from Government and consumer-facing peak bodies to endorse self-management as a key marker for working toward meeting Standard One of the aged care quality standards.

2. Objectives of the evaluation and the evaluation questions being addressed

[The objectives of the evaluation are to assess the relevance, effectiveness, efficiency, impacts and sustainability of the project and its activities].

Self-management gives consumers and carers:

- more control of how their funding is spent,
- shared authority to decide on purchases,
- a way of directly paying for services, products and activities relevant to their care.
- a way to choose support workers and other contractors,

The model being tested:

Objectives of the evaluation are to determine:

1. How effective self-management is for participants in delivering more choice and control compared to provider-managed support alone.
2. What participants report as the benefits, and risks if any, involved in high-level self-management.
3. What participants want in terms of capacity building support to ensure the best outcomes for themselves.
4. The most effective way to increase awareness of the tasks and activities required to manage a home care package – from assessment to goal setting to appropriate spending to financial management and accountability.
5. How easily can an externally developed model of self-management be integrated into an existing provider business model, whilst assuring providers that their governance and compliance obligations are being met or even exceeded?
6. The cost implications of offering consumer self-management from the provider perspective. i.e. what are the costs and where are the savings in terms of back-of-house functions – finance dept, care management ratios, and so forth.
7. What are the cost or other resource implications for providers in building consumer capacity to self-manage?
8. Potential risks, challenges and barriers to self-management for participants, and ways to mitigate these.
9. What capacity building is required in the broader aged care sector to increase the number of providers offering high level self-management?
10. To evaluate whether self-management impacts on the quality of support, opportunities available and quality of life achieved by the people receiving home care packages (and their carers).
11. Comparative analysis from before self-management to after self-management in terms of:
    a. Access to services
    b. Quality of support
    c. Range of supports

d. Reported outcomes in health, community, social and economic wellbeing, relationships and enjoyment of living at home

e. Knowledge, skills and personal attributes of successfully self-managing people.

Effectiveness of the self-management model developed

The evaluation methods for this project are varied in order to capture the outcomes from a range of perspectives. COTA Australia partnered with RMIT University to evaluate the self-management model in terms of its impact on participants on a range of measures. Pre-trial and post-trial comparisons were made on quality of life and wellbeing; current knowledge of self-management activities; understanding of potential risks; willingness to self-manage. See Appendices 8.a & 8.b for full pre-trial and post-trial survey questions. The evaluation findings are divided into two sections: 1) the RMIT University research evaluation, and 2) the COTA evaluation activities.

1) **RMIT University research evaluation**

RMIT University conducted a comprehensive literature review (see Appendix 7) that discusses national and international literature relevant to COTA Australia's self-managed trial.

RMIT University ethics approval was granted for the following activities:

Quantitative:

- Participant pre-trial survey (see Appendix 8.a)
- Carer pre-trial survey
- Participant post-trial evaluation survey (see Appendix 8.b)
- Carer post-trial evaluation survey

Qualitative:

- 18 participant interviews pre-trial
- 25 participant interviews post-trial

2) **COTA Evaluation Activities:**

Complementing the RMIT University evaluation, COTA Australia conducted additional evaluation activities. These were:

a) Preliminary scoping survey – pre-model development.

We scoped the level of self-management implementation across the sector in the early phase of the project. GEN data analysis (2017) of the fields providers had completed on the My Aged Care website indicated that approximately 48% of providers offered a self-managed option to consumers. We anticipated that we would have the opportunity to review a range of provider self-management models to identify best practice elements that were already being used in place in the sector. Two online surveys were conducted nationally in October 2017 (see Appendices 9.a & 9.b). The survey for *Participants* attracted 258 respondents. The survey for *Providers* attracted 130 respondents. Preliminary data were analysed and major themes identified. Following the surveys, consultation focus groups were conducted in five States, and the data were transcribed and analysed. At this early stage of the project, the analysis focused mainly on descriptive statistics to gain an understanding of the general mood of the provider sector, as well as an understanding of what participants indicated they wanted out of self-management in home care.

b) During the trial each participant was offered 2 x 30-minute consultations with a self-management expert consultant contracted by COTA.

The consultant offered each participant and/or their carer to conversations to provide information about the trial and responded to questions. The consultant gained insights into each participant's level of knowledge, skill and attitude towards self-management. In total, approximately 140 conversations took place, providing rich and useful insights into the day-to-day issues of participants.

c) Mid-trial face-to-face workshop with participants to review and refine consumer Implementation Toolkit.

The project team conducted 2 workshops with 26 participants and made 5 home visits to review the content and usefulness of the consumer toolkit. Feedback from these sessions influenced the style and content of the final consumer implementation toolkit.

3. The method for evaluating the outcomes of the project including:

- The data that was collected and a detailed description of the approach used to analyse the data, including any tools that were used;
- Characteristics and the number of participants in the evaluation process and the recruitment strategy;
- Statistical analysis used to validate findings (where applicable).

[Define the methods of research (quantitative/ qualitative) used, sampling techniques and methods of data collection (surveys, interviews, etc.)]

Data collected:

Based on the thematic analysis of the COTA Australia 2017 consultations and quantitative survey data, a self-management practice model was drafted. This model was presented to the seven providers participating in the project for feedback and comments before being further refined as the participant *Welcome Pack* and *Implementation Toolkit*. These tools were sent to each project participant in the pre-trial phase to orientate them to the model and the expectations of the trial self-management project (implementation) phase.

During the implementation phase, which spanned from 4 July 2018 to 31 March 2019, 98 participants from seven provider partners were engaged in the self-management trial. We employed a range of measures to evaluate participants' progression during the trial. An independent evaluation was conducted by RMIT University with formal University Ethics approval. Written consent was given by all participants after they received plain language statements about the project and their right to withdraw at any time from the evaluation without affecting their services from their provider.

Two data collection methods were used: surveys and interviews. Surveys and interviews gathered baseline data pre-trial, and were repeated to gather post-trial data. There were separate online surveys for participants, with carers often assisting

participants to complete their survey. The pre-trial surveys were completed by 103 participants and 66 carers. The post-trial evaluation survey was completed by participants or their carers (n=60), which is approximately two-thirds of participants who completed the trial.

Semi-structured telephone interviews were conducted pre-trial with a stratified sample of older people belonging to the seven providers (n=18). Sometimes the carer supported the consumer or spoke on their behalf. Post-trial, semi-structured telephone interviews were repeated with these 18 participants [where possible], plus an additional seven participants to provide a broader perspective.

Participant profile and recruitment strategy:

Recruitment of provider partners

First, COTA Australia recruited provider partners for the trial. The recruitment process began when providers were invited to contribute to an online survey designed to scope the uptake of self-management by providers in the sector. One hundred and thirty providers contributed to the survey. Subsequently, providers were invited to attend consultation workshops held in five States. Workshop attendees, as well as all providers who shared contact details during the survey, were invited to submit an expression of interest in becoming a trial partner. Partners were selected based on their willingness to co-design a best-practice high level self-management model, trial the model, and their commitment to the full 2-year project. For the purposes of the trial, high level self-management was defined by the complexity and range of tasks and activities that participants would take responsibility for in relation to the day-to-day functions of their home care package Seven approved providers from five states and territories accepted the invitation and these conditions. These partners represented the diversity of providers in Australia. They included for-profit and not-for-profit; large, medium and small; regional and metro located; experience of self-management options, and new to self-management.

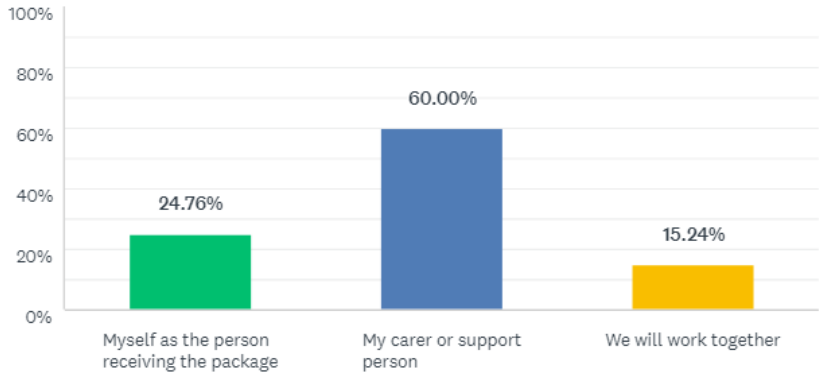
Recruitment of participants/carers

The second recruitment phase engaged consumer/carer participants in the trial. Participants were existing home care package participants of the seven provider partners. Providers invited participants who had previously expressed interest in self-managing, and others they thought might be suitable and interested in the trial. Additional participants self-selected into the trial after hearing about it from their provider or the COTA Australia publicity. It is not known how many people chose not to become involved.

Providers sent participant contact details to COTA Australia with their consent. COTA Australia emailed participants a link to the online baseline and follow-up surveys. The surveys were designed and hosted by SurveyMonkey via a COTA Australia account. One hundred and three participants, sometimes represented by their carers, accepted the invitation to participate in the trial and completed the baseline (pre-trial) survey. See Table 1. This survey formed part of the RMIT University evaluation. All participants received a project *Welcome Pack* to explain the project and outline their obligations. Seven people did not continue to the trial implementation phase*.

Table 1. Who is likely to take on most tasks of self-management in the trial:

Answered: 105 Skipped: 0



One hundred and three participants commenced the self-management trial in July 2018, hereafter referred to as participants. During the trial, approximately 20% of participants discontinued, primarily due to moving to residential care or passing away. Ten participants withdrew because the project did not meet their initial expectations. Sixty participants completed the baseline and follow-up surveys.

Trial participant demographics

Table 1 summarises the demographic characteristics of the sample of 60 participants and family carers who completed both the baseline and follow-up surveys.

Table 1: demographic characteristics of trial participants (both pre- and post-trial matched respondents)

	n	%
Gender		
Male	20	33%
Female	40	67%
Age group		
Under 70	8	15%
70s	16	30%
80s	21	40%
90+	8	15%
State		
VIC	23	38%
WA	20	33%
TAS	9	15%
QLD	5	8%
NSW	3	5%

Education		
High School (Years 7 – 9)	3	5%
High School (Years 10 – 12)	12	20%
Trade or technical certificate	8	13%
University or tertiary studies	37	62%
Diversity		
CALD	6	10%
LGBTIQ	0	0%
ATSI	2	3%
Veteran	1	2%
Home care package level		
Level 1	3	5%
Level 2	25	42%
Level 3	9	15%
Level 4	23	38%
Home care package - years		
0 - 6 months	16	27%
6 - 12 months	10	17%
1 - 2 years	7	12%
2 - 5 years	17	28%
Over 5 years	10	17%

The surveys

The pre- and post-trial online surveys were designed by the project team and the RMIT University researcher to assess if the self-management model's consumer/carer objectives had been achieved. The surveys contained quantitative questions about demographics, satisfaction with their current service model, motivations for self-managing, and perceptions of associated risks, and the opportunity to provide qualitative comments. The surveys included questions about support, health and wellbeing that mirrored the English 'Personal Outcomes Evaluation Tool (POET)' survey. With permission from the POET authors, these questions were included so that results could be compared internationally (In Control & Lancaster University, 2017). The baseline and follow-up surveys can be viewed in Appendices 8a and 8b.

Participants were asked to use a 7-point Likert scale from 'strongly agree' to 'strongly disagree' to rate statements about *Satisfaction with choice and control in their package*; *Knowledge about package use;* and *Perceived positive and negative outcomes of self-management* [1]. Participants rated statements about *Perceived risks of self-management* on a 5-point Likert scale from 'very likely' to 'very unlikely' at baseline, and from 'strongly agree' to 'strongly disagree' at follow-up. The change in response set was to maintain temporal relevance.

The post-trial survey asked which sources of information and support participants had used throughout the trial to assist them with self-management, and to rate the usefulness of specified sources using a 4-point scale from 'very useful' to 'not at all useful'.

Footnote: In Control, & Lancaster University. (2017). *POET: A framework for measuring wellbeing.* Retrieved from England: htttp://www.in-control.org.uk/news/in-control-news/personal-outcomes-evaluation-tool-june-2016-update.aspx

COTA invited participants who withdrew from the trial implementation period to complete a brief survey to tell us why they withdrew. This information is valuable in understanding the motivations of participants and the obstacles they faced and is also presented below.

Statistical analysis:

Data was analysed on a range of measures. Pre-trial and post-trial data for participants as a whole group is presented for illustrative purposes throughout this report.

Quantitative data gathered in pre- and post-trial surveys were analysed to identify any significant differences in responses between these two points in time, and to identify any significant trends. The quantitative data analysis was compared with key findings from the qualitative survey and interview data to reinforce or question findings.

The data gathered from the pre-trial consumer survey was sorted into three categories: i) provided by independent participants; ii) participants assisted by a carer; and iii) carers on behalf of participants. It appeared that responses in the three categories were different. To test if there were significant differences between the answers given by participants, that is categories i) and ii), an Independent Samples Mann-Whitney U-Test was used. This was selected because the assumptions of normality were not met for parametric tests. The results showed that a statistically significant different response was given by the two groups to most statements.

Participants were significantly more likely than their family carers to expect **more stress** ($M = 5.35$, $SD = 1.64$ cf. $M = 3.79$, $SD = 1.82$, respectively; $p < .001$); **face more risk** ($M = 5.58$, $SD = 1.59$ cf. $M = 3.77$, $SD = 1.65$, respectively; $p < .001$); and have **positive changes in their relationship with the paid support workers** ($M = 5.94$, $SD = 0.81$ cf . $M = 4.95$, $SD = 1.53$, respectively; $p < .001$).

Family carers had significantly higher expectations of having **more money to spend on services and supports** (M = 6.03, SD = 1.16 cf. M = 5.22, SD = 1.79, respectively; p = .025); **experience positive changes in their relationship with the provider** (M = 4.71, SD = 1.30 cf. M = 2.39, SD = 1.38, respectively; p < .001); and experience **positive changes in their relationship with their family member** (the consumer) (M = 4.85, SD = 1.71 cf. M = 3.23, SD = 1.78), respectively; p < .001).

These findings are important because they show that consumer participants (as care recipients) held different views from carer participants (acting for care recipients). Further analysis of the quantitative data was performed. Data was sorted into two categories: i) participants whose provider was new to self-management overall, and ii) participants whose provider was already offering certain types of self-management. Results are explored from page 19.

4. Evaluation of Performance against:

- The proposed objectives and associated performance indicators;
- Benefits of the project;
- Issues and barriers to implementation and evaluation.

[A performance indicator or key performance indicator is a type of performance measurement. KPI's evaluate the success of a particular activity.]

This report outlines the trial outcomes specified in qualitative data gathered in interviews and open comments on the online survey, plus quantitative data from the survey. While the interviews were semi-structured using guiding questions, they had the flexibility to explore issues in depth in response participants' comments. As the interviews did not always cover all questions, the responses given are indicative and are not numerical.

The seven approved providers in the study adapted the COTA Australia self-management model to their experience and context and implemented different versions of the model. Some providers had been offering a self-management option for some years and had a well-developed business model, staff training, and systems to support this. Other providers were taking their first steps towards supporting self-management. These providers faced major cultural and organisational change. While the differences in the model each provider used prohibit direct comparisons, they provide natural comparisons that assist in identifying factors that contribute to positive outcomes.

Evaluation of performance against the original objectives:

Consumer expectations of self-managing

The pre-trial qualitative data analysis shows that participants had high expectations that self-management would result in them having better services and improved outcomes. Seventeen of the eighteen participants in the pre-trial interviews spoke of dissatisfaction with previous provider managed support, and similar sentiments were expressed in the online survey. Participants mentioned providers not being

responsive to their needs and preferences, rostering staff who were strangers to come to their home to provide personal care, and charging high administration fees. These widely expressed sentiments were captured by one participant in the online pre-trial survey:

> The (previous) provider I have been using has caused me undue stress over the last 18 months. I believe that I would have more control of the time I require support workers and I would also not have the administration costs that are presently imposed. I would work with support workers who understand my needs and are very professional and yet very caring and gentle. I am looking forward to the card which I expect will make payments easier. I would like to think my current service provider will provide relevant information to support a smooth transition to self-management, i.e. work with me during the transition period. Takes time learning. *(Participant 1, no prior self-management experience, online survey completed independently)*

Outcomes:

Benefits of self-management

The quantitative data analysis showed that participants' high expectations of self-management were largely met. A comparison of pre- and post-trial data showed that by the end of the trial participants were statistically significantly **more knowledgeable** about using and navigating their package, including managing finances, purchasing regulations and processes, and hiring care staff (Mdn: 5.3 vs 5.9; z = -3.24, p = .001). Participants also experienced statistically significantly **more positive outcomes** than they had expected (Mdn: 4.0 vs 4.4; z = -2.90, p = .004), and statistically significantly **better health and wellbeing** (Mdn: 5.0 vs 5.14; z = -2.70, p = .006).

Notably, participants reported experiencing statistically significantly **less risk than they had expected** (Baseline: M = 3.38, SD = 1.7 vs Post: M = 2.75, SD = 1.7), and their subjective **physical health** statistically significantly improved (Baseline: M = 3.52, SD = 2.0 vs Post: M = 5.18, SD = 1.7).

Access to greater levels of self-management from their provider at baseline was associated with better outcomes for participants at the end of the trial on almost all survey questions related to knowledge and navigating the system, confidence with self-management, and outcomes of self-management.

The statistical analysis of post-trial data shows the benefits of self-management for participants whose provider was already established at offering self-management. Meaning, that throughout the trial, these providers were building on their existing self-management models by offering more options and more capacity building information to participants than they had before. Four of seven providers previously offered certain elements of self-management, but not the full range of options as was trialled in the project implementation period. We separated the seven project partners into two groups for this part of the analysis, and revealed these findings:

- Participants whose provider already had a model of self-management before the trial were significantly more likely to report positive outcomes than those whose provider was new to self-management.
- The statistical findings which emerged from the qualitative findings, evidenced that a well-developed, robust self-management business model had the capacity to deliver effective self-management with positive tangible health and wellbeing outcomes for participants.
- Participant self-management was associated with improved relationships with paid support workers, however this improvement was not reported by those whose provider was new to self-management, who either experienced a poorer relationship, or no change ($F(1,57) = 5.31$, $p = .025$, eta = .085). At follow-up, participants whose provider was new to self-management were statistically significantly less likely to report positive change with their paid support workers compared to baseline.

- These participants were significantly more likely than their counterparts to report by the trial's end that they had all the information they needed to make decisions about their care and support (F(1,56) = 8.44, p = .005, eta = .131), to manage their package finances (F(1,57) = 4.94, p = .030, eta = .080), and to have a method of paying (at their discretion) for care services and items (F (1,57) = 5.31, p = .025, eta = .085).

Quality of life

A comparison of pre- and post-trial scores on items taken from the UK, *'POET: A framework for measuring wellbeing* survey was conducted using the Wilcoxon Signed Rank test. The only item that showed a significant change, but small effect size, was an improvement in physical health ("My physical well-being is as good as it can be") from baseline to post-trial (Mdn = 5, M = 4.58, SD = 1.7; Mdn = 6, M = 5.18, SD = 1.7; Z = 2.71, p = .006, r = .25). Other items examined such as community involvement, social wellbeing, economic wellbeing, friendships, family, and control over everyday decisions showed no significant differences. Finding no differences on these items was surprising as most participants spoke positively in post-trial interviews of having control over their self-managed funds and achieving better outcomes by using funds flexibly and creatively. Possibly no pre- and post-trial differences resulted because a large proportion of participants were already self-managing to some extent prior to the trial. It was not known, prior to trial, how many participants would already have experienced self-management, so the pre-trial surveys did not ask if participants were already self-managing to some extent. However, in pre-trial interviews, 9 of the 18 participants/carers reported that they had been self-managing prior to the trial. The trial may have continued their former practices, with the exception of the debit card which was new to everyone.

Qualitative data

The quantitative data showing that participants with high level packages benefitted from self-management while facing minimal risks were supported by the qualitative data.

The qualitative interview data show a variety of opinions regarding each aspect of the self-management trial. While there was overwhelming support for self-management, each participant had unique demographics, circumstances, needs and preferences. Most people welcomed self-management and were pleased with their outcomes. Some participants reported that they were less stressed self-managing than working with a service provider; a few who were already self-managing found little difference in the trial; and some found managing the accounts and recruiting staff to be a burden.

Twenty participants (approx. 20%) withdrew during the trial. Of these, one died and two went to residential care. Ten participants completed a withdrawal survey and six responded to suggested reasons as to why they left. Categories were not mutually exclusive and there are more than six responses.

- I didn't see any benefit in self-management (n=3/6)
- I found self-management confusing (n=2/6)
- I didn't know how to get started on my own with self-management (n=1/6)
- I couldn't get the help I needed when I needed it (n=1/6)
- I preferred things the way they were before I tried self-management (n=1/6)

Four additional comments indicated the trial was:

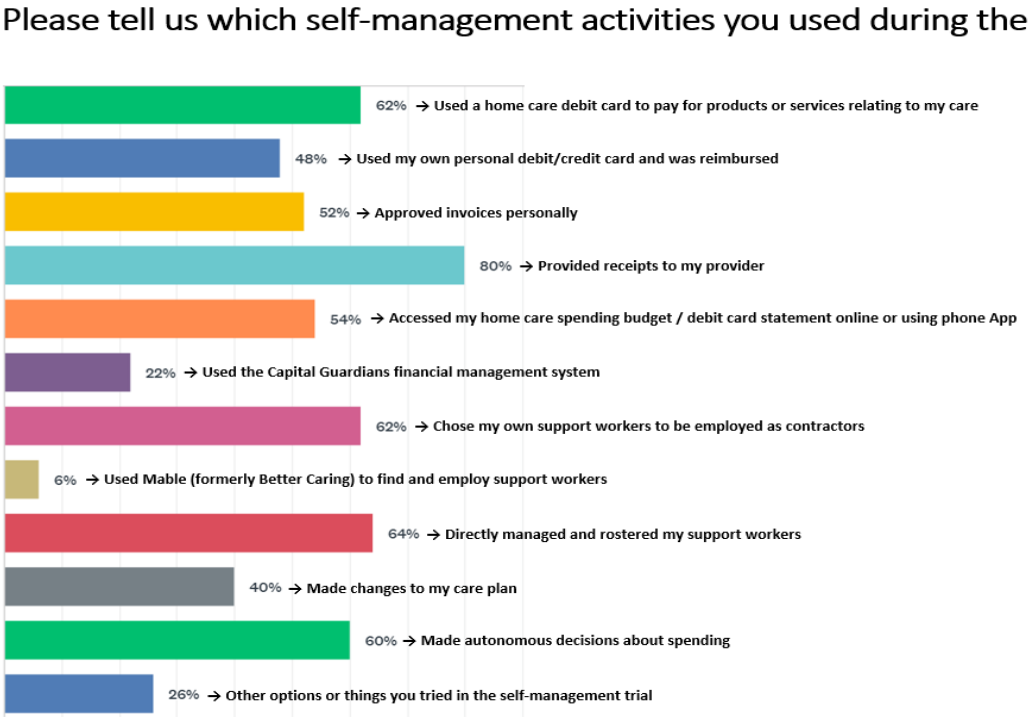
- Too time consuming (n=2)
- Anxiety provoking (n=1)
- Of no help to some already self-managing (n=1)

Four participants who completed the withdrawal survey came from one provider. This provider offered self-management prior to the trial, with the difference being

that the trial offered a debit card. A post-trial interview was conducted with one of these carers. The reasons given for withdrawing were that the trial was no different to previous self-management except for the bank debit card, which was *'lots of hassles'*. The carer resumed self-managing with the provider under the previous model.

Participants self-selected which activities they tested during the trial, however, they could only choose from the model elements their provider agreed to offer. Providers, for various operational reasons, did not embrace every aspect of the COTA model. COTA is aware of two participants who changed providers mid-trial to one of our other participating providers who would enable the particular self-management activity the participant wanted to test. See table 2 for the post-trial results for which activities were tested.

Table 2. Activities of self-management tested during trial:



The following summaries and quotes in italics from participants present a summary of the benefits and the challenges that were discussed in interviews or reported on the online surveys.

The advantages of self-management reported by participants were:

Autonomy

- *In past years when we got government money we felt like were begging. This is so refreshing. It is life changing.* (Carer)

- *Not having to deal with the care managers to the extent we used to has been great! We've had the autonomy to spend money…make your own decisions and be able to execute it in a timely manner.* (Carer)

Remaining at home

- Self-managing *enabled my father to remain living at home until 28 days before his death. Self-managing was easier than working with my provider.* (Carer)

Selecting staff

- *Self-management encourages people to use skills and take control… I interview and train my own staff. At [previous provider] I paid for most staff training myself because they could not train staff to meet my needs, and I got 4-5 different workers each week because of their rosters. The training for quadriplegics is different is different to old age generally.* (Consumer)

Saving money

- *We have an extra full-time staff come each week [for my wife] now because costs are cheaper. They give me a break more than anything.* (Carer)

Accessing the community

- *I have more access to community now I self-manage. It has been a godsend because of extra money, and because I can pay Uber on the card. It is less cumbersome than previous reimbursement. I get an invoice on my phone from Uber, and just mark what it was. It is transparent and runs smoothly.* (Consumer)

Flexible and creative

- One woman who had previously taken taxis used the debit card to occasionally buy petrol for her car, which was cheaper and more efficient use of funds. (Consumer)

- A voice activated Google Home Max system enabled one consumer to control his TV and home lights. He was blind and his hands couldn't manage the small buttons on the Foxtel controller. This kept him connected to current affairs and his mind active. His daughter said, "*this was a big big help"*. They also bought a second-hand electric lift chair with heat and massage which helped his condition. (Carer & Consumer)

- One woman bought an iPad that was used to photograph receipts, and to enable her to keep in daily contact with her daughter who lived some distance away. (Consumer)

- *Mum was able to have therapeutic massage. We also have a foot Care person who will wash and check her feet, massage her legs and apply moisturizer once a month for far less than the podiatrist charged for a fifteen-minute rush appointment*. (Carer)

- *I was able to order incontinence aids at greater ease without the middleman.* (Carer)

- *I subscribed to Italian TV which became my social outlet being alone a lot - this was not previously offered to me. Also, because it wasn't huge process to get a approval for or reimbursed for expenses, I was more likely to use a cab and pay for it with my Load&Go card as I didn't have to wait to get reimbursed. The trial pushed us to investigate other options that the money can be used for.* (Consumer)

- *I had some safety features put into the house to keep my wife from wandering off. A lockable gate at the top of the verandah. A higher balustrade on the back deck because she is active and could easily get over it. A gate across the kitchen to prevent her from going in. Things like that.* (Carer)

- *We adjusted the balance of Speech and Physio depending on what was preferable based on availability of providers and schedules. There was no need to have a set routine or pattern, we just booked in as needed or preferred.* (Carer)

- *My mother is a diabetic and prescriptive footwear was required because of pressure on her toes. I accessed funds to purchase the appropriate footwear.* (Carer)

- *I was able to be creative with the resources for my physical needs. Membership of a sporting facility to do exercise and swimming with a personal trainer.* (Consumer)

- One couple faced the prospect of moving into separate bedrooms because the husband had night episodes where he lashed out and was a danger to his

wife in their double bed. They were delighted to buy single beds and new linen to stay together in the same room. (Carer)

Less stress and more efficient

- *It is less stressful being on the trial than not being on it. Going through [provider] for little things takes a lot of my time and energy. It has given me extra time to do other things. Mainly I don't like leaving my wife by herself, so I don't have to go out as much anymore.* (Carer)

- *The admin has been easy [recruiting and paying staff]. It has enabled me to keep mum at home for longer. It is likely to be prolonging Mum's life*. (Carer)

Debit card

Almost 60% of participants used a debit card with package funds to: pay for care and services; employ their own staff as contractors; and manage and roster their own staff.

- *Having the debit card has revolutionised buying items, it is wonderful. I can see the balance online*. (Consumer)

- *I like the card because I can get what I need when I need it. It is better than paying myself and waiting a long time to be reimbursed. If I buy items on the approved list from disability stores, they can be twice the price as buying from others. The goods are the same. … For example, I can buy incontinence pads on specials. The savings add up, a bit here and there.* (Carer)

- *Card and access to account has given Mum peace of mind. She always knows how much money she has. Working online also gave her cognitive*

stimulation and satisfaction that she could do it. Her hand got arthritis and stopped her using the computer, which she liked to do. Now I do the online work. (Carer)

- The debit card was a key reason why one family liked self-management. The daughter liked the increased autonomy and flexibility of agreeing to pre-approved items, not having to ask permission to use funds in advance, and being able to spend at their discretion. The daughter said, *this means that my dad can spend money in ways that are convenient to him, so he is more likely to do so. He also feels empowered and free to respond to his curiosity about services that advertise through mail drops or similar.* (Carer)

Workforce

- *We slowly got a new team. This self-management model is a much better because the carers come because they want to. If they are paid by an organisation they work for their coordinator. But if I employ people they are working for me, and we can have a more personal relationship – that is a much better situation… our staff's loyalty is to our family… They're happier when they come here.*

Participants' mixed views on aspects of self-management.

Capital Guardians:

COTA Australia collaborated with Capital Guardians, a financial services intermediary, experienced in managing government subsidies on behalf of providers and consumers.

Participants had mixed opinions about Capital Guardians. Some found that they provided an excellent service for managing funds and giving real-time online access to their accounts and balance. For example:

- *I went to the Capital Guardian website, it was brilliant, I could not speak more highly about it, easy to use their website, a dream come true, Also, I could*

phone them if needed advice, especially initially, I always got the same person, they bent over backwards to make things work… It was idiot proof. (Consumer)

However, others found Capital Guardian's processes to be confusing and difficult to use. Some did not like Capital Guardians charging contractors and suppliers 2% to process accounts. However, once this became known and the fee was incorporated into the rate paid to workers, this ceased to be a problem. Contractors themselves reported appreciating prompt payments despite the 2% handling fee, as they could sometimes previously have waited up to 45 days for payment if they submitted invoices directly to the consumer's provider. Other participant complaints were:

- *It has a clunky website, it is painful because I couldn't delete an entry. Once I forgot to upload a PDF invoice, I could not change the entry. I'm a trained auditor, it was irritating. Is too rigid. I could not get reports; reports were not good; graphs didn't work.* (Carer)

- *I stopped using Capital Guardians long time ago – is easier without using them.* (Carer)

Most providers in the trial who used Capital Guardians also found their systems and processes difficult. Some providers were continuing negotiations and were still to decide whether they would continue using Capital Guardians to manage the finances after the trial.

Mable [formerly Better Caring]:

This online platform that connects contract workers with consumers also drew mixed views from participants and strong support from providers. Some participants found it enabled them to locate and recruit suitable support workers. For example:

- *Mable has been okay. I'm conscious of bringing people into mum's life who she is not familiar with. I was anxious about checks the platform does, are*

people really who they say they are? I'm satisfied now. I have used one person a lot and two a bit. (Carer)

However, others were more reticent. For example:

- *I did look at Mable. It seemed a step back from self-management. I thought it was a rip-off deducting 10% from worker's salary. It didn't make sense. I use Gumtree where I advertise for free.* (Consumer)

Providers who worked with Mable expressed satisfaction with their service. They often directed participants to Mable to find suitable staff because their costs were typically 20-40% less than other providers; Mable ensured that staff had police checks and all necessary insurances; and some providers had access to the Mable management website to see accounts. One provider said, *We can see everything that is happening: weekly progress reports, billing, staff qualifications, if the consumer changes worker. It is a huge advantage over any other platform. It is brilliant. We worked together a long time before the trial.*

Participants' difficulties with self-management

The difficulties that participants faced when self-managing resulted mainly from the limitations of financial and process systems.

Debit cards

One provider negotiated a debit card with a bank, while all other offered the Australia Post Load'n'Go reloadable debit card. Many participants found the cards difficult to organise initially, and both had issues. The Australia Post Load'nGo card was not universally accepted by services, and did not reflect the total home care package balance, only the portion that had been loaded onto the card. Therefore, participants had to view their fund statements from their providers and the card statement to understand their total amount of funds available. Many participants liked the convenience of using a debit card and recommended that it be continued using an alternative company.

- *We set it up [self-managing] and got the card, but that were lots of hassles with the bank.* (Carer, using bank debit card)

Providers' views on self-management

The seven providers involved in the trial varied on all parameters: big, medium, small size; for-profit, not-for-profit; national, city, regional; years of experience offering self-management, new to self-management. With different backgrounds and locations, they came with different expectations of the trial. Those with self-management experience were committed to principles of consumer choice and control and wanted to learn from others and ensure their systems were the best possible. Others came to learn how to offer self-management as an option or to explore new possibilities. Consequently, providers' experiences and views on the trial varied greatly. An analysis of the provider interview data identified eight factors that contributed to the successful implementation of self-management programs, and conversely, to difficulties when these factors were missing. These factors align with management theory organisational change models and are presented below following their feedback on debit cards.

Debit card

The debit card was a great success for participants after the initial establishment difficulties. However, it was an administrative challenge for providers. Some had to employ extra staff to acquit the items charged with each person's budget, and others found both the bank debit card and the Australia Post Load and Go card was 'clunky'. It lacked the functionality providers wanted and they were looking for an alternative. One provider reverted to participants paying personally on their credit card and reimbursing. A major administrative problem was that participants did not send receipts, in a timely manner, or indeed at all in some cases, to the approved provider for items purchased on the card, which were needed for accountability. This was a major problem for one provider who channeled all funds through the card. Other providers found it easier when they only 'topped up' the card after receipts were received and approved.

Limitations of this study

This study has limitations in its ability to generalise to others who want to self-manage. First, all participants were endorsed by their service provider as suitable to self-manage. Second, participants received considerable input from the project team, which provided an unsustainable level of support. Third, the trial required providers to offer oversight and support, which may not be available to others in the future. Consequently, the findings cannot be generalised to everyone who might want to self-manage. However, they do indicate factors that can lead to positive outcomes.

Success factors for providers

An analysis of the provider and consumer interview transcripts identified eight factors that contributed to building successful businesses supporting participants to self-manage. Provider CEOs and senior managers said these factors facilitated their success, or conversely, were obstacles when they were underdeveloped or missing. Future research is required to determine if these factors correlate with positive consumer outcomes. The eight factors identified are:

1. Shared principles of choice, control and self-determination

Having a shared understanding across the organisation of the principles of consumer choice, control and maximising independence is necessary to develop consistent and coherent implementation policies and practices. CEOs and senior managers said if staff give 'lip service' to these principles and retain professional control, it limits consumer choice, control and self-determination. One CEO, who was committed to transitioning a large, long-established traditional organisation to offer participants more choice and control, spoke of the challenges changing organisational culture and educating staff to understand these principles. Another CEO, who was operating a successful self-managing program said, *I interview every staff member, if they are on board with our values good, if not go elsewhere.*

2. Working together as a team

Having all staff in an organisation implement their shared understanding of the principles of choice and control and self-determination contributes to success. This factor was evident from an analysis of the interviews with the two CEOs referred to in the previous section and others. The importance of this factor was reinforced in interviews with staff and consumers. In one organisation, a staff member spoke of their work in terms of arranging services for consumers rather than empowering older people to manage for themselves as much as possible. A consumer from another organisation reported having asked a care manager for advice about self-managing. The care manager replied that they knew nothing about it and was 'bamboozled' by self-management, even though the organisation was part of the trial.

3. Clear business model

Having a clear business model to implement self-management facilitated its successful implementation. This factor became evident after comparing interview responses from CEOs and senior managers. Some said they knew the cost of each aspect of their business and could adapt to the new pricing structures, they were confident they had quality and safety measures in place to offer quality services and minimise risks, and that self-management was straightforward to administer.

In contrast, some others said they were not sure of their unit costs, were worried about how to respond to the new pricing structures, were still developing strategies to manage risks when participants had more choice and control, and found developing procedures to administer self-management challenging. The important factor was having a clearly articulated and well-integrated model, rather than having specific features in the model. For example, some confident providers offered a pre-loaded debit card, while others required participants to pay using their private credit card receive reimbursement. Some encouraged participants to recruit and employ staff through Mable's recruitment service, while others suggested Gumtree or elsewhere. The important factor was having a well-integrated and costed model as well as support at key levels of the organisation.

4. Risk management policies

Having risk management policies gave CEOs and senior managers confidence in their self-management program. In addition to having policies that met the general aged care requirements stemming from the new Charter of Aged Care Rights (2019), and the Aged Care Quality Standards (2019), they had policies to ensure self-management was safe for the organisation and the consumer. They had strategies to manage the tensions between giving people choice and control while managing risks. The interviews indicated that each provider had determined their own risk tolerance level. For example, with regard to debit cards, some providers minimised risk by requiring participants to submit receipts before 'topping up' the balance. With regard to employing staff, one provider minimised risk by asking participants to find suitable staff on Mable or elsewhere before accepting them as a consumer. This minimised the risk of not finding suitable workers. Each successful provider had determined their risk profile and strategies.

5. Efficient administrative processes

Having efficient administrative processes assured CEOs and senior managers that they could deliver a successful self-management program. They spoke of continuous improvements in administrative processes and striving for efficiency to respond to consumer and carer demands and enhance their financial viability. Interviews with participants confirmed these expectations They wanted claims and reimbursements to be processed quickly and efficiently. While they also wanted online access to their account balance, this feature was not currently available. Participants were highly critical of providers that had inaccurate accounts or were slow to respond to queries.

6. Efficient IT systems

Efficient IT systems designed to process individual payments and give participants access to their account enabled providers administer self-management. Providers confident of their ability often spoke of their considerable efforts to ensure their IT systems were fit for purpose. Conversely, some providers transitioning to self-management spoke of difficulties aligning new and old systems. Participants often

wanted ‘real time’ access to their account balance. However, because there were delays in payments and reimbursements, this was not possible. Some IT and financial management systems delivered this better than others. However, providing an accurate 'real time' balance was a challenge for all providers. One provider was contracting an IT development company to show real time transitions and balances online, a feature that participants wanted but no provider was yet delivering.

7. Information and support

Providing participants with necessary information and support was an important factor in delivering an effective service. Participants were clear that they needed information and support, and they looked to their provider as a primary source. This was despite COTA Australia providing toolkits and free telephone and email consultations. Participants required intensive support during the start-up phase, and there were different ways of providing this. The trial included providers who had two arms to their business. One arm provided traditional agency managed support and charged higher fees. The other arm supported self-management and charged lower fees. Participants could work with a care manager under the traditional model to learn about and set up self-management and transfer to managing it themselves when ready. Participants had the option to transfer back to the agency managed service at any time. This model made it clear to participants that they could pay for extra support or take on more responsibilities through self-management and pay lower fees. Providers who did not have these two arms to their business sometimes found they were giving considerable support while charging low fees.

8. Responsive and adaptable

Being responsive and adaptable was a characteristic of CEOs and senior managers who were confident of their ability to support self-management. This was evident in discussions about consumer requests, administrative processes, IT system design, opportunities and responses to legal and standards requirements. One CEO said, “I am continually making adjustments to government changes”.

Risks: general

The literature review and discussions with industry members raised concerns that self-management might expose vulnerable older people to risks, especially those with high support needs, those with high level packages, and those without the presence and support of a carer. At various stages of the model development and points of data collection, COTA asked participants to self-assess their perceived exposure to risk.

By asking people about their perception of exposure to these risks, we attempted to determine whether the risks to participants were actually risks that the sector was projecting on to participants, or whether these were risks that participants perceived for themselves. As the majority of participants with Level 3 and Level 4 packages were assisted by a family carer, it is possible that their support mitigated against management risks.

a) Risks: pre-trial findings

The pre-trial data show that participants at all package levels expected that self-management would bring minimal risks. Table 3 shows consumer expectations, and Table 4 shows carer expectations.

Table 3. Consumer Survey expectations of risk when self-managing, online survey, (n=103)

To what extent do you agree with the following statements:		Consumer completed survey independently n=32		Consumer completed survey together with family carer n=16		Family carer completed 'Consumer' survey n=54	
I might run out of money and leave myself short.	**Agree**	0	0.%	0	0%	9	17%
	Neutral	3	9%	1	6%	7	13%
	Disagree	29	91%	15	94%	36	70%
I might make mistakes and spend my funds inappropriately	**Agree**	1	3%	1	6%	4	8%
	Neutral	1	3%	0	0%	8	15%
	Disagree	30	94%	15	94%	40	77%
I might compromise my clinical care needs because I have less care manager oversight	**Agree**	1	3%	0	0%	7	13%
	Neutral	1	3%	0	0%	7	13%
	Disagree	30	94%	16	100%	37	71%
I might employ unsuitable/unqualified care staff who are unable to meet my needs	**Agree**	1	3%	0	0%	6	12%
	Neutral	1	3%	1	6%	7	13%
	Disagree	30	94%	15	94%	39	75%

I might have difficulty setting goals for myself to develop my care plan	**Agree**	0	0%	1	6%	7	13%
	Neutral	3	9%	0	0%	11	21%
	Disagree	29	90%	15	94%	34	66%
I might have poorer outcomes because I don't know how to navigate the aged care system	**Agree**	1	3%	2	13%	13	24%
	Neutral	4	13%	2	13%	12	22%
	Disagree	27	84%	12	75%	29	54%

Table 4. Carer Survey expectations of risk when self-managing, online survey, (n=66)

Will self-management result in more risks?	Agree	Neutral	Disagree
Carers	22	21	23

b) Risks: post-trial findings

The post-trial qualitative and quantitative data show that participants thought that self-management would give them **many benefits and few risks, including those with high level packages.**

In the post-trial interviews, the great majority of participants considered that self-management presented no risks to them at all. Indeed, most seemed surprised to

be asked about possible risks. Only three of the 25 participants interviewed mentioned possible risks, and most thought there were possible risks for others and not to themselves. They were concerned that others with less financial literacy might misuse the debit card, and they might have problems recruiting staff.

What participants want in terms of capacity building support to ensure the best outcomes for themselves.

Initial COTA Australia surveys and workshops that helped to scope the study, focused on defining the tasks and activities associated with self-management. We identified the types of supports that participants requested in order to build their capacity to self-manage. The project *Welcome Pack* and *Consumer Implementation Toolkit* reflected what participants requested. Providers also contributed to this by identifying the types of tasks generally undertaken by care managers in their day-to-day work. This helped describe the types of activities participants may be required to undertake as a self-managing consumer.

In the formal pre-trial interviews and survey, participants made it clear that they wanted and needed clear information about self-management and access to advice when they needed it. Most were confident about their ability to self-manage as long as they had information about policies and procedures. Personal knowledge and experience was rated as useful by 93% of survey participants, and rated the highest in usefulness of all resources (M = 3.20, SD = 0.89, Mode = 4, Range = 1-4). Many cited their experience managing accounts and using online banking, and some referred to their professional backgrounds as managers and other positions having financial responsibilities. Nine of the 18 people interviewed pre-trial were already self-managing elements of their home care package. Their confidence may be a consequence of their education levels, which are higher than the general population, as shown in Table 1 above. The interviews were conducted before the *Welcome Pack* and *Consumer Implementation Toolkit* were distributed, and participants were keen to find out details about the trial. They stressed the need for accurate information and competent accounting processes.

The post-trial data interviews and qualitative survey comments showed that participants expected providers to make all necessary information and support available to them. Those who were already self-managing spoke of the importance of having someone to contact when they needed advice. Participants expected clear information, easy to use and efficient account processes, and support when required. This counters any view that self-management will be an easy, 'hands off' option for providers.

Feedback regarding the COTA Australia *Consumer Toolkit* shows how challenging it can be to provide information that suits everyone. Overall, the *Consumer Toolkit* was well received and found to be useful, with some people saying it provided all the information they needed. Case studies and examples were particularly helpful in providing new ideas for how funds can be spent. However, according to the responses in the online consumer and carer survey 13% of people never read it. Some who did read it found it too detailed as they felt they were already doing most of the activities already. These findings are consistent with those from other studies cited in the literature review. Providing information in formats that meets diverse needs is one of the greatest challenges of self-managed programs. These difficulties were exacerbated in the trial because the seven providers implemented the COTA Australia self-management model differently. Being responsive to feedback, COTA Australia has revised its *Consumer Toolkit,* see Appendix 10. However, this provides generic information and providers must specify their self-management model and their particular requirements.

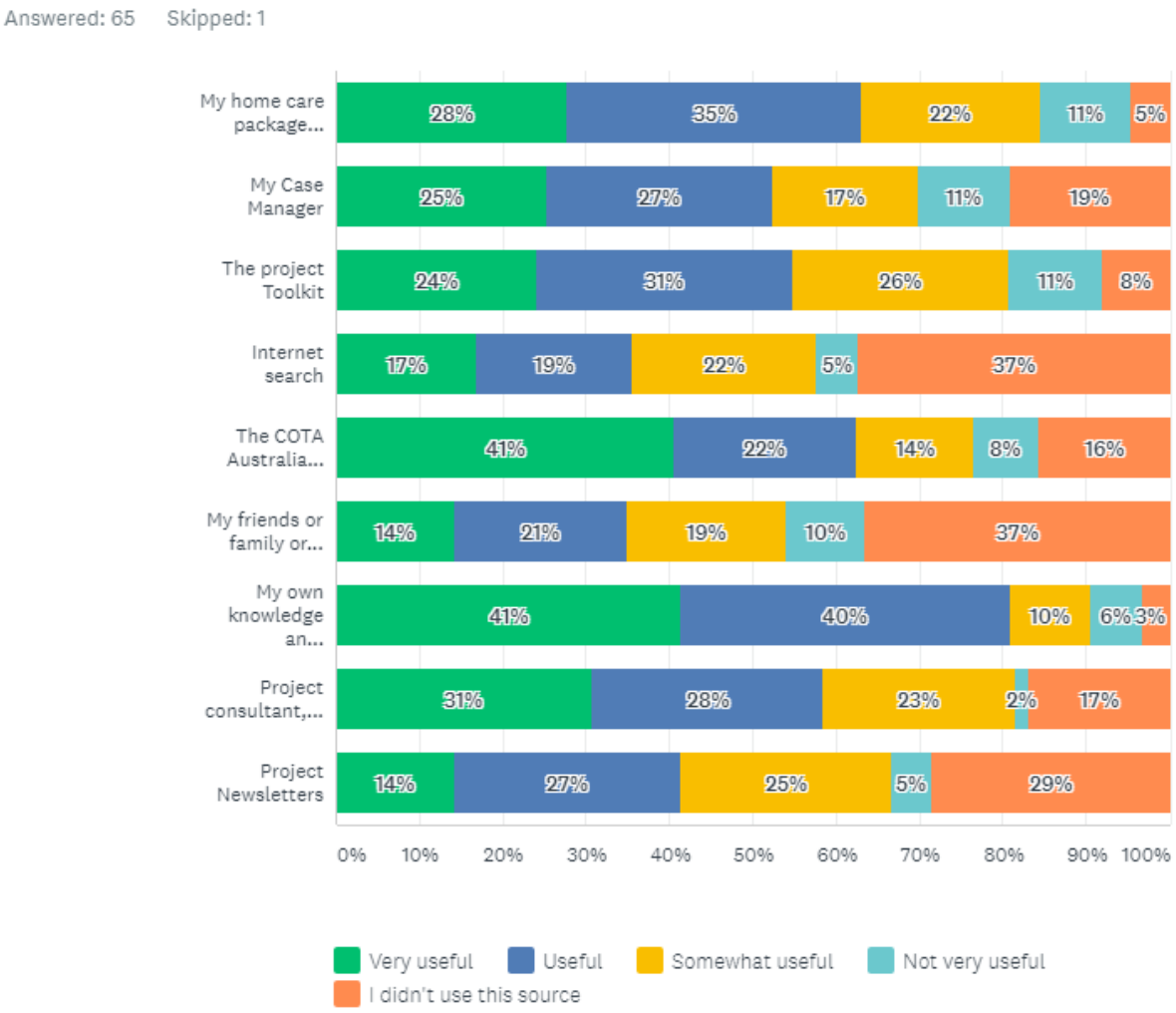
The most effective way to increase awareness of the tasks and activities required to manage a home care package – from assessment to goal setting to appropriate spending to financial management

COTA Australia's self-management model articulated typical activities that care managers do in their day-to-day work. The Consumer Toolkit encourages participants to think critically about their own care needs, how to prioritise these care needs, how to translate care needs into functional care goals, and finally, how to best utilise their home care funding to meet their goals. The evaluation showed that

most participants worked through these processes successfully and achieved outcomes they wanted.

The COTA Australia team and Angus Kerr, consultant to the project, provided information and support and were a resource throughout the trial that was used by 80% and 83% of participants respectively. They were rated the second and third highest useful resources respectively. The important role of providers in supporting the transition to self-management, and providing the requisite infrastructure was reinforced statistically. Almost all participants (95%) sought support from their provider and many from their care manager (75%), and these two sources were rated almost as highly in usefulness as the COTA team. See Table 5 for the table of most used resources.

Table 5: Most useful sources of help and information during trial.



How easily can an externally developed model of self-management be integrated into an existing provider business model, whilst assuring providers that their governance and compliance obligations are being met or even exceeded?

The seven partner providers contributed to the design and ongoing adaptation of the self-management model through a Steering Committee and group workshops. Their input assisted in ensuring that the model reflected contemporary practice and compliance.

Each provider was at a different stage in implementing a self-management program. Some had years of experience and established processes to manage information and support, finances and risks. Others were beginning their journey towards self-management. Even the most experienced providers faced challenges implementing self-management as aged care regulations changed and they had to adapt their model. Two experienced providers trialed a debit card for the first time. One is keen to continue its use, although it is difficult reconciling the card with existing accounting systems; and the other reverted to participants paying with personal funds and being reimbursed. These examples show that it is difficult to adapt service models. Providers that designed their business from the beginning for self-management found it easier than those who were adapting existing services.
Established providers faced many difficulties adapting their processes, with possibly the biggest challenge being changing organisational culture.

The cost implications of offering consumer self-management from the provider perspective. i.e. what are the costs and where are the savings in terms of back-of-house functions – finance dept, care management ratios, and so forth.

This objective appeared more difficult to quantify as project providers did not give specific dollar values to represent the type or amount of work they performed to support their participants. Throughout the regular Steering Committee meetings and during face to face workshops, providers described having to increase the human

resources to cater for the increase in communication between participants and their finance personnel in particular. Some also found their care managers were called upon by participants when they had specific questions about tasks or responsibilities. Not all project providers readily responded to the participant requests as they stated that the participant 'ought to work things out for themselves', because 'that is what self-management is all about'. This issue caused some problems for participants who reported in their feedback that they felt they were without any back-up from their provider.

Providers who exclusively offer a self-manage model of care reported requiring fewer staff compared to providers who offer various levels of self-managed or provider-managed care. Self-management only providers report that once their consumers have commenced been set up on the system, they do not require frequent assistance. Two of the seven provider partners did not specifically employ care managers, but their existing staff deliver core care management plus additional care management supports should the consumer request it, and at no additional cost to the consumer. This type of staffing model is reportedly more efficient and lower cost than the more traditional larger providers. Similarly, providers who also deliver other program types, such as Commonwealth Home Support Program, disability services, housing or mental health services, and so on, reported continuing to have much higher overheads than their self-management-only counterparts. This is, in part, due to the need to comply with different legislative requirements for each program-type and needing different expertise to support each consumer group. The brevity of the trial did not allow providers to predict the likelihood or otherwise of whether they would reduce their care management personnel or vary the care manager:consumer ratio. Anecdotally, providers referred to possibilities of having their self-managed consumers 'quarantined' so that those consumers were supported by a self-management expert from within their organisation. Conversely, the fully self-manage providers did not express an intention to change their current model.

What are the cost or other resource implications for providers in building consumer capacity to self-manage.

We know, anecdotally, that providers who had a previously existing model of self-management spent considerably less time on capacity building activities with their consumer group compared to providers who were new to self-management. They attributed this to the fact that their consumers had become accustomed to provider-lead support and took longer to feel confident to take on responsibility for themselves. The providers also reported that these consumers tended to wait for their care manager to make things happen rather than being proactive. Providers whose models gave more autonomy to consumers in the first instance, did not have as many issues with their consumers being slow to uptake the COTA self-management model. The post-trial data supports this anecdotal feedback.

What capacity building is required in the broader aged care sector to increase the number of providers offering high level self-management.

During the trial, the project team engaged with the broader sector to discover the mood of providers and associated organisations such as provider peak bodies, Government departments, private consultancy firms, legal firms, technology development companies and so forth. COTA's project team had several publications, media articles, and were invited to present at numerous sector networks, seminars, conferences and educational workshops attended by providers. These opportunities led to a growing database of providers who are interested in following the project and are keen to receive the tools and resources once the final versions have been completed. This is testament to the increased profile of self-management across the aged care sector. Lessons from other sectors including international examples of cashed-out models, self-directed care, and, closer to home - disability through NDIS, self-managed superannuation, and self-managed compensable injury programs have all contributed to the body of evidence in aged care self-management. The key for the COTA project is to explore other sectors to contribute to developing a best-practice model that is unique to Australian aged care.

The project learnings reveal that the sector wants consistently applicable information to support them and their participants to implement self-management. Many providers explained that they believed they did not have the financial or time resources of their own to develop a unique model. Hence, project resources for the sector will be welcomed by providers who fall into this group.

5. Learnings from the project.

[Document what worked well, what could be improved and recommendations for improvement.]

What worked well:

- Broadening the scope of provider partners
- Consumer recruitment strategy
- Co-design with Providers
- Co-design with Consumer

Broadening the scope of provider partners

Over time, the project team widened our scope for provider partners to include providers who did not have an existing self-management model, but they expressed a strong willingness to expedite and implement the elements of the trial self-management model with their work teams. The project team had initially sought provider partners that had some knowledge and/or experience in offering consumer self-management. It was thought that these providers would already have the cultural mindset required to integrate a high-level self-management model into their existing structure, thereby being ready to commence as soon as the model had been developed. As mentioned earlier in the report, the number of providers who already had an articulated model of self-management was significantly fewer that the My Aged Care service finder data suggested.

Consumer recruitment strategy

Following the signing of our project Agreements, the seven provider partners began recruiting their consumer and carer participants for the trial. The process of contacting participants directly and inviting them to participate was well-received by consumers and generated a high rate of acceptance to commence the pre-trial information process. The option of self-selection for consumer participants was considered as an option for recruitment, and despite the concern around participant

selection bias, it was rejected on the basis that there were certain pre-requisites for participation. These included proficiency with email, internet and mobile phone. Those participants who did not have these proficiencies could nominate a carer or other representative to be the participant in the trial.

Co-design with Providers

Pre-model development phase:

Development of a provider survey to scope the sector for attitudes towards self-management was very revealing. The data showed that there were mixed attitudes – for example: 75% of providers are in agreement that self-management is an important part of consumer directed care. Conversely, over 40% of providers felt that older people were not generally good candidates for self-management. All providers specified a range of tools and resources that would help them to introduce self-management into their organisation. This formed the foundation for the general sector workshops that the project arranged in six States to formulate the model to be trialled.

Co-design and collaboration after project partner recruitment:

Conducting a Melbourne-based pre-trial workshop for our provider partners was an excellent step in consolidating the providers into one cohesive group with common interests and mutual understanding of what was required for their on-going participation. The sharing and collegiate environment was an important beginning for all involved.

Involving the project collaborators at an early stage in the project worked well. COTA had engaged and partnered with a financial services intermediary to explain to provider partners about options for streamlining the financial management of home care packages. We had also engaged and partnered with a staff employment company to educate providers about participants selecting, employing and managing their own direct care workers. The two external collaborators were integral to the overall project model being trialled by consumer participants.

Monthly Steering committee meetings for the entire duration of the project kept the project plan on track and allowed for proactive identification of any issues that may impact on implementation for both providers and participants.

In total, COTA hosted three Melbourne-based workshops for provider partners, consumer representatives and project collaborators. Each of these workshops successfully built on the knowledge and understanding from the project to-date, and to test the learnings with the group in order to make adjustments and plans for the next phase of the trial.

Co-design with Participants

Co-design: COTA Australia recognises that the success of the self-management model and trial depended on how well it resonated with the needs of the people who will use the model. Namely, participants, carers and approved providers. It was important to the project sustainability to design a model with participants that was customised to the unique Australian home care packages context. Using co-design principles, the project engaged with participants via online surveys, face-to-face workshops, education articles, working groups and expert reviewer activities.

Working party involvement - working groups and Expert Reviewer members were invited in the pre-implementation and model development phase of the project. Working groups met by teleconference to discuss key elements such as: consumer self-management readiness checklist; self-management tasks and activities lists; consumer knowledge, skills and attributes for self-management; survey question development; model content and design. Once the working party had their input into these various elements, the Expert Reviewers were given drafts for comment and edits. Following this, the project team incorporated feedback and developed the final version for inclusion in the project model for testing.

What could be improved and recommendations for improvement:

Initially COTA Australia expected the provider partners to trial the COTA self-management mode. However, each provider partner adapted and integrated elements of the project model into their organisation. This provided an opportunity to identify factors that resulted in positive outcomes for participants dependent on the structure and operational maturity of their model. From the project implementation perspective, there were pros and cons associated with partnering with providers who were both new to self-management and those who were established. Results showed that the outcomes were measurably better for participants who had some experience with the activities and then built upon that experience in a measured and structured way. These measurable differences require further research into the reasons why new to self-management providers were not able to replicate the positive outcomes with their consumer group.

Challenges

During this project, a major Government reform was introduced that impacted on the application of the self-management model. The Aged Care Legislation Amendment (Comparability of Home Care Pricing Information) Principles 2019 impacts on some of the elements of the model that have previously centred around the application of administration and care management charges against a person's home care package. Following the announcement of the pricing reform one provider suggested that unit pricing will "spell the end of self-management" because of a perceived disincentive for providers to offer a self-management opportunity to make any income from the consumer's package were at best diminished, or at worst, eliminated altogether. However, other providers in the trial saw no conflict and were planning to adapt their charges to conform with the new requirement. The model content and format was reviewed to take these reforms into account. By the time the reforms were formalized in practice, our provider partners has determined how their pricing model would translate and most had simply reconfigured their existing prices into the new template.

The approved providers working as project partners with COTA were required to continue with their own integration of the national reform agenda into their business models. Our self-management model required additional commitment of people and resources to ensure the best possible outcomes could be achieved, but there were times when the imperatives of the project and the imperatives of the provider were incompatible. Careful diplomacy and flexibility around project timelines were needed to ensure the relationships remained supportive, cordial and productive.

Following the July 1, 2019 deadline for providers to publish their new pricing on the My Aged Care website, our project partners were confident that their new pricing structure would have little to no impact on their financial bottom line, nor would it adversely impact on consumers and the price they paid for the same level of service. The project team fully revised the toolkits and other resources to reflect the new terminology. Additionally, the transition to the new Aged Care Quality Standards has also been reflected in the updates of the project self-management resources.

6. An assessment of how the project could be adopted more widely.

The project found that self-managing home care packages was embraced by many older carers and their families and resulted in better outcomes for those who chose this option. The factors found to promote and sustain self-management programs for consumers and providers are detailed in the Consumer resources and the Provider resources. Additionally, the 'success factors for providers' identify organisational factors to successfully transition to, and sustain, self-management models.

Numerous carers spoke of being able to maintain their family member at home because of the flexibility self-management provided. More specifically for some, the reduction in hourly rate costs by contracting their support workers meant their subsidy dollars had increased purchasing power. One participant stated that by contracting his own workers, he doubled the hours of care for his wife from 14 to 28 hours per week.

While this study did not include an economic analysis, it seems feasible that governments could save money in the long term if they invest in promoting and supporting self-management programs to enable people to continue to live at home instead of moving to residential care.

Many consumers and providers know little about self-management and will need support and encouragement to consider this option. In summary and to consolidate the many and varied learnings from this project, COTA proposes the following recommendations:

Government can play a key role in the transition to self-management by:

1. promoting self-management as an option in policies and publications, while acknowledging that it is not for everyone
2. promoting the benefits of self-management to providers and consumers

3. offering advice and assistance to providers as to how they can adapt their existing model of service to offer a self-management option that aligns with their philosophy, history and interests

During the project period, there has been a rise in commentary about consumer self-management in the aged care sector. This included both positive sentiments as well as some cautionary messages to providers about enabling their consumers to have more autonomy and control. This played out in several ways. Several articles were published in sector media that warned providers to proceed with caution, making assumptions about consumers' general incapacity for self-management, the lack of regulatory compliance in some self-management models, and concerns over financial viability if consumers take on more administrative and care management functions for themselves. Conversely, articles and reports describing positive consequences of consumer self-management have generated interest and positive dialogue in the sector. The commonality between the various articles is that self-management needs to be well-defined and the model must maintain regulatory compliance for providers. Importantly, capacity building activities to ensure consumers have the knowledge and skills needed to deliver optimal individual outcomes must be a priority feature of any model.

Project outcomes will be widely distributed to ensure they develop the momentum to keep them 'alive' in the sector. The Steering Committee developed a Strategic Action Plan to ensure long-term uptake of self-management for consumers. We noted that it is equally important to get up-take of self-management by both providers as well as consumers themselves to ensure high-level self-management is not diluted to the extent that genuine consumer choice and control is compromised.

Additional Key Messages:

1. A recent COTA review of the GEN aged care data spreadsheet containing available data for home care service outlets across Australia reveals the number of providers indicating whether they offer self-management to their consumers in the My Aged Care Service Finder. See Table 6. It is notable

how the numbers have reduced significantly across the three timepoints. This analysis is consistent with observational and anecdotal information that fewer providers are offering self-management in 2019 than ever before. This is despite the self-determined, tech-savvy cohort of baby-boomers entering the aged care market, either for themselves or as carers of ageing parents.

Table 6. GEN data analysis, Home Care Packages Program data report March 2019.

GEN data analysis. Home Care Packages Program Data Report: Providers indicating whether they offer self-managed option to consumers on My Aged Care Service Finder:						
Offer self-management	**Dec 2017 n =**	%	**Jun 2018 n =**	%	**Mar 2019 n =**	%
Yes	1133	*46%*	1398	*52%* *(+6%)*	305	*12%* *(-40%)*
No	915	*37%*	974	*36%* *(-1%)*	215	*8%* *(-28%)*
Left blank	412	*17%*	327	*12%* *(-5%)*	2075	*80%* *(+68%)*
TOTAL **	**2460**		**2699**		**2595**	

** the total number of providers in this table is not a true representation of the number of approved providers. The above data analysed the total number of **unique outlets** as they appear via the data available from My Aged Care, and as they appear in the GEN data spreadsheets. There is no definitive data available that isolates each approved provider as a single entity, however this is consistent data across all timepoints.

Source: https://www.gen-agedcaredata.gov.au/Resources/Access-data?page=1

1. Some explanations for why home care providers have scaled back their models of self-management include the default position most providers take by reducing, or removing, care management as a core function of the package delivery. Self-management ought not be a euphemism for 'no care management'. COTA's project outcomes, in fact, demonstrate the most effective model of self-management offers a spectrum of involvement, where consumers are supported with capacity building and a schedule of ongoing support.

2. Debit Card solutions can work to empower consumers to manage their package subsidy to meet their care needs and goals. However, robust upfront training, along with checks and balances, and a clear and objective decision process is needed for it to work.

3. While currently the majority of participants in the COTA project trial (70%) reported that a loved one or carer represented the actual care recipient in self-management, we anticipate the cohort of older Australians accessing home care packages into the future will be likely to have managed their own services all their lives and will wish to continue to do so. Accordingly we must continue to develop the support for both consumers and carers as the driver of self-management.

COTA's project model describes the fundamental features of how consumers want to engage with a system that is set up to support them. Consumers and carers are not looking for a one-size-fits-all approach to home care, rather they want options that enable them to tailor their package management to match their personal circumstances and preferences.

Current consumers of home care, together with people who are not yet receiving care but are thinking toward the future, are typically pragmatic about their desire and capacity to self-manage. Consumers have emphatically told us they want:

- to maintain their autonomy and self-determination;
- information and tools to increase their knowledge and skills;

- clear parameters around decision-making responsibilities and obligations;
- to make informed choices regarding suitable spending of their government subsidy;
- a safety net to support them when they need help or if they want to revert to provider-managed care.

7. An assessment of which elements of the project could be sustained beyond the trial period.

The project team has developed the following resources to promote self-management into the future.

1. Self-management definition
2. Self-management model
3. Process for adapting model to practice
4. Resources for providers
5. Resources for consumers
6. Videos

Self-management definition

This definition of self-management was developed with the working parties involved in the 'Increasing Self-management in Home Care' project. The two working parties included key representatives from home care providers and people receiving home care and their carers. This definition also included the input of leading experts in Australia and academic evidence.

Self-management of home care packages gives consumers and/or carers direct access to funds and financial information regarding their package. They have more control over spending and authority to decide what services, products and activities relevant to their care are purchased. Self-management requires consumers and/or carer to actively engage in managing and directing their home care. The level of involvement is flexible and may include activities such as scheduling care staff and appointments, paying bills and general administration. Self-management gives consumers and carers more control of their funding, including authority to decide what services, products and activities relevant to their care. Self-management allows direct access to funds and financial information regarding the package.

Resources for providers

The project team developed the following resources to assist providers transition to self-management.

a) "Evidence base for self-management":

The Literature Review helps providers understand:

- the academic justification of COTA Australia's project about Self-management in Home Care
- domestic and international commentary, research and exemplars
- the future of Self-management and aged care in Australia
- where to go for further resources and information

b) PROVIDER IMPLEMENTATION GUIDE

This document helps providers understand:

- how to define self-management in home care
- how self-management works in practice
- how to support your organisation to prepare for self-management
- how to support your consumers to prepare for self-managing their home care
- managing risks involved in self-management
- examples of self-management including implementation

c) PROVIDER GUIDE TO DEVELOPING A SELF-MANAGEMENT AGREEMENT

This document helps providers understand:

- guidance, processes and tools to help integrate self-management
- defining your self-management service and options to consumers including model pricing
- shaping your organisation's home care agreement to include self-management including processes, clauses and schedules

Resources for consumers

The project team developed the following resources to assist consumers and their representatives transition to self-management.

d) CONSUMER GUIDE TO SELF-MANAGEMENT

This document helps consumers understand:

- how to define self-management in home care
- how self-management works in practice
- identifying risks involved in self-management
- examples of self-management including spending parameters

e) CONSUMER TOOLKIT

This document helps consumers understand:

- how to build capacity to prepare for self-management
- self-assessment tools to work through independently

8 A summary of all communication activities used to share information about the project and any findings including;

- Copies of publications relating to the project should be provided to the department with a report. Please include URLs created by your organisation for web pages referencing your project.

Report	Content	Frequency	Responsible person/s	Recipients
Appendices 31, 3b, 3c, 3d: ONECOTA Quarterly Magazine	Articles about the project	Quarterly	Anna Millicer Jacqui Storey	Older people around Australia – existing mailing list
Community Care Review	Project update and a summary about self-management in home care	One time only	Anna Millicer Jacqui Storey	Audience of publication – mailing list. Primarily aged care providers
Fusion Magazine	Project update and a summary about self-management in home care	One time only	Anna Millicer Jacqui Storey	Audience of publication – mailing list. Primarily aged care providers

Hello Care (same as Fusion Magazine article)	Project update and a summary about self-management in home care	One time only	Anna Millicer Jacqui Storey	Audience of publication – mailing list. Primarily aged care consumers and providers
Literature Review Report	Review of all relevant literature to the project	One time only	Dr Carmel Laragy Anna Millicer	Audience of COTA Australia website
COTA Website	All resources developed in the project (will continue adding more resources as they are completed) https://www.cota.org.au/information/self-management-in-home-care/	On-going	Anna Millicer Jacqui Storey	Audience of COTA Australia website

- Include details of any planned communication activities.

Resources completed - presented in DRAFT report April 2019	**Resources presented in FINAL report September 2019 See zip folder of attachments**
Appendix 1: Welcome Pack for Participants (consumers)	Final Consumer Guide to Self-management
Appendix 2: Participant Toolkit	Final Consumer Toolkit
Appendix 2a: Fact Sheet: Debit Card	Provider Implementation Guide
Appendix 2b: Fact Sheet: Flexible Staff Management	Provider Guide to Developing a Self-management Agreement
Appendix 2c: Fact Sheet: Mable Brochure	Literature Review
Appendix 2d: Fact Sheet: Capital Guardians	
Self-management Definition	
Consumer Toolkit	
Provider Toolkit	

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