



**Consumer Engagement in Aged Care Project  
Phase Two Report**

# Navigating the maze



**Consumer and Carer Solutions  
for Aged Care System Issues  
2016**

COTA Australia, Consumer Engagement in Aged Care Project  
Report written and compiled by the CEAC Team, September 2016  
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Consumer engagement for healthy and active ageing – co-design, co-production and co-operation.

# Table of Contents

Table of Contents .....	3
Acronyms .....	4
Executive Summary .....	5
Overview .....	7
Phase 2 Consultations .....	9
Top Three Consumer and Carer Concerns .....	10
Fees and Costs.....	10
Support to Access Support and Services .....	13
Contribution to Good Service Design .....	15
Co-Design.....	16
Recruitment of participants.....	16
Approaches to Co-Design .....	17
Design of CEAC Co-Design Phase .....	18
Outline of Co-Design Sessions .....	20
Co-Design Groups by Location .....	21
Newcastle Co-Design Group .....	21
Hobart Co-Design Group.....	21
Melbourne Co-Design Group .....	22
Conclusion .....	22
Next Stage.....	23
Appendix 1: Phase 1 Key Themes .....	25
Appendix 2: Overview of Phase 2 Consultations .....	26
Appendix 3: Evaluation of Co-Design Groups.....	36
Appendix 4: Logistics: Engaging Consumers and Carers in Co-Design.....	42

## Acronyms

ACAT – Aged Care Assessment Team

ACSIHAG – Aged Care Service Improvement and Healthy Ageing Grant/s

Consumer – The consumer is the person receiving the service

Carer – Family, partner, spouse of consumer

CALD – Culturally and Linguistically Diverse

CEAC – Consumer Engagement in Aged Care

CHSP – Commonwealth Home Support Programme

COTA – Council on the Ageing

DAP – Daily Accommodation Payment

DoH – Department of Health

GP – General Practitioner

HACC – Home and Community Care

HCP – Home Care Package/s

ITF – Income Tested Fee

LGBTI – Lesbian, Gay, Bisexual, Transgender and Intersex

NACCHO – National Aboriginal Community Controlled Health Organisation

NDIS – National Disability Insurance Scheme

RAS – Regional Assessment Service

## Executive Summary

Last year COTA Australia, through the Consumer Engagement in Aged Care (CEAC) project, undertook an Australia-wide consultation to talk to people about their experiences of utilising aged care services. In particular, we asked about the following:

- How did you find and access information about the options available to you?
- Did you get the right type of support or service, at the right time, in a location that suited you?
- Were you happy with your level of involvement in making choices and decisions about the support you received?
- To what extent did service providers engage with you at a systemic level to improve service delivery and care, for example a consumer advisory group or panel?

Data was collected and analysed after conducting the Phase 1 Coffee and Conversations consultation across Australia. The CEAC Team followed this phase up with a further 18 workshops conducted across Australia. The purpose of this second phase was:

- To report on our findings, and
- Prioritise the key issues and discuss possible solutions with consumers and carers.

In the workshops, consumers and carers voted on the issues that they thought were most important to them and to older people in general. Each consumer was given three votes. At the end of each workshop, the votes were tallied and the top three issues were identified. A cumulative total of all voting across all workshops ultimately identified the top three areas of concern that would be addressed in the co-design groups. The top three concerns identified were:

- People find fees and costs confusing
- People need support to access support and services
- People want to contribute to good service design

To address these issues, COTA Australia then engaged organisations, staff, consumers and carers in Newcastle, Hobart and Melbourne in order to establish and facilitate three co-design groups. A variety of service providers, consumers and family carers from entry point into the system, to home care recipients and residential care recipients participated. Each co-design group developed and prototyped three solutions to address the area of concern that their co-design group focused on.

The CEAC team also engaged previous participants of consultations, the Lived Experience Advisory Panel (LEAP), the project reference group (PRG) and senior COTA Australia management who provided feedback and recommendations to build on all of the solutions.

Each solution was also analysed in line with the CEAC project brief so that it would be:

1. Implemented by the project and services involved
2. Tested within the timelines of the project
3. Cost effective
4. Original and not repeated elsewhere
5. Able to be scaled up or implemented in other organisations

In the final session of each co-design group participants chose one of the three solutions to develop for implementation into participating organisations. These solutions were:

1. DVD – lived experience snapshots to support understanding of fees and costs
2. Flyer – information to support access to aged care services and support
3. Staff Training – to build empathy and understanding of the experience of receiving care

Detailed project plans inclusive of content development, trial and evaluation mechanisms for each of the solutions will be developed in Phase 3 of this project.

## Overview

The lack of choice and control that consumers and carers experienced in regard to the delivery of their care and support was highlighted by the title story of the Phase 1 report, *No More Gravy*. The top issues within the aged care service system, as identified by consumers and carers, and how they can be addressed using a co-design methodology to develop user-friendly and targeted solutions will be addressed by this report.

Participants in the Phase 2 consultations identified that choice and control were underpinned and enhanced by access to appropriate information regarding the service providers available to them, the services they could access and an accurate understanding of the fees and costs associated with each of these. Unfortunately, many consumers and carers reported that they were not provided with the information they needed and did not understand the ramifications of entering the aged care sector. These issues left many participants feeling less than confident about choosing the right supports and care at times that were already challenging.

The three solutions chosen for development and trial by the three co-design groups initiated in this Phase 2 of the CEAC project will deal directly with the above issues. These solutions were:

1. DVD – lived experience snapshots to support understanding of fees and costs
2. Flyer – information to support access to aged care services and support
3. Staff training – to build empathy and understanding of the experience of receiving care

Solution 1 (DVD) and Solution 2 (Flyer) will provide consumers and carers with the appropriate pathway and targeted information needed to access and navigate aged care services. Solution 3 (Staff training) will be delivered by consumers and carers and will raise service provider and aged care staff awareness on consumer and carer experiences of receiving services and support.

Participants of the workshops and co-design groups of this phase of the COTA Australia CEAC Project consistently spoke of the misunderstandings associated with consumer choice and control, and the role services could and should play in better facilitating this. The following lived experience stories echoed participants' sentiments throughout the consultations of this phase, regardless of their experience of home care or residential care. It provides a backdrop for understanding the findings and outcomes of this report.

## Consumer and Carer Lived Experiences

### What's the secret?

I've been fighting for six months, since this *My Package* thing came out, to see if I could get three hours a week to be driven around - you know, the *My Age* thing. I've managed now to get one extra hour a fortnight. Nobody will tell me what my package is or what I'm allowed. So it's the same old thing in a different way all over again.

Consumer

As my mum became increasingly unwell we were upgraded to a level four package. The response from the service provider when I asked what was available in this package was, *'What do you want?'* So I asked, *'What is available?'* The response was, *'Oh, you just tell us what you want and we'll see if it's on it the list.'* Not knowing there was a list I then asked if I could see it and what was available. This then elicited the response, *'Oh, we don't have a list. You just tell us what you want and we'll see if we can do it.'* This went on, back and forth for some time. I could not make it clear that I just didn't know what we could choose from or what was available to my mum. It became so frustrating.

*I don't understand what the big secret is? It's like a secret society and if you're not in, you're not in! What stops people from telling you what's available? It's useless and makes it hard to discuss what you want because you don't have any context or information to assist that choice.*

Carer

I never, ever understood why I was paying what I was paying ... and I never, ever met anybody who understood it either.

Consumer/carers

## Phase 2 Consultations

A key priority of the Consumer Engagement in Aged Care project has been to adhere to best practice in co-production methodology.

The *Social Care Institute for Excellence (SCIE 2015)*<sup>1</sup> proposes that co-production denotes a process that can be broken down into the following substrates:

- Co-design
- Co-decision making or co-governance
- Co-delivery
- Co-evaluation

To ensure consumers participated in decision making and priority setting, a second round of workshops was commissioned and facilitated nationally. Over 130 participants attended one of 18 sessions that were held in the following cities:

- Adelaide
- Canberra
- Darwin
- Melbourne
- Perth
- Alice Springs
- Cairns
- Hobart
- Newcastle
- Sydney

Overarching themes developed from the analysis of the Phase 1 consultation workshop transcripts, 18 in all, were explored at each Phase 2 workshop to confirm their validity and relevance (See Appendix 1 for a table of themes). Consumers and carers were asked if their concerns had been captured correctly during Phase 1 consultations. With strong and positive confirmation offered by all participants on the themes, a vote was conducted in each consultation workshop to identify the top three themes to be prioritised for allocation to one of three co-design groups. A report on these themes was made available in the COTA Australia CEAC Phase 1 report, *No More Gravy*<sup>2</sup>.

By enabling consumers and carers to participate in the decision making and priority setting, this project has moved beyond *'just another consultation'* to genuine and equal participation of consumers and carers, and staff, utilising best practice methods for co-production and co-design. Consumers and carers have reported that their participation in

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1 Social Care Institute for Excellence, *Co-production in social care: what it is and how to do it*  
<http://www.scie.org.uk/publications/guides/guide51/what-is-coproduction/defining-coproduction.asp?ad=yes>  
Retrieved 5/10/2016

2 Contact COTA Australia for a copy of this report: [www.cota.org.au](http://www.cota.org.au)

this phase of the CEAC project was transformative as it placed them at the forefront of defining the issues, solution development and decision making.

The following feedback on their experiences of being involved in the co-production process was provided:

*'My involvement has given me confidence to engage more effectively with my service provider. I now want to ensure that all consumers at this service get the support that they need.'*

**Consumer**

*'I have identified and begun to understand the valuable experience that I have been able to bring to the table. It's not just staff who are 'experts'. By supporting my wife to receive support from a service provider, I have built up valuable knowledge about what worked well or needed to be improved, and that this knowledge could directly lead to change.'*

**Carer**

*'It was the first time in 40 years of working in the aged care system that I have been engaged and felt confident that there would be change as a result of my participation; and that this change would result in positive benefits to the people who access aged care services.'*

**Staff member and carer**

### **Top Three Consumer and Carer Concerns**

The top three concerns across Australia were identified by consumers and carers during Phase 2 consultations via a democratic process of voting. Each participant was given the opportunity to choose their top three concerns from the 18 themes identified during the Phase 1 consultations and workshops. The key elements of the top three concerns are discussed below. A table of the key themes, votes and ranking can be found in Appendix 1 of this report.

#### **Fees and Costs**

Consultation findings identified that appropriate information was a key driver for consumers and carers and enabled:

- Access to support and care
- Timely assessment and choice of a service provider
- Choice of service that met the real need

Consumers and carers provided first-hand accounts of the many struggles experienced when trying to find information and the right type of information that they needed to help them navigate the service system, and the difficulty associated with understanding the various fees and costs structures. Typical questions people asked when they began to look for services were, *'What does aged care cost?'* and *'Can I afford the care I need?'*

Participants reported experiencing great anxiety over being unable to access information or have their questions answered on these topics. Uncertainty about affordability placed consumers and carers in a precarious position; especially given their need for care was often driven by crisis. Participants who were able to access information on fees and costs reported considerable frustration with understanding the information. The collateral they had access to was deemed to be inappropriately targeted to an aged care audience and did not adequately meet their needs.

Trying to identify the required level of personal contributions to care caused considerable concern for consumers and carers. In some instances, participants reported that they did not engage a service provider because they believed that they could not afford services and would struggle financially if they committed to this.

Key issues articulated by participants included:

- Means tested care fees: Income assessment (home care) and an income and asset assessment (residential aged care)  
Participants reported considerable confusion and/or frustration regarding the requirement to contribute more fees than other care recipients who were receiving the same or, in some cases, a higher level of care.
- Acronyms  
Participants did not understand or identify with the acronyms and terms used in aged care. Such descriptors were reported as prohibiting the understanding of fees and costs, and the services that did or did not attract these or additional charges. This also varied depending on the service providers they spoke to.
- Not being able to compare charges  
Participants reported that, more often, they were not provided with financial information upfront to support decision making and choice of service provider and/or services. This also prohibited service provider comparisons and capacity to assess if they were getting value for money given service providers often had vastly different cost structures. This was due to considerable discrepancies between service provider charges for administration fees and costs per hour for personal care. As a result, trying to compare services and determine how far a package would stretch caused unnecessary anxiety and uncertainty.

- Hidden costs

Participants identified a number of unexpected costs that were additional to those associated to their care and administration charges. These costs, referred to as hidden costs in our consultations, covered items or services that were optional extras or necessary health related costs (i.e. out-of-pocket expenses for a specialist or GP home visit, hairdressing, podiatry, medications). Discrepancies in consumer's monthly statements identified these charges which impacted on funds needed for care; a requirement that many consumers reported being unaware of when engaging a service and necessary or additional care and support options.

*Well try \$600 a month administration costs and another \$667 for case management. Hello? Are we double dipping or what? Charging twice the hours for a gardener, twice the hours for a cleaner once a week? Yeah, all this sort of stuff goes on.*

Consumer

*Well when we got our package, the person said look, I'll come out and I'll give you some information on it, in a little binder made up for you. She came out and walked around the house. Said: It's a nice house. Like your garden. Would you like a cup of tea, all of this. Then we get on the first statement. \$400 for her trip to see us!*

Carer

- Grandfathering of fees and costs

Due to reforms, a number of user contribution levels have been grandfathered. This means that there have been different contribution levels for different consumers depending on when they began receiving care and the aged care program they were receiving that service from. While grandfathering is standard practice in health and community services, it has been confusing when consumers and carers rely on their peers and friends to ascertain information about fees and costs.

Solution:

Co-design group solution 1 (DVD) and Solution 2 (Flyer), itemised on page 7 of this report, were identified by participants as being the most appropriate mechanisms for communicating targeted information on fees and costs to consumers and carers. These solutions will be developed to ensure higher rates of understanding and ease of transition into and through the aged care system. See pages 21 – 22 of this report for more information on the solution development processes.

## Support to Access Support and Services

Consumers and carers reported that access to appropriate supports at the right time was important to maintaining quality of life and independence.

Over the course of the CEAC Phase 2 consultations consumers and carers spoke of their difficulties navigating the aged care system. Many were not sure where to access care and support or if their services were actually meeting their needs. Others were waiting to transition to residential aged care but were unable to engage a service provider (bed) in a timely manner or location of their choice. Accessing and engaging support and care had been a complex process in each of these situations.

In particular, consumers and carers reported that accessing aged care services for the first time had been extremely complex across the following areas:

1. Information needs were not met – type needed and availability/location
2. My Aged Care website/call centre, and screening for assessment was largely unknown
3. Assessment requirements by the Aged Care Assessment Team (ACAT) or Regional Assessment Service (RAS) to determine the level of care were unknown
4. Centrelink income and income and assets tests were often delayed without establishing the fees and charges until after a service provider was engaged
5. Comparing all local or available service providers to determine value and capacity to meet needs was difficult or impossible

While most people indicated that visiting residential services to discuss care needs was preferred, a visit to every service was impractical and required family support, transport and respite support, and often financial and/or legal advice (i.e. Enduring Power of Attorney, Wills, support to understand costs and refundable/non-refundable deposits, etc.).

Many people reported having to manage for very long periods whilst waiting for a vacancy to become available. Waiting lists for home and community support have continued to grow over recent years which ostensibly means that this issue continues to become more and more common and precarious for those who have not received the care and support they need.

The key issues identified were:

### Information

- My Aged Care has been developed as the primary source of all information on and screening for aged care. However, consumers and carers reported that they were not aware of this facility or the requirement to contact it in order to access care.
- Participants who accessed My Aged Care reported that it was difficult to navigate and didn't always give them the information that they needed.

- Despite information being available from a variety of sources participants did not have a full understanding of what services were available, how to access those services and how to combine those services to get the support they needed, (e.g. aged care and community support).
- Some information sources were contradictory or out-of-date which made it difficult for people to trust, understand and navigate the system.
- Participants reported that the service providers presumed that consumers and carers would have a level of understanding about the aged care system. This expectation subsequently created a barrier to entering the system without difficulty or undue stress.
- Information provision was reported as being generic and didn't identify the service options that were available locally (e.g. not all local providers offered the same services or were flexible in how their services were delivered).

#### Support

- Most participants reported the need for support to assist them with understanding information and to complete the forms required at the various stages of screening and assessment. Face-to-face contact at a help-desk, with an advocate, case manager or peer support worker was preferred for this purpose. In many cases, participants identified how valuable having someone reliable to talk to would have been and how it would have supported them through this period of adjustment. Centrelink services of this nature were not viewed as consistent or reliable.

#### Crisis

- Consumers and carers reported that access to aged care services often happened as a result of crisis. Finding appropriate support became very time consuming and many participants stated that learning about a system that was foreign to them and meeting the requirements to access services in a time of crisis was extremely stressful and often debilitating.

#### Expectations

- Consumers in need of care were often too proud or embarrassed to ask for help. Family members were often required to provide support that they were not equipped or trained for. Cultural expectations were seen as a barrier to seeking help from service providers. This meant that consumers were not receiving the support they needed and carers were often unnecessarily burdened as the person they cared for became frail and unwell (e.g. heavy lifting and high-level personal care).

#### Solution:

Solution 1(DVD) and Solution 2 (Flyer) will again provide timely information and advice, delivered in a manner that will meet the needs of consumers and carers for support. Tips to help with accessing and navigating the aged care system, and to normalise an experience that is often driven by crisis, have also been identified by the co-design teams for inclusion.

See pages 21 – 22 of this report for more information on the solution development processes.

### Contribution to Good Service Design

Consumer and carer participation and engagement needs significantly more attention and application for service development and improvement within service provider organisations and the aged care sector as a whole.

The CEAC team identified that many service providers conduct satisfaction surveys, hold resident meetings and have complaint processes. However, participants indicated that these mechanisms often produced fairly shallow results and felt tokenistic. The following information represents the recommendations of consumers and carers participating in the Phase 2 consultations for systemic improvement in relation to consumer engagement.

#### Engagement

- Service providers must systemically engage with consumers and carers to provide opportunities to identify and discuss issues and concerns, compliments and improvement.
- Engagement must include opportunities for consumers and carers who may be uncomfortable participating in group settings and prefer talking one-on-one.
- Easy and supportive access to well publicised, robust compliment and complaint systems are required. Appropriate and transparent feedback mechanisms must also be provided so that recommendations are acted upon, reported and evaluated at a service program level, e.g. co-design, co-production.

#### Evaluation

- Ongoing resident evaluation must be included in processes for service development and improvement.

#### Stigma and fear

- A troubling theme articulated by many consumers and carers concerned their fear of speaking up and making a complaint. In addition, many were afraid of discrimination or being unfairly targeted for raising issues and concerns. As with the findings of the CEAC Phase 1 report, discussions covered the fear of retribution and the vulnerability felt by older people who had identified that aspects of their care were not meeting their needs.

#### Accountability

- To ensure accountability in complaints systems and capacity to confidently access these, it was felt that key issues, decisions and actions needed to be fed back to all consumers and carers at the service.

Solution:

Solution 3 (Staff Training) identified by the co-design groups will provide an effective source of consumer engagement whilst also developing relationships of value, mutual respect and equality between consumers, carers, staff and management of service provider organisations. In addition, the training is directed toward building capacity for empathy by articulating consumer and carer experiences of receiving care and support. See pages 21 – 22 of this report for more information on the solution development processes.

## Co-Design

### Recruitment of participants

Adequate recruitment of service providers, consumers, carers and staff was vital to achieving the Phase 2 project co-design group requirements. The Chief Executive and senior program managers of aged care service provider organisations were approached in each co-design group location to garner interest in the project. All participating organisations were enthusiastic and receptive to being engaged. The following objectives were crucial to ensuring robust engagement from participating organisations and their consumers and carers:

- Equal participation of consumers and carers, and aged care staff (consumer engagement champions)
- Agreement to trial the solution selected by the co-design group in their location
- Input from senior managers/management at strategic points regarding progress updates, solution development, buy-in for and capacity to trial a solution

While some service providers and participants had participated in Phase 1 and/or 2 consultation workshops, many were entirely new to the co-design stage of this project.

The provision of education and support, relationship building and the care of participants were primary considerations during the recruitment process and co-design sessions. These factors required considerable time to develop relationships of trust, mutual respect and confidence between the participants and the project facilitators. In addition, a very high level of open communication and co-operation was achieved and beyond expectations.

Participants were kept well informed during planning for, facilitation of and follow-up on the Phase 2 co-design groups. Information on the co-design process, levels of engagement and potential benefits to the organisation/s were provided to all participants when they were invited to engage with the project. Commitment from consumers and carers was iterated as acceptable within their own capabilities and comfort zones. As a result, attrition and absentee rates were kept to a minimum with most participants reporting that their attendance and participation was well managed and supported.

## **Approaches to Co-Design**

Co-design is a process where consumers, carers and staff have been actively involved as equal partners in the design and development of effective solutions that improve service delivery and the experience of receiving care.

Principles of co-design must include:

- Consumers and carers as active participants throughout the co-design process from problem-setting (defining the issues) to problem-solving (developing the solutions).
- Consumers and carers as equal design partners in idea generation, implementation feedback and evaluation processes.
- Ongoing evaluation of solutions and co-design processes to determine the impact on consumer and carer wellbeing and service delivery, and capacity to create meaningful and lasting change

The following co-design methods were synthesised by the CEAC team to inform, develop and deliver the co-design phase of this project.

### **Experience Based Co-Design:**

The Kings Fund (United Kingdom) defines Experience-based co-design (EBCD) as an approach that enables consumers, family carers and staff to come together to plan and co-design services and/or pathways, together in partnership. It involves gathering information and data about the experiences of consumers, carers and staff to find key 'touch points' to identify which areas of concern need to be addressed; and then, in partnership, engage participants to identify and develop solutions together.

### **Double Diamond Design Process:**

This approach, common in the design field, is a process that allows groups or collaborators to identify the common areas of concern and develop workable solutions to these concerns. Shown in figure one, it is a four-step process that covers:

1. Discover: explore the area of concern together.
2. Define the focus: identify a key question within the area of concern.
3. Develop Solutions: generate a variety of solutions based on the key question.
4. Deliver and prototype: develop a workable model based on the optimal solution.

See Double Diamond diagram over page.

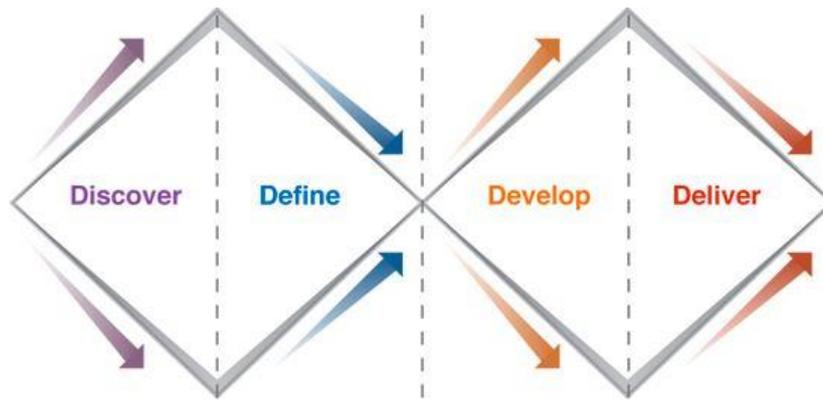


Figure 1 Double Diamond<sup>3</sup>

## Design of CEAC Co-Design Phase

### Aims

A key feature of the Consumer Engagement in Aged Care project was to develop and trial models of consumer engagement. In adapting and enhancing a model of co-design for older people a number of project design features (listed below) were considered important by the CEAC project staff and in turn, the co-design groups. These features, integrated with solution-focussed and human-centred design approaches, ensured the success of each co-design group and the development of creative solutions that could positively affect the aged care sector.

### Independent facilitation

A vital component of the Phase 2 co-design project's success rests with independent facilitation which minimised fear of judgement and stigma, and any self-censorship or withholding by consumers and carers in relation to frank discussions on sensitive and confronting issues. Staff participants who had facilitated co-design groups within their own organisations reported issues with ensuring liberal and open contributions from consumers and carers, and less satisfactory outcomes as a consequence of not utilising independent facilitation.

### Participant Sample

Home care and residential care recipients and key staff were identified to participate in the co-design groups. Limitations on capacity and access issues for older consumers and carers were given serious consideration in order to ensure optimal inclusion. Organisations were encouraged to scope for staff who were known champions of consumer engagement and consumer-directed care to ensure adequate promotion of the consumer and carer voice once all participants came together in their co-design groups. The deliberate combination of

<sup>3</sup> <http://www.designcouncil.org.uk/news-opinion/design-process-what-double-diamond>, retrieved 06/10/2016

residential and home care participants also ensured lively discussion and considerable insight. As a result, a wide variety of perspectives were enthusiastically shared within each group resulting in the development of solutions that would support the largest possible cohort of people looking to enter or transitioning through aged care services. While combining residential and home care consumers presented potential problems of differing levels of capacity and cognitive functioning, all participants reported the positive results of combining both service recipient types and the depth of discussion that it allowed.

### Training

Consumer and carer training was held separately to staff training at all three co-design group locations. Consumers and carers attended training in the morning, with staff attending an afternoon session. A total of six training sessions were held over Phase 2 of the project. Training was pitched at a level that would accommodate the diverse nature of the participant group.

This strategy was employed to develop participant understanding of the value of lived experience, and confidence in sharing stories as an equal member of a co-design team. Staff were encouraged, as part of their training, to support consumers and carers to voice their experiences regardless of how confronting or negative toward service providers the story may have been. Participants were upskilled to positively utilise their experiences of aged care to effect change.

A key benefit, identified by staff as a consequence of separate training, was that they were more open to hearing consumer and carer experiences and could better support open participation by being deliberately mindful of providing a safe space for this voice to flourish. These elements of the CEAC co-design processes eliminated potential imbalances of power and ensured robust and respectful participation.

‘The whole thing gives me confidence talking with my provider. It’s a really valuable experience for all involved.’

### **Consumer**

#### Co-Design Sessions: Timing

CEAC facilitators held four sessions with each co-design group. Each group had a minimum of 18 participants who were divided into three groups of six with representation from each organisation, homecare and residential care spread evenly across each group. The sessions were no longer than four hours in length and were held over a period of several weeks.

The timing and delivery of sessions was well considered and intentional, and ensured that consumers and carers with capacity or health issues were not unduly taxed by the demands of their participation. The delay between sessions provided many participants with adequate time to reflect, investigate the viability of identified issues and solutions, and

provide additional feedback. The result of this strategy was that the majority of participants were enthusiastic about participating in one of three Phase 3 co-design project advisory groups, bolstering the co-design process as it transitions to co-governance.

## **Outline of Co-Design Sessions**

### **Day 1 – Training**

This session contributed to the skills, knowledge and confidence of participants, reinforcing the value and necessity of their participation in the following areas:

- Context: The CEAC project aims, parameters and progress
- Using your voice and the value of lived experience
- Working in a group
- The benefits of co-production and co-design methods
- Skill development to support the co-design process

### **Day 2 – Discover, Define and Develop**

This session familiarised the participants with consumer and carer perspectives on the area of concern from the data that had been gathered in Phase 1 and 2 of the project. Working in groups of 6, participants discussed the issue, identified a key focus question from the information that had been presented, and generated a range of solutions to address the area of concern.

### **Day 3 – Develop and Deliver**

Working in the same groups, this session encouraged participants to choose one of their solutions to prototype. After creative development on their solution, participants presented their prototype to the other groups for feedback to develop the solution further.

Participants then formed a draft project plan for consultation.

After day three, draft plans were presented to the CEAC project key stakeholders for further development and review. Feasibility was then rated against the project's criterion for trial as follows.

The solution:

- can be implemented by the project and services involved
- can be tested within the timelines of the project
- will be cost effective
- is original and not being repeated elsewhere
- can be implemented or scaled-up in other areas
- will have a positive and sustainable impact on consumers and carers

#### Day 4 – Choosing a Prototype to Implement

This session informed participants on the feedback and recommendation provided by key stakeholders on their prototypes. Each co-design member then cast a single vote, selecting their preferred solution to be trialled.

Once the preferred solution was identified, further development of the solution was undertaken by the group as a whole. This encouraged a sense of ownership over the solution prototyped as participants worked to ensure that viable elements of the remaining two prototypes were used to add value to the chosen solution.

#### Co-Design Groups by Location

The three co-design groups were held between June to September (2016) and each group addressed one of the top areas of concern. The following is a description of each group and the solutions that they came up with.

##### Newcastle Co-Design Group

The Newcastle co-design group focused on the top area of concern: fees and costs are complex and confusing. This group was comprised of consumers, carers and staff from the following organisations: Anglican Care (NSW), NovaCare (Newcastle) and Salvation Army (NSW).

The three solutions prototyped by this group were:

- A DVD of short videos using the stories of consumers and carers to inform people about fees and costs
- An app/website that allowed people to access information and assess fees and costs
- A financial information service that could provide support to understand fees and costs

The solution that was chosen by the group to be trialled was a DVD of short videos based on consumer and carer experiences of identifying and understanding fees and costs. In addition, consumer and carer stories that support access to aged care and develop capacity for greater engagement in service delivery and care needs will also be scoped. A strength-based approach to information provision of this nature will be adopted.

##### Hobart Co-Design Group

The Hobart co-design group focused on the second-top area of concern: support is needed to access support and services. This group was comprised of consumers, carers and staff from the following organisations: COTA Tasmania, Migrant Resource Centre (Hobart), South East Community Care (Tasmania) and Uniting Age Well (Tasmania)

The three solutions prototyped by this group were:

- A checklist of information and tips that included information for consumers on what they need to do when they seek support
- An information booklet that articulated the types of support and services that are available
- An A5 information flyer that identified key organisations and contact details to get support

The solution that was chosen by the group to be trialled was an A5 information flyer that comprised a simple directory of essential organisations and their contact details for entering and transition through aged care. In addition, positive messaging on ageing and receiving support and services will also be included.

### Melbourne Co-Design Group

The Melbourne co-design group focused on the third-top area of concern: Consumers want better services and have a lot to contribute to improve services. This group was comprised of consumers, carers and staff from the following organisations: ACH, Benetas (Victoria), SAI Community Care (Melbourne), as well as a number of consumers, carers and aged care staff who were engaged in the first and second rounds of consultations for this project.

The three solutions prototyped by this group were:

- Training developed and delivered by consumers and carers that immerses staff in the lived-experience of receiving care and support.
- A DVD collection of consumer stories on how to make complaints, change a service, choose a provider, etc.
- A volunteer peer advocacy service and complementary training package prototype.

The solution that was chosen by the group to be trialled was a consumer and carer developed and delivered training package to educate staff more deeply on the lived experience of receiving aged care services and to foster greater empathy.

## Conclusion

Navigating the aged care sector has been reported by consumers and carers participating in Phase 1 and Phase 2 of this project as being akin to navigating a maze. The difficulties experienced by participants, and further articulated by staff from the co-design groups, have clearly articulated the gaps in service provision and identified what needs to change and how that can happen.

Consumers and carers are therefore well equipped to identify the issues in need of development within the sector. Their lived experience and, often, significant career related expertise made them very well qualified to design solutions that can have a positive impact

on the experience of all individuals entering, utilising and working in aged care services. This has been clearly evidenced by the openness, co-operation and trust experienced by those attending sessions in this Phase 2 of the project. Importantly, the commitment to engage with the project and the solutions prototyped by the CEAC co-design participants positively confirms what has been and can be achieved through robust, evidence-based co-production and co-design methods.

## **Next Stage**

The next stage of the project, Phase 3, is concerned with the development of the three chosen solutions and their trial and evaluation in the project's participating aged care service provider organisations. Co-design and co-governance will underpin the framework for initiating and delivering on Phase 3 by utilising the participants of Phase 2 who have expressed interest in becoming members of the co-design reference groups. The CEAC Lived Experience Reference Group and CEAC Project Reference Group will also be consulted and will contribute to Phase 3.

# Appendices

## Appendix 1: Phase 1 Key Themes

The following salient issues regarding access to and usage of aged care services were identified by consumers and carers attending the COTA Australia Consumer Engagement in Aged Care project Australia-wide Phase 1 consultations and workshops.

Areas of Concern		Votes	Rank
<b>Information</b>			
1	Information about fees and costs is complex and confusing	39	1
2	Over reliance on internet based solutions is problematic	20	6
3	Knowledge about aged care is limited	17	8
4	Limited Information is provided on the quality of services	17	8
<b>Support and access</b>			
5	Support to access support and services is needed	36	2
6	Consumers and carers on waiting lists need more support	21	5
7	Special support needs to be given to consumers and carers accessing support for the first time	15	10
8	Consumers from CaLD, LGBTI and Aboriginal and Torres Strait Islander communities don't always get the support they need	16	9
9	Service quality and support is inconsistent and needs to improve	15	10
<b>Choice, flexibility and control</b>			
10	There is a lack of choice of service options in rural and remote areas	22	4
11	Peer support is limited but widely needed	21	5
12	Consumers need more choice in who their (care) worker is	17	8
13	Improving communication is integral to improving quality service provision	15	10
14	Choice and flexibility needs to increase at residential services	14	11
15	Consumers don't always get to choose the service or support they receive	7	12
<b>Engagement and participation</b>			
16	Consumers want better services and have a lot to contribute to improve the services	24	3
17	Consumers are afraid to complain	19	7
18	The imbalance of power and nature of bureaucracy inhibits choice, flexibility and control	16	9

Table 1: Phase 1 key themes and Phase 2 voting tallies

## Appendix 2: Overview of Phase 2 Consultations

### Procedure/Background

Consultations conducted in Phase 1 explored four key issues for consumers and carers in relation to a) finding information, b) accessing services, c) having flexibility, choice and control in service delivery, and d) the extent that services engaged service users in systems development.

These consultations yielded in-depth insights which were categorised into 18 themes under the above four topic areas. In Phase 2, the pertinence of these themes was examined and verified through consumer and carer workshops held in 18 locations across Australia. These workshops identified the top three concerns that became the focus of three co-design groups formed to develop practical solutions that would be trialled by service providers participating in Phase 2 of this project.

At these workshops, consumers and carers shared rich and in-depth stories of their lived experience of aged care services. Participants explained that they were motivated to contribute to the project by the desire to improve service standards and to participate in peer knowledge exchange and dissemination.

This report presents a summary of the key themes identified from consultation narratives and the lived experiences of aged care consumers and carers across Australia.

### Data Analysis

The workshops were audio recorded with participants' consent, and recordings were transcribed by a professional transcription service. Transcripts were analysed using NVivo 11 Pro for Windows. The findings presented are of a preliminary analysis conducted to further articulate the four key topic areas identified and validated through the numerous consultations and workshops conducted, i.e. Information, Access to Services, Flexibility and Choice, Engagement and Participation.

A thematic analysis was conducted to organise, identify, and describe recurring and salient themes in the data<sup>4</sup>. Thematic analysis is a commonly used technique to analyse qualitative data, such as transcripts, by exploring the patterns within data, which are grouped into 'themes'. This includes identifying which themes arise in the data often, which are determining or notable to the area of interest, or how the themes relate to each other. An advantage of thematic analysis is that even a cursory descriptive analysis can yield rich and detailed insights. A range of approaches can be taken to thematic analysis, according to the questions being investigated and objectives of the project. The preliminary analysis

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<sup>4</sup> Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). pp. 77-101. ISSN 1478-0887 Available from: <http://eprints.uwe.ac.uk/11735>

presented in this report included a semantic thematic analysis approach to identify the issues raised by participants in their lived experience accounts, and group them into themes.

The identified themes were examined using a deductive thematic analysis approach to examine how they relate to each of the key topic areas that have shaped Phase 2 of the project. This is a quick approach that can provide detailed articulation of the key topic areas. Additionally, this approach is a means of validating the topic areas, whereby good fit of the data to the topic areas would indicate good validity of the topics.

## Results

### *Information*

Primary barriers to service utilisation included information sources and collateral that were difficult to find or not always reliable, were reliant on internet access and know-how, and used jargon. Participants reported that significant effort was required to determine the appropriate pathway into the aged care service system and to then find a service provider that could meet their needs.

Notably, many consumers and carers attended the consultations in order to gain information about service access and utilisation. Participants were seeking information on the process of assessment and eligibility, what 'packages' are and what is available through the different levels, and the cost of accessing providers and services (residential and home care). A common statement was, '*...that's why I'm here. I don't know how to access information. Can you [help me]?'.* Others intended to pass on any knowledge and insights they gained, '*to make it easier for... friends that are completely in the dark and...turning away from it because it's too complex.'*

The process of gaining information to select an appropriate home care provider was a common cause of frustration and confusion for participants. Many consumers and carers expressed concern that there was no 'menu' to select services from. However, they also noted that service providers had expectations that consumers should just ask for what they wanted regardless of any knowledge gaps in service or availability or information on costs. One carer stated that signing up for services without prior knowledge of availability or costs would be unacceptable in any other sector. Yet most participants reported being expected to do so in aged care.

Participants were also concerned that the information they received from services could be biased or limited. Greater transparency was called for, including suggestions for an independent body that provided unbiased information that is, '*clear, undiluted, to take home, peruse and think about at each stage'*.

Some participants reported limited advice from General Practitioners (GPs), but very useful and reliable advice from hospital staff, and gerontologists. There were reports that GPs had a poor understanding of consumer and carer needs (e.g. not recognising early signs of dementia) and the basic processes of the aged care system (e.g. referring consumers to the wrong catchment area). Participants demonstrated a preference for seeking support from their GP. Word-of-mouth referrals to 'good' GPs were also highly sought after.

Consumers and carers expressed considerable confusion and suspicion over the damaging consequences of poor information provision and delivery. Their resulting lack of trust in service providers and government is illustrated by the following exchange between participants:

*'When I said what is available, what does a three/four package entail, how can you get on that? she said "Oh you just tell us what you want and we will see if it's on it". See that is useless information. I thought, what's the secret? What's this big secret that you can't say what's available?'*

*'If they don't tell you what's on the menu, you have to work out what you actually need...so maybe it's a rationing system. Is that possible?'*

**Consumer**

The findings of Phase 2 consultations demonstrated unequivocally that the relevance and accessibility of information provision, and the method and timing of its delivery are vital to establishing trust and rapport with, and enablement of, consumers and carers.

The quality of care delivered by a provider was of primary concern to participants when attempting to choose a service. Common sources of information were:

- Word-of-mouth
- Medical professionals such as their GP
- Hospital staff
- Specialist: gerontologist
- Meeting with or visiting services

However, useful sources of information were difficult to find and reliability was often difficult to determine. This compounded the distress and sense of helplessness experienced by consumers and carers who were often in a crisis or challenging time when faced with entering the aged care system.

A number of participants reported visiting residential care services and speaking with staff who were able to help them to choose a service provider. Participants indicated that their choice of provider was greatly influenced by a positive culture and open communication. Good rapport, trust and respectful interactions between positive and optimistic staff,

consumers and carers, and attractive facilities and service options were also very important factors.

Whether receiving home care or in a residential care facility, participants consistently stated that they sought familiarity, if not friendship, with their care staff. This relationship helped to enable a sense of safety and reassurance regarding the level of care they received, and extended their sphere of social connectedness. Services that provided above average care were also able to achieve a workable balance between risk management and flexibility in service delivery, and included consumer and carer participation in the service model. Accessible and anonymous (if preferred) communication channels facilitate this balance. Importantly, protocols for provider accountability to consumers and carers reinforced these channels and supported the establishment of trust and mutual respect.

The above analysis demonstrates that consumers and carers do not have the information they need to access appropriate aged care supports or to understand the aged care system. This lack of information significantly impacts on their access to support and the types of support they receive. A significant gap in the knowledge of consumers and service providers was identified – one which has created an unnecessary power imbalance between services and consumers, and led to stigmatisation of aged care service delivery. To address discrepancy, significant effort must be directed toward the development and distribution of appropriate information that increases agency and the capacity of consumers, and their carers, to be self-directors of their own care.

#### *Support to Access Support and Services*

Access to aged care services and navigating the requirements of assessment were deemed to be a complicated and difficult experience for many participants who had not only been unsure of the pathway but also struggled to ascertain where to access information about this pathway (i.e. the process of assessment and service selection). The ensuing stress was often compounded by concurrent problems such as an acute health condition, complex family dynamics, or the relocation to a different city or town that was closer to family members who could provide support.

The impetus to apply for home or residential care may be an acute, severe illness, or a less severe condition that cannot be reasonably managed without immediate support from care services. Participant accounts indicated that those who experienced acute, severe illness were more often required to choose a care service with little notice and with a planned discharge looming.

*Case Study: A Melbourne carer reported that hospital staff gave him 'some massive tome' from which to select a facility for his partner. He was given one week in which to prepare for the hospital discharge and move to a residential care facility. With only days in which to make all necessary*

*arrangements, and in great distress, he selected and visited four facilities on the basis that they were close to their house. He was confident that the staff could have determined his partner's prognosis earlier in his three-and-a-half weeks of hospitalisation, giving him more time to make more informed and considered choices. He considered himself 'very, very lucky' that hospital staff recommended a suitable facility but received no other support for his partner or himself to make this significant transition. He reported the event as being very traumatic; a sentiment echoed by many of the participants in both Phase 2 and 1 of the project.*

**Carer**

Participants also reported being 'dropped off' waiting lists after 12 months and without notice; their health conditions having deteriorated and a re-assessment required to return to the same waiting list. The quote below illustrates this lapse in best practice protocol and lack of care provided to those who often feel that they are languishing without support whilst on a waiting list.

*'A retired professor, my friend, was caring for his wife who had an ACAT assessment and then nothing happened. They went on living their lives and when he suddenly became ill they realised that 12 months had passed and the ACAT had fallen away. There was no follow up from ACAT to keep them in the loop. They've had to go through the whole lot again at a time of crisis. It's mad. It's cruel because the older you get, the simpler the system needs to be.'*

**Carer**

It became evident that lapsed ACAT assessments have cost service providers and caused a significant emotional toll on consumers and their carers. The responsibility rests with the system in which ACATs operates. To dispel any assumptions that consumers in these circumstances were confused, incompetent or negligent, participants stressed that they would have been responsive to any notice of the upcoming lapse from ACAT if they had been informed. The disempowerment of older people experienced within the administrative system of aged care was compounded by their vulnerability and deteriorating health. Not to mention the unfortunate by-product of stigmatising ageing.

Consumers strongly indicated that they did not receive the support they needed in a timely manner or in a location of their choosing. Significant systemic issues, such as capping of supply, siloing of service sectors, lack of peer support services, and the misinterpretation of consumer directed care, were also identified as pertinent barriers to accessing care. Addressing these problems requires a multifaceted approach that places the consumer and their needs in the centre of service delivery. Furthermore, considerable focus is still required to ensure ease of access, transition and navigation of services for consumers.

### *Flexibility and Choice*

Participants greatly valued service providers' flexibility in tailoring services to meet their needs and preferences as this greatly enhanced the experience of service quality, health and wellbeing, self-determination and control. Positive experiences of care were seen as supporting a practical need and empowering consumers and carers through a strengths-based approach.

*'Where my father is at the moment, they have cooking classes, right, so he goes off and he can't see but they eat the contents after, and they have new recipes, and they have a men's woodwork group. Bunnings come in and show them how to do things. It's unbelievable.'*

#### **Carer**

Communication with providers about service preferences and tailored delivery was very challenging for many. Some participants expressed a sense of helplessness when trying to communicate their needs, being locked into services without any idea of when a care worker would be arriving or who that worker would be. One participant reported being unable to negotiate a time as she did not know how to contact the organisation that was administering her service and was told that she, *'couldn't state a time because they're here, there and everywhere.'*

Participants also reported that providers resisted requests for services that were less routine, despite participants' willingness to pay for the additional service. In some instance, services were simply unavailable (e.g., poor availability of a suitable gardener). Participants were not supported to make other arrangements privately for this work to be done or informed that private contractor fees may be equivalent to aged care service fees for the same service. Participants also indicated that they did not receive adequate explanations for failure to provide the requested services.

Participant accounts also indicated that policies and regulations can restrict providers' flexibility and responsiveness to consumers' needs and preferences. One account of this was provided by a frustrated carer whose mother required wound dressing at home that was not provided under home care services.

*'But she can't get that [wound dressing] – she can get cleaning. I can do the cleaning! [Laughs]. But seriously, I don't feel confident with dressing wounds ... but that's not the service she can get. It just doesn't work.'*

#### **Carer**

Many participants reported that package consumers were unable to access level 3 and 4 packages due to high demand or funding constraints. As noted in the CEAC Phase 1 report,

these packages were often unavailable in some areas for long periods of time, sometimes years.

*'I don't know of anyone who's actually got the right level that they've been assessed for in those CDC packages. You might get assessed as Level 4 High Care but none of the service providers have packages beyond Level 2. Yet they can't get rid of Level 1. Nobody needs them.'*

**Consumer**

As noted in the CEAC Phase 1 report, few providers had made consumer engagement a priority. There were many accounts from participants of immense frustration over the lack of flexibility and disregard for consumers' needs. Underlying the expression of frustration was a sincere fear that pursuing their needs would adversely affect their support and care and that their health and wellbeing would be significantly compromised as a result. Many participants were seen to generalise this fear to the aged care sector as a whole and avoided interaction with providers as a consequence.

Experiences of resistance from service providers to tailor support to the specific needs of each consumer has led to suspicion among some consumers and carers as to service providers' motivations and dedication to consumer-directed care. The quote below is an example of the tension that can arise between consumer and provider.

*'You could see the light go on in people's eyes that no, I didn't know what I could be asking for. No one had ever told me that I could be asking for this as part of my package. But they didn't know. So they're not going to give you too many options unless you know that you can ask for them.'*

**Consumer**

Stories of residential care recipients being bullied into paying for 'additional service options' were also provided by consumers and carers. By contrast, some participants found that they needed to be 'very strong' when requesting particular or additional services because requests were sometimes met with resistance from the service provider.

The quote below illustrates the difficulty that service providers can have with consumer directed care and being sufficiently flexible to meet the needs of consumers and carers. This was a common theme and resonated with participants throughout the consultations.

*'I'm a keen golfer. So we put that hour and a half each day for care into one day. It gives me the chance for seven and a half hours of respite in one day. They said, 'Oh, I don't know about that'. I said, 'Well why can't you? It's an hour and a half a day. Why can't you put it all into one day? Just have the carer visit, do the house work, the washing, and then leave'. They*

*said, 'We don't do that'. It took some time to convince them but they did it in the end as a test.'*

### **Carer**

In residential care additional support options are not tailored to individual needs but rather made available to all residents to be accessed at their discretion (e.g. a choice between two meals, attending a workshop or an entertainment event). Conversely, home care services can be 'tailored' when consumers and carers have the ability to articulate their needs and negotiate service delivery to their satisfaction and according to their changing needs.

Phase 2 of the CEAC project found that children of consumers often played an important role in either identifying suitable service providers for consumers to choose from or had to choose on the consumer's behalf. This scenario was particularly common when the consumer had:

- Reduced physical abilities
- Cognitive impairment
- English as a second language
- Limited or no internet access
- No computer

Consumers and carers also explicitly communicated their need and preference for face-to-face contact with an independent peer consultant, advisor or a broker from a single organisation independent of service providers.

Choice, flexibility and information that is timely and appropriate ensures that consumers and carers are empowered to make choices about their care. Participants expressed their frustrations with service providers and the aged care system, (e.g. ACAT, My Aged Care) for causing unnecessary barriers to choice, flexibility and control. Consumers continually argued for a change of culture within aged care services that would ensure that consumers and carers would feel empowered to choose the service provider and determine the types of services that would meet their needs.

### *Engagement and Participation*

Consumers and carers reported that positive experiences of engagement and participation were largely contingent on strong relationships with service provider staff. Relationships were often established by a staff member who built rapport through in-depth, face-to-face conversations with the participant.

*'I find if I need anything, now I just ring up my coordinator and we just sort it out between ourselves – you know, what my needs are, when something has to be changed. She's marvellous. She comes out and you feel as if*

*you're a friend.'*

### **Consumer**

Where engagement with services was provided participants reported vastly different experiences of participation in systemic development and improvement. More often there had been little time or encouragement dedicated to systemic engagement. Participants identified that, when they were provided with opportunities to voice their concerns, provider responses were generally unsatisfactory, ineffective or temporary. The majority of participants reported that they had not been actively engaged in service development or improvement and did not feel their voice was heard or personal agency was promoted.

However, where participants indicated that they felt comfortable raising concerns, suggestions, and requests within a structured format, a satisfactory level of engagement was achieved, establishing mutual trust and respect through provider responsiveness that was meaningful and enduring (i.e. new or revised policy or processes, transparent reporting on issues and resolutions).

Independent peer advocates or an advocacy council were often recommended by consumers and carers as solutions to the helplessness and exclusion experienced by consumers and carers when service providers did not have adequate engagement practices. Carers noted that their participation was limited by the time and energy required to provide care and meet their other commitments (work, families, health concerns).

*'... [the service provider] had a monthly meeting in a fairly big dementia block. So it's a little bit pointless but that's reality. Only about four or five carers turned up. It was the same four or five of us every single time.'*

### **Carer**

Consumers and carers often reported despair at the dismissive attitudes directed toward them and the restrictions to their independence that were not explained or followed up on when they voiced their concerns. In some instances, consumer health issues (smoking, dementia, diabetes) required closer monitoring of personal finances to both safeguard the consumer's health and the funding of additional care needs in relation to this. However, many consumers reported being largely unaware of the costs of care and extras, and the requirement of service providers to issue monthly invoices. Complaints and feedback mechanisms were also a point of contention for many participants who felt that the procedure was tokenistic and yielded very little change or response. In addition, attempts to obtain explanations for these restrictions and overlooked concerns went unaddressed.

*We are treated as if we have passed our use-by dates. We don't have a social life. We don't go down the street or go shopping or things like that. We don't have that capability anymore and so what do we need*

*money for.*

## **Consumer**

### *Conclusion*

The CEAC project identified that additional reforms within the aged care sector still need to occur in order to facilitate significant culture change that will enable consumers and carers to exercise choice and control in regard to service development, delivery and their care.

Consumers and carers reported a power imbalance within their relationships with service staff due to lack of:

- appropriate and timely information
- understanding of consumer and carer needs
- or limited choice of subsidised local services due to high demand

Significant capacity building to enable service providers to engage consumers and carers in equal partnership is also needed. Where this had occurred, consumers reported positive interactions and better outcomes as a result. Unfortunately for most consumers and carers this change has yet to occur.

### Appendix 3: Evaluation of Co-Design Groups

An aim of the COTA Australia CEAC project was to evaluate the application of co-design in the aged care sector. Self-completion evaluation forms were provided to participants across the three sites, Newcastle, Hobart and Melbourne in order to achieve this aim.

For participants, the co-design process began with an invitation and information on the CEAC Project which was provided on behalf of the CEAC Team by their service organisation. Training was then provided on the first day of interaction to prepare participants for the co-design group days and processes.

A self-completion evaluation form was provided at the commencement of the training session to establish a base-line for confidence, skills and knowledge levels on co-design prior to commencement. A self-completion evaluation form was again provided at the completion of the fourth co-design session to ascertain confidence, skills and knowledge levels post-co-design group experience. The findings presented here relate to the results of these evaluations.

Ratings of level of knowledge, confidence and skill in participating in the co-design process were assessed throughout the project. These factors were assessed because they were recognised as being the primary components of learning and behaviour change models.

High scores on knowledge, confidence and skill indicated that a participant had requisite knowledge, motivation, sense of self-efficacy and resources to engage in the co-design process. Participants rated their knowledge on a scale of 'Very Good', 'Good', 'Average', 'Poor' and 'Very Poor'.



Newcastle Co-design group



Hobart Co-design group

## Knowledge of Co-Design

An aim of the CEAC co-design process was to improve participants' knowledge of the co-design process. Despite a quarter of participants reporting prior experience with co-design, more than half rated their knowledge of co-design as 'Very Poor' or 'Poor'. The process and facilitation methods used in the CEAC project improved co-design knowledge for almost all participants, as 89% rated their knowledge as 'Good' or 'Very Good' at follow-up. See Figure 1 and 2 below for participant ratings of prior and post knowledge levels on co-design for this project.

### Knowledge Levels Pre and Post Co-design Group Participation

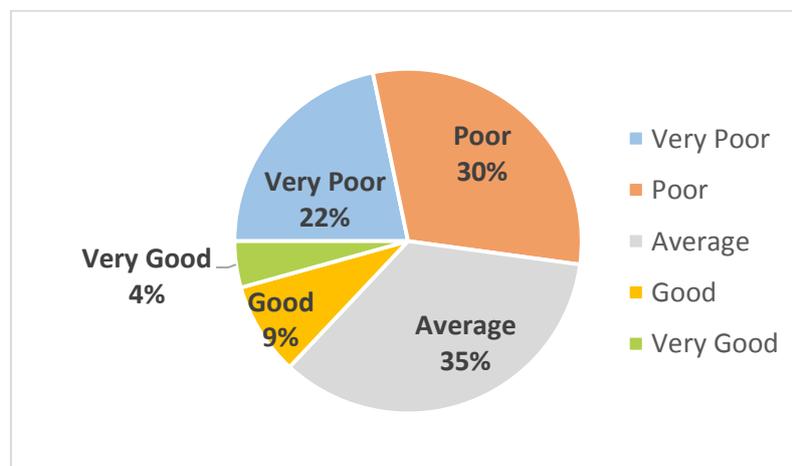


Figure 1: Participants' knowledge before co-design participation

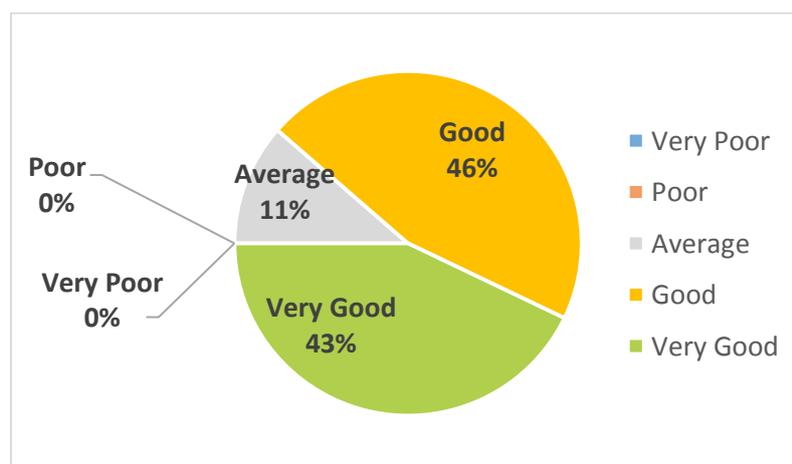


Figure 2: Participants' knowledge after co-design participation

### Confidence to Co-Design

An aim of the CEAC co-design process was to raise participants' confidence to engage in the co-design process. Confidence with co-design at baseline was moderate, with 74% of participants rating their confidence as 'Average' or 'Good'. This baseline level of confidence among participants may point to their motivation for participating in the CEAC project. Importantly, in discussion with participants, it became clear that this confidence also emerged as a result of their considerable life experience (e.g. careers, as engaged members of their community). Participation in the project increased participants' confidence to either 'Good' (55%) or 'Very Good' (30%). See Figures 3 and 4 below for participant ratings of prior and post confidence with co-design.

### Confidence Levels Pre and Post Co-design Participation

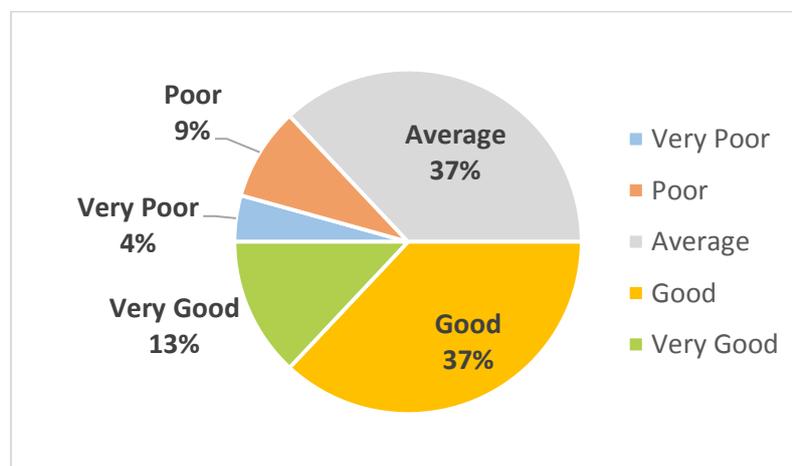


Figure 3: Participants' confidence before working with co-design

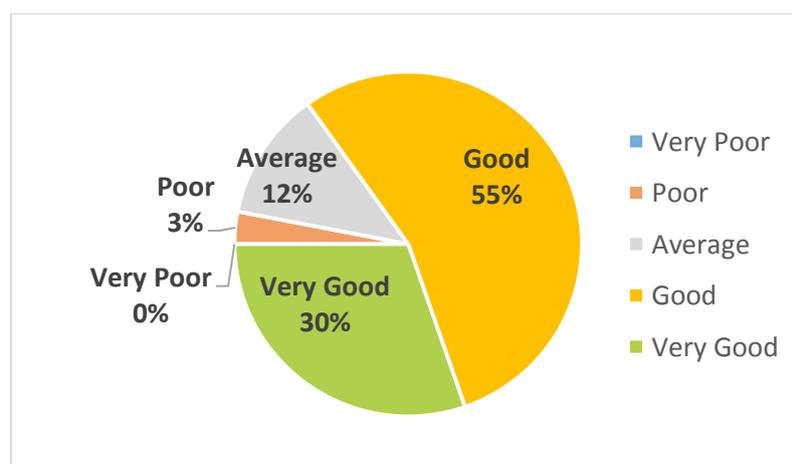


Figure 4: Participants' confidence after working with co-design

### Skill in Co-Design

An aim of the CEAC co-design process was to raise participants' skills relevant to the co-design process. The proportion of participants who rated their skill level as 'Poor' or 'Very Poor' fell from 24% at baseline to just 3% at follow-up. Further, at follow-up, one quarter of participants rated their skill as 'Very Good' and almost one half as 'Good'. Comments from participants illustrated additional skills acquired through the process, including "how to speak quickly, succinctly and in the public service jargon. It will equip me to go to more conferences". See Figures 5 and 6 for participant ratings of prior and post skill development in co-design.

### Skill Levels Pre and Post Co-design Group Participation

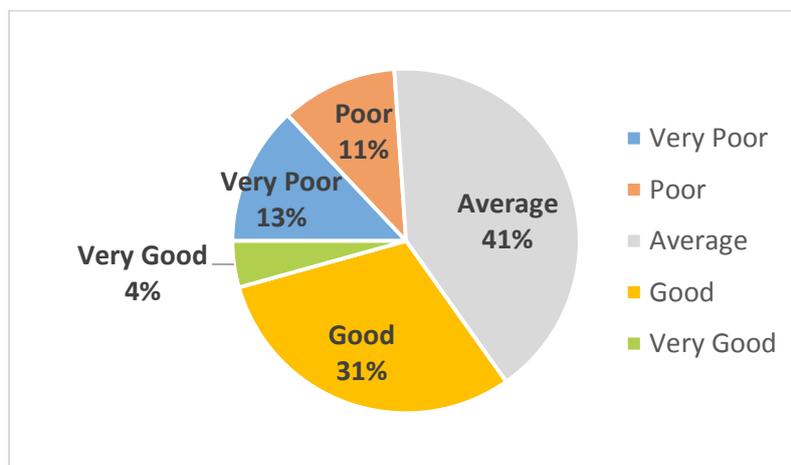


Figure 5: Participants' skill level before working with co-design

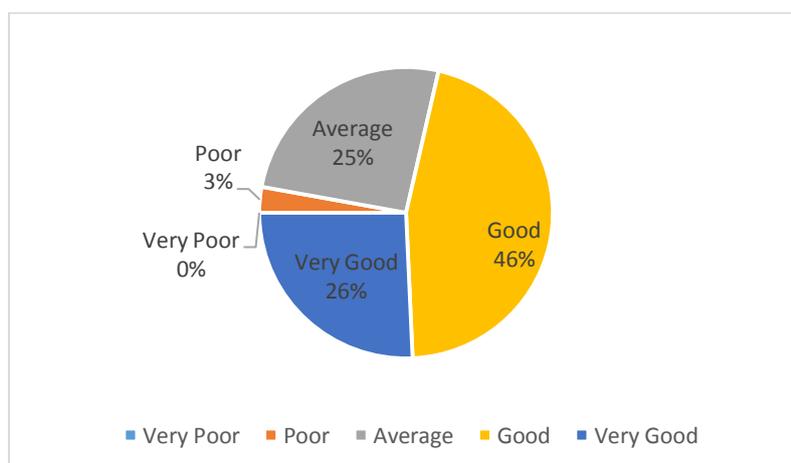


Figure 6: Participants' skill level after working with co-design

## Benefits of Participation and Solutions

Evaluation forms included open-ended questions that asked participants to identify the highlights of participation in the co-design process and how it might benefit them and aged care. Interestingly, more participants listed benefits to themselves as a result of their participation than benefits to the sector through the trial of prototypes. Responses also indicated that participants were highly motivated to improve services and sector practices but were unclear that their participation/action could achieve positive sector change.

Consumers and carers were consistently hopeful that engagement would lead to positive outcomes at all levels (i.e. personally, locally and nationally). However, their scepticism that their engagement could result in systemic change was evident. Participants reported that to date, their calls for change had been largely unheard and they had had few opportunities for meaningful aged care consumer engagement or co-design participation. Additionally, policy or provider responses to their concerns or preferences had been rare, superficial, or briefly implemented without due diligence or reporting. The CEAC co-design process was successful in converting these considerable barriers into a benefit by providing a platform for consumers and carers to be heard. This increased participant confidence in engagement by co-operatively identifying and delivering achievable and positive outcomes for the sector as a whole and for the individuals accessing and utilising it.

An additional and invaluable outcome of Phase 2 of the CEAC project was participants' opportunities to engage with each other and in a project with broad and meaningful implications for social wellbeing. Many consumers and carers greatly valued the opportunity to connect with their peers on a personal level and in relation to a shared objective, and to express their experiences and opinions in a non-judgemental and empathetic setting. In personal interactions with the CEAC team, participants became emotional and passionate about the opportunity to connect as it also represented a first-time opportunity to be heard, respected and valued, and effect meaningful change through the development of solutions that would meet the real needs of consumers and carers.

Participatory, strengths-based and human-centred approaches such as co-design strengthen resilience and reduce the negative effects of disempowerment on health and wellbeing that many aged care consumers and carers have experienced. Consumers and carers who participated in Phase 1 and Phase 2 of this project also consistently reported these benefits.

A number of service provider staff reported that the primary usefulness of the project was hearing the experiences and views of consumers and carers, and appreciated the respect that was fostered through the process of open discussion. For some staff, the project presented the first opportunity to *'share a room'* and engage meaningfully with aged care consumers and carers. Staff noticed that they were becoming *'more open to hearing from clients, more open to suggestions, responding to suggestions ... just more aware'* as the co-

design process enhanced their *'understanding of consumers' aspirations and concerns, and ... strategies to meet their needs'*.

The value of the CEAC Phase 2 co-design process was not solely in the identification and development of grass-roots solutions. It also achieved a palpable sense of inclusion, understanding and openness that was fostered among participants; building capacity for positive reablement and improved wellbeing. In addition, it converted conceivably high levels of stigma toward a system perceived as largely apathetic in regards of consumer and carer needs to one of fostering hope and confidence in a reality of proactive, inclusive and positive change that can benefit all concerned.

## **Appendix 4: Logistics: Engaging Consumers and Carers in Co-Design**

### *Logistics*

The currency of successful participation within this project has been genuine, open and empathetic communication. A great deal of mutual respect and buy-in from participating organisations, their staff, and consumers and carers was achieved in a short space of time by consciously utilising these skills. Given the diverse needs of the people engaged during Phase 2 of this project, it was important to listen carefully and respond appropriately so that a benchmark for successful co-production and co-design was set. As a result, participants felt confident and well supported, could maintain their enthusiasm and commitment to the project over its duration, and readily contributed beyond expectations.

### *Administration and Events Management*

Coordination of a project of this size across multiple states and territories, and with a diverse aged care cohort requires considerable strategic planning and contingency plans. Ensuring that consumers and carers were extremely well supported to attend workshops and co-design groups was of primary consideration. Timing and location of sessions, all-access facilities, well managed travel and accommodation, and close coordination with participating organisations were vital components. To foster reablement and empowerment, co-design participants were supported to self-manage their travel and participation needs wherever possible. As a result, key stakeholder confidence in the CEAC team remained very high throughout this phase.

### *Organisational Involvement*

Enthusiasm and engagement of participating organisations across Phase 2 of this project was achieved. It was noted that, in some instances, increased expectations on services and their staff created challenges to buy-in and involvement. This was overcome by the respectful use of teleconference facilities and email. However, some services deemed their workload and responsibilities as prohibitive to participation and regardless of reduced expectations and support they were still unable to meet their commitment to participate. Additional participant organisations were quickly sourced to manage any shortfall.

### *Consumer and Carer Participation*

Consistent consumer and carer participation in Phase 2 was, at times, difficult to achieve across all four sessions of the co-design process. It became apparent any shortfall in consumer and carer participation that could adversely affect the project would need to be scoped for. Contingency plans were operationalised to cover this shortfall and ensure that participants could contribute their knowledge and ideas readily without being unduly taxed. Most organisations were subsequently encouraged to identify more participants than required at any given session. These additional participants often attended all remaining sessions as a result. Absentees who were unable to participate for all sessions were actively

encouraged and supported to continue to feed into the project via phone call, email and their organisation.

### *Training*

A half day training session was developed to support consumers and carers coming into Phase 2 of the project. The aim was to ensure that consumers and carers would feel confident to have frank discussions with staff and managers of the organisations participating in the project; particularly given difficult discussions may result from identifying issues within the services participating. Staff were also provided with this training in a separate session.

The training focussed on the following:

1. Utilising your lived experience
2. Working in groups and supporting participation
3. Understanding co-production and the co-design process

The majority of participants attended the training. Trained participants then became an asset and, along with the support of co-design session facilitators, ensured that those who had not attended the training were coached through the co-design workshop processes as they occurred.

### *Travel and Accommodation*

A wide variety of supports to travel, travel options, all-ability facilities and accommodation were made available to participants and organisations to ensure both adequate attendance and appropriate support for consumers and carers. Participants reported very high levels of satisfaction with all aspects of event and travel management, communications and support.

### *Additional Support*

Additional financial support was necessary to ensure that some consumers and carers could participate in Phase 2. A protocol for initiating sensitive discussions on this matter was developed and implemented. The resulting participation and enthusiasm of such individuals, when appropriately supported to attend, was noteworthy.

Organisations were required to support staff participation, travel expenses and overtime to attend as part of their workplace agreements. Negotiation of this expectation was required in some instances.

### *Outcomes*

Building and maintaining positive relationships with key stakeholders required considerable commitment and was imperative to the success of this phase. Budget requirements for achieving significant stakeholder engagement throughout workshop consultations and co-design groups, and in a manner that truly meets participant needs and builds confidence, should not be underestimated.