CO-DESIGNING AGED CARE:

VIEWS OF 4,562 OLDER AUSTRALIANS

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National Seniors AUSTRALIA

EveryAGE Counts

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Preface

> *"Given that older people are the primary users of the aged care system, it's a sad indictment on the creators of the system that a Royal Commission finding calls for 'co-designing' involving older people. And the call for 'co-design' is not simply about giving older people a voice or sympathetic ear, it's using their involvement to drive the design of improvements to the current system."*
>
> *– Survey Participant, National Seniors Social Survey 9*

In recent years, Australians have become painfully aware of the many failures of the current aged care system, highlighted by the Royal Commission into Aged Care Quality and Safety whose Final Report was tabled on 26 February 2021.

In its submission to the Royal Commission's inquiry, Australia's national coalition-based campaign to end ageism, EveryAGE Counts, identified that ageism is a key driver of these failures. EveryAGE Counts articulated several broad recommendations to address the underlying ageism problem, including:

> *"reforms to legislation, policy and research to ensure that the design of the aged care system is informed by rights-based principles and responsive to the full diversity of older Australians."*[1]

Consistent with this sentiment, in its Final Report the Royal Commission recommended:

> *"priority [be] given to research and innovation that involves co-design with older people, their families and the aged care workforce"*[2]

This was based on the Royal Commission's stated vision that:

> *"there should be places where researchers and technology developers can access real care environments and work directly with people receiving care, employees, training and education specialists and students to co-design and evaluate new and innovative care models and technological support and solutions."*[3]

The principle of co-design is increasingly gaining traction in the global public policy arena. The Australia and New Zealand School of Government (ANZSOG) describes co-design as a

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[1] EveryAGE Counts (n.d.) 'Ageism a key driver of Failures within aged care system', *EveryAGE Counts*, https://www.everyagecounts.org.au/ageism_key_driver_of_failures_within_aged_care_system.
[2] Royal Commission into Aged Care Quality and Safety (2021) *Final Report: Care, Dignity and Respect, Volume 1 Summary and Recommendations*, Commonwealth of Australia. Recommendation 107, clauses 7.a.ii. and 8.b.i.B., pp. 278-279.
[3] Royal Commission, *Final Report Volume 1* (ibid), p. 43.

set of processes, principles and practical tools for "generating and testing new solutions to public problems" by "empowering people affected by a policy issue to contribute to its solution".[4] Co-design requires more than mere consultation, with participants actively involved in innovating new systems all the way from the ideas stage through to delivery and implementation. ANZSOG notes that co-design can be complex and time-consuming if done properly, and that governments are not currently well-structured to support genuine co-design processes, but that co-design has the potential to deliver long term benefits. Benefits of co-design have been demonstrated internationally in some sectors such as healthcare as ANZSOG identifies, and we further illustrate its potential benefits in this report.

The Australian Government has accepted the Royal Commission's co-design recommendation in principle, in its response to the Royal Commission's Final Report.[5] In addition, a Council of Elders is now in play, with the Australian Government stating that this Council will be established to provide a voice to Government from senior Australians.[6] Australia thus finds itself at a unique point in history in which to consider, as a nation, how co-design of the aged care system might proceed.

To explore older Australians' thoughts on the concept of co-design, National Seniors Australia's 9th Annual Social Survey asked:

> *"The Royal Commission into Aged Care recommends that older people should be involved in 'co-designing' improvements to the aged care system.*
>
> *"Can you please describe what 'co-design' means to you? If you don't know or are unsure, please say so."*

In this report we detail how the thousands of older Australians who completed the survey in February-March 2021 answered this question. The answers give us insight into seniors' expectations and ideals when it comes to co-designing improvements to the aged care system. These results have the potential to make future community engagement more effective by revealing what seniors are concerned about regarding co-design proposals, and how they would most like to be involved. Pressing home the value of co-design for senior Australians, we also outline some successful co-design case studies in this report's appendix.

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[4] ANZSOG (Australia and New Zealand School of Government) (2020, March 24), 'The promise of co-design for public policy', *ANZSOG Resource Library*, https://www.anzsog.edu.au/resource-library/research/the-promise-of-co-design-for-public-policy.

[5] Australian Government (2021) *Australian Government Response to the Final Report of the Royal Commission into Aged Care Quality and Safety*, Commonwealth of Australia as represented by the Department of Health. Response to Recommendation 107, p. 68.

[6] Australian Government, *Response to the Royal Commission* (ibid). Response to Recommendation 9, p. 11.

The Royal Commission has made it clear that autonomy and self-determination for older Australians must be embedded in aged care models of the future. If the community is not paying attention to what seniors are saying they want from the aged care system, then we are not allowing seniors the same entitlement to autonomy and self-determination that other Australians expect. That has the potential to contribute further to the cycle of ageism.

Ageism has been a key driver of failures in safety, quality of care and quality of life within the Australian aged care system. Pervasive, unquestioned, negative attitudes about ageing and older people are inevitably carried into aged care by the workforce, family members, decision makers and older people themselves. Embedding co-design in a genuine and ongoing way, in various forms and in various settings, directly challenges ageist norms and assumptions and mitigates against the most pernicious impacts of ageism: disempowerment, lack of control and autonomy, loss of rights. Like all prejudices, stereotypes and discrimination, ageism rests on the 'otherness' of older people. Co-design has the potential to create reform that is about all of us, whether it is now or in the future, because we will all grow older…if we are lucky.

That is why National Seniors and EveryAGE Counts are co-publishing this report. To ensure ageism is not embedded in the reform process and in new policy, there is an immediate need to properly engage older Australians and to build reform around their rights, needs and preferences.

Because ageism is so pervasive and largely invisible, genuine co-design is a prerequisite for the human rights of older people to be exercised and upheld. Reform will not be done 'to them' or 'for them', but *with* older people – in an authentic and sustained way. Co-design ensures voice, ageism denies voice. Co-design empowers, ageism disempowers. Co-design optimises choice and control, ageism diminishes choice and control. Co-designing aged care reform is tackling ageism at its root.

Executive Summary

- In a 2021 survey of 5430 Australian seniors, 4562 people answered a question about what "co-design" means to them in the context of co-designing improvements to the aged care system.
- Australian seniors overwhelmingly support the prospect of older people being involved in co-designing the aged care system. In particular, they are committed to the principle that the system's users should play a significant role in its ongoing design.
- Many seniors have a strong desire to engage in co-designing the aged care system themselves, and already have insights and ideas to contribute in this domain, at all levels from policies, laws and funding through to residential care room design, food quality and staff pay.
- Seniors feel that opportunities for them to be involved in co-designing or managing the aged care system are currently minimal. For many, any chance to have input and voice their opinions would be highly valued given this current state of disenfranchisement and disillusionment.
- Seniors ideally want a "seat at the table" for older people and at least an equal say in decisions about all aspects of the aged care system.
- Direct input to the system through dedicated positions for seniors on boards and committees, with real decision-making power, is a desirable model, together with strategies to gather, communicate and implement the suggestions of the diverse community of older Australians.
- The primary reason seniors seek to co-design the aged care system is to ensure the system meets older people's needs. Specifically, seniors recognise that the population of older Australians is diverse and aged care facilities and services must be tailored to suit different needs and preferences, in terms of health, ability and disability, culture, lifestyle and more. In their experience, services and facilities do not currently meet these needs.
- Seniors recognise that co-design processes need to incorporate diverse voices, and that this presents a practical challenge that must be dealt with for co-design to succeed. Within this issue there are specific challenges such as finding ways to best incorporate the perspectives of older people with limited cognitive capacity so that they are not left behind.
- Support for developing diverse accommodation options is a high priority area for senior Australians so they may choose how and where they age.
- Seniors seek control over decisions about their individual care plans and packages. They would value the opportunity to have decision-making power and greater choice about all aspects of their care within the options currently available, as well as avenues to propose and develop new options.
- Seniors recognise that co-design means working with other people. They value collaborating with others if those others genuinely listen to older people and if the

process is driven by older people's priorities and requirements rather than competing priorities such as profit.

- Seniors are not just aged care recipients. Many have experience and expertise they would like to put to use in making changes to the aged care system. This includes work experience in relevant sectors as well as past and present involvement in age-related matters as activists, advocates and public educators.
- Seniors are wary of tokenistic gestures of involvement such as consultation processes that invite contributions but do not act on them, or surveys constructed with predetermined agendas. Genuine co-design processes must acknowledge and address this before seniors will trust that the process is serving their best interests.
- Many seniors are unsure what the term "co-design" means and may feel profoundly alienated when unfamiliar terminology is used. Communication about co-design initiatives should take this into account and ensure that intentions and parameters are clear. As a starting point, the term "co-design" could be explained as "an opportunity for older people to imagine, develop and implement new approaches to aged care together with governments and aged care providers".
- A first step in combatting ageism is to grant older people self-determination. This report shows how important that is to senior Australians.

Introduction to the survey results

Older Australians' ideas about what co-design means to them are important to understand if there is to be effective community engagement implemented for the aged care system.

In early 2021, 5430 people participated in National Seniors' 9th Annual Social Survey (NSSS-9). The survey included the question about co-design detailed in the Preface of this report, and 4562 survey respondents answered it (84.02%, Figure 1).

From those thousands of completed surveys, we identified several types of response to co-design prevalent among the community of Australian seniors. About half of the participants constructively and sincerely engaged with the meanings of co-design in their responses, offering their definitions or ideals for what co-design means to them in this context. Different people discussed different components of co-design that interested them, which together build up a picture of what co-design might look like. Those components include:

- *Who* should be involved in co-designing improvements to the aged care system.
- *Why* co-design is needed.
- *What* exactly is to be co-designed.
- *How* the co-design process would work.

We also asked about the kinds of consultative activities respondents would participate in to improve the aged care system if they knew their voices would be heard. Around 80% of survey participants selected one or more activities from the list given, and about 500 people wrote a comment about this.

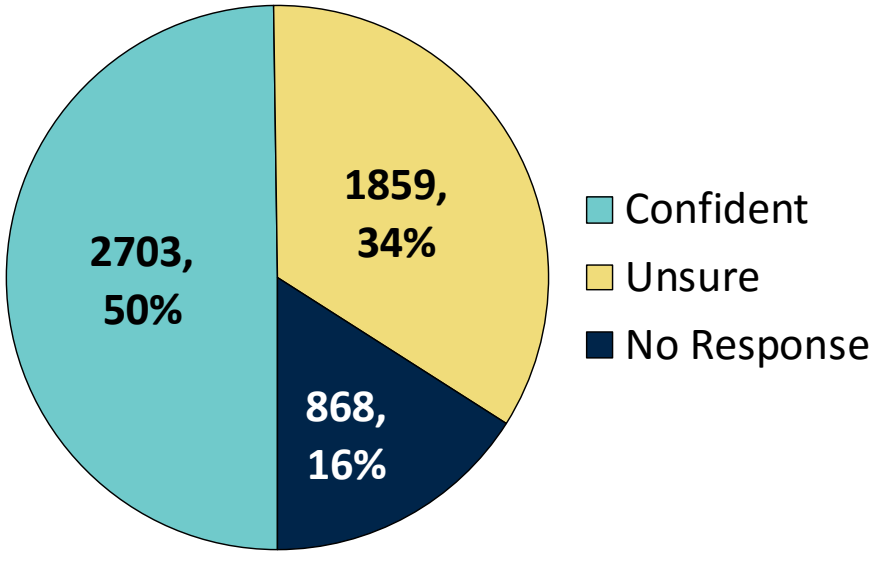

Figure 1 The number of survey respondents who answered the co-design question. About a sixth of the total of 5430 participants did not respond or did not respond coherently (dark blue), a third expressed uncertainty about co-design (yellow), and half did not express uncertainty (teal, here labelled "confident").

About a third of the participants indicated they were uncertain about the meaning of the word co-design or how the concept applied to the aged care context (Figure 1). A sizeable minority were cynical about the possibility that older people would be genuinely invited to co-design the aged care system or about the likelihood of a co-design process being implemented effectively.

These themes are each discussed in dedicated sections of this report.

Survey and analysis methods

National Seniors Australia is a not-for-profit, non-government advocacy organisation for Australians aged 50 years and over. Every year, National Seniors conducts an online survey of members' behaviours and views across a range of topics relevant to older peoples' lifestyle, health and wellbeing and asks a range of demographic questions. The survey is open to members and non-members aged 50 plus from all states and territories. The survey is made available on the National Seniors website and circulated via a member online newsletter and in the quarterly magazine. The 9th National Seniors Social Survey (NSSS-9), on which this report is based, was approved by the NHMRC accredited Human Research Ethics Committee of Bellberry Limited (APP 2020-12-1319). The survey was open from 15 February 2021 to 1 March 2021. A demographic snapshot of the 5430 people surveyed can be found in Appendix A.

This report is primarily based on text comments that respondents submitted to the co-design question and a follow-up question about which practical activities seniors would participate in to contribute to improving the aged care system. We analysed text comments using the thematic analysis framework described by Braun and Clarke.[7] Themes were identified primarily through inductive analysis, i.e. data were coded without reference to an explicit pre-existing theoretical framework. The analysis was guided by a critical realist approach which primarily aimed to summarise and reflect participants' views. Emphasis was placed both on highlighting common ideas expressed by tens or hundreds of participants and on describing the diversity of ideas present, some of which were expressed by fewer people. The researchers acknowledge the influence of their pre-existing theoretical knowledge and understandings on the codes and themes identified from the data.

Quotes from survey participants were selected to illustrate some of the variety of ideas expressed by the cohort, and to demonstrate that some ideas were commonly expressed by a large number of people. We endeavoured to reproduce each selected quote verbatim whenever possible. In four cases we omitted or altered part of a quote for context and

[7] Braun V & Clarke V (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3:2, 77-101, doi:10.1191/1478088706qp063oa.

indicated this with square brackets []. In a few additional cases, minor typos and obvious spelling errors were corrected for readability (not indicated with square brackets). Quotes were only corrected in this way if there was no ambiguity about the participant's intended meaning in the part of the quote that was corrected. All other phrasing idiosyncrasies were retained in the quotes.

The report includes word clouds as illustrations of some of the prominent ideas being expressed, generated at WordClouds.co.uk. Words that appeared frequently but did not speak to the theme in an obvious sense were removed from the final word lists (e.g. words such as "working", "make", "live"). This was usually because those words were part of longer phrases that the word clouds did not capture (e.g. "what is working", "make decisions", "how I want to live"). Word clouds were used as illustrations only, not as analytical tools.

Who should be involved in co-design?

The 9th National Seniors' Social Survey showed that older Australians are interested in co-design and are keen to be engaged in co-design processes.

About half of the answers to the survey question comprised responses in which people engaged constructively and sincerely with the meanings of co-design (2807 responses, 51.69% of NSSS-9 participants). Four key components recurred within these responses: *who* should be involved, *why* co-design is needed, *what* is to be co-designed and *how* the process would work. This first section addresses the key component of *who* should be involved.

One third of survey participants alluded to groups of people who they thought should be involved in co-designing improvements to the aged care system (1781 responses, 32.80%). Our question wording specifically mentioned older people, and consistent with that, older people were overwhelmingly the most frequently mentioned group that respondents associated with co-design. Many respondents saw themselves as part of this "older people" cohort and personally welcomed the opportunity to be involved in co-designing the aged care system:

> *"In other words we should be involved !!"*
>
> *"I like that idea. We should have a say in the designing and treatment of aged care."*
>
> *"I know that there would be many areas that I could provide good advice based on my experience."*
>
> *"I haven't heard about this but if I could make some recommendations or have my voice heard I would like to know more."*

Participants gave numerous reasons to support the centrality of older people's involvement, including that younger people in any industry or sector cannot know what older people need; older people have gained wisdom and expertise from a lifetime of living; many older people have specific knowledge and skills to offer gained from relevant careers and education; and generally older people should be treated as intelligent people just like anyone else.

More specifically, a large number of respondents said current and future users of the aged care system should be involved in co-designing aspects of that system. In other words, there was widespread support for the idea that the people most affected by a system should co-design it:

"Makes sense to involve the people using the system to have a say in the way it should operate"

"People should have the right to make decisions that will affect them."

"Older people should be included in the design and planning of aged care - asked what their requirements are - currently this does not apply."

"Definitely, you think you understand how age affects you but when you get there you really do understand and older people should definitely be involved."

"I totally agree. No one understands, can criticise, improve and design Age Care better than those that live in it and can see the faults, inconsistencies and the levels of failure and their reasons."

Among those specifying seniors' involvement, 140 people said the meaning of co-design to them is that they (or other seniors) will be able to choose the care they will receive themselves, as an individual, from the range of options currently available:

"You have a say in your age care plan"

"older persons should have a say in their own aged care. At home or in a retirement village"

"I think it means being able to have some input into where you live as you age, who you live with, what you are allowed to do. It is important to be allowed to make your own decisions, and be consulted before major decisions are made about you living circumstances."

"I will work with a service provider to design the type of help I require and the frequency that it will be provided. There will be discussions around pricing. If necessary I will access several service providers concurrently to get the service I require. The care design will respond to my needs."

"I can only assume that 'co-design' would be similar to the current NDIS scheme in that a 'tailored' option to suit the individual needs would be considered."

This relatively weak application of co-design implies that many older people do not expect to have control over their own life as they age but do desire that control. Having genuine agency to choose among existing options is thus one basic principle for co-designing the aged care system. At that level, co-design involvement must be extended to every individual.

However, for the vast majority of respondents, co-design means seniors' involvement in designing the system as a whole or aspects of it, beyond choices made for one individual:

> *"I understand what co-design means. In the case of aged care I would see it as meaning that older people had input into the system at all levels, from high-level policy through to day-to-day operations."*

> *"Firmly believe any aged persons should have constant input into all areas of care factors, facilities, staff and specific training and needs."*

> *"Yes, older people should be involved, as far as possible, in all decisions relating to the aged care system."*

> *"Older people should have the opportunity to have input to systemic planning for future provision of aged care as well as being involved in choosing what services are provided and where the services are provided. For those involved in using the system, co design should include the ability for the person to design the way services are provided and have the opportunity to decline services if not wanted and be able to take risks as long as the risks are understood."*

Details regarding the specific elements of the system that might be co-designed are discussed in the later section of this report on *what* is to be co-designed.

A subset of respondents put conditions on the kinds of seniors who should be involved in co-design processes. Several people suggested that a diverse range of older people should be involved in co-designing the aged care system rather than *"a very limited group"*, or as one person put it, *"a group of ego-driven and financially secure people […] identified as 'spokespeople'".* While a great many respondents felt all older people should be able to participate, some felt only those currently using the aged care system should be involved in co-designing it, while others specified only future users should be involved. Some specified an appropriate age range for involvement (e.g. *"over 40"*, *"over 50"*, *"60-100"*). Another recurring theme was that seniors will often have diminished capacity to contribute to a co-design process. Most respondents who mentioned this factor implied it should be anticipated, and addressed earlier in a person's life:

> *"Old people who need to live in a nursing home do not have the capacity and drive to be involved in co-designing"*

> *"It assumes I have 'power' in the situation, which I won't have if I'm frail enough to require it."*

> *"Not older people, People who are still aware and know what they want or expect."*

> *"co-design needs involvement of aged persons BEFORE they reach a level that limits their input."*

Presentation of seniors' perspectives by a representative sample or elected group of older people, or by advocacy organisations such as National Seniors Australia, was for some a desirable alternative or accompaniment to older individuals' direct involvement in co-design. One of the reasons for this was to speak for those who cannot speak for themselves:

> *"I take this to mean that older people and or representative organisations like National Seniors would be involved in the formulation of a new aged care system."*

> *"Obtaining the services of a 'sharp advocate' who understands the range of issues that are important to older people and have them bat for us with the pollies."*

Other groups of people respondents commonly identified as desirable participants in co-design included:

- Family members, loved ones and caregivers of people in the aged care system; or for people without personal connections, nominated Powers of Attorney or external advocates.
- Experts in fields such as health, community services, disability support, ethics and the law.
- Interested members of the general public and local community.
- Aged care staff and others experienced in engaging with the aged care system.

Independence is a desirable trait in these participants, meaning that, in the words of one respondent, their *"loyalty and duty of care is NOT to the [aged care] organisation"*.

Respondents had differing expectations of who seniors and their allies would be engaging with as part of co-design processes. Commonly mentioned groups they imagined as co-designers alongside older people included:

- Governments at all levels; public servants; *"those in power"*; the Royal Commission itself.
- Aged care service managers and owners; aged care industry bodies; companies and developers of aged care facilities; church organisations that provide aged care; aged care staff; aged care service advisers.
- Architects, builders, designers and planners.
- Unions; social services; NDIS experts.
- More broadly, *"experts"*, *"stakeholders"* and *"interested parties"*.

A desirable trait for these participants is that they will listen to older people's views:

"Co-designing aged care system means involving people over the age of 60 in better identifying the needs of senior citizens. More importantly it means that the bureaucrats listen to the input and action it."

"Until elderly persons (like disabled persons) have their wants, needs, views respected and listened to by their own children, 'experts', professionals, researchers, younger people - you can see where this list is going - true co-design is a dream!!!!"

Finally, parties respondents often derided as undesirable participants in designing the aged care system included governments, public servants, industry lobbyists, *"profiteers"*, *"money men"*, professionals and *"so-called experts"*. People in these groups are undesirable participants when they are ignorant about older people and aged care, or when their primary motivations are money or careerist self-interest.

In short, there is a great deal of support among seniors for older Australians being involved in co-designing improvements to the aged care system. Many would like to be involved in such a process themselves. It is important to seniors that they have control over a system they rely upon now or will rely upon in the future. Seniors also recognise the need for others to be involved, especially given some older people have limited capacity, but crucially these others should genuinely listen to seniors' perspectives. People involved in co-designing must place users' interests at the centre of decisions rather than any competing priorities.

Why is co-design needed?

Over a thousand survey responses spoke to the question of *why* Australia needs a co-design process that involves seniors in making improvements to the aged care system. Putting aside the many respondents who conceived of co-design as a strategy for controlling their own personal aged care choices (discussed above), a sixth of the survey responses gave insights into other reasons why the co-design proposal is important to older Australians (906 responses, 16.69%).

In over 400 cases, respondents interpreted the question as an opportunity to start co-designing the aged care system by offering views on specific things they would change about the system today. Most areas respondents highlighted for urgent action concerned residential aged care, but people also made suggestions for improving support for older people outside of residential care.

The improvements suggested for residential aged care included:

- More staff; greater staff to resident ratios; better staff pay and conditions; more rigorous vetting and training of staff; greater value placed on caring attitudes among staff; more medically trained staff on site including nurses, doctors and allied health professionals.
- Running residences as a service not a business; de-privatising residences; capping profit margins.
- Higher penalties for abuse and neglect; more accountability and monitoring; transparent, accessible channels for complaints without fear of reprisals.
- Less institutionalised environments with greater quality and diversity of options for food, personal care scheduling, leisure activities, exercise, amenities such as hairdressers and so forth; larger rooms that are more home-like and whose fixtures and fittings are accessible and appropriate; flexible options for maintaining interpersonal relationships including visiting and co-dwelling opportunities for spouses.

The improvements suggested for support outside of residential care included:

- More diverse choices for aged care including innovative housing arrangements; more government support for people to age at home through funding to modify their houses.
- Increased government funding for aged care services; more care packages; simplifying the bureaucracy around accessing aged care and enabling offline paperwork; accessible, easy to understand information about available options; fairer and more equitable funding for aged care irrespective of an individual's income; better pension provisions.

Figure 2 Word cloud of respondents' most commonly expressed aspirations for an improved aged care system, indicating why a co-design process is needed. Font size indicates relative frequency of the word, with larger words mentioned more frequently. This world cloud includes the 50 words most frequently appearing in the 'why' dataset.

- Expansion of public transport, including near aged care residences to allow non-drivers to visit residents more easily.
- Access to voluntary assisted dying provisions.

A formal co-design process would elicit older people's thoughts on such topics more directly and systematically than this question was designed to do. Therefore, to keep the focus on the co-design concept rather than people's concerns about the current system, we did not analyse these responses in more depth. However, these themes give us insight into where a co-design process might start. They demonstrate that older Australians are heavily invested in a desire to improve the aged care system. They are also well placed to identify key problem areas and to offer positive visions of what aged care could be. The responses clearly demonstrate why a formal co-design process that captures these insights comprehensively and acts on them is desired by respondents.

Beyond these specific practical suggestions, 564 responses used aspirational words and phrases to highlight what an ideal aged care system might be or do. These words and phrases offer a vision of the kinds of *general qualities* seniors are looking for in an improved aged care system. Figure 2 shows the 50 words most frequently appearing in these responses.

Overwhelmingly, the most common reason people gave for seeking to co-design the aged care system was to create a system that genuinely meets people's needs and requirements:

> *"have a real part in determining how the 'system' will cater for aged care needs"*
>
> *"We older people should be consulted on what we actually need and want. As opposed to having some state and Federal bureaucrats deciding for us!"*
>
> *"have input from the coal face about what is really required in a practical sense"*
>
> *"Have more say in what their needs actually are, and how to satisfy them"*

The fact that more than 200 respondents felt it necessary to state this suggests the current system does not meet people's needs adequately. It also suggests the system does not adequately recognise what seniors consider to be their *actual* needs, as opposed to their *assumed* needs.

More specifically, many people expressed a desire for the aged care system to meet people's *"individual needs"* and *"specific needs"*, observing that different people have *"different needs"*. Accordingly, they seek *"appropriate"*, *"suitable"*, *"relevant"* and *"tailored"* care, with *"choices"*, *"flexibility"* and *"options"* that account for cultural, linguistic and lifestyle diversity as well as different medical conditions, abilities and disabilities:

> *"A system that caters for all and covers the broader spectrum of the population needs and requirements."*
>
> *"I would like to think that a plan for 'co-design' reflects an attitude of individually designed care to meet the specific needs of individuals"*
>
> *"There is a clear need to cater for individual needs and to avoid the 'one cap fits all' approach."*
>
> *"Creating residences and services that reflect the lifestyles of those that use them."*
>
> *"Both being of Aboriginal Background we would like to see a better care plan put in place for our people"*
>
> *"As much involvement as possible discussing cultural needs and services required to cater for the many specific requirements of individuals."*
>
> *"Residents in aged care, and those receiving in home care services must have the ability to help design the accommodation and services to ensure*

they are appropriate for the individual. Such as mentally alert must be able to engage with others with similar capacity (or better) no matter what their physical capacity might be - they must not be cared for in dementia care situations."

This overarching desire for tailored care demonstrates that co-design with aged care system users will be critical if aged care providers are to understand and meet such a diverse range of needs.

The survey responses suggest a system that meets people's *"wants"*, *"wishes"* and *"preferences"* would be part of this picture too. As Figure 2 illustrates though, this kind of word was mentioned less often than words related to meeting needs. This again reinforces the sense that the system does not currently meet the minimum expected standards, while also demonstrating that older people would like an improved aged care system to do more than the bare minimum.

In addition to this kind of outcome-oriented thinking, respondents mentioned more specific aspirational traits of an improved aged care system. Key aspects of people's ideals for older life included living with *"comfort"*, *"dignity"*, *"freedom"*, *"health"*, *"privacy"*, *"safety"*, *"security"* and *"wellbeing"*; feeling *"happy"*; and being treated with *"kindness"* and *"respect"*. *"Quality of life"*, *"a life worth living"*, *"stimulation for bodies and minds"*, *"human rights"*, and a system that makes *"old age easier"* were also concepts appearing in more than one response. Many of these aspirations cannot be met with a single standard approach, so working towards them will certainly necessitate older Australians' involvement in co-designing improvements.

What is to be co-designed?

Respondents had different aspects of the aged care system in mind when sharing their visions for *what* the focus of a co-design process should be. About a fifth of survey respondents provided their thoughts on this (1047 responses, 19.28%).

As discussed in the section on *who* should be involved in co-design, a sizeable minority of respondents saw co-design as the ability to control their own individual aged care plans under the current system. The most frequently mentioned aspect of this that they sought to co-design was choices about where they live as they age, for example at home, in a retirement village or in residential care, and who to live with, including choice about living with pets. In particular, people do not want to be forced into accommodation they do not choose:

> *"To understand the methods and have the opportunity to provide personal input to what one may be subjected to. In other words I have no desire to be railroaded into some of the centres I have witnessed."*

> *"because I live on my own, there is no way I would want to move into single bedroom accommodation, which I understand there is no choice in some cases"*

> *"Older people should have a say about how they want to live the remainder of their years. Not just be put into whatever care that can be found for them when they can't remain at home."*

Other aspects of choice and control mentioned by these respondents were:

- Having the power to curate their own package or program of services, activities and health plans.
- Being able to choose their providers based on the standards, costs and frequency of care services offered.
- Being offered clear and honest guidance, with effective oversight processes and measures in place to protect their rights.

The other 909 respondents who discussed *what* is to be co-designed all mentioned aspects of the aged care system beyond an individual's choices, or they envisioned deeper changes to the system than choosing between existing options. Facilities and services were the most frequently mentioned targets for co-design, with each of those words used by at least 200 people. This indicates that the hands-on aspects of aged care were most likely to be flagged as the key objects needing improvement. Older Australians want to co-design the *"types"* of care services and facilities that are made available to seniors, not just to be able to choose between existing types.

Figure 3 Word cloud of what aspects of the aged care system respondents imagine would be co-designed. The 51 top terms are shown, excluding the very top responses of "facility"/"facilities" and "service"/"services".

These responses were similarly dominated by concerns about accommodation (Figure 3). Choice and control over accommodation options is clearly a high priority for seniors. Residential aged care facilities, nursing homes and other housing arrangements were explicitly targeted for co-design by 402 people (7.40%), with others less directly alluding to residential aged care too (for example, using the words *"facility"* or *"residents"*):

> *"Excellent idea! If I went into age care I would have something to say about how services are provided, how buildings are designed, etc."*
>
> *"Co-designing means that older people are consulted/ included/ listen to as to what they require/need/want in an aged care facility so that it meets their medical, physical and emotional needs as they age and perhaps become more frail."*
>
> *"Let them have their say about how they live, and LISTEN to the people involved."*
>
> *"People should have choices in how they live their lives. If people want to age at home there should be some financial support available to do this."*

> *"I fully support this action. Government should look at designing a communal project with a defined number of households of varying ages and income. Provide a section of land and allow each household to design the residence that suits their needs."*

And, ironically:

> *"Where Prison Guards and Inmates agree on the amenity of the confined spaces Inmates should live in."*

People also identified specific aspects of care institutions and homecare services as targets for co-design, including how people live in terms of activities, food and medical support, and where they live, in terms of the physical layout of rooms, the construction of whole environments and buildings, and the geographical locations of services and facilities. The "design" part of the word "co-design" seemed to imply architectural design to a reasonably large number of participants, who perhaps associate designing with visual drawings and diagrams. This common understanding of the word "design" should be taken into account in future communications about co-designing aged care, with the full scope of what might be co-designed made clear.

Being involved with co-designing staffing arrangements was also a priority for respondents, including on key matters such as staff-resident ratios and staff training. Some mentioned wanting to extend co-design beyond the physical environment to social, emotional, mental and (in one case) spiritual aspects of care.

Beyond facilities and services, respondents commonly expressed interest in co-designing oversight aspects of the aged care system. Policy was the oversight mechanism mentioned most often, with funding and finances, legislation and laws, rules and regulations, minimum standards, guidelines, monitoring tools, feedback mechanisms and decision-making processes themselves also highlighted for co-design:

> *"Older people should be consulted and have input into the design of the aged care framework including strategy, policy, funding, facilities, services, health care, home care packages and financial support"*

> *"Co- designing means to me that a cross section of the senior population will be involved in a consultative process to review the policies and procedures of residential homes. The significant parties involved in this improvement of aged care system need to hear what the senior citizens want and expect from these facilities. The standards need to be reviewed and monitoring systems need to be put into place to ensure that minimum standards are exactly that in the day to day running of a residential home."*

"Having an input and involvement into the planning of facilities, services and regulations that govern the systems. The involvement to include feedback on progress and success/failure of the designs."

"Co-design to me means that people will have a say in how future decisions will be made."

Taken together, survey respondents were keen to see the entirety of the aged care system co-designed by older people. Some felt older people should be involved when major changes are proposed or decisions are being made, or to identify priority *"issues"*. Others said *"all"*, *"any"* or *"every"* aspect of the system should be co-designed, from the *"framework"*, *"models"*, *"strategies"* and *"structures"* at the macro level down to *"procedures"*, *"protocols"* and *"processes"* on the ground. People mentioned being involved in co-design at the *"research"*, *"planning"*, *"development"*, *"implementation"*, *"delivery"* and *"evaluation"* phases of improvement. They also identified the need for *"continuous improvement"*. They sought to review how things *"operate"* and what is and isn't *"working"*, and to co-design how aspects of the system are *"set up"*, *"run"* and *"managed"*.

All of this indicates that every senior has a different sense of which aspects of the aged care system should be co-designed. But as a collective, older Australians possess strong interest in co-designing every aspect of it. A genuine proposal to involve older people in co-designing improvements to the system would take heed of this and open the agenda widely to what they have to offer.

How would the co-design process work?

The majority of people offering perspectives on co-design included ideas, or at least hints, as to how they thought the co-design process might work (2376 responses, 43.76%). In most cases this was implied rather than elaborated, but even short answers grant us insight into what older Australians expect from a co-design process. Longer answers which spoke to questions of process in detail demonstrate that many seniors care deeply about such processes. Some hold strong views on how to craft a co-design initiative to maximise its effectiveness.

When respondents referred to the processes involved in co-design only briefly, the language they used was quite modest for the most part (Figure 4). Around 2000 responses primarily characterised co-design as an opportunity to be *"included"*, to have *"input"*, *"involvement"*, *"participation"*, *"a say"*, to offer *"contributions"*, *"feedback"* or *"opinions"*, to *"put forward suggestions"* or to *"help"*, possibly via *"consultation"*, *"discussions"*, or being *"asked"* for their views. This suggests many seniors feel they do not currently have much (or any) opportunity for input into the aged care system, and any role would be an improvement. This general sense of disenfranchisement was reinforced by the large number of people who specified that their contributions should be *"listened to"*, *"taken seriously"*, *"respected"*,

Figure 4 Word cloud of respondents' ideas about how co-design would work. The top 50 terms are shown, excluding variations on the words "involve" and "design" which appeared in the survey question.

"taken into account", and where possible *"acted on"*. Many of these answers had emphasisers attached to indicate that older people desire more than tokenism, for example they seek involvement that is *"meaningful"*, *"genuine"*, *"active"*, *"direct"*, *"significant"*, *"integral"* and *"valued"*.

Most of the remaining responses sought a more empowered role for seniors in co-design, in which they have a *"seat at the table"* and work actively with other stakeholders. Respondents used phrases such as *"working together"*, *"collaboration"*, *"joint decisions"* and other terms indicating that co-design is a *"shared"* and *"cooperative"* endeavour in which, ideally, all parties reach *"agreement"* and act in *"partnership"*. In some cases, people specified the balance of decision-making power in the co-design arrangement, most often saying it should be *"equal"* between seniors and others. Occasionally respondents sought a greater role for seniors in decision-making, especially about their own care but not limited to that, envisioning seniors *"defining"*, *"designing"*, *"deciding"* and *"advising"*. Once again aware of the risk of tokenism, some people specified that older people should have *"a good measure of actual control"*, *"full agency"* and *"primary input"*, with *"more input than others"*, *"a majority say"* and perhaps *"the final say"*:

> *"To me it means that older people should be at least as much as others involved in designing improvements to the aged care system."*
>
> *"This feedback would have the same if nor more weight than those [of] bureaucrats, Service Providers and other commercial entities"*
>
> *"We design it and politicians are forced to implement it"*
>
> *"This will be a power struggle with service providers and government who currently have control."*

In terms of the methods for eliciting seniors' input, those giving short responses often mentioned surveys, focus groups, representation through advocacy organisations, and older people sitting on advisory committees and the boards of aged care residential facilities. Some commented that *"surveys like this one"* were a good method for them. A few people mentioned think-tanks, one-on-one interviews, workshops, working parties and lobbying politicians. Some specified that the timing of co-design processes was important, stating seniors should be part of them *"from the start"*, *"all the way"* and *"ongoing"*. Factors enabling participation include independent facilitators, clear communication, transparency, geographic accessibility, and the opportunity to learn more about the aged care system from other stakeholders prior to making decisions. A few people specified the process should be *"constructive"*, focusing on both *"pluses and minuses"*.

Some respondents shared longer responses about co-design processes, demonstrating considerable knowledge and experience in this space. They emphasised the level of deep

engagement and relationship-building required to implement effective and genuine co-design. They also noted that a co-design initiative must not prescribe options in advance but enable *"real innovative choices"* for *"remodelling the system"*. Expectations of the process should be made clear to all participants, and if older people's recommendations are not implemented, there should be a transparent feedback mechanism to explain why with reasons given:

> *"Co-design is where it seeks to include individuals or groups of individuals to share their knowledge, capabilities, experience and build up relationships with people who make important decisions about their lives."*

> *"Genuine collaboration whereby older people are given the appropriate information to make informed decisions - particularly important to demonstrate flexibility and preparedness to think outside the box. Accepting a range of options other than the existing ones means clear communication about the co-design process and the potential opportunities and choices it provides."*

> *"Co-design is a concept whereby I have a role in how something will affect me. For example, an aged care facility where there is co-design means that I have input into my care and am consulted (or my family are consulted.) There will be procedures/rules that govern how the co-design works and what I can expect out of the process. It will also list what my options are if I don't agree with the outcome."*

> *"In this context, 'co-design' means a collaborative effort between the parties such that older people are engaged to provide input into the design process. The form of the input should not just mean asking for feedback about proposed designs, but making the effort to capture older people's requirements and have these reflected in the design decisions of the aged care system. Given that older people are the primary users of the aged care system, it's a sad indictment on the creators of the system that a Royal Commission finding calls for 'co-designing' involving older people. And the call for 'co-design' is not simply about giving older people a voice or sympathetic ear, it's using their involvement to drive the design of improvements to the current system. There should be clear traceability that their requirements are reflected in the implemented changes. The real performance metrics for the co-design process are not the number of workshops held, the number of older people who attended etc. Instead, they will relate to the requirements captured (volume, coverage) and requirements implemented."*

Two people summed up the benefits of a genuine co-design initiative, for everyone involved:

> *"Proper co-design and engagement with all parties should ensure a marked improvement over time. Letting the older person participate in co-design should result in better care delivery and life satisfaction for the older person. It should also assist with reducing the fear factor and negative press around aged care."*

> *"I have been involved in co-design activities and at their best they are useful and meaningful for all those involved. End users feel valued and empowered and are more likely to value and use a service or product they have helped design"*

The key lesson to be learned from the survey respondents' views of how the co-design process might work is that it must be crafted thoughtfully in a way that will enable seniors to have meaningful input and genuine decision-making power. Those surveyed were attuned to the likelihood that they could be consulted and subsequently ignored, and they rejected that possibility unequivocally.

Older Australians recognise that co-designing anything is not necessarily a straightforward task. At the same time as recounting their visions for it, some respondents raised issues they felt were practical challenges to implementation, including:

- How to ensure a substantial, representative number of older people would be involved.
- How to define "older people" for this purpose, for example relative representation of current aged care system users versus future users of the system who have not yet experienced it first-hand.
- How to adequately represent the diversity of older Australians.
- How to manage potential conflicts between parties with different needs, different opinions, different vested interests or different expectations of co-design.
- What the best methods are for gathering older people's views.
- The amount of power and control older people would be granted to make change in a co-design process.
- The complexity and magnitude of the undertaking inhibiting its chances of success, especially if, in the words of one respondent, the *"very hard work of listening, exploring, consulting, negotiating and genuinely engaging"* is to be accomplished.

These challenges show it will be important to communicate about the practical aspects of the co-design strategy if it is to be successful, and that older people will not be placated by rhetoric or vague ideals. To be effective, communication about a co-design process will need

to demonstrate how it will work, how it will represent the diverse community of older Australians, and how its results will be implemented in real terms.

Older Australians want to have a voice that is listened to and acted upon to improve the aged care system. Sincere co-design initiatives would be heartily welcomed by this community.

Activities to improve the aged care system

In NSSS-9 we asked a practical follow-up question to the question about co-design:

> *"If you knew your views about aged care would make a difference, what activities would you participate in to improve the aged care system in Australia? You can select as many options as you like.*
>
> - ☐ *Answering online survey questions*
> - ☐ *Answering paper-based survey questions*
> - ☐ *Telephone/video call interviews*
> - ☐ *Face-to-face focus group (with social distancing in place if necessary)*
> - ☐ *Online focus group (using zoom or other video calling)*
> - ☐ *Informal discussion in a group I belong to. For example; a community group, National Seniors branch meeting (with social distancing in place if necessary).*
> - ☐ *Testing out a product/website and giving feedback in person or over the phone*
> - ☐ *Discussing care needs with a professional who visits your home*
> - ☐ *Providing feedback from an older person's perspective at a health or care facility*
> - ☐ *I would not participate in any of these activities*
>
> *"Please tell us more if you would like to."*

A comment box was available for additional comments.

The distribution of the options respondents selected for this question is shown in Figure 5. A total of 4356 people (80.22%) selected one or more of the listed activities, with most selecting more than one (3143 people, 57.89%) and a small proportion selecting all of them (167 people, 3.08%). Overwhelmingly then, this cohort of seniors would like the opportunity to contribute to improving the aged care system and would be open to multiple means of doing so.

Figure 5 shows that completing online surveys was the activity participants were most likely to select (3598 people, 66.26%). This was followed by the substantially less popular option of completing paper-based surveys (1662, 30.61%). These results are unsurprising given all 5430 participants were completing a survey (NSSS-9) at the time they were asked the question, and most did so online. Different kinds of face-to-face conversations and product or facility feedback activities were the next most popular options (all selected by between 24.77% and 29.21% of survey participants). The least popular options were conversations mediated by communications technologies, with online focus groups selected by just 898 people (16.54%). About a tenth of those

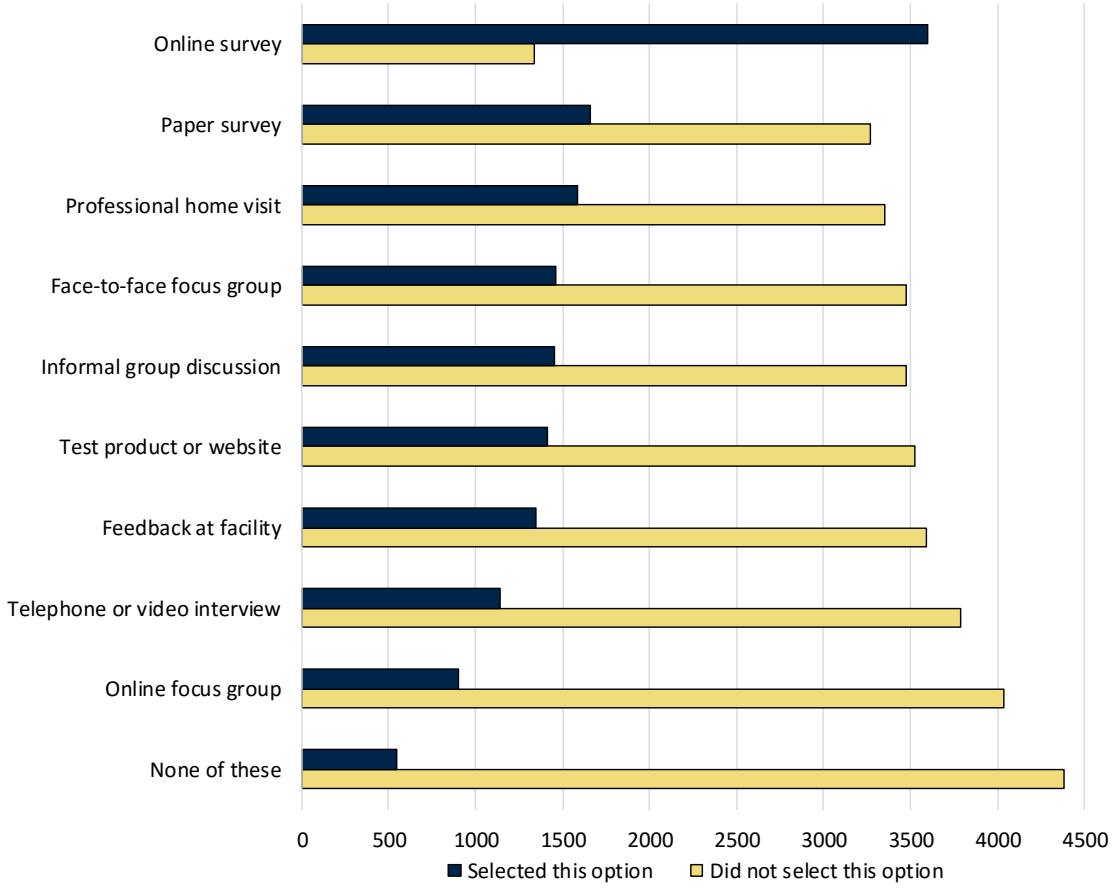

Figure 5 Activities respondents are willing to participate in to improve the aged care system, from most to least popular. For each activity, respondents were given the option to select it (dark blue) or leave it blank (yellow). The 496 respondents who did not select any option are excluded from the graph.

surveyed (514 people, 9.47%) selected 'I would not participate in any of these activities', while a further tenth (496 people, 9.13%) did not select any of the listed options.

A subset of the survey participants wrote a comment in the comment box (503 people, 9.26%), including some of those who did not select any of the activities. As with responses to the co-design question, comments ranged over diverse topics, but a few common themes were apparent.

Over 100 participants offered thoughts on the limitations or benefits of activities we listed, shared their previous experiences with specific activities, and/or made suggestions for additional activities they thought would be beneficial. A few expressed disappointment that the options given in the question did not include co-design methods:

"Where's the joint decision making option? Surveys are generally a waste of time, with answers determined via tunnel vision format questioning."

"All help, but not a lot... as none are really codesign. I and most of the people I talk to would participate in codesign. Because there are no great aged care services at the moment it's not really possible to point at something we want. Providers need to work with us so that we can be part of imagining, designing and testing new services. All of the above operate in the current paradigm and risk just trying to improve the unimprovable."

"I would be interested in a questionnaire, more "Co-Design" based, so that an expression can be heard/read. Rigid forms, (Yes/No or question with limited answers), keep things on the same path instead of improving the situation being looked at."

Others also flagged problems with methods that allow only predetermined responses:

"Survey questions are no good as they miss too many options"

"Survey questions need multiple answers and explanations - and the chance to explain which answer I give"

"I would do most of the above but hesitate because the answers are not black and white and surveys are an easy way of getting the answers you want."

"I am suspicious of focus groups. From my experience they tend to be run with an agenda to achieve a predetermined outcome."

As with the co-design question, a substantial number of respondents expressed cynicism about their views being listened to and acted upon. While general demoralisation was the most common reason given for this, some people noted that having perspectives others consider marginal was another reason, for example, one person said: *"As a transgendered person, my particular views and circumstances are not often heard."*

Other identified limitations of the listed activities included:

- Poorly chaired discussions can allow dominant voices to take over. Some respondents felt group discussions in general may have this effect too, compared to one-on-one interviews.
- Interviews and focus groups may be limited by people not having much to contribute since *"People don't know what they don't know".*
- Online discussions can be less personal than face-to-face discussions.

Features that respondents wanted to see in co-design or consultative methods included:

- For some, methods that enable face-to-face conversation. For others, methods that allow them to contribute a considered response in their own time, such as a written survey.
- Methods that enable two-way communication, i.e. opportunities to ask questions as well as giving views.
- Careful facilitation of any group discussions.
- Including an independent person in discussion forums, boards and committees to prevent *"blinkered"* views from predominating and pre-existing *"barrows"* from being pushed.
- Methods that ask for input before proposals are begun and that continue into the future, rather than being one-off.
- A guarantee that views would be valued and acted upon, and a process of reporting back on outcomes to everyone who participates in the activities.
- A requirement for endorsement of proposals by those affected before putting them into effect.

Alternative ideas respondents proposed included:

- Initiating targeted discussions about aged care policies and proposals at local groups seniors are involved with such as National Seniors branches, U3A, dementia support groups, technology training workshops, retirement village meetings and visitor schemes designed to combat loneliness among older people.
- Enabling direct input via government-appointed bodies and other recognised authorities that include seniors as members, and giving them control over decisions.
- Undertaking systematic feedback regimes that target facilities and services across Australia and comprehensively survey their clients and/or review the organisations' operations.
- Introducing a TripAdvisor-type online review system for aged care facilities and services.
- Providing feedback at aged care facility open days or during home care package communications.
- Acting on existing data and knowledge drawn from previous studies and from models implemented successfully in other countries.
- Campaigning for change via petitions, voting and political lobbying, though some respondents shared their experiences of trying these in the past and felt they were not effective.
- One person suggested creating *"a network of Aged Care Advocates all around the country, who report to an Aged Care Ombudsman on issues raised by residents in aged care. The Ombudsman would report to Government against criteria identified in the Co-design process."*
- One person suggested *"politicians and other policy makers anonymously stay at an aged care facility for a fortnight to test the conditions personally."*

- One person mentioned direct protest, i.e. *"stand[ing] on the steps of Parliament House in Canberra waving a placard"*.

In addition to these suggestions and considerations, over 80 responses signalled accessibility issues for the activities we listed in the question:

- Physical illness, mental illness and physical disabilities can prevent people from committing to activities in advance or at all. Specific points people raised about conditions that would need to be accommodated include the inability to sit on regular chairs, being wheelchair-bound or reliant on a walking frame, hearing difficulties, tracheostomy, noise sensitivity, anxiety and depression.
- Some people remain concerned about COVID risks.
- Declining mental capacity can inhibit some people's ability to understand and respond to questions.
- Time is a major limitation for many seniors if they have care responsibilities, paid work, family or community obligations or indeed all of these.
- Geographic distance can prevent people from attending activities in person. This is true for people living in regional and remote areas and for others with limited travel options, the inability to drive at night or dependence on public transport.
- Poverty can limit travel and involvement. Several people said they would need monetary compensation to participate.
- A lack of confidence in communications technology can inhibit people's involvement. This includes limitations to individuals' technological abilities, unreliable phone or internet services, and concerns about online security and privacy when using platforms such as Zoom. Some respondents were also concerned about telephone security, being hesitant to answer unknown callers because of potential scammers.
- Trust in the process was frequently mentioned as a determinant of whether or not a person would become involved in these activities. Seniors want genuine processes that will give them plenty of time and space to speak, that will demonstrate that their views have been heard, and that will lead to action, not merely an opportunity to air views. Respondents also mentioned needing to trust the organisation facilitating the process.
- Some respondents seek communication in everyday language or more access to information about the aged care system to be fully involved in discussions about it.
- The presence of aged care providers during discussions would inhibit some people's ability to speak freely because of fears about reprisals.

These points suggest that it is important to offer seniors multiple avenues for involvement to ensure everyone has the opportunity to participate, since needs differ. As for the co-design question, some respondents enthusiastically embraced the possibility of being involved in making improvements to the aged care system, and just need the opportunity:

"If I thought for a moment that my opinion was needed, valued and acted upon, I would happily participate."

"I am keen to change the system"

"Anything to help"

"Happy to be significantly involved in any of these activities."

"I would like to help in any way I can. I would be happy to volunteer in some aspects"

"In recent months, part of me wants to stand up & be an advocate for Aged Care/Retirement Living, but until this survey, felt that no one would be interested!"

"We have to speak up because the needs and desires of every person is different."

Finally, over 60 respondents volunteered information about existing expertise they wanted to bring to the table. This included:

- Past experience and current involvement in activism, advocacy and public education about issues important to seniors.
- Past and present experience working in aged care service provision, aged care policy, health care, public health, health management, health communication, the disability sector, government service delivery and other relevant fields.
- Past and present experience volunteering at aged care facilities in various roles.
- Past and present experience as active members of boards, committees and advisory groups in aged care and other sectors.
- Past and present experience as a researcher, including in aged care research, health research and qualitative social research.

The expertise and experience seniors have to offer extends to the high level of engagement many have with the issues at hand, through being an aged care system user or family member, or simply by being part of a community of engaged older Australians:

"As I am part of groups of similar ages, this conversation is had often and thrashed out as many have experiences through visits, friends, family in the Aged care system."

"We already discuss these matters at National Seniors Meetings and amongst friends."

These responses show that seniors should not be thought of only as affected people who must be consulted, but as a ready potential pool of experienced, knowledgeable people who can play an active role in eliciting and analysing community views and in implementing change.

Uncertainty about co-design

A major trend to emerge from the survey responses was that co-design means little or nothing to many older Australians. A large proportion of those surveyed were unsure of the meaning of the term or were sceptical about its application in the real world. This is not surprising, but these kinds of responses highlight issues that must be addressed when initiating a co-design process.

One third of survey respondents expressed uncertainty about co-design (1859 responses, 34.24%, Figure 1). Just over a quarter answered the co-design question by simply stating *"unsure"*, *"I don't know"* or similar without further elaboration (1506 responses, 27.73%). As we discuss below, respondents expressed a few different kinds of uncertainty, so we cannot say definitively what those who just said "unsure" or similar meant exactly. However, it is likely that many of them were not sure how to interpret the term "co-design". Some respondents who we placed in this category did say specifically things like *"this term is new to me"* or *"I don't know what co-design means"*.

A substantial number expressed some uncertainty about the question while also giving insights into their thoughts about it (353 responses, 6.50%). The largest portion of these were people who hadn't heard the term but guessed at its meaning. Another group said they were unsure about co-design but went on to offer their views on different aspects of the aged care system. Both these kinds of responses were included above in our analyses of what co-design means to seniors.

Two other groups of "unsure" respondents answered the question in different ways. One group said they were unsure what governments or other authorities might mean by the term "co-design". It was not clear if the respondents themselves were also unsure of its meaning. This group was generally quite cynical about the term, with many respondents branding it *"weasel words"* or similar (discussed further in the next section). The final group of "unsure" responses was made up of people who interpreted the question as asking about the meaning of "co-design" for their personal aged care choices. They gave different kinds of reasons for saying they were unsure, for example that they hadn't thought about it very much or hadn't got to the point of making such choices yet. It was not always clear if they were also uncertain about the term "co-design" itself.

Even amongst responses we did not classify as being "unsure", many people expressed other kinds of uncertainty. For example, some respondents who seemed comfortable with the term "co-design" remained unsure about how it might be applied to the aged care system in practice. Other respondents hinted at uncertainty about the term's meaning, for example using phrases such as *"I assume it means…"* or *"I guess it refers to…"*. Given this,

there may have been still other respondents who did not indicate they were uncertain of the term's meaning but were nonetheless guessing at it.

Altogether, this high degree of uncertainty among survey respondents tells us that a lot of older Australians are baffled, sceptical or unconfident about the concept of co-design as it applies to the aged care system. If the Royal Commission's recommendation is to be acted on, one of the first steps should be to communicate about the idea of co-design in meaningful ways that all older Australians can understand and relate to. They can then feel confident to discuss it themselves and, ideally, to participate in co-design processes.

Cynicism regarding co-design

A sizeable group of 405 survey respondents (7.46%) primarily expressed doubts about how co-design of the aged care system could work in a practical sense, or cynicism towards the possibility that an effective co-design process would be implemented in the near future. Note that these figures do not include the substantial number of respondents who shared their negative views of the aged care system itself or expressed cynical views towards past and present governance and consultation processes as discussed above.

At the most basic level, about 100 people expressed their feelings of cynicism or doubt about co-design simply. Some of them made comments such as:

> *"Sounds a good idea but how would it – practically – work?"*
>
> *"It simply means that older people should have a say. It doesn't indicate how we should do this."*
>
> *"I would not know where to start trying to co-design the aged care system."*

Others among them queried whether specific elements of co-design would be possible in reality, sometimes expressing strong cynicism about this. We incorporated their concerns into the discussion about *how* co-design might work, above. A few respondents queried *what* aspect of aged care the co-design was intended to apply to (e.g. care plans or buildings, individual or general levels), and felt unable to comment further until the parameters were defined.

For 55 people, the term "co-design" seemed a major source of alienation and discontent. This group was dominated by respondents who expressed uncertainty about co-design, as discussed above, whether they didn't know what it meant themselves or didn't know what the government or the Royal Commission meant by it. They used a range of descriptions to express their frustration with the term, including *"weasel words"*, *"buzzword"*, *"government waffle"*, *"polly-speak"*, *"Newspeak"*, *"bureaucratic jargon"*, *"gobbledy gook"*, *"politically correct bullshit"* and more. While in some cases this may represent annoyance at unclear communication, many of these phrases also imply cynicism towards the reasons governments and others may use such terminology.

Indeed, 66 other respondents directly asserted that governments use terms like "co-design" as obfuscating language, *"lip service"*, *"spin"* or *"empty words"* to give the impression that they would take action when they would actually do little. Views expressed along these lines included:

"Co- Design means the Government tell us what we can get but we get to decorate it."

"Government wants older people's involvement so they can rubber stamp their decisions and involvement."

"It means having your say and being ignored"

"It means making suggestions to an enquiry of some sort knowing that they will come to nought"

"I believe that from my experience with my brother I could identify areas that need urgent improvement, but i believe that from previous involvement in these 'consultations' nothing but the preordained solution will be enacted."

This kind of response was part of a group of 239 responses (4.40%) that were the most deeply cynical about the possibility that genuine co-design would occur. Responses in this group covered a range of interrelated concerns about the motivations and interests of government, and to a lesser extent the motivations of aged care service providers and the Royal Commission. In about a quarter of these cases people simply expressed pessimism that anything would ever change in the aged care system or under the current Australian Government. Others articulated more specific concerns, sometimes expressing more than one concern per response. The point noted above – that what is touted as co-design will in reality be a tokenistic exercise – was the most commonly expressed concern. The second most common concern was that Government and aged care service providers are primarily interested in money, so any proposed options that cost them are unlikely to be acted on, including a co-design process itself if it is expensive:

"It is a political term designed to make people think they are listening to but in effect only money and costs will count."

"This is a great recommendation but when it comes to the $$$ co-designing involvement will be ignored."

"No co-design exists at present, it's all for profit and has been for years. This will make co-design hard to work / trusted by general public."

Other concerns included that most Royal Commissions are expensive but have no material impact because governments don't implement their recommendations, that historically governments have not acted on the outcomes of other consultation processes, and that there is a general lack of will in government to follow through talk with action:

> *"To me the Royal Commission is a waste of resources especially in today's climate as so many have made recommendations that have been swept under the carpet."*

> *"Means another report going no where and in another 5 years another will be done with the same result."*

> *"Honestly, it is a load of bunkum. There is a lot of talk but nothing eventuates*."

Some respondents expressed the concern that talk about co-design is a stalling tactic to delay or obstruct meaningful action, or it is a strategy to pass the buck, to put the onus for action and responsibility for failure on someone other than government:

> *"Is 'co-design' just the usual meaningless speak to pacify voters and delay doing anything to resolve the issue."*

> *"My understanding of 'co-design' is an opportunity for others to play the 'blame game' if the situation should warrant such a facility."*

For some, radical change is required before co-design could work:

> *"Co-design just means we will have some input, what needs to happen is to go back to the drawing board & start again, with a caring patient/person centred system that is about looking after people not profits"*

> *"before any co-design can take place there needs to be systemic change. Aged care is a service not a commodity".*

Finally, and perhaps most dishearteningly, some felt that the Government does not care about older people and simply is not interested in listening to them or acting in accordance with their wishes:

> *"It suggests we can become involved in improving the system. Sorry, but I think it's all a bit of 'fluff! The current coalition government doesn't give a rats about us. Morrison would prefer it if we just all crawled away and died."*

> *"It wouldn't make any difference in what we say, the government won't listen to us"*

> "*Co-design means improving the system together, although I have no confidence in 'the powers that be' will take any notice, or act accordingly with the people concerned."*

"I think I understand the term, but can't see anyone being interested in the opinions of ordinary old people like me let alone taking advice from us"

"It probably means that the people who need aged care should have some say in the nature of that care. This is far too revolutionary an idea for governments to take seriously."

These cynical responses indicate that many older Australians harbour feelings of profound disempowerment regarding both the aged care system and ordinary people's ability to create change. They remain unconvinced that a genuine co-design process could happen, or they believe that any such process would not be meaningful if administered by the Australian Government.

If there is genuine political will to implement a co-design strategy for transforming the aged care system, carefully addressing these reasons for doubt will be critical to build trust. Trust is hard won and easily lost, but it will be a crucial part of any co-design process if older Australians are to feel they can contribute to it in good faith and that their voices will be heard.

Conclusions

This survey has shown very clearly that older Australians support the idea of seniors co-designing improvements to the aged care system. Many of them would like to be personally involved in this, to bring their preferences, insights, expertise and innovative ideas to the table as equal partners with other aged care stakeholders. It is clear that a market-based solution to aged care problems, whereby individuals choose between existing services and avoid providers with bad reputations, is not enough. Senior Australians want change, and they want to co-design it.

Consumer sentiments and opinions are now a routine element of business planning, sometimes derived from simple questions and methods. In political and policy areas the methods can be coloured by dominant voices, activist groups, and formal positions of organisations. These biases need to be controlled or overcome if we are to use co-design effectively. In the case of aged care, that means bringing in the voices of diverse older people.

The fact that in this study over 4500 respondents freely chose to write text in response to an optional co-design question in their own words is a surprising result. Even those who had little idea of what co-design was often wrote extensive comments indicating a yearning for engagement with the reform of Australian aged care. Older Australians are acutely aware of problems with the current aged care system and where improvements might be made. Without necessarily naming it, they are also aware that ageism underlies many of these problems, including the assumption that older people are not capable of managing their own lives. In opposition to this, they seek to assert that they do have the capacity to make decisions about their own lives and about the aged care system in general.

The older Australians surveyed were generally modest in their expectations and a vocal minority were cynical or negative. Such comments are worthy of consideration to maximise seniors' engagement and to address their concerns through better communication. Critically, the range of sentiments and opinions that seniors express must be carefully recorded and heard to ensure that important, minority views are not buried in majority or "leader-preferred" views. Such fresh ideas can provide useful pathways into creative possibilities. Ideally, they should be incorporated into a reimagined aged care system, in line with the expectation that genuine co-design involves action and accountability not mere consultation. Co-design experts and the older Australians surveyed share this expectation of co-design.

Older people are known to undervalue their potential contributions and understate their knowledge and skills in policy areas. This is one manifestation of internalised ageism. With the anonymity of a textbox completed in a private, safe, home environment, their insights

can be brought into the public domain. This technique has been effective in this investigation and efficient in dealing with large numbers of views. This allows a strong base of opinion and ideas to be considered when providing advice, instigating policy changes and informing implementation strategies. These methods may be first steps towards co-design of aged care by senior Australians, acknowledging the complexities that true co-design entails and that a co-design process will always be ongoing, never one off.

A Council of Elders to inform the Australian Government about matters relevant to seniors will incorporate the experience of member elders themselves but will also benefit from access to broader views in the population. Any true co-design process must meaningfully incorporate those broader views, since co-design is intended to empower those who are most affected by the system in question. The seniors surveyed reiterated this principle, that users of the aged care system should be at the centre of any decisions about that system. If Australia is to meet the aspirations outlined in the Royal Commission's Report as supported by the Australian Government, the views of these "quiet Australians" need to be brought into the public space so they may have a material impact on an aged care system that is in desperate need of change, as declared by the Royal Commission.

The report identified the need for co-design of the aged care system at several different levels. Co-design will manifest differently at each level, with the *how* of co-design tailored to suit the *who*, *why* and *what* of each context. For example, the survey showed that:

- Co-design is required at the *individual* level, for every senior to have choice and control over their own care plans, accommodation, transitions and supports, given the immense diversity of needs and preferences present within the community.
- Co-design is required at the *service* level, for system users to innovate appropriate service options and types, including attention to key traits such as locations, staffing levels, procedures and provisions.
- Co-design is required at the *facility* level, for aged care residents to be involved in designing spaces and places that enhance safety, accessibility, privacy and comfort for every older Australian.
- Co-design is required at the *policy* level, for senior Australians to be actively involved in developing new reform initiatives, new legislation, new funding frameworks, and more, for the aged care system as a whole.

These are examples, but genuine co-design would open the conversation widely to incorporate the full breadth and depth of the aged care system. This report is not a roadmap for co-design; it is the starting point for enabling Australian seniors to draw such a map. If co-design starts with seniors' visions of how they want to live as they age, rather than starting with the status quo, who knows what directions that road will take us.

Appendix A: National Seniors Social Survey 9 demographics

The NSSS-9 collected a range of demographic details from survey participants. We present a selection of those demographics here to characterise the survey sample and contextualise the responses.

Some participants did not answer every demographic question, so the total number of participants for each question varies.

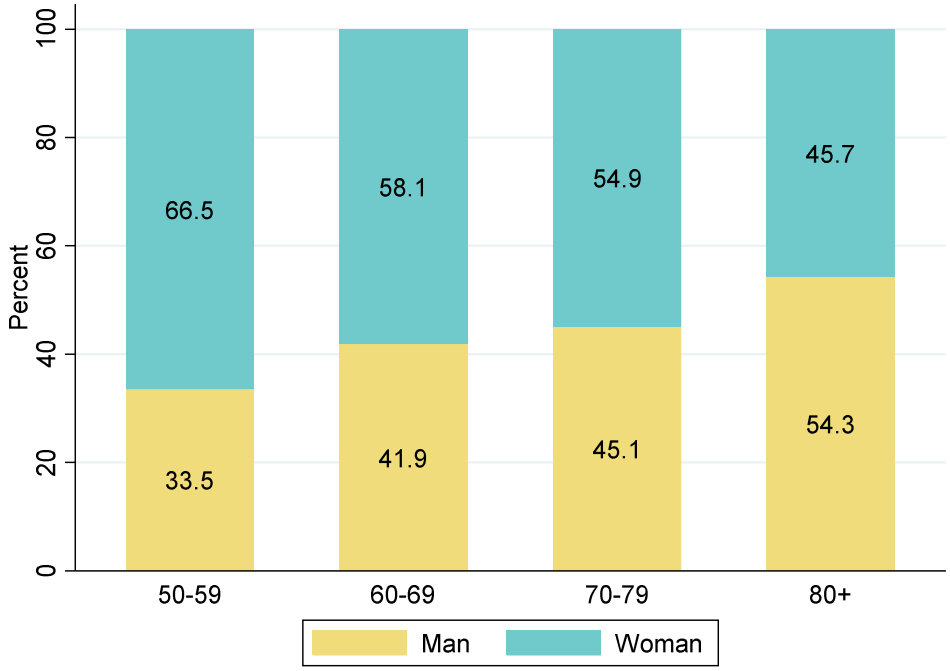

Figure A1. Age group proportions according to binary gender (n=5297).
Non-binary and other gender participants are not graphed because of small numbers.

Gender distribution for the whole survey sample (n=5430):
54.88% women; 44.03% men; 0.06% non-binary; 0.06% other gender;
0.26% preferred not to say; 0.72% did not answer the gender question.

Age group distribution for the whole survey sample (n=5430):
6.06% 50-59 years; 31.88% 60-69 years; 45.91% 70-79 years; 14.33% 80+ years;
1.82% did not answer the age question. The oldest participant was 102.

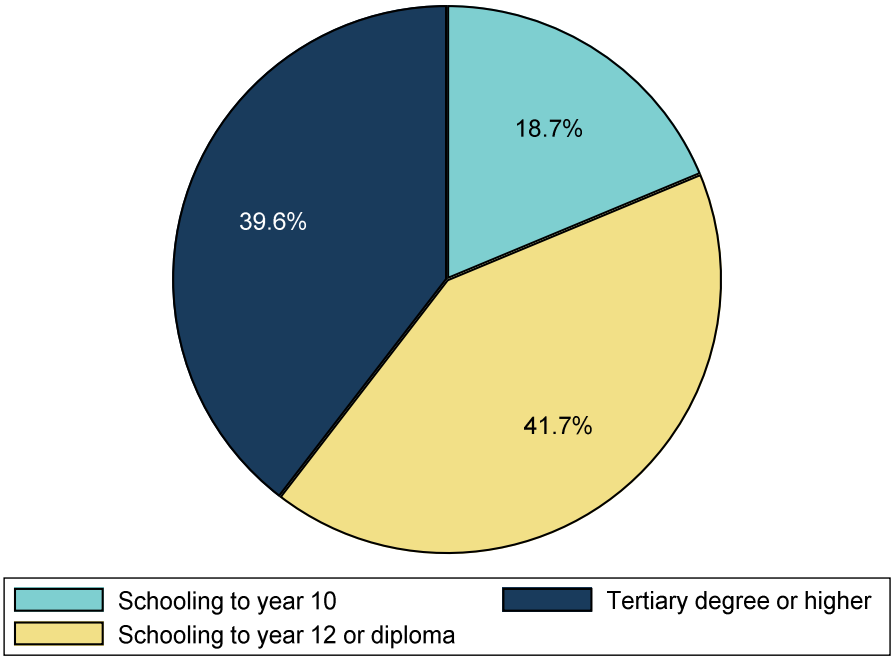

Figure A2. Participants' formal education level (n=5124).

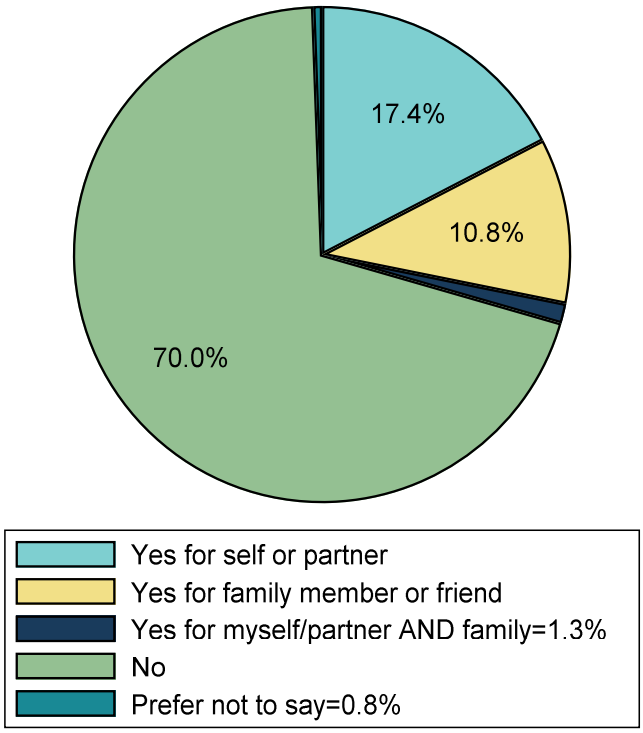

Figure A3 Whether participants accessed aged care services in the previous 5 years (n=5259).

Appendix B: Australian co-design case studies

This appendix includes case studies in which Australian seniors have been involved in co-designing an aged care service or facility. Each was provided by a member of the EveryAGE Counts Coalition Steering Group. They highlight different ways that co-design of the aged care system might manifest, and lessons learned for future co-design endeavours.

Case Study 1: ECH LGBTI Connect Service

David Panter, ECH Chief Executive

ECH is a not-for-profit provider of independent living, home care and wellness services in South Australia. Five years ago, we made the decision to look at how we could enable our services to be more accessible to older members of the LGBTI community. To do this we undertook a co-design process with members of that community. This required us to approach the community with a 'blank sheet' and not a set of ideas we had already come up. Presenting our own ideas would have been, at best, consultation not co-design.

In the first instance we worked with a group of volunteers from the community who were identified by word of mouth and social media (there are no LGBTI venues or publications now within South Australia through which we could advertise directly for participants). This group of about 15 people participated in a number of workshops over a period of time facilitated by our Diversity Manager. No other ECH staff participated. This created the space for participants to identify, from their experience, the challenges they faced in utilising aged care services. Having identified the issues, they were encouraged to turn their minds to solutions. These issues and potential solutions were then tested out with other LGBTI elders through publicly advertised events and gatherings, for example, running a session as part of FEAST, Adelaide's annual queer cultural festival. This enabled ECH to get a sense of which issues and solutions resonated with the community. Whilst many concerns were raised through this process about services being culturally appropriate and safe for LGBTI elders to use, the overwhelming issue was one of anxiety about actually getting into the 'system' (for example, using My Aged Care) because of how LGBTI community members would be perceived and reacted to.

Having arrived at this point ECH needed to take responsibility for what we had heard and look at how we could respond to these potential solutions through our internal business case process. This led to the prototype of what became our LGBTI Connect Service. In essence this service employs, on a part-time basis, LGBTI elders (currently two lesbians, two gay men and one transgender woman) to undertake outreach work in the community. This is not a 'navigation' or 'finder' service, it is a service aimed at building trust and confidence

in the community such that people feel able and supported to take up aged care services. It is largely funded through our benevolent funds. This prototype was further refined and developed as part of the co-design work and currently 'connects' with several hundred LGBTI elders. The co-design activity continues under the auspices of the LGBTI Connect team and has subsequently prototyped further adjuncts to the service such as a specific LGBTI home-visiting scheme. It is currently designing a 24 hour 'buddy' volunteer system to provide support to the many LGBTI elders who live alone and have to face moments of crisis with no family and very limited social networks.

The creation of the very successful LGBTI Connect service – unique within Australia – was only possible because of the co-design process.

Case Study 2: Residential Care Accommodation in Strathalbyn SA

Mike Rungie, Global Centre for Modern Ageing Co-Director

In 2019 the South Australian Government Health Department, SA Health, commissioned The Australian Centre for Social Innovation (TACSI) and the Global Centre for Modern Ageing (GCMA) to co-design residential care accommodation for 40 older people living in Strathalbyn, South Australia.

TACSI and GCMA worked with over 180 participants, including older people in the community, people already in residential care, health professionals and community members. Those participants contributed their views through a series of workshops, interviews and a community forum.

Discussions focused first on older participants' current lives and what they would want to sustain if they became frail, building a co-understanding of this amongst all participants and also the TACSI/GCMA team.

Older people wanted to largely sustain their current lifestyles and wanted care that would enable this. Together they developed six design principles:

1. Home – not institution: Creating a sense of 'home' for any context where people are living.
2. Social connectedness: Enable meaningful connections with others and the places where people live.
3. Meaning and purpose: Maintain meaning and purpose in an individual's life.
4. Choice and control: Offer greater choice and control in how individuals can live their lives.
5. Valuing people: Value people, their experience and their contribution.
6. Transitions: Enable resilience and access to the proper supports that help people successfully navigate transitions.

TACSI and GCMA drew out of the co-design sessions descriptors for each of these design principles. This process acknowledged the need to deliver high levels of care, but also many examples of what people actually wanted in each of the six principles. All the examples were largely unheard-of in residential care. The design principles covered what kind of building would support people's wishes but also what kind of practices would be needed in the functioning service.

Sadly, the architect interpreted the design brief to be a conventional residential care facility with single bedrooms and a collection of modern communal spaces, and this was accepted by both SA Health and the planning requirements.

Still, the design brief is a strong example of what can be achieved with co-design and still stands as an exemplar of what residential care could become. The exercise also demonstrates the need for older people to continue to be involved through the co-implementation and co-operational stages.

More information about this case study, including detailed descriptions and examples of the six principles, can be found in the project report *Co-designing Aged Care in Strathalbyn: Outcomes Report*[8] and associated media coverage, available for viewing and download at the GCMA website https://www.gcma.net.au/case-study/sa-health.

[8] Mustonen V, McCabe A, Jones K & O'Brien B (2019) *Co-designing Aged Care in Strathalbyn: Outcomes Report*, Australia: Global Centre for Modern Ageing and The Australian Centre for Social Innovation.

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