

Older Australians' Sentiments about vaccination, and planning, financing and 'co-design' of aged care

National Seniors Social Survey (9): Report 1

19 March 2021

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The National Seniors Social Survey (9) was approved by the NHMRC accredited Human Research Ethics Committee of Bellberry Limited: APP 2020-12-1319.

This document is a 'first cut' on new national data and prepared for internal use only.

Suggested title: McCallum, J., Hosking, D. and Ee, N. (2021) *Older Australians' Sentiments about vaccination, and planning, financing and 'co-design' of aged care*. Canberra: National Seniors 19/3/21.

National Seniors survey research was supported by the National Aged Care Grants through the Commonwealth Department of Health.

Details of National Seniors Social Survey NSSS (9)

Respondents: 5,430 Australians aged 50 and over
Survey closure: March 1st the day the Royal Commission Report was released by the PM
Who were the respondents?
<ul style="list-style-type: none">• 68% of respondents were aged 65-79 and 15% 80+ - age groups who need care plans• As expected, the majority were women 55% and 44% identified as men• 75% rated their health as good or better• 60% were married or living with a partner• 15% widowed, 13% single, 12% divorced/separated• 38% had a bachelor's degree or higher• The majority of participants were from QLD (37%) with 23% from NSW and 16% from VIC. Other states represented 23% of the sample

Summary of results

1. The majority **86%** were likely or very likely to **get vaccinated**
2. About a third, **32%**, expected needing **future aged care**
3. Only **21%** were **considering options** for future aged care services
4. Constant **reports** of abuse and neglect **affected the care plans of 48%** of respondents
5. Only **4%** had **financial plans for aged care costs** but **13%** **didn't have enough money** to plan
6. The dominant **preference for government funding of improvements** in the aged care system was funding through **general revenue – 53%**
7. About a third said they didn't understand '**co-design**' but both **strong positive and negative sentiments** were expressed in *verbatim* comments by about 4,800 respondents
8. The dominant preference for participation in aged care reforms was in **online surveys** with *verbatim* comments – **66%**

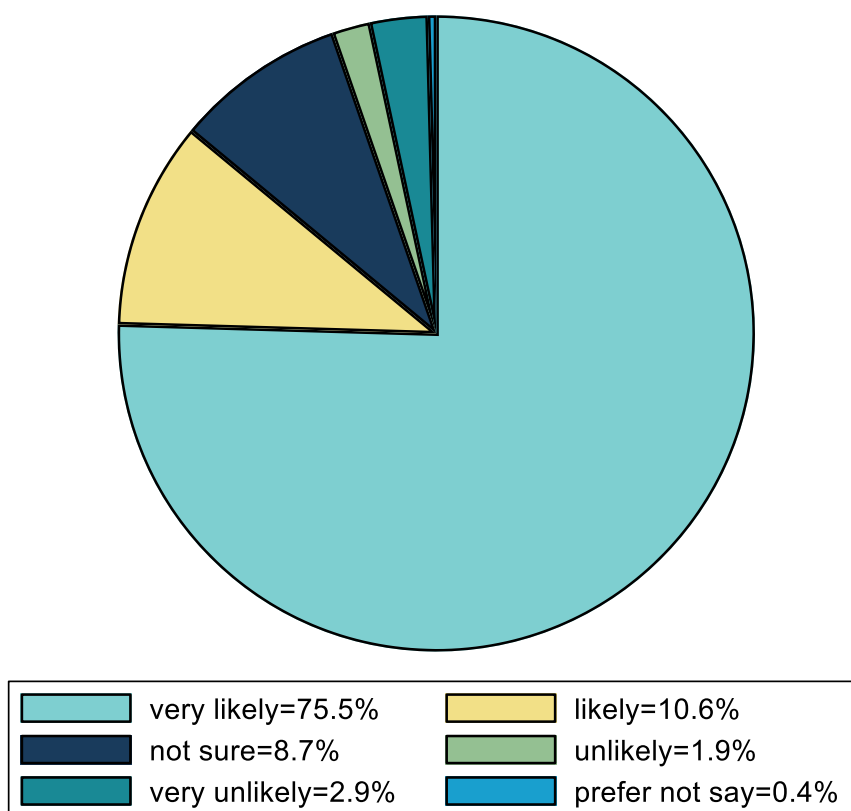
1. Intent to vaccinate for COVID-19

The final of our three reports reporting older Australians experiences during COVID¹ finished with the view: “Having done exceptionally well with strong leadership and excellent applied epidemiology, Australians now face the new task of coming out of ‘the valley’ of the pandemic. The medical and short-term social impacts of COVID for Australians can be expected to be minor compared to the economic, intergenerational, and mental health impacts expected to emerge in the longer term.”

It is worthy of note that two months later consumer sentiments appear more positive, perhaps boosted by the arrival of vaccines. In February 2021 we find that there was a very strong intent to vaccinate. Three quarters were ‘Very Likely’ and only five percent ‘Unlikely’ or ‘Very Unlikely’. The respondents here are not alone in these intentions and having a growing sense of optimism about life with COVID.

Question: ‘Now a COVID-19 vaccine will be available and approved in Australia, how likely are you to get vaccinated against the COVID-19 vaccine

*Figure 1. Likelihood of getting vaccinated against COVID-19
n=4498*

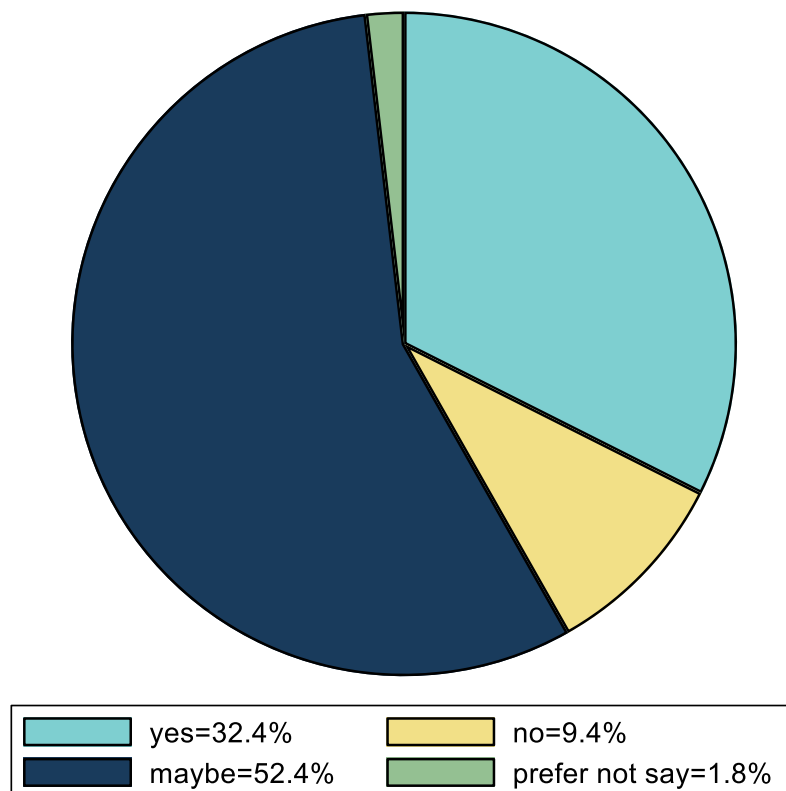


2. Expectations of need for aged care

We investigated to what extent do older people, and their families, expect to need aged care services as they grow older. Only a third of people in the survey expected themselves or spouse/partner would need age care, however another 52% indicate a ‘maybe’. Whether with optimism or denial, another 10% of respondents don’t think they’ll need it. These expectations suggest that people don’t have clear information on risk or don’t want to think about the sometimes distressing needs acquired in later life.

Question: Do you expect you or your spouse/partner will need age care services as you get older?

*Figure 2. Expectation of needing future aged care
n=5098*

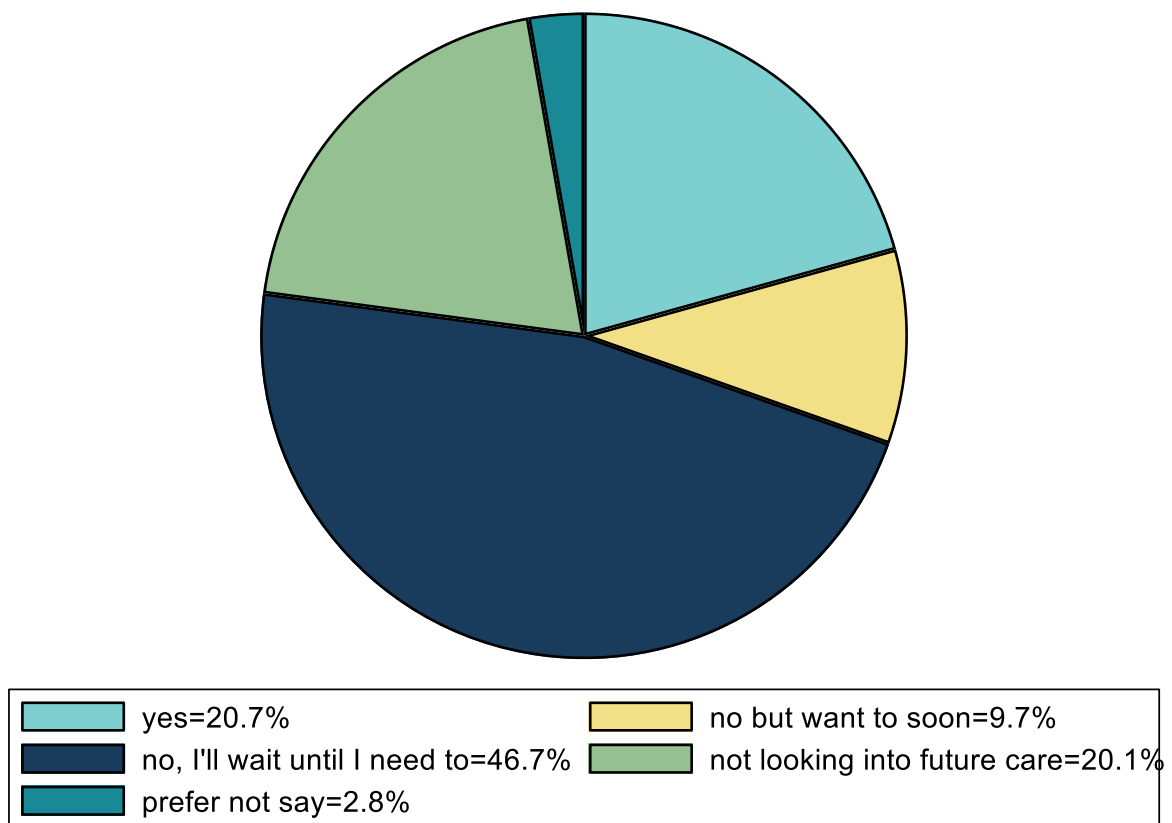


Next, we asked next if people were considering future needs for care. The dominant position was ‘I’ll wait until I need to’ with 47% choosing this option. On the positive side, a third either were looking into care options or wanted to do this soon. There were 20% who weren’t looking into future options.

There's been much academic and public discussion about the lack of interest in planning for a 'negative' future. Generally speaking, if people don't realistically 'own' their future states they aren't going to consider or plan for it.

Question: Have you looked into future aged care service options for yourself of your spouse/partner?

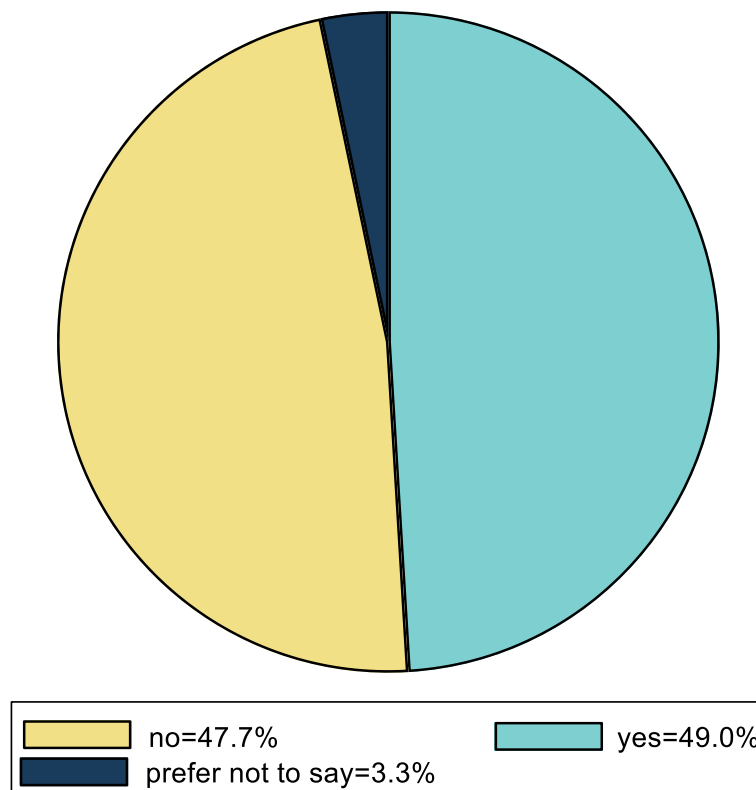
*Figure 3. Considering options for future aged care services
n=5203*



Older Australians sentiments about care have been significantly impacted by over 2 years of exposés of extremely negative events in residential care. The awful findings of the Royal Commission, amplified by the media, have provided a negative scenario for care planning. They have created an environment for denial of risks and avoidance of planning.

Question: Have the reports of neglect and abuse in the aged care system affected your aged care planning or decisions?

*Figure 4. Effects of reported abuse and neglect on age care planning
n=5147*



In previous surveys³ members have consistently expressed negative attitudes to planning for residential care. Recent direct discussions with respondents confirmed that this negative picture of aged care has translated into changing financial plans for residential care. National Seniors research² has found that older Australians don't consider home care as 'aged care' and don't give consideration to having to pay for it. It is therefore a cause for concern that half of all respondents were dropping financial plans for residential care but not necessarily planning for alternatives. The effects of this indicate the importance now of promoting positive images and stories about aged care.

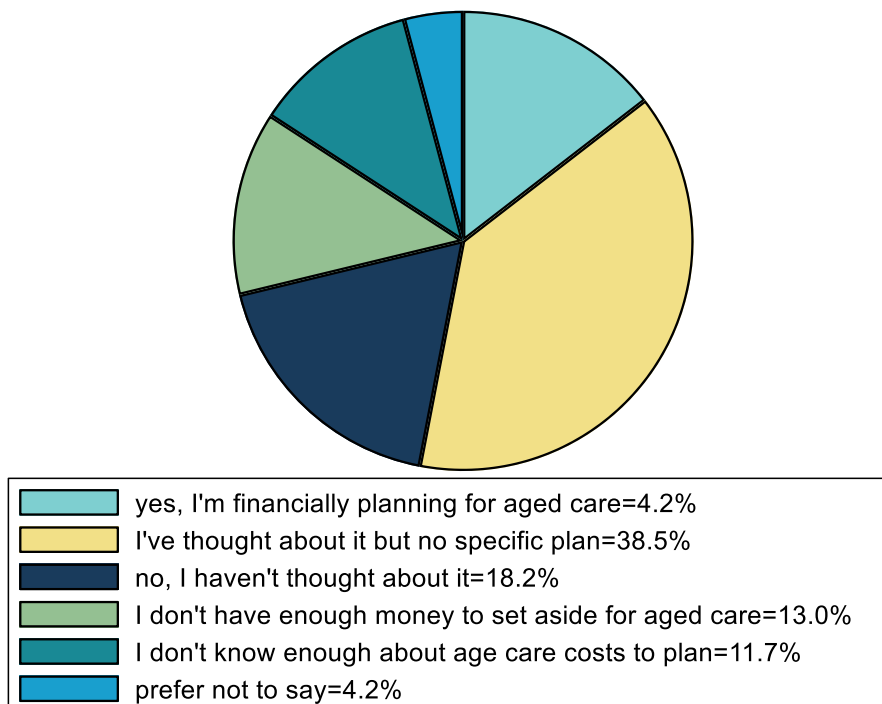
3. Planning for aged care costs

A National Seniors Report released February 2018³ found that 22% of survey participants ‘hadn’t planned at all’ for an increasing lifespan. Around 50% of all survey participants had made financial plans for living longer, 46% for health, 38% for lifestyle and travel, 35% had plans for accommodation, and a minimal 3% for care needs.

In the current survey we asked specifically about care planning. While still a low proportion, 14%, there were now more people planning of aged care than 3 years ago. It was still a lower proportion than those who honestly said that they hadn’t thought about it, namely 18%. The highest proportion was 38% for having thought about it but not made any specific plans. It is also notable that 13% revealed that they didn’t have enough money to plan for care and would, by implication be dependent on government support. Overall, three quarters who had the financial resources to plan hadn’t planned for their future care needs and 13% couldn’t plan without more money. Positive action could be taken with the 4 out of 10 who thought about but not done it yet.

Question: Have you planned for aged care costs? Aged care costs may be for either residential care or home care.

*Figure 5. Planning for cost of age care
n=5180*



4. Paying for aged care

National Seniors previously found that 8 out of 10 older people were willing to contribute to the cost of their care in later life according to their means to pay⁴ however times may have changed. Older Australians retirement incomes were recently in free fall due to an unprecedented convergence of negative trends in: savings interest rates, a flat stock market at best, negative to zero returns on Superannuation Guarantee (SG) balances, loss of bank dividends, less work, loss of rent on properties and business income in the crisis. All these factors have left many older Australians in a precarious financial position with far less money than they had previously to pay for aged care services and are likely to be more cautious with their spending.⁵

National Seniors' *Response the Royal Commission Consultation Paper 2*⁶ proposed various options for financing aged care services. In all service types, other than unpaid care at home, the impost on general revenue was predicted as large with a potential demand for substantial social insurance levies to generate revenue.

A Schema for Future Aged Care Mixed Funding Options

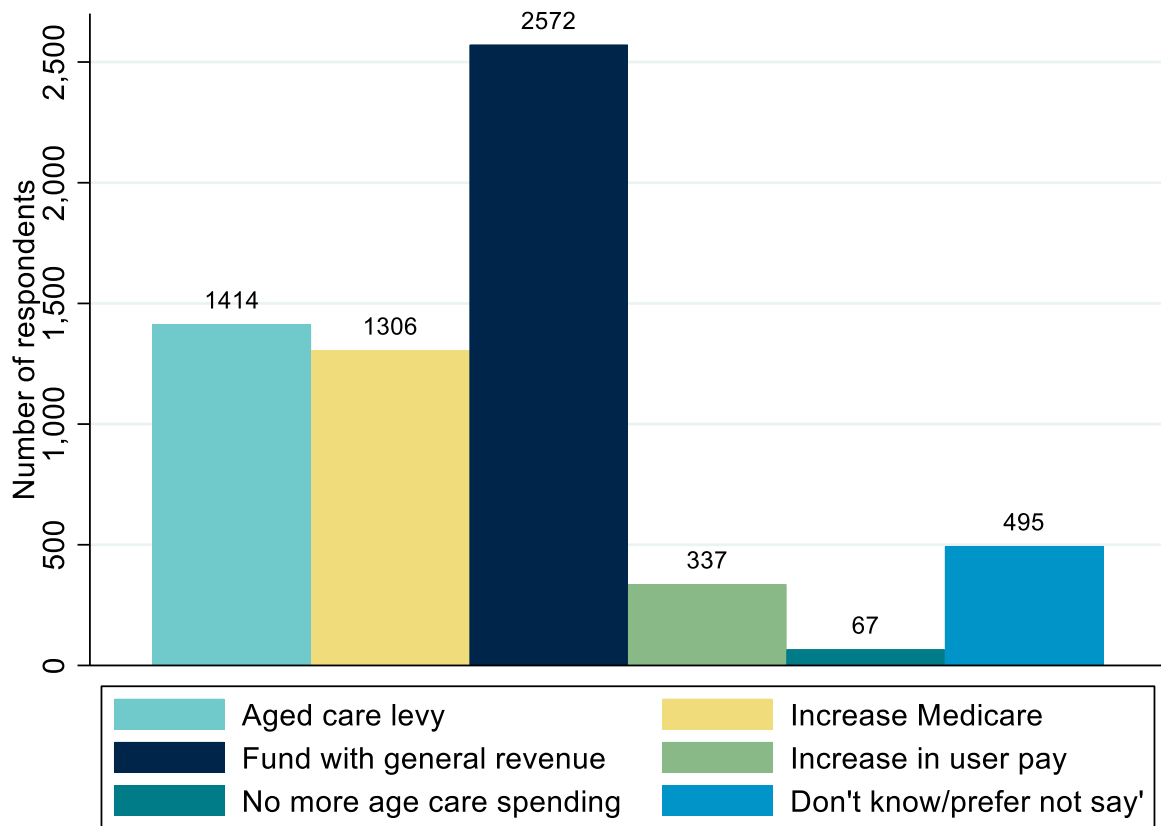
	Residential Care	Home Care	Unpaid Home Care
Government general revenue	large	large	minimal
Private insurance - optional	minor	minor	negligible
Social insurance - compulsory	large	large	negligible
User Contributions:			
RADs/DAPs	major	x	X
Pension loans scheme - optional	Not competing with RADs/DAPs	large	large
Deferred annuities - optional	minor	minor	minor

Question: 'How do you think the federal government should pay for improvements in the aged care system? You may select more than one option.'

RESPONSES (each item is out of 100%)

1. Funded through general revenue...**52.64%**
2. An aged care levy (similar to the NDIS)...**26.04 %**
3. An increase to the Medicare Levy... **24.05%**
4. Increase in user pay for aged care services... **6.21%**
5. I don't think more money should be spent on the aged care system... **1.23%**
6. Don't know... **9.12**

Figure 6. How Government should pay for aged care
n=5430



**participants could nominate more than one option*

These consumer sentiments are consistent with options put to the Royal Commission by various parties. The low 6% preference for ‘user pays’ is notable in the Budget context.

5. Understanding ‘co-design’

The Aged Care Royal Commission recommended that older people should be involved in co-design improvements to the aged care system. So, what is co-design? The NSW Health Agency for Clinical Innovation⁷ describes it as ‘a way of bringing consumers, carers, families and health workers together to improve services... Planning, designing and producing services with people that have experience of the problem or service means the final solution is more likely to meet their needs. This way of working demonstrates a shift from seeking involvement or participation after an agenda has already been set, to seeking consumer leadership from the outset so that consumers are involved in defining the problem and designing the solution. Co-design typically uses a staged process that adopts participatory and narrative methods to understand the experiences of receiving and delivering services, followed by consumers and health professionals co-designing improvements collaboratively’.

Since the concept is now widely used and recommended by the Royal Commission, we invited respondents to describe what they thought it was. This invitation elicited strong sentiments, positive and negative, about co-design.

Question: 'Can you please describe what "co-design" means to you? If you don't know or are unsure, please say so.'

One third of responses to this question contained words like 'unsure', 'had no idea' or 'don't know' but also added comments about what they thought. The range of sentiments provoked by the concept are evident in the following *verbatim* quotes:

- 1. Co-designing should be driven by those currently in aged care supported by family and friends. It is effective representation that sees actual changes made driven by lived experience. Personally, I still "don't know what I don't know" so I would have limited useful input into a co-designing process.*
- 2. I've attended many Conferences & Forums etc. put on by many different "experts" over many years regarding Health, advanced planning for Housing, Aged Care, etc. organised by many different Commonwealth, State, Private Groups etc. They have all been lacking in their understanding of the actual problems ... as they aren't directly affected themselves, they don't want to acknowledge the problems as then they'd have to actually do something about addressing what's happening. If you don't know what the issues are, how can you possibly solve anything!*
- 3. Sounds like government bullshit!*
- 4. I don't expect any help from government to achieve or even co-design my 'ageing my way' plan. In fact I've planned - since I was 50 - not to rely on government. On the other hand, I absolutely support the concept of the 'safety net' for those who fall between the cracks - and that they should be engaged in designing services that will deliver them security in all its forms. That's why I am happy to pay taxes. In the '70s my parents led the creation of a Catholic aged care home in their country town. It's a long story unsuited to this format - but that it was possible at the time is telling. Briefly, they were enacting the wishes of two of my father's childless elderly clients who left money in trust with him to partner with the church for this purpose - and fortuitously the government offered matched funding to set up facilities at the time. I think my father was prescient and clever about this. Many years later my mother spent her last 5 years there and chose to die a week after they moved her into a new building - as she said - over my dead body! As a resident she tried many times to get onto the management committee and even though she had been a town councillor (as well as a founder of the home) she was told she was not competent - bullshit! So, to co-design! 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!!!! In our current conceptual framework old people are done to - they do not do for themselves and, often, if they do they are considered variously - resistant, eccentric, deluded, stubborn, etc etc. However, despite the negative attitudes expressed above I'm willing to give it a go. But then I'm a privileged and powerful white woman with lots of capability and assets. I'm not the one who needs a voice, I wonder who will speak for 'others' in the co-design process?"

5. *I presume it means being given a chance to have a say, but I don't know how this would be done*
6. *There are plenty of "young old" and wise and articulate elders who could ably contribute to a new system but will the government fund improvements? As I said, I have worked in aged care for 40 years and have held senior management positions for 25yrs. I have seen many reviews and various campaigns - Living Longer Living Better in 2012 and the Productivity Commission review that was supposed to provide consumer directed care at home and thereby avoid admission to residential care. A dismal failure with elderly dying before receiving a CDC package or entering residential care. My own mother was already in residential care when 12 months later, she was finally offered a community care package. The Aged Care Roadmap in 2018 was another attempt at improving aged care but again, no funding to effect any improvements. For the past few years, the DoH has been working on sanctioning and closing down smaller providers and leaving only the bigger players in operation. I don't know that this is working either.*
7. *Unsure, but think it would mean organizations such as National Seniors, Social Services, church groups, Senior Citizens and individuals could submit suggestions and plans to the Commission.*
8. *"Co-Designing" - I don't know what it means! But I'll bet it's a FAT Word. Meaning its got lots of different meanings for lots of different people.*
9. *Unsure, of course, but... It would need to involve a range (age, gender, CALD, number of years living within aged care residences and family members with relatives/friends living or who have lived within aged care residences, members of for profit and not for profit 'homes', representative from the Seniors Rights Service - a family member works there -: in other words as close as possible to a truly representative group of stakeholders) of people with expertise and experience of involvement in the sector, working with skilled facilitators over a reasonable time-frame to explore possible follow ups to the RC.*
10. *I am unsure but presume planning for older persons to live together with care support services.*

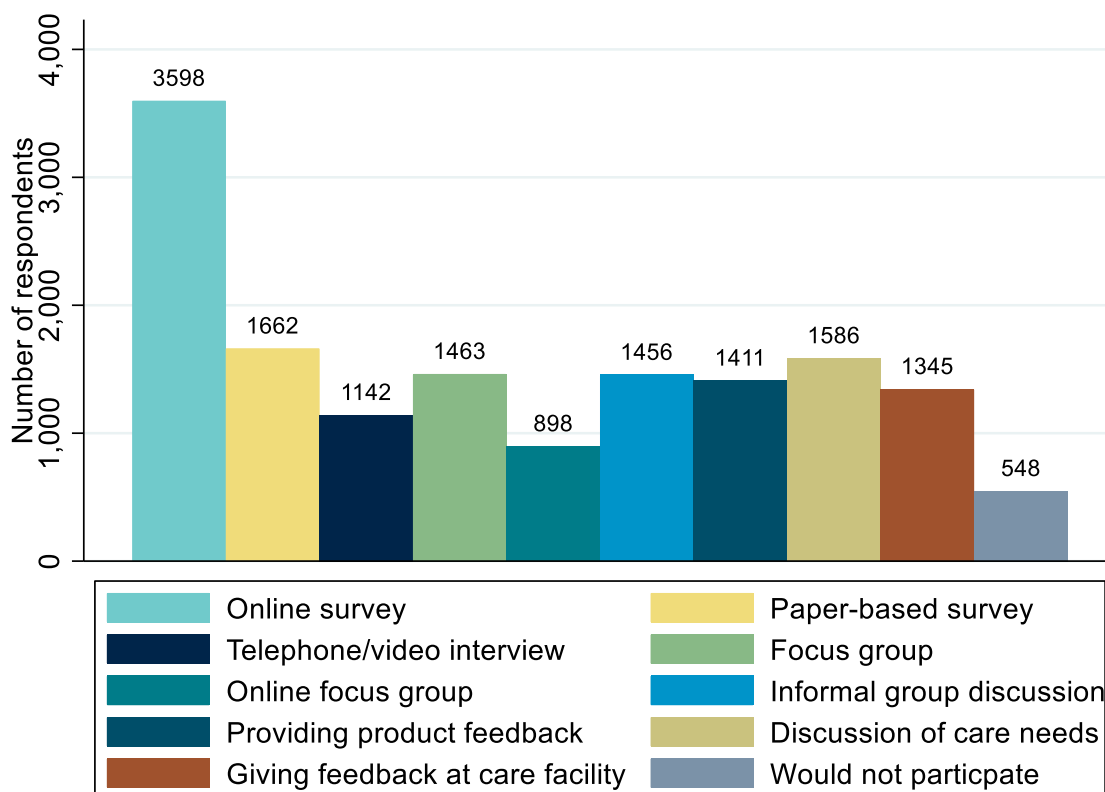
While it is unsurprising that many respondents didn't understand what 'co-design' meant, it was important in the context of Royal Commission recommendations to see that older people were engaged energetically with consumer participation in reform and expressed interesting versions of what that meant to them.

6. Preferences for participation in policy discussions

Given the sentiments and opinions for consumer codesign the preferences for participation in policy discussions were explored in the general population. This question had a high response rate in the survey and only 11% said they would not wish to participate in any of these activities.

Question: '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.

*Figure 7. Nominated activities by participants to help improve the aged care system (participants could nominate more than one option)
n=5430*



**participants could nominate more than one option*

RESPONSES (each item is out of 100%)

1. Answering online survey questions... 66.26%
2. Answering paper-based survey questions... 30.61%
3. Discussing care needs with a professional who visits your home...29.21%
4. Face-to-face focus group (with social distancing in place if necessary) ... 26.94%
5. Informal discussion in a group I belong to. For example, a community group, National Seniors branch meeting (with social distancing in place if necessary)...26.81%
6. Testing out a product/website and giving feedback in person or over the phone...25.99%
7. Providing feedback from an older person's perspective at a health or care facility
24.77%
8. Telephone/video call interviews... 21.03%
9. Online focus group (using zoom or other video calling)...16.54%
10. I would not participate in any of these activities...10.09%.

There is an expected bias for people answering a survey online to have a preference for that modality of involvement in system design. Regardless of this, older Australians desire direct personal involvement in appropriate discussions on the future of aged care services, as proposed in the Final Report of the Royal Commission. It is reasonable that the least intrusive and easiest modality for this, online surveys, was the top preference. Any such initiative would also need to accommodate people who prefer not to communicate on digital devices and other groups such as those who don't speak English.

7. Conclusion

The data presented here is a 'first cut' on elements of the survey which will be developed further with statistical analyses. Further areas in the survey will also be worked up, namely:

- planning for care needs
- technology use compared with use before the pandemic NSSF 7
- well being states compared with NSSF 6
- views on end of life choices
- current community issues, and
- finance and money matters.

All reports will be published and made in the public domain through National Seniors website.

6. References:

¹ Ee, N., D Hosking., Maccora, J., McCallum, J. *COVID-19 (3): Evolving Concerns of Older Australians*. Canberra: National Seniors 30/11/20, p 28.

² McCallum, J., Rees, K. & Maccora, J. (2018). *Accentuating the positive: Consumer experiences of aged care at home*. Brisbane: National Seniors. Published 30/4/18.

³ McCallum, J., Maccora, J., & Rees, K. (2018). *Hope for the best, plan for the worst? Insights into our planning for longer life*. Brisbane: National Seniors. Published 1/2/18

⁴ *Legislated Review of Aged Care 2017*, Department of Health: Canberra. p. 10.

⁵ McCallum, J., Ee, N., Hosking, D. (2020) *COVID19: Self-funded Retirees distress*. Canberra: National Seniors 2/09/20.

⁶ National Seniors' *'Response to Visions for Aged Care Consultation Paper 2 'Policy development from the base up' (4/8/20)*,

⁷ Agency for Clinical Innovation, *Consumers and staff coming together to improve healthcare*. Version: V1; 0289 [08/19] Date amended: August 2019.

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1. *Witness Statement* 31/1/19;
2. *Review of recommendations of prior reviews that were not implemented* 6/2/19;
3. *The dementia journey legacy of trauma and what to do about it* 9/5/19;
4. *Response to the Interim Report of the Aged Care Royal Commission* 22/11/19

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1. *Aged care redesign from the consumer point of view.* 24/1/20
2. *The role of downsizing in homecare* 20/7/20
3. *COVID-19 impacts in Aged Care “Re-writing the scripts”* 4/09/20
4. *Financing aged care: Policy development from the base up* 14/09/20

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