



# PROJECT REPORT:

# Measuring Quality and Consumer Choice in Aged Care

**Prepared by COTA Australia**

February 2018

## About COTA Australia

COTA Australia is the national consumer peak body for older Australians. Its members are the State and Territory COTAs (Councils on the Ageing) in each of the eight States and Territories of Australia. The State and Territory COTAs have around 30,000 individual members and more than 1,000 seniors' organisation members, which jointly represent over 500,000 older Australians.

COTA Australia's focus is on national policy issues from the perspective of older people as citizens and consumers and we seek to promote, improve and protect the circumstances and wellbeing of older people in Australia. Information about, and the views of, our constituents and members are gathered through a wide variety of consultative and engagement mechanisms and processes.

## About the Project

COTA Australia received funds from the Department of Health to develop a '*consumer led consultation process to consider systems and indicators of quality and safety in aged care*'. COTA expanded upon the core requirements of the project set out by the Department of Health to broaden our investigation to also consider information consumers think most relevant for choosing an aged care provider; in addition to information about quality and safety within aged care.

The results contained herein should not be interpreted as implying the view of Government or the Department of Health.

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## Summary of key findings

COTA Australia was contracted by the Department of Health to conduct a short consultation on Measuring Quality and Consumer Choice in Aged Care. The project conducted an online survey with consumers, including their representatives (yielding 676 respondents) and providers of aged care services (yielding 416 respondents). In addition, focus groups were held in 7 capital cities (with 65 consumers and 93 providers registering to attend, and 30 consumers and 64 providers participating). This section summarises the findings of the survey and focus groups under thematic groupings. More detail of the consultations can be found in the subsequent section of the report - Project Findings and the appendix summarising the findings of the online survey of provider and consumers.

In addition to the survey and focus groups, 67 consumer participants were engaged by the SA based deeper dive consultation through The Plug-in run by COTA South Australia. Its report of this engagement is attached as an appendix.

COTA notes that there was strong support by consumers on a range of measures in the survey with very little statistical difference in results. If the research were to be conducted again, COTA would recommend the inclusion of ranking / prioritisation to determine what was “most important” amongst all the items identified as important/very important. This approach was tested as part of later focus groups and provided insight into what things consumers valued more than others and has informed COTA’s positions below when recommending future courses of action, given the limited resources within the sector and the unenviable task of having to prioritise those resources for actions to improve the quality and safety of aged care in Australia. Further testing of any action by Government is warranted to ensure effective implementation.

## Consumer Experience Metrics

- Powerful support is found in both the survey and focus groups for increased ‘consumer experience’ information that will help consumers make informed choices when selecting an aged care provider. This includes consumer ratings and reviews by other service users of an aged care provider. Focus groups discussed the importance of such information being developed/provided by an entity ‘independent’ of Government or the provider, but there was support for the information being displayed via My Aged Care. This would correlate with the survey results showing 67.4% support for information being on “an independent organisation’s website where all information about aged care is available” followed by “the Australian Government’s My Aged Care website” (65.3%).
- Unsurprisingly, Home Care consumer respondents identified the most important source of information as ‘word of mouth’ from people they personally knew who have used the service (71.4% of respondents). Additionally, consumers valued the views of any service user (69.7%) and online reviews by service users, family or friends (59.4%). In residential care the priority was also word of mouth (71.4%), followed by views of any service user (67.9%) and online reviews (58.07%). While not explicitly tested in the survey, the higher results linked to “service users” (compared with lower results that included service users and “family or friends”) imply consumers and their carers value knowing the experience of the service user/consumer over information from the consumer’s representative/family/friends.
- In focus groups, support for the proposed ‘Aged Care Quality & Safety Commission’ to expand consumer experience reports to include home care as well as residential care was raised. Providers identified the need for collection cycles to be more frequent in order to provide timely and relevant information. However, consumers identified a strong desire to be able to review both quantitative information (which is published today) as well as qualitative information (comments are currently not published).
- There were solid indications that consumer experiences would be used when choosing providers, however comparability of this ‘experience’ was not identified as a critical element in the focus groups. Rather consumers identified they wanted to read the comments/reviews of the service user to gain

insights into the values of the author providing the consumer experience information, and then give more weight to the reviewers who they felt were most aligned with their own values.

- 74.8% of consumer survey respondents saw value in publishing the Australian Aged Care Quality Agency's (AACQA) 'Consumer Experience Report' for other consumers.
- 85% of providers identified they measured consumer experience (213 out of 250) with 174 providers identifying they had developed their own survey. In discussions in the focus groups however it became clear to facilitators that many providers did not distinguish 'consumer experience' from 'consumer satisfaction'. It would appear that beyond encouraging compliments and complaints, most metrics collected today by providers focus on satisfaction, either of individual service, staff or the organisation overall. A number of providers did however indicate they were collecting measures similar to the Net Promoter Score 'likely to recommend' indicator which can be extrapolated as a form of consumer experience indicator.
- **COTA recommends that Government acknowledge the consistent view of consumers that consumer experience information is the most important piece of information requested when seeking to choose aged care providers. Government should prioritise resources to explore measures that increase consumer experience information in aged care by:**
  - Promoting the benefits of consumer experiences and reviews of aged care services.
  - Exploring the appropriateness of how such reviews may be linked from My Aged Care.
  - Expanding AACQA Consumer Experience Reports (CER) to all aged care services (including home care and other services) and explore how the qualitative evidence collected as part of the CER may be published to provide the context of the rating system.<sup>1</sup>
  - Increasing the percentage of consumers required to be surveyed as part of the AACQA consumer experience report process from 10% of residents to 20% of residents. Consideration should also be given to how CER information can be collected annually to provide timely information.

## Quality of Life Metrics

- Information about Quality of Life and what service providers were doing to improve the quality of life of consumers in their care was important to respondents – 74.4% of respondents in relation to residential care (2<sup>nd</sup> highest after information on costs) and 70.5% in relation to home care (3<sup>rd</sup> highest after costs and word of mouth).
- When asked in the survey how important specific quality of life measures were to consumers in choosing any aged care provider, they ranked<sup>2</sup> them as: Being treated with respect and dignity (98.7%); Staff friendliness (98.1%); Feeling safe and secure (97.7%); Being supported and encouraged to raise any concerns I have with the service (96.6%); Food satisfaction (96.4%); Their sense of independence (96.2%); Having control over their daily life (95.6%); Being supported to maintain social relationships and connections with the community (95.6%); Maintaining and supporting spiritual, cultural, sexual and religious identity (90%); How likely they would be to recommend the service to a family or friend (89.4%).
- When discussing these findings with the consumer focus groups there were indications that quality of life metrics would be used by consumers when choosing a provider. A message heard across the focus

<sup>1</sup> COTA recognises that AACQA has indicated its intention to expand the Consumer Experience Report into home care services, but has not yet indicated it would publish qualitative information captured through the system.

<sup>2</sup> Given the similarities in feedback percentages and the sampling sizing, there is minimal statistical variation between how these items ranked. Broadly, we would suggest that the results should be considered of equal weighting where results are over 91% (particularly those in the 95-97.1% range).

groups was that consumers believed an 'indication of good or poor quality of life can provide insight into quality of care, but not the other way around'.

- There was strong support for the collection and publication of quality of life (QoL) metrics by aged care providers (67.6%). 93% of consumers agreed that it should be mandatory for providers to publicly report on quality of life measures.
- However, there was very little evidence in the focus groups that the types of measures valued by consumers in the survey were currently being collected by providers today (beyond satisfaction with food) and certainly no provider identified they were publishing quality of life metrics. This contradicts the survey where 64% of providers who responded to the question (160 providers out of 250) identified they did use a system/tool to collect quality of life metrics, but only 68 of those could identify what tool was used. This could be due to a range of reasons including some providers may believe they collect quality of life information through the recording of case notes on quality of life areas and consumer satisfaction surveys. Further exploration of provider views on what 'quality of life' information is collected that can be conveyed in a metric is worthy of future exploration.
- There was merit identified in focus groups that Government should provide flexibility of which tool/metric should/could be used by providers in order to have ready availability of quality of life measures for consumers. (COTA notes this approach would need to ensure that data and results are independently verified – i.e. not an in-house program.)
- **COTA recommends that priority be given by Government to developing strategies to increase the collection of quality of life metrics amongst providers and consideration of how such metrics could and should be published to inform consumer choice:**
  - **Should participation/collection/publication of a QoL indicator be made mandatory, COTA suggests that consideration be given to permitting providers to use *a range of tools*, rather than one prescribed tool. During the focus group discussions there was no call for comparison of quality of life metrics, rather such measures would be used as one piece of information to inform consumers about the provider. Such an approach may make implementation quicker and easier given the length of time to develop and then test new tools.**
  - **It should be recognised that providers noted their concern about the potential costs and time involved in a Government mandated tool that provides less benefit than the existing tools providers may use. Consideration of the duplication of work to refine data into the prescribed format of one tool should also be given.**
  - **If the purpose of collecting and reporting quality of life measures is for consumer choice and consumers have indicated they are seeking information on quality of life not necessarily comparison of two providers' performances, then mandating the indices that should be measured and leaving providers to implement would seem the most efficient way of ensuring quick publication.**
  - **Accordingly, the external benchmarking programs which provide quality of life metrics could be adopted by those who use them currently or elect to use them in the future. They are already proven tools, tested within the sector, and will take less time to develop for publication than commencing a new process.**
  - **Alternatively, or in addition, Government's free-of-charge national quality indicator program (if retained) should be updated to include quality of life measure/s as a priority. If retained as an option amongst others, those providers who don't use more sophisticated tools today or don't have alternative options available in their current systems would be provided with a low-cost implementation strategy.**
  - **Since the Government's trial of the various quality of life tools in 2016, including the ASCOT, a number of providers have introduced a modified ASCOT tool for their own internal purposes. Given the lessons learnt both through the trial of ASCOT, along with the various**



**implementations around the country, should Government decide to implement a single tool there may be benefit in further exploring the appropriateness of the ASCOT tool (or similar).**

### Quality of Care Metrics

- Consumer survey results indicate that 67.9% of respondents to residential (6<sup>th</sup> out of 12 items) and 53.5% of respondents to home care (10<sup>th</sup> out of 12 items) Indicated that “I want information about care measures by that aged care provider (e.g. residents experiencing pressure injuries, unplanned weight loss, use physical restraints)”
- This is compared with 82.6% of respondents who said, “I would use information about aged care measures if it were displayed on My Aged Care” and 97.8% of respondents who said, “I want consistent, easy to understand information that allows me to compare aged care providers”. These results indicate that while information generally is highly sought after by consumers for comparison, consumers are seeking a broader suite of results than simply quality of care metrics. As previously discussed quality of life and consumer experience information was ranked higher than quality of care metrics by consumers.
- 92.7% of consumer respondents also believed that “It should be mandatory for all aged care providers to report on quality of care information (e.g. pressure injuries, unplanned weight loss, physical restraint)”.
- When asked in the survey how important specific quality of care measures were to consumers in choosing a residential care provider they ranked them as medication incidents (93.0%); falls and fractures (91.3%); infections (91.1%); physical restraint (89.3%); pressure injuries (89.1%); unexplained weight loss (86.7%); depression (84.2%); vaccinations (78.1%).
- While not strictly a measure of Quality of ‘Care’, it’s appropriate here to note the results on staffing information received as part of the survey and discussed as part of ‘The Plug-In’ results. Consumers wanted to know about the qualifications and skills of staff (6<sup>th</sup> most important in-home care at 68.1% and 3<sup>rd</sup> most important in residential at 71.8%) and the staff mix in terms of hours of care provided each day (68.3% in home care [5<sup>th</sup> most important] and 65.9% in residential [8<sup>th</sup> most important]). Of the six quality dimensions identified by The Plug-In, 3 related to staff, including ensuring staff were able to support dignity, self-expression and choice, had the resources to support quality of life and were trained and empowered to provide appropriate care.
- In discussions in the focus groups when consumers were asked to prioritise the information they wanted, quality of care metrics were chosen by those who identified their loved one had particular health needs/issues they wanted to assess a provider’s service on. However, this was only around 10-15% of focus group participants. The short ranking exercise conducted in some focus groups indicated that the majority of consumer participants did not prioritise quality of care metrics placing greater importance on consumer experience or quality of life measures when asked to choose only two pieces of information.
- When asked about how quality of care metrics were collected provider survey respondents indicated that 71.6% used a software program to collect/manage clinical or care data, with the remaining 28% of organisations indicating they only used paper-based notes. 34.5% indicated they used a benchmarking program though when asked which program, 11% of these reported a financial benchmarking service. Providers noted their support that “any measures are nationally consistent” (94.4%).
- When providers were surveyed regarding whether all providers should report how they meet mandated national standards, 88.4% agreed, with 82.8% stating information about the performance against the mandated minimum national standards of aged care services should be publicly available online (82.8%). Further they noted any quality indicator program should be Government run at no cost to providers (80%) with 45.2% believing that providers should be able to use existing benchmarking systems to participate in a quality indicator program at their own cost (Table 20, Q10).

- Discussions in focus groups identified that consumers caring for a loved one with particular health needs greatly valued quality of care indicators. However, for others (the majority of participants in the focus groups) there was minimal indication that quality of care metrics would be used when comparing two providers. There was however strong support for publicly accessible information on quality of care metrics when seeking to verify carer concerns about quality of care being provided. In unpacking these tension points with consumers, they spoke of wanting to see safety and quality reports when they were unsure about the quality of care their loved one was receiving and while many wouldn't review this material before entering aged care where comparison was needed, they would seek out this information if it was publicly available when investigating a concern, they may have. This distinction between making information available publicly and making it available publicly for the purposes of comparison, is important when considering how to implement any future policy measures in this area. In particular COTA considers that it would bring into question the cost benefit of national consistency if the utilisation of the data were such that it was for information/investigation purposes and not comparison for choice.
- Integrity in the published results was a critical issue raised by both providers and consumers. Providers, in particular the quality expert focus group, raised concerns about dirty data resulting in inaccurate reporting requiring independent oversight to ensure the quality of reporting. Additionally, providers spoke of their concerns around the administrative burden of preparing the data in specified formats that were unable to be simply produced from their existing care and quality systems.
- **COTA supports the continued collection of 'quality of care' metrics and supports the mandatory publication of these metrics for consumers to be able to see. However, the difficulties in achieving the dual policy objectives of the National Quality Indicator Program (for 'continuous quality improvements' and to 'aid (consumer) decision making') have hindered the publication of quality of care data for too long. This would be consistent with our understanding of the advice provided by the National Aged Care Alliance to Minister Wyatt, that the current QI Program does not assist in consumer decision making and is unlikely to ever do so.**
- COTA acknowledges the primary purpose of any QI program is to improve the quality of care consumers receive and that publication of such data is primarily to use market forces to increase quality care, with a secondary benefit of providing information for consumers to decide which provider to use. The timeframe to develop care metrics in a manner that can confidently be published in a nationally consistent, easy to understand for consumers format, is far longer than it would take to allow providers to publish their own quality and safety reports with quality of care metrics and the context to be provided around them. In addition, COTA notes the priority placed by consumers on quality of life metrics (over quality of care metrics) and the consistent focus group feedback that quality of life metrics provide insight into quality of care, but care indicators may not indicate a good quality of life.
- Given the above, COTA recommends:
  - Priority be given to introducing metrics around medication incidents.
  - Government seek to identify and introduce 'staffing' related metrics as part of any future information available for consumers. The project identified no stand out indicator, likely meaning that there is no 'silver bullet' to this issue identified by consumers. Nevertheless, improvement on information available about staff can and should be considered.
  - Future requirements around 'quality of care' metrics focus on continuous quality improvement metrics for providers and not providing information for comparison / to aid decision making for consumers.
  - Government require providers to publish quality of care metrics, but allow the provider to utilise their own format to enable the provider to give context of results. Government should explore requiring the provider to have independent oversight of their quality data before being published, such as through the use of an external benchmarking service. This will provide consumer confidence in the veracity of the data, while permitting providers to fulfil

**their obligations through lower cost methods and with greater confidence that their data will be presented with the appropriate surrounding context.**

- **The Australian Government maintain National Quality Indicator Program (including its current model of being accessible by providers at no cost to them) and that Government consider introducing quality of life metrics and expanding the number of quality of care metrics (in particular around medication management). This will be particularly important for the (around) 1 in 4 providers still utilising a paper-based care system.**
- **That should Government accept the recommendation that providers may self- identify the most appropriate care metrics their organisation will focus on (in line with continuous improvement best practice) that Government also require the provider to state publicly, in advance, the indicators it will publish in the forward 12 months. This should be a minimum of three metrics and be part of its continuous improvement program.**

### National Aged Care Quality Indicator Program (QI Program)

- 80% of providers surveyed believed the QI Program should be run by Government with no cost to providers, with only 45% of providers believing that providers should be able to use existing benchmarking systems “to participate in the QI Program”.
- 40 out of 248 providers indicated they participated in the QI Program trial in residential care, with 46 indicating participation in home-based care. When asked why participants did not participate, 92 responses were received. 58.6% of respondents did not know about the free national program<sup>3</sup>. 33.6% identified burden of data collection as a barrier, 7.6% identified no value in the indicators, and 16.3% already used another system.
- In focus groups, providers identified that the QI Program contained only a few of the indicators available in other programs. This correlates with the survey results showing 54% of provider respondents did not believe the current suite of quality indicators that form the QI Program were adequate.
- Providers also raised in the focus groups concerns about the effort involved in preparing the data for the QI Program in the required format compared to other programs which were automated from their care systems as a barrier to participating.
- For those starting their quality indicator program, the National Quality Indicator Program is a good low-cost service. For those with an established quality indicator program the project heard in the focus groups that the QI Program was cumbersome and time consuming with little value-add compared to alternatives. The project also heard concerns that the poor participation rates of the current QI Program meant the smaller sample size provided little value for comparison between providers or meaningful information for consumers.
- Focus group participants identified benefits in maintaining the QI Program, especially for new participants and those who don't have alternative benchmarked systems in place as part of their continuous improvement processes.
- Question 14 of the survey sought the views of providers as to whether it should be mandatory or voluntary to both collect and report indicators on Quality of Care, Quality of Life and Consumer Experience. The results were reported by providers who offered residential, home care packages or CHSP.
  - When thinking of quality of care measures 53.9% of residential care providers, 48.9% of home care providers and 38.2% of CHSP providers thought it should be both mandatory to collect and report quality of care indicators.

<sup>3</sup> We find that this result is anomalous as we are aware all providers were invited to participate in the program by the Department. We can only conclude that the respondents to the survey were not also the recipients of the Department's email broadcasts.

- An additional 15.1% of residential care providers, 18.4% of home care packages providers and 18.4% of CHSP providers thought collection should be mandatory, but not mandatory to report publicly.
- In focus groups, there were mixed views on voluntary vs mandatory participation of the QI Program. However, in the quality expert focus group there was overwhelming advice from those participants that there would be concerns about poor data quality if the program were made mandatory.
- Importantly, as discussed below with existing quality systems, should Government implement mandatory or significant changes to the QI Program, it should actively and early on engage with the ACIITC to facilitate clear briefings with suppliers of IT systems in aged care, in order to ease the implementation burden on providers.
- As mentioned in the quality of care summary there was strong support amongst consumers in both surveys and focus groups for other indicators to be introduced, especially medication related incidents.
- **COTA notes the tension between ensuring accurate data that the quality experts consulted indicate is more prevalent in voluntary programs and providing nationally consistent indicators that generally a mandatory program would deliver. COTA also notes the distinction between consumers wanting publicly available information to use in assessing a potential aged care provider and the desire of consumers to compare two or more providers side by side. COTA notes the long-standing discussion on improved data and the challenges involved in requiring the entire sector to utilise the one standardised approach, which by its very nature will include only the minimum requirements. Finally, COTA recognises the legitimate concerns by some providers about the potential business impacts of public data being displayed without context explaining any variations (e.g. seemingly high fall rates being a result of introducing greater reablement and independence programs).**
- **COTA recommends that the Government:**
  - **Introduce a mandatory requirement on providers to collect and publish quality of life indicators along with quality of care indicators. Over time, once the requirement has been established Government could consider which specific indicators it would require the sector to publish in a particular year/time period.**
  - **Be flexible about the systems and methods of collecting and reporting such indicator data, whilst requiring providers to demonstrate the independent oversight of their data quality assurance methods.**
  - **Ensure that any publication of QI information by a provider is linked from My Aged Care and is presented in a format that allows providers to provide context around how and why their results have occurred.**
  - **Continue to offer the QI Program as a voluntary, no cost to the provider solution to deliver upon the requirements outlined above, while also permitting the integration of these requirements within alternative programs used by providers.**

## Role of Government

- In focus group discussions there was a range of views by providers about the role of Government in the context of providing information about choices to consumers. Most prevalent was that the role of Government should continue focusing on 'minimum requirements', with industry and 'the market' best suited to accommodate 'above the minimum' solutions.
- Nevertheless, 69% of providers (most favoured survey response) and 65% of consumers (second most favoured survey response) supported public reporting on quality information of care and/or quality of life indicators on My Aged Care. We submit that this demonstrates the importance of all information being easy to access (i.e. linked from My Aged Care), and not necessarily support for "Government" to require it. Rather it recognises a role for Government to facilitate such information.

- A significant majority (80%) of survey participant providers believed that Government should continue to provide the no-cost option offered through the QI Program, while others believed mandated participation in a program that provided less information than alternative benchmarking services gives little benefit to the provider. Many stated they currently paid for a benchmarking service because of the holistic benefit they got from the results. As discussed above in the QI Program section, implementing requirements to publish, and allowing the market to devise solutions to best implement those requirements, one of which may be the QI Program, would seem the most appropriate way forward. As discussed in the Existing Systems section below, any mandating of the QI Program would need to involve close liaison between Government and Aged Care IT suppliers to ensure the streamlining of reporting processes.
- Consumers in focus groups identified that they assumed that quality of care would be provided. Where quality of care was not provided, they expected that clear information would be made available to them.

### Making Choices: choosing an aged care provider

- Making choices about aged care is broader than simply quality. This section discussed the broader concept of choices and the processes consumers identified of filtering information to a manageable number of providers, making comparisons between providers and then finalising their choice of provider.
- Research from psychology and marketing literature identifies that people can only process up to seven pieces of information at any point in time (Miller, 1956) while others argue no more than five choices (Schwartz, 2004) could paralyse decision making because people become overwhelmed by information. Accordingly, we would recommend comparing 3-5 providers as best practice.
- This means filtering of the available options needs to occur in order to identify those providers to be compared. Availability of requested service, location (for residential) and price are all indicators that could be used to filter available services. In discussions with consumers during the focus groups, it was unlikely that any quality indicators (Quality of Care, Quality of Life, Consumer Experience) would be used to “filter” providers – rather it seemed that such measures would be used in the final stage of comparing providers who have been filtered on other criteria.
- Discussions in focus groups indicate that making a decision about which residential aged care provider to use continues to involve a site visit to inspect the location and meet the staff, followed by a comparison of costs. However, home care consumers were less inclined to have potential providers come to their home without having filtered them in some way.
- Research shows consumers would value information on My Aged Care. When asked where consumer respondents had looked for information on aged care providers 32.92% indicated they searched for information using My Aged Care and 13.23% spoke with My Aged Care call centre. In looking to the future when asked where you’d like information to compare two or more aged care providers 65.3% of consumers stated My Aged Care and 82.6% agreed/strongly agreed “I would use information about aged care measures if it were displayed on My Aged Care”.
- Nevertheless, research by COTA identified that many of the current fields available for comparison on My Aged Care are not filled in by providers and thus are useless for consumers attempting to compare.<sup>4</sup> This includes only 9.4% of providers publishing their prices on My Aged Care, 83.9% not stating if they charge public holiday loading, 67.0% provide no information on religions they support, 58.9% provide no information on the cultures they support and 72.2% provide no information about the languages they support.

<sup>4</sup> Analysis by COTA was prepared for the National Aged Care Alliance’s Gateway Advisory Group and was conducted based on pricing information for 3 random postcodes and for other fields based on the from December 2017 My Aged Care data released on [www.gen-agedcaredata.gov.au](http://www.gen-agedcaredata.gov.au). Results are summarised on page 27 of this report.

- Comparison for home care services could occur on a variety of data elements being provided. However, the data presented from My Aged Care identifies that these fields in the My Aged Care service finder are not currently being consistently populated and thus provide insufficient information to enable comparisons between providers.
- The role of trusted supporters (either family/friends or a health care professional) is critical for many in making choices about their aged care provider.
- In focus group discussions, when asked to consider what information they would utilise for making decisions about which aged care provider, the quality of care metrics were seen as less useful when making a choice of aged care provider, while consumer experience and quality of life metrics were felt to be more informative when making choice of provider. This is correlated with the survey results which indicated more consumers wanted information about quality of life and consumer experience than they did about clinical care measures. In Question 8 when asking consumers to think about choosing a home care provider 70.5% of consumers wanted information on how services improve quality of life, and over 70% wanted to know the views of other service users, compared with 53.5% wanting information on care measures. In residential care 74.4% wanted quality of life information, with over 68% wanting views of service users and 68% wanting to know care measures.

### Existing Quality Systems

- Many providers use existing benchmarking services to report to their monthly/regular quality committee meetings. However, it is unclear how many of these benchmarking services are independent of the organisation or are within the organisation and benchmarking across sites.
- External benchmarking services like QPS and Moving On Audits provide a degree of verification in the data provided, and thus the benefits. However, participation reported by QPS and providers amongst home care services is particularly low compared to residential. The survey results would indicate few providers across the aged care sector participate in such programs (23%) and the focus groups would indicate that many providers use in house quality assurance systems rather than external benchmark systems (though some multi-site providers benchmark between their own organisation's site data)
- Customer Data systems appear to have built standardised extracts in the required QPS / Moving On Audit format, minimising the staff time to adjust data to conform to the existing requirements. Future activity by Government should consider the importance of developing similar extracts for any Government program. In discussions, the ACIITC has advised that some IT suppliers to aged care would have a maximum of 12-months product update cycle (i.e. release an all user update). In discussions with some IT suppliers, it would seem that if there were new regulatory requirements they would automatically fold these requirements into updates for all users. However, while the QI Program has been voluntary such extracts have been seen as a customisation to be paid for by those providers who requested the enhancement.
- The suite of metrics across the different benchmarking systems cover similar topics. However their definitions are not exactly the same (e.g. numerator and denominator, along with supporting material setting categories of responses). This means that the indicators within the different systems cannot be compared to one another in an exacting manner. They can however still provide consumers with much sought after information about how a provider is performing in regard to that particular quality metric (and does provide comparison to other providers who use the same benchmarking system). With the cohorts of providers participating in the benchmarking service and collecting information on that particular indicator, consumers will be provided with guidance on where the provider sits within its peers for each metric.
- Given time to develop, the existing quality systems have a solid foundation to provide publication of quality information to inform consumers.

- **COTA recommends any actions by Government in the area of quality of care data required should include discussions with the ACIITC regarding briefing and engagement with Aged Care IT system suppliers to explore the ways such information can be presented.**



## Project Methodology

COTA Australia was approached by the Department of Health to conduct a short consultation with consumers and providers in relation to the future of quality indicators in aged care. COTA Australia decided to approach the project in a broader method that discussed the process/es used by consumers to make choices about their aged care, in order to increase participation by consumers and to appropriately frame questions about quality information in the consumer-centric context of making choices.

The project was approved in late September with a reporting date of the end of January. The four-month window for the project provided no testing or co-design of methodology with consumers and required reliance on COTA's internal experience with comparable consultations to inform the project design. Due to competing demands on internal resources during this window, an external consultant, Carrie Hayter Consulting, was engaged to complete a literature review, and to design and analyse the online survey and provide feedback to the original focus group approaches.

To compensate for an inability to test or co-design the methodology with consumers, COTA Australia utilised The Plug-In methodology with consumers in South Australia. As discussed below, this provided the ability to have more unstructured conversation and thus a deeper understanding of consumer views on this topic. To control for the fact consumers were not included in the design of the main consultation, we provided an initial brief to The Plug-In team and let them progress on their own journey to test and refine their own approach.

The online Survey had 676 **respondents** to the Consumer / Carer Survey, with 416 respondents to the Provider Survey. Focus Groups were completed across 7 capital cities and received 65 consumers and 93 providers registrations, with 30 consumers and 64 providers **participants**. An additional 67 consumer participants were engaged by the SA based deeper dive consultation through The Plug-in run by COTA South Australia. This occurred across 1 workshop, 6 focus groups and 17 one-to-one interviews.

## Promotion

COTA Australia used a mixed method of recruitment including:

- Emailing the national COTA Australia supporters database in a dedicated email.
- Issuing a media release calling for participation to industry and media focused on older Australians. This resulted in several online news sites featuring the events being held and promoting the survey.
- Promoting through National Aged Care Alliance, Aged and Community Services Australia, Leading Age Services Australia and the Department of Health e-newsletters targeting provider participation. Spikes in participation rates were noticed demonstrably in the days after the Department of Health email.
- Promoting on COTA Australia social media channels including Facebook advertisements in Melbourne and Canberra (the earlier sessions) to compensate for a lower lead time via traditional channels. In the Canberra area the ad reached 5,801 people with 226 click throughs costing \$1.11 per click (total cost \$250.86). For the original Melbourne focus group, the ad reached 4,583 people, with 81 clicks, each costing \$1.58 (Total spend \$127.98)
- A dedicated page on [cota.org.au](http://cota.org.au) resulting in 1940-page views, 1689 of which were unique and an average time on page of just over 3 minutes.



## Online Survey

COTA developed an online survey for consumers, along with a separate survey for providers. The survey was designed by Carrie Hayter Consulting, in consultation with COTA Australia who in turn consulted with the Department of Health about the questions to be included. The survey was open until the end of December 2017 and received:

- 643 responses to the Consumer Survey who identified themselves as
  - 347 (54.0%) people over 65 years - including 81 (12.6%) respondents between 76-85 and 14 (2.7%) respondents over 86
  - 354 (55.0%) people who provide support to an older person
  - 13 (2.0%) people who previously supported an older person
  - 5 (0.7%) identified as Aboriginal or Torres Strait Islander, 15 (2.3%) identified as speaking a language other than English, 19 (3.0%) identified as LGBTI, 49 (7.6%) identified as socially or financially disadvantaged, 13 (2.0%) identified they were a veteran, 68 identified they had a disability (10.6%) and 73 (11.4%) identified themselves as living in rural or remote Australia.
- 416 responses to the provider survey, who identified the types of services they deliver as:
  - 326 (78.3%) Commonwealth Home Support Program
  - 284 (68.2%) Home Care Packages
  - 171 (41.1%) Residential Care
  - a wide range of small to large providers (88 (21.2%) respondents servicing 0-100 clients, 91 (21.8%) servicing over 3000),
  - 277 (66.6%) operating in capital cities, 132 (31.7%) in regional centres, 203 (48.8%) operating in rural areas and 86 (20.7%) in remote

## Focus Groups

COTA Australia ran focus groups in Sydney, Canberra, Melbourne, Hobart, Brisbane and Perth for both consumers and providers. An additional provider-only session was run in Adelaide, with consumers in Adelaide engaged via The Plug-In consultation methodology. Across these focus groups, COTA received:

- 65 consumers and 93 providers **registrations**
- 30 consumers and 64 providers **participants attending on the day.**

The Focus Group facilitation guide was refined along the way, including introducing a ranking activity to provide insight into the priority areas that were not distinguishable from the online survey results. This exercise was only conducted in Hobart, Perth, Brisbane for both consumers and providers, along with Sydney for Consumers and Providers in Adelaide. Accordingly, this ranking activity cannot be seen as statistically representative, however it has provided insights into the priorities and preferences of consumers when asked to make choices in these areas.

## 'The Plug-In' consultations with SA consumers – a deeper dive

At the time of the consultation COTA Australia was piloting use of "The Plug-In" consultation method with COTA South Australia to demonstrate its applicability to the policy development process. The Plug-In is designed for industry, innovators and researchers to help create technology, products and services that will better meet the future needs of older people.

Originally planned to review consumers' thoughts around the Aged Care Legislated Review, COTA decided to refocus this work on the issues of quality, safety and choices in aged care. Given the time-limited nature of this project The Plug-in approach was asked to design and execute their consultation based on the brief provided to the Department by COTA Australia and the subsequent project questions developed.

The Plug-in activity conducted 1 workshop, 6 focus groups and 17 one-to-one interviews, engaging a total of 67 consumer participants. Full details on The Plug-in are available in the Plug-in report attached as an appendix.

### Additional Consultations

Additionally, we met with participants of the voluntary National Quality Indicator Program (via a group teleconference), the Aged Care Industry Information Technology Council (via teleconference with their then Chair), care system software providers and benchmarking companies (CareXPS, and QPS).

## Project Findings

The project has provided transcripts of the focus groups, analysis of the online survey and a literature review. In this section of the project report we discuss key elements of the findings across these three deliverables.

### What does Safety & Quality Mean to consumers?

The online survey asked consumers to identify what safety and quality meant to consumers before commencing the survey. These open-ended responses were then coded and the top five coded responses are available below:

1	Staff attitude and skills	210
2	Reliable and consistent staff	202
3	Showing respect for older people and their allies	167
4	Good communication with older people and their allies	95
5	Supporting independence	89

*Top 5 responses of Q7 from Table 4 (N - 473)*

Importantly, this key focus on staff is correlated with the consultations by The Plug-In showing similar emphasis on the importance of staff in considering these items.

### Indicators of quality in aged care that will help consumers make informed choices

The literature review tells us that consumers make choices in different ways. It confirms that most people do not use quality of care metrics when making informed choices. Both the literature and this project's findings back up the view that it is the experience of the service user (consumer experience) indicators that are of most value to consumers when making choices. In particular it is important to note that less than 1% of respondents to the survey who had experience with aged care stated they had read a report from the Australian Aged Care Quality Agency (AACQA). While this may be due to the inaccessibility of the historical reporting, or its lack of connectivity from My Aged Care, the focus group discussions led us to believe it is largely due to such information being seen as irrelevant in the decision-making process.

**Quality of Care indicators were not seen as the most important thing when choosing an aged care provider.** When asked to prioritise metrics across the three broad types of indicators, consumer rankings in the focus group discussions were Consumer Experience followed by Quality of Life and then Quality of Care (although this was a lineball outcome in terms of residential, with many carers in particularly speaking of the importance of quality of care outcomes in residential higher than quality of life). The online survey did not seek ranking of issues, though given the comparable results across questions, ranking/prioritising consumer views should form part of any future investigations.

This is correlated with the survey results which indicated more consumers wanted information about quality of life and consumer experience than they did about clinical care measures. In Question 8 when asking consumers to think about choosing a home care provider 70.5% of consumers wanted information on how services improve quality of life, and over 70% wanted to know the views of other service users, compared with 53.5% wanting information on care measures. In residential care 74.4% wanted quality of life information, with over 68% wanting views of service users and 68% wanting to know care measures.

Importantly, when consumers were asked to indicate where they wanted to find information to help them make informed choices and compare providers, their clear preference was 'an independent organisation's website where all information about aged care is available' (67.34% - 325 respondents) or 'the Australian Government's My Aged Care website' (65.35% - 315 respondents).

## Quality of Care Indicators

Quality of Care indicators are identified as important by consumers, but play a negligible role in deciding which provider to choose. They play an important function in continuous improvement and monitoring of the organisation's outcomes. COTA recommends that future work on Quality of Care indicators should focus on the goal of continuous improvement and **discontinue policy objectives around 'aid consumer decision making' in favour of a policy focusing on continuous improvement and making quality information publicly available.**

Quality of Care indicators are of benefit to consumers when seeking assurances about the type of care they are receiving (i.e. after their choice has been made) and consumers broadly support the publication of such data. However, providers rightly note that indicators without context can be damaging to their business. Accordingly, we believe **requiring providers to publish their quality of care results**, but allowing them to publish them within the context of their own 'safety and compliance report' or even a standardised format on their website that provides the ability to produce context, would be appropriate.

When asked in the survey to indicate for home care and residential care whether they wanted 'information about care measures by that aged care provider (e.g. residents experiencing pressure injuries, unplanned weight loss, use physical restraints)', consumers disagreed for home care but agreed for residential care. Consumers provided the lowest support of all statements asked in home care (272 respondents, 68.34%) and amongst the highest responses for residential care (345 responses, 86.68%).

This appears to correlate to the focus group discussions that such information is important, but would not be used for making choices. When looking at the indicators of quality of care without the additional overlay of consumers making choice of their aged care provider, we observe a few things from the focus groups:

- Consumers find there is value in providers collecting this information from a service improvement / monitoring perspective. Consumers thought there was value in publishing this information and some consumers identified they might seek to access this information when determining if their concerns about poor care outcomes were an isolated case or a systemic one.
- Providers were hesitant about publishing indicators, unless they had the ability to provide a narrative around the indicator (e.g. Facility Z's falls metric were up in Quarter 3, due to an increased focus on reablement and empowering consumers to be more independent, resulting in an increased number of falls).
- Care Indicators were of most value as a continuous improvement process, rather than for the purpose of publishing data for consumer choice. Indeed, throughout the consultations we heard several concerns that any indicator program would "game" the system through either reporting inaccurately or introducing anti-consumer behaviours (e.g. reduced independence to reduce risk of falls) in order to improve their statistics.
- **While COTA maintains its support for care indicators being made public in some form (either by the provider or Government), it does not see value in this being designed for the purpose of comparability and choice by the consumer for these reasons.**
- As part of the online survey (results below) we received high levels of support for all clinical indicators in residential care. Knowing that if further indicators were to be introduced, new metrics would likely be progressively introduced we asked consumers to choose only 2 indicators in order to collectively prioritise them. As part of the focus group, an indicator on 'Medication Incidents' was the stand out highest metric in discussions, followed by 'Falls and Fractures', and then Infections tied with Physical Restraint. This was further backed up by the online survey statistics of all consumer respondents which was largely reflective of these priorities (see Table 1). When looking at the data split between the over 65 and carer/supporter of an older person, we saw consistency in the issues identified, though some (like depression and infections) were of less importance to the supporter than the older person themselves.

Rank	Key Area	Very Important	Important	Total Very Important & Important	%
1	medication incidents	365	97	462	93.3%
2	falls and fractures	334	118	452	91.3%
3	infections	357	94	451	91.1%
4	physical restraint	351	90	441	89.1%
5	pressure injuries	327	110	437	88.3%
6	unexplained weight loss	313	116	429	86.7%
7	depression	290	127	417	84.2%
8	vaccinations	239	148	387	78.2%

*Table 9 - Ranked Important or Very Important ranking of quality of care indicators in choosing a residential care provider, Consumer Survey, Q10 (N – 495)*

### Quality of Life Indicators

Consumer Experience and Quality of Life indicators were ranked higher in both survey and focus group discussions compared to Quality of Care information, though both were highly supported (with Quality of Care less supported in a home care setting than in a residential care setting). This was particularly prevalent when making choices about providers. This correlates with the international research identified in the literature review. Government should accordingly introduce Consumer Experience information and Quality of Life information from all providers.

The online consumer survey identifies that:

- Unprompted when asked what's the most important issue to you 26.8% of responses were coded as relating to Quality of Care and Quality of Life, with a further 9.8% only about Quality of Life. This is around a third of consumer responses identifying 'the most important consideration for you and/or the person you support in choosing an aged care provider' as relating to Quality of Life (Consumer Survey Q2)
- For home care services:
  - 358 consumers (or 70.8% of respondents to Q8) want to see 'I want information about how the service improves the quality of life of older people (e.g. provides choices around food, social activities, etc)'
  - 320 (or 62%) indicating 'I want information about the quality of life of people using the service'.
- For residential care services:
  - 378 consumers (or 74.4% of respondents to Q8) want to see 'I want information about how the service improves the quality of life of older people (e.g. provides choices around food, social activities, etc)'
  - 345 (or 67.9%) indicating 'I want information about the quality of life of people using the service'.
- 94% of respondents to Q9 agreed or strongly agreed to the statement 'If I used an aged care service I would be happy to complete a quality of life survey'
- 92.7% of respondents to Q9 agreed or strongly agreed that it should be mandatory for all aged care services to make available information on older people's experiences and report on quality of life

When asked how important various quality of life indicators were, the respondents to the online survey identified:

Rank	Key Area	Very important	Important	Total	%
1	Being treated with respect and dignity	443	33	476	98.7
2	Staff friendliness	385	88	473	98.1
3	Feeling safe and secure	426	45	471	97.7
4	Being supported and encouraged to raise any concerns I have with the service	400	66	466	96.6
5	Food satisfaction	340	125	465	96.4
6	Their sense of independence	342	122	464	96.2
7	Having control over their daily life	335	126	461	95.6
8	Being supported to maintain social relationships and connections with the community	341	120	461	95.6
9	Maintaining and supporting spiritual, cultural, sexual and religious identity	288	146	434	90
10	How likely they would be to recommend the service to a family or friend	300	131	431	89.4

*Table Ten – Consumer Survey Q11 – (N – 482)*

When asked 'Are there any other measures of 'quality of life' or 'consumer experience' you would like to know about?' (Consumer Survey Q12), responses were coded as below:

Measure Topic	%	No.
Activities/Social	21.60%	35
Complaints	21.60%	35
Staff	21.60%	35
Services	7.41%	12
Dignity/Individuality	6.17%	10
Dignity of Risk	2.47%	4
Other	8.64%	14
N/A	20.99%	34

*Table 11 – (N -162)*

When providers were asked if they currently collected information and if so, from what tool, 160/250 respondents (64%) indicated 'yes' with various tools identified:

Tool	No
Use our existing software system	48
Quality of Life	9
ASCOT	5
ECASE Health Metrics	3
Outcome Star	2
ICRM	1

Table 16

The literature review identifies that while there is a distinction between quality of life and quality of care, there is, however, an interconnected relationship between the two. When exploring this theme with the focus groups, consumers expressed that quality of life indicators would provide an insight into whether the care that person received was good or bad.

In Brisbane, a consumer said

*"For me, the quality of life is most important for both because I think that if the quality of life is good in terms of the kind of support that you're getting, and the individual person feels that they have some control over their life. And their life is lived to the quality that they expect in their life. I would assume, maybe wrongly, that it would include care."*

- Participant, Brisbane Consumer Focus Group

While Quality of Life indicators were the preference of consumers in both the focus groups and the survey results, above Quality of Care metrics, it should be noted that a running theme that may be underpinning this preference is an assumption that the care a person received would be good. For those carers who participated where their loved one had poor quality of life prospects due to their individual condition, we saw a higher preference towards Quality of Care metrics in discussions:

*"It wouldn't have mattered how much care she got, her quality of life wasn't going to be made higher because she was already on a dysfunctional level. She didn't enjoy much. She didn't even know my name. She didn't recognize me. .... So, that's why I say quality of care to me is great."*

- Participant, Brisbane Consumer Focus Group

## Consumer Experience Metrics

The primary method of receiving “**Consumer Experience**” information was identified in the online survey as:

- word of mouth from friends and family (368 online respondents),
- generally, ‘views of people who have used that service’ (354 online respondents)
- reading online reviews from older people, friends or family (302 online respondents).

This was broadly reflected in the focus group rankings when consumers were asked to choose only 2 of the possible 9 things they would want to know when choosing an aged care provider. **Accordingly, COTA would encourage the Government to increase the visibility of ‘consumer experience’ as part of any future enhancements to consumer choice.**

While the Consumer Experience Survey and Report (CER) by AACQA is a good start, consumers identify that a number without context of that experience does not allow them to analyse whether such results / reviews correlate with their own values. Additionally, COTA recognises that the current quantitative metrics in the AACQA’s CER are not appropriate for home-based care and are currently collected too infrequently to be of significant value to consumers. Further work with consumers should be done before determining if the CER is a viable solution to consumers’ call for consumer experience information.

Since the Government’s trial of the various quality of life tools, including the ASCOT, several providers have introduced a modified ASCOT tool for their own internal purposes. Given the lessons learnt both through the trial of ASCOT, along with the various implementations around the country, there may be benefit in further trialling the mandatory introduction of the ASCOT tool (or similar).

A look at Provider Survey Q6 shows that 213 of 250 respondents identified they were measuring consumer experience, with the predominant method being surveys developed by the provider. Discussions in the focus group however led us to believe that many of these ‘experience’ measures were actually ‘satisfaction’ measures, usually on the client’s specific service or staff members or the organisation overall.

Response	No
Consumer Surveys developed by the provider	174
Use existing software to collect data	14
Forums or focus groups	9
Consumer survey developed by external agency	7
Consumer Advisory Group	6
Internal surveys based on the AACQA Consumer Experience Surveys	3

Table 17 – coded responses of Consumer Experience tools used by service providers (N – 250)

In the online survey, one provider said:

*“We have commissioned the University of Sydney to run one on one interviews with residents and clients every year across a number of different services to gain feedback against our Model of Care outcome areas, and consumer experience. We have just begun to partner with CareXpress (Aged Care Report Card) on consumer satisfaction and experience surveys at key touchpoints. In the past we have used QPS consumer experience and family satisfaction surveys.”*

- Additional Comments by Provider # 19 to Q6



Another said:

*“We have a Director, Consumer Engagement to assist consumer engagement program delivery. We measure satisfaction, Net promoter score, complaints and compliments and perform random spot checks of telephone calls through service areas and central support centre. We are currently developing our organisational approach to innovation and human centred design.”*

- Additional Comments by Provider # 64 to Q6

Many providers who participated in the focus groups identified they collected the ‘Net Promoter Score’ as part of their consumer satisfaction annual surveys. This may be the simplest numerical / visual indicator of consumer experience when considering what to include. While this was the lowest of the 10 areas provided when choosing an aged care service, it still received 89% support as important or very important by respondents (Consumer Survey Q11). Importantly, during the focus groups consumers noted their preference to not simply see a ‘rating’ by other consumers, but rather to see their rating in the context of their values and preferences by also seeing their review of any service provider.

### A note on Public Reporting of Quality Metrics

While it has been discussed above, it is important to emphasise that should public reporting of quality metrics occur, both consumers and providers raised in focus groups the importance of qualitative information not just quantitative information. In the case of providers, this is to ensure protection of their reputation by being able to contextualise the information and present it in an appropriate and understood light. From a consumer perspective, they wish to understand a bit about the reviewer/consumer experience reporter’s values in order to decipher and associate such information with those that best align to their own values.

### Role of Government

97.5% of consumer survey respondents either strongly agree or agree with the statement ‘I want to know if an aged care provider had failed, met or exceeded national minimum standards’, with 95.5% of survey respondents saying they strongly agree or agree that “All aged care providers should report on how they meet mandated national standards”.

As part of the focus group discussion we identified that consumers assume quality of care will be provided unless there is an issue. They see Government and its functionaries such as the AACQA as responsible for telling the public when a provider is not meeting or has not met the assumed / minimum standard of care.

Providers in the focus groups were clearly of the view that the role of Government is to facilitate the minimum standards and not to require / put pressure on the sector to deliver beyond that scope. Rather, many providers saw this as the role of competition and the market. While COTA broadly acknowledges this, it would point out that the only way a market can be effective and efficient for a consumer is if they are an informed and active participant in it.

If Government were to mandate participation in a quality metrics / benchmarking program, providers consulted in the focus group believed that Government should continue providing a low/no cost option, given the likely resource implications that will be borne by providers to prepare and manage participation.

## National Quality Indicators Program

The majority of providers saw benefit in **mandatory participation** in an indicator program such as the National Quality Indicator Program. Primarily this seems to be because mandatory participation would make the burden on providers equal, and would increase the pool of providers to develop, over time, an accurate benchmarking service.

Considerations of using external quality systems like QPS were explored by the project. While this is much more developed in the area of residential care for the purposes of quality of care metrics, it is far less developed in home-based care settings. For quality of life metrics there currently appears to be a low take up.

There are however several considerations to making participation mandatory:

- Focus groups consistently raised concerns by quality specialists during the consultation that non-voluntary participation may lead to a tick-a-box culture of results, weakening the accuracy of any benchmarking system.
- Providers surveyed believed that the current three indicators are insufficient and should be expanded. This was broadly supported by consumers in their indication of the importance for metrics that do not currently form part of the QI Program. One of the benefits of alternatives to the QI Program was the ability to select from 18 or more indicators and allow a provider to tailor which indicators they were measuring for any particular site/facility/service.

## Existing Quality Systems

165 of the 252 Provider respondents to Q9 indicate they do NOT participate in a Benchmarking system (65%). Of the 87 (34.5%) who indicated they do, 28 (11.1%) of them indicated they participated in Stewart Brown which is a financial, not care, benchmarking service.

COTA spoke with 'QPS' and 'Care XPS' but was unable to connect with 'Moving On Audits' to understand their services. While Care XPS only delivers Quality of Life metrics, QPS and we understand Moving on Audit, provides all three types of metrics – Quality of Care, Quality of Life and Consumer Experience.

The definitions, numerators and denominators of the various metrics were not identified to be consistent but broadly similar issues collected. The one advantage of many of these indicators is that various care systems have already mapped their data to produce the reports in the format needed for easy extract into the Benchmarking service. This reduces the cost and time for participating in such programs.

In preliminary discussions with the Aged Care Industry Information Technology Council, it was suggested that their experience is that a 12-month window would be required by Care Systems once details were finalised in order to develop, test, deploy and train staff. It is probable that if the Government required such items as mandatory that most providers would include such outputs in their next software release, while if it were optional the cost would be borne by the individual providers to pay for customised changes.

Given that the existing quality systems, particularly QPS, have such established data sets and wide range of metrics, our conclusion from conversations and focus group discussions is that including considerations of using such systems as part of future policy decisions could deliver a better outcome for consumers with less impact on providers.

## The desire for greater information about staff

The Plug-in deeper dive with consumers identified **staff issues as a key element of quality**. While this did not feature heavily in the national focus groups, open ended questions in the national survey saw strong staff themes within them including:

- Consumer Survey's Question 2 had open ended responses that when coded identified 112 comments about reliable staff, 66 comments about staff qualifications and 33 comments about relationship with staff;
- Consumer Survey Q7 provided 210 comments about Staff Attitude and Skills and 202 comments about reliable consistent staff;
- Consumer Survey Question 8 showed 'I want information about the qualifications and skills of staff' as the 6<sup>th</sup> highest ranked response for home/community care and the 3<sup>rd</sup> highest ranked response for residential care; and
- Consumer Survey Question 11 showed that "Staff friendliness" was the second highest ranked response for home/community care (473 respondents) and the 3<sup>rd</sup> ranked response in residential care (365 respondents).

This has led the project team to acknowledge a weakness of the focus group's structured approach meant that this issue did not appear in the same vein as the less structured approaches of The Plug-in's one-on-one interviews and open-ended questions. **COTA would encourage the Government to seek to identify staff related metrics as part of any future information available for consumers. The project identified no stand out indicator, likely meaning that there is no 'silver bullet' to this issue identified by consumers. Nevertheless, improvement on information available about staff can and should be considered.**

In residential care, this could be done through developing an appropriate formula to simply represent staff hours per resident against the distinct types and levels of staff on duty at a residential facility. Providers identified as part of the focus group discussions that any inclusion of 'staff ratios' however would need to account for the acuity of residents in order to be comparable. It was suggested that ACFI formulas could be used to provide consistent approaches to this. While COTA recognises this is a worthy goal to strive for, should this not be felt to be feasible, given the changing nature of client profiles, even a basic level of staff hours per resident, against bands of qualifications/experience would be of benefit.

For home care it would appear the pre-dominant issue is not ratios, but rather the consistency of staff attending in the home. In both systems, inclusion of staff satisfaction survey results, or staff net promoter score results, which many providers are already collecting, may assist. Work could be done at the simplest level by encouraging providers to provide information on the mix of skills and qualifications that staff have during the day or night time hours.

### The lack of information for consumers to make informed choices

One of the most concerning aspects of choice for consumers was a lack of readily available information.

In a recent pilot of an Aged Care Advisory Service by COTA Victoria, it was identified that no providers contacted as part of the pilot displayed their prices via My Aged Care, with only 30% displaying them online. During a Mystery Shopping process, COTA staff and volunteers made 25 mystery calls to random providers in Victoria. COTA identified through this process that if a consumer asks for the pricing information over the phone, one of the following (or a combination of all) responses might be received:

- That no price list is available
- A refusal of prices if the consumer is not willing to sign up with them (customer centric sales technique)
- That an appointment in the home must be made to discuss their options (customer centric sales technique)
- A follow up email of options (if you had enough information about what services you wanted)

It is unacceptable in a market system where consumers are often in moments of stress and in need of information to make informed choices, that such barriers to receiving information exist.

My Aged Care information to assist consumers in making choices is inconsistent, with not all providers readily sharing information as part of the data available. A quick analysis of the My Aged Care data released on [www.gen-agedcaredata.gov.au](http://www.gen-agedcaredata.gov.au) shows many pieces of critical information that a consumer might use to filter their choices simply are not available in My Aged Care.

#	%	Description
3475	83.9%	Do not state their public holiday loading charges
2991	72.2%	Provide no information on the languages they service
2774	67.0%	Provide no information on the religions they identify their services with
2716	65.6%	Do not provide an average percentage of package funds available for services
2440	58.9%	Provide no information on the culture/s they support
1888	45.6%	State they offer Self-Management Services
1688	40.7%	State they don't provide any specialised services
1641	39.6%	Do not state whether 24/7 care is or is not available
1589	38.4%	State they don't provide services to any Special Needs Groups
1395	33.7%	State their exit fees are \$0
1321	31.9%	State their exit fees are \$500 or more
865	20.9%	State they do not provide case management services
783	18.9%	State they don't provide Case Management Services
778	18.8%	Do not provide a URL for their organisation
404	9.8%	State they don't have availability to take on Level 1 HCPs
242	5.8%	State they don't provide Level 1 HCPs
85	2.1%	State their exit fees are \$900 or more
40	1.0%	State the average % of services is 50% or less
18	0.4%	Don't state whether they do or don't provide Level 1 HCP's
<b>4143</b>	<b>100%</b>	<b>Total Provider Entries in Gen Data Search Finder Information dated December 2017</b>

*COTA Australia My Aged Care Data Analysis – Service Finder Populated fields summary table*

This industry wide challenge of a lack of data was first identified by COTA in May 2017 when COTA conducted a preliminary analysis of My Aged Care identifying that there were multiple entries for many providers in a single postcode search.

While we are unable to provide system wide data on publication of prices as this information is not contained in the My Aged Care data provided COTA Australia's analysis of all providers in the three postcodes found 9.4% of providers in that sample had pricing information available. Broad results of the three random postcodes analysed the results are as below.

A review of this work in January 2018 identifies the same number of issues remain.

	<b>Number of providers in search results</b>	<b>Number of results that are unique providers</b>	<b>Number of providers repeated in search</b>	<b>Number of providers who appeared more than once</b>	<b>Range of repeat occurrence</b>	<b>Most commonly appearing frequency (Mode)</b>
Postcode A VIC Metro	100	47% (47)	53% (53)	16% (16)	2 – 17 times each	2
Postcode B Remote NSW	55	41.8% (23)	58.19% (32)	18.2% (10)	2 – 7 times each	3
Postcode C Regional QLD	57	45.6% (26)	54.3% (31)	19.2% (11)	2 – 19 times each	2

*COTA Australia My Aged Care Data Analysis Summary Table*

## Appendices

### 1. Sample of Promotional Materials

- a. Social Media promotion
- b. Email to COTA members
- c. Media Release

### 2. Literature Review<sup>^</sup>

**Completed by Carrie Hayter Consulting**

### 3. Online Survey – Providers and Consumers

- a. **Online Survey Summary Report (Word)<sup>^</sup>**
- b. Consumer Survey with open-ended responses (PDF)
- c. Consumer Survey Data Summary Responses including open ended text (Excel)
- d. Consumer Survey comparing older people to support people responses (PDF)
- e. Provider Survey with open-ended responses (PDF)
- f. Provider Survey Data Summary Responses including open ended text (Excel)

### 4. Transcripts of Focus Groups

### 5. **The Plug-In Report<sup>^</sup>** – Quality in aged care through consumers eyes

Summary of the outcome of the deeper dive consultation with consumers in South Australia

<sup>^</sup> - *The Literature Review, The Summary of the online report and The Plug-In Report will be released publicly. All other appendices have been provided to the Department for their information.*



# APPENDIX - LITERATURE REVIEW: Thinking about choices and quality in aged care

**Prepared by Carrie Hayter Consulting  
for COTA Australia**

**January 2018**

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## Executive Summary

This literature review is part of a COTA Australia policy project, *Thinking about Quality and Choices in Aged Care*. The project has four broad aims:

1. To identify with older people and their supporters what types of quality information they need to make informed choices about aged care;
2. To explore the role of government in providing indicators of quality in aged care;
3. To explore how providers can be encouraged to deliver services that are higher quality than the core standards?
4. Identify what quality (including benchmarking & continuous improvement systems) are currently used *by aged care providers*.

For older people and their supporters, the research questions for the literature review included:

- How do older people and/or their supporters make decisions, in particular, in choosing an aged care provider?
- What information do older people and/or their supporters need to choose an aged care provider?
- What support do older people and/or their supporters need to choose an aged care provider?

In relation to the public reporting of quality information and the role of government and aged care providers the literature review has the following questions:

- What publicly available quality information is shared in comparable countries (Europe, America, Canada and Australia)?
- What impact does publicly available quality information (quality of care, quality of life, quality indicators) in comparable countries (Europe, America, Canada and Australia) have on how older people and/or their supporters choose an aged care provider?
- What is the role of government in comparable countries (Europe, America, Canada, and Australia) in collecting and providing quality information about aged care?

The literature review uses the term 'older people' to describe a person who is aged 65 years and over. A person who provides unpaid support to an older person is referred to as a supporter.

The term 'public reporting' is used to describe the publication of information and reports on the quality of care of aged care providers for use by older people and their families, purchasers, regulators and other providers.

## Key themes from the literature review

### Choice and Control for Older People

A central policy premise of aged care reforms in Australia is choice and control for older people and their supporters who use aged care services (Aged Care Sector Committee, 2016 ; Productivity Commission, 2011 ). Choice policies can be used to improve access to providers or services, encourage new entrants to markets, and send signals to care providers to improve their quality, efficiency, and performance to attract more users (Kate Baxter & Glendinning, 2011). For older people and their supporters, choice may derive a sense of autonomy and control from being able to choose who supports them and in what context.

Section 2.1 explores the challenges and opportunities of choice. For choice policies to meet their potential a range of supportive factors is needed. Firstly, there needs to be a market for care providers so that people can choose (Kumpunen, Trigg, & Rodrigues., 2014 ). Secondly, older people and their supporters need good knowledge of the system, as well as access to timely, accurate and meaningful information on the quality of providers to compare providers and to choose (Victoor, 2012). Thirdly, there needs to be some flexibility and portability of funding to enable people to choose or change providers.

### Decision making, older people, and their supporters

Section 2.2 explores how people and their supporters make decisions and highlights that rational decision making for actual and potential users of aged care (older people and the people who support them) is challenging. The provision of comparative quality information, in theory, should enable users to seek out the data and the information they need to compare and choose a provider. However, for this to constitute a rational choice, people need to identify their own preferences, to understand there are differences in quality between providers, to know how to access quality information about providers and be able to interpret complex pieces of information to choose a provider that can benefit them(Kumpunen et al., 2014 ). Furthermore, there is limited publicly available information for older people and their supporters in Australia which makes it difficult for people to compare information.

Older people and the people who support them to choose an aged care service are not a homogenous group and make choices in different ways. While some people make conscious deliberate decisions based on comparing information, other people make choices based on emotional or social processes, often relying on word of mouth or recommendations from friends, families and/or aged care professionals. Furthermore, research from psychology and marketing literature identifies that people can only process up to seven pieces of information at any point in time (Miller, 1956) while others argue any more than five choices (Schwartz, 2004) could paralyse decision making because people become overwhelmed by information.

Research also identifies that families, friends, and supporters play an important role in choosing an aged care provider with some difference between choosing in-home support and residential aged care. Choosing a residential provider is heavily influenced by carers, friends, family, and professionals because of the vulnerability of older people moving into residential aged care (Armstrong, Armstrong, & Daly, 2012; Carnell & Patterson, 2017; Castle, 2002; Jeon & Forsyth, 2016). However, because of a lack of prior planning, families and older people often have very few criteria on which to base an informed choice (Lundis, 2000) of residential provider which is further complicated by a 'crisis escalation' where the older person and their family have limited time and options to choose an appropriate provider. This may be further complicated by people not having access to appropriate and timely information to able to compare residential aged care providers, the levels of comprehension and literacy of people to interpret quality information as well as the availability of residential aged care.

The complexity of decision making processes for older people and their supporters in choosing an aged care provider is poorly understood with evidence of the public reporting of quality information not influencing consumer behaviour in health and long-term care (M. Marshall, Hiscock, & Sibbald, 2002; N. Marshall, Skellele, Davies, & Smith, 2003; Rodriguez, Trigg, Schmidt, & Leichsenring, 2014; L. Trigg, 2012b; Lisa Trigg et al., 2017). The amount of publicly available information does not in itself influence the decisions or decision making processes of older people (Rodriguez et al., 2014; Lisa Trigg et al., 2017). Furthermore,

information about quality of aged care could be communicated in more accessible ways to facilitate decision-making processes (Lisa Trigg et al., 2017) that includes engaging users (older people, carers, and purchasers) in the design of quality information.

## Public Reporting of Quality in Aged Care

### **What is Quality?**

Section 2.3 explore why quality in aged care is multi-dimensional and difficult to define. Common meanings of quality often include notions of efficiency, effectiveness, safety, comfort, and dignity (O'Keeffe, 2014). Quality may also include service accessibility, attitudes and behaviours of staff, continuity of support workers or staff, dignity, reliability and responsiveness of care workers (Malley & Fernandes, 2010) as well as clinical care, the physical environment and how people are encouraged to express their choices (Jeon & Forsyth, 2016).

Quality may also include 'quality of care' and 'quality of life' which are often used interchangeably because they are inter-related. Quality of care refers to the structure and process of care (for example, how care or support is delivered and where care is delivered (eg in the community or in residential aged care) or clinical care. In contrast, quality of life is an umbrella term that encompasses "many life dimensions, including, but not exclusively, physical, psychological, social economic and spiritual wellbeing" (Tomyn, 2017, p. 9) and it may include objective and subjective elements.

### **Public Reporting of Quality Information**

Section 2.4 explores what types of quality information in aged care are publicly reported. The public reporting of quality information may include information on mandated minimum standards, information on clinical care or outcomes (often referred to as quality of care) or information on how services change the quality of life (often referred to quality of life) of people who use them or consumer experience (the experience of people using a service). They can be targeted at different audiences such as purchasers, regulators, users or consumers of services and may be used to achieve accountability, reassurance, performance, failures, purchasing, efficiency, and as marketing tools ((Kumpunen et al., 2014 ; Longo DR., Land, & Schramm, 1997):

## Public reporting of quality information and changes in provider and consumer behaviour

Section 2.5 explores the evidence of the impact of reporting of quality information on changes in provider and consumer behaviour. There is mixed evidence of the impact on the public reporting of quality in health, long-term care, and aged care in changing provider and consumer behaviour (Mannion, Davies. H., & Marshall, 2005; N. Marshall et al., 2003; Rodriguez et al., 2014; Lisa Trigg et al., 2017). While research identifies that public reporting can change providers' behaviour (Rodriguez et al., 2014), there is limited evidence that public reporting has an impact on consumers choice of providers (Rodriguez et al., 2014, p. 84). Furthermore, there is low awareness of quality indicators among potential users with information often not presented in accessible formats. The literature identifies the importance of involving consumers in the design of public reporting systems on quality information to ensure they are accessible and easy to understand.

The importance of consumer experience is also identified in Section 2.6 which explores the evidence for on-line trip advisor type systems as a mechanism for consumers to report on their consumer experience of using services. Some key themes include involving older people and their supporters in the design of any system and making sure it is simple and in accessible formats.

### Role of Government across OECD nations in collecting and reporting quality information in aged care

Across OECD countries comparable to Australia, most have some form of public reporting of quality information of aged care (both in-home support and residential aged care). However, there are differences in terms of what is reported with some countries focusing on quality of care and others focusing on quality of life and quality of care. Recent developments focus more on the consumer experience of aged care and mechanisms to publicly report consumer experience as well as quality of life of people using the aged care service. Section 2.6 discusses the role of government in collecting and reporting quality information. An overview of current systems across comparable nations is at Appendix One.

The research also identifies the importance of designing public reporting systems to meet the needs of different stakeholders and actors who use the aged care system. The information that consumers need to make informed choices may be different from the government who want to ensure that aged care services meet mandated national standards.

## Background

This literature review is part of a COTA Australia policy project, *Thinking about Quality and Choices in Aged Care*. The project has four broad aims:

1. To identify with older people and their supporters what types of quality information they need to make informed choices about aged care;
2. To explore the role of government in providing indicators of quality in aged care;
3. To explore how providers can be encouraged to deliver services that are higher quality than the core standards?
4. Identify what quality (including benchmarking & continuous improvement systems) are currently used by aged care providers.

For older people and their supporters, the research questions for the literature review included:

- How do older people and/or their supporters make decisions, in particular, in choosing an aged care provider?
- What information do older people and/or their supporters need to choose an aged care provider?
- What support do older people and/or their supporters need to choose an aged care provider?

In relation to the public reporting of quality information and the role of government and aged care providers the literature review has the following questions:

- What publicly available quality information is shared in comparable countries (Europe, America, Canada and Australia)?
- What impact does publicly available quality information (quality of care, quality of life, quality indicators) in comparable countries (Europe, America, Canada and Australia) have on how older people and/or their supporters choose an aged care provider?
- What is the role of government in comparable countries (Europe, America, Canada, and Australia) in collecting and providing quality information about aged care?

## Terminology

The literature review uses the term 'older people' to describe a person who is aged 65 years and over. A person who provides unpaid support to an older person is referred to as either a supporter.

'Public reporting' is used to describe the publication of information and reports on the quality of care of aged care providers for use by older people and their families, purchasers, regulators and other providers. This can include information on the quality of care, quality of life, quality indicators or consumer experience as well as meeting mandatory standards (see Section 2.3).

## Literature Review Process

The literature review used a snowballing technique based on existing national and international literature on quality, and choice, information, older people and carers from existing national and international research. The literature review included academic peer-reviewed research articles and some non – academic or grey literature.

## Literature Review

### Background

A central policy premise of aged care reforms in Australia is choice and control for older people and their carers or supporters who use aged care services (Aged Care Sector Committee, 2016 ; Productivity Commission, 2011 ). Le Grand argues that choice and competition is fundamental in bringing about improved outcomes for service users and responsiveness and efficiency of services (Le Grand, 2007). Policies promoting choice can improve access to services, encourage new entrants to markets, and send signals to service providers to improve their quality, efficiency, and performance to attract more users (Kate Baxter & Glendenning, 2011). For older people and their supporters, choice may derive a sense of autonomy and control from being able to choose who supports them and in what context.

For choice policies to meet their potential for older people and their supporters, a number of supportive factors are needed. Firstly, there needs to be a market for care providers so that people can choose (Kumpunen et al., 2014 ). Secondly, older people and their supporters need a good knowledge of the system, as well as access to timely, accurate and meaningful information on the quality of providers to enable people to compare providers and to choose (Victoor, 2012). However, the type of information users or potential users of aged care need and use is poorly understood (Rodriguez et al., 2014; Lisa Trigg et al., 2017). Thirdly, there needs to be some flexibility and portability of funding to enable people to choose or change providers.

In principle, most would not argue against 'choice' because it supports the independence of older people. However, the issue of choice and how to empower older people and their supporters to make informed decisions and choose an aged care provider is complex. In particular, there are questions about how older people act in a market of care, the decision making processes (for older people and their supporters or allies) in choosing a provider, the types of information people need to support informed choices including how this information could be presented in accessible formats.

One way of overcoming the information divide between older people and their supporters and the people working in the aged care system is through the provision of information about quality. There is significant debate about whether the public reporting of quality information in health care and aged care changes consumer behaviour. However, in order to understand this, it is important to explore how older people and their supporters make decisions when choosing an aged care provider.

### Decision making for older people and their supporters

There is significant debate about how people make decisions (particularly older people and their supporter) in choosing a health or aged care provider. Some contend that people make planned and deliberate approaches to choosing a care provider, weighing up the pros and cons of any decision (Kumpunen et al., 2014 ). Others contend that it is a complex social and emotional process influenced by changing circumstances and life course events over time (K. Baxter & Glendenning, 2013; Hillcoat - Nalletamby, 2017; Moffat, Higgs, Rummery, & Ree Jones, 2012). Decision-making processes are often influenced by the complex interdependence between older people and their friends, families or carer and/or aged care staff and professionals (Petriwskyj, Gibson, & Webby, 2015). Furthermore, it has been described by consumers as an emotional process (K. Baxter & Glendenning, 2013) with some people who use social care services reporting poor decision-making ability, and many people relying on professionals or personal networks to guide decision-making processes. Despite the differences in how people choose (whether it is a process of weighing up different pieces of information or an emotional, social and cognitive process) people are applying a logic to decision making that makes sense for them.

Rational decision making for actual and potential users of aged care (older people and their supporters) is challenging. The provision of comparative quality information, in theory, should enable users to seek out the data and the information they need to compare and choose a provider. However, for this to constitute a rational choice, people need to identify their own preferences, to understand there are differences in

quality between providers, to know how to access quality information about providers and be able to interpret complex pieces of information to choose a provider that can benefit them (Kumpunen et al., 2014 ).

Decisions made by people about their current and future care arrangements are complex and the positioning of older people and their supporters as 'choosers' may have oversimplified how people choose providers and engage with services. Some researchers question the positioning of older people and their supporters as rational 'choosers' (Barnes & Prior, 1995; Clarke, 2006; Kumpunen et al., 2014 ). Furthermore research from the UK in in-home care contends that some older people are often reluctant to take control or be 'choosers' and make decisions about their budgets and support (Glendinning et al., 2008; Moffat et al., 2012; Rabiee, Baxter, & Glendenning, 2016) despite the potential benefits (Glendinning, 2008). Although research on the impact of personalised budgets across ten local authorities in England identified positive outcomes for older people (Hatton & Waters, 2013) with engagement and participation of older people in planning as critical to achieving positive outcomes. This suggests that engaging older people in planning processes, and providing timely information in a format they understand may enhance decision-making processes.

The role of families, friends and supporters in assisting older people to make decisions about aged care is important, particularly in choosing residential care. Because of the vulnerability of many older people moving into residential aged care, carers, friends, family, and professionals are often involved in decision-making processes (Armstrong et al., 2012; Carnell & Patterson, 2017; Castle, 2002; Jeon & Forsyth, 2016). However, because of a lack of prior planning, families and older people often have very few criteria on which to base an informed choice (Lundis, 2000) of residential provider which is further complicated by a 'crisis escalation' where the older person and their family have limited time and options to choose a provider. This may be further complicated by people not having access to appropriate and timely information to be able to compare residential aged care providers, the levels of comprehension and literacy of people to interpret quality information as well as the availability of a residential aged care.

There are also differences in drivers of choice and the types of information that people need, prior to entry to residential aged care service and after admission (Jeon & Forsyth, 2016). In a review of Australian research and grey literature between 2006 and 2016 reviewing 47 articles, the drivers of choice of a residential aged care home for people include:

- physical environment;
- location;
- maintaining identity;
- keeping independence;
- maintaining continuity;
- staff capability;
- provision of care with respect and dignity;
- availability of care and health services; and
- trusting management.

The key domains of quality for residential aged care included: choice, respect and dignity, physical environment, social environment, functional environment, staff actions and interactions, organisational environment and resources; and clinical and personal care (Jeon & Forsyth, 2016). The review contended that it is important to connect the types of information that people need to choose a residential provider with the key domains of quality that residential aged care services should report on.

## What is quality in aged care?

### **Quality of Life and Quality of Care**

Quality in aged care is multi-dimensional and difficult to define. Common meanings of quality often include notions of efficiency, effectiveness, safety, comfort, and dignity (O'Keeffe, 2014). Quality may also include service accessibility, attitudes and behaviours of staff, continuity of support workers or staff, dignity, reliability and responsiveness of care workers (Malley & Fernandes, 2010) as well as clinical care, the physical environment and how people are encouraged to express their choices (Jeon & Forsyth, 2016). Research identifies many challenges in assessing quality because:

- it is complex and some aspects of quality may be in conflict with one another ( for example, providing a safe environment may restrict a person's quality of life – such as providing a safe environment that restricts a person's access to the community);
- it may not be immediately visible to people and the outcomes of support may take time to have an impact;
- the understanding and interpretations of quality may be subjective based on an individual's experience with significant differences between stakeholders such as older people, their supporters and aged care staff;
- assessing the impact of support is affected by the relationship between the consumer and the person who supports them which may impact on objective assessments of support;
- There are clinical or technical aspects of quality that require detailed skills and expertise to assess such as complex nursing care (Kumpunen et al., 2014 ; Malley & Fernandes, 2010).

The terms 'quality of care' and 'quality of life' are often used interchangeably and they are inter-related. However, quality of care and quality of life are different concepts and measure different aspects of care or support. Quality of care refers to the structure and process of care, for example, how care or support is delivered and where care is delivered (eg in the community or in a residential aged care service) and is often referred to as 'clinical care'. In contrast, quality of life is an umbrella term that encompasses "many life dimensions, including, but not exclusively, physical, psychological, social economic and spiritual wellbeing" (Tomyn, 2017, p. 9) and it may include objective and subjective elements. For example, objective quality of life may measure a person's physical health, whereas subjective measures are about how a person feels about their state of health. Quality of life measures in aged care tends to measure the impact of support on aspects of a person's life ( eg, health, having control over daily life). There is a relationship between quality of care and quality of life because "effective aged care delivers quality of life for care recipients, not just quality of care"(Carnell & Patterson, 2017, p. 3)

In terms of developing quality indicators in aged care, they tend to focus on the structure, process, and outcomes of care. For example, quality in aged care could be about outcomes for people who use aged care, the process of care (for example how clinical care or medication is managed for people), and the settings in which care takes place often referred to as the structure of care (Donabedian, 2005; Kumpunen et al., 2014 ). Some examples of structural, process and outcome indicators are described in Table One.



**Table One – Examples of structural, process and outcome indicators**

Structural Indicators	Process indicators	Outcome indicators
Staff ratios	People who have had vaccinations (eg for the flu)	Mortality rates and what people died from
Single rooms	Administration of prescribed medications)	Whether people have choice over what they eat
Availability of particular equipment (eg hoists, wheelchairs)	Unexplained changes in the weight of people	Supporting people to maintain social relationships and connections

*Adapted from (Kumpunen et al., 2014 p. 20)*

Historically in aged care in Australia, the reporting of quality information has focused on structural and process indicators rather than outcome indicators or the experiences of consumers using aged care services (both residential and in-home support). Relying on structural and process measures and attributing them to outcomes can be misleading (Kumpunen et al., 2014 ). However, there is a growing awareness of the importance of the relationship between support and quality of life and capturing the experiences of consumers using services.

Research highlights the importance of quality of life and quality of care in supporting people to live well in residential aged care (Bradshaw, Playford, & Riaz, 2012; Jeon & Forsyth, 2016). In a systematic literature review of residential care home life and how to enhance residents quality of life, 31 research articles were analysed (Bradshaw et al., 2012). Four key themes impacted on residents' quality of life: acceptance and adaptation to life in residential care; connections with others; having a home-like environment and the caring practices (how care is provided to residents). The research suggests that quality of life and quality of care are equally important in how older people and their supporters choose a residential service (Bradshaw et al., 2012; Jeon & Forsyth, 2016).

There is also growing awareness of the importance of quality of life for older people using in-home supports. For example, the Adult Social Care Outcomes Tool (ASCOT) developed and tested in the United Kingdom and to a lesser extent in Australia, aims to capture information about an individual's social care-related quality of life (Personal Social Services Research Unit & Kent, 2017). Research and evaluation of the ASCOT indicates validity in measuring the relationship between quality of life of people using social care across a range of contexts (including residential aged care services) (Netten et al., 2011; Netten et al., 2012; Towers, Smith, Palmer, Welch, & Netten, 2016). The ASCOT also takes into account the different perspectives of carers with specific measures of quality of life developed for carers of people who use social care. Furthermore, Australian research used the ASCOT (as well as other measures including Activities of Daily Living) to test and develop an Australian Community Care Outcomes Measurement (ACCOM) Tool designed to measure the outcomes of in-home support for older people using case management and in-home support services (Cardona et al., 2017).

### **Consumer Experience**

The lived and subjective experience of older people and their supporters in using aged care services and how this information is captured and recorded is becoming increasingly important (OECD European Commission, 2013). In many OECD countries such as Denmark, Germany, Spain, United States, Netherlands and Canada there is an increasing focus on the experience of older people and their supporters in how they experience a service (OECD European Commission, 2013) Research highlights that many older people make decisions about support through accessing information through their personal networks and via 'word of mouth' recommendations (Rodriguez et al., 2014; Lisa Trigg et al., 2017). There is a growing interest in understanding how people share experiences through via online communities where consumers share information and experiences (Brown, Broderick, & Lee, 2007). In Australia, the recent Carnell Review of the National Aged Care Quality Regulatory processes (focusing on residential aged care) identified that more could be done to include specific indicators that reflect consumer perspectives and quality of life of people living in residential aged care (Carnell & Patterson, 2017, p. 65).

## Public reporting of quality information and the impact on consumer and provider behaviour

### **Why public reporting?**

The public reporting of indicators in long-term care (including aged care) emerged out of the United States (Rodriguez et al., 2014) largely in response to a deregulated health care system. Proponents contend that public reporting of quality information improves providers' performance and acts as a motivator for change (Berweck, James, & Coye, 2003), as well as providing transparent information to purchasers and users of long term care systems. Public reporting systems can be targeted at different audiences such as purchasers, regulators, users or consumers of services and may be used to achieve the following ((Kumpunen et al., 2014 ; Longo DR. et al., 1997):

- **Accountability:** increase accountability of providers to the public, patients, users or consumers, funders, and purchasers;
- **Reassurance:** Provide the public with reassurance as to the quality of care of aged care;
- **Performance:** Help improve the performance of providers by:
  - Helping to establish benchmarking (encouraging poor performers to catch up with other providers);
  - By creating concern among strong performers about losing their good reputation; and
  - By increasing responsiveness of providers overall.
- **Failures-** Identify and prevent failures in quality of care by encouraging providers to focus on quality problems;
- **Purchasing** – assist institutional purchasers of care in developing quality focused contracts and/ or payment schemes;
- **Efficiency** – Promote the efficiency in purchasing and the provision of services across aged care systems; and
- **Marketing tools** – allow providers to use results marketing tools to users of services.

The public reporting of quality in aged care or long-term care in America, Canada, Australia and Europe may include information about quality of care, quality of life or whether funded services have met mandated standards (see Appendix One - Table Two).

## Relationship between public reporting on quality and changes in consumer and provider behaviour

There is mixed evidence of the impact on the public reporting of quality in health, long-term care and aged care for changing provider and consumer behaviour (Mannion et al., 2005; N. Marshall et al., 2003; Rodriguez et al., 2014; Lisa Trigg et al., 2017). In a literature review on the impact of public reporting in long-term care in the United States it concluded "there were no clear signals regarding the types of health practitioners or services, or the format of public reporting most likely to influence consumers' selections of providers" (Shekelle et al 2008, pg 6). They concluded that "the empirical literature on using publicly reported performance data to improve health outcomes is still scant.... with limited assessments of their usefulness to improve patient safety and patient-centredness" (Shekelle et al 2008, pg 6). Similar findings were demonstrated in a comparative study of the experiences of public reporting in long-term care in Europe (Austria, England, Finland, Germany, Netherlands, Spain and Sweden) with little evidence to show that public reporting has a significant impact on service users choice of providers (Rodriguez et al., 2014, p. 84). Furthermore, there was low awareness of quality indicators among potential users with information often not presented in accessible formats. Although the study identified that public reporting mechanisms on quality had contributed to discussions about quality measures in the different countries (Rodriguez et al., 2014).

The complexity of decision making processes for older people and/or their carers in choosing an aged care provider is poorly understood with evidence of the public reporting of quality information not influencing consumer behaviour (older people and their unpaid supporters) in health and long-term care (M. Marshall et al., 2002; N. Marshall et al., 2003; Rodriguez et al., 2014; L. Trigg, 2012b; Lisa Trigg et al., 2017). In a comparative study between England, the Netherlands and Spain of how older people use quality information to choose a residential aged care provider, it found that older people were most interested in “subjective experiences of other residents and relatives, rather than ‘hard’ objective indicators of aspects such as clinical care” (Lisa Trigg et al., 2017, p. 1). The study found that older people across the three countries were more interested in the quality of life issues including how residents rated their quality of life as well as whether residents thought it was a pleasant place to be. The findings indicate that the amount of publicly available information does not in itself influence the decisions or decision making processes of older people (Lisa Trigg et al., 2017). The study found that information about the quality of aged care could be communicated in more accessible ways to facilitate decision-making processes (Lisa Trigg et al., 2017) through engaging users (older people, carers, and purchasers) in the design of quality information. Recent developments in Australia with the piloting of a Consumer Experience Report with eleven items reported (Wells, Herd, & Fetherstonhaugh, 2017) for the Australian Aged Care Quality Agency, are promising, however, further research and testing is needed for in-home care.

A further complicating factor is the amount of information that people can process to aid decision-making processes. Some contend that people can only process up to seven pieces of information (Miller, 1956) while others argue any more than five choices (Schwartz, 2004) could paralyse decision making because people become overwhelmed by information. The ability to process information and make choices could be further complicated by many older people and their supporters having limited knowledge or direct experience of the aged care system. Furthermore, these issues may be complicated by the access to appropriate professional support to navigate transition periods and make informed decisions about care or support options for older people (K. Baxter & Glendenning, 2013; Lisa Trigg et al., 2017), and particularly for entry to residential aged care.

The impact of public reporting of quality on changing provider behaviour and improving quality of care in different settings is also mixed, with possible unintended consequences for staff and providers. An in-depth case study of the star rating system introduced in the NHS in 2005 in six acute hospitals in England (Mannion et al., 2005) concluded that “the star ratings as presently constituted did not represent a rounded or balanced scorecard of their own organisation’s performance and a widespread belief that the information used to calculate the ratings was often incomplete and inaccurate” (Mannion et al., 2005, p. 18). While the star ratings were viewed by some managers as useful (in that they gave the opportunity for driving change) the rating system had unintended consequences. The rating system had “inadvertently induced a range of unintended and dysfunctional consequences including tunnel vision and a distortion of clinical priorities, bullying and intimidation, erosion of public trust and reduced staff morale, and ghettoization” (Mannion et al., 2005, p. 18). While the study was small scale, it raised further questions such as:

- To what extent do global measures, such as star ratings, capture a valid and reliable assessment of overall performance?
- What is the most appropriate time period to be covered by performance ratings?
- How can organisations be encouraged and facilitated to make more productive use of performance data? (Mannion et al., 2005, p. 23).

### Consumer experience or user-generated reviews

There has been considerable debate about how to improve access and the type of information that older people and their supporters can use to make informed choices and decisions about their care and support (Fine, 2016; L. Trigg, 2012a). Some argue for a 'trip advisor' type online system that allows people to choose and compare information. In a discussion paper and literature review on using online reviews in social care, Trigg (2012) contends that any online system in social care needs careful planning, consideration, and design with end users of the system. The key issues identified in the paper include:

- Strategic policies are needed to ensure that sufficient and meaningful quality information is collected from users, carers and other representatives and that it is presented in ways which can be used effectively by both information-seekers and providers;
- Investment in a single site would reduce concern about low volume of traffic and comments (and anonymity), allow consolidation of information and advice and ensure economies of scale;
- The need for provision of reliable provider information – make one body responsible for managing information on the site, including inclusion and exclusion criteria;
- The need for effective integration with other channels, with clear sign-posting to other resources. Also, site investment would improve credibility and would be a driver for use and promotion by other stakeholders and other resources;
- Allowing people to communicate in different ways on the site, (eg users of services being able to communicate with other users). This helps preserve the anonymity of consumers and care professionals using the site, allows users to use preferred or alternative communication methods, and offers alternative means for sharing information;
- Validating and protecting identities would be important, to prevent care staff posing as a consumer; and
- Careful thought and planning are needed for design processes which support the effective routing of feedback to providers, helping one another to get better at sharing instructive stories (L. Trigg, 2012b).

The research and evidence identify that any online review system should be co-designed by the participants who will be using the site to enable people to use the information on the site for appropriate purposes.

### Role of government in comparable countries in collecting quality information and public reporting systems

Most OECD countries such as the United States, Canada, Germany, England, Netherlands, Denmark, Sweden and Spain have mandatory minimum standards of reporting in aged care or long-term care (see Appendix One – Table One) using the 'responsive regulation' framework. Braithwaite (2011) contends that responsive regulation should be about collaborative capacity building based on a pyramid of supports for business compliance and continuous improvement. He argues that "by conceiving regulatory culture not as a rulebook but as a storybook" (Braithwaite, J., 2011, p. 520) it will support different stakeholders to share stories about changing cultures in organisations. He contends that there are nine principles of responsive regulation that include:

1. Think in context, don't impose a preconceived theory;
2. Listen actively and structure a dialogue that:
  - Gives voice to stakeholders;
  - Settles agreed outcomes and how to monitor them;
  - Builds commitment to helping actors find their own motivation to improve;
  - Communicates firm resolve to stick with a problem until it is fixed.

3. Engage those who resist with fairness, show them respect by construing their resistance as an opportunity to learn how to improve regulatory design;
4. Praise those who show their commitment;
5. Signal that you prefer to achieve outcomes by support and education to build capacity;
6. Signal, but do not threaten, a range of sanctions to which you can escalate; signal that the ultimate sanctions are formidable and are used when necessary, though only as a last resort;
7. Network pyramidal governance by engaging wider networks of partners as you move up a pyramid;
8. Elicit active responsibility, resorting to passive responsibility (holding actors responsible for past actions) when active responsibility fails;
9. Learn; evaluate how well and at what cost outcomes have been achieved; communicate the lessons learned (Braithwaite. J., 2011, p. 476).

The difficulties in implementing 'responsive regulation' in Australia's residential aged care system was identified in the recent Carnell review (Carnell & Patterson, 2017) which reviewed the regulatory processes and systems in residential aged care in Australia. The review examined the best practice regulatory principles for residential aged care through a review of seven countries that faced similar challenges to Australia that included New Zealand, Canada, England, Germany, the United States, the Netherlands, and Norway. The best practice key principles include good governance, appropriate choice of standards and responsive regulation to encourage and enforce compliance. The review identified that Australia currently does not meet the best practice regulatory principles for residential aged care in:

- good governance (particularly in relation to publicly available data which impacts the scope for independent and comprehensive assessment of the system);
- appropriate choice of standards (with a need to focus on outcomes for consumers or users of the aged care system); and
- the use of responsive regulation to encourage and enforce compliance (Carnell & Patterson, 2017).

Policy directions across many OECD countries in aged care is not just about meeting minimum standards but also about innovation, with a focus on collecting information and data on consumer experience. This information is collected through an agreed process and tends to be publicly reported in a format that older people and their supporters understand (eg a traffic light system, or a ranking system). A comparison of the key differences between OECD countries is included in Appendix One- Table Two.

## Conclusion

This literature review identified some key evidence in relation to how older people and their unpaid carers make decisions and choose services in a deregulated market. Some of the key messages from the literature in designing a system for Australia include:

- Older people and their supporters often don't act rationally when choosing an aged care provider. Some people may want to systematically compare different pieces of information, however, many people rely on word-of-mouth or advice from friends, families and other health professionals. This means that the provision and reporting of quality information need to cater for the diversity of older people and their supporters.
- Many older people use family and friends to make choices about an aged care provider, particularly when choosing a residential care service. This means that quality information needs to be provided in a format that also meets the needs of these stakeholders.
- Different actors or stakeholders in the aged care system want different information. While Government regulators and funders want information about quality and safety and clinical care, older people and their supporters may want information about how the service improves a person's quality of life rather than focusing on quality of care;
- Any quality information needs to be accessible and in a format that has meaning for older people and their supporters. It is possible that some people may use online communities to share information, however, it is more likely with the current cohort of older people that they use their existing networks or word of mouth to choose an aged care provider.
- Providers need to consider the importance of providing publicly available quality information as a way of marketing their services to older people. It needs to include information that is also relevant to the aged care provider and purchasers in an increasingly marketised system.

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## Attachment One - Overview of approaches to public mandatory reporting in aged care across comparable OECD Countries

Country	Responsibility for publishing quality information	Responsibility for data collection	Information Displayed	Format	Method of Collection	Coverage	Access
Australia	Australian Aged Care Quality Agency	Australian Aged Care Quality Agency	Residential Aged Care standards ( 44 outcomes) 4 standards <ul style="list-style-type: none"> <li>• Management systems, staffing, and organisational philosophy</li> <li>• Health and Personal care –</li> <li>• Care recipient lifestyle</li> <li>• Physical environment and safe systems</li> </ul> Home Care Common Standards Three Standards ( 19 outcomes ) <ul style="list-style-type: none"> <li>• Effective management</li> <li>• Appropriate access and service delivery</li> <li>• Service user rights and responsibilities</li> </ul>	Mandatory Accreditation on a three-yearly basis. Spot checks and unannounced visits	Inspections by reviewers. Sample of interviews with service users  Consumer experience reports being introduced in 2018	All approved providers in residential and in-home or community care	Information published on the Agency website <a href="https://www.aacqa.gov.au">https://www.aacqa.gov.au</a>  Not in accessible formats for users, difficult to understand, however, the consumer experience report is in more accessible formats but not clear what this will look like for in-home care
Austria	Federal Ministry of labour, Social Affairs and Consumer Protection	Providers Independent quality organisations	Themes of criteria <ul style="list-style-type: none"> <li>• Residents (9) eg autonomy, communication, nursing care palliative care</li> <li>• Staff (7)</li> <li>• Management (8)</li> <li>• Social context (3)</li> <li>• Learning organisation (3)</li> <li>• Plus at least 10 related performance indicators</li> </ul>	Voluntary certification is awarded based on average scores in indicators	Self-collected data as part of quality management systems in place rolled out since 2013 (pilot phase 2008-2012)	Residential care providers with quality management systems in place – rolled out since 2013 following a pilot phase (2008-2012)	Future: selected results to be published.

Country	Responsibility for publishing quality information	Responsibility for data collection	Information Displayed	Format	Method of Collection	Coverage	Access
England	Care Quality Commission	Care Quality Commission	Essential standards of safety and quality (28 standards in total, the following 16 apply to all providers) <ul style="list-style-type: none"> <li>• Involvement and information (2)</li> <li>• Personalised care, treatment, and support (3)</li> <li>• Safeguarding and safety (5)</li> <li>• Suitability of staffing (3)</li> <li>• Quality and Management (3)</li> </ul>	Compliance with each essential standards is marked with a green tick (complaint), a red cross (not compliant) or a grey cross (improvement needed)	Inspections supplemented	All registered providers of residential and domiciliary care	<a href="http://www.cqc.org.uk">www.cqc.org.uk</a>
Finland	National Institute for Health and Welfare (THL)	National Institute for Health and Welfare (THL)	Indicators (residential care) <ul style="list-style-type: none"> <li>• Health condition of residents</li> <li>• Residents' quality of life and care</li> <li>• Staff (eg staff-ratios and qualifications)</li> <li>• Housing, privacy</li> </ul>	Percentages, scores out of five and yes/no answers. Achievement of percentages of scores are shown using green coloured bar	Use of Minimum data set – Resident Assessment Instrument Data collected by qualified nurses	Residential care only, restricted to providers who consent to have their information displayed	<a href="http://www.palveluvaaka.fi">www.palveluvaaka.fi</a>
Germany	Medical Boards of the Sickness and LTC Insurers (MDK – Medizinischer Dienst der Krankenversicherung) an independent agency funded by the health insurers	Medical Boards of the Sickness and LTC Insurers (MDK – Medizinischer Dienst der Krankenversicherung)	Residential Care (82 items in total): <ul style="list-style-type: none"> <li>• Nursing and medical care</li> <li>• Care of residents with dementia</li> <li>• Social and everyday life support</li> <li>• Housing, meals, housekeeping, Home Care (49 Items in total)</li> <li>• Nursing care</li> <li>• Activities prescribed by a physician</li> <li>• Quality of organisation and grade of service</li> <li>• User survey</li> </ul>	Each element graded ( 1- Excellent, 5 – failing), plus composite grade for each provider (not including user survey grade)	Inspections and user survey	Compulsory for all residential and home care providers	<a href="http://www.mdk.de">www.mdk.de</a>

Country	Responsibility for publishing quality information	Responsibility for data collection	Information Displayed	Format	Method of Collection	Coverage	Access
Netherlands	IGZ/CVZ	From 2014 Quality Framework for Responsible Care (Kwaliteitsinstituut )	From 2014 Quality Framework for Responsible Care (Kwaliteitsinstituut) incorporating the Consumer Quality Index <ul style="list-style-type: none"> <li>Care (treatment)\life plan</li> <li>Communication and information</li> <li>Physical well-being</li> <li>Safety care content</li> <li>Domestic and living conditions</li> <li>Participation and social handiness</li> <li>Mental well-being</li> <li>Safety living/residence</li> <li>Sufficient and competent staff</li> <li>Coherence in care</li> </ul>	Star ratings ( 1- poor performance, 5 – good performer) determined using the numeric score assigned to the provider. Displayed with the mean of all participating organisations for comparison	Face to face interviews with a sample of nursing home residents; surveys with a sample of relatives representing residents with cognitive impairment; surveys with home care users	Compulsory for all residential and home care providers	Choose Better website <a href="http://www.kiesbeter.nl">www.kiesbeter.nl</a> which publishes information from the Quality Framework for Responsible Care
Sweden	Social styrlsen/ SKL National Board of Health	Social styrlsen/ SKL National Board of Health	Aidreguiden: All providers of residential, home and day care: <ul style="list-style-type: none"> <li>Residents with an updated care plan (%)</li> <li>Residents actively involved in the planning and implementation of their care plan (%)</li> <li>Staff with adequate training (%)</li> <li>Staff turnover (%)</li> <li>Procedures to prevent malnutrition implemented</li> </ul> For residential care providers only: <ul style="list-style-type: none"> <li>Risk assessment for pressure ulcers, falls and malnutrition</li> <li>Facilities (eg private rooms)</li> <li>Nutrition and meal planning</li> </ul>	Percentage of achievement shown, national average for comparison		Compulsory for all residential, home and day care providers. Information is gathered through mandatory reports from care providers and feedback from users of residential and home care. Providers are required to provide clinical data for national quality registries for specific conditions	<a href="http://www.socialstyrelsen.se/jamfor/aldreguiden/jamfor">www.socialstyrelsen.se/jamfor/aldreguiden/jamfor</a>

Country	Responsibility for publishing quality information	Responsibility for data collection	Information Displayed	Format	Method of Collection	Coverage	Access
Spain (Catalonia)	Department de Salut	Department de Salut	<ul style="list-style-type: none"> <li>• Accessibility indicators (3)</li> <li>• Effectiveness ( 7 indicators eg functional improvement after stroke, mortality rates)</li> <li>• Cost –efficiency ( 4 indicators)</li> </ul>	Numerical indicators	Self-collected clinical indicators	Pilot with 35 public nursing home providers	Not available
The United States of America	US Government Medicare	US Government Medicare		Star rating system			<a href="https://www.cms.gov/medicare/provider-enrollment-and-certification/certificationandcompliance/fsqrs.html">https://www.cms.gov/medicare/provider-enrollment-and-certification/certificationandcompliance/fsqrs.html</a>
New Zealand				Traffic light system			
Canada				Ranking System			

Source Adapted from (Rodriguez et al., 2014, pp. 86-88)  
(Carnell & Patterson, 2017)



# APPENDIX:

## Online Survey – Summary of Results

### Measuring Quality and Consumer Choice in Aged Care Project

**This summary was prepared by Carrie Hayter Consulting and COTA Australia.**

***January 2018***

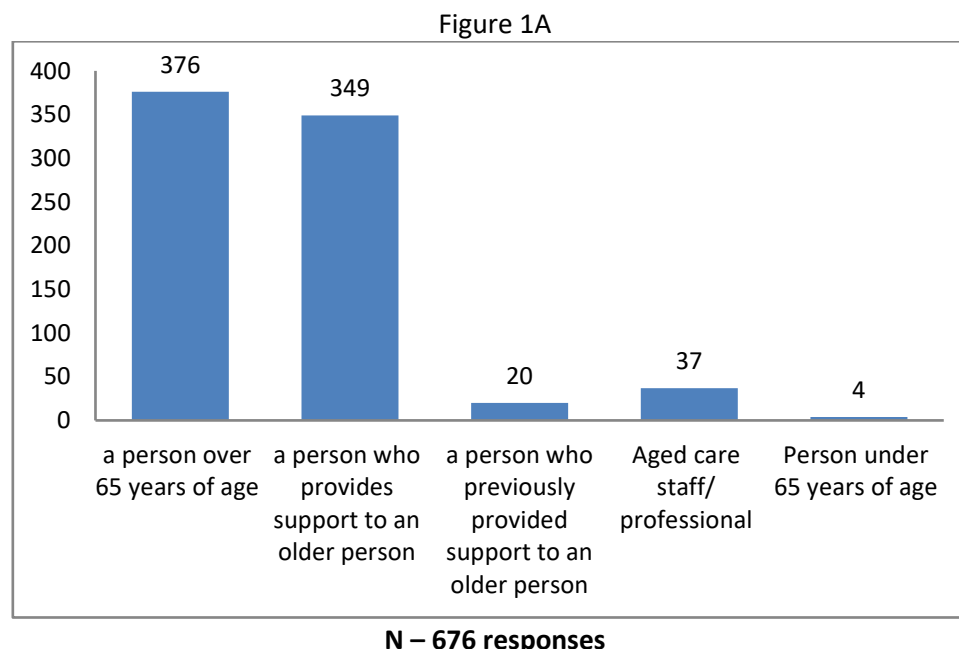
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## Consumer Survey Data

### Question 1 – Older Person, Support Person or Aged Care Staff

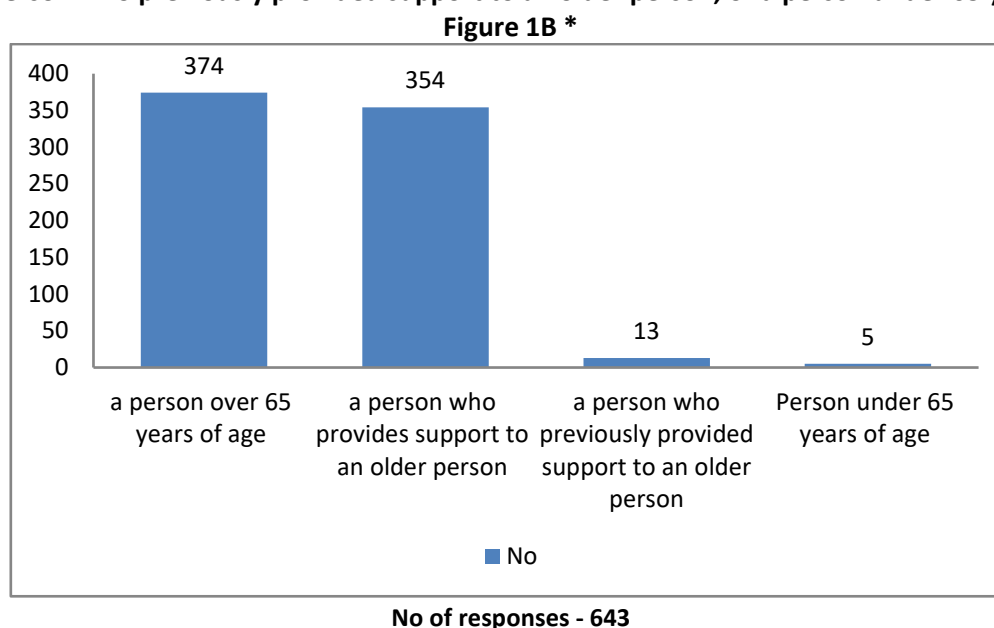
**Q1: Are you: a person over 65 years of age (an older person), a person who provides support to an older person, a person who previously provided support to an older person, aged care staff, professional, person under 65 years of age?**



This data was analysed and responses that were solely aged care staff and/or professionals and not also a person who provides support to an older person or an older person were taken out of the survey data. The number of responses after this analysis was 643 (see Figure 1B below). The data was analysed to create additional codes:

- a person who previously provided support to an older person; and
- a person under 65 years of age.

**1: Are you: a person over 65 years of age (an older person), a person who provides support to an older person, a person who previously provided support to an older person, or a person under 65 years of age?**



\*This figure is the coded data



**Question 2 - Most important consideration in choosing aged care (open ended)**

**Q2: What is the most important consideration for you and/or the person you support in choosing an aged care provider?**

Table 1 - What is the most important consideration for you and/or the person you support in choosing an aged care provider? (Coded Qualitative Data)

Ranking	Issue	No	%
1	Quality of care/ quality of life	170	26.44
2	Reliable Staff	112	17.42
3	Cost	89	13.84
4	Respecting the rights of older people	83	12.91
5	Personalised and Individualised Support	71	11.04
6	Staff qualifications	66	10.62
7	Quality of life	63	9.8
8	Promotes the independence of older people	52	8.09
9	Availability of Service	42	6.53
10	Relationship with Staff	33	5.13
11	Access to Medical and Allied Health	38	5.91
12	Location and proximity to family and community	36	5.6
13	Relationship with the Service	33	5.13
14	Good Food	25	3.89
15	Flexible Service	18	2.8
16	Access to meaningful activities	15	2.33
17	Dementia Friendly	7	1.09
18	LGBTI Inclusive	6	0.93
19	Culturally Inclusive	6	0.93

**No of Responses – 643**

See Excel spreadsheet Consumer Survey Data, Question 2 analysed data.

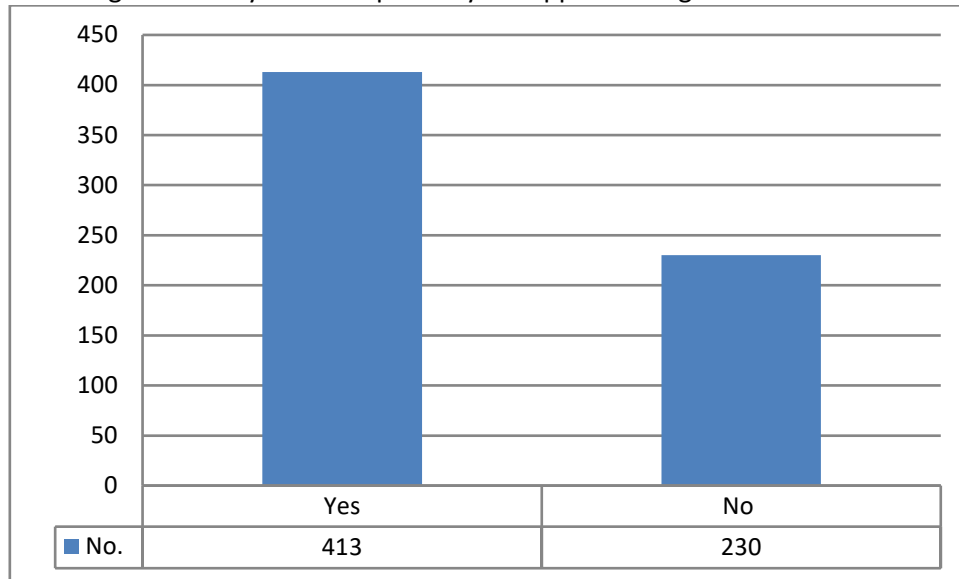
Q2 What is the most important consideration for you and/or the person you support in choosing an aged care provider?

Location Nursing Home Dignity Privacy Able Say Reliability  
 Place Cost Trust Service Communication  
 Quality Security Care Independence Staff  
 Not for Profit Needs Safe Respect Freedom  
 Honesty Cleanliness Access Easy to Understand Live  
 Able Provision of Genuine Standard Workers Safety Local  
 Aged Care Organisation Cost Level of Care  
 Needs Honesty Staff Affordability Quality  
 Happy Services Consideration Respect  
 Atmosphere Environment Trustworthy Life  
 Genuine Understanding Communication Proximity to Family Health  
 Family Member

### Question 3 – Using Aged Care Services

**Q3: Do you or the person you support use aged care services?**

Figure 2 - Do you or the person you support use aged care services?

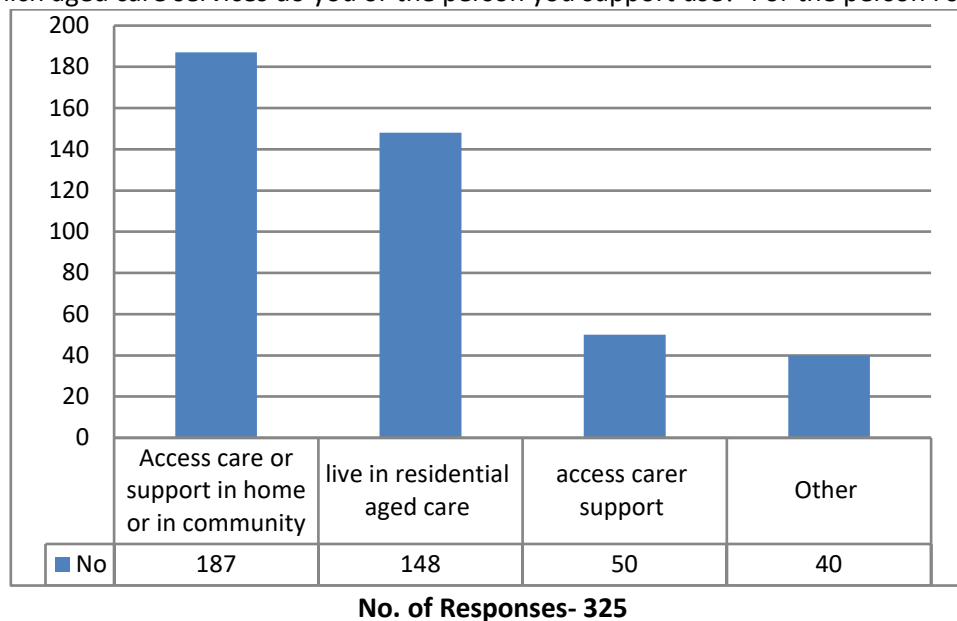


**No. of responses - 643**

### Question 4 – What aged care services are used

**Q4. Which aged care services do you or the person you support use? I or the person I support:**

Figure 3 - Which aged care services do you or the person you support use? I or the person I support:



The other category included: transport services, living in a retirement village, retirement living

**Question 5: Who helped you choose aged care?****Q5 - Who helped you choose your aged care provider (select all that apply)?**

The highest to lowest ranking of total responses is in Table Three.

Table 2 – Who helped you choose your aged care provider (select all that apply)?

Rank	Who helped you choose your aged care provider?	No of Responses	%
1	I was supported by my friends and family	90	27.6
2	I was supported by an aged care professional (e.g. Aged Care Assessment Team, Regional Assessment Team, staff working in aged care)	81	24.9
3	I made my own decision without any help	79	24.3
4	I feel I had no choice/ I was told which service I should use	56	17.2
5	I was supported by a health professional (e.g. Doctor, Social Worker, Physiotherapist, Occupational Therapist)	55	16.9
6	I was supported by my partner	27	8.3
7	I had no choice as there is only one provider in my area	24	7.2
8	I was supported by an aged care advocate	20	6.1
9	I had limited or no choice because of a lack of providers in my area	19	5.8
10	I had limited or no choice because of waiting lists	14	4.3
11	Difficult to choose because of lack of information	10	3
12	I was forced into the aged care system by the health system	8	2.4
13	I was recommended a provider by my partner	5	1.5
14	I had no choice because providers would not take the person I support	4	1.2
15	I was supported by other carers and their experiences	2	0.6

**No. of Responses- 325**

**Question 6: Where did you go for information?**

**Q6. Where did you (or the person you support) go for information about aged care providers (select all that apply)?**

The highest to lowest ranking of total responses is in Table Three.

Table 3 – Where did you (or the person you support) go for information about aged care providers (select all that apply)?

Rank	Answer Choices	No. of Responses	%
1	I visited the aged care service	134	41.23%
2	I spoke to people I trust (e.g. family and friends)	132	40.62%
3	I read promotional material from the provider (e.g. website, read a brochure)	119	36.62%
4	I searched for information using My Aged Care	107	32.92%
5	I searched for aged care providers via the internet	96	29.53%
6	I used the information from the Assessment team (e.g. list of services)	84	25.85%
7	I read information in a booklet about aged care providers (e.g. DPS Guide to Aged Care)	77	23.69%
8	I read reviews from people who use the service (e.g. I used a comparison website such as Aged Care Report Card or Aged Care Guide)	47	14.46%
9	I spoke to the My Aged Care contact centre	43	13.23%
10	I read the Accreditation report from the Aged Care Standards and Accreditation Agency	27	8.31%
11	I read information from a consumer advocacy service (e.g. Older Person's Advocacy Service)	16	4.92%
12	I read the Consumer Experience Report from the Aged Care Standards and Accreditation Agency	14	4.31%
13	I was not aware that information was available to compare	8	2.46%

**No of responses – 325**

## Question 7: What does quality & safety mean (open-ended responses)

### Q7 - What does quality and safety in aged care mean to you or the person you support?

This was an open-ended question, data was coded using thematic analysis and categorised according to key themes as described by respondents. These key themes are listed in Table Four.

Table 4 - What does quality and safety in aged care mean to you or the person you support? (Coded Qualitative Data)

Rank	Key Area	Number
1	Staff Attitude and Skills	210
2	Reliable and consistent staff	202
3	Showing respect for older people and their allies	167
4	Good communication with older people and their allies	95
5	Supporting independence	89
6	Providing individualised and being treated as an individual	67
7	Access to health and medical care as needed	53
8	People are supported to make choices	52
9	Nutritious and good quality food	49
10	That the person is safe	29
11	Meaningful activities	22
12	Access to support in the home or community	22
13	Meeting legislated standards of care	22
14	Value for money	15
15	Expertise in supporting people living with dementia	13
16	Happiness of people using the service	10

**N - 473**

Q7 What does quality and safety in aged care mean to you or the person you support?

Competent Regardless Nursing Home Freedom Checks  
 Language Important Staff 24/7 Trained Staff  
 Outings Services Listen Safety Secure  
 Provider Number of Staff Means Good Job  
 Support Maintain Independence Residents Recipient  
 Clean Effective Physical Environment Huge Amount  
 Easy Access  
 Great Deal Remain Independent Outside Common Sense  
 Good Standard Essential Quality of Life  
 Registered Nurse Important Big Aged Care  
 Compassion Safety Accommodation Needs  
 Palliative Care Services Pleasant Surroundings  
 Means Confidence Trained Staff Showering  
 Comfortable Regular Basis Future Able to Remain  
 Professional Staff Able to Trust

...

**Question 8: What information would you want to know**

**Q8. If in the future you had to CHOOSE an aged care provider (either residential or in-home or community) what information would you want to know and how would you want to access this information? (select all that apply)**

*NB: Due to the closeness of the responses, participants in the focus groups were asked to choose two of the below items as part of later focus groups to provide a clearer indication of consumer priority areas*

Table 5 – If in the future you had to CHOOSE an aged care provider (either residential or in-home or community) what information would you want to know and how would you want to access this information? (select all that apply)

	In Home or Community Service		Residential Aged Care Facility	
I want views from the people I know who have used the service (e.g. word of mouth from family and friends)	71.4%	363	71.4%	363
I want the views of people who have used that service	69.7%	354	67.9%	345
I would read online reviews from older people, friends and/or family who use that service	59.4%	302	58.07%	295
I want information about how the service improves the quality of life of older people (e.g. provides choices around food, social activities, etc)	70.5%	358	74.4%	378
I want information about how the service caters for people with diverse needs (e.g. Non English background, LGBTI, indigenous)	35%	178	38.6%	196
I would read Government auditor's reports on how the service meets or does not meet the national minimum standards	51.2%	260	57.7%	293
I would review information about complaints about the service	63.4%	322	66.7%	339
I want information about care measures by that aged care provider (e.g. residents experiencing pressure injuries, unplanned weight loss, use physical restraints)	53.5%	272	67.9%	345
I want clear information about how much I need to pay	76.2%	387	77.2%	392
I want to know the average hours of care per day that a service gives each person	68.3%	347	65.9%	335
I want information about the qualifications and skills of staff	68.1%	346	71.9%	365
I want information about the quality of life of people using the service	62.9%	320	71.9%	365
I don't know	3.1%	16	3.7%	19
Other (please specify) or comments				190

**No of responses – 508**

### In Home Care Ranked

If in the future you had to CHOOSE an **in-home or community provider** what information would you want to know and how would you want to access this information? (Question 8 – Analysed Data)

Responses were ranked from highest to lowest response by the no. of responses which is in Table Six.

Table 6 – Ranked Information needed to choose an in home or community provider

Ranking	Answer	No of responses
1	I want clear information about how much I need to pay	387
2	I want views from the people I know who have used the service (e.g. word of mouth from family and friends)	367
3	I want information about how the service improves the quality of life of older people (e.g. provides choices around food, social activities, etc)	358
4	I want the views of people who have used that service	354
5	I want to know the average hours of care per day that a service gives each person	347
6	I want information about the qualifications and skills of staff	346
7	I would review information about complaints about the service	322
8	I want information about the quality of life of people using the service	320
9	I would read online reviews from older people, friends and/or family who use that service	302
10	I want information about care measures by that aged care provider (e.g. residents experiencing pressure injuries, unplanned weight loss, use physical restraints)	272
11	I would read Government auditor's reports on how the service meets or does not meet the national minimum standards	260
12	I want information about how the service caters for people with diverse needs (e.g. Non-English background, LGBTI, indigenous)	178
11	I don't know	16

**No of responses – 508**



### Residential Care Ranked

If in the future you had to CHOOSE a **residential care provider** what information would you want to know and how would you want to access this information? (select all that apply) (Q8 of consumer survey – analysed data). Responses were ranked from highest to lowest response by the no. of responses which is in Table Seven.

Table 7 - Ranked Information needed to choose a residential care provider

Rank	Answer	No of responses
1	I want clear information about how much I need to pay	392
2	I want information about how the service improves the quality of life of older people (e.g. provides choices around food, social activities, etc)	378
3	I want information about the qualifications and skills of staff	365
4	I want views from the people I know who have used the service (e.g. word of mouth from family and friends)	363
5	I want information about the quality of life of people using the service	345
6	I want information about care measures by that aged care provider (e.g. residents experiencing pressure injuries, unplanned weight loss, use physical restraints)	345
7	I would review information about complaints about the service	339
8	I want to know the average hours of care per day that a service gives each person	335
9	I would read online reviews from older people, friends and/or family who use that service	295
10	I would read Government auditor's reports on how the service meets or does not meet the national minimum standards	293
11	I want information about how the service caters for people with diverse needs (e.g. Non-English background, LGBTI, indigenous)	196
12	I don't know	19

**No of responses – 508**

**Question 9: Statements (likert scale)****Q9 Please read the following statements and pick the response that most closely reflects your view**

Responses were ranked from highest to lowest response by the no. of responses which is in Table Eight.

Table 8- Ranked agreement with statements

Rank	Key Issue	Strongly Agree (SA)	Agree (A)	Strongly Agree (SA) and Agree (A) Total	% SA & A
1	I want consistent, easy to understand information that allows me to compare aged care providers	430	67	497	97.8
2	I want to know if an aged care provider has failed, met or exceeded national minimum standards	408	87	495	97.4
3	All aged care providers should report on how they meet mandated national standards	405	81	486	95.6
4	If I used an aged care service I would be happy to complete a quality of life survey	368	111	479	94
5	I would review information on care measures when choosing an aged care provider	384	93	477	94
6	It should be mandatory for all aged care providers to report on quality of care information (e.g. pressure injuries, unplanned weight loss, physical restraint)	380	91	471	92.7
7	It should be mandatory for all aged care services to make available information on older people's experiences and report on quality of life	380	91	471	92.7
8	I would use information about aged care measures if it were displayed on My Aged Care	333	87	420	82.6
9	I would like access to an advisory service to help me choose an aged care provider	261	116	377	74.2

**No of responses - 508**

**Question 10: Importance of Quality of Care Indicators**

**Q 10 - How important are the following measures for you in choosing a residential care provider? The number of people who have had:**

Responses were ranked from highest to lowest response by the no. of responses which is in Table Nine.

Table 9 – Ranked Important or Very Important ranking of quality of care indicators in choosing a residential care provider

Rank	Key Area	Very Important (VI)	Important (I)	Total Very Important and Important	% VI & I
1	medication incidents	365	97	462	93.00%
2	falls and fractures	334	118	452	91.3%
3	infections	357	94	451	91.1%
4	physical restraint	351	90	441	89.3%
5	pressure injuries	327	110	437	89.09%
6	unexplained weight loss	313	116	429	86.66%
7	depression	290	127	417	84.2%
8	vaccinations	239	148	387	78.1%

**No of responses - 495**

**Question 11: Importance of Quality of Life Indicators****Q11. How important are the following areas for you in choosing ANY AGED CARE provider?****Views of current residents or aged care consumers about:**

Responses were ranked from highest to lowest response by the no. of responses which is in Table Ten.

**Table 10 – Ranked Important or Very Important ranking of key areas in choosing any aged care provider**

Rank	Key Area	Very important	Important	Total	%
1	Being treated with respect and dignity	443	33	476	98.7
2	Staff friendliness	385	88	473	98.1
3	Feeling safe and secure	426	45	471	97.7
4	Being supported and encouraged to raise any concerns I have with the service	400	66	466	96.6
5	Food satisfaction	340	125	465	96.4
6	Their sense of independence	342	122	464	96.2
7	Having control over their daily life	335	126	461	95.6
8	Being supported to maintain social relationships and connections with the community	341	120	461	95.6
9	Maintaining and supporting spiritual, cultural, sexual and religious identity	288	146	434	90
10	How likely they would be to recommend the service to a family or friend	300	131	431	89.4

**No of responses – 482****Question 12: Any other Quality of Life / Consumer Experience Measures (open-ended)****Q12 Are there any other measures of 'quality of life' or 'consumer experience' you would like to know about?****Table 11 - Other measures of 'quality of life' or 'consumer experience' domains (coded)**

Measure Topic	%	No.
Activities/Social	21.60%	35
Complaints	13.58%	35
Staff	21.60%	35
Services	7.41%	12
Dignity/Individuality	6.17%	10
Dignity of Risk	2.47%	4
Other	8.64%	14
N/A	20.99%	34

**N -162** (See raw data in excel spreadsheet/PDF of open-ended responses)

**Question 13: Location of comparison information**

**Q13. Where should you be able to COMPARE information about two or more aged care providers? (select all that apply). I want information to compare available on:**

Table 12 – Where should you be able to compare information about two or more aged care providers (ranked)

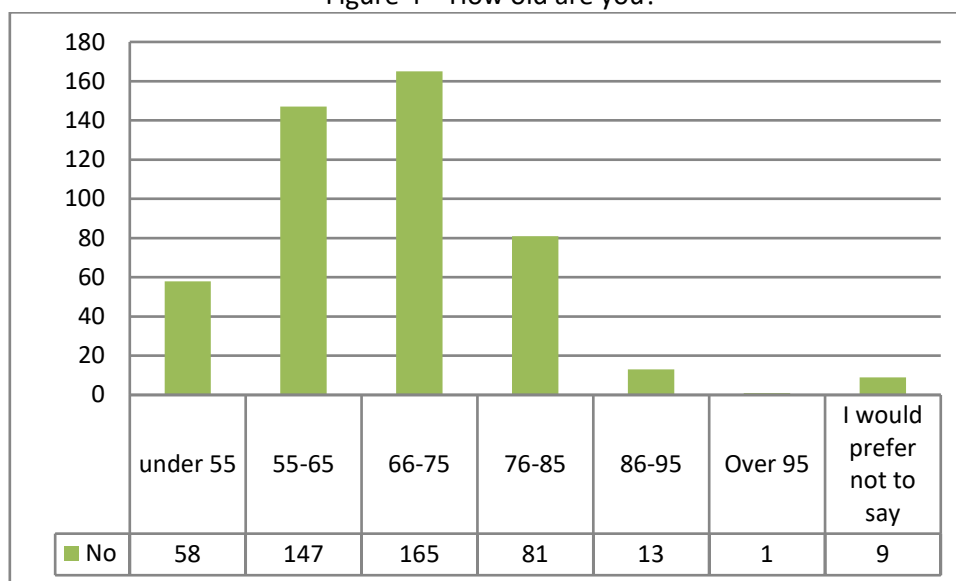
Rank	Answer Choices	Responses	
1	an independent organisation's website where all information about aged care is available	67.42%	325
2	the Australian Government's My Aged Care website	65.3%	315
3	a government website such as the Australian Aged Care Quality Agency's website	50.83%	245
4	a commercial comparison website, e.g. Aged Care Report Card	35.89%	173
5	the aged care provider's website	27.39%	132
6	I don't know	4.97%	24
7	I am not interested in comparing information	3.11%	15

**No of responses - 482**

## Questions 14 & 15 – Demographic Information

### Q14 – How old are you?

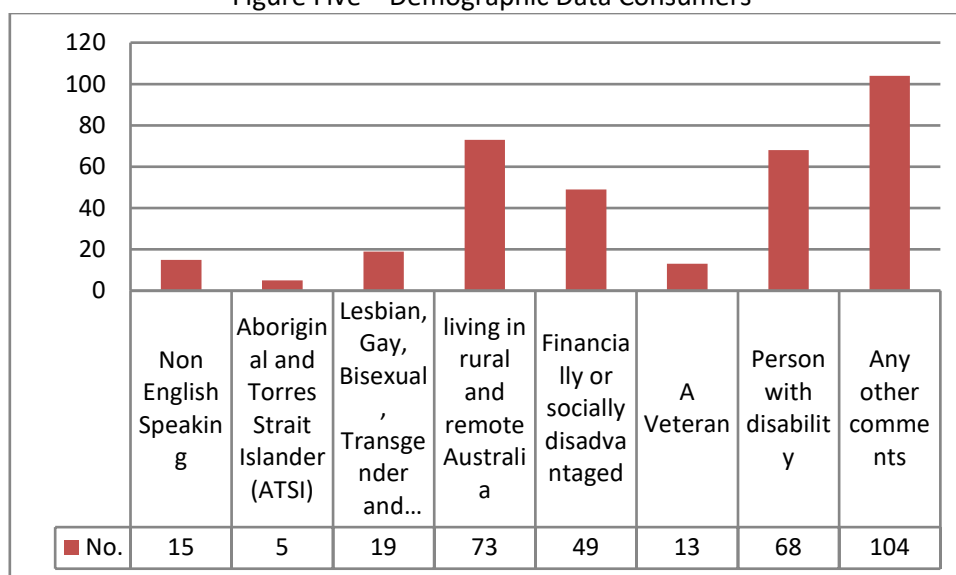
Figure 4 – How old are you?



No of responses – 474

### Q 15. Do you identify as?

Figure Five – Demographic Data Consumers



N- 258

## Service Provider Data

### Question 1 – 3 Background Data

#### Q1. Which aged care services does your organisation provide?

Table 13 - Which aged care services does your organisation provide?

Response	No	%
CHSP	326	78.3
HCP	284	68.2
Residential Aged Care	171	41.1
Other	71	17

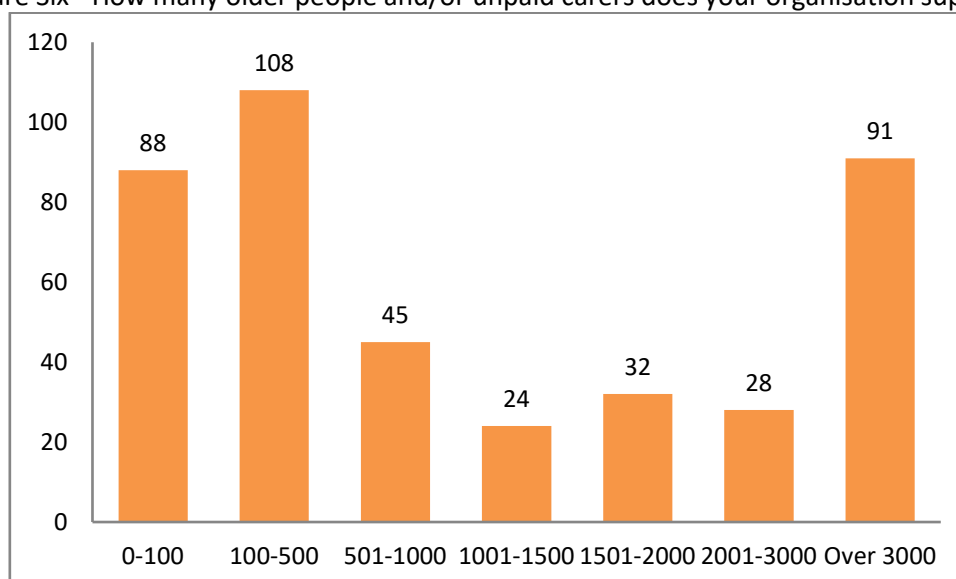
**No of Responses – 416**

Table 14 - Which aged care services does your organisation provide?

Response	No
CHSP	326
HCP	284
Residential Aged Care	171
Retirement/ Independent Living	18
Veterans	11
HACC state based	10
NDIS and Disability	8
Carer Support	7
Short Term Restorative Care	5
Allied Health	4
Community Visitor Scheme	3

#### 2. How many older people and/or unpaid carers does your organisation support?

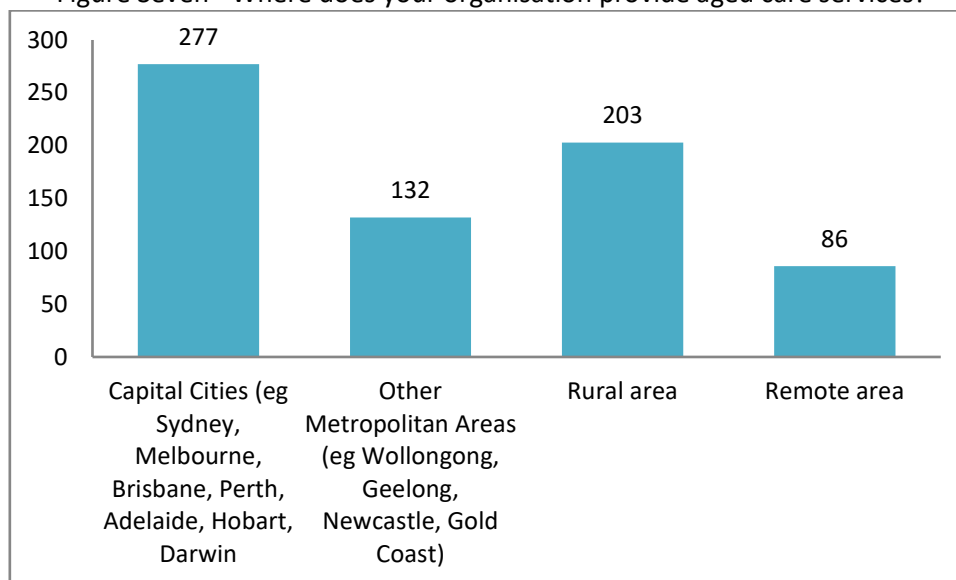
Figure Six - How many older people and/or unpaid carers does your organisation support?



### No of Responses – 416

#### Q3. Where does your organisation provide aged care services?

Figure Seven - Where does your organisation provide aged care services?

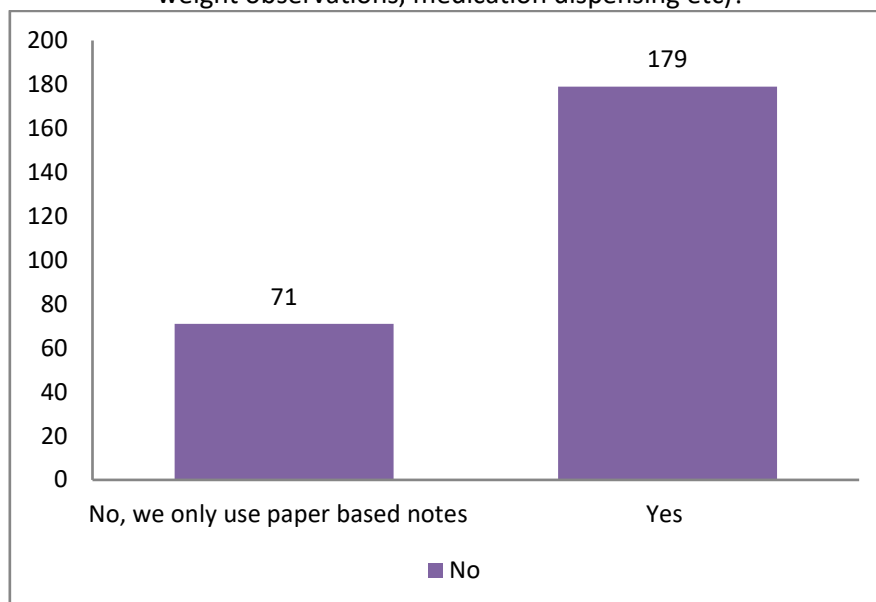


No of Responses – 416

#### Question 4: Quality Systems (Software programs to collect clinical data)

#### Q4. Does your organisation use a software program to collect/manage clinical or care data (e.g. weight observations, medication dispensing etc)?

Figure Eight - Does your organisation use a software program to collect/manage clinical or care data (e.g. weight observations, medication dispensing etc)?



N -250



Table 15 - Software systems that organisations used

Software System	No
ICARE	21
Procura	18
LeeCare	14
TCM	13
Autumn Care	10
TRACS	8
CommCare	7
TelstraHealth	6
ManAd	5
Gold Care	4
RiskMan	4
Platinum	2
ICRM	2
Routematch	2
TrakCare	1
SmartSheet	1
Microsoft Dynamics	1
Home Care Manager	1
Antares	1
Carnet	1

### Question 5: Quality of Life metrics collected

**Q5 Quality of Life is a broad term that encompasses many life dimensions such as physical, psychological, social, economic and spiritual well-being. Does your organisation use any system / tool to collect 'quality of life' metrics?**

Figure Nine – Does your organisation use any system/tool to collect 'quality of life' metrics?

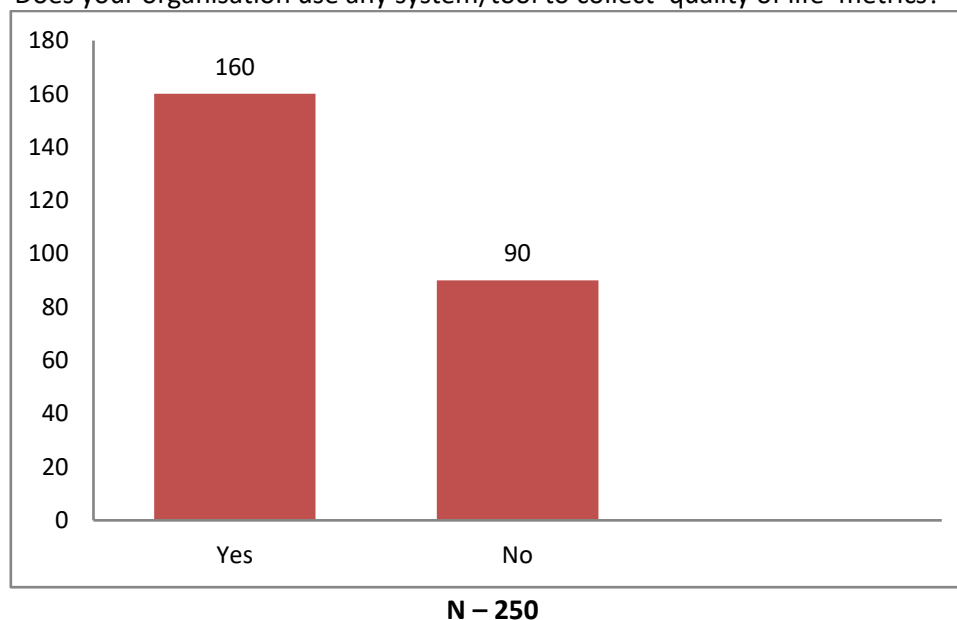


Table 16 – Tools used by service providers

Tool	No
Use our existing software system	48
Quality of Life	9
ASCOT	5
ECASE Health Metrics	3
Outcome Star	2
ICRM	1

### Question 6: Consumer Experience metrics collected

**Q6 Consumer Experience can be defined as how people experience a service - it could be about whether people feel listened to, it could be about whether people feel that staff respond to their issues or concerns. Does your organisation measure 'Consumer Experience'?**

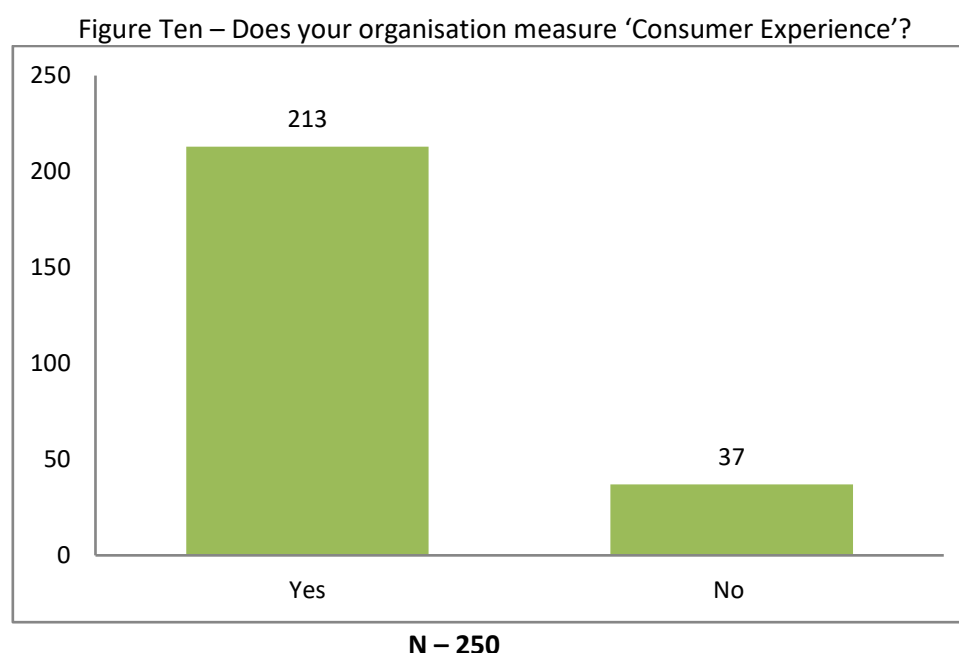


Table 17 – Consumer Experience tools used by service providers (\*)

Response	No
Consumer Surveys developed by the provider	174
Use existing software to collect data	14
Forums or focus groups	9
Consumer survey developed by external agency	7
Consumer Advisory Group	6
Internal surveys based on the AACQA Consumer Experience Surveys	3

\*This data was coded using thematic analysis

#### Qualitative data

The Qualitative data indicates a range of understanding of 'Consumer Experience'

#### **Some providers clearly have a sophisticated understanding :**

"Consumer experience is at the core of HCP (CDC model), with consumer's designing their services to meet their lifestyle preferences (including frequency of review)

- Residential and community services: annual consumer focus groups per site/region with a sample of consumers and representatives. Includes questions relating to communication, satisfaction with services, responsiveness to needs/concerns, choice, staff practices/respect, etc
- Collation and trending of formal compliments and complaints data
- Bi - Annual surveys (residential) regarding lifestyle program, hospitality services
- Survey of Retirement Living residents and residents using residential respite

<provider name> has recently conducted a large scale (one-off) project including consulting with consumers (18 focus groups) on what would be the optimal customer experience, to inform our business transformation. The Customer Experience Blueprint will inform the way we move forward. Consumer

sentiment and experience is also gathered and monitored via a range of social media channels “#9

“We have commissioned the <university name> to run one on one interviews with residents and clients every year across a number of different services to gain feedback against our Model of Care outcome areas, and consumer experience. We have just begun to partner with CareXpress (Aged Care Report Card) on consumer satisfaction and experience surveys at key touchpoints. In the past we have used QPS consumer experience and family satisfaction surveys.” # 19

“We have a Director, Consumer engagement to assist consumer engagement program delivery. We measure satisfaction, Net promoter score, complaints and compliments and perform random spot checks of incoming and ongoing telephone calls through service areas and central support centre. We are currently developing our organizational approach to innovation and human centred design.” # 64

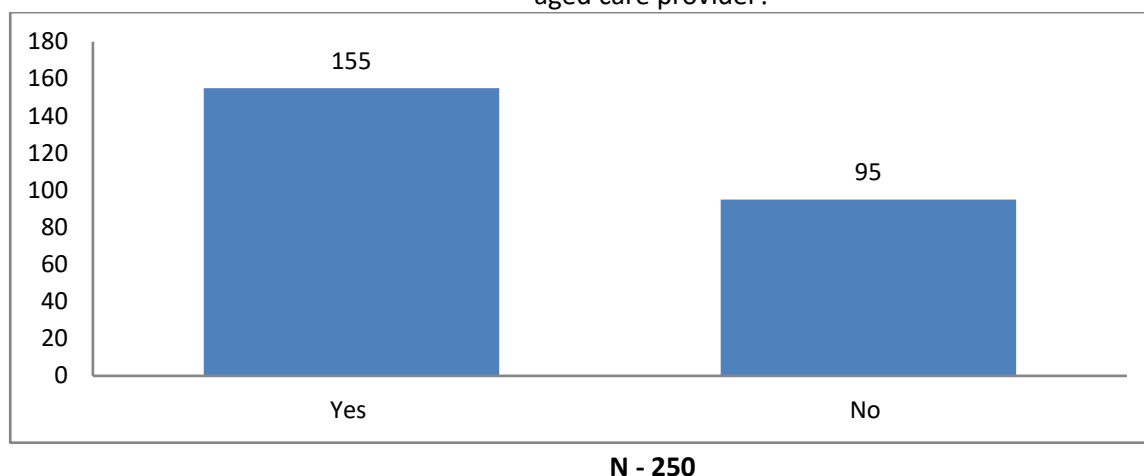
**Though COTA would note that ‘satisfaction’ is not the ideal measure of ‘experience. Nevertheless, there are a number of providers who have a less sophisticated understanding of ‘consumer experience’ as highlighted by this example:**

“We collate feedback about compliments, comments and complaints” # 84

## Question 7 – Other information helpful for consumers choosing a provider

**Q7: Does your organisation collect any other information that may help consumers in choosing an aged care provider?**

Figure 11- Does your organisation collect any other information that may help consumers in choosing an aged care provider?



If, yes please describe

Table 18 – Other information provided to consumers to support them to choose (\*)

Response	No of responses
Information we provide to consumers	19
Information about clinical indicators	12
Information on our website	10
Marketing information	10
Consumer Engagement Activities	7
Information on My Aged Care	6
Access to KPI or benchmarking data for consumers	6
Consumer Surveys or what consumers say about us	6
Social Media (e.g. Facebook)	3
Newsletters	2
Awards that our organisation has won	1
Outcomes of Accreditation or meeting National Standards	1
Staff satisfaction surveys	1

\*This qualitative data was coded using the categories listed in the table above.

### Qualitative comments

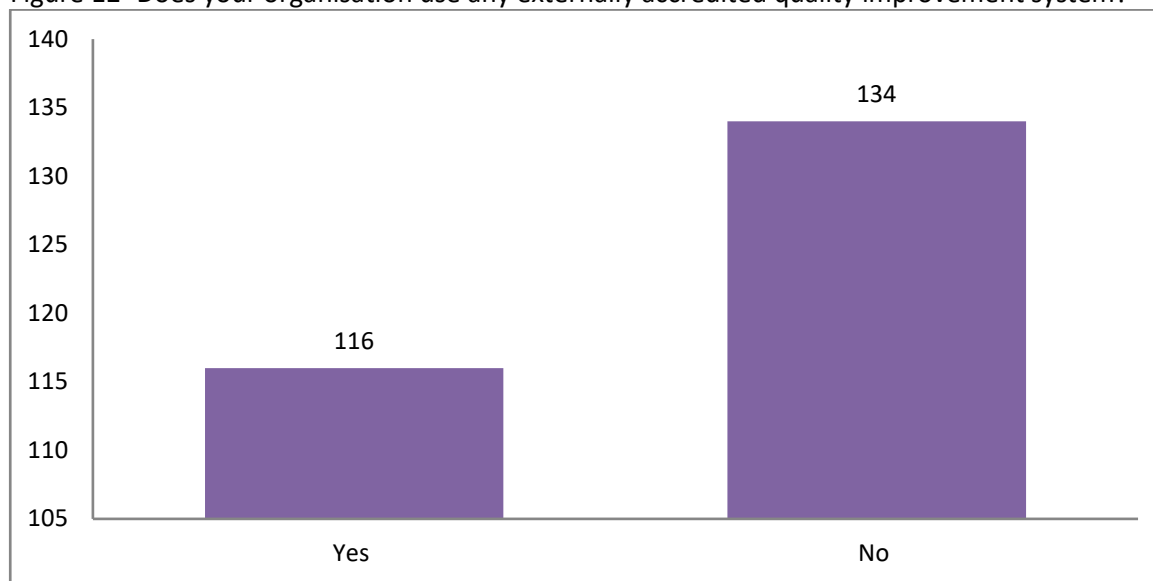
"<provider name> collects information about a range of clinical indicators that inform and support <provider name>'s continuous improvement program. At this stage we do not publish for public (or for consumer) view. We have recently conducted a project "Customer Engagement: What do People want to know about <provider name>" which will inform action to provide more transparent and publically available information. The top themes were feedback/consultation, customer wellbeing, organisational and customer finances, workforce, services provided, quality of services (including accreditation, incidents, review)" # 29

"As in the <remote location>'s people really don't have a choice of providers" # 21

## Question 8 – Externally Accredited Quality Improvement Systems

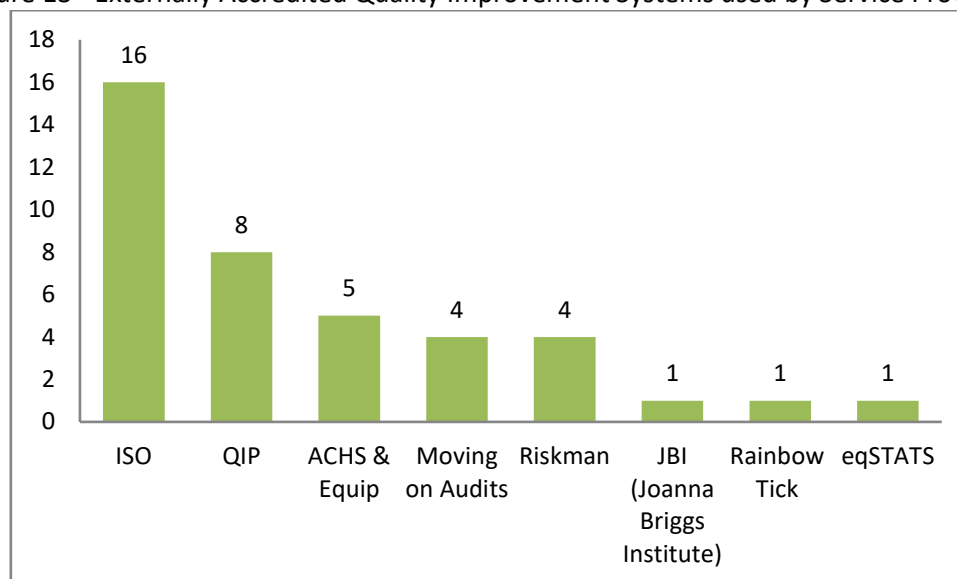
**Q8: Does your organisation use any externally accredited quality improvement system?**

Figure 12- Does your organisation use any externally accredited quality improvement system?



**N – 250**

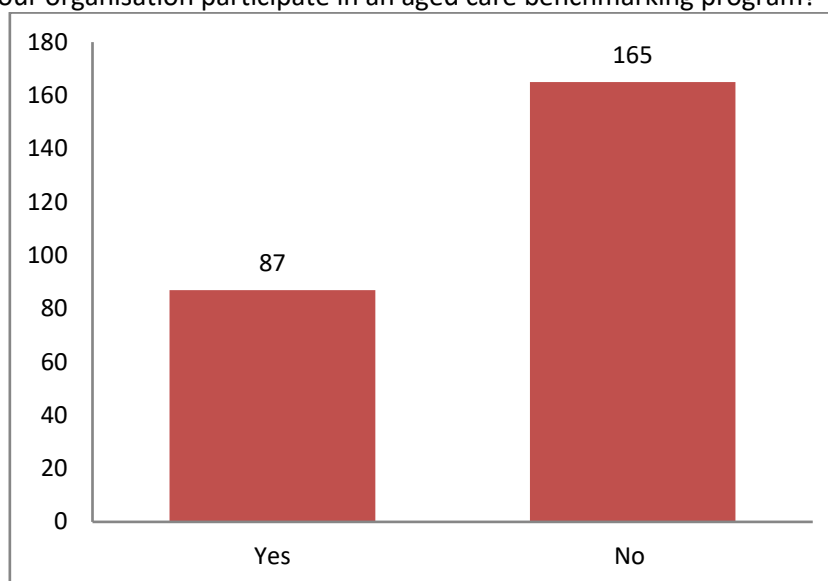
Figure 13 - Externally Accredited Quality Improvement Systems used by Service Providers



### Question 9 – Benchmarking Programs

#### Q9. Does your organisation participate in an aged care benchmarking program?

Figure 14 - Does your organisation participate in an aged care benchmarking program?



**N – 252**

Table 19 – Benchmarking programs used by service providers ranked in number of responses

Rank	Benchmarking program	No
1	Stewart Brown	28
2	Moving on Audits	16
3	QPS	13
4	Our organisations own system	6
5	Australian Aged Care Agency Quality Audits	4
6	Aged Care Quality Indicator Program	2
7	DHS Dex	2
8	Other	2
9	Quality Use of Medicine	1
10	Ministry of Health	1

**Question 10 – Statements (likert scale)****Q 10 Please read the following statements and tick the response that most closely reflects your view**

Table 20 – Service providers response to statement - Strongly Agree or Agree – Most common to least common

Rank-	Key Issue	Strongly Agree or Agree (N)
1	It is important that any measures are nationally consistent	236
2	All aged care providers should report on how they meet mandated national standards	221
3	Information about the performance against the mandated minimum national standards of aged care services should be publicly available online	207
4	Information about the quality of aged care services should be published on service provider's websites	207
5	Information about the quality of aged care services should be published on <a href="http://www.myagedcare.gov.au">www.myagedcare.gov.au</a>	203
6	Any quality indicator program should be Government run at no cost to providers	200
7	I see value in the Agency's new 'Consumer Experience Report' for residents in aged care being publicly available for other consumers	187
8	It should be mandatory for all aged care services to make available information on older people's experiences and report on quality of life	169
9	Providers should be able to use their existing benchmarking systems to participate in a quality indicator program at their own cost	113
	<b>N- 250</b>	



Table 21 – Service providers response to statements

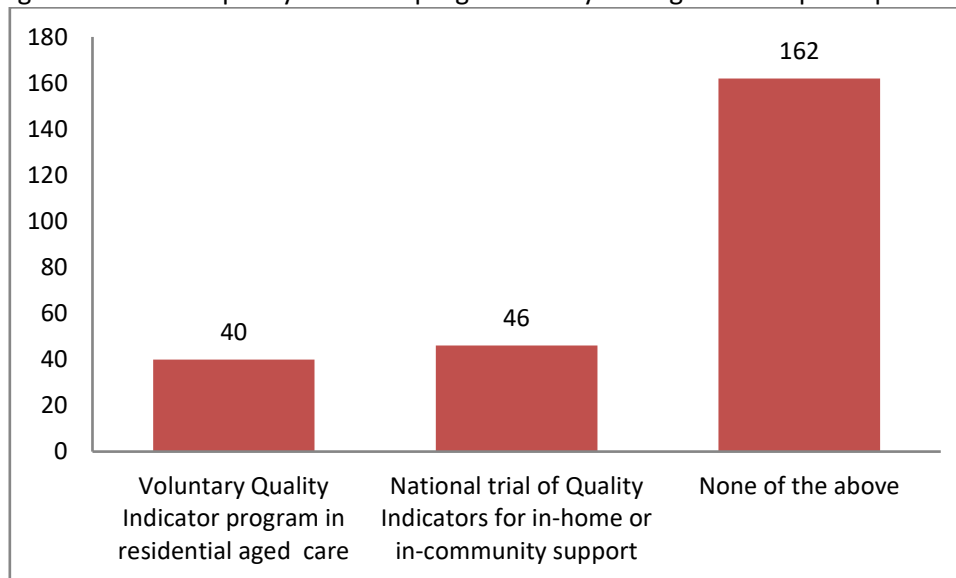
Key Issue	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
All aged care providers should report on how they meet mandated national standards	135	86	18	8	3
Any quality indicator program should be Government run at no cost to providers	136	64	33	10	8
It should be mandatory for all aged care services to make available information on older people's experiences and report on quality of life	102	67	44	25	14
Information about the performance against the mandated minimum national standards of aged care services should be publicly available online	103	104	32	7	5
I see value in the Agency's new 'Consumer Experience Report' for residents in aged care being publicly available for other consumers	81	106	40	16	7
Information about the quality of aged care services should be published on service provider's websites	97	110	34	7	4
Information about the quality of aged care services should be published on <a href="http://www.myagedcare.gov.au">www.myagedcare.gov.au</a>	104	99	32	8	7
It is important that any measures are nationally consistent	173	63	12	1	3
Providers should be able to use their existing benchmarking systems to participate in a quality indicator program at their own cost	46	67	81	41	19

N - 250

## Question 11-14 – National Quality Indicator Trials/Programs

### Q11. Which quality indicator programs has your organisation participated in?

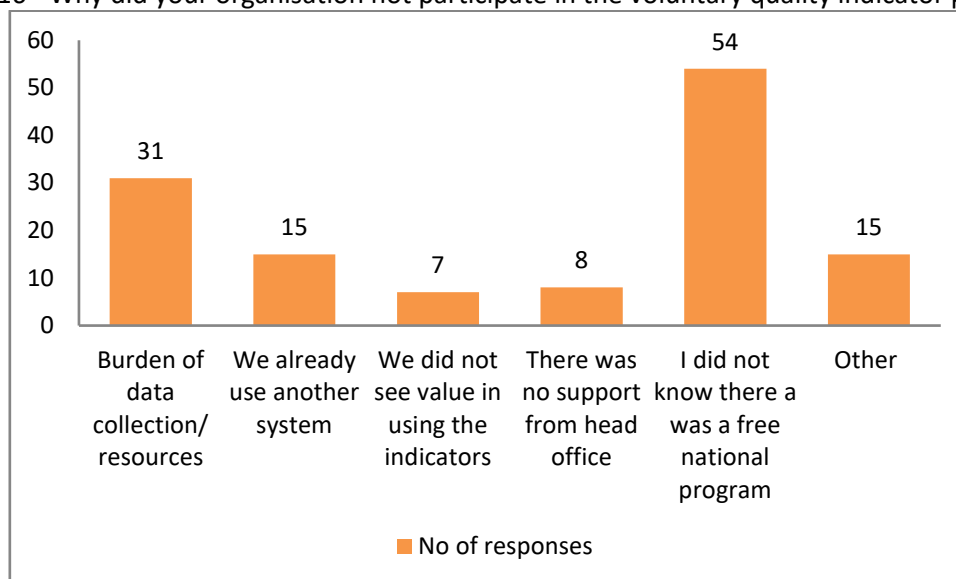
Figure 15 - Which quality indicator programs has your organisation participated in?



N – 248

### Q 12 Why did your organisation not participate in the voluntary quality indicator program?

Figure 16 - Why did your organisation not participate in the voluntary quality indicator program?

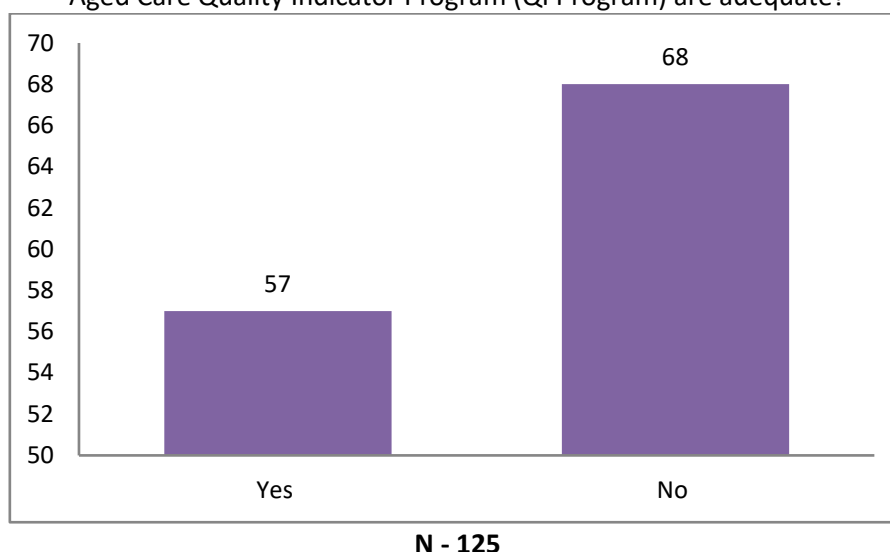


■ No of responses

N – 92

**Q 13. Do you believe the current suite of Quality Indicators (QIs) that comprise the voluntary National Aged Care Quality Indicator Program (QI Program) are adequate?**

Figure 17 - Do you believe the current suite of Quality Indicators (QIs) that comprise the voluntary National Aged Care Quality Indicator Program (QI Program) are adequate?



**Qualitative comments**

Qualitative comments on why providers didn't include concerns that there was too focused on narrow clinical indicators rather than quality of life as reflected in the following comments:

"They do not meet the minimum requirements of a quality indicator. Quality Indicators should be evidence based, achievable, appropriate, effective, efficient, client focused and correlate with greater safety measures. They should be able to be risk adjusted and guarantee precision of measure with minimum bias. Quality indicator data should not be used to compare services. If the data collected is to be compared across services this may lead to an adverse effect. For example, if the only way to achieve excellence in results is to not admit people with pressure injuries then these people will find it increasingly difficult to find services. Where there are performance cards, services will focus on them and not the service users" # 2, Q13

"The QIs in the voluntary QI Program are driven by compliance rather than quality improvement" #5, Q13

"The initial intent of any indicator program was to respond to the Productivity Commission's recommendation about providing meaningful information to consumers to help them choose services. The clinical indicators used are often misunderstood by consumers when out of context. They also do not reflect what we know consumers want to know: being treated with respect and dignity, being listened to and able to raise issues/complaint, having control over daily life, feeling safe and secure. We need to consider what is meaningful to the audience, measured by an acceptable definition. We found with the pilot that:

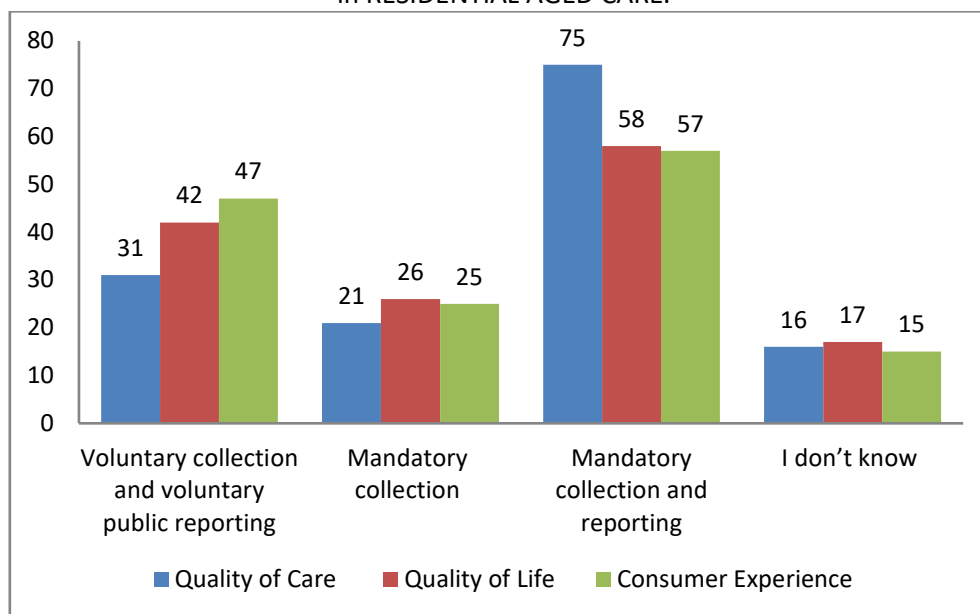
- Unplanned weight loss: very labour intensive to collect this information for the data collection trial and variable day by day (also, AACQA assesses systems for aged care organisations to monitor nutritional status and health of residents, including use of weight monitoring).
- Restraint: requires observation of each resident three times per day at set times (not practical in all cases)
- Pressure injuries: not defined as on-site/off-site" # 10, Q 13

"They are very narrow and only clinical in focus. Consumers need information about a wide range of measures including those associated holistically with their quality of life." # 11, Q 13

### Views on voluntary vs mandatory and public reporting - Residential

**Q14 - Quality information can include quality of care (e.g. pressure injuries, falls), quality of life and consumer experience. Please tick whether your organisation believes this information should be collected on a mandatory or voluntary basis and publicly reported in RESIDENTIAL AGED CARE.**

Figure 18 – mandatory, voluntary reporting of Quality of care, quality of life and consumer experience in RESIDENTIAL AGED CARE.



N – 139

#### Qualitative comments

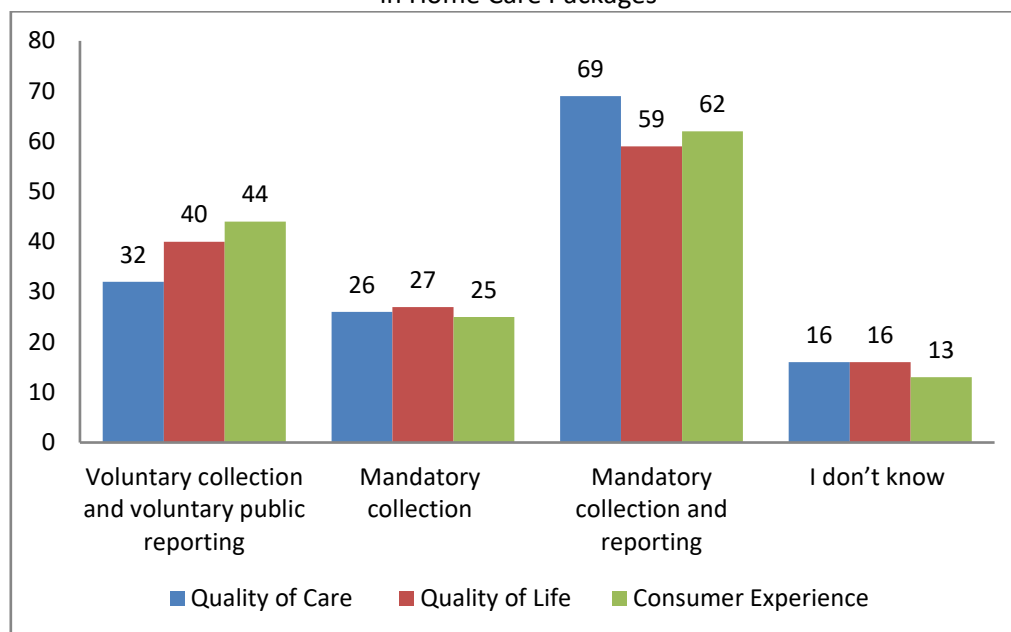
“While responsible care providers should collect Quality of Care and Quality of Life data to track performance and inform their own quality improvement programs, much of this data is meaningless to potential customers, and could be misleading around the quality of services provided. We know from our experience of benchmarking data over time, that the data has to be viewed in the context of the resident and care profile of each individual service. Some of our services are offering much higher care than others, and would superficially seem to have high levels of pressure sores etc Trend data is more important, however understanding the nuances of context and individual resident care profiles would be beyond most consumers, and too complex to report on.

The same applies to collecting quality of life data, in particular in residential aged care. We are dealing with a cohort who are unfortunately likely to experience a decline in quality of life due to increasing care needs. The job of the provider is to maintain quality of life or minimise decline in quality of life despite health decline. We are therefore measuring the impact of care services, not global quality of life. Impact of care services is a much more accurate measure of how successful a provider is at maintaining and improving quality of life. Quality of life scores on their own are meaningless if they are looked at in isolation. We know from our own experience of using the ASCOT tool that our homes offering the highest quality care and the best quality of life programs often have the lowest SCRQoL (Social care quality of life) scores. However, they have high impact of care services scores.” # 8 Q 14 raw data

### Views on voluntary vs mandatory and public reporting – Home Care Packages

**Q 15 Quality information can include quality of care (e.g. pressure injuries, falls), quality of life and consumer experience. Please tick whether your organisation believes this information should be collected on a mandatory or voluntary basis and publicly reported in HOME CARE PACKAGES (HCP)**

Figure 19 – mandatory, voluntary reporting of quality of care, quality of life and consumer experience in Home Care Packages



**N – 141**

#### Qualitative comments

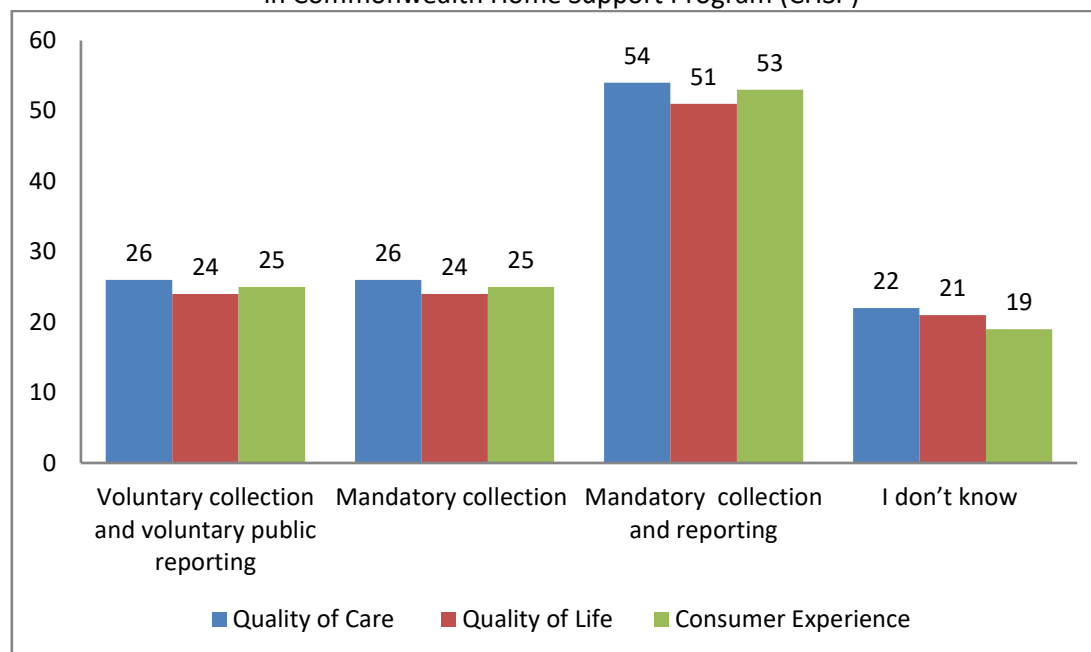
“The indicators that are suitable for residential aged care are not suitable for Home Care programs”

“Quality of Life is a subjective and ill-defined indicator and the complexities in consumer understanding limit the usefulness of this indicator. Quality of Care is an important indicator for mandatory collection and it arguably is mandatory now under the accreditation framework. Mandatory public reporting is only viable if achieved in a robust and independently validated framework. Consumer experience is a commercial tool best managed by the operator.” #16

## Views on voluntary vs mandatory and public reporting – CHSP

**Q 16 Quality information can include quality of care (e.g. pressure injuries, falls), quality of life and consumer experience. Please tick whether your organisation believes this information should be collected on a mandatory or voluntary basis and publicly reported in the Commonwealth Home Support Program (CHSP).**

Figure 20 – mandatory, voluntary reporting of quality of care, quality of life and consumer experience in Commonwealth Home Support Program (CHSP)



N – 141

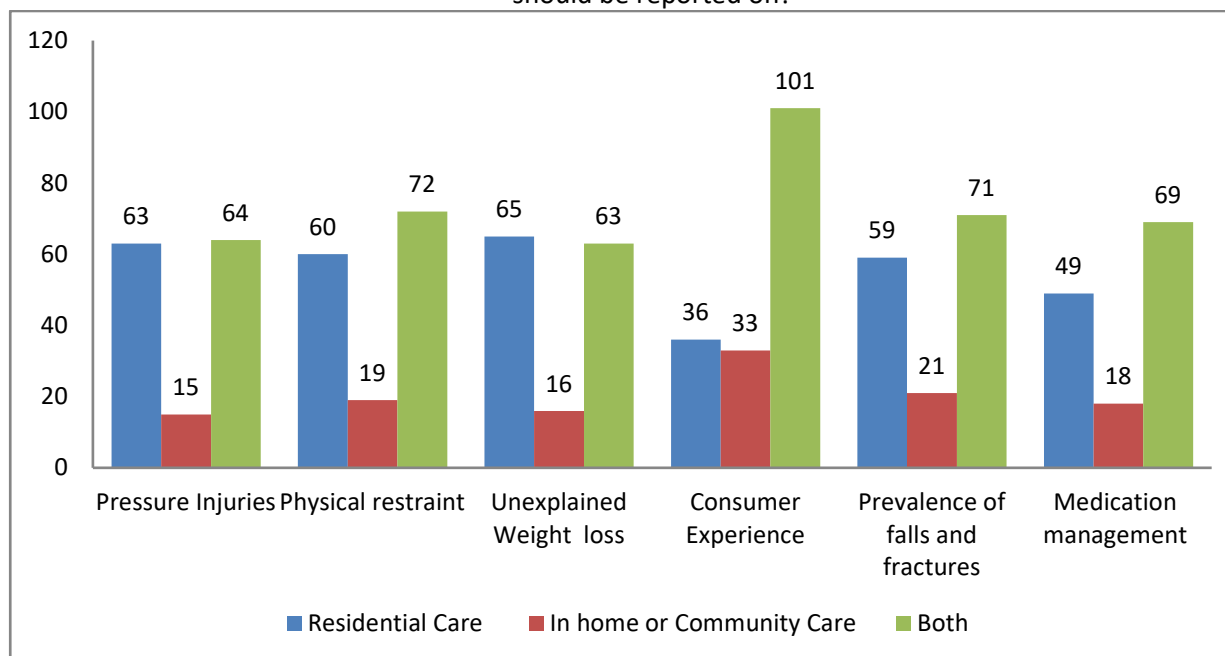
## Qualitative comments

“I repeat what I have said previously. It is difficult to answer this questions when we don't know what the measures are. The current suite of measures seem very narrow in focus, we also lack QOL measures which are appropriate in Australian context, in particular Ascot is not a useful tool. Until we have more reliable measures which are demonstrated to measure what they say they do, I don't believe we should mandate the measurements. Also consideration needs to be given to the time and resources required to administer these tools if they are to be mandatory.” #11

### Question 17 – Which quality of care indicators should be reported on

**Q17 - Which quality of care indicators in residential care and in-home support or community care should be reported on?**

Figure 21 - Which quality of care indicators in residential care and in-home support or community care should be reported on?



N – 143

#### Qualitative comments

“Public reporting of quality indicator data will not bring about meaningful change for consumers. What is needed is to have services collecting and monitoring information and then using it to improve services. The research shows that quality indicator data is useful for service providers (to drive improvement), for quality surveyors and for researchers, but not for consumers.

Quality of care indicators can be collected and included as part of the information assessed by AACQA through the accreditation process. This enables Providers to present information within context and with a focus on improvement and taking action where necessary. These results can be presented as part of the information made available to the public by AAQCA within a broader narrative context by qualified assessors” # 3

“It would be up to each organisation to determine how they would want to use their internal data collection to provide information to current and potential consumers.

AACQA currently assess against national standards (including clinical care) and are now measuring consumer experience. This information is publically available to consumers.” # 4

**Question 18 – Which tools do organisations currently use?****Q18 Does your organisation use any of the following tools in residential or in-home support?**

Table 22- Does your organisation use any of the following tools in residential or in-home support?

<b>Tool</b>	<b>Residential Care</b>	<b>In-Home or Community Care</b>	<b>Residential and Community Care</b>
Adult Social Care Outcomes Tool (ASCOT)	1	4	9
Personal Wellbeing Index	2	4	7
Consumer Choice Index	0	0	5
LTC-QoL Long Term Care - Quality of Life Index (used by QPS)	3	1	6
World Health Organisation Quality of Life (WHO-QoL)	2	2	7
Goal Attainment Scale	1	7	7
Your Experience of Service (YES) Survey	2	4	10

**N – 35****Qualitative comments**

“We adopted the ASCOT and customised to form part of the Home Care assessment tools.

We modified and customised YES survey into “My Experience” survey and implement it to all services” # 5 – Q19 service provider survey

“WHOQoL-BREF – pre- and post-restorative/re-ablement programs

GAS – Sometimes used by occupational therapists and physiotherapists to evaluate the outcomes of physical and equipment-related interventions” # 18 – Q19 service provider survey

See Q19 of service provider data in the excel file for more quotes.



### Question 20 – Quality of Life Indicators

**Q20. If your organisation were looking to publicly report on quality of life indicators and/or use them for continuous quality improvement, which indicators would your organisation use?**

Table 23 – If your organisation were looking to publicly report on quality of life indicators and/or use them for continuous quality improvement, which indicators would your organisation use?

	Residential Care	In home or community	Residential and Community
Having control over your daily life	15	46	64
Access to a nutritious, varied and culturally appropriate food	26	28	52
Unexplained Weight loss of older people using the service	34	21	44
Personal safety – feeling safe and secure	20	40	63
Social participation and involvement to maintain social relationships and connections with the local community	12	51	66
Accommodation and cleanliness – the environment is clean and comfortable	40	21	43
Being treated with dignity and respect	10	47	79
Maintaining and supporting spiritual, cultural, sexual and religious identities	14	41	69

**N- 131**

#### Qualitative comments

“We would not choose any of the above indicators without context. Prior to this, there needs to be clear, consistent definitions and valid tools for collection of quality of life and care data.”

### Question 21 – What support would be needed to publicly report?

**Q 21 What support would your organisation need to collect data on quality of care or quality of life and to publicly report this information?**

Table 24- What support would your organisation need to collect data on quality of care or quality of life and to publicly report this information?

Response	No	%
Clear definitions and the process for collecting and reporting data	135	94.41%
Training for our staff	126	88.11%
Additional support to collect and report data and adapt our systems	124	86.71%
Additional support for purchasing technology/software	119	83.22%
Other	20	13.90%

**N – 143**

#### Qualitative comments

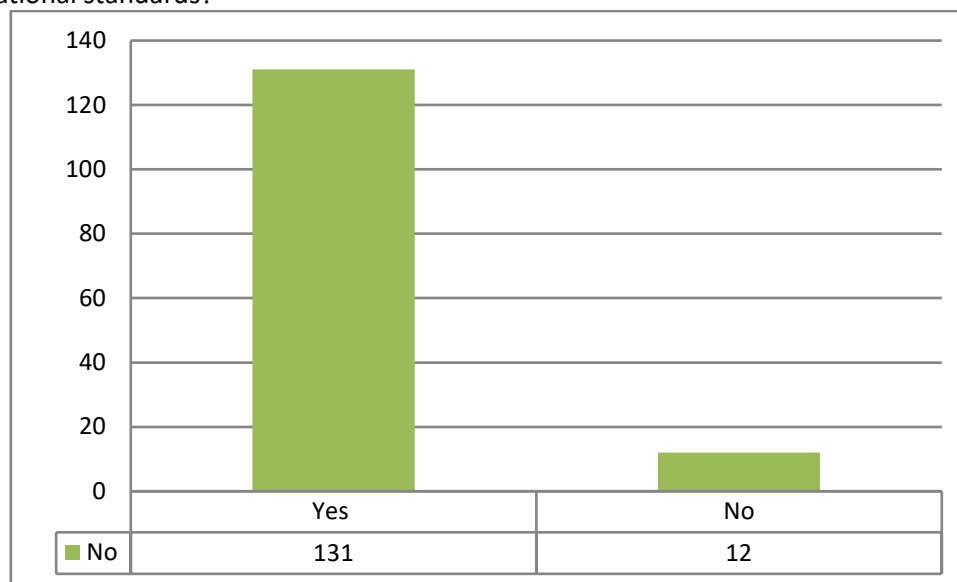
“I am personally very committed to the concept but do not have the resources. The support and training provided by the Dept. has been minimal to zero, the help line provided is no help, I have trouble every quarter generating my reports despite numerous efforts to sort the problem via the help line who are no help, the only way I can get my reports is directly from a contact at the Dept. of Health who kindly emails them to me when I ask. The whole process has been a disaster and if I was not so committed to the concept I would have given up ages ago. If the indicator program is going to be made mandatory the industry needs a lot more training, support, and resources to make it happen” # 1 Provider Survey

“Substantial funding increase across all services. Substantial notice for staff training. Substantial TESTING of any proposed software and reporting platform to ensure it works and is easily accessible to consumers. Help desk by trained staff (timely responsiveness). High level of interpreting services for people of CALD background (translated material will not suffice as many older people born overseas have low levels of literacy in their own language). Clarification of the use of proxies in data collection for people with dementia (including resourcing if the proxy is an internal staff member). Key issue prior to any external benchmarking is a clear and consistent system where all participants are contributing data in the exact same way. Should the government system provide aged care providers with internal information, this would provide no benefit to <provider name> as compared to the data we already collect and review” # 2 Provider Survey

## Question 22 – Services that are higher than minimum standards

### Q22 - Should providers be encouraged to deliver services that are higher quality than the minimum mandated national standards?

Figure 22- Should providers be encouraged to deliver services that are higher quality than the minimum mandated national standards?



N – 143

#### Qualitative comments

“Of course, all organisations should be encouraged to deliver standard of higher quality than the minimum mandated national standards. In an increasingly competitive market, this will be a natural consequence. However, what should be reported is how minimum standards are met (as currently done by AACQA): if organisations wish to demonstrate how they are going above minimum, standards, there are processes to support that (Better Practice Awards, for example)” # 3

“Just because it is a minimum requirement, does not mean that that is all you should be doing. You should always go above and beyond, if given the means, and do more” #14


**Question 23 - Where should quality information be published?**

**Q.23 If it were mandatory for all providers to publicly report on quality information of care and/or quality of life indicators, where should this information be published?**

Table 25- If it were mandatory for all providers to publicly report on quality information of care and/or quality of life indicators, where should this information be published?

Rank	Issue	No	%
1	My Aged Care	98	68.53%
2	a government website such as the Australian Aged Care Quality Agency's website	73	51.05%
3	the aged care provider's website	67	46.85%
4	an independent organisation's website where all information about aged care services is available	30	20.98%
5	a commercial comparison website, e.g. Aged Care Report Card	21	14.69%
6	I don't know	9	6.29%

**N - 143**



# Quality in Aged Care through the eyes of consumers

A report for COTA Australia  
18 January 2018



# The Plug-in.

Powered by COTA SA

## Document Control

Copywrite:	Council on the Ageing SA Inc.
Authors:	Kirsty Rawlings Sharmilla Toor
First published:	18 January 2018
Version:	1.1 (issued 29 January 2018)
Audience:	For COTA Australia
Related documents:	<p>Qualitative research undertaken by The Plug-in, COTA SA, in South Australia was commissioned by COTA Australia to support their national research into quality &amp; safety in aged care.</p> <p>For national context, this research should be read in conjunction with COTA Australia's research and response to the Department of Health.</p>

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*What does quality mean to you?*

“You must feel at home – not in a place that feels like a hospital. That’s not what you want when you get older.

“The staffing – the care workers and nurses. They are all friendly, they all knock the door, they always say thank you and I always say thank you to them. [...] You need to feel at home – not like a visitor. It is very difficult to move in – you like to have control over your own decisions. You do here – I do make decisions.”

*Elka, aged care consumer*



# Executive Summary

In response to the October 2017 Review of National Aged Care Quality Regulatory Processes, COTA SA has undertaken consumer research with 67 people across the cohorts of consumers, family members and decision-makers in Aged Care to understand what quality means to people and what quality indicators will enable people to make informed choices.

From a consumer perspective, quality was seen to have six key dimensions. Quality is:

**1. Staff who are able to support dignity, self-expression and choice:**

People using aged care services continue to be themselves and wish to express their individuality and preferences, even when those preferences may go against what is technically and medically best for them. They seek staff who understand and act from a perspective that defends this dignity and individuality. Organisational leadership and business models need to support and enable staff to have the ability to spend time not only caring for immediate physical needs, but also enable the development of meaningful relationships and support the continuation of the whole self.

**2. Staff who are resourced to support quality of life:**

Consumers recognise that, even with the best of intentions, staff who are under-resourced and are overstretched through unrealistic time frames and low staff to consumer ratios will be unable to adequately deliver support that honours quality of life.

**3. Staff who are trained and empowered to provide appropriate care:**

Training was seen to be an indicator of a provider's commitment to delivering high quality care, not simply generic induction training or external qualifications but on-going training in customer-centric service delivery.

**4. Listening and responding to the voice of consumers and families:**

Responsiveness to the desires, wishes and priorities of individual consumers and families is seen to be critical, particularly when feedback is highlighting problems or issues. People want to be sure that issues are dealt with and not 'swept under the carpet'.

**5. Accurate and transparent systems and fees:**

Clunky systems and inaccurate accounts are stressful and unsettling for older consumers and time-consuming for family members, leading to people not getting important services as and when they expect them. Addressing internal systems and processes that impact on the customer experience is a key comment of consumer-centric quality.

**6. Leadership that puts consumers at the centre:**

Consumers and their families identify that the elements of quality that matter to them are driven from the top down and the leadership commitment of leadership to supporting quality of life for the people they serve.

Considerations for quality indicators that will enable consumers to make informed choices and which serve as useful indicators of the above dimensions of quality being met are listed below.

---

+ Staff to consumer ratios

---

+ Staff roles and training

---

+ Staff permanency & turnover

---

+ Dignity in hygiene & care

---

+ Confidence in complaints & feedback

---

+ Transparency of fees

---

+ Self-expression & choice

---

+ Access to consumer experience

Consumers and their families value quality of life indicators much more than clinical indicators. Although not all consumers, families or carers feel they receive quality clinical care, most see clinical care as assumed services of *all* providers rather than as a differentiator. Where decision-makers, be that the consumer themselves or their authorised guardian, make a decision to compromise clinical care in order to enhance quality of life, they want that to be respected.

Consumers want to know that the voice and experience of other consumers and family members is represented in accreditation and monitoring and that loopholes are closed, such as unannounced accreditation visits, to make it harder for providers to 'work the system'. All consumers, family members and delegated decision makers sought a much simpler and more user-friendly system to support them to make informed decisions.

A number of other factors sit alongside, and at times compete with, quality indicators in consumer decision-making, as outlined below. In many cases, consumers and their families feel that all choice is stripped away from them and quality-driven decisions are impossible because the three factors of price, location and availability effectively make the actual choice between receiving a service or not.

Quality	vs	Price
		Location
		Availability

Consumers and their families identify a number of roles that government can play, and responsibilities that they believe government have, to make the aged care system one that truly fulfils the vision of being consumer-driven. These include to:

- i) Increase accountability and consistency of providers in maintaining standards and delivering quality
- ii) Improve financial clarity and ensure consumers can get timely insight into their actual financial position and the costs of required services
- iii) Make the aged care system easier to navigate, so that consumers are empowered to make informed decisions rather than choosing services that don't suit them because the system was too difficult
- iv) Enable access to independent advice, even for those with no financial means, to ensure people, particularly people without any family support or no prior experience of using aged care services, can get the information and support they need
- v) Make the measures that matter to individual consumers more easily accessible, such as specialist support for specific conditions, e.g. dementia specific services
- vi) Capture and communicate family and consumer experiences, to ensure that providers cannot hide issues and are transparent to consumers

## Case study:

### *So, what does 'Quality' look like in action?*

My colleague and I approach a residential aged care facility at around 10:00am on a quiet, residential street to meet with 4 residents who are participating in our research. We walk through an open and welcoming entrance into a foyer that, to my surprise, doesn't feel like a ghost town or institution. I take a deep breath and instead of a smell of staleness (or worse), I am pleasantly surprised to note there is no foul air or alternately no strong smell of bleach/cleaning products – the air seems, well, normal!

Within a few moments, we are approached by a friendly staff member – all smiles – who genuinely seems happy to see us and not flustered at all about our presence... we are, after all, here to learn about the experiences of residents but there is no hint of concern.

We are introduced to 2 people who wanted to be interviewed and are given the names of 2 others we will meet with later. The staff member guides us to our first interviewees leaves it completely up to the resident about where they would like to meet with us.

My colleague and I part ways to conduct interviews separately. I follow my interviewee 'Phil' into a common area of the home on the second level. As I look around, there is a kitchen that looks like my own, lots of tables of different sizes in the dining area, little unique furnishings and ornaments adorning bookshelves and cabinets, and lovely big windows. Beside one, I see that another resident sitting watching activity on the street – she later tells me it's her favourite spot. Phil and I sit down. He tells me he moved into the home for his wife who has dementia so he can still be with her – they have rooms next to each other.

As Phil and I chat, I notice lots of movement in, out and around the room. There is a lot of playful banter between Phil and other visitors or residents throughout the time we are together. Everyone I meet here is at ease and the common areas genuinely feel lively. One lady keeps popping in and out of the kitchen randomly chatting to Phil and I quickly learn she is his wife.

Phil does talk about feeling sad from time to time as he loses friendships of those who have passed away in the home, but he also enjoys helping others. Phil used to garden at the home which he mentions is no longer allowed to do, but then tells me he is now responsible for the mail rounds in the home which helps give him a sense of purpose.

"I help my 99 year old friend make breakfast in the morning because he is up at 7:00am and none of the carers are around at that time [for breakfast]. I like helping people anyway so that is good."

*Phil, resident*

After our chat, I head back downstairs to the café to meet my colleague who is interviewing another resident, interspersed with conversations with other passing staff and residents. In the café there's lots of activity and interaction – a young barista strikes up conversation and asks if I work there. I explain that I'm just visiting and talking to residents and he introduces me to a lady sitting nearby. I'm surprised to learn that she doesn't live at the home, but just likes to pop in daily to have coffee and visit people.

As I drink my coffee, one of the exercise physiologists comes past. He tells us his motto for every resident is "Unless residents have my voice in their head every day then I'm failing. Stretch regularly, move every hour, exercise twice a week and be active every day!". From everything we had observed over a period of just over 2 hours, we realise we've seen his words in action.

And so I could keep writing, but what we observed is this:

1. Mutual respect between residents and staff – staff who seem to feel valued and genuinely enjoy the work they do.
2. Residents encouraged and enabled to retain control and choice in their day to day lives.
3. Spaces that are designed and curated to create a sense of home.

Some of these observations are based on witnessing interactions that contrasted between different homes. For example, a staff member entering a room and automatically turning off a T.V to get someone's attention which, in stark contrast to this home, staff ask and see if it would be okay to turn off a T.V, let the resident decide and take action themselves – it's their home, it's their choice.

Certainly, the physical environment helps. This home feels open, welcoming, spacious with access to lots of natural light. The wide hallways have unique paintings that seem to reflect people living in the home. Yet the spaces, whilst practical, are also homely and on a domestic rather than institutional scale: sideboards with ornaments or bookshelves with an occasional chair and a desk lamp. Large windows in rooms overlook easily accessible gardens or activity on the surrounding streets.

The organisational values we observed in the home were not about quality of care or clinical standards, but about more fundamental values of how people treat each other: about hospitality and friendship and human connection.

From being there and observing our surrounds, it seemed clear a major priority of the leadership at the home is helping residents maintain a level of independence and choice. With all the staff we had an opportunity to interact with, whether they were carers, café workers or medical professionals, there was an obvious culture of friendliness, sense of fun and "get up and go". It seemed as though everyone enjoyed their work, were valued for their contribution, and were happy to be there.

**This 'home' did not feel like a place where life ends...**

**"I love the relationships you build with people – you get to know them really well. And most of them have quite complex issues to deal with – I enjoy that professionally."**

*Ivan, Exercise Physiologist*

# Introduction

This research follows the independent review of the Commonwealth aged care quality regulatory process in response to failures in the care of consumers at the Oakden Older Persons Mental Health Service in South Australia.

The review, led by Ms Kate Carnell AO in conjunction with Professor Ron Paterson ONZM, examined in detail why systemic failures to deliver quality care at Oakden were not detected by regulatory processes. The report, Review of National Aged Care Quality Regulatory Processes Report, was released to the public in late October 2017.

In response to the report, COTA Australia led a national review to hear experiences and views of consumers of aged care services, their friends, family and other supporters, and the views of people working within the aged care industry.

For many years, COTA Australia has been an advocate for the development of quality indicators, above and beyond the basic clinical indicators, that will better assist people in making decisions about aged care providers. Quality indicators should provide an individual considering aged care services with an understanding of how a provider will support their quality of life.

As part of their national review, COTA Australia commissioned The Plug-in, a new social enterprise of COTA South Australia, to lead a qualitative engagement with consumers, family members and carers (unpaid) to understand in more detail the lived experiences of individuals navigating the aged care system, and what quality indicators are important beyond the indicators currently gathered and reported.

This report, Quality and Safety in Aged Care, supports the national review of COTA Australia and is a detailed examination that outlines the experiences of consumers, families and carers within in the aged care system; their views on the current quality indicators; define what 'quality' means and what information is useful to know about an aged care service provider when making a decision; and provides recommendations for new quality indicators, data, and access to information that would assist consumers, families and support people with making a decision that optimizes the consumer's experience in aged care.

## Research engagement & method

The Plug-in, COTA South Australia, led a detailed engagement process in late November and early December 2017 across a diverse community in the north, south, east and west of metropolitan Adelaide.

To ensure depth and representation across the aged care system, recruitment to the research project encompassed the following cohorts:

- Older persons considering aged care services
- Consumers of aged care services
- Partners, family members or carers (unpaid) of aged care consumers

Through our recruitment process, we did engage with a small percentage of people who also had current or former experience as a professional in the aged care industry.

The method of engagement ranged from small focus groups to 1:1 interviews. Initially, we held one large workshop at a residential aged care facility to gather some high-level information and assist with structuring the engagement activities in focus groups and interviews.

Overall, we engaged with 67 participants to hear their views and experiences in the aged care system.

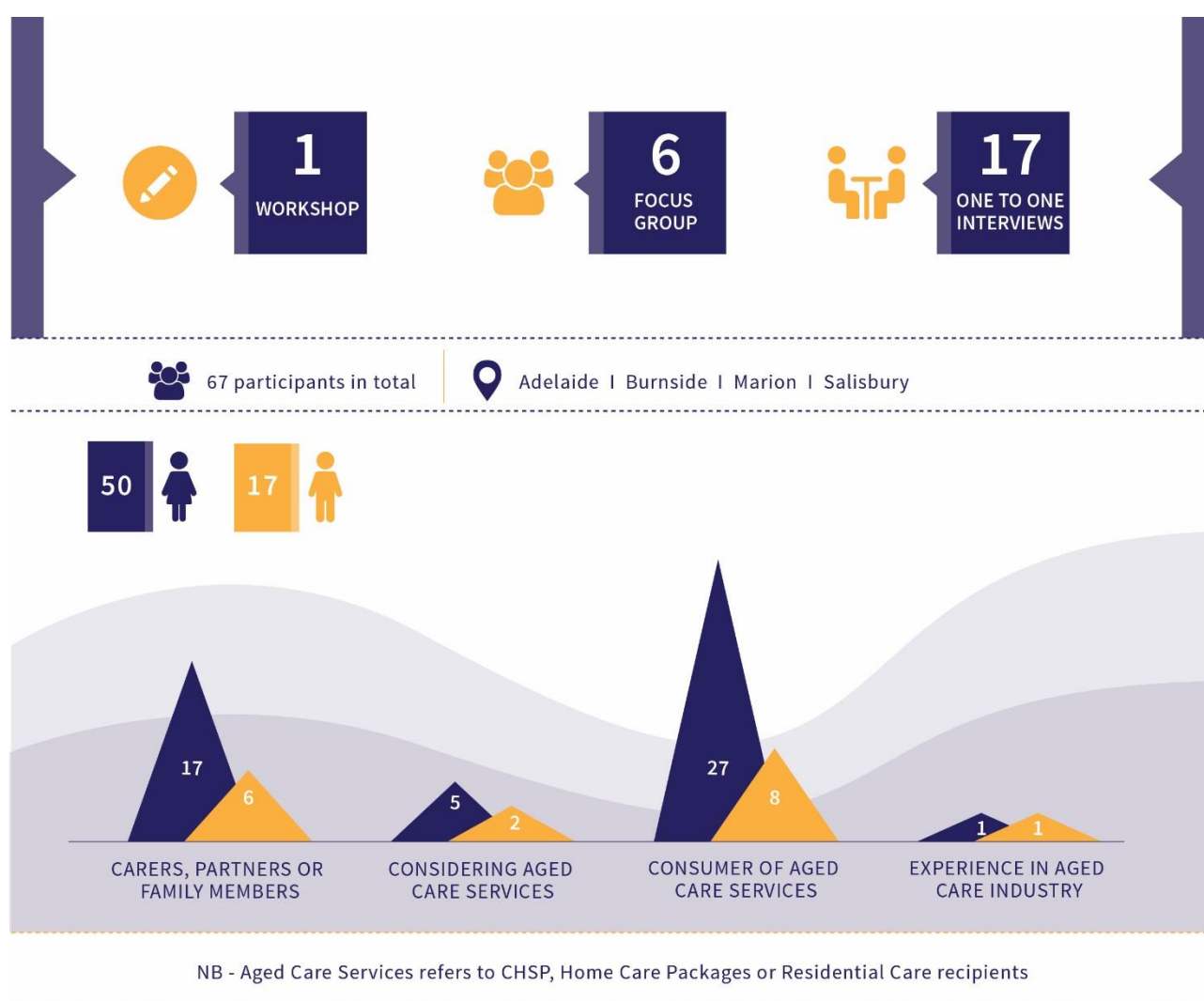


Figure 1: Participant demographic information

	Carers, Partners or Family Members	Considering Aged Care Services	Consumer of Aged Care Services	Experience in Aged Care Industry	TOTAL
Focus Group Adelaide	3				3
Focus Group Adelaide*	5				5
Focus Group Burnside	1	2	2		5
Focus Group Dutch Home Care			6		6
Focus Group Glandore	3		2		5
Focus Group Salisbury	2	2	3	1	8
Interview One to One	6	3	7	1	17
Workshop**	3		15		18
<b>TOTAL</b>	<b>23</b>	<b>7</b>	<b>35</b>	<b>2</b>	<b>67</b>

\* What are some possible solutions? / \*\* Aged Care Residents Meeting

Figure 2: Participation by cohort and level of engagement



“Quality: It’s a word that’s bandied about. It’s meaningless. We should be asking: ‘What do you need to live a reasonable, well, safe life? How do we know [she] is comfortable?’”

*Angeline, family member*





# What is quality in the eyes of consumers?

“Quality: It’s a word that’s bandied about. It’s meaningless. We should be asking: ‘What do you need to live a reasonable, well, safe life? How do we know [she] is comfortable?’”

*Angeline, family member*

Quality in aged care should be defined entirely by the consumer. The 67 participants in the South Australian consumer engagement process were asked to describe and define what ‘quality’ meant to them. Quality was most frequently described in terms of staff. Participants felt that quality aged care could only be delivered with empathic, caring staff who are not stretched beyond capacity and who are trained and enabled to support older people with dignity and respect. Participants described quality staff as those who ask people what they need rather than simply being knowledgeable and acting on their own professional judgement without respect for an individual’s wishes. Participants also discussed staff training and a ‘one size fits all’ approach as being insufficient, describing the need for tailored training to better assist the individual needs and circumstances of consumers and a consumer-centric approach.

Whilst staff-related factors were the most frequently cited aspect of quality, other factors also come into play, as outlined below.



Figure 3: What is Quality in Aged Care for consumers?

**Quality** is staff who support dignity, self-expression and choice

**“It’s about having a voice. When you don’t know anything, it’s hard to have a voice.”**

*Marie*

Many examples were given of what was *not* quality in staff practice. Tim described his brother, a younger man in a residential facility, who on occasion wants to have a sleep in but is made to get out of bed. Being non-verbal, his only means of expressing his displeasure with this decision is to resist physically and then he gets branded as ‘aggressive’. Marcia told us that when people refuse to eat modified food at her husband’s nursing home they are force-fed. Another participant told us:

**“Two staff at my mum’s place got chunked out. I saw one of them grab an old woman by the mouth to make her eat - they were so rough. The old woman was terrified to tell anyone.”**

*Sonia, consumer and family member*

Sharon, a family member and social worker who works for the Office of the Public Advocate, described the need to balance giving care with supporting human rights, specifically people’s rights to take informed risks. She said that there were some aged care facilities where on principle she would not place people as they are too ‘restrictive’. She gave the example of swallowing, where she and her colleagues can often find themselves advocating for someone’s right to enjoy an occasional treat and take a risk rather than always eat their prescribed diet. This came up with family members and consumers in the context of diabetes, where people were clear that they did not want themselves or loved ones to be refused ‘treats’ by staff if they wished them.

**“People are entitled to take risks - even people with dementia.”**

*Sharon, social worker*

An important aspect of dignity and self-expression is the ability to exercise choice and control over medications management, if appropriate. Brigitte, who lives in residential care, controls her own medication and keeps them in a locked cabinet in her room. Ken voiced concerns for his wife if she ever had to move into residential care, as she uses a lot of naturopath remedies and he supposes that in aged care the staff would take control of that and might not be sensitive to her preferences. Greta has taken control of her father’s medication purchases:

**“They were getting all the medications from [pharmacy]... I found out that I didn’t have to go that way, so I took control of his medications - most people don’t know that they can do that...”**

*Greta, family member*

In Home Care settings, dignity is equally important but described differently:

**“They need to remember that you are inviting people into your home. [...] I expect care services to be professional and friendly. And they need to be on time! Continuity of care is important - you can become institutionalised in your own home.”**

*Ken, consumer*

Sonia is considering Home Care services, but is clear on what she will or won't accept:

"I don't have any help yet, but if I did, they'd have to be polite - I don't want people telling me off, you know, being bossy."

*Sonia, consumer*

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## The tale of two TVs

We went to visit Don in a Residential Aged Care Facility. A member of staff enters his room without knocking, tells him two people are here to see him and ask him if he likes it here. The support worker then takes their remote control off his table and turns off the TV.

The next day, we visit Elka in another Residential Aged Care Facility. She is also in her room watching TV. A member of staff knocks on the door and waits a moment or two before putting her head around the door and introducing herself. We wait at the door whilst the staff member has a conversation with Elka to check she remembers that we are visiting and for what purpose. She then invites us into the room. As we get settled, she suggests to Elka that it might be easier to chat with the TV turned off. Elka agrees; she takes the remote control and turns it off herself.

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## Quality is staff who are resourced to support quality of life

Family members and consumers commented extensively on issues in residential care that to them indicate that staff are stretched beyond capacity. Hygiene and sanitation were key indicators of this: Participants, particularly family members, told distressing stories of hearing residents being told to 'just do it in your pants' because staff don't have time to take them to the toilet, or people sitting in urine-soaked pants for hours at a time because of understaffing.

"The medications weren't coming at the right time. Mum is meant to have a suppository when she gets up. On one day, it was 11:30 before she had it and by that time accidents have happened."

*Marie, family member*

In Home Care settings, this understaffing is apparent in consumers' stories of staff rushing to get the job done quickly and get to their next client. Whilst we heard a few stories of staff asking what else needs done when they have some time left at the end of their allocated shift, more often the stories were of staff leaving after 20 minutes although they were rostered for half an hour because the defined job was complete, yet consumers are paying for the full time allocation. One family member told us she had encouraged her mum to write a list of '10 minute jobs' and to ask the staff member to complete one of these each time she was finished early.

Home Care consumers and family members spoke to us about the distractedness of staff, rushing to complete work whilst answering their phone. Lorna told us:

"The first person who came whizzed through, they were on their phone all the time. So they didn't come back. The second person was fantastic, but then the next time she came, she was on the phone too..."

*Marie, family member*

For consumers from other ethnic backgrounds, quality of life and care seemed to override a desire for support from specific cultural organisations as there was an assumption that paying attention to quality of life would include caring about cultural needs. Ella, one family member we spoke to in a focus group, was considering options for her mother who had specific religious and cultural needs. Ella saw this as part of the wider concern about supporting quality of life for her mum. Maria, an Italian woman in her 90s, was very critical of her local Italian facility:

**“In the Italian place, there’s too much ‘yappy yappy’. They’re not cared for properly.”**

*Maria, consumer*

This was reinforced by Maria’s friend Sonia who had looked at the Italian facility for her own mother and had found that her Italian family values of hospitality and care were more on display at another facility that didn’t specify any particular cultural association. As a result, her mum moved in there instead.

Another key indicator of quality of life that came up repeatedly was movement and mobility. In one aged care facility we visited we had incidental conversations with numerous residents as people were up and around. We also had the opportunity to talk with the exercise physiologist and the physiotherapist, with the former telling us:

**“Unless residents have my voice in their head every day then I’m failing. Stretch regularly, move every hour, exercise twice a week and be active every day!”**

*Ivan, staff member*

Brigitte, who lived there, told us that she could hardly walk when she moved in. When we arrived, we had to wait for her to finish her gym session before we could chat with her. In contrast, Diana told us how her father lost a lot of mobility in three weeks in respite, and Don told us that after he fell soon after moving in to his aged care facility he has spent most of his time in his room. Many participants told us that when they have visited aged care facilities they see no-one around. We heard many stories of, and in some cases observed, people in front of TVs, often in their own room.

## **Quality is staff who are trained and empowered to provide appropriate care**

In addition to short staffing, in both Residential and Home Care settings consumers commented on the training of staff - both to deal with specific conditions and to deliver human-centric services. Marie was one of many family members to express the view that staff having a Certificate III in Aged Care is not a sufficient indicator of quality but that staff attitude and behaviour is more critical to a positive consumer experience. Many spoke of the desire for staff to have ongoing training on the job in how to treat people with dignity and respect. Clinical training as the most critical aspect only came up in conversations with family members of people with specific conditions, such as Alzheimer’s Disease, Motor Neuron Disease or terminal illness. In these cases, all participants identified the requirement to have specialist staff appropriately trained to provide care.

The need for staff to be able to communicate clearly with consumers came up in both Residential and Home Care contexts. This was an issue where consumers had cognitive impairment and staff were not adequately trained, or did not have adequate time and resource, to respond appropriately or take time to listen and genuinely understand the person’s needs and wishes. It also came up in the context of staff with English as a second language. In these cases, we did not meet anyone who felt that all staff needed to be native English speakers, but rather that organisations needed to ensure staff could communicate clearly in English, and that staff could draw in a colleague to assist with communication if it was a barrier. A good example of this was in one aged care organisation providing residential care to a specific ethnic group, where English could be the barrier. Whilst fewer than a third of staff came from that ethnic group, there

was an expectation that these staff members could be called upon to help with translation if required with older residents.

“For me, staff training is so important. Their awareness of what people need, and learning to communicate with residents. I don’t have an issue with non-English speaking staff but they need to be able to communicate.”

*Di, family member*

**Quality** is listening to the voice of consumers and families.

Consumers and families voiced much more interest in being active participants in care and in how it’s delivered than in having strong clinical care without freedom, self-expression and the ability to make choices. Marie was frustrated that, when an agency could not provide enough home care hours for her mother, they were not open to her auntie being involved in working alongside them. Her auntie had worked for many years in a rehabilitation facility. Others echoed this frustration that they were not encouraged or enabled to be part other loved one’s care, yet see that care is not being delivered adequately by staff:

They’re not looked after properly there. A friend was there and she wanted me to take her to the loo. I got told off - the staff member said, ‘no, I’ll do it’, but she went away and 30 minutes later she still hadn’t come back.”

*Sonia, consumer, referring to an Aged Care facility*

Focus group participants suggested that they would want to ask an aged care provider specific questions about the role partners and family could play in their care, citing the example of wanting family to be able to help with intimate care when possible.

Tim feels that his voice is ignored in decisions about his brother’s care, despite him being his delegated decision-maker and having medical training. He told us of a recent frustration when the provider’s senior manager contracted a mediator to listen to Tim’s concerns.

“I wouldn’t meet with him. Don’t try to fix me - fix the situation. They try to keep the complainant happy, but the complainant isn’t the problem.”

*Tim, family member*

At one focus group, participants shared an example of the provider at their Aged Care facility listening to feedback about the lack of quality in food. In response, the provider re-evaluated their existing catering contract and subsequently found a new catering company better suited to deliver food to the expectations of their residents. Jenny’s mother recently moved into a residential Aged Care facility reflected on the little things that help her mum feel comfortable:

“She misses fresh fruit and veg – she did tell them and now they have a fruit bowl in the dining room. But just those little things to make it feel... well, more normal, would be good.”

*Jenny, family member*

## **Quality is** accurate and transparent systems and fees

Home Care customers also felt quality was compromised by inflexible and inaccurate systems. Asheni was regularly billed for services although she had cancelled them in the stipulated notice period; Jenny's father-in-law Brian nearly gave up on Home Care services because they came too early in both the morning and evening to help him out of and into bed; Lorna's mother was hit with unexpected fees and charges on her first bill which far exceeded what she had expected. Asheni summed up some of these issues in a focus group:

"I have had severe communication problems with the care provider. I have had to chase accounts for having been charged for services cancelled. I have had 'support' workers who have been aggressive and unable to do the job required, or who try to get my signature without completing the house. There is a high staff turnover."

*Asheni, focus group participant.*

## **Quality is** leadership that puts consumers at the centre

Many participants had a keen interest to know about the leadership of organisations and believed that the culture and the staff behaviours they had experienced or expected to experience stemmed from the leadership values and philosophy. Ken described it as the leadership developing and building a good team, from laundering through to catering and through to care, whilst keeping agency staff to a minimum. In focus groups, many people said that to make decisions they would research the leadership and what they stood for; this included an interest in the background and sector experience of Board members. Sharon, a social worker, said that the flexibility of the intake policy all stemmed from the business model of the organisation. She described a couple of not for profit providers who stood out in her research as she knew they would be flexible because of their business model and social justice philosophy, rather than being strict about entry criteria as many others were.

One aged care facility, which was a privately operated independent facility, described how the CEO was present and involved in the recent Christmas party, whilst others felt that senior leadership was almost entirely absent and families were kept at arm's length.

“I can see what staff do. I observe them slowly walking about the halls on their phones. They don’t know about my brother’s condition or enough full information. They [...] do not have enough empathy to be working with people.”

*Elizabeth, family member*

## Help for consumers: Key considerations for the development of quality indicators

In making choices about Aged Care Providers, consumers and their families describe looking for indicators that will reassure them that they or their family member will have dignity and be able to enjoy a reasonable quality of life. Medical and clinical indicators are seen as 'basic hygiene' factors and not something that would distinguish one provider from another.

Key quality indicators that matter to consumers and their families are outlined below.



Figure 4: Key Considerations for the Development of Quality Indicators based on consumer experience



i. Staff to consumer ratios

Key indicators of quality of care relate to staff. Almost all participants who had experience of residential aged care said that they wanted to know what the organisation's staff to resident ratios were: they saw staff under pressure as a clear indicator of being unable to provide good levels of care. Di described staff having five minutes to get her relative into and out of the shower, leading to poor levels of care and safety.

Ken, who was retired from a long career working in the aged care industry, identified the need for a prescribed and appropriate staff ratio as critical to improving care, and this was reinforced by family members and consumers throughout the research. This came up as both a question that prospective consumers would ask a provider, and as a question that family members of existing consumers wished they had asked. Not only do people seek out ratio information, but also want the breakdown of staff ratios during the day and overnight, a time when older people feel particularly vulnerable.

*"For government, instead of monitoring falls and whatever else, they need to monitor staffing... especially staff ratios"*

*Ken, former Aged Care Sector manager*

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## Staffing ratios

*"With the ratio, these are very vulnerable people. They have health needs, they often can't speak for themselves. I have a younger client - in her 50s - with a disability, living in a group home. Her family got the idea she should be in aged care and she was made eligible. I encouraged her to try respite - I thought if she'd tried it she could then give more informed consent. She didn't like it, but family still thought it was best. Finally I said to them, 'In the group home the staff ratio is 1:4; at night in residential care it could be 1:80.' That finally convinced them."*

*Sharon, social worker*

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## ii. Staff roles & training

For both Residential Care and Home Care, consumers and their families want to be sure that the staff are trained for the specific role they are doing, not simply generically trained. Consumers seek indicators that enable them to find out which organisations, for example, designate garden tasks to skilled gardeners rather than care workers: We heard several stories of herb gardens being destroyed by well-meaning care staff who didn't know a weed from a herb. In residential care, families and consumers want to know the policy for staff by qualification and delegation, e.g. whilst a ratio may seem reasonable, can families be confident that there are enough registered nurses, for example, to make a decision on an Aged Care provider? In the case of specific conditions, how can families find providers that can deliver appropriate care, for example for individuals with Motor Neuron Disease or Dementia?

"I can see what staff do. I observe them slowly walking about the halls on their phones. They don't know about my brother's condition or enough full information. They [...] do not have enough empathy to be working with people."

*Elizabeth, family member*

Consumers and families would value indicators of how staff are trained, what sort of training they receive and how they perform in the human aspects of their role: treating people with respect, dignity, and their ability to show empathy: in short, as one participant put it, do they have a heart for the people they support? The ability to capture the consumer and family voice in these indicators would be highly valued, in a way that enables people to be free of fear of repercussions if they are critical of the provider. People trust the lived experience of others using the same services. Lorna described how she would try to find out what they really thought, even if a provider did not make it easy:

"I would definitely seek advice from other families. I'd wait outside [a facility] and bail up family members on the way out the door and ask them what it was like. That would give me a better idea..."

*Lorna, family member*

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## Sharing stories & experiences

Every Friday in the Residential Care facility where Brigitte lives there is a club for Home Care customers to join in social activities with residents. Brigitte knows many of the Home Care customers well: "Every Friday morning, someone comes up to me and asks me, 'Do you like it in here? What's it like to live here?'"

*Bridgette, residential aged care consumer*

When we meet with some of these Home Care customers the following Friday morning, we ask them what they would do if they required more help. "We'd move in here" they tell us. "They make you so welcome. We hear the whole story from the people who live here. Everything's good - although sometimes the food isn't brilliant - we like the people who work here."

*Home care consumers*

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“I would definitely seek advice from other families. I’d wait outside [a facility] and bail up family members on the way out the door and ask them what it was like. That would give me a better idea...”

*Lorna, family member*

### iii. Staff permanency & turnover

Many participants commented on the increasing use of agency staff in the sector and would value indicators that specify an organisation's commitment to salaried positions and the ongoing ratio of agency to salaried staff. Likewise, continuity of care, in both the Home Care and Residential setting, was seen as an important indicator to aid decision-making, so insight to providers' staff allocation policies and overall staff turnover would be welcomed.

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## An insider's perspective

The make or break issue is the staff. Their attitude, the continuity of care. I'm not interested if they use a lot of agency staff. They need to be trained in aged care, friendly, they need to understand your needs. I'd go to the accreditation agency reports - I'd look at staffing ratios - both day and night. I'd look at the number of agency staff, and staff turnover. If turnover is high there's something wrong. Night-time is a critical time - it's costly, but people need to feel safe. I used to look at the call bell response times - but sometimes that was wrong as staff attend but forgot to turn the bell off.

*Ken, retired Aged Care Sector manager*

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### iv. Dignity in hygiene & care

Many of the research participants had visited aged care facilities, whether they or their family were currently involved with Residential Aged Care at the time of meeting. The most immediate indicator for people on entering a facility was smell. This theme came up repeatedly, be it the smell of food, the smell of urine or, in some cases, the smell of faeces. Whilst this indicator is a very powerful and relevant indicator for people entering a facility, it is challenging to capture in a set of formal indicators. However, participants suggested that providers should be required to publish their policies on continence management and that for this indicator, the experience of consumers and families should be captured and included in accreditation and monitoring reports. Likewise, food satisfaction ratings would also provide consumers and families with valuable data to make decisions.

People also want indicators that make it easier for them to find providers that can deliver specialist care if required, including dementia support or age-appropriate support for younger people.

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## The smell of care

"My son fixes computers. He tells me that when he goes to other nursing homes, the smell...! He says I'm lucky to be where I am."

*Amy, resident*

"I rang around lots and started visiting [for my ex-husband]. In so many, I nearly passed out with the smell: urine, vomit and faeces. One looked lovely, but I nearly vomited when I went in the door..."

*Marcia, family member*

"When dad was in the 'Repat', I chatted with another woman who was there with her father. I asked her what she'd done to choose a residential facility and she gave me some advice: 'As you walk in the door, inhale the deepest breath you can. If you like what you smell, keep walking. If you don't turn around...'"

*Greta, family member*

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v. Confidence in systems for complaints & feedback

The handling and resolution of complaints and feedback was seen by participants as a valuable, but potentially problematic, indicator of quality. People voiced concerns that when they complained, things could become more difficult for their family member in care, and there was a sense that things that go wrong can get 'swept under the carpet.' Jenny told the story of her mother who has moved into residential care in the last year and on the whole is quite settled. However, one day Jenny went to visit late in the afternoon and found her mum quite distressed. She found out that a new member of staff had gone into her mum's room during the night, thinking she was another resident, and had shaken her awake. Jenny says that unless her mum had been able to tell her, she would not have known.

**"You run the risk of things like that disappearing if people can't say what happened."**

*Jenny, family member*

Likewise, there is a risk that agencies or providers only report the major issues in their complaints data, rather than the niggling things that go wrong each day, for example, where consumers and family members give regular feedback of poor performance but the agency does not classify it as a 'complaint'.

**"A lot of stuff is fixable, but when I bring it to the attention of the provider, they say sorry, they fix it, then it happens again. They're clever - they keep fixing it so I can't ever make a formal complaint to the Aged Care Commissioner. I've seen them giving the wrong medication, force-feeding people their medication... But how do I complain? They acknowledge, they fix it, then it happens again..."**

*Tim, family member*

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## What happens behind closed doors

**"My husband had a run in with a nurse one evening when he went to visit dad. They had put eye drops in dad's eyes and his eyes were reacting badly. Dad doesn't use eye drops. So I got in the car and headed down there.[...]"**

**"I found two agency staff by his bedside. I made them leave him and immediately take me to the nurses' station to show me exactly what they had put in his eyes. One of them opened a drawer and took out a small bottle. It was his Vitamin D drops - it goes on his Weetbix in the morning."**

**"The next day I insisted on seeing the report, but they refused - they said it was an internal document."**

*Greta, family member*

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## vi. Transparency of fees

Consumers and family members seek greater transparency in how providers manage profit at an organisational level and how they break down costs and fees at an individual account level. Linda, a participant in a focus group, had a Level 4 package for her husband until he died earlier this year. She voiced frustration that she had no visibility into what the 46% administration fees covered, and then questioned why the hourly rate that they were charged for staff was also inflated from what staff were actually being paid. Others echoed the desire for providers to be held more accountable for their financial accounting and prioritisation of spend. Many voiced an assumption that not-for-profit providers returned all the profit made in a service area back into that specific service, rather than into other parts of their business. Consumers want to be able to make a decision for a provider who manages their finances in a way that aligns with the consumer's value base. Likewise, making data available on financial accuracy in consumer invoicing would also be valuable in decision-making, particularly for consumers who are less confident or less able to challenge authority or interpret invoices.

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## Don't worry about the money...

"I wanted to know about fees - admin fees, hidden costs. I got a vague answer, it was around in circles. I was told not to worry about the admin fee, it's not too much. But there were hidden costs like equipment, for example, a walking frame that I wanted to get for mum, and that was all extra.

"I was told the fee would be \$75 per month - which mum could pay for with her package. They didn't tell us that because mum has Super, that comes into the calculation - it ended up being nearly \$200 per month. If she was getting more services it would have been fine, but for minimal services it works out expensive.

"We found out about the \$200 at the first bill. Mum got upset - the bill was hard to understand and it was a lot more than she expected. After a few visits I cut it and we went private - now mum gets a gardener and cleaner privately. "I rang up when we got the bill - it was then I was told about the Super. It had never come up before. Not all the information is divulged."

*Lorna, family member*

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## vii. Self-expression & choice

Whether it be home care support or care in residential facilities, family members spoke of the importance of respect. This covered matters such as an understanding past experiences, respect for individual choices, and preservation of personal identity. A common sentiment amongst participants was that the personality of an individual is easily lost in the aged care system.

Care tends to be provided at times suitable to staffing arrangements and rostering regardless of individual needs of a consumer or their family member(s).

“After a hospital stay, Brian was getting some help with (provider name) – showering, dressing, etc. – but [...] they came too early – too early in the evening and too early in the morning. They wanted to come at 6:30am – we managed to get it shifted to 7:00am.”

*Jenny, family member*

“You also should be able to choose your carer to help you with your own *intimate* care. I’ve got my own routine for my shower, but do carers actually bother to ask people *how* they want to be showered?”

*Angeline, former unpaid carer and considering aged care services*

Respecting the individual choices of consumers came up regularly throughout engagement with participants in relation to the management of dietary needs for diabetes, and consumers having the right to choose to have a treat every now and then.

Don spoke of his transition into a residential Aged Care facility and needing to adjust to support in his personal care:

“The staff vary – some I enjoy, some I don’t – it’s the attitude...”

[Don pauses as though he’s considering sharing further information and then decides not to]

“You get used to being dressed and undressed by females – it was a bit strange at first. I do sometimes wish you could specify who was going to look after you.”

*Don, aged care consumer*

A metric and data that is based on consumer’s ability to maintain personal choices in aged care services when it comes matters such as diet, intimate care, involvement of family in care, independence, and understanding of past personal experiences and their ongoing relevance and importance to an individual’s life. This type of information being available to consumers and family members would help decision-making, particularly for individuals who have no intellectual impairment or may be younger with high care needs.

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## Their life story is accessible

“Staff need to know about the life stories of residents. No one is going to - or has time to - get a big folder out to find out about a person’s life. I’ve seen it and I know from experience, it just doesn’t happen.

“There needs to be a quick way for staff to find out about key events and interests – don’t hide it away in a file somewhere... create a quick reference that can be displayed in each room or accessed easily that helps tell the life story of that person.

“Personal information that is accessible! It’s not hard, but would make a big difference in maintaining a person’s individuality.”

*Stefan, family member and former professional in dementia care, community, residential and general health settings*

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“They need to remember that the people they care for have had vibrant lives – they have families and stories [...]. I’d tell them about mum – her story, she’s a real person, what sort of person she is.”

*Marie, family member*



#### viii. Access to consumer experience

The road to finding the right service provider is complex. Participants beginning to explore aged care service options, those already in services, and family or carers all spoke about their experiences in navigating different providers, their service offerings and finally making the 'right' choice. Accessing the experiences of consumers is difficult. It's hard to get an impression of aged care services in advance, and is even harder to make decisions if you don't have any previous experience in the aged care sector: you don't know what you don't know. It's also hard to 'try out' a service or to spend time in aged care facilities.

For this reason, participants talked about accessing consumer experiences in a variety of ways to help decision-making. Consumers and families rely on word of mouth, reputation and the experiences of others to make decisions. There are other factors such as location and cost that impact choice, however people still rely on knowledge of how a service is delivered, what staff (and ratios) are like, social setting, fit for individual lifestyle and needs, and the feeling of a place to make a decision within their means. For example, location may be sacrificed as a priority if it means personal choice and self-expression are supported.

Providing access to consumer experiences would give those considering aged care services an opportunity to explore this information up front – being able to determine whether consumer experiences match information being given by a service provider is an important part in the decision-making process.

"[...] I'd like to talk to current customers about the aged care provider. In aged care, it's not like when you go shopping. I'd like to be able to interview them."

*Marie, family member*

“Government needs to look at where people cycle through the system. Why are they still auditing any kind of government service? It’s a big flaw in the system.”

*Greta, family member*

## What is the consumer view on ‘below the line’ quality indicators?

Across the interviews and focus groups with 67 people, ‘below the line’ indicators of quality such as safety and clinical measures came up very rarely. In most cases, these seemed to be assumed as a minimum requirement rather than a differentiator that would help in decision-making. A summary of what consumers and family members did say about ‘below the line’ indicators is outlined below.

### Views on Compliance

“When they know they are coming they just run around and clean up!”

*Marcia*

Consumers are on the whole fairly skeptical about the efficacy of current indicators and accreditation methods; this is perhaps particularly true in South Australia where the Oakden case is very close to home. One man, when asked about the care at his facility said:

“Well, it’s not Oakden if that’s what you mean!”

*Don, consumer*

Another participant questioned how a facility she knew was deemed compliant:

“Bob is in a place nearby where he used to live. There are not enough staff to look after the residents. At relative meetings we tell them there aren’t enough staff. Recently there was a lady who was so upset because she had wet the bed and was told she had to wait 30 minutes! Where is people’s dignity? Apparently they’re ‘meeting current standards’ and I don’t see how that can be.”

*Elizabeth, family member*

A third person, who is using aged care services for family whilst also working for an agency that is a CHSP provider, commented that the person who had come out to undertake their compliance audit had been a key player in signing off the Oakden audit. She said:

“Government needs to look at where people cycle through the system. Why are they still auditing any kind of government service? It’s a big flaw in the system.”

*Greta, family member*

Greta is keeping detailed notes of what is happening in residential care where her dad lives and has engaged advocacy support. She is determined to make sure that things don’t get ignored and that voices of complaint get heard:

“Look at Oakden - that’s what happens when relatives aren’t listened to...”

*Greta, family member*

Others described ‘Googling’ board members and leadership teams as part of their decision-making process:

“I wrote to [senior manager] to have a meeting. I’d done my homework before I went to see her - she was impressive...”

*Tim, family member*

“I consulted Dr. Google. This is Adelaide! There’s less than 7 degrees of separation. I was easily able to find out that [person] is still working in the industry.”

*Greta, family member*

This all suggests that family members are doing their own research and investigation beyond what is available through formal channels.

## Views on safety indicators

Participants in focus groups were specifically asked to reflect on what various dimensions of ‘quality in aged care’ meant to them. On the topic of safety, participants spoke of emotional safety and feeling heard and respected as key aspects of what they would need to feel safe. Two groups also talked about physical security, which was described both in terms of being able to lock their own door and in terms of the wider environment being a safe and secure place for them.

One focus group spoke strongly about the misuse of the term ‘safety’ in aged care to justify, in their eyes, the limitation of human rights. One participant included in this the denial of exercise, as people were constrained inside; another agreed, saying that his brother is often constipated until he takes him out for a walk around the block.

“Safety is used to control people and lock them up. In the Netherlands and Europe people can walk about freely in a village-style environment.”

*Tim, family member*

A number of participants also voiced concerns that ‘safety’ was being used to justify chemical or physical restraint. Marcia described going around nursing homes to find a place for her ex-husband:

“There are so many people in princess chairs. I thought, ‘Oh my God, this is how they control people!’”

*Marcia, family member*

Consumers themselves want to be allowed to take informed risks, or partake in life-giving activities that enable them to still contribute and help:

“Activities were an important part of choosing to come here, I was helping in the garden but then I was told I can’t do it any more for safety reasons. [...] I help my 99 year old friend make breakfast in the morning because he is up at 7:00am and none of the carers are around at that time. I like helping anyway so that is good.”

*Phil, consumer*

Consumers and families also feel that safety can be used to unnecessarily limit family or an individual consumer’s involvement in their own care. When done well, it can be empowering, as was the case for a focus group participant, Denise, who told us that when staff came to spring clean her house earlier that week she had been involved too, doing the tasks that she was able to do herself.

## Views on clinical indicators

Clinical care indicators did not come up as key criteria for making decision in any context, either interviews or focus groups. In focus groups, participants were specifically asked to describe quality care, and they used descriptions such as listening to me, responding to individual needs, supporting carers and families, and demonstrating empathy and compassion.

Management of Diabetes was an interesting example that came up several times in interviews and illustrates where people's priorities are. A number of family members said that they wanted their parent to be allowed to choose to have a dessert occasionally if that is what they wanted, or to have a glass of wine with dinner, rather than be denied it because it was against medical advice.

"I'm not so worried if they have diabetes which is poorly managed if they can get out and live their life."

*Sharon, social worker*

Ella summed up the sentiment of many participants on the priority of clinical versus quality of life indicators:

"I come from a culture where ageing is revered. I don't like the medical model. You should be able to have tomato and basil growing and have value in your life until you don't have life anymore. It is achievable."

*Ella, family member*

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## Unexplained sleepiness

"We did have an awful experience with respite. Dad went into [a facility] close by for three weeks. It was walking distance from home. The rooms were spartan. We visited a few times and all the people were parked in front of the TV. There was a lifestyle person who came in in the late afternoon but otherwise... There wasn't much space and he didn't walk much. In 3 weeks his walking really deteriorated.


They day we were picking him up - we were told he hadn't had a good night, but the nurse wasn't forthcoming. He was asleep, we could hardly wake him up. [...]

When we got him into the car, the manager smiled and waved us off. But we could hardly get him out of the car at the other end and later in the day, Mum couldn't wake him again. We phoned the doctor and he told us to get an ambulance.

When he was assessed at the hospital, they thought he had been drugged. Mum had to work really hard to get him walking again after his stay."

*Diana, family member*

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A woman with short brown hair, wearing glasses and a bright orange scarf, is smiling. She is wearing a black long-sleeved top. A watch is visible on her left wrist. The background is a plain, light blue wall.

“I come from a culture where ageing is revered. I don’t like the medical model.

You should be able to have tomato and basil growing and have value in your life until you don’t have life anymore. It is achievable.”

*Ella, family member*

# What is the role of quality indicators in decision-making?

The quality indicators described in this report, that are meaningful and significant to consumers and give people confidence that providers can and will support quality of life for all consumers, are important but go hand in hand with other key factors in enabling an informed decision.

## Decision-making trade off: Quality vs price

A critical factor, and one that unfortunately can lead to people making compromised decisions on quality, is price. Affordability is a significant limiting factor on people's choices, and in the current system many people reported finding it hard to do side by side comparisons of what each provider offered and for what price. For consumers who are looking ahead, they are anxious about the impact that having little disposable income or savings will have on their choices:

"My biggest problem would be if I had to, god forbid, move into an Aged Care facility. We don't own our own home, have very little in the way of savings so would not be able to pay a bond to go in. I would be at the mercy of the government who would, I believe, put me into a facility anywhere from Elizabeth or further north to Victor Harbour with no thought of whether family could visit easily or whether I wanted to be in a particular area. I find this quite distressing and hope I never find myself, or my husband, in this situation. I know the things I would want should I have to go into residential care, but fear that I would have very little voice in this matter."

*Lynsey, focus group participant*

Many people we spoke to felt their choices for Home Care were severely compromised by availability and the 'top up costs' they would incur by taking the available lower level package. In all the interviews and focus groups, we met one person who had successfully accessed a Level 4 package, with many others feeling they were forced to move into, or move family into, residential care because they couldn't afford to top up a Level 2 package. Marie described her mum's circumstances:

"She [mum] made the decision to go into a nursing home - but it was somewhat taken out of her hands, because she was assessed for a Level 4 package but none are available. [...] Regarding Home Care, she's worried that if she's using all the money, what will there be left for Dad? So the main reasons for not doing home care is impact on Dad, and me, and finances. If I won the lotto tomorrow, would she be at home? Yes, she would."

*Marie, family member*

Sharon says that for her as a social worker, cost is one of the three key factors clients consider when making a decisions, along with location and availability:

"Some are flexible with the RAD, while some just look at the dollars and are very firm. It all depends on their business plan."

*Sharon, family member and social worker*

“She [mum] made the decision to go into a nursing home - but it was somewhat taken out of her hands, because she was assessed for a Level 4 package but none are available. [...]

Regarding Home Care, she’s worried that if she’s using all the money, what will there be left for Dad? So the main reasons for not doing home care is impact on Dad, and me, and finances. If I won the lotto tomorrow, would she be at home? Yes, she would.”

*Marie, family member*



### Decision-making trade off: Quality vs location

For consumers with families and strong community connections, the ability to find aged care available in their local area is important, or in a location close to family. Greta told us that, although there was culturally specific aged care available for her parents in the northern suburbs, the convenience of other facilities near her home in the south overrode the desire for cultural connection, no matter how good those facilities were. Likewise, Marie's family, including her mum, sought the best support they could that was available near to home:

"We put her name down for a number of homes - but she'd been in the [Royal Adelaide] hospital for a month and in Hampstead [Rehabilitation Centre] for a month - and that takes a toll on a family, with travel, visiting, spending time with Mum - we really wanted her close to home, so we only looked at homes in the area."

*Marie, family member*

Sharon, a social worker, had a different view of location:

"How it looks doesn't matter! It can look great but you call out and get an echoing response – there's no-one to be seen. If I was making the decision for my Mum [...] I would actually look to regional small-town facilities. They are usually more community-oriented. The director of nursing is more hands on and gives direct support."

*Sharon, social worker*

### Decision-making trade off: Quality vs availability

As already mentioned under price, availability or lack of it is a limiting factor on people's ability to make a quality-based decision. For Home Care, and particularly for higher level packages, people feel that they have virtually no choice; if a Level 4 package becomes available, their choice is to take it or not take it, regardless of the provider. Likewise, residential care places are in short supply in some areas.

"I went to five providers, only one had a Level 4 package, so we have no choice..."

*Focus group participant*

Whilst people would ideally like to make care decisions based on quality indicators that matter to them, in the current context too often the choice is simply between getting services and not getting services, and people being pressured to make a decision quickly.

"[...] it's like you need something and they've got it and they say, 'We've got a place, do you want it or not?!' It would be good to be able to talk to people living there and their families..."

*Marie, family member*



“My Aged Care and the Minister has a role in stamping out the ‘retribution issue’ so we can comment on behalf of our family members”

*Focus group participant*

# Participant views on existing indicators, data, and communication and the development of new quality indicators

## Gathering quality indicator data

Consumers have low levels of trust in current accreditation standards indicators and the methods used to monitor compliance. The exception to this was amongst older consumers we spoke to, some of whom had a greater sense of trust in both what providers told them and in formal accreditation. Having said that, only one person, Ken, who had previously worked in management in the sector, described seeking out accreditation agency reports as part of his decision-making process.

A recurring theme was the desire for more monitoring and accreditation to be done unannounced, with 'spot checks' to see what's really happening day to day, rather than providers having a chance to prepare for an accreditation visit.

Consumers and family members also want current consumer and family experiences to inform accreditation, although there was some uncertainty about how this could be done in a way that protected people from repercussions if they said something negative. Greta, an outspoken family member, said:

**"I do worry about what retribution my father will suffer when I'm not there."**

*Greta, family member*

Yet Greta is a professional woman with a long career in Human Resource Management, and would provide strong and important perspectives on a provider's performance if her voice was included in accreditation processes. Likewise Marcia, another strident family member, had a similar suggestion:

**"They need to make contact with residents' families to find out what's going on. And simpler still, just go in and see how many people smile?"**

*Marcia, family member*

Tim told us he was aware that there was a new questionnaire that the accreditation authority could send to residents to ask them their opinions, but again, fear was seen as a barrier to this being effective. Likewise in a focus group, one participant suggested greater transparency was required to assure people of their rights to give feedback without fear:

**"I would like to see a printed statement on display in Res Care Centres signed by the CEO that there is no 'retribution to consumers' if their advocate makes a complaint - this needs to be enforced to allow people to speak up to improve the care."**

*Focus group participant*

## Communicating quality indicator data

“Red tape is out of control! My Aged Care is too complicated and confusing, even for someone with some familiarity with the system and familiar with the internet...”

*Margaret, consumer*

When we asked consumers where they would go to help them make their decision about aged care services, many relied on already known and trusted partner agencies or key people in their lives. A number of the people interviewed were COTA SA members, and some of them saw COTA SA as a reliable source, whilst for others this included Red Cross, DVA, their local council or a family member who worked in the industry. These may not all be seen to be the ‘right’ source, but at times of stress and anxiety, which is often the case when making aged care decisions, people go to the agency that they trust to help them.

“Without my daughters, I would have needed to find someone else to help. Maybe COTA? Also the DVA - I’m a war widow and they looked after me really well.”

*Jane, consumer*

For many of those who had relied on family, or family members who had been key in helping older relatives, the thought of navigating the system on their own and finding out the data and information that they needed to make an informed decision was hard to imagine:

“If someone doesn’t have family, they’d be lost. Mum wouldn’t know what to do... (pauses, then repeats quietly) She wouldn’t know what to do. That’s a scary thought.”

*Lorna, family member*

Participants did not voice strong opinions about the platform on which quality data should be recorded and communicated, although some were concerned about access for those who are not computer literate. Where people had active family, they tended to share the research and gathering of information, regardless of whom was making the final decision. Where consumers themselves were in a position to do so, it tended to be them who had the final say, but this became less the case as people became more frail. The reliance on trusted partners, where these existed, also meant that the platform was less critical than the ease of navigation and the relevance of data being captured. Indeed, everyone we spoke to who was seeking information and navigating the system was under pressure and sought ease, simplicity and efficiency.

“My Aged Care website is very wordy, repetitive and not intuitive. It needs more graphics to make it easier to understand.”

*Angeline, consumer and family member*

Trusted support agencies, whilst free from the emotional stress and anxiety that families and consumers may feel, are incredibly time poor and as a result cannot dedicate time to navigating a complex system:

“We don’t have full appreciation of the sector. It would be ideal to go through in detail for each case, but we don’t have time [...] In the last year there are 48% more providers. That might give more choice, but it also gives more confusion.”

*Sharon, social worker*



## A consumer's view of accreditation of the future

"I saw in the review there was an idea for a star rating system - I'm against that. It's flawed, it can be manipulated. I've visited hotels that have 5 star ratings and the reality doesn't match up. You wonder if they are describing the same place.

'It's got to be independent, I don't trust the government. They have to have access to the quality criteria. They need to be honest - not fed by the providers or the government. And independent accreditation reviews should be on the spot - not planned in advance.

"It needs to be an external commissioner with its own authority. It needs to be able to act without intimidation. It needs access to the complaints - all of them - to understand the nature for these, and have they been formally dealt with.

*Tim, family member*



# Recommendations to address the current challenges for consumers & families entering (or in) the aged care system

In our conversations with consumers and family members, it is apparent there are still significant challenges in understanding, accessing and navigating the Aged Care system.

It appears that in the early stages of seeking support, there are relatively low levels of awareness of what is available for families who have had no previous contact with the aged care system. Indeed, many of the conversations went in such a direction that it was clear people equate 'aged care' with 'nursing homes' and interviewers had to prompt conversations about support at home. Tahlia and her mother Sonia, who are Italian, said that when Sonia needs support they would go straight to an Italian service provider. They had heard of My Aged Care but assumed that it was only to get assessed for residential care and had no idea that government funding was available for low-level care at home.

Some recommended key roles and responsibilities for government that emerged from the research are outlined below.

## i. Increase accountability and consistency

It was clear from conversations that making informed decisions based on quality indicators is only valuable if consumers can rely on these quality measures to be consistently measured and maintained. Events like Oakden have led to high levels of consumer skepticism and a widespread belief that current accreditation measures are unreliable indicators of what they deem to be quality aged care. Others suggest that providers work the system to make it seem like they are meeting standards when they aren't:

"They say waiting times have gone down. But actually what happens is the carer goes in straight away, they turn the bell off, then they say they're busy and they'll come back. Then they forget to go back."

*Tim, family member*

Likewise, consumers seek greater clarity on how providers spend their package money. As previously mentioned, Linda had no visibility into what the 46% administration fee for her husband's package was spent on, in addition to an inflated hourly rate for staff. Lorna found that once fees and other financial issues were factored in, her mother's home care services were well in excess of market rates and of what she had been told to expect.

## ii. Increase financial clarity

Government has a responsibility to make the system responsive and timely enough that people are able to make decisions based on quality and be confident of affordability. The social worker who we met, Sharon, is involved in numerous aged care placements and told us several stories of people who had been in respite or had been placed, only to discover when the financial assessments came through that they couldn't afford it.

"I have a current client - she has DVA pension, Super, an average unit. She has been in respite near her home for 8 weeks. She's 94 years old, she's settled in well, but the RAD is \$550k and now we've discovered she can only afford \$450k. I have had to fight this one, and reluctantly [they] have agreed she could stay. But it's only because she's 94, and they assume she'll die soon. If she was 70..."

*Sharon, family member and social worker*

For Diana's father it was only once they got help from a financial advisor who specialises in aged care that they started to believe it *might* possible that her parents could afford to get the support he needs. However, it was a full month after he moved in that they received final confirmation of the finances:

"I talked to the financial advisor, and then we said, 'We think it might be OK... they have good care, and Mum won't have to live on baked beans.' I just heard today that the financial advisor got confirmation on Friday that he is eligible for government support, so Mum will know what she has to live on."

*Diana, family member*

### iii. Ease of navigation

Consumers find the current system hard to navigate and understand, which makes it challenging for people to find and decipher current indicators of quality or to undertake side by side comparisons. Diana, a consultant who has been running her own business for 18 years, said:

"I thought I was intelligent until I came across My Aged Care."

*Diana, family member*

Diana described herself as "a little magpie", picking up and learning something new every time she phoned My Aged Care, but never getting the full picture. Different people told her different things each time she made contact; this was a similar experience once she began talking to aged care providers.

"I wanted a roadmap through Aged Care. Where do the services fit? Who should I talk to? I talked to friends who've been through it. It all just felt random - the randomness of picking up the phone and making six phone calls, hoping you hit on the right one. MAC is a call centre - they just point you to the website. But I can see the website - I wanted more [...] I felt MAC didn't so much give conflicting information as not fully disclosed information. They only gave me the information required by my specific question, rather than the whole picture."

*Diana, family member*

Many people empathised with older people who are on their own and trying to navigate the system without support of family. Sharon said that for some of her clients, without someone to help them through it, they end up in hospital where a placement coordinator does that for them. Whilst they would like to be able to do that for each client that her team sees, they are not resourced to do it.

"I've been seven years in this job, I have a good understanding of the system, and I still struggle. Imagine if you were an elderly person, with a son or daughter in their 60s, and you know nothing about the system - how do they do it?! MAC is just a call centre with a script..."

*Sharon, family member and social worker*

Betty, who attended a focus group, used CHSP services for a few years but after her husband died she moved house, and because she had moved to a different council area, she had to go through MAC again to be assessed in order to continue receiving the same services.

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## Endless rounds of bureaucracy

"I had a client who was from a non-English speaking background, but he had excellent English, with an accent. We made a referral and it didn't get to ACAT - it stopped at the RAS. He was assessed as eligible for 3-4 things, but he only accepted one thing. Then he needed some more - we had to apply again. This time it went through to ACAT and he was assessed for Level 4. But he only got Level 2. The organisation was topping up with bulk funding and he had some private funds to top it up as well. But the organisation couldn't continue with the bulk funding, so we had to go back to MAC to get another assessment to bump him up the national queue as urgent to get Level 4. Thankfully they didn't come out again and I knew this client well, but I spent one hour with an assessor on the phone - just to increase the urgency. Without his own funds, he would have been in residential care. And at Level 4 now, he's still topping up with his own money."

*Sharon, family member and social worker*

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### iv. Enable access to independent advice

A number of people commented that brokers are good but only if you are seeking residential placement and have money. Many participants, consumers, family and professionals, suggested that there was a need for an independent and free advice and signposting service funded by government, particularly at the Home Care end of aged care services and for those with limited or no financial means. Tim spoke of concerns about brokers and said:

"I'm skeptical of anyone who stands to profit for their advice... Brokers must have a good relationship with providers to get people in."

*Tim, family member*

"Government should have an independent aged care person you could go to talk to or who could come to you."

*Lorna, family member*

Marie's mum was in rehabilitation and as a result that facility helped them coordinate the move into residential care. Marie talked often of the member of staff whom they trusted, who knew the system and who helped them navigate the decision-making. Staff from the rehabilitation centre were also working as strong advocates for her mother in residential aged care:

"They've almost been a voice for Mum [...] they've taught Mum about having a voice [...] Without Denise, we'd have been lost in the woods."

*Marie, family member*



“Sue wanted a place with likeminded people [...]. She wanted to be able to continue to do a wide range of activities – there was nothing wrong up here [points to head].”

*Elizabeth, family member*

v. Making available the quality of life measures that matter to consumers

In selecting aged care services, and where people do have real choice between providers, they want to be able to filter out unsuitable providers in terms of personal fit in an efficient manner. Government has a role in enabling people with specific needs to find providers who can meet their needs; we heard this from consumers and family members of people with specific conditions such as Motor Neuron Disease or Alzheimer's. Elizabeth, whose sister has a degenerative condition, described her experience of visiting aged care facilities:

"I had a list of 30 nursing homes to look at for Sarah. Rooms weren't big enough for her electric wheelchair. I turned up at one home with Sarah and as soon as we went in, the lady peered over the desk and said "well you didn't tell me she was in an electric chair! We can't have that in here" and then she made a comment about Sarah's weight implying that she was also too large. Well, she hadn't been able to exercise for a long time because of her muscles!

"I would never have gone to the bother of getting an accessible cab and taking Sarah there if it wasn't going to be an appropriate home!"

*Elizabeth, family member*

vi. Capturing and communicating family and consumer experiences

Ultimately, people want to know if particular services are going to suit them, be reliable and support them to live a reasonable quality of life. Whilst some much older consumers are still inclined to trust aged care providers to deliver this, many younger consumers and family members seek peer feedback and consumer experiences as a reliable litmus test of what actually happens and how care is actually delivered. Greta described her experience with an aged care provider where she felt that the agency was actively trying to prevent families from talking to each other, whilst in a focus group a participant said that when they tried to organise some family events they were told by the [faith-based] provider: "If families want to talk to each other they can go to church!" Consistently however consumers voiced concerns about retribution for consumers involved in giving feedback, and in a focus group consumers and families articulated their expectation on this:

"My Aged Care and the Minister has a role in stamping out the 'retribution issue' so we can comment on behalf of our family members"

*Focus group participant*

Government has a responsibility to ensure that consumer perspectives and experiences are captured through accreditation processes, and not simply those whom a provider has 'cherry picked' to give the best responses. In one residential care facility, when a staff member suggested to her manager that we could chat to Philomena, the interview team saw the manager subtly shake her head and suggest another resident. Whilst we do not know why Philomena was deemed unsuitable, it is our strong recommendation that accreditation authorities should seek out a broad range of consumer and family voices; in short, they need to speak to people like Philomena.

“My biggest concern is the level of care – they’re not equipped to look after people like my Mum. She’s only 72 – she’s been active, was planning to travel, she’s not an old woman.”

*Marie, family member*

# Proposed solutions from a consumer perspective

We posed the following query to focus group participants: What might some possible solutions be? Responses varied and participants rely on different sources of information to form trusted opinions and help decision-making.

As mentioned previously, there are expectations from consumers and families regarding the role of government in terms of increased accountability of providers, financial transparency, ensuring the My Aged System is easier to navigate, and access to trusted sources of information that capture family and consumer experiences in a way that reflect quality indicators that help people make more informed choices.

What does this look like? It is worth consideration and investigation into the following:

- + Centralised rating and review system
- + Centralised complaints and feedback monitoring system
- + Centralised reporting on key indicators such as ratios (staff to resident, permanent to agency staff), complaints and recurrence of common complaints, and service provider finances
- + Support to access and navigate the Aged Care system

## Centralised rating and review system

Participants are somewhat skeptical yet still seek out online reviews. What some participants explained is worry or lack of trust in the validity of some reviews; some discussion centered around organisations being able to 'purchase' reviews from overseas. Also discussed was a fear of submitting reviews and retribution to consumers from providers.

Still, the ability to access reviews and experiences of consumers and family members is an important way of making informed decisions. Participants discussed different models such as Uber or Air BnB that has a dual rating system, one for the customer and one for the service provider. Participants believed this type of system is transparent, seems to be a way of keeping both parties accountable, and important to providers being able to have right of reply.

*"... there needs to be an opportunity for providers to 'make good' on complaints."*

*Focus group participant speaking of online reviews*

Participants had mixed views as to whether it was the role of government to provide an independent, centralised and robust system that could be relied on for accuracy. Participants agreed the source needed to be independent of aged care service providers, but allow providers to co-rate and respond to reviews.

## Centralised complaints and feedback monitoring system

Participants discussed the existing Aged Care Quality Agency having broader scope than dealing with significant issues, for example, all complaints being handled centrally to assist better monitoring of service providers and the recurrence of reported issues whether minor or significant in nature. Participants felt that centralised management of complaints would provide a more robust system and stronger accountability and awareness of issues within the aged care system. Complaints being managed independently would assist in reducing the fear of retribution for consumers or family members in reporting issues.

“There is a new questionnaire that can go to the residents to ask them their opinions... but residents are scared of intimidation. I knew a physio who was working with someone and even he was scared to report things.”

*Tim, family member*

As well as keeping providers accountable, participants also indicated they felt this would provide better supports for providers and staff members. One participant in particular described concerns for the wellbeing of staff and their treatment.

“I’ve heard terrible things in homes, and that is residents yelling at staff, racial slurs, you name it. Respect has to go both ways.”

*Focus group participant*

### Centralised reporting on key quality indicators

Centralised and accessible reporting is another key element to forming well-rounded knowledge of provider(s) to assist decision-making.

It is evident from all interviews and focus groups, participants use different approaches to access information due to a lack of centralised information / reporting on indicators that don’t yet exist (refer to Figure 4: Key Considerations for the Development of Quality Indicators based on consumer experience – page 20).

There are certain indicators participants place strong emphasis on for centralised reporting such as staff to resident ratios, permanent to agency staff, complaints and recurrence of common complaints, and transparency in finances of service providers including funding arrangements.

Reporting on other possible indicators such as ‘self-expression and choice’, or ‘dignity in hygiene and care’, would be supported by other methods to form views on the suitability of a service or home, particularly for residential facilities. For example, participants advised they would use available reporting to shortlist service providers, but would still attempt to complement this information with in-person site visits to be assured of organisational leadership, staff values, respect of residents, and the ‘feel’ of a place.

“Sue wanted a place with likeminded people [...]. She wanted to be able to continue to do a wide range of activities – there was nothing wrong up here [points to head].”

*Elizabeth, family member*

### Support to access and navigate the Aged Care system

In all focus groups and interviews, we asked participants to tell us how they made their decision on a service provider. We heard many stories from consumers or family members about the difficulties of navigating the My Aged Care website or call centre, and even greater difficulty in choosing the ‘right’ service provider.

Most participants, other than those who had to make decisions in crisis, relied on independent sources for information to assist their decision. Generally, this was because information can be hard to access or decipher, or in the case of service providers, the information is seen to be the ‘glossy’ and biased version.

Some participants specifically sought support from independent advocacy agencies for assistance in navigating My Aged Care. Other participants shared about their reliance on brokers for in-person services and for help finding availability and care that met individual needs. In both instances, participants said this provided some level of reassurance that their decision was based on some unbiased information and therefore better informed.

In contrast, others discussed their hesitation toward broker services feeling as though the advice would be compromised by the receipt of monetary benefits from recommending aged care service providers.

There are differing levels of trust of the 'major players' in the aged care industry. Generally, however, consumers and family members share a common view:

1. **Government** is seen to be the governing body of the overarching system, ultimately responsible for creating opportunities for a better future, and the regulator that ensures service providers are compliant with standards. Government is where an individual goes first to understand what level of care and financial assistance they are entitled to.
2. **Aged Care Service Providers** are organisations who provide services to individuals who need assistance to continue living their day-to-day lives; some are better than others. It's up to consumers to navigate the best fit within their means.
3. **Independent Sources** provide a way for individuals to compliment information from the above sources that is based on understanding unbiased, personal experiences and provides insight that can't be gained without some level of experience in the industry. These sources range from families, friends, consumers of aged care services, brokers, research papers, news articles, and advocacy agencies.

It is vitally important to recognise the important role that independent sources of information play in assisting people to navigate the aged care system and have some understanding of what it might be like to receive services from any given provider.

In summary, consumers, family members and carers expect reporting on quality indicators as a minimum to help navigation of the Aged Care system, and ultimately deciding on the right service provider for them. In addition, people seek information from independent sources to 'fill the gaps' in information that is provided by the government or service providers: Independent sources will continue to be a critical step to providing individuals with a sense they've obtained well-rounded and unbiased information before finalising any decision to select an aged care service provider.

Information must be easy to access for people of all abilities to be a helpful guide for consumers and families, and importantly, help reduce any unnecessary anxiety in what is often a difficult time for people.

*What does quality mean to you?*

“Food! Here they are cooking for 87 people, 3 different types of food – it’s okay, but I have my own spices. And if I don’t like the bread I buy some sourdough.

“Quality is also having enough to do. The nursing is good, but I look after myself. The doctor is also very good. I wasn’t walking when I came in. The only outside health professional I see is the podiatrist – I’ve been with them for years. The chemist comes in on a Wednesday – I do all my own medications and keep them locked away.

“I’m happy here.”

*Brigitte, aged care consumer*

## The future of Aged Care

In undertaking this qualitative piece of research, it is clear there are still fundamental concerns about the aged care system despite events such as Oakden, the launch of a government inquiry and recent release of the Kate Carnell report.

There is an underlying tone that craves change to the aged care system. Although there is a push toward 'ageing-in-place' with recent changes to government funding, many participants spoke of assessment outcomes at Level 4 packages, yet none being available and therefore no alternative to care other than residential aged care facilities particularly for individuals with financial pressures.

One participant, predicting a turn toward consumer directed care in residential care nationally, voiced concerns about impact to the industry. This included a sense that by enabling people to change service providers if they are not satisfied this minimizes the role of government and opportunity for systemic issues to be noted and addressed.

For older people who do not have the assistance of family or friends, or the ability to navigate or advocate for themselves, their ability to raise issues or change providers is also compromised.

Ken also spoke of the need to support evolution of the industry:

"[...] If service providers don't receive any funding to allow for the future planning and thinking around aged care services, and the government don't have any involvement, how will the industry evolve?"

Ken, retired Aged Care Sector manager

Whilst findings of the South Australian research point the way to better quality indicators that will support consumer decision-making in aged care services, there are greater concerns about the aged care system. In short, people want to continue to be supported in their own communities, surrounded by familiar people and places, be valued as an individual with ability to make own choices, and continue to have a role in contributing to society. The existing system of My Aged Care is limited in options.

In focus groups or 1:1 interviews, multiple participants referenced co-housing examples that have been established in several European countries for years, and more recently, the development of communities such as 'dementia villages' that create living situations resembling normal and everyday lives.

Through listening in detail to the lived experiences of our 67 participants, the research is clear: Development and easy access to centralised information of new quality indicators will better assist decision-making of aged care consumers.



The launch of My Aged Care in 2013 was the first step to change. It is COTA SA's strong view that further strategic reforms are needed to encourage growth and transformation in the aged care sector: Reforms and funding arrangements that drive further exploration into sustainable communities that respect and support individuals of all ages to maintain levels of independence, contribute to society and be better placed to age in their own homes. Where high levels of support are needed, these facilities, as much as possible, should mimic everyday neighbourhoods.

This will see longer term social transformation on a national scale and a brighter future for ageing in Australia.

"The care is so important – physical, emotional and also the social setting. For younger people like my brother who is only 65, there is no where that is appropriate for him to go..."

*Elizabeth, family member*



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