

New single quality standards: consumer information resources

Phase 1: Report



Australian Government

Australian Aged Care Quality Agency

APRIL 2018

© Commonwealth of Australia April 2018

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Introduction

The Quality Agency has undertaken this project to identify and develop key messages for consumers on the new Aged Care Quality Standards and quality assessment. The objective has been to increase consumers' understanding of the quality standards and how they relate to their care. The project has included consumer consultations, across a number of geographical locations, service types, service provider types, and with different consumers.

The plan for engagement has included a survey of relevant literature, discussions with several key government stakeholders, and consultation with consumers, as well as consumer organisations.

The project has included two phases for the consultations:

- Phase 1 - Learning about the information channels and key themes that consumers find most helpful
- Phase 2 - Piloting information resources

Phase 1 consultations have now concluded. This report outlines learnings from a review of existing literature and advice, including valuable advice and insights from meeting with the Aged Care Complaints Commissioner and staff at the Department of Health who have responsibility for the My Aged Care site design. It then explains the engagement methodology used, and what was heard in the consultations.

This project did not focus on information resources to meet the specific needs of Aboriginal and Torres Strait Islander people. The Agency has separate work underway to consult in this regard. However, many of the themes identified about the design of information resources have the potential to improve the quality of information for this community.

Existing knowledge

Engaging with older people - designing the engagement

The project involved a review of publications that addressed engaging with older people. It also involved talking with consumer organisations to seek their expert advice around consumer experiences. This research informed the development of the consumer engagement plan.

The review found that general literature on engagement methods often referred to the elderly as a particular market segment, much like the young or disadvantaged. The literature emphasised how important it is to engage with older people, highlighting that researchers often leave out the views of the elderly. There was also information on how best to communicate with the elderly in health care settings, with a focus on helping the elderly understand required medical treatment, or on how to provide them with ageing or health-related information. There was recognition that different communication methods may be more appropriate, and that the elderly may be difficult to reach by standard and mainstream communication methods.

However, there was little academic research that actually drew out what might be different in stakeholder engagement with the elderly, particularly those over 80.

This project involved reviewing a number of practical guides produced in Australia, and incorporating their insights into the engagement plan. This included guidance produced by

the Tasmanian Government¹ and by the South Australian government². The latter, in particular, provided a significant amount of information about the best techniques to employ, with case studies illustrating the different lessons learned. This project also drew on an evidence review on engaging with older people, from the UK.³

An examination of the literature, coupled with extensive stakeholder engagement experience, informed this project's consultation plan, which was presented to the National Aged Care Alliance (NACA) consumer forum members at a meeting on 14 February 2018.

Content of information resources

The project team conducted a review of existing information about how older people think, and find out, about aged care services, so that the engagement adds to, rather than duplicates existing knowledge.

The meaning of 'quality'

For consumers, quality is something that has meaning in the context of their care, not in isolation. This was evident in the Agency's engagement in its 2016 dialogue with the sector about quality.⁴ Consumers may not want to talk about quality explicitly, and are not engaged in detail about quality. Accordingly, information about 'quality' needs to be framed in a way that is accessible to consumers, by being related to their whole care experience.

Further, there is low consumer understanding of different aged care services available and the structure of aged care services, so information resources on quality under a single set of quality standards will be better if they are not specific to particular programs or services but to the consumer's needs.

At least for residential care, there is a disjuncture between the most common sources of formal complaints (health and clinical care) and the most important domains of quality commonly identified by consumers (which are neither clinical or health care).

Information channels

Consumers entering the aged care system tell us they already receive a lot of information, and it can be overwhelming rather than informing. Additional information resources on the new standards may be unlikely to be read or retained. People receive and retain information best when it is relevant to what they are dealing with at the time, so information on quality or standards for example may only be taken in if someone is experiencing a problem.

¹ Department of Premier and Cabinet, Tasmanian Government, *Older people. A Guide to Engagement*. http://www.dpac.tas.gov.au/_data/assets/pdf_file/0009/214389/Engaging_with_older_people.pdf

² Government of South Australia, *Better Together. A Practical Guide of Effective Engagement with Older People*.

<https://www.google.com.au/search?q=SA+government+better+together+a+practical+guide+to+effective+engagement+with+older+people&nfpr=1&sa=X&ved=0ahUKEwiHrPvqk4TbAhXFspQKHVUrDwQQvgUIJSgB&biw=849&bih=909>

³ Age UK, *Engaging with Older People Evidence Review*. https://www.ageuk.org.uk/documents/EN-GB/For-professionals/Research/Evidence_Review_Engagement_with_Older_People.pdf?dtrk=true

⁴ Australian Aged Care Quality Agency, *Let's Talk About Quality*, 2016

<https://www.aacqa.gov.au/providers/promoting-quality/lets-talk-about-quality-report-1>

<https://www.aacqa.gov.au/providers/education/the-standard/2016-issues/QualityStandardFebruary2016.pdf>

Our engagement and existing knowledge suggests that many users of aged care may not be directly accessing electronic information, and are receiving a lot of information through their peers, families, aged care providers, community organisations, General Practitioners (GPs) and other supports. However, while GPs are a key information channel, they face knowledge and time constraints that mean they are not always equipped or able to provide the assistance their aged clients might be looking for. New systems and products such as video information dissemination in GP and other consulting rooms are recognising this.

Aged care provider staff are an important source of information for consumers. Aged care professionals who are in contact with people accessing the aged care system, but are not provider staff, are also important; both can be considered as consumer information channels. These include assessment workforces (both Aged Care Assessment Teams and Quality Agency quality surveyors), and allied health professionals.

Diversity

Taking into account the diversity of aged care consumers is obviously critical in designing information resources. There is firstly the age range (around 30 years) that needs to be taken into account when wanting to engage both current and future consumers. Information channels, particularly electronic ones, are used differently and for different purposes by different consumers.

There was a strong theme in the project's review of existing resources and in stakeholder discussions that information resources need to take into account the culturally and linguistically diverse (CALD) community. Beyond translating resources into different community languages, it was suggested that it would be useful to design all resources with the CALD community in mind – clearly, plain English will help ensure resources take into account a range of English literacy levels. General communication skills and cognitive impairments all require resources to be available in different forms.

The review indicated that for CALD communities, community organisations and GPs are a particularly important information channel. For Aboriginal and Torres Strait Islander communities, local community organisations were similarly important.

Psychographic segmentation

As well as population diversity, such as age and ethnicity, individuals can be clustered according to aspects of their psychological characteristics. This is referred to as psychographic segmentation, and can be an important tool in communication and marketing. Some American research⁵ showed how older consumers of healthcare can be grouped according to aspects of their beliefs, motivations and preferences in relation to their health and care. These factors influence receptiveness to health information according to how it is framed, so different approaches to the same message will be effective in reaching different people.

Who was asked to participate?

Organisations, particularly members of the NACA consumer forum, were asked to identify participants who could contribute to the project. Intentional sampling was conducted using a diversity frame. That is, the team deliberately sought to sample a range of consumers with

⁵ Brent Walker (2017), *7 tips for communicating with elderly healthcare consumers*.
<https://insights.c2bsolutions.com/blog/7-tips-for-communicating-with-elderly-patients>

distinctive needs, in order to get a picture of what information needs consumers as a whole would have, and issued targeted invitations to those consumers. This ensured in depth talks with a diverse group of people, and diverse perspectives were included.

The project team undertook a number of steps to identify and recruit consumers and explain the project to them. This involved:

- holding discussions with the NACA consumer forum on 14 February, at which several organisations agreed to assist in inviting their members to participate.
- producing a video invitation which was emailed to organisations that were assisting to recruit participants, as well as being made available via the project website.
- producing a consumer invitation flyer entitled “Help improve information about aged care”, which was emailed to contacts in those organisations. (**Attachment A**)
- contacting by email some Melbourne consumers who were unable to attend planned consultations. This email included a set of questions individuals were invited to answer and return (**Attachment B**).

The consumer conversations would not have been possible without the willing assistance of committed individuals in several organisations, particularly ADA Australia, LGBTI Health Alliance, Dementia Australia, Ethnic Community Councils of Victoria, Goodwin Aged Care Homes, Lifeview Residential Care, Matrix Guild, Celebrating Ageing, Vintage Men, and Val's LGBTI Ageing & Aged Care.

The phase 1 face-to-face consultations included:

- One focus group in Sydney with consumers living with dementia
- Two focus groups in the Melbourne area with CALD consumers
- Two focus groups in the Melbourne area with LGBTI consumers
- One focus group in Brisbane with advocates for vulnerable consumers
- Four interviews in Brisbane with vulnerable consumers
- One interview in Caboolture with a vulnerable consumer
- One focus group in Canberra with residential care consumers.

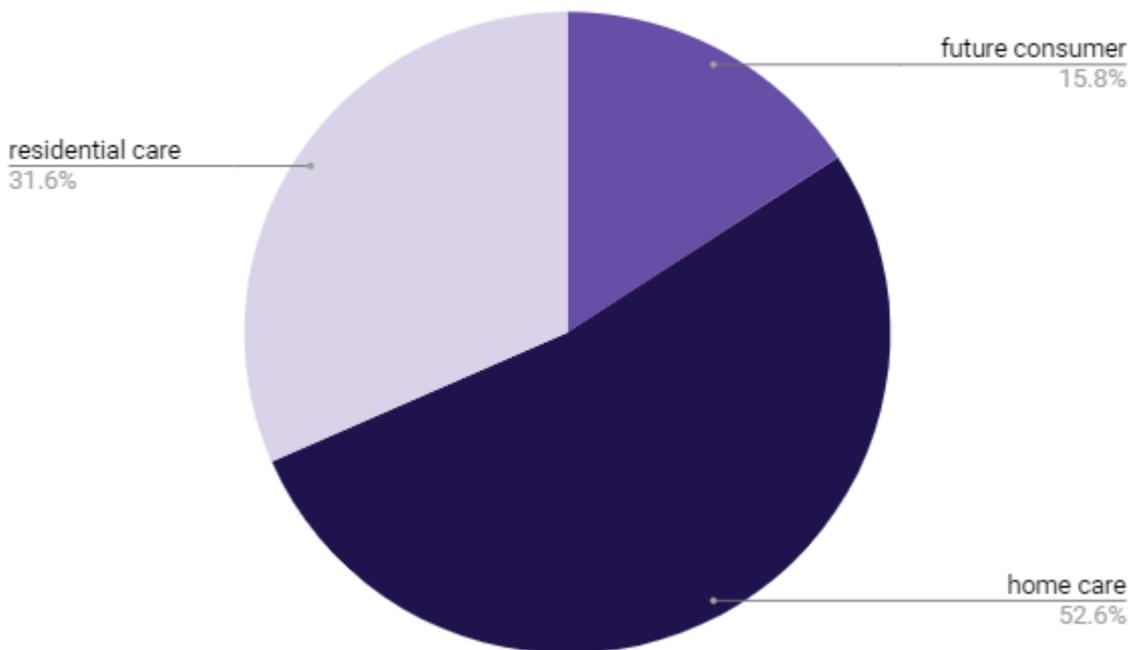
In addition, emails were received, that responded to written questions from several consumers in Victoria. The team sent written questions to all NACA consumer forum member organisations, to which most provided responses, building on the input they provided at the February 14 meeting. The questions are at **Attachment C**.

The project team expects to receive further input from consumers and carers by email, in response to callouts made by stakeholders. Insights from this will be incorporated into both the phase 2 consultations and the proposed information resources.

Participants represented a diverse range of community groups. In general, participants were not asked for details about themselves, but many volunteered information in the course of discussions, allowing a rich picture to be built of who participants were and often of their stories of care.

The project's phase 1 in-depth conversations took place with 41 people. As intended, the project team spoke primarily with current aged care consumers. Figure 1 shows that over four-fifths were current users of care, with many of those using home care (either Commonwealth Home Support Program or Home Care Packages), while just under a third were using residential care. Several of the future consumers were also previously or currently carers for people using aged care services.

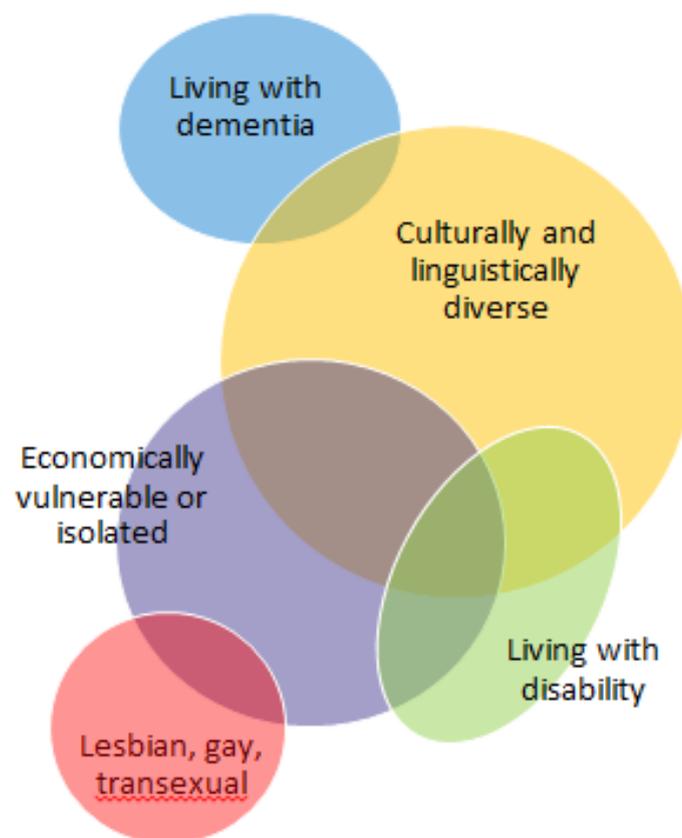
Figure 1. What care were the consumers we talked to receiving?



People were not asked about their age, but around half the consumers provided their age during conversation, while others often provided indications of approximate age. Of those who stated their age, the youngest was 58 (with early onset dementia) and the oldest 97.

The sample was intentionally diverse, and many people who participated had more than one distinctive need or belonged to one or more of the special needs groups identified in the *Aged Care Act 1997*. Figure 2 shows the main features of the population and how they overlapped among the sample, based on what was known about the participants. Whether people were included in one or more of these categories was based on self-disclosure by participants, so it probably under-represents some needs.

Figure 2. Mapping the consumers involved in discussions



What was asked in the focus groups and interviews?

The focus group and one-to-one consultations in this project were built around some key questions to draw out themes about information channels and quality. The focus groups ran for 1 to 2 hours in total, usually including a morning or afternoon tea. The one-to-one discussions lasted from 45 minutes to 1.5 hours. Participants' expertise was acknowledged in various ways, usually through the providing of specially-catered refreshments and/or gift vouchers for participants.

Consultation sessions were divided into two broad parts to address the themes. Open ended questions were used, as well as case study and interactive techniques to guide discussions and stimulate ideas.

- *Information channels*

Research indicated that it was best not to directly talk about aged care quality information. Accordingly, focus groups were structured as a conversation to learn from consumers' experience, with the aim of drawing out inferences about information channels. In most settings, this discussion was initiated by showing consumers examples of different information materials and seeking their responses to them. Participants talked about whether they recognised the type of resource, and when and where they might use them.

- *Quality of aged care*

The second part of the session followed the same approach of learning from consumers' experience to isolate key themes about quality in aged care. Consumers were asked about their pathway into care, and how they found things out about care. They were asked how they might offer advice to others seeking care, and how they might go about addressing a problem with their care, if they had one.

Feedback from consumer conversations

How consumers get information

Aged care consumers are a diverse group of people, like any other section of the community: diverse in culture, education, wealth, interests and personalities. They are using diverse channels to get their information, and what they want to find out also varies. Information resources need to be designed to cater for this diversity.

Within this diverse context, there were nevertheless patterns and themes around how consumers get their information.

Different information channels are used for finding out about things and for taking action. Many people find information through one medium (word of mouth, the Internet) but take action through another (telephone, group meetings).

Word-of-mouth is most important

The strongest theme was that information is obtained by word of mouth. However, this occurred in a range of forms:

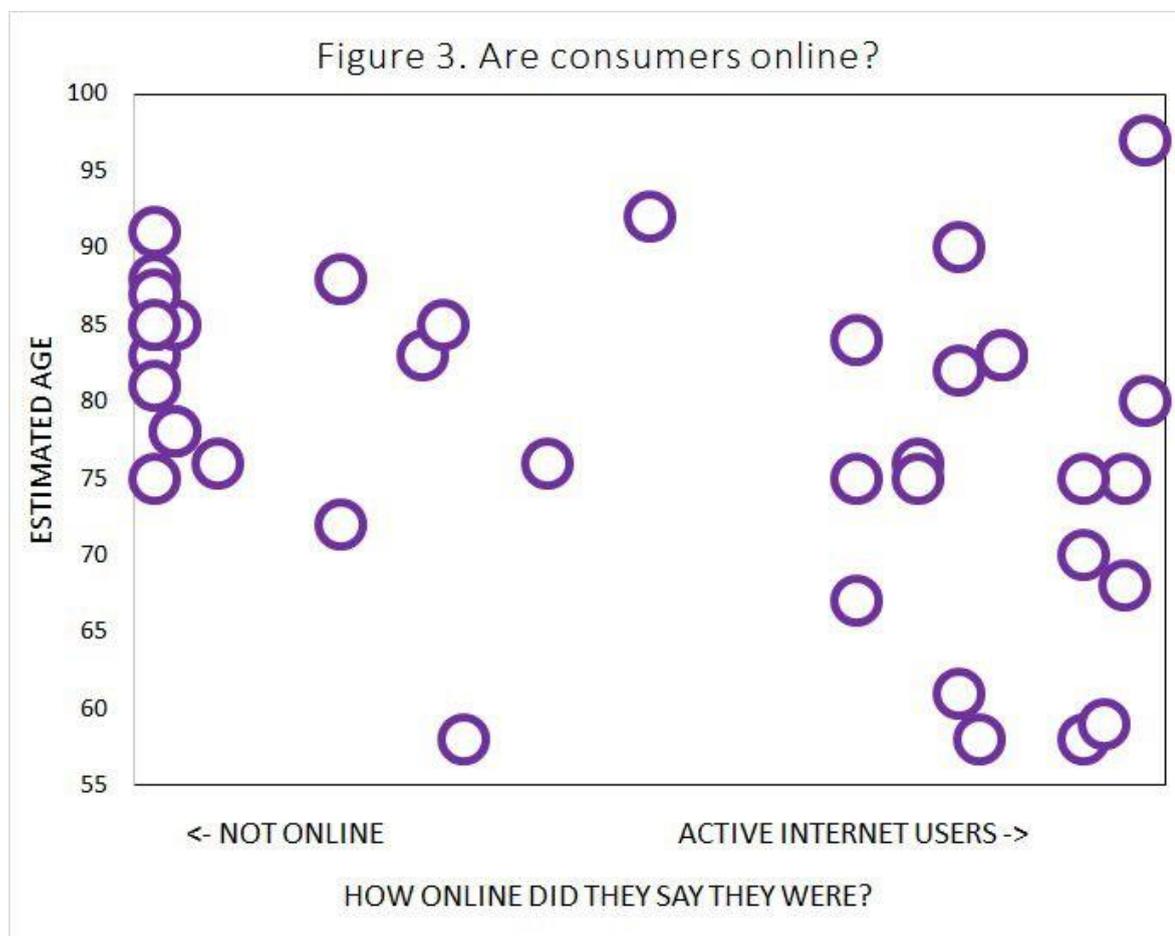
- Most common was relying on family relationships and assistance.
- Also common was reference to peers, particularly listening to or observing those who are receiving services (talking to people they knew who got care; walking around and talking to people at facilities; visiting a service and getting the 'feel' of it).
- Frequently mentioned was existing trusted professional relationships (the most often cited was with GPs).
- Also mentioned was the advice and guidance of community organisations with whom people had pre-existing connections.

Consumers valued face-to-face information. In one case a consumer already had hard copy information from an agency. She was an organised and assertive person, but only recalled, retrieved and used the hard copy brochure after an information session conducted by agency staff visiting their service. Some CALD consumers did value written material in their first language, but they preferred face-to-face communication in their first language when matters were important.

Care staff were an important information channel. In home care, this was most evident as a common source of information about how to improve care. At least two case examples were given where a provider's home care staff facilitated or prompted consumers to get an advocate or helped the consumer identify a formal complaint channel. In residential care, staff acted as filters and were sometimes the go-to point for everything related to care.

Going online

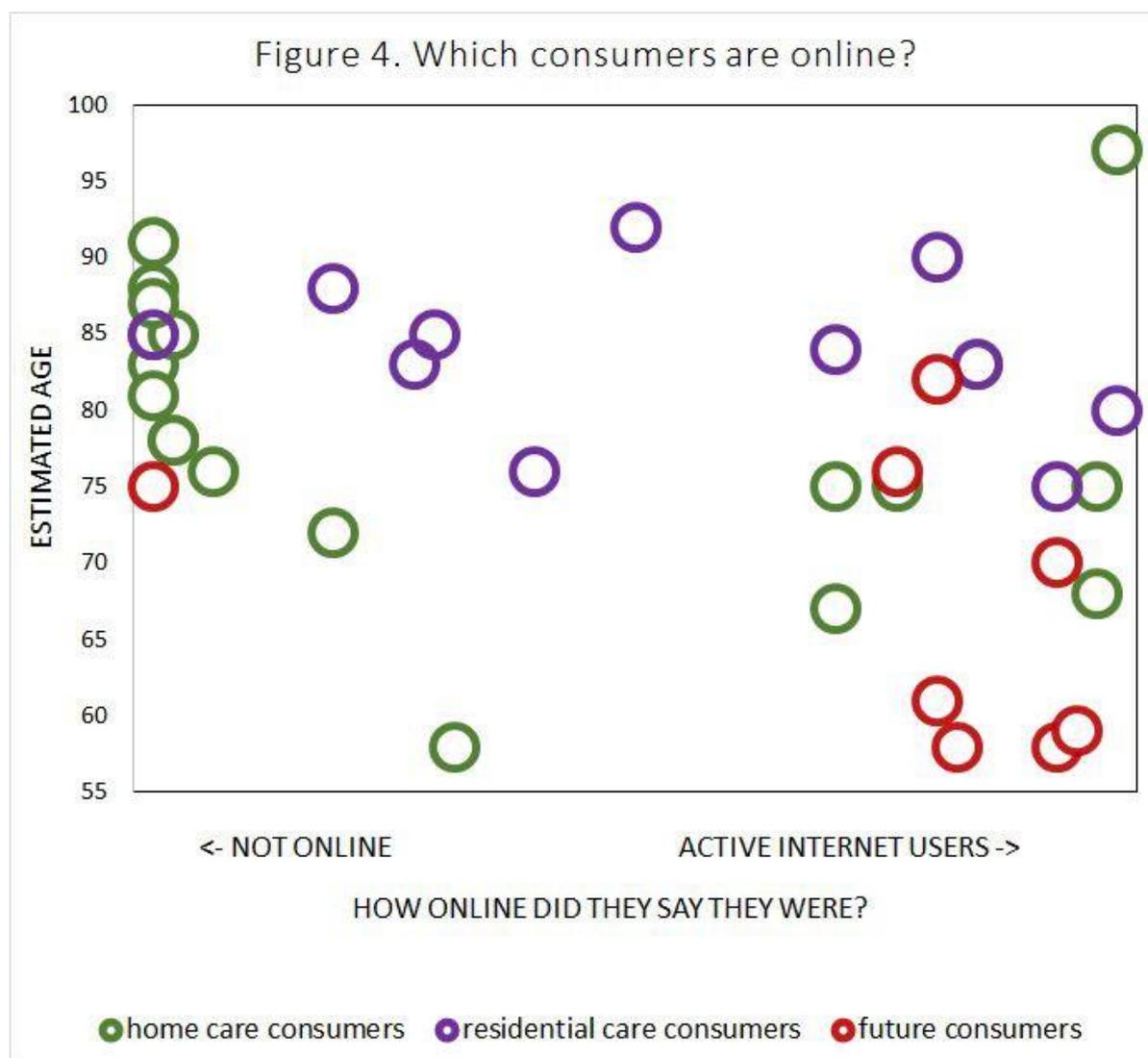
A lot of the participants were online and, contrary to expectations, this was not strongly age-related (Figure 3).



One of the oldest participants (97) was one of the most active and skilled online users, and this was not an isolated instance. However, there was not a strong sense that existing consumers are using online sources to find information about aged care. Participants were frequently skilled in using computers, and some were on social media, but most use appeared oriented toward hobbies, interests, and staying in touch with people. This indicates that, while current consumers may not be using the Internet extensively around their care, they have the skills that could enable them to do so. Only a minority made extensive use of the Internet in researching first entry to care.

Consumers who were online reported difficulties in locating information through Government websites. There was low recognition of the My Aged Care brand among people already using care. Those transitioning between care types, or their carers, were more likely to recognise it.

There were some differences between consumers of different kinds of care, as Figure 4 shows.



While there was a wide variation in the extent to which *existing* consumers were online, *future* consumers are overwhelmingly likely to be using the Internet and electronic information.

Among participants, there were some patterns in how electronic information was used. In particular, the experience of online connection varied greatly between CALD communities. In one cultural group, none of the care recipients were using computers; in another they were among the most internet-connected of all participants. CALD participants who were online spoke about how using the Internet helped meet their cultural or language needs better than hard copy information. As with the rest of the community, it's important not to generalise about whether CALD consumers prefer Internet-based or paper resources. It was clear, however, from the responses of the CALD group who were not using

Some aged care consumers are online, and some are not. Their age is not a driving factor behind whether they are using the Internet. More important are factors like wealth or education.

computers, that they all had children who were doing so. This was often the case across all types of consumers; in that CALD group, family members were identified particularly strongly as a pathway for information and the arranging of care.

Support to access information

A strong theme across the consultations was that consumers want someone 'standing beside' them when dealing with information and decisions. This was expressed in different ways including:

- Many talked about the value of having another set of eyes and ears when they visited a potential aged care service.
- A large proportion reported they had family finding/filtering information for them.
- When directly prompted on what advice they would give to those who do not have a family member helping them, one focus group went silent, highlighting their reliance on family support to navigate care information, and that they struggled to imagine how to proceed without family.
- Those who had used an advocacy service spoke glowingly about their advocates, and when asked what advice they would give about finding out about care, all jumped to the answer 'have an advocate'. This group were also likely not to have relatives who could assist them.

People used their phones (including many with smartphones) a lot. This was the main channel used by consumers for taking action to address concerns.

Residential and home care different

While the ways information was accessed were diverse, there was a delineation between those currently living in residential care and others. People in residential care appear less engaged with all forms of information, less likely to want it, more focused on the facility itself, and more likely to let information be handled by children or spouses. This difference appeared not to be a product of frailty or cognitive decline, but on being in residential care itself. A number of consumers considered one of the definite assets of being in residential care was that they were shielded from information and decisions: other people filtered and handled that for them. Those of the participants who did not have children or a spouse outside the facility appeared least engaged with information from outside the facility.

Information overload

The discussion with participants was used to indirectly assess how people felt about and responded to the volume of information they were exposed to. The large volume of information resources was seen as unhelpful. Some people were confused or disengaged because of the large number of discrete pieces of information, from multiple sources. Consumers frequently made comments that indicated they did not understand where information was coming from, why they were receiving it, or what the roles were of different organisations in the sector.

People were adept at screening or filtering material, and also at simply ignoring it. This was driven by unsurprising factors like the perceived large volume of material. However one surprisingly common factor, mentioned by numerous participants, was having suspicions raised through experience of dealing with scammers or thieves.

The screening of information was done in different ways. Examples included:

- keeping brochure folders or drawers only for items they wished to retain
- asking a family member to read everything and only tell them about things the family member thought important
- throwing everything out, with the view that someone else should be taking care of it, now that they were receiving care
- indicating that if too many emails came from a source, they would block it
- folding official correspondence down to just name, phone number and reference ID, than sticking it on a cabinet or board.

There were a lot of comments about the design and writing of information resources. These focused on:

- plain English and accessible style
- other aspects of readability such as font size, colour, contrast or length
- graphic design
- clarity of intention expressed in headlines, taglines or slogans.

Responses to specific information resources

A number of information items were circulated to participants. These related to ageing in some way though not necessarily care quality. Public sector resources were not generally well received, for a range of reasons, including overly formal language, disconnect between content and the reader's experience, and poor design.

Discussions showed fridge magnets were only good for high-importance phone numbers. Posters were only good for captive audiences (e.g. waiting rooms) and needed to be on topic at the right time. They were perhaps the least effective medium that we explored with consumers.

Short hard copy resources, like brochures, were often retained. They were almost universally filtered for relevance, so were only kept if somehow linked to current or perceived future need. However, it was not clear whether they were then located and referred to when needed or relevant.

Magazine articles were dependent on individual interest, and general circulation magazines were rarely relevant. However, there was evidence that community-specific newsletters or magazines were used, most clearly in residential care settings.

What information consumers want or need

No participant demonstrated unprompted awareness of statutory quality standards. Consumers did not talk explicitly in terms of quality of care. It confirmed previous research that quality needs to be framed in terms of the consumer's everyday experience and what they want to talk about; it was not able to be framed in terms of 'quality' or of 'standards of care'.

There were many indirect ways in which quality or standards were touched upon. Consumers were forthcoming in talking about what was good, whether they liked their providers, or what was wrong. They responded to the concept of giving advice to others based on their experiences. As a result, this project was able to learn a lot about what information might be sought by consumers about quality, and what will influence its effectiveness.

The research showed people want to know what other people's experience of care is like. Participants regularly described conversations with other people receiving care and made comparisons of their experience with others. A few expressed concern for, and sometimes acted to intervene on behalf of, others receiving care, on the basis of what they saw of that care.

The research also showed some consumers do not want information about quality or standards. They consider that ensuring safe care is the government's responsibility once they are in care. This may reflect internalised values that will not readily alter, and this group will not be receptive to information about standards regardless of format or channel.

Getting good care and solving problems

Many people demonstrated a strong internal sense of what is ok or not ok in their care. Their willingness to communicate about their quality of life or care, or whether to complain, is built on that. This will need to form a foundation for designing information resources about standards.

Some people embodied an ethic of 'not complaining'. For some, the word 'complaint' itself was seen as negative. For them, it was not necessarily an option to seek improvements to quality of care.

Consumers were overwhelmingly focused on ensuring their current care worked, rather than on changing their care provider. Care consumers were almost universally loyal to their provider because of their relationship with their care staff. Several complained about their providers, both home and residential; when doing so, it was directed at the managers or administration, but there was usually praise for the care staff. Few consumers reported making choices themselves between providers at the point of first receiving service, and almost none changed providers as a matter of choice after that (several reported changes in providers for other reasons, but not of their choosing).

Consumers are almost universally loyal to their current service provider. Loyalty is not generally related to quality or satisfaction with the service.

Choice was not a strong theme in the consumer groups. There was little evidence that consumers made choices between providers, even among consumers who would appear to have had other options available in theory. The almost universal experience of current consumers was that they did not choose: across a spectrum of decisions ranging from who their care provider was, to what time they got to have a shower. However, among people not yet receiving care, and a few who had recently commenced care (all being among the younger participants and aged in their 60s or 70s), there were more narratives that touched on researching care providers, though the language of 'choice' was not explicitly used.

Home care consumers did ring their providers to try to sort things out. Residential care consumers did speak to staff or at resident meetings. Opinions about the effectiveness of these channels was varied, and there was also evidence that a significant number of people would not try and address concerns, out of fear of consequences, or because they did not feel they were entitled to.

Other things important to consumers

Consumers raised other issues not specifically related to care standards or information sources, but of significance to their quality of life and experience of care.

Money was a significant issue, particularly in home care. There were two dimensions to this. Among low income consumers, there was concern about how to make ends meet and pay bills. This was a common - and sometimes strongly expressed - complaint.

The second dimension around money was a sense that it was motivating providers to be very keen to sign people up. Consumers used phrases like “get their hands on your dollars”; and that “they’ll promise everything to get you to sign, but the actual service delivery is then different”. This may provide an interesting opportunity to cut through in information resources. There is scope to use messages around receiving ‘value for money’.

Feedback from consumer organisations

Questionnaires were supplied to organisations that were members of the NACA consumer forum. Responses were received from:

- National LGBTI Health Alliance
- Older Persons Advocacy Network (OPAN)
- Dementia Australia
- Federation of Ethnic Communities Council Australia (FECCA)
- Partners in Culturally Appropriate Care (PICAC)
- Legacy Australia

In addition, further information was received from Aged and Disability Advocacy Australia (ADA Australia)⁶ and discussions were held with the Institute for Urban Indigenous Health.

Input received by the various organisations mirrored the feedback from face-to-face consultations in its diversity. As one respondent put it: “Older People are one of the least homogenous cohorts in the country”.

That lack of homogeneity was evident in the different ways aged care consumers received and sought information. Commentary revolved around a relatively even split between those who sought their own information and those who sought support. Among those who sought their own information, there was generally a higher use of the internet.

For CALD people, however, the percentage who sought their own information was much lower, with stakeholder groups suggesting possibly as low as 10 per cent. Use of the internet was also generally much lower among the CALD community, and print (in their language, but simplified) was preferred.

Dementia Australia commented that information needs to target ‘points of action’. Consumers usually only sought out information if there were triggers to do so, such as when they needed something or wanted to complain or address a concern.

Whether consumers sought their own information or relied on others to find it for them, most feedback received from stakeholder groups commented on the importance of design

⁶ ADA Australia is a member of OPAN, but supplied information to the project separately, resulting from a meeting with some of their advocates in Brisbane.

elements in both written and electronic information: improved accessibility through appropriate colours, font sizes, infographics, plain English, easy navigation (for websites), clear and simple messages, and links to other actions (e.g. contact phone numbers etc).

While stakeholder groups provided design advice, their feedback indicated a general preference for more oral information – face to face communication remained the most preferred form of communication. More oral information (including through education sessions where people can ask questions) reduced the difficulty faced by consumers with impairments or cognitive issues. Oral communication was also preferred particularly by CALD consumers, who may have low literacy levels in their own language. Referral to specific aged care support organisations was also mostly through word-of-mouth or information sessions.

Views about written information materials (brochures, posters and magnets) were mixed. Generally regarded as of less worth than word-of-mouth, some did see magnets as important for emergency contacts, and brochures and the like as potentially useful to communicate more complex messages, especially if they are placed in appropriate outlets. Mention was also made of broadcast media or short videos as potentially being useful. For CALD communities, this would need to be in language and via ethno-specific media.

While GPs were often seen as a good source of information, that depended on consumers' access to supportive GPs. Word-of-mouth information through community networks, organisations, and family, friends or existing carers was usually more important. CALD consumers were far less likely to rely on GPs, in favour of their specific community organisations and bilingual community care workers, who were seen as the trusted professionals.

A number of consumer groups comments emphasised the importance of advocates. According to one respondent: "No information source can replace a personal, well informed and empowered advocate so it is those advocates who need the resources to enable them to do their job". Comments indicated that while many consumers relied on family members, carers and other advocates, efforts still needed to be made to communicate with older people themselves, given that a large cohort of older people do actively research and take control of their own care.

There was agreement that consumers needed to be informed about their rights, and that information materials needed to include the standards, and explain how to escalate issues.

Those organisations that provided personalised advocacy services usually dealt with complaints locally; in other words, they preferred a process of resolution at the provider level. Formal complaints processes were generally viewed as a last resort. Local and less formal resolution was viewed as more appropriate, because consumers were often fearful of retribution if making complaints. This fear was often magnified among LGBTI and CALD consumers, who were more likely to feel unsafe, as a result of past traumatic experiences and/or feelings of isolation and lack of inclusion.

Consumer organisations were asked to identify what they thought were the most significant quality issues for consumers. This was asked to help determine what case studies or concrete examples were most likely to resonate for consumers, for inclusion in information resources.

Respondents generally agreed quality issues raised with them were similar to those recorded by the Complaints Commissioner.

- **transparency of fees and charges** - the level of fees and charges, including 'hidden' fees, and the level of fees limiting choice of providers.
- **consultation and communication** with the individual consumer, and understanding of their specific needs, (This was often a particular issue for dementia sufferers or others with cognitive impairments). Language difficulties creating communication barriers for CALD consumers.
LGBTI consumers also often experienced a lack of understanding of their needs. Consumers from both CALD and LGBTI groups reported feelings of exclusion and isolation as a result
- **choice and input into decision-making**, especially when entering residential care, care planning independence and privacy particularly in-home care
- **holistic management of mental health**, dementia and behavioural issues, clinical and personal care (over-medication, lack of culturally appropriate care, lack of communication with family).
- **quality, consistency and sufficiency of staff** in residential care, and consistency of staff particularly in home care, to minimize misunderstandings and disruptions to care, and lack of rapport. It was emphasised that staff need to be well versed in the standards, what is expected of them, and what consumers can expect.
- **Culture of 'doing for' to 'doing with'**, to create a person-centred culture.

What it means for consumer information resources

The consultations to date have indicated a great deal about both how consumer information resources should be designed, and what should be in them. This information is relevant to the Single Quality Framework, and will guide the development of materials that will be tested with consumers. However, there are important implications here for the Quality Agency's messaging more broadly.

Strategic advice for the development of consumer resources on the new aged care quality standards is:

- Because consumers have limited awareness that there are existing standards, focusing specifically on *changes* to quality standards is of limited relevance
- Information should relate to the consumer's journey in aged care, and the concepts that consumers already use in thinking about their care
- Information should build on consumers' existing knowledge of what constitutes good care
- Discrete additional information resources are less likely to achieve 'cut through' than integration of messages into existing resources.
- Information should respond to consumer preferences for word-of-mouth information, and for having someone 'stand alongside' them in the process.

Materials that say 'it's all about you', 'consumer choice' or 'these standards put you at the centre' risk being put in the recycle bin because the experience of most consumers' during this project was that they aren't at the centre, and therefore they won't trust the message. This does not mean they were unhappy with their care; just that they did not feel in control.

Messages that say "you are at the centre", "it's about meeting your individual needs", or "you have choice" do not resonate with consumers. They don't reflect most consumers' lived reality.

A better approach will be to look at what consumers do want to talk about, map those things onto the standards, and then talk about those topics. Examples might include: “if you’re at home and you aren’t getting your shower on time, you can raise that”; or “If you’ve tried to sort things out with your provider and it hasn’t been fixed, there are others who can help you”. There is a range of concrete messages like these that embody one or more of the quality standards, but are expressed in terms of issues and experiences that are common among consumers.

Consumer information resources can communicate the experience or ‘feel’ of having somebody there alongside them on their care journey. For example, giving the Consumer Experience Reports (CERs) more prominence, making them as user-friendly and accessible as possible, and making comparisons between services easier, would accord with the desire of consumers to know about others’ experience of care, and with the importance of peer-based information and word-of-mouth. This has the greatest potential in providing relevant information to consumers, and to increase consumer awareness of standards.

Another clear message is to offer material that personifies the Quality Agency and the standards: expressing them as the reassurance of someone beside you. For example, “There are quality assessors standing beside you, helping to identify where your care can be improved”, or “care providers are working to continuously improve your care, this is supported by government standards and regular assessment”. Care will need to be taken, however, not to set a tone that is too far removed from consumers’ experience.

Information about standards will be most effective if it acknowledges people’s existing knowledge and their ‘radar’ for good quality or sub-standard service. This will be important in designing the information resources. The resources will need to say things along the lines of the standards being “everyone’s”, and “common sense” or that they reflect what a person already knows is ok or not ok. The Quality Agency needs to communicate on the premise that the standards reflect people’s expectations, rather than explaining the standards ‘to’ them. Standards could be framed as a partnership in improving care quality; they relate to and build on people’s existing knowledge, rather than being designed and implemented ‘by’ government ‘for’ consumers.

It is likely that magazines produced by residential care providers for their own residents may be particularly important, as they may be one of the few sources of information accessed in this care setting.

Placing information in the consumer’s aged care journey

The research and preliminary findings from the consultations suggests that the consumer audience for information resources about the new Aged Care Quality Standards can be placed along a spectrum of where they are in their care journey. Different themes may be appropriate to different stages in that care journey. Within those themes, it may be appropriate to design information resources to appeal to consumers who respond to different kinds of messaging.

Theme 1: How can I find good quality care?

The consumers targeted here are those who are starting to look into care options or are actively looking for aged care services. The new Aged Care Quality Standards would most likely be addressed under the guise of finding quality care, and the information might be linked to existing Consumer Experience Reports. Integrating quality messages with My Aged Care will be prominent in this theme.

Theme 2: Getting the most from my care

The target group under this theme are consumers who have recently entered care, whether that be residential aged care or home care, or have been ACAT assessed. Conversations with consumer advocates suggest that when consumers first enter care, they want positive affirmation that they have made the right choice and it is not a moment to be considering potential negative outcomes, so resources would be positively framed to reflect this. Therefore, information about the new standards would be expressed as providing consumers with a tool for a partnership between the Quality Agency, the consumer and their provider to get the best care possible.

Theme 3: Is everything going ok?

Information resources developed within this theme are targeted for those who have already spent some time in care. These resources will be open to the possibility that consumers' expectations have not been met and they have had to make significant adjustments to their lives. Those consumers are more likely to be ready for information that helps them understand that the new standards are about expectations of quality. Messages would be framed around the standards as a safety net and providing an avenue for complaint if required.

Attachment A. Generic consumer invitation

Help improve information about aged care

Some changes will be happening soon in aged care – do you want to know about these changes? How would you like to find out?

Are you interested in helping other older people know what they can expect from aged care services?

Would you be happy to share with us how you like to find out about things, and let the government know the best ways to communicate with you?

We would love to meet and talk with you, and learn from your experience.



Why are we asking?

Hello, we are Lisa Fenn and Ian Holland. We are consulting with people who use aged care services, or who are thinking about using aged care services, about their information needs. You don't need to have any special knowledge or skills to be

involved - we want to learn from your views and experience.

New standards, setting out what people can expect from aged care services, are being introduced this year. The new standards are about making sure you get good quality care, whether you live in an aged care home or get help in your own home.

The government agency responsible for promoting and regulating quality in aged care have asked us to talk with you. They want to know what sorts of information will be useful to you in understanding the new standards. We need your input to make sure that everything you want to know is there, and it's easy to understand.

The standards aim to be clear about what you can expect from aged care services, and also what you can do if your care is not what you expect.

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Who are we talking with?

We are talking with people who use aged care services, and people who are thinking about using aged care services in the future. Some of these people live in aged care homes, others get help at home. We are having group discussions, or one-to-one conversations, depending what they

prefer. We are meeting with a whole range of people, with different backgrounds, different health and care needs, and different ideas.

There are no right or wrong answers - we want to know what YOU think.

What will we do with the information?

We will use everything we hear to help other older people understand the new standards. We will report back to government what we heard, but we won't use any individual names and nothing you say will be identifiable to you.

We will also report back to you. We will send you a summary report of what consumers had to say.

Do you have to participate?

No! It is entirely up to you whether you would like to participate or not. You might like to come along and join the discussion for some questions and not others. That's fine too.

The more people that get involved the better. We want the information that comes out of this project to meet the diverse needs of all aged care consumers.

We think the discussions and interviews will be interesting. We will share some morning or afternoon tea, so hopefully they will be fun too.

We hope that you will join us and have a say. We look forward to hearing your views.

If you would like to know more you can call Ian on 0401 557 193, or if you use email, send us a message at ian@hamiltonstone.com.au

Attachment B. Emailed questions to individuals

How do you find information about services you need?

Do you get information from the internet?

If so, do you do this yourself or does someone else help you?

What kinds of information on the internet are most helpful?

If you had a friend who was thinking about getting help at home, or thinking about moving into an aged care home, what advice would you give them about making sure they get good quality care?

If you were worried that something was not right about your care, what would you do about it?

If something is not right about a service you receive, how do you know if it is important enough to make a complaint about?

Some questions about you:

Are you currently using aged care services?

Yes, I live in a residential care home ____

Yes, I get care at home ____

No, but I'm thinking about it ____

No, and I'm not currently thinking about it ____

Do you care for someone else who receives aged care services?

Yes, I am a carer ____

No, but I have previously been a carer ____

No ____

How old are you? 50s ____ 60s ____ 70s ____ 80s ____ 90s ____ Other ____

Do you identify as: Female ____ Male ____ Other ____

Would you like to tell us anything else about yourself, including any cultural or other diversity groups you identify with?

Attachment C. Stakeholder questionnaire email

{{First Name}} {{Last Name}}, {{Organisation}}

Dear {{First Name}}

I am writing to you today to ask for input from {{Organisation}} to the consumer information resources that will support the new aged care quality standards. Your knowledge and insight are vital to producing information resources that meet consumer needs.

You would recall that, at the 14 February meeting of National Aged Care Alliance consumer stakeholders, my colleague Lisa Fenn and I talked about our project on behalf of the Quality Agency, developing information resources for aged care consumers. The resources aim to help consumers understand the new quality standards, how the standards relate to their care, and what they and their families or representatives can do if the standards are not being met. We are currently talking directly with consumers to see what is important to them.

However, as we outlined to you at the meeting, we think it is an important element of the effectiveness of the project that we are able to draw on any views you have.

We would very much appreciate hearing your thoughts on five questions that are at the heart of our consultations with consumers:

1. What kinds of information work?

As you know, older Australians are currently receiving information in lots of different ways. There are brochures, booklets, government websites, letters, fridge magnets, videos, posters, magazine stories, advertisements, advice from GPs or family - and many more. It's a long list! Which ways do you think are the most effective ways for current consumers to get information related to aged care? When, or for what purpose, are particular kinds of information most useful?

2. Who is accessing the information?

Thinking about the aged care consumers that your organisation supports, do you have any information you can share with us about the proportion that mostly find information for themselves, versus those who get their information through others, or rely on others to do things for them? (whether that be family, advocates, GPs, or others).

3. What advice do people get, or need?

When {{Organisation}} assists a new aged care consumer, what advice do you give them about making sure they get good quality care? Do you normally mention standards of care? And if so, how do you do that? Do you provide them with any written material about the standards?

4. What advice would you give them about making sure they get good quality care?

In cases where you are assisting consumers who are not happy with some aspect of their care, what information does {{Organisation}} give them about their options? Do you help consumers work out if they should make a formal complaint about their issue? How do you do that?

5. What are the important quality issues?

Would {{Organisation}} agree that the quality of service issues where consumers most often have concerns align with the most common complaint topics listed in the Complaints Commissioner's latest annual report? The topics are: 1. clinical and personal care, 2. fees and charges, 3. lack of consultation and communication. That annual report also indicates the greatest proportion of complaints are in residential care. Further, Quality Agency data suggests that food quality is also a common concern in residential care. If there are any other common themes you are aware of, could you tell us what they are and what leads you to think they are widespread?

We would greatly appreciate your input to these questions and I thank you for your time. Your perspective is very important to produce relevant and targeted information for consumers about the new standards.

I would be grateful if you could email me your thoughts, by 31 March. If you wish to discuss further, please do not hesitate to contact me on 0401 557 193.

Yours sincerely