



Accessing Information and Supports

This publication is available on the COTA NSW website (below).

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Executive Summary

This study aimed to explore the experiences and perspectives of older adults across New South Wales who seek information about services and support for themselves, their families/friends, and the people they care for.

Over 1800 people aged 50 and over completed an online survey on a range of topics about accessing information and their experiences during hospital admissions. The survey was completed with four focus groups. Individuals from across New South Wales participated in this study.

As expected, this study's findings highlight that accessing information for older adults is challenging. However, the challenges that older adults face when accessing information about services and supports can be reduced by including additional support to meet their needs.

The main findings from the surveys and focus group include:

- While older people can access information about services and supports online, it is not their preferred way of accessing information.
- Participants preferred getting information from staff either through telephone calls or visiting services in person.
- Telephone support, however, left many participants feeling frustrated. They reported spending many hours waiting on the phone and finding that customer service staff were not able to provide the information they needed.
- Participants often felt that finding information about services and supports required a lot of information and often needed lengthy discussions with people who knew the 'system' to be able to get the information and support they needed.
- Participants had varied positive and negative experiences whilst in hospital.

Key recommendations from this survey:

- That accessibility needs be considered when sharing information with older people across the public and private sectors.
- That intensive advocacy support be provided to older adults to offer the information and support they need to be able to access the information they need.
- Services across the public and private sectors on how information is presented and shared with older people, including providing staff with training in how to communicate with older people.

Methodology

A survey of people aged 50 and over was conducted during the months of June, July, and August in NSW.

The survey was self-administered and constructed with the use of survey software 'SurveyMonkey'. A callout for survey participation commenced through the COTA NSW e-newsletter subscribers, COTA NSW members and COTA NSW Facebook, Twitter and LinkedIn accounts. The survey was also promoted through the Seniors Card e-newsletter and distributed by community organisations and local council websites that have particular access to NSW residents over the age of 50 in metropolitan, regional and rural areas.

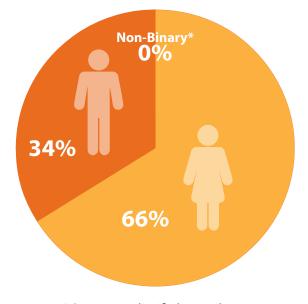
The survey data was analysed using crosstabulations with the data analysis software program SPSS. The findings were interpreted and used as evidence to inform this 50+ report, accompanied by quotes of experiences and opinions taken from the four focus groups conducted during the survey rollout.

Survey sample

The survey was completed by 1880 people across New South Wales.

1846 people completed the survey themselves, and 19 respondents completed it with the support of someone else.

Gender



^{*} One person identified as non-binary

Age group

50 - 59 years	5.5%
60 - 69 years	32.0%
70 - 79 years	46.0%
80 years and over	16.5%

Diversity

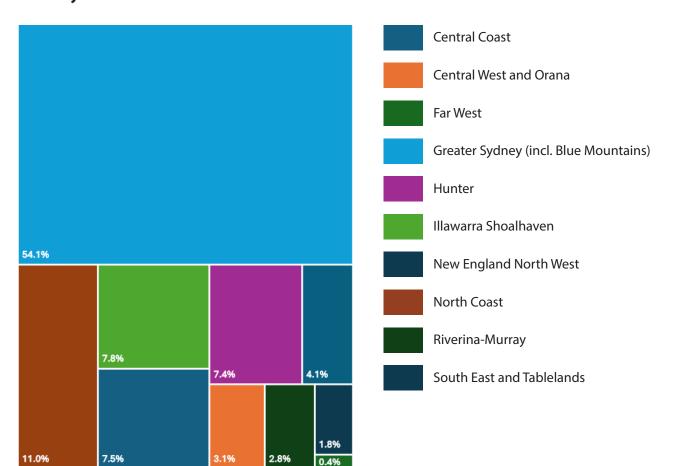
1.2%	Respondents identified as Aboriginal & Torres Strait Islander
9.4%	Respondents identified as a person with a disability
3.2%	Respondents identified as LGBTQI+
10.4%	Respondents identified as a carer
9.1%	Respondents speak a language other than English at home

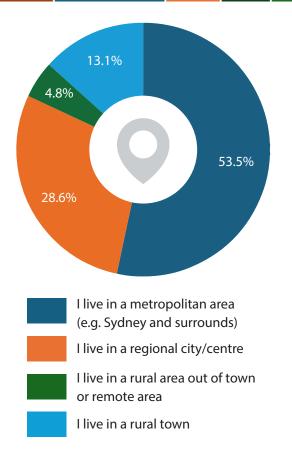
Marital status

19.8%	Respondents were divorced/separated
54.2%	Respondents were married/partnered
10.1%	Respondents were single, never married
14.2%	Respondents were widowed
1.7%	Respondents preferred not to answer



Where you live



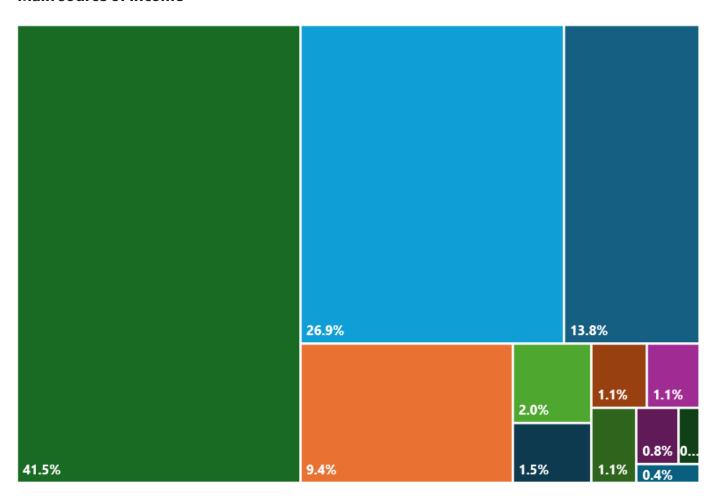


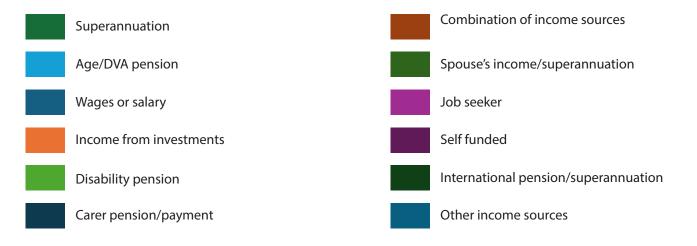


Work status

7.3%	70.1%	3.6%	1.8%	4.2%	5.2%	7.8%
Respondents	Respondents	Respondents	Respondents	Respondents	Respondents	Respondents
were	were retired	were self-	were	were working	were working	were working
volunteers	from paid	employed	unemployed	on casual	full-time	part-time
	work			basis		

Main source of income





Limitations

This survey was primarily conducted online and required participants to have access to the internet and be competent users of technology and the internet to complete it. This requirement may skew the responses across multiple variables. Due to the small proportion of responses from older people in NSW in relation to the actual proportion of older people living in the state, the responses from this survey were not weighted to the population to prevent additional bias in the data.

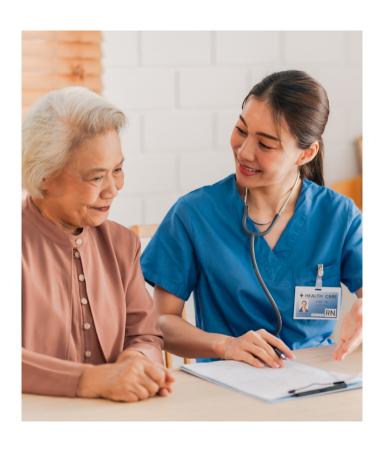
The majority of the respondents of this survey were English-speaking and were from traditionally English-speaking backgrounds. The respondents of this survey were primarily female, with only one respondent identifying as being from the LGBTIQ+ community. Additionally, people from culturally and linguistically diverse (CALD) backgrounds responded to this survey at a low rate. These demographics are not representative of the diversity of the people in NSW. While the responses from this survey provide insights into the experiences and needs of older people in seeking and accessing information, these findings are not generalisable to all older people living in New South Wales.

Consumer Reference Groups

To complement the quantitative research, four focus groups were conducted online and in-person in October of 2023.

Each group had 4-8 participants and included older people from various age groups and backgrounds. The focus groups were an opportunity to discuss the finer details of how older people seek information and their recent experiences, if any, of hospital admissions.

The discussions from these focus groups supported the understanding and framing of more nuanced insights into what information older people seek, how they access it and their experiences in accessing the information and services they need.



Seeking information

Information relating to financial support and services is of greatest need for older people living in New South Wales. 27.6% of respondents identified they most recently sought information about government concessions and pensions and 23% identified they most recently sought information about financial services generally.

Top four information categories for queries

one	two	three	four
Health Care	Government pensions and concessions	Community and/or aged care	Financial services
35.5%	27.6%	24.4%	23%

Health care is also of key importance to older people in New South Wales, with 35.5% of survey respondents indicating they most recently sought information about health care. This is consistent with respondents across all age groups and all regions across the state.

Interestingly, further analysis of the data showed that there were differences in information being sought based on the attributes of respondents. For example, the top three topics carers sought information on most were community and/or aged care, health care, followed by carer support.

Participants from the LGBTIQ+ communities reported legal services as the 3rd most common topic they sought information for. Additionally, participants who responded as being unemployed reported seeking information on employment services as their 3rd most sought after topic of information.

26.2% of participants indicated they did not seek information for any services recently. 3.6% of participants reported seeking information about other services. Most often, the information they sought was related to concessions and rebates for utilities, local government supports and services, support for home help, support with technology such as using computers and navigating internet portals for government services, information to support others, and support related to home renovations, travel, end-of-life, and funeral planning.

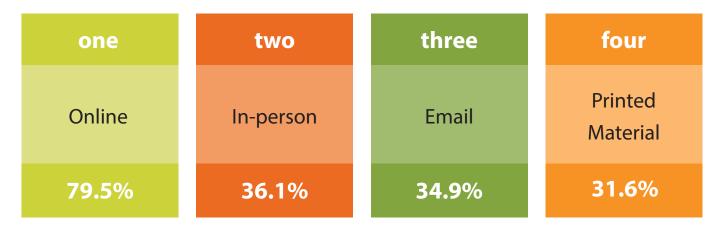
Survey respondents and focus group participants often reported seeking information on supports like the Commonwealth funded MyAgedCare or the NSW State Government funded seniors discounts.

"The way that I found out about [MyAgedCare] was to go through a number of government websites. It was fairly convoluted. It took a bit of detective work, and a bit of time to actually negotiate my way through that process. I'm a retired allied health professional, so I've worked in hospitals and community health, and I know my way around the health system. But I was pretty surprised about that lack of entry into the MyAgedCare System."

Focus group participant



Top four ways of finding information



The majority of survey respondents reported their preferred way of finding information about services was online. However, through the focus group discussions it became apparent that while many older adults do seek information online, they also prefer to seek information through active conversation with people, for example, visiting services in-person or through phone calls.

"Most of the people I know that are in the older age bracket, and are accessing government [supports and services], they don't have the internet. Why is it that everybody expects that everybody has, first of all, a mobile phone? I find that myself, I don't want to go online. I want to actually speak to a person because that way, I'm confident in what I'm doing."

Focus group participant

Participants reported seeking information from professional services that supported them as well as through information presentations and support groups run by organisations that they engage with. Interestingly, only participants aged 50-59 reported seeking information from family and friends as their second most preferred source of information.

"I do find that my relatives and friends, we're all in the same age group, and we share information. I recently found out [through friends] that I can get a C registration where your electricity bill is slightly subsidised, because you've got a CPAP machine. I wouldn't have known that."

Focus group participant



Carers reported seeking information via telephone and in-person as their second most preferred way. However, for participants who reported living with a disability, their most preferred ways of seeking information were online, via email, and through telephone. This indicates that information needs to be available across different formats to support accessibility for people with disabilities.

While many participants reported online or the telephone as key ways of finding information, these methods were not without challenges. Participants reported issues with online systems not working or not accepting information that had been entered or having difficulties communicating with staff over the phone.

"I can get on a train and get up to [the office in] Chatswood or in the city pretty well. I prefer to do that, then get on the phone. It's much more effective. It is unbelievable. But the frustration and loss of energy in waiting on a phone to be told constantly, you can do this online, when in fact, I tried."

Focus group participant



Ease of finding information

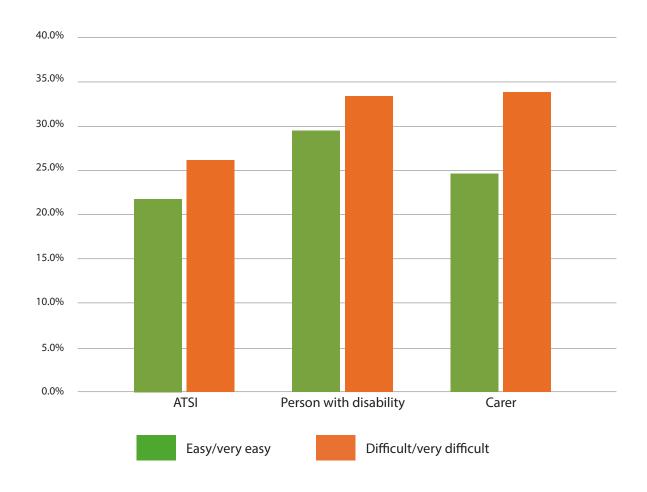
When asked about the difficulty of finding information, 33.6% of participants reported that it was either easy or very easy to find the information they needed, 24.3% reported that it was either difficult or very difficult to find information, and 37.2% reported that it was neither difficult nor easy to find information. This was consistent across all age groups.

However, participants who lived in remote areas or rural areas outside of town reported finding information for their needs more difficult than adults who lived in metropolitan areas or regional cities and towns.

"Accessing services in regional areas is a huge issue. And I'm not working at the moment, so there are also financial barriers to accessing services and health."

Focus group participant

Unsurprisingly, people from often marginalised backgrounds reported having difficulty finding the information they needed for their care. People living with disabilities, carers and people from Aboriginal and Torres Strait Islander backgrounds reported that it was difficult to find information for their needs.



Challenges finding information

The main challenges faced by participants in accessing information related to seeking information from services.

These challenges included long wait times for telephone support, issues with support staff not having the knowledge to answer participants' questions, and lack of knowledge about who can support them.



While 30.6% of participants reported that nothing stood in their way when it came to accessing information. For many participants, this was related to how information was received from services they accessed. Older people felt a lot of frustration around long wait times when calling for support, and they expressed frustration in finding staff who could provide the support they needed over the phone.

"...it's hard because you don't get on the phone and you're on the phone for a long time. Then you might get through to somebody who quite clearly cannot deal with your question, so they have to pass you on to someone else. Then you have to go back and talk through the whole issue. In some calls, you might be on the phone for an hour and a half, and you've gone through this rigmarole three times get to the endpoint, and maybe you've got an issue resolved, or maybe not. That's incredibly frustrating."

Focus group participant

As a result, some participants reported a preference for accessing information in-person, as they felt an active conversation with a person helped them get the information they needed. They reported being able to use body language cues within the conversation as well as being able to take more time to visually present information and explain their needs.

"On the phone, it is very difficult to understand. And they often speak very quickly. And I'm trying to be tolerant and saying, 'I need you to slow down because a lot of elderly people don't have great hearing'. You don't have the body language and communication tools that you have off the phone."

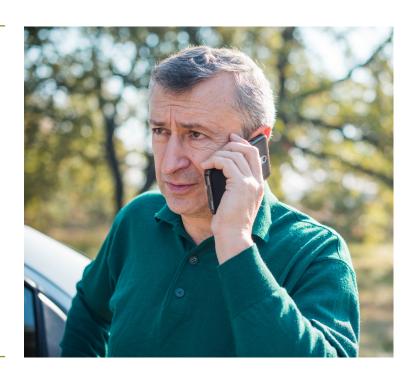
Focus group participant

11.8% of participants reported that the main challenge they faced when accessing information was not knowing where to go for information and support.

When participants were provided information, 19.6% reported that information was not provided in a way that was clear or easy to understand, which made it challenging to use.

"I don't have confidence in the information that was provided. Plus, the information provided verbally wasn't clear and it's difficult to keep asking the person to repeat."

Survey respondent



Of 1732 participants, 75% of respondents did not need additional support to make an informed decision, and 19% did require additional support. Of the participants who did require additional support, some reported that they consulted with family/friends or trusted professionals to ensure they were making the right decisions. For others, it was about not being able to access the information they needed as it was provided.



"I am always inclined to seek a 'second opinion' just to put the final touch to my considerations, to try and ensure my decision making is soundly based."

Survey respondent

"Had difficulty hearing. My wife helped with phone conversations."

Survey respondent

When participants were asked if they felt their age impacted how information was provided to them (n=1551):

21% of participants felt that their age had a positive impact on how information was presented to them.

19.8% felt that their age had a negative impact on how information was presented.

49.5% of participants felt their age made no difference, and

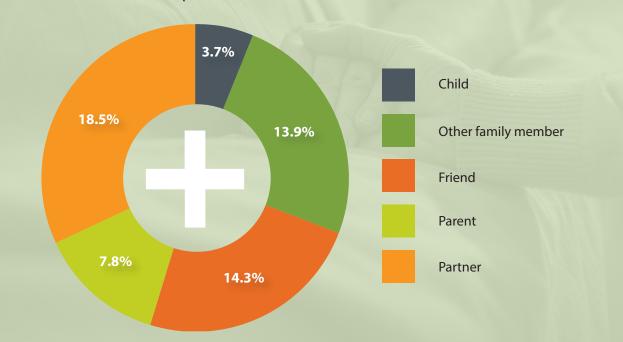
9.8% were unsure if their age had any impact.

Hospital experiences

Older people consistently reported always receiving information about care and treatment while in hospital, and that they knew where to go for further information about their or their loved one's care.

However, when it came to having information about leaving feedback or making complaints about their care, almost 30% of respondents reported either not knowing or only sometimes knowing how to make complaints.

721 (44.8%) participants reported that either they or someone close to them had recently been an in-patient in a hospital (n=1608). Of these, 41.8% of respondents said it was themselves who had recently been an in-patient in a hospital. Where it was someone close to the respondent, it was:



Receiving information about health, treatment and care

While in hospital, survey respondents overwhelmingly felt they always or usually received the information they needed about their health, treatment or care.

"I had a reaction to dye for an x ray procedure, and an ambulance had to be called, and I had to be taken to [the Emergency Department]. I felt that everybody in that process kept me and my husband really well informed."

Focus group participant

Similarly, the majority of survey respondents reported they always or usually knew the roles of the health professionals involved in their care and knew how to get more information about their care or treatment if they needed it. This was also consistent with survey respondents who had most recently cared for someone who had been in a hospital.

Discussions in the focus groups, however, highlighted that many older adults had many different experiences of accessing care and treatment while in hospital or while supporting someone they loved in hospital. Participants described not getting timely access to care, particularly when waiting in Emergency Departments, or that some services they received while in hospital were not appropriate for all.

"I do get very concerned that the health institutions have food, which is not really food or good food. I, for example, a diabetic am being fed white bread and juices that are full of sugar. That's what goes on and it is very difficult to change the dietary circumstances."

Focus group participant

Participants raised the need for having an advocate to support people while they were in the hospital to ensure they were getting the care they needed. This is particularly true for those who may not be able to advocate or care for themselves or may not know how. This is consistent with survey respondents where people with disabilities (n=47) reported being least able to provide feedback or make complaints about their care, with 25.6% reporting they never knew the process.

"If people are sick, they need somebody. And not everybody has that. Because what really is needed is somebody that cares for them that can be an advocate. And sadly, that's not always available. And so therefore there should be things within the hospital system that provide that."

Focus group participant



"I think advocacy [that can be] readily contacted, for people that really do struggle with bureaucracy or are overwhelmed. Sometimes they don't have computer skills. And they need an advocate in hospital. But [advocacy] is required in lots of areas. [It can provide] that confidence and understanding of some of the processes, sometimes clarify or make a process easier."

Focus group participant

Planning for discharge

While most participants reported they received information about and were referred to services that could support them on discharge from the hospital, almost 30% of people with disabilities (n=46) reported they never received referrals to support they needed when being discharged.

This was consistent with some focus group participants, who discussed a lack of support when they or their loved ones were discharged from the hospital. However, other participants reported positive experiences while in the hospital.

"I asked, could [my friend] please have a social worker visit him? Or come and talk to him before he left hospital. Nobody came near him. But he was just sent [home] after this major surgery. He was just sent home on his own, with no food there. Nothing."

Focus group participant

These discussions highlight that it is possible to make information accessible to adults in hospitals. It requires a consistent approach to making information available and consistency in the training provided to hospital staff so that they can share it with their patients both within individual hospitals and across hospitals in the state.

When participants were asked if they felt their age impacted their treatment or care, they overwhelmingly felt that their age had made no difference (52.7%, n=636).

25.8% of participants felt their age had positive impacts on their treatment or care while in hospital and 21.6% felt their age had negative impacts.

Participants aged 50-59 (n=13) were more likely to report their age had negative impacts (30.8%) on their treatment and care in hospital than positive (15.4%).



Recommendations for future action

The survey and focus group findings highlight that older people across NSW experience a range of challenges when seeking information. They also have varied experiences when presenting to a hospital for care or when caring for loved ones who may be in hospital.

"The information that you find online, do you think it's well articulated? Is it difficult to find out that information? Is it presented in a way that's accessible to a whole range of people? Or do you think you need a degree to understand some of the information that you find online?"



1. The study has shown that older people who may be living in marginalised circumstances, for example, people living with disabilities, face greater challenges in accessing information. This can be a result of accessibility needs, such as not having access to the internet or not being able to travel to services to access information and support.

It is recommended that accessibility needs be considered when sharing information with older people across the public and private sectors. For example, for older people who prefer to seek information over the phone, customer service staff have more intensive support and training to be able to better understand and communicate information.

2. This study's findings clearly show that older adults across NSW are increasingly facing challenges in accessing information about the services and supports they need, particularly regarding their healthcare.

It is recommended that intensive advocacy support be provided to older adults to offer the information and support they need to be able to access the information they need. In particular, these advocacy services can provide older adults with support during finite times of need, for example, during hospital visits to ensure they are able to access the care they need or when trying to access information about government services and supports such as MyAgedCare packages.

3. Older people have unique methods of accessing information and support and seek information in various ways, including online, in-person, and over the phone. While there is a lot of information available to older people, it is not readily found or easily accessible.

It is recommended that services across the public and private sectors place greater consideration on how information is presented and shared with older people, including providing staff with training in how to communicate with older people.

Addressing information accessibility supports older people to be better informed and make informed decisions about their life and care needs. It ensures that older people are able to access information about the supports that are available to them and take action to ensure they have access to the resources to age well and live with dignity.

When supporting a population that is ageing and that may fall through the gaps, it is essential to ensure older people can access information in a way that considers their needs.





