

Research into the need for an individual health advocacy service in South Australia

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HCA acknowledges the Traditional Custodians of Country. We pay respect to Elders past and present, and recognise that their cultural heritage, beliefs and relationship to Country are important for sustaining health and wellbeing.

Glossary of Terms

Advocacy	<p>Advocacy is the process of supporting an individual to be heard. The individual is placed at the centre of this process and is supported to:</p> <ul style="list-style-type: none"> ○ Understand and exercise their rights; and ○ Participate, to their maximum ability, in conversations and decisions affecting their lifeⁱ
Advocate	<p>An advocate is a person who represents and works with a person or group of people who may need support and encouragement to exercise their rights, in order to ensure that their rights are upheld.ⁱⁱ</p>
Carers	<p><i>Australian Government – Carer Recognition Act 2010</i> A person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail or aged. An individual is not a carer merely because they are a spouse, de facto, partner, parent, child, or other relative or guardian of an individual, or live with an individual who requires care. A person is not considered a carer if they are paid, a volunteer from an organisation, or part of a training or education program.ⁱⁱⁱ</p> <p><i>SA Health – A Framework for Active Partnership with Consumers and the Community 2013</i> A family carer is someone who provides care and support for their parent, partner, child or friend who has a disability, is frail aged, or who has a chronic mental or physical illness.^{iv}</p>
Consumer	<p>Patients and potential patients, carers and organisations representing consumers' interests. When referring to consumers, SA Health is referring to patients, consumers, families, carers and other support people.^v</p>
Individual Advocacy	<p>Individual advocacy occurs at a person-to-person level. This may be via phone, online or in-person. This level of advocacy aims to support the individual with singular or ongoing issues and in situations where the individual believes they would benefit from having another person to walk alongside them.</p>
Systemic Advocacy	<p>Systemic advocacy happens at a policy and systemic level. This includes strengthening the voice of groups of people, responding to policy and legislation and aiming to improve services or policy to benefit a large group of people.</p>
Health Care	<p>The prevention, treatment and management of illness, and the preservation of mental and physical wellbeing through the services offered by the medical and allied health professionals.</p>

Executive Summary

Health Consumers Alliance of SA Inc (HCA) was established in 2002 as the peak health consumer organisation in South Australia. HCA are a member-based, independent, not-for-profit organisation, funded by SA Health. We work with our members and supporters to achieve our vision: *Consumers at the centre of health in South Australia*.

HCA's mission is to engage consumers and health services to achieve high quality, safe, consumer centred care for all South Australians. In 2013, SA Health published *A Framework for Active Partnership with Consumers and the Community 2013* and its companion document, the *Guide for Engaging with Consumers and the Community*. These documents are the centrepiece for the consumer-centred framework within all SA Health services. The guide works on scales of engagement and levels of engagement. The guide outlines four scales of engagement: individual, service, network and system. HCA currently looks at advocacy on three of these scales: service, network and system. However, in 2017 HCA began considering the need for individual advocacy for South Australian consumers.

In February 2018, HCA working with a social work placement student from the University of South Australia, commenced a research project into the need for an individual advocacy service in South Australia. For many consumers in South Australia, advocacy support is provided at an individual level by family members or friends. However, consumers and carers have consistently identified there is a gap in providing independent professional support and advocacy to the individual consumer or carer. It is this service gap that an individual advocacy service can fill.

Over the course of five months South Australian consumers were consulted with via focus groups, interviews and surveys. From these various methods, 223 consumers and sixteen healthcare professionals responded to HCA with feedback regarding the need for an individual advocacy service in South Australia. The feedback we received from consumers was overwhelmingly in favour of an individual advocacy service in South Australia. Of 153 people who responded to the question *"Has there ever been a situation that you, your family or friends, have experienced that could have been improved with the support of a health advocate?"* 77.78% responded with "Yes"¹.

The information provided from South Australian health consumers was deeply personal and enlightening and at times, also distressing. Many shared stories from times where they felt as though they had lost their power and control, caught in a health system that they believed was too complicated for them to navigate. Some shared the experiences of loved ones that were no longer here to share it for themselves.

¹ This question was asked in the short online-survey, 153 consumers answered this question.

The overarching theme drawn from the responses was that, yes – further support is required for South Australian Health consumers and that an individual advocacy service could provide this support. Health literacy, transparency, flexibility, accessibility, meaningful consultation and a commitment to consumer-centred practice were other strong themes regarding why an individual advocacy service was needed and how it should function. Below is a list of recommendations that have come from feedback from health consumers that participated in focus groups, interviews and, surveys (online and in hard-copy).

Recommendations

- The establishment of an individual advocacy service in South Australia
- Multi-access service (phone, online and in-person) to cater to consumers across South Australia, including those not able to physically access the service
- Services should be free or subsidised to be accessible for low-income consumers
- Advocates to be specifically trained to work with a wide variety of consumers including; culturally and linguistically diverse (CALD) consumers, consumers from the LGBTQI+ community, consumers with mental health issues, aged persons, vulnerable groups, as well as Aboriginal or Torres Strait Islander (ATSI) consumers
- Accessible services designed with disabled consumers in mind
- Options for long-term case management as well as issue-based advocacy
- Potential for expansion into LHNs to service consumers in their own communities
- Further research into the implementation of an individual advocacy service in South Australia

Purpose

The purpose of this report is to deliver the findings from research conducted with health consumers in South Australia regarding the need for an individual health advocacy service. This project and research has been conducted to provide HCA with evidence-based recommendations regarding the need and efficacy of an individual advocacy service. This report will provide the following based on consumer input and further research;

- Recommendations regarding what an individual advocacy service could look like
- Recommendations regarding the requirements to establish one
- Recommendations regarding the attributes of an effective program
- Contribute to ongoing discussions and rationale in relation to the need for an individual advocacy service for health consumers in South Australia
- Provide a platform for consumer voice to be represented in identifying the need for an individual advocacy service in South Australia.

This report supports the achievement of HCA's Strategic Direction 2: *We lead systemic advocacy and policy to shape consumer centred care.*

Background

Australia, in line with many Western countries, is moving toward a consumer-centred approach to healthcare. A healthcare system that is consumer-centred provides a stronger emphasis on individualised care, multi-disciplinary team management and enhanced consumer health-literacy, including improved accessibility to more information for more diverse groups of consumers. Australian healthcare systems are choosing to embrace consumer-centred care and are bringing community experiences and consumer involvement into decision making on day-to-day practices and longer-term policy development. The academic evidence supporting the efficacy of consumer-centred model is increasing steadily as more systems adopt this approach to healthcare. Some of the benefits cited include “... *increased adherence to management protocols, reduced morbidity and improved quality of life for patients*” as well as increased doctor satisfaction (Bauman et al 2003, p 253-254).

Advocacy is a prominent feature of the consumer-centred care model. In 2012 a report was commissioned by the Australian Government Department of Health and Ageing, *Advocacy and action in public health: Lessons from Australia, 1901 > 2006*. This report praised the role of advocacy in advancing Australia’s public health system. By encouraging consumers, along with their family, carers and the wider community, to engage with advocacy and become more active in their own health better health, outcomes can be achieved (Bauman et al 2003). In line with this report, HCA had received feedback from consumers stating that there was a gap in services at an individual level in providing professional advocacy support. It was a result of this feedback that HCA began this research into the need for an individual advocacy service for South Australian health consumers.

Methodology and Process

The first stage of this research project was to review the current advocacy services in South Australia to see if a separate advocacy service was required to fill this reported gap. This review was conducted by searching for all health-related advocacy services listed in South Australia and examining what level of advocacy they provided and who their target audience was, including any required criteria the consumer had to meet (ie having a disability). HCA has an existing document with a register of all advocacy groups and the services they deliver, this document can be found on the [HCA website](#). It was found that, while there are numerous advocacy services in South Australia, these services are specialised to groups of consumers (ie consumers with a disability, aged persons, CALD consumers, asthma support services and other services supporting specific health conditions), this leaves a large cohort of consumers with nowhere to go if they fall outside of these groups or have coinciding issues that are not covered by existing advocacy services. Of the organisations that are more generalised, none provide an individual advocacy service.

Many will help with complaints and grievances but won't be able to call a health services on a consumer's behalf and gather information or act in other ways as an individual advocate like specialised organisations do. This is where the gap in services exists a generalised individual advocacy service that a consumer from the general population can call to receive personalised advocacy support.

One of the key requirements of this research was to hear directly from consumers, by doing this we would ensure that any recommendations provided to HCA would be evidence-based and consumer-centred. To achieve this requirement, it was crucial that all methods of research and consultation were flexible and adaptive. The original intent of this project was to use focus groups as the primary information-gathering technique. However, due to the constraints both of time and difficulties in organising groups of consumers from different local health networks and communities to come together at once, two online surveys, one short survey with three key questions and a longer survey with 15 more in-depth questions, were set up to make research more accessible to a wider range of health consumers across South Australia. By using this method, it also allowed us to reach a higher number of consumers including those in rural areas and other key demographics. The original goal was to consult with 100 consumers and health care professionals but upon the closing of our surveys and consultation processes, we had gathered feedback from 223 consumers and sixteen health care professionals from a variety of backgrounds.

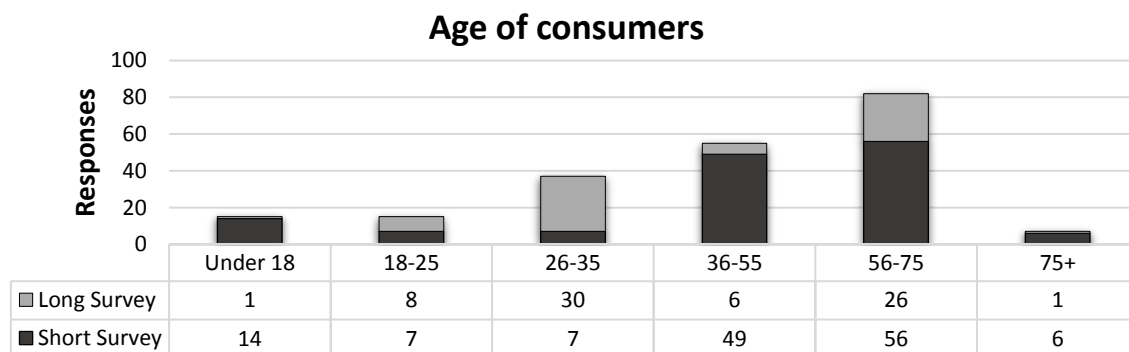


Figure 1: Age of consumers from short and long survey

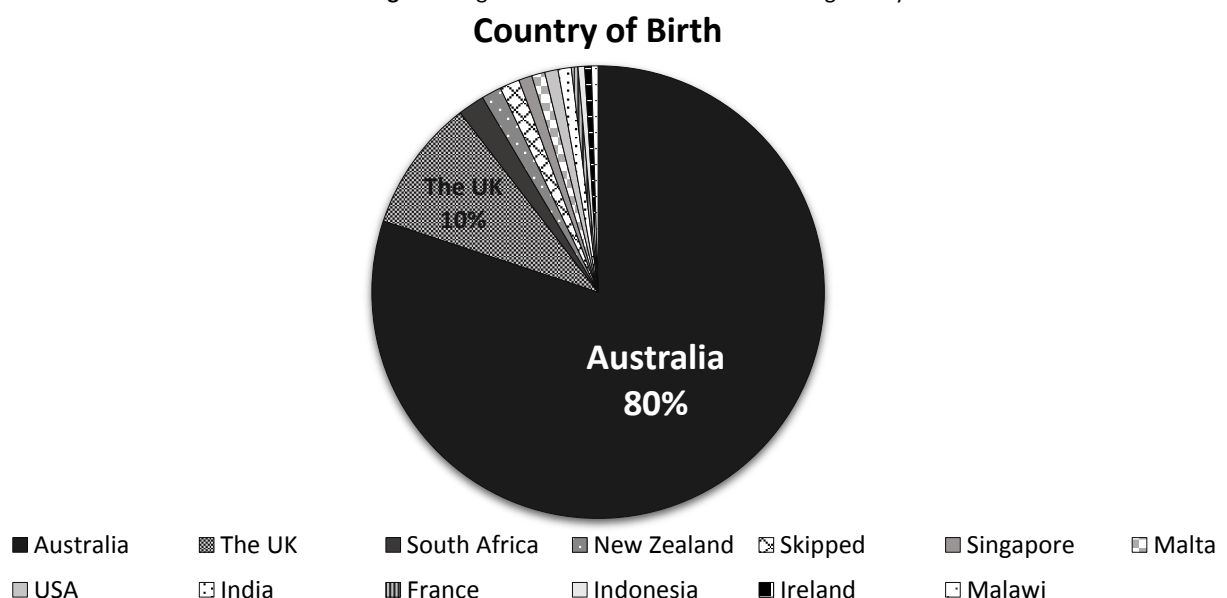


Figure 2: Respondent's country of birth from short and long survey

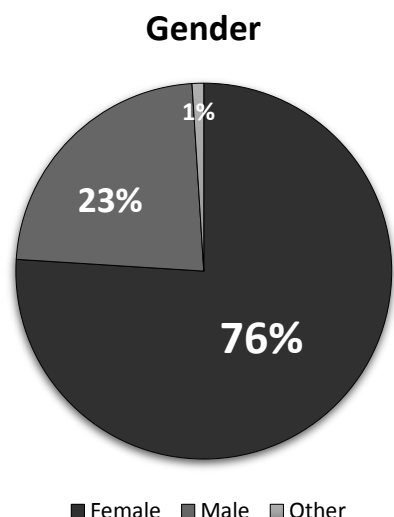


Figure 3: Gender representation across both surveys was similar with a much higher female response rate.

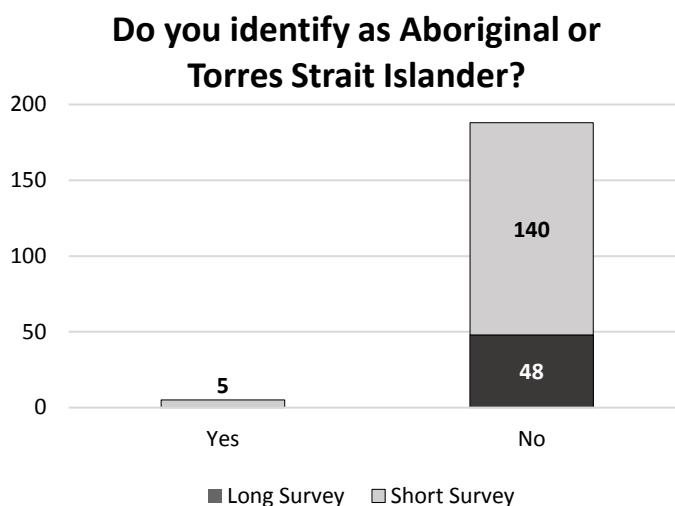


Figure 4: Overall, ATSI representation was low but representative of the total South Australian population. ATSI consumers showed a preference for the shorter of the two surveys as indicated above.

Surveys

It was decided that online surveys would be utilised to capture a wider audience as they are more accessible and easier to administer. A mixed method approach was taken to the design of the survey, using both quantitative (closed-ended) and qualitative (open-ended) questions (AHRQ 2013). This method was chosen as it allowed us to provide a voice to consumers to share their experiences while also giving us enough data to validate what was being shared. Initially, one eighteen-question survey was developed, however an additional shorter version was created to be shared on social media with people that may not have as much experience with health advocacy as some of HCA's members and friends. The shorter version consisted of demographic data questions and three key-point questions. The longer survey was offered as an option to consumers that had existing experience and knowledge regarding consumer advocacy or wished to provide more in-depth feedback (both surveys can be found in the appendix).

These surveys were initially distributed to HCA's eNews subscribers via email and post (1,311 subscribers), and was also shared on the HCA website and Facebook page in the weekly eNews post. The surveys were also emailed directly to the consumer engagement officers within all local health networks (NALHN, CALHN, SALHN, WCHN and CHSALHN) to be distributed to their consumer networks. SHine SA, Multicultural Communities Council of SA and Nunkuwarrin Yunti of South Australia were also contacted to share the short version of the survey with their consumer networks. SHine SA shared the short survey on their social media, but we were not notified by the other organisations as to whether this survey was distributed. Physical copies of the short survey and links to the shorter online survey were left at Nunkuwarrin Yunti and Headspace in their city offices both on Wakefield street to be displayed and shared with consumers. We chose to employ a multimode design, providing online, hard-copy and over-the-phone versions of the survey, surveys were also

posted directly to consumers who made this request with return-address envelopes. This was done to reduce any coverage errors and improve accessibility options for all South Australian consumers (Ponto 2015).

Social media played a significant role in sharing the shorter survey. Two paid posts were shared on the HCA Facebook page with a total of \$44.81 spent to boost these posts. The initial post targeted consumers aged 14-35+ living in South Australia. We chose this age range as it was underrepresented in our survey consumers at that stage. This post reached 1,349 people and had 93 engagements, including 53 people going to survey link because of this post. 75% of people who engaged with this post were female and 25% were male. Our second paid post targeted people aged 28-65+ living in South Australia and we chose to include filters that would target ATSI people (such as having an interest in ATSI culture and art) and those from a CALD background (such as an interest in English classes and English as a Second Language) as we wanted to ensure a fair and equal representation in our data from consumers from these groups. This post had a lower reach, 378 people, with only fifteen engagements including sharing and liking the post but only three people went to the survey as because of the post. 78% of people who engaged with the post were women while 21.5% were men.



Figure 5



Figure 6



Figure 7



Figure 8



Figure 9

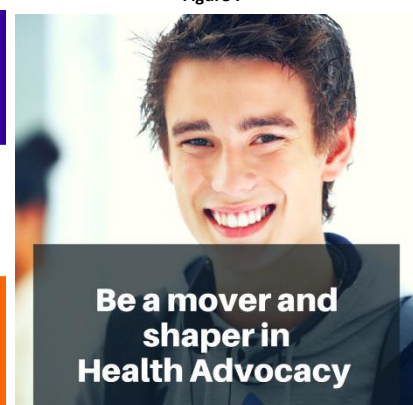


Figure 10

Figures 5-10: Images used in our boosted social media posts. These images were created for our posts to appeal to ATSI, CALD and young (14-25-year-old) consumers as we found these groups to be underrepresented in our survey

To extend our reach within the NALHN consumer-base, we visited the Lyell McEwin Hospital, based in Elizabeth Vale, with hard-copy versions of our short survey and invited members of the public visiting the service to complete the surveys. The completed surveys were added manually and have been accounted for with the total number of online-survey responses. We were also invited to talk to a group of consumers based within CALHN at the Cross Roads Forum, a monthly meeting that invites speakers to address theology, spirituality, politics, social welfare and justice (The Monastery 2018). We introduced the topic of an individual advocacy service and invited participants to complete the hard-copy survey, these were also entered to our online survey manually and have been included in our total number of survey consumers. We were also able to attend the Youth Advisory Group (YAG) meeting in early June to talk about our project and to get the perspective of the young people involved at the Women's and Children Health Network (WCHN). We invited the YAG members to critique the project from a youth perspective and asked them to complete our short survey. We wanted to ensure that we had meaningful consultation with young people to make any service accessible to all ages.

Both surveys were closed on Friday the 7th of July and were reviewed for patterns and themes in results. The results of these surveys will be discussed in the findings and analysis sections.

Consumer Focus Group

Our consumer focus group was held at the New Royal Adelaide Hospital (NRAH), part of Central Adelaide Local Health Network (CALHN). This focus group was held with the CALHN consumer engagement project officer at HCA, Ellie Hodges, this took place on the 11th of May 2018 at the New Royal Adelaide Hospital (NRAH). It was attended by twelve consumers from various groups within CALHN including consumer advisory committees, volunteer groups, ATSI consumer groups, CALD consumer groups and mental health consumer groups. The group were split into two smaller groups of six. We spent approximately 40 minutes going over three key discussion points (included in the appendix). Themes from the focus group echoed those from the two surveys: a need for individual health advocacy, health literacy, additional and impartial support, help resolving ongoing issues, support for vulnerable persons. The results from the focus group will be used in the analysis but will not be included in the findings.

Consultation with Health Care Professionals

Health care professionals were also approached to provide feedback as we felt that it would provide an insight into where the gap lies between health consumer and health care professional understanding of the need for an individual advocacy service. We contacted SA Health to get contact details for social workers across SA Health and were advised that we could write an email requesting input that would be shared with the social work leads across SA Health. We did not receive any responses from this method. After reaching out directly to several organisations we received

responses from a small number of workers in both acute and community settings however, the response we received was less than what we had hoped for. Overall, we received feedback, via individual interviews and a teleconference-based focus group, from sixteen health care professionals. One social worker in a metropolitan hospital, a sexual health counsellor from SHine SA, a community worker with the Multicultural Communities Council of South Australia and thirteen social workers from Country Health SA via a teleconference where a shortened version of a focus group was held. We reached out to several sectors across different demographics, including ATSI health, but did not receive responses after several attempts. The responses received will be used in our analysis to compare between professional and consumer opinions but will not be discussed in the findings due to the small number.

Limitations to Methodology and Process

Data collection and consultation methods had to be quite adaptive and flexible. At times, it was challenging to get responses from consumers, health care professionals and organisations. The introduction of the online survey helped with consumer consultation, however it made it challenging to track the exact reach of our research. We can account for the 3,038-people reached via our eNews subscriptions and Facebook posts, but we have no way of definitively knowing the true number of people that were sent copies of our survey or were reached in some manner. This also limited our chance of following up with nonresponders (Ponto 2015 p169).

While we have representation in our consultation from ATSI, CALD and LGBT+ consumers it is not accurately representative of the South Australian population. Engagement from ATSI health organisations was minimal and as such our reach for consultation with ATSI consumers was limited. However, 2% of our consumers identified as ATSI which is representative of the total ATSI population of South Australia (ABS 2017). Another limitation upon review was that we did not include a specific question that asked whether a person identified as part of the LGBT community. As such the only data that shows the LGBT+ community were represented were the few people who selected a gender other than male or female. We did consult with SHine SA, who work closely with LGBT+ consumers, and there was a small spike in responses after SHine SA shared our survey on their Facebook page on the 3rd of July. Going forward, should any further research be done, it would be a recommendation that a question be included to address this.

While providing multiple options for consumers to provide feedback made the research more accessible, it also meant that we cannot be certain that consumers did not complete more than one form of survey or participate in the focus group as well as completing the surveys. This means the number of responses may not be representative of the true number of individuals that have participated in this research. However, if a consumer had completed the survey, their IP address would

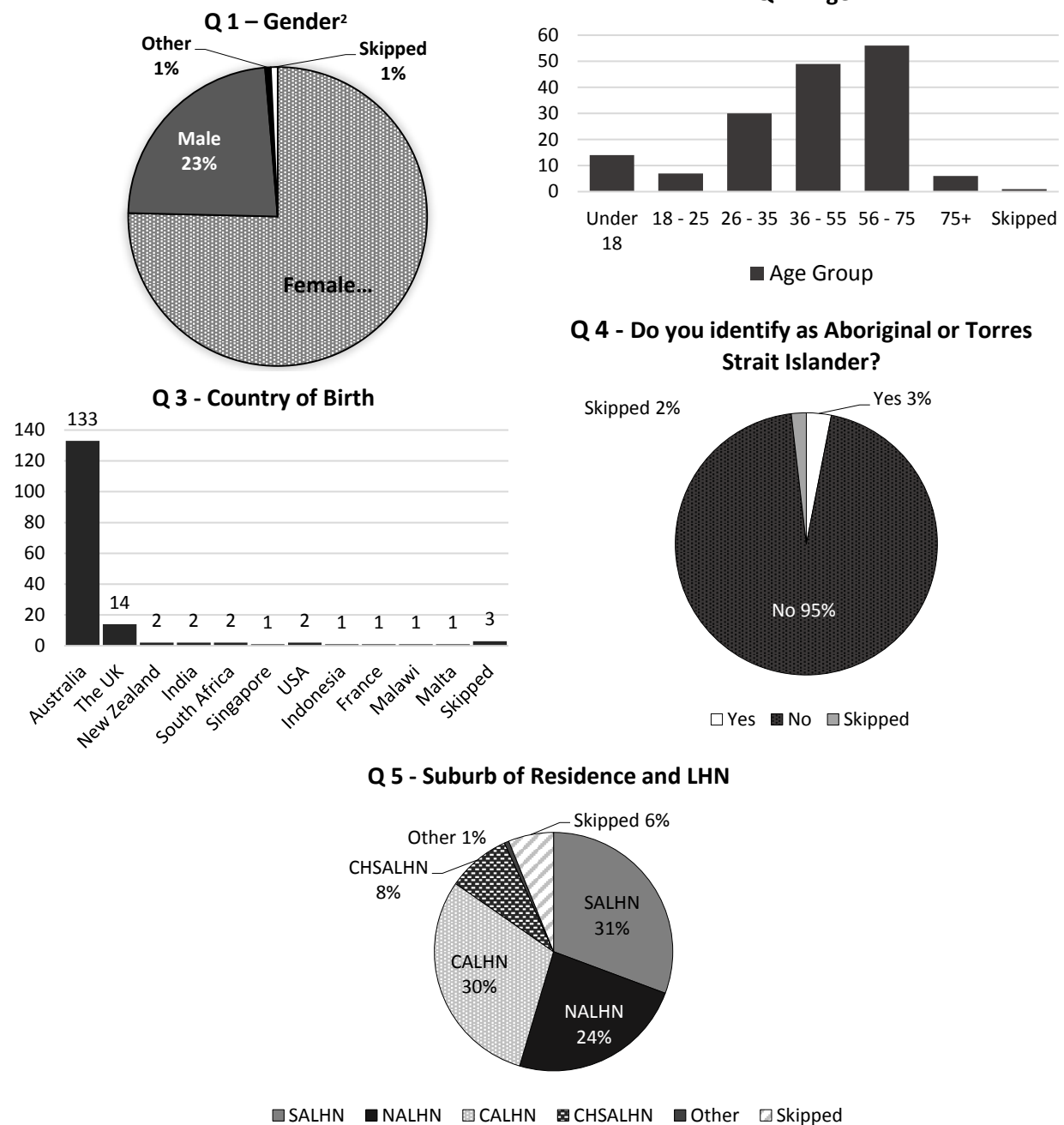
not be allowed to do it again. This ensures that an individual cannot complete the same online survey numerous times from the same computer.

Findings

Short Survey (online and manually entered)

163 people commenced the short survey with a completion rate of 74%.

Part 1 – Demographic Data:

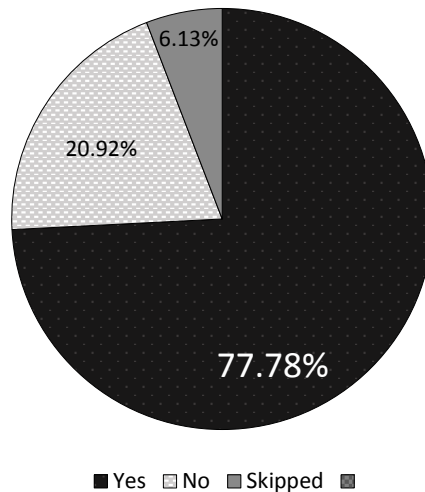


² The consumer that selected "Other" for question one, specified that they are non-binary

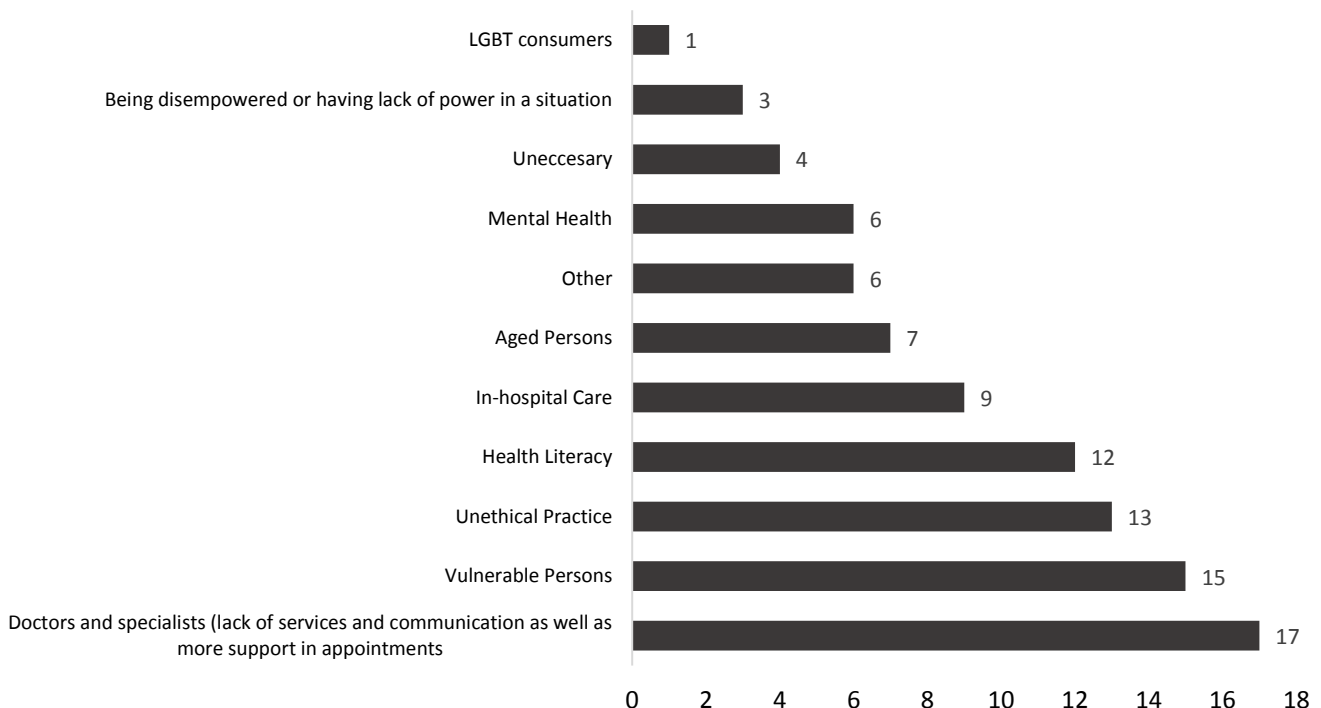
Part 2 – Research into the need for an Individual Advocacy Service “Our Short Survey”

“Our short survey” was the title of the second part of the shorter online-survey. In this part we asked three key questions to find our consumer opinion on the need for a n individual advocacy service.

Q 6 - Has there ever been a situation that you, your family or friends, have experienced that could have been improved with the support of a health advocate?



Of the 153 people that responded, 51 people chose to provide additional information about this experience. Two people selected this as their only answer, opting not to select “Yes” or “No”. Below is a summary of themes taken from these responses. Below is a graph depicting the themes drawn from responses to the question “*Please feel free to provide more detail if you wish*”. Multiple themes were applied to some responses if more than one theme was apparent in the answer.



The most common theme, as displayed above, was the lack of service, communication and support from doctors and specialists in both appointments and during treatments. Consumers expressed that they had experiences with doctors who *“weren’t willing to investigate their concerns”*, that they had to wait more than two years for appointments with specialists, and that they had specialists who were *“cutting appointments short”* without adequate advice about management for their medication among other things and that this made them feel voiceless. Consumers shared experiences from both acute and primary services. Some of the stories that consumers shared were deeply upsetting, including stories of doctors pressuring older people to have invasive surgeries and treatments that they and their families did not want and not respecting what was written in the consumer’s Advance Care Directive. There was an overall motif within these responses, a lack of understanding, communication and care from treating doctors and specialists which, ultimately, made the consumers and their families feel powerless. Many consumers expressed that these situations and experiences are when they would have liked to have had an individual advocate to call upon to support them. Below is a response from a consumer regarding how they felt they could utilise an individual advocate;

“... when an appointment is long and too full of complex information for that information to be retained. And when hospitals and doctors are not responding to important information about a person whose health situation is placing them at risk of imminent and dramatic deterioration.” - Consumer # 13

A lot of consumers also identified experiences where a person from a vulnerable group, (ie aged people, consumers with a disability, trans consumers, CALD consumers, consumers with severe mental health issues and consumers who were extremely unwell and had no personal supports to advocate for them) were not supported or would have benefited from an individual advocate.

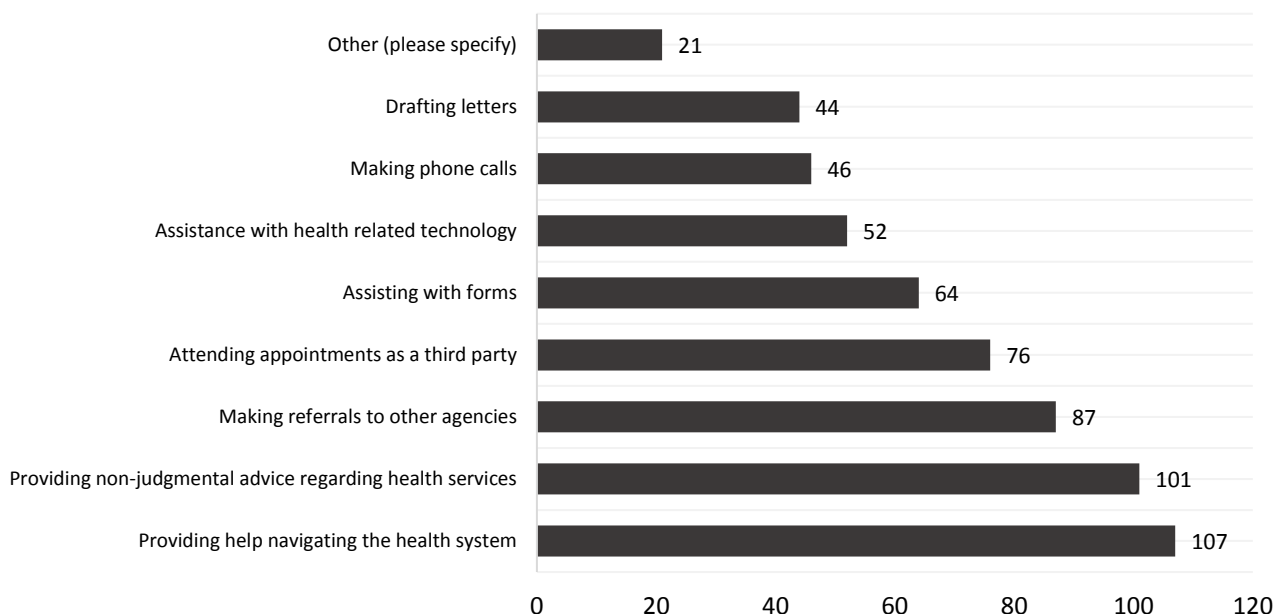
“I supported a friend with a previous (incorrect) diagnosis of schizophrenia during an appointment with an ENT who laughed at her behind a closed door and said there was nothing wrong with her she's just crazy.” - Consumer #44

Below is a response from a consumer sharing an experience where advocacy was provided by a family member as they were not supported by medical staff;

*“I presented to an ER in the Southern suburbs explaining in graphic detail my desire to commit suicide. I was seen by a psychiatric intern and was very quickly dismissed, because I was lucid and articulate. Had my partner not driven past me as I was walking to the Bunnings store next door to purchase the rope to actually commit suicide and forced me back to the ER, demanding I be held for some sort of observation, I would not be here right now. Even then, I was not held for observation, I voluntarily stayed in a spare bed in the corner of a noisy and restless ER. That there was no trauma-informed practice put into application with regard to my treatment and diagnosis actually intensified the situation. Had it not been possible for my partner to take time off of work and look after me for a couple of weeks, I can adamantly say that I would not be here now.” - **Consumer #71***

This was another common theme in these responses, had it not been for a family member or friend helping them, they would not have received the care they needed. As some consumers highlighted, unfortunately, many people do not have those friends and family that are able to support them.

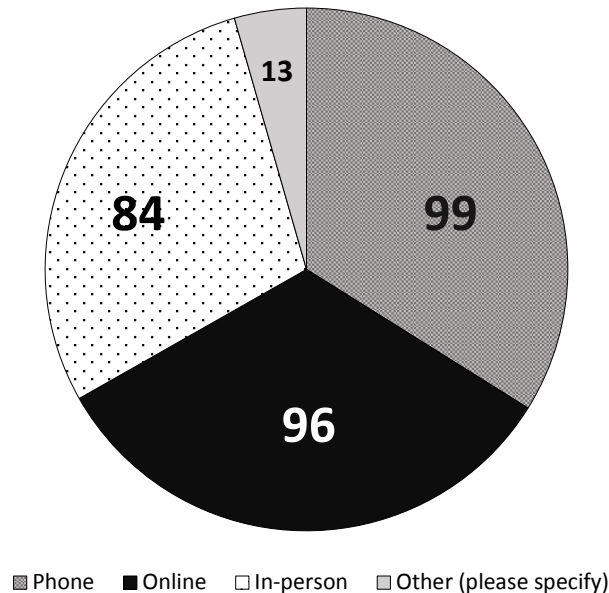
Q 7 - What services could an advocacy service provide to best support you?



150 consumers answered this question and consumers could select as many of the services listed as they liked. They were also given an option to provide any other services they believe an individual advocacy service could supply to best support them if it wasn't already listed. One of the most apparent themes from comments made on this question was the need for flexibility. Consumers also stated the need for ongoing support as well as support with singular issues. The need for a general

advocacy services, someone to help provide insight, provide advice and to help empower the individual consumer was apparent from the responses.

Q 8 - How would you access advocacy services?



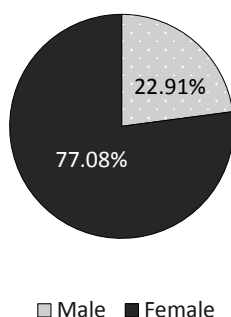
151 consumers answered this question, consumers could select multiple answers. In the “Other” responses, consumers strongly identified a need for specially trained advocates to work with CALD, ATSI and LGBT+ consumers. Consumers also noted that they would like a service that was able to visit communities or visit consumers directly. Many consumers noted that a service that offered multiple points of access would be the best option for consumers.

Long Survey (online)

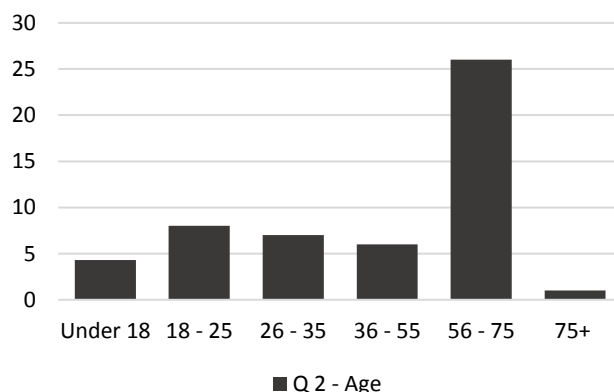
48 people have completed the long survey with a completion rate of 83%. Six responses were deleted as the consumers had commenced the survey but had not answered questions past the demographic data section.

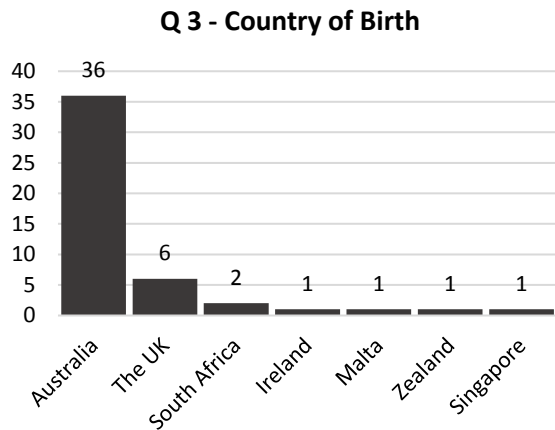
Part 1 - Demographic Data:

Q 1 - Gender

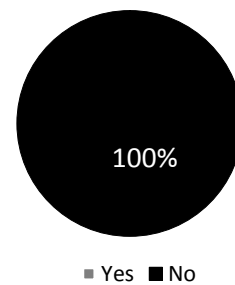


Q 2 - Age

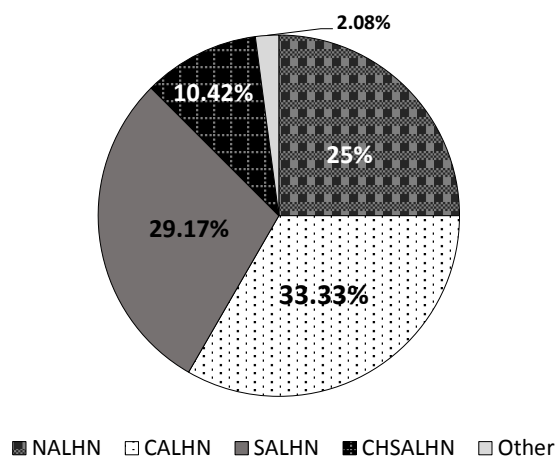




Q 4 - Do you identify as Aboriginal or Torres Strait Islander?



Q 5 - Local Health Network (suburb of residence)



Part 2 – Understanding Advocacy

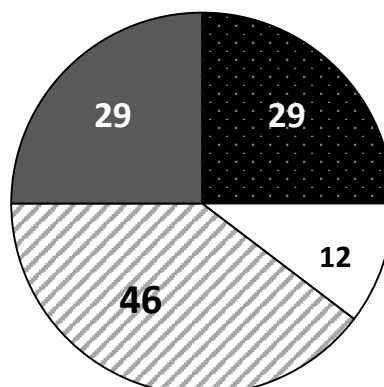
Part two of the longer survey aimed to understand the level of value a consumer placed upon advocacy and the level of knowledge they had regarding advocacy, particularly regarding health. Part two was prefaced by the following introduction; *“We would like to know your thoughts on advocacy. These questions provide the opportunity for you to share your views and opinions on what health advocacy in South Australia means to you.”*

Q 6 – What does advocacy mean to you? (47 answered 1 skipped)

From this question we found four key themes; *Types of Advocacy*, *Who Requires Advocacy*, *What an Advocate Does* and *Modes of Advocacy*.

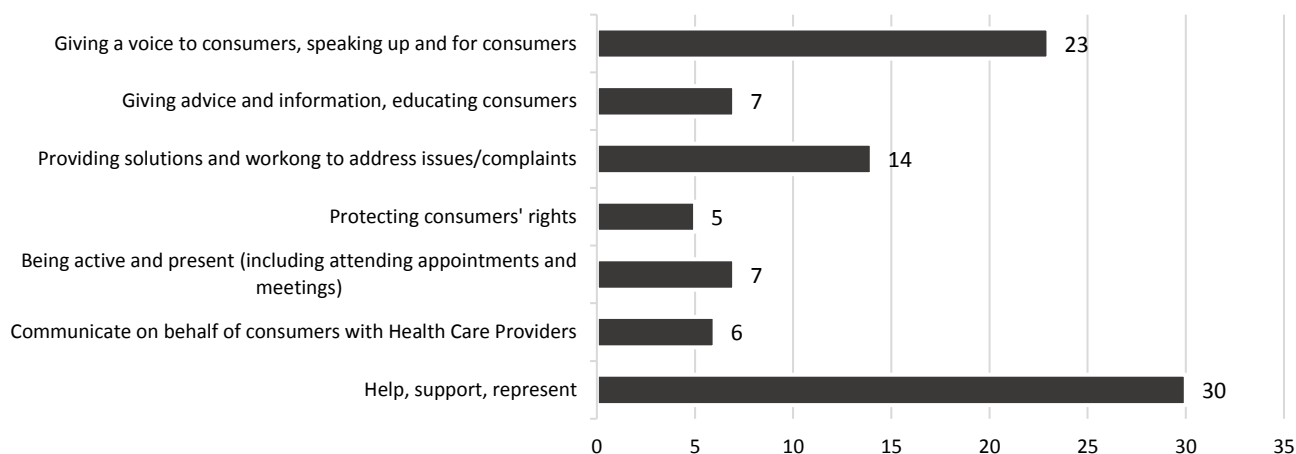
Key Themes

- Types of Advocacy
- Who Requires or Accesses Advocacy
- ▨ What an Advocate Does
- Modes of Advocacy

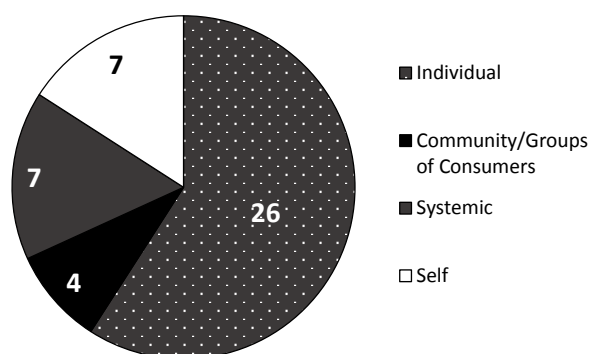


Within these key themes we saw several sub-themes also, below are a summary of these sub-themes:

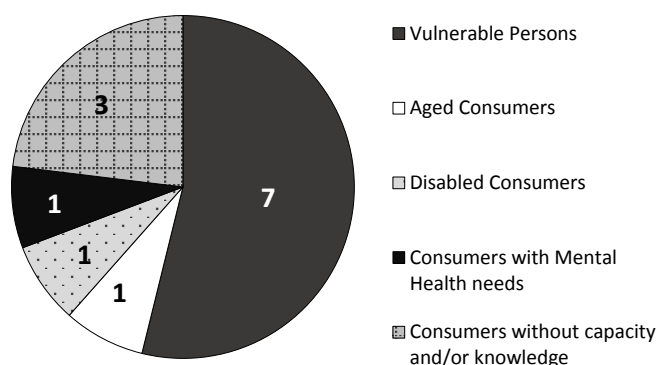
What an Advocate Does



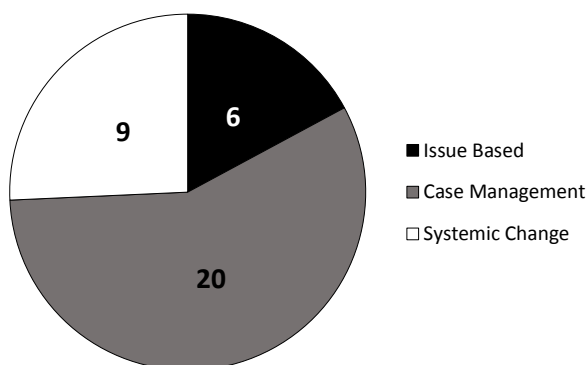
Types of Advocacy



Who requires advocacy

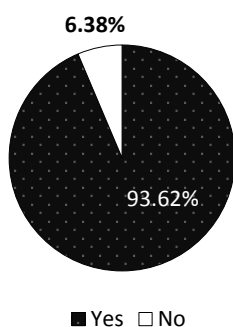


Mode of Advocacy



From this information we have a foundation of knowledge of what consumers think of when they talk about “advocacy”, this was important for us to establish and understand as it illustrates what consumers see advocacy “doing” for them and how. From these findings we can also see that individual advocacy is already a key part of what consumers see advocacy to be.

Q 7 - Is advocacy in healthcare important to you? (47 answered 1 skipped)



Forty-seven consumers answered this question with an overwhelming 93.62% stating that advocacy in healthcare was important to them. Of the 6.38% of consumers who answered “no”, some interpreted advocacy to be conducted by another person, and that they were already able to advocate for themselves. Others felt that advocacy was not helpful as it meant their health was out of their control and we should be empowering individuals to advocate for themselves.

Q 8- Can you explain why advocacy is or isn't an important concern for you? (47 answered 1 skipped)

Consumers were invited to elaborate on the previous question. Below is a summary of the most common themes as to why advocacy was or wasn't a concern to consumers.

a) Better Health Outcomes (19 occurrences)

- I. Consumers shared experiences where they believe they, or family and friends, would have had better health outcomes if they had accessed an individual advocate during their health journey. Many stated that, due to the vulnerable state people are in when seeking medical support, having another person there in the moment to help make sense of what was going on. Consumers spoke about the advantages of having a person there to “be on your side” and to make sure that any decisions being made were informed and, in the consumers,’ best interest.

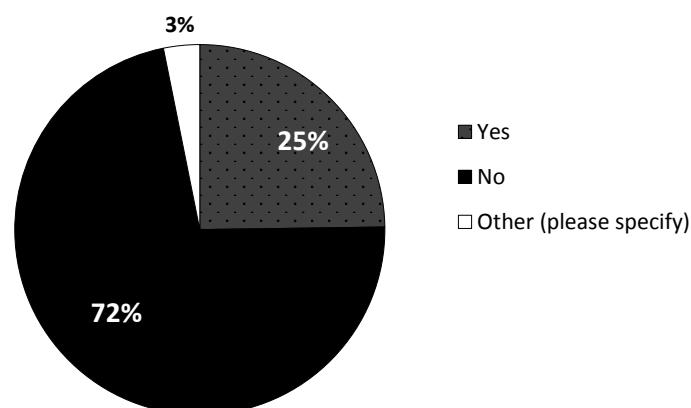
b) Health Literacy (12 occurrences)

- I. Health literacy and the importance of having simple and easily understood information was a principal concern for consumers. The medical terminology and jargon used by health care professionals disadvantages consumers and makes it harder for them to make informed decisions. Having an individual advocate who has knowledge of medical terminology or who can request plan-English interpretations will empower consumers to made decisions that are right for their personal situation.

c) Confusing/Complex Health System (8 occurrences)

- I. Difficulty in navigating the health system, which consumers state has become increasingly complex, was another reason given for the need for individual advocacy and why advocacy in healthcare was important to consumers. Some consumers stated that due to the complexity of both medical language and the health system, they felt intimidated by medical professionals. This was listed as a barrier for consumers to make good health care decisions.

Q 9 – Have you used an advocacy service previously? (46 answered 2 skipped)



Question 10 - Please provide further details regarding why or why not? (46 answered 2 skipped)

There were three common themes from consumer responses, summarised below:

a) Haven't needed an advocate (23 occurrences)

Many consumers have stated that the reason they haven't used an advocacy service so far was that they hadn't required one at this point. Some state that as they already have extensive knowledge of the healthcare system they were able to advocate for themselves. Others stated that as they had family members to support them with advocacy they haven't needed an external advocacy service. Some consumers also stated that, while they haven't used an advocacy service previously, they believe that an advocacy service could be useful in situations in the future.

b) Examples of advocacy services used (12 occurrences)

Twelve consumers gave examples of when they had used advocacy services or when they would, some gave examples of specific organisations they had accessed advocacy services from, other simply stated when or why they accessed the advocacy. Some experiences were not confined to healthcare, some of the healthcare advocacy services included; *CAFHS, Northern Carers, Ward Managers at the RAH, GPs.*

c) Unaware of advocacy services/too hard to access an advocate (7 occurrences)

Consumers that stated it was too hard to access advocacy services, some stated that this was the key factor that stopped them from accessing advocacy services. Some consumers said that they did not know that there were advocacy services available to them, for some this may have been true.

Part 3 – Individual Advocacy

“The following questions will cover the individualised aspect of advocacy services. We want to know how an individual advocacy service would best accommodate your specific needs. This may have to do with the type of health concerns you have or the type of support you require.”

Q 11 – In what situation would an individual healthcare advocacy service help you? (43 answered 5 skipped)

There were four common themes from consumer responses, summarised below:

a) Instances of feeling unsupported, not listened to by healthcare professionals and helping to resolve issues (13 occurrences)

Consumers expressed that at times during their health journeys they felt intimidated by doctors or as though they were not properly listened to and thus, treated accordingly.

Consumers stated that in this instance an individual advocate could step in and help resolve these feelings and help the consumer feel listened to and empowered.

b) Providing support for consumers navigating the health system and understanding treatments and best options (12 occurrences)

Consumers provided examples of experiences when they had not felt they understood what options they were being given and that in those times, having an individual advocate would have helped them. Many used the term ‘*in my best interest*’ in regard to their options for treatments, noting that an advocate would have their best interests when supporting them, but they felt that health professionals may not.

c) Helping navigate between specialist services, e.g mental health, aged services and disability support services (8 occurrences)

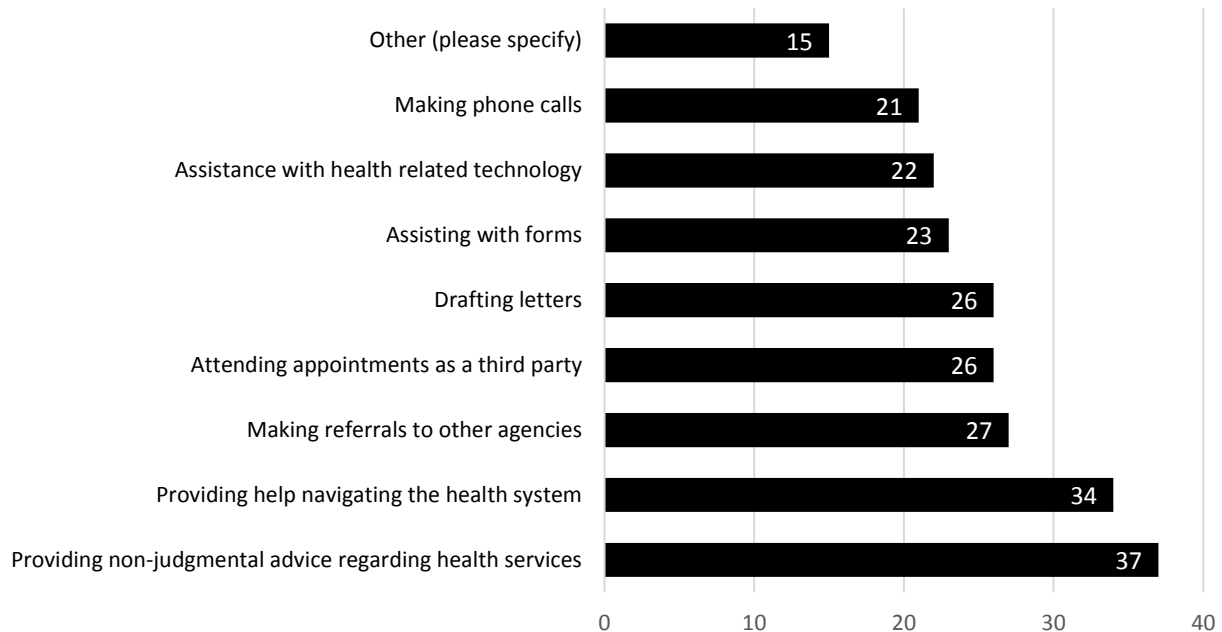
The flow between generalised health services and specialist services was given as an example of how an individual advocate could support consumers. Some consumers gave the example of navigating between the National Disability Insurance Scheme (NDIS) and the health system and that additional support was needed there. Mental health was also a common response and that the need for someone to provide advice on rights of people with mental health issues was high. Other examples of specialist services were linking with aged care services, Centrelink, podiatry and housing services.

d) When a family member or friend is not available to help, and consumers do not have the capacity to advocate for themselves (6 occurrences)

Consumers raised that their family and friends can act as advocates and that they also advocate for their friends and family but, there have been or could be times where this was

not an option. Some consumers also noted that if they did not have the capacity to make informed decisions, an individual advocate may be an appropriate support person.

Q 12 – What services could an individual advocacy service provide to best support you? (43 answered 5 skipped)



15 consumers selected “other” as an option for services that an individual advocate could provide, many stated that they chose that option as they believed an individual advocate should provide all of the listed services. Some consumers also stated that it was a difficult question to answer as they could not determine what services they may need in the future.

Q 13 - If an individual advocacy service was developed, what do you think should be considered in the design of the service? Please provide some general ideas and comments. (43 answered 5 skipped)

There were five common themes from consumer responses, summarised below:

a) Access and format of the service (19 occurrences)

Respondents shared their ideas for how an individual advocacy service should operate. As with an earlier question, respondents believe that the service should operate in different modes: online, phone services and in-person services. Respondents have also stated that having services outside of regular 9-5 business hours as this is restrictive for some consumers. It was suggested that a model like lifeline, with a 24hour phone service, be employed. However, it was also noted that this would require many trained volunteers and paid employees. There is a need for flexibility for consumers, not strict appointment times but something they can work around. Respondents stressed the need for the service to be accessible for all people from all walks of life regardless of: age, gender, sexuality, disability,

race or anything else. Another factor respondents raised was that the service should be a non-government organisation and independent of health services.

b) *Trained Advocates (9 occurrences)*

Respondents have expressed that regardless of whether an advocate is a volunteer or a paid employee, training will be pivotal for them to be effective in their role. Recommendations were made for specialised training for advocates so that if a consumer with a specialised issue comes to the service they will have a deeper understanding of this issue. Some examples of this specialised training included working with CALD and ATSI consumers and working with aged persons. Respondents have also stated that advocates should have access to referral processes to try and support consumers to work with groups that suited their individual needs best.

c) *Codesigned with Consumers (7 occurrences)*

Respondents explicitly stated that codesign with consumers should be central to any individual advocacy service that is established in South Australia. A consumer raised the 7 *Principles of Universal Design*^{vi} and stated that these principles, used in conjunction with codesign and inclusivity, would be the best starting point for designing an individual advocacy service. Some practical suggestions raised were to get consumer input through consultation methods such as consumer workshops. The overall message from these responses was that without codesign, whatever service was developed would not capture the true needs of the consumer.

d) *Cost of service (6 occurrences)*

Many consumers stated that cost could be a prohibitive factor for them to access the service, some stated that for a service to be accessible for them it would need to be free. Some wanted it to be covered by Medicare or an equivalent service. Consumers stated that they did not believe the service should be mean tested, that it should be open and accessible for all.

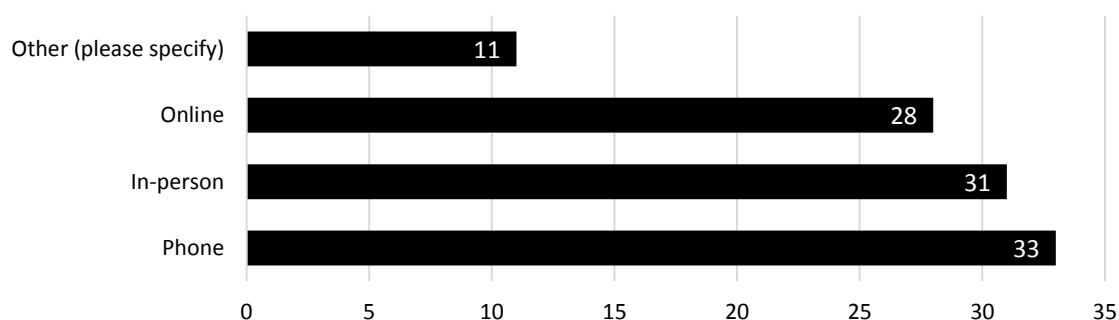
e) *Non-judgmental service (5 occurrences)*

Respondents made it clear that any service must be non-judgmental, and the advocates and the environment of the service must make the consumers feel welcome and comfortable. A suggestion was to use peer-mentors or consumers with lived experience as trained volunteers. This was suggested as, utilizing those with lived experience will give consumers the reassurance that the advocate understands and can empathise with their journey.

Part 4 – Practical Considerations

“In this section we would like your input on the practical considerations of establishing an individual health advocacy service. We would like feedback on how you would interact and use the service and what barriers would prevent you from using it. We are collecting data on the ways you would contact an advocate, how you would attend appointments, and barriers / ease of access to services.”

Q 14 – How would you access advocacy services? (41 answered 7 skipped)



11 consumers selected “other” and many noted that there should be the option for other organisations or health professionals to refer to the individual advocacy service. Others noted that having the option for consumers to send emails to the service.

Q 15 What are some potential or existing barriers you may have in accessing support, particularly advocacy support, regarding your health? (41 answered 7 skipped)

There were four common themes from consumer responses, summarised below:

a) Lack of accessibility at a service (14 occurrences)

Respondents have stated that a lack of accessibility to the service would be their biggest barrier to an individual advocacy service. Some examples that the respondents gave were: physically inaccessible services for consumers with disabilities, lack of translation services for people with little or no English, geographic limitations i.e. consumers that are based in rural areas and consumers that don’t have access to particular services online etc.

b) Lack of awareness of service and poor advertising (8 occurrences)

Many respondents stated that any potential service would need to be well advertised as one of the faults with other consumer services was that consumers were unaware they existed. A comment made was that some consumers do not have access to online advertising and as such, the service would need to be advertised via methods such as The Yellow Pages or to have flyers at health services.

c) Stigma and anxiety about accessing services (6 occurrences)

Anxiety about sharing an experience with a stranger and relaying a story that may be quite traumatic that they have already had to tell people many times. Anxiety and fear about what

judgement they might receive from not only the service but from people generally about needing to access the service.

d) *Lack of trust in advocates, health services and health system (6 occurrences)*

Some respondents stated that due to negative personal experiences with health professionals, they would have a hard time trusting an advocate or health professionals again in the future. The respondents also stated that they would not feel certain that advocates were adequately knowledgeable enough. There was also a fear that the system would be too bureaucratic and potentially prohibitive to consumers.

Q 16 What are some practical considerations an organisation should take into account when setting up an individual advocacy service? (41 answered 7 skipped)

a) *Accessibility and Individualised Care (11 occurrences)*

Respondents have raised the need for an accessible service numerous times in previous questions and in the practical considerations. Consumers have again expressed that any service created must take into consideration the needs of all consumers and be inclusive of all levels of ability, gender, language and age. Further to this, the care and services that an advocate provides should be able to be individualised to the consumer's needs.

b) *Location of service (7 occurrences)*

Location of any service has also been raised a number of times over several questions. Consumers from rural areas in particular are concerned about being able to access a service of this nature. Consumers have also stated that location would be important for them if they had children and needed to attend the service in-person, if they had a disability and had to travel long distances. Some provided solutions such as online and phone services as well as services based in local communities.

c) *Training of advocates (6 occurrences)*

Respondents not only stated that advocates should be adequately and appropriately trained, some respondents believed that advocates should have a certificate III or certificate IV in a relevant field.

Q 17 How could a health advocacy service be designed to be accessible for you? (41 answered 7 skipped)

There were two common themes from consumer responses, summarised below:

a) Mixed mode of service (20 occurrences)

Respondents indicate there needs to be multiple sources of access to any individual advocacy service that is established. Many stated that online services would be important but that a phone service would be vital as it would be accessible to the younger and older generations. There were still many respondents stating that in-person meetings would be important also.

b) Location and set-up of service (12 occurrences)

As with the above, respondents stated that in-person meetings were important but that having a single office in the city would not be accessible to them. They would require regional spaces to meet or home-visits where possible. Some consumers suggested having access to advocates through local hospitals, GPs and other health services. Respondents also noted that the space itself needs to be accessible for people in wheelchairs, ensuring doorways are wide enough for wheelchairs, ramps where required, automatic doors, near to parking or taxi ranks and having access to disabled toilets.

Respondents also made recommendations that the service be advertised in spaces such as GPs, hospitals and other health services as well as in the Yellow Pages. The respondents noted that if it were not well advertised, it was not going to be effective. Consistency was also mentioned by some respondents, stating that there needed to be consistency with who was representing and supporting them. Having multiple or changing advocates would make the process inaccessible for them.

There was a strong emphasis on making any service accessible for those from different cultural backgrounds also, having translation services as well as advocates from different cultural backgrounds.

Part 5 – Measuring the Success of Individual Advocacy

“Making sure that a service is effective is one of the most important parts of establishing one. We want to know what you think an effective service would look like and do.”

Q 18 Are you aware of an individual advocacy service that exists that works well that we could learn from? (41 answered 7 skipped)

Of the 41 respondents who answered this question, 23 were not aware of any individual advocacy services that could inform the practices of a new service.

The following are the services respondents gave as examples;

- HCCSA X2
- Health Rights and Community Action
- Hospital Chaplains
- Veterans welfare service
- COTA
- ARAS X 2
- SANDS Australia
- Health Consumer Council WA
- Housing Tenancy Advocacy Service
- Aged Care Advocacy Service
- Community Visitor Scheme
- Northern Carers Network
- OPAL
- PMHCN
- Minda
- meals on wheels
- NSW Consumer & Carer Advisory Group
- Cancer Foundation
- Bridges & Pathways
- Fibromyalgia Australia Adelaide
- Victorian Health Centre Advocacy group
- CAHLN CCAG
- NAHLN CCAG

Q 19 What outcomes would show you that an individual advocacy service was effective in supporting you? (41 answered 7 skipped)

There were two common themes from consumer responses, summarised below;

a) *Feeling in control, listened to and more health literate (14 occurrences)*

Respondents felt that an effective advocacy service would support them to take control of their health journey and give them the tools to effectively navigate the health system with confidence. They wanted to feel respected and listened to in their meetings with advocates but also with health professionals, consumers want to ensure they are not humiliated during the process. An effective service would help facilitate these outcomes.

b) *A feeling of satisfaction and resolution of issues (11 occurrences)*

Respondents have stated that a self-reported feeling of satisfaction would be a good measure of an effective service. The issues that the consumers presented to the service with would be resolved or there would be evidence that system or practice changes were in process so that this issue would not arise again.

Respondents also stated that reduced wait-times would be a key indicator of an effective service as would a reduction of time spent worrying about their health in general.

Part 6 – Summary

Q 20 Do you have any additional comments? (27 answered 21 skipped)

The general theme of these responses was one of support and gratitude. Respondents were grateful that this was a service being investigated. They stated that a service such as this was long overdue and that they welcomed it. Respondents also restated the need for support for rural consumers and that country health needed to be considered adequately during any planning.

Q 21 Would you like a copy of the research report sent to you once it is complete? (39 answered 9 skipped)

32 consumers responded yes to this, 8 consumers responded with no.

Q 22 If you answered yes, please provide your email address. (33 answered 15 skipped)

32 consumers requested a copy be emailed to them 1 consumer requested a hard copy be posted to them.

Analysis

Throughout the findings, consumers' strongest message was – yes, an individual advocacy service for health consumers is wanted and needed in South Australia. Consumers expressed some harrowing experiences they endured that, they believe, could have been supported or minimised with the help of an individual advocate. Many stated that they had family and friends who could act in this position at times, but that the complexity of the healthcare system often made it hard for them to navigate through their options and their health journeys feeling empowered and included.

These opinions were echoed in the focus groups held with consumers at CALHN and conversations with healthcare professionals from CHSALHN, CALHN and community organisations SHine SA and MCCSA. The healthcare and community service workers consulted with gave examples of what situations their consumers/clients experience that would be supported by an individual advocate. These also mirrored what was expressed by consumers; giving a voice in situations where a consumer may feel powerless, providing physical support by attending appointments/meetings, supporting underfunded community service organisations with health-specific needs, helping the transition from hospital to community care, providing referrals to appropriate services, assisting consumers in accessing medical appointments that have been delayed.

The most prominent underlying theme was a feeling of voicelessness. By simply providing a trained individual to speak up for a consumer, consumers felt that their experiences would have been better. Consumers want something akin to a trained friend. Someone who can act in place of their loved ones

and carers who, even with their best intentions and love, do not have the skills or professional networks to navigate through the health system.

What would an individual advocacy service look like?

An individual advocacy service in South Australia would be a multi-access service, utilising phone, online services and in-person meetings with consumers. The service would be flexible and accessible, would be considerate of consumers of CALD backgrounds, ATSI consumers, LGBTQI+ consumers and consumers with disabilities. In practice, this accessibility would mean appointments would be flexible and advocates could travel to community locations to meet with consumers and attend appointments if requested. The physical set up would be accessible for people with physical disabilities with open spaces, doors wide enough for wheelchairs with ramps and open accessible spaces, access to disabled toilets and would take on feedback from consumers with disabilities about the physical space. The cost would be minimal or free if possible, consumers along with health professionals and community workers consulted with indicated that cost would be a barrier for access.

Advocates would support consumers in two ways; ongoing case management, issue-based requirement. Both advocacy styles would be goal-based and have a measurable end-point to be determined with the consumer and advocate. Consumers would contact the advocacy service via phone, online or in-person to commence the process, or could be referred from other services. An initial meeting with an advocate would determine whether an ongoing or issue-based service is required. Using a customer relationship management (CRM) system enabled with case management functions, consumers advocacy requirements would be tracked and maintained and allocated to the appropriate advocate.

Advocates would support consumers by; Providing help navigating the health system, providing non-judgmental advice regarding health services, making referrals to other agencies, attending appointments as a third party, assisting with forms, assistance with health-related technology, making phone calls, drafting letters, improving consumers health literacy, help resolving issues with health professionals and organisations and providing support with complaints procedures for unethical practice.

What are the requirements to establish an individual advocacy service?

Adequate funding to support the structure and financial requirements of the service, such as hiring staff, IT infrastructure, office spaces and other resources, will be the most important requirement to establish an individual advocacy service.

Well trained advocates, potentially with a qualification in either health or community services, will be the cornerstone of any effective service. Consumers have noted that having one consistent advocate

throughout their involvement with the service would be beneficial to them. Advocates will need to be culturally proficient and well-versed in disability and accessibility requirements. Advocates with lived experience would also be greatly advantageous to the service.

A dedicated space would be essential, this does not need to be one central office necessarily but an established location or locations where consumers can come and meet with advocates will be necessary. Establishing a phone services outside of the regular 9-5 business hours will be available to make the service more accessible to consumers that work standard business hours. Online services ranging from email to chat services would be used, as well as skype or tele-link services for consumers in rural areas who cannot attend face-to-face meetings in-person.

What are the attributes of an effective individual advocacy service?

An effective service would be accessible, it would be consumer-centred and co-designed with consumers. There would be a high level of consumer involvement throughout the advocacy process and the manner of the advocacy would be driven by the consumer.

An effective service would empower consumers through health literacy promotion and supporting the confidence of consumers. Users of an effective individual advocacy service would feel listened to and in-control of their health. They would have a high level of self-reported satisfaction with both the service and the outcome of their own issues that brought them to the service. An effective service would work with the consumer to set goals and outlines for the advocacy and would set realistic guidelines for what can be achieved.

The service would be accountable, would have clear processes that give consumers an easy to understand outline of what the service was able to offer and what it was not able to offer. The service would also be equipped with good referral processes so that if a consumer cannot be supported by the service, an appropriate alternative can be found or a service that can support the consumer at the same time as the individual advocacy service.

Conclusion

Consumers are calling out for an individual advocacy service in South Australia to help represent their needs and have their voices heard. The findings from this research indicate that consumers have had less than positive health experiences. Some shared distressing stories of health professionals ignoring their needs and feelings and being left humiliated and not in control. Consumers shared the times they had wished an advocate had been available to them and times where they were lucky enough to have a family member, friend or values health professional to advocate on their behalf. The general sentiment and themes from the findings are, consumers want there to be a constant safety net. They don't want some consumers to have advocacy and others to not.

Through the summary of findings and analysis it has been shown that accessibility and cultural awareness are key factors consumers consider to be essential to any effective individual advocacy service. An advocacy service that caters to the needs of all South Australians, not just those with the means and resources to access support.

Overall, the voices of the consumers that participated in this project tell a collective story of a health system with too many winding paths and unsure wandering consumers who want to empower themselves to take their health into their own hands. An individual advocacy service could be that guide for consumers as well as an architect to help better design the health system to make it easier for health consumers to navigate.

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Appendix 2 – Resources and Research Instruments

Short Online Survey

To gain a clearer understanding of consumer needs we are collecting some general information about our respondents. This will help us in understanding the specific needs of a range of consumers. All responses are confidential.

1. Gender

Male

Female

Other (please specify if comfortable)

2. Age

18-25

26-35

36-55

56-75

75+

Under 18

3. Country of Birth

4. Do you identify as Aboriginal or Torres Strait Islander?

5. Suburb of residence

The following questions will provide us with insight regarding your opinion on health advocacy. We want to know if an advocacy service would make health consumers' experience with health better and how we could best design this service.

6. Has there ever been a situation that you, your family or friends, have experienced that could have been improved with the support of a health advocate?

Yes

No

Please feel free to provide more detail if you wish;

7. What services could an advocacy service provide to best support you?

Attending appointments as a third party

Providing help navigating the health system

Providing non-judgmental advice regarding health services

Making referrals to other agencies

Drafting letters

Making phone calls

Assisting with forms

Assistance with health-related technology

Other (please specify)

8. How would you access advocacy services?

phone

online

in-person

Other (please specify)

9. Contact Number:

10. Email Address:

Long Online Survey

1. Gender

Male

Female

Other (please specify if comfortable)

2. Age

18-25

26-35

36-55

56-75

75+

3. Country of Birth

4. Do you identify as Aboriginal or Torres Strait Islander?

Yes

No

5. Suburb of residence

6. What does advocacy mean to you?

7. Is advocacy in healthcare important to you?

Yes

No

8. Can you explain why advocacy is or isn't an important concern for you?

9. Have you used an advocacy service previously?

Yes

No

Other (please specify)

10. Please provide further details regarding why or why not?

The following questions will cover the individualised aspect of advocacy services.

We want to know how an individual advocacy service would best accommodate your specific needs. This may have to do with the type of health concerns you have or the type of support you require.

11. In what situation would an individual healthcare advocacy service help you?

12. What services could an individual advocacy service provide to best support you?

Attending appointments as a third party

Providing help navigating the health system

Providing non-judgmental advice regarding health services

Making referrals to other agencies

Drafting letters

Making phone calls

Assisting with forms

Assistance with health-related technology

Other (please specify)

13. If an individual advocacy service was developed, what do you think should be considered in the design of the service? Please provide some general ideas and comments.

In this section we would like your input on the practical considerations of establishing an individual health advocacy service.

We would like feedback on how you would interact and use the service and what barriers would prevent you from using it. We are collecting data on the ways you would contact an advocate, how you would attend appointments, and barriers / ease of access to services.

14. How would you access advocacy services?

phone

online

in-person

Other (please specify)

15. What are some potential or existing barriers you may have in accessing support, particularly advocacy support, regarding your health?

16. What are some practical considerations an organisation should take into account when setting up an individual advocacy service?

17. How could a health advocacy service be designed to be accessible for you?

Making sure that a service is effective is one of the most important parts of establishing one. We want to know what you think an effective service would look like and do.

18. Are you aware of an individual advocacy service that exists that works well that we could learn from?

19. What outcomes would show you that an individual advocacy service was effective in supporting you?

Thank you for completing our survey. Your feedback is greatly appreciated!

For more information or if you would like to get in touch with HCA regarding this project please email bbarrett@hcasa.asn.au or call 8231 4169

20. Do you have any additional comments?

21. Would you like a copy of the research report sent to you once it is complete?

Yes

No

Focus Group Questions and Responses

	Group 1 Responses	Group 2 Responses
<p>Question 1 In what circumstances do you believe an individual advocacy program could help you? (past, present or future)</p>	<ul style="list-style-type: none"> • Consumers from other cultures, having someone that can support would make a big difference • When they don't have family or friends OR when they don't want their family or friends involved • So they have an impartial person • If you are scared of being judged • A person might be so stressed and won't be able to retain info especially when getting bad news • Can ask questions when they're (the consumer) is unable to do so • When your own family will be too emotionally involved • When you've had a bad experience and you need a voice and representation • Resolving negative experiences • Encourage health involvement 	<ul style="list-style-type: none"> • To help them understand because of health literacy and jargon • Help to understand medical stuff • Literacy is assumed for things and so help is needed for this (and with jargon) • Needs to be broad there are different sized issues • Advocate get more information • Link to other advocacy services as well (e.g brain injury) • Negotiate getting appointments (when on waiting lists)
<p>Question 2 How would you access an individual advocacy service (e.g. via phone, in-person, online etc) and what accessibility requirements would we need to consider for your health needs?</p>	<ul style="list-style-type: none"> • Email • Social media (online chat or groups on Facebook) • Having a number of sites – in major suburban medical clinics • Phone calls with a call back service where you can call and make an appointment to be called back • Pamphlets at health services (so that people know about the service) • Drop-in places within services (wellness centre) • In-person 	<ul style="list-style-type: none"> • Needs to be publicised • Via the phone • Other professionals you work with and can access on your behalf • Drop-in service • Via schools • Connect to service around the state (councils, libraries etc)

<p>Question 3 How would an individual advocacy service support you? (attending appointments, making phone calls, helping with forms etc)</p>	<ul style="list-style-type: none"> • Attend appointments • Providing interpreters (advocates that can also be interpreters) • Asking questions • Help with filling in forms (within legal reason – can't sign for consumers) • Follow ups with the health consumer to make sure they understand what they were told and what their options are • Clear communication • Knowledge of networks to be able to make referrals • Standing up for rights and knowing the legal rights of consumers • (the advocates should have formal training) 	<ul style="list-style-type: none"> • Translate meetings when advocacy is required • Strategies for getting to appointments (plan journeys, organise volunteers to help (driver)?)
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Consumer Fact Sheet – Double Sided A4 Sheet



Research into the need for an Individual Advocacy Service

Consumer Fact Sheet

Health Consumers Alliance of SA Inc (HCA) is seeking input from health consumers and professionals across South Australia about establishing an individual advocacy service. This fact sheet covers the why, what and how of our information gathering.

› Consumer-centred care

HCA's vision is consumers at the centre of health in South Australia. Advocacy is a cornerstone of consumer-centred care, and HCA believes that an individual advocacy service would help South Australian health consumers in receiving quality, safe, consumer-centred care.

› Current Advocacy Services

A review of existing advocacy services in South Australia reveals that there is little access to individual advocacy services. If a health consumer needed support in arranging appointments, or would like someone to advocate for them when they are not receiving the service they require, there are few organisations that can help. Through our research with consumers and health professionals, we aim to gather feedback about what an individual advocacy service could look like.

› Gathering Feedback

HCA will consult with consumers through focus groups, meetings and individual interviews. Throughout this process we will gather feedback about how an individual advocacy service may help and what considerations should be examined before one is established. By engaging consumers from the start, any service developed will be consumer driven and centred.

To achieve a broad view of the needs of consumers, HCA will also be contacting health professionals for their feedback. HCA wants to know what professionals think an individual advocacy service could look like, as well as why and how it may be helpful to the consumers they work with.

› Representation

To make the information gathered as representative as possible, HCA will aim to talk with a range of people from across South Australia. This will include consumers and professionals from Local Health Networks across the state; a diversity of ages, genders, cultures; and meaningful representation from Aboriginal and Torres Strait Islander consumers.

➤ Reporting and Use of Information

The information and feedback gathered at this stage will feed into a report. It will be used to provide feedback to policy makers and key funding bodies to consider how an individual advocacy service would support South Australian consumers. An individual advocacy service was HCA's number one call to action in our 2018 State Election Platform.

➤ Confidentiality

Any and all recordings of interviews and focus groups will be stored safely and confidentially. No personal information, including names, contact details or personal experiences, will be published with any identifying detail. Participants can request a copy of their responses at any time.

Conclusion:

HCA encourages health consumers to provide feedback regarding the need for an individual advocacy service in South Australia.

This feedback and all connected research will be gathered ethically and within a consumer-centred framework. All consumers involved are able to access information regarding the project at any time, by using the contact details below.

Contact information:

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