Consumer Perspectives

Ageing Residents' Access to Health Services in Gippsland

Level 1, 255 Bourke Street, Melbourne Victoria 3000

Phone (03) 8676 9050

www.healthissuescentre.org.au

info@healthissuescentre.org.au

Inc. Reg No: A14282J

ABN: 96 599 565 577

Executive Summary

Health Issues Centre (HIC) was commissioned by Gippsland Primary Health Network to conduct *intercept conversations*© using a combination of digital tools and in-person interviews to gather sentiments about the barriers to health and social care service access by people aged over 65 years. The consultations explored the views of residents in the Gippsland region, comprising the six Local Government Areas: Bass Coast, Baw Baw, South Gippsland, Wellington, Latrobe, and East Gippsland.

Summary of key findings

Loss of capacity and incremental decline - The loss of both physical and cognitive capacity was a major concern for people aged over 65. Many people indicated the impact their declining health and capacity had on their personal identity and emotional wellbeing.

Identity - A number of people indicated a struggle to maintain their own identity as they age. This was commonly linked to the realisation of their diminishing physical and mental capacity. Negative interactions with health services and other environments exacerbated rather than addressed this problem.

Empathy and validation - Many respondents were scathing in reporting personal experiences where they believed they had been patronised or treated as unreliable witnesses to their own lived experience. Health and social service providers' inability to demonstrate empathy and validation was a key barrier to health and social care.

Communication of clinical information - A number of consumers including those diagnosed with dementia as well as those with high cognitive function, were concerned about doctors not taking the time to explain their diagnoses, reasons for treatments and treatment instructions.

Gender - In some instances, the 'traditional' role older women undertake as the nominated carer of family members, and 'housewife' responsible for upkeep of the home, extends to their responsibility to access home care and health services for themselves and on behalf of their husbands.

Access logistics - A number of logistical barriers were frequently identified as major inhibitors to accessing health and social care services in rural areas. These barriers included: long waiting times for GP and other clinical appointments; cost of services and travel; distance and transport to and from services; reduced access to technology including phones and internet; and dependence on temporary accommodation nearby to services.

Carer support - Responses from adult children of ageing parents highlighted the burden of responsibility on families to provide care for people in advanced stages of health decline and dependency.

Spiral of Decline & Withdrawal – HIC identifies six stages of declining capacity and low self-esteem, reinforced by interactions with health services that fail to empathise and validate experiences of ageing, leading to health crisis and further loss of capacity. The Spiral indicates critical intervention points for health and social service providers.

Summary of recommendations

Identity
- Safeguard personal identity, self-esteem and relevance to improve quality of life
- Arrest decline by assisting older people to reinvent themselves as their life-long identity diminishes
- Design and deliver human-centered programs to shape identity within the ageing process

Gender
- Consider the importance of gender identity to communities in rural and diverse cultural and religious settings
- Target communications about prevention to women as well as men, even for male-specific conditions

Clinical empathy and communication
- Design and deliver human-centered training programs for clinicians and service providers to restore consumer self-esteem and support independent ageing
- Educate health and social service providers about their key role to intercept the Spiral of Decline and Withdrawal, and the critical opportunities for intervention
- Reshape primary care as a means to maintain independence and assist consumers to age independently and safely at home

Withdrawn consumers – clinical engagement and monitoring
- Facilitate clinical behavioural change by providing consumers with regular, face-to-face clinical consultations both in healthcare facilities and consumers' homes, and dedicating sufficient time to explain conditions, diagnoses, treatment, service and care options
- Design long-term grass roots engagement strategies to restore withdrawn consumers' trust in the health system
- Design and deliver clinician-led information sessions on topics relevant to ageing, local aged care services, and participation in community groups and activities
- Design and deliver a strategy to address the gap in family and medical history records
- Introduce the role of Systems Navigator to provide personalised care, follow-up and referrals for consumers

Access logistics
- Apply a 'minimally disruptive medicine' approach to place the consumer at the centre of health and social care decision making
- Increase transport to and from health and social care services and low-cost accommodation close to services.
- Educate health and social care providers about the rural consumer experience of isolation and distance from services

Carer support
- Promote existing carer support services using a variety of communication methods including online, hardcopy materials, and word of mouth through existing community locations, groups and activities
- Design and deliver self-facilitated carer support groups using digital tools such as social media and video conferencing to connect carers in rural and geographically isolated areas

Contents

Introduction

The Health Issues Centre (HIC) specialises in ensuring the consumer perspective and experience informs improvements to health care systems. For the past three years, HIC has focused on the challenge of broadening consumer involvement beyond the more formal roles played by Consumer Representatives. This recognises that most people do not have the skills, inclination, availability and/or self-confidence to participate in formal processes but nevertheless are entitled to the opportunity to express their sentiments and have those views represented at the point of decision-making.

Gippsland Primary Health Network (GPHN) enlisted HIC to engage with consumers aged over 65, and experiencing 'declining capacity' and 'dependency', to explore a reported decline in access to health and social care services. HIC was invited to explore alternative consultation methods that would effectively contribute the consumer perspective.

Method

Underpinning HIC methodology is a sociological premise of ageing. Ageing is a social and biological construct rather than a medical 'problem'. Therefore, HIC begins by examining people's lives and progresses to consider how their interaction with the clinical world is shaped by their social context. The strength of this research approach is that HIC views the world through the social lens of the consumer, rather than through a medical or institutional lens.

HIC conducted *intercept conversations*© using a mixed-methods approach of digital tools and in-person interviews to gather sentiments about the barriers to health and social care service access by people aged over 65 years old in the Gippsland region. *Intercept conversations*© involve meeting people as they go about their daily lives. To achieve this, HIC cast a broad net through digital engagement with consumers, which was then narrowed to target specific groups, especially those who were largely unrepresented in initial consultations.

Respondents were living and/or working in Gippsland, and included people that reflect primary, secondary and tertiary levels of experience:

- primary - males and females aged over 65;

- secondary - male and female adult children of people aged over 65; and

- tertiary - health, social care and community professionals working with people aged over 65.

Digital Tools

HIC used Facebook to engage with consumers across Gippsland. A Facebook page was established to support the conversation and posts were promoted on other local Facebook pages. Six questions were posed to targeted groups, encouraging people to engage in the

social media conversation, and share or react to (for example 'like') the post. Refer to the Appendix for an explanation of HIC's Facebook method and examples of posts.

In addition, two de-identified online surveys were created using Survey Monkey. Both surveys were promoted via the Facebook page. This tool allowed for respondents' data to remain private and to provide more detail about their experiences.

For participants interested in finding out more about local aged care services, the details of My Aged Care were provided.

Interviews

Interviews were conducted in person and over the phone with both Gippsland residents aged over 65, and with health, social care and community professionals working with people aged over 65 across the Gippsland region.

All the interviews were voluntary and informal in structure. They explored the day-to-day lives of respondents and their experiences of accessing local health and social care services. The research methodology developed by HIC relies on initiating open-ended conversations where participants can define "what matters most".

With permission, a number of the interviews and participant photographs were recorded and hardcopy notes taken as a record of each interview.

For participants interested in finding out more about local aged care services, My Aged Care and Council of the Ageing brochures were provided. They also had the option to provide their email address and stay informed about the outcomes of this research.

In order to encapsulate the differentiated experiences, needs and challenges of 'declining capacity' and 'dependency' groups, HIC broadened the interview process to include the perspectives of other key stakeholders who have contact with older people in these two groups. This included professionals working in the fields of social work, bush nursing, community services, aged care mental health, and rural financial counselling.

Limitations of consultations

The numbers of respondents did not allow for an analysis by Local Government Area (LGA).

While HIC consulted with some consumers from vulnerable groups including Aboriginal Elders, and consumers diagnosed with dementia, the sample of respondents is relatively small and does not present a complete picture of these groups' diverse needs. The Aboriginal Elders consulted as part of this project were highly engaged with health and social care services and well supported by a committed social worker. As a result, they did not reflect the withdrawn groups that HIC aimed to engage with.

Further engagement of consumers could be conducted to include broader representation from vulnerable and marginalised groups who are withdrawn from the health system. This should include larger numbers of people diagnosed with early stages of dementia and

Aboriginal and Torres Strait Islanders, people with mental health conditions, people with drug and alcohol dependency, homeless people, CALD communities, and refugees.

Further broad engagement of consumers, particularly vulnerable groups and males aged over 65, using digital tools and in-person interviews could be conducted to gain more perspectives and validate the findings of this report.

Learnings - engaging with 'hard to reach' cohorts

Efforts were made to consult with older people who are withdrawn from health and social care services by approaching consumers in public places such as pubs and markets. By their very nature this group proved difficult to reach, as people who had withdrawn from health and social services were likely to concurrently withdraw from attending community meeting places and social activities. As a result, withdrawn consumers with 'dependency' and 'high dependency' needs were largely represented in this research by respondents who had previously withdrawn from services and had since re-engaged. The benefit of these interviews was the inclusion of consumers' reflections on the 'before' and 'after' of withdrawal from services, and their reasons for both withdrawal and re-engagement.

HIC conducted a number of consultations with professionals to encapsulate the views of withdrawn consumers in 'dependency' and 'high dependency' categories. This method proved to be effective, and resulted in identification of a number of themes that had not yet emerged during consumer consultations. These themes include gender, ethnicity of clinicians, rushed appointments, and the role of a 'systems navigator'.

Results and Discussion

Please note: All comments in this report remain unedited to maintain the authentic voice of the consumer. All responses have been de-identified and names have been changed.

Age
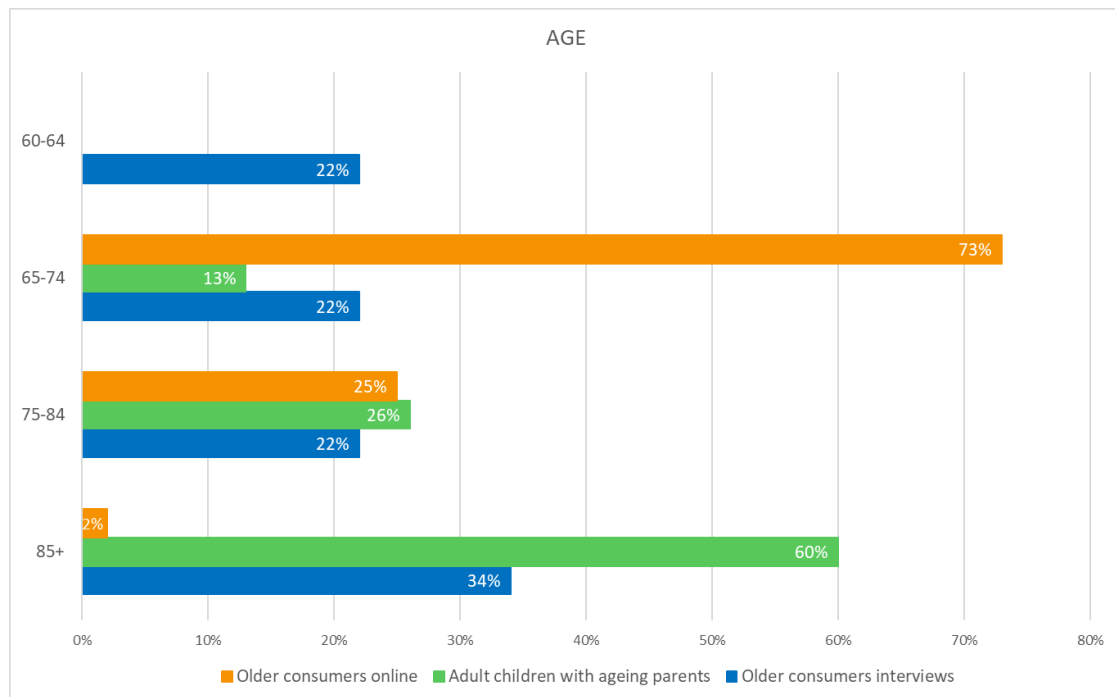
The age breadth of participants varied across the two online surveys with 98% of participants in Survey 1 under the age of 85. Contrastingly, in Survey 2, 60% of adult children surveyed had parents aged 85 years and over. A factor affecting these results may be smaller numbers of Facebook users over the age of 85.

Applying a mixed-methods approach to engage with both groups online and face-to-face was an effective way to obtain a broad range of experiences of people with an even spread across age groups and at various stages of declining capacity.

Gender
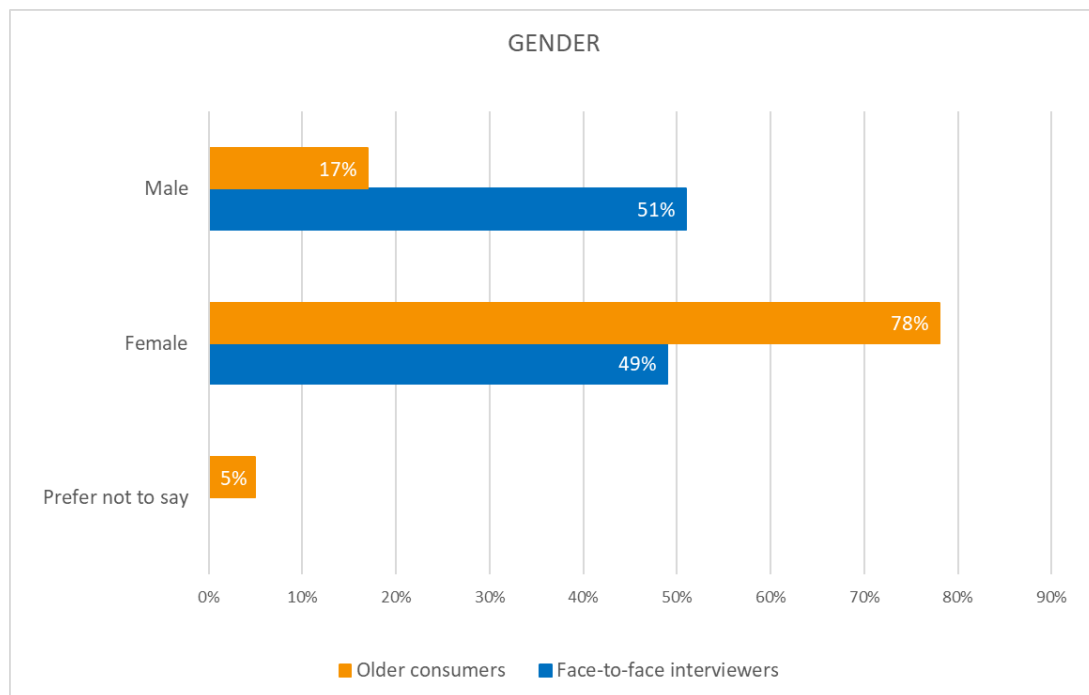
A limitation of Survey 1 is the lack of gender diversity in the respondents; 78% of the respondents were female, while only 17% were male. HIC addressed this imbalance in interviews with consumers and professionals to increase the number of male voices.

The high level of female engagement in Survey 1 corresponds with the interview findings that females are more engaged with and communicative about their own health and services overall, even accessing them on behalf of male spouses and relatives.

The gender of respondents' parents was not specified in Survey 2.

Males comprised 52% of total face-to-face interviewees, while 48% of responses were from female interviewees. Specific efforts were made to incorporate the views of male voices in the interview process such as attending men's activity groups, to counteract the largely female pool of online survey respondents.

Capturing 'declining capacity' and 'dependency' groups

The use of social media and digital tools enabled HIC to connect with people reflective of a broad range of ages, declining stages of health, and people with hearing impairment. The inclusion of online consultations with adult children provided additional valuable insights into their own experiences of supporting parents as they age, and in particular people aged over 85 experiencing high dependency on carers and services.

Offering the option of participating in face-to-face interviews enabled respondents without Internet access and reduced cognitive function to participate in this research. Locations for interviews were selected to prioritise the number of respondents experiencing the early stages of dementia, declining capacity and dependency on carers and services. The decision

to include interviews with professionals in this research also enabled HIC to incorporate the voices of people in the 'declining capacity' and 'dependency' stages of physical and mental health.

Survey completion rates

The online Survey Monkey questionnaires were completed by 102 people in total.

Survey 1: The Challenges and Opportunities of Ageing survey was completed by 64 people aged over 65.

In order to encapsulate the differentiated experiences, needs and challenges of 'declining capacity' and 'dependency' groups, HIC broadened the survey process to include Survey 2 which gathered the views of adult children of ageing parents.

Survey 2: Ageing Parents survey was completed by 38 adult children of people aged over 65.

Number of interviews with consumers

In total, 23 face-to-face interviews were conducted with Gippsland residents over the age of 65. Each interview took approximately 20-40 minutes per person.

Interviews were undertaken in a variety of settings:

- Loch Winter Market, South Gippsland
- Buchan Bush Nursing Centre, East Gippsland
- Morwell Koorie Elders Activity Group, Latrobe
- Traralgon Aged & Disability Services Community Activities, Latrobe

A holistic approach was applied to these conversations with consumers. They were flexible in structure, and included questions such as:

- How would you describe your health?
- Where would you go if you got sick tomorrow and you weren't feeling well?
- What health care services do you know of in your local area?
- Do you have to travel far for health services?
- What makes a 'good' doctor?
- What would you change about the health and care services in your area?
- Why do you think some people don't go to the doctor?
- Why do you think you waited so long before getting help?
- Do you rely on your wife to find out about health services or call the doctor for you?

Interviews with professionals

Phone interviews were conducted with nine professionals working with people aged over 65. Interviewees work in the fields of nursing, RSL welfare, aged mental health services, dementia support services, community services, and rural financial counseling across the 6 Local Government Areas of the Gippsland region.

Overview of survey findings

Question 1

Survey 1: The things **I** find most challenging about getting older are:

Survey 2: The things **my parents** find most challenging about getting older are:

Category	Survey 1: Older consumers	Survey 2: Adult children with ageing parents
Maintaining contact with friends and family	17%	42%
Making ends meet	25%	32%
Looking after myself and/or their spouse	16%	61%
Not being able to do simple things	28%	58%
Doing things that make me happy	14%	47%
other	28%	29%

Question 2

Survey 1: What concerns **you** most about ageing?

Survey 2: As they age, I am most concerned about **my parent(s)**:

Category	Survey 1: Older consumers	Survey 2: Adult children with ageing parents
Losing independence	41%	18%
Becoming a burden	23%	18%
Losing physical capacity	41%	63%
Losing mental capacity	37%	60%
pain and suffering	17%	66%
becoming irrelevant	17%	
Becoming lonely		60%
other	8%	8%

Question 3

Survey 1: Three (or more) things that would make **my** life better are:

Survey 2: Some things that would make **my parent(s)** day-to-day life better are:

Category	Survey 1: Older consumers	Survey 2: Adult children with ageing parents
More contact with my Family	25%	47%
Money	45%	24%
Better healthcare assistance	23%	58%
Good company	22%	34%
A new hobby	11%	13%
Help with going out	12%	53%
Home help	20%	55%
other	20%	8%

Survey 1: The Challenges & Opportunities of Ageing

Survey 1 sought to better understand the challenges and concerns associated with ageing by asking for personal experiences directly from respondents aged over 65.

Question 1

HIC began the survey with a simple proposition asking ageing consumers what they find most challenging about getting older. Respondents were provided with five pre-determined categories plus the flexibility to nominate additional priorities. Making ends meet (25%), and not being able to do simple things (26%) were selected as most challenging for respondents as they age.

18 participants nominated additional priorities under the "other" category. Out of the 18 open responses, two major challenges were most prevalent: 10 people commented on loss of capacity and physical limitations, in particular memory loss, and 6 people commented on being patronised and ignored as an older person. Other comments indicated the responsibility of looking after ageing relatives, and the emotional impact of friends dying as most challenging.

Question 2

Loss of capacity was reiterated as a major concern in question 2, where respondents were asked to nominate what concerns them most about ageing. Losing their independence, and losing physical capacity were the two predominant concerns (each 41%), followed by 37% of people reporting losing mental capacity as a major concern. Some people nominated 'all of the above' and elaborated on their loss of physical capacity in the open comment box.

Question 3

In comparison to Survey 2, where adult children placed emphasis on logistical solutions to their parents loss of capacity such as healthcare assistance and home help, older people's responses prioritised money followed by social interventions such as spending more contact time with family (25%) to improve their lives. While better healthcare assistance was also important to older people (23%), good company gained almost the same number of responses (23%), which may indicate a prevalence of loneliness and lack of social support.

Survey 2: Ageing Parents

Survey 2 posed the same questions to the adult children of ageing parents; to gain candid insight into the concerns and challenges faced by people over 65. This enabled for 'proxy' respondents to communicate on behalf of a parent in more developed stages of decline, including both 'declining capacity' and 'dependency' groups, who may not have been able to complete the survey themselves, or may be in denial about their declining state of health.

Question 1

Corresponding to Survey 1, the Ageing Parents questionnaire began with the same question about the challenges of ageing, but requested the perspective of the adult children of ageing parents. It offered the same six responses as the first question of Survey 1.

Completion of everyday tasks and self-care were the major challenges that adult children believed their parents face, with 61% selecting 'looking after themselves and/or spouse' and 58% selecting 'not being able to do simple things' as the most challenging things their parents face as they grow older. This was followed closely by the challenges of maintaining their emotional wellbeing and social relationships with 47% responding that 'doing things that make them happy' and 42% responding that 'maintaining contact with friends and family' were most challenging.

Question 2

The next question offered some of the same selections as the second question of Survey 1 when asking about adult children's concerns as their parents age, and included the additional selections 'becoming lonely' and 'becoming depressed'.

The majority of people (66%) selected their parents' loss of independence and experiencing pain and suffering as the greatest concerns as their parents age. While loss of independence was also a top concern for older people in Survey 1 (41%), pain and suffering was one of the lesser concerns for older people themselves (17%).

The majority of responses were selected by over 60% of respondents, except for 'becoming a burden' which was only selected by 18% of respondents. In comparison, over a fifth of older people in Survey 1 selected this as their main concern. These results reflect the differing familial roles of respondents. Older people may feel guilty for relying on adult children for care and support, and see it as a major concern. Whereas adult children may not see their older parents as being a burden, either because they are happy to provide care and support, or they are not responsible for doing so.

Question 3

This question offered the same selections as the third question of Survey 1. Notably, the majority (22%) of responses indicated that better healthcare assistance would make respondents' parents' lives better. This was followed closely by other care and social services including home help (21%) and help with going out (20%).

'Better' healthcare assistance could refer to both access to existing services and provision of higher quality services. Open comments in response to the question provided insight into healthcare concerns. These included parents failing to receive services commensurate with their level of capacity, and the need for healthcare providers who take time to talk with their parents and identify when "things aren't right but the parent says all the right things". In comparison to Survey 1, where the majority of older people selected money as the thing that would most improve their life (45%), this was the second least nominated response by adult children.

Question 4 (Open response)

Survey 2 asked the direct question: 'What barriers do your parents face when accessing health-care services where they live?'

This question provided an open comment response only. All 40 participants responded to the question, and their responses can be categorised into the predominant themes of: waiting times, cost, distance and transport, and clinical care. 20 of the responses indicated distance and transport issues as the major barrier their parents face when accessing health services.

Please see Appendix Figure 2.5 for a comprehensive list of responses received to this survey question.

Key Findings

Key Finding 1: Loss of capacity and incremental decline

The loss of both physical and cognitive capacity was a major concern for people aged over 65, who reported 'not being able to do simple things' as the predominant challenge as they age, with particular reference to memory loss. When asked to elaborate on what concerns them most about ageing, they responded that 'losing my independence' and 'losing physical capacity' were the predominant concerns, followed closely by 'losing mental capacity'.

The declining stages of health that people reported to be experiencing were not in most cases triggered by one single health-related crisis or incident. Instead, people described an incremental decrease in their ability to accomplish day-to-day tasks. In the majority of responses, the decline began with small changes such as taking more time to complete chores and tasks, participating in less physical activity, and problems remembering basic information such as where they parked their car.

> *I can no longer take a holiday, or go and visit my family, I can't even see a movie any more unless I can get a cd. I have 4 children, but only see one, my grandchildren + their family's live interstate, at the top end of Australia, and I have to wait until they can come.* (Ageing person)
>
> *It is frustrating for me not being able to walk distances and do simple things like walking the dog.* (Ageing person)
>
> *My memory is not as good as it used to be. I deal with this by making notes. Physically I can't do as much as I used to without needing a break.* (Ageing person)
>
> *Trying to remember where I parked my car at the supermarket.* (Ageing person)

Many people indicated the impact their declining health and capacity had on their personal identity and emotional wellbeing. As one person stated, their main concern is "maintaining my identity as an individual, not being put into a box as an 'elderly citizen'". This concern appeared to be equally important to those experiencing changes in the early stages of decline, as well as those in the later stages of dependency.

> *The depression changed my life a lot. I shut myself up which seems to be typical. I withdrew. I lost interest. I couldn't be bothered watching TV. I was quite a talented pianist. I stopped playing piano. I avoided people. I couldn't become active to do anything very much, such as washing dishes. Everything was sort of left, as though I'd come to a standstill. And sometime after I sat at the piano, and with some music. Something went click in my head, and I was not able to link the music to moving my hands on the keyboard. I'd lost all ability to read the music and to play, and I was an advanced pianist. I can't listen to music like I used to.* (Ageing Person)

Concerns regarding declining capacity were reflected by the majority of adult children of ageing parents, who stated that their parents find 'looking after themselves and/or their spouse' the most challenging aspect of getting older, followed by 'not being able to do simple things'.

While older people were most concerned with 'not being able to do simple things', they were far less likely to select 'looking after myself', and instead prioritised financial concerns under the selection 'making ends meet'. This may refer to a denial of their own health deterioration, and to the fact that they were younger than the majority of parents referred to in Survey 2, who were aged over 85 and in more advanced stages of health decline, according to their children.

The adult children of ageing parents were key to obtaining candid responses regarding older people's denial of their diminishing capacity and refusal to obtain support. In response to questions about their main concerns as their parents age, a number of respondents in this group identified their parents' health concerns as inseparable from their parents' denial, loss of independence, and identity changed by their declining capacity. For many, this denial of declining health also manifested in an unwillingness to seek out or accept any form of support from day-to-day help around the home, to government pensions for injured veterans.

Acknowledging they need help. (Adult child of ageing parent)

Finding things are more challenging and not saying anything. (Adult child of ageing parent)

To accept the help that is available to him/them. (Adult child of ageing parent)

Key Finding 2: Identity

A number of people indicated a struggle to maintain their own identity as they age. This was commonly linked to the realisation of their diminishing physical and mental capacity. Negative interactions with health services and other environments exacerbated rather than addressed this problem. In turn, participants reflected a sense of loss and low self-esteem, which manifested in some cases in social isolation and depression, and frequently in complete withdrawal from clinical services. As a result of withdrawal from primary and preventative services, and further unmonitored health deterioration, the dependency on crisis services is critical.

Some people have personal problems. No longer really active people, and possibly don't have anybody to take them to places, and not fit enough to do it themselves, that might keep them housebound. And some people just I think get to a point where they're not well enough and they're tired and they don't want to participate anymore. That happens too. (Ageing person)

In response to Survey 1, 45% of older people identified that money would most improve their lives while 23% selected better healthcare assistance. Some participants elaborated on this by demonstrating the links between the cost of healthcare, financial insecurity and loss of identity. For some ageing consumers, paying incidental costs associated with attending appointments such as taxis, car maintenance to travel long distances if they can still drive, and parking fees at the hospital, had the cumulative effect of both inhibiting access to

services and absorbing funds available for crucial socialising and leisure activities. Another adult child commented that because their parent no longer drives, they are reliant on others for transport to access health services, which undermines their identity and reinforces their loss of independence. This reflection captures the critical links between diminishing capacity, resulting low self-esteem and their effect on a person's identity as they age.

> *I have a taxi card, but I can't use it very often as I can't afford the amount I have to pay with each trip, I use it for emergency's such as Doctors or specialist, but how Id love to be able to visit a friend now and again without worry about how Im going to pay the fare. My trip to the specialist one way cost $72 plus dollars, then I have to pay half and have the same coming home, so going on a trip to visit family or friends is well out of the question when you only have the pension to survive on, and no super to back up with.* (Ageing person)

Key Finding 3: Empathy and validation

Many respondents to the surveys, interviews and Facebook comments nominated what they saw as significant inadequacies in existing services. In particular, a large number were scathing in reporting personal experiences where they believed they had been invalidated, patronised, belittled or treated as unreliable witnesses to their own lived experience.

> *Some doctors just don't want to listen. You're just there for a reason and let's deal with that and they don't want to listen past what your complaint is. This particular doctor will, and it makes you feel better if they give you that little more time to discuss things and I think that leaves you feeling a bit more like you're a person, not a nothing.* (Ageing person)
>
> *She was interviewing me from a manual and expected yes or no answers, and the answers needed qualification, they couldn't be just yes or no…She was going by the book and life is not by a book, everybody's different. She asked me a week after I'd been diagnosed…if breast cancer had changed my life. I hadn't even had time to process it…she just needed a yes or no.* (Ageing person)

The Facebook post comments in response to the question 'do people treat you differently because you're old?' also revealed the frustrating experience of age discrimination, and importance of treating people as individuals with different needs based on their capacity, rather than their age group alone.

> *Not being listened to. Being dismissed as being irrelevant.* (Ageing person)

> *Being invisible and being talked down to.* (Ageing person)

> *…Then there are others that treat us as if we only have half a brain, like as if we are stupid, then there are others that can't even bother to ask if they can help us.* (Ageing person)

> *…they wud knock u over than walk around u.* (Ageing person)

Many interviewees described the most important feature of a good doctor as one who listens and hears what they have to say. Crucially, health and social service providers' inability to demonstrate empathy and validation was a key barrier to accessing health and social care. For some people, negative experiences with clinical staff and services emphasised the compounding effects of loss of self-esteem, emotional wellbeing, and personal identity.

> *Well, my husband has…got a kidney tumour and that had increased in size, but when the nurse said 'oh it's only increased 12mm' well, I thought that might not be a big amount to you, but it is to us… it's not good news, like she said, and I knew she didn't really care. That really annoyed me.* (Ageing person)

> *Michael lives on his own, although he has a son nearby…He calls the ambulance officers quite frequently and refers to the time he called them on two consecutive days only to be told he was okay and stay-at-home. On the third day he was admitted to hospital. The doctor said he just had emphysema but ultimately it turned out to be pneumonia and he and the group observed that there is sometimes the general submissiveness of all old people presenting themselves, and the health professionals just dismiss them as being old.* (Ageing person)

Key Finding 4: Communication of Clinical Information

A number of consumers were concerned about doctors not taking the time to explain their diagnoses or reasons for treatments and treatment instructions. According to professionals, in some cases, this had the compound effect with loss of self-esteem, to result in a complete withdrawal from clinical services, and in some circumstances led to critical incidents. One professional reported on a client who had been diagnosed with thrush and given pessaries as treatment. Without understanding how they should be properly administered, the client had taken them orally, causing potential damage to her oesophagus.

While this was particularly critical in the context of people with hearing impairment, reduced cognitive function, and those in the early stages of dementia, some respondents who exhibited high cognitive function during interviews expressed that they did not know why they had been prescribed certain medications. As a result, they had altered the

recommended dosage and frequency, and for one respondent, this had led to hospitalisation.

[Doctors] need a written set of instructions for seeing an older person, or a means of verifying that they understood what the doctor said. So the doctor is also covered too. For people with cognitive impairment, some people have poor memory and if you give them a written set of instructions, they're fine as long as it's legible and not some scribble by the doctor's hand. Then they're far more likely to follow it. (Professional)

You could have a document called 'my doctor's visit' with the date, diagnosis, outcome, treatment. Some template could be used for the doctor in the right size font and they could print it out in doctor's surgery. Approach it from the level of understanding of the client. (Professional)

Professionals also commented on the perceived threat to independence, and a lack of understanding about conditions such as dementia, as major factors in older people's reluctance to access care. This was something they believed to be resolvable by taking time to explain conditions, services and care options while face-to-face with consumers. As one professional stated, "People around here are more receptive to face-to-face, trust is really important". Another professional pointed out the need for public health messaging about primary care as a way to help people maintain their independence, not remove it, so they can age safely at home for as long as possible.

Just the word 'respite' is so confusing for older people. They think it means going to an aged care facility and immediately think it means they have to give up their home and money. It's worth discussing this face-to-face, when we do it takes a huge amount of effort to build trust and explain that respite isn't the same as full time aged care, it would just give their carer a break. (Professional)

There is a stigma [associated with dementia]. People are worried about being judged for it, nihilism. They also think "oh well, there's no cure no tablet to fix it". There's a lack of awareness. GPs and nurses are not particularly good at identifying it, or taking action if they even get a diagnosis. There are people that never receive a diagnosis. Doctors and nurses aren't dementia-literate; they need help with early identifying. (Professional)

Another key issue identified during interviews with professionals were problems communicating and establishing trust with doctors whose first language is not English. While overall most professionals noted that there are communication problems due to language barriers, others also confirmed that when a clinician demonstrates empathy and takes the time to listen to consumers' stories "they feel like they're being heard".

> *This is not a multicultural area, it's rural and the doctors are different ethnicities. Older people struggle to hear their accents…Lots of older people say 'Couldn't understand a work they said so I just left it', and we're then called when it hits a crisis.* (Professional)

> *… I will say if you're slightly hard of hearing and you can't hear what he's saying and the doctor has an accent, you'll leave that consultation instead of speaking out for yourself. I know of lots of people who have told them they've understood what the doctor said but they didn't. I hear that all the time. Every doctor we get in this area is a bonus, but there are difficulties with communication.* (Professional)

> *… If the doctor can display empathy, understanding, reassurance and good rapport with that person, it should work. [One doctor] had good English, not great, but he was very engaging, clients just love him. They'll sit there and tell him their story. They feel like they're being heard, he takes the time to explain things to them. If it's not right, you have to re-explain to the patient. It's more to do with manner than racism.* (Professional)

Key Finding 5: Gender

In response to questions specifically concerning barriers faced by ageing male consumers, professionals introduced the key issue of traditional gender roles taken on by older people living in typically conservative farming and rural communities. In some instances, the 'traditional' role older women undertake as the nominated carer of family members, and 'housewife' responsible for upkeep of the home, extends to their responsibility to access home care and health services for themselves, and on behalf of their husbands.

> *Home care services are always accessed by women in a female name, because that's the traditional role of the woman, to look after the house, even if it's the male who needs more care around the home.* (Professional)

> *I'd say 40% of cases are women coming forward for their husbands, and partners. Men wait to for things to get worse before they actually do something. Females are more likely to stop it before it happens.* (Professional)

> *Yes, there are people saying they're depressed and struggling. We have a home and hospital visit program, for someone who's lost their wife, women seem to have family networks, but for men they feel exposed because it's not normal for the woman to go first.* (Professional)

Male consumers reaffirmed this observation by acknowledging their own hesitance to engage with services themselves. Some openly stated that it is the traditional role of the woman to make contact with doctors and home help.

Men around here with the farming community might be seen as weaker if they access care, they're stoic, lived all their lives here and their parents never asked for help, so wouldn't see a doctor unless their leg fell off. (Professional)

Farming affects [men's] income and that brings mental health issues. Usually what we see is that physical sickness gets them down, and that affects their decision-making and financial decision-making. It could also affect their healthcare decision-making. They put their head in the sand. (Professional)

Men don't think they qualify or don't know about the care. They're too proud. Sometimes people keep going for as long as they can, not realising it's getting worse and worse. It comes through as a mental health condition, even though it might have started as something that could have been treated by a GP. (Professional)

Both consumers and professionals noted that men rely on their wives for societal inclusion in local communities. It was further identified that those who had lost their wives were suffering from social isolation, which in turn affected their mental health.

My husband doesn't like anyone else caring for him. He's got depression, had it for years. He calls it the 'black dog' and says it's come to visit so I know. After years I know what to look for, and he lets me know he needs to be left alone. (Ageing person)

I'm a loner at times. I don't like being around older people. I see them when they're together and I don't think it's good. (Ageing person)

It came on suddenly, I was in an awful state. Despair, unhappy, crying, lost. Wanting to get back to what I was doing. Couldn't. The university retired me…It was a very quiet lonely life. Then I was in the hospital for three weeks with the hip operation. People came to me from Latrobe City Council to check me out, help, offer assistance. This area group came along, a group of people with similar age and experiences. I never knew about it before. I've only got a nephew, no one else. I put off coming here, and then I thought I'd try and see, and it was the best thing I ever did. It was magnificent. I didn't know what to make of it at first, I kept very quiet… I've come back from all those years, I've come out of my horrible mess, but I've come alive again. (Ageing person)

For some male consumers, the feeling of social isolation and depression, coupled with the effects of their diminishing capacity on their notions of masculinity and virility, reinforced their resistance to seek clinical advice for basic medical concerns. Male consumers and professionals also cited stoicism, pride, stubbornness, putting things off to maintain independence, and placing others before themselves as barriers affecting access to services.

I have trouble with urinary flow and when standing at the urinal with other men who have similar problems, I find they're highly unlikely to make comment or seek help. I think they're embarrassed even though it can be debilitating in their lives. (Ageing person)

He observed that the struggle of his parents and himself as a single father of six young children during depression years, which built strength and resilience which younger people don't have. He thinks 90% of health issues for people are in their own head and they lack resilience. (Ageing person)

Key Finding 6: Access logistics

A number of logistical barriers were frequently identified as major inhibitors to accessing health and social care services in rural areas. These barriers included: long waiting times for GP and other clinical appointments; cost of services and travel; distance and transport to and from services; reduced access to technology including phones and internet; and dependence on temporary accommodation nearby to services.

One of the main barriers to accessing health services that featured repeatedly and prominently across all interview and survey groups and in every region in Gippsland, was travel. This included long distances, lack of transport, and costly journeys to from services. When asked outright what barriers their parents face in accessing healthcare services an overwhelming majority of respondents nominated distance and transport. Almost all other respondents nominated logistical access issues including waiting times and cost of healthcare services to be the most significant barriers to access.

Distance, sometimes tests or specialists are not close and also there can be issues with transport and costs, even parking fees at hospitals add up quickly. (Adult child of ageing parent)

Dad refuses help and walks to appointments but has had falls on the way. (Adult child of ageing parent)

Most is ok but extras like hearing, sight and cancer follow-up all require family to coordinate which can be difficult as we all live far away. (Adult child of ageing parent)

> *As my mother is reluctant to get out of bed, she doesn't often leave her granny flat. The doctor will only do an annual visit as we live 15kms from their practice.* (Adult child of ageing parent)

Older consumers were concerned about the scarcity of temporary accommodation at hospitals and for overnight stays to break up journeys. The cost both in time and money of travelling to and from appointments across the region, sometimes while very ill, was also a major inhibitor for ageing consumers. Both consumers and professionals expressed frustration with clinicians' lack of geographical knowledge of the Gippsland region. Some consumers described the farce of being told by a clinician to "come back tomorrow" for another test or scan, when it had taken them hours of travel to get to their current appointment. Another example of this was being told by specialists to "just follow up with your GP next week", when consumers might have to wait weeks to get a GP appointment or travel long distances to attend. This became a further inhibitor for consumers as clinicians made appointments for basic scans and tests in distant towns that could have been facilitated closer to their home.

> *My husband has kidney cancer… he travels [for treatment] while he's sick, and back home after treatment. We could call an ambulance, but he refuses because it's not life threatening.* (Ageing person, carer)
>
> *When travel is an hour each way to get to the nearest GPs and hospital, it becomes a full day event. To get access to healthcare, last Friday Sarah was unwell and was recommended by the bush nurse to go to hospital. Her daughter drove her to emergency at Bairnsdale where she waited the whole day with her daughter to be seen and then to drive home at night.* (Carer)
>
> *…it is the access, and inconvenience, that creates the stress. People are kind, but generally, specialists are completely ignorant of the rural situation, and the inconvenience some of their recommendations and appointments have.* (Ageing person)

When coupled with long distances, logistical access to health services comes with high costs attached for rural residents. For some consumers healthcare is considered a luxury when there are bills and other fees to pay. One respondent commented that her ageing mother-in-law struggles to pay for her rent and medications, so eats cheaper, poor quality food in order to prioritise those costs. Professionals in particular noted the challenge of encouraging consumers to prioritise their health as a worthwhile investment.

> *…with 17% of our population 75 years and over, and 49% living on their own, access to care is a challenge. People who fail to access refer to the cost, the availability of transport to medical services or simply having enough wood to heat their homes.* (Professional)

> *Cost [of health services] is a major concern for people. They don't want to use money for themselves, just for the farm, and for the family. They put things off but saying 'working harder will make it better'.* (Professional)

The majority of people participating in this research cited long waiting times as another major barrier to accessing health and social care services, from GP appointments to Council services, and My Aged Care assessments. Many consumers reported waiting weeks for a GP appointment - some up to six weeks - and in smaller towns bush nurses have begun to take appointments due to the high demand for consultations.

> *GP waiting times prevent people from accessing care. People can't get in to see a doctor sometimes for as long as a month.* (Professional)

> *When people finally get to see a GP they take a big list with them of things to talk about, and the GP only has a few minutes so has to prioritise on the day.* (Professional)

Professionals identified a concerning consequence of long waiting times: that doctors are forced to prioritise one or two issues when older people present with lists of multiple things they want to discuss. Rushed appointments have two severe consequences. Firstly, the older person is not seen empathetically as a whole person, and their concerns are not validated or considered holistically by the doctor, which contributes to low self-esteem and may contribute to social and clinical withdrawal. Secondly, from a clinical perspective, rushing appointments with older people increases the opportunity for doctor-patient miscommunications relating to diagnosis and treatment information, increasing the potential for life-threatening clinical outcomes.

Dissemination of information was also identified as a key barrier to access. This was identified directly by professionals, and indirectly by consumers, who were asked about where they would go to access information about health services in their local area. Some professionals noted the problematic practice of using the Internet to disseminate health service information, a method of communication that is inaccessible for some consumers who did not have phone access, let alone Internet capability. During the connection of the NBN in Gippsland, many consumers in isolated rural communities were left without phone connections in case of an emergency. One consumer mentioned that his 'back-up' if phone lines were down, would be to run into the street and ask passers-by for help. Another consumer said he was not sure about which sites to trust on the Internet and preferred to find out about services and activities by word of mouth.

> *Most people don't have phone, or internet. With changes to the NBN lots of people lost their phone line, so they had no contact. They're not sure where to go, there's a lack of understanding to find information.* (Professional)

> *I don't know. There's hundreds of brochures out there… we've talked about how information dissemination isn't working. We've got endless websites and brochures but it's not helping people.* (Professional)

> *A lot of people aren't aware of services until it's too late.* (Professional)

Vulnerable consumers and those located in geographically isolated rural communities expressed high reliance on a single, enthusiastic and hardworking professional contact with the health system such as a bush nurse, social worker, or community service worker. These professionals serve to connect reluctant consumers with relevant services, and in some instances where there is no local GP practice, they provide this service for the residents of entire towns. Given the high demand for this kind of health system navigation service, these individuals are undertaking additional work outside the confines of their roles to bridge gaps in the health system and provide the required personalised care, follow-up and referrals for consumers in declining stages of health. This was viewed by professionals and consumers as an unsustainable long-term solution that places an unmanageable burden of responsibility on a single professional. Consumers reported a sense of anxiety in the community about the future of care, remarking how strong their reliance is on the individual healthcare worker, and fear that the community may be left without access to care in their absence.

Key Finding 7: Carer support

Responses from adult children of ageing parents highlighted the burden of responsibility on families to provide care for people in advanced stages of health decline and dependency. This was a particular challenge for adult children who are beginning the ageing journey themselves, and those balancing this responsibility with the care of their own children.

> *Ageing is not a disease but it does put a lot of pressure on children who are aging as well to try and do right by everyone parents spouses children and grandchildren as well as maintain work. (Adult child of ageing parent)*

> *Remaining parent has a level 2 plan [My Aged Care] but doesn't understand it and is not well. I have a handicapped (mid twenty's child still at home) so I am left sometimes feeling very overworked and stressed as mum doesn't ever want to live in a nursing home. (Adult child of ageing parent, carer)*

I'm so tired. I waited over 12 months for a carers pension to be approved and although I did receive back pay it put tremendous strain on my marriage which still hasn't recovered. (Adult child of ageing parent, carer)

Some people expressed the frustration, isolation and lack of support for their complex role as carer for an ageing parent or spouse, particularly in circumstances when the carer is also ageing themselves, and where they live far distances away from services in rural areas.

Frustrating! No one listens to me, and I have no support for myself, no family members left. (Adult child of ageing parent, carer)

Support networks and information sessions for those with a spouse who is declining in physical and/or mental health would be great, especially in regional and rural communities. (Ageing person, carer)

Analysis

The Spiral of Decline & Withdrawal©

    ——————▶ Continued decline

    ——————▶ Opportunities for intervention
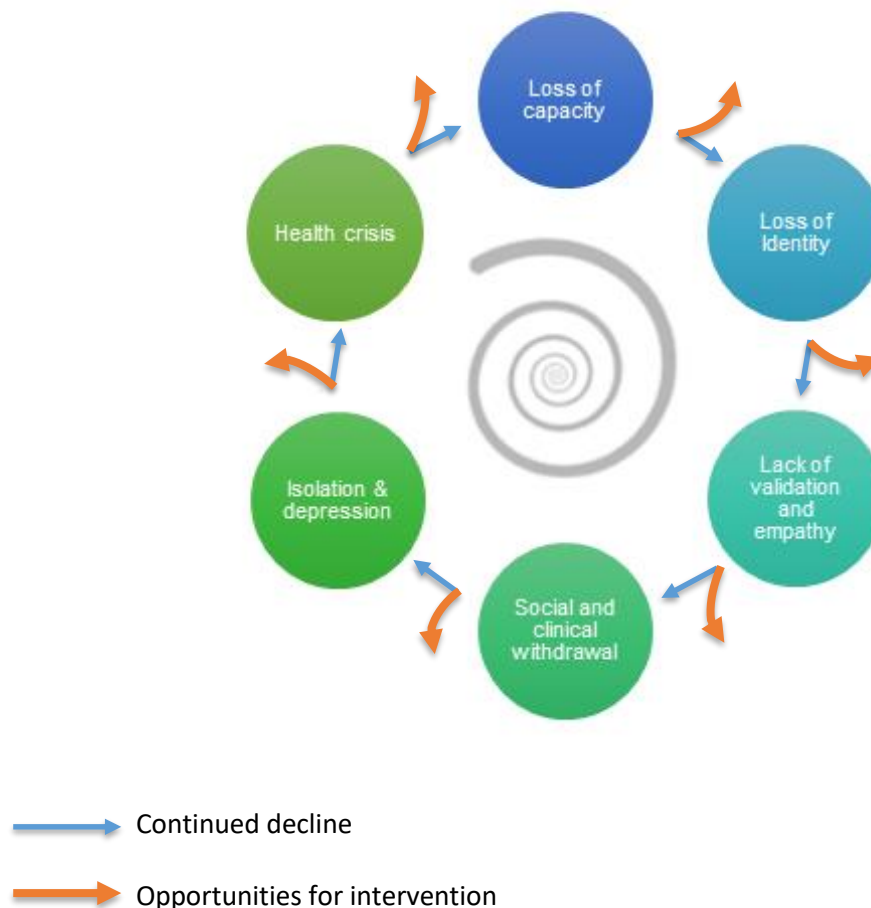
By investigating older people's withdrawal from health services through a consumer lens, HIC has identified six stages in their spiral of declining capacity.

Loss of capacity and self-esteem

Older people experience gradual declining capacity that can prevent them from participating in activities they used to enjoy such as walking their dog, gardening, and playing the piano. These reductions in capability can impact their sense of identity, and the effects of these physical and cognitive changes manifests for some people in low self-esteem and emotional vulnerability.

Loss of self-esteem and clinical withdrawal

Ageing consumers express emphatically that they do not want to be viewed by health service providers simply as an 'elderly person'. For those who attend consultations with a GP who fails to listen, express empathy towards their situation, or validate them as a witness to

their own experiences, this results in withdrawal from that particular doctor, and in some cases from clinical services as a whole. Interactions with health services that exacerbate, rather than address a consumer's low self-esteem about their reduced capacity triggers ageism and the inclination to withdraw.

Social and geographical isolation

With support from their social and family networks, some people seek out another doctor or travel longer distances for appointments to see a preferred clinician. Others struggle to restore self-esteem and, coupled with social withdrawal, isolate themselves at home. In geographically remote communities this sense of isolation is exacerbated by the landscape and distance from their neighbours. In conjunction with faulty or non-existent phone connections, family living far away, and long distances to services, older people's physical and social isolation is extreme.

Further heath deterioration and crisis

Physical and social isolation coupled with continued deterioration in physical and mental health, places the consumer in a precarious position. The potential for a health crisis in these situations is acute, and results in a high reliance on emergency response services. According to professionals, there is a population within the community who are 'not on the books', with no record of having attended health and social care services. For those consumers there is no established record or relationship with the system, which in turn, makes an emergency response more difficult for the system to address effectively. If a consumer experiences a poor response to a health crisis, and they lose trust in the system's competence, this may result in further withdrawal from services and perpetuate the cycle of deterioration and withdrawal once again, this time in a worsened state of declining health.

Intercepting the spiral

The orange arrows in the graphic above indicate the points of interception that present numerous opportunities to intercept spiraling health decline and withdrawal. This research suggests the critical intervention role that health and social care service providers play in pausing and decelerating the spiraling effect of withdrawal. This can be achieved by providers actively listening to consumers, communicating effectively and demonstrating empathy.

Clinical interactions that validate ageing consumers' experiences of ageing not only serve to restore consumers' sense of self, they also provide valuable early intervention opportunities to implement preventative health care during the incremental experience of declining capacity. Ideally, social interventions such as empathic clinical communication should be implemented in the early stages of declining capacity to reduce the incidence of low self-esteem and consequent withdrawal. However, where consumers are already withdrawn from services, it is probable that empathic and validating clinical care delivered at either of the interception points in the Spiral could restore trust in the health system and increase clinical attendance.

Recommendations

The recommendations listed below are proposed next steps to address the key findings that emerged as a result of this consumer consultation project. Prior to implementation of these recommendations, HIC recommends further exploration of the key findings and recommendations of this report through additional focused consultations with consumers and health and social care professionals in the Gippsland region.

Identity

- Safeguard personal identity, self-esteem and relevance to improve quality of life

- Arrest decline by assisting older people to reinvent themselves as their life-long identity diminishes

- Design and deliver human-centered programs to shape identity within the ageing process

The Spiral model demonstrates that for ageing consumers, personal identity, self-esteem and relevance are more meaningful determinants of quality of life than physical independence, and need to be safeguarded to achieve this goal. A critical social intervention to arrest decline would be to assist older consumers to reinvent themselves as their life-long identity defined by work, parenting and social interaction diminishes. This could include social activities that build on existing formal and informal community groups, connect ageing consumers with people of all ages, and stimulate and challenge the mind.

HIC recommends the design and development of prototype programs to shape identity and strengthen self-esteem as consumers age. These programs should be based on a human-centered design process in order to be most impactful in the Gippsland region, similar to the model HIC is currently applying to the design of a women's health centre in Maryborough.

Gender

- Consider the importance of gender identity to communities in rural and diverse cultural and religious settings

- Target communications about prevention to women as well as men, even for male-specific conditions

These findings suggest that primary health and prevention campaigns should consider the importance of 'traditional' gender identities to communities in both rural and other contexts where people may take on specific roles that reflect historical societal and patriarchal views. This may include diverse cultural and religious settings. Targeting communications about preventative interventions to women as well as men, even for male-specific conditions, may increase male participation in primary health and prevention services. Conversely, where strict gender roles limit women's independence and access to health services and

treatments, health campaigns should uphold personal privacy, and address existing gender inequalities, disadvantage and discrimination.

Clinical empathy and communication

- Educate health and social service providers about their key role to intercept the Spiral of Decline and Withdrawal, and the critical opportunities for intervention

- Reshape primary care as a means to maintain independence and assist consumers to age independently and safely at home

- Design and deliver human-centered training programs for clinicians and service providers to restore consumer self-esteem and support independent ageing

Health and service providers play a key role in preventing the spiraling effect of withdrawal, by actively listening to consumers, communicating effectively, demonstrating empathy, and validating consumers' experiences of ageing. Clinical behaviours that exacerbate, rather than address consumers' low self-esteem should be identified to increase attendance at health services, and reduce older consumers' inclination to withdraw after negative clinical experiences. This includes failing to demonstrate empathy and respect, confirm patient understanding of diagnosis and treatment, validate the challenges of decline, and the practice of dealing with only one condition per presentation. Offering person-centered training programs to develop skills in empathy, identity and ageing to health and social care providers may result in increased attendance at health clinics and participation in preventative services.

HIC findings suggest that some ageing consumers who withdraw from services associate basic system engagement with reduced independence and relocation into retirement homes against their will. These misconceptions demonstrate the need for a cultural shift in clinical approaches to communicating with consumers. In particular, approaches that support independent ageing, and normalise conversations about death and end of life options. Good communication by health and social care professionals is vital to reverse the perceived threat to independence associated with accessing health and social care services. Dialogues with consumers should reshape primary care as a means to maintain independence, not remove it, that will assist consumers to age safely at home for as long as possible.

Withdrawn consumers – clinical engagement and monitoring

- Facilitate clinical behavioural change by providing consumers with regular, face-to-face clinical consultations both in healthcare facilities and consumers' homes, and dedicating sufficient time to explain conditions, diagnoses, treatment, service and care options

- Design long-term grass roots engagement strategies to restore withdrawn consumers' trust in the health system

- Design and deliver clinician-led information sessions on topics relevant to ageing, local aged care services, and participation in community groups and activities

- Design and deliver a strategy to address the gap in family and medical history records and restore withdrawn consumers' trust in the health system

HIC recommends a grass roots strategy to facilitate behavioural change within clinical culture, and to reinforce trust between withdrawn individuals and the health system. As reiterated in HIC consultations, older consumers desire to be respected as multifaceted individuals beyond the label of 'elderly person' whose identity is defined entirely by age. As such, strategies to reinforce trust between withdrawn individuals and the health system should apply a multifaceted approach and acknowledge the variations in ageing consumers' needs and stages of withdrawal they may be experiencing. For example, a consumer who has experienced a lack of empathic care most recently, but has historically experienced positive engagement with the health system, may be receptive to grass roots engagement strategies over a shorter period of time. In contrast, where the majority of interactions a consumer has had with the health system are patronising, confusing and dismissive, grass roots engagement strategies need to consider alternative methods of engagement that rebuild trust over a longer period of time.

A grass roots strategy for clinical behavioural change should identify every interaction (from primary health to crisis services) with withdrawn consumers as an opportunity to provide empathic care that validates their experiences and identity as an individual. According to consumer sentiments, this should include the provision of regular, face-to-face clinical consultations both in healthcare facilities and consumers' homes. Clinicians should also dedicate sufficient time to explain conditions, diagnoses, treatment, service and care options. In conjunction with person-centered training for clinicians, a grass roots strategy could be applied more broadly to include the provision of clinician-led information sessions about topics relevant to ageing, local services, and encourage participation in community groups and activities. This may generate broader engagement and encourage persistently withdrawn and geographically isolated consumers to begin to re-engage in social interactions and gradually restore their trust in the health system.

Consultations with professionals working in Gippsland identified a population of older consumers who are completely withdrawn from health and social care, including no health record held by any services. The health system is ill-equipped to deal with a clinical emergency where there is no relationship or medical history established with a consumer. Getting consumers 'on the books' is a critical determinant of health outcomes, and could become a vital intervention for future access, relationship-building and service provision.

To address this issue and facilitate behavioural change, HIC recommends a strategy to establish records of each person's family history, medical history and needs to support their independent ageing at home. This should include a communications strategy for reaching out to these typically 'hard to reach' populations, using a broad range of approaches beyond online channels and hardcopy brochures. A communications strategy should consider alternative avenues to approach consumers, such as engaging with their adult children and female spouses, and face-to-face approaches in non-clinical settings such as supermarkets and community activities. Once located and identified, the grass roots clinical

communication strategy outlined above could be applied to reinforce trust and reverse the perceived threat to independence by accessing health services.

Health literacy strategies to address the needs of vulnerable and marginalised consumers should feature face-to-face interaction, hardcopy information, and the role of a 'systems' navigator' to talk consumers through information in person.

The role of Systems Navigator

- Introduce the role of Systems Navigator to provide personalised care, follow-up and referrals for consumers

Ageing consumers in geographically isolated rural communities expressed a strong reliance on individual, enthusiastic and hardworking professional contact with the health system such as a bush nurse, social worker, or community service worker. These individuals serve to connect reluctant consumers with relevant services, provide the required personalised care, follow-up and referrals for consumers in declining stages of health, and in some instances where there is no local GP practice, they provide these services for the residents of entire towns. The immense value that isolated communities place on these hardworking individuals demonstrates the need to ensure this grass roots service is maintained in a sustainable form.

HIC recommends introducing the role of Systems Navigator responsible for connecting consumers to relevant services, and applying a case-management style of service provision, including follow-up and home visits. This is particularly necessary for consumers located in geographically isolated communities, vulnerable cohorts, and people with early stage and advanced cognitive decline.

Access logistics

- Apply a 'minimally disruptive medicine' approach to place the consumer at the centre of health and social care decision making

- Increase transport to and from health and social care services and low-cost accommodation close to services.

- Educate health and social care providers about the rural consumer experience of isolation and distance from services

One of the main barriers to accessing health services that featured repeatedly and prominently across all interview and survey groups and in every region in Gippsland, was travel. This included long distances, lack of transport, and costly journeys to from services. In order to address this major barrier to health care access in Gippsland, HIC recommends to increase transport to and from health and social care services, and increase low-cost accommodation available close to services.

As part of this design of infrastructure delivery to reduce onerous travel involved in accessing medical treatments and interventions, HIC recommends education of health and

social care providers based on a 'minimally disruptive medicine' (Leppin, Montori, Gionfriddo 2015) approach. This places the patient at the centre of decision making, and takes into account factors that exacerbate their burden of treatment. Such an approach requires health and social care providers to assess the nature, distance, time required and frequency of healthcare tasks, and consider how they may affect consumer attendance in a broad range of geographical settings. An education program could inform providers about the geographical limitations of the Gippsland region for ageing consumers, and encourage providers to facilitate basic services closer to home.

Carer support

- Promote existing carer support services using a variety of communication methods including online, hardcopy materials, and word of mouth through existing community locations, groups and activities

- Design and deliver self-facilitated carer support groups using digital tools such as social media and video conferencing to connect carers in rural and geographically isolated areas

Responses from adult children of ageing parents highlighted the burden of responsibility on families to provide care for people in advanced stages of health decline and dependency. This was a particular challenge for adult children who are beginning the ageing journey themselves, and those balancing this responsibility with the care of their own children. This group also confirmed the need for increased numbers of accessible carer support groups, to provide emotional support, and share information about services for themselves and their dependent family member.

HIC recommends the design of campaigns to promote existing carer support services, and introduce self-facilitated carer groups. A self-facilitated group prototype could be based on the model of post-natal mother's groups. This would involve members coming together with a qualified facilitator in the first instance, and continuing on as a member-managed social support group with access to support as required. The flexibility of this approach allows for group members to connect using alternative channels such as social media, video conferencing and phone where distance prevents them meeting face-to-face.

Conducting interviews during community activities enabled HIC to observe first-hand the strength of rural communities to orally communicate and disseminate information about available services. In order to capitalise on the strength of present community gatherings, HIC recommends that existing carer support services be promoted in community locations such as markets, libraries, RSLs, bowls clubs, pubs, cafes, Men's Sheds, and through prominent community organisations such as the Country Women's Association, University of the Third Age, Rotary and Probus groups. These active and well-attended organisations could also be engaged with more broadly to promote and disseminate information about primary health and local aged care services.

Conclusion

HIC has gathered the sentiments of older people in Gippsland and considered how their interaction with the clinical world is shaped by their social context and personal experiences of ageing. Viewing the ageing process from the consumer perspective has revealed a number of important findings for Gippsland residents that identify opportunities for preventative health care that could slow the process of incremental decline.

Health and social care providers play a critical role to intercept the spiraling effect of decline and withdrawal. The Spiral of Decline and Withdrawal© demonstrates the critical opportunities to express clinical empathy, and restore consumer self-esteem and trust in the health system. With improvements based on strengthening consumer identity and validating experiences of ageing, significant gains could be made to reduce severe physical and mental health decline.