Consumers Health Forum of Australia

SUBMISSION TO HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH, DISABILITY AND AGEING

Inquiry into access and affordability of medical specialists

Views from consumers

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Department of Health, Disability and Ageing Inquiry into access and affordability of medical specialists. Views from consumers.



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Executive Summary

This submission draws on qualitative research with 19 consumers who had accessed, or attempted to access, specialist care in the previous three years, together with a roundtable involving ten of those consumers. The research looked at the whole specialist care journey, from referral and finding the right specialist through to waiting, paying, travelling, receiving care and securing follow-up.

The central finding is that consumers experience specialist care as one journey, but the system is organised in fragments. People move between general practice, specialists, hospitals, diagnostic services and public and private care, yet responsibility for connecting those parts is often unclear. Too often, consumers and carers are left to chase referrals, confirm appointments, obtain records, compare costs, organise travel, coordinate between clinicians and work out what should happen next.

Access is therefore about much more than whether a specialist appointment exists. Consumers described long and uncertain waits, difficulty finding the right specialist, high and unpredictable out-of-pocket costs, poor visibility of referral and waitlist status, regional workforce shortages, fragmented communication and inconsistent follow-up. For regional, rural and remote consumers, travel, accommodation, time away from work and caring responsibilities added further cost and complexity.

Consumers also did not experience public and private care as two separate systems. They moved between them according to clinical need, waiting times, affordability, specialist availability and location. Some paid privately to obtain an assessment and then returned to public care. Others used private care because public waits were too long, while some remained in public care because private fees were unaffordable. The practical reality for consumers is a mixed specialist-care system, not a simple public-or-private choice.

These barriers have consequences beyond inconvenience. Consumers described worsening symptoms, emotional distress, lost income, disruption to work and education, family strain and, in some cases, avoidable escalation to hospital or emergency care. The burden is not shared equally. People with more money, time, confidence, health literacy, digital access and family support are better able to navigate a fragmented system. Those with fewer resources are at greater risk of delay, loss to follow-up and unmet need.

Consumer feedback points to practical improvements, including clearer information, more transparent costs and waiting times, better referral tracking, stronger follow-up, care navigation, telehealth where clinically appropriate and improved regional access. CHF supports these directions, but our policy conclusion goes further. Consumers should not be expected to compensate for poor system design. Reform should reduce fragmentation, make responsibility clearer and make the specialist care journey easier to see and navigate.

CHF recommends that governments and specialist services:

- Make referral and waiting pathways visible and accountable. Consumers should be able to confirm that referrals have been received and triaged, understand expected timeframes, receive updates while waiting and know how to escalate concerns if their condition changes.
- Make the full cost of specialist care clear before care begins. Consumers need timely information about fees, Medicare rebates, likely out-of-pocket costs and associated costs across the episode of care, not just the first consultation.

- Strengthen continuity and responsibility across the care journey. Referral, discharge and follow-up systems should operate as closed loops, with clear responsibility for the next step and navigation support where care is complex.
- Reduce geographic inequity in specialist access. Reform should combine stronger regional workforce and outreach models, clinically appropriate telehealth, coordinated appointments and travel assistance that reflects the real cost of accessing care.
- Design reform around the whole consumer journey across public and private care. Policy should recognise that consumers move between both systems and should improve information sharing, coordination and accountability across settings.

Consumers should be active partners in their care. They should not be required to hold a fragmented specialist-care system together.

Introduction

Consumers Health Forum of Australia (CHF) welcomes the opportunity to contribute further to the House of Representatives Standing Committee on Health, Disability and Ageing inquiry into access to and affordability of medical specialists.

CHF is the national peak body for healthcare consumers. We work with consumers, our members and partners to ensure health policy, programs and services reflect the needs and experiences of the people who use them.

This is CHF's second submission to the Inquiry. It draws on qualitative research undertaken in August 2026 with 19 consumers who had accessed, or attempted to access, specialist care in the previous three years. We also held a consumer roundtable in September to test the emerging findings and explore what could improve the specialist care journey.

The purpose of this work was to understand the consumer experience in greater depth. We wanted to look beyond individual appointments and examine the whole journey: getting a referral, finding the right specialist, waiting for care, understanding and managing costs, travelling where necessary, moving between public and private services, and securing follow-up.

The research provides detailed evidence about where the specialist care system works well for consumers and where it creates avoidable burden, delay, cost and risk. It also helps identify where policy and service reform could make specialist care more accessible, affordable and easier to navigate.

Relationship to Submission 1

CHF made Submission 1 to the Inquiry in July 2026. Submission 1 drew together existing CHF evidence and policy analysis on specialist access and affordability.

Submission 2 builds on that work by adding detailed qualitative evidence from consumers' lived experience. It gives the Committee a closer view of how specialist care is experienced in practice, including the interaction between public and private care, the cumulative impact of costs and waiting, and the work consumers and carers are often required to do to hold the care journey together.

The two submissions are intended to be read as complementary. Submission 1 established the broader policy issues. Submission 2 adds depth through direct consumer evidence and uses that evidence to inform CHF's recommendations for reform.

Consumer recruitment and inclusion criteria

In July 2026, CHF invited consumers across Australia to take part in interviews about their experiences of accessing specialist care. Recruitment was undertaken through CHF's social media channels and networks.

We sought people who had accessed, or attempted to access, a medical specialist in the previous three years. Participants were selected to provide a range of experiences, including differences in location, age, gender, health status, private health insurance status, socioeconomic circumstances, caring responsibilities and use of public and private care.

Twenty-one eligible consumers were invited to participate and 19 completed an interview. The semi-structured interviews were conducted online in August 2026 and generally lasted around 90 minutes. Participants were asked to describe their specialist care journey in detail, from recognising the need for specialist advice through referral, access, costs, treatment and follow-up.

The interviews were recorded and analysed thematically to identify common experiences, barriers and enabling factors.

Ten interview participants then took part in an online consumer roundtable on 10 September 2026. The roundtable was used to test and validate the emerging findings and, importantly, to explore what consumers thought could improve access to and affordability of specialist care.

The research is qualitative. It is intended to provide depth and insight into consumer experiences rather than produce findings that are statistically representative of all Australian consumers.

Key themes from consumer evidence

1. Access and wait times

Consumers described long waits as a common and harmful feature of specialist care. Waiting periods ranged from weeks and months to years, particularly in public pathways. But the problem was not only how long people waited. Consumers often had little visibility of where they were in the queue, whether their referral had been received or appropriately triaged, or what they should do if their condition worsened while they waited.

> ***You're kept in the dark… you're not told, 'you're 10th in the queue'… you're just told… you just wait.*** *- Man participant, 36-45*, Metropolitan, VIC

Limited specialist availability compounded these delays. Consumers described shortages in particular specialties, limited paediatric services and regional workforce gaps. Some faced a choice between seeing a less preferred specialist sooner or waiting much longer for the specialist recommended by their GP. Private care did not always remove the delay.

For regional, rural and remote consumers, access often also meant travel. Specialist care could require long distances, accommodation, time away from work or school and support from family members. For some, travel was not an occasional inconvenience but the normal way they accessed specialist care.

> ***For where I live, there's no close by. You've got to go and drive in and drive out to the specialist. That's just the way it is. -*** *Woman participant*, 66-75, Remote, QLD

Delays had consequences. Consumers described worsening symptoms, unresolved pain and anxiety while waiting, and in some cases escalation to hospital or emergency care. The evidence suggests that specialist access is not simply about appointment availability. Consumers also need timely access, visibility of where they are in the pathway and a clear way to seek review if their circumstances change.

2. Affordability and out-of-pocket costs

Consumers described affordability as a problem across the whole specialist care journey, not just at the point of consultation. Costs included specialist fees, tests, imaging, procedures, private hospital care, travel, accommodation, lost income and repeat appointments. For people with chronic or complex conditions, these costs could accumulate over months or years.

Cost uncertainty made the problem worse. Consumers often did not know what they would be expected to pay until late in the process, and some had to repeatedly ask for information about fees, rebates and other charges.

> ***There was no fee schedule posted anywhere… There was no clear information beyond… you should be prepared to pay a gap.*** *- Non-binary participant*, 26-35, Regional, SA

For regional and remote consumers, the cost of specialist care extended well beyond medical fees. Travel, accommodation, meals, fuel and time away from work added substantially to the cost of accessing care. Patient travel assistance schemes were valued, but participants said they did not always reflect the real costs involved.

> ***There's accommodation, meals, petrol, you know, all of that for those couple of days that you're there.*** *- Woman participant*, 46-55, Metropolitan, ACT

Affordability affected whether and when people received care. Consumers described delaying appointments, skipping investigations, relying on family for financial support, using savings or deciding against recommended treatment because the total cost was too high.

The evidence shows that affordability should be understood across the whole episode of specialist care. Consumers need to know the likely total cost, not simply the fee for one appointment.

3. Communication and information

Consumers described communication as a major factor in whether specialist care felt safe, coordinated and manageable. Problems occurred across referrals, appointments, discharge, costs, test results, treatment options and follow-up.

Poor communication between GPs, specialists, hospitals and diagnostic services often shifted responsibility back to the consumer. Participants described having to chase appointments, request records, repeat their history, reconcile conflicting advice and work out what should happen next.

> ***That scares me because I'm thinking if I wasn't proactively managing my care, who would be?*** - Woman participant, 46-55, Regional, WA

Consumers valued the opposite experience: clinicians and services that explained options clearly, disclosed costs early, invited questions, acknowledged uncertainty, provided written information and followed up when they said they would.

Communication failures were especially difficult for consumers who had less time, confidence, health literacy, family support or professional knowledge to compensate for gaps in the system.

The evidence suggests that good communication is not an optional aspect of service quality. It is central to continuity, informed decision-making and whether consumers can safely navigate specialist care.

4. Person-centred and culturally safe care

Consumers valued specialist care that recognised them as a whole person, not simply as a diagnosis or condition. Positive experiences were associated with clinicians who listened, respected consumers' knowledge of their own health, explained uncertainty, supported shared decision-making and took account of family, cultural and personal circumstances.

When care was not person-centred, consumers described feeling dismissed, dehumanised or unheard. Some felt they had to prepare carefully, assert themselves strongly or use formal language about their rights before their concerns were taken seriously.

> ***I have to forget that I'm an Indigenous person because my culture does not fit into specialist care and that's really crushing.*** - Woman participant, 46-55, Regional, WA

Consumers also described assumptions being made on the basis of language, ethnicity, disability, gender, age, health literacy or stigmatised conditions. These experiences reduced trust and could make people less willing to ask questions, challenge recommendations or return for care.

Consumers did not expect every specialist to have every answer. They valued clinicians who were open about the limits of their expertise, sought advice where needed and referred appropriately rather than dismissing unfamiliar or complex presentations.

The evidence shows that person-centred and culturally safe care is not just about communication style. It affects trust, participation in decisions and whether consumers feel safe to continue engaging with specialist care.

5. Public and private pathways

Consumers did not experience public and private specialist care as two separate systems. Instead, they moved between them depending on urgency, cost, waiting times, specialist availability and location.

Some consumers paid privately to obtain an assessment and then returned to public care. Others used private care because public waits were too long, while some stayed in the public system because private fees were unaffordable. In some cases, consumers saw the same clinician across both settings.

> ***Initially I was reluctant to go [to a private consultation] ... But then I was left with no option.*** *- Woman participant, 36-45*, Regional, NSW

Public care was valued because it protected consumers from major direct costs and supported complex hospital-based care. However, consumers also described long waits, limited choice and little visibility over triage or progress.

Private care could offer greater certainty and choice, but it did not guarantee timely access and could create substantial out-of-pocket costs. Private health insurance did not always protect consumers from specialist fees or gaps.

> ***With money. Then you've got choice... people are realising, well, this is never going to get done at a public system. I need to pay and get this done***. - Man participant, 46-55, Regional, VIC

The evidence suggests that the key consumer trade-off is often time versus money. Consumers with greater financial resources may have more options, but geography and specialist shortages can still limit access. Reform therefore needs to recognise that consumers move across public and private settings as part of one specialist care journey.

6. The role of primary care

Consumers often described general practice as the anchor of the specialist care journey. A trusted GP could help identify the right specialist, prepare referrals, explain options, interpret specialist advice and support consumers to move between public and private care.

> ***My GP will always be like the main anchor in my life when it comes to life advice and talking about lived experiences and navigating life relationships and so forth.*** *- Man participant, 18-25*, Metropolitan, NSW

But that support was not consistently available. Some consumers did not have a regular GP, faced long waits for appointments or had short consultations that did not allow enough time for coordination. Where primary care could not play an active role, consumers were more likely to be left researching specialists, seeking referrals and managing next steps themselves.

> ***A lot of the times it's when they ask, oh, who's your GP? I'm like, oh, I have to think about the last five that I saw. And I think that's quite a common thing.*** *- Man participant, 18-25*, Metropolitan, ACT

The evidence also points to structural limits on what primary care can do. GP access, consultation time, referral rules and communication between GPs and specialists all affect whether primary care can effectively support the specialist journey.

The role of primary care is therefore important, but it should not be treated as the solution to system fragmentation. Better GP-specialist communication and stronger shared-care arrangements can help, particularly for chronic, complex and lifelong conditions, but

consumers should not have to rely on an individual GP to compensate for gaps elsewhere in the system.

7. Emotional and social impacts

Consumers described the effects of specialist access barriers as extending well beyond clinical outcomes. Long waits, uncertainty, high costs and fragmented care affected work, education, family life, independence and emotional wellbeing.

For some consumers, the uncertainty itself was exhausting. Waiting for diagnosis or treatment while symptoms worsened could create fear and distress, particularly for parents seeking care for children or people trying to continue working while unwell.

> ***It feels life is diminishing...And then it's feels like you lose your position or you lose your [ability to live].*** *- Man participant, 36-45*, Rural, NSW

Families and carers also absorbed a significant part of the burden. They provided transport, accommodation, emotional support, personal care and administrative coordination. Some reduced work or study to support a family member through care.

> ***The role of the carer isn't always understood or valued… There's no, like they don't have inbuilt mechanisms to include the carer meaningfully.*** *- Woman participant, 36-45*, Regional, TAS

The impact was greater where consumers felt dismissed, culturally unsafe or unsupported. Conversely, responsive clinicians, community support and culturally safe care could restore trust and reduce distress.

The evidence shows that delays and access barriers create social and emotional costs as well as financial and clinical ones. Those impacts should be considered when assessing the effectiveness of specialist care pathways.

8. Continuity of care

Consumers described continuity of care as a major weakness in the specialist care journey. Breakdowns occurred after hospital discharge, referrals, tests and specialist consultations. Follow-up appointments were sometimes delayed, lost or never arranged, leaving consumers unsure about what should happen next.

> ***…the hospital, when I got discharged, there was no continuum of care.*** *- Woman participant, 46-55*, Regional, TAS

Consumers valued care most when a clinician or service retained responsibility for the next step. Clear plans, confirmed follow-up, communication between providers and access to their own records made the pathway feel safer and more coordinated.

Fragmented information systems also undermined continuity. Consumers described having to carry information between clinicians or being the only person who understood their full care history. For people with complex conditions or multiple specialists, this created additional burden and risk.

> ***So, when two weeks went by, I ended up starting to call the hospital… But it took 7 calls to finally get the telehealth appointment, by which time, it was week 3.*** *- Woman participant, 66-75*, Metropolitan, WA

The evidence suggests that continuity depends on clear responsibility as much as repeated contact. Consumers need to know who is responsible for the next step, whether follow-up has been arranged and what to do when the expected pathway breaks down.

9. Self-advocacy and coordination

Consumers frequently described becoming the de facto coordinators of their own specialist care. They searched for specialists, chased referrals, confirmed appointments, organised records, compared costs, arranged travel and followed up when care did not progress as expected.

> ***I feel like I'm a full-time manager of my health. And it puts a big burden on me to have all these things in place so that I can ensure that I can maintain that medical engagement with my medical team that are so far away from me.*** *- Woman participant, 46-55*, Regional, WA

For some consumers, persistence and confidence helped them secure care. But the need for constant self-advocacy also exposed inequity. Access should not depend on a person having the time, health literacy, professional knowledge, confidence, money or family support required to keep pushing the system forward.

> ***You kind of need to be your own case manager.*** *- Man participant, 18-25*, Metropolitan, ACT

The burden was particularly high for people with complex conditions, regional and remote consumers, families supporting children and people already unwell or distressed. Those with fewer resources were more likely to be delayed, lost to follow-up or unable to challenge poor care.

The evidence suggests that consumer participation is important, but it should not be confused with responsibility for holding the system together. Consumers should be partners in their care, not the default coordinators of fragmented services.

10. Digital health and innovation

Consumers saw digital health as an important way to improve specialist access, particularly for people living in regional, rural and remote areas. Telehealth could reduce unnecessary travel, time away from work or family, and the disruption involved in travelling long distances for appointments that did not require a physical examination.

> ***I've driven 5 hours staying overnight where you could have just dismissed me on telehealth and that's it.*** *- Woman participant, 46-55*, Regional, TAS

Consumers did not support telehealth as a blanket replacement for in-person care. Its value depended on clinical need, consumer preference, communication needs, the stability of the person's condition and whether the right clinician was available.

> ***Telehealth is fantastic, but it needs to be used judiciously... It cannot be a band aid solution or considered as a blanket fix all approach.*** *- Non- binary participant, 26-35*, Regional, SA

Consumers also valued digital systems that made the care pathway more visible. Patient portals and interoperable records could help people see referrals, appointments, results, records, costs and next steps, reducing uncertainty and the need to repeatedly chase information.

Digital reform also needs to be equitable. Consumers noted that not everyone has reliable internet access, digital literacy or suitable communication tools. Digital systems should expand choice and transparency rather than create new barriers.

The evidence suggests that digital tools work best when they reduce burden, improve visibility and increase choice. They should support the specialist care journey, not become another layer that consumers have to navigate.

What consumers said could improve the specialist care journey

The consumer roundtable tested the themes emerging from the interviews and asked participants what would make the specialist care journey work better.

Consumers were clear that the problems they experienced were interconnected. Cost affected access. Long waits could worsen health. Poor communication increased uncertainty and shifted coordination back to consumers. Regional access brought additional travel and financial burdens. People with greater time, money, confidence and knowledge were better able to navigate these problems than those with fewer resources.

Participants consistently called for a system that was easier to see, easier to navigate and clearer about who was responsible for the next step.

Ideas raised by consumers included:

- clearer information about fees, rebates and the likely total cost of care before treatment begins

a) greater visibility of referrals, waiting times and where a consumer sits in the pathway

- regular updates while waiting and a clear way to seek reassessment if circumstances change
- closed-loop referral, discharge and follow-up processes
- better sharing of information between GPs, specialists, hospitals and consumers

b) care navigation or coordination support for people with complex needs

c) more flexible referral arrangements for chronic and lifelong conditions

- clinically appropriate telehealth, outreach and visiting specialist services

- stronger regional specialist capacity and travel assistance that reflects the real costs of accessing care

d) coordinated appointments and reduced duplication of investigations and visits

e) hardship arrangements and other affordability supports

f) better inclusion of families and carers where the consumer wants them involved

- digital portals that allow consumers to see referrals, appointments, results, records and next steps.

These ideas provide important evidence about where consumers experience friction and what they believe would make specialist care easier to access and navigate. They are not, however, automatically CHF policy recommendations. CHF has considered them alongside the wider evidence and the Inquiry's terms of reference in developing the recommendations that follow.

Recommendations

CHF recommends that governments, funders and specialist services:

1. Make referral and waiting pathways visible and accountable

Consumers should be able to confirm that referrals have been received and triaged, understand expected waiting times and know who is responsible for the next step.

This should include:

- consumer-visible and portable referrals
- regular updates while people are waiting
- clear escalation and re-triage pathways when a person's condition changes
- closed-loop referral, discharge and follow-up processes.

2. Make the full cost of specialist care clear before care begins

Consumers should receive clear, timely information about the likely cost of their whole episode of care, not only the fee for the first consultation. This should include specialist fees, Medicare rebates, expected out-of-pocket costs, likely investigation and follow-up costs, and information about available financial assistance.

Government should also improve access to reliable and comparable information about specialist fees and out-of-pocket costs, while recognising that transparency alone will not make care affordable where consumers have limited choice or face high cumulative costs.

CHF has addressed options for identifying and responding to excessive specialist fees in its separate submission to the Department of Health, Disability and Ageing on specialist affordability.

3. Strengthen continuity and coordination across the specialist care journey

Responsibility for coordinating care should not default to consumers and carers.

Governments and services should:

- improve information sharing between GPs, specialists, hospitals and consumers
- provide care navigation or coordination for people with complex, chronic, rare or multidisciplinary needs
- reduce unnecessary duplication of appointments and investigations
- review referral requirements that create avoidable administrative burden for people with chronic and lifelong conditions
- ensure families and carers can be involved where the consumer wants their participation.

4. Reduce geographic inequity in specialist access

Regional, rural and remote consumers should not face substantially greater financial and practical barriers simply because of where they live.

Reform should include:

- stronger regional specialist workforce and training strategies
- outreach and visiting specialist models
- clinically appropriate telehealth
- better coordination of appointments to reduce unnecessary travel
- travel and accommodation assistance that reflects the real costs consumers face.

5. Design specialist reform around the whole consumer journey

Consumers move between public and private care and across multiple services. Reform should therefore be assessed against whether it makes the overall journey more accessible, affordable, coordinated and accountable.

This should include:

- better integration between public and private pathways
- interoperable records and consumer-facing digital systems
- person-centred and culturally safe communication
- consumer feedback and outcome measures
- clear accountability for follow-up and continuity.

Conclusion

Consumers experience specialist care as one journey, but the system is often organised in fragments. Long waits, unclear costs, poor communication, weak follow-up, geographic barriers and limited specialist availability interact in ways that make care harder to access and harder to navigate.

These problems do not affect everyone equally. Consumers with more money, time, confidence, health literacy, digital access and family support are better able to work around system gaps. Others face greater risk of delay, financial hardship, loss to follow-up and worsening health.

The evidence from this research points to a clear direction for reform. Consumers need greater visibility of referrals and waiting times, clearer information about the full cost of care, stronger continuity and coordination, better regional access and systems that work across public and private settings.

Consumer participation is important, but it should not be used to shift responsibility for coordination onto consumers and carers. A well-functioning specialist care system should make responsibility clear, reduce avoidable burden and support people to move through care without having to hold the system together themselves.

CHF therefore urges the Committee to consider specialist access and affordability as connected system issues rather than separate problems of workforce, fees, referrals or geography. Reform should be judged by whether it makes the whole consumer journey more accessible, affordable, coordinated and accountable.