Global Healthy Living Foundation Australia
Tower 1, Level 2,
495 Victoria Avenue, Chatswood, NSW 2067
ABN: 82 609 039 134
+61 413 005 246
info@ghlf.org.au
www.ghlf.org.au

Global Healthy Living Foundation Australia and CreakyJoints Australia

Submission for the Inquiry into Access to and Affordability of Medical Specialists in Australia

For the consideration of the Parliament of Australia House of Representatives Standing Committee on Health, Aged Care and Disability

Global Healthy Living Foundation Australia (GHLF Australia) and CreakyJoints Australia submit these comments on behalf of our patient community. We congratulate the Committee on initiating this Parliamentary Inquiry and welcome the opportunity to provide this submission.

About GHLF Australia and CreakyJoints Australia

GHLF Australia is a not-for-profit organisation founded in 2015. GHLF Australia is part of the US-based Global Healthy Living Foundation (GHLF), a disease-agnostic non-profit organisation whose mission is to improve the quality of life for people with chronic conditions. GHLF and its rheumatology community, CreakyJoints, have championed patients' voices worldwide for over 25 years.

GHLF Australia engages the Australian patient and caregiver community and provides current, relevant, condition-specific information, advocacy and research to improve health outcomes. We also share research and advocacy opportunities to empower patients to have a voice in healthcare access and policy at all levels.

GHLF Australia is the parent organisation of CreakyJoints Australia, the vibrant online patient community for autoimmune and inflammatory arthritis patients and their families throughout Australia. Since CreakyJoints Australia was established in 2016, we have published extensive online resources for our patient community, including information on accessing government benefits, conventional and complementary therapies, types of arthritis and related conditions, practical tips for daily living and more.

Our experience with chronic and complex conditions

We connect closely with our patient community through online social platforms, webinars, podcasts, events and focus groups, and by sharing their stories. We support and collaborate with other patient organisations that share our experiences and goals. We also work with healthcare professionals to learn their perspectives on the barriers their patients face.

This combination of lived experience and ongoing engagement with patients informs our advocacy. It helps us understand unmet needs, what matters most to patients and where new and emerging approaches may improve their lives. We bring those perspectives to our work with policymakers, healthcare professionals and other stakeholders as we advocate for better access to care and better health outcomes.

Our experience with rheumatology conditions

While we represent people with a range of chronic conditions, our submission will focus on rheumatology, as we have the deepest understanding of this cohort and the most data relating to it. We are confident that the barriers and impacts we raise in this submission will reflect those faced by other patient communities.

Around 15 per cent of Australians of all ages are currently living with arthritis, one of our most common chronic diseases, and a leading cause of pain and disability. Arthritis is also one of the most costly conditions for our health system, with expenditure of $5.26 billion in 2020-21 for osteoarthritis and rheumatoid arthritis. Overall, arthritis affects females more than males in Australia. Over 2.17 million males and over 3.24 million females are forecast to be living with arthritis by 2040.[1]

There are over 100 different forms of arthritis affecting people of all ages. These forms have different causes, symptoms and treatments. Beyond the joints, arthritis can affect other parts of the body, including the skin, connective tissues, eyes, lungs and other organs. Many types of arthritis can progress over time, with worsening symptoms and joint damage if the condition is not appropriately managed.

Common symptoms include pain, inflammation, stiffness, persistent fatigue and restricted physical function. The effects of arthritis on people's mental health, mobility, ability to work, relationships and financial stability are also significant and often overlooked.

Some forms of arthritis, such as rheumatoid arthritis (RA), axial spondyloarthritis (axSpA) and psoriatic arthritis (PsA), are immune-mediated inflammatory conditions. These conditions involve abnormal immune responses that cause inflammation and can damage joints and other tissues. Their causes are complex and may involve genetic and environmental factors.

Osteoarthritis (OA) results from a gradual breakdown of joint cartilage, eventually leading to bone-on-bone friction and damage. Like autoimmune arthritis, there is currently no cure.

In many cases, people can manage these conditions with pain relief and anti-inflammatory medications, physical therapy and lifestyle changes. Doctors generally treat autoimmune conditions with medications that suppress the immune system. These can be very effective but also come with various side effects.

We know that many people in our arthritis community deal with related conditions such as osteoporosis, psoriasis, fibromyalgia, inflammatory bowel disease, diabetes and more. Some treatments for certain forms of arthritis can also increase the risk of developing other conditions. For example, those who need the corticosteroid prednisolone to manage their autoimmune condition have a greater risk of developing type 2 diabetes, osteoporosis and cataracts.

Our response to the Terms of Reference

To inform our response to the Terms of Reference, we invited our community to share their lived-experience perspectives with us. We have included each reply we received in the appendices of this document.

We have also drawn on the themes raised by these members, along with themes we have identified over the years through our engagement with community members, health professionals and industry representatives across various platforms.

Terms of reference – A

Examine current access to medical specialists in cities, regional and rural communities, with consideration of workforce distribution, shortages, waiting times and barriers to recruitment, retention and training.

We recognise that many factors influence the barriers addressed in this Term of Reference. While other stakeholders are better placed to discuss the key factors mentioned from an industry perspective, we will focus on our understanding of the rheumatologist and nurse practitioner workforces.

Rheumatologists in Australia

The *2025 Australian Rheumatology Association (ARA) Workforce Report* highlights a significant and worsening crisis in the rheumatology workforce. The report highlights the following key findings.[2]

Critical workforce shortfall: Australia currently has 506 adult and 25 paediatric rheumatologists. These are significantly below the internationally recognised benchmarks, which would mean a workforce requirement of 749 adult rheumatologists and 80 paediatric rheumatologists. The paediatric workforce has remained largely static since 2022, which is highly concerning as the patient caseload continues to rise.

Geographic inequity in access to care: The workforce is overwhelmingly concentrated in metropolitan areas, leaving regional and rural Australia critically underserviced. Queensland and Western Australia are significantly underrepresented in rheumatologist numbers relative to their populations.

Future workforce pressures: A large proportion of advanced trainees (52 per cent) indicate they do not intend to take on a full clinical workload, while only 72 per cent expect to conduct clinical work solely in rheumatology. This signals that future headcount numbers will need to increase above current forecasts to meet expected patient demand. The growth of the workforce is constrained by the limited number of funded training positions.

Systemic and financial considerations: The majority of rheumatology care (approx. 60 per cent) is delivered in private clinics, where only 5-10 per cent of appointments are bulk billed, creating significant out-of-pocket costs for patients. Given the majority of care occurs in the private setting, there is a critical need to expand training from the public setting to private practice settings.

Workforce demographics: While the gender balance among rheumatologists is nearing parity (47.5 per cent female), women are still underrepresented in senior academic and leadership positions. Additionally, the workforce lacks diversity, with Aboriginal and Torres Strait Islander peoples significantly underrepresented (1 per cent of rheumatologists).

Depending on their location and whether they access public or private care, patients can face waiting times exceeding six months for an initial rheumatology appointment.

Nurse practitioners in Australia

About 3,000 qualified NPs work in Australia, and about 30 per cent work in regional and remote areas.[3]

NPs are the most senior and experienced clinical nurses in the healthcare workforce. They have authority to practice independently and collaboratively in an expanded clinical role. They collaborate with other nurses and healthcare professionals, such as GPs, specialists and allied health professionals, and work in a variety of settings, including hospital and community settings.

NPs are endorsed registered nurses with Master's-level clinical training and professional endorsement to practice at an advanced level. They can diagnose and treat many common conditions, order pathology and imaging and refer to specialists.[4]

NPs can also prescribe medications within their scope of practice. Patients pay the same subsidised price for nurse-prescribed medicines as for doctor-prescribed medicines.

In Australia, the cost of an NP appointment varies depending on the appointment length, whether the NP bulk bills, and whether you are eligible for Medicare. Generally, NP fees are significantly lower than specialist doctors'.

Their presence increases the flexibility of the health workforce and improves access to care for Australian communities, particularly those in underserved and marginalised populations. As advanced clinicians, NPs often spend more time on consultations, providing clinical assessment, diagnostic reasoning and care evaluation, as well as health promotion and education.

We do not know the current number of rheumatology nurse practitioners in Australia; however, of the 308 healthcare professionals who completed a national survey used to inform the *Australian Rheumatology Association Clinical Care Standard for the Diagnosis and Management of Rheumatoid Arthritis in Adults*, only 3 were rheumatology nurse practitioners.[5]

Terms of reference – B

Examine the effectiveness, transparency and equity of referral pathways from the perspective of patients, primary health care practitioners and medical specialists across the public and private health sectors, with consideration of factors affecting referral patterns and any systemic, regulatory or administrative barriers to the appropriate utilisation of these pathways.

Getting a referral from a GP

We believe most members of our community get referrals from GPs to medical specialists when needed. However, those in regional and remote communities can wait weeks or months to see a GP in the first place. GPs and specialists may also practise in the region but not be taking new patients at that time.

We have heard members raise several common barriers to getting a specialist referral from their GP.

For example, GPs may be reluctant to refer when symptoms, such as pain, rashes or inflamed joints, come and go in different parts of the body or don't match typical disease patterns.

The *Axial Spondyloarthritis International Foundation: Delay to Diagnosis Report* drew on the lived experiences of people with AS across several countries, including some of our associates at Ankylosing Spondylitis Victoria. The report found that one of the most common barriers to timely diagnosis was incorrect or missed diagnosis at the first point of healthcare system diagnosis.[6]

Sometimes, GPs lack knowledge of less common conditions and symptom patterns, so they miss the cues that would otherwise lead them to refer the person to an appropriate specialist. This can also happen if the GP doesn't listen properly to the patient or rushes the appointment.

Some people may not know they could benefit from a specialist appointment or may lack the skills or ability to advocate for a referral. Others may not know they have the right to find their own specialist and then ask their GP for a referral letter.

Medical gaslighting

Unfortunately, we also hear members say their GPs make them feel gaslit. They might be told the pain in their knees or hips is due to being overweight when it could actually be RA or a similar condition. Some have had their symptoms downplayed or been told they're all in their head. As a result, they don't get referred to the specialists they need when they need them.

Of course, medical gaslighting is not limited to our community. The *Bridging the Gender Pain Gap report on the Victorian Government's Inquiry into Women's Pain* found seventy-one per cent of respondents reported being ignored, dismissed or having their pain minimised by healthcare professionals.[7] These findings are consistent with the experiences shared by members of our community, many of whom are women, and reinforce the importance of listening to patients and taking their symptoms seriously.

Communication and administrative barriers

The *Australian Rheumatology Association Rheumatoid Arthritis Clinical Care Standard* states:

People with rheumatoid arthritis require access to specialist care when their symptoms get significantly worse or they experience treatment-related adverse effects. To accommodate this, rheumatology service providers must ensure that a person with rheumatoid arthritis can contact a member of their rheumatology care team by telephone, email or virtual technology for specialist advice and interim management until a definitive review can be arranged.[8]

Including this quality statement in the Standard shows that the researchers identified inconsistencies in how patients access their rheumatologists between appointments. From our engagement with community members, we know most people can reach their rheumatologists most of the time. However, we have also heard cases where this doesn't happen, such as over weekends or when the rheumatologist is away.

We also understand that sometimes the communication options provided by the rheumatology service aren't accessible to some patients. If the service offers only one communication option, it may exclude those who cannot use it. For example, some people cannot, or struggle to, communicate over the phone, so they need to use email or message services. Some cannot use electronic communication methods, so they need phone calls.

Terms of reference – C

Examine the affordability of specialist services, including out of pocket costs for consultations, diagnostics, procedures, and patient access to specialists through public health services, as well as factors influencing fee setting by specialists in the public and private health sectors.

The conditions people in our community live with do not go away. In addition, people develop other related conditions that compound their burden of disease and reduce life expectancy. The specialists our members might see include, but are not limited to:

- Rheumatologists
- Dermatologists,
- Endocrinologists
- Gastroenterologists/hepatologists
- Haematologists
- Neurologists

- Orthopaedic surgeons
- Ophthalmologists
- Nephrologists
- Cardiologists
- Respiratory physicians
- Psychiatrists

According to the *Australian Government Department of Health Medical Costs Finder*, the typical fee for an initial appointment with a private rheumatologist for someone with a complex disorder is $430. After the Medicare rebate, patients typically pay about $180 out of pocket. For a follow-up appointment, the typical fee is $225, and the out-of-pocket amount is $99.[9]

A person with a stable condition would generally see their rheumatologist once or twice a year. However, a new patient may have multiple appointments for diagnostic tests, new symptoms or treatment adjustments. Some members see multiple specialists each year.

Those using the public system, or whose specialists bulk-bill them, can still incur significant costs to access health services. For example, petrol, parking, public transport or taxis. Those travelling from regional or remote areas may also need to include transport, accommodation and meal costs. Some need unpaid or paid support people to help them get to appointments, so their costs also need to be factored in.

Add in the costs of treatments, regular visits to GPs and allied health professionals, missed wages and the cost of care, and they can quickly add up to thousands of dollars each year.

Terms of reference – D

Examine the impact on patient outcomes by delays due to cost, distance and waiting times, and broader system impacts on primary care, emergency departments, public hospitals, chronic disease management, as well as impacts on people due to deferred or missed care.

Impacts due to waiting times, delays to diagnosis or interruptions to continuity of care

For people with autoimmune conditions, such as RA, the ideal time to begin one or more appropriate treatments, such as disease-modifying anti-rheumatic drugs (DMARDs), is within the first few months of initial symptoms. Intervening during this brief window has been shown to significantly slow disease progression. This is the time when seeing a GP, having a GP who suspects their patient may need a specialist, having a specialist appointment and meeting the criteria for DMARDs are all critical and urgent.

An example of what this can look like is the difference between having hands that can clench, flex and rotate freely and hands with painfully distorted joints that are permanently stuck in a curled position.

People with diagnosed conditions who have begun a medical treatment regimen can still be adversely affected by interruptions to their continuity of care. These interruptions might be due to a range of factors, including:

- Unavailability of their treating doctors
- Seeing different doctors at each appointment (especially in the public system)
- Inability to get to their appointments in person
- Technical barriers to online appointments

During these interruptions, people may miss getting new prescriptions when they need them, and their symptoms may worsen. In turn, this can affect their ability to do everyday activities such as work, study, socialise, cook or walk.

People in these situations often present to local Urgent Care Clinics, hospitals or ambulance services to get the care they desperately need. As a result, these services face more pressure.

People affected by appointments cancelled by their service provider may need to change many plans, including work rosters or arranging someone to take them to the appointment. This could increase stress and negatively affect relationships with those around them.

Impacts due to cost and distance

Our response to Term of Reference C shows some of the costs our members experience every year.

While some people can absorb these costs into their household budgets, many cannot, particularly when their condition affects their ability to work. For these people, finding this money means cutting other areas of their budget, starting with luxury items and sometimes continuing until they need to cut back essential spending, such as food, clothing and power.

Sometimes, it means missing out on essential care. People postpone getting their prescriptions filled. They stop seeing allied health professionals and skip essential medical appointments. They spend many hours in public hospital emergency departments because they can't afford to see their treating doctors. Together, these factors contribute to poorer mental and physical health outcomes.

We have heard countless stories of people avoiding emergency departments due to previous medical gaslighting, the increased risk of infection in those settings or because they are tired of sharing their medical history over and over.

Persistent fatigue is a common symptom of many people with autoimmune or other chronic conditions. For those in regional or remote areas, travelling for hours or days for specialist appointments often makes their fatigue so debilitating that they can't function for days (or even weeks) afterwards. Long travel times can also trigger painful symptoms to flare, requiring more medication to manage them.

In the long term, all these factors can contribute to the need to change roles or stop working/studying, rethink career paths and put pressure on relationships. It is not surprising that the longer people deal with the impacts of their chronic conditions, the more likely they are to experience deteriorated mental health.

Impacts due to broader systemic issues

One impact we regularly hear community members raise is administrative and communication barriers within and between healthcare settings. Our healthcare system operates in silos with inconsistent approaches to communication and record-keeping. For patients, that can mean their medical notes are outdated or incorrect, key members of their healthcare team are left out of the loop, or providers miss aspects of their care because they assume another team member is responsible for managing them.

People who have the capacity to advocate for themselves are often forced to become their own case manager. They need to track their prescriptions, research possible contraindications, ensure the right information reaches the right person and more. Many say this aspect of managing their health feels like a full-time job and can be harder than dealing with the condition itself.

Terms of reference – E

Assess innovative and emerging models of care that may improve access to medical specialists.

We understand that the Australian Government has worked with relevant stakeholders for some years to expand nurse practitioners' scope of practice and increase the size of this workforce.

We also know organisations such as the Australian Rheumatology Association, the Royal Australian College of General Practitioners and medical training universities all play a role in educating GPs about rheumatology and related conditions. However, the extent and depth of this training can vary greatly.

We call on the Australian Government to:

- Remove systemic barriers to quality care, such as poor referral pathways and limited communication between medical specialists.
- Fund more training and jobs for rheumatologists, GPs and rheumatology nurse practitioners in Australia, particularly in regional and remote areas. We believe their presence will help alleviate pressure on existing healthcare professionals and fill concerning gaps in continuity of care.
- Facilitate the expansion of rheumatology training programs, in partnership with these stakeholders and others, such as the National Rural Health Alliance, Arthritis Australia, CreakyJoints Australia and other patient organisations.
- Establish more transparent referral pathways, including clear explanations when specialist referrals are declined and accessible processes for reconsideration or alternative care.
- Support improved care coordination between GPs, specialists and other healthcare providers, particularly for patients managing multiple chronic conditions.
- Fund research and programs that will expand the role of telehealth, AI and other appropriate technologies to help improve the costs of and access to medical specialists.
- Expand financial assistance programs that address the direct and indirect costs of specialist care, including travel, accommodation and other expenses for patients in regional and remote communities.

Thank you again for the opportunity to provide input into this Parliamentary Inquiry.

Appendix 1. Lived experience comments — Melinda Barrett

Inquiry into Access to and Affordability of Medical Specialists in Australia

I live in regional Victoria with systemic lupus erythematosus and a number of complex associated and co-existing health conditions. Over many years, I have required care across numerous medical specialties, including rheumatology, cardiology, electrophysiology, neurology and migraine services, immunology, endocrinology, gastroenterology and respiratory medicine. At times, I have needed several of these specialties concurrently.

My experience has taught me that for people living with complex chronic disease, specialist access is not simply about whether a specialist exists. It is whether you can find one; whether they will accept you; whether your referral will be accepted; whether you can afford to see them; whether you can physically get to them; whether you can maintain continuity of care when a specialist leaves; and, once you have multiple specialists, whether anybody is actually coordinating the whole picture.

Increasingly, that responsibility falls on the patient.

Losing a cardiologist — and being unable to replace one

I had established cardiology care. I did not choose to stop receiving that care. The cardiologist I was seeing stopped visiting the regional area in which I live, and I therefore needed another cardiologist.

My GP referred me to the public health network.

At that time, my medical history included sick sinus syndrome and a permanent pacemaker. I had experienced a major stroke and three transient ischaemic attacks (TIAs). I also had known atrial fibrillation, including an episode lasting more than ten hours that had resulted in an emergency department presentation within the same health service.

Despite this history, my GP received advice that my referral had been reviewed and it had been determined that I did not require a cardiologist.

I was left without one.

This was not simply an unsuccessful attempt to access a new specialist. It was a breakdown in continuity of established specialist care.

When a patient who requires ongoing specialist management loses access because their existing specialist retires, relocates or stops servicing their area, where does responsibility for continuity of care sit?

A rejected referral should not simply be the end of the pathway. Patients and their GPs need to understand why a referral has been declined, what alternative pathway exists and how a decision can be reconsidered or escalated when the referring doctor continues to believe specialist care is required.

I received care because someone opened a door for me

After the public referral was declined, I still needed a cardiologist.

I eventually obtained an appointment with a private cardiologist approximately 122 kilometres from where I live. However, even obtaining that appointment was not straightforward.

My cousin worked at the private hospital. She went personally to the cardiologist's rooms and pleaded with them to accept me as a patient. They did.

I was fortunate. I had someone who knew where to go, who was willing to advocate for me and who could help open a door that I had been unable to open through the usual pathway.

I subsequently received private cardiology care and ultimately underwent catheter ablation for atrial fibrillation.

I remain enormously grateful that my cousin advocated for me. But I also find the experience deeply troubling.

What would have happened if I had not had her?

What happens to the patient who does not have a family member working within a hospital? What happens to someone who cannot travel 122 kilometres? What happens to someone who cannot afford private specialist fees? What happens to the person who does not have the health literacy, confidence, family support or sheer persistence required to keep searching after a referral has been declined?

Access to medically necessary specialist care should not depend upon social capital, personal connections, financial resources, geography or a patient's ability to advocate relentlessly for themselves.

We should not become so desperate for healthcare that we have to resort to whatever means are available to obtain care that we genuinely need.

The real cost of specialist care is cumulative

Affordability is not adequately represented by the gap payment attached to a single specialist consultation.

Following my atrial fibrillation surgery, a cardiology follow-up appointment left me almost $400 out of pocket.

I also receive treatment for chronic migraine approximately every eight weeks. The treatment itself costs me around $400 each time.

But the treatment fee is only part of its real cost.

Accessing my migraine treatment requires a round trip of approximately 136 kilometres and close to two hours of driving.

I cannot drive myself home after treatment, which means another person must take me.

I generally give that person around $25 towards fuel and pay for their lunch, coffee and other reasonable costs during the trip. I need their help to access my healthcare, and I do not believe doing so should leave them financially worse off.

There is also parking. There is my time. There is their time. And approximately eight weeks later, we do it again.

For someone living with complex chronic disease, this is occurring alongside the costs associated with other specialists, GP care, investigations, medications and other healthcare.

At different times I have required rheumatology, cardiology, electrophysiology, neurology and migraine services, immunology, endocrinology, gastroenterology and respiratory medicine. Sometimes multiple specialists have been required at the same time.

The health system may see these as separate episodes of care and separate financial transactions. The patient experiences them as the cumulative cost of being chronically ill.

Affordability therefore needs to be considered at the level of the whole patient, not simply one appointment at a time.

When the specialist simply isn't available

Rheumatology presents another significant problem for me.

I live with systemic lupus erythematosus, a systemic autoimmune disease for which rheumatology care is important.

Yet I have not had the appropriate ongoing rheumatology care I need for approximately five years. I am currently trying to find a rheumatologist.

This is not because I do not understand the importance of specialist care, have chosen not to seek it, or lack a GP willing to refer me.

Appropriate rheumatology care has simply been extremely difficult to access.

For people living with chronic disease, waiting for specialist care is not necessarily a temporary inconvenience. Months can become years, while the disease continues to require management.

The patient becomes the care coordinator

There is another aspect of specialist access that receives less attention: what happens after you successfully access multiple specialists.

Someone has to coordinate them.

In my experience, much of that responsibility falls on the patient.

I need to remain aware of what different specialists are doing, what has changed, what medications I am taking, what investigations have been ordered, what needs following up and what information one clinician may need from another.

An excellent GP can make an enormous difference and will try to coordinate the whole picture. But GPs are working within significant time constraints, and there is an enormous amount to manage when a patient has complex, multisystem chronic disease.

I currently have a GP appointment every week. That is how much there can be to monitor, discuss, coordinate, refer, review and follow up. It never really ends.

This creates another form of inequity.

A patient who is organised, confident, health literate and able to advocate for themselves may navigate a fragmented system more successfully than someone who is exhausted, unwell, cognitively affected, socially isolated, unfamiliar with the health system, has limited English, or does not have family support.

Being better at navigating healthcare should not result in better access to healthcare.

Access is not achieved merely because a patient eventually manages to see several individual specialists. For people with complex chronic disease, meaningful access requires continuity, communication and coordination between services.

Without that, the patient becomes the coordinator of their own highly complex medical care.

Regional access changes the equation

Living regionally magnifies these issues.

A specialist who stops visiting an area can mean the sudden loss of established care. Another specialist may be more than 100 kilometres away. Treatment may require somebody else to drive.

Every appointment can bring fuel, parking and food costs as well as hours of travel.

The ability to attend therefore depends not only on whether an appointment is available, but on transport, money, time and often the goodwill and availability of another person.

These indirect costs should not be treated as peripheral to healthcare affordability. For regional patients, they are part of the cost of accessing healthcare.

Watching Australia's health system change

I have also experienced healthcare from another perspective because I previously lived in the United States for approximately eleven years.

While I lived there, people frequently spoke to me about Australia's healthcare system and Medicare. Australia's system was something people admired.

When I left Australia, I also regarded our healthcare system extraordinarily highly, although I felt that some cracks were beginning to appear.

I returned to Australia in 2019.

I do not suggest that Australia has become the United States. It has not.

But as a patient requiring complex ongoing care, I am increasingly concerned by something that feels uncomfortably familiar: the emergence of the haves and the have-nots.

The difference may be the ability to pay privately. It may be where somebody lives. It may be whether they have transport. It may be whether they have an exceptional GP. It may be whether they know someone who can advocate for them. It may be their health literacy. Or it may simply be whether a sick and exhausted person has enough capacity left to make another phone call, chase another referral and try another door.

A universal healthcare system can be universal in principle while becoming increasingly unequal in people's ability to actually access it.

What I would like to see change

- Protect continuity of specialist care when a clinician retires, relocates, ceases regional outreach or otherwise becomes unavailable.
- Require clear and transparent reasons when specialist referrals are declined.
- Ensure that a declined referral includes an appropriate alternative pathway rather than simply returning responsibility to the patient and GP.
- Provide straightforward mechanisms through which GPs can seek reconsideration or escalation of rejected specialist referrals.
- Consider the cumulative annual cost of specialist care for people living with complex chronic and multisystem disease, rather than assessing affordability consultation by consultation.

- Recognise travel, transport, parking, accommodation and the need for carers or support people as genuine components of specialist access and affordability, particularly for regional patients.
- Strengthen coordination between specialists, primary care and other services for people with complex chronic disease.
- Consider models of care that provide meaningful care coordination rather than requiring patients to integrate multiple specialist services themselves.
- Ensure that access to medically necessary specialist care does not depend on wealth, geography, personal connections, health literacy, family support or exceptional persistence.

Why this matters to me

I remain deeply grateful for Australia's healthcare system and for the individual healthcare professionals who have cared for me.

My concern is not about individual doctors trying to work within a difficult system. It is about what happens between them.

I have experienced excellent healthcare in Australia.

I have also experienced what happens when a specialist disappears, a referral pathway ends, appropriate care is difficult to find, private care becomes the only practical option, geography adds another barrier, and responsibility for holding everything together lands with the patient.

I have been fortunate enough, so far, to find another way through.

Sometimes that has been because I could pay. Sometimes because I could travel. Sometimes because I had an exceptional GP. And on one particularly important occasion, because someone I loved was able to walk into a specialist's rooms and ask them to please help me.

I am grateful for every one of those things.

But access to necessary healthcare should not depend on being fortunate enough to have them.

Melinda Barrett

Appendix 2. Lived experience comments — Annette Brown

I am aware of the privilege that I have in that I can afford to pay for a specialist, and I live in a major city, yet the wait times are ridiculous. I am thinking of a recent experience I had with my daughter.

What is it like for rural or regional people, or for those waiting in the public system?

The impact of not getting a diagnosis or treatment will vary for different people, but for us it has resulted in frustration, having to guess what may be wrong and worrying that for years we/she may not be doing the right thing for that condition. This will directly impact her quality of life.

Regards Annette

Appendix 3. Lived experience comments — Marilyn M

I had a reasonable rheumatologist until she semi-retired and took patients only at Hospital A. I had a reasonable though disillusioned GP, but he also retired, being fed up with less ability to spend enough time with patients' consultations.

I was without a GP for a month, then found one whose responses to my four flus and five bladder infections in six months at age 71 were less than adequate. When I was brave enough to describe some of my symptoms, he grinned stupidly at me, wrote prescriptions and shooed me out the door.

I was without a rheumatologist for two years because none would see patients north of Adelaide, and eventually went to a public hospital rheumatologist who, despite long-term problems with methotrexate medication for over 10 years, grinned at me and put me back on it. Eventually, I found a rheumatologist who practices this side of Adelaide, but my earliest appointment was for December 2026. My referral was written a year before.

I have had irritable bowel syndrome (IBS) for over 30 years now, but nobody ever sent me to a gastroenterologist until I demanded it last year. I will see them this next month.

I am 71, with a 94-year-old deaf mother whom I provide financial management, appointment transport and liaison for her medical needs. I have psoriasis, psoriatic arthritis, HEDS, fibromyalgia, IBS, chronic constipation, faecal incontinence and have had two knee replacements, one hip replacement and a broken hip repaired.

My husband and I pay almost $800 a month in health benefits out of his meagre superannuation, since I have none. We are retired and live on full pensions, and specialist fees of $300 plus are extremely difficult for us.

The Arthritis Foundation recommends coordinating your medical team (?). There is no team! GPs have no time to listen and no skills to judge what is happening. I can't get appointments in time to deal with urgent illness or injury. I have used an Urgent Care Clinic more often than should be necessary, but one time when I had a bladder infection and no GP appointment for two weeks, I went to our local one on a Sunday. It was closed due to a lack of doctors. I went to a different one, but they were full and taking no patients, so I was sent to a third one! I then attended Hospital B instead — after I had defecated on the journey home from the first clinic and had to shower again first.

One time at Hospital B, I told them on arrival that I had a bladder infection and the flu. They asked irrelevant questions about my pain (which I always have, but it was not the issue). They kept me overnight, sent me for chest X-rays because, as I had told them I did have the flu, then a head X-ray because I had headaches, but forgot to check the result of a urine test until they told me I could go home as there was nothing wrong. I asked about the urine test, but no result had been added to my record. 10 minutes later, they told me I had a bladder infection!

Medicare is underfunded, and overcharging is rampant by specialists. GPs were the basis of good general patient care, but that was when our GPs took the time to listen and keep up to date with skills.

The last GP I stopped seeing appeared to be afraid to have contact with me; I assume for religious reasons. He was inexperienced, as shown by the major burn on my arm when I asked him to remove a growing wart. He held the freezing device four inches from the wart, so that the area burned was quite large and very deep. If he is so afraid to be near a woman, then he needs to be restricted to men only as patients.

Our old GPs diagnosed, not dithered, prescribed like guesswork and referred at the drop of a hat. Specialists have a narrow field of knowledge and focus. We need GPs to look at the whole patient and have time to know which people have pain and deal with it, and which are lonely or bored, which know their bodies and those who don't. This takes time!

I deal with pain by distraction daily; it works better than medication, but at night, when I can normally sleep well, I cannot distract from being woken constantly. I can go for a walk and go back to sleep, but it won't stop being woken a while later.

Marilyn M

Appendix 4. Lived experience comments — Veronica Miller

These comments were taken from the draft of a GHLF Australia article featuring Veronica Miller in 2025. Veronica gave signed consent for GHLF Australia to use her comments in other projects.

“Many Australian regional towns have doctor shortages and it can take weeks to get an appointment. You just have to wait, or you call first thing every morning to try and get a last-minute appointment. That makes it really hard to get continuity of care, and it makes conditions like mine much harder to manage,” said Veronica.

“Thankfully, I know my body and the steps I need to take. I've had arguments with GPs about which blood tests I need done because they've disagreed, so it’s required quite strong advocacy at times to get the help I need”, she continued.

Veronica needed to resort to telehealth appointments with doctors far from her home. She also had some of her prescription medicines dispensed online. What she couldn’t get was regular blood tests to monitor how well her medications were working and whether her doses were right.

That meant another trip to Sydney, as her ophthalmologist wasn’t sure a regional radiologist had the specialty and knowledge needed to take and interpret her MRI.

Travelling to Sydney for her half-hour infusion takes five and a half hours by bus, then local trains in Sydney. Not to mention an overnight stay and returning home the next day. Also, being treated in the public health system meant she had no control over the appointment times. “All I wanted to do was get there, get it done and get home. I had very little energy for anything else,” said Veronica.

Of course, Veronica wanted to have her treatment done locally. Her advocacy background gave her the confidence to negotiate that, but it involved a lot of red tape and conversations between her care team and her local hospital. Part of the challenge was working out details such as who had admitting rights, who would monitor her and so on. Also, most health professionals in regional areas don’t have the experience to treat thyroid eye disease, as it's a highly specialised field.

Eventually, Veronica managed to arrange four of her 12 treatments locally, saving her a lot of time, energy and money. It has other benefits, too. “I've got some local staff at the hospital who know what's going on for me and they've been learning as well. They've been interested in understanding thyroid eye disease as they probably don't come across it a great deal,” she said.

Veronica experiences other barriers to care as well. She doesn’t have private health cover, so she pays hundreds of dollars a year to see her endocrinologist and ophthalmologist. Her MRI cost around $700, and she received around $300 back from Medicare. While she can claim some costs from Medicare and the New South Wales Government, the overall cost of Veronica’s care has been extremely significant.

Health system changes Veronica would like to see

While Veronica knows the issues with access to healthcare in rural and regional areas of Australia will take a long time to work through, there are two things she would really like to happen.

The first is to ensure local GPs and optometrists have training in TED and managing its early symptoms. She believes many people are currently undiagnosed and put up with the symptoms without knowing it is a serious autoimmune condition that needs specialist care.

Veronica would also like to see case managers for people with chronic health conditions to help them navigate multiple specialists, treatments, and different levels of the healthcare system. “It would be

great to think that there was some case conferencing process within Medicare where I could get all of my specialists on a video call together, we could discuss my case, we could discuss who's going to do what, we could do that in the space of half an hour. It would save me a lot of back and forth. It would mean everyone's on the same page and it would provide a better continuity of care," she said.

"I feel that it's really unfair for people that don't have the skills to negotiate or navigate the system", she continued.

Appendix 5. Lived experience comments — MyFlareUp

To: The House of Representatives Standing Committee on Health, Aged Care and Disability

Re: Medical Specialist Workforce and Affordability

Dragon Claw Charity t/a as MyFlareUp welcomes the opportunity to comment, via our partner CreakyJoints Australia, on the challenges facing Australians living with autoimmune inflammatory diseases who rely on ongoing specialist medical care.

More than **five million Australians** live with autoimmune conditions, many of which require lifelong management by medical specialists such as rheumatologists, immunologists, neurologists, gastroenterologists and dermatologists. Access to timely and affordable specialist care is essential to preventing disease progression, disability and avoidable hospital admissions.

Unfortunately, many patients delay or forgo specialist appointments because they cannot afford the out-of-pocket gap fees. This often leads to worsening health, reduced workforce participation, increased reliance on social supports, and higher long-term costs to the Australian healthcare system. Investing in affordable specialist care is therefore both a health and an economic imperative.

Our community is also experiencing a severe shortage of rheumatologists and other specialists with expertise in autoimmune diseases. Waiting times for appointments are often many months, delaying diagnosis and treatment during critical periods when early intervention can prevent irreversible damage.

Public hospitals have very long waiting times, making them inaccessible and forcing some people down the private system route after waiting a considerable amount of time to be seen. If patients are accepted at the public hospital, there is no consistency in seeing the same specialist to maintain an ongoing therapeutic relationship, and it is often a case of turning up for an appointment and seeing an unfamiliar specialist.

In addition to expensive specialist fees, some of our patients also have to pay for off-label prescriptions. For example, a single female lupus patient is paying $12,000 p.a. out of her average wage and a bullous pemphigoid patient is paying $22,000 p.a., leaving no retirement fund income and adding to the overall disease cost burden for these patients.

The Australian Government should increase investment in specialist training positions, particularly within teaching hospitals, to build a sustainable workforce capable of meeting current and future demand.

Regional, rural and remote Australians face even greater barriers. Many of our members travel hundreds of kilometres, or even interstate, to access medical specialists.

Indigenous Australians in isolated regions have highly restricted access to medical specialists. For example, patients in the Kimberley suffer from lupus five times more than the average national indigenous Australian. In the meantime, their organs have a higher incidence of damage.

In summary, reliance on ongoing specialist medical care is a necessity that can come with extreme financial burden for patients living with autoimmune inflammatory diseases. We welcome the expansion of the available workforce to assist in timely and more cost-effective avenues for our patients.

Susan Hughes

Director, Chair of Patient/Caregiver Committee, Dragon Claw Charity Limited t/a MyFlareUp

My Autoimmunity Community

susanh@myflare.org

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