

Emerge Australia's Submission to:

Inquiry into Access to and Affordability of Medical Specialists in Australia

Standing Committee on Health, Aged Care and Disability

October 2026

Emerge Australia is the national organisation leading action on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), long COVID and overlapping conditions. We work to improve the lives of those impacted through clinical education, policy and advocacy, biomedical research and health and support services.

Emerge Australia welcomes the opportunity to make a submission to the House of Representatives Standing Committee on Health, Aged Care and Disability's Inquiry into the Access to and Affordability of Medical Specialists in Australia. People with ME/CFS and long COVID are among the most severely affected by the problems this inquiry has been asked to examine. Due to their limited functional capacity, many rely on medical specialist care that is frequently unavailable, unaffordable, poorly coordinated, or delivered by clinicians without the knowledge required to treat them safely.

Executive Summary

Emerge Australia's 2026 consultation with its Community Advisory Panel (CAP), conducted to inform this submission, paints a consistent and disturbing picture: people with ME/CFS and long COVID face substantial barriers to accessing medical specialists, pay significant amounts out of pocket for care that is frequently inadequate, and are often harmed physically, financially and psychologically by the very system meant to help them.

People with ME/CFS and long COVID may need to consult a range of medical specialists, including cardiologists, neurologists, gastroenterologists, immunologists, rheumatologists and general physicians, to investigate and manage different aspects of these multisystem conditions. References to medical specialists in this submission therefore describe respondents' experiences across specialties, rather than with any one medical specialty.

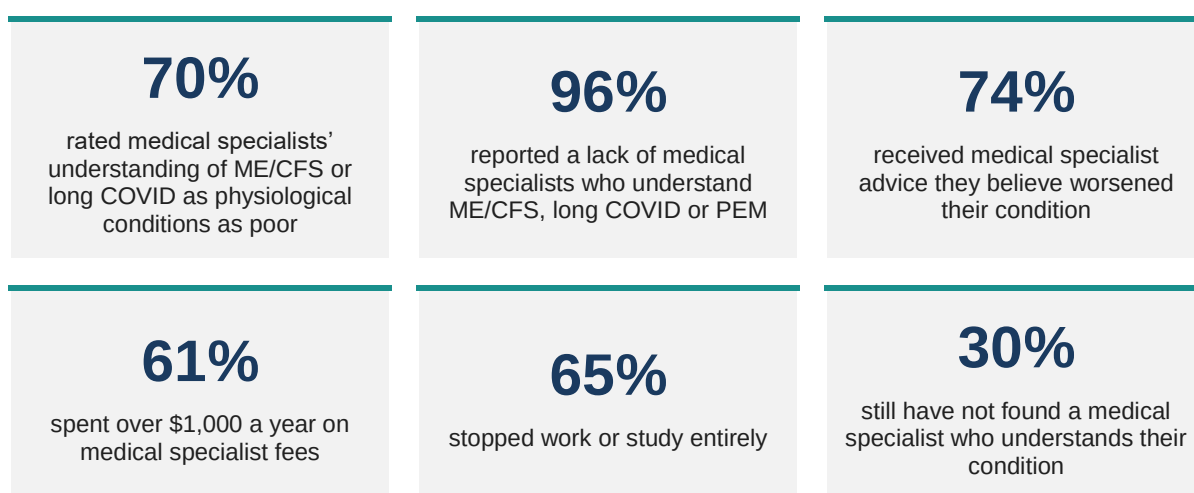


Figure 1. Headline findings from the 2026 Emerge Australia Community Advisory Panel consultation (n=23).

Key findings:

- 70% of respondents rated medical specialists' understanding of ME/CFS or long COVID as a physiological condition as "not very well" or "not at all". Only 9% rated understanding as "very well".
- 96% of respondents identified a lack of medical specialists who understand ME/CFS, long COVID or post-exertional malaise (PEM) as a barrier to care; 91% cited high out-of-pocket costs and 87% cited long waiting times.
- 74% of respondents said they had been given medical specialist advice they believe worsened their condition, most commonly being told to push through symptoms, being referred for graded exercise therapy (GET), or being told their illness was primarily psychological.
- 61% of respondents reported spending more than \$1,000 a year on out-of-pocket medical specialist costs, with 22% spending more than \$5,000 a year. This is on top of lost income, with 65% having had to stop work or study entirely because of their condition.
- 65% of respondents reported needing at least two referrals before finding a medical specialist with relevant understanding of their condition. A further 30% still have not found a medical specialist.

- There is no nationally recognised or consistently available medical specialist pathway responsible for the comprehensive management of ME/CFS or long COVID in Australia. Respondents described being referred to organ-specific medical specialists who would diagnose and treat individual body system, with no clinician taking overall responsibility for their ongoing care.
- 74% of respondents have used telehealth for medical specialist care, but experiences of quality were mixed, and several respondents reported telehealth being refused for patients too unwell to attend in person.
- The two changes respondents most wanted were publicly funded medical specialist services for ME/CFS or long COVID (61%) and better medical specialist education on ME/CFS, long COVID and PEM (57%).

These findings speak directly to all five terms of reference for this inquiry. Emerge Australia's recommendations focus on nationally consistent multidisciplinary service networks for ME/CFS, long COVID and associated energy-limiting conditions; Medicare structures that reflect the complexity and duration of care; coordinated referral pathways; clinician education; and safe, flexible access through telehealth, outreach and home-based care.

Recommendations

Emerge Australia recommends the Committee consider the following measures:

1. Establish nationally consistent, condition-informed multidisciplinary service networks.

The Australian Government should work with state and territory governments to ensure equitable, publicly accessible medical specialist care for people with ME/CFS, long COVID and related post-infectious and energy-limiting conditions. This should include nationally consistent referral pathways, timely access to medical specialists with relevant condition-specific expertise, and care coordination across specialties. Funding arrangements should support telehealth, regional outreach and home-based options for people too unwell to safely attend appointments in person.

2. Reform Medicare rebates for complex medical specialist care.

Review and amend relevant Medicare Benefits Schedule items and related funding arrangements so that rebates better reflect the time and complexity involved in comprehensive medical specialist assessment, treatment and management planning, multidisciplinary case conferencing and shared care for people with ME/CFS, long COVID and related conditions. Current funding arrangements should not encourage consultations that are too short for comprehensive assessment and care coordination.

3. Develop coordinated referral and shared-care pathways.

Establish nationally consistent referral and shared-care pathways that help GPs connect patients with appropriate medical specialists and facilitate communication and shared care between treating clinicians.

4. Fund national clinical education and workforce development.

Fund current, evidence-based education for medical specialists, GPs, nurses and allied health professionals on ME/CFS, long COVID and PEM, alongside clinical networks, supervision and training pathways that build and retain condition-specific expertise.

5. Guarantee safe and flexible access to care.

Require service models to provide telehealth as a genuine option, home-based medical care for people who are housebound or bedbound, and flexible appointment structures including shorter or split appointments, flexible timing and accessible waiting environments to reduce the risk of PEM, infection and deterioration in functional capacity caused by attending medical specialist appointments in person. Public hospital outpatient services should be included in these reforms. Appointment scheduling should minimise waiting and accommodate each patient's functional capacity, reduce time spent in crowded environments and, wherever possible, match patients with medical specialists who have relevant condition-specific expertise.

6. Address regional and rural inequity through integrated outreach.

Fund telehealth-enabled hub-and-spoke services that connect regional, rural and remote patients and local clinicians with medical specialists who have relevant condition-specific expertise. Where feasible, support periodic visiting medical specialist services through regional health services or commissioned programs. Funding should include the coordination and administrative infrastructure needed to manage referrals, appointments and communication between services. Condition-specific expertise and long waits must also be addressed for metropolitan patients.

7. Collect national access, cost and outcome data and evaluate service models.

Establish consistent data collection on referral outcomes, waiting times, out-of-pocket expenditure, geographic access, illness severity, safety and patient outcomes, and require evaluation of funded models to identify what improves timely, affordable and effective medical specialist care.

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Evidence and analysis

Evidence informing this submission

This submission draws on Emerge Australia’s experience supporting people with ME/CFS and long COVID; a 2026 online consultation with 23 members of Emerge Australia’s Community Advisory Panel; service data showing how often people sought help finding or working with GPs and medical specialists; and published evidence cited throughout the submission. The CAP consultation provides detailed lived-experience evidence but was a self-selected, non-random sample and should not be interpreted as representative of the broader population. Further information about the consultation method and respondents is provided in Appendices A and B.

1. Current Access to Medical Specialists (Term of Reference (a))

Respondents reported needing to see a wide range of medical specialists to manage a complex, multi-system illness. Cardiologists (78%), neurologists (61%) and gastroenterologists (61%) were the most commonly needed, followed by immunologists (52%), rheumatologists (48%) and psychiatrists (39%). This breadth reflects the multi-system nature of ME/CFS and long COVID and is a recurring theme in respondents’ own words: patients are shuttled between organ-specific medical specialists rather than treated by a ME/CFS and long COVID trained clinician equipped to manage these conditions as a whole.

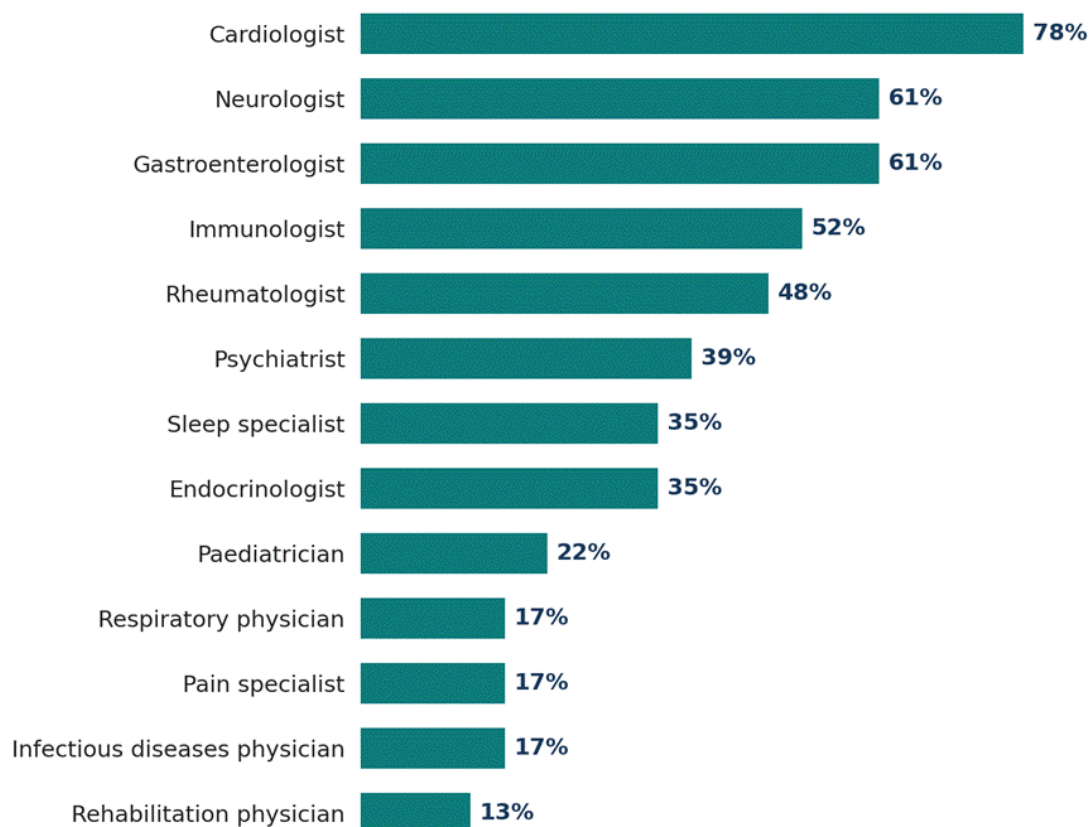


Figure 2. medical specialist types respondents have needed to see (% of respondents, n=23; multiple responses allowed).

Access to appropriate medical specialists is a significant and ongoing struggle. 96% of respondents cited a lack of medical specialists who understand ME/CFS, long COVID or PEM as a barrier, 87% cited long waiting times, 61% cited travel distance, and 57% said no appropriate medical specialist, or no medical specialist at all, was available. 65% reported needing at least two referrals before finding a medical specialist with relevant understanding, and a further 30% still have not found one. Waiting times compound the problem: 35% of respondents waited one to two years, and 26% waited more than two years, before seeing any medical specialist at all, let alone one who understood their condition.

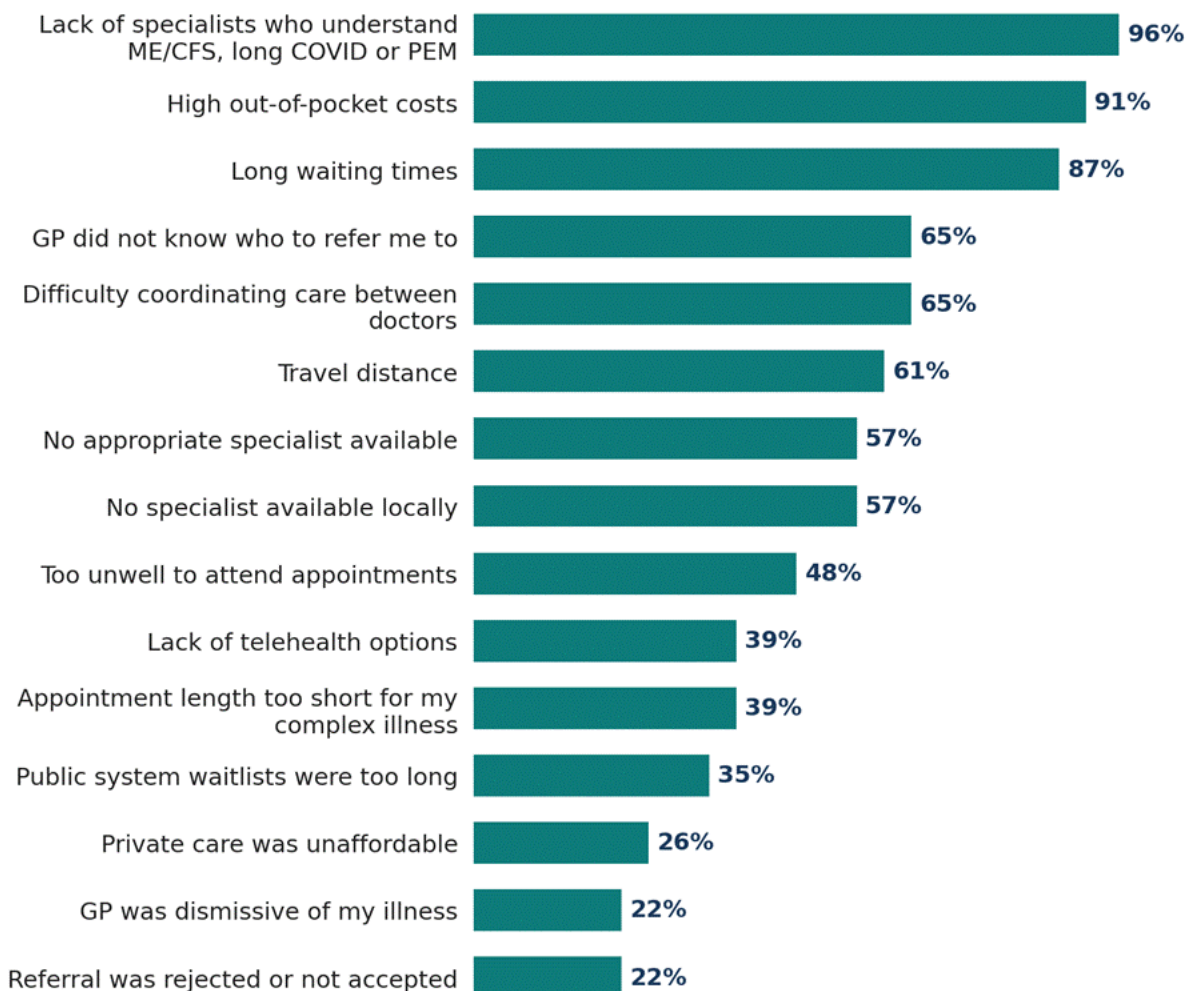
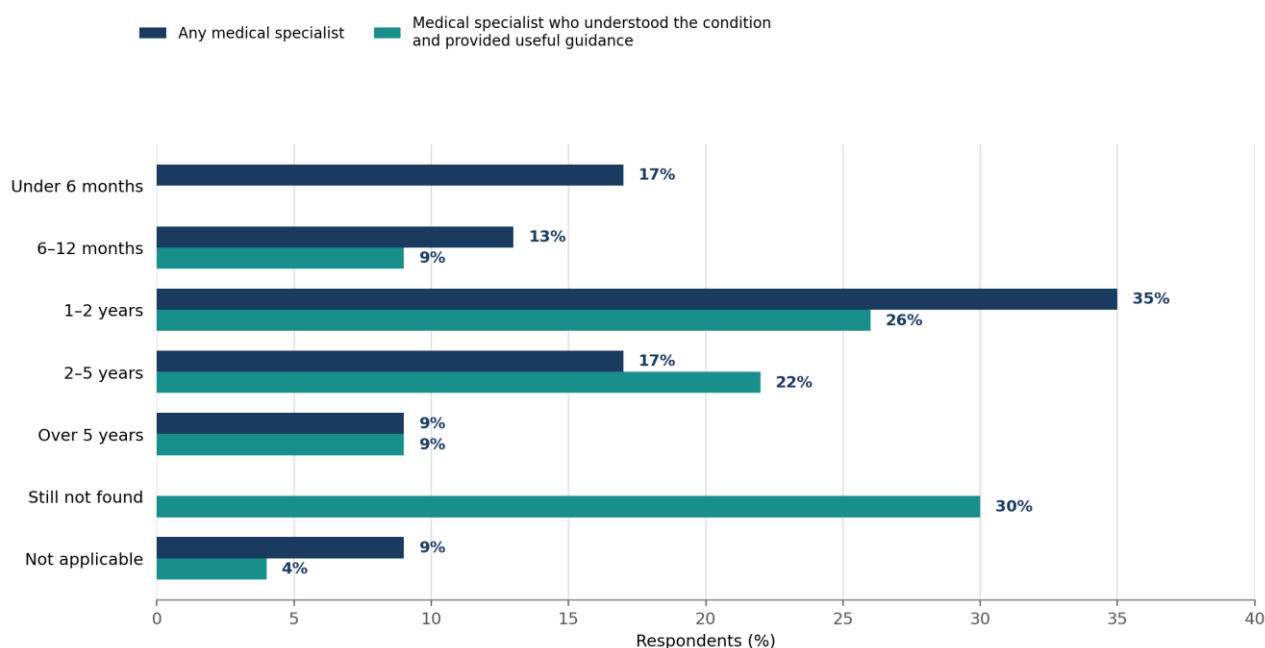


Figure 3. Barriers experienced when trying to access medical specialist care (% of respondents, n=23; multiple responses allowed).

Access to a medical specialist did not necessarily result in informed or useful care. Although 30% of respondents saw a medical specialist within 12 months of symptom onset, only 9% saw one who understood their condition and provided useful guidance within that period. Seven respondents (30%) had still not found such a medical specialist at the time of the survey.

Time from symptom onset to medical specialist care



Percentages are based on all 23 respondents and may not total 100% because of rounding.

Figure 4. Time from symptom onset to seeing any medical specialist, compared with time to seeing a medical specialist who actually understood and helpfully managed the condition (% of respondents, n=23).

“Wait times for public access are excessive e.g. a neurologist appointment has been quoted just recently as 18 months wait. Each week and month that passes is time that I don’t get back.”

— Tracey

“I live in Canberra and most of the very few well regarded ME/CFS specialists are in the major capital cities... For people with limited and unpredictable energy, navigating this fragmented system is overwhelming and often impossible.”

— James

Difficulty accessing appropriate medical specialist care for diagnosis also affects recognition of ME/CFS and long COVID as disabling conditions within Australia's broader support systems. 39% of respondents identified difficulty accessing NDIS supports as one impact of delayed, unaffordable or unavailable medical specialist care, consistent with the difficulty many people with ME/CFS report establishing eligibility for disability and social supports. The consultation did not ask whether every respondent had applied for the NDIS, so this figure should not be read as a NDIS rejection rate; rather, it points to how a lack of informed medical specialist assessment can flow through to other support systems.¹

These barriers fall hardest on people who are already the sickest. 48% of respondents described being too unwell to attend appointments, and several noted that the physical toll of travel and waiting rooms can trigger a post-exertional malaise (a severe exacerbation of all ME/CFS or long COVID symptoms) lasting days, meaning the process of seeking care can itself cause harm (see Section 4.4).

¹ Zhao, T., *et al.* (2023). The economic burden of myalgic encephalomyelitis/chronic fatigue syndrome in Australia. *Australian Health Review*, 47:707–715.

2. Referral Pathways (Term of Reference (b))

Difficulty finding and working with GPs and medical specialists is one of the most common reasons people contact Emerge Australia for support. An analysis of 2,367 online enquiries to Emerge Australia's Telehealth Support Service from October 2023 to July 2026 found:

- 640 (27.0%) related to finding or working with a GP or medical specialist
- 358 inquiries (15.1%) specifically about GPs
- 390 (16.5%) about medical specialists or other doctors.

This proportion was broadly consistent across the country, clustering between 25–28% in most states and territories, with Victoria recording the highest volume (256 inquiries) and the Northern Territory and ACT recording the highest rates (46.7% and 33.3% respectively).

That more than one in four people contacting Emerge Australia for support are asking how to find or communicate with a healthcare provider, rather than about symptom management, treatment or other aspects of living with the condition, points to a substantial unmet need for GP education on ME/CFS, long COVID and related conditions, clearer medical specialist referral pathways and directories, and resources to help patients navigate conversations with their doctors.

A dominant and consistent theme across CAP responses is that the medical specialist referral system is not designed for conditions such as ME/CFS or long COVID, for which there is no nationally recognised or consistently available comprehensive medical specialist pathway. GPs are often ideally placed to coordinate ongoing care because they can provide continuity and take a whole-person view. However, they cannot do this effectively without access to condition-informed medical specialist input, clear referral pathways and coordination between the medical specialists involved. Patients are commonly referred symptom by symptom to organ-specific medical specialists, each of whom may examine only one system and fail to recognise the interconnections between body systems. These medical specialists may then refer the patient onwards or back to the GP, creating further costs and delays without any clinician taking responsibility for coordinating care as a whole.

Although the need for care coordination is widely recognised, the time and infrastructure required to perform this role are not consistently funded. Existing Commonwealth mechanisms could form part of the response: the Workforce Incentive Program can support multidisciplinary staff within general practice, while Primary Health Networks can help develop and commission locally appropriate referral and shared-care pathways. However, these mechanisms must be adequately designed and funded to address the specific gaps experienced by people with ME/CFS and long COVID.

"A referral system built on the assumption that every patient has a specialist destination simply does not work when no such destination exists... Each specialist examines only their own organ system, the usual outcome is being told that organ is "fine" and come back in a year with another (\$\$) GP referral yet with no treatment, no coordination, and no one taking responsibility for the condition as a whole."

— Jess, carer

"Most specialists only focus on their area of expertise with little ability to see me as a whole person... which costs me more money (and time and energy) with substandard outcomes in terms of holistic care."

— Andrea

65% of respondents identified their GP not knowing who to refer them to as a barrier, and 65% identified difficulty coordinating care between multiple doctors. 22% reported their GP being dismissive of their illness, and 22% reported a referral being rejected or not accepted. Several respondents described becoming the de facto coordinator of their own care involving multiple medical specialists; researching conditions, identifying which medical specialists might be receptive, and managing conflicting advice between clinicians themselves, without any formal support to do so.

This can place patients in a double bind: they are required to research options, request referrals and reconcile conflicting advice because no clinician is coordinating their care, yet may then be dismissed or criticised for appearing to overstep the patient role. This dynamic can further erode trust and compound experiences of dismissal and mistreatment within the health system.

"What I really need is one specialist who takes control of my medical treatment. Who coordinates my care, knows who to refer me to, knows how to prioritise my issues and various conditions, and who I can trust so I can hand over the cognitive load of trying to do this all by myself."

— Tracey

Parliament has previously examined this problem. The 2023 report of the Inquiry into Long COVID and Repeated COVID Infections, *Sick and Tired: Casting a Long Shadow*, recommended evidence-based living guidelines with tiered models of care and referral pathways, and, in a dedicated addendum recognising the longstanding unmet needs of people with ME/CFS, recommended funding for ME/CFS research and patient support (Recommendation 8). The Government's response, tabled in 2024, accepted this recommendation in principle. While the development of new clinical guidelines for ME/CFS are underway, the consultation findings indicate that the underlying need for a coordinated medical specialist pathway remains substantially unmet.

3. Affordability of Medical Specialist Care (Term of Reference (c))

Cost was one of the most frequently cited barriers to medical specialist care, reported by 91% of respondents. When asked specifically about out-of-pocket fees for medical specialist consultations, 61% reported spending more than \$1,000 a year and 22% reported spending more than \$5,000 a year. These amounts do not include other healthcare expenses such as GP and allied health appointments, diagnostic testing, medications or travel.

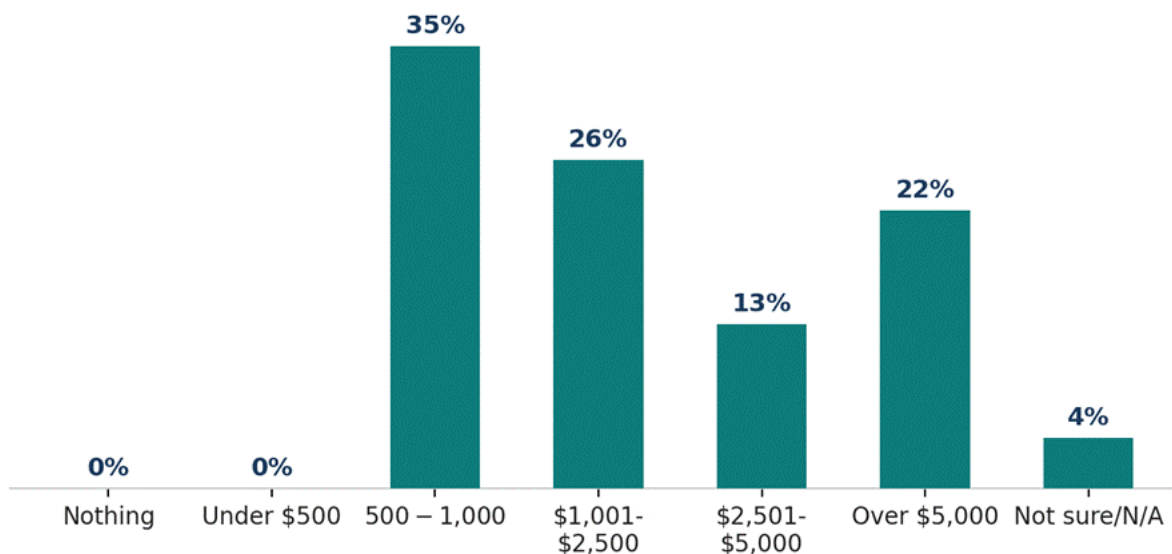


Figure 5. Approximate annual out-of-pocket medical specialist care spend (% of respondents, n=23).

61% of respondents said Medicare rebates have not covered enough of the cost of their medical specialist care, and 48% have had to reduce how often they see medical specialists because of cost. 35% have only been able to access private medical specialist care with financial assistance from family members, and 17% have had to forgo medical specialist care altogether due to cost.

"It costs me over a hundred dollars per week just to access my core medications... plus the ongoing specialist appointments that are several hundred dollars out of pocket for a 15 minute telehealth appointment. It is not sustainable on the DSP/working a very small amount, my Mum — who is also classified as low income and on the age pension — pays for some of my medications and specialist appointments because the maths just doesn't work otherwise."

— Erin

"In the first year we spent \$10,000... The costs thus far have been over \$50,000 as it includes my loss of income, from FT to PT work (and carers leave) to support my child."

— Jess, carer

"Firstly that there needs to even be a specialist and secondly that we cannot afford to pay private fees."

— Dorothy

4. Impact on Patient Outcomes (Term of Reference (d))

Respondents reported serious harms arising from delayed, unaffordable or unavailable medical specialist care and, more concerning still, from the quality of medical specialist advice received. 74% said they had been given advice by a medical specialist that they believe worsened their condition, most commonly, being told to push through symptoms, being referred for graded exercise therapy – a treatment which is no longer recommended internationally due to lack of effectiveness and risk of harm, or being incorrectly told their illness was primarily psychological.

This pattern is reflected in how well respondents believe medical specialists understand core concepts central to safely treating ME/CFS and long COVID. Across the four concepts tested, the great majority of respondents rated medical specialist understanding as “not very well” or “not at all”:

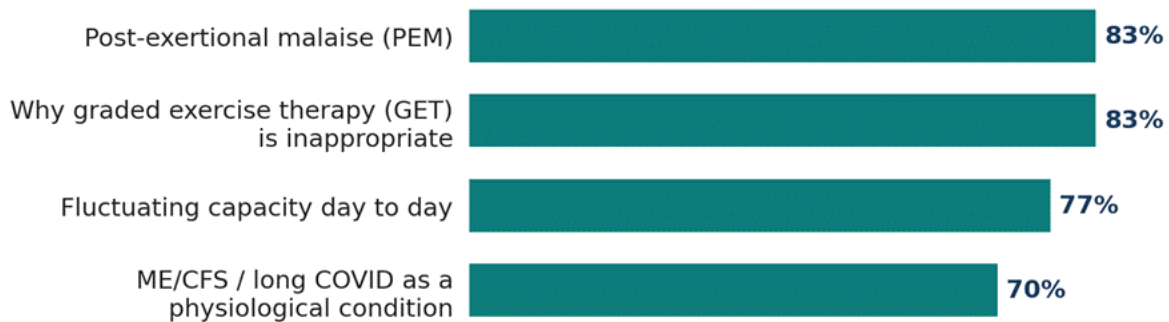


Figure 6. Share of respondents rating medical specialist understanding of each concept as “not very well” or “not at all” (n=23).

“My sleep doctor... suggested that I try to exercise more which made my condition worse until I could see a long COVID specialist doctor who advised the opposite. This has left me with strong distrust of the health system.”

— Kelly

“I had just spent ages explaining I was too unwell to go to uni, let alone walk up hills as this would trigger PEM due to my ME/CFS. They must understand that ME/CFS needs consideration of how it will be impacted from the treatment they are suggesting. They must not think in silos.”

— Ella

The effects of barriers to medical specialist care were wide-ranging. Seventy-eight per cent of respondents reported delays in receiving treatment or management advice, and the same proportion reported increased reliance on family, carers or informal support. Seventy-four per cent reported emotional distress or loss of trust in the health system; 65% each reported delayed diagnosis, worsening symptoms and reduced ability to work; and 61% experienced PEM (a serious worsening of symptoms following exertion) as a direct result of travelling to or attending medical appointments.

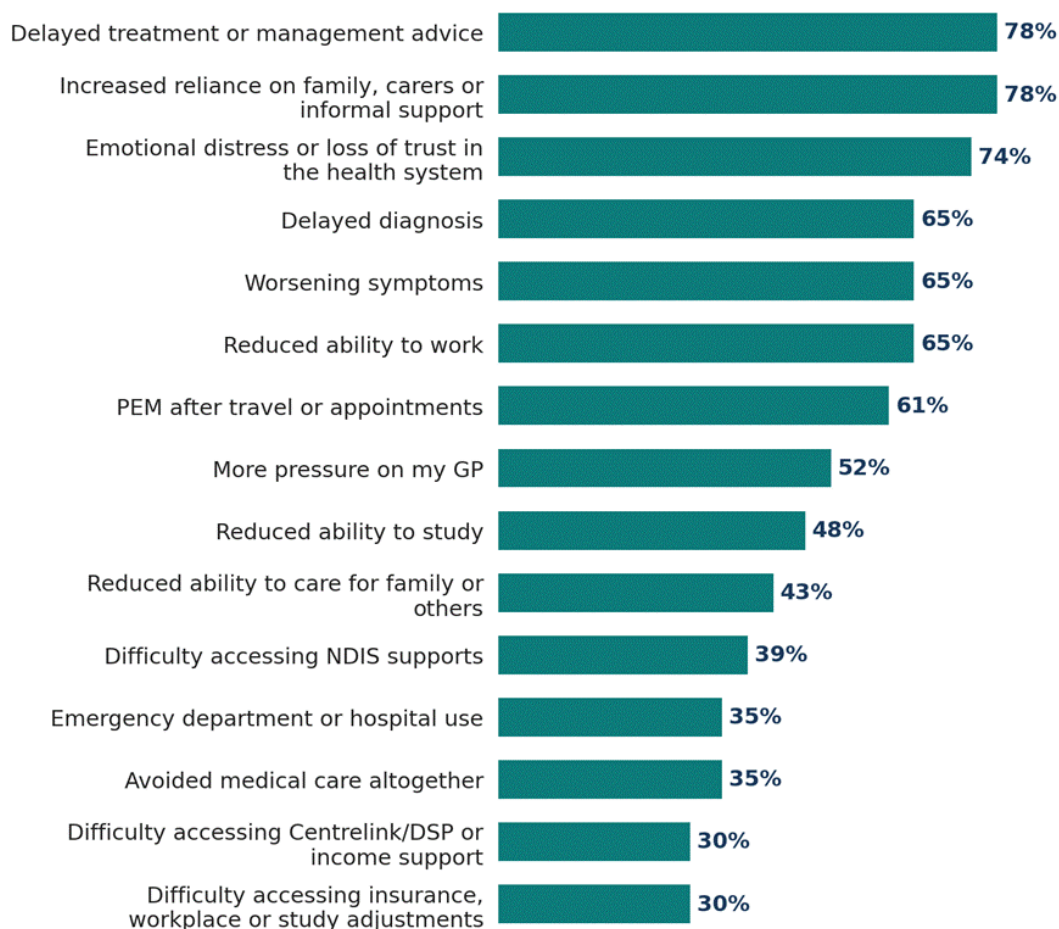


Figure 7. Impact of delayed, unaffordable or unavailable medical specialist care (% of respondents, n=23; multiple responses allowed).

For the most severely affected, attempting to access medical specialist care can itself cause serious and sometimes lasting deterioration. Travel, sitting upright, waiting rooms, noise, bright light and rushed or inflexible consultations can trigger PEM or other symptom exacerbation. Where clinicians lack sufficient knowledge of ME/CFS or long COVID, respondents described the risk of attending as outweighing the likely benefit.

“ME severely limits energy, sensory tolerance, and physical resilience. Travelling long distances, sitting upright, coping with noise, light, waiting rooms and rushed appointments can cause serious and sometimes permanent deterioration... Accessing specialists becomes something you risk your health to attempt, rather than something that protects it.”

— Karin, carer

“Some specialists have been dismissive of the severity of her illness and refused to accommodate Telehealth so she was then unable to access a consultation... We need multi disciplinary specialist home visiting clinics for bed bound very severe me/cfs people.”

— Linda, carer

5. Innovative and Emerging Models of Care (Term of Reference (e))

74% of respondents have accessed medical specialist care via telehealth, and a further 17% said telehealth was not offered to them. Experience of telehealth quality was mixed: among respondents who rated it, just over half rated the quality as good or excellent, while the remainder rated it as only fair or poor. Several respondents said flexible telehealth had enabled them to access care they otherwise could not have reached, while others reported telehealth being refused outright, including for patients too unwell to attend in person.

“A flexible approach to telehealth appointments enabled timely and effective care.”

— **Simon**

“Living in a rural/regional area means all specialist care has to be via telehealth or it causes months-long recovery periods due to the significant travel required.”

— **Tracey**

When asked which changes would most improve access to medical specialist care, respondents’ top priorities were:

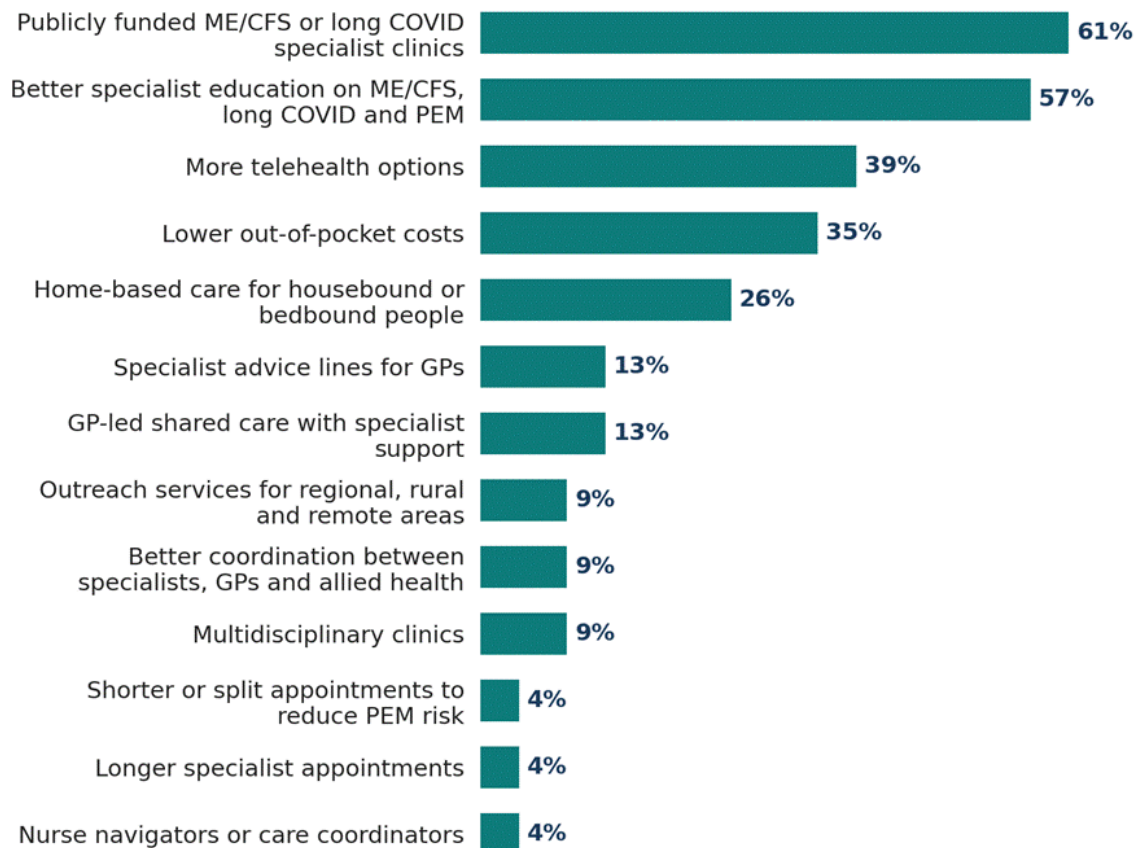


Figure 8. Changes respondents said would most improve access to medical specialist care (top 3 priorities per respondent, % selecting, n=23).

“We need a fully subsidised specialist clinic or centre of excellence to cover ME/CFS, hEDS, POTS, MCAS, SFN etc. This needs to have GP, Specialist, Nurse and Allied Health practitioners to provide holistic care... Having access to early diagnosis and well designed care pathways would reduce illness severity for many and significantly reduce the cost to the economy.”

— Tracey

Conclusion

The experiences shared by Emerge Australia's Community Advisory Panel show a health system that is not currently equipped to provide timely, affordable, coordinated or safe medical specialist care to people with the complexities that ME/CFS and long COVID encompass. Patients face long waits, high costs, fragmented referral pathways, and, most seriously, a real risk of harm from medical specialists who do not understand their condition. At the same time, respondents were clear about what would help: publicly funded multidisciplinary care with access to medical specialists; better education for the clinicians they already see; and flexible, safe models of care, including telehealth and home visits, that meet patients where they are rather than requiring the sickest people to put themselves at risk to be seen.

Emerge Australia thanks the Committee for the opportunity to contribute to this inquiry and would welcome the opportunity to provide further information, including additional de-identified case studies, or to give oral evidence.

Appendix A: Consultation Methodology

The consultation ran as an online survey distributed to Emerge Australia's Community Advisory Panel. It asked panel members about the types of medical specialists they had needed to see, the quality of understanding they encountered, barriers to access, the cost of medical specialist consultations, the impact of delayed or unavailable care, experiences of telehealth, and the changes they would most like to see.

Twenty-three responses were received and form the basis of the analysis in this submission. Respondent characteristics are set out in Appendix B.

Where percentages are quoted in this submission, the denominator is the 23 survey respondents unless otherwise stated. Because several questions allowed multiple responses, percentages for those questions do not sum to 100%.

For questions about affordability, 'medical specialist care' referred specifically to fees paid for medical specialist consultations. Respondents were not asked to include GP or allied health appointments, medications, diagnostic testing or travel expenses.

Where a carer, family member or support person completed the survey, they answered subsequent questions on behalf of the person with ME/CFS or long COVID. For readability, references to 'respondents' throughout this submission include the experiences of the person represented by those respondents.

This was a self-selected, non-random sample. Findings should be read as illustrative of lived experience within Emerge Australia's Community Advisory Panel rather than as population-representative statistics; however, the consistency of themes raised, and their alignment with the broader published research cited throughout this submission, support their value as evidence for this inquiry.

Direct quotations from respondents included throughout this submission illustrate the lived experience behind the data, attributed by first name as recorded in the consultation. Pseudonyms have been used when requested by the respondent. Emerge Australia can provide the Committee with further case studies or connect the Committee with individual respondents willing to give evidence directly, upon request.

Appendix B: Consultation Respondent Profile

Characteristic	Category	Number	Percentage
Respondent group	ME/CFS	15	65%
	Long COVID	1	4%
	ME/CFS and long COVID	1	4%
	Carer, family member or support person	6	27%
Location	Metropolitan	16	70%
	Regional	4	17%
	Rural or remote	3	13%
Illness severity	Mild	7	30%
	Moderate	7	30%
	Severe	7	30%
	Very severe	2	9%

Note: Percentages are based on 23 respondents and may not total 100% because of rounding. Where a carer completed the survey, they answered on behalf of the person with ME/CFS or long COVID.

This was a self-selected, non-random sample of 23 members of Emerge Australia's Community Advisory Panel. The findings are indicative of the range and severity of experiences reported by this group and are not statistically representative of the broader ME/CFS and long COVID population.