MS AUSTRALIA

Submission to the Australian National Audit Office's (ANAO) performance audit of the Australian Government Department of Health's management of the expansion of telehealth services in response to the COVID-19 pandemic

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About MS Australia

MS Australia (MSA) is pleased to provide a submission to the Australian National Audit Office (ANAO) performance audit of the Australian Government Department of Health's management of the expansion of telehealth services in response to the COVID-19 pandemic.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our state organisations provide services and support. Included are comments provided by representatives of our state organisations and, in some instances, directly from people living with MS. MS Australia's role is to work on behalf of our state and territory-based member organisations to provide a voice for people living with MS across the country.

MS Australia's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MS Ltd (providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services and advice to people living with MS regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, online resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

Our submission will focus on the inquiry questions to determine if the expansion of telehealth supported by the Medical Benefits Scheme were informed by robust planning and policy advice.

We will additionally provide the unique input of an organisation that represents the views of people living with chronic health conditions and neurological conditions, such as MS. We represent over 25,600 people living with MS in Australia.

According to the latest Health Economic Impact of MS report[1], 'the total economic cost of MS to the community now stands at $1.75 billion - an

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[1] https://www.msaustralia.org.au/wp-content/uploads/2018/08/executive-summary_health-economic-impact-of-ms-in-australia-in-2017-report_ms-research-australia.pdf

increase of $0.51 billion since 2010 (when it was $1.24 billion (in 2017 dollars).'[2]

'The costs for people living with more advanced MS are incredibly high, more than triple per person compared to those with milder disease (from $30,561 for people with no disability to $114,813 for people with severe disability).

The quality of life (QoL) impact for people living with severe disability is comparable to, or even lower than that reported for terminal metastatic cancer, chronic kidney disease and severe heart disease.'

The majority of our submission will highlight how the expansion of telehealth impacted on our organisation and members.

We will also attempt to highlight the consequences of these telehealth arrangements on people's lived experiences. We hope that by highlighting these issues around potential telehealth improvements, we can provide feedback on areas of expansion that could inform future decision-making processes.

Summary of recommendations

Recommendation 1:

Improve access to primary healthcare in rural and remote areas by addressing barriers to health outcomes such as:

1. **Applying an exemption from the "active patient" definition for people with MS in rural and remote locations**
2. **Expansion of telehealth Medicare item numbers to all health professionals including allied health professionals**
3. **Improved and affordable internet connectivity in rural Australia**

Recommendation 2:

Improve the digital literacy and connectivity of older Australians through the expansion of programs such as Be Connected.

Recommendation 3:

Expand telehealth services to improve access to MS Nurse care by amending Medicare item numbers which currently cover telehealth appointments with neurologists, to include MS Nurses.

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[2] https://www.menzies.utas.edu.au/news-and-events/media-releases/2018/multiple-sclerosis-rising,-costing-people-with-ms-and-australia-$1.75-billion

Introduction – Policy Setting for the introduction of Telehealth

Telehealth was introduced as an MBS-funded measure during the COVID-19 pandemic and quickly became a permanent alternative method of healthcare delivery. Whilst the use of telehealth was new to many patients and clinicians during the pandemic, many in Australia were already using telehealth, especially to support regional health professionals. [3]

The rapid pace, change and scale of the COVID-19 pandemic amplified existing system failures due to under-funding, barriers to access, regional disparities[4], vulnerable populations and socio-economic insecurities in Australia. This was particularly evident in the state of our Nation's health sector.

The pandemic further highlighted the complexity of our multi-level architecture[5] of government and the need for State, Commonwealth and local governments to work more closely together to increase system flexibility and performance.

The value of informed, transparent and collective decision making (i.e. creation of the National Cabinet and the National COVID-19 Commission Advisory Board (NCCAB)) was underlined by the Senate Select Committee on COVID-19's First Interim Report.[6]

As the Australian Medical Association (AMA) President, Dr Omar Khorshid pointed out in a recent AMA media release (dated 31 May)[7], the growing health crisis and lack of appropriate funding must be addressed, including extending the current short term 50/50 funding arrangements. MS Australia also agrees that Medicare and General Practice reforms are urgently needed to avoid more unintended outcomes for patients.

In fact, as lessons are being learnt during the pandemic, state and federal governments should realise opportunities for co-design and co-commissioning to create innovative solutions, such as articulated health pathways (i.e. for people with neurological conditions), clear standards (similar to the NICE Guidelines in the UK[8]) and models of care to ensure health outcomes are delivered against proposed additional investment.

As a result, and in response to the pandemic, we saw a reorganisation of services, changes in deployment and utilisation of healthcare workforce with additional impacts on patients and health outcomes, noting that:

- Healthcare utilisation reduced by about a third during the pandemic[9]

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[3] https://www.frontiersin.org/articles/10.3389/fpubh.2021.648009/full

[4] https://www.oecd.org/coronavirus/policy-responses/the-territorial-impact-of-COVID-19-managing-the-crisis-and-recovery-across-levels-of-government-a2c6abaf/

[5] See https://law.unimelb.edu.au/__data/assets/pdf_file/0003/3473832/MF20-Web3-Aust-ATwomey-FINAL.pdf

[6] https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/COVID-19/COVID19/Interim_Report/section?id=committees%2Freportsen%2F024513%2F73986

[7] https://www.ama.com.au/media/ama-welcomes-new-health-minister-and-calls-urgent-solution-hospital-crisis

[8] https://www.nice.org.uk/guidance/cg186

[9] https://bmjopen.bmj.com/content/11/3/e045343?versioned=TRUE; https://bmjopen.bmj.com/content/bmjopen/11/3/e045343.full.pdf and https://bmjopen.bmj.com/content/11/3/e045343

  - Service shut down and/or delays in planned procedures placed additional pressure on the already overloaded health system with severe consequences for the Australian patient population[10].

Unfortunately, inconsistencies and lack of coordinated public messaging[11] and community engagement have been particularly problematic to date, often causing more confusion and reduced public trust.

The term ‘infodemic’ was coined, referring to the overabundance of information (often wrong, misleading and conflicting) not necessarily from trusted sources. Consequently, the Australian public had a heightened sense of confusion and anxiety. This was particularly the case for diverse communities and those living with multicultural language needs, disability, ageing and patients with complex health needs i.e. those deemed immune compromised, including people with MS.

This communications issue had real consequences for the eventual roll out of vaccines[12] and particularly pertained to our MS cohort and people with disabilities[13].

The benefit for patients, particularly those who lived with a chronic disease, to have access to a trusted, key point of contact in the health system became more important than ever before.[14] Similarly, the value of coordination and access to care[15] and the importance of trust in medical advice[16] were highlighted.

The critical role of telehealth

As the Department of Health webpage states: “Telehealth has been transformational to Australia’s universal healthcare program, Medicare. It has played a critical role in ensuring the continuity of care for hundreds of thousands of Australian patients.”[17]

Telehealth became a powerful and reactive tool in the clinic-to-in-home-continuum, providing an alternative method of healthcare provision

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[10] See https://www1.racgp.org.au/newsgp/professional/the-system-will-fail-racgp-warning-on-10-year-plan and https://www.msaustralia.org.au/wp- ; and content/uploads/2021/10/ms-australia-submission-to-gps-in-rural-remote-aust-inquiry.pdf; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1459465/

[11] https://journals.sagepub.com/doi/full/10.1177/1329878X20948289; https://www.theguardian.com/australia-news/2020/mar/24/australia-is-crying-out-for-clearer-messaging-on-coronavirus-rambling-politicians-told; https://www.abc.net.au/news/2022-01-08/confusion-around-COVID-information-diverse-communities/100741306; https://www.nature.com/articles/s41599-020-00701-w

[12] https://www.cnbc.com/2021/07/01/australias-mixed-messages-on-COVID-vaccines-sow-confusion.html; https://www.abc.net.au/news/2021-05-09/COVID-19-vaccine-recipients-frustrated-by-mixed-messages/100125432; https://www1.racgp.org.au/newsgp/professional/racgp-calls-for-COVID-vaccine-consistency; https://www.mja.com.au/journal/2021/communicating-patients-and-public-about-COVID-19-vaccine-safety-recommendations; https://www.smh.com.au/politics/federal/literacy-hotline-hit-with-calls-about-confusing-vaccine-information-20211112-p598jm.html

[13] https://pwd.org.au/disability-advocates-say-new-COVID-19-vaccine-data-show-people-with-disability-are-being-left-behind/; https://www.abc.net.au/news/2021-05-17/people-with-disabilities-left-behind-in-vaccine/13347920

[14] https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-framework-for-chronic-conditions.pdf and https://www.who.int/docs/default-source/primary-health/vision.pdf

[15] https://www.msaustralia.org.au/wp-content/uploads/2021/10/ms-australia-submission-to-gps-in-rural-remote-aust-inquiry.pdf

[16] https://theconversation.com/a-matter-of-trust-coronavirus-shows-again-why-we-value-expertise-when-it-comes-to-our-health-134779 and https://www.phrp.com.au/issues/december-2020-volume-30-issue-4/health-literacy-and-disparities-in-COVID-19-related-knowledge-attitudes-beliefs-and-behaviours-in-australia/

[17] See https://www.health.gov.au/health-topics/health-technologies-and-digital-health/about/telehealth

during the pandemic.[18] Retrospectively, the introduction of telehealth during the COVID pandemic could be viewed as a catalyst for the ‘forced adoption’ of digital healthcare, growth in the telemedicine industry and becoming an acceptable form or mode of medical care provision for both healthcare providers and patients.[19]

Telehealth especially allowed people living with neurological conditions such as MS to access primary healthcare practitioners and MS-specific or specialised MS neurological supports, despite barriers of distance, travel, disability, economic or health reasons[20]. This is of benefit for people with MS who were taking disease modifying therapies to treat the disease and contributing to an immunocompromised state.

Table 1 Jessie's story

Jessie was diagnosed with MS in the early days of COVID-19. From the moment of her diagnosis, Jessie has felt a connection to services and support - despite living regionally and during a pandemic.

After living for 15 years with what she now knows as neurological symptoms, Jessie was finally sent for an MRI two years ago and was relieved to finally have a diagnosis.

At her MS assessment at an MS clinic, Jessie was supported by an MS Nurse who works in conjunction with the clinic.

“That initial appointment was how I found out about how MS services and support could help me,” Jessie explains.

Shortly after, Jessie was pleased to automatically receive paperwork from the NDIS. “This was all instigated by the MS clinic and the MS Nurse,” she says.

Through her NDIS funding, Jessie receives Support Coordination, Occupational Therapy and Speech Pathology from an MS organisation. “I saw a specialist MS Counsellor when I was first diagnosed. I don’t need help with that side of things yet, but it’s good to know they’re just a phone call away.”

Jessie is an advocate for the practical benefits of telehealth and has been dialling in to fortnightly appointments with her MS Speech Pathologist, Jan.

“We use phone, Zoom, or WhatsApp – the choice is countless these days isn’t it!” says Jessie.

“There’s no difference than if we were in a room together. It works just fine. There’s no disadvantage to it except that I can’t offer to make Jan a coffee!”

Jan explains, “Telehealth ensures Clients stay connected to services regardless of geographic location. It’s a COVID-safe, convenient, and effective way to provide speech pathology assessment and intervention. Online platforms such as Zoom allow for innovative ways to work with Clients who experience a variety of communication and/or swallowing difficulties.”

Without access to these virtual appointments, Jessie would not have felt the meaningful benefits of speech pathology input.

“Before I had my assessment, I didn’t know what speech pathology was! It’s not just about talking. It’s about swallowing too, and it’s about how your brain sends signals. Looking back over the years, I was often choking or coughing on things. I didn’t realise that’s classic MS."

Understanding MS within this policy context

Multiple Sclerosis (MS) is an immune-mediated, chronic inflammatory disease that attacks the central nervous system (the brain, spinal cord and

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[18] https://practicalneurology.com/articles/2019-mar-apr/multiple-sclerosis-minute-telemedicine-and-multiple-sclerosis

[19] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8979849/

[20] https://www.tandfonline.com/doi/full/10.1080/03091902.2022.2040625

optic nerves). The ‘multiple sclerosis’ or ‘many scars’ [21] are the result of an autoimmune response where the immune system, almost at random, attacks the fatty layer around nerves in the brain, optic nerves and spinal cord, resulting in a variety of disabling neurological symptoms[22]. Every system in the central nervous system or CNS (myelin, white matter, neurons, axons and blood vessels) can experience damage and loss as a result of MS[23]. MS is further characterised by focal or diffuse inflammation, demyelination, axonal loss and neurodegeneration[24] and progressive brain atrophy.

The position where these attacks occur within the CNS corresponds with the potential impacts or symptoms experienced i.e. if an attack occurs in the optic nerve a person can experience double vision or diplopia; attacks in the spinal cord might result in weakness and numbness in their limbs; the cerebellum - loss of balance[25]. MS is therefore a very individual disease as the effects of the attacks are unique. Similarly, the progress, severity and specific symptoms of MS cannot be predicted. Many of the symptoms of MS are invisible but can have profound impacts on a person’s day-to-day ability to function and tackle everyday roles and responsibilities.

Management of the disease course and symptoms associated with MS requires regular contact between the person with MS and their healthcare team.

Demographics and disease course

MS, like other autoimmune diseases, is more common in females. Roughly three quarters of all people with MS are women. The disease usually manifests clinical symptoms during young adulthood, mostly between the ages 20-40 years, but it can affect younger and older people too. In fact, in young adults, MS is the most commonly acquired disease of the CNS and the leading cause of disability.

There are over 25,600 people living with MS in Australia. Often a diagnosis of MS occurs when people are fully employed, planning a family and making significant career choices.

There are three courses MS can take. Around 15% of the MS population is diagnosed with a progressive form of MS with no periods of remission, termed Primary Progressive MS (PPMS). How fast the disease progresses may vary, but the declining neurological progression is constant. Relapsing remitting MS (RRMS), the most common form of MS, is characterised by partial or total recovery after attacks (also called

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[21] Institute of Medicine (US) Committee on Multiple Sclerosis: Current Status and Strategies for the Future; Joy JE, Johnston RB Jr., editors. Multiple Sclerosis: Current Status and Strategies for the Future. Washington (DC): National Academies Press (US); 2001. 2, Clinical and Biological Features. Available from: https://www.ncbi.nlm.nih.gov/books/NBK222386/

[22] Høglund, R. A., & Maghazachi, A. A. (2014). Multiple sclerosis and the role of immune cells.World journal of experimental medicine,4(3), 27–37. https://doi.org/10.5493/wjem.v4.i3.27

[23] Cerqueira JJ, Compston DAS, Geraldes R, et al Time matters in multiple sclerosis: can early treatment and long-term follow-up ensure everyone benefits from the latest advances in multiple sclerosis? Journal of Neurology, Neurosurgery & Psychiatry 2018;89:844-850.

[24] Andravizou, A., Dardiotis, E., Artemiadis, A. et al. Brain atrophy in multiple sclerosis: mechanisms, clinical relevance and treatment options. Autoimmun Highlights 10, 7 (2019). https://doi.org/10.1186/s13317-019-0117-5

[25] Institute of Medicine (US) Committee on Multiple Sclerosis: Current Status and Strategies for the Future; Joy JE, Johnston RB Jr., editors. Multiple Sclerosis: Current Status and Strategies for the Future. Washington (DC): National Academies Press (US); 2001. 2, Clinical and Biological Features. Available from: https://www.ncbi.nlm.nih.gov/books/NBK222386/

exacerbations, relapses or flares). 70 to 75% of people affected by MS initially begin with a relapsing remitting course. Secondary progressive MS (SPMS) is a relapsing remitting course which later becomes steadily progressive. Attacks and partial recoveries may continue to occur. Of the 70-75% who start with relapsing-remitting disease, more than 50% will develop SPMS within 10 years; 90% within 25 years. A further differentiation is made by categorising disease activity as active (with or without worsening) or stable.

MS Treatments, brain health and impacts of COVID

MS is a chronic disease requiring constant adjustment, management, monitoring and resilience. The effects, symptoms and impacts are very individual and require day to day adaptations and management strategies. No two people experience MS in the same way.

Additionally, people with MS can live with comorbidities, such as diabetes, heart-related conditions and mental health conditions, that directly impact disability progression, treatment choice, treatment adherence and outcomes.[26]

Within the chronic care model, and with an emphasis on patient-centred care, self-management strategies have become key to achieving optimal health outcomes – especially relevant during a health pandemic.

The consensus findings of an international report, *Brain Health: Time Matters in MS*[27], recommended a therapeutic strategy based on early diagnosis and access to efficacious treatment options, proactive monitoring and access to specialist MS supports to minimise relapses, lesions and brain atrophy.

Medications and treatments for MS[28] fall broadly into three groups: those that reduce the risk of relapses and disease progression (also known as disease modifying therapies or DMTs), those that treat an active relapse or those that can help to ease specific symptoms.

Adherence to MS treatments has a direct relation to clinical effectiveness and poor adherence adversely impacts disease progression, causing an increase in MS-related hospitalisations and poor clinical health outcomes[29].

Access to specialist MS healthcare professionals such as neurologists and MS nurses is critical to support informed decision making (health literacy), treatment adherence, managing potential adverse events and monitoring protocols. Similarly, it is important for patients to have access to primary healthcare practitioners to manage their day-to-day health needs, universal screening and any comorbidities.

COVID has introduced a further layer of complexity to MS disease management, not only in terms of access to specialist supports or a primary healthcare team, but also the impact of some of the disease

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[26] https://www.frontiersin.org/articles/10.3389/fneur.2020.00851/full
[27] https://www.msbrainhealth.org/recommendations/brain-health-report/
[28] https://www.msaustralia.org.au/treatments/
[29] https://link.springer.com/article/10.1007/s00415-021-10850-w

modifying therapies which can cause patients to be immunocompromised[30].

There are also specific recommendations from the Australian Technical Advisory Group for Immunisations (ATAGI) for people with MS who have undergone haematopoietic stem cell transplants (HSCT) and are immune compromised. [31]

MS Australia has had to work closely with the Australian Government's Department of Health to seek clarity about the inclusion of people diagnosed with MS in phase 1b of the vaccine roll out, as set out in the National Roll-out Strategy. This was to clarify if people with MS were considered under the then 2,000,000 vaccine doses held for 'younger adults with an underlying condition, including those with a disability' noted in the Phase 1b roll-out.

Comment from an MS Australia staff member:

"Keeping my eye out for all of the new COVID information was almost a full-time job at some stages, a few times I rang the COVID hotline for advice if something was unclear, but mostly it was internet based information I sought out, sometimes daily. ATAGI provided a constant review of information daily to weekly for statements and supporting evidence.

The main websites accessed:

ATAGI: https://www.health.gov.au/committees-and-groups/australian-technical-advisory-group-on-immunisation-atagi

National advice including vaccines: https://www.health.gov.au/health-alerts/COVID-19

The National government helpline to clarify information or circumstances: 1800 020 080
https://www.health.gov.au/contacts/national-coronavirus-helpline

TGA website as vaccines were being approved or considered for approval:
https://www.tga.gov.au/COVID-19-vaccines"

Results of our enquiries relating to COVID-19 on behalf of people with MS are hosted and constantly updated on a specially created MS Australia COVID landing page: https://www.msaustralia.org.au/COVID-19-and-ms/).

Because of the level of confusion in the health sector relating to key messages around COVID-19, we also provided this information to healthcare providers and closely worked with our member organisations in each state and territory who provide regional services and supports.[32]

Since the start of the pandemic, MS Australia supported efforts by the Multiple Sclerosis International Federation (MSIF) [33] to coordinate a global data sharing initiative working group, along with colleagues in the Australian and New Zealand Association of Neurologists (ANZAN). Due to the impact of COVID-19 on MS, and the unique nature of MS medications, broad generalist healthcare advice to people living with MS was not realistic or relevant, requiring specific recommendations to patients and healthcare providers.

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[30] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8876554/
[31] https://www.health.gov.au/sites/default/files/documents/2022/03/atagi-provider-guide-to-COVID-19-vaccination-of-people-with-immunocompromise.pdf
[32] https://www1.racgp.org.au/newsgp/racgp/health-of-the-nation-2021-the-current-shape-of-gen
[33] See https://www.msif.org/news/2020/02/10/the-coronavirus-and-ms-what-you-need-to-know/

This initiative has informed healthcare advice ranging from general advice and key messages to COVID-19 vaccines for people with MS, for children diagnosed with MS, timing of disease modifying therapies and COVID-19 vaccines to treatments for COVID-19.

The clinical interest in healthcare design and intervention for people living with MS during the pandemic has also led to international research studies, including studies to investigate the impact of telehealth in MS care and research[34].

Experiences of People with MS and telehealth

Utilisation, benefits and outcomes

The initial incorporation of telehealth access in Australia has in the first instance aimed to minimise harm. Health decision makers strived to reduce the amount of physical, psychological, social and economic harm that the outbreak might cause to individuals and communities; values that MS Australia wholeheartedly supports.

Harm reduction strategies included universal measures such as campaigns supporting regular handwashing, the use of Personal Protective Equipment (PPE) and the creation of flexible policy settings that would allow telehealth to be an alternative to face-to-face consultations.

In the context of MS, harm minimisation also implies that patients and their health providers have access to evidence based trusted information that enables informed decision-making.

Delays to seeking medical support, participating in regular medical screening and follow-up appointments and access to a trusted health professional were mitigated through telehealth, providing the option for patients to continue to manage their chronic healthcare plan and negate avoidable adverse events as a result.[35]

Telehealth provided people with MS, like many others in the community, the initial choice[36] of accessing needed healthcare whilst staying home, due to local restrictions, lockdowns or stay at home orders.[37]

As the pandemic progressed, it also provided them with an individual choice to prevent contracting the disease or prevent the spread of the disease caused by attending congregated healthcare settings. Individual choice was dependant on personal preference, risk assessment (i.e. being immunocompromised), attitude, or reason for access.[38]

One Australian study that examined the impact of telehealth on healthcare in an MS outpatient clinic during the COVID-19 pandemic

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[34] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7917521/

[35] https://www.msaustralia.org.au/news/refining-diagnosis-people-ms/

[36] https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-020-09301-4; https://www.jmir.org/2020/12/e24531/ ;

[37] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8535411/

[38] https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-020-09301-4; https://onlinelibrary.wiley.com/doi/full/10.1111/hex.13284

reported that patient satisfaction with telehealth was high, but both clinicians and patients preferred in-person appointments[39.]

Although we do not have specific data on the rate of telehealth utilisation by people diagnosed with MS, the most recent report entitled '*The Voice of Australian Health Consumers*' (2022) by the Consumer Health Forum (CHF) in partnership with Macquarie University and Health Systems Sustainability found that:

- 'Almost half of respondents (46.7%) reported using digital health technologies (including, telehealth, helplines, apps and websites) in 2021, an increase from just 11.8% in 2018'
- Access to telehealth services through phone or video consultations in the previous 12 months increased considerably from a modest 5.5% in 2018, to 37.1% in 2021
- In the 2021 survey, of the respondents who reported using telehealth in the previous 12 months, 1254 (66%) accessed a health professional via telephone, 289 (15%) had a videoconference, and 347 (18%) had both video and phone. Accessing a health appointment through telehealth provided an unintended benefit as it removed some of the economic burden of travel and having to take sick leave or time off work. Based on the lived experiences of Australian patients living with neurological conditions, one study on patient benefits to cost savings due to accessing telehealth found an average saving of $550 and 937km avoided travel per patient.[40]

Further health technology innovation, often accessed through telehealth, was the developing of a capacity to deliver electronic prescriptions[41]. This avoided the need for in person consultations, creating system flexibility that benefits the patient.

Although the adoption and utilisation of My Health Record amongst healthcare practitioners and patients has not been optimal,[42] people living with MS have voiced their support for this initiative as it prevented them from having to re-tell their stories repeatedly and enabled all members of their healthcare team access to consistent information.

Electronic health records can overcome distance barriers, provide instant access to essential health information during medical emergencies and support self-management and monitoring of symptoms for healthcare users (and therefore improved health outcomes). [43]

> 'I wanted to say I'm a huge fan of the Telehealth program. I had a Telehealth consult with my GP tonight because I've got a bad sinus infection.
>
> It saved me so much time and effort when I'm already feeling very fatigued with MS and feeling unwell.

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39 https://www.sciencedirect.com/science/article/pii/S2211034822004242

40 https://onlinelibrary.wiley.com/doi/epdf/10.1111/imj.14841

41 https://www.digitalhealth.gov.au/newsroom/media-releases/electronic-prescriptions-making-telehealth-easier-for-australians

42 https://www.theguardian.com/australia-news/2020/jan/23/my-health-record-almost-2bn-spent-but-half-the-23m-records-created-are-empty; https://www.mja.com.au/journal/2019/210/6/towards-routine-use-national-electronic-health-records-australian-emergency ;

43 https://www.aihw.gov.au/reports/australias-health/digital-health

I am a huge advocate for the continuation of Telehealth in conjunction with 'in person' treatment as needed.

I have also used Telehealth for my neurologist appointments during lockdown and when I was living in the country for a period of time. Very useful where there are no regional services available as well.

Thanks for your continued advocacy and education.'**Name withheld*

Barriers, Access and Affordability

Telehealth access was, however, problematic for some patients either through personal infrastructure barriers (e.g. no access to reliable internet), lack of confidence in using digital health solutions, concerns about privacy and the perceived usefulness of a non-direct consultation.[44]

According to the latest *Australian Digital Inclusion Index 2020*, released by RMIT and Swinburne University of Technology for Telstra[45] 'the rapid acceleration of the digital economy is emerging at a time when some members of the community still face real barriers to online participation.' This includes families without internet access, older and vulnerable Australians.

Health providers had similar initial problems or barriers ranging from their willingness to participate in telehealth options, the lack of Medicare cover for consultations, infrastructure issues such as system compatibility to compliance with various legislative requirements and regulations. Adoption issues had unfortunate implications on patients' ability to optimally utilise telehealth.

In response, various medical peak bodies[46] as well as the Department of Health provided information and advice to practitioners on how to provide telehealth options to patients. This includes those items covered under the Medical Benefits Scheme (MBS), 'how to' guides to provide safe and effective telehealth options to practical steps needed to set up a practice for telephone and video consultations.

A Medical Benefits Schedule Review in 2020[47] recommended that telehealth '*should be provided in the context of continuity of care between patient and practitioner*'. This recommendation rests on the premise that a patient should be deemed an '*active patient'* first before being allowed to access telehealth options, something the RACGP[48] strongly advocated for, fearing the surge in what they deemed as 'pop-up' telehealth services delivered by pharmacies, suggesting that telehealth should strengthen the GP patient relationships. They viewed these business models as a 'threat to both health outcomes of our patients, as

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[44] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7059083/; https://onlinelibrary.wiley.com/doi/full/10.1111/hex.13284

[45] https://www.digitalinclusionindex.org.au/

[46] https://www.racgp.org.au/clinical-resources/COVID-19-resources/telehealth; https://www.ahpra.gov.au/news/COVID-19/workforce-resources/telehealth-guidance-for-practitioners.aspx ; https://www.racp.edu.au/docs/default-source/advocacy-library/telehealth-guidelines-and-practical-tips.pdf ; https://www.medicalboard.gov.au/codes-guidelines-policies/technology-based-consultation-guidelines.aspx ; https://www.ranzcp.org/practice-education/telehealth-in-psychiatry

[47] https://www.health.gov.au/sites/default/files/documents/2020/12/taskforce-recommendations-telehealth-telehealth-recommendations-2020.pdf

[48] https://www1.racgp.org.au/newsgp/professional/government-restricts-telehealth-mbs-access-to-pati#:~:text=Patients%20will%20now%20only%20be,a%20referred%20non%2DGP%20specialist.

well as to the viability of traditional family GP clinics, particularly those in rural and remote communities.'

The experience of people living in these rural and remote communities are however very different and the above MBS accepted recommendation seems to have had unintended consequences.

Anecdotally, lack of access to GPs in rural and remote areas of Australia are often experienced by people living with MS. They often hear that a practice does not take on new clients, or that their 'books are closed', or that their GP has moved on. Often there are 'fly-in-fly-out' arrangements in place. They have no continuity of care and in fact are locked out of bulked billed telehealth consults because of these MBS restrictions requiring an existing relationship of at least 12 months[49].

Although we do not have specific evidence relating to people living with MS and access to GPs, '*The Deloitte Access Economics General Practitioner Workforce Report 2019'* [50] has noted that the GP shortage currently experienced in especially rural and remote Australia is only going to get worse. The report found the GP deficit could be worse in urban areas by 2030, with a projected shortfall of 7,535 full-time GPs or 31.7%, whilst regional areas could experience a deficit of 1,763 GPs or 12%.

Their follow-up *General Practitioner workforce report 2022*[51] noted that demand for GP services is projected to increase by 38% by 2032 (and by 47% in our cities) and that there will be a shortfall of 11,392 GPs by 2032, or almost 1 in 3 (28%) of the GP workforce.

MS Australia supports the central notion of the Department of Health's Stronger Rural Health Strategy and The National Strategic Framework for Rural and Remote Health shared commitment, across state and federal boundaries, to provide healthcare planning, programs and service delivery models that are adapted and reflective of community need.

Notwithstanding this, 28% of all Australians (those living in rural and remote areas) still have differing levels of life expectancy, disease burden and outcomes, risk of injury and access to health services. Even with adjustments for age, the total burden of disease and injury still appears to increase with remoteness. Poorer access to health services persists. Non-hospital non-referred attendances per person (such as a visit to a GP) remain lower per person than those living in inner regional and major cities. And while such barriers and inequalities exist - the postcode lottery for health outcomes of people living in rural Australia continues. Australians living in rural/remote locations continue to achieve poorer health outcomes due to lower rates of prevention and screening, higher rates of preventable hospitalisations, poorer access to early intervention and lack of coordination and access to treatment and management of especially chronic health conditions.

These systemic issues, compounded by this MBS "active patient" stipulation have real patient consequences. MS Australia adds our voice to

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[49] https://www.theguardian.com/australia-news/2022/feb/10/australians-without-regular-gp-locked-out-of-bulk-billed-telehealth-consults?CMP=Share_iOSApp_Other

[50] https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-economics-general-practitioners-workforce-2019-021219.pdf

[51] https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-cornerstone-health-gp-workforce-06052022.pdf

those participating in the various workshops held by the Consumer Health Forum's *'Rural, regional and remote roundtable on health service access report 2022'* [52] and support the position of the National Rural Health Alliance in this regard [53] seeking:

- expansion of telehealth Medicare item numbers to all health professionals including allied health professionals, for any reason during the ongoing COVID-19 pandemic
- improved internet connectivity in rural Australia; NBN Co and the Government must ensure that people in all parts of Australia can access these services, include not only improving connectivity and internet infrastructure in rural Australia, but also working with retail service providers to ensure that internet and data packages are affordable and accessible for everyone.

We note that during the recent election campaign, the ALP, that has since formed government, made promises to change the rules to allow regional and outer metro communities to recruit more doctors of their choosing, both locals and overseas trained GPs, and committed $135m for a trial of 50 urgent care bulk billing clinics.[54]

Recommendation 1:

Improve access to primary healthcare in rural and remote areas by addressing barriers to health outcomes such as:

1. **Applying an exemption from the "active patient" definition for people with MS in rural and remote locations**
2. **Expansion of telehealth Medicare item numbers to all health professionals including allied health professionals**
3. **Improved and affordable internet connectivity in rural Australia**

Older Australians with MS and those living in residential aged care

A June 2020 Report from Swinburne University, *Improving the digital inclusion of older Australians*, stated, "Older Australians have faced some of the greatest challenges to accessing health, welfare and business services online, and maintaining social connection, especially during the COVID-19 pandemic. And yet, they are least equipped to deal with the mass shift to life online".

Further, "There is a strong need to support the development of older Australians' digital skills, safety, and confidence, to enable them to participate fully in the digital society".[55]

The Report was commissioned by the Department of Social Services as part of the Australian Government's Digital Literacy for Older Australians strategy and presented a social impact evaluation of "Be Connected", an Australian Government Digital Literacy for Older

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[52] https://chf.org.au/sites/default/files/220222_rural_regional_remote_roundtable_report_final.pdf
[53] https://www.ruralhealth.org.au/media-release/telehealth-expansion-welcomed-more-needs-be-done
[54] https://www.alp.org.au/policies/medicare-and-your-health
[55] https://www.dss.gov.au/sites/default/files/documents/03_2021/improving-digital-inclusion-older-australians-social-impact-be-connected-16-june-2020.pdf

Australians program[56]. This initiative was designed to increase the confidence, skills and online safety of older Australians and aimed to "empower everyone to use the internet and everyday technology to thrive in our digital world".

The ability for many older Australians to successfully use telehealth may be hampered by many of the barriers discussed previously in this report and despite every best effort may remain inaccessible for many.

Recommendation 2:

Improve the digital literacy and connectivity of older Australians through the expansion of programs such as Be Connected.

Increase access to telehealth for specialist MS Nurses

In April 2022, MS Australia launched a special report, *MS Nurse Care in Australia: Patterns of access and impact on health outcomes.*[57]

The findings in this Report indicate that people with MS who are unable to access MS Nurses care are adversely affected in terms of health outcomes.

Specifically, the findings stated that, "an increased use of telehealth services is another avenue to improve access and reduce inequity. Telehealth services are theoretically not dependent on the location where people live. However, rules around Medicare payments for telehealth pose restrictions on what is possible. Telehealth not only assists with reduced clinic visits access due to geographical remoteness, but also with reduced access due to other reasons such as mental health difficulties, social isolation, physical difficulties such as impaired mobility and fatigue, lack of access to transport or the financial burden associated with attending clinic visits. This telehealth model would need to provide adequate remuneration for the MS Nurse service to allow this to be a continuing, long-term option."

Telehealth with video on mobile devices can offer some opportunity to 'see people in their own space'. Expanding access to this option could potentially increase access to MS nursing services in a way that suits people living with MS while supporting greater productivity and time management for MS Nurses. Existing evidence suggests that telehealth, for both new and established neurological patients, can be an important and workable form of healthcare. Of course, telehealth appointments do not allow for thorough clinical examination which may be necessary to identify certain neurological signs, evidence of disability progression, and other functional changes in MS. While telehealth appointments will never replace clinical examination, telehealth usage interspersed with face-to-face appointments could remove logistical barriers and enable more regular monitoring and care where this is acceptable and available for those with MS.

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[56] https://beconnected.esafety.gov.au/
[57] https://www.msaustralia.org.au/about-us/reports-and-financials/

Recommendation 3:

Expand telehealth services to improve access to MS Nurse care by amending Medicare item numbers which currently cover telehealth appointments with neurologists, to include MS Nurses.

Conclusion

MS Australia is pleased to provide this submission to the Australian National Audit Office's (ANAO) performance audit of the Australian Government Department of Health's management of the expansion of telehealth services in response to the COVID-19 pandemic.

In this submission, the terms of reference have been addressed in the context of the impact on people affected by MS and other neurological conditions.

Overall, we can report positive experiences regarding the expanded use of telehealth by the MS community during the COVID-pandemic and we have made suggestions for the permanent expansion of telehealth to include allied health professionals and MS Nurses. Although clinical examination is essential to the management and care of people with MS, and whilst more work needs to be done to improve digital literacy and connectedness especially for older Australians, telehealth has now become a well-established, viable option for people with MS and their healthcare teams.

KEY FACTS ABOUT MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.