



Response to the Senate Standing Committees on Community Affairs

Inquiry into ‘the provision of general practitioner (GP) and related primary health services to outer metropolitan, rural, and regional Australians’

30 September 2021

For information contact:

Ms. Liz Callaghan
Chief Executive Officer
Carers Australia

Unit 2, 11 McKay Lane TURNER ACT 2612
Telephone: 02 6122 9900
Email: ceo@carersaustralia.com.au
Website: www.carersaustralia.com.au

About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- That are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies and abilities.

Introduction

Carers Australia welcomes the opportunity to comment on the provision of general practitioner (GP) and related primary health services to outer metropolitan, rural, and regional Australians. We agree that access to primary care services in rural and regional areas is a critical issue affecting communities and applaud the Senate Standing Committees on Community Affairs (the Committee) for examining the delivery of health services and ways to improve access.

This submission focuses on carer recognition, carer-inclusive practice, access to respite and system integration and infrastructure, while also drawing attention to carers own health and wellbeing. This does not negate the impact of the following issues, which Carers Australia are confident will be highlighted in other submissions in more detail:

- The cost in accessing general practice and related primary health services, including out-of-pocket costs, transport and time away from employment if distance is an issue,
- The lack of access to, or choice of GP, due to factors such as availability (closed books or one-GP towns), waiting lists, workforce maldistribution, and the lack of financial viability for private practice,
- Issues surrounding access to allied health and psychological services to support GP referral (many of which are similar to those outlined above) negating the benefit of Chronic Disease Management Plans and Mental Health Care Plans that result in subsidised allied health and psychological services, and
- The availability of culturally safe and appropriate primary health services.

The *Carer Recognition Act 2010*¹ (Commonwealth) aims to increase recognition and awareness of carers and acknowledge the valuable contribution they make to society. The cornerstone of the Act is the Statement for Australia's Carers, which sets out ten principles that articulate how carers should be treated and considered. First and foremost, "all carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality". In addition, the relationship between carers and the persons for whom they care should be recognised and respected, and carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

It is with the Statement for Australia's Carers in mind that Carers Australia provides the following commentary, which has been informed by the National Carer Network – our members who are the carer peak organisations in each state and territory.

The need to improve carer recognition

It is a long-standing concern that carers continue to be largely mentioned or considered only in relation to "consumers, their families and carers" without recognition of their specific needs. This is despite carers underpinning the sustainability of the health, aged care, mental health, and disability care systems, by providing care beyond being a friend or family member to those with a chronic condition, terminal illness, mental illness, people living with a disability, drug or alcohol problem, or who are frail aged, where the estimated cost to replace this informal care was \$77.9 billion in 2020 alone².

¹ Australian Government, *Carer Recognition Act 2010*, No.123,2010 [[accessed online](#)]

² Deloitte Access Economics (2020) 'The value of informal care in 2020' for Carers Australia [[accessed online](#)]

We draw attention to the Committee this is despite significant national policy work in health care reform over past decade recommending improved recognition, and embedded supports in system transformation, which have not been translated into practice or improved access. This includes as examples:

- The National Health and Hospitals Reform Commission 2009 Report³ specifically refers to “recognition and support for carers” as a Transformative Action and includes a number of standalone recommendations for carers, including Recommendation 14: “We acknowledge the vital role of informal/family carers in supporting and caring for people with chronic conditions, mental disorders, disabilities and frailty. We recommend that carers be supported through educational programs, information, mentoring, timely advice and, subject to the consent of those they care for, suitable engagement in health decisions and communications. We also recommend improved access to respite care arrangements to assist carers sustain their role over time and that the health of carers should also be a priority of primary health care services dealing with people with chronic conditions”.
- The Productivity Commission in the recent mental health inquiry report⁴ also included a recommendation specific to the needs of families and carers (Recommendation 18), where “Carers are an important, but too often forgotten, part of the mental health system. They play a vital role in the recovery of people with mental illness, but their own needs are not always considered by the mental health system. They are often excluded from discussions on their care recipient’s needs — regardless of the consumer’s preferences — and not made aware of services that can assist them. Embedding family- and carer- inclusive practices across the mental health system would enable more effective support to people accessing services and their carers.”
- The Royal Commission into Aged Care Quality and Safety Final Report⁵ highlighted “Providing informal care for an ageing family member or friend can bring personal rewards and satisfaction. But we learned that a caring role can also have detrimental effects on the health, wellbeing and financial security of the carer. Over time, this can affect the quality of care an older person receives and the sustainability of the caring relationship. The Australian Government should ensure that informal carers are properly supported.”

We urge the Committee to recognise carers and their specific issues and needs, including the role they play in supporting GP’s and related primary care services. This becomes arguably more important in regional, rural and remote locations due to workforce shortages, where the responsibilities and expectations of what a carer can and should do are often increased with little support. Carers Australia also note to the Committee that while we share the aim of the Government’s Primary Health Care 10 Year Plan - to maintain and strengthen our world-class primary health care system in order to deliver the best possible health outcomes for all Australians – we were disappointed in the draft recommendations released for public consultation recently.⁶ Developed by the Primary Health Reform Steering Group (Steering Group) which does not have Carers Australia or a carer representative, it was not clear in any of the Actions what specifically will be aimed at carers distinct needs, and there was no carer-specific

³ Australian Government, National Health and Hospitals Reform Commission (2009) ‘A Healthier Future For All Australians – Final Report of the National Health and Hospitals Reform Commission – June 2009’ [\[accessed online\]](#)

⁴ Australian Government, Productivity Commission: Final Report on the Inquiry into the role of improving mental health to support economic participation and enhancing productivity and economic growth Productivity Commission Final Report - p.148 Vol 2 [\[accessed online\]](#)

⁵ Australian Government, Royal Commission into Aged Care Quality and Safety Final Report: Care, Dignity and Respect – p.103 Vol 1 [\[accessed online\]](#)

⁶ Department of Health, Primary Health Reform Steering Group ‘Discussion Paper to inform the development of the Primary Health Reform Steering Group recommendations on the Australian Government’s Primary Health Care 10 Year Plan’ [\[accessed online\]](#)

targeted consultations similar to the roundtables and other mechanisms that occurred to explore the health needs of the LGBTI+ community and those from culturally and ethnically diverse backgrounds. We also highlight to the Committee that this Inquiry provides an **opportunity for improved responsibility and accountability for primary health care related carer support within the Department of Health** and relevant authorities, to address a diffusion of responsibility and perception that carer supports are a Department of Social Services only-role, or primarily focused on carers of people with a disability.

Carers own health and wellbeing

As is the case for all carers, caring can at the best of times be a rewarding yet demanding and socially isolating experience, where **carers have among the lowest levels of wellbeing of any group of Australians⁷ and need to be encouraged to prioritise their own physical and mental health needs, where GPs and other primary care professionals could play a significant role in this area.** Despite experiencing poorer physical health, carers often report that they delay attending to their own health needs, and in some cases, the health needs of the care receiver were considered first and foremost, and with limited resources to the exclusion of considering their own health⁸.

The COVID-19 pandemic has added another level of complexity for carers, where they have had, and in some cases continue to have, periods of reduced social support and formal and informal respite options. Add to this reduced employment and income, increased risk of violence and abuse within the home, due to associated household changes, and financial impacts and/or the challenging behaviors among the people they care for, balancing home-learning, including for children with disability and/or learning difficulties, and concern regarding access to and the logistics for having a COVID-19 immunisation for themselves and the person they are caring for. For carers of the frail aged within residential care or those living with a disability within supported accommodation, COVID-19 has also seen them isolated from the person they continue to provide a level of care for, and at times they have made the decision to take the person back home for the foreseeable future. Carers are at breaking point.

Primary care professionals should be actively identifying if a patient has a carer, even if the carer does not identify themselves that way, and all patients within primary health care need to be asked about their care responsibilities and we would also encourage the inclusion of carers within data collection. Increased recognition of carers and proactive identification will assist in addressing carers' rights and needs, together with and separately from the people they care for.

Carer-inclusive practices

Carers Australia highlight that the wellbeing of patients accessing primary care and their carers are interdependent. **The primary health care system does not proactively identify carers or include carers in appropriate discussions or decision-making, which in effect ignores the impact that a person's care needs have on the carer.** A distressed or exhausted carer is not well-placed to support the person they care for, noting carers have their own care needs, may be in multiple care relationships, include young carers (aged under 25 years) as well as 'grandparent carers' (aged over 65 years) and be balancing their caring role with employment and/or education commitments. More carer-inclusive practices will support a patient-centred approach, as well as linking the carer to services and supports that can assist them, such as the Carer Gateway and activities like social prescribing.

⁷ Deloitte Access Economics (2020) 'The value of informal care in 2020' for Carers Australia [[accessed online](#)]

⁸ Parliament of Australia (2009) House of Representatives Standing Committee on Family, Community, Housing and Youth 'Who Cares...? Report on the inquiry into better support for carers' [[accessed online](#)]

Health professionals typically do not see value in the information that carers hold across the patients care journey. The carer role can include prevention, early intervention and forming a diagnosis, through to complex medical support. The encompasses monitoring of symptoms, side effects and decline, medication management including administering medicines, self-management, hospital avoidance and medical decision making. They are the hidden ‘care coordinators’ including system navigation, social supports, attendance at and travel to appointments, which can be more of an issue for families in rural or regional areas, and communication with broader health professionals and maintenance of records and processes including services linked to my.gov such as managing NDIS packages, My Aged Care and My Health Record. Carers also often assume responsibility of household tasks and related stressors, including personal hygiene, meal preparation and financial issues, as well as communicating and reinforcing information from the primary care professional back to the consumer and broader family – playing a key role in tackling health literacy.

Carers Australia are strong advocates for carer inclusion in services delivered to those they care for – whether these be clinical services or other types of support services. This is at the heart of the concept of “partners in care” which is a central principle of the *Carer Recognition Act*. **Considering the carer as a part of the care team and embedding specific supports to carer identification will enable community-based models of care, whereby consumers are able to manage much of their health issues outside of clinical settings.** The importance of for regional, remote and rural locations with primary care access issues cannot be understated and requires targeted investment and co-design.

Access to respite

It is also essential to highlight that **early referral and timely access by primary care professionals to respite services, planned and emergency, are critical to many carers’ own health and wellbeing** and can, in many cases, mean the difference between a carer being able to provide care and support or having no alternative but to seek other accommodation options, ceasing employment or risk further strain on the carer and wider family. This is noting cessation of funding for previous programs such as Mental Health Carer Respite Services, difficulty accessing respite, particularly community-based cottage respite, through the Carer Gateway, issues with aged care focused respite pathways (both community and residential) or palliative care-focused respite options, and very limited access to carer respite via the NDIS.

As with many services, respite is even more difficult if not impossible to access in many regional, rural and remote locations. For many, being able to ‘access’ respite means the person being cared for being separated by great distances from the carer, adding greater emotional, practical and financial strain. Greater availability of respite will mean that carers can have regular breaks that allow them to attend to other responsibilities or to sustain their personal health and wellbeing - which in turn will sustain and support the caring relationship. **Respite must be considered in any design of a high performing and sustainable primary health care system that is responsive to the needs of individuals, families, and carers.**

Integrated care systems

We note interface issues already occurring and being scrutinised within processes related to aged care, disability care and mental health, and highlight that reform across settings and sectors including social services, while well intentioned has potential to further fragment the provision of supports and services available to carers in all care relationships. We raise to the Committee that primary care referral, integration and support for coordinated care systems must also be considered from the lens of both the consumer and the person caring for them, that are focused on integration, including in aged care,

community care, disability and mental health services, as well as other social support services linked to the determinants of health.

Carers Australia urge more action to strengthen cooperation between Primary Health Networks (PHNs), Local Hospital Networks (LHNs) and Carer Organisations who are providing much needed services and supports based on local need. Further, **PHNs should be required to liaise with Carer Gateway providers during regional planning** as enhanced information provision between primary health care and the Carer Gateway would support the identification and monitoring of the ongoing needs of carers across settings and services.

We would also encourage improved data linkage and use of data, including between providers and across health and care systems, in order to inform policy and funding to address population health needs and support services that improve patient *and carer* outcomes based on collected, nationally consistent and comparable data. However, **if data on carers is not consistently collected or carers are not proactively identified within primary care, further fragmentation of services and redirection of funding away from carers needs will occur.** Careful consideration needs to be given to how this will relate to carers, for example, individual carer information held within the Carer Gateway, or My Aged Care through the impending carer assessment processes.

Digital infrastructure

Carers Australia also broadly support an increase in digital infrastructure and development of clinical systems and integration to better support safe and effective primary care, however, with an increased reliance on technology it is important to note that while many carers do use digital technology a significant number are digitally disadvantaged⁹. It is critical to continue offline service delivery options for those who cannot, or do not want to for various reasons, engage in an online environment. There are variety of reasons non-face to face standards are not suitable for many people, for example, cultural norms, level of comfort, disabilities that may affect communication, and accessibility needs, for example, availability of translators, and hearing or vision impairment. In addition, the cost associated with acquiring and setting up various IT equipment, maintaining an adequate internet connection, especially in outside of metropolitan regions, and a private space within a home.

Actions must also improve carer digital inclusion and readiness or risk increasing the 'digital divide' which will impact on carers ability to not only undertake their caring responsibilities, but also manage their own health and wellbeing. On telehealth specifically, it risks removing the 'social' aspect and opportunity to discover other issues that people may not be as forthcoming to raise, or where it is harder (or impossible with phone) to see body language and general 'look' which is really important for carers wellbeing when the appointment is for the individual, but the carer is 'seen'.

⁹ Australia, Government, Australian Bureau of Statistics, Use of information technology by people with disability, older people and primary carers, 2020 [[accessed online](#)]