



Response to the Australian Government Department of Health Primary Health Care Reform Taskforce

‘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’

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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 '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' (Discussion Paper), developed by the Primary Health Reform Steering Group (Steering Group).

Broadly, we agree that without attention, the primary health care system will have limited ability to respond to challenges in caring for Australian people over the next ten years and beyond, noting the Discussion Paper states this particularly applies to care continuity for the growing number of Australians with chronic disease, mental health needs and frailty¹. Carers are mentioned in the Discussion paper only in relation to "consumers, their families and carers" however it is not clear in any of the Actions what specifically will be aimed at carers distinct needs. Providing care can be rewarding yet demanding and socially isolating, where carers have among the lowest levels of wellbeing of any group of Australians and are at a greater risk of negative physical and mental health effects².

None of the draft recommendations acknowledge that carers underpin the sustainability of the health, aged care, mental health and disability care systems by providing care to the same target populations of the Discussion paper - those with a chronic condition, mental illness or who are frail aged. This is in addition to caring for people living with a disability, drug or alcohol problem, or terminal illness, where the estimated cost to replace this informal care was \$77.9 billion in 2020 alone.³

We request that the Steering Group review the draft recommendations and outline how to address carers' rights and needs, together with and separately from the people they care for.

The *Carer Recognition Act 2010*⁴ (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, carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life, should be acknowledged as individuals with their own needs within and beyond the caring role; 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 key concerns with the Discussion Paper rather than commenting on each recommendation individually, noting many of these issues were raised at previous consultation opportunities, including consumer consultations undertaken by Consumers Health Forum on 7 and 18 August 2020, and the Steering Group's interactive webinar on 16 July 2021. To begin with, we suggest addition of 'carer' within the definitions in-line with the *Carer Recognition Act (2010)*.

¹ Primary Health Reform Steering Group - Discussion Paper p.1

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

³ Op. cit (2)

⁴ Australian Government, *Carer Recognition Act 2010*, No.123,2010 [\[accessed online\]](#)

The need to improve carer recognition

The Discussion paper states the report (and its recommendations) acknowledges and builds upon significant national policy work in primary health care reform over past decades⁵, providing examples such as the National Health and Hospitals Reform Commission 2009 Report, the recent Productivity Commission Inquiry into mental health and the Royal Commission into Aged Care Quality and Safety. With respect to these reports, we draw the Steering Groups attention to the following:

- The National Health and Hospitals Reform Commission 2009 Report⁶ 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 mental health inquiry report⁷ 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 Report⁸ highlighted “They [carers] nurture, they support, they care, they advocate, and they speak up when something’s not right. The value of informal carers to the sustainability of the aged care system is difficult to overstate, but their work is largely invisible. From the number of informal carers, the economic value they contribute, and the important care and support they provide, there is no doubt the aged care system depends on the contribution of informal carers. 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. The current aged care system fails to do so and provides reactive, inadequate support. Supports are often not provided until the strain on a caring relationship has already reached crisis point. We propose instead a preventative approach to support informal carers. A preventative approach would equip carers with skills at an early stage in their caring role, and access to timely, well-coordinated supports and respite throughout. Early access to services is critical to supporting the wellbeing of the informal carer as well as the sustainability of the caring relationship.”

⁵ Primary Health Reform Steering Group - Discussion Paper p.1

⁶ 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 [\[accessed online\]](#)

⁷ 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 [\[accessed online\]](#)

⁸ Australian Government, Royal Commission into Aged Care Quality and Safety Final Report: Care, Dignity and Respect – p.103 Vol 1 [\[accessed online\]](#)

Carer recognition must be considered across all draft recommendations, including Recommendation 8 (Improved access for people with poor access or at risk of poorer health outcomes). Carers Australia argue that carers should be included as a target population, and embedded within actions that are focused on streamlining health system navigation, social prescribing, and co-design of local campaigns and programs to increase awareness and communicate services that are available to people.

Carer-inclusive practices

There are many references to person-centred care and we note the definition⁹ provided is “Person-centred describes treatment, care and support that places the person at the centre and in control of the design and delivery of their own care and considers the needs of the person’s carers and family.”

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 through activities such as social prescribing. 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*.

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 their care recipient, 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.

Carers aren’t always instantly identifiable. Coming from all walks of life, cultural backgrounds and age groups, health professionals should be actively identifying if a patient has a carer, even if the carer does not identify themselves that way. 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.

Considering the carer as a part of the care team and embedding specific supports to carer identification supports a number of the recommendations, including those focused on innovation and progressive models. Health professionals typically do not see value in the information that carers hold across the patients care journey, from prevention, early intervention and forming a diagnosis, to treatment, system navigation, social supports, medication management, self-management and hospital avoidance. As a ‘partner in care’ carers must feel able to raise queries or concerns at any stage to assist the person they are caring for.

Integrated care systems

There are many recommendations and actions that are focused on integration and support for coordinated care system, including in aged care, community care, disability and mental health services, as well as other social support services linked to the determinants of health. 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

⁹ Primary Health Reform Steering Group - Discussion Paper p.51

intentioned has potential to further fragment the provision of supports and services available to carers in all care relationships.

Carers Australia agrees with actions to strengthen cooperation between Primary Health Networks (PHNs) and Local Hospital Networks (LHNs), however, PHNs should be required to liaise with Carer Gateway providers during regional planning. Further, 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, how these will be embedded within the Carer Action Plan. Increased interface between primary health care and the Carer Gateway Providers compliments Recommendation 9 (Leadership), where Action 9.2.6 'utilise existing structures' aims to leverage off existing structures to train and embed continuous quality improvement and reform thinking across professional development and primary / integrated health care.

With respect to integration of care across systems and settings, there are issues with data collection if carers are not identified appropriately, and linkages to carer-specific data, noting Recommendation 17 (Data) includes:

- Action 17.2 'Integration and use' to integrate, link and use data across the life course, including between providers and across health and care systems. Careful consideration needs to be given to how this will relate to carers, for example, information held within the Carer Gateway, or My Aged Care through the impending carer assessment processes.
- Action 17.5 'Redirected funding based on data' to redirect funding to address population health needs and support services that improve patient 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.
- Action 17.6 'Consumer information' to educate consumers about their rights, as well as complaint and feedback processes. It is essential that carers rights and needs are separated from those of the person they are caring for, with clear complaint and advocacy processes would these be required that support the carer.

It is also essential to highlight that early referral and timely access 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.

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 under many of the Discussion paper recommendations and actions, including:

- Recommendation 1 (One system focus) which will "future-proof a high performing and agile primary health care system that delivers coordinated services, integrated care and team-based approaches that are responsive to the needs of individuals, families, carers and communities."

- Recommendation 2 (Single primary health care destination) which “aims to foster single primary health care destinations and equip them to provide multi-disciplinary, wrap-around care. This service base should be well connected with the people they serve, as well as other services, networks and supports, both in the community and secondary care systems.”
- Recommendation 3 (Funding reform) to “deliver appropriate and sustainable funding reform that underpins and incentivises the best models of primary/integrated health care tailored to local circumstances, supporting access, affordability, equity and continuity of care for local people.”

Carers Australia also broadly support an increase in digital infrastructure and development of clinical systems to better support safe and effective care within recommendations and actions, 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 disadvantaged¹⁰. 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 nonface 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.

Recommendation 15 (digital infrastructure) should consider the costs associated with acquiring and setting up various IT equipment, maintaining an adequate internet connection and a private space within a home, as well as reference alignment with the National Digital Health Strategy. 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'.

Leadership and governance

While we applaud the emphasis on leadership, cultural change, regional governance involving consumers and co-design with community within many recommendations, we highlight carers will need to be adequately supported to engage in review, consultation, co-design and reform processes.

We note within Recommendation 20 (Implementation)to “ensure consumers, communities, service providers and peak organisations are engaged throughout implementation, evaluation and refinement of primary health care reform” and request:

1. Carers Australia representation on the Independent Oversight Group (Action 20.1) is group, where currently in the Discussion paper membership is limited to ‘relevant health sector bodies.’ and
2. Inclusion of carers within Action 20.2 - Implementation, evaluation and refinement, specifically within 20.2.3. Collaboration: Collaborate closely with and ensure ongoing involvement of the broad range of leadership, institutions and organisations across the health sector, including users of health services *and carers*.

These requests are based on no representation, either through Carers Australia or a carer representative, on the Steering Group, as well as no carer-specific targeted consultations with carers similar to the

¹⁰ Australia, Government, Australian Bureau of Statistics, Use of information technology by people with disability, older people and primary carers, 2020 [[accessed online](#)]

roundtables and other mechanisms that occurred to explore the health needs of the LGBTI+ community and those from CALD backgrounds¹¹.

Ultimately, Carers Australia 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. It is 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.

Carers Australia Recommendation: The Steering Group should review the draft recommendations and outline how to address carers' rights and needs, together with and separately from the people they care for.

This would show leadership within developing the 10 Year Plan, and create 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.

We are looking forward to continuing involvement in development of this Plan and welcome the opportunity for more in-depth discussion.

¹¹ Primary Health Reform Steering Group - Discussion Paper p.57