



**Response to the Australian Government
Department of Health**

‘National Medicines Policy Review - Discussion Paper’

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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 Review of the National Medicines Policy Discussion Paper¹ (Discussion Paper) following a consultation with the Expert Steering Committee (Committee). We agree that it is timely for the National Medicines Policy (NMP) to be reviewed to ensure that the changes in the health system environment are addressed, and where applicable, the policy updated to take account of these changes.

This submission focuses on carer recognition and carer-inclusive practice while also drawing attention to carers own health and wellbeing. The *Carer Recognition Act 2010*² (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 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 commentary, which has been informed by the National Carer Network – our members who are the carer peak organisations in each state and territory. Overall, **we urge the Committee to recognise carers and their specific issues and needs related to the principles (proposed) and objectives of the updated NMP, and any related activities focused on health literacy, digital health, governance, communications, and evaluation.**

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 within policy. 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 alone³.

We draw attention to the Committee that the current National Medicines Policy⁴ does not mention the term 'carer' despite significant national policy work in health care reform over past decade recommending improved recognition and embedded supports for carer in system transformation, which have not been translated into practice or improved access.

¹ Australia Government, Department of Health (2021) 'Review of the National Medicines Policy Discussion Paper' (Discussion Paper) [\[accessed online\]](#)

² Australian Government, *Carer Recognition Act 2010*, No.123,2010 [\[accessed online\]](#)

³ Deloitte Access Economics (2020) 'The value of informal care in 2020' for Carers Australia [\[accessed online\]](#)

⁴ Australian Government, Department of Health and Ageing (2000) 'National Medicines Policy' [\[accessed online\]](#)

This includes as examples:

- The National Health and Hospitals Reform Commission 2009 Report⁵ 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.”
- The Productivity Commission in the recent mental health inquiry report⁶ 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 Report⁷ 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.”

Carer-inclusive practices

Carers Australia highlights that the wellbeing of consumers accessing medicines and related services and their carers are interdependent. **Prescribers and dispensers of medicines do 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 by prescribers and dispensers of medicines will support a true person-centred approach, as well as linking the carer to services that can assist them, such as the Carer Gateway and medication management support.

Health professionals such as GPs and community pharmacists typically do not see value in the information that carers hold across the patient 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,

⁵ 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](#)]

⁶ 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](#)]

⁷ Australian Government, Royal Commission into Aged Care Quality and Safety Final Report: Care, Dignity and Respect – p.103 Vol 1 [[accessed online](#)]

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, continence care, meal preparation and financial issues, as well as communicating and reinforcing information from the prescriber or dispenser 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*. However carers aren’t always easily identifiable. **Health professionals such as GPs and pharmacists should be actively identifying if a person has a carer, even if the carer does not identify themselves that way.** 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, noting that carers will also often be accessing similar services and may be experiencing polypharmacy themselves. As a ‘partner in care’ carers must feel able to raise queries or concerns about medicines and associated products at any stage to assist the person they are caring for.

Response to Consultation Questions

Terms of Reference 1: Evaluate the current NMP objectives and determine whether these should be modified or additional objectives included. This includes consideration of the proposed Principles to be included within the NMP.

A. Are these proposed principles appropriate? With regard to the proposed principles, is anything missing or needing to change?

Carers Australia agree with the inclusion of principles in the updated NMP, noting the intent is that they should be evident in the planning, design and implementation of programs, systems and initiatives created to deliver positive health outcomes for all Australians through their access to, and appropriate use of, medicines. We request the addition of:

- **Consumer centred approach** – consumers **and their carers**, should be informed, engaged, and empowered to participate in medicines policy, recognising their key role in supporting the achievement of the policy’s objectives.

B. Consumer centred approach – consumers and their carers, should be informed, engaged, and empowered to participate in medicines policy, recognising their key role in supporting the achievement of the policy’s objectives.

Carers Australia highlight the need for greater emphasis on prescriber’s requirement within Quality use of Medicines, to discuss medicine selection, reasoning, use, and safety with a consumer, and their carer where appropriate. We request the addition of:

- timely access to the medicines that Australians need, at a cost individuals, **families** and the community can afford;
- medicines **and related products and services** meeting appropriate standards of quality, safety and efficacy;
- quality use of medicines, **including deprescribing and monitoring adverse events**; and
- maintaining a responsible and viable medicines industry.

Terms of Reference 2: Consider the definition of medicines and whether the NMP needs to be expanded to include health technologies.

A. Should the current NMP definition of medicines be expanded to include medical devices and vaccines? Why or why not? How would a change in definition of medicines be reflected in the policy's high-level framework?

B. Does the policy's current title, the "National Medicines Policy", reflect the breadth of health technology developments within the policy's scope? If not, how best can these and future health technologies be better represented in the policy's title?

Carers Australia comment that the addition of a clear outline or explainer at the start of the NMP and associated documents would be beneficial, based on what input is provided by subject matter experts on the issue of definition and scope. That said:

- if the NMP is not expanded, it is important to cross reference or direct people to where information is available on medical devices and vaccines, in addition to consumables and medicines-related aids and equipment.
- if the NMP is expanded, the title needs to be amended so that it is clear to consumers and carers what is within scope.

Terms of Reference 3. Assess the NMP's utility in the context of rapidly evolving treatment options, population changes, interconnected relationships, and system-wide capacities.

A. How has the NMP been able to maintain its relevance and respond to the changes in the health landscape?

B. How could the NMP be refreshed so that the policy framework is able to better address current and future changes in the health landscape? What is missing and what needs to be added to the policy framework, and why?

Carers Australia broadly support an increase in digital infrastructure and development of clinical systems and integration to better support safe and effective medical 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 disadvantaged⁸. We raise to the Committee that digital health activities need to be considered from the lens of the health professional, consumer *and* the person caring for them. As an example, accessing the My Health Record as a carer is not necessarily a simple process, adding to other issues navigating digital infrastructure for themselves and the person (or multiple people) they may be caring for such as electronic prescriptions, immunisation (e.g. COVID-19) records/evidence, and My Aged Care, NDIS and Services Australia portals.

In addition, the cost associated with acquiring and setting up various IT equipment or digital infrastructure, maintaining an adequate internet connection, especially outside of metropolitan regions, and the educational or on-boarding needs and ongoing 'tech support' in accessible and varied formats needs to be considered. It is also important to highlight that while we agree with the Discussion Paper statement of 'an increase in digitally enhanced models of care is also presenting new ways of engaging with health services, at a time and place convenient to consumers', there must be recognition that not all

⁸ Australia, Government, Australian Bureau of Statistics, Use of information technology by people with disability, older people and primary carers, 2020 [[accessed online](#)]

consumers or their carers have an adequate private space within a home to have discussions, use devices or view information.

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.

Terms of Reference 4: Consider the centrality of the consumer within the NMP and whether it captures the diversity of consumers' needs and expectations.

A. How can the NMP's focus on consumer centrality and engagement be strengthened? Is anything missing, and what needs to change?

Carers Australia agree that the updated NMP will need to recognise that consumers *and carers* are becoming more active and informed participants in care provision and broader health policy. **The need for carer recognition and carer-inclusive practices as outlined previously, within the context of medicines related policy, programs, communications, and governance is essential.** The Discussion Paper states that "The NMP emphasises the fundamental role of the consumer in achieving the policy's four objectives and identifies responsibilities for consumers in its discussion on making the partnership work" – this needs to also recognise that carers are often responsible many actions to support QuM, including but not limited to:

- Discussions with prescriber and/or pharmacist
- Collecting prescriptions from pharmacy and managing/monitoring repeats
- Relaying and/or reinforcing information from prescriber and/or pharmacist
- Maintaining medicines lists and medicines reconciliation activities
- Assistance with taking medicines – right medicine, right dose, right time, right route
- Storage and safety, including disposal
- Monitoring for side effects or adverse events
- Monitoring for decline, effectiveness or break through issues, and
- Monitoring challenging behavior i.e., caused by an illness or a side effect of a medicine?

Terms of Reference 5: Identify options to improve the NMP's governance; communications, implementation (including enablers) and evaluation.

A. What opportunities are there to strengthen governance arrangements for the NMP? What would these be, and why?

B. How can communication about the NMP be enhanced or improved?

C. What would be effective mechanisms to support communication about the policy?

Not all consumers are carers, however all carers are consumers - highlighting the need to ensure not only consumer representation, but also dedicated carer representation within relevant governance structures and co-design processes, including on the HTA Consumer Consultative Committee. We note increased and welcome engagement by the Therapeutic Goods Administration and specific consideration of carers information needs in recent activities, as well as our strengthened relationship with NPS MedicineWise and inclusion of Carers Australia on advisory groups as well as carer representation in co-design processes.

We draw attention to the importance of engaging carers appropriately in discussions and communication activities, to ensure clear and consistent positive messaging regarding issues such as privacy, consent, access to and administration of medicines, and informed supported decision making. This is particularly important for carers who are caring for people with cognitive impairment such as conditions related to aged care or disability, as well as young carers, noting there are over 235,000 young carers aged under 25 years. To date we have not been approached by the Consumer Evidence and Engagement Unit, however we look forward to building a relationship in future to support increased awareness of carer issues and improved engagement with carers, as well as enable communication of the policy and associated activities to Australia's carers through our communication channels and networks.

Terms of Reference 6: Review the NMP partners and provide options for building greater accountability including addressing conflicts of interest.

A. How should the NMP's 'partnership-based' approach be defined?

B. What is missing from the policy's reference to the NMP partners? Are there other partners that should be included in the policy? Who would they be and why?

C. How could the NMP be refreshed to support greater accountability amongst the NMP partners? How could the partnership approach be improved?

D. How are conflicts of interest currently managed and should more be done to address this amongst the NMP partners? What approaches could be taken?

While Carers Australia appreciate the noted challenges associated with delivering an integrated approach whilst remaining a high-level overarching principle-based framework, the NMP must recognise carers proactively within the partnership-based approach herein. **We request inclusion of carers and Carers Australia both 'on paper' and within all subsequent relevant activities following release of the updated NMP, noting carers will need to be adequately supported to engage in review, consultation, co-design, and reform processes.**

This would show leadership within implementing the updated NMP and alignment with the *Carer Recognition Act*, as well as creating an opportunity for improved responsibility and accountability for carer-related support within the Department of Health, 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.

[End of submission]