2 October 2012

Dr Rohan Hammett  
Deputy Director-General, Strategy and Resources  
NSW Ministry of Health  
NSWPHC@doh.health.nsw.gov.au

Dear Dr Hammett,

**Re: Consultation on the National Primary Health Care Strategic Framework**

Carers NSW welcomes the opportunity to respond to the *National Primary Health Care Strategic Framework* consultation draft which has been developed by the NSW Ministry of Health in collaboration with the Department of Health and Ageing and other states and territories.

As the peak body for carers in NSW, our primary concern in responding to the consultation draft is to ensure that consumers and carers are recognised as partners in care, and that carers have access to the primary health care services and support they need to maintain their own health and wellbeing.

**About this submission**

This submission will focus on the four strategic outcomes and potential actions which have been identified in the Framework, and will comment on these with attention to how recognition of carers will strengthen the Framework, add value to the health system and maximise patient and carer health outcomes and experiences. This submission will also draw attention to how the Framework can be implemented to realise these goals and enact Commonwealth and State legislation relating to carers.

This submission will directly address Question 5 by outlining the significance of the *Carer (Recognition) Act 2010* in NSW to ensure carers are recognised and appropriately supported in primary health care plans.
About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The vision of Carers NSW is that all carers in NSW are recognised, valued and supported by the community and by governments.

About carers

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

The 2009 Survey of Ageing, Disability and Carers (SDAC), undertaken by the Australian Bureau of Statistics, provides a snapshot of carers and their role:

- 12 per cent of the Australian population are carers (2.6 million people).
- There are 771,400 primary carers (the person who provides the most informal assistance to an individual).
- Almost a third of primary carers have been caring for ten years or more.
- Six per cent of primary carers have been caring for 25 years or more.
- 66 per cent of primary carers care for 20 hours or more per week.¹

1. Strategic Outcome 1: Build a consumer-focused integrated primary health care system

Carers NSW welcomes moves to ensure that consumer’s needs and preferences are central to service provision.

However the Framework’s exclusive focus on consumers and providers disregards the critical role of the 2.6 million Australians who are carers, many of whom support people who are health consumers. Carers are the main providers of care in the community, and have been described by the National Health and Hospital Reform Commission (NHHRC) as the “invisible health workforce” in acknowledgement of their critical and often unrecognised role as the major providers of care.² In 2010 Access Economics estimated that the financial cost of replacing the care provided by carers would be over $40 billion, for that year.³

Despite the introduction of the National Carer Recognition Framework and the development of carer policies and legislation at the state and territory level, carers are still not systematically included as partners in care. Although there are some commendable instances of carer inclusion occurring, these are often limited to particular programs, locations or service providers, and are not indicative of the general situation for carers in the health system.

Including carers as partners in care can benefit the carer, the care recipient and the health service provider, and can lead to improved information and feedback, increased compliance and improved quality of care for the care recipient.
Recommendation 1: Carers NSW recommends that the Framework be amended to acknowledge that carers perform a critical role in supporting consumers and should be supported as partners in care.

Potential Actions

1.3 Work together, and with Medicare Locals, to examine innovative care coordination and/or case management arrangements for people with complex chronic conditions that focus on secondary and tertiary prevention, improve health outcomes and literacy and reduce avoidable hospitalisations.

The National Primary Health Care Strategy recognised the difficulties that patients with complex, chronic conditions have in navigating the fragmented healthcare system. Action to better integrate the primary health care system so it is easier for consumers and carers to negotiate is strongly supported by Carers NSW.

The Framework asserts that caring for people with chronic complex conditions at home and in the community ‘will not only result in better health outcomes for them, but also reduce the pressure on the acute hospital system and on the community more broadly’. This statement does not address how carers, who provide the majority of care in the community, are impacted by their caring role. It is essential that the Framework consider the impact that increasing care at home will have on carers looking after their loved ones, often with a significant cost for their own health and wellbeing.

Carers have a significantly higher incidence of chronic diseases, and carers have been shown to be at least 40 per cent more likely to suffer from a chronic health condition than the rest of the population. Carers of people with chronic conditions are particularly vulnerable to physical and emotional exhaustion that affects their ability to undertake their caring role, with research demonstrating that more hours spent caring results in a greater decline in a carer’s health.

This vulnerability was acknowledged by the final report of the NHHRC, which recommended that the health of carers should be a priority of primary health care services working with people with chronic conditions. Carer health and wellbeing is discussed further in section 2.

In its current state the Framework continues the tendency for the health system to focus on the patient and overlook the carer’s individual support and health needs. In order to ensure that carers are recognised and supported as partners in care with their own health needs, to holistic models of team care coordination need to be identified, which consider carers in the planning, delivery and review of services that will impact upon them. This would involve assessment and identification of carer needs, and the provision of information so that carers are able to access the services and support they need. Establishing holistic models of care coordination and case management ensures that consumers and their carers are able to maintain their own health and wellbeing.

Recommendation 2: Carers NSW recommends that carer health and wellbeing are given due consideration when examining innovative models of care for people with complex chronic conditions at home and in the community.
Recommmendation 3: Carers NSW recommends that holistic models of team care coordination are identified that include recognition of carers in the assessment, planning, delivery and review of services that impact on carers and their role as carers.

1.5 Develop and promote innovative ‘pathways through care’ models which support more integrated and seamless care for consumers.

Carers NSW often hears from carers navigating the health system who are overwhelmed by the different service providers who are involved in their loved one’s care. Australian research into the experience of carers demonstrate that it is often these family members who provide care who are left to take on the role of care co-ordinators and advocates for their loved ones. Carers may find themselves lost in a service maze, and they may be communicating information between health professionals who do not communicate with each other. Carers often work through this process with little or no support, and most health professionals are not trained to be able to adequately identify and address carer needs.

The NHHRC recognised that carers need to be supported through educational programs, information, mentoring and timely advice. Carers NSW advocates for integrated and seamless care in the primary health service for carers in their own right.

Recommendation 4: Carers NSW recommends that ‘pathways through care’ be designed which ensure that carers navigating the health system alongside their loved one are able to access appropriate services to assist them in their caring role.

2. Strategic Outcome 2: Improve access and reduce inequity

Carers NSW supports initiatives which actively address gaps in service and are tailored to the particular needs of population subgroups, including carers.

It is well established that carers experience reduced physical, mental and emotional health. Australian studies have demonstrated that carers have an average rating on the depression scale that is classified as moderate depression, are more likely to be experiencing chronic pain or carrying an injury associated with caring, and are more likely to report high blood pressure and high cholesterol when compared to non-carers. Carers NSW advocates for the health sector to recognise carers reduced health and wellbeing as an unacceptable inequity, and to seek to actively address this inequity.

Carers NSW also suggests that initiatives to improve access and reduce inequity in population subgroups are more likely to be successful when family members and/or friends are engaged alongside consumers.
Potential Actions

2.1 Promote models that facilitate long term relationships between consumers and general practices to address service gaps.

In 2007 the Australian General Practice Network acknowledged that the health needs of carers are often overlooked due to poor identification rates by health professionals. However many carers are unlikely to seek help for their own health needs as they are so focused on the health of the person for whom they are caring. In order to address carers health needs GPs must practice carer identification, particularly when carer’s present with the person they support, rather than a patient.

Carer identification would also encourage GPs to be more conscious of involving carers as partners in care. The NSW Carers Charter calls for service providers to respect the relationship between carers and the person for whom they care. This respect needs to be extended into general practice, and Carers NSW recommends that the Framework recognise carers as an essential partner in the long term relationship between consumers and GPs. This inclusive approach would promote respect for carer’s unique expertise, and where appropriate, support carers involvement in treatment and management plans.

Recommendation 5: Carers NSW recommends that the Framework promote models of healthcare that improve recognition and inclusion of carers by General Practitioners.

2.2 Examine ways to improve access for people who experience difficulty accessing primary health care, including Aboriginal and Torres Strait Islander people, people living in rural and remote areas, people with additional or specialised health care needs and people with lower socio-economic status.

There are a number of different groups of people who experience difficulty accessing primary health care, and Carers NSW recommends that in addition to the groups identified, the Framework should recognise carers and people from culturally and linguistically diverse backgrounds (CALD).

As stated above, carers are a population subgroup who experience poorer health outcomes than the majority of the population, particularly if they are one of Australia’s 771,400 primary carers (the person who provides the most informal assistance to an individual).

Carers are also likely to be people with lower socio-economic status, with evidence consistently showing that carers suffer from higher poverty rates and increased risk of financial stress. The 2009 Survey of Ageing, Disability and Carers undertaken by the Australian Bureau of Statistics found that 39 per cent of carers occupied the lowest two quintiles of Gross Household Income, and 54 per cent of primary carers and 35 per cent of all carers stated that government benefits or allowances were their principal source of income. Many carers sacrifice employment to care for a friend or family member, and high costs and poor income security exacerbate their financial problems.

Recommendation 6: Carers NSW recommends that Action 2.2 recognise carers as a population subgroup that experience reduced health and wellbeing, and require targeted intervention and support to improve their health outcomes.
Patients from a CALD background are also more likely to experience difficulties accessing primary health care. This can be due to a number of reasons including lack of knowledge about services available, and language, religious or other cultural barriers.\textsuperscript{xiv}

It is vital for government agencies to deliver culturally competent health services that respect each person's ethnic, religious and linguistic background. Not responding to the cultural, linguistic, spiritual and/or religious needs of people of CALD backgrounds can contribute to a range of problems, including:\textsuperscript{xv}

- poor communication between the patient and the health care provider
- misdiagnosis and/or inappropriate treatment
- poor patient adherence to treatment and preventative health care regimes
- loss of trust and dissatisfaction with the health care provider
- increased incidents of racism and discrimination
- poorer health outcomes.

The NSW Government has recognised the challenges faced by those from CALD backgrounds and recently launched the \textit{NSW Health Policy and Implementation Plan for Healthy Culturally Diverse Communities 2012–2016} to achieve "an equitable health system that ensures that cultural and linguistic diversity is at the heart of service planning, service delivery and policy development."\textsuperscript{xvi}

Carers NSW encourages the Framework to recognise these health inequities so that the health sector can continue to explore ways of improving health outcomes for these groups.

**Recommendation 7:** Carers NSW recommends that Action 2.2 recognise people from CALD backgrounds as a population subgroup that experiences difficulties in accessing primary health care, and require culturally appropriate service provision in order improve their health outcomes.

\textbf{2.5 Maximise the opportunities enabled by the transformations occurring through eHealth, including the Personally Controlled Electronic Health Record (PCEHR) and Secure Messaging initiatives.}

Carers NSW advocates for the health sector to capitalise on the potential offered by information and communication technology. The importance of telehealthcare for carers will be discussed in section three.

\textbf{3. Strategic Outcome 3: Increase the focus on prevention, screening and early intervention}

**Potential Actions**

\textbf{3.3 Undertake research and evaluation to identify the best use of new technologies and enable increasing use of home based monitoring, treatment and support.}

The health sector has been relatively slow to take advantage of information and communication technology and Carers NSW believes that action to capitalise on its potential should be prioritised. As a strong advocate for telehealthcare (a convergence of telecare and
telehealth), Carers NSW welcomes moves to prioritise Telehealth within Medicare Locals and Local Health Districts.

Telehealthcare has been shown to have considerable, manifold benefits, for care recipients, carers and for the systems that support them. One of the largest randomised trials of telehealth, with over 3100 participants, was recently conducted in the UK with funding from the Department of Health. It demonstrated that telehealth users had lower mortality rates, reduced emergency admissions, and shorter hospital stays than non users.xvii

International studies on telecare (the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems) have shown that it can:

- enable people to stay in their homes for longer
- reduce the need for acute home care
- delay admissions to residential care
- reduce the number of unplanned hospital admissions
- reduce the number of delayed discharges from hospital.xviii

Evidence from Scotland demonstrates that carers using telecare services experience:

- feeling more relaxed and less stressed
- more confidence about the safety and wellbeing of the care recipient
- more opportunity to get away from their caring situation and take a break
- feeling better supported in their caring role
- improvements in their relationship with the care recipient
- the ability to remain in paid employment (for some carers).xix

Telehealthcare has the potential to deliver considerable savings to the Government. According to the evaluation of the Scottish Government’s National Telecare Development Programme, in 2007-08 (the first main year of operation) savings totalling £11.15 million were identified.xx Australian research supports this, and Access Economics has made the conservative estimate that steady state benefits to Australia from wide scale implementation of telehealth may be in the vicinity of $2 billion to $4 billion per annum.xxii

Carers NSW supports action to research and implement telehealthcare, and encourages governments to mainstream telehealthcare in order to reduce inequities in service utilisation, particularly for rural and regional carers.

**Recommendation 8:** Carer NSW recommends that the Framework be amended to strengthen the government’s commitment to the mainstreaming of telehealthcare as a priority action.
4. Strategic Outcome 4: Improve quality, safety, performance and accountability

Potential Actions

4.3 Promote the role of consumers as key members of the health care team and empower them to make decisions about their own health and social needs.

Throughout this submission Carers NSW has advocated for carers to be recognised as partners in care. This is of particular importance to decision making processes, as decisions are often made by consumers with the assistance of their close family members and/or friends, and their decisions will impact on their loved ones who care for them.

The NSW Carers Charter calls for the unique knowledge and experience of carers to be acknowledged and recognised. With the consumer’s consent, carers can play an important role in contributing to and being involved in decision making and treatment plans. Health professionals can benefit from the knowledge carers provide, and their inclusion results in better health outcomes for the person requiring care. It is therefore important that opportunities to improve consumer health literacy are also extended to carers.

Recommendation 9: Carers NSW recommends that Action 4.3 be amended to promote the empowerment of carers and their inclusion as key members of the health care team.

5. Carers (Recognition) Act 2010 and the implementation of the Framework in NSW

Carers NSW proposes that the principles of the NSW Carers Charter, which were established by the Carers (Recognition) Act 2010, be utilised to inform the ongoing development and implementation of the Framework in NSW.

These principles have been recognised in the NSW Carers Action Plan 2007-2012, which outlines the NSW Government’s commitment to carers. The NSW Carers Action Plan committed service providers, including NSW Health, to prioritise action which focuses on including carers as partners in care. The NSW Carers Action Plan 2007-2012 and the Carers (Recognition) Act 2010 remain relevant to the implementation of the Framework in NSW, and provide an opportunity for the NSW Government to commit to best practice principles in the health system.

Recommendation 10: Carers NSW recommends that the principles of the NSW Carers Charter inform the ongoing development and implementation of the Framework in NSW.
Conclusion

Carers NSW thanks the NSW Ministry of Health and the Department of Health and Ageing for the opportunity to provide feedback to the draft of the National Primary Health Care Strategic Framework.

Carers NSW believes that the inclusion and consideration of carers in the National Primary Health Care Strategic Framework will result in a stronger, more sustainable foundation for Australia's future health system.

For further information about this submission, please contact Carolina Simpson, Policy and Development Officer, on (02) 9280 4744 or by email carolinas@carersnsw.org.au.

Yours sincerely,

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Carers NSW

Endnotes

8 ibid.
15 ibid.
18 ibid.
19 ibid.
20 ibid.