

# Key Directions 2024-2028

## Summary of Consultation Feedback: Key themes

The *NSW Health Recognition and Support for Carers: Key Directions 2023-2027* (the Key Directions) is designed to provide a framework for NSW Health's response to the needs of carers across the NSW public health system and provides context for planning Local Health District, Specialty Health Network and state-wide activities.

The NSW Ministry of Health (the Ministry) sought feedback on a draft of the Key Directions and a wide variety of responses were received from consumers, community partners, non-government organisations, along with key stakeholders from across NSW government sectors.

We greatly appreciate the feedback and stories that were shared and the information below highlights how this has been implemented into the final version of the Key Directions.

## Summary

**Key theme 1: Consistency of language and terminology used with regards to carers**

**Key theme 2: Further consideration for carers within a variety of priority population groups**

**Key theme 3: Engaging carers as partners in care (both in clinical settings, policy-making and monitoring and evaluation of services)**

**Key theme 4: For inpatient admissions, health systems should engage carers in meaningful discharge planning**

**Key theme 5: Improved training for health professionals working with carers**

**Key theme 6: Improved identification of carers within healthcare settings**

**Key theme 7: Ensure the Key Directions consider carers within a variety of different healthcare settings, including inpatient, outpatient and community**

**Key theme 8: Enhanced consideration and support for staff that are carers**

**Key theme 9: Improved coordination, referral and support for carers to access services. This includes supporting carers at an individual level to navigate and link in with appropriate services, as well as high level initiatives to support system integration and streamlined services for carers.**

**Key theme 10: Ongoing and expanded stakeholder engagement and partnerships, to support improved identification and data on carers, as well as integrated systems and services**

## Feedback: Key Themes

### Key theme 1: Consistency of language and terminology used with regards to carers

A wide variety of feedback was received on terminology around carers. Several NSW Health and government stakeholders noted that the term “carer” should be correct and aligned with the terminology outlined in the Carers (Recognition) Act 2010.

However, several district, community and consumer representatives suggested that wording should be simplified and incorporate terms such as ‘kin,’ ‘family,’ ‘neighbour/s’ or ‘friends’ when referring to carers. This feedback was in acknowledgement of the fact that many carers may be “hidden” or do not relate to being a formal “carer,” despite potentially having significant carer duties.

The Ministry acknowledges the diversity of feedback received on language describing carers. As a key policy document, the Key Directions seeks to align language and terminology with other NSW Health and NSW Government policies and guidance, in particular the Carers (Recognition) Act 2010. However, we acknowledge that language around carers needs to be more accessible and easily understood by a variety of different carers. To support this, we have committed to reviewing carer terminology and language, as part of a broader review of NSW Health information and resources to meet carers’ needs across the health system.

### Key theme 2: Further consideration for carers within a variety or priority population groups

Several key population groups were identified as needing further consideration within the Key Directions, including:

- young carers
- carers from culturally and linguistically diverse backgrounds
- Aboriginal and Torres Strait Islander carers
- older carers
- newly arrived migrants or refugee carers
- carers with their own disabilities or health conditions (i.e. patients who are carers)
- carers of patients in community and other settings e.g. mental health carers
- carers from rural, regional and remote areas
- couples admitted to hospital, who care for each other.
- former or bereaved carers.

We have addressed this in the Key Directions through further consultation with key stakeholders, such as NSW Health priority populations team along with Centre for Aboriginal Health. We have also ensured consideration under each Key Direction priority for priority population groups and included a population data snapshot, to highlight and recognise the diversity of carers.

### Key theme 3: Engaging carers as partners in care (both in clinical settings, policy development and monitoring and evaluation of services)

One of the strongest themes that emerged from the feedback, was the need to partner with carers across all aspects of the health system. We appreciate the knowledge, stories and experiences shared regarding carers unique needs, expertise and challenges when interacting with the public health system and healthcare staff. A key piece of feedback provided was:

*“It is advised that carers are not only notified but actively consulted with about changes in a patient's condition or treatment as partners in care. Currently, carers continue to report that they are not included in care planning and decision-making. Therefore, greater emphasis on inclusion and partnership is needed across all Key Directions.”*

There were many examples provided around how the health system can better partner with and support carers. This feedback has been woven into the Key Directions document, by strengthening language and commitment to action throughout the document. Several of the examples provided through consultation feedback are included in the Key Directions priorities demonstrating how NSW Health can commit to engaging carers as partners in care.

### Key theme 4: With regards to inpatient admissions, health systems should engage carers in meaningful discharge planning

Carers and other system stakeholders report that meaningful discharge planning should start at the beginning and continue throughout a patient’s admission (this relates to both inpatient and community settings).

Where able, carers should be involved in decision making around a patient’s discharge, including discharge location and information and support to link in with appropriate services should be communicated with carers. This should be a two-way communication and discharge planning should take place in a way that is supportive of

carers needs i.e. considering wait times and transport needs. Discharge planning has been considered under Key Directions 1 and 2 to align with this feedback.

### **Key theme 5: Improved training for health professionals working with carers**

Feedback consistently highlighted the need for improved training for health professionals working with carers, including:

- Mandatory training for health professionals on carer awareness and the importance of prioritising partnerships in busy clinical environments, along with **how to identify carers effectively and appropriately**.
- Provide carer awareness training for employers to improve carer identification, reduce discrimination, and raise awareness and access to carer employment entitlements.
- Training must be co-designed in partnership with consumer and carer representatives.
- Education and up-skilling for GPs when it comes to engaging with carers and providing support.
- Ensure training supports patients and carer safety.
- Build the capacity of NSW Health managers and executives to support carers, through policy, cultural and systemic change.

This feedback has been considered under Key Direction 4 along with Statewide Actions for implementation at the local level.

### **Key theme 6: Improved identification of carers within healthcare settings**

It is mandatory within NSW Health settings that from the first time a service is provided, it's recorded whether a patient has or is a carer (IB2019\_031 *Identifying the Carer at Patient Registration*). The translation of this in practice, including the need for improved awareness and practices for identifying carers, was a recurring theme in the Key Directions feedback.

Key points highlighted:

- The need to specifically ask people if they are carers in order to effectively identify them, as people may not openly offer up this information if not asked.
- Noting that a patient may have more than one carer sharing responsibility for their care.
- Often hospitalisation is the first time it's identified that a person needs a carer, this is a time to share information about what support services are available for both the patient and carer.
- The need for a cultural shift to improve carer awareness and support, so that NSW Health employees can identify themselves as carers.
- Clearer identification of all type of carers in electronic medical record system - often paid carers are identified and informal carers are not, there may also be multiple carers of the same person within family or social systems.
- Embedded mandatory questions for every presentation to ensure accurate information around carers are captured and updated.
- In addition to identifying carers on admission/registration of a patient and linking medical data to allow health staff to document their encounters with the carer and what support services they are referred to, which would also reduce carers having to repeat information.
- Suggest that carer identification and information is easily located on medical record systems to support continuity of care.
- Ensure that carers are identified in all healthcare settings, including for example, maternity and perinatal services.

Beyond the Key Directions, the Ministry supports ongoing actions as part of the Department of Communities and Justice (DCJ) *NSW Carers Strategy: Caring in NSW 2020-2030* Action Plan and the Regional Health Plan Roadmap to improve and identify opportunities to better use carer data in NSW Health. As part of this ongoing work the Ministry is currently engaging with a range of key stakeholder to improve carer identification at a local level and system level, as well as improved digital systems to support this.

## **Key theme 7: Ensure the Key Directions consider carers within a variety of different healthcare settings, including inpatient, outpatient and community**

Another key theme that emerged from the feedback was that the current draft has a strong focus on inpatient care and facilities. It's acknowledged that the Key Directions should support a system-wide approach to recognising and partnering with carers **across all areas of the health system**, including community settings, emergency departments, outpatient clinics and general practice and the document has been adjusted to reflect this.

## **Key theme 8: Enhanced consideration and support for staff that are carers**

Key Direction 3, is that 'NSW Health will support its employees who are carers.' This point also aligns with the *Future Health Guiding the next decade of care in NSW 2022-2032: Report* (the Future Health Report), which has a key strategic outcome to ensure "our staff are engaged and well supported." Suggestions for improving support for NSW Health staff that are carers included:

- Offer and promote flexible working arrangements related to hours, patterns and location for staff with caring responsibilities on placement and reduce barriers to accessing these arrangements, noting that current leave allowances are often insufficient for staff with caring responsibilities.
- Publicly communicate organisational support for staff with caring responsibilities and connect carers to relevant policies and resources through Carer Networks, 'Carer Hubs', handbooks, or on intranet sites.
- Invest in carer-focused employment initiatives aimed at supporting diverse and hidden carer groups to enter or remain in employment.
- Include carers in People Matters Employment Survey (PMES) and other employee surveys relevant to carer-focused policies.
- Establishing an environment where staff can access peer support.
- Enhancing the employment process for carers so they can factor in their needs from the initial stages of employment.

Increased support for staff who are carers is addressed under Key Direction 4, along with the Statewide Actions, where the Ministry has committed to obtaining the Carers and Employers accreditation.

## **Key theme 9: Improved coordination, referral and support for carers to access services. This includes supporting carers at an individual level to navigate and link in with appropriate services, as well as high level initiatives to support system integration and streamlined services for carers.**

Another key theme that emerged was around support services and systems, and how carers access these. This theme was multi-faceted and included the need to support carers in how they are referred to, and engage with support services and systems, but also the nature of the systems and services available and how these can be better integrated.

It's acknowledged from the feedback, that there are often challenges and carers can be overwhelmed, making it difficult to access the right types of support, at key times during their journey through the health system. **More consideration needs to be given to ensure that where possible, systems and services are streamlined, coordinated and digitally enabled, to improve access.**

It's also acknowledged that digital systems won't work for everyone, especially certain cohorts of carers such as older carers, hence **carers also need support at key times to navigate the health system and engage with services that are relevant to them.**

Carer Gateway was acknowledged as a key service available to carers, however limitations to this service were also recognised. A number of stakeholders also suggested that more specific and appropriate services should be identified, developed and enhanced, relevant to a variety of carers' needs, such as:

- A crisis support line, to support carers in both a local and statewide sense.
- Culturally appropriate and accessible information.
- Increased education and awareness on other support programs, including the Out of Hospital Home support program, SASH, Compacts and end of life packages.
- Funding or support for carers to access respite and accommodation support for carers travelling to support patients in hospital.
- Increased psychosocial support for carers in the form of peer or support groups, acknowledging that some carers may have limited social networks or support.

Overwhelmingly it's noted that a key area of focus for carers, is improved access and support to navigate the healthcare system that meets carers where they are at and is relevant to a variety of different carer cohorts.

NSW Health is committed to supporting access and integration of services through review and provision of NSW Health information and resources to meet carers' needs, improving consistency and accuracy of carer data across the health system and supporting Carer Program Managers in each local health district to implement local initiatives that support access and support for carers.

**Key theme 10: Ongoing and expanded stakeholder engagement and partnerships, to support improved identification and data on carers, as well as integrated systems and services**

Following on from the above theme of improving system coordination and integration, feedback on the Key Directions highlighted the need for ongoing focus on improved stakeholder relationships and networks.

Carer engagement and co-design within the health system remains an overarching focus of the Key Directions and we have further strengthened language throughout the updated document to promote the need for increased engagement across the system, including in clinical settings, policy development, planning, monitoring and evaluation of services.

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