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Deeble Institute for Health Policy Research

## Issues Brief

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# Prioritising carers' health and wellbeing in the healthcare system

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We would like to acknowledge that there are sub-groups of carers in the community that require additional support unique to their situation, including: young carers, aged care carers, and carers looking after an adult with disability. The content in this brief is accurate to the best of our knowledge.

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## Key Messages

- Approximately 13% of Australians provide unpaid care to family members or friends living with chronic illness or disability and have no formal healthcare training. In 2020 carers saved the government \$77.9 billion in healthcare expenditure. Carers experience negative impacts on their physical, mental, social and financial status as a result of their caring role. There is limited support for carers in our community resulting in poor health and wellbeing outcomes for carers.
- Minimal data are available to provide a clear picture of carer demographics, and how their needs can best be met. Frameworks to assess carers' needs exist, however these are not nationally implemented resulting in inconsistencies in the amount and type of resources recommended and inequalities in the delivery of health care. The development and implementation of a national standardised framework will assist in identifying carers and their needs and will be critical to facilitate appropriate allocation of resources.
- No standards exist related to carers' own health and wellbeing needs. The NSQHS Partnering with Consumers Standard acknowledges carers as part of the consumers' health care team. Furthermore, this standard relates to the inpatient hospital setting and is limited in its usefulness for carers providing care in the community setting. To bridge this gap, widening key principles for carers that focus on the transition from hospital to home and in the community setting are required.
- Clinicians have limited time to assess carers' needs, including the capacity to address psychosocial needs. As a result, inequalities in the provision of care exist. Additional resources are required to undertake assessment of carer needs and this should be supported through MBS funded assessments.
- Limited education is provided to clinicians in how to deliver care to carers. When carers' needs are identified, clinicians can lack awareness of available resources. A co-designed learning health system, facilitated by clinicians, can link carers' health and wellbeing needs with supportive care resources.

## Recommendations

### **Recommendation 1**

Collect comprehensive data related to carers' wellbeing, service use, and clinicians' knowledge of carer assessment to inform allocation of government spending and distribution of services for carers.

### **Recommendation 2**

Co-design a health care system to include carers through a 'carer needs' assessment framework, expanding the Transition of Care standard, and shifting healthcare models.

### **Recommendation 3**

Implement strategies to support change including education for practicing clinicians, undergraduate education through clinical placement, and MBS funded wellbeing support.

### **Recommendation 4**

Engage in permanent and ongoing evaluation to ensure that carers' health and wellbeing continue to be supported and that government funding is optimised.

## Executive Summary

Carers provide significant cost savings to the healthcare system by caring for people living with chronic illness or disability at home, to the detriment of their own health and wellbeing. Carers require support to improve their outcomes, however, little is known about carers and how and when they can best be supported. This is particularly evident for carers from priority population groups and those who do not identify with the term 'carer'.

Frameworks exist to assess carers; however these are poorly implemented creating inequalities in healthcare and access to services. More data collected through standardised assessment frameworks is needed to guide government spending and allocation of resources and services for carers. Comprehensive data will identify carers' outcomes, the suitability of existing services, and clinicians' knowledge, skills and practices in conducting carer assessments.

There is capacity to support carers within the healthcare system, but it is necessary to shift away from a person-centred model of care and allow space for carers and their own wellbeing. Health system restructures can be supported with existing platforms such as electronic medical records, which will ensure consistent care is provided within one streamlined system. Time to conduct assessment and burden on clinicians are

crucial barriers in supporting carers, and this can be addressed through Medicare funded items focusing on carer assessment and provision of support.

Incorporating carers in the healthcare system will require change to promote adoption and sustainability of new practices. Co-design is needed to develop strategies that support carer wellbeing and minimise additional burden on clinicians and the healthcare system.

Inclusion of all key stakeholders including carers, patients, clinicians from all professions, hospital and health service leaders, consumer groups, administration staff, researchers and policy makers, will provide a strong evidence base for implementing strategies which are appropriate for all involved in carer health.

This issues brief highlights the gaps in care for carers in the community. It focuses on limitations in data collected about carers and how assessment is conducted among clinicians. It identifies where healthcare systems, carer assessment and delivery of care can be improved by using a co-design approach with key stakeholders. It outlines strategies to implement carer support in the healthcare setting utilising existing platforms, and how education for clinicians can be provided to upskill and prepare them for essential changes in delivery of care.

## The need to support carers in the community

The term carer describes any individual (family, friends, colleagues or neighbours) who provide personal care to someone living with chronic illness, mental illness, disability, or those who are frail and aged (Federal Register of Legislation 2010). In Australia there are 2.65 million carers (13 % of the population) (Carers Australia, 2022), outweighing the healthcare workforce of 640,000 medical, nursing and allied health practitioners (Australian Institute of Health and Welfare [AIHW] 2022c).

Involvement of carers in conversation during patient appointments is vital to ensure carers have the knowledge and skills to manage care in the home setting (Cameron et al. 2016; Soong et al. 2020). Yet communication between clinicians and carers is complex.

Carers have described that their knowledge of the patient's health and concerns are often dismissed by clinicians (Mason & Hodgkin 2019; Miller & Porter 2021). While clinicians have noted the importance of carers in providing evidence about what is 'normal' for patients and in aiding conversation (Fry et al. 2015). It has also been reported that clinicians have experienced carers withholding information or dominating conversation (Laisaar-Powell et al. 2016).

The Australian Commission on Safety and Quality in Health Care (ACSQHC) deterioration standard outlines the need for clinicians to respond to carers' concerns (ACSQHC n.d-c) and strategies have been implemented to allow carers to activate a rapid response system in the hospital setting to seek additional care for patients beyond the immediate treating team (Anstey et al. 2019).

Communication between clinicians and carers regarding carers own wellbeing is lacking, and carers are responsible for managing their own wellbeing during periods of distress (Heynsbergh et al. 2018a).

### Cost to the government

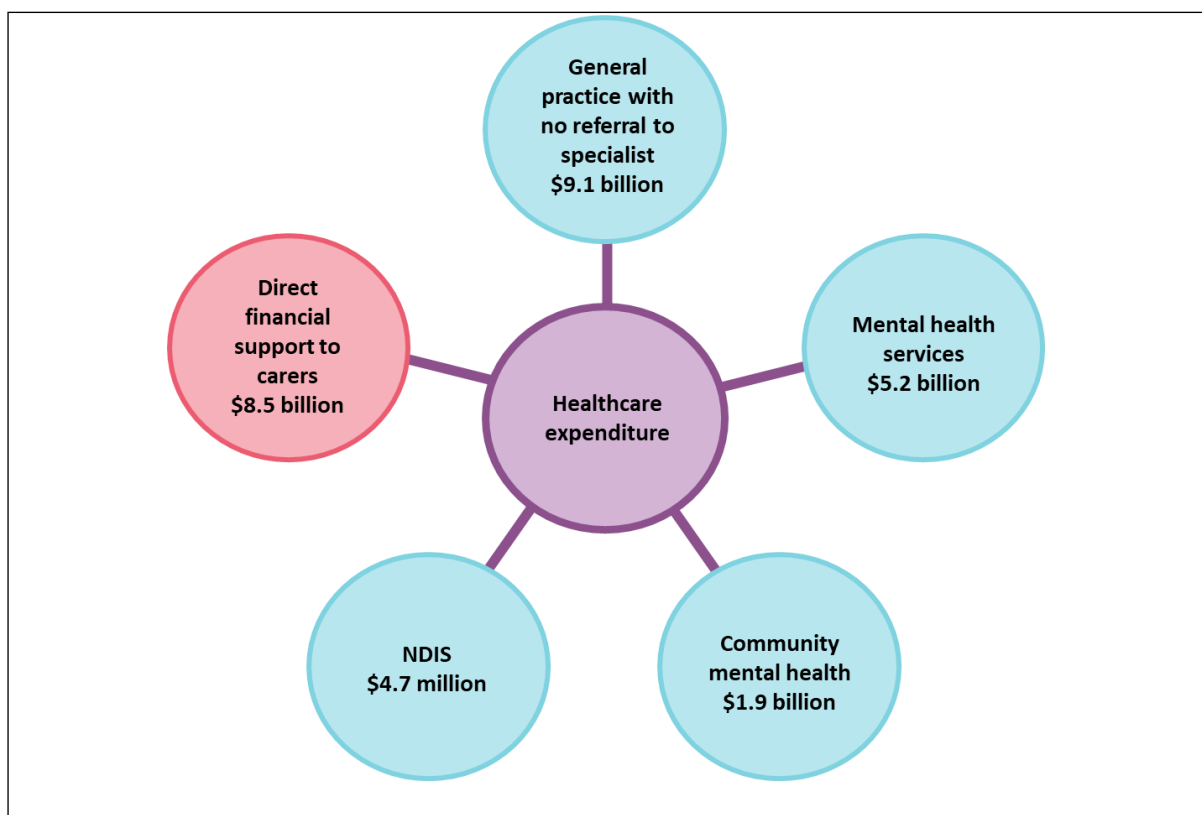
In 2020 carers saved the government \$77.9 billion in unpaid healthcare costs (Carers Australia 2023), compared to a total healthcare expenditure of \$81.8 billion within the same timeframe (Parliament of Australia 2020). This indicates a huge cost saving to the government. In turn, however, poor outcomes for carers contribute to government healthcare expenditure. For example, management of chronic conditions that develop as a result of caring (Stacey et al. 2018).

Government supported healthcare services funded through the Medicare Benefit Scheme (MBS) cover bulk billing general practice and psychology (Swerissen et al., 2018). Further support for carers looking after someone with a disability, or who have a disability is available via the National Disability Insurance Scheme (NDIS) funding (Swerissen et al., 2018). In 2022, the NDIS was accessed by over 500,000 people. A report from 2018 indicated that two-thirds of people living with a disability have a carer (Australian Institute of Health and Welfare [AIHW] 2020) and 40% rely solely on support from carers (Furnival and Cullen, 2022).

Financial support for daily living can be claimed through carers payment (Services Australia 2020), carers allowance (AIHW

2021a), and carer supplement benefits (Services Australia 2021). The total healthcare costs to government have been identified (Figure 1). In 2018, government assistance was the main income for one-quarter of carers (Australian Bureau of Statistics [ABS], 2019). In 2021, over 50% of carers had received

financial support for longer than 5 years and 20% for longer than 10 years (Furnival and Cullen, 2022). Preventative interventions for carers are needed to improve outcomes and reduce additional strain on the healthcare system.



*Figure 1. Cost of government funded support. Blue: population expenditure in 2018 (Swerissen, Duckett & Moran 2018). Pink: total expenditure on financial assistance for carers 2017-18 (Royal Commission 2019).*

Gender-based inequalities exist in the provision of care where the majority of carers are female (70%) (ABS 2019) and unemployed (50%) (ABS 2019); this has long term impact on society. Time away from the work force perpetuates gender-based pay discrepancies (Australian Human Rights Commission 2017), decreases chance of promotion and affects

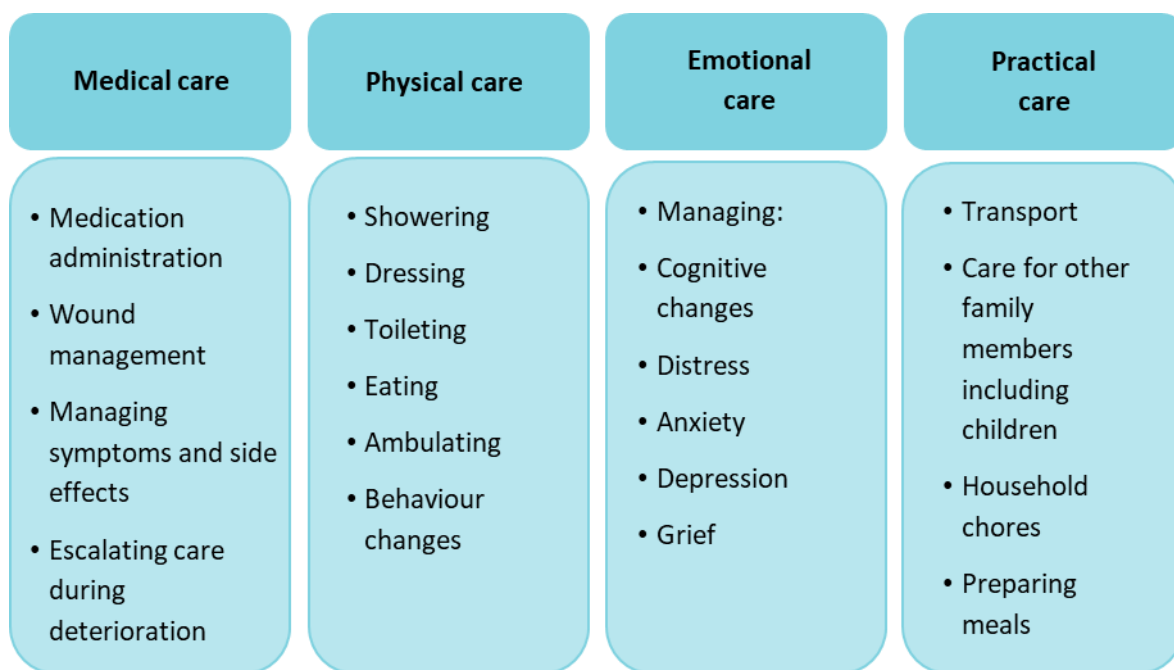
superannuation contributions (Workplace Gender Equality Agency n.d). Return to work is key in healthcare to ensure there are enough skilled and practising clinicians to support the aging population (Workplace Gender Equality Agency 2018). Investing in resources to support the health and wellbeing needs of women facilitates re-integration into the workforce (Pit and Byles 2012).



## Underfunding and poor health outcomes

Carers provide short term care such as recovery after surgery, as well as ongoing care for those with chronic conditions, disability and those receiving aged care. The amount and type of

care provided is highly individualised and can include medical care, attending to physical and emotional needs and undertaking practical tasks (Figure 2).



*Figure 2. Types of care provided by carers to care recipients. Medical care: (Cameron et al. 2016; Furnival and Cullen 2022; Soong et al. 2020); physical care: (Cameron et al. 2016; Furnival and Cullen 2022; Soong et al. 2020); emotional care: (Soong et al. 2020; Ussher et al., 2011; Whitehead et al. 2018); practical care: (Cameron et al. 2016; Furnival and Cullen 2022; Soong et al. 2020)*

Carers experience negative impacts on their own health and wellbeing which can be present for years after onset of the caring period (Girgis et al. 2013; Poon et al. 2018). Carers are time poor, over-burdened, and experience guilt at prioritising their needs (Heynsbergh et al. 2018a), as a result they have reduced capacity to seek assistance. Grouped into four broad categories, health outcomes include physical, social, financial, and emotional status (Girgis et al. 2011;

Temple and Dow 2018). Negative outcomes are complex and interlink between these four categories:

### Physical health

Carers have an increased risk of physical health concerns including cardiac and respiratory disease, diabetes, and osteoporosis (Stacey et al. 2018), arthritis, back pain, fatigue, sleep and appetite disturbance (Gibbins et al. 2009; Kim et al. 2015; Reynolds

et al. 2020). In Australia, carers are twice as likely to have a disability compared to the general population (ABS 2019). Modifiable lifestyle factors decline, including diet quality and physical activity, and there is an increase in harmful levels of alcohol consumption, obesity and smoking (Bailey et al. 2019; Stacey et al. 2018).

### Social health

Social isolation and loneliness are common among carers (Li et al. 2020). Carers' opportunities to seek social connection can be inhibited by the level of care required by recipients, for example the inability to leave patients unattended due to safety concerns (McConigley et al. 2010). For those in rural and regional areas there are fewer organised social interactions, and longer travel distances create a time barrier for carers who have limited time away from the caring role (Hussain et al. 2018).

Deterioration in existing social and familial networks can occur as carers role in life changes (Dunsmore et al. 2020). Peer support provides carers with an opportunity to seek assistance for their own emotional wellbeing (Heynsbergh et al., 2018a; Winter et al. 2022), as well as learning about practical tasks. Yet only 30% of carers can access peer support (Carers Australia 2022). There is a need to facilitate cohesive social connection as this serves as a protective factor in the development of disability (Giles et al. 2004), mental illness and general wellbeing (Mohanty et al. 2020).

### Financial status

50% of carers provide 20 to 40 or more hours of unpaid care per week (Furnival and Cullen 2022; Hung et al. 2013). 50% of carers earn

\$1000 or less gross income per week (ABS 2022b) around \$200 above the national minimum wage (Fairwork Ombudsman n.d). On average carers lose over \$500,000 in lifetime earnings and superannuation (Furnival and Cullen 2022). This results in the need for additional financial assistance from the government to support home services, respite and resources for carers own wellbeing for example counselling (Heynsbergh et al. 2018a) and aged care pensions (Furnival and Cullen 2022).

In December 2022, 303,000 carers received a Carer Payment and 628,000 received a Carer Allowance (Dept of Social Services 2022). These figures have grown from December 2019 where 284,000 carers received carer payment and 610,000 received carers allowance (Dept of Social Services 2019). While the number of carers accessing financial support is growing, the majority of carers are still wearing the costs associated with caring.

On average each household spends \$3000 per year out of pocket on appointments with clinicians, medications and private health insurance (Callander et al. 2019), however this figure does not encompass costs of every day care items such as continence products (Farrar et al. 2018), or non-pharmacological / complementary therapies to promote comfort and wellbeing. Uptake of financial aid from the government is low in part due to the complexity of the application process (Dept of Families 2009; Miller and Porter 2021) as well as lack of awareness of available financial support (Farrar et al. 2018).

Poor financial status leads to limited capacity to participate in non-essential activities and has been shown cause declines in carers'

physical, social and emotional health (Carers Australia 2021a; Farrar et al. 2018).

### Emotional health

Carers experience elevated levels of distress, depressions and anxiety compared to the general population and the people they care for and have high levels of burden in response to their caring responsibilities (Chambers et al. 2012). Compared to the general population carers are four times more likely to have suicidal thoughts (Suicide Prevention Australia 2022). Consequently, they require additional coping strategies to improve their emotional wellbeing as their needs are not being met (Lloyd et al. 2019). Negative impacts on emotional wellbeing are multifactorial and can be amplified by physical health problems,

social isolation (Butterworth et al. 2010) and financial hardship. Mental health conditions are one of the leading reasons of general practitioner (GP) referral to specialist services among the general population (Swerissen et al. 2018).

Over the last 15 years, since 2008, it has been documented that carers experience the lowest wellbeing in the community compared to any other population group (Cummins et al. 2007). Poor outcomes for carers have been further exacerbated by the COVID-19 pandemic (Carers Australia 2022). There is a need to increase funding and support for carers to improve their health and wellbeing outcomes.

## Frameworks to support screening of carers' needs are lacking

Within the healthcare setting there is the opportunity to assess carers' needs individually or as party of a family unit. However, frameworks to assess carers' health and wellbeing are not standardised and are poorly implemented in Australia (Coyne et al. 2017).

### Individual

Assessing carers' needs individually captures their health and wellbeing and identifies barriers in delivering quality care at home (Eagar et al. 2007; Ramsay et al. 2007). Carers' needs differ from those of patients and can include carers' own ill health during the caring period (Girgis et al. 2013), information related to dying in the home (ACSQHC 2021a; Miller and Porter 2021), bereavement care (ACSQHC 2021a) and when to escalate care during patient deterioration (Heynsbergh et al. 2018b).

The Carer Needs Assessment (CNA) tool, developed through the University of Wollongong, uses an evidence and consumer based approach (Ramsay et al. 2007). The CNA outlines principles of use to meet carers needs including screening of all carers, assessing cultural needs, recommending resources and performing ongoing assessment (Ramsay et al. 2007). No further information exists as to whether subsequent testing occurred.

In the United Kingdom, the Carers Support Needs Assessment Tool (CSNAT) is used widely and has been tested in Australian settings including palliative care (Aoun et al. 2015), dementia (Aoun et al. 2018b) and motor neurone disease (Ewing et al. 2020) and has shown to capture and address carers' needs.

Neither the CAN or CSNAT are currently implemented into routine practice in Australia.

Other frameworks used in Australia include:

- the Carer Star, the Needs Assessment Tool (Care Search 2022)
- the Integrated Assessment Tool (Dept of Health and Aged Care 2022b).

However, these are used within specific context and illness such as Carer Gateway assessments (Dept of Social Services 2023), among people living with advanced cancer or chronic health conditions (Care Search 2022), or in the aged care setting (Dept of Health and Aged Care 2022b). These inconsistencies in assessment can create gaps in care and inequalities in delivery of services. While carers' needs can be unique in response to the disability or illness of the person for whom they care, one assessment framework would standardise data collected, identify hidden carers, and inform allocation of government spending.

People who do not self-identify as a carer or who are not recognised by clinicians are known as 'hidden carers' and are unlikely to be linked with supportive care resources (South Eastern Sydney LHD n.d).

### Family

Assessing family needs looks at the role of each family member (including patients) and identifies how support can be offered to the family as a unit to promote health for everyone (International Family Nursing Association 2013).

In 2000, the WHO recommended that countries adopt at least one international family assessment framework to promote equitable care worldwide (World Health Organisation 2000).

Internationally, a multitude of family nursing frameworks exist (Anderson et al. 2011) creating discrepancies in assessment between countries (Anderson 2015). The International Family Nursing Association (IFNA) guidelines promote a universal method of incorporating family in health care and to facilitate care in the home setting (International Family Nursing Association 2013). Nursing competencies developed by IFNA guide the development of family nursing skills at an undergraduate and graduate level (International Family Nursing Association 2013). No international frameworks to assess family needs have been incorporated into clinical or educational settings in Australia (Anderson 2015), resulting in poor visibility of the need to assess and support carers' wellbeing.

Inconsistencies exist in assessment of carers' needs. For example, variance in carers discussing burnout, ability to complete caring tasks, and their own health (Riffin, Wolff and Pillemer 2021). Nurses are the largest profession within health care (AIHW 2022c), spend over 30% of their time in direct contact with patients in hospital settings (Butler et al. 2018; Westbrook et al. 2011), and are ideally placed to conduct assessment. Nursing assessment of carers during hospital discharge can prevent the likelihood of patient readmission (Scott 2010; Toye et al. 2016), however carers' experience of discharge is that it does not prepare them for the level of care needed at home (Considine et al. 2020). Nurse led interventions in the home setting to

support carers improve carers' use of services and increase confidence in caring (Slatyer et al. 2019).

Nursing assessment is used successfully within some settings such as paediatric care (Analytis et al. 2022) and intensive care units (Kean and Mitchell 2014). There is poor guidance in how to conduct assessment of carers looking after another adult, and techniques vary from semi-structured interviews, to questionnaires, to informal conversations (Anderson et al. 2011; Coyne and Dieperink 2017), and is similar within the general practice setting (Riffin, Wolff and Pillemer 2021). Decisions to conduct assessments differ based on nursing experience, and rapport between patients, carers and clinicians (Coyne and Dieperink 2017). Lack of clear policy surrounding carer assessment (Frakking et al. 2020) influences nurses' ownership in provision of care as it is viewed as outside their scope of practice (Coyne et al. 2017) and there is little systemic support to conduct assessment during clinical time (Anderson 2015). Lack of support for nursing assessment in the hospital setting is a missed opportunity to routinely assess carers, collect data on their needs and deliver care.

### Data collection

Nationwide data that captures the needs and resources required to effectively support carers is lacking. Nationally, there are limited data collected about carers within existing population surveys.

For example, the Australian Bureau of Statistics (ABS) collects characteristics on carer demographics and basic health data such as disabilities (Australian Bureau of Statistics 2019), this information is only collected every three to four years meaning that outdated

evidence is used to inform decision making and delivery of services for carers (AIHW 2023).

In 2021, Carers Australia conducted a national survey of 5800 carers, collecting demographic and outcome data such as prevalence of distress, social isolation, and which services were routinely accessed by carers (Carers Australia 2021a). It was found that those carers who had accessed support groups, psychological support, respite or financial assistance, and carers who utilised services had better health outcomes (Carers Australia 2021a).

Standardised comprehensive data collected routinely at a national level that identifies carers' need for support, will be essential for guiding the development and implementation of interventions that improve outcomes for carers, for example education for carers and programs to support carers coping mechanisms (Analytis et al. 2022).

### Care terminology

Identifying with the term 'carer' is a barrier in data collection as assessments, delivery of care and monitoring of carers in the community occurs for those who regard themselves as 'carers' (South Eastern Sydney LHD n.d).

In the wider healthcare setting, the term 'carer' can refer to unpaid family members, volunteers and paid care workers for example home care workers and personal care workers (Better Health Channel 2015). In clinical settings, 'carer' often refers to next of kin and contributes to lack of uptake of the term among children, friends and extended family (Burns et al. 2013).

Understanding the roles and responsibilities of a 'carer' further influences individuals' association with the term. Caring includes tasks such as dressing and cooking, which are viewed as a natural part of the relationship between intimate partners (Ugalde, Krishnasamy and Schofield 2012). Utilisation of the term 'carer' also varies among different cultural and ethnic groups as their norms involve caring for family and community members (Eagar et al. 2007; Poon et al. 2020).

Adopting the term 'carer' can be a gradual process in response to a decline in patient health (Private Mental Health Consumer Carer Network (Australia) 2010), in these situations there is minimal opportunity for early implementation of resources.

The ambiguity associated with the terminology and role of carers results in low identification with the term 'carer' (Private Mental Health Consumer Carer Network (Australia) 2010; Smyth et al. 2011; Ugalde et al. 2012). The clarity of terminology within government and, clinical and community health services should be improved and is critical for allowing more comprehensive data collection to occur which can inform where government funding and resources would be best allocated.

### Inequities

No characteristics are provided within the existing ABS '*Disability, Aging and Carers: Summary of Findings*' dataset about carers from priority groups (ABS 2019) such as those who speak languages other than English, who live in rural and remote areas or who are from lesbian, gay, bisexual or transgender (LGBT+) communities (Dept of Health and Aged Care 2021).

Carers from priority groups are more likely to be hidden carers (South Eastern Sydney LHD n.d).

Available data on the utilisation of resources by carers is distorted, as those carers who are already linked with supportive care resources, or who have access to social media to view survey invitations have greater opportunity to complete surveys (Carers Australia 2021a).

A large group of carers in the community are unseen and how best to support them is unknown. Incomplete data results in inequities in the provision care (Poon et al. 2020; Riggs et al. 2020) and those in priority groups are more likely to be missed and have poorer outcomes. To ensure equitable access to care and to reduce disparities among population groups (Eagar et al. 2007) the development and implementation of a national assessment framework is needed.

## We live in a person-centred model of care

### Who is a ‘consumer’?

The Australian Commission on Safety and Quality Health Care Standards (ACSQHC) do not include carers’ health and wellbeing as part of their standards. As a national model of care, person-centred care involves consumers as active partners in the delivery of healthcare (ACSQHC n.d-d). The term consumer is poorly and inconsistently defined across Australian healthcare standards. Within the National Safety and Quality Health Service Standards (NSQHS) consumers refer to patients, carers and family as one unit (ACSQHC 2017a). The National Safety and Quality Digital Mental Health Standards and National Safety and Quality Mental Health Standards for Community Managed Organisations define patients as consumers, and carers and family are acknowledged separately (ACSQHC 2020a, 2020b). The National Safety and Quality Primary and Community Standards define consumers as people who have previously used a service or who advise on the development and monitoring of standards,

and patients as someone currently receiving a service (ACSQHC 2021b). Transitions of Care key principles have been developed to guide patient transition between care locations, or healthcare professionals (ACSQHC n.d-e). Within the key principles, the word consumer is not used and person-centred care is poorly defined (ACSQHC n.d-e). Variance and ambiguity in the definition of consumer leaves gaps in when and how carers and patients are involved in care.

Nevertheless, consistent among these standards is the inclusion of carers as part of the patient’s healthcare team and carers involvement in shared decision making (Table 1). Yet carers remain unseen and unheard by clinicians (Carrotte et al. 2021), despite the intent to involve carers in shared decision making.

Standards / Principles	Carers defined as a consumer	Carers included in a healthcare team	Carers involved in shared decision making for patient care	Carers linked with services for patient care. eg. GP	Carers included in developing and monitoring standards
National Safety and Quality Health Service Standards (ACSQHC 2017a)	✓	✓	✓		✓
National Safety and Quality Primary and Community Standards (ACSQHC 2021 b)		✓	✓		✓
National Safety and Quality Digital Mental Health Standards (ACSQHC 2020a)		✓	✓		✓
National Safety and Quality Mental Health Standards for Community Managed Organisations (ACSQHC 2020b)		✓	✓		✓
Transitions of Care Key Principles (ACSQHC n.d.e)		✓	✓	✓	

**Table 1. Inclusion of carers within current healthcare standards and principles**



Person-centred care is facilitated by communication between clinicians and consumers to assess needs and using a shared decision-making process in clinical care (ACSQHC n.d-d). Person-centred care is successful in improving patient outcomes including self-management of disease and satisfaction with health care (Delaney 2018). Person-centred care also benefits health care services by reducing length of hospital stay and risk of readmission (Delaney 2018). Reduced hospital admission time and limited inclusion within the healthcare standards means that carers are having to provide care for longer in the community setting with little support.

### The need for standards and governance in the community setting

Gaps exist in the healthcare standards within inpatient hospital care and during transition from hospital to home. The NSQHS Standards are the only mandated standards in Australia and focus on inpatient hospital care, day care procedures and dental practices (ACSQHC 2017a), where there are measurable outcomes through accreditation processes (ACSQHC n.d-b).

However, the majority of patient care is delivered in the community, where accreditation for health services is voluntary (ACSQHC 2020b; Quality Innovation Performance n.d). The National Safety and Quality Primary and Community Healthcare Standards (ACSQHC 2021b) and Mental Health Standards for Community Managed Organisations (ACSQHC 2020b) provide structure to how consistent care is delivered across community health service providers.

Yet, there are no clear guidelines as to how carers can be supported.

The Transitions of Care key principles (ACSQHC n.d-e) outline the need for carers to be linked to resources, only in regard to managing patient's needs, but have the potential to bridge gaps between inpatient and community care. For example, linking to patients' GPs (ACSQHC n.d-e). While this facilitates carers' management of patients' healthcare needs, it fails to recognise and support carers in the importance of maintaining their own health and wellbeing.

The Mental Health Standards for Community Managed Organisations are alone in identifying the need to support self-care of carers (ACSQHC 2020b); and yet variation in the success of psychological interventions on carers mental wellbeing has been reported (Bartholomaeus et al. 2019; Chambers et al. 2015; Murfield, Moyle and O'Donovan 2021). Little is known about how carers can best be supported. This provides limited evidence to guide government funding for interventions for carers.

### How the scope of standards can be widened to support carers

Support for carers in the community during transition from hospital to home is limited. Carers are inconsistently included in discharge planning (Buikstra et al. 2020) and this planning process can be interrupted or vary in over 60 ways, such as the unexpected need to discharge patients early (Buikstra et al. 2020). Carers are left out of discussions, uninformed of plans, and unable to ask questions prior to discharge (Considine et al. 2020).

This means that they do not have the necessary information to support the care needs of patients, and that they are not referred to services for their own wellbeing.

The Transitions of Care key principles guide transition between hospital wards, and between clinical staff (ACSQHC n.d-e) but do not incorporate transition from hospital to home (ACSQHC 2017b), creating a barrier in the provision of standardised care in the community. In this regard, hospital discharge presents an opportunity for clinicians to identify carers and family members who support patients at home; this is already carried out in some circumstances where patients have complex needs such as dementia, however a worldwide systematic review found discharge processes for dementia patients is still inadequate in meeting carers informational and support

needs (Beardon et al. 2018). Lack of identification with the term 'carer' also contributes to barriers around inclusion in discharge planning, support eligibility and resource allocation (South Eastern Sydney LHD n.d).

Discharge planning inclusive of carers should be implemented more widely and with a direct focus on carers' own health and wellbeing needs (South Eastern Sydney LHD n.d).

Discharge planning offers the opportunity for carers to be linked in with community-based resources such as GPs, Carers Australia or Carer Gateway. Such resources can provide support for carers' own health and wellbeing and can increase access to peer support programs (Carer Gateway n.d; Carers Australia n.d), these need to be supported by government to provide long-term care for carers.

## Systemic issues in the healthcare workforce impacts carers

Prioritising workforce retention and training is necessary to not only support future health care in Australia by providing safe and quality care (National Skills Commission 2021), but also to safeguard carer wellbeing. Workforce

shortages will increase the demand on carers, and the government needs to take steps to ensure carers' health and wellbeing are prioritised.

### The workforce

It is predicted that by 2030 there will be a shortage of healthcare workers worldwide (WHO 2022). Australia will face a deficit of 130,000 nurses by 2030 (PWC 2018) and over 11,000 general practitioners by 2032 (Deloitte 2022). Burnout contributes to intention to leave the workforce (Holland et al. 2018) among nurses (worldwide trend) (Chan et al. 2013), doctors (Hunter et al. 2022) and midwives (Harvie et al. 2019) with less than five to seven years' experience. Intention to leave has further been exacerbated by the COVID-19 pandemic (Hunter et al. 2022).

Over 70% of doctors (Hoffman et al. 2023) and nurses are burnt out, and 60% of nurses experience anxiety or depression (Smallwood et al. 2021). In part, burnout occurs due to high workload and negative workplace culture (Hunter et al. 2022), and results in poor patient care, leading to adverse events, and negative patient experiences (Hunter et al. 2022; Jun et al. 2021).

High workforce turnover and lack of skilled clinicians is particularly evident in rural and regional areas, and among First Nations communities, increasing existing disparities and inequalities in care (AIHW 2022d). 30% of Australians live in rural and regional areas and people between 25-55 years of age are the largest demographic (AIHW 2022d).

### Healthcare system changes

Clinician workload and the patient-centred model of care are key barriers in extending care to carers (Franklin et al. 2017; Furst et al. 2021; Surbone et al. 2010) and over 80% of clinicians report not having enough time to assess carers (Riffin et al. 2021). In the community setting an international comparison showed that Australia provides the least amount of nursing care in particular for social health (Furst et al. 2021). Systemic shifts in social health care are required to support carers, however, system changes to

prioritise psychosocial care have rarely been tested (Sanson-Fisher et al. 2019) and there is little to guide how carers can best be supported. The healthcare system is complex and necessary changes to incorporate carers into the system need to be balanced with patient care to ensure that access to, and the standard of care quality, is not impacted. One way to achieve this is developing and implementing strategies using a co-design process with stakeholders, buy-in from clinicians, and strategies needs to be led by

government to support change (Rodin 2018; Sanson-Fisher et al. 2019).

### Coordinating care

Care coordination centralises services and resources needed to manage patient health and facilitates communication among clinicians, however it often does not extend care to carers.

Care coordinator clinicians and case managers assist patients and carers in navigating the healthcare system, provide education and support to manage patients' health, and link in with relevant services (Dept of Health and Aged Care 2015). Care coordination delivered by clinicians varies across disease and rarely focus on carers' wellbeing (Betihavas et al. 2011; Smith et al. 2022), resulting in inequalities in the provision of information and support for carers. Alternatively, coordination of care can occur at a service provider level and has been shown to support carers' and families' needs within rural and regional settings (Whyte 2009). Care coordination has the capacity to support carers in the community but will not be consistently and routinely provided within the person-centred model of care.

There is opportunity for care coordination to be improved within primary care settings by GPs. GPs are more likely to deliver ongoing care and have capacity to refer carers to community-based resources. Identification of carers is paramount to ensure best outcomes and can be better supported in the GP setting. For example, patient registration forms can be extended to include a question about identification as a carer (Carers Australia 2021c). This can also be incorporated into

online appointment booking platforms such as Health Engine.

### Impact of interventions for carers

Interventions to improve psychosocial outcomes are primarily developed for patients or patients and spouses as one unit (worldwide) (Coyne et al. 2020); but are also required for supporting carers outside of the healthcare system (Franklin et al. 2017).

Success of interventions in meeting carers' needs vary across chronic disease. In stroke and dementia care there is no clear impact of interventions on carers' health and wellbeing (Minshall et al. 2020; Stockwell-Smith, Moyle and Kellett 2018). Assessment of psychosocial needs has been practiced within dementia care, but low uptake of services occurs as services fail to address carers' or patients' needs (Cations et al. 2017). Within the cancer setting there is a global initiative to provide psychosocial interventions for patients and carers, with interventions showing positive results in improving carers' outcomes (Rodin 2018). Clinician led implementation of interventions and supportive care resources for carers can be improved (Ugalde et al. 2021) and evaluating carers' outcomes can highlight gaps in the healthcare system (Tuffaha et al. 2019).

### The role of telehealth

The shift to telehealth and imposed hospital restrictions during the COVID-19 pandemic had variable impacts on carers' experiences such as altered ability to take time off or attend patient appointments and changes in the opportunity to receive information to manage patients' care needs. This led to uncertainty for carers when providing care (Edge et al. 2021; Smith et al. 2022; White et al. 2022).

### **MBS support for carers**

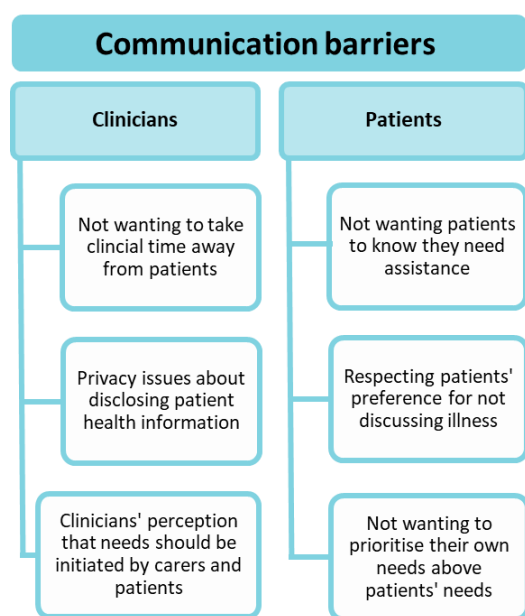
During the COVID-19 pandemic carers experienced additional burden as the healthcare system increased reliance on home care, and supportive care services such as respite were unable to be accessed (Edge et al. 2021). Carers were among one of the vulnerable groups in society at higher risk for mental health concerns, including, for example those with low socio-economic status, and those living in regional and remote areas (Fisher et al. 2020). There are no MBS items to support assessment of carers' own health and wellbeing either in clinic or via telehealth. The MBS includes carers as part of patients' healthcare team in certain circumstances such as eating disorders (MBS Online n.d-d), group therapy (MBS Online n.d-a), geriatric care (MBS Online n.d-c) and managing comorbidities (MBS Online n.d-b). A limited capacity to identify carers in the care process remains post-pandemic. This has several implications including lack of acknowledgement of carers by clinicians, continued poor uptake of services by carers as they are unaware of them, poor clinician familiarity of available resources and inequalities in access to care for carers.

MBS funded telehealth benefits patients and reduces disparities, such as improved access to care and adherence to medical appointments by 30% among people from First Nations communities (Couch et al. 2021). Pre-pandemic studies assessing telehealth for carers showed that carers had the opportunity to speak to clinicians about their own needs (Halkett et al. 2018) and those in rural settings had increased access to care (van Ast and Larson 2007). Delivery of care via telehealth is

nearly half the cost of face-to-face appointments (van Ast and Larson 2007). Nurse-led care via telehealth includes linking carers with existing resources (Halkett et al. 2018; van Ast and Larson 2007), however clinicians' skills in carer assessment vary (van Ast and Larson 2007), resulting in inequalities in care. Telehealth has the capacity to support carers' wellbeing in the community, however government support via the MBS will be required.

## Supporting clinicians to care for carers

Communication barriers exist between carers, clinicians and patients (Figure 3), making it difficult for clinicians to assess and provide support for carers in routine practice.



**Figure 3. Communication barriers between carers, clinicians and patients (Gold et al. 2009; Heynsbergh et al. 2018a)**

Timely access to support and services is able to promote carers' wellbeing and can be improved within the general practice setting (Ugalde et al. 2021; Wang and Du 2019; Wangler and Jansky 2021). However, there are little data available about how carers are identified, assessed and provided with support in primary care.

Carers are more likely to engage with services when they are recommended by clinicians (Phillipson et al. 2019; Wangler and Jansky 2021). However, clinician led referrals are inadequate. For example, in 2022 40% of people living with or caring for someone with disability knew of the Disability Gateway, yet

only 20% of them were referred by clinicians (Dept of Social Services 2022).

This is similar in the cancer setting where out of 42,000 calls from family or friends to the Cancer Council Australia 13 11 20 telephone line, only 10% were referred by a clinician (Heckel et al. 2014). Most commonly carers were referred by a friend (40%) (Dept of Social Services 2022) or by the organisations' self-promotion (Heckel et al. 2014). My Health Record provides carers with the opportunity to access their own and patients' health care information, yet engagement is low (34%) and it has been reported that only 13% of carers have spoken with their GP about the platform (Carers Australia 2022). These highlight gaps in which clinician communication can be improved to support carers' needs.

Coordination of community services such as nursing based care is only provided by 15% of GPs, and a key barrier is lack of standardised referral systems (Doty et al. 2019). Carers rely on recommendations from informal networks, and this creates inequalities in carers' awareness of services and access to care (Heynsbergh et al. 2018a). To promote uptake and equitable use of services, conversations related to carer health need to be initiated by clinicians and supported by standardised referral pathways.

### Training

The medical and nursing workforce receive little undergraduate education on carer assessment beyond the context of carers as part of the patients' healthcare team (ABS 2022; Australian Medical Council Limited 2012).

Post graduate training for clinicians is needed to improve skills in conducting carer assessments (Wangler and Jansky 2021). Post graduate training and workshops to address carers' wellbeing needs are available (North Western Melbourne Primary Health Network 2020) and have been incentivised to contribute to clinicians' Continuing Professional Development requirements (Victorian-Tasmania Alliance Primary Health Network n.d). Little data exists about whether this training is widely or systematically undertaken. Education at an undergraduate and post-graduate level is needed to highlight the importance of carers' wellbeing and to develop skills in conducting assessment both for upcoming and registered practicing clinicians.

Variability in clinicians' knowledge and expertise in assessing carers results in inequalities in support for carers, particularly for First Nations' People and those living in rural and remote areas as there are fewer clinicians (AIHW 2022d) and coordination of community services is poor (Nolan-Isles et al. 2021). There is no information collected about clinicians' knowledge of carer wellbeing, the frequency of carer assessment or frequency of referrals to services and resources. More data are needed from clinicians to highlight gaps in knowledge, guide the delivery of training programs, and inform how existing carer resources can be made more visible to clinicians (Phillipson et al. 2019).

## Conclusion and recommendations

Change in the healthcare system is needed to support carers' health and wellbeing, which in turn will facilitate care in the community and reduce the burden on the healthcare system.

Expansions to existing systems and healthcare standards can be made to include carers as separate consumers, to identify their areas of need and to guide government allocation of fundings and services. To improve carers' health and wellbeing, four steps can be taken to address the issues identified (Figure 4).



**Figure 4. The pathway to supporting carers' health and wellbeing**

### Step 1 - Collect comprehensive data

Comprehensive data related to carers' wellbeing, service use, and clinicians' knowledge of carer assessment are needed to inform allocation of government spending and distribution of services for carers.

#### Carer wellbeing data

To identify gaps in care, regular and comprehensive data are needed to assess carers' wellbeing, service utilisation and outcomes post service utilisation. These data will complement *Carer Wellbeing* surveys conducted by Carers Australia (Carers Australia 2021a) and inform government allocation of resources.

Accurate assessment of carers and their wellbeing can be achieved by:

- 1) Asking detailed questions about carers' outcomes before and after service use.

The Carer Wellbeing Survey collected information such as satisfaction with services, general wellbeing and distress (Carers Australia 2021a). To complement this, outcomes such as stress, anxiety, depression and burden should also be collected and with reference to provide detailed information about the impact of existing services. This can be achieved using broad statements, for example "have you experienced anxiety?", "which services have you access for anxiety?" and "how did these services impact on your symptoms of anxiety?"

- 2) Including questions to identify people from priority groups such as geographical location, primarily language spoken, identification as First Nations' people, or identification with LGBT+ communities.

To promote equal opportunity for carers to complete surveys, they should:

- 1) Be distributed nationally through known data collection agencies such as the Australian Institute for Health and Welfare (AIHW) or the Australian Bureau of Statistics, to reach carers who are not linked in with services and organisations.
- 2) Be translated into the most common languages in Australia to reach people from non-English speaking backgrounds. The top five languages in Australia other than English are Mandarin, Arabic, Vietnamese, Cantonese and Punjab (AIHW 2022b).



### Regular clinical assessment of carers' wellbeing

A nationally implemented framework for assessing carers outcomes during clinical encounters is needed to assist clinicians in referring carers to services and enable monitoring of carer wellbeing on a regular basis. To facilitate this, brief tools can be used such as the *Short Form-36 (SF-36)* (Lins and Carvalho 2016; Ware and Sherbourne 1992), and the *Zarit Burden Interview (ZBI)* (Bedard et al. 2001).

The SF-36 is already used in clinical practice to collect patient reported outcomes measures (PROMs) (ACSQHC n.d-a) and can be used to assess carers' own health and wellbeing. The ZBI indicates the level of burden experienced by carers due to their caring role (Bedard et al. 2001) and combined with the SF-36 can indicate carers' overall health and wellbeing. When conducted routinely, these assessments can indicate how carers' wellbeing changes over time. Carer reported outcomes have the capacity to be delivered alongside PROMs and can serve as a prompt in communication between clinicians and carers.

In 2018 the AIHW report *Patient reported experience and outcome measures* identified that PROMs are published annually (AIHW 2018), however there is no clear indication of where subsequent findings are reported. Carer reported outcomes and PROMs should be included consistently in existing reports e.g. *Australia's Health*, to provide timely and accurate data on carers' wellbeing, and to allow for evaluation of healthcare services and gaps in care.

More comprehensive assessment tools exist such as the CNA (Ramsay et al. 2007) and the

CSNAT (Aoun et al. 2015; Aoun et al. 2018b; Ewing et al. 2020), however these pose a larger time burden for clinicians to complete routinely. The CSNAT or CNA would be better implemented during transition from hospital to home, or on initial identification of carers to allow for early intervention of services and support.

### Clinician knowledge and practices

Data are needed about clinicians' knowledge and practices in supporting carers. This includes:

- 1) Knowledge of carer assessment.
- 2) Knowledge of carer resources, including how clinicians learned of resources.
- 3) Use of assessment frameworks in clinical practice, including type and frequency of assessment.
- 4) Use of referral pathways in clinical practice, including frequency of use and process used.

Baseline data are needed in these areas to highlight where systems can be improved. Benchmarking can then be used to determine success of any implemented strategies, encourage continued practice, and identify areas which can be revised. Benchmarking has been used in the delivery of healthcare internationally and has shown to improve quality of care and patient outcomes (Willmington et al. 2022).

Implementing the SF-26 and ZBI will reduce the need to introduce additional assessment tools for clinicians to complete, as information about frequency of carer assessment and the framework used will already be collected. Strategies to monitor and support clinicians' knowledge and skills need to be developed and can be achieved using co-design and clinical education.

## Step 2 - Co-design a health care system to include carers

Co-design principles involve working with consumers to develop a product or service that is fit for purpose (Victorian State Government 2020). To support carers in the healthcare system, co-design must involve: carers, patients, clinicians from all professions, hospital and health service leaders, consumer groups (Carers Australia, Carer Gateway), administration staff, researchers, and policy makers. Co-design workshops can be led by ACSQHC to determine how a national approach to supporting carers can be designed and implemented to fit within the current healthcare system and standards.

### Develop and implement an assessment framework to identify carers and their needs

Implementing the SF-36 and ZBI scales into routine practice as frequent and quick assessments will identify carers' wellbeing outcomes, but how best to implement this assessment is unknown. Co-designing a framework to guide delivery of carer assessment is vital in ensuring equal access to support for all carers. Workshops with consumers should answer (but not be limited to) the following questions, in order to provide a clear pathway for clinicians to assess carers:

- 1) In which settings will assessment take place? For example, general practice, outpatient clinics, community services.
- 2) How frequently should assessment be conducted, in particular for long-term carers?
- 3) How will carers complete the assessment? For example, prior to appointments, during appointments, or after a service has been accessed, or with interpreters.
- 4) In what format can carers complete the assessment? For example, online or paper based.
- 5) How can carers who are not currently linked in with services access the assessment themselves? For example, promotion via consumer and government organisations.
- 6) Are the SF-36 and ZBI scales sufficient in addressing carers' own health and wellbeing needs?
- 7) How can carer assessment be implemented to minimise time burden on clinicians within the existing healthcare system?
- 8) How are carers supported once a need is identified?

### Expanding the Transition of Care key principles

The current healthcare standards need to acknowledge and support carers as separate consumers who have unique needs.

Broadening the *Transitions of Care* key principles to encompass the hospital to home transition and carer wellbeing, will prepare carers for their role prior to leaving hospital and provide them with the opportunity to ask clinicians questions. Home based interventions can address gaps in support during transition to home and promote problem solving and self-care among carers (Aoun et al. 2018a). However, widening the scope of the principles promotes pre-emptive access to resources to prevent poor health outcomes.

Co-design is needed to ensure that expansion of this standard addresses carers' needs and can be translated into the clinical setting without resulting in additional burden on clinicians.

To achieve this, it is recommended that a standardised assessment and referral system is developed within one centralised system. Electronic medical records (EMR) used within inpatient hospital settings distribute patient discharge summaries to GPs (Dept of Health and Aged Care 2022). EMR offers the opportunity to extend discharge summaries to support carers by incorporating assessment tools such as the Carer Needs Assessment tool (Ramsay et al. 2007) or the Carer Support Needs Assessment Tool (Aoun et al. 2015; Aoun et al. 2018b; Ewing et al. 2020) which can also be forwarded to GPs.

Hospital discharge summaries already include a description of discharge information provided by clinicians to patients and family. Despite 70% of GPs finding this information important, less than 1% receive adequate information (Mahfouz et al. 2017). The *Transition of Care* key principles needs revision with stakeholders to ensure that carer information is consistently collected by hospital clinicians and provided to GPs upon discharge to promote continuity of care and equal access to support among carers.

Strategies to support carers who do not have a regular GP can include providing carers with a printed list of compiled resources alongside patient discharge summaries distributed to patients and families. Resource lists can be developed with stakeholders and can include existing support services such as Carers Australia and Carer Gateway, with recommendations to find a regular GP for ongoing support.

#### **Shifting away from person-centred care**

Shifting the healthcare model is necessary to be able to support carers' wellbeing. Change

to healthcare systems requires a co-design approach to ensure that any new model is fully adopted into practice (Sanson-Fisher et al. 2019), minimises potential burden on clinicians, and maintains safe and quality care for patients. The Victorian Carer Strategy 2018-2022 outlines key areas in which the government can support carers' wellbeing such as supporting carers from diverse population groups and providing accessible support services. This strategy can be used to inform nationwide policy (Dept of Health and Human Services 2018).

Additionally, the Carer Recognition Act of 2010 outlines 10 principles in which carers' needs can be addressed (Dept of Social Services 2016). These principles incorporate the needs of carers as part of the patient's healthcare team, as well as their own health and wellbeing outcomes (Dept of Social Services 2016). Principles which would benefit from further action include carers' impact on social and economic outcomes, acknowledgement of carers and recognising their need for individualised care, and support for carers own wellbeing needs.

One strategy to support systemic change includes widening clinicians' scope of practice to include carer assessment. In this process, roles and responsibilities need to be clearly defined for each healthcare discipline to avoid gaps in care for carers (Wiggins et al. 2022), and training is required to upskill and prepare clinicians for the change in scope of practice (Leggat 2014).

The model of health care is shifting towards digital healthcare being provided in community setting (Australian Digital Health Agency n.d), and adoption of digital solutions

for carers is necessary to ensure that any implemented strategies are not outdated and unable to support the growing carer population. Shifting the healthcare focus to encompass carer assessment can be achieved using existing platforms, for example My Health Record is one centralised system which provides a central source of information across providers, and 90% of Australians are registered (Victorian State Government 2019). With the planned development of My Health Record, it should adopt additional features such as referral systems and compiled resources for carers to access. Carers seeking support via My Health Record is still low (35%) (Carers Australia 2022) and adoption by carers can be further facilitated by using standardised referral pathways and improving coordination of care for carers. In reducing the digital divide among community groups, these referrals and resources need to be followed up and reinforced by treating clinicians such as GPs during appointments.

Shifts in healthcare systems and expansion of existing platforms needs to be developed by all end-users and strategies need to be supported by government to ensure that carers' health and wellbeing are prioritised at a national level.

### Step 3 - Implementing strategies to support change

#### Education for clinicians

Education for practising clinicians is needed to i) improve understanding of carers' roles and outcomes ii) conduct carer assessment and iii) learn updated systems such as EMR and My Health Record.

In collaboration with carer consumers groups, for example Carers Australia, government needs to provide training for clinicians to improve their knowledge and develop skills in carer assessment. Training workshops need to be supported by government with paid professional development leave, and education contributing to clinicians' CPD to encourage attendance. Workshops provided should be underpinned by the train-the-trainer model, which is effective in improving clinicians' knowledge, skills and confidence with new practices (Hollis et al. 2022). Train-the-trainer models have also resulted in shifts in models of care within rural and regional health to better meet community healthcare needs (Brumby and Smith 2009). While online training exists such as e-learning modules, there is little evidence to support their cost-effectiveness (Meinert et al. 2021; Ruggeri, Farrington and Brayne 2013), or their impact on clinicians' practices (Ruggeri, Farrington & Brayne 2013; Vaona et al. 2018). However, online modalities can be incorporated such as video-based group training, which will overcome barriers such as travel and time burden for clinicians and trainers.

Workplace training related to updated systems (EMR and My Health Record) is needed for successful adoption among clinicians to ensure that support for carers is continuous (Mullins et al. 2021).

To supplement training workshops and promote adoption, several approaches need to be taken including workplace policy (Wiggins et al. 2022), local education, and behaviour change techniques such as peer support, dedicated time for learning, support from management (Lloyd et al. 2014) and clinical 'champions' (Hespe et al. 2018).

Adoption of new practices can be further assisted by including gamification principles during training such as points systems for individuals or departments and prizes (van Gaalen et al. 2021).

#### Undergraduates

To prepare the upcoming workforce but reduce introducing new concepts into overloaded undergraduate courses, learning can occur during clinical placements including clinical education sessions, shadowing practicing clinicians and being involved in the discharge process. Clinical placement education sessions should encompass theoretical concepts such as carers' roles and outcomes, and their value to the healthcare system, as well as teaching communication skills and how to conduct carer assessment.

Education and skills development on carer assessment needs to be provided as standard clinical process similar to patient discharge processes, learning how to use the EMR and understanding and accessing local hospital policies and procedures (Nursing and Midwifery Board of Australia 2006; Royal Australian College of General Practitioners 2022).

Extending clinical placement competencies to include carer assessment can ensure that clinicians have the knowledge and skills to support carers upon completion of undergraduate courses.

#### MBS funded support for carers' wellbeing

Allocation of MBS funding is needed to provide clinicians with time to identify carers and conduct assessments. Transition from hospital to home is an ideal time to conduct an initial assessment, however initial and follow up assessments are also needed in specialty areas

such as oncology and GP clinics, and funding for carers needs to span across primary, secondary, and tertiary healthcare.

Coordination of care and MBS funded services will be guided by data collected (outlined in Step 1). However, carers need immediate assistance and cannot wait for comprehensive data collection and co-design of systems. MBS funded assessment and support services need to be implemented first, with evaluation and refinement occurring concurrently in conjunction with data collection.

To promote equal access to care, funding needs to incorporate multi-modal services including face-to-face, telephone and video-based care to ensure equal access to services regardless of their geographical location, access to digital devices or digital literacy (Carers Australia 2021b).

#### Step 4 - Ongoing evaluation

Permanent and ongoing evaluation is needed to ensure that carers' health and wellbeing continue to be supported and that government funding is optimised.

Comprehensive data will provide information needed to understand the demographics and needs of carers in the community, highlight the success of interventions, and identify remaining gaps in care.

The ABS *Disability, Aging and Carers* survey is conducted four yearly, but is inadequate in providing data to support change for carers wellbeing with the evolving healthcare system. It is recommended that these data are collected two-yearly, similar to nationwide health and wellbeing data collected by the Australian Institute of Health and Welfare (AIHW 2022a).

The same survey intervals are needed for assessing clinicians’ knowledge, skills and adoption of carer assessment to allow for comparisons to be drawn between implemented strategies for clinicians, and

carers’ outcomes within the same timeframe. Evaluation data should be encompassing and address carers outcomes, clinicians’ knowledge, and practices and impact on the healthcare system (Table 2).

Carer data	Clinicians’ knowledge and practices	Healthcare service data
<ul style="list-style-type: none"> <li>• Demographics</li> <li>• Outcomes</li> <li>• SF36 and ZBI outcomes</li> <li>• CAN or CSNAT findings</li> <li>• Perception of inclusivity in the healthcare system</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge of carer assessment</li> <li>• Adoption of carer assessment by clinicians e.g., frequency</li> <li>• Frameworks used to assess carers</li> <li>• Knowledge of services available for carers</li> <li>• Frequency of referrals made for carers</li> </ul>	<ul style="list-style-type: none"> <li>• Hospital admissions for carers’ health</li> <li>• Hospital admissions related to patient care</li> <li>• Impact of carer assessment on clinician workload</li> <li>• Community services utilised</li> <li>• MBS services utilised (carer assessment appointments and services)</li> <li>• Impact of system model changes on carer/patient outcomes</li> </ul>

*Table 2. Examples of evaluations data to be collected two-yearly*

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