Palliative Care Social Work Australia
ADVOCACY | COLLABORATION | EXCELLENCE

PCSWA submission to the Australian Institute of Health & Welfare (AIHW)

National Palliative Care & End of Life Care Information Priorities

8 November 2020

Introduction and overarching headings

- **People with a life limiting illness**
- **Families and carers**
- **Workforce**
- **Service and system planning and design**
- **Service delivery and integration**
- **Performance and public reporting**
- **Understanding**

The headings or domains provide a good framework for identifying where information is needed to adequately inform service planning, policy and quality palliative care provision to enhance patient/carer outcomes and experiences.

One gap in the Priorities document is the data that needs to be collected on the palliative care allied health workforce, particularly social work. Palliative Care Social Work Australia (PCSWA) believes that data on the social work role is essential for any future service and policy development and planning.

Social work is a well-established profession that has a long-standing history in health care. Although social work has been a core member of the palliative care team since the origin of the hospice movement by Dame Cecily Saunders in the 1960's, there is an absence in policy and research agendas by the social work profession

Efforts to capture the contribution of allied health, specifically social work data in relation to gaps identified in *Figure 1: Availability of national data across the various health settings* would make a significant contribution to policy development and service planning. AIHW would need to support systems that can capture data on social work and include this as part of AIHWs regular reporting on palliative care.

The scope of social work in palliative and end of life care is diverse and extensive, placing social work as an integral profession to the delivery of palliative and end of life care. It is difficult to get accurate data on social work profession and their role in caring for patients requiring palliative and end of life care, which includes care and support of carers and families. Based on the Commonwealth Department of Jobs and Small Business reports, there were 40,300 social workers employed in Australia in 2019 and just over 70% of social workers worked in the health and social care industry (1). As palliative care is provided in a diverse range of settings where health care is provided (2) and as social workers work across health and social care or community services in a range of roles, most patients and their carers or families will receive a social work service at some point in their illness trajectory. Social work interventions in specialist palliative care services have demonstrated positive patient, carer and family outcomes and experiences There is thus the potential positive impact of the social work profession on the lives of a large population who will require palliative and end of life care (3).

Based on the Palliative Care Outcome Collaboration (PCOC) January to June 2020 report, 190 palliative care services in Australia submitted data (4). Most services have a social worker as a core part of the multidisciplinary team with some services having two or more. In 2017, there were 160,000 deaths in Australia and almost half of all deaths in Australians occurred as an admitted patient (over 80,000 people die in Australian hospitals each year) and the proportion of deaths at home ranged between 4-12%. It is anticipated that total deaths will surge by 135% to 400,000 between 2019-2060. of these, it is anticipated 214,000 will require palliative care services (5). Additionally, there is an estimated 32 children per 10,000 children aged 0-19 years living with a life limiting condition, with one child death for every sixty adult deaths in Australia (6).

Most people with palliative care needs will encounter a social worker at some time during their illness trajectory. The need to include social work in national data in the future is essential. This is particularly salient as many patients who wish to be cared for in the community may need to access the National Disability Insurance Scheme

(NDIS) for those under 65 years of age and MyAged Care to enable them to remain in the home as many palliative care services do not provide broader domiciliary support services.

Social work interventions in specialist palliative care services have demonstrated positive patient, carer and family outcomes and experiences (5). As a profession, social work has a significant role and perspective to contribute to palliative care policy, reform and workforce planning. It is essential that social workers have a voice at the table as they are best place to highlight what the profession can offer (rather than the opinion of medical and nursing staff representing what they think social work does and offers. PCSWA would embrace the opportunity to for any consultation in relation to the role of the profession in palliative care.

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People with a life-limiting illness

Patient-reported experience measures (PREMS)

PREMS are an essential component to measuring quality processes in service provision however the ability to capture PREMS are constrained by systems (IT, limited staffing, short length of stay etc.) and lack of standardised brief tools to capture PREMs. Palliative care services may administer surveys to bereaved family members with the intent of evaluating care and service provision. The use of surveys in this way to garner experiences of patients or carers/family is often challenging as responses may not relate specifically to the care provided by a specific palliative care service. For example, a patient may receive palliative care from specialist clinicians or services, general nursing or allied health services and general practitioners. Although the intent is to obtain information on patient and/or carer/family experiences, as patients may be cared for by different teams from specialist and generalist services, in inpatient and community settings, responses can become conflated where it is difficult for services to identify what is relevant to them. The information from these surveys may be helpful at a health district or health service area level but may not be as helpful for individual services within the area/district. This in turn, can provide inaccurate information or data to inform any improvements required in care provision or for adequate resourcing and workforce planning.

Patient-reported outcome measures (PROMS)

Social workers in specialist palliative care settings use PCOC although this is used inconsistently by social work clinicians and is dependent on service protocols and whether it is an expectation that allied health undertake PCOC assessments. Although the PCOC tools can be useful to social workers to screen for symptom distress, such as fatigue, breathing problems or pain, which may benefit from non-pharmacological interventions, the PSS tool commonly used by palliative care clinicians to trigger referrals to social work or is used by social workers to screen severity of problems, is a crude tool that does not provide adequate data on a patients’ family or carer issues or a patients’ psychological or spiritual issues. A standardised tool that can more accurately measure outcomes in psychosocial-spiritual issues would be beneficial and could be added to the national PCOC program.

Identifying and supporting people without carers

Social isolation and lone-person households have been identified as a Grand Challenge for Social Work (1). Single person households are an identified driver for the demand for social work as there is increased risk of social isolation which is linked to poorer health outcomes and increased used of health services. The number of lone-person households is expected to grow to between 3 and 3.5 million in 2041 which will make up around a quarter of all Australian households (2). The increase in single person households between 2011 to 2036 represents an increase of between 61 to 65 percent and is the largest anticipated growth of any household type (3).

The literature identifies a range of factors that may influence future demand for social work and demographic and social changes leading to increased lone-person households. Changes in family structures, relocation of individuals from family or support networks due to work or other life circumstances, mental health or drug and alcohol issues, domestic violence or homelessness often mean that people may not be able to return to where they were living or receive care in the home without the additional support. the size and demand of services under NDIS or via MyAgedCare may have an impact on availability of services. Coordinating care of services requires considerable time and liaison for which social workers play an essential role (3).

An additional challenge where social workers play a significant role is when, in the process of advance care planning, patients are supported to discuss and document their end of life wishes and they identify that they do not have anyone they could designate as a health care surrogate (4). Lone-person households, or those in unstable living situations or are homeless, often have very limited social support and do not have an identified decision-making surrogate. Despite social workers often initiating or supporting patients to apply for or arrange guardianship and/or administration orders (when indicated), appointed guardians may not be familiar enough with the persons to effectively guide end of life care congruent with the persons values and wishes.

Anecdotally, a palliative care social worker in Victoria discussed a patient who lived on their own with no support networks who had requested Voluntary Assisted Dying. Although VAD is not part of the palliative care continuum, the patient was concurrently referred to palliative care while undergoing the process for VAD. The social worker described the 'wrap around' support the patient received from the palliative care service by the medical and nursing staff and the social workers along with the volunteers and that this influenced the patients decision regarding VAD as they expressed they did not know they would receive such excellent and compassionate care. This is a scenario where health service systems do not capture the stories behind the request for VAD. With WA and Queensland introducing VAD legislation, scenarios such as this will require some level of monitoring – particularly if requests from people from sole-person households are associated with higher level requests for VAD. Social workers are at the forefront of patients wanting to communicate their wishes to hasten their death and international research shows that psychosocial needs are more often the motivators or requests for VAD (5-6).

Social workers are thus an essential allied health discipline in meeting the needs of lone-person households and are well placed to bridge the gap between the biomedical paradigm of the health system and the social realities of peoples' lives.

Information systems that capture this level of social work activity when working with palliative care patients could help identify this cohort and evaluate the quality of care people living alone receive to identify opportunities to improve that care.

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Conversations people are having and how they are planning for their future care

A large proportion of palliative care social workers lead and conduct advance care planning (ACP) discussions and are responsible for educating patients and families on advance care planning options. Social workers play a main role in facilitating the identification and appointments of surrogate decision makers and are sensitive to underserved and marginalised groups and cultural factors which all impact on a person's participation in advance care planning processes. Palliative care social workers have awareness of predictable trajectories of disease and can identify key times when to introduce ACP discussions. They advocate for and support patient decisions and help to communicate patient wishes to family members and other health care professionals (1-2). Service planners, policy makers and administrators need to incorporate the vital contribution of social work in ACP related activities into health care systems to capture this data (3). Evidence shows that social workers involvement in ACP increased the rate of patients discussing ACP with their care providers, documentation of ACP discussions, completion rates of ACP and appointment of surrogate decision makers (4). Evidence suggests adults from low income backgrounds have lower completion rates of ACPs. Social workers are strong advocates for people from diverse socioeconomic, social and cultural backgrounds and play an essential role in ACP (5). As more social workers in generalist health or community settings such disability sector have increased awareness and training of ACP, the broader areas of practice in which social workers are situated are engaging in facilitating ACP discussions.

Standardising data collection for preferences for place of care and place of death should be captured as part of specialist palliative care service provision and there may be benefit to include these as part of a national minimum data set.

In palliative and non-palliative specific client groups, there are challenges in uploading of ACPs on to hospital or health service electronic medical records as IT systems and records management may not have processes in place to record this. Additionally, some health services have endeavoured to upload ACPs and put an alert on patient medical records of an ACD however this is often not readily extractable data items. Health services need to be supported to enable IT systems to upload ACPs and have capacity to easily extract data on these.

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Families and carers

Identifying who is providing care to Australians at their end of life.

Informal carers who do not consider themselves carers are an invisible group in Australia data and information and systems are not necessarily set up to capture this data. There needs to be capacity to link cross-sector data from health, mental health, Primary Health, Department of Social Services, community or social care services and business.

There are carers within marginalised groups such as the homeless populations where members within this group provide an informal caring role. Additionally, service providers who provide case management role for underserved groups such those with drug and alcohol or mental health issues and those who are homeless, often adopt de-facto informal caring roles within their work with these groups (1-2)

Caring at end of life has been associated with a broad range of issues including poor health, economic disadvantage, financial burden and employment related strain with psychosocial sequelae. Carers can experience heightened precariousness and structural burden associated with welfare and navigating systems at end of life to better support carers is essential. Factors such as age, language, literacy and pre-existing poverty increase an individuals' difficulty with navigating welfare systems and have the potential to lead to greater risk of disadvantage. Social needs related to housing and income need to be considered as 'essential components of palliative care'. Exploration and evaluation of structural determinants of caring experiences is necessary to enable systemic investment in cultivating inter-agency partnerships to better serve vulnerably positioned carers but to also build the social capital of other professionals in the welfare field (3-4).

There is a need for intersectoral collaboration to promote information sharing between government organisations in a way that facilitates connection with carers, minimises additional administrative burden, and promotes identification of psychosocial complexity, including post-death when carers are no longer connected with formal health services/specialist palliative care.

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3. Bindley, K., Lewis, J., Travaglia, J. & DiGiacomo, M. (2020). Caring precariously. An interpretive description of palliative care and welfare worker perspectives on end of life carers navigating social welfare. Palliative Medicine, [online epub]. DOI: 10.1177/0269216320966492.
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Identifying the needs of carers

Opportunistic gathering of information through surveys and specific research studies may promote or perpetuate certain biases for example those who participate in surveys or research tend to have more positive experiences, women have a higher representation and Culturally and Linguistically Diverse and other vulnerable or marginalised groups don't tend to be readily engaged in these surveys or studies. Accessibility to surveys or research studies may also be hindered by 'gatekeeping' behaviours. Systematic gathering of carer information regarding the experience of families and carers is required.

There is increased promotion of death and grief literacy across all sectors (not just health), however vulnerability for adverse bereavement outcomes is often misunderstood, missed or perpetuated by structures and systems.

PCSWA acknowledges 'identifying those at highest risk of complex grief and bereavement' and the provision of appropriate support is essential, support is not however, a one-off straight forward process. Additionally, there is an implicit assumption that services are broadly available however from practice immersion, social workers who provide specialist bereavement counselling or other bereavement support know that this is not the case. Systematic scoping of existing grief and bereavement support is an essential action that would advance palliative and end of life care and understanding of gaps in support.

Although bereavement is part of palliative care models of care, bereavement needs to be understood as a public health issue and is a loud silence in the carer narrative at the policy level. Adequate bereavement support is a carer need. Studies have shown that the costs of bereavement are significant to health and mental health services, with studies in Scotland on spousal bereavement indicating the estimated economic costs for inpatient days is £20m to the National Health Service and costs in the primary health sector costs approximate £2.2m each year. There is also an association with bereavement and excess inpatient days (1). Research indicates that carers have an 18% higher mortality rate in bereavement and carers who have pre-existing or long-term illness prior to bereavement have a 35% higher mortality rate and when this figure is delineated by gender, males have a 54.8% higher mortality rate (1). Studies undertaken in Germany and Australia on bereaved parents indicate adverse outcomes on general and mental health (2,3). Research on bereaved parents following the loss of a child from cancer showed costs to family in Australia for general medical and mental health services is around $3,200 per family, in terms of productivity, there was 15.5 weeks leave without pay that cost families around $8,000 on average and that parents either chose or were forced to resign from their employment with estimated lost income averaging nearly $60,000 (3). Research has indicated that there is a lag in mental health related to bereavement and medical service utilisation so bereavement needs to be viewed within the context of longer-term support (1-2). It has been estimated that one in four people are grieving at work and the notion of 'presenteeism' costs an estimated $34.1 billion on the Australian economy with an average of 6.5 working days of productivity per employee lost annually (4). Additional costs to the Australian economy is related to a government carer allowance where a bereaved person can receive up to $6,500 that can be paid as a lump sum or periodically over 14 weeks after a persons death (5). Some bereaved at risk of poverty and homelessness which have additional costs socially and economically to individuals, services and the broader economy.

Although the Australian Government has prioritised mental health and allocated significant funding in recent times, funding is provided to disparate service providers. There is an assumption that mental health clinicians, psychologists or counsellors have the expertise to deliver services to bereaved carers however they may not have the appropriate skills and expertise in contemporary grief and bereavement specific modalities to effectively alleviate poor bereavement outcomes. A national framework such as the UK National Bereavement Alliance's *Bereavement Care Service Standards* on which to measure Standards with criteria for what carers, clients, staff and volunteers can expect from a bereavement care service would enable services to appraise, develop and improve their services to be both safe and effective in meeting the needs of bereaved people and provide a mechanism for closer oversight and regulation. Bereavement Care Service Standards would ensure equality and governance across different services and lead to a more integrated approach to the delivery of bereavement care for bereaved carers. Bereavement Standards would provide the Government with a framework to develop a minimum dataset to capture information on needs of bereaved carers, quality of service provided. When linked with other datasets such as health and mental health service utilisation, bereaved carer payments, bereavement leave and productivity reports related to lost productivity as a result of bereavement and deaths by suicide related to bereavement etc. this would provide Government with robust data on carer needs, service utilisation patterns and economic costs of bereavement. Additionally, IT systems in health, primary health and other services do not often record bereavement related activities and this would need to be addressed. For example, GPs do not have a data item for issues related to bereavement that is an extractable data item.

Standardising data collection for an identified carer or 'named support person' should be captured on IT systems for different sectors ie. health, disability etc. Although this information is often captured on admission to a service or if circumstances change for the person, this is often not recorded as easily extractable data items. Services need to be encouraged to amend IT systems to enable this as a data item that can be reported on. Additionally, services need to capture carer experiences along the illness trajectory and not rely on retrospective survey or research data. The use of carer screening tools such as the Carer Support Needs Assessment Tool could be built into systems and triggers identified ie. change in PCOC phase or admission to hospital from community etc. could initiate carer needs or experience data.

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Are there additional actions relevant to this section (Families and carers) that would advance palliative care and end-of-life care in the next 10 years?

Comprehensive evaluation of the carer support payment and carer allowance is long overdue, particularly in relation to the end of life/palliative care context, and given the recognised flaws or issues associated with these payments already, alongside calls for consideration of other approaches to payment structures this sort of action could shape future payment mechanisms.

Workforce

- **Complexity and capacity of the workforce supporting end-of-life care *(Monitor the distribution, skill levels and numbers of professionals in line with projected need to inform and plan).***
- **Capacity across the workforce to deliver high-quality and person-centred care *(Inform workforce capability in the palliative approach outside the specialist palliative care workforce; Monitor capacity to deliver culturally sensitive care; Provide insights into the continuing education requirements; Collect volunteer workforce data***

Palliative care social work has rapidly developed into a specialist health related form of practice in hospital, community and hospice settings (1). The scope of social work in palliative and end of life care extends across many practice settings and populations, and provides intervention at the individual, family, group, community, and organizational levels. Palliative care patients have been identified as complex and having complex needs when examined within an Ecological Systems Theory (5). This is the 'bread and butter' work of social work and skill mix of clinicians, even allied health, needs to be taken into consideration to ensure high quality and safe palliative care.

Social workers have expertise in working with complexity, assessing social determinants of health and providing psychosocial (psychological, emotional, social and spiritual) interventions that aim to improve and optimise quality of life for the person and their significant others. Social workers provide multidimensional symptom management, collaborate in interdisciplinary ways of working, engage with communities and navigate systems to influence service delivery, policy and legislation. Social workers adopt social justice approaches to influence resource allocation in order to address gaps and fragmentation across health and social care. To improve access to quality of care and outcomes for people who receive palliative and end of life care, social work interventions take into account social determinants of health in the context of political and power structures and work to address issues that impact a persons' structural vulnerability and disadvantage (2,3).

Palliative Care Australia (PCA) Services Levels are aligned with State and Territory Department of Health Clinical Services Capability Frameworks that guide health service planning and delivery. The aim of these frameworks is to describe capability criteria that identifies minimum requirements for planning health services including clinical governance systems, scope of practice and credentialing criteria, systems for identifying and managing risk and enhancing patient safety through providing safe quality services (4). An issue with PCA guidelines and State Capability Frameworks is that models to inform service planning ie. Level 1-3 PCA or 1-6 for State Health Depts refer to 'access to allied health.' implicit in these criteria is that social workers, or allied health clinicians in general, have the skills, knowledge and experience in supporting patients with complex needs who are receiving palliative or end of life care. Although palliative care education in allied health is growing in Australia, it remains limited and there is often not organisational support for upskilling qualified social workers (5).

Palliative Care Australia Level 3 services category and Department of Health Level 5-6 Capability Frameworks in some States require clinicians to have extensive experience and skills in palliative care and specialist qualifications. The term specialist is defined as "a non-physician specialist who has had more training in a specific area of healthcare (6). Competencies required by palliative care social workers are outlined extensively in the National Palliative and End-of-Life Care Standards for Social Work, endorsed by Palliative Care Social Work Australia (7). End-of-life care is not part of the social work undergraduate curriculum, additional specialist training is required to expand scope of practice to be able to safely and competently fulfil the tasks required of the role.

Social workers who work in specialist palliative care services have formal specialist qualifications and extended training in palliative, end of life and bereavement care and are considered to be advanced practitioners. Specialist palliative care social workers have advanced knowledge of life limiting illness, disease trajectories and treatment options and complex medico-ethical legal issues and use this knowledge to respond to and pre-emptively anticipate needs and provide psychosocial interventions to mitigate adverse outcomes along the disease trajectory and in bereavement. Social workers have a multidimensional role as clinicians, educators, researchers and advocates and community and sector leaders, providing consultation on end of life policy, practice standards and clinical pathways at state and national levels (7).

The specialist palliative care workforce in Australia is limited in meeting the significant demand for psychosocial care at end of life due to the growing ageing population, the number of people with multiple chronic illness and advancements in medical technology and treatments prolonging life expectancy (7). The need for social workers to be trained in palliative and end of life care is essential, irrespective of the workplace setting or role in which they work. Palliative Care Social Work Australia (PCSWA) was established to support the development of skills and knowledge of generalist social workers and specialist palliative care social workers and enhance quality care to patients and carers/families.

PCSWA is a relatively new organisation and is growing. Membership to date provides an emerging profile of specialist palliative care social workers. For example, 60% of members work in specialist settings, 3% work in private practice representing accredited mental health social workers who provide counselling and mental health support to palliative care patients and/or their carers or family members and 3% work in aged care. It is anticipated that along with social work membership of the specialist palliative care sector, membership by social workers in other sectors who support palliative care patients and their carers/families will continue to grow. Over a third of the members from specialist palliative care services have post graduate qualifications specific to palliative and end of life care or bereavement, with six undertaking PhDs, one undertaking a Masters and two more members in the process of enrolling for higher degree research courses related to this arena. Four members already possess PhDs. Social work membership continues to grow and is anticipated to increase significantly with the launch of State/Territory PCSWA Networks.

Despite the skills, experience and academic backgrounds of social workers in palliative care, there is a notable absence of social work representation at leadership or formal roles at State and National groups. Due to the high level of clinical skills of social workers that lead to significant positive outcomes for patients and carers/families, capturing data on the social work profession in the provision of palliative care is essential and including social work as part of AIHW palliative care workforce would provide more robust data on the psychosocial issues impacting palliative care patients and their carers/families.

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Planning for future workforce requirements *(Improve workforce planning data).*

The recommendations for allied health FTE outlined in Palliative Care Australia (PCA) Service Guidelines is woefully inadequate. According to Apex Consulting who were commissioned to undertake a review of these guidelines highlights that PCA notes there are no national benchmarks on access to palliative care allied health clinicians and that there was no robust basis on which to set national allied health workforce ratios. PCA utilise a population-based approach for recommended allied health FTE based on 100,000 population (1). Workforce planning has been undertaken in Canada and the USA that may provide more accurate information to guide appropriate FTE (2). Recommendations for palliative care social workers include (2):

- ***Community:*** for every six palliative care RNs (150 patients), the program would require one PCSW and that 10% of PCSW time is dedicated to nonclinical responsibilities such as education, administration and research and must be considered in any calculations.

Based on a region with 3,000 deaths per year, 4.5 FTE PCSW is recommended.

- ***Hospital:*** based on an average of 44 referrals per month (532 per year), 1.1 FTE PCSW is recommended.
- ***Consult:*** based on an average of 25 referrals per month, 0.5 FTE PCSW is recommended which should increase by 0.5FTE for every additional 25 referrals.

For a regional community-based specialist palliative care program based on 525 referrals per year, 1.2FTE PCSW is recommended.

- ***Clinics*****:** based on 4 x clinic days per week, 0.6FTE PCSW is recommended.

Although the specialist palliative care sector will not be able to meet demand and there is a need to ensure all social work clinicians working in health are equipped with the skills and knowledge to provide effective and quality palliative and end of life care, there is a need to adequately resource specialist services in Australia with adequate social work FTE such as the social work workforce profile identified in Canada.

1. Apex Consulting. (2017). Palliative Care Service Development Guidelines. [Report].
2. Henderson, J., Boyle, A., Herx, L., Alexiadis, A., Barwich, D., Connidis, S., Lysecki, D. & Sinnarajah, A. (2019). Journal of Palliative Medicine, 22(11): 1318-1323 DOI: 10.1089/jpm.2019.0314 Report Available here: https://www.cspcp.ca/information/reports-publications/

Service and system planning and design

- **Unmet need for palliative care and end-of-life care to support system and service planning**
- **Vulnerable populations**
- **People's preferences and actual place of care and death**

Social workers are well placed to work with people with unmet palliative and end of life care needs as they often work with underserved groups. Social workers have a multi-faceted role in being an agent of change across the health system and in meeting the needs of culturally diverse, marginalised and underserved populations, through education, advocacy and collaboration. PCSWA has developed practice standards for social workers to guide end of life care for marginalised and vulnerable groups such as those with a lived experience of mental illness, developmental and physical disabilities, children, prisoners and the homeless. PCSWA Palliative and End of Life Care Standards reflect Australian contexts, the complex and diverse populations requiring palliative and end of life care and the values and attitudes, knowledge and skills that underpin the social work profession.

Unmet need of people living in rural, regional and remote Australia is also significant. Social workers in these settings provide innovative and holistic interventions to provide the best optimal psychosocial care. Unmet need in populations from low socio-economic areas has demonstrated to be significant in a range of research studies..

Other areas of unmet need relate to family functioning and interpersonal abuse or violence. Providing end of life care where there is complex family dynamics, estrangement, abuse and viodlence is extremely challenging. Social workers are the main discipline who primarily assesses the history of relationships within the immediate and extensive family and explores patterns of behaviour or other factors that enhance capacity or increase vulnerability (1). Older aged patients experiencing elder abuse often live with the person of concern and Australian research has indicated that of 466 episodes of care over a five year period, half of those cases where elder abuse was identified based on system alerts were aged over 80 years and two thirds were from culturally and linguistically diverse backgrounds and a third had cognitive impairment (2). Family conflict can occur in a high number of palliative care patients and family stress or conflict can be attributed to unmet need (3). Often patients disclose intimate details of conflict or abuse and Social workers play an essential role in the safeguarding of vulnerable clients and these issues continue even when a person is dying.

PCSWA reiterates the need for health services and Government to capture social work activity or data that can provide in depth insights into unmet need and to understand the impact of systemic influences on access, receptivity and utilisation of palliative and end of life care services by marginalised and vulnerable population groups (including children, carers, people with intellectual disabilities and communication limitations, people experiencing mental health difficulties, LBGTQI, incarcerated people, refugees and migrants, Aboriginal and Torres Strait Islander people, homeless people and patients where family conflict or stress is significant).

1. Payne, M. (2008) Safeguarding Adults at End of Life: Audit and Case Analysis in a Palliative Care Setting, Journal of Social Work in End-Of-Life & Palliative Care, 3(4): 31-46. DOI: 10.1080/15524250802003265
2. Collins, M. Posenelli, S., Cleak, H., O'Brien, M., Braddy, L., Donley E, & Joubert, L. (2020) Elder Abuse Identification by an Australian Health Service: A Five-Year, Social-Work Audit, Australian Social Work, 73:4, 462-476, DOI: 10.1080/0312407X.2020.1778050
3. Kylie Agllias (2018): A snapshot of Australian social workers in palliative care and their work with estranged clients, Social Work in Health Care, DOI: 10.1080/00981389.2018.1474163

Service delivery and integration

- **Data capture on care at home and in the community**
- **Ease of access, Coordination and transition between services**
- **Data sharing for appropriate and coherent care across services and care settings**

Social workers play a key role in coordinating transitions for patients between services and can reduce health service demand through identifying and removing barriers that impact or limit effective engagement with services, but not when there are limited services in the community.

PCSWA is aware through its members that there is a significant lack of sufficient external referral options beyond the health system to support palliative care patients in the community. Referral pathways to services and supports outside the health system have either not kept pace with the increasingly complex needs of patients or present significant administrative burden that impact access to services in a timely manner, if at all. The complex nature of applications for NDIS and the high rates of palliative care patients under 65 years who are not eligible for NDIS based on their eligibility criteria pose significant barriers to support for patients who wish to remain at home. Although social workers have exceptional advocacy skills, social workers are finding they are having to expend a significantly high amount of time supporting people under 65 years of age to access services and support in the community. There are also extremely limited community aged care packages that are available. Some population groups such as adults with severe intellectual disabilities may experience more difficulty finding services that are able to meet thir needs adequately. The NDIS and MyAgedCare sectors do not meet the needs of palliative care patients, their carers and families and palliative care services are stretched to capacity so the imperative to support care in the home and home deaths is unrealistic without a significant investment. As a result, patients will often require admission or re-admission to hospitals (1).

Palliative Care social workers play a key role in smoothing the transition between settings but in the absence or limited availability of other support services, social workers are spending more time attending to administrative tasks to facilitate care and access to support services rather than meeting care needs requisite of their skill level. Allied Health Social Work Assistants or Welfare Officers would be best place to address administrative tasks enabling social workers to address those with complex needs.

It is not possible to accurately capture the profile of social workers (in specialist palliative care services or broader health and community services) due to the different titles and roles social workers occupy. Linked data across sectors would enable more accurate data on issues related to access and coordination and transition between services. It is also imperative that social workers are included in service delivery and integration to guide what data is helpful to inform policy.

1. Urbis Consultancy. (2018). NSW Health social work workforce horizon scanning and scenario generation final report [NSW Ministry of Health Workforce Planning and Development Branch]. Available Urbis.com.au

Performance and public reporting

- **Improve the quality of existing data**
- **Identify the characteristics of people at the end of life**
- **Monitor the quality and provision of palliative care in the system overall**

PCSWA is aware that social workers provide end of life care in a range of other settings outside specialist palliative care such as general medical, aged care and surgical wards and emergency departments however care type change of patients in hospital to a 'palliative care care type' is ad hoc and in some health sites, rarely occurs. As a result, health services may not be funded appropriately, ultimately impacting service planning through under-resourcing.

As access to services in the community is a current and likely continued issue and barrier to supporting palliative and end of life care in the home, public reporting can promote increased oversight and accountability, particularly in relation to access to NDIS and Aged Care packages. Public reporting on the number of applications to NDIS for palliative care patients under 65 years of age, the timeframe for processing applications and the number of applications that were successful can provide data at a population level that can inform gaps, barriers and trends. PCSWA believe more transparency and public reporting around community aged care services and NDIS can ultimately improve access, performance and public accountability.

PCSWA reiterates the need for health services and Government to capture social work activity or data that can provide in depth insights to understand issues related to access and utilisation of aged care and NDIS services in the community.

PCSWA wish to highlight it is not possible to accurately capture the profile of social workers in health and community services due to the different titles and roles social workers occupy. Linked data across sectors would enable more accurate data on issues related to access and coordination and transition between services.

Understanding

- **Data is easily understood and accessible to improve understanding**
- **Data supports meaningful discussions and informed and shared decision making**
- **Data is appropriately shared**

PCSWA agrees that a framework for national data is essential and that clinicians and consumers should inform priorities and what data is relevant and helpful. Data on palliative care social workers can enable significant contributions to insights on psychosocial needs and access and equity of resources.

PCSWA agrees that community understanding of palliative care is required however this needs to be broadened to health professionals and those service providers in other organisations who support palliative care patients, their carers and families. Palliative Care clinicians who are best placed to raise awareness due to their experiences and insights often have limited capacity to engage in community or professional education and seminars so need to be supported to be able to do this.

There are many professionals and organisations who provide information and education on Advance Care Planning and support patients to complete these. There are challenges however on how ACPs are stored and made easily accessible to clinicians in local health sites.

The availability of PROMs and PREMs data linked with other cross- sector data such as NDIS and aged care service providers discussed in previous points above, can provide key metrics on which patients and families can identify options in their areas and inform decision making.

The data described above can be shared with the public and presented in easy to read formats and suites of data reports can be made available to the public similar to the suite of reports provided by PCOC. Additionally, access to data by clinicians and health services can better inform service planning.

Overall Feedback

Do you support the overall content in this document?

What is your overall feedback on the draft National Palliative Care and End -of-Life Care Information Priorities document?

PCSWA agrees that The Priorities outlined in the document provides a sound framework for information needs of palliative care patients and their carers/families in the future.

PCSWA advocates that social work is a key profession whose activity and workforce profile needs to be included within data capture systems. The contribution of social work to data and information systems can help to identify unmet needs, care provided to vulnerable and underserved populations and patient complexity that can inform specialist social work education and training requirements.

PCSWA also advocates that the use of technology in the provision of psychosocial care needs to be reported on. The use of telehealth and other technologies in the provision of psychosocial support will increase however issues of connectivity, technological equity in terms of access to virtual support and computer literacy of patients, carers and clinicians are areas that need to be factored in to information systems in the future as this will