Palliative Care
NEW SOUTH WALES

Homelessness and Palliative Care

A Scoping Study in Metropolitan Sydney

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Introduction

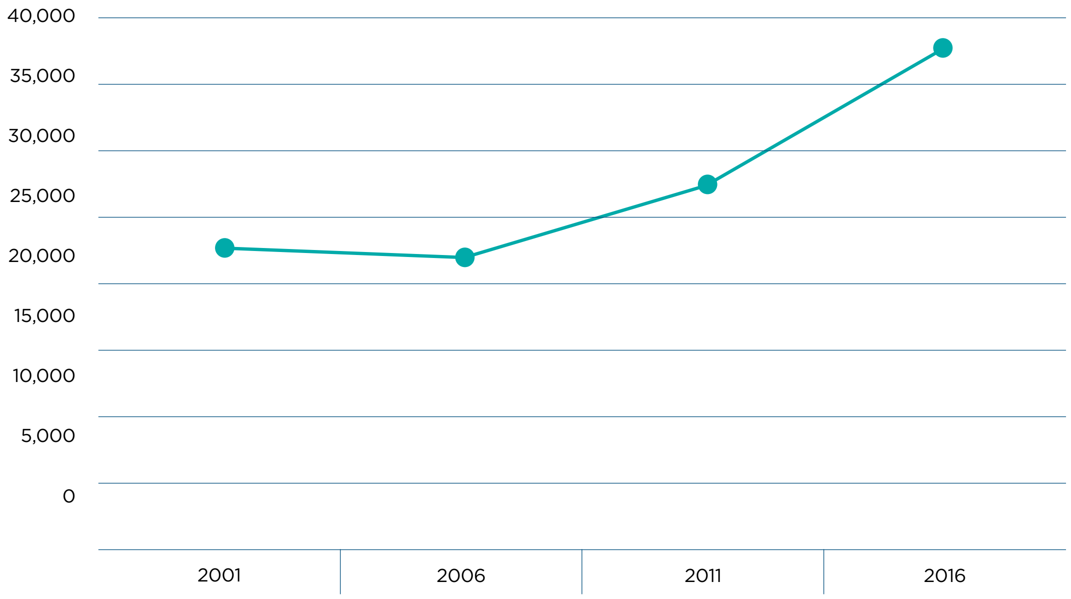
As part of a National Project funded by Palliative Care Australia (PCA), Palliative Care NSW (PCNSW) completed this scoping study to examine the availability and accessibility of Palliative Care services for homeless individuals within Metropolitan Sydney. PCNSW hosted a Homelessness and Palliative Care forum with key stakeholders from health and homelessness organisations, in order to identify the barriers that inhibit or prevent access to Palliative Care by those experiencing homelessness. This study also seeks to improve access to high quality Palliative Care for homeless individuals, with a particular focus on the disconnections which exist between health and social services, the barriers which impact the provision and reception of Palliative Care, and the importance of person-centred care within this discussion. To date, there is little available data illustrating the current measures taken when a homeless individual requires Palliative Care.

The International Association for Hospice & Palliative Care (2018) defines *Palliative Care* as "the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life". As suggested within the *Exploratory Analysis of Barriers to Palliative Care: Issues Report on People Experiencing Homelessness*, Palliative Care should "be strongly responsive to the needs, preferences and values of people, their families and carers; be available to all people with an active, progressive, advanced disease, regardless of diagnosis; and affirm life while recognising that dying is an inevitable part of life" (Australian Government Department of Health and Aged Care, 2019). Palliative Care is recognised as a human right under Article 12 of the *International Covenant on Economic, Social and Cultural Rights* (United Nations General Assembly, 1966), which outlines the broader human right to health. The World Health Assembly (2014) also determined that Palliative Care is "an ethical responsibility of health systems", and that the integration of such care into health systems is "essential for the achievement of the Sustainable Development Goal on universal health coverage" (Yamamoto, 2018).

There is no single definition of homelessness, due to the complex nature of the topic. For the purposes of this scoping study, Mackenzie and Chamberlain's (1992) cultural definition of homelessness is used. This definition focuses on three main types of homelessness: primary, secondary and tertiary homelessness. The Australian Bureau of Statistics (2012) further defines homelessness as the lack of one or more elements which form a 'home'. These elements can include, but are not limited to, "a sense of security, stability, privacy, safety, and the ability to control living space" (Australian Bureau of Statistics, 2012). Therefore, the term homelessness is not only used to describe individuals experiencing primary homelessness, but also those who are currently residing in temporary or inadequate housing.

The number of homeless individuals within New South Wales has steadily increased throughout recent years. According to the 2016 *Census of Population and Housing: Estimating Homelessness* (Australian Bureau of Statistics, 2018), there were an estimated 37,715 homeless individuals within New South Wales during 2016. As depicted within *Graph 1*, this number has increased by 14,674 individuals since 2001 (Australian Bureau of Statistics, 2018), with the steepest incline occurring between 2011–2016. However, it is also important to recognise that this latest estimated data on the homeless population within New South Wales is from 2016, and therefore there may have been similar increases in the years following. As the number of homeless individuals within New South Wales increases, so too will the need for care within these populations.

Graph 1. Estimated number of homeless individuals in NSW (2001–2016)



(Australian Bureau of Statistics, 2018)

Individuals who are homeless typically face a complex range of issues which impact their health and wellbeing. Homeless individuals face higher rates of health issues and premature death than non-homeless individuals (Smith, 2019). Death resulting from ‘unknown causes’ occurred “60 times more frequently for those who were homeless” (Smith, 2019), with the average life expectancy for homeless individuals being only 47 years of age (Konduru, 2019), which is significantly lower than the Australian national life expectancy of 82.8 years (Australian Institute of Health and Welfare, 2022). Premature deaths amongst homeless populations can often be attributed to illness, as such individuals "suffer the same illnesses experienced by people with homes, but at rates three to six times higher" (Smith, 2019). These illnesses are often "rooted in the circumstances of homelessness: poor nutrition, poor hygiene, stress, and exposure to extremes of heat and cold" (Smith, 2019). Premature deaths can also be related to "adverse life events", as occurrences of suicide, accidental overdose, homicide and life-threatening accidents are significantly higher amongst homeless populations (Smith, 2019). The increased exposure to death which results from such occurrences can lead to significant trauma amongst homeless individuals, as they are faced with the threat of premature death to both themselves and those within their communities (Kenney, 2019). Such trauma can substantially impact the likelihood of these individuals seeking the healthcare they require, and this extends to Palliative Care.

Homeless individuals face unique barriers to accessing Palliative Care services. People experiencing homelessness often prioritise their day-to-day needs, such as food, shelter and personal care, rather than addressing less immediate concerns, such as more complicated health care (Australian Government Department of Health and Aged Care, 2019). Access to Palliative Care services can also be impacted by unstable living environments, in which prerequisites of permanent residences or particular housing standards may prevent individuals from receiving the care they need (Australian Government Department of Health and Aged Care, 2019). The prevalence of mental health issues and substance use amongst individuals experiencing homelessness also impacts their access to Palliative Care services, as well as "disparities in social status – including lifestyle and education level", "fear of stigma and judgement" and "distrust of institutions and authority" (Australian Government Department of Health and Aged Care, 2019).

While there is an existing demand for Palliative Care services amongst people experiencing homelessness within Metropolitan Sydney, information regarding current services is limited. A forum, attended by key stakeholders within the homelessness and Palliative Care sectors, provided insight into their experiences regarding the accessibility of Palliative Care services.

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Method

In March 2022, Palliative Care NSW (PCNSW) hosted a forum of key stakeholders in the Palliative Care and homelessness sectors within Metropolitan Sydney, supported by Palliative Care Australia (PCA). Similar scoping studies have been conducted within each State and Territory throughout Australia to gather information as part of the National Project.

The participants of the forum (n=20) were considered to be key stakeholders within the area of study, and all had professional backgrounds in health and social services within New South Wales. These organisations mainly consisted of Palliative Care services, homelessness services, hospitals, non-government organisations and charities. The roles of the participants included managers of homelessness programs, registered nurses, bereavement counsellors, clinical nurse consultants, social workers, and general practitioners. Examples of specific organisations which took part in the forum include St Vincent's Homeless Health, City of Sydney, HammondCare, RPA Hospital and Homelessness NSW, as depicted within *Table 1*.

PCA provided a list of set questions which needed to be addressed within the forum, as depicted within *Table 2*. The questions focused on the participants' experiences with death and dying amongst the homeless population in Metropolitan Sydney. Invitations were emailed to relevant services within these fields, and attendance was confirmed prior to the forum. Participation in the study was voluntary, and participants were ensured anonymity and confidentiality throughout the study.

The forum consisted of roundtable discussions and individual reports from stakeholders within the Palliative Care and homelessness sectors. Presentations were delivered by several recognised health professionals, which focused on the experiences of homeless patients within Metropolitan Sydney who have required Palliative Care, and the difficulties faced by health practitioners when providing care for these patients. The presentations provided context surrounding the obstacles of accessing Palliative Care by homeless individuals living with a life-limiting illness, and instigated valuable group discussions by encouraging attendees to consider their own experiences. The participants were seated across four tables and provided with pens and paper to engage in collaborative brainstorming. The data was collected through a combination of audio and visual recordings, group answers during discussions, and individual notes which were taken throughout the day.

Secondary research was used to establish an initial foundation for the study, and a literature review was conducted to summarise key information prior to the forum. This included scholarly articles and reports on the topics of Palliative Care and homelessness; Australian state and federal reports; and international case studies which mirrored the occurrences being investigated, such as Dr Naheed Dosani's *Palliative Education and Care for the Homeless* (PEACH) project in Canada (Inner City Health Associates, 2022). Upon the completion of the forum, further study was conducted to explore the themes raised by the PCNSW Forum Participants in greater depth.

Table 1. Organisations in attendance at the 2022 PCNSW Homelessness and Palliative Care Forum

Participating Organisations

- St Vincent's Homeless Health
- Homelessness NSW
- Public Interest Advocacy Centre and Street Care
- City of Sydney
- Mount Druitt Supportive & Palliative Care Unit
- SESLHD Southern Sector
- Salvation Army
- Royal Prince Alfred Hospital
- Mission Australia
- HammondCare
- GPCanShare
- Canterbury Hospital

Table 2. PCA Questions for 2022 Forum

Forum Questions
1. Do you know of homeless people that have died (e.g. when they were part of your service)?
2. Can you describe what those deaths have been like in terms of supports and Palliative Care?
3. Are there any models that are working well in the jurisdiction which specifically provide Palliative Care to people who are homeless?
4. What Palliative Care outreach services that already exist in your jurisdiction could be extended to support homeless people?
5. What are the existing linkages between health and social services in your jurisdiction?
6. What are the specific barriers you know exist in your jurisdiction that prevent homeless people accessing appropriate Palliative Care?
7. What are the specific investments you see are essential to support homeless people access Palliative Care when they need it – and who should be making this investment?

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Preliminary Findings

This project aimed to identify services providing Palliative Care to homeless individuals within Metropolitan Sydney. There was a consensus amongst forum participants surrounding the lack of services available to provide this type of care, despite the increasing rates of homelessness and the correlated increase in the need for such services. The majority of participants either weren't aware of existing services or had minimal knowledge of the procedures to be followed if they encountered a person approaching end-of-life while also facing an insecure housing crisis. Three main issues arose from discussions: the disconnections between health and social services; barriers to the provision and reception of care; and how the concept of person-centred care could serve this population.

The literature review and forum responses highlighted the difficulties experienced by homeless individuals in need of Palliative Care. While there are some services available within Metropolitan Sydney providing general health care or assistance to the homeless, services specialising in both homelessness and Palliative Care are essentially non-existent. The health services that do provide general support often struggle to provide adequate Palliative Care to patients when required, primarily due to a lack of expertise and inflexible models of care. As a result, it is not unusual for homeless patients requiring Palliative Care to instead find themselves in places which are not appropriately equipped to provide holistic end-of-life care, such as hospital emergency departments (PCNSW Forum, 2022).

The personal experiences discussed by the participants showed cause for concern. One of the most impactful statements from the forum highlighted the need for critical improvements within this sector:

> *"There is a responsibility to provide Palliative Care to whoever you are, whoever wants it, whoever needs it … and we're not doing that."*
>
> – PCNSW Forum Participant, 2022

Question one and **question two** (*Table 2*) discussed whether the participants had encountered homeless individuals who had died while in the care of their service or organisation, and which Palliative Care services were available to these patients. The majority of care providers had encountered such a situation, though there was little support available to them to help care for these patients, particularly in regard to accessing specialised Palliative Care services.

Disconnections between services

One of the most notable themes to emerge throughout the forum discussions was the issue of the severely fractured connections that exist between the health and social services catering to those experiencing homelessness. As a result, the homeless patients these services encountered often "fell through the cracks following their care" (PCNSW Forum, 2022), preventing them from being identified as palliative or being properly supported through their end-of-life journey. An overall lack of understanding of the role of Palliative Care within homelessness services was also evident. This was another barrier to recognising patients early on in their illness trajectory as well as knowing where to direct them for specialised care and support.

Question three (*Table 2*) discussed effective models that specifically provided Palliative Care to homeless individuals within the jurisdictions of the participants. It became apparent that many of the participants were not aware of Palliative Care services specifically catering to homeless individuals. Many forum participants noted that the main access point to healthcare for many homeless people is the emergency department. This is problematic due to the transient care provided in these settings. High quality Palliative Care and long-term care cannot be provided in emergency departments or even general hospital wards in most cases, again exacerbating the already limited care these people receive at the end of their lives.

> *"Where are homeless individuals spending the last six months of their lives and where are they dying?"*
>
> *"I'm not sure anyone really knows."*
>
> – Conversation between PCNSW Forum Participants, 2022

Question four (*Table 2*) delved further into this topic, assessing the Palliative Care outreach services already in existence within the participants' jurisdictions. Similarly, the majority of participants were not familiar with any Palliative Care outreach services, but rather general homelessness services and programs. While some participants were aware of aged care and health services such as HammondCare and the St Vincent's Hospital outreach program, it was understood that these services were often limited in the care they were able to provide. Participants explained that members of the homeless community were also typically unaware of the existing Palliative Care services which are available to them. There were discussions on how to improve the way such information is communicated across a community when the individuals can prove difficult to contact (PCNSW Forum, 2022).

When discussing **question five** (*Table 2*) there was an overall sense of dissatisfaction amongst stakeholders in the room who had witnessed the lack of linkages between social and health services firsthand. Feelings of frustration and disappointment were expressed by the participants, due to their inability to source care for these patients, despite their best efforts.

> *"Everyone is genuinely concerned, but it's not a well-coordinated system. There are pockets of care. Overall, it could be done so much better. Even [in regard to] links with Palliative Care [and homelessness]."*
>
> – PCNSW Forum Participant, 2022

The forum itself provided some of the participants with information about connections that could be made between services for homelessness and services for Palliative Care. As many of the participants were previously unaware of such services, this was certainly a positive outcome of the forum.

Barriers to care

While addressing **question six** (*Table 2*), the participants highlighted a number of barriers they had faced while attempting to provide Palliative Care to homeless patients. Organisations that could provide Palliative Care to these individuals often had strict criteria for patient entry, creating barriers for those attempting to provide care for patients in need, as well as for the patients themselves. Some of the criteria across various services included: patient age limits, narcotic and other drug bans on-site, regulations requiring Medicare cards and the requirement of referrals in order for patients to be accepted into specialised services. While some of these restrictions initially appear to be of little issue, they create significant hurdles for many people experiencing homelessness due to their complex care needs and insecure living situations. Multiple participants recounted times when they were forced to either deny a homeless person the Palliative Care services they required, or break the rules of their organisation in order to provide the health care they are committed to delivering. Health providers acknowledged that although they were putting their job at risk, they felt they were unable to refuse medical care to a person in need (PCNSW Forum, 2022).

The age limits currently enforced within some services can result in patients who do not meet these specific requirements being refused the care they seek. Palliative Care services are often targeted towards older patients, although terminal illnesses can occur at any stage of life. As a result, those who are younger, homeless and faced with a life-limiting illness can struggle to find a service to care for them. One participant from an organisation specialising in aged and Palliative Care noted that while care would be provided for patients over 60 years of age, there was a "huge resistance to placing people [in the service] under-aged", even if the facilities were available for use (PCNSW Forum, 2022). The participant further explained that "exceptional circumstances" were required to admit younger patients, and although this would occasionally occur, applicants would expect to be rejected initially before being seriously considered for admission (PCNSW Forum, 2022).

The 2016 *Census of Population and Housing: Estimating Homelessness* (Australian Bureau of Statistics, 2018) estimated that out of 37,715 homeless individuals within NSW (*Table 3*), only 16.9%* of this population were between the ages of 55-75 and over (*Table 4*). Despite this age category representing less than one quarter of the homeless population within NSW (Australian Bureau of Statistics, 2018), the Palliative Care services available within Metropolitan Sydney appear to be mainly targeted towards this particular demographic. Palliative Care services need to adjust some admission criteria if they are to effectively accommodate the unique needs of younger homeless people facing unexpected terminal illnesses. Alternatively, services could be developed which specifically cater for this younger demographic instead, with a particular focus on individuals between the ages of 18-65 years. This could provide an adequate solution, as children's hospice services such as Bear Cottage (Sydney Children's Hospital Network, 2022) typically provide care for patients up to around 18 years of age, and aged-care facilities are now expected to provide care for individuals 65 years and older, in line with the Australian Government Department of Health and Aged Care (2022) targets.

* This percentage was developed by combining the percentages from the Age Group categories of '55-64', '65-74' and '75 and over' as depicted within Table 3. For clarity, this can also be seen in Table 4 as the 'Older' age category.

Table 3: NSW Homelessness by Age Groups (2016)

Age Groups	**Number of Homeless Individuals in NSW (2016)**	**Percentage of Total**
Under 12	3,963	10.5%
12–18	2,677	7.1%
19–24	6,365	16.9%
25–34	8,715	23.1%
35–44	5,041	13.4%
45–54	4,537	12.0%
55–64	3,626	9.6%
65–74	1,939	5.1%
75 and over	846	2.2%
Total	**37,715****	**100%*****

**The data of 6 individuals is missing from the dataset due to the confidential nature of the data, therefore the 2016 total is only 37,709, although officially being listed as 37,715.

*** Total percentage = 99.9% due to missing confidential data, although officially listed as 100%.

(Australian Bureau of Statistics, 2018)

Table 4: NSW Homelessness Age Groups (2016) Condensed

Age Groups	Percentage of Total
Younger (Under 12 + 12–18 + 19–24)	34.5 %
Middle (25–34 + 35–44 + 45-54)	48.5%
Older (55–64 + 65–74 + 75 and over)	16.9%%
Total	**100%******

**** Total percentage = 99.9% due to missing confidential data, although officially listed as 100%.

(Australian Bureau of Statistics, 2018)

The restriction of narcotic and other drug use on the premises of services providing Palliative Care to homeless individuals also contributes to the problem of exclusion, as patients can find themselves prevented from receiving Palliative Care even when it is otherwise accessible. There is a strong correlation between addiction to drugs and alcohol, and rates of homelessness within Australia (Australian Institute of Health and Welfare, 2022). Although a complicated issue to manage, these restrictions can cause extreme difficulties with securing and maintaining Palliative Care services for homeless individuals struggling with addiction. As a result, addiction, mental health issues and complex trauma can often mean that homeless people at the end of their life are excluded from most mainstream health and Palliative Care services, often due to social disturbances with other patients or residents (PCNSW Forum, 2022). This leads to a tendency for people to be transported to emergency departments at a time of crisis, or they will likely die on the streets.

Regulations requiring homeless patients to have access to their Medicare details and referrals in order to access Palliative Care services, create further barriers to the provision of care. Participants discussed the difficulties associated with maintaining personal health records and accessing individual medical assessments while homeless. Such obstacles are not often considered when regulations regarding these policies are formed, further restricting these patients from accessing care which they would otherwise be able to. Forum attendees acknowledged that there is an inherent willingness by service providers to assist these individuals, yet this willingness to help is often prevented by these systemic barriers and strict policies (PCNSW Forum, 2022). As a result, issues of inclusivity and accessibility within the healthcare system regularly prevented homeless people from having their illnesses adequately managed.

Person-centred care

A recurring concern throughout the forum was the concept of person-centred care, which the respondents believed should be the focus of all palliative and homelessness care. However, participants discussed the fact that the care provided to homeless individuals did not often undertake a holistic approach, resulting in further trauma and disconnection experienced by the patients.

Person-centred care focuses on working with the patient to establish what is most important to them, as well as maintaining mutual respect and trust (Australian Commission on Safety and Quality in Health Care, 2022). This concept is "widely recognised as a foundation to safe, high-quality healthcare" (Australian Commission on Safety and Quality in Health Care, 2022), and aims to provide patients with ideal experiences throughout their care. A holistic approach to care is also recommended by NSW Health, which considers the physical, emotional, social and spiritual wellbeing of a patient (NSW Health, 2020). The following quote, presented within the PCNSW Forum (2022), highlights the importance of maintaining person-centred care for all patients due to their vulnerability:

> *"Unfortunately, in end-of-life care, we do not have a vocal constituency: the dead are no longer here to speak, the dying cannot speak, and the bereaved are often too overcome by their loss to speak."*
>
> – Dr. Harvey Chochinov, 2000 (Brennan and Gwyther, 2021)

Participants agreed that homeless patients are seldom provided with the same person-centred and holistic approaches to care as the non-homeless patients they have encountered (PCNSW Forum, 2022). Due to the homeless individuals' circumstances, they often do not have the same ability to advocate for themselves in the ways that non-homeless patients are able to. Participants also stated that there is not enough flexibility within these services to provide holistic care to homeless patients (PCNSW Forum, 2022). As a result, the aspects of care which are considered to be of high importance to individual patients are not often provided.

Participants discussed the social wellbeing of homeless individuals when faced with Palliative Care for themselves or members of their community. One stated that "relationships are the most important thing" to homeless individuals, highlighting the desire patients often have to maintain their social connections throughout their care (PCNSW Forum, 2022). Another participant addressed the concept of companionship within these settings, highlighting the traumas which occur when homeless communities are "faced with friends dying", and the "massive hole" left within the community as a result (PCNSW Forum, 2022). It was further stated that the social wellbeing of homeless patients is "not addressed" amongst the current services for homelessness and Palliative Care, although the participants considered this issue to be of significant importance (PCNSW Forum, 2022).

The emotional wellbeing of patients was also not often prioritised, leading to discomforts which were out of their control. Participants discussed how “models of care are not trauma informed”, which is problematic due to the prevalence of trauma experienced by homeless patients (PCNSW Forum, 2022). Homeless individuals may also have had previous negative experiences with health care services, leading to an “individual fear of engaging with healthcare” (PCNSW Forum, 2022). Healthcare providers who do not specialise in providing Palliative Care may also find it difficult to do so, due to the extreme complexity of such care. Managing a progressing illness, while also providing comfort and holistic care to a dying individual is incredibly difficult, even when provided with the best specialised training and facilities available.

A study examining the experience of general practitioners (GPs) when tasked with providing Palliative Care to home-based patients found that “31% [of GPs] lacked confidence in providing this care because of patient complexity, inadequate training and insufficient resources” (Le et al., 2017). While this example relates specifically to GPs and non-homeless patients, it provides evidence of the difficulties faced by healthcare workers who are required to provide Palliative Care when not specialising in that form of care. It could then be assumed that this task would prove even more difficult when faced with an individual with no permanent residence and possible complex trauma.

The cultural and spiritual needs of patients were also often overlooked, causing further distress amongst individuals. A participant explained that one of the first things asked of a Palliative Care patient is “Where would you like to die?” (PCNSW Forum, 2022). This question is not often asked of homeless patients, who are rather placed in whichever service is first available. A participant further outlined that this becomes especially concerning when the patient is a First Nations individual who wishes to return to Country for cultural, spiritual or emotional reasons (PCNSW Forum, 2022). This participant had encountered such an instance, stating that returning the patient to their desired place “did not need to be this difficult” (PCNSW Forum, 2022), as there were many barriers which prevented an easy relocation. The participant further stated that health services need to be “more aware, more attuned” to the cultural needs of homeless patients, and that health services need to “have that awareness so that this is always part of the discussion” (PCNSW Forum, 2022).

Opportunities for Improvement

Prior to this study, there was little awareness surrounding the availability and accessibility of Palliative Care services for those experiencing homelessness within Metropolitan Sydney. Through the forum, it became clear that those involved in healthcare and homelessness organisations were typically unaware of the policies that should be followed when such a situation occurs. This appeared largely due to procedural obscurity at organisational and governmental levels. This widespread lack of awareness can result in additional pain and suffering for the homeless individuals who find themselves unable to access necessary care.

While addressing **question 7** (*Table 2*), the participants discussed methods which could improve the inadequacies of current services. There was a heavy focus on further developing services that specialise in Palliative Care for homeless individuals, as well as improving connections between general health, Palliative Care and homelessness services. With greater networking and collaboration between services, healthcare providers would be able to better care for their patients in optimal environments. In particular, there was a collective desire to ensure that hospital emergency departments are no longer the main provider of Palliative Care for homeless individuals.

The services that do exist face availability and accessibility issues, which also need to be addressed. As highlighted throughout the forum, services specifically providing Palliative Care are often restricted by age limits and other exclusions based on demographics of the general population, essentially excluding homeless people from accessing care. In response to this issue, it was suggested that these restrictions be re-examined, with the goal of extending and establishing greater services to cater to a broader range of patients in need (PCNSW Forum, 2022).

Collectively, the participants displayed a strong desire to improve service delivery to the homeless population, and intended to take the findings of the forum back to their individual organisations. The forum successfully engaged key members of the health and social sectors in Metropolitan Sydney, and the data collected will provide valuable insight throughout the development and improvement of Palliative Care services for homeless populations within the area. It is imperative that these issues are addressed within NSW, and it is hoped that this study will lead to significant changes in the provision of Palliative Care within the homeless community.

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