Palliative Care New South Wales

Volunteer Services Support Program

Tracking the post-COVID recovery of palliative care volunteer services in NSW

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Suggested citation:

MacDonald, J. & Bowman, K. (2024). *Tracking the post-COVID recovery of palliative care volunteer services in NSW*. Palliative Care NSW, Sydney.

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Executive summary

VOLUNTEER SERVICE CAPACITY

There are **1,049 active volunteers in NSW** working across **38 palliative care volunteer services**

30 services are active in **community settings**

21 are active in **inpatient settings**

11 are active in **residential aged care**

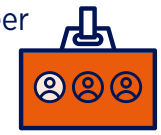
19 are active in **other capacities** such as biography and life stories, or non-client facing roles such as fundraising and administration.

Since 2022, active volunteer numbers have increased by **40%**

The total volunteer hours worked in 2024 was **66,495**

15% of palliative care volunteer services in NSW either closed permanently or have not resumed operations since 2022.

Nearly **one third** of volunteer workforce was inactive.



Almost **HALF** of our services have not yet returned to their pre-COVID capacity.

of services said they were still operating with restrictions on volunteer activity.

RESUMPTION OF SERVICE

Barriers to service resumption:

Risk of infection and changing landscape of policy directives.

High staff turnover and interruptions to referral pathways.

Significant drop in the number of available volunteers.

Volunteer Managers were split

on whether their volunteers could or could not have resumed activity safely sooner than they did.

HALF of Volunteer Managers were **consulted in decision making** regarding the resumption of volunteer activity.

LOOKING AHEAD

82%
of Volunteer Managers are feeling optimistic about the future of their service.

80% of services
are planning to recruit more volunteers in the next 12 months.

Challenges to meeting the future needs of clients:

Recruitment
Restoring a volunteer workforce that aligns with community needs.

Promotion
Educating staff and community members about the volunteer role.

Referrals
Are appropriate and timely, reestablishing referral pathways.

Leadership
Volunteer Managers have enough time and resources to manage the needs of their service.

Palliative Care NSW and the Volunteer Services Support Program

Palliative Care New South Wales is a member-based organisation and state peak body that promotes access to equitable and quality palliative care. Palliative Care NSW empowers the broader community and health professionals, providing resources needed to assist with quality palliative care service delivery.

The Volunteer Services Support Program (VSSP) is funded by the NSW Ministry of Health. As a part of Palliative Care NSW, it champions palliative care volunteering across the state. The VSSP regularly conducts research to help inform service delivery and work towards building capacity in the sector. In addition to research, the VSSP supports volunteer services, volunteer managers, and palliative care volunteers through resourcing, education, and fostering professional networks (PCNSW, 2023).

Palliative care and volunteering

Palliative care addresses the psychosocial, spiritual and physical needs of people diagnosed with a life-limiting illness and supports carers and families (PCNSW, 2024). Palliative care is recommended for patients that are at risk of dying within the next 12 months. This approach encourages conversations about the dying process and focuses on delivering active comfort care while alleviating distressing symptoms (Department of Health. Victoria, 2023). The World Health Organisation regards palliative care as a human right and recommends it be integrated into national health services (WHO, 2020).

Palliative care volunteers provide valuable support to people managing life-limiting illnesses, their families, and their carers offering much-needed comfort and companionship. Volunteers bring ease and dignity to those in need, and their efforts remind us of the power of human connection and empathy. They offer not just help but warmth, compassion, and a listening ear, making a world of difference every single day.

Volunteers provide psychosocial support, carer respite, grief and bereavement support. They might take a client out for a coffee or a walk, write a biography or life story, help transport people to appointments, or be present at memorial services. A public health approach to palliative care views the community and volunteers as equal partners in the complex task of providing quality healthcare at the end of life.

Palliative care volunteers are highly trained and are active across inpatient settings such as specialist palliative care units and other hospital wards, within the community visiting people at home, and in residential aged care facilities. Some volunteers do not have client-facing roles and instead work behind the scenes fundraising, providing linen or other home care equipment (Bowman, 2022).

About this research

Background

Palliative Care NSW began the systematic mapping of palliative care volunteer services in 2014 following the NSW government's commitment of an additional $35 million to improve access to care and support for people who are dying, their families, and carers. This initiative prompted the creation of *A Snapshot of Palliative Care Volunteering in NSW 2014* (Hansen & Huntir), the first research report to address the lack of information on volunteer services in NSW.

Additional Snapshot research was undertaken in 2018 (Bowman & Huntir) and again in 2022 (Bowman). To ensure a longitudinal understanding, PCNSW will continue to conduct this research every four years. The Snapshot reports provide important insights on service delivery and serve as a vehicle to measure change within the palliative care volunteering sector.

2022 Snapshot and the impact of COVID-19

The 2014 and 2018 Snapshot reports both indicated growth in the palliative care volunteer sector. Data from the 2018 Snapshot indicated that the number of active volunteers had increased by 33% in the past 4 years.

Unfortunately, the 2022 Snapshot captured the direct fallout from the COVID pandemic. COVID-19 had a dramatic impact on health services, with most volunteer services completely ceasing or severely restricting operations for periods of time between 2020 and 2021.

During COVID, service delivery fell significantly, with only 53% of services managing to transition their volunteers into supporting clients remotely. In 2022, palliative care volunteer services showed an alarming 54% decline in active volunteers from 2018 and a 22% decline from 2014 numbers.

Service restrictions altered volunteer roles, procedures, and activities. Services were subject to varying operational restrictions depending on their Local Health District and current COVID alert levels. This meant that volunteers performing the same tasks across NSW operated under differing constraints and risk assessments.

At the time of the 2022 Snapshot, only 5 out of 43 known volunteer services were operating at pre-COVID levels. By 2024, COVID restrictions on service had significantly eased and more research was necessary to gauge the extent to which services had recovered.

Aim

This research aims to map the current extent and activities of palliative care volunteer services in NSW, tracking the health and recovery of the sector since COVID restrictions. It seeks to identify lingering barriers resulting from the lockdowns and ramifications for the sector. In addition, this research will add to insights gathered during previous Snapshot research.

Tracking the post-COVID Recovery of Palliative Care Volunteer Services in NSW seeks to understand how the palliative care volunteer sector is recovering post-COVID and whether the new activities and procedures introduced during the pandemic are revealing lasting benefits or ongoing challenges.

Scope

To emphasise recovery efforts and compare mapping data, research participation was restricted to the 45 volunteer services previously identified in the 2022 Snapshot report.

Since our last survey in 2022, three volunteer services have closed permanently, and four remain inactive or have not resumed operations. There are 38 volunteer services in NSW. This study was able to collect responses from 37 palliative care volunteer services.

Interviewing volunteers or people diagnosed with a life-limiting illness, carers, and families was beyond the scope of this project.

Method

Research was undertaken from March to June 2024, employing a mixed methods approach to gather data. Purposive sampling ensured volunteer managers from previously identified palliative care volunteer services were selected. Data was collected by interview survey and compared with data captured in previous Snapshots.

Volunteer managers were contacted with an introductory email, inviting them to participate in the study. Online booking software enabled respondents to select an interview time. Follow-up emails and phone calls were made to schedule interview times with respondents that did not reply to ensure the full cohort was included in the study.

Survey questions were provided in advance to allow respondents to gather relevant information and minimise interview time. Interviews were conducted primarily on Microsoft Teams, where transcription software allowed for precise data collection. Telephone interviews and email responses were accepted in cases of internet unavailability or when data revision was needed.

A structured survey of 26 questions was used as the data collection tool, with a mix of closed, scaling, probing, and open-ended questions. Questions were chosen to compare with previous Snapshot data, measure service activity, and provide insights into post-COVID recovery. On average, interviews took 30 minutes.

Responses were entered into Survey Monkey for analysis. Quantitative data was analysed to identify trends. Qualitative data underwent thematic analysis (Boyatzis, 1998) and inductive coding (Crabtree & Miller, 1999) to identify common themes and patterns.

By combining current survey data with previous Snapshots, the study provides a comprehensive view of the sector's recovery. The design highlights both measurable changes and personal narratives illustrating the experience of operating palliative care volunteer services in post-COVID NSW.

A limitation of this research is the use of inductive reasoning for thematic analysis, which generalises findings from observations. As the research was conducted with NSW services, findings may not apply to other states or countries.

Findings

Measuring service delivery

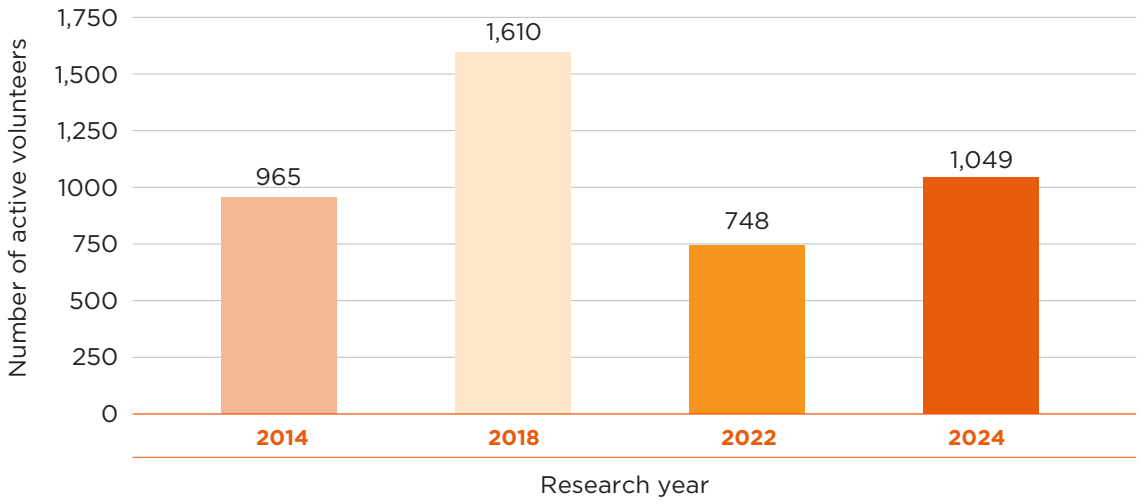
This research aims to track the recovery of services post-COVID. Data were compared to figures collected in 2022, when service delivery was greatly impacted by COVID restrictions.

Of the 45 palliative care volunteer services previously identified in the 2022 Snapshot report, only 38 were active during this research period, showing an activity rate of 84%.

Services operate in a variety of settings. 30 services operate in community settings, 21 in inpatient settings, and 11 in residential aged care facilities. Biography or life stories programs are in place at 13 services. 14 services are active in non-client-facing roles such as fundraising, administration, and equipment hire.

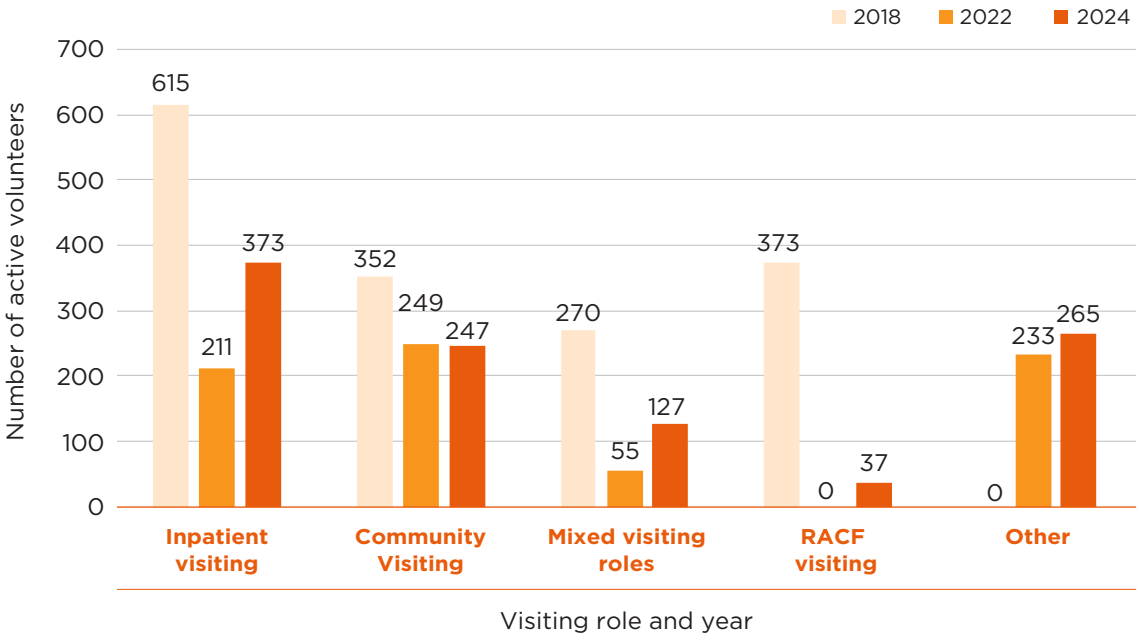
There are currently 1,049 active palliative care volunteers in NSW across these various settings. This represents a 40% increase in active volunteers as recorded in 2022 during COVID restrictions.

Figure 1. Numbers of active volunteers by year



We can further break down these active volunteer numbers into the types of roles in which they are active and compare them to numbers from previous snapshots. This time, data on biography and bereavement-specific volunteers has been identified separately to represent the growth in these activities. In previous studies, it was included under 'other'.

Figure 2. Active volunteer numbers by role and year.



Findings show that since 2022 during COVID restrictions, inpatient visiting volunteers have increased by 77% while community visiting volunteer numbers have remained relatively stable. However, this is still a 39% decrease from the 2018 peak. Interestingly, while the majority of services operate in community settings, the largest number of volunteers are active within inpatient settings.

Volunteers who are known to a service but have not performed duties in the last 6 months are considered 'inactive'. This category was prevalent during the COVID 2022 Snapshot, with 516 volunteers—41% of the total—being inactive.

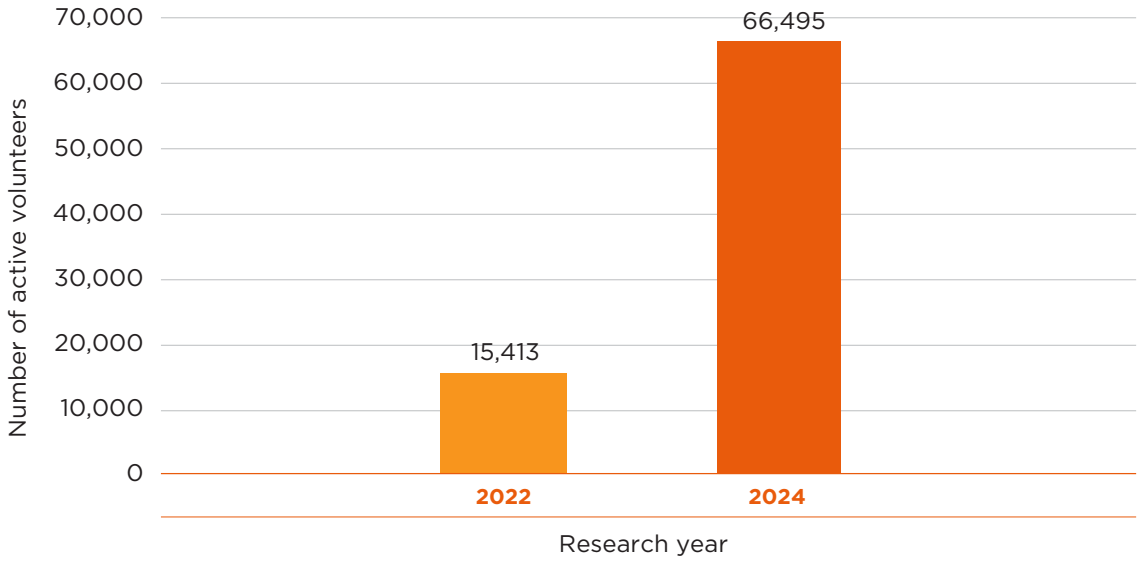
2024 data show a welcome decrease in inactivity. The 347 inactive volunteers represent only 29% of the total, indicating that as we move away from the pandemic, greater engagement from palliative care volunteers is emerging.

There has been a high volunteer turnover, with inpatient volunteers showing the most change. In the 12 months prior to this study, 217 people ceased volunteering, almost half of whom were inpatient visiting volunteers. However, more people started volunteering than quit, with 322 new volunteers joining in the last 12 months.

Overall, the data suggests a positive trajectory in volunteer recruitment, with notable changes in the types of volunteer roles being filled. There is, however, still a gap to bridge in reaching pre-pandemic volunteer numbers.

The total volunteer hours worked in 2024 were 66,495—an increase of 331% compared to 2022. According to The Centre for Volunteering's Value of Volunteering Calculator (2024), this is equivalent to $2,877,234 in paid labour.

Figure 3. Total volunteer hours contributed by year



These findings show that the easing of COVID restrictions had a marked impact on service delivery. While 15% of palliative care services have ceased operation altogether since 2022, positive trends are emerging. Volunteer numbers and engagement have increased significantly, and new services are coming on board.

While volunteer numbers have not yet returned to pre-pandemic levels, we can report a net increase of 9% over the past 10 years since data collection began.

Resumption of service post-COVID

Restrictions to service

Since the easing of the pandemic, services are beginning to return to normal. 35% of respondents stated they were still operating with some service delivery restrictions still in place, although these restrictions are now minimal. The most common requirement was for volunteers and clients to pass a wellness screening each morning before visits, with visits being cancelled if any signs of illness were present. Masks were no longer mandatory in most services; however, volunteers were still strongly encouraged to wear them. Only four services reported that mask wearing was compulsory.

At the start of this study, a government mandate required all workers in health settings, including volunteers, to have received two doses of a COVID-19 vaccine. This restriction was lifted on 16 May 2024.

Services reported that their less "core" activities, such as hand massage and aromatherapy, had been discontinued, and education and promotional activities ceased. One service stated that they could no longer provide transport to clients due to the risks involved with volunteers using their own vehicles.

Nearly half of the participants reported their service had not yet returned to pre-COVID capacity. Of these, 78% expected to reach full capacity within two years, but an alarming 21% said they would never recover. However, there is good news: 31% of services reported that they had returned to capacity, and 22% said they are even exceeding it.

Barriers to resuming service

The restrictions imposed on services due to COVID-19 have had lasting impacts on volunteer service delivery. According to 71% of participants, the most common barrier was the risk of infection and the inconsistent, ever-changing landscape of regulations and policies that this situation created. Other barriers were a high turnover of staff which led to interrupted referral pathways and the dramatic decrease in volunteer numbers which left services unable to meet the needs of their communities.

NSW Health organisations must comply with the *Infection Prevention and Control in Healthcare Settings* policy directive (2023), which outlines mandatory infection prevention and control requirements. During COVID, the NSW Government monitored infection risks and issued alert levels based on the *NSW Framework for Respiratory and COVID Safe Healthcare* (NSW Clinical Excellence Commission, 2023). These alert levels were location-specific and depended on the prevalence of COVID in each community.

Health services commonly use alert level notifications to determine appropriate infection control responses. At any given time, alert levels could vary across the state, within local health districts, and even between operational settings within a single service.

This fluctuating risk landscape meant that volunteer service activity was either restricted or approved depending on the alert level, making it difficult to manage changes in service policy and operating guidelines.

Organisational decision makers interpreted risks and controlled volunteer activity, but responses to the same risks varied and were managed inconsistently across settings and services. Some services classified volunteers as visitors, some as health workers, and this distinction meant they were subject to different restrictions. Some services were reluctant to reintroduce volunteers even after restrictions had eased for visitors, erring on the side of caution with the potential for alert levels to rise at any time.

> ***"It was the policy of the hospital to have no volunteers."***

> ***"The local hospital here refused to let them volunteer at home, if they can't do it at the hospital then they can't do it at home."***

There were significant risks to manage. Services had a duty of care to keep their workforce safe and avoid exposing them to unacceptable risks. Clients, already sick and vulnerable, were reluctant to accept unnecessary visitors, and many volunteers did not want to risk being infected or infecting others. Moreover, many volunteers fell into a high-risk category due to their age. Ensuring that volunteer activities resumed safely was critical.

> ***"It was a matter of making sure that when visits resumed, they were done in line with infection control procedures. There was a hesitancy to go back but we wanted to make sure we went back safely; volunteers and clients were both safe"***

The COVID crisis also prompted many changes for health professionals, as clinicians were seconded to other duties. Many volunteer managers also left their roles during this time. Although there were always clients who could benefit from volunteer support, these services relied on health staff to refer clients. All this turnover disrupted referral pathways, making it necessary to educate new staff, build trust, and re-establish connections.

As one participant stated, without referrals, they would lose their current volunteers, resulting in no service at all.

> ***"We rely on hospitals for referrals, and the new workers don't understand the service. It's a process of re-education and re-establishing connections."***

As reported in the 2022 Snapshot, volunteer numbers had dropped to less than half of the pre-pandemic levels. Many volunteers left and never returned, leaving services depleted and unable to resume service at previous levels once restrictions eased.

> ***"Inconsistency of decision making meant that a lot of my regular volunteers got sick of waiting and volunteered elsewhere."***

When a volunteer leaves, they take with them all the knowledge and expertise they have built up over their time with the service. Often volunteers stay with a service for years and the loss of this body of knowledge and experience is immeasurable. Recruiting a new volunteer does not compensate for the loss of an experienced one. The process of recruiting, onboarding, and training new volunteers requires significant time and resources, making the loss of so many volunteers a major barrier to the resumption of service.

Volunteer Managers' reflections on the resumption of service

In exploring whether palliative care volunteers could have safely resumed activities sooner than they did, participants were divided. Eleven respondents (32%) agreed that volunteers could have safely resumed activity earlier. However, government organisations did not prioritise volunteers in their broader plans. As one participant explained:

> *"We were waiting and waiting for the hospital to let us know, volunteers were seen as a sideline."*

Another participant added:

> *"Being in health, they were so risk adverse. They had all the systems in place and risk assessed each role three times. They would bring them back and be overly reactive with one case and withdraw volunteers. They would move the markers back on compliance and people would get sick of it."*

Non-government organisations (NGOs) were not bound by the same NSW Government policy directives as NSW Health services. They assessed their own risks and controlled their volunteers independently, but they still relied on referrals from risk-averse staff working in specialist palliative care services.

> *"Our service was restricted as we rely on referrals from NSW Health and our local health district, which ceased all volunteer services for an extended period."*

Meanwhile, 40% of participants indicated that volunteers could not have safely resumed activity earlier. Some participants shared the following concerns:

> *"I think that while it was physically safe, the mental anxiety was still there."*

> *"We had a lot of COVID around and didn't want to put people at risk, family or volunteers."*

Although volunteer managers possess valuable expertise and insights into the volunteering landscape, half (n = 15) of them reported that they were not consulted in decisions about resuming volunteer activity.

> *"I was requested to do continuous risk assessments; I wonder if they ever read them or took them into consideration because it still took ages to get back to service."*

> *"They frustrated me because of a lack of communication with constantly changing goalposts. Uncertain for volunteers and management. Inconsistent and uncertain."*

The other half of participants were included in consultations, which correlated with more collaborative working relationships. Services with strong leadership had more input.

> *"Can't say that I wasn't consulted, but things like the restoration plan were required for me to complete and send to the decision makers. Initially they were meeting me and updating me about decisions, but not a consultation."*

> *'We met with managers and worked out a return protocol that would allow volunteers to safely resume contact with clients."*

After reflecting on whether the resumption of services could have been handled differently, volunteer managers expressed mixed views. 42% stated that things could not have been managed differently given the circumstances:

"We did the best we could under the circumstances."

"As a health district, we approached resumption based on the guidelines and classification of the health conditions."

However, 33% felt that services could have resumed sooner with more consultation and consistency in the response to risk.

"I just thought they were too cautious compared to other aspects of life. We allowed visitors in to see patients but not volunteers, which made no sense."

"If volunteers are considered a part of the workforce, then the same rules should apply to both volunteers and health workers."

Participants also reflected on how COVID impacted the entire palliative care volunteering sector and the management of service resumption. The most common responses highlighted the inconsistencies in management strategies and the need for a more standardised approach. There were some instances of confusion about where volunteers fit within the multidisciplinary team.

"It was very uncoordinated, in terms of volunteers. They are meant to fit under staff but were classified as visitors. No visitors meant no vols. We should put them under the staff."

"The lack of consistency or lack of any kind of leadership from NSW Health in relation to volunteers for quite a long time. Even from health service to health service within the state, there was no consistency in approach. Some services came back quickly, but another took two years."

"I wish that NSW health had a more standardised approach. A standardised approach would have provided clarity for the services."

Looking ahead

Plans for the future of service delivery

80% of palliative care volunteer services plan to recruit new cohorts of volunteers in the next 12 months. This will significantly boost capacity and begin the process of returning to pre-pandemic numbers.

Success depends on the number of referrals that can be serviced, and much work remains to be done in refreshing connections with existing referral partners and engaging with new ones. 43% of participants have plans to promote their service by educating clinicians and GPs about the role of volunteers and engaging with their community to raise awareness of palliative care and the supports available.

40% of participants stated they have plans to grow their service either by expanding on existing volunteer activities or by diversifying the skillsets of volunteers and introducing new activities. Eleven services plan to launch a new biography program or further develop an existing one. Seven services are branching out into the bereavement space with new grief supports and bereavement navigator roles.

The mood is positive with 82% of volunteer managers reporting they were feeling optimistic about the future of their service, but some uncertainty remains. As two participants stated:

> *"I'm not certain about a return to the pre-covid level of interest in volunteering. Cost of living pressures have resulted in people having less time to volunteer because they are returning to work or undertaking carer roles to support family members who have returned to work or working more hours."*

> *"Optimistic for inpatient volunteering, pessimistic for community visiting because I can advocate for it and see the benefit of volunteers, but the clinical team isn't on board."*

Challenges to meeting future needs

Even though sentiment is positive, there are still challenges to be overcome when imagining how to meet the needs of future clients.

Increasing the number of volunteers was reported as a high priority by more than half of participants; however, recruitment is not an easy process. It is time-consuming and involves a marked increase in administrative workload as new volunteers progress through the stages of recruitment, onboarding, and training.

The right kind of volunteers are required to fill the gaps and meet the needs of their community. Volunteer cohorts must be diverse and reflect the demographics of the clients they support, including factors such as culture, age, gender, and language. Volunteers must also be matched to activities by temperament and be physically capable of tasks, such as lifting wheelchairs into vehicles when transporting clients. In rural and regional areas, volunteers may be expected to regularly travel long distances (Bowman, Burke & Huntir, 2017). The burden on volunteer managers can be onerous, especially when they are time-poor and under-resourced in their role.

> ***"There is always more need than supply. Increasing volunteer numbers would require more time and resources than I have available, so I have to be happy with the current balance of numbers and skill mix."***

A lack of understanding about the role of volunteers and the support they can offer was a challenge identified by a third of respondents. Health professionals need to be educated about how volunteer support can benefit clients and their families, so they feel confident to refer. Members of the community and potential clients also need to understand this, so they take up offers of support and boost engagement.

A third of participants reported concerns about managing referrals. COVID restrictions and high staff turnover have damaged established referral pathways. New staff need to be educated on how and when to make an appropriate referral. Volunteer managers are worried they would not have enough volunteers to meet demand or might struggle to match suitable volunteers with client needs.

This report highlighted that 21% of volunteer managers did not have enough time to adequately manage the workload.

> ***"It's not having enough hours as a coordinator. I only get 2.5 days a week."***

> ***"It's important to have a specific position dedicated to managing volunteers and providing training. The role of volunteer manager is important, hospital staff have a lot on their plate and are too time poor to manage volunteers properly."***

Recommendations

Volunteers provide essential support to people approaching the end of life and their families. They play a crucial role in delivering holistic, person-centred palliative care, and their contributions should be recognised and valued. Educating clinicians and referring partners about the benefits and impact of volunteer support could strengthen referral pathways and embed volunteer services as a fundamental component of end of life care.

A successful volunteer service depends on strong leadership. Volunteer Managers are highly skilled professionals but are often time-poor and under-resourced for their workload. Palliative care services would benefit from investing in dedicated personnel to lead volunteers and providing them with sufficient resources to succeed in their roles. In areas where non-government organisations manage volunteer services, fostering strong connections and communication with Volunteer Managers could enhance confidence in service standards and boost referrals.

Organisational decision-makers interpret risks and control volunteer activities, but inconsistent responses to similar risks across settings and services have been a source of frustration. It is reasonable to expect that services operating under the same alert level, offering similar volunteer support in comparable settings, should apply the same rules. Greater consistency across the sector would be welcomed. Developing state-wide palliative care volunteer standards could help unify work practices and processes. Additionally, regular reviews and updates to the NSW Health Framework for Engaging, Supporting, and Managing Volunteers (2011) would better guide volunteer management and optimise the experience and impact of volunteering within the NSW Health system.

To convince service providers of the value of palliative care volunteering, more evidence is needed. Engaging in research on this topic could provide insights into the psychosocial benefits of volunteer support for people living with life-limiting illnesses, their families, and carers. It could also begin to quantify the economic value of volunteers to these services.

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Palliative Care New South Wales

Volunteer Services Support Program

The Volunteer Services Support Program is funded by the NSW Ministry of Health