



Palliative Care Workstream

South Island Hospice Benchmarking Survey

Executive Summary

Specialist palliative care is provided by health professionals with skills and/or qualifications in palliative care who work within a team structure – either as part of a Hospice or in a hospital setting. Their role is to help manage patients with complex palliative care needs, to champion the importance of palliative and hospice care across the health system and to ensure that the speciality is forward focussed through education, research and audit. Palliative Care Services also support the many others who provide palliative and end of life care through advice, education and access to specialist input.

The Palliative Care Workstream (PCW) undertook a survey of all South Island hospices in mid-2015 to understand the provision of specialist palliative care in the hospice setting and what progress has been made towards the implementation of the *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (Jan 2013) – The Framework*. The Framework was developed to support more consistent access to and purchasing of palliative care services through providing clarity about which components of palliative care should be provided and by whom. The hub and spoke model was outlined in *The Framework* and services were encouraged to collaborate with each other and with all primary palliative care providers. It is important to note that hospice services can sit outside the line of sight of District Health Boards (DHB) given that they are partially funded by charitable donations and this needs to be taken into consideration when assessing progress and planning for future development.

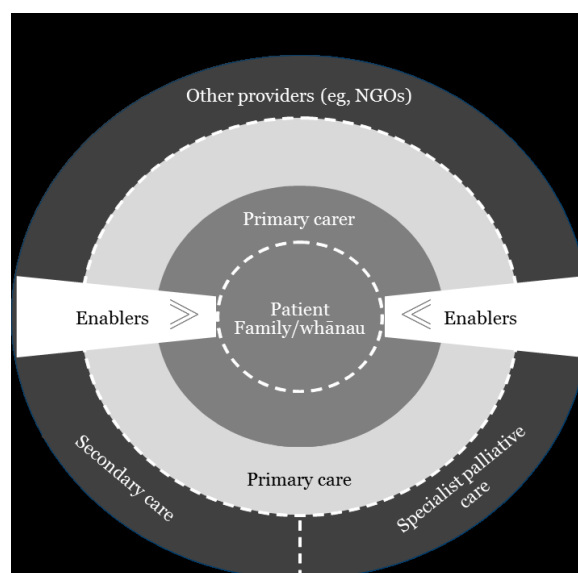
Although there are eight hospices in the South Island, two do not have inpatient beds or specialist clinical services so the majority of the report pertains to those six hospices with an inpatient unit (IPU).

It is apparent from the survey results that hospice services are generally well aligned to *The Framework* but there are notable differences across services and significant areas for improvement. A number of recommendations have been made that need to be brought to the attention of hospices organisations and the DHB.

Ensuring that all staff meet the competency standards is a priority, as is ensuring access to the full range of allied health services and this is as much a DHB responsibility as it is for hospices themselves. The need for access to and sustainability of specialist medical staff is essential and may require sharing across services or regions. Improving access to Telehealth should be addressed with urgency and alignment of information systems is a long term project that needs to be actively supported by the South Island Alliance.

Introduction

Across New Zealand, specialist palliative care is provided by hospices (IPU and/or community services) and by hospital palliative care teams. The *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (Jan 2013) – The Framework* - emphasises that most of the care for people with palliative needs and their family/whānau will be delivered by *primary* palliative care providers, accessing advice, support and education as needed from specialist services. This specialist back-up should be available in **all** settings - private homes, aged residential care facilities, in hospitals and also in rural areas.



In addition to *The Framework*, hospices are guided by the Hospice New Zealand Standards for palliative care. This quality review programme and guide was funded by the Ministry of Health and released in 2012 with the aim of supporting quality palliative care in New Zealand. The standards are designed to enable services to undertake self-assessments utilising standardised tools and processes to determine opportunities for improvement.

Appendix A of *The Framework* is titled “Hospice Capability Recommendations” and was written in consultation with Hospice New Zealand. It focusses on the issue of what communities should reasonably expect of their hospice services in New Zealand. The overarching purpose was that “services are delivered by the right people, at the right time, in the right place for the patient and their family”. *The Framework* outlines what is considered the “core of local community hospice care” and aims through its’ implementation “to strengthen and position hospices to lead palliative care in the future”. The recommendations cover clinical and non-clinical functions that hospices will provide, specific expertise and competencies that staff should meet and qualifications they need to hold. *The Framework* acknowledges and honours the range of services and diversity of hospice models and supports adaptations to meet communities’ needs with expectations regarding regional collaboration. The recommendations were endorsed by the sector and could be considered as the “gold standard” for hospices throughout New Zealand.

Leadership teams from the eight hospices¹ in the South Island were asked to participate in a survey to help the PCW improve the understanding of hospice services across the region. The survey

¹ Nelson Region Hospice, Hospice Marlborough, Nurse Maude Hospice, Hospice South Canterbury, Otago Community Hospice, Hospice Southland, Hospice Mid-Canterbury Trust and Buller West Coast Home Hospice Trust

questions were based around *The Framework* (specifically Appendix A) and asked about types of staff employed, staffing levels, education and services offered. All eight hospices responded.

A similar survey has been conducted with Hospitals in the South Island. The aim of the two surveys was to evaluate the status of *specialist* palliative care within both hospices and hospitals in the South Island and to establish the extent of integration and collaboration at a local level as well as across DHB boundaries. The intent of the two surveys was to find gaps and areas of possible need whilst highlighting examples of innovation, cooperation and service development so that this information can be showcased for the greater good.

There are two hospices in the Nelson Marlborough DHB, two in the Canterbury DHB, one in the West Coast DHB, one in South Canterbury DHB and two in Southern DHB. The hospice trust covering the West Coast, together with the hospice trust in Mid Canterbury are limited to provision of supportive services having no inpatient beds and minimal or no clinical staff.

The initial section of the report will detail the responses from the two hospice trusts and the main report will cover feedback from the six hospices with inpatient beds.

Hospice services in the South Island

Hospice services are contracted by all five of the South Island DHBs. Six of the eight hospices offer inpatient beds and five of those provide *community* palliative care delivered by an interdisciplinary team, generally involving nursing, medical, allied health and family support. These hospices employ a range of staff, many of their staff hold specialist qualifications and the hospices work closely with their DHB to provide services to meet the needs of the population. Hospices are assessed against national accreditation criteria.

Hospice Mid-Canterbury Trust and Buller West Coast Home Hospice Trust

One hospice in mid Canterbury and one on the West Coast offer supportive services only. These hospices provide pastoral care, chaplaincy, home support, counselling, biography, massage therapy, financial support, non-specified support in the care and management of patients and support in the education of health professionals. They are both supported by their regional hospice (Nurse Maude) for all other requirements. They were established as Trusts and are a collaboration between the DHB and the community, being reliant on local fundraising and donations.

Buller West Coast is a charitable trust which provides limited financial support for patients and families for costs incurred by medication, power, phone, food and transport including ambulance. In addition, the Trust provides financial support to health professionals for the purposes of education.

Hospice Mid-Canterbury Trust is run by volunteers and offers community day services with biography writing, mobile massage, counselling, chaplaincy, pastoral care and home support. They loan some equipment and conduct education to community groups. At the time of the survey there were three biography writers, a physiotherapist, a counsellor, a trained massage therapist and a manager with a plan to increase the volunteer workforce further.

What is not clear through the survey results is whether any formal arrangements exist between these Trusts and specialist palliative care providers to ensure no duplication of services exists, to advise and/or support staff to achieve the necessary competencies, and/or contribute to the development of a collaborative approach to strengthen the interdisciplinary team.

The remainder of this report will detail the composition and activities of the **six hospices** with inpatient beds.

Specialist palliative care staff

In an effort to ensure consistent and quality care, *The Framework* outlines the clinical functions that all hospices should be capable of providing as a minimum standard of care. These include community palliative care services delivered by an interdisciplinary team with the subsequent required competencies depending on profession.

The majority of staff employed by hospices are nurses. Hospices also employ a wide range of allied health staff including family and bereavement support and a small number of doctors. They recruit and support volunteers, who undertake a wide variety of tasks. It has been acknowledged nationally and internationally that as services grow and accept more patients with a non-cancer diagnosis and with greater complexity, the mix of staff also needs to change. It is recommended within *The Framework* that each hospice has a mix of experienced and specialist qualified staff and outlines the minimum requirement. In the case of nursing staff *The Framework* has also offered a breakdown of percentages of staff who should achieve the relevant qualifications. *The Framework* is clear on both the relevant qualifications required and the percentage of staff employed that should meet these criteria so that a required level of expertise can be assured.

Nursing

The Framework outlines key clinical functions that all hospices should be capable of providing and one such function is advanced assessment and care planning which includes nursing assessment at an advanced level. Standard 13 of the Hospice New Zealand Standards for palliative care requires that staff are appropriately qualified for the level of service offered and they demonstrate ongoing participation in continuing professional development (CPD). Nurses have a range of post graduate qualifications available to them and many opportunities for CPD that need to be supported.

The Framework advises that hospice IPUs will have a mix of experienced and specialist qualified staff and suggests minimum requirements. *The Framework* also recommends that at least 60% of RN's employed in IPU will have relevant qualifications, PG cert in Palliative Care and proficient expert level on PDRP, with 60% of EN's at least attaining proficient/expert.

Senior nursing roles are increasingly present in hospices. These include any of the following;

- nurse practitioner (NP)
- clinical nurse specialist (CNS)
- clinical nurse educator (CNE)
- "team leader"

The qualification for NP is set by nursing council but the other roles are open to a degree of interpretation. The survey did not ask hospices to confirm that their nurses actually held the qualification recommended in *The Framework* for senior nursing roles.

Table 1: Palliative Care Nursing Staff

Hospice	1	2	3	4	5	6
Nurse Practitioner			✓			
Clinical Nurse Specialists	✓		✓	✓		
Clinical Nurse Educator	✓	✓	✓	✓		✓
Other Senior Nurse (e.g. team leader)		✓		✓	✓	✓
Registered Nurse (with relevant qualifications)	✓	✓	✓	✓	✓	✓

Registered Nurse (without relevant qualifications)		✓	✓	✓	✓	✓
Enrolled Nurse (proficient/expert within scope)	✓		✓	✓	✓	✓
Enrolled Nurse (Not proficient/expert within scope)				✓		
Healthcare Assistant	✓	✓	✓	✓		✓

There is considerable variation in how hospices utilise senior nursing roles between IPU and community. Two hospices have multiple CNS roles working in the community only. One hospice has a CNS who works across IPU and the community. Five hospices employ CNEs, including all three hospices with CNSs. The CNE in one hospice works only in the IPU, the remaining four hospices have the CNE role cover IPU and the community. One hospice employs only a senior nurse (Team Leader) with no other senior nursing positions. This hospice falls short of the 60 percent target outlined in *The Framework* for RN's holding a relevant qualification and also fails to meet the target of 60 percent EN's achieving the proficient/expert level within scope.

Ensuring that there is an appropriate mix between experienced nursing staff and relevantly qualified nursing staff working together in hospice to meet the required competency standards is a priority.

Allied Health/family support

The survey responses provide an insight into how well hospices are tracking towards a comprehensive interdisciplinary team (IDT). As noted in *The Framework*, the psychosocial team is pivotal to the delivery of comprehensive and holistic patient and family/whanau care. There are clear competency frameworks available for occupational therapy, physiotherapy, clinical pharmacy, speech language therapy and dietetics. Social work, counselling and spiritual care competencies are yet to be developed for palliative care. All allied health professional are able to undertake a post graduate certificate in palliative care and should be encouraged as a minimum qualification in addition to or in lieu of approved competencies.

In addition, *The Framework* states that each hospice team will include cultural support staff who are competent in palliative care. Two hospices employ a Kai Awhina and one receives service via the DHB. What is not evident through the survey responses is whether the other three hospices with neither Kai Awhina nor other cultural liaison have any access to such support at a local or regional level.

Allied health and psychosocial support staff need to be able to access professional development in palliative care when working within a specialist environment.

Table 2: Allied Health Workforce

Hospice	1	2	3	4	5	6
Occupational therapist	✓	via DHB	✓	✓	✓	
Physiotherapist	✓	✓	via DHB	community via DHB	via DHB	
Social worker	✓	✓	✓	✓	✓	
Needs assessor	✓	undertaken by RN's	✓	via DHB	via DHB	

Counsellor	✓	✓	✓	✓	✓	✓
Dietician	✓	via DHB	via DHB	via DHB	via DHB	
Clinical pharmacist	✓		✓	✓		
End of life pathway facilitator	✓		✓	✓	✓	
Kai Awhina	✓		✓		via DHB	
Other Cultural Liaison					via DHB	
Clinical psychologist			via DHB		via DHB	
Speech Language therapist		via DHB			via DHB	
Lymphoedema therapist		✓	✓		via DHB	
Advance care planning facilitator		Two trained staff	✓			
Other	Spiritual care facilitator Family support coordinator or	Spiritual care Provided by a chaplain at 0.5FTE	Spiritual care provided by volunteers and access to chaplain through DHB		Spiritual care worker	

Medical

Some key assumptions are asserted within *The Framework* surrounding hospice capability, one of which is that people will have access to skilled staff who can provide “expert symptom management”. *The Framework* states that hospices will need vocationally registered general practitioners and/or medical officers on staff, suggesting it be preferable these doctors hold a post graduate diploma or clinical diploma. It goes on to indicate that medical staff working at this level of practice in hospice will need to be supervised by, and have access to, a palliative medicine specialist.

The survey asked respondents to indicate the Medical staff FTE employed across the service and their level of qualification. Page 36 of *The Framework* provides guidance on qualifications and competencies.

Table 3: Palliative Care Medical Staff

Hospice	1	2	3	4	5	6
SMO (with Specialist qualification)	✓			✓	✓	
MOSS/Medical officer/GP (with diploma or equivalent)	✓	✓	✓		✓	
MOSS/Medical officer/GP (with no palliative care training/qualification)	✓	✓	✓	✓	✓	✓
RMO (Registrar/House surgeon)	✓			✓	✓	

Only three hospices employ an SMO (with specialist qualification) and only two have met the RACP criteria as accredited training sites for registrars (advanced trainees) in Palliative Medicine.

There was no opportunity within the survey results to understand the plans of those hospices lacking SMO (with specialist qualification), or medical staff (with relevant qualifications), on how they will address this gap in future. As well, access to and supervision of medical staff by a SMO was not clearly stated.

After hours services

Patients in receipt of palliative care in the community need to be able to access advice and support 24/7. All six hospices have specialist palliative care **advice** available from a nurse 24/7, while five have specialist palliative care advice available from a doctor 24/7.

For one hospice advice is available only for patients in current receipt of hospice services, but five reported that advice is available after-hours to health professionals for all patients in need.

Two hospices enable their nurses to visit patients after-hours, with one able to provide after-hours medical visits *in exceptional circumstances only*. The other four hospices do not provide after-hours visits, and the assumption is that other community-based services fulfill this role although this was not evaluated as part of the survey.

There are clear gaps in provision of after-hours care and ideally this should be standardized across the South Island.

Clinical supervision

This is generally considered an essential component of safe practice in palliative care given the challenging nature of the work. Across the six hospices, 3 provide staff with individual supervision on request but the other three only offer group supervision. This issue would be worthy of standardisation.

Other workforce

Volunteers

The Framework asserts that all hospices will have a volunteer workforce, undertaking roles that enhance their service delivery. Each hospice across the South Island has at least 18 volunteers. Four hospices stated they had around 20 community volunteers and one hospice has up to 250.

All six hospices utilise volunteers in the IPU, with duties including kitchen, meals, flowers, cleaning, administration, library and companionship to patients. One hospice utilises volunteers to help nurses in the morning shift.

Five hospices utilise volunteers in the community, with duties including sitting with patients, transport, delivering equipment, biography service, walking group for bereaved family/whanau, counselling, phone calls and remembrance services.

All six hospices have volunteers undertaking retail and marketing on their behalf.

The Framework also states that volunteers will be managed by trained managers who will demonstrate competencies in palliative care. As yet these competencies have not been defined. This is a recognised area for future development

Health care assistants

Five hospices employ health care assistants (HCAs) who are unregistered. *The Framework* offers no guidance on the level of training necessary for these roles. Four hospices use HCAs only in the IPU and one hospice has HCAs work only in the community. Clarifying the tasks undertaken by the HCA role, the level of supervision and training provided to HCA's would provide a clearer picture of how these roles fit with specialist palliative care provision.

Administration staff

It is important that staff working in specialist palliative care are not required to do administration duties that could be undertaken more efficiently and cost effectively by personnel trained for this purpose. All six of the hospices with inpatient beds have administration staff supporting clinical staff such as secretarial duties but no attempt was made to assess the adequacy of this resource.

Paediatric palliative care

The care of paediatric patients lends itself very nicely to the principles of partnership intrinsic within the hub and spoke model outlined in *The Framework*.

Only two hospices stated that they provide a Specialist Paediatric Palliative Care service. Of these two hospices one did not elaborate on the service provision but is noted to have a Paediatric Palliative Care CNS on staff. The other hospice stated the service was limited to an SMO with a paediatric palliative care qualification and a collaborative approach with Starship hospital palliative care staff.

As paediatric trained staff cannot be available in all hospices, linkages with existing services is essential and use of the document "*Paediatric palliative care in New Zealand - clinical guidelines for end of life care, 2015*" should be actively encouraged.

Access to other specialist services

Patients in hospice care may on occasions require the input of other specialists or specialist services. A list was included in the survey and the responses were quite variable. This indicates that patients in hospice may be unable to access vital input if required or can only do so off site which requires them to travel to their local acute hospital.

This is a summary of the survey responses;

- Acute pain consultation is available in 3 hospices on site (3 off site only)
- Chronic pain consultation is available in 4 on site (2 off site only)
- Clinical Psychologist is available in 2 hospices on site (3 off site only)
- Mental health consultation/Liaison Psychiatry is available in 2 hospices on site (4 off site only)
- Paediatric specialist palliative care input is available in 3 hospices on site (3 off site only)
- Interventional pain services (e.g. intra-spinal analgesia, nerve blocks) is available in 3 hospices on site (3 off site only)
- Interpreter services are available in 4 hospices on site. In 2 hospices interpreter services are only available off site.
- ACP facilitation is available in 5 hospices on site and in 1 hospice off site only.

This is an area worthy of focus, with the aim of improving access for hospice patients to essential services.

Workforce development

Workforce development consists of both ensuring that there are sufficient personnel with palliative care qualifications to grow the specialist workforce and ensure sustainability AND ensuring that the general health care workforce is educated in palliative and end of life care.

As providers of specialist palliative care all Hospices should be in a position to contribute to the development of a sustainable specialist palliative care workforce.

Five hospices provide varying levels of nurse training positions. Responses included NEtP, Batchelors, CAP, Donny fellow. Only two hospices are accredited training site for Registrars (Advanced Trainees) in Palliative Medicine and have permanently funded positions.

All six hospices offer ongoing training for volunteers, including orientation, infection control, education sessions, guidance on boundaries and Hospice New Zealand *Fundamentals of Palliative Care*.

The following formal palliative care education is provided by hospices:

- Nursing students – All
- Post Graduate Nurses (including Polytechnic and University) – All
- Medical students – five out of six hospices. Note: the hospice that does not provide education to medical students does provide training for GPs, practice nurses and IDEA service workers.
- Allied Health Professionals – All
- Aged Residential Care Staff (on site in ARC) – All
- One hospice stated that they provide education as requested by any professional group.

The focus of education includes formal sessions on particular topics e.g. advance care planning, fundamentals of palliative care, syringe driver training, palliative care for care givers.

The amount of educator hours varied significantly with one hospice having 1.2 FTE dedicated to preparation and delivery of education. Among the other hospices, they recorded 123 hours, 423 hours, 722 hours and 800 hours of educator time.

There is clear evidence that education for nurses is provided to a more comprehensive degree than for doctors. To compound this issue, at the time of the survey a shortage of palliative medicine specialists in New Zealand was affecting two of the six hospices. These hospices reported unfilled vacancies over the previous two years for SMO positions. Neither provided comment on the duration of the vacancies.

Other services provided by hospice

The following services referred to in *The Framework* as possible contributors to the care provided to patients, whānau and families. The addition of these services it is acknowledged will be financial and human resource dependent.

Day programmes

Throughout New Zealand, day programmes are increasingly regarded as a worthwhile investment. Day programmes improve access for some patients to the range of services and support provided by hospice and can improve the relationship of communities with hospice as somewhere that offers more than just a place to die. Three hospices offer a day programme and one hospice had plans to recommence theirs within 6 months. All three run their day programmes weekly and are facilitated/coordinated by at least one health care professional.

The purpose or design of services provided by day hospice is not defined.

Complimentary therapies

The Framework asks hospices to ensure the deliverers of complimentary therapies are qualified and registered with competencies in palliative care, through encouraging these staff to undertake palliative care specific qualifications to enable them to be specialist within their respective roles.

There were two distinct questions within the survey requesting information on supportive therapies offered. The first question was regarding provision by the service of music, art, massage therapies and aromatherapy. One hospice offers the full range of therapies listed; music therapy, art therapy, massage therapy and aromatherapy. Three other hospices only offer massage therapy and state the staff providing these services hold a qualification and/or are registered. One hospice provides massage therapy with relevant qualifications and aromatherapy with no qualification stated. One hospice offers only aromatherapy and no mention is made of qualifications held.

In response to the second question regarding the provision of or access to any complementary or alternative medicines or therapies (CAM) whilst patients are in Hospice IPU, two hospices do not provide CAM although both support patients to continue the use of CAM. One hospice simply stated “yes” in response to the question and one hospice provides reiki only. The two remaining hospices provide reiki, and/or aromatherapy and/or mindfulness and/or acupuncture. One hospice stated alternative medicines and therapists can be accessed by the patient or their family/whānau or via a staff referral.

The second question did not ask for any further information regarding qualifications or competencies of the therapists providing the services.

Support to families/whanau/communities

Most hospices provide support for patients’ whanau/family/carers on a regular basis, including debriefing during and after a critical event, bereavement meetings, monthly care groups, bereavement support/grief groups, Kowhai programme and formal education for carers.

Most hospices also provide education or engagement in the community regularly through community groups such as Lions, Rotary, RSA, women’s groups, Age Concern and other service groups or clubs

Equipment provision

Equipment provision requires assessment by trained staff and then a process for loaning and maintaining that equipment. Five of the six hospices have loan equipment, but there is significant variance between hospices in what equipment is available and how it is funded and maintained. Items loaned include oxygen concentrators, commodes, overhead tables, syringe drivers, wheelchairs, scooters, lazy boy chairs, shower chairs and beds.

One hospice funds the equipment; others make use of community grants and fundraising. One hospice charges primary palliative care providers for the loan of syringe drivers. At least two hospices make use of DHB hospital loan equipment.

Standardisation across the South Island regarding equipment provision for patients receiving community based palliative care services would be highly beneficial and would assist in developing partnerships with the wider DHB.

Support to local acute hospital(s)

Specialist palliative care in the hospital setting can either be provided by a team employed by the hospital/DHB itself, or via an in-reach arrangement from the local hospice. Four hospices provide in-reach for existing patients as well as new referrals, one hospice sees only patients on their hospice

programme and one sees patients on referral only. The qualifications held by staff providing the support to hospitals varies considerably. Interestingly, one hospice provides a counsellor to the local DHB.

All six hospices provide some degree of palliative care support and/or input via this in-reach arrangement but the type of support/input varies widely. No assessment was made as to the proportion of work done by hospice staff in a hospital setting or what priority is given to this role or the support provided for it by the DHB. This variation in provision has the potential to leave patients vulnerable due to the lack of attention and visibility of this issue at a DHB level This would be worthy of further assessment

Hospital palliative care is covered more fully in the companion report by the PCW.

Outpatient clinics

Outpatient clinics are a way of meeting the needs of palliative patients who are mobile, in a way that may be more efficient for staff. Clinics are particularly useful for patients who live in rural areas and this is an area of service innovation that could be expanded.

Five of the six hospices hold outpatient clinics for new patients or for follow-ups at least once a week. The ideal proportion of clinics v home visits as a mode of service delivery is unknown and would be worthy of more attention across the South Island. Telehealth may also assist in this area, and is covered below.

Support to aged residential care (ARC)

One of the challenges is variable access to palliative care services for specified population groups. This variation is, *The Framework* suggests, influenced by factors other than the assessed need for palliative care, one such identified population are those living in aged-residential care (ARC) facilities.

The Framework supports the Australian Productivity Commissions report from 2011 which suggests that palliative care should be core business for ARC facilities and provides guidance on how specialist palliative care services can support staff.

All six hospices report the provision of clinical support to ARC facilities through a range of channels. However, the variation in services available and the level of qualification held by those providing support requires further understanding.

One hospice employs a CNS to work within ARC, whilst another hospice limits involvement to grief and loss support after critical events and routine scheduled education.

Two hospices provide care coordination into ARC, with these and another offering 24/7 phone consultation and advice.

Hospices were asked to provide comment on any gaps they perceived in the services they were able to provide to ARC. Hospices identified this was a priority area for them with particular challenges around difficulty in following up with patients who have moved to ARC for continued care; after hours services; staff rotation in ARC. However, two hospices have, or plan to have, regular contact with ARC through a pilot programme placing a PCNS in ARC and through daily NP visits. Almost all hospices identified availability of GP support, particularly after hours, along with GP knowledge of palliative care as a barrier to care.

Hospices also commented that lack of integration with other services is an issue, with one particularly highlighting the lack of electronic information sharing with both GPs and hospitals.

Service use, quality improvement and research

All the hospices regularly collect data, including referral numbers and characteristics (for example diagnosis, referral source).

- Four hospices recorded that between 11 and 22 percent of their admissions were 'respite'
- Four hospices recorded that between 9 and 40 percent of their admissions had a non-cancer diagnosis (9, 26, 30, 40 percent), while six hospices recorded that between 16 and 40 percent of their new referrals had a non-cancer diagnosis (16, 17, 24, 26, 30, 40 percent)
- Five hospices recorded that average length of stay was 8-9 days, while one recorded 12 days
- Four hospices recorded they received referrals requesting allied health input only, while five received referrals requesting counselling or bereavement support only

Note: one hospice has established a new system for collecting referral data in 2015.

The national referral criteria/ guidelines are used by all six hospices, either in their original format or as a guide for local adaptation or alongside contractual obligations.

Six hospices undertook at least four audits, consumer surveys or quality improvement activities each year. The types of activities included: patient and family satisfaction surveys (covering both community and inpatient services); QPS-HNZ standards; audits of patient files, inpatient discharge, medicine management, infection control, falls, pressure injuries or to meet DHB requirements; and ongoing quality improvement activities, which may be supported by a quality improvement plan.

Hospices sometimes participate in formal research, with one working regularly through a research institute, two occasionally through universities, and two occasionally through other channels. Ideally all Hospices should be in position to conduct research as a way of understanding and promoting service development.

Engagement with DHB, local, regional, national networks

Five hospices report involvement in DHB strategic planning or priority setting, through participation in planning days, being integrated with the DHB planning processes, involvement in DHB and regional palliative care meetings or workgroups. The remaining hospice reports that it consults with the DHB on their strategic plan. One reports that the engagement with the DHB is improving over time.

Four hospices report they are involved in a range of networks or groups, including HNZ, local educators meetings, regional intravenous therapies group and auditing, ARC groups, Palliative Care Nurses NZ, Psycho-oncology NZ, and Australia and New Zealand Society of Palliative Medicine.

Although the responses provide insight into the existence of collaboration between hospices and primary palliative care providers, further information regarding how these collaborations are contributing to the implementation of *The Framework* is required.

The Framework emphasises that Hospices are an integral component of the whole population health sector and need to be included proactively in strategic planning and service improvement collaboratively with their DHB.

Information Services

Fully integrated information services are vital across all sectors of the health system. This requires to ensure that hospice patients have certainly that up to date information is readily available to the health care professionals caring for them. It appears from the survey results to be an area requiring further development for all but one hospice. This one hospice has unlimited access to Telehealth (teleconferencing and videoconferencing) and all clinical staff have access to the DHB health record. In addition, hospice letters are visible on the DHB health record.

Telehealth (teleconferencing and videoconferencing) is now considered standard practice across DHBs both to allow patients with travel limitations to access care remotely and also to improve staff access to education and support. Four hospices report limited access to Telehealth and one has no access at all. At the time of the survey one hospice was investigating the use of hand held devices for remote rural patients with network access.

Regarding access to the DHB electronic health record and visibility of hospice letters to DHB staff;

- One hospice has full access for all staff and hospice letters are fully visible (as above)
- One hospice is able to view DHB health records but hospice letters are not visible on the DHB health record.
- One hospice has access to a limited portion of the DHB health record with hospice letters visible on the DHB health record.
- The medical director alone of one hospice has access to the DHB health record with hospice letters not being visible within the DHB health record.
- One hospice has neither access to the DHB health records or has hospice letters visible on the DHB health records.

Improving hospice access to Telehealth should be addressed with urgency and alignment of information systems is a long term project that needs to be actively supported by the SIA.

Recommendations

1. Hospices are an integral component of the whole population health sector. They can sit outside the line of sight of DHBs given that they are partially funded by charitable donations, but despite this, they need to be included proactively in strategic planning and service improvement collaboratively with their DHB.
2. The use of the term “Hospice Trusts” compromises the public’s understanding of what constitutes specialist palliative care services. Collaboration, cooperation and memorandums of understanding should be developed to clarify roles and mitigate any duplication of services.
3. Access to and sustainability of specialist palliative medicine is essential and may require collaboration across services or DHBs.
4. There should be an appropriate mix of experienced nursing staff and relevantly qualified nursing staff working together in hospice to meet the required competency standards.
5. There should be consistent availability of cultural and psychosocial support staff in all hospices. Staff require access to ongoing professional development.
6. There should be consistent availability to the full range of allied health services with staff trained in palliative care in all hospices. Staff require access to ongoing professional development.
7. 24/7 after-hours specialist palliative care availability is a requirement for all hospices. The extent to which this is via phone as opposed to in person is dependent on the model of care but needs to be sufficient to meet the needs of the population.
8. Due to the nature of the work, all hospices should offer clinical staff access to individual supervision on request.
9. Standardisation of the tasks and nature of work undertaken by health care assistants, as well as the level of supervision and training required within a specialist service is needed.

10. Linkages with existing paediatric palliative care services is essential as paediatric trained staff cannot be available in all hospices
11. Equitable access to specialist services such as interventional pain, clinical psychologist and interpreter services is essential for patients in hospice care. Active collaboration with the wider DHB is required to ensure that this happens as part of a whole of system approach.
12. Education and training opportunities for nurses and doctors who wish to specialise in palliative care need to be available and funded. This initiative could be addressed and coordinated regionally.
13. Education for doctors such as GPs is limited due to the shortage of palliative medicine specialists. To ensure meaningful opportunities are available strategic planning at a South Island level is required.
14. Equipment should be provided in a standardised way across the South Island. This would assist in developing and strengthening partnerships with the wider DHB.
15. Hospital palliative care provision has not been adequately addressed in number of DHBs. This is important for large and small hospital and requires strong collaboration between hospices and their DHBs. Improvements in this area would demonstrate a whole of sector approach to patients at the end of life.
16. Clinical support by hospices to ARC facilities is a current focus nationally with new MOH funding. All new initiatives must be evaluated and, where successful, replicated across the South Island.
17. Hospices should be supported to conduct research as a way of understanding, supporting and promoting service development.
18. Open access to Telehealth should be a priority for all hospices both for patient assessments and for education/support.
19. Alignment of information systems to enable sharing of patient information is a long term project that needs continued support by the SIA.