

South Island specialist and primary palliative care surveys

Summary of findings and next steps

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Introduction

During 2015 and 2016 the South Island Palliative Care Workstream (PCW) undertook five surveys to ascertain the status of palliative care across the South Island and what progress has been made towards the implementation of the *Resource and Capability Framework for Adult and Palliative Care Services in New Zealand* (2013).¹ The first two surveys examined specialist palliative care services. Online surveys were sent to all South Island hospitals in June 2015 and to the seven South Island hospices in August 2015.

The PCW then undertook three further surveys to understand the provision of primary palliative care across the wider health system. This relates to all individuals and organisations who deliver palliative care as a component of their work, but who are not part of a specialist palliative care team. The groups surveyed were: DHB Planning and Funding, aged residential care and primary health organisations.

It is acknowledged that in some cases, considerable time has lapsed between survey completion and analysis, and that the care model delivery variables in question may have evolved. Accepting this fact, the major findings from the full suite of surveys are summarised below.

¹ <http://www.health.govt.nz/system/files/documents/publications/resource-capability-framework-adult-palliative-care-services-v2.pdf>

Findings

- The definition of palliative care is inconsistent across the South Island. No stated distinction is made in the five DHB's annual plans between primary and specialist palliative care and there is no explicit action towards implementing a palliative care strategy. Progress towards the goals stated in the *Resource and Capability Framework for Adult Palliative Care Services in New Zealand* require greater clarity on these points.
- There are gaps and inconsistencies in general practice coverage and medication availability after-hours in community settings, including aged residential care. With the goal of providing *the right care at the right time in the right place*, this is a significant barrier to the effective and timely delivery of care at the end of life. There are professional and quality specific imperatives to ensure adequate access to primary palliative care. In addition, given that people in their final months of life are particularly high users of acute services, there are clear opportunities to reduce emergency department and hospital utilisation that can only be achieved if these issues are addressed.
- There is a high degree of variability in funding models. This raises concerns regarding access and equity for patients across and within each DHB. While recognising that unique local factors may account for some of this variability, further exploration is recommended. Examples include: inconsistencies between which professional groups can access funding (most indicating medical/GP access only); eligibility criteria for funding and requirements for service provision; and the level of support for general practice.
- The degree of IT integration between primary and specialist palliative care is variable across DHBs. The increased use of and access to HealthPathways has been viewed positively. However, the lack of a fully integrated information service network, essential for patient safety and optimal information flow between providers, remains problematic. There is a positive move to bring on board more community providers including aged residential care facilities and district nursing but this process has a long way to go.
- Hospital palliative care staffing models vary widely and most remain under-resourced. The majority of hospitals are reliant on collegial relationships to ensure medical support from local hospices and this has often developed in an ad hoc way. Only a minority of hospitals employ or contract a palliative medicine specialist and most have limited nursing cover especially for periods of planned or unplanned leave. The availability of a dedicated specialist resource in acute care (which includes both medical and nursing) has been identified as best practice. The well-documented quality and utilisation benefits of appropriately staffed, multidisciplinary, hospital-based palliative care will be difficult to realise without greater consistency and a clear commitment in this regard.

- There are gaps in the availability of support for all people (and providers) with palliative care needs, independent of diagnosis, location, time of day or referral status. These include:
 - clinical integration, guidance and support provided by hospices for patients not formally referred remains variable.
 - lack of consistency between districts regarding availability of 24/7 after-hours specialist palliative care back-up and advice for primary palliative care providers.
- Access to psychological, social and spiritual support is variable for patients/whānau who have palliative care needs but who have not been formally referred to a hospice. This includes palliative patients both in community settings and in hospital (and for the family of those who die in hospital). The availability of multidisciplinary services is central to ensuring adequate support for people with life-limiting illnesses and their families. Caregiver and patient stress is a well-recognised driver of acute hospital presentations, which also highlights the importance of psychosocial, social and spiritual support.
- The provision of comprehensive education programmes in palliative care and care in the last days of life is a core component of hospice palliative care services. Staff turnover across the health system is high and ensuring that the wider workforce is appropriately skilled requires a dedicated resource that is ongoing. This is not currently possible across the South Island. Universal mechanisms to help staff identify dying patients is an example of the systemic need.

Conclusion

The South Island PCW is extremely grateful for the willingness exhibited by individuals and organisations across the length and breadth of the South Island to complete the surveys and share their information. Our system is complex and the cumulative acquisition of very rich and interesting data from survey responses has enabled us to build a comprehensive picture of how palliative care is currently provided.

There are numerous examples of excellent service development, collaboration and integration across the South Island and hospice/palliative care is better understood and more visible across the wider health system than it has ever been. However, the variability with respect to service design and funding and the gaps in availability of specialist support is striking. Even those of us working within specialist services have been surprised by many of the findings.

Every South Island resident will die, and all will be witness to the care and treatment of loved ones at the end of their lives. This snapshot of the status of palliative care in the South Island gives us an opportunity to see how far we have come, but also of where we need to go.

Next steps

It is now important that the findings of these surveys are examined carefully and thoroughly. While it is clear that local solutions will be needed for the different services and regions, the surveys have provided a unique view of the gaps and challenges that exist and the need for consistency of care.

A survey of bereaved people across the South Island (VOICES, Views of Informal Carers – Evaluation of Services) is also currently underway. This is a collaboration between the University of Canterbury and the South Island Alliance and will give us rich and valuable information to work with as we evaluate the way forward.

PCW will be assessing its own workplan in light of the findings of these surveys and in the knowledge that data from VOICES will also be forthcoming in the near future. We will be inviting those involved in the provision of palliative care in all sectors to meet to discuss collectively what has changed since the surveys were completed and how we can all use these findings to drive improvements. Dr Kate Grundy as chair of the PCW is planning to facilitate a meeting in each South Island DHB.

Given it is now five years since the *Resource and Capability Framework for Adult Palliative Care Services in New Zealand* was released, it is timely to assess its implementation and relevancy as a foundation for palliative care provision in the South Island.

The findings in this paper and the input of local discussions will be platform on which we can build regional consensus for an updated overarching model of care that fits the needs of our South Island community and delivers consistent, high quality care and equitable outcomes for everyone.