

Terms of reference

Review of Adult Palliative Care Services

Purpose

The purpose of the Review is to recommend actions to ensure that all New Zealand adults who would benefit from palliative care at the end of their life receive high quality care, and a seamless experience of care regardless of whether they are at home, in hospital, in a hospice, or in an aged residential care (ARC) facility.

The Review will report to the Minister of Health on:

- current service capability and capacity across all care settings and providers
- projected need for palliative care services over the next 10 to 20 years
- gaps and barriers to achieving high quality and equitable provision of care, including workforce issues, funding settings, and standards of care
- actions to improve integrated services across all providers and care settings over the next 3 to 5 years
- actions to improve access to, and quality and standards of care, and ensure equitable provision of care over the next 3 to 5 years, including within existing funding levels.

Background

At the time of confirming new funding of \$76.1 million for improving hospice community palliative care services in Budget 2015, Cabinet directed officials to undertake a review of hospice and palliative care services and report back to joint Ministers [CAB Min (15) 12/2(26)].

While many New Zealanders are receiving excellent palliative care, the Government is not confident that all New Zealanders are receiving the level and quality of palliative care that they can expect from a modern health system.

Access to palliative care varies depending on diagnosis and prognosis, and the availability of services in each region, rather than being based on assessed need. There is some evidence that some population groups are missing out on care appropriate to their needs. There is also room for improvement in the quality of care across all care settings.

New Zealand has a fragmented system of palliative care providers. While services are working well together in some regions, they are not working as well in others. The integration of services across primary and specialist care, and between fully-funded public providers and independent private and charitable providers, is understood to be a critical component of ensuring people are able to receive the appropriate level and quality of care.

Finally, it is not clear that current service and funding arrangements will meet future demand, and deliver affordable services in the medium term, as the health system responds to an increasing number of older people, and an increasing number of older people with complex health conditions.

Scope

The scope of the Review includes:

- establishing a definition of palliative care for the purposes of the Review that focuses the Review on palliative care towards the end of people's life
- palliative care services for adults (defined as people 18 years of age and over, subject to this aligning with data availability and the practical provision of care)
- primary and specialist palliative care services
- palliative care services provided across all places of care, including at home, in hospital, in a hospice, or in an ARC facility
- actions to improve services over the next 3 to 5 years
- policy options within existing legislative settings.

The Review does not cover:

- person-centred chronic disease management that focuses on improving quality of life for those people with life-limiting conditions, when death may still be many years away
- paediatric palliative care services
- the legal status of voluntary euthanasia, which is the subject of a petition currently before the Health Select Committee in 2015/16 (terms of reference for an inquiry are under development).

The Review findings and recommendations will align with the update of the New Zealand Health Strategy, due for completion at the end of 2015, and the refresh of the Health of Older People's Strategy, due for completion in 2016.

Approach

The Review will be undertaken by the Ministry of Health.

An initial focus for the Review will be to assess current services against the *Resource and Capability Framework for Integrated Adult Palliative Care Services (2013)* through a process to be developed in consultation with district health boards.

The Review will leverage existing information and/or reporting and accountability mechanisms and is likely to include:

- review of existing documentation
- literature review
- liaison with international agencies
- targeted interviews
- national, regional and local workshops
- development of working and discussion papers
- public engagement and consultation.

A new advisory group to the Ministry on palliative care is being established to replace the Palliative Care Council. This advisory group will provide advice to the Review.

The Ministry will seek the views of service users, and may form additional advisory groups in targeted areas, or to represent particular stakeholders, as required.

The health sector will expect a high level of engagement in the Review, and there is strong public interest in end-of-life care. As far as is practicable, and within the constraints of the Ministry's advisory role to Ministers, the Review will:

- work closely with district health boards as the Crown agencies with statutory responsibility for planning and purchasing health services for their region
- demonstrate and foster the open, collaborative relationships that are necessary for successful integrated services between multiple and different organisations
- provide open and regular communication about the Review to the sector and public.

Review deliverables

The Ministry will report to the Minister of Health with the following deliverables:

- An interim report by 30 April 2016
- A final report by 30 September 2016.

Related work

Other work underway will be relevant to the Review, and may provide opportunities to leverage existing processes. This includes:

- work currently underway between the Ministry, district health boards, and Hospice New Zealand to roll out the new Budget 2015 funding
- finalising the *Palliative Care Needs Assessment*, developed by the former New Zealand Palliative Care Council
- finalising the *Palliative Care Glossary*, developed by the former New Zealand Palliative Care Council
- implementation of the *Resource and Capability Framework for Integrated Adult Palliative Care Services* (2013)
- implementation of national guidance on end-of-life care, developed by the former New Zealand Palliative Care Council
- quality improvement projects led by Hospice New Zealand
- a pilot of a managed clinical network for palliative care in the lower North Island, led by Health Workforce New Zealand
- the refresh of the Health of Older People's Strategy.

The Ministry will liaise with the Treasury and the Ministry of Social Development on the content of the Review and ensure the Review's processes and findings are well aligned across Government.