**Webinar Q&A - *Planning for Palliative Care services in Aotearoa; what our population data tells us***

**23 May 2023**

This document is not a transcript of the answers given during the webinar. Here, we reflect on some of the questions asked via the Q&A tool, add additional responses and suggest resources for further information.

Where slides are referred to below, the slides are as numbered in: “Slide pack, Planning for palliative care services in Aotearoa, May 2023”.

There is a video recording of the questions asked and answered during the webinar at: <https://vimeo.com/829578999/44ac9fa03c> The questions begin at the 1.28.09 time mark.

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| Q |  | What was most surprising to Heather and Jo? or was it as expected? |
|  | A | Jo – we knew there were pockets of variance in Aotearoa, but I was surprised to see just how many differences there are between some districts and regions.  Heather – Agreed. The slide I was most surprised by was #43, the place of death for those with cancer, comparing the four regions. Slide #42 is the same regions but for all other need for palliative care. The reasons for differences should be a fruitful place to begin regional discussions about models of care.  I was also surprised about the similarity of the Māori and non-Māori patterns by age band. See slides #61 on residential care and #62 on dementia that I found most surprising. There were others we were unable to include in the time available. Slides #61 and 62 have important implications about preparing for Māori deaths at older ages. |
| Q |  | Has there been any updates on expected hospital inpatient use in last year of life with new updated expected deaths or is it still OK use old studies on this? |
|  | A | Heather – there is no update on the patterns used, as they still come from the Trajectories Study 2015. But yes, we do now have new projections of deaths from Stats NZ (slides #86 and 87 show the differences in the projections). The old patterns with the new projections are in a new model prepared for Te Whatu Ora.  It is wise to abandon all the previous models (listed on slide #86) and to only use the new Palliative Care Projection Model. |
| Q |  | It would be good to analyse place of death with "quality of death". The quality of dying is missing and how can we measure that?  Would the more widespread use of PROMs be used to measure the quality of care? |
|  | A | Heather – Agreed to both questions! Measuring quality is complex. There is all the good work done on measuring outcomes by hospices. Patient-reported outcome measures (PROMs) are usually part of a suite of outcomes measures. All these are quantitative measures and I suggest you contact Hospice NZ to discuss how those measures have worked out or evolved in practice. It is several years since I was last involved, but we did do a first analysis of measures in 2019.  For qualitative information, my preference is for “VOICES” type studies where we can listen to the experience of families and whānau. Pilot “VOICES” studies have been done for Auckland by Merryn Gott’s team at the University of Auckland, and for the South Island by the South Island Alliance Programme Office (SIAPO). Some links:  <https://www.sialliance.health.nz/voices-survey-results-released/>  <https://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.13053>  <https://pubmed.ncbi.nlm.nih.gov/33849502/>  <https://pubmed.ncbi.nlm.nih.gov/32076928/>  <https://journals.sagepub.com/doi/10.1177/0269216319843026>  <https://journal.nzma.org.nz/journal-articles/voices-south-island-pilot-survey-of-bereaved-people>  See on the video Kate Grundy’s comments about a measure of quality developed for hospitals and adopted by Round Table. |
| Q |  | Will Assisted Dying deaths be included in your projections going forward?  Do you envisage including data in the future that looks at place of death for those who die by an assisted death? |
|  | A | Heather - No. See video for answer on why we will not get access to this on an individual basis. The Ministry of Health does provide regular reports on the numbers at <https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/assisted-dying-service-data-and-reporting>  The team of academic researchers that meets to discuss research related to assisted dying is called the Assisted Dying Research Network. |
| Q |  | Will the regional data be further broken into districts? i.e. Northland data differs from Auckland but in same region |
|  | A | Heather - We have all that data, and it is available for Te Whatu Ora to use in discussions. The Palliative Care Projection Model has both regions and districts. It also has a new section where districts within a region are compared. |
| Q |  | Is there work being undertaken on hospice episodes of care? criteria is often restrictive for Chronic illness understandable however hospice may be in for short episodes? |
|  | A | Heather – The Trajectories Study 2015 produced some good information on the time before death of first referral to hospice. Yes, time is often very short for palliative care. That study also produced information on timing of the first admission to aged residential care (ARC). Those times are much shorter than many people thought.  More detail on hospice episodes of care was investigated using only Hospice data a few years ago. Contact Hospice NZ for that and any newer information. |
| Q |  | Do you expect palliative care InterRAI assessments could enhance the ARC data |
|  | A | Heather – interRAI assessments are a very valuable source of data for work like the Trajectories Study. Michal Boyd and I have also done some thinking about frailty at the end of life, using data from interRAI.  The palliative care assessment is one of a suite of interRAI assessments and we use data on all the instruments. The palliative care assessment is shorter, so the most important issue is how it helps the change in focus within ARC at the end of life.  See <https://www.interrai.co.nz/news-and-media/first-data-from-the-palliative-care-assessment/> |
| Q |  | We talk about where people die but one of the big problems is who people are being cared for by. Do you have any thoughts or data on who cares for people currently and who could be assisting in palliation in the future. E.g. death doulas, rural community paramedics etc.? |
|  | A | Heather – see also the extensive material on daily place of care from the Trajectories Study 2015. I would certainly like to include Hospital Palliative Care NZ, the Paediatric Palliative Care Network, district nursing, and paramedics in a future Trajectories Study. Anyone who has patient information by NHI number can be included (we de-identify the NHI numbers before using the data). I would doubt that death doulas or other community support people are collecting NHI information. |
| Q |  | I would love to see non-normalised data - context of weighting is essential to truly understand this data. Percentages can muddy the context making low incidence appear high based on a percentage of a low number. |
|  | A | Heather - See video for answer. Have also been in touch with the person who asked this question, to see if we can pull out something more meaningful for them. |
| Q |  | Will the transitions in care within 3 or 6 months of death be available to access? |
|  | A | Heather – yes, the animations of transitions from the Trajectories Study 2015 are available on the project site:  [Heather McLeod & Associates Ltd OneDrive Trajectories Project Shared Animations](https://heathermcleodnz-my.sharepoint.com/:f:/g/personal/heather_heathermcleodnz_onmicrosoft_com/EkTQniYgpWVDpbdHtjAFtfUByGEeS5x_6v3XBiaFUpNebA?e=oxMaGa)  There are five animations available. Slide #77 shows the last day for one of those animations, that showing four of the five Trajectory Groups. Read the instructions document first. |
| Q |  | Will Te Whatu Ora also consider how to attract nurses to resource the increasing need for palliative care and Jo is Te Whatu Ora or Hospice NZ considering a post graduate certification in palliative care? |
|  | A | Jo – hopefully the Pay Disparities funding recently offered to community providers (including hospices) will help them to both retain and attract nurses. We are fortunate to have several academic institutions in Aotearoa that already offer post graduate courses and certificates in palliative care. |
| Q |  | Thank you, Heather, a very useful and informative presentation. Very pleased to see 'Asian' data included in your presentation :). Thank you. I would like to ask if we have data available to look a bit more into the 'Ethnic' population to better understand their needs- for instance the Middle Eastern, Latin American and African (MELAA) population. Thank you. |
|  | A | Heather – the projections Stats NZ does annually for the Ministry of Health and Te Whatu Ora use only four groups: Māori, Pacific, Asian and Other. The groups are prioritised in that order. In other words, the palliative care projections cannot be done separately for MELAA.  In the MORT study 2000-2018, I can see ethnicity in more detail. However the MELAA group is very small: a total of 1,779 deaths out of 571,122 deaths in the study, or only 0.31 of a percent. By contrast, there are 59,815 Māori deaths, 22,574 Pacific deaths and 15,723 Asian deaths in the study. We simply can’t get smooth and stable patterns with such a small number.  Stats NZ has more on MELAA population projections but only at a national level: <https://www.stats.govt.nz/information-releases/national-ethnic-population-projections-2018base2043-update/> |
| Q |  | Given the significant proportion of patients dying in hospitals- should all hospitals have a HPCT or role funded by TWO? |
|  | A | Jo – our first task is to understand what resources currently exist, and where, and map these against what the needs of people are, and where. Then we can look at areas that require a review of resources. |
| Q |  | Will work be done/or has been done on mapping RACF availability in the regions? |
|  | A | Jo – yes, Te Whatu Ora already maps services such as aged residential care facilities and General Practice Teams by districts and regions. We hope to combine this information with our knowledge of palliative care need and service availability. |
| Q |  | There is no information on the rural measure for my district [*named*]. |
|  | A | Heather – in terms of maps, like slide #66, we were only able to choose one for the time available. There is a very useful interactive map for the country, that uses SA1 areas, and also has facilities mapped at:  <https://storymaps.arcgis.com/stories/da035e374dbb4ea0ae3b31b6777924ad>  More detail on how the GCH measure is derived is at: <https://blogs.otago.ac.nz/rural-urbannz/>  See also the NZ Medical Journal paper on this new measure: <https://pubmed.ncbi.nlm.nih.gov/35999779/>  The maps only show the size of the area that is classified. The size of the rural area can be very different to where the deaths are – as we know for Te Waipounamu. There are two slides that show the proportion of deaths by this urban-rural measure, only for deaths in the definition of need for palliative care. See slide #69 for the region and #70 for the same analysis by district. |
| Q |  | Thank you for this very informative presentation. What is the age structure in rural areas? Difference with urban. |
|  | A | Heather – across all causes of deaths, the deaths in the most rural areas tend to be younger, and more male, and are more likely to be from cancer.  We thus analyse all the cancers together, and all the other need for palliative care together, taking out the sudden causes of death. The age differences are smaller when the sudden deaths are removed. |
| Q |  | Have you looked into the reasons why Māori have not been accessing Hospice IPU? |
|  | A | Heather – we have begun, but certainly don’t have all the answers yet. We have looked at differences between regions by age, sex, ethnicity, deprivation, the urban-rural measure, and by grouped cause of death.  Te Manawa Taki is the highest proportion of Māori deaths, relative to total deaths. We also know that the model of care in this region is much more community-oriented. Slide #43 shows that Te Manawa Taki only developed hospice IPU beds after 2000, and the numbers having hospice IPU as a place of death have grown steadily, although still much lower than for Central. There are some other complexities in Te Manawa Taki. For example, several hospices have no IPU beds, but Tairawhiti Hospice uses beds in Gisborne public hospital, and the hospice in the Eastern Bay of Plenty used to contract for some aged residential care beds.  So is the difference for Māori model of care? Or preference? Or the way contracts are set up? Or something else?  At best, I can put the evidence on the table for more detailed discussions, so that we can listen to people who work in that region. |
| Q |  | Given workforce issues in specialist palliative care, the cost of hospice care and the emphasis now on primary care-led palliative care should there be more emphasis on generalist palliative care and also on community enablement to support dying at home? |
|  | A | Jo – this will be a pivotal question in the models of care work that we will be establishing in the coming months. |
| Q |  | On reflection - the model does not make a distinction between specialist and generalist palliative care - should we just lump it as Palliative care in the future - Hospices will be overwhelmed pretty quickly without resourcing |
|  | A | Jo – how services work together to support patients and whānau will be key to the models of care work that we will be establishing in the coming months.  Heather – listen to the answer on the video. |

**Other comments and ideas received from attendees (via the Q&A tool) during the webinar:**

* The ability for people to be cared for at home in future will depend on our housing stock as well. In the major centres a lot of new housing is multi-level with poor accessibility.
* Need to express Hospice IPU death numbers on slide 70 as percentage of IPU Beds available in each region.
* Excellent presentation, thank you Heather! I think we need to get better data on generalist palliative care. If we had more funding and a more consistent approach to our community-based generalist palliative care we may help many more people with palliative care needs in the community.
* Many thanks Heather, very informative session, insightful data sets and analysis
* So good to see all this data! Extremely helpful data to assist in decision making
* It's very refreshing to hear that the differences have been discovered. There is no one size fits all solution. Future care must be determined by local providers in partnership with their community.
* Agree the Voices survey would be valuable to overlap some of this mahi and help us all understand more fully the experiences of family carers supporting EOL care in the home. There are also a number of small qualitative studies in New Zealand in this space as well.
* With enough funding and staff we can manage more care in the community
* I wonder what the 'aged residential care' sector makes of this information. I wonder too, how Te Whatu Ora might ensure high quality of care in all settings..... urban/rural, place of care, settings where most palliative care is provided in the primary care setting.
* Publicly funded hospitals need to have palliative care beds where the leader of care needs to be palliative care after a decision with other specialities and according to goals of care, is to take the palliative care approach. These will be the beds where patients are cared for with the primary focus being palliation of symptoms, physical or psychosocial, etc, and where patients can also be cared for when they are dying. We cannot rely on the current model, which is outdated, not effective, and not reflective of where deaths are happening. Your talk is shedding great light on this. Thank-you.
* With regard to impact on family/whanau carers, there is a relatively new NZ report - The State of Caring in Aotearoa available here: <https://carers.net.nz/state-caring-report/>

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