

Policy Brief on Trajectories of Care at the End of Life in New Zealand

The aim of the project was to use national data linked by NHI number to provide an answer to the question: who is not reached by specialist palliative care (hospices and hospital palliative care) or by aged residential care (ARC). This identifies the size of the primary palliative care work-load, which needs to be met by Primary Health Organisations (PHOs) and district nursing services. The overlaps and gaps in service by cause of death, place of death, age, gender, ethnicity and deprivation were to be investigated. The results nationally, regionally and by DHB would inform service development.

The intention was also to provide an understanding of the different trajectories of care at the end of life, contrasting sudden deaths, cancer patients, chronic disease, and those with frailty and dementia¹. Sub-components of the project were to advise on the feasibility of collecting a minimum data set for hospital palliative care and to identify funding flows for end of life care. The Ministry of Health commissioned the project, which began in September 2017.

All deaths occurring and registered in 2015 were studied, with a history of health care utilisation going back ten years where feasible. This brief describes the key findings from the research. A separate technical note, "Technical Note on Trajectories of Care at the End of Life Research", describes key methodological choices and decisions in the research.

1. The Trajectories Groups

The trajectories groups were extracted sequentially as follows:

- **Dementia:** anyone with any evidence of dementia².
- **Cancer:** no evidence of dementia but evidence of cancer from the Cancer Registry and died of a neoplasm, or no evidence of cancer in the Cancer Registry but cause of death on the death certificate was a neoplasm.
- **Chronic Disease:** no evidence of dementia and cause of death not a neoplasm; any aged residential care (ARC) subsidy or place of death was residential care, or any interRAI assessment. These are effectively the frail older people who need some assistance (in ARC or assessed for home care).
- **Need and Maximal Need:** all other causes of death that are included in the need for palliative care³ or the maximal need for palliative care⁴. They may have chronic disease but are generally younger. It includes those dying of congenital diseases and those receiving Disability Support Services, if not already allocated.
- **Other Sudden Deaths:** the balance of total deaths, where the cause of death is not in the maximal need for palliative care and not already allocated above. These are generally deaths from accidents, drownings, poisonings and self-harm.

¹ Lynn, J., & Adamson, D. M. (2003). Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. RAND Health. Retrieved from http://www.rand.org/pubs/white_papers/WP137.html

² McLeod, H., & Atkinson, J. (2019). Technical Note on Trajectories of Care at the End of Life Research.

³ McLeod, H. (2016). The Need for Palliative Care in New Zealand. Technical Report prepared for the Ministry of Health, June 2016. Retrieved from <http://centraltas.co.nz/health-of-older-people/tools-and-guidance/>

McLeod, H. (2016). Model of the Need for Palliative Care in New Zealand. Prepared for the Ministry of Health, June 2016. (Version 3.0). Retrieved from <http://centraltas.co.nz/health-of-older-people/tools-and-guidance/>

⁴ The maximal need for palliative care is an upper bound for projected need. As an indication, total deaths in financial year 2016 (FY2016) had been projected by Statistics New Zealand for the Ministry of Health to be 30,500. The Need for Palliative Care in FY2016 was projected to be 24,680 (80.9% of total deaths) and the Maximal Need for Palliative Care was 29,010 (95.1% of total deaths).

The relative sizes of the groups are shown in Figure 1 and the proportional profile by age band is shown in Figure 2. There is a very distinctive pattern by age band. The solid black line shows, using the right-hand vertical axis, the number of deaths in each age band.

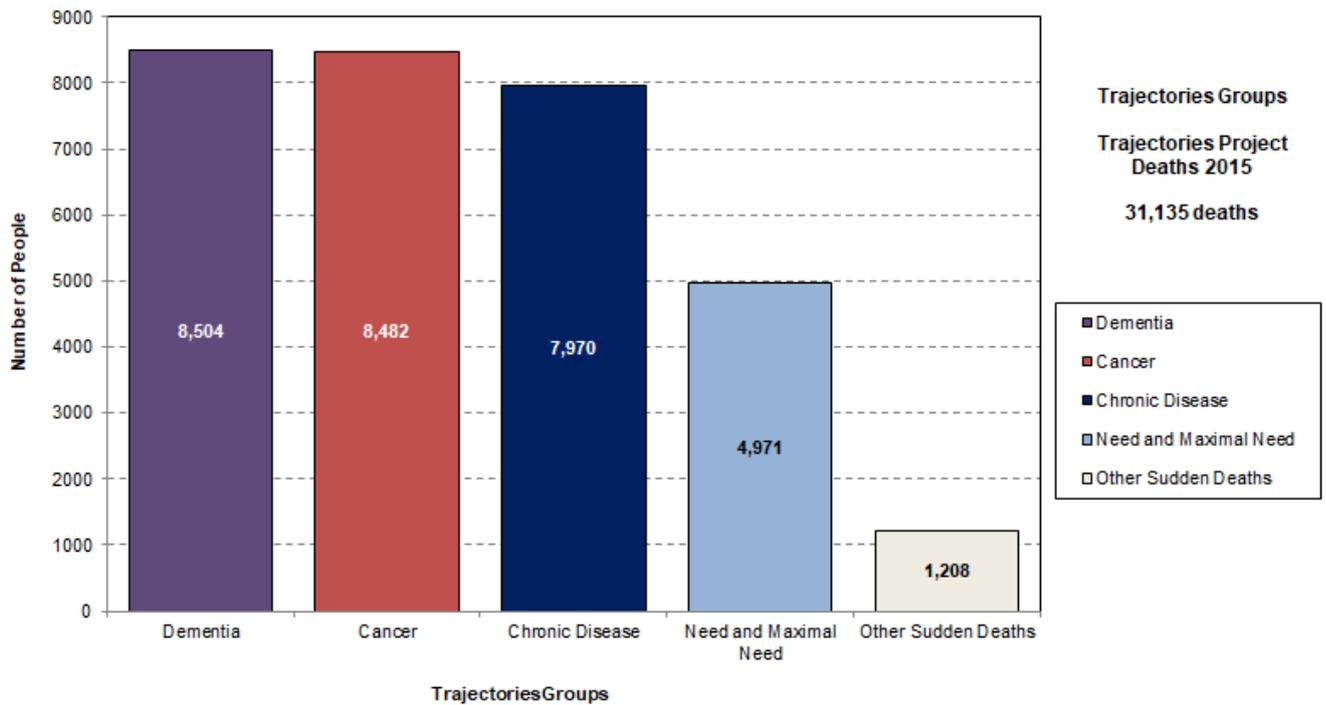


Figure 1: Trajectories Groups in New Zealand in 2015

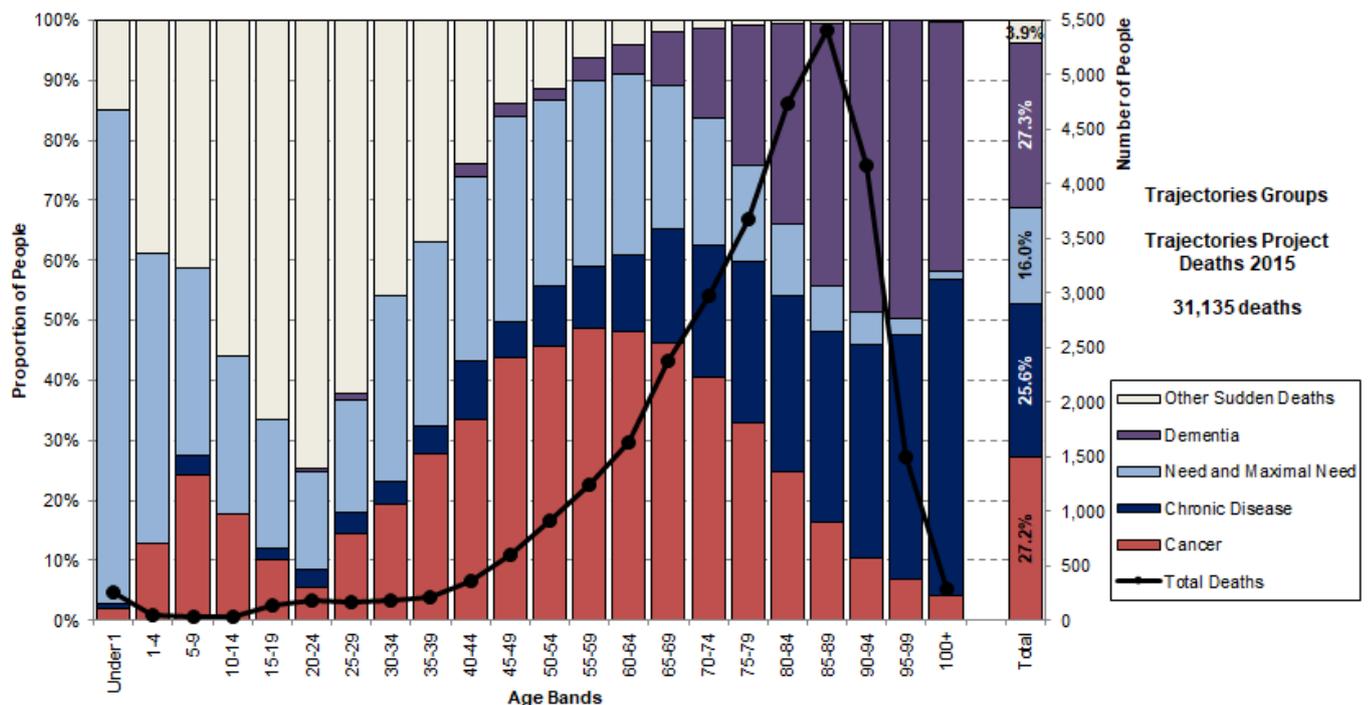


Figure 2: Trajectories Groups in New Zealand in 2015, by Age Band

In the childhood years, the Need and Maximal Need group is most evident. For deaths occurring in the teenage and early adult years, Other Sudden Deaths become the dominant group. The Cancer group has some childhood cases but begins to climb rapidly as a proportion of total deaths from a low point at age 20, reaching a peak around ages 45 to 69. At older ages, the proportions in the Cancer group decline, while the proportions in the Dementia and Chronic Disease groups increase rapidly.

These trajectory groups are used to explore services used in the graphs which follow. The shapes by age band are also sometimes shown as these give an indication of where pressure will be greatest as the number of deaths increases and as the age of deaths increases. Figure 3 shows projected deaths, as provided to the Ministry of Health by Statistics New Zealand in the 2017 update.

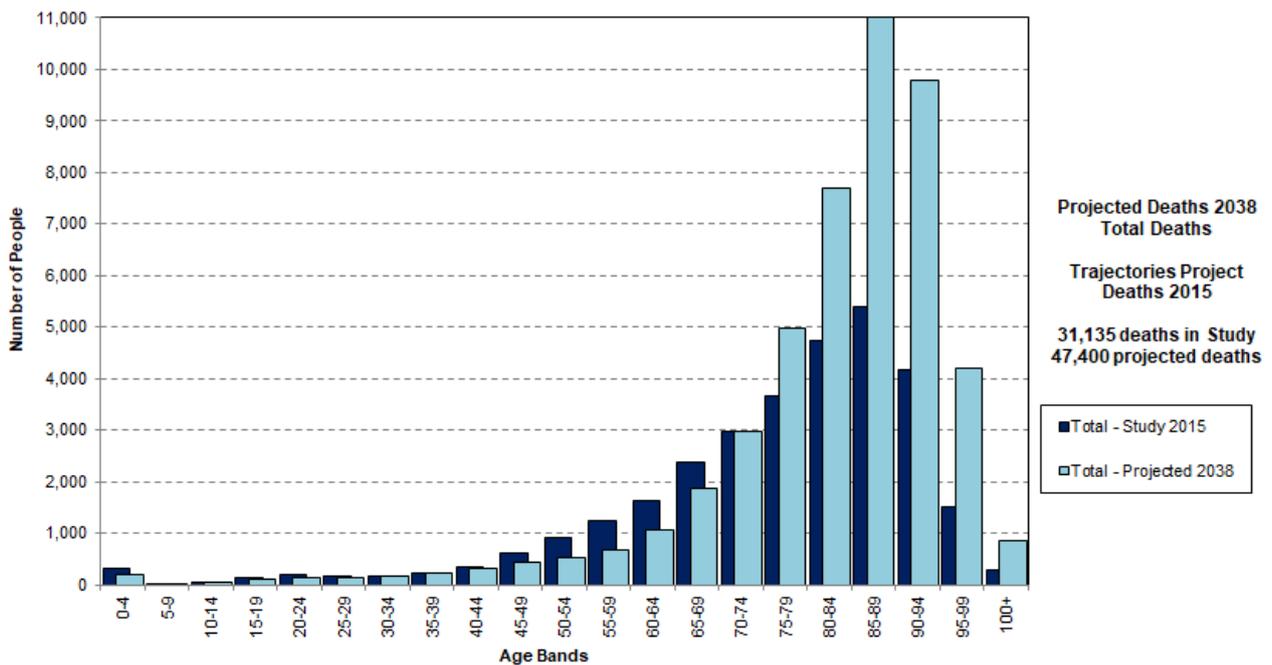


Figure 3: Increase in Numbers and Ageing of Projected Deaths by 2038

2. Utilisation of Hospital and Emergency Department

Figures 4 and 5 below show the use of public hospital and the emergency department (ED) in the last years of life.

In Figure 4, by trajectory group, 71.0% of all deaths have both public hospital admissions and ED events in the last year of life (LYOL). The Cancer group has the highest level at 84.7%. A significant proportion of those in the Dementia group have no use of public hospital or any ED event (30.5%).

The impact on public hospitals and ED by age band is shown in Figure 5. The strong decline in use of both services at older ages is a function of the numbers entering aged residential care at older ages. (see Figure 7).

Overall, 5.8% of people used public hospitals in the LYOL where there was no specialist palliative care service. Chronic Disease has the highest gap at 7.5% of deaths. The list of hospital palliative care services was developed in early 2018 and the coverage in 2015 may not have been as good as in 2018. Issues with collecting data on hospital palliative care are described in the Technical Note.

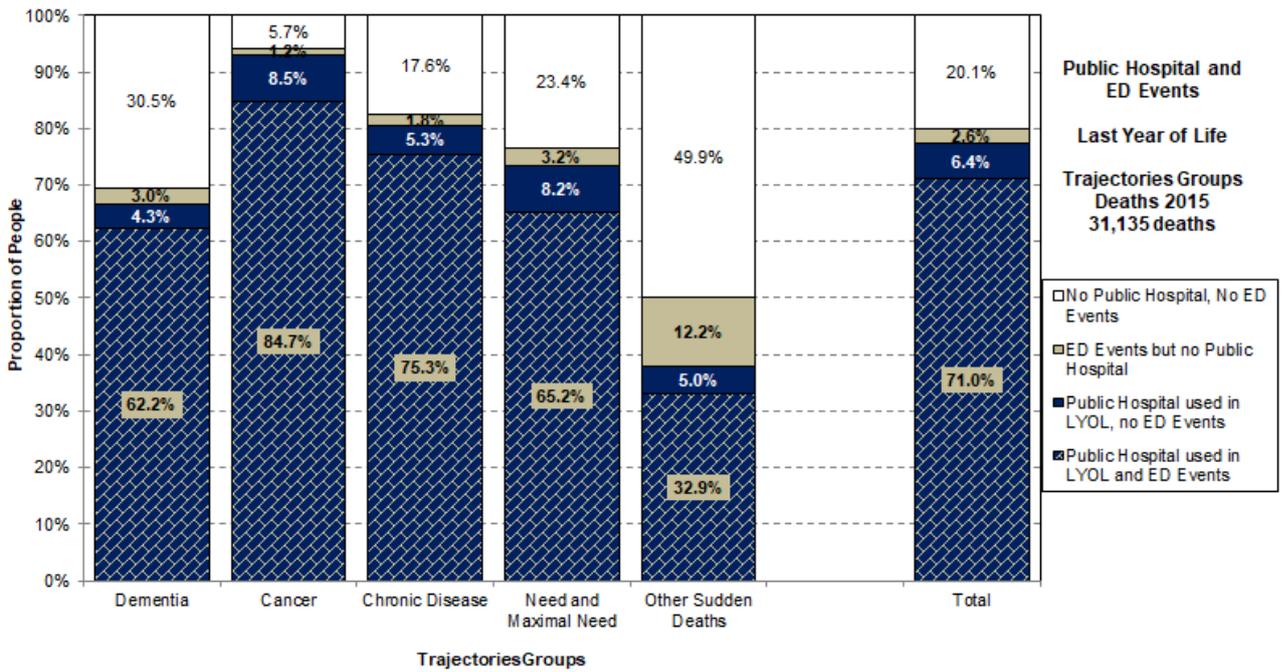


Figure 4: Public Hospital and Emergency Department Events

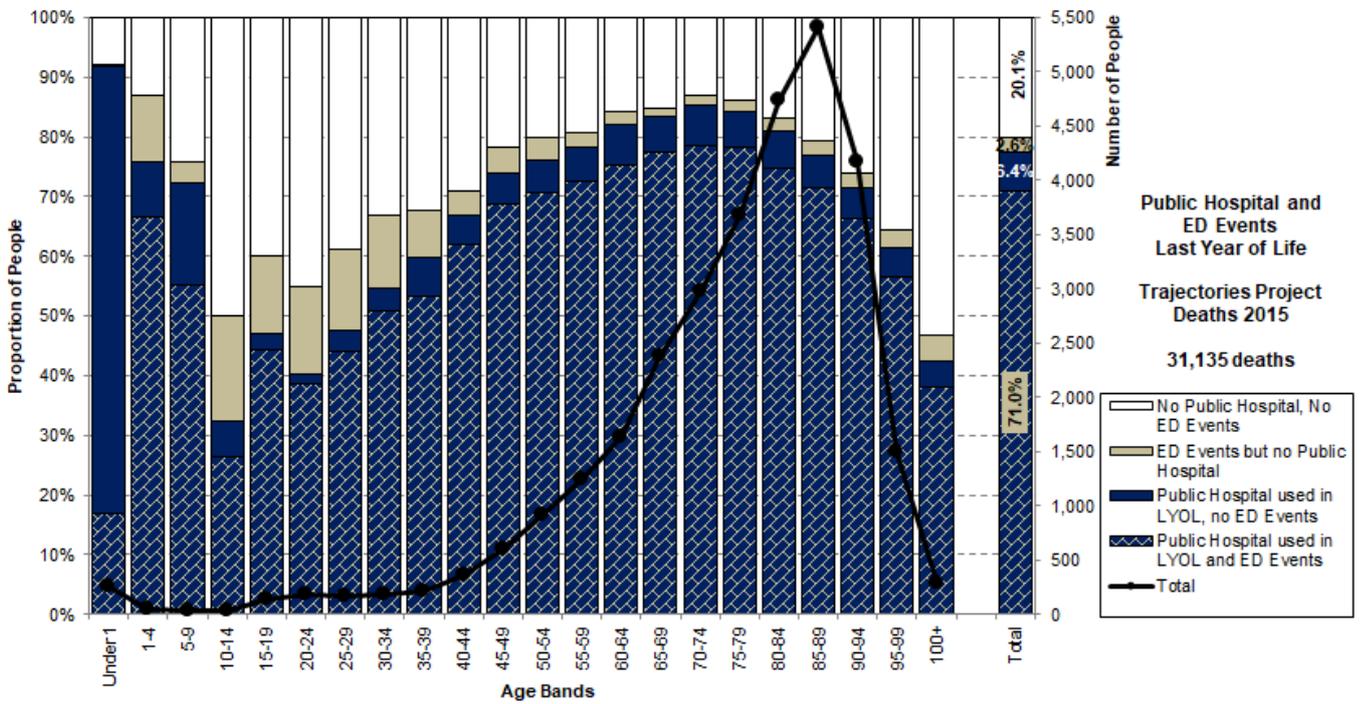


Figure 5: Public Hospital and Emergency Department Events by Age Band

3. Palliative Care Needed in Aged Residential Care

Aged residential care is a very important site for the provision of palliative care. In total, 38.4% of all deaths have an ARC subsidy at some stage in their trajectory. For the first time, in Figure 6, we can see the 5.5% who died in residential care but had no ARC subsidy. Thus, of all deaths in New Zealand in 2015, 43.8% have either an ARC subsidy or died in residential care.

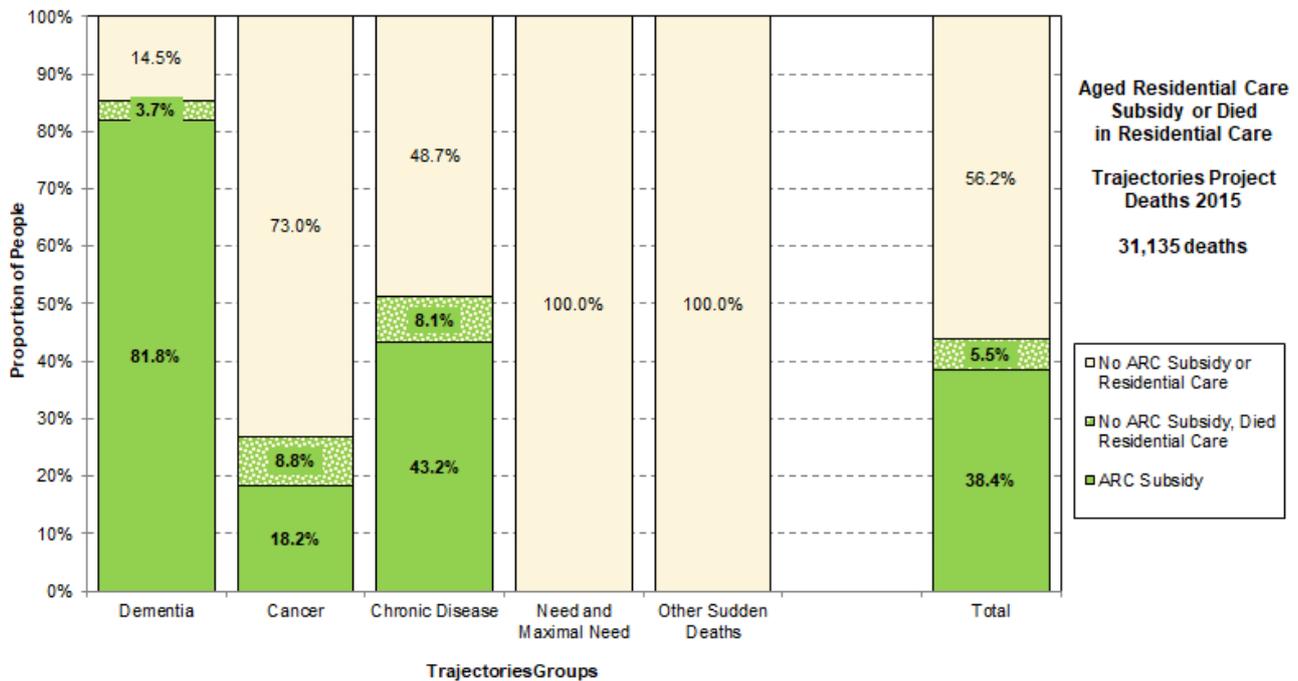


Figure 6: Aged Residential Care Subsidy or Died in Residential Care

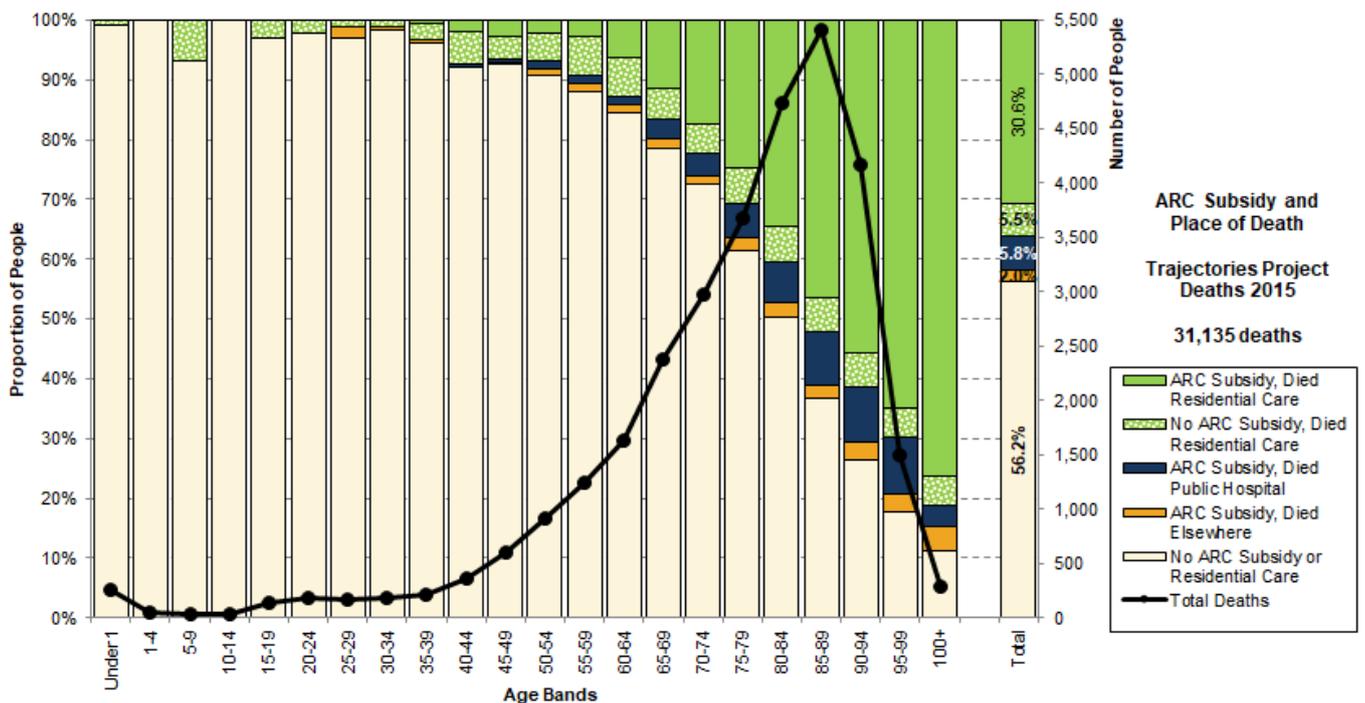


Figure 7: Aged Residential Care Subsidy and Place of Death

In Figure 7 we see that 5.8% had an ARC subsidy at some time and died in a public hospital, while 2.0% had a subsidy and died elsewhere. At older ages, the proportion with an ARC subsidy who die in residential care increases substantially.

4. Needing an Institutional Bed at the End of Life

In earlier work, residential care was sometimes seen as being “home” as it was thought likely that people were in aged residential care for long periods of time. Other researchers have shown how people are increasingly more frail on entry⁵ and have challenged the understanding of aged residential care as home^{6,7}. Our research shows the very short times that some people are spending in aged residential care facilities in New Zealand.

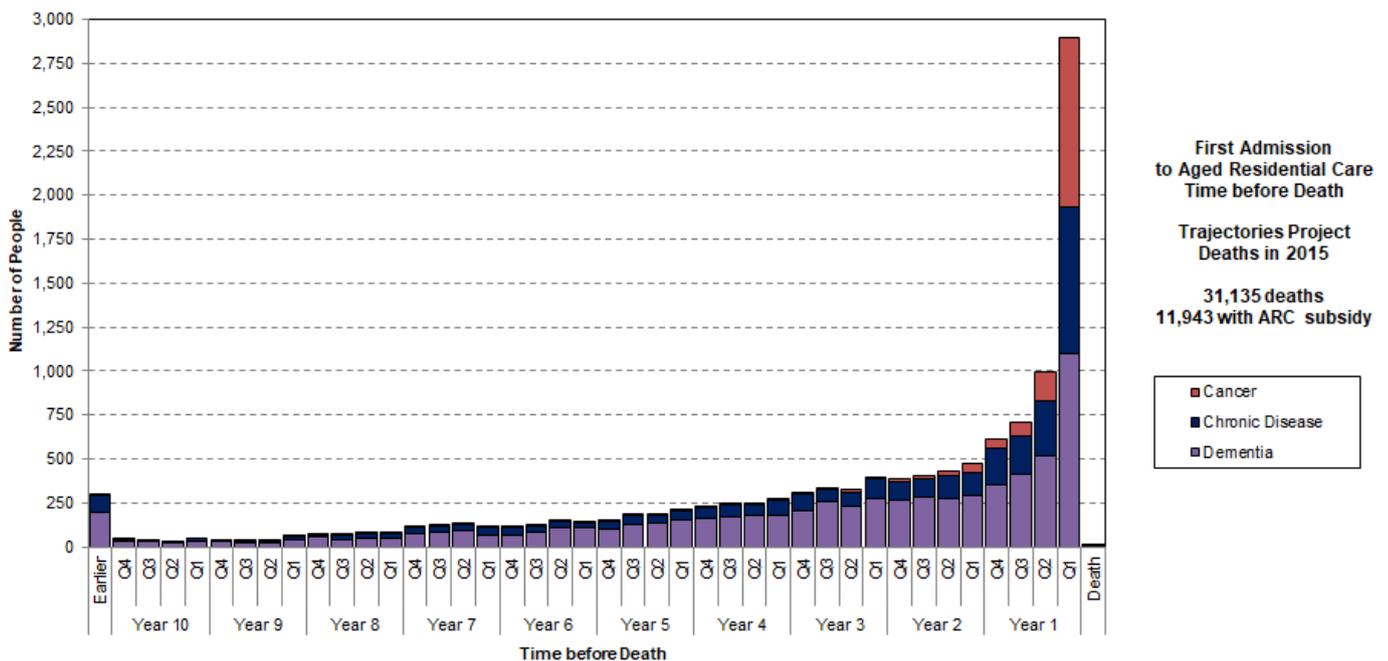


Figure 8: Timing of First Admission to Aged Residential Care

While there are some people with long stays in ARC facilities, so that ARC has become “home”, for many people there are very short stays in aged residential care. Overall, 43.7% of those with an ARC subsidy have their first admission less than one year before death and 24.3% are admitted for the first time in the last three months of life.

The proportion admitted in the last three months of life differs by trajectory group, with 15.9% for Dementia, 24.0% for Chronic Disease and 63.0% for the Cancer group.

⁵ Boyd, M., Broad, J. B., Kerse, N., Foster, S., von Randow, M., Lay-Yee, R., . . . Connolly, M. J. (2011). Twenty-year trends in dependency in residential aged care in Auckland, New Zealand: a descriptive study. *J Am Med Dir Assoc*, 12(7), 535-540. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/21450250>

⁶ Connolly, M. J., Broad, J. B., Boyd, M., Kerse, N., & Gott, M. (2014). Residential aged care: the de facto hospice for New Zealand's older people. *Australas J Ageing*, 33(2), 114-120. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/24521449>

⁷ Phillips, J. L., & Currow, D. C. (2017). Would reframing aged care facilities as a 'hospice' instead of a 'home' enable older people to get the care they need? *Collegian*, 24(1), 1-2. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/29218955>

We can look at the place of death data with a different lens by combining the three key places providing a bed at the end of life: public hospital, aged residential care and hospice in-patient units. Overall, 73.9% of the deaths in 2015 had some sort of institutional bed as the place of death (public hospital, aged residential care or hospice IPU).

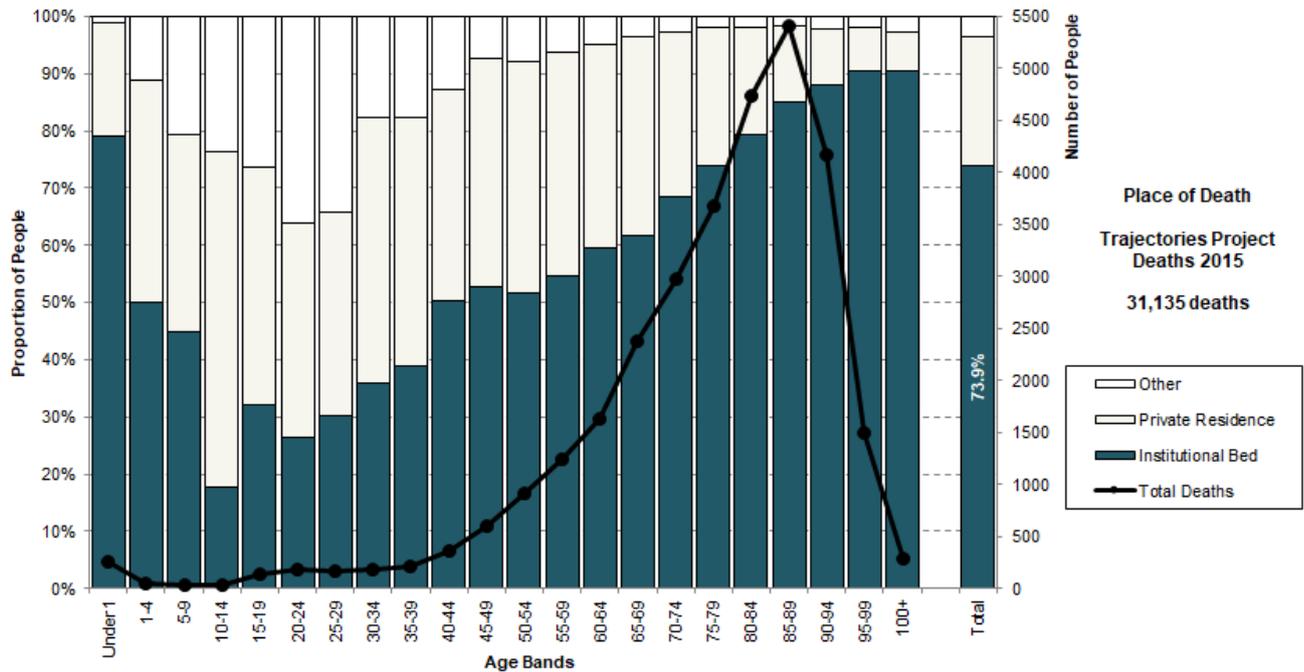


Figure 9: Institutional Bed as the Place of Death, by Age Band

In Figure 9 by age band, the use of some form of institutional bed is almost linear with age from age 10 onwards, reaching over 90% by age 95. The use of an institutional bed at the end of life is 91.1% for Dementia, 81.1% for Chronic Disease and 68.5% for the Cancer group. This analysis challenges the understanding that care at the end of life can be delivered entirely at home at older ages.

It has been recognised that New Zealand has a much lower usage of public hospital at the end of life for older people than in other countries⁸. For those over age 65, New Zealand has the lowest proportion of deaths in public hospital and the highest proportion of deaths in aged residential care.

It seems that District Health Boards (DHBs) have been highly successful at discharging older people from public hospitals to aged residential care, but this means that the burden of providing quality palliative care is transferred to staff in ARC facilities.

Eight people were admitted to aged residential care for the first time on the day of death and 343 in the last week of life. In the last four weeks of life, 1,423 were admitted, which is 11.9% of those with any ARC subsidy.

⁸ Broad, J. B., Gott, M., Kim, H., Boyd, M., Chen, H., & Connolly, M. J. (2013). Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *Int J Public Health*, 58(2), 257-267. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/22892713>

5. Specialist Palliative Care provided by Hospices

Hospices have been expanding care from their traditional roots in cancer care, but coverage of those in groups other than cancer remains very low.

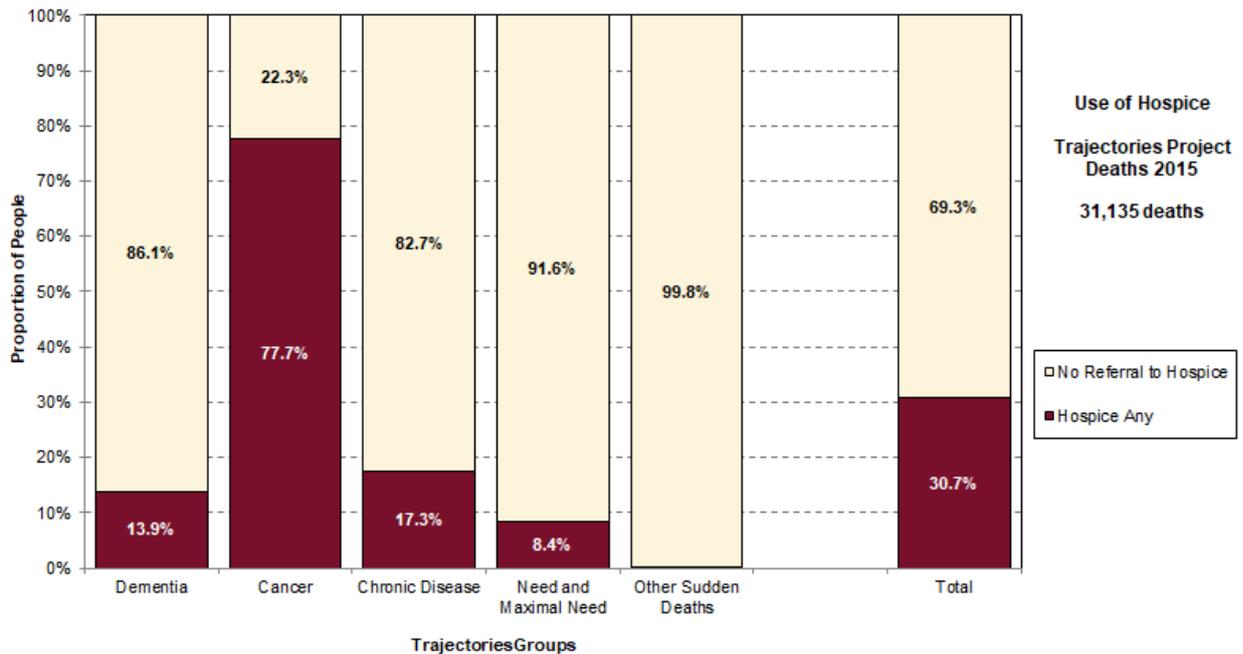


Figure 10: Referral to Hospice

Overall, 30.7% of people in the Trajectories study used hospice as part of their end of life trajectory. This was highest for the Cancer group at 77.7%. Only 13.9% of those with Dementia and 17.3% of the Chronic Disease group used hospice.

There is evidence that early palliative care in the community^{9,10} is associated with reduced usage of the emergency department at the end of life. However, referral to hospice is occurring relatively late in the trajectory.

Overall, 89.4% of people using hospice are referred to hospice in the year of death, with only 10.6% referred prior to that period. Of people using hospice, 60.3% were referred in the last three months of life and 33.8% in the last four weeks of life.

Those in the Cancer group tend to be referred to hospice earlier, with 25.9% in the last four weeks of life, compared to 47.8% for Chronic Disease, 53.1% for Dementia and 57.3% for the Need and Maximal Need group. In total, 117 referrals were received on the date of death and 16 referrals were only received by hospices after the date of death. Earlier referral to palliative care needs to be encouraged for those with a non-cancer diagnosis.

⁹ McNamara, B. A., Rosenwax, L. K., Murray, K., & Currow, D. C. (2013). Early admission to community-based palliative care reduces use of emergency departments in the ninety days before death. *J Palliat Med*, 16(7), 774-779. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/23676094>

¹⁰ Rosenwax, L., Spilsbury, K., Arendts, G., McNamara, B., & Semmens, J. (2015). Community-based palliative care is associated with reduced emergency department use by people with dementia in their last year of life: A retrospective cohort study. *Palliative medicine*, 29(8), 727-736. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/25783598>

6. Estimate of Specialist Palliative Care

Specialist palliative care is defined in New Zealand¹¹ as palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care is provided by hospice or hospital-based palliative care services directly to the person, family and whānau. A first estimate of the provision of specialist palliative care in New Zealand was made, as shown in Figure 11.

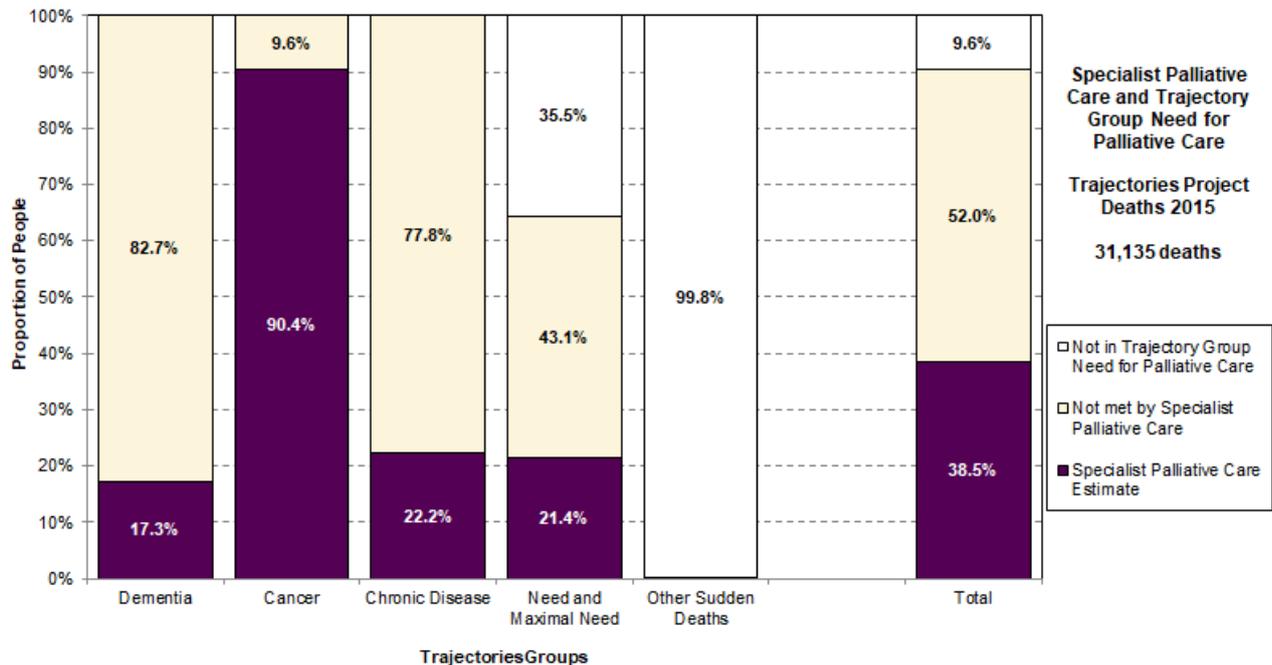


Figure 11: Estimate of Specialist Palliative Care, with Need for Palliative Care

It is estimated that specialist palliative care was provided to 38.5% of total deaths. If the assumptions about overlap and spread between groups are valid, then 90% of the Cancer group received specialist palliative care, while only around 18-22% of the Dementia, Chronic Disease, and “Need and Maximal Need” groups did so. Note that this is only an estimate, based on available data¹². The accompanying technical note¹³ describes the issues with obtaining national data on hospital palliative care services.

It was found that in the last year of life, 1,817 people used a hospital (or hospitals) with no specialist palliative care service. This is 7.5% of people using a public hospital in the LYOL and 5.8% of all deaths. The group that have the largest gap in potential service are Māori, with 9.2% using a hospital in the LYOL with no access to specialist palliative care.

Specialist palliative care also provides an indirect service to provide advice, support, education and training to others to support the primary provision of palliative care. This activity was not able to be measured in this study.

¹¹ Ministry of Health. (2015). New Zealand Palliative Care Glossary. Wellington: Ministry of Health Retrieved from <http://www.health.govt.nz/publication/new-zealand-palliative-care-glossary>

¹² There is no national collection of data from hospital palliative care services and we were unable to obtain service coverage by NHI number, as described in the Technical Note. Summary data was available from a Hospital Palliative Care Working Group convened for this project.

¹³ McLeod, H., & Atkinson, J. (2019). Technical Note on Trajectories of Care at the End of Life Research.

7. Hospice, Aged Residential Care and Primary Care

As specialist palliative care reaches only 38.5% of deaths in the country, it is important to consider which parts of the health system are therefore called on to provide primary palliative care. Figure 12 shows this relative to the need for palliative care, adapted for the trajectory groups, while Figure 13 shows the pattern by age bands.

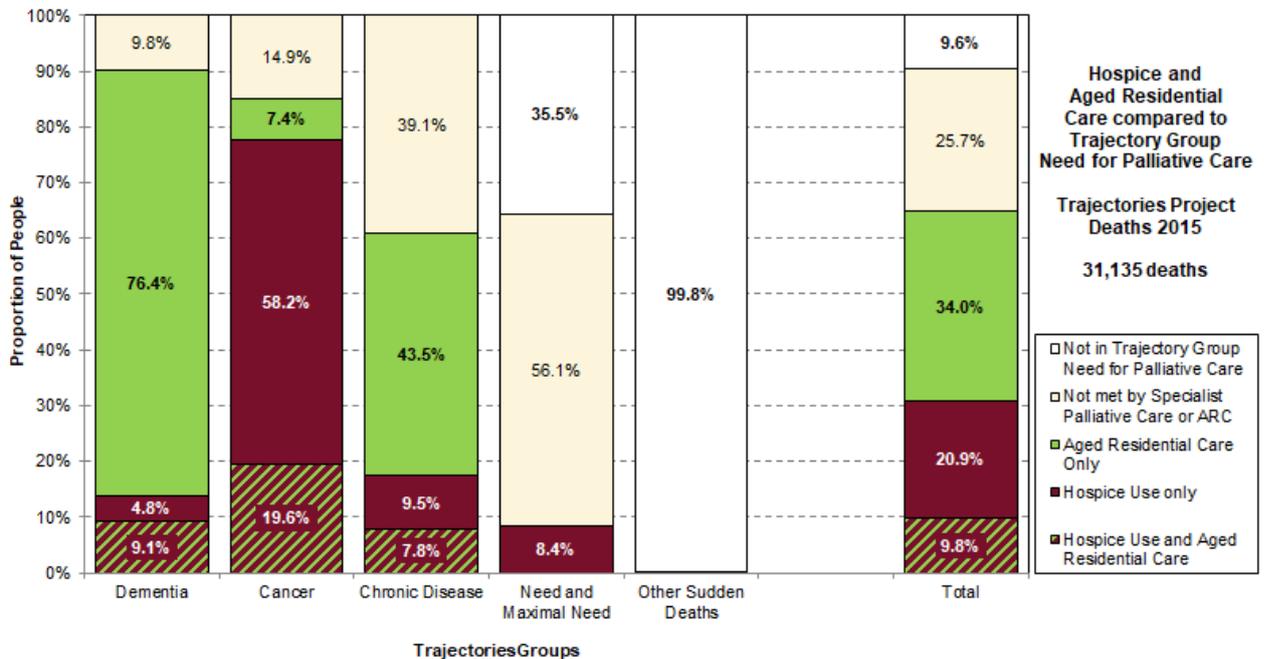


Figure 12: Hospice and Aged Residential Care compared to Need for Palliative Care

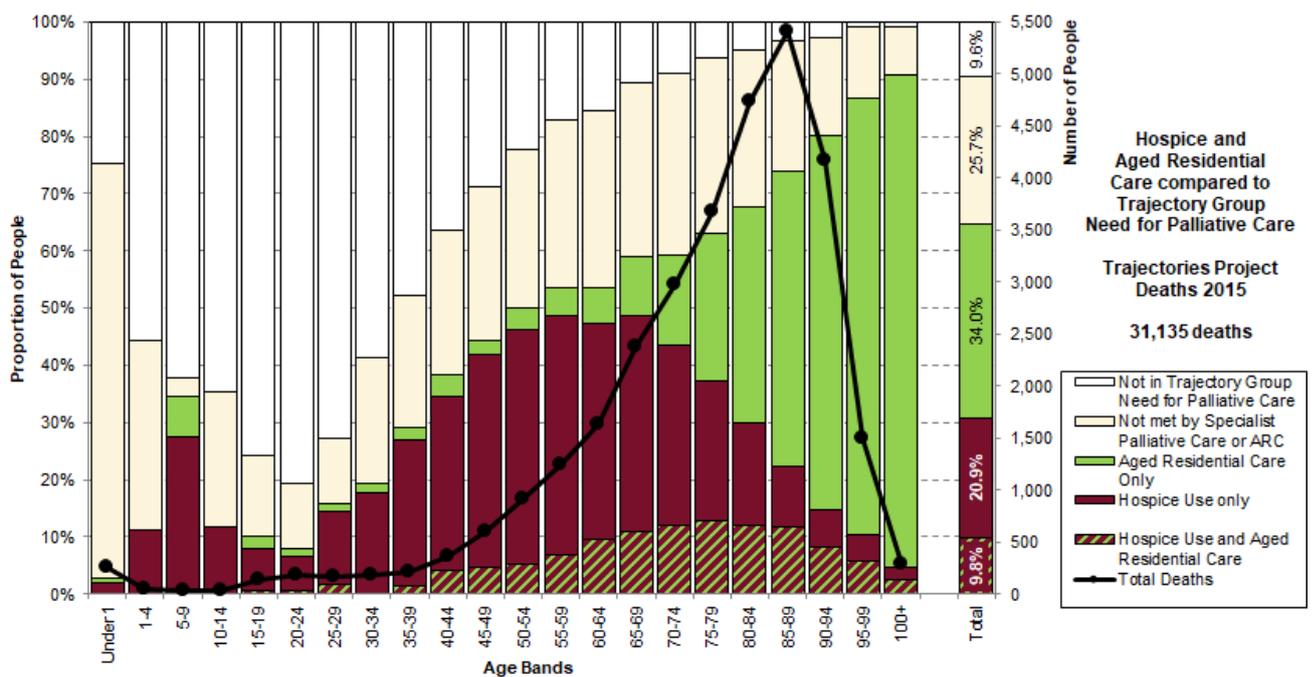


Figure 13: Hospice and Aged Residential Care compared to Need for Palliative Care, by Age Band

Overall, 64.8% used hospice services or aged residential care (ARC). 9.6% of total deaths fall outside the Trajectory Group Need for Palliative Care¹⁴, leaving a cream group of 25.7% needing on-going palliative care from the primary care team. Some may have seen a hospital palliative care team, but this would have been a short intervention before discharge from public hospital.

Primary palliative care therefore is a vitally important component to end of life care. Primary palliative care is provided by district nursing, GPs and PHOs, and by aged residential care. These teams need to be able to draw on support from specialist palliative care (hospices and hospital palliative care) in a fully integrated hub-and-spoke model¹⁵.

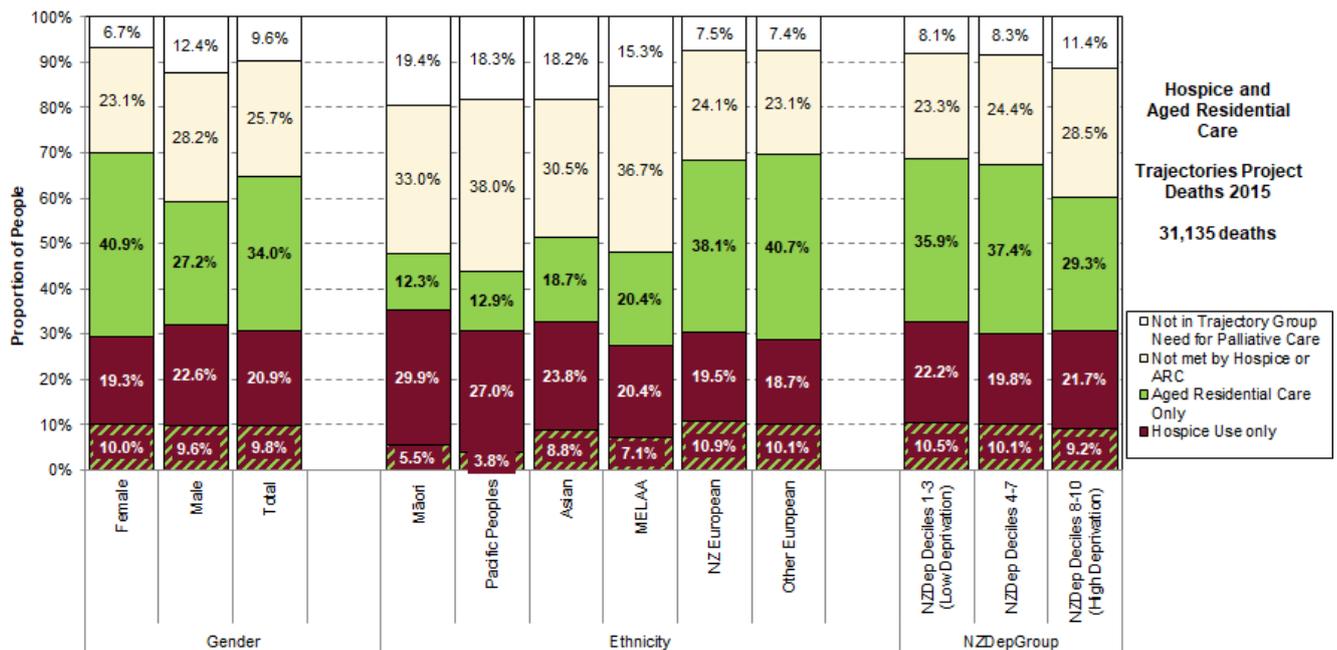


Figure 14: Hospice and Aged Residential Care compared to Need for Palliative Care, by Gender, Ethnicity and Deprivation

Considering hospice care alone, 30.7% of people used hospice as part of their end of life trajectory. The proportion was higher for men (32.2%) than women. By ethnicity, usage was highest for Māori (35.4%) and Asian (32.6%). The low deprivation group (NZDep 1-3) had higher proportional usage than the other groups. The gap between hospice care and the need for palliative care is highest for women, European and middle levels of deprivation.

When aged residential care as a place for the delivery of palliative care is included, the gap between hospice or ARC and the need for palliative care changes. As shown in Figure 14, the proportion in cream relying on primary care from district nursing, GPs and PHOs is highest for MELAA (36.7%), Pacific (36.0%) and Māori (33.0%).

¹⁴ This is an extension of the earlier work on the Need for Palliative Care. There were some in the Dementia and Chronic Disease (frail elderly) groups that died of causes not in the original list. These have now been included in an expanded definition of Trajectory Group Need for Palliative Care.

¹⁵ Ministry of Health. Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand. Wellington: Ministry of Health Manatū Hauora; 2012. URL: <http://www.health.govt.nz/publication/resource-and-capability-framework-integrated-adult-palliative-care-services-new-zealand>

8. Utilisation of Public Hospital, Aged Residential Care and Hospice IPU

The Trajectories Project has extensive information on the patterns of use of healthcare services by trajectory groups over the last ten years of life. The days in institutional beds (public hospital, aged residential care or hospice IPU) are shown in Figure 15.

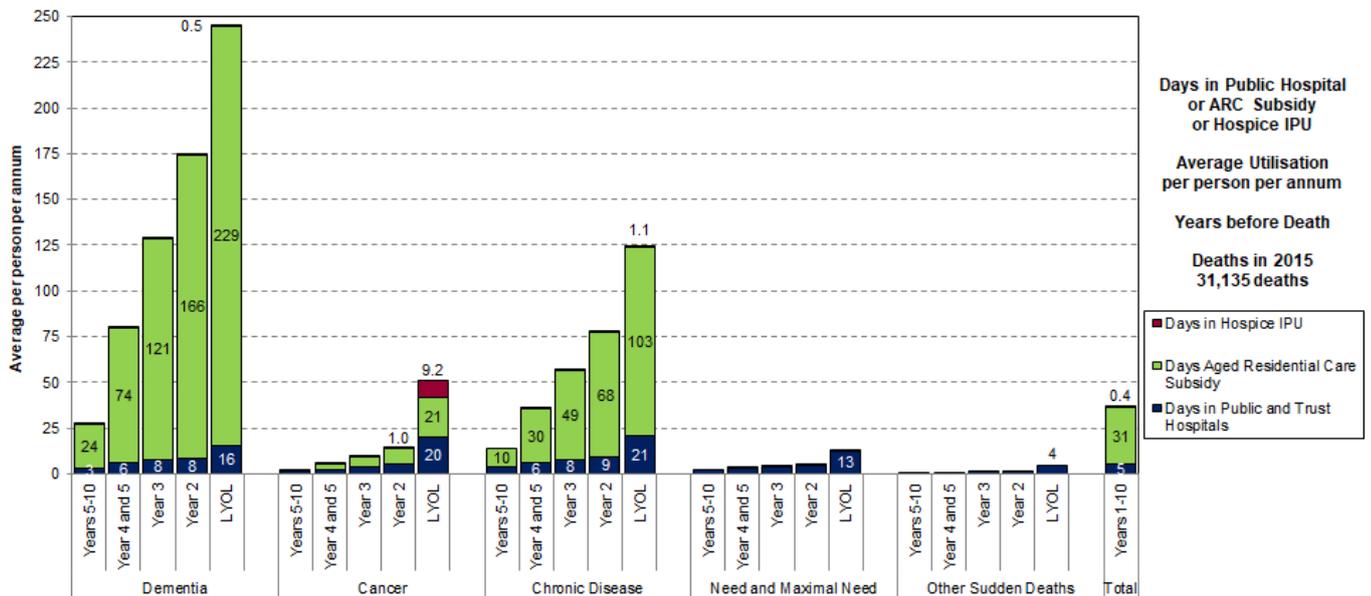


Figure 15: Utilisation of Public Hospital, Aged Residential Care Subsidy and Hospice Inpatient Unit, by Years before Death

The Dementia group have on average 246 days per person per annum (pppa) in public hospital or with an ARC subsidy in the LYOL, which is 67.4% of the time that year. Chronic Disease have 124 days or 34.0% of the time, while Cancer have 42 days or 11.4% of the last year. Need and Maximal Need have only 13 days, and Other Sudden Deaths only 4 days pppa in the LYOL.

The Cancer group has an added 9.2 days from hospice IPU in the LYOL with 1.0 days in Year 2 before death. The Chronic disease group has an added 1.1 days in the LYOL. For all other groups and time periods, the addition of hospice IPU adds small amounts less than one day on average.

Utilisation was analysed for days in public hospital, emergency department events, outpatient visits, medicines dispensed, laboratory tests, days of ARC subsidy, days of hospice care (community and IPU care), days in hospice IPU, registration with PHOs, use of other GPs, days with CarePlus, utilisation of Disability Support Services, and interRAI assessments. Results are available from the authors¹⁶.

9. Implications of Findings

The numbers dying with dementia (as opposed to from dementia) were much higher than had previously been known. This study was on deaths in 2015 and the strong pattern by age suggests even higher numbers with dementia with an ageing population. Palliative care in dementia needs a greater focus and needs to be integrated in all palliative care planning.

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We see for the first time the high proportions of older people who have cancer but die of other causes. This has implications for how supportive care in cancer is organised and how it interfaces with other non-cancer services.

There are very high proportions using aged residential care at older ages. The groups with the highest proportional usage are the Dementia and Chronic Disease groups, both of which can be expected to increase with more deaths happening at older ages.

There are very short time periods in aged residential care. Referral to hospice services is also occurring very late, particularly for non-cancer groups. Thus, the time available to provide quality palliative care and support to families and whānau is very short.

There are a surprisingly high proportions using an institutional bed (public hospital, aged residential care or hospice IPU) as the place of death. This challenges the thinking around more care being provided at home and the use of all beds (including at home) needs to be considered more comprehensively. An element of the project was to identify funding flows for end of life care, and this has been done with the four options for bed usage in mind, as illustrated in the summary below¹⁷.

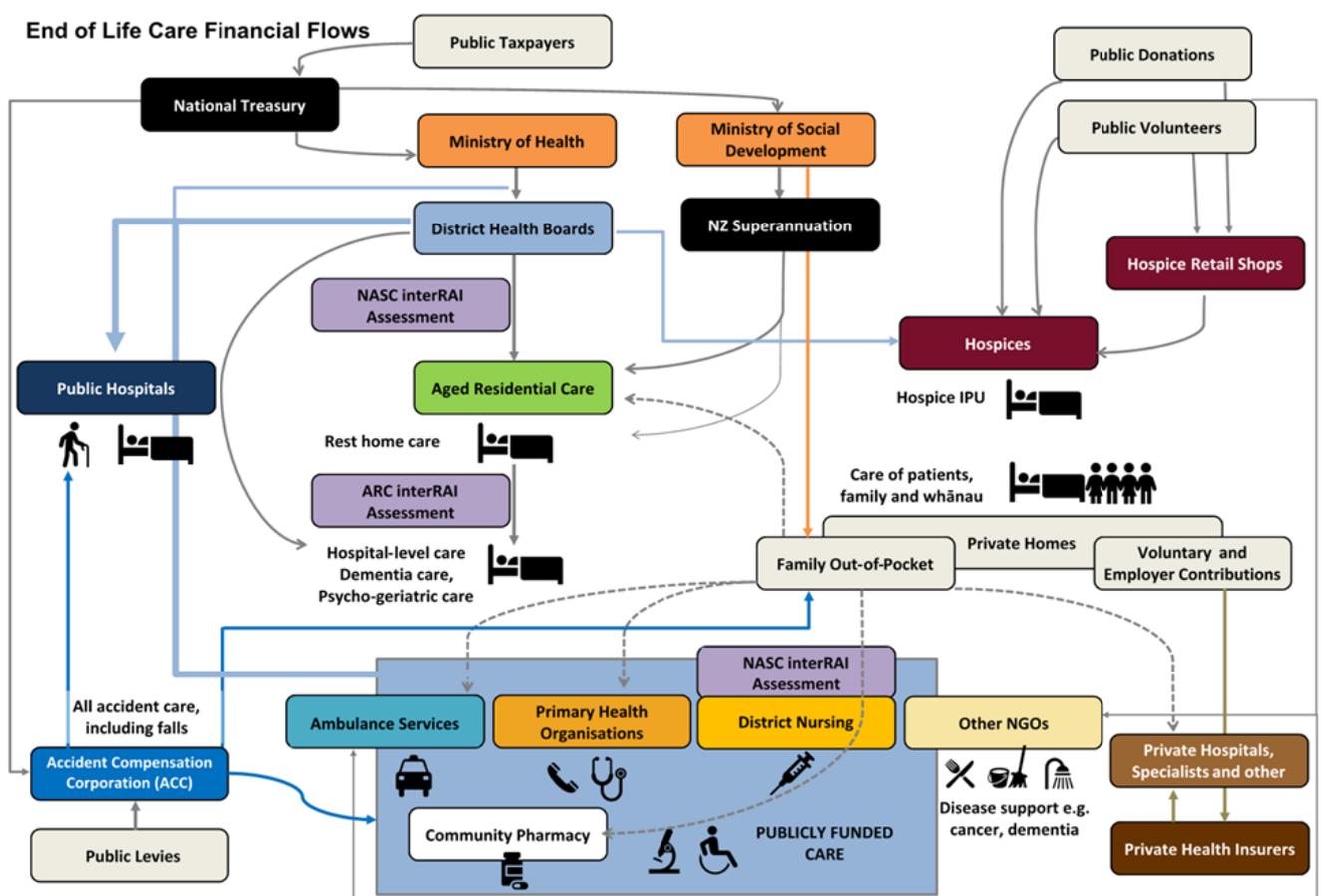


Figure 16: Financial Flows for End of Life Care in New Zealand

¹⁷ There are more detailed flow diagrams for each bed type in a set of slides "Funding Flows for End of Life Care in New Zealand vF2.xlsx"

There are currently anomalies in the funding of the different places that people may use at the end of life as well as differences in the impact on families and whānau. Aligning the reimbursement for end of life care across all providers and considering the out-of-pocket impacts is essential.

Indirect specialist palliative care is intended to be provided in a “hub and spoke” model. Specialist palliative care support needs to include hospitals that do not currently have a specialist palliative care service. Ways to measure the extent of indirect support are needed, as are improvements in national collection of data on specialist palliative care provision.

The very high utilisation of some services in the last year of life has been demonstrated. The implications of more deaths at older ages, and hence more people in the Dementia and Chronic Disease groups, as well as nearly 50% more deaths by 2038, need to be factored into planning.

10. Extensions of the Research

The data for all deaths in 2015 has provided useful insights but the value of this large linked set of data has not yet been exhausted. The following extensions to the project are being undertaken during 2019:

- **Projections of Trajectory Groups to 2038:** use the pattern of trajectory groups by age, together with the projections of deaths by Statistics New Zealand for the Ministry of Health, to prepare projections of the numbers in each trajectory group through to 2038 for national and DHB planning.
- **Projections of Healthcare Utilisation by Trajectory Groups to 2038:** an extension to the work above, incorporating the average utilisation figures for each trajectory group for the components of care, such as days in public hospital, ED presentations, number of medicines dispensed, number of laboratory tests, days in aged residential care and days in hospice IPU.
- **Time in Community by Trajectory Groups:** this is another way of looking at the linked data, to determine how many days of care people need in the community, by trajectory groups and demographic factors. This will be useful for hospices, district nursing, GPs and PHOs, and for NGO support groups.
- **Transitions of Care by Trajectory Groups:** Transitions of care can be a stressful time. Quantifying the number of transitions in the months prior to death will also give us a sense of the emotional burden on families and whānau.
- **Projections of Time in Community by Trajectory Groups to 2038:** an extension of the first two elements to include a projection to 2038 of the time in community.
- **Initial Costing of Alternative Options for Place of Care in 2015:** using the data already gathered, indicates a cost by type of institutional bed (public hospital, aged residential care and hospice IPU). While not a complete costing of end of life care, this will enable a focus on the cost envelope for alternatives to providing care in an institutional bed and for providing more support to district nursing and hospices.

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