Trajectories of Deaths in New Zealand

Prepared for Hospice NZ
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Trajectories Study and Period

- All deaths occurring and registered in 2015
- History of health care utilisation going back ten years where feasible.
  - Cancer Registry and NMDS are longer (around 25 years).
  - interRAI is shorter (mostly 3 years, with earlier pilots)

Study question: who is **not** reached by specialist palliative care (hospices and hospitals) or by aged residential care (ARC).

The intention is to provide an understanding of the different trajectories of care at the end of life.

- Advise on feasibility of a minimum data set for hospital palliative care.
- Identify funding flows for end of life care.
Trajectories Study Data

- Linked data sets, using de-identified NHI number:
  - Mortality Collection (MORT)
  - New Zealand Cancer Registry (NZCR)
  - National Minimum Dataset (Hospital Events) (NMDS) - inpatients
  - National Non-Admitted Patients Collection (NNPAC) - outpatients
  - PRIMHD mental health data (PRIMHD)
  - Laboratory Claims Collection (Labs)
  - Pharmaceutical Collection (Pharms)
  - PHO Enrolment Collection (PHO)
  - General Medical Subsidy Collection (GMS) – other GP used
  - Disability Support Services (SOCRATES)
  - Aged Residential Care Subsidies (CCPS)
  - interRAI Assessments (interRAI)
  - History of Hospice Care and Hospice IPU for 30 hospices
New Insights from Linked Data
In total, 43.0% of all deaths are in the Cancer Registry. 29.5% are in the Cancer Registry and have neoplasm as cause of death. A further 1.0% have neoplasm as cause of death, but are not in the Cancer Registry (neoplasm includes some benign tumours). Of interest are the 13.4% who are in the Cancer Registry but died of another cause – they tend to be older.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Overall, 4,182 people (13.4% of all deaths) are in the Cancer Registry but died of other causes. Circulatory system conditions accounted for 51.1%, External causes for 5.4% and Other conditions for 43.4%. Of the Other conditions, Respiratory system causes were the largest group.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
In total, 43.8% of all deaths have an aged residential care subsidy or were recorded as having died in residential care. There is a very strong pattern that increases sharply with age: 73.6% by age 90-94, 82.2% by age 95-99 and 88.7% for those aged 100 or more.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
In total, 38.4% of all deaths had an ARC subsidy at some stage in their trajectory. For the first time we can see the 5.5% who died in residential care but had no ARC subsidy. 5.8% had an ARC subsidy at some time and died in a public hospital, while 2.0% had a subsidy and died elsewhere. Overall, 43.8% have an ARC subsidy or died in residential care.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
In total, 51.8% of total deaths had one or more interRAI assessments. A further 6.8% had an ARC subsidy at some time. With interRAI assessments becoming mandatory in aged residential care from 1 July 2015, the potential total is 58.6% of all deaths, with a very strong pattern by age.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
In total there are 1,162 people found in the SOCRATES data, which is 3.7% of all deaths. DSS are typically provided for those under age 65. Disability Support Services only are provided for 2.6% and a further 1.1% have DSS and an ARC subsidy at some stage (not necessarily at the same time).

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
27.8% of all dementia identified from mortality data. This shows the impact of the main sources of data and the extent of overlaps. National Collections (NMDS and PHARMS) and interRAI (diagnosis and Cognitive Performance Scale) are the most important sources. There is significant overlap.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Of those identified with dementia, only 27.8% had dementia as a cause of death on the death certificate. 72.2% of people with dementia died of other causes. Circulatory system causes are the largest group, followed by deaths from cancer and respiratory system causes.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
Dementia is known to be poorly represented as a cause of death. Only 7.6% of all deaths identified as having a form of dementia from mortality data. By combining any evidence of dementia from other sources, we find that a further 19.7% have dementia, making 27.3% of total deaths.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Dementia

As a proportion of total deaths:
- Any evidence of dementia: 27.3%

As a proportion of those with any evidence of dementia:
- Received an aged residential care subsidy: 81.8%
- No ARC subsidy (at home, private paying or other funding): 18.2%
- Had an interRAI assessment (or potential interRAI in ARC): 96.6%

As a proportion of those with an ARC subsidy:
- Any evidence of dementia: 58.3%
Trajectory Groups

Development of Groups
Trajectories Groups

The trajectories groups are extracted sequentially as follows:

- **Dementia:** anyone with any evidence of dementia (MORT, hospital, medicines, interRAI diagnosis or Cognitive Performance Scale).
- **Cancer:** no evidence of dementia, any cancer and died of neoplasm, or died of neoplasm (Cancer Registry, MORT).
- **Chronic Disease:** no evidence of dementia, cause of death not neoplasm, any aged residential care subsidy or place of death residential care, or any interRAI. These are effectively the frail older people who need some assistance (ARC or assessed for home care).
- **Need and Maximal Need:** all other causes of death that are included in the need for palliative care or the maximal need for palliative care. They may have chronic disease but are generally younger. Includes a young group receiving Disability Support Services if not already allocated.
- **Other Sudden Deaths:** cause of death is not in maximal need for palliative care and not already allocated above.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Trajectories Groups allocated sequentially: Dementia, Cancer (diagnosed cancer, died of neoplasm), Chronic Disease (needing ARC or interRAI assessment for home care), Need and Maximal Need (including Disability Support Services), Other Sudden Deaths.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
The groups are allocated from left to right. The Dementia and Cancer groups are large in their own right. The amalgamated Chronic Disease group is almost the same size. The analysis that follows will typically use these five major groups.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
Overall 43.8% of people used residential care at some time in their trajectory. This is highest for the Dementia group at 85.5%. More than half of Chronic Disease (51.3%) and more than a quarter of the Cancer group (27.0%) had an ARC subsidy or died in residential care.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Utilisation of Services

Time before Death
All groups have increasing utilisation throughout the ten years and much higher utilisation in the last year of life. Cancer and Chronic Disease have almost the same in LYOL, but Cancer is lower in earlier years. The lowest users of public hospital days are the Other Sudden Death group.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
The Dementia group have a high and increasing utilisation throughout the ten years. Chronic Disease also have a sustained increase over time but to less than half of the level. Cancer has some usage, particularly in the last year of life. Two groups have no days of ARC subsidy in the last ten years.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
All groups have higher ED utilisation in LYOL. The Cancer group has the largest increase in the LYOL, followed by Chronic Disease and then Need and Maximal Need. Would be useful to study impact of early referral to hospice on the Cancer group usage of ED.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
The Cancer group have the highest utilisation and highest increase in outpatient visits in the last year of life. Chronic Disease have higher usage initially, but not as high as Cancer in the LYOL. Dementia group have lower OP visits in last years – perhaps impacted by being in ARC.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Chronic Disease have the highest average number of medicines dispensed pppa, followed by Dementia. Cancer group have a large increase in the LYOL from a lower base usage. Need and Maximal Need have relatively constant utilisation, at about half the levels of those in Chronic Disease.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
Chronic Disease have the highest sustained utilisation of laboratory tests pppa, but Cancer group increases rapidly and in the highest in the LYOL. Dementia group is similar in shape to Need and Maximal Need, but slightly higher each period.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
This shows the average utilisation of hospice across all deaths in each trajectory group. For every person in the Cancer group, on average there were 96.7 days with hospice in the last year of life and 16.7 days in the previous year. Be wary of averages as some people have much shorter trajectories while some are with hospice the whole of that year.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
This shows the average utilisation of hospice IPU across all deaths in each trajectory group. For every person in the Cancer group, on average there were 9.2 days in IPU in the last year of life and 1.0 days in the previous year.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
The Cancer group has an added 9.2 days from hospice IPU in the LYOL with 1.0 days in Year 2. 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.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Time before Death
First Admission to ARC
Timing of First Admission to ARC

There are people with very short stays in aged residential care: overall, 43.7% have their first admission less than one year before death and 24.3% have their first admission in the last three months of life.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Eight people were admitted 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 (11.9% of those with any ARC subsidy). In the last three months of life, 2,897 were admitted for the first time (24.3% of those with an ARC subsidy).

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
For Dementia, 2,385 were admitted for the first time in the LYOL (34.3% of those with Dementia and an ARC subsidy). In the last three months of life, 1,106 were admitted for the first time (15.9%).

_data source_: Trajectories Project, linked data for deaths in New Zealand in 2015
For Chronic Disease, 1,573 were admitted for the first time in the LYOL (45.7% of those in the Chronic Disease group with an ARC subsidy). In the last three months of life, 827 were admitted for the first time (24.0%).

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
For Cancer, 1,265 were admitted for the first time in the LYOL (81.9% of those in the Cancer group with an ARC subsidy). In the last three months of life, 973 were admitted for the first time (63.0%).

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
Time before Death
First Admission to Hospice or Aged Residential Care
56.3% have their first admission to ARC before the last year of life, while only 8.6% were referred to hospice more than a year before death. Referrals to hospice and first admission to ARC are both much higher closer to death. Referrals to hospice are double the admissions to ARC in the last quarter of life.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
For the Cancer group, referrals to hospice were 4.7 times the number of ARC admissions in the last year of life. Admissions to ARC for this group tend to happen late in the trajectory. Referrals to hospice exceed ARC admissions in the last week of life by a factor of 3.6 times.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
For the remaining groups, referrals to hospice were 78.0% of admissions to ARC in the last year of life. Admissions to ARC happen earlier in the trajectory and hospice referrals are very late. Referrals to hospice exceed ARC admissions in the last week by a factor of 3.2 times.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
For the Dementia group, referrals to hospice were a little under half (45.4%) of admissions to ARC in the last year of life. Admissions to ARC happen earlier in the trajectory and hospice referrals are very late. Referrals to hospice exceed ARC admissions in the last week by a factor of 3.8 times.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Utilisation in LYOL
Public Hospital and ED Events
71.0% of all deaths have both public hospital admissions and ED events in the 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%).

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
71.0% of all deaths have both public hospital and ED events in the LYOL. The highest proportional use of ED only and of neither is in the accident years. A strong decline in ED events and public hospital use at older ages.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
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 this.
Comment

- The Hospital Palliative Care Working Group attempted to gather a minimum standard data set.
  - We know which hospitals have a specialist palliative care service as of early 2018. Previous study was in FY2011.
  - We have an estimate of total patients seen in FY2016.
  - We were unable to get to having data by NHI number from each service in order to link with the other data sets.
- This analysis uses the list of hospitals with a specialist palliative care service and considers the potential availability of specialist palliative care during hospital events in the last year of life.
- The list of hospital palliative care services was developed in early 2018 and the coverage in 2015 may not have been as good as shown.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Specialist Palliative Care
Use of Hospice Services
Overall, 30.7% of people in the Trajectories study used hospice as part of their end of life trajectory. There is a strong and characteristic pattern by age, with almost 50% of those dying in the age bands from 55 to 70 using hospice.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Use of Hospice and Hospice IPU

Hospice is a philosophy and not a place of care. While 30.7% of people in the Trajectories study used hospice as part of their end of life trajectory, only 10.5% used a hospice inpatient unit (IPU). The proportion using hospice IPU peaks at ages 45 to 55, which is consistent with deaths from cancer at these ages.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Overall, 30.7% used hospice services and 43.8% used aged residential care (ARC), with an overlap of 9.8% of people using both. At older ages, an increasing proportion of people are supported by hospice or receive end of life care in an aged residential care facility.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
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%. 13.9% of those with Dementia and 17.3% of the Chronic Disease group used hospice.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
Use of Hospice and Hospice IPU

Hospice is a philosophy and not a place of care. While 30.7% of people in the Trajectories study used hospice as part of their end of life trajectory, only 10.5% used a hospice inpatient unit (IPU). Use of hospice IPU was highest for the Cancer group at 31.2%.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Overall, 30.7% used hospice services and 43.8% used aged residential care (ARC), with an overlap of 9.8% of people using both. The Dementia group has a high proportion using ARC only, while cancer has a high proportion using hospice only.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Specialist Palliative Care
Hospice and Estimate of Hospital Palliative Care
Those using hospice are known directly from the Trajectories Study. Overall, 30.7% of those in the study used hospice as part of their end of life trajectory.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
This is the current best estimate of the age profile of hospital palliative care services in New Zealand. Overall, estimated that 24% of all deaths might have used hospital palliative care. For adults, the proportion is highest in the age bands 30 to 64. The shape is surprisingly similar to that of hospices with a decline at older ages.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
This uses an overlap of hospital palliative care of 53% of hospice patients, with a pattern derived from two DHBs. This produces the first estimate of the use of specialist palliative care. Overall, 14.6% of total deaths only used hospice, 7.7% only used hospital palliative care and 16.2% used both. In total, **specialist palliative care was 38.5% of total deaths.**

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
It is estimated that specialist palliative care was provided to **38.5% of total deaths**. 52.0% of total deaths fall within the definition of need, but were not seen by specialist palliative care (hospices or hospital palliative care).

**Specialist palliative care met 42.5% of the Trajectory Group Need for Palliative Care.**

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
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. This seems plausible.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
Summary of Findings on Specialist Palliative Care

- The proportion using hospice is known directly from the data but the proportion using hospital palliative care, and the overlap to hospice usage, is an informed estimate.
- We will only know this with certainty if Hospital Palliative Care NZ can aggregate data and provide NHI numbers to allow direct linking.
- Overall, 14.6% of total deaths only used hospice, 7.7% only used hospital palliative care and 16.2% used both.
- In total, **specialist palliative care was 38.5% of total deaths**.
- The Trajectory Group Need for Palliative Care is **90.4% of total deaths**.
- **It is estimated that Specialist palliative care met 42.5% of the need for palliative care.**

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Need for Palliative Care
Hospices, Aged Residential Care and Primary Care
Overall, 64.8% used hospice services or aged residential care (ARC). 9.6% of total deaths fall outside the Trajectory Group Need for Palliative Care, 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.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Overall, 64.8% used hospice services or aged residential care (ARC). 9.6% of total deaths fall outside the Trajectory Group Need for Palliative Care, 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.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Overall, 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 cream gap is highest for women, European and middle levels of deprivation.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
For deaths at older ages, aged residential care is the setting where palliative care needs to be delivered. The cream group is seen by neither hospice nor aged residential care, and thus relies on primary care and district nursing for palliative care at the end of life.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Days in Community
Trajectories Research 2019

[Work-in-progress]
Important Findings and Implications

- Very high numbers with dementia
  - This was in 2015 already – implications for an ageing population?
  - Palliative care for dementia integrated in all the PCAP priorities.
- Older people who have cancer but die of other causes
  - Implications for supportive care in cancer.
- Very high proportion using aged residential care at older ages
  - Very short periods of time in ARC.
- Very high proportion reaching an institutional bed as the place of death
  - How does this affect our thinking about models of care?
- Specialist palliative care “hub and spoke” – needs to include hospitals that do not have a palliative care service.
- Very high utilisation in last year of life for some services
  - Implications for 50% more deaths by 2038?

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
Statistics NZ projects that total deaths will reach 47,400 a year by 2038, which is 52.2% higher than in the Trajectories Study. We expect a greater number of deaths and an ageing of those deaths by 2038.

The Cancer group has an added 9.2 days from hospice IPU in the LYOL with 1.0 days in Year 2. 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.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Looking at the place of death data with a different lens by combining the three key places providing a bed at the end of life. The use of some form of institutional bed (public hospital or residential care or hospice IPU) is almost linear with age from age 10 onwards, reaching over 90% by age 95.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
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). This is 91.1% for Dementia, 81.1% for Chronic Disease and 68.5% for the Cancer group.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
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