Trajectories of Care at the End of Life
Implications for health systems with ageing populations

Economics of Palliative and End-of-Life Care SIG (EPEC)
iHEA Webinar, February 2020
Baby Boomers are usually regarded as those born in the years 1946–65. In New Zealand the increase in births began earlier, in 1935, and the number of births peaked in 1961.

Data Source: Statistics New Zealand, New Zealand Cohort Life Tables 1876-2015 and 2019 update
The median projection from Statistics NZ is that deaths will rise from around 30,000 a year to 55,500 a year by 2068. These deaths are projected to be at much older ages than currently experienced. Note the increase in deaths age 85-94 and age 95+.

Data source: Statistics New Zealand. Historic estimates and National population projections, 2014(base)-2068
Statistics NZ projects for the Ministry of Health in the “2018 Update” that total deaths will increase from **32,600** a year in FY2019 to **45,500** a year by FY2038, an increase of **40%**. There are two important effects: the greater number of deaths and the ageing of those deaths.

**Data Source:** Statistics NZ, DHB Births and Deaths Projections 2019-38 (2018 Update)
Trajectories at the End of Life

- Accidents - early adult years
- The three characteristic trajectories illustrated are **roughly sequential**: 
  - Cancer - peaking around age 65
  - Organ failure - about a decade later, around age 75
  - Frailty and dementia - those who live past their mid-80s.

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 hospital admissions 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).

- Provide an understanding of the trajectories of care at the end of life.
- Identify funding flows for end of life care.
- Place of Care and Time in the Community.
- Transitions in the Place of Care
- Projections of Trajectories Groups, Place of Care and Utilisation
- Health System Costing in the Last Years of Life
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 all hospices
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
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
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
Dementia and Cause of Death

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
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
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.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015, Projections by Statistics NZ for Ministry of Health, 2017 Update.
The patterns by age for the five trajectory groups are from the Trajectories Study 2015. The projected ageing of deaths results in the Dementia and Chronic Disease groups growing much faster than other groups.

**Data Source:** Projections of Trajectories at the End of Life Model Version vF1 Trajectory Groups
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
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%).

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

Last Three Years of Life

Last Year of Life
Daily place of care for each day in the last three years of life, showing all trajectory groups combined. The next slides show the five trajectory groups in the reverse order in which they are extracted.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Other Sudden Deaths Group

Daily place of care for each day in the last three years of life, showing the group Other Sudden Deaths. These are deaths not in the definition of Need for Palliative Care and are typically accidents, violence or self-harm.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Daily place of care for each day in the last three years of life, showing the group Need and Maximal Need. These are generally younger people, including those who died of congenital conditions.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Daily place of care for each day in the last three years of life, showing the Chronic Disease group. This group is effectively the frail elderly with chronic disease: they either use ARC or have had an interRAI assessment. They have no evidence of dementia and did not die of a neoplasm.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Daily place of care for each day in the last three years of life, showing the Cancer group. This group has no evidence of dementia, are in the Cancer Registry and died of neoplasms. It also includes some who are not in the Cancer Registry but have a neoplasm as the underlying cause of death.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Daily place of care for each day in the last three years of life, showing the Dementia group. This group died of dementia or has evidence of dementia from the National Collections, or interRAI, or is in a secure dementia facility.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Daily place of care for each day in the last year of life (LYOL), showing each trajectory group. Shown as a percentage of each group.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Projected Dementia group deaths increase from 9,221 in 2019 to 15,938 in 2038, an increase of 173%. Projected days in public hospital increase by 168%, days in aged residential care by 178% and days at home (without hospice) by 165%.

Data Source: Projections of Trajectories at the End of Life Model Version vF2 Community
Transitions in the Place of Care

Animation of Last Year of Life
Animations of Transitions

- Five animations of groupings are available:
  - Animation Place of Care LYOL Trajectory Groups vF
  - Animation Place of Care LYOL Age Groups vF
  - Animation Place of Care LYOL Māori and Gender vF
  - Animation Place of Care LYOL Transition Groups vF
  - Animation Place of Care LYOL Seasonal Groups vF.

- Heather McLeod & Associates Ltd OneDrive Trajectories Project Shared Animations

- Instructions: Open the PowerPoint and start the presentation (Shift-F5). Go “next slide” until the second slide that has Day 365 in the heading. The animation will run automatically from there, until day 0 where it will go back to manually needing to move to the next slide. If you wish to stop the animation or see parts again, right-mouse click on a slide and "go to section", then choose a section to start from. Sections have been inserted about every 30 days.
Health System Costs at the End of Life in New Zealand

Prepared for the Ministry of Health and the Palliative Care Advisory Panel
August 2019
The total health system cost per person in the last year of life (LYOL) is \$44,785.69 in FY2018 terms. Costs pppa are highest for those who die under age 1 and are lowest in the age band 20-24, when many deaths are sudden. Costs pppa rise slowly with age from age 40 to age 84, then from age 85 onwards, costs rise steeply with age.

**Data Source**: Trajectories Project, linked data for deaths in New Zealand in 2015
Total cost for the hospital inpatient component is $18,464.08 per person in the LYOL, which is 41.2% of the total health system cost. Easier to see on scale truncated at $65,000. Hospital inpatient costs pppa are very high in the childhood years, lowest at age band 20-24, rise in the early adult years and decline noticeably from age 55 onwards.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Total cost is $17,322.97 per person in the LYOL for those in the ARC subsidy database and at least $551.65 per person for those without a subsidy. Together these are $17,874.62 per person which is 39.9% of total health system costs. The without subsidy component is potentially understated as there is no national database of everyone in ARC.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Total cost for the outpatient and ED component is **$3,492.84** per person in the LYOL, which is **7.8%** of the total health system cost. The small cost pp for the Under 1 group is hard to see. Highest outpatient and ED costs are age 5-9 and then age 40 to 74, with a very strong decline at older ages.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Total cost for the community LABS component is $227.16 per person in the LYOL, which is 0.5% of the total health system cost. Costs are very low in the childhood and teenage years, rising steeply in the early adult years and peaking in the decade 65-74. Costs decline sharply at older ages.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Total cost for the community PHARMS component is $2,040.21 per person in the LYOL, which is 4.6% of the total health system cost. Costs are further towards the younger ages than for community LABS. Costs are highest between ages 40 and 69, with a decline from age 70 onwards.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Total cost for PHO capitation and the non-enrolled GP and PHO out of area components is $298.51 per person in the LYOL, which is only 0.7% of the total health system cost. The shape depends on the PHO capitation formula. At the time, young children received the largest amount, with capitation increasing from age 65.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Total cost for DHB-funded hospice services is $2,388.27 per person in the LYOL, which is 5.3% of the total health system cost. Note that the cost is spread over all deaths in the study and is not the per person cost for those using hospice services. The cost pppa is highest from age 40 to 69.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Health System Costs by Trajectory Group
Costs in FY2018 Terms
Overall, the health system cost is $44,785.69 per person in the LYOL. The amount varies substantially by trajectory group: Dementia $59,989.03, Cancer $47,336.96, Chronic Disease (frail elderly) $43,721.44, Need and Maximal Need $24,568.73, and Other Sudden Deaths $10,059.96.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Overall, the health system cost is $84,969.93 per person over the L3YOL. This varies substantially by trajectory group: Dementia $128,633.01, Cancer $73,534.47, Chronic Disease (frail elderly) $86,918.63, Need and Maximal Need $42,259.73, and Other Sudden Deaths $15,539.62.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Institutional Beds, Outpatient and Primary Care Costs
Last Year of Life Costs in FY2018 Terms
The total health system cost per person in the last year of life (LYOL) is $\$44,785.69$. The cost of institutional beds (hospital, aged residential care or hospice inpatient unit) is $\$37,429.03$ per person (spread over all deaths, not those who use an institutional bed). Institutional beds are 83.6% of the total cost in the LYOL.

**Data Source:** Trajectories Project, linked data for deaths in New Zealand in 2015
Community Costs in LYOL

On same scale. The cost of all other services (Outpatients and ED, Community LABS, Community PHARMS, PHO Capitation and other visits to GPs, and DHB-funded Hospice services in the community or to support primary care) is $7,346.55 per person. All the care provided in the community or on an outpatient basis is 16.4% of the total cost in the LYOL.

Data Source: Trajectories Project, linked data for deaths in New Zealand in 2015
Overall, the amount (with proportion in brackets) spent on institutional beds is $37,439.03 (83.6%) per person in the LYOL. By trajectory group: Dementia $55,788.17 (93.0%), Cancer $33,310.69 (70.4%), Chronic Disease (frail elderly) $37,473.53 (85.7%), Need and Maximal Need $20,009.66 (81.4%), and Other Sudden Deaths $8,748.60 (87.0%).

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