

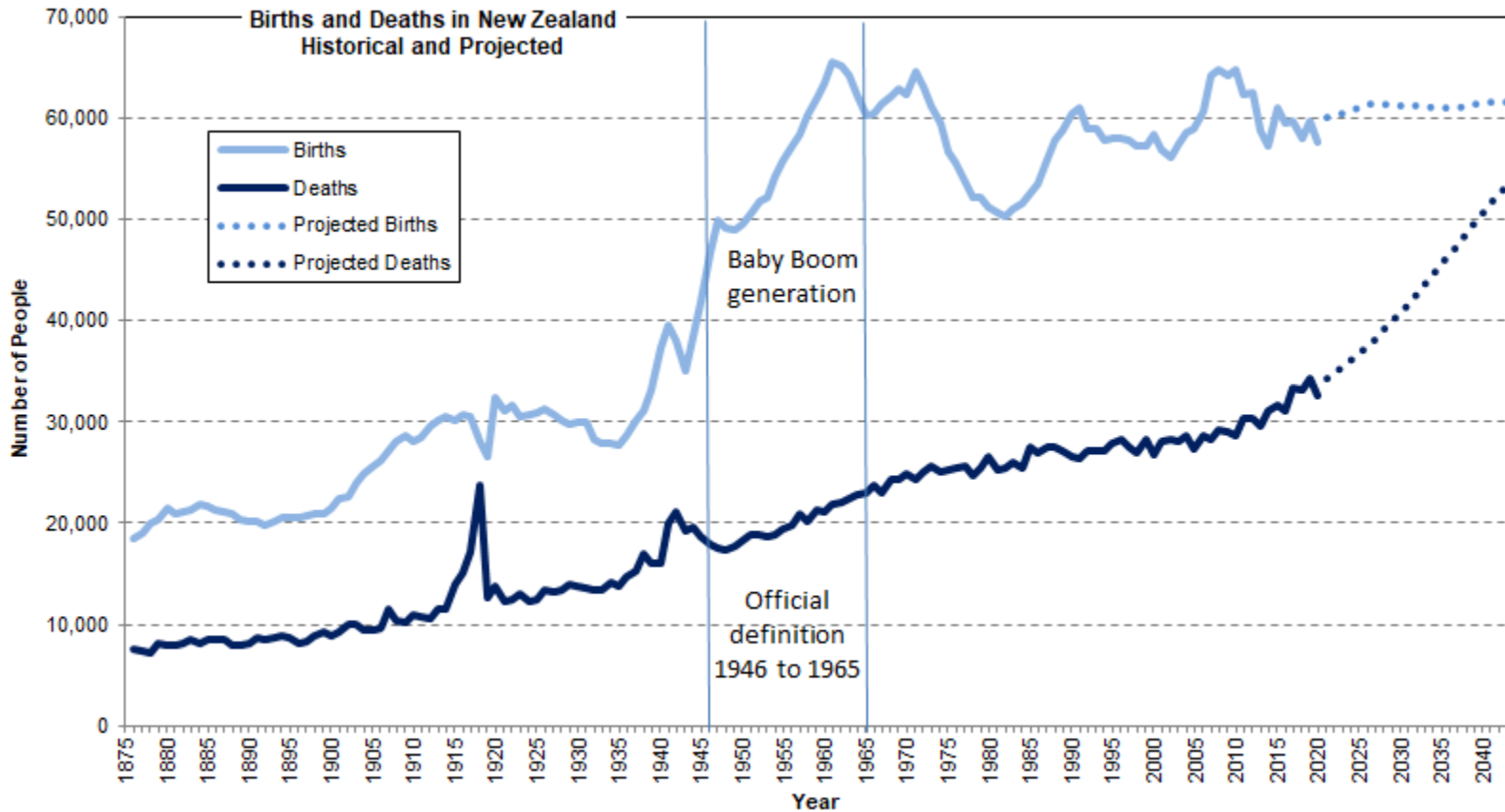
The Price of Success

Longer, slower and more costly trajectories at the end of life

2021 Joint SAS-IAAHS Health Conference
Singapore and virtual, September 2021



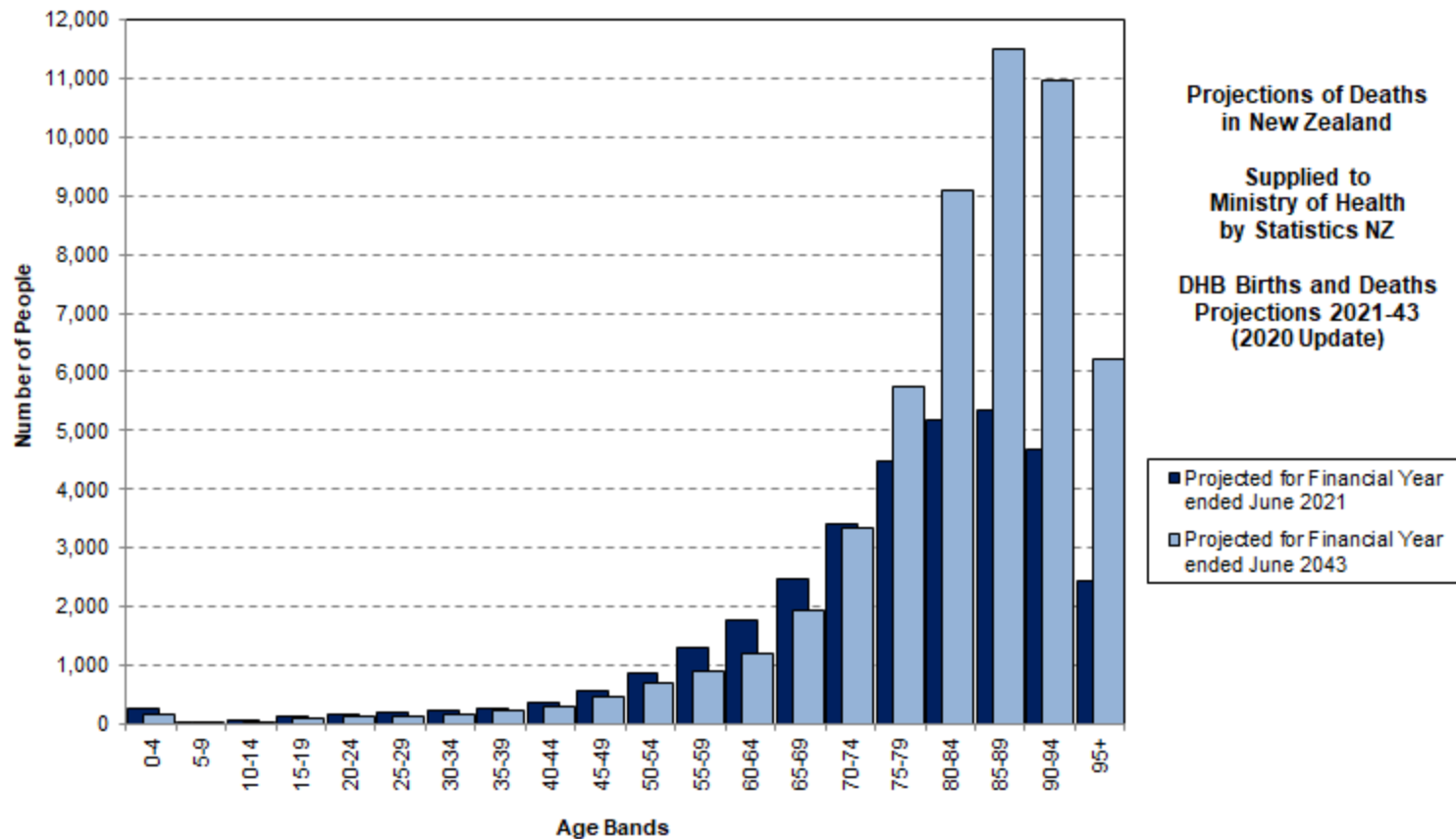
New Zealand Births and Deaths 1876 to 2020, projected to 2043



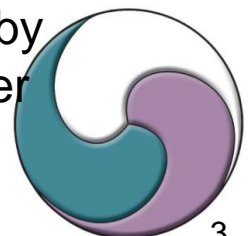
Baby Boomers are usually regarded as those born in the years 1946–65. In New Zealand the increase in births began earlier, in 1935, and the number of births peaked in 1961.



Ageing of Deaths 2021 to 2043

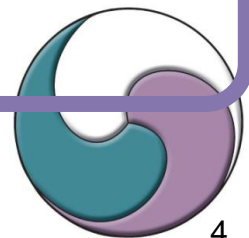


Statistics NZ projects for the Ministry of Health in the “2020 Update” that total deaths will increase from **34,200** a year in FY2021 to **53,300** a year by FY2043, an increase of **156%**. There are two important effects: the greater number of deaths and the ageing of those deaths.

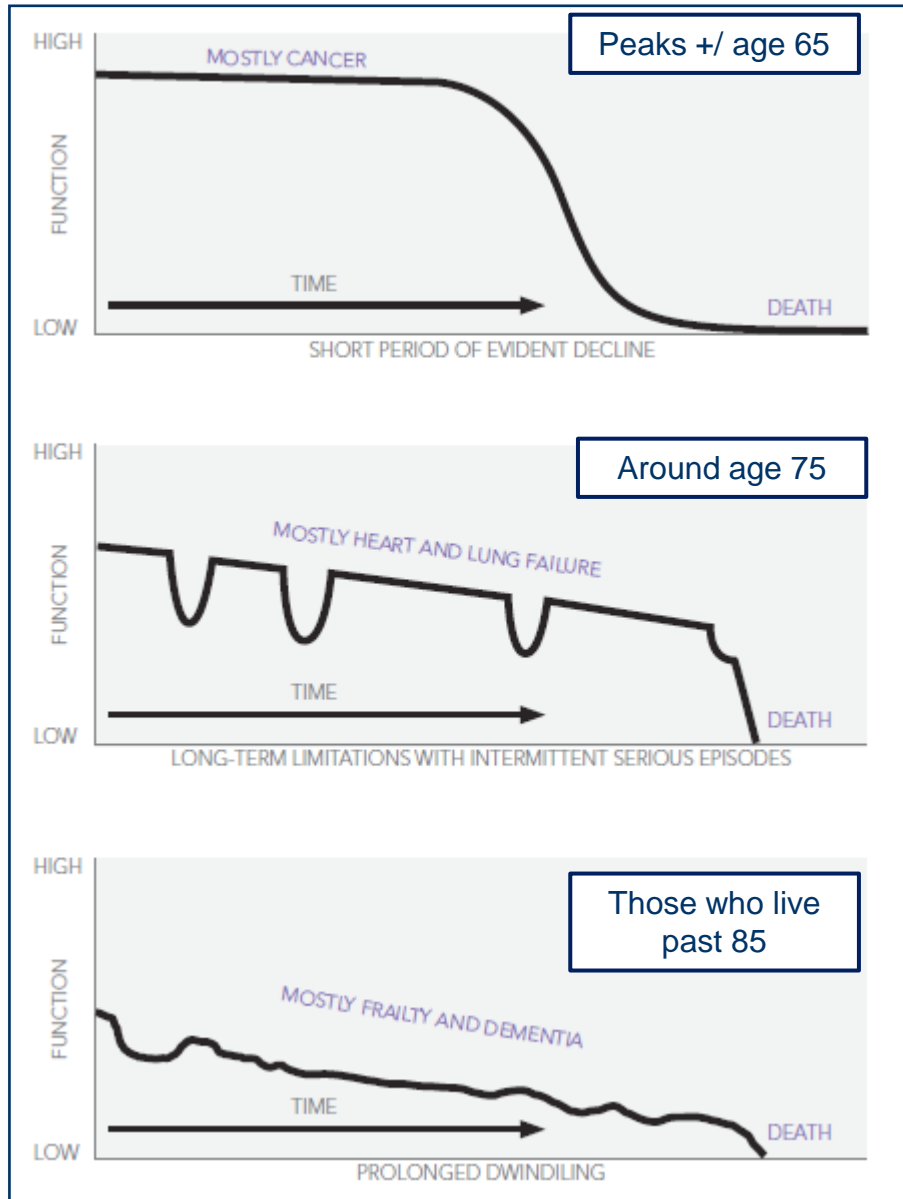


Independent Life Expectancy New Zealand Study 1996–2013

- **Female New Zealander at 65 years of age** in 2013 can expect to live:
 - another **10.6 years** independently, on average, which is 49.5% of her remaining life
 - a further **10.7 years** with functional limitations requiring assistance
 - non-daily assistance for **5.9 years**
 - daily assistance for final **4.8 years**.
- **Male New Zealander at 65 years of age** in 2013 can expect to live :
 - another **10.2 years** independently, on average, which is 54.1% of his remaining life
 - a further **8.7 years** with functional limitations requiring assistance
 - non-daily assistance for **5.6 years**
 - daily assistance for the final **3.1 years**.



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.

Source: Palliative Care Australia (2010). Health System Reform and Care at the End of Life: a Guidance Document. 2010. Canberra: Palliative Care Australia.
Diagram from Lynn, J., & Adamson, D. M. (2003). *Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age*. 2003. RAND Health.

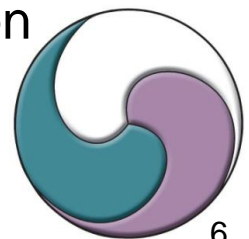


Trajectories Study and Period

- **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).

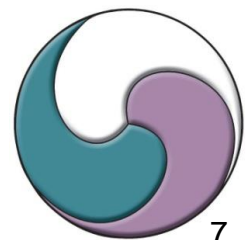
● Study question: who is not reached by specialist palliative care (hospices and hospitals) or by aged residential care (ARC).

- 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

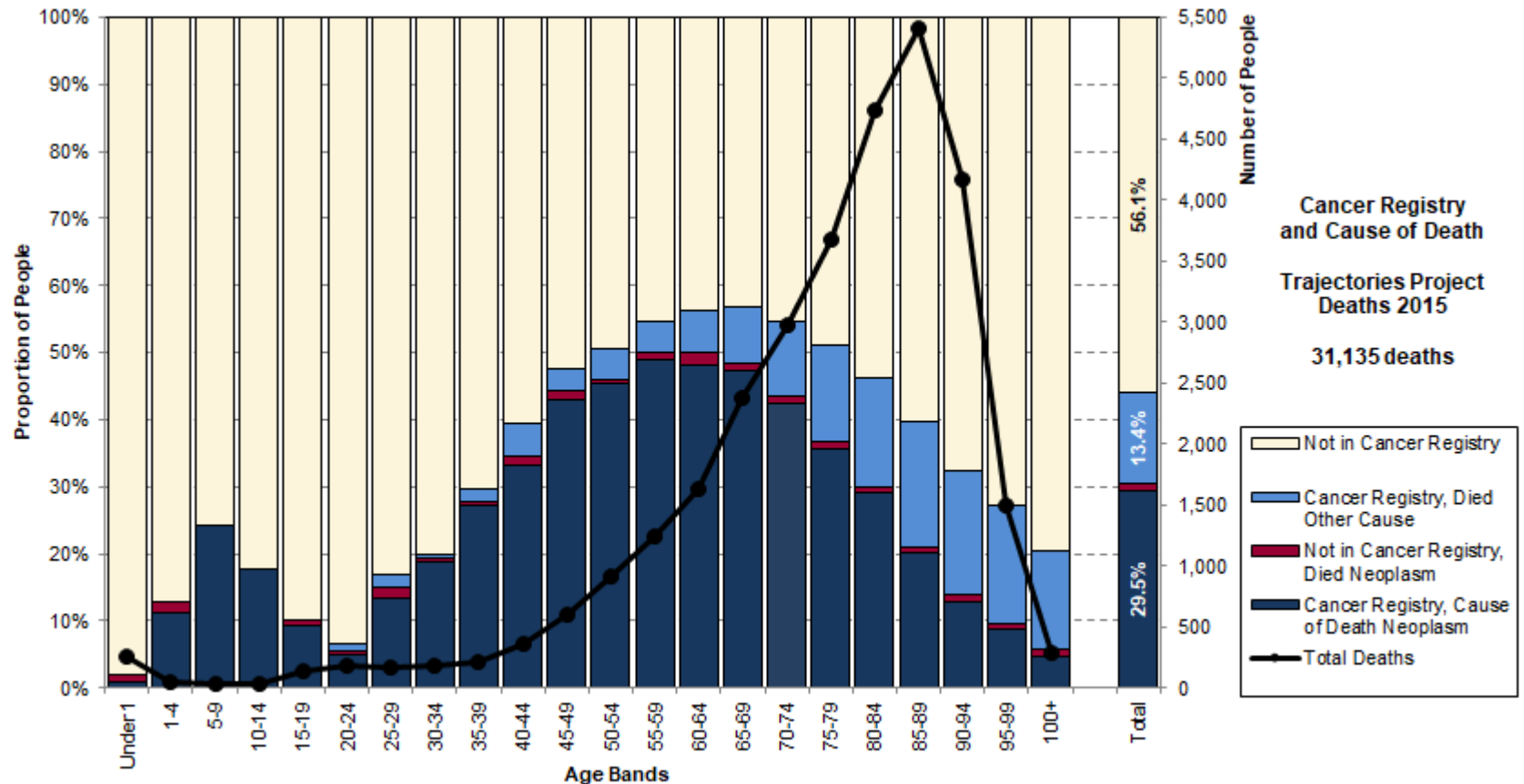


Trajectories Study Data

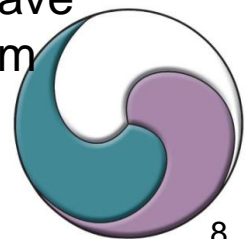
- Linked data sets, using de-identified NHI number:
 - Mortality Collection (MORT)
 - New Zealand Cancer Registry (NZCR)
 - National Minimum Dataset (Hospital Events) (NMDS) - inpatients
 - National Non-Admitted Patients Collection (NNPAC) - outpatients
 - PRIMHD mental health data (PRIMHD)
 - Laboratory Claims Collection (Labs) - pathology and tests
 - Pharmaceutical Collection (Pharms) - medicines
 - PHO Enrolment Collection (PHO) - primary care GPs
 - 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
 - Hospital Palliative Care [summarised data only]



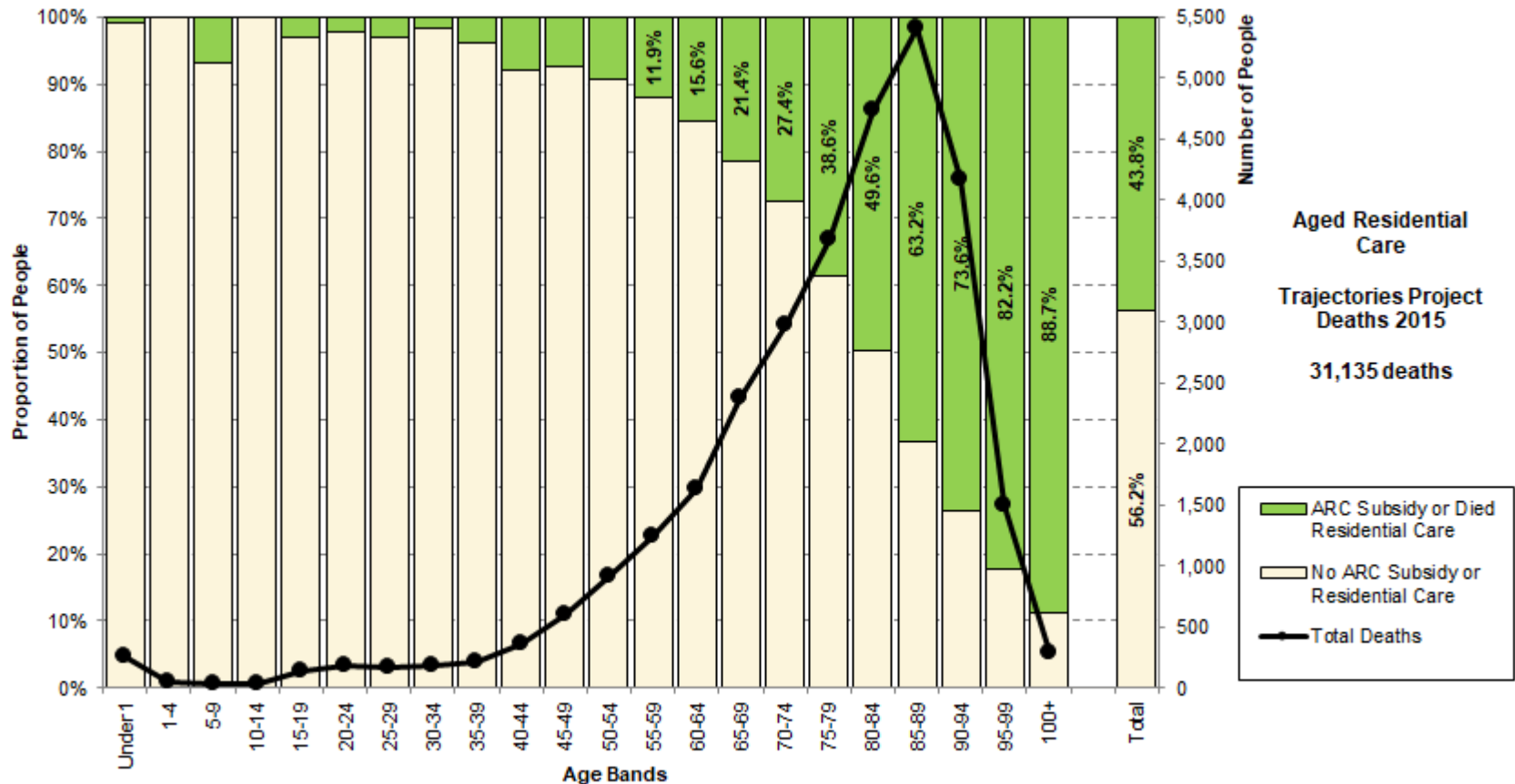
Cancer Registry and Cause of Death



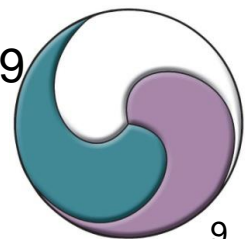
In total, 43.0% of all deaths are in the Cancer Registry. 29.5% are in the Cancer Registry and have neoplasm as cause of death. A further 1.0% have neoplasm as cause of death, but are not in the Cancer Registry (neoplasm includes some benign tumours). Of interest are the 13.4% who are in the Cancer Registry but died of another cause – they tend to be older.



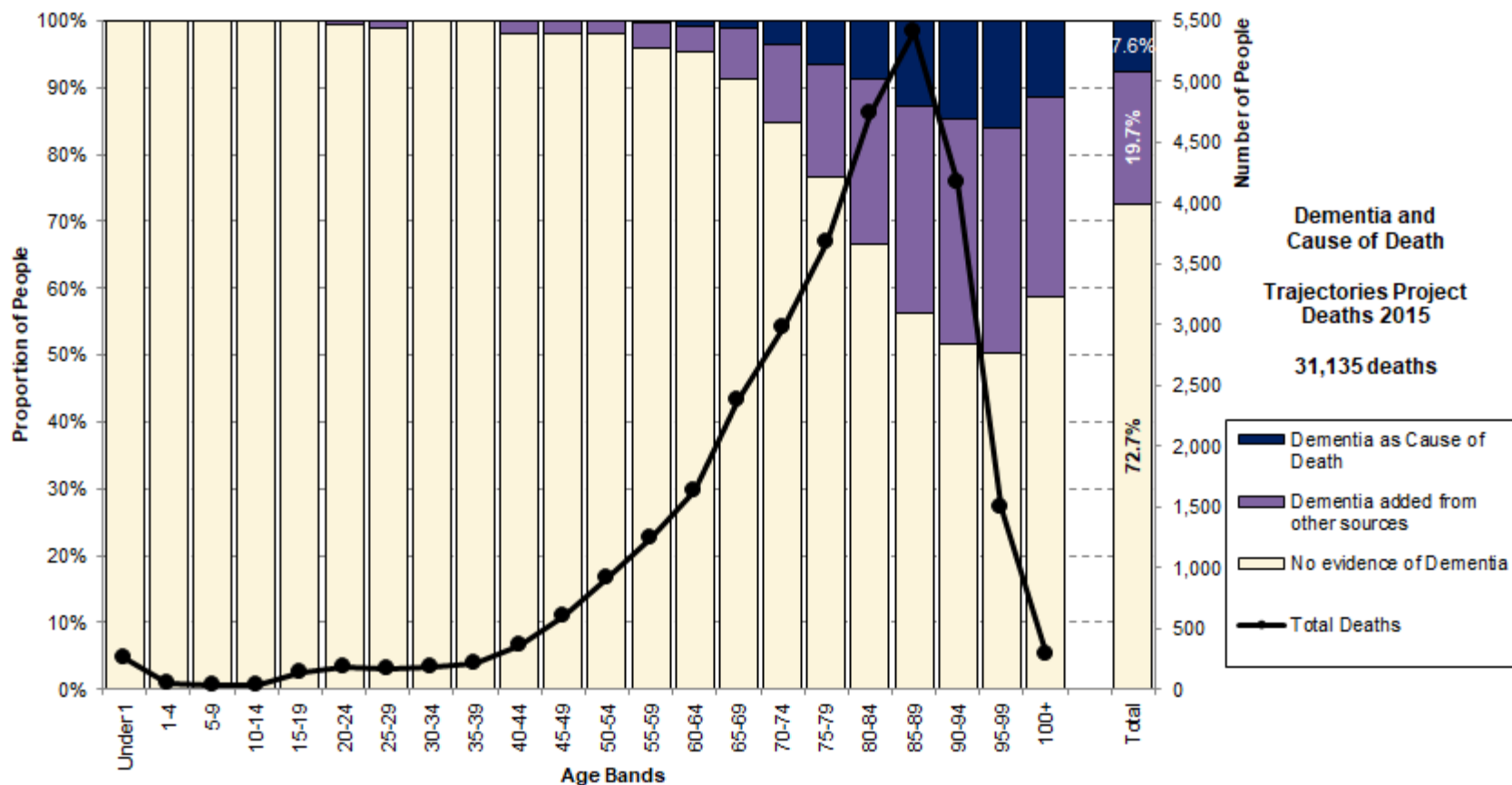
Aged Residential Care



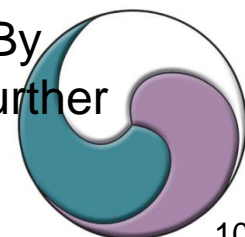
In total, 43.8% of all deaths have an aged residential care subsidy or were recorded as having died in residential care. There is a very strong pattern that increases sharply with age: 73.6% by age 90-94, 82.2% by age 95-99 and 88.7% for those aged 100 or more.



Dementia and Cause of Death

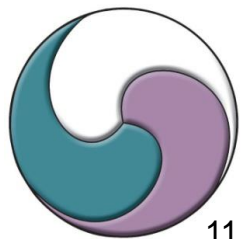


Dementia is known to be poorly represented as a cause of death. Only 7.6% of all deaths identified as having a form of dementia from mortality data. By combining any evidence of dementia from other sources, we find that a further 19.7% have dementia, making 27.3% of total deaths.



Trajectory Groups

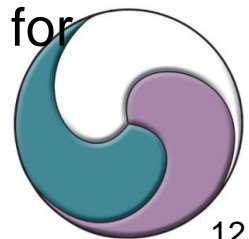
Development of Groups



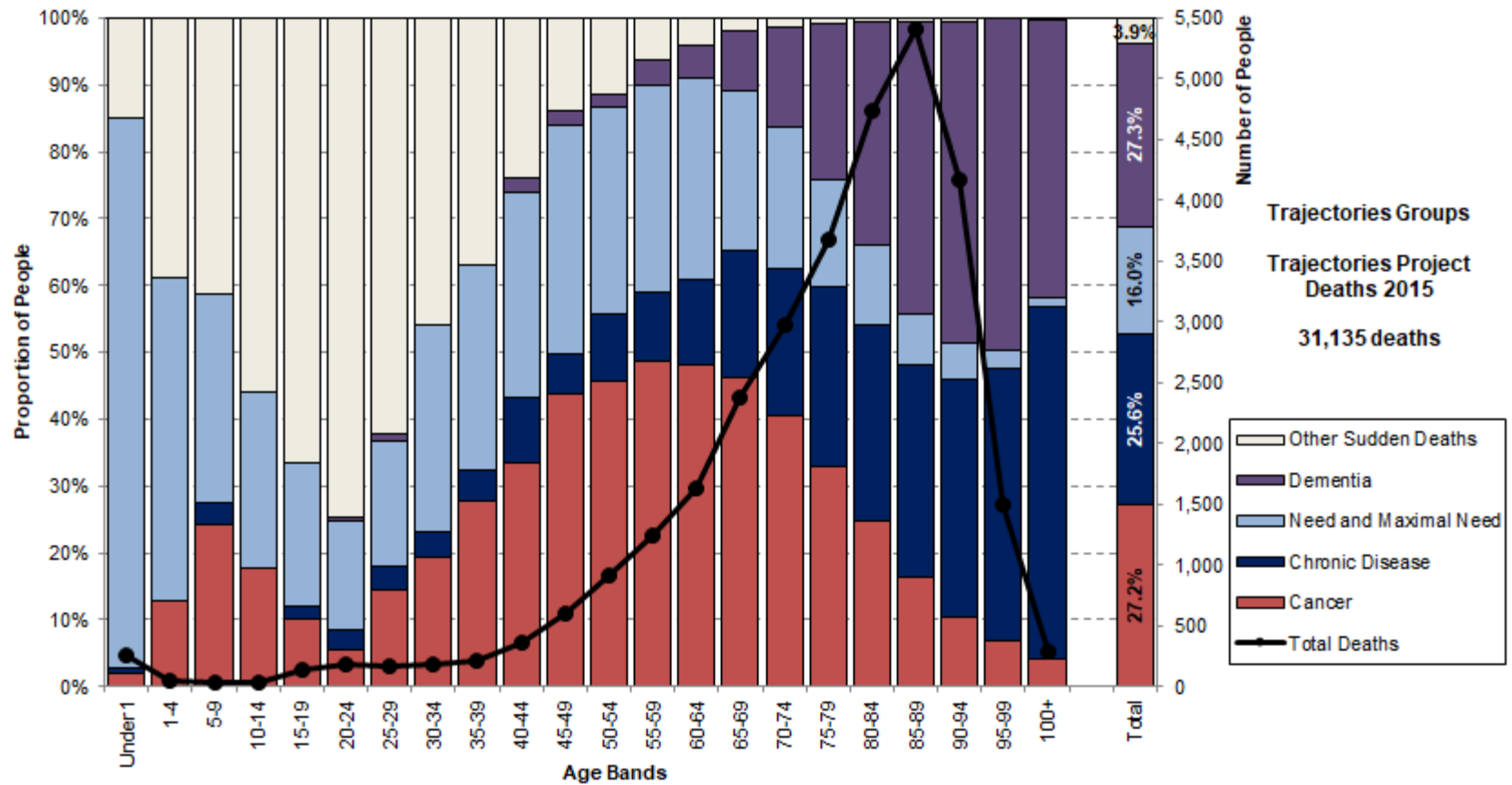
Trajectories Groups

The trajectories groups are extracted sequentially as follows:

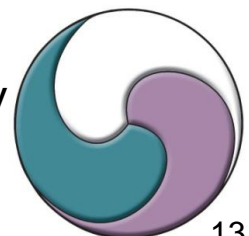
- **Dementia:** anyone with any evidence of dementia (MORT, hospital, medicines, interRAI diagnosis or Cognitive Performance Scale).
- **Cancer:** no evidence of dementia, any cancer and died of neoplasm, or died of neoplasm (Cancer Registry, MORT).
- **Chronic Disease:** no evidence of dementia, cause 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.



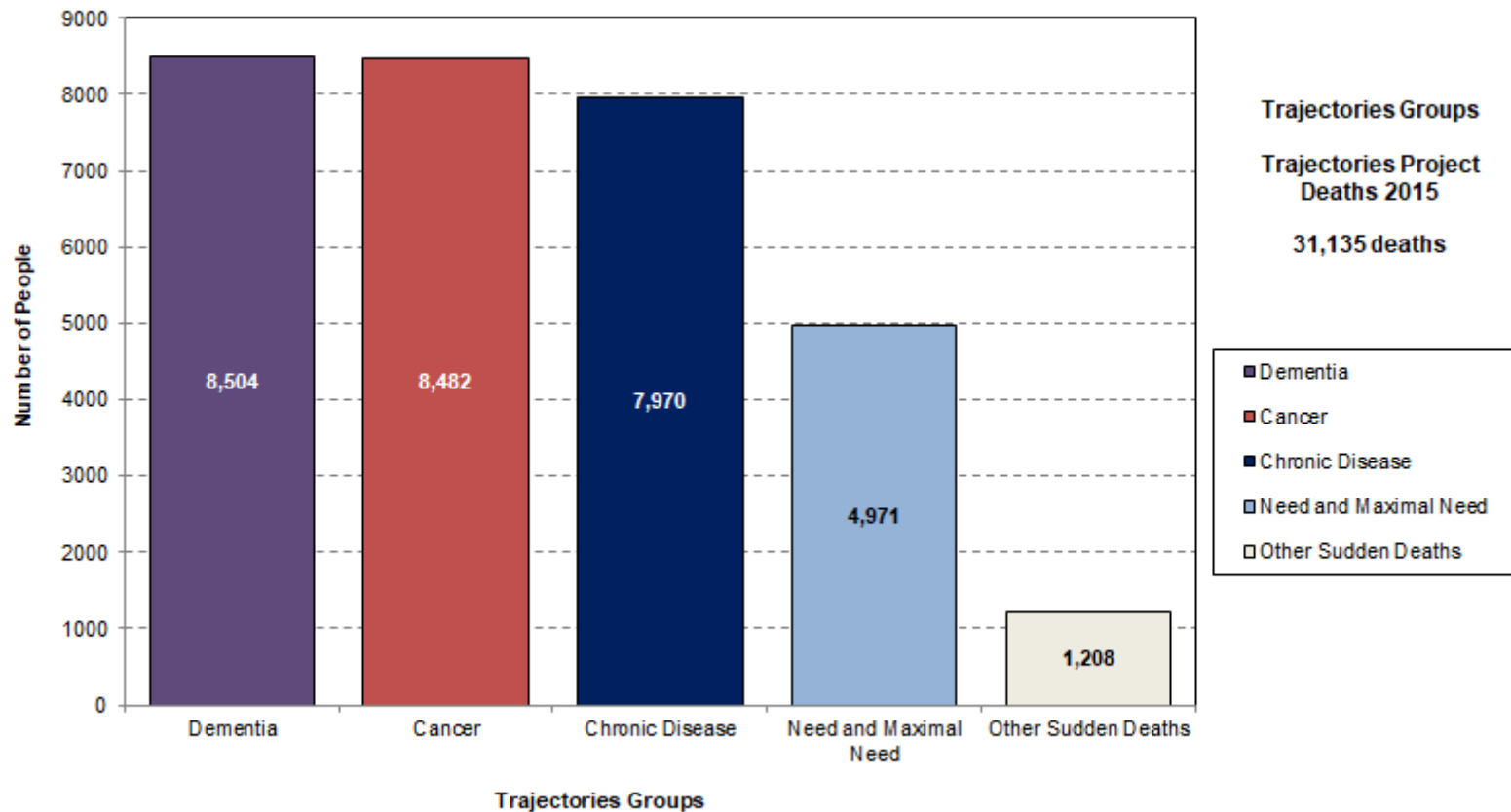
Trajectories Groups



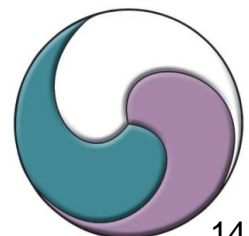
Trajectories Groups allocated sequentially: Dementia, Cancer (diagnosed cancer, died of neoplasm), Chronic Disease (needing ARC or interRAI assessment for home care), Need and Maximal Need (including Disability Support Services), Other Sudden Deaths.



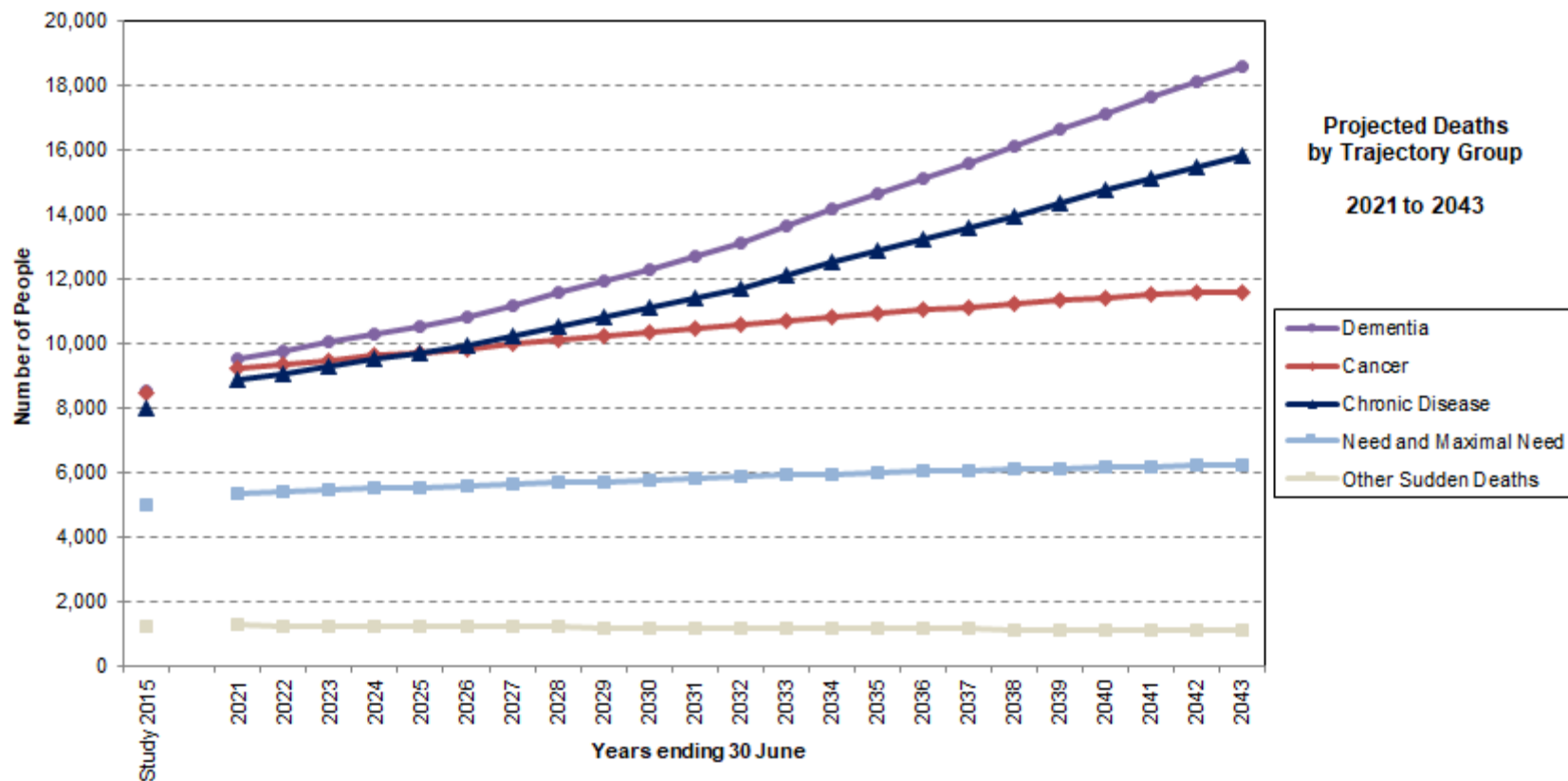
Trajectories Groups



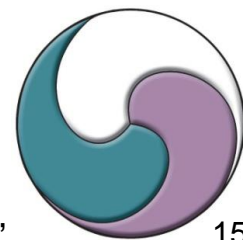
The groups are allocated from left to right. The Dementia and Cancer groups are large in their own right. The amalgamated Chronic Disease group is almost the same size. The analysis that follows will typically use these five major groups.



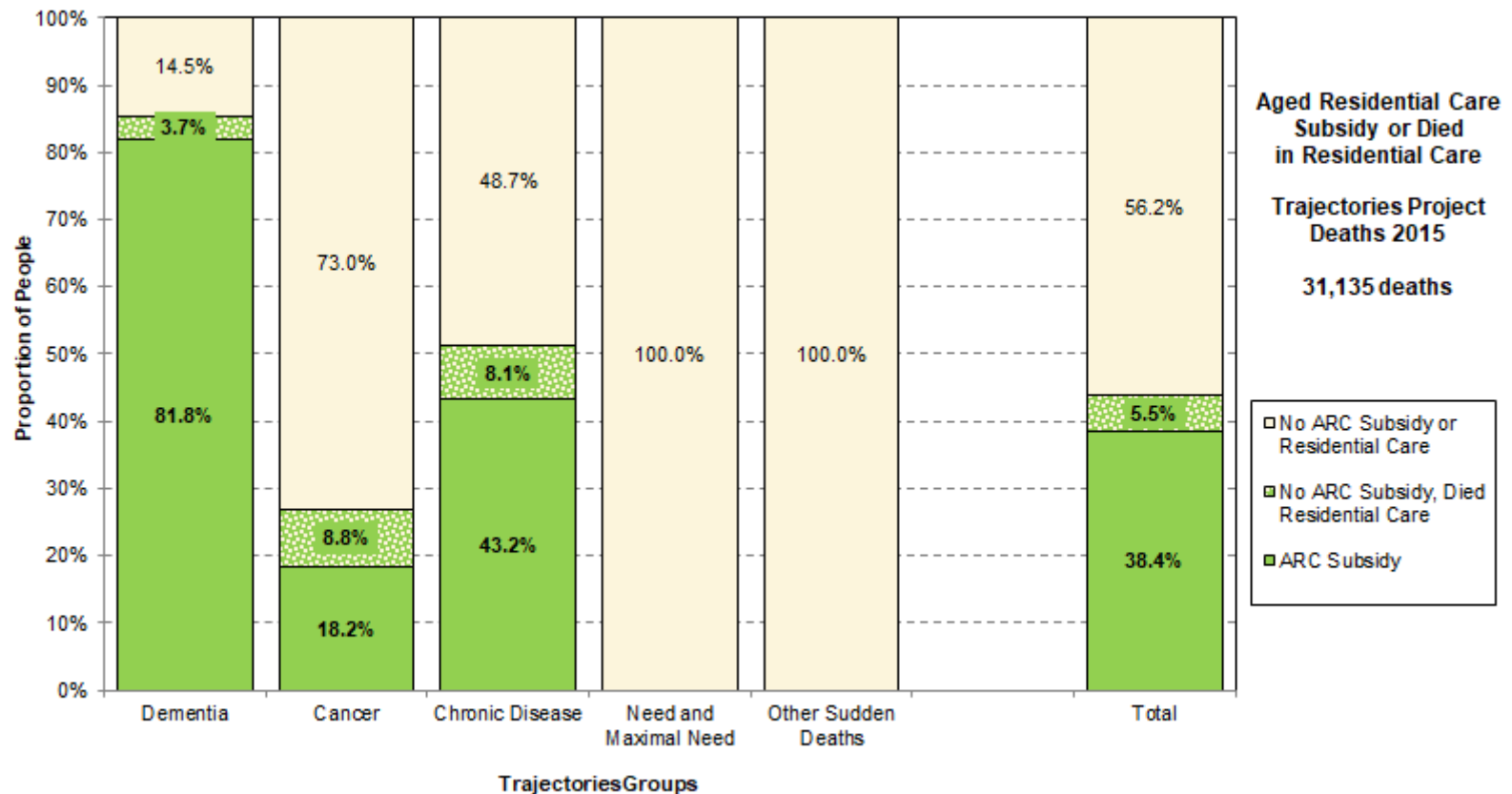
Projected Deaths by Trajectory Group



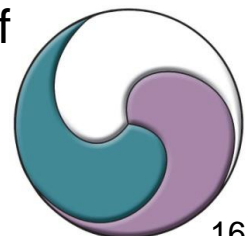
The patterns by age for the five trajectory groups are from the Trajectories Study 2015. The projected ageing of deaths results in the Dementia and Chronic Disease groups growing much faster than other groups.



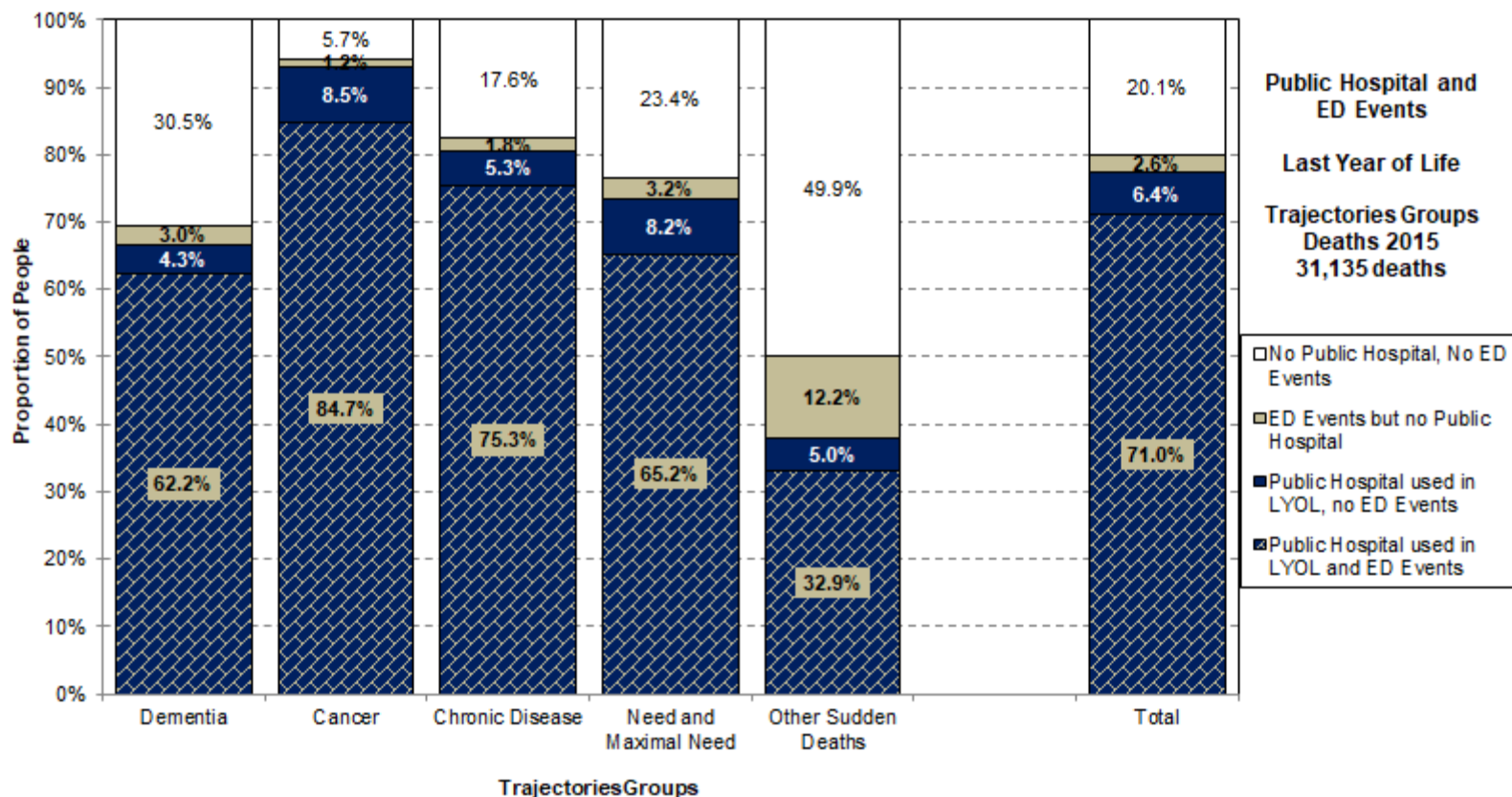
ARC Subsidy or Residential Care



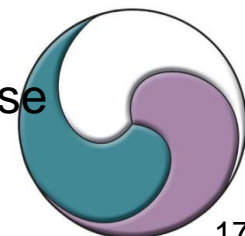
Overall 43.8% of people used residential care at some time in their trajectory. This is highest for the Dementia group at 85.5%. More than half of Chronic Disease (51.3%) and more than a quarter of the Cancer group (27.0%) had an ARC subsidy or died in residential care.



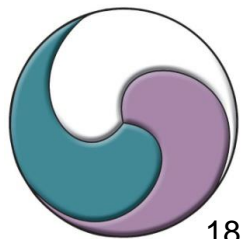
Public Hospital and ED in LYOL



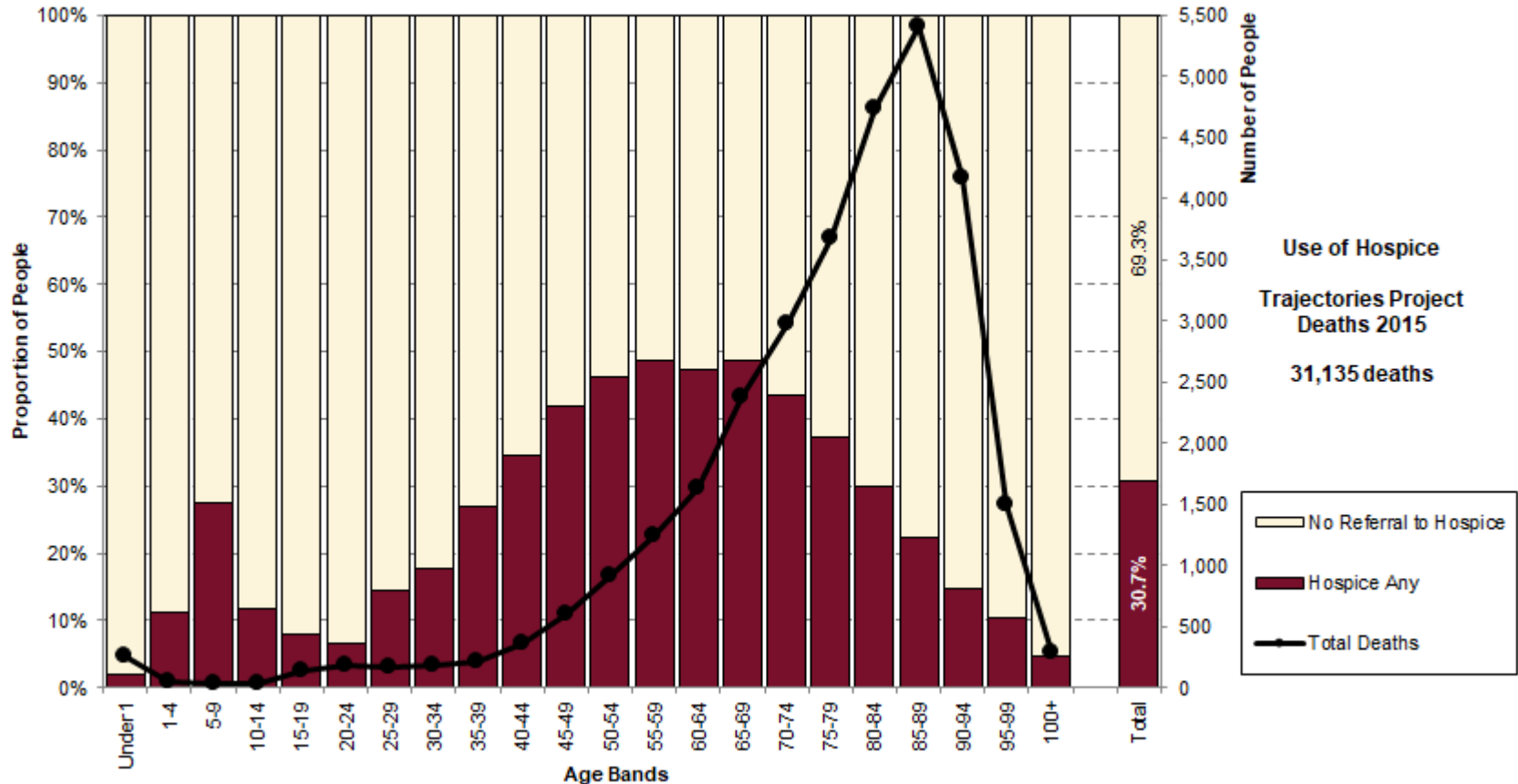
71.0% of all deaths have both public hospital admissions and ED events in the last year of life (LYOL). The Cancer group has the highest level at 84.7%. A significant proportion of those in the Dementia group have no use of public hospital or any ED event (30.5%).



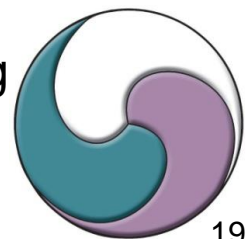
Need for Palliative Care Hospices, Aged Residential Care and Primary Care



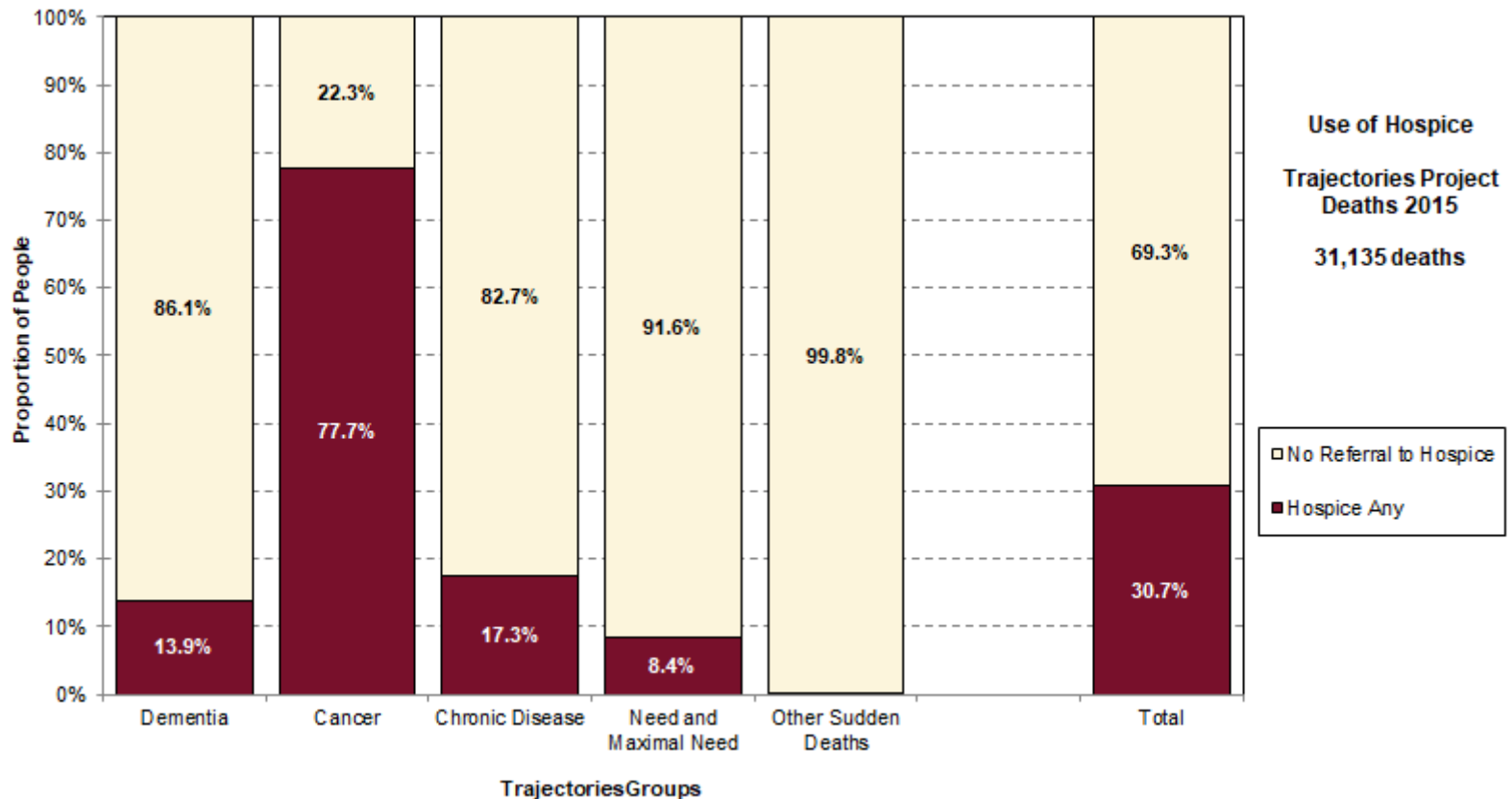
Use of Hospice Services



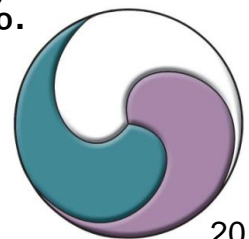
Overall, 30.7% of people in the Trajectories study used hospice as part of their end of life trajectory. There is a strong and characteristic pattern by age, with almost 50% of those dying in the age bands from 55 to 70 using hospice.



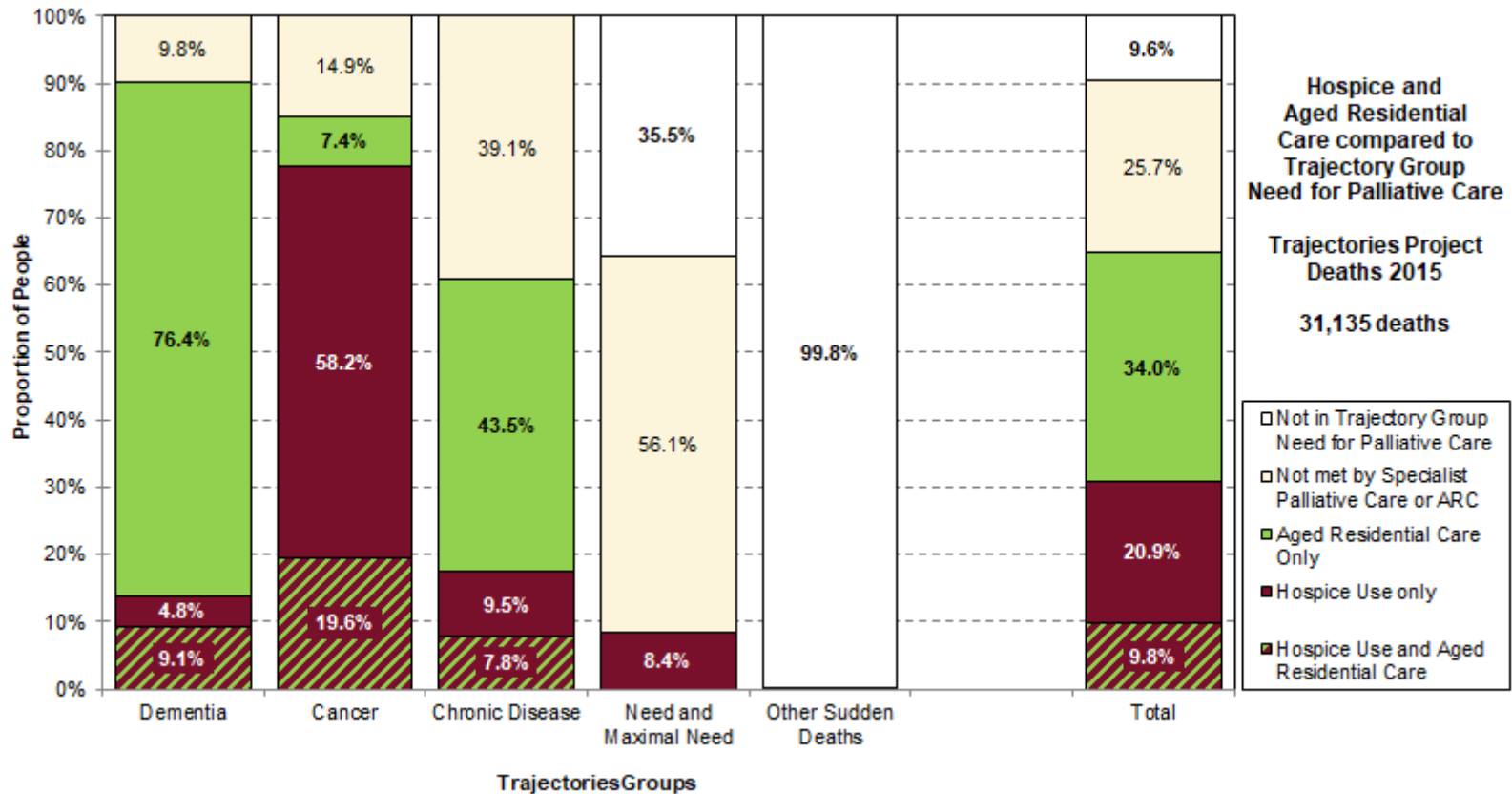
Use of Hospice Services



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.



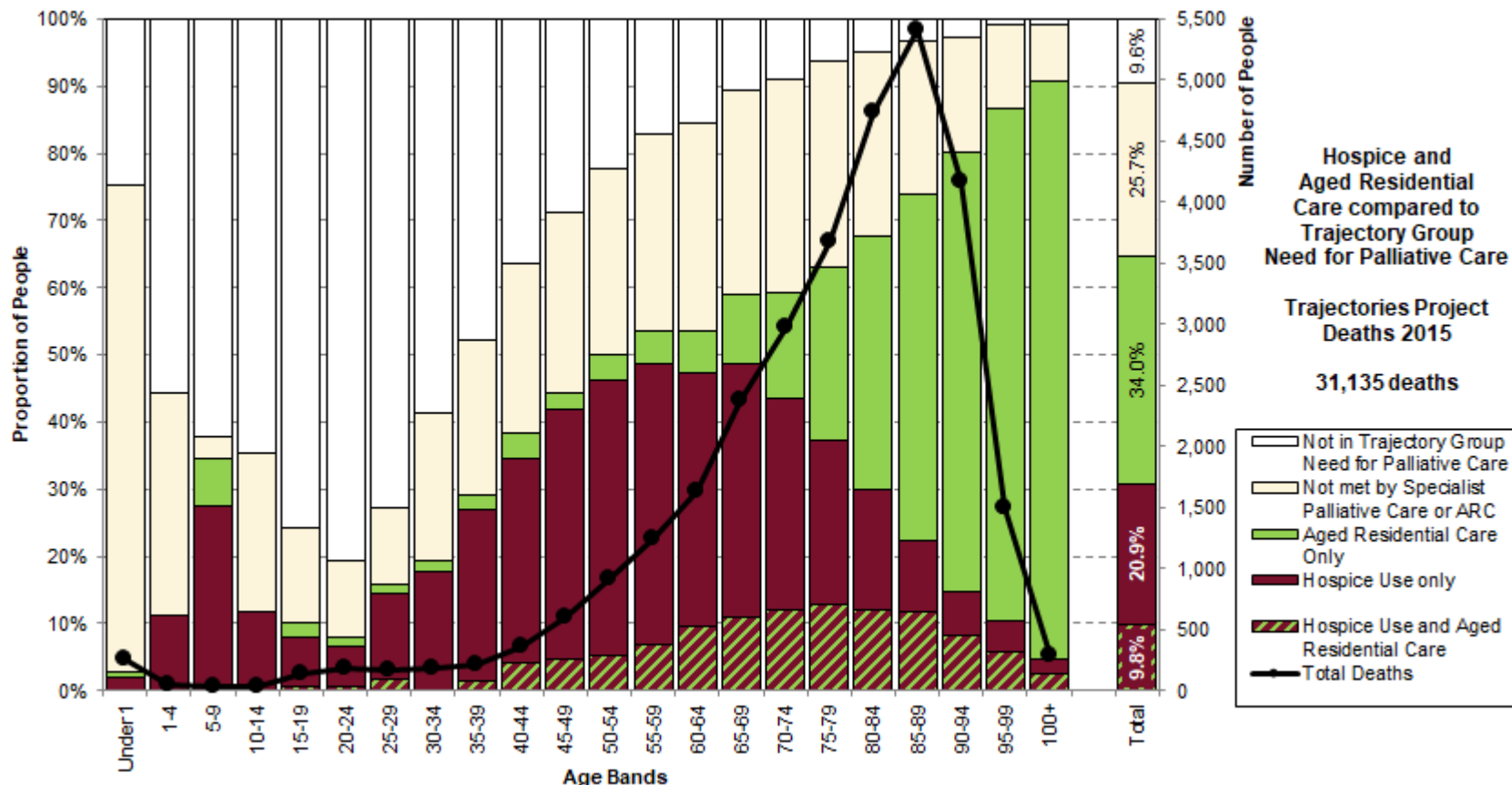
Hospice, Aged Residential Care, Need



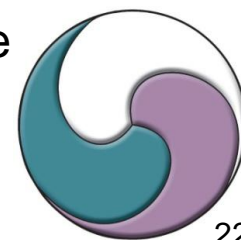
Overall, 64.8% used hospice services or aged residential care (ARC). 9.6% of total deaths fall outside the Trajectory Group Need for Palliative Care, leaving a cream group of 25.7% needing on-going palliative care from the primary care team. Some may have seen a hospital palliative care team, but this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



Hospice, Aged Residential Care, Need



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.



Place of Care

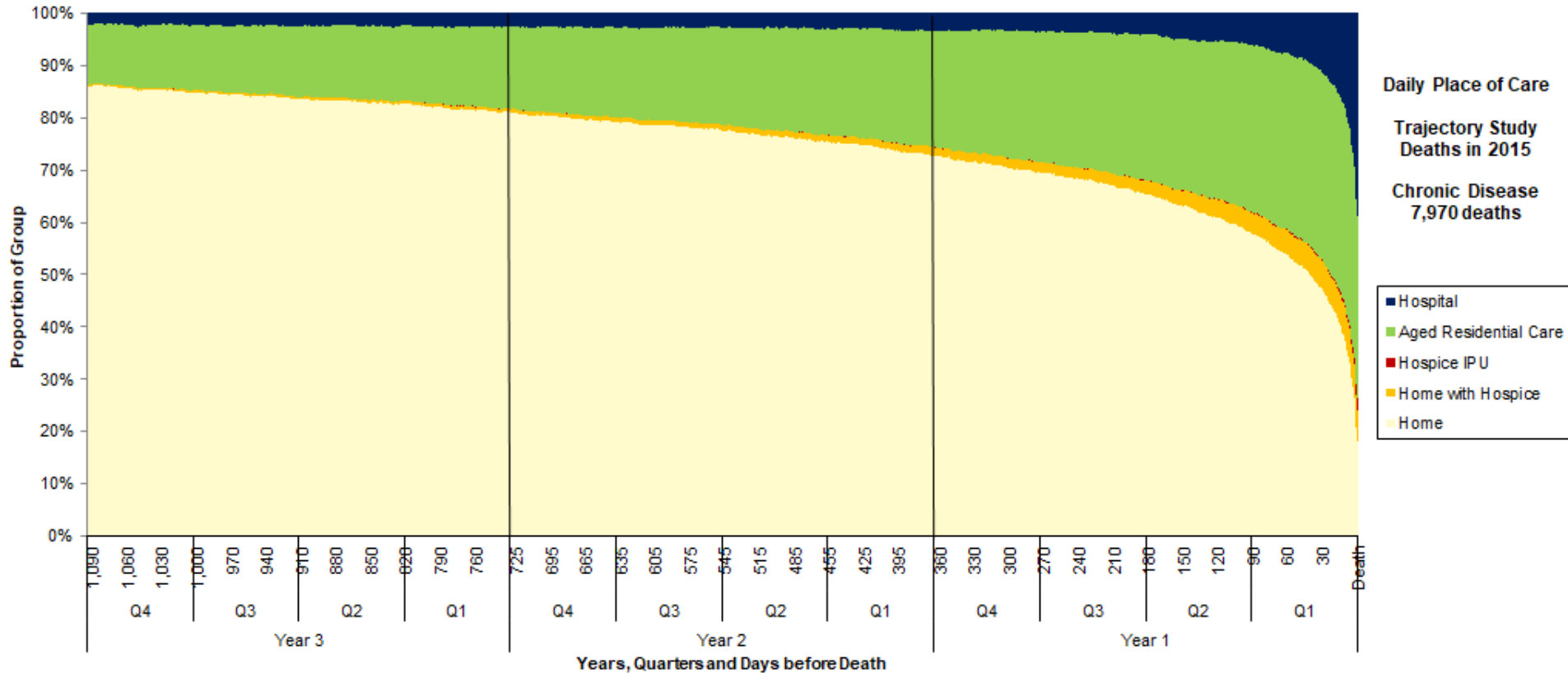
Last Three Years of Life

Last Year of Life

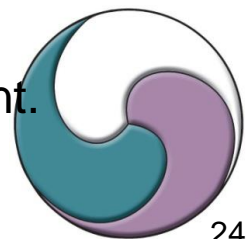
Transitions



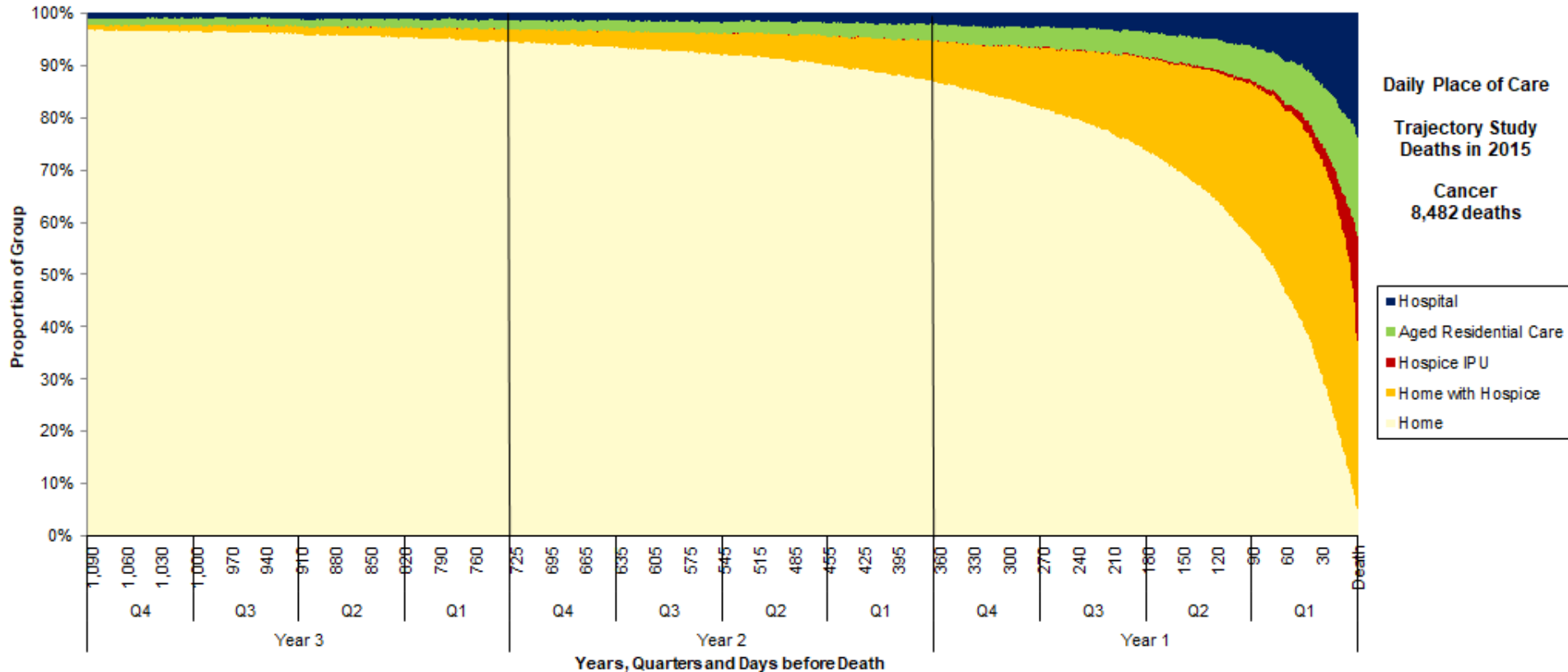
Chronic Disease Group



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.



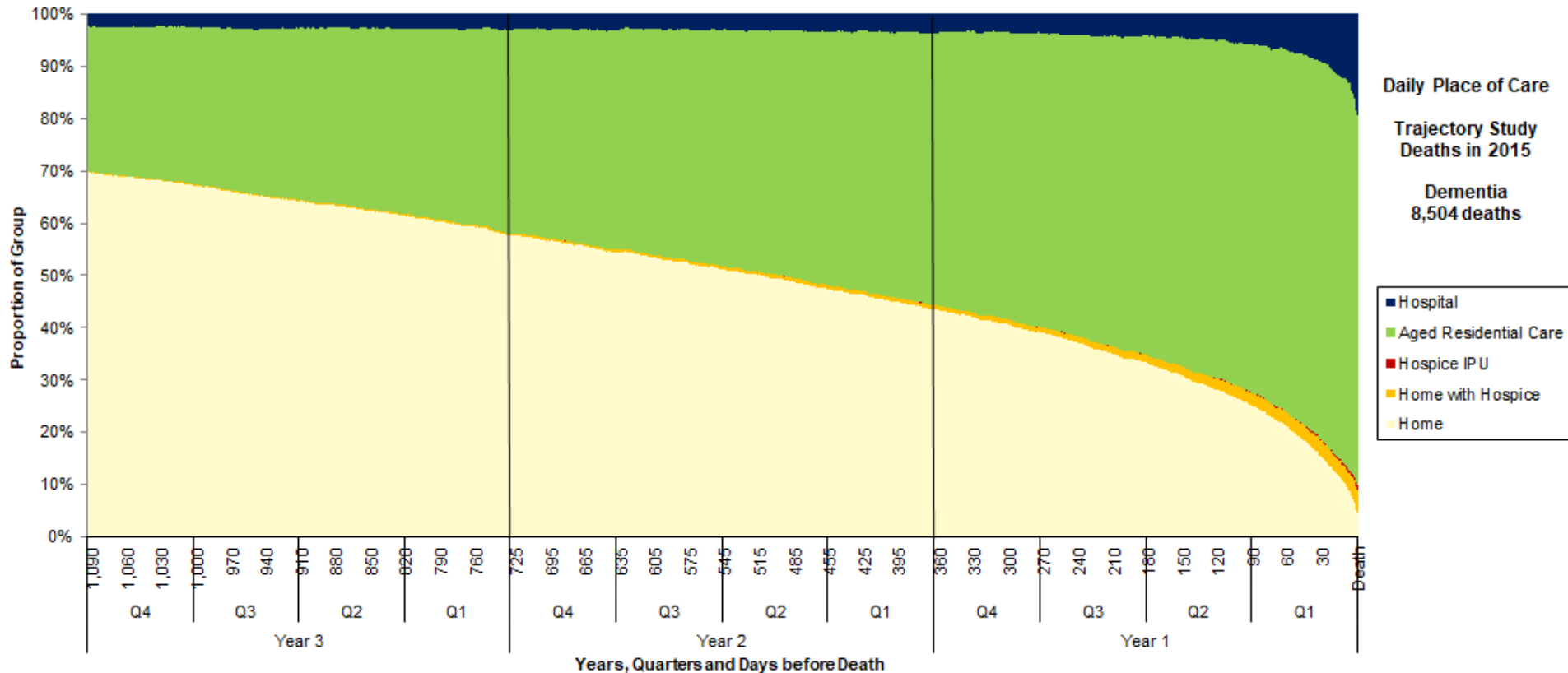
Cancer Group



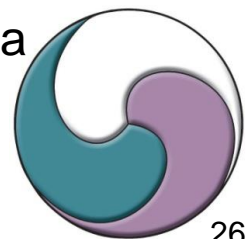
Daily place of care for each day in the last three years of life, showing the Cancer group. This group has no evidence of dementia, are in the Cancer Registry and died of neoplasms. It also includes some who are not in the Cancer Registry but have a neoplasm as the underlying cause of death.



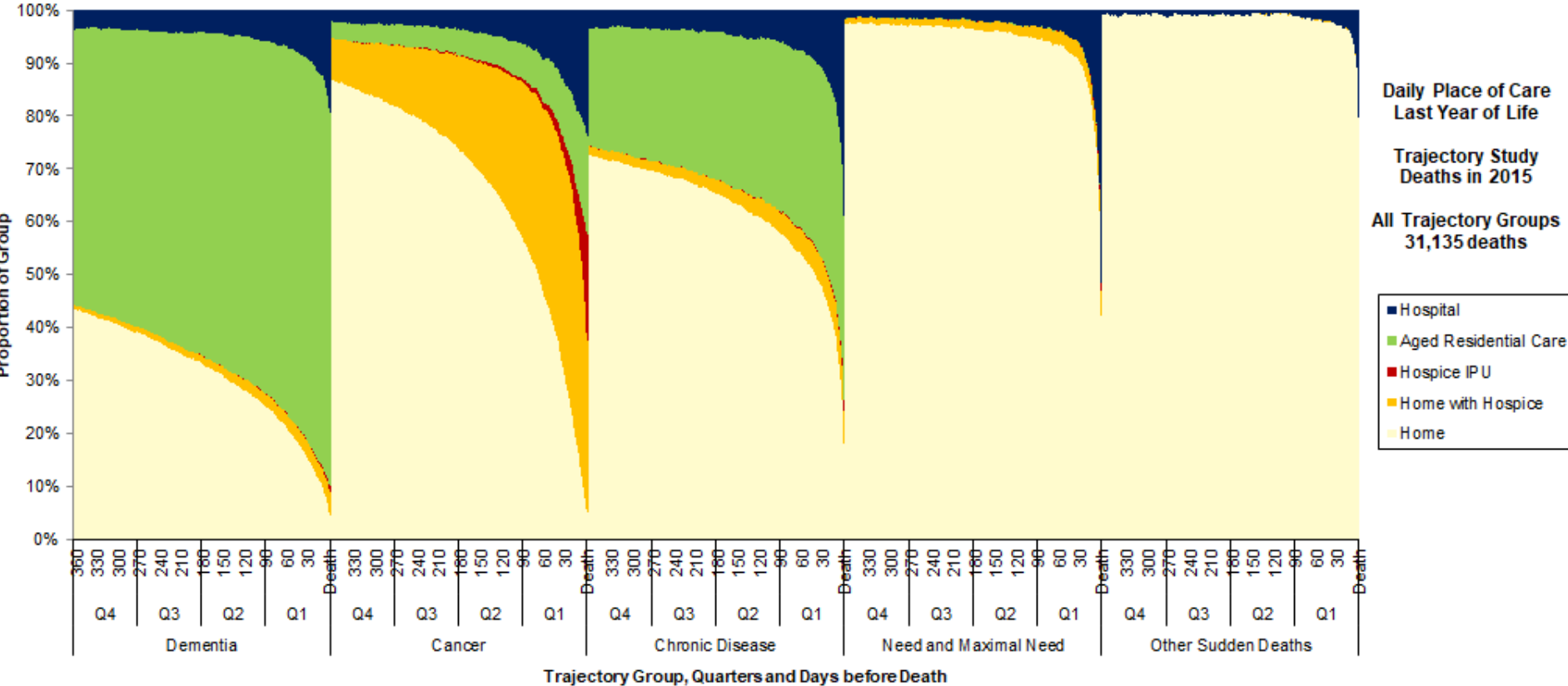
Dementia Group



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.



Last Year of Life by Trajectory Group

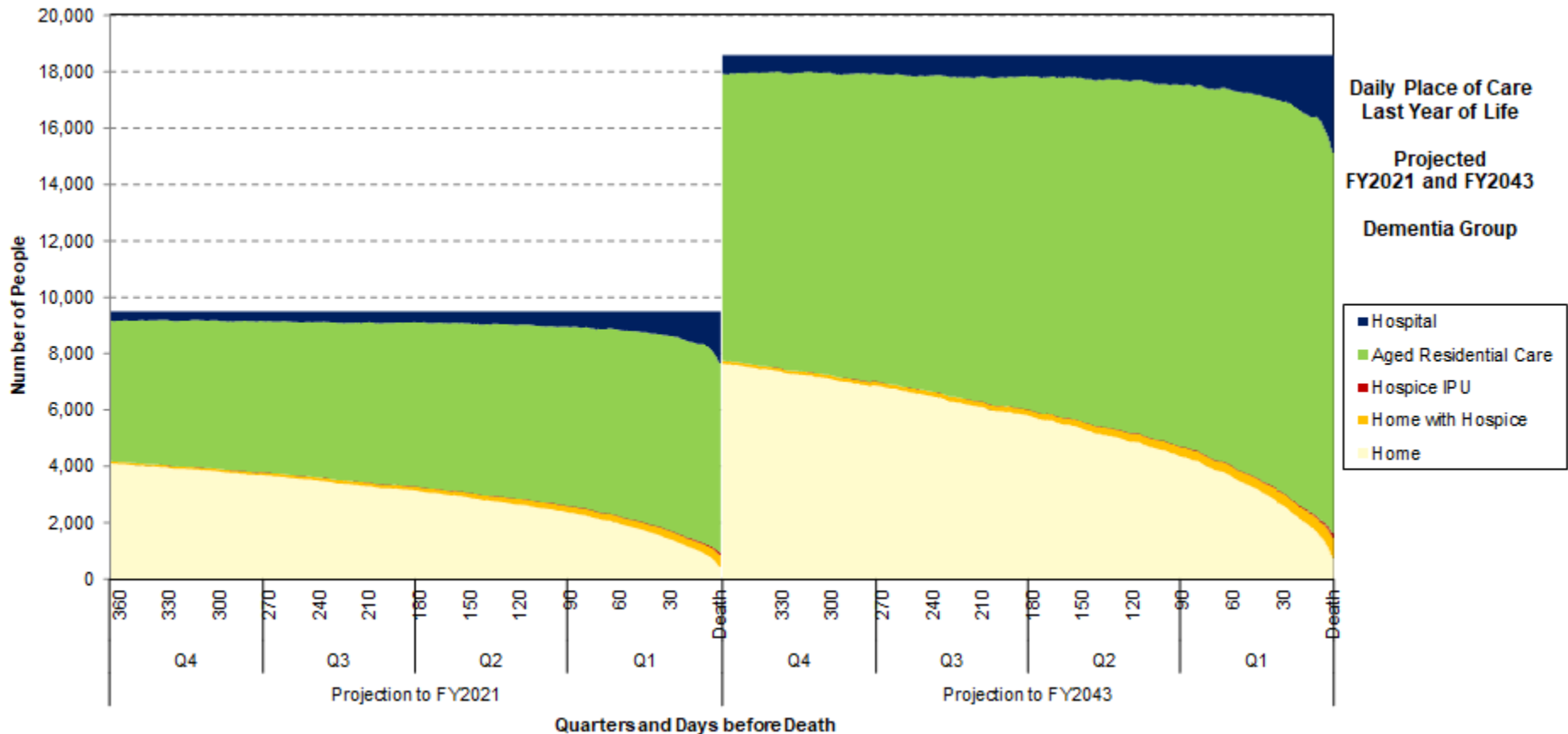


Daily place of care for each day in the last year of life (LYOL), showing each trajectory group. Shown as a percentage of each group.



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

Dementia Group, 2021 and 2043

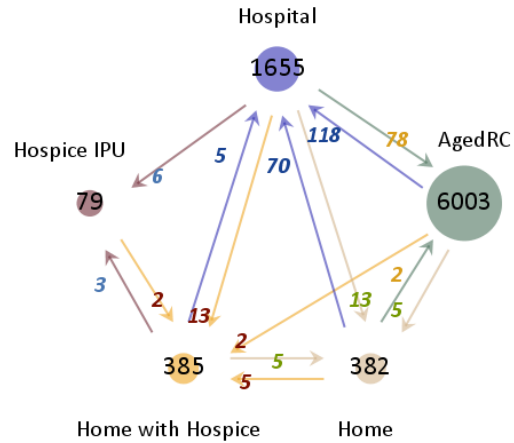


Projected Dementia group deaths increase from 9,499 in 2021 to 18,585 in 2043, an increase of 196%. Projected days in public hospital increase by 189%, days in aged residential care by 203% and days at home (without hospice) by 185%.

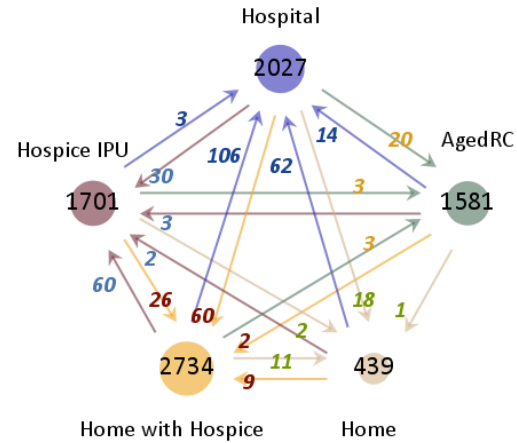


Transitions on the Day of Death

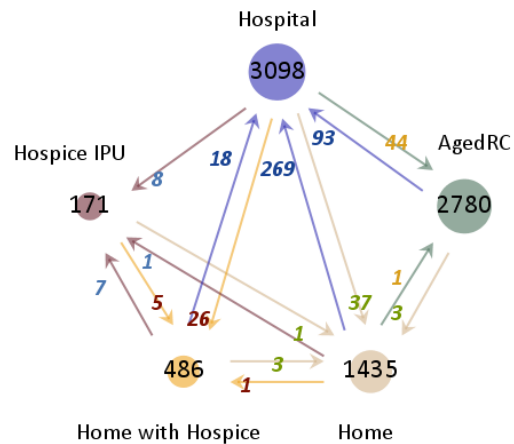
Dementia



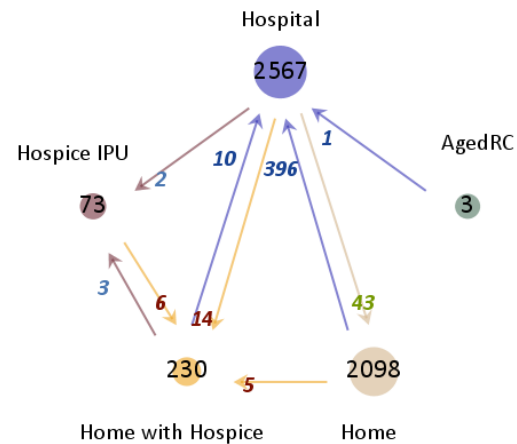
Cancer



Chronic Disease



Need and Maximal Need



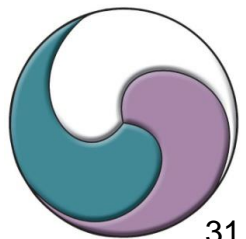
Animations of Transitions

- Animations of five groupings are available, with instructions:
 - Trajectory Groups; Age Groups; Māori and Gender; Transition Groups; Seasonal Groups.
- [Heather McLeod & Associates Ltd OneDrive Trajectories Project Shared Animations](#)

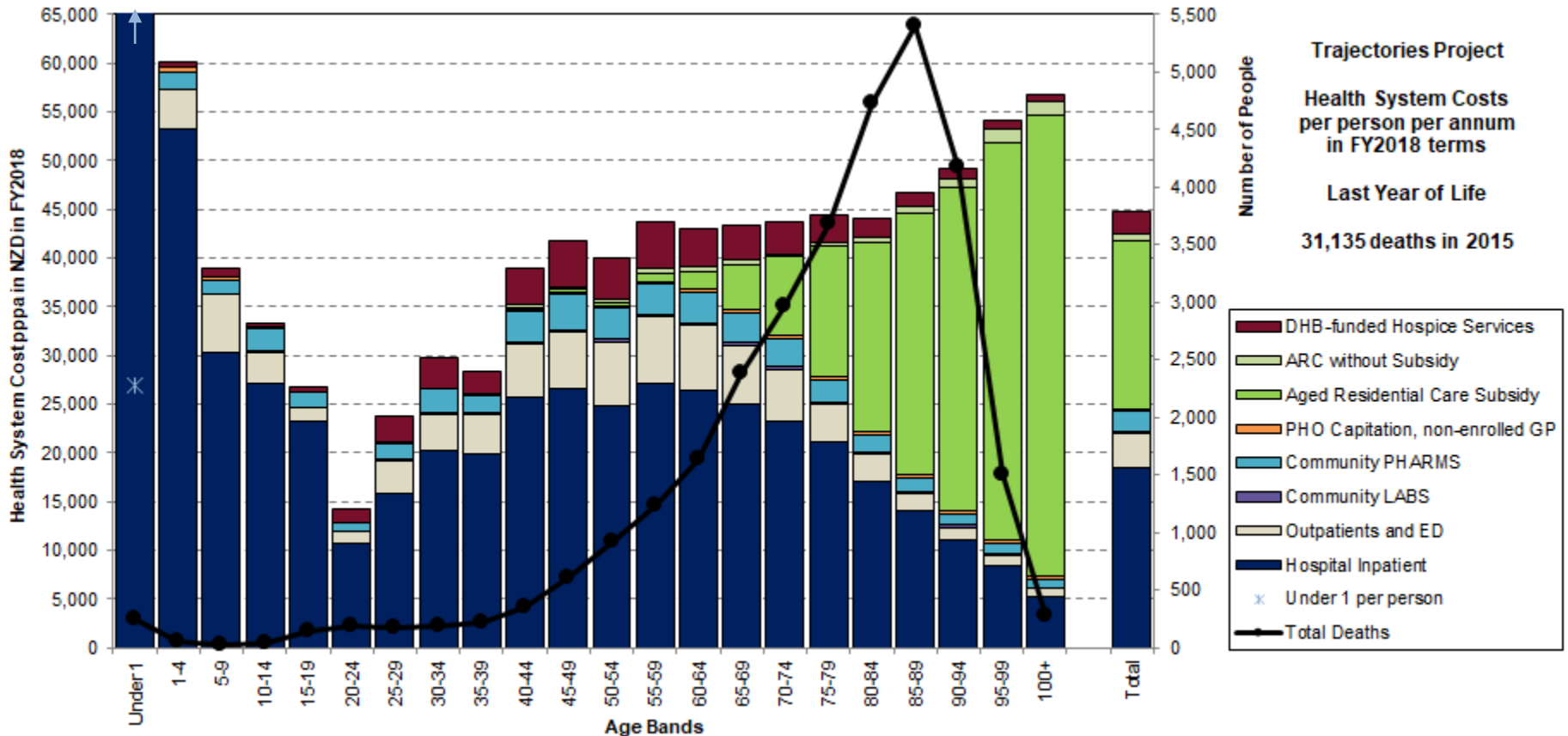
- Transitions are useful for clinicians to think more carefully about the consequences of treatment plans.
- Encourage conversations about advanced care planning.
- Used for planning by emergency transport (ambulance) groups.
- Used to improve care centred on the person, rather than the system.
- Targets set by funders to reduce transitions at the end of life.



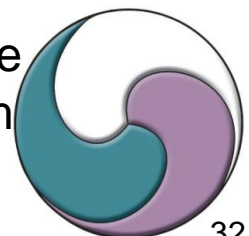
Health System Costs by Trajectory Group Costs in FY2018 Terms



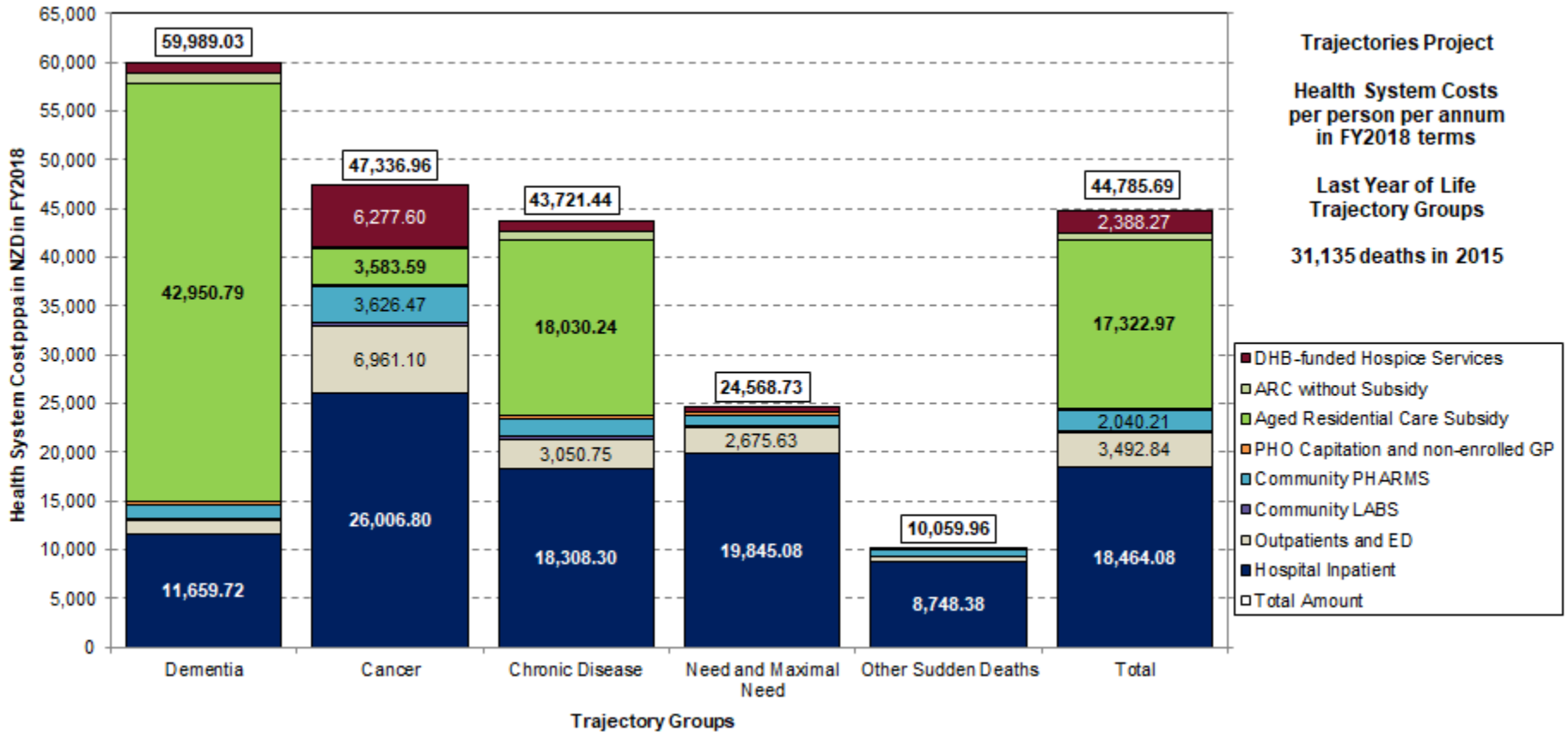
Health System Costs in LYOL



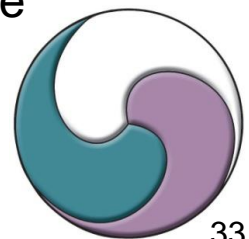
The total health system cost per person in the last year of life (LYOL) is **\$44,785.69** in FY2018 terms. Costs pppa are highest for those who die under age 1 and are lowest in the age band 20-24, when many deaths are sudden. Costs pppa rise slowly with age from age 40 to age 84, then from age 85 onwards,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



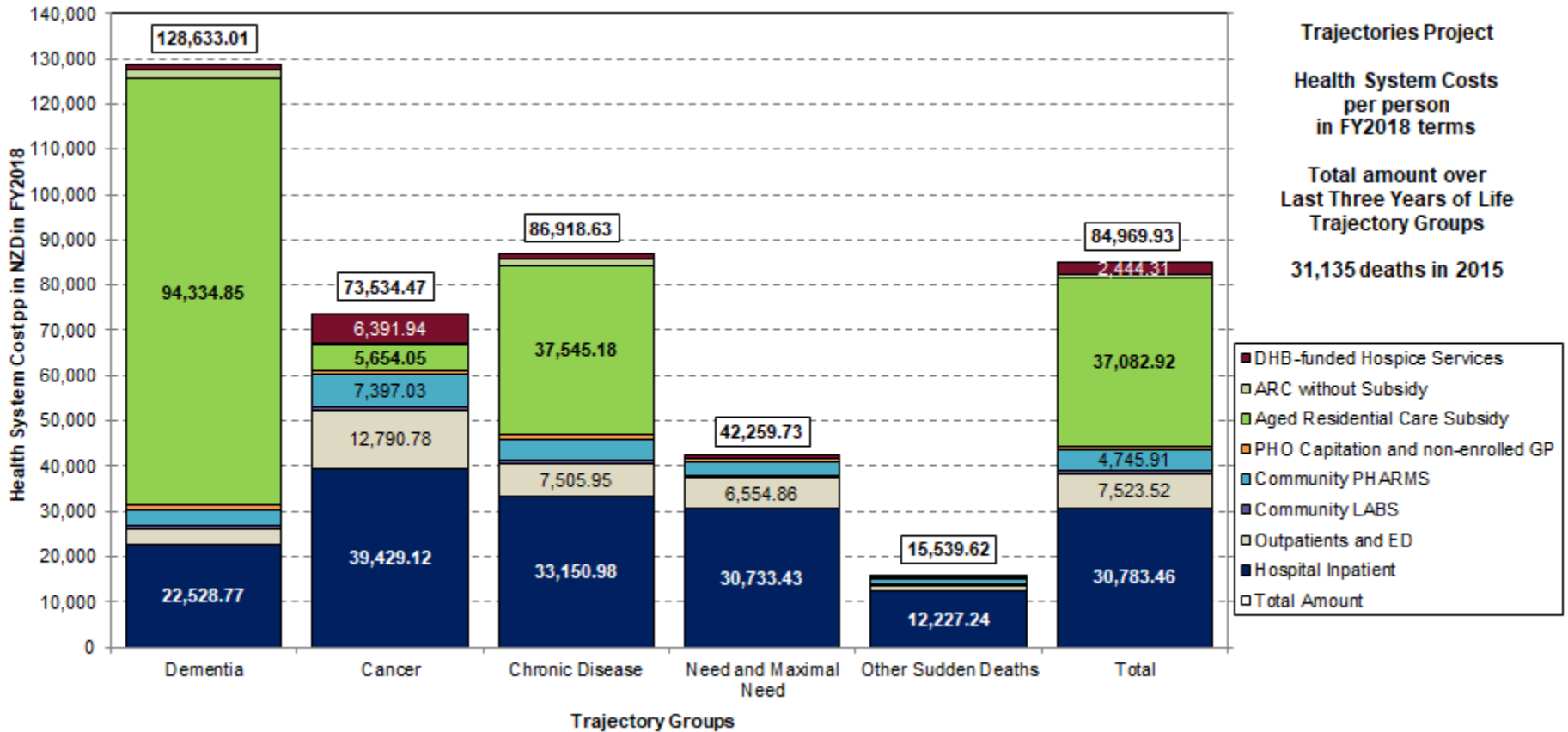
Health System Costs in LYOL Trajectory Groups



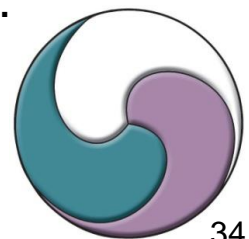
Overall, the health system cost is **\$44,785.69** per person in the LYOL. The amount varies substantially by trajectory group: Dementia **\$59,989.03**, Cancer **\$47,336.96**, Chronic Disease (frail elderly) **\$43,721.44**, Need and Maximal Need **\$24,568.73**, and Other Sudden Deaths **\$10,059.96**.



Health System Costs for L3YOL Trajectory Groups



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**.



June Atkinson

Senior Data Analyst/Data Manager
Department of Public Health
University of Otago, Wellington

Email: june.atkinson@otago.ac.nz
Phone: 04 918-6085

bode³

Burden of Disease Epidemiology, Equity
and Cost Effectiveness Programme



W E L L I N G T O N



**Body, Mind, Soul
Earth**

Heather McLeod

Heather McLeod & Associates Ltd

Honorary Senior Research Fellow, School of Nursing, University of Auckland

Adjunct Professor, Actuarial Science, University of Cape Town

Extraordinary Professor, Department of Statistics and Actuarial Science,
University of Stellenbosch

heather@heathermcleodnz.com

www.heathermcleodnz.com