

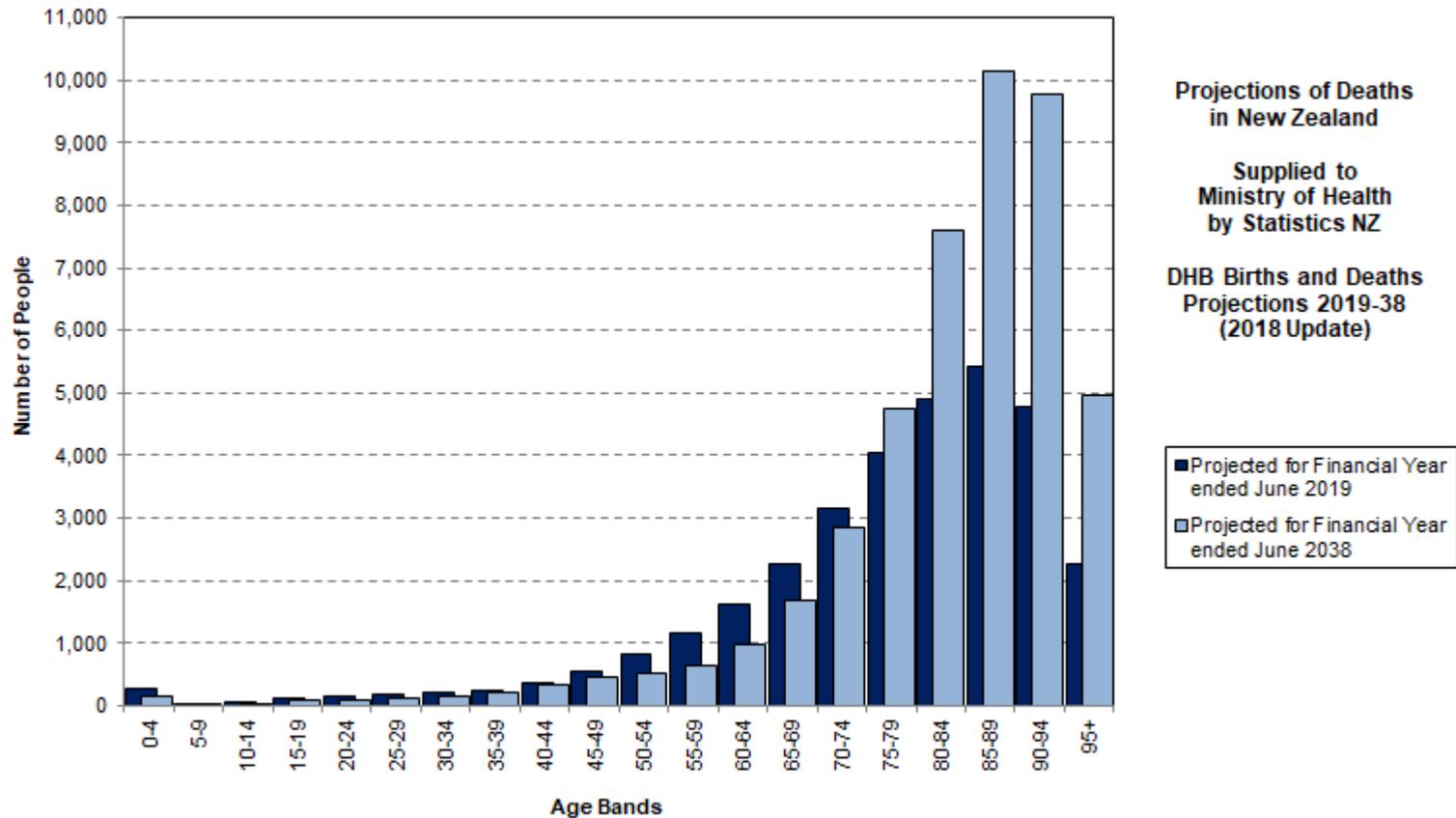
The Price of a Successful Health System?

Changing trajectories at the end of life

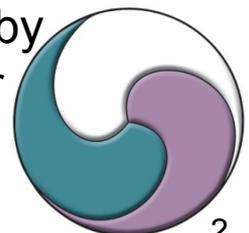
**Population Association of New Zealand
Wellington, June 2019**



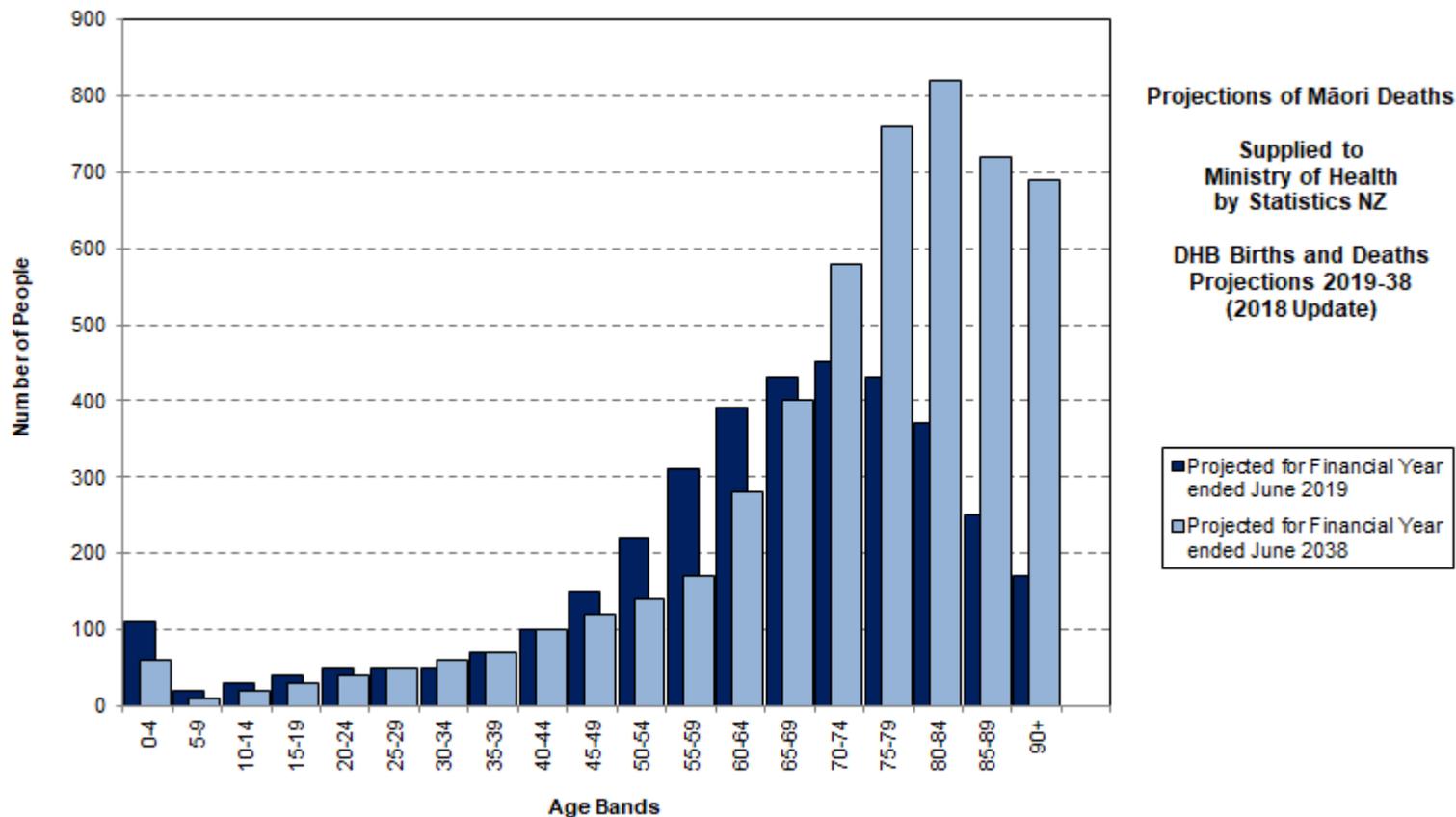
Ageing of Deaths 2019 to 2038



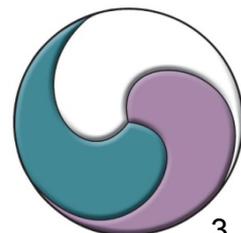
Statistics NZ projects for the Ministry of Health in the “2018 Update” that total deaths will increase from **32,600** a year in FY2019 to **45,500** a year by FY2038, an increase of **40%**. There are two important effects: the greater number of deaths and the ageing of those deaths.



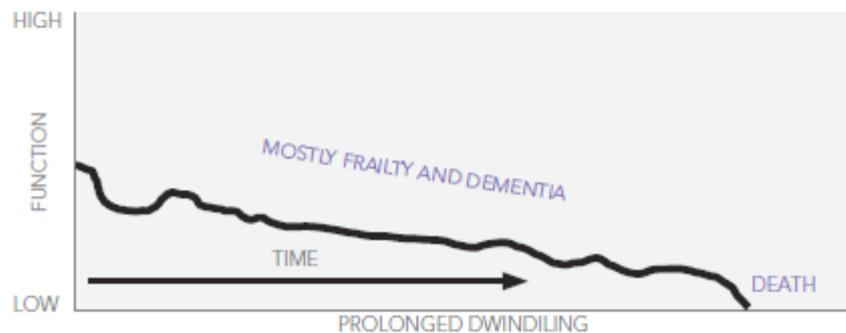
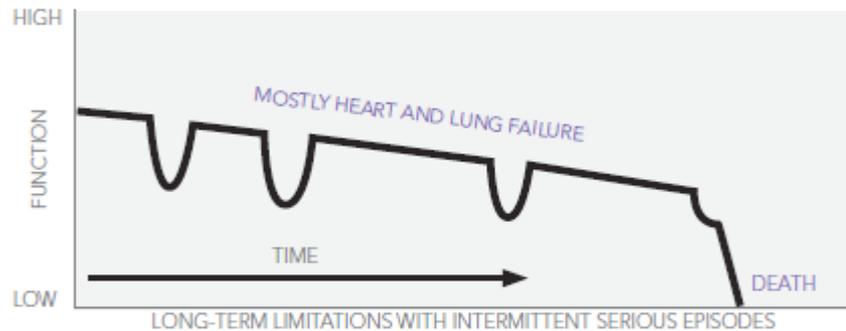
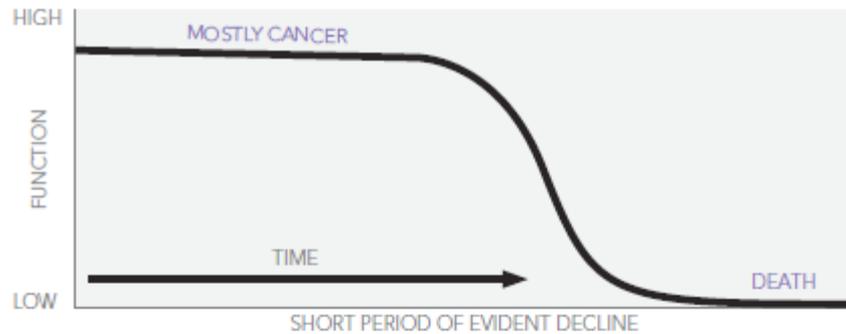
Ageing of Māori Deaths 2018 to 2038



Māori deaths are projected to increase from **3,700** a year in FY2019 to **5,100** a year by FY2038, an increase of **38%**. There is projected to be a change in the shape with fewer deaths in the 45-69 range and a substantial increase in deaths from age 70 onwards.



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.

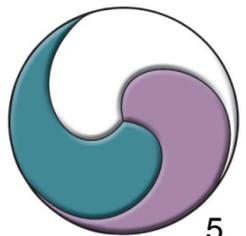
Source: Palliative Care Australia (2010). Health System Reform and Care at the End of Life: a Guidance Document. 2010. Canberra: Palliative Care Australia.

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.



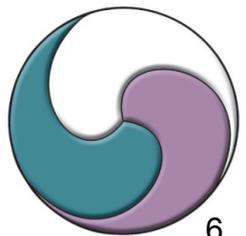
Trajectories Study and Period

- **All deaths occurring and registered in 2015**
 - History of health care utilisation going back ten years where feasible.
 - Cancer Registry and 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.
 - Extension using same data sets to consider place of care, time spent in the community and transitions of care in the last three years of life.

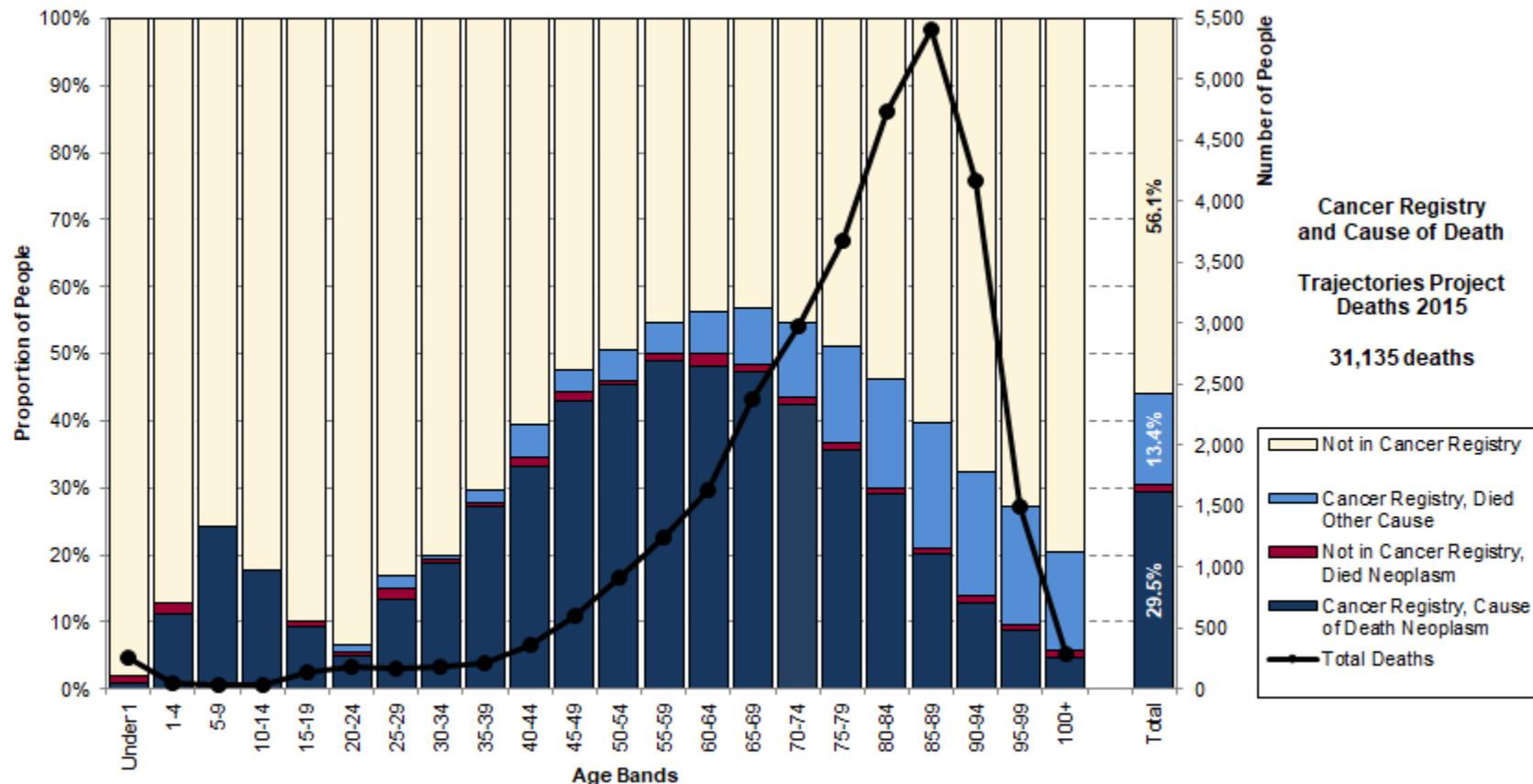


Trajectories Study Data

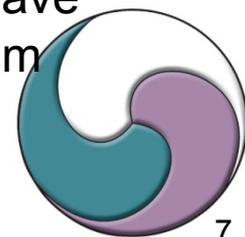
- Linked data sets, using de-identified NHI number:
 - Mortality Collection (MORT)
 - New Zealand Cancer Registry (NZCR)
 - National Minimum Dataset (Hospital Events) (NMDS) - inpatients
 - National Non-Admitted Patients Collection (NNPAC) - outpatients
 - PRIMHD mental health data (PRIMHD)
 - Laboratory 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 30 hospices



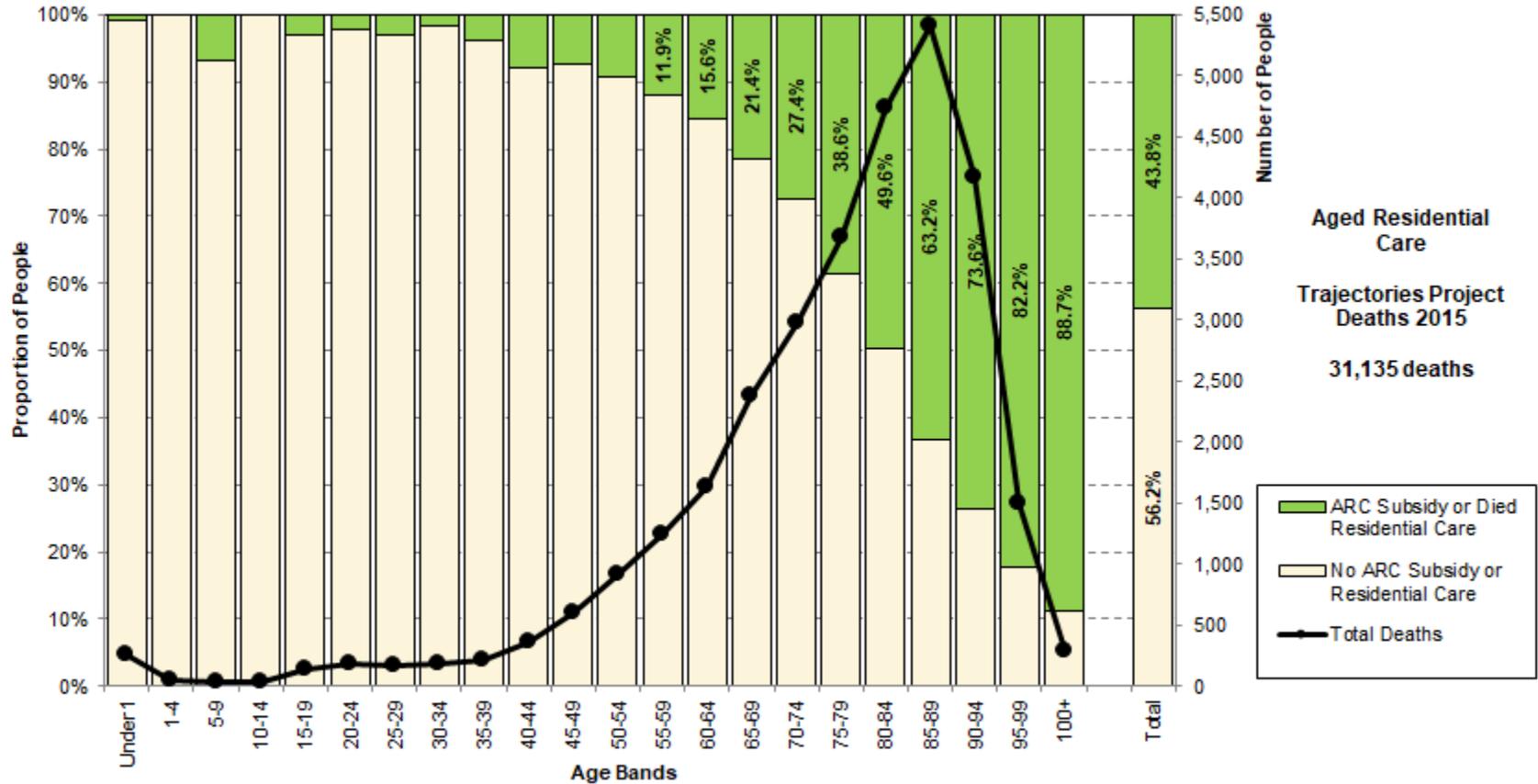
Cancer Registry and Cause of Death



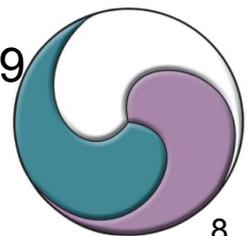
In total, 43.0% of all deaths are in the Cancer Registry. 29.5% are in the Cancer Registry and have neoplasm as cause of death. A further 1.0% have neoplasm as cause of death, but are not in the Cancer Registry (neoplasm includes some benign tumours). Of interest are the 13.4% who are in the Cancer Registry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



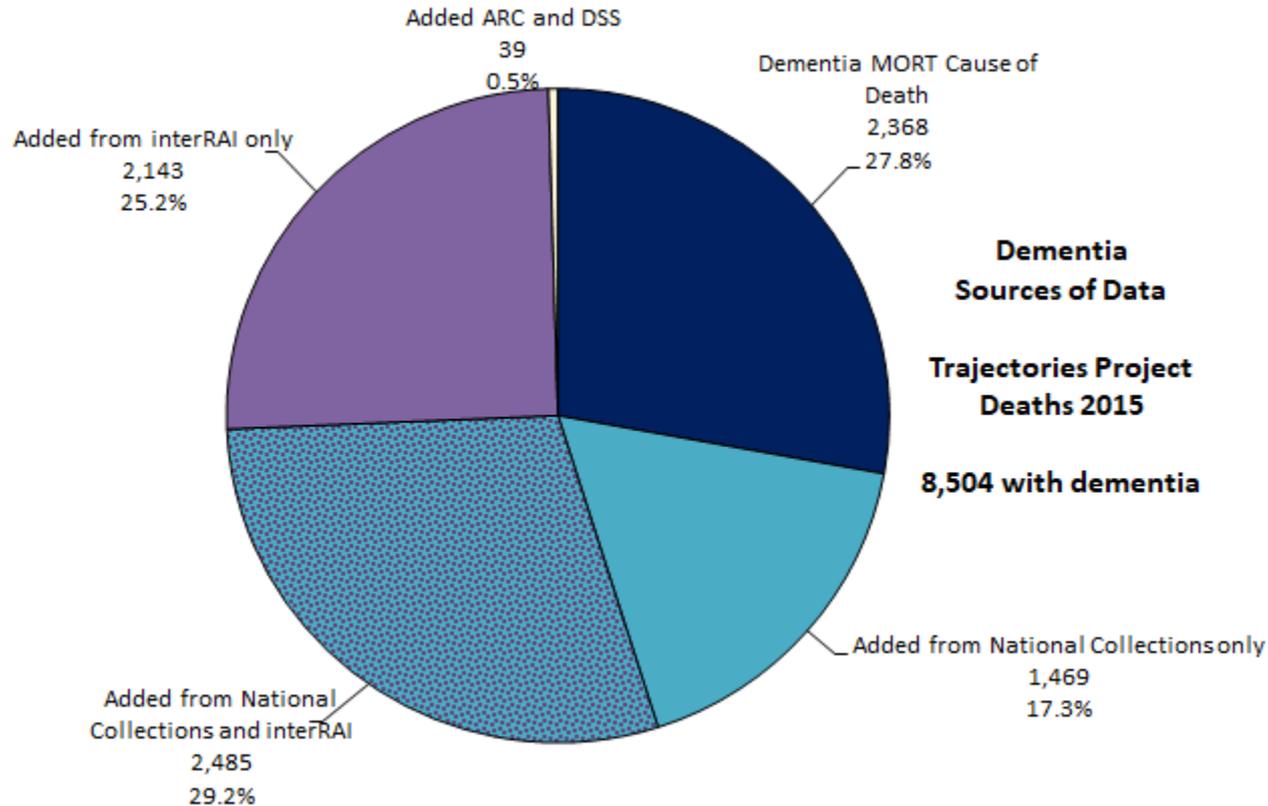
Aged Residential Care



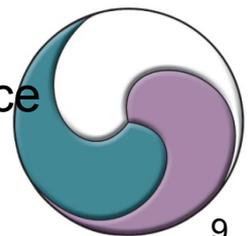
In total, 43.8% of all deaths have an aged residential care subsidy or were recorded as having died in residential care. There is a very strong pattern that increases sharply with age: 73.6% by age 90-94, 82.2% by age 95-99 and 88.7% for those aged 100 or more.



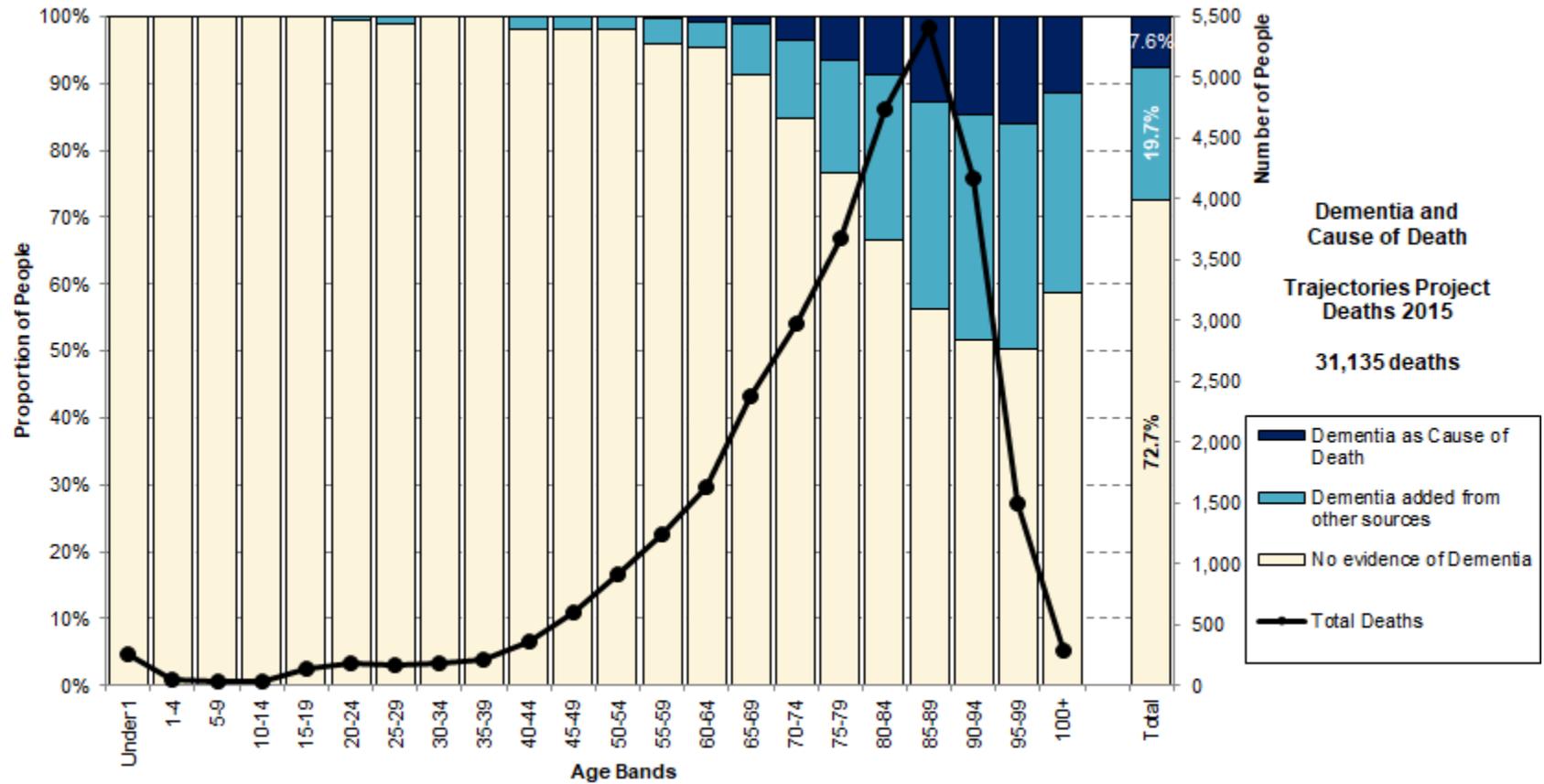
Dementia Sources of Data Importance



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.



Dementia and Cause of Death

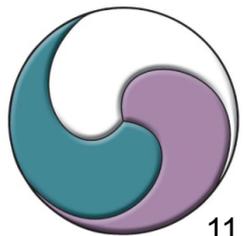


Dementia is known to be poorly represented as a cause of death. Only 7.6% of all deaths identified as having a form of dementia from mortality data. By combining any evidence of dementia from other sources, we find that a further 19.7% have dementia, making 27.3% of total deaths.



Trajectory Groups

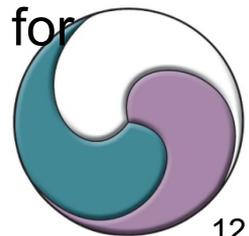
Development of Groups



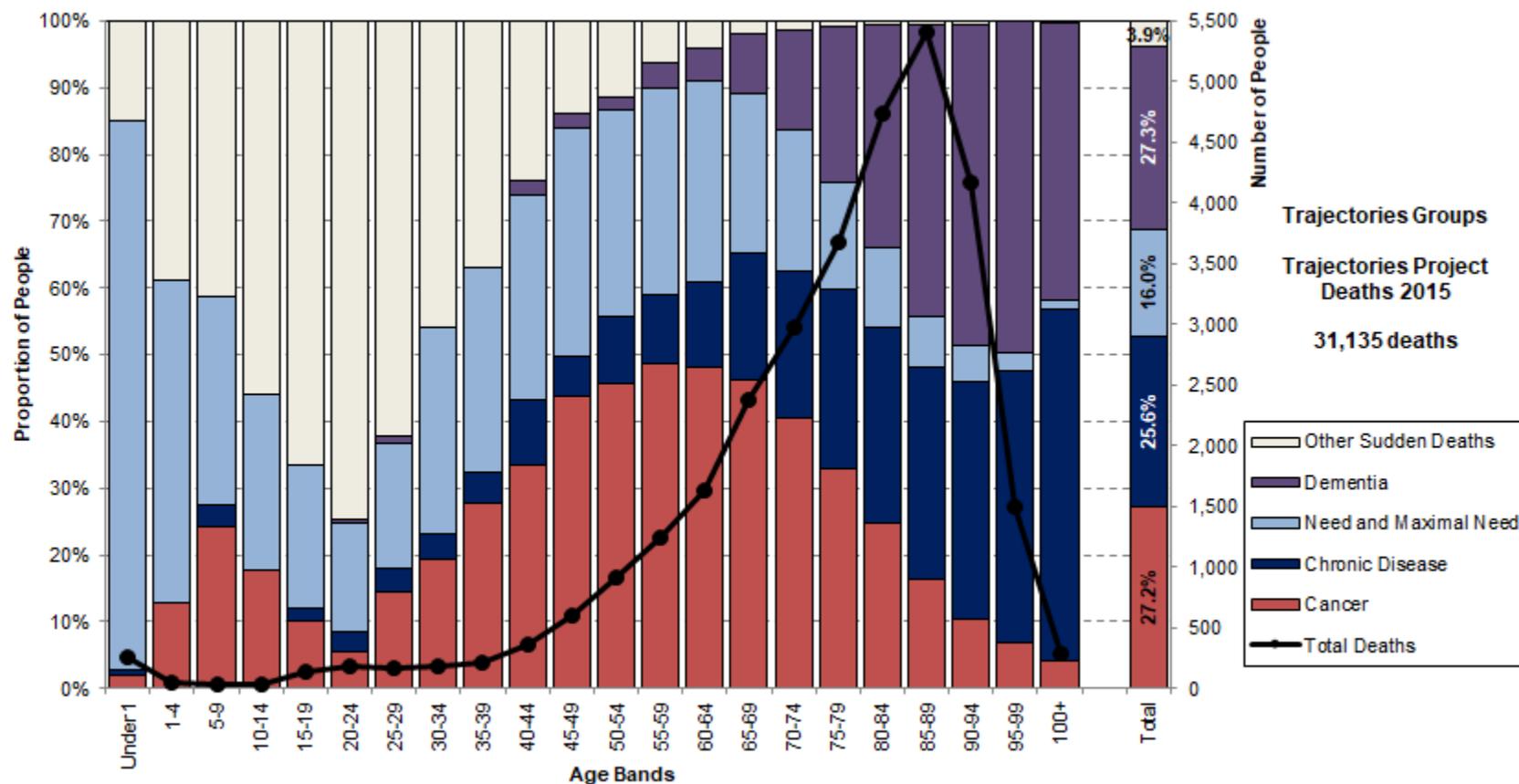
Trajectories Groups

The trajectories groups are extracted sequentially as follows:

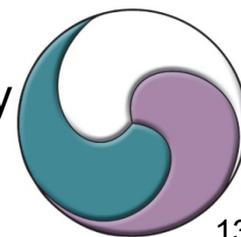
- **Dementia:** anyone with any evidence of dementia (MORT, hospital, medicines, interRAI diagnosis or Cognitive Performance Scale).
- **Cancer:** no evidence of dementia, any cancer and died of neoplasm, or died of neoplasm (Cancer Registry, MORT).
- **Chronic Disease:** no evidence of dementia, cause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



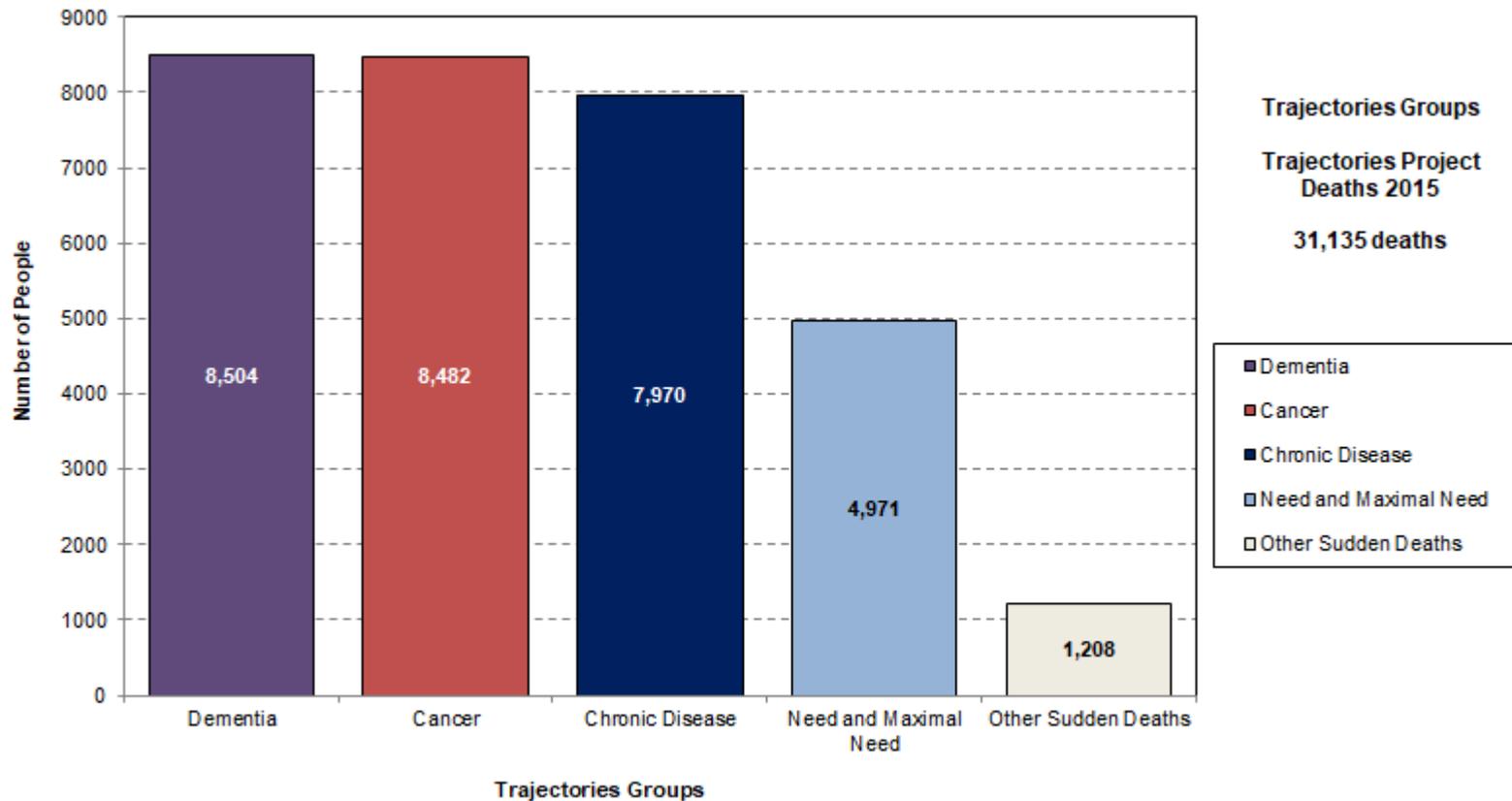
Trajectories Groups



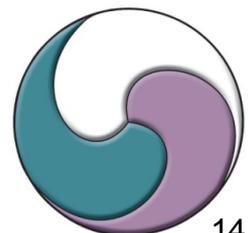
Trajectories Groups allocated sequentially: Dementia, Cancer (diagnosed cancer, died of neoplasm), Chronic Disease (needing ARC or interRAI assessment for home care), Need and Maximal Need (including Disability Support Services), Other Sudden Deaths.



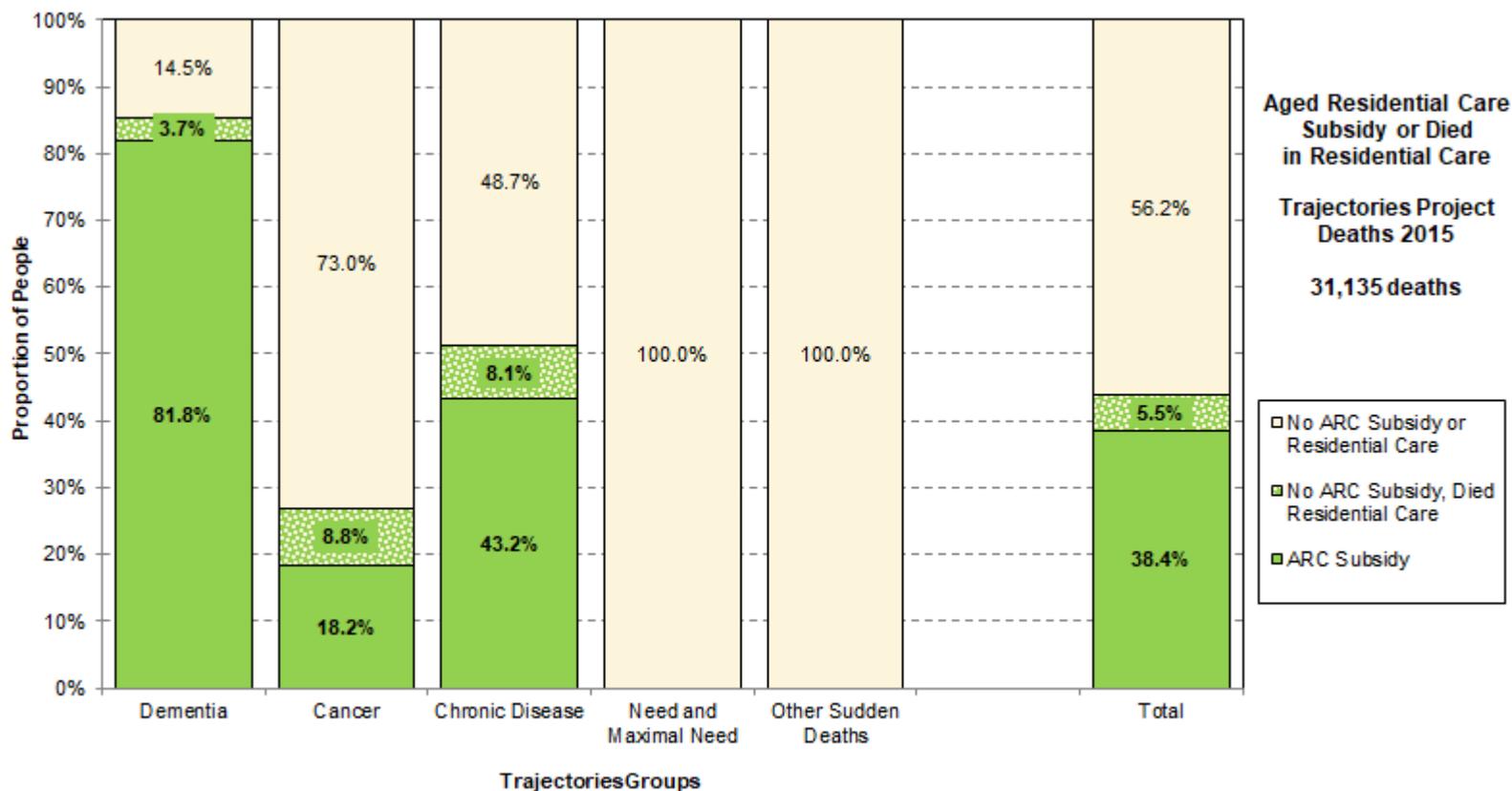
Trajectories Groups



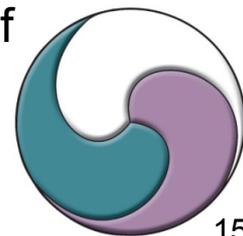
The groups are allocated from left to right. The Dementia and Cancer groups are large in their own right. The amalgamated Chronic Disease group is almost the same size. The analysis that follows will typically use these five major groups.



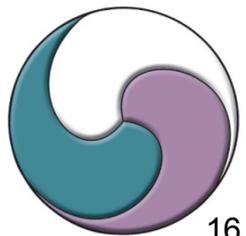
ARC Subsidy or Residential Care



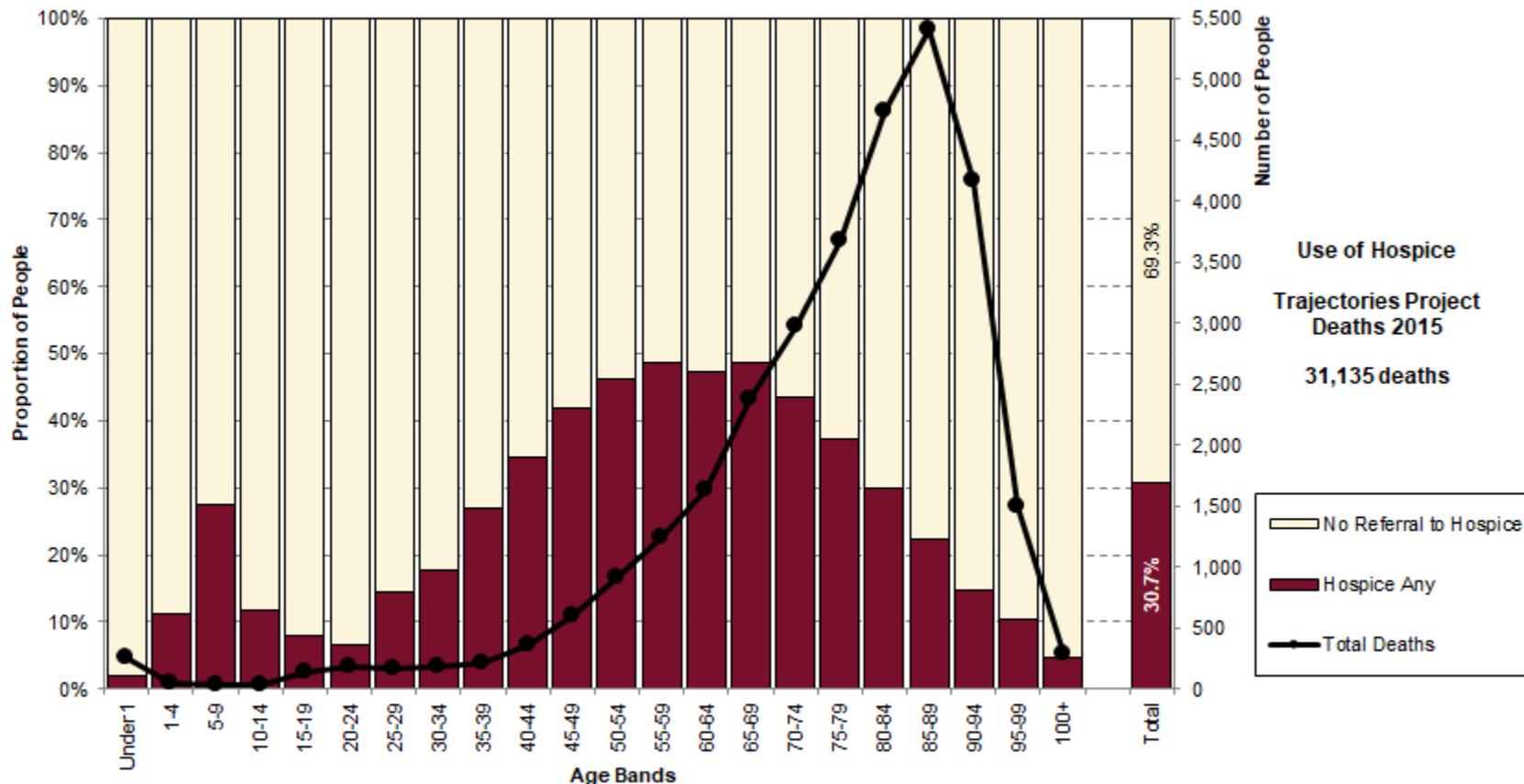
Overall 43.8% of people used residential care at some time in their trajectory. This is highest for the Dementia group at 85.5%. More than half of Chronic Disease (51.3%) and more than a quarter of the Cancer group (27.0%) had an ARC subsidy or died in residential care.



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



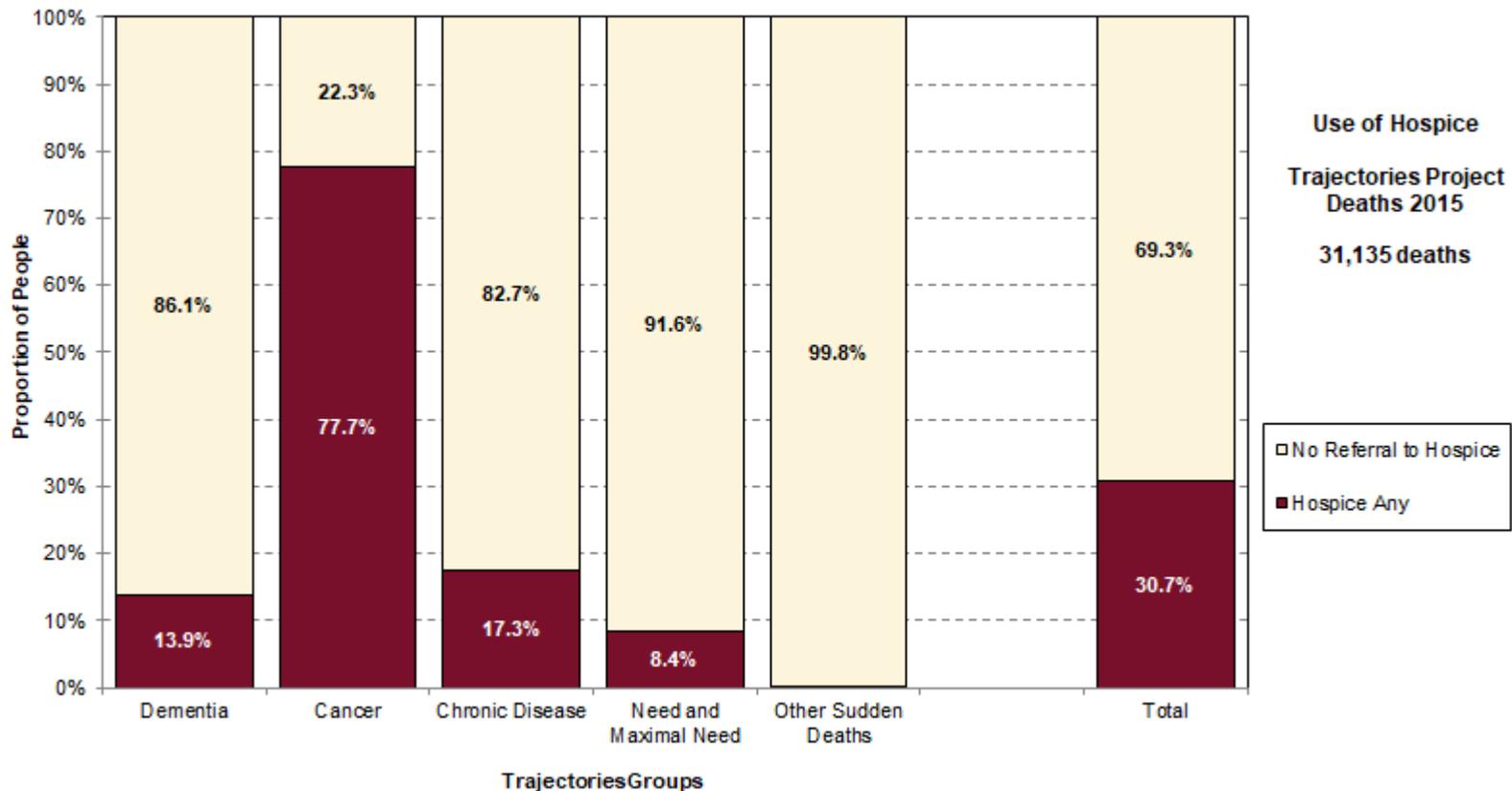
Use of Hospice Services



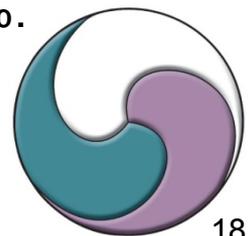
Overall, 30.7% of people in the Trajectories study used hospice as part of their end of life trajectory. There is a strong and characteristic pattern by age, with almost 50% of those dying in the age bands from 55 to 70 using hospice.



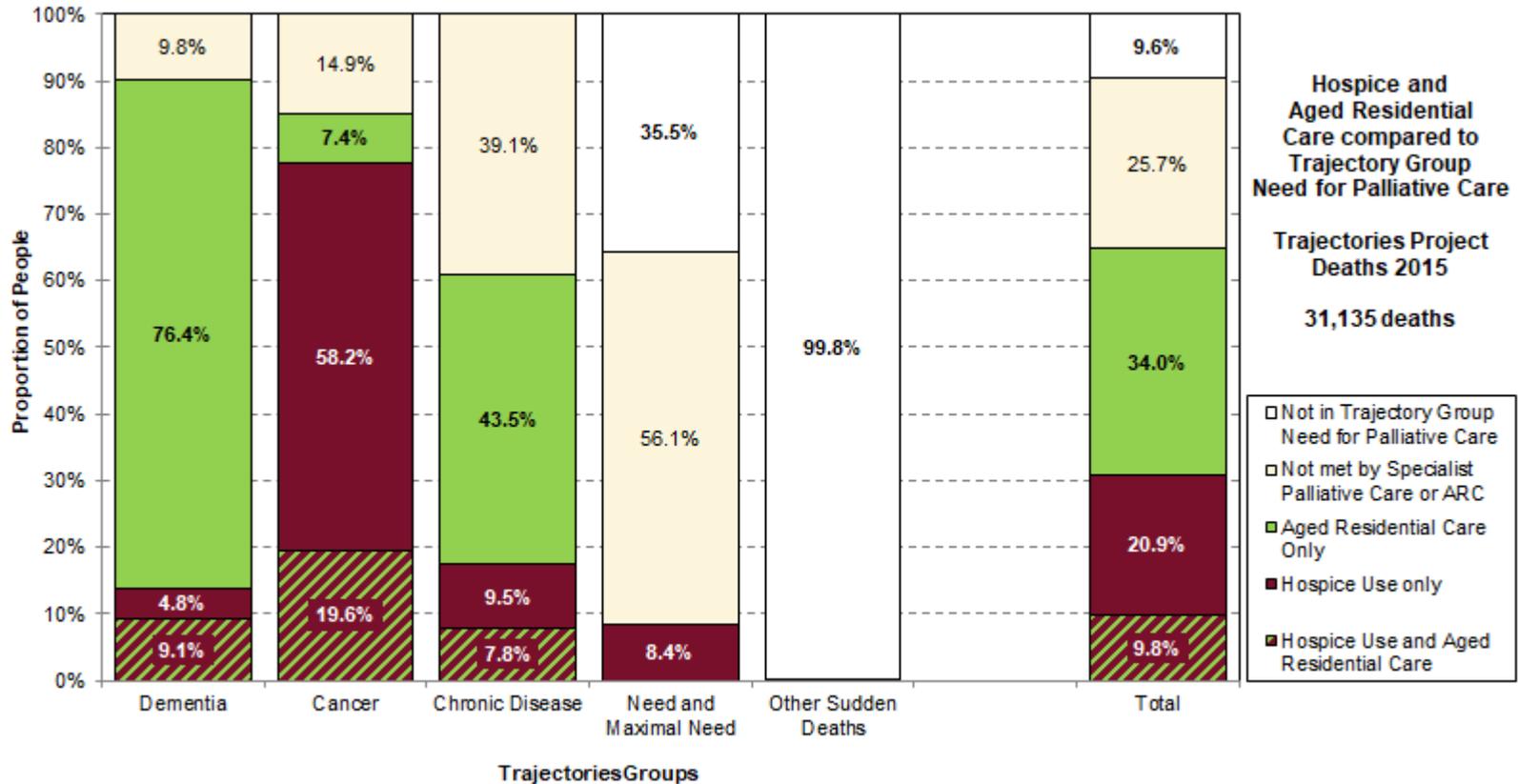
Use of Hospice Services



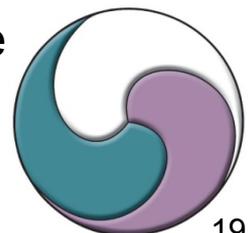
Overall, 30.7% of people in the Trajectories study used hospice as part of their end of life trajectory. This was highest for the Cancer group at 77.7%. 13.9% of those with Dementia and 17.3% of the Chronic Disease group used hospice.



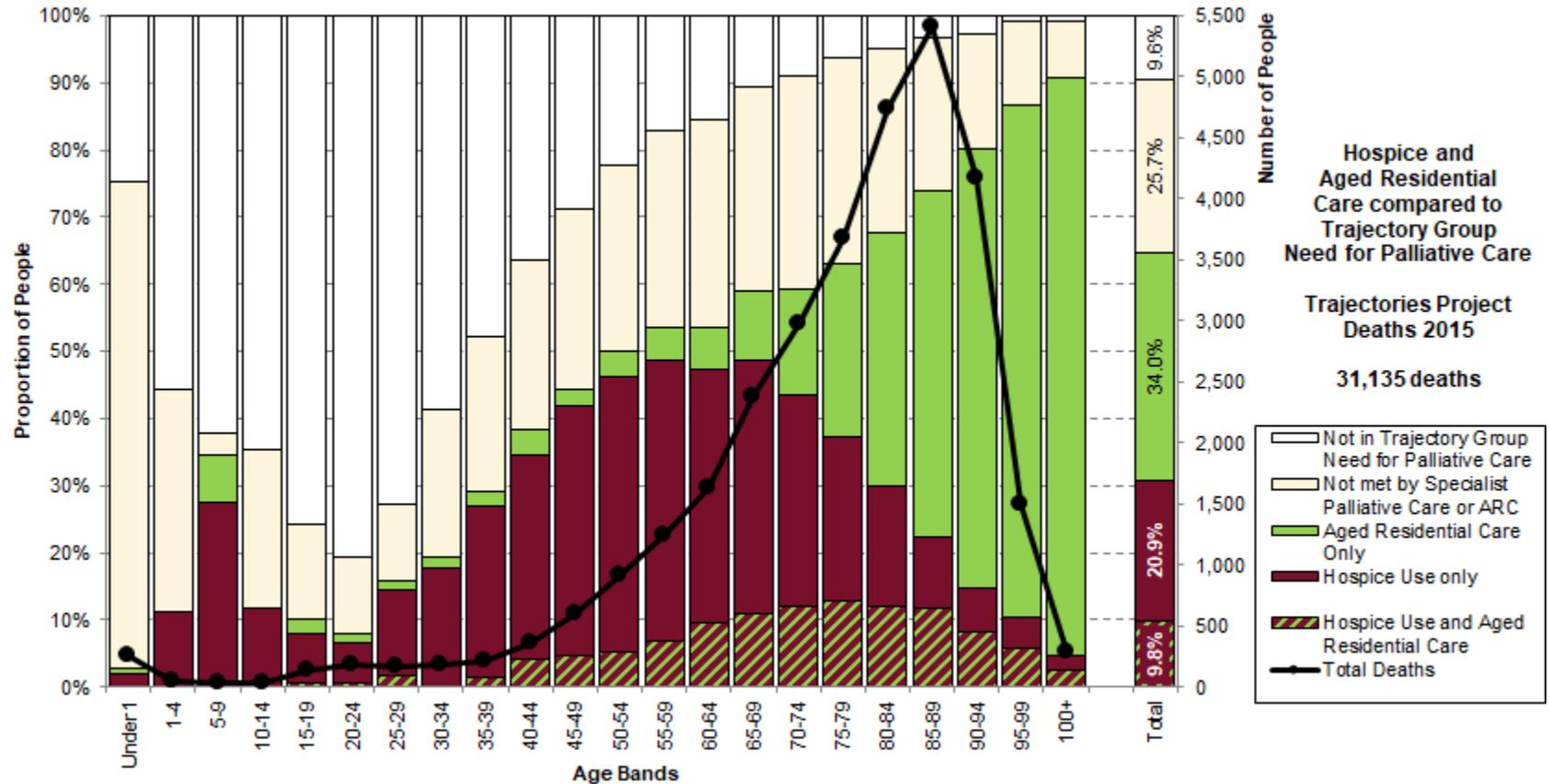
Hospice, Aged Residential Care, Need



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



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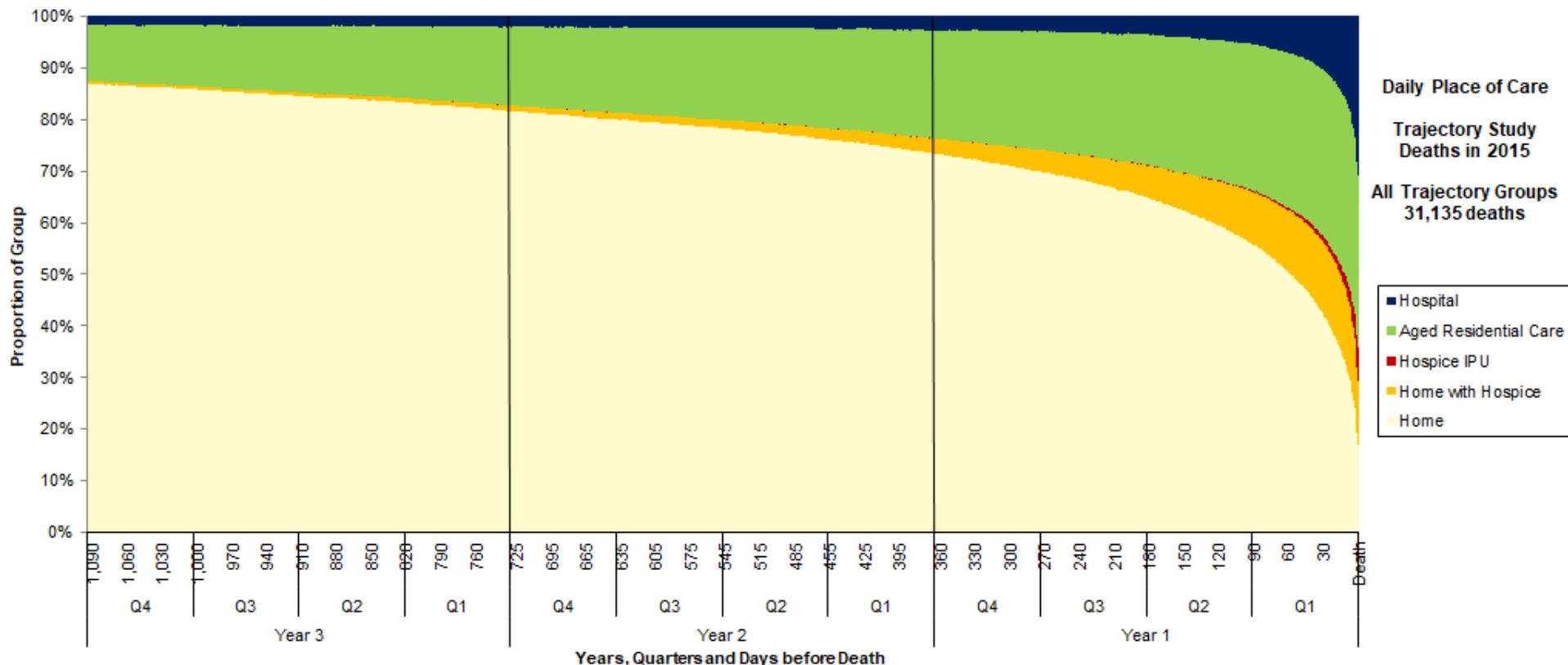
Time in Community

Last Three Years of Life

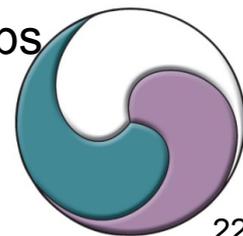
Last Year of Life



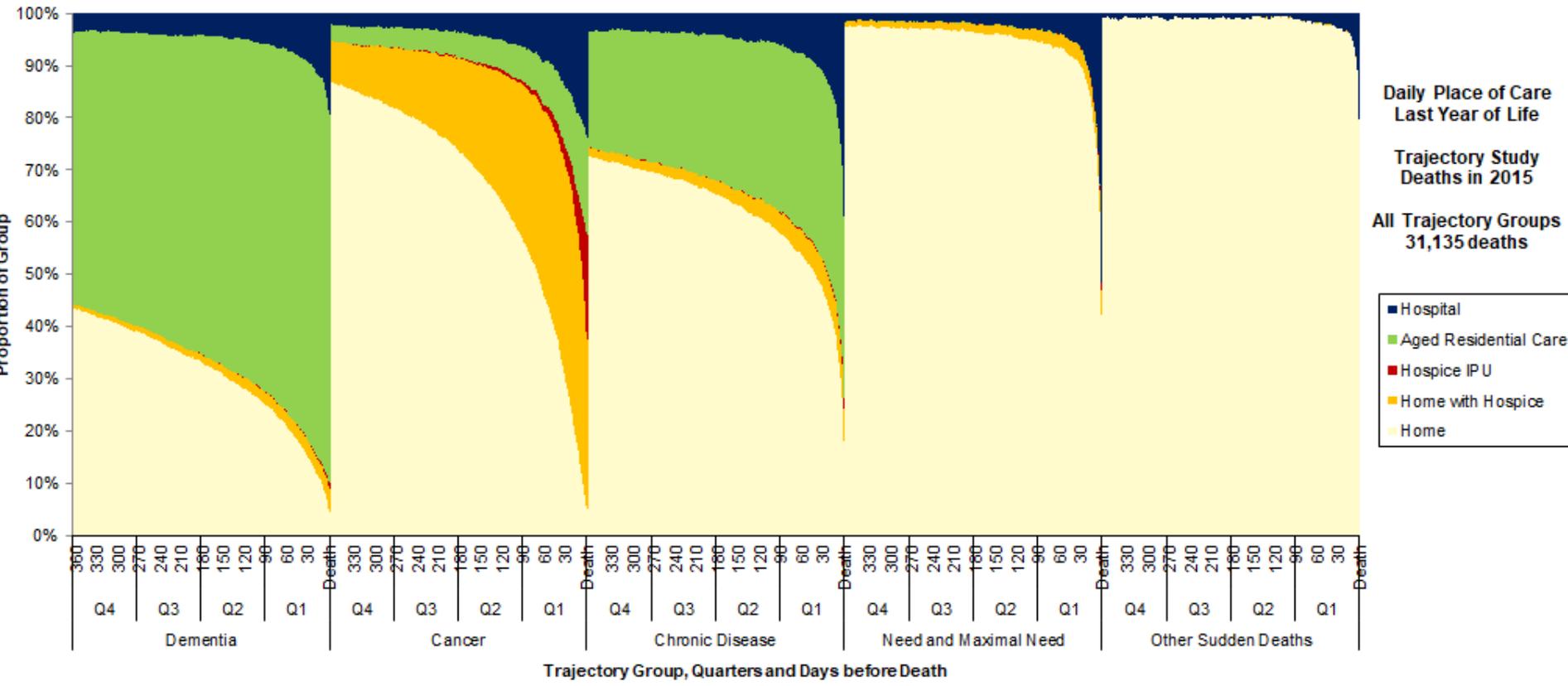
All Trajectory Groups



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.



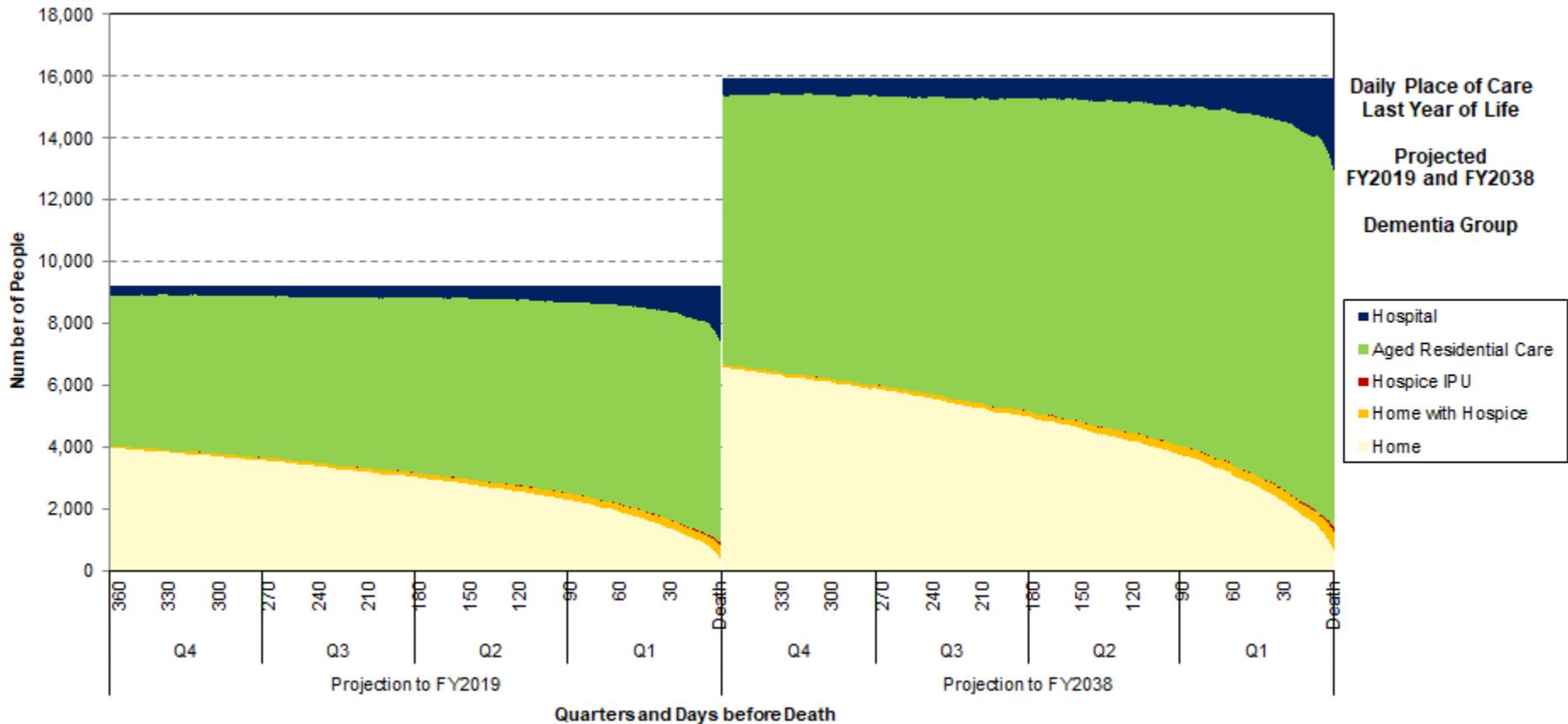
Last Year of Life by Trajectory Group



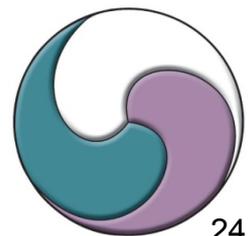
Daily place of care for each day in the last year of life (LYOL), showing each trajectory group. Shown as a percentage of each group.



Dementia Group, 2019 and 2038



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%.

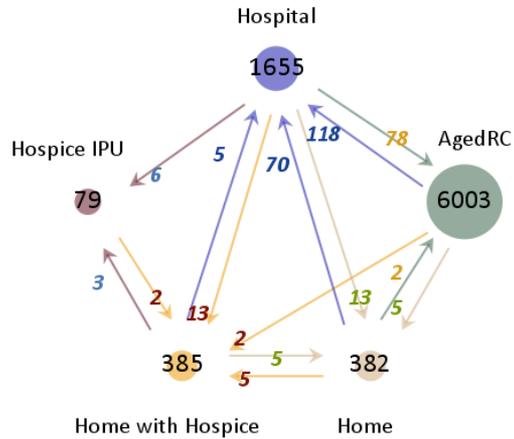


Animation of Place of Care Last Three Years of Life

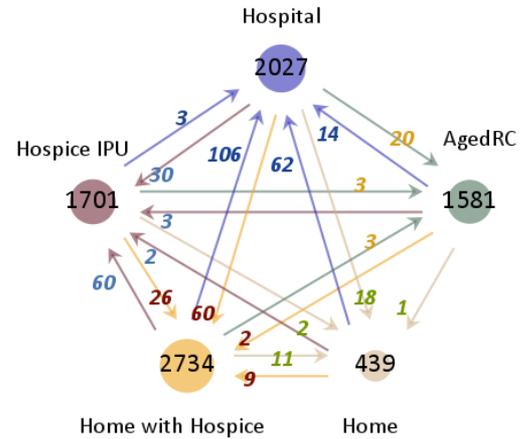


Days before Death=0

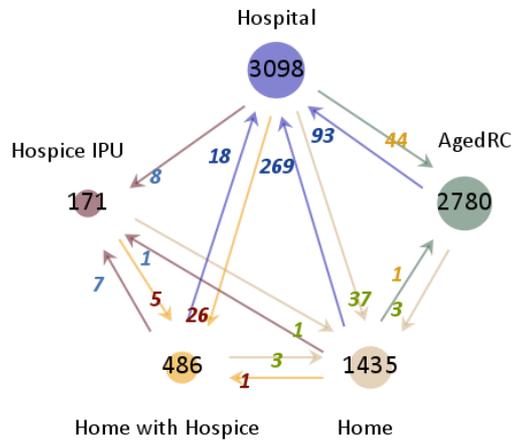
Dementia



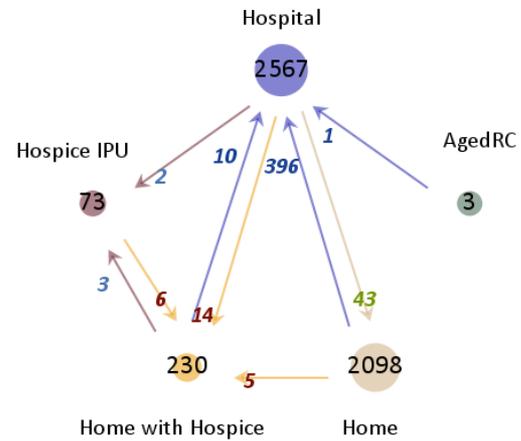
Cancer



Chronic Disease



Need and Maximal Need



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bode³

Burden of Disease Epidemiology, Equity
and Cost Effectiveness Programme





**Body, Mind, Soul
Earth**

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