

## Technical Note on Trajectories of Care at the End of Life Research

This note describes key methodological choices and decisions in the research. The note is illustrated with results by age band, as this is an important understanding for the development of the trajectory groups in section 13.

### 1. Data Sets Linked

The Trajectories Project used the data sets listed in the table below.

**Table 1: Data Sets Linked for Trajectories Project**

Data Supplier	Data Set	Starting Date
Ministry of Health National Collections	Mortality Collection (MORT)	January 1990, used only deaths occurring and recorded in calendar 2015
	National Health Index details (NHI)	As at February 2018
	New Zealand Cancer Registry (NZCR)	1991
	National Minimum Dataset (Publicly Funded Hospital Events) (NMDS) - inpatients	1990
	National Non-Admitted Patients Collection (NNPAC) - outpatients	July 2006
	Mental Health Information National Collection (MHINC) (superceded by PRIMHD)	July 2001 to June 2008
	PRIMHD mental health data (PRIMHD)	July 2008
	Laboratory Claims Collection (Labs)	2000
	Pharmaceutical Collection (Pharms)	2005
	PHO Enrolment Collection (PHO)	Q3 2004
	General Medical Subsidy Collection (GMS) – other GPs used	2000
Virtual Diabetes Registry (VDR)	2006	
Other Ministry of Health Data	Disability Support Services (SOCRATES)	1990
	Aged Residential Care Subsidies (CCPS)	July 2004
interRAI New Zealand	interRAI Assessments (interRAI)	January 2012, some earlier pilot assessments
Hospital Palliative Care Working Group <sup>1</sup>	Hospitals with a hospital palliative care service. Patient numbers and profiles from six services. Estimate of total patients for others.	FY2015 and FY2016 <sup>2</sup>
Hospice New Zealand, PalCare and individual hospices	History of hospice community care and hospice IPU events for 30 hospices.	Deaths in calendar 2015

<sup>1</sup> The Hospital Palliative Care Working Group was convened by Heather McLeod for this project. See section 5.

<sup>2</sup> FY indicates the financial year ending 30 June of that year.

## **2. Ethics Approval for Data Linkage of De-identified Data**

The Trajectories Project used data sets effectively linked by National Health Index (NHI) number<sup>3</sup>, although the actual NHI number was never visible to the researchers.

We sought and obtained data ethics approval from the Health and Disability Ethics Committees (HDEC) secretariat at the Ministry of Health, who confirmed that the use of deidentified data for an audit was out of scope and did not require HDEC review.

The proposal was also submitted to the University of Otago Wellington Ethics Committee who found the proposal to be a “Minimal Risk Health Research – Audit and Audit related studies” proposal, saying<sup>4</sup> “The outcome of that consideration was that the Committee was of the view that the study as described is consistent with Rule 11(2) (c) of the Health Information Privacy Code 1994 and was approved.”

## **3. De-identified Data from Ministry of Health**

The Ministry of Health routinely applies a unique patient identifier using repeatable encryption to the National Collections before sending to June Atkinson at the University of Otago Wellington (UOW). This UOW ID enables linkage of records over time at UOW, without having the actual NHI number.

Other identifying fields are removed before the data is provided to UOW. Names and addresses are always removed, and geographical location is only available at the domicile level (i.e. area unit). We do have actual date of birth and death in order to be able to accurately determine age and time before death of the services provided.

June Atkinson applied a project ID applicable to this Trajectories Project only, described as the Trajectory ID below. All analytical work was done using this Trajectory ID.

## **4. De-identified Data from interRAI New Zealand**

Discussions were held with staff from interRAI NZ and the Ministry of Health as to the best method of extracting the interRAI data for the required people. Several possibilities were explored, and it was finally agreed by all parties that interRAI send the Ministry of Health (MoH) Analytical Services team a list of all NHI numbers in their system. These were checked for validity and feedback given to interRAI on invalid NHI numbers. The interRAI Annual Report describes the results of this process and the actions taken to prevent invalid NHIs in future<sup>5</sup>.

June Atkinson sent a list of the required UOW IDs plus a newly created “interRAI ID” to the MoH Analytical Services team. The MoH then sent the actual NHI numbers and the “InterRAI ID”s to interRAI NZ. The data team at interRAI NZ then sent June Atkinson the actual interRAI data using only the “InterRAI ID” as identifier.

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<sup>3</sup> Health Information Standards Organisation. (2017). Consumer Health Identity Standard, HISO 10046. Wellington: Health Information Standards Organisation, Ministry of Health. Retrieved from <https://www.health.govt.nz/publication/hiso-10046-consumer-health-identity-standard>

<sup>4</sup> “Research Trajectories and Palliative Care”, Ethics Committee reference number HD17/055.

<sup>5</sup> See page 18 of the interRAI Annual Report for 2017/18:

<https://www.interrai.co.nz/assets/Documents/Publications-and-Reports/interRAI-Annual-Report-2017-18.pdf>

## 5. Data on Hospital Palliative Care

Heather McLeod convened a Hospital Palliative Care Working Group in September 2017. Two reports document the data, analysis and findings<sup>6</sup>. A spreadsheet, a set of slides and two case studies (Northland DHB and Auckland DHB) were also prepared.

In attempting to determine the hospitals that would be called on to submit data, it was realised that there was no national list of hospital palliative care services. As part of the Trajectories Project work, a list of hospital palliative care services in 2018 was therefore developed and shared with Hospital Palliative Care New Zealand and the Ministry of Health.

We were unable to get to having data by NHI number from each service in order to link with the other data sets. The biggest issues are that the HISO standards for specialist palliative care<sup>7</sup> have only been implemented by Northland DHB; data is not collected to a consistent template or definitions across all hospital palliative care services; there is little sharing of the data collected by each service, even within DHBs; and there is no regional or national collation or sharing of the data.

With no central or even DHB data collection, it means that ethics permissions for patient data would need to be obtained for each hospital separately. With 21 identified services covering 28 hospitals, this was an impossible task in the time available. As a compromise, the Working Group was asked to submit summarised activity data for FY2015 and FY2016. The tables requested were age bands, gender, ethnicity, and summarised diagnosis (cancer, non-cancer). An attempt was made to get total patients seen and deaths on service, but this was not managed by all who submitted data.

Although the goal of linking hospital palliative care services by NHI number was not reached, the information gathered enabled some analysis to be carried out. It was possible to link individual hospital events in the last year of life to whether a specialist palliative care service was available in that hospital facility<sup>8</sup>. A report on the gaps in hospital palliative care services was therefore possible, despite the difference in timing.

The summary data supplied enabled a first profile of hospital palliative care services by age band to be drawn. Hospice data at a patient level was fully available nationally (see section 6). Two case studies, in Northland DHB and Auckland DHB, showed the overlap between hospital palliative care and hospice care by patient. These patterns were used to estimate the possible overlap at a national level and hence produce an estimate of total specialist palliative care for the first time.

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<sup>6</sup> McLeod (2018) The Visibility of Specialist Palliative Care in the Ministry of Health Data. Notes prepared by Heather McLeod for Hospital Palliative Care NZ, the Trajectories Project Hospital Palliative Care Working Group, and Hospice NZ. 17 April 2018

McLeod (2018) Hospital Palliative Care Data: Summary and Recommendations. Notes prepared by Heather McLeod for the Ministry of Health, the Trajectories Project Hospital Palliative Care Working Group, and Hospital Palliative Care NZ. 30 April 2018.

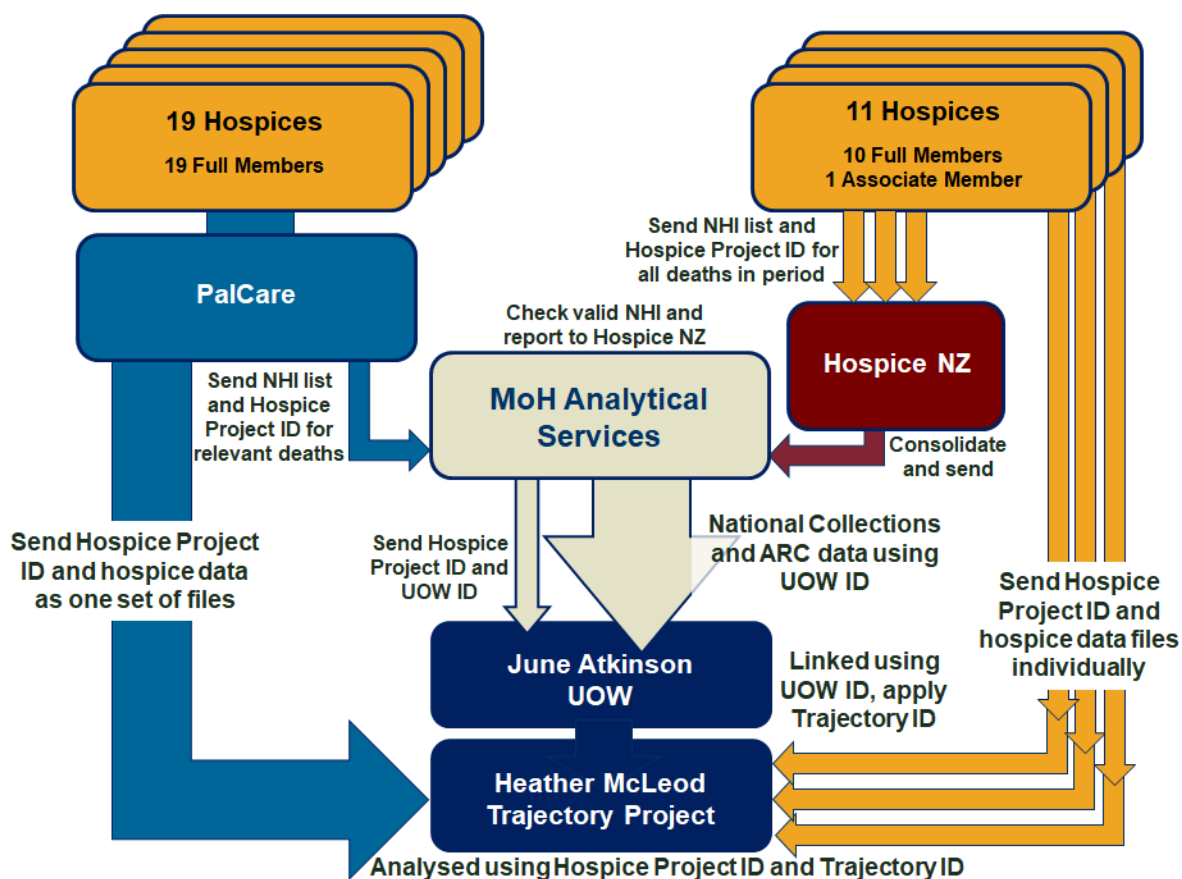
<sup>7</sup> Health Information Standards Organisation. (2013). National Specialist Palliative Care Data Business Process Standard, HISO 10039.1. Wellington: Health Information Standards Organisation, Ministry of Health. Retrieved from <https://www.health.govt.nz/publication/hiso-1003912011-national-specialist-palliative-care-data-business-process-standard>

Health Information Standards Organisation. (2013). National Specialist Palliative Care Data Definitions Standard, HISO 10039.2. Wellington: Health Information Standards Organisation, Ministry of Health. Retrieved from <https://www.health.govt.nz/publication/hiso-1003922011-national-specialist-palliative-care-data-definitions-standard>

<sup>8</sup> 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.

## 6. De-identified Data from Hospices

The process for obtaining data from all hospices was more complex than the data obtained from the Ministry of Health or interRAI NZ, as there is no national data set and not all hospices use the same software system. Heather McLeod works routinely with hospices to analyse annual data and worked with Hospice New Zealand and the Ministry of Health Analytical Services to de-identify the data, using the process illustrated below.



**Figure 1: Process for Obtaining De-identified Data from Hospices**

Note that the process for obtaining hospice data from the 11 individual hospices on the right of the diagram is similar to what would be needed to obtain data from the 28 individual hospital palliative care services. The complicating factor is that while Hospice New Zealand has a data project management capability and extensive annual data collection, Hospital Palliative Care New Zealand has no secretariat and no data collection function as of 2018.

## 7. Choice of Date and Centrality of MORT Data

The choice of period was a pragmatic balance between having the most recent data, having data aligned to financial years (for potential future costing) and the availability of data. The major constraint was that the Mortality Collection (MORT) from the Ministry of Health was only available up to December 2015 at the time of the project. Service data was generally available to end 2017 or for FY2017.

The MORT data was central to the linked records<sup>9</sup> as it provided a single “point of truth” for key demographic fields like date of birth, date of death, gender, ethnicity, region and District Health Board (DHB) of domicile. Age was determined as the age last birthday on the date of death.

The MORT data is the source of information on underlying and contributory causes of death (from the death certificate) and has a place of death determined by the Ministry of Health. Cause of death and place of death were important to the study. They were also needed for determining the need for palliative care<sup>10</sup>, as the intention was to test how the trajectories related to the definition of the need for palliative care.

While a complete year of data for a financial year was our first choice, it was the availability of the most recent MORT data that determined we needed to use those who died in calendar 2015 and whose deaths were registered in calendar 2015 as the definition of our cohort. Note that using all deaths registered in a particular year is not viable as there are a small number of registrations that occur years and even decades after the date of death, once coronial investigations have been completed.

The consequence of using all deaths occurring and registered in calendar 2015, is that some deaths occurring near the end of December 2015 were not yet in the MORT data. We identified potential deaths from other health data sources and found that there were possibly 31,836 deaths in New Zealand in calendar 2015. MORT records were supplied for 31,135 deaths that occurred in 2015 and were registered by 31 December 2015. The 2.2% of possible deaths that were not yet registered are excluded from analysis. Confirmation of those deaths will only be when the MORT data for calendar 2016 is released (late 2018).

As many of the excluded deaths occur in the Christmas to New Year period, they are likely to have a slightly higher number of sudden deaths from accidents than at other times of the year.

## **8. Identification of Cancer**

The New Zealand Cancer Registry is a population-based register of all primary malignant diseases diagnosed in New Zealand, excluding squamous and basal cell skin cancers.

The Cancer Registry was used to determine all people who had one or more malignant cancer registrations. This was combined with the underlying cause of death in the MORT data, with results as shown in Figure 2. The solid black line shows, using the right-hand vertical axis, the number of deaths in each age band.

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 and may have been diagnosed with cancer some years before death.

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<sup>9</sup> Previous work on a pilot study for Auckland District Health Board has showed that there were discrepancies in date of birth, date of death and demographic variables between different data bases.

<sup>10</sup> 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/>

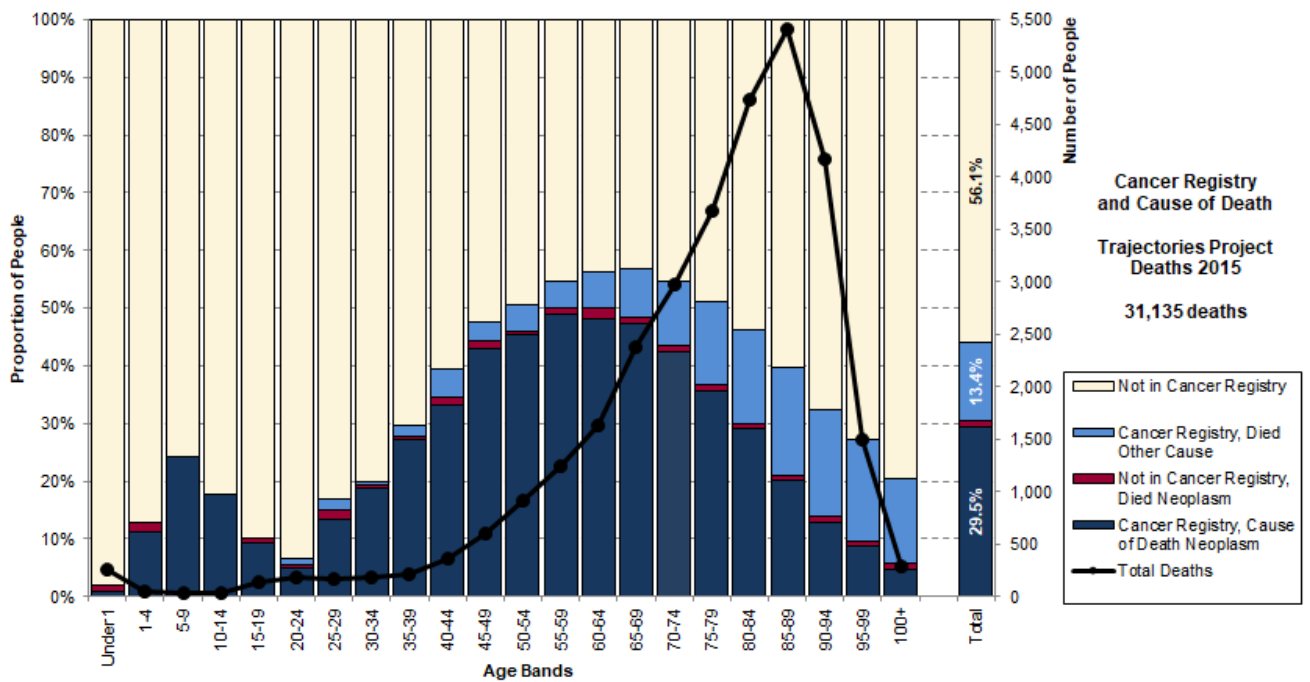


Figure 2: Cancer Registry and Cause of Death

9. Identification of interRAI Assessments

Deaths in the Trajectory Study are for calendar 2015. interRAI Long-Term Care Facility (LTCF) assessments became mandatory for aged residential care only from 1 July 2015. LCTF assessments were increasing rapidly over the period, as shown below, and the levels seen in the study data are likely to underestimate the number of assessments.

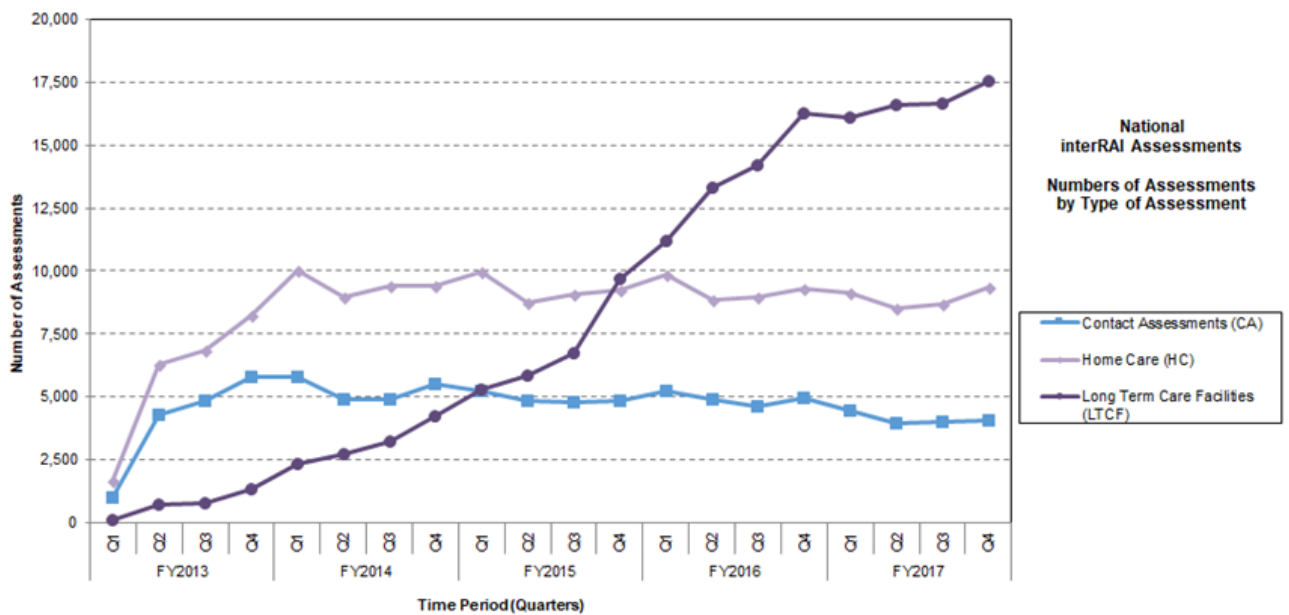
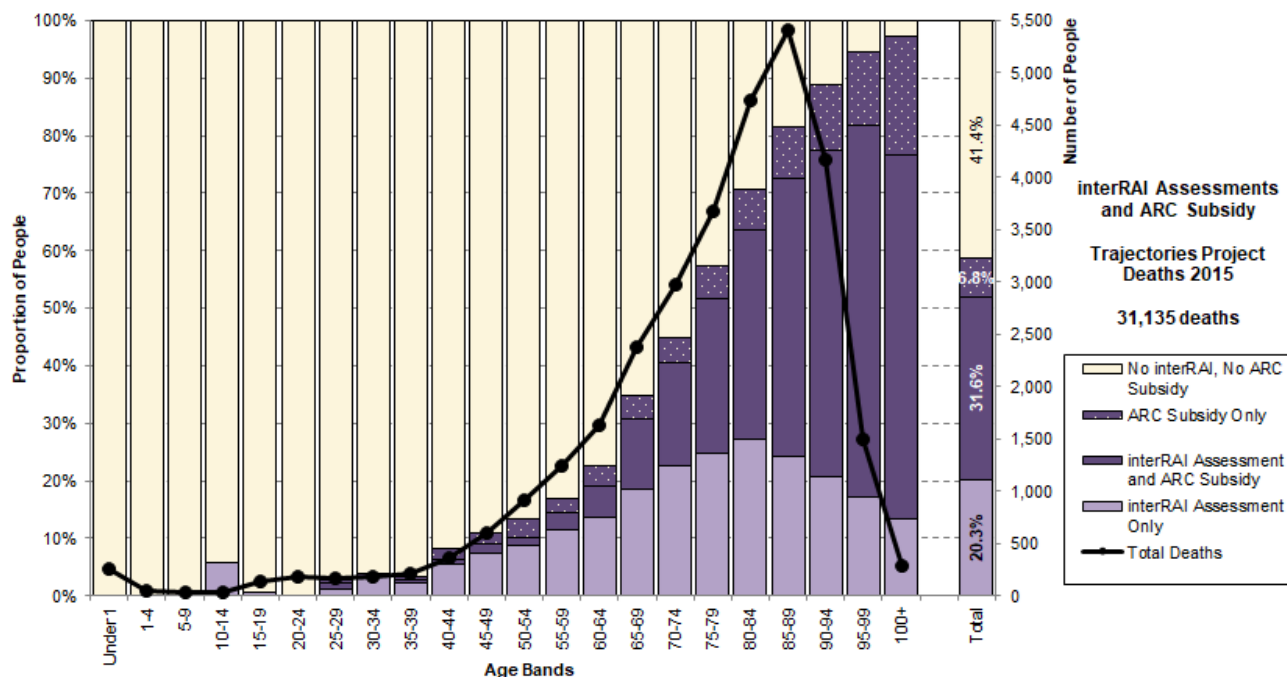


Figure 3: National Numbers of interRAI Assessments by Type of Assessment  
 Data Source: interRAI New Zealand

The interRAI history is also shorter than other data sets, with Home Care (HC) and Contact Assessments (CA) becoming widespread by quarter two of FY2013.



**Figure 4: interRAI Assessments and Aged Residential Care Subsidy**

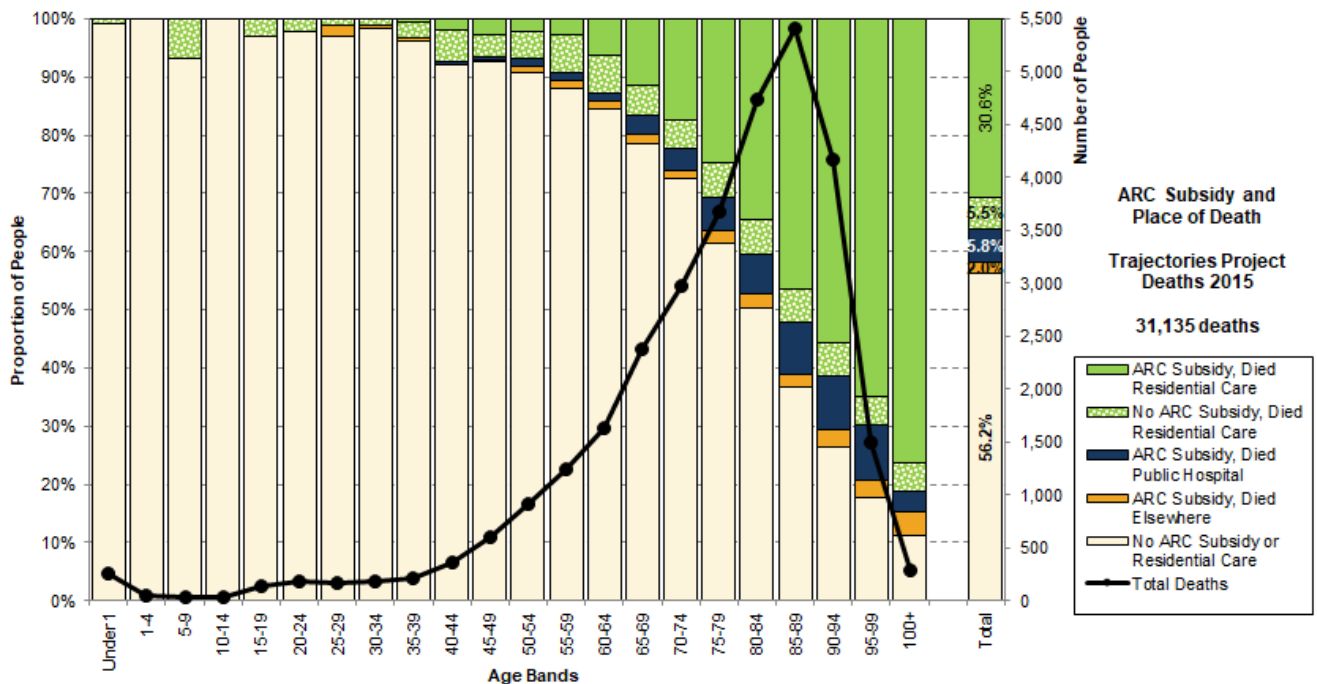
In order to allow for LTCF assessments that should have happened, the interRAI data was cross-checked to the aged residential care (ARC) subsidy data (see section 9 below). The results are shown in Figure 4. In total, 51.8% of total deaths had one or more interRAI assessments. A further 6.8% had an ARC subsidy at some time. With interRAI assessments becoming mandatory in aged residential care from 1 July 2015, the potential total of interRAI assessments is 58.6% of all deaths, with a very strong pattern by age.

## 10. Identification of Use of Aged Residential Care

There is no national database of all the people in aged residential care (ARC). The Ministry of Health Client Claims Processing System (CCPS) database has the people who were in ARC and received a subsidy. The CCPS data has some people who did not receive a subsidy, with an estimate by the Ministry of Health that perhaps half of the non-subsidised people might be in the data.

We cross-checked the CCPS subsidy data with the MORT having residential care as the place of death, with the results as shown in Figure 5.

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.



**Figure 5: Aged Residential Care Subsidy and Place of Death**

The issue with some people not being in the data because they did not receive a subsidy is mitigated by many of those dying having moved from rest home care to hospital-level care, dementia care or psycho-geriatric care. These that are completely private payers are in rest-home care. When a person is transferred to more intensive levels of care, the difference between the cost of rest home care and the higher level of care is always paid as a subsidy and thus is in the CCPS data.

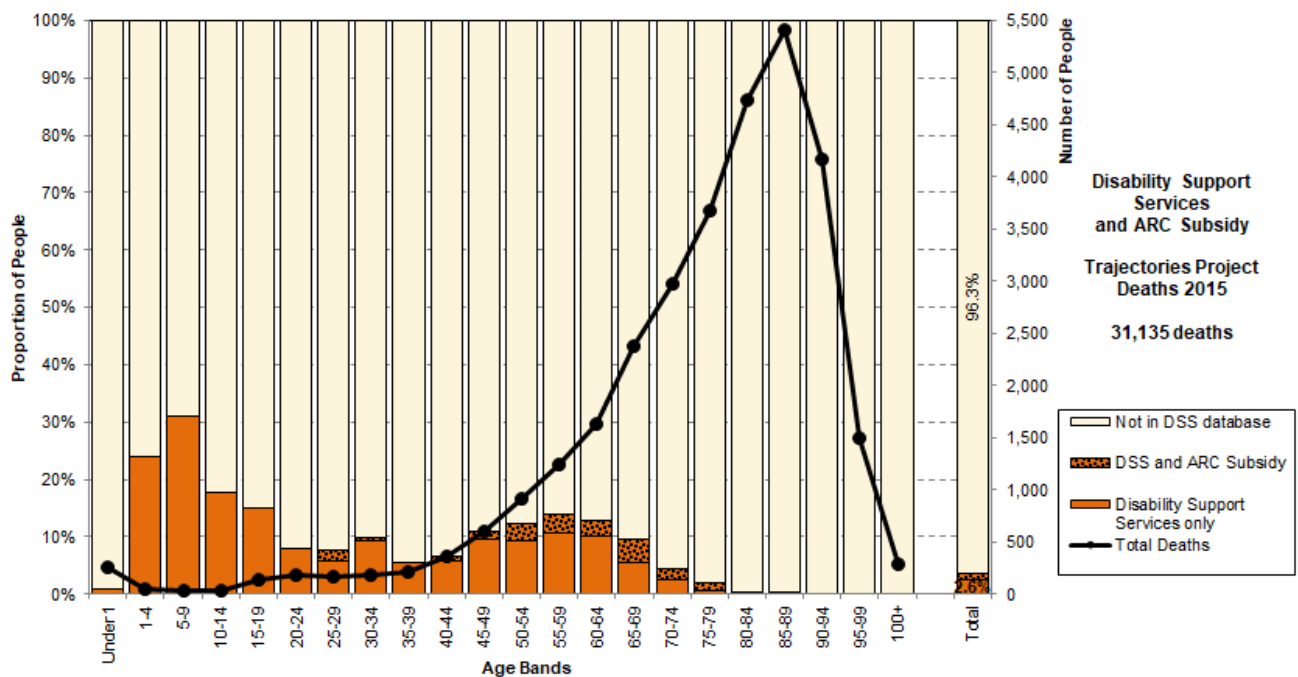
There is a further way to identify private-paying people in aged residential care that was not used in the initial study but identified in subsequent work. LTCF assessments must occur within specified periods of time and be repeated at defined intervals, regardless of whether the person is receiving a subsidy or not. Hence, a cross-check of LTCF assessments against those with any ARC usage (CCPS data plus MORT data) can also be carried out.

### 11. Identification of use of Disability Support Services

The SOCRATES database is used for Disability Support Services (DSS) visits. We calculated minimum and maximum dates of interaction within the various SOCRATES databases (client, disability, eligibility assessment, ethnicity, functional support needs, needs assessment, service co-ordination, referral) and also used it when identifying those with dementia.

We cross-checked those in SOCRATES and the CCPS database, as shown in Figure 6.





**Figure 6: Disability Support Services and Aged Residential Care Subsidy**

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).

## 12. Identification of Dementia

The identification of dementia across multiple data sets was an innovation in the Trajectories Project. The approach was informed by New Zealand work on the Burden of Disease<sup>11</sup> project and the following data sets and fields were used:

- **MORT data:** ICD-10-AM codes F00-F019, F03 and G30-309 are definite.
  - F000 Dementia in Alzheimer's disease with early onset (G30.0+)
  - F001 Dementia in Alzheimer's disease with late onset (G30.1+)
  - F002 Dementia in Alzheimer's disease, atypical or mixed type (G30.8+)
  - F009 Dementia in Alzheimer's disease, unspecified (G30.9+)
  - F010 Vascular dementia of acute onset
  - F011 Multi-infarct dementia
  - F012 Subcortical vascular dementia
  - F013 Mixed cortical and subcortical vascular dementia
  - F018 Other vascular dementia
  - F019 Vascular dementia, unspecified
  - F03 Unspecified dementia
  - G30 Alzheimer disease
  - G300 Alzheimer disease with early onset (Onset usually before the age of 65)

<sup>11</sup> Blakely, T., Kvizhinadze, G., Atkinson, J., Dieleman, J., & Clarke, P. (2019). Health system costs for individual and comorbid noncommunicable diseases: An analysis of publicly funded health events from New Zealand. *PLoS Medicine*, 16(1), e1002716. doi: [10.1371/journal.pmed.1002716](https://doi.org/10.1371/journal.pmed.1002716)

- G301 Alzheimer disease with late onset (Onset usually after the age of 65)
  - G308 Other Alzheimer disease
  - G309 Alzheimer disease, unspecified
- **NMDS data:** as for MORT above, use ICD-10-AM codes F00-F019, F03 and G30-309.
  - **PRIMHD data:** DSM IV codes (clinical system 07) that might be used are 2900-29043, 2941 and 2948. However, after evaluation these were not used as PRIMHD data is not consistent across all DHBs for those over age 65 and diagnosis values are often missing.
  - **Pharms data:** chemical code 3923 for Donepezil, and 3750 for Rivastigmine, based on work in Australia<sup>12</sup>. We added 4037 as the code for Rivastigmine (Rivastigmine Patch 4.6mg and Patch 9.5mg as treatment for dementia) as there is no code 3750 in the New Zealand data.
  - **interRAI data:** variables il1c, il1d and Scale\_CPS were used.
    - il1c Disease diagnosis - Alzheimer's disease, values 1, 2 or 3
    - il1d Disease diagnosis - Dementia other than Alzheimer's disease, values 1, 2 or 3
    - Scale\_CPS Cognitive performance scale, values 3, 4, 5 or 6
  - **SOCRATES data** (needs some caution using): codes 1401 (Alzheimer's Dementia) and 1405 (Other Dementia) are definite and were used. Code 1499 includes mixtures of dementia with other diseases, such as Huntingtons, and was excluded to be consistent with the treatment of the ICD-10-AM codes.
  - **CCPS data:** those with service\_category 'DEMENTIA-AGE'.

Figure 7 shows the sequential application of the data sets to determine the total number of people with dementia, as opposed to only those who had dementia as the underlying cause of death on their death certificate.

The MORT data on its own produces only 2,368 people who died of dementia, but by combining all the data sources above, it was found that 8,504 people died with dementia. In other words, the MORT data identified only 27.8% of all dementia. The causes of death of the whole dementia group were also explored.

Figure 7 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, and there is significant overlap.

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<sup>12</sup> Australian Institute of Health and Welfare (2014). Improving dementia data in Australia: supplement to Dementia in Australia 2012. Cat. no. AGE 76. Canberra: AIHW.  
<https://www.aihw.gov.au/reports/dementia/improving-dementia-data-in-australia-supplement-to-dementia-in-australia-2012/contents/table-of-contents>

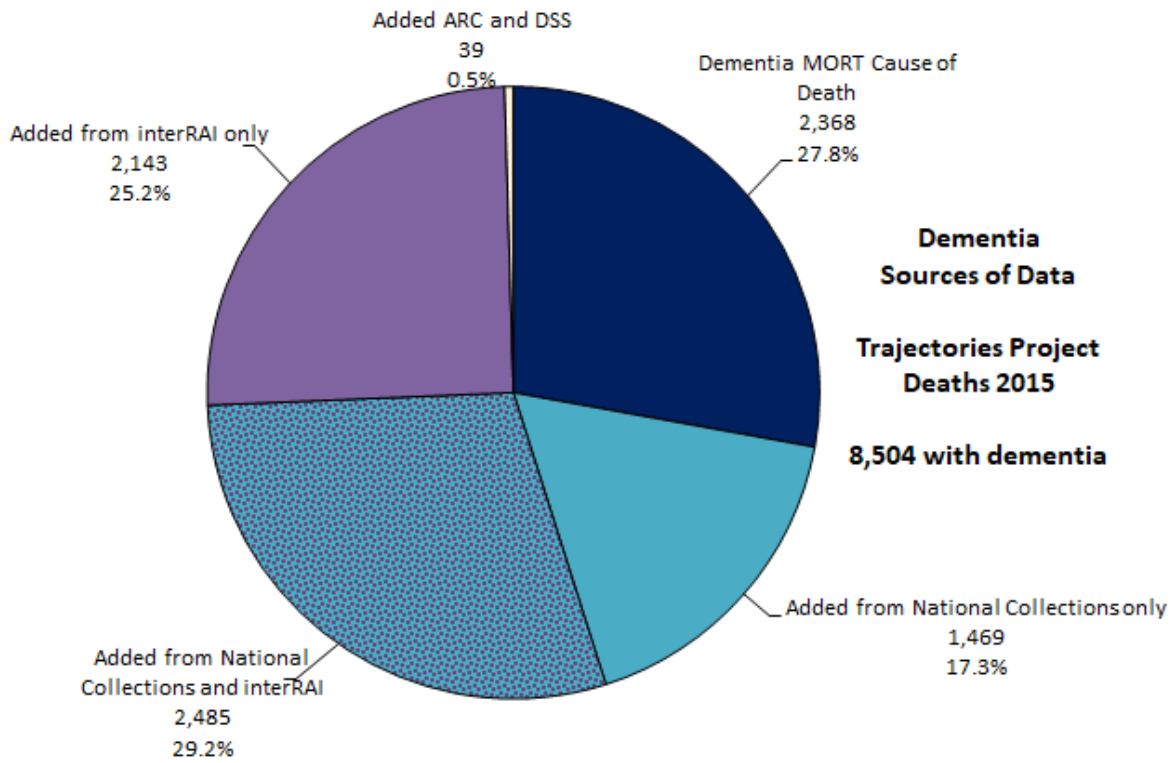


Figure 7: Source of Dementia Data (sequential clockwise from 12.00)

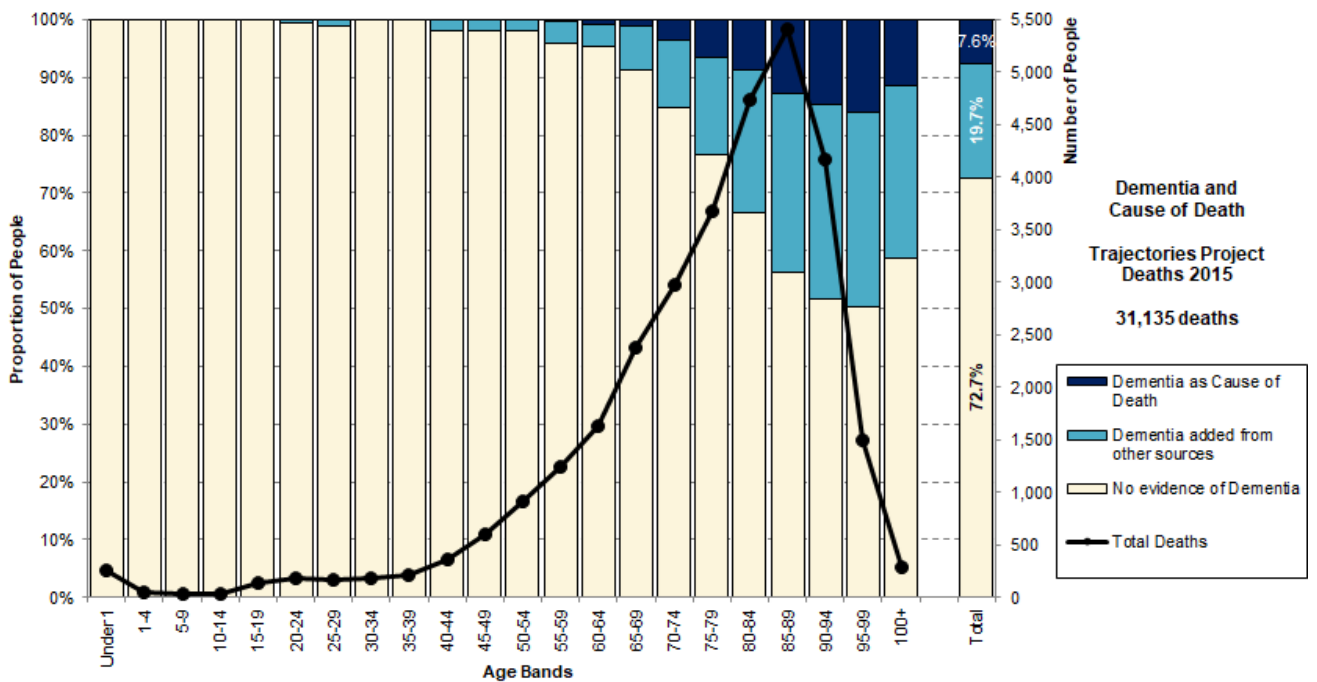


Figure 8: Deaths with Dementia and Dementia as a Cause of Death

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.

Note that in using the pattern by age bands for projection that the seeming reduction in dementia at age 100+ is likely to be an artefact of the data collection. LTCF assessments might not have been done on those in residential care with the most advanced dementia. The proportion is better extended at the same level as for the age band 95-99.

### 13. Sequential Allocation of Trajectories Groups

The material above gives the evidence for the basis on which the trajectories groups have been allocated. The groups are extracted sequentially and named 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<sup>10</sup>. 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.

The image below gives a detailed breakdown of the components of the groups.

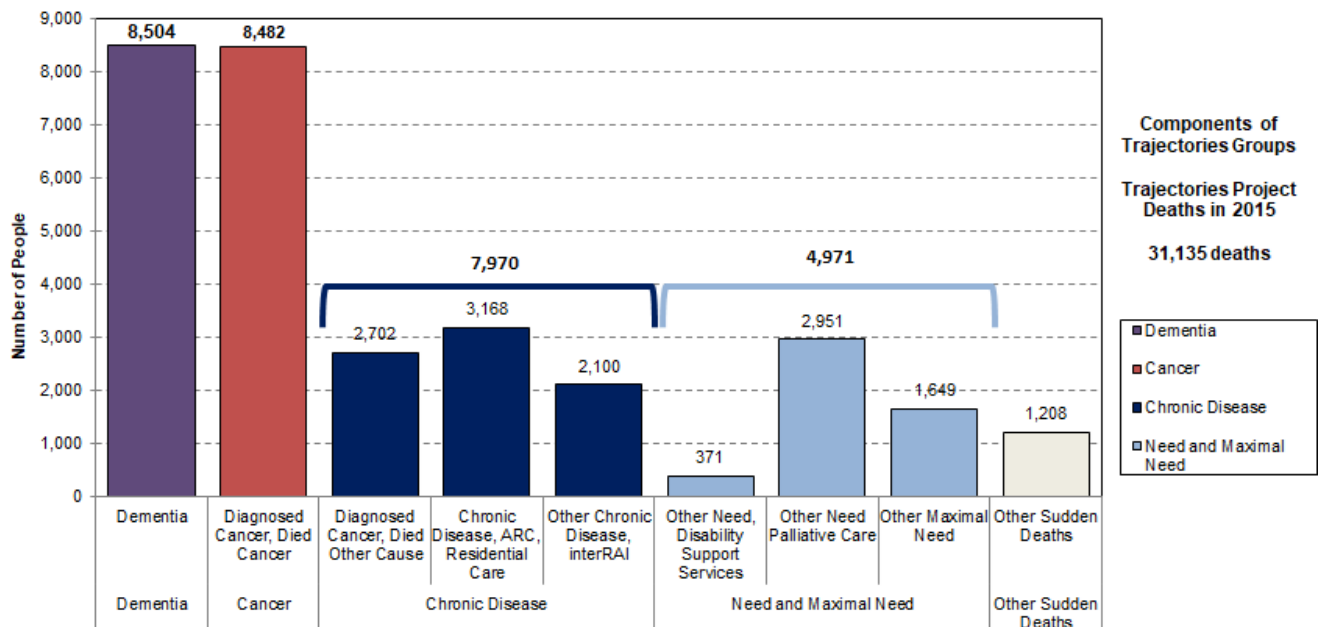


Figure 9: Components of Trajectories Groups

The Dementia and Cancer groups are large, but some of the components of other groups are too small to analyse separately. For most of the analysis, will show only the five major groups, although the sub-groups are always available for analysis.

The five major groups are illustrated by age band below.

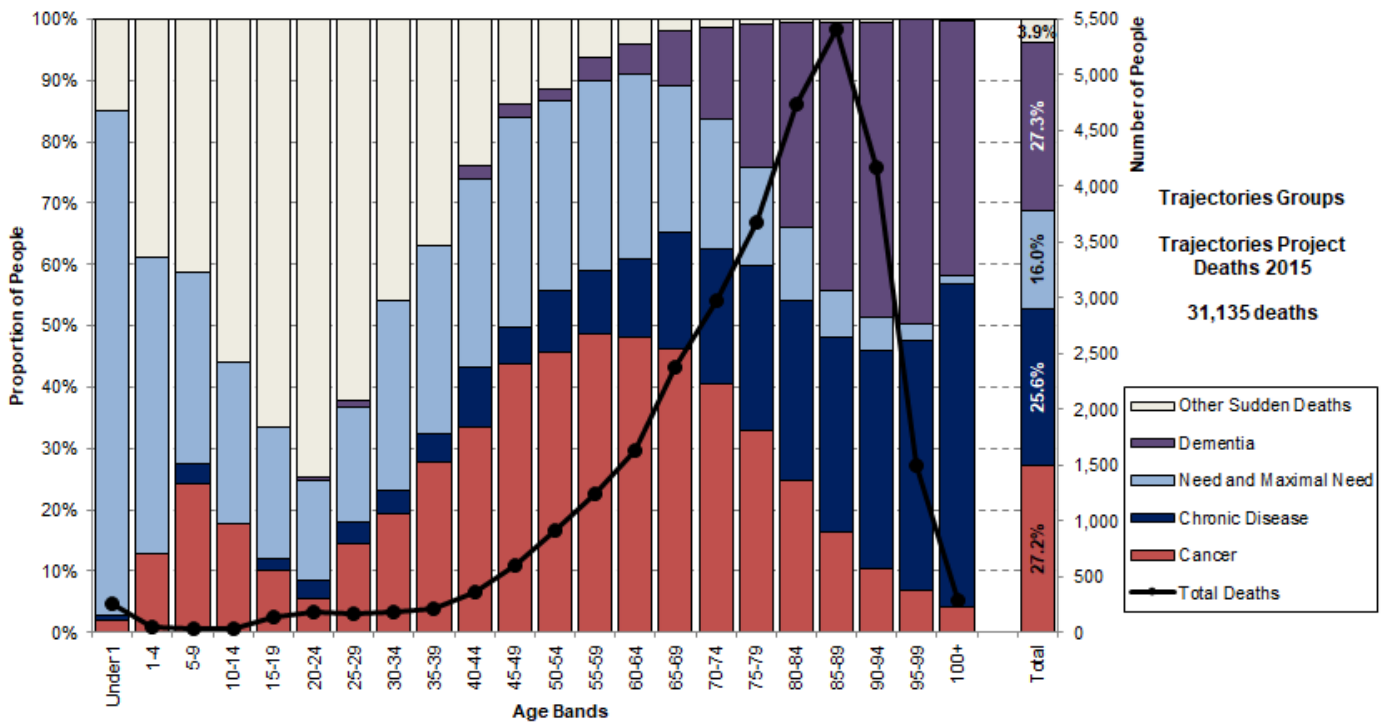


Figure 10: Trajectories Groups by Age Band

A summary of the results for the five groups is given in the document “Policy Brief on Trajectories of Care at the End of Life in New Zealand”. Researchers who need further information on the data linkage or methodology are welcome to contact the authors directly.

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7 February 2019

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