Palliative Care and Residential care settings

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Hospice New Zealand
Palliative Care Lecture Series
7 August 2014

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Overview

- My background
- Some context
- What is aged residential care (ARC) in NZ?
- What is the extent of palliative care provision in ARC
- Perceptions of ARC
- Challenges – a case study
- Innovations
- Opportunities for the future

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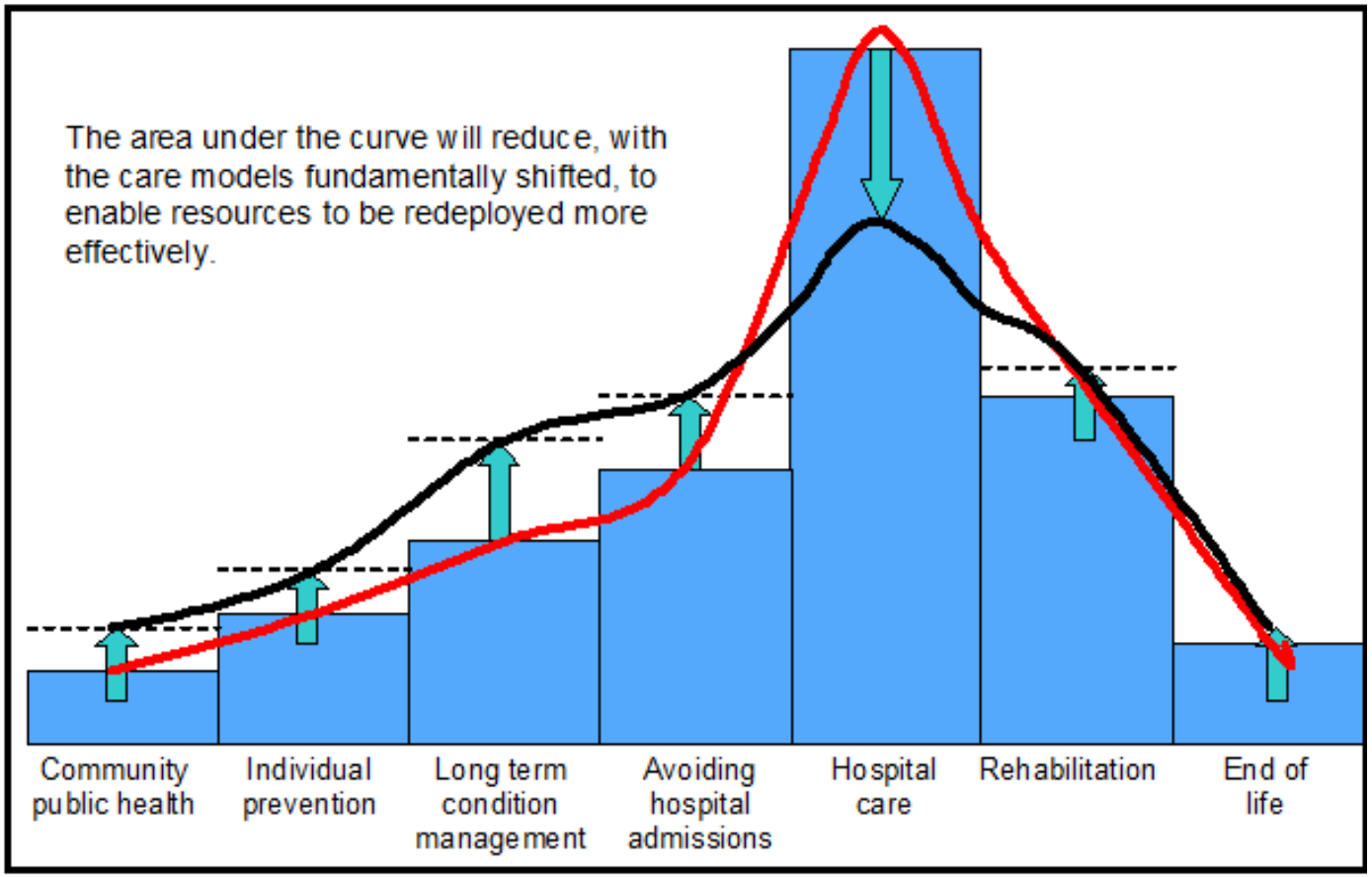
Our population is ageing

The population aged 65 years and over has increased from 11 per cent of the total population in 1991 to 13 per cent in 2009.

By the late 2020s, the number of older New Zealanders is forecast to outnumber the youth and child populations, with one million New Zealanders predicted to be aged over 65.

Direction of travel…



Source: Bevan 2011.

Source: Ministry of Health (2012) Briefing to the Incoming Minister

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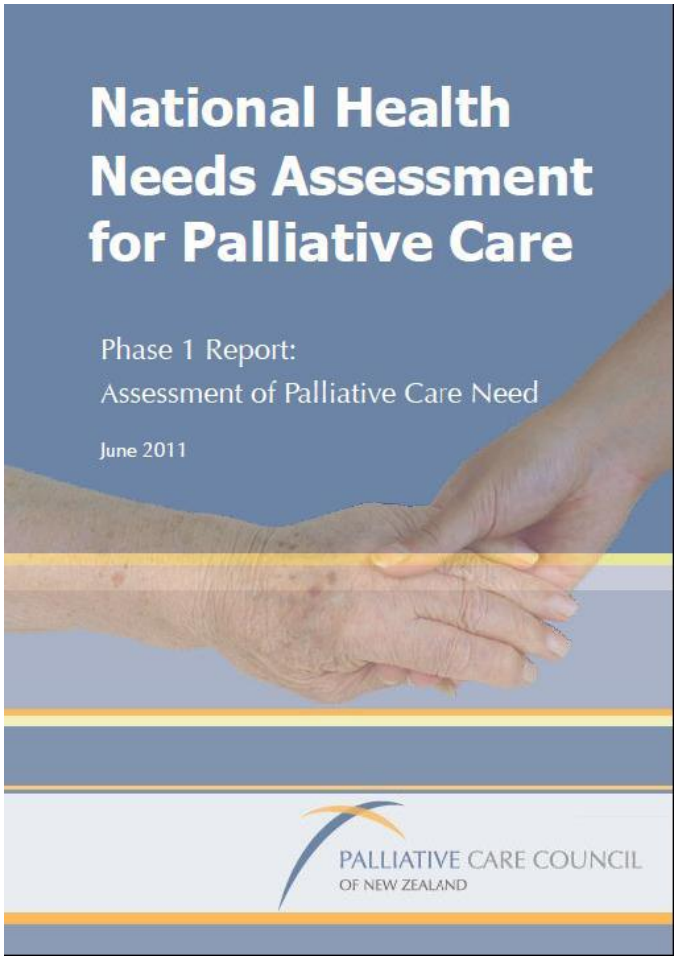
Palliative Care Council



- Phase 1 (2011) –
  - 511,200 people over 65years in NZ; 1 in 20 living in residential care
  - Over 40% of those over 85yrs who die of a condition amendable to palliative care, did so in residential care
- Phase 2 (2013) –
  - Limited data on the extent of palliative care provision in ARC
  - Increasing dependency overall
  - Increased utilisation as a setting for end of life care on discharge from acute hospitals
- Work in progress –
  - PCC Project: *Palliative Care in Aged Residential Care*

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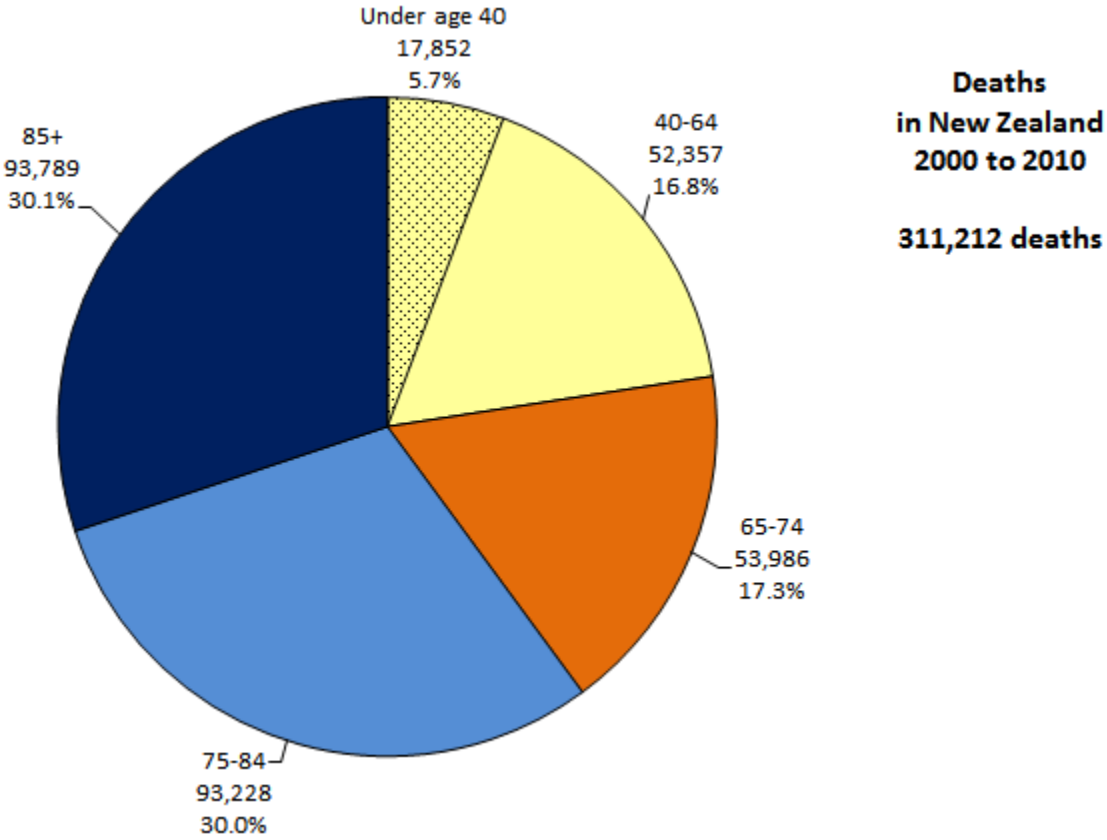
Deaths in New Zealand 2000-2010



30.1% of all deaths are over age 85; 60.1% are over age 75 and 77.4% are over age 65.

Source: Analysis of Ministry of Health MORT data 2000 to 2010

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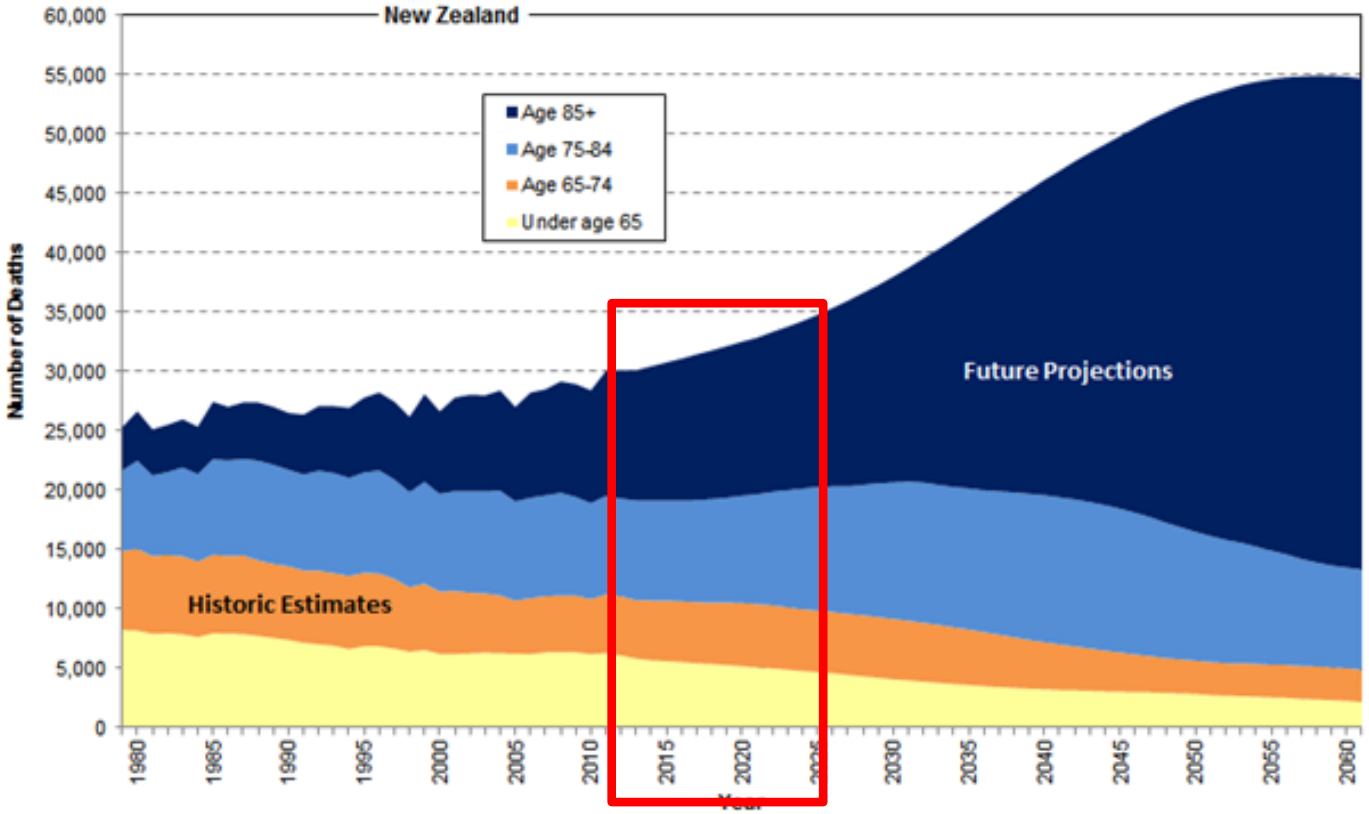
Historic Deaths and Future Projections by Age Band



Deaths will change in their distribution across age groups. Expected to be a continued decline in deaths under age 65 and age 65-74, with a dramatic increase in the number of deaths over age 85.

Source: Palliative Care Council, Working Paper No. 1, July 2013. Drawn using data from Statistics New Zealand; personal communication Joanna Broad.

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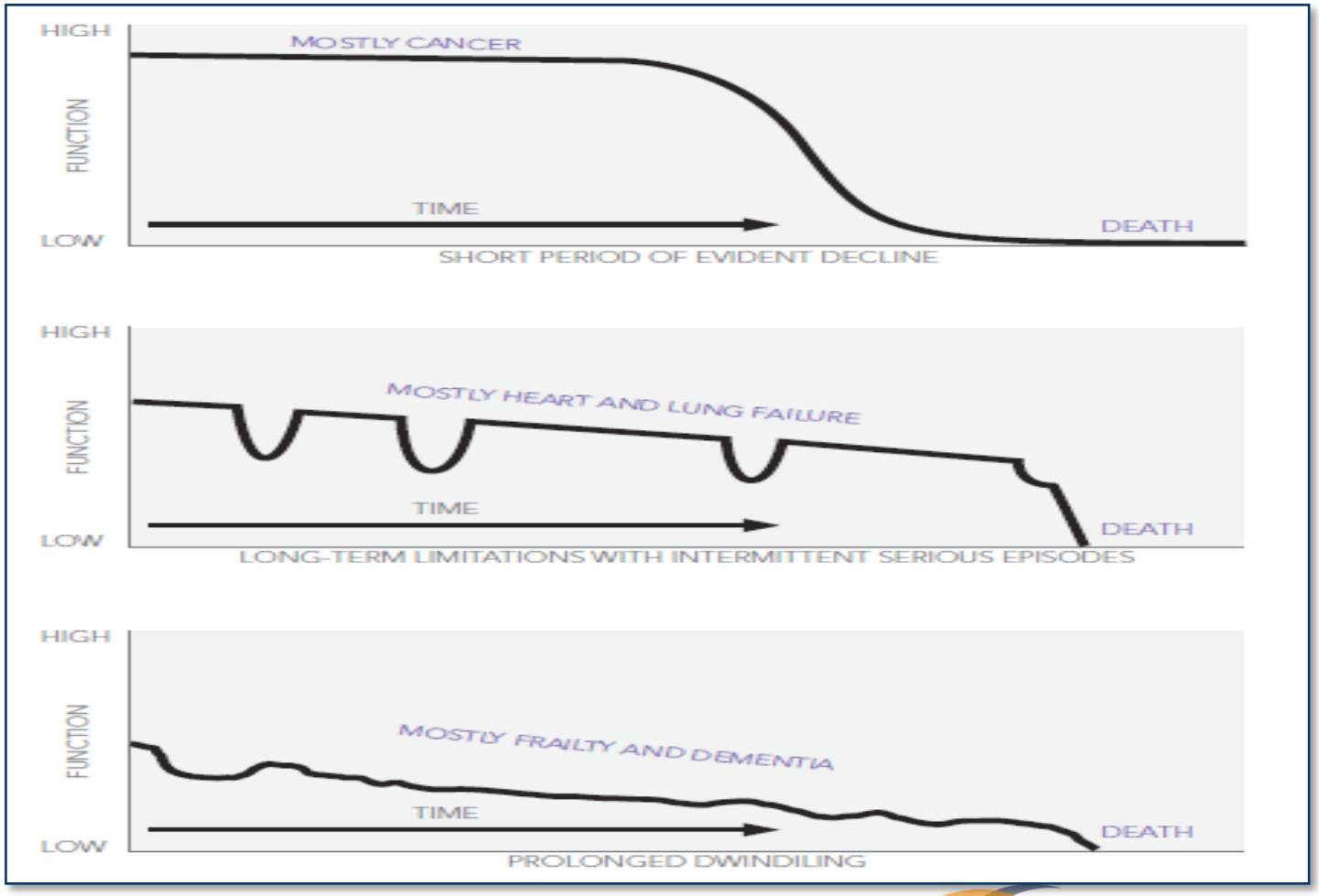
Trajectories at the End of Life



Source: 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.

Implications of older deaths

- The major challenge for palliative care will be that not only will the number of deaths be increasing, but they will be increasing in older age bands.

- These deaths are likely to be occurring to people with more co-morbidities and a high prevalence of dementia.

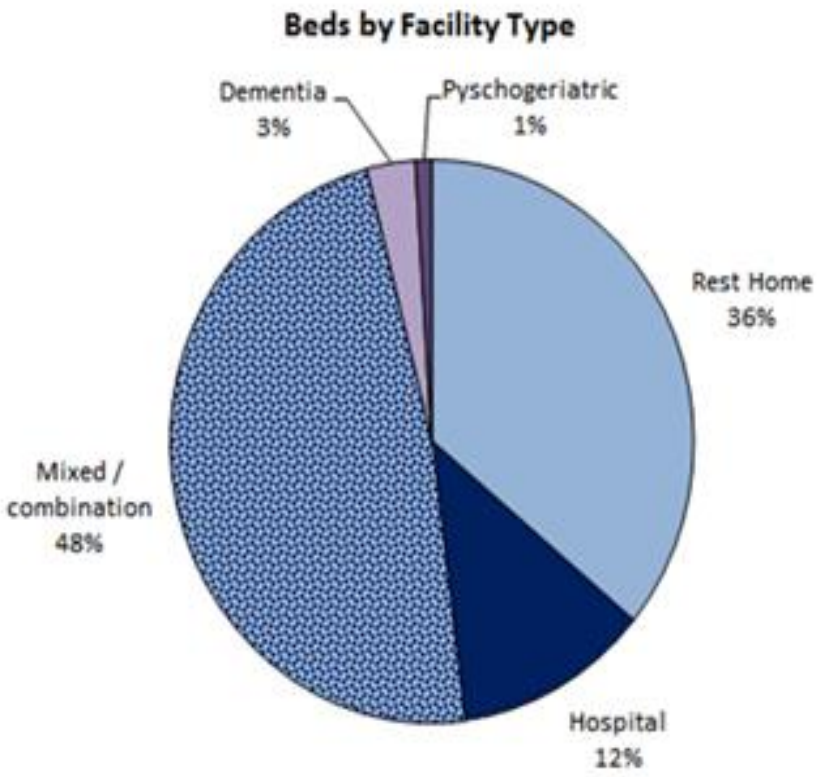
- If current patterns of end-of-life care continue most of these deaths over age 85 will occur in residential aged care facilities after an extended period of care.

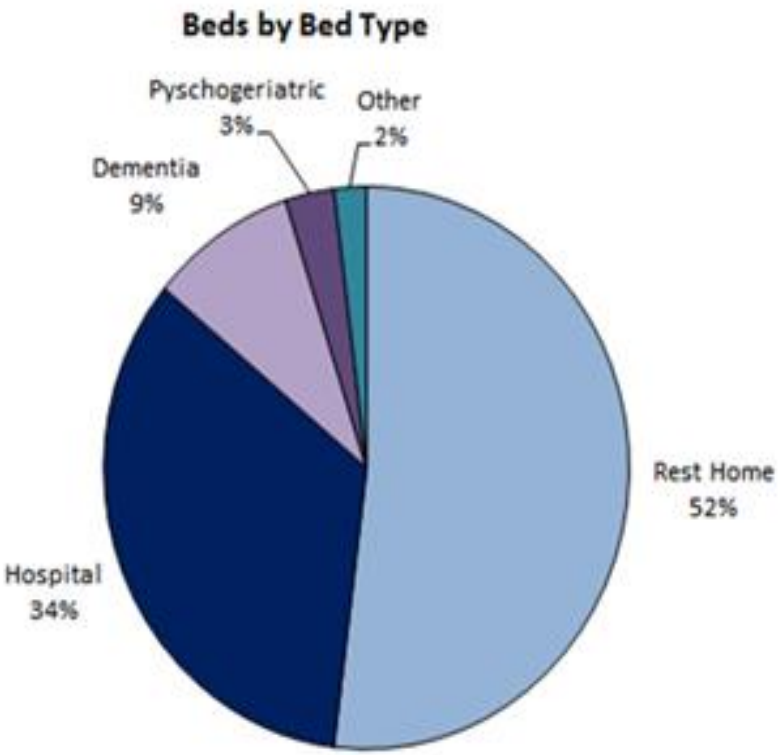
What is aged residential care in NZ?

Four service types:

- **Rest home**, intended for residents with the lowest level of dependency in residential care
- **Private geriatric hospital**, intended for residents who require 24-hour nursing supervision
- **Specialist dementia services**, intended to minimise risks associated with the confused states of residents with dementia
- **Psychogeriatric**, intended for residents with an organic illness at the extreme end of dementia and defined by clinicians as those with features of behavioural and psychological symptoms of dementia (BPSD).

Facilities and bed types





Aged Residential Care Facilities and Bed Types in New Zealand in 2009

Source: Grant Thorndon (2010) *Aged Residential Care Service Review*. September 2010. Wellington: District Health Board Shared Services, New Zealand Aged Care Association.

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- 36,100 beds in the sector as at January 2014

(Ministry of Health, 2014)

- 68% for profit; 32% not-for-profit
- 37% of residential care facilities co-located with retirement villages

(Grant Thorndon ARC Service Review, 2010)

- Roughly 30,000 NZers in residential care at any one time

(NZ Treasury, 2013)

- Age of entry to residential care is progressively increasing: median age at admission 79yrs in 1988; 83yrs in 2008

(Broad et.al. 2011; analysis of data from the OPAL study 1988-2008)

The changing face of aged residential care

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The changing face of ARC

- Between 1998 and 2008, the proportion of the population of NZers
  - over 65yrs
    - in rest home care ↓
    - in hospital care ↑
  - over 85yrs
    - in rest home care ↓
    - in hospital care ↑ (**113%** increase in this population)

- More women in care than men but the gap is closing

- Age at admission ↑
- Length of stay ↓

(Boyd, 2009)

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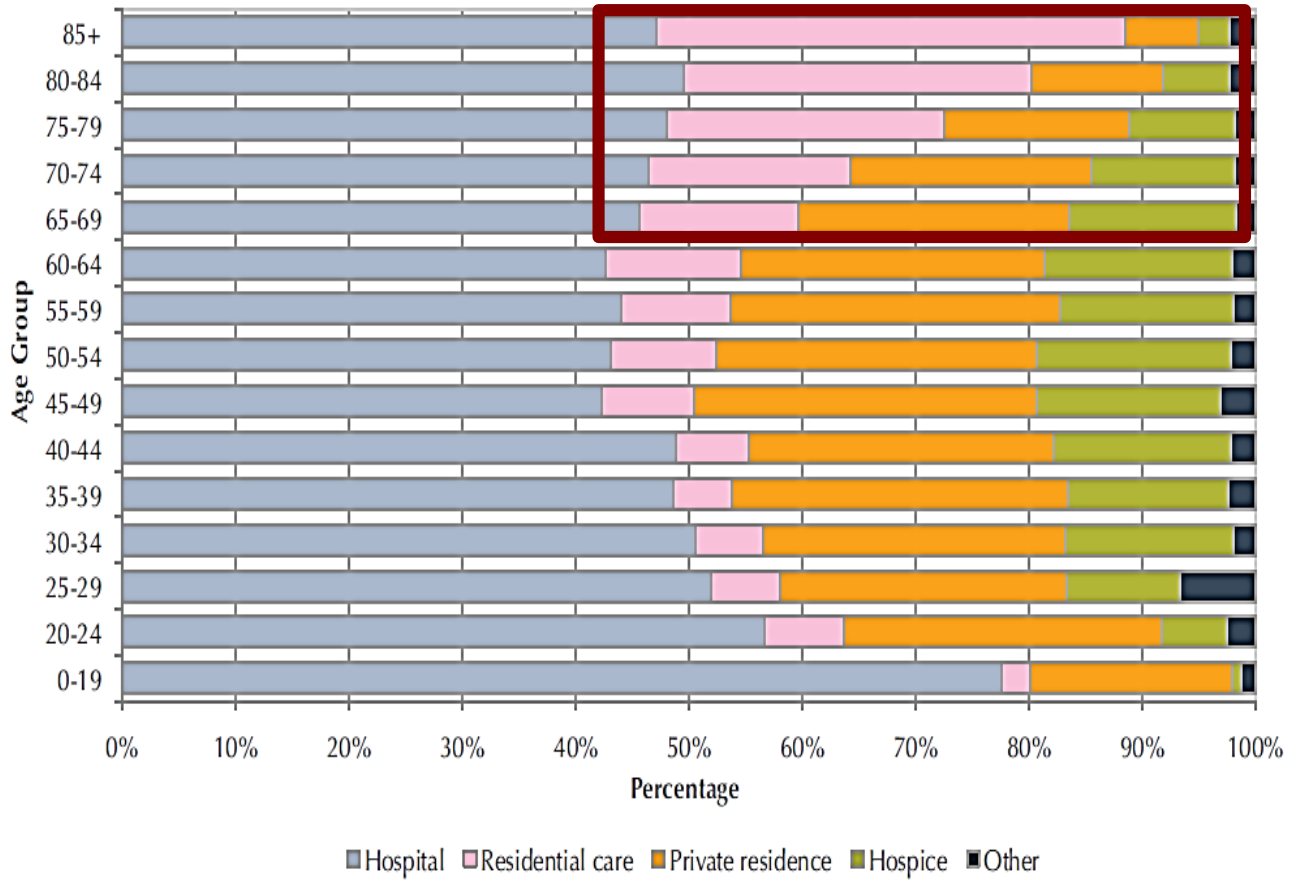
The changing face of ARC

- Increasing dependency:
  - Bedbound patients - ↑to 21% from 14%
  - Memory loss, disorientation to time, persistent wandering, complete disorientation – all ↑
  - Continence –
    - Independent toileting ↓
    - Dependent toileting ↑
    - Urinary and faecal incontinence ↑
  - Night care – needing help at least once / night ↑
  - Impaired communication ↑

(Boyd, 2009)

Palliative care and aged residential care



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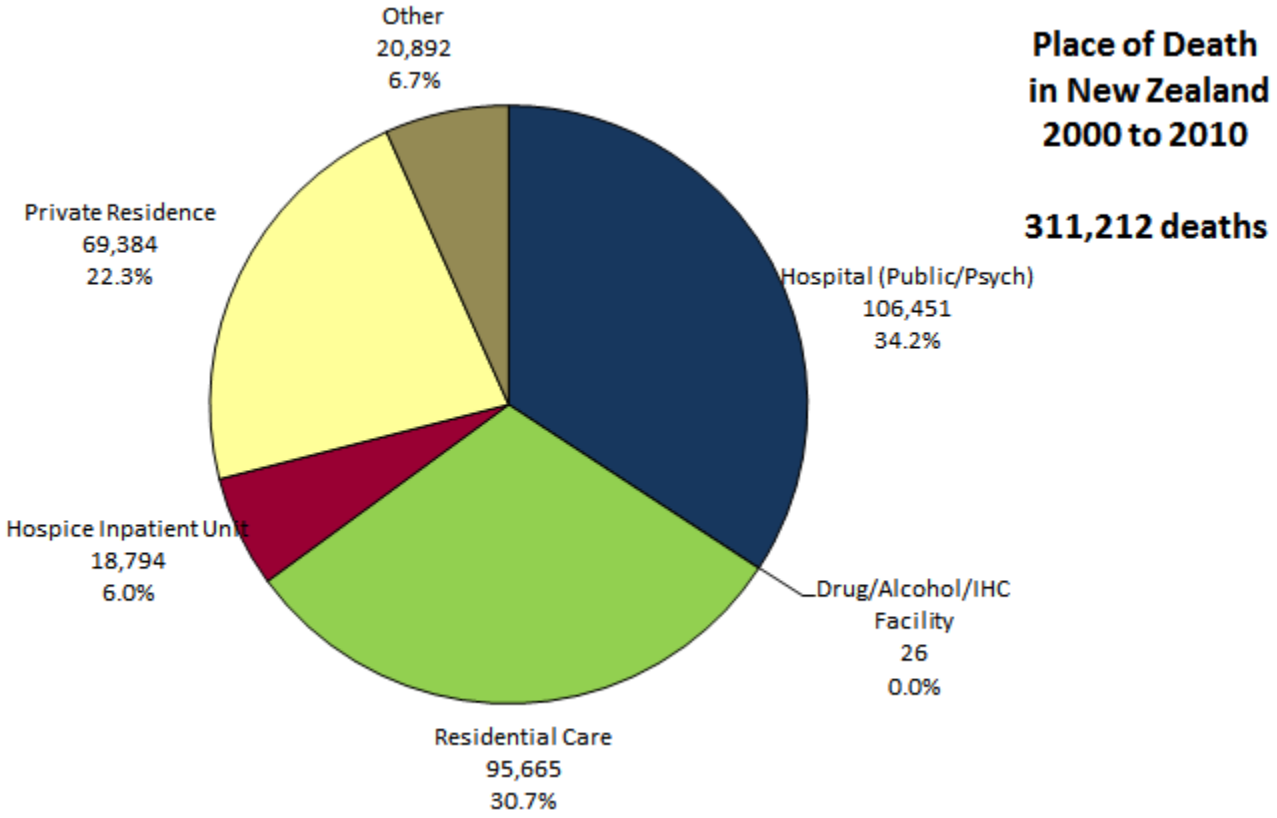
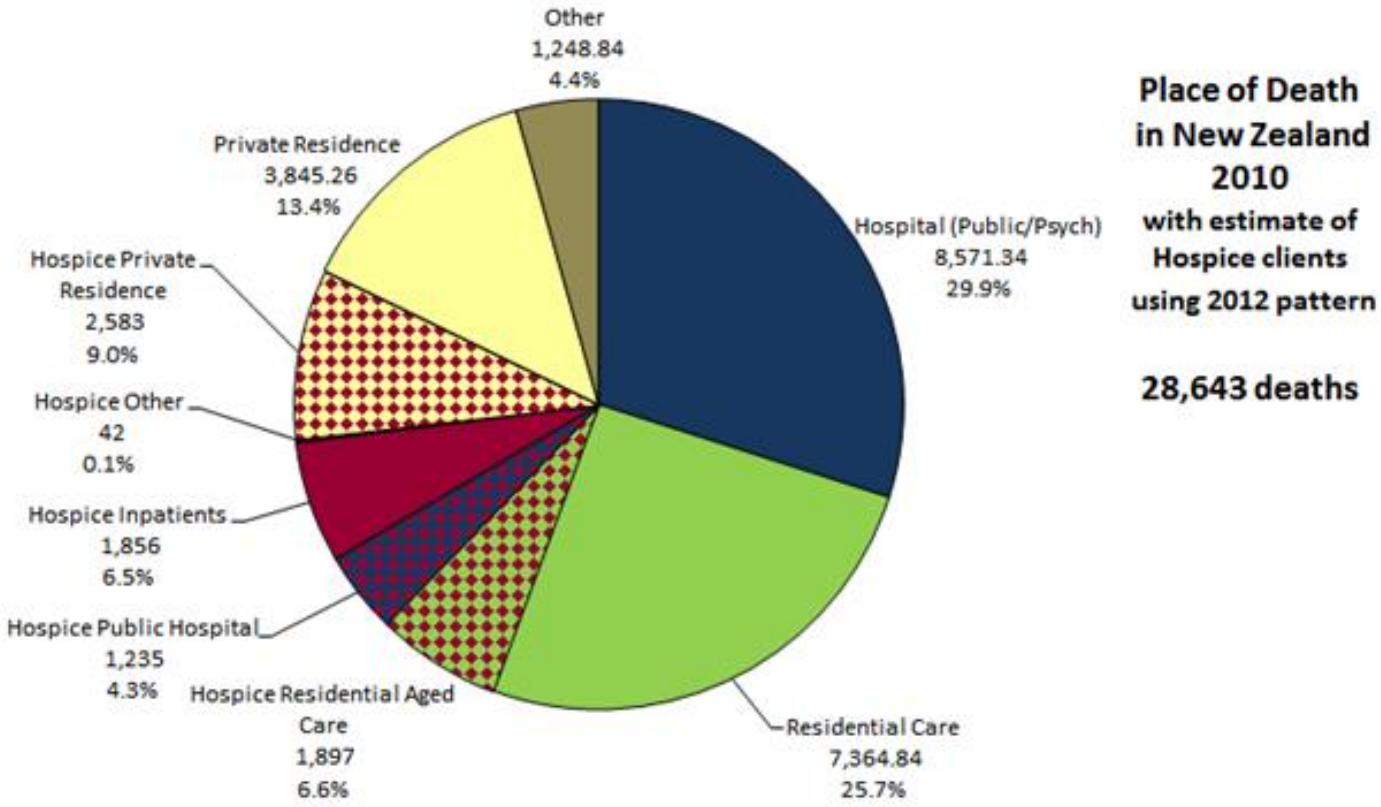
Place of Death 2000-2010



34.2% in hospital, 30.7% in residential care and 22.3% in private residence. Note that this seriously undercounts hospice involvement as only hospice inpatient unit available as a place of death.

Source: Analysis of Ministry of Health MORT data 2000 to 2010

Place of Death 2010 after Hospice Adjustment



The patterns (not actual data) from the hospice benchmarking data in 2012 have been applied by indexing the deaths of clients in other settings to deaths in hospice inpatient units. The patterns were then applied to this MORT data.

Source: Analysis of Ministry of Health MORT data 2000 to 2010; with data from Hospice NZ

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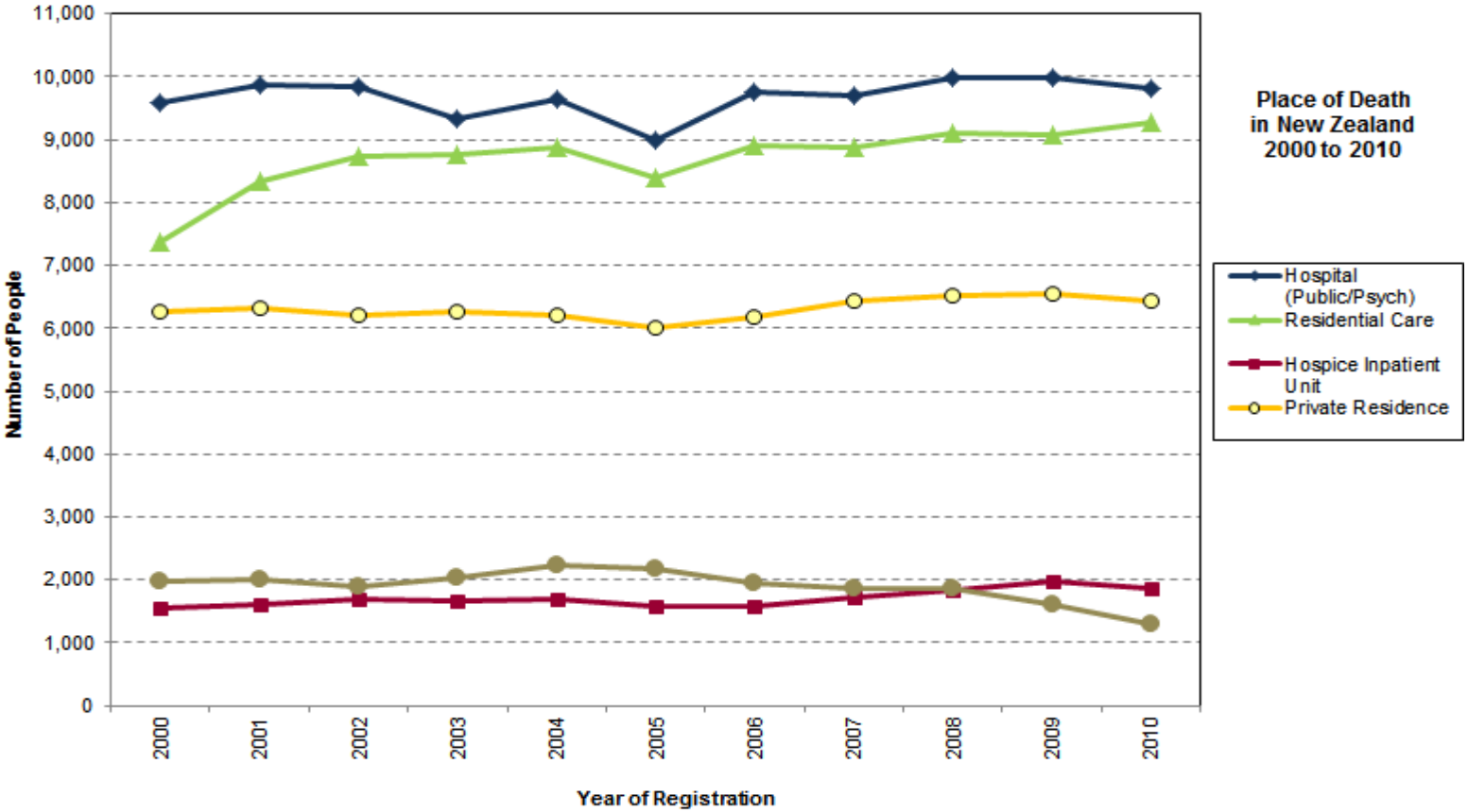
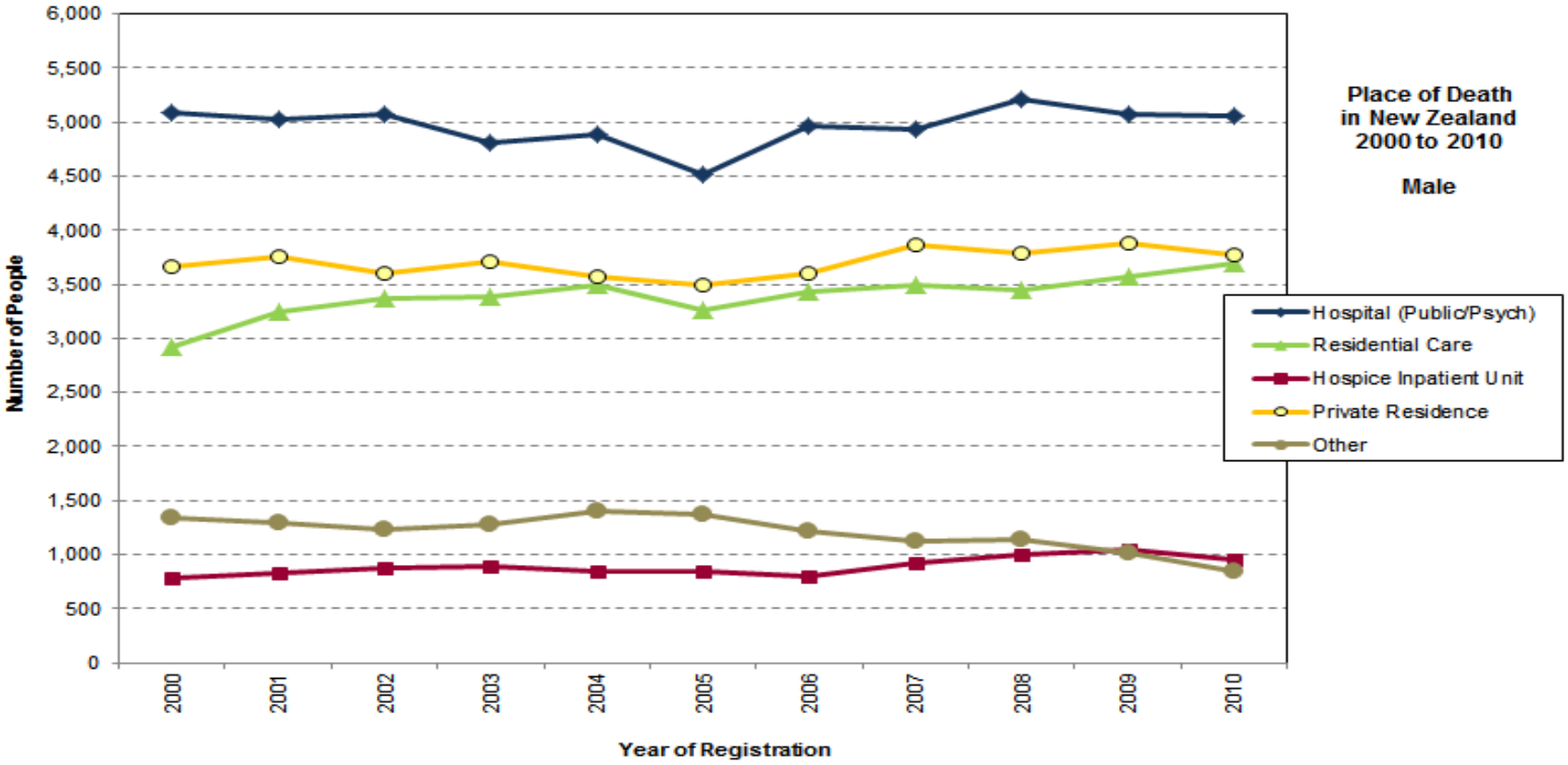
Place of Death 2000-2010



Over the period, deaths in public hospital and residential care have narrowed with the growth in deaths in residential care. Some increase in deaths in hospice inpatient unit.

Analysis of Ministry of Health MORT data 2000 to 2010

Place of Death 2000-2010 Male



Hospital and private residence are most common places for male deaths.

Analysis of Ministry of Health MORT data 2000 to 2010

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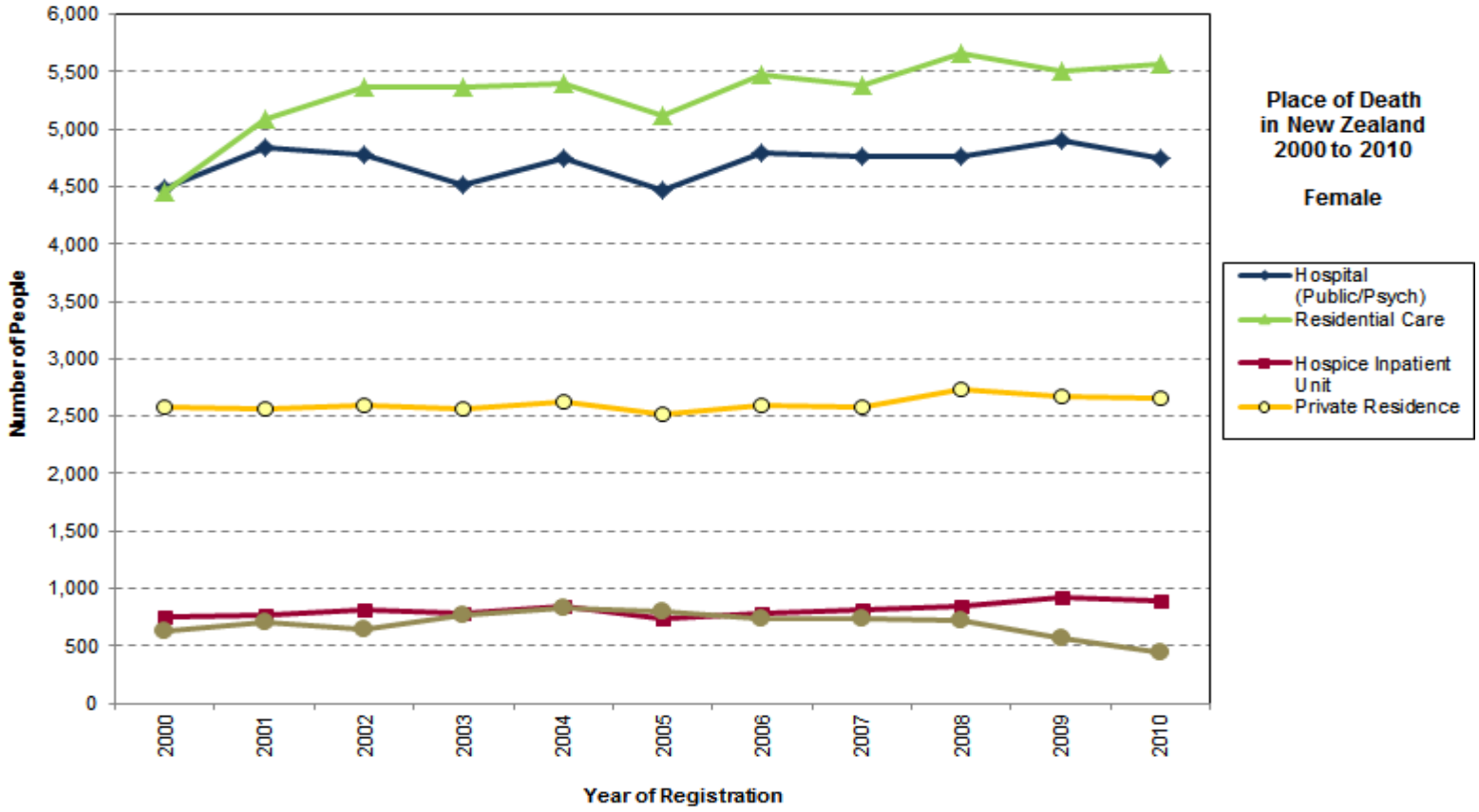
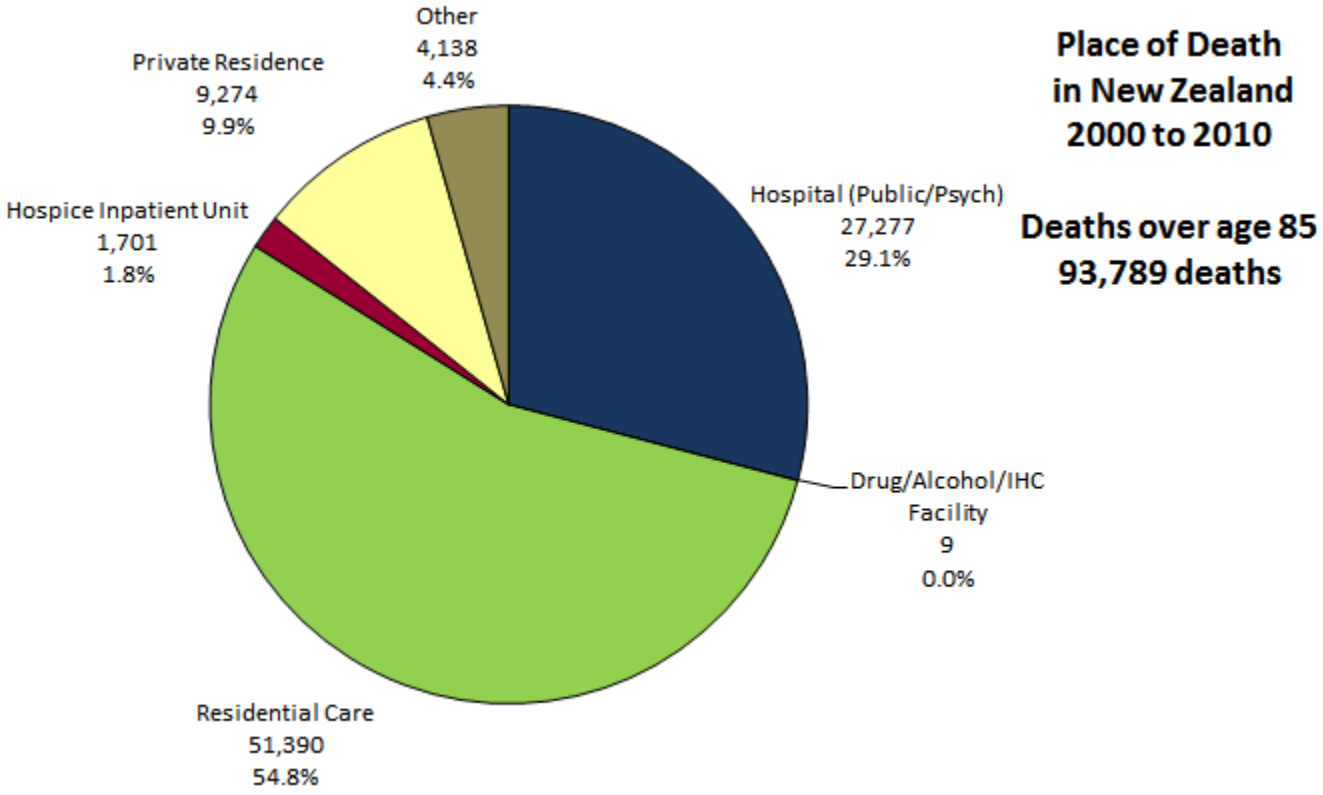
Place of Death 2000-2010 Female



Residential care is most common place for female deaths, with private residence much smaller than residential care or hospital.

Analysis of Ministry of Health MORT data 2000 to 2010

Place of Death 2000-2010 Age 85+



For deaths over age 85, 54.8% in residential care and only 9.9% in private residence. Some deaths in public hospital likely to be after transfer from residential care.

Source: Analysis of Ministry of Health MORT data 2000 to 2010

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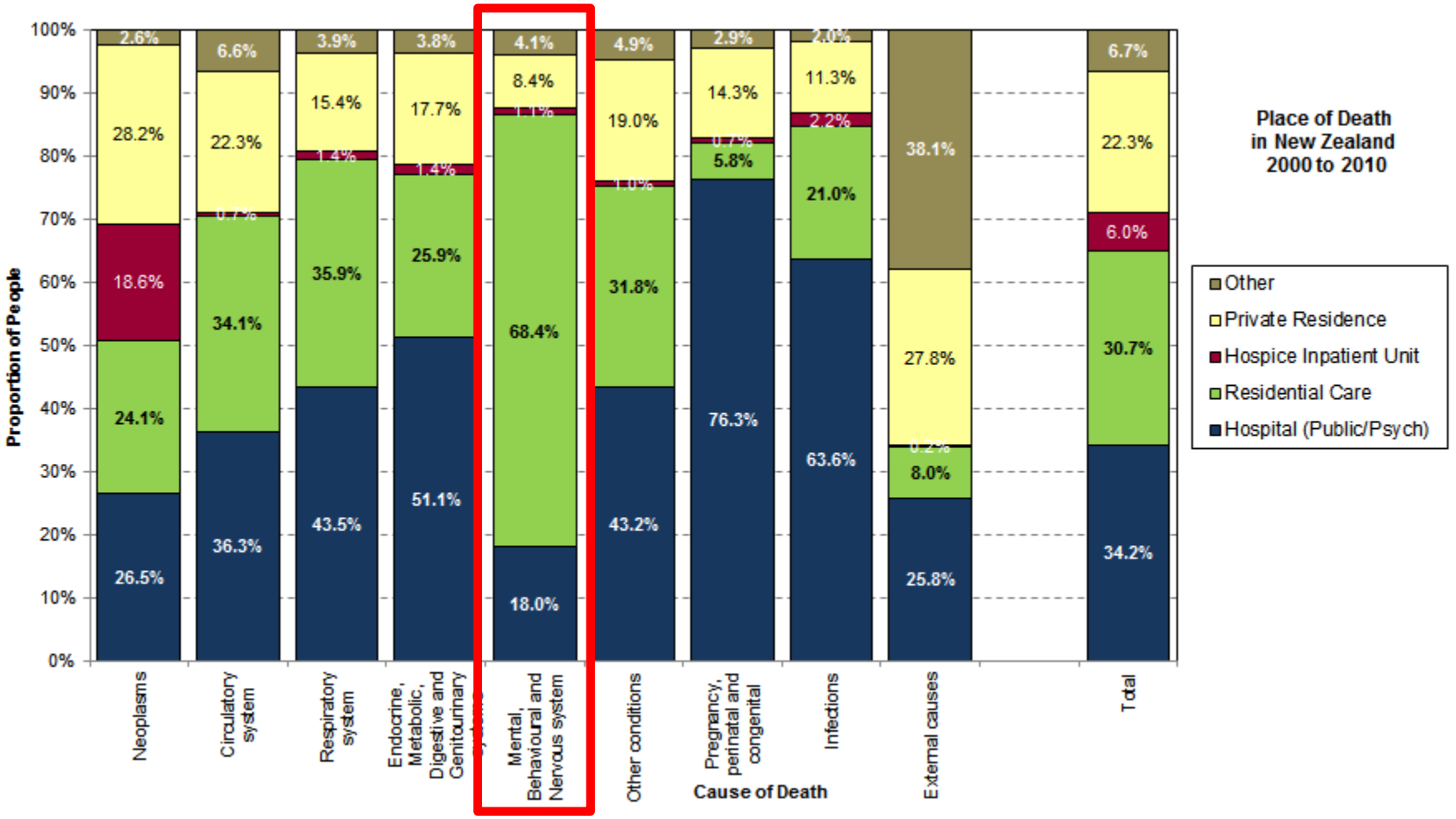
Place of Death 2000-2010



18.6% of deaths from Neoplasms in hospice inpatient unit. 68.4% of deaths from mental, behavioural and nervous system conditions are in residential care.

Source: Analysis of Ministry of Health MORT data 2000 to 2010

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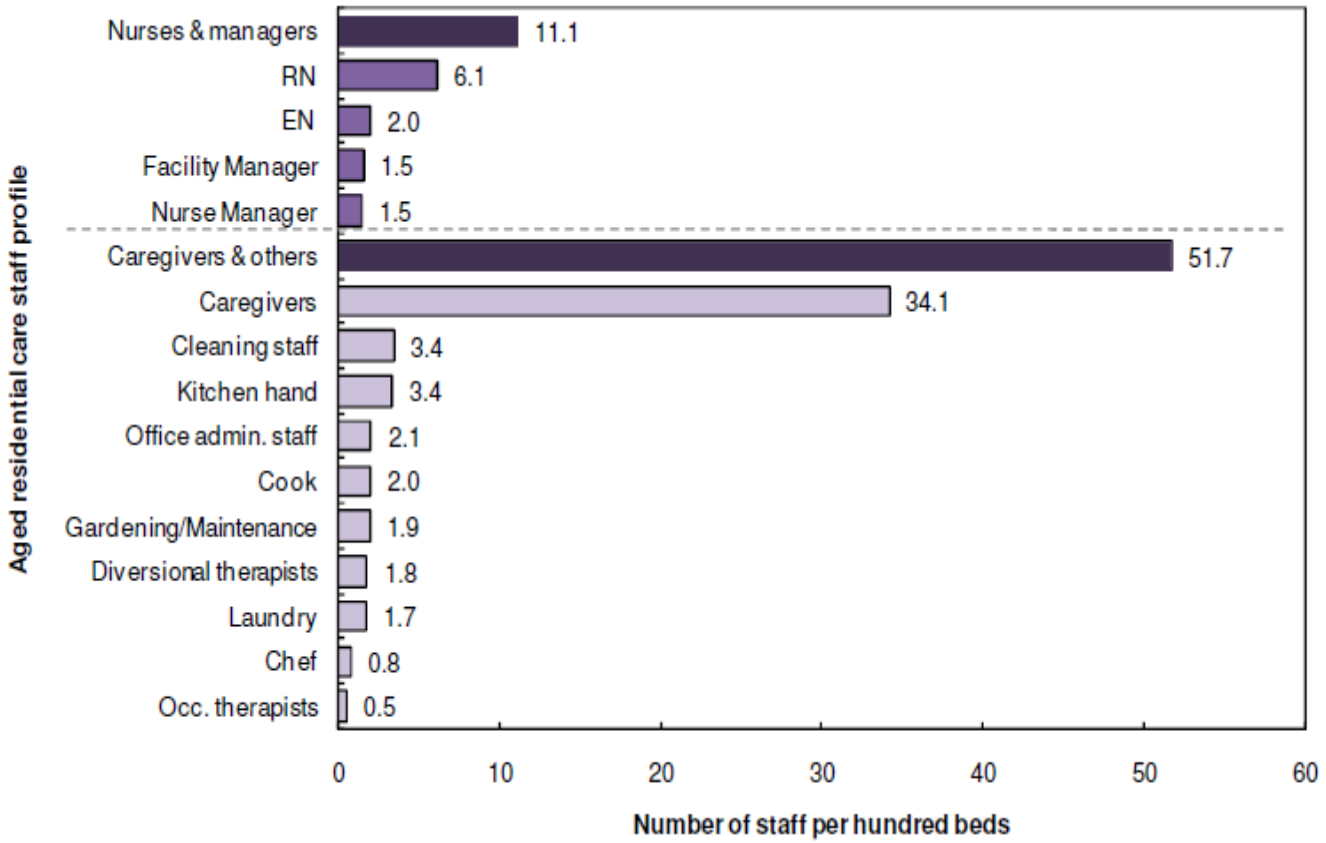
ARC staff profile



Aged care staff profile in 2008

Source: Grant Thorndon Review, 2010

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Hospice capability

Capability component			Category of service		
			Comprehensive hospice palliative care service	Community hospice palliative care service	Hospice palliative care support service
Will have	Clinical functions	Community care	100%	100%	100%
		Assessment	100%	100%	40%
		Care planning	100%	100%	40%
		Care coordination	95%	100%	40%
		Liaison roles	100%	75%	20%
		Education	100%	50%	80%
		Bereavement care	100%	75%	80%
		End-of-life pathway	100%	42%	20%
		Quality improvement	100%	83%	20%
		Clinical data collection	100%	75%	20%
	Roles	Registered nurses	100%	100%	0%
		Medical officer or GP	100%	33%	0%
		Spiritual care	100%	42%	60%
		Social work	89%	25%	0%
		Counselling	95%	67%	60%
		Cultural advisor	79%	67%	0%
		Volunteer manager/coordinator	100%	67%	20%
		Volunteer workforce	100%	75%	60%

Source: Palliative Care Council National Health Needs Assessment for Palliative Care, Phase 2 Report (2013)

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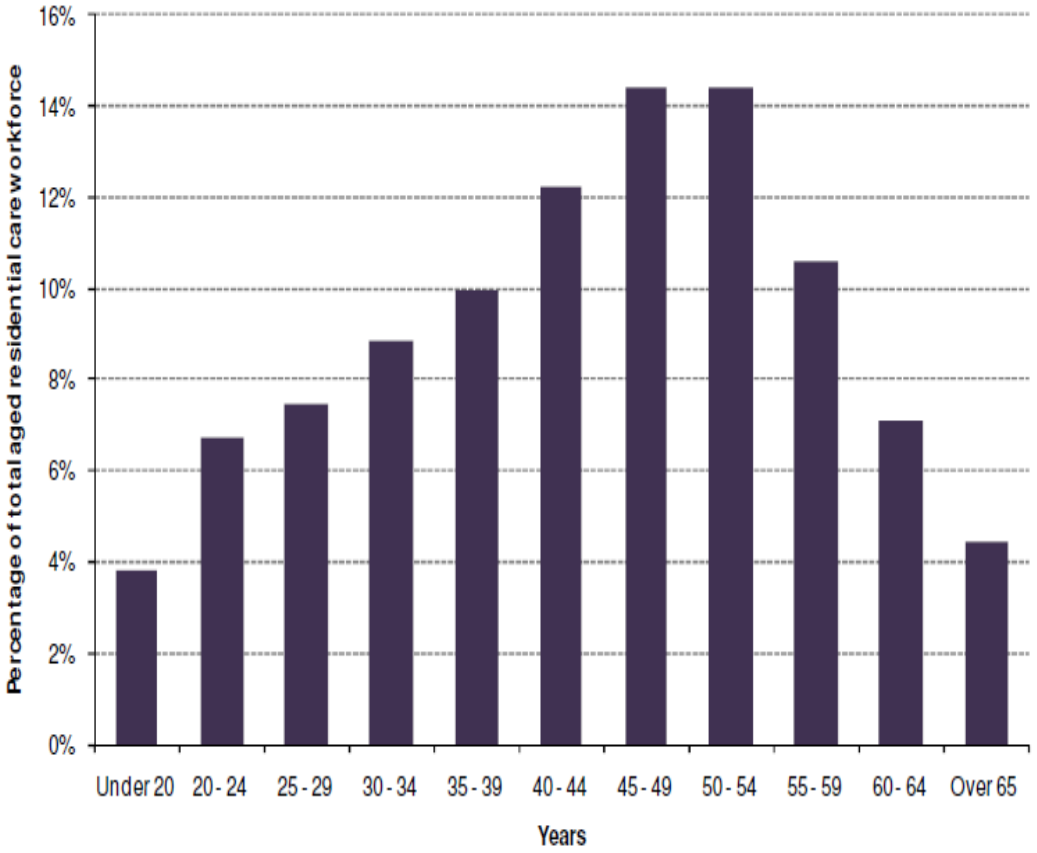
An ageing workforce



Age profile of aged residential care workforce in 2008

Source: (Grant Thornton, 2010, pp. 109, citing In Touch issue 112, April 2010, New Zealand Aged Care Association)

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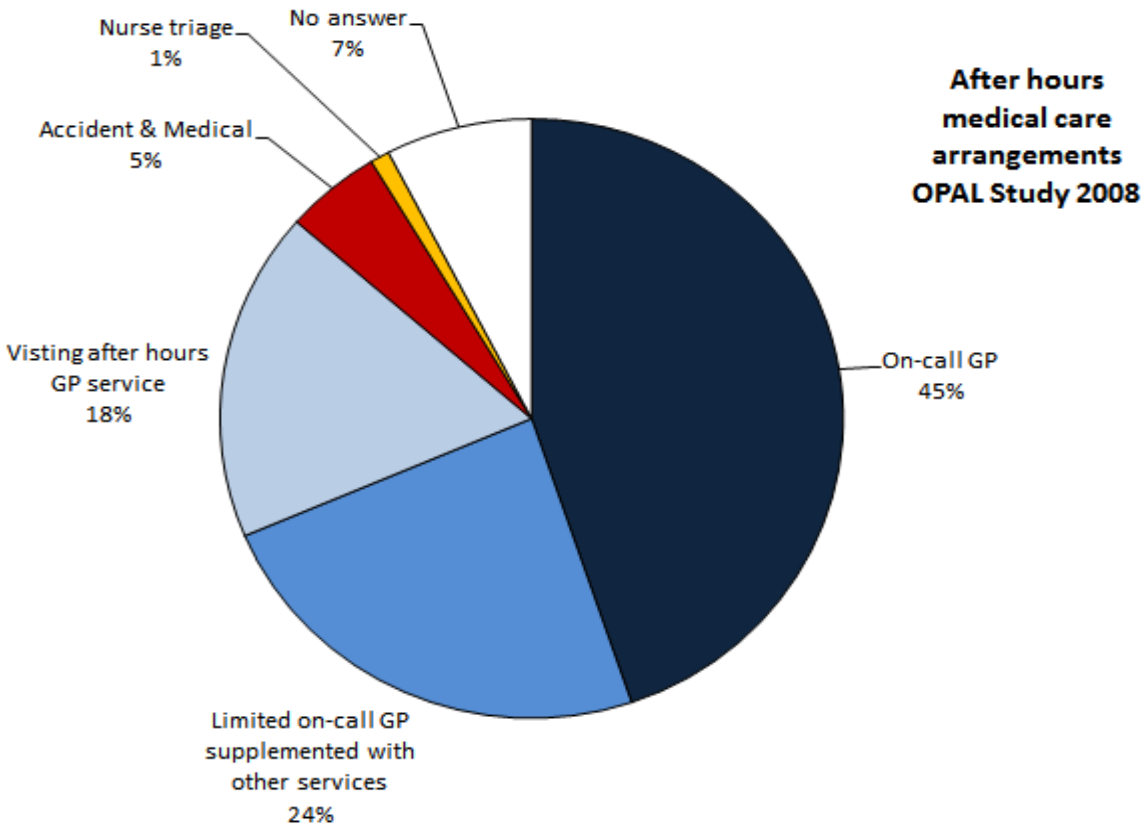
General practice and ARC



After-hours Medical Care Arrangements in Residential Aged Care, OPAL Study 2008

Data source: Boyd et; al. (2009) *Changes in Aged Care Residents' Characteristics and Dependency in Auckland 1988 to 2008. Findings from OPAL 10/9/8 Older Persons' Ability Level Census*. 2009. Auckland: University of Auckland.

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Perceptions of ARC

- “Our dirty little secret – abuse of the elderly””
- “Carnage at the rest home door”
- “Rest home residents fight eviction”
- “Flesh disease at rest homes”
- “Rest home complaints soar”
- “Immigrants “degraded” by work in rest homes”
- “Deadly secrets could be exposed”
- “Resthome lockdown ends”
- “Lifting the lid on aged care in New Zealand … some facilities likened to chicken farms”
- ***“I think it’s a system of wrenching people out of their natural environment and sticking them into an institution and charging them their life savings to stay there and kidding them that they are happy when they are not. I look upon them as battery hens”***

Perceptions of ARC

Colmar Brunton telephone survey conducted in May 2010 (1009 participants):

- Over 1/3 had experience of the sector
- Those “with experience” were much more favourable than those without experience
- Nearly six in ten of those with experience think the sector is better than how it is presented in the news media
- Those with friends or family who have been in care for a longer period are more likely to think the sector is better than what is presented in the news media
- 71% of those “with experience” reported their overall impression of aged care facilities as “good” or “very good”, compared with 55% with no direct experience
- Those with no direct experience base their opinion on other personal experience, stories in the media, and what close friends or family have said
- 17% of those with **no direct experience** thought rest homes and aged residential care facilities had worsened over the previous three years

Caring counts

"The respect and value shown to older people in New Zealand is linked to the respect and value shown to their carers.

While society continues to devalue older people, the aged care sector will remain marginalised in terms of both status and in adequacy of resourcing."

'Caring Counts'
Human Rights Commission Enquiry into Aged Care, 2012

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Case study – “inappropriate hospitalisation”

- Resident with advanced dementia, appears “unwell”. No close relatives living nearby; designated “family contact” some distance away and rarely in contact
- No obvious sign of infection, constipation, or serious illness, but staff ‘instinctively’ knew something was wrong
- Suspected a bronchopneumonia and that she was now in a terminal phase
- GP visit requested; no obvious physiological changes so felt no significant issues to address
- Resident continued to deteriorate; no definite diagnosis or plan in place so a further GP visit requested via After Hours service
- After Hours GP ordered transfer to hospital despite nursing staff feeling this wasn’t the appropriate course of action. Relative contacted and updated, did not attend.
- Ambulance took some time to arrive
- Carer accompanied resident to A&E; resident significantly deteriorated by this time.
- Tests and investigations commenced in ED however the resident passed away soon after arrival, on an emergency department trolley, with the carer present
- An A&E consultant emailed the facility manager the following week expressing concern about their practice in “sending residents to hospital to die”

“Inappropriate hospitalisation”

- Underlying issues:
  - Access to diagnostics
  - Poor communication between primary and secondary care
  - Excessive cautiousness of clinicians to manage patients in the community
  - Clinicians unfamiliar with the resident – eg mistaking problems as acute rather than chronic

- Also –
  - Lack of recognition of the importance of nursing staff assessments of subtle behavioural change, in the absence of specific physiological change (eg elevated temp)

- And –
  - **society’s understanding of death and dying, in the context of medicalization, and beliefs around the role of the acute hospital**

Ensuring residents' wishes are respected in the event of a deterioration requires …

- Knowing what a resident wants in terms of future care and ensuring these wishes are clearly documented in a format which will be recognisable and credible to clinicians involved in the resident's care

- Recognition and anticipation of potential problems and early intervention to prevent crisis events

- Confidence of nursing staff when talking to other people involved in the resident's care whether family members, other staff, doctors or out of hours providers and a willingness to act as an advocate for the resident where required

- **Confident staff are able to challenge plans that they feel are not in the resident's best interest**

To recap …

- An ageing population, and an increasing demand projected for ARC over time
- Increasing dependency of ARC population, and decreased length of stay – residents are admitted older, frailer, and with more complex needs
- The most common place of death for women, over 85s, and for people with dementia
- Increasingly, less time to establish relationships with residents and families who have been under significant stress during acute illness and after prolonged period of care in the community
- Pre-existing perceptions and beliefs about the likely standard of care on admission to ARC, and long held beliefs around the role of the acute hospital, and ‘rescue medicine’

Innovations and opportunities

- Integrated approach to palliative care in ARC
- Advance Care Planning
- Tailored education, training and support – Hospice NZ Fundamentals of palliative care
- InterRAI Palliative Care Assessment

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- Develop linkages and integration across ARC, Older Persons Health, and palliative care specialist services
- A *palliative approach* to aged care
- Consideration of quality standards and guidelines for palliative care in ARC

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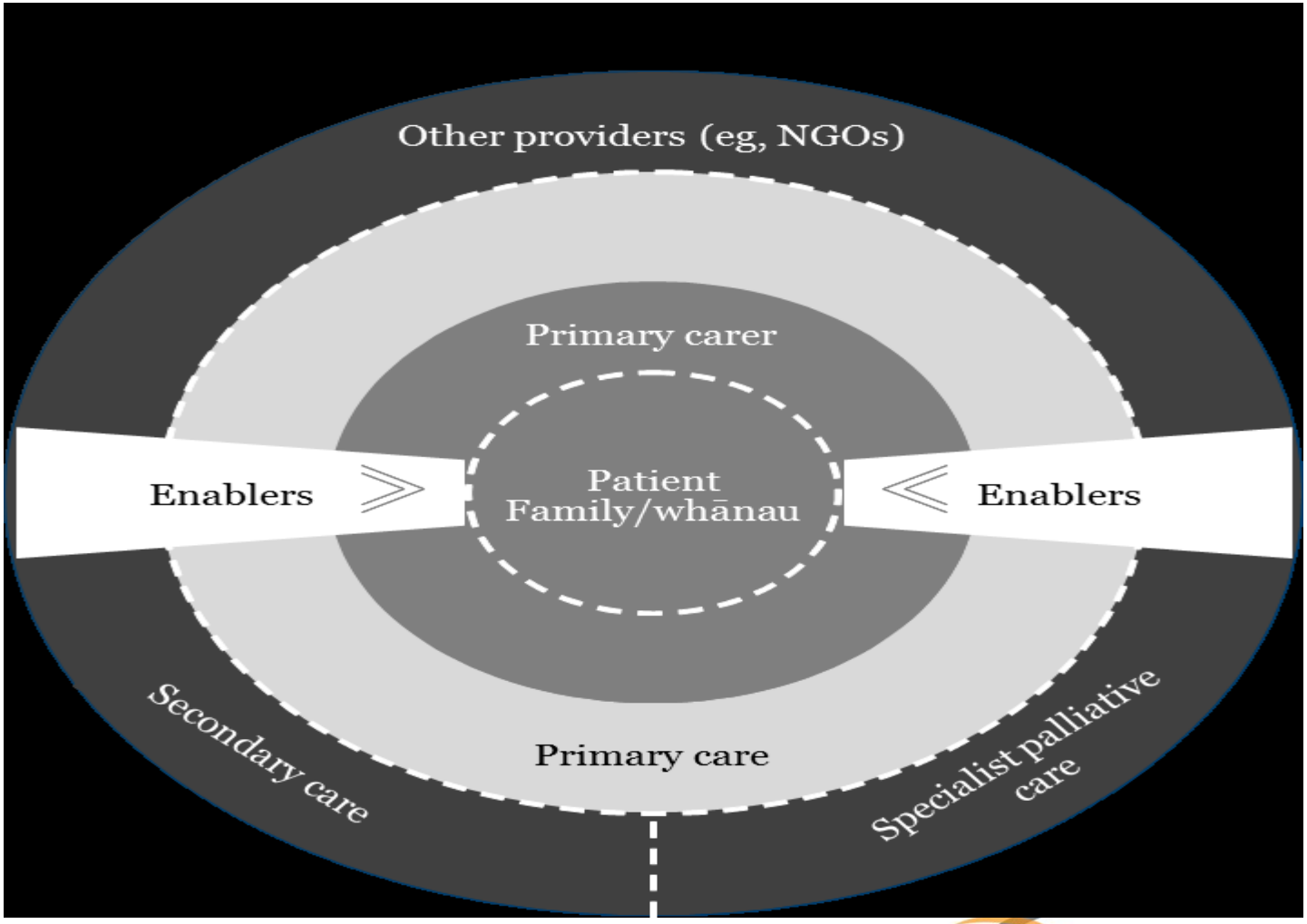
A framework for integrated care



Source: Ministry of Health (2012) *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand*. December 2012. Wellington: Ministry of Health Manatū Hauora

Strengthening the older persons nursing workforce

- Strategies to strengthen ARC nursing:
  - Creating a learning environment
  - Availability of support and expertise
  - Effective succession planning
  - Strengthening linkages and integrated care

Positively promoting and valuing the breadth of the ARC nurse role and the education and career opportunities in ARC.

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