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Approaches to
informing policy and planning in
residential aged care:
new knowledge from existing data

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A thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy (PhD) in Community Health.

School of Population Health,
Faculty of Medical and Health Sciences,
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Abstract

Background

In public health policy, where decisions are made that affect the health and wellbeing of thousands or millions of people, relevant information to aid decision-making may be sparse or misleading. With rapidly ageing populations, decisions are increasingly needed to inform service provision for late-life care of older people. In New Zealand, residential aged care (RAC, equivalent to nursing homes and/or care homes elsewhere) is part of that service, but is not well described. Data such as administrative or transactional data are frequently used for official reports but much is unknown about usage patterns or future demand. If analysed differently, data currently held in information systems have potential to reduce information gaps.

Objectives

To answer fundamental questions about the use of RAC and hospital services by older people in New Zealand (NZ) using analytic methods that are often used in population surveys but seldom used in epidemiology or health services research.

Methods

Data from many administrative, survey and research sources are employed, using ratio estimation and survey reweighting when needed to adjust for study design. Analytical methods include logistic regression, generalised linear regression, point-process renewal methods, and proportional hazards models.

Findings

In recent decades, reports of the percentage of those aged 65 years and over living in RAC varied markedly for a range of reasons. Since 2008 reports were more consistent, stabilising between 4%-6%. When using payments data to describe residents, bias is introduced because the 25% who are not subsidised differ systematically from the subsidised.

At least 47% of individuals reaching 65 years of age enter RAC for late-life care. After the age of 85 years that likelihood reaches over 58% for men and 70% for women. Using survey reweighting techniques, the median length of completed stay in RAC was estimated at 2.0 years, with 17% dying within 3 months and 23% surviving more than 5 years.

Over a 12 month period, an estimated 64 new admissions to RAC occur for every 100 occupied beds, 14 being transfers from other facilities. Half the new residents enter directly from an acute hospital stay and these are likely to die sooner than others. Over the period of a year, for every 100 residents, an estimated 41 emergency department presentations and 52 hospitalisations occur, of which 38 are acute.

When seeking to identify facilities with higher use of acute hospitals, for example to offer support to facility staff, studies must choose between several measures of level of use. Different measures produce very different rankings of RAC facilities and the choice is best determined by the reason for making the selection.

Conclusions

Planning for long-term care needs of older people deserves high priority given the costs of such care and expected growth in demand. Identified weaknesses and information gaps in information systems may hamper good debate and policy. The novel use of existing data has answered questions that were previously unanswerable. Survey and other research sources, in conjunction with administrative data and with adjustments for length-biased sampling, are useful in this and other settings.

The results demonstrate the entrenched role RAC plays in NZ. For some, that signals the importance of strategies to better support people living at home, to avoid or delay RAC entry. For others, it emphasises the need for better planning for the provision and funding of care for older people. Yet others will be interested in developing and testing options that provide both support and choice to individuals and their families. It is important for the ageing population of the future to create and maintain information systems that measure service utilisation consistently and that monitor and project trends across time in order to inform policy and practice.

Co-authorship forms

The following six pages include co-authorship forms for the papers listed below.

Broad JB, Ashton T, Lumley T, Connolly MJ. Reports of the proportion of older people living in long-term care: a cautionary tale from New Zealand. *Australian and New Zealand Journal of Public Health* 2013;37(3):264-71. DOI: 10.1111/1753-6405.12069.

Broad JB, Ashton, T, Lumley T, Boyd M, Kerse N, Connolly MJ. Selecting long-term care facilities with high use of acute hospitalisations: issues and options. *BMC Medical Research Methodology* 2014, 14:93. DOI: 10.1186/1471-2288-14-93.

Broad JB, Ashton T, Lumley T, Boyd M, Kerse N, Connolly MJ. Biases in describing residents in long-term residential aged care. *New Zealand Medical Journal* 2014;127(1402):50-61.

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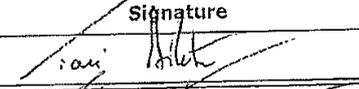
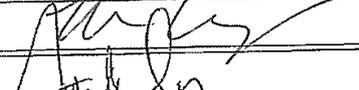
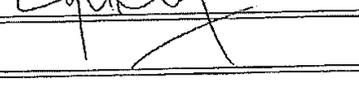
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| Prof Toni Ashton | discussion re limits of topic, arranging departmental "Think Tank" discussion, advice & support, critical review and final approval |
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Nature of contribution by PhD candidate: conception, data search & collection, results presentation, discussion, all drafts and revisions, coordination and submission

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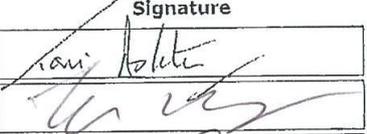
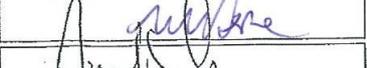
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| Dr Michal Boyd | original conception of work, advice & support, critical review, final approval |
| Prof Ngaire Kerse | original conception of work, advice & support, critical review, final approval |
| Prof Martin Connolly | original conception of work, advice & support, critical review, final approval |
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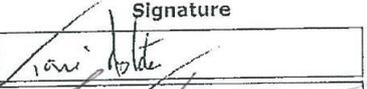
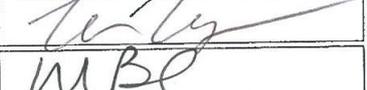
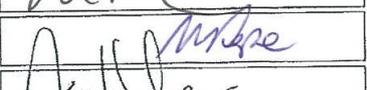
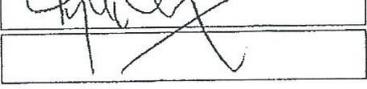
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Broad J, Ashton T, Gott M, McLeod H, Davls P, Connolly M. Likelihood of residential aged care use in later life: a simple approach to estimation, with International comparison. Aust N Z J Public Health accepted.

Nature of contribution by PhD candidate

conception, data search & collection, results presentation, all drafts and revisions, coordination and submission

Extent of contribution by PhD candidate (%)

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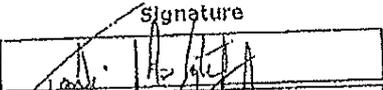
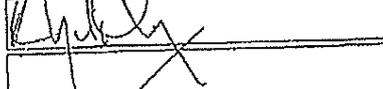
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| Prof. Peter Davls | advice & support, critical review, final approval |
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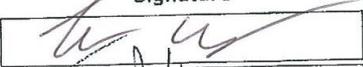
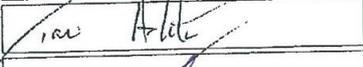
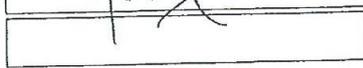
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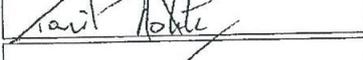
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*In recognition of Nancy Light (deceased), David Swain,
Ruth Bonita and Robert Beaglehole.*

*Decades ago, they recognised in me some ability
and in their own ways, pointed me along this path.*

*Dedicated to my parents,
Bunny and John, with love.*

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Table of Abbreviations

| | |
|---------------|--|
| 95%CI | 95% confidence interval |
| APRU | Association of Pacific Rim Universities |
| ARCHUS | Aged residential care healthcare utilization study |
| ASH | ambulatory sensitive hospitalisations; |
| CCPS | Client Claims Processing System |
| COPD | chronic obstructive pulmonary disease |
| DHB | District Health Board |
| DHBSS | DHB Shared Services |
| ED | Emergency Department; |
| GP | General Practitioner |
| HR | Hazard ratio (from time-to-event model) |
| interRAI LTCF | interRAI Long-Term Care Facilities Assessment System |
| IQR | inter-quartile range |
| LoS | length of stay |
| LTC | Long-term care |
| MoH | Ministry of Health |
| NASC | National Assessment and Co-ordination Service |
| NHI | National Health Index |
| NMDS | National Minimum Data Set; |
| NZ | New Zealand |
| NZACA | New Zealand Aged Care Association |
| OECD | Organisation for Economic Co-operation and Development |
| OPAL | Older People's Ability Level survey |
| PAH | potentially avoidable hospitalisations |
| PHO | Primary Health Organisation |
| RAC | Residential aged care |
| SD | standard deviation |
| SE | standard error |
| UK | United Kingdom |
| UN | United Nations |
| USA | United States of America |

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- Broad JB**, Ashton, T, Lumley T, Boyd M, Kerse N, Connolly MJ. Selecting long-term care facilities with high use of acute hospitalisations: issues and options. *BMC Medical Research Methodology* 2014, 14:93. DOI: 10.1186/1471-2288-14-93.
- Broad JB**, Ashton T, Lumley T, Boyd M, Kerse N, Connolly MJ. Biases in describing residents in long-term residential aged care. *New Zealand Medical Journal* 2014;127(1402):50-61.
- Broad JB**, Ashton T, Gott M, McLeod H, Davis PB, Connolly MJ. Likelihood of residential aged care use in later life: a simple approach to estimation, with international comparison. *Australian and New Zealand Journal of Public Health* in press.

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- Broad JB**, Ashton T, Davis PB. Measuring residential aged care in New Zealand - methodological challenges in using available data [Abstract]. *Australasian Epidemiologist* 2014;20(3):61.

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- Broad JB**, Lumley T, Ashton T, Kerse N, Boyd M, Connolly MJ. Which residential long-term care facilities have residents at high risk of acute hospitalisation? Why would we want to know? Which method of selection might we use? Health Services & Policy Research Conference. Wellington, 2013.
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Other presentations

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- Broad J**, Ashton T, Davis P, Boyd M, Connolly M. Residential aged care in New Zealand - what is known and unknown about service use, and how can available data be used to address the unknowns? [symposium presentation]. Auckland: HOPE Selwyn Foundation; 2014.

Chapter 1. Introduction

1.1 Rationale

Longer lives are a success story for public health and medical care. Improvements in survival, particularly survival in later life, have extended life expectancy beyond any expectations^{1 2}. Following the advent of the contraceptive pill in the 1960s, fertility declined dramatically in most developed countries. The combination of reducing fertility and growing life expectancy has led to massive shifts in population structures, shifts that are still evolving but are changing the face of most societies in remarkable ways. Societies worldwide now face the challenge of providing good care to growing numbers of very old people³⁻⁵.

In late life, if the body or mind fails, some people can no longer live independently. Their health conditions may require daily attention from health professionals, or they may need help with daily tasks and personal cares. Many societies provide long-term care (LTC) services in a person's own home to meet these needs. Should home-based services become insufficient (for example because of lack of service providers, high costs of delivery or a need for specialised equipment) a move may be made to a residential aged care (RAC) establishment where round-the-clock care is available. RAC facilities provide personal cares, meals, housekeeping, other supports and social activities. Some provide higher-level care including round-the clock nursing care. Once a person has entered RAC in New Zealand (NZ), the long-term care establishment typically becomes their last place of living.

Population ageing is not only growing numbers of older people, but also a higher ratio of older people compared to those who are younger. As a proportion of the population, those aged 85 years and over (85+) will increase from 2% of the total population in 2014, to 3% by 2033 then to 6% by 2053. Numbers of deaths of people aged 85+ in NZ are forecast to double from about 78,000 a year in 2014 to 173,000 by 2033, and then to double again to 353,000 by 2053⁶. Given that RAC exists to meet the care needs of people late in life, continuing declines in mortality rates may lead to even higher counts of the very old. But all eventually die, so

unless there are marked changes in the patterns of use of RAC, massive increases in demand for all LTC, including RAC, should be anticipated.

Risk of entry to RAC is associated with several factors other than age. Cognitive, physical and/or functional decline, living alone and unavailability of informal or unpaid support are all well recognised as risk factors for RAC use⁷⁻⁹. Other societal changes are occurring that may hasten demand growth. There is an increasing trend for older people to live alone, with corresponding reductions in the proportion being married and increases in those who remain single or are divorced¹⁰. Rates of remaining in paid employment until of older age, particularly of women, are rising¹¹. Family members, neighbours and friends who in the past may have given informal or unpaid services at home are consequently less likely to be available during the day.

In NZ, RAC sits within the health sector. Government subsidies are available to pay for the living and care costs of those who pass needs assessment and asset tests. In the absence of any more reliable (more complete, less biased, consistently reported) information, it is these payments data which are most often used in reports of use of RAC. Partly because of limitations in these data and how they have been analysed, characterising the usage patterns of RAC in NZ has long been problematic and inconsistent. Little use is made of other sources of available information, and only very recently (after commencement of this thesis), has reporting of use been required of RAC facilities.

Reliable information is central to policy and planning in health as in any other major political or service sector. If the true state of affairs is invisible or ignored, it is unlikely that policy decisions will be optimal – whether in planning future demand, in resource allocation, or in identification of need for new service models. Further, without understanding usage patterns, it is impossible to anticipate the impacts, intended or otherwise, of any changes proposed to government funding criteria for RAC specifically, or for other related services,.

1.2 Purpose

This thesis evaluates the quality of existing data and analyses, and draws attention to limitations of existing reports that describe demand for or patterns of use of RAC in NZ. It offers new ways to address information gaps by re-analyzing

available data. This work is intended to inform information systems, service management, planning and policy in the healthcare sector and enhance understanding of utilisation of RAC facilities and other health services. Additionally, it will inform individuals wishing to understand better their risks of costly care, in order to prepare, financially or otherwise, for their later years.

It does this by providing new information:

- First, it provides new understandings of the adequacy and limitations (e.g. reliability, biases and impact of missing data) of current RAC reports
- Second, it sheds light on the patterns of use of RAC in NZ as characterised by demographic characteristics of those entering RAC, turnover and length of stay
- Third, it estimates use of hospital-based services by RAC residents and develops methods to identify facilities with higher-than-expected rates of acute, admissions that may be used for targeting health services for those living in RAC
- Fourth, it recommends how information systems may better inform the future, through improved collection, analysis and reporting.

This work does not set out to be a policy analysis of the accommodation and services needs of older people. It does not promote any policy over another. The purpose is to illuminate the extent to which RAC services are used in NZ, to demonstrate that it is possible to produce new and useful evidence by combining data from a variety of information systems, and analysing them with less well known analytical methods.

1.3 Quantifying service use

Figure 1-1 illustrates the flow of residents to and from RAC facilities, centred around residents living in RAC facilities and identifies the information gaps that this thesis addresses. Shaded arrows represent flows of residents through RAC facilities, the shaded shape in the centre. People who can no longer live independently in spite of any available home-based services move from private homes into RAC as shown in the wide downward arrow at the top.

The narrow upward arrow indicates the few who move home again - typically those using the facilities for short-stay such as rehabilitation, recuperation or respite care. Most residents live out their remaining lives in RAC, their daily health and support needs being met by the facility. Medical care within the facility is provided by their general practitioner (GP, or primary care provider), although some will occasionally require acute hospital care and other services, shown by smaller arrows. Death of RAC residents almost always occurs either in the facility or in an acute hospital.

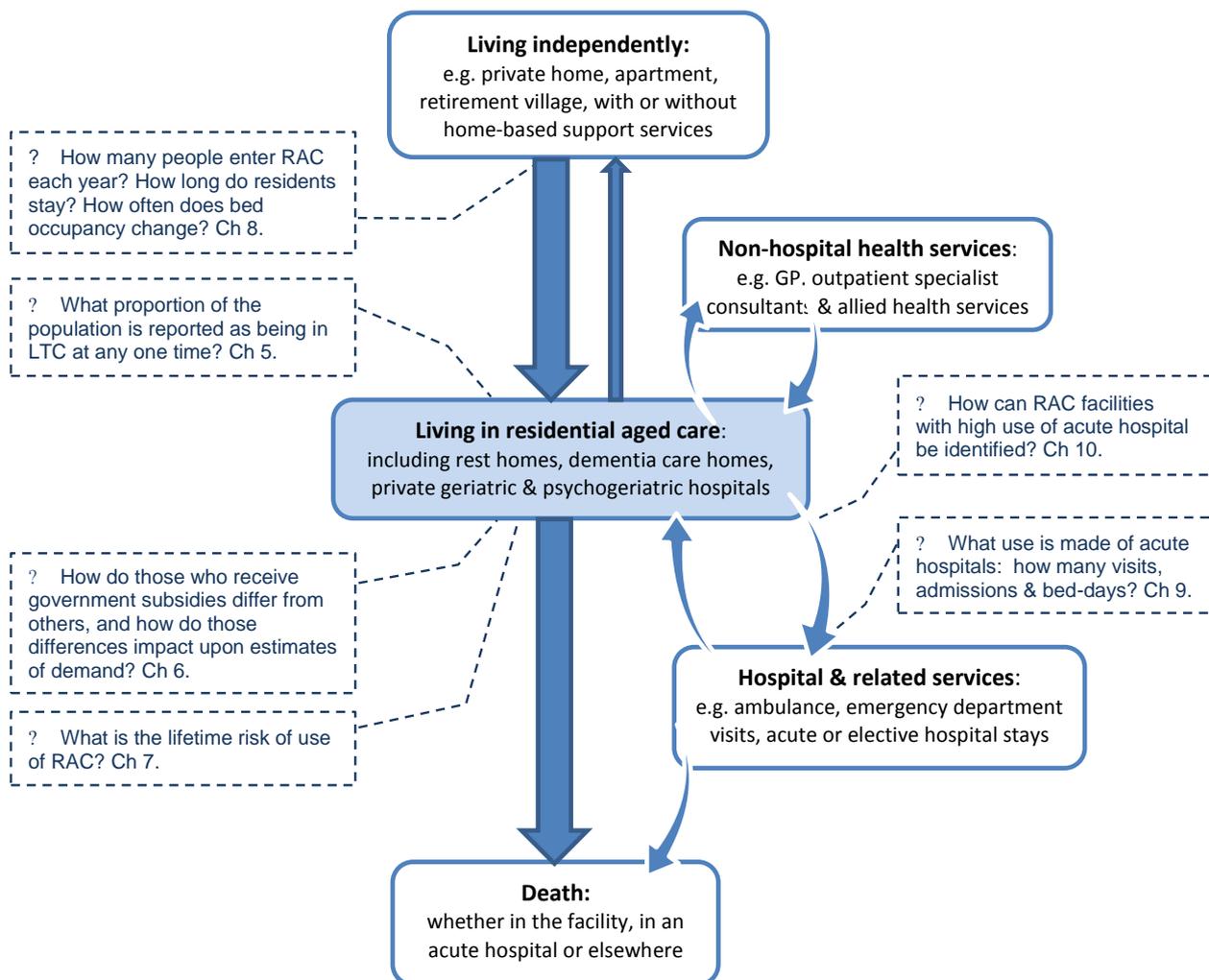


Figure 1-1. Service use by residents of long-term care facilities in New Zealand, and the information gaps this thesis addresses

Although there are routinely collected data about some service use in the RAC sector, even the most fundamental questions about service use, volumes, lengths of stay, and the proportion of older people who will use RAC, are not well answered. Information gaps that this thesis addresses are shown as research questions (dashed boxes at the sides of Figure 1-1), linked as appropriate to the resident flows by dashed lines.

RAC use in the longitudinal or incidence sense is not currently well described for NZ. A report jointly commissioned by the Ministry of Health (MoH) and providers in 2010 provided national estimates of provision and utilisation, including some projections based on population data¹². Four research studies of RAC facilities and their residents in Auckland region have described cross-sectional utilisation, including trends over time^{13 14}. None provides an accurate picture of patterns of utilisation and demand at a national level.

Further, use of non-RAC health services (including primary care, emergency departments, acute and out-patient hospital services), by RAC residents is unknown. For example in other countries it is reported that on average RAC residents use acute hospital services more often than do community-dwelling residents^{15 16}. Information about service use is not available for the population of NZ. Attempts have been made to quantify the use of acute hospital services by RAC residents in only a few regions, yet anecdotal reports of large numbers of RAC residents accessing acute hospital services are common. Furthermore, there is a prevailing belief that by improving quality of care within RAC facilities, some deteriorating conditions could be identified sooner, or others prevented by, for example, immunisation, better clinical care, more nutritious diet or improved physical design within the facility. If this is so, then interventions to educate or support facilities with high use of acute care may be promoted. These are desirable because of the risks to many RAC residents when admitted to hospital – recognised harms include skin tears, pressure ulcers, falls, under-nutrition, confusion, infections and new disability^{17 18}.

In 2011 when this course of enquiry commenced, even most basic questions could not be answered reliably. Because those questions (in *italics* below) underpin understandings of how systems work, other questions (not in italics) are also not

able to be addressed. If information were available, then it is likely that relevant planning and policy could be better informed across the aged care sector.

1. *What statistics on use of RAC have been reported in recent decades? How reliable are they?*
2. *How many people newly enter RAC facilities each year? What are the demographic characteristics of new residents? What are their care needs? Could care for some be provided more effectively and efficiently in their own homes?*
3. *What are the patterns in length of stay? Would greater use of short stays provide better respite care or rehabilitative care, and reduce demand for long-stay care? To what extent are RAC facilities being used as short-stay hospices for older people? Could (or should) those who are known to be close to the end of life be encouraged to remain at home instead, for end-of-life care?*
4. *How do care needs of unsubsidised residents differ from those of subsidised residents? What are the consequences of policies that are based on information from subsidy payments for private payers and other unsubsidised residents?*
5. *What health services do residents of RAC use? How much are acute hospital admissions and hospital bed-days used by people in RAC? How much do RAC residents receive specialist outpatient and post-discharge care? How many ambulance trips and emergency department presentations are used by the sector? If an intervention were found that reduced acute admissions, how many hospital bed days might it save, and how could those interventions best be targeted? How often do residents access dental or optometry services? How do these compare to community dwelling older people?*
6. *What is the likelihood an older person will use RAC? How does this vary by demographic group or region? Once entered, for how long are they likely to stay? Who will finance their RAC? What trends over time are anticipated?*

This thesis addresses these gaps by answering the underlying questions in *italics*. The subsequent questions (not in italics) are not covered, but the answers to the underlying questions will help address them in the future. Because purpose-specific data are unavailable, a common thread is finding relevant administrative and research data and to use them in fresh or novel ways.

1.4 Aims and Objectives

The thesis is based upon the premise that sound information will inform the reshaping of models of care, enabling funders and providers to fund or offer flexible yet effective services to people most in need, and for individuals to better plan their own care pathways. The aim is to evaluate existing quantitative reports relating to RAC utilisation in NZ, and to derive new knowledge for the purposes of informing planning, guiding policy and developing services. It reanalyses existing data using both well-established epidemiologic measures and less-used analytical methods to describe and analyse RAC utilisation in NZ for which information is currently scant or lacking, particularly those perennial questions listed above. By demonstrating reuse of existing data and analytical methods not used in this context before, it will reveal more accurate estimates, informing management, planning and policy in the sector and drawing attention to areas that most sorely need further research.

Specifically, the objectives of this thesis are:

1. to raise issues relating to reporting of RAC use in NZ;
2. to draw attention to the extent of RAC use near the end of life;
3. to estimate numbers who newly enter RAC (incidence) and their length-of-stay;
4. to describe and quantify public health service utilisation (e.g. emergency department visits) by RAC residents;
5. to develop and compare models of identifying and targeting high-use facilities (defined as those with unexplained frequent use of acute hospital admissions by RAC residents in Auckland) in which to offer services or target for randomised trials;

6. to demonstrate use of analytical methods that may be useful in other epidemiologic and health research settings; and
7. to consider how measures and quality of reports from information systems could be improved to inform future decision-making.

1.5 Thesis outline

This thesis includes original work that has been presented and published as peer-reviewed research papers under doctoral supervision. Each paper addresses one or more aspects of the objectives listed, and is presented in the thesis as a chapter. The structure is tabulated in Table 1-1.

The first four chapters of the thesis provide background to the work. Following this introductory chapter (Chapter 1), two chapters provide theoretical (Chapter 2) and contextual (Chapter 3) frameworks. Chapter 4 outlines the current reporting and monitoring data sources available. Additional details of the data and statistical methods employed and the significance of findings for planning and policy are included within each chapter.

Four chapters then measure a variety of aspects of use of RAC. Chapter 5 illustrates the variability and difficulty in cross-sectional measures, and outlines some of the reasons for that variability. Chapter 6 addresses the question of how subsidised residents differ from those not subsidised and the biases in reporting that occur as a result.

Chapter 7 estimates the proportion of the population that use RAC in NZ after the age of 65 years, and compares that to reports from other countries. Chapter 8 assesses turnover of residents and describes for the first time lengths of completed RAC stay.

Two chapters follow that describe utilisation of non-RAC public hospital services by RAC residents – acute hospitalisations (in Chapter 9) and the complexity in selecting or targeting facilities with high use of acute hospitalisations (in Chapter 10).

Finally, the findings are reviewed and discussed in Chapter 11. An Appendix contains details the ethics approvals for the various research studies and additional components to make the work possible.

Table 1-1 Chapter outline

-
1. **Introduction:** residential care in New Zealand, population ageing, policy adaptations and sectoral changes, quantifying service use. Thesis aims, research questions and structure.

 2. **Theoretical frameworks:** introduce theoretical models used to describe policy-development and implementing social change, and consider individual responsibility in managing health-related conditions.

 3. **Contextual frameworks:** population ageing and related social change, regulatory and other systems of care provision; funding; sectoral changes and policy adaptations.

 4. **Reporting and monitoring:** importance of health statistics, with a brief overview of available data sources and analytical methods used in the thesis.

 5. **Cross-sectional rates in RAC in NZ 1998-2008:** the variability between Auckland survey data, NZ census data and other national sources over 20 years.

 6. **Bias in population estimates:** the implications of using subsidy data to estimate total use, with a comparison of subsidised versus non-subsidised residents, and considering the impact for policy and planning purposes.

 7. **Likelihood of use of RAC:** based on counts of RAC residents who die in acute hospitals, what proportion of older people in NZ use RAC for late-life care, and how does that compare internationally?

 8. **Transitions and length of completed stay:** using reweighted statistical models of cross-sectional data to estimate transitions into and out of RAC, length of stay etc.

 9. **Hospital service use from RAC:** ED presentations and admissions per 100 occupied RAC beds per year, bed-days, main diagnoses.

 10. **Selecting facilities with high acute hospitalisations:** methods of identifying facilities with high use of acute hospital beds, and predicting hospitalisation rates using facility-level information.

 11. **Discussion:** impact and use of current data, modifications to data collection, changes coming with reporting and monitoring, impact of findings.
-

Chapter 2. Theoretical frameworks

Preamble

This thesis is founded on the premise that sound information is central to health policy and planning and for individual decision-making. Such information includes monitoring trends and making projections, identifying groups with high or low participation or utilisation, and anticipating the potential impact of changes to funding criteria. With sound information, there is greater power. Without sound information, rational allocation of resources is unlikely to be optimal. This chapter explores the theoretical foundations of such a viewpoint.

2.1 Information informs policy

Modern technologies accumulate vast amounts of data. It is unwise, however, to expect that appropriate analyses will transform all these data into information, or that they will be melded with other information to form knowledge, and made available and accessible for use in decision-making. There are many obstacles to this process. Indeed, perceived information gaps can be seen as an “escape hatch” for public decision-makers. But the converse is likely to apply, i.e. that reliable information, or best unbiased estimates, are more likely to lead to good decisions than are decisions made in the absence of information or with wrong information.

Information relevant to RAC can be useful at all levels of policy and decision-making, from national government or organisations, at regional and at local levels, and also for decision-making by businesses and individuals. Politicians may wish to encourage the markets to self-determine provision and prices. Government officials may be interested in effectively supporting frail older people by providing affordable, acceptable but not over-generous subsidies to residents. District Health Boards (DHBs, which own and operate public hospitals in NZ and which also fund, certify and audit RAC facilities) may aim to avoid costs of acute care by delivering preventive supports in RAC facilities. Large RAC chain operators may want to determine where there is need for their next new facility. A sole-operator of a RAC facility may be considering whether to alter the focus of the care they provide. A couple planning retirement may wish to ensure any future care they may need is provided for so as not to consider they will be a burden on

their families. Each decision requires one or more estimates or projections – of volumes, duration or likelihood for example – to be available.

In attempting to inform decisions such as these, this thesis will demonstrate that sound information can be obtained that is valuable for policy decision-making and for individuals and commercial enterprises wishing to act with good understanding of risks and opportunities. Various theoretical frameworks are presented. Together, the frameworks form a fresh approach to drawing together new information from available sources. Although sound information may provide relevant evidence for policy, commercial and individual decisions, there is no one ‘ideal’ theory of policy analysis that covers all these aspects. Expecting a single policy framework to apply across this complex sector is unrealistic. Here, three selected theories of policy development are employed. The first describes policy reform and how it occurs. The second describes a more general approach to evidence-informed policy. The third covers individual responsibility for health.

2.1.1 Health policy triangle

The first of the three theoretical frameworks promoted for use for policy making in the health sector is from Walt and Gilson in 1994¹⁹. Their “health policy triangle” sought to place emphasis not only on policy *content*, but to draw attention to the *process* of changing policy and the *context* in which policy is developed, each influenced by the *actors* involved (Figure 2-1).

Public policies are required that pull together these various aspects in order to enable efficient and sustainable provision of RAC for NZ’s ageing population in a changing social setting. Walt and Gilson’s triangle demonstrates highly simplified model for health policy analysis, with four main aspects: *content*, *actors*, *context* and *process*.

Content

Walt and Gilson contended that much health policy wrongly focuses attention on the content of reform, i.e. how to improve access or coverage, how to increase efficiency, or what structural or systems adjustments should be made¹⁹. They argued that this diverts attention to the context of health reform, the actors and process which may in the end prove to be why a policy outcome fails to emerge. The triangle is designed to ensure attention is given to all four aspects.

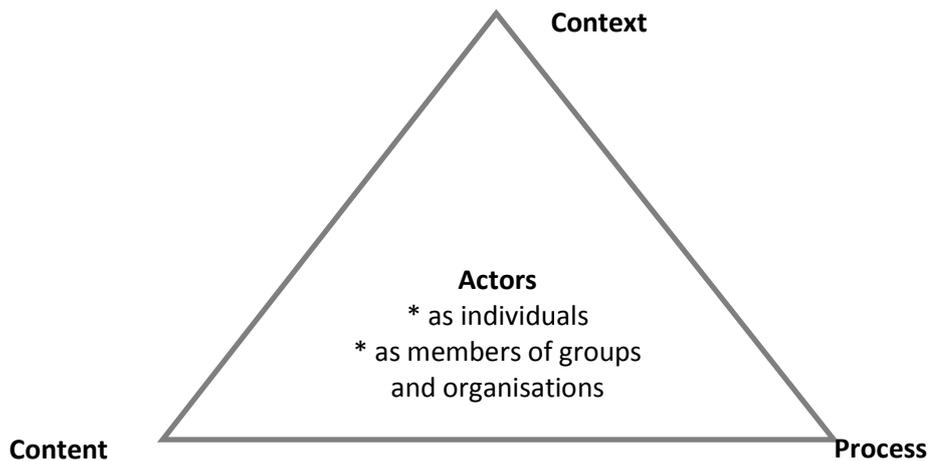


Figure 2-1. Walt and Gilson’s Policy analysis triangle

Source: Walt and Gilson, 1994¹⁹

Actors

By “actors” Walt and Gilson referred to the individuals, groups and organisations that influence or are impacted by policies. In the health sector, that includes those who wield most power, such as politicians and their advisors, chief executive officers (CEOs), senior health professionals, commercial and charitable service providers, labour unions, health activists and the media²⁰. Exercise of power may be evident not only by the obvious or overt making of decisions, but also by the non-making of decisions (by negligence or deliberate manipulation of the policy agenda), or by what they term *thought control*. This is a more insidious and subtle shaping of meanings and perceptions through controlling information, or influencing power-brokers, such as sponsoring those who are influential to attend festivities or sporting events. The different actors naturally behave, and expect others to behave, according to their own preferred approach.

Context

The context in which a health policy sits covers an extensive range of societal, health, social, industry and population characteristics and trends. More details of these in the NZ context are described in Chapter 3. For RAC, context incorporates policies relating directly to needs assessments, service provision, funding decisions and quality of care, but also, less directly, to acute hospital services, housing options, retirement income and human rights. Aspects of preventative, restorative and palliative options of health care must be considered. Socio-

demographic trends and time-period are contextual too – short-term gains arguably may need to be offset to achieve long-term benefits, for example current generations may need to make sacrifices to ensure provision for future generations. Knowledge is contextual in time and location, thus may be limited in its transferability.

Process

Having an understanding of these aspects that are at play, there is a theory that draws them together, the process of policy-making. Sabatier and Jenkins-Smith described the process in four stages²¹:

- problem identification and issue recognition - how issues are put on, or kept off, the policy agenda
- policy formulation – who is involved, how policies are determined, agreed upon and communicated
- policy implementation – whether policy is implemented, and how
- policy evaluation – once a new or altered policy is in place, whether and how it is monitored, what unintended consequences arise, and the extent to which its objectives are achieved.

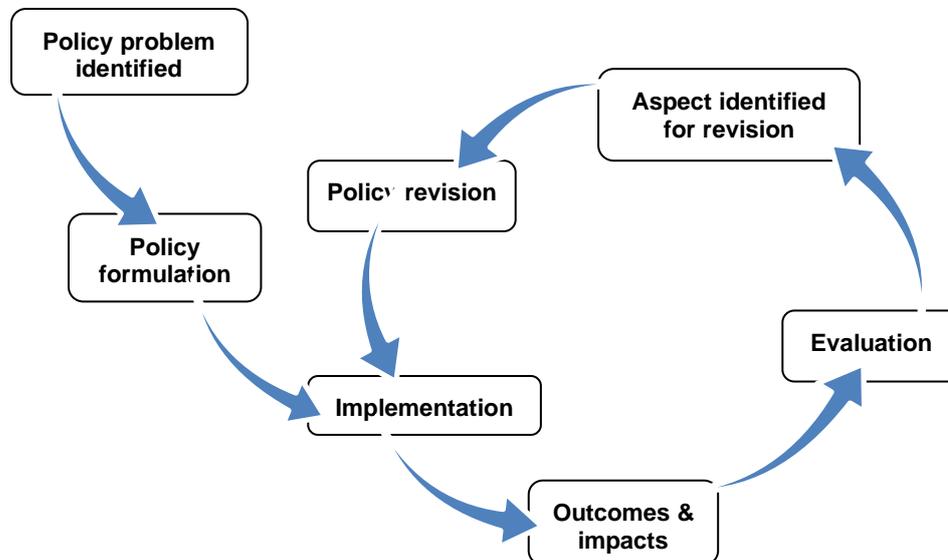
Although these steps were seen by Sabatier and Jenkins-Smith as linear, the policy-making process may be better viewed as part of a continuous cycle, in which evaluation leads routinely and systematically back into policy formulation or revision – as an ongoing quality improvement cycle – in an iterative fashion (Figure 2-2)^{22 23}.

From a rational perspective, it is reasonable to seek relevant information and use it to inform each of these stages. If information identifies an issue as important and inadequately addressed, then a policy advisor may bring it to the attention of policy-makers; if it is of small significance it may be overlooked or demoted. Information should indicate the size of a problem, in volumes, costs or numbers impacted, and so guide which of several competing problems demand greater priority. For example, it may indicate where geographically a problem is biggest and needs most urgent attention. It may reveal crucial interrelationships between various actors/players, or inform how demand or delivery may change according

to circumstances. Monitoring outcomes of a policy will yield some information about how effective the implementation has been, and whether further policy changes are required. At each stage, reliable information informs policy.

Figure 2-2. Schematic process of policy development

Source: Adapted from Sabatier and Jenkins-Smith, 1993²¹



Under the Sabatier and Jenkins-Smith model, each ‘actor’ must have an accurate perception of their ‘real’ interests and wants and be able to articulate them, and also have an understanding of the causal relationships involved, i.e. what changes are necessary to address those wants. Some actors are out of touch with each other and voiceless, some are acting as unpaid volunteers for non-governmental or charitable organisations, others are market-driven, with their interests centred on profit, and yet others are elected or salaried government officials. There is little opportunity for ‘round-the-table’ discussions or for sharing perspectives of what changes are needed and why. In the RAC system, the wishes and vested interests of some are much more readily obtained than those of others. Access to information too is hugely variable.

2.1.2 Aspects of policy development

The second theoretical framework finds patterns in how these aspects of policy development are drawn together, making it simpler to compare systems, their strengths and weaknesses. Each pattern implies different emphasis on the roles played by various actors, and also of evidence.

Though many such patterns have been described, Tenbenschel and Gauld identify four patterns most commonly encountered²⁴.

- 1) The *stakeholder approach to policy development* recognises that the exercise of power is inevitable, so focuses on understanding the interactions between actors through facilitating dialogue. Self-interests may be detrimental to the policy-making process in that not all actors' needs may be considered. Sound information may or may not be sought, or used even where it exists.
- 2) The *neo-liberal* policy approach is market-led, providing consumers with choice and therefore power, with government-provided incentives and reduced government provision of services; competition can lead to reduced cooperation between providers as the aim is for economic freedom and performance. Information may not be shared as information is recognised as being the source of power. Under this approach, however, less evidence is sought centrally as less planning is undertaken – there is in general a less coordinated approach to service development and delivery. Inequities in access or uptake of services is likely.
- 3) A *participatory* policy process develops within a democratic society, with broad public consultations and less involvement of individual stakeholders. Such democratic processes are extremely difficult and resource-intensive to achieve – those without knowledge or expertise are often less able to contribute, and instead those who are vocal or can assemble support, for whatever interests, are likely to lead decisions. If those participating in the democratic process have information (reliable or otherwise), then that may be presented and used in debates.
- 4) The *rationalist model* is characterised by an orderly, shaped response to problem identification. This model requires value-neutral analysis using expert knowledge and information, and if well-reasoned makes possible informed decisions of current strengths, risks, opportunities and threats. It may be vulnerable to

influence by power-holders especially if information is limited or weak, or not widely accessible.

Under a *stakeholder model*, some voices or perspectives may be overlooked. There are many who are likely the most influenced by policy decisions but who hold little power. In the long-term care sector that includes perhaps vulnerable elders, caregivers, their families and residents – residents are for the most part invisible and voiceless, living within the facility, out of the public eye both in everyday life and even in population estimates such as are derived from surveys and opinion polls^{25 26}. Voices of families are heard mainly through the media or occasionally through an official such as a Health Commissioner, there being little opportunity for a gathering of energy and impetus to give them voice. For example, registered nurses working in RAC in NZ have spoken of their struggle to deliver the appropriate quality of care to residents as needs increase, GP availability decreases and the opportunities for increasing their own knowledge and competence remain limited²⁷. Paid RAC caregivers too are relatively powerless – with low levels of education, high turnover, low wages, often new migrants, with few being members of labour unions and many not native speakers of English²⁸⁻³⁰. Although they may observe much and directly experience the impact of policy changes (or lack thereof) their voices are seldom heard.

Under a *neo-liberal model*, such as emerged during the mid-1980s when NZ changed from a rather closed and centrally controlled economy to one of the most open economies in the Organisation for Economic Cooperation and Development (OECD), the market was encouraged, new RAC facilities were built, residents were moved from public beds to private facilities, and long-stay hospital beds were closed down. Failure of some facilities put the industry under scrutiny. A Prime Ministerial Task Force was established to explore the options and priorities recognising the impact of future population ageing³¹. The Task Force undertook wide consultation – in an example of a *participatory model* – with written and face-to-face meetings throughout the country. In moving towards a more ethical and rational approach with high value placed on consultation^{31 32}, it drew attention to a lack of information about health needs of older people. For a time this fostered a focus on older people in the MoH and communication between professional and community organisations improved^{31 32}.

It is under a *rationalist approach*, though, that information is most crucial. Important issues are more readily identified where appropriate reliable information is produced and widely accessible. If information is reliable and used fairly, the rationalist approach is arguably more likely to lead to fair outcomes for older people and the population as a whole. More informed choices are possible if information is accessible to all involved: to central government policy-makers, to operators and owners of RAC facilities with primary interest in the balance sheet bottom line, to health and applied health professionals who seek greater resourcing of their specialty, to groups who feel disadvantaged by proposed policies and wish to be heard, and to individuals or organisations wishing to understand their personal, commercial or operational risks.

No single approach can, or should, prevail. Most systems comprise an element of each approach, and political pressures are inevitable. In all, greater transparency in the form of better and more accessible information can improve understanding; better information, if readily available, can improve decision-making.

2.1.3 Individual responsibility

The third theoretical framework relates to individuals being able and informed to take responsibility for decisions about their own care – in the present or future. One of the central tensions of a national health system is that between collective and individual responsibility. In traditional societies, ageing is a collective responsibility, each family or community taking care of their own. The shift in Western societies from a collective or welfare model to more individual responsibility has been a matter of considerable public debate and the subject of scholarly attention³³. In setting national policies, greater individual responsibility is encouraged for economic security in later life³⁴. For example, in NZ the Commission for Financial Literacy and Retirement Income (formerly the Retirement Commission) was established to encourage savings and investments for retirement, and the KiwiSaver scheme was promoted (or seen to have been) to help people be responsible for saving for their own retirement income and reduce the need for the state to provide. But policies that encourage privatisation are known to heighten inequalities in old age³³. The ability and willingness of individuals to gather and interpret information, to understand risk and to

appreciate how risk may be managed is not the same. Although investment schemes provide advice and support, one risk is the scheme may lead to greater inequities in living conditions and access to support services.

Little is understood about how individuals start to plan or what factors they consider when making their choices about savings and living options in older age. Do individuals focus on the good life that they desire as they age, or do they also consider the likely need for care and support in the future? Do they speak to their families about their preferences for care should they become dependent? Evidence of this may be recorded in advance care planning, advance directives and powers of attorney. Regardless, if an individual does not have access to information that informs them of their likely risk, for example of entering RAC, then there may be less motivation to take personal responsibility.

2.2 Moving from theory to policy to implementation

In moving from the theory of how information is used and how health policies and decisions are made, to actual implementation, no one theoretical model is adequate to fully explain the relationship between evidence and policy – the field is broad and complex. Decisions will necessarily be made, and on an ongoing basis, impacting on the health of older people individually and population-wide, now and in the future. How that occurs for RAC, with a wide array of organisations, motivations and players, is variable.

Policy adaptations and sectoral changes in different settings – whether driven by politicians, market leaders, clinicians, a vocal group of activists, or other stakeholders – are inevitably impacted by a range of forces and principles. Speed and direction of change vary markedly according to the influence of various players, the stability or entrenchment of existing systems, and the resources and drivers of change. Whether occurring under a predominantly ethical or rational model or not, how those forces and principles are handled and processed is influenced by the reliability and appropriateness of available information. If the direction or speed of change does not fit with the evidence, one or more other actors in the change process can more clearly to make the case to alter course.

In an effort to help researchers and policy-makers bridge the gap between evidence and implementation in the public health sector, Bowen proposed an

“evidence-informed policy and practice pathway”, shown in Figure 2-3³⁵. She describes the steps in which evidence and information is gathered and used, and the circumstances under which it is not used.

Bowen’s view was that:

A key challenge to public health is to better contextualize evidence for more effective policymaking and practice. Theory on the translation of research findings into policy and practice, and on knowledge utilization, offers only part of the solution to this complex task. The policymaking context is highly political and rapidly changing, and depends on a variety of factors, inputs, and relationships³⁵.

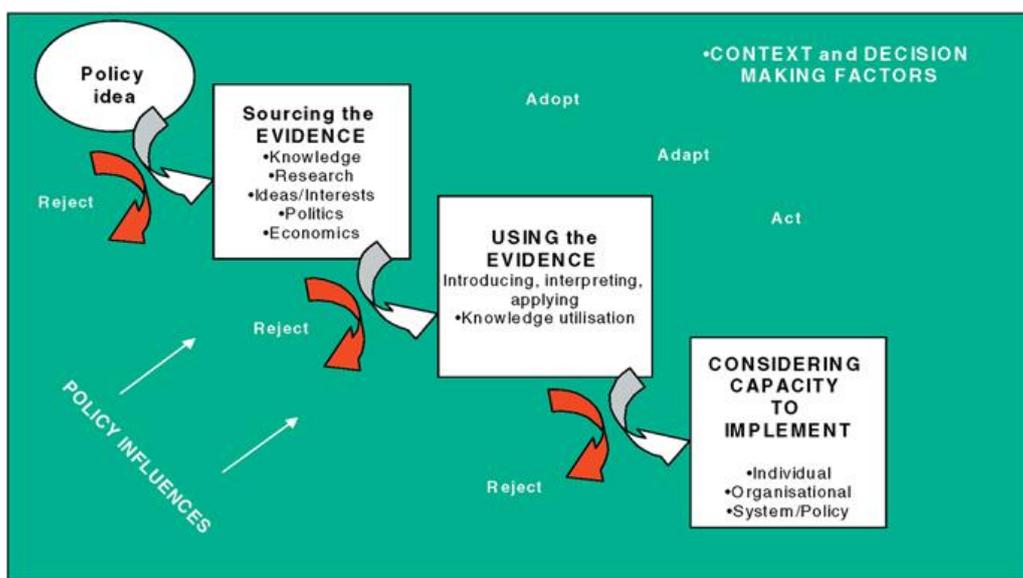


Figure 2-3. An evidence-informed policy and practice pathway

Source: Bowen et al. 2005³⁵.

Under Bowen’s pathway, three main steps occur: 1) sourcing, 2) using and 3) implementing evidence-informed policy. She discusses how evidence might inform not only a policy decision itself, but also how it is implemented and whether there is capacity within the organisation or policy setting.

In another framework from a WHO-led collaboration, Moat and Lavis acknowledged that that information is often overlooked³⁶. Three types of evidence were identified: social science-orientated research (context-sensitive scientific evidence); medically-orientated effectiveness research (context-free scientific evidence); and the expertise, views and realities of stakeholders (colloquial evidence). In their view, each has a role to play in informing policy.

In spite of this acknowledgment of the usefulness of, if not dependence upon, information, many facts about RAC service use in NZ remain unknown. Even those which could be regarded as the most fundamental – of volumes, lengths of stay or the proportion of older people who use RAC during their lifetimes, the trends in them and the factors that influence them – are not readily available.

*The public good is undoubtedly advanced by knowledge-informed policy formation, evaluation and implementation. The challenge is how to do better in two related domains: the generation and application of knowledge to inform policy making, and the use of scientific approaches to the monitoring and evaluation of policy initiatives.
... addressing this issue of the relationship between science and knowledge on one hand, and policy formation and implementation on the other, [is] one of critical importance in this increasingly complex and interconnected world.*

Gluckman 2011³⁷

From both demand (increasing numbers of older people, changing care preferences) and supply (tax-payers, care-givers, facilities, models of care) perspectives, population ageing and apparently unstoppable increasing longevity compels a continual rethink about how LTC services are funded and provided. Optimal policies will strive to improve well-being for our older population, ensuring adequate and appropriate high quality accommodation and supports are available to those in need, avoiding excessive costs to taxpayers and private payers of present and future generations. The interests of all stakeholders must be considered. Policies which favour the interests of taxpayers, investors or operators above those in care may fail to meet the care needs of residents and caregivers. Policies which favour the care needs of residents may put impossible demands on taxpayers and providers. Given limitations in public funding, politicians and their advisors have a major role in balancing the needs of present and future generations. They can do that well only if impartial and fair estimates of utilisation and demand are available and if care pathways and systems are well understood. Society is reliant upon information systems that gather and process data and convert them to useful knowledge, in order to improve public policy advice.

Chapter 3. Contextual frameworks

Preamble

In this chapter some of the population, demographic, health systems, organisational, legal and regulatory aspects of RAC are outlined in order to contextualise subsequent chapters and discussion. In summarising the provision of RAC services, it outlines how RAC services are organised in NZ and locates RAC in population, societal and historic settings.

3.1 The reality of demographic change

3.1.1 Population ageing

Terminology

In its popular sense, *ageing* is a term used to refer to biological changes in an individual that occur over time – changes that are associated with gradual functional decline and increasing risk of death in the near future. It is essentially the simple observation that older members of a population are more likely to become sick, to need help for daily living, and to die, than younger members. The proportion with multi-morbidity is associated with age, such that at about the age of 20 years, 80% of people have no chronic health condition, by age 50 years, half have at least one, and by about 80 years, 15% have six or more co-morbid conditions and fewer than 10% have none³⁸. In the nationally-representative 2012/13 NZ Health Survey, respondents were asked about eight specific chronic conditions; the number reported increased with age group (Figure 3-1)³⁹.

Population ageing however is not this age-related decline in individuals, but is a shift in the age distribution of a whole population towards older age. As societies transition from pre-industrial economies to more highly developed structures, changes are experienced such that population structures age, a change known as the *demographic transition*. These increases in the proportion who are old are due mainly to the combined effects of two features of the last century: increased longevity and a drop in fertility since contraceptive use became common^{1 40 41}. During the early twentieth century, longevity increased primarily as a result of reduced mortality in younger people because of better control of infectious diseases early in life. In more recent decades, gains made have been mostly at

older ages, in improved primary and secondary prevention of chronic conditions and better medical treatments⁴².

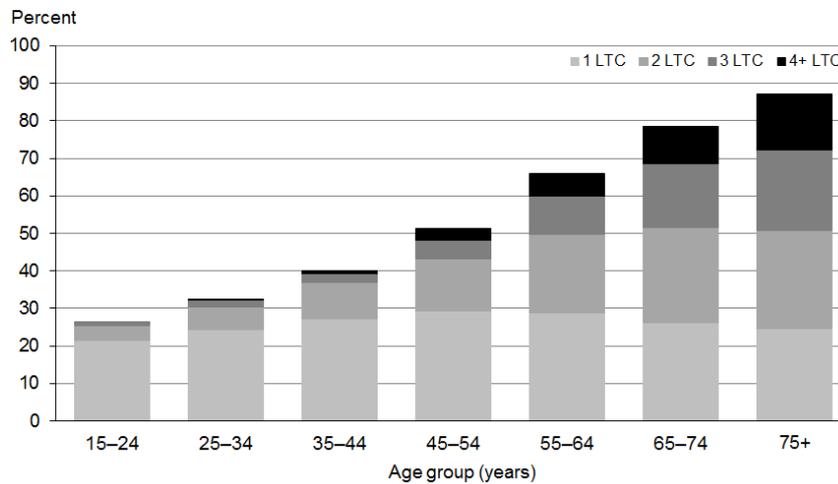


Figure 3-1. Adults with one or more long-term condition, NZ, by age group, 2012/13

LTC= long-term condition (here). Eight LTCs were included: ischaemic heart disease (angina, heart attack), stroke, high blood pressure (medicated), diabetes, asthma (medicated), arthritis, mental disorders (depression, anxiety and bipolar disorder) and chronic pain.

Source: MoH Health and Independence Report 2014³⁹

Population ageing

Massive shifts are occurring in population structures. The global trend in increasing life expectancy has been increasing for almost 200 years, and shows no sign of slowing^{1 2 43}. Population ageing is widespread across the world, becoming evident in several measures: an increase in the population's median age, increased longevity, and a rise in the proportion of the population that is elderly, however defined. While living longer is regarded as a huge success story for public health and medical care, remarkable increases in numbers of older people in conjunction with relatively fewer younger people to support them or to finance their care will challenge all but the youngest societies within 50 years. The projected growth in frail older people greatly outweighs the growth in potential family caregivers¹¹.

Few countries are exempt from the effects. Globally, the share of older persons aged 80 years or over (the “oldest old”) was 1.7% in 2013 and increasing at 2.0% a year⁴³. For the OECD, the proportion aged 80+ years is expected to increase from 4% in 2010 to 9.4% in 2050¹¹.

The costs of population ageing to the health system in NZ were modelled by Bryant et al., suggesting significant changes in the spread of spending through the population⁴⁴. The share used by those aged 65+ rose from about 29% of total government health expenditure in 1951 to about 40% in 2004, and was forecast to rise further to 63% in 2051.

Of particular relevance to RAC is the population proportion aged 85+ years. In most countries, NZ included, that ‘oldest old’ group has the greatest use of RAC. Demographic projections indicate that numbers aged 85+ will more than double within 20 years, from 78,000 in 2014 to 173,000 by 2033, then double again by 2053⁶. The proportion aged 85+ will double within 25 years, to 6% by 2053.

The pyramid charts in Figure 3-2 illustrate the dramatic changes to the population structure in NZ. From a classic wide-based “pyramid” shape of a youthful, growing population in 1951, to the rectangular shape projected for a population that has ceased to grow by 2051, the transition to an ageing population is relatively easily predicted and has been anticipated for some time.

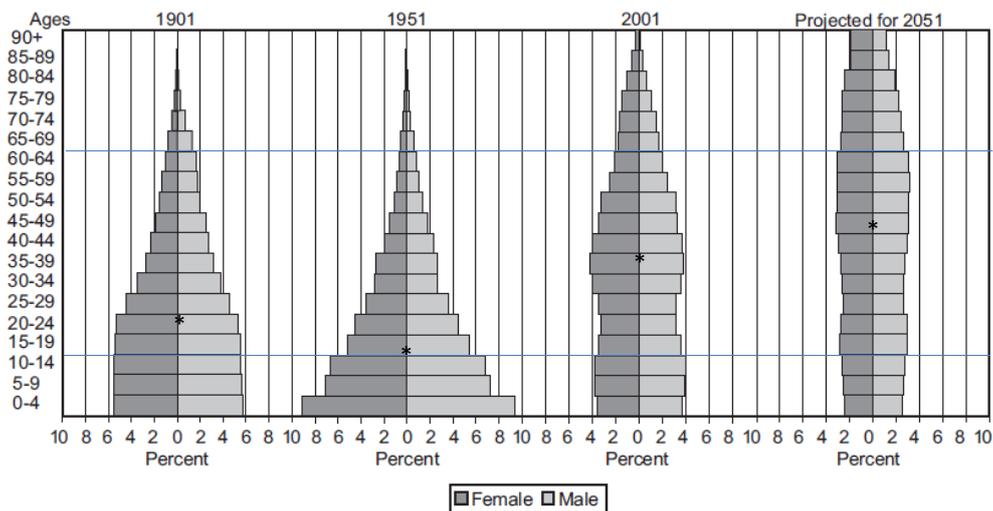


Figure 3-2. New Zealand population by age and sex: 1901, 1951, 2001 and projections for 2051

Asterisks mark median ages

Horizontal lines at ages 15 and 65 mark traditional “working age” limits

Source: Adapted from Statistics New Zealand

It is easy to comprehend that in the 1950s, policy attention was most needed for maternity services, education and housing of families, and that now, in the 2010s, more attention is needed on providing for the health and accommodation needs of

older people. Other societal impacts are less easily understood; adaptive responses from the economic and health service sectors will emerge more slowly.

Speed of demographic change

Speed of increase in ageing is typically measured by the years a population takes for the proportion aged 65+ to rise from 7% to 14%. NZ reached 14% in 2013, 74 years after 7% was reached. In France this interval was long, at 115 years; somewhat shorter were other established economies, Sweden 85 years, the United Kingdom (UK) 45 years and Japan 26 years⁴⁵. Singapore and South Korea are both projected to make that step from 7% to 14% within just 25 years⁴⁶ – a staggering rate of change that will create even greater challenges than long-established market economies have had to face.

Another indicator of the speed of demographic change is to monitor death counts and age at death. Figure 3-3 illustrates that annual death counts in NZ were relatively stable for the 25 years between 1985 and 2010, but will increase

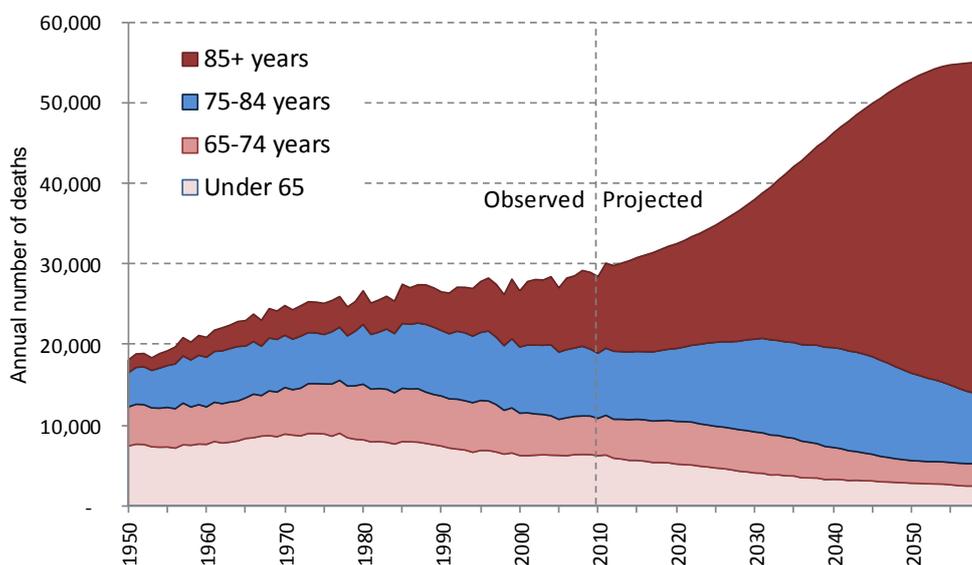


Figure 3-3. New Zealand deaths by age group: 1950 to 2011, and projected 2012 to 2060

Source: Data provided by Statistics New Zealand. This work uses customised Statistics New Zealand data which are licensed for re-use under the Creative Commons Attribution 3.0 New Zealand licence.

quickly after 2012. While deaths are decreasing in younger people, within the coming 25 years total death numbers are projected to increase by 40%, and to double in those aged 85+ at death. It seems reasonable to anticipate that, if current usage patterns continue, demand for health services at the end of life, including

RAC, will grow similarly. Obviously, should patterns change and average health either worsens or improves on those current, demand projections will be awry.

Healthcare implications

Population ageing poses challenges to governments, health service providers and individuals around the globe. Provision of care for older people with several co-existing chronic or progressive degenerative diseases, but for whom death is not imminent, is one of those challenges⁴⁷. Mangin et al., showed that people with multiple comorbidities require both supports for daily living and complex health management to optimise well-being⁴⁸. Existing care services are already inadequate for these people, with little coherence in long-term medical care. While legislation and other health promotion campaigns in NZ have reduced tobacco smoking with clear health benefits in terms of cardiovascular disease, stroke and chronic obstructive pulmonary disease (COPD), efforts to encourage healthy eating and physical activity have shown little benefit, if any, in reducing the impact of population ageing. Anticipated improvements in health and function later in life due to lifestyle changes (e.g. smoking cessation) and preventive health practices (e.g. immunisations, bone health supplements) are not yet clearly demonstrated, and even if they occur may be countered by ever-growing levels of obesity and diabetes.

New person-centred approaches could reduce futile or expensive treatments while promoting well-being. Mangin et al. concluded that there

...is a pressing need to reverse the current trend towards management of individual diseases in silos so that care of patients with chronic comorbid illness is much more closely driven by their particular symptoms, needs, and treatment effects and their own priorities for care.

Mangin et al. 2012⁴⁸

Population ageing also poses challenges to health and medical education. The medicine that is typically taught in medical schools, and practiced in both primary and secondary care, focuses on managing individual diseases. While this is appropriate during early training, it is important that treatment and management plans consider interacting and co-existing conditions. Revising the current model to one in which the care of patients with chronic comorbid illness and/or frailty is more closely driven by their particular symptoms, needs and priorities, as well as

likely effect of treatments, is quite a departure from that model. If such a revolution were to occur, it will be necessary to develop alternative models of care and support for people with long-term conditions, including those currently cared for in RAC settings. For example, where expensive services exist but demand will likely outstrip supply, innovative models of meeting demand may be preferable to supplying and funding more of the same. RAC may be one such service.

Social trends

Social trends are occurring in conjunction with population ageing – in NZ and elsewhere – that could directly impact on future demand for RAC. These include an increasing trend to live alone and reducing rates of private home ownership¹⁰. Both have been well-recognised risk factors for admissions into a residential care facility^{7 8}.

Reducing availability of informal (unpaid) caregivers is also expected to increase demand for RAC¹¹. Smaller family sizes than in past generations, and indeed the increase in people having no children, will reduce availability of informal carers¹¹. Where an older person's adult children remain in work longer, or move far from the older parent, the chances reduce that they are available to provide intensive support. Regional and local variations exist however. For example, internal migration in NZ, particularly of younger people to Auckland and of older people away from Auckland, has already exacerbated the trend towards ageing for many regional populations⁴⁹. A further aspect that may impact availability of caregivers is the growing participation of older people in the workforce (already higher in NZ than in most OECD countries, especially women)⁵⁰.

If these trends are not anticipated and planned for in a timely fashion, growing needs may shift demand to the more expensive acute care sector, and increase total health care needs⁵¹. Planning is necessary in order to manage system delays such as in building new facilities, initiating and trialling alternative models of care, increasing workforce recruitment and development, expanding licensing and auditing processes, and addressing issues of cross-generational funding.

3.2 Residential aged care (RAC) in New Zealand

For any person, the need for long term RAC is usually the result of a combination of circumstances. These include deteriorating health, increasing disability, unavailability of family care or appropriate community resources such as meals on wheels, and home help; or the inability of the person to cope despite home-based services provided⁵². In NZ, when the person can no longer live independently, they may receive LTC support services. Provision may be in their own home informally by family and friends, or formally by paid caregivers. Home-based assistance may include personal care (for example showering and dressing), help with mobility (for example shopping or getting to appointments), and/or with household management (for example cleaning floors, laundry) and maintenance (for example window cleaning, changing light bulbs). If government funding is sought for these services, then a needs assessment (but not usually a means assessment) is required.

For those assessed as having around-the-clock needs, a move to RAC may be necessary. Certified RAC facilities provide accommodation, full meal service, housekeeping, assistance with activities of daily living (ADLs), together with nursing care as needed. Some enter intending only to stay temporarily, for example for rehabilitation, convalescence or to give family carers a holiday, a so-called “respite care” stay. For most that enter, however, there is usually no expectation of being discharged back into a life in the community. Care is offered either in a “rest-home” (for low-level, social or supportive living, or for secure dementia care), or in a continuing care “private hospital” (for 24-hour geriatric nursing care, or for psychogeriatric care).

3.2.1 Evolution of RAC

It is widely accepted, indeed expected, that nations should, in principle and within available resources, develop health and disability support services in ways that are designed and equipped to respond to complex and changing needs of their populations. Care of older and disabled people is a fundamental part of that population approach and has adapted as society has changed. During and prior to the 18th century, people without support were provided for by parishes, a result of litigation by Henry VII after he dissolved monasteries that had previously

provided such care in much of Europe. From the early 19th century social welfare-type institutions known in England as poorhouses or alms-houses gradually became responsible for destitute and disabled people, including older people^{53 54}. Many were supported by charitable (not-for-profit) societies. In the late 19th century, the Poor Law hospitals catered for the ageing pauper⁵⁵. But much earlier care has been described, for example those from the fourth century AD in Byzantine Constantinople that were based not only on long-held respect for the aged, but also religious concepts of ethical and social conduct⁵⁶.

By early in the 20th century, provision of institutional care for old and infirm people in NZ was a mix of social and supported care in home-type environments, with beds provided for long-term or permanent stays in public acute hospitals^{13 57}. Since these public beds were closed in the early 1990s, RAC services have increasingly been provided in purpose-built privately-owned facilities, either commercial or charitable. Ownership and service provision now largely sits as an industry within the health sector, with licensing and auditing but much less control exerted by the government. Funding too has moved, from charitable societies to a mix of social welfare, private and not-for-profit funding. There is now considerable input from government health budgets through subsidy payments for those eligible.

3.2.2 Funding of RAC

Subsidy criteria

People resident in NZ are eligible for government financial assistance for the costs of RAC if they meet certain conditions involving both a needs assessment and a financial means assessment. Each of the following conditions must be met:

- a needs assessment must show an ongoing need for 24-hour residential care in a rest-home or hospital indefinitely
- the person must be aged 65 or older, or aged 50-64 years and single with no dependent children
- financial eligibility criteria must be met, as ascertained in a means assessment of both assets and income

- care must be provided by a facility that is certified by the MoH under the Health and Disability Service (Safety) Act 2001⁵⁸ and that has a current contract with a DHB.

Additionally, residents who demonstrate a need for 24-hour care but who are ineligible for subsidy are entitled to a “top-up” payment to the extent that the weekly costs of their basic care exceed a defined maximum personal contribution, up to a limit determined by the agreed rate for care at that level within their geographic region. Services regarded as not covered by the service contract may be charged a separately premium fee (see 3.3.5), for example for the costs of a larger room, a private bathroom, or a daily newspaper.

Residents with proven need who are assessed as not passing the asset test and thus are ineligible for a subsidy, may, if they have real estate or other assets, elect to participate in home equity release schemes, effectively taking a loan against property, to be repaid on sale of the property or on death. The long-term financial impact of the scheme is not clear, but in 2014 about \$12 million was owed to the government by those who have taken this equity release option. Interest-free loans are also available to assist people in residential long term care, with a further \$3 million owed to the government under this option⁵⁹.

Finally, those who need 24-hour care but can remain at home with support from family carers may receive funding assistance for short-term respite care in a RAC facility. This may be used for example when carers take a holiday or require a hospital stay themselves, and is one of the few patterns of RAC stay that is not regarded as long-term.

Public spending on RAC

In terms of public expenditure for RAC, the MoH reported that during the 2007/08 financial year, 27,300 different people received a residential care subsidy for some period. In 2008, their RAC costs amounted to \$1,054 million, 0.75% of GDP^{60 61}. In that year, costs of RAC care were on average \$35,600 per year for a bed in rest-home care, \$45,000 for dementia care, \$60,500 for hospital care and \$66,000 for psychogeriatric care. It is estimated that 35% of these costs were borne by personal contributions though this varied by level of care, ranging from 27% of those in psychogeriatric care to 47% in dementia care⁶². In 2008, 46% of

bed-days occupied by those on subsidies were for rest-home care, 35% for hospital care, 17% for secure dementia care and 2% for psychogeriatric care⁶².

At any one time, considerable variation occurs between DHB-defined geographic regions, such that between 20% and 40% of residents do not receive a subsidy. It is not known what the differences are, if any, between the care needs or the lengths of stay of subsidised and unsubsidised residents.

3.2.3 Utilisation of RAC

A non-trivial proportion of NZ's older population live in RAC, but while it is widely accepted that proportion is 5-6% at any one time, similar to many westernised countries, no source provides reliable data.

NZ census data from 2006 showed that 4.1% of people aged 65+ years or over (the age cut-off typically used to define "older people" in NZ and many other westernised societies) lived in RAC. The proportion increased with age, starting from about 1.1% of those aged 65-74 years then roughly doubled with each 5-year increase in age, so that 5.6% of those aged 75-84 years, and 25.4% of people aged 85+ years were reported as living in residential care⁶³. In general, in each age group the proportions for women were about 30% higher than for men. But censuses misreport both census-night counts and usual-resident counts in several respects (see 4.3.1). Recognising the need for ongoing data, NZ has instead relied on MoH-derived subsidy payments data for official reports (see 4.3.2). These reports either exclude unsubsidised residents or inflate counts of those subsidised to derive national and regional estimates.

In other countries, use of RAC has been shown to be associated more closely with time to death than with ageing itself^{64 65}. The reality in NZ is that residential long-term care has become entrenched as a common place of living near the end of life, apparently more so than other countries. Recent research by the candidate demonstrated that between 2003-2007, almost 38% of all deaths in those aged 65+ years were in RAC facilities⁶⁶. This is higher than in 20 other populations with comparable data, and even so, it does not include those who live in RAC but are admitted to acute hospital and die there.

3.2.4 Provision of RAC

Provision of public funding for RAC is subject to change. The industry has lobbied government for increased funding per resident because of increased dependency levels; higher needs require more staff hours per resident and higher levels of staff training and remuneration. When changes to subsidy levels are proposed, the financial implications may be reasonably estimable based on existing volumes and trends in subsidy payments data. In contrast, when changes are proposed that affect eligibility for subsidies or alter the subsidy structures, then under current systems, estimates of change in demand would be challenging.

Income for most older New Zealanders needing LTC includes universal national superannuation (NZS) or Invalids (or other) benefits, most of which are compulsorily used to offset RAC costs when a move to RAC care is made. Recent discussion papers from both the Treasury and the Ministry of Social Development discuss options that reduce the future burden of NZS to taxpayers^{67 68}. It is reasonable to expect that the implications on RAC funding of these and other relevant policy changes should be assessed using data that fairly represent the reality of RAC use in NZ and how changes to policy might impact on usage.

The burgeoning growth in the older population coincident with low growth in younger populations has implications for at least three aspects of health services: funding, provision and utilisation. Of the total amount spent per person on healthcare in NZ, about half is spent on those aged 75 years and over, and nearly half of that is spent on LTC support services (whether provided at home or in RAC)⁶⁹. The changing demographic balance means an increasing proportion of the health budget will be needed for older New Zealanders⁶⁹. Assuming an otherwise steady state, forecast costs of disability support services, including residential care and home-based support services, are regarded as unsustainable because of population ageing^{44 70 71}. Policy changes will be needed to address issues arising from the growing proportion of older people and the diminishing proportion of people of working age who will be taxpayers in the future.

3.3 Sectoral and policy changes

The impact of population ageing on RAC use, and potential for further growth, was recognised when the RAC sector grew rapidly in the late 1980s and 1990s. Population projections showed how the baby boomers might swamp health services in the future. Demand for subsidies grew rapidly, in part because raising the asset threshold was allowing more people to receive subsidised care⁷². Budgetary considerations led to the introduction of policies designed to control expenditure in the sector. The main policy changes are outlined below.

3.3.1 Needs assessment at entry

In the 1980s, it was noted that some private payers were entering RAC more as a lifestyle option, unjustified by the care levels they needed. When their funds were exhausted, the state then found there was no option but for it to provide for their welfare and pay their costs⁷³. In the first of several policy changes, those wishing to move into RAC, even if privately funded, were required to undertake a needs assessment before entry to avoid the state then becoming “caught with the bill”. When first compulsorily introduced, a geriatrician’s assessment was required. Later, a NASC (National Assessment and Co-ordination Service) using a locally-developed standard instrument and contracted assessors was mandated. Assessors were not medically qualified, but they could request a geriatrician’s review.

In 2011, the MoH signalled the introduction of a thorough resident reporting system, interRAI, a set of assessment instruments that are widely used internationally that cover needs assessments for home-based care services and also for pre-admission to RAC. Following admission, residents’ assessments will be updated at regular intervals and include discharge information. Facility staff are being trained to undertake assessments and the interRAI information system is now established.

3.3.2 Retirement villages

A second significant and ongoing change in the sector occurred with the establishment and rapid growth of retirement villages by both commercial and charitable organisations. Villages provide housing and lifestyle options for older people in communities comprising purpose-built housing units, usually some

communal social facilities and perhaps other care services (at extra cost) on one site. They are not regarded as RAC facilities, but are either charitable or commercial operations, not policy-driven. They are thought to be providing accommodation for people with less disability than those of RAC residents and thereby delaying or avoiding entry to RAC⁷⁴. Some provide RAC-level services, while others require residents to move elsewhere should they need 24-hour care. Little is known about disability levels in villages or whether the village concept can be extended to include those without the capital for investment in the village lifestyle. In Auckland in 1988, there were very few retirement villages. By 2010, rapid growth had occurred, with an estimated 9,000 older people living in retirement villages, beyond the numbers in RAC in the Auckland region (personal communication, Retirement Villages Association, 2010).

3.3.3 Home-based supports and services

The third policy change was the promotion and funding of home-based supports and services to allow older people to remain at home longer. Surveys around the world have shown that, in general, older people prefer to live at home until they die, rather than move into an institutional facility⁷⁵⁻⁷⁷. In NZ in 2001, the government signalled acceptance of these preferences by developing “ageing in place” policies, partly in the hope that they would lead to reduced costs of institutional care⁷⁸. It was a foundation element of the Health of Older People Strategy⁷⁹, to which central and local government and health providers were thereafter expected to adhere.

Policy interests in this area continue, with the Minister of Health in February 2012 informing all DHBs they must develop services that support continued safe independent living at home⁸⁰. In its most recent annual report to the Minister, the MoH credits effective health care and support services for enabling older to live independently for longer. By their estimates for 2013/14, 23% of people aged 85+ lived in aged residential care, reduced from 28% in 2006/07.

3.3.4 Threshold for subsidy eligibility

In conjunction with the needs assessment is an asset test for those who wish to apply for a subsidy to help pay for their care. Between 1951 and 1961 financial assistance for the cost of rest-home care was available under the Supplementary

Assistance Programme (administered by the Department of Social Welfare), and was subject to an income and asset test. This took into account not only the person's ability to contribute to the cost of their care, but also their family's ability to contribute. People who needed geriatric (higher level) nursing care were subsidised by hospital boards. The amount they had to contribute themselves therefore varied depending on whether they received their care in a public or psychogeriatric hospital, or a in convalescent or rest-home. From 1966, a series of policy changes brought in the Rest-home Subsidy Scheme for those in commercial facilities⁸¹.

Income assessed includes New Zealand Superannuation (to which all NZ residents aged over 65 years who meet residential criteria are eligible) and private superannuation income, earnings or income from interest and dividends. Assets assessed typically include the value of house and property, car, shares and other investments. The income and asset eligibility thresholds vary between those living alone, those who are cohabiting with a spouse or partner, and those who have a spouse or partner already in care.

Threshold levels for selected years are shown in Table 3-1, though exceptions apply. In 1989 the scheme was extended to cover those in religious and welfare homes. In 1993 the government introduced a universal income and asset test to replace the ad hoc and muddled arrangements that had developed over the years.

Table 3-1 Changes In assets thresholds for subsidy eligibility, selected years 1961-2005

| | 1961 | 1971 | 1984 | 1993 | 1994 | 2004 | 2005 |
|--|-------|-------|---------|----------|----------|----------|---------------------------|
| Single | \$200 | \$300 | \$1,500 | \$6,500 | \$6,500 | \$15,000 | \$150,000 |
| Married (both in care) | \$400 | \$600 | \$3,000 | \$13,000 | \$13,000 | \$30,000 | \$150,000 |
| Married (one in care & one at home) | \$400 | \$600 | \$3,000 | \$20,000 | \$40,000 | \$45,000 | \$50,000 or \$150,000* |

*Depending on the option selected

Source: Data from Shipley 1996⁸¹ and Dyson 2004⁸²

Asset thresholds for eligibility changed dramatically in 2005, increasing the threshold by \$10,000 per year automatically⁸³. An anticipated 5,600 additional

people were expected to receive the subsidy. In the 2012 Budget thresholds were again revised, this time to rise with inflation to ensure RAC viability in the long term. By 2015 the thresholds were \$218,423 for a single person or a couple where both are in care, and \$119,614 or \$218,423 (depending on which assets are included) for a couple where only one is in care.

Before making changes to policies relating to asset thresholds, policy advisors seek input from ministry staff as to how proposed changes are likely to impact on the budgets. Clearly, the numbers of current residents paying privately who may become eligible for a subsidy, and the changes in numbers entering in the future, need to be anticipated. If the estimates are inadequate and larger-than-expected numbers become eligible, then budget-holders may be ill-advised.

3.3.5 Premium services

As previously noted, to be eligible for any resident to receive a government subsidy, a facility must be an approved provider and have a contract with the DHB. Standard contracts provide that residents in a standard room have at least 12 square metres for the bedroom, with use of a shared bathroom. Under the standard contract, the *maximum contribution* paid by the resident with or without government subsidy covers accommodation, food, laundry, nursing, medical review by a GP at least 3-monthly, prescribed medicines, incontinence products and transport to health services⁸⁴. For those receiving a subsidy, an additional allowance may be made annually for clothing.

Extra services – including reading glasses, hearing aids and dental care, private phone, hairdressing, newspapers or magazines – are not included in the standard service package; resident must pay extra for these. Further, “premium rooms” such as rooms with en suite bathrooms or fixed luxury features, attract an additional charge as a co-payment, unless certain conditions apply. Some facilities comprise only “premium” rooms, requiring all residents to make co-payments. Co-payments can be quite large, even by residents with advanced dementia who may not appreciate the additional features or luxury appointments. The risk is that the charges place some RAC facilities beyond the reach of would-be residents, making it more difficult for them to remain close to family, their own GP or the communities to which they have links.

Further changes, of less relevance to this thesis, include the recent additional financial support allocated to funding dementia care and palliative care services and for training of RAC caregivers – the staff who provide much of the daily care of residents – in part to provide resource for the introduction of interRAI-based needs assessments.

3.4 Reports covering RAC

In 1976, the Department of Health described the accommodation and service needs of older people in NZ. It used a mix of official and research survey data gathered specifically to ascertain the best mix of services for the population at that time, and to prepare and implement a corporate plan⁵⁷. The report noted that

Health services have in the past developed as a result of “incremental change” or “muddling through rather than on the basis of so called “rational planning”.

While there is something to be said for the flexibility of the “muddling through” approach it is essentially conservative for, rather than actively seeking optimal solutions, it makes do with those which satisfy the pressure of the moment. This traditional mode of “planning” health services tends to give emphasis to the interests of the most vocal and powerful pressure groups in the system. It is least likely to give satisfactory results if the intention is to achieve a more equal distribution of resources in a situation where some kind of rationing is essential.

This certainty applies to services for the aged. There has been an absolute dearth of reliable information about the needs of the elderly.

Salmond GC. 1976 pp. 89-90⁵⁷

On the basis of this report and subsequent research, policy changes were initiated. Changes included mandated needs assessment, alignment of benefits and social supports across the sector (between rest-homes, private hospitals and psychogeriatric hospitals), providing specific facilities for people needing secure dementia care and moving of younger disabled into facilities designed for their needs and preferences.

More than 30 years later, in 2009-10, the Grant Thornton report was undertaken to comprehensively assess the cost, capacity and service delivery implications of the increasing number of older people likely to require RAC services¹². On its release, further policy changes were made: almost all public RAC funding was devolved

to DHBs, the new interRAI assessment tool was mandated, and monitoring use of RAC was initiated with quarterly reporting required from certified facilities.

Given the continuing changes within the sector and population ageing, policy changes in funding of health services will be inevitable to ensure that sustainable personal cares and supports are available. Policy-makers, health service providers and funders are likely to encounter challenges from organisations and individuals with vested interests as they modify policies. Some policy proposals may be unpalatable. A better understanding of current patterns in RAC use will be helpful for those debates and important if all perspectives are to be heard.

3.5 Trends in rates of use and dependency in RAC

As discussed in 3.2.3, understanding trends of utilisation within the RAC sector has been, and remains, difficult. Currently, few data describe the characteristics of people at admission or their lengths of stay in RAC. Instead, most estimates of use and projections for future demand are based upon subsidy payments data, limiting their usefulness to anticipate change in demand or to enable simulations of the impact proposed policies may have on demand. Measures are discussed further in Chapter 4.

The changes described above and other changes in the sector do however appear to have led to reduced rates of use of RAC, accompanied by rising levels of dependency, as evident in four Auckland Long Term Care studies. These form a series of population-based, census-type studies of the demographic, functional and care characteristics of RAC residents. The first, in 1988, showed that 16% of RAC residents were “apparently independent” and thus may not have needed residential care⁸⁵. The latest, in 2008, showed that there had been no growth (in terms of bed numbers) in the RAC sector over 20 years although the population aged over 65 years had grown by 43%. Age-specific rates of men and women living in rest-homes (lower-level care) almost halved over the period, accompanied by a 22% reduction in private hospital (higher-level care)⁸⁶. There was a marked increase in dependency levels of those living in RAC, with a fall to only 4% “apparently independent”⁸⁷. It seems that people with higher levels of dependency are indeed staying at home longer, delaying or avoiding admission into residential care. One

example is the attention currently being given in other countries to improved post-acute hospital discharge care such as via transitional support services.

Any innovations that aim to offer alternatives to RAC should understand existing usage patterns, in order to assess demand and evaluate unexpected risks during periods of change. It is likely that models of care being developed elsewhere in the world will be considered for NZ. It is possible that valuable lessons could be learnt from how low-use population subgroups within NZ avoid RAC entry, or that historic models could be reworked to provide options. Alternative models of care and support will be possible for some.

Understanding what currently exists is essential if options are being discussed and possibilities for change are being considered. The assumption that existing services in NZ operate in a similar fashion to those elsewhere is not necessarily true, even if it is assumed that needs of older people, across the populations, are comparable. Currently, information is inadequate to describe use in NZ, let alone to understand if and how NZ differs from apparently equivalent services in other countries.

Chapter 4. Reporting and monitoring

Preamble

For information to be useful for policy and planning, data need to be collected and processed into information. Data exist that remain unused, or are used for purposes for which they are unsuited. What sources of information exist that may be used to describe current use of RAC? How can they be used to inform decisions? How is reporting and monitoring currently undertaken and how may that mislead? This chapter reviews data sources, and their use, and introduces those that are used in this thesis.

4.1 Role of epidemiology

In approaching a thesis on the topic of RAC statistics, this work utilises an epidemiological approach in what might otherwise be regarded as a health services or health policy field of enquiry. It does so because fundamentally the question addresses population health. Walt recognised that most often epidemiology contributes more through a broader process of “enlightenment” of policy-makers – raising awareness of need for certain areas to receive greater attention, i.e. for priority setting⁸⁸. Epidemiology’s contribution to health policy is not always directly evident.

Spasoff⁸⁹ suggests the contribution of epidemiology occurs through several pathways:

- a population focus – a population’s size, characteristics and structure are central both to epidemiology and to public health policy
- health and prevention – while epidemiology contributes to understanding aetiology and treatment of disease, it may also contribute to prevention through descriptive and aetiologic work
- health services – epidemiology has a major role in monitoring the quality and quantity of health care, in measuring health outcomes and conducting evaluations
- health information – perhaps the most important direct contribution of epidemiology has been the information it has produced on the

magnitude of health problems and risk factors, and on prevention and control of health conditions.

The last point is supported by Shapiro, who asserted that there is a need for yet better information, in particular the need to integrate data from routine information systems with data from research projects⁹⁰. Such an approach is central to this thesis. Good outcomes of this work would be if it could contribute to discussion and debate about current and future needs for care of older people and lead to improved information systems and reporting.

4.2 Health statistics

Health statistics provide information about aggregations of people, institutions, organisations or health events rather than information about an individual person. Friedman et al. described how statistical reports are typically based upon numerous data sources, obtained through several different modes of data collection⁹¹. Data may have been collected purposefully to describe the health of a population, or been collected during a health-care process such as an ambulance ride or laboratory test, a financial transaction, for a research project or as a whole-of-population census. Data may have been compulsorily provided, for example as part of a service contract or audit process, or they may have been collected for an entirely different purpose, but are assembled and employed for convenience and because of cost considerations. A summary of the main parameters of RAC-related health statistics is shown in Table 4-1, adapted from Friedman et al.⁹¹.

Importantly, data may or may not be representative of the population from which they are derived. To avoid being misled, wise users will critically evaluate the purpose, conditions and process of data collection, including assessing issues of privacy for the protection of individuals and service providers. Measurement theory considers the connection between data and reality, regarding precision, accuracy, reliability and validity of measures as essential for quality reports⁹². Elements of quality might include data completeness, quality of data capture and management, clarity of definitions used, reliability of coding, accessibility and transparency of data structures, and accuracy of key identifiers. Quality of measurement and data collection, together with the sensible choice and execution of analytical methods are essential for useful inference and projections^{93 94}.

Table 4-1 Major parameters of RAC health statistics

| Parameter | Level of analysis | Examples for RAC sector |
|---------------------------------------|---|--|
| Source of data | Population surveys & censuses | national censuses |
| | Health-care financial transactions and administrative records | dispensing or subsidy payment records |
| | Research studies | intervention trials, pilot projects, provider surveys |
| | Individual investigation, service or examination records | hospital, ambulance & needs assessment records, laboratory tests |
| | Individual response | interviews |
| Methods of data collection | Record or transaction review | clinical audit, ARC Demand Planner |
| | Registration | subsidy applications |
| | Notification | asset test records |
| | Interview | key informant interviews |
| | Mandated report | quarterly RAC facility returns |
| Geopolitical level | International | OECD, EU & WHO reports |
| | National | Prime Ministerial Task Force |
| | Regional | DHB monitoring reports |
| | Local authority | social housing records |
| | Service provider | facility and resident summaries |
| Time frame for collecting data | Continuous | subsidy payment records |
| | Fixed time period | cohort followed over time |
| | Periodic | quarterly or annual |
| | Point-in-time | at entry to or departure from RAC facility, or at certain date |
| Analytical methods | Descriptive | ARC Demand Planner, census counts |
| | Aetiological | Factor identification |
| | Predictive | Forecasting |

Adapted from Friedman et al. 2005⁹¹

Schäfer et al.⁹⁵ built on the work of Aday et al.⁹⁶ and others to structure data input in the health system according to the level at which processes of care take place, as follows:

- the macro level or *population* perspective, on the determinants of the health of populations and operations of the health system as a whole

- the meso or intermediate level, focusing more on *inter-organisational* and *inter-organisational* structures, processes, systems and institutions, and
- the micro level, a more clinical views of the factors that contribute to health of *individuals*, their individual care services and technologies.

Table 4-2 presents an adaptation of their classification table as it relates particularly to RAC in NZ, summarising the data sources potentially available and the level at which they might inform understandings. Inevitably it is incomplete. Some sources are used routinely, such as subsidy payment transaction records. Others have been used occasionally, including census summaries and research projects.

In the following section (4.3) selected sources available for RAC utilisation in NZ are described and discussed. Data sources relating particularly to hospital records of RAC residents cannot generally be distinguished from those of non-residents, so are rarely used for information policy.

4.3 New Zealand data sources

Two main official sources have been virtually the sole sources of information about RAC use in NZ – subsidy payments data and national census data. Both are from national collections representing the NZ population, but both have limitations. New reporting systems that are coming on stream are also outlined.

4.3.1 National census data

Censuses collect the most complete population data for the country. Information about both the facilities (“dwelling” forms) and individuals is compulsorily provided for all in the country on census night, and is usually held every five years. Comprehensive demographic data are collected, including for example previous address and length of stay at this address. In most circumstances they would be expected to quantify cross-sectional RAC use more reliably than other methods. However, census-based published reports of those dwelling in RAC have been few, most describing only those living in “non-private dwellings”. RAC counts have not been routinely reported, but have been made available upon request.

Table 4-2 Potential sources of data for residential aged care in New Zealand, and associated levels of analysis

| Data sources | Level of analysis | | | |
|--|-------------------|--------|-------------|------------|
| | Population | System | Institution | Individual |
| Census | ✓ | | | |
| Public health surveillance systems | ✓ | | | |
| Vital statistics (esp. records of fact and place of death) | ✓ | | | |
| Surveys | | | | |
| Population (e.g. health & disability surveys) | ✓ | ✓ | ✓ | |
| Organisations (facilities) | ✓ | ✓ | ✓ | |
| Providers (staff, GPs) | ✓ | ✓ | ✓ | ✓ |
| Residents & their families | | | | ✓ |
| Administrative data | | | | |
| Facility audits | | ✓ | ✓ | ✓ |
| Subsidy applications | ✓ | ✓ | | ✓ |
| Subsidy payments | ✓ | ✓ | ✓ | ✓ |
| Facility databases | | ✓ | | |
| Effectiveness and evaluation studies | | | | |
| Intervention trials | | | | ✓ |
| Service evaluations | | ✓ | ✓ | |
| Pilot schemes | | ✓ | | |
| Clinical records | | | | |
| Needs assessments | | ✓ | ✓ | ✓ |
| Primary care records | | ✓ | ✓ | ✓ |
| Laboratory results | | ✓ | ✓ | ✓ |
| Dispensing records | | ✓ | ✓ | ✓ |
| Ambulance records | | ✓ | ✓ | ✓ |
| Hospital encounters | | ✓ | ✓ | ✓ |
| Disease or screening registries | | ✓ | | ✓ |
| Qualitative studies | | | | |
| Key informant interviews | | ✓ | ✓ | ✓ |
| Participant observation | | ✓ | ✓ | ✓ |
| Case studies | | ✓ | ✓ | ✓ |
| Focus groups | | | | ✓ |
| Ethnographic interviews | | | | ✓ |

Adapted from Schafer et al, 2007⁹⁵, following Aday et al. 1998⁹⁶

It is likely that census data misreport cross-sectional RAC use in at least the following ways:

- undercounting short-stayers and others who state on their census forms that they usually reside at a private address,
- excluding those temporarily absent for example in acute hospital on census night,
- excluding people living in serviced apartments but who receive RAC-level care, such as those in retirement villages that include both RAC and independent living facilities, and
- under definitions used in previous censuses, those in long-stay hospital-level care were not classified as RAC but reported as in acute hospital.

Nevertheless, census data have been used. In 2004, Bryant et al. noted marked variations in the proportions of RAC use across DHBs using census data⁴⁴. Inter-DHB variations may be associated with differential bed provision, access to home-based support services, some acute hospitals providing long-stay care, distances to population centres, entry level criteria, differential length of stay, or to socio-economic characteristics of residents in the region. It is important to understand the reasons, because variations in utilisation may signal better (or worse) management and provide options for DHBs reviewing their systems. Apparent regional inequities in provision, access, or funding are easy prey for journalists or the Health Commissioner.

4.3.2 National subsidy databases

MoH financial transaction records of payments made to persons in receipt of a residential care subsidy capture dates of subsidy start and stop. Therefore duration of subsidised stay and also level of care at the last assessment can be summarised. The records are used by MoH to generalise to all residents for almost all official reports, including routine annual reports to government, its Ministers and international organisations such as OECD and WHO. They are also used in preparing special publications describing health of older people^{32 97 98}.

When necessary in MoH reports, counts of RAC subsidy recipients aged under 65 may be excluded or counts of subsidised persons counts inflated in an effort to adjust for non-subsidised people. MoH estimates that perhaps 20%-40% do not receive a subsidy. It is not known what the differences, if any, are between the care needs or the lengths of stay of subsidised and unsubsidised residents.

Data extraction regarding subsidy payments has been conducted inconsistently, with confusing results. For example, in four OECD publications for the year 2006, NZ estimates of the percentage of the 65+ population living in RAC in NZ ranged from 4.6%⁹⁹ to 8.2%³, taking the country from being in the middle-range of OECD countries in terms of percentage in RAC, to the highest. While the source of some variability in published reports is known (for example, some include subsidised residents only, some also include people receiving home-based LTC services, some are cross-sectional; while some are based on year-long counts, some include only those aged over 65 and others count all residents), reports that purport to represent the national proportion using RAC should be roughly comparable and the differences explainable. Instead, they led to confusion that is not helpful for policy setting, for service development, for analysis of trends or for international comparisons.

4.3.3 Reporting systems initiatives

The following three initiatives in data collection were introduced to the sector after commencement of this course of study. In the future they will become central to consistent information for the sector, forming the basis of monitoring trends over time and being made available for approved research purposes. As yet, data quality standards are still being attended to, and few data have been accrued or released that are reliable and useful. None has been analysed in this work.

InterRAI

In 2011, the MoH signalled the introduction of a thorough resident reporting system, interRAI, which will cover needs assessments pre-admission to RAC. Following admission, residents' assessments will be updated at regular intervals and include discharge information, in a system that will permit statistical analysis of data nationally or sub-nationally. Facilities in some regions have commenced the scheme, so that, within one region as at January 2014, approximately 10% of

all residents had been formally assessed using the new tool (personal communication, Waitemata DHB). It will be years yet before sufficient staff are trained, additional assessment resources provided, and data management systems become well established. Once that is achieved, interRAI will become a valued dataset useful for many purposes including international studies.

ARC Demand Planner

DHB Shared Services (DHBSS), a crown entity, has since 2012 provided summaries of the subsidy-payments data to approved users, through what is known as the ARC (Aged Residential Care) Demand Planner. This aggregates subsidy payments data nationally or regionally, by age group, service type (rest-home, hospital, dementia, psychogeriatric) or total. It permits different scenarios, such as population change or past five-year trends and to make bed-day projections¹⁰⁰. Additionally, it allows comparisons between regions. It is becoming the main information source used by DHBs and MoH to inform planning and funding.

Mandated quarterly reporting by RAC facilities

In Australia, annual returns of all admissions and discharges are required of RAC facilities by federal authorities. Details required include demographic characteristics and completed lengths of stay. The aggregated data are analysed and published annually. The USA also requires regular reporting.

In NZ, authorities have only recently imposed reporting requirements upon RAC operators. In late 2012, a new online quarterly reporting system was instituted by the MoH in conjunction with the industry. This requires each certified facility to provide cross-sectional counts of bed numbers and number of current residents every 3 months⁸⁴. About 95% of certified facilities were participating in this by May 2015, and the data are now regarded as reasonably reliable (MoH, personal communication). No routine reports are yet produced or made public but it is expected that this will occur.

Other sources

The developments described above are much-needed initiatives to assemble data consistently for the sector and thereby address information gaps. Official reports have been produced by government departments and stakeholder groups outlining

the current and future burden of home-based LTC and of RAC^{12 57 101-104}. The NZ Treasury has reported models that assess future funding needs for RAC⁷¹, and there have been calls for a review of the economic funding models for LTC⁷².

A few independent research studies have been conducted: to describe needs of RAC residents in a specified geographical region^{14 85 87 105-107}, to identify and understand better the reasons for moving into care^{9 108}, to trial interventions of supportive home-based services to delay or avoid entry to RAC¹⁰⁹⁻¹¹¹ and to reduce RAC demands on acute health services^{112 113}. Several DHB-based initiatives to delay building and operating expensive new hospital wards have been trialled in some regions and evaluated (with varying levels of rigour).

4.4 Data sources used in this thesis

The range of research questions addressed in this thesis entails reusing some of the data sources described in 4.3 above. Four of the first five data sources listed in Table 4-1 are used. They are described and referenced in greater detail in the relevant Chapters but are introduced below.

4.4.1 National-level official population data

- Census data from Statistics NZ showing type of residence and demographic data for all individuals from the national 5-yearly censuses in 1986, 1991, 1996, 2001, 2006 and 2013.
- Statistics NZ annual population data by age group and gender, both retrospective and projected.
- Statistics NZ annual summaries of deaths, by age group and gender, both retrospective and projected.

Aggregated data were obtained under the University Conzul agreement with Statistics NZ.

4.4.2 Regional-level official health data

- MoH subsidy payments and service use data for subsidised residents in the latest (2008) of the Auckland surveys mentioned above. Transactions data were obtained summarised to individual level.

- MoH data morbidity (acute hospital admissions) and mortality for those in the 2008 OPAL survey and ARCHUS trial.

The above databases use NZ's system of recording routinely all deaths, hospital stays, subsidy payments and other health service use for each individual through a unique patient identifier known as National Health Index (NHI) numbers.

- Summary data from two DHBs: Waitemata and Canterbury, regarding deaths of RAC in their acute hospitals.
- Shared DHB Services' ARC Demand Planner (aggregated data that became available in 2013 during the candidate's term of study).

4.4.3 Research data

- A series of four cross-sectional census-type research surveys have described use of RAC in the Auckland area over a 20 year period (in 1988, 1993, 1998 and 2008). For each, all RAC facilities currently authorised to provide care were surveyed. Basic information was collected for each facility, and facility staff completed a form for each resident. Items included demographic, RAC stay, functional and dependency data. Methods are described in detailed reports^{13 107 114 115}, and in various publications cited elsewhere. The latest, the 2008 study known as OPAL (Older People's Ability Level survey), also collected NHI unique identifiers for residents to enable data linkage with MoH databases.
- Data from ARCHUS (Aged Residential Care Healthcare Utilisation Study), a clustered, randomised controlled trial set in Auckland RAC facilities with a multi-disciplinary, complex intervention. NHI identifiers were collected for all residents of the facilities during the course of the study.

The candidate was involved with all these projects, and was authorized to access the data. In both OPAL and ARCHUS, health service use was merged with the research data by the unique identifier, making possible the analyses conducted in Chapters 6, 8, 9 and 10. More information is provided in the relevant Chapters.

4.5 Analytical methods used in this thesis

Analytical methods used are also described within the relevant chapters. They include a mix of standard epidemiological methods (age-specific rates, age-standardised rates, logistic and other regressions) and also some less frequently encountered methods such as ratio estimation and adjustments for length-biased sampling. Methods used are described further in each chapter but are outlined below.

4.5.1 Standard epidemiological and statistical methods

Descriptive analyses are undertaken and population rates are derived using standard analytical techniques, as follows:

- Age- and gender-specific rates using standard methods are used for descriptive analyses
- Chi-square and t-tests are used to test differences in characteristics (categorical and continuous respectively) of groups of residents
- Cochran Mantel-Haenszel tests for 2*n data where n ordinal categories trends were involved
- Where statistical testing was undertaken and unless otherwise stated, two-sided p-values were used and p-values less than 0.05 accepted as statistically significant
- Where uncertainty of estimates is expressed as 95% confidence intervals; unless otherwise specified these were calculated using the Wald method.

4.5.2 Adjustment for missingness

Missingness, in the data analysed during this thesis, arose from missing data items in the Auckland LTC survey data collection forms, or missing people in the same or other datasets. When analysing at a population-level, as desired here, such missingness can mean individuals with missing data drop out of analyses, and the consequent population estimates under-represent those with missing data.

Depending on the circumstances, and where necessary to avoid omitting residents

from analyses and to better represent the population, missing data items were imputed for a small number of residents in the Auckland LTC studies, as follows:

- Where either age or gender was missing on the survey forms, MoH information was used.
- When only summary data were involved, for example when calculating age- and gender specific rates or numbers of medications, use of the mean or median (if data were skewed), and pro-rata estimation for categorical variables was used.
- Where any other data item in the survey was incomplete and in order to avoid loss of observations during statistical modelling, categorical variables were imputed using monotonic discriminant function, continuous variables with conditional means¹¹⁶.

4.5.3 Adjustment for survey non-response

It is common in surveys that some characteristics of the unit sampled are associated with non-response. Where this is the case, unless adjusted for, overall results may be biased. In the case of the Auckland LTC studies, for example, it was evident that high-level care facilities had significantly higher participation rates than rest-homes; response rates were not associated with DHB or other facility-level characteristics.

- In consequence, in analyses that use the Auckland LTC study data for cross-sectional reports, non-response of facilities is handled using simple non-response weights, stratified by four types of facility (rest-home, dementia care, hospital care and psychogeriatric care). The weights used were simply the inverse of the proportion participating at each type of facility.

4.5.4 Adjustment for cluster-correlated data

In the Auckland LTC survey, residents were living within an institutional environment, with many decisions about lifestyle and their care being determined by the facilities' policies, staff or traditions. In consequence, outcomes for individuals within any facility's care should be expected to be somewhat similar, leading to problems during analyses of individual level outcomes.

- Cluster-correlated data in this thesis has been handled by inclusion in models a statement that identifies the facility in which the resident lived
- When a cluster is identified in this manner, modelling processes take this within-cluster correlation into account, adjusting for uncertainty around the estimates.

4.5.5 Ratio estimation

When estimating the likelihood of use of RAC (Chapter 7), no single data source provided reliable and unbiased estimates of those who died in hospital but who had come from RAC. These people would otherwise have been overlooked in estimation of the likelihood of RAC use. Ratio estimators employing the correlation between an unknown population parameter of interest and an auxiliary variable that is known, were used in order to increase precision of the population estimates¹¹⁷⁻¹¹⁹.

- For the estimation of in-hospital deaths, advantage was taken of four small studies which, when combined, provide a summary proportion for the group of people from RAC who died in acute hospital
- Ratio estimators were used for this purpose
- An estimate of the parameter of interest is derived, then inflated by the inverse of the relevant summary proportion.

Further details are provided in the chapter.

4.5.6 Adjustment for length-biased sampling

Cross-sectional survey data, while providing unbiased estimates of point-in-time data, will mislead if used to derive duration data. For example, if length of stay (LoS) is measured cross-sectionally across all residents of an RAC facility, and if the mean length-of-stay to date was (say) 15 months, it could be anticipated that the average completed LoS would be 30 months – on the basis that on average a survey is measured half-way through the stay so the estimated total LoS might be double that observed. However this would be a biased measure of completed LoS of all those leaving over a one-year period, for example. While some beds will

have one resident for a whole year, others may have several shorter-stay residents during the course of the year. A cross-sectional study will count only those there at any one time, yet several residents may use the bed during the year. This is a problem known by survey researchers as *length-biased sampling*¹²⁰⁻¹²².

- In Chapters 8 and 9 – where estimates of length-of-stay, turnover and hospital service use over a 12 month period were wanted – survey regression models are used to address the problem of both clustered and length-biased observations in the Auckland LTC survey data^{120 123}
- Revised weights, based on length-of-stay to date, are used to up-weight each resident's record in order to best represent all residents using the beds over the period of interest – here a 12-month period. Details are provided in the relevant chapters.
- Effectively, the reweighted analyses convert cross-sectional data to prevalence data.

4.5.7 Statistical analyses

Models were used on several occasions to test the association of resident or facility characteristics with selected outcomes.

- Generalised linear regression models (logistic, poisson and negative binomial) were used to develop and evaluate predictive rules to identify facilities that may be targeted for interventions designed to reduce acute hospitalisations
- Proportional hazards models were used to model time to emergency department (ED) presentation where not everyone presents to hospital
- Renewal methods were used to characterise transitions through RAC where bed numbers remain constant through the period^{124 125}
- Reweighting and clustering were included as needed.

Analyses were conducted by the candidate using SAS© Versions 9.3 or 9.4, R 3.2 and Microsoft Excel 2010©.

4.6 Ethics approval

Ethics approvals were sought and obtained for use of the data by the appropriate authority, and are specified within each chapter. A list of all the various ethics approvals encompassed appears as an Appendix.

4.7 Post-script

The limitations of existing databases and reports have been noted in this and previous chapters. In particular, the claim has been that population measures of RAC use in NZ have been poorly measured and reported, and that there is much that is unknown. To demonstrate the limitations of published counts, in Chapter 5 the variability in reporting even the single most basic monitoring indicator – simple, cross-sectional RAC utilisation counts and derived rates – is demonstrated.

Chapter 5. Reports of the proportion of older people living in long-term care in New Zealand 1998 to 2008

Preamble

Claims were made in the previous chapter that information about RAC use has been unreliable. Those statements require justification. In the first of six research chapters included in this thesis, reports that describe the proportion of older people living in residential aged in NZ are assembled, summarised and reviewed. All known reports of counts or proportions from a wide range of publications for a 20 year period were sought. In order to illustrate the wide variability of reports in what is essentially a fairly stable demographic group, this chapter draws attention to the variation, discusses why those differences have occurred, and raises concerns about inconsistent reporting. Other than minor edits, the chapter is presented much as originally published.^a

5.1 Abstract

Objective

Population ageing is driving many countries to review health and social care policies. For many, an important component is RAC. RAC policies are best when based on sound estimates of current utilisation. Counting RAC residents should be straightforward, but different data are collected for different purposes. Moreover, data can be inconsistent and inaccurate. This study uses NZ sources to ascertain the extent different reports provide consistent and accurate estimates of RAC use.

Methods

We searched for available cross-sectional information about use of RAC by people aged 65 years or over in NZ's population since 1988. In addition, for one geographic region, Auckland, we compared research survey data at three time-points with the nearest census estimates.

a. Broad JB, Ashton T, Lumley T, Connolly MJ. Reports of the proportion of older people living in long-term care: a cautionary tale from New Zealand. *Australian and New Zealand Journal of Public Health* 2013;37(3):264-71 doi: 10.1111/1753-6405.12069.

Results

Fifty-eight national-level estimates (census, subsidy payments and population surveys) were found. Since 2000, estimates of the percentage of older people living in long-term care ranged from 3.4 to 9.2. Comparisons with Auckland studies demonstrated improved reporting in the 2006 census.

Conclusion

Estimates of the proportion of people living in RAC varied widely, even from the same source. OECD reports, often used for cross-national comparisons, were particularly inconsistent.

Implications

While estimates of the proportion of people living in RAC in NZ are inconsistent, improvements are evident in census and subsidy data. Reconciling new data with previous reports prior to publication may reduce variations in reporting. Improved reliability will assist understanding of within-country trends and international comparisons, and better inform decisions shaping health services for older people.

5.2 Background

Population ageing is raising dilemmas regarding health and social care policies for older people¹²⁶. Beyond questions about service funding and provision, issues relating to changes in demographic mix, social and cultural expectations must be addressed. It is widely accepted that countries should develop an integrated approach to health and social care services in ways that can respond to the complex and changing needs of the growing numbers of older people. Accurate, clear and consistent information is required to inform policy-making as well as service planning and development.

RAC is a component of an integrated care service for older people who need ongoing health care and personal assistance at levels that are difficult or impossible to provide at home. The package of care delivered in a residential setting can be a mix of health and social services including personal care, nursing, supervision and/or other types of care¹²⁷.

Sound information informs decisions that shape health services, and may be used to describe long-term trends and project future demand. Counting residents living in care settings should be straightforward – countries usually have licensing or certification schemes that identify approved care providers, and each resident usually stays in care for a distinct period with few excursions away from the facility. The way of counting depends upon the purpose of counting. To capture RAC utilisation information, some countries use regular reports that care providers are obligated by authorities to provide. Some countries rely upon census data, while others generalise to the population based upon information collected from subsets of facilities e.g. those belonging to one service provider chain or from a random sample in a research study. Other sources of information include population surveys of disabled people or regional surveys.

This study compares various NZ estimates to illustrate differing estimates of utilisation of RAC. We suggest more reliable methods of reporting with a view to understand better within-country trends. We also consider the implications of our findings for international data collections such as those compiled by the OECD for use in cross-national comparisons and for monitoring international trends.

New Zealand

In NZ, RAC is provided in *private hospitals* (higher level nursing care) or *rest-homes* (lower level or social care). Residential care subsidies, funded through general taxation, are available for people assessed by a DHB¹²⁸ if a) there is a clear need for care, b) if care is provided within an approved facility and c) if an assets and income assessment shows that private funds are below defined thresholds.

NZ has been portrayed as having a higher proportion of its older population in RAC than most OECD countries (despite a lower median age of its 65+ population)^{129 130}. About 70% of RAC residents are (partially or fully) subsidised¹², therefore any growth in utilisation is an underlying concern for public funding. Across the whole of the 2007/08 financial year, 27,300 people received a residential care subsidy at some time, amounting to NZ\$1,054 million of public funds, with a further NZ\$568 million estimated from private funding⁶². In the 2009-10 fiscal year, RAC expenditure (public and private) represented 0.75% of GDP^{60 61}.

Based simply on current counts and population projections, significant growth in demand for RAC is anticipated in NZ – the impact of greater longevity and the ‘baby boomers’ (those born between 1945 and 1960). Trends in marital status, living alone, home ownership, and migration will impact too. The size of growth however will be influenced also by personal preferences and circumstances, options available, and willingness to pay. Estimates of demand growth are usually based upon population projections combined with RAC utilisation rates.

Projections vary considerably. In 2004 the NZ Institute of Economic Research (NZIER) projections for NZ suggested a 94% increase in the demand for RAC between 2001 and 2021, assuming low or medium population growth¹⁰². In 2006, Statistics NZ projected that the number of older people living in non-private dwellings (mainly, but not only, RAC) could more than double between 2001 and 2021¹³¹. In 2010, Grant Thornton projected an increase of 12,000 to 20,000 residents between 2008 and 2026¹², an increase of 40 to 66%.

Several other factors have influenced utilisation rates in recent years, aside from demographic trends. Needs assessment before entry into RAC has been mandated, funding of home-based services has been expanded to enable more disabled or frail older people to remain living at home, and a growing number of older people are choosing to move into retirement villages (purpose-built independent-living units with some shared social spaces or facilities) that are not counted as RAC. Over the past two decades dependency levels in RAC have increased⁸⁷, entry to care is later in life and stays are shorter, leading to reduced use of RAC⁸⁶.

In NZ, data on utilisation of RAC have not been published routinely. While a national census is completed every five years and all those in the country on census night are required to participate, reports of those living in long-term care are not readily available. Funding policies have instead been informed by data for residents receiving a RAC subsidy. These data for subsidised residents are then scaled upward to account for those who pay privately in order to estimate national RAC use. This study uses NZ reports as an example to ascertain the extent to which differing data sources provide consistent and credible estimates of use of RAC.

5.3 Methods

National utilisation

Information sources describing national utilisation of RAC by those aged 65 years and over in NZ were searched for in academic and government publications, and on official government and international websites. Reports for 1988 or later were included. We sought reports expressing the proportion living in RAC. Where the proportion was not presented but both counts and population data were available from the same or related sources we derived proportions directly, and where counts only were provided we calculated population proportions using the estimated population aged 65 years and over as at June each year, obtained from Statistics NZ¹³². Population proportions (not standardised for age) were plotted against time.

Comparisons of utilisation

For the Auckland region only, where a third of NZ's population lives, we included results from four cross-sectional population-based Auckland Long-Term Care surveys conducted in 1988¹³, 1993¹⁴, 1998¹⁰⁷ and 2008^{87,86}. Study methods are described in detail in the cited publications and full ethics approvals obtained. Briefly, all facilities licensed to provide RAC were surveyed, demographic and dependency information was collected for each current resident and population proportions derived using latest census data.

Finally, to assess accuracy of reporting, we compared counts of people in RAC in Auckland in the 1993, 1998 and 2008 studies with those described as in a *home for the elderly, retirement home or residential aged care facility* at the previous census (1991, 1996 and 2006) for the Auckland geographical region, by age group.

5.4 Results

5.4.1 Search results

Fifty-eight national estimates of use of RAC were found and are detailed in Table 5-1. They drew upon three primary data sources: national censuses, disability surveys and subsidy payment data.

National censuses are conducted in NZ every five years, with two form types completed, one for each household/dwelling, and one for each individual in any dwelling type. Census tables report people usually resident in non-private dwellings. Until 2001 the relevant classification for RAC was *home for the elderly or retirement home*. In 2006 the classification was revised to *residential care for older people* including long-stay hospital-level care. We used several Statistics NZ sources: a customised extract of census data obtained for the purpose, one table obtained on request⁶³, and three Statistics NZ publications^{131 133 134}.

We found estimates from population-based post-censal Disability Surveys conducted jointly by Statistics NZ and the MoH¹³⁵, four in published reports¹³⁵⁻¹³⁸ and one table available online¹³⁹. Other MoH reports used numbers of residents in receipt of RAC subsidies, sometimes adjusted upward to represent all residents including those paying privately^{97 140}. Two commissioned reports also used subsidy data: the Grant Thornton Aged Residential Care Service Review¹² and an earlier NZIER discussion document¹⁰²; both included estimates for residents paying the full cost of care privately.

The OECD compiles an international online database from national official sources using definitions that are intended to be consistent cross-nationally in order to facilitate international comparisons. For NZ, data are provided to the OECD by MoH, from subsidy payments data. We accessed OECD Health Indicators online for the years 2003-2006¹⁴¹ and OECD iLibrary Health Data 2011 series (for 2004-2010)⁹⁹ and 2012 series (for 2006-2011)¹⁴². In addition, we found eight OECD publications covering the years 1991¹⁴³, two for 2000^{4,144}, 2003¹⁴⁵, 2004¹⁴⁶, 2006¹²⁹, 2008¹¹ and 2009¹²⁷, and a United Nations report⁴⁶.

Finally, we found four relevant policy statements (speeches and media releases) and a policy issues paper^{81 82 147 148}. Sources are detailed in Table 5-1.

Table 5-1. Reporting sources of the proportion of people aged 65 years and over living in long-term residential care in New Zealand

| Report | Purpose | Numerator data source | Definition of numerator and years covered | Denominator used in calculating proportions |
|---|--|---|--|---|
| Statistics NZ: Census Online TableBuilder ⁶³ | Public use extraction of data | Online data from the 2001 and 2006 censuses | 2001: Proportion of all persons present on census night in a <i>home for the elderly</i> or <i>retirement home</i> [29 312] 2006: All persons 65+ present on census night in <i>residential care for older people</i> [29 733] | Census night 65+ population counts by age group, for 2001 [462 491] |
| Statistics NZ: NZ Census data | Customised table | 2006 table obtained from Statistics NZ on request by authors, May 2012 | Counts of all persons present on 2006 census night in <i>residential care for older people</i> [29 733] | Census night 65+ population counts by age group for 2006 [513 596] |
| Statistics NZ: NZ Census data | Customised tables | Census data for 1986, 1991, 1996, 2001 & 2006 supplied at authors' request by Statistics NZ, April 2010 | 1986, 1991, 1996 & 2001: All persons 65+ usually resident in a <i>home for the elderly</i> or <i>retirement home</i> on census night [12 675, 17 910, 19 929, 24 003] 2006: All persons 65+ usually resident in <i>residential care for older people</i> [25 854] | Census usually resident 65+ population counts [343 570, 379 098, 422 655, 460 490, 511 590] |
| Statistics NZ: Demographic Aspects ¹³¹ | To summarise the demographic aspects of population ageing in New Zealand | Older people living in non-private dwellings (which includes rest-homes) | Non-private dwellings (which includes rest-homes and other long-term care but also includes acute hospitals, prisons etc) in 2001 [31 000] | Usually resident 65+ population as at June 2001 [460 600] |
| Statistics NZ: 65 Plus ^{133 134} | To profile the population aged 65 and over | 1996 and 2006 censuses | Usual residents of non-private dwellings, subgroup <i>homes for the elderly</i> and <i>retirement homes</i> , and excluding <i>private</i> or <i>public hospitals</i> in 1996 and 2006 [19 926, 25 854] | 1996: Proportion reported 2006: Usually resident 65+ population from same report [495 603] |

| Report | Purpose | Numerator data source | Definition of numerator and years covered | Denominator used in calculating proportions |
|--|---|---|--|--|
| Ministry of Health: NZ Disability Survey reports ¹³⁵ 137 138 143 | To profile the population that lives with a significant disability | Reports of post-censal Disability Surveys, representative sample surveys following the 1991, 1996, 2001 and 2006 census | 1991: proportion of all people aged 65+ in long-stay residential facilities [6.3] 1996, 2001 & 2006: people 65+ in long-stay residential facilities excluding those in psychogeriatric hospitals [23 900, 25 116, 31 000] | Proportion (only) reported for 1991. De facto resident 65+ population as at June 1996, obtained from the Statistics NZ website [430 100] Usually resident 65+ population as at June 2001 and 2006, obtained from the Statistics NZ website [460 600, 511 600] |
| Ministry of Health: NZ Disability Survey tables ¹³⁹ | To profile the population that lives with a significant disability | Table obtained using 2006 post-censal Disability Surveys online | Population 65+ with disabilities living in residential facilities in the 2006 survey, excluding people in psychogeriatric hospitals [29 500] | Total population 65+ with place of residence information within TableBuilder [494 200] |
| Ministry of Health: Health of Older People report ⁹⁷ | To assist implementation of the Health of Older People Strategy | Not stated | Estimated average number of residential care residents on 2000-2001 [29 192] | Mean of usually resident 65+ population as at June 2000-2001, obtained from the Statistics NZ website |
| Ministry of Health: Director-General's Annual Report 2008 ¹⁴⁰ | To inform Parliament about the work of the Ministry of Health | CCPS (benefit payments) database | Proportion of the population in subsidised RAC, by age group, 2003 to 2007 (converted using population data to counts) [19 669, 20 227, 22 933, 23 430, 22 854] | Mean of usually resident 65+ population as at June 2003-2007, obtained from the Statistics NZ website |
| NZIER: Ageing NZ ¹⁰² | To model scenarios of future demand for health and disability services; a discussion document | CCPS (benefit payments) database scaled up for private payers | Number of people in residential care (including and rest-homes, dementia units, long-stay hospitals, and psycho-geriatric hospitals) in 2003/04 [45 110] | Average of usually resident 65+ populations as at June 2003 and 2004, obtained from the Statistics NZ website [480 150] |

| Report | Purpose | Numerator data source | Definition of numerator and years covered | Denominator used in calculating proportions |
|---|---|---|---|--|
| Grant Thornton: Aged Residential Care Service Review ¹² | To report to members the present and future utilisation of the sector and evaluate financial operations | Subsidised client data from MoH benefit payments system | Estimates of all people (including those aged under 65 years) living in residential aged care for the years 2004 & 2008, scaled up using estimates of private payers derived from the 2008 Health Care Providers New Zealand Member Survey that recorded numbers of subsidised and unsubsidised residents [32 400, 30 300] | Estimated usually resident 65+ population as at June 2004 & 2008, obtained from the Statistics NZ website [484 600, 537 900] |
| OECD Dataset: OECD Health Data 2009: Long-term care recipients ¹⁴¹ | To provide cross-national comparative health statistics | Online Health Indicators database 2009, data supplied by MoH from benefit payments database | Number of long-term care recipients in institutions, 65 years and older in NZ each year from 2003 to 2006. NZ data do not refer to a specific day in the year but to the entire year [29 977, 31 344, 38 724, 41 837] | Usually resident 65+ population as at June for the years 2003-2006, obtained from the Statistics NZ website [475 700, 484 600, 496 400, 511 600] |
| OECD iLibrary: Health Data 2011, LTC recipients ⁹⁹ | To provide cross-national health statistics for the years 2003 to 2009 for comparative purposes | Data supplied by NZ MoH from MoH CCPS (benefit payments) database, not scaled up | All residents in long-term care (rest-homes and hospitals, not psycho-geriatric care) who are publicly-funded, i.e. not private payers [16 165, 16 837, 21 407, 23 578, 20 317, 19 896, 19 852, 19 699] | Usually resident 65+ population as at June for the years 2003-2006, obtained from the Statistics NZ website [475 700, 484 600, 496 400, 511 600, 526 700, 537 900, 552 600, 569 200] |
| OECD iLibrary: Health Data 2012, LTC recipients ¹⁴² | To provide cross-national comparative health statistics | Data supplied to OECD by MoH from CCPS (benefit payments) database | Estimated daily average of people 65+ living in RAC for each of the years 2006-2011, based on counts of people publicly-funded, and scaled up to include private payers based on the 2008 Health Care Providers New Zealand Member Survey that recorded numbers of subsidised and unsubsidised residents (28 700, 28 200, 28 000, 28 200, 28 400, 29 900) | Proportion reported , but population stated as mid-year 65+ population estimates from Statistics NZ [511 600, 526 700, 537 900, 552 600, 569 200, 587 000] |

| Report | Purpose | Numerator data source | Definition of numerator and years covered | Denominator used in calculating proportions |
|--|--|---|--|---|
| OECD occasional reports ^{11 127 129 143-146} | To describe utilisation of institutional care for comparative purposes | Data supplied to OECD by MoH, varied sources | Proportion of 65+ in residential long-term care 1991: in response to OECD questionnaire, based on census counts of those in hospitals & homes for the elderly ¹⁴³ [6.7] 2000: Recipients of institutional and home-care services aged 65 and over, during the entire year ¹²⁹ [6.3] 2000: Recipients aged 65 and over in long-term care institutions ¹⁴⁴ [5.9] 2003: Recipients of institutional LTC ¹⁴⁵ [3.4] 2004: Older people receiving publicly-funded long-term care in institutions ¹⁴⁶ [4.5] 2006: All in institutional LTC during the entire year ¹²⁹ [8.2] 2008: Recipients of institutional LTC ¹¹ [3.9] 2009: Population receiving LTC in institutions ¹²⁷ [5.3] | Proportions (only) reported, but population stated as from OECD 65+ population estimates provided by NZ authorities |
| United Nations: World Population Prospects ⁴⁶ | To provide global information | OECD data for 2009 | See OECD iLibrary: Health Statistics 2011 above [3.59] | Proportions (only) reported |
| Miscellaneous policy statements: McDonald 1996 ¹⁴⁷ , Shipley 1996 ⁸¹ , Dyson 2004 ⁸² , Cunliffe 2008 ¹⁴⁸ | To inform public and/or policy | Reports sourced from parliamentary website, data sources not reported | Proportion in RAC, in 1991 7% ¹⁴⁷ ; counts in 1996, 2004 and 2008 [31 000 ⁸¹ , 31 000 ⁸² , 28 000 ¹⁴⁸] | Proportions (only) reported for 1991. Estimated resident 65+ population as at June 1996, 2004 & 2008, obtained from the Statistics NZ website [430 100, 484 600, 537 900] |

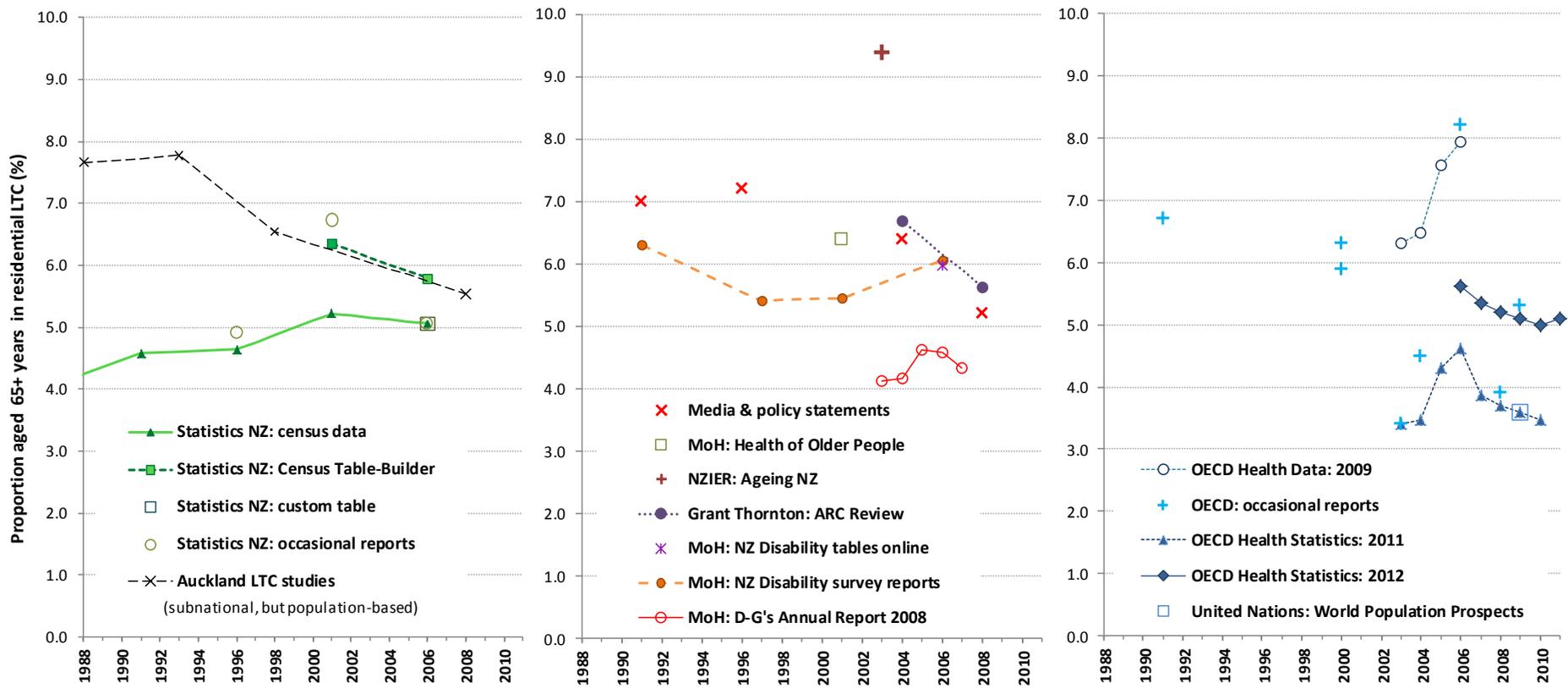


Figure 5-1. Proportion of population aged 65 years and over reported living in residential long-term care in New Zealand

5.4.2 National use of LTC for all aged 65+ years

Reports of the percentage of people aged 65 years and over living in RAC ranged from 3.4% in 2003 in two OECD sources^{99 145}, to 9.4% in the NZIER report for 2003/04¹⁰² also published in Cox and Hope¹⁰¹. Figure 5-1 demonstrates the variability of estimates between sources, even within series. In 2006, the single year with the highest number of reports available (eight), estimates ranged from a low of 4.6%²⁴ to almost twice that, 8.2%³. In general, census-based reports were lower than others, and political and disability sources higher.

5.4.3 Trends

In general, the census reports appeared to show percentages that increased with time, but in most other sources percentages reduced over time. Two of the OECD series and the OECD occasional reports were markedly inconsistent.

5.4.4 Comparison of counts in the Auckland region

Figure 5-2 compares census counts for the Auckland region with counts in residential RAC from three of the Auckland studies, showing an undercount of 28% in 1998 reducing to 8% in 2006. In all three comparisons, census counts for the youngest age group (65-74 years) were fairly well matched, with the discrepancies increasing with age, though reducing over time.

5.5 Discussion

These results demonstrate how problematic has been the reporting of service use within this sector. It does appear that reporting is improving in MoH, the census, and OECD, but it is concerning that discrepancies appear to have been undetected and/or unaddressed for so many years, particularly in OECD reports.

In the census-based rates variability occurred for several reasons. Pre-1996 census counts included only rest-home residents, as counts of long-stay residents in private or public hospitals (where much long-term care was provided) could not easily be separated from those receiving acute or short-stay care. People in other non-private dwellings such as prisons, hospices or acute public hospitals (not only RAC facilities) were sometimes included¹³¹. Census-night counts exclude people

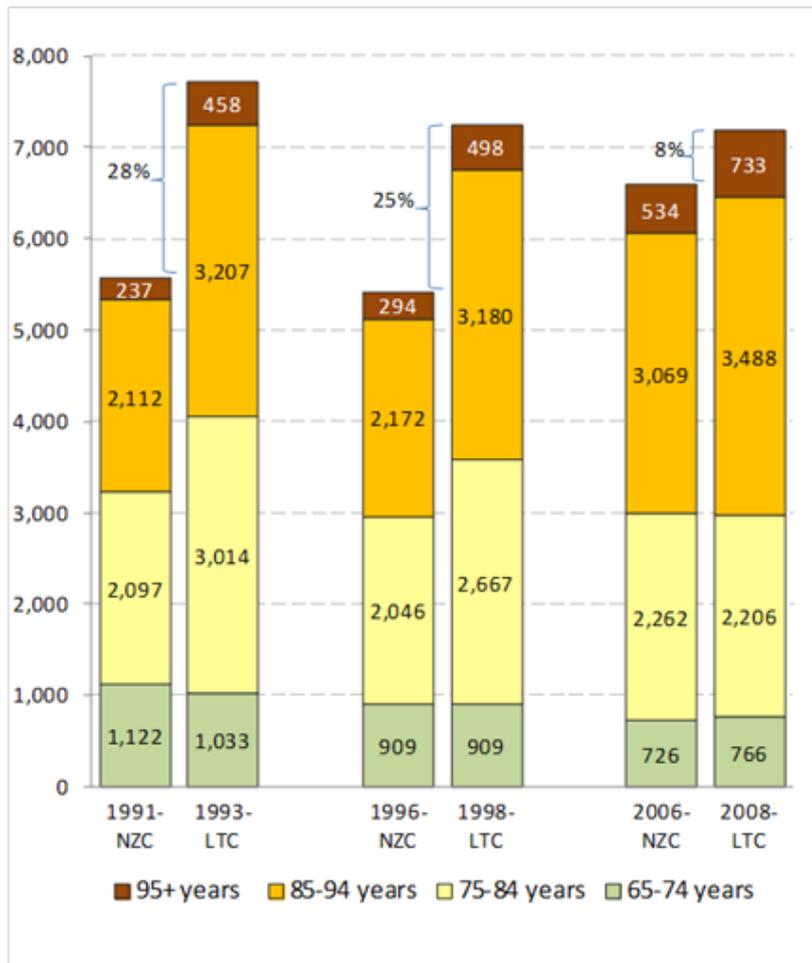


Figure 5-2. Number of people aged over 65 years reported living in residential long-term care in the Auckland region, comparing three Auckland Long-Term Care Studies (LTC) with three NZ National Censuses (NZN)

Source: Adapted from data provided by Statistics New Zealand and the Auckland LTC studies

usually resident in a facility but absent on census night, for example those in acute hospital and also include people who are temporarily in care, for example respite care⁶³.

Slight variability in the denominator in calculations also occurs. In 1996, Statistics NZ moved to use more stable estimates of the *normally resident population* (instead of *de facto* population), in order to adjust for census undercounts and for seasonal variations in temporary absences¹⁴⁹⁻¹⁵¹. These are likely to be responsible for only minor differences in percentages.

As noted in Figure 5-2, the Auckland LTC studies found considerably more people living in care than appear in the census two years previously, using the same geographic boundaries. It is reassuring that with the change in census definitions,

differences between the two sources reduce over time (Figure 5-2), and indeed some of the differences may result from population increases between the relevant census and survey date. Available bed numbers changed little over the 20-year period of the surveys^{86 87}, in spite of population growth, so rates in RAC must have fallen markedly rather than increased as suggested by the census (Figure 5-1).

New Zealand's OECD results were particularly disparate and frequently at variance with other sources. Reasons for this vary, and not all are explainable. In the OECD Health Data series for 2003-2006¹⁴¹, accompanying notes describe that all users over an entire 12-month period are included, thus counts overstate current use to the extent that more than one person uses any bed during the course of a year. For the 2006¹² OECD publication, counts included those receiving LTC services at home as well as those in RAC, consequently over-stating utilisation by about 45%.

In general, variations between estimates (aside from changes over time) appear explainable by definitions used in both the numerator and to a lesser extent the denominator:

- Dwelling type definition: the residential types included, the terminology used and how facilities are classified in the report – through e.g. licensing information, survey or census processes
- Numerator population time definition: all present over a period or a daily average taken across a defined period, or resident on a particular reference date (and if the last, were those temporarily absent included in counts)
- Numerator resident type of stay: only long-stay residents, or also short stay e.g. respite or rehabilitative care, or staff and/or families
- Numerator age: only those aged 65 years and over (or other specified age), or all residents
- Numerator population coverage: provided directly from all residential facilities, or estimated from a sample of facilities, or estimated from scaled-up partial information (and if so, how that was undertaken)

- Denominator reference population: de facto (pre-1991), usual residents (post-1991) or census night
- Denominator time definition – ‘as at’ a particular date, or mean over a period.

Implications for New Zealand policy and practice

Given the inconsistencies in RAC reports, the question arises as to how the quality of the data could be improved – in accuracy, clarity, transparency and consistency. For NZ census purposes, classification of RAC as a place of residence is now well specified. For sources using subsidy data, MoH in 2013 (subsequent to the analyses reported above) generated a new, more stable series based on up-scaled subsidy data and now used by OECD. This series could now be aligned to census counts and then used for estimates during inter-censal periods. Publications and online tables using census counts broken down by age group and gender will permit tracking of trends and improve projections of demand.

RAC residents are costly to governments, not only in direct subsidies but arguably also in primary care consultations, presentations at emergency medical departments, pharmaceutical consumption and acute hospitalisations. It is important therefore that consistent measures are available for monitoring the impacts of policy, during periods of economic and social change. Death certificate data show that a move to a RAC facility is an option eventually taken by more than 38% of older people in New Zealand, and more than 55% of those aged 85+¹³⁰. In order to avert threatened increases in demand (and costs) due to anticipated population ageing, community-based alternatives to RAC are being sought. Improved accuracy and availability of information could assist in developing and testing initiatives to better address the needs of frail older people, and their families and supporters, and in describing the impact of innovations in services.

Implications for international comparisons

International comparisons of health reports are used by countries to benchmark their own health systems. We have shown how variable OECD results are for New Zealand. While OECD reports for 2006 (8.2%) substantially overstated actual RAC use, at the time of release these NZ percentages were assumed to be reasonably comparable with

reports from other countries, for example Norway 4.4%, Netherlands 5.3% and Australia 5.5%¹⁴⁶. If reports for NZ have been so unreliable, for how many other countries does such variability exist? How valid are these international comparisons? Since 1999 the OECD has recognised long-term care receipt as one of a set of health indicators^{152 153}. It has acknowledged the limited comparability of its international data, and has been working to improve the quality and comparability of reporting by more clearly stating the purpose, i.e. to include all those receiving long-term personal or nursing cares and by clarifying definitions^{11 127 154}. While the onus to provide reliable information must be on contributing countries, we suggest all reports describe data derivation and that pre-publication practices include reconciliation with previous OECD reports and with known domestic reports.

Conclusion

Developing good policies requires sound, relevant and credible data. Funders, owners, and operators wishing to invest in RAC facilities depend upon reliable data describing past and present utilisation in order to estimate future demand. This study has shown that such data are only now becoming available for RAC use in New Zealand. If wide variations in reports are common, they may compromise decisions shaping health services for older people.

5.6 Post-script

Publication history

The article first appeared online on 4 June 2013, and in print in June 2013. The work has been presented at several academic conferences and research meetings, as listed at the front of this thesis. The work has also been discussed with policy advisors at the Ministry of Health, Statistics NZ and with NZACA, the industry organisation. The work has also been shared with relevant officers at OECD offices in Paris.

Developments

Since the paper appeared, additional relevant data have become available. The 2015 version of the DHSS ARC Demand Planner estimates 32,034 occupants, of whom

30,829 were aged 65+ (4.8% of the estimated population aged 65+ years) on average during the financial year 2013/14.

Reports from the 2013 Census (postponed because of the Canterbury earthquakes in February 2011) commenced in 2014. Customised tables show that in total 30,762 were *usually resident* in those facilities on census night. Of these, 1,656 (5.4%) were aged under 65 years, most of whom probably entered as young, physically disabled residents, with a few being live-in staff or their families. A further 795 in a RAC facility on census night were recorded as usually resident elsewhere – presumably those in for short-stay. Not included are those RAC residents absent on census night, such as those in acute hospital or on temporary family leave.

The demand planner reports are methodologically consistent with those for the previous seven years, and are very close to census counts.

Figure 5-3 illustrates recent dramatic increases in census counts of RAC residents aged over 85 years, while numbers at ages below 85 years changed less dramatically.

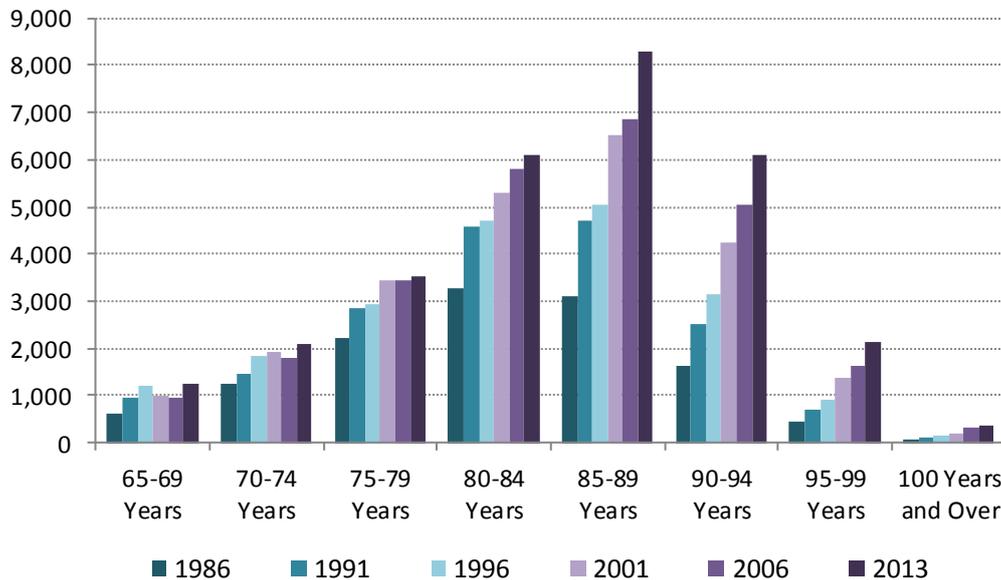


Figure 5-3. Usual residents in RAC census year, by age group

Source: Statistics New Zealand 1986-2013 census counts. This work uses customised Statistics New Zealand data which are licensed for re-use under the Creative Commons Attribution 3.0 New Zealand licence. Note that changes of definition have occurred which make the growth between 2001 and 2006 appear greater than is actual.

Based on the 2013 census data reported above, the percentage of all those aged over 65 years in RAC appears to have fallen to 4.8 (6.1 for women, 3.4 for men) unadjusted

for age. There remains an apparent discrepancy with the higher proportions reported in the NZ Disability Survey which are unexplained.

Though the number of residents has increased since 2006, the number of facilities classified in the census as residential care for older people decreased, from 848 nationwide to 822 in 2013. Whereas in the 2006 national census, 20.9% of facilities had more than 50 residents, by 2013 this had increased by almost seven percentage points to 27.7% (personal communication, Statistics NZ). Increasing facility size has been noted in other countries. Efficiencies of scale are important if adequate returns on investment are to be gained by service providers¹², the changes may signal the gradual demise of smaller 'mum and pop' local community facilities. It is possible too that larger sizes reflect that new facilities may more likely be members of an international chain.

These and other results were discussed with representatives of Statistics NZ. Since that discussion, reports on housing in NZ have begun to include sections on RAC when previous reports included only those living in private dwellings¹⁵⁵. This is advisedly at least partly in response to those discussions.

Research direction

Chapter 5 demonstrated problems in counting of RAC in NZ and indicated the many parties involved and/or interested in measuring RAC. Only very simple counts and percentages of cross-sectional use of RAC were included. Rates are known to vary by gender and age, and likely (albeit not well documented) to vary by ethnicity and/or country of birth. In these analyses, no account was made for changing population structures (in age distributions, gender balance, ethnicity or country of birth). Further, the reasons for some of the variability are valid and understood; for example, in reports that relate to government expenditure it is reasonable to report numbers in receipt of government subsidies rather than also include those who pay entirely privately. Nevertheless, for overall perspectives on the sector, there seems little reason to exclude RAC residents aged under 65 years or those who pay privately.

An underlying difficulty with most of the counts most often used is that they are based upon subsidy payment data. The following chapter identifies and demonstrates methodological biases that arise as a result.

Chapter 6. Biases in describing residents in long-term residential aged care

Preamble

In the Chapter 5, wide discrepancies in reporting were demonstrated. In the current chapter, the focus moves to another source of misreporting: that relating to the method of using government subsidy payment records to derive total numbers using RAC. The chapter assesses firstly the method of national estimation of total RAC use using subsidy payment records, to demonstrate how current methods of generalising from counts of subsidised residents underestimates counts of unsubsidised residents, and describes how characteristics of the unsubsidised differ from the subsidised. The problem of estimation of private payers is discussed and a suggestion of how more accurate counts may be obtained. This chapter is presented much as published, with minor edits.^b

6.1 Abstract

Objective

In New Zealand, no reliable information describes use of long-term residential aged care. Instead, when estimating use, records of government subsidy payments are upscaled to adjust for private payers. This paper assesses consequential bias in reporting use of long-term care and considers the implications.

Methods

Data from OPAL (Older Persons' Ability Level), a census-type survey of residents of aged-care facilities in Auckland in 2008, linked to routinely-collected hospitalisation, mortality and subsidy data from national databases. Demographic, functional and service use characteristics of unsubsidised residents were compared to those of subsidised residents.

Results

Records of 5961 OPAL residents aged 65+ years were matched with subsidy data; 25% were unsubsidised. In low-level care (51% of all), unsubsidised residents had similar care needs to subsidised residents, but were 1.7 years older on average

^b Broad JB, Ashton T, Lumley T, Boyd M, Kerse N, Connolly MJ. Biases in describing residents in long-term residential aged care. N Z Med J. 2014;127(1402):50-61.

($p < 0.001$) with shorter length of stay. In high-level care (41% of all), unsubsidised residents had significantly lower care needs on six different measures and were less likely to die during the follow-up period. Upscaling yields undercounts at all care levels.

Conclusions

National reports derived from current upscaling methods undercount residents. Stratification by region and age group would improve estimates. Age and care needs are misrepresented. Population policies that depend upon upscaled counts should, where possible, ascertain the biases introduced.

6.2 Background

Information used to describe use of residential aged care (RAC) in New Zealand (NZ) has been poor, there being no organisation or system that records all residents¹⁵⁶. As a result, when estimates of demand are required – for improving care quality, workforce or service planning, financial budgeting or investment planning – estimates are based upon the only available data, namely payments for government-subsidised RAC. Means-tested subsidies are available to NZ residents aged 65 years or over (65+) who are assessed as needing residential care, whether in rest-home care (lower level care), or in higher levels of care (specialised secure dementia care, hospital or psychogeriatrics care)¹⁵⁷. However those not subsidised – believed to be 33% to 38% – are not included¹⁴². Upscaling is therefore used in official counts to adjust for private payers. NZ counts supplied for international comparisons, e.g. to the United Nations⁴⁶ (not upscaled) and the OECD¹⁵³ (upscaled) are also based on subsidy payments records.

Upscaling of data to account for people with absent, incomplete or missing information is a long-established and accepted method of counting whole populations^{158 159}. Unless explicitly manipulated, upscaling inherently assumes that the unknown ‘people’ are similar in all relevant respects to those for whom information is available. If residents who pay privately or are funded through other sources such as regional schemes for palliative care (and therefore are absent from the government payments systems) are dissimilar to those in the subsidy databases – by gender, age or care needs for example – demand estimates may mislead. In other populations those

who pay privately differ from those whose care is subsidised, for example private payers in Korea need lower levels of care¹⁶⁰, and in USA are hospitalised less^{161 162}. Whether use of upscaled information from subsidised residents fairly describes total use in NZ is unknown. Assessing the accuracy of information about utilisation and demand is important to address, especially given that in NZ use of RAC in late-life appears higher than other countries¹³⁰.

Subsidy systems in New Zealand

Means-tested RAC subsidies for those aged 65+ years cover the full costs of care where assets are below a defined threshold¹⁶³. Additionally, those in high-level care and who would otherwise pay privately (because their assets are higher than the threshold) are entitled to receive a “top-up” subsidy for costs that exceed an amount known as the “maximum contribution”. This maximum contribution is central to upscaling. The level is set at the most recently agreed contract price in each local authority area for 24-hour rest-home care. It is the same for all residents regardless of the level of care they receive¹⁶⁴. The proportion of residents receiving a government subsidy varies by place and over time, partly through normal fluctuations and partly because, after 2006, the asset threshold increased by \$10,000 annually (until 2012, after which the annual increase is set by the Consumer Price Index)^{157 165}. In July 2013 the asset threshold was \$215,132. Subsidy recipients retain a small personal allowance, but otherwise their superannuation or other pension or main benefit contributes directly to the costs of care¹⁵⁷.

Upscaling to count RAC use

Because the cost of high-level care is always greater than the maximum contribution, all those in high-level care are assumed to receive a subsidy. Counts of the number of residents in this level of care are therefore not upscaled. But for counting those in rest-home care, counts of the “known”, i.e. those receiving a subsidy, are upscaled. The extent of upscaling, the “upscaling factor”, is determined by the proportion of all in continuing high-level care (continuing hospital care, specialist dementia care or psychogeriatrics care) who pay the maximum contribution privately and receive a “top-up” payment [MoH personal communication, April 2013]. The expressed assumption is that the proportion subsidised is the same across all levels of care.

MoH estimates that in 2008 32% of residents in high-level care received a “top-up” subsidy¹⁶⁶ and would not have been subsidised if in lower-level care. The upscaling factor applied to counts of residents known to be in rest-home care was therefore:

$$\begin{aligned} &1 / (\text{proportion on higher-level care subsidy}) \\ &= 1 / (1 - 0.32) \\ &= 1 / 0.68 \\ &= 1.47 \end{aligned}$$

The impact of upscaling is therefore substantial, for it implies an increase of 47% over the residents known to receive subsidy payments. Based on that, for 2008, MoH official estimates were that 5.2% of the population aged 65+ years were in RAC at any one time, 15.4% of those aged 85 years or over¹⁴².

This paper examines whether unsubsidised residents differ systematically from private payers in demographic or functional characteristics, considers whether current upscaling methods lead to bias, and makes suggestions to improve national RAC estimates.

6.3 Methods

In 2008, we conducted OPAL, a census-type survey of RAC facilities in the Auckland region^{86 87}. Pre-coded forms were delivered to all certified facilities, with facility staff completing one form for each resident on the survey night (10 September 2008). Questions covered 36 demographic, functional and care items. Residents were classified by bed type - predominantly rest-home care, dementia care, continuing hospital care or psychogeriatrics care. In all, 154 (89%) of all 172 eligible facilities participated. Of these, 149 also provided separate, numbered lists of National Health Index (NHI) numbers, the unique personal health identifiers enabling linkage to national service use datasets. Validity of NHI numbers was checked using a check-digit calculator and corrections made where possible. Survey methods are described in detail elsewhere^{86 87}.

OPAL residents (n=6816) were categorised into one of three distinct care groups: rest-home (including short-stay such as respite care but excluding dementia care), dementia care, and hospital care (including psychogeriatrics care). We dropped people with no suitable matching NHI (n=525), those aged under 65 years (n=341) because subsidy criteria differ for younger residents, and those in other care groups (n=92). Some were

dropped for more than one reason. Thus we retained for these analyses only those 5961 residents who were matched (by NHI, gender and age).

Subsidy data for residents were sourced from transactions data from the MoH Client Claims Processing System (CCPS). Each resident was classified as in receipt of a rest-home care subsidy, a dementia care subsidy, a hospital care subsidy, or as having no record of a subsidy in the two-week subsidy payment period around the survey. In the few instances where a resident received two or more subsidies, such as during a period of change, the higher-level subsidy was used. Electronic records of public hospitalisations, emergency department presentations and deaths during the 22-months following the survey were obtained from routinely collected MoH data.

Demographic, selected functional characteristics and service use (retrospectively and prospectively) of subsidised and non-subsidised residents were compared. Absolute differences with 95% confidence intervals were tabulated and tested using chi-square and t-tests. Upscaling factors for each of three age-groups in rest-home care were recalculated based on OPAL data using the formula shown above. Ethics approvals were obtained for the survey ([NTX/08/49/EXP](#)) and for matching to health and subsidy data ([NTX/10/EXP/087](#)).

6.4 Results

6.4.1 Receipt of subsidy

Of the 5961 residents, about half (3059, 51%) were classified by the facility staff as in rest-home care, 445 (8%) were in specialised dementia care, and 2457 (41%) in hospital-level care. In hospital-level care and dementia care almost all OPAL residents were known to MoH because they received either a full subsidy or a top-up; those who were on OPAL but not subsidised are shown in red (Figure 6-1). In rest-home care, the unsubsidised proportion in OPAL (shown in orange) that is incompletely estimated by MoH upscaling (shown in tan), is again shown in red.

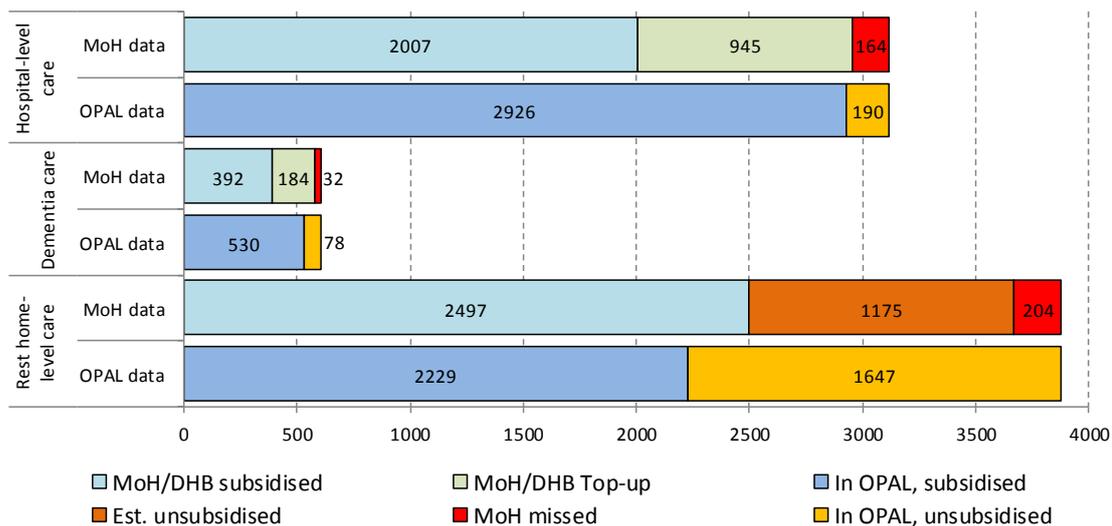


Figure 6-1 Comparison of Auckland OPAL counts with MoH upscaled counts for the same region at the same time

Linkage with subsidy payments data revealed that overall 30% received a rest-home subsidy, 6% a dementia care subsidy and 39% a hospital subsidy (Table 6-1). No subsidy was paid for 25%: 43% of those in rest-home care, 13% in dementia care and 6% in hospital-level care. Of those in rest-home care, 55% received a rest-home subsidy and 2% a higher level subsidy. Of those in hospital-level care, 92% received a hospital-level care subsidy and 2% a lower level subsidy (Table 6-1).

Table 6-1 Receipt of subsidies among residents aged 65+ years

| | Care type in OPAL | | | |
|-----------------------------------|------------------------------|---------------------------|-----------------------------|-----------------------|
| | Rest-home n=3059 51.3% | Dementia n=445 7.5% | Hospital n=2457 41.2% | All n=5961 100% |
| | % | % | % | % |
| Subsidy type: | | | | |
| Rest-home subsidy | 55.3* | 6.3 | 1.9 | 29.6 |
| Dementia care subsidy | 0.2 | 77.1 | 0.3 | 6.0 |
| Hospital subsidy | 2.0 | 3.8 | 91.7 | 39.1 |
| No subsidy, private paying | 42.5 | 12.8 | 6.1 | 25.3 |

*Values shown in bold font indicate agreement between subsidy data and OPAL care type.

6.4.2 Upscaling factors

To estimate the total number of rest-home residents (unsubsidised and subsidised) from subsidy records, the upscaling factor would be:

$$\begin{aligned} \text{Number in rest-home care in OPAL / Number on rest-home subsidy} \\ = 3059 / (0.296 * 5961) \\ = 3059 / 1764 \\ = 1.73 \end{aligned}$$

Effectively, each 100 residents on a rest-home care subsidy in Auckland represented 173 residents. Use of a scaling factor of 1.47 would “miss” 466 Auckland rest-home residents (Figure 6-1). The unsubsidised proportion rose with age group, so improved age-specific upscaling factors for rest-home care increased from 1.31 in those aged 65-74 years, to 1.69 in those aged 75-84 years and 1.84 in those aged 85+ years.

Unsubsidised residents were identified in higher care levels as well as rest-home level care. Upscaling factors specific to care level would be: 1.24 (=445/(0.06*5961)) for dementia care and 1.05 (=2457/(0.391*5961)) for high-level care.

6.4.3 Resident characteristics

On average, unsubsidised *rest-home* residents were 1.7 years older than subsidised residents at the time of survey ($p < 0.001$), 3.1 years older when first admitted to the facility ($p < 0.001$) and their stay-to-date in the facility 1.4 years shorter ($p < 0.001$) (Table 6-2). In most functional and care needs unsubsidised and subsidised residents were similar. However, the unsubsidised appear to be less bed- or chair-bound (2% vs. 4%, $p = 0.05$), need less help to eat (2% vs. 4%, $p = 0.04$), and more often visited an emergency department during the following 22 months (50% vs. 43%, $p < 0.001$).

In *hospital-level care*, in many respects the unsubsidised and subsidised were similar (Table 6-3). However the unsubsidised were significantly more likely to be men, were as likely to be married or partnered, and were less dependent – in needing help to walk, being chair or bed-bound, needing attention at night, orientation to time and/or place, and urinary incontinence. More were seen urgently in the 2-weeks prior to OPAL (11.3% vs. 3.8% respectively, $p < 0.001$) however fewer died within the 22-month follow-up period (39.3% vs. 54.5%, $p = 0.003$).

Table 6-2 Characteristics of rest-home care level residents aged 65 years and over

| | Unsubsidised n=1299 | Subsidised n=1760 | Difference (95%CI) | p-value |
|------------------------------------|------------------------|----------------------|-----------------------|---------|
| Men (%) | 26.3 | 27.6 | -1.36 (-4.54, 1.81) | 0.40 |
| Married or partnered (%) | 14.6 | 16.0 | -1.42 (-3.99, 1.15) | 0.28 |
| Age group at survey (%): | | | | |
| 65-74 years | 6.3 | 12.8 | | |
| 75-84 years | 28.5 | 30.7 | | |
| 85+ years | 65.2 | 56.5 | | <0.001 |
| Age at survey, years (mean, SD) | 86.4 (6.9) | 84.7 (7.9) | 1.7 (0.1, 2.2) | <0.001 |
| Age at admission, years (mean, SD) | 84.5 (7.0) | 81.4 (8.5) | 3.1 (2.6, 3.7) | <0.001 |
| Length of stay, years (mean, SD) | 1.8 (2.1) | 3.3 (3.6) | -1.4 (-1.6, -1.2) | <0.001 |
| Admitted from acute hospital (%) | 31.4 | 30.9 | 0.56 (-2.76, 3.88) | 0.74 |
| Needs help to walk (%) | 4.8 | 4.7 | 0.11 (-1.41, 1.63) | 0.88 |
| Chair or bed-bound (%) | 2.4 | 3.6 | -1.25 (-2.46, -0.04) | 0.049 |
| Needs help to eat (%) | 2.2 | 3.5 | -1.29 (-2.47, -0.11) | 0.038 |
| Needs help to use toilet (%) | 20.3 | 19.1 | 1.23 (-1.62, 4.09) | 0.40 |
| Needs attention at night (%) | 36.6 | 36.1 | 0.43 (-3.02, 3.88) | 0.81 |
| Lost orientation to time (%) | 29.3 | 26.3 | 3.02 (-0.20, 6.24) | 0.064 |
| Lost orientation to place (%) | 12.0 | 11.3 | 0.70 (-1.60, 3.01) | 0.55 |
| Incontinent of urine (%) | 26.1 | 27.7 | -1.57 (-4.75, 1.60) | 0.33 |
| Persistently wanders (%) | 3.7 | 3.9 | -0.23 (-1.59, 1.14) | 0.75 |
| Behaviour disturbs (%) | 13.1 | 14.6 | -1.46 (-3.92, 1.01) | 0.25 |
| In two weeks prior to OPAL survey: | | | | |
| Seen acutely by GP (%) | 12.4 | 10.9 | 1.54 (-0.77, 3.85) | 0.19 |
| Seen urgently in hospital (%) | 3.8 | 3.4 | 0.36 (-0.98, 1.70) | 0.59 |
| In 22-months after OPAL survey: | | | | |
| Emergency department visit (%) | 50.4 | 42.6 | 7.73 (4.16, 11.30) | <0.001 |
| Any hospital stay (%) | 56.3 | 55.3 | 0.99 (-2.57, 4.55) | 0.78 |
| Death (%) | 32.3 | 33.1 | -0.74 (4.10, 2.63) | 0.67 |

Comparisons for those in *dementia care* showed the 13% unsubsidised were similar to the subsidised except they were less likely to require attention at night (63.2% vs. 78.9%, $p=0.009$) and less often seen by a GP in the 2-weeks prior to OPAL (3.5% vs. 15.5%, $p=0.015$) (results not shown).

Table 6-3 Characteristics of hospital care level residents aged 65 years and over

| | Unsubsidised n=150 | Subsidised n=2307 | Difference (95% CIs) | p-value |
|------------------------------------|-----------------------|----------------------|-------------------------|---------|
| Men (%) | 38.0 | 30.4 | 7.61 (-0.38, 15.61) | 0.050 |
| Married or partnered (%) | 26.7 | 26.9 | -0.21 (-7.51, 7.10) | 0.96 |
| Age group at survey (%): | | | | |
| 65-74 years | 16.0 | 11.6 | | |
| 75-84 years | 28.0 | 33.4 | | |
| 85+ years | 56.0 | 55.0 | 0.17 | |
| Age at survey, years (mean, SD) | 84.1 (8.8) | 84.7 (7.7) | -0.6 (-2.0, 0.9) | 0.42 |
| Age at admission, years (mean, SD) | 81.7 (9.8) | 82.3 (8.0) | -0.5 (-1.8, 0.8) | 0.51 |
| Length of stay, years (mean, SD) | 2.3 (3.7) | 2.4 (2.6) | -0.1 (-0.5, 0.4) | 0.75 |
| Admitted from acute hospital (%) | 56.7 | 55.6 | 1.10 (-7.09, 9.28) | 0.79 |
| Needs help to walk (%) | 9.3 | 17.6 | -8.31 (-13.22, -3.40) | 0.009 |
| Chair or bed-bound (%) | 36.7 | 46.3 | -9.58 (-17.56, -1.61) | 0.022 |
| Needs help to eat (%) | 28.0 | 35.0 | -7.02 (-14.47, 0.42) | 0.080 |
| Needs help to use toilet (%) | 54.7 | 58.3 | -3.59 (-11.82, 4.63) | 0.39 |
| Needs attention at night (%) | 80.7 | 88.3 | -7.63 (-14.08, -1.18) | 0.006 |
| Lost orientation to time (%) | 42.7 | 58.3 | -15.68 (-23.84, -7.51) | 0.002 |
| Lost orientation to place (%) | 34.7 | 46.7 | -12.06 (-19.94, -4.18) | 0.004 |
| Incontinent of urine (%) | 46.0 | 60.6 | -14.55 (-22.78, -6.33) | 0.004 |
| Persistently wanders (%) | 6.7 | 5.9 | 0.77 (-3.33, 4.88) | 0.70 |
| Behaviour disturbs (%) | 19.3 | 22.0 | -2.69 (-9.33, 3.86) | 0.44 |
| In two weeks prior to OPAL survey: | | | | |
| Seen acutely by GP (%) | 20.9 | 16.6 | -4.11 (-2.55, 10.76) | 0.19 |
| Seen urgently in hospital (%) | 11.3 | 3.8 | 7.52 (2.39, 12.65) | <0.001 |
| In 22-months after OPAL survey: | | | | |
| Emergency department visit (%) | 55.3 | 49.8 | 5.57 (-2.64, 13.79) | 0.19 |
| Any hospital stay (%) | 56.7 | 50.8 | 5.91 (-2.28, 14.10) | 0.16 |
| Death (%) | 39.3 | 54.5 | -15.15 (-23.23, -7.08) | <0.001 |

6.5 Discussion

Resident characteristics

Of all residents matched, 25% were unsubsidised: 43% in rest-home care, 6% in hospital-level care and 13% in dementia care. Differences between unsubsidised residents and others were observed in demographic and functional characteristics, and in service use.

In *rest-home* care, the 43% that were unsubsidised appear to be similarly dependent as those subsidised, although older and having shorter lengths of stay. Mortality of the two groups was also similar. Small differences between unsubsidised and subsidised residents in being bed- or chair-bound and in needing help to eat are not compelling given the number of statistical tests. It is curious that the higher rate of urgent hospital presentation post-survey was not observed in the 2-weeks prior to the survey as reported by facility staff nor in actual admissions post-survey. For this care level, the current upscaling method does not bias estimates with respect to care needed, but bias does arise in terms of resident age (undercounting the very old) and length of stay (overstating duration of stay). If not adjusted correctly, overall counts are marked underestimates.

A dissimilar pattern was seen in the 6% who were unsubsidised in *hospital-level care*; they had better function and longer survival than the subsidised. The reasons are unclear: they or their families may be more able to access services, facilities could accept their entry in part as a less resource-intensive income stream, or subsidised residents could enter later in their disability process than others. A longitudinal population-based study would describe care pathways and address these questions and yield more information about how it is that people in this level of care are not receiving a subsidy.

Geographic variability

With 43% of OPAL rest-home residents being unsubsidised, an upscaling factor for Auckland would be 1.73, rather than the 1.47 MoH uses for NZ overall. When the MoH national upscaling factor was used, 466 Auckland residents were missed (Table 6-1). To cross-check these results, the CCPS data were checked for Auckland; 40% of residents in high-level care received top-up payments¹⁶⁶, giving an upscaling factor of 1.67 for rest-home counts, very similar to OPAL's 1.73. Arguably upscaling factors should be region-specific, so higher in Auckland and correspondingly smaller in other regions, according to the CCPS proportions.

That a higher proportion of Auckland residents are assessed as eligible for care yet do not receive a subsidy indicates they are assessed as having greater financial assets than their counterparts elsewhere. The average value of a home is higher in large urban regions including Auckland, where even a small flat or apartment would have a government valuation over the asset threshold of \$215,132. For those where the family

home is not exempt from consideration, it is usually the single most valuable asset when assessing subsidy eligibility. The proportion who need care but who are deemed ineligible for a subsidy will thus be influenced by regional differences in housing values, and such differences are currently increasing rapidly. These geographic variations, together with variations in bed availability, the proportion ineligible (such as those without NZ citizenship or residency), dependency, and health service utilisation will differentially impact subsidy uptake even among those having equal incomes. In an apparent anomaly, weekly subsidy rates are permitted to differ by region while asset thresholds are the same throughout the country. Review of the assets and income tests is suggested in order to avoid geographic inequities.

Unsubsidised residents in high-level care

The finding that use of subsidy data under-reports high-level care is a concern. It has been⁸⁶ and currently (MoH, personal communication) constitutes the area of fastest growth in the RAC sector. Those in dementia or high-level care are not upscaled in national demand estimates as it is assumed that all receive top-up payments and therefore will appear in the payments systems. Contrary to MoH expectations, in Auckland, 6% of people in hospital-level care and 13% in dementia care were unsubsidised. Even if in other regions this percentage is lower, national undercounting is likely.

The policy is that all new or intending residents are formally needs assessed, even if intending to pay privately. Otherwise, should private funds be exhausted the resident could require a government subsidy even if the care assessment did not justify RAC care⁷³. Different reasons may explain non-receipt of subsidy in hospital-level care. Official NZ citizenship or residency is a pre-requisite for subsidy receipt, and Auckland likely has disproportionately more people without citizenship or residency visas than elsewhere¹⁶⁷. But in each region, delays in assessment or in completing the application for subsidy may mean some period is not covered because of mandated time limits. Various regional schemes exist that fund RAC care for palliative care, short-term rehabilitative or convalescent care, or long-term mental health care, rendering a subsidy application unnecessary. For all these reasons, the assumption that all in higher-level care will appear in the CCPS database is invalid. Geographic variations will lead to regional differences in reliability of estimates.

National reporting

Unless specifically addressed, upscaling to account for people with absent (or incomplete) information inevitably assumes that the unknown ‘people’ are similar to those for whom information is available. The proportion that was unsubsidised in Auckland, even in MoH data, differed markedly from national figures, indicating that more accurate national estimates would likely be achieved if stratified by region. Further, in OPAL the proportion paying privately increased with age. Estimation stratified by age group would avoid undercounting at higher ages and over-counting at lower ages. This is important because the older age groups are growing the fastest.

In recent years MoH has vastly improved and standardised its methods of measuring present and future use of RAC¹⁵⁶. In their reports provided to and published by the OECD for the financial years 2006/07 to 2011/12, the proportion of long-term care residents nationally who paid the whole cost of care themselves reportedly rose from 33% to 38%¹⁴². Those estimates use a new database that facilitates ongoing reporting, providing recent counts and projections by age group, by region, and for the nation¹⁶⁶. However neither MoH nor OPAL data can be used to estimate residents missing from high-level care. Though it seems reasonable to use an upscaling factor derived from incomplete high-level care data to low-level counts, the method is not validated. A more accurate method of measurement is needed.

Accurate tracking of residents from RAC entry until discharge is currently possible only for those who are subsidised, and only from the date first subsidised. By 1 July 2015, all facilities will use the suite of health and support needs assessment tools known as interRAI, in particular, the interRAI LTCF (Long-Term Care Facilities Assessment System)¹⁶⁸⁻¹⁷⁰. Extensive international testing of these instruments has demonstrated success in reporting needs for care provision, funding and quality improvement¹⁷¹. It is hoped that roll-out of interRAI will enable prospective tracking of all people receiving long-term RAC, including hospital-level care, from prior to admission through to discharge from the facility.

Strengths and limitations

The OPAL survey was population-based with very high participation. Assessments of dependency, function and care needs were recorded by the usual nurses and/or caregivers within facilities based on the bed-type currently occupied. It covered three

large district health boards that together provide healthcare services to 26% of the older population in NZ^{12 172}. The study is limited in that it describes the situation in 2008, in a region that has been regarded as over-endowed with RAC beds^{12 57}.

Nevertheless, the 25% who were un-subsidised in OPAL is considerably lower than the 37% and 42% in prior Auckland RAC surveys in 1988 and 1993^{13 14}.

Although the response rate of 89% of certified facilities was high, it is possible that the survey does not represent all in RAC at the survey date. When analyses were weighted to adjust for non-response, to test the impact of non-participation, percentages changed only at the 2nd decimal place. In the interests of simplicity these were not reported.

For 525 (under 8%) of residents surveyed, data matching was not possible because no NHI was provided or because important identifiers (age, gender, location) in the MoH record were very different from the OPAL record. There is therefore a risk that matching led to bias. However, the unmatched proportion was small and care levels and other characteristics of those dropped correspond well those with linkage data – for example, 52% (vs. 51% with linkage data) were in rest-home care, 7% (vs. 8%) in dementia care and 41% (vs. 41%) in hospital-level care. In comparison, in an industry survey of all NZ facilities, 57% were in rest-home care, 8% in dementia care and 33% in hospital care, but survey participation was much lower, at 43%, and may itself be biased¹⁷³.

Conclusions

Policy and service provision should be informed by the knowledge that unsubsidised residents differ in demographic characteristics from subsidised residents in low-level care, by age and probably by region. Once quality checked, interRAI data may eventually render redundant the current method of estimation. Until then, in deriving NZ estimates of RAC demand, upscaling should take age and region into account to provide for regional variability and to reduce inaccuracies in international comparisons. Research is needed to describe care pathways near the end of life and to understand how those in hospital-level care are not receiving financial assistance for their care.

6.6 Post-script

Publication history

The article was first published online 12 September 2014. Part of the work was presented at the HOPE Selwyn Foundation in Auckland in 2014. The findings have been shared with policy advisors at the MoH and to planners and managers of one DHB.

Developments

Chapter 6 has demonstrated how even when using what are apparently rational and sensible techniques to estimate those not included in subsidy datasets, estimates may mislead. When evaluated against the Auckland 2008 data, use of upscaling of subsidy data for Auckland under-counted residents in both high- and low-level care. Other possible reasons for the undercount at high-level care include that some residents may be classified in OPAL as receiving high-level care but were classified in their last assessment as at low-level care. Another possibility is that OPAL records did not track those in receipt of a loan against the home to cover the costs of care.

The method of estimation used in the latest (2015) ARC Demand Planner has now been amended to stratify not only by Territorial Local Authority (i.e. local body) but also by age group (personal communication, Health Partners Consulting Group).

Research direction

In the next chapter, the emphasis shifts from demonstrating problems with existing measures, to deriving new knowledge – estimating the proportion of older people (aged 65+ years) who use RAC during their lifetime.

Chapter 7 again uses data from the Auckland OPAL cohort and three other smaller datasets to estimate numbers of RAC residents who die in public hospitals, then adds those to the numbers who die in RAC, in order to estimate numbers and proportions who in their lifetimes (after the age of 65 years) enter RAC.

Chapter 7. Likelihood of residential aged care use in later life

Preamble

Chapter 7 presents a novel but relatively simple approach to estimating “lifetime” risk of using RAC. This has not previously been estimated for the NZ population, yet is of interest to older people themselves, informing them in managing their personal savings, and to assist discussion with family members about their preferences for late-life care. It will also inform insurance companies and policy-makers who may contemplate introducing LTC schemes in NZ such as are offered elsewhere including Germany, Japan and South Korea. Equivalent statistics for other countries have used a range of methods, including some that are complex and assumption-laden. NZ estimates are made, and compared with five other countries for which reports are available. This chapter is presented much as originally published, but with the supplementary online material incorporated into the main text, and with minor edits^c

7.1 Abstract

Objectives

In NZ, place of death among decedents aged 65+ years has been reported as occurring in RAC, (38%), acute hospital (34%) or elsewhere (28%). However, “lifetime” risk of use of RAC (or nursing homes) is unknown. A simple method of estimation is demonstrated for NZ and Australia, with comparisons to other countries.

Methods

Deaths of RAC residents in acute hospitals were estimated for NZ from four separate studies and added to deaths occurring in RAC, to derive the likelihood of using RAC after age 65 years. Academic and other sources were searched for comparative reports.

Results

An estimated 18% of RAC residents died in acute hospital in NZ. When added to those who die in RAC, the proportion using RAC for late-life care is estimated at over 47% (66% if aged 85+ years). Of 12 USA reports, the median report was 41%.

Elsewhere, Finland was 47%, UK 28%, Australia 34% to 53%, and Germany 22% & 26%.

^c Broad J, Ashton T, Gott M, *et al.* Likelihood of residential aged care use in later life: a simple approach to estimation, with international comparison. *Aust NZ J Public Health*, 2015;39(4):374-79.

Discussion and Conclusion

Simple estimation using existing data demonstrates that RAC in late life is common. Late-life care services will continue to evolve. Monitoring RAC utilisation is necessary for informed debate about palliative care provision in RAC, use of hospital by RAC residents, and for planning and policy setting.

7.2 Introduction

Long-term RAC is used at any one time by about 4-6% of those aged 65 years or over in many developed countries, including NZ^{127 156 174}. This figure – usually derived from research adopting cross-sectional methods such as censuses and surveys – sometimes leads to the erroneous assumption that only few people use RAC during their lifetimes¹⁷⁵. Inappropriate use of cross-sectional figures for estimating the likelihood of use of RAC – which Kastenbaum and Candy referred to as “the four percent fallacy”^{176 177} – may suggest that the sector is small and affects few people. To avoid such misunderstandings, and for policy and planning purposes, estimates are needed of the likelihood people who having reached the age of 65 years, use RAC at any time before they die, hereafter termed “lifetime use”.

Studies of place of death have been used to answer this question^{176 178-180}. Counts of deaths occurring in RAC are widely available, based on death certificate information. For example, a large international comparison of 21 populations aged 65+ years showed RAC was the place of death for a median of 18% (inter-quartile range [IQR] 14–29%) of decedents¹³⁰. In the USA the proportion was 29% and in Australia and Canada 32%, but in Iceland and NZ the proportion was higher, 38%. Even so, deaths in RAC underestimate total RAC use wherever a non-ignorable proportion of RAC residents die in an acute hospital.

Other than place of death, three methodologies have previously been used to assess lifetime use of nursing homes. These include 1) assembling a population-representative cohort and following it either prospectively until death or from death retrospectively, 2) using the lifetable method (i.e. combining the proportions who enter at each year of age in any given year) as used in demographic projections, 3) using macrosimulation models to describe change of state (here place of residence) e.g. using Markov chains or networks, and 4) using microsimulation models of transition

probabilities between residence at home, residence in RAC, and death, and then simulating lifetime risk. All these methods require the assembly of large or long-established cohorts. In countries including NZ where at present there are no such cohorts, another method of estimation is required if an answer is to be found within a short timeframe. The need for simple methods to estimate lifetime use has previously been recognised¹⁸⁰.

This paper describes a simple method of estimation of lifetime use of RAC for people who reach the age of 65 years. Administrative data for place of death obtained from death certificates are obtained first for the NZ population, derived from all death certificates over a 5 year period. To that figure is added an estimate of the number of RAC residents who die, not in RAC, but in acute hospital. It then compares NZ estimates to published reports for other countries.

7.3 Methods

7.3.1 New Zealand

Deaths in public hospital

National counts of all 112,176 deaths registered for people aged 65+ years during the years 2006-2010 were obtained from the MoH Mortality Collection, summarised by year, age, gender and place of death¹⁸¹. Place of death classification was based on a previously-developed algorithm to categorise place of death recorded as text on the Certificate of Cause of Death, described elsewhere¹³⁰. All those who died in a RAC facility were assumed to be living there – any other death in the facility (such as of a visitor, staff member or family of staff member aged 65+) is likely to be extremely rare and to change counts only fractionally. This count becomes the first component of the overall estimates of lifetime use.

Deaths in public hospital of those who are living in RAC

The second component is the count of deaths that occur in acute hospital but are of RAC residents aged 65+ years shown diagrammatically in Figure 7-2.

For this study four independent sources were used. Briefly, two studies, OPAL and ARCHUS, were of RAC resident cohorts from which were derived the proportions of RAC residents who died in acute hospital. Two other studies were used to describe the

proportion of in-hospital deaths that were of RAC residents. All were analysed by age group (65-74, 75-84, 85+ years) and, where numbers permitted, separately by gender. For each year and age-by-gender group, counts of hospital deaths of RAC residents were estimated in all four studies independently, and the average expressed as a percentage of all deaths each year. The mean percentage across the 5 years was taken as a best estimate of deaths of RAC residents that occurred in hospital. These were added to those that died in RAC to yield estimated lifetime use of RAC. Details of these contributing studies are provided below.

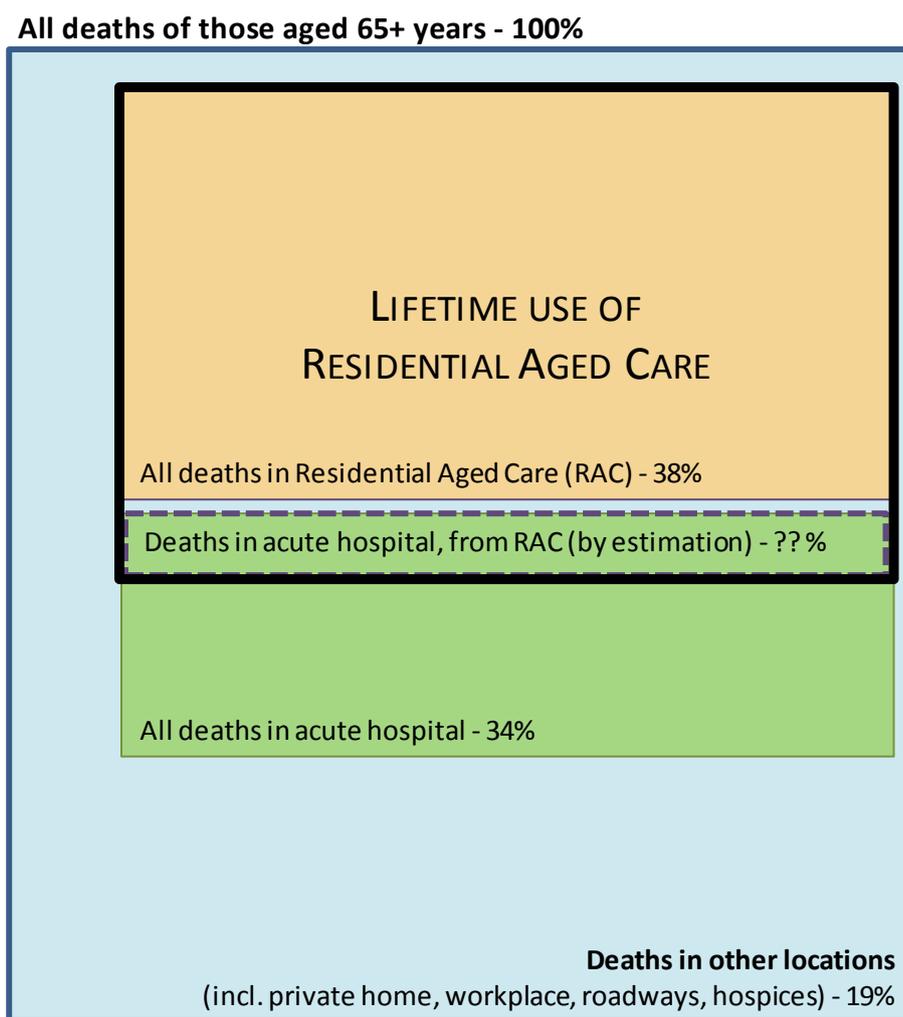


Figure 7-1 Lifetime use of residential aged care in those aged 65+ years in New Zealand, with estimation of deaths in acute hospital

Sources of data

Four different data sources were used to estimate in-hospital RAC deaths.

1. The OPAL study assembled a cohort of all people living in RAC facilities in the Auckland region on 10 September 2008^{86 87}. Follow-up of the OPAL cohort used linkage to national mortality data to 31 December 2009; 2495 deaths in people aged 65+ occurred during the 22 month period. The proportions of all those whose death was in an acute hospital discharge was calculated for each gender and age-group.
2. ARCHUS was a randomised trial of a multi-disciplinary intervention conducted in 36 RAC facilities in the Auckland region 2011-2013^{112 113}. It followed 1998 residents for a period of up to 14 months, recording 402 deaths in people aged 65+ during the follow-up period. The proportion of all those whose death was in an acute hospital was determined by age group, but not gender as counts were small.
3. Records from a DHB in the Auckland region provided information about deaths in its two main hospitals (864 beds) serving a geographical population of about 482,000¹⁸². During the years 2011-2013, 2139 deaths occurred of people aged 65+. RAC deaths in hospital were identified by an indicator that was based on having a date of first placement after a needs assessment for RAC and/or from a hospital admission record if the RAC facility was within the DHB. The proportion of decedents that were aged 65+ and known to be admitted from RAC was derived from the total deaths in the hospital.
4. Records from a non-Auckland DHB provided data for deaths in its 10 acute hospitals serving a geographical population of about 510,000¹⁸³. During the years 2011-2012, 1987 in-hospital deaths occurred. RAC deaths in hospital were identified by having any record of a RAC subsidy payment and were expressed as a proportion of all in-hospital deaths of people aged 65+.

Method of estimation of RAC deaths in hospital

For Sources 1 and 2, with the base being a RAC resident cohort, the number of RAC deaths that occurred in hospital for each age and gender group was derived from death counts as follows:

$$EstRACH = cohHosp / (coh - cohHosp) * popnRAC$$

where:

EstRACH = est. deaths in acute hospital of residents from RAC in NZ population

coh = number of deaths in the RAC cohort

cohHosp = number of deaths in acute public hospital in the RAC cohort

popnRAC = total number of deaths in RAC in NZ population.

For Sources 3 and 4, with the base being in-hospital deaths, the equation was:

$$EstRACH = (hospRAC / hosp) * popnHosp$$

where:

EstRACH = est. deaths in acute hospital of residents from RAC in NZ population

hospRAC = number of deaths in acute public hospital with prior RAC

hosp = number of deaths in acute public hospital in the DHB

popnHosp = total number of deaths in hospital in NZ population.

Official data for deaths (actual registrations and projections) were obtained from Statistics NZ by age group and gender for years 2000-2040¹⁸⁴. Annual death projections for the years between 2030 and 2050 were then used to project future RAC deaths for NZ (see Figure 3-3).

7.3.2 Australia

Unpublished aggregated data for deaths during the years 2004-05 were obtained from AIHW, Australia¹⁸⁵. Similar methods were applied to derive estimated lifetime risk for Australia.

7.3.3 International comparison

For comparison with RAC lifetime use in other countries, PubMed and Google Scholar were searched for population-based reports from other countries. Because of differences in terminology for the sector, and because literature is not necessarily in the academic literature, a wide range of search strategies was used. Reference lists and citations were followed. Studies were excluded if 1) based purely on data for place of death unadjusted for any undercount, 2) if they were for specific diagnostic groups or a subset of the population, or 3) were for years prior to 1990. Estimates were extracted for risk from the age of 65 years if provided, otherwise lifetime risk. Where the report

did not show the mean for the whole population aged 65+, the mean of the gender-specific proportions was used. Official government offices in 26 nations were emailed but none was able to provide relevant data.

No ethical approval was necessary for acquiring national data for deaths, death projections or hospital deaths data due to the summary nature of the data. Ethical approvals for the two research studies that used records for individuals were obtained from the North Health Ethics Committees ([NTX/08/49/EXP](#) for OPAL and [NTY/10/11/090](#) for ARCHUS).

7.4 Results

7.4.1 Place of death in NZ

During the period 2006-2010 an annual average of 28,806 deaths (range 28,389 to 29,312) were registered in NZ. On average 22,464 (78%) occurred among people aged 65 years or over. Of these, about 8,600 deaths (38% of all, 31% of men, 45% of women) occurred in a RAC facility, and 7,700 (34% of all, 37% of men, 32% of women) in an acute hospital (Table 7-2). The proportion dying in RAC increased with age: of decedents aged 85+ years, 54% died in RAC (47% of men, 59% of women). There was no observable trend in percentages of deaths in acute hospital or RAC over the period.

7.4.2 Deaths in hospital of RAC residents in NZ

As described, four data sources were used to estimate deaths that occurred in hospital patients who had previously used RAC, i.e. the second component.

OPAL

Sixteen percent of deaths of RAC residents (19% for men, 15% for women) occurred in an acute public hospital. Among residents who died aged 85+ years (the age group with the largest numbers of deaths), 15% of all (19% of men, 15% of women) died in a public hospital. For men the proportion was similar across age groups, but older women were less likely to die in acute hospital (Mantel Haenszel test for trend p -value=0.001). A summary of the results of these four estimations forms Table 7-1.

ARCHUS

Twenty percent of deaths of ARCHUS residents occurred in an acute hospital setting. There were no significant differences by age group or gender.

DHB A

Of all 2,139 people who died in DHB hospital aged 65+ during the years 2011-2013, 466 (22%), were of residents known to have resided in a RAC facility. Prior to the age of 75, under 10% of deaths of men and women were from RAC. The proportion rose with age, more steeply for women than for men. Fewer men than women were from RAC (16% vs. 23% at ages 75-84, 24% vs. 33% at ages 85+), after adjustment for age (Mantel Haenszel Odds Ratio =0.75 (95% confidence interval =0.64 to 0.88).

Table 7-1 Hospital deaths of RAC residents from four contributing studies

| | 1. OPAL | | 2. ARCHUS | | 3. DHB A | | 4. DHB B | |
|--------------|------------|--------------------|------------|--------------------|------------|-----------------|------------|-----------------|
| | All Deaths | Deaths in hospital | All deaths | Deaths in hospital | All deaths | Deaths from RAC | All deaths | Deaths from RAC |
| | N | % | N | % | N | % | N | % |
| Men | | | | | | | | |
| Aged 65-74 | 100 | 17 | 13 | 8 | 189 | 10 | 126 | 17 |
| Aged 75-84 | 292 | 19 | 30 | 13 | 413 | 16 | 208 | 27 |
| Aged 85+ | 408 | 19 | 81 | 21 | 465 | 24 | 173 | 34 |
| Total 65+ | 800 | 19 | 124 | 18 | 1067 | 18 | 507 | 27 |
| Women | | | | | | | | |
| Aged 65-74 | 68 | 25 | 17 | 24 | 197 | 9 | 75 | 15 |
| Aged 75-84 | 409 | 18 | 45 | 16 | 345 | 23 | 179 | 35 |
| Aged 85+ | 1218 | 13 | 216 | 22 | 530 | 33 | 234 | 48 |
| Total 65+ | 1695 | 15 | 278 | 21 | 1072 | 25 | 488 | 38 |
| All | | | | | | | | |
| Aged 65-74 | 168 | 20 | 30 | 17 | 386 | 9 | 201 | 16 |
| Aged 75-84 | 701 | 18 | 75 | 15 | 758 | 19 | 387 | 31 |
| Aged 85+ | 1626 | 15 | 297 | 22 | 995 | 29 | 407 | 42 |
| Total 65+ | 2495 | 16 | 402 | 20 | 466 | 22 | 995 | 32 |

DHB B

Of decedents aged 65+ in the second DHB, 644 (32%), were of residents for whom an RAC subsidy had been recorded. This rose with age, from 16% among decedents aged 65-74 years, to 42% of those aged 85+ (34% of men, 48% of women).

Among decedents aged 65+ years in the two RAC cohort studies, 16% and 20% of deaths occurred in acute hospital. Of decedents in the two hospital studies, 22% and 32% were known to have used RAC. Applying the mean age- and gender-specific proportions to NZ deaths of those aged 65+ in the years 2006-2010, an estimated 1941 RAC residents annually were admitted to an acute hospital during their last days or weeks of life, and died there. This represents 18% of deaths of RAC residents and 9% of all deaths of those aged 65+.

Table 7-2 Deaths and lifetime use of residential aged care in New Zealand 2006-2010

| | Annual deaths registered in period | | | Estimations | |
|-------------------|------------------------------------|------------------------|-------------|---------------------------------------|----------------------------------|
| | Annual average | Died in acute hospital | Died in RAC | Hospital deaths from RAC ^a | Lifetime use of RAC ^b |
| | N | % | % | % | % |
| Men | | | | | |
| 65-74 years | 2,770 | 36.9 | 15.3 | 4.0 | 19.3 |
| 75-84 years | 4,522 | 37.9 | 29.7 | 7.2 | 36.9 |
| 85+ years | 3,273 | 34.1 | 46.7 | 10.9 | 57.6 |
| Men 65+ | 10,565 | 36.5 | 31.2 | 7.5 | 38.7 |
| Women | | | | | |
| 65-74 years | 1,988 | 38.9 | 18.7 | 4.8 | 23.5 |
| 75-84 years | 3,903 | 37.6 | 36.7 | 9.0 | 45.7 |
| 85+ years | 5,979 | 26.8 | 58.5 | 11.8 | 70.3 |
| Women 65+ | 11,870 | 32.4 | 44.7 | 9.7 | 54.4 |
| All deaths | | | | | |
| 65-74 years | 4,758 | 37.8 | 16.8 | 4.3 | 21.1 |
| 75-84 years | 8,425 | 37.8 | 33.0 | 8.0 | 41.0 |
| 85+ years | 9,253 | 29.4 | 54.3 | 11.5 | 65.8 |
| All 65+ | 22,435 | 34.3 | 38.3 | 8.7 | 47.0 |

Notes:

^a Those who died in acute hospital having previously been in RAC

^b Estimated from summing deaths in RAC and deaths in acute hospital from RAC

7.4.3 Estimated lifetime use of RAC in NZ

When the two components were combined, estimated lifetime risk of RAC use in NZ is 38% (RAC deaths) + 9% (in-hospital deaths from RAC) = 47% overall (39% of men, 54% of women, Table 7-1). For those aged 85+, estimated lifetime use of RAC was much higher, 66% overall (58% of men, 70% of women) (Figure 7-2).

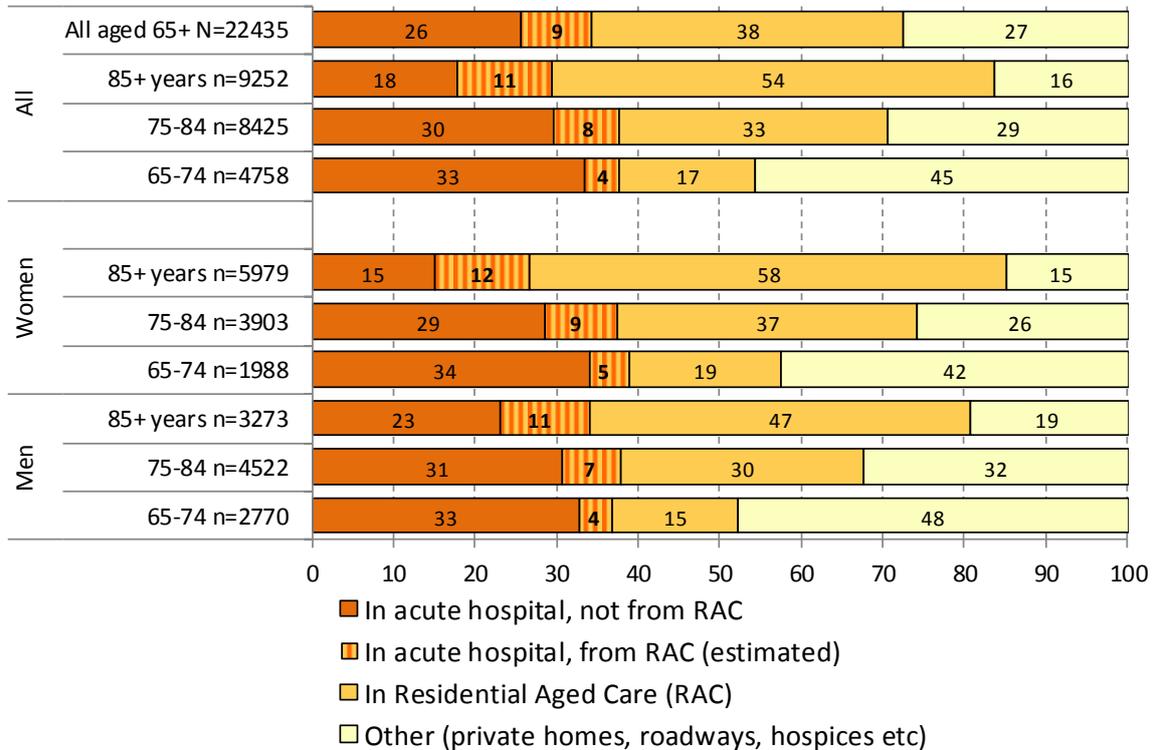


Figure 7-2 Percentage of decedents using residential aged care (RAC) in New Zealand 2006-2010, based on place of death with adjustment for RAC residents who die in acute hospital

7.4.4 Estimated lifetime use of RAC in Australia

A similar method to the one described was applied to place of death data from Australia for decedents over the age of 65 years. A summary of discharges from RAC facilities ‘because of death’ was obtained from the Australian Institute of Health and Welfare (AIHW) for the 2 years from July 2004, whether from a long- or short-term stay. Overall, 54% of all deaths of those aged 65+ occurred in acute hospital, and 32% in RAC¹³⁰. Of all in-hospital deaths of people aged 65 years and over, 13% occurred while ‘on leave’ from RAC, i.e. during an admission to acute hospital directly from

their long-term care facility (based on dates of leave discharge and death). Thus a further 13% of 54% must therefore be added. The estimated lifetime use of LTC in Australia after age 65 years is therefore 32% (from RAC) plus 7% (in-hospital deaths from RAC), making a total of 39%. Again, these estimates do not include those returning to the community and dying there. In comparison, previous reports for lifetime RAC use in Australia were for 34%¹⁸⁶ and 38% when short-stay residents were excluded and 53% when included¹⁸⁷.

7.4.5 International comparisons

In this first known international comparison, 18 reports for other countries were found in a range of publications since 1990 – in clinical and health services, population and demography, sociological, economic, mathematics and insurance industry literature (Table 7-3). Twelve were from the USA, three from Australia and one each from Finland, Germany and the UK. Seven cohort studies were either prospective cohort studies or decedent follow-back studies¹⁸⁸⁻¹⁹⁴. Lifetable studies estimated likelihoods for Australia^{186 187}, USA¹⁹⁵ and UK¹⁹⁶. Six simulation models were from the USA¹⁹⁷⁻²⁰² and one from Finland²⁰³.

Median overall estimates of lifetime use of RAC for people aged 65+ varied substantially: 39% (range 22% to 47%) for decedent cohorts, 34% (26% to 53%) for lifetables and 53% for simulations (35% to 60%). Of the 12 studies from the USA, decedent cohort studies in general yielded lower estimates than other studies, but there was wide variation, from 35%¹⁹⁸ to 60%^{201 202}. Likelihoods for women aged 65+ were on average 1.6 times that of men (after adjusting for age).

7.5 Discussion

New Zealand findings

This method estimates that at least 47% of New Zealanders use RAC after reaching the age of 65 years (and two-thirds of those aged over 85 years). This level of lifetime use in NZ is nearly double the only previous rough estimate of 25%-30%, which was based on non-NZ data⁹⁷. Population ageing will particularly impact NZ given its reliance on residential facilities for late-life care. Given that RAC is funded mainly from general taxation and from private (co-)payments⁶⁷, rather than insurance funds or investments where the hazard is monitored, it is important to monitor RAC use.

Table 7-3 International comparison of lifetime use of residential aged care since 1990

| Country, year & author | Method | Risk from age 65 years* (%) | | | | Risk from higher age (%) | | | |
|--|--|-----------------------------|----------|----------|------------------------|--------------------------|----------|----------|----------|
| | | Note | Men | Women | All | From age... | Men | Women | All |
| Decedent cohort studies: | | | | | | | | | |
| USA 1990, Murtaugh ¹⁸⁸ | Decedents from national long-term care cohort, with next-of-kin interviews | NH 1982-84 | 28 | 45 | 37 | Aged 90+ | 53 | 70 | 64 |
| USA 1991, Kemper ¹⁸⁹ | Survey of next-of-kin of adult decedents in NMFS | As at 1986 | 28 | 46 | 37 | Aged 95+ | 52 | 77 | 71 |
| USA 1991, Kemper ¹⁹⁰ | Lifetime use if turning 65, as previous report ¹⁸⁹ | Projected as at 1990 | 32 | 52 | 43 | | | | |
| USA 1997, Murtaugh ¹⁹¹ | NNHS 1985 NH discharge data with next-of-kin interviews, lifetime NZ use | Projected as at 1995 | | | 39 | Aged 85+ | | | 56 |
| USA 2002, Spillman ¹⁹² | 2 mortality follow-back cohorts, and projected mortality data | As at 1986 As at 1993 | 28 33 | 46 47 | 37 41 | Aged 95+ Aged 95+ | 52 74 | 77 76 | 71 74 |
| Germany 2012, Rothgang ¹⁹³ | Insurance claims of decedents | As at 2000 As at 2009 | 13 16 | 32 35 | 22 (est.) 26 (est.) | | | | |
| Australia 2014, (this report) | Administrative reports of RAC deaths plus hospital deaths during RAC leave | 2004-2006 | | | 39 | | | | |
| Australia 2014, AIHW ¹⁹⁴ | PIAC database, use of permanent RAC during last year of life | 2010-2011 | 34 | 52 | 43 | Aged 85+ | 52 | 68 | 62 |

| | | | | | | | | | |
|--|---|-----------------------|----|----|-----------|-----------|----|----|----|
| New Zealand 2014, (this report) | Place of death, +/- adjustment for deaths of RAC residents occurring in acute hospital, 2006-2010 | Unadjusted | 31 | 45 | 38 | Aged 85+ | 47 | 59 | 54 |
| | | Adjusted | 38 | 55 | 47 | Aged 85+ | 58 | 71 | 66 |
| Lifetable studies: | | | | | | | | | |
| USA 1996, Liang ¹⁹⁵ | Multi-state life-table using four cohort studies, death in NH | | | | 52 | Aged 85+ | | | 70 |
| UK 1997, Bebbington ¹⁹⁶ | National statistics and surveys | 1994-95 | 18 | 33 | 26 (est.) | | | | |
| | | 1995-96 | 20 | 36 | 28 (est.) | Aged 85+ | 30 | 47 | |
| Australia 2000, Liu ¹⁸⁶ | NH care, i.e. excludes low-level care, 1994-95 | permanent only | 25 | 39 | 32 (est.) | Aged 85+ | 48 | 76 | |
| | | + respite | 27 | 41 | 34 (est.) | Aged 85+ | 49 | 78 | |
| Australia 2002, Rowland ¹⁸⁷ | Lifetime use of aged care home, permanent +/- respite care, 1990-2000 | permanent only | 29 | 46 | 38 (est.) | Aged 85+ | 46 | 62 | |
| | | + respite | 40 | 65 | 53 (est.) | Aged 85+ | 62 | 65 | |
| Transition probability simulations: | | | | | | | | | |
| USA 1992, Arling ¹⁹⁷ | 3-state transition probability of residential LTC, in middle-income | Wisconsin NH | | | 55 | | | | |
| USA 1994, Dick ¹⁹⁸ | 3-state transition probabilities, based on 1982--1985 NLTCs & NNHS data | Ever-use NH | | | 35 | At age 85 | 30 | 53 | |
| USA 2005, Kemper ¹⁹⁹ | Microsimulation model using Current Population Surveys from 1993 & 1994 | If turning 65 in 2005 | 58 | 79 | 69 | | | | |
| USA 2007, Brown ²⁰⁰ | Robinson model, NH only, based on NLTCs & NNHS | 1982--1994 | 30 | 48 | 39 | | | | |
| USA 2013, Hurd ²⁰¹ | Robinson's Markov transition model of ever use, using NLTCs & NNHS data | NH 1982--1985 | 27 | 44 | 36 (est.) | | | | |
| | | ALF 1982--1985 | 12 | 20 | 16 (est.) | | | | |

| | | | | | | | |
|---|---|---------------------------|----|----|-----------|------------|----|
| | HRS War Babies & Early Baby Boomer 1992-2004 cohorts, 50+ years | non-parametric simulation | 50 | 65 | 53 59 | Aged 70-74 | 58 |
| USA 2014, Friedberg ²⁰² | Updated Robinson model using 1999-2004 NLTCS & 1998-2010 HRS data | NH | 52 | 67 | 60 | | |
| Finland 2014, Martikainen ²⁰³ | Multistate lifetables using transition probabilities from population register | 1997-2003 | 36 | 59 | 47 (est.) | | |

Abbreviations:

NH = nursing home, LTC = long-term care, ECF = extended care facility incl. nursing home, ALF = assisted living facility, DthCert= Death certificate, USA = United States of America, UK = United Kingdom, NZ = New Zealand, est. =estimated from mean of results provided, proj. = as projected by authors NMFS = National Mortality Followback Survey (USA), NLTCS = National Long-Term Care Survey (USA), NNHS = National Nursing Home Survey (USA), HRS = Health and Retirement Study (USA), PIAC = Pathways in Aged Care database (Australia)

RAC is used mainly for late-life care, Death projections anticipate changes in population structure arising from changing fertility, mortality and migration. Under current care provision and utilisation, population ageing alone will likely lead to increased likelihood of use of RAC in NZ. When the age- and gender-specific rates are applied to projected death counts sourced from Statistics NZ, estimated lifetime use of RAC will increase from 47% in 2010, to 48% in 2020, and to 53% by 2040 (assuming a steady state). This increase is similar to the increase projected for the USA, from 37% in 1986 to 46% over 34 years¹⁹². Changes to entry criteria, funding or service provision, to social preferences and lifestyles (for example as may arise from ageing of new migrants), availability of informal caregivers, and prevalence of disability or functional decline could push estimates up or down¹²⁷. As yet, increased longevity in NZ has been roughly matched by improved health and less disability until later in life – a dynamic equilibrium²⁰⁴. The best measure of current use therefore serves as the best estimate of future use if related to years to end of life rather than years from birth. Sensitivity analyses could be conducted to assess the impact of any overall change in dependency-related demand.

International comparisons

In Australia, the five different estimates range from 34% (not including low-level care) to 53% (including both high and low level of care plus respite care), and seem relatively consistent between reports and over time^{186 187 194}. The latest report covers a 7 year period and clearly shows permanent (only) RAC use rising by 0.5% annually, from 39% in 2003-04 to 43% in 2010-11¹⁹⁴.

In Germany, an insurance decedent cohort over the period 2000 to 2009 had very low risk (26%; 13% of men, 32% of women) of claiming a long-term care benefit¹⁹³. However, studies published in 1994 based on place of death alone reported lifetime risk for Germany more than double these rates (57%; 43% for men, 70% for women)²⁰⁵. Possible explanations for these differences include: that the insurance cohort may not be representative of the population as a whole, that only some care types were included in the insurance estimate, or that major changes occurred over the intervening period.

That most reports were from the USA possibly reflects the comparatively larger role of the insurance industry in long-term care, with corresponding interest and capacity to conduct complex studies. Some aspects of decision-making around use of insurance

are included in the recent paper by Freidburg et al.²⁰². Greater use of RAC for restorative or “step-down” care in the USA will also lead to higher lifetime risk of RAC.

The most striking finding of the international comparison is the variability between countries, and indeed within countries where there is more than one study. Health systems differences are likely to account for much of the variability. Comparisons are complicated by methodological variations – not only because of the different settings and health services available and in analytical methods employed¹⁸⁶, but also in the differing periods of time over which data were collected, in the representativeness of samples, in the choice of age cut-off (if any), in the population of interest (e.g. the total population or an insurance cohort), in definitions of RAC applied (e.g. all or only high levels of care), of stay type (any stay or only long-term stays) and of measure of risk (lifetime use, first use, or accumulative).

Implications

Late-life care has already evolved. In several countries including NZ, RAC has moved from a predominantly housing and social welfare model to a health and care model. Although RAC beds outnumber acute hospital beds by more than three times and it is well recognised that population ageing will bring major challenges¹²⁷, the RAC sector remains largely invisible, residents not included in many population surveys and few reports at a population level²⁵. Beyond the continued surveillance of mortality and other dynamic indicators there is a need to monitor RAC use, to understand better the pressures that lead to RAC entry, and the determinants of length of stay. To avert large increases in demand for RAC, alternatives are needed. Public debate and research is justified – for example to determine if entry to RAC may be avoided or delayed for people with high dependency, without reducing quality of life. Such initiatives may, for example, improve management of chronic diseases, reduce falls, facilitate transitions back into the community post-discharge, provide day-care for people with dementia or other needs, and/or enable shared or sheltered accommodation. Research to investigate risk factors for entry to RAC in a variety of populations may contribute to a better understanding of the reasons for high levels of RAC, and facilitate reassessment of evidence-based alternatives.

Secondly, differences in lifetime risk between countries should caution readers of possible lack of generalisability of research studies. There are fundamental differences

in RAC utilisation, whether in the care provided by RAC facilities or in the mix of residents. Other reports suggest this is so^{206 207}. Findings from intervention studies, whether randomised or not, and also from studies assessing risk factors for RAC care or for acute hospitalisation from RAC, may not be generalisable to other health systems.

Thirdly, the findings have implications for personal financial and care planning¹⁷⁵. Public recognition of personal future risk may raise awareness of the issues around managing housing and investment options, and may clarify expectations for financial advisors, family trusts, attorneys and others. Further, acknowledgement of the high risk of RAC may facilitate or ease discussions with families about preferences for late-life care.

Finally, for immediate needs, knowing that such substantial proportions of older people use RAC for late-life care indicates a need for a palliative care approach within RAC. For example, in NZ, RAC appears to serve as a de facto hospice following an acute hospital stay²⁰⁸. RAC staff are reportedly less willing to undertake training in palliative care when scoring more highly on a measure of burnout²⁰⁹. Yet given that almost half of older people die having lived in RAC, a palliative care approach is relevant and appropriate.

This study offers a method of estimation of lifetime probability of RAC use in countries where large prospective cohorts are not assembled but where place of death information is available from death certificates. In this method, ratio estimators are derived from several smaller studies and applied to known information about place of death in the population. As such, it is simpler and cheaper than methods requiring cohorts of long duration and complex statistical models. The method could be viewed as a first step in developing more complex or refined methods if desired. Because it is based on recent data about place of death, it is less subject to time-related societal changes, unlike those that occur over decades-long cohort studies, and so may be more accurate. Because the method uses the mean of smaller contributing studies (here four separate studies) to adjust place of death information for RAC residents who die in acute hospital, the ratio estimators may be more reliable than using any single source of data. It is likely that in many countries, such smaller datasets will be available to inform the ratio adjustment.

Limitations

Although based primarily on official death counts that are regarded as reliable, the method has some limitations. Four studies were used to estimate the under-count for NZ that arises from RAC residents dying in acute hospital care. Three were Auckland-based, and may differ from other regions. However, more than 25% of NZ's older population lives in the Auckland region, so any regional bias would need to be large and consistent to have a substantial effect on the results.

For several reasons, the estimates of RAC use based on the two NZ cohort studies are undercounts. While they account for RAC residents who die in an acute hospital, they under-represent people who enter RAC for short stays only. In one of the RAC cohort studies, analyses of place of death stratified by duration of stay suggested that residents who had entered RAC within the past year were more likely to die in acute hospital than those with longer stays (19% vs. 15%, chi-square p-value =0.007, unpublished results). Short-stayers are under-represented when cross-sectional studies are used for period prevalence. Accordingly, estimates based on cohorts assembled from cross-sectional studies will emphasise that undercount. Further, counts in the two hospital-based studies will have missed some RAC deaths if not associated with a government RAC care subsidy or if RAC entry was before a formal care needs assessment. In all four studies, some deaths that occurred following RAC may have been miscounted if occurring at home or in a hospice. However, these are believed to be few because in NZ, RAC is almost always regarded as the last place of living, and seldom used for rehabilitation, “step-down” or convalescent care. Therefore for most who use RAC it is, or becomes, a permanent move.

For the comparisons between populations, the lack of a consistent international terminology for RAC means that reports that do not use the most common terms such as “long-term care”, “nursing home” or “long-term care” may have been overlooked.

7.6 Conclusions

This is the first known original study of lifetime use of RAC for NZ. It confirms that the RAC model of late-life care is common. Indeed, in NZ and many other countries it has become the norm by about the age of 85 years. The method used in this study – using recent summaries of place of death in conjunction with estimates of in-hospital

deaths of RAC residents – is simpler and requires less complex data and analyses than other methods used for estimating lifetime risk. Given that the only prior NZ estimate was 20-30%, these results provide significant new information.

Late-life care services have evolved and will continue to do so. High usage of RAC indicates a demand and/or need for such services, a lack of appropriate alternatives and/or use of these alternatives, and emphasises the need for utilisation information. Monitoring RAC utilisation is necessary for informed debate about late-life care in general, including palliative care provision in RAC and use of hospital by RAC residents and to inform planning and provision of care for older people in general.

7.7 Post-script

Publication history

Although at the time of writing the paper is in press, early work on this topic was presented at geriatrics and public health meetings prior to publication, including presentations at the Universitas 21 Celebrating Ageing Graduate Research Conference in Auckland in 2014²¹⁰, and in part at the Australasian Epidemiological Society in 2014 in Auckland²¹¹. Key findings were used in the lead article (front page) and again in subsequent articles in a series of RAC-related articles published by New Zealand's leading daily newspaper, the NZ Herald, in November 2013. Early results were used in a financial advice column in the New Zealand Herald in 2011¹⁷⁵ and again in 2015²¹².

Developments

If the assumption is made that entry to RAC is more closely associated with time to death, rather than time from birth (i.e. age), simple pro-rata calculations can be used to estimate deaths in RAC in the future based on numbers of deaths at different ages for men and women separately as projected by Statistics NZ. The expected numbers of deaths in RAC rise to over 13,000 as soon as 2020, and by 2040 will be close to 20,000 (Figure 7-3) if current patterns continue. Clearly there will be variations based on trends in marital status, ethnicity, home ownership and lifestyles – physical activity and dietary choices in particular.

There are innumerable models in NZ and other countries, both in the present and in the past, of how societies provide late-life care. The main finding of this study – that currently, once they reach the age of 65 years, 47% of New Zealanders use RAC during their lifetimes – signals the importance of measuring and reporting basic counts and rates of the nation’s use of health services and individual needs.

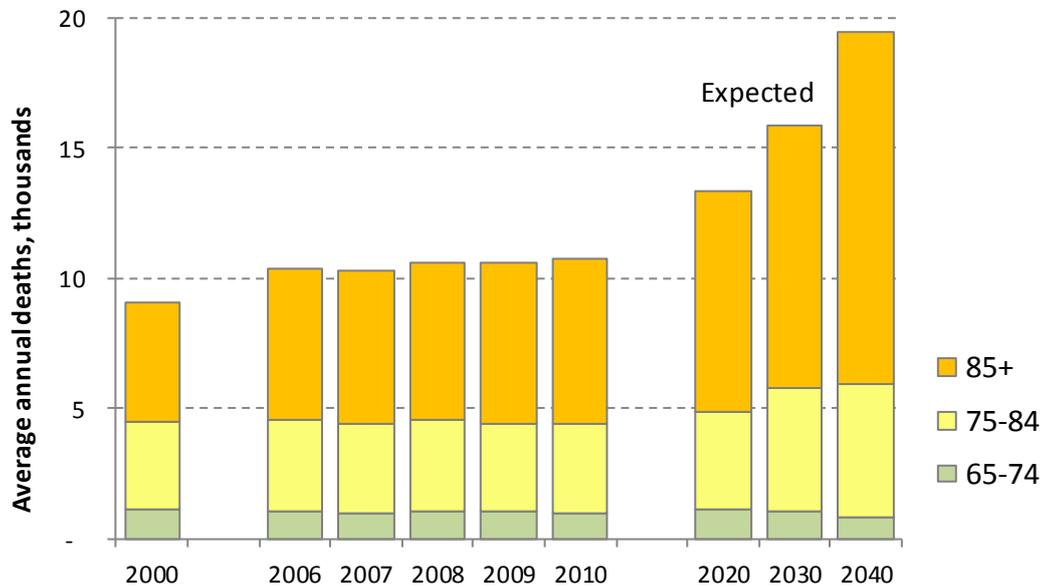


Figure 7-3 Observed and expected numbers of deaths in RAC, selected years.

Until these findings were known, lifetime use was expected to be much lower. For example, in 1996, Jenny Shipley, the soon-to-be Prime Minister of NZ, issued a media release stating “Only a small percentage (7.4%) of people over the age of 65 will ever need residential care”⁸¹. The contrast of this with the evidence that at least 47% use RAC, demonstrates both how under-recognised the sector was, and also how much RAC has become the norm for late-life care in NZ. That currently 66% of people who live to the age of 85 years will use RAC for late life care, with the coming increased numbers of older people, should give needed attention to the sector.

By way of validating these results, MoH counts of those whose RAC subsidies ceased during a recent calendar year because of death were obtained. When expressed as a proportion of all deaths of people in NZ aged 65+, deaths of subsidised people reached 46%. This is only one percent lower than the estimated 47% presented here. It could suggest that the estimates could still understate reality given the numbers of RAC

residents who do not receive a subsidy, or may indicate that that almost all private payers in RAC do eventually exhaust their private funds and receive a government subsidy for late-life care.

Blakely et al. recently estimated health system costs by sex, age and proximity to death in order to estimate future health expenditure²¹³. They reported the health system costs over their full life people dying at particular ages. Costs included were hospital services, pharmaceuticals, laboratory tests and primary care consultations, but not RAC. They reported that the health system costs were \$113,000 for someone dying at age 70 years, compared to \$223,000 for someone dying at age 90 years. Given that almost half the 90-year olds would have used RAC for say two years before death, and that the costs of RAC care were not included, the estimate seriously underrepresents actual costs.

In 2014, informed partly by preliminary findings of this work, the preceding work about place of death, and death projections by age group, Hospice NZ refocused from hospice-provided or hospice-based care to one that attends more to the needs of those living the end of their lives in RAC. To address this, in November 2012 the Minister of Health granted an additional \$15 million over two years to Hospice NZ in order to secure community services to provide for care either in private homes or in RAC.

The simple implication is that about half of all older people use RAC for late-life care – a substantial political lever that should move RAC higher in policy and research priorities. The Board of the NZACA, the Palliative Care Council and other organisations are awaiting the published paper with interest.

Research direction

The ARC Demand Planner suggests that use of RAC varies across NZ. As policies intended to reduce use of RAC are implemented, lifetime risk may be an enduring measure of the impact of policies and service changes, being relatively simple to measure and with clear definitions.

Investigations then turned to how long people stay once they enter RAC, how often the occupant of a bed changes, the patterns of moving through RAC facilities, and the characteristics of new residents. That is the focus of Chapter 8.

Chapter 8. Transitions into long-term care facilities and length of completed stay: a population-based study

Preamble

Perhaps half of all older people use RAC facilities for late-life care in developed countries, yet in only few countries is there information about length of stay or rate of turnover. Estimates of these in other countries have involved expensive, technically complex and/or long-duration research processes. In this chapter reweighting is used, re-analysing available survey data to derive estimates of turnover and length of stay, and to describe characteristics of new residents. The chapter is presented as submitted for peer-reviewed publication, with minor edits^d.

8.1 Abstract

Objective

Almost half those who reach 65 years will use nursing homes for late-life care, but use is not well described. This paper estimates length of completed stay and resident transitions over 12 months in Auckland (population 1.4m).

Methods

Census-type survey of nursing home residents, matched with the National Mortality data to describe transitions. Proportional hazard and renewal methods were used to describe and assess length of stay. Variance estimates were reweighted to account for incompleteness of data and length-biased sampling.

Results

When adjusted for length-biased sampling, an estimated 9676 residents (95% CI 8368-10985) used care over 12-months, with turnover of 64 per 100 occupied beds. Median length of completed stay was 2.0 years, 17% dying within 3 months; 23% surviving over 5 years. After adjustment for gender, age group and level of care, those who entered via acute hospital were at higher hazard.

^d Broad JB, Lumley T, Ashton T, Davis PB, Boyd M, Connolly MJ. Transitions into long-term care facilities and length of completed stay: a population-based study. Submitted.

Conclusions

Survey data adjusted for length-biased sampling can be useful when long-term cohort studies are unavailable. Appropriate reweighting enables estimation of period prevalence, to identify risk factors, and to derive transition probabilities useful for simulations. Reweighted analyses may therefore yield new and useful information about transitions into, between and out of RAC.

8.2 Background

In Finland²⁰³, Australia¹⁹⁴ and the USA²⁰², at least 40% of those who reach the age of 65 years use residential aged care (RAC) late in life because they can no longer live independently. In many countries, beds in RAC facilities (including nursing homes or other aged-care institutions) number more than three times those in acute hospitals. Yet despite the well-recognised fact that populations are ageing and numbers of deaths rapidly rising, the sector is often invisible – in policy debates, strategic planning, and government reports²⁵. If decisions about models of clinical care, policy, planning and allocation of population resources are to be well-founded, it is important to understand the care dynamics in late life^{214 215}.

This lack of information is apparent in NZ, where at least 47% of those who reach the age of 65 years use RAC for late-life care²¹⁶. Declining population rates of RAC use since the 1980s⁸⁶ have been accompanied by higher dependency⁸⁷. But NZ has no population-based information on how often an occupant of a bed is replaced by another, nor, once a resident enters RAC care, or how long they remain. Instead, as in Ireland²¹⁷ and British Columbia, Canada²¹⁸, national reports about RAC utilisation in NZ depend upon government subsidy payment records which incompletely report those paying privately for their care^{12 71}. Dependence on payments data may unwittingly mislead because unsubsidised residents differ systematically from those subsidised in demographic characteristics, care needs and in stay duration²¹⁹.

In stable populations, epidemiologic methods have long recognised that prevalence is estimable if incidence and duration are known²²⁰. The converse, algebraically, is less well recognised, i.e. cross-sectional survey (prevalence) data may be used to estimate incidence. The probability an individual is included in cross-sectional surveys is related to length of “exposure” or “survival” – in this case, to the length of stay in the

facility. If using cross-sectional data to describe all those who enter or leave RAC facilities over a period, survey estimates simply derived will inevitably be biased towards those with greater length of stay²²¹. This *length-biased sampling* impacts not only length of stay estimation but also that of age at admission or prevalence of other characteristics. More formally, the sample mean becomes a biased estimator of the population mean. Recognised statistical methods that allow estimates adjusting for this bias include: direct standardisation²²², truncation and censoring in survival analysis²²³, probability weighting in multi-stage samples²²⁴, case-cohort²²⁵ and counter-matched designs²²⁴.

In the current chapter we effectively use reweighting to convert a cross-sectional survey to a population-based study of period-prevalence in Auckland RAC facilities, in conjunction with nationally-collected mortality data. We characterise residents at entry to RAC, describe RAC transitions, then estimate *length of completed stay* and *turnover* (proportion of residents being replaced each year).

8.3 Methods

Data collection

A census-type survey (OPAL) was conducted of RAC facilities certified to provide long-term care for older people within the Auckland region (population 1.4 million). Survey methods are reported in detail elsewhere^{86 87}. Briefly, all certified RAC facilities (elsewhere known as nursing homes), whether *rest-homes* (lower-level care) or *private hospitals* (continuing care facilities with 24-hour nursing cover) were invited to participate. Staff in the facilities completed a three-page form for each resident, covering demographic, stay, care level and functional information.

Resident details retained included age, gender, marital status, previous residence, whether entry was via an acute hospital and date of entry to this facility. Resident care level, or bed-class, was classified as temporary (respite or rehabilitation), long-term rest-home care (low level care), long-term hospital (high level) care (usually in a private hospital), long-term secure dementia care, or long-term psychogeriatrics care. Using each resident's unique National Health Index identifier (NHI), dates of death were obtained from the National Mortality database. Length of completed stay of those who died was determined from date of entry to this facility and date of death.

For those with no date of death within 22-months, length of stay was assumed to be from date of entry to this facility to 22-months post-OPAL and censored at that date. MoH also provided indicators of government subsidy payments, if any, for the two week period around the survey date, regardless of date of payment. Subsidy receipt was classified as rest-home (low-level) or high-level (dementia, hospital or psychogeriatric) care. Residents who entered the facility within the 30 days prior to OPAL date were analysed as new residents.

Weighting

Using standard adjustment methods for survey data, weights were derived to represent residents who were not present in the final dataset, and also to adjust for length-biased sampling. Firstly, for non-response: 19 of 172 facilities (11%) did not participate in the OPAL survey. Participation differed by facility type (rest-home or private hospitals) and for-profit status. Non-response weights were derived for each participating facility and applied to resident records. This initial adjustment (1°) *non-response weight* was based on facility type and for-profit status. Previously reports have used this non-response weight^{86 87 208 219}.

Six further adjustments were then made. Facility size was obtained from formal certification data and also from the facility coversheet that recorded number of residents on the survey night. Because survey forms received did not always match that count, often (but not always) being lower than anticipated, a second facility-specific weight (2°) was derived to adjust for *missing forms*. The third source of loss was from non-matching with MoH data. This arose because some facilities chose not to provide their residents' unique NHI numbers and some NHIs that were provided did not match any resident, either because of an invalid NHI or non-matching key characteristics (e.g. highly improbable age). A (3°) weight for *non-matching* was calculated based on the ratio of number of residents to matched records within the bed-class. The product of these four weights (4°) was termed the *population weight*, and used for the cross-sectional analyses in this paper.

To describe residents entering over a 12-month period based on the 42 days prior to OPAL, and to derive appropriate confidence intervals, a (5°) *new resident weight* was calculated from the population weight multiplied by 365/42. Where the resident lived at least 12-months, effectively the bed would have been occupied throughout, so no adjustment for length-biased sampling was required. Otherwise, a (6°) *length-biased*

correction was used to estimate 12-month prevalence. It depended upon the length of stay to date (`lengthofstay`, in days) and length of post-OPAL follow-up, i.e. time from survey to death (`fu12m`, in days):

$$1 + ((365 - fu12m) / (lengthofstay + fu12m))$$

Finally, the product of this and the population weight was calculated, termed the (7°) *combination* weight and used for period-prevalence analyses including for estimates of turnover, deaths and length of completed stays.

Statistical analyses

Descriptive analyses were conducted using the survey analysis procedures available in SAS 9.4 and R 3.2. These use weights to compute variance estimates based on survey design using Taylor series linearisation. Turnover was expressed as the ratio of new residents over a 12-month period per 100 occupied beds.

Hazard ratios for time to death were modelled using proportional hazards models, also using Taylor series linearisation. The survival function was estimated from the length-biased cross-sectional data using the left-truncated product-limit¹²⁴. Given the survival function, the events form a renewal process, where residents enter, leave, and are replaced. Blackwell's Theorem states that this process settles to an equilibrium where the number of events per bed in t years is t/μ , where μ is the mean length of stay¹²⁵. Rounding of estimates has resulted in small discrepancies in summation.

8.4 Results

Health authority records in 2008 identified 8816 certified beds in 172 RAC facilities in greater Auckland. In the OPAL survey, 6816 useable forms were received; 23 were unusable (Table 8-1). Previously-published reports were adjusted for facility non-response only: 7611 residents (59% in rest-home care); 69% were women (median age 87 years) and 31% men (median age 82 years); length of stay to date was markedly skewed with 13% under 3 months and 19% over 4 years^{86 87}.

NHI records were matched for 6271 residents. Before weighting and across the full study dataset, 5033 (80%) had no items missing; 1070 (17%) had one or two variables imputed. The mean (unadjusted) revised population weight was 1.29 (maximum 3.11). The impacts of re-weighting are shown in Table 8-1. Using the population weight, cross-sectional counts were estimated as 8076 (4792 or 59% in rest-home care, 3284

or 41% in hospital care), an overall occupancy of 92%; few (105, 1.3%) were classified as temporary residents, i.e. for rehabilitation or respite care.

Table 8-1 Residential aged care residents in Auckland derived from OPAL cross-sectional data and the impact of adjustments

| | All | Bed class | |
|--|--------------|-----------------------------------|-----------------------------------|
| | | Rest-home or secure dementia care | Hospital or psycho-geriatric care |
| Certification | | | |
| Facilities with certified beds (N=172) | | | |
| Number of beds certified | 8816 | 5177 | 3639 |
| | 100.0% | 58.7% | 41.3% |
| Participation | | | |
| Facilities participating in OPAL (N=152) | | | |
| Occupancy reported on facility cover sheet | 6783 | 3968 | 2815 |
| | 100.0% | 58.5% | 41.5% |
| Unadjusted counts | | | |
| Number of forms received | 6839 | - | - |
| (→23 not useable) % | | | |
| Forms in basic dataset | 6816 | 4022 | 2794 |
| (→545 unmatched) % | 100.0% | 59.0% | 41.0% |
| Matched with outcomes data | 6271 | 3659 | 2612 |
| % | 100.0% | 59.3% | 40.7% |
| For cross-sectional counts | | | |
| Adjusted for facility non-response only | 6980 | 4069 | 2910 |
| 95%CIs | (6037-7922) | (3503-4636) | (2269-3551) |
| % | 100.0% | 58.3% | 41.7% |
| 95%CIs | - | (52.6-64.0) | (36.0-47.4) |
| Adjusted also for non-matching, missing forms & clustering | 8076 | 4792 | 3284 |
| 95%CIs | (7028-9123) | (4148-5436) | (2569-3998) |
| % | 100.0% | 59.3% | 40.7% |
| 95%CIs | - | (53.7-65.0) | (35.0-46.3) |
| For 12-month period prevalence | | | |
| Adjusted also for length-biased sampling | 9676 | 5314 | 4363 |
| 95%CIs | (8368-10985) | (4558-6050) | (3382-5343) |
| % | 100.0% | 54.9% | 45.1% |
| 95%CIs | - | (48.8-61.0) | (39.0-51.1) |

#95%CI = 95% confidence intervals obtained using Taylor series linearisation

8.4.1 Characteristics of new residents

Based on reweighting, an estimated 5147 (95% CI=4327-5968) new residents entered during a 12-month period: 67% from a private home, 10% from a retirement village, and 23% from another RAC facility (Table 8-1). Of all new residents, 63% were women; 57% were widowed. For the first 30 days, 46% received no government subsidy, 44% received a high-level subsidy and 11% a rest-home subsidy.

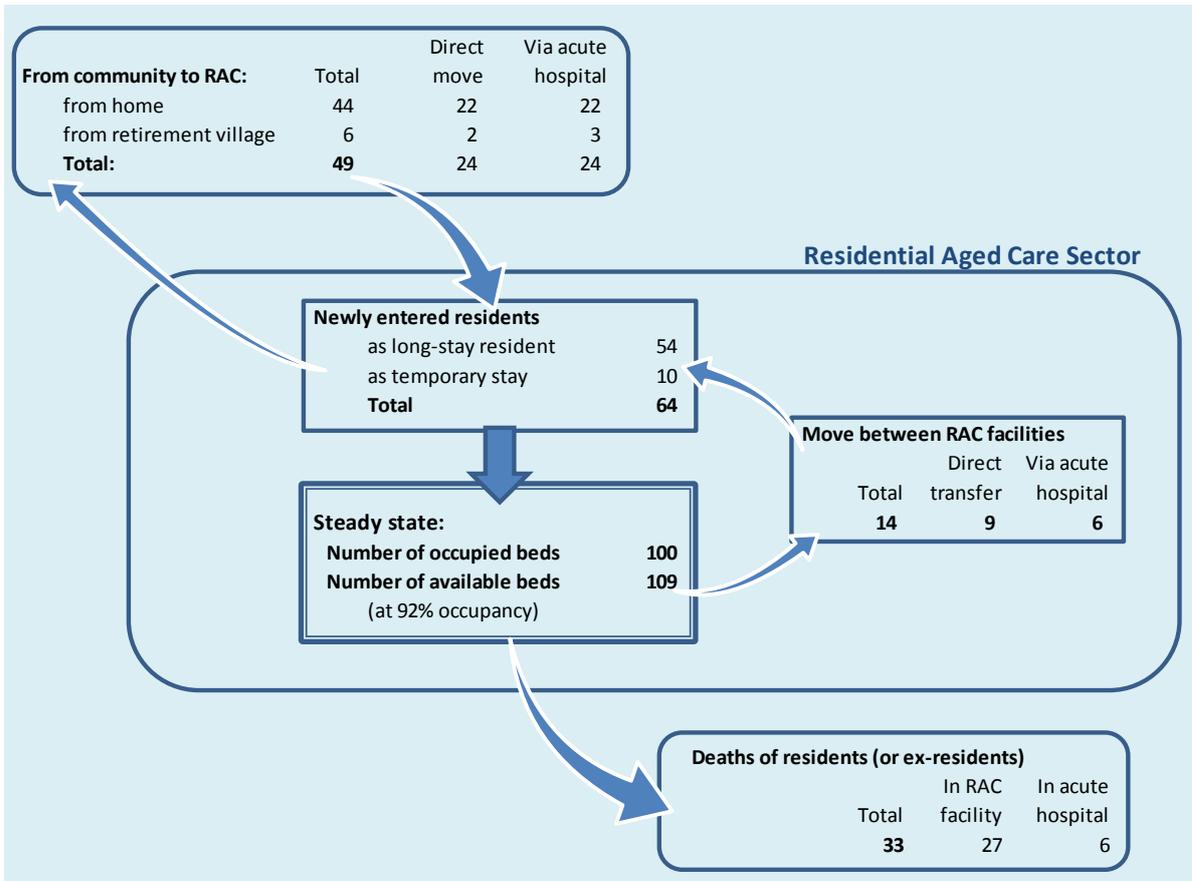


Figure 8-1 Transitions through the Auckland residential aged care (RAC) sector, showing numbers of inward and outward movements per 100 occupied beds over 12 months

* Summation of rounded estimates results in minor discrepancies in totals
Hospitalisations are shown only when part of entry or exit pathways.

8.4.2 Care transitions

Using the combination weight, an estimated 9676 (95% CI=8368-10,985) residents used RAC beds over a 12-month period. Resident turnover during 12-months was estimated at 64 newly-entering per 100 occupied beds (Figure 8-1). Forty-nine of these entered from the community, including 24 via acute hospital; 14 entered from another facility, of which six were via an acute hospital (Table 8-2).

Table 8-2 Entry to residential aged care during a 12-month period

| | % of all new residents (N=5147) | Per 100 occupied beds per year |
|------------------------------------|--|---|
| All new entrants | 100 % | 64 (54-74) |
| Pathways into RAC, from: | | |
| home, direct to this RAC | 34 (28-40) | 22 (17-26) |
| home, via hospital | 35 (29-40) | 22 (17-27) |
| other RAC, direct to this RAC | 13 (10-17) | 9 (6-11) |
| other RAC, via hospital | 9 (6-12) | 6 (3-8) |
| village, direct to this RAC | 4 (2-6) | 2 (1-4) |
| village, via hospital | 5 (3-7) | 3 (2-5) |
| Subsidy status at this entry | | |
| on higher-level care subsidy | 41 (35-47) | 26 (20-32) |
| on rest-home subsidy | 11 (8-15) | 7 (5-9) |
| no subsidy at entry | 48 (42-53) | 30 (24-36) |
| Gender and age group at admission | | |
| all women | 62 (57-68) | 40 (32-47) |
| 18-64 years | 3 (1-5) | 1 (0-2) |
| 65-74 years | 13 (9-17) | 5 (3-7) |
| 75-84 years | 27 (22-32) | 11 (8-13) |
| 85+ years | 57 (52-62) | 23 (18-27) |
| all men | 38 (32-43) | 24 (19-29) |
| 18-64 years | 8 (4-12) | 2 (1-3) |
| 65-74 years | 17 (10-23) | 4 (2-6) |
| 75-84 years | 29 (22-36) | 7 (5-9) |
| 85+ years | 46 (38-55) | 11 (8-14) |
| Marital status: | | |
| widowed | 57 (52-62) | 36 (30-43) |
| married or partnered | 32 (27-37) | 20 (16-25) |
| single, separated or divorced | 11 (8-14) | 7 (4-9) |
| Bed class at survey | | |
| to long-stay hospital-level care | 38 (30-45) | 24 (17-31) |
| to long-stay rest-home care | 40 (33-46) | 25 (20-30) |
| to long-stay secure dementia care | 7 (3-10) | 4 (2-6) |
| to long-stay psychogeriatrics care | 1 (0-4) | 1 (0-2) |
| to short-stay or temporary care | 15 (10-20) | 10 (6-13) |

* Based on residents who entered within 6-weeks prior to the OPAL survey, adjusted for facility non-response, data incompleteness, non-matching to outcomes data, and clustering within facility

#95%CI = 95% confidence intervals obtained using Taylor series linearisation

8.4.3 Deaths and length of stay

Over 12 months, 2511 deaths were estimated to have occurred (33 per 100 residents). Based on previous work, six of these occurred in acute hospital²¹⁶. Median length of completed stay for long-stay residents was 2.0 years (Table 8-3), mean=3.0 years); 17% died within 3 months of entry, 25% by 6 months, and 23% lived over 5 years.

Table 8-3 Length of completed stay (i.e. time from entry to residential aged care to death), of long-stay residents

| | Median length of completed stay (years) | Proportion surviving: to 3mths | to 5yrs |
|-----------------------------------|---|-----------------------------------|---------|
| All deaths within 12-month period | 2.0 | 0.83 | 0.23 |
| Gender | | | |
| women | 2.2 | 0.84 | 0.22 |
| men | 1.6 | 0.81 | 0.18 |
| Age group at admission | | | |
| 18-64 years | 5.0 | 0.90 | 0.50 |
| 65-74 years | 3.1 | 0.85 | 0.33 |
| 75-84 years | 2.0 | 0.82 | 0.23 |
| 85+ years | 1.7 | 0.82 | 0.16 |
| Previous residence | | | |
| Home | 2.0 | 0.80 | 0.22 |
| Retirement village | 2.7 | 0.94 | 0.26 |
| Other RAC | 1.7 | 0.87 | 0.20 |
| Entry via acute hospital | | | |
| yes, via hospital | 1.4 | 0.76 | 0.16 |
| no, direct | 2.7 | 0.91 | 0.28 |
| Bed class at survey | | | |
| long-stay rest-home care | 3.3 | 0.92 | 0.36 |
| long-stay secure dementia care | 3.2 | 0.93 | 0.31 |
| long-stay hospital-level care | 1.0 | 0.73 | 0.10 |
| long-stay psychogeriatrics care | 2.0 | 0.81 | 0.27 |

* Adjusted for facility non-response, data incompleteness, and non-matching to outcomes data, with time maximum set to 10 years and excluding temporary residents

In proportional hazard models, those admitted in the oldest age group, 95+ years, were at much higher hazard (HR=2.33, 95% CI=1.93-2.82) compared to those aged 75-84 years; those admitted at younger age were at lower risk (Table 8-4). The hazard ratio

for men was higher than for women (HR=1.72, 95%CI=1.57-1.89), and higher levels of care were associated with higher risk, e.g. hospital-level care HR=1.83 (95%CI=1.65-2.04). RAC as prior residence (HR=1.25, 95%CI=1.12-1.39) and entry to the facility was via an acute hospital stay (HR=1.23, 95%CI=1.13-1.60) were also associated with shorter survival.

Table 8-4 Hazard ratios for time to death from entry to this facility, for long-stay residents

| | Hazard ratio* & 95%CI# | p-value |
|---|---------------------------------------|----------------|
| Men (vs. women) | 1.72 (1.57-1.89) | <0.0001 |
| Age group at admission (vs. 75-84 years): | | |
| 18-64 years | 0.24 (0.18-0.31) | <0.0001 |
| 65-74 years | 0.56 (0.49-0.66) | <0.0001 |
| 85-94 years | 1.77 (1.61-1.95) | <0.0001 |
| 95+ years | 2.33 (1.93-2.82) | <0.0001 |
| Entry via acute hospital (vs. direct) | 1.23 (1.13-1.60) | <0.0001 |
| Bed-class at survey (vs. long-stay rest-home care): | | |
| long-stay secure dementia care | 1.34 (1.20-1.51) | <0.0001 |
| long-stay psychogeriatric care | 1.35 (1.13-1.61) | 0.0009 |
| long-stay hospital-level care | 1.83 (1.65-2.04) | <0.0001 |
| Previous residence (vs. home) | | |
| Retirement village | 1.13 (0.94-1.36) | 0.19 |
| Other RAC | 1.25 (1.12-1.39) | <0.0001 |

*Adjusted for facility non-response; data incompleteness, non-matching to outcomes data and length-biased sampling, clustered within facility

#95%CI = 95% confidence intervals obtained using Taylor series linearisation

8.5 Discussion

Length of stay

Of all who entered as long-stay residents, half died within two years of entry. This is considerably sooner than might be expected from survey data alone, for on average the residents surveyed would be half-way into their total stay. In the 2008 survey this was 1.7 years, lower than in previous Auckland surveys (mean stay to date was 2.2 years in 1988, 1.9 in 1998, unpublished results), indicating the extent that length-biased sampling occurs in cross-sectional studies. Further, although at survey only 1.3% were for temporary care, 15% of new residents each year were for temporary stays; they may well return for either short- or long-term stays later.

Of long-stay residents, 17% died within 3 months of entry and a further 8% by 6 months. These stay durations are very similar to those in Australia, where, of residents who left permanent care due to death (90% of all discharges), 17% died within 3 months and another 8% by 6 months¹⁹⁴. However in England, 50% of long-term RAC residents in low-level care and 55% of those in high-level care died within 30 days of entry, however almost 40% of these stays were for temporary care²²⁶. In care home facilities in Bupa (a large international provider chain), mean length of stay to death was shorter, 600 days (1.64 years) compared to 3.0 years in Auckland⁵⁵. These disparate results confirm previous findings that long-term care use varies between countries¹³⁰.

With reweighted analyses effectively ‘filling’ beds as they became vacant, 49% of residents are shown to enter via acute hospital stay, whereas the cross-sectional data showed only 40% entered via acute hospital. As expected, the hazard ratio for death was related not only to care level but also to age at admission, to gender, and to prior residence. After adjustment for these variables, the 23% higher hazard for those entering from an acute hospital stay suggests that different entry pathways could lead to opportunities for improved care provision. Indeed, Kane has recently argued that entry direct from hospital should not be permitted but that improved models of post-discharge and sub-acute care be developed that provide for more thoughtful decision-making in the time of stress or when rehabilitation and recovery are incomplete²²⁷.

Transitions

Overall, turnover is estimated at 64%, i.e. 64 in 100 residents change over 12-months. Higher resident turnover has consequences for facilities. Each new resident requires additional staff time to settle, to have their needs assessed and preferences for care and attention recognised, and for staff to understand the indications of any instability (more likely in new residents). It is well recognised that staffing resources should rise in response to increased dependency⁸⁷. These analyses suggest they should also respond to faster resident turnover.

In Auckland, cross-sectional rates of use of RAC have fallen over a 20 year period⁸⁶. These trends may not continue. In many countries, policies and planning relating to RAC have become high priority because of the costs of ongoing care and expected growth in demand from ageing populations. Kemper and others in USA used

microsimulation to estimate demand for LTC by people turning 65 years in 2005. They predicted that 69% will have some long-term care need (at home or in RAC), 37% will use RAC, with mean predicted length of stay 1.1 years¹⁹⁹. In Australia, microsimulation models predicted that numbers of older people needing low-level RAC will double and those requiring high-level RAC will more than triple between 2006 and 2051²²⁸. Microsimulation studies using NZ and Australian data to test different health service scenarios do not yet include RAC²²⁹. Findings from this study could inform credible transition probabilities in appropriate models.

Strengths and limitations

Usually incidence studies seek a closed cohort, that is a complete set of new or 'incident' cases followed until no longer prevalent (i.e. in this case to discharge or death) or a complete set of discharge records. Such long-term cohort studies can take many decades, and in many countries, including NZ, no unbiased cohort exists. When a closed cohort is unavailable, reweighted analyses may provide valid incidence estimation, as demonstrated here.

These estimates improve our understanding of pathways through RAC during a 'usual' year. They are based on a large population-based sample, albeit now six years old. With 33 deaths per 100 occupied beds per year on average, they draw attention to the high use of RAC for end-of-life care and also to the high rate of transfer between facilities. Residents were followed up only through death records; length-of-stay estimates therefore under-report because stays in previous facilities were not included as part of the total length-of-stay. Length-of-stay may be decreasing, because facilities now exist that provide for long-term care of younger disabled people who previously have had few options other than RAC.

Use of population weights assumes that missingness, in item non-response or in missing or non-matched forms, occurs randomly at each step. None of these assumptions is likely. Generalising from new residents over a single 6-week period assumes that trends and seasonal variations are unimportant. Repeated entry of short-stayers may in part explain why there are 48 new residents per 100 entering while only 33 deaths. Because the hazard was found to be not constant, a 10-year maximum was imposed in the models and may also contribute to the imbalance. The relationship between hospitalisations and the risk of death is ignored; estimates may improve if that relationship were modelled.

Conclusions

Survey data adjusted for length-biased sampling can be useful when long-term cohort studies are unavailable. With appropriate reweighting, such data may be employed to estimate period prevalence, to identify risk factors in predictive or explanatory models, and to derive transition probabilities useful for simulations. Reweighted analyses may yield new and useful information about transitions into, between and out of RAC in NZ. There are opportunities to intervene to avert or delay RAC admission and a need to plan for long-term care needs of older people given the costs of ongoing care and expected growth in demand.

8.6 Post-script

Publication history

This chapter was submitted to a journal early 2015 and was favourably reviewed. Revisions were made in response to reviewer feedback, and the paper resubmitted. Parts were presented at the Australasian Epidemiological Society meeting in Auckland in September 2014²¹¹, at a HOPE Foundation symposium in Auckland in 2014²³⁰, and at a University of Auckland Continuing Education public lecture in October 2014²³¹.

Research direction

Robert Kane, a highly-regarded researcher in the field in the USA, recently produced a provocative paper arguing strongly for a completely new model of LTC, one that does not allow admission to LTC directly from hospital, but instead requires a “cooling off” period, with support²²⁷. The usefulness, feasibility and costs of these and other options need to be considered and tested, with attention focussed on the quality of life of older people, fit for the society and local conditions, and permitting choices.

The following chapter describes use of hospital services – admissions and emergency department presentations – after people have moved into RAC facilities.

Chapter 9. Hospital stays and emergency department (ED) presentations in residents of aged care facilities: a population-based study

Preamble

Following on from estimating turnover and completed length of stay in the Chapter 8, this chapter estimates the use of secondary care services from RAC facilities – emergency department presentations and hospital admissions. Currently available estimates, including those presented in the Grant Thornton Service Review, were based on residents in receipt of a subsidy.^e

9.1 Abstract

Objectives

International attention is being given to the need to reduce hospital admissions from residential aged care (RAC) facilities. For New Zealand (NZ), little is known about hospital utilisation from RAC. This paper aims to address this lack of information.

Design, setting and participants

Observational study based on a cohort assembled from a census-type survey of residents of all RAC facilities in the Auckland population.

Measurements and analysis

Hospitalisations and emergency department (ED) presentations data for a 12 month period, sourced from national health databases. Re-weighted analyses adjusted for length-biased sampling to estimate annual rates, and proportional hazards models were used to predict ED presentation.

Results

Of 172 participating facilities, 152 returned forms for 6,816 residents. Once re-weighted, an estimated 9,677 people used RAC over 12 months; 69% were not admitted to public hospital care. For every 100 occupied RAC beds, 51 (95% CI 47-56) admissions occurred, of which 38 (95% CI 35-42) were acute. Rate of ED presentation

^e Broad JB, Davis PB, Boyd M, Connolly MJ, Ashton T. Hospital stays and emergency department presentations in residents of aged care facilities: a population-based study. Submitted.

was 41 (95% CI 37-45) per 100 occupied beds per year. In the proportional hazards model predicting ED presentation, residents in higher level care (including nursing-homes) were less likely to present to ED than those in rest-homes (low-level care); men, those aged 85+, and those recently entered RAC were more likely to present to ED, as were those in for-profit facilities.

Conclusion

Rates of ED presentation in Auckland were comparable with those in other countries but hospitalisation rates were lower than reported elsewhere. Factors associated with ED presentation may indicate how better to manage acutely unwell residents within the place they call home.

9.2 Introduction

It is widely recognised that acute admission to hospital is not always the best option when an older person requires immediate health care²³². Transfer from residential aged care (RAC) to acute care may lead to disorientation, discomfort and anxiety, cause iatrogenic events (e.g. infections and falls) and can incur needless cost¹⁸. Developing and testing interventions such as supports, education or advice to staff that may help manage residents with acute care needs within the facility, under the care of their primary physicians, is therefore attractive^{233 234}. Further incentive for improving within-facility care has come from reports that RAC residents have rates of emergency department (ED) presentations and hospitalisations that are twice those of community-dwelling older people^{15 16}. Population ageing and fears of related cost increases suggest a need for strategies and health policies both to improve the quality of care of those living in RAC facilities and to reduce the frequency and costs of hospital presentations.

In the USA, reports have described the frequency, diagnoses and costs of admissions from RAC facilities²³⁵⁻²³⁷. Reports are also available for Australia²³⁸, Canada²³⁹ and Sweden¹⁵. Almost all these focus on admissions from nursing homes, or higher-level care. Rates of ED presentations from RAC have also been investigated^{16 27 240}. In NZ, a major sector review reported that RAC clients used almost 2,500 hospital bed-days per 1,000 people, or about 2.5 bed-days per resident per year¹². Two NZ trials of RAC-based interventions have reported hospital admissions from RAC. One conducted in

2007-08 reported 2267 admissions from 1553 beds over 24 months, a rate of 0.73 admissions per bed per year, but did not include unsubsidised residents (about 25% of residents)²⁴¹. Another, conducted in 2012-14 reported 0.67 acute admissions per year of resident follow-up¹¹³.

In some ways however, ED presentations are of greater interest than admissions because they are more in the control of RAC facility staff. Compared to long-stay RAC residents, ED presentations and hospital admissions are more frequent in residents who have recently entered RAC²⁴²⁻²⁴⁴. Our recent report of hospital admissions in new entrants to RAC describes rates of admission from 12 months before entry to 12 months post entry showed rates post-entry reduced to 0.42 per year during months 1-6 post-entry, falling to 0.37 per year during months 7-12²⁴⁵. While this work confirms for NZ the patterns found by Kristensson et al. in Sweden²⁴⁶ and Ramroth et al. in Germany²⁴⁷, those studies were not population-based. In 1996, Castle & Mor, in a review of USA research reports from 1980-1995, found the percentage of residents hospitalised ranged from 25 to 49 percent per year²³⁷. But RAC care practices have changed since, and local issues are best informed by local information.

The current chapter therefore aims to address several questions. What are the hospitalisation rates for a population of RAC residents? What are the main clinical conditions at presentation? What are the ED presentation rates from RAC, and, because most ED presentations convert to admissions, what factors are associated with higher ED rates?

In NZ routinely-collected data collected at hospital admission do not reliably record whether a patient lives in RAC (with a few exceptions). This paper uses NZ's National Health Index (NHI) unique identifiers to gather prospective records for a population-based cohort of residents in RAC facilities in the Auckland region (population 1.3 million). It estimates the total numbers of admissions (acute and non-acute) and of ED presentations from RAC over a 12-month period. But when a cohort formed from cross-sectional (prevalence) data is used to make estimates over a period, it likely systematically under-represents short stayers and over-represents long-stayers^{221 248}. This paper uses statistical reweighting techniques that adjust for this length-biased sampling, effectively "filling" beds vacated during the period, to report at population level^{116 120}.

9.3 Methods

This study uses admissions data from a cohort of residents of RAC facilities. In September 2008, our department conducted OPAL, a census-type survey of all residents in all RAC facilities in the Auckland region. Forms containing 41 items, including demographic, care level, function and dependency items were completed by facility staff. Of the 172 facilities certified for long term care of older people in the Auckland health care region, 153 facilities (89%) participated. Survey forms were returned for 6,271 residents, of an estimated 7,603 total residents (90%) at the time. Ethics approvals were given by Auckland Ethics Committee X for the OPAL survey (NTX/08/49/EXP) and for follow-up (NTX/10/EXP/087). Further details are published elsewhere⁸⁶.

Most facilities entered resident's NHI identifiers on lists separate from the main survey forms. After the period of follow-up, the lists were submitted to the Ministry of Health (MoH), which extracted from national databases any date of death, details of all public hospital stays and all ED presentations subsequent to OPAL. These data were merged with the OPAL record matching on NHI, age and gender. Residents were categorised by care type: lower-level rest-home care (elsewhere termed assisted living facilities), secure dementia care, private hospital care (where 24-hour nursing care is required), psychogeriatric care, or temporary/short stay (e.g. respite or rehabilitation). Events that began during the 12-months post OPAL were retained for analysis.

Because it is likely that the policies and practices of each facility impact on decisions about referring a resident to acute hospital, analyses took clustering into account. Re-weighting was used to represent all people who use RAC facilities over 12-months, effectively filling beds as they became empty. In summary, weights adjusted for facility non-response, incomplete capture, non-matching to outcomes data, clustering within facility, and for length-biased sampling. Full details of weights derivation are described elsewhere²⁴⁸. Survey procedures in SAS 9.3 were used to assess variability around the reweighted estimates and also to handle clustering within facilities.

Counts and rates per occupied bed were based on follow-up time accrued during the 12-months following OPAL, or date of death, whichever occurred first. We used the MoH-classified code for Australian Refined Diagnosis Related Groups v6.0x (DRG) to group inpatient stays by body system (first character of code) and whether primarily

a medical condition or a procedure (second character). If a person had two immediately consecutive hospital stays the second was classified as an internal transfer. “Waitlisted” and “arranged” stays, and internal transfers, were regarded as non-acute, all others were coded as acute. Where admission length of stay was recorded as zero because no overnight stay was involved, a half-day stay was ascribed in order that the stay contributed to summation and estimation of means.

Proportional hazards models were developed to predict time to ED presentation. Age group, gender and care type (specified above) were forced into the model, then other resident-level demographic, functional or dependency variables were introduced. Variables relating to the facility, such as availability of after-hours medical care, whether for-profit or not, and distance from the facility to the nearest acute public hospital were also tested. They were removed if judged not to contribute to the model fit.

9.4 Results

9.4.1 Hospitalisations

Records for 6,271 individuals (92% of all forms returned) were matched successfully with NHI identifier, and weights were calculated that adjusted for length-biased sampling. With overall occupancy held stable at 92%, there was an estimated daily average of 7,239 residents. Over the 12-month period post-OPAL, 9,677 (95% confidence interval [95% CI] 8,368-10,985) individuals occupied the available beds. Sixty-nine percent had no admission to public hospital and 20% had one hospitalisation over 12 months (Table 9-1); 72% had no ED presentation and 20% only one.

Over a 12-month period, an estimated 5,003 (95% CI 4,368-5,639) hospitalisations occurred from RAC, of which 3,694 (74%) were acute, 813 (16%) planned or wait-listed, and 497 (10%) internal transfers (Table 9-2). On average, a rate of 0.51 (0.47-0.56) admissions occurred per occupied RAC bed per 12 months; most were acute, at a rate of 0.38 (0.35-0.42) per occupied RAC bed per 12 months.

Table 9-1 Number of hospital services from RAC in Auckland, over the 12-month post-OPAL period

| | Cross-sectional OPAL cohort (observed) | | Estimated population count (re-weighted) | |
|--|--|-------------|--|-------------|
| | N | % | N | % |
| Total | 6,271 | 100* | 9,677 | 100* |
| All admissions (acute & non-acute, including transfers) post OPAL | | | | |
| Nil | 4,326 | 69 | 6,667 | 69 |
| 1 | 1,184 | 19 | 1,901 | 20 |
| 2 | 450 | 7 | 646 | 7 |
| 3 | 187 | 3 | 288 | 3 |
| 4+ | 123 | 2 | 174 | 2 |
| Acute admissions post OPAL | | | | |
| Nil | 4,589 | 73 | 7,023 | 73 |
| 1 | 1,216 | 19 | 1,956 | 20 |
| 2 | 340 | 5 | 508 | 5 |
| 3 | 81 | 1 | 123 | 1 |
| 4+ | 45 | 1 | 66 | 1 |
| Non-acute admissions post OPAL | | | | |
| Nil | 5,597 | 89 | 8,741 | 90 |
| 1 | 517 | 8 | 716 | 7 |
| 2 | 103 | 2 | 142 | 1 |
| 3 | 34 | 1 | 52 | 1 |
| 4+ | 19 | 0 | 26 | 0 |
| ED presentations post OPAL | | | | |
| Nil | 4,556 | 73 | 6,953 | 72 |
| 1 | 1,199 | 19 | 1,959 | 20 |
| 2 | 352 | 6 | 521 | 5 |
| 3 | 102 | 2 | 152 | 2 |
| 4+ | 62 | 1 | 91 | 1 |

*Due to rounding, individual figures may not sum to counts or percentages shown.

Rates of admission from rest-home or dementia care (lower-level care) were higher at 0.50 (0.46-0.53) than from higher-level care at 0.28 (0.24-0.32). Admissions accounted for a total of 32,793 (27,478-37,690) hospital bed-days (Table 9-2). This is an average of 90 (75-103) beds each day across the region, just under 7 beds per 10,000 aged 65+ years.

Table 9-2 Hospital admissions and emergency department presentations from residential aged care facilities in Auckland over a 12-month period

| | Cross-sectional OPAL cohort (observed) | Estimated 12-month count (95% CIs)^a | Incidence per occupied bed (95% CIs)^a |
|---|---|---|---|
| Number of residents | 6,271 | 9,677 (8,368-10,985) | - |
| Total follow-up time (years) | 5,420 | 7,239 (6,318-8,160) | - |
| Hospital admissions: | | | |
| Total admissions | 3,320 | 5,003 (4,368-5,639) | 0.51 (0.47-0.56) |
| Acute admissions | 2,382 | 3,694 (3,212-4,175) | 0.38 (0.35-0.42) |
| - from lower level RAC care ^b | 1,474 | 2,239 (1,902-2,575) | 0.50 (0.46-0.53) |
| - from higher level RAC care ^b | 908 | 1,455 (1,155-1,755) | 0.28 (0.24-0.32) |
| Non-acute admissions | 937 | 1,310 (1,109-1,511) | 0.14 (0.12-0.15) |
| - planned or wait-listed | 604 | 813 (673-954) | 0.08 (0.07-0.10) |
| - internal transfers | 335 | 497 (403-590) | 0.05 (0.04-0.06) |
| Total hospital bed-days | 21,662 | 32,793 (27,478-37,690) | 3.39 (3.00-3.79) |
| Emergency presentations | | | |
| Total presentations | 2,553 | 3,957 (3,456-4,459) | 0.41 (0.37-0.45) |
| - care complete within 3 hours | 174 | 243 (188-299) | 0.03 (0.02-0.03) |
| - to admission or 3+ hours in ED | 2,381 | 3,714 (3,236-4,192) | 0.38 (0.35-0.42) |

^a Adjusted for facility non-response, incomplete capture, non-matching to outcomes data, clustering within facility and for length-biased sampling. 95% confidence intervals obtained using Taylor series linearisation.

^b Lower level care here is rest-home or secure dementia care, high-level includes private hospital (sim. nursing home) and psychogeriatric care.

The most frequent disease category was Circulatory, with 13% of all stays and a median stay of 3 days (Table 9-3). Second most frequent was Respiratory, with 11% of all stays and a median stay of 4 days. The most frequent procedural or treatment grouping was Musculoskeletal with 7% of all stays and median stay of 10 days. Rates of admission under these DRG categories were 6.5 (95%CI 5.3-7.7) per 100 occupied RAC beds per 12-months for Circulatory, 5.9 (95%CI 4.9-6.8) for respiratory and 3.4 (95%CI 2.8-4.0) for Musculoskeletal. Rehabilitation was ascribed as the main reason for stay for 5.0 (95%CI 4.1-5.9) admissions (10%) and this group that had the longest median stay at 13 days.

Table 9-3 Diagnostic-related groupings of discharges (acute and non-acute) from residential aged care facilities in Auckland, over a 12-month period

| | Mean per year (95%CI) ^a | % of discharges | Median (IQR) bed-days ^b |
|--|---------------------------------------|--------------------|---------------------------------------|
| All hospital discharges | 51.7 (46.9-56.5) | 100.0 | 3 (1,9) |
| Grouped primarily by diseases & disorders ^c : | | | |
| Circulatory system (F) | 6.5 (5.3-7.7) | 12.6 | 3 (1,6) |
| Respiratory system (E) | 5.9 (4.9-6.8) | 11.3 | 4 (2,8) |
| Nervous system incl. stroke (B) | 4.3 (3.6-5.1) | 8.4 | 5 (1,10) |
| Kidney & urinary tract (L) | 3.3 (2.6-4.1) | 6.5 | 3 (1,6) |
| Musculoskeletal system (I) | 3.0 (2.4-3.5) | 5.7 | 1 (½ ^d ,6) |
| Digestive system (G) | 2.8 (2.1-3.5) | 5.4 | 2 (½,5) |
| Skin, subcutaneous, breast (J) | 2.3 (1.7-2.8) | 4.4 | 2 (½,6) |
| Injuries, poisoning, burns (WXY) | 2.1 (1.7-2.5) | 4.1 | 1 (½,2) |
| Blood & blood-forming organs (Q) | 1.4 (0.9-1.8) | 2.7 | 1 (½,3) |
| Infections & parasitic disease (ST) | 1.1 (0.7-1.5) | 2.1 | 4 (2,7) |
| Endocrine, nutritional & metabolic system (K) | 1.1 (0.8-1.3) | 2.0 | 4 (2,8) |
| Other | - | 2.1 | - |
| Grouped primarily by procedure &/or treatment: | | | |
| Musculoskeletal system (I) | 3.4 (2.8-4.0) | 6.5 | 10 (6,15) |
| Digestive system (G) | 1.8 (1.3-2.3) | 3.5 | 4 (1,8) |
| Eye (C) | 1.4 (1.1-1.6) | 2.6 | ½ (½,½) |
| Skin, subcutaneous, breast (J) | 1.4 (1.0-1.7) | 2.6 | ½ (½,2) |
| Other | - | 3.7 | - |
| Rehabilitation (Z) | 5.0 (4.1-5.9) | 9.6 | 13 (8,21) |

^a per 100 occupied beds, adjusted for facility non-response, incomplete capture, non-matching to outcomes data and clustering within facility. 95% confidence intervals obtained using Taylor series linearisation

^b Where an acute admission is followed by an inward transfer, bed-days were combined with subsequent Rehabilitation stay

^c Grouped according to DRG (Diagnostic Related Grouping) classification

^d ½ represents same-day discharges, such as for a short procedure, e.g. cataract surgery

9.4.2 Emergency Department presentations

The number of ED presentations was 3,957 (95%CI 3,456-4,459), a rate of 0.41 (95%CI 0.37-0.45) per 100 occupied beds (Table 9-2). This was only slightly higher than the number of acute hospitalisations – only 243 (6%) of ED presentations were turned around within 3 hours; under the rules of the database, all others were recorded as admissions (Table 9-2). Sixty-four percent presented during normal hours - i.e.

between 9.00am and 6.00pm, and a further 22% between 6.00pm and midnight; 25% presented during the weekend (Table 9-4). The majority, 47%, were seen by emergency medicine specialists, 33% by general medicine specialists, and 18% by either orthopaedic or other surgical specialists. Less than 1% were recorded as having been seen by a geriatrician during their ED visit.

Table 9-4 Emergency department presentations from residential aged care facilities in Auckland, over a 12-month period

| | Mean per year (95% CIs) ^a | % of ED visits |
|-----------------------------|---|-------------------|
| All ED visits | 40.9 (36.9-44.9) | 100.0 |
| Hours of presentation | | |
| Daytime 09:00 – 17:59 hours | 26.3 (23.7-29.0) | 64.3 |
| Evening 18:00 – 23:59 hours | 9.1 (7.8-10.4) | 22.4 |
| Early 24:00 – 08:59 hours | 5.4 (4.6-6.4) | 13.3 |
| Weekend | 10.1 (8.8-11.4) | 24.7 |
| Specialty ^b | | |
| Emergency medicine | 19.2 (15.5-22.9) | 47.0 |
| General medicine | 13.4 (11.1-15.7) | 32.8 |
| Orthopaedic surgery | 2.9 (2.2-3.6) | 8.6 |
| General surgery | 2.0 (1.5-2.4) | 7.1 |
| Other medicine | 1.4 (0.9-1.9) | 3.4 |
| Other surgical | 0.8 (0.5-1.1) | 1.9 |
| Urology | 0.6 (0.3-0.8) | 1.4 |
| Cardiology | 0.4 (0.0-0.8) | 1.0 |
| Geriatric & ATR | 0.3 (0.1-0.5) | 0.7 |

^a Per 100 occupied beds, adjusted for facility non-response, incomplete capture, non-matching to outcomes data & clustering within facility, and for length-biased sampling. 95% confidence intervals obtained using Taylor series linearisation

^b Some were seen by more than one speciality

9.4.3 Predictive models for ED presentation

In the proportional hazards model testing the association of demographic and facility characteristics with risk of ED presentation, just five variables were used (Table 9-5). Those who had entered the RAC facility within the past six months were significantly more likely to present to ED (HR=1.8, 95% CI 1.5-2.1). Higher risk was also seen among men (HR=1.2, 95% CI 1.1-1.4) and residents who were in for-profit facilities

(HR=1.2, 95%CI 1.0-1.4). Compared to those aged 85-94 years, all other age groups were at lower risk of ED presentation. Compared to those in rest-home care, those in dementia (HR=0.7, 95%CI 0.6-0.9), psychogeriatric (HR=0.4, 95%CI 0.2-0.6) and private hospital care (HR=0.7, 95%CI 0.6-0.8) were at lower risk. No other resident variables (marital status, functional or dependency levels), or facility-related variables (after-hours primary care cover or distance to acute hospital) improved the model.

Table 9-5 Reweighted proportional hazards model predicting risk of emergency department presentation from RAC during a 12 month period

| Characteristic | Hazard ratio (95%CI) ^a | p-value |
|-------------------------------------|--------------------------------------|---------|
| Men (vs. women) | 1.2 (1.1-1.4) | 0.0002 |
| Age at OPAL (vs. 85-94 years) | | |
| 18-74 | 0.7 (0.6-0.9) | 0.006 |
| 75-84 | 0.9 (0.7-1.0) | 0.05 |
| 95+ years | 0.8 (0.6-1.0) | 0.06 |
| Entered facility in last six months | 1.8 (1.5-2.1) | <0.0001 |
| Facility is for-profit | 1.2 (1.0-1.4) | 0.04 |
| Bed class (vs. rest-home) | | |
| Dementia care | 0.7 (0.6,0.9) | 0.008 |
| Hospital level care | 0.7 (0.6-0.8) | <0.0001 |
| Psychogeriatric care | 0.4 (0.2,0.6) | 0.0004 |
| Temporary stay | 1.0 (0.7-1.5) | 0.97 |

^a Adjusted for facility non-response, data incompleteness, non-matching to outcomes data, clustering within facility, and length-biased sampling. Variables tested in the model and dropped because of non-contribution included widowed, never married, entered following acute hospital stay, facility within 5 km of acute hospital, limited GP cover after usual hours, & other GP used for after-hours urgent care. 95% confidence intervals obtained using Taylor series linearisation.

9.5 Discussion

Admissions

An estimated 5,003 hospital admissions from Auckland RAC facilities occurred during the course of 12 months. This represents a rate of 51 hospitalisations for every 100 occupied RAC beds per year, 38 of which were acute, with 8 planned or wait-

listed, and 5 internal transfers. Acute presentations were more frequent from lower level care (50 per 100 occupied rest-home or dementia care beds per year) than from higher level care (28 per 100 occupied private hospital or psychogeriatric care beds per year).

These are lower than comparable rates recently reported elsewhere. Ouslander et al., in 377 nursing homes in Georgia, USA, found 1.62 hospitalisations per 100 resident days, equivalent to 59 per 100 residents per year²³⁵. In Sweden, Graverholt reported an annual rate of 58 acute admissions per 100 nursing home beds¹⁵, equivalent to 70 acute admissions per 100 residents if occupancy was say 90%. In Canada, Hogan et al. reported rates by care level: 56 acute admissions per 100 person-years from assisted living facilities (low-level care) and 18 per 100 person-years from long-term care²⁴⁹. It is known that dependency levels in RAC residents are higher than previously⁸⁷; as those in higher-level care have lower rates of admission, the fact that this NZ report is the most recent may in part explain the lower rates than in earlier international studies. Median length of hospital stay was 3 days (inter-quartile range [IQR] 1-9 days), with on average, 90 hospital beds occupied by RAC residents on any one day. For about 10% of residents admitted, an inward transfer followed an acute admission, so the lengths of stay would be accumulative. Overall bed use from RAC is equivalent to 7 hospital beds for each 10,000 people aged 65+ years in the population. In 2008-09 in Australia, RAC residents occupied almost 9% of all acute hospital beds used by those aged 65+ years²³⁸.

The model predicting ED presentation demonstrated that men, those in for-profit facilities, those in lower levels of care, and those who have been newly admitted to the facility were more likely to present. Grabowski reviewed many studies of predictors of hospitalisation, noting that existing studies lack generalizability and acknowledged the difficulties in conducting rigorous research²³⁶. More recently, a review by Dwyer et al. reported higher risk among men and a range of other factors. The association of time since entry to RAC was not described in either review.

A systematic review has summarised the evidence for interventions aiming to reduce hospital admissions from RAC, but studies were assessed as being of generally low quality²³⁴. In particular, few were controlled trials or analysed using methods that accounted for clustered data. ARCHUS, our randomised controlled trial of a package of education and supports to facility staff attempted to reduce hospital stays from

RAC^{112 113}. No benefit was found in any of the four main endpoints, including acute admissions and hospital bed-days. It also showed a high cluster effect of 3.67, indicating that studies that ignore clustering in analyses will underestimate confidence intervals about the estimated treatment effect¹¹³.

Emergency department presentations

The rate of ED presentation in Auckland was 41 (95%CI 37-45) per 100 occupied beds per year. In the NZ service review, the rate reported was twice that, 83 ED presentations per 100 person-years, based on data for subsidised residents¹². Compared to subsidised residents, unsubsidised residents in rest-homes have much shorter stays, and in high-level care, have significantly lower care needs, so these two factors may partially account for differences in rates²¹⁹. Based on the PACE programme in the USA, the service review cited a benchmark of 41 ED presentations per 100 person-years, exactly as found in the current study¹². In a systematic review, Arendts and Howard reported ED presentation rates that varied widely between 27 sources²⁴⁰. Most reported at least 30 per 100 RAC beds per year, with two reporting rates over 110. Grunier et al. reported 77 ED visits per 100 resident years – a higher rate that may be partially explained by having just six months of follow-up and not adjusting for the fact that longer stayers have lower rates²⁵⁰. Burke et al. in a nationally-representative study of nursing homes (higher level care) in the USA found a considerably higher rate of 180 ED visits per 100 residents per year, with 54% not leading to admission²⁵¹. In Western Australia, Ingarfield reported the age- sex-standardised rate of 23.9 ED presentations per year, so permitting comparisons with populations of differing age and gender structures, but few other studies have used the age-standardised measure¹⁶. In many clinical trials, for example of drug treatments for specific diseases, results are assumed to be generalisable to other locations or populations. However in RAC, if a study of an intervention in one locality reduces ED presentations, that intervention will not necessarily impact similarly where another model of service delivery applies. Residents of the various care types may be impacted differently, resident characteristics differ, there may be variable expectations of care, and there are obstacles, mostly resource-related, in implementing facility-based initiatives that vary by location. Facility nurses in NZ, perhaps the best placed to understand the levels of care provided to their residents, report their struggle to deliver quality care to residents with increasing care needs, an ageing workforce, low pay and poorly recognised skill-

set, with only moderate support from their employers for upskilling and training, and with struggles to find and contract willing general practitioners to provide medical cover²⁵². Similar concerns have been expressed elsewhere^{29 253}. This study suggests that it may be wise to assess the baseline rate of ED presentations before attempting interventions designed to reduce presentation rates. These results suggest that many facilities in NZ already have low rates. Attempts to lower them may prove futile or hazardous.

Strengths and limitations

No previous studies have reported hospital utilisation from RAC in NZ in this detail. The population-approach uses a census-type database, combined with independently-collected deaths, admissions and ED presentations data, for a region that covers one-third of the population in NZ. The survey had excellent participation, and use of NHI numbers yielded a high proportion of good matches. Nevertheless, it includes only one region of NZ. Use of established reweighting methods to adjust for length-biased sampling assumes that those not measured, e.g. new RAC admissions post-OPAL, are similar to those who leave, that there is a steady state over time in characteristics and needs of residents, in their lengths of RAC stay, and that survival is stable, none of which may be true. It is also dependent on accuracy of the diagnosis codes ascribed in hospital discharge records. While there are quality control standards for coders, they in turn depend upon records made by junior doctors, registrars and hospital physicians; the coded classifications can only ever be as good as the diagnoses recorded in patient notes.

Conclusions

This study suggests that rates of hospitalisation from RAC in Auckland may be lower than elsewhere, possibly as a result of earlier supports provided to RAC facilities. There is an opportunity to use these estimates to map trends in the future. A comparison of rates of hospitalisation of RAC residents against age-gender matched older people living at home, including those with and without home-based care services, would be useful to understand differential service utilisation.

9.6 Post-script

Publication history

This manuscript was submitted to a peer-reviewed journal in mid-2015 and will be resubmitted.

Research direction

As a result of this work, a comparison of rates of hospitalisation from the community is underway, to ascertain how much RAC use differs from that from the community. Preliminary results from a candidate-supervised summer student show that while rates of hospitalisations by community-dwelling older people rise markedly with age, admission rates for those in RAC remain almost flat as age increases, and are much lower than community-dwellers. This somewhat surprising result supports shifting the focus of research from RAC care to community-based care, in particular post-discharge care. This is discussed further in the Postscript to Chapter 10.

In the final research chapter in this thesis, methods of selecting facilities whose residents with high rates of acute hospital admission were developed and compared. The original purpose was to select facilities for a randomised controlled trial of a facility-based intervention that aimed to reduce admissions.

Chapter 10. Selecting long-term care facilities with high use of acute hospitalizations

Preamble

Considerable international effort has been expended in trying to identify and reduce what were perceived as high rates of hospital presentations from RAC. The intention has been to develop interventions to reduce acute hospital admissions from RAC, by improving the care received to enable residents to remain at their “home”, and so avoid being exposed to hospital pathogens, unfamiliar environments and other recognised harms of hospital care, and also to reduce costs. To implement such practices it may be helpful to identify those facilities where hospital presentations are high. There are issues in such an approach since residents in high-admitting facilities may differ in several ways. They be particularly unwell or have more complex medical needs than those in other facilities, there may be constraints such as distance, staff resourcing and training, the time of day or day or week, or access to a primary care physician. This final research chapter, Chapter 10, uses four different measures of hospitalisations to rank facilities, and discusses the usefulness of the various methods. The work is presented largely as originally published.^f

10.1 Abstract

Background

This paper considers approaches to the question “Which long-term care facilities have residents with high use of acute hospitalisations?” It compares four methods of identifying long-term care facilities with high use of acute hospitalisations by demonstrating four selection methods, identifies key factors to be resolved when deciding which methods to employ, and discusses their appropriateness for different research questions.

Methods

OPAL was a census-type survey of aged care facilities and residents in Auckland, New Zealand, in 2008. It collected information about facility management and resident demographics, needs and care. Survey records (149 aged care facilities, 6271 residents) were linked to hospital and mortality records routinely assembled by health authorities. The main ranking endpoint was acute hospitalisations for diagnoses that

^f Broad J, Ashton T, Lumley T, Boyd M, Kerse N, Connolly MJ. Selecting long-term care facilities with high use of acute hospitalizations: issues and options *BMC Medical Research Methodology* 2014;14.

were classified as potentially avoidable. Facilities were ranked using 1) simple event counts per person, 2) event rates per year of resident follow-up, 3) statistical model of rates using four predictors, and 4) change in ranks between methods 2) and 3). A generalized mixed model was used for Method 3 to handle the clustered nature of the data.

Results and discussion

3048 potentially avoidable hospitalisations were observed during 22 months' follow-up. The same "top ten" facilities were selected by Methods 1 and 2. The statistical model predicting rates from resident and facility characteristics (Method 3), ranked facilities differently than these two simple methods. The change-in-ranks method identified a very different set of "top ten" facilities. All methods showed a continuum of use, with no clear distinction between facilities with higher use.

Choice of selection method should depend upon the purpose of selection. To monitor performance during a period of change, a recent simple rate, count per resident, or even count per bed, may suffice. To find high-use facilities regardless of resident needs, recent history of admissions is highly predictive. To target a few high-use facilities that have high rates after considering facility and resident characteristics, model residuals or a large increase in rank may be preferable.

10.2 Background

The question "Which long-term care facilities have residents with high use of acute hospitalisations?" may seem straightforward, though may be asked for many purposes. This study arose when our health research group wished to recruit high-use facilities to test an intervention aiming to reduce hospitalisations by improving care within facilities. But other researchers may wish to select a few facilities with high rates of acute admissions in order to test a resident-specific intervention. In other contexts a manager of a hospital clinical outreach programme may want to provide better supports and services to residential LTC facility staff, to avert resident admissions to acute hospital care. An auditing authority may wish to include avoidable hospital presentations in its monitoring of facility performance. In general, such questions frequently relate to an interest in reducing admissions through trials or service

interventions, and this is the main justification of this paper, but questions may also regard admissions as a marker of care quality or have other purposes.

Although some admissions are needed for good care, reducing acute admissions from LTC appears well justified. Better preventive care and emphasis on managing acute illness in situ may improve resident health outcomes^{254 255}. Older adults hospitalized acutely can be harmed; some decline in a few days, and iatrogenic complications of acute illness may occur because of a hospital's more aggressive interventions, less attention to mobility and nutritional needs, and exposure to infections^{17 256-259}. Care transitions are more disruptive for older people, particularly those with dementia²⁶⁰. Acute hospitalisations are often associated with negative impacts at the end-of-life²⁶¹. From an economic perspective, hospital care costs more than LTC, so where outcomes are similar or better for a given condition, funds may be better used elsewhere^{262 263}.

Acute hospital admissions from LTC are of wide importance as LTC is often used in later life. In Auckland (population 1.3 million), 28% of those aged 85+ years live in LTC⁸⁶. In other countries, LTC residents have twice the rate of acute hospitalisations and longer age/sex adjusted acute length of stay than non-residents^{16 242 264}. In OPAL, a census-type survey of all residents in LTC conducted in Auckland in 2008, 4% of all LTC residents were referred to a hospital ED in the two weeks prior to the survey. However, there are no routine reports of hospital presentations, hospital admissions, bed-days or costs of LTC residents available for NZ.

The research question – how to identify facilities with high use – arose for these investigators when planning the Aged Residential Care Healthcare Utilization Study (ARCHUS), a randomized controlled trial of a complex, multi-disciplinary facility-level intervention intended to reduce avoidable acute hospitalisations conducted in Auckland¹¹². The study design required that before commencing recruitment, high-use facilities be identified in order to enrol those with greatest chance of demonstrating a change in resident outcomes. (Separate modelling was undertaken to identify characteristics of residents and facilities to inform care model development). Selection methods that were discussed early on ranged from simple rates of hospital admissions per facility bed over a defined period, to those that attempted to adjust for facility characteristics and resident need levels in complex statistical models.

To identify high-use facilities in situations where suitable data are not readily available but neither are research funds for the purpose, the question becomes “If reliant on

existing data, which of many possible selection methods is most appropriate?” In this reflective paper we consider some issues and options that may be relevant when responding to the question, we form these into a framework, use the ARCHUS study to demonstrate four selection methods and show the variation in selections they make, and discuss when methods may be more appropriate than others. The paper intends to focus more on the approach taken rather than provide specific results which we consider are unlikely to be of great relevance to others not in our particular situation.

10.3 Methods

10.3.1 Aspects of selection

During the ARCHUS trial planning, much discussion revolved around methods of addressing the question of facility selection, with a large number of aspects or measures that could be relevant, of residents and of facilities. In choosing the method for ARCHUS, several issues immediately demanded consideration. These included whether data from OPAL would suffice (and so exclude the 11% of facilities not participating in OPAL), or whether to acquire updated data; whether to count all hospital presentations (including ED visits that did not lead to an admission), or whether to limit rankings to admissions of particular diagnoses. The primary endpoint for ARCHUS was potentially avoidable hospitalisations (PAH). So, should selection be limited to admission within the trial outcome definition, or should all admissions be included – given that at the time of acute referral or presentation the diagnosis may be unclear? Were all care types (high, low, or specialist dementia care) of interest, or should some levels of care be excluded? Should facilities be ranked separately by level of care, or should case-mix be taken into account in some other way? Should analyses be limited to residents in long-stay care (i.e. exclude short-stayers)? What impact would missing data have? What timeframes were relevant? These and other considerations encountered since are structured into Table 10-1. We suggest these as a framework for others addressing similar problems. In the years since 2008 OPAL was conducted, several new facilities had opened, and others had changed ownership or closed. We wished to ensure that all facilities with current certification, regardless of how long in operation, level of care, ownership (part of chain, private or public) should be eligible for selection. It was anticipated that 36 facilities would be recruited for ARCHUS¹¹². Investigators determined therefore that a selection process that used

OPAL data would be used but would need to be updated using current facility lists and equivalent but more recent data.

10.3.2 Study outline

The decision was made that we would use data from OPAL, linked to nationally-collected hospitalisation data from 2008–09. The definition of a PAH would match that planned for ARCHUS. Based on statistical models of these resident records and related hospitalisations we would select particular variables that were most predictive of PAHs and that could be updated. New data would then be collected for those variables only, applied at facility-level and facilities ranked accordingly.

10.3.3 Data sources

OPAL collected data for all residents in 152 of all 172 certified facilities in the region for an estimated 7601 residents^{86 87}. Of all certified facilities, 150 provided rest-home or lower-level care beds, and 81 provided hospital or higher-level care (59 provided both). Over 98% of residents were long-stay, 71% were women, 91% were aged 65+ years and 34% aged 85+ years^{86 87}. Information describing *facility-level characteristics* included structural and process aspects: e.g. size, type (rest-home, dementia care, private hospital, psychogeriatric hospital), ownership (for profit or corporate or not-for-profit charitable), levels of nursing and care assistant staffing cover, medical cover, distance from nearest acute hospital, and whether part of a corporate chain or not.

Individual residents' information (36 items) included age, ethnicity, length of stay, care level, prior residence, marital status, family contact, function, dependency (mobility, toileting, continence), aspects of cognition, need of night care, 'problem' and wandering behaviour, activities of daily living, speech, hearing, vision, medication, recent unplanned GP visits, recent hospital attendance and need for specialized nursing care. Any of these characteristics have potential to be associated with hospitalisations.

Table 10-1 Selected dimensions when assessing facilities for high use of acute hospitalisations

| | |
|--|---|
| Research question: to ... | <ul style="list-style-type: none"> • Find the fewest facilities to accumulate numbers of hospital events? • Identify resident- or facility-level characteristics associated with higher (or lower) event rates so as to inform intervention design? • Find facilities that have high hospital presentation rates even if explained by resident characteristics? • Find facilities that, independently of their facility or resident characteristics, have high event rates? • Find facilities that after adjusting for non-modifiable characteristics, have unexplained high rates of presentations? |
| Hospital event type as endpoint of interest | <ul style="list-style-type: none"> • All hospital visits, or acute/ED presentations, or acute admissions? • All or selected diagnoses only, e.g. those classified as potentially avoidable (PAH)? • If only selected diagnoses, e.g. PAH, were codes predefined or selected/amended after data was gathered? |
| LTC facility type | <ul style="list-style-type: none"> • Limit to particular facility types – e.g. lower-level care? • Use only facilities with complete or near-complete data? • Is distance or time to hospital likely to impact referral decisions? • Use only facilities of a certain size (for power & cost considerations) • Need to stratify by e.g. geography, or match in pairs for randomisation? |
| Resident care type | <ul style="list-style-type: none"> • Use only long-stay residents, or include short-stayers? • Limit to those in certain levels of care, e.g. low-level care, or dementia care, or in one age group, or those with public funding, or those with a particular clinical history? |
| Cohort assembly | <ul style="list-style-type: none"> • Include all residents at any one time, i.e. cross-sectional? or all entering (or leaving) the facility during a pre-defined period? or all using the facility at any time during a period? |
| Time period of events | <ul style="list-style-type: none"> • Hospital events over what time period? • Data collected retrospectively or prospectively? • In a special study, or with routine data collection? |
| Adjustments during analysis | <ul style="list-style-type: none"> • Can results consider person-time, e.g. on death or moving away? • Can results consider facility-level characteristics? If so, how? • Can results consider resident-level characteristics? If so, how? |
| Measure for reporting and ranking | <ul style="list-style-type: none"> • Report a count, a proportion, a rate over time, a facility-related effect size from model, a residual from a fitted statistical model, or a change in rank between two methods? • Express as rate per bed, per resident, per resident year, or relative to other facilities, to an earlier report or to a “best practice” target? |
| Data quality, completeness & recency | <ul style="list-style-type: none"> • What is the extent of missingness in data – facilities, outcomes or data items? • Is missing data correlated with particular variables so as to lead to bias? • Are data current, or could changes have occurred since collection? • How reliable are measures, ratings, and coding? |

Outcomes were obtained from Ministry of Health (MoH) records linked to OPAL data via the National Health Identification number (NHI), NZ's unique personal health identifier. Historical hospital presentation data included emergency department (ED) presentations and acute unplanned admissions during the two years prior to OPAL. Hospital admission records for the 22 months following OPAL were extracted and all those meeting the definition of potentially avoidable (see below) were selected. Information included diagnoses recorded for discharges following admissions (but not for ED visits not leading to admission), hospital admission date, length of stay and discharge status. Mortality records provided date of death.

Data for hospitalisations within the Auckland region of people in receipt of a residential care subsidy (believed to be about 60-65% of all LTC residents) during the period January to June 2010, together with summary data for the few predictor variables selected by the model (see below), were obtained from the DHBs.

10.3.4 Classification of potentially avoidable hospitalisations

The two closely-allied concepts of PAH and ambulatory sensitive hospitalisations (ASH) have been discussed in the literature. Both PAH and ASH, typically identified by primary diagnosis, are widely accepted in monitoring hospitalisations²⁶⁵⁻²⁶⁹. Purdy et al. have drawn attention to the inconsistent definitions used²⁷⁰. Others are developing an international agreed classifications of ASH²⁶⁶ and PAH²⁷⁰. However as yet there are no widely accepted definitions. Two MoH reports focus on people aged under 75 years for whom the benefits of long-term prevention, for example, is clear. In the Ministry's view such preventative treatments may not be effective or justified in older people living in LTC settings^{182 265}.

For this study, we decided that the definition should be purpose-specific and accordingly PAH events was defined as a set of diagnoses broadly congruent with previous studies, but emphasising conditions that related to the ARCHUS trial intervention. Discharges were classified as PAH if the first, second or third diagnosis was one or more of a list including chronic obstructive pulmonary disease, bronchitis, pneumonia, congestive heart failure, dehydration, urinary tract infection, anaemia, cellulitis, leg ulcers, collapse or syncope, constipation, influenza, accidental fractures and other injuries rising from falls, and some less frequently common diagnoses. For

the purposes of ARCHUS, the list of diagnoses, including detailed ICD-10 codes, is included in Figure 10-1.

| Conditions to include | Principal Diagnosis Codes (ICD10) | Comment, reason for inclusion |
|--|---|--|
| Angina and chest pain | I20, R072-R074 | MoH list |
| Behavioural, psychological disorders of dementia (BPSD) & problems related to dementia | F00-F09, G30 | Noted in discussions |
| Cellulitis | H000, H010, J340, L01-L04, L08, L980 | MoH list |
| Chronic obstructive pulmonary disease (COPD) & asthma | J20-J22, J44-J46 | Avoidable conditions of older people |
| Collapse or syncope | R55 | Avoidable conditions of older people |
| Congestive heart failure (CHF) | I50, J81 | MoH list |
| Constipation | K590 | MoH list |
| Dehydration, weight loss, gastroenteritis, volume depletion | A02-A09, R11, E86, E87 | MoH list |
| Diabetes & diabetes-related complications | E10-E14, E162 | MoH list |
| Haemorrhage (not GI) | K25-K29, D62, R58 not K922 | Noted in discussions |
| Hypotension | I95 | Noted in discussions |
| Falls and fractures | [Injury codes W01, W03, W07-W08, W10, W13, W17-W19], S02-S92, T02-T14 | Common avoidable condition of older people |
| Kidney or urinary tract infection (UTI) | N10, N12, N136, N309, N390 | MoH list |
| Lower respiratory tract infection: pneumonia, influenza, bronchitis | J10-J16, J18 | MoH list |
| Myocardial infarction | I21-I23; I241 | MoH list |
| Nutrition deficiency and anaemia | D50-D53, E40-E46, E50-E64, M833 | MoH list |
| Other ischaemic heart disease | I240, I248, I249, I25 | MoH list |
| Pain | F454, M25, M79, R52 | Noted in discussions |
| Skin tears, lacerations, pressure ulcers, leg ulcers | I83, L89, L97, L984, T14 | Noted in discussions |
| Stroke | I61, I63-I66 | MoH list |
| Tube block: catheter, PEG or naso-gastric | T830-T832, T834-T839 | Avoidable conditions of older people |
| Upper respiratory tract (URTI) & ENT infections | J00-J04, J06, H65-H67 | MoH list |
| Venous thromboembolism (PE & DVT) | I126, I802 | Noted in WDHB email June 2012 |
| Conditions considered potentially adversely impacted by ARCHUS intervention | Principal Diagnosis Codes | Comment, reason for potential inclusion |
| Gastrointestinal (GI) bleed and peptic ulcer | K92 & K25-K28 | MoH list |
| Hypertensive disease | I10-I15, I674 | MoH list |
| Gastro-oesophageal reflux disease (GORD) | K21 | MoH list |
| Conditions considered, but excluded | Principal Diagnosis Codes | Comment, reason for potential inclusion |
| Cervical cancer | C53 | MoH list |
| Rheumatic fever/heart disease | I00-I02, I05-I09 | MoH list |
| Dental conditions | K02, K04, K05 | MoH list |
| Dermatitis & eczema | L20-L30 | MoH list |
| Epilepsy & convulsion | G40-G41, O15, R560, R568 | MoH list |
| Sexually transmitted Infections | A50-A59, A60, A63, A64, I980, M023, M031, M730, M731, N290, N341 | MoH list |

Figure 10-1 List of conditions defined by ICD code that ARCHUS Investigators determined to regard as being potentially preventable hospital admissions.

10.3.5 Methods of ranking

Facility lists were updated from those used in 2008; (new certified facilities were added, those closed were dropped) to reflect what was current in late 2010. Having determined to use updated data, but without conducting a complete regional survey, data for subsidised residents were assembled from administrative data. Four methods of identifying facilities with high PAH rates were selected for comparison purposes. The first two methods used observed counts of all facilities, the third used predicted counts, and the fourth a combination, but all used updated 2010 data. In all methods, a rank of one signified the lowest PAH use, and a rank of 149 identified the facility ranked highest.

Method 1 – ratio of events to residents

The first (Method 1) was based simply upon the ratio of events to residents, without considering deaths or discharges from the facility. This was used as a comparator for other rankings as it is the simplest and most similar to data available in other settings. This method is likely to be the easiest to replicate in other settings.

Method 2 – PAH rates

Secondly, event counts were divided by the sum of resident survival time to derive PAH rates (Method 2) using mean survival time (from OPAL to death) given the resident care level applied to current counts of subsidised residents.

Method 3 – predictive model

Thirdly, a predictive model was developed that would reduce the number of variables to a few based on what was known about residents currently in the facilities (model-building described below). Data for important variables were updated, converted to facility-level variables (e.g. proportions) and the models applied. Predicted values were the estimated number of events per facility, effectively becoming a predictive risk score for each facility that adjusted for important resident case-mix, and used for ranking in Method 3.

Method 4 – change in ranks

Finally, in Method 4 the ranks derived from Method 3 were compared with those observed from Method 2, and ordered by the change in ranks. The intention was to

identify how much use each facility was observed above or below what was expected, given facility characteristics and resident case-mix.

10.3.6 Predictive models

In the first step of statistical modelling, multilevel predictive models were used to account for the hierarchical nature of the data in which residents were nested within facilities, acknowledging that residents within a facility are likely to be somewhat similar²⁷¹. Data were used from residents in all 149 participating facilities that provided linkage information. A generalized mixed model was used to predict event counts for each facility assuming a negative binomial distribution. Facility identifier was entered as a random effect. In all, 146 variables were initially made available to the model, and progressively eliminated if the effect size was closer to zero and the p-value closer to 1.

The final model (using information updated from administrative records) included four predictors: residents seen by GP urgently within 2 weeks prior, the proportion of residents seen in ED in the 3-months period 1 year prior, the proportion of residents with a previous history of an admission for diabetes, and the proportion of residents with a previous history of an admission for dementia. All variables retained in the final model had a p-value of 0.05 or under (Table 10-2).

Table 10-2 Model used in ARCHUS to select facilities with high risk of Potentially Avoidable Hospitalisation

| | Rate ratio | 95%CI |
|---|------------|--------------|
| Resident seen by GP urgently within 2 weeks prior to OPAL (Y vs. N) | 1.79 | 1.55 to 2.06 |
| Proportion of residents seen in ED in the 3-months period 1year prior (each 10%) | 1.14 | 1.07 to 1.20 |
| Proportion of residents with a previous history of an admission for diabetes (each 10%) | 1.17 | 1.00 to 1.36 |
| Proportion of residents with a previous history of an admission for dementia (each 10%) | 1.10 | 0.99 to 1.22 |

*PAH = potentially avoidable admissions

In practice, in the ARCHUS study, a method similar to Method 3 was used because of the trial design. For delivery and resource reasons treatment allocation was to be stratified by and ranked within DHB (12 facilities from each of the three DHBs to provide adequate statistical power). The actual predictive models used were therefore adjusted for stratum.

Analyses were conducted using SAS 9.3 (SAS, Cary, NC). Full ethics approvals for the study were given by the Northern X Regional Ethics Committee ([NTX/08/49/EXP](#) and [NTX/10/EXP/087](#)).

10.4 Results

In all, 3048 PAH events were observed during the 22 months of follow-up following OPAL. The facility-level median PAH event rate in the OPAL cohort was 34 PAH events per 100 person-years of follow-up, and is the best estimate of an overall event rate during the period.

Results from all four methods are shown in Figure 10-2 a-d, in which each vertical bar represents one facility. The facility with the lowest PAH event in each method is ranked 1 (left-most), and the highest ranked 149 (right-most) overall across all DHBs. The “top ten” facilities ranked the highest by Method 1, and the “top ten” facilities ranked highest in Method 4, are highlighted in yellow and brown respectively in all charts to visualise the variation between methods. Method 1 was simplest – the ratio of PAH events during the 22 months post-OPAL to 100 residents in that facility in OPAL (Figure 10-1a). Although simplest, it takes no account of duration of survival, nor of residents leaving during the follow-up period. When so adjusted, as shown in Method 2, few changes in rankings occur (Figure 10-1b) – all the “top ten” facilities in Method 1 remained in the “top ten” in Method 2.

The statistical model developed in Method 3 found four facility-level predictors as described. Because the models with OPAL data found no high-level care facilities with high admission rates, all high-level care facilities were excluded from facility selection. In the model based on OPAL data, all top 20 facilities in each DHB had an observed PAH rate of at least 35 per 100 resident years of follow-up. When updated data were used, the predictive models assessed all top 20-ranked facilities at 31 or more events per 100 years of follow-up. When ranked by predicted score, one facility

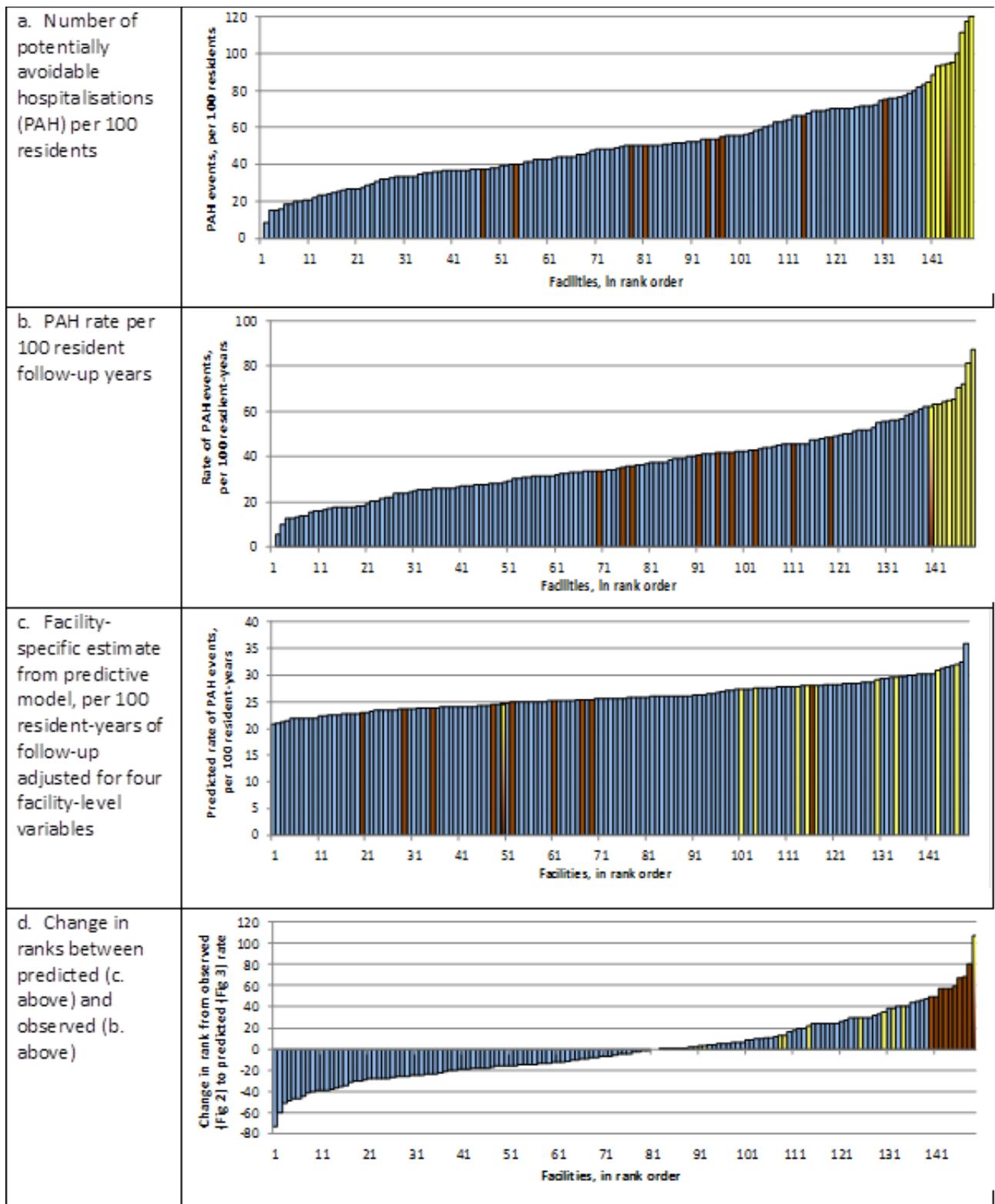


Figure 10-2 Comparison of facility rankings by four methods

Method 1 (a) uses simple event counts per person, Method 2 (b) event rates per year of resident follow-up, Method 3 (c) statistical model of rates using four predictors, and Method 4 (d) the change in ranks between methods 2) and 3). The 10 facilities ranked the highest in a) are shown in yellow, and the 10 ranked highest in d) are shown in brown in all charts, to demonstrate variability between methods. One facility is shown as both yellow and brown.

that was highly-listed in earlier rankings became middle-ranked (49th) in overall rankings, and the rankings of five others reduced by 18 or more places (Figure 10-1c), indicating that the higher observed rates in some facilities in Methods 1) and 2) were accounted for by some of the predictors. Using Method 4, the change-in-ranks method (Figure 10-1d), only one facility previously identified as highly-ranked remained so.

10.5 Discussion

This study demonstrates a few possible methods for selecting LTC facilities with high use of acute hospital admissions, ranging from simpler methods to complex statistical models. Rankings varied markedly. Use of one method without considering other options may well have selected facilities in which the trial intervention would have been irrelevant, defeating the purpose of running a selection process. No method identified a group with clearly higher use – the figures indicate a continuum of risk, not any obvious distinction between facilities with higher or lower use.

This comparison of methods shows that for ARCHUS, a simple assessment of rate of admission given facility size would not adequately select facilities that should fairly be regarded as high users of acute hospital services. To illustrate how different the methods were, one facility (with progressive shading in the plots) ranked in the top ten in Methods 1, 2 and 4, but ranked only 50th of 149 in Method 3, indicating that its predicted need was not high. In others this change did not occur: two facilities ranked in the top ten by three methods (1, 2 and 3), suggesting that although rates in these facilities were high, they were expected to be so given the casemix of their residents. The highest-ranked facility in Method 3 was ranked outside the top ten (129th and 132nd) in Methods 1 and 2, suggesting that although the rate of PAH admissions was not high, resident care needs were relatively low and PAH rates were higher than expected.

Statistical approaches to provider profiling and risk adjustment have been previously discussed. Berlowitz et al. showed that using Bayesian methods reduced numbers of outlying LTC facilities by adjusting not to the norm but to clinical best practice²⁷². Roy and Mor drew attention to measurement of quality and the importance of unbiased coding in data collection²⁷³. Li et al. showed the importance of adjusting for individual and facility-level characteristics when describing nursing home care quality²⁷⁴. Austin and Reeves, in a study assessing models of hospital care quality,

concluded that the c-statistic was of little use to assess model fit although widely-accepted²⁷⁵. Ieva and Paganoni successfully used mixed effect models and funnel plots in hospital readmission rates²⁷⁶. Most recently, Eijkenaar and van Vliet compared rankings of quality, not of LTC facilities but of primary care providers, using many different statistical models to identify outliers²⁷⁷. They observed similar results from the models but very varied outliers and rankings, notably that the models better detected *high*-performing providers than *low*-performing providers. They too emphasised the care needed in selecting the model and noted variability over time. All these methods assume the availability of good, recent data, such as are available in jurisdictions such as the USA where NMDS data and other large datasets exist. In other settings such as NZ, reusing available data presents additional challenges.

Less discussion has centred on non-statistical aspects. In the ARCHUS trial, the aim was to select and target high-use facilities in order to provide a multi-disciplinary intervention comprising staff education, clinical supports, and medical and pharmacologic reviews of residents. A model that included admissions over a prior period as well as what was known about current (albeit subsidised) residents was used. Detailed results of models and rankings are not central to this paper; the intent is to identify more general issues and options, analytical and otherwise, that warrant consideration in determining appropriate methods. In hindsight, the ARCHUS team may have done things differently – for example we did not anticipate that facility non-participation would be as high as it was. The concept of selecting only high-use facilities, once the number had been reduced by removing a few high-level care facilities that declined to participate, meant that to recruit 12 facilities in each DHB region, some mid-ranked facilities had to be recruited. The concept of outliers as discussed by Ieva and Paganoni indicates that selecting high-use facilities is feasible only if numbers of facilities are sufficient that outliers can realistically be identified, not when smaller numbers are available²⁷⁶. But even then, the work of Eijkenaar and van Vliet suggests that modelling lower-use facilities may have achieved greater discrimination²⁷⁷.

The variations in rankings derived under different methods show the need for careful attention, in particular to the purpose of the question. Had we wished simply to identify facilities with *highest numbers* of hospital events (e.g. to monitor performance during a period of service change, regardless of resident needs), then a recent simple

rate, count per resident, or count per bed, may have sufficed. Had we wished to *predict high counts* (e.g. to recruit the fewest possible facilities to most quickly accumulate events for a research project while minimising travel and overhead costs), then use of recent history of events is highly predictive, though it takes no account of whether the high rates are due to resident needs or case-mix within the facilities, to quality of care or to other factors such as distance from hospital that may impact on the decision to send a resident to hospital. Had we wished to *identify characteristics* that may lead to high expenditure on hospital events to inform service design, statistical models to identify factors most associated with costs of event are more appropriate. In that case, unlike when good predictive ability is required, measures of actual recent observed events would probably not be considered in the model in order not to perpetuate existing patterns but to allow them to be identified.

However, when the purpose is to *identify and target* high-use facilities where changes may be achievable, for example to benchmark quality of care more robustly, or to trial an intervention (as was intended in ARCHUS), it is preferable to select facilities with higher-than-expected rates i.e. higher than predicted after adjustment for underlying facility-level risk factors and/or resident case-mix, without including observed rates for an earlier period. In such cases, if current and reliable data is available, then differences between predicted (viz. modelled) rates and observed rates (i.e. model residuals) would have been preferred. The combinations of the issues listed in Table 10-1 are many but each issue should be explicitly considered.

Definitional issues of PAH events have been raised above and elsewhere. It is possible that simply using the first, or first three, diagnosis codes does not adequately take into account complex cares such as typically occurs in multi-morbid presentations of frail older people. One option is to clinically review all medical records in detail, but that is extremely resource intensive and subject to personal opinion. Even then, review is unlikely to correctly classify all cases as “avoidable” or “unavoidable”; data limitations are unlikely for example to describe competing demands being placed upon facility staff at the time of an episode needing greater care and which may clinch the decision to hospitalise. Regardless, the definition itself is not central to his report, though having a definition is.

10.6 Conclusions

Countries including NZ have strategies to reduce LTC placement by supporting ‘ageing in place’⁷⁹. However there will always be a need for LTC as the scope for home care for the highly dependent is limited²⁷⁸. It is important to ‘better manage’ LTC care to improve quality²⁷⁹ and to use funding efficiently. With the healthcare workforce in short supply^{102 279 280}, new ways of working are called for, to better support the industry and improve resident outcomes, for example by reducing acute hospitalisations. If an intervention designed to reduce acute referrals to hospital (assuming reasonable preventive care has been undertaken) by providing some hospital-level care within the LTC facility, then all acute presentations are likely to be the outcome of interest. Where an intervention focuses on preventive care to reduce admissions from consequences of care over a longer period, such as avoiding pressure sores, then a model predicting all hospital presentations (including non-acute admissions) with appropriate discharge diagnoses may be more relevant, with recognition given to underlying need levels of residents. In some instances, acute hospital referrals managed within an ED, and not admitted, may be as relevant, or more, than admissions themselves.

This paper offers some considerations when making choices about methods. Not all dimensions shown in Table 1 will be meaningful for all occasions, but a review of them may avert needless effort and rework, and provide clarity earlier in the selection process.

10.7 Post-script

Publication history

This paper was first presented as a poster at the European Geriatrics Society meeting in Venice in October 2013 and as a conference abstract²⁸¹, then was published in full in BMC Medical Research Methodology in 2014²⁸². It was also, with permission, presented at the Health Services & Policy Research Conference in Wellington in December 2013²⁸³.

Developments

The work was originally undertaken to select high-risk facilities for ARCHUS, a randomised trial of a complex multi-disciplinary intervention intended to reduce acute hospitalisations from RAC facilities already outlined. That trial is completed, but did not show benefit in any of the planned end-points¹¹³.

In seeking to understand why this was so, especially since other studies have shown benefit from similar interventions²⁴¹, several options were considered:

- Use of the modelling tools described above may not have selected those facilities most amenable to change in care standards (even if at higher risk). This chapter has gone some way in addressing this question.
- Facilities selected were only those certified for providing low-level care because these facilities had highest rates of admissions. It may be that the interventions were more appropriate for high-level care.
- The use of a PAH definition that was diagnosis-related used either diagnoses that were harder to modify than anticipated, or excluded ones that were easier to modify. There is some evidence for this²⁸⁴.
- The focus on admissions (PAH and all acute admissions) and death were inappropriate, and that ED presentations would have been a better main endpoint, given that is what is in the control of facility staff.
- It may be impossible to implement the combined set of gerontology nurse specialists (GNS)-led interventions, particularly given budget constraints on resources available in facilities (time and skill of facility staff). In addition, more attention to the role of general practitioners (GPs) may have been effective.
- Acute hospitalisation rates from RAC residents were already as low as could reasonably be expected given the complex needs of these residents and previous initiatives to support facility staff.

To shed light on this final option, hospitalisation rates immediately before and after entry to RAC were compared. Accordingly, the candidate oversaw analyses and production of the following plot which shows graphically how dramatically rates of acute hospitalisation fall after entry to RAC facility, and how they continued to fall

during the following year (Figure 10-3). It is a simple but striking plot, derived from weekly admission counts expressed as a rate, yet powerful enough to need no complex analytical analyses or models.

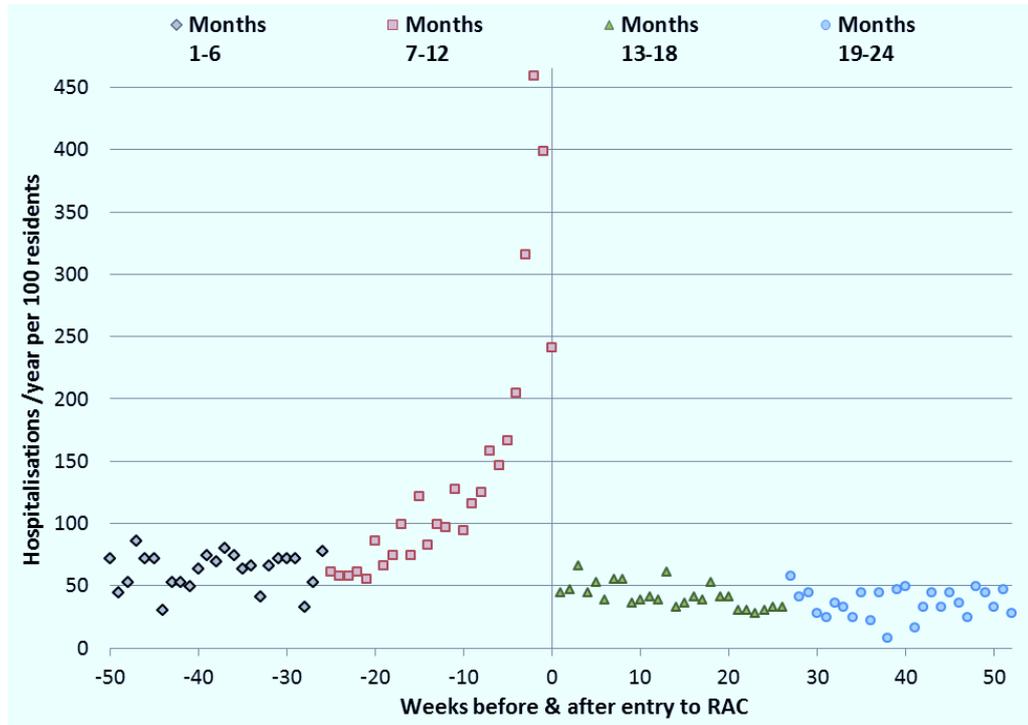


Figure 10-3 Rate of hospitalisation (per year per 100 residents) 12 months before & 12 months after entry to LTC.

Source: This plot was included in a poster presented at the European Geriatric Medicine Society Meeting in Rotterdam, September 2014²⁴⁵, and a research paper submitted.

Had this investigation been carried out prior to designing the ARCHUS trial, a different trial may have been conducted, focusing instead on interventions that enable people to live at home for longer while avoiding escalating rates of admission. This is the likely direction that research work in the sector should now take, especially given the comparison with hospitalisation rates from the community versus RAC residents illustrated in the Postscript to Chapter 9.

Of perhaps greatest priority for further research is the high levels of instability of older people immediately prior to RAC admission. Improvements in in-patient and/or post-discharge care may delay or prevent RAC entry without loss of quality of life, and may also improve outcomes for those who do not enter RAC. A wide array of lines of enquiry have potential to improve post-discharge care, including for example better models of discharge planning from acute hospital care, greater emphasis on rehabilitation and convalescent support perhaps in dedicated community facilities,

integrated care, and facilitation of community networks of visitors or other volunteer support systems.

Alternative accommodation options include offering home-based models of end-of-life care in order to avoid short-term entry to RAC prior to death, extra-care residences more like retirement homes of old in which like-minded people live together with minimal help, and supported living arrangements such as co-residence to avoid the risks that come with living alone. Work has begun on some of these, with a pilot study describing post-discharge follow-up and at least one intervention that aims to improve the quantity and quality of post-discharge follow-up by hospital based specialists – revising the discharge summary template to incorporate specific questions relating to post-discharge follow-up. A comparative study between hospitals in the United Kingdom and in New Zealand is also planned. Several initiatives could be discussed, refined and tested. The new databases offer further research opportunities in the area of RAC and ageing more generally. Some of these may be used to confirm or update results presented here.

Chapter 11. Discussion and Conclusions

Ipsa scientia potestas est ('Knowledge itself is power')

Francis Bacon. Meditationes Sacrae, 1597[§]

11.1 Overview

In Chapter 3, it was argued that policies and practices are better when founded on reliable data that are analysed well and presented as sound information. Information is useful particularly to assess the challenges presented by demographic change and to allow selection of those with highest priority for attention. For many years, reports have been informed by data derived from administrative or transactional records. Because of the nature of these data and the variable method of analysis, the provision and utilisation of RAC for older people in NZ was misrepresented. This work aimed to describe how misunderstandings occurred and to seek more reliable and appropriate information. The approach taken was to re-use available data to avoid costly and time-consuming customised data collection. Analytical methods were employed that are well used in analyses of survey data but seldom used in epidemiology or health services research.

In this final chapter, the implications relating to the theoretic frameworks are reviewed, main findings are outlined and their practical implications discussed. Strengths and weaknesses of the work are reviewed. Selected challenges for the future are briefly considered.

11.2 Theoretical implications

Four theoretical models relating to the value of information in policy and planning were described in Chapter 2. The first, Walt and Gibson's health policy triangle (2.1.1) described how policy content, process, context and actors were drawn together. The exercise of power – by deliberate action or non-action – could be influenced or guided by information that indicates the size of a problem, in volumes, costs or numbers impacted. Thus, if DHB planners were aware of the proportion of new residents who enter RAC direct from acute hospital stay, then perhaps they might review hospital discharge processes, and offer more post-acute care (supports and rehabilitation) when

[§] Cited on http://en.wikipedia.org/wiki/Scientia_potentia_est

older people with multiple chronic conditions are discharged from hospital. Statistical models that describe the association between entry pathways to RAC (via acute hospital or not) may lead to better ways of working. If more people were aware of their chances of entering RAC later in life, then it is likely some would put aside savings to fund them to receive support to remain at home for longer.

Under Walt and Gilson's model, information alone does not prevail. The rationalist approach is impacted by other stakeholders and market forces. Given the unreliability of the data, perhaps that is just as well. But information is needed that is reliable. This is now recognised by current MoH and other government officers, and by the industry itself. Since embarking on this course of study, considerable efforts have improved reporting and monitoring of many aspects of the RAC sector. Facilities are required to provide quarterly reports to the MoH, interRAI assessments are being rolled out, and more consistent census definitions are more relevant and more useful. Nevertheless there remains a need for making reports accessible to interested parties and the public, not limited to those within the government policy environment.

Four policy development patterns were described (2.1.2). For each there are clear advantages in having greater understanding, not only of volumes, counts, rates, trends and the like, but also of what factors influence the behaviour and decisions of other stakeholders, and how that occurs. While MoH has long used subsidy data to inform its policies, this information was less reliable than thought and less accessible.

Under the *stakeholder model*, the mantra "knowledge is power" becomes pertinent for all stakeholders; those with access to more or better information are able to influence decisions in ways that others cannot. Under a *neo-liberal approach*, less planning is undertaken centrally, although for a competitive market to thrive, perfect information must be available to all parties, including consumers and producers. In RAC in NZ, this thesis has shown that reliable, regular and up-to-date information has not been available. As a result, the neo-liberal approach could never have functioned well even in the presence of a market-led government. The *participatory model*, if the democratic process is provided with provided with robust and appropriate information, will be strengthened. For example, advocates of this model will appreciate the new knowledge about patterns in length of stay, especially the number of residents who enter for short stays. Improved outcomes can be expected if that is in conjunction with the sense of shared decision-making. From a *rationalist perspective*, that depends

upon sound information being widely available, learning of the number of people who move into RAC for only a few last weeks or months of life suggests an unmet demand for short-term home-based support systems.

11.3 Empirical findings

As noted in Chapter 4, epidemiology often contributes more through a broader process of “enlightenment” of policy-makers – raising awareness of need for certain areas to receive greater attention by identifying problems and recognising issues, i.e. for priority setting. As Spasoff⁸⁹ suggested, the contribution of this work includes several potential pathways, namely, being focused on health of a population and the health services used, and providing information on the magnitude of health problems and risk factors. The thesis has undertaken enquiry based upon approaches identified by Shapiro, in particular the need to integrate data from routine information systems with data from research projects⁹⁰. The findings have already, and hopefully will continue to, contribute to discussion and debate about current and future needs for care of older people.

For example, following discussion of these combined results with Statistics NZ, recent reports on housing in NZ have included sections on RAC, when previous reports included only those living in private dwellings¹⁵⁵. This is advisedly at least partly a result of those discussions. Of many stakeholders with whom this finding has been discussed, very few anticipated that almost 50% of people aged 65+ use RAC for late-life care. Now, with these estimates of likelihood of use of RAC, together with previous reports on place of death and the use of RAC as de facto hospices for older people, greater attention is being given to policies concerning provision of palliative care and around RAC training of caregivers and recognition of their role.

Chapters 5 and 6 demonstrate how little was known reliably about the numbers of people living in RAC at any one time and has drawn attention to inadequacies in existing reports. In Chapters 7 to 10 some of the most basic questions about RAC in NZ have been answered, shedding light on the current demand for care, how it is provided, and how the health services are used. For the first time there are evidence-based estimates for a NZ population of 1) the proportion of the population who, having reached the age of 65 years, will use RAC for late-life care, 2) the extent of turnover in the RAC sector and length of stay and 3) use by RAC residents of hospital-

based services and 3) a comparison of methods for identifying facilities with high use of hospital services. In developing these estimates it has demonstrated how to convert incidence-type information to prevalence-type information, methods that will be useful in other settings. Further, it has developed models relating to RAC that will inform the ongoing rethinking of RAC in NZ and elsewhere.

Recall the diagram shown in Figure 1-1, and the questions raised in it. Each dashed box in the figure posed a question that this thesis has addressed. In Figure 11-1 below the findings are outlined in the dashed boxes. The paragraphs that follow summarise the results and consider their application for enhancing planning and decision-making.

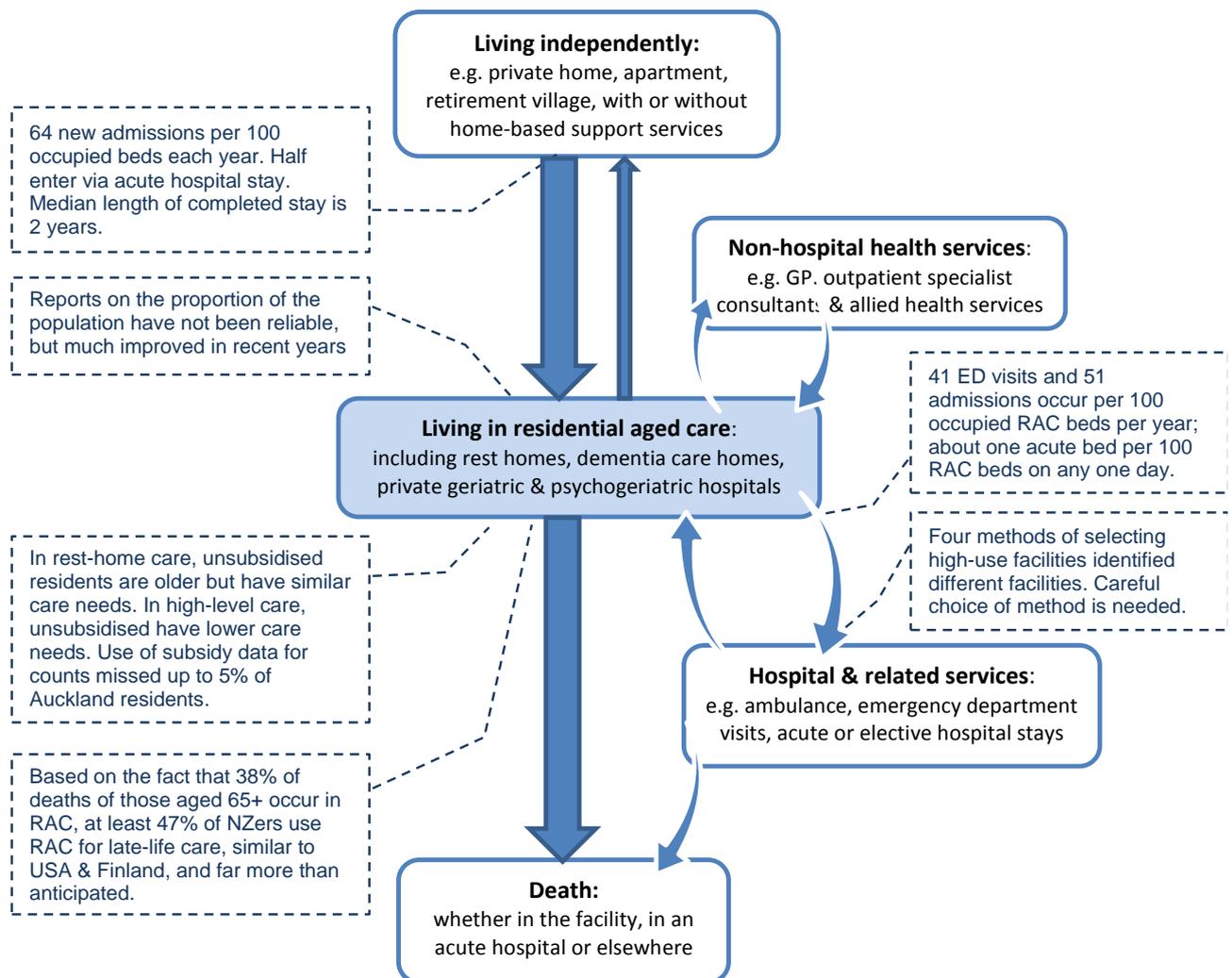


Figure 11-1 Summary of findings from this thesis

How many people enter RAC each year?

Chapter 8 described turnover in RAC, using reweighting techniques developed for the analysis of population surveys. For every 100 occupied beds in RAC facilities, there are on average 64 new admissions and 33 deaths each year. Of the new admissions, 49 enter directly from the community and 14 are internal transfers from another facility. From each of these sources, half enter via an acute hospital stay. This indicates the key role played by acute hospitals in determining when an individual enters RAC, and opens opportunities for re-shaping post-discharge care that for some could enable better quality of life at home, delay or even prevent entry to RAC.

Median length of completed stay in RAC was 2.0 years, with a mean of 1.97 years; 17% dying within 3 months and 23% surviving longer than 5 years. These are very similar to a national report out of Australia. In the UK significant regional variation in length of stay may suggest potential to defer entry to RAC and thereby shorten stays⁵⁵, though it also could be that later entry means people are sicker at entry and die sooner. In the Auckland LTC studies, length of stay to date has declined over time; if that trend continues, turnover will increase beyond current levels. Microsimulation studies could develop credible transition models to test the impacts of different health service scenarios, and assess options for the future.

What proportion of the older population is in RAC at any one time?

Chapter 5 demonstrated that population estimates of cross-sectional use of RAC published over the 20 years since 1990 varied more widely than is plausible or sensible – in 2006 for example, ranging from 4.6% to 8.2%. As a result, it has been impossible to monitor or understand reported trends in utilisation or geographic differences in utilisation rates, and policy advice and debate will have suffered.

In previous years, international comparisons published by the OECD have put NZ as the highest, or nearly highest, user of RAC per head of population than other members of the OECD. Were New Zealanders institutionalising their older people more than necessary? It is inevitable that these data, often used for the purposes of international comparison, could imply use of RAC in NZ was extreme. Having seen these results, a policy advisor, Minister or health professional, apparently with justification, may set off in a policy direction that tries to reduce RAC use. In doing so, considerable damage might accrue for individuals and businesses, with undesirable consequences

for acute health care services. Conversely, if in subsequent years NZ seemed to rank lower in the order purely as a result of measurement variation, a change in policy may be viewed as having been successful when it may not have been, and may indeed have been harmful. While no evidence is presented that that has occurred in NZ, if this is just one such instance of misinformation, then at some times the making of decisions in policy and practice will have been misled.

The wide variations in reporting over a relatively short period indicate that these extreme international rankings were incorrect. Use of simple quality assurance measures during reporting, such as checking against information provided for earlier years – either at MoH when providing the results or at OECD before publishing – could easily have avoided these concerns.

Many would expect census-based estimates to be the most reliable for describing cross-sectional RAC use and trends in use over time. However, censuses in recent decades have undergone, necessarily, changing definitions of what was classified as RAC. In particular, earlier censuses classified many long-stay high-level care residents as not being in the RAC sector but in acute hospital. Census classifications were revised for the 2006 census and recent measures are much improved, being more consistent and accurate. The most recent census, in 2013, indicates that 5.0% of those aged 65+ and 14.6% of those aged 80+ were in RAC on census night¹⁵⁵. If, as Chapter 9 suggests, more than one in a hundred long-term residents were away in acute hospital on census night, actual proportions may be slightly higher, and that still excludes people in retirement villages who receive a package of care that is equivalent to RAC care and may even be subsidised. Nevertheless, the latest MoH estimates based on subsidy data are now closer to census counts; estimates of RAC residents since 2008 have ranged between 3.7% and 5.7% of the population aged 65+ years.

How do those who receive government subsidies differ from others?

Chapter 6 presented results that showed that for Auckland (at least), MoH estimates systematically undercount unsubsidised payers. In the 2008 OPAL survey, 25% of all Auckland RAC residents were not receiving a subsidy: 43% of those in rest-homes, 6% in hospital-level care and 13% in secure dementia care. As reported in the Postscript to Chapter 6, this represented an undercount of perhaps 450 people in Auckland. The extent to which miscounting applies in regions other than Auckland remains unknown.

Undercounts in official data are a concern because for policy purposes these are the numbers that are most used for describing and projecting counts, resident characteristics, rates and costs of RAC in NZ. Fundamental differences between subsidised residents and unsubsidised, in terms of demographic characteristics, lengths of stay or care needs, if not adjusted for in projections for example, will mislead. A note later in the postscript to Chapter 6 indicates that most private payers do eventually become eligible for a subsidy, either by moving into high-level care or by exhausting their personal funds. If proposals to modify eligibility criteria for subsidies are being made, then it is vital to anticipate the shift in numbers who may become (or perhaps cease to be) eligible.

What is the lifetime risk of use of RAC?

Using relatively simple ratio estimators based on data for place of death and four small cohort studies, Chapter 7 showed that an individual reaching the age of 65 years currently has an estimated likelihood of at least 47% of RAC entry. After the age of 85 years that reaches at least 58% for men and 70% for women. These figures are higher than those in most other countries for which reports are available; countries with higher use of RAC use it more for rehabilitation than is the case in NZ. In comparison, one previous report of 25%–30% was based on non-NZ data⁹⁷. Clearly that is not credible when it is known that 38% of deaths occur in RAC facilities¹³⁰.

The simple implication is that presently about half of older people use RAC for late life care. This is a substantial political lever that should move RAC higher in policy and research priorities, for small changes in utilisation have potential to markedly change costs to the tax-payer. It is also a key finding for individuals planning investments to anticipate future care needs and to provoke discussions within families.

What use is made from RAC of acute hospitals?

Anecdotal accounts have regarded RAC residents as frequent, and perhaps unnecessary, users of hospital in-patient services. Indeed, overseas studies have reported rates of hospital admission as 1.6 times those of community dwelling older people²³⁵. As a result, effort has been expended in trialling interventions to reduce rates of hospitalisation from RAC. Chapter 9, using Auckland data again using reweighted analyses or existing data, reports that for every 100 occupied RAC beds over a 12-month period (i.e. per 100 resident-years), an estimated 41 (95% CI 37-45)

emergency department presentations occurred. This is important not only because most ED visits become acute admissions funded by taxpayers, but also because admissions expose patients to hospital-acquired infections, confusion, and other iatrogenic harms. In reweighted analyses predicting ED presentation from RAC, residents in dementia, psychogeriatric or hospital-level care were *less* likely to present to ED than those in rest-home (lower-level) care; men, and those aged 85-94 years were *more* likely to present to ED. Even after adjustment for those (expected) differences, newly-entered residents and residents in for-profit facilities were more likely to present. These results may indicate there exists a period of settling during which facility staff become attuned to the needs of newly entered residents, families and residents become more trusting of facility staff and also perhaps that the threshold for referral to ED varies between facility types. Further research in this area would be useful to understand the factors at play here.

Reweighted analyses also demonstrated that 52 (95% CI 47-56) hospital admissions occurred for every 100 occupied RAC beds over a 12 month period, 38 of which were acute. Typically, 90 public hospital beds were occupied by an RAC resident at any time in the Auckland region, effectively over one hospital bed for each 100 current RAC residents. The most frequent conditions recorded at hospital discharge were circulatory (12.6%), respiratory (11.3%) and rehabilitation (9.6%), in accord with other countries. Anecdotal reports expressing concern from hospital staff about high numbers of RAC residents occupying hospital beds are common, but it is now clear that in people recently entering RAC, hospitalisation rates in the 12-months immediately following entry are far lower than those for the same people in the 6 months immediately before. This also supports the need for a shift in emphasis to addressing instability prior to RAC entry ahead of care provided within RAC.

That hospitalisation rates from RAC were found to be lower than those reported in other countries supports the argument that RAC provision varies from country to country. Interventions that are effective in one jurisdiction may therefore not be appropriate, or similarly effective, in others, particularly if they provide a different level of care need.

How can RAC facilities that are high users of acute hospitals be identified?

Chapter 10 compared four methods of selecting facilities that have high acute hospitalisations, in the expectation that a model that distinguished well those facilities

that had higher rates of hospitalisation might be selected for efforts to reduce hospitalisations. Two of the methods selected a similar group of facilities, and two selected quite different facilities. Options included hospitalisation rates per bed or per resident, with or without adjustment for the complexity of care needed by residents. Each method could be useful, depending on the purpose, for example whether to focus on service provision or to trial interventions.

This finding reinforces that the choice of a risk selection method should focus clearly on the purpose intended, as should the end-point of interest. In RAC settings, ED presentations or acute admissions may be more relevant than a classification such as “potentially avoidable admissions”, particularly when high levels of co-morbidity exist in this population. Targeting of facilities of any type, if undertaken, should be based on relatively common measures taken at several time-points and in many facilities, in order to avoid simply reporting some measure of random variation.

In combination

These questions may seem to be separate questions, and indeed that is how they are presented in this thesis. Together, they form part of the story of health care, social support, personal assistance and optimising quality of life for older people nearing the end of their lives (notwithstanding that some enter at much younger ages and stay for over 40 years). The value of evidence-based information is exemplified by Paul Samuelson, the Nobel laureate from the Massachusetts Institute of Technology, who recalled John Maynard Keynes once being challenged for altering his position on some economic issue. He recalled that Keynes had said ...

“When my information changes, I change my mind. What do you do?”

Lindley H. Clark. Wall Street Journal, 1978^h

Reviews of policy and practice that are informed by evidence are now possible. But the value of the findings reported in this thesis lies more in improving public policy advice – through informing planning decisions – in order to optimise health and wellbeing most efficiently, whether for private or public funding.

^h Cited on <http://quoteinvestigator.com/2011/07/22/keynes-change-mind>

11.4 Practical implications

RAC is a long-established aged care service in NZ, yet there were large gaps in knowledge at a population level. Epidemiological methods are fundamental to describing health of populations, including population sub-groups such as the very old. This work provides estimates for some population parameters that were previously unknown. The results are informative for policy and planning environments, for service providers at national, regional or local level, and for communities and individuals planning their futures.

There is much in this work that has relevance to RAC and other health care in the future. Potential discussion starters may include the following, addressing perspectives for each group of stakeholders in turn.

Firstly, individuals and their families can be better informed of the likelihood of need for long-term care. Older people considering their futures and potential care needs, and their families, financial advisors and insurers, realising that the chances are roughly 50:50 that they will enter RAC care for late-life care. Plans could be discussed for providing care should disability or care needs arise that require support, mindful of older people's wishes to not be a burden on their families.

Communities of like-minded people may develop models of co-dependency or village-type support that permits people to remain at home or in a local home-like setting for longer, where they have greater control of the daily decisions that shape their days.

More GPs and home-based service providers may choose to provide services to RAC residents, assisting residents to achieve a level of well-being that is less focused on their chronic disease conditions but accepts them and works around them to improve well-being. The growing market indicates there are opportunities for developing new models of care of older people with frailty, multi-morbidity and/or disability, both RAC-based or perhaps more particularly, home-based services.

Facility owners, operators and managers will be informed as to how often residents present to ED departments and may be encouraged to address early warning signs or seek advice from a GP rather than transfer residents directly. They may more effectively lobby for funding that reflects better the costs of providing care for their residents without transferring to acute hospital or if levels of turnover increase.

For hospitals, including geriatricians, gerontology nurses and secondary care service providers, the high rate of entry to RAC following a hospital stay indicates potential for older people to be better assessed before discharge and provided with rehabilitation and slow-stream recovery support, and thereby improve their chances of returning home.

CEOs of DHBs now can better understand the movement into and out of RAC facilities, including the bias in reports when subsidised data are used for population estimates. DHBs, hospital administrators, clinical leaders, planners and funders, need to anticipate increases in use of RAC in the future as a result of increased longevity. They may like to consider alternative means of providing support to facilities and their GPs, for example visiting geriatricians. It should be noted that caution should be exercised if proposing the adoption of overseas models of innovation in assessment, treatment or care services until evaluated in NZ settings.

For MoH and DHBSS analysts, when the new information sources become bedded in and are demonstrated to be consistently collected and reported, making best use of the data will be important. Desirable outcomes include population-based projections, monitoring trends in utilisation, length of stay and care need levels by subsidy status. Assessing regional variability could discover innovative models of care that are excellent, using projections of future demand and evaluating the delivery of after-hours primary care to assess the impact of various types of provision.

Report writers from MoH, Statistics NZ and other ministries and government departments might assist by producing reports that include analyses that split the 65+s into at least two age groups.

Government ministers, politicians, political parties, policy-makers, and their advisers can for the first time recognise how large a proportion of the population the RAC sector affects, and how much it is the norm for late-life care of older people. All may be informed by the differences in needs for care by those who are subsidised compared to those who are not, together with the shorter stays among the private payers.

If local governments were to encourage or enforce universal design in new housing, with more apartments and other accessible housing near community facilities including shops, social activities and healthcare providers, older people may be enabled to remain at home longer.

11.5 Challenges and future research

It is inevitable that important questions remain in this field of enquiry. The first is to measure across New Zealand the actual cross-sectional use of RAC. Studies that include regions other than Auckland would be particularly useful, even if not census-type surveys (i.e. inclusive of all facilities and all residents), to improve estimates of those using RAC at any one time. It would be also useful to estimate the numbers of people assessed as needing 24-hour care and who live in retirement villages or similar conjugate housing.

Once the validity of the new interRAI data is assured and they are proven to adequately represent the RAC population, many research studies will be possible that draw on the resources of this large international collaboration. Firstly, cross-sectional studies will enable point-in-time descriptors of the characteristics and needs of current residents. Secondly, it will be possible both to form new cohorts of residents and to track them over time to understand their care trajectories. Thirdly, studies that characterise risk of certain outcomes or test interventions using routinely collected data will facilitate new research findings with potential to improve future care. Fourthly, and arguably the most informative for generations to come, is to monitor trends over time in the patterns of presentation and stay within facilities. Such studies, in conjunction with the equivalent data for those receiving home-based support services and with population socio-demographic data, there is potential for demonstrating the impact of any new services introduced to address the growing numbers of older people with chronic illness and multiple morbidities who need care. Better information (than presented in Chapter 8) about turnover and length of stay would be achieved from a longitudinal study of people who newly enter RAC. It could also more accurately track service use over time, including use of other services such as ambulance, hospital out-patient visits and primary care services. International comparisons of longitudinal cohorts assembled at entry would help understand the variability between countries, and could identify innovations that would help support people at home longer if that is what they would prefer. Again, interRAI data could be valuable for this purpose.

Investigation into health service needs, entitlements and access – for example physiotherapy, dental and primary care, including after-hours – may be informative. It

may be helpful to survey the views and preferences of older people in order to develop and evaluate innovative care options that provide for choice and flexibility. Options may include foster homes, extra-care homes, supported co-habiting and live-in support carers to avoid loneliness and social isolation.

Improvements in rates estimations and projections that more specifically address age, gender and ethnicity of future populations could explore regional variations and the reasons for them, as a basis for future monitoring and for comparison with other jurisdictions. Micro-simulation methods would be useful for this as they could permit testing “what if” scenarios, allowing for variations in rates of entry, length of stay, level of need at entry, etc.

In a more long-term view, better understanding of the patterns of disability, multi-morbidity and chronic conditions of older people in NZ could provide a platform from which to assess future needs. These are big problems that, with population ageing, will only become bigger, until addressed – from the incapacitating impacts of arthritis, congestive heart failure, depression and dementia, to the loss of independence by those suffering from macular degeneration.

A final challenge is to share the results of this work with relevant planners and policy-makers, for the point of this research is to inform policy and practice. Although not definitive, the information that this work provides is useful only to the extent it is used to inform decisions and actions. There are opportunities to share the findings with more DHB planning and funding teams, with the Ministries of Health and Social Development, provider organisations such as facility operators and chains and the NZACA, with geriatricians and gerontology groups, with financial advisors and with organisations such as the Palliative Care Council and Age Concern.

11.6 Limitations of the study

All studies are open to criticism as a result of the methods used. In this thesis, several of the findings are based on data for one region, Auckland. Results may therefore be biased to the extent that this population and its health services differ importantly from those living elsewhere in NZ. Further, some data used are now dated, the OPAL cohort having been assembled in 2008.

In analyses where missing data are adjusted for by re-weighting, the assumption is made that those that are missing are similar to those for whom data are held. In fact, this is unlikely, i.e. there are usually differences between the people for whom data are held and those without. However, there is a good body of knowledge that demonstrates that weighted estimates are usually better than unweighted in this type of situation, and are certainly better than having no knowledge.

Although in many cases findings were expressed with appropriate confidence intervals to express uncertainty, on some occasions, such as the work estimating the likelihood of RAC use, derived estimates were presented without acknowledging their uncertainty. In part this is because these were regarded likely underestimates given the method, and partly because of the complexity of deriving and expressing the uncertainty. Further work could improve these estimates. Limitations specific to the specific questions are listed in the relevant chapters.

The purpose of this thesis was to provide estimates to fill information gaps, supposing that some information, even if weaknesses, would be better than none. Scientific enquiry, even if it uses reliable data and is well analysed, always leaves some questions unanswered, and raises others. Information derived in the process needs to be contextualised, to ensure that the move from “data” to “information”, to “evidence” and to “advice”, is sound. Accordingly, many subsequent questions could be raised – this work allows some assessment of the priorities for those questions.

11.7 Concluding comments

[An] important role that public servants play is to help Ministers and the community in general to understand the options and choices they have. It is too easy, perhaps even negligent, to leave Ministers to make decisions with insufficient information, without the best possible evidence, and without learning from what has gone before. And the point here is that there is rarely something where the issues are clear-cut, or where choices don't have to be made.

The policy advice that informs these decisions must be built on a strong foundation. We have to make sure what looks like a good policy idea is backed up by solid evidence and quality analysis.

Excerpts from a speech by Gabriel Makhoulf, Secretary to the NZ Treasury, April 2013, Part of the Better Public Services Initiative of the State Services Commission, cited in Gluckman 2013²⁸⁵

Reliable, consistent information should be central to policy and planning in health as in any other major service sector. If the true state of affairs is invisible or ignored, it is

unlikely that policy decisions will be optimal – whether in planning future demand, in resource allocation, or in identification of need for revising and renewing service models. Further, anticipating the intended or unintended impacts of any proposed changes to government funding criteria for RAC specifically or for other related services is impossible without understanding usage patterns.

This thesis has evaluated the quality of existing data and analyses, and found them wanting: previous and current reports that describe demand for or patterns of use of RAC are limited or biased. Unreliable reports hamper good debate and policy. The thesis offers new ways to address information gaps by re-analyzing available data using analytical methods seldom used in epidemiology or health services research. In doing so it has taken advantage of access to research data, incorporating them with data from official sources. It provides opportunities for benefit for management, planning and policy in the healthcare sector and enhances understanding of utilisation of other services by RAC residents. Additionally, it informs individuals and their families who wish to understand better their risks of costly care in order to prepare for their later years.

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Appendix: Ethics approvals

The following table summarises the relevant ethics approvals for the research concerning residential aged care in the Auckland region, including observational and intervention studies and sub-studies.

| Study name & Principal Investigator | Approval body, date & number (if known) | For what work? |
|--|---|--|
| Auckland Long-term Care Study 1988. PI: Ruth Bonita | North Shore Hospital Ethical Committee 22-Dec-1987 | Collect data for residents, describe bed numbers, rates & dependency levels of residents |
| Auckland Long-term Care Study 1988. PI: Ruth Bonita | Middlemore Hospital 24-Feb-1988 | Collect data for residents, describe bed numbers, rates & dependency levels of residents |
| Auckland Long-term Care Study 1993. PI: Ruth Bonita / Joanna Broad | North Health Ethics Committee 1993 | Collect data for residents, describe bed numbers, rates & dependency trends |
| Stage Three and Long-Term Care Study (STALT) 1998 PI: Phil Wood / Stephen Chalcraft | North Health Ethics Committee X 14-Aug-1999 (98/07/125) | Collect data for residents, describe bed numbers, rates & dependency trends |
| Older Persons Ability Levels Study (OPAL) 2008. PI: Michal Boyd | Northern X Regional Ethics Committee, Auckland expedited review May-2008 (NTX/08/49/EXP) | Collect data for residents, describe bed numbers, rates & dependency trends |
| OPAL Part II 2010. PI: Martin Connolly | Northern X Regional Ethics Committee, Auckland, expedited review, 21-May-2010 (NTX/10/EXP/087) | Match the 2008 OPAL survey data with healthcare utilisation data, to identify individual and facility level factors & create a model to predict avoidable acute hospitalisation – as Phase 1 of ARCHUS |

| | | |
|---|---|--|
| Aged Residential Care Healthcare Utilisation Study (ARCHUS) 2010. PI: Martin Connolly | Northern Y Regional Ethics Committee, Hamilton, 21-Jan-2011, (NTY/10/11/090) | Randomised trial of multi-disciplinary team to reduce hospitalisations |
| ARCHUS 2011. PI: Martin Connolly | Auckland DHB, 7-Mar- 2011, (Study no. 5043) | Randomised trial of multi-disciplinary team to reduce hospitalisations |
| ARCHUS 2011. PI: Martin Connolly | Waitemata DHB, advised Jul-2011, online website | Randomised trial of multi-disciplinary team to reduce hospitalisations |
| ARCHUS amendment #1 2012. PI: Martin Connolly | Northern B Regional Ethics Committee, Wellington, 13-Aug-2012, (NTY/10/11/090/AM01) | In ARCHUS, to widen data collection to include data from PHARMS (dispensing records) and NN PAC (ED & out-patient visits) databases, and to merge with trial databases |
| ARCHUS amendment #2 2013. PI: Martin Connolly | Central Health and Ethics Committee, Wellington 26-Jun-2013, expedited (NTY/10/11/090/AM02) | To retrieve CCPS (subsidy payments) data from NDSA, and to merge with trial databases |
| ARCHUS amendment #3 2013. PI: Martin Connolly | Central Health and Ethics Committee, Wellington 26-Jun-2013, expedited (NTY/10/11/090/AM03) | To cross-check ARCHUS results using hospitalisations for subsidised residents only |
| Aged Residential Care Healthcare Implementation Project (ARCHIP) 2013. PI: Martin Connolly | Northern B Health and Ethics Committee, 22-Jan-2014, (13/NTB/172) | To implement an ARCHUS-type multidisciplinary intervention in RAC, focussing on residents with a history of the “big-5” diagnoses, using a step-wedge design. |

