

Ageing Well at Home: Measuring the Impact of Community Care for Older People

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www.agedcareoutcomes.net

In the face of the economic and demographic pressures associated with an ageing population, how can we know whether the support we call community care meets the needs of those who depend on it? How can we know what is effective and how can care be best provided? In the increasingly competitive environment of aged care in Australasia, how can consumers, providers and funders be sure that the care support and services delivered is both efficient and makes a positive difference?

This report provides details of the research undertaken in 2015-16 to develop and test the Australian Community Care Outcome Measurement tool (ACCOM), a set of measures of community care suitable for use in the Australian context. It is set out in three parts. Part I covers the background and methodology of the study; Part 2 the trial results. Part III concludes with an overview of the important lessons from the trial and a discussion of options for the future.

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The Australian Community Care Outcomes Measurement Tool (ACCOM)*

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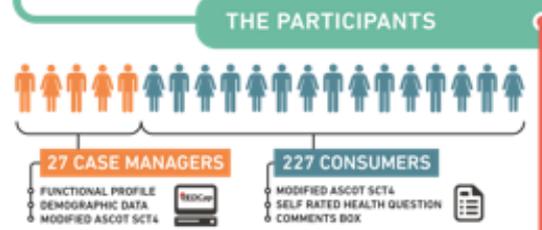
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*The ACCOM uses questions from the Adult Social Care Outcome Toolkit (ASCOT). The ASCOT questionnaire has been developed by members of the Personal Social Services Research Unit (PSSRU) at the University of Kent at Canterbury, United Kingdom (UK). The work has been substantially funded by the Quality and Outcomes of Person-Centred Care Research Unit (QORU) under the Policy Research Programme in the UK Department of Health. The University of Kent is the sole owner of the copyright in these materials. The University of Kent authorises non-commercial use of this questionnaire on the condition that anyone who uses it contacts the ASCOT team (ascot@kent.ac.uk) to discuss this use and enable the PSSRU at University of Kent to track authorised non-commercial use. The University of Kent does not authorise commercial use of this questionnaire. Anyone wishing to obtain a licence for commercial use of any of the ASCOT materials should contact the ASCOT team, who will put them in touch with Kent Innovation & Enterprise.

² During 2017 Aged and Community Services NSW & ACT transitioned into the new entity Aged and Community Services Australia.

AUSTRALIAN COMMUNITY CARE₁ OUTCOME MEASURES (ACCOM)₁

The ACCOM has been developed to measure Outcomes of Community Care in the Australian Context



- ### THE OBJECTIVES
- TEST THE USEABILITY, VALIDITY AND RELIABILITY OF THE ACCOM TOOL
 - TEST THE POTENTIAL USES OF ACCOM
 - TEST THE VALUE OF THE CONSUMERS AND CASE MANAGER RESPONSES
 - TEST THE VALUE OF ACCOM AS AN OUTCOMES MEASUREMENT TOOL FOR COMMUNITY AGED CARE IN THE AUSTRALIAN CONTEXT

THE RESULTS

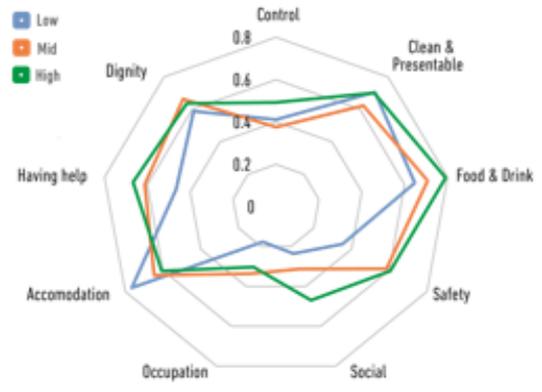
CASE MANAGERS AND CONSUMER RESPONSES



- Shows Quality of Life ratings by both individual consumers & staff
- Data can be used for individual consumers, as well as combined for agency level analysis
- Staff and consumers both rate 'occupation' and 'control' domains as low
- Consumers report low levels of satisfaction with 'social participation'

RELIABILITY & VALIDITY

Strong evidence to support the construct validity of the ACCOM attributes. Expected correlation between variables



Clients who selected the most positive response for each QoL item by functional score in R1

Consumers with high functional capability scored higher in social participation than those with medium and low functional scores.

Consumers with low functional capability face additional challenges to social participation compared to the more able consumer.

Capturing functional capability provides a valuable tool in the assessment of consumers quality of life responses.

USABILITY

- 95%** CM completed the tool in less than 10 minutes
- 80%** Consumers completed the tool in less than 10 minutes
- 90%** CM found the tool very easy or easy to complete
- 60%** Consumers found the tool very easy or easy to complete

USES OF ACCOM:

- Care Planning and Review
- Quality Review and Benchmarking
- Case Management Training

FUTURE WORK:

- NATIONAL INDUSTRY RUN RATINGS PROGRAM
- CARER MEASURES ACCOM
- EXTEND TO CHSP SERVICES

Further information: <http://www.agedcareoutcomes.net/presentations-1/>

Acknowledgements

Like many other research projects, this study is the product of the combined work of a great many people, working in long partnerships over a number of years.

Most importantly, the study would not have been possible without the contribution of the consumers, their family carers, case managers and other service staff. The informed consent agreements they each signed means that we are unable to thank all by name, but as all readers of this report will quickly realise, the study could not have taken place without their assistance. We hope that over time the results achieved will indeed help lead to a better future for community care recipients and for those who work in the system.

The current study was a true collaboration between the researchers, the authors of this report, and the research partners from the collaborating services: namely Lisa Ralphs, Aged and Community Services NSW and ACT; Helen Wilson, Deborah Fraser, Wendy Hill, KinCare; Jane Crowe, Maree O'Rourke, Ken Johnson, Community Options Australia Inc; Wendy Mason, Robyn Helm, Nicole Donohoo, BaptistCare NSW and ACT; and Karn Nelson and Alyson Jarrett of The Whiddon Group. To each of them and to their senior managers and directors from the sponsoring services who supported their participation and contributed to the financial resources of the study, we remain deeply grateful. It is also not possible to thank Professor Ann Netten of the PSSRU sufficiently for all that she has brought to this work. There have been many others, colleagues at Macquarie and Wollongong Universities and elsewhere, for whose timely assistance we remain truly grateful. We acknowledge the vital financial support provided for two years by the Australian Research Council (ARC) through ARC Linkage Grant LP140100458.

It is also important to recognise the contribution of those prior to this study who helped make it possible. The research is deeply indebted to the work of Alan Owen from the Australian Health Services Research Institute (AHSRI) at the University of Wollongong, who not only wrote a seminal report on the issue of measuring outcomes in community care but was a leading member of the current research consortium, sadly passing away before funding was awarded. We owe another longstanding debt to the partners from the NSW Case Management Collaboration, especially Eliza Pross and Prue Sky (CCNB), Ruth Wilson (ACSA NSW) and Vivian (NSW COPs), who instigated research into case management practices in aged care in 2007 that laid the groundwork for the research on community care outcomes many years later. Others who subsequently contributed to the development of this study on outcome measurement include Dr Virginia Simpson-Young (Macquarie), Judith Teicke, Annette Michaux, Sarah Fogg, Tom Sitek and Saul Flaxman (Benevolent Society of NSW) and Helen Wilson and Royden Howie (KinCare). We also wish to acknowledge the work of Dr Sarah Redshaw, then of Macquarie University, who made a very significant contribution to the pilot study that preceded this and to the research proposal that was subsequently funded by the Australian Research Council.

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Chapter I

Introduction

In the face of the economic and demographic pressures associated with an ageing population, how can we know whether the support we call community and aged care meets the needs of those who depend on it? How can we know what is effective and how care can be best provided? In the increasingly competitive market based environment of community and aged care in Australia, how can funders, providers and consumers be sure that the support delivered is efficient and makes a positive difference?

Expectations about what is suitable in the world of community and aged care are changing rapidly. A shift in preferences away from residential care towards care in the home has long been evident. But what do consumers want from care at home? Should it continue to focus on the provision of basic support for activities of daily living (ADLs) as a sort of quasi-hospital like home health system? Or should it aim higher, helping recipients live life as they would choose? Community care is also becoming less standardised and more individualised. Pressures to ensure that the assistance each recipient receives is adapted to their personal circumstances and able to be personally controlled by the consumers make it ever more difficult to know whether the care provided is having the right impact.

Community care is not simply a matter of concern for immediate consumers, the recipients of support. It is also a social responsibility, one that often depends on the contributions of unpaid family carers. How much should formal services work with unpaid carers? Do services delivered at home actually help carers, or do they become yet another responsibility for them to manage and contend with?

Alongside the competitive demands faced by services to meet the preferences of consumers, economic pressures to ensure that the assistance provided is affordable and sustainable over time also shape provision. With the need for community care projected to increase, significant policy changes planned or implemented in recent years in Australia have stimulated competition between care providers. Under these uncertain conditions, it is increasingly important to know when services work well and when they don't and to be able to reliably demonstrate when the assistance provides value and when it does not.

A robust, reliable and effective system for collecting and measuring information related to the outcomes of community care is essential to enable service providers to demonstrate that they are able to provide high quality care that will effectively support older people to remain at home while meeting each of these goals.

This report documents the research undertaken in New South Wales in 2015-16 by researchers from Macquarie University and the University of Wollongong to develop, refine and field test a new tool to measure these care outcomes: the *Australian Community Care Outcomes Measure* or ACCOM¹. The research was undertaken in partnership with research

partners in the Aged and Community Services NSW and ACT³, Community Options Australia, BaptistCare NSW & ACT, The Whiddon Group and KinCare, with each organisation contributing both financially and organisationally. Field trials were undertaken with BaptistCare NSW & ACT, The Whiddon Group and KinCare. Significant additional financial support was provided by the Australian Research Council under research award LP140100458, part of the Linkage Research Program Awards for the support of research that involves collaboration between academic researchers and industry practitioners.

Research Aims and Objectives

The study addresses a key research question: what data is needed to understand the effects of the provision of community and home based care for older people and how can it be most effectively incorporated into a robust, practical and reliable measure of outcomes to inform service practitioners, consumers and researchers?

The research was intended to refine and maximise the use of data collected as part of existing administrative processes to provide evidence of the impact of the care provided to consumers and carers in their own home.

Specifically, this study set out to identify and rigorously test outcome measures of community care through:

- i. Refinement and testing of the Australian Community Care Outcome Measures (ACCOM) for case management in community care as the first of a suite of outcomes measures in a range of service settings;
- ii. Comparing experience and quality of life outcomes between consumers and case managers with the use of agreed, consistent goal collection and outcome measurement tools;
- iii. Demonstrating the value of agreed practical outcome measures for policy and practice in community care;
- iv. Establishing an ongoing process for consistent data collection and review of community care data;
- v. Developing a process of collaboration between academic researchers, community care practitioners and consumers for the exchange of research and experience on the design and use of outcome measurement in this field;
- vi. Extending the knowledge base and expertise in case managed community care to inform practice and policy, future innovation and further academic research.

³ During 2017 Aged and Community Services NSW & ACT transitioned into the new entity Aged and Community Services Australia.

Outline of this Report

This report provides details of the research undertaken to develop and test a measure of community care - suitable for use in the Australian context, the ACCOM, in 2015-16. It is set out in three parts. Part I covers the background and methodology of the study; Part 2 the trial results. Part III concludes with an overview of the important lessons from the trial and a discussion of options for the future.

In the remaining two chapters of Part 1 an overview of the background to the research is provided together with details of the research methodology. Chapter 2 discusses the background and presents a brief literature review of relevant studies. Following this, a succinct account of the research methodology is presented in Chapter 3. The first part of the chapter covers the development and construction of the ACCOM including the processes before the recent field trial. In the second part, details of the trial and the research processes and methodology are presented. The discussion includes the ethics approval process and requirements, sampling, administration and management of the trial.

The initial results of the trial are presented in Part 2 of the report. Chapter 4 gives an overview of the findings of the quality of life experienced by community care recipients as reported using the ASCOT, one of the three key components of the ACCOM. The responses provide powerful insights into the different perspectives of consumers and their case managers. The following chapter, Chapter 5, goes beyond this data to explore the extent to which the results are determined by demographic factors – such as the age of consumers, whether they live alone or with others, their cultural background and source of income, or by their personal capabilities and the level of their need for care. In Chapter 6 we turn our attention to the ACCOM, reporting the results of tests of its useability, reliability and validity.

In Part 3 of the report we reflect on the findings of the study and consider the implications for the future of the ACCOM. The research reported here has demonstrated that the ACCOM is able to provide a robust, practical set of measures with which to track and understand the outcomes of community care for older consumers in a way that can be readily completed by consumers and case managers. But will it be taken up by community care services? In the final chapter of this report we therefore consider the challenges remaining. We identify further developmental work that needs to be undertaken and the difficulties encountered in fostering widespread adoption of the measure, and explore a number of options for future progress.

Chapter 2

Background to the Development of the ACCOM

Although it is easy to identify achievements and results in many fields of human activity such as manufacturing, education, health care or consumer sales, it is notoriously difficult in the fields of aged and community care. Aged care has many features in common with some of these fields, especially health care. But while the goal of health services is typically to help restore the recipients to good health, this is not always possible in aged care. Maintaining and where possible strengthening and restoring the health of care recipients is of course desirable, but as it is not always achievable due to the incurable nature of chronic disease and severe disability as well as the natural decline associated with ageing. It is also not good enough just to keep people alive for months and years as an end in itself, without any sense of further purpose or recognition of the social meaning and connectedness of life.

In the absence of clear goals and measurable indicators of success, the aged care production system often defaults to focus on measurable units of output – such as how much an hour of care costs. But to be able to demonstrate that a service is achieving high standards of quality care and assisting consumers to make the most of the life that they have, it is important to focus on the outcomes of care – the results or consequences of the interventions undertaken and the assistance provided.

In social care services an outcome is commonly understood as the result, impact or consequence of a process of service provision. As shown in Figure 2.1, outcomes in this way can be distinguished from inputs, service provision processes and outputs. ‘The production of welfare’ framework, developed and employed by the Personal Social Services Research Unit (PSSRU) in the UK (<http://www.pssru.ac.uk/>) provides a framework that distinguishes resource inputs, costs, non-resource inputs, from intermediate outputs and final outputs or outcomes. This emphasis on objective definition and measurement has been extended in a recent formulation by linking the definition to vulnerability, defining outcomes more directly and subjectively in terms of the states that people facing threats to their wellbeing or existence seek to attain or avoid.

Figure 2.1 Outcomes as Products of the Production of Social Care

Inputs ⇨	Service Production Process	⇨	Outputs ⇨	Outcomes
-Funds (public and private) -Consumers (care recipients) -Staff	Organisation and conduct of work		Types and amounts of services or other products provided.	Wellbeing of individual consumer; -Health, -Family/carer wellbeing; -Residential outcome (e.g. remain at home).

Although there is currently no agreed and reliable set of data collection instruments that can be readily applied in Australia, measuring client outcomes in community care is an integral part of quality service delivery. This is particularly important under the current Consumer Directed Care (CDC) approach recommended in Australia by the Productivity Commission in 2011 and implemented since 2015 in the case managed home care packages sector. Yet despite the emphasis placed on service outcomes at the policy level, there is currently no consistency applied or officially recognised approach for measuring outcomes as part of everyday service delivery². Existing service record collection processes do not lend themselves to the collection and analysis of outcome data and client goals during the case management process. Furthermore, in pilot research undertaken for this study in 2010-13 there was a lack of consensus amongst community care providers as to what kind of outcomes should be collected³.

This Study

To address these issues, this study was developed as part of an existing program of applied research undertaken at Macquarie University and University of Wollongong in collaboration with a number of community care providers and in response to interest expressed by the State Government of NSW in 2009. The first stage of research undertaken by Fine and Simpson-Young at Macquarie University and published in 2010 involved a comprehensive survey of all case managed and packaged community care services for the older people in NSW⁴. The survey identified and documented the extent of confusion in the measurement of outcomes in the sector. Although 84% of the 233 respondents rated outcome data as 'very important', there was no common outcome item collected by all services, nor any systematic approach available for capturing and reporting on the outcomes of care for consumers.

Research by Owen, Samsa et al. undertaken at the University of Wollongong over the same period⁵ demonstrated, the lack of central policy requiring outcome measures be collected as part of the Minimum Data Set (MDS) for community care services. This has hampered demonstrations of service effectiveness and has potentially contributed to over-servicing by some agencies that have competed for contracts on the basis of low unit-cost service outputs.

Further field research in 2011-12 by Redshaw and Fine⁶ undertaken with collaborating services at Macquarie University found that research partners sought to recognise the importance of collecting data on outcomes using a diverse array of tools that were available. There were two measures used by each of the services for some consumers: the Personal Wellbeing Index (PWI) and the Ongoing Needs Identification (ONI) scales. Neither of these measures was designed for the purpose of measuring outcomes in community care, nor were they considered truly fit for purpose by the service staff. In addition, a variety of different measures of physical function and social isolation scales were also deployed. Because there was no commonly agreed industry approach, different combinations of instruments were used by each service. Within each agency only limited use was made of outcomes measures, as those used were found to be very time consuming, as 60-120

minutes were required for each client. In consequence, the use of different measures was often quite selective, so that many consumers were not covered.

In 2014, the National Screening and Assessment Form was introduced as part of the assessment arrangements for community care services across Australia. This provides a common assessment data on all new applicants for service. It is used by My Aged Care contact centre staff, the Regional Assessment Service who assess people for entry level CHSP services and existing ACATs as part of recent aged care reform⁷ and provides a baseline measure of each consumer's physical functioning and need for assistance. In 2016, the Commonwealth Department of Health also commenced piloting a program to measure quality in residential aged care using three quality indicators – pressure injuries, use of physical restraint and unplanned weight loss. Quality of life measures have been identified as important measures of quality, but at the time of writing a suitable set of indicators developed and a common framework for collecting data on service quality has yet to be finalised⁴. Neither is there an accepted framework for documenting outcomes.

The Creative Process: Imagining the ACCOM

The study by Owen et al.⁸ had argued for the development of outcomes measures that would be based on measuring changes over time in comparison to the standardised information reporting collected at assessment. It was suggested that these would include changes in ADL and IADL (functionality), physical and mental capabilities for independent living and measures of the personal and social context, carer status and care network sustainability and social isolation. The literature review published by Redshaw and Fine in 2013 on comprehensive approaches to measuring outcomes in case managed community care had also identified the use of outcome domains as a promising area for a comprehensive outcome measurement model. This approach considered the various needs of consumers in relation to particular domains of need and is particularly associated with the work of the Personal Social Services Research Unit (PSSRU) in the United Kingdom, responsible for research in social and health care, including mental health, long-term care funding, cost and outcome measurement, and cost-effectiveness evaluation over several decades.

The focus of much of the research at the PSSRU has been on determining the value of social care on the quality of life of those in need. Aspects of quality of life that are the target of social care that have been identified as important domains to monitor as care outcomes include being clean and comfortable, maintaining good access to and enjoyment of suitable food and drink, feeling safe, and a clean and comfortable environment. Additional 'higher order' domains of occupation (having something to do), social participation, control and dignity are also regarded as important⁹. In this approach the consequences or outcomes of service use are interpreted as improvements in a range of quality of life dimensions¹⁰. The

⁴ There was a pilot for home care quality indicators conducted in 2016 looking at goal achievement, quality of life and consumer experience. The findings have not yet been shared <https://agedcare.health.gov.au/ensuring-quality/quality-indicators/home-care-quality-indicators>

Adult Social Care Outcomes Toolkit (ASCOT) was developed to cover the domains identified and a measure of social care related quality of life (SCRQoL) developed and validated¹¹.

In measuring the impact of service innovations in aged care, researchers in health economics and other disciplines are increasingly recognising that quality of life outcomes are important measures for older people. The need to move understandings of quality beyond compliance with standards and accreditation recognises that the impact of interventions for older people goes beyond health status, incorporating psychosocial and emotional well-being, independence, personal beliefs, material well-being and the external environment that influences development and activity¹². Older people's interpretation of quality of life is based on their capability to achieve those things or participate in activities they value, viewing health as a resource to facilitate their participation in activities of daily living and social interactions. It is therefore important that instruments used to measure and value quality of life outcomes in the aged care sector capture such broader quality of life outcomes.

Health related utility measures, principally the quality adjusted life year (QALY), have been widely utilised to value the benefits of medications and other interventions, including health care services and programs within cost utility analysis¹³. However, in research on social care outcomes¹⁴, QALYs have been criticised for their focus upon survival and health alone. While this is quite appropriate for health care services, community care services have been developed to foster quality of life more broadly¹⁵. The provision of care and support at home, for example, may have little or no direct impact upon clinical aspects of an individual's health, it may still lead to significant improvements in the quality of life of those who receive support.¹⁶ These improvements will not be reflected by the incorporation of QALY's as the main measure of outcome within a cost utility analysis of these types of interventions.

A more recent review of instruments for measuring outcomes in economic evaluation within aged care emphasised the importance of including a range of issues when considering the quality of life (QoL) amongst older people in community care. These include physical and cognitive functioning, sustaining independence in activities of daily living and maintaining and fostering social relationships as well as the absence of morbidity or health impairments and a sense of psycho-social wellbeing, connectedness and accessibility within the home and community.¹⁷ These elements highlight the multi-dimensional character of QoL concepts, which need to encompass health status and functional ability alongside wider quality of life dimensions of importance to older people needing care. The review noted that the ASCOT takes a broader quality of life focus including dimensions such as dignity, safety, control over daily life and social participation which are important for older people in both community and residential aged care.

The review concluded that although the ASCOT and an alternative instrument, ICECAP-O¹⁸, (ICEpop CAPability measure for Older people) do not directly measure changes in health condition, they are sensitive to change and are more associated with broader quality of life beyond health. It also argued that the choice of instrument is determined by the objective of the intervention being assessed; with the EuroQol-5 Dimensions (EQ-5D) being preferred for interventions aimed at maintaining health while the ASCOT and ICECAP-O are preferred for interventions with broader benefits beyond health such as service delivery innovations

in the aged care sector¹⁹. The review noted that currently no single instrument exists which is preference based and commensurate with the QALY scale (and therefore appropriate for application in economic evaluation) incorporating both health status and the broader elements of quality of life previously highlighted. In the absence of a single ideal instrument to assess the cost effectiveness of service innovations in the aged care sector, the review recommended the use of a generic preference based instrument, the EQ-5D to obtain QALYs in combination with the ICECAP-O or the ASCOT to facilitate the measurement and valuation of broader quality of life benefits as defined by older people. A related study of the use of QoL indicators by older South Australians²⁰ also concluded that the administration of two instruments simultaneously results in an increase in respondent burden, a particular concern in populations of older adults.

In summary, to measure outcomes of community care services, it was clear that we needed a tool that could reflect the compensatory activity of social care, that is sensitive to subjective choice and that captures social care-related quality of life (SCRQoL). Outcomes measures in the social care field also need to be sensitive to national service and policy environments because of difficulties in attributing causation, as well as the variable nature and impact of interventions²¹. Social care services intervene to compensate consumers for impairments that affect their quality of life (QoL), in accordance with local and national policies such as the Consumer Directed Care (CDC) models that have been mandated as a condition of funding in Australia to provide consumers with increasing choice and flexibility as to how services are provided since 2015.

The Next Steps: Developing and Testing the ACCOM

The Australian Community Care Outcomes Measure was developed to address the gap identified in the preliminary stages of this research. The project *Ageing Well at Home: Measuring the Impact of Community Care for Older People* was supported by an ARC Linkage funded partnership between Macquarie University and Australian Health Services Research Institute (AHSRI) at the University of Wollongong in partnership with KinCare, The Whiddon Group, BaptistCare NSW & ACT, Community Options Australia and Aged and Community Services NSW & ACT⁵. The project also worked in collaboration with Professor Ann Netten from the University of Kent, co-author of the Adult Social Care Outcomes Toolkit (ASCOT) which has been adapted and used in this study, as outlined in the following chapter of this report.

⁵ During 2017 Aged and Community Services NSW & ACT transitioned into the new entity Aged and Community Services Australia.

Chapter 3

Methodology

The objective of this study, as discussed earlier, was to refine, finalise and field test an outcome measurement tool (the ACCOM) to be used to document outcomes of community care for older service users (65 years of age and above or Aboriginal and Torres Strait Islander people aged 50 and above) of community care services. The study was undertaken over two years (2015-16), as set out in Figure 3.1.

The methodology underpinning the research is co-operative Inquiry, also known as collaborative inquiry. Co-operative inquiry is an action research based methodology. Fundamental to co-operative inquiry is the concept of research partnerships; research conducted 'with' rather than 'on' people (Heron and Reason, 2001). Maruyama et al describe co-operative inquiry as a research methodology that engages the academic researcher in a role of collaborator with community members. It can accomplish more through collaboration than could be achieved by partners alone. Central to co-operative inquiry is the concept that problems are examined with a goal of transforming practice in applied settings. Results have both practical and conceptual value (Maruyama, 2014).

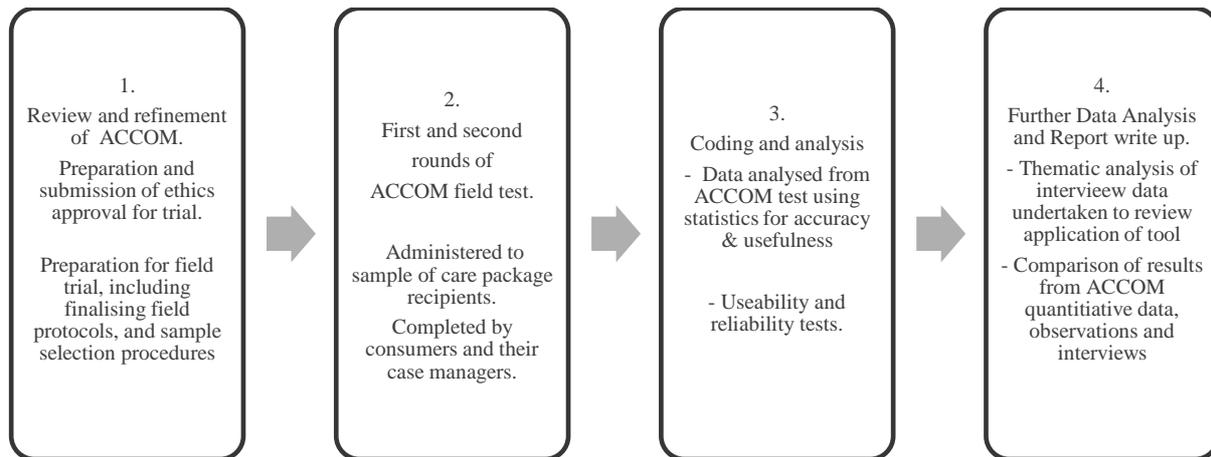
The benefit of collaborative inquiry as a research methodology is that as it involves the people who are most impacted by the research in the process of designing and undertaking the research and interpreting the data, that the research findings are readily applied in the process of transforming practice in the health service organisation or setting. The primary method used to facilitate the partnership approach to this research was the establishment of a 'research collaboration steering group' or 'partners meeting'; involving the research team, and representatives from each of the industry partner organisations. The group met quarterly throughout the project timeframe. This structure empowered the industry representatives as research partners to co-design the project. A key outcome of this approach, and example of the value of a co-operative approach, is that the design of the ACCOM changed from the original concept being a desktop audit tool for use by case managers to being a consumer self-rated outcome measurement tool with a case manager rated outcomes component. This fundamental change to the design of the project resulted in a tool that has significant practical value in the aged care industry context of both consumer directed care and in the need to demonstrate quality processes in the increasingly competitive aged care market.

In the research project, collaboration between the university researchers and the industry partners took the form of a number of specific activities, in particular:

- discussion and agreement on a standard set of consumer and case manager rated outcome measures to be trialled across all industry partners;
- consensus regarding the core functional, demographic and service data fields;

- collaborative interpretation of data to ensure researchers attributed the correct meaning to the data;
- co-presenting the project at the national AAG conference in 2016
- sharing and pooling data related to service delivery outcomes.

Figure 3.1 Four Stages of the Research Design



In the first part of this chapter we consider the development and design of the ACCOM tool. Following on from this, we move on to set out details of the field trials and analysis in the second section. Here we outline the importance of the collaboration with our research partners, discuss the methods for the selection of a sample and the procedures for the administration of the ACCOM and the collection of additional research data. In the final section we outline the approach taken to the preliminary analysis of the data. Details of the findings from the study are set out in following this, in Chapters 4-6.

3.1 Developing the ACCOM: Component Logic

The final stages of the pilot study undertaken in 2012-13 had tested the feasibility of developing a new, unique and innovative measure of outcomes which incorporated the domains identified in the Adult Social Care Outcome Toolkit as well as a number of additional domains that were recommended by our research partners at the time as being of importance in the Australian context.²² A total of 14 outcome domains were identified addressing the following areas: Personal Cleanliness/comfort, Health, Home Maintenance and Mobility, Food and nutrition, Occupation, Social Connection, Communication, Safety, Carer wellbeing, Control, Home Tenure, Dignity and Future Plan. In a review of information held on a sample of 79 consumers from the three services that participated in the study, it was found that data on each of these 14 domains were readily available in the client service records. There had been no attempt to formalise the tool or administer it.

The first stages of the research in early 2015 involved a review of this still embryonic tool and of the steps required to develop it for a field trial. Although there are merits in developing new measures and tools, there are also significant problems if the measures are to be more than simply a professionally informed list of areas thought to be relevant to the issue. In this case, the costs of development – direct financial costs as well as the extended time required, were substantial. In each case these costs probably exceeded the research funds and time available. Furthermore, the unique character of the measure would have ensured that it was not possible to directly compare the results with those obtained elsewhere. With the collaborative input from our research partners, a decision was quickly made to build on the benefits in using one of the existing standardised scales that captured consumer ratings of outcomes.²³

Drawing on the literature review and previous research, three key component measures were identified for all consumers:

- i. quality of life measures;
- ii. functional measures of the capabilities and care needs; and
- iii. data on the basic demographics and living conditions.

To measure quality of life, a number of instruments were considered, with particular attention being given to the Australian Personal Wellbeing Index²⁴ (PWI), discussed in the previous chapter. As the PWI has been developed for the general population and is not specialised for care recipients, a decision was made to adopt the ASCOT as a core component of the ACCOM. The ASCOT, developed by the Personal Social Services Research Unit at the University of Kent, (www.pssru.ac.uk/ASCOT) provides a concise, robust and readily completed measure of quality of life suitable for documenting outcomes among care those who are dependent on care, as discussed further below. The use of the ASCOT was seen to have further benefits, including the fact that it had already been extensively tested and revised, the validity and reliability of its scales is well known and the psychometric properties of its instruments found to be reliable. Using it as a core component of the ACCOM would also ensure that all instances can be compared to international norms. One of the goals of this pilot study was to look at the benefits and challenges of adapting the tool to the Australian context and adding the feature of comparing case manager and consumer perspectives.

Information on the capabilities and care needs of consumers was already collected by collaborating services at the point of initial assessment, using instruments such as the Functional Screen developed by AHSRI. The Functional Screen is a standardised instrument already used by most community care services and available data can be used to track the capability of consumers to perform activities of daily living (ADLs). It is key indicator of a care recipient's needs for care and capacity to stay at home²⁵. Rather than requiring new data to be collected, the Functional Screen of the ACCOM is a standardised instrument that tracks the ability of consumers to perform activities of daily living (ADLs) over time. Functional ability (or capability)²⁶ is a key indicator of a care recipient's ability to stay at home²⁷. For many progressive and chronic diseases, it is particularly important to understand functional abilities and limitations. While it is not possible to prevent all

functional status losses, measuring improvements that result from recovery or enablement practices and slowing the impact of these diseases is an important goal for most consumers and care workers. Many Australian community care case managers are familiar with the screen which is routinely used in the 'Document Storage System', previously the HACC MDS. The combination of the functional screen with the capabilities based framework of the ASCOT SCT4 four-level self-report version allows a more comprehensive collection of health and social related QoL indicators reflecting the wider range of services provided in the community age care system in Australia. The Functional Screen tool also allows testing the level of functioning relationship to the capabilities framework of the ASCOT SCT4 instrument, where the domains are phrased in the language of capabilities at the high quality of life end of the spectrum and in terms of functionings when reflecting lower quality of life²⁸.

Demographic data, including age, income, living circumstances and cultural background is also utilised in the ACCOM. This is already collected as part of service records for each consumer and updated where changes, such as death of spouse, occur. These additional elements enable quality of life outcomes to be linked to the capabilities, care needs and demographic characteristics of consumers.

To complete the ACCOM, two further questions were added to the three measures already outlined. While quantitative measures typically form the basis of outcomes monitoring systems to enable accurate measurement and comparison, less structured qualitative data can provide an opportunity for consumers to provide more individualised feedback.²⁹ It can also help identify concerns that are not documented by the closed questions required for quantitative measures.^{30 31} An open question - *'Please provide any comments or suggestions you would like to make'* - was therefore added to the ACCOM to ensure consumers have the option of commenting. The qualitative data collected through such an open question can provide case managers with valuable insights regarding important unmet consumer needs from the consumer perspective and identify areas of change that 'fall through the gaps' of the quantitative measures. The administrative burden of entering and analysing this data and consensus was minimal compared to the value of providing consumers with an opportunity to provide comments.

Reflecting the value of collecting data on subjective perceptions of health, an additional, previously validated question concerning self-reported health³² was also added to the ACCOM to be completed by each consumer.

Measuring Quality of Life

The ACCOM tool uses the ASCOT four-level self-completion questionnaire (SCT4) as this has sensitivity for assessing social care-related QOL in the top states, that is, in community-based people with low care needs³³. The ASCOT assesses social care-related QOL across eight domains (see Figure 3.2). Each domain of the SCT4 has four options: 'ideal state', 'no needs', 'some needs' and 'high needs'. For each domain, participants are asked to select the option that best reflects their level of needs in that aspect of their life. Responses for each

domain are allocated preference weights through application of a scoring algorithm based upon UK general population values for all possible health states defined by the instrument.³⁴ This can be used to calculate an overall ASCOT well-being score for individuals ranging from 0 to 1, with higher scores indicating better social care-related QOL and 1 indicating the “ideal” state.

The ACCOM tool used a version of the ASCOT well suited to the purpose of measuring SCRQoL amongst consumers – the ASCOT SCT4. This version, designed as written survey but also able to be administered in an interview, has 9 questions for consumers that permit responses at 4 levels. The 9 questions cover the 8 domains listed in Fig 3.2, with an additional ‘filter’ question to document personal attitudes towards receiving help linked to the question on dignity (Which of these statements best describes how the way you are helped and treated makes you think and feel about yourself?). As discussed earlier, the ASCOT also collects information on how well needs are met for basic needs, such as food and drink, safety, and for ‘higher order’ needs, such as control over daily life, social participation and dignity.

Figure 3.2 ASCOT Quality of Life Domains

DOMAIN	DEFINITION*
Control over daily life (b)	I can choose what to do and when to do it, having control over my daily life and activities
Personal cleanliness and comfort(a)	I feel I am personally clean and comfortable and look presentable or at best am dressed and have my hair done in a way that reflects my personal preferences
Food and drink (a)	I feel I have a nutritious, varied and culturally appropriate diet with enough food and non-alcoholic, hydrating fluids I enjoys at regular times during the day
Personal safety (a)	I feel safe and secure inside and outside the home. This means feeling free from fear of abuse, falling or other physical harm
Social participation and involvement (b)	I am content with my social situation and feel I have meaningful relationships with friends and family and I feel part of the community (should this be important to me)
Occupation (b)	I feel I have access to a range of meaningful activities whether it be unpaid (or paid) work, caring for others or hobby and leisure activities
Accommodation cleanliness and comfort (a)	I feel my environment including all the rooms are clean and comfortable
Dignity (b)	I feel I am being treated with respect by my service provider and my views and preferences are valued and taken into consideration

Notes: *The definitions provided here were modified slightly from those used in the UK, edited slightly for Australian respondents following pilot testing. (a) ‘Basic’ or ‘fundamental’ needs; (b) ‘Higher order’ needs.

Previous research in the UK on the construct validity of ASCOT³⁵ supported its validity and feasibility for use to measure SCRQoL among older people. Research in Australia by Domiciliary Care in South Australia³⁶ found that the domains based on QoL questions were valued by clients and staff as a background to goal setting and service planning. In the early piloting of the ACCOM tool, it became clear that as well as transposing definitions into the first person ('I am' or 'I feel' in place of 'The service user feels he/she...') it was necessary to adjust some of the ASCOT domain definitions a little for use in the Australian context. For example, after finding that the term 'drink' was often interpreted to mean alcoholic beverage by our Australian pilot sample, the UK text for the domain 'Food and Drink' was changed from 'The service user feels he/she has a nutritious, varied and culturally appropriate diet with enough food and drink he/she enjoys at regular and timely intervals' the one used in the Fig 3.2 above, which refers to 'non-alcoholic, hydrating fluids' in place of drink.³⁷

Comparing Perspectives – Consumers and Case Managers

The use of consumer's and a case managers' (CM) version of SCT4 is an innovative component of the ACCOM tool. It was introduced at the planning stage in response to feedback from case managers and community representatives who identified the importance of capturing not only consumers' self-rating on QoL domains but also case managers' perspectives on consumer outcomes. Research on self-reported outcomes has highlighted the value of multiple vantage points which can provide a more reliable estimate of change.³⁸ Research on response shift in QoL appraisals³⁹ supports the value of comparing self-reported change in QoL to other external measures of QoL change that are independent of consumer self-report including clinician judgment, performance tests, or family caregiver ratings. In developing and refining the ACCOM before the field trial, we reasoned that case managers' rating of their consumers' QoL would provide a useful addition to self-report for consumers that may trigger assessment and goal plan review if significant discrepancies emerge in outcomes scoring.

3.2 Field Trials: Research Process and Methods

To test the viability of measuring outcomes using the ACCOM, discussion with the research industry partners led to agreement that the ACCOM would ideally be administered twice over a period of approximately six months. Repeating the data collection over time was a critical aspect to the trial and enabled measuring change in outcomes over time based on the principle of outcome measurement that an outcome is the difference between the results at two points in time, taking into account what might have happened without the intervention. The ACCOM was distributed to consumers as a paper based survey form and was to be completed in each round by both consumers and by their case managers. As the data was collected it was checked, cleaned where necessary and prepared for analysis, and repeated approximately three to six months later, before final field work and preliminary data analysis was completed. Figure 3.3 provides an overview of the research stages.

Figure 3.3 Research Timeline, Summary

STAGE	RESEARCH ACTIVITY	Timing
1	Preparation and sample selection: <ul style="list-style-type: none"> • Research workshop with managers and CMs for participating services and research staff. • Finalise ACCOM and research protocols; • Complete documentation required and obtain ethics approval; • Research workshop and staff training; • Sample selection 	March-October 2015
	Pilot study with 2 case managers and 4 consumers from each partner organisation	
	Training and distribution of information to case managers. Consumer consent forms sent to research team in each organisation for distribution to consumers.	
2	R1 Case managers' distribution of information to consumers: consent forms, surveys and consumer guide.	November 2015 – April 2016
	Completed consent forms and surveys from consumers returned to research team.	
	Case managers informed of consumers who consented to participate and case managers complete ACCOM using Redcap.	
	Research team uploads consumers' responses into RedCap.	
3	R2 ACCOM tool completed again 3-6 months later by consumers and case managers. Research team uploads consumers' responses in Redcap.	May–August 2016
4	Data cleaning, focus groups with service staff analysis, data analysis and preliminary findings	September 2016- February 2017

Research Stage 1. Research Preparation and Sample Selection

The first stage of the research program was focussed on the revision and redevelopment of the revised ACCOM (discussed above), the preparation of a detailed research protocol and the ethics application required by the Human Ethics Committee at Macquarie University. This planning and preparation period involved close collaboration between the research team, senior service managers (our formal industry partners represented at the regular partners meeting) and case management staff.

To mark the commencement of the study and to build the strengths of the collaborative research approach that underlies this research, one of the first initiatives in preparing the study for implementation was a full day research workshop in which researchers, service

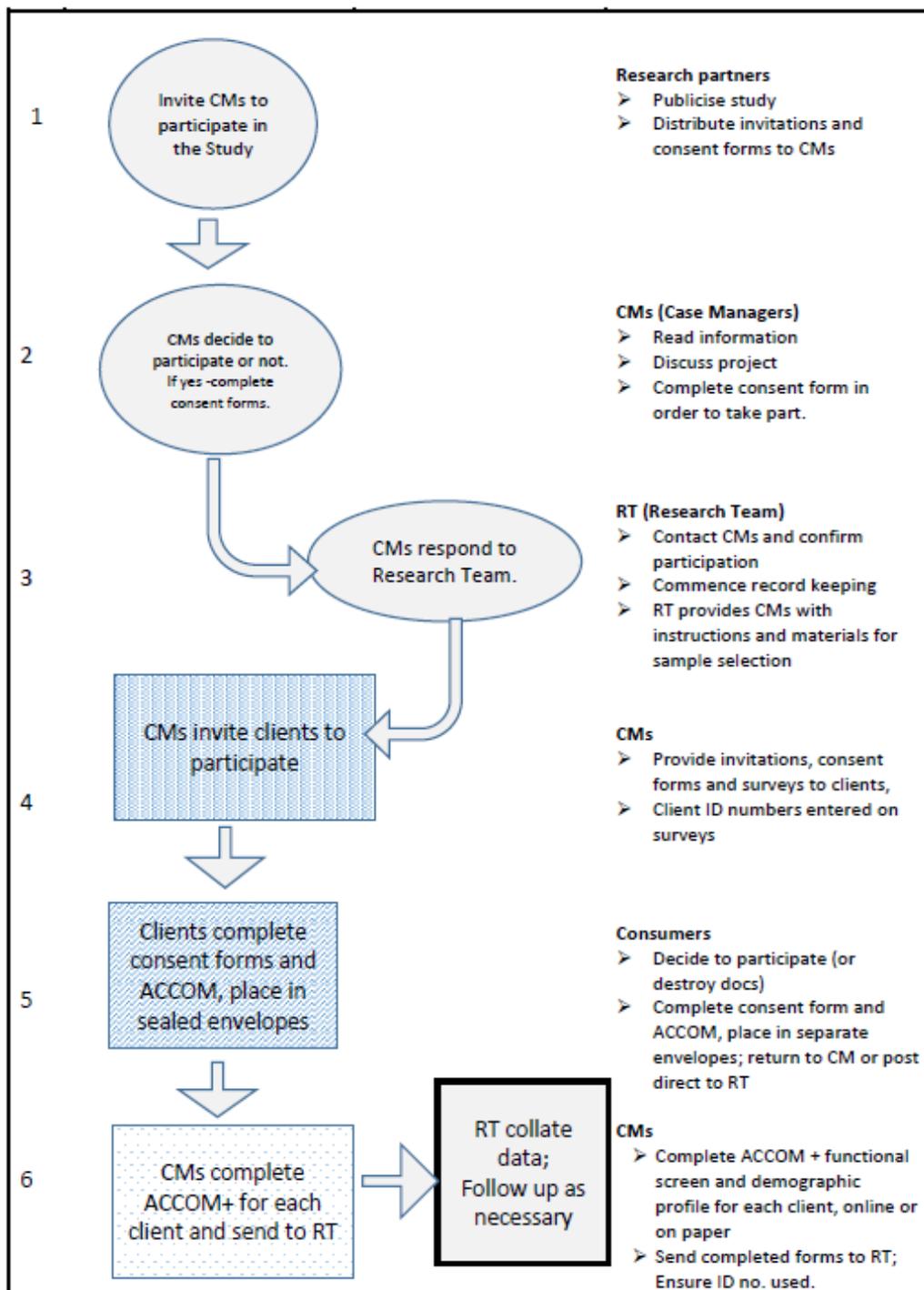
management and case managers (CMs) from each of the collaborating services took part. Professor Ann Netten, the co-creator of the ASCOT and Partner Investigator in this study, attended from the UK and presented a detailed and compelling overview of the history of research into outcomes and the conceptual thinking behind the ASCOT. This was followed by other presentations and detailed discussions in which the research team and service staff considered and reviewed the proposed research project. The research conversation that developed and the mutual respect evident in the interaction between practitioners and researchers, helped develop a sense of trust across the collaboration. This has subsequently helped the research program to adapt to what at times is a difficult almost conflicting task, in which the priorities of a service delivery culture and the importance of innovative, practical research are brought together.

Policy changes and significant administrative and market reforms being introduced to the Australian community care system at the time imposed considerable burden on service personnel. The membership of one of the original research partners, *Community Options Australia*. This peak state organisation had been severely affected by changes to their funding program as from 2015 the newly developed Commonwealth Home Support Program no longer funded the service type of case management. This restricted the number of potential research sites significantly and had direct impact on the anticipated size of the sample of consumers that could be recruited for the study. Many staff reported problems dealing with increased insecurity and administrative burden that had accompanied the adoption of the CDC model for all community care packages at the time. Some CMs found themselves protecting consumers from further formal demands having already spent many hours explaining new funding arrangements, and seeking signatures for new service contracts and new care plans. These additional demands also appear to have affected the sample selection, narrowing the possibilities of recruitment in some agencies of the partner organisations.

The research ethics proposal was first submitted to the Human Ethics Committee at Macquarie University in June and finally approved in October 2015. Modifications of the protocol originally negotiated with the partner organisations were required to meet the conditions of confidentiality and the complex consent procedure required by the Human Ethics Committee.

The consent procedures required, summarised in Figure 3.4, made it necessary to first recruit CMs to the study from the services in the research partnership. A total of 27 CMs agreed to participate in the study, providing freely given informed consent to undertake the extra work involved in the trial, in response to the invitations issued by the research team. In providing consent and signing the forms approved by the Human Ethics Committee, they indicated that they had volunteered to participate in the study and not been required by senior managers to take part. The number participating was somewhat lower than had been estimated at the time that the original proposal was prepared, when the intention had been for case managers to directly request consumers to take part, however this was perceived by the Human Ethics Committee as potentially coercive. The final number of CMs collaborating with the research was, nonetheless, an encouraging endorsement of the project by front line staff with direct responsibility for managing the support provided to each consumer.

Figure 3.4 ACCOM Field Study, Informed Consent Procedures



The CM version of the SCT4 instrument was tested with a group of CMs in order to ascertain their understanding of using a third party/professional perspective when completing the SCT4 questionnaire. A Case Manager’s Guidelines document was developed as a result of these consultations specifying the process for completion and uploading of the ACCOM data to RedCap (see below) and instructions for care workers who may act as proxy respondents for consumers unable to complete the questionnaire independently.

A preliminary trial of the tools and procedures was then conducted with 6 case managers and 14 consumers to test the administrative processes, rate of return of questionnaire by consumers and the procedures for CMs to provide data for each participating consumer. This trial also tested the use of the RedCap system by case managers. Useability testing of the client version of the ACCOM was conducted with a small number of older participants, who provided useful feedback on the final design of the tool. RedCap (Research Electronic Data Capture) is an electronic data capture tool hosted at the University of Wollongong.⁴⁰ It is a secure, web-based application designed to support data capture for research studies, providing an intuitive interface for validated data entry, audit trails for tracking data manipulation and export procedures as well as automated export procedures for data storage and management.

The training provided on the use of RedCap allowed the CMs to complete the forms electronically and update information as well as provide feedback to the research team on any issue pertinent to the study. Interviews with CMs testing the validity of ASCOT's descriptive system in the Australian context were also conducted and the findings were used to develop a set of Users' Guidelines consistent with Australian language and understandings of the meanings of each of the domains in the ASCOT tool. Following the trial, changes in case manager training were implemented, including the inclusion of ID numbers in mail outs to consumers to enable the research team to enter their data in the RedCap tools.

Research Stage 2. The First Field Trial

The next stage of the research was the crucial first round of the field trial, R1. Following staff training and information sessions in October and November 2015, data collection took place from December - April 2016.

The collaborative research approach utilised for this study was based on the principle of close working relationships between service staff and researchers. A central aspect of this was that CMs from each of the three services would both collect and complete ACCOM data for each of the consumers participating in the study, as well as test out and report back on the practicality and value of using the measure on a regular basis as part of their ongoing responsibility for organising and managing support for consumers. This required each case manager to be trained, as well as provided with forms to be distributed to consumers who might participate in the study. To accommodate the work demands placed on CMs who were dispersed across metropolitan and regional NSW, training workshops were organised in October and November 2015 using both face to face and webinar formats. A number of workshops were held at the branch offices of the participating services. In addition, workshops were organised at Macquarie University and made available online for any CM unable to attend. The approach was interactive – research staff learning about the practical steps involved in the administrative work of CMs, as well as providing detailed supportive training about the consumer information, consent and data collection procedures, and those required in turn of the CMs.

The original research proposal had sought to invite a sufficiently large number of consumers (recipients of CDC packages or other case managed care) to participate in the study to ensure that the final sample would be 400 or more. This sample size became unattainable in the time available due to the inability of Community Options Services to participate in the trials as a result of the termination of the Home and Community Care Program that had led to cessation of funding for their service. This significantly reduced the number of services taking part in the trial and reduced the potential size of the sample. The number of case managers from the remaining three service providers participating in the study and the number of invitations distributed to consumers, over 300 in total, was a strong achievement.

In subsequent discussion with CMs we were informed that the ethics procedures had created an administrative burden on both case managers and consumers that could have been a disincentive for consumers participating in the trial. They also reported that it was not possible to recruit non-English speaking consumers due to the complex ethics process and lack of access to interpreters. The timing of R1, commencing in December 2015 (in some locations in January 2016) was also not ideal for maximum recruitment, due to this being festive season and peak summer school holiday time in Australia, during which many organisations are operating on 'skeleton staff' numbers. Consumers also reported to case managers that they were 'overloaded' with a number of other research trials that were occurring at the same time. As reported above, Community Options services were also not able to participate in the live trial.

The results were that a total of 520 information packages with consent forms were requested by the services (Service 1: 250 packages; Service 2: 150 and Service 3: 120). However not all were delivered to consumers. A final and definitive account of this process was not possible. A few of the forms appeared unfortunately to be mislaid or lost in the post. An unknown number of forms also appear to have been simply disposed of by agencies, without careful counting of the number involved. Clearly this was a deficiency in the research administration process for which we take collective responsibility, but which we cannot reverse. From subsequent discussion with CMs, it appears that in many cases the request to provide the invitations to up to 10 and if possible more of their consumers was followed up. Some CMs were more selective with the requests to consumers, and only provided the research invitation and associated material to a limited number of consumers they felt confident would not be overwhelmed with the administrative and consent procedures.

By March 2016, a total of 224 consumers from across NSW had returned completed consent forms to the research team and went on to complete the ACCOM. While confidentiality requirements ensured that the research team did not know the names or any identifying information of any of the consumers, each CM had entered the individual ID numbers for each consumer onto the form. This provided the data link that enabled the research team to inform each service, and in turn each CM, about the consumers who had agreed to participate in the study. Once this was forwarded to the services, each of the 27 CMs was able to use the data link to identify the consumers for whom they were responsible, and to then complete their components of the ACCOM. At the time they did so, due to an ethics requirement, they were not aware of the responses provided by consumers.

The information package and ACCOM tool provided to respondents consisted of the following components:

For Consumers (paper copy, to be completed by pen):

- The ASCOT SCT4 questionnaire with 2 additional questions and a comments box.
- An information pack with guidelines for consumers and their carers/families on how to complete the questionnaire.

For Case Managers (electronic tools, for data to be entered online):

- The CM version of the ASCOT SCT4 questionnaire with additional questions and a comments box; and
- The HACC Functional Screen;
- The demographic data-set;
- Information pack and guidelines on how to complete the questionnaires.

Information and Consent forms along with the modified ASCOT were sent to consumers receiving Home Care Packages levels 1 to 4. They were provided with a return envelope to send the questionnaires directly to the research team who entered the data in the RedCap system. A total of 224 questionnaires were returned in round 1 and from these 211 completed all the questions in the ASCOT tool.

Where clients were unable to complete the ACCOM and there were no suitable family or friend carers to complete the ACCOM on their behalf, as a proxy, care workers completed the proxy version of the QoL survey (the ASCOT) along with data required by the HACC Functional Screen (AHRSI 2002). The use of the HACC Functional Screen by CM has been widely used by community aged care providers as a standard tool to classify the functional capability of each consumer. CMs also collected demographic information, most of it already available in their consumers' files during initial assessment.

Research Stage 3. The Field Trial Follow-up, R2

The ACCOM is not intended to be a one-off snapshot of consumer wellbeing, but an ongoing measure sensitive to change. Re-administration of the measure after a period of time is necessary if it is to detect change over time and help identify crucial gains or losses that may be attributed to the care and support received or to other factors, such as an improvement or deterioration in health or change in social circumstances such as may occur after the loss of a spouse.

Consumers and CMs were thus asked to complete the questionnaire again 4-6 months after their initial administration. In the second follow up round of the study (R2) the completion rates were much reduced. Case managers provided data and completed ACCOM returns for

174 consumers but a reduced total of just 136 questionnaires were received from consumers. Of those, 132 completed all response items. The reduction in numbers of returns from consumers was substantial, although a reduced level of return in any such sample (attrition) is to be expected. Precise data on the rates of death and admission to residential care among the sample are not known and is still being compiled at the time of writing of this report. The fact that CMs had returned data for a larger number of consumers suggests that some consumers who had been expected to provide returns did not do so. CMs had also reported that many of the original respondents in R1 had either died or been admitted to residential care. This is not surprising as the length of time that an individual consumer receive care packages is relatively low – the most recent figures available show that median length of stay on a CACP Package (as Level 2 CDC packages were known before 2015) in 2012-13 was just under 60 weeks⁴¹. For those on high dependency (Level 4) packages (former EACH and EACH-D packages), length of stay was typically much shorter.

Research Stage 4: The Final Field Work

The final months of the field research involved follow-up research with the CMs and further preliminary analysis of the data collected to date.

Ongoing consultations and feedback from project partners and case managers provided key information and expert knowledge on community aged care outcome issues, consumers' communication preferences, and logistics to administer the tool. During the data analysis phase of the project, CMs also provided feedback and assisted in the identification of background variables and their potential relationship to specific attributes of the ACCOM tool.

Three discussion groups (face to face and webinars for CMs in regional areas) were conducted with a total of 28 case managers from the partner organisations, BaptistCare, The Whiddon Group and Kinicare. The first focus group, conducted during the design phase of the project, had allowed the development of a shared understanding on the goals and objectives of the study, and the use of key terminology including the language of capabilities and functionalities, outcomes versus output measurement and information on the various components of the ACCOM tool.

In the final months of the study, the results from round 1 and 2 of the data collection were presented to the CMs, in a de-identified form, and a more in-depth comparative analysis of the CM and consumers' responses was undertaken. As well, at the final research workshop with research staff and practitioners held in November 2016, there were extended discussions and qualitative evaluations of the potential value and uses of the ACCOM tool. The findings from these discussion groups and consultations are presented in section Chapter 6.

Chapter 4

Results: Consumers and their Quality of Life at Home

The field study of the ACCOM aimed to test the viability of the tool as a practical tool for collecting data to measure outcomes in community age care settings across New South Wales.

The results presented in this chapter demonstrate the capacity of the ACCOM to capture data that provides concise and meaningful evidence of the characteristics and life of consumers, their need for assistance, and the outcomes of their receipt of care at home. It presents basic descriptive data on the demographic profile of community aged care consumers who participated in the pilot study and an initial overview of key findings, covering aspects of their need for care as revealed through the functional score and through the general health question, consumer and case manager ratings of quality of life and details of the consumers' responses to the open question. The next two chapters draw on this data, exploring first the extent to which these descriptive outcomes reflect underlying patterns of demography and the functional capacity of consumers, and testing the useability, reliability and validity of the ACCOM tool.

Profile of Participating Consumers

The study recruited consumers of community age care services in New South Wales between September 2015 and March 2016. As discussed in the previous chapter, both new and existing consumers were invited to participate. A total of 224 consumers agreed to participate in the study.

Two rounds of data were collected from participating consumers and case managers. Both groups completed the ASCOT questionnaire about participants' quality of life and a few additional questions. Case managers also provided consumers' demographic information and filled out the functional questions to inform analysis.

There was sample attrition in the pilot study (as discussed in chapter 3). A total of 211 consumers participated in round 1, 132 consumers participated in round 2. Case managers provided responses for 209 of their consumers in round 1 and 193 consumers in round 2. Table 4.1 provides demographic profiles of participants for both rounds of the pilot.

Table 4.1 Demographic Profile of ACCOM Pilot Study Sample

	Round 1		Round 2	
	n	%	n	%
Gender				
Male	68	32	60	31
Female	147	68	131	68
Unknown	1	1	1	1
Age group				
60 to 64 years	3	1	3	2
65 to 84 years	106	49	94	49
85 years & over	107	50	95	49
Marital status				
Married/ De-facto	74	35	68	36
Divorced	16	7	13	7
Separated	4	2	4	2
Widowed	103	48	90	47
Never married	10	5	10	5
Not specified/applicable	6	3	5	3
Accommodation				
Owner-occupier/mortgagee	144	72	119	69
Independent living	23	12	21	12
Private rental	5	3	6	3
Social housing	18	9	16	9
Related person	9	5	9	5
Other	1	1	2	12
Home Care Package level				
Level 1	4	2	3	2
Level 2	155	72	121	71
Level 3	7	3	8	5
Level 4	50	23	39	23
Government benefit				
Aged pension	167	74	139	81
Disability support pension	4	2	4	2
Veterans pension	5	2	7	4
Other government benefit	2	1	0	0
No government benefit	7	3	4	2
Unknown	41	18	17	10
Informal carer availability				
Yes	136	60	139	72
No	66	29	32	17
Unknown	24	11	22	11

Living arrangements				
Living alone	115	53	93	54
Living with a spouse or partner	69	32	50	29
Living with a son or daughter	20	9	26	15
Living with other relative	5	2	1	1

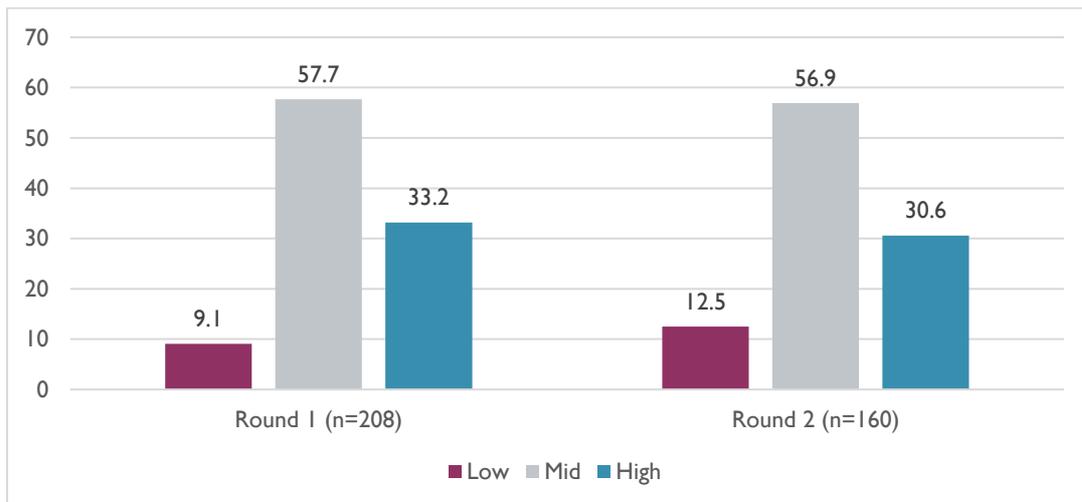
The living situations of participants remained similar in both rounds. More than half lived alone, while 30 per cent lived with a spouse or partner. Most owned their housing; around 70 per cent were owner-occupiers and 12 per cent lived in independent housing. Only 9 per cent lived in social housing. Almost all participants drew government benefits, with most receiving an age pension.

Participating consumers were often able to supplement their Home Care Packages with support from informal carers. More than 70 per cent of participants received Level 2 packages and around a quarter received Level 4 packages in both rounds. Around 5 per cent of participants received Level 1 or 3 packages. This is unsurprising given that these packages were recently introduced. Informal carers provided additional support to around 60 per cent of consumers in round 1 and over 70 per cent of consumers in round 2.

Overall, the profile of participants in this study is consistent with that reported in other studies of community aged care.⁴² This is not to claim that the data are representative. While the rich demographic profile of participants collected by the tool is interesting, the primary purpose of this data is to provide valuable context for the quality of life measures and to identify underlying trends in client outcomes.

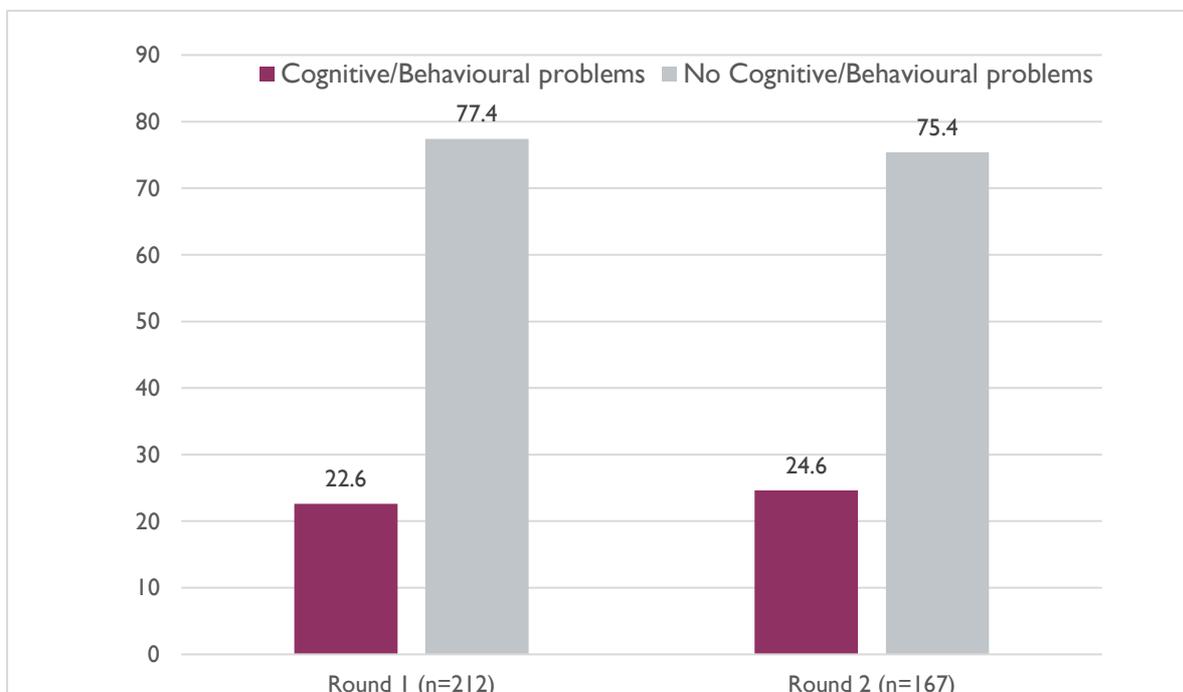
The case manager version of the ACCOM includes the functional questions as a measure of the ability of participating consumers to undertake key activities of daily living. The screen includes an algorithm that calculates a functional score for consumers based on responses to all of items (see Chart 4.1). Previous research has established that the functional score provides a valid and reliable indication of the differences in the abilities of aged care consumers to undertake daily activities⁴³. Most participating consumers had mid-range or high functional scores, with relatively few having low functional scores. This is consistent with most participating consumers being in receipt of Level 2 Home Care Packages.

Chart 4.1 Functional Score of Consumers for Rounds 1 and 2 (percent of all respondents)



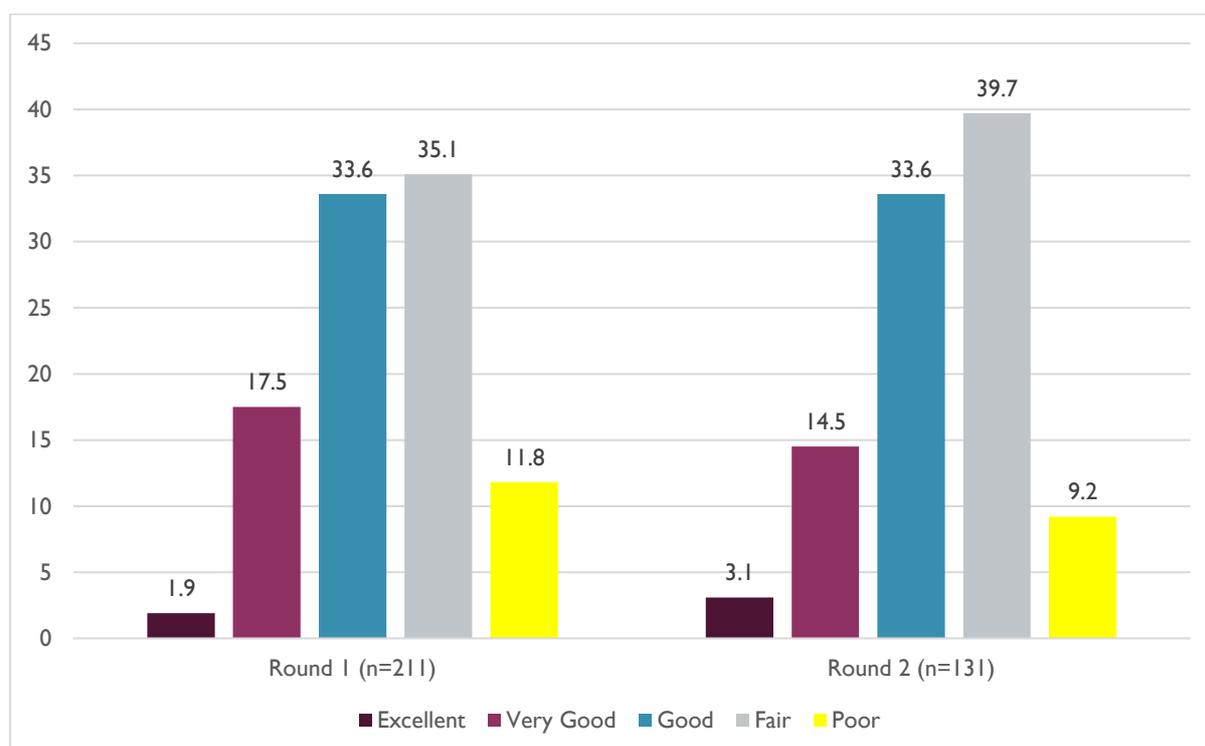
Included with the functional questions is a question about whether consumers exhibit memory issues or confusion. Around three quarters of participating consumers did not present with confusion or memory problems (Chart 4.2). This finding is consistent with the relatively high functional scores of consumers and low level care packages received. That one quarter of consumers did experience confusion or memory problems seems to explain the high number of proxy responses. It should be noted that this does not give an indication of the severity of cognitive issues, nor is it a direct alternative for diagnosed dementia.

Chart 4.2 Consumers with Cognitive or Behavioural Problems, Rounds 1 & 2, Percent of Total



In addition, the client version of the ACCOM asks consumers to self-rate their health. Chart 4.3 shows that about half of respondents rated their health as good or above, around 35 per cent rated their health as fair and roughly 10 per cent rated their health as poor. This pattern is similar in both rounds of the pilot study and consistent with case manager responses to the functional screen.

Chart 4.3 Consumer Self-Rated Health in Rounds 1 & 2, Percent of Total



Overview of Initial Findings

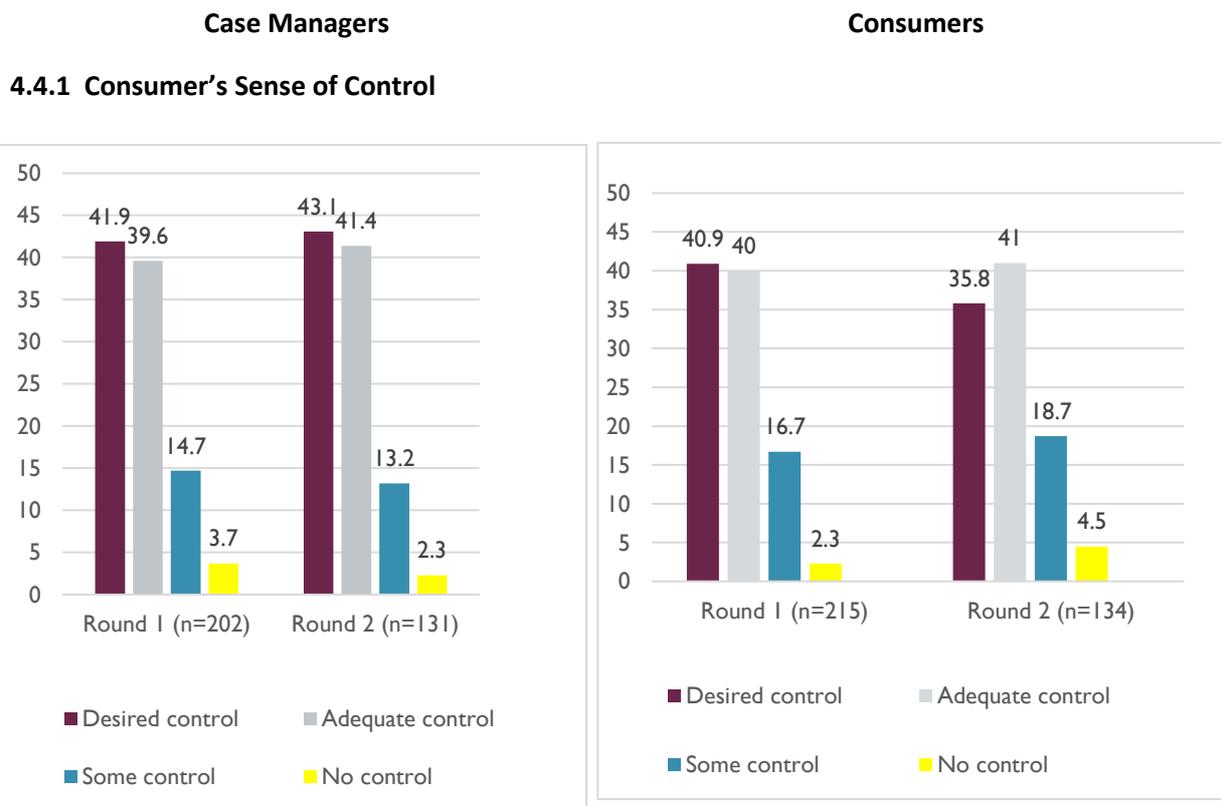
Both consumer and CM versions of the ACCOM include the ASCOT SCT4 instrument. In the following section of this chapter we focus on the results from this component of the ACCOM. It provides a series of measures that capture perceptions of the consumer's quality of life (the Social Care Related Quality of Life or SCRQoL) from the perspective of both consumers and CMs. The ASCOT component is a preference-weighted instrument with 8 major items, each of which relates to an attribute of the client's quality of life that community aged care interventions focus on. These items consist of four basic domains (personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, and safety), three higher order domains (control over daily life, social participation and occupation) and dignity (impact of care on self-perception)⁴⁴. In addition, in the version included in the field study, a ninth question is included which provides data on the psychological disposition of the consumer towards receiving personal assistance.

The results for the personal cleanliness and comfort domain from both rounds of data

collection are presented in *Chart 4.4*. In each case, the aggregated results of ratings by case managers, presented in the left column, are close, but not identical to, those of consumers, presented in the right. Findings are presented and discussed in the order in which they follow in the SCT4.

When asked to rate ‘*how much control do you have over your daily life?*’ in the first round of the study, just over 40 percent of consumers, reported that they felt they had as much control as they desired, as shown on item 4.4.1). A further 40 percent reported that the level of control they felt was adequate. By *control*, it was explained in the survey, we mean ‘*the choice to do things or have things done for you as you like and when you want*’. Almost the same proportion of CMs reported that consumers had desired or adequate levels of control. In the second round, differences between consumer’s and CM ratings had increased slightly. While the level of overall correspondence with CMs remains striking, more consumers pointed to a somewhat less positive direct experience of their level of control, with almost one in twenty reporting that they felt they exercised no control over what happened to them.

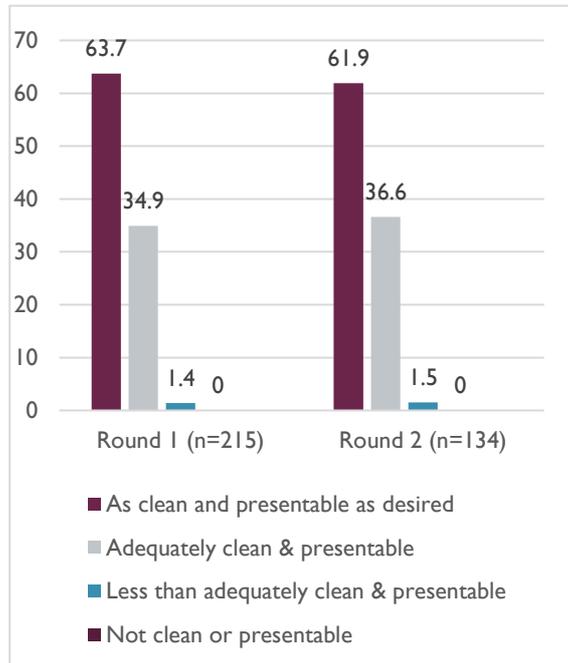
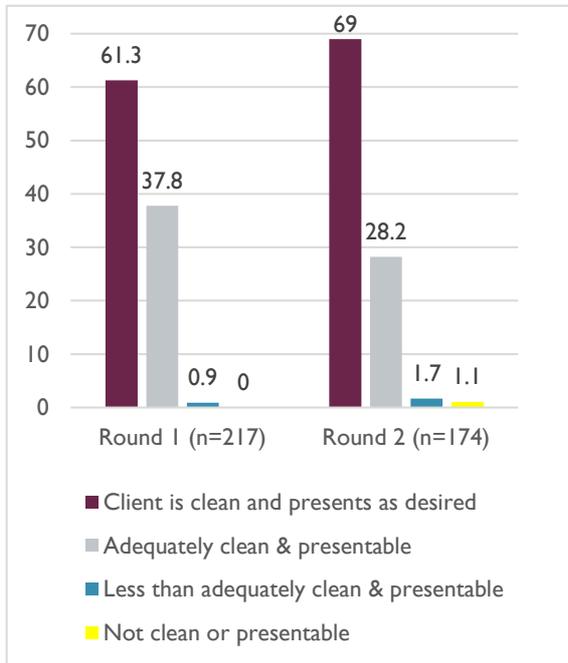
Chart 4.4 ASCOT Quality of Life Ratings. Comparison of Case Manager and Consumer Responses



Case Managers

Consumers

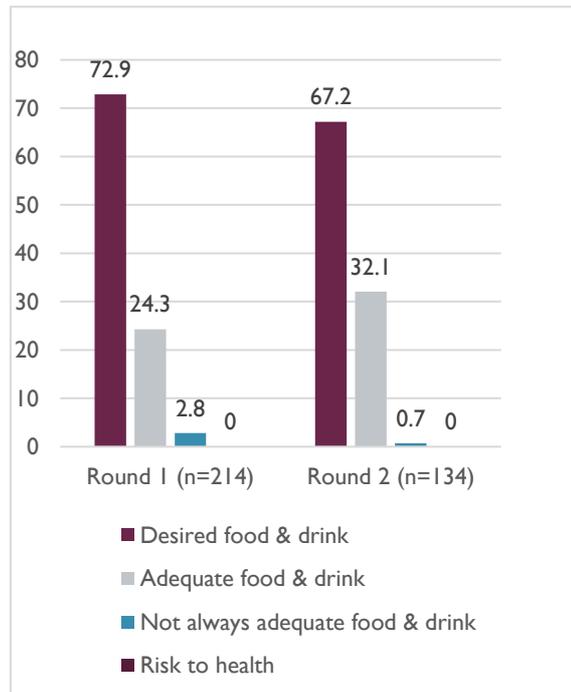
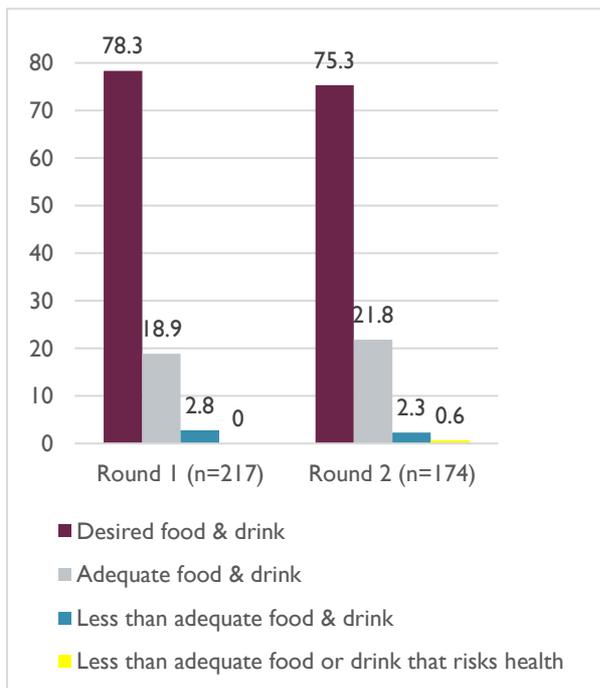
4.4.2 Personal Presentation



Case Managers

Consumers

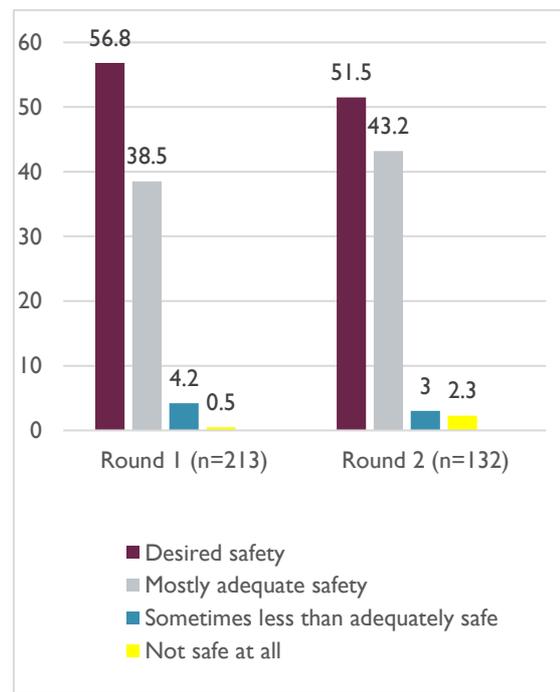
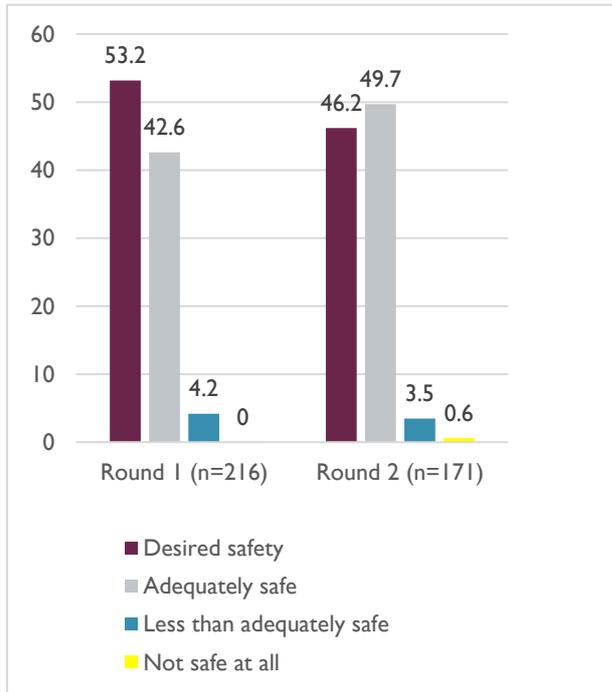
4.4.3 Food and Drink



Case Managers

Consumers

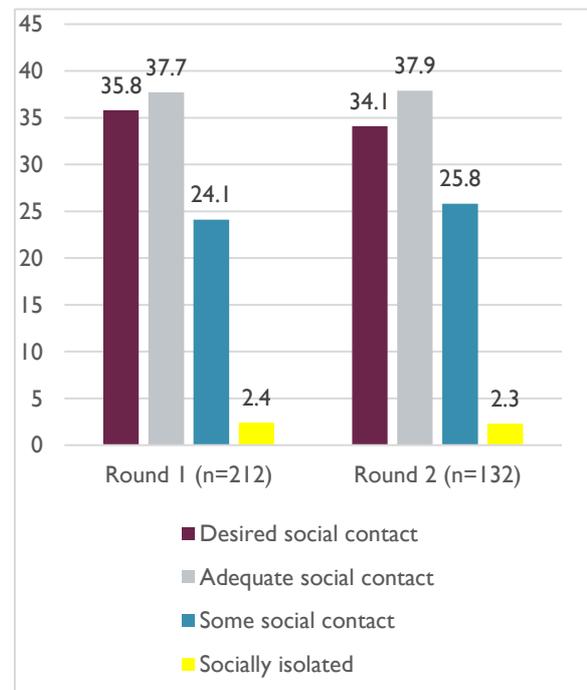
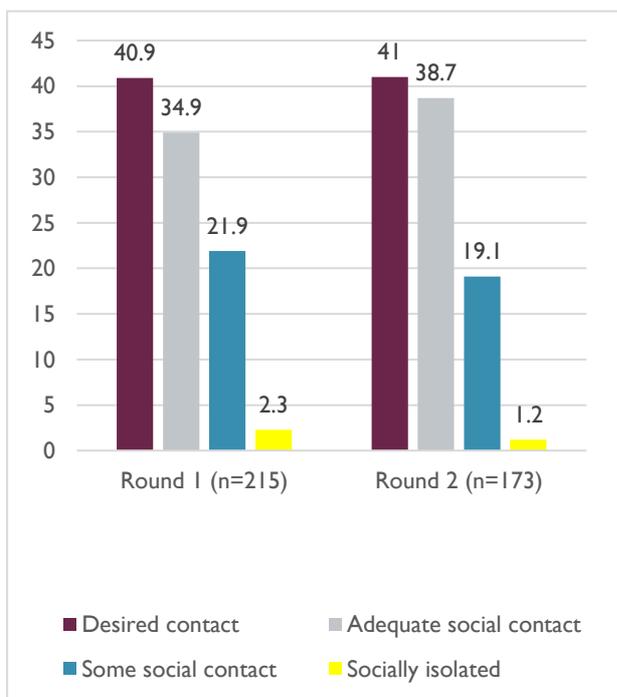
4.4.4 Consumer Safety



Case Managers

Consumers

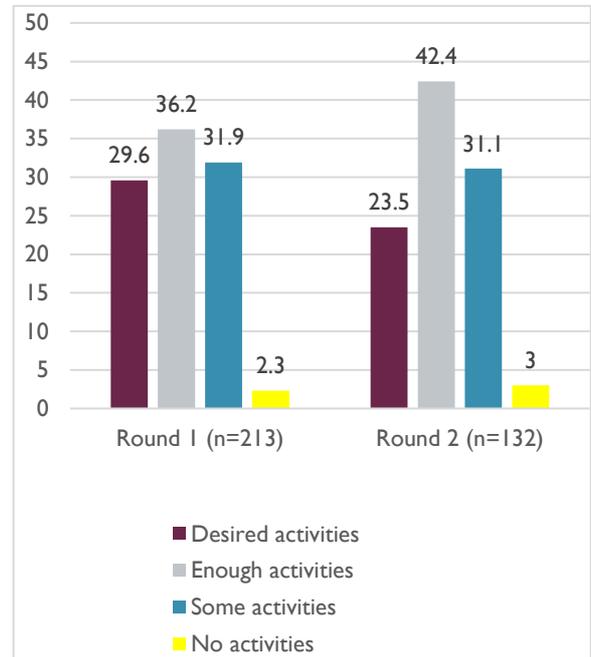
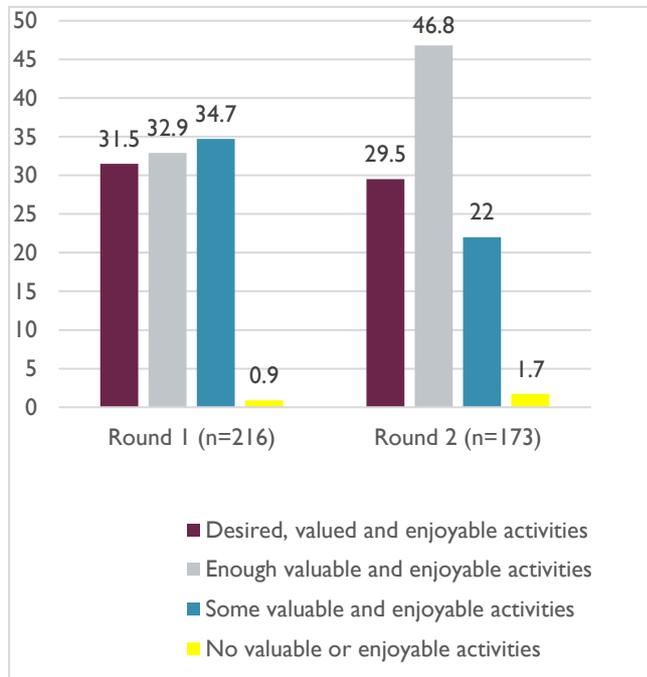
4.4.5 Social Participation



Case Managers

Consumers

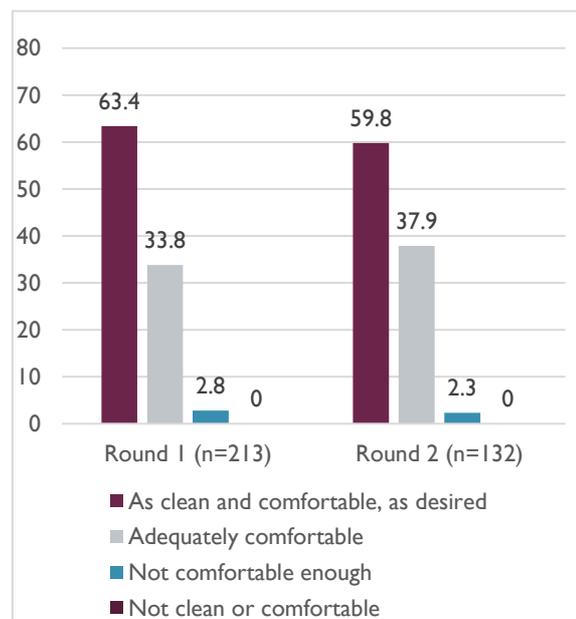
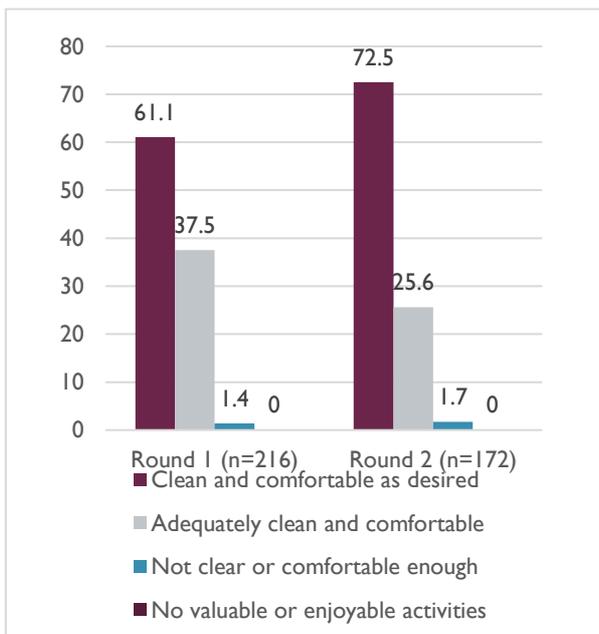
4.4.6 Activity (Occupation)



Case Managers

Consumers

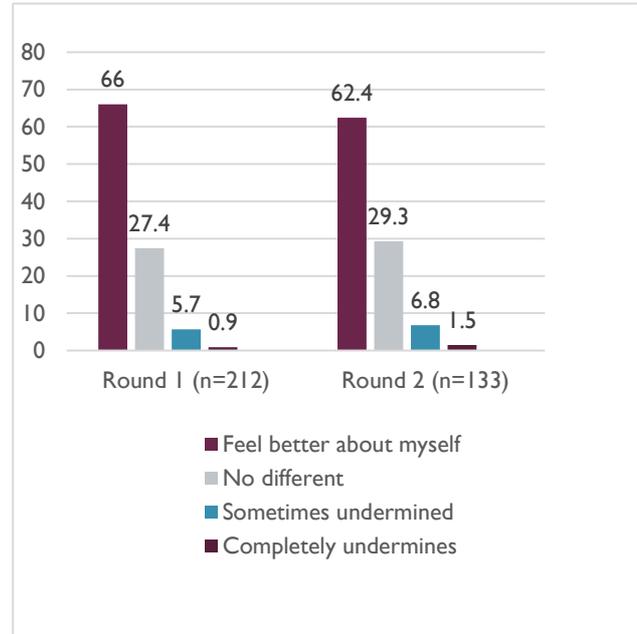
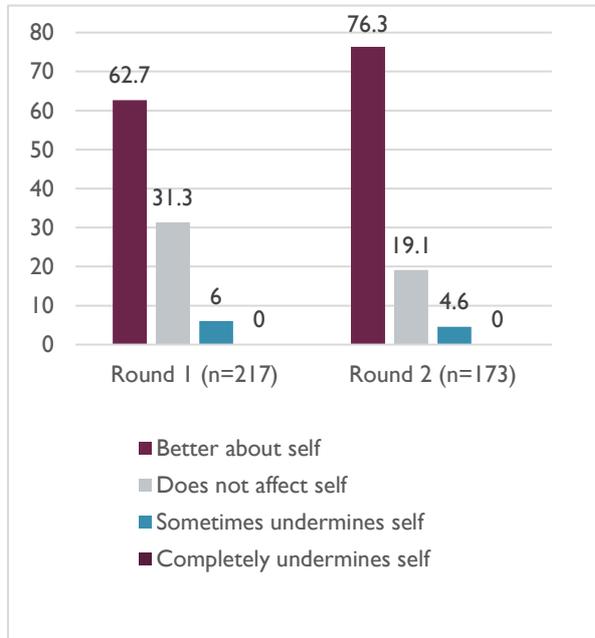
4.4.7 Accommodation



Case Managers

Consumers

4.4.8 Dignity (Effect of Services on Consumer)



Similar results were reported for each of the other variables. When asked about 'keeping clean and presentable in appearance' almost two thirds of consumers reported that 'I feel clean and am able to present myself the way I like.' As shown under 4.4.2, more than 60 per cent of CMs also viewed participants as being as clean and presentable as they desired, in both rounds. A further 30 per cent of both groups perceived consumers to be adequately clean and presentable. Very few case managers or consumers indicated that participants were not clean or presentable. While there is greater variation in the responses from round 2, there appears to be considerable overall agreement with 97 per cent of case managers and consumers selected the two most positive responses in both rounds.

Some apparent differences between the aggregated responses of CMs and consumers were noted. The adequacy of food and drink (item 4.4.3), for example, was rated slightly more positively by CMs than consumers in each round. In contrast, their ratings of levels of social participation (figures 4.4.5) and activity (figures 4.4.6) were much closer. Consumers, in turn rated their sense of safety and security (figures 4.4.4) at home slightly higher than did CMs.

A slightly surprising result was the differences between CMs and consumers when rating the cleanliness and comfort of the home. While there was a strong level of comparability between CMs and consumers' assessment of the comfort offered by the home (accommodation, see figures 4.4.7) in round 1, by round 2 quite a striking degree of difference had become apparent. Fewer of the remaining consumers rated their home as optimal, whilst precisely the opposite tendency became apparent amongst CMs.

The Open Question

Another innovative component of the ACCOM tool is the inclusion of an open question to allow consumers to identify issues not covered by the ASCOT or health question. The open question enables us to test the added value that can be gained through encouraging consumers to identify issues or areas of importance that may affect the quality of life for consumers or that otherwise be important for them but have not been recorded elsewhere in the ACCOM tool. As the preliminary findings of the field test indicate below, having this option raises important questions about the value and use of capturing diversity and subtlety of experience particularly in the early stages of developing outcomes measurement systems, when the range of possible intended and unintended outcomes are yet to be determined. The following analysis looks at the themes coming from the participants' qualitative data to ascertain whether they add value to the ACCOM tool.

A total of 102 consumers provided comments and feedback in the comments box added to the ASCOT tool. To ascertain the 'added value' character of these comments it is useful to consider the framework to map consumer defined outcomes developed by the Social Policy Research Unit (SPRU) at the University of York⁴⁵ when they undertook research with social service users to identify the outcomes they saw as important. Three main categories of outcome were identified:

- *Quality of Life or Maintenance outcomes*, the aspects of a person's whole life that they are working to achieve or maintain;
- *Process outcomes* which concern the experience that individuals have in seeking, obtaining and using services and supports; and
- *Change outcomes*, improvements in physical, mental or emotional functioning that individuals are seeking from services or support (Qureshi et al 2001).

These three broad categories - quality of life, process and change - were further developed in the study *Talking Points Personal Outcomes Approach*⁴⁶ and compared to the ASCOT domains.

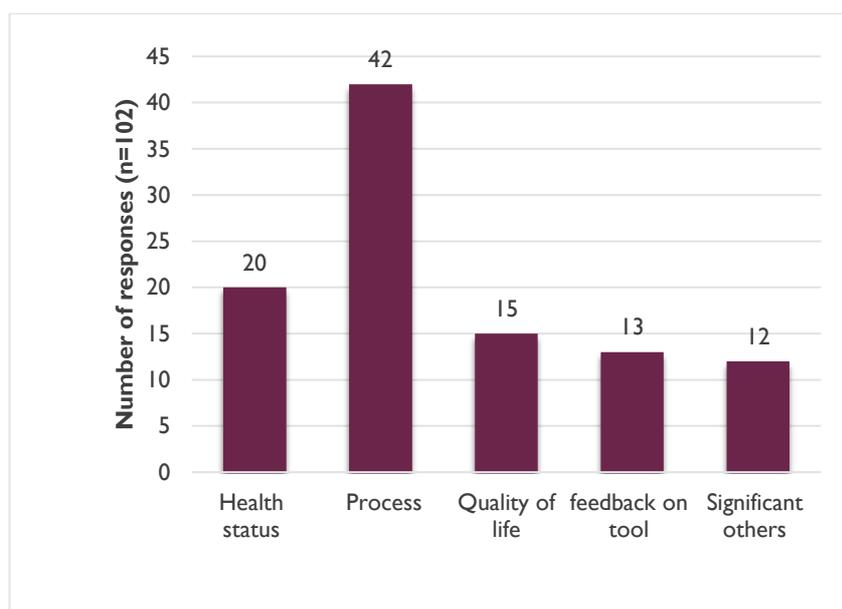
Table 4.5 Talking Points Categories

Quality of Life	Process	Change
<ul style="list-style-type: none"> • Feeling safe • Having things to do • Seeing people • Personal cleanliness and comfort • Staying as well as you can • Living where you want/as you want 	<ul style="list-style-type: none"> • Listened to • Having a say • Treated with respect • Responded to • Reliability 	<ul style="list-style-type: none"> • Improved confidence / morale • Improved skills • Improved mobility • Reduced symptoms • Dealing with stigma

Source: Cook and Miller, 2012

Using this framework to map the responses from the consumers in the ACCOM study shows a significant number of responses that fall within these 3 broad categories aligned with ASCOT domains and the Functional Screen capturing ADL. However other quality of life indicators are not fully captured by this framework suggesting that they don't have equivalents in the ACCOM tool. These include significant others and continuity of care. The following table captures the number of comments by categories.

Figure 4.6 **Numbers of Comments, by Thematic Category**



Responses relating to *Process* (perhaps best understood as care process) received 33 positive and 9 negative comments. Positive comments made references to the attitude and qualities of the care workers and the assistance provided. Examples include the following:

The care has been mostly very helpful. I am grateful to all the staff who come to help and assist me.

I am very happy with the care support as Case Managers staff go above and beyond. Staff show their support with respect always.

I think having care is excellent as I could not live without it.

Previous research on home care satisfaction surveys highlight the potential of biases in older people's responses⁴⁷, in particular what is termed 'gratitude bias' – the tendency to gloss over negative concerns about services and treatment because the recipient feels they should be grateful for what they receive⁴⁸. Perhaps because the ACCOM does not elsewhere provide respondents with an opportunity to express gratitude, such positive comments were greatly valued by CMs as they acknowledge the inter-personal nature of the care relationship and the importance of care workers being recognised for their good service.

Negative comments on care processes related mainly to problems experienced with the continuity of staff and the direct impact this had on the interpersonal relationship between the consumer and the care worker, and on the subjective experience of quality of care. The following examples illustrate this:

What made the care frustrating is when the office replaces the usual staff I normally have without my knowledge

Continuity of staff would make my life easier. I often have to retell staff how to do things

I often have to retell new carers how/where to do tasks. i.e. meal preparation, needing to tell people where things are. Often multicultural staff are not familiar with the way my husband and I like to have 3 vegetables and meat for a meal (I don't like stir fry - due to my medical condition and I can't have crunchy vegetables)

These sorts of comments illustrate the frustration and negative impact that may result from frequent changes in the care staff assigned to work with consumers. This was especially concerning for consumers receiving personal care involving toileting, dressing and other intimate contact activities. In discussions about this, CMs and project partners pointed out that they recognised the importance of consistent care staff but also pointed to the challenges of achieving this given staff turn-over and the increasing casualization of the workforce. For consumers, continuity of care is an important process outcome as it enables a sense of connection with the formal carer⁴⁹. This connection allows the care recipient to reconstruct the meaning of their care experience in terms of connection with a close supportive individual. Predictability and continuity of care provided care recipients with a sense of normality and routine. It also provided care workers with the opportunity to develop an understanding of the needs and preferences of the care recipients.

Comments related to *Significant others* also merit discussion, given research on the influence of close family, friends or carers on the health, wellbeing and mortality among older people⁵⁰. Positive relationships with a spouse, child or best friend is associated with increased wellbeing among older people⁵¹. Many of the relationships alluded to by the participants in the ACCOM study revolved around caring roles and support networks provided by a family member or close friend. These relationships were significant to the participants in various ways including as a source of carer responsibility, emotional and practical support, as well as a source of anxiety and concern. Some examples include:

As my husband has no vision and a stroke I am here all day to make sure he has as many comforts he needs. he has help from ... for PC 3 days a week. I am extremely grateful for these services. Thanks.

I have been my wife's carer full time for (?) years. She has hearing and (?) ... I have very little spare time. I am 92 years old and my wife is 90.

My wife has dementia cannot be left alone so we live mainly indoor enjoying respite. I have a balance problem causing falls, riddle with

arthritis. Respite gives me a chance to manage banking, and paying bills and to just get out. My neighbours are great.

I feel I can look after myself but I need help with taking my medication. However my daughter doesn't think I am capable to look after myself. She said I am physically active and healthy but unable to do many daily tasks on my own such as meal preparation.

These comments illustrate the centrality of relationships in the participants' lives and the impact they may have in their wellbeing and QoL outcomes. The references to caring responsibilities also remind us that some recipients of care packages are themselves also informal carers. As well as being of immediate practical importance, it suggests the importance of a sense of purpose and the feeling of usefulness generated by having a responsibility. This is consistent with research with older people in England⁵² which found that having a role and having support networks were important factors in determining their QoL.

Using the 'Purpose in Life' Test to measure the value of a sense of purpose among older people Sarvamiki and Stenbock⁵³ found that not all social contacts have the same significance. Intimate and close family contacts seem to provide meaning in life, while other relatives, friends and neighbors have a different significance. Long standing relationships based on family, community, (including religious community) and paid work were particularly important, offering the individuals an opportunity to give something back, to feel useful and valuable, of continuing to make a contribution at older ages⁵⁴.

These findings raise important questions regarding the value of capturing purpose and quality of relationships when measuring QoL among older people. As CMs pointed out when reviewing these quotes, having insight into the dynamics of interpersonal relationships can assist services in developing strategies to support relationships with family and meaningful others and identify additional support for consumers who lack these connections and may feel unable to reciprocate or contribute in any meaningful way to the wellbeing of others.

The examples above seem to suggest important benefits of using a general open question at the end of the questionnaire. There were two clear benefits: First, they enabled consumers to identify unique issues of any kind that may lie outside the standardised quantitative framework. Second, they provided CMs with additional information making visible specific issues impacting on the consumers' QoL. This ability to capture what matters to consumers is even more important for services today given the rhetoric of Consumer Directed Care which purports to position the consumer's needs and voice at the centre of the care equation.

The use of the comments box highlights the importance of not only measuring quality through quantifying tools but acknowledging the value of consumers' self-identified QoL issues and concerns as providing a broader and richer understanding on the impact of external and internal factors on care outcomes.

Conclusion

The results presented in this chapter are encouraging. One of the primary aims of the ACCOM tool is to measure client outcomes from community aged care by tracking changes in consumers' quality of life, while accounting for differences that arise from other client characteristics and determinates. These aggregate level results demonstrate that the measures reported in this chapter are able to achieve these goals well. Although not presented in this chapter, comparison of the results between services are also both simple and interesting.

The basic demographic data and data on the capabilities of consumers provide an accurate, concise and valuable profile of the population of those receiving packaged care at home. Similarly, the responses of consumers and CMs concerning QoL are revealing, presenting quite powerful insights into the way that quality of life at home is experienced by consumers. The level of concordance with the reports of consumers and CMs is also reassuring.

Nonetheless, the overall similarity in rankings should not be read as meaning that consumers and their case managers generally agreed or selected the same response category. Nor can the basic figures presented in this chapter tell us all we need to know about the factors that underlie differences experienced by consumers. In the next chapter we examine these issues more closely, with the help of more in-depth statistical techniques that permit analysis of variance.

Chapter 5

Results: Looking Deeper

Comparing Case Manager and Consumer Responses

A key feature of the ACCOM Tool is its ability to compare consumers' self-reported scores with those of their case managers. This provides a comparative vantage point that can deliver a more reliable estimate of need and outcome, as pointed in other studies.⁵⁵ When significant discrepancies emerge in outcomes scoring, the case managers' rating of their consumers' QoL domains can provide an important addition to self-report for consumers and may trigger assessment and goal plan review. A comparative study of consumers and case managers' responses to a questionnaire assessing their perceived level of need for seven domains (personal care, food and nutrition, social inclusion, mental and physical health and risk, choice and control)⁵⁶ found that older people tend to assess their own care needs as lower than their professionally trained case managers. This suggests that it would be valuable to obtain information regarding care needs from both consumers and care professionals.

To ascertain the degree to which consumer participants' self-assessed needs match the assessment conducted by case managers in our study, an analysis of differences in rating, by domain, was undertaken. As can be seen in Table 5.1, the domains with the higher percentage of agreement between consumer and case managers in rounds 1 and 2 were Food and Drink and Personal Care. The domains with the greater difference in both rounds were Social participation and Activity. The domain of Social participation generated the largest percentage of differing scores – just over 42 percent in round 1 and 45 percent in round 2.

Table 5.1 Agreement Between CM and Consumers by Domain - Rounds 1 and 2

Domain	Case managers who agreed with consumers (n)		Case managers who agreed with consumers (%)	
	R1	R2	R1	R2
Control over daily life	107	59	51.69	46.83
Personal cleanliness and comfort	142	88	68.60	69.84
Food and drink	149	80	71.98	63.49
Personal safety	117	72	56.52	57.14
Social participation and involvement	87	57	42.03	45.24
Occupation	93	56	44.93	44.44
Accommodation cleanliness and comfort	128	79	61.84	62.70
Dignity	114	77	55.07	61.11

Figure 5.2 further illustrates the level of agreement between CM and consumers' responses to QoL items.

Figure 5.2 Consumers and Case Manager Agreement on QoL Items. Round 1 and Round 2, as Percent

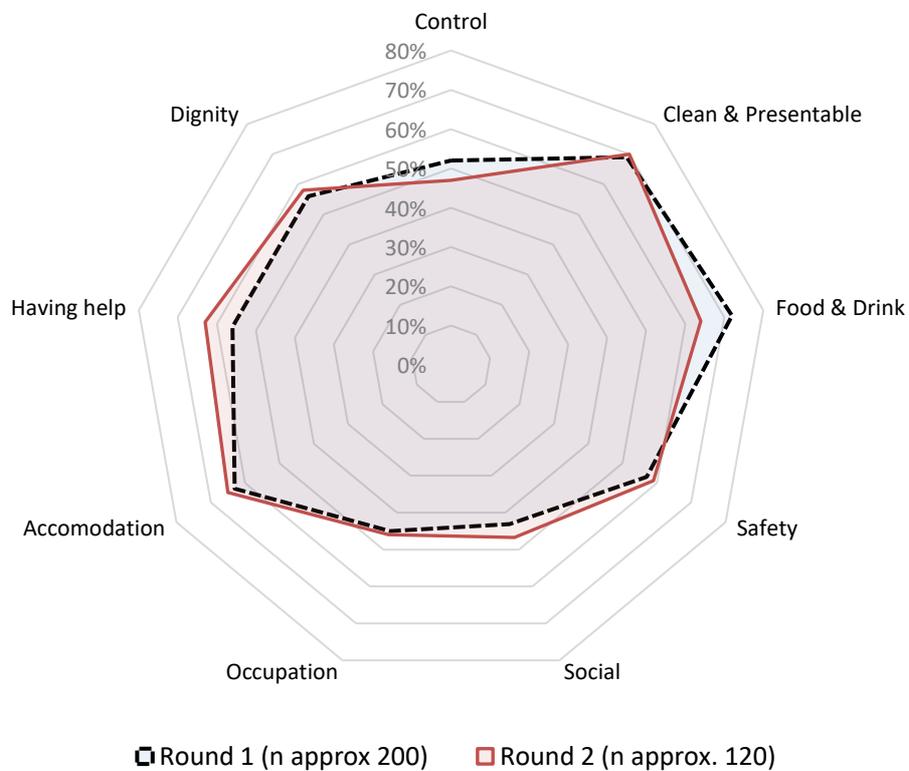
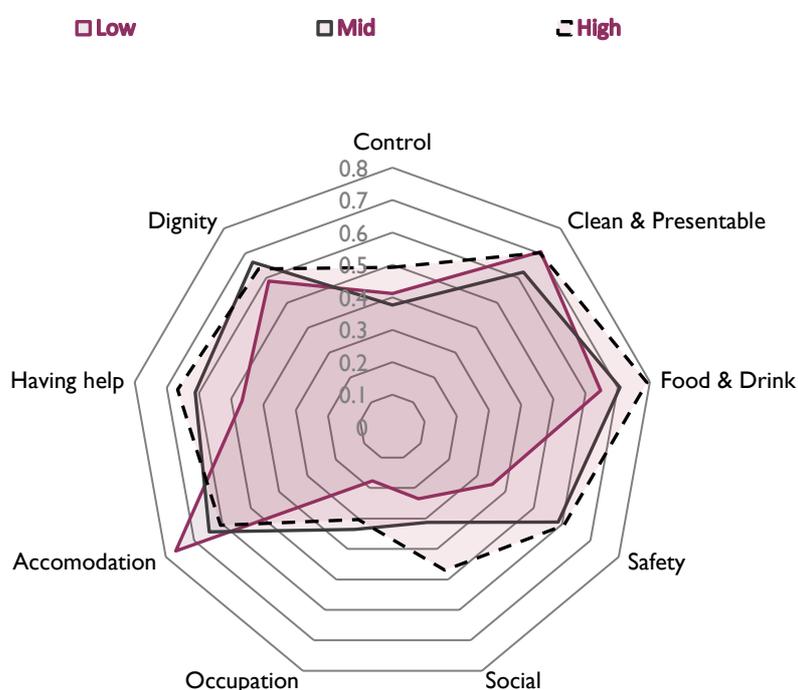


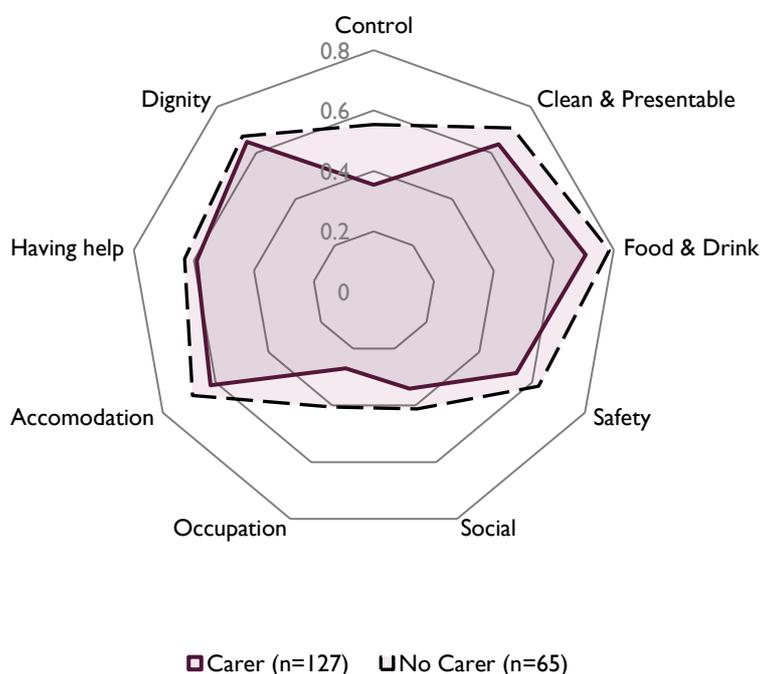
Figure 5.3 examines the link between consumer responses to the SCRQoL domains and their functional capacity in R1. In almost every domain, a higher proportion of those with high levels of functioning reported the most positive response possible. While not unexpected, this suggests that QoL responses also reflect the personal capacity of each consumer to undertake tasks for her or himself. Interestingly, while the social participation scores of the high functioning group were clearly the highest of all groups, their rating of the adequacy of their housing was below that of each of the other groups.

Figure 5.3. Consumers who Selected the Most Positive Response for each QoL Item by Functional Score in Round 1 (n=227)



Another factor shown to have affected QoL scores of consumers is the availability of an informal carer to provide support. In most cases the carer was a spouse, partner, daughter of other family member. As figure 5.4 shows, there were slightly fewer consumers who selected the highest category of most QoL domains amongst those who had a carer than those without – a finding that at first seems unexpected. The explanation that seems most likely is that those who depend on carers are more likely to require high levels of ongoing assistance and be less capable of undertaking activities independently than those who are without a carer.

Figure 5.4 Consumers who Selected the Most Positive Response for each QoL Item by Availability of Carer in Round 1



A more comprehensive set of measures that identify a link between personal capacity, as indicated by the functional screen score, and the impact of the receipt of different levels of care, is presented in Table 5.5. Summary SCRQoL scores have been calculated using the ASCOT preference weightings, with a higher score indicating a higher all round quality of life.

Table 5.5 Mean Social Care Related Quality of Life (SCRQoL) Score, for all Participants in Round 1. Comparison of Case Manager and Consumer Ratings

	Mean SCRQoL Case Managers (n)	Mean SCRQoL Consumers (n)
<i>Home care package type</i>		
Level 1	0.8775 (4)	0.8275 (4)
Level 2	0.8309 (151)	0.8444 (143)
Level 3	0.8357 (7)	0.8233 (6)
Level 4	0.8013 (48)	0.7698 (48)
<i>Functional screen score</i>		
High capability	0.8821 (68)	0.8492 (66)
Mid	0.8319 (117)	0.8287 (115)
Low capability (Most assistance needed)	0.6239 (18)	0.7244 (16)

Note: Level 1 and 3 packages are received by low numbers of consumers (4 and 7 respectively). These figures should therefore be disregarded in seeking to understand this table.

In the upper section of the table, the mean of these scores for consumers on different levels of package (from Level 1, the least intensive level of support to Level 4, the most intensive) are shown for both CM and consumer ratings. The trend (best understood by excluding the low numbers of service users on Level 1 and 3) is the same for both sets of respondents – the highest QoL scores are associated with the less intensive services. This trend is also strongly marked in the figures showing the level of functional capacity of service users. Those with the lowest QoL scores were those with the lowest level of capability and the greatest need for assistance.

Table 5.5 also shows the close association between the ratings provided by consumer and those of their CMs. Interestingly, mean scores for those with low levels of personal capability differ significantly between CMs and consumers – a feature that may reflect the relatively small numbers of individuals concerned.

A more complex analysis of the relationship between functional status and SCRQoL is provided in Table 5.6. which shows positive correlations between the functional scores of consumers and the SCRQoL scores provided by both consumers and CMs in Rounds 1 and 2. The statistical procedure used is a Pearson correlation, which produces two measures: an r-value, which provides a measure of the association between two numeric variables, and the p-value, a measure of whether the sample data corresponds to the population parameter. Both scores are typically reported, although the r-value is of most interest here.

Table 5.6 The Determinants of Quality of Life. Correlations of Respondents and Variables in the Field Trial (Pearson Correlation test, R1 and R2)

Correlations of SCRQoL	r-value	sample size
Consumers with functional score in R1	0.207**	197
Consumers with functional score in R2	0.258*	113
Case managers with functional scores R1	0.387**	203
Case managers with functional scores R2	0.390**	158
Consumers & case managers in R1	0.408**	199
Consumers & case managers in R2	0.276*	118
Consumers in R1 & R2	0.505**	128
Consumers in R1 & R2	0.526**	164

Note: The Pearson correlation produces an r-value, a measure of the association between two numeric variables, and the p-value, a measure of whether the sample data corresponds to the population parameter.

The asterisks in Table 5.6 indicate the p-values. In this case a single asterisk (*) indicates a p-value less than 0.05 (a 95% level of certainty that the two variables are linked). Two asterisks (**) indicates a p-value less than 0.01, or 99% certainty that two are associated. In this case, the linkage demonstrates that SCRQoL scores are affected by the level of functional incapacity of the consumer.

The Pearson Correlation r-values are somewhat more complex. They vary from -1 (perfect negative correlation) to +1 (perfect positive correlation), with an r-value of 0 indicating that there is no correlation. The closer r is to 0 the weaker the association and the closer it is to +1 or -1 the stronger the association. The r-values presented in the first four rows of Table 5.6 indicate that functional capacity is correlated with SCRQoL, but that the need for assistance does not explain all the variation in QoL scores. While a number of explanations for this are plausible, this is not necessarily of concern given that respondents are in receipt of Home Care Packages. In fact, the lack of a strong correlation between the quality of life measure and the functional score suggests that community aged care is having considerable success.

A further interesting result revealed by the analysis is that in each case the ratings provided by CMs were more closely correlated with SCRQoL than the ratings provided by consumers, indicated by both p and r values. What this suggests is not that CMs were more 'accurate' than consumers, but that in their assessment of consumer's QoL they were more strongly influenced by their knowledge of the consumers' level of need for assistance than were the service users themselves.

It is also interesting to note that there was a positive correlation between client and case manager Social Care Related Quality of Life Scores in round 1 ($r=0.408$, $n=199$). In round 2, the level of correlation was lower ($r=0.276$, $n=118$). This level of analysis compares the ratings of CMs with those of the consumers, finding a lower level of agreement between CMs and consumers than the aggregate descriptive statistics presented in the previous chapter appear to indicate. Further analysis and testing of the ACCOM is warranted to investigate the extent to which differences in client and case manager responses reflect significant subjective differences or other considerations. Nonetheless, the positive correlations between client and case manager scores are in line with expectations.

The higher correlations among client-rated and case manager-rated SCRQoLs suggest a reasonable level of stability for their responses to the ASCOT in both rounds of data collection. This is encouraging, given the intention to use the ASCOT questionnaire to chart changes in consumers' quality of life as part of a weighted outcomes measure in the longer term.

The value of Collecting Both Consumer and Case Manager Responses

The introduction of a consumer as well as a case manager perspective on consumers' QoL in the ACCOM tool had not originally been planned. The decision to ask both parties to complete the ASCOT SCT4 form was informed by previous research, by developments in policy emphasising Consumer Directed Care and advocacy from the research partners. It

was followed up by consultations with case managers and project partners on the value of having both perspectives in research and practice⁵⁷. The ASCOT SCT4 tool was designed to collect the perspectives from consumers only, and differs in this way from other forms of the ASCOT, such as those used in residential care, intended to be completed by staff together with facility residents. Is there value in collecting data from both consumers and CMs?

As the primary recipient of social care services, consumers are arguably uniquely well-qualified to identify for themselves what their SCRQoL status and outcomes are. Consumer's self-report is regarded in the literature as the most desirable, and often the only way to obtain this critical information⁵⁸. Thus, accurate and meaningful measures of the various dimensions of QoL are vitally important. However as pointed out by Netten et al. (2012)⁵⁹ issues such as adaptation behaviour (positive or negative), preferences and expectations colour consumer responses and inevitably lead to an adaptation effect impacting on overall or individual domain scores. Response shift which includes changes in the meaning of one's self-evaluation of QoL resulting from changes in internal standards, values, or conceptualization⁶⁰ can also impact on how consumers interpret the questions and the meaning of the domains.

Conclusion

The tables, figures and other analyses presented in this chapter are not intended to be comprehensive or exhaustive. Rather, they serve to illustrate the potential of the ACCOM to drill down to reveal hidden patterns and to understand the link between a very wide range of variables. In this chapter, we have been focussed on exploring the QoL data, derived from the ASCOT component of the ACCOM, examining correlations with functional capabilities and demography. Throughout, we have used tests such as Pearson and Kappa to examine correlations and have not allowed directional relationships to be directly tested nor sought to test causality as the emphasis has been on understanding links between the QoL experienced by consumers and factors that may influence it, such as the type and amount of services provided, the health and overall level of needs of the consumers concerned, the availability and importance of informal social support. This does not exhaust the possibilities in any way. Further analysis of this data and more extensive research will enable us in future to examine the extent to which other variables, including demographic and functional data, may serve alone or in combination as measures of outcome.

In the following chapter, we turn to consider the ACCOM itself, examining its useability, reliability and validity.

Chapter 6

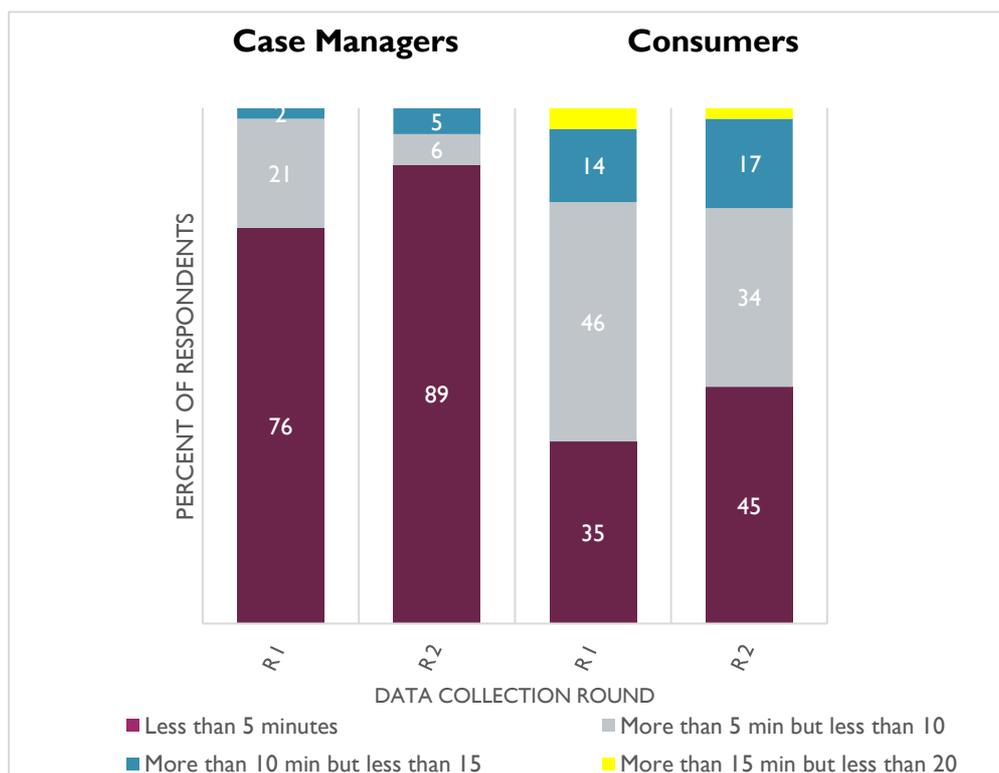
Useability, Reliability and Validity of the ACCOM

Having examined the initial results from the ACCOM, this chapter turns to two key questions about its use in practice: how useable did participating consumers and case managers find the tool? What evidence is there of the tool's validity and reliability? We start by exploring the useability of the ACCOM by examining questionnaire responses and comparing this to qualitative data gleaned from workshops and comment boxes. Then, we turn to the validity and reliability of the ACCOM, concluding that while results from the pilot study are promising, there is still more work to be done in this area.

Useability Issues

The time that case managers and consumers took to complete the ACCOM provides one indicator of useability. A total of 221 completed consumer questionnaires were returned in round 1 and a total of 131 in round 2. As Figure 6.1 shows, more than 95 percent of case managers completed the ACCOM tool in less than 10 minutes, most of these in less than 5 minutes. Consumers took longer to complete the questions, but overall 80 percent indicated that they completed it in less than 10 minutes.

Figure 6.1. Time to Complete ACCOM



Around half of all consumers received assistance completing the form in each round, as Figures 6.2 shows. Cognitive issues including memory loss and confusion affected 24 percent of consumers, which could in part explain the high percentage of proxy responses. Consumers who filled out the form without assistance took less time to complete the tool than those who received help from care workers or family/friends, completing it in slightly shorter time, as shown in Table 6.3.

Table 6.2 Assistance with Completion of ACCOM by Consumers, Round 1 and Round 2, Percent of Respondents.

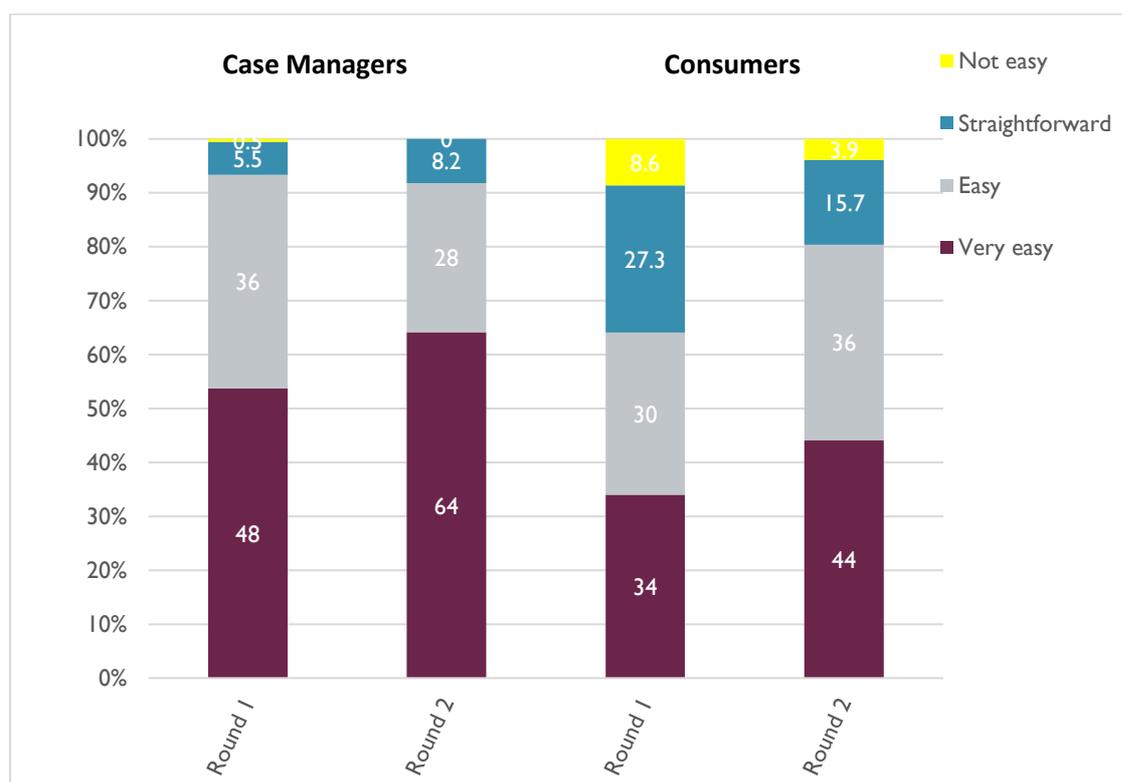
Consumer completed ACCOM	R1 (n= 211)	R2 (n=135)
By myself	51	47
With the help of a care worker	12	26
With the help of family or friend	37	27

Table 6.3 Time Taken to Complete ACCOM, Proxy Responses as a Percent of Respondents in each Category

Completion time	Self-complete	Assisted by care worker	Assisted by family or friends	Total
<i>Round 1 (n=211)</i>				
Less than 5 min	41	15	35	35
5 - 10 mins	43	65	43	46
10 - 15 mins	11	15	17	14
15 - 20 mins	5	4	4	4
More than 20 mins	1	0	1	1
Total % (n)	100 (108)	100 (26)	100 (75)	100 (209)
<i>Round 2 (n=135)</i>				
Less than 5 min	45	49	43	45
5 - 10 mins	31	30	43	34
10 - 15 mins	23	15	9	17
15 - 20 mins	2	3	3	2
More than 20 min	0	3	3	2
Total % (n)	100 (62)	100 (33)	100 (35)	100 (130)

Being able to complete the questionnaire in less than 15 minutes is an important indication of useability. Equally important is whether it was easy to complete. 90 percent of CMs and more than 60 percent of consumers indicated that they found it easy of very easy. While most other consumers found it 'straightforward', as many as 8.6 percent in Round 1 reported that they found it was not easy to compete, as shown in Figure 6.4.

Figure 6.4 Degree of Difficulty Competing the Form. Percent of Respondents, R1 and R2.



The low level of difficulty completing the ACCOM, as shown in Table 6.5 is an encouraging finding, which shows the potential of the measure to be a low-burden tool with high acceptability levels by users. However, the significant number of proxy responses highlights useability issues for consumers who require assistance in completing the tool, including those with cognitive issues or impairment. Current research by the Quality and Outcomes of Person-Centred Care Policy Research Unit (QORU) in the UK has identified the need to widen inclusion in outcome measures to currently excluded groups, such as those with cognitive impairment, and to alternative methods for identifying the perspectives of excluded groups.⁶¹ The findings and recommendations from these projects can assist future research on ACCOM use by people with cognitive impairments or other health or psychological conditions that prevent their participation in outcome research using questionnaires.

Table 6.5 Level of Difficulty by Proxy Responses, Rounds 1 and 2. Percent of Respondents in each Category

Ease of Use	Self-Complete	Assisted by Care Worker	Assisted by Family or Friend	Total
<i>Round 1</i>				
Very easy	45	23	21	34
Easy	28	39	29	30
Straightforward	21	39	32	27
Not very easy	6	0	15	9
Not easy	0	0	4	1
Total	100 (110)	100 (26)	100 (76)	100 (212)
<i>Round 2</i>				
Very easy	49	39	38	44
Easy	39	36	32	37
Straightforward	10	24	18	16
Not very easy	2	0	12	4
Not easy	0	0	0	0
Total	100 (61)	100 (33)	100 (34)	100 (128)

The Validity of the ACCOM Tool

Construct validity is based on testing how a measure should behave in relation to other measures or other factors that should be associated with it.⁶² Expected relationships and associations with variables such as abilities in activities of daily living, presence and extent of support from others and living arrangements were selected based on evidence from the literature⁶³ and the views of the project partners and research team members on key indicators and their possible impact on consumers' rating for each domain. The association between SCRQoL scores and physical capability, captured in the ACCOM tool through the Functional Screen, has been demonstrated in previous research in the UK and was not tested in this Australian study⁶⁴.

A mean SCRQoL score of 0.82, shown in Table 6.6, represents a value that is towards the upper end of the weighted scale and indicative of a reasonable to high level of life quality for the consumers in this study. This is higher than the mean score of 0.71 for current SCRQoL in a UK sample of residents living in care homes⁶⁵, but slightly lower than the 0.86 mean score of the general population in the UK.⁶⁶ A study with a small sample (n=24) from a day rehabilitation facility in Southern Adelaide, South Australia which used ASCOT and Euroqol (EQ-5D), reported a mean score of 0.87⁶⁷. The sample size is, however, too small to be confident of the results. In another study of older Australians receiving home care

programs, using a larger sample (n= 83) and targeting self-selected groups who were reported as fairly healthy and not cognitively impaired, the mean score was 0.852.⁶⁸

As noted earlier, one of the key attributes of the ACCOM Tool is its ability to compare consumers' self-reported current QoL scores to case managers' rating of their consumers. This provides a useful comparative vantage point from which to derive a more reliable estimate of need and outcome, as pointed in other studies⁶⁹. Case managers' rating of their consumers' SCRQoL can provide a useful addition to self-report for consumers and may trigger assessment and goal plan review when significant discrepancies emerge in outcomes scoring. A comparative study of consumers and case managers' responses to a questionnaire assessing their perceived level of need for seven domains (personal care, food and nutrition, social inclusion, mental and physical health and risk, choice and control)⁷⁰ found that older people have a tendency to assess their own care needs as lower than assessed by their case managers. The approach vindicates the advice from Ottmann et al. who have previously argued that it would be valuable to obtain information regarding care needs from both consumers and care professionals.

The comparison of the mean SCRQoL scores by CMs and consumers, shown in Table 6.6, suggests a reasonable level of agreement between both sets of respondents.

Table 6.6 SCRQoL Scores as Reported by CMs and Consumers

Consumers	Count (N)	Mean	Case Managers	Count (N)	Mean
R1	211	0.82	R1	212	0.82
R2	132	0.81	R2	166	0.83

Note: By only focusing on measures of central tendency, Table 6.6 potentially overstates the extent to which there is high levels of agreement. A larger sample and the use of a measure of dispersion, such as variation or standard deviation is necessary to examine this issue further.

As shown in Figure 6.7, a relatively high degree of consistency is also evident in the rating of Quality of Life items by both consumers and CMs in both rounds of the trial. This is indicated by the fact that there was a high percent agreement for most items. Table 6.9 also shows that the associations between consumer and CM ratings for all domains in each round (except for the food and drink domain in round 2).

Figure 6.7 Consumer and Case Manager Agreement on Quality of Life Items in Round 1 and 2, Percent

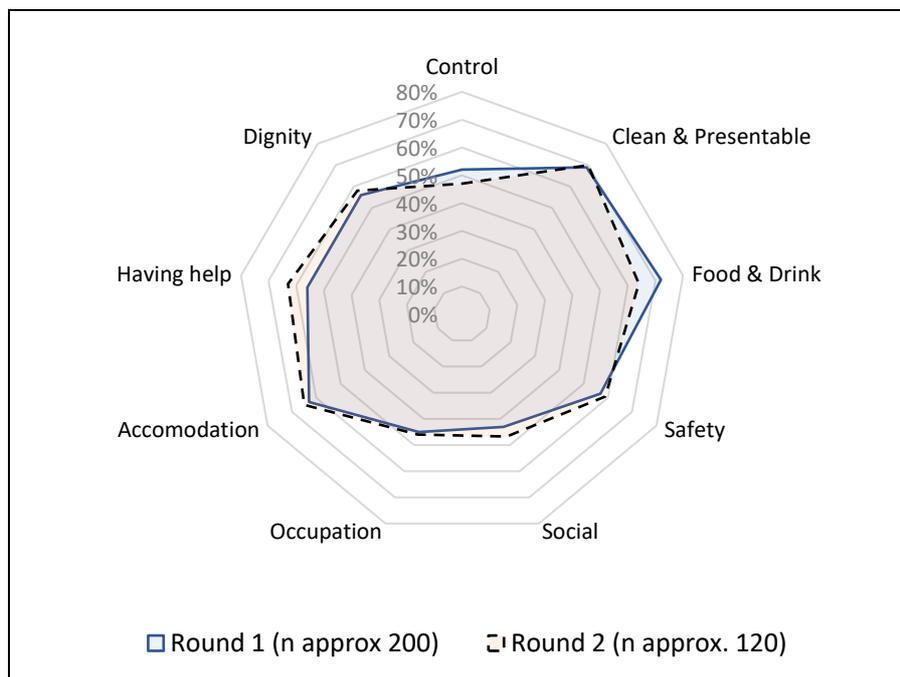


Table 6.8 Congruous Case Manager and Consumer Ratings for ASCOT Items in Round 1 and 2 (Percent of Total)

Domain	R1 (%)	Kappa	R2 (%)	Kappa
Control	52	0.25**	47	0.17*
Clean & Presentable	69	0.34**	70	0.36**
Food & Drink	72	0.27**	64	0.16
Safety	57	0.20**	59	0.26**
Social	43	0.15**	47	0.20*
Occupation	45	0.19**	46	0.17*
Accommodation	63	0.23**	65	0.26*
Dignity	56	0.11**	58	0.10

But when seeking to confirm the content validity of items, it is important to pay regard to, but not to overstate the level of agreement between CMs and consumers. The Kappa correlation coefficients shown in Table 6.8 indicate that while there is a measurable degree of congruity (agreement) between CMs and consumers, the level is at best moderate, not strong⁷¹. Much the same could be said of the consistency of ratings by CMs and of consumers of individual consumers in each round, as shown in Table 6.9. These results

could be interpreted as indicating only a moderate level of inter-rater reliability. Alternatively, the figures in Table 6.8 could be seen as accurately documenting differences in perception between consumers, who directly and personally experience the phenomenon in a unique manner, and CMs, who use their professional judgement when comparing cases and perhaps are seek to be objective. Similarly, the results in Table 6.9 appear to reflect perceptions of real change in the QoL of consumers over time, and should not be seen as indicating poor consistency of ratings.

Table 6.9 Congruity of CM and Consumer Ratings in Rounds 1 and 2

Domain	Congruous CM domains in R1 and R2 (%)	Kappa	Congruous consumer ratings of in R1 and R2 (%)	Kappa
Control	56	0.32**	55	0.30**
Clean & Presentable	64	0.39**	62	0.21**
Food & Drink	72	0.26**	65	0.16
Safety	66	0.20**	60	0.26**
Social	57	0.35**	42	0.26**
Occupation	51	0.29**	49	0.24**
Accommodation	64	0.20*	67	0.33**
Dignity	64	0.20**	61	0.23**

Notes: * p < 0.05, ** p < 0.001

The technical accuracy of both the percent agreement and kappa coefficients are somewhat contentious. In a detailed review of the procedures, McHugh argues that

Both percent agreement and kappa have strengths and limitations. The percent agreement statistic is easily calculated and directly interpretable. Its key limitation is that it does not take account of the possibility that raters guessed on scores. It thus may overestimate the true agreement among raters. The kappa was designed to take account of the possibility of guessing, but the assumptions it makes about rater independence and other factors are not well supported, and thus it may lower the estimate of agreement excessively.⁷²

The results, in our view, provide confidence in the continued use of the scales, but indicate a need for more rigorous study of this issue in future research.

Associations Between Background Variables

An analysis of the extent to which each attribute has the expected association with other variables and concepts is an important part of an assessment of the validity of the ACCOM Tool. The choice of variables was informed by previous research on the construct validity of the ASCOT tool⁷³ and expected associations with variables were based on insights from the literature, and the views of case managers, project partners and consumer representatives gathered during initial consultations and ongoing collaboration processes. Case managers brought their expertise in this area, as well as detailed knowledge of the consumers' care needs and personal circumstances. Table 6.10 summarises the hypothesised associations for each attribute. Relationships were analysed between all the ASCOT attributes and each variable for transparency and counterfactual evidence.

Table 6.10 Variables and Expected Associations

<i>Variables</i>	<i>Expected Associations</i>
Functionality and SCRQoL	We expect an association between low functional scores and overall low SCRQoL scores
Socio-demographics: Living arrangements and carer availability	We expect consumers with a partner or those with access to an informal carer to have a higher SCRQoL score. We also expect there to be a positive association for these consumers with Social participation as co-residents provide a source of social contact and stimulation (ASCOT Construct validity)
Functionality and self-rated health status	We expect consumers who self-rated their health as very good or good to have a positive association with Functional score.
Home care package level	We expect consumers with Level 4 packages to score lower in key ASCOT domains than those on Level 2 packages
Functionality and social participation subscale	Consumers with low functionality are expected to have a negative association with social participation (question 5 SCT4)
Proxy responses and SCRQoL scores	We expect possible differences in scores between consumers who completed the tool by themselves and proxy consumer responses. Care worker assistance in the client self-assessment process is expected to result in similar scores to case managers than an un-assisted consumer self-assessment.

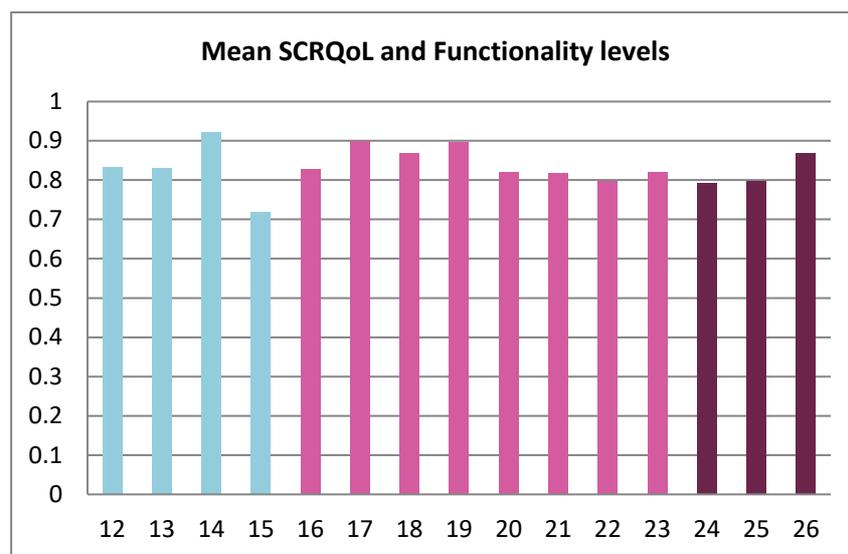
An analysis of the associations between all the ASCOT attributes and the above variables were done using Chi-squared tests (for unordered or ordered categorical variables) or the Pearson correlation) for numeric variables.

A study on the construct validity of the ASCOT⁷⁴ in the UK pointed to its design capability to capture the impact of ADL differences on SCRQoL scores. A comparative study of the differences in correlations of the self-perceived quality of life and self-perceived health

scales with the EQ-5D-3L on the one hand and ICECAP-O and ASCOT on the other hand found that in fact although ASCOT does not directly measure health, it is able to capture some of the effects of health that are important to older adults⁷⁵.

As Figure 6.11 compares functionality and SCRQoL scores between subgroups: those with low functional (15 or less), medium (16-23) and high (23 or more) showed, as we might expect with people receiving services, that not being able to perform ADLs was not necessarily associated with needs (low/high).

Figure 6.11 Mean SCRQoL Score and Functional Profile



It is, however, worth noting the lowest SCRQoL score of 0.72 was for participants with a low functional score. We can hypothesize that given that the nature of community care interventions is to compensate a person for their lost functional ability, a negative association between low functionality and high SCRQoL scores could be the result of service interventions intended to maintain people’s QoL, responding to deteriorating or varying levels of impairment⁷⁶.

If the above hypothesis is correct and the high SCRQoL scores could be attributed or partly attributed to the fact that the sample group in the study is made of individuals receiving care interventions, then we might expect that any gains in SCRQoL will have a positive correlation with intensity of service receipt. The Pearson correlation scores (r-values) presented earlier in Table 5.6 support such an association. The strength of the correlation, as argued by Netten et al.⁷⁷, will depend on a number of factors that affect the production of welfare, including the quality of the care delivered and other factors that may influence the ability of workers to deliver optimal care, such as the design of the person’s home and the behaviour of the consumer.

A more extensive review of the validity of ratings for all domains is currently being undertaken. To demonstrate the importance placed on attribution and validity, we focus below on some of the key variables.

Living Arrangements and Carer Availability

The relationship expected between consumers with a partner or those with access to an informal carer to have a higher SCRQoL score as well as a positive association with Social participation as co-residents have the potential to provide a source of social contact and stimulation⁷⁸. Consumers who had a carer scored lower in all the domains and had a lower mean SCRQoL score than those without a carer, as shown in Figure 5.4, presented in the previous chapter.

Consultation with CMs identified some possible explanations for this result, including the need for higher levels of independent decision making and control by consumers who do not have a carer to on whom to depend daily. Also important is the higher functional profile of consumers without a carer compared to those with a carer. Other variables that may need to be considered is the impact of age, gender and the nature of the care relationship. The link between carer availability and SCRQoL, while at first counterintuitive, reflects the well-established understanding that consumers without a carer need to be capable of functioning more independently than those who receive such support.

Self-rated Health Status and Functional Score

We expect consumers who self-rated their health as *very good* or *good* to have positive association with Functional score. As Figure 6.12 indicates, Functional Profile scores of medium to high were more prevalent among consumers who scored *very good, good* or *fair*. However, there was also variation with consumers who self-rated their health as *poor* having a *medium* to *high* functional profile. Part of the reason for these variations lies in the fact that professional-rated health scores such as the Functional Profile focuses on the more objective symptoms of health status, whereas the self-rated individuals may focus more on subjective symptoms, functional limitations and quality of life. This alerts us to the value both perspectives and their role as predictors of mortality and quality of life. Consumers' self-rated health can provide CM and service providers with important additional information to help them optimise decision making around services, hospital referral and support programs to achieve consumer-centred care and enhance QoL outcomes.

Table 6.12 Self-rated Health and Functional Profile (Number of Consumers)

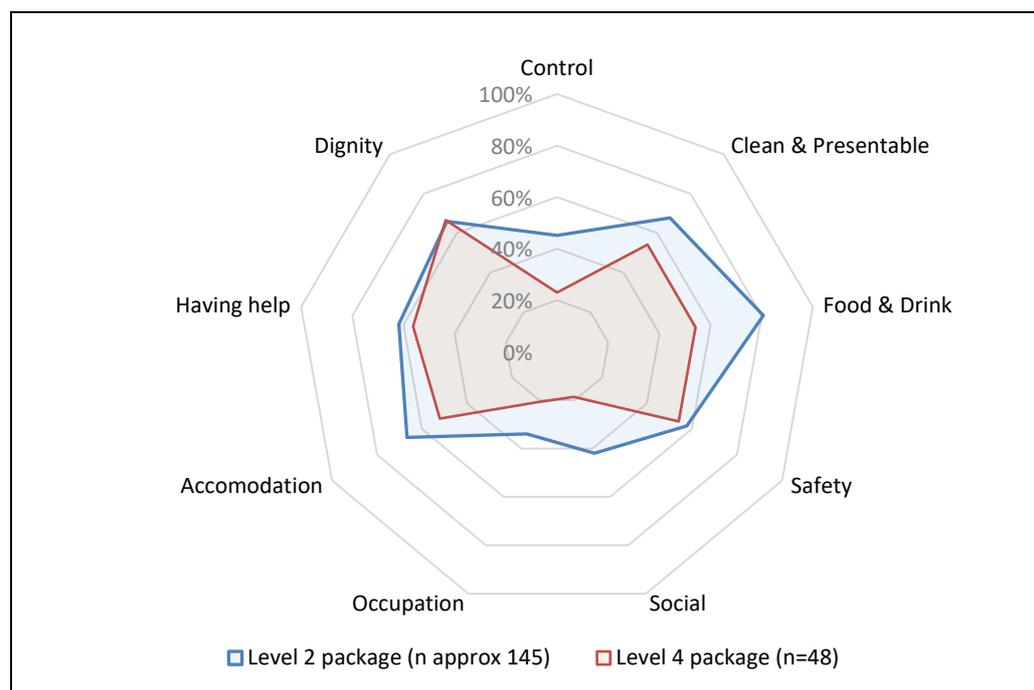
Self-Rated Health	Functional Profile Round 1				Functional Profile Round 2			
	Low	Medium	High	Total	Low	Medium	High	Total
Excellent	0	3	1	4	0	3	1	4
Very Good	1	16	18	35	2	10	4	16
Good	5	46	18	69	3	18	12	33
Fair	3	38	25	66	3	34	11	48
Poor	7	12	4	23	2	5	4	11
Total	16	115	66	197	10	70	32	112

Cognitive issues including memory loss and confusion affected 24 percent of respondents which can in part explain the high percentage of proxy responses. The potential association between proxy responses and SCRQoL scores was analysed in order to ascertain whether, as found in previous research⁷⁹ direct case manager or care worker assistance in the client self-assessment process leads to higher or lower scoring than an un-assisted client self-assessment.

Home Care Package Level

We expected consumers with Level 4 packages to score lower in key ASCOT domains than those on Level 2 packages. This hypothesis is based on the argument that higher package level is an indication of higher needs and lower levels of control and functional ability. As Figure 6.13 below indicates, consumers with Level 4 packages scored lower in almost all the domains except Dignity. Significant lower scores in the Food and Drink domain require further investigation given they are part of core service delivery. Various reasons cited by CMs for poor scores in this domain include declining or not accessing meal services, unavailability of a carer to assist with meal preparation, as well as financial and transport issues.

Figure 6.13 Response by Package Level



Discussion

The analyses presented in this chapter provide extensive evidence to support the construct validity of the ACCOM attributes. As expected, we found a positive correlation between consumers' high mean SCRQoL scores and the demographic and functional characteristics of the participating sample. More than 70 per cent of the consumers in the study had a functional score of medium to high and were in receipt of level 2 packages. As expected, consumers with Level 4 packages scored lower in almost all the domains specially the higher order needs domains, which as pointed out earlier are more difficult to meet and are impacted by multiple variables including geographical location, difficulty or inability to perform ADLs and the restriction this places on the activities a person can enjoy.

Given that the role of services and more specifically Home Care Packages is to assist people to remain living at home by compensating them for the effect of their impairments on their quality of life, the negative association found in our study between low functionality and high SCRQoL scores is expected. As pointed earlier, this could be interpreted as the result of interventions capable of maintaining people's QoL, and responding in the face of deteriorating or varying levels of impairment. A mean scale of 0.82 in round 1, and 0.81 in round 2, represents a value that is towards the upper end of the weighted scale and indicative of a reasonable to high level of life quality.

The unexpected negative correlation between carer availability and lower SCRQoL scores, as pointed out earlier, needs to be understood in relation to other demographic characteristics. Research on the impact of carers on the QoL of consumers has identified a

number of different factors, including the nature of the physical, mental or emotional impairment experienced by the consumer and his/her carer and relationship quality and mutuality, and shared coping strategies and support, that affect the outcomes of care for both carers and care recipients⁸⁰. The findings in this pilot study raises further research questions to be addressed in future research. There is also a need to explore, as concluded by research on carers and care recipients in the UK how the design of services impact on carers' outcomes and what is the impact of services on outcomes for both carers and consumers⁸¹. While further work will be required to adapt the ACCOM to measuring outcomes for carers in Australia, it appears to be a practical tool for use with consumers and worthy of further development.

In the final chapter of this report, we turn to consider a number of the future options for the research and the challenges that need to be addressed if the ACCOM is to be used more extensively.

Chapter 7

The Future – Next Steps and Challenges

The results presented in this report demonstrate the broad viability of the ACCOM instrument as a comprehensive tool for different purposes including

- i. Quality Assessment and Benchmarking;
- ii. Care Planning and Care Review; and
- iii. Measuring Care Outcomes.

As the research presented in the report has shown, the attributes of the tool, in particular its capacity to capture both health and quality of life elements; the collection of demographic data; and the capability of collecting and comparing Case Manager and consumer versions of the modified ASCOT SCT4 questionnaire, have been found to be robust. The field study has demonstrated that the ACCOM worked well under the pressures of everyday service delivery at a demanding time for field staff that coincided with much change and uncertainty arising from the implementation of a significant national reforms. As shown in previous chapters, the results bring together valuable data, including scale measurements and other information, in a concise and readily comprehensible manner that has the potential to inform and enhance service provision in a powerfully productive manner.

Measuring the outcomes of older people receiving services in their homes is not a straightforward process. As the report demonstrated, through the description of the results, and the analysis of the data, there are multiple external factors beyond the control of service providers that account for SCRQoL outcomes for service users. By isolating the impact of these factors an adjusted SCRQoL score can be calculated. The various instruments and attributes comprising the ACCOM tool constitute, in the view of the research team and project partners, one of the most comprehensive and systematic efforts in Australia to achieve this goal. The collection of health and capability related outcomes through the Functional Screen addressed the specific outcomes of services delivering nursing, allied health and other clinical services. Demographic data also provides key outcome measures and made correlation of key variables possible to determine attribution and the CM and consumer version of the ASCOT tool enabled the robust and reliable collection of outcomes.

Much of the potential of the tool lies in its harnessing of data collected for each consumer. Subsequently it has either been ignored or has been difficult to use, dispersed in various places such as the client's file, care planning records, case management reports as well as funding reporting instruments. The tool has also been shown to provide additional scope in a number of the domains covered by the quality of life measures set out in the ASCOT component. Case managers reported, for example, that the domains of control and dignity,

occupation and social relations were typically not collected in standard care planning tools. The use of Redcap for CM to enter data and the simple structure of the ACCOM tool meant that there was low administrative burden for CM as the useability analysis found.

Aggregated, the data can also provide effective comparative benchmarking measures to inform service provision at an agency or service provider level. Similarly, data from the functional screen indicating patterns of stability or change in care needs, and demographic data, documenting changes personal circumstances, relationships or place of residence is also significant and can be used to inform and compare service provision.

The research study has focussed on the development and field testing of the ACCOM tool. But it is important to emphasise that the data reported in this report has not as yet included a final set of outcome measures. Based on the data collection and analysis undertaken, the following discussion explores the potential uses of the ACCOM tool and the challenges that need to be addressed in the next stages of work.

Quality Assessment and Benchmarking

Current work by The Department of Health National Aged Care Quality Indicator Programme (QI) on the development of quality indicators for the home care programme identifies the consumer experience and quality of life measures as core measures of quality⁸². They have recently trialled various evidence based tools including ASCOT to measure consumer experience and quality of life in the Australian residential and community aged care environment. The QI has identified the complexities in developing quality indicators for the home care sector given the broad range of care services provided through the Commonwealth Home Support Programme (CHSP), the base level service, and the Home Care Packages Programme (HCP).

The ACCOM tool was piloted with consumers receiving Home Care Packages but its applicability for CHSP and other community support programs is feasible given its capacity to disaggregate data and identify potential variables and their impact on attribution. Current planning by the Department of Health to streamline the Home Care Packages and the Commonwealth Home Support Programme into a single care in the home programme from July 2018 could provide an opportunity to extend outcome and quality measurement approaches to the wider objectives of programs and services delivered in the home. These are, as stated by the Department, to assist people to remain living at home; to maximise their independence and to enable consumers to have choice and flexibility in the way that the consumer's aged care and support is provided at home.⁸³ The attributes of the ACCOM tool allow service providers to identify specific health, personal care and social needs of consumers, and the services required to meet them, to monitor changes in personal circumstances and to measure impact of services. Measuring service impact is a powerful quality indicator that can give consumers transparent, comparable information about quality in aged care to aid decision making and for providers to have robust, valid data to measure and monitor their performance and support continuous quality improvement. Benchmarking across services would provide a strong incentive for services to improve programs and social care related outcomes as well as identify areas where further work is

needed. The capabilities framework can also assist consumers to think beyond specific services and focus instead on the outcomes they wish to achieve to live meaningful and fulfilling lives and the extent to which services can assist them to achieve them.

Adopting this model requires an integration of data collection and reporting systems to allow the ACCOM instrument to avoid data duplication and administrative burden. Management of ACCOM needs to remain independent of the service provider to ensure objectivity and confidence in the reliability and robustness of the data.

Care Planning and Care Review

The potential to use the ACCOM for care planning and care review was a key finding from the consultations with CM and project partners. The capabilities framework and QoL dimensions of the tool delivered previously unavailable information to CMs on their consumers' SCRQoL status and needs. The comparison of CM and consumers' scores on each of the domains generated new insights for CMs on how needs are identified and reviewed and how changes in personal circumstances and other variables may impact on consumers' health and SCRQoL outcomes. Case managers regarded this as one of the most important attributes of the ACCOM tool. They suggested that the 'ideal time' to administer the ACCOM would be around 6 weeks after the package service had commenced. They felt that this would provide the client with time to get to know the services and be in a position to comment on areas of unmet need and where they would like more assistance or for the services to be provided in a slightly revised priority. The capability framework of the ACCOM tool also was regarded as useful for care planning due to its consistency with Consumer Directed Care (CDC) approaches and person-centred models.

Measuring Care Outcomes

As this report has demonstrated, the quality of life experienced by consumers can prove to be a powerful measure of outcomes in the community care field. We emphasised the importance of QoL variables collected through the ASCOT component of the tool, in Chapter 4 of this report. By isolating the impact of demographic and functional factors, an adjusted SCRQoL score can be calculated. But a range of other factors may also influence the quality of life of service users. Many of these are long-term demographic and biographical factors, some of which may be beyond the control of service providers. Chapter 5 went on to explore how QoL scores varied with changes in functional and demographic variables.

Demographic and functional data are not merely independent variables with which to qualify data on quality of life. They also present the opportunity to identify significant measures of the outcomes of community care in their own right. The continued maintenance of residence at home, a simple demographic indicator, has long been used as a core outcome measure in evaluations of complex community care, as have changes in clinical condition and the need for care⁸⁴. In turn, each of the QoL measures, on their own and in combination, is revealing and can be used in the current form to inform and to adjust

service delivery for individual consumers. Measuring change over time is also central to documenting outcomes.

Next Steps

i. Refining Concise Outcome Measures Utilising the ACCOM

Having demonstrated the viability of the ACCOM tool as data collection tool, a key question to be posed in further research is the following: Is it possible to move beyond the item measurements recorded by the tool to identify a robust set of concise outcome measures across each of the three key component areas covered by the ACCOM – Consumer Quality of Life; Demographics and Functional Capacity?

The development of more concise and summative measures of outcome would offer further insights into the impact of providing care to help maintain those who need assistance remain in the own homes as long as possible while maximising the personal capabilities and quality of life. Future work that would encompass change over time. Similarly, the feasibility and desirability of developing outcome benchmarks utilising measurements of the ACCOM requires further investigation.

ii. Further Development of the ACCOM Tool

As discussed earlier in this report, further development work is required on IT aspects of the ACCOM. Both the Functional Screen and Demographic Data component of the tool needed to be re-entered to ensure these records could be used in the trial. It is technically possible to ensure that these records can be directly incorporated into the ACCOM without such wasteful duplication of effort and this needs to be given high priority. This would also provide an opportunity to review these components of the tool, and to address data collection issues that meant that often only selected data was available, as full records were not always completed for each consumer.

Developing additional specialised modules or by adapting the existing tool to cover outcomes for carers and to test, refine and where necessary adapt the ACCOM for use with specific groups of consumers would also be of value. Incorporating the Carer ASCOT into the ACCOM suite of tools would provide a mechanism for capturing carer outcome data for those who provide unpaid care to family members, partners and friends. Such a move would provide a more comprehensive picture of the impact of services on both clients and carers. This could cover issues of linguistic and cultural diversity, especially ensuring that the ASCOT component of the tool is available in other languages for consumers who have difficulty with English, Aboriginal and Torres Strait Islander people. Given the increasing numbers of consumers with cognitive impairment issues, there is also recognition of the need to develop strategies to target them more effectively. Equally important, the views of carers were considered by CMs as significant given their critical role in the care relationship and knowledge of consumers' needs and care issues.

iii. Develop Means for Extending the Adoption of the ACCOM more Extensively

While this ACCOM has been demonstrated as suitable for use in future research on community care, its potential as a tool for practical use in community care services would be significantly enhanced if it is used on an industry basis. While the actual form that such a development would take is beyond the scope of this report, a range of different options could be considered. Perhaps the most attractive proposition to be considered to date is the development of an industry run and controlled program in collaboration with an independent academic unit responsible for staff training and education, as well as ongoing measurement and data analysis. Such an approach would enable further refinement and development of the tool, as discussed above, while also ensuring ethical integrity of the system and a concern for effective and efficient operation.

Last Words

This study has clearly demonstrated both the need for and the practical potential of the existing ACCOM instrument. While further options for the development of such an innovation are required, the real challenge is moving from the stage of field trials to implementation. This challenge is one that goes beyond research. It must, necessarily, extend to the take up of the instrument by practitioners and consumers. Such an engagement with service providers concerned with introducing meaningful ways of developing service provision beyond the rhetoric of choice and quality to seek real means for improving the delivery of care to those who need assistance to remain at home and to participate in the life of the community will, in turn, lead to further development of the technology of review and reporting.

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