Collaboration, Context and Cost: A realist-informed process evaluation of a quality improvement collaborative to improve dementia care in Australia

by

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ABSTRACT

With increasing numbers of people living with dementia worldwide, there is an urgent need to support people with dementia to live as well as possible. While evidence exists for treatments to improve the quality of life of people living with dementia and their caregivers, they are not routinely offered in clinical practice. This gap between research and practice means that poor quality or inconsistent treatment is offered in dementia care and results in the underutilisation of research effort.

The aim of this research is to examine the feasibility and acceptability of the trial of a quality improvement collaborative strategy to understand how, why, in what circumstances and at what cost it worked (or not) to improve adherence by clinicians to clinical guidelines for dementia. This evaluation of the implementation process examined three questions: how the implementation strategy works to build knowledge and skills in clinicians to improve dementia care,what value is added by the involvement of people with dementia and caregivers in the research and what costs and benefits that accrue from the strategy. By considering how context, collaboration efforts, and costs can influence outcomes, this research developed an understanding of the mechanisms of the quality improvement collaborative strategy in dementia care.

Methods

A realist-informed process evaluation, using mixed methods, examined the experience of clinicians and experts-by-experience of dementia involved in the trial, to identify mechanisms of the strategy. A cost-benefit analysis identified the resources required to improve practice and a business case for future use of the strategy.

Results

The 28 clinicians involved in the evaluation of the trial found the quality improvement strategy enabled them to make changes in practice. By overcoming pessimism about the benefits for people with dementia and resistance to change by others, the quality improvement collaborative strategy gave clinicians confidence in a credible process. With expert advice and coaching most clinicians were able to implement change in their practice and involve others in changes. Experts-by-experience ofdementia made contributions at all stages of the research trial. The evaluation found that their perspective improved the relevance of the research and their involvement convinced clinicians that the clinical guidelines would meet the needs of people living with dementia. The strategy was found to be cost-beneficial if 150 clinicians participated and this provided a business case for the reuse of the strategy in future.

Conclusion

The evaluation of the trial of the quality improvement collaborative to improve adherence to evidence-based guidelines in dementia care found it both acceptable and feasible to clinicians. A refined program theory showed that supportive reflective practice, a credible and flexible process empowered clinicians to overcome constraints and attitudes about routine practice in dementia care. The involvement of experts-by-experience of dementia added perspective and focus on priority needs which benefited the clinicians and the research. The resources required for the collaborative strategy were cost-beneficial when scaled up to includemore clinicians. Lessons learnt from this research may be applied to up-scale the collaborative strategy to improve the quality of post-diagnostic dementia care.

DECLARATION

I certify that this thesis does not incorporate, without acknowledgment, any material previously submitted for a degree or diploma in any university; and to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

This research was embedded in the Agents of Change research project which trialled the use of a quality improvement collaborative to improve adherence to clinical dementia guidelines for dementia. The trial was funded by the National Health and Medical Research Council Cognitive Decline Partnership Centre (grant no: GNT9100000) and a NHMRC Boosting Dementia Research Grant (APP1135667). The research trial objectives and investigator team were established when I commenced my candidature.

I was responsible for addressing three of the five objectives of the larger research trial. I designed the process evaluation, the theoretical approach, the methods for data collection and analysis, contributed to the ethics application for the trial to incorporate consent for the evaluation and interview guides (Southern Adelaide Clinical Human Research Ethics Committee (HREC/17/SAC/88), the assessment of value added by involvement of experts-by-experience of dementia in the trial, a full ethics application for that study (SBREC no: 8057) and the design and conduct of the economic evaluation. I contributed to the design of the online surveys of participants, extracted data from the trial platform, analysed the surveys and devised an activity costing method. I recruited participants from the trial for the evaluation, completed participant interviews, collected, and analysed the data, then wrote the evaluation study results and conclusions. I was included in the research team and contributed to regular meetings of the management committee. I reported on progress with the evaluation and provided feedback on issues affecting participants and experts-by-experience of dementia in the trial. I contributed to several publications by the research team and wrote articles for publication.

The results of the process evaluations and the economic evaluation directly contributed to the Agents of Change research trial and provided evidence for theory about how implementation strategies and the involvement of experts-by-experience of dementia contribute to research.

Signed: 

Lenore de la Perrelle

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To my children who inspire me with hope for the future.

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CONFERENCE PRESENTATIONS

International Conferences

de la Perrelle, L. *et al.* "*Can Quality Improvement Collaboratives improve adherence to clinical guidelines for dementia care"* concurrent oral presentation. Global Implementation and Evaluation Summit (GIES), Melbourne, October 2018

de la Perrelle, L. et at. *What works? A process evaluation of translation of dementia care guidelines into practice*. concurrent oral presentation at 34th International Conference of Alzheimer's Disease International, Singapore, March 2020, rescheduled to December 2020 due to COVID 19.

de la Perrelle, L. *et al. Valuing Expert Experience: involving people with lived experience of dementia and care partners in translational research*. poster presentation at 34th International Conference of Alzheimer's Disease International, Singapore, March 2020, rescheduled to December 2020 due to COVID19.

de la Perrelle, L. and Gladstone, I. *Involvement of people with dementia and caregivers in Agents of Change research trial.* oral co-presentation at Public Involvement in Health Service Research International Symposium, Sydney, February 2019.

National Conferences

de la Perrelle, L. *et al. Valuing expert experience: involving people with lived experience of dementia and care partners in translational research.* oral presentation at Theo Murray Australian Frontiers of Science Symposium, Redefining Healthy Ageing Together, Adelaide, April 2019.

de la Perrelle, L. *et al. Are quality improvement collaboratives cost effective in translating research to practice? A systematic review.* poster presentation at NHMRC National Institute of Dementia Research Australian Dementia Forum, Hobart, July 2019.

de la Perrelle, L. *et al. Valuing expert experience: evaluating the involvement of people with dementia and care-partners as expert advisors in Agents of Change research*. poster presentation at NHMRC National Institute of Dementia Research Australian Dementia Forum, Hobart, July 2019.

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de la Perrelle, L. *et al. Context, Collaboration and Costs: evaluation of an implementation strategy to improve dementia care in Australia*" oral presentation accepted for Evidence and Implementation Summit, Sydney, March 2021.

Local Conferences

de la Perrelle, L**.** *Residential care for people living with dementia: rethinking models.* oral presentation at Australian Association of Gerontology SA Division conference, Adelaide, July 2018.

de la Perrelle, L. *et al. Evaluating what works: Clinical guidelines into practice.* poster and oral presentation at DocFest, Flinders University, Adelaide, August 2018*.*

de la Perrelle, L. *et al. Can Quality Improvement Collaboratives improve dementia care?"* poster presentation at Emerging Leaders Showcase, College of Medicine and Public Health, Flinders University, Adelaide, November 2019.

de la Perrelle, L. *et al. Connecting people with dementia, researchers, and clinicians in translational research* oral presentation awarded the Gary Andrews Student Award for best presentation at Australian Association of Gerontology SA Division conference, Adelaide, July 2019.

de la Perrelle, L. *et al. Translating evidence-based guidelines into dementia care. What implementation strategy works?* poster presentation at DocFest, Flinders University Adelaide October 2020.

de la Perrelle, L. *et al. Building Knowledge and Skills in clinicians working with people with dementia.* poster presentation cancelled due to COVID19, Emerging Leaders Showcase College of Medicine and Public Health, Flinders University, Adelaide, November 2020.

DEFINITIONS, ABBREVIATIONS AND ACRONYMS

Definitions

In this thesis the following terms and definitions are used:

Dementia

The World Health Organisation defines dementia as a chronic or progressive condition involving deterioration in cognitive function (i.e. the ability to process thought) It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (1)
Dementia results from a variety of diseases and injuries that affect the brain, such as Alzheimer's disease or stroke and is one of the major causes of disability, dependency, and death of older people worldwide.

Implementation Science

Implementation science is the scientific study of methods to improve the use of evidence in routine health care practice and policy (2).

Quality Improvement

Quality Improvement is the scientific approach to achieve better patient outcomes and experience through changing organisational behaviour and systems (2).

Quality Improvement Collaborative

A Quality Improvement Collaborative is a method to improve the quality, safety, and efficiency of healthcare, where teams from multiple organisations come together in a structured way to share lessons and improve the delivery of services. The process involves a topic of improvement being specified and then clinical and quality improvement experts providing advice for improvement to multi-disciplinary teams who undertake activities to identify gaps, set goals and test out planned changes in their setting (3).

People with dementia/ living with dementia and their family members or unpaid caregivers

The Dementia Australia language guidelines promote the consistent use of inclusive language when referring to a person with a diagnosis of dementia and their family members (4). The terms ‘people with dementia’ or ‘people living with dementia’ are used throughout this thesis. A family member or friend providing support is referred to as a caregiver in this thesis.

Public and patient involvement

This term refers to the involvement of members of the public and people using healthcare services in advising or improving those services. When used in relation to research, it means research ‘with or by’ members of the public rather than being ‘to, about or for’ them as defined by INVOLVE in

United Kingdom p.6 (5).

Experts-by-experience of dementia
This term was coined to define the people living with dementia and family members who provide support to a person with dementia, who were engaged in the Agents of Change research trial (6) as expert advisors to the researchers and clinicians, on priorities, learning materials, improvement plans and plans for dissemination of findings from the research.

Theory-driven/ theory-informed evaluation
This term refers to the prospective use of realistic evaluation methods to identify and test a program theory for quality improvement collaboratives, linking to mid-range implementation theories and the broader theories of social science for analysis.

Context
Used interchangeably with the term 'setting' in the literature, this term refers to the three levels of environment in which healthcare operates and into which clinicians and interventions are introduced. The micro level of patient influence, the meso level of organisational structures and climate, and the macro level of broader external influences.

Setting
Used interchangeably 'with context' in the literature, but here 'setting' refers to the local service system in which the clinician works.

Ontology
Used to describe the nature of the real world, what actually exists in the world about which we can acquire knowledge.

Epistemology
Used to describe the study of knowledge, what we can know about the world and the limits to our knowledge.

Methodology
Used to describe the strategy and basis of the research approach and the specific methods used.

Abbreviations and Acronyms

The following abbreviations and acronyms have been used in this thesis.

ACE Inhibitor: Angiotensin-converting enzyme inhibitor

AUD: Australian Dollars

CDPC: Cognitive Decline Partnership Centre

CHEERS: Consolidated Health Economic Evaluation Reporting Standards

CEA: Cost Effectiveness Analysis

CER: Cost Effectiveness Ratio

CUA: Cost Utility Analysis

DALY: Disability Adjusted Life Year

DRM: Dominance Ranking Matrix

€: European Euros

EQ-5D 3L: European Quality Group 5 dimensions 3 levels measure of quality of life

EVERS CHEC-List: Consensus on Health Economic Criteria checklist by Evers *et al.*

ICER: Incremental Cost Effectiveness Ratio

IHI: Institute for Healthcare Improvement

JBI: Johanna Briggs Institute

MeSH: Medical subject Search Headings

NHMRC: National Health and Medical Research Council

NDRI: National Dementia Research Institute

PPI: Public and Patient Involvement

PRISMA: Preferred Reporting Items for a Systematic Review and Meta-Analysis of Diagnostic Test Accuracy Studies

QALY: Quality Adjusted Life Year

QI: Quality Improvement.

QIC: Quality Improvement Collaborative

QoL: Quality of Life

UK: United Kingdom of Great Britain

US/USA: United States/United States of America

CHAPTER 1 INTRODUCTION

1.1 Introduction

This thesis examines an applied knowledge translation project seeking to achieve better care by improving adherence to clinical guidelines for dementia. By investigating the implementation process this research provides an understanding of how, why, under what circumstances and at what cost a quality improvement collaborative (QIC) built skills and knowledge in clinicians to improve dementia care. It identifies the contribution made by people with dementia and caregivers to the research process. It addresses a significant gap between what is known about evidence-based practice and effective implementation strategies in dementia care. Using a realist-informed process evaluation and an economic evaluation, it also builds theory to identify the mechanisms at work in the collaborative strategy that reinforce the motivation and skills of clinicians to improve practice, and the resources required to further implement improved dementia care.

1.1.1 Thesis aim and research questions

The aim of this research is to examine the feasibility and acceptability of the trial of a quality improvement collaborative strategy by identifying how it worked (or not) to improve adherence by clinicians to clinical guidelines for dementia.

The objective is to evaluate the process of a quality improvement collaborative to understand how the implementation strategy works and to identify contextual influences and mechanisms of change that build knowledge and skills in clinicians to improve dementia care.

The research questions are:

1) How, why and in what circumstances could a quality improvement collaborative build knowledge, skills and acceptance of clinicians who were participants? (Chapters 5 and 6).
2) What was the value of involving people with dementia and caregivers as expert advisors in the quality improvement collaborative? (Chapter 7).
3) What were the costs and benefits of the quality improvement collaborative aiming to improve dementia care? (Chapters 8 and 9).

The hypothesis to be tested is that the context, collaboration processes and the cost-benefit of a quality improvement collaborative can influence the building of clinicians' skills and knowledge in quality improvement in dementia care.

1.1.2 Need for this research

Improving and maintaining wellbeing as much as possible given the progressive condition, is the goal of much dementia care (7). Evidence-based, non-pharmacological interventions are known to

improve health and wellbeing for people with dementia and their caregivers, yet they are not routinely or consistently available. Access to post-diagnostic treatment by people with dementia and caregivers, depends on the extent that clinicians integrate that evidence into their practice (8).

The gap between evidence and practice in dementia care remains despite dissemination of guidelines, staff training and the existence of quality standards. This gap between research and practice results in the under-utilisation of research effort and poor quality or inconsistent treatment being offered to people living with dementia.

Given the increasing prevalence of dementia in an ageing population in Australia (9) and worldwide (10) there is an urgent need to improve the quality of dementia care. However, the process of implementing evidence has proven to be more complex than simply delivering the knowledge. Implementation strategies that can be adapted to various settings and use multiple learning strategies to build relationships and workplace change are needed to improve dementia care .

Quality improvement collaboratives have been used in healthcare for over 20 years to improve the uptake of clinical guidelines across a range of conditions such as diabetes, Parkinson's disease, and mental health (3). Evaluations have identified factors that contribute to successful outcomes which can improve design of collaboratives. They have shown modest improvements in practice in community care, outpatient clinics, hospital and long-term care (11, 12). However, few examples have been used to improve dementia care across the range of settings where interventions are offered. Fewer still have examined the costs of the investment in collaboratives.

This thesis examines the use of a 'light touch' quality improvement collaborative to build knowledge and skills in clinicians to improve dementia care across Australia. Lessons learnt from this work add to program theory for quality improvement collaboratives to inform how to spread implementation of evidence-based practice to geographically dispersed clinicians who work in a range of settings of dementia care.

1.2 Background

1.2.1 Approach to this research

Implementation science promotes implementation of evidence-based knowledge can be translated into healthcare practice through the use of various implementation strategies (13). The aims of implementation science identified by Grol and Grimshaw (14), include: understanding the characteristics of the evidence, identifying the barriers and facilitators for change, and examining ways to improve the effectiveness of implementation strategies. To date much of the research focus in dementia care has been on identifying the barriers and facilitators for the implementation of evidence-based guidelines. Understanding how and why barriers occur in different contexts is

the next step in improving the effectiveness of implementation strategies. A theory-based approach has been proposed (15) to better identify effective strategies and to understand how processes lead to outcomes. The developing use of a realist review approach in implementation studies focuses on understanding how and why the context of implementation interacts with interventions to generate outcomes (16). This approach can be used to gain a deep understanding of complex social interventions when implementing public health programs across regions. Despite the growing interest in using realist methods to evaluate healthcare and social programs, very few studies have applied these methods to implementation strategies for evidence-based guidelines in dementia care.

1.2.2 Context and settings

Dementia care in Australia is delivered by clinicians working in a range of organisations, geographically spread across cities and in regions with low population base. Clinicians work with people with dementia in public hospitals, outpatient clinics, rehabilitation services, as well as in community aged care services, long term residential care, private allied health organisations, and as sole providers in private practice. In Australia, public health services are funded primarily by state governments and aged care (community and residential) is funded by the federal government. Private hospitals and private allied health services are subsidised by optional health insurance policies held by individuals. Aged care and healthcare in Australia have been characterised by change over the last two decades (17). *Figure **1*** presents a summary of the recent policy influences.

With major policy and funding reforms since 2014, and ongoing reviews, the aged care sector has responded with changes to their organisational structures, the services provided and operating processes. New quality accreditation standards were introduced in 2019 (18) for funded aged care services and a commission of inquiry into the quality and safety of aged care commenced in 2018 (19). These changes have required many organisations and clinicians to focus on developing new approaches to accreditation and in providing evidence to the commission. Funding of aged care services changed in 2017 from allocation to aged care providers to individual budgets for older people, adding a market style approach to service provision and competition amongst providers (20).

The policy context of the public hospital system in Australia is characterised by negotiation of joint funding by state and national levels of government to improve performance. Productivity Commission reviews in 2015 and 2018, on the public hospital system, provide a focus on efficiency and recommendations for implementation of clinical guidelines to improve clinical and cost effectiveness (21, 22). This focus on funding and efficiency was intended to drive quality improvement.

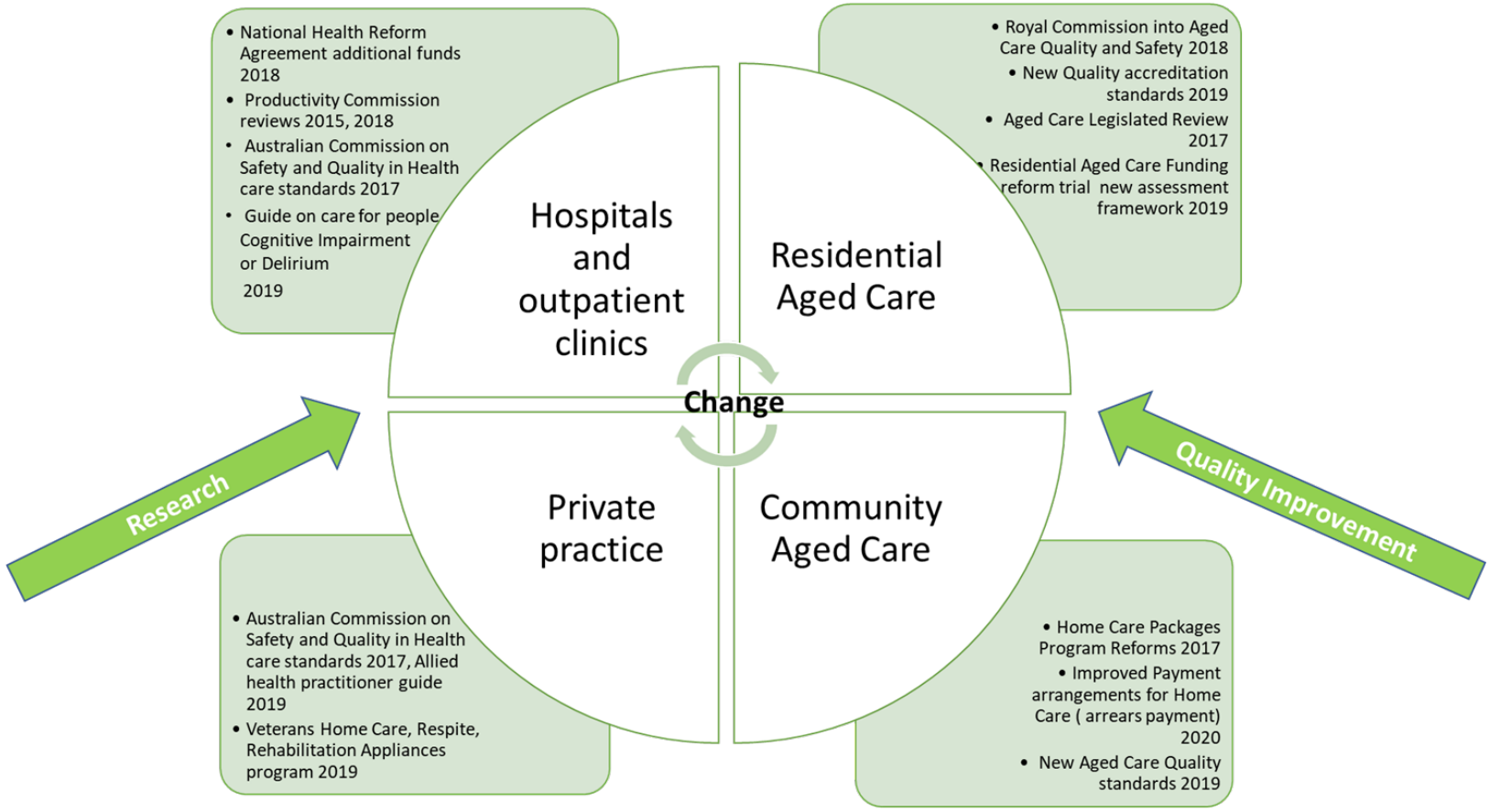

Figure 1 Contextual changes and reforms affecting organisational contexts of clinicians working with people with dementia

1.3 Scope of this thesis

This thesis evaluates the process and costs of a collaborative implementation strategy in dementia care in Australia between 2018-2019. The process evaluation and economic evaluation were embedded within a larger translational trial to assess feasibility and acceptability of the implementation strategy to improve adherence to Australian Clinical Practice Guidelines for Dementia Care (6). The evaluation was undertaken by the author to improve understanding of how, why, and in what circumstances a quality improvement collaborative worked (or not) to build knowledge and skills for clinicians in quality improvement.

1.3.1 The 'Agents of Change' trial

The translational trial, named 'Agents of Change', aimed to increase adherence to three key recommendations from the Australian guidelines (23):

1) Occupational therapy should be offered to people living with dementia in the community.
2) People with dementia should be strongly encouraged to exercise.
3) Carers and family of people with dementia should have access to programs of respite and support to optimise their ability to care for the person with dementia (6).

It used a quasi-experimental time series design to measure changes in adherence to clinical guidelines over time by the clinicians participating in a quality improvement collaborative. The protocol is at Appendix 1. The trial focused on implementation outcomes of objectives 1) and 2):

1) Developing and delivering a quality improvement collaborative for clinicians to improve their practice with people living with dementia and caregivers.
2) Evaluating adherence to clinical care guidelines for dementia care by participant clinicians, and sustainability of improvements.
3) Evaluating the process of the quality improvement collaborative and how it built knowledge, skills, and acceptance of participants.
4) Identifying the value of involving people with dementia and caregivers as expert advisors in the quality improvement collaborative.
5) Identifying the cost benefit of a light-touch approach to quality improvement collaboratives to improve dementia care.

The evaluation of the trial examined in this thesis focusses on objectives 3), 4) and 5). Rather than identifying if the process worked, this thesis examines how, why, and under what circumstances does the process work to improve clinical practice in dementia care and what are the costs required to achieve the improvement. This approach to the evaluation was developed by the author to understand the influence of context, collaboration, and cost on the quality improvement collaborative

strategy, to build theory of how the strategy works (or not) and the resources required to achieve changes in dementia care.
Participants in the process evaluation and economic evaluation studies for this thesis were a sub-sample of participants in the Agents of Change trial.

Participant clinicians in the trial were from all states and settings, including public hospitals, outpatient clinics and rehabilitation programs, community and residential aged care services and private allied health practice, were recruited to engage in collaborative learning to implement quality improvements in their setting. They represented a range of professions including physician, dietician, physiotherapist, occupational therapist, clinical nurse consultant, social worker, and health services professional. All were clinicians experienced in working with people with dementia in their routine practice. Each clinician selected one of the recommendations to implement in their own setting and consequently three sub-groups were formed. A purposive sub-sample of the trial participants, covering all types of settings, clinicians, and locations, were invited to participate in the process evaluation (Study 1 part A and B).

People with dementia and caregivers were recruited as experts-by-experience of dementia to be involved in the trial in a number of roles. They were advisors to identify priorities, as part of the investigator group and management committee to guide the research, to review content of learning modules, to review and provide feedback on improvement plans and to disseminate theresearch. . These participants were invited to participate in an evaluation of their experience and contribution in the trial (Study 2).

1.3.2 Process and economic evaluation of the trial

The evaluation sought to identify the feasibility and acceptability, and the costs and benefits of thetrial of a quality improvement collaborative strategy and to identify the resources required to improve practice in dementia care. A process evaluation examined how, why and in what circumstances the quality improvement collaborative built knowledge and skills in clinicians to improve practice and the value added by involving people with dementia and caregivers in the research. Mechanisms of change were identified which could inform further use of this collaborative strategy to improve dementia care.

An economic evaluation examined the costs and benefits of the quality improvement collaborative as a strategy to implement clinical guidelines in dementia care. The clinicians and experts-by-experience of dementia who were involved in the trial, participated in the process evaluation and the clinicians also provided an assessment of benefit for the economic evaluation.

1.4 Ontology and Epistemology

This thesis sought to understand how, why, in what circumstances and at what cost the complex contextual and social processes generated change in the knowledge and skill of clinicians participating in the collaboratives to improve theirpractice. As this approach differed from the trial methodology, a Critical Realist ontology (24, 25) was chosen by the author to understand the real world and the relationship between human agency and social structure to explain why things occur in implementation and how they are related. This theory-driven approach offers the opportunity to examine the unseen mechanisms in the external and internal contexts that generate outcomes of the collaborative strategy used to build knowledge and skills in clinicians. A realist evaluation epistemology then informed the process evaluation.

A layered framework of existing implementation theories was developed by the author to guide the data collection and analysis. Mixed methods were used to gather data to identify mechanisms of changefor participants, to quantify the costs, the level of knowledge and skills gained, and the change in understanding of the processes involved in normalising a change in practice.

The methods of realistic evaluation (26) draw on a realist ontology and informed the process evaluation approach. A retroductive approach, combining inductive, deductive and researcher insights to data analysis allowed an understanding of what lay behind themes identified in the data (27) Integration of the knowledge gained from the different methods provided an opportunity to consider alternative explanations (28). The rationale for this choice is provided in the theoretical framework in Chapter 3

An economic evaluation draws on a positivist ontology of Rational Choice theory and an epistemology to monetise the costs and benefits (29) to attribute value of the collaborative strategy. This approach to compare costs and benefits was used to focus on the economic mechanisms (30) to identify the resources required in the collaborative to generate change and to propose a business case for investment in implementation strategies.

1.5 Outline of the thesis

This thesis is divided into three main parts:
1) the Literature Review (Chapter 2), Theoretical Framework (Chapter 3), and Methodology (Chapter 4)
2) Studies 1, 2, and 3 (Chapters 5-9), and
3) the Discussion and Conclusion (Chapter 10).

1.5.1 Part 1

1.5.1.1 Literature review

Chapter 2 reviews the literature on the three main areas of focus in this thesis. The literature on the translation of knowledge into practice and development of implementation science in healthcare is explored to identify how that has been applied to clinical guideline uptake in dementia care. Understanding the scope and limits of knowledge in implementation science and the influence of context on outcomes, provides insights into the approaches needed to study the process of a quality improvement collaborative.

The involvement of the public and patients in healthcare research is identified as both a moral and democratic ideal for research. The literature on the involvement of people with dementia and care partners as co-researchers is examined to understand the impact this has on dementia research, on researchers and on the people themselves.

Economic evaluation of healthcare improvements has become an important consideration in research. The literature on ways to identify costs and benefits and how they apply to collaborative improvement strategies and dementia care is reviewed to identify the approaches that have been used and how they contribute to implementing evidence into practice in health care.

1.5.1.2 Theoretical framework

Chapter 3 presents the theoretical framework applied in this study. A realist philosophy of science is used to understand the social processes in complex interventions. Methods that identify the influence of the context and resources of the intervention to generate mechanisms and outcomes, inform the process evaluation of the collaborative strategy.

1.5.1.3 Methodology

Chapter 4 describes the mixed methods used for undertaking the theory-driven evaluation and the cost-benefit analysis.

1.5.2 Part 2.

In Part 2 are the five chapters describing the studies undertaken in this thesis

1.5.2.1 Study 1

Chapter 5 presents Study 1-part A: the pre-intervention process evaluation to identify the expectations, motivations, and interest of clinicians in participating in the quality improvement collaborative to implement clinical dementia care guidelines.

Chapter 6 presents Study 1-part B: the post-intervention process evaluation identifies how, why and under what circumstances quality improvement collaboratives build skills and knowledge to improve dementia care. This study evaluates the experience of the clinicians after their participation in the collaborative.

1.5.2.2 Study 2

Chapter 7 presents Study 2: the evaluation of the involvement of people with dementia and caregivers in this research and how the experts-by-experience of dementia added value to the collaborative process.

1.5.2.3 Study 3

In Chapter 8, Study 3-part A, presents a systematic review of the costs and cost effectiveness of quality improvement collaboratives to identify how the relationship between costs and effectiveness of collaboratives has been studied. The nature of costs identified in these studies informed the cost-benefit analysis undertaken in this thesis.

Chapter 9 presents Study 3-part B: the cost benefit analysis of the quality improvement collaborative to identify the costs incurred, the benefits identified, and the numbers of participants needed to participate to provide a return on investment

1.5.3 Part 3

1.5.3.1 Discussion and Conclusion

In the final part of the thesis (Part 3), Chapter 10 presents a discussion of the findings from the three studies and compares results with other studies to identify significance and limitations of the findings. It concludes the thesis outlining the implications of this research and recommendations for future implementation and research.

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction

Given the increasing numbers of people living with dementia worldwide there is an urgent need to implement known evidence into practice to support people with dementia to live as well as possible. This review describes dementia and what we have learnt to date from implementing evidence-based practice in dementia care settings. The review then describes knowledge translation, implementation science, and quality improvement. Theories to be used in this research are identified and described. Specific challenges for implementing evidence-based practice in dementia care are described. The review concludes by describing recent literature in relation to patient and public involvement in research and economic evaluation of implementation studies.

2.2 Understanding dementia and care provision

2.2.1 Dementia

Dementia is a global public health priority, with over 50 million people living with the condition and primarily relying on family and friends to provide care (10). It is a progressive, terminal, neuro-degenerative syndrome with over 100 known causes, and no cure currently. It causes disability and dependency in older people worldwide and a significant impact on the person with dementia and their families and caregivers (31). Dementia cost over US$ 800 billion globally in 2015, with significant increases expected to strain healthcare (1). In Australia it is the leading cause of death in women and the third cause of death for men (32). While dementia is not an inevitable result of ageing, the risk of developing dementia increases with age. With an ageing population worldwide, a marked increase in the prevalence is expected (1).

Despite variations due to disease and co-morbidities in individuals, dementia is characterised as having three stages: early-stage, middle-stage and late-stage (33). In early stage the impact of symptoms is mild, and the person can live with minimal assistance. In mid-stage, the symptoms interfere with daily functions and increasing levels of assistance are needed. In late-stage, symptoms are severe, and people become totally dependent on care.

Dementia is complex to treat due to progressive effects across many domains of function over an average of 10 years. Dementia commonly causes progressive impairments in cognition, memory, judgement, orientation, and worsening of other physical or psychiatric illnesses (34). Common symptoms include 1) memory loss that interferes with the ability to plan and carry out regular activities, 2) confusion and disorientation, requiring increasing support and reassurance from caregivers,3) problems with thinking which reduce ability to perform tasks or handle money, 4) mood changes including apathy, anxiety, depression and delusions, 5) behavioural changes which

may include repetitive behaviour, agitation, sleep disturbance and risk-taking (33). Dementia effects the person by loss of abilities and increasing dependence on others for all daily living tasks. Family carers become distressed by the decline and the need to support their partner or family member. Often partners are ageing and have health related conditions as well (34). Over time, more assistance is required and usually partners or family are no longer able to provide the level of physical assistance, behavioural and mood support needed. The use of long-term care is often prompted by caregiver exhaustion or severe behavioural or psychological symptoms. The complexity of dementia is compounded by stigma, fragmentation of services and costs of providing care.

2.2.2 Dementia care

Stigma and misunderstanding about dementia, can cause delays in seeking diagnosis and treatment, shame, or in many cases, a belief that there was nothing that could be done about it (35, 36). Stigma and a sense of 'therapeutic nihilism' has contributed to ineffective care in many parts of the world (37, 38).

A fragmented health and aged care system (39) necessitates coordination of care, yet no system orservice adequately provides in Australia. There are barriers between services with different fundingsources and poor quality of care when dementia is not recognised or considered amenable to treatment (39). Yet timely diagnosis and continuous post-diagnosis support and treatment are known to improve quality of life and enable people to live as well as possible (40). There is also potential to reduce costs by reducing or delaying admissions to acute and long-term care (41).

Despite the expected progressive deterioration in function there is evidence that reablement focused interventions can delay decline and optimise independence and quality of life. Meta-analyses demonstrate that exercise programs can improve the ability of people with dementia to perform their daily activities (42) and may delay cognitive decline (43). Occupational therapy programs can improve the ability of people with dementia to perform daily tasks, reduce behavioural symptoms and improve quality of life for caregivers (44). Caregiver interventions can improve caregiver wellbeing and reduce dependence and symptoms of the person with dementia in the short to mid-term (45). Through focusing on keeping the person in good physical condition, applying strategies to promote independence, modifying the environment and training caregivers it is possible to improve quality of life and delay decline. These types of interventions are recommended by Alzheimer's Disease International (40) and in Australian Clinical Practice Guidelines for Dementia.

The Clinical Practice Guidelines for Dementia in Australia (23) provide evidence-based recommendations for the assessment, diagnosis, and care of people with dementia and caregivers. The Guidelines promote a 'reablement approach' to post diagnostic care to maintain

functions and adapt to decline through non-pharmacological interventions (46). People with dementia and caregivers contributed to the Guideline development process and identification of priorities for implementation. Their perspective contributes to the relevance and validity of research (47) and improvement of services to meet the needs of people with dementia. However, guideline dissemination does not necessarily bring about change or lead to quality improvement.

2.3 Understanding the evidence to practice gap in dementia care

2.3.1 Evidence to practice gaps in healthcare

Despite increased investment in dementia research, an increasing number of high-quality studies and the existence of clinical practice guidelines in many countries, gaps in dementia care exist. This is not unique to dementia care. One of the most concerning issues in healthcare research is the gap between the evidence for effective treatments and what is offered in routine clinical practice (14, 48, 49). Improvement in healthcare has been driven by safety concerns (50), the development of new technology, and evidence from research on new healthcare approaches. The synthesis of clinical guidelines from research evidence has been a common approach to guide practice and assess quality in healthcare (14). However, the process of translating evidence into practice has proven to be more complex than simply delivering the knowledge through clinical guidelines and education. Improved healthcare interventions involve the interaction of multiple factors, such as policy, funding, service systems and processes, and human interactions at all levels (51). Making changes to practice requires buy-in from across staff teams, the resources, and structures to make the changes and a belief that the changes will improve outcomes for staff and the people who use services.

A recent systematic review by Lau and colleagues identified many causes of the evidence to practice gap for complex health interventions in primary care (52). The factors included the external context of policies, the organisational context and culture, availability of resources, the nature of relationships, professional roles, and philosophy across teams and organisations. The intervention itself can be a factor, its perceived benefit, ease, and adaptability will affect uptake. This review highlights the importance of the context in which evidence is to be introduced and the need to understand the interactions and relationships between the systems and the people working within them.

2.3.2 Specific barriers and enablers to evidence-based practice in dementia

The delivery of evidence-based dementia care remains challenging for clinicians due to several different barriers. Insufficient availability of time and assistance, a lack of focus on dementia specific interventions and lack of confidence were identified by clinicians for low adherence to recommendations from clinical guidelines in Australia (53).

Draper and colleagues (54) identified a poor profile and low status in aged care which reduced the interest of clinicians in dementia care. Gaps in knowledge and training for aged care staff and low levels of training in dementia care strategies, increase reliance on medications to modify behaviours (55). Services lack funding and the required leadership to translate evidence into practice to suit their setting (56, 57). Clinicians lack support in their workplace and mentoring to undertake changes to practice (8). The general community and their doctors do not know of effective treatments or where to access them. The health and aged care services are fragmented into a range of agencies, with complex assessment and eligibility criteria and inequity in services (58). Overcoming these barriers requires complex and multi-modal strategies to motivate change. Strategies such as tailoring evidence-based practice to the context, identifying interventions that are easy to implement, developing partnerships between researchers, policy makers and service providers and adequate funding, can create service wide acceptance of practice change, and link practice change to outcomes for the service and the people living with dementia (8, 57).

In dementia care in Australia, understanding complexity is essential to identifying how to improve clinical care. *Figure **1*** summarises four different settings, each with different funding and criteria for eligibility for services. There are multiple organisations and professionals providing care to people living with dementia across national (59) and state levels (60). People receive treatment for dementia and their other health conditions in hospitals, from their local general medical practitioner, in aged care services and through private practitioners. A lack of consistent pathways of care for people with dementia in geographically dispersed, low population services compound the complexity of delivering improvement in post-diagnostic dementia care.

Strategies are needed to support changes in practice that can be adapted to the different settings and roles of clinicians in dementia care (8). Planning for both improved clinical interventions and a strategy for spread is considered necessary for better uptake of clinical guidelines across dementia care (61).

2.3.3 Knowledge translation, implementation science and quality improvement

A range of models and frameworks have been used in healthcare to improve the use of evidencein practice. These include knowledge translation (62) implementation science (63) and quality improvement (2). While terms used in this developing field overlap, the following definitions provide a guide to how they are understood.

2.3.3.1 Knowledge Translation

The knowledge translation approach to bridging the evidence to practice gap involves the translation of best available knowledge from research and integration of that knowledge with clinical expertise and patient needs (64). Knowledge translation is described as an iterative process that includes guideline dissemination and the application of knowledge to engineer change

in organisations and professionals (62). Examples include the Knowledge to Action framework (K2A) (65, 66) and the Canadian Institutes of Health Research (CIHR) model of Knowledge Translation (KT) (67) where facilitation processes support change.

A recent overarching framework uses the term 'translational science', a broad problem-oriented practical process of turning knowledge into interventions to improve public health (68). This goal suggests the drivers are from research rather than from public needs or the healthcare system where quality improvement, safety and access dominate many of the priorities.
Kitson (69) has proposed 'KT Complexity Network' as a meta-term to describe the process as problem identification, knowledge creation, knowledge synthesis, implementation, and evaluation. This organisation of types of study assists in clarifying the area of focus for this research and location of the literature in the field. The topic of this research falls most clearly within the implementation and evaluation subsets as the knowledge creation and synthesis aspects (development of clinical guidelines) (23) have preceded this current research.

2.3.3.2 Implementation Science

Implementation science is defined as the study of strategies to promote the systematic uptake of research findings and evidence-based practice into routine use, to improve the quality and effectiveness of health services (63, 70). By addressing factors that affect the uptake of evidence, implementation science engages with the context of the healthcare system (70) to increase adherence and generalise knowledge to be applied widely (63).

Three main aims in implementation science were identified by Grol and Grimshaw as; a) understanding the characteristics of the evidence, b) identifying the barriers and facilitators to change and c) improving the effectiveness of implementation strategies (14). Implementation strategies are defined as a set of integrated interventions designed to address multiple barriers and include education of clinicians, promoting teamwork, and supporting systems change (63). This reflects the need to focus implementation efforts at different layers of services and systems and the use of a range of techniques. Research has until recently focused on identifying barriers and enablers of implementation (71), identifying determinants of success or failure to translate knowledge into practice (72, 73). Enablers that have been identified across studies included motivation of healthcare workers, multidisciplinary teams, and local managers' support, while low trust of staff in organisational hierarchies, lack of time and resources acted as barriers to implementation. This provides information to design better multimodal strategies to improve healthcare.

2.3.3.3 Quality Improvement

Quality improvement is defined as the scientific approach to achieve better patient outcomes and experience through improving organisational behaviour and systems (2). This focus on improving the systems requires a continued effort of all people involved (health professionals, administrators,

patients and families, researchers, and funders) to make changes that lead to better health outcomes, care and learning (2). By collaborating in quality improvement, efforts can be coordinated and shared. Quality Improvement Collaboratives have been used widely to implement evidence-based guidelines into practice in healthcare. This collaborative approach developed by the US Institute for Healthcare Improvement in 1995 was designed to bridge the "gap between what we know and what we do" p.1 (74). By combining experts in specific clinical areas with quality improvement experts, clinicians from a range of organisations come together to learn from each other and plan changes over time to suit their settings. The use of a production model cycle of change, described as Plan-Do-Study-Act (PDSA) (75), Model for Improvement (76), tests planned changes to processes and tracks progress to make and embed changes. See *Figure **2***

Figure 2 The model for improvement using the Plan-Do-Study-Act process Langley et al 2009 (76)[1]**.**

The quality improvement approach draws on a systems approach beyond the provision of training and guidelines, to engage in change making in healthcare organisations (77). The logic is that when clinicians understand organisational systems and aims, the accountabilities and power relationships, and combine them with knowledge of the evidence and implementation strategies, the opportunity for change is possible (2). The role of clinical leaders is described as framing and mobilising collective action (78) a dual role "to do their work and to improve it" p.3 (2). Quality

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improvement collaboratives provide a good example of an integrated and multimodal implementation strategy described by Bauer and colleagues (63).

2.3.4 Issues in closing the evidence-practice gap

2.3.4.1 Issues in healthcare

Both the knowledge translation and quality improvement approaches are limited in their ability to address complex contextual factors across a range of different settings.

The knowledge translation approach has been criticised for not adequately reflecting the interacting factors (69) and being an oversimplification of a complex area (79). Rather than a top-down iterative model (80), critics propose engagement with the complex interactions between systems, policies, funding, people, and settings. Understanding how organisational structures and professional processes interact with financial and societal influences, and patient and public needs, is required. Combining these interactions with how knowledge is transferred to practice is complex (81). Braithwaite identifies healthcare as a 'complex adaptive system' where change in individual components is insufficient to improve the whole system (82). His principles for a more productive approach to healthcare improvement, involve a focus on the clinicians and patient needs at the local level, with small scale initiatives involving collaboration, tailored to the setting (82). This focused approach may make more sense to clinicians.

While quality improvement approaches are widely used, Dixon-Woods considers that the evidence for the use of the quality improvement model developed for healthcare is mixed (83). The application of methods such as the quality improvement collaborative may be compromised due to poor fidelity to the model, a lack of authority by the implementers to make change, and the risk of overlooking the crucial role of context when transferring a method to other settings (83). She warns that a lack of understanding of the internal mechanisms of the collaborative model that produce positive outcomes, may mean that the outcomes are not replicated. It risks an "improvement evaporation effect" p.192 (83) where gains may be reduced in effect when tried elsewhere. Critics of the quality improvement approach consider that it focuses on the technical processes to improve existing structures and practices, rather than addressing broader issues of inequity in healthcare (77). Berwick (84) identifies the need for a different approach to studying quality improvement outcomes, seeing it as a process of social change rather than as a scientific trial. Many reports of quality improvement rely on identifying whether a program works rather than why or how it works and have a limited exploration of the complex nature of healthcare contexts and policy (12, 84, 85).

The development of many theories, frameworks and models of implementation reflects the complexity of the implementation process and the search for a better way to implement evidence-based healthcare practices. This draws on organisational and social psychology theories, change management approaches and policy processes which require further articulation of assumptions

and how they fit with the implementation aim.

2.3.4.2 issues in dementia care

In dementia care, most knowledge translation research has been focused on training and education of professionals with stepwise strategies to introduce change (86). It is now understood that training alone has not improved dementia care practice (87, 88) although it has built awareness of the research to practice gap. The training approach overlooks the policy and organisational factors that have been identified as the main barriers to knowledge translation. In educational programs to promote best practice in dementia care, successful strategies included, multimodal and tailored approaches to education, building of relationships and organisational support for change in the workplace (8). A combination of strategies at the local level and attention to the policy and organisational factors is needed.

Most studies of quality improvement collaboratives in dementia care have been in long term care settings where the focus of the improvement is not related to dementia care specifically, but in reducing harms, such as pressure ulcers, falls and injury from falls (89). In community care, four national approaches to collaborative dementia care to improve quality of care have been compared (90, 91). The various approaches combined education in dementia care and guidelines, multidisciplinary teamwork and restructuring roles and coordination of care across services. However, a general lack of knowledge of dementia care and collaborative practice in healthcare professionals limited anticipated outcomes of improved quality of life (90).

In implementation studies in dementia care, almost 70% focus on barriers or enablers of care practice in residential care settings (86). Less is reported about implementation strategies for services that provide care for the majority of people with dementia, who live in the community (92) or are in hospital (93).

Key barriers identified in residential care settings related to organisational factors, including time constraints, leadership, resources, and workloads (86). An improved understanding of change management and contextual influences in dementia care is needed to replace existing practices in with evidence-based practice and to support implementation strategies (88). Devi and colleagues recently reviewed six quality improvement projects in care homes and identified contextual issues in using the quality improvement collaborative approach (94). They noted that infrastructure to collect needed data for improvement was lacking. Time to develop trust and relationships was needed to overcome negative perceptions, and competition amongst care homes, and to reduce hierarchical differences between staff. Directly relating quality improvement to team members' roles and responsibilities was needed to make the changes relevant. Facilitators of quality improvement needed to be flexible in approach to adapt improvements to suit the needs and understanding of the staff of care homes (94). In Canada, a partnership approach in long-term dementia care is clearly focused on a collaborative approach to culture change. Dupuis and

colleagues (95) describe a theoretical framework applied in community and long-term care which challenges the way dementia care is delivered and the misunderstandings and stigma associated with dementia. This differs from a quality improvement approach but highlights the limitations in improving existing task-centered care or reducing harms. It requires that individuals and communities think differently about how to support people, seeing dementia as a social issue to be addressed through human interaction. A study on this approach by De Witt and Fortune (96) found that several relationship factors between people with dementia, their family, and the healthcare staff contributed to improved dementia care experiences. They included commonality of experience, trust, being appreciated, reciprocity and time.

To provide substance to implementation and improvement methods, a link to theoretical models can broaden the scope to include the nature of healthcare and the type of improvement that is undertaken. An example from Entwistle *et al. (*97*)*, related to self-management approaches in healthcare, argues that disease control is not the only thing that matters for health, especially for people with long-term conditions. Their concerns are often about living well and maintaining identity. A narrow focus on deficits or physical function can medicalise these priorities (98). This critique can be applied to dementia care improvement. Instead of promoting well-being and quality of life (99) for people living with dementia, a narrow view of dementia care may give priority to managing behaviour rather than supporting abilities, roles, and relationships for people living with the condition (100).

2.4 Understanding theoretical models of implementation

Knowledge about implementation strategies has increased rapidly in recent decades and is now organised in a diverse array of theories, frameworks, and models (101). These theories, frameworks and models link understanding of how a health or social program works with the broader theories of social science through developing mid-range theories (101). Models and frameworks are differentiated as generalisations, to provide useful guidance, to organise elements for investigation and to provide comparison across studies. In clarifying the use of theory in implementation research, Damschroder (13) describes theory as a way of approaching the study of implementation, with frameworks used to guide the process and to connect findings across diverse studies. She advocates better use of implementation theory and linked frameworks as a way of building knowledge in implementation.

2.4.1 A Taxonomy of frameworks

Nilsen (102) has attempted to make sense of the array of frameworks, models, and theories used to better understand implementation success or failure. His taxonomy proposes three overarching

aims of implementation science: a) describing the translation of research into practice, b) explaining what influences implementation and c) for evaluating implementation (102). *Figure **3*** shows this taxonomy.

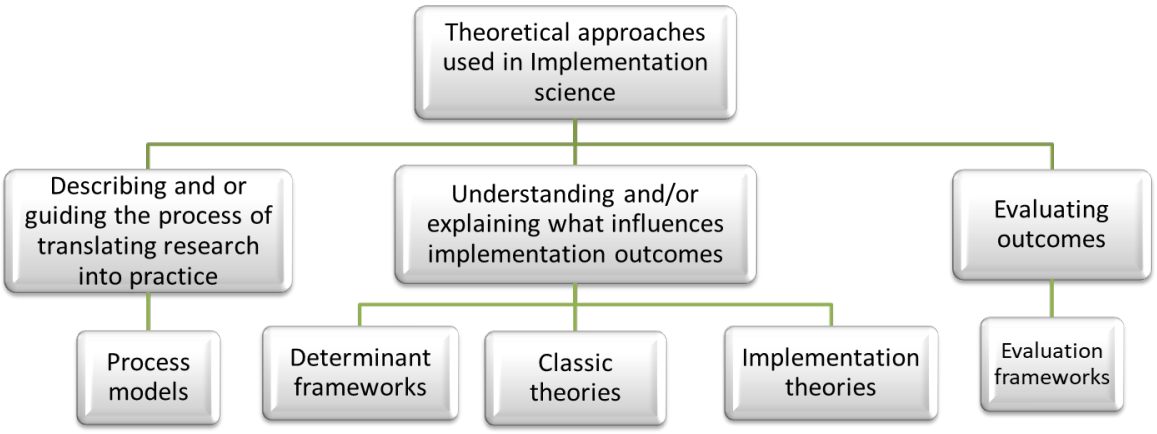

Figure 3 Three aims of the use of theoretical approaches in implementation science and the categories of frameworks adapted (Nilsen, 2015) [2]

Nilsen's (102) taxonomy offers a guide to approaches according to the aim of the implementation being undertaken. A layered approach to implementation, using several frameworks is often needed to reflect the complexity of the work of implementation (103).

Damschroder (13) extends Nilsen's taxonomy by including phases of implementation to show how frameworks, theories and models apply to the focus of implementation and stage of a study. She describes a layered approach to the use of theories, frameworks, and models. This approach is shown at Figure 4, with the focus of implementation science shown in black boxes which interact with and are part of layers of contextual domains (indicated by surrounding lines). The white boxes show the three categories of frameworks identified by Nilsen (102) which guide the identification of contextual influences, implementation outcomes and mechanisms of change (13). This approach clarifies the focus on phases and supporting frameworks available to guide the implementation process. The focus of my research is on the implementation outcome phase and the associated theories and evaluation frameworks to identify how and why the quality improvement collaborative strategy, built knowledge and skills in clinicians in dementia care.

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2.4.2 Applying models and frameworks

There are over 100 existing models, theories, and frameworks (104) which are organised into categories in Figure 3 and it is beyond the scope of this review to detail all existing models. The work described in this thesis draws on the Consolidated Framework for Implementation Research (CFIR) (105), Normalization Process Theory (NPT) (106) and Realist Evaluation (RE) (26). Rationale for choice of these models is presented in Chapter 3. The models selected are described below. In this research, the focus is on understanding how and what influences implementation outcomes (*Figure **4***) using the associated determinant frameworks and evaluation models.

2.4.2.1 Consolidated Framework for Implementation Research (CFIR)

The influential Consolidated Framework for Implementation Research (CFIR) (105) provides a pragmatic framework to guide evaluation of implementation strategies (38). It is considered a mid-range theory (101) as it identifies five major domains each with several constructs which influence implementation and evaluation. The articulation of the outer and inner setting of implementation recognises the importance of the context of dementia care and the policy and structural settings in which it operates. The adaptability of the intervention and process also influences the people who will implement the changes. *Figure **5*** shows how the five domains of the CFIR are linked within the framework.

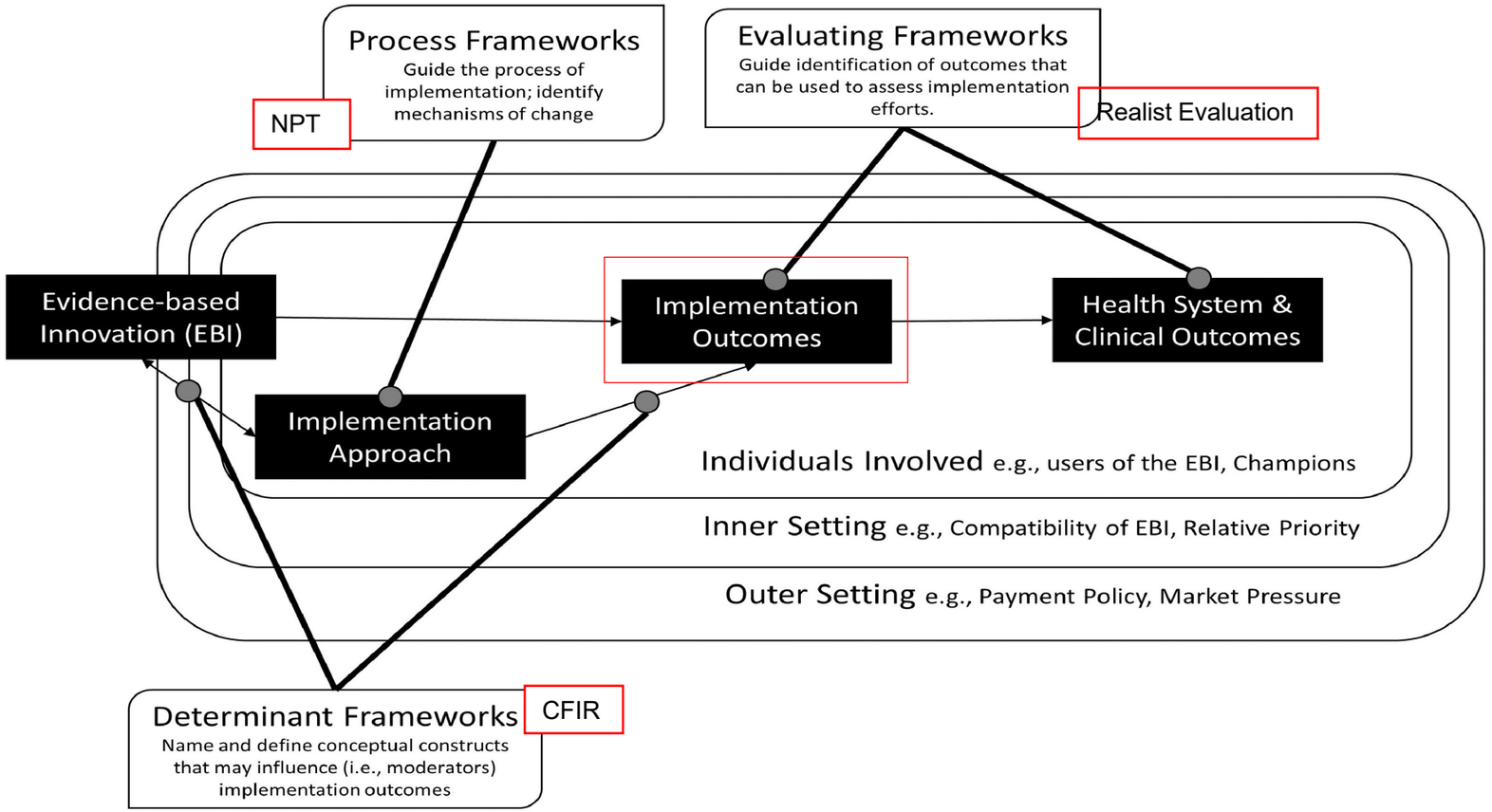

Figure 4 Focus of Implementation showing links to three theories used in this research Adapted from Damschroder 2020 (13)[3]

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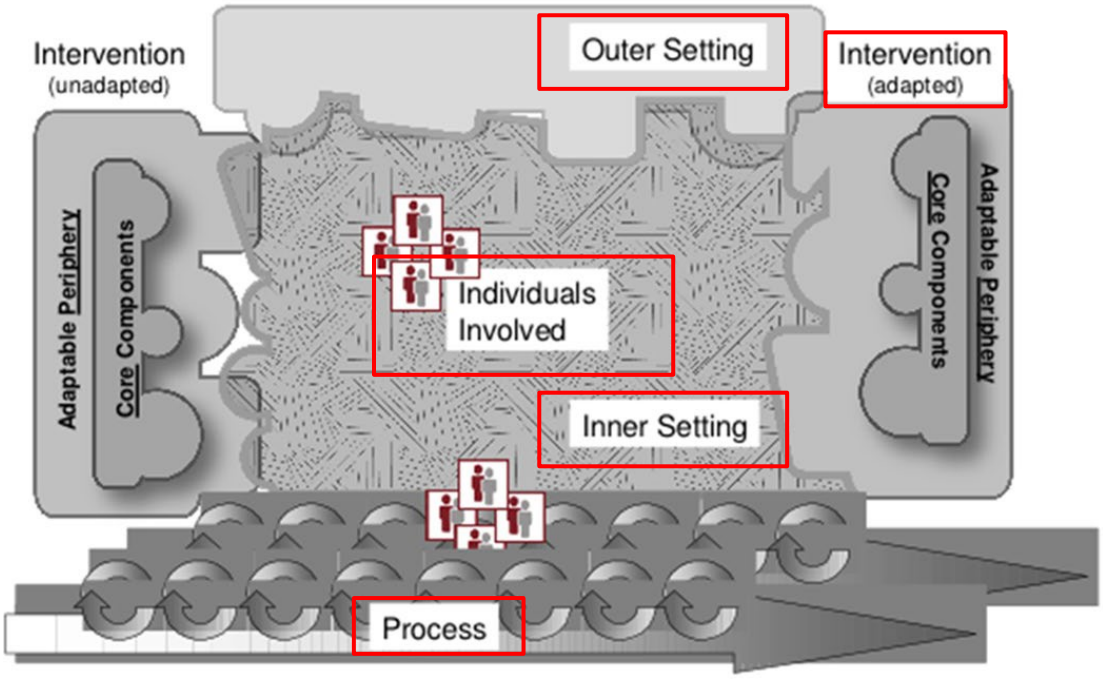

Figure 5 Diagram of CFIR showing 5 major domains in the framework, Damschroder 2009 (105)[4]

The CFIR provides a structure to inform implementation strategies across a range of contexts. It serves as a standardized list of variables, mostly used to identify areas for data collection. There is little evidence however regarding the use of CFIR to test hypotheses about key domains for advancing implementation theory or to explain why and how the context affects the implementation outcomes (107). The complexity of the process and the layers of influence on outcomes requires a theory-driven approach to evaluation of the implementation strategy to compare outcomes and to test theory (108).

2.4.3 Choosing a theory of implementation

While the CFIR includes the process of implementation as one of the constructs, it does not articulate a theory of the implementation process. Damschroder identifies the increasing need to use multiple frameworks in multi-component implementation studies (13). The use of CFIR complements theory in implementation to strengthen efforts to improve the quality of care and facilitate evaluation of implementation processes (109). The diversity of choice of implementation theories, models and frameworks has prompted the development of web-based lists (110) and guidance for selecting theories and linking frameworks (104). This is hoped to overcome 'pseudo-innovation' by limiting framework reinvention (111), however these lists do not cover the range of available theories.

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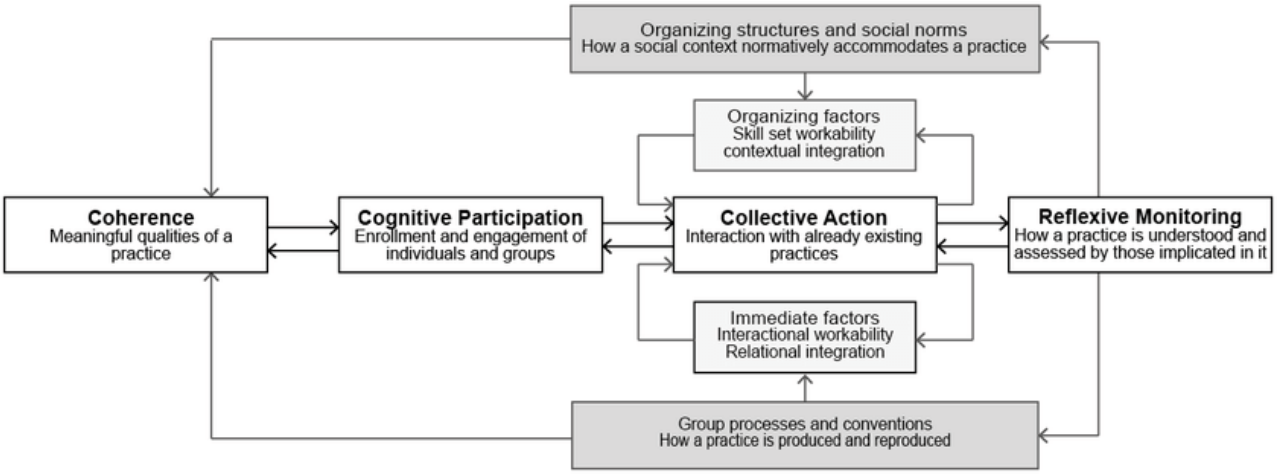
2.4.3.1 Normalization Process Theory

According to May (112) the development of a generalised theory of implementation is needed to integrate other theories and provide an explanation of implementation processes that can be applied broadly. Normalization Process Theory (NPT) (106) was developed to understand the process of embedding and normalising a practice in routine work. NTP focuses on the social organisation of the work of implementation (106) and has provided a coherent set of explanations of the implementation process within clinical trials (113). The theory can be used to test and evaluate implementation efforts and identify mechanisms for success or failure. The four mechanisms identified are a) coherence (sense making and utility), b) cognitive participation (engagement in the work), c) collective action (organising practice) and d) reflective monitoring (appraisal and evaluation) which are required of the people in organisations to make a new practice routine and embedded (106). See *Figure **6*** .

These constructs appear to focus on the internal context of implementation and the work that people do to normalise a change to practice (114). It does not directly address the policy drivers, funding, power structures and governance issues that create complexity in healthcare and affect implementation outcomes. May and colleagues (115) have extended NPT and address the way context is understood in implementation. Rather than conceptualising context as a problem in implementation, they argue that the context is part of the real-world conditions of improving healthcare. Context is incorporated in NPT by understanding it as a dynamic process, with which people engage to act within an implementation activity (115). Assessment of contextual influences is not explicit in this theory.

Figure 6 Model of the Normalization Process Theory showing four constructs required to normalise a new practice May and Finch 2009 (106)[5].



[5] *Reproduced with permission SAGE Publishing*

Increasing numbers of studies are using NPT as an organising framework to develop, implement and evaluate complex interventions in healthcare (113, 116-118). Most of the studies focused on translating evidence into practice. A recent review identified a small number of studies using NPT to study guideline implementation in nutrition, osteoarthritis, and kidney disease (113). NPT was found to be effective in identifying barriers to practice and guiding the choice of intervention (113). Two main strategies were identified to integrate the constructs of NPT into research methods. Some used the four constructs as a framework to structure analysis deductively (119). Others used an inductive approach then mapped that on to the NPT framework, which allowed for emerging themes to be considered (120).

NPT offers the opportunity to be guided by theory and to allow for an inductive or deductive approach to qualitative data analysis. Few studies justified their choice of the model over other theories and few used it prospectively to design and test mechanisms of implementation and the influence of context on the process (117). NPT provides organising constructs that help identify where an implementation process succeeds or fails. By using this theory prospectively, it is possible to identify phases in the implementation process to support embedding change in practice.

2.4.4 Issues and limitations in applying theories in implementation studies

Several recent studies critique the superficial use of theory in implementation and evaluation. They offer guidance in selecting among the many theoretical approaches in implementation (104, 121, 122) . The most common approaches used included frameworks to inform data collection and guideimplementation such as CFIR, and theories such as NPT to better understand how implementationworks (121, 122). McIntyre and colleagues identified that while NPT was the most common implementation theory to inform process evaluations, few tested the theory (122).

Critics argue that the diversity of theories, frameworks and models provide an eclectic approach, with implementation theories caught between interpretivist and positivist methodologies (123). Interpretation of behaviour of people and the outcomes of implementation activity is founded in social science methodologies. While they may not offer definitive evidence on what works, they help understand how and why implementation strategies work. The use of classic theories from the social sciences and specific organisational theories appears limited (102). This is counter to recommendations for more systematic use of theories to develop testable hypotheses about the factors that influence implementation of guidelines.

2.5 Evaluating implementation efforts

Evaluation of implementation outcomes focuses on what worked, how and why in real world practice. Experimental designs evaluate effectiveness of interventions (what worked) in comparison to no or other interventions, using a randomised control or quasi-experimental design

(124). These studies are intended to produce generalisable knowledge that can be used at scale or in other programs (125). Evaluation of an implementation strategy often focuses on a particular setting with less ability to generalise findings due the differences between contexts (125). Process evaluations by comparison focus on the implementation process, (how and why) exploring how the resources, structures, people, and roles interact to produce outcomes in different contexts (126).

2.5.1 Theory-driven evaluation

The development of healthcare interventions is based on assumptions or theories of how they are expected to work. These assumptions may be postulated as program theories in an '*if-then'* statement, for example: 'if resources and interventions are provided then they will influence people's thinking and a change in behaviour will result' (127). They may however be ambiguous or so familiar, such that they are not articulated or reviewed. Pawson argues that realist evaluation explores this logic to test the theory of how an intervention works and as such is theory-driven (127).

McIntyre and colleagues recommend conducting process evaluations and using theoretical approaches, to better understand implementation interventions (122). Theory use can provide a more transparent process to explore causal mechanisms and generalise findings beyond a specific context. The opening up of the so called 'black box' of health programs can investigate the assumptions about how and why programs bring about change (128). The use of a theory-driven evaluation that aligns with the use of an implementation theory or framework is needed to improve implementation strategies

McIntyre and colleagues (122) reviewed the use of theory in process evaluations and found that while most process evaluations cited theory use, only a quarter were informed by, applied, or tested the theory. Few used theories to hypothesise then test mechanisms of change in the implementation process to explain why and under what circumstances did an implementation strategy work (122). The most common theory used in implementation studies was Normalization Process Theory and the key evaluation frameworks identified were the Medical Research Council UK (MRC) guide to process evaluation (129) and Realist Evaluation (26).

2.5.2 Process Evaluation

Process evaluation explores the implementation process to explain differences between expected and observed outcomes and the feasibility of an intervention at trial stage (124) . Assessing the influence of context on implementation outcomes and including an economic evaluation is intended to make the results of evaluations useful to decision-makers (130).

The MRC process evaluation framework developed by Moore and colleagues (129) provides practical guidance on developing and evaluating complex interventions (130). For instance, they recommend strong relationships between researchers responsible for the design and

implementation of the trial and those responsible for the evaluation of process and outcome. The framework identifies the complexity of implementation and emphasises the links between implementation, mechanism, and context to explain variations in outcomes. Adaptation of the framework for this research, is presented at *Figure 7*, describes the key functions of process evaluation and how they are related. The focus of process evaluation depends on the stage of implementation. At a trial stage, Moore and colleagues (129) recommend a focus on feasibility of the intervention to further develop the design of the trial. At implementation stage they suggest that process evaluation can draw conclusions about effectiveness of the intervention and generalisability.

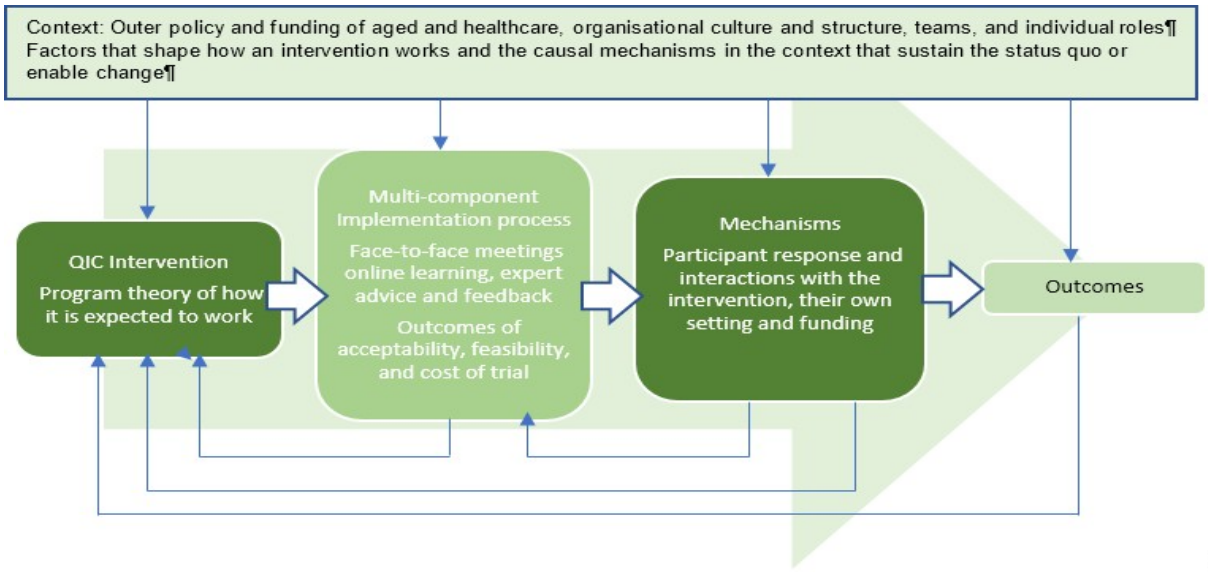


Figure 7 Key functions of the process evaluation of the QIC intervention adapted from Moore et al 2015 (129)

Critics of the framework point out the while it recommends a theory driven approach, it does not include specific theories of evaluation (131). Rather, Moore and Evans (15) highlight the need for selection of evaluation theories that focus on understanding the mechanisms of a program, rather than an 'off the shelf' approach (p132). The development of program theory is recommended to test underlying assumptions and identify key evaluation questions, data collection and analysis techniques (128). While this approach does not provide the evidence of causality claimed by randomised controlled trials, process evaluation can establish the impact of mechanisms on effectiveness of programs in different contexts (132). The feasibility of a trial and understanding the contextual factors and resources needed to create change are key to the value of process evaluations (133).

2.5.3 Realistic Evaluation

Realistic evaluation offers an applied theory which aims to explain the mechanisms involved in an intervention and the outcomes that are produced in particular contexts (134, 135). It invites researchers to "dive into the black box of implementation" to find out what works, how, in what

context and for whom (p. xv) (136). Developed by Pawson and Tilley in 1997 (26), realistic evaluation is described as a type of applied realism, describing an understanding of the world and how we can know about it (137). The process of theory testing and exploring hypotheses adds complexity in analysis but aids understanding of the reasoning of people in the intervention (138). This approach can help make sense of the range of implementation approaches and to make explicit the assumptions often implicit in the so-called 'black box' of implementation. It can also guide the methods used and ways to report results that can be compared with other studies.

Pawson and Tilley (26) argue that most interventions will work for some people under some circumstances. They propose that the purpose of evaluation is to identify for whom and under what conditions are interventions effective (26). Critics point out limitations of realist evaluation on the basis that it identifies plausibility not probability of the effects of an intervention as would occur in an experimental design (132, 135). A combination of experimental trial and realist evaluation is suggested by several authors (132, 139) to assess both effectiveness and the influence of context on implementation. As they come from different ontological positions, the challenges in dealing with causation are not simply resolved. A theory-informed approach is proposed to deepen understanding in experimental design (140). In embedding a process evaluation in an experimental designed trial, a realist-informed approach is possible to unpack the 'black box' to explore the influence of context on mechanisms and the outcomes generated (141).

Several realist evaluations alongside experimental designs have been undertaken in healthcare to identify how and why a strategy worked to improve care. Examples include mental health care (142), hospital response to deteriorating patients (143) and urinary continence care (144). The evaluations informed how and why implementation worked and in what contexts and added to evidence of what worked in these trials. This approach retains the realist focus and provides insight into how context influences outcomes. The dynamics of the contextual influence on the intervention is explored through interviews that describe the reasoning of the people implementing the intervention (145). Realist evaluation has been used in improving healthcare outcomes for people with dementia in care homes (146), in implementing open visiting hours for older people in hospital (147), and in supporting hospital staff to provide dementia care. While realist evaluation has been used extensively in improving healthcare and the use of evidence-based practice (144, 148-150), there are few examples of the use of realist evaluation in implementing clinical guidelines for dementia care.

2.6 Economic Evaluation of implementation strategies

2.6.1 The basis of economic evaluation

Economic evaluation encompasses a range of approaches to compare the benefits and costs of use of resources, and is described as a pragmatic, decision-informing, summative evaluation (151). Health economics seeks to judge the relative benefits of alternative ways of delivering healthcare by providing evidence to inform decisions. Morris and colleagues (152) outline the foundations of economic evaluation which can be considered in relation to a realist approach to evaluation. They outline how the views of individuals affected by allocation of scarce resources are gathered to achieve a logical ranking of alternatives. The individual is assumed to be the best judge of their own welfare and that their choices maximise their welfare (152). This judgement is based on utility which is not easily observed. A money value is then used to measure changes in utility or benefit. For example, if a person judges one course over another to be better at maximising their welfare, a higher price is estimated. Individual judgements and prices are aggregated to identify a benefit. A cost-benefit analysis is one form of economic evaluation where a societal perspective is taken to weigh up costs and benefits as a measure of efficiency (153).

Implementation strategies can bridge the gap between research and practice but due to complexities in healthcare, they can be expensive. Cost is often a barrier to implementation of evidence to improve healthcare, yet it is an important consideration by healthcare leaders. A business case is considered essential to capture costs and identify return on investment for decision makers as well as guide resource allocation in implementation processes (154). However, few implementation studies include costs of strategies or economic evaluations and similarly few evaluations of quality improvement collaboratives include an economic evaluation (154, 155).

2.6.2 Differences in realist and economic evaluation concepts

There are significant differences between economic and realist evaluation approaches based on ontology, aims and methods. Economic evaluation in healthcare is based on welfare economics, to maximise outcomes for society. By aggregating self-assessed utility of individuals, economists can identify which state of the world (or which intervention) is better than another (156). It aims to measure value in monetary terms, compared to other programs or to doing mothing but it does not account for differences in distribution or equity. It is pragmatic, quantitative, and summative evaluation (156). Economic evaluation has limitations in explaining multiple outcomes or attributing those outcomes to interventions.

Realist evaluation on the other hand, aims to build explanations of how and why a program works in different contexts and for whom (151). In dealing with complex health interventions, realist evaluation identifies links and interactions between contexts and outcomes and how these vary according to circumstances. Mechanisms at work within programs can explain multiple outcomes

and attribute them to interventions and the resources required or provided.

In evaluating a quality improvement strategy in healthcare, understanding the resources needed to make changes and where and when they need to be applied, is important for decision makers.

Anderson and Hardwick (151) propose a possible synergy between realist evaluation and economic evaluation that seeks to explain resource use. They propose that by identifying the cost of resources offered in an intervention and the ways they change the reasoning of participants (157), might better capture the resource requirements and resource consequences of programs. This can then be used to inform decisions over budgets for future programs.

This synergy allows for a comparison of the costs and benefits of the intervention and can compare the costs with the program theory to identify if the costs of resources were required for that mechanism. Rather than a measure of cost effectiveness per patient receiving the intervention, this approach offers an understanding of the resources required for implementation of evidence-based practice in dementia care.

2.6.3 Measuring costs and benefits of implementation methods

Economic evaluation is often based on clinical outcomes for patients, with a cost effectiveness analysis conducted from the perspective of the healthcare system. A broader societal perspective is needed when considering long term chronic and terminal conditions like dementia. By improving dementia care an improvement in quality of life of the person is assumed. However, when considering that many people living with dementia have multi-morbidities, it may not be possible to identify significant improvements in quality of life. Access to healthcare for people living with dementia is a human rights issue rather than a cost-effectiveness issue. For example, an economic evaluation of a collaborative to reduce preventable pressure ulcers in older people in long term care was not able to demonstrate cost effectiveness (158). While the intervention reduced the number of pressure ulcers, the costs to do so increased. Given that these ulcers are preventable, the intervention is not simply a choice based on individual preferences but a basic healthcare responsibility (159).

Where implementation outcomes rather than clinical outcomes are the focus, a preferred cost-benefit analysis is that which takes a broad societal perspective and monetises the benefits for comparison with costs.

2.6.4 Issues and limitations in evaluation approaches

The key limitations of experimental study designs can be identified in the design, conduct and analysis of a study. Bias in process evaluation can arise from the selection of participants, in the information obtained from them and how they are interpreted (160). Purposive sampling methods may ensure views are sought from information rich participants are included in the evaluation (161).

The risk of recall and intentional bias by participants can result from difficulty in recalling how or why they responded to an intervention or the wish to present a positive or expected response to the intervention. Designs of process evaluations usually include multiple methods and timing of data collection which can be cross referenced to identify congruency or disparity in responses (129). Use of pre-planned framework analysis and researcher reflection can allow transparency of interpretation of responses (162). By comparing process evaluation results with outcomes evaluation to explain results may identify if biases are apparent. Limitations in economic evaluation of implementation processes in healthcare most often relate to reporting bias, omitting costs and the methods of valuing costs and benefit (163). Including economic evaluation within a trial and alongside process evaluation can ensure plans for data collection and reporting reduce these biases (129).

2.7 Involving the public in research

2.7.1 Definition of involvement

There is a considerable body of literature about public and patient involvement (PPI) in healthcare and service delivery, with involvement in research, as a distinct addition. This section examines the principles and methods of involvement of patients and the public in research and the contribution that people with lived experience of dementia and caregivers can make. Several definitions exist of what involvement means. In the United States and Canada, the term engagement is used. In the United Kingdom (UK), involvement means research with or by members of the public rather than being ‘to, about or for them’ p.6 (5) and is used in this research.

2.7.2 Principles of public and patient involvement

The study of public and patient involvement in healthcare research has been growing internationally in the last 20 years (164). Failings in care and the need to improve quality and safety (165, 166) have led to involvement of patients and the public in healthcare services. They providea patient perspective and experience of what is needed to improve services or identify where gaps exist. While this represents a utilitarian approach to improving patient care, involvement in research can reinforce principles of democratic rights and accountability for public funding.

A range of ethical issues of engagement between healthcare providers, researchers, patients, and members of the public are involved (167). An ethical framework for public involvement by the National Coordinating Centre of Public Engagement (NCCPE) in UK developed four principles of high-quality involvement. They are focused on 1) the purpose of involvement, 2) who is involved, 3) what processes are used and 4) evaluation of the involvement (168). These principles are supported by the UK Standards for Public Involvement in health and social care research (169). The standards advocate a shared purpose, inclusive involvement, using processes that are

respectful and suit the needs of the public members, and evaluation. They provide a framework of what good public involvement is and a reflection process to learn from experiences which apply internationally.

2.7.3 Methods, roles, and purpose of public and patient involvement

A continuum from high to low involvement has been used to describe the various purpose and roles offered to the public in healthcare (170). At the lowest level, consultation with patients and the public provides information on personal experiences and perspectives. Involvement, as a mid-point in the continuum, describes where they can offer advice and recommendations. At the highest level is partnership, where people share leadership and decision making in services and policy. This continuum has been applied to involvement in healthcare improvement at multiple levels (171). Table 1 presents this continuum of involvement for patients and the public for roles undertaken in healthcare services, policy, and research. This table is adapted from an example by Ocloo and Mathews (170) who argue that models of involvement have been too narrow. The adapted **Table 1** extends the level of engagement to research and provides examples across the continuum for the involvement of people with lived experience in research. This continuum shows increasing collaboration between the public, service providers, policy makers, and researchers. However, it does not describe the many phases of research and different roles, where members of the public can contribute.

By working on research, public involvement can inform research agendas and policy at the broadest level of involvement. Priorities for research programs can be attuned to public needs or infrastructure support can be developed for involvement of the public. By working in research, at different stages, the public can add diverse experience and knowledge in planning, during a study and in disseminating findings (171). Some typical roles that the public and people with lived experience have taken in research are as participants, members of focus groups or advisory committees, recruiters of participants, collection of data or dissemination of results (172).These roles provide information for research and to the public.

Table 1 Levels of involvement of public in healthcare services and research across a continuum of involvement

Levels of involvement	**Continuum of involvement** →		
	Consultation	Involvement	Partnership and shared leadership
Direct Care	Patients and caregivers consulted about diagnostic and treatment processes and priorities	Patients and caregivers provide advice on information needs, processes, and raise questions	Patients and caregivers develop information with healthcare providers to be provided to users of the service
Organisational design and governance Policy making	Patients and caregivers asked for feedback on their experience of care and opinions for improvement	Patients and caregivers involved on advisory committees and planning groups to provide their perspective	Patients and caregivers partner with organisations to monitor and decide on quality and safety priorities
Policy making	Public focus groups seek opinions on health care issues	Patients and caregivers' recommendations help set priorities for development and budgeting	Joint decision making about priorities, funding, and policy directions
Research	*People with lived experience are consulted about proposed research and advised about outcomes*	*People with lived experience provide recommendations on priorities, advise on language, gaps, perspectives, and monitor progress*	*People with lived experience partner as co researchers, expert advisors, develop submissions, oversee conduct of research, analyse data, co-author publications and disseminate results*

Other roles are possible, such as: lead orco-researchers, identifiers of research topics, priority setters, developers of content, reviewer of plans and data, co-authors, and co-disseminators of findings (173). **Table 2** presents examples ofroles for involvement of the public both in and on research through different stages of research.

Table 2 Roles for the public in and on research at different stages of research

Roles for the public *in* research studies	Advice on priorities, topics, content	Advice and feedback on process	Suggesting topics and methods	Advice on interest groups
	Member of steering group	Recommending recruitment strategies	Identifying scope	Plain language summaries
	Co-research planning	Partner in data collection and analysis	Reviewing drafts	Co-authorship of publications and presentations
	Lead researcher design and grant submission	Leading process with co-researchers	Identifying findings, reviewing impact	Lead author of publications and presentations
Roles for the public *on* research strategy	Topics of research agendas Standards of involvement	Advising on priorities and methods	Assessing involvement processes	Presentations
	Role descriptions, recruitment, and payment policies	Promoting	Reviewing roles	Policy reports
	Networks and training	Supporting involvement and monitoring processes	Reviewing training, reporting of involvement and gaps	Publications
	Leading Public involvement strategy	Training public and researchers	Outcomes and areas for development	Reports and guidelines

A shift to co-production and partnership roles recognises the complexity of public involvement. It emphasises the need to consider the context and purpose of public involvement in research rather than focus entirely on specific roles (174). People with lived experience and members of the public may need education in research methods, and support to take on and maintain involvement.

Researchers may need to learn new ways to communicate and share t research roles. This type of investment in public involvement will enable equity in research involvement. A best practice framework developed in UK identifies a typology of public involvement in collaborative data analysis in the field of mental health (175). This demonstrates that successful collaboration is based on co-production, realistic time frames and resources, and manageable group expectations. It identifies the costs in terms of time to engage and support co-researchers, the benefits for the quality of research and reflective practice by researchers (175). This framework applies readily to other roles and fields of research and adds to research repertoire and funding, to provide the support needed.

2.7.4 The value of public and patient involvement

The value that public and patient involvement brings to research is recognised as contributing the perspective of the lived experience. This adds to the research and clinical knowledge in the area being investigated through insights of what is needed or what does not work well. It has the ability to generate new ideas and ways of exploring an issue to bring benefit to research outcomes (176). Beyond the utility of improved research, involvement can be beneficial to people with lived experience and to researchers, while increasing public support for research. Members of the public identify a sense of empowerment, through contributing and feeling valued (177). Researchers may develop new ideas or learn what is important to patients and focus research better. A two-way learning process has been identified by Staley and Barron (178) to ensure the quality of involvement. They argue that the outcomes are subjective and unpredictable, making it difficult to quantify (178). The value of public involvement in research to the wider society is similarly difficult to quantify. A review of values associated with public involvement in research identified three categories (179). They are 1) ethical and political value, 2) consequences for research and 3) conduct of the process. Examples of the value added in these categories are presented in ***Table 3***. The impact of this type of contribution to research is not always identified or quantified in research reports.

Table 3 Examples of value added by public involvement in healthcare research (adapted from Gradinger et al. 2015 (179))

Ethical and political value	Consequences for research	Conduct of the process of involvement
Empowerment by providing evidence and advice	Open to diverse perspectives	Collaboration and partnerships
Democratic right to have a say in research that affects the person	Improves relevance and credibility of research	Respect for diverse knowledge and experience
Improve responsiveness of healthcare to the person	Focus on needs and improved healthcare	Flexible and supportive
Accountability to people affected by research	Represents public priorities	Open to range of processes
Promotes wellbeing in healthcare	Broadens focus from medical treatment to health and wellbeing	Communication and clear roles

Involvement in research by members of the public and people affected by the topic of research is also expected to improve research quality and relevance (180). By bringing the lived-experience perspective, public involvement improves relevance to patients, improves involvement of participants in the research and widens dissemination. It also is expected to improve the accountability and transparency of the research to the public (181). Brett and colleagues found that when service users are involved throughout all stages of research, they may have a greater impact. However, reporting of the impacts, costs, and processes of public involvement in research has been limited (180).

2.7.5 Involving people with dementia and caregivers in research

Due to significant cognitive and communication difficulties experienced by people at some stages of dementia, it was previously assumed that people with dementia could not participate in research equally. As a result, people with dementia were easily overlooked (182). Over the last 10 years that has changed globally. The voice of people with dementia has challenged many attitudes and practices in care and research in Europe, UK, USA, Canada and Australia (183-187). The establishment of Dementia Alliance International (DAI), run by and for people with dementia, has demonstrated the abilities of people with dementia to organise and speak for themselves and advocate their priorities for research, rights, and services (188).

In Australia the Consumer Dementia Research Network (CDRN) set up by the then Alzheimer's Australia engaged many people with dementia and care partners in a range of roles in research (189). The evaluation of that network found that the involvement of people with dementia was firmly embedded in dementia research. The network was able to influence research priorities and focus on translational research.

A recent international review found many examples of people with dementia and caregivers involved in developing, conducting, and translating research into practice (186). People with dementia and caregivers have been able to be involved in research and have much to offer. Barriers remain however such as the costs of involvement, sharing decision making between researchers and people with dementia, identifying who can represent people with dementia who experience communication barriers, the complexity of the research process and the lack of research training. Enablers identified included early planning, adequate resources, consideration of consent and capacity and the support for people with dementia to remain involved. Further evaluation of the impact and cost of involving people with dementia and care partners in research is needed to understand the costs and the benefits that can accrue.

2.7.6 Impact evaluation of Public and Patient involvement in research

While public involvement in research may democratise research, evaluation can help to

understand how it works and what impact it has. Several literature reviews have explored the impact of public involvement on research (164, 170, 184, 190-192). Some focus on how to involve patients or people with dementia in healthcare research and identify the benefits (184, 190). Others focus on the impact of involvement at various stages of research and the various components of involvement (170, 191). These reviews attempt to quantify the impact to justify the involvement. They include increased recruitment to studies and improved knowledge about dementia by researchers (192). The impact on people with dementia and service users of their involvement in research was also reported (164, 193). Other studies found that barriers existed to the engagement of patients and members of the public, and a lack of consistent reporting made it difficult to judge impact (186). Staley (171) however argues that the type of evidence for impact of public involvement in research is different to the usual quantitative data sought in research. In the context of implementation research, researchers may gain an improved understanding of the topic and process through working with people with lived experience of the condition being researched. Qualitative evidence from interviews with researchers and clinicians implementing guidelines, may therefore provide insight into the impact of their involvement. This type of evidence may describe realisations, consideration of other perspectives and examples for clinicians to adapt to their practice (171). They suggest more complex causal chains than a simple cause and effect process. A realistic evaluation process has been suggested to better test causal links and identify how and in what circumstances does involvement of the public impact research (194).

People with lived experience of dementia identify positive impacts from their involvement in research (176). They report a sense of value and purpose, support, and networking that makes sense of their experience of dementia (189). A recent review, by Blackburn and colleagues in primary care research, found beneficial impacts of public involvement in designing studies and writing participant information, but inconsistent reporting of findings and costs (195). There are few studies demonstrating the costs or impact of public involvement in research relating to dementia (186). Better reporting on costs and effects on process and outcomes may provide impetus for more public involvement in research.

2.8 Gaps identified in current literature

2.8.1 Five areas of gaps

The issues identified in this literature review point to five main gaps in knowledge of current research approaches. They are: 1) how to conduct theory-driven implementation and evaluation methods, 2) the efficient use of layered approaches to implementation research in a complex context; 3) how best to implement evidence based guidelines in dementia care, 4) how economic evaluation of strategies can be used to improve dementia care; and 5) better reporting and processes of involving people with dementia in implementation research.

The lack of attention to theory-driven implementation and evaluation was highlighted as limiting the building of knowledge and testing of theories. Selecting theories, frameworks and models has been recognised as challenging and several on-line tools are offered. However, these tools often suggest selection of the most often used theories or to frameworks linked to types of implementation studies. The gap identified was how to layer approaches to implementation research and link assumptions of the theories with methodology. Chapter 3 explores the use of realism as an overarching theory to inform my choice of approaches and methods to answer my research questions of how and why a collaborative builds knowledge and skills in clinicians to improve dementia care.

Few economic evaluations of quality improvement collaboratives have been identified and none were identified in dementia care. Valuing the investment in quality improvement in dementia care can inform decision-makers in healthcare.

Finally, while public involvement in research has been a growing trend, there appears to be uncertainty about involvement of the public in implementation studies. Involving people living with dementia and caregivers in quality improvement research in dementia care is rarely reported but may provide wider perspectives and build knowledge in research. Guidance and further research is needed in the involvement of the public in implementation and quality improvement studies.

2.8.2 Summary

Implementation strategies to improve dementia care, using evidence based clinical guidelines, is a complex area. It is not extensively explored or reported yet given the increase in numbers of people living with dementia and reports of poor care, it is much needed. Clearer justification of the selection and use of theories in implementation and evaluation is needed to build knowledge. People with dementia and caregivers are rarely involved in implementation strategies with healthcare professionals yet they offer value to research in other areas. The costs of implementation strategies are seldom reported.

This research seeks to understand how, why and in what circumstances a quality improvement collaborative improves knowledge and skills of clinicians. By using a theory-driven evaluation of the collaborative strategy, the benefit of involving people with dementia in the research, and identifying costs and benefits, this research addresses the gaps identified in the literature. This research builds knowledge in the complex field of implementation strategies to improve the quality of dementia care. It takes a wider view of the ‘wicked problem’ of poor dementia care, where issues are related to the impact of dementia or the behaviour of the person with dementia. The focus in this research is on how to improve the skills of clinicians to support quality of life and well-being of the person with dementia and their caregiver.

CHAPTER 3 THEORETICAL FRAMEWORK

3.1 Research aims and objectives

This chapter presents the theoretical framework developed by the author to conduct this explanatory case study research (196). The framework articulates the assumptions and links between broad social science theory, the mid-range theories of implementation science and the program theory developed for the implementation strategy.

The process evaluation and cost benefit analysis included in this research was embedded in a larger translational trial called 'Agents of Change (AOC): establishing quality improvement collaboratives to improve adherence to Australian clinical guidelines for dementia care' (6). As described in Chapter 1, this thesis evaluates the process of the trial to develop program theory for the quality improvement collaborative strategy.

The aim of this research is to examine the feasibility and acceptability of the use of a quality improvement collaborative strategy to understand the implementation of clinical guidelines for dementia.
The objective is to evaluate the process of a quality improvement collaborative to understand the costs and how the implementation strategy works to build knowledge and skills in clinicians to improve dementia care.

The research questions are:

1) How, why and in what circumstances did a quality improvement collaborative build knowledge, skills and acceptance of clinicians who were participants? (Chapters 5 and 6)
2) What was the value of involving people with dementia and caregivers as expert advisors in the quality improvement collaborative? (Chapter 7)
3) What were the costs and benefits of a light touch approach to a quality improvement collaborative to improve dementia care? (Chapters 8 and 9)

3.2 Composition of the framework

The framework for this research shows the links between the theories of social science to mid-range implementation theories and the practical logic of the implementation strategy (a quality improvement collaborative) used in this research. The following sections present:

- The nature of the research questions and how they are addressed
- The philosophical position adopted and the rationale for this approach
- The implications for evaluation and data analysis
- How this approach has been applied in other evaluations.

3.2.1 Addressing the nature of the research questions

Healthcare is based on evidence-based practice, with evidence from research interpreted into guidance for making decisions in practice. Many questions in healthcare research are based on identifying effectiveness and efficiency of a clinical intervention, what works in practice, how well and when? Empirical research is based on cause and effect. When the questions relate to implementing guidelines, the social and organisational process of how, why, under what circumstances and for whom the strategy of implementation works, the questions are more appropriately addressed by social science theories.

3.3 Theoretical position

Implementation science draws on the classic theories or philosophies of social science which help in understanding the real world. The social processes of implementation use mid-range theories of change and relationships between people and structures for example. Defining these links requires the use of ontology and epistemology to clarify assumptions. Ontology refers to how the nature of reality and relations between properties of the real world is understood. Epistemology refers to how to carry out the study considering the assumptions made (25).

A key theory of social sciences is Realism. This meta-theory has developed from the writings of Popper, Merton, Bhaskar, Pawson and others (197). It describes the nature of reality as layered and interconnected which exists independent of our knowledge of it (24). Realism explores the social processes that exist and the relationship with systems, groups, and individuals, to identify hidden mechanisms that cause events in the world. This approach addresses the problem of a 'black box' of implementation (138). It provides a methodological stance for research based on the realist philosophy of science (24), a philosophy that sits between positivism and constructivism (198). A brief comparison of the approaches follows.

3.3.1 Alternative perspectives: Positivism and Constructivism

Based on the writings of nineteenth century philosopher, August Comte, Positivism described a positive scientific research approach of observation, experiment, and comparison (199). This approach is used to investigate the world to identify positive facts and to develop natural laws in science. It asserts that human behaviour could be explored using the same laws of physical and natural sciences (200). By controlled experiments on causes and effect, outcomes focus on 'what works?'. It has become the basis of empirical science for the randomised controlled trial (RCT) design which has been considered the best evidence for much healthcare research (201). Positivism offers the measurement of outcomes associated with interventions. In the larger translational trial in which this thesis is based, the level of adherence to clinical guidelines by clinicians was assessed over time to identify changes in practice expected as a result of participation in the collaborative (202). The use of positivism as a philosophy for the social

sciences, however, lacks an explanation of how things work and why. It does not align well with the study of complex open systems which typically characterise human organisations and human agency. To explain how and why things work, the exploration of interacting systems is needed rather than on observing facts through experimentation (203). Often experimentation is not possible or ethical in healthcare and alternative approaches are required to understand how interventions work.

Constructivism was first described in the twentieth century in reaction to the argument for a rational foundation of knowledge (204, 205). It values and describes socially constructed beliefs about the world, how they can be understood and studied to construct something that works cognitively (204). What is known of the world is understood as actively constructed by humans through their own subjective experience and context (206). Patterns and cause and effect relationships can then be understood through the "webs of meaning and practices" (207). Constructivism is seen as anti-realist (205) and relativist (208) as it assumes there is not one known reality and understanding of the world comes from the meaning made by individuals with different perspectives. Knowledge is seen as constantly open to change which makes the generalisation of knowledge to other situations meaningless. It is influential in the social sciences as it identifies the importance of the social construction of knowledge and systems in society. The familiar sense of individual experience and meaning limits understanding of how and why systems may cause events and change outcomes.

3.3.2 Realism

Realism in contrast asserts that reality exists independently of our knowledge of it and we can understand reality through exploration of social processes (198, 209). It links the ideas about society with evidence of complex interventions (210).

Realism provides a theoretical framework for healthcare implementation research as it explores causes and explanations of the social processes such as those used in healthcare. It is a philosophical approach that distinguishes between what is real and what we can know about reality. Critical Realism (CR) developed by Bhaskar (24) and others (211), takes a critical values stance in relation to the nature of the social world. Understanding inequity and power relationships in social structures is needed where people construct their own world yet are constrained by structures that exist in the real world (212). Bhaskar advocates a scientific approach to testing hypotheses of why we experience particular events to advance our understanding of what happens in the real world. Reality is understood as a "complex, multi-layered, multi-causal web" of interactions with empirical, actual, and real layers (p.374) (213). While we may not be able to observe them, underlying causal mechanisms exist in the real world and act in ways that affect outcomes. We make sense of reality through attempts to describe events with language and concepts (214). Through a realist lens, to understand the real world, we need to understand the contextual influences on mechanisms that produce events, and the concepts that we use to

describe those sensations. Realism is positioned between the positivist approach of identifying facts and laws and the constructivist approach of socially constructed perspectives in society.

Realism describes a layered approach to reality: the empirical, actual, and real levels (215). A flow chart at ***Figure 8*** adapts an iceberg metaphor by Fletcher (215) to show this stratification. Hidden mechanisms in the real level may cause events to occur in the actual level which may then be experienced and observed at the empirical level. It is these hidden mechanisms which can explain how and why events occur and provide the focus for research on social systems and processes.

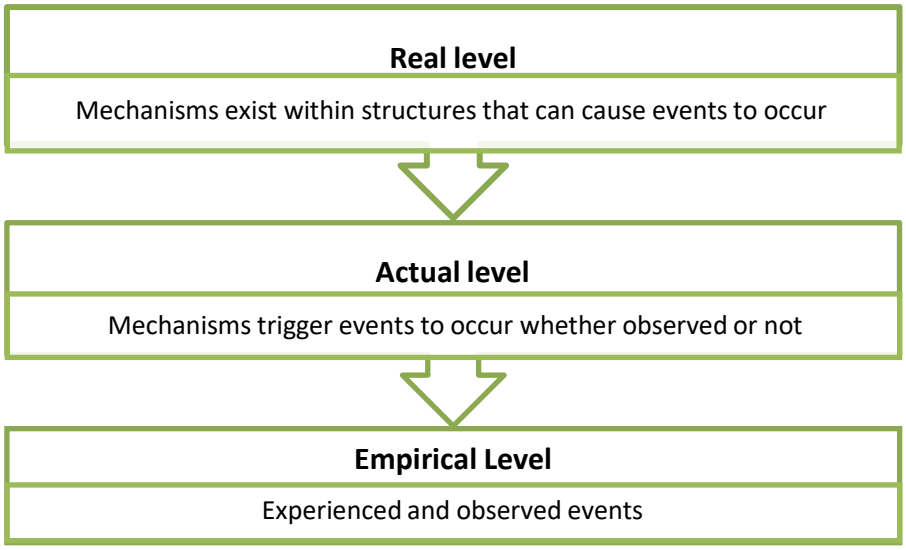


Figure 8 A layered approach to reality adapted from Fletcher 2017(215)[6]

To explore how, why and for whom an implementation process works, the hidden mechanisms at the real and actual level need to be explored. Realism provides the ontology to understand both the nature of the world and the social processes at work that influence the outcomes of implementation. Realism assumes that we have theories in mind about how a program works, often identified as mid-range theories (216) in relation to organisations, management, social behaviour and beliefs of individuals and groups.

3.4 Rationale for the research approach

An approach is required to link the layers of a theoretical stance with research methodology and methods. The relationship between ontology, epistemology and methodology and the social theories and practical research methods used in this study is presented at Figure 9.

Figure 9 shows the relationships between the layers of the framework for this study, adapted from 'The Research Onion' diagram by Saunders and Tosey (217). On the outer layer the ontology is

[6] adapted with permission Taylor and Francis Online, tandfonline.com

placed which identifies the assumptions of the realist position taken for the research. The focus of the research then identifies the approach taken for the evaluation research. As evaluation is the focus of this study, a realist evaluation approach follows methodologically from the ontology. The use of Normalization Process Theory (NPT) as a mid-range theory of implementation, and a realist evaluation approach calls for mixed methods to gather data in enough depth to allow understanding of the mechanisms at work. Both qualitative and quantitative data is synthesised to examine the mechanisms in the intervention. The methods chosen to gather data include surveys where validated tools gather quantitative data, semi-structured interviews provide a narrative of the clinician's experiences and perspectives of experts-by-experience of dementia of the intervention, and economic evaluation.

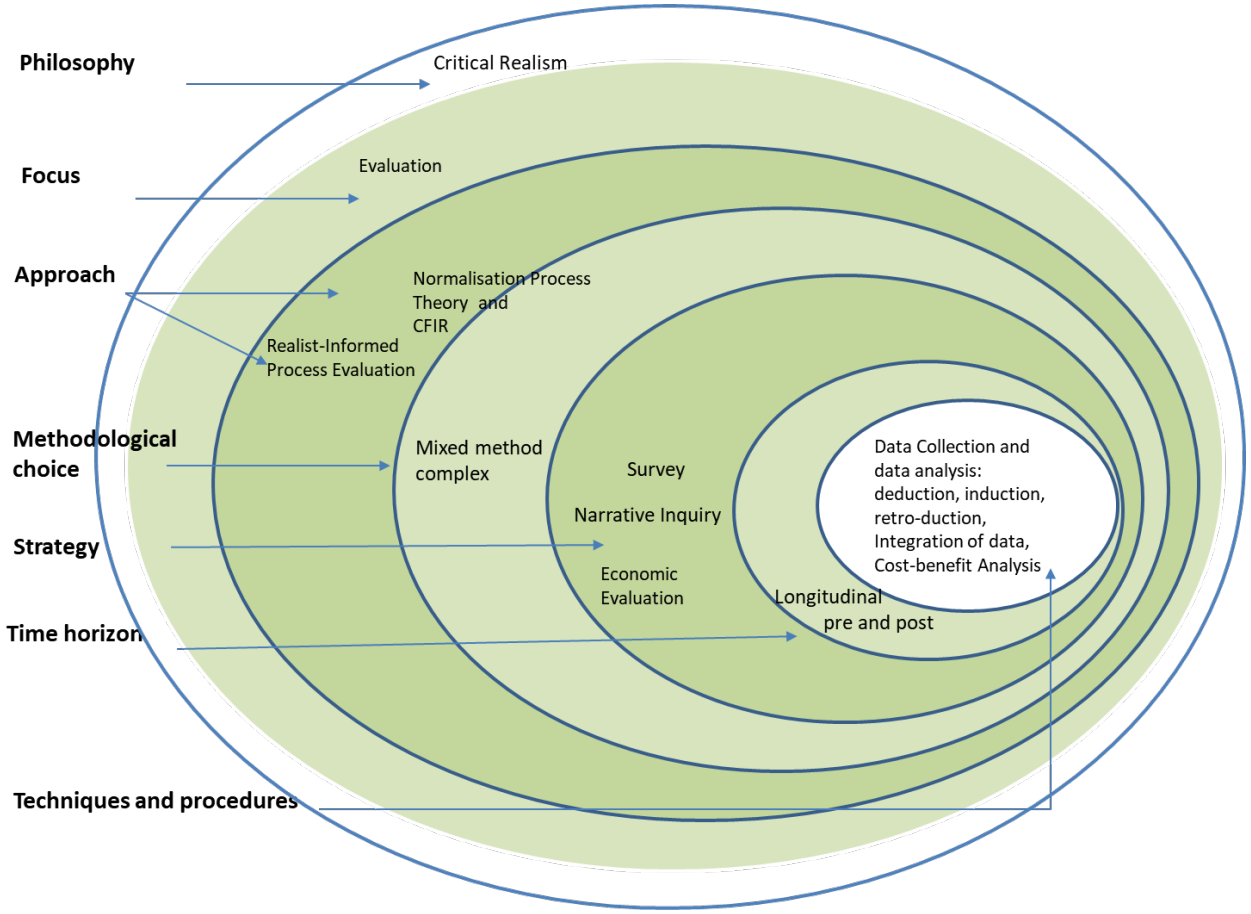


Figure 9 Layered research methodology adapted with permission from Saunders et al. 2011(217)

A recent analysis by Fletcher and colleagues integrates realist principles across all phases of the Medical Review Council evaluation framework (218). This approach guides evaluations to identifywhat works, for whom and in what context. Further it offers the opportunity to test and refine theories of interventions to create broader knowledge for policy and practice. Similarly, a methodological framework by Minary (219), guides the choice of evaluation design according to evaluation questions. Randomised controlled trial designs are not favoured where validity in real world settings and interest in the mechanisms of the intervention are the focus. This framework places process evaluations within implementation research in a realist evaluation design.

To test the hypothesis (identified in Chapter 1), that the context, collaboration processes, and cost-benefit of quality improvement collaboratives, can influence clinicians' skills and knowledge in quality improvement in dementia care, an exploration of causal mechanisms within the quality improvement collaboratives on participants is needed. The realist approach to evaluation research and NPT examines the concepts underlying programs and interventions to identify whether they work as they are intended and how this occurs. NPT identifies the work to be done by the clinicians in the implementation of change in their setting and can be used to demonstrate where the efforts need more support. A realist-informed evaluation approach was chosen to explain how interventions work within the quality improvement collaboratives for clinicians who then apply their knowledge and skills in their different contexts. A full realist evaluation would have examined the outcomes of the program in each setting which was outside the scope of this research.

3.5 Implications of a realist-informed approach

What works, how, in what circumstances and at what cost? are questions designed to understand and explain the process, not just describe outcomes of a program. These questions can advance the evidence for more successful implementation methods. A realist-informed process evaluation was chosen for this study as a theory-based approach to evaluation of a trial.

This process evaluation is an explanatory case study (196) of a larger quasi-experimental design interrupted time series trial, Agents of Change (6). The evaluation of that trial included a focus on outcomes of fidelity, sustainability, and penetration (202). This research seeks to understand how the quality improvement collaborative trial built knowledge and skills of clinicians, the value of the contribution of experts-by-experience of dementia and evaluate its costs. It focuses on outcomes of feasibility, acceptability, and cost. A realist-informed approach will allow an adaption of realist evaluation methods to suit the focus of the current study and contribute to the understanding of the quality improvement collaborative program. It draws on an exemplar of a realist informed process evaluation embedded in a randomised controlled trial (144).

More conventional approaches to empirical evaluation would examine whether implementation was effective by measuring clinical outcomes and costs and identifying barriers and enablers of the result. These approaches are less able to identify how context and processes combine to create outcomes or to explain the way people and resources interact with their context within which quality improvement takes place. While economic evaluation can be included in realist research, few examples exist (151). In implementation studies, the co-existence of different paradigms of analysis is accepted to inform explanations (101). The more pragmatic economic evaluation provides cost-benefit data from the short time frame of the larger trial. Its purpose is to measure costs and benefits to inform decision making on the effectiveness of the use of a quality improvement collaborative (153).

A realist-informed process evaluation draws on the methodology developed for realist evaluation to test hypotheses about the assumed mechanisms at work within a program. It identifies in which contexts and circumstances these mechanisms produce the expected outcomes. This approach offers a prospective stance to implementation strategies. It develops the theory of how the intervention is expected to work first, considering the context and costs to test propositions of whether it worked that way or not and why (198, 199).

3.6 How a realist-informed approach has been applied in other studies

Several recent studies have used a realist-informed approach or realist evaluation as part of larger implementation trials. These are summarised in **Table 4**. Rycroft-Malone and colleagues provide an exemplar for combining a realist informed process evaluation with a randomised controlled trial across multiple countries (144). This approach is like the embedded process evaluation in Agents of Change, a quasi-experimental design trial (6) and can be adapted to inform the theory framework for this study. Rycroft-Malone and others (220) also undertook a realist evaluation of collaboration between researchers and service providers in healthcare in England. This provides useful insights into the interpersonal interactions within collaboratives.

Shearn and colleagues (221) developed a method for building initial program theories to use in realist evaluations. They used a layered theory approach to develop their framework (221) combining a morphogenetic approach in Critical Realism (222) with Normalization Process Theory (106), and behaviour change theories (COM-B) (223). The results of that realist evaluation provided insights into the barriers at the societal, organisational, and interpersonal levels (224).The method informs the program theory developed in this research to evaluate the process of thequality improvement collaborative.

Flynn and colleagues (225) conducted a realist evaluation of the sustainability of Lean process change in paediatric healthcare in Canada. They identified contextual factors of top down implementation and lack of adaptation to local settings that affected mechanisms in the Lean (226) process for sustainability.

Devi and colleagues (227) describe a realist evaluation protocol to a quality improvement collaborative to deliver comprehensive geriatric assessment in care homes in UK. A change in planned delivery was required due to the complexity of the geriatric assessment process for the program members (94). Jeon and colleagues (228) describe a protocol of a hybrid design to implement a reablement program for people with dementia in Australia. The use of economic evaluation and a realist approach to process evaluation was designed to evaluate of how the interdisciplinary program is intended to work and at what cost. These examples demonstrate an interest in hybrid models and the coexistence of methods from different paradigms in implementation studies.

Table 4 Summary of recent uses of a Realist- informed approach to evaluating implementation in healthcare

Author	Title	Focus	Use of Realist Evaluation
Rycroft-Malone *et al.* 2018 (144)	A Realist process evaluation within the Facilitating Implementation of Research Evidence (FIRE) cluster randomized controlled trial: an exemplar	Theory-informed process evaluation of implementing urinary continence care recommendations (multi-country) for two facilitation methods to identify what worked. how, why, and in what circumstances	Theory development, testing and refinement, identifying the impact of the external and internal context on implementation using PARiHS framework of facilitation
Rycroft-Malone *et al.* 2015 (220)	Collective action for implementation: a realist evaluation of organisational collaboration in healthcare	Longitudinal realist evaluation of three collaborations for leadership in applied health research in care (UK) to identify how collaborations affected implementation	CMO configurations Identified the academic practice divide between health service staff collaboration and mechanisms for improved collaboration and implementation
Flynn *et al.* 2019 (225)	A realist evaluation to identify contexts and mechanisms in implementation in pediatric healthcare	Realist evaluation of the sustainability of Lean in pediatric healthcare in Canada across four units in one hospital	CMO configurations developed. To show how contextual factors and mechanisms affect Lean sustainment. Top down mandated implementation and lack of customization to context led to pitfalls
Shearn *et al.* 2017 (221)	Building realist program theory for large complex and messy interventions	A method for developing initial program theory for realist evaluation explaining key processes in local delivery of youth sexual health services in UK	Use of Normalization Process Theory, COM-B and Morphogenetic Approach to Critical Realism demonstrated a layered and interacting framework approach to realist evaluation program theory.
Devi *et al.* 2018 (227)	Quality Improvement Collaborative (QIC): Proactive Healthcare of older people in Care Homes (PEACH): A realist evaluation protocol	Realist evaluation to develop program theory of how QICs work to implement geriatric assessment in care homes	Protocol to develop and test program theory and CMO configurations in the first part of PEACH project to improve geriatric assessment.
Jeon *et al.* 2019 (228)	A pragmatic randomised-controlled trial and realist evaluation of the interdisciplinary home based reablement program: effectiveness-implementation hybrid design	Protocol for design of an effectiveness and process evaluation of the implementation of home based interdisciplinary reablement	Design for implementation outcomes to identify for whom and how the intervention works and what organisational and services factors influenced the implementation.

Abbreviations: PARiHS: Promoting Action on Research Implementation in Health Services Framework (229, 230); Lean: an approach to business process improvement adapted to healthcare from a manufacturing model (231); CMO: Context- Mechanism-Outcome configurations used in Realist Evaluation (26); COM-B: Capability, Opportunity, Motivation Behaviour change wheel (223); Morphogenic Approach: an approach to Critical Realism that identifies changes and interplay of structures over time (232)

The research in this thesis differs from these recent examples yet shares some methods that are adapted for this framework. It is situated within an implementation trial to improve adherence to clinical guidelines in dementia care across diverse settings. This research examines the strategy used in the Agents of Change Trial and evaluates how and why the process worked and at what cost (6). The purpose is to inform how and why the intervention worked, in what circumstances and at what cost to improve knowledge and skills in clinicians to improve dementia care. It tests the program theory of the intervention process to identify improvements and adaptions that may be needed for use of collaboratives in future. It explores the value of the involvement of people with experience of dementia in the collaboratives and identifies the costs and benefits of the collaborative strategy. The use of mixed methods to gather data on context, structures, processes, and costs allows for an integration of results to strengthen the findings. The factors in the broader context of the implementation trial, such as funding and policy changes, structural and cultural constraints or developments will be explored to develop understanding of in what circumstances the intervention works and the factors that may enable success (221).

3.7 Relationships between elements in the theoretical framework

A layered theoretical framework is used in realist evaluation to identify how mechanisms at the interpersonal, structural, and societal context interact and influence outcomes. This is especially relevant in complex interventions in healthcare where clinicians work with clients and teams of colleagues, within an organisational structure and culture, subject to funding and policy constraints and priorities from external contexts.

In this research, the strategy of a quality improvement collaborative attempts to improve the knowledge and skills of clinicians to implement improved practice that adheres to clinical guidelines for dementia care. The clinicians from diverse backgrounds work in different settings and locations across Australia with their own organisational, cultural, and structural influences. Each of the settings are affected by societal level policy, funding, and strategic directions.

The framework developed presents a layered approach to understanding the theories relevant to each level of the context. The theories identified are drawn from a review of theories of collaboration and communities of practice with the most common theories incorporated into the framework to test the assumptions within them. Within the quality improvement collaborative mid-level theories of motivation, learning, community of practice, leadership and accountability offer explanations of the mechanisms assumed to act. At the broader organisation level of implementation, mid-level theories of implementation related to context, teamwork, individual and organisational buy in and sustainment are relevant. Normalization Process Theory (NPT) (106) is used to conceptualise the process of translating an intervention into routine practice. At the societal context, both constraining and innovative influences impact the implementation process (233) and

are conceptualised as the external context in the Consolidated Framework for Implementation Research (CFIR) (105). ***Figure 10*** presents the relationship between theories acting at different layers of the framework. Each layer is examined in the process evaluation and their relationships with each other are explored to understand how and why the implementation strategy worked.

3.8 Summary

In response to the complexity of implementing evidence-based guidelines in healthcare and the range of theories, frameworks and models, a layered approach to a theoretical framework is needed to guide the methodology of this research. This novel theoretical framework links the layers of contextual influence in implementation with the theories that explain the work to be done by people in implementing changed practice, and the interactions between those layers. A realist informed evaluation approach to the process evaluation offers a method to explore and explain the mechanisms at work at the inter-personal, structural, and cultural setting and the external context of the intervention. A program theory was developed to make explicit the assumed rationale of the intervention and to test the theory in the evaluation. The economic evaluation identifies costs and benefits to inform decision making at the organisational and broader societal level.

This framework sits at the outer three layers within the ‘research onion’ methodology presented at Figure 9 explaining philosophy, focus and approach taken in this research. The next chapter outlines the methodology used in the inner four layers of the ‘research onion’, methods, strategy, time horizon and procedures used to gather and analyse the data and integrate the findings.

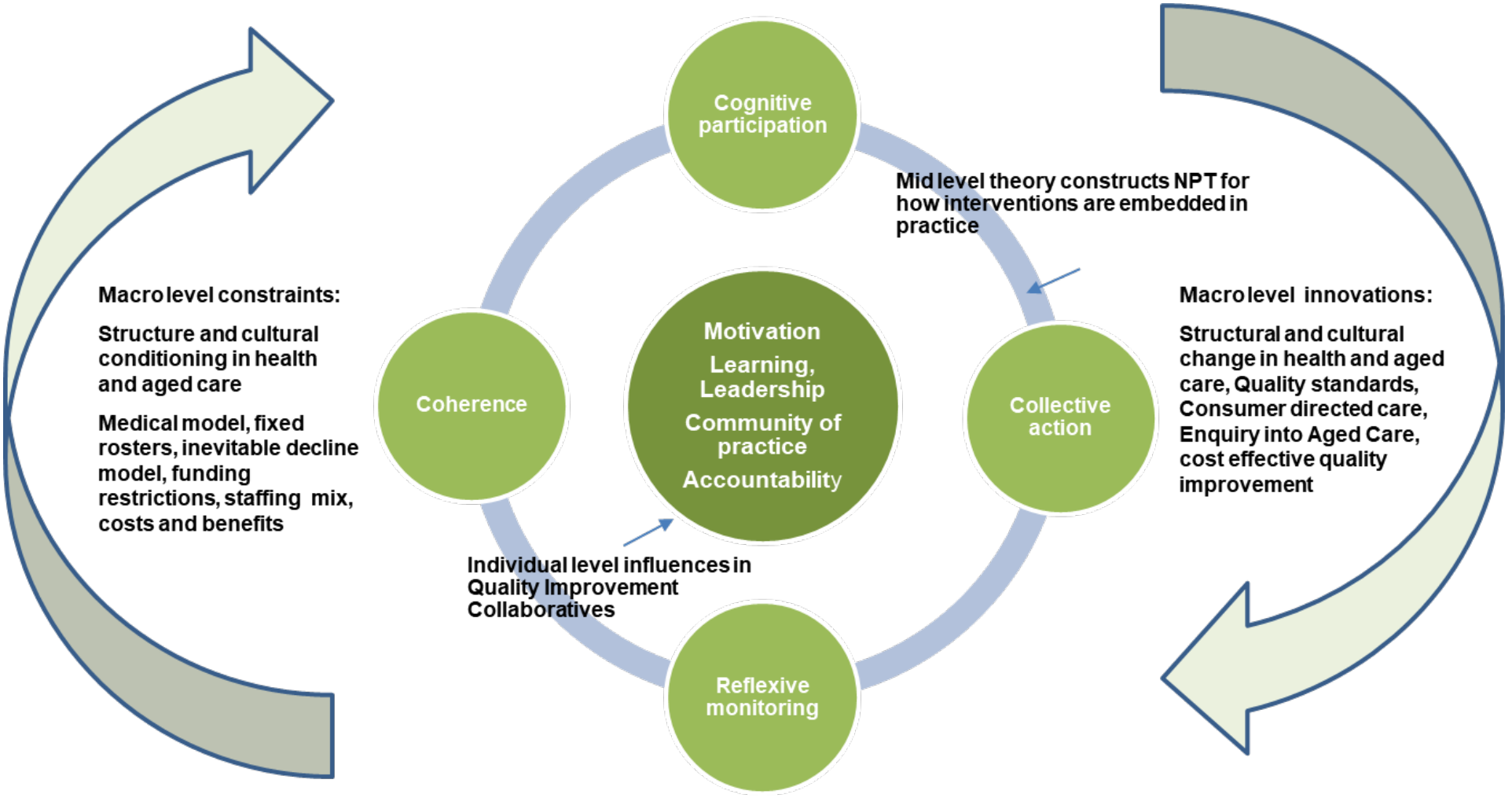


Figure 10 Framework of theories acting at different levels adapted from Shearn et al. 2017 (221)[7]

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CHAPTER 4 METHODOLOGY

4.1 Introduction

This chapter presents the overarching methods used to undertake the three studies in this thesis:

Study 1. (Parts A and B)

Evaluating the process of the quality improvement collaborative and whether they worked, how, why and in what circumstances, to build knowledge, skills and acceptance of clinicians who were participants (Chapters 5 and 6).

Study 2.

Identifying the value of involving people with dementia and caregivers as expert advisorsin the quality improvement collaborative (Chapter 7).

Study 3. (Parts A and B)

Identifying the cost benefit of a quality improvement collaborative to improve dementia care. (Chapters 8 and 9).

4.1.1 Theoretical framework

As outlined in the theoretical framework at Chapter 3, the methodology described here is represented by the inner four rings of the research onion design presented at ***Figure 9*** **(**217**)**.

Mixed methods (234) are recommended in realist evaluation to provide multiple sources of data (26, 27) and were used to understand why and how the collaborative process worked. Both qualitative and quantitative data were used throughout the three parts of this thesis with a qualitative approach more weighted for studies 1 and 2. Data were mixed at pre-and post-intervention, analysed separately, and integrated to identify patterns.

4.1.2 Link with Agents of Change trial

The three studies described here were explanatory case studies of the process and costs and benefits of the Agents of Change trial (6). The process and economic evaluations were included in the protocol for the Agents of Change trial which is attached at Appendix 1 for further background (6). The author, as a PhD candidate identified theoretical frameworks for the three studies, designed and developed the evaluations, contributed to the protocol, and ethics application for the trial, and wrote an ethics application to assess the value added by experts-by-experience of dementia. The author developed interview guides, data analysis frameworks, recruited participants from the trial, conducted the evaluations and wrote results and

conclusions. The principal and associate supervisors provided guidance and supervision throughout the candidature. A research associate in the trial assisted with screening articles for the systematic review, checking coding of 30% of the qualitative data and enabled extraction of quantitative data from the online platform of the trial.

Figure 11 shows how the process evaluation (Studies 1 and 2) and cost benefit analysis (Study 3) are linked to the Agents of Change trial (6). The process evaluation was conducted by the author over 18 months with data collection occurring before, during and post-intervention.

Figure 12 shows the timeline for the quality improvement collaborative intervention in the Agents of Change trial and when each component of the process evaluation was undertaken.

A description of the elements of the quality Improvement collaborative is provided at Appendix 4. At **Table 5**, the components that were considered in the process evaluation and identification of costs are itemised based on the template for intervention description and replication (TIDieR) checklist and guide, developed by Hoffmann and colleagues (235).

Agents of Change

A quasi-experimental, interrupted times series design trial to assess adherence to clinical guidelines for dementia care by clinicians participating in quality improvement collaboratives over 18 months.

Aim

To improve the implementation of three key recommendations from the Clinical Practice Guidelines for Dementia in Australia:

Occupational Therapy: People with dementia living in the community should be offered occupational therapy (reflecting evidence-based programs).

Exercise: People with dementia should strongly be encouraged to exercise.

Carers: Carers and family of people with dementia should be offered respite and have access to programs to support and optimise their ability to provide care for the person with dementia.

Intervention

Implementation clinicians will:

Participate in an online training course about quality improvement and translating evidence into practice.

Develop their own implementation plan using plan-do-study-act (PDSA) cycles.

Be supported to implement their plan within their workplace with the resources available to them.

They will have access to:

Online training and tools,

Ongoing meetings with the team of clinical, consumer and quality improvement experts, and

Online communication with their Quality Collaborative to manage any barriers.

Outcomes

Part 1: Guideline Adherence

Proportion of checklists submitted over time by clinicians that show adherence to guidelines.

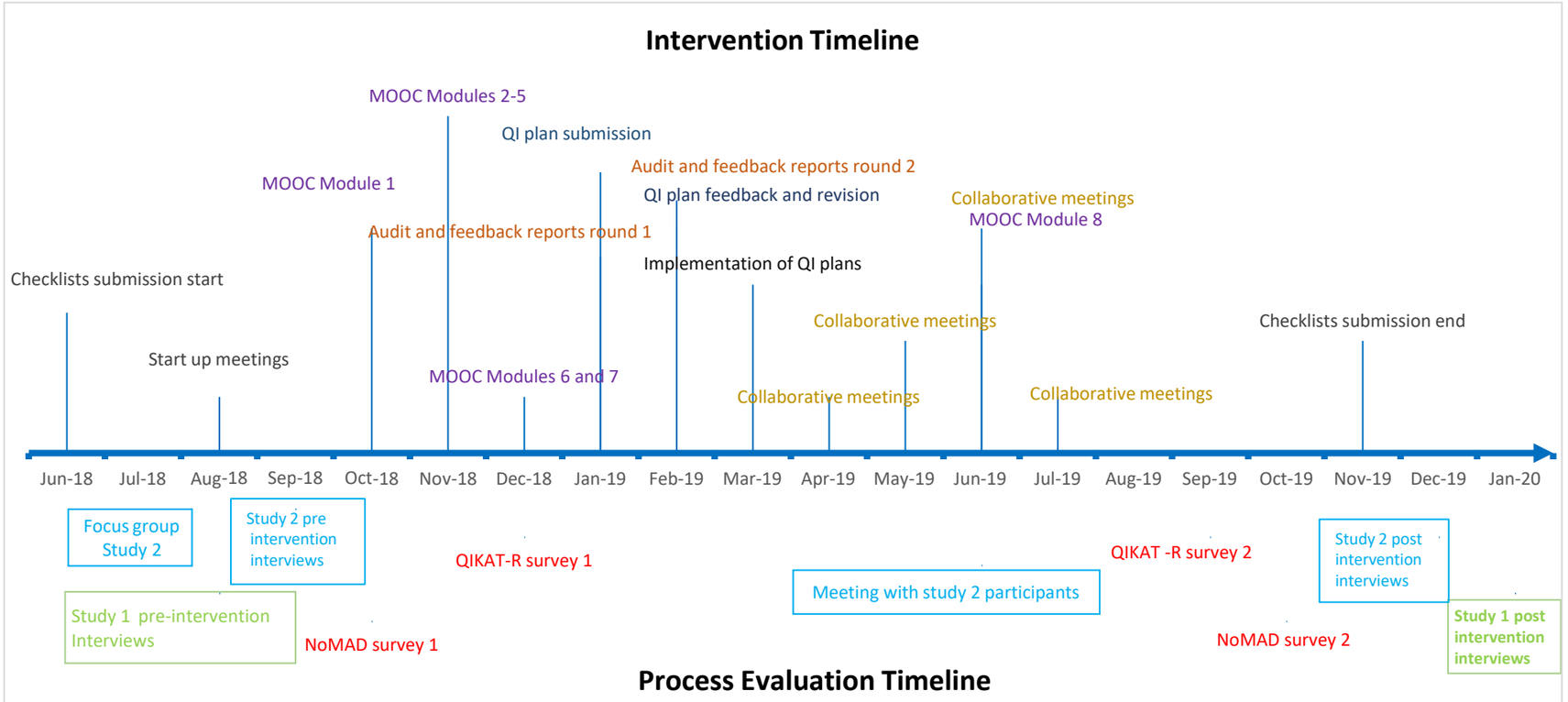
Part 2: Process evaluation

How, why, for whom and at what cost do quality improvement collaboratives work to improve knowledge and skills of clinicians in the quality improvement of dementia care?

Implementation outcomes (examined in this thesis)

Main study: guideline adherence	PhD Study 1: Pre- and post-intervention evaluation of clinician experiences	PhD Study 2: Consumer involvement in the research	PhD Study 3: Cost-benefit analysis of intervention
Fidelity, penetration, uptake.	Feasibility, acceptability	Feasibility, acceptability	Costs

Figure 11 Implementation outcomes of the Agents of Change trial showing the three studies examined in this thesis



Abbreviations: MOOC: massive open online course (training Modules), NoMAD: Normalization measure development tool, QIKAT-R: quality improvement knowledge assessment tool- revised, QI:quality improvement

Figure 12 Timeline of intervention and process evaluation showing pre and post intervention components

Table 5. Description of the QIC process of Agents of Change trial (based on elements of TIDieR check list developed by Hoffmann et al. 2014 (235))

Item	Description
Name	**Agents of Change**: establishing a quality improvement collaborative trial to improve adherence to clinical guidelines for dementia
Why	The aim was to increase adherence to three priority recommendations of the Australian Clinical Guidelines for Dementia by clinicians working with people with dementia and their caregivers.
Who provided	Agents of Change was delivered by a team of clinician researchers (Occupational Therapist, Psychologist, Geriatricians, Health Management academics, Health Economist, Clinical experts from health and aged care services, quality improvement and change management experts and experts by experience of dementia. The program was led by Associate Professor Kate Laver at Flinders University in South Australia and funded by the National Health and Medical Research Council (NHMRC) Cognitive Decline Partnership Centre (CDPC) (grant no: GNT9100000) and a NHMRC Boosting Dementia Research Grant (APP1135667).
What	• A Face-to-Face start-up meeting over 3 hours to meet participants and experts and share the program • An online quality improvement collaborative with 8 modules of learning on: Guideline recommendations for exercise, occupational therapy, and carer support to improve dementia care Quality improvement processes such as stakeholder analysis, Plan-Do-Study-Act cycles Change management processes Implementation planning and processes for monitoring progress • On-line surveys of skills and knowledge, checklists, workbooks, and interactive comments for participants and researchers to share • An audit and feedback report on gaps identified and adherence rate • Feedback on implementation plans with coaching and support from experts and research team as required • Webinars on topics of interest to participants to support implementation • Sub-group collaboration and sharing of ideas • Monthly teleconferences for collaboration, monitoring progress, providing information, and planning next steps
Where	Half day Start Up meetings Face-to-Face in Adelaide and Sydney, Australia with participants traveling to the closest meeting On-line learning and teleconferences for the 9 months of the collaborative program Participants joined online from 30 different locations across Australia
Participants	Experienced clinicians were selected who had some leadership role, provided clinical services to people with dementia and their care givers, and volunteered to participate with consent of their managers. They self-selected a subgroup for exercise, occupational therapy or carer support based on their interest and practice. They worked in public hospitals and outpatient clinics, community, and residential aged care services, and in private practices or as sole providers. They worked across all states of Australia from metropolitan, regional, and remote areas. They were physiotherapists, occupational therapists, nurses, medical practitioner, health services professional, dietician who engaged in the program individually and worked with others in their work setting to change practice to adhere to the clinical guidelines.

Item	Description
How	Recruitment through advertising on clinical websites, dementia and allied health newsletters and bulletins Telephone orientation to the process, activities, and expectations Face-to Face start-up meetings with presentations by clinical experts, researchers, and experts by experience On-line learning modules, interactive quizzes and comments sections and activity monitoring program Telephone collaborative sub-groups for exercise, occupational therapy, and carer support related to share ideas Telephone links with other participants Audit and feedback report of adherence by use of monthly check lists and feedback on implementation plans by experts Telephone support and coaching offered to assist participants to complete the program Email newsletters, follow up, regular incentives offered Certificates of completion and CPD achievements.
When and how much	30 participants recruited initially, with a second group of 15 participants recruited to cover those who dropped out. The collaborative operated for 18 months with initial data collection then learning modules released in stages over 12 months to encourage learning together, submitting checklists of practice monthly, and the development of improvement plans.
Tailoring	Participants identified gaps in adherence to guidelines through audit and feedback, identified a plan and adapted the recommendations to suit their own setting and priorities.
Modifications	During the course, webinars were offered based on feedback from participants and interest in learning more about specific topics. Separate sub-group teleconferences were phased out with combined teleconferences offered for all participants monthly.
How well	Planned: the rate of adherence to the guideline recommendations was tracked over12 months to show improvement and the process evaluation was planned to identify feasibility and acceptance of the trial and cost-benefit of the quality improvement collaborative strategy.
	Actual: an improvement in adherence from 24% initially to 82% by the end of the program with an increase in the rate of adherence noted after the release of the online learning modules. Participants reported satisfaction with the extent to which aims were achieved, improved outcomes, success in implementing quality improvement, beneficial to their clients and their practice. The process evaluation found that clinicians gained knowledge and skills in implementing improvements to practice, where their motivation and sense of identity was supported by their managers and others in the group. They developed confidence to improve their practice with credible resources, reflective practice and support that was adapted to meet their needs for flexibility and local settings. Where the improvements aligned with organisational priorities and drivers, clinicians gained recognition for their achievements. Clinicians reported that the QIC was acceptable to their needs and the delivery online was feasible and suited their needs for flexibility.

The studies in this thesis addressed feasibility, acceptability, and cost outcomes of the implementation strategy. Other outcomes are reported in a separate results paper (202). ***Figure 13*** highlights the outcomes evaluated in studies 1,2 and 3.

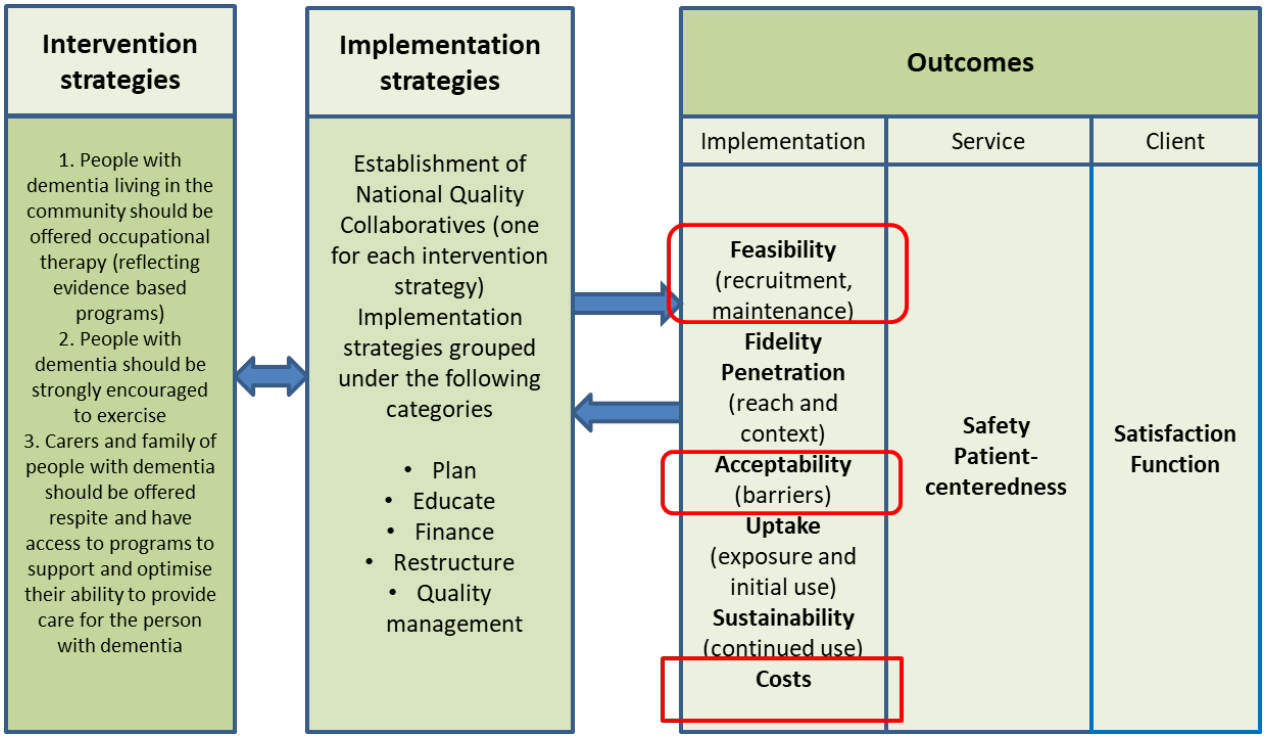


Figure 13 Implementation model used within Agents of Change (6) research trial based on Proctor et al.(48) showing the focus on three implementation outcomes for this thesis.

4.1.3 Ethical considerations

The author contributed information on the evaluation processes to the ethics application for the Agents of Change study which was granted by the Southern Adelaide Clinical Human Research Ethics Committee (HREC/17/SAC/88). The author sought ethical approval for the Valuing Expert Experience study to evaluate of the involvement of experts-by-experience of dementia in the trial, which was granted by the Social and Behavioural Research Ethics Committee of Flinders University #8057. These approvals at Appendix 2 a) and b), included the process of recruitment, use of consent forms for voluntary participation in the process evaluation, privacy and de-identification of data, opportunities for review of transcripts and withdrawal from the evaluation.

4.2 The research design

4.2.1 Mixed methods case study

An explanatory case study design (236) was chosen for an in-depth examination of the process of the quality improvement collaborative and the cost-benefits of the intervention in the context of healthcare (237). Mixed methods were used concurrently (238, 239) as recommended by a realist

perspective(209, 240), in realist evaluation (26). The Mixed Methods Appraisal Tool (MMAT) (241) was used to guide the design and to assess quality of the study. The checklist is presented at Appendix 3. The research questions about what worked, how, why, in what circumstances, and at what cost were best answered by connecting qualitative and quantitative data pre-and post-intervention (242). This approach allowed the opportunity to use data to confirm, refute or refine program logic, and assess the costs and benefits of the intervention. This provides understanding for future quality improvement collaboratives and the implementation of clinical guidelines.

4.2.2 Realist-informed Process Evaluation

This evaluation followed available guidance on process evaluation (129, 242) and realist evaluation (26) when applied in complex implementation (243) and knowledge translation interventions (138). The process evaluation was designed in two parts to answer two research questions:

Study 1: How and why the quality improvement collaboratives improved skills, knowledge, and acceptance of quality improvement among participating clinicians

Study 2: What value was added to the Agents of Change trial by the involvement of experts-by-experience of dementia in the research strategy and as advisors.

The designs for the two studies are presented below. ***Figure 14*** shows how these two studies are linked and contribute to answering the first two questions of this thesis.

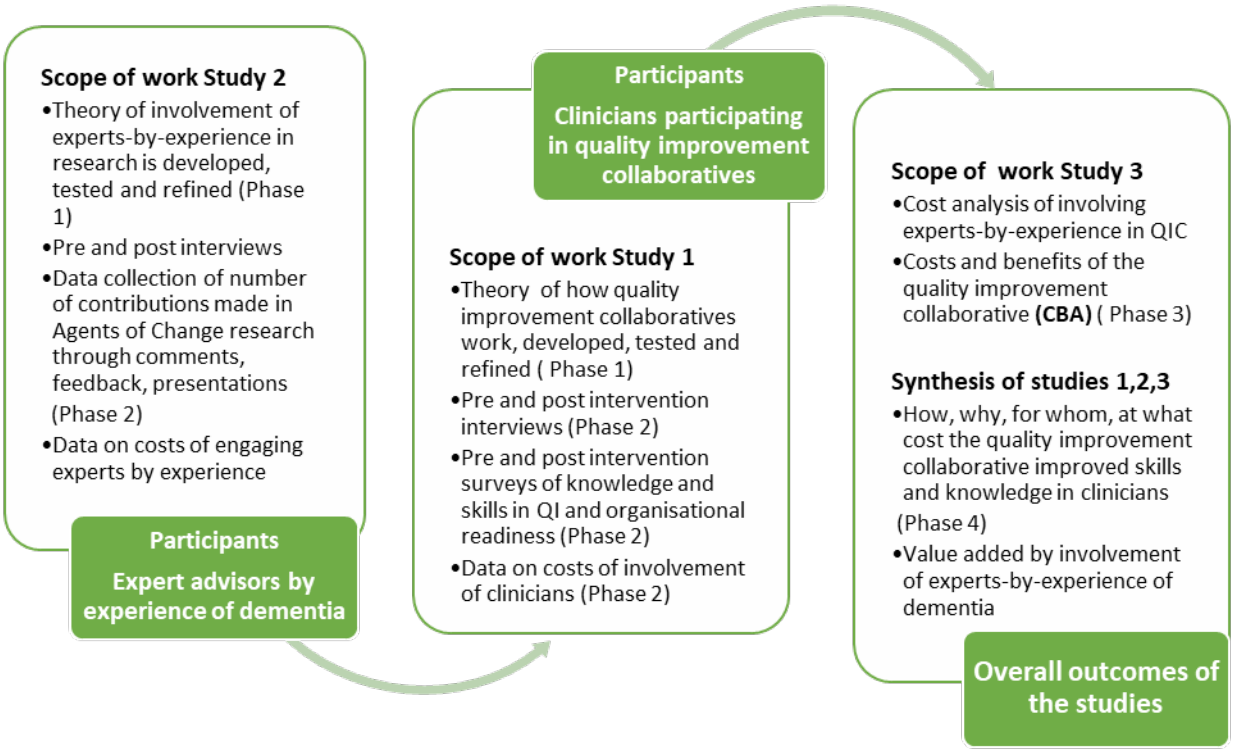


Figure 14. Relationship between Studies 1, 2 and 3 and outcomes

The process evaluation was completed in four phases:

- Phase 1: Realist evaluation program theory development and statement of hypotheses to

be tested

- Phase 2: Pre-and Post-intervention data collection surveys (Study 1) and interviews (Studies 1 and 2)
- Phase 3: Data Analysis, outcome patterns identified and hypothesis testing
- Phase 4: Refinement of the initial program theory based on mixing of the data and analysis

In Phase 1 the steps of the realist informed evaluation involved: 1) describing the strategy and logic of the program (see Appendix 4) , 2) considering the context (C) of the intervention, 3) identifying underlying mechanisms (M) of the intervention and 4) reporting on the implementation outcomes (O) achieved (15, 129, 242).This is denoted as Context (C), Mechanism (M) and Outcome (O) configurations (26, 240) in realist evaluation to understand the relationship between these aspects of a program.

In Phase 2, pre-and post-intervention data collection methods were developed to gather data on context of the intervention, the process of implementation, the mechanisms at work within the collaborative and in the setting, and the implementation outcomes achieved. In Study 1, surveys gathered data from a sub sample of Agents of Change participants on quality improvement knowledge (244) and understanding of implementation processes (245). In Study 1, semi-structured interviews were based on major domains in the Consolidated Framework for Implementation Research (CFIR) (105) and conducted using a realist interviewing approach (145). In Study 2 interview questions were based on frameworks for public involvement (246, 247).

In Phase 3, for Study 1 pre-and post-intervention survey results were analysed to identify change in knowledge and skills in clinicians while pre-and post-interview data were analysed to identify participants' reasoning for how and why the collaborative process worked or not for them. The results were integrated to test the hypothesis of the initial program theory. For study 2, pre-and post-intervention interviews with experts-by-experience of dementia were analysed to identify how they understood the role and to compare with comments by clinicians on the impact their input had on the collaborative. Illustrative quotations were presented to support the analysis of responses.

Phase 4 drew on the analysis of results to confirm, refute, or refine the initial program theory by integrating the analysis for each study. Where patterns matched initial hypotheses, the program theory was confirmed. Where data did not match the hypothesis was refuted and where additional patterns were identified, the program theory was refined. A revised program theory was proposed to include the evidence from the analysis and to contribute to understanding and building theory on how collaboratives build knowledge and skills for participants (138).

4.2.3 Participants and recruitment

A purposeful sub-sampling method was used for the process evaluation of the Agents of Change trial. This method is widely used in qualitative and quantitative research to select information-rich participants who cover therange of variation in the topic of study (161).
*Figure **15*** shows the participants involved in the Agents of Change research trial and the two main groups who participated in this evaluation.

4.2.3.1 Participant Clinicians

The clinicians were recruited to participate in the quality improvement collaborative trial via targeted advertising and an opt-in approach. They were eligible to participate if they were registered with aprofessional body (e.g. the Australian Health Practitioner Regulation Agency), had prior written support from their organisation, regularly worked with people with dementia and had influence or leadership roles in their organisation (6). They consented to participate in the quality improvement collaboratives and the process and outcomes evaluation. The participant clinicians were from a range of professions: occupational therapy, physiotherapy, nursing, medical practice, dietetics, social work, and community health. They worked in diverse healthcare settings across Australia, where people with dementia and care partners seek treatment and support. These included metropolitan and rural settings of general practice, community care organisations, aged care services, in-home and residential facilities, acute and sub-acute hospitals, outpatient clinics and private practice (6).

A sub-sample of participant clinicians in the trial were recruited to the evaluation and interviewed on first joining the quality improvement collaborative and towards the end of the project for the process evaluation If they withdrew before completion of the project, they were offeredan exit interview. They contributed qualitative and quantitative data as presented in **Table 6** Sources of data collection for Studies 1, 2 and 3.

4.2.3.2 Experts-by-experience of dementia

The second group of participants were experts-by-experience of dementia (both people living with dementia (*n*=3) and caregivers (*n*=5) who acted as expert advisors to the researchers and clinicians throughout the research trial (6, 248). They were recruited to the trial through existing working relationships with the research team from previous research involvement. To increase the number of people with dementia and caregivers with different perspectives, an advertisement was posted through Dementia Australia seeking expressions of interest for research involvement (6). The experts were invited to participate in the evaluation by the author after an email introduction from the trial coordinator. They were paid fortheir time to provide expert advice and participate in the evaluation. Their roles included:

- participating on the management committee,

- reviewing content for the on-line educational modules,
- providing expert advice and feedback to the researchers and to the participating clinicians,
- presenting at forums and conferences about the trial.

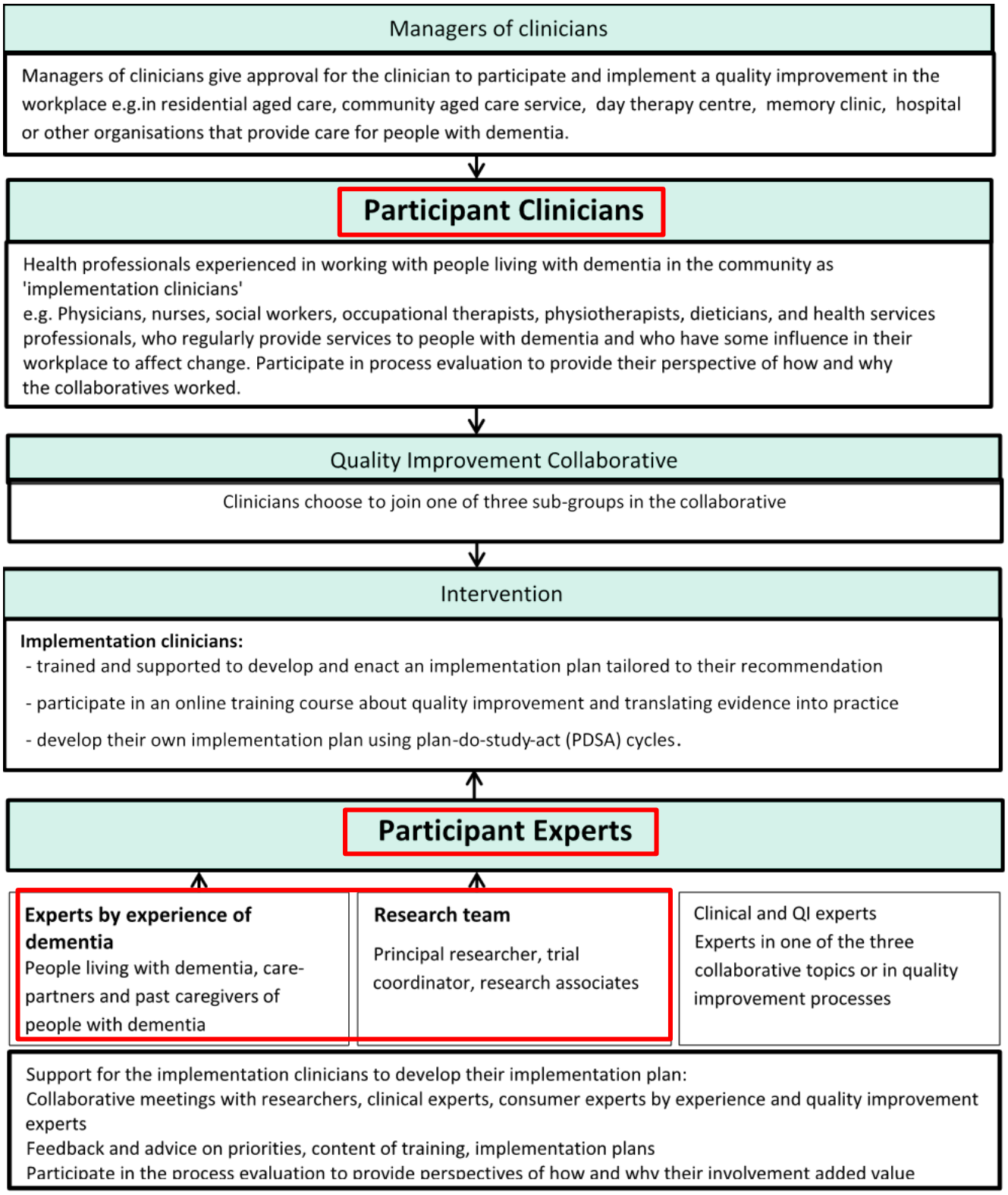


Figure 15 Agents of Change trial participants in the evaluation (clinicians, experts-by-experience and researchers highlighted

4.2.4 Data collection

Sources of data collection for Studies 1, 2 and 3 are presented at **Table 6.**

Table 6 Sources of data collection for Studies 1, 2 and 3

Participant	Data Collection	Study
Clinicians	Interviews pre-and post QIC/ Exit	Study 1
	Survey QIKAT pre-and post-QIC	Study 1
	Survey NoMAD pre-and post-QIC	Study 1
	Survey Willingness to Pay post-QIC	Study 3
	Expression of interest form	Study 1
	Orientation interview data on setting	Study 1
	Comments in online learning modules and emails	Studies 1 and 2
	Survey of hours spent on QIC modules	Studies1 and 3
Experts-by-experience	Focus Group via video conference	Study 2
	Interviews pre-and post-QIC	Study 2
	Meeting face to face midway through QIC	Study 2
	Newsletter articles and profiles	Study 2
	Comments on online learning modules	Study 2
	Claims for time spent on AOC duties	Studies2 and 3
Research team	Comments on Initial program theory	Study 1 and 2
	Newsletter articles	Study 2
	Minutes of meetings	Study 2
	Field notes	Study 1 and 2
	Expenses / activity spreadsheet	Study 3
	Promotion materials	Study 2

Abbreviations: QIC: Quality Improvement Collaborative; QIKAT: Quality Improvement Knowledge Assessment Tool; NoMAD: Normalization Measure Development; AOC: Agents of Change Trial

4.2.4.1 Study 1 Evaluating how and why clinicians built knowledge and skills in the QIC

i) Developing program theory

The initial program theory of how quality improvement collaboratives worked was developed by combining substantive theory such as learning theory, collaboration, communities of practice and motivation (249) with the researchers' theories of how the collaboration was expected to work in the trial. Discussion with the researcher team included group and individual discussions (250). Pawson outlines the stages in theory formulation, synthesising data from a wide range of sources (literature review and stakeholder consultation) (198). Data are then presented as a series of *'if…then'* propositions which describe the logic of the program of implementation (128).

For example, it is assumed that quality improvement collaboratives facilitate faster learning due to sharing ideas and plans, and the availability of feedback and coaching (251). Program theory describes how these mechanisms lead actions and outcomes. The initial program theory is presented as the resources provided to clinicians, configurations of context (C), anticipated responses as expected mechanisms (M), both positive and negative, and outcomes (O) at **Table 7.**

The program theory is used in the final interviews with clinicians which provides the opportunity to confirm, refute or refine the statements. This step preserves the elements of realist methodology to focus on context specific explanations of how quality improvement collaboratives work (136). This draws a boundary in this study to focus on the question to be answered about the role of quality improvement collaboratives in influencing clinicians' knowledge and acceptance of quality improvement skills to implement plans to improve dementia care (209).

The RAMESES standards for realist evaluation (252) were used as reference for the process, relevance and rigour in exploring program theory, developing context, mechanism and outcomes configurations and including stakeholders in the hypotheses to be tested. The checklist for these standards is at Appendix 5.

Table 7 Initial Program theory for clinicians participating in a quality improvement collaborative developed for testing in process evaluation

Initial Program Theory **Resources provided by the QIC**	**Context C +**	**Mechanism M +ve/-ve** **Response to the resource and context**	**= Outcome O**
Motivated clinicians with leadership responsibilities or influence, volunteer to participate in a free program to improve qualityof dementia care	Safety and quality focus, scrutiny of healthcare, aged care, reforms in policy, funding and accreditation, constraints in funding and increased demands	***+ ve Identity*** *(253) (254)* Passionate about improved dementia care / leadership in service development and support to make changes *-ve* ***Profession centric*** *(254, 255)* Not my role/ not my priority/ limits to my work	Expectations to learn new skills and knowledge to improve dementia care
Agree to use checklists to collect data and engage in learning	Time constraints and funding driven services prioritise clinical work	***+ve Accountability*** (256) Clinicians can check own practice, contribute to research on adherence to guidelines and gain access to learning modules ***-ve Fear of scrutiny*** *(257, 258)* Focus on work targets and limits to role	Commitment to project and learning
Incentives offered to encourage clinicians to complete the program	Required CPD for registration/ accreditation Deliver outcome in setting	***+ve Commitment*** *(259)* CDP helps clinicians to retain accreditation and adds credibility ***-ve Not a priority/incentive*** for some *(260)*	Continue with the program to the end
Learning with others online aids understanding and reduces time away from home and work	Travel for learning would reduce appeal due to time constraints but online learning allows opportunity to work together needed by clinicians	***+ve Doing it together*** *(261)* ***Easy/possible*** *(262)* Shared experience and confidence but provided flexible learning to fit in with workload -**ve** ***Prefer face to face/ not in own time*** *(263)*	Complete the learning modules and share insights
Collaborating with others results in faster uptake of the guidelines	Competing priorities would slow uptake of guidelines. Learning needs to be practical and flexible	***+ve Shared passion*** *(264)* Increases confidence to adapt improvements and provides role models in a community of practice ***-ve Competition/disengagement*** *(265)*	Guidelines understood and ways to adapt to settings shared
Expert advice, feedback and coaching enables improved strategies and plans	Limited access to experts or practice reflection due to isolation and system barriers	***+ve Credibility and authority*** *(266)* Confidence to learn / evidence of benefit ***-ve Doubt relevance practicality*** *(266)*	Adaptations to suit settings and to adhere to guidelines
Clinicians use the quality improvement process to make small changes and involve others in their setting	Resource constraints and reform priorities limit ability to make major changes	***+ve Influence*** *(267)* Clinicians learn to engage others in acceptable small steps to adapt ***-ve Lack authority or priority*** *(260)*	Changes are acceptable to others and more likely tobe implemented
Quality improvement process is accepted by others and benefits are seen	Practical improvements are valued by other staff who are likely to supportchanges	***+ve Ownership and commitment*** *(267)* Clinicians show improvements to staff and benefits to clients which increases commitment ***-ve Resistance*** *(267)from others due to role boundaries*	Successful implementation
Dissemination of results to others promotes awareness and benefits	Interest in wider services increases in low cost flexible improvements	***+ve Recognition and Reputation*** (268) Professional satisfaction and recognition of achievements by organisation and peers ***-ve Competition and disengagement*** *(269)*	Leadership in dementia care.

Table 8 Initial Program theory for involvement of experts-by-experience of dementia in quality improvement research

Initial Program theory Resources provided in research roles	**Context C+**	**Mechanism M +ve/ -ve Response to the resources and context**	**=Outcome**
Involving people with dementia and carepartners in research adds another perspective to benefit research.	NHMRC guidance on involvement of consumers in research follows from international approaches (NIHR) to involvement, co design and consumer ledresearch. Social science approach to perceptions.	***+ve Holistic inclusive approach*** *(270)* People with dementia and caregivers can offer different perspectives which contribute to better research. ***-ve Diluted quality of research*** Unable to contribute/ unscientific knowledge.(271)	New approaches and perspectives improve research.
People with dementia and care partnersvolunteer to be involved in conducting research and advising on research priorities and content.	Earlier diagnosis and younger people diagnosed with dementia provided a stronger voice for people with dementiaglobally. They aim for cure and better care through research for better approaches.	***+ve Nothing about us without us*** *(182, 270, 272, 273)* Consumer and citizen power/ democratic rights expressed by involvement in research and identifying priorities. **-ve Unrepresentative *self-interest*** *(47)* Diminish research efforts.	Research focusses on relevant areas and needs.
Researchers collaborate with people with dementia and care partners to identify rolesto allow contribution.	A range of ways to involve people with dementia are encouraged to allow researchers to recruit people who want to contribute.	**+ve *Forms of knowledge legitimised*** (274) A range of evidence of needs and methods are accepted. Empowerment of people who often feel left out ***-ve Leave the science to the scientists*** *(275, 276)* Researchers want to control the process to achieve rigour	Research matters to the people concerned and their experience.
People with dementia and care partners add unique perspectives and priorities to improve research.	Democratic and ethical approach by funders to involve those affected to identifyconcerns priorities and perspectives.	***+ve Meaning and relevance*** *(277, 278)* Creative interplay of perspectives adds meaning to the research and adds depth to the issues investigated. ***-ve Relevance of evidence*** *(271)* Hierarchy ofevidence still stands.	Improved research relevance.
People with dementia and care partnerslearn new skills and adopt new roles.	Consumer involvement is encouraged forimpact.	***+ve Learning and contribution gives hope*** *(279-281)* . People with dementia and caregivers learn to work with researchers and see how their work can influence research ***-ve False hope/ disability*** *(280, 282)* Learning too demanding.	Motivated co-researchers as stakeholders.
Researchers learn new ways to incorporatedifferent evidence and perspectives.	Consumer involvement is encouraged forimpact.	**+ve *Development of researcher skills*** *(283)* Learning offer new research methods to involve people with dementia and caregivers. ***-ve Extra work/ inequality of skills*** *(278)* Professional technical hierarchy of skills and effort required by researchers.	Abilities enhanced and range of methods widened.
Better research impact achieved by collaboration with consumers.	Public support for research that is relevantand addresses concerns of people with dementia and care partners.	***+ve Buy in*** *(284)* Impact improved by stakeholder involvement. ***-ve makes no difference*** *(171)* Hard to measure and disincentives exist.	Research is relevant and credible, supported by public and research community.

ii) Interviews

Developing the interview guide:

The interview questions were developed based on concepts drawn from three frameworks: The Consolidated framework for Implementation Research (CFIR) (105), the four constructs of Normalization Theory (NPT) (106) and Realist Evaluation (RE) (26). The framework for the development of the questions for clinician interviews is presented at **Table 9**.

Semi-structured private telephone interviews were piloted with two different participant clinicians both pre-and post-intervention, to check timing and order of the topics. Minor modifications were made before the rest of the interviews were conducted.

Recruitment:

Participants were invited to participate in interviews pre-and post-intervention and were introduced to the evaluator via an email from the project coordinator. The author undertook the evaluation as a PhD student with prior experience as a clinician and manager in aged care. Appendix 12 provides a reflection on this position in relation to the evaluation. An evaluator stance was taken which focused on understanding rather than managing improvement, through use of an interview guide. Consent to participate was sought using the approved ethics process for the evaluation of the Southern Adelaide Clinical Human Research Ethics committee (HREC/17/SAC/88) at Appendix 2a.

Participants from diverse settings were recruited to identify the range of mechanisms working within the program. Rather than a saturation process (as in traditional qualitative data collection and analysis), sufficient interviews were conducted to refine or refute as well as consolidate the program theory (145). The identified mechanisms were analysed by context, outcome, and participants to develop an understanding of what worked or not, how, why, for whom and in what context.

Conduct of interviews:

Telephone interviews lasting up to an hour, were conducted with participant clinicians, on commencement andon completion of the program. In initial interviews all participants were asked the same questions using an interview guide (see Appendix 6) and an opportunity was given for them to describe their setting, role, clients, and how they expected the collaborative to work. In the subsequent interviewson completion of the collaborative, another set of questions were used, relating to their experience of the collaborative, their achievements, and any barriers. This was supplemented with a realist interviewing approach, to share the program theory and seek their views of how the collaborative worked or not for them (145). Interviews focused on expectations and experiences with the collaborative and were audio-recorded and transcribed by an external company with consent, checked for accuracy, and sent to participants for comment or correction. Field notes made by the author during the interviews added information for accuracy, emphasis, or requests for no recording of parts of the interview.

Table 9. Alignment of framework concepts for development of interview questions

Context Setting, team,and individual elements: CFIR	Mechanisms of change in QIC explored: RE	Social processes in normalising the change: NPT	Questions for interviews with participant clinicians
Context	Identity, motivation to improve quality of dementia care	Coherence: changes make sense	Changes in policy funding processes, fit with organisation and practice, needs of clients, barriers to services or change
Organisation	Accountability and reward drivers internally and in organisation	Cognitive participation: engaging others in planning for changes Collective action: Engaging others in change actions	Support provided from manager and team, resources available, accountability for outcomes, recognition
Professionals	Collaboration, doing it together, motivation, commitment	Collective action: Engaging others in change actions	Learning about evidence-based practice, quality improvements, networking, achievements, CPD and other incentives
Intervention	Easy to do, credible, achievement and recognition	Collective action- Engaging others in change actions Reflexive monitoring- reviewing effects, evaluating changes	Fit with service and values, flexibility, acceptability, practicality, outcomes

CFIR: Consolidated Framework for Implementation Research (105); QIC: Quality improvement Collaborative; RE: Realist Evaluation (26); NPT: Normalization Process Theory (106); CPD: Continuing Professional Development

iii) Survey

Interview data in Study 1 were supplemented with quantitative data, gathered for the evaluation from the Normalization Measure Development questionnaire (NoMAD) (245), and the use of the Quality ImprovementKnowledge Application Tool-revised (QIKAT-R) (244).

Processes of normalising-NoMAD

The NoMAD survey instrument was used to assess clinician engagement in processes of implementing and embedding (normalising) change. The NoMAD tool (see Appendix 8) was developed and validated as a survey instrument (285) to investigate implementation processes across and between settings (286). The tool identifies the perspectives of professionals directly involved in the work of implementing complex interventions in healthcare and measures the level of agreement with statements describing processes of implementation. Results indicate which ones may be more significant than others to the respondent (287-289). The 23-item survey (245) collects information related to the four constructs of Normalization Process Theory (106, 285) coherence (does it make sense), cognitive participation (who is involved and supports the changes), collective action (how the change is implemented with others) and reflexive monitoring (how the change is

monitored and evaluated). This instrument is particularly useful as it can be used at different time points, to see if perceptions have changed after a period. It may also be usedto identify areas needing further work to progress an implementation project. The survey instrument was chosen as it was designed to be adapted and tailored for use in specific studies and can provide descriptive statistics on the implementation process (245, 285, 290). It has been used in several similar implementation studies (289, 291, 292).

Clinicians were invited to complete the NoMAD survey at the beginning and end of the online learning program, six months apart in the implementation process (see timeline at *Figure 12*). Data were extracted from the on-line modules into Excel (293) spreadsheets, converted to a five -point Likert scale (294) and independently scored by the author and an experienced research associate in the implementation team, to check for consistency in assessment.

Knowledge gained-QIKAT-R

The QIKAT-R (244) tool was used to measure the knowledge of quality improvement by participant clinicians both pre-and post-participation in the quality improvement collaborative. This instrument is designed to assess clinicians' ability to write an aim, a measure and change for a quality improvement scenario. A copy of the instrument is at Appendix 9. It measures change in knowledge across locations and health professions (244). The QIKAT-R maintains the validity of the original QIKAT but offers improved interrater reliability (295). This revised tool has been used to measure knowledge gained in medical education and multidisciplinary training in quality improvement (295, 296). The key subsections of the tool, (Aim, Measure and Change), align the assessment of quality improvement knowledge of participants in developing a quality Improvement plan for implementation. Each subsection has three items, scored using a yes=1 or no=0 with a total QIKAT-R score ranging from 0-9.

Clinicians responded to a vignette of a gap in quality service to identify relevant quality improvement methods. Data were extracted from an online survey into an Excel (293) spreadsheet and scored independently, using the rubric provided, by the author and an experienced research associate.

The quantitative data was used to assess the extent to which the data confirmed, refuted, or refined the program theory and the qualitative data, to enhance interpretation of program outcomes (145, 240).

4.2.4.2 Study 2 Valuing Experts by Experience

i) Developing program theory

A similar process to that used to for the program logic of the quality improvement collaborative was developed to explore the contribution of people with dementia and caregivers to the research (198,

250, 297). The literature review included iterative searches (297) for guidelines (248), discussion papers and components of substantive theory such as emancipation and developmental theory, collaboration, consumer rights, legitimate forms of knowledge and meaning. Discussion with the researcher teamincluded group and individual discussions (250). This method followed the stages in theory formulation and synthesising data from a wide range of sources (literature review and stakeholder consultation) (198). A series of *'if…then'* propositions were developed which describe the logic of the involvement of experts-by-experience of dementia (128).

For example, it is assumed that the involvement of experts-by-experience of dementia will be able to add to the research by providing their perspective, improving the relevance of the research, the examples and language used in the learning modules, and add credibility through the use of testimonials and feedback to clinicians. Program theory describes how these mechanisms lead thinking and actions. The initial program theory is presented as the resources provided to experts-by-experience, configurations of context (C) anticipated responses as expected mechanisms (M), both positive and negative, and outcomes (O) in **Table 8.**

The program theory is used in the final interviews with experts-by-experience of dementia which provides the opportunity to confirm, refute or revise the statements. This step in realist methodology focuses on a component of the quality improvement collaborative and explores the context and influence of the involvement of experts-by-experience of dementia in research (251).

The RAMESES standards for realist evaluation (252) were used as reference for the process, relevance, and rigour in exploring program theory, developing context, mechanism, and outcome configurations, and including stakeholders in the hypotheses to be tested. A checklist for these standards is at Appendix 5.

ii) Focus group and meeting

A pre-intervention focus group was conducted on request of the experts-by-experience to discuss the various roles and expectations, to connect with each other and to support their involvement. The focus group conducted by videoconference fulfilled two purposes: to provide a forum to meet and exchange information; and to gather data about expectations and supports required for them to be genuinely involved in the research. This process was developed following guidance on running focus groups with people with disabilities and in articulating strategies for involving people with dementia in research (298, 299). The videoconference was audio-recorded and transcribed by an external company with consent and checked for accuracy. A further face to face meeting was held to exchange information on the progress of the research, the experience of the experts and to provide support for their roles in the research. This was held mid-way through the intervention. Field notes were made of the meeting, recording attendance, topics of discussion and areas of change or clarification. The timeline at ***Figure 12*** shows where the focus group and meeting fitted

within the evaluation plan.

iii) Interviews

Interview guide development:

The interview questions were developed based on concepts drawn from guidelines on involving the public and patients in healthcare research from the Australian NHMRC Consumer Health Forum (248), the INVOLVE (247) framework for public involvement in research, and the public involvement impact assessment framework (PiiAF) (300). **Table 10** presents how questions align with values and principles in the INVOLVE framework.

Semi-structured private telephone interviews were conducted pre-and post-intervention with experts-by-experience of dementia (see *Figure 12*). These were undertaken to develop an understanding from their perspective, of what worked or not, how, why, for whom and in what context.

Recruitment: experts-by-experience of dementia who were recruited to provide advice in the trial were introduced to the evaluator via an email from the project coordinator. They were invited to participate in the evaluation interviews. The author undertook the evaluation as a PhD student with experience as a clinician and manager in aged care. Consent to participate was sought using the approved ethics process of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University (SBREC 8057). See Appendix 2 b).

Table 10. Alignment of interview questions with values in INVOLVE framework for public involvement in research (247)

Values	Principles	Questions explored in interviews
Respect	For roles and perspectives	How clear were roles, how suitable were tasks, and what relationships were established? How were they able to influence the research?
Support	Access to practical support	Was orientation, training, IT support, and payment arrangements practical? and what supports were available? Were any changes made?
Transparency	Clear and open about aims	What discussions, meetings were available to clarify scope? How would they discuss limitations, abilities, and type of input? What reporting and feedback was provided?
Responsiveness	Respond to input	What kept them committed to the research and how were decisions made?
Fairness of opportunity	Open to all	How accessible was the process? Were alternative formats available, and process inclusive?
Accountability	For involvement and impacts	What kept them accountable to each other? What were they able to contribute and how did they assess impact of the contribution? What improvements were needed? How relevant was the program logic to their experience?

Conduct of interviews:

Telephone interviews lasting up to an hour, were conducted with experts-by-experience of dementia. Each expert was offered a separate interview time. Two couples (a person with dementia and a caregiver) asked to be interviewed together for support and convenience. Interview questions (at Appendix 7) were emailed in advance of interviews to allow time to consider their response. The interviews focused on experience in prior research, expectations, and their experience in this project. The initial program theory was shared in the final interview, using a realist interviewing approach (145) to confirm, refute or refine the theory. Interviews were audio-recorded and transcribed by an external company with consent, checked for accuracy and sent to experts-by-experience of dementia for comment or addition. Field notes made by the author during the interviews added information for accuracy, emphasis, or requests for additional information.

iv) Document analysis for contributions made by experts-by-experience of dementia

Comments made by experts-by-experience of dementia in online modules, in minutes of meetings, in presentations, on review of plans, and notes of feedback were reviewed. Data were extracted to

quantify the number and type of contributions made and where the contribution resulted in changes to the research. This data describes the activity, time and number of contributions made in the research trial for use in identifying benefit.

Comments made by clinicians about the involvement of experts-by-experience of dementia, in interviews, in online modules and in feedback to the research team were extracted to identify where the contribution resulted in change of thinking or action by clinicians. Sources of data are presented at **Table 6.**

4.2.5 The design of the Cost-Benefit Analysis

Economic evaluation provides an assessment of the 'worthwhileness' of a program by comparing the costs and benefits (29). A cost-benefit analysis was chosen for this study as a type of economic evaluation to compare and value broad costs and healthcare goods associated with a quality improvement collaborative. As a preferred approach of the Australian Government, cost-benefit analysis provides an objective framework for accounting for the effects of a program (301). Researchers and decision-makers can identify the benefits and costs from societal, service provider and user perspectives and to appraise the use of scarce resources (302). It provided a systematic framework to compare costs and benefits of the collaborative implementation strategy from a societal perspective (303). The costs and benefits were monetised to allow comparison of the costs of the implementation process with the benefits it provided to clinicians in collaboratives, over time.

4.2.5.1 Measuring Benefit

While benefits are usually measured in market terms, this is rare in health care implementation projects as they are usually publicly funded (304). In this study for instance, the value to participant clinicians of networking with others with similar aspirations does not have a market price. A stated preference survey technique was used to ask clinicians directly what they would be willing to pay for participation in the collaborative. This provides a viable alternative to valuing goods where there is no market price (29). This creates a shadow price (the cost of using resources in a project) to value the benefits (through a contingent valuation approach), exploring participant's stated preferences for willingness to pay for the intervention (29).

An open ended 'Willingness-to-Pay' questionnaire was administered in the interviews with clinicians at the end of the project (305). This was used to identify a contingent value (an accurate estimate of the value of benefits contingent on a market existing) (306) that participants in the quality improvement collaborative were prepared to pay for the intervention. The willingness-to-pay questionnaire described the possible benefits that accrued from the quality improvement collaboratives. This information was sent to participant clinicians by email prior to telephone

interviews when possible, and then discussed during the interviews. Drawing on the program theory developed for the quality improvement collaborative, the potential benefits identified were as listed in **Table 11.**

Table 11. Potential benefits accrued from participating in the Quality Improvement Collaborative

Benefits	Measure	Unit
Skills and knowledge in quality improvement	QIKAT-R	Score out of 9 pre and post intervention for each clinician
Value of CPD points gained	Hourly rate for time spent	AU$
Involvement in research	Hourly rate for specific CPD points	AU$
Addition to role competency	Increase in hourly rates of pay	AU$
Future promotion or recognition	Increase in hourly rates Attendance at conferences	AU$ AU$
Improved practice in organisation	Reduced hours for accreditation admin	AU$
Improved services to people with dementia and care partners	Increased satisfaction, new clients	Satisfaction rate % improvement No of new clients
Improved reputation of service	Hourly rate for marketing New referrals	AU$ No of new referrals
Little travel away from work	Hours saved by reduced travel	AU$
Network with other clinicians	New connections made	No of new connections
Access to coaching, feedback and advice	Hours accessed	AU$

Abbreviations: QIKAT-R: tool to assess knowledge and skills in quality improvement, CPD: continuing professional development, AU$: Australian Dollars 2020, No: number

Participant clinicians were asked to describe their experience of being involved in the quality improvement collaboratives in the post intervention interview. This process provided an indication of the benefits they experienced, how they came about or were hampered and the outcomes they achieved. They were then asked to identify whether their experience in the collaborative was the same, better, or worse than other professional development activities that they have undertaken to accrue continuing professional development (CPD) points for accreditation. Clinicians were asked to suggest an amount they would be willing to pay per week or month or overall, to receive all the benefits associated with the collaboratives over the 12 months of the program and the reasons for that value. This approach weighs up all components and transforms them into a single value (307).The questions for the post-intervention interviews and willingness-to-pay questionnaire are provided at **Table 12.**

Table 12. Questions for clinicians in post-intervention interviews incorporating a willingness to pay questionnaire

Alignment with CFIR **(105)**	Questions for clinicians	Mechanisms explored (26)	Alignment with NPT **(106)**
Context	Changes, fit, needs, barriers	Identity, motivation	Coherence
Organisation	Support provided, accountability, recognition	Accountability and reward	Cognitive participation and collective action
Professionals	Learning, continuing networking, achievements, CPD	Collaboration, motivation	Collective action
Intervention	Fit, flexibility, acceptability, practicality, outcomes	Easy to do, credible, achievement	Collective action Reflexive monitoring
Costs	Rating of collaborative quality	Judging benefit and effort	Reflexive monitoring
	Willingness to Pay $ for benefits	Value of project	Reflexive monitoring
	Realistic payment $	Consider value	

Abbreviations: CFIR: Consolidated Framework for Implementation Research, NTP: Normalization Process Theory, CPD: continuing professional development, $: Australian dollars

4.2.5.2 Identifying costs to determine cost-benefit

Three elements of costs were identified: Start-up costs, support costs and research costs. The research costs involving the ethics applications and evaluation were excluded from the costs of the collaboratives as they were part of the trial expenditure.

Start-up costs included:

- development of the on-line modules
- review of content by expert advisors
- cost of on-line platform for modules
- recruitment of participants and experts
- face to face and start-up meetings.

Support costs included:

- time spent by research team on collaborative teleconferences, coaching sessions
- expert advisors time to contribute to the teleconferences and provide feedback on implementation plans
- time spent in meetings and discussion
- webinars developed and presented
- maintaining connections, newsletters, information, and incentives provided (materials and funding for conference attendance).

4.3. Data analysis

4.3.1 Qualitative analysis

4.3.1.1 Clinician Interviews

Transcriptions of interview data were entered into QSR NVivo version 12 (308) for analysis.
A framework analysis (309) coding matrix was developed as a conceptual device to consider data from three different perspectives, CFIR (105), Realist Evaluation (26) and NPT (106).

The three coding sets were:

- The five major domains of the CFIR (105):
  (the outer setting, inner setting, the individuals involved, the intervention characteristics and the process of implementation)
- The four constructs of NPT (106):
  (coherence, cognitive participation, collective action, and reflexive monitoring)
- The nine initial C-M-O configurations of the program logic used from a Realist Evaluation (26) approach (listed at Table 7).

Transcripts were reviewed deductively for each perspective and data extracted to each coding set. This process allowed a theory-led analysis rather than confining analysis to one specific framework (84) (136, 310). An inductive process of analysis was then conducted to identify other themes that did not fit within the frameworks and where the same comment applied to multiple codes.
A retroductive or backtracking approach was then used to identify where similar comments may apply in different perspectives or differ by context. This provided a review of coding and interpretation of the elements of each perspective. A 30% check of coding by another researcher showed general agreement for coding, but with fewer excerpts selected. Any differences were resolved by discussion to clarify the meaning of the codes. The combination of induction, deduction and retroduction (backtracking) methods allowed the exploration of relationships between outcomes, context, and mechanisms for the participants (215) (311, 312).

A framework of excellence in qualitative research (313) was used to review the process of analysis. The criteria of high quality research in this framework, involving a worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethical approach, and meaningful coherence, has been used to provide a common way to report on quality of qualitative research where some methodological practices overlap in practice (313). The extent to which these criteria are addressed is described at Appendix 12 following a “researcher reflexivity” process.

4.3.1.3 Experts-by-experience of dementia interviews, focus group and meeting

A similar framework analysis approach was used to analyse the interview data obtained from the experts-by-experience of dementia. The frameworks used for the experts-by-experience of dementia were:

- The seven C-M-O configurations from the program logic developed for involvement of experts-by-experience of dementia in research:
  (Listed at **Table 8)**
- The six values in the INVOLVE framework (247):
  (Respect, support, transparency, responsiveness, fairness, and accountability).

The reporting of the involvement of experts-by-experience of dementia followed the guidance for reporting on patient and public in research checklists (246) . This aims to improve the evidence base for patient and public involvement (PPI) in research. This checklist is at Appendix10.

4.3.1.4 Field notes

Notes were made during the pre-and post-intervention evaluation contact with clinicians and experts by experience. These were reviewed to clarify any transcription gaps and to identify issues discussed during the intervention that may have indicated barriers, mechanisms, or additional influences in the collaborative process. This process of reflection on notes provided another exploration to refine, refute or consolidate the program theory and context, mechanisms, and outcome configurations. It also provided transparency and views during the evaluation which may have reflected bias (313).

4.3.2 Quantitative analysis

4.3.2.1 Analysis of costs and benefits

The benefit-cost ratio method was used to assess value of the intervention overall. The approach was based on methods developed by McIntosh and others (29) and information was evaluated from a societal perspective. The analysis included the costs and benefits for participant clinicians, their employers, the research project team, and the expert advisors. The benefit analysis considered the impact of the quality improvement collaborative in terms of improved knowledge and skills of clinicians and improved adherence to guidelines, expressed as a willingness to pay value. A Benefit-Cost Ratio method summed the total benefits of the quality improvement collaboratives over the 12 months of the project for each clinician in the program and divided that by the total costs. A discount rate was not required as the program did not extend beyond a year.

Analyses were undertaken to explore benefit-cost ratios for three scenarios and to identify the number of participants needed for the collaborative strategy to break even. The scenarios incorporated; i) all base costs, ii) excluding costs of clinicians to participate in the collaborative, iii) excluding start-up costs and costs of clinicians to participate, and excluding some incentives, to explore the impact on the benefit-cost ratio. Where benefits outweigh the costs there is a net social benefit which can be considered in deciding on resource allocation for future collaboratives or for scaling up the reach of collaboratives across dementia care in Australia.

reporting of economic evaluations, provides a checklist that was used in reporting on the cost-benefit analysis undertaken as part of this research (314). The completed checklist is at Appendix 11.

4.3.2.2 Survey analysis

NoMAD

Descriptive statistics were used to present the level of and frequency of agreement by participant clinicians to each question pre-and post-intervention on the NoMAD tool (245). Areas where increased agreement with statements were identified post-intervention, indicated improved understanding of the processes of implementation. Areas where no change or reductions in agreement to the statements were reported post-intervention, indicated processes were less understood or less successful. One question from the Collective Action construct (*the intervention disrupts working relationships)* with a negative valence, was interpreted as disagreement being related to success innormalising improvement.

Total scores were not calculated as per guidance by the developers (245) and other researchers (291)(289). The items of the NoMAD tool are grouped under four NPT (106) constructs (Coherence-4 items-Cognitive Participation-4 items, Collective Action-7 items, and Reflexive Monitoring-5 items). The data from clinician interviews on context, mechanisms and outcomes were compared to results from the pre-and post-intervention surveys for individual clinicians and for key settings to identify patterns which help to explain how the collaboratives built skills and knowledge for the clinicians and how settings influenced outcomes.

QIKAT-R

The measurement of change pre-and post-intervention was intended to assess impact of the intervention on knowledge and skills in quality improvement. Scores were calculated using the rubric provided with the tool (244), with a maximum score of nine. A score of five or more was considered good on the rubric. There are several limitations in using statistical analysis tests on this data (315). A small sample, no control group, and missing data limits the claims that can be made about cause of the changes observed. Descriptive statistics are therefore used to indicate the differences in pre-and post-intervention scores.

4.3.3 Integration of data

Data from interviews and surveys were integrated at both the pre-and post-intervention stages through description and joint display (234, 316) to identify where they confirmed, refuted, or modified the initial program theory. The measurement of change at two time points was intended to identify the impact of the intervention on clinicians' knowledge and skills in quality improvement and in implementation processes. These results were aligned with the mechanisms of change identified through the interviews and displayed jointly to assess the influence of the quality improvement collaborative. A revised program theory was developed at the post-intervention process evaluation stage to explain how and why the collaborative built knowledge and skills in quality improvement for participant clinicians.

Cost-benefit ratios were calculated for the quality improvement collaborative intervention and costs of involvement of experts-by-experience of dementia were reported. These were used to identify the costs of elements of the intervention strategy that aligned with the program logic of mechanisms of change.

CHAPTER 5 (STUDY 1:PART A) PRE-INTERVENTION PROCESS EVALUATION

Identifying context, motivation, expectations, support, and confidence upon commencement of the quality improvement collaborative: a mixedmethods study

5.1 Introduction

The process evaluation (Study 1) was designed and conducted by the author in two parts: Part A pre-intervention and Part B post-intervention to compare the expectations of clinicians in the collaborative to their experience on completion. This chapter presents Part A, pre-intervention stage of the evaluation. The author developed the theoretical framework (Ch 3) and methodology (Ch 4) to conduct the process evaluation as a realist-informed evaluation to build theory on the quality improvement collaborative strategy. A sub-sample of the trial participants were recruited and interviewed by the author. The data was analysed by the author and the coding was checked by and experienced researcher on the trial. The principal Investigator for the trial included the process evaluation in the protocol for the trial and supervised the work of the author.

The objectiveof this research was to understand motivations, expectations, context, support, and confidence of clinicians as they enrolled in the trial of a quality improvement collaborative (6). An excerpt from *Figure 14 Relationship between Studies 1, 2 and 3 and outcomes* at Chapter 4 is presented here (*Figure 16)* to focus on the scope of Study 1.

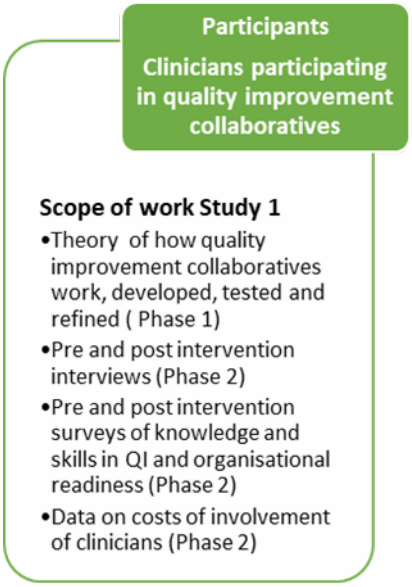


Figure 16 Excerpt from Figure 14 focusing on the phases of Study 1

As described in Chapter 4, clinicians were eligible to enrol in the quality improvement collaborative trial if they were experienced clinicians working with people living with dementia and had some

form ofleadership role within their workplace. They selected one of three sub-groups of the collaborative to join, related to guideline recommendations on; occupational therapy; or exercise, or carer support, to improve their practice with people living with dementia.

To my knowledge, the Agents of Change (6) trial was the first to use a quality improvement collaborative approach to improve adherence to clinical guidelines for dementia care in Australia. A light-touch, low-cost intervention was trialled, involving online learning modules, teleconference meetings, telephone, and email communication, to reduce time and costs of participation. People living with dementia and caregivers (hereafter referred to as experts-by-experience of dementia) were involved in all stages of the research trial and the impact of their involvement is discussed in Chapter 7.

Understanding how and why quality improvement collaboratives work under different circumstances helps to assess feasibility and acceptability of the trial (129), to justify the use of the strategy for wider implementation. In applying the quality improvement collaborative approach to dementia care, it was hypothesised in the trial that if motivated, supported, and experienced clinicians were able to engage with the collaborative strategy, they would learn quickly, maintain their commitmentand influence others to improve practice. This pre-intervention process evaluation (Study 1-Part A) was designed by the author to explore the context and expectations with clinicians as they enrolled in the trial and to develop the initial program theory for the quality improvement strategy to test at the post-intervention stage of the strategy.

5.2 Methods

This mixed-methods research (316) followed guidance on process evaluation (129, 240, 242) and realist evaluation (26) in knowledge translation interventions (138).

The methods used are described in detail at section 4.2 of Chapter 4 and are summarised briefly here.

Phase 1. The initial program theory was developed by consultation with stakeholders and reference to literature and theories of collaborative learning. The theory included expected mechanisms and those that may present barriers. These are presented as possible positive and negative mechanisms in relation to expected program theory at **Table 7** in Chapter 4.

Phase 2. Data collection:

Interview data: Clinicians were invited to participate in pre-intervention evaluation interviews and introduced to the evaluator by email. Telephone interviews were conducted at times to suit the clinicians, recorded, transcribed, and analysed on NVivo (308) software using a framework analysis method described in Chapter 4. This framework was used as a conceptual device to

consider datafrom three different perspectives to allow constant comparisons between data from different settings and collaborative sub-groups. It allowed a theory-led analysis rather than confining analysis to one specific framework (84, 136, 309).The framework and questions are presented at **Table 9** in Chapter 4.

Surveys: Clinicians were also invited to complete pre-intervention surveys of quality improvement knowledge (QIKAT-R) (244) and implementation processes (NoMAD) (245) which were embedded in the online leaning platform. Responses to QIKAT-R were scored using the template provided to assess knowledge of quality improvement resulting in a score out of nine possible points. Responses to the NoMAD survey are presented as descriptive statistics of the strength of agreement by clinicians with the 23 statements in the survey, related to their own situation. The stronger the agreement with statements indicated understanding of the processes of implementation and weaker agreement indicated where additional work may be needed to progress the implementation project.

Phase 3. Quantitative Data were scored using templates provided with the surveys and analysed using descriptive statistics. Qualitative data from interviews were coded inductively and deductively using the framework analysis approach (120, 309) and reviewed retroductively in line with a realist approach (27, 317), to identify other patterns or possibilities emerging from the data. Data were integrated by description and joint display to confirm, refute, or modify the initial program theory (234, 316).

5.3 Results

5.3.1 Participants in the process evaluation (Phase 2)

A purposive sample (161) of 29 clinicians (64% of all clinicians in the Agents of Change trial) who had completed their orientation to the collaborative, were invited to participate in the evaluation. Of these, 28 participated in the process evaluation, while one did not respond to invitations. The QIKAT-R was completed by 26 (58%) at pre-intervention. The NoMAD survey was completed by 13 (29%) at pre-intervention. ***Figure 17*** presents the numbers of participants in the evaluation in relation to the total number of participants on enrolment and at completion of the trial.

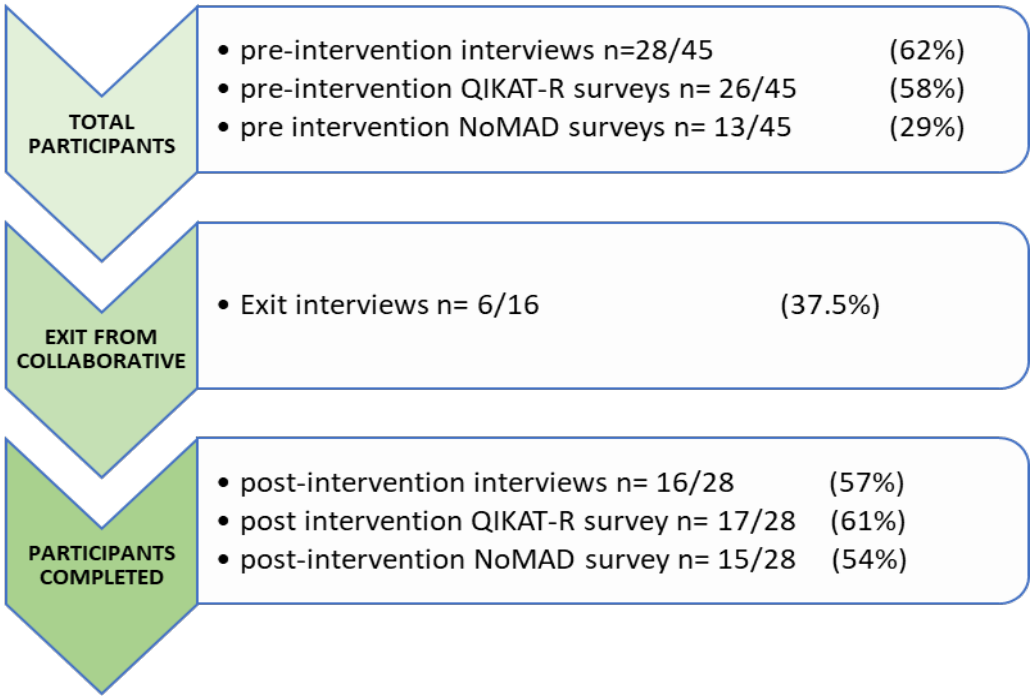


Figure 17 Participants in evaluation compared to total participants in the trial pre-and post-intervention

Participants in the evaluation represented the variety of professions, settings, and locations of the whole group of clinicians in the Agents of Change trial. Most of the participants in the evaluation were female (92%) and 78% were physiotherapists or occupational therapists. They worked predominantly in public health services and not for profit residential and community aged care settings as employees or contractors from private practice. The private practitioners worked in both the community, seeing private clients, or were contracted to work in residential aged care settings. Participants were based in all states and territories of Australia with the majority (70%) in metropolitan settings, 20% in regional locations and 10% in rural or remote locations. Most clinicians interviewed (62%) worked at or over 4 days per week, with 25% of participants working half time or less. Of those working over 4 days per week, 50% had supervisory responsibilities. **Table 13** presents the characteristics of clinicians, showing the range of professions, settings, locations, type of organisation as well as the subgroup chosen for the collaborative.

Table 13. Characteristics of participant clinicians involved in the process evaluation of the Agents of Change trial

Characteristics	*n* (%)		
Collaborative sub-group	Exercise *n*=12	Carer support *n*=6	Occupational Therapy *n*=10
Female	10 (83%)	6 (100%)	10 (100%)
Male	2 (17%)		
Regional/rural/remote	3 (25%)	2 (33%)	2 (20%)
Profession			
Physiotherapy	10 (83.4%)	1 (16.7%)	0 (0%)
Occupational Therapy	0 (0%)	1 (16.7%)	10 (100%)
Nursing	1 (8.3%)	2 (33.3%)	0 (0%)
Medicine	1 (8.3%)	0 (0%)	0 (0%)
Dietetics	0 (0%)	1 (16.7%)	0 (0%)
Health services	0 (0%)	1 (16.7%)	0 (0%)
Organisation Type			
Public	3 (25%)	3 (50%)	4 (40%)
Private	2 (16.7%)	0 (0%)	0 (0%)
Not for profit	7 (58.3%)	2 (33.3%)	4 (40%)
Sole provider	0 (0%)	1 (16.7%)	2 (20%)
Service setting			
Acute	1 (8.3%)	1 (16.7%)	3 (30%)
Sub-acute / Transition Care	2 (16.7%)	0 (0%)	1 (10%)
Community / Outpatient	2 (16.7%)	5 (83.3%)	6 (60%)
Residential	5 (41.6%)	0 (0%)	0 (0%)
Residential and Community	2 (16.7%)	0 (0%)	0 (0%)

5.3.2 Themes arising from interviews

Of the 28 participant clinicians in the evaluation, 24 participated in pre-intervention interviews conducted on commencement of the quality improvement collaboratives. The interviews focused on 1) understanding the context in which clinicians worked (CFIR), 2) understanding the work to be done to make changes to practice (NPT), and 3) understanding the expected mechanisms in the collaborative and in their workplaces that could generate change (RE).

5.3.2.1 Understanding context and settings (CFIR)

The five major domains in CFIR (105) provided a framework for discussing how and why the context would impact on clinicians' learning and use of quality improvement methods to implement guidelines. Clinicians described their setting and roles in the interviews and identified competing priorities and constraints that may affect their success in improving quality. ***Figure 5*** in Chapter 2

shows the five major domains of the CFIR and the three key areas discussed by clinicians in interviews.

i) *Outer setting*

Major change in systems affected how people obtained aged care services and changed the processes for clinicians to provide services and make referrals. The My Aged Care system implemented in 2017 centralised assessment and approval of eligibility for aged care services. These changes meant that aged care providers no longer held funded aged care packages directly and needed to refer older people to a new online system for assessment of eligibility. Clinicians in aged care settings considered My Aged Care "*such a complex system for carers now* "(participant C01) for older people in navigating the steps.

Both aged care and public hospital settings had been affected by changes in systems, accreditation, and funding priorities. Participants stated that "*allied health services are strained in the community"* (participant C05) and spoke about the loss of flexibility in services and constraints of the system requirements, especially in aged care.

"We've got to work within the guidelines that they've given us. There's no way around that" "It's much more about the requirements of the system and the funding really" participant C01.

Sole providers working in the community with younger people with dementia found the eligibility for service based on age added to the complexity. These participants identified changes to government policies for equipment, referral processes, access to care for people under 65 years living with dementia and carer support services.

"I'm registered for NDIS, but I'm actually loath to get too involved. There's (sic) so many problems with it. But they've just gone through changing their structure into an NDIS commission and there's a whole list of compliance things that providers have to now follow" participant O03.

Community Aged Care clinicians and sole providers identified fragmentation in services with "*not a great deal of linking between the hospital or public system and the community"* (participant CO5), due to changes to government policies, referral processes and coordination of services. These were seen as a constraint on their practice.

"when we receive a referral, they're at a point of transition, so it's like a mini crisis, usually from a hospital admission back home, so there's a whole lot of stuff to think about as well as thinking about the future. And we're a short-term program, so we see people for a maximum of 12 weeks. It

gives us limited time" participant O08.

Although some sole providers saw opportunities for more individualised care under the consumer directed care model giving "*a lot of breadth now"* compared to *"previously, they all just did the bare minimum. Now, if there's money in a package, you can …really tailor it"* participant S11.

ii) *Inner setting*

The changes in the outer setting appeared to drive changes within the inner (workplace) settings of clinicians. Most participants commented on changes in structure, leadership, expansion in some areas and contraction in other areas. *"We're going through a major org change…staff are unhappy, we are having a high turnover"* participant S11. The major effect of these changes was funding and time constraints for their work, stress, competing priorities.

Participants in public hospital settings spoke of the effects of structural changes on their roles in terms of stress and change of direction. Some indicated the transitions meant "*bridging a dual role"* (participant O09) or combining areas of work, such as *"with mental health now as well as dementia"* (participant O09). Others identified their loss of engagement in their work.

"*I think personally that's quite difficult to find that level of engagement or even enjoyment when you're trying to strive for change and getting better outcomes for the patients when there are so many other competing priorities in hospitals*" participant C06.

Time constraints were identified by most clinicians across the range of settings, impacting on *"having the time to talk to patients about anything"* (participant E12), or getting *" the timing right… it may not be right at the moment"* (participant C06) because of the amount of change they had been through. In aged care however, participants identified that *"everything that we do in a residential setting istied to funding and if there's no money that can come from a service that we offer, you need a strong justification to …be doing that"* participant E11.

The inner setting was characterised by most clinicians as time poor, stressed and with limited funding. In aged care the change in roles and funding priorities, limited the scope of service. In hospitals the combination of changes to funding and roles increased time pressures. Despite this, clinicians were keen to find a way to improve their practice and looked for support from co-workers and the opportunity to participate in the collaborative.

iii) *Individuals involved*

Clinicians described their own roles and the teams, managers, and networks in which they operated and how these features affected their expectations of the project. They all had a clinical workload, and a few had supervisory roles. All had manager support to be involved in the quality improvement collaboratives and several participants identified supporters outside their setting or

team. All participants identified being motivated to be involved in improving dementia care as they could see gaps but were unsure of how to make improvements.

In hospitals, multidisciplinary team processes were identified as good supports by clinicians to *"network through the hospital with-OTs as well as physios and social workers*." *participant C05.* Having a range of clinicians such as "mental *health nurses…mental health social workers …neuropsychologists… occupational therapists", was seen as a good resource as they "cross over extremely well with our psycho-geriatricians"* participant O09.

Participants in aged care settings commented on the interest of their teams and networks in improving dementia care.

"One key person I forgot to mention is our geriatrician who has done his own research and he is really interested in what I'm doing" participant O13.

"I've got the senior physio and senior OT then we have a number of allied health assistant staff as well that work through the programs. They're all very aware of the types of things that we're trying to improve and work on. I think we've got a good team in place. (they are) ... *all very proactive and interested and keen in this client group so having their backing and support I think will make it successful"* participant S13.

In public hospitals, clinicians identified formalised quality improvement systems as supportive networks where, by registering a quality improvement project into a system, participant S15 stated that *"other departments will be able to see what we're doing and, obviously, can take an interest".*

In aged care settings, clinicians identified role boundaries and workloads as barriers to quality improvement. Participants commented about specific roles constrained by funding such as "*I don't think that the nurses will be much involved"* (participant E02) and expecting that they would be running it themselves and "*maybe asking for some help from care staff if I needed it*" *participant O01.* They expected resistance to change by some staff.

"*No doubt there'll be a bit of resistance from care staff, that is often the thing with change. … why should I do it your way I've done it this way my whole entire life"* participant E11.

Some clinicians working part time, identified that despite support for their manager to participate in the collaborative they would *"still have to get through my specific workload that I need to do in my paid hours"* (participant E05). Others identified competing demands on their time to make improvements to their practice.

"The other demand of our job is our pain management, our obligations with our falls reviews and manual handling training obligations, so particularly on a time basis…" participant E05.

For sole providers and contractors, their networks, peers, and community service providers had a strong influence on their feelings of support. Participant E05 thought that her peers were "*all fairly keen inside my practice"* and participant C05 had *"a couple of really supportive GPs in this area".*

iv) Intervention characteristics

At the pre-intervention stage, most clinicians were uncertain of how the guidelines would be adapted in their practice. Some were familiar with the guidelines and had thought about what might be possible or needed for their clients. Others had little insight into what the change would be and were waiting to see what the online learning modules about the guidelines and quality improvement process would bring. Most clinicians were optimistic about their participation in the quality improvement collaborative and their confidence in implementing improved practice.

"I'm happy because it's just a way to create changes by implementing something, trial it and if it works then we can trial it on a bigger scale" participant E02.

They envisaged small step-by-step changes and adapting the guidelines to their own setting as most useful considering the many changes occurring in their settings. Participant E08 explained that she felt *"fairly confident we'll be able to take on this small change".*

v) *Implementation process*

At the pre-intervention stage clinicians did not have a clear understanding of what the process would be. They were however wanting to improve their practice, as participant O01 stated "*if it involves best practice then it's probably something that we should be looking at".* For those who had attended a start-up meeting for the Agents of Change trial, before the evaluation interview, the steps of the quality improvement collaboratives and data collection were clearer. As stated by participant E06 *"I feel fairly confident that we will be able to get things off the ground and make some changes, yeah"* participant E06.

A few clinicians who had experience of quality improvement or process change in their work setting, had begun to identify who they needed to speak with, what process needed changing and had started gathering information.

"*We work through quality projects… and we actually use that model and that cycle to (work) through the steps of our projects"* participant S15.

Clinicians clearly understood the intent of the quality improvement collaboration was to adapt the guidelines to suit their setting and expressed confidence that this approach would be useful and appropriate.

A summary of the main contextual influences expected to impact on project success for three main work settings are provided in **Table 14.**

Table 14. Summary of contextual influences

Contextual elements (CFIR)	*Hospitals and outpatient clinics*	*Community and residential aged care*	*Sole providers/private practice*
Outer setting	Funding changes and constraints	Complex navigation and funding changes	Increased regulation and opportunities
Inner Setting	Role changes and time constraints	Leadership and structural changes	Contracting changes and coordination gaps
Individuals involved	Support from multidisciplinary teams	Role boundaries limited teamwork	Networks important and extra work on business expected
Intervention characteristics	Quality improvement process familiar for some	Little knowledge of quality improvement approaches	Uncertainty about quality improvement approach
Implementation process	Prior experience gave confidence	Uncertainty about how possible it would be	Open to change in their own practice

Abbreviation: CFIR: Consolidated Framework for Implementation Research

5.3.3 Understanding the work to be done (NPT)

Clinicians responded to questions about the work that needed to be done to implement a change, based on the four NTP (106) constructs. The questions explored if the changes made sense (coherence) if they and others in their workplace would be engaged in thinking about the changes (cognitive participation), who would be needed to help them make changes (collective action), and how they would review the changes once in practice (reflexive monitoring).

5.3.3.1 Coherence (Makes sense)

Clinicians identified clear needs of clients to be more supported through exercise, strategies for independence at home and support for caregivers. They identified the difference between the guidelines and current practice and anticipated what changes may be needed. While they identified barriers to delivery of improved services, they recognised that the guidelines made sense and would improve the quality of life for their clients. They were looking forward to learning more about the guidelines and sharing ideas with other participants through the quality improvement collaboratives.

'It's an area that I'm really committed to, wanting to improve, and just ensuring that my practice is based on research and best practice because of the clients that I'm seeing, wanting to provide them with the best possible service I can.' participant C05.

5.3.3.2 Cognitive participation (enrolment and engagement of individuals)

Clinicians were highly motivated to join the collaboratives to work with others with similar interest in improving dementia care. Participant C06 stated that the motivation came from working with other *"people that really genuinely see the value in supporting the person (with dementia)*". They identified with the need to improve quality of life of people living with dementia but felt isolated in their workplace. One participant (O08) stated that "*trying to make changes is probably not going to go down all that well".* Although, the requirement for their manager to approve of their enrolment legitimised the participation.

"…being a part of this and being supported by my work is a bit of a time investment but hoping for the ultimate pay out at the end of having an intervention that's going to increase the efficiency of what we do…" participant E11.

5.3.3.3 Collective action (operationalizing a practice)

All clinicians were aware of the need to involve others in the process of changing practice and improving services. Some were confident of their ability and support from their team or manager. Others working as sole providers or contractors identified their referrers, networks, and peers as key to involve in the process to inform them of the guidelines and to refer for improved services. Participant C05 thought that "*knowing what's available, how to link people in with certain supports in the community - ones other than what currently know"* would be key to putting the changes into practice.

At the pre-intervention stage, most clinicians had started to talk with others about their involvement in the quality improvement collaboratives and possible education of other staff about the changes needed. Some identified the changes needed to current processes and who they would need to be involved in implementing them.

"…and it makes sense and it all fits well with making people's lives better, then I think we can get more people - yeah, it will make a difference to our team." participant O08.

A few clinicians identified that they would have little involvement or engagement from others with participant C08 stating that *"without a bit more buy-in from the organisation, I think that it will be quite limited".*

5.3.3.4 Reflexive monitoring (review of new practices)

While clinicians had not implemented any changes at the stage of the interviews, a number identified that sustaining the change would be a key component of the quality improvement and that funding, procedures and ongoing information and review would be needed to keep the practice in mind. Participant C08 stated that *"those are the skills that I want to learn. That's why I'm on this project. It's not just about having something there that then everybody forgets about".* Similarly, participant E09 actively engaged her colleagues "*about streamlining that referral process, which I*

think was a big thing" in embedding change.

The framework of NPT was used to elicit the reasoning of clinicians about how complex the changes might be and who would be involved in trying out changes and sustaining them in their settings. **Table 15** presents a summary of the key themes from the NPT framework across the three main settings identified.

Table 15. Summary of key themes from NPT constructs across three settings

NPT constructs	*Hospitals and outpatient clinics*	*Residential and community aged care*	*Sole providers/private practice*
Coherence	Clear gaps in services identified	Difference to usual practice understood	Barriers and opportunities identified
Cognitive participation	Improved services needed and the opportunity to learn QI methods	Professional development and improved quality of life for people with dementia	Networking and sharing knowledge to improve practice
Collective action	Multidisciplinary teams were supportive of the project	Needing to convince others to be involved where the roles were differentiated	Independence to act and supportive networks were important
Reflexive monitoring	Focus on the goal of service improvement	Focus on quality of life improvements	Focus on practice improvements

Abbreviations: NTP: Normalization Process Theory, QI: quality improvement

5.3.4 Exploring initial program theory (Realist Evaluation)

The initial program theory was developed into a series of configurations of context, mechanism, and outcomes (C+M=O) at **Table 7.** Questions then developed (see **Table 9),** related to the proposed mechanisms to explore how and why they did or did not represent their views. This provided the opportunity to understand the reasoning for their involvement in the collaborative and how they expected that they would build knowledge and skills in quality improvement in dementia care.

5.3.4.1 Motivation

The mechanism of motivation suggested that if clinicians volunteered to be involved, committed to an 18-month project, and were interested in both improved dementia care and learning about quality improvement, then they would remain engaged and be successful. All clinicians reported a high level of motivation to be involved in the quality improvement collaboratives.

"It's an area that I'm really committed to, wanting to improve, and just ensuring that my practice is based on research and best practice because of the clients that I'm seeing, wanting to provide them with the best possible service I can" participant C05.

Most were volunteers who sought out the opportunity through an advertisement with professional associations. Clinicians in public hospitals, commented on how their involvement provided motivation and increased job satisfaction.

"…sometimes it's easy and if your mood isn't right or your workloads a bit heavy – to just be… a bit negative – like drop your bundle a bit. …as far as my professional life goes it's really made me feel better about my work and better …outlook about things" participant E09.

"Do you know, for me, it's the inspiration. I keep getting inspired by seeing what work is being done, it gives me hope. It makes my job worthwhile" participant O08.

Some in aged care were encouraged to express interest by their manager but were very pleased to have that encouragement. Participant E11 explained *"we may have been more approached, prompted again, and that's where an email went around – 'if anyone was interested in participating' – and so I put my hand up. I thought it was a good opportunity to participate in research".*

For sole providers it was both a goal for their business and an interest. Participant E05 explained that *"I'm sort of wanting to get my title in gerontology through the APA and so obviously gerontology is a field that I am very interested in and passionate about and that's what I work in"*

One person in a hospital was volunteered by her manager and while she felt it was an added commitment, she was really interested in the topic and opportunity.

"'I want you to go for this thing tomorrow,' and that's how I got involved. It was still relatively a choice, and it is something that's new and exciting, and it's probably going to be something that I think every … practitioner will get into" participant E12.

5.3.4.2 Accountability

The idea of accountability resonated with most clinicians. If they were accountable to continue with the project, gather data, learn together, and develop knowledge and skills they would continue to implement a quality improvement. In residential aged care settings participants appreciated the structure.

"I think by formally being involved in something and having to go through the more formal task of writing and recording and going through that process will help me personally not only better understand the demands and requirements of a resident with dementia but help me reinforce that critical thinking and that professional planning sort of thing as well" participant E11.

Clinicians in community services identified how the monthly data collection sheets would act as a reminder by *"being accountable that you actually have to get something done"* participant E05.

They understood that there would be regular reminders to send data and to complete modules. Participant O09 *explained that "if you've got a framework or a structure that you're working with, it is helpful and it's protective, in some respects"* to keep focused.

Those in hospital settings identified their commitment to the project once they had taken it on and were determined to complete it. Participant E09 explained that by making regular times to talk about the project *"it was there every Monday, you know…so, it sort of forced my hand as well not to let it go".* Similarly, the structure supported participant E04 to *"stick to how we're going to implement this plan".*

5.3.4.3 Identity

Clinicians described themselves as having a strong sense of identity either as a dementia advocate wanting to improve quality of dementia care, or as an agent of change in clinical services and organisations. The reasoning suggested by participant O04 was "*I'm very passionate about people with dementia so with my values I want to make sure that they're maintaining their independence and participating in things they want to participate in"*.

Others with leadership roles were keen to add the quality improvement of health services to their skills to allow them to continue to develop health services or to overcome identified gaps.

"I've worked in aged care for quite a while now so it's something that I have a strong interest in and I can see that there's an area that potentially has some gaps in it so that's why I'm keen to get on board and see if we can make some positive changes for the patients." participant S13.

The identity as an 'agent of change' appealed to participants who felt part of something more than their jobs, by improving health services or contributing to research. Participant O05 explained *"what appealed to me about this was that you're participating in a research project and you're getting exposure to how that is being done, and then you're also getting that mentoring and peer support as well to be implementing a change in your workplace"*

Sole providers commented on how it fit with their business and specialty. *Participant O13 stated "I feel it's a great match for where I'm at in my practice"* while participant E04 was *"aiming for our OT practice to be specialist in services for older people".* For most clinicians, their involvement was a way of investing in themselves and improving services.

"Probably job satisfaction and I guess understanding the process as well so applying it to this project, a quality improvement framework and then having that skill base and knowledge" participant S13.

5.3.4.4 Collective learning

The mechanism proposed for collective learning was identified in the literature for quality improvement collaboratives and learning theory (74, 76, 264). The reasoning suggested was 'if we come together to learn and share methods to improve care, then we can assess our own progress, benchmark with other professionals, and facilitate faster and wider implementation of quality improvement practices'. Having a sense of what other clinicians' practice looked like was identified several times in the interviews as a way to compare and identify where improvements could be made.

"there are people that have worked in different areas and, specifically, in dementia care, nursing or a mixture of programs and projects. And I'd like to know more about those to use them as a tool for servicing my clients, knowing what's available, how to link people in with certain supports in the community". participant C05.

Participants in hospital settings saw the value of sharing knowledge to improve dementia care. For participant C06 *"the opportunity of the networking as well, again to share and to problem solve, I think that's going to be a very positive experience as well"* because many roles were generic rather than dementia specific. They wanted to understand what best practice looked like. Sole providers particularly valued the collaborative approach with participant E02 explaining that she wanted to "*just be… part of something that we are all sharing information or all sharing our experiences, I think that that enriches anyone's practice".*

5.3.4.5 Doing it together

Many clinicians described feeling isolated despite working in a team or with other clinicians.

"…the benefit is knowing that there's a group of about 30 people Australia-wide who have been involved in it and are basing their practice on research and the evidence that's out there and it's more than just me that's interested in it" participant C05.

Some in aged care needed to be re-energised after coping with many changes. Participant S11 explained *"this is probably what I needed… well, because of things that have happened …so this gives me an exciting kind of opportunity".* Some sole providers and contractors to aged care related to something "*more practical, which appeals to me, rather than just going to a conference"* (participant O07) to keep them motivated and to achieve a result. The reasoning suggested by participant C06 was "*I think it helps in a group situation too, to feel more motivated about changing practice"*. Similarly, participant O05 explained that *"you're also getting that mentoring and peer support as well to be implementing a change in your workplace".*

5.3.4.6 Credibility

Most clinicians identified the link with evidence-based practice and research added credibility to

their involvement in the quality improvement collaboratives. The reasoning that was tested was ‘if the professional associations have credited the program with CPD, the evidence for the Guidelines is provided for participants to share, the coaching from experts and perspectives of people with dementia, make the quality improvement collaboratives credible to organisations, to professionals and to clients. The credibility gives confidence to the clinicians to engage with peers and organisational change to complete the project and implement guidelines.

In hospital settings, clinicians commented that the evidence was important to their organisations and their motivation. As participant O09 explained, *“I mean, the evidence is really there and it’s exciting to work with people who are on that same train of thought. That’s the joy of it”.*

In residential aged care, participant E05 connected participation with aged care quality standards. *“I’m actually doing something that’s evidence based and so I think that’s really important”*. Sole providers also recognised the link between the guidelines, their professional accreditation and research.

“Well that's one of my motivating reasons for getting involved; that it will increase my knowledge of what's best practice and what the evidence shows” participant O07.

“what appealed to me about this was that you're participating in a research project and you’re getting exposure to how that is being done” participant O05.

By identifying and exploring mechanisms at the pre-intervention evaluation it was possible to check the postulated mechanisms in the initial program theory and the opportunity to identify others that may be working within various settings. A summary of the mechanisms identified across three settings is provided at **Table 16.**

Table 16. Mechanisms proposed and identified for the collaborative across three settings

Mechanisms	*Hospitals and outpatient clinics*	*Residential and community aged care*	*Sole providers/ private practice*
Motivation and confidence to engage in change	*Job satisfaction and interest*	Encouragement and interest	Business goal and interest
Accountability and commitment to change	Formal schedule to fit in with time constraints	Structure to guide the process	Regular reminders
Sense of identity was reinforced	Leadership in improving services	Commitment to improved quality of services for people with dementia	Business specialty and fit with patient needs
Collective learning increased confidence	Value of sharing knowledge for improvement	Learning from others and comparing services	Sharing information and knowledge enhanced satisfaction
Doing it together increased safety to learn and make mistakes	Overcoming isolation and motivating, confidence	Motivating and reenergizing by working with like-minded others	Practical and guided approach motivated involvement
Credibility increased acceptance	Evidence base and shared focus on improvement	Evidence base for accreditation standards	The connection between best practice and research

5.3.5 Pre-intervention quantitative data

5.3.5.1 QIKAT-R survey results

Clinicians who participated in the evaluation were asked to complete the QIKAT-R survey (244) online, before they submitted their quality improvement plan for feedback. Results are presented descriptively at ***Figure 18*** showing mean scores for each sub-group of the collaborative before thesubmission of a quality improvement plan for feedback from experts.

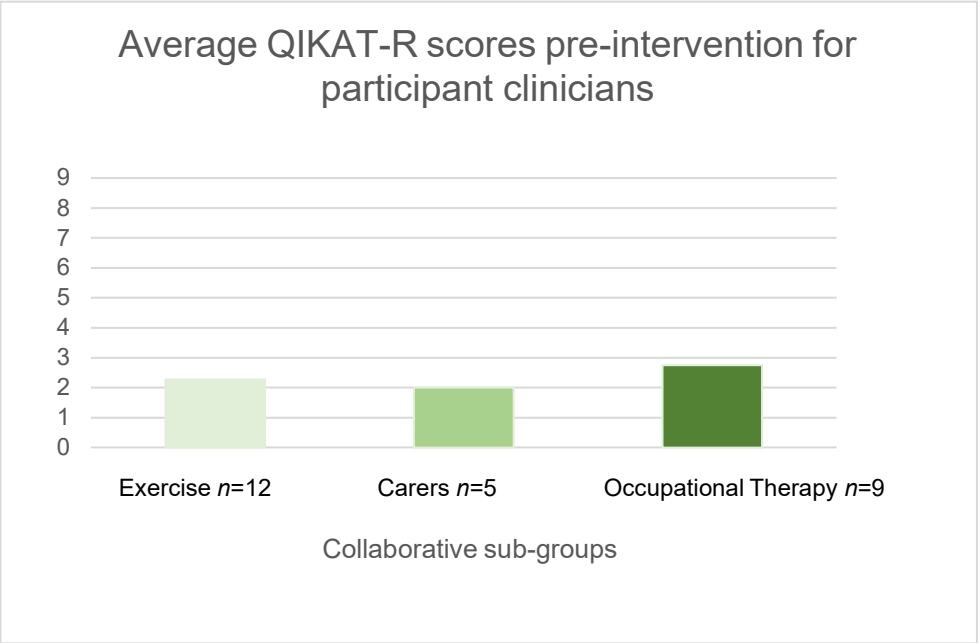


Figure 18 Mean scores on QIKAT-R for Clinicians in 3 collaborative sub-groups at pre-intervention

In the pre-intervention survey, most clinicians reported a low level of knowledge and skills in quality improvement processes with median scores of 2 out of a total of 9 points achieved. Two participants had been involved in other quality improvement processes in their work settings and had good knowledge and skills of quality improvement already, with individual scores of 6 and 7 out of 9 points. Responses from two clinicians focused on individual case management rather than quality improvement processes and were not awarded points for quality improvement aims, measures or the changes expected. From this low base of knowledge and skill in quality improvement, the quality improvement collaboratives were expected to increase scores on the QIKAT-R for the participating clinicians.

5.3.5.2 NoMAD survey results

Clinicians who commenced the online learning modules in the Agents of Change trial, were invited to complete the NoMAD survey (245) at the pre-intervention stage. Responses to each of the 23 statements in the NoMAD tool varied considerably, from nine to 15, with 18 clinicians not undertaking the survey or not completing all questions. Some participants commented in interviews that the survey was not related to their circumstances and omitted it. Others did not complete the survey due to time constraints. All responses were cross checked by another researcher and converted to percentages to show the degree of agreement with statements in the NoMAD tool at the pre-intervention stage.

Figure 19 shows the degree of agreement across the 23 statements included in the NoMAD (245) tool and the number of respondents for each question. Groups of questions relate to the four constructs of NPT, coherence, cognitive participation, collective action, and reflexive monitoring (106, 245). A summary of the responses in Figure 19 is grouped by the four constructs

below.

5.3.5.3 Summary of responses presented in ***Figure 19***

i) *Coherence*: making sense of the quality improvements

Clinicians indicated clearly that the proposed changes were differentiated from usual practice and they expected the changes they made would become part of their work. They highly valued the proposed changes to practice as they could see the benefits for their clients.

ii) *Cognitive participation*: who is involved, and who supports the changes

There was strong agreement from clinicians that their role included making changes to practice which could be integrated into their work. They agreed that they would drive changes to their regular practice and that they would work in new ways. They were optimistic that they would be supported by co-workers.

This level of agreement indicates that the clinicians themselves were engaged in the change process and saw it as a legitimate practice (285). This reflected their participation in changing their own practice.

iii) *Collective action*: how the change is implemented in the context of resources and skills

Most clinicians did not think that the changes would disrupt work relationships and the changes could be integrated into their practice. However, less than half agreed that they had confidence in others' abilities to implement changes. While most agreed that they were the right people to make the changes to their practice with the training provided in the collaboratives, they were less certain about the level of resources available in their setting. Almost all agreed that management supported the changes. They had received approval to be involved in the collaboratives and expected to be supported in that process by peers and experts. These responses indicated that resources may be a concern in skilling others in implementing changes in their setting (285).

iv) *Reflexive Monitoring:* how the change process is understood and evaluated

Most clinicians agreed that they would receive feedback on the changes, that they would make the changes and that others would consider changes worthwhile. This appraisal by participant clinicians and others in their setting indicates their comprehension of and investment in the changes to be made (285).

The survey results indicated that most of the clinicians were invested in the proposed changes and had the support of their managers or others to implement a quality improvement in dementia care. These patterns confirm that clinicians could see how the changes were different to usual practice and that they were engaged with wanting to make changes that would fit with their role and relationships with others. The uncertainties indicated by neutral or disagreement with statements, included 60% who lacked confidence of others' skills, 30% who disagreed that it would be easy to integrate the changes and 40% who were neutral about the level of resources available to support

them in their setting. These results indicated the relative priorities and constraints in their settings, and which may hinder the proposed changes.

Applying Normalization Process Theory (106) to these results suggests that positive attitudes of clinicians who engaged with thinking about the changes, achieved a readiness by participants to take on quality improvement at the pre-intervention stage. Contextual factors were reflected in some of the results related to skills of co-workers and resources available in their setting.
The NoMAD survey results combined with the QIKAT-R assessment suggest that while knowledge and skills in quality improvement were low upon commencement, clinicians expected that the changes in practice would be valued and supported by others and they would have training provided in the collaboratives to achieve the changes to practice.

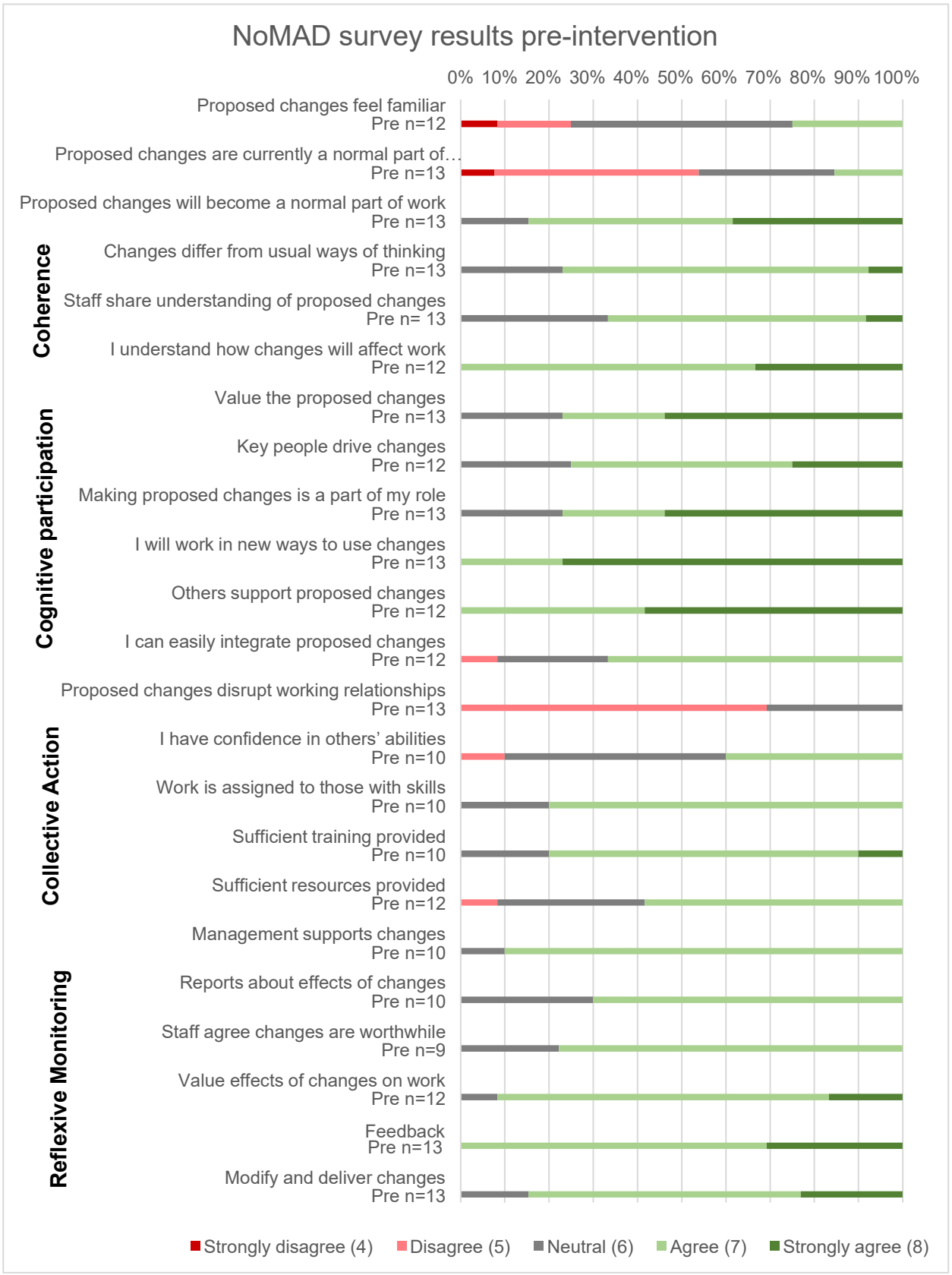


Figure 19 Clinicians' responses to statements in the NoMAD survey pre-intervention

5.3.6 Synthesising the results

The results from the interviews and the surveys were compared to identify any patterns or differences across settings. Due to low numbers of responses in surveys, statistical analysis was not considered feasible.

5.3.6.1 Survey results

In the QIKAT-R survey, the mean scores were low (less than 4/9). The responses tended to focus on individual responses to a client issue rather than seeing the need for a process change for all clients. The interview responses confirmed the limited knowledge of quality improvement processes of participating clinicians. For two clinicians who had good scores (above 5/9), they indicated in interviews that had some experience in working in organisational quality improvement projects in the past but had not planned or led improvements. These projects were described as part of an organisational quality improvement process where multidisciplinary teams were resourced to work together to achieve change. Examples of how participants worked together in their workplaces were then explored to identify contextual influences expected to influence project success.

In the NoMAD survey, the collective action construct identifies how changes will be integrated with existing practices. Differences in strength of agreement were noticed between settings in the collective action construct which is related to the expected success in incorporating a change in the workplace (106). The responses from 60% of participants indicated low confidence in the abilities of others in their work settings to incorporate changes to existing practices and few resources being available in their workplace.

When considering the interview data, differences in the confidence of co-worker abilities by clinicians, were also indicated. In hospital settings where multidisciplinary teams were operating, participants expressed more confidence in the ability of the team to support them. In aged care settings there was more uncertainty about teamwork. Where the participant worked with other clinicians, they felt supported but were less confident where role and professional boundaries were in place. Clinicians said that they had little control over colleagues' abilities and tasks, or the resources available in their workplace to make changes. Sole providers were confident in their ability to make changes to their own practice, and they expected their networks to provide support.

Table 17 shows the links between the components of the collective action construct within Normalization Process Theory with the setting of the participants.

Table 17 Differences in how confidence in collective action by clinicians appeared across three settings

Collective Action components	Hospitals and outpatient clinics	Residential and community aged care	Sole providers/private practice
Confidence in working together (Interactional workability)	Multidisciplinary team processes were supportive to improve practice	Differentiated roles related to funding and tasks, limited flexibility to make changes	Independence and network support to use learnt skills
Confidence in teams to support changes (Relational integration)	Team structure and understanding of roles supported sharing of skills	Task structure drove workloads for each role and reduced flexibility	Contracts with funders allowed for clinical discretion to make changes
Confidence in skills of others (Skill set workability)	Specific skills recognized and used in patient goal setting	Differences between skills, values, and hours of work constrained changes	Flexibility to change and opportunities to specialise their practice
Confidence in how structures work together to make changes (Contextual integration)	Well integrated multidisciplinary teams and QI accountability	Differentiated teams by task and role made integration complicated	Community network and contracts for services provided opportunities to integrate new skills.

5.3.6.2 Interview results

The mechanisms identified in the interviews with participants also show some differences across settings and the effects of changes in the context. For participants in hospitals, motivation to be involved related to job satisfaction and leadership and were clearer than in other settings. In aged care settings, participants were motivated more by the sense of encouragement and support from a group of like-minded clinicians. For sole providers, the mechanisms related to their interest in improving their practice with support.

The reasoning about working together to improve the quality of dementia care differed between settings. In hospitals, participants saw the collaborative as a way of overcoming isolation from other services, while participants in aged care were interested to work together as a way of re-energising themselves and finding like-minded others. Sole practitioners reasoned that the collaboratives provided guidance and confidence in making changes. The credibility of the program, having a sense of identity and accountability, and the value of collective learning were similar across settings.
The impact of contextual pressures on participant clinicians provided slightly different motivations to participate. **Table 18** shows how the pressures in three contexts influenced motivation and working together for clinicians involved in the collaborative.

Table 18 Contextual pressures as drivers for involvement of clinicians in the collaborative across three settings

	Context pressures in 3 settings		
	Hospitals and outpatient clinics	Residential and community agedcare	Sole provider/private practice
Motivation	Job satisfaction by overcoming time constraints	Support and encouragement to overcome role constraints	Support to improve business specialty
Doing it together	Overcome isolation from other services and confidence to make changes	Re-energizing and finding like-minded others to support changes	Need for formal support to gain confidence to make changes

5.4 Summary of findings from the pre-intervention process evaluation (Part A of Study 1)

Mixed methods were used to understand the context, motivations, expectations, support, and confidence of clinicians as they commenced participation in the quality improvement collaborative. Two surveys, NoMAD and QIKAT provided data on participant knowledge of quality improvement and the social processes of implementation required to make changes in workplaces. Three perspectives were used in analysing qualitative data from interviews. Information on the context and people involved in implementing quality improvement in dementia care was identified through the lens of CFIR (105). The expectations of participants in implementing improved practice was identified through the lens of NPT constructs (106). The realist evaluation (26) approach of identifying mechanisms of action was used to identify how context influenced participants to engage in the collaborative.

5.4.1 Similarities and differences between participants

There were similarities in motivation, expectations, optimism about support levels and self-confidence as clinicians entered the collaborative process. The support and guidance anticipated by participants differed according to their assessment of colleagues' abilities and motivations to be involved, but expectation of support through the collaborative and the credibility of the program was a high motivator for all participants.

There were differences between participants in the level of skills and knowledge in quality improvement and implementation process knowledge, contextual influences and in how the context influenced some mechanisms. Most participants had little prior knowledge of quality improvement processes, and those who did had been involved in organisational projects. The contextual

pressures differed between three identified settings and influenced why clinicians were motivated to be involved in the collaborative and what they expected to gain from it.

From these results it can be postulated that knowledge and skills in quality improvement and implementation processes would increase through collaborative learning and support from peers and experts. The collaborative process was expected to develop confidence in clinicians to apply their skills and knowledge to overcome resistance and constraints, to make changes to practice. The post-intervention process evaluation will test the expectations of the initial program theory and integrate the results for both qualitative and quantitative data analysis.

5.4.2 Strengths and limitations of the pre-intervention process evaluation

At the pre-intervention stage of the collaborative, many clinicians enrolled were uncertain of what to expect and had little exposure to the clinical practice guidelines for dementia or quality improvement. They were highly motivated to improve dementia care and joined the collaborative with expectations that they would learn with support.

The evaluation design provided an opportunity to identify outer and inner contextual influences, that influenced the motivation, expectations, support, and confidence of clinicians as they enrolled in the collaborative. The broad categories of settings were identified as public hospital and outpatient clinics, residential and community aged care and private practice and sole providers. Each category of setting shared a similar funding and policy context, similar structures, culture, and clinicians. Some differences in mechanisms were identified between these settings due to contextual influences such as the infrastructure to support quality improvement, boundaries between roles and availability of support to improve dementia care. Assessment of the context for individual settings was not feasible where only one clinician was involved in implementing a change to practice. The use of realist evaluation methods focused on identifying the program theory and postulating mechanisms of change that may be generated because of the collaborative intervention.

The small numbers of clinicians involved in the pre-intervention evaluation meant that statistical analysis of differences in survey data and between the contexts or subgroups of the collaborative was not feasible. There were missing data within surveys and several participants did not complete the online NoMAD. Those who were in sole provider practices were unable to respond to several questions about team and manager involvement. Some participants interpreted the QIKAT-R scenario as a clinical issue for an individual rather than a quality improvement issue. This restricted scores on that survey.

The interpretation of interview and survey data by the author may have influenced the evaluation. The involvement of another researcher to check 30% of the coding of interviews and all the scoring of the survey data was designed to reduce the influence. The reflection at Appendix 12 identifies

the potential influence on the author's interpretations.

5.5.3 Next chapter

Following from Study 1-part A, pre-intervention process evaluation is the part B- post-intervention process evaluation at Chapter 6. The initial program theory will be tested to confirm, refute of modify the program theory and the results from the surveys will be compared to identify differences over the two time points.

CHAPTER 6 STUDY 1 PART B: POST-INTERVENTION PROCESS EVALUATION

How, why and under what circumstances did a quality improvement collaborative build skills and knowledge to improve dementia care? A mixed-methods study

6.1 Introduction

The objective of Part B of Study 1 at post-intervention, was to understand how, why and for whom did the quality improvement collaboratives build knowledge and skills in quality improvement for participant clinicians. The purpose was to examine variations in outcomes for participants observed in relation to the mechanisms at work within the collaborative and in their own local setting (see **Table 7** in Chapter 4). This chapter describes the results of the post-intervention interviews and surveys which were used to seek this information (see ***Figure 15*** in Chapter 5).

The author developed the theoretical framework (Ch 3) and methodology (Ch 4) to conduct the process evaluation as a realist-informed evaluation to build theory on the quality improvement collaborative strategy. A sub-sample of the trial participants were recruited and interviewed by the author. The data was analysed by the author and the coding was checked by an experienced researcher on the trial. The principal Investigator for the trial included the process evaluation in the protocol for the trial and supervised the work of the author.

6.1.1 Completion of the quality improvement collaboratives

Participant clinicians were involved with the on-line collaboratives over nine months, learning through interactive online training modules, collaborating with peers and experts online, and trying out their practice improvements by using a 'plan-do-study-act cycle' (75, 318) to adapt clinical dementia care guidelines to their practice and setting. They completed two surveys, QIKAT-R (244) and NoMAD (245) to assess their post-intervention knowledge of quality improvement and the implementation process needed to normalize a change. Participants submitted an improvement plan for feedback from clinical experts and experts-by-experience of dementia, then they were encouraged to implement and embed their plans in their practice.

This post-intervention Part B of Study 1 focused on the implementation process, the feasibility of the collaborative, and the acceptability to clinicians of learning quality improvement knowledge and skills. These are highlighted in *Figure 11* in Chapter 4, along with cost outcomes which are addressed in Chapter 9.

6.2 Methods used

This mixed methods study (234) used a realist-informed process evaluation (26, 319), as

discussed at Chapter 4, Section 4.2.2, by gathering data to identify participants' level of knowledge and skills in quality improvement, how and why the collaborative worked to build knowledge and skills to improve dementia care, and in what circumstances it worked (or not). Full methods are described in Chapter 4, with a summary provided here. This post-intervention process evaluation tested the proposed mechanisms of the initial program theory, in the following steps.

6.2.1 Program Theory

The key assumptions underlying the quality improvement collaboratives were described as program logic (320) from which a program theory for the intervention was constructed. This was presented at **Table 7** in Chapter 4. After initial checking in pre-intervention interviews, the program theory was reviewed in the post-intervention interviews with clinicians. This allowed refinement of the program theory considering the data, to develop an evidence informed theory of how and why a quality improvement collaborative built knowledge and skill for clinicians in the trial (134).

6.2.1 Post-Intervention surveys of participant clinicians

Clinicians were asked to repeat the two online surveys (QIKAT-R (244) and NoMAD (245)) on completion of the intervention to provide an assessment of what they had learnt about quality improvement and the processes of implementation. The description of the surveys, their validity and use is presented at 4.2.4 in Chapter 4.

6.2.2 Post-intervention interviews with participant clinicians

Semi-structured interviews were conducted with participant clinicians at the completion of the collaborative program (see timeline ***Figure 12*****,** Chapter 4) to explore their outcomes and how theyexperienced the learning and implementing process. The interviews were based on three frameworks as described at 4.2.4 in Chapter 4: The initial program theory for the quality improvement collaborative presented at **Table 7** in Chapter 4 was tested during interview using a realist interviewing approach (145), exploring the reasoning of the participant clinicians.

6.2.3 Configurations of Context + Mechanism = Outcome

Mechanisms were proposed in Chapter 4 for how the quality improvement collaboratives would operate through social processes to transfer skills to participating clinicians. These configurations were shared with participant clinicians in the post-intervention interviews to provide an opportunity for them to refine, refute or modify the mechanisms at work in their experience. Additional insights into the mechanisms and contextual factors at work were then analysed to develop an evidence-informed theory of how and why quality improvement collaboratives build knowledge and skills.

6.2.4 Analysis of qualitative data

Qualitative data were collected in semi-structured interviews exploring the outcomes, how the collaborative process worked for clinicians, and what enablers or barriers were experienced in

normalising the quality improvement. The framework analysis as described at 4.2.4 in Chapter 4 was used to explore clinicians' experience of contextual influences, how the implementation process suited their settings, and the mechanisms at work within the collaborative.

6.2.5 Analysis of quantitative data

Data from the post-intervention surveys using QIKAT-R and NOMAD were compared to pre-intervention survey results to identify change in knowledge and skills of quality improvement and processes of normalising implementation. The measurement of change pre-and post-intervention was intended to assess impact of the intervention on knowledge and skills in quality improvement and the implementation process. Descriptive statistics are presented to show change in mean scores on QIKAT-R survey.

Descriptive statistics were also used to present the spread of responses from participant clinicians to each question pre-and post-intervention on the NoMAD tool. This was intended to identify areas where processes were successful or where additional focus may be needed to normalize the improvement in practice. Small sample sizes and missing data within cases and in matched pairs limited the value of statistical analysis (321).

6.3 Results

6.3.1 Participants in the post-intervention process evaluation

All participant clinicians who had completed module eight of the online training and all project elements by 1st December 2019 were eligible to participate in the post-intervention evaluation interviews. A total of 21 clinicians met this criterion and were invited to participate in the evaluation. Of this group, two clinicians did not respond, two were on annual leave and one had resigned from her position. A total of 16 clinicians participated in interviews, 17 completed the QIKAT-R and 15 completed the NoMAD survey. (see ***Figure 16*** *Excerpt from Figure 14 focusing on the phases of Study 1*in Chapter 5)

As seen in **Table 19,** the professions of the participants included occupational therapists (*n*=6), physiotherapists (*n*=6), Clinical Nurse Consultants (*n*=3), and a health services professional. They were mostly female and worked predominantly in publicly funded hospitals and not for profit residential and community aged care settings as employees or contractors from private practice. The private practitioners worked in the community, seeing private clients, or were contracted to work in residential aged care settings. Participants were based in all states and territories of Australia with most in metropolitan settings, 25% in regional locations and 12% in rural locations. Most clinicians interviewed (62%) worked at or over four days per week, with 31% of participants working half time or less. Of those working over four days per week, 44% had supervisory responsibilities.

Most clinicians who participated in the quality improvement collaboratives were senior experienced staff who had influence in their work teams either as supervisors, or as key members of a multidisciplinary team. Sole providers were well known members of local networks of referrers. **Table 19** presents the characteristics of those who participated in the post-intervention interviews according to the sub-group chosen (exercise, carer support or occupational therapy).

Table 19. Characteristics of participant clinicians in post-intervention interviews

Characteristics	*n* (%)		
Collaborative sub-groups	Exercise *n*=6	Carer support *n*=5	Occupational therapy *n*=5
Female	4 (67%)	5(100%)	5 (100%)
Male	2 (33%)		
Regional/rural/remote	3 (50%)	2 (40%)	1 (20%)
Profession			
Physiotherapy	5 (83.3%)	1 (20%)	0 (0%)
Occupational therapy	0 (0%)	1 (20%)	5 (100%)
Nursing	1 (16.7%)	2 (40%)	0 (0%)
Medicine	0 (0%)	0 (0%)	0 (0%)
Dietetics	0 (0%)	0 (0%)	0 (0%)
Health services	0 (0%)	1 (20%)	0 (0%)
Organisation Type			
Public	3 (50%)	3 (60%)	4 (80%)
Private	1 (16.7%)	0 (0%)	0 (0%)
Not for profit	2 (33.3%)	1 (20%)	0 (0%)
Sole provider	0 (0%)	1 (20%)	1 (20%)
Service setting			
Acute	1 (16.7%)	1 (20%)	3 (60%)
Sub-acute / Transition Care	0 (0%)	0 (0%)	0 (0%)
Community / Outpatient	2 (33.3%)	4 (80%)	2 (40%)
Residential	3 (50%)	0 (0%)	0 (0%)

6.3.2 Results from post-intervention interviews

6.3.2.1 Semi-structured interviews

Of the 28 participant clinicians who completed the trial, 16 participated in the evaluation interviews conducted on completion of the quality improvement collaborative. These interviews explored the outcomes that were achieved by the clinicians, the contextual factors which played a role in the outcomes and their reasoning about how and why the quality improvement collaborative worked (or not) for them and their setting.

6.3.2.2 Implementation outcomes achieved

The interviews provided the opportunity for participant clinicians to reflect on the outcomes from the perspective of what they were able to implement in their practice as well as the collaborative process. Online responses from clinicians on their degree of success in implementing their plans,

were assigned a four-point scale, and extracted by setting and collaborative sub-groups. Most participants were successful in implementing change in practice with varying degrees of self-assessed achievement. Half were completely or mostly successful, with six participants continuing with implementation after the collaborative process finished or reducing the scope of their implementation. One participant did not implement a change at all and resigned from the role. **Table 20** shows the range of success and reasons provided by clinicians for their assessment, by collaborative sub-group and setting.

Table 20 Degree of success of clinicians in implementing change through the Quality Improvement Collaborative

Degree of implementation	Collaborative sub-group			Setting			Reasons
	Ex	CS	OT	Hospital/ outpatient	Aged Care	Private/sole provider	
Completely *n* = 2	1	1	0	2	0	0	Community, Team, manager support
Mostly *n* = 6	1	2	3	5	0	1	Later start/changed role
Middle/ Somewhat *n* = 7	3	2	2	3	3	1	Later start/ slow progress/ plan only
Not at all *n* = 1	1	0	0	1	0	0	Role changed resigned
Total *n* = 16							

Abbreviations: Ex: Exercise, CS: Carer Support, OT: Occupational Therapy, Aged Care: Residential and community care, Private /Sole: private practice or sole provider

Participants reflected on the benefits and limits of the collaborative process for their learning and support in implementing change. Most participants found the collaborative process useful to learn and adapt guidelines to their setting. They commented on the value of having structure to the learning and timing of steps in the process, the quality of the learning resources and benefits of the advice, feedback and coaching available. Some commented on the limitations of the online versus face to face learning, but most found the flexibility and lack of time away from work or home beneficial.

The main limitation commented on was the inconsistent peer collaboration during the process. While some had regular contact with others in their collaborative sub-group, others noted the time differences between states and the part-time nature of their work as barriers to collaboration. All participants found the collaboration with researchers, clinical experts, and experts-by-experience of dementia very valuable. They described prompt feedback, individual coaching, formal audit and feedback of checklist data, and feedback and advice on implementation plans by experts as particularly helpful in maintaining engagement and completing the project. More detailed exploration of the experience of the participants in the collaboratives follows using the frameworks

of context, implementation process and mechanisms which contributed to outcomes.

6.3.3 Understanding contextual factors

6.3.3.1 Outer setting

The change in aged care funding and accreditation took priority for some clinicians in residential and community aged care. Participant E11 *explained that "the new aged care quality standards actually did direct my attention a little bit",* into complying with changed standards to varying degrees. Participant E10 described being *"virtually trapped by the time required to complete all the accreditation and that you end up just having no time or mental energy probably to do anything else".*

Clinicians in publicly funded hospitals, outpatient clinics, and sole providers commented on the change in funding and the loss of some services available in the community. Participant C01 explained the impact on regional services as *"running out of services and support things for people. There's waiting lists for everything" as community aged care services reorganised to deliver individualised care.*

This gap became an opportunity for sole providers where they could offer a service to individuals through an individualised home care package. Participant CO5 explained "*it was really just working with the client and the care provider"*. Clinicians working in outpatient clinics were able to extend the service they provided while others created a new service or partnerships with other services in line with the clinical guidelines for dementia care.

"We started a monthly carer support clinic… where carers can come in without the person, they care for living with Dementia, and have a conversation about any challenges they may have…" participant C01.

In residential aged care however, there was variation between settings in terms of what clinicians were funded to do or the scope of their practice. Funding arrangements were applied differently in similar settings according to the organisational expectations of the benefits of interventions.

"What we do is treat pain or put things into place to prevent falls, but that's all you can do" participant E10.

"…really lucky that I work for an organisation that values exercise and that values allied health input in regard to resident management" participant E11.

6.3.3.2 Internal setting

In residential aged care settings, clinicians commented on attitudes and culture of the organisation as barriers to change.

Participant E05 explained the impact on team work as, *"I think it's a general culture thing at the nursing facility that I work at. Just getting them (care workers) to do anything some days seems like a challenge*". For sole providers who contracted to aged care services, the challenge was in overcoming scepticism about the benefits of the intervention for people with dementia. Participant E11 explained that *"there was a bit of education with the staff … at that particular site… had some preconceived notions about whether people could attend or not"* and *"some sites that we first approached didn't see it as valuable use of the clinicians time".* These comments reflect how low valuing of the work in aged care and attitudes about dementia (322) may translate into barriers to quality improvement in dementia care.

In public hospital settings, participants reported varying degrees of support due to some key stakeholders leaving the organisation or the constraints on time of others. Where there were established quality improvement structures in place, they experienced few difficulties.

"It all went pretty well to plan, and everyone is pretty open here, and admin were on board. I put the plan up to them and there were no barriers from them" participant C01.

In residential aged care and public hospital settings, time constraints due to demand and part time hours impacted on participants ability to participate in the collaboratives, with many undertaking learning in their own time.

6.3.3.3 Individuals involved

Where clinicians had support, it was often a team member who co-sponsored the change, or it was an organisational structure of quality improvement that assisted them to implement a change. In public hospital services, multidisciplinary teams and administrative staff provided support.

Participant S09 explained that she *"work (ed) closely with the social worker on our team"* and in aged care*,* participant E11 felt lucky to have *"good team cohesion sort of network going on already".* Support from administrative staff in public hospital clinics was important to success.

"it's probably created a little bit of extra work for one of our secretaries who agreed to take it on, which was good of her, because the patients still need to go through our systems, as in, through our …formal bookings and those sorts of things" participant C01.

Others had formalised organisational meetings in which to share the quality improvement and to monitor progress. In public hospitals, formal multidisciplinary meetings provided opportunities for clinicians to show the benefit of their improvements.

"…the doctors we see know we have this now available. So, in fact, I have found that it's not unusual for the doctors to say, 'Actually, can you see this person and their family?'" participant S09.

Sole or private providers used their referral networks well to share their improvements through reports and verbally in meetings and in residential aged care, clinicians worked closely with other staff to change approaches and coach skills.

"…through really informal, very small group, on-the-spot sort of stuff - where opportunistic training, basically, where a care staff would come up to a resident, say "Come on, it's time to go to exercises." And they'd say, "No." And then I'd follow up and say, "Okay, so how could we have changed that?" participant E11.

Clinicians identified supporters and transferred their skills and knowledge in quality improvement to build support. In publicly funded health services, clinicians involved colleagues through mentorship and teamwork. Participant C01 described how she had "*been able to champion someone …along with me, who is interested in quality and doing carer work".* Those with leadership roles were able to engage the whole team. Participant S13 identified how *"an incredible effort for a ward (staff team)"* created *"a huge achievement from the team, so they're really celebrating that success as well".*

6.3.3.4 Relationships

Partnerships and support from external organisations were beneficial for sole providers and clinicians in public hospitals to expand the benefit of improvements and in creating a sense of achievement.

"The other positive things were the people that are actually doing stuff in town were really enthusiastic to take on as many people as they could" participant E09.

"We collaborated with Carers (organisation) and we actually completed as part of the organisation a self-assessment, how we were … supporting our carers within the workforce. …achieving this recognition and accreditation … for being a carer-friendly employer" participant C06.

6.3.3.5 Role changes

Several clinicians reported changes to their role or employment status during the collaborative process which limited their achievements or redirected their efforts. In residential aged care, clinicians were disappointed not to be able to implement the planned improvement processes as work hours were reduced. Participant E10 was disappointed that *"because my employment situation changed, I wasn't really able to apply them".* Similarly, participant E05 explained that "*changes in my personal circumstances,.....So, I cut back my hours and I just did not have the time to do what I wanted to do unfortunately*"

Others in public hospitals, moved from clinical roles to leadership positions, limiting their direct practice but allowing them to influence others.

A summary of contextual influences that impact on implementation success for three main settings is provided in **Table 21**.

Table 21. Summary of contextual influences that impacted implementation success for three main settings

Contextual elements (CFIR)	*Hospitals and outpatient clinics*	*Community and residential aged care*	*Sole providers/ private practice*
Outer setting	Funding changes and constraints continued	Funding constraints continued	Opportunities arose from policy changes
Inner Setting	Varying degrees of support from managers and role changes redirected effort	Culture and attitudes of other staff to changes made changes challenging Reduced hours and constrained roles limited opportunities	Own time to invest Contract limitations and opportunities were explored
Individuals involved	Support from multidisciplinary teams and organisational structures assisted improvements	Worked across boundaries with individuals to counter un-supportive attitudes	Referral networks were important to convincing others of benefit
Relationships	Partnerships with external organisations and local networks legitimized changes	Support from leaders of other teams helped engage others	Networking and feedback to referrers enhanced acceptance of changes

6.3.4 Understanding implementation processes

Using a lens of Normalization Process Theory (106) clinicians were asked to reflect on the processes they used. They identified the value of the evidence base for the guidelines to convince others of the sense of the improvements, and how they worked to engage others in the steps of change. While some participants were more successful than others in implementing a change to practice, all participants gained from learning about change processes and thought they could use it for other improvements in their work. The framework of the four constructs of Normalization Process Theory: coherence, cognitive engagement, collective action, and reflexive monitoring was used to provide examples of how they understood the implementation process through the collaboratives.

6.3.4.1 ***Coherence*** *(implementation process makes sense)*

The recommendations from the clinical guidelines for dementia needed to make sense to the clinicians and others in their workplace and be differentiated from current practice to achieve an improvement in practice.

Clinicians in public hospitals used their personal experience of other change or implementation projects to judge the benefits of the collaborative methods and content. Participant C06 explained that *"I could really see the potential …and thinking, this has got so much potential so I'm excited about that. It did make sense".* Participant E09 understood the personal benefit of exercise so explained *"because I knew it helped me… I've had to keep looking to see what changes might have happened"* for the people she referred to exercise*.*

In aged care settings, clinicians understood how important is was that other staff understand the changes and the evidence behind the guidelines. There was evidence of attitudes, beliefs and routines which demonstrated pessimism that people with dementia could benefit from the interventions and the participants needed to counter that. Participant E05 suggested that staff *"think that maybe they're not well enough, that it's not appropriate for them'',* while participant E11 *saw the need for time for staff to adjust, "I think it's them being familiar with it too".*

Sole providers and private clinicians identified how the collaboratives provided the opportunity to improve their understanding of how to support people with dementia. Participant C05 explained that *"it's been one area that I've wanted some more information on and wanting to know how to better support people in that progression*".

6.3.4.2 ***Cognitive participation*** *(enrolment and engagement of individuals in the implementation process)*

For some clinicians the processes for implementing improvement was new. In aged care settings, role, and task boundaries limited exposure to change methods. As participant E11 revealed *"it was a bit of an eye-opener. This is the first sort of project I've been involved with".* However, clinicians in public hospitals with experience in other projects appreciated the focus on engaging others in the process.

> *"…clearer understanding of the processes of getting other people onboard with a change, some techniques that could be used to encourage their understanding of the situation and make them feel like they're involved in the change rather than just telling people what to do"* participant E10*.*

The use of checklists to collect base line data and for feedback to clinicians, enabled them to see what was needed to be changed for adherence to the guidelines. As participant E10 indicated, "*It was potentially slightly embarrassing filling it in because I knew I wasn't doing enough, but I didn't really know how to improve that"* until after the online learning. Identifying the gap between usual practice and the recommendations from the clinical guidelines for dementia care was a key process in motivating clinicians to make changes.

> *"I actually didn't provide a lot of written information to the clients and their care providers, so I made a point of ensuring that as the project went along that I was actually incorporating that in my checklist"* participant C05.

6.3.4.3 ***Collective action*** *(operationalising a change process)*

Clinicians reported feeling supported by the structure and steps in the process of the collaborative. They could fit in the learning and actions over time with some flexibility and understood the process was a series of iterations to improve their plans. Participant E11 stated that *"the really clear expectation that your first iteration of your goal will not be your final goal. It's not a failure to change your goal".*

In aged care, the small steps and support from the collaborative was important to success in learning and engaging others in implementing changes. One clinician expressed the value of this support as:

> *"… just to have the confidence of having other people check your work and give you the seal of approval. That was good."* participant E13.

The peer collaborative sub-groups varied in their importance. For some people in public hospitals and others in the occupational therapy collaborative sub-group, they were considered useful. Participant O07 found them to be "*really worthwhile just sharing, also any issues that came up. Yeah, I found that really, really relevant".* This overcame a sense of isolation and offered ideas and a comparison with others.

Others in aged care or those who worked part time, found them hard to connect with across different time zones, different workdays or did not have time.

The strategies learnt through the collaboratives and webinars were particularly useful for clinicians in driving change and involving others in the change process. In public hospitals, clinicians reported using regular meetings effectively to remind others of the purpose of the change and challenge preconceived ideas.

> *"…just have a five-minute thing on exercise and the importance of it in our intake meeting. I could see from there that people go "Oh yes. Oh no, I haven't really had anyone that's suitable." And I say 'Well, who have you had?'"* participant E09.

This strategy was useful for clinicians to keep the improvement on the agenda and to give time for people to adjust to changes.

In aged care that strategy was important to cross boundaries between roles. Participant E11 indicated that her strategy was "*mostly because of some of the education, …identifying your local*

heroes, and putting responsibility on other people that, you know This isn't just me doing this. This is us doing this". This engagement of others in implementing changes was identified as important and the most challenging aspects of implementing quality improvement.
Participant E13 identified that they *"had a bit of bad luck trying to get it started at some sites where – just because of business decisions, so we kind of picked it up again in an alternative site… so it's quite popular there".*

Finding ways to engage other services in change was key to clinicians in private or solo practice. They found change strategies useful for marketing their services and contracts *"I think I probably achieved a better understanding of some processes that could be applied to achieve change"* participant E10.

Most clinicians considered the feedback reports on current practice and then on their implementation plans to be very valuable. It provided expert advice from an external perspective and incorporated the perspective of expert-by-experience of dementia. In hospital settings, clinicians reported that the focus and quality was helpful in developing an implementation plan.

"A solid methodology and a solid quality improvement plan have been really critical in getting us to a point where it's working and sustainable" participant S13.

In aged care and sole practice, clinicians found the external perspective helpful to review their practice. Participant O09 explained that *"it's a nice report to have because you really focus on what you're doing…gives you an opportunity to review, re-evaluate, focus, what could I do better?"*

The collaborative process provided a collective action to developing plans and the skills in engaging others in the workplace in implementing change.

6.3.4.4 ***Reflexive monitoring*** *(review of new practices)*
At the completion of the collaboratives, clinicians had reflected on the process and what they had achieved and also reported their comments in the online modules. In the interviews, clinicians had the opportunity to consider the program theory and how it related to their experience. They also reported how they reviewed the changes that had been made or those still in progress in their practice. They appreciated the opportunity to identify what worked for them and how the process could be improved.

"It's actually been helpful to talk about it, and just think about these questions" participant S09.

In aged care settings the length of the process was important in being able to make changes. Participant E10 considered that the benefit was *"it was an ongoing process rather than just attend this conference for two days and go home".* The ongoing small changes accumulated and participant O09 reported that "*I thought that every month, changes were so small, and I didn't feel*

that I was getting anywhere by doing anything. But overall, over the year, yes there's massive change''. For participant C07, completing the checklists was good practice *"because it made you reflect on it".*

For sole practitioners and private organisations, the checklists were particularly useful to review practice and see progress towards guideline adherence.

"I'd go back and look at who I saw and what the interventions were… it was helpful to look at what was I doing and what follow-up was there" participant S09.

"a way to reflect at the end of the month of, okay, how did I go this month? … change had been somewhat sustained through that period" participant E11.

In hospitals, clinicians found reflecting on the improvement helped sustain the change and link it into the organisation. Participant S13 reported that *"the flow on from that is a program that we've been able to sustain moving forward and we've planned for another review session again next week"*. The building in of review processes provided satisfaction with achievements and a way of identifying what other changes may be needed. Reporting on that within organisations provided recognition for clinicians in improving quality.

"there's …a framework that goes right up the chain of leadership about what quality activities are being done in the unit. So, I gave that to my manager who was able to say, "Yes, we're doing this..." Then that got fed up the chain of hierarchy to say, "This is what's happening in practice." participant O13.

Being able to track changes and identify when they were embedded into practice gave clinicians a sense of achievement.

"I think that's really important that it doesn't just stop here….
It's been good but it's not been embedded. But that's something that I will keep working on… over the next 12 months at least" participant C06.

"once the clinic was set up, I was …tracking the gap as such, and the implementation. For clients …it's completely embedded now in our comprehensive cognitive assessments that we give out…" participant C01.

One clinician in a hospital setting was able to link the implementation to workforce and wider social effects.

"the ripple effect will be that if the workforce then feels supported and empowered and knowledgeable and comfortable and safe, they can then share that or recognise that within other carers that are consumers of the healthcare service" participant C06.

A summary of the post-intervention processes that aided success from participants across three settings using the Normalization Process Theory lens, are presented at **Table 22**.

Table 22. Summary of post-intervention processes through an NPT lens across three settings

NPT constructs	*Hospitals and outpatient clinics*	*Residential and community aged care*	*Sole providers/ private practice*
Coherence	Clearly identified value of improvement	Used evidence base to convince others	Identified a service improvement opportunity
Cognitive participation	Developed strategies to engage others in change	Identified gaps and small steps to improvement	Identified gaps and set goals to increase adherence to guidelines
Collective action	Drove changes through teams and challenged routine practice	Used strategies to engage others across role boundaries coaching and feedback	Sought out feedback and advice in collaborative and networks
Reflexive monitoring	Monitored and reported change in team and to QI process, which helped sustain and embed change in organisation	Reflecting on change with co-workers over time made improvements possible	Linked changes to accreditation and quality improvement in business

Abbreviations: NPT: Normalization Process Theory, QI: Quality Improvement

6.3.5 Understanding the Mechanisms involved in the Collaboratives

The initial program theory was shared with clinicians in the post-intervention interviews for each step in the quality improvement collaborative process. Their response and reasoning was sought on how the theory applied to them or not. The initial program theory (see **Table 7** in Chapter 4) was described as *'If… then'* statements for each of the components of the quality improvement collaborative strategy and responses were sought from clinicians about how and why they did or did not represent their experience. This provided the opportunity to examine and explain their reasoning for how they participated in the collaborative and how they built knowledge and skills in quality improvement in dementia care. This enabled the program theory to be tested and modified based on the evidence provided. Of the nine mechanisms initially proposed, six were identified in the pre-intervention interviews including motivation, accountability, collective learning, doing it together and credibility. From the post-intervention interview results presented here**,** the program theory was revised with redescription of some mechanisms and the addition of a mechanism related to achievement.

6.3.5.1 Maintaining Motivation

All participating clinicians identified a high level of motivation to participate in the quality

improvement collaborative. In the post-intervention interviews clinicians focused on their motivation to complete the process.

In public hospitals and aged care organisations, clinicians who experienced time constraints identified the structured and supported process as helpful to keep engaged with the collaborative. Participant 013 reported that the collaborative process *"helped with my level of motivation and level of confidence to implement and get involved in the evaluation process".* Similarly, participant E13 identified the regular prompting as important*. "It was actually you guys kind of driving us to get the work done which is a good motivating factor for people like me who get distracted easily".* Participant C07 identified dual motivations that meant *"I was much more motivated to do it, I felt like it had work outcomes and a personal outcome".*

For sole providers and those working in private practices, the motivation to continue was explained as due to a useful and relevant process. Participant O04 "*noticed patterns early on. I could change my focus … thinking more about future planning".* By taking on a simple project, participant O07 explained that *"I knew I could do it and still maintain a private practice".*

6.3.5.2 Accountability

The processes in the collaboratives of establishing a base line, using check lists to review practice, written feedback on adherence, regular contact and encouragement and a stepwise process enabled clinicians to be accountable to complete the steps.

In aged care, clinicians described their willingness for scrutiny and how the timing of steps kept them moving ahead. Participant E10 explained that*." I knew I wasn't doing enough, but I didn't really know how to improve that*" before this collaborative process*.* The structure of the program suited the need for flexibility and milestones for participants.

> *"it was a good balance of having enough milestones to keep you moving and building in those teleconferences was good because that kind of made you think, "Oh I better do something before I talk to people again"* participant C07*.*

In public hospitals, participation in the collaborative met organisational quality improvement requirements and professional accreditation. Participant C06 described how *"it crosses over many of the domains from the organisational point of view and accountability point of view. It's been great to have that recognised".* That alignment between organisational requirements and the quality improvement collaborative process strengthened the effect of this mechanism.

Similarly, when professional accreditation and quality improvement aligned, participants identified a synergy between the two.

"I'm a CNC and it's one of my domains, that I have to be doing something or working towards something at any point. So, it was great. It fulfilled that criteria for two whole years." participant C01.

For sole providers and some contractors working in aged care, the alignment of the collaborative process with professional accreditation was important. Participant E05.explained *"because I work in a part-time role and with completing all the checklists and doing the online learning, that really helped me to maintain my accreditation for that 12-month period".*

While not all clinicians needed the accreditation for their profession as they had other opportunities, they all considered the endorsement of the collaborative activity by professional associations and the opportunity to earn continuing professional development points, was valuable.

6.3.5.3 Identity

The sense of an identity for participants in the collaboratives covered two main areas. For some it was related to a passion for improving the quality of life for people living with dementia. For others it was a professional identity as a leader in evidence-based practice and service improvement.

In aged care settings, clinicians more often identified a passion for improving the quality of life of people living with dementia. Participant C03 described herself as *"probably more an advocate, rather than an agent of change, although I'm happy to be considered an agent of change".*

In public hospitals, clinicians valued an identity related to maintaining standards for the profession and service improvement. Participant O07 considered *"it was all to do with best practice, … and that's what kept me going with it*", while participant O13 identified that *"as far as the impact it's had on me as a professional, I think it's been excellent".* When improving dementia care was coupled with increased knowledge of implementation, clinicians recognised the effect on their competence. In sole practice or for private contractors their sense of identity related to their competence and service improvement as well. For instance, participant E13 thought *"it's made a positive impact on my own practice methods'* and participant C05 believed the collaborative had *"improved my practice and sense of empowerment I guess, working with clients with dementia and their carers".*

Clinicians often made the link between dementia advocacy and professional development as part of their identity and values.

"It's lovely if you can do that and grow and be in the position to apply for different roles and demonstrate that you've gone above and beyond on some occasions to be able to advocate for people with dementia" participant C06.

6.3.5.4 Doing it together/ collective learning

Clinicians offered several rationales for how they valued the collaborative nature of the process. For some in hospital or aged care settings their appreciation for the collaborative related to a sense

of community of interest. Participant O13 explained that *"knowing that we're all trying to make positive changes and we're all interested in the same thing; I could also have the support of the collaboration as well".* Hearing other perspectives was important as described by participant E11. *"I found it particularly helpful for listening to those who aren't physios… what their priorities were for the study".*

For participants in sole practice or working in settings where there are no other like-minded clinicians, it was important for overcoming isolation as participant C06 explained, *"It can feel quite isolated so having a collaborative for the Agents of Change was quite exciting*". Similarly, participant C07 identified the benefits "*to hear what other people were doing and yeah, feel like you're part of a community''*

Some clinicians described how the online modules provided an opportunity to share ideas and collaborate with other professionals. Participant S13 explained that *"having that online forum where everyone can input into it is a good way to learn"*. Participant E13 expanded on this, stating that *"you're …getting a much more detailed answer than what I could just provide myself"* and how *"it was good to brainstorm that with other people, even if it wasn't necessarily in real-time, just seeing all their answers collated together was certainly helpful for me".* For participant O04 the benefit was in the combination of identity and interest*. "people were in the same boat and have the same aspirations as well".*

Some clinicians who had prior experience in quality improvement did not value the collective learning and community of practice as much after the initial learning.

> *"I did the group thing for a little while, but that kind of fell off towards the end. I think we kind of talked a lot at the beginning and then you kind of found your feet and you knew what you were doing"* participant C01*.*

Some clinicians found the peer collaboration process did not work well for them. The flexible nature of the online modules meant that some clinicians started later while the different time zones and days worked meant that the peer collaboration was not what some participants expected.

> *"I found that a bit clunky. …some people started a little bit later and earlier. Some people went through the modules more quickly. So even though we were in the same group, we weren't all up to the same level"* participant C03*.*

6.3.5.5 Credibility

There were several factors mentioned by clinicians that linked to the credibility of the collaboratives and a reason for them participating and learning. The evidence base for the guidelines, the link to recognised researchers who were clinicians and to the university for up to date resources, provided confidence and trust by clinicians in the process.

In public hospitals this was particularly influential. Participant E10 believed that "*it's the sense about credibility and trust, isn't it?".* Similarly, participant O13 *"had faith in (*knowing*) who was running all your disciplines and that makes a huge difference that you understand practice".*

For most clinicians, the acceptance of the collaboratives by professional bodies for continuing professional development points provided reassurance that the effort and time put in would be recognised in their accreditation. Participant C01 saw the combination as *"a winner*" because "*you're getting your CPD points and you're learning while you're at work, in work time".* Participant C06 also recognised the value of the collaborative by stating that *"with the CPD, I could see how it would attract people… because …the MOOC is extensive and very, very valuable".*

In aged care and sole practice where access to professional development was reported as limited, the opportunity to combine participation in the collaborative with continuing professional development accreditation was important.

"It was incredibly important for me because I work in a part-time role and with completing all the checklists and doing the online learning, that really helped me to maintain my accreditation for that 12-month period" participant C05.

A further factor identified by several clinicians was the validity brought to the collaborations by involving people with dementia and caregivers in the process. The value of hearing the perspective of people with dementia, gaining feedback about language and the implementation plans provided another level of credibility to the collaboratives.

Clinicians in aged care recognised the expertise offered by people with dementia and caregivers. Participant C07 considered that *"the feedback that I got on my plan was really helpful from the people living with dementia because they spoke about having done something similar with Dementia Australia".* Similarly, in public hospital settings, clinicians appreciated the advice.

Participant O13 explained that "*to hear from people that have actually had dementia and their perspective on what I am presenting and writing, I found that excellent"* because *"it's a different relationship, absolutely"* to working with clients.

"They came at it at a really practical angle and I kind of took that into consideration when we did that clinic" participant C01.

6.3.5.6 Achievement and reputation

Most clinicians identified the desire to improve services for clients or to enhance quality of life for people living with dementia. They could see gaps in services, where services were not adequately addressing needs. This was a source of stress and frustration for many participants. The achievement of improved services, adherence to guidelines or a new service where a gap existed

gave participants an emotional boost and a sense of achievement. That added to their reputation or that of their team or service. In public hospital settings clinicians felt able to address gaps and identified the satisfaction of achieving improvement.

"…*gave us an opportunity to see that's where that gap was and have a process to…come up with something that may…fill that hole, So, it was good to be able to be able to go through those steps to formally develop the carer clinic"* participant C01.

"we've found some really significant and positive results from intervention that we've put in place. …falls have reduced significantly over the past three months" participant S13.

By aligning organisational and collaborative priorities, participant C06 was able to achieve. *"a really large piece of work that was actually delivered as part of the focus from the Agents of Change program but also the concurrent work that's happening here"* The transferrable skills were important to participant C07 who stated that *"it would be something that I could do again, and I would know… how to do that and how to make the changes and go through that bit of a cycle when you make any change".*

In aged care, clinicians were able to see change at a wider level than their own practice. By engaging other staff in making changes participant E11 stated that "*what's been the most valuable is the implementation of change, basically, in a larger setting rather than just me and my actions"* participant E11. Sole providers and a range of clinicians identified the satisfaction they felt from their achievement.

"…as far as my professional life goes it's really made me feel better about my work and …positive …outlook about things" participant E09.

One clinician believed that a promotion was related to demonstrating that she had implemented a quality improvement. Others were able to align the improvement with organisational goals which improved their reputation within their organisation and professionally.

A summary of the mechanisms identified across three settings is provided at **Table 22**. This shows slight differences between the settings in relation to the importance of alignment with organisational goals in hospital and outpatient clinics and how involvement with others for people in aged care or private practice overcame isolation and gained support.

Table 23 Summary of mechanisms of change identified at the post-intervention stage across three settings

Mechanisms of change	Hospital/ outpatient clinics	Residential and community aged care	Sole providers/ private practice
Motivation and confidence to engage in change	Structured and supportive	Structured and supportive	Relevant and useful
Accountability and increased commitment to change	Fitted in with organisational requirements	To maintain engagement and accreditation	Maintained accreditation
Sense of identity reinforced	Professional evidence-based practice	Advocate for improved quality of services for people with dementia	Professional competence
Doing it together/ Collective learning increased confidence	Value of sharing perspectives and learning from others for improvement	Overcoming isolation and gaining support	Sense of community and overcoming isolation
	Initial learning gave confidence to apply the process	Motivating by working with like-minded others	Confidence in changing practice
Credibility increased commitment	Trustworthy, evidence base, aligned with organisation needs Accepted by professional bodies Advice from people with dementia and caregivers respected	Evidence-based CPD points through a work project Perspective of people with dementia gave useful advice	Evidence base and acceptance by professional body Experts gave validity of improvements
Achievement of change Enhanced reputation	Alignment with Organisational goals and recognition of improved services	Influencing wider service change to improve care	Satisfaction with competence and professional value in network

6.3.6 Post-intervention Survey results

6.3.6.1 QIKAT-R survey results

Results are presented at *Figure 20* comparing scores for 18 clinicians who responded to QIKAT-R survey at post-intervention with scores at pre-intervention. (see ***Figure 12*** Chapter 4).

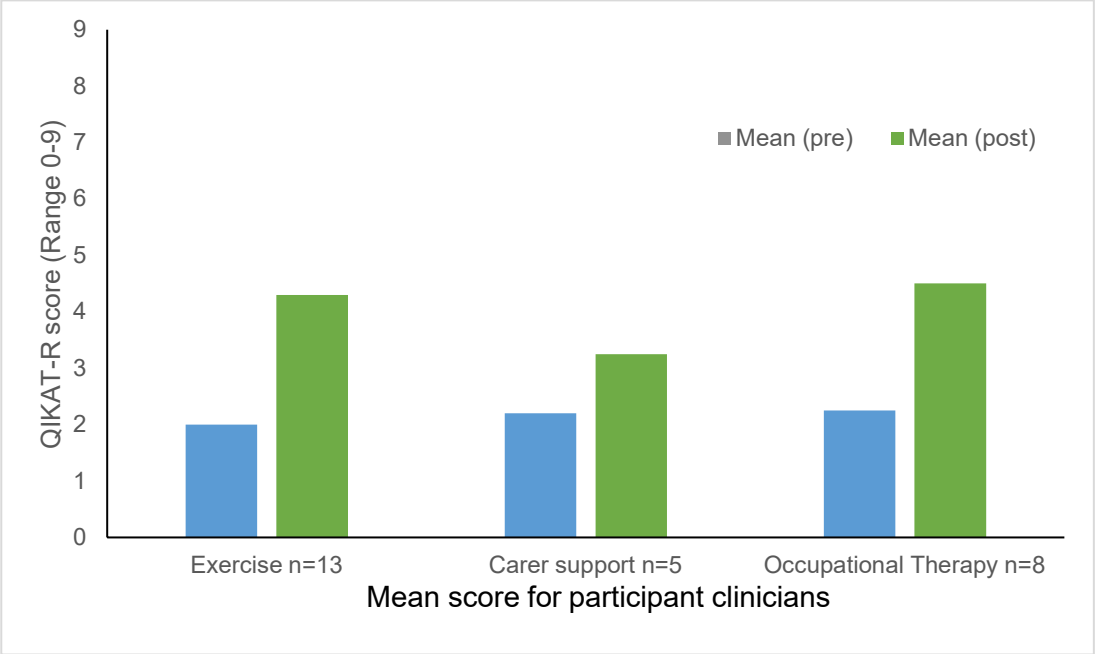


Figure 20 Post Intervention QIKAT-R scores for clinicians by collaborative sub-groups

There was a modest rise in scores for most clinicians compared to the pre-intervention results as shown in ***Figure 18.*** Not all clinicians completed both pre-and post-QIKAT-R surveys but of those who did, three clinicians scored lower on the post-intervention survey.

On review of written responses, it appeared that the scenario presented in the survey may have been interpreted as a clinical issue. Most responses identified individual clinical investigations rather than process improvements as intended by the survey tool. This led to lower scores allocated to each component of those surveys where the process aims, measure, and change effect was not provided.

6.3.6.2 NoMAD survey results

The number of clinicians responding to each of the 23 questions in the NoMAD tool, varied from 10 to 15 clinicians. Sole providers indicated that some questions were not relevant, while others left answers blank.

Figure 21 shows a comparison of the degree of agreement by clinicians to the 23 statements included in the NoMAD tool, between the pre-and post-intervention surveys. Groups of questions relate to the four constructs of NPT: coherence, cognitive participation, collective action, and reflexive monitoring (106, 245). A summary of responses grouped by these four constructs follows.

Coherence: making sense of the quality improvements

Participant clinicians indicated clearly that they agreed that the selected clinical guideline for dementia care was different from their usual practice and the changes they made to adhere to the

guideline was part of their work. They highly valued the proposed changes to practice as they could see the benefit for their clients. The degree of agreement clearly increased in the post-intervention survey indicating that they had made sense of and valued the changes (245).

Cognitive participation: who is involved, and who supports the changes

There was agreement from clinicians that their role included making changes to practice and they were supported by other staff. The degree of agreement was lower post intervention, for responses about key people driving changes, their ways of working and the level of support from others. This lower level of agreement suggests that the clinicians were engaged in the change process and saw it as a legitimate practice but had less support from others to drive change than they initially expected (245).

Collective action: how the change is implemented in the context of resources and skills

Most clinicians agreed clearly that the changes would not disrupt work relationships and that they had support from managers. Their confidence in others' abilities to implement changes improved, and their agreement with the level of training they received improved. They indicated less agreement however, about the level of resources available in their setting to make changes. These responses suggested that resource constraints may have limited collective action in making changes (245).

Reflexive Monitoring: how the change process is understood and evaluated

Most clinicians clearly agreed that they valued the changes to their practice and that others considered changes worthwhile. They received feedback on the changes and clearly agreed that they modified changes to suit the setting. This appraisal by participant clinicians and others in their setting suggests that clinicians were able to review and adapt changes in practice (245).

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Figure 21 Comparison of degree of agreement by clinicians to statements in NoMAD survey pre-and post-intervention

Overall, the survey results suggest that participant clinicians considered that the changes made sense and were highly valued by them. The training provided was sufficient for them to implement changes that were considered worthwhile by others and adapted to their setting. The clinicians may have had less support and resources to drive the change than initially expected. This may have impacted on the level of change they could introduce in their work. The interpretation of these post-intervention results through Normalization Process Theory (106), suggests that most participant clinicians understood and engaged with the implementation process to make changes to their practice. Most were able to engage co-workers in changes but maintaining support from managers was more challenging. They engaged in monitoring of changes and reflection on the process to involve others. Contextual factors affecting local resources and support to drive changes, impacted on the level of change made.

The combined post-intervention NoMAD and QIKAT-R survey suggest that knowledge and skills in quality improvement improved modestly, and that clinicians agreed that the training was acceptable for them to engage with the implementation process and involve others in a worthwhile change. Contextual constraints on resources and support to drive change may have affected the level of change achieved.

6.3.7 Integrating the results

The clinicians involved in the post-intervention evaluation provided rich qualitative data through interviews and completed two surveys. This indicated their commitment to continue with the collaboratives to learn and apply their knowledge to an improvement in their practice. While not all participants completed the implementation, they indicated the usefulness of the process to enable them to learn and in some cases achieve significant improvements. The QIKAT-R scores showed modest improvements in quality improvement knowledge, but qualitative data provided evidence of understanding of the process and uses of quality improvement. Similarly, the NoMAD results showed increased understanding, engagement and monitoring of changes. While collective action was less clear from the NoMAD results in their settings, the qualitative data showed the variations of how clinicians worked together in collaboratives and with experts and researchers. The collaboration with experts gave them confidence to continue and commit to the changes. The collaboration with peers in the project was less clear, however.

Table 24 shows the level of agreement between the program theory and the findings related to mechanisms, constructs of NPT, QIKAT-R scores, and contextual factors. Medium to high agreement was identified for most data except for the QIKAT-R results. The low scores were related to the interpretation of the survey rather than level of learning. **Table 25** summarises the main influences on the QIC strategy and integrates the results to confirm refute or refine the initial program theory.

Table 24. Degree of agreement between results and initial program theory

Program theory	*Mechanisms*	*NPT*	*QIKAT-R*	*Contextual factors*
Motivated clinicians join the collaborative to learn to make changes in practice	High agreement	High agreement	High agreement (low scores)	High need
They collect data on current practice to identify gaps and engage in learning about QI	High agreement	Medium agreement	Unclear (low scores)	High impact of constraints
Incentives (CPD and conference) are offered through the program to maintain commitment	Medium agreement (CPD)	Medium agreement	No connection	Low/ medium value
Clinicians complete online learning modules with peers	Medium agreement (flexibility)	Medium agreement (engagement)	Unclear (high learning not shown in scores)	Medium value
Clinicians collaborate with peers via teleconferences and online to share ideas and comments	Medium agreement (sense of community)	Medium agreement (connection with others)	Unclear (sharing of learning not shown in scores)	High need to reduce isolation
Advice, feedback, and coaching is provided by experts and researchers to support application of skills	High agreement (credibility and authority)	Medium agreement (collective action)	Low: scores did not reflect learning	High need for coaching
Clinicians apply QI steps in their workplace and adapt recommendations to suit their context	Medium influence	Medium collective action	Low: scores did not reflect learning	Medium influence due to low cost/ small scale changes
QI process is accepted benefits seen	Medium agreement (ownership and commitment)	Medium agreement (collective action)	Low: scores not reflected in process	Medium support of changes in own settings
Results promote awareness and benefits	Medium agreement (recognition and empowerment	Medium level of embedding	Low: scores not reflected in learning	Medium interest in organisations

Abbreviations: NPT: Normalization Process Theory; QIKAT-R: Quality Improvement Knowledge Assessment Tool, CPD: continuing professional development. QI: quality improvement

Table 25. Integration of main findings pre-and post-intervention

	INTERVIEW DATA	**NOMAD**	**QIKAT-R**
Pre-intervention program theory	Confirmed	Confirmed	Confirmed
Motivation, need for learning and support	*"I'm confident in my ability so I'm hoping with the right help and guidance it will be a success" (*participant O01)	Made sense, buy in and optimistic of support	Low score on QI knowledge and skills
Identity and Uncertainty	*"I need to have a little bit more understanding of what will be required from me before I could really go further…"* (participant O09)	Uncertainty about time	
Concern about constraints and changes in setting	*"…that particular part of the sector is facing quite dramatic reform…, -our focus upon managing dementia in the community, may not be a priority going forward"* (participant S06)	Concern about team action and skills of co-workers would hinder implementation	
Post-intervention Program theory	**Modified**	**Confirmed**	**Modified**
Commitment, credibility, and achievement	*"A solid methodology and a solid quality improvement plan have been really critical in getting us to a point where it's working and sustainable"* (participant S13) *"…quite a bit of reading and reflection that was involved in the project, especially when you're going through that PDSA cycle"* (participant C05)	Made sense, buy in, team action and monitoring change contributed to success	Modest improvement in score on QI knowledge and skills
Impact of context and constraint	*"…the dynamics were more difficult than I had anticipated, and making any change was going to alienate me"* (participant O08)	Lack of team action and time constraints hindered implementation	

6.4.6 Outcomes achieved

Four case studies are summarised in **Table 26** to show how the resources provided in the quality improvement collaborative link with mechanisms and outcomes.

Table 26. Summary of four participant case studies linking context mechanism and outcome

Case examples	Resources in QIC	Mechanisms	Outcomes
1.Outpatient carer support clinic developed.	Online learning about carer support strategies QI learning about processes and relationships to develop new services Feedback about funding options andorganisations structures.	*Credibility* of evidence and guidelines for developing response to identified need and gap in services *Confidence* to develop a plan, try it out and adapt with support *Identity* as dementia advocate, job satisfaction and development.	Monthly clinic commenced with regular referrals for appointments made by team. Reaching carers not served Partnership with local medical clinics, admin staff, use of organisational systems.
2. Value of exercise increased in residential aged care.	Online learning about benefits of exercise QI learning about processes and relationships to change culture Feedback and advice on plans and ways to gain buy-in.	*Credibility* of evidence and guidelines for exercise for people with dementia in aged care. *Confidence* to engage care-workers about the benefits and strategies for increasing attendance *Identity* as agent of change to influence staff and residents' attitudes to exercise.	Supported care workers to understand value of exercise and to try different strategies to encourage residents to participate Increased participation and adapted exercise to include positive social and physical benefits Engaged nursing staff in recognising change and effort by care workers.
3. Additional carer support strategies offered in private practice.	Online learning about carer support strategies and use of Occupational Therapy to reduce stress. QI learning about how to develop and market new services to referral networks Feedback, and advice.	*Credibility* of evidence about occupational therapy to support carers and reduce stress *Identity* as dementia advocate, agent of change to improve quality of life for people with dementia and care partners.	Offered extended consultations to develop strategies and engagement for people with dementia and care partners. Marketed to referral networks and evaluated satisfaction.
4. Recognition of employer as carer friendly.	Online learning of carer support strategies QI learning of plan-do-study-act process Coaching provided.	*Credibility* of evidence and learning about carer support strategies and Quality Improvement. *Not doing it alone* Support and coaching to adapt plans when role changed.	Resources and hub developed for hospital staff who are caregivers. Partnership with QI structure, carer support organisation, staff. Well-being of staff improved and recognition as carer friendly workplace.

6.4.7 Participants in exit interviews

Clinicians who withdrew from the research prematurely were offered exit interviews by the author to identify the reasons for withdrawal and to seek feedback on the process. Of the six who withdrew, five clinicians were interviewed, and a framework analysis was applied to the

transcripts to explore contextual and social mechanisms influencing their decisions. **Table 27** presents the characteristics of the clinicians who participated in exit interviews by the collaborative sub-group they originally chose (exercise, carer support or occupational therapy).

Table 27. Characteristics of participants in exit interviews

Characteristics	*n*		
	Exercise *n*=2	Carer support *n*=1	Occupational therapy *n*=2
Female			2
Male	2	1	
Regional/rural/remote			2
Profession			
Physiotherapy	2	0	0
Occupational therapy	0	0	2
Health services	0	1	0
Organisation Type			
Public	2	1	1
Private	0	0	0
Not for profit	0	0	1
Service setting			
Acute	1	0	0
Sub-acute / Transition Care	0	0	1
Community / Outpatient	1	1	0
Residential and Community	0	0	1

6.4.7.1 Methods

Interviews were conducted with clinicians who were involved in the process evaluation but did not complete the program. The questions were simplified to identify changes from the initial expectations and context identified in pre-intervention interviews, and to explore the reasons for withdrawal. Their opinions and feedback were sought on the process they experienced and improvements that would be of benefit.

6.4.7.2 Results:

For two clinicians the major changes in funding sources and policy changes at a national level led to their roles changing and an organisational restructure. This meant that the focus of their work no longer suited the intervention.

> *"…that particular part of the sector is facing quite dramatic reform, and… our focus upon managing dementia in the community, may not be a priority going forward"* participant S06.

Changes to manager support of their involvement were affected by the restructuring and funding changes. Participant S02 stated that "*the support from management is very limited because their*

energy is all being focused on the change itself and implementing the change" and as a result the manager withdrew support "*she probably felt…not the right time".*

One clinician found little support from the manager once the approval had been given, reflecting little buy in to the project. There were high workloads and resource constraints on the team, but the clinician thought this lack of support also reflected the culture of the organisation and team to just do the work, not try to improve it.

> "*my line manager, who… didn't care one way or another whether it was going to happen or not. It meant nothing. I'm just doing a job basically that's all I'm wanted to do…*" participant O08.

The clinician explained how the improvement project was viewed as a disruption to the routine of clinicians in other disciplines and she felt excluded from the team. Participant O08 stated that *"the dynamics were more difficult than I had anticipated, and making any change was going to alienate me. I feel like the other members of the team would have been threatened".*

Personal circumstances changed for three clinicians. For one person there was a health issue, another a family change and another had a competing priority at work. The combination of contextual changes, personal circumstances and constrained time or support, led the clinicians to withdraw from the project.

Interpreting these results through a NPT (106) lens, these results suggest that while the improvements made sense to them and their clients, and the clinicians had engaged with the changes, there were competing priorities on their time and role, limited resources, and low levels of support from managers and co-workers, to undertake the change. Where co-workers saw the proposed improvement as a disruption, they opposed the change. The authority and professional autonomy of clinicians to make improvements to practice is mediated through contextual, organisational, and individual factors which may constrain change.

Participants who dropped out of the program retained positive expectations of the project and provided feedback on the benefits of the structured approach, the evidence-based guidelines, and the collaborative nature of the project as important to them. The delay in starting the project while ethical approvals were sought was disappointing for one clinician who withdrew because another priority overlapped the time frame.

6.5 Summary of findings from the post-intervention process evaluation (Part B of study 1)

A realist-informed process evaluation provided understanding of how and why the quality improvement collaborative worked and in what circumstances, for the participant clinicians.

6.5.1 Mechanisms of change in the collaborative

The quality improvement collaborative attracted clinicians with a passion to improve dementia care in a context of resource constraints and pessimism about the benefits of interventions to improve the quality of life of people with dementia. It provided resources and opportunities for clinicians that were not usually available in their setting and met their needs for support, coaching, practice reflection and a flexible structure. They valued the credibility of the program, the flexible approach which suited their work needs, and the process of trying out changes before adopting a new practice. By being part of a dementia-specific collaborative with access to experts and peers for support and advice, they developed the confidence to pursue change in practice. Access to experts-by-experience of dementia and clinical experts convinced clinicians of the benefits and empowered them to challenge pre-conceived ideas and routine practice. When their personal motivation aligned with organisational structures and resources, clinicians successfully built the knowledge and skills to implement significant systems improvements and were recognised for their achievements.

Others were able to change their practice for the selected recommendations of the guidelines and reported improvements for their clients. Many faced contextual barriers through time and resource constraints, manager or co-worker resistance, major organisational restructures, and policy changes. While some clinicians withdrew due to contextual barriers, most completed the program and gained knowledge, skills, and the confidence to engage in quality improvement which improved practice in their setting. There was a sense of empowerment for many clinicians in overcoming barriers to change. Seven mechanisms in the collaborative were identified: motivation, accountability, identity, collective learning, credibility, reflective practice, and empowerment.

6.5.2 Acceptability and feasibility

The flexible, on-line delivery and guidance through the collaborative program, made the process acceptable and feasible for most clinicians. They appreciated the incremental, stepwise approach, identifying gaps and adapting guideline recommendations to their settings over time. While some clinicians wanted more collaboration and valued the initial face-to face start-up meeting, they all identified it was possible for them to participate because it was online and could be accessed when they had time. They appreciated the link to researchers and experts who had clinical and personal expertise. Clinicians reported that seeing the comments of other participants online and sharing ideas was helpful although the opportunity to collaborate with others was difficult because of differences in days worked or time zones across Australia. The opportunity to hear the perspective of people with dementia and caregivers and have their feedback on implementation plans was valued by participants. The trial of collaborative was feasible with most participants completing the trial and improving adherence to the clinical guidelines for dementia care (202). They were committed to completing the program as it was structured over time for small changes and with regular feedback and prompts to achieve milestones. A mix of face-to-face and online meetings,

and the involvement of experts, made the collaboratives possible for involvement of busy clinicians. The collaboratives provided a valued resource that was not otherwise available to clinicians, through a mix of face-to-face meetings, webinars and email contact. More extensive use of videoconferences during the pandemic in 2020 has made this mode more readily acceptable and familiar to clinicians. In future implementation of this collaborative, greater use of video-conferencing at predetermined times may suit more participants for peer-to-peer collaboration and ongoing networking.

6.5.3 Impact of context on clinicians and implementation

The major changes in the external context had an impact on organisational funding, structures, and roles of clinicians. Several clinicians in aged care and hospital settings identified distress at the changes and withdrew from the collaborative because their roles changed significantly, or they left their employment.

Despite constraints in most workplaces, clinicians were able to make small step-by-step changes to their own practice and to processes and systems in their workplaces, which added up to bigger changes. Clinicians in public hospitals and aged care where they were supported by managers and systems, were successful in implementing change. Private practitioners were able to make changes to their own practice and to the opportunity to offer services that were needed in their networks. Clinicians were able to adapt the recommendations of the guidelines to suit their roles and settings and found the audit and feedback process helpful to reflect on their practice. This stepwise and manageable approach suited clinicians who were constrained by time, resources, and support in their workplaces.

6.5.4 Building knowledge and skills in quality improvement and implementation

Clinicians were able to learn about the clinical guidelines for dementia and build knowledge and skills in quality improvement and in implementation processes. The QIKAT-R survey used to assess knowledge and skills showed modest improvements for most clinicians. Due to the small sample size and missing data, it was not possible to claim the collaborative process caused the increase. However, the interview data showed how clinicians used the knowledge provided in the collaborative to implement stepwise changes and engage others in the process. Similarly, the NoMAD survey showed that clinicians thought the changes were worthwhile and understood the importance of engaging others in putting changes into place and reviewing practice over time. The survey showed how collective action to implement the changes varied due to contextual influences. Where clinicians were able to engage others in the implementation process, they demonstrated their ability to harness collective action in the process of implementation.

6.5.5 Refined program theory

The process evaluation tested the initial program theory and some refinements were added at the

conclusion of the collaborative. The initial and refined program theory is presented at ***Figure 22*** Box 1 and 2 in a series of '*if…then'* statements and contributes to understanding of the processes of the collaborative strategy to improve adherence to the clinical guidelines for dementia.

Box 1. **Initial Program theory presented as *'If…then'* statements**

If motivated clinicians from diverse settings join a quality improvement collaborative with the support of their managers, they *then* engage with the process and commit to completing the program. *If* they learn online with other like-minded clinicians, *then* they can collaborate in a virtual space to share and adapt evidence-based guideline recommendations to their setting. *If* credible experts provide advice, feedback, and coaching to improve plans *then* clinicians have confidence and skills to make small stepwise changes, involve co-workers, and implement changes to their practice. *If* the benefits are seen and there is little disruption, *then* the quality improvement process is accepted in their workplace, and clinicians are recognised for their work to improve dementia care.

Box 2. **Refined Program theory presented as *'If…then'* statements**

If motivated clinicians from diverse settings join a quality improvement collaborative with the support of their managers, organisations, and networks, *they* then engage with the process, **believe that improvement is possible** and commit to the program**. *If* the topic of the collaborative fits their professional role and identity and is linked to credible sources, *then* clinicians have confidence to put effort into completing the program. *If* clinicians see that the program is flexible, structured, and practical with time to learn and implement change *then* they accept that it is possible for them to participate.** *If* they learn online with other like-minded clinicians, *then* they can connect in a flexible virtual space that fits their work demands and roles, to share and adapt evidence-based guidelines to their setting. *If* credible experts provide advice, feedback, and coaching to improve plans *then* clinicians are encouraged to make small stepwise changes, involve co-workers, and implement changes to their practice. ***If* the benefits are seen and there arelinks to organisational drivers, *then* the quality improvement process is accepted in their workplace, and clinicians are recognised for their work to improve dementia care. *If* clinicians reflect on the process of improving quality and the contextual constraints, *then* they gain a sense of empowerment in their practice.**

Figure 22 Initial Program Theory Box 1 and Revised Program Theory Box 2

6.6 Strengths and limitations of the evaluation

The use of a theory-driven evaluation was a key strength as it addressed a gap in the literature about process evaluations, implementation studies and in dementia care. Realist Evaluation methods provided ways to understand how and why quality improvement collaboratives worked for the participant clinicians and under what circumstances. By creating an initial program theory then

testing it with participants the refinement added depth of understanding of the influence of context and the response of participants to the resources provided in the QIC. In doing so this adds to knowledge by building program theory of quality improvement collaboratives used in different areas of healthcareand with different designs.

The use of mixed methods offered the opportunity to collect comprehensive data and provided a more complete understanding of the influence of the resources provided in the collaborative strategy. The integration of the mixed methods used to gather data and analyse results provided the evidence to refine the program theory of how the quality improvement collaborative worked in this case study.

The small sample and instances of missing data, and lack of a control group, limited statistical analysis of the survey data. Claims of causality cannot be made about the change in responses on skills and knowledge of quality improvement or in understanding implementation processes through statistical inference. Cause in critical realism is understood as emerging from the interaction between people, their actions, and the structures in which they act (27). Causality of the mechanisms identified within the collaborative can be understood as dependent on the range of contextual influences which were explored through the interviews (218). Validity in this case is established by review of the program theory in light of the mechanisms identified, rather than statistical generalizations (27). The use of a critical realist approach does not require a control group as the research questions are about understanding how and why participants experienced the program and drawing theoretical generalisations from that (323). The qualitative data however provided examples of the learning in the online module, being applied to the clinicians' implementation plans and reported outcomes from the program.

Attempts were made to collect survey data and conduct interviews with all clinicians who completed the program. However, after two follow up emails were sent, those who did not reply were not included in the evaluation. Several clinicians took annual leave at the end of the collaborative program and one participant resigned from her position due to reduction in her hours of work.

While the coding and analysis of the data was undertaken by the author and cross checked by another researcher in the team, there may have been some bias in interpreting surveys and interviews. The use of a framework analysis method provided guidance for analysis and going back through the data provided the opportunity to reconsider comments made and responses to survey questions. Reporting standards for realist evaluations were used to assess the evaluation quality (252) at Appendix 5.

CHAPTER 7 STUDY 2: VALUING THE EXPERIENCE OF PEOPLE WITH DEMENTIA AND CAREGIVERS IN RESEARCH

7.1 Introduction

This chapter presents the results of Study 2: Identifying the value of involving people with dementia and caregivers as expert advisors in the quality improvement collaborative (see Figure14 at Chapter 4.). The objective was to understand how people with dementia and caregivers (hereafter referred to as experts-by-experience of dementia) who were involved in the Agents of Change trial (6), added value to the collaborative strategy to implement clinical guidelines in dementia care.
This chapter describes the range of roles undertaken in the research trial by experts-by-experience of dementia and the perspectives of the participant clinicians, the researchers, and the experts themselves on the contributions made, the cost of that involvement and the value added to the research.
The author developed the theoretical framework (Ch 3) and methodology (Ch 4) to conduct the evaluation. A realist-informed approach was chosen to build theory on the value of involving people with dementia and caregivers in research. The experts-by-experience in the trial were invited to participate in the evaluation and interviewed by the author. The data was analysed by the author and the coding was checked by an experienced researcher on the trial. The principal Investigator for the trial included the assessment of value of involving people with dementia and caregivers in the protocol for the trial and supervised the work of the author.

7.2 Background

7.2.1 Recognition of public involvement

The importance of the involvement of members of the public in research is widely recognised internationally and increasingly in Australia (246-248). Benefits include increasing relevanceto community needs, effective translation of research into improved health outcomes and increased public confidence in research (246, 324). In the UK, INVOLVE was founded in 2003 to develop ways to involve people in decisions that affect their lives, including in research (5). The definition of involvement used here derives from the INVOLVE briefing notes for researchers as research carried out ‘with or by members of the public’ rather than research being ‘to, about or forthem’ p.5 (5). In healthcare research, funders recommend and, in some cases, require public involvement in all phases of research (5, 246). In doing so, researchers may involve the public initially to comply with funding requirements but then realise the potential benefits of different perspectives on the quality of the research (325).

The involvement of people with dementia in research has faced several barriers, and there had been few examples of such involvement until the last decade (326). Barriers such as the complexity of research and research processes, research costs, ethics approvals, identifying

appropriate roles and representatives, have limited the opportunities (186). In Australia, researchers encounter differences between state laws in obtaining ethical and legal approval in relation to capacity of the person with dementia to make decisions and seeking consent from substitute decision makers (327). Fixed ideas about the limitations of people with dementia to contribute to research have also limited the roles offered (328). The strategies that enable involvement in research include early planning by researchers, adequate resources, specific strategies for relationship building, and clear roles to match individual strengths (186, 329).

More recently there has been increased involvement of people with dementia and caregivers in dementia research (330). The reporting on the involvement of people with dementia and caregivers in research is growing, describing co-design (331), processes for involvement (332), and impacts such as improving relevance of research (333). Yet there are few studies on how the involvement of people with dementia and caregivers has been designed or evaluated (334). Few have addressed drawbacks in the process, the roles played by researchers or their attitudes to co-research (171). Evaluation of the value and cost of involvement (335), has been suggested to counter perceptionsthat it is too difficult to identify impact.

Reporting of costs or economic evaluation of the involvement by experts-by-experience of dementia is limited (335). It is difficult to directly attribute costs and benefits of public involvement in research to specific outcomes (334). Often public involvement in research creates benefits in processes, perspectives, relevance, and skills development which cannot be simply measured in terms of outcomes for services or health (336). To date, the assessment of costs of public involvement has been used to budget for and manage the resources needed (337). Identifying direct costs offers an opportunity to plan for investment in public involvement in research (335).

In Australia, the value of public involvement in healthcare research is widely accepted, but the reporting on roles, processes, support, costs, or value to research is not well established (338).

7.2.2 Involvement of experts-by-experience of dementia in this research

The Agents of Change trial (6), was designed with involvement of experts-by-experience of dementia at a number of levels. Consultation with experts-by-experience of dementia revealed three priority areas for implementation of the guidelines: exercise, occupational therapy interventions, and carer support strategies (6). Experts-by-experience of dementia were involved in the research process at all levels and stages of the trial. They were paid for their time and for any costs incurred as a result of their involvement and supported by the research coordinator to fulfil their roles.

The roles undertaken by people with dementia and caregivers in the trial were:

- Member of investigator group involved in research design

- Member of the management group to advise and monitor the progress of the research project team
- Member of expert working groups to develop and review content of online learning
- Member of the advisor groups to provide advice and feedback to participant clinicians on their implementation plans.

Figure 23 presents the team structure of the Agents of Change research trial highlighting the roles undertaken by experts-by-experience of dementia.

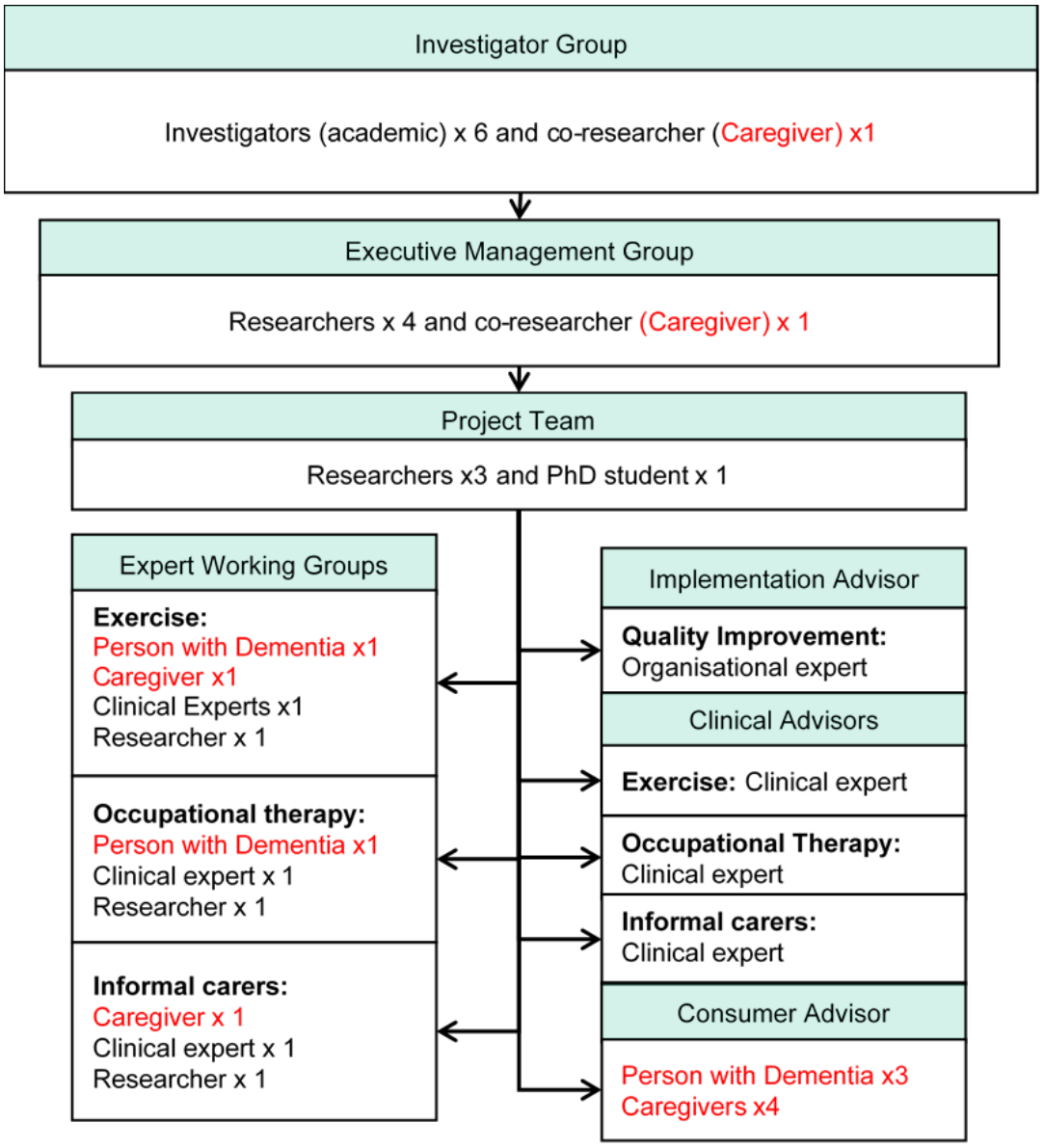

Figure 23 Team structure of Agents of Change trial showing roles of experts-by-experience of dementia

7.2.3 Recruitment of experts-by-experience of dementia

Experts-by-experience of dementia were recruited to the trial initially (see 4.2.3.2) and were invited to participate in the evaluation by the author after an email introduction from the trial coordinator according to the approved ethics process for Study 2 (see Appendix 2b).

7.3 Aims

This evaluation aimed to understand how experts-by-experience of dementia added value to the collaborative strategy to implement clinical guidelines for dementia. This was achieved by:

- Identifying the roles and contributions made
- Identifying the value added to the research through those contributions
- Describing the perspectives of the experts-by-experience of dementia, the researchers and the clinicians involved in the research
- Reporting costs of involving experts-by-experience of dementia
- Testing the initial program theory presented at **Table 8.**

Figure 14 in chapter 4 presents the three studies in this research and the part related to this Study 2 is selected and presented here as ***Figure 24***.

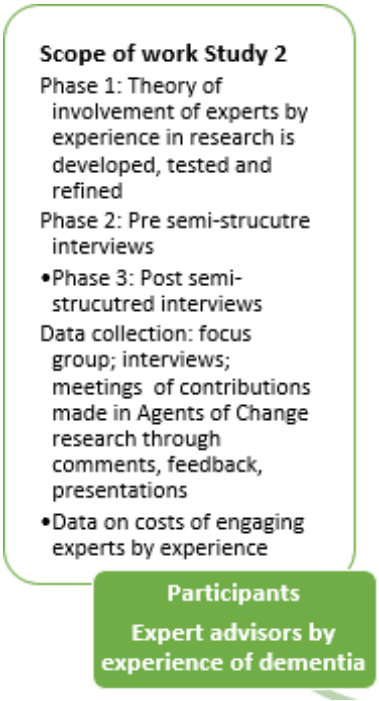

Figure 24 Scope of work for Study 2 Valuing the involvement of experts-by-experience in collaborative research

7.4 Methods used

The evaluation of the involvement of experts-by-experience of dementia followed guidance on process evaluation (129, 242) realist evaluation (26) and key principles for evaluating patient and public involvement in healthcare research (334). A realist-informed process evaluation was undertaken to understand how and why experts-by-experience of dementia added value (or not) to the collaborative trial. A range of perspectives and data collected from semi-structured interviews

and a focus group discussion, with document analysis, and a review of comments from participant clinicians in online learning modules, was used to understand how the involvement of experts-by-experience of dementia influenced the trial outcomes. A detailed description of the methods used is presented in Chapter 4 at section 4.2. A summary is presented here.

7.4.1 Realist-informed process evaluation

The process evaluation was conducted in three phases. First, an initial program theory was developed from a review of literature to identify theories of involvement of members of the publicand people with lived experience of dementia. **Table 8** in Chapter 4 presents the initial program theory and mechanisms which were then tested during this evaluation and revised. The perspective of the experts by experience of dementia was explored at pre-intervention and post-intervention interviews and developed into '*if…then'* statements at Box 3 and 5 *Figure 25 and 27*.

The perspectives of the researchers and clinicians were identified through minutes of meetings, comments written on the online training platform and field notes from meetings and interviews. These were distilled into *'if…then*' statements at Box 4, *Figure 26*. The data were integrated to identify refinements to the initial program theory. A refined program theory was developed combining perspectives of experts-by-dementia and researchers and presented as *'if…then'* statements at Box 6, *Figure 28*.

Second, data was recorded with consent from experts-by-experience of dementia, in a video-conference focus group at the beginning of the collaborative, in a face-to-face meeting part way through the trial and in semi-structured telephone interviews with individual experts-by-experience with dementia at the beginning of the collaborative and on completion (pre-and post-intervention). Project documents and online training materials were also examined to identify contributions made by experts-by-experience of dementia throughout the trial. Field notes and minutes of meetings with researchers were examined for discussion on the involvement by experts-by-experience of dementia. Comments made in interviews by participant clinicians about the contributions of experts-by-experience of dementia, as part of the evaluation of the collaborative in Chapter 6, were extracted for this research.

Third, a framework analysis approach synthesised the data to identify how the involvement of experts-by-experience of dementia contributed to the trial and to quantify the contributions made. The initial program theory was revised in light of the data to explain how the experts-by-experience of dementia added value to the collaborative.

7.4.1 Cost analysis

An analysis of the costs of involvement of experts-by-experience of dementia in the trial was

conducted. Experts-by-experience of dementia were paid an hourly rate based on a research associate position, for their time spent on the research project and for any expenses associated with the trial. The time spent by the research staff to provide support was also included in assessing total costs of involvement. In preparation for a cost-benefit analysis of collaborative trial,the costs of involving experts by experience with dementia in the research were collected and included in total costs of the collaborative strategy (reported in Chapter 9). These costs were extracted and are reported here to add understanding of the value of their involvement.

7.5 Results

7.5.1 Characteristics of the experts-by-experience of dementia

The characteristics of the experts-by-experience of dementia are provided at **Table 28** with their roles within the collaborative trial.

Table 28. Characteristics and roles of experts-by-experience of dementia involved in the collaborative trial

Characteristics		Person with dementia *n*=3	Caregiver *n*=5
Female			5
Male		3	
Regional/rural/remote		1	1
Roles	Research/Steering committee	0	1
	Review online training content	1	2
	Provide feedback on implementation plans	2	4
Additional Roles			
	Presentations at meetings and conferences	2	1
	Review publications	1	3
	Provide case study	1	1
	Advice from previous experience and support for experts		1
Previous experience			
	Quite a lot	2	3
	Some	0	1
	None	1	1

7.5.2 Pre-implementation evaluation (Phase 2)

7.5.2.1 Focus Group

The video conference provided the opportunity for the experts-by-experience of dementia to meet each other and share their experience of dementia and any experience of or involvement in research roles. This process provided background and support to the two members who did not have prior experience. Their experiences ranged from a relatively recent diagnosis, to living with dementia and to caregivers where they lived with their partner or where the partner had died.

Their motivation was similar in that they wanted to be able to contribute in some way to improve

services for themselves and others. They were particularly interested in being able to work directly with clinicians in implementing clinical guidelines for dementia. Caregiver 1 explained that she had been involved in developing the guidelines and wanted to see them implemented so she was *"…involved in actually the process of submitting the grant which was successful to get the funding for this project".* Others became involved once the project was funded.

"to be able to help in a project that can help with clinicians to deal with it. So, we're really pleased to be a part of this and hopefully we can contribute something and get somethingout of it as well." caregiver 3.

"research work for me is very interesting, and I find this what now we're doing a change. I think that's probably more important to me than a lot of the little fiddly things we've done in the past, to be honest with you." Person with dementia 2.

Experience of being involved in research varied considerably, with four people having been involved in several projects over the years. Three people had been members in the successful Consumer Dementia Research Network (CDRN) established by the then Alzheimer's Australia in 2010 and supported until 2015. Members of the CDRN were involved in the NHMRC Cognitive Decline Partnership Centre (CDPC) from its beginnings in 2012 and thereby gained considerable experience as public contributors to research.

"… that was a very successful group. We had training, we had support, we were networked to each other, we used to have regular meetings so we could bounce ideas off each other." caregiver 1.

Others were involved in state-based research as well as the work of the CDPC (339). The person with dementia 1 explained their involvement with a Brain Institute on an advisory group and in a number of the research projects through the CDPC. Caregiver 2. explained how she and her partner were *"involved with the research for the … International airport to become dementia friendly*" through their experience of navigating airports when traveling.

Most members were particularly interested in the collaborative research trial because it had an interest and direct relevance for them.

"… exercise is one of the things that I do on a daily basis and I'm sure it's one of the things that …slow(s) down the progression of my dementia" Person with dementia 1.

"I can vouch for the fact that you do feel much better, and even this morning being involved, engaged in doing something like this, you feel more comfortable doing it" Person with dementia 2.

"I exercise quite a bit and I swim quite a lot, and I simply see the very positive things and I can say that with swimming it seems to clear my head a lot and helps to keep me going a lot more

positively" Person with dementia 3.

"…also, to be part of a support group where you'll talk to others and you'll say, 'That's my life. That's …the same as I do' and you realise, well you're not on your own here." Person with dementia 2.

Members of the focus group were at different stages of their involvement with the research project so had different ideas of what they might contribute and how they might measure their contribution.They identified the potential to influence others in their thinking about people with dementia was key to their involvement. Caregiver 2 stated that *"researchers say to (us) repeatedly how much they learn from the people who are consumers in the project, perspectives they can't get from a textbook"* and how that *"felt powerful that we had been able to influence something".*

Those who had started reviewing the online modules could see how the impact of their comments may be measured.

"I suppose the only way you can gauge that is the sort of comments they make when they're interacting with the MOOC, 'I read about this and (a person with dementia)… made this comment and that's really changed my mindset about how I go about doing things' " Person with dementia 1.

7.5.2.2 Pre-intervention interviews

Individual interviews with the experts-by-experience of dementia provided insights into their motivations and expectations. Two interviews were conducted with couples where the person with dementia wanted the support of their partner in answering questions. Their individual contributions were recorded.

There was a strong altruistic tone to reasons given for being involved in research. In the absence of a cure, exerts by experience of dementia wanted to help others to get better support, and to see change in practice.

"…having developed a guideline is all well and good but we really wanted to see them implemented into practice and this seemed to me a really exciting project which was going to focus on getting at least some of those recommendations into practice." caregiver 1.

The experts also identified the benefits for themselves in being involved in research. Most had been required to stop working because of dementia or caring responsibilities, but still wanted to be involved in something meaningful and purposeful. Caregiver 3 explained that the person she cared for was "*quite interested in knowing what research is out there and what he can be involved in because I think it also leads back to his nursing background".*

"You've actually got to have something to do in retirement and I guess this provides me with that

sort of satisfaction that I can still make some sort of a contribution, gives me this thing called purpose in life which is important for my health." caregiver 1.

"I'm always looking out for things that might help with the Alzheimer's side of it and interested in what any other people have to say too because I find things like swimming and walking have a positive effect for me" Person with dementia 3.

There were high expectations that the trial would result in improved care and that their contributions would directly influence clinicians. Person with dementia 2 thought that *"it's the anticipation of progress. Any form of progress is exciting. So, I look forward to results from Agents of Change".* For person with dementia 1, involvement in research was part of his ongoing advocacy as he had *"often spoken publicly about the need for rehab to be provided on diagnosis for people with dementia, and also provide support immediately".* Caregivers wanted to emphasise the need for support.

"…help develop people's understanding and give a different perspective or feedback about the importance of support for the carer and the sorts of things that they are living with" caregiver 4.

In summary, the mechanisms identified that influenced motivation of experts-by-experience of dementia to be involved and the expectations of their influence in research are presented as *'If… then'* statements in Box 3 at ***Figure 25.***

Box 3 *"If… then"* statements from initial program theory

If experts-by-experience of dementia shared their experiences with others, *then* people with dementia and caregivers may be able to get the support needed to improve their lives.

If experts-by-experience of dementia continued to be involved in this translation research, *then* they anticipated progress and satisfaction in getting recommendations into practice.

If experts-by-experience of dementia were involved in research activities that drew on their interests and abilities, *then* it gave a sense of purpose to their experiences and stimulation in their present life

Figure 25 'If…then' statements to describe expectations of experts-by-experience of dementia in this research'

7.5.2.3 Researcher team perspectives

The principal investigator and many in the investigator team had prior experience in involving people with dementia and caregivers in a range of research projects in the past (339).

The involvement of experts-by-experience of dementia was described positively in project documentation and in communications to recruit and maintain participant clinicians.

"The clinicians will be supported by an experienced team of clinical, consumer, and quality improvement experts to create and implement their own unique plan to improve their practice." Researcher 1 in Community Care Review summer 2017.

In the minutes of meetings an explanation of the purpose was documented.

"*This is very important for our clinicians as it will help them understand the best ways to help people with dementia and tailor services to best suit their needs*." *Researcher 1.*

In quarterly newsletters, researchers gave their perspectives about the value of the involvement of experts-by-experience of dementia in the research.

"Their involvement improves the quality and relevance of our work and helps to bridge the gap between research evidence and clinical care." Researcher 1.

"(person with dementia) shared his views about how health professionals can take a proactive and positive approach in their practice" Researcher 2.

"*It's collaborative and applied research like this that can make a real difference*." Researcher 2.

"(Caregiver) is a member of the project investigator team. She shares with us her top tips for successfully involving the people who will be impacted by research and implementation into practice" Researcher 1 in newsletter 3 September 2018.

The minutes of steering committee meetings recorded the action taken on suggestions made by experts-by-experience of dementia.

" (Caregiver as member of investigator team) suggested meetings with all project consumer reps together, to avoid feelings of isolation… (and) …suggested to explore the impact of having extensive PPI (consumer involvement) at all levels of this project … (action to arrange meeting and follow up evaluation)". Researcher 2 in minutes of steering committee meeting Dec 2017.

The positive framing of the involvement of people with dementia and caregivers by researchers gave clear indications of the roles they would undertake and the expected outcomes of their involvement on the research and on clinical practice.

The mechanisms identified from the researcher perspective of the involvement of experts-by-experience of dementia in research are summarised as *if… then* statements in Box 4 at ***Figure 26***.

Box 4 "if…then" statements of researchers

If researchers have experience of consulting with people with dementia and caregivers, *then* they have expectations that collaboration will improve the relevance and quality of the research.

If researchers identify clear roles for and match roles to interests for people with dementia and caregivers in research, *then* they optimise the contribution that experts-by-experience of dementia make to the research

If researchers present positive descriptions of the role of people with dementia and caregivers in research, *then* their suggestions are well received by participants and other researchers.

Figure 26 Mechanisms identified from researcher perspective for the involvement of experts-by-experience of dementia in this research

7.5.3 Post Implementation evaluation (Phase 3)

7.5.3.1 Meeting to discuss progress and contribution

A meeting was convened by the author in June 2019 at the request of the experts-by-experience of dementia, where all but one expert was present. Experts and researchers discussed the progress of the trial, heard about how their contributions to the online learning modules were received and considered extending the numbers of experts to review the clinicians' implementation plans. The initial research plan was to involve experts-by-experience of dementia in time limited specific roles to reduce the workload for the individuals. The research coordinator reviewed that plan with individuals and confirmed at the meeting that experts would all be offered the opportunity to review participant implementation plans.

This meeting provided the opportunity for experts-by-experience of dementia to make suggestions and changes to their roles in the research process and provided the researchers with added flexibility around tasks.

7.5.3.2 Post-implementation interviews with experts-by-experience of dementia.

Individual interviews and joint interviews with two dyads (i.e. the person with dementia and their caregiver) were conducted by telephone after the collaborative trial ended. In these interviews experts-by-experience of dementia reflected on their experience and commented on the initial program theory developed for how the involvement of people with dementia and caregivers added value to the research. They also made suggestions for improvement.

All experts interviewed found their involvement satisfying and believed that they had contributed to the research. They enjoyed the opportunity to share their expertise with researchers and clinicians and felt valued in the process. Person with dementia 2 found the involvement interesting and "*gave*

it a great amount of credence…I was able to stay focused as much as I could". Caregiver 1 found "*it was very satisfying… to see a project come to fruition… to see implementation plans…".*

Two experts who worked as a dyad, identified their contribution as influencing clinicians.

"We see it as co-production…we made comments ... (in the online modules) and if the clinicians read that they could think… differently, maybe try something different" Person with dementia1 and caregiver 2.

While some experts were able to commit to the duration the project, two people identified that the time frame was challenging. Person with dementia 2 recognised that *"if it were another 18 months, I don't know…"* if he would have been able to maintain his involvement. Caregiver 3 identified that the person she cared for *"found it harder to hold the focus… lost touch with the project"* without her involvement to support him.

However, they identified the inclusive nature of the project and how their roles assisted them to contribute. Caregiver 1 considered that the trial had the *"right model"* to "*respectfully recognise time and expertise"* and person with dementia 2 thought that *"you know that what you are saying is being taken seriously".* This was apparent in responses about the nature of their roles and the relevance to their expertise.

"We gave a better response to the ones we could relate to, although we gave our viewpoint on all the plans that came to us" caregiver 3.

"…we were so impressed about the exercise plans and wanted to encourage (the clinicians) to do more because we could see the benefit" PWD1 and caregiver 2.

The experts-by-experience of dementia lived in different states and undertook various roles over the duration of the project. The clarity of the roles was identified as helpful, but they also wanted to understand what others were doing and the effects of their involvement in the trial.

"I had a different role to the others… being on the executive management committee ... so I did not see what the others were doing" caregiver 1.

"We both come from an educational background, so reviewing the modules… we committed to that with lots of comments, …put a lot of time into that… so we wanted to see how that influenced the clinicians" Person with dementia 1, caregiver 2.

Several suggestions were made for improvements to the way their involvement was supported. They all preferred face to face meetings to be able to get to know each other and to better participate in conversations about their roles. They recognised the logistical difficulties of travel

however and appreciated the video conference and a face-to-face meeting that coincided with their attendance at a conference. Suggestions included:

"… more contact meetings so we could ask questions along the way" Person with dementia 2.

"…haven't always got feedback…if anything that an expert advisor did, made a difference, that should be fed back to them" caregiver 1.

"…more opportunity for communication amongst ourselves… the newsletters were good but teleconferences with just advisors and… (principle investigator) to see how we were going…" caregiver 1.

"…breaking it down into smaller sections or a shorter time, snapshots…" caregiver 3.

"…being able to see how clinicians responded to our comments in the MOOC (online learning module)" Person with dementia 1.

For most of the experts-by-experience of dementia, it was hard to see their impact directly. Some had experience in public speaking and hearing how their story had changed minds. Others had been involved on committees and had their suggestions accepted at the time in person. In this research, where expert advisors provided comments online or by email and teleconference, the need for regular feedback was identified. Caregiver1 wanted more discussion "*considering all feedback…and why some things not taken up", while person with dementia 2 suggested "letting people know the outcomes"* of their suggestions as they went along would have helped. Feedback was important for experts to judge their contribution.

"I was unable to come to meetings, with work commitments but it would be good to know what was useful" caregiver 4.

Many of the decisions made on the contributions of the expert advisors were discussed at the executive management committee and recorded in minutes. Some information was provided in newsletters and meetings, but the impression given in interviews was these were broad areas rather than the specific feedback they wanted. The geographic spread of the experts led to use of email and teleconferences to provide information, and while that was appreciated and convenient, it was not always an optimal method of engagement for the experts-by-experience of dementia.

Summary of mechanisms identified in the post-intervention interviews with experts-by-experience of dementia at the end of the collaborative are presented as "*if…then"* statements in Box 5 ***Figure 27.***

Box 5 *'if …then"* statements identified by experts-by-experience of dementia post-intervention

If experts-by-experience of dementia feel valued by researchers, *then* they commit to the research and contribute as much as they can

If experts-by-experience of dementia are well matched to the research focus and roles, *then* they gain satisfaction inknowing their contributions help

If experts-by-experience of dementia receive regular feedback from researchers and can share their experience together, *then* they see their impact on research and the value of their contribution.

Figure 27 Mechanisms identified by experts-by-experience of dementia

7.5.3.3 Post intervention Clinician comments

In post intervention interviews, clinicians were asked to identify what value they found from having people with dementia and caregivers involved in the research as expert advisors along with clinical and quality improvement advisors. There were three main themes that were identified by clinicians.

First, they appreciated the perspective given by the experts-by-experience of dementia. They gained an understanding of the impact of the clinical approach and the value of clinical interventions from the perspective of the person receiving them, sometimes for the first time.

"Having the gentleman…, (with) younger onset dementia, speaking face to face, that was excellent… it's a different relationship, absolutely" participant O13.

Second, clinicians valued hearing the stories of people with dementia and caregivers in the learning modules as providing additional credibility to the collaborative program. The stories confirmed the relevance of the evidence base which gave clinicians confidence to then use in their practice.

"It gave me more justification for what I was doing" participant C05.

"…having some of that …perspective has been very useful. Not losing that voice and making it too clinical" participant S13.

Third, clinicians valued the opportunity to ask questions of the experts and have feedback on their implementation plans that would not have been available without the collaborative. They could check their use of language and ideas before implementing them.

"I think the feedback that I got on my report … was really helpful from the people living with dementia because they spoke about having done something similar…" participant C07.

7.5.3.4 Post implementation research team perspectives

At the conclusion of the collaborative trial the research team reviewed outcomes for clinicians and the process evaluation of the trial to report to the funders. The role of experts-by-experience of dementia was reviewed regularly at team management meetings and in steering committee meetings during the collaborative. Notes made in discussions and minutes of meetings were examined to identify research team perspectives. The main areas reviewed were:

- the impact of the workload
- support required
- opportunities for final meeting
- the process evaluation findings
- clinicians' feedback on the impact of involving experts-by-experience of dementia.

Workload: The principal investigator reviewed the workload of the expert advisors quarterly with the steering group and sought feedback from the project coordinator monthly. They noted the requests for some experts to do additional roles within the trial and they identified changes in capacity to complete some roles. Changes were made to the tasks allocated to two experts due difficulties in completing reviews and additional tasks were allocated to experts who had capacity to do more reviewing of participant plans.

The duration of the trial process over18 months was noted as a potential limit on continued involvement in some roles by people with dementia. Some experts were invited to join other research projects which overlapped the collaborative trial. The time and availability of these experts-by-experience of dementia became limited by their other commitments and contributed to some delays with tasks. Others became less able to contribute due to worsening impairment.

Support required: Most experts-by-experience with dementia were clear about the roles that they undertook and sought support with email and telephone contact. The research team reported that expert advisors sought additional information and the opportunity to meet face-to-face to discuss feedback and the results of the collaborative.

Feedback meeting: The researchers planned a final face-to-face meeting to report outcomes of the collaborative and provide feedback to expert advisors on their roles and contributions. This was to coincide with a conference to be held in June 2020. Three experts were unable to attend but were willing to link by videoconference for a discussion. Unfortunately, the conference and meeting were cancelled due to the COVID-!9 pandemic and restrictions on travel and meetings that continued through 2020. Email, newsletters, and post-collaborative evaluation interviews by telephone provided feedback and opportunities for expert advisors to provide comments on their experience.

Evaluation findings: Researchers reviewed the list of contributions of the experts-by-experience of

dementia on the collaborative and the comments made by the participant clinicians in the online learning module and evaluation interviews. They identified the significant contribution made by having an expert advisor on the investigator group and steering group. Her skills and perspective helped to prioritise the guidelines to be included in the trial, added respite for carers to the collaborative learning module on carer support, and it was her suggestion that the value added by experts-by-experience of dementia be formally evaluated. The contribution to the content and language of the online learning modules by experts-by-experience of dementia was identified as important to the relevance of the modules. The use of testimonials and examples from people with experience of dementia in the online learning modules was engaging for clinicians. The inclusion of experts-by-experience of dementia with clinical and quality improvement experts at start up meetings and in the collaborative process, was identified as a conscious strategy to provide different and equal perspectives on the guidelines for the clinicians. Researchers thought that the credibility of the collaboration process was enhanced by their involvement.

Potentially problematic issues identified by researchers included the time needed to provide support, information, and feedback to expert advisors; the cost and logistics involved if face to face meetings were used more often; and the length of time for experts to commit to the collaborative trial.

7.5.4 Data from records, activity logs and notes

7.5.4.1 Review of the content and style of the online learning modules

Four experts-by-experience of dementia were involved in expert working groups with clinical and quality improvement experts to review the proposed content of the online training modules.

Their comments related to the language used and examples of concerns and practical solutions needed by people with dementia and caregivers, in relation to maintaining independence and quality of life. Over 300 comments were added to the modules, representing a considerable investment of time in the review. They were considered by the expert working groups and the research team with 40% of the comments used to improve the content and examples. The rest of comments duplicated other comments or were not directly relevant to the specific recommendation from the guidelines.

Three experts-by-experience of dementia were asked to provide testimonials for use by participant clinicians within the learning modules to better understand the needs and concerns of people with dementia and caregivers.

7.5.4.2 Activities undertaken

An activity log was compiled to include the range of contributions recorded in minutes of meetings, from field notes and in telephone interviews. An impact assessment was made by the author on completion of the process evaluation and reviewed by the principal investigator. This approach

drew on an activity log developed by Mann *et al. (*177*)* in relation to reporting and appraising the context, process, and impact of public involvement in research.

This activity and impact log is presented at **Table 29**. It summarises the activities and assesses the impact of those activities on the collaborative trial.

Table 29. Log of activity and impact of experts-by-experience of dementia in research

Activity of experts-by-experience of dementia	Impact on research
Identified priority guideline recommendations for translation to practice	Demonstrated relevance of research to people with dementia and caregivers
Advice on roles of people with dementia and caregivers in research	Clear roles created relevant to research trial, interests, and capacities of people with dementia and caregivers
Attended and contributed to investigator group meetings x4	Maintained a focus on the relevance of the research trial to people with dementia and caregivers
Attended and contributed steering committee meetings x5	Clarified roles and stages of research relevant to the experts-by-experience of dementia
Reviewed grant submissions	Demonstrated relevance of research to people with dementia and caregivers. Demonstrated compliance with NHMRC recommendations for involvement of people with dementia and caregivers
Provided advice on language used in development of trial grant submission	Demonstrated appropriate language use and role descriptions
Advocated for the evaluation of the impact of experts-by-experience of dementia in the trial	Inclusion of the evaluation of the value added by experts-by-experience of dementia in the research trial
Advised on PPI involvement in research guidelines and provided references	Directed evaluation approach to meet reporting guidelines
Advised on appropriate language for use in Online learning modules	Demonstrated appropriate language and modelled use with clinicians
Reviewed content of 3 learning modules for clinicians and provided comments for revision	Provided over 300 comments on content of modules and proposed revisions or additions to modules 40% adopted by research team

Activity of experts-by-experience of dementia (cont.)	Impact on research
Presented to clinicians in start-up meetings about the priorities for people with dementia and caregivers	Demonstrated relevance and priority of guidelines and credibility of the research trial to clinicians
Requested extension and addition of roles of expert advisors to continue contribution beyond initial roles	Expanded the group of people contributing to review of implementation plans, increasing range of perspectives and spreading workload
Participated in pre-and post-collaborative evaluation processes Focus group, meeting, and interviews	Co-created support, training and data collection processes for evaluation, shared knowledge, and linked trial to other research activities
Reviewed implementation plans by 28 clinicians and provided feedback	Demonstrated capacity to review, provide feedback and advice to clinicians in developing implementation plans
Reviewed draft articles for publication	Provided wording for acknowledgement of role of experts-by-experience of dementia Provided guidance in language used and plain language versions of publications
Presented at conferences about the public role in Agents of Change	Demonstrated ability of people with dementia and caregivers to be involved in research. Advocated for involvement of people with dementia and caregivers in research for relevance
Disseminated results of Agents of Change trial	Promoted the results of the trial and their role in research to networks and other researchers.

7.5.5 Costs of involvement of experts-by-experience of dementia

Experts-by-experience of dementia were involved in the collaborative strategy primarily through email, online, teleconference and video-conferencing interactions, like the model adopted for participation by clinicians in the collaborative. This reduced costs of venues, travel, accommodation, catering, and parking as part of a 'light-touch' collaborative strategy. The costs of time and expenses were extracted from the project accounts and record of activities. This included:

- Staff time to recruit, orient, support and maintain engagement with experts-by-experience of dementia
- IT costs for video and tele-conferences by the collaborative
- Travel and accommodation costs for start-up meeting and conference presentations for two people
- Payment to experts-by-experience of dementia for time spent on the research.

7.5.5.1 Costs of components

An estimate of time away from home or work (not already paid) and for internet fees was made after seeking information in interviews with the experts-by-experience of dementia. Experts were paid for their time on the research and indicated there were no opportunities lost to them due to their involvement. **Table 30** shows the costs of components of the involvement of experts-by-experience of dementia in the collaborative research.

Table 30. Costs of components of the involvement of experts-by-experience of dementia in the collaborative research

Components	Calculation	Total AU$
	Staff time	
Recruitment	8 hours @$65	$520
Orientation	4 hours@$65	$260
Support	12 hours x@ $65	$780
Meetings	4 hours@$65	$260
	Expert time	
Time away from home or work (not paid in fees)	4 hours@$43	$172
	Direct costs	
Payment of fees/ vouchers	$2768	$2768
Travel and accommodation: Start up meeting	$326	$326
Travel and accommodation for conference	$450	$450
Tele-and video conferences	$20	$20
Postage	$27	$27
IT costs for experts (estimate)	$50	$50
Total		$5633

7.5.5.2 Costs as a proportion of the cost of the collaborative research.

The total cost of the development of the collaborative process for this research was collected from project accounts and through a time-driven activity-based costing method (340). See Table 39 and Chapter 9.3.3. There were few face-to-face meetings of the experts-by-experience of dementia, in line with the online nature of the collaborative research trial, to reduce costs of the collaborative. There were few examples of opportunity costs as only one expert by experience of dementia was in paid employment and they all indicated a desire to take on the project in their own time. One person who was working indicated her flexibility at work and ability to prioritise the work she did.

The total cost overall for the collaborative strategy was A$229,668.47 (see Chapter 9.3.3) and with the total costs of the involvement of experts-by-experience of dementia totalling $5633, this represented less than 2.5 % of the total cost overall. Without any standard cost-benefit data for comparison (341) it appears that this is a modest cost to realise contributions to improve the relevance and credibility of addressing priority needs.

7.5.6 Integration of data

Data collected from experts, researchers, documents, and accounts are presented at **Table 31** withthe initial program theory for analysis to compare results and identify patterns.

Table 31. Degree of agreement of data with initial program theory of involvement of experts-by-experience of dementia in research

Program theory	Mechanisms pre	Mechanisms post	Activity log	Costs
Involving people with dementia and caregivers in research adds another perspective to benefit research	High agreement: expectations from researchers and experts-by-experience of dementia	High agreement: engagement in the research process at all levels	High agreement: identifying priorities, roles, and advocating evaluation of involvement of experts	Low cost: online and teleconference interactions
People with dementia and caregivers volunteer to be involved in conducting research and advising on research priorities and content	High agreement: motivation and interest	High agreement: commitment to continue and provide advice on improvements	High agreement: presentations, testimonials, review of modules, review of implementation plans, review of publications, attendance at meetings	Low cost: little travel required, appropriate payment for time offered in $ or Vouchers
Researchers collaborate with people with dementia and caregivers to identify roles to allow contribution	High agreement: commitment to review contributions and make changes	Medium agreement: engagement to extend roles, support experts to complete tasks	Medium agreement: support to undertake extended roles, modify roles, follow up meeting, evaluation of involvement of experts	Low cost: online, teleconferences and coinciding conference meeting
People with dementia and caregivers add unique perspectives and priorities to improve research	High agreement: priority areas identified, language reviewed, relevance to people with dementia	High agreement: engagement in roles, examples and tips provided, improvements suggested	High agreement: detailed comments on modules, testimonials, presentations, clinicians identify benefits of advice	Low cost: online, teleconference interactions
People with dementia and caregivers learn new skills and adopt new roles	Medium agreement: familiar roles in advice and presentation, some new roles offered	Medium agreement: new roles in reviewing implementation plans and participation in implementation research	High agreement: participation in all levels of research, review of implementation plans extended to all experts, evaluation involvement, language use advice	Low cost: online, video and teleconference interactions
Researchers learn new ways to incorporate different evidence and perspectives	Medium agreement: involvement on investigator team and influence in evaluation	Medium agreement: incorporation of additional meetings, changes in roles undertaken	Medium agreement: planned follow up on meetings affected by pandemic cancellations	Low cost: request for additional meetings not able to be met
Better research impact achieved by collaboration with people with lived experience of the condition being researched	Medium agreement: influence on priorities and relevance	Medium agreement: credibility of research to clinicians, evaluation of involvement of experts, improvements identified	High agreement: compliance, relevance, credibility, new roles, recommended improvements, public support	Low cost: online, video and teleconference interactions

Unfortunately, two opportunities to meet were cancelled due to the ongoing restrictions related to the COVID19 pandemic in Australia in 2020.

Most experts-by-experience of dementia had prior experience in research, providing advice to researchers, sharing their experience, deciding on priorities and grant recipients. Their involvement in the collaborative introduced some new roles such as, being an investigator on the steering committee of the research project, co-author on publication of results and as reviewers of quality improvement implementation plans produced by clinicians. The involvement in an implementation trial was new for all experts and provided satisfaction in working to influence the clinicians in the trial to use the clinical guidelines in their practice.

Due to the geographical distribution of the experts-by-experience of dementia across Australia, the collaboration was planned to be conducted via teleconferences, email, online review of training modules and online participation in meetings. This presented both advantages and disadvantages. It lowered the cost of the involvement of experts-by-experience of dementia and reduced the time and cost of travel and accommodation for meetings to the start-up meetings, like the approach taken with clinicians. It however provided difficulties for some experts in connecting to video conferences and keeping up with emails. They preferred face to face meetings to allow time and space to think and offer suggestions or reflections. They also identified the need for more regular connections for verbal feedback and updates of progress, and to connect with each other to share their experience in the research. A refined program theory was developed from the integrated data.

7.5.7 Refined program theory

This process evaluation tested the initial program theory of involving experts-by-experience of dementia in research through analysis of a wide range of data and some refinements were added. The refined program theory, combining the perspectives of the experts-by-experience of dementia and the researchers, is presented at ***Figure 28*** (Box 6) in a series of '*if…then'* statements and contributes to understanding of the processes of the involvement of experts-by-experience of dementia in research.

Box 6 Refined program theory combining perspectives presented as '*If…then'* statements

If researchers involve people with dementia and caregivers in research related to dementia care, *then* the research complies with funder recommendations, has greater relevance to the needs of people with dementia and caregivers and addresses priority needs.

If people with dementia and caregivers feel supported and valued in their involvement, *then* they can share their experience and perspectives to add value to the research process.

If researchers collaborate with people with dementia and caregivers, *then* new skills are developed by researchers to add capacity to improve outcomes

If people with dementia and caregivers are encouraged and supported to contribute and feel part of the research, *then* they experience a sense of empowerment and satisfaction with their involvement.

If researchers develop ways to support involvement of people with dementia and caregivers in research, *then* the research benefits, public support is increased, and they achieve impact on dementia care.

Figure 28 *Refined program theory presented as 'If…then' statements*

7.6 Discussion

Involvement of people with dementia and caregivers in research has been a component in a national dementia research initiative in Australia recently (330). This follows developments in Europe (342), in the UK and North America (343).This emphasis has promoted evaluation ofthe impact of their involvement and the collaborative approaches needed to support engagement between people with dementia and caregivers, and researchers. However, the impact and outcomes of patient and public involvement in implementation research is highly dependent on the context of the research and the nature of the involvement (194). With a supportive context and appropriate roles better research and greater relevance are the anticipated outcomes.

7.6.1 Better research

This evaluation identified how people with dementia and caregivers acted as expert advisors in a collaborative research trial. By bringing their perspectives, values and understanding of the needs of people with dementia to the research, they improved the relevance of the research, contributed to the process, and influenced the perspectives of participant clinicians and researchers. The involvement of experts-by-experience of dementia in implementing clinical dementia guidelines, added credibility to the value of post-diagnostic support for people with dementia and caregivers

and helped target the research (344). They influenced attitudes and confidence of clinicians to make changes in their practice and advised researchers on ways to improve the research design, the content of learning modules, and the process of involving them through the evaluation process. By collaboration with experts experience of dementia, the research design, process and outcomes were better.

7.6.2 Impact on the experts-by-experience of dementia

This evaluation focused on the benefits added to the research by the involvement of experts-by-experience of dementia. However, the experts themselves identified benefits they accrued in the process. Examples were provided of the interest, stimulation, new roles, and the hope gained by their involvement. As identified by the Alzheimer's Society in UK, this has an impact on quality of life and provides satisfaction that they may benefit others (176). While this benefit may be shared by any public contribution to research, it becomes particularly important when considering the inconsistent access to post-diagnosis services for people with dementia and caregivers.

7.6.3 Value added at what stage?

This evaluation has shown how involvement of experts-by-experience of dementia can have an impact on research at all stages and at different levels of involvement. A conceptual framework for describing involvement in research developed in 2008 assists the evaluation and identification of gaps in knowledge about levels of involvement (273). The recent encouragement of the involvement of people with dementia and caregivers in research in Australia (189, 248, 330), provides the opportunity to consider multiple components of involvement of the public in research. A strategic role for people with dementia and caregivers to be involved in research can be identified. This includes membership of governing boards of national research institutes, research priority advisory committees and as investigators on research projects. These strategic roles are needed at all levels of involvement, from consulting about options for research directions, through to setting priorities for funding and infrastructure for public involvement, to advocating for public led research. **Table 32** builds on the framework and provides an example of what public involvement can contribute at different levels, at different stages and for different strategic purposes. In this evaluation experts-by-experience of dementia were involved across all stages at the collaborative level.

Table 32. Levels and stages of involvement of the public in research

Level of involvement	Stages: Strategic	Planning	Conducting	Evaluating
Consultation	Gathering views and opinions for priority setting and funding applications	Testing research ideas and public interest	Recruitment, consents, wording	Testing of questions Advising on plan, dissemination of outcomes
Collaboration	National or local priority setting, deciding on funding of grant submissions, developing methods to support involvement.	Deciding on priorities, methods, roles for public involvement	Providing expert advice, working with researchers and participants, gathering data, reviewing progress, and identifying options	Providing feedback, comparing expectations, identifying themes, questions and focus of evaluation Assisting with dissemination.
Public-led	Identifying further research, advocating for co-researchers, implementing evidence and funding	Identifying needs, funding, design, ethics and protocols	Recruiting, conducting research, analysis of data, decide progress	Identifying impact, methods and focus of evaluation

7.6.4 Strengths and limitations of this evaluation

Strengths

The evaluation of the involvement of experts-by-experience of dementia was recommended by one of the experts involved in the research at the initial planning stages of the research trial. The use of a realist evaluation approach and mixed methods explained how processes of the involvement over the course of the trial worked in complex real-world settings (345).

Training on involving people with dementia and caregivers in research was provided for four of the experts and the evaluator at commencement of the trial by the NHMRC National Institute for Dementia Research (NNIDR).

The identification of costs provided a perspective on the need to budget for and design ways to engage people with dementia and caregivers. It may be that not all costs were identified, as opportunity costs were not explored extensively, and new information technology options became more widely available in 2020.

Limitations

The difficulty in measuring impacts of the involvement of public in research stems from the lack of

agreement on models, methods, and outcomes of involvement (334). Defining the impacts narrowly may have missed some and a control group was not feasible or ethically appropriate in this research.

Most of the people who were involved as experts-by-experience of dementia had prior experience in research (or as a researcher themselves), were middle-aged generally and had access to information technology. There were no representatives from diverse cultural and linguistic groups or from indigenous people. Interviews with the two couples involved were conducted with both the person with dementia and their caregiver present. This may have limited the opportunity for the individuals to speak or offer their own opinions, although those couples did decline the offer to be interviewed separately. All other experts were interviewed individually.

Improvements could have been made to the evaluation by involving experts in the design of the evaluation, supporting experts to collect the data for the impact log, and in analysing data to identify context-mechanism-outcome configurations.

7.7 Conclusions

7.7.1 A strategic approach to involvement

This evaluation suggests that future research in implementing improved dementia care would benefit from the involvement of people with dementia and caregivers at all phases of the research process. However, support for the process and training of researchers and experts-by-experience of dementia is required. A national coordinating body is needed, to encourage public involvement in dementia research, to provide training to researchers and people with dementia and caregivers, and to communicate research findings to the wider community (330).

This approach would provide researchers and people with dementia and caregivers with nationally consistent guidelines and language about the purposes and methods of public involvement in research. It would connect wider groups of people with research on dementia care. The recent publication of an Australian guide for people with dementia and caregivers to become involved in research is designed to accelerate research, enhance collaboration, and create change (346). This publication is a strategic step in Australia's plan for dementia research and improved translation of knowledge. It adds to the growing resources (247, 347) and commitment to co-designed and co-produced research globally (348). However, the existence of documents alone does not guarantee a shared strategic aim (349) or increased collaboration that creates change. Recent funding for a coordinator at Dementia Australia (350), to support a network of people with dementia and caregivers to be involved in research, is a first step. Funding for a national coordinating body and a supported research network of lived-experience experts such as in the UK (176), is needed to increase collaboration and create change.

Feedback from people with dementia and caregivers on the process of involvement provides some valuable lessons. In the UK and Australia, people with dementia and caregivers have provided advice on some simple processes that respect the person, their abilities and adjust for disabilities to improve involvement (332, 351). Researcher characteristics and their actions to build relationships and facilitate two-way feedback made a difference to the outcomes in palliative care and rehabilitation research (352). In dementia research in Canada, the importance of feedback on how contributions shaped research and regular meetings made a difference (47). A key element of the emerging literature and experience of involvement of the public in research is a focus on the quality of the interaction between researchers and public members of the research team (178). A wide range of approaches may need to be developed to suit the needs of people with dementia and the context of the research. Understanding the initial outcome of involvement of people with dementia and caregivers in research as two-way learning may be the first step in addressing stigma, misunderstanding and inequity in access to healthcare interventions (353).

As stated by an expert by experience of dementia on the topic of involvement of people with dementia and caregivers in research.

"It is the right thing to do but it is also a good thing to do" caregiver 1.

7.7.2 Next chapter

The next two chapters in this research thesis turn to examine the costs and benefits of the use quality improvement collaboratives to implement improved health and dementia care. Chapter 8 presents Study 3-part A: a systematic review of costs and economic evaluations of quality improvement collaboratives to identify the costs and cost effectiveness of these approaches. Chapter 9 then presents Study 3-part B: a cost benefit analysis of the quality improvement collaborative examined in this research.

CHAPTER 8 STUDY 3 PART A
What are the costs and types of economic evaluations of quality improvement collaboratives in healthcare? A systematic review

8.1 Overview

This chapter presents results of a systematic review that was conducted to identify the potential for quality improvement collaborative interventions in healthcare to be cost-effective. The review examined the types of economic evaluation undertaken to determine a suitable approach to evaluating the economic outcomes of the quality improvement collaborative strategy in this research. Results presented in this chapter have been published and are adapted with minor changes for thesis formatting and consistency, from the published article in *BMC HSR (2020) 20:155 (*155*)*

As the main author for the publication, my contribution was 80% of the complete work included in this chapter. I constructed the research question and completed and registered the study protocol with the International Prospective Register of Systematic Reviews (PROSPERO CRD42018107417). I liaised with research librarians regarding search terms and strategy, completed data collection and screening, as well as analysis and writing of results. Co-author GR assisted with screening of articles, checking, and agreeing on inclusion in the review. Supervisors MC and GB assisted with reviewing drafts. Supervisor BK provided guidance on tools for assessing quality, data extraction and interpretation of economic evaluations, reviewed drafts, and revisions. My principal supervisor KL proposed the review, guided the steps, refined the research question, and reviewed drafts and revisions. All authors were involved in editing and proof-reading of the final manuscript. Each author has provided permission to use this work in the thesis as per the submission of thesis form.

8.2 Rationale

As discussed in Chapter 2, a significant challenge facing health care settings is how to implement proven clinical interventions in practice in a cost-effective manner (354). Scarce resources, including lack of time and staff are often cited as barriers to implementation (355). A recent review of medical research shows health savings from broad research translation, significantly outweigh the cost of delivering them (356) but the field of economic evaluation of implementation strategies is still developing (357). Decisions to use specific implementation methods can be betterinformed by identifying the economic outcomes of methods in addition to health outcomes (358, 359).

8.2.1 Difficulty in identifying costs

Methods of knowledge translation and implementation have been tested with mixed results (360). For example, clinical practice guidelines aim to translate research into practice and improve the

quality of care and health outcomes for people. Delays from research to implementation and differences between results in randomised controlled trials and the healthcare setting, create barriers to uptake (361). However, studies have shown that the dissemination of guidelines alone is insufficient to effect change in routine clinical practice (362). Education and training of clinicians, the development of champions of change in organisations, and audit and feedback mechanisms have been trialled to improve adherence to guidelines (73). However, these strategies lead to only modest effects in quality improvement (73). A recent review found that while multifaceted strategies are more effective, costs associated with components were difficult to discern and cost-effectiveness was not explicitly evaluated (73). Knowledge translation approaches which are tailored to an organisation can be successful but may lack transferability to other settings (14, 363, 364).

8.2.2 Mixed results for Quality Improvement Collaboratives

Quality improvement collaboratives have been adapted from process improvement methods in manufacturing industry (365), for use across multiple healthcare settings by the United States Institute for Healthcare Improvement (IHI) (74). A quality improvement collaborative is a multifaceted approach to implementation of evidence-based practices, clinical guidelines or improved methods for quality and safety. Typically, they draw participants from multiple healthcare organisations to learn, apply and share improvement methods over a year or more. Teams are supported by experts who coach participants to test strategies adapted to their own setting. By collaborating, participants learn more effectively, spread improvement ideas and benchmark their progress against other organisations (12, 74). Common components of quality Improvement collaboratives include face to face training sessions focusing on healthcare improvement and quality improvement methods, telephone meetings, feedback, and the use of process improvement methods (366). Quality improvement collaboratives have been used in healthcare systems in several countries to improve implementation outcomes (12, 366, 367). They are adaptable within complex healthcare systems and offer a way to scale out implementation across many different organisations. However, inconsistent results, multiple elements, and perceived cost of establishing, conducting. and sustaining a collaborative are barriers to their use (12, 367, 368). Wells and colleagues (12) recently identified 64 quality improvement collaboratives reporting effectiveness measures that met their inclusion criteria. The review (12) results demonstrated that 73% of these collaboratives reported significant results in diverse settings such as hospitals, health clinics and nursing homes. Improvement was associated with targeted clinical practice related to infection control, management of chronic conditions or prevention of falls, wounds, or pain management (12).While these improvements were associated with cost savings, only four studies reported on cost-effectiveness outcomes (12).They identified gaps in design, reporting and assessment of costs which limited the information on cost-effectiveness. The costs of establishing a quality

Improvement collaborative can be significant, including personnel to recruit and coordinate activities, development of materials and education, the time spent by all participants involved in the collaborative and expenses associated with face to face meetings (369).

8.2.3 Identifying costs and economic outcomes

With increasing pressure on the healthcare system to deliver evidence-based practice with scarce resources, there is a need to evaluate the financial impact of healthcare improvement and knowledge translation strategies. Economic evaluation can assess implementation strategies to guide decisions about the choice of strategy providing value for money. The aim of this systematic review was to identify and describe studies that report on the costs and cost-effectiveness of quality improvement collaboratives to inform strategies to implement clinical guideline recommendations in healthcare.

8.3 Methods

The protocol for this systematic review was developed in advance and was registered with PROSPERO on 7 September 2018; registration number CRD42018107417 (see Appendix 13).

8.3.1 Eligibility criteria

Studies were included in this review if they reported on initiatives that comprised healthcare clinicians across teams, professions, or organisations involved in a quality improvement collaborative or a quality improvement team with the aim of improving practice over time. Quality improvement teams were included if they included the most common components of quality improvement collaboratives as identified by Nadeem *et al. (*366*)*. These components included collaboratives that used multi-modal interventions, such as training, developing implementation plans, trying out a practice improvement, seeking advice from experts and people with lived experience and reviewing plans over time to improve practice (12).We included quantitative studies that used full economic evaluation (i.e. cost-effectiveness, cost-utility analysis, cost-benefit analysis, cost-consequences analysis). Cost-minimisation analysis compares interventions to find the least expensive alternative when these strategies have equivalent outcomes. Cost-effectiveness analysis compares the relative costs and outcomes for different interventions to achieve the same health outcome measured as an incremental cost-effectiveness ratio (ICER) In cost-utility analyses, the outcome considered is the quality-adjusted life year (QALYs). A QALY is a generic outcome that combines the quality and quantity of life into a single index of effect (370). In a cost-benefit analysis, outcomes for competing strategies are expressed in monetary terms (371). Cost- consequence analyses show all the resource use, costs and health consequences to compare interventions and their consequences to allow decision-makers to judge the importance of costs and outcomes (372). Partial economic evaluations (i.e. cost analyses, cost descriptions, cost outcome descriptions); and randomised trials reporting estimates of resource use or costs

associated with implementation or improvement were also included. We excluded systematic reviews, study protocols, conference proceedings, editorials and commentary papers, effectiveness analyses with no analysis of costs, burden of disease studies, and cost of illness studies. The primary outcome of interest was the cost-effectiveness or cost-benefit of the use of elements of quality Improvement collaboratives to implement improvement in healthcare or adherence to clinical guidelines. A secondary outcome was costs associated with quality Improvement collaboratives.

8.3.2 Search Strategy and study selection

Five electronic databases were searched on 19 November 2018 (CINAHL, Medline, PsycINFO, EconLit, ProQuest (Health and Medicine: Social Sciences subsets only)). Embase was searched on 20 August 2019. Websites of large organisations interested in healthcare improvement such as the Institute of Healthcare Improvement (IHI, USA) and government bodies such as National Health and Medical Research Council (Australia), National Health Services and the National Institute for Health and Care Excellence (UK) and the European Network of Health Economic Evaluation Databases were searched for grey literature. Reference lists of included studies were scanned for potentially eligible studies. Studies were limited to English language, but no time limits were imposed on the search strategies. Research librarians with expertise in systematic reviews assisted with the development of the search strategies. The search strategy was developed for MEDLINE using medical subject search headings (MeSH) and text words and then adapted for use with the other databases. The strategy combined terms relating to quality improvement, collaborative, guidelines implementation and cost, cost-benefit, or economic analysis. The search strategy for MEDLINE is at Appendix 14. Results are reported per the Preferred Reporting Items of Systematic Reviews and Meta-Analyses (PRISMA) guidelines (373). Two authors (LdlP and GR) independently screened titles and abstracts based on the inclusion criteria detailed in the review protocol. Full texts of studies identified by abstract and title screen as having met the inclusion criteria were obtained and reviewed independently (LdlP and GR). Differences between reviewer's results were resolved by discussion and when necessary in consultation with a third review author (MC).

8.3.3 Data extraction

One author (LdlP) extracted data using a modified version of the Joanna Briggs Institute (JBI) Data Extraction form for Economic Evaluations (374). Another author (GR) checked the extraction for accuracy. Data was extracted about the study method, evaluation design, participants, intervention used, comparator, outcomes, prices, and currency used for costing, time period of analysis, setting, tools used to measure outcomes and authors conclusions. This information was presented descriptively and summarised in **Table 33** .

Both costs of care resulting from improved care and costs of establishing quality improvement

collaboratives were identified. Cost components were standardised by converting currency and year to US dollars for 2018 through the Eurostat-OECD data base and manual on purchasing power parities for Euros and The World Bank GDP deflator data base for United States dollar values (375, 376).

8.3.4 Risk of bias assessment

Two checklists were used to critically appraise the studies due to the variation in design of studies included. Some were cost analyses; some cost effectiveness studies and one compared elements of the collaborative strategy. The 24 item Health Economic Evaluation Reporting Standards (CHEERS) checklist was used to determine methodological quality of all the included studies as it applies to any form of economic evaluation (314) (at **Table 34**). The Evers CHEC-List (377) was used to assess the quality of the full economic evaluations and is at Table 35. A score of one point was assigned to each positive response zero to a negative response or for items that did not apply. A summary score is calculated at the bottom of each table with a maximum score of 24 and 19 respectively. This scoring provides an indication of total items present for each study

8.3.5 Assessment of Generalizability

The currency and year of studies was converted to US dollars for 2018 using the Eurostat-OECD purchasing power parities data base for Euros and the World Bank deflator data base for US dollar updates. This provided an option to compare results but due to the varied type of studies and focus on the implementation method rather than the healthcare intervention, a full transferability assessment was not conducted.

8.3.6 Data Synthesis

Included studies were subjected to data extraction by the author (LdlP) and information was synthesised to interpret the findings of full and partial economic evaluations and cost analysis studies. As recommended by the Johanna Briggs Institute (JBI) a specific tool, the ‘three by three dominance ranking matrix’ was used to appraise findings, separating intervention costs and effectiveness measures (378). This synthesis was checked by another author (GR) for consistency. Any inconsistencies were resolved by discussion and by consultation with a third review author (BK). This tool assists in drawing conclusions about the results of studies in terms of both cost and effectiveness (health benefits). It classifies results as favoured, unclear, or rejected in favour of the comparator. An intervention was favoured if relative to its comparator it either (i) was cheaper but more effective, (ii) was cheaper but just as effective or (iii) cost the same but was more effective. An intervention was rejected if, relative to its comparator, it either (i) was more expensive and less effective, (ii) was more expensive and just as effective or (iii) cost the same but was less effective. A judgement was made about all other scenarios based on other criteria (378). For instance, an intervention was favoured if it was more expensive and more effective than a

comparator provided the associated incremental cost-effectiveness ratio (ICER) was below the threshold used for assessing cost-effectiveness e.g. €80,000 per quality adjusted life years (QALY) in the Netherlands.

8.4 Results

8.4.1 Study selection

The search identified 8505 citations and after removing duplicates, 3481 titles and abstracts were reviewed. Twenty-two full text reviews revealed eight papers that met the inclusion criteria. PRISMA flowchart at *Figure 29* describes the process of selection (373).

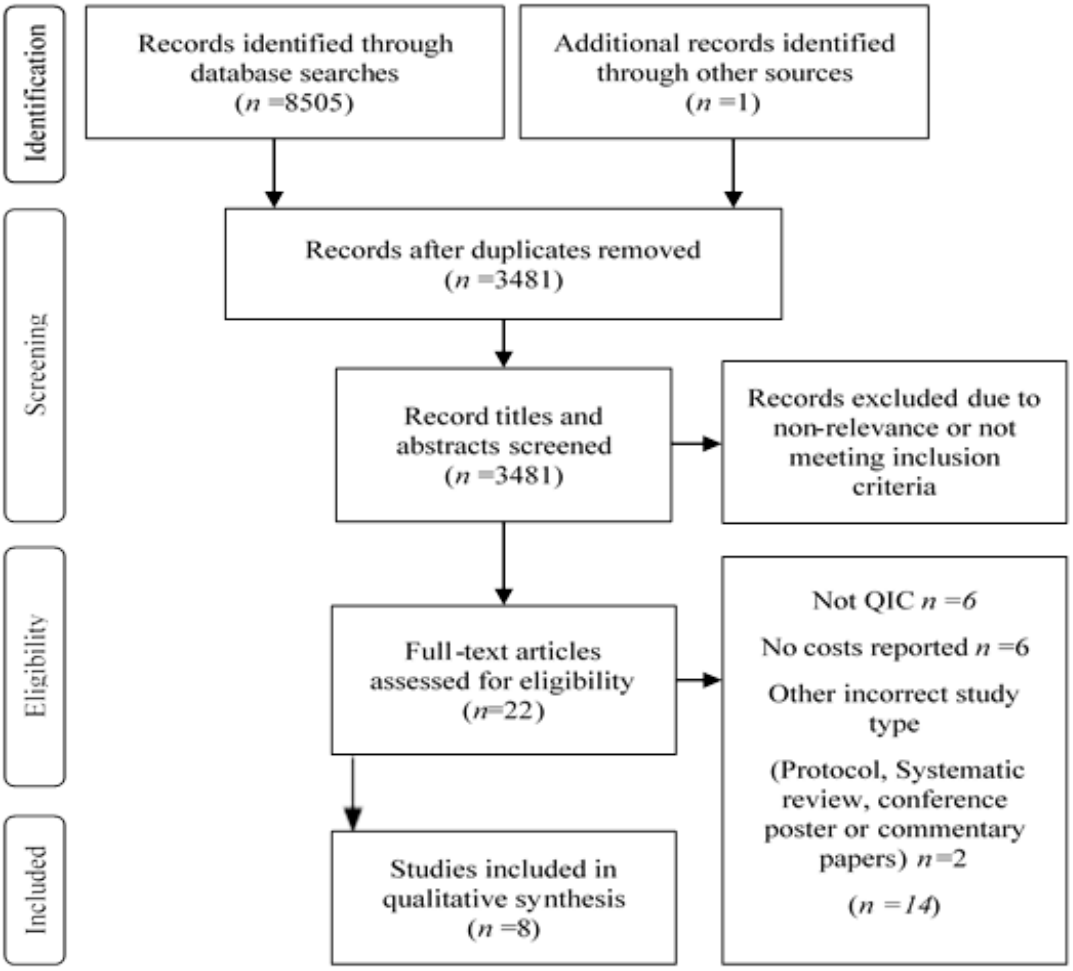

Figure 29 PRISMA flowchart describing the process of study selection

8.4.2 Overview of studies

Table 33 presents the overview of characteristics of the studies included in this review. Most studies describe the costs of establishing a collaborative to improve quality in healthcare and compared costs to outcomes. Five of the included studies involved full economic analyses using cost-effectiveness analysis (CEA) or cost utility analysis (CUA) (158, 369, 379-381) whereas three studies were cost analyses (382-384).

All studies were set in multi-centre healthcare settings, hospitals, long term care or community clinics, and related to diverse health conditions such as Parkinson's disease, diabetes, obstetrics, neonatal intensive care, hip fractures, pressure ulcers, cardiac care, or addiction treatment. All included clinicians working either nationally or across multiple states.

Table 33. Summary of data extracted from Economic Evaluations included in systematic review of costs and cost-effectiveness of Quality Improvement Collaboratives in Healthcare

Full Economic Evaluations									
Author	Study design	Target population	Intervention comparator	Time horizon	Model	Costs included	Measures of health and cost-effectiveness	Conclusions	ICER/ overall result
Broughton *et al.* 2013, Niger	• Measures of Health benefits and cost-effectiveness, Cost Effectiveness Analysis (CEA) and Cost Utility Analysis (CUA) of Obstetric and newborn care • Limited to the perspective of National Ministry of Health.	Medical and nursing staff in clinics for the care of women and newborns	Pre intervention compared to post intervention data for participating clinics	2 years using 2008 USD and 3% discount rate	Monte Carlo simulation and synthesis /decision tree analysis to compare outcomes and costs pre-and post-intervention.	• Estimates of clinical costs before and after intervention from Ministry of Health user fees and survey of managers • Capital costs per clinic • QI costs of development, capital costs of equipment • Salaries of QI staff consultants, fees, travel, vehicles, fuel.	• Costs per normal delivery compared to costs, costs of complications due to moderate to severe Post-Partum Haemorrhage.	• Decreased average cost per delivery from $35 to $28 • Incremental cost of QI per delivery $2.43 • QI modest cost per delivery and decreased average cost per delivery • 89% decrease in PPH • Overall cost saving and improved health outcomes.	• Estimated ICER $286/ DALY • 2.6% decrease in DALY's for clinics post collaborative improvement. • 3% decrease ICER between pre and post incidence of PPH.
Gustafson *et al.* 2013 United States of America	• Cost Effectiveness Analysis (CEA) of elements of QIC in addition treatment • Limited to the perspective of National healthcare system.	Clinical allied health staff and managers of clinics treating people with addictions.	Cluster randomised trial of 4 intervention groups to treat addiction. Evaluated pre, during, and post intervention and compared to each other.	1.5 years using USD (year and discount rate not stated).	Drug abuse cost analysis program to measure process improvements.	Cost of personnel, capital, travel, accommodation, data management.	Improvements in retention, waiting times, new patients. Comparison between four interventions.	Coaching and combination of collaborative elements produces significant improvements in waiting time and new patients. No significant effect on retention Coaching is more cost effective to achieve improvemen.t	CER of US$0.56 per patient per waiting day saved in the coaching group compared to CER of US$37.30 per patient per day saved for the combination group. No statistically significant effect found for retention of patients.

Full Economic Evaluations									
Author	Study design	Target population	Intervention comparator	Time horizon	Model	Costs included	Measures of health and cost-effectiveness	Conclusions	ICER/ overall result
Schouten *et al.* 2010, The Netherlands	• Cost Utility Analysis of a QIC focusing on patients with diabetes • Limited to the perspective of the National Healthcare system	Multi-disciplinary teams treating people with type 2 diabetes in outpatient hospital and community clinics	Controlled before and after study in 8 clinics compared to usual care in matching control clinics	2 years using 2006 Euros and 3% discount rate	Dutch Diabetes model (based on Markov model) to calculate lifetime medical costs and health outcomes.	• Diabetes control measures score (UKPDS) • QALY based on the EQ-5D 3L Numbers of diabetes related health visits, volume and type of medication	• Improved blood pressure, high density lipids and cholesterol control • QOL, life expectancy improved and QALYs	• QIC is cost effective • Implementation costs €**22** per patient	• ICER €1937for men and €1751 for women per QALY compared to usual care. • Probability of collaborative being cost effective using threshold of €20, 000 per quality adjusted life year was >95%
Makai et al 2010 The Netherlands	• Cost Utility Analysis (CUA) of QIC to reduce pressure ulcer wounds • Limited to the perspective of the long-term care system	Medical and nursing staff of long-term care of older people in nursing homes to end of life	Pre intervention cases of pressure ulcers compared to post intervention and to control group in participating care homes	2 years using 2006 Euros and 4% discount rate for costs and 1.5% for effects	Markov decision analytical model	• Program and organisational costs of time spent in training planning and implementation, materials and miscellaneous costs • Cost of materials and equipment used in patient care • Time spent in preventative patient care	• Pre and post differences in preventive measures used • Numbers of pressure ulcer free patients, numbers of pressure ulcer grades1-4 and mortality, QoL Sustainability of prevention	• Reduced prevalence of pressure ulcers • Increase in healthcare costs overall • Uncertainty in cost effectiveness of the QIC due to the end of life stage of patient population Cost effectiveness likely if results sustained	• ICER € 78,517 per QALY for most sustained change • ICER € 88,692 per QALY for partially sustained change and • ICER €131,253 per QALY for not sustained with threshold of ICER €80,000 per QALY for patients with high disease severity
Huang *et al.* 2007 United States of America	• Cost Utility Analysis (CUA) of QIC to improve diabetes care • Societal perspective of long-term costs	Medical nursing and administrative staff in Community health	Serial cross section data of 80 randomly selected patients	4 years using 2004 US $ and 3% discount rate for	Markov Monte Carlo simulation and synthesis to compare costs, outcomes over 4 time periods	• Estimates based on observed services and national use of medications studies for diabetes care, costs of medicines from wholesale	• Improved processes of screening and prescribing • Reduced intermediate and end stage complications Improved QALYs	• Diabetes HDC program is cost effective compared to other healthcare technology • Effectiveness of individual elements of care varied widely but greatest	• ICER use of ACE inhibitor $26,653 per QALY • ICER for individual therapies were not cost effective

Full Economic Evaluations									
Author	Study design	Target population	Intervention comparator	Time horizon	Model	Costs included	Measures of health and cost-effectiveness	Conclusions	ICER/ overall result
		centres treating people with chronic health conditions	treated reviewed over 4 years	costs and outcomes		drug prices, costs of projected complications • Estimates of cost of the collaboration were based on case studies at Year 1, 2, 3 and Year 4 costs required for remainder of persons life to sustain benefits		health benefits in lowering glucose levels and increasing ACE inhibitors • Costs borne by health centres and health insurance	• Multiple processes of care improved and led to lower lifetime incidence of complications • Overall ICER $54,060 / QALY with program costs of $100/patient/year

Partial Economic Evaluations									
Author	Study design and cost perspective	Target population	Comparator	Time horizon and reported date	Model	Costs included	Measures of health outcomes/ cost-effectiveness	Conclusions	Overall results
Bloem *et al.* 2017, The Netherlands	• QI costs of development, capital costs of equipment • Salaries of QI staff consultants, fees, travel, vehicles, fuel.	Allied health clinicians treating people diagnosed with Parkinson's Disease in community	9 non-randomised control services not in ParkinsonNet	5 years /2017 USD	Comparison of cost savings per person to cost of network per capita over 5 years Comparison of costs of network staff to usual care	• Medical claims data for patients with PD and caregivers, total annual medical costs pa per patient with PD, • Set up costs of network and maintenance costs over 5 years	• Reduced treatment sessions, reduced disease complications, reduced dependence on medical care • Infrastructure and personnel costs, annual maintenance costs of network	• Modest cost savings per patient with PD of US $439 pa or 5% of expenditure per patient with PD pa • Cost of Parkinson Net spread over 5 years was US$29 per patient pa • Savings expected for total population in Netherlands with PD far outweigh costs of the ParkinsonNet	Potential cost savings pa in Netherlands between US$17-$66 million pa
Dranove *et al.* 1999,	• Cost Analysis	Hospital staff involved in QI related to hip	Comparison of cost of QI with patient	Not reported / 1997	Correlation between direct costs and meeting costs of QI	Costs of QI per hospital admission	QI costs per hospital: meeting costs, training, accreditation, personnel	Wide variation in costs of QI across hospitals and no	No correlation between costs per hospital for CQI

Partial Economic Evaluations									
Author	Study design and cost perspective	Target population	Comparator	Time horizon and reported date	Model	Costs included	Measures of health outcomes/ cost-effectiveness	Conclusions	Overall results
United States of America	Limited to the perspective of the National Health care system	replacement and coronary care of adult patients	outcomes and condition specific costs to hospitals without QI	USD	compared to patient costs and outcomes		costs, overheads, consultants' fees	significant correlation between mature CQI hospitals and immature hospital CQI programs	and outcome
Rogowski *et al*. 2001, United States of America	• Cost Analysis Limited to the perspective of the National Health care system	Staff of neonatal intensive care clinics treating infants with low birth weight and lung infections	Comparison of costs between intervention hospitals and control hospitals for treatment and pre and post costs in intervention hospitals	2 years 1996 USD	Pre-post statistical comparison of treatment costs to test for significance between control and intervention groups	Hospital Treatment cost per infant from hospital bills Costs of staff time spent in meetings education, reporting collecting data, travel costs conference calls, benchmark costs, data costs, survey	Treatment cost per infant and resources spent by hospital on QIC	• Average cost savings in treatment far outweighed the cost of the QIC. Savings of $14 million for a cost of $1.5 million investment • Wide variations in costs and savings, however	Average cost savings far outweigh the cost of the QIC and was sustainable in the short term at least
Abbreviations used: QI: quality improvement, QIC: quality improvement collaborative, MoH: Ministry of Health in Niger, HDL: high density lipids, PPH: post-partum haemorrhage. ICER: incremental cost effectiveness ratio, CER; cost effectiveness ratio DALY: disability-adjusted life year, NIAT: network for the improvement of addiction treatment, QALY: quality adjusted life years, UKPDS: United Kingdom Prospective Diabetes Score, CQI: continuous quality improvement, PD: Parkinson's Disease, pa: per annum, pp: per person US$: United States Dollars, €: European Euros									

8.4.3 Methodological quality

Table 34 and **Table 35** summarise the methodological quality of the studies included in this review. At Table 34, the cost effectiveness study conducted by Broughton *et al. (*379*)* and cost utility studies by Schouten *et al. (*369*)*, Makai *et al. (*158*)* and Huang *et al. (*381*)* were considered high quality, complying with most of the items on CHEERS checklist (314). Item 12 related to valuation of preferences for outcomes was not addressed in these studies (314). A cost analysis by Bloem *etal.* (382) and a cost effectiveness study by Gustafson and colleagues (380) were of moderate quality. They did not address item 13, related to estimating costs via a model-based evaluation, items 15 and 16, the choice of model or assumptions or item 20, how uncertainty was addressed. The cost analysis by Rogowski *et al. (*384*)* was rated low quality on CHEERS checklist and the cost study by Dranove *et al. (*383*)* study was considered lowest quality as less than half of all itemswere addressed. At Table 35, using the Evers CHEC-List (377), the full economic evaluations (158, 369, 379-381) were rated good quality.

Conflicts of interest and uncertainties in data were addressed by five studies(158, 369, 379-381). An incremental cost-effectiveness ratio (ICER) was not applicable for the cost analyses(382-384) and future costs were not directly considered by those studies.

Table 34. CHEERS checklist of quality of included economic evaluation studies [8]

Items	Broughton *et al.* 2013	Gustafson *et al.* 2013	Schouten *et al.* 2010	Bloem *et al.* 2017	Dranove *et al.* 1999	Rogowski *et al.* 2001	Makai *et al.* 2010	Huang *et al.* 2007
1.Identified as full Economic evaluation	Y CEA and CUA	N within-study CEA	Y model based CUA	N	N	N	Y CUA	Y model based CUA
2.Structured Summary/ Abstract	Y	Y	Y	N	Y	Y	Y	Y
3.Broader context for study stated, question, and relevance	Y	Y	Y	Y	Y	Y	Y	Y
4.Characteristics of population and subgroups, why chosen	Y	Y	Y	Y	Y	Y	Y	Y
5.Setting and location stated	Y	Y	Y	Y	Y	Y	Y	Y
6.Study perspective related to costs	Y	Y	Y	Y	Not stated	Not stated	Y	Y
7.Comparators stated and why	Y	Y	Y	Y	Y	Y	Y	Y
8.Time horizon and why chosen	Y	Y	Y	Y	N	Y	Y	Y
9.Discount rate used and why chosen	Y	N	Y	N	N	N	Y	Y
10.Choice of health outcomes and relevance to analysis	Y	Y	Y	Y	N	Y	Y	Y
11. Measure of effectiveness b) SYNTHESIS based study	Y	Y	Y	N	N	N	Y	Y
12.Measure and Valuation of preference of outcomes	N	N/A	N/A	N	N	N	N	N

13.Estimating resources and costs described b) model based economic evaluation	Y	N	Y	N	N	N	Y	Y
14. Currency date and conversion	Y	Y	Y	Y	N	Y	Y	Y
15. Choice of model for analysis	Y	N	Y	N	N	N	Y	Y
16. Assumptions described	Y	N	Y	N	Y	N	Y	Y
17. Analytical methods described	Y	N	Y	Y	Y	Y	Y	Y
18. Study parameters reported	Y	N	Y	Y	N	N	Y	Y
19. Incremental costs and outcomes, means and difference	Y	Y	Y	N	N	N	Y	Y
20 Uncertainty described b) model based	N	N	Y	N	N	N	Y	Y
21. Heterogeneity differences in cost or variability	Y	Y	Y	N	N	N	Y	Y
22. Study findings	Y	Y	Y	Y	Y	Y	Y	Y
23. Source of funding	Y	Y	Y	Y	Y	Y	Y	Y
24. Conflicts of interest	N	Y	Y	Y	N	N	Y	Y
Summary score	22/24	15/24	23/24	13/24	9/24	11/24	23/24	23/24

[8] CHEERS: Consolidated Health Economic Evaluation Reporting Standards statement

Table 35. Evers CHEC-List of quality of full economic evaluations only[9]

Items	Broughton *et al.* 2013	Gustafson *et al.* 2013	Schouten *et al.* 2010	Makai *et al.* 2010	Huang *et al.* 2007
1. Is the study population clearly described?	Y	Y	Y	Y	Y
2. Are competing alternatives clearly described?	Y	Y	Y	Y	Y
3. Is a well-defined research question posed in answerable form?	Y	Y	Y	Y	Y
4. Is the economic study design appropriate to the stated objective?	Y	Y	Y	Y	Y
5. Is the chosen time horizon appropriate to include relevant costs and consequences?	Y	Y	Y	Y	Y
6. Is the actual perspective chosen appropriate?	Y	Y	Y	Y	Y
7. Are all relevant costs for each alternative identified?	Y	Y	Y	Y	Y
8. Are all costs measured appropriately in physical units?	Y	Y	Y	Y	Y
9. Are all costs valued appropriately?	Y	Y	Y	Y	Y
10. Are all important and relevant outcomes of alternatives performed?	Y	Y	Y	Y	Y
11. Are all outcomes measured appropriately?	Y	Y	Y	Y	Y
12. Are outcomes valued appropriately?	Y	Y	Y	Y	Y
13. Is an incremental analysis of costs and outcomes of alternative performed?	Y	Y	Y	Y	Y
14. Are all future costs and outcomes discounted appropriately?	Y	N	Y	Y	Y
15. Are all important variables, whose values are uncertain, appropriately subjected to sensitivity analysis?	Y	N	Y	Y	Y
16. Do the conclusions follow from the data reported?	Y	Y	Y	Y	Y
17. Does the study discuss the generalisability of the results to other settings and patient and client groups?	Y	Y	Y	Y	Y
18. Does the article indicate that there is no potential conflict of interest of study researcher and funder?	N	N	Y	Y	Y
19. Are ethical and distributional issues discussed appropriately?	Y	N	Y	Y	Y
Summary score	18/19	15/19	19/19	19/19	19/19

[9] CHEC-List: Consensus on Health Economic Criteria- criteria list for assessment of methodological quality of economic evaluations

8.4.4 Data synthesis

Table 36 presents the studies using the three by three dominance ranking matrix (JBI DRM) tool to assist in interpreting the cost-effectiveness results of the studies included (378). In this review, five studies were classified as favoured interventions (strong dominance) (369, 379, 380, 382, 384) two as unclear (158, 381) and one rejected (383). Bloem *et al.* (382) Broughton *et al.* (379) and Schouten *et al.* (369) all showed reduced costs and improved health outcomes and are the most favoured interventions. The studies by Gustafson *et al.* (380) and Rogowski *et al.*(384) show reduced costs for equally effective processes which are the next favoured interventions. The study by Makai *et al.* (158) reported increased costs and reduced pressure ulcers while Huang *et al.*(381) reported that the improvements in diabetes care were not cost effective. These results are uncertain because while the interventions were more expensive but also cost effective, most scenarios analysed yielded ICERs that were above the traditionally accepted thresholds of €80,000/QALY (158) and US$100,000/QALY (381). They therefore need to be assessed against specific priorities for health improvements and expenditure. In a cost analysis, Dranove *et al.* (383) were unable to identify cost savings or health improvements as a result of quality improvement.

Table 36. JBI Dominance Ranking Matrix to interpret cost-effectiveness results of economic evaluations

Most favoured interventions (in green) are lower cost and have increased health benefits			
Cost	Health benefit	Implication for decision-makers	No. of studies
+	-	Reject intervention	
0	-	Reject intervention	
+	0	Reject intervention	1 (Dranove *et al.* (386))
-	-	Unclear – Judgment required on whether intervention preferable considering incremental cost-effectiveness measures and priorities/willingness to pay	
0	0	Unclear – Judgment required on whether intervention preferable considering incremental cost -effectiveness measures and priorities/willingness to pay	
+	+	Unclear – Judgment required on whether intervention preferable considering incremental cost-effectiveness measures and priorities/willingness to pay	1 (Makai *et al.* (158))
+	+	ICER below cost-effectiveness threshold	1 (Huang *et al.* (381))
-	0	Favour intervention	2 (Gustafson *et al.* (380) and Rogowski et al (384))
0	+	Favour intervention	
-	+	Favour intervention	3 (Bloem *et al.* (382), (Broughton *et al.* (379) and Schouten *et al.* (369))

8.4.5 Effectiveness and cost-effectiveness:

8.4.5.1 Clinical effectiveness

Five studies (158, 369, 379, 382, 384) reported positive clinical outcomes of the quality improvement collaborative approach. In studies involving people with chronic health conditions, quality improvements led to reduced mortality risk and reduction in associated health events (369, 382). For example, adherence to guidelines for Parkinson's disease care achieved via the collaboratives produced improved outcomes, such as reduction in hip fractures, fewer hospital admissions, lower mortality risk and fewer disease related complications (382). Quality improvement in diabetes care (369, 381) resulted in reduced scores for diabetes risk for cardiovascular disease events and mortality, reduced lifetime incidence of complications, and improved life expectancy for both men and women. In both acute and critical care, the improvements led to reduced associated illness but differed in relation to the effect on mortality risk (379, 384). In obstetric care, establishment of a quality improvement collaborative resulted in reduced post-partum haemorrhage, reduced mortality, and increased numbers of births in clinics (379). In neonatal intensive care, a quality improvement collaborative achieved reductions in infections in critically ill pre-term babies and reduced surgical interventions but no significant difference in mortality was found (384). Residents in long term care had reduced incidence of pressure ulcers and slightly improved quality of life because of a quality improvement collaborative (158).

Gustafson and colleagues tested the effectiveness of four different elements of a quality improvement collaborative in the context of addiction treatment clinics (380).This study compared clinic level coaching, group telephone calls to clinicians, face to face learning sessions and a combination of these elements to see which methods were more effective. This study did not collect patient outcomes but focused on three primary process outcomes: waiting time, retention of patients and annual numbers of new patients. These process outcomes were chosen, as the link between treatment programs and patient outcomes was considered weak (380). Significant improvements in waiting time and number of new patients were identified for two of the interventions: coaching and the combination of all three elements (380). A combination of all elements was found to be more costly than coaching alone although it was similarly effective (380). Dranove and colleagues found no direct links between the clinical outcomes for patients of hospitals studied and the amount they spent on general quality improvement activities (383).

8.4.5.2 Cost-effectiveness and cost savings

Five studies ((369, 379, 380, 382, 384) reported favourable cost findings from the use of quality improvement collaboratives. These were related to savings in the health care system and did not consider broader costs and benefits such as lost productivity, non-medical patient costs and carer time. These studies are considered here in relation to cost effectiveness and cost savings achieved

for the use of quality improvement collaboratives across a range of health conditions and countries. Values provided below are conversions to US$ for 2018 (369, 375, 376) where the price year was provided.

8.4.5.3 Cost-effectiveness

Within the context of diabetes care in the Netherlands (369) the quality improvement collaborative was found to be cost-effective. For the large populations of people who live with diabetes there are significant medical costs related to medicines and cardio-vascular disease (369, 381). With a cost of about US$19 per patient for the quality improvement collaborative over two years, the cost-effectiveness was reported to be significant. In the US, a diabetes care improvement in public health clinics (381) found lower incidence of complications but the cost of individual improvements in care varied and all interventions but the use of an Angiotensin-converting enzyme (ACE) inhibitor, were not cost- effective (381).

The cost effectiveness study examining obstetric and newborn care in Niger (379) found the cost per normal delivery reduced, with a similar decrease in both numbers and costs of deliveries with post-partum haemorrhage. The cost of the quality improvement collaborative was calculated to be US$2.84 per delivery. The incremental cost-effectiveness was US$335 per disability-adjustedlife year (DALY) averted and the study concluded that if other obstetric clinics used the collaborative approach, substantive cost savings could be achieved (379).

In long-term care (158), reduction in incidence of non-severe pressure ulcers using a quality improvement collaborative approach increased costs of care in the short term. Cost-effectiveness in the longer term was unclear due to small effects on quality of life in nursing home populations near the end of life, and the difficulty in sustaining trained staff to continue to prevent pressure ulcers. As a preventable condition however, quality improvement in the prevention and care of pressure ulcers for a vulnerable population was a worthy goal (158).

A comparison of four different approaches to implementing quality improvement collaboratives (in the context of addiction treatment) identified cost-effective elements (380). This study found that while both coaching and a combination of interventions were equally effective in reducing waiting times and increasing numbers of new patients there were significant differences in costs of the interventions. They found the estimated cost per clinic for a coaching intervention was US$2,878 (no year) compared to US$7,930 (no year) for the combination of interventions. They concluded that the coaching intervention was substantially more cost-effective (380).

8.4.5.4 Cost Analyses

A cost analysis of ParkinsonNet (382) showed annual cost savings of US$449 per patient by

avoiding or delaying complications or high cost treatments of Parkinson's disease. The cost per patient per annum was around US$30. However, based on a population of 40,000 people with Parkinson's disease in The Netherlands, they predicted a national cost saving of over US$17.4 million per annum as a result of the quality improvement (382).

In the costly area of neonatal intensive care, a cost analysis study (384) reported significant cost savings per infant were achieved. While costs varied, the average savings per hospital in the post intervention year was US$2.3 million for an average cost of $68,206 per hospital in resources to undertake the quality improvement collaborative (384).

Finally, the study of costs to improve quality of care in hospitals in United States (383) found a wide variety in expenditures on quality improvement activities which were not correlated with condition specific costs. Differences in costs were not statistically significant. They presumed that a lack of consensus about the purpose of quality improvement efforts at the time, led to this variation in costs and disconnection with outcomes (383).

8.4.6 Costs

8.4.6.1 Costs of care:

The costs of clinical treatment were measured in most studies and included clinic visits or treatment provided in hospital such as ventilation, surgery and medications, complications, or infections (158, 369, 379, 381, 382, 384). Costs were extracted from hospital bills, medical claims and records maintained by clinicians. Some studies used estimations of costs to form their data, or surveyed managers to identify costs from budgets (369, 379). One used weekly diaries of activities and applied hourly costs for personnel time (384). Costs of care were not reported in two studies (380, 383).

8.4.6.2 Costs of establishing quality improvement collaboratives

All reported costs are presented in **Table 37**. The most common costs identified were program management costs for the quality improvement collaborative coordinators, time of the participating clinicians in face to face meetings and education sessions, collecting data, travel costs, conference calls, data analysis costs, overhead costs and some capital costs. The cost of developing evidence-based guidelines was included in the ParkinsonNet study to give a complete cost of start-up of the network (382). Four studies provided a cost per patient of establishment of the quality improvement collaborative. These included US$3.67 per infant delivery (379), US$30 per person with Parkinson's disease (382), US$19 per person with diabetes in Europe (369), and US$130 per patient with diabetes in USA (381). Dranove *et al.* reported a wide variation in costs of quality improvement activities between hospitals with the highest costs attributed to meetings (383).

Table 37. Costs of aspects of Quality Improvement Collaboratives in selected studies

Type of costs	Bloem *et al* 2017	Broughton *et al.* 2013	Dranove *et al.* 1999	Gustafson *et al.* 2013	Rogowski *et al.* 2001	Schouten *et al.* 2010	Makai *et al.* 2010	Huang *et al.* 2007
Set up and maintenance of QIC, personnel, experts, training, regional support, promotion	• 2017 US$ 2.24 Million (US$2.3M 2018) national network over 5 years • 2017 USD1.5 million (US$1.54M 2018) maintenance of network	• 2008 US$ 188,400 (US$221,000 2018) development costs • 33 hospitals over 3 years	1998 US$ 1.1 million (US$1.6 M 2018) mean costs over 16 hospitals per annum	2011 US$1.6 million (US$1.8 M 2018) for 201 clinics across 5 states over 2 years	1996 US$ 820,000 (US$1.14M 2018) 10 hospitals over 3 years	2006 € 261,500 (US$293,902 2018) national over 6 regions and 50 clinics over 1 year	2006 €50,000 (US$56,4902018) project materials and $64,000 (US$72,306 2018) for collaborative costs	Not provided Estimates of between 2004 US $712/yr1-$378 yr4 (US$928/yr1-$493/yr4 2018) per patient for the QIC’
Staff time and travel to participate in meetings, education, capital costs	Not provided	2008 US$ 583,000 (US$684,000 2018)	1998 US$250,000 (US$367,0002018) mean included in the per hospital mean costs	2011 US$ 804,915 (US$907,000 2018) for all groups	1996 US$682,060 (US$945,000 2018)	2006 €381,604 (US$431,129 2018)	Travel costs not separated	Not provided.
IT Costs	2017 US$ 346,000 (US$354,427 2018)	Not identified	Not identified	Not identified	Not identified	Not identified	Not identified	Not identified.

8.5 Discussion

8.5.1 Identifying costs and benefits

There is a need for larger scale and more rapid translation of evidence-based interventions into practice (385). However, the cost associated with research translation is an important consideration for constrained health care budgets. Quality improvement collaboratives have been used widely in diverse healthcare settings and have been effective in improving outcomes for patients (386) although the costs of the collaboratives may be a barrier to their use (382). This review sought to identify and describe studies that report on the costs and effects of quality improvement collaboratives in healthcare settings. Although a recent systematic review of quality improvement collaboratives identified 64 studies on effectiveness, only four reported on economic outcomes (12). We identified eight studies that reported on economic outcomes of quality improvement collaboratives. This included the four studies identified in the review by Wells *et al.* and updated that aspect of the review (12). Our results confirm that the consideration of costs of quality improvement collaboratives has not been reported in many studies. This may be because of the difficulty in defining costs associated with quality improvement collaboratives over time and in different contexts (386, 387). It may be that costs are small in comparison to operating costs or funded separately to the health system and of less importance for research (388).

Five of the eight studies in this review showed that quality improvement collaboratives were cost-effective in implementing clinical guidelines (369, 379, 380, 382, 384). They identified cost savings and improvement in health outcomes for patients in both acute care and chronic condition management. The costs associated with the quality improvement collaborative appeared low in relation to savings across large populations or for reducing the need for high cost treatments (384, 389). These studies calculated the cost of the quality Improvement collaborative per patient for the duration of the intervention which provided useful data compared to overall outcomes and savings achieved. Where smaller populations are treated with high cost interventions, the cost per patient for the quality improvement collaboratives would be expected to be higher.

These studies were conducted in different countries or across states, with different infrastructure costs and resources. It would be difficult to generalize the costs of the quality Improvement collaboratives across such different countries and conditions. However, they used a similar process to engage clinicians and modify practices locally. This indicated that the quality improvement collaborative methodology was adapted to different conditions with similar set up structures needed. An investment in quality Improvement collaboratives was needed and the costs per person could be best spread across large populations of people with a condition or where high cost treatments can be reduced (386).

One study evaluated which element of the quality improvement collaborative intervention was more

cost-effective (380). This demonstrated that differences that can be achieved in both effectiveness and cost by the choice of how education or support was provided to clinicians. Only one study found no correlation between health outcomes and the costs of quality improvement activities in hospitals (383).

8.5.2 Societal vs healthcare perspectives

Although most of the studies captured only medical costs, most considered that societal effects of health improvements may increase the cost-effectiveness due to improved quality of life (QoL). For treatment of chronic conditions, improved care is likely to result in long-term cost savings, however QoL in long-term care populations was more difficult to measure (158). Schouten *et al.* (369) found that a wide range of disease risk control was achieved in diabetes treatment. They suggested that outcomes of other chronic conditions may be improved through a quality improvement collaborative approach and the societal effects may also be higher when considering better quality of life outcomes. Bloem *et al.* (382) similarly identified the potential for improvement of cost-effectiveness of healthcare for other chronic disorders. They also reported the need to structure funding sources and medical insurance related to improvements in health outcomes.

Rogowski *et al. (*384*)* identified the potential for higher cost savings for expensive health interventions and at least short-term sustainability of quality improvement collaboratives. Widespread adoption of the interventions may increase costs of interventions but Rogowski *et al.* considered that expected savings and benefits would offset these (384). The potential for higher cost savings and effectiveness through a wider use or broader scale of quality improvement collaboratives is a pertinent aspect of these studies for healthcare budgets.

8.5.3 Establishment costs

The establishment of collaboratives was shown to require considerable investment in the initial phases of the improvements, which then decreased over time of the collaborative process. quality Improvement collaboratives were funded in most studies by national agencies with specialist healthcare improvement staff involved in developing the collaborative, engaging participants, and providing education, guidance, and support for the duration. Only one study identified the relative cost-effectiveness of different combinations of elements of a quality improvement collaborative (380). This suggests an opportunity to improve better economic outcomes of quality improvement collaboratives by selecting key elements for use.

Despite increasing acknowledgement of the importance of public involvement in research, there was no involvement reported in these studies. Costs were spread across state and national healthcare systems to scale up improvements for low clinic or patient cost. One study included the external cost of developing guidelines in the assessment of cost-effectiveness (382), which provided an additional insight into the costs of developing or adapting international guidelines to

national conditions. In most cases the clinical guidelines were developed separately to implementation in healthcare services and funded separately. Despite this inclusion of the cost of developing guidelines, the use of the quality improvement collaborative was shown to be cost-effective (382).

The identified costs of the quality improvement collaborative had similar elements across the five studies showing cost-effectiveness (369, 380-382, 384). Costs were highest for the initial development of collaboratives, face to face meetings and travel for participants, and for multi-factored interventions. While most studies used similar components of quality improvement collaboratives as described by Nadeem *et al. (*366*)* and IHI (74), only one study compared the costs of different elements of the quality improvement collaborative (380). There is an opportunity to consider which elements of quality improvement collaboratives contribute to cost effectiveness and in which setting they may be useful. One study included the cost of development of guidelines and a maintenance cost for an ongoing collaborative (382). This provides a wider consideration of all set up costs for quality improvement and the costs to maintain the collaborative beyond a research study. The local infrastructure costs varied widely in four studies (380, 381, 383, 384) which made the cost assessments difficult to compare within and between studies. Inclusions and exclusions of costs varied between studies which also made comparisons between studies difficult. It would be of use to identify common costs to consider when budgeting for quality improvement collaboratives and to allow for local differences in infrastructure.

8.5.4 Potential savings

The value of these studies is to show that savings can be made to healthcare for quality improvements, the real set up costs and how to assess benefit. Caution in interpreting results is needed as the studies varied in what was included and costed and the perspective from which assessment of economic outcome was judged. Similarly, few studies of cost effectiveness of quality improvement collaboratives were identified suggesting that studies with negative results may not have been published.

8.5.5 Strengths and limitations

A strength of this review is the rigorous and systematic method used to identify studies and synthesise data. A comprehensive search strategy was developed and used in a range of databases. Our search of the grey literature was an important step given the variety of ways in which healthcare improvements are reported. The use of both the CHEERS checklist (314) and Evers CHEC-List (377) to assess the mixed designs found most studies to be of good to medium quality. The main limitations of the review are that only studies published in English were considered and we did not search trial registers. The few papers identified may reflect a publication bias or may indicate economic evaluations of quality improvement collaboratives have not been conducted.

8.6 Conclusion

Few full or partial economic evaluation studies were identified to assess the costs and benefits of quality improvement collaboratives to translate research and knowledge into practice. Most that are included in this review show cost savings or improvement in healthcare process and patient outcomes across acute, long term care and chronic conditions. Judgement by decision makers is required in relation to the priority given to healthcare improvement from a societal perspective compared to the cost of quality improvement collaboratives. The potential to scale up knowledge translation through quality improvement collaboratives and to improve cost-effectiveness based on these studies is suggested. The costs of quality improvement collaboratives need to be factored into translation of improvements, and their costs or economic outcomes evaluated to identify savings to healthcare budgets and benefits to society. A detailed break-down of costs of quality improvement collaboratives may assist in identifying elements of greatest cost and alternatives that may be effective for cost savings to the quality improvement process.

CHAPTER 9 STUDY 3 PART B
Assessing the benefits and costs of investing in a quality improvement strategy to build skills and knowledge in clinicians working with people with dementia

9.1 Introduction

An economic evaluation of the implementation of evidence-based healthcare guidelines, provides information to bridge the gap between research and practice. While evidence from research is synthesised into guidelines and various strategies to implement guidelines successfully have been demonstrated, a gap remains in knowledge about the associated costs and benefits. In resource-constrained healthcare budgets, the costs of implementation strategies are often cited as a barrier to implementation and leaders may be reluctant to commit resources without knowing the potential benefits (11, 390).

Quality improvement collaboratives have been designed for use in healthcare to improve quality and to translate evidence-based guidelines into practice. As discussed in Chapter 8, outcomes and costs of quality improvement collaboratives vary between settings and designs (12, 391). The context in which collaborative strategies are used can influence outcomes and costs (30). While considerable effort has been made to evaluate effectiveness, little attention has been paid to carrying out economic evaluations of the collaborative strategy itself (12, 367). The systematic review presented in Chapter 8 identified only a few studies on the costs or economic evaluations of quality improvement collaboratives despite their widespread use in health care (155).

As author, I conducted the economic evaluation, designed the framework and assessment of benefits survey, extracted the data on costs, developed the activity-based costing for staff time spent on the program, calculated the cost benefit ratios, and wrote the results and conclusions. I was supervised in the economic evaluation by a secondary supervisor while the principal supervisor provided access to data and feedback on the drafts. In this chapter I developed a method to align an economic evaluation with the components of the collaborative program logic (316) to better understand the value for money of the collaborative strategy. The initial program logic described in Chapter 4 **Table 7** linked with resources allocated to deliver the program for clinicians (30, 391). This assists in understanding the relationship between the costs of the implementation process and the outcomes for the clinicians involved (356). Explaining the differences in costs between settings or generalising findings to other groups is limited because resource costs and decisions will differ in diverse contexts. However, valuing the components of the strategy that have influenced the participants' knowledge and skills provides evidence for the design of strategies across settings.

A link between economic evaluation and a realist-informed evaluation of an implementation strategy is challenging due to different ontological bases. However, by articulating the costs of the resources used in quality improvement collaboratives and explaining how that contributed to identified benefits, a potential synergy is possible (30).

9.1.1 Aim of this chapter

This chapter aims to assess the costs and benefits, using an economic evaluation framework, of the quality improvement collaborative strategy used in the Agents of Change(6) trial to improve adherence to clinical dementia guidelines by clinicians working with people with dementia in Australia. The Agents of Change trial, as described in Chapter 1, section 1.3.1, aimed to increase adherence to three priority recommendations (occupational therapy, exercise and carer support) of the Australian clinical guidelines for dementia .A light touch, quality improvement collaborative strategy was used to build knowledge and skills in clinicians to improve dementia care.

The research questions are:

i) What are the costs of establishing and offering a quality improvement collaborative?
ii) Do the benefits outweigh the costs of participation by clinicians?
iii) What combination of program components, resources and participants is needed to maintain costs and benefits in equilibrium?

9.2 Methods

Economic evaluation provides an assessment of the programs' 'worthwhileness' by comparing its associated costs and benefits (29, 356). While a new intervention strategy may be more effective than existing ones, there are costs to consider resulting from the choice and design of resources which may affect outcomes. While typical economic evaluations are not focused on how and why resource components change outcomes, it is possible to demonstrate how resources are allocated to affect outcomes (30). In this project these components included: the development of on-line training modules; the involvement of experts (including, people with dementia and their caregivers); face-to-face meetings; feedback reports to clinicians; expert coaching; and regular communication with participants. The so-called hidden costs identified in a recent review of economic evaluations (356) (such as clinical time, training, and monitoring) are key to understanding costs and benefitsof particular components in implementation strategies.

The main types of economic evaluation, which differ only in the type of outcome measured, are 1) cost-minimisation analysis, 2) cost-effectiveness analysis, 3) cost-utility analysis, 4) cost-consequence analysis and 4) cost-benefit analysis which can be used to identify value (153). Cost minimisation analysis compares interventions to find the least expensive alternative when these strategies are assumed to have equivalent outcomes. Cost-effectiveness analysis compares

outcomes of various interventions in healthcare, measured in incremental cost effectiveness ratios (ICER). Examples are process measures such as the number of clinicians adhering to guidelines or health effects measured in natural units (358). In cost-utility analyses, the outcome considered is the quality-adjusted life-year (QALYs). A QALY is a generic outcome that combines the quality and quantity of life into a single index of effect (370). In cost-consequence analysis all costs and a catalogue of outcomes of alternatives are provided to allow the decision-maker to form their opinion on the priority (392). In a cost-benefit analysis, outcomes for competing strategies are expressed in monetary terms (371). Cost-benefit analysis has been applied to value a wide variety of health care interventions, as distinct from health outcomes (307) and establishes a net monetary benefit of the implementation strategy (392).

9.2.1 Use of Cost-Benefit Analysis

While cost-effectiveness is the most used approach for patient care outcomes in healthcare research, cost-benefit analysis has long been used to aid decision making in monetary terms for healthcare strategies and is considered beneficial information for policy makers (153). An advantage of using this approach is that it is possible to determine the value for money of a strategy without the need to compare it to an alternative. Cost-benefit analysis was chosen for this study as there was no comparator (303). A societal perspective was taken, reflecting the perspective of government in allocating resources across sectors for adherence to clinical guidelines in dementia which is a public health priority (393). The costs and benefits were monetised to allow comparison of the implementation process's costs to the benefits it provided to clinicians in the collaborative.

9.2.2 Measuring benefits of the quality improvement collaborative

As a quality improvement collaborative is not a traded good, there is no market price available to measure benefits to clinicians (306). A contingent valuation approach is used in economic evaluation to elicit a valuation of a hypothetical program or health status (394). A willingness-to-pay questionnaire was therefore needed to identify a price the participants would pay for the quality improvement collaborative based on the existence of a hypothetical market for the program (306, 307). ***Figure 30*** shows the decision process and the steps taken the determine a price through contingent valuation.

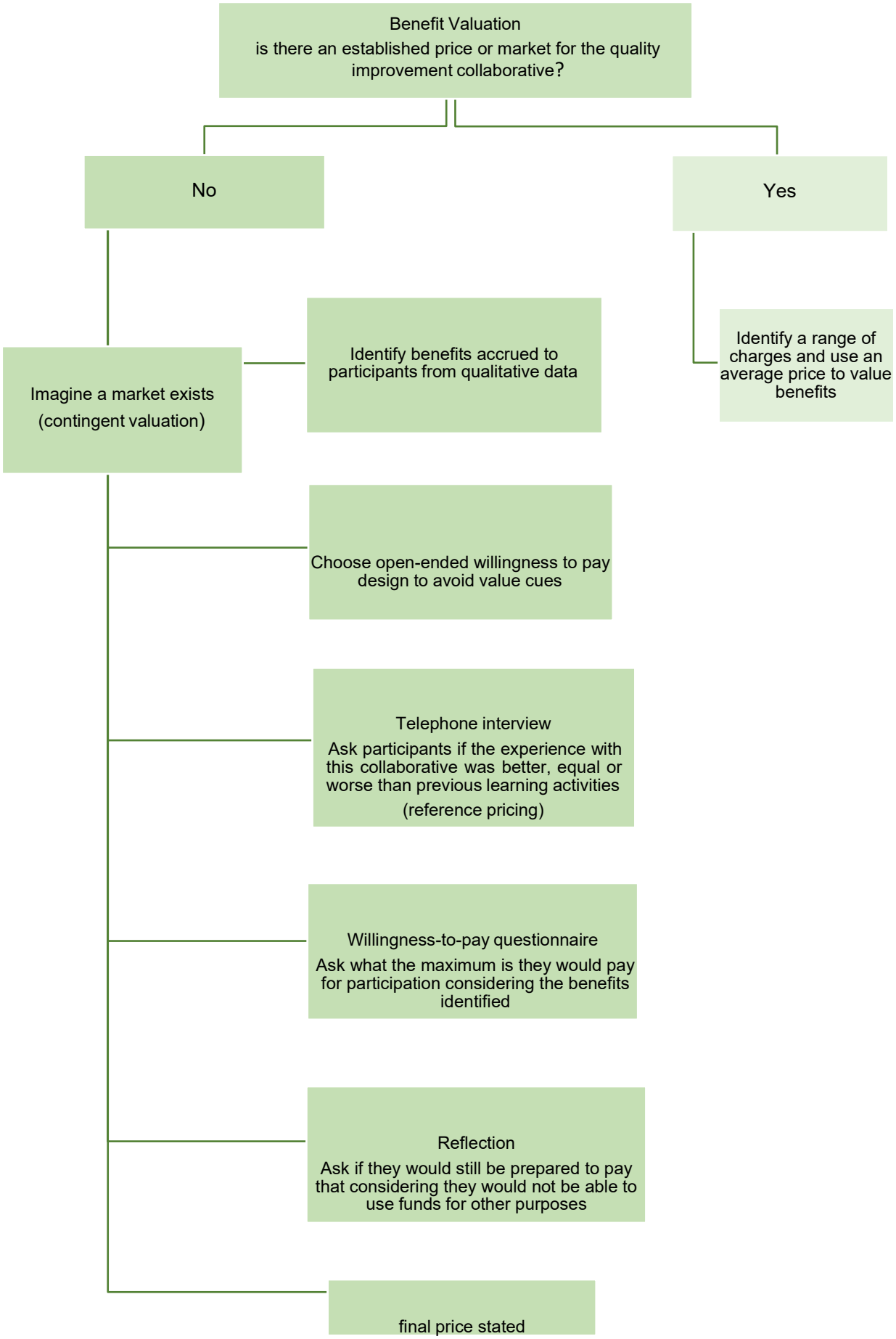

Figure 30 Flow chart for steps in contingent valuation in Cost-Benefit Analysis of a quality improvement collaborative

A sub-sample of clinicians in the trial were asked, through a stated preference technique, what benefit they placed on the collaborative, and to identify how much they would be willing to pay to participate. An open-ended question design was chosen to estimate the willingness to pay value (305, 307). An advantage of this design is that it does not introduce a range or starting-point biases (395). The questionnaire was initially piloted with two clinicians before it was rolled-out with other clinicians. Interviews with these clinicians were pre-arranged by email and conducted by telephone in a private office at a time to suit the clinician. Feedback from the two trial interviews indicated a preference to discuss the benefits rather than read the questionnaire and to consider the costs for the whole program rather than a weekly amount. Further interviews with participant clinicians were similarly pre- arranged by email and conducted as part of the post-intervention evaluation by telephone in a private office. All clinicians were offered the option to have the willingness to pay questionnaire emailed to them in advance of the interview. The willingness to pay questionnaire was then administered at the end of the post-intervention process evaluation interviews and lasted up to 15 minutes. Participants were first asked to rate their experience in the collaborative as better than, equal to or worse than previous experiences in professional development. The possible benefits ofparticipation were described, and participant clinicians were asked how much they would be prepared to pay either for the whole program or per week. Some clinicians provided a weekly amount which was then converted to a value for a 12-month program. (see Appendix 6). The average price that participants were prepared to pay was calculated to identify a monetised benefitof the quality improvement collaborative.

9.2.3 Measuring costs of the quality improvement collaborative

Establishment costs, recurrent staff salaries and fees for advisors, participant time in the collaborative, equipment and administration costs were considered for the three scenarios described in section 9.2.6 to measure the costs of the collaborative (396). The three scenarios were considered as separate subgroups for analysis. Costs were in 2020 Australian Dollars (AUD) using the Australian Bureau of Statistics Consumer Price Index for the September quarter for 2020 (397)

Each component of the collaborative was identified by reference to the program theory developed for the process evaluation and the phases of implementing the collaborative (see Chapter 4 **Table 7**). Costs were determined by extracting data about payments made for components from project spreadsheets for tracking expenditure, financial accounts, and staff salaries. Costs for staff and experts involved in the collaborative were identified through a time-driven activity-based (time-motion study) costing method (340, 398). This method allows for the estimation of costs relating to the intensive support given by staff and expert advisors in developing the online modules, coaching, review, and feedback to clinicians. Costs for participant time were extracted from online modules where the time spent on each activity were recorded within the online program

dashboard. Hourly rates for staff salaries were identified from 2020 university pay rates for university staff involved with a loading of 30% for indirect costs that are commonly applied in Australia (such as superannuation, workers compensation levy and provision for long service leave). Hourly rates for clinicians similarly included a 30% loading and were identified from Fair Work Australia web site for Allied Health (MA000027), for Nurses (MA000034) July 2020 and SA Health web site for Medical officers (SA Health Medical officers award) 2020 (399).
Table 39 presents the cost components for each phase of the collaborative and category of costs using activity-based costing. This allows for variations in costs for three different scenarios (396).

9.2.4 Analysis methods

The costs and benefits of participants' involvement in the collaborative were monetised and compared to identify a benefit-cost ratio (29). The ratio is defined as:

$$Value\ realised\ for\ each\ dollar\ spent = \frac{Value\ of\ all\ benefits\ (Total\ Benefits)}{Total\ Costs}$$

Total benefits were calculated by finding the mean price of benefits that respondents to the questionnaire were willing to pay and multiplying by the total number of participants in the trial collaborative. The total costs were calculated as the mean cost per participant and multiplied by the total number of participants in the collaborative. Discounting was not required as the costs and benefits were accrued in the same 12-month period (400).

Where the ratio equals one, the benefits and costs are in equilibrium or balanced to a break-even result. Where the ratio is less than one, the costs outweigh the benefits implying that the collaborative is not cost-beneficial. Where the ratio is greater than one, the benefits outweigh the costs, suggesting that the collaborative is cost-beneficial.

9.2.5 Cost components for the quality improvement collaborative strategy

Table 38 presents the cost components included in assessing the costs for the quality improvement collaborative strategy. Each component may be included or excluded for different scenarios according to variations in the numbers of participants, the number of face-to-face meetings included and the need to develop or review the modules.

Table 38. Cost components of the quality improvement collaborative to be considered in assessing three scenarios

Component	Hours and rates	Travel/ Accom	Advisors	Equip/services	Admin costs
Module development	30 hours x Rates AUD for 3 staff	0	QI: 8 hours Clinical: 26 hours Experts by experience: 8 hours x fees	Designer fee Platform fee IT/Tel costs	Postage Accounting
Module review	8 hours x Rate AUD for 1 staff	0	QI: 1 hour Clinical: 3 hours Experts by experience: 4 hours	IT/Tel costs	0
Recruitment	20 hours x Rate AUD for 1 staff	0	0	Advertisements x 4	Postage
Face to Face meeting	8 hours x Rates AUD for 3 staff	3 Fares 3 Accom 3 Taxi	1 Fare 1 Fee	Hire/Cater	Accounting
Participant time	53 hours pp x Rates AUD for participants	20 Fares 5 Accom 5 Taxi	0	0	0
Monitoring	60 Hours x Rates AUD for 2 staff	0	0	IT/Tel	Postage
Communications/ newsletters	12 hours x Rate AUD for 1 staff	0	0	IT/Tel	0
Audit	1 hour per report x Rate AUD 1 staff	0	0	IT	Postage
Webinars	12 hours x Rate AUD for 1 staff	0	0	Presenter Fee IT/Video	0
Coaching	5 hours x Rate AUD for 1 staff	0	0	IT/Tel	0
Teleconference	4.5 hours x Rate AUD for 1 staff	0	0	Presenter Fee IT/Tel	0
Review of plans	0.5 hour per plan x Rates AUD for 2 staff	0	0	IT/Tel	Postage
Follow up	20 hours x Rate for 1 staff	0	0	IT/Tel	0
Completion	0.5 hours pp x Rate AUD for 1 staff	0	0	IT/Tel	Postage Accounting

Abbreviations: Accom: Accommodation, Equip/services: equipment and services for collaborative, Admin: administration costs for collaborative, p h: per hour, QI: quality improvement advisor, IT/Tel: Information technology and telecommunications, Hire/Cater: venue hire and catering costs for face to face meetings AUD: Australian Dollars 2020, pp: per participant.

9.2.6 Consideration of alternate scenarios

Three scenarios or subgroups, defined by the type of costs included, were explored to identify the impact on the benefit-cost ratio and to establish break-even and cost beneficial outcomes.

Scenario 1 describes the base case in the current study with 45 participant clinicians at commencement. Costs included were for the development of the online modules with staff and expert contributions, operation of the collaborative with two start-up face to face meetings, and feedback on audits of current practice. Other costs were for incentives offered to participants to continue, staff and experts time to review plans, coaching for some clinicians, email follow up and monitoring of progress, and the time spent by participants on the modules.

Scenario 2 describes the current study as above but without the inclusion of costs relating to participants' time to participate in the collaborative. This option was considered for two reasons: 1) employers allow employees' professional development and quality improvement activities within work hours. In private practice, clinicians complete professional development, and quality improvement activities as part of their registration expectations and factor in time as part of their practice activities. 2) most clinicians indicated that they undertook the learning components in their own time, therefore organisation costs did not apply to this activity.

Scenario 3 describes a future option to re-run the existing collaborative for 100 participants and excluded costs of the initial development of online modules and participants' time in the collaborative, making use of the existing learning modules The scenario also limits incentives offered but includes staff and experts time to review modules for current evidence. Costs for operating the collaborative for additional participants were estimated by adding in extra costs for recruitment, reviewing checklists and implementation plans, adding more face-to-face meetings and time for experts to review plans. **Table 39** below, summarises the components included in each scenario.

9.3 Results

9.3.1 Participants

A total of 45 clinicians participated in the trial of the quality improvement collaborative at the time of commencement. A sub-sample of 28 clinicians participated in the economic evaluation and recorded details of the time spent on the collaborative program, in the online modules. The total time spent on the collaboratives was 53 hours, ranging from three hours to 180 hours per participant, over 9-12 months. All participants in the sub-sample were invited to participate in the post-intervention interviews, however, 18 responded to the request. Sixteen clinicians completed the willingness-to-pay questionnaire at the end of the program. Two clinicians declined to do so. By the end of the program several clinicians had changed roles and six others were on leave and

were not available for post-intervention interviews. The respondents to the willingness-to-pay questionnaire, represented most of the professions and all the settings included in the collaborative program. Five occupational therapists, seven physiotherapists, three nurses, and one health professional responded. The one physician involved withdrew from the program on rotation to another area of work and the one dietitian withdrew due to the limitations of her part-time role. Participants worked in private practice (*n*=3) aged care (*n*=4) and public hospitals (*n*=9). At the end of the program the clinicians provided positive feedback in interviews on the benefits of the collaboratives to their knowledge and skills, which has been reported separately in Chapter 6.

9.3.2 Benefits

The mean amount of money that clinicians indicated they would be willing to pay for a 12-month program of the quality improvement collaborative was AU$1535 (±802.44 SD) with a range of values from AU$100 to AU$2600. This represents the monetised value of benefits of the quality improvement collaborative.

When applied to 45 participants in the current study the total benefit was AU$69,060.

For scenario 3 when applied to 100 participants in the program the total benefit was AU$153,467.

Table 39. Components of collaborative included in costing for three scenarios

Components of collaborative	Scenario 1	Scenario 2	Scenario 3
Development of Collaborative Modules	√	√	X
• Staff costs	√	√	
• Expert costs	√	√	
• Platform design	√	√	
• IT costs	√	√	
Recruitment of participants	45	45	100
Face to face meetings	2	2	4
• Staff time	√	√	√
• Travel and accom	√	√	√
• staff	√	√	√
• participants	√	√	√
• Venue hire/catering	√	√	√
Participant time in collaboratives	√	X	X
Audit and feedback	√	√	√
Monitoring and communication	√	√	√
Webinars	√	√	√
Coaching by staff	√	√	√
Tele/video conferences	√	√	√
Review of implementation plans	√	√	√
Follow up			
• Staff time	√	√	√
• Incentives	√	√ Limited	X
Completion CPD certificates	√	√	√

9.3.3 Costs

Total costs were calculated combining fixed and variable costs for a 12-month program. **Table 39** presents the components of the collaborative included in costing for the three scenarios.

For scenario 1 the total cost for 45 participants was AU$229,668 including AU$124,646 in costs of participant time in the collaborative.

For scenario 2 the total cost for 45 participants excluded the participant time in the collaborative and amounted to AU$104,972.

For scenario 3 the total cost for 100 participants excluded the cost of participant time in the collaborative, the initial development costs, and the larger incentives for attendance at conferences. This cost therefore amounted to AU$136,233

9.3.4 Cost-benefit analysis undertaken for three scenarios.

Table 40 presents a summary of the benefit-cost ratios for three scenarios.

Table 40 Summary of benefit-cost ratios for three scenarios

Component	Scenario 1	Scenario 2	Scenario3
Costs	$229,668	$104,972	$136,233
Benefits	$69,060	$69,060	$153,462
Benefit-Cost Ratio	0.30	0.66	1.13
Participants to break even	150	70	89
Result	Not Cost-beneficial	Not Cost-beneficial	Cost-beneficial
n	45 participants	**45 participants**	**100** participants

9.3.4.1 Scenario 1

With 45 participants, costs outweighed the benefits identified for the trial of the quality improvement collaborative. The benefit to cost ratio was 0.30. This means that for every dollar spent on the collaborative, only 30 cents' worth of benefits were realised. In this trial, small numbers of participants were recruited as a trial to test if the program was feasible, acceptable, and effective. Benefits and costs were balanced if 150 participants participated in the collaborative under this scenario.

9.3.4.2 Scenario 2

With 45 participants, costs still outweighed the benefits of the trial of the collaborative even with the costs of the participants time excluded. The benefit to cost ratio was 0.66. This means that for every dollar spent on the collaborative, only 66 cents' worth of benefits were realised. Benefits and costs were balanced in this scenario if 70 participants were involved.

9.3.4.3 Scenario 3

With 100 participants and four face to face meetings, benefits outweigh costs when initial development costs are removed, and participant time in the collaborative is excluded. The benefit to cost ratio was 1.13. This means that for every dollar spent on the collaborative, $1.13' worth of benefits were realised. By excluding development costs and replacing them with review of the modules, costs are lower and a return on the investment is seen. Benefits and costs were balanced in this scenario if 90 clinicians participated.

9.4 Discussion

The cost of developing and providing a multicomponent quality improvement collaborative is a significant investment. The set-up costs for improvement and implementation projects are not systematically reported, increasing the difficulty associated with comparing costs to benefits or outcomes (358). Most quality improvement collaboratives include face-to-face meetings of participants and site visits by experts. A trend of increasing use of online and email communications to reduce costs has been noticed (12). The collaborative at the focus of this study was designed as a low cost, light touch strategy by reducing face to-face-meetings, reducing travel costs, providing online learning modules for geographically spread participants, and using email and telephone communication to maintain engagement and commitment to the strategy. Individual clinicians from varied settings accessed coaching and feedback on their implementation plans by telephone and email then applied the implementation plan in their own setting. Nonetheless, the initial establishment costs in this trial were significant and in line with recommended cost inclusions for quality improvement collaboratives (401).

9.4.1 Major costs

The breakdown of the costs of these types of activities is considered important to organisational decision-makers in planning, designing and resourcing interventions (402). The major costs incurred related to the development of online training modules and workbooks, design of the interface, the involvement of experts in the development and operation stages, the face-to-face start-up meetings and the time spent by participants and staff on the collaborative process. The cost of participants' time in learning and working on improvement plans is a significant investment in practice change. They are however part of the costs of professional development of healthcare staff and in maintaining accreditation through use of evidence-based practice and quality improvement. The rationale for inclusion of this cost was to value the time spent by clinicians in the collaborative and to identify hours for accreditation for continuing professional development (CPD) points for each clinician. This time spent is usually paid for by employers within hours of employment or by the clinicians themselves and the benefit accrued is the required CPD points to retain professional registration or accreditation.

When development costs and costs of participant time were removed from the benefit-cost ratio it was clear that the benefits outweighed the costs. A break-even outcome would be possible with 70 participants. However, the development costs are an essential component of a quality improvement collaborative strategy (402). A well planned and resourced collaborative is considered key to implementation success (3). The resources already created for the Agents of Change trial could be leveraged to reduce future costs of conducting the collaborative at scale. Ensuring that the researchers and experts were credible, and an interactive and supportive approach was offered, participants engaged in a largely online trial. These components are part of the resources provided in the context of a quality improvement collaborative. They helped trigger the mechanisms identified in Chapter 6, (motivation, accountability, identity, collective learning, credibility, and achievement) as producing outcomes of increased knowledge and skills for clinicians and successful implementation by most participants. For example, the regular prompting and follow up of participants to complete activities in the collaborative, required resources but triggered the accountability of the motivated participants to keep up with the process. Similarly, the involvement of clinical and quality improvement experts and experts-by-experience of dementia to provide advice and feedback to clinicians required resources to be used but created a credible and trustworthy collaborative which was highly valued by participants. The costs and benefits of these components are aligned with the mechanisms identified in the program theory in Chapter 6. They allow for consideration of the reasons for uses of resources and the benefits identified. In this evaluation they justify the decisions made in the design and use of resources in the collaborative strategy to produce outcomes for clinicians. **Table 41** presents this comparison of the uses and benefits of resources with the mechanisms identified.

9.4.2 Benefits identified

The willingness-to-pay questionnaire used to identify benefits was novel to most participants who found it difficult to put a price on the benefits from the collaborative. Most indicated that they rarely would pay for professional development activities, with organisations funding their participation or their use of free online education. Of the participants who did pay for their professional development, most used short online courses offered through professional organisations. In line with the cost-benefit analysis guidelines (301, 403) contextual information was offered which helped participants to give informed willingness to pay values. Most used a reference price to assist in assessing benefits (307), such as cost of conferences, annual amounts allowed by employers for professional development, or the costs they paid for the online training from professional websites. This indicated both their unfamiliarity with payment for participation in a quality improvement collaborative and a process of ‘value clarification’ to reflect on their stated value (404). This unfamiliarity may have resulted in an over (405) or undervaluing (307) of the collaborative process and may have also accounted for the wide range of prices proposed by participants.

Table 41. Alignment of mechanisms of the collaborative with cost components and benefits

Mechanisms (as identified in the program theory in Chapter 6)	*Cost component*	*Costs*	*Benefits*
Motivation and confidence to engage in change	Recruitment and face to face meetings	Staff, experts, participants time, travel, accommodation, venues, and catering	Networking, support, confidence building
Accountability strengthened Commitment to change	Monitoring of progress Checklists and development of plans, CPD points	Staff time, audit and feedback, review of plans, follow up, incentives	Step by step progress, adapted to setting, accumulated hours
Sense of Identity reinforced	Face-to-face meetings Involvement of people with dementia and caregivers	Staff, experts, participants time, travel and accommodation, venues, and catering	Dementia focus with peers, experts, and people with dementia inspired participants
Doing it together/ Collective learning increased confidence	Learning online together, posting comments, collaborative sub- groups teleconferences	Interactive online platform for learning, staff time to monitor, host teleconferences, Feedback and advice by staff and experts	Regular interaction, advice and guidance assisted with confidence
Credibility built trust and Confidence in process	Reputation of researchers, involvement of clinical and quality improvement experts and people with dementia and care partners	Time of staff, expert and people with dementia and caregivers, quality on online learning modules, regular communication	Access to experts, advice, feedback and coaching not otherwise available
Reflection on efforts helped recognise achievements	Review of checklists, review of plans, advice, and coaching, follow up, monitoring	Time of staff to provide feedback, write stories for newsletter, provide completion certificates	External feedback, benchmarking with others, review of progress

A higher return on the investment in developing the collaborative may have been possible by involving a greater number of participants initially. Recruitment of 150 clinicians to deliver a cost-neutral collaborative as in scenario 1 (including establishment and participant costs) would be possible as many clinicians work with people with dementia in Australia and would be motivated to improve their practice. When costs of participants' time are removed from the costs included, as in scenario 2, recruitment of only 70 clinicians would be needed to break even. By excluding the participants' time and the establishment costs, as in scenario 3, 90 clinicians would need to participate to allow the collaborative to be cost neutral. This scenario factors in additional face-to-face meetings and time spent by staff and experts with higher numbers of participants.

Participants reflected on the value of the collaborative to clinicians working in rural and remote locations, or in circumstances where they may be the only clinician in their profession within a

service or a location. They indicated that the online collaborative was particularly beneficial in those circumstances, overcoming isolation and limited opportunities to participate in quality improvement.

The aim of this research was to test if the method was feasible and acceptable and in doing so set an initial target of 30 participants. Many more applied to participate and 45 commenced the program. With the outcomes of the program now known, a further offering of the collaborative to an increased number of participants would realise a positive return on the investment. The description of three different scenarios and benefit-cost ratios for each provides information for decision-makers.

9.4.3 Strengths and limitations

The strengths of this study include the detailed costing undertaken and the choice of a cost-benefit analysis to provide a societal perspective of the implementation strategy. Tracking of all costs in a project spreadsheet, financial accounts and salaries paid, resulted in transparent reporting. Benefits were identified with participants by exploring the initial program theory of the collaborative to enable them to consider how each step related to them and to consider the benefit that they enjoyed. This approach aligned the theory-based evaluation at Chapter 6 with a pragmatic cost-benefit analysis.

The limitations of this study centre on the small number of participants involved in the assessments of benefits and their unfamiliarity with pricing a collaborative strategy to improve practice. However adequate information of the context and probable costs associated with the collaborative was provided as part of the contingent valuation approach, to aid participants. Participants were able to provide examples of the benefit in terms of quality of life for their clients during the process evaluation interviews, reported in Chapter 6. These were not measured in this study.

The checklist for assessment of quality (CHEERS) is presented at Appendix 11.

9.5 Conclusion

The trial of this implementation strategy was designed to incorporate multiple components known to improve the success of quality improvement collaboratives while also reducing costs. The cost-benefit analysis demonstrated a cost-beneficial outcome of the collaborative strategy could be achieved with more participants or with the exclusion of initial development costs and/or participant time in the collaborative. The resources provided by the collaborative were clearly linked to the success of the strategy. This study aligned the mechanisms identified in the program theory for the quality improvement collaborative (in Chapter 6), with costs of the collaborative. This enriched the analysis and understanding of which resource costs were important in influencing the outcomes.

This study can be used to develop a business case (396) for the use of quality improvement collaboratives and to inform design choices to improve dementia care. This is one of few economic evaluations of the use of a quality improvement collaborative as an implementation strategy. This is also the only cost-benefit analysis of a quality improvement collaborative strategy to improve the quality of dementia care. Further research on costs of implementation strategies could provide a business case to aid decision making on bridging the research to practice gap.

CHAPTER 10 DISCUSSION

10.1 Introduction

In this chapter I discuss the findings of the three studies completed in this research:

i) Study 1, Parts A and B a realist informed process evaluation of how and why clinicians built skills and knowledge in the quality improvement collaborative
ii) Study 2 a realist-informed process evaluation of the value added by experts-by-experience of dementia in the quality improvement collaborative, and
iii) Study 3 Parts A and B Assessing the costs and benefits of the quality Improvement collaborative. ***Figure 14*** in Chapter 4 shows the relationship between these studies.

The discussion includes how the findings relate to other literature on translating evidence into practice, and the implications for improving research and practice particularly in dementia care.

The evidence to practice gap in healthcare has a negative impact on health outcomes and represents a waste of research effort and organisational resources. The need to improve the quality of dementia care has been emphasised globally with priorities set for translation of research evidence into practice and better education of professionals in care of people with dementia (1) This research focused on evaluating a strategy to improve adherence to evidence based clinical guidelines for dementia. Improved translation of evidence into practice is achievable by understanding how, why and at what cost an implementation strategy worked (138, 406). As such this study provides a key step to improving outcomes for people with dementia and their care-partners.

This research used a realist-informed process evaluation and an economic evaluation to address the research questions:

1. How, why and in what circumstances did a quality improvement collaborative build knowledge, skills and acceptance of clinicians who were participants?
2. What is the value of involving people with dementia and care partners as expert advisors in research?
3. What are the costs and benefits of a light touch quality improvement collaborative to implement evidence-based guidelines in dementia care?

10.2 Summary of key findings

This research found that dementia care can be improved even despite constraints in time, policy changes, and local contextual barriers. The focus on improving dementia care in this research

engaged motivated clinicians who saw the need for better practice. A well designed and credible implementation strategy, bringing together motivated clinicians, across diverse settings, provided the context for participants to learn and develop skills to make change in their own setting. The collaboration of researchers with clinical skills, expert advisors from quality improvement, clinical expertise, and experience of dementia, with participant clinicians provided opportunities to support changes to practice. The access to this expertise was needed by participants to overcome barriers and lack of confidence to implement evidence-based practice. The cost of a quality improvement collaborative was shown to be beneficial with modest increases in numbers of participants and a return on investment could be realised with future use of the resources.

10.2.1 Context collaboration and cost

Context, collaboration, and costs matter when selecting implementation strategies to improve the use of evidence-based practice in dementia care, because these components interact to affect the implementation outcomes. The context of the collaborative itself provided clinicians with confidence to learn and try out changes in their setting with guidance by experts. External and internal contextual changes in their different settings competed with their time and priority to improve dementia care. Some services and roles changed with policy and funding changes, causing several participants to withdraw and others to leave their workplaces. In some settings, managers were not able to support participants due to priority to manage organisational change rather than clinical change. In some settings resistance to change by colleagues and beliefs that people with dementia could not benefit from interventions created barriers to collective action in workplaces.

Most participants were able to complete the implementation program, regardless of variations in support, resources, and organisational structures. Some participants limited their improvements to their own practice, improving the information given to their clients and developing resources for use by others in their setting. Others were successful in engaging colleagues in their change processes. They created new caregiver support services, improved opportunities for exercise, increased use of assistive technology and environmental changes for independence.

The collaborative reinforced a sense of identity and gave credibility to the change process. It provided the support needed by clinicians to learn in a safe environment, to overcome isolation, and gain the confidence needed to be able to make changes in their practice settings. Where changes aligned with organisational priorities and structures, clinicians were recognised for their efforts. The structured support provided the flexibility to adapt the recommendations from the guidelines to local settings and suited the range of settings and roles represented by the participants. Importantly, clinicians felt empowered to make changes that they saw were needed to improve dementia care. A collaborative approach driven by clinicians, rather than one driven by the organisation, proved to be successful. By using a theory-driven evaluation of how these components influence the building of knowledge and skills in participants, this research provided a

unique insight into how quality improvement collaboratives generate change in practice of clinicians to improve dementia care.

The value of involving experts-by-experience of dementia in all stages of the research process was shown for the research, for the researchers and for the experts themselves. The experts-by-experience were able to improve the relevance of the research, contribute to the process, and influence the rationale of participant clinicians and researchers. They added credibility to the research by providing their perspective of the value of post diagnostic support for people with dementia and caregivers. They influenced attitudes and confidence of clinicians to make changes in their practice and advised researchers on ways to improve the research design, the content of learning modules, and the process of involving them in research.

A systematic review showed that few studies have reported economic evaluations of quality improvement collaboratives and none have been used to implement clinical guidelines in dementia care. As cost may be a barrier to the use of quality improvement collaboratives, detailed reporting of costs and benefits was suggested to inform decision makers of the required investment.

As such an economic evaluation of the trial showed that the costs of establishing and running the program outweighed the benefits accrued with 45 participants in the trial. By increasing numbers to 70 participants, the current collaborative would break even. By reducing costs of participation time in the collaborative, and the re-use of the collaborative modules the benefits would outweigh the costs with 60 participants. A business case was made for running further collaboratives to scale up the implementation of clinical guidelines for dementia.

10.2.2 Key findings of three studies in this research

Table 42 presents a summary of the key findings from the three studies included in this thesis.

Table 42. Summary of findings of Study 1, 2 and 3 in this research

Study Phase	Aims and Objectives	Summary Findings/ outcomes
Study 1 Part A Process evaluation	*Pre intervention*	
Phase 1.	1. Identify how QICs might work by exploring theories, literature, expectations of participants and reflection with research team	Identified key mechanisms by which QICs were expected to work : Motivation and accountability to stay engaged; a sense of identity as dementia advocates and agents of change; collective learning to share knowledge and doing it together to access support advice and guidance; from a credible evidence base and experts, CPD points as an incentive to complete the program.
Phase 2.	2. Identify initial expectations of clinicians	Identified key contextual pressures of funding and role changes, time constraints, role boundaries and pessimism about the ability of interventions to benefit people with dementia. For the process most clinicians were uncertain and lacked confidence but were excited to be involved and understood what would be needed to make changes.
	3. Survey of knowledge and skills in QI and implementation	Low scores on QIKAT-R (m =2/9) indicated low level of knowledge and skill in QI Agreement with NoMAD statements indicated clinicians expected change would become part of their work, and they would be supported to make changes that would be worthwhile.
Phase 3.	4. Integration of data	High motivation, uncertainty, expectations of learning and support to make changes in organisations.

Study Phase	Aims and Objectives	Summary Findings/ outcomes
Study 1 Part B Process evaluation	*Post intervention*	
Phase 1	1. Confirm, refute, or refine initial program theory	Refined program theory and added new mechanisms that were identified: Motivation to engage and accountability increased commitment, the sense of identity was reinforced and doing it together in a credible process increased confidence and trust and achievements enhanced reputation and empowerment of clinicians.
Phase 2	2. Survey of knowledge and skills in QI and Implementation	Modest improvement of scores on QIKAT-R (m=4/9) indicated clinicians learnt about QI but may have misinterpreted the survey scenario. Response to NoMAD statements indicated increased value of the effect of changes but slightly reduced support from managers and others. Small sample size limited statistical analysis, effect size calculated for future implementation projects.
Phase 3	3. Integration of data	Motivation and identity as change agents, maintained engagement, overcoming isolation, and gaining support through doing it together helped most clinicians complete QI projects. The credible process with access to experts promoted trust and confidence to engage in change.

Study Phase	Aims and Objectives	Summary Findings/ outcomes
Study 2 Evaluation of the value of involving experts by experience of dementia in the research	4. Identify the value added by involvement of experts by experience of dementia in the research	For the modest costs of involving people with dementia and care-partners as expert advisors in the research, significant benefits accrued to the research project, the credibility of the process and content, and to the researchers, clinicians, and the experts themselves. Improvements were suggested for future processes.
Study 3 Part A Systematic review of costs and economic evaluations of QICs	5. Identify what costs and benefits of QICs are known	Few studies published on costs and benefits of QICs. Most found cost savings and most used cost-effectiveness analysis from perspective of the healthcare provider. No cost benefit analyses. Coaching was found to be a cost-effective intervention and the use of QICs on a national basis resulted in savings to the healthcare system. Need to identify costs and benefits for decision making on investment in QICs.
Study 3 Part B Cost-Benefit Analysis	6. Assessing the costs and benefits of investing in a QIC process	Costs outweighed benefits in the trial but increasing numbers of participants to 70 and making use of the developed online resources would produce a cost-beneficial ratio. This provided a business case to consider for future use of the QIC to upscale the implementation of clinical dementia guidelines.

Abbreviations: QIC: Quality Improvement Collaborative; QI: Quality Improvement; QIKAT-R: Quality Improvement Knowledge Assessment Tool-revised; NoMAD: Normalization Measure Development

10.3 Research questions answered

10.3.1 Research question 1.

> How, why and in what circumstances did a quality improvement collaborative build knowledge, skills and acceptance of clinicians who were participants?

The process evaluation described in Chapters 5 and 6 used a realist-informed approach to explore how, why and in what circumstances a trial quality improvement collaborative built knowledge, skills and acceptance of clinicians working with people with dementia. Using a framework analysis, I explored the contextual factors that influenced the participation of clinicians in the collaborative and how and why they were able to build knowledge and skills to make changes in their setting. By focusing on the reasoning of the clinicians through interviews, seven mechanisms of change were identified in the collaborative process that enabled clinicians to make changes in their practice. Survey tools NoMAD (245) and QIKAT-R (244) provided confirmation of the increase in knowledge and skills in quality improvement and implementation processes for clinicians.

Despite constraints across aged care and healthcare contexts, and within local settings, participant clinicians were motivated by a shared identity as agents of change in dementia care and the desire to work together to improve their practice. The support from credible experts (research, quality improvement, clinical and experience of dementia) in a trusted process enabled clinicians to commit to learn, try out, reflect on practice, and overcome pessimism or resistance to change. Where support to make changes was present in their organisation, (and the changes to practice aligned with internal quality improvement systems), clinicians were able to involve others in the change process and were recognised for their efforts. Clinicians expressed a sense of empowerment in making changes to both individual practice and to organisational processes which increased their motivation and commitment to improved dementia care.

While many evaluations focus on outcomes for clients, in this evaluation the focus was the implementation outcome for clinicians. By understanding how the resources provided in the context of a quality improvement collaborative interacted with the individual settings of clinicians, it was possible to identify why clinicians were able to build knowledge and skills and how they were applied in their own organisations. Critical elements of quality improvement collaboratives were the credibility of the process, access to researchers and experts for advice, feedback and coaching, ongoing support for progress, flexibility in the process and being empowered to overcome barriers to improved dementia care.

10.3.2 Research question 2

> What value is added by involving people with dementia and care partners as expert advisors in research?

The value of involving people with dementia and caregivers as expert advisors in this research was again identified using a realist-informed process evaluation. This process aimed to understand what impact the involvement of experts had on the research, how their contribution was used, and why it made a difference to the research. Researchers identified the value of meeting recommendations of the research funding body, adding relevance and quality to the research, providing a public perspective and advice on priorities and implementation plans. Clinicians identified the value of having people with dementia and care-partners involved in the collaborative as providing credibility to the research, making it credible and relevant to their work. They appreciated the opportunity to ask questions of people with dementia about preferences, language, and options for improvement in their practice. People with dementia and caregivers valued the opportunity to contribute their experience and opinions to research and to current practice. They found the process stimulating and gained hope that dementia care would improve because of their involvement, though they found the involvement demanding at times and indicated a desire for more support, more information on the impact of their advice and greater flexibility in the process. The time over which the trial operated coincided with cognitive and health changes for some of the people involved or competed with other commitments to research or community services. Recommendations from the evaluation presented at 7.6.3 suggest improvements to the process of involvement and confirm the value of the involvement of people with dementia and caregivers in research. The costs of their involvement were modest, at 2.5% of total costs.

10.3.3 Research question 3

> What are the costs and benefits of a light touch quality improvement collaborative to implement evidence-based guidelines in dementia care?

An economic evaluation identified the investment required in establishing a quality improvement collaborative and a business case for a light touch approach for future collaboratives to implement clinical guidelines in dementia care in the Australian context. A cost-benefit analysis identified the costs for each component of the quality improvement collaborative strategy and the benefits identified by clinicians in a willingness to pay questionnaire. This process identified the investment required to establish a collaborative that was designed to meet the needs of clinicians working with people with dementia in geographically dispersed locations, and a range of different settings in Australia. In this research the costs outweighed the benefits when including the establishment costs and the time of clinicians to participate. As a trial the collaborative enrolled 45 clinicians but 150 would be needed to participate for the benefits of the collaborative to outweigh the costs. With reuse of the collaborative learning modules and resources, 90 participants would be required to outweigh the costs. With approximately half of allied health professionals in Australia working with older people (407, 408), the need for evidence-based clinical dementia care is clear. Greater benefits than costs of delivery would be expected over time. A business case for decision-makers

can be strengthened by the identification of the costs and benefits of quality improvement collaboratives.

This study developed a novel approach to align a realist-informed evaluation with an economic evaluation to focus on the resources required in the context of clinical dementia care to trigger mechanisms of change in practice.

10.4 Comparison with existing literature

10.4.1 Implementation strategies

The search for ways to improve the translation of evidence into practice in healthcare is a pressing concern. A focus on implementation strategies in implementation science aims to improve the effectiveness of the translation of evidence into practice in healthcare. The recent priorities suggested by Powell and colleagues (409) confirm the focus of this thesis. These priorities to improve the impact of implementation strategies, are addressed in this research. They are 1) enhanced methods for designing and tailoring implementation strategies; 2) identifying and testing mechanisms of change; 3) researching the effectiveness of multifaceted and tailored strategies; 4) increase economic evaluation of the strategies; and 5) improve the reporting of strategies (409).

By constructing the program logic and testing the program theory for the quality improvement collaborative, the evaluation identified mechanisms of change in the collaborative strategy which resonated with clinicians. By including an economic evaluation of the collaborative strategy, evidence is available for decision makers on the investments required and the numbers of participants needed for benefits to outweigh the costs.

Smith and colleagues' recent implementation methods study (410) integrated existing frameworks models and theories to provide a tool to plan and undertake implementation studies. They address the complexity in developing multi-layered processes in improving the use of evidence-based guidelines in healthcare. The methodology suggested compares well with my research. Logic models for quality improvement collaboratives were used to develop links between components as program theories for testing. My research used the taxonomy of implementation outcomes by Proctor and colleagues (411) and a determinant framework by Damschroder *et al.* (105) as recommended in this recent methods study (410) . While secondary outcomes such as costs were noted, a framework for economic evaluation was not provided. There was no mention of approaches to the involvement of the public in their research model. In my research I included an economic evaluation and aligned costs with the mechanisms identified in the quality improvement collaborative. The evaluation of the involvement of experts-by-experience of dementia in my research goes beyond the methods proposed by Smith and colleagues (410). This recent study supports the methodology used to open the 'black box' of quality improvement collaboratives.

10.4.2 Theory-driven evaluation

The purpose of theory-driven evaluation in implementation science is to provide an understanding of how and why a program achieves a result (412). Process evaluation identifies how implementation strategies work to translate evidence-based health interventions and change practice patterns (125, 126). These 'how and why" questions were a key component of the choice of methodology for this research. For instance, the advice on evaluation from the Medical Research Council (UK) identifies the importance of theory-based process evaluation and the use of economic evaluations in healthcare (243). However, this advice is not used routinely. A recent systematic review found only 38% of process evaluations were informed by theory and they were of mixed quality (124). While several theories and frameworks have been suggested for use in evaluation of implementation strategies, caution is advised on the use of so-called 'off-the-shelf' theories due to limited utility (15). A recent review by Damschroder (13) suggests the value of the use of theories lies in building the knowledge base and translating that knowledge into practice in healthcare.

Evaluation, as one of the three aims of implementation research, may assess the value of implementation efforts (102). Realist-informed evaluation provides understanding of how and why the implementation worked or not. Recent use of realist reviews (134, 225, 413) or realist evaluations (413-415) have demonstrated an interest in using theory to understand how and why strategies work. Several protocols for studies have been published recently (227, 228, 416, 417) indicating current work underway. Several process evaluations of implementation strategies have used realist evaluation or realist-informed approaches (16, 134, 144, 224, 414). Some are embedded within trials and others are stand-alone evaluations seeking an explanatory account of implementation practices in healthcare. Very few have studied quality improvement implementation strategies (418, 419). Schierhout and others (418) identified patterns of change in large scale quality improvement data gathering in Australian Indigenous healthcare and the impact of context on the outcomes .Feather (419) focused on the complexity in developing program theories and defining mechanisms in improving transition for young people with complex healthcare needs to adult health care. Lacouture and colleagues (420) identified a range of recurring mechanisms found in evaluating public health interventions, such asmotivation and satisfaction, confidence, a sense of belonging, and empowerment. These are similar to the mechanisms identified through this research and reflect the social processes of collaboration to improve healthcare practice. These studies were not related to implementing clinical guidelines but adopted similar methods to this research.

In dementia care there are few examples of realist evaluations of implementation or of quality improvement strategies (146, 228, 421). Studies have focused on the mechanisms to optimise health care for people with dementia in care homes and in hospitals. Jeon and colleagues' (228)

ongoing study to evaluate the implementation of support at home for people with dementia has similarities to this research. It focusses on an Australian multi-centre implementation of a clinical guideline for dementia care embedded within a randomised controlled trial. It will address processes, contexts, variations, andcosts of implementation and includes people with dementia on an advisory committee with other stakeholders. It differs in that it focuses on a newly developed reablement program rather than a quality improvement collaborative. Results are not available at present. This research builds the knowledge base in both realist evaluation and implementation science as applied to quality improvement in dementia care.

10.4.3 Quality improvement collaboratives as an implementation strategy

A recently published review by Coles and colleagues (422), offers an overarching realist program theory for quality improvement confirming the approach taken in this research. The study reinforcedthe role of a quality improvement collaborative as an implementation strategy. As part of the review, they developed a theoretical framework to describe the influence of context on implementing quality improvement strategies. They describe two levels of influence, the macro level of context which influences the micro level context of clinical practice (422). Nilsen and Bernhardsson (423) identify three levels of context that matters in implementation, the micro level of patient influence, the meso level of organisational structures and climate, and the macro level of broader external influences. While there is variation in how context is described, their review found most frameworks have a limited definition of context. The most common dimensions identified were organisational support, financial resources, social relations and support, leadership and organisational culture and climate (423). In this research, I found that the national context of policy and funding change (macro level) was an overarching influence on whether clinicians could participate in the collaborative strategy. A number withdrew when national policy and funding changed, resulting in changes to the organisational structure (meso level). The descriptions of organisational contexts in the aforementioned reviews reflected my findings about the infrastructure to support improvement, leadership by the participants and of their managers, and trust in the process (micro level). The context matters at the macro level as well as at the individual and organisational level. This influence was key to how and why a quality improvement collaborative worked to change the practice of clinicians in dementia.

Another recent review by Zamboni and colleagues (85), highlights the use of a realist approach to understand how quality improvement collaboratives lead to better outcomes. They developed a program theory of quality improvement collaboratives across a range of fields of healthcare to unpack the complexity of the strategy. They identify how participation may improve knowledge and skills of clinicians for improvement and how collaboration may contribute to capacity building and recognition (85). While no dementia specific collaboratives were included in the review, the mechanisms of change identified had similarities with the mechanisms identified in my research. I was able to add how a sense of community reinforced motivation and multi-professional

collaboration developed confidence in achieving improvements. Both inter-organisational and intra-organisational mechanisms of change were identified in the review. They were similarly reflected in the identification of three contextual levels of influence and the involvement of inter-disciplinary teams of clinicians in my research.

10.4.4 Economic evaluation of quality improvement collaboratives

While there has been continued advice to include economic evaluations of implementation strategies, few have been undertaken (12, 357, 393). Economic evaluation of complex interventions such as clinical dementia care is complex as there are multiple aims in interventions and the condition is progressive and terminal (424). Improvement in the condition is rare but improvement in quality of life of people with dementia and care-partners is possible (425). Costs of care will likely increase over the progression of the condition due to increased dependency and co-morbidity (426). However, treatments to delay progression, reduce symptoms and improve quality of life remain an important societal goal (427) and may reduce use of acute medical services and reduce caregiver stress (7, 428).

An economic evaluation of improvement in dementia care is unlikely to demonstrate reduction in direct costs of an organisation and needs to take a broader societal scope (424). A focus on the costs and benefits of implementation strategies to improve the use of evidence-based guidelines, provided the opportunity to consider the steps to improve dementia care. A cost effectiveness analysis of efforts to reduce preventable pressure ulcers for residents in aged care identified the need to sustain the effects to regain initial investment in the collaborative (158). Similarly, a recent review of economic evaluations of a range of quality improvement strategies in diabetes care, indicated the costs of implementation needed to be offset in the short term, depending on society's willingness to pay for improvements for people with chronic long term conditions (429). The review of the costs and economic evaluation of quality improvement collaboratives undertaken as part of my research, showed few were published and cost-benefit analysis was not used (155). While there may be publication bias, with negative results not published, the few studies identified in the review provided economic information for decision making about use of the strategy. In this thesis, the identification of costs and benefits of the collaborative strategy provided information that could be used as a business case for investment in the establishment of collaboratives and scenarios for when benefits would outweigh costs.

10.5 Clinical and policy implications

The exploration of context and collaboration in this research identified several insights into the nature of clinical dementia practice in Australia. Three insights identified were 1) the strength of the motivation to participate was linked to overcoming a sense of isolation and pessimism in dementia care, 2) the impact of the changes in the external context of funding, policy and accreditation was

experienced both organisationally and individually by clinicians in the study and 3) the need for a safe learning environment reflected the pressure of market competition and the need to perform.

10.5.1 Motivation to participate

Despite significant constraints on time and funding in many settings, most clinicians were highly motivated to participate and opted into the collaborative program. As a result, they were committed to complete the program and may not represent the average clinician. Most participants described completing the learning modules in their own time and doing extra hours to fit their implementation activities around their clinical practice. The level of motivation was in part due to their shared passion to improve dementia care and a sense of inadequacy of routine practice. Much of the literature about quality improvement focusses on the success of the collaborative team skills and the work undertaken by a team within an organisation (430). However, in this study individual clinicians came from different organisations and learnt in a virtual team to then implement in their own setting. The motivation for joining the collaborative appeared to both reinforce their identity (254) as advocates of improved dementia care and overcome pessimism about the benefits that would accrue to people with dementia. Being with a like-minded group of clinicians helped overcome a sense of being devalued in their work setting or impotent to make changes they saw as needed (431).

Most clinicians indicated that their sense of isolation (in both their interest in improving dementia care and in their work-place teams) led them to take the opportunity of the collaborative to overcome that isolation. Some participants were geographically isolated and had few professional colleagues in their workplace. Others who worked in teams in large organisations also indicated a desire to join a like-minded group who shared interests and identity as advocates of improved dementia care. This insight suggests that clinicians who participated were not empowered to improve dementia care within teams in aged and healthcare organisations. This was surprising given the approval of managers was needed to participate and that all participants worked with others in their settings.

10.5.2 Impact of structural changes and support

Several participants over-anticipated the level of support they would have from managers and teams on enrolment in the program. Where external changes to funding, policy and accreditation led to changes in organisational structures, some participants lost their jobs or had significant changes in role. In aged care where increase in demand for staff is predicted, these were significant changes to long standing services (432). Clinicians described distress in losing their jobs, no longer working in dementia care or in seeing organisational values change (433). Some participants experienced opposition to improvement of dementia care in their team. One participant described being ostracised for her interest as colleagues did not want her to increase workloads or ‘rock the boat’. A strong investment by the team in maintaining the status quo may have been a

reaction to time constraints and limited understanding of the value of improving dementia care.

These reactions had been identified previously in primary care (434), with dementia wrongly seen as a normal part of ageing and therefore a sense of therapeutic nihilism: that it is 'pointless' to focus on dementia when there is no treatment (38). Similarly, recent research showed that clinicians believed that rehabilitation outcomes for people with dementia were not worthwhile, based on theinvestment that would need to made (322). This suggests that there is a continued need to increase understanding of dementia in health and aged care and to improve awareness of the interventions available and the potential to improve quality of life and delay symptoms.

10.5.3 Safety to learn and reflect

The lack of opportunity in usual roles and routines for reflective practice and little access to experts for advice for clinicians was reported in interviews by most clinicians. Clinicians indicated the need for a trusted and safe place to learn, to try out new practices and implement plans adapted to their setting. These features of professional development have been identified for successful e-learning in particular (435) and many healthcare organisations rely on online training methods to save staff time. However, the culture in many workplaces was described by participants as competitive, with the expectation of competence and satisfaction with current practice. Some clinicians appeared to have little access to experts or supervisors to review practice and professional development opportunities were limited. The requirement for continuing professional development for accreditation of clinicians working with older adults, should address how clinicians can access expert advice and reflective practice, to improve the culture of dementia care.

10.6 Significance of the research

This research has identified four main areas of significance to bridging the research to practice gap in healthcare with a focus on dementia care.

10.6.1 Successful Implementation in dementia care

The quality improvement method used in the trial was considered successful and empowered clinicians to lead improvement activities in their own setting (202). There was an immediate increase in adherence to recommendations from clinical guidelines, sustained over nine months as a result of the quality improvement collaborative (202). By identifying the key contextual resources and mechanisms for successful implementation,this research makes possible better use of evidence-based interventions for much needed improvement in dementia care. This new knowledge about the context, mechanisms, and outcomes in implementing clinical guidelines, recognises the need to overcome stigma and pessimism in dementia care by empowering clinical advocates with knowledge and skills in quality improvement, with credible processes of support and practice reflection, and with coaching from clinical experts and experts-by-experience of dementia. Translating this knowledge in the design offuture implementation strategies is required

and a social innovation strategy using up-scaling, out-scaling, and scaling deep (436) is needed to change routine dementia care. An ‘up-scaling’ approach is needed to engage policy leaders and accreditation standards to include a focus on evidence- based clinical guidelines for dementia and a quality improvement process to implement them. An ‘out-scaling’ strategy to increase numbers of clinicians using quality improvement strategies to implement evidence-based clinical guidelines for dementia will address the much needed upskilling of the workforce and reduce a ‘one-size fits all’ model of training p18 (437). A ‘scaling deep’ strategy is needed to change beliefs of clinicians and the public about the benefits ofinterventions for people living with dementia. While the online learning modules from the Agents of Change trial have been made freely available for clinicians to use to learn about the guidelines andthe quality improvement process, the interaction with peers researchers and experts for feedback, advice, guidance, and coaching is needed to overcome pessimism and resistance to change in routine care. A reuse of the online learning modules with interaction for support is cost-beneficial when increased numbers participate and suits a geographically dispersed workforce. Funding to coordinate the interaction and support is needed.

This is the first study in Australia and one of few globally to systematically explore the program theory and the mechanisms of change, and the costs and benefits that underlie a quality improvement collaborative, when used as a strategy to implement evidence-based guidelines in dementia care nationally. It demonstrates a way of improving clinical practice in diverse settings by engaging interest and commitment by allied health and other clinicians in quality improvement (202).This study informs decision makers about scaling the implementation of clinical guidelines in dementia care through collaborative strategies and the level of investment needed to do that.

10.6.2 Combining realist-informed process evaluation and economic evaluation

Implementing clinical guidelines in dementia care involves complex and diverse systems, and an understanding of how different contexts interact with the implementation process to create outcomes (251) in dementia care. Understanding the cost constraints in dementia care and health care generally is needed to overcome barriers to implementation. Few evaluations look beyond what worked or the identification of barriers and enablers to implementation strategies (85). There are few examples of the use of a realist-informed approach to evaluate the use of a quality improvement collaborative strategy (85). There are also few examples of economic evaluations of the use of quality improvement collaboratives as an implementation strategy. To my knowledge this is the only realist-informed process evaluation and cost-benefit analysis of a quality improvement collaborative in dementia care. It provides decision makers with information how and in what circumstances clinicians build their quality improvement skills. It shows the investment required for the strategy and the options for benefits to outweigh costs (155). Further examples of a mixed methods approach incorporating realist evaluation and economic evaluation in implementation strategies are needed to explore methodological differences (30).

10.6.3 Improvements to clinical dementia practice

Many improvements to practice were identified by clinicians (202). They described improvements to individual practice such as providing written treatment plans, to organisational process changes such as modifying checklists to reflect guidelines and referral processes and to the development of new services to support care-partners and provide assistive technology. Clinicians found that small process changes were achievable in routine practice and felt empowered to lead change in their teams and settings to improve dementia care. The process of reflecting on current practice allowed clinicians to identify a gap between their practice and the guidelines and to try out ways to improve. The audit of checklists provided feedback on the rate of adherence and provided clinicians an opportunity to set a goal for improvement. The support from experts to develop and implement improvement plans was appreciated by clinicians and identified a gap in professional supervision and mentoring for many participants. This was a strength of the quality improvement collaborative method and is an important component to be considered in improving clinical practice in dementia in future.

10.6.3 Involving people with dementia and care-partners in research

The involvement of experts-by-experience of dementia in research is supported by national dementia research funding in Australia and is required internationally. Despite this, questions about the role of public involvement in implementation research are raised (438) and involvement is rarely reported in research evaluating implementation strategies. In this research the value of involving people living with dementia and care-partners is demonstrated by the added credibility and relevance of the process for clinicians. By undertaking a range of roles in the research, experts-by-experience of dementia were able to demonstrate their capacity to contribute to the learning of clinicians, researchers, and other experts. This work also identified opportunities to improve processes of support for their involvement and the value of their contribution for future studies.

10.7 Strengths and imitations of this research

10.7.1 Strengths

Dementia care is critical for governments due to increasing numbers of people now living with dementia. The cost and capacity to provide care for people living with dementia has the potential to overwhelm health systems in the future (40). Improving care and equipping the workforce with evidence-based practice and implementation skills is needed to respond to the challenge and reduce the impact of dementia on the community.

This research showed that a collaborative process to improve dementia care is feasible and acceptable and the return on investment in the strategy is clear. Most participant clinicians

completed the collaborative process and demonstrated their knowledge and skills in implementing evidence-based guidelines into their practice. They indicated that the collaborative was useful to them as a professional development strategy to improve their practice. The changes made to practice ranged from individual clinical practice changes to the development of networks and new services to respond to unmet needs. The collaborative strategy equipped and empowered clinicians to lead improvement activities (202).

The use of mixed methods in this evaluation was a strength to integrate diverse findings. They provided rich data to explore and compare. The use of realist-informed evaluation methods with surveys based on NPT and the assessment of quality improvement knowledge added quantitative data and layers of analysis. Similarly, the use of three frameworks to assess elements of how and why the collaborative worked added depth to the evidence collected. The alignment of a realist-informed approach with a positivist economic evaluation provided information for decision makers on costs and benefits of the components of the collaborative approach. An embedded process evaluation within a quasi-experimental time series trial (202) addressed a range of implementation outcomes identified by Proctor and colleagues (411) to improve dementia care.

The addition of an evaluation of the involvement of people with dementia and care-partners in the research process and a cost analysis of the involvement were also strengths of this research.

10.7.1 Limitations

10.7.1 Design of evaluation

This research was a small explanatory case study (439) of a trial of the use of a quality improvement collaborative to improve adherence to clinical guidelines for dementia in Australia (6). That trial used a quasi-experimental time series design to evaluate benefits of a specific intervention in the real world (440). While a randomised controlled trial is regarded as the best design in testing causality, randomisation was not considered appropriate due to the small sample size and as it would withhold an evidence-based intervention from a control group (202). As a result, the embedded process evaluation used mixed methods, a pre-post intervention design, and no control group. Interviews and surveys were conducted pre-and post-intervention while other data collection occurred during the collaborative. This included written comments made by clinicians in the online modules, numbers of checklists and implementation plans submitted, and exit interviewswith clinicians to provide additional information during the process and possible confounders. While changes in clinicians' skills and knowledge were identified, those changes may not necessarily lead to improved care or outcomes for people living with dementia and their caregivers. The design offers better evidence than non-experimental studies by monitoring ongoing engagement inthe collaborative and the regular feedback and coaching over nine months. The interval between pre-and post-intervention data collection however may limit internal validity and claims of causality due to the possibility of other influences or chance during that time (441).

The external validity or generalisability may be stronger as all participants were included in the evaluation and were from a wide variety of settings nationally (442). Missing data (see 10.7.3) however may have been a source of bias by missing the views of all participants.

While experts-by-experience of dementia were recruited to the trial from a range of locations across Australia, there was a lack of diversity in age, cultural background, and language. This limited the range of views explored in the evaluation. Future trials would benefit from ensuring diversity among experts-by-experience in research.

The use of a realist-informed process evaluation of the trial stage of the intervention, sought to understand the social processes of the strategy through a case study design (439). This adapted approach did not include a realist review prior to the intervention and the initial program theory was not included in the pre-intervention interviews. The program theory was developed and tested at the post-intervention interviews with clinicians. The focus on identifying patterns and mechanisms in different contexts differs from identifying relationships between variables in causal testing. A realist-informed evaluation provides qualitative and quantitative evidence on the reasoning of participants during the collaboratives. The mechanisms identified were particular to this case study, but resembled groups of mechanisms identified in the literature about health care and quality improvement (85, 420). The mechanisms may be generalizable to similar implementation strategies as they refer to the program theory of a how a collaborative learning strategy works. This knowledge building approach is a hallmark of realist evaluation (26). Causality cannot be inferred. The collaborative intervention cannot be claimed as the cause of increased adherence to guidelines; however, this case study builds an understanding of how change is generated in differing contexts.

The design of the surveys may need to be adapted to better align with a realist-informed approach of the evaluation. Providing opportunities for clinicians to reflect on differences between the clinical and the quality improvement focus of the collaborative may have strengthened the use of the surveys in this research. In addition, combining a realist-informed process evaluation with an economic evaluation of the collaborative strategy is not well aligned methodologically. The realist approach seeks to understand how and why the collaborative worked and in what circumstances, while the cost benefit analysis is a pragmatic assessment of a specific instance. The cost-benefit analysis does not consider contexts whereas realist-informed evaluation seeks to understand how context generates mechanisms (30). The desire to identify the costs of the collaborative was based on the need to provide information for decision makers. An attempt to align costs considered with the components of program theory of the collaborative was designed to justify the investment in the components which generated mechanisms. While there were conceptual challenges, an explanatory economic evaluation approach was possible which identified the resources needed in

the context of a collaborative. This approach may also identify those that are 'superfluous' to generating change (30).

10.7.2 Survey tools

The use of QIKAT-R tool to survey knowledge and skills of participants in quality improvement was designed to compare scores pre-and post-intervention and quantify a change in knowledge and skills. This tool was particularly designed for use with healthcare professionals in clinical quality improvement initiatives and has been revised to improve validity and simplify scoring (244). The use of the rubric provided with the tool and scored separately by two researchers provided validity. However, the scenario developed for use in this trial may have been interpreted by some clinicians as a clinical rather than a quality improvement process. The respondents were new to quality improvement and may have had limited understanding of the quality improvement model (443). This limited the use of the tool to quantify change in knowledge and skills in quality improvement. Additionally, one scenario was used in the survey to limit burden on the participants, when the developer recommends use of three scenarios to assess knowledge in identifying a quality improvement solution (244). The tool does however discriminate between poor and good scores which were observed for clinicians who had less or more experience in quality improvement (244). In future uses the scenarios used may need to be piloted to ensure that the respondents understand the focus on quality improvement processes.

The NoMAD (245) survey tool was similarly used pre-and post-intervention to identify changes in understanding of implementation processes. It offers a tool to measure implementation activity based on Normalization Process Theory (NPT) (106). There have been few uses of NoMAD with a statistical analysis, with most uses presenting descriptive bar charts and few studies concerned with guideline implementation (113, 289). As a result, a descriptive analysis was used to compare pre-and post-intervention results. The NoMAD survey has been validated with internal consistency but has been critiqued for overlapping concepts (443). While it can be used across multiple settings there may be different interpretations of statements and limitations in quantitative validity (443) of the collective action factor. Low numbers of participants and data collection pre and post intervention limits the ability to analyse the data for significance. Responses to the survey were similar pre-and post-intervention with small differences related to collective action such as manager support and adequacy of resources. There may have been a normative bias in responses (444) with respondents identifying hoped-for support and changes. The use of NPT constructs in analysing interviews was more useful in understanding issues faced in implementing a change and confirmed the differences identified in collective action, resources, and manager support. The use of the NoMAD survey tool may be more appropriately used to identify the process in team-based changes. In this study several private practitioners did not complete the surveys and other respondents may have omitted some questions due to their focus on interventions with individuals. This may have limited the perspectives given in the surveys.

10.7.3 Missing Data

Missing data between the pre-and post-intervention surveys and interviews and within the survey responses of individuals, limited statistical analysis and may have biased results. Two attempts were made to follow up invitations for interviews, but no further to avoid undue pressure. The clinicians who withdrew only completed pre-intervention surveys and interviews. This limited statistical analysis of the difference between matched pairs in pre-and post-intervention surveys. The small sample size at each time for surveys and interviews may have missed some perspectives and added bias. However, specific attempts were made to collect data from clinicians in the range of professions and settings represented in the trial. Exit interviews with clinicians who withdrew, attempted to mitigate this bias by identifying reasons for withdrawal and perspectives on the collaborative process. The study may have shown stronger results if all clinicians completed online surveys and interviews as part of the enrolment and exit process.

There were also missing data in the willingness-to-pay survey in the cost benefit analysis. A smaller number of post-intervention interviews were conducted than at pre-intervention. Two respondents declined to put a value on the benefit they experienced from the collaborative. This resulted in a smaller number of participants who provided a value than those who were enrolled and may have affected the mean value used in cost calculations. Most clinicians were unfamiliar with payment for professional development beyond short courses and conference attendance and had difficulty in identifying a monetary benefit for the collaborative. This is however considered the viable option to valuing goods when respondents are not familiar with payment (29).

10.7.4 Economic Evaluation

A cost-benefit analysis was chosen to evaluate the implementation strategy to allow for accounting of costs by decision makers. The benefit of the collaborative was based on the willingness-to-pay questionnaire discussed above. Most responses were based on the cost of conferences or amounts previously allowed for professional development by employers for each clinician in a year. This may have affected the benefit value ascribed to the collaborative. The rational choice model underlying the willingness-to pay-questionnaire assumes that the respondent considers available information and decides a value in relation to their goals (304). However, measurement biases may have been be introduced (405). Responses may not have considered all the elements of the collaboratives or the valuation may have been inflated as they were asked about the collaborative in isolation. The questionnaire attempted to allow for this by listing the benefits expected and offering a written questionnaire. Similarly, the telephone interview for the willingness-to-pay questionnaire allowed reflection on other types of professional development that was undertaken and the effect of paying the amount would have on other uses of their budget. A larger sample of respondents to the willingness-to pay-questionnaire would benefit the valuation of benefits and use

of face to face interviews may have reduced biases (29).

In assessing the costs of the implementation, attempts were made to identify all costs in the development, initial implementation, and maintenance phases of the collaborative as advised in a recent framework for costing implementation strategies (445). While a process to monitor costs was developed prospectively, the assessment of time devoted by research staff to each phase was estimated retrospectively and may have introduced recall bias (456). The use of an activity-based costing approach (340) mediated this recall bias by breaking down time spent in each phase and reviewing the work in each phase. The research related costs were not included in this analysis as they are not considered relevant to the costs of the intervention (445) and attempts were made to differentiate research and implementation costs.

10.8 Conclusion

This research took place at a time when national governments are investing in research and services for people living with dementia. In Australia, recent policy initiatives including the Boosting Dementia Research Initiative (330), increase in funded home care packages, funding for specialised dementia care units and the Dementia Ageing and Aged Care Mission (446) all aim to support people with dementia to maintain health and quality of life. Yet the path forward for dementia care is unclear with fragmented pathways, lack of consistent access for services nationally and ongoing problems that haunt the aged care sector (19). The evidence to practice gap, expansion of the work force, needed upskilling, and quality of care has been negatively affected by ongoing stigma and therapeutic nihilism, where scepticism regarding benefits of treatments results in little use of evidence-based treatment.(447, 448) The effect of the COVID-19 pandemic has also exposed the lack of planning and priority given to dementia care worldwide (449-451).

In this changing environment the positive findings of this evaluation show a potentially cost-beneficial strategy which can be scaled up and adapted to dementia care services to build capacity in the workforce and the sector. Lessons learnt from this research may be applied to up-scale this collaborative strategy to improve adherence to the clinical guidelines and the quality of post-diagnostic dementia care.

This research demonstrates that:

- Many clinicians are motivated to improve dementia care.
- It is possible to build knowledge and skills that can be applied in different settings.
- A collaborative opt-in approach builds a sense of identity and shared values for clinicians in dementia care.
- A virtual online learning quality improvement collaborative provided the flexibility needed by many clinicians in time constrained settings.
- Collaboration between clinicians, researchers, and experts builds confidence and

commitment to improvement.

- The combination of clinical learning and quality improvement skills equips clinicians with implementation skills to make changes in practice.
- Experts-by-experience of dementia can help focus research on priority needs and improve the understanding of clinicians about supporting abilities of people with dementia.
- Despite contextual constraints, clinicians were empowered to make changes to their practice and processes in organisations spread across Australia.
- Investment in well designed and resourced implementation strategies is required to improve dementia care.
- The return on investment in a light touch quality improvement collaborative to improve dementia care is achievable with small increases in numbers of participants.
- A business case can be made for the scale-up of the quality improvement collaborative approach to implementing clinical guidelines to improve dementia care.

The complexity of dementia care requires an implementation approach that recognises the interactions between the context, the intervention and the people who will improve outcomes for people with dementia. A collaborative approach rather than a top down strategy recognises the mechanisms at work at different levels and contexts.

The expanding dementia care workforce needs upskilling and support in countering the stigma still associated with dementia, and the barriers to change in practice (86, 450). Training alone is not effective (8). A workforce strategy that combines increased involvement of allied health clinicians in dementia care, with evidence based-based interventions and infra structure to support change in practice and models of care is needed. A multidisciplinary approach to quality of life for people with dementia requires a change of focus of care, away from managing symptoms to promoting wellbeing. Individual services may struggle to implement these changes and a policy and network approach is needed to drive change. Examples of national upskilling of workforce to support people with chronic long-term conditions can be seen in the use of quality improvement approaches in the Netherlands (91, 381). There is an opportunity for national approaches in Australia for workforce development and support in response to recommendations from the Royal Commission into Quality and Safety in Aged Care due in 2021 (19).

The perspectives, priorities and contributions to the research made by experts-by-experience of dementia demonstrated that better research is possible through collaboration. Networks of support, training and monitoring of the involvement of people with dementia and caregivers in research are needed to meet the values and aims proposed by leading public involvement advocates and the needs of researchers (247, 452). A nationally funded network is needed to promote involvement of people with dementia in research, to provide training and guidance, to connect interested researchers and members of the public, and to monitor and evaluate processes and outcomes

(453). Further research on strategies is needed to adapt implementation to the different contexts, economic, and cultural circumstances, in which the 50 million people with dementia live (454). Comparative research in different locations and at larger scale is needed to further understand how the collaborative strategy works in different circumstances Further examples of quality improvement in dementia care, realist evaluation methodologies and economic models to explain program theories is needed to refine and improve dementia care. An emphasis on improving dementia care in Australia is anticipated with the recommendations from the Royal Commission of Inquiry into the Quality and Safety of Aged Care (19) final report due in 2021. Research to evaluate the translation strategies used to improve care will provide evidence for successful implementation and improved quality.

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LIST OF APPENDICES

Appendix 1 Protocol for Agents of Change: establishing quality improvement collaboratives to improve adherence to Australian clinical guidelines for dementia care

Appendix 2 Ethics Approval

2a) Southern Adelaide Clinical Human Research Ethics Committee (HREC/17/SAC88) and

2b) Social and Behavioural Research Ethics Committee (SBREC) at Flinders University (8057 5 July 20180

Appendix 3 Mixed methods appraisal tool (MMAT)

Appendix 4 Components of the Agents of Change Quality Improvement Collaborative

Appendix 5 RAMESES II checklist for realist evaluation

Appendix 6 Interview Guide for Clinicians

Appendix 7 Interview Guide for experts by experience

Appendix 8 NoMAD survey from website

Appendix 9 QIKAT-R survey questions

Appendix 10 GRIPP 2 for reporting public involvement in research

Appendix 11 CHEERS check list cost-benefit analysis

Appendix 12 Framework of excellence for qualitative research: Researcher reflections

Appendix 13 Prospero registration No. CRD42018107417 for systematic review

Appendix 14 Medline Search Strategy using MeSH headings and text word to search for studies and adapted to search other data bases

Appendix 1

STUDY PROTOCOL Open Access

Agents of change: establishing quality improvement collaboratives to improve adherence to Australian clinical guidelines for dementia care

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Abstract

Background: Dissemination of clinical practice guidelines alone is insufficient to create meaningful change in clinical practice. Quality improvement collaborative models have potential to address the evidence-practice gap in dementia care because they capitalise on known knowledge translation enablers and incorporate optimal approaches to implementation. Non-pharmacological interventions focused on promoting independence are effective and favoured by people with dementia and their carers but are not routinely implemented. The objective of this translational project is to assess the impact of quality improvement collaboratives (QICs) on adherence to non-pharmacological recommendations from the Clinical Practice Guidelines for Dementia in Australia.

Methods: This project will employ an interrupted time-series design with process evaluation to assess the impact, uptake, feasibility, accessibility, cost, and sustainability of the QICs over 18 months. Thirty clinicians from across Australia will be invited to join the QICs to build their capacity in leading innovation in dementia care. Clinicians will participate in a training program and be supported to develop and implement a quality improvement project unique to their service context using plan-do-study-act cycles. Regular online meetings with their peers in the QIC will facilitate benchmarking and problem-solving. Clinicians will describe their practice via monthly checklists, and guideline adherence will be determined against a set of defined criteria. Phone interviews with up to 180 client dyads will be used to assess satisfaction with care and client outcomes. Clinician interviews and field note data will be used to explore implementation and costs. Involvement of people with dementia and carers will be embedded in the study design, conduct, and reporting, in addition to clinical and industry expertise.

Discussion: The quality of dementia care in Australia is largely dependent on the clinician involved and the extent to which they apply best available evidence in their practice. This study will determine the elements of this multifaceted implementation strategy that contributed to guideline adherence and client outcomes. The findings will inform future translational approaches to improving care and outcomes for people with dementia and their carers.

(Continued on next page)

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(Continued from previous page)
Trial registration: Registered with the Australian New Zealand Clinical Trials Registry 21 February 2018 (ACTRN12618000268246).

Keywords: Quality improvement collaborative, Dementia, Guideline adherence, Implementation science, Aged care, Public involvement

Background

Care for people with dementia and their carers is complex because of the condition's multi-domain symptom profile, progressive and individualised course, and wide-reaching impact on the individual, their family, and the broader community [1]. In Australia and elsewhere,the quality of care received depends largely on the health professional involved and the extent to which they apply best available evidence in their practice [1–3].

The 2016 release of the *Clinical Practice Guidelines and Principles of Care for People with Dementia in Australia* (the Guidelines) included a systematic overview of evidence-based and best practice care that should be provided to people with dementia and informal carers (hereafter referred to as 'carers') in Australia [2]. However, dissemination of guidelines via promotion or word-of-mouth is insufficient to effect change in clinical practice [4]. Historically, implementation of clinical practice guidelines has occurred via two mechanisms: first, 'early adopters' attempt to implement recommendations in practice but do so in an unpredictable manner because they rarely have theoretical or methodological skills in implementation [5, 6]. Second, research teams conduct more rigorously designed implementation projects such as stepped wedge or cluster randomised trials in partnership with health or aged care services. Typically, these projects involve identification of barriers followed by the use of tailored interventions strategies which may include training, education, reminders, and audit and feedback [7]. Such projects usually focus on changing a single health professional behaviour and often result in only modest effects [8]. Additionally, sustainability of the change can be jeopardised when research resources are withdrawn [6].

More effective methods of guideline implementation are required based on the knowledge that health care professional behaviour is influenced by a wide range of personal and contextual factors. One systematic review identified 57 clusters of factors that played a role in professional practice [9]. In dementia care, barriers to knowledge translation include insufficient time to implement strategies; a lack of financial, leadership, or staff support; inadequate levels of knowledge or training; high staff turnover; inappropriate staffing or resources; lack of perceived 'power' in creating change; and previous unsuccessful attempts to implement change [3, 10]. Effective implementation of evidence in this context requires integrated, multimodal learning strategies that are tailored to the learner preferences, allow learners to 'try-out' new knowledge with expert follow-up, use simple messaging, provide incentives, and target the whole workplace rather than the individual health professional [3].

A quality improvement collaborative (QIC) is an innovative knowledge translation strategy incorporating these principles. Collaboratives bring together health professionals from multiple sites to facilitate learning about and sharing of methods to improve care. They generally include five elements: (1) focus on a specific healthcare topic, (2) participants from multiple sites, (3) a group of clinical and quality improvement experts available to guide the QIC members, (4) a set of structured activities to promote collaborative learning, and (5) a model for improvement that tracks progress against measurable aims [11, 12]. The QIC model is based on evidence that assessing one's own progress and benchmarking with other professionals can facilitate faster and wider implementation of quality improvement practices [13]. QIC models have potential to address the evidence-practice gap in dementia care because they capitalise on known knowledge translation enablers: sufficient knowledge, access to feedback, a combined learning experience, formulating an incremental action plan, iterative practical experience with new knowledge, and realistic goal setting.

Quality improvement collaboratives have been successfully implemented to increase rates of breast feeding [14] and organ donation [15], reduce central line-associated bloodstream infection [16], and decrease post-stroke length of stay [17]. To our knowledge, QICs have not yet been used as an implementation strategy in community-based dementia care. Whether they are an accessible, feasible, cost-effective, and sustainable method of improving guideline adherence in dementia care is not known.

Objectives

The primary aim of this project is to implement and sustain improvements in post-diagnosis care for people with dementia and their carers by increasing adherence to three key recommendations from the *Clinical Practice Guidelines for Dementia in Australia* [2]:

1. People with dementia living in the community should be offered occupational therapy (reflecting evidence-based programs)

2. People with dementia should be strongly encouraged to exercise
3. Carers and family of people with dementia should have access to programs that provide respite and support to optimise their ability to provide care for the person with dementia.

This will be achieved by establishing three nationwide QICs (of approximately ten health professionals and their sites each) who regularly work with people with dementia and their carers. The three guideline recommendations were chosen to be implemented because adherence to them is known to be poor. Occupational therapy intervention involving home modification, education, problem solving, and activity engagement is shown to be cost-effective [18], yet in practice occupational therapistsfocus on assessment at the expense of intervention [19].People with dementia are not routinely encouraged to ex-ercise or participate in physical activity [20] despite exer-cise being the most effective intervention demonstrated to delay functional decline [21]. Supporting carers of peoplewith dementia to maintain their wellbeing and to inde-pendently problem solve and manage their own needs can reduce negative carer impacts as well as delaying func-tional decline and reducing the occurrence of changed be-haviours in the person they care for [22, 23]. Yet these types of programs are not widely available, and carers re-port that they need more education, skills counselling, res-pite, and emotional support to help them in their caring role [24, 25]. Implementation of these guideline recom-mendations reflects the priorities of people with dementia and carers, who have called for improved post-diagnostic care which facilitates independence and social engagement for people with dementia and provides effective support for their carers [26]. The recommendations are low-cost, acceptable, and feasible interventions that reflect broader policies around healthy ageing [27].

The secondary aim of this project is to assess the im-pact of the QIC on experiences and outcomes for people with dementia and their carers.

The research questions are:

1. Can the establishment of a national dementia QIC increase adherence to three non-pharmacological recommendations from the guidelines? If so, are increases sustained?
2. How feasible is the establishment of the QICs?
3. What is the impact of the QIC on experiences and outcomes for people with dementia and carers?
4. What is the return on investment (cost-benefit) of establishing QICs?
5. How does participation in the QIC build knowledge and skills in quality improvement among the implementation clinicians?
6. How acceptable is the addition of quality improvement implementation skills and knowledge to clinicians' existing skill sets, workload, and responsibilities?
7. What is the impact of involvement of people with dementia and carers in project design, conduct, and reporting?

Methods

Design

An overview of the project per guidelines by Proctor et al. [28] appears in Table 1. The impact of QICs on guideline implementation and outcomes for people with dementia and carers ('client dyads') will be evaluated in this implementation research project using an inter-rupted time-series design [29]. Interrupted time series is a strong evaluative design for estimating the impact of an intervention in non-randomised settings because it allows for detailed assessment of longitudinal trends as-sociated with an intervention [30]. Feasibility, acceptabil-ity, cost-effectiveness, and sustainability of the model will be evaluated using an inbuilt mixed-methods process evaluation [31]. Both administrative data and data collected from participating health professionals, their employing organisations, and their clients with dementia and carers will inform the outcomes for this study.

Participating clinicians will be taught and supported to undertake a quality improvement project using a frame-work modelled on the Institute for Healthcare Improve-ment Model for Improvement [32]. They will learn about key change management models, conduct stake-holder analysis, and assess their organisation's readiness for change. They will use plan-do-study-act (PDSA) methods to make iterative and self-directed quality im-provements. Iterative quality improvement methods allow for clinicians to learn by testing practice changes, rapidly assess their impact, and adapting according to feedback and reflection [33, 34].

Context and setting

Formal support services for people with dementia in Australia are primarily delivered via hospitals and the Commonwealth subsidised aged care system [35]. Diagno-sis occurs in primary care, specialist physician rooms, or hospital outpatient settings, but psychoeducation and ser-vice navigation and provision after this time vary. Therapy services to optimise function and independence are avail-able in some, but not all, settings. People with dementia and their carers can access helplines and advisory services, and subsidised ongoing home care packages are available (based on need) with the primary aim of maintaining in-dependence and delaying institutionalisation. Programs that provide respite for carers are available as well as

Table 1 Overview of project per guidelines by Proctor et al. [28]

Action	Description
Name it	Establishment of QICs to improve care for people with dementia and their carers
Define it	QICs enable rapid, sustainable improvements in care by bringing together health services to learn together, share ideas, and benchmark outcomes
Specify it	
a) The actor	The project team establishes and supports the QICs; Implementation clinicians form the QICs and conduct quality improvement (using PDSA cycles)
b) The action	Completion of an online training course, development of a site-specific implementation plan, and enactment of this plan (using PDSA cycles)
c) Action target	"Implementation clinicians": health professionals across Australia who have some leadership responsibilities yet are still closely connected to the delivery of services and can introduce changes to practice
d) Temporality	The clinicians will participate in online training, develop a sites-specific implementation plan, and then enact the plan.
e) Dose	Seven education modules of 2 hours each, to be completed over 8 weeks; 11 virtual QIC meetings
f) Implementation outcome affected	Primary outcome: adherence to recommendation as described in the criteria in Table 3.
g) Justification	The intervention was designed to match with factors known to enable evidence-based care for people with dementia and their carers and to be relatively 'light touch' and promote rapid change

Abbreviations: *PDSA* plan-study-do-act, *QIC* quality improvement collaborative

short- or long-term care accommodation options, and these may include some access to regular physiotherapy, occupational therapy, and other allied health services. Younger people with dementia (under the age of 65) are eligible for disability support packages and can choose to move to the aged care system when they turn 65 or remain in the disability sector. Over-all, service provision is fragmented and varies accord- ing to demographic, organisational, and policy factors [36–39]. We aim to recruit from a broad range of geographical and professional settings to gather a variety of perspectives about the acceptability and effectiveness of the QIC methodology.

Participants

Participants in this project include the health professionals (*implementation clinicians*), their workplaces (*implementation sites*), and the people with dementia and/or carers to whom they provide service (*client dyads*).

Implementation clinicians will be health professionals across Australia who regularly work with people with dementia and/or their carers, have influence within their workplace (and possibly leadership responsibilities), and maintain a clinical workload. Implementation clinicians are sought from a variety of service contexts, professional backgrounds, and geographical locations. Recruitment will occur via targeted advertising with professional associations, aged care organisations, peak bodies, and health services. Clinicians who apply to join the QIC will be assessed for suitability based on their experience, seniority within their organisation, and existing caseload of people with dementia and/or carers. They will be re- quired to demonstrate that they have the support of their management to participate. Eligible implementation clinicians will:

a) Be medical, allied health, or nursing professionals registered with a professional body
b) Regularly treat/work with people with dementia and/or their carers (i.e. at least twice a week)
c) Have some influence within their workplace (e.g. via leadership responsibilities)
d) Maintain a clinical workload of at least 30% of their working hours
e) Give informed written consent
f)) Have signed approval to participate from their manager/supervisor

Implementation clinician workplaces will participate in the collaborative as 'implementation sites'. An implementation site may include a general practice, a community care organisation, a day therapy centre, a memory clinic, a residential care facility, a hospital department, or any other organisation providing care for people with dementia. Direct managers/supervisors of implementation clinicians will participate in the process evaluation to gather their perspectives on the QIC and change management.

Client dyads will be existing patients with dementia and/or their carers within the caseload of the implementation clinician at the implementation site. Strict inclusion criteria will not be applied, and implementation clinicians will be asked to use their judgement; eligible people with dementia will be any client with a diagnosis of dementia (or suspected dementia) who attends a consultation with or without a carer. Carers will be any person attending the consultation who provides substantive

care for a person with dementia and identifies as a carer. Implementation clinicians will complete the checklists about their consultation with each person with dementia (or carer, or dyad, where applicable) they see and return these to the study team. They will also ask for verbal assent (from both members of the dyad, where applicable) to pass contact details onto the study team for the purposes of two follow-up phone interviews. The study team will randomly select one dyad (per clinician) from among those assenting each month to receive these phone interviews (details below), for a total of 180 dyads.

Intervention

The implementation strategy for this project was developed based on guidelines by Proctor et al. [28] and informed by the Johns Hopkins Quality and Safety Research Group translating evidence into practice model [40] (Table 2). It involves a comprehensive process of identifying candidates for QIC membership, planning and establishing the QICs, delivery of an evidence-based education package, provision of ongoing clinical and quality improvement expertise, regular financial and other incentives, and facilitation of QIC engagementover 18 months. The QIC model centres the health professional as the experts in their own service context and grants autonomy in enacting and tracking quality improvement activities over time.

Plan

We will build the QIC by developing relationships with implementation clinicians and the managers of their organisations. Organisational support for the implementation clinician will be confirmed with a formal research agreement that will outline the expectations and role of the clinician, the site, and the research team. Detailed interviews with implementation clinicians and management, as well as organisational mapping and local needs assessment, will establish barriers to best practice care, opportunities for improvement, readiness for change, and expectations from the QIC. Implementation clinicians will be identified as change champions within their organisation via internal media and will be encouraged to establish a small team of colleagues with whom they can regularly report back on their project activity and gain feedback. This phase will also include development of partnerships with clinical, quality improvement and industry experts to provide guidance and advice throughout the life of the project. A once-off face-to-face meeting with all implementation clinicians, the research team, and clinical leaders will build buy-in, further develop relationships, and give credibility to the project.

People with dementia and/or carers will be recruited to be involved at all levels of the project including in the senior investigator and management teams, as members of an advisory committee, in intervention development workgroups, and for ongoing implementation clinician support. This involvement is embedded into the implementation strategy and wider project management across the life of the project to avoid tokenism [41] and to capitalise on demonstrated benefits for researchers, ethical and scientific standards, and the wider community [42–44]. Saunders et al. [45] argue that health research is a social process and should therefore be informed by interactions between researchers, research participants, and potential end beneficiaries (especially where the research will directly inform health care, as in this project). Feedback and ongoing support from people with dementia and/or carers are anticipated to contribute to project buy-in, motivation for change, and quality of plans for change among implementation clinicians [43, 46]. Recruit- ment for this purpose will be conducted separately from implementation sites via peak body and research centre networks. Per Australian guidelines [42], all of those recruited will be reimbursed for the time they spend providing expert advice and oversight.

Educate

Education for implementation clinicians will be delivered after a 9-month pre-intervention period and include written resources, webinars, expert feedback, collaboration and peer supervision, and online learning. The main component of the education will be an intensive, eight-module 'massive open online course' (MOOC) to upskill implementation clinicians on the clinical evidence base related to occupational therapy for people with dementia, physical activity for people with dementia, or carer support. The MOOC will focus on quality improvement techniques in clinical settings. Implementation clinicians will be guided through the development of an associated implementation plan unique to their service context and informed by service gaps and barriers and facilitators to improvement identified during the planning phase. The MOOC willbe co-designed with people with dementia and carers to ensure it reflects their needs and experiences. Input will also be sought from clinical, aged care industry, quality improvement, and educational design experts to ensure it is rigorous, up-to-date, and effectively facilitates learning. Implementation clinicians will have access to people with dementia, carers, and clinical and quality improvement experts to review their plan and provide feedback. A peer review process will also allow implementation clinicians to give and receive feedback from another member of their QIC.

Restructure

Through their work to develop and implement a quality improvement activity to be delivered in their service, it

Table 2 Overview of implementation strategy for Agents of Change project, informed by Straus et al. [40]

Implementation strategies	Description
Plan	
Gather information	• Literature review to establish known barriers and facilitators to implementation of evidence-based dementia care • Implementation clinicians conduct local needs assessment and organisational mapping • In-depth interviews with implementation clinicians and management • Establish steering committee with representation from people with dementia and carers to guide project conduct
Select strategies	• Implementation clinicians develop a formal implementation plan • Implementation clinicians develop tailored strategies to overcome barriers
Build buy-in	• Identify and prepare implementation clinicians • Involve organisation managers who confirm the clinicians' involvement in the project and commitment to support • Involve members of the public (people with dementia and carers) and industry in all phases of the project
Initiate leadership	• Implementation clinicians identified as 'Agents of Change' within their organisation • Implementation clinicians establish 'practice teams' within their organisation to whom they will regularly report back and gather feedback
Develop relationships	• Build the QICs • Obtain formal research agreements • Develop partnerships between the implementation clinicians, members of the public (people with dementia and carers), industry, expert clinicians, and research team • One face-to-face start-up meeting
Educate	
Develop materials	• Development of MOOC with clinical content and focus on quality improvement in clinical settings • MOOC developed in consultation with people with dementia and carers, industry experts, educational designer • Development of implementation plan pro forma for clinicians • Establish group norms and standards of collaboration • Support for implementation clinicians to develop further site-specific resources
Educate	• Provision of training through seven-module MOOC • Phone orientation meeting with research team and face-to-face start up meeting to begin implementation plan brainstorming • Implementation plan reviewed by a person with dementia and their carer, quality improvement expert, and clinical expert • Support for implementation clinicians to gather feedback from 'practice teams' within their organisation • Regular audit and feedback based on clinician self-report and client dyad-report
Educate through peers	• Implementation plan reviewed by QIC peer • Ongoing communications within the QIC via online forums and monthly videoconferencing
Inform and influence stakeholders	• Use mass media, professional organisation newsletters, and industry publications to share information about the project and highlight implementation clinician plans
Restructure	• Implementation clinicians take a lead in quality improvement in their organisations • Site-specific implementation plan may involve restructuring or changes in structure, equipment, or records
Quality management	• Iterative quality improvement process using PDSA cycles • Ongoing peer supervision with subgroup of QIC members • Support for implementation clinicians to gather ongoing feedback from 'practice teams' within their organisation • Fidelity checking based on content of clinical interactions (via clinician self-report and patient and client dyad-report) • Monthly QIC meetings in which each clinician will report their plan activity for the month • Revisiting of implementation plan after each monthly meeting with update log; revised plan submitted 6 months after implementation • Reminders • Provision of client tools to increase uptake of best practice (to half of the sites) • Ongoing access to people with dementia and carers and clinical, quality improvement experts throughout implementation and follow-up
Finance	
Incentive scheme	• Implementation clinicians who complete 18 months follow-up receive access up to $1000 stipend to present their work at a meeting or conference • Provision of regular incentives to encourage fidelity (e.g. webinars and other resources, branded materials)

Abbreviations: *MOOC* massive open online course, *QIC* quality improvement collaborative

is anticipated that the implementation clinician will become recognised as a clinical leader in their organisation. Their plan may include some restructuring of organisation policies, service delivery, resources, records, or staffing.

Quality management

Once reviewed, clinicians will implement their plan and participate in monthly virtual meetings with their QICto benchmark and brainstorm strategies to overcome any noted roadblocks. They will iteratively review and

update their plans using PDSA cycles [47] with support from people with dementia and carers and clinical and quality improvement experts. Clinician reports of the consultation will be audited, cross-referenced with client dyad reports, and anonymously fed back to facilitate self-assessment.

Finance

Travel costs for clinicians to attend the face-to-face meeting will be covered by the project. Regular incentives will be provided to encourage clinicians to remain engaged with the project and their implementation plan, including staggered provision of written resources (e.g. books,peer-reviewed journal articles), branded materials, gift cards, and exclusive webinars. The work by implementa-tion clinicians to make clinical improvements will be highlighted by the research team in collaboration with their organisation in both mass media and internal organisation media. At the completion of their 18-month project commitment, implementation clinicians will have access to a $1000 stipend to attend a meeting or conference of their choice to present their work.

Outcomes

The outcomes and measures that will be used for this study are presented in Table 3. Outcomes of interest relate to guideline adherence, implementation of the QIC methodology, service level effectiveness and harms, and client dyad outcomes.

Guideline adherence

The primary outcome of the implementation evaluation is changes in guideline adherence over time. Guideline adherence will be assessed using monthly checklists completed by implementation clinicians about their consultations with people with dementia and/or carers. Clinicians will complete the checklists for the first ten consecutive consultations each month. Clinicians will be asked to provide a 'snapshot' of the consultation including its purpose, content, and outcomes. A process for guideline adherence scoring was modelled on methods used in Kortekaas et al. [48] and van Fenema et al. [49]. Key indicators of guideline adherence were developed in consultation with clinical and consumer experts (see Table 3). Two independent researchers will rate whether the practice reported by the clinician was inadequately (− 1), partially (or unclear; 0), or fully adherent (+ 1) to the relevant recommendation. In cases of disagreement, a third external clinical academic will be contracted to make a final decision. A follow-up phone interview with a random selection of client dyads each month up to 5 weeks after the consultation will be used to verify these reports, and 'agreement' between the client dyad and clinician will be assessed. Phone interviews will be conducted by the study team with both the person with dementia and their carer where possible, or just the carer where they are directly participating as a client of clinicians in the 'carer support' or the person with dementia is unable to participate in a phone call. People with dementia who attend the consultation alone (including those who live in long-term care) will not be contacted by phone. Interviews will gather perspectives from the dyad or carer about their recollection of the consultation and the extent of guideline adherence from their perspective. Clinician and client dyad data will be triangulated with field notes from QIC meetings, online message board participation, and other contact with the research team.

Process evaluation

Feasibility and acceptability among service providers of the QIC model for improving service provision for people with dementia and carers will be assessed by tracking the level of interest from potential implementation clinicians and following up with those who originally expressed interest but declined participation after receiving further information to identify key barriers. We will also track the consent rate of client dyads agree-ing to be contacted by phone following the consultation to determine acceptability of this method of data collection. In-depth interviews with implementation clinicians and their managers early in the project will establish expectations, perceived acceptability of the QIC, potential barriers to participation, current practice, organisational cultures, and previous experiences with innovation. Interviews will be repeated at the end of the 18 months to understand their experience of the QIC and the education package and factors that influenced their uptake. The interview questions were developed based on the Consolidated Framework for Implementation Research qualitative interview guide, developed to capture the many constructs known to be important to implementation success [50].

Interview data will be supplemented with the 23-item NoMAD survey instrument based on Normalisation Process Theory, completed by implementation clinicians to assess their perception of the integration of their quality improvement plan [51]. Practical knowledge of the implementation clinicians in quality improvement will be measured using vignettes and the Quality Improvement Knowledge Application Tool Revised [52]. Detailed field notes related to project acceptability, feasibility, and sustainability will be kept and analysed including email, online messaging, phone, and face-to-face contact between the implementation clinicians and research team.

Costs associated with establishing and running the QIC will be estimated. Total costs include costs of providing

Table 3 Project outcomes

Outcome domain	Details of measurement
Guideline adherence	
Exercise guideline adherence	Full adherence when: a) Clinician checklist explicitly references a discussion about current physical activity levels, and; b) Specific needs and barriers to physical activity are identified, and; c) Treatments/strategies recommended are clinical indicated based on needs/barriers, and; d) A written treatment plan for physical activity or exercise is provided to the person with dementia
Occupational therapy guideline adherence	Full adherence when: a) Home environment assessment has occurred (where applicable), and; b) Clinician checklist explicitly references identification of primary concern/s of person with dementia and carer, and; c) A written treatment plan to address needs of person with dementia and carer or give specific advice about suitable activities (that are tailored, of interest, and match capabilities) is provided
Carer support guideline adherence	Full adherence when: a) Clinician checklist explicitly references that the needs of the carer have been discussed during the consultation, and; b) Clinician checklist explicitly references clinically indicated provision of information about programs providing respite for the carer and/or other carer support services, and; c) A written treatment plan detailing key carer concerns and strategies to manage these is provided
Implementation	
Uptake	• Exposure: the extent to which clinicians use the materials and online training course • Initial use: initial changes in adherence to guideline recommendations
Sustainability	• Continued changes in adherence to guideline recommendation.
Feasibility	• Recruitment: attraction of implementation clinicians and participating organisations • Consent rate for people with dementia and their carers agreeing to be contacted for follow-up • Maintenance: involvement in the program and contribution to data collection • Withdrawals
Acceptability	• Interviews with implementation clinicians regarding participation in the program and the acceptability of the intervention and process • QIKAT-R tool: a three-item tool that identifies the skills and knowledge of the implementation clinicians in quality improvement (i.e. how well they can assess the need for change and identify appropriate strategies) • NOMAD tool: a validated method of exploring why clinicians change their practice and why they do not, and this is a key aim of process evaluation.
Fidelity	• Fidelity determined via checklists on the content of clinician-patient/carers interactions. Data captured via clinician self-report checklist and phone call surveys with patients and carers
Penetration	• Context: information about the sites and funding models, as well as the different types of clinicians (professional background, level of seniority, and type of role). • Reach: does the project reach a variety of different sites and people with dementia and carers
Costs	• Calculation of costs of providing the intervention (personnel, technology, stipends, development and distribution of educational materials) and in-kind contribution required for each site estimated using a 'bottom-up' micro-costing approach. • Willingness to pay questionnaire
Impact of involvement of people with dementia and carers at all levels of the project	• Impact of involvement of people with dementia and carers on intervention quality, success • Expectations and experiences of people with dementia and carers involved in the project
Service	
Safety	• Implementation clinicians will record any adverse events and discuss any unintended consequences
Client	
Satisfaction	• Amended version of the Patient Satisfaction Questionnaire Short-Form
Function/QOL	• DEMQOL assesses the quality of life of clients with dementia (exercise and OT groups only) • ZBI assesses the burden experienced by carers of people with dementia ('carer support' group only)

Abbreviations: *DEMQOL* Dementia Quality of Life Questionnaire, *MOOC* massive open online course, *NOMAD* questionnaire tool based on Normalisation Process Theory, *OT* occupational therapy, *QIKAT-R* Quality Improvement Knowledge Application Tool Revised, *QOL* quality of life, *ZBI* Zarit Burden Interview

the intervention (personnel, technology, stipends, and development and distribution of educational materials) and in-kind contribution required for each site estimated using a 'bottom-up' micro-costing approach. Costs will be estimated using administrative data and resource use questionnaires administered to key implementation site

personnel. The monetary benefits of adopting and implementing the QIC, from implementation clinicians' point of view, will be determined using contingent valuation techniques [53]. This technique allows for a monetary value to be placed on a good or service that is not yet available in the marketplace. The maximum amount of money that implementation clinicians would be willing to pay for the perceived benefits (buying price) of implementing the QIC will be estimated using their responses to a willingness to pay (WTP) questionnaire. As per best practice guidelines [53, 54], the WTP questionnaire will (a) identify the benefits that are likely to be realised from the QIC, (b) assess prior knowledge about QIC and attitudes toward it, and (c) establish respondents' WTP.

Finally, implementation clinicians and managers will complete an organisational network map of their implementation site to describe the structure of their services, relationships between staff members, and potential sources and supporters of innovation. These maps can be used to examine the complex interactions between structures and people that might not be captured in an interview [55]. Maps will also be used to examine the penetration of the project in terms of the variety of sites, funding models, professional backgrounds, level of seniority, and types of roles engaged with the QICs. Clinician checklists, interviews, client dyad phone calls, and field notes will be examined to assess whether participation improved the reach of services to previously underserviced clients.

Involvement of people with dementia and carers

We will assess the impact of involvement of people with dementia and carers in the study design, conduct, and reporting on the quality of the intervention (from the perspective of clinicians) during the process evaluation. The impact of involvement in research of people directly affected by the conditions being researched on research quality and outcomes is underreported [56], and knowledge of impact is important to establishing best practice and policy directives [45, 56]. Modelled on Dudley et al. [46], qualitative interview questions will be included to assess implementation clinicians' perspectives on the value of the contributions of people with dementia and carers, impact on clinicians' learning and quality improvement activities, and any negative impacts. Results will be reported per recommendations by Staniszewska et al. [57].

Service and client-level outcomes

During the client dyad phone interview up to 5 weeks after the consultation, both the person with dementia (where applicable) and their carer will be asked to rate their satisfaction with the consultation using an amended version of the Patient Satisfaction Questionnaire Short-Form (PSQ-18) [58]. Seven PSQ-18 items were selected because they were relevant to the types of consultations delivered by QIC clinicians. They assess satisfaction with the time spent with the health professional and their communication and interpersonal manner on a 5-point Likert scale (total score range 7–35). Items on the PSQ-18 have adequate internal consistency (all > 0.65) [58].

Adverse events that may reflect the safety of the QIC model will be reported by implementation clini- cians during monthly QIC meetings and in in-depth interviews. Client dyads will also be asked to reflect on the recommendations made during the consult- ation by the implementation clinician and report any negative consequences.

We will also assess the impact of the QIC model and guideline adherence on quality of life for the person with dementia (clients of clinicians in the exercise and occupational therapy QICs) or burden for the carer (clients of clinicians in the 'carer support' QIC) during this phone interview. These outcomes will be assessed a second time with a follow-up phone interview up to 7 weeks after the first, to identify sustained impact.

Quality of life will be assessed using the DEMQOL-Proxy [59], a 31-item questionnaire adminis- tered with the carer. The DEMQOL-Proxy asks the carer to report the extent to which the person with de- mentia has exhibited a variety of emotions and func- tional behaviours in the past week on a 4-point Likert scale, as well as a global quality of life item. Scores are summed to a total of 31–124, with higher scores indicat-ing better QOL. The DEMQOL-Proxy has demonstrated good discriminant validity and converges well with the non-dementia-specific EQ-5D-5L [60]. The shortened12-item version of the Zarit Burden Interview will be used to establish and monitor carer burden for client dyads of clinicians in the 'carer support' QIC. This short- ened version correlates well with the original 21- and 22-item versions [61] and has high internal consistency($\alpha = 0.87$) and discriminant validity (AUC = 0.99) [62]. Carers are asked to report the frequency of their feelingsof stress and burden associated with caring for the per-son with dementia on a 5-point Likert scale, summed to a maximum score of 48.

Analysis

Quantitative analysis

Guideline adherence and client outcomes over time will be evaluated with a segmented regression analysis using the PROC NLIN function of SAS version 13.2 [63]. This technique uses modelling to draw conclusions about an outcome (in this case guideline adherence) across distinct segments of time (in this case, before and after quality improvement implementation) [64]. Data points for the time series will be the extent of guideline

adherence each month over 18 months. Potential confounding variables will be fitted as covariates, and the most parsimonious model will be determined via stepwise backward elimination. The hypothesised outcomes of interest for this study are level and trend changes reflecting increasing adherence to the relevant guideline recommendation after the intervention (post-education quality improvement implementation) and over the 18 months. We will also calculate the counterfactual value and its proportionate distance from the actual estimated value [65]. The PROC AUTOREG function will be used to control for autocorrelation [63].

The sample size calculation for segmented regression analysis is related to the estimated number of time points at which data will be recorded. It is necessary to have enough time points before and after the intervention. This study incorporates 18 months of data collection (9 months pre-intervention and 9 months post-intervention) and is powered at 83% to detect a minimum 15% change in guideline adherence based on an estimated effect size of 1, autocorrelation of 0.3, and $\alpha = 0.05$ [66]. This change in guideline adherence was used for power analysis based on literature suggesting an average of 10–15% improvement in adherence from traditional guideline dissemination activities [7]. Per recommendations from Wagner et al. [65], clinicians will submit up to ten checklists for each data point in the time series (for a total of up to 300 checklists each month) to achieve an acceptable level of variability of the estimate at each time point. The study design therefore meets the criteria for a robust interrupted time-series [67].

Feasibility data elicited from field notes and records will be provided descriptively so that it is possible to determine how many people expressed interest, how many formally participated, and how many people withdrew (and reasons for withdrawal). We will present information about the characteristics of the clinicians and their workplaces. We will also describe engagement and exposure to the intervention through presentation of time spent participating in the online training and participation in other components of the intervention such as number of contributions to the online community of practice and completion of the implementation plan. Data from the NOMAD and QIKAT tools regarding implementation readiness and proficiency will be presented descriptively (with means and standard deviations where appropriate).

The mixed sources of data will be used to explore factors underlying successful implementation. The percentage increase in average guideline adherence during the 9-month pre- and post-intervention periods will be calculated for individual clinicians, to represent implementation success. *T* or correlation tests (where appropriate) will be used to identify the impact of workplace characteristics, time engaged in the intervention, and NOMAD/QIKAT scores on implementation success. Qualitative data will be used to explore and contextualise the findings.

A cost-benefit analysis will be used for the economic evaluation [54]. The costs associated with establishing and running the QIC will be compared to the monetary benefits of implementing this strategy. The QIC will be considered value for money (i.e. cost-beneficial) if benefits exceed costs. Benefits will be considered from the perspective of implementation clinicians' point of view. The return on investment will also be estimated as the ratio of benefits divided by total costs of the intervention (i.e. the benefit-cost ratio) [54].

Qualitative analysis

Qualitative interview and field note data will be transcribed verbatim and entered into QSR NVivo version 10 [68], and two people will code the data. A combination of inductive and deductive thematic analysis will be used to identify themes within the data related to implementation of quality improvement programs, organisational culture and innovation, evaluation of the QIC model, and key barriers and facilitators to guideline adherence [69] The structure of the interview (based around questions from the Consolidated Framework for Implementation Research guide) will assist with linking the findings with theoretical models though we will not restrict our themes to those described in the model.

Discussion

This implementation research project seeks to examine the efficacy of establishing QICs to improve adherence to key evidence-based clinical guidelines for dementia care. To our knowledge, this is the first study to implement QICs to improve the quality of non-pharmacological care programs for people with dementia and carers living in the community. Dementia service provision is highly complex and is largely dependent on the knowledge, skills, and resources available to the health professional. Quality improvement collaboratives are an innovative method of implementation science that address known barriers to adherence to evidence-based clinical guidelines, including a lack of perceived skills in quality improvement and insufficient clinical support [3, 10].

This study benefits from several strengths. The intervention is low-cost and 'light-touch' in that it centres practising clinicians as experts in their own service and supports them to become leaders in effecting change. The mechanisms for embedding change are pragmatic and draw on theories of implementation and quality improvement methodology. The implementation sites and clinicians are diverse, and thus, the project is not susceptible to changes in the policy or funding environment. Time series designs are the strongest quasi-experimental

designs for estimating effects of an intervention where randomisation is not possible. Segmented regression analysis of time series data can provide insights into the dynamics of change while controlling for prior trends in the outcome [65].

Despite these strengths, the approach for this study has some important limitations. First, the inclusion of a control group was considered unethical because clients would be deprived of best-practice care, and engaging clinicians to provide data without any intervention would be difficult. Effects occurring at the same time but separate to the intervention will notbe separated and controlled for, threatening validity. Nonetheless, even without a control group, segmented regression analysis makes multiple assessments of the outcome and therefore addresses important threats to internal validity. Second, the primary outcome measure (guideline adherence) will be self-reported by the implementation clinicians and is therefore vulnerable to a responding bias. The triangulation of data from client dyad phone calls will help to address this problem, and adherence (according to the criteria described in Table 3) will be independently judged by two members of the research team and an external third party where needed based on clinician reported 'snapshots' of the consultation. Nonetheless, some responding bias may still exist. Third, a selection bias may be present in the participating implementation clinicians. The 'opt-in' approach to recruitment will likely lead to a group of passionate and engaged clinicians who may not represent the wider popula-tion of clinicians working with people with dementiaand their carers. Finally, there are some limitations associated with segmented regression analysis. These models assume a linear trend in the outcome within each segment, but this may not hold over longer intervals [65]. Segmented regression analysis also does not allow for statistical controlling of individual-level covariates. However, these covariates will only become confounding where they both predict the outcome and change in relationship to the time of the intervention. No such covariates are anticipated.

Clinical guidelines aim to promote evidence-based practice, improve patient outcomes, and allow more efficient use of resources [70]. However, dissemin- ation of guidelines alone is insufficient to effect change in clinical practice. This study will identify the elements of a multifaceted implementation strat- egy that contributed to improved guideline adher- ence, client outcomes, and clinician skills. Outcomes will inform large-scale strategies to promote profes- sional and organisational innovation and effect sus- tainable improvements to the quality of dementia care more widely.

Abbreviations
MOOC: Massive open online course; PDSA: Plan-do-study-act; PSQ-18: Patient Satisfaction Questionnaire Short-Form; QIC: Quality improvement collaborative; WTP: Willingness to pay; ZBI: Zarit Burden Interview

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Authors' contributions
KL conceptualised and designed the study, obtained the funding, and assisted with the drafting, reviewing, and editing the manuscript. MCa coordinates the Agents of Change project and drafted, reviewed, and edited the manuscript. MCr, SK, AF, IDC, CW, JT, KH, and BK provided theoretical support to the project and assisted with manuscript review and editing. LDLP and GR assisted with the project management and contributed to the manuscript drafting, reviewing, and editing. All authors read and approved the final manuscript.

Ethics approval and consent to participate
Ethical approval for this study has been granted by the Southern Adelaide Clinical Human Research Ethics Committee (HREC/17/SAC/88).

Consent for publication
No person's individual data are contained in this manuscript.

Competing interests
Monica Cations has been employed in the past 5 years to assist with data collection for Alzheimer's disease drug trials funded by Janssen and Merck. Maria Crotty receives funding from Novartis for trials of hip fracture involving treatments for sarcopenia. Ian Cameron has received funding for lecturing from Amgen. AF, SK, CW, JT, BK, KH, GR, LDLP, and KL have no competing interests to declare.

Publisher's Note

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Appendix 2a)

Office for Research

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Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia

SA Health
Southern Adelaide Local Health Network

Final Approval for Ethics Application

21 August 2017

Dr Kate Laver

Dear Dr Kate Laver

OFR Number: 62.17

HREC reference number: HREC/17/SAC/88

Project title: A pilot project for 'Agents of Change': Improving post diagnosis care for people with dementia and their carers through the establishment of a National Quality Collaborative to implement guideline recommendations

Chief Investigator: Dr Kate Laver

Ethics Approval Period: 16 August 2017 - 16 August 2020

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188) have reviewed and provided approval for this application which appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research (2007).*

You are reminded that this letter constitutes **Ethics** approval only. **Ethics approval is one aspect of the research governance process.**

You must not commence this research project at any SA Health sites listed in the application until a Site Specific Assessment (SSA), or Access Request for data or tissue form, has been approved by the Chief Executive or delegate of each site.

The below documents have been reviewed and approved:

- National Ethics Application Form dated 31st March 2017
- Participant Information Sheet/Consent Form - Client, v3 dated 31 July 2017
- Participant Information Sheet/Consent Form - Clinician v4 dated 31 July 2017
- Participant Information Sheet/Consent Form - Carer, v3 dated 31 July 2017
- Flyer NQC Final, v1 dated 20 April 2017
- Letter from Head of Department, Nadja Hartzenberg dated 10 March 2017
- Overview training module in Implementation for implementation clinicians, v1 dated 20 April 2017
- NQC Data Collection Form - clinician, v1 dated 30 March 2017
- NQC Data Collection Form - patient and carer, v1 dated 30 March 2017

Terms And Conditions Of Ethics Approval:

As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below and with the *National Statement chapter 5.5.*

Final ethics approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. The approval only covers the science and ethics component of the application. A SSA will need to be submitted and authorised before this research project can commence at any of the approved sites identified in the application.
2. If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
3. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007).
4. To immediately report to SAC HREC anything that may change the ethics or scientific integrity of the project.
5. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.
6. Submit an annual report on each anniversary of the date of final approval and in the correct template from the SAC HREC website.
7. Confidentiality of research participants MUST be maintained at all times.
8. A copy of the signed consent form must be given to the participant unless the project is an audit.
9. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
10. All requests for access to medical records at any SALHN site must be accompanied by this approval email.
11. To regularly review the SAC HREC website and comply with all submission requirements, as they change from time to time.
12. Once your research project has concluded, any new product/procedure/intervention cannot be conducted in the SALHN as standard practice without the approval of the SALHN New Medical Products and Standardisation Committee or the SALHN New Health Technology and Clinical Practice Innovation Committee (as applicable). Please refer to the relevant committee link on the SALHN intranet for further information.

For any queries about this matter, please contact the Office for Research on (08) 8204 7433 or via email to Health.SALHNOfficeforResearch@sa.gov.au.

Yours sincerely

A/Professor Bernadette Richards
Chair, SAC HREC

Appendix 2b)

From: Human Research Ethics
To: Lenore de la Perrelle; Kate Laver; Monica Cations
Subject: 8057 SBREC Final approval notice (5 July 2018)
Date: Thursday, 5 July 2018 14:28:06

Dear Lenore,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.:	**8057**
Project Title:	Valuing Expert Experience: Involving people living with dementia, their family carers and members of the community in a translational research project to implement dementia care guidelines
Principal Researcher:	Ms Lenore de la Perrelle
Email:	Lenore.delaperrelle@flinders.edu.au
Approval Date:	5 July 2018
Ethics Approval Expiry Date:	**30 January 2022**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information

regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **5 July** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **5 July 2019** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-

3116 or 8201-7938 human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Wendy

On behalf of Andrea Mather

Ms Andrea Mather (formerly Fiegert) **and Ms Rae Tyler**
Ethics Officers and Executive Officers, Social and Behavioural Research Ethics Committee

Ms Andrea Mather | Monday - Friday	T: +61 8201-3116 | E: human.researchethics@flinders.edu.au
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SBREC Website	Social and Behavioural Research Ethics Committee (SBREC)

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Appendix 3

MIXED METHODS APPRAISAL TOOL (MMAT) VERSION 2018

User guide

Prepared by
Quan Nha HONG[a], Pierre PLUYE[a,], Sergi FÀBREGUES[b], Gillian BARTLETT[a], Felicity BOARDMAN[c], Margaret CARGO[d], Pierre DAGENAIS[e], Marie-Pierre GAGNON[f], Frances GRIFFITHS[c], Belinda NICOLAU[a], Alicia O'CATHAIN[g], Marie-Claude ROUSSEAU[h], & Isabelle VEDEL[a]

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Department of Family Medicine | Département de médecine de famille
Academic excellence and innovation in care, teaching and research
Innovation et excellence académique dans les soins, l'enseignement et la recherche

Last update: August 1st, 2018

What is the MMAT?

The MMAT is a critical appraisal tool that is designed for the appraisal stage of systematic mixed studies reviews, i.e., reviews that include qualitative, quantitative and mixed methods studies. It permits to appraise the methodological quality of five categories to studies: qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed methods studies.

How to cite this document?

Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, Gagnon M-P, Griffiths F, Nicolau B, O'Cathain A, Rousseau M-C, Vedel I. Mixed Methods Appraisal Tool (MMAT), version 2018. Registration of Copyright (#1148552), Canadian Intellectual Property Office, Industry Canada.

How to use the MMAT?

This document comprises two parts: checklist (Part I) and explanation of the criteria(Part II).

1. Respond to the two screening questions. Responding 'No' or 'Can't tell' to one or both questions might indicate that the paper is not an empirical study, and thuscannot be appraised using the MMAT. MMAT users might decide not to use these questions, especially if the selection criteria of their review are limited to empirical studies.
2. For each included study, choose the appropriate category of studies to appraise. Lookat the description of the methods used in the included studies. If needed, use the algorithm at the end of this document.
3. Rate the criteria of the chosen category. For example, if the paper is a qualitative study, only rate the five criteria in the qualitative category. The 'Can't tell' response category means that the paper do not report appropriate information to answer 'Yes' or 'No', or that report unclear information related to the criterion. Rating 'Can't tell' could lead to look for companion papers or contact authors to ask more information or clarification when needed. In Part II of this document, indicators are added for some criteria. The list is not exhaustive and not all indicators are necessary. You should agree among your team which ones are important to consider for your field and apply them uniformly across all included studies from the same category.

How to score?

It is discouraged to calculate an overall score from the ratings of each criterion. Instead,it is advised to provide a more detailed presentation of the ratings of each criterion to better inform the quality of the included studies. This may lead to perform a sensitivity analysis (i.e., to consider the quality of studies by contrasting their results). Excluding studies with low methodological quality is usually discouraged.

What the MMAT can be used for?

The MMAT can be used to appraise the quality of empirical studies, i.e., primaryresearch based on experiment, observation or simulation (Abbott, 1998; Porta et al., 2014). It cannot be used for non-empirical papers such as review and theoretical papers. Also, the MMAT allows the appraisal of most common types of study methodologiesand designs. However, some specific designs such as economic and diagnostic accuracy studies cannot be assessed with the MMAT. Other critical appraisal tools might be relevant for these designs.

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	Y			Ch ! and 4
	S2. Do the collected data allow to address the research questions?	Y			Ch 1, 4 5, 6, 7,
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				8, 9.
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	Y			rationale in
	1.2. Are the qualitative data collection methods adequate to address the research question?	Y			methodology C 4
	1.3. Are the findings adequately derived from the data?	Y			
	1.4. Is the interpretation of results sufficiently substantiated by data?	Y			Results intehrated
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	Y			in Ch 5,6, 7,
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?	Y			Purposive
	4.2. Is the sample representative of the target population?		Y		
	4.3. Are the measurements appropriate?	Y			
	4.4. Is the risk of nonresponse bias low?	Y			
	4.5. Is the statistical analysis appropriate to answer the research question?	Y			Descriptive
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	Y			Ch 4
	5.2. Are the different components of the study effectively integrated to answer the research question?	Y			Integrated in C h 5, 6,
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?		Y		7, 9
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Y			Ch 5,6
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods	Y			**Study design 5-1 +3**

Part II: Explanations

1. Qualitative studies	Methodological quality criteria
"Qualitative research is an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem" (Creswell, 2013b, p. 3). Common qualitative research approaches include (this list if not exhaustive): **Ethnography** The aim of the study is to describe and interpret the shared cultural behaviour of a group of individuals. **Phenomenology** The study focuses on the subjective experiences and interpretations of a phenomenon encountered by individuals. **Narrative research** The study analyzes life experiences of an individual or a group. **Grounded theory** Generation of theory from data in the process of conducting research (data collection occurs first). **Case study** In-depth exploration and/or explanation of issues intrinsic to a particular case. A case can be anything from a decision-making process, to a person, an organization, or a country. **Qualitative description** There is no specific methodology, but a qualitative data collection and analysis, e.g., in-depth interviews or focus groups, and hybrid thematic analysis (inductive and deductive). Key references: Creswell (2013a); Sandelowski (2010); Schwandt (2015)	1.1. Is the qualitative approach appropriate to answer the research question? Explanations The qualitative approach used in a study (see non-exhaustive list on the left side of this table) should be appropriate for the research question and problem. For example, the use of a grounded theory approach should address the development of a theory and ethnography should study human cultures and societies. This criterion was considered important to add in the MMAT since there is only one category of criteria for qualitative studies (compared to three for quantitative studies).
	1.2. Are the qualitative data collection methods adequate to address the research question? Explanations This criterion is related to data collection method, including data sources (e.g., archives, documents), used to address the research question. To judge this criterion, consider whether the method of data collection (e.g., in depth interviews and/or group interviews, and/or observations) and the form of the data (e.g., tape recording, video material, diary, photo, and/or field notes) are adequate. Also, clear justifications are needed when data collection methods are modified during the study.
	1.3. Are the findings adequately derived from the data? Explanations This criterion is related to the data analysis used. Several data analysis methods have been developed and their use depends on the research question and qualitative approach. For example, open, axial and selective coding is often associated with grounded theory, and within- and cross-case analysis is often seen in case study.
	1.4. Is the interpretation of results sufficiently substantiated by data? Explanations The interpretation of results should be supported by the data collected. For example, the quotes provided to justify the themes should be adequate.
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation? Explanations There should be clear links between data sources, collection, analysis and interpretation.

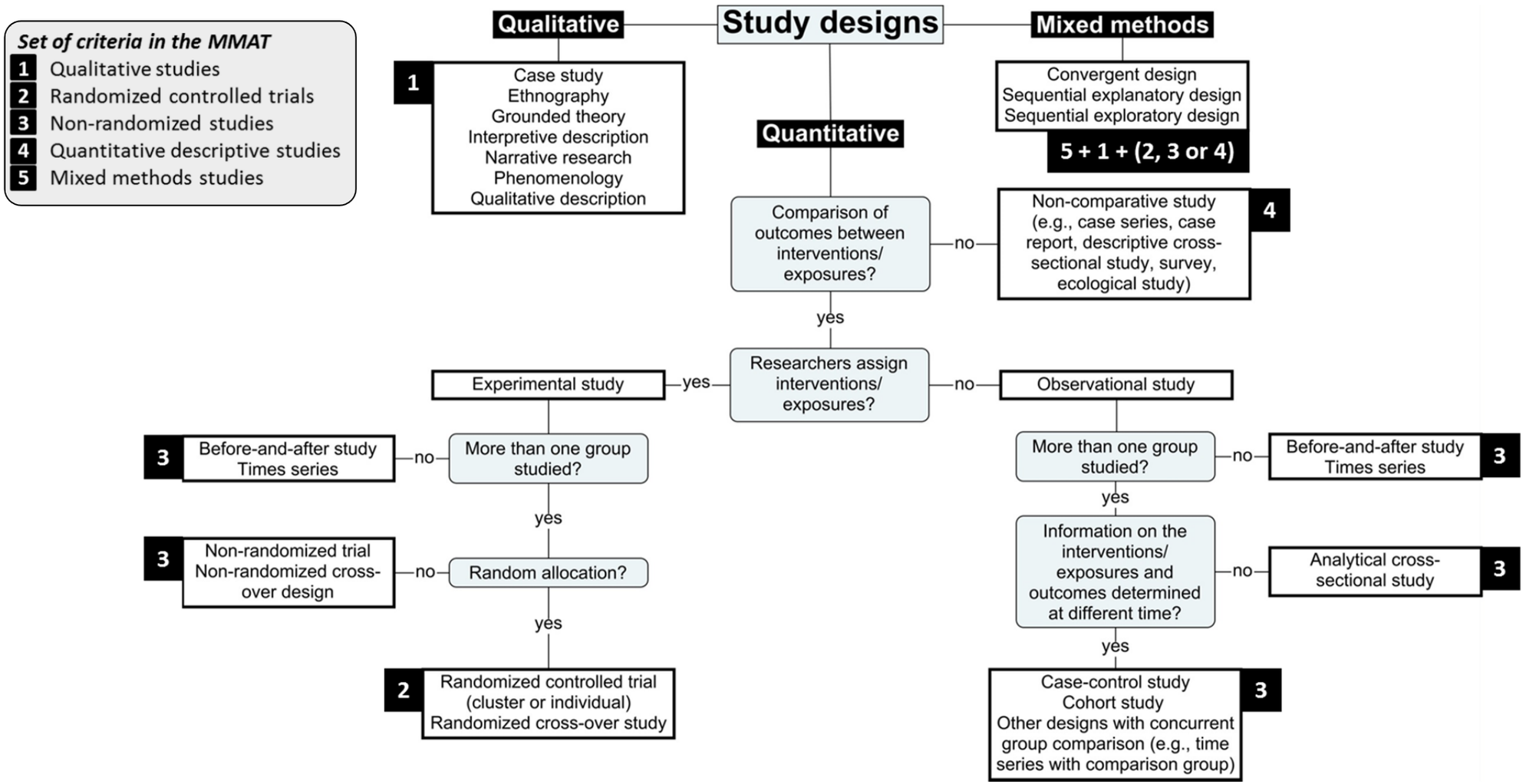
2. Quantitative randomized controlled trials	Methodological quality criteria
Randomized controlled clinical trial: A clinical study in which individual participants are allocated to intervention or control groups by randomization (intervention assigned by researchers). Key references: Higgins and Green (2008); Higgins et al. (2016); Oxford Centre for Evidence-based Medicine (2016); Porta et al. (2014)	2.1. Is randomization appropriately performed? Explanations In a randomized controlled trial, the allocation of a participant (or a data collection unit, e.g., a school) into the intervention or control group is based solely on chance. Researchers should describe how the randomization schedule was generated. A simple statement such as 'we randomly allocated' or 'using a randomized design' is insufficient to judge if randomization was appropriately performed. Also, assignment that is predictable such as using odd and even record numbers or dates is not appropriate. At minimum, a simple allocation (or unrestricted allocation) should be performed by following a predetermined plan/sequence. It is usually achieved by referring to a published list of random numbers, or to a list of random assignments generated by a computer. Also, restricted allocation can be performed such as blocked randomization (to ensure particular allocation ratios to the intervention groups), stratified randomization (randomization performed separately within strata), or minimization (to make small groups closely similar with respect to several characteristics). Another important characteristic to judge if randomization was appropriately performed is allocation concealment that protects assignment sequence until allocation. Researchers and participants should be unaware of the assignment sequence up to the point of allocation. Several strategies can be used to ensure allocation concealment such relying on a central randomization by a third party, or the use of sequentially numbered, opaque, sealed envelopes (Higgins et al., 2016).
	2.2. Are the groups comparable at baseline? Explanations Baseline imbalance between groups suggests that there are problems with the randomization. Indicators from baseline imbalance include: "(1) unusually large differences between intervention group sizes; (2) a substantial excess in statistically significant differences in baseline characteristics than would be expected by chance alone; (3) imbalance in key prognostic factors (or baseline measures of outcome variables) that are unlikely to be due to chance; (4) excessive similarity in baseline characteristics that is not compatible with chance; (5) surprising absence of one or more key characteristics that would be expected to be reported" (Higgins et al., 2016, p. 10).
	2.3. Are there complete outcome data? Explanations Almost all the participants contributed to almost all measures. There is no absolute and standard cut-off value for acceptable complete outcome data. Agree among your team what is considered complete outcome data in your field and apply this uniformly across all the included studies. For instance, in the literature, acceptable complete data value ranged from 80% (Thomas et al., 2004; Zaza et al., 2000) to 95% (Higgins et al., 2016). Similarly, different acceptable withdrawal/dropouts rates have been suggested: 5% (de Vet et al., 1997; MacLehose et al., 2000), 20% (Sindhu et al., 1997; Van Tulder et al., 2003) and 30% for a follow-up of more than one year (Viswanathan and Berkman, 2012).
	2.4. Are outcome assessors blinded to the intervention provided? Explanations Outcome assessors should be unaware of who is receiving which interventions. The assessors can be the participants if using participant reported outcome (e.g., pain), the intervention provider (e.g., clinical exam), or other persons not involved in the intervention (Higgins et al., 2016).
	2.5 Did the participants adhere to the assigned intervention? Explanations To judge this criterion, consider the proportion of participants who continued with their assigned intervention throughout follow-up. "Lack of adherence includes imperfect compliance, cessation of intervention, crossovers to the comparator intervention and switches to another active intervention." (Higgins et al., 2016, p. 25).

3. Quantitative non-randomized studies	Methodological quality criteria
Non-randomized studies are defined as any quantitative studies estimating the effectiveness of an intervention or studying other exposures that do not use randomization to allocate units to comparison groups (Higgins and Green, 2008). Common designs include (this list if not exhaustive): **Non-randomized controlled trials** The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups. **Cohort study** Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal). **Case-control study** Cases, e.g., patients, associated with a certain outcome are selected, alongside a corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective). **Cross-sectional analytic study** At one particular time, the relationship between health-related characteristics (outcome) and other factors (intervention/exposure) is examined. E.g., the frequency of outcomes is compared in different population subgroups according to the presence/absence (or level) of the intervention/exposure. Key references for non-randomized studies: Higgins and Green (2008); Porta et al. (2014); Sterne et al. (2016); Wells et al. (2000)	3.1. Are the participants representative of the target population? Explanations Indicators of representativeness include: clear description of the target population and of the sample (inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate, and any attempts to achieve a sample of participants that represents the target population.
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? Explanations Indicators of appropriate measurements include: the variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the intervention/exposure and outcome of interest are used, or variables are measured using 'gold standard'.
	3.3. Are there complete outcome data? Explanations Almost all the participants contributed to almost all measures. There is no absolute and standard cut-off value for acceptable complete outcome data. Agree among your team what is considered complete outcome data in your field (and based on the targeted journal) and apply this uniformly across all the included studies. For example, in the literature, acceptable complete data value ranged from 80% (Thomas et al., 2004; Zaza et al., 2000) to 95% (Higgins et al., 2016). Similarly, different acceptable withdrawal/dropouts rates have been suggested: 5% (de Vet et al., 1997; MacLehose et al., 2000), 20% (Sindhu et al., 1997; Van Tulder et al., 2003) and 30% for follow-up of more than one year (Viswanathan and Berkman, 2012).
	3.4. Are the confounders accounted for in the design and analysis? Explanations Confounders are factors that predict both the outcome of interest and the intervention received/exposure at baseline. They can distort the interpretation of findings and need to be considered in the design and analysis of a non-randomized study. Confounding bias is low if there is no confounding expected, or appropriate methods to control for confounders are used (such as stratification, regression, matching, standardization, and inverse probability weighting).
	3.5 During the study period, is the intervention administered (or exposure occurred) as intended? Explanations For intervention studies, consider whether the participants were treated in a way that is consistent with the planned intervention. Since the intervention is assigned by researchers, consider whether there was a presence of contamination (e.g., the control group may be indirectly exposed to the intervention) or whether unplanned co-interventions were present in one group (Sterne et al., 2016). For observational studies, consider whether changes occurred in the exposure status among the participants. If yes, check if these changes are likely to influence the outcome of interest, were adjusted for, or whether unplanned co-exposures were present in one group (Morgan et al., 2017).

4. Quantitative descriptive studies	Methodological quality criteria
Quantitative descriptive studies are "concerned with and designed only to describe the existing distribution of variables without much regard to causal relationships or other hypotheses" (Porta et al., 2014, p. 72). They are used to monitoring the population, planning, and generating hypothesis (Grimes and Schulz, 2002). Common designs include the following single-group studies (this list if not exhaustive): **Incidence or prevalence study without comparison group** In a defined population at one particular time, what is happening in a population, e.g., frequencies of factors (importance of problems), is described (portrayed). **Survey** "Research method by which information is gathered by asking people questions on a specific topic and the data collection procedure is standardized and well defined." (Bennett et al., 2011, p. 3). **Case series** A collection of individuals with similar characteristics are used to describe an outcome. **Case report** An individual or a group with a unique/unusual outcome is described in detail. Key references: Critical Appraisal Skills Programme (2017); Draugalis et al. (2008)	4.1. Is the sampling strategy relevant to address the research question? Explanations Sampling strategy refers to the way the sample was selected. There are two main categories of sampling strategies: probability sampling (involve random selection) and non-probability sampling. Depending on the research question, probability sampling might be preferable. Non-probability sampling does not provide equal chance of being selected. To judge this criterion, consider whether the source of sample is relevant to the target population; a clear justification of the sample frame used is provided; or the sampling procedure is adequate.
	4.2. Is the sample representative of the target population? Explanations There should be a match between respondents and the target population. Indicators of representativeness include: clear description of the target population and of the sample (such as respective sizes and inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate, and any attempts to achieve a sample of participants that represents the target population.
	4.3. Are the measurements appropriate? Explanations Indicators of appropriate measurements include: the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the outcome of interest are used, variables are measured using 'gold standard', or questionnaires are pre-tested prior to data collection.
	4.4. Is the risk of nonresponse bias low? Explanations Nonresponse bias consists of "an error of nonobservation reflecting an unsuccessful attempt to obtain the desired information from an eligible unit." (Federal Committee on Statistical Methodology, 2001, p. 6). To judge this criterion, consider whether the respondents and non-respondents are different on the variable of interest. This information might not always be reported in a paper. Some indicators of low nonresponse bias can be considered such as a low nonresponse rate, reasons for nonresponse (e.g., noncontacts vs. refusals), and statistical compensation for nonresponse (e.g., imputation). The nonresponse bias is might not be pertinent for case series and case report. This criterion could be adapted. For instance, complete data on the cases might be important to consider in these designs.
	4.5. Is the statistical analysis appropriate to answer the research question? Explanations The statistical analyses used should be clearly stated and justified in order to judge if they are appropriate for the design and research question, and if any problems with data analysis limited the interpretation of the results.

5. Mixed methods studies	Methodological quality criteria
Mixed methods (MM) research involves combining qualitative (QUAL) and quantitative (QUAN) methods. In this tool, to be considered MM, studies have to meet the following criteria (Creswell and Plano Clark, 2017): (a) at least one QUAL method and one QUAN method are combined; (b) each method is used rigorously in accordance to the generally accepted criteria in the area (or tradition) of research invoked; and (c) the combination of the methods is carried out at the minimum through a MM design (defined *a priori*, or emerging) and the integration of the QUAL and QUAN phases, results, and data. Common designs include (this list if not exhaustive): **Convergent design** The QUAL and QUAN components are usually (but not necessarily) concomitant. The purpose is to examine the same phenomenon by interpreting QUAL and QUAN results (bringing data analysis together at the interpretation stage), or by integrating QUAL and QUAN datasets (e.g., data on same cases), or by transforming data (e.g., quantization of qualitative data). **Sequential explanatory design** Results of the phase 1 - QUAN component inform the phase 2 - QUAL component. The purpose is to explain QUAN results using QUAL findings. E.g., the QUAN results guide the selection of QUAL data sources and data collection, and the QUAL findings contribute to the interpretation of QUAN results. **Sequential exploratory design** Results of the phase 1 - QUAL component inform the phase 2 - QUAN component. The purpose is to explore, develop and test an instrument (or taxonomy), or a conceptual framework (or theoretical model). E.g., the QUAL findings inform the QUAN data collection, and the QUAN results allow a statistical generalization of the QUAL findings. Key references: Creswell et al. (2011); Creswell and Plano Clark, (2017); O'Cathain (2010)	5.1. Is there an adequate rationale for using a mixed methods design to address the research question? **Yes Convergent design used** Explanations **Use of mixed methods in this study included QUAL, and QUAN components to provide a complete picture of how and why clinicians built skills and knowledge in the collaborative. the assessment of costs was also compared to QUAL and quan data to provide information for decision makers on the resources required to offer the collaboratives**
	2. Are the different components of the study effectively integrated to answer the research question? **Yes** planations **QUAL and QUAN data were collected at pre and post phases analysed separately then brought together to confirm, refute or refine the program theory developed and presented as joint display. Cost data was gathered during the evaluation and analysed post intervention. costs were compared to contributions in Ch 7 and costs were compared to mechanisms in program theory in ch 9 to present a full picture od the investment required**
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? **Yes** Explanations **f. indings were interpreted by testing results against program theory developed for the evalustion to see which data confirmed, refuted or refined the program theory. in this evaluation the QUAN data did not confirm the QUAL data fully and additional analysis was able to identify reasons. this enabled a confirmation of the porgram theory, refinement of aspects and review of the procedures for use of the QUAN survey,**
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? **Yes** Explanations **Differences between survey data and QUAL data identified and explained by reference to survey responses, how it was conducted and how it was interpreted. while not contradicting QUAL results divergences were reconciled**
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? **Yes** Explanations The quality of the qualitative and quantitative components should be individually appraised to ensure that no important threats to trustworthiness are present. To appraise 5.5, use criteria for the qualitative component (1.1 to 1.5), and the appropriate criteria for the quantitative component (2.1 to 2.5, or 3.1 to 3.5, or 4.1 to 4.5). The quality of both components should be high for the mixed methods study to be considered of good quality. The premise is that the overall quality of a mixed methods study cannot exceed the quality of its weakest component. For example, if the quantitative component is rated high quality and the qualitative component is rated low quality, the overall rating for this criterion will be of low quality.

Algorithm for selecting the study categories to rate in the MMAT*



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*Adapted from National Institute for Health Care Excellence. (2012). *Methods for the development of nice public health guidance*. London: National Institute for Health and Care Excellence; and Scottish Intercollegiate Guidelines Network. (2017). *Algorithm for classifying study design for questions of effectiveness*. Retrieved December 1, 2017, from http://www.sign.ac.uk/assets/study_design.pdf.

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Appendix 4

Components of the Agents of Change Quality Improvement Collaborativeintervention.

1. Motivated senior clinicians volunteered to join the quality improvement collaborative to improve dementia care
2. Manager approval was obtained for participation
3. Base line data on usual practice was collected prior to commencement and monthly during the program
4. Face to face meetings provide connections and information for shared understanding
5. Clinical guidelines for dementia care provided the evidence base for the interventions
6. Online learning modules developed with input from people with dementia, care partners, and clinical experts, offered opportunities to consider different perspectives and learn in stages.
7. Staged online learning over time allowed clinicians flexibility and reduced time away from work and home
8. Interactive components of modules offered opportunities to connect with other participants
9. Regular communication between researchers and participants provided information, encouragement and problem solving
10. Feature articles on clinicians were included in newsletters to share experiences
11. Audit and feedback reports on level of adherence to guidelines provided to each clinician to identify gaps
12. Incentives provided during the program and continuing professional development (CPD) certification or funding to present at a conference on successful completion
13. Online collaborative meetings were hosted by researchers to offer discussion and sharing of the process
14. Opportunity to co-author a publication on current practice was offered by researchers
15. Advice and coaching offered by clinical experts and researchers
16. Feedback on implementation plans provided by clinical experts, implementation experts and experts by experience of dementia
17. Reflection on the process and achievements, provided online and in evaluation interviews
18. Certificates of completion and CPD accreditation provided
19. Information on results, publications and reports provided to participants.

Appendix 5

RAMESES II List of Items to be included in reporting realist evaluations Wong *et al.* 2016 RAMESES II, DOI 10.1186/s12916-016-0643-1

Title:	**Collaboration, Context, and Costs: a realist-informed process evaluation**	**Reported in Document**	**Page in document**
1. Identify document as realist evaluation	Identified as realist-informed	Title	p. i
2. Abstract	A realist-informed process evaluation, using mixed methods, examined the experience of clinicians and experts-by-experience of dementia involved in the trial, to identify how and why the strategy worked or not. A cost-benefit-analysis identified the resources required to improve practice and a business case for future use of the strategy		p. xi
Introduction			
3. Rationale for evaluation	The aim of this research is to examine the feasibility and acceptability of the trial of a quality improvement collaborative strategy to improve adherence by clinicians to clinical guidelines for dementia. The objective is to evaluate the process of a quality improvement collaborative to understand how the implementation strategy works and to identify contextual influences and mechanisms of change that build knowledge and skills in clinicians to improve dementia care.		p. 21
4. Program theory	Developed for Study 1 and study 2	Yes at Tables 6 and 7	pp.81-82
5. Evaluation questions	1) How, why and in what circumstances could a quality improvement collaborative build knowledge, skills and acceptance of clinicians who were participants? (Chapters 5 and 6). 2) What was the value of involving people with dementia and caregivers as expert advisors in the quality improvement collaborative? (Chapter 7).		p. 21
6. Ethical approval	Ethical approval for the Agents of Change study was granted by the Southern Adelaide Clinical Human Research Ethics Committee (HREC/17/SAC/88). The ethical approval for the Valuing Expert Experience study to evaluate of the involvement of experts-by-experience of dementia was granted by the Social and Behavioural Research Ethics Committee of Flinders University #8057.		p.74
Methods			
7. Rationale for using realist evaluation	What works, how, in what circumstances and at what cost? are questions designed to understand and explain the process, not just describe outcomes of		p.63

	a program. These questions can advance the evidence for more successful implementation methods. A realist-informed process evaluation was chosen for this study as a theory-based approach to evaluation of a trial. This process evaluation is situated within a larger quasi-experimental design interrupted time series trial, Agents of Change (6). The evaluation of that trial included a focus on outcomes of fidelity, sustainability, and penetration (201). This research seeks to understand how the quality improvement collaborative trial built knowledge and skills of clinicians, the value of the contribution of experts-by-experience of dementia and evaluate its costs. It focuses on outcomes of feasibility, acceptability, and cost. A realist-informed approach will allow an adaption of realist evaluation methods to suit the focus of the current study and contribute to the larger research trial. It draws on an exemplar of a realist informed process evaluation embedded in a randomised controlled trial (145)		
8. Environment surrounding evaluation	Context and settings described	Yes	pp 23-24
9. Describe the programme evaluated	Agents of Change Trial using a quality improvement collaborative strategy	Yes and the protocol for the trial in the appendix	pp25 and Appendix 1
10. Describe and justify the evaluation design	This evaluation followed available guidance on process evaluation (130, 239) and realist evaluation (26) when applied in complex implementation (240) and knowledge translation interventions (139). The process evaluation was designed in two parts to answer two research questions: Study 1: How and why the quality improvement collaboratives improved skills, knowledge, and acceptance of quality improvement among participating clinicians Study 2: What value was added to the Agents of Change trial by the involvement of experts-by-experience of dementia in the research strategy and as advisors		pp. 75
11. Data collection methods	Semi-structured interviews, surveys pre-and post-intervention, document analysis	Yes	pp. 79-89
12. Recruitment process and sampling strategy	The clinicians were recruited to participate in the quality improvement collaborative via	Yes	pp.77-78

	targeted advertising and an opt-in approach A purposeful sampling method was used for the Agents of Change trial The second group of participants were experts-by-experience of dementia (both people living with dementia (*n*=3) and caregivers (*n*=5) who acted as expert advisors to the researchers and clinicians throughout the research (6, 247). They were recruited through researcher networks, general advertising, to specific roles within the Agents of Change research trial.		
13. Data Analysis	Detailed description of qualitative and quantitative data analysis and integration methods	Yes	pp.92-95
Results			
14. Details of participants	Study I pre and post-intervention evaluation Ch 5 and 6 Study 2 value added by experts by experience of dementia Ch 7	Yes Yes Yes	pp. 98-99 pp. 124-125 pp 160
15. Main findings	Study 1 Ch 5 and Ch 6 Study 2 Ch 7	Yes Yes Yes	pp 117-119 pp 125-147 pp.160-176
Discussion			
16. Summary of findings	Study 1 Ch 5 and Ch 6 Study 2 Ch 7	Yes Yes Yes	pp.119-120 pp. 150-153 pp.177-178
17. Strengths, limitations, and future directions	Study 1 Ch 5 and Ch 6 Study 2	Yes Yes Yes	pp 120-121 pp. 153-154 pp. 180-181
18. Comparison with existing literature	Study I Ch 5 and 6 Study 2 Ch 7	Yes Yes	pp 64-67, pp 229-233 pp 178-180

19. Conclusions and recommendations	Study 1 Ch 5 and Ch 6 Study 2 Ch 7 Discussion Ch 10	Yes Yes Yes Yes	pp119 pp.151-153 pp.181-182 pp. 242-244
20. Funding and conflict of interest	In appendices In declaration	Yes Yes	Appendix 1, declaration of interests appendix 12 p. xiii

Appendix 6

Clinician Pre-intervention interview questions

Script: Thank you for your time and participation in the Agents of Change Quality Improvement Collaboratives (AOC QIC) to improve Dementia Care.

Telephone interviews are being conducted to gain an understanding of your role and organisationalcontext of implementing change

60 minute interview will be Audio Recorded and transcribed to analyse themes. All identifying information about individuals will be deleted and a code will be allocated to match the interviewswith the site for research purposes. Recordings are stored on confidential, password protected computers at Flinders University and transcribing service has signed confidentiality agreements.

Only general information on themes will be reported and we will provide you a copy of the transcript and a summary of the themes.

Participation is voluntary and you may withdraw from interviews if you wish, with no impact on participation in the research trial.

1.How did you and your organization become involved in AOC QIC?

- How was the decision made to participate?
- Who participated in the decision-making process?
- Will you lead implementation of the improvement OT/Exercise/Carer support?
- How did you come into this role? Appointed? Volunteered? Voluntold?
- Do you have authority to do what is necessary to implement the improvement?

3.Who else is involved?

- Are there people in your organization who are likely to champion (go aboveand beyond what might be expected) the improvement?
- Are they formally involved, or is it an informal support?
- What position do these champions have in your organization?
- How do you think they will help with implementation? ie: Getting people touse the improvement?

4.What do you know about the Dementia Care Clinical guidelines or their implementation?

5.Do you think the OT/Exercise/Carer Support improvement will be effective in your setting?

- Do you have any feelings of anticipation? Stress? Enthusiasm? Why?
- How complicated is the improvement? ie: duration, scope, intricacy andnumber of steps involved and whether the intervention reflects a clear departure from previous practices

6.How confident are you that you will be able to successfully implement the improvement?

- What gives you that level of confidence (or lack of confidence)?

7.How confident do you think your colleagues feel about implementing the improvement?

- What kind of supporting evidence or proof is needed about the effectiveness of OT/Exercise/Carer Support to get others on board?

8.How well do you think the improvement will meet the needs of the individuals served byyour organization?

- In what ways will the improvement meet their needs? E.g. improved accessto services? Help with self-management?

9.What barriers will the individuals served by your organization face to participating in theOT/Exercise/Carer Support improvement?

- Time, cost, cultural values/beliefs, lack of family supports, other?

10.How would you describe the culture of your organization? Of your own setting or unit?

- Do you feel like the culture of your own unit is different from the overallorganization? In what ways?
- Are new ideas embraced and used to make improvements in yourorganisation or unit?
- Do you think the organisation's culture will affect the outcome of theimprovement?

11.How well does OT/Exercise/Carer Support improvement fit with your values and normsand the values and norms within the organization?

- Values relating to wellbeing/ goals of individuals vs. services offered?
- Values related to referring to other programs and discharge?
- Norms of offering in home support/clinic based appointments/ongoingprograms?
- Differences between your and the organisation's values or norms?

12.How well does the OT/Exercise/Care support improvement fit with existing workprocesses and practices in your setting?

- What are likely issues or complications that may arise?
- What kinds of changes may be needed to accommodate the improvement?i.e.: Changes in scope of practice? Changes in formal policies? Changes in information systems or records? Other?

13.What kinds of high-priority initiatives or activities are already happening in your setting?

- What is the priority of getting the improvement implemented relative toother initiatives that are happening now?
- Will the improvement conflict with these priorities?
- Will the improvement help achieve (or relieve pressure related to) thesepriorities?
- How will you juggle competing priorities in your own work?
- How do you think involvement in the AOC QIC will enable you to implement the OT/Exercise/Care Support improvement?
- To what extent do you think your role in the AOC QIC will help you: develop professionally/ learn new skills/ be recognised in your (next) evaluation/lead to satisfaction or promotion?
- What kinds of incentives are there to help ensure that the implementation of the OT/Exercise/Carer support is successful?

Any other comments?

Hopes or expectations?

Clinician Post-intervention interview questions

Script: Thank you for your time and participation in the Agents of Change Quality Improvement Collaboratives (AOC QIC) to improve Dementia Care.

Telephone interviews are being conducted to gain an understanding of your experience in the collaborative to contribute to the evaluation.

60minute interview will be Audio Recorded and transcribed to analyse themes. All identifying information about individuals will be deleted and a code will be allocated to match the interviews with the subgroup for research purposes. Recordings are stored on confidential, password protected computers at Flinders University and transcribing service has signed confidentiality agreements.

Only general information on themes will be reported and we will provide you a copy of the transcript and a summary of the themes.

Participation is voluntary and you may withdraw from interviews if you wish, with no impact on participation in the research trial.

Consent to record interview requested

1. Describe the outcomes you were able to achieve; for yourself, the organisation, the clients

   Explore acceptability and feasibility of QIC for clinicians and organisation

2. Explore the program theory to reconstruct experience and explore their meaning

   - Clinicians volunteer to be involved because they want to be agents of change/ identify as dementia advocates and are motivated to work together
   - Send in checklists to track changes, be accountable feedback on progress and adherence over time
   - CPD points offered retains accreditation and incentive motivation to stay engaged
   - Startup meetings help clinicians to connect meet likeminded others sense of identity as agents of change and commitment to program and networking
   - Learning with others on-line reduces travel, increased flexibility, but not alone in it so can feel like being involved with others learning together
   - Collaboration in teleconferences and on-line allows for shared learning, ideas and confidence in trying changes, role modelling

- Experts, clinical and by experience of dementia provide inspiration and credibility increasing aspiration to improve knowledge and practice

- Once learnt new skills you can influence others to improve quality, develop leadership and authority/ confidence

- The program is low cost and light touch to make it easy to be involved, can adapt to own setting and needs, so develops ownership and commitment to change by encouraging presentation at forums you can disseminate research outcomes, your achievements and be recognised by employer and others to improve quality

- Improving clinical practice will improve quality of life and services for people with dementia and care partners, keeping your service accountable, improving reputation and accreditation

3. Explore context culture and values
    - How were you able to involve others in the improvement?
    - How well did the Agents of Change program fit with the values and norms of the organisation and you?
    - How well did it fit with needs of clients?
    - Any barriers along the way and why did these arise? How did you deal with it?
    - How did you feel during the process/ at start? During the learning modules, implementation plan, implementing?
    - Why did you keep involved? What helped and why?
    - How will being involved with the Agents of Change affect your role, knowledge, and skills?
    - Would your manager be interested in being interviewed for the evaluation? if not why?
    - Contact details?

4. Valuing the Agents of Change collaborative

    Willingness to pay questionnaire for clinicians involved in Agents of Change research trial: establishing quality improvement collaboratives to improve adherence to clinical guidelines for dementia care

    Post intervention questionnaire:

    Think about the experience you have had in the Agents of change trial over the last 18 months:

    - The motivation you had to participate originally
    - The contact with researchers in dementia care
    - The face to face start-up meetings and networking with other dementia care clinicians
    - The 8 modules of the MOOC on-line to learn and share information
    - Little time away from home and work, no time lost in travel for training

- Flexibility in learning and working on a project to suit your needs and other priorities
- Learning about the guidelines and about quality improvement processes in the modules with examples and resources all in one place
- Ability to adapt the implementation to your own setting and client needs
- The opportunity for collaboration with other clinicians, with clinical experts, with experts by experience of dementia and researchers to focus your project
- Coaching and advice from researchers and experts; both clinical and people with experience of dementia
- Feedback and advice on implementation plans from experts
- Monitoring of practice over the duration of the trial through checklists and feedback
- Regular updates and reminders of the next steps
- Incentives to keep you involved:
- agents of change cups, pens and bags, reference book, CPD points, stipend to attenda conference, newsletters, and emails, collaborative teleconferences, individual coaching and advice, involvement in publication of articles, certificate of completion
- Professional development, recognition, satisfaction, achievement of change

Considering all these benefits:
Do you think that the impact of this collaborative process was less, the same or better than other clinical learning and development programs you have been involved with in previous years?

How much would you be willing to pay realistically in Dollars each week / each month to participate in a quality improvement collaborative to improve adherence to clinical guidelines in dementia care?

Answer to be recorded $x per week or per month

This would mean that you have precisely this amount less to spend on other things each week/ each month

Do you still think that this represents the amount you would realistically pay for participation in Agents of change on- line quality improvement collaborative each week/ each month?

If you would like to change your estimate, on further reflection what would you be willing to pay for the benefits brought about by the Agents of Change program?

Appendix 7

Agents of Change

Creating National Quality Collaboratives to improve dementia care

Chief Investigator: Dr Kate Laver
Ethics Approval Number: 62.17
Contact: 08 7221 8335

Valuing Expert Experience: Involving people living with dementia, their family carers and members of the community in translational research to implement dementia care guidelines

Individual consumer interviews Pre AOC intervention (members of AOC expert working groups)

Investigator:	Lenore de la Perrelle	Purpose:	Brief description
Information sheet:	Read and understood Y/N	Consent forms	Signed and returned Y/N
Any process questions?	Data, time, F/U contact	Test recording:	Ok/ agreed

Interview questions:

1. Can you tell me how you came to be involved in the Agents of Change Expert Working Groups?

2. What interests you in this trial?

3. What has been your previous experience with research?
   ie a subject of research, member of advisory group, member of DCRN/ DCN, co researcher, previous research work/ career

4. What do you hope to contribute? ie knowledge, perspective of person living with dementia, family carer, advice on what's important, comments on training materials, wording on client information sheets, recruiting consumers, other?

5. How will you know if you have influenced the research? Ie Changes made, advice used by clinicians, priorities reflect consumer views, successful outcomes of research

6. What do you hope to achieve or learn through your involvement? About the topics, about how things are implemented, what helps or hinders, how I can contribute, meet others involved, being part of a working group, new role, other?

7. What are the barriers to your involvement/ what makes it difficult for you to be involved? Time, cost, fatigue, other competing demands, health, need for support, IT and telephone equipment

8. What are the enablers to your involvement/ what helps you to be involved?
   Fee, support from team, regular time, information provided, by telephone, no travel

9. What are the key questions you want to explore in this research?

10. What do you want to find out about Consumer involvement in research?

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Agents of Change
Creating National Quality Collaboratives to improve dementia care

Appendix 7

Chief Investigator: Dr Kate Laver
Ethics Approval Number: 62.17
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Valuing Expert Experience: Involving people living with dementia, their family carers and members of the community in translational research to implement dementia care guidelines

Individual consumer interviews POST AOC intervention (members of AOC expert working groups)

Introduction:

Investigator:	Lenore de la Perrelle	Purpose:	Brief description
Information sheet:	Read and understood Y/N	Consent forms	Signed and returned Y/N
Any process questions?	Data, time, F/U contact	Test recording:	Ok/ agreed

Interview questions:

1. Can you tell me how the Agents of Change Expert Working Groups went for you?

2. What did you find most satisfying and why?

3. What did you find least satisfying and why?

4. What were you able to contribute? ie knowledge, perspective of person living with dementia, family carer, advice on what's important, comments on training materials, wording on client information sheets, recruiting consumers, other?

5. Do you think your involvement had an influence on the research? Please give an example Ie Changes made, advice used by clinicians, priorities reflected consumer views, successful outcomes of research

6. What did you achieve or learn through your involvement? About the topics, about how things are implemented, what helps or hinders, how I can contribute, meet others involved, being part of a working group, new role, other?

7. Were there times you could not do other things or had to cancel arrangements to be involved? Please give examples

8. Were there times you found the involvement difficult? please give examples

9. What helped you to remain involved?
   Fee, support from team, regular time, information provided, by telephone, no travel, purpose, satisfaction

10. Would you do this again? If no fees? If travel involved?

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Appendix 8

Supplementary file 3.
NoMAD survey used in Agents of Change trial to gather information from participant clinicians

One last thing before you submit your plan.

We're interested to know **how ready you feel to implement your plan**. There are no right or wrong answers. This just gives us (and you!) an opportunity to learn about your confidence in making your changes happen. The answers **won't be seen** by anyone except for the research team.

Part A: About yourself

How many years have you worked for your organisation/department?

	Less than 1 year	1 - 3 years	3 - 5 years	5 - 10 years	10 - 15 years	More than 15 years
Please select	○	○	○	○	○	○

How would you describe your professional job category?

Part B: General questions about your Quality Improvement Plan

When you use your proposed changes (perhaps during your initial test of change), how familiar does it feel?

	0 = Still feels very new	1	2	3	4	5	6	7	8	9	10 = feels completely familiar
Please select	○	◉	○	○	○	○	○	○	○	○	○

Do you feel the proposed changes are currently a normal part of your work?

	0 = Not at all	1	2	3	4	5 = Somewhat	6	7	8	9	10 = Completely
Please select	○	○	○	○	○	○	○	○	○	○	○

Supplementary file 3.
NoMAD survey used in Agents of Change trial to gather information from participant clinicians

Do you feel the proposed changes are currently a normal part of your work?

	0 = Not at all	1	2	3	4	5 = Somewhat	6	7	8	9	10 = Completely
Please select	○	○	○	○	○	○	○	○	○	○	○

Do you feel that the proposed changes will become a normal part of your work?

	0 = Not at all	1	2	3	4	5 = Somewhat	6	7	8	9	10 = Completely
Please select	○	○	○	○	○	○	○	○	○	○	○

Part C: Detailed questions about your Quality Improvement Plan

For each statement please select an answer that best suits your experience. If the statement is not relevant to you please select an answer from the three selections on the right hand side.

Section C1

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Not relevant to my role	Not relevant at this stage	Not relevant to my proposed changes
I can see how my proposed changes differ from usual ways of thinking	○	○	○	○	○	○	○	○
Staff in this organisation have a shared understanding of the purpose of the changes I am proposing	○	○	○	○	○	○	○	○
I understand how the proposed changes will affect the nature of my own work	○	○	○	○	○	○	○	○
I can see the potential value of the proposed changes for my work	○	○	○	○	○	○	○	○

Supplementary file 3.
NoMAD survey used in Agents of Change trial to gather information from participant clinicians

understanding of the purpose of the changes I am proposing	○	○	○	○	○	○	○	○
I understand how the proposed changes will affect the nature of my own work	○	○	○	○	○	○	○	○
I can see the potential value of the proposed changes for my work	○	○	○	○	○	○	○	○

Section C2

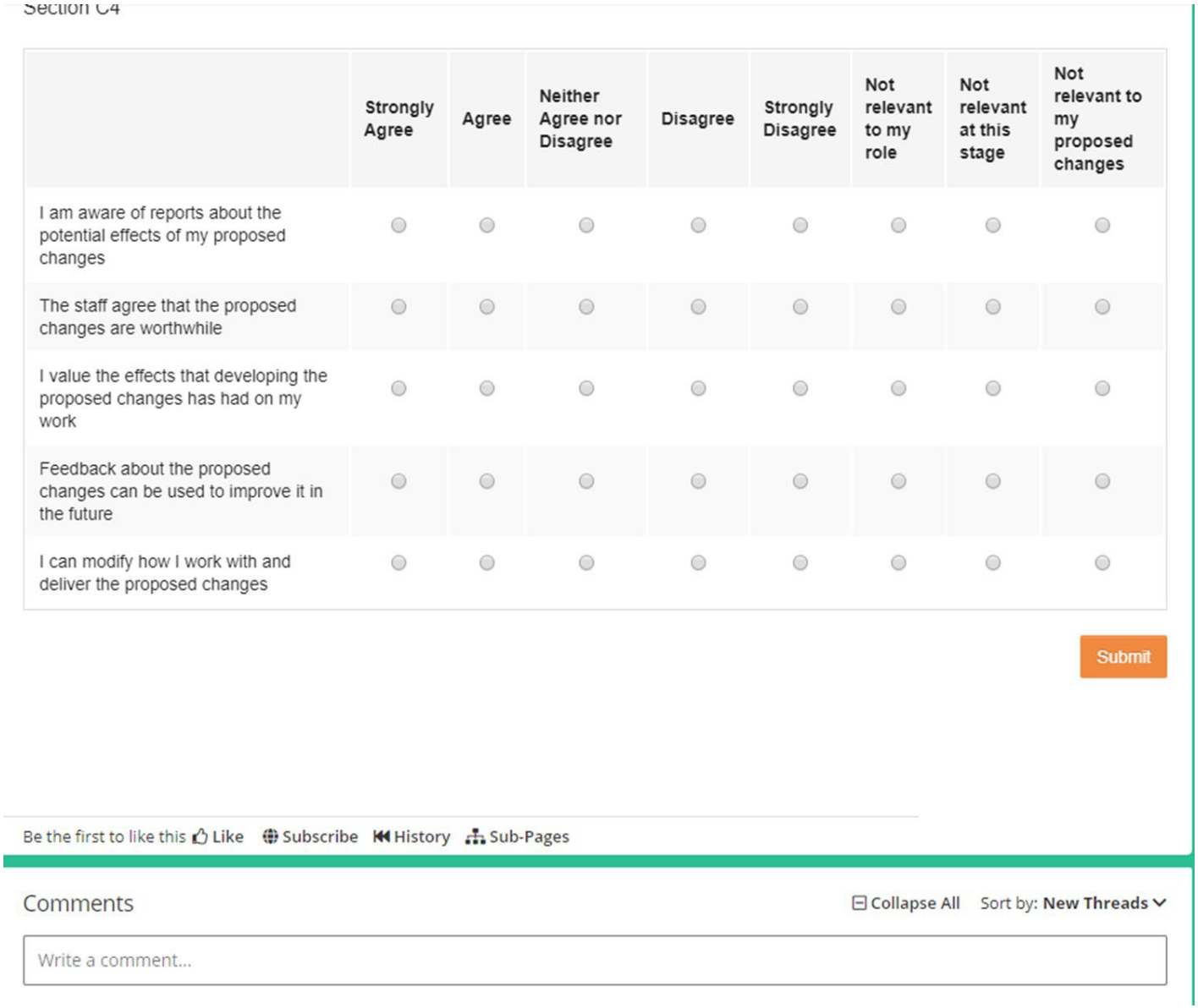
	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Not relevant to my role	Not relevant at this stage	Not relevant to my proposed changes
There are key people who will drive my proposed changes forward and get others involved	○	○	○	○	○	○	○	○
I believe that making the proposed changes is a legitimate part of my role	○	○	○	○	○	○	○	○
I'm open to working with colleagues in new ways to use the proposed changes	○	○	○	○	○	○	○	○
I will continue to support the proposed changes	○	○	○	○	○	○	○	○

Supplementary file 3.
NoMAD survey used in Agents of Change trial to gather information from participant clinicians

Section C3

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Not relevant to my role	Not relevant at this stage	Not relevant to my proposed changes
I can easily integrate the proposed changes into my existing work	○	○	○	○	○	○	○	○
The proposed changes will disrupt working relationships	○	○	○	○	○	○	○	○
I have confidence in other people's ability to implement the proposed changes	○	○	○	○	○	○	○	○
Work is assigned to those with skills appropriate to implement the proposed changes	○	○	○	○	○	○	○	○
Sufficient training is provided or will be provided to enable staff to implement the proposed changes	○	○	○	○	○	○	○	○
Sufficient resources are available to support the proposed changes	○	○	○	○	○	○	○	○
Management adequately supports the proposed changes	○	○	○	○	○	○	○	○

Supplementary file 3.
NoMAD survey used in Agents of Change trial to gather information from participant clinicians



Section C4

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Not relevant to my role	Not relevant at this stage	Not relevant to my proposed changes
I am aware of reports about the potential effects of my proposed changes	○	○	○	○	○	○	○	○
The staff agree that the proposed changes are worthwhile	○	○	○	○	○	○	○	○
I value the effects that developing the proposed changes has had on my work	○	○	○	○	○	○	○	○
Feedback about the proposed changes can be used to improve it in the future	○	○	○	○	○	○	○	○
I can modify how I work with and deliver the proposed changes	○	○	○	○	○	○	○	○

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Appendix 9

QIKAT-R survey used to assess knowledge and skills of participant clinicians in Agents of Change Trial

QIKAT-R Scenario: Mr. Jones

You are a clinician (allied health or nursing) working in a day service for older people, many whom have a diagnosis of dementia. Your service offers group programs, but you also offer individual consultations related to people's needs (which may be related to specialist nursing review, mobility, home safety, support services, residential care placement and carer support).

On Monday morning you see your first client, Mr Jones, in a private consultation at 9am. He has been referred by his GP for 'review of managing alone at home' as the GP has some concerns about his cognition (though has not performed a formal cognitive assessment). He is dropped off at the appointment by his daughter who has headed off to do some shopping and will collect him from the reception area in one hour. Unfortunately, the daughter has left before you go to meet Mr Jones, so you don't get a chance to talk to her.

Mr Jones is very articulate and brushes off questions you have about how he is managing at home. He is well presented and gives a good description of his weekly and daily routines. He does have a lot of questions about his sore hip though and what he could do to reduce the pain and the sorts of activities he should and shouldn't be doing. You provide some advice about daily activities, pain management, equipment, and services available and then walk back with Mr Jones to the reception area so his daughter can collect him. Then you must go straight to lead your 9:45am group.

On Tuesday, the team leader wants to meet with you. She has had a very angry complaint phone call from Mr Jones's daughter who reports that Mr. Jones has great difficulty at home alone and has several concerning symptoms (particularly in the evenings). The daughter wanted the consultation to address these issues but instead Mr Jones reported that he received advice for his hip (and that was all).

QIKAT-R Prompts for Scenario

Please answer each of the following questions as if you were developing a program to investigate and improve the problem presented above.

1) What would be the aim?
2) What would you measure to assess the situation?
3) Identify one change that might be worth testing

Revised QIKAT Scoring Rubric (QIKAT-R)

Each item receives one point if the response adequately addresses the item and zero points if it does not. The total possible score is 9 points for each scenario.

3 points for the AIM. The AIM …	
A1	is focused on the system-level of the problem presented
A2	includes direction of change (increase or decrease)
A3	includes at least <u>one</u> specific characteristic such as magnitude (% change) or time frame
3 points for the MEASURE. The MEASURE…	
M1	is relevant to the aim
M2	is readily available so data can be analysed over time
M3	captures a key process or outcome
3 points for the CHANGE. The CHANGE…	
C1	is linked directly with the aim
C2	proposes to use existing resources
C3	provides sufficient details to initiate a test of change

Singh M, Ogrinc G, Cox K, et al. The Quality improvement Knowledge Application Tool Revised (QIKAT-R), Academic Medicine, October 2014, Vol 89, Issue 10, p 1386-1391 doi: 10.1097/ACM.0000000000000456

Appendix 10 GRIPP 2 short form (Staniszewska *et al. 2017, 10.1136/bmj.j3453*

Section and Topic	Item	Reported on Page No
1. Aim	Report the aim of PPI in the study	p.25, overall aims for thesis p158 aims of study 2
2. Methods	Provide a clear description of the methods used for PPI in the study	pp 74-83 describes the methods used three phases of studies 1 and 2 pp158-9 describes the methods used for Study 2
3. Study results	Outcomes- Report the results of PPI in the study, including both positive and negative outcomes	pp 160-178 describe interview, document and cost analysis results
4. Discussion and conclusions	Outcomes-comment on the extent to which PPI influenced the study overall describe positive and negative effects	pp 178-180 discusses results and areas for improvement
5. Reflections/ critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not so others can learn from this experience	Pp 180-182 identifies limits and the needs for networking and coordination of future PPI

Abbreviations PPI: Patient and Public Involvement

Appendix 11 Consolidated Health Economic Evaluation Reporting Standards

CHEERS Checklist
Items to include when reporting economic evaluations of health interventions

The **ISPOR CHEERS Task Force Report**, *Consolidated Health Economic Evaluation Reporting Standards (CHEERS)—Explanation and Elaboration: A Report of the ISPOR Health Economic Evaluations Publication Guidelines Good Reporting Practices Task Force,* provides examples and further discussion of the 24-item CHEERS Checklist and the CHEERS Statement. It may be accessed via the *Value in Health* or via the ISPOR Health Economic Evaluation Publication Guidelines – CHEERS: Good Reporting Practices webpage: http://www.ispor.org/TaskForces/EconomicPubGuidelines.asp

Section/item	Item No	Recommendation	Reported on page No/ line No
Title and abstract			
Title	1	Identify the study as an economic evaluation or use more specific terms such as "cost-effectiveness analysis", and describe the interventions compared.	Ch 9 p. 222
Abstract	2	Provide a structured summary of objectives, perspective, setting, methods (including study design and inputs), results (including base case and uncertainty analyses), and conclusions.	Abstract at p. xiii Ch 1 at p. 28 Ch 9 p.223
Introduction			
Background and objectives	3	Provide an explicit statement of the broader context for the study. Present the study question and its relevance for health policy or practice decisions.	Ch 4 p. 91-93
Methods			
Target population and subgroups	4	Describe characteristics of the base case population and subgroups analysed, including why they were chosen.	Ch 4 p. 91 Ch 9 p. 216
Setting and location	5	State relevant aspects of the system(s) in which the decision(s) need(s) to be made.	Ch 9 p. 216
Study perspective	6	Describe the perspective of the study and relate this to the costs being evaluated.	Ch 4 p. 91 Ch 9 p. 211
Comparators	7	Describe the interventions or strategies being compared and state why they were chosen.	Ch 9 p. 215
Time horizon	8	State the time horizon(s) over which costs and consequences are being evaluated and say why appropriate.	Ch 9 p. 214
Discount rate	9	Report the choice of discount rate(s) used for costs and outcomes and say why appropriate.	Ch 9 p. 214
Choice of health outcomes	10	Describe what outcomes were used as the measure(s) of benefit in the evaluation and their relevance for the type of analysis performed.	Ch 9 p. 211-212
Measurement of effectiveness	11a	*Single study-based estimates:* Describe fully the design features of the single effectiveness study and why the single study was a sufficient source of clinical effectiveness data.	Ch 9 p.211

	11b	*Synthesis-based estimates:* Describe fully the methods used for identification of included studies and synthesis of clinical effectiveness data.	
Measurement and valuation of preference based outcomes	12	If applicable, describe the population and methods used to elicit preferences for outcomes.	Ch 9 p.212
Estimating resources and costs	13a	*Single study-based economic evaluation:* Describe approaches used to estimate resource use associated with the alternative interventions. Describe primary or secondary research methods for valuing each resource item in terms of its unit cost. Describe any adjustments made to approximate to opportunity costs.	Ch 9 p. 213-4
	13b	*Model-based economic evaluation:* Describe approaches and data sources used to estimate resource use associated with model health states. Describe primary or secondary research methods for valuing each resource item in terms of its unit cost. Describe any adjustments made to approximate to opportunity costs.	N/A
Currency, price date, and conversion	14	Report the dates of the estimated resource quantities and unit costs. Describe methods for adjusting estimated unit costs to the year of reported costs if necessary. Describe methods for converting costs into a common currency base and the exchange rate.	Ch 9 p. 213
Choice of model	15	Describe and give reasons for the specific type of decision-analytical model used. Providing a figure to show model structure is strongly recommended.	N/A
Assumptions	16	Describe all structural or other assumptions underpinning the decision-analytical model.	N/A
Analytical methods	17	Describe all analytical methods supporting the evaluation. This could include methods for dealing with skewed, missing, or censored data; extrapolation methods; methods for pooling data; approaches to validate or make adjustments (such as half cycle corrections) to a model; and methods for handling population heterogeneity and uncertainty.	Ch 9 p. 215
Results			
Study parameters	18	Report the values, ranges, references, and, if used, probability distributions for all parameters. Report reasons or sources for distributions used to represent uncertainty where appropriate. Providing a table to show the input values is strongly recommended.	Ch 9 p.218
Incremental costs and outcomes	19	For each intervention, report mean values for the main categories of estimated costs and outcomes of interest, as wellas mean differences between the comparator groups. If applicable, report incremental cost-effectiveness ratios.	N/A
Characterising uncertainty	20a	*Single study-based economic evaluation:* Describe the effects	

of sampling uncertainty for the estimated incremental cost and incremental effectiveness parameters together with the impact

		of methodological assumptions (such as discount rate, study perspective).	Ch 9 p. 222
	20b	*Model-based economic evaluation:* Describe the effects on the results of uncertainty for all input parameters, and uncertainty related to the structure of the model and assumptions.	N/A
Characterising heterogeneity	21	If applicable, report differences in costs, outcomes, or cost-effectiveness that can be explained by variations between subgroups of patients with different baseline characteristics or other observed variability in effects that are not reducible by more information.	Ch 9 p.221
Discussion			
Study findings, limitations, generalisability, and current knowledge	22	Summarise key study findings and describe how they support the conclusions reached. Discuss limitations and the generalisability of the findings and how the findings fit with current knowledge.	Ch 9 p.219-222
Other			
Source of funding	23	Describe how the study was funded and the role of the funder in the identification, design, conduct, and reporting of the analysis. Describe other non-monetary sources of support.	PhD Thesis acknowledged scholarship
Conflicts of interest	24	Describe any potential for conflict of interest of study contributors in accordance with journal policy. In the absence of a journal policy, we recommend authors comply with International Committee of Medical Journal Editors recommendations.	No Conflict of interest

For consistency, the CHEERS Statement checklist format is based on the format of the CONSORT statement checklist

The **ISPOR CHEERS Task Force Report** provides examples and further discussion of the 24-item CHEERS Checklist and the CHEERS Statement. It may be accessed via the *Value in Health* link or via the ISPOR Health Economic Evaluation Publication Guidelines – CHEERS: Good Reporting Practices webpage: http://www.ispor.org/TaskForces/EconomicPubGuidelines.asp

The citation for the CHEERS Task Force Report is:
Husereau D, Drummond M, Petrou S, et al. Consolidated health economic evaluation reporting standards (CHEERS)—Explanation and elaboration: A report of the ISPOR health economic evaluations publication guidelines good reporting practices task force. Value Health 2013;16:231-50.

Appendix 12

Researcher reflection using Eight Criteria for Excellent Qualitative Research (Tracy, 2010 DOI: 10.1177/1077800410383121)

Criteria for Quality (Goal)	Means Methods to achieve	Comments
Worthy Topic	Relevant. Timely Significant Interesting	Improving the quality of life for people with dementia has been a personal and a career goal after my father and aunt lived with dementia, and a friend developed younger onset dementia. With approximately half a million Australians affected now, with global increases in numbers due to an ageing population it is a significant challenge to healthcare. The inconsistent use of evidence based practice was clear to me in aged care and the identification of abuse and poor care in Australia from 2017 made the topic of improving dementia care timely, significant, and important. The development of clinical guidelines for dementia care in Australia and an implementation trial provided the opportunity to discover how and why dementia care could be improved.
Rich Rigour	Use of theoretical constructs Data and time in the field Samples Contexts Data Collection and analysis	The choice of a theory driven evaluation method enabled understanding of how and why improvements could be made. By hypothesising the program logic, the trial strategy could be evaluated for feasibility and acceptability, considering the diverse settings and the changing policy context of aged and healthcare in Australia. The participants in the trial were highly motivated and agreed to participate in the evaluation. The use of telephone interviews and online surveys responded to the time constraints of clinicians who were geographically dispersed. I visited a rural clinician to understand the setting and I had experience of community and residential aged care and was based in a healthcare setting which added to my understanding of different contexts. Clinicians who were interviewed were provided with copies of transcripts and opportunities to review content. Any identifying information was removed in the analysis and presentation of results to preserve privacy.
Sincerity	Self-reflexivity about subjective values, biases, inclinations Transparency about the methods and challenges	My motivations to undertake this research were strongly based in wanting to make a difference in dementia care. With a career in social work, training, and service development in human services, I could see what needed to be done and was impatient.

		I needed to take an evaluators stance of enquiry to understand not direct by using an interview guide to direct the line of discussion and length of time used. I needed to use my social work skills in interviewing clinicians to understand their perspectives and settings and to restrain myself from providing advice. When asked for advice or suggestions in interviews, I was able to use general information, referral back to the trial coordinator, and techniques for the interviewee to identify what was in their own role that could be a first step. When a number of barriers were identified, I discussed them with the principal researcher and a webinar was arranged to address these questions on identifying opportunities and funds for changes in practice, by an expert and me and a meeting with experts by experience of dementia was arranged for feedback and discussion. In some cases, my values did not align with how clinicians described their situation which caused me some concern. Most clinicians however felt comfortable in expressing themselves honestly in interviews and I concluded that my views did not show in the process. The pre-and post-intervention interviews provided an opportunity to get to know the clinician and experts by experience of dementia to reflect with them on the process and outcomes. Exit interviews allowed some clinicians to express their distress about contextual changes and resistance to change. This provided an opportunity for them to reflect and to provide advice to the research team on improvements. By taking field notes and listening to audio recordings of the interviews I could reflect on the issues that I responded to or where my approach was leading or directive. That helped in modifying my approach.
Credibility	Thick description, concrete detail, explication of knowledge Triangulation or integration Multivocality Member reflections	In analysis and write up of the research I wanted to provide detailed descriptions and quotes and had to focus on the research questions to refine what data was required. I used direct quotes to provide different perspectives on the topic of discussion and I worked carefully to identify information from each person interviewed. That included ensuring that a person with dementia was given enough time and had questions directed to them in focus groups and when a dyad was interviewed. Some clinicians commented that the interviews were helpful to them to reflect on their achievements and what helped or hindered them in their work.

Resonance	Aesthetic evocative representation Naturalistic generalisations Transferrable findings	I used quotes from the interview which showed both the passion of the interviewees and the issues of concern. Emotive quotes in relation to professional work was surprising in some ways but were included to demonstrate the level of motivation. By identifying mechanisms of change I was able to make generalisations that could build theory and be transferrable to other collaborative trials. Some were similar to previous literature and others were specific to dementia care.
Significant contributions	Conceptually/ theoretically Practically Morally Methodologically heuristically	The theory driven approach to the evaluation had not been used before in evaluating feasibility and acceptability of a collaborative trial to improve dementia care. It was a complex process that required a lot of work in analysis, but which provided rich understandings of mechanisms. Rather than focusing on the behaviour of individuals to use the clinical guidelines, the method allowed me to look at the social process in which clinicians and experts by experience of dementia operate. This appealed morally as it looked at the wider pressures at different levels that enabled or constrained effort. The detailed methods provided a guide to four phases of the evaluation and allowed a similar analysis to data from clinicians, researchers, experts by experience of dementia. I could also consider costs in relation to the investment in the program rather than be concerned about a focus on savings.
Ethical	Procedural ethics Situational and cultural ethics Relational ethics Exiting ethics	In developing the ethics applications for the evaluation of the experience of people with dementia and caregivers in the research, I paid particular attention to the needs of the interviewees, the timing, flexibility and preview of questions so they could think about them ahead and prepare to discuss them. This approach also was appreciated by clinicians, who were often busy or fitting in an interview at the end of a day, at home or in noisy offices. They commented that knowing that the researchers and the evaluator was a clinician with experience in dementia care created trust and credibility. The pre and post intervention interviews also allowed for feedback, sharing of success or difficulties which they appreciated. For reflection. The process of sending links to published articles, of inviting clinicians and experts by experience of dementia to be co-authors or acknowledged for their contribution demonstrated the value of the relationships. For the experts by experience of dementia, the process was at times emotional and changes in abilities were noticed and roles changed over the

		course of the evaluation. A fine balance was needed to provide support during difficult times and to decide about continuing or rescheduling. Individual follow up with information or contacts helped retain that balance. Similarly, forclinicians who exited the trial before completion, there were some who were upset and an exit interview allowed them to reflect and express their feelings. By offering to send links to published articles on the trial they were able to opt to remain engaged if they were interested.
Meaningful Coherence	Methods fit stated goals Meaningful connections with literature, questions, findings and interpretations	The pre and post intervention evaluation process made sense to the clinicians. It fitted the goals of identifying motivations, expectations, and context first, then identifying outcomes and processes that helped or hindered their achievements. The review of program theory and inclusion of a willingness to pay questionnaire was novel to the clinicians and created some difficulties in deciding on processes and prices. Interviews with experts by experience of dementia were more broad ranging due to their interests. These experiences were similar to other published methods and demonstrated an engagement with the judgements about the value of the program and what worked for them. The findings helped understand what was needed to support involvement of people with dementia and caregivers in research as co researchers, and what components were influential to engage clinicians in practice change in their workplaces. This was satisfying for me in recognising the dynamic nature of complex processes of change.

NHS National Institute for Health Research

UNIVERSITY of York
Centre for Reviews and Dissemination

Systematic review

1.*Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

Systematic review of economic evaluations of quality improvement collaboratives in health care
38 words remaining

2.Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

50 words remaining

3. Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

20/08/2018

4.* Anticipated completion date.

Give the date by which the review is expected to be completed.

22/02/2019

5. *Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.
Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.
This field should be updated when any amendments are made to a published record and on completion and publication of the review.

The review has not yet started: Yes

6. Review stage

	Started	Completed
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

* Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Lenore de la Perrelle

7.Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Ms de la Perrelle

8.* Named contact email.

Give the electronic mail address of the named contact.

lenore.delaperrelle@flinders.edu.au

9.Named contact address

Give the full postal address for the named contact.

Department of Rehabilitation, Aged and Extended Care | College of Medicine and Public Health\nFlinders University GPO Box 2100 | Adelaide SA 5001\n

10.Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

+61 8 8201 3504

11.* Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

Flinders University

12.Organisation web address:

https://www.flinders.edu.au

13.Review team members and their organisational affiliations.

Give the title, first name, last name and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.

Ms Lenore de la Perrelle. Flinders University

Assistant/Associate Professor Billingsley Kaambwa. Flinders University
Dr Monica Cations. Flinders University
Dr Kate Laver. Flinders University

14.* Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

Funding for this work was provided by the National Health and Medical Research Council Cognitive Decline Partnership Centre (CDPC1327) and the National Health and Medical Research Council National Institute for Dementia Research (1135667).

15.* Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

16.Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members.

1. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

How cost effective are quality improvement collaboratives as a strategy to implement clinical guidelines in health care?
233 words remaining

2. * Searches.

Give details of the sources to be searched, search dates (from and to), and any restrictions (e.g. language or publication period). The full search strategy is not required, but may be supplied as a link or attachment.

CINAHL, Econlit, MEDLINE, NHS EED database, PsycINFO, ProQuest (Health & Medicine; social science Subscription only) searches will include databases for Research in Health, Flinders University, the Australian Institute of Health and Welfare, the Institute for Health Care Improvement (IHI) and the Grey Literature Report to identify institutional studies. Manual searching of reference lists from included studies will also be conducted to identify other potentially eligible studies or reports.
English language.
229 words remaining

3. URL to search strategy.

Give a link to the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies).

https://www.crd.york.ac.uk/PROSPEROFILES/107417_STRATEGY_20180820.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

4. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Implementation of clinical practice guidelines in health care. Any health care condition.
188 words remaining

5. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

Any health care professionals.
196 words remaining

6. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

A Quality Improvement Collaborative is a structured approach that brings together groups of clinicians from different health care organisations to learn, share and implement improvement methods for one aspect of quality of their service. Over a series of meetings, clinicians are supported by experts to learn about best practice and implement change strategies to improve quality. Cost effectiveness evaluations of the use of a quality improvement collaborative as an implementation strategy will provide information on the monetary units, choice of analytic method, setting, perspective and comparators.
114 words remaining

7. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Not relevant.
197 words remaining

8. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

Studies will be included if they meet the following criteria:
1) Evaluate a quality improvement collaborative established to address any health care need or condition in any population in any country
2) An economic evaluation was carried out (this includes studies using a cost-minimisation, cost-effectiveness, cost-utility or cost-benefit approach).
Study Methods: We will include randomised and non-randomised trials that include full or partial economic evaluations (e.g. estimates of resource use or cost associated with intervention or comparator), multiple baseline cohort studies, interrupted time series and pre and post studies with cost comparators. We will exclude systematic reviews, study protocols, conference proceedings, editorials and commentary papers. We will also exclude efficacy or effectiveness analyses with no analysis of costs, burden of disease studies and cost-of-illness studies.
26 words remaining

9. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

Any health care setting, any condition, use of quality improvement collaborative, English language.
237 words remaining

10. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Cost effectiveness or cost benefit of the use of quality improvement collaboratives to implement improvement in health care or in implementing clinical guidelines guidelines.
176 words remaining

Timing and effect measures

Monetary units to measure costs and benefits.
193 words remaining

11. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

None.

299 words remaining

Timing and effect measures

298 words remaining

12. Data extraction (selection and coding).

Give the procedure for selecting studies for the review and extracting data, including the number of researchers involved and how discrepancies will be resolved. List the data to be extracted.

Two reviewers will independently screen title and/or abstracts based on the inclusion criteria. Any discrepancies will be discussed and if necessary assessed by a third reviewer and where consensus cannot be reached the study will be included for full-text review.

Full text of the studies identified at the title/abstract stage and reviewed by two authors. Any differences between reviewers will be resolved by a third reviewer. Reasons for excluding studies will be documented as per Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) standards.

Data will be extracted using a standardised form adapted from the Joanna Briggs Institute Data Extraction Form for Economic Evaluations and entered in Excel. Information will include, study design, perspective, setting (acute or sub-acute), geographical location of study, participant characteristics description of intervention and comparator, methods or models used, source of cost and effectiveness data, costs and outcomes included, time horizon and discount rate, and authors' summary of findings. The primary reviewer will extract data independently and a second reviewer will check extracted data, with any discrepancies resolved through discussion or consultation with a third reviewer.

118 words remaining

13. * Risk of bias (quality) assessment.

State whether and how risk of bias will be assessed (including the number of researchers involved and how discrepancies will be resolved), how the quality of individual studies will be assessed, and whether and how this will influence the planned synthesis.

Risk of bias and quality of individual studies will be addressed using the guidance of the Cochrane Systematic Review Handbook. EVERS checklist (Evers et al 2005) will be used to appraise studies across for example study population, study design, perspective, comparators, identification of costs and outcomes, generalisability of results and ethical implications. Methodological quality of economic evaluations will be assessed using the 24 item Health Economic Evaluation Reporting Standards (CHEERS) checklist(Husereau et al., 2013). The CHEERS checklist optimises reporting of health economic evaluations and enables transparent and complete reporting of methods and findings to facilitate interpretation and comparison of studies. It covers for example: target population, setting of the intervention, perspective of the study, choice of analytical model, comparators and monetary unit chosen. Both assessments will be presented in summary tables allowing assessment of both the quality of economic evaluation and the quality of the study where cost effectiveness is an aspect of the study.

45 words remaining

14. * Strategy for data synthesis.

Give the planned general approach to synthesis, e.g. whether aggregate or individual participant data will be used and whether a quantitative or narrative (descriptive) synthesis is planned. It is acceptable to state that a quantitative synthesis will be used if the included studies are sufficiently homogenous.

We will conduct a narrative synthesis of studies reporting on the economic evaluation of Quality Improvement Collaborative interventions to improve health care. As it is anticipated that both qualitative and quantitative studies will be included, a textual description of the studies by type of economic evaluation (full, partial and cost analysis) and by quality of economic reporting assessed by CHEERS checklist (full, partial and non compliant) will provide a synthesis of preliminary data. Relationships in the data will be explored by summary tables will be presented and comparison of key characteristics of the intervention, their evaluation, including clinical and cost-effectiveness outcomes and key characteristics of the type of study where quality improvement collaboratives were found to have cost benefits.

Summary tables will be presented and comparison of key characteristics of the intervention, their evaluation, including clinical and cost-effectiveness outcomes and key characteristics of the type of study where quality improvement collaboratives were found to have cost benefits.

170 words remaining

15. * Analysis of subgroups or subsets.

Give details of any plans for the separate presentation, exploration or analysis of different types of participants (e.g. by age, disease status, ethnicity, socioeconomic status, presence or absence or co-morbidities); different types of intervention (e.g. drug dose, presence or absence of particular components of intervention); different settings (e.g. country, acute or primary care sector, professional or family care); or different types of study (e.g. randomised or non-randomised).

None.

249 words remaining

16. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

Type of review

Cost effectiveness
Yes

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention
Yes

Meta-analysis
No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
Yes

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
Yes

Care of the elderly
Yes

Child health
No

Complementary therapies
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
Yes

Musculoskeletal
No

Neurological
Yes

Nursing
Yes

Obstetrics and gynaecology
No

Oral health

No

Palliative care
Yes

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
Yes

Rehabilitation
Yes

Respiratory disorders
No

Service delivery
Yes

Skin disorders
No

Social care
Yes

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

17. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is an English language summary.

18. Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

Australia

19. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

50 words remaining

20. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

21. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

In addition to reporting for the research project funders, which will be available on the NHMRC website, a paper will be submitted to a leading journal in the field of Health Economics Implementation Science or Public Health. This review will be included as part of a PhD thesis and used to provide guidance for future implementation strategy plans

Do you intend to publish the review on completion?

Yes

22. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

quality improvement; quality improvement collaborative; translational research; implementation; practice guidelines; cost benefit analysis; economic evaluation; cost effectiveness

23. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

50 words remaining

24. * Current review status.

Review status should be updated when the review is completed and when it is published.
Please provide anticipated publication date

Review_Ongoing

25. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

I have updated the sections 27 and 28 as requested. the inclusion of the EVERS and CHEERS checklists to assess quality and risk of bias may have been overlooked or improperly inserted into the original submission.

26. Details of final report/publication(s).

This field should be left empty until details of the completed review are available.

Give the link to the published review.

Appendix 14

	MEDLINE search strategy	
#	**Searches**	**Results**
1	quality improvement/ or value-based insurance/	21226
2	(quality improvement or QI).ti,ab,kf.	38432
3	quality collaborat*.ti,ab,kf.	301
4	or/1-3	51672
5	(guidelines as topic/ or practice guidelines as topic/ or Total Quality Management/ or evidence based medicine/ or evidence based practice/) and ("Diffusion of Innovation"/ or Translational Medical Research/ or Cooperative behavior/)	6246
6	((implementation or diffusion or adher* or follow* or align* or based) adj2 guideline*).tw,kf.	29179
7	or/5-6	35186
8	or/4,7	85363
9	Cost-Benefit Analysis/	77500
10	economics/ or "costs and cost analysis"/ or "cost allocation"/ or "cost control"/ or "cost of illness"/ or health care costs/ or direct service costs/ or hospital costs/ or health expenditures/ or economics, hospital/ or hospital charges/ or economics, medical/ or fees, medical/ or economics, nursing/ or economics, pharmaceutical/ or quality-adjusted life years/	206691
11	((cost* or economic*) adj3 (minimi* or utilit* or evaluat* or review* or outcome* or analys* or effect* or benefit)).tw,kf.	193532
12	(CBA or BCA).tw,kf.	12738
13	(marginal analy* or economic impact* or QALY*).tw,kf.	19571
14	or/9-13	400949
15	8 and 14	5149
16	limit 15 to English language	4935