Homelessness as a Barrier to Cognitive Wellbeing and Dementia Risk Reduction

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Thesis
Submitted to Flinders University
for the degree of

Doctor of Philosophy
College of Medicine and Public Health
01/12/2023

ABSTRACT

This thesis aims to contribute knowledge of dementia risk factors in people experiencing homelessness. In 2020, a seminal report of the Lancet Commission identified twelve potentially modifiable risk factors over the life course that account for 40% of all dementia, being: low education, hypertension, hearing loss, smoking, obesity, depression, physical inactivity, diabetes, social isolation, excessive alcohol, traumatic brain injury, and air pollution with far-reaching significance for delaying or preventing the onset of dementia. This ground-breaking work recognises, but does not elaborate on, how factors of poverty and inequity may influence or add to its modelling, nor consider the social barriers preventing the meaningful implementation of dementia risk reduction in a population with extreme socioeconomic disadvantage. Considering this knowledge gap, this thesis seeks to build an understanding of dementia risk in homelessness based on the premise that the mechanisms and exposures may both present and coalesce differently in people experiencing homelessness than seen in the general population, creating distinct challenges for dementia risk reduction.

This thesis employs two studies, each using mixed methods research. The first study is focused on the lived experience of people living with, or at risk of, homelessness. The study design is parallel mixed methods. Quantitative data from *Journeys Home*, an Australian national longitudinal survey of 1,682 people experiencing, or at risk of, homelessness, was used for descriptive statistical analysis. Participants' common characteristics related to known risk factors for dementia were analysed using descriptive statistics. Concurrent, qualitative interviews were conducted with fifteen people experiencing primary homelessness in Adelaide, South Australia, and revealed devastating stories that underlie poor cognitive and psychosocial wellbeing and concern for brain health. The findings of both elements were integrated using a 'merging' technique to indicate that people experiencing, or at risk of, homelessness had high susceptibility to dementia risk exposure across a range of health, social and behavioural factors that included historical but also continuing psychological distress, and poor educational opportunity.

The second study used an explanatory sequential design. A 25-question, four-factor dementia knowledge survey was circulated to specialist homelessness services in South Australia to ascertain baseline dementia knowledge. Descriptive statistics from 95 respondents identified a whole-sample mean score of 24.8 (SD:10.1) (*n*=95) from a maximum possible score of 50. The survey is a verified measure of identifying baseline dementia knowledge and post-education change, making scores subjective, however, this ostensibly low score has repercussions for program managers, direct supports, referrals to appropriate services, and as de-facto carers of people experiencing homelessness. A ‘building’ technique was used for data integration where quantitative data informed the methods for qualitative interviews of seven key stakeholders in homelessness services. Interviews revealed both barriers and facilitators to building workforce dementia knowledge and supporting clients’ cognitive health, with suggestions for improving client dementia awareness and opportunities for implementing system-level dementia risk reduction.

Findings across both studies illustrate the importance of understanding how the experience of homelessness shapes exposure to dementia risk. Using evidence from this thesis, I argue why modelling dementia risk reduction in homelessness must include an additional ten potentially modifiable risk factors to those included in the Lancet Commission report: oral disease and dental decay, illicit drug use, childhood neglect and trauma, neurologically impacting infections, stress, incarceration, nutritional deficiency, mental health, sleep inadequacy, and premature ageing. Dementia risk reduction should target the root cause and consequences of exposure to dementia risk, and not merely focus on lifestyle health promotion for people unable to action them.

This thesis concludes with a new model of mechanisms and pathways for dementia risk in people experiencing homelessness. Then, because of this unique perspective, I offer recommendations on how that risk can be ameliorated.

DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university

2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and

3. 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.

Signed……………………………………. Clare Beard

Date 16/08/2023

ACKNOWLEDGEMENTS

This thesis begins with an Acknowledgement of Country. Whilst this thesis has been completed on Kaurna land, Flinders University recognises the traditional owners and custodians across all lands on which it is located. These are lands of the Arrernte, Dagoman, First Nations of the South East, First Peoples of the River Murray & Mallee region, Jawoyn, Kaurna, Larrakia, Ngadjuri, Ngarrindjeri, Ramindjeri, Warumungu, Wardaman and Yolngu people. We honour their Elders past, present and emerging.

I want to begin by acknowledging those who made this thesis possible. First, Associate Professor Annabelle Wilson who graciously agreed to be my primary supervisor. I have benefited so much from your kind encouragement and leadership that has allowed me to evolve this research. Second, Dr Monica Cations. I learnt so much from your expertise and support as you helped guide me through my inexperience and many challenges with quantitative data. You both have been wonderful and very generous with your time and support. I have been very fortunate to have you both as my supervisors. I would also like to acknowledge Dr Kathryn Browne-Yung, whose research interests included homelessness, and who helped me get started with this thesis. I was sincerely grateful for that early support and the long, interesting talks we had on this topic. Additionally, I acknowledge Flinders University and the contribution of an Australian Government Research Training Program Scholarship.

I am profoundly grateful to the people experiencing homelessness who took the time to engage with me for this research. Without you, this thesis would lack the authenticity of a lived experience. I am extraordinarily grateful for your participation, especially whilst enduring the hardship of homelessness, and living in the bleakest of conditions. I hope I do justice to your generous contribution. I once read a statement about Melbourne's primary homeless population – that more than half of those living homeless on the streets would likely die within five years without intervention. This statement lays bare the stark reality of homelessness, and it has never left me. My gratitude to those who participated in this research is heartfelt, and I hope everything changes for them, living under such extraordinary difficult circumstances.

In a similar fashion, I want to acknowledge the key stakeholders who provided me their precious time to be interviewed. I know that some of you were challenged in the enormity of picking through multi-level issues surrounding cognitive wellbeing and in deliberating on dementia risk reduction interventions for clients, and I thank you for doing so. You have all been such wonderful advocates for your clients, earnest in your thoughtful and insightful contributions. I sadly think that your hard work, dedication and proficiency in providing services is often invisible from the broader general community. You are all very much appreciated and acknowledged for your expertise and capabilities. This thanks extends to Tony, who provided me helpful support in understanding the intricacies of Excel and other software platforms that helped me approach data analysis.

I have much gratitude for Dementia Australia, a not-for-profit specialist dementia service where I had a long and inspiring career alongside some great colleagues. The pinnacle of my career was managing the homelessness and dementia project. This brought me into a new world of working with people experiencing, or at risk of, homelessness and collaborating with homelessness and housing services. Every workday I felt challenged, inspired, humbled. So much did I love working in this space that without it, I was unlikely to ever find my fervour to take this next step.

Finally, I must acknowledge those in my personal life. Beginning with Jonathan, who provided all the support and space I needed to do this. You encouraged me to keep going whilst you picked up the slack, always seeing the bigger picture, and provided much appreciated reassurance. Thank you, you have been an amazing support throughout. To my family, both here in Australia and in the United Kingdom, I am so grateful that you all were behind my effort to complete this journey. My wonderful mother who always enquired of my progression and, who along with my brother, championed from afar. To my children, I have so much appreciation for you all, remember, you can pursue your aspirations, no matter when. I especially want to acknowledge my father, a compassionate and intelligent man who died from dementia. He would have been so proud to see me complete this journey. To my well-travelled, ever-adventurous, clever and generous sister, Christine, who wanted to pursue her own doctoral work before her relapse with cancer, I submit this thesis on the anniversary of your birthday. Dad and Christine, both of you are firmly embedded in this endeavour, and I dedicate this thesis in memory of you both.

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ABBREVIATIONS

ABS	Australian Bureau of Statistics
AD	Alzheimer’s Disease
ADA	Australian Data Archive
AIHW	Australian Institute of Health and Welfare
APOE4	Apolipoprotein E4
BPSD	Behavioural and Psychological Symptoms of Dementia
CDC	Centre for Disease Control
CSDH	Commission of the Social Determinants of Health
DEEWR	Department of Education, Employment and Workplace Relations
DKAS	Dementia Knowledge Assessment Scale
DLB	Dementia with Lewy Bodies
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition)
ETHOS	European Typology of Homelessness and Housing Exclusion
FASD	Foetal Alcohol Spectrum Disorder
FTD	Frontotemporal Dementia
GP	General Practitioner
HIV	Human Immunodeficiency Virus
MIHS	Melbourne Institute Classification of Housing Status
PRISMA-ScR	Systematic Reviews and Meta-Analysis Extension for Scoping Reviews
RED	Research Evaluation Database
SES	Socioeconomic status
SDoH	Social Determinants of Health
SHS	Specialist Homelessness Services
YOD	Young-onset Dementia
VD	Vascular Dementia

PREFACE TO THESIS

A quote by Daniel Quinn

I begin this preface with a quote on homelessness by Daniel Quinn, culture critic and novelist, known for his work on human relationships and the environment. It is quite a well-known quote, and I heard it many years ago when first reading up on the issue of homelessness. I have revisited it on many occasions over the years, and I include it here because, although succinct, Quinn inspires a thought-provoking interpretation on the struggle and disempowerment of homelessness.

> *"A castaway in the sea was going down for the third time when he caught sight of a passing ship. Gathering his last strength, he waved frantically and called for help. Someone on board peered at him scornfully and shouted back, 'Get a boat'" A quote by Daniel Quinn [1].*

This quote makes me think hard about homelessness and its implications for people experiencing it. It begins with Quinn's use of the word castaway; an outcast, outsider, a vagrant, a pariah, someone apart from mainstream society, an undesirable. This castaway is in trouble, this is the third time that he is sinking, literally. How much longer can he hold on? There is nothing around him to help, he has no supports and is alone, and he is drowning in despair and despondency. I envisage the ship as a society, full of comparative privilege and normality. When the castaway does call for help, he receives nothing but withering disregard. "Get a boat" is what he hears, but where does he get a boat from? Is he expected to make one whilst fighting to stay afloat? Are there any resources around him? Is he expected to build the boat by himself? Where can he find help in this hostile and deadly environment? Should he feel lucky that someone saw him, or is it best to drown quietly? Just as "get a boat" is proffered here, is it just as easy to expect people experiencing homelessness to just 'get a job' or 'get a home', without comprehending why they are there in the first place, and what keeps them there?

A theatre performance

Early in 2021 I was thrilled to be offered a small theatre ticket to watch ‘A Good Life’ in Adelaide. Named to reflect positivity, a series of nine drama vignettes were being performed by the aged care clients of a well-known homelessness service in Adelaide, South Australia. This homelessness service, located in the Central Business District, offered wide-ranging supports including meals freshly cooked on the premises and a range of social and support services across the broader homeless community, and is one of several inner-city homelessness services.

The theatre initiative was inspired by the then homelessness centre’s diversional therapist. We had previously worked together nutting out brain healthy resources for people experiencing homelessness. She had successfully sought out a small grant that involved working with external stakeholders with the aim of managing a co-designed theatre project. An aim of the project was to place the client group central to all discussion and decision making. The invited audience consisted of trusted contacts who would provide a supportive and non-judgemental presence. We were all fully aware of critical social, health and housing challenges that were faced by the ‘actors’. This knowledge was forefront in minds as we reflected on the enormous effort that had gone into making this show. I knew several of the ‘actors’ who were performing, and I was aware of their cognitive challenges, but as I watched, I realised this was a wonderful example of a strengths-based activity, tailored to meet individual abilities.

Reminiscent of The Choir of Hard Knocks, this activity empowered a group of vulnerable, housing disadvantaged people who were otherwise diminished in society. It enabled them to focus on what made or makes them feel good. The show was marvellous. The man who spent many years busking in his youth performed a splendid, self-written song accompanied with some very fine guitar playing, the frail lady, supported by an on-stage ‘buddy’, went through a routine of planting and harvesting flowers. Other performers played out their vignettes reflecting on past feel-good activities such as fishing, dancing, or singing. Each vignette showed that they had a different life before becoming homeless.

Performances were interspersed with some amazing artwork, self-produced by the ‘actors’ and which were accompanied with cheerful, uplifting music. To watch, was a very special and emotional experience. Undoubtedly, what I witnessed that night was a great example of a brain health activity in action. This small theatre production tapped into new learnings and challenges, bestowed a sense of purpose and self-worth, and provided socialisation and interaction. For those two hours these ‘actors’ were centre-stage, and in control, and they loved it. It was especially wonderful that the Adelaide Festival Theatre had come to the party and the performance was staged within the Adelaide theatre complex, supported by some serious professional technology and theatre expertise.

A few days after the performance I contacted the diversional therapist to convey my profound thanks for the invitation and we talked about the emotional impact the performance had on both ‘actors’ and audience. It was hard to convey just how amazing and extraordinary the evening had been, and I was so pleased to have been invited. Her reply was overwhelming. She stated that she wanted me to attend, partly because I knew most of the ‘actors’ from my time working with Dementia Australia, but particularly because, in her words, *“you just get it… the whole homeless thing, the struggle, the people, the challenges they face”.*

Homelessness presents many obstacles that impede any sense of purpose and satisfaction. This activity was a shining example for inclusion and promoted good cognitive wellbeing. Although this theatre production presented a one-time opportunity, hopefully, there will be other occasions that something similar will come their way again, even if not on such a grand scale. Pondering on this experience and how it encapsulates the crux of cognitive wellbeing in homelessness and what that means for dementia risk has been motivating. How do we understand dementia risk exposure for people experiencing homelessness and why would dementia risk reduction look differently for this population than it does for the general population?

To illustrate this point further, I next include a poem written by a gentleman who was experiencing primary homelessness at the time of its writing.

‘Although I Wish…’ A poem by Jacob Folger

All I got is this bag
Tattered and so frayed
One pair of socks to call my own
No place for my head to lay

Beg for money to buy my food
No fork or knife, man this is crude
I wish I knew what I could do
I should slam a six of booze

People passing me in fine business suits
As if I am not here
“I am a man!” I want to shout
This life is hard to bear

There is no job to be had
So, I sit and wait for better things
I organise my tattered bag
Whatever it takes not to feel sad

The sun is setting it is night
My fight has just begun
I pray I won’t freeze before it’s through
Although I wish my life was done

Reproduced in its entirety, with kind permission from Jacob Folger [2]
Formally homeless.

This poem by Jacob Folger illustrates how exposure to dementia risk can inadvertently become an integral part of the experience of homelessness. Jacob is experiencing primary homelessness and marginalisation. He is experiencing social isolation, feeling lonely, and is ignored by the wider community. His words describe feelings of sadness and despondency, suggesting depression. He questions living. Jacob is hungry, with no money for food. He is likely to be nutritionally deficient. Jacob is wishing he had beer because it helps blunt the day. All the time, Jacob is outside, exposed to the weather, knowing that the cold and damp will impact his health and wellbeing. Jacob is exposed to multiple potentially modifiable risk factors for dementia, just because he is experiencing homelessness.

Why this research?

This idea for this research grew from when I was working with people experiencing homelessness whilst employed by a major, not-for-profit, national peak body for dementia services in South Australia. The role began as a venture into a previously underexplored demographic, driven from a noble concern for equity and inclusion within a predominantly mainstream service provider. Prior to what I saw as a new and exciting role I was working with the general population where I would assist people understand their diagnosis of dementia and provide support in navigating through the maze of disability or aged care systems, general practitioners (GP) neurologists, gerontologists and anything else that had suddenly come into sharp focus. However, these were people with mostly good health literacy who actively sought out furthering their understanding of what a dementia diagnosis would mean and who were willing to join programs with others in similar positions. Transitioning from this reasonably stable environment into the world of homelessness was a challenge and it required a lot of relearning in how to offer realistic supports, suggestions, education and appropriate responses to referrals. In this diverse environment I needed to think and work differently than how I had previously so that I could better engage with a community intensely sensitive to being labelled and who already felt highly marginalised from mainstream services. As part of this change, I had to completely adjust my approach in how to introduce discussion of dementia and make sure that I did this in ways that were purposeful and considerate of the circumstance of homelessness. I quickly realised that quite often, people felt embarrassed or helpless, and defined by their homelessness.

Diversity and inclusiveness are paramount for a well-balanced and healthy society, however very few, if any, specific dementia programs had worked exclusively with people experiencing homelessness before this one. I was keen to ensure its success because I knew that people experiencing homelessness did not routinely interact with mainstream dementia services, and they likely struggled for advice and support if concerned with their cognition, especially short-term memory loss. However, very early on, three concerns became apparent. First, existing dementia resources and services designed for the general population were wholly inappropriate for those experiencing homelessness and alternatives were non-existent. Second, it was very important to wind dementia awareness right back to a basic understanding of brain health and what that means in the context of homelessness. Third, there was a need to address the supposition that cognitive problems were an inevitable consequence of homelessness, and I should not make any assumptions around lived experiences or lifestyle choices. Therefore, both the way I communicated dementia information and the content of information being communicated needed to profoundly change. Additionally, I also learnt that I could not expect people living in such dire circumstances to actively come to me, rather, I had to take the program to them using outreach pathways. In line with these principles, I began an exploration of trying to understand what is known about dementia and dementia risk exposure in homelessness and to look how it may differ from what we know in the general population. The consistent question I asked myself was how can we provide best practice for people experiencing homelessness who have cognitive problems if we do not first understand the issues for cognitive wellbeing and dementia risk exposure in homelessness? This was the conundrum that became the driver for undertaking this research, and which helped to identify the research problem: *homelessness as a barrier to cognitive wellbeing and dementia risk reduction*.

Prior to, and during the evolution of this thesis, I was aware that I should recognise the intrinsic influence that will have bearing on this research. For example, understanding what inherently informs me and how I evolve this research. I regard this as a form of personal ontology, such as knowing what is the inherent me, what are the properties of self, and in being aware of how my viewpoints came to be. I provide this as a standpoint, described in the next section.

Standpoint

This section conceptualises my standpoint. Like most people, I hold critical philosophical beliefs that influence how I perceive the world. These includes my objective and subjective perspectives and assumptions that position the way I view the nature of reality, situate knowledge, and in how I value human nature. My standpoint represents my position on how I view society and how I understand values influences how I inform my viewpoint. These should be acknowledged because these are theoretical beliefs that underlie how I approach my research[3]. These theoretical beliefs are constructed from day-to-day and historic influences, for example, in beliefs and tradition, and they are the factors that shape my perception.

Recognising one's own standpoint is desirable because standpoint is based on essentialism, and there are times that we should adjourn our own point of view to metaphorically see the world from the perspective of others.[4] Whilst I acknowledge my own set of ideals and the lens from which I approach this work, I must further acknowledge these have been formed from vastly different life experiences than those who are at the centre of this research. Nonetheless, my history of working with people experiencing homelessness and alongside homelessness service providers has itself shaped my held assumptions. This declaration of standpoint is relevant in how it influences and frames my approach and analysis of the data in this research, and the ways in which I intemperate and present the data findings.

In many ways, my cultural and social background was typical of that seen among families living in an English village. I have fond memories of childhood, filled with adventures, freedom and friendships, and parents who implemented lenient but fair and consistent boundaries. They were the relaxed childhood norms of the decade, where children spent considerable time playing outdoors, socialising with friends, and cycling around having general fun. I had access to the village schools and a tertiary education at a time when job and housing security was regarded as custom. I was able to forge opportunities for my own future and at my own pace.

However, my philosophical beliefs are not neutral. A childhood influenced by parents who actively supported Amnesty International, Greenpeace, the World Wildlife Fund, and safe water, sanitation and food programs in Africa, and the need for a more equitable and fairer world were foundational. In my later years, I included homelessness as a moral cause, and I concur that homelessness is a human rights issue. People experiencing homelessness are disempowered and lack agency in matters that affect them and are unable to change structural forces that disenfranchise them. I believe that protracted, entrenched homelessness is brutalising, dehumanising, and is generally poorly governed by people who lack political will to do something about it. I am aware that I have not endured what others have, and therefore I cannot fully appreciate their challenges, injustices or life adversities. What I have is a vicarious understanding, and I hold empathy and concern. My viewpoint of homelessness is centred on social justice principles, that homelessness is an impediment to living well, is a societal problem rather than an individual one, and the avoidable psychosocial and biological consequences of homelessness are a moral tragedy. Homelessness is a measure of our social conscience.

I believe that language is not always impartial, and words have power which places responsibility on those who are privileged to use them, so I am mindful of the language and phrasing used in this thesis. I strive to reduce deficit language in respect to both homelessness and dementia because each are discriminatory and disempowering. I am an advocate for improving cognitive wellbeing and dementia risk reduction opportunities across all vulnerable communities and believe this should be enabled from the highest authority through governance and policy making. My standpoint explains how I will inherently make sense of this research, the importance this research has at a personal level, and clarifies the perspective of how I approach and present this thesis.

Notes on thesis

- Throughout this thesis, I endeavour to maintain a sequential and logical flow between and within the chapters. To assist this process, I have included several figures to illustrate the movement through the chapters of the thesis whilst keeping them cohesive.
- At the beginning of each chapter, I will include a figure (i.e., Figure 1, shown on the next page) to show how the thesis is progressing and which highlights the chapter purpose, For example, whether the chapter relates to context, theory, investigation, or outcomes and new knowledge.
- The thesis contains two studies which are presented in Chapter 5: *The Lived Experience* and Chapter 6: *Stakeholders in Homelessness*. Both chapters are lengthy, containing quantitative and qualitative methods, data results, and an integrative discussion. To enhance readability, each study contains a graphic to indicate its progress through its design and purpose.
- This thesis explores two socially vulnerable topics of 1: homelessness, and 2: dementia. To maintain confidentiality, I have deidentified all references that may expose the identity of any person or service provider who participated in this research. This complies with the Human Research Ethics Committee approval for this research (project number: 1861) which is in accordance with the National Statement on Ethical Conduct in Human Research 2007 (updated in 2018).
- All participants, whether people experiencing homelessness or stakeholders in homelessness voluntarily gave their consent for participation with the expectation of anonymity and that confidentiality would be preserved. People experiencing homelessness who participated in this research were renumerated for their time with a card voucher ($40) for a major supermarket.

CHAPTER 1: INTRODUCTION TO THESIS

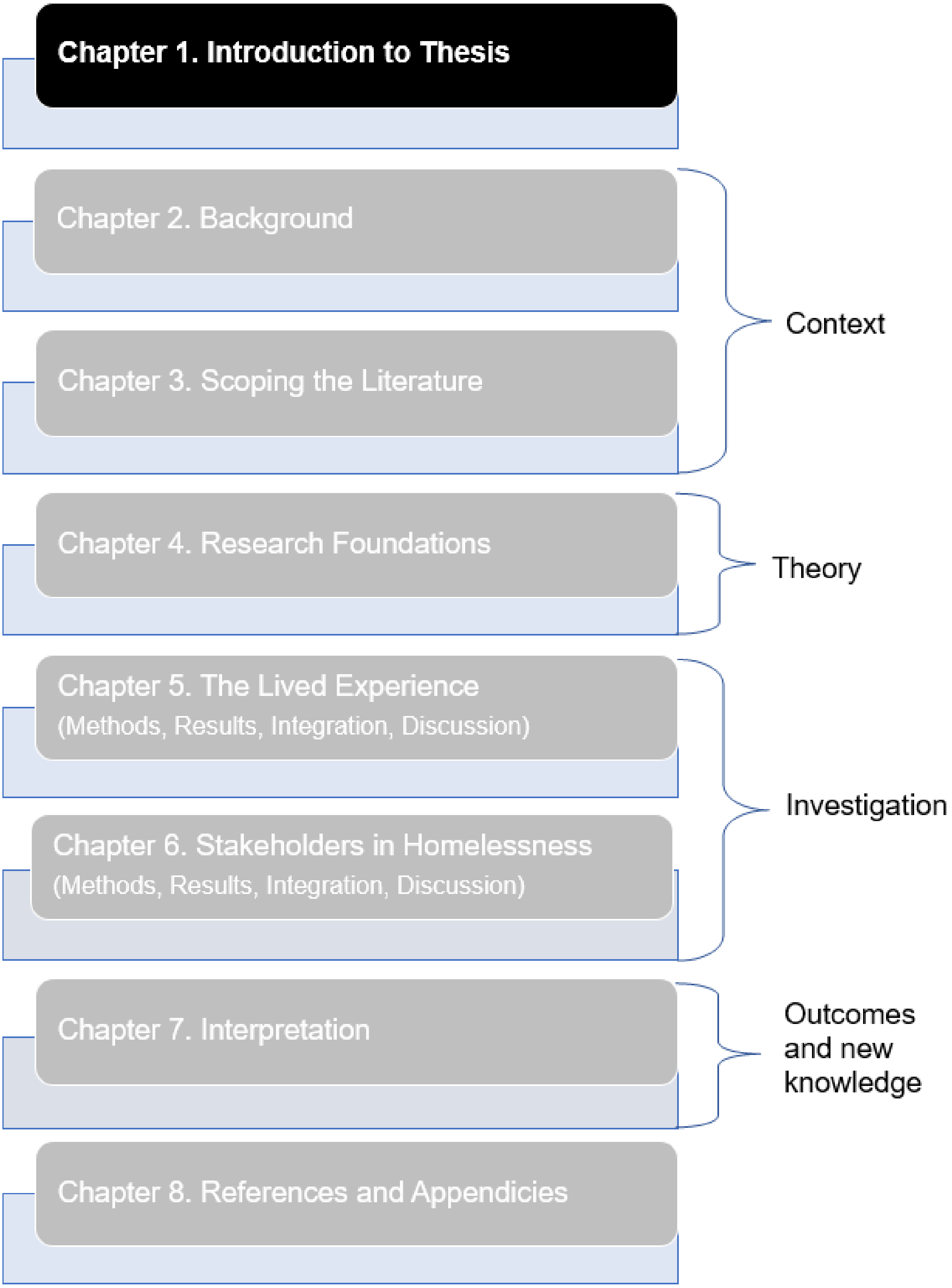

Figure 1. Thesis structure - Chapter 1

Introduction to Chapter

In this chapter I introduce this thesis. I begin by providing an outline of the thesis structure and a summary of the chapter contents. I then proceed with a section on the definitions and explanations of concepts and understandings that are discussed throughout the thesis. These definitions and explanations represent important and central concepts applied to the research and are provided to maintain consistency in their application and use across the thesis. I follow this with an overview of the research where I provide the research questions, aims and objectives. The research aims will describe the overall goals of the research, and I indicate how I intend to achieve those aims. I then close the chapter with a summary of what has been covered.

Thesis structure

The thesis comprises eight chapters, including this introduction (Chapter 1) and the reference list and appendices (Chapter 8). The remaining chapters are arranged into the following components: Context, Theory, Investigation, and Outcomes and New Knowledge, shown in Figure 2, and the chapter contents are shown in Table 1.

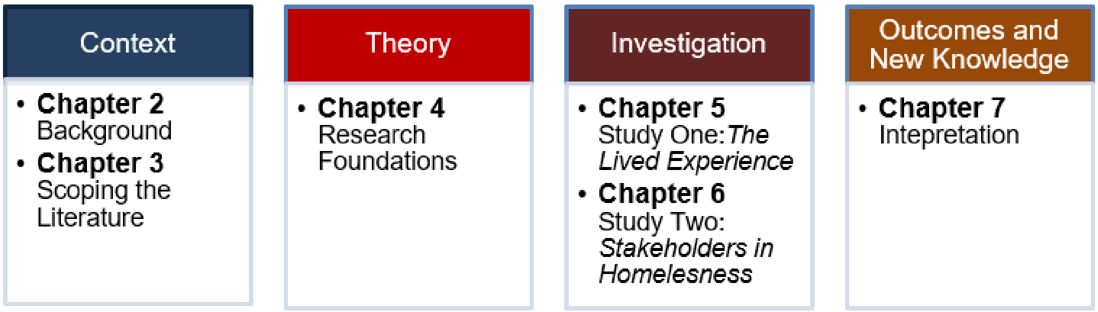

Figure 2. The four components of the thesis

Table 1: Overview of chapters included in this thesis

Chapter Number	**Contents**
Chapter 1: Introduction The thesis structure Definitions and explanations The research overview The research questions, aims and objectives	In this chapter I present the overall construction of the thesis. It presents the research questions, aims and objectives, and explains how these will be answered. Definitions used in this thesis for homelessness and dementia are provided. Explanations that are used throughout the thesis, such as what is meant by ‘life course’, ‘brain health, social determinants of health, and other important and frequently used concepts.
Chapter 2: Background Homelessness Dementia	This chapter introduces the background and context for homelessness, presented using an Australian perspective. Background and context for dementia is subsequently considered, including risk factors for dementia.
Chapter 3: Scoping the Literature	This chapter focusses on understanding what is known about potentially modifiable risk factors for dementia in homelessness in the literature. This component is important for identifying whether a research gap exists.
Chapter 4: Research Foundations Research design Epistemology Theoretical perspective Methodology Methods	In this theoretically-based chapter I introduce the research process, guided by the research design of Michael Crotty and his work on the Foundations of Social Research [5] This chapter outlines how this mixed methods research will apply a pragmatist epistemology, use a critical theory theoretical perspective, and the methodological lenses of the Social Determinants of Health and Transformative Approaches to guide the research
Chapter 5: The Lived Experience (Methods, Results, Discussion) *Part One*: Analysis of a longitudinal survey	This is the first of two mixed methods studies and presents the methods, findings and discussion of *The Lived Experience*. It places a focus on how homelessness confers exposure to potentially modifiable risk factors for dementia. The study has

Part Two: People experiencing homelessness	two components, a quantitative analysis of a longitudinal survey, and qualitative interviews of people experiencing homelessness.
Chapter 6: Stakeholders in Homelessness (Methods, Results, Discussion) *Part One:* Dementia knowledge survey results and analysis *Part Two*: Interviews with key stakeholders in homelessness	This is the second of two mixed methods studies and presents the methods, findings and discussion of *Stakeholders in Homelessness*. It begins by identifying the level of dementia knowledge across a cohort of the South Australian homelessness workforce and elucidates a quantitative understanding of gaps, barriers, facilitators and opportunities for improving cognitive wellbeing and dementia risk reduction for people experiencing homelessness.
Chapter 7: Interpretation Presentation of findings Interpretation of findings Original contribution to knowledge Implications	This chapter begins by providing a summary of the findings from the two studies in line with mixed methods. It is followed by an interpretation from of the whole thesis and clarifies what is the new contribution to knowledge and the implications of this contribution. I present a new model for considering dementia risk reduction in homelessness and provide recommendations. This chapter concludes the research process.
Chapter 8: References and Appendices Reference list Appendix	This final chapter presents the reference list presented using Vancouver referencing convention, followed by appendices.

This next section of the Introduction presents a summary of existing definitions and highlights those which will be used in this thesis. This is a point of clarity as definitions may vary within and outside of Australia. I also use this section to explain how I am interpreting concepts that are an integral component of this research.

Definitions of key terms, concepts and explanations used in this thesis

In this section I cover a several definitions and terms used throughout this thesis. This is for clarity because several definitions can be used to explain a concept that may confound or misinterpret meaning. This section therefore establishes a shared understanding of definitions for key terms, concepts and explanations.

Homelessness

‘Homelessness’ is an ambiguous term because no internationally agreed definition of homelessness or commonly accepted framework for measuring homelessness exists. The terms ‘homeless’ and ‘roofless’ can have multiple meanings relative to different housing circumstances, therefore conceptualising homelessness has been much debated.[6]

Historically, Australia’s national-level homelessness data had been mostly defined by either Chamberlain and MacKenzie’s (1992) cultural definition of homelessness,[7] that was largely adopted across community services and which served as a principle definition until 2012.[8] The fundamental contention underpinning Chamberlain (2014) cultural definition is that homelessness is a relative concept to housing norms within a particular culture [9] and shared community standards exist that should be achievable in a contemporary Australia.[10] For example, having access to a small rental unit (apartment or flat) that consisted of a bedroom, living room, kitchen and bathroom became the minimum community standard from which a primary, secondary, and tertiary criteria of homelessness emerged.[10] Primary homelessness includes people who do not have conventional accommodation such as rough sleeping (on the streets), living in cars or other temporary shelters. Secondary homelessness represents those who move frequently from one form of shelter to another, mainly identified as couch surfing, or moving between emergency shelters, whilst tertiary homelessness refers to those staying in boarding houses on a medium or long-term basis (13 weeks or more) in accommodation that lacks the minimum community standard.[10]

However, the cultural definition of homelessness was not enshrined in Australian legislation and the legal positioning of homelessness deferred to the Supported Accommodation and Assistance Act (1994) which asserts that a person is homeless only if he or she has inadequate access to safe and secure housing, where that access:

- damages, or is likely to damage, the persons health; or

- threatens the person's safety; or
- marginalises the person through failing to:
    - provide adequate personal amenities; or
    - the economic and social supports that a home normally affords; or
- places the person in circumstances which threaten or adversely affect the adequacy, safety, security and affordability of that housing

Australian Government (1994)[11]

The official Australian legislative definition up to 2008 was subjectively used to identify service eligibility, with the cultural definition of homelessness being used to explore the extent of homelessness in the quinquennial population Census between 1996 and 2006. It was also used for the first Australian Bureau of Statistics (ABS) publication *'Counting the Homeless'* [8] that presented the findings from the 2001 Census. However, subsequent ABS publications have relied on a statistical definition of homelessness, developed by the Australian Bureau of Statistics that was operationalised for improved enumeration for the purpose of the Australian Census of Population and Housing.[8] The Australian statistical definition was informed by a Eurocentric framework for defining homelessness, known as the European Typology of Homelessness and Housing Exclusion (ETHOS), developed by the European Observatory on Homelessness for a consistent measure of homelessness across Europe.[8, 12-14] However, ETHOS itself is not internationally standardised where enumerating homelessness remains notoriously challenging given the variance of definitions and the methodologies used.[15]

Nonetheless, in making the change toward a statistical definition the ABS moved to address concerns of empirical ambiguity observed in Chamberlain and Mackenzie's cultural definition and better recognise the complex dimensions of homelessness represented in changed cultural perceptions.[16] Briefly, the ABS statistical definition states that "when a person does not have suitable accommodation alternatives, they are considered homeless if their current living arrangement is in a dwelling that is inadequate; or has no tenure, or if their initial tenue is short and not extendable; or does not allow them control of, and access to space for social relations."[8] Within this overarching definition, six categories of homelessness are recognised:

- Persons living in improvised dwellings, tents or sleeping out
- Persons in supported accommodation
- Persons staying temporarily with other households
- Persons living in boarding houses
- Persons in other temporary lodgings
- Persons living in severely crowded dwellings

Australian Bureau of Statistics, 2018.[17]

Defining 'crowding' has been an important aspect of recent social policy within Australia, and people living in severely overcrowded houses are seen as the fastest growing category of homelessness.[18] Based on the Canadian National Occupancy Standard (CNOS), the ABS regard severe overcrowding as a dwelling which needs four or more extra bedrooms to house the people living there.[17]

Whilst the statistical definition has since become the standard definition for Australian data collection, difficulties still arise in identifying people who are housed, but not homed, and who remain potentially unrecognised within the framework definition. Examples include adults and children experiencing domestic violence, family exposure to physical and sexual abuse for children and young people, vague rental arrangements without security of tenure, and having residence in a room lacking adequate facilities.[16]

To help address issues of inclusivity the ABS 2014 information paper: *Aboriginal and Torres Strait Islander perspectives on homelessness*[19] used a consultation process in which First Nations peoples' connection to country, kinship obligations and cultural mobility were recognised, with guidance on how cultural considerations should be interpreted within the statistical definition framework.

I refer to national and international literature throughout this thesis and each has inherently referenced to its own country's definition of homelessness. Notwithstanding this point, a commonality exists across Western models of homelessness in identifying homelessness as a complex public health concern that goes beyond 'rooflessness'.

When used in this thesis, the term 'homelessness' refers to all types of homelessness under the statistical definition, and include those at risk of homelessness, people supported by homelessness service providers, and those in community accommodation or housing with a history of homelessness or who would otherwise be homeless.

Dementia

Current definitions of dementia have evolved from a historical context where they stem from the Latin root word *demens*, which means to be out of one's mind.[20] In antiquity, concepts of dementia were described in Greek and Byzantine texts that separated a historical understanding of dementia across two periods, those that precede Posidonius, and those after which differentiated dementia in old age from dementia from other causes (referred to as morosis).[21] However, in modern history, the work of psychiatrist and neuropathologist Alois Alzheimer (1854-1915) and his patient, Auguste Deter at the Frankfurt Asylum advanced the understanding of Alzheimer's disease, regarded the major sub-type of dementia.[22] Since then, more than 100 types of neurodegenerative conditions have been identified that fall under the broad definition of dementia.[23]

Several definitions of dementia exist. Alzheimer's Disease International (ADI) refers to dementia as a term used to describe different brain disorders that affect memory, thinking, behaviour, and emotion.[23] The World Health Organisation (WHO) describes dementia as a term for several diseases that affect memory, thinking, and the ability to perform daily activities.[24] The Centres for Disease Control and Prevention (CDC) states that dementia is not a specific disease, but rather a general term for the impaired ability to remember, think, or make decisions that interferes with doing everyday activities.[25]

When used in this thesis, the term 'dementia' means a collective group of neurodegenerative diseases that, in most cases, cause progressive cognitive decline.

Differences in dementia etiology and expressed characteristics have also attracted a range of various terminologies. For example, dementia in people under the age of sixty-five has been subject to multiple nomenclatures including pre-senile dementia, young onset dementia, adult-onset dementia, working-age dementia, younger people with dementia, childhood dementia, and early onset dementia.[26]

When used in this thesis, the term 'young onset dementia' refers to dementia diagnosed in adults under the age of sixty-five years.

Brain Health

The concept of brain health is discussed throughout this thesis and therefore it is important to clarify what is meant by 'brain health'. Brain health is synonymous with the term cognitive health[27] and refers to how well the brain functions across cognitive, sensory, social-emotional behavioural and motor domains.[28] It is a distinct concept from mental health, although brain health can be affected by functional brain disorders that include mental health conditions, along with a broad range of other brain disorders and neurological diseases.[29, 30]

My experience of working with people experiencing homelessness has shown me that the concept of brain health was best understood as the brain being in the best condition that it can be. Lifestyles that are cognitively and socially stimulating, including physical activity, are thought best for preserving cognitive wellbeing through the actions of building cognitive reserve,[31] which is defined next.

When used in this thesis, the term 'brain health' relates to having optimal and multidimensional brain functioning.

Cognitive Reserve

Cognitive reserve is reflected in the brain's structural characteristics, the number and density of neurones, and how well they connect and communicate.[32, 33] It is an important concept used in this thesis when discussing characteristics of homelessness, life course and risk for dementia. Cognitive reserve relates to the ability to improve the structural integrity of the brain and results from cognitively enhancing endeavours, such as childhood education, occupation and the choice of leisure activities.[32, 33] While theorising that greater cognitive reserve compensates for neuropathological changes for a longer time than in people with less cognitive reserve, a paradox may exist where cognitive reserve attenuates the pre-dementia stages but worsens cognitive decline after the diagnosis of Alzheimer's disease.[34] Being brain healthy and having ability to accumulate cognitive reserve from early-life is linked to life course perspectives of dementia risk.[35]

When used in this thesis, the term 'cognitive reserve' means the resistance the brain has to neuropathological damage, measured by how it can maintain normal cognitive function in the presence of that damage.

Life Course

Chapter 5: A Lived Experience identifies a common set of characteristics seen in homelessness that are associated with events occurring from childhood through adolescence and adulthood. Some of these events coincide with risk factors occurring at critical time periods that may influence late-life social, behavioural and health outcomes.

'Life Course' is a framework, perspective or paradigm focused on the relationship between variables associated with social and behavioural factors.[36] Its premise is based on understanding late-life health outcomes by accounting for a past of exposure to interdependent factors that cross time and life domains.[37] The original concept of life course emerged from sociology[37, 38] and has similarities with lifespan perspectives, developed from the field of psychology[38] resulting in these terms often being used interchangeably.[36] However, apparent differences lie in how life course places its emphasis on external forces in the social context.[37] These forces influence mechanisms that shape individual health outcomes though societal systems (family, education, occupation, welfare systems), individual life histories (poverty, accumulated resources, work experiences), and social roles (social norms, gender norms, socioeconomic status).[38] They are particularly related to socially-structured inequalities.[37] On the other hand, lifespan places its focus on internal factors that are biogenetic, behavioural and cognitively motivational.[37] These factors influence individual development from conception to death over the duration of life.[36]

Whilst the concept of life course is provided here, I also discuss the life course approach to dementia risk in Chapter 2.

When used in this thesis the term 'Life Course' relates to a series of socially defined interactions with factors occurring at specific times throughout the lifespan that influence late-life health.

Models of health

Dementia, as a neurodegenerative condition is mostly pathologised and pharmacologically managed within a biomedical model of health. However, exposure to dementia risk over the life course may be best explained in the perspective of a person's social health background [39] and with consideration for their sociocultural context.[40] Therefore, whilst both biomedical and social models of health have relevance for this thesis much of the research is approached from the perspective of a social model of health. This approach, however, does not mitigate the opportunity to integrate biomedical and psychosocial features seen across homelessness and risk for dementia. For example, including social health is relevant to understanding exposure to dementia risk, and is consistent with the multifactorial nature of dementia,[41] and the social problem of homelessness has biomedical consequences affecting people's health outcomes.[42] For this thesis, I accept that biology alone does not create health and illness [43] or account for all health outcomes, and that health outcomes cannot exclude social factors. Moreover, the social model of health outcomes are well documented, and will be observed in this thesis using the work of the World Health Organisation's A *Conceptual Framework for Action on the Social Determinants of Health* by Solar and Irwin[44] discussed in Chapter 4. Using this approach is further supported by Weinstock [45] and others who place emphasis on the distribution of social goods (i.e., income, housing, education) that exert a strong, and sometimes dominant impact on health.

In this thesis I consider the 'biomedical model of health' to mean health defined by absence of disease in the biological and genetic sense. I consider social models of health (i.e., psychosocial) related to the social, cultural, political and environmental contributors of health and wellbeing.

Health equity and health inequities

I consider health equity as being a principal construct for this thesis because the thesis focuses on some of the most impoverished and vulnerable members in our society who experience poor health outcomes. Equity is an ethical concept, based on principles of social justice,[46] defined as "the absence of unfair, avoidable or remedial differences among groups of people, whether those groups are defined socially, economically, demographically or geographically or by other dimensions of inequality (sex, gender, ethnicity, disability, or sexual orientation).[47] This ethical concept is a central tenet underpinning the methodology used in the first study in this thesis. More specifically, health equity is the guiding ethical principle of the Commission of the Social Determinants of Health (CSDH) framework[44] from which I examine causes for poor cognitive health outcomes in people experiencing homelessness. I discuss the detail of the CSDH framework in the methodology in Chapter 4.

Conversely, health inequities are unjust, systemic and not random, avoidable and unnecessary.[48] Because health inequities, and consequently the adverse outcomes for health, can theoretically be ameliorated, they are conceptually linked to power differentials and health injustices that operate in homelessness. It is this principal that underlies the second methodology used in this research which takes a transformative approach to examine health inequity as a social justice and human rights issue, as championed by Mertens[49-51] and which should be reflected in transformative values that are incorporated in homelessness service provision.[52]

When used in this thesis, the term 'health equity' as having a fair and just opportunity to reach the highest level of health. I use the term 'health inequities' to mean the systemic, avoidable and unfair differences that result in poor health outcomes.

Lifestyle drift

The concept of lifestyle drift is important for this thesis. Lifestyle drift is an identified barrier in addressing the broad determinants of health, explained through understanding the role of government action on upstream and downstream factors known to shape health outcomes. In this thesis I relate upstream determinants to be macro factors, such as welfare, emerging from global forces and national policies that determine the distribution of economic and social goods,[53] allowing for discriminatory power differentials [54] advantaging some and disadvantaging others generating a source of health inequity.[54, 55] Downstream factors are mostly the individual lifestyle aspects that impact on health, for example, cigarette smoking, obesity or low physical activity.

Lifestyle drift can be considered in literal terms, where government policy once began by recognising the need for action on upstream, social determinants of health, to then ‘drift’ toward downstream factors which focus on individual lifestyles.[56] The concept of lifestyle drift is an established phenomenon, although there is scare empirical explanation of why it occurs,[57] other than it is easier, or politically strategic for governments to focus on individual factors rather than implementing systemic change to overarching policies. The problem with lifestyle drift is how responsibility for health outcomes becomes focused on proximal (downstream) factors where blame can be placed on individuals without need for addressing distal (upstream) social determinants of health.[56, 57] This in part, explains why lifestyle health promotion interventions are often not successful or sustainable in making significant change in individual behaviours [58, 59] which becomes an important point for understanding public health actions and the recommendations arising from this thesis. One result of lifestyle drift is that it retains the structural obstacles that impede meaningful change, and additionally, any failure of lifestyle health promotion interventions further contributes to negative public perceptions of people experiencing homelessness, especially where anti-social behaviours are observed, that are seen as community-level social harms.

When used in this thesis, the term 'lifestyle drift' means the phenomenon of 'drift' that begins with government commitment to address social determinants of health through broad policies to later refocus on individual level and lifestyle factors to explain poor health outcomes or target interventions.

Social Determinants of Health

In this thesis, in Study One : *The Lived Experience*, I have embraced the World Health Organisation's theoretical Framework for Action on the Social Determinants of Health [44] from which to examine cognitive health outcomes in people experiencing homelessness. This framework is based around social determinants of health. Social determinants of health are described as the forces that shape health for the better or for the worse, with consistency and reproducibility [43]. The World Health Organisation (WHO) list social determinants as being:

- Income and social protection
- Education
- Unemployment and job insecurity
- Working life conditions
- Food insecurity
- Housing, basic amenities and the environment
- Early childhood development
- Social inclusion and non-discrimination
- Structural conflict
- Access to affordable health services of decent quality

World Health Organisation [60]

Note: social determinants of health are distinguishable from population health. Population health is a broad term describing the health outcomes of a group of individuals where social determinants of health are one set of factors involved in shaping those outcomes.[43, 61]

In this thesis I use the term ‘social determinants of health’ (SDoH) according to the World Health Organisation definition (2022), to mean the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems.

I now move on to provide an overview of this research, including the research questions and aims.

Research overview

This thesis presents an original investigation into potentially modifiable risk factors for dementia in people experiencing homelessness and dementia risk reduction.

Research scope

The scope of this research is on the experience of homelessness and how it may or may not influence exposure to risk factors for dementia and the role of dementia risk reduction. It does not evaluate the incidence of dementia nor extend research to include the clinical management of dementia in people experiencing homelessness.

The research

In this thesis I present a mixed methods study to investigate and combine two important public health concerns of homelessness and dementia to explain homelessness as a barrier to cognitive wellbeing and dementia risk reduction. Both homelessness and dementia are emotive topics, that combined, provide a dire circumstance for cognitive health and wellbeing. The cognitive wellbeing of people experiencing homelessness is poor and deficits in psychosocial and cognitive abilities account for 24-42% of reduced life satisfaction.[62] In addition, homelessness is associated with high rates of premature morbidity and mortality,[63, 64] and trends suggest that Australia’s homeless population has rapidly aged,[65] making the concern of risk for dementia a highly relevant topic for investigation.

This investigation will provide an original contribution to knowledge by presenting a new understanding of how the experience of homelessness contributes to exposure for dementia risk and provide a picture of risk factors associated with dementia in people experiencing, or at risk of, homelessness. Finally, this research will present suggestions for public health actions and health promotion interventions that may help cognitive wellbeing and attenuate potential risk for dementia risk in people experiencing homelessness.

Research questions

This thesis poses two questions using the perspective of critical theory through the lenses of social determinants of health and a transformative approach. These concepts will be explained later in the thesis. The first research question relates to the lived experience of people experiencing homelessness gained from the perspectives of people who are homeless. I hope that by doing this, I can help provide them some agency by having their voices heard and by ethically representing what they feel is important for others to comprehend and account for when considering their cognitive wellbeing. The second research question is related to stakeholders in homelessness and explains their understanding of dementia and what system constraints and enablers exist for promoting better cognitive wellbeing for their clients. The two research questions are:

1. *How does homelessness impact cognitive wellbeing and exposure to dementia risk?*
2. *How can dementia risk reduction for people experiencing homelessness be improved?*

To approach these questions, I have developed the following research aims and objectives:

Research aims

The aims of this thesis are to:

- To determine characteristics of homelessness that may lead to cognitive harm and confer risk for late-life dementia.
- To understand themes arising from the experience of homelessness in the context of potentially modifiable risk factors for dementia.

- To understand dementia knowledge in services to people experiencing homelessness.
- To describe how cognitive wellbeing and dementia risk reduction strategies may be supported and improved.

Research objectives

Several objectives have been developed to explain what I will do to achieve sufficiency of investigation so that I can answer the research questions. These research objectives are to:

- Present patterns seen in data identifying characteristics of people experiencing homelessness.
- Explore parallels seen between the experience of homelessness and potentially modifiable risk factors for dementia.
- Quantify the level of dementia knowledge in a cohort of specialist homelessness services in South Australia.
- Synthesize data gathered from stakeholders in homelessness to improve understanding of barriers and facilitators to dementia risk reduction.

Chapter summary

This chapter provided an introduction and overview of the thesis structure, including an introductory summary of the chapter contents. Terms and explanations used in the thesis were described. The research overview was provided, including the scope of research, research questions, aims and objectives. The next chapter provides background and context to the research.

CHAPTER 2: BACKGROUND

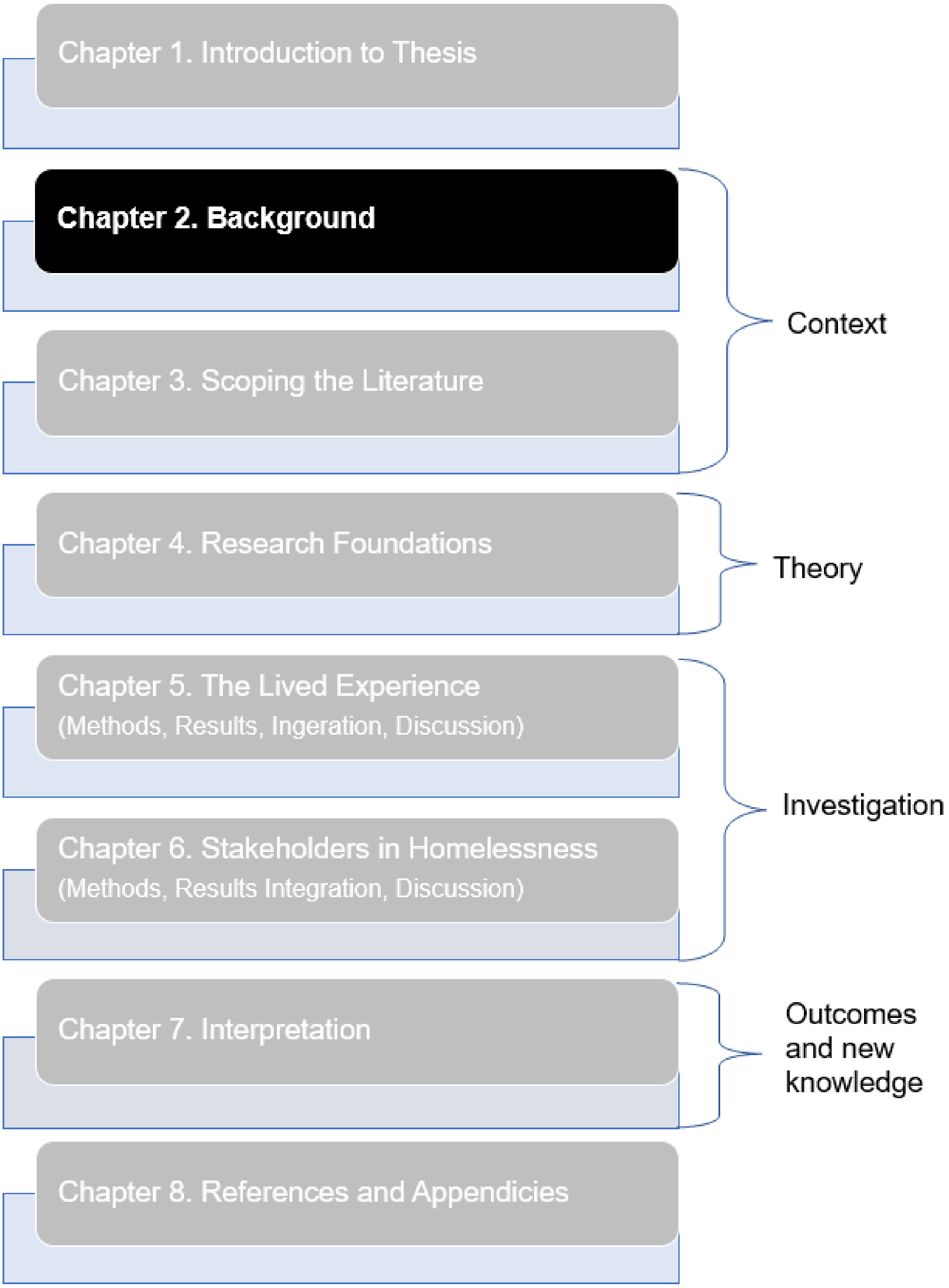

Figure 3. Thesis structure - Chapter 2

Introduction to Chapter

This chapter is presented in two parts. The first part provides the background and context of homelessness and emphasises the Australian perspective. It includes homelessness service provision, current trends and housing models. The second part presents the background and context of dementia and introduces twelve potentially modifiable risk factors seen through a life course model. This model is demonstrated in the influential work of Livingston et al[66] and their report on dementia prevention, intervention and care.

In this thesis I consider the two components of homelessness and dementia separately because each are a concern for public health. Presenting them separately helps provide a clearer understanding of background and context of each topic as a public health concern, and allows for a nuanced understanding from which to consider the research questions: *How does homelessness impact cognitive wellbeing and exposure to dementia risk? and*, *How can dementia risk reduction for people experiencing homelessness be improved?*

Homelessness

In this next section, I present an Australian perspective of homelessness. I provide a brief descriptive statistical overview of how homelessness currently presents in Australia before discussing major contributors to homelessness. I will then provide some First Nations perspectives of homelessness, present housing models relevant to homelessness, service provision, and finally discuss wellbeing and health in homelessness.

Homelessness in Australia, reported from current literature

Homelessness is considered a profound public health concern, with the 2021 Census indicating that 122,494 people in Australia are reported as experiencing homelessness.[67] This calculates to be an estimated fifty people are experiencing homelessness for every 10,000 people and Australian specialist homelessness services (SHS) assisted 272,700 people in the 2021-2022 period at a rate of 106.2 per 10,000 people.[65] The most recent monthly data (March 2023) indicates that of 95,767 clients receiving support from specialist homelessness services, 60.62% (*n*=58.051) were female, 39.38% (*n*=37,716) were male.[67]

First presentations at specialist homelessness services indicate that around 57% (*n*=44,500 clients) were at risk of homelessness and 435 (*n*=11,100 clients) were experiencing homelessness. The remainder of clients had an unknown or undisclosed housing status. In addition, the length of agency support has increased of late, with a median of 53 days of support in 2021-2022, up from 39 days of support in 2017-2018. There is a trend towards increased numbers of older people who are engaging with SHS agencies with 25,300 people aged 50 years and older, compared to 24,100 people in 2017-2018.[65] Data for non-specialist homelessness services is unknown.

Contributors to homelessness

A major contributor to homelessness is housing affordability, which has significantly declined across Western countries, including Australia.[68] Limited social housing stock and high private rental costs push housing security out of reach for increasing numbers of people seeking accommodation. Substandard, precarious, or absent housing has a negating effect on a person's ability to participate well across broad-scale activities such as having constructive social interaction, education, employment, and life-positive experiences.[69] However, it is known that homelessness extends beyond a lack of housing, is a cumulative experience and presents a multidimensional social dilemma.[70-72] However, past explanations of homelessness have not always addressed these complex layers, as seen in the definitions of homelessness previously presented in Chapter 1. For example, historically, people were initially thought culpable for their own homelessness, citing alcoholism, drug taking, or irresponsible behaviours.[71] Stigma and stereotyping paid attention to individual flaws and poverty was regarded as an avoidable fault.[73] Later, it was understood that structural factors were relevant contributors to homelessness, including job insecurity, low wages, and unavailable housing, and more recently, health traits such as mental health conditions, personality disorders, disabilities and incapacities have seen to make-up a cohort of vulnerabilities for homelessness.[71]

Instead, such factors contribute to a constellation of risk, and includes experiences of criminality and incarceration, childhood institutionalisation, abuse, and low socio-economic and educational positioning, all of which span individual, socio-economic and environmental exposures for homelessness. These risks can coalesce sufficiently to impact and destabilise existing housing security or in being able to attain housing, placing a person along a continuum of situational, episodic, or chronic homelessness.[74] Likewise, systemic determinants that create disadvantages are often ill-addressed through inadequate funding and housing policy decisions.[75]

Australian First Nations perspectives

Whilst different concepts and definitions of homelessness exist between countries, this is also true for Australia. Australian First Nations people constitute around 3.8% of the total Australian population yet are an over-represented group in homelessness,[76] accounting for around 28% (72,900) of people linked to SHS agencies. This equates to 798.7 First Nations clients linked to homelessness services per 10,000 First Nations population and compares with 79.0 per 10,000 of non-First Nations clients.[65]

A historical context contributes to Australian First Nations homelessness which dates back to colonisation with the dispossession of Australian First Nations land and culture,[77] including the forced removal of children from families that only ended in the 1970s.[78] As a result, Australian First Nations cultural and historical values and beliefs are often situated within a form of spiritual homelessness where living apart from one's homeland, being separated from family or kinship networks, being unfamiliar with one’s heritage or 'sleeping rough in the long grass' are defining.[79] The consequence of spiritual homelessness is, in part, seen when Australian First Nations people have adequate shelter, security of tenure and can control social activity (and therefore not be enumerated as experiencing homelessness); however, still regard themselves as homeless due to the disconnection from their family, culture or community.[80]

Although some Australian First Nations people may live outside the ABS definition of homelessness, it is likely that the 28% (72,900) representation of Australian First Nations people, previously mentioned, reflects a large under-enumeration of Australian First Nations homelessness. In contrast to Western cultural practices and homelessness definitions, some Australian First Nations people temporarily housed with extended family may not regard themselves as being homeless because they are with their kinship group, or they may associate home as being a place or location rather than a physical house.[17] Another dilemma recognised in Australian First Nations culture and homelessness lies with the definition of overcrowding and of Australian First Nations people's perception of what constitutes inadequate space (bathrooms, bedrooms and kitchen facilities). Western housing designs, particularly in remote Australia, are climatically and culturally inappropriate[81] and fail to recognise traditional norms of accommodating large numbers of immediate and extended family. As such, homelessness definitions for overcrowding do not account for antecedent factors that contribute to individual situations, nor personal or cultural situations.[82]

Despite some progress, initiatives to end homelessness remain elusive to Australian First Nations accommodation and health needs, with a 2021 report indicating 15 Australian First Nations people sleeping rough in the Adelaide parklands were determined to have died, despite having in excess of 800 collective interactions with the housing department.[83]

Other housing vulnerable communities

Alongside Australian First Nations people, other communities vulnerable to social exclusion make them particularly susceptible to homelessness. For example, in Australia, refugees comprise one in four young people experiencing homelessness, most have highly limited social and family connections and face significant barriers to accessing safe and affordable housing.[84] In addition, people with a disability risk homelessness due to their financial and social circumstances,[85] and being lesbian, gay, bisexual, transgender, intersex or queer (LGBTIQ) or gender diverse increases the potential for discrimination that can exclude people from accessing tenancies.[86]

Typologies

Australian homelessness typologies are articulated in the definitions of homelessness described in Chapter 1, with primary homelessness, such as rough sleepers, representing the quintessential public face of homelessness. People experiencing primary homelessness have few personal possessions, limited access to sanitary facilities, high reliance on homeless food services, and frequently encounter unsafe and unhealthy situations.[74] The typical profile of a rough sleeper is male, aged 35 years or over, and likely to report a mental health condition.[87] In general, primary homelessness is linked with less high school education, a history of incarceration or foster care, and more informal sources of income compared to their sheltered counterparts.[88]

However, many other types of homelessness exist. For example, people who stay temporarily with friends or extended family without having a dedicated bedroom are known as couch surfers, often the domain of homeless youth.[89] In Australia, couch surfers who are female are likely to be young and have experienced domestic or family violence,[87] whilst male couch surfers are more likely to report problematic drug and alcohol use and have a diagnosed mental health issue.[87] Self-harming and suicidal behaviours are reported as commonplace among this homeless cohort.[89] Furthermore, there may be a disparity between our understanding of the mechanisms to lift youth out of homelessness and their lived experience. For example, the theoretical pathways considered to be mechanisms for lifting youth out of homelessness do not necessarily accord with their actualities of experiencing those pathways, and providing a stable accommodation does not inevitably mean that they will have a sense of connection and belonging to community or mainstream society.[90]

At local proximity to this thesis, and therefore of high relevance, a recent study investigating the descriptive profiles of the health and demographics of an Adelaide, South Australia, cohort of people experiencing homelessness found that 28%-40% of people were receiving Jobseeker allowance at a rate of $457 per week, currently under the Australian poverty line.[76] In addition, the leading causes of homelessness were found to be the housing crisis (49%), mostly related to housing affordability and availability, with inappropriate or inadequate housing accounting for 18% of homelessness cause, and domestic violence reported as 10% of causes (14.4% for females and 5% for males).[76] In the broader Australian context, women living in regional and remote areas were more likely to experience secondary and tertiary homelessness rather than primary homelessness, often due to domestic and family violence associated with geographically defined social and financial stress; however, most people gravitate to urbanised service providers located in major towns and cities.[91]

Ecological models of homelessness

Many scholars place homelessness within ecological models of homelessness.[74, 92-94] Ecological models account for the interplay of factors across biophysical and social dimensions[92] and the structural, environmental and individual factors[74] which are interconnected and increase risk homelessness. Ecological models of homelessness inform policy makers and homelessness services providers to influence the direction of strategies, the integration of services and the allocation of resources.[95]

Housing models as examples for homelessness

Solutions to homelessness have attracted limited success, both nationally and internationally. At a global level, Finland has been observed to reduce homelessness to minimal levels, as seen in their comprehensive point-in-time annual count of people experiencing homelessness.[96] The Finnish approach to reducing homelessness is policy-driven, embedded across national and local governmental levels, and incorporates a *Housing First* model. *Housing First* emerged from the American ‘Pathways to Housing’ model in the late 1990’s and takes a human rights approach to have permanent housing, encourages client agency through empowerment, and provides choice for supportive services based on need and self-determination.[97, 98] As a model for addressing homelessness, *Housing First* has become an international model that champions the economic claim that providing housing and services compensates costs associated with poor health outcomes, social disengagement, welfare services and the impact of interactions with the justice system.[97] It is therefore regarded as a cost-effective measure in addressing homelessness.[99]

What makes the *Housing First* model in Finland more successful than those seen in other countries is in how it was implementation and sustained within public policy.[98] Finland paid attention to including ‘hidden’ tertiary homelessness in their homelessness action plan, with broad policy scope and supports to provide for all types of homelessness.[96] Rather than continuing with multiple shelters and hostels for people experiencing homelessness, Finland converted buildings into apartment units, and built housing specifically for *Housing First*. In 1985, Helsinki had 2,121 shelter and hostel beds that reduced to just 52 in 2016, with formally homeless people now holding leases in congregate and scattered housing sites.[100] Moreover, social acceptance and integration of the Finnish *Housing First* model works because tenants become invested in their communities, engaging in neighbourhood work, such as tending to public gardens.[100]

In Australia, *Housing First* models exist nationally, without pre-conditions, as a model to help break cyclic homelessness, with positive outcomes. Nonetheless, Australia has not duplicated the same success as Finland, and there are several reasons why. First, there is a lack of available social housing. At the time of writing, a federal Government proposal for a $10 billion housing plan that includes 20,000 social housing properties has not attracted cross-party support.[101] Second, *Housing First* providers have inadequate funds to purchase from the highly limited affordable housing stock to provide the immediate access to permanent accommodation that the model relies on. Third, there has been little political will to make structural amendments, meaning *Housing First* (and other) models have been hampered by unhelpful homelessness and housing reforms, and any implementation and integration policies.[102] An example includes regional service providers funded to deliver *Housing First*, who rely extensively upon temporary or short-term transitional housing for their most complex clients to firstly ensure housing preparedness. This prerequisite both contradicts *Housing First* principles of having no pre-conditions for clients and subjects the most vulnerable of people experiencing homelessness to be indefinitely accommodated across various temporary or shared housing facilities.[103]

Projects and services in South Australia

Other types of homelessness services exist in Australia, including day centre (non-residential) options, those that provide short-term crisis accommodation, and longer-term accommodation options based in community housing programs. In South Australia, in addition to the Government supportive housing program and transitional housing, multiple non-government organisations form alliances that partner to provide services for people experiencing homelessness, and all specialist agencies use the same client and care management system for continuity.[104] Other, not-for profit agencies provide complimentary support services or target specific groups, such as women who are escaping domestic violence or homeless youth. In Adelaide, South Australia, the inner city area has the highest concentration of primary homelessness, that has been targeted by the Adelaide Zero Project, a recent initiative to end street homelessness.[105] Following an American-developed *Functional Zero* approach, achieved when the number of rough sleepers is no greater than the average housing placements at any point in time,[105] the Adelaide Zero Project represents a system engagement where the names and needs of every person sleeping rough are known to services on a 'By-Name' list.[76] Services react by providing rapidly coordinated responses to individual health and housing need. The Adelaide Zero project models a *Housing First* (but not housing only) approach[105] that is in addition to other local *Housing First* initiatives situated in Adelaide.

Wellbeing of people experiencing homelessness

Whilst wellbeing is a familiar concept, it can be hard to define. In general, the descriptive approach to wellbeing is salutogenic, focussing on wellness and health rather than disease and illness. For example, subjective wellbeing refers to how an individual perceives their state of fulfilment, in having life satisfaction, happiness, and contentment[106] that essentially embrace hedonic approaches.[107] Another broad understanding of wellbeing is eudemonic, which adopts self-advancement of psychological or behavioural aspects that include resilience and positivity.[107]

Whatever definition is used, orientating Deweyan philosophy in wellbeing is to acknowledge the uncertainty that is inherent in people's circumstance.[108] In line with this, Fisher[107] reasons that wellbeing is shaped by its linkage to the social determinants of health (SDoH). In Australia, the expanding wealth inequity is a problem often shaped by SDoH, in which poverty contributes to housing insecurity and homelessness and where nearly half of all wealth is owned by the richest 10%, whilst the lowest 60%, measured by wealth, held just 16% of all wealth.[109] For those at the very bottom of the lowest wealth scale, house ownership is firmly out of reach. People vulnerable to poverty and consistently poor socioenvironmental conditions provokes a chronic stress response and the release of adrenaline and cortisol, which, in turn, interrupts and changes behaviours and influences physical ill-health.[107] In addition persistently unmet needs are detrimental to wellbeing,[110] including deprivations in physical comfort (warmth, food and hydration), positive emotion (enjoyment, content, and a sense of hope, purpose and self-worth), emotional support (family, productive friendships), financial self-determination and a lack of privacy, whilst encountering social challenges and anomie.[71]

Homelessness and health

Evidence points to increased mortality rates in people experiencing homelessness. In addition to having shorter overall life expectancies, Australian data shows that people experiencing homelessness are twice more likely to die by suicide than those in the general population. The most common group affected is mostly unemployed single males of a young age who had a physical illness or stressful life event, untreated mental illness and problems with alcohol and drug misuse.[111] Homelessness mortality rates in Australia are not currently formally measured, however international indicators show homelessness reduces life expectancy by up to 30 years, with much mortality attributed to amendable causes.[112-114] Rates for premature mortality are reported as three to six times those of in the general population,[115] and are especially noted across young people experiencing homelessness.[116] Higher mortality rates are more likely to be seen in primary homelessness, with an informal conservate estimate placing 424 people who died on the streets in Australia in a twelve months period across 2020 – 2021.[117] One 15-year longitudinal cohort study comparing mortality rates between homeless and non-homeless adults at a Melbourne, Australia, inner-city emergency department reported people who had experienced more than one episode of primary, secondary or tertiary homelessness had higher mortality than those who had no episodes of homelessness over the fifteen year study period (11.89 vs 8.10 per 1,000 people, respectively).[116]

The health of homeless people is noticeably and measurably worse than the health of the general population, with many chronic health conditions over-represented.[99, 118, 119] Mutual and bidirectional relationships can be observed between poor health and homelessness. For example, severe mental health conditions affects 20% - 25% of people experiencing homelessness and persistent homelessness compounds poor mental health.[120] Similar examples are found in disability,[121] and acquired brain injury.[122, 123] Homelessness places people at greater risk of developing cardiovascular disease, diabetes, and hepatic disease,[124, 125] accidental injury, musculoskeletal and skin issues, respiratory problems, poor oral health, alcoholism and drug misuse[126] and a range of infections such as scabies, hepatitis, human immunodeficiency virus (HIV), pneumonia, and syphilis.[127]

Exposure to the outdoor elements creates further health problems for people experiencing primary homelessness. Weather-related events can generate heat stroke and sunburn, dehydration, and skin and vector-borne infections caused by insect bites that can worsen psychosocial and other pre-existing health conditions.[128] Cold temperatures are similarly associated with exacerbating respiratory and cardiovascular illness, and aggravated by wet clothing and damp bedding.[128] Living outdoors also complicates hygiene and toiletry needs, access to washing facilities, and storing, heating or refrigerating food.[99, 125, 129, 130]

Explanations for inequitable health outcomes are multifactorial, generally based upon adverse life experiences and risk factors that include, but are not exclusive to poverty, mental health, childhood trauma and substance misuse disorders.[119, 131] Differences in health outcomes can be understood from a social determinants of health inequities lens, where health outcomes and the social determinants of health are intertwined.[99] Health outcomes related to persistent socioeconomic disadvantage, social and educational exclusion, low social capital, discrimination and institutionalisation are some examples of structural and social determinants that people endure in homelessness.[74, 99, 125, 132] Additionally, social determinants can also account for anti-social, health-impacting risky behaviours, including alcohol and drug misuse, and unsafe sexual practices.[126] Poor health in homelessness is unsurprising considering the socioeconomic positioning of people experiencing it. Marmot[133] describes a social gradient for health where people positioned higher up on the social ladder have better health outcomes than those positioned at the bottom, and as some of the most disadvantaged and marginalised people in society, people experiencing homelessness are firmly positioned at the bottom of this gradient. Homelessness and socially determined health inequity are often seen as interconnected, with entrenched homelessness further exacerbating worsening health outcomes.[99] To this end, poor health resulting from homelessness represents a late indicator of complex and severe disadvantage and inequity,[113] with failures in housing situations regarded a combined medical and social health issue.[99]

Health services

The health care system itself is an important social determinant of health[44, 125] and inequitable access risks further decline in the health of people experiencing homelessness.[134] People experiencing homelessness have a low uptake of primary health care and preventative health services [113] in comparison to frequent presentations at hospital emergency departments, where they present with more complex health needs compared to the general population.[118, 135] At the aggregated level, there is a costly revolving-door scenario between homelessness and the hospital healthcare system, with increased risk for late-stage diagnosis, and poor control of potentially manageable conditions,[99, 136] resulting in longer hospital admissions when compared to their non-homeless counterparts.[74]

Barriers to accessing healthcare include competing priorities (accommodation needs, food), stigma, lack of means for transport and remembering appointments[115, 137] and the generally fragmented environment that homelessness brings.[134] People experiencing homelessness report feeling isolated from mainstream health services, including those specialising in drug and alcohol use.[113] Whilst inflexible health care systems and negative attitudes of staff compound barriers to health care and other consumers, continuity of care is problematic.[113] Specialist referrals and follow-up appointments are difficult to accomplish due to the transient and turbulent nature of homelessness, and discontinued care for chronic conditions is commonplace.[118] Further difficulties arise where suboptimal medication adherence may result in a worsening health profile, for example, the need to take medications with food, or difficulties in getting prescriptions dispensed.[125] However ongoing medication costs, communication, low health service engagement and mental health conditions all contribute to pharmacological non-compliance.[138] These barriers are health-harming issues driven by socioeconomic inequity that results from structural, policy driven choices.[139] Rather, outreach, tailored primary health care programs for people experiencing homelessness are more likely to be effective in achieving better health outcomes.[113, 140]

In summary, homelessness is a global problem that results from structural, social and individual factors that creates a biopsychosocial health risk. The health of people experiencing homelessness is considerable worse than seen in the general population, with increased mortality and morbidity. Poor health is compounded by structural barriers to timely healthcare, pharmacological management and continuity of care. Clearly, there is an urgent need to address health within a homelessness context.

The next section will focus on the health condition of dementia and dementia risk factors.

Dementia

Dementia is the second foundational topic of this thesis. In this next section I discuss dementia, its impact and risk factors.

Dementia is a generic term for a neurocognitive disorder with cognitive dysfunction and associated deterioration in memory.[141] Dementia is primarily considered an acquired syndrome that will ultimately disrupt a person's social and occupational functioning.[142] Its cause is heterogenous and usually follows an insidious onset, demonstrated by a progressive decline from a previous level of cognition.[35, 143] Neurodegeneration, vascular injury and metabolic disorders are major causes of dementia[143] with Alzheimer's disease being the most common of all dementia.[141]

Alzheimer's disease is closely associated with the excessive accumulation of amyloid-beta and tau proteins that produce plaques and neurofibrillary tangles affecting the functioning of brain neurones.[142, 144] A distinction is often made between primary degenerative types of dementia, for example, Alzheimer's disease (AD), dementia with Lewy Bodies (DLB), and frontotemporal dementia (FTD) from those secondary to other diseases or conditions, such as vascular dementia (VD) and human immunodeficiency virus (HIV) associated dementia.[145] Furthermore, dementia can be multi-causal and mixed pathologies are commonplace[146] which may present a different clinical course than single pathology dementia.[147] Furthermore, the protein accumulation associated with some types of dementia can overlap with other neurodegenerative conditions, for example, Parkinson's disease, where both similar and divergent presentations occur.[147]

Dementia is a leading public health concern[148] with prevalence and incidence of dementia expected to increase globally. An expected worldwide projection indicates that 66 million people will be diagnosed with dementia by 2030, and 115 million by 2050.[149] It is largely thought to be an older person's condition, and prevalence increases exponentially with age, with diagnosis doubling with every five-year age increment, making older age the dominant non-modifiable risk factor.[150, 151] However, its prolonged latency period of 20 to 30 years means that many thousands more are developing undetected brain pathologies that underly dementia well before the onset of clinical symptoms.[35] Young-onset dementia (YOD) affects people under the age of 65 years, with an estimated prevalence of 119 per 100,000 of all global dementia,[152] equating to around 28,000 people in Australia.[153]

In Australia, in 2020, dementia was the second leading cause of death overall. More than 14,500 people died from dementia (9.6% of all deaths). It is also the leading cause of death in women, representing 9,100 deaths (12.6%) compared to 5,300 deaths in men (6.8%). An estimated 401,300 Australians currently have a dementia diagnosis.[154] Australian First Nations people have a prevalence of dementia reported as 12.4% that is five times greater than the non-First Nations people at 2.4%.[153] Approximately 28,000 of all diagnoses of dementia in Australia are YOD, which can have rarer pathology and aetiological diversity than late-onset dementia, or may present as a secondary outcome from a range of conditions such as traumatic head injury, Down syndrome, neurosyphilis, Huntington disease, or alcoholism.[153]

Impact of dementia

There are significant and growing costs linked to the increasing prevalence of dementia. In Australia, an estimated forecast of $25.8 billion in the year 2036 will likely be spent on direct and indirect costs associated with dementia. Direct costs include primary health care, social care, hospitalisation and aged care. In-direct costs include lost productivity of person and carers, or non-material costs due to the emotional toll and stress associated with living with, or dying from dementia.[155] In addition to economic costs, dementia holds an enormous personal cost, in part due to stigma and the perception of others, often affecting self-disclosure.[156] A loss of self-identity, dignity and independence, and living with aphasia, ambulation, incontinence, and inability to recognise family members, are all feared outcomes of dementia.[157] For young people diagnosed with dementia, the personal cost is even greater, with significant implications for occupational, economic, social, and relational disruption affecting people in the prime years of their life.[153, 158, 159]

Neuropsychiatric (non-cognitive) symptoms of dementia (apathy, psychosis, agitation, aggression, depression, disinhibition, anxiety paranoia, social withdrawal, and mood changes) affect more than 90% of people with dementia and present a profound but common challenge.[160, 161] In 2020, in Australia, 623,300 prescriptions for dementia-specific medications were dispensed to 64,600 people aged 30 years and older diagnosed with dementia. One-fifth of people receiving dementia-specific medications were additionally prescribed antipsychotics to help manage behavioural and psychological symptoms of dementia (BPSD).[154]

Risk factors for dementia

This thesis follows the description of health risk factors as presented by the Australian Institute of Health and Welfare (AIHW), described as “attributes, characteristics or exposures that increase the likelihood of a person developing a disease or health disorder”.[162] Generally, risk factors for dementia can be considered non-modifiable or modifiable. Non-modifiable risk factors are mostly associated with increasing age, ethnicity, gender, familial history, and genetics (i.e., APOE4 allele),[35, 163, 164] while potentially modifiable risk factors relate to lifestyles, behaviours, or environmental circumstances can be amendable to change, and help ameliorate risk at an individual, community or population level. Some types of dementia, for example Alzheimer’s disease, is multifactorial and can combine non-modifiable genetic and modifiable lifestyle risk factors, for example, in the case of cholesterol homeostasis[165] or cerebral small vessel disease seen in both Alzheimer’s disease and vascular dementia.[164] However, how non-modifiable risk factors for dementia interact with modifiable risk factors are largely unclear, making dementia risk reduction interventions beneficial for everyone, regardless of whether someone has a high genetic risk or not.[166]

A life course approach to dementia risk

In Chapter 1: Introduction, *Definitions of Terms and Explanations for this thesis* I explained the concept of life course as a risk model for late-life health adversities. In this section I explain dementia risk using the life course model to examine the link between early life risk exposures or events and late life cognitive health through biological, behavioural (lifestyle) and psychosocial factors.

There are many factors that occur across all stages of life that contribute to the risk of developing late life dementia.[167] However, the life-course approach recognises that risk operates at critical periods over the lifespan, with different time points determining the strength of association of risk.[151] Where risk coincides with times of rapid individual development, adverse exposures to risk may have a future detrimental effect on later life cognitive health outcomes.

Some of these critical periods are particularly relevant to homelessness. For example, homelessness during pregnancy presents health challenges that are associated with low birthweight and pre-term deliveries.[168] Poor *in utero* conditions may result from socioeconomic disadvantage because homeless pregnant women are most likely to be undernourished and experience depression, anxiety, exposure to substance misuse and be disengaged from prenatal care.[168, 169] These *in utero* adversities fall within a critical period of prenatal growth and subsequently influence early life brain development and are important for determining final brain size.[170, 171] In turn, small brain size may affect a child's ability to build cognitive reserve by capitalising on cognitive opportunities, such as early life education. Low levels of education, especially during critical neurodevelopmental periods in childhood, may be less resilient to structural brain changes in later life.

Lower socioeconomic status is a life course determinant that can accelerate health problems in later life,[172] and low socioeconomic positioning in childhood can contribute to cognitive difficulties seen in mid to late life.[173, 174] However, disadvantaged children who experience upward socioeconomic mobility over the life course present an attenuated risk for mid-life cognitive difficulties when compared to those without socioeconomic improvement, observed in improved cognitive functioning measures.[173] This has significant implications for interventions to improve cognitive wellbeing in homelessness and reduce risk for developing dementia over the life course.

The seminal work of Livingston et al,[66] published as the Lancet Commission on dementia prevention, intervention, and care identified twelve modifiable factors that may account for up to 40% of dementia (less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, social isolation, excessive alcohol, traumatic brain injury, and air pollution). Risk exposure was understood across life-course modelling across early, mid and later life. Livingston et al. (2020) is of paramount importance for this thesis because it provides the benchmark from which I map potentially modifiable risk factors.

Considering this significance that the model has for this research, I present *The Lancet Commission on dementia, prevention and care,*[66] on potentially modifiable risk factors for dementia from a life course perspective in Figure 4 (hereafter, referred to a Livingston et al. (2020)).

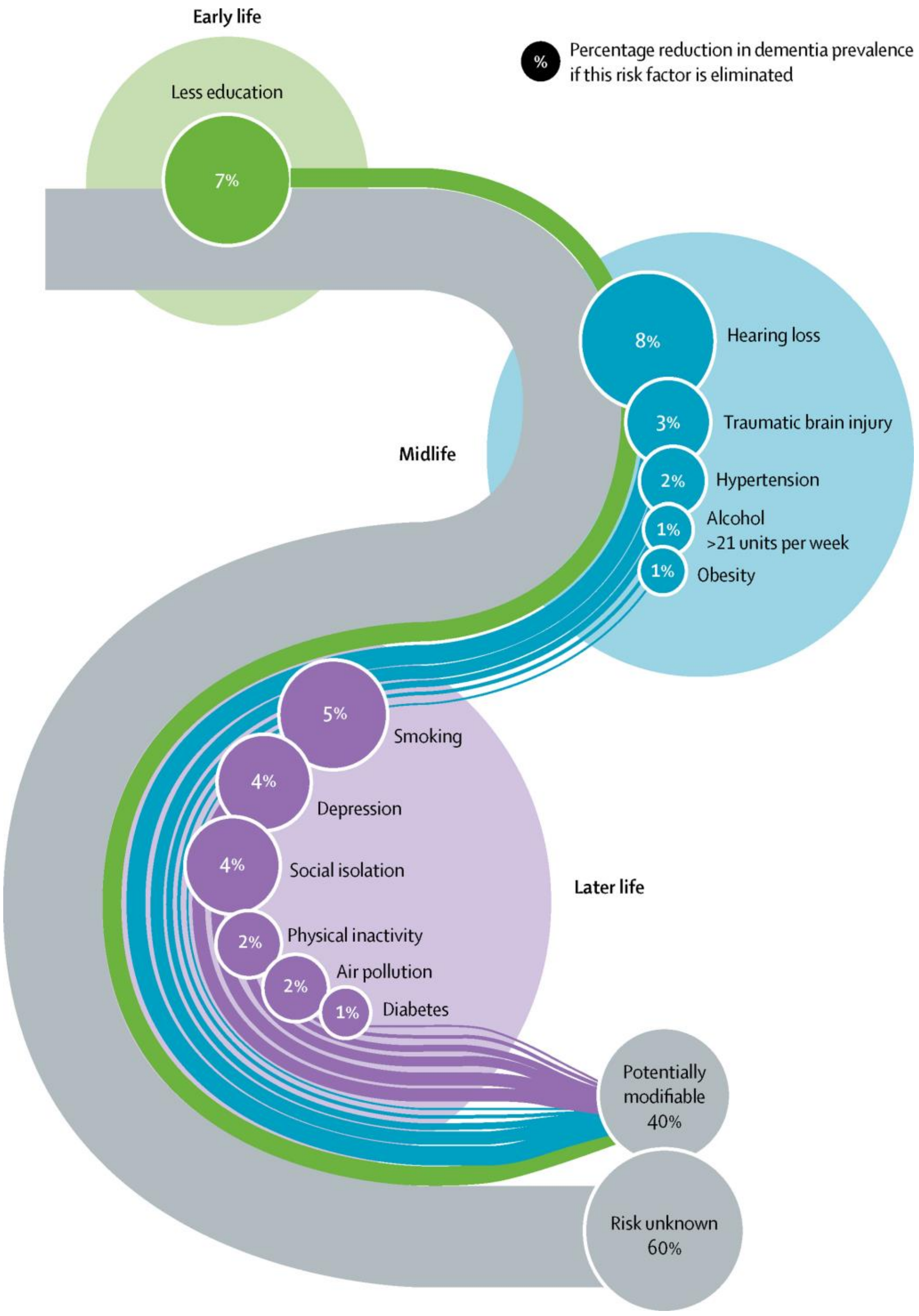

Figure 4. The *Lancet Commission* (2020) on dementia prevention, intervention and care

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Dementia risk reduction

With a cure for dementia remaining elusive, attention has turned to risk reduction and prevention to reduce the incidence of dementia, with individual-level interventions generally marketed towards middle-aged people.[175] These interventions usually target lifestyle activities that may lead to an increased risk of Alzheimer's disease. However, types of dementia are not heterogenous, often presenting with mixed subsets, meaning risk reduction approaches should be broader than explicitly targeting Alzheimer's disease.[176] Whilst primary prevention aims for dementia risk reduction through improving lifestyle factors,[175] the applicability to people experiencing homelessness is contested without first addressing root causes of homelessness.

The World Health Organisation provide recommendations for risk reduction targeting cognitive decline and dementia to help guide health care providers and policy makers when supporting or programming interventions.[177] These fall under the broad headings of lifestyle and behaviour interventions, interventions for physical health conditions, and other, specific interventions.[178] The recommendations outline responses targeted to physical activity, tobacco cessation, nutritional recommendations, interventions for alcohol use disorders, cognitive interventions, weight management, management of hypertension, management of diabetes, and management of dyslipidaemia, indicating the quality of evidence supporting each risk reduction intervention, and the strength of recommendation.[178] However, issues lie with the suitability of implementing contemporary dementia risk reduction health promotion interventions in homeliness settings. This includes whether interventions are likely successful or not considering the challenges in meeting health care needs. Nonetheless, health promotion interventions must consider how they are modified and implemented or reflect upon an ethical understanding that dementia risk reduction interventions may be disadvantageous for personal survival or coping strategies (i.e., smoking), or any harm to wellbeing through compounding perceived blame and labelling.

Chapter summary

This chapter provided background and context to homelessness, with attention on homelessness in the Australian setting. It also discussed the wellbeing and health challenges of people experiencing homelessness which are important when considering risk exposure to dementia. The background and context of dementia was also provided, including its impact, risk factors, life course perspectives, and dementia risk reduction. This is relevant for this thesis with its strong focus on dementia risk exposure in homelessness, which underpins the following chapter which explores what is known about potentially modifiable risk factors in people experiencing homelessness.

CHAPTER 3: SCOPING THE LITERATURE

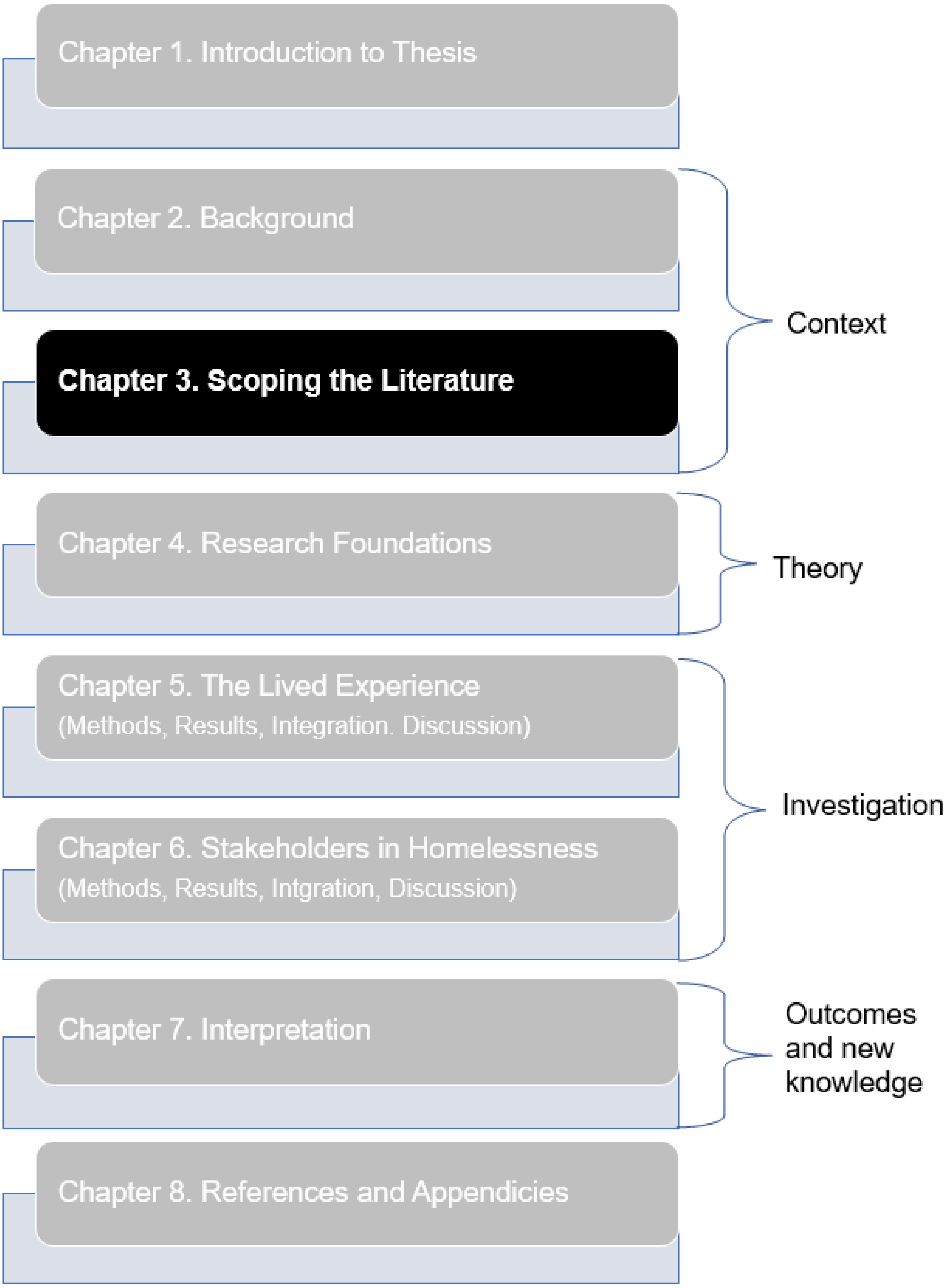

Figure 5. Thesis structure - Chapter 3

Introduction to Chapter

This chapter introduces discussion to why potentially modifiable risk factors for dementia in people experiencing homelessness are important to scope. The previous chapter examines homelessness and dementia as two separate public health concerns. However, in this chapter, I bring homelessness and dementia together for the purpose of identifying what is known in the literature about potentially modifiable risk factors for dementia in people experiencing homelessness. To assist this thesis a scoping review was undertaken to understand the extent of literature investigating dementia risk in homelessness. The scoping review was published in 2022, titled *Potentially modifiable risk factors for dementia in people experiencing homelessness by Beard, Wilson, Withall and Cations.*[179]

This chapter speaks to the relevance of conducting the scoping review, describes the processes used to complete the review, and summarises the findings and insights that resulted from the review. It does not present the completed scoping review in its, rather this chapter presents an outline of the 'why, how and what' of the scoping review: <u>*Why*</u> complete a scoping review? <u>*How*</u> did it contribute to the overall themes contained in the thesis? <u>*What*</u> was the outline of the scoping review process, content, and the significance of its findings?

The rationale for completing a scoping review?

Systematic and scoping reviews were both considered for their role in assisting this thesis. Both are concerned with evidence synthesis, however, have methodological differences that indicate their suitability for a particular purpose of inquiry.[180] Key differences include the focus of systematic reviews on identifying and retrieving evidence, and in appraising and synthesising results. In contrast, scoping reviews determine the coverage of a given topic by 'scoping' across literature to indicate volume, provide an overview of what evidence is available, and address how research has been conducted.[180]

The scoping review was chosen for several reasons. First, it provides a methodological procedure in which homelessness and dementia risk factors can be brought together for the purpose of examining emerging evidence through the literature. Second, the nature of a scoping review is exploratory, and therefore would be helpful in assessing the extent of existing research on homelessness and dementia risk factors. Scoping the literature represents an important component for this research because its findings influence the direction of this thesis. Should a considerable amount of knowledge already exist on potentially modifiable risk factors for dementia in people experiencing homelessness, then the stated thesis investigation, as an original contribution to knowledge, becomes disputable. However, should the review identify that little is known about potentially modifiable risk factors for dementia in people experiencing homelessness, then there is a knowledge gap in the existing body of literature that will justify the purpose of this thesis. Procedurally, scoping the literature would confirm or deny a research gap. Third, the scoping review assists to clarify key characteristics and concepts, contained in existing literature and identify the definitions used and how they relate to homelessness and dementia risk factors.[180]

The aim of completing the scoping review was to identify and synthesise studies that examined potentially modifiable risk factors for dementia that were contextualised to homelessness. However, the scoping methodology is more than an unstructured search across a body of literature. It begins with a leading question on which to anchor the review and followed procedures guided by the Joanna Briggs Institute scoping review resources.[181] However, because a scoping review provides more flexibility than the more rigid systematic review, it can account for greater diversity identified across the literature.[182] This flexibility proved to be helpful. For example, in being able to make subtle changes to the search parameters that permitted the search to be broadened. This was required to make the literature search more inclusive of different terminologies (for example, cognitive impairment, neurocognitive disability rather than dementia), resulting in a more productive exploration of the literature.

How does the scoping review contribute to the overall themes in this thesis?

There are biopsychosocial circumstances linked to homelessness that results in poor health outcomes.[42, 119] This includes a poor cognitive profile that may increase risk for dementia. In Chapter 2, I discussed that dementia has been recognised as a global public health concern and up to 40% of all potentially modifiable risk factors may be responsible for its prevalence.[66] It is commonly reported that Alzheimer's disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies are regarded the most frequently seen types of dementia,[154] however, the experience of homelessness may be influential in other types of dementia being more frequently observed, including alcohol dementia and HIV associated dementia.

Consistent with international literature, and discussed in Chapter 2, people experiencing homelessness are a socially marginalised population who present with a poor health profile.[119, 183, 184] This health profile can pose significant challenges to cognitive wellbeing, including high rates of cognitive impairment,[185] mental health conditions such as depression,[186] and traumatic brain injury,[187] In addition, homelessness makes people vulnerable to a range of socially defined lifestyle factors, including risk of alcohol dependency,[184] substance misuse,[183,184] and chronic smoking.[188] The socioeconomic-related features of homelessness can further extend the dementia risk profile through mechanisms associated with low levels of education,[185,189] and historic or acute psychological trauma.[74,190,191]

An accumulating evidence base highlights the role that potentially modifiable risk factors have in dementia prevalence. Previously discussed in Chapter 2, The Lancet Commissions report on dementia prevention, intervention and care 2020,[66] modelled a total of twelve modifiable factors for dementia (less education, hypertension, obesity, hearing impairment, traumatic brain injury, alcohol misuse, smoking, depression, physical inactivity, social isolation, diabetes, and air pollution). Whilst these risk factors notably resonate with the health profile of people experiencing homelessness, the Lancet Commissions Report (2020) does not attribute risk to any population group. It does, however, highlight the need to better understand dementia in the context of life-course disadvantage.[66] People experiencing homelessness are one of the most socioeconomically disadvantaged population groups in society and international literature shows that low socioeconomic status (SES) has implications for cognitive dysfunction or dementia in later life.[174, 192-198]

What was the outline of the scoping review process, content and key points?

First, people experiencing homelessness are an ageing population who are additionally subject to premature (accelerated) ageing,[119, 172] and advancing age is the dominant risk factor for dementia.[35] Second, risk for dementia may accumulate through the lifespan, with exposures to dementia risk occurring at critical periods of the life course.[35, 66, 199] An example would be that youth comprise a considerable percentage of all persons living homeless,[200] which occurs at a major developmental period for building cognitive reserve through social connectedness.[201] Third, low socioeconomic disadvantage is linked to poverty that can incapacitate a person's ability to reach their educational and cognitive developmental potential.[202] For example, a relationship is observed between the socioeconomic position experienced in childhood, educational attainment and adult cognitive functioning.[195] This is important because a high educational attainment in childhood may lower risk for late-life dementia, and therefore is thought protective in cognitive decline.[202] Finally, the scoping review revealed a complex relationship exists between health inequity, historic and current socially defined factors that compound socioeconomic disadvantage and poor health. This makes homelessness both a modifiable risk factor for dementia and a barrier to dementia risk reduction.[179]

Process*: what was involved in conducting the scoping review*

The updated methodological framework by Levac et al. (2010), based on the Arksey & O'Malley (2005) scoping review design[203, 204] appeared to be the most appropriate to use for this review. This framework involved five stages of identifying the research question and what it is asking from the review, identifying relevant studies through conducting a literature search, making the selection from the identified studies, charting the data, and finally, in collating, summarising and the reporting of results,[203] shown in Figure 6.

Figure 6. The Scoping Review Framework adapted from Levac et al. (2010)

Protocols for data charting were implemented by generating tables of descriptive summaries of studies that included their methodology and design, the potentially modifiable risk factors for dementia that was being examined, and the study outcome. A priori protocol was used to define the study objective and methods used. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews (PRISMA-ScR) extension checklist can be seen in the original published study by Beard et al.[179]

To begin the scoping review, I began by searching five databases (CINAHL, PsycINFO, Informit, Web of Science, PubMed) using the key words of ‘homelessness’, ‘homeless’, ‘cognitive impairment’ and ‘risk factors’ and that must include the word ‘dementia’. Scoping review methodology was used to identify studies that explored potentially modifiable risk factors for dementia in people experiencing homelessness. This first search did not identify any useful studies. It did identify a single review (a scoping review prepared for a dementia training study centre in 2015), dementia prevalence studies in American homelessness veterans, and several prevalence studies or scoping reviews of cognitive impairment in homeless people. None of these findings accorded with the intended purpose of the scoping review, and consequently, the search terms and inclusion criteria were adjusted to capture any singular potentially modifiable risk factor for dementia in the context of community-based homelessness. I mention this because at the time it highlighted the disparity between literature search findings for ‘risk factors for dementia’, which was profuse, and literature search findings for ‘risk factors for dementia in people experiencing homelessness’ which was minimal. This search finding was based on the hypothesis that potentially, risk factors for dementia in the homeless population may not necessarily be the same factors seen between the general population, and this may account for differences in research outputs.

The subsequent data search used the search terms: homeless*, hous*, roofless*, margini* disadvantage, *combined with* risk, factor, caus*, contribu*, socio*, social, determinant*, *combined with* dementia, Alzheimer*, “cognitive impairment”, “memory loss”, “brain health”. This approach was more successful, yielding 1023 results. After studies were screened for relevance, duplication and full-text availability, a total of 307 studies were included for further screening. Following an initial screen of studies, first by title, and then by abstract, a remaining 30 studies were uploaded into an Excel spreadsheet for final selection.

Applying the inclusion and exclusion criteria

Studies related to cognitive impairment were included into the final selection because cognitive impairment is itself a risk factor for dementia. However, if the focus of the study was not directly related to cognitive impairment as a potentially modifiable risk factor for dementia, then that study was excluded. A distinction was made between community homelessness populations, that were included, and ex-homeless people living in residential care facilities, or homes for veterans, that were excluded. Studies related to housing outcomes in the presence of cognitive impairment or dementia were excluded. All systematic and scoping reviews, prevalence studies, commentary papers, editorials, conference papers, protocols, reviews were excluded. All reasons for inclusions and exclusions were documented and any conflicts or uncertainties were resolved through discussion or third author referral. A further 21 studies were removed by consensus of co-authors. Full text articles of the remaining nine studies were read and screened for relevance, with two further studies removed.

To ensure thoroughness, a manual search was conducted from reference lists and grey literature with no further studies identified. This process resulted in a total of seven studies that had a focus on at least one potentially modifiable risk factor for dementia in people experiencing homelessness. This final selection consisted published, original research studies that presented on a potentially modifiable risk factor for dementia in people experiencing homelessness. The small number of studies reflected the paucity of literature on potentially modifiable risk factor for dementia in people experiencing homelessness. The procedure for study selection is contained in the Prisma-ScR, Figure 7.

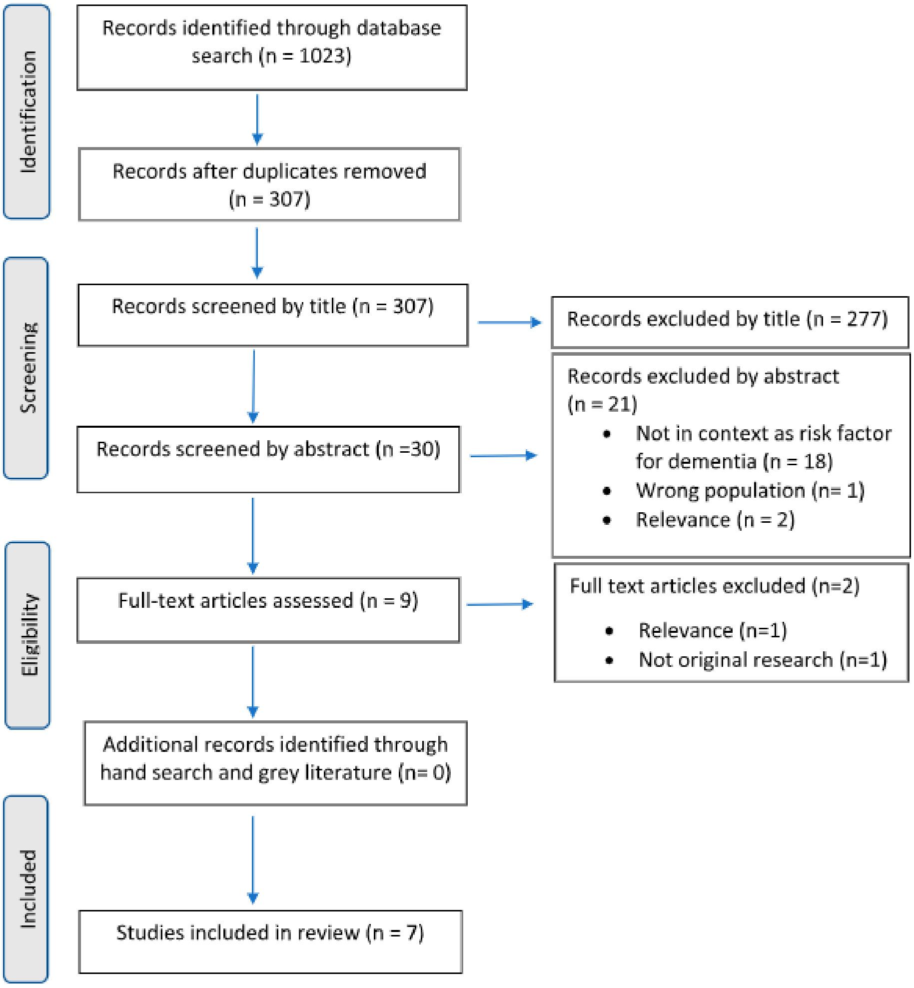

Figure 7. Prisma-ScR. The screening process of search results by Beard et al

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The quality appraisal checklists used to assess the methodological quality of the included studies were sourced from the Joanna Briggs Critical Appraisal toolkit and were specific for cohort studies, analytical cross-sectional studies, and qualitative research.[205] Studies were assessed to determine bias and quality based on a full-text review. A descriptive summary of results was added to the Excel spreadsheet tables as part of the data charting, and included data relating to study aims, participant numbers and age, the research design and its limitations, the setting of the original research, and which potentially modifiable risk factor was under investigation. This was a helpful exercise that assisted with the thematic coding of studies and the synthesis of their findings.

***Content**: The summary of the literature*

A summary of the content of included studies is provided here, however, greater detail can be accessed in the publication: *Potentially modifiable risk factors for dementia in people experiencing homelessness: a scoping review by Beard, Wilson, Withall and Cations.*[179]

The seven included studies, published between 2011 and 2020, were conducted in America,[200, 206] Canada,[207, 208] Japan,[209] Australia,[78] and the UK.[191] In line with this thesis, all study participants' were recruited from homelessness services and were unsheltered persons' (primary homeless), in temporary sheltered accommodation or were precariously housed. Three studies were sub-studies of ongoing or research.[78, 200, 208] The design of studies was heterogeneous with two cohort studies, four cross-sectional studies and one qualitative research. Participant sample sizes ranged from 6 to 354 and studies were categorised into adult studies (*n*=5) and youth studies (*n*=2) for perspective.

Only three studies made any in-text reference to dementia or the risk of dementia.[78, 207, 209] Additionally, different terminology or phrasing for cognitive impairment was used across studies, including "neurocognitive disability",[78] "cognitive impairment",[206, 208, 209] "cognitive decline",[207] "neurobehavioural and cognitive function",[191] and "cognitive deficit and mental health".[200] The scoping review adopted the term "cognitive impairment' to be inclusive of these differing terminologies.

***Key Points**: The findings of the scoping review and importance for this thesis*

Identifying studies that had explored the relationship between the experience of homelessness and potentially modifiable risk factors for dementia was challenging. People experiencing homelessness potentially are highly likely to encounter multiple exposures to dementia risk and have limited resources to manage the trajectory of those risk exposures. However, the scoping review highlighted that the words 'risk' connected to 'dementia' was infrequently phrased across literature titles. Instead, 'risk' connected to 'cognitive impairment', or variations of that phrasing, were more often used. This flagged two things. First, did 'cognitive impairment' include non-specified dementia, and second, why was the literature limited in the mention of dementia as a homelessness health concern? Nonetheless, risk factors for cognitive impairment were not well delineated, the literature supported multifactorial aetiology,[207] and most risk factors for cognitive impairment appeared to be the same as risk factors for dementia. These risk factors included cognitive impairment,[200, 206, 208, 209] traumatic brain injury (head injury),[78, 206, 209] alcohol dependence,[78, 206, 207] addition to specified illicit drugs,[200, 206, 208, 209] unskilled work history,[206] traumatic childhood events (childhood abuse or neglect),[78, 191] premature ageing,[207] Foetal Alcohol Spectrum Disorder (FASD),[78] infections,[208] trauma,[78] mental health conditions,[78, 200, 209] and anxiety,[200] and low educational attainment.[78, 206, 208] Several studies linked longer duration of homelessness to higher rates of cognitive impairment.[206, 207, 209]

Cognitive impairment relates to any disorder of the brain that may affect cognition, or the brains physical, emotional, or behavioural functioning, and can include traumatic brain injury, impairment related to alcohol, the neurocognitive effects of drug use, infections, and Foetal Alcohol Spectrum Disorder (FASD),[78] which are all likely to raise the risk for dementia. However, even across the small number of studies, inconsistencies were identified. For example, one study reported a positive association between head injury and a decline in verbal memory,[207] while another study did not identify any significant difference across the reported rates of apathy, disinhibition executive or cognitive scores seen between participants with and without head injury.[191]

Several studies did report heavy alcohol use among participants.[78, 191, 206, 207] Alcohol dependency, a known potentially modifiable risk factor for dementia in itself, is socially patterned to poor nutrition, low physical activity, heavy smoking, and impaired cardiovascular health.[210, 211] However, one small cohort study in a Japanese homeless community (*n*=16) assessed participants for their alcohol use. They found low levels of overall dependency and did not observe a correlation between the level of alcohol use and measured cognitive variables.[209] This contrasts with Western studies which widely reported alcohol dependency as a feature seen in their homeless participants.[78, 206, 207] Possibly, differences may reflect cultural norms or results elucidated from a small sample size.

Adversity in childhood, including abuse, neglect, trauma, family conflict, and the effects of socioeconomic hardship increase the vulnerability for homelessness.[74] Childhood adversity is also a relevant feature for life course risk exposure for dementia, which is possibly mediated through its connections with adult disease, post-traumatic stress disorder, and depression.[35, 190, 212-214] Homeless youth report high rates of cognitive impairment and mental health conditions,[200, 208] viral infection,[208] substance use.[200, 208] These potentially modifiable risk factors for dementia are compounded by younger age when first homeless and the duration of experiencing homelessness.[200, 208]

The role of drug misuse featured across several of the included studies. Some illicit drugs, such as methamphetamine, are known for their neurotoxicity[215] and are a cause of cognitive impairment.[216] A wide range of illicit drugs were identified across the included studies, which, in addition to methamphetamine, include other stimulants such as cocaine,[191, 206] depressants including opioids such as heroin,[191, 206, 207, 209] and mixed effect drugs such as cannabis (or marijuana).[191, 206] However, one study did not find a positive association between substance use and cognitive impairment but concluded that premature mortality in individuals with substance dependency was a factor in their findings.

Summary of the scoping review

The scoping review identified that the lack of longitudinal cohort studies is a limitation in understanding the role of potentially modifiable risk factors for dementia in people experiencing homelessness. These study designs would provide the most beneficial lens from which to evaluate potentially modifiable risk factors for dementia in the context of homelessness. There are inherent limitations seen in cross-sectional studies because this study design cannot determine causality.[206] Other limitations observed in the studies include small sample sizes and a select focus within a single homelessness service. No studies completed after 2014[78, 206-209] referred to the influential international publication: *World Alzheimer Report 2014: Dementia and Risk Reduction*[35] or similar work. Finally, because the data search was broadened, no studies directly referred to risk factors for dementia. Instead, they focused on risk for the broader terms of cognitive impairment, neurocognitive disability or cognitive deficit. This was regardless of whether it was clear if these impairments or deficits were static or progressive.

At the same time the scoping review was published, a systematic review by Babulal et al[167] looked at literature on the associations between homelessness and Alzheimer's disease and other dementia. It mostly focussed on studies conducted in the American veteran population (*n*=6/9) and suggests that homelessness accelerates cognitive decline, and that homelessness appears to be a risk factor for dementia, with social forces being likely moderators. Both the scoping review, and the systematic review by Babulal et al,[167] regardless of differences in criteria, identify that research on the relationship between homelessness and exposure to dementia risk is understudied.

The research gap

The scoping review has identified a research gap by bringing together homelessness and dementia as two distinct public health concerns. Given increasing numbers of people experiencing homelessness, there is an urgent need to explore the relationship between homelessness and exposure to dementia risk. A more precise understanding of the pathways that connect and intersect between homelessness and exposure to dementia risk is required and provides an important finding for this thesis. This thesis, in part, seeks to fill that gap.

Chapter summary

The focus of this chapter was placed on the relationship between homelessness and potentially modifiable risk factors for dementia and brings together homelessness and dementia for the first time in this thesis. This chapter discussed the rationale for the scoping review, how it was completed, and how the review highlighted a research gap. The research gap was evidenced by the paucity of literature examining the relationship between homelessness and potentially modifiable risk factors for dementia, supported by a coinciding systematic review. Findings demonstrate the need for investigation into the interface between homelessness and exposure to potentially modifiable risk factors for dementia.

CHAPTER 4: RESEARCH FOUNDATIONS

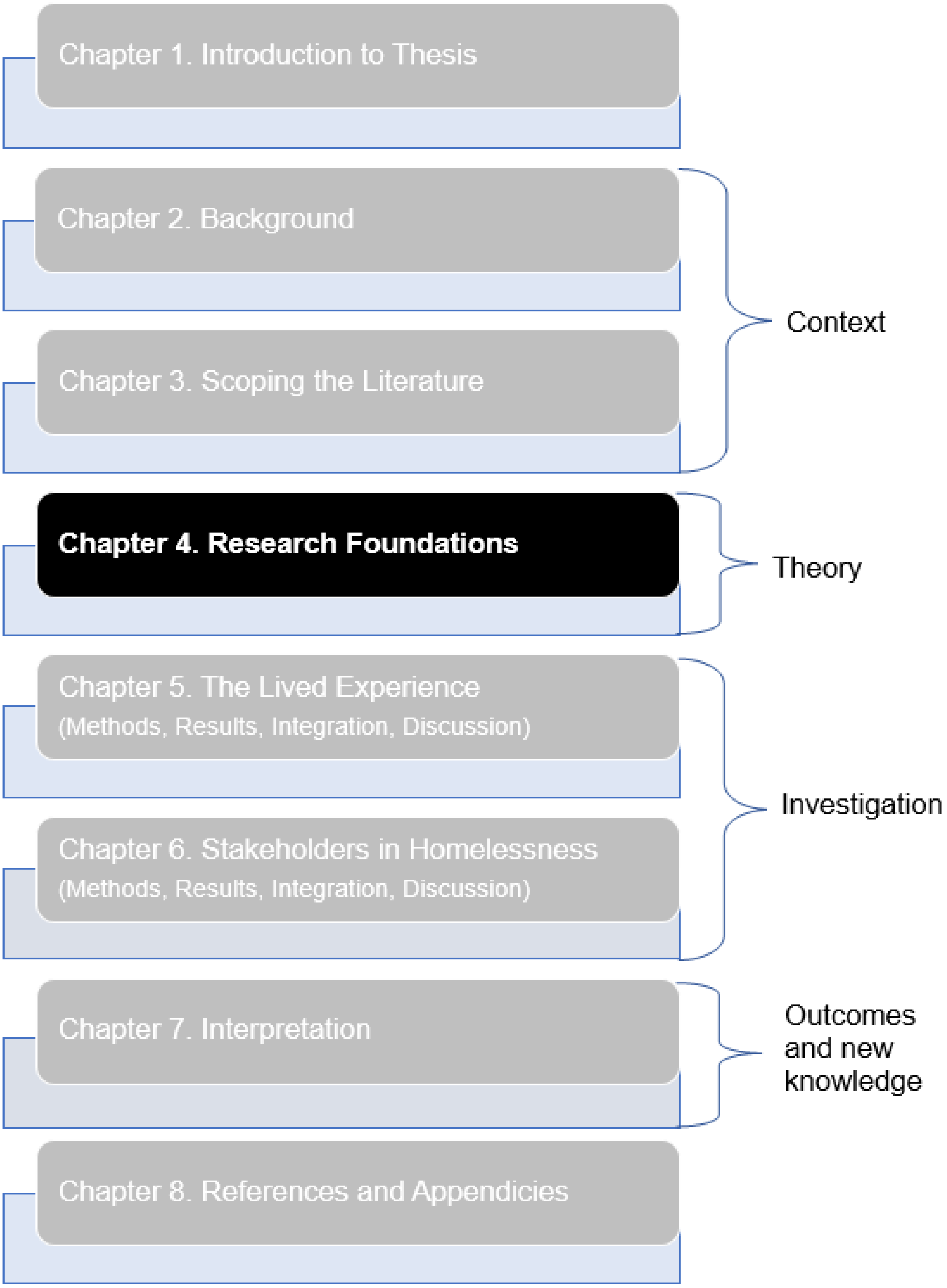


Figure 8. Thesis structure - Chapter 4

Introduction to Chapter

This chapter will discuss the framework and philosophical underpinnings used in this research and discuss methods for data collection and analysis to address the research gap identified in Chapter 3. This theoretical approach will highlight the significance and importance of undertaking the study.[217] The theoretical perspective provides context for the research process, the chosen methodology, and provides the basis for design logic and research criteria.[5] Throughout this section, I will explain the choices made within the theoretical framework and discuss how they guided the research.

Crotty's four elements of research design

Crotty's 1998 scaffolding framework provides direction for research design using four elements, epistemology (how we come to understand reality and what we know), theoretical perspective (the theoretical stance that describes the contextual viewpoint that informs the methodology), methodology (the theoretically informed process that links the choice of methods to the study outcomes) and methods (the techniques and mechanisms used for data collection and analysis, linked to the research question or hypothesis).[5]

Important features of Crotty's (1998) framework are that it (i) conflates ontology and epistemology and (ii) clearly distinguishes methods from methodology.[218] Crotty's framework invites researchers to justify their decision-making processes, beginning with the epistemology of how researchers gain knowledge about what they know. The epistemology informs the theoretical perspective or lens applied to the research theory, which in turn inspires the methodological choices and determines the appropriate methods used for data collection.[219] The four elements of research design are shown in Figure 9, illustrating the order of interconnected steps to guide this research to focus on the research problem.

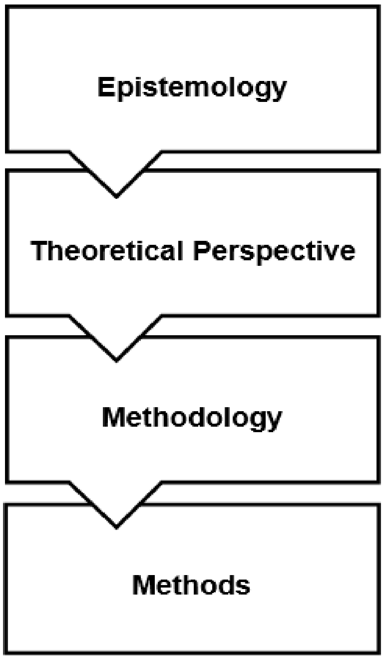


Figure 9. Four elements of research design adapted from Crotty (1998)

The next section will move through the four elements of research to explain the research design applied to this inquiry. At the end of each part, I illustrate how each element has added to the research design for this thesis.

Crotty's Element One: Epistemology

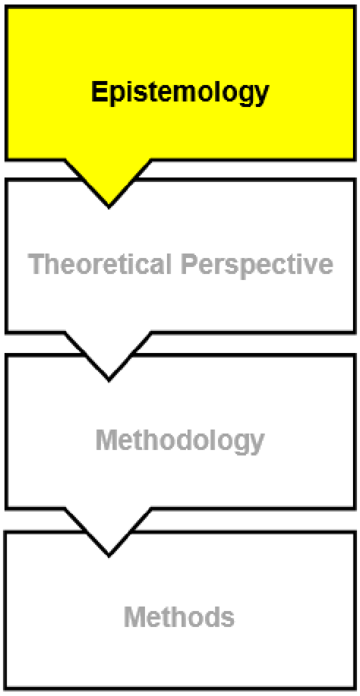


Figure 10. Element One. Epistemology.

Epistemology is the theory of knowledge, how we know knowledge, its scope and its limits.[220] Epistemological assumptions are especially helpful to generate knowledge that guides research practice,[221] and to provide the theoretical grounding for decision-making.[5] Epistemological assumptions are used as a theoretical frame for methodology, the construction of research questions, data collection methods, and the nature of the investigation.[221]

Pragmatism is the specific epistemological approach chosen for this research. Pragmatist philosophy assumes that knowledge and reality are founded on socially constructed beliefs and practices, focuses on the nature of the human experience, and suggests that the world is inseparable from the agency within it.[222-225] Pragmatism does not commit to a single system of philosophy and reality, believing that research always occurs in social, historical, political, and other contexts [226]. Pragmatism also rejects the traditional dualism of objectivity and subjectivity.[222] Because pragmatism abandons the need to singularly orientate to either post-positivism (objective) or constructivism (subjective), instead it advocates applying a pluralistic approach to knowledge of the research problem, and ensures knowledge is based on experience.[222, 226]

Pragmatism is an appropriate epistemological approach for this study for several reasons. First, pragmatists acquire knowledge through a process of inquiry to evolve beliefs around actions and their consequences.[222, 224] This is a suitable approach to understand the social origin of cognitive concern and dementia risk exposure in homelessness and of social factors that may potentially prevent dementia risk reduction. Second, a pragmatist approach understands inquiry as a process of knowledge-seeking to progress ways to improve and identify solutions when addressing problems that persist in society.[223] This research draws on the experiences of people experiencing homelessness and stakeholders involved in homelessness services to identify exposure to dementia risk and provide recommendations for cognitive wellbeing and dementia risk reduction. These actions comply with a pragmatist approach towards implementing solutions. Third, pragmatism allows for examining problems of injustice by utilising empirical research and first-order experiences together to provide advocacy for social justice concerns, such as equity and fairness, and freedom from structural oppression.[222, 223] This should be facilitated by identifying persistent and relevant social problems (poverty, housing, mental health outcomes) and seek movement towards addressing those problems through increased awareness and advocacy. There are political and moral dimensions to pragmatism that require a deliberation beyond its practical application, extending thought to empowerment and principles of social justice.[227] The social justice attribute embedded in pragmatism will overarch the mixed methods methodology design and will fundamentally ground the integration of data in this research.

In keeping with the pragmatist paradigm, pragmatic research questions have been formulated for two distinct studies, with (i) people experiencing homelessness and (ii) stakeholders in homelessness. This pragmatic inquiry will understand the lived experience by asking: *how do we understand the impact of homelessness on cognitive wellbeing and exposure to dementia risk* (Study One) and will explore dementia knowledge and the role of stakeholders in risk reduction by asking: *how can we encourage dementia risk reduction for people experiencing homelessness* (Study Two).

In this research, I explicitly refer to Dewey's pragmatic constructivism[228-230] and Dewey's concept of social inquiry,[227] explained in the next section.

Deweyan pragmatism and concept for social inquiry

Dewey reorientated pragmatism away from abstract concerns (metaphysical inquiry such as the nature of reality) towards knowledge with a requisite emphasis on the human experience.[227, 231] Dewey proposed that beliefs acquired from prior experiences need interpretation to generate actions, and the outcomes of those actions are identified in our beliefs.[227] This creates a philosophical process whereby knowledge is created through a series of actions and reflections.[227] Dewey's pragmatic concept for social inquiry encompasses more than just epistemology and provides a five-step model linking beliefs and actions through a process of reflective decision making.[227] This allows for refinements of the research problem, the research questions, and the methodology as part of Dewey's reflective process.[227]

Because Deweyan pragmatism allows for a methods-centric approach to inquiry, it provides flexibility in how theory can be applied to this research. No limitations are placed upon the reflective process in Dewey's concept of social inquiry, which allows for decisions to be continually refined and adjusted until settled. Dewey's reflective model is used in this research to aid the research planning using a system of processing ideas and decisions. Reflections began with the research problem, for which initial research questions were reformulated and refined until they were fully developed. Dewey's process of social inquiry continued with cycles of reflection when deciding appropriate methods for the research, in line with pragmatist theory. An overview of Dewey's concept of social inquiry is shown in Figure 11.

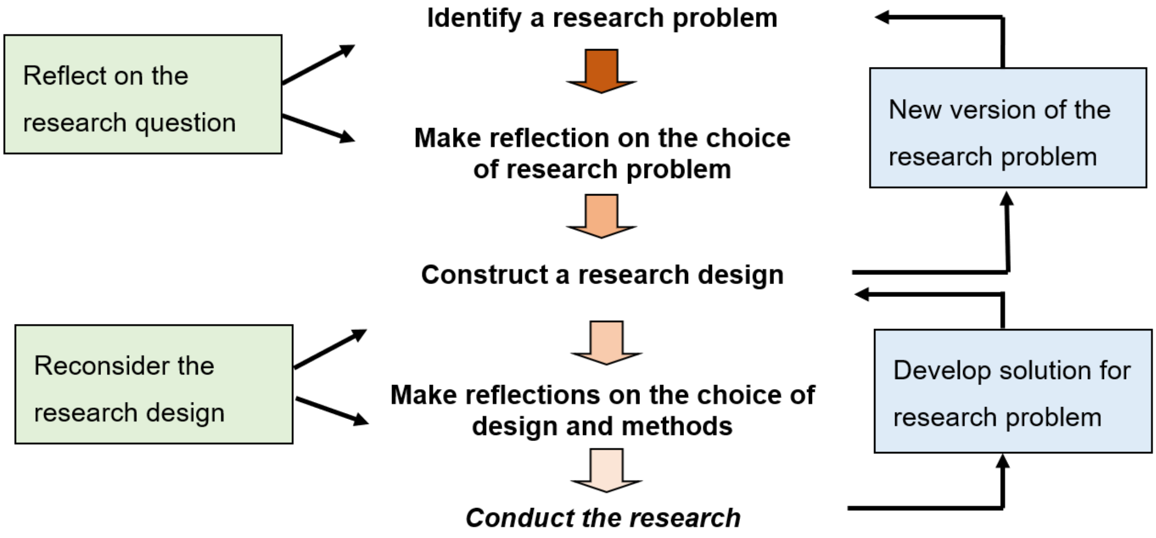


Figure 11. Dewey's concept of social inquiry process adapted from Morgan (2014)

Deliberations using Dewey's concept of social inquiry in this research.

Using Dewey's concept of social inquiry, the following deliberations were made:

First, a basic research dilemma was identified as 'do people experiencing homelessness have an increased risk of dementia'. I recognised that the research problem posed in this rudimentary way required further reflection to better capture the complexity of the nature of the problem.

Second, I reflected on how best to frame the research question to consider the many factors that expose people to dementia risk, and to reflect how dementia risk reduction initiatives in homelessness can be understood. This reflective process allowed for revised phrasing of the research question, subsequently changed to *how is homelessness a barrier to cognitive wellbeing and dementia risk reduction?* This reflection generated two research questions, first, *how does homelessness impact cognitive wellbeing and exposure to dementia risk*, and second, *how can dementia risk reduction for people experiencing homelessness*?

Third, the methods used in this research needed to advance from Deweyan pragmatist epistemology to provide theoretically informed mechanisms for data collection. A mixed methods approach was chosen to yield robust findings gathered from integrating quantitative and qualitative data. The need to employ two distinct studies was identified because the research problem is addressed through the contributions of both people experiencing homelessness and stakeholders in homelessness. In line with Dewey's concept of social inquiry,[227] previously shown in Figure 11, I decided that a parallel convergent mixed methods design would fit best for the first study, and an explanatory sequential mixed methods design would be used for the second study. The rationale for these choices was supported by Dewey's concept of experience, built around the questions of 'what are the sources of our beliefs' and 'what are the meanings of our actions'.

The epistemological positioning provides the first step in building the research design (Figure 12). This diagram will be developed as the discussion moves through this chapter on research foundations.

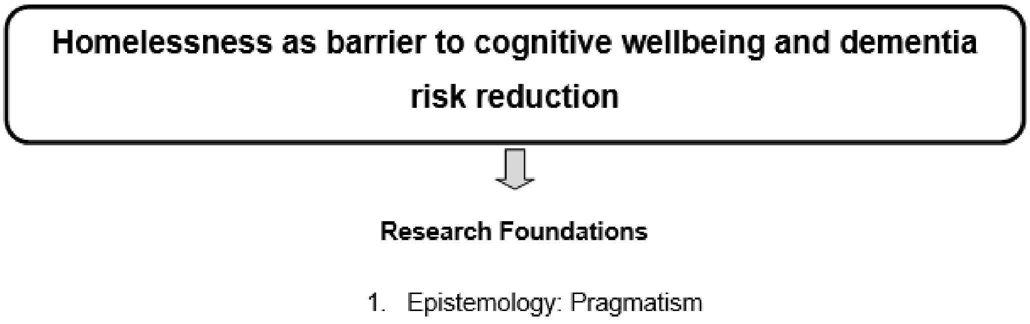


Figure 12. Step 1 of building the research design

Crotty's Element Two: Theoretical Perspective

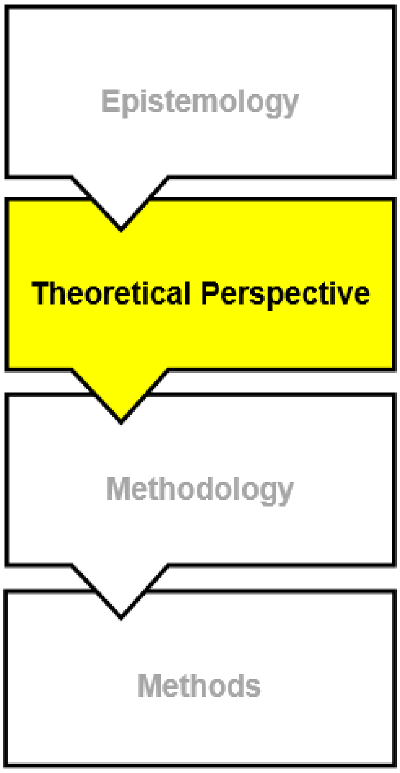


Figure 13. Element Two: Theoretical Perspective

The theoretical perspective provides an orientating lens that anchors the research standpoint.[226] Many theoretical perspectives exist and hold multiple lenses,[218] however, critical theory is used here, with a social determinants of health and transformative lens applied. I begin this section by discussing critical theory, then I explain why critical theory perspectives interface with the social determinants of health and a transformative lens chosen for the studies undertaken in this research.

Critical theory

Critical theory has important philosophical synergies with pragmatism,[232, 233] that connect the epistemological and theoretical perspective of this research. Critical theory is a dialectic approach to analysing social ideologies that exist in society,[234] and seen as the space encompassing areas of social concern, attentive to the dynamics that subject people to oppression and inequitable power relationships. It promotes emancipation,[229] and can offer scaffolding to link philosophical principles, theories and new phenomena.[235] Contemporary critical theory is particularly useful when scrutinising social suffering and injustice[236] and seen as the space encompassing areas of social concern.[237] The underlying principle that "knowledge cannot be separated from the agents of the system in which it exists"[238 p.235] makes critical theory appropriate for this thesis because understanding the perspectives of people experiencing homelessness is essential to the success of how this research represents and advocates for people experiencing homelessness. Additionally, critical theory supports this research in several ways. It promotes a social justice approach, orientating research towards redressing domination and promoting emancipation.[239] Research using a critical theory perspective aims to empower people to move past control and restrictions placed on them by socially determined race and class,[226] and embeds a social justice orientation with advocacy for marginalised groups.[219, 240]

The focus on society and culture is central to critical theory principles, where it must hold the three dimensions of being explanatory, practical and normative.[241] Power relationships create normative positions, and the key goal of research is to understand or challenge these positions, highlighting the need for dignity for every individual regardless of position.[237, 242] Whilst contemporary critical theory maintains a normative dimension of critiquing and confronting dominance in society,[234] it challenges assumed normative positions.[237, 242] This is well suited to social research in homelessness that embeds social determinants of health and transformative lenses across its investigation. This is because homelessness persists in society and is an enduring challenge for social justice and health equity that imposes influence on a person's health, including their exposure to dementia risk. Unfair and inequitable exposure to dementia risk requires a thorough critique and challenge.

Using a critical theory standpoint sustains the research focus on social justice and advocacy aspects that confront normative positions of cognitive wellbeing and dementia risk in homelessness, which, to date, have remained unchallenged and unchanged. Questions can be asked using the application of critical theory. For example, whilst we know that the cognitive health of people experiencing homelessness is worse than the general population (as explained in Chapter 2), does inaction determine that it should be so? Dementia risk reduction recommendations attracts global recognition as evidenced through the World Health Organisation guidelines: *Risk reduction of cognitive decline and dementia*[177] and is the topic of much research and health promotional activities, but the recommendations preclude people experiencing homelessness who neither have the resources or independent ability to act on them.

Critical theory, where a critique of social suffering is required, provides the foundations on which the mixed methods methodology was chosen.[236] The orientation of critical theory in social suffering is used to recognise reality and to have knowledge of what that brings.[236] This fundamental tenet will guide the methodological approach of the first study in this thesis by examining social determinants of health focussing on socioeconomic, political and cultural factors underpinning health outcomes.[237, 243] Additionally, critical theory is transformative, concerned with empowering humans, helps to ground inquiry toward change, and is able to inform data collection and analysis.[49, 226] It is this philosophy that provides the transformative methodological lens that is used in the second study in this research. More is explained about the methodological lenses in the next section on methodology, however their application is presented in Chapter 5: *The Lived Experience,* and Chapter 6: S*takeholders in Homelessness.*

Critical theory, as the theoretical perspective, is the second step of building the design for this research (Figure 14).

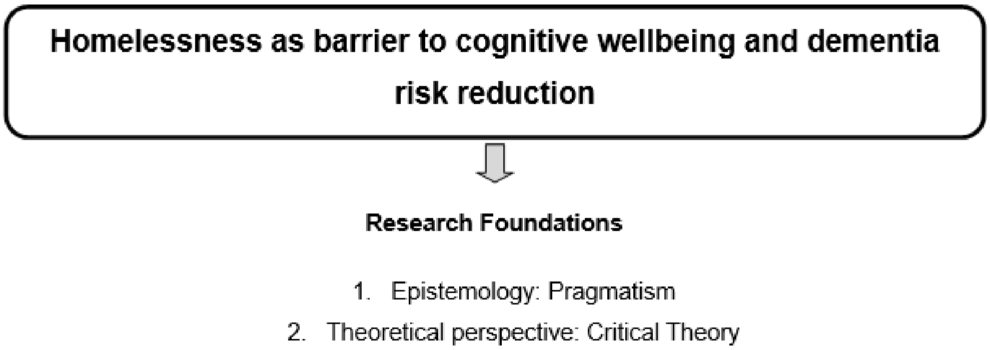


Figure 14. Step 2 of building the research design.

Crotty’s Element Three: Methodology

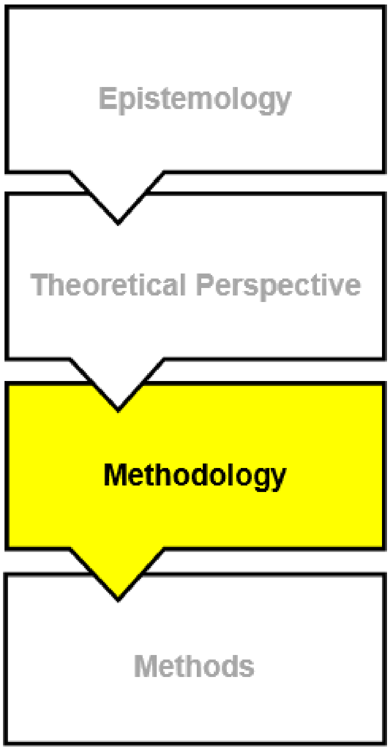


Figure 15. Element Three. Methodology.

Research methodology is an essential theoretical and procedural link that brings epistemology and methods together.[244] Methodology relates to the study of methods and reveals the practices and assumptions of using a particular method and how they should be approached. These practices and assumptions typically manifest in the specific techniques used to gather data, including surveys, questionnaires, and interviews.[245]

Mixed Methods is a distinct research methodology, with its own identity that accords with pragmatic foundations of investigating *how* and *why* using Deweyan philosophy.[227, 246, 247] The following section will discuss mixed methods as a methodology used for this research.

Mixed methods methodology

A mixed methods study requires a conceptual framework to promote deep thinking on how the philosophy embeds with the study design.[219] The philosophical positioning of mixed methods research sits between the paradigms of post-positivism (traditionally aligned with quantitative research) and constructivism (traditionally aligned with qualitative research).[226, 231] This separation from binary concepts allows for combining quantitative and qualitative data to strengthen evidence and provide more balance to the natural limitations of singular approaches. This is because mixed methods lack the need to 'choose' one epistemology over the other because both are recognised and therefore permits the use of methods that traditionally sit in different epistemologies. Additionally, in mixed methods, the quantitative and qualitative elements may come from different sample groups (as in this research), combining evidence to present inclusive and wide-ranging perspectives that cannot be gained from singular-method research frameworks.[248]

The pragmatist foundations of mixed methods allow this approach to be malleable in its philosophy of having multiple perspectives of inquiry that are understood through the integration of different perspectives.[249] Thus, pragmatism represents distinct world views and assumptions that allows for different forms of data analysis brought together through empirical inquiry.[226, 249] An imperative ideological stance of mixed methods methodology is the existence of multiple kinds of reality, which is built on pragmatist understandings of dialectic social issues using critical inquiry in this research.[250]

Abductive reasoning

Research is frequently framed within opposing perspectives, with approaches categorised as deductive or inductive.[251] Traditionally, deductive reasoning is more closely associated with quantitative data, often beginning with a concept or theory and moving towards a hypothesis that can be tested, which data findings can proved or disproved. Deductive reasoning progresses from the general to the specific.[252] In contrast, inductive reasoning is frequently applied to qualitative data, generally beginning with specific observations, noting patterns or organisation, and advancing towards a theory.[251] However, when mixed methods are deployed, a third, combined approach of abductive reasoning may be helpful.[253]

Abductive reasoning addresses weaknesses in deductive and inductive approaches where each approach has natural boundaries. Instead, abductive reasoning follows a pragmatist perspective, allowing for a flexible application that follows logic in its meaning and how it relates to social actors.[254] This is especially useful when managing data gathered from chaotic life experiences, such as in this research, where observations often require organisation to envisage best truth, or create or build on existing theories.[252] Therefore, the pragmatic inference of abductive reasoning, and how it explores data to identify new themes and relationships, compliment the compatibility of pragmatism and mixed methods research methodology applied to this research. Abductive reasoning balances pragmatist epistemology, advocating its use in mixed method research methodology where pragmatism underpins data evaluation and interpretation of findings.[253]

Mixed methods research methodology: Benefits for this research

> *"…. A mixed methods way of thinking actively engages us with difference and diversity in service of both better understanding and greater equity of voice" Greene (2008).*[255 p.20]

As a methodology, a mixed methods approach to this research is well suited to the heterogeneity of homelessness combined with the complexity of exposure to dementia risk. There are several reasons why a mixed methods methodology is a good choice. First, integrating qualitative and quantitative data expands and extends the scope for gaining unique perspectives that cannot be achieved through single methods alone. In this research, I apply a broad investigation that includes a range of methods for data collection. Second, the integration of both statistical and thematic data, and their subsequent analysis and synthesis, using mixed methods methodology allows for an interpretation that can draw upon the combined strengths of each data set.[253, 256] This has the additional benefit of being able to frame narratives with numbers and situate numbers alongside the words.[219] A third benefit of mixed methods research methodology is that combining methods expands both scope and depth of data sufficiently so that diverse and complex questions can be addressed.[256] Finally, a fourth benefit is a mixed methods methodological approach is suitable for this research is because it separates into two distinct mixed method study streams, explained in the following section.

The methodological lenses applied to this research

The methodological lens interjects a critical theoretical perspective into the methodological understanding. In *The Lived Experience*, I use a social determinants of health methodological lens, and in *Stakeholders in Homelessness*, I use a transformative methodological lens. Each are relevant in how they orientate an understanding of dementia risk in homelessness. For example, the lens provides the perspective from which to examine life course exposure to dementia risk factors, mechanisms for cognitive change, lifestyle determinants that disadvantage cognition wellbeing, and cognitive health ramifications that are secondary to illness or disease, which all have important trajectories for dementia aetiology.[257] These factors will be highly relevant for people experiencing homelessness and targeting dementia risk reduction across the life course can bring potential cognitive benefits.[258]

This next section will provide the background and rationale for each methodological lens.

Study One: The Lived Experience: Methodological lens of the social determinants of health

In Study One: *The Lived Experience* I use the framework of the Commission on the Social Determinants of Health by Solar and Irwin (2010).[44]

Background of the Commission on the Social Determinants of Health

The World Health Organisation set up the Commission on Social Determinants of Health (CSDH) in 2005 to respond to global health inequity and reorientate the effort to address health inequity.[259] Sir Michael Marmot, Chair of the CSDH, and colleagues highlighted a health gradient. They paid attention to the inequitable health distribution seen within communities by looking at poverty, inequality in income and assets and social exclusion that are all seen to widen the gap in health equity.[260] However, a synthesis of international reports arising from burgeoning literature on the social determinants of health and their resulting theoretical models of social health outcomes was needed, and in response the 2010 CSDH Conceptual Framework for Action on The Social Determinants of Health emerged. This evolution of this framework positioned health as a social phenomenon, and more broadly, elevating health as a topic for equity and social justice.[44]

The directive for the CDSH conceptual framework was to consider how taking action on the SDoH could improve health outcomes, especially focused on the social determinants of health inequity, both globally and within countries.[261] This process consisted of summarising of evidence on the structures of societies by examining how social interactions, social norms and institutional settings influence people's health. The CSDH directive included a focus on how it could inform policy directions and interventions through an analysis and decision-making model.[44] In doing this, the

CSDH conceptual framework identified intervention points and policy directions for taking action to address health inequity and improve health outcomes. However, whilst the CSDH conceptual framework and reported recommendations have been used to guide health principles and policies, it has not led to a fundamental and anticipated change.[262] In part, this is because of unchallenged socio-political environments that focus on alternative priorities and the continuance of policy-driven pathways that disfavour low economic and societal positions.[262, 263] Nonetheless, the resulting CSDH conceptual framework is viewed as a formative framework model to examine the critical role of social determinants, both in health and health inequity.[263]

Methodologically, using the lens of the CSDH framework supports this research in different ways. First, it helps establish techniques to identify socially generated, potentially modifiable risk for developing dementia for people experiencing homelessness. This framework helps to inform questions asked in the semi-structured interviews with people experiencing homelessness. Second, it helps identify barriers for cognitive health seen in homelessness. Third, it provides direction to where intervention points can be made. Although a SDoH theoretical perspective is often thought to closely align towards a constructivist paradigm, it also complements a critical theory lens because health inequity issues draw attention to power structures and ideologies that shape societies in which they occur, and of dominant socioeconomic, political, and historical influences.[264, 265] In essence, the CSDH conceptual framework provides congruency with critical pragmatist principles through its social justice positioning of identifying the social determinants of health inequities. The CSDH conceptual framework is shown in Figure 16.

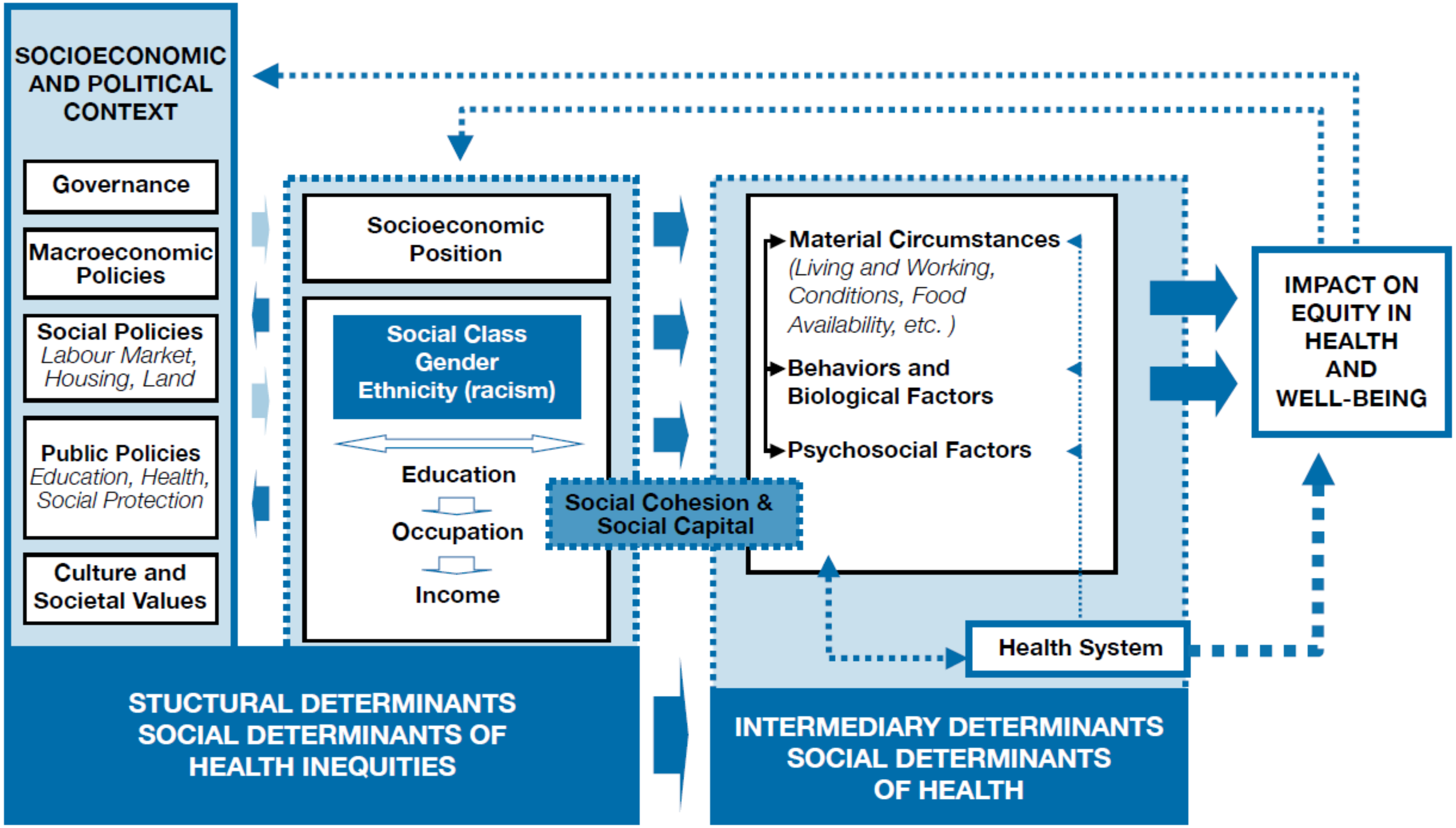


Figure 16. World Health Organisation Conceptual Framework for the Social Determinants of Health

Reprinted with permission from The World Health Organisation. Solar and Irwin (2010) A Conceptual Framework for the Social Determinants of Health. Social Determinants of Health Discussion Paper 2. P.6. Copyright 2010.

Study Two: Stakeholders in Homelessness: Methodological lens used is the Transformative Approach

Study Two engages a transformative lens.

The Transformative Approach Lens used for Study Two

The tenet of transformative mixed methods occurs in its advocacy stance, amplifying issues by focussing on power dynamics, and elevating the needs of marginalised communities, including people experiencing homelessness.[266] As a leading champion of transformative research, Mertens promotes a methodological perspective inspired by critical theoretical tradition and encompasses paradigmatic perspectives that are fundamentally emancipatory, participatory, and inclusive.[267] The transformative paradigm requires a social justice scrutiny of power differentials and privilege that influences how research in marginalised populations is approached, linking to actions that attenuate disparity.[268] It examines socio-political structures[269] revealing unequal power relationships that are important to questions regarding social equity and social justice.[49, 270]

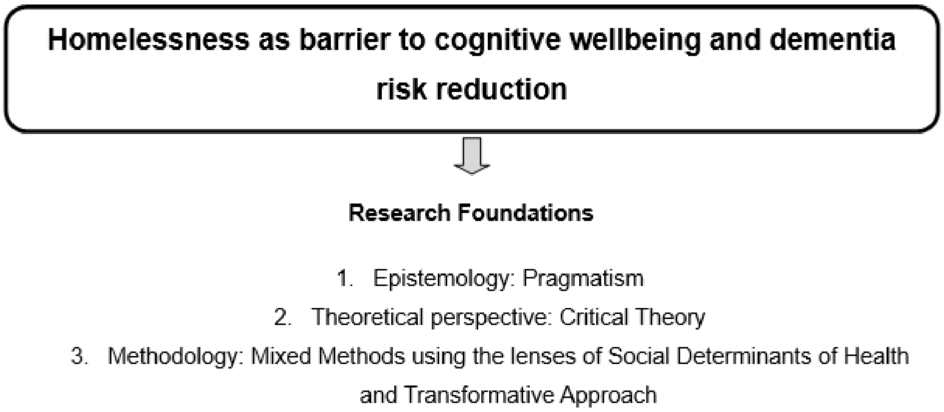
Important values are attached to transformative research. These values include having an ethical focus on the needs of people who are marginalised and having concern for human circumstance.[266] Values that amplify transformative actions aim to improve social and environmental fairness, including economic justice, that must consciously act to address inequities rather than maintain the status quo.[51] Transformative values would recognise the discriminatory ecological complexities attributed to homelessness and its impact on cognitive wellbeing and exposure to dementia risk. Within the philosophy underpinning the transformative approach there is an expectation for researchers to apply transformative assumptions in how they learn about the community under study and build trust relationships, include the navigation of power relationships.[50]

The transformative approach provides a rigorous framework to engage with members of culturally diverse groups.[271] However, the same transformative values have relevance for *Stakeholders in Homelessness* because stakeholders are seen as both gatekeepers and vicarious carers of people experiencing homelessness. As primary advocates stakeholders represent the subjective voices of people experiencing homelessness and are integral to centring homelessness as a concern for social justice. Stakeholder actions are emersed in improving and supporting the lives of clients which are transformative values. I argue for its use as a guiding methodological lens for Study Two: *Stakeholders in Homelessness* because service design that benefits the cognitive wellbeing of people experiencing homelessness must embed these transformative values and cocreate transformative service provision and promote human agency.[52]

Stakeholders are well positioned to assess client needs and offer pragmatically-positioned solutions that logically fit within a transformative approach to understanding community needs.[268] However, stakeholders hold different power relationships than their clients do. Whilst they provide strong client advocacy and support, they also work within funding and service constraints positioned within larger socio-political environments. This structure generates all-encompassing power differentials between stakeholders who represent their clients and structures of governance who control funding and who can influence the delivery of that funding, depending on their focus of monetary worth. In Study Two: *Stakeholders in Homelessness*, I consider stakeholders as the proponents and protectors for people experiencing homelessness, fundamental in understanding the diverse needs of homeless communities, and for these reasons, a transformative lens is an appropriate methodological choice.

This methodology section has explained the choice of mixed methods methodology and the methodological lenses of each mixed methods study.

This element adds step 3 to the research design (Figure 17).



Homelessness as barrier to cognitive wellbeing and dementia risk reduction

Research Foundations

1. Epistemology: Pragmatism
2. Theoretical perspective: Critical Theory
3. Methodology: Mixed Methods using the lenses of Social Determinants of Health and Transformative Approach

Figure 17. Step 3 of the research design

Crotty’s Element Four Methods (Mixed)

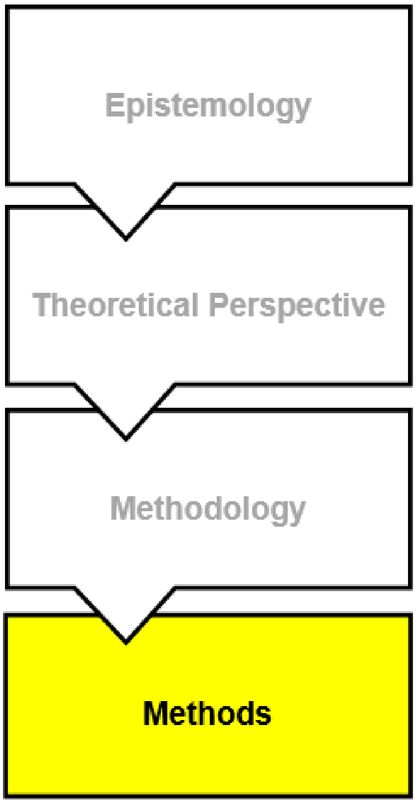


Figure 18. Element Four. Methods

Methods across two mixed methods studies

In this section, I outline the methods used across two separate studies, *The Lived Experience* and *Stakeholders in Homelessness*. However, whilst I identify the methods design used for each study here in the context of Crotty’s research design, I detail these methods in their respective chapters: Chapter 5: *The Lived Experience* and Chapter 6: *Stakeholders in Homelessness*. Each study requires different modes of data collection to best fit with separate research questions, aims and objectives described in their respective chapters. This approach helps compartmentalise each study’s distinctiveness in line with their different standpoints concerning power, agency and influence. However, having two distinct mixed methods study streams invests in this research's diversity and the intrinsic nature of mixed methods research.

Pragmatism and mixed methods are complementary because the philosophy of pragmatism is affiliated to mixed method research by providing the theoretical framework on which mixed methods is based,[3] and critical theory's focus on critiquing and challenging society.

I will now outline the methods used for each study separately.

The Lived Experience

The first study *The Lived Experience,* uses a parallel convergent mixed methods design to collect and analyse quantitative and qualitative data elements that are subsequently compared, related and integrated.[272] As the name suggests, the parallel convergent mixed methods is a concurrent approach, involving the collection of separate but complementary data.[273]

The *Lived Experience* mixed methods methodology design consists of two concurrent elements comprising of quantitative data analysis of a longitudinal study (Part One) and qualitative semi-structured interviews (Part Two), shown in Figure 19. The detail of methods for *The Lived Experience* will be described in Chapter 5.

***The Lived Experience*. Parallel Convergent Mixed Methods**

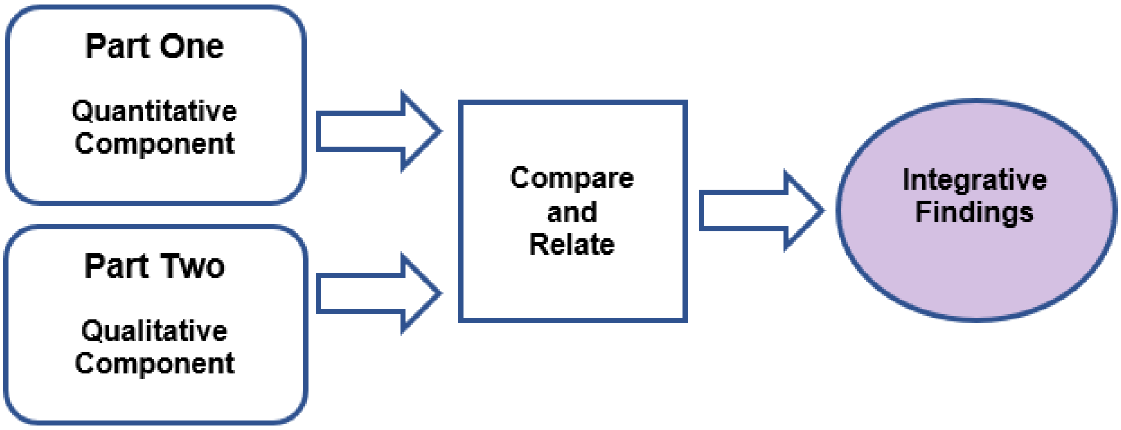


Figure 19. Parallel Convergent Mixed Methods design. Study One: *The Lived Experience*

Stakeholders in Homelessness

The second study, *Stakeholders in Homelessness,* employs an explanatory sequential mixed methods design. Here, research is conducted over two phases (Part One and Part Two), illustrated in Figure 20. Procedurally, explanatory sequential mixed methods always begin with collecting quantitative data (Part One), and findings are linked to qualitative data (Part Two) by informing the methods used for data collection.[274] In this study, part one of this design consisted of a dementia knowledge survey that will be quantitatively analysed with findings used to inform questions posed in qualitative in-depth interviews. This sequential process aimed to 'build' on the knowledge gained and allows for a deep exploration of the mechanisms and nuances of information so that elaboration can be made on key concepts.[275-277] The explanatory sequential design is shown in Figure 20. The detail of methods for *Stakeholders in Homelessness* will be described in Chapter 6.

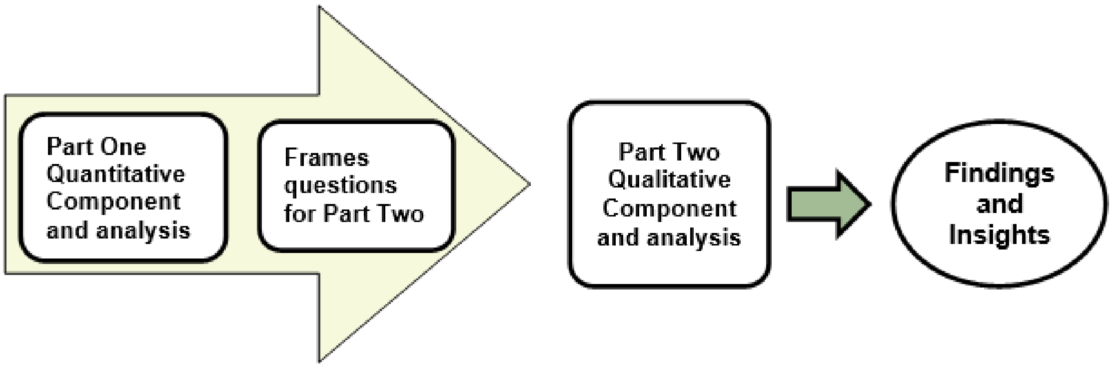


Figure 20. Explanatory Sequential Mixed Methods design. Study Two: *Stakeholders in Homelessness*

The research design model

The completed research design illustrates the progression from the research problem: *homelessness as a barrier to cognitive wellbeing and dementia risk reduction* through the research foundations (Epistemology, theoretical perspective, methodology, and methods), to explain the methods design of a parallel convergent mixed methods design for Study One: *The Lived Experience* and an explanatory sequential mixed methods design for Study Two: *Stakeholders in Homelessness.* Relevant sections of the complete research design (Figure 17) will be referred to in

Chapter 5: *The Lived Experience* and Chapter 6: *Stakeholders in Homelessness* as the thesis progresses.

The methods add the final step 4 to the research design, shown in Figure 21.

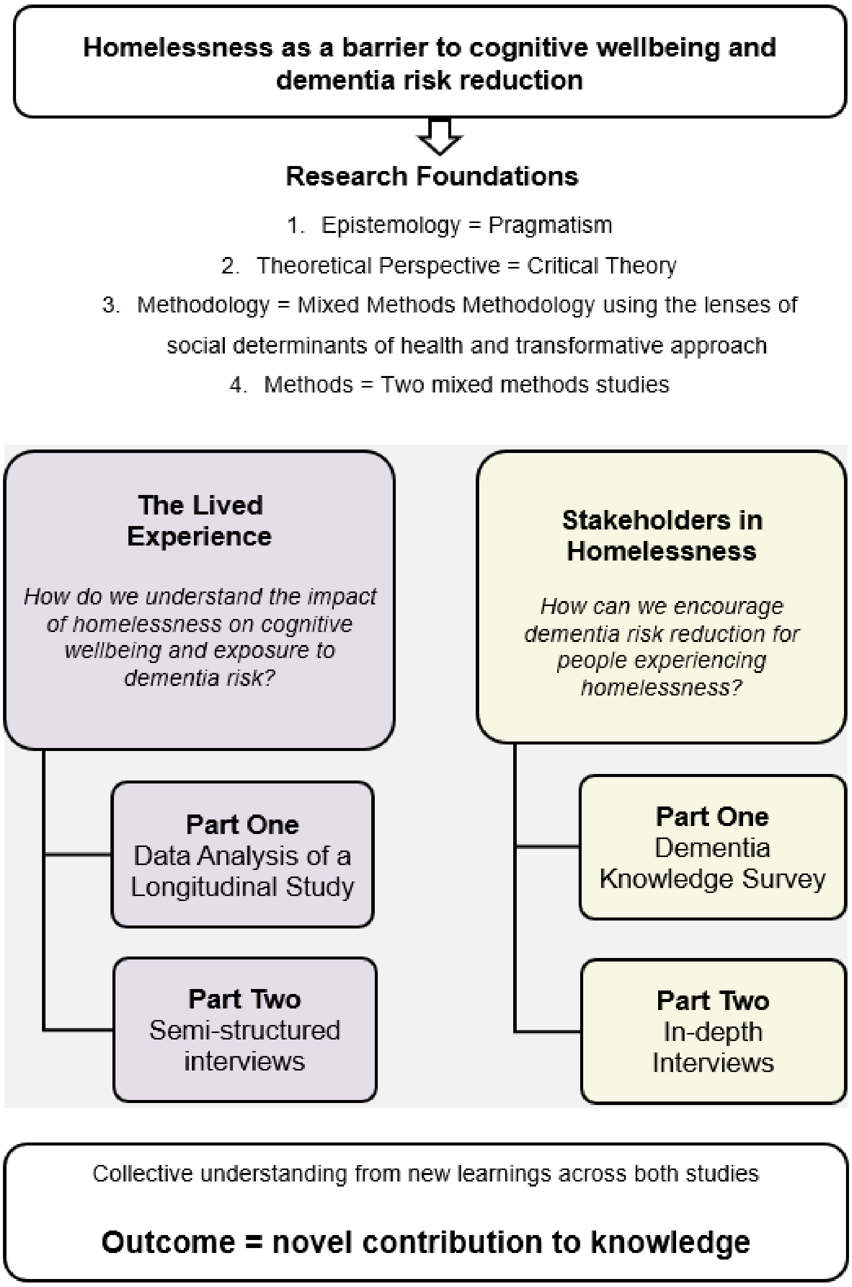


Figure 21. The Research Design

Methods for Data Integration

> *"The linking of qualitative and quantitative approaches and dimensions together to create a new whole or holistic understanding than achieved by either alone"*
>
> Fetters (2017)[278]

Integration of data in mixed methods study is an integral component that distinguishes mixed methods from multi-method approaches.[277, 279] Data integration occurs when there is interrelation or incorporation of data. It can be conceptualised by linking different data sets and data collection methods.[219] Information produced from combining quantitative and qualitative perspectives is a central tenet for mixed methods research, separating it from single-method and multi-method research. Integration should be a multiple level approach of combining data, consolidated throughout the study designs, including methods, analysis, interpretation and reporting so that numbers and text are positioned together.[276, 277] Four main types of data integration exist and are illustrated in Table 2.

Table 2. Types of Data Integration

Type of integration	Description of Integration
Connecting	Where one type of data set links to another type of data through the sampling frame. For example, interview participants for qualitative data are selected from a previous quantitative survey.
Building	Where one type of data informs the data collection approach for the second data set to build on the information. For example, qualitative participants are asked questions that are directly informed by a previous quantitative survey.
Merging	Where a quantitative and a qualitative data set is brought together for further for comparison. For example, quantitative and qualitative data are typically integrated after each data set has been collected and analysed.
Embedding	Where data collection and analysis are directly linked throughout multiple points and is often used for advanced study designs that require an understanding of contextual factors for control of bias, or for developing measurement tools.

Adapted from Fetters and Curry. Achieving Integration in Mixed Methods Designs – Principles and Practices[276]

I use 'merging' integration in *The Lived Experience*, and 'building' integration in *Stakeholders in Homelessness*. Procedures for integration in this thesis largely follow integrative examples seen across other mixed methods studies such as Bradley (2012)[280] and Zhang and Drabier.[281]

Integration is where points of convergence and divergence occur between disparate data collections and their analysis is achieved through linking procedures to create a single data source. This is used to provide key insights and understandings of the data, with integrative processes drawing from the philosophical and methodological foundations and methods design.[278]

Each technique of integration attracts its own procedures. In *The Lived Experience*, QSR NVivo software 12 version 1.3 (QSR NVivo hereafter) was used to code frequencies of themed narratives and to examine patterns. The stories behind quotes were accounted for, and cross-referenced, across themes to ensure that their meanings were not diminished in the process of integration. The strength of theme patterns was determined by the number of QSR NVivo entries as a process of quantifying narratives and compared with the quantitative findings resulting from descriptive statistics. In Chapter 6: *Stakeholders in Homelessness* data integration was multi-level and occurred across several stages to build and inform the subsequent component of the study, with integrated data used in the analysis. In both integrative approaches, unlinked data provided additional, important detail, used to add context and strengthen stories and provide further meaning.

The detail of process for each study data integration and subsequent results, presented as an integrative discussion, are provided in Chapter 5: *The Lived Experience* and Chapter 6: *Stakeholders in Homelessness.*

Chapter summary

This Chapter provided the research foundations and research design, including the epistemology, theoretical perspective, methodology and methods. The research foundations proposed by Crotty[5] will address the two research questions: *How does homelessness impact cognitive wellbeing and exposure to dementia risk* (Study One) and *How can dementia risk reduction for people experiencing homelessness be improved* (Study Two). Pragmatism is the chosen epistemology and critical theory provides the theoretical perspective. The methodology is mixed methods methodology using the different methodological lens of social determinants of health (Study One) and transformative approach lens (Study Two). Data will be integrated in line with each study design and inform the interpretive discussion in Chapter 8 to demonstrate the new knowledge emerging from the research.

The next chapter, Chapter 5, describes *The Lived Experience*, which is the first study in this thesis.

CHAPTER 5: THE LIVED EXPERIENCE

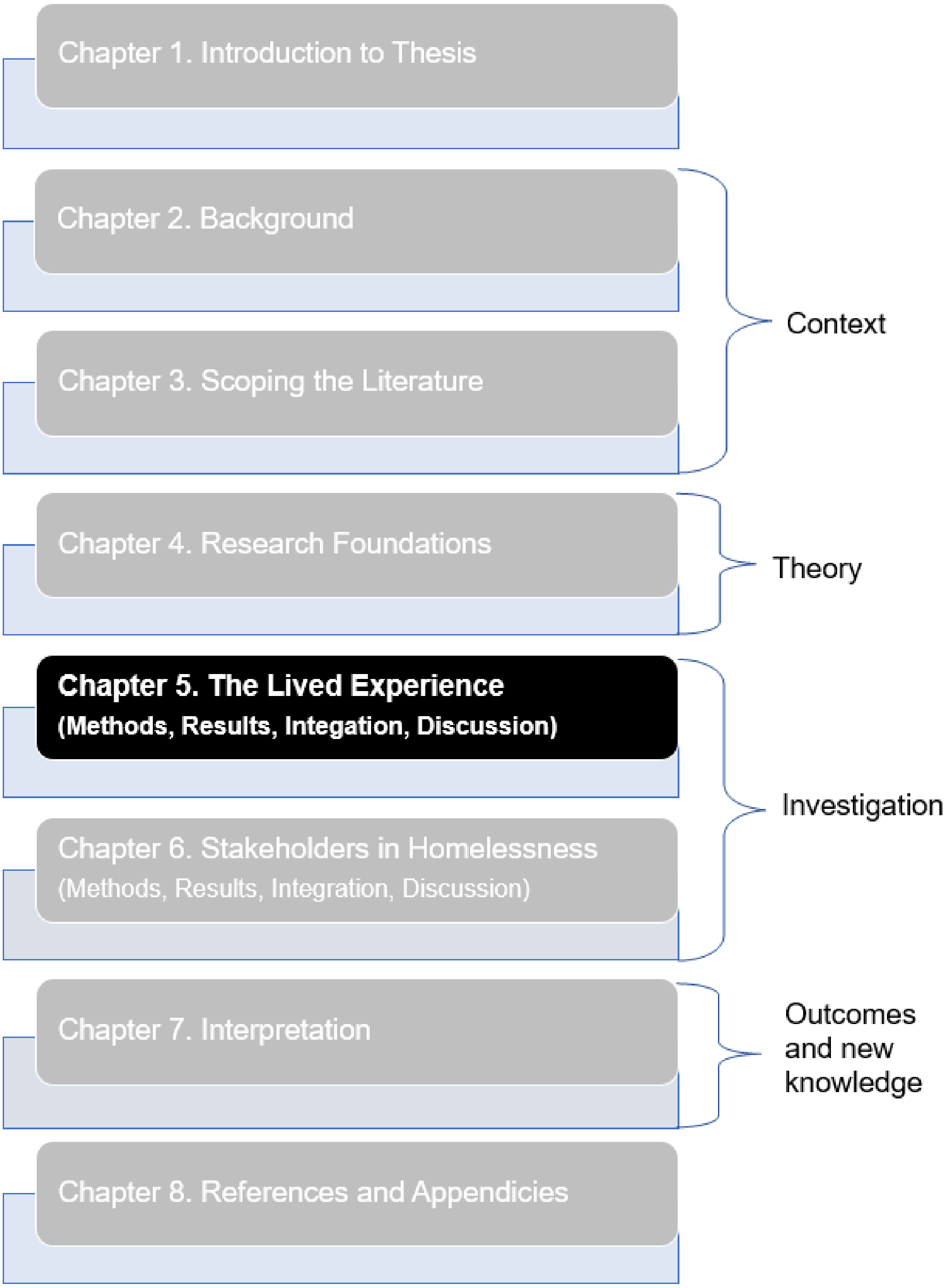


Figure 22. Thesis structure - Chapter 5

Introduction to Chapter

In this chapter, I present the first of two mixed methods studies. It is presented in four sections, as follows:

- **Study One, Part One (Quantitative)**
  - Introduction
  - Methods
  - Results
- **Study One, Part Two (Qualitative)**
  - Introduction
  - Methods
  - Results
- **The Data Integration**
- **Integrative Discussion**

I first begin by reiterating the research question, aims and objectives and methodological lens for *The Lived Experience.*

The Study One investigation is conducted over two parts: a descriptive statistical analysis of *Journeys Home,* an Australian national longitudinal survey of 1,682 people experiencing, or at risk of, homelessness (Part One), and qualitative interviews, conducted with fifteen people experiencing primary homelessness in Adelaide, South Australia (Part Two). The data is integrated using a merging technique. The chapter then concludes with a discussion of the integrated data.

The Lived Experience addresses the research question: *How does homelessness impact cognitive wellbeing and exposure to dementia risk*? with the following research aims and objectives as previously outlined in Chapter 1.

Aims

- To determine characteristics of homelessness that may lead to cognitive harm and confer risk for late-life dementia.
- To understand themes arising from the experience of homelessness in the context of potentially modifiable risk factors for dementia.

Objectives

- Present patterns seen in data identifying characteristics of people experiencing homelessness.
- Explore parallels seen between the experience of homelessness and potentially modifiable risk factors for dementia.

Applying the methodological lens of the social determinants of health

As outlined in Chapter 4, Study One: *The Lived Experience* will apply a social determinants of health lens which is underpinned by pragmatic epistemology and a critical theory perspective. To apply this lens, I draw extensively upon the work of Solar and Irwin's The Conceptual Framework for Action on the Social Determinants of Health[44] discussed in Chapter 4 (methodology section) which is used to guide the data collection, analysis and discussion of Study One: *The Lived Experience*.

Study One, Part One: The Lived Experience

The study design for Study One, Part One: *The Lived Experience* is presented in Figure 23.

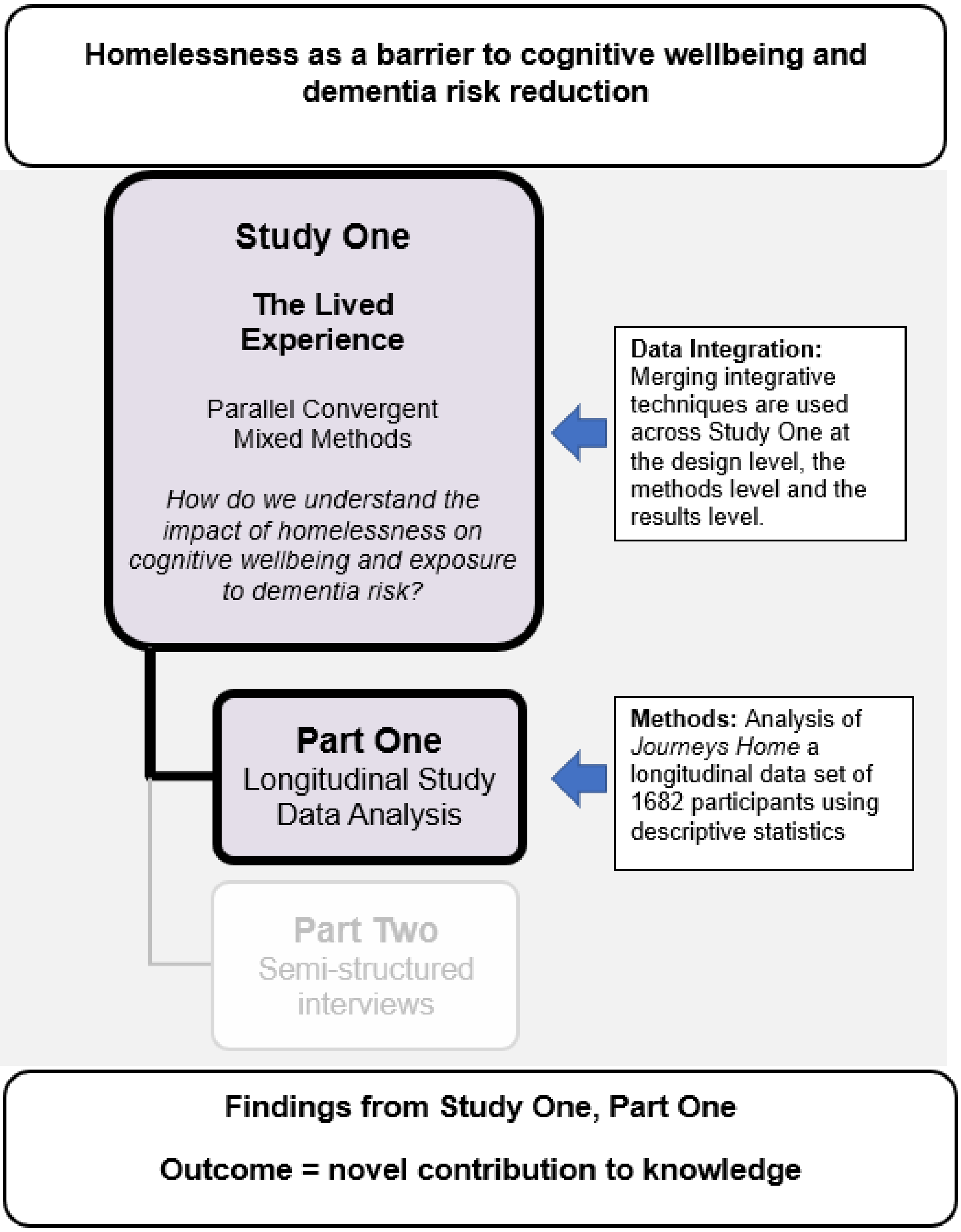


Figure 23. Study Design for Study One, Part One

Overview of Study One, Part One: The Lived Experience

Study One, Part One of *The Lived Experience* is an analysis of the *Journeys Home* longitudinal study to answer the research question: *How does homelessness impact cognitive wellbeing and exposure to dementia risk?* Part One explores characteristics of homelessness that may lead to cognitive harm and confer risk for dementia. Risk for dementia is mapped to potentially modifiable risk factors for dementia identified in Livingston et al (2020)[66] discussed in Chapter 1. The *Journeys Home* longitudinal study was chosen because it was the largest, most comprehensive survey of homelessness undertaken in Australia, tracking 1682 people who were homeless or at risk of homelessness.[282] Part One: *The Lived Experience* comprise a parallel convergent mixed methods design, introduced in Chapter 4 (Methods section).

Methods for Study One, Part One: The Lived Experience

Study One, Part One methods are provided in this next section, and include the following:

1. Identifying the *Journeys Home* data sample.
2. How the *Journeys Home* data was used, including data variables.
3. Complete and present the Study One, Part One, findings.

Methods for Study One, Part One: *The Lived Experience* are shown in Figure 24.

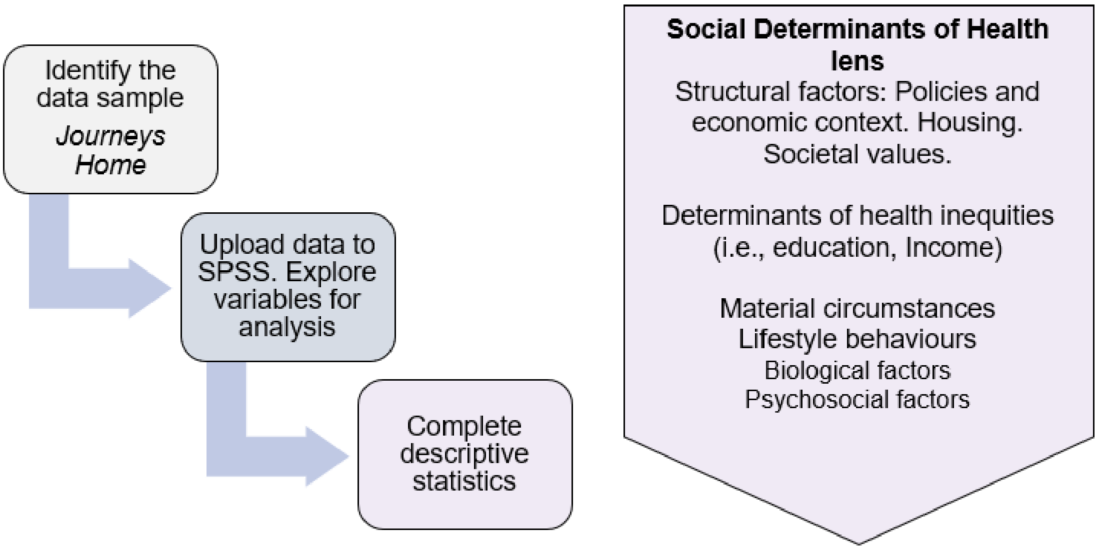


Figure 24. Methods for Study One, Part One: *The Lived Experience*

Identifying the Journeys Home data sample

Journeys Home was a longitudinal cohort study that followed 1,682 people experiencing homelessness from September 2011 to May 2014, across six waves of interviews, who were experiencing significant housing insecurity, including homelessness.[283] The Australian Data Archive (ADA), a Core Trust Seal certified repository of digital data, based in the Centre for Social Research and Methods at the Australian National University[284] was approached for general access to the *Journeys Home* data set. ADA provides a national service of maintaining quality data related to social, political and economic affairs with the purpose of making this data available to researchers. Permission to access the *Journeys Home* data set general release was granted in February 2022.

Introduction to Journeys Home Sample

The *Journeys Home* survey was funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) with the primary purpose of assisting researchers to increase their knowledge and understanding of diverse, social and economic factors associated with homelessness.[283] The Melbourne Institute of Applied Economic and Social Research

(MIAESR) based at the University of Melbourne was engaged to run the survey, with Roy Morgan Research sub-contracted to undertake the required fieldwork.[285]

The *Journeys Home* study design included close control of document design, fieldwork protocol, interview length and interviewer feedback, response rate, and description of characteristics, methods used for weighting (design weight, response weight and population weight). Participants were surveyed over six waves of data collection in a three-year timeframe (2011 -2014) with response and retention rates of 84% (n = 1,406) of original participants still engaged with the survey at Wave 6.[286]

Recruitment for Journeys Home

Participants for *Journeys Home* sample were selected using Centrelink's Homelessness Indicator to identify participants from the Australian National Research Evaluation Database (RED) that had been developed by the Department of Education, Employment and Workplace Relations (DEEWR).[287] The RED database contained records of all Centrelink income support recipients, including approximately 83% to 85% consumers of government-funded specialist homelessness services who had been administratively flagged as homeless or at risk of homelessness by Centrelink staff.[10, 283]

The population scope for the original study included all persons aged fifteen years and older, in receipt of any income support payment at any time during the month prior to the start of the study, and flagged as homeless or at risk of homelessness.[288] Exclusions were identified by DEEWR using the RED database and included people in prison, overseas requiring an interpreter, those who specifically indicated to Centrelink that they were not willing to participate in research studies, and people who had a record marked as 'sensitive', those who moved into locations outside eight pre-identified groups (i.e., Sydney, Melbourne, Brisbane, Adelaide, Perth, other major cities and regional centres, including one centre in the Northern Territory), stratified into 36 eligible clusters, and to account for unexpected events during fieldwork.[288] In this last category, effort was made to remove bias toward easy-to-find cases by increasing the buffer of a cluster from 20% to 100% in six areas with the greatest proportion of Australian First Nations people.[288]

This recruitment process identified 2719 potentially eligible individuals located across 36 areas (defined to have a 10-kilometre radius in major cities or a 20-kilometre radius in regional centres).[286] Participants were invited for participation by letter or phone using Centrelink contact details, with 62% (*n*=1682) consenting to either face-to-face interview (preferred method) or by telephone interview if located outside the geographical capacity of an assigned interviewer.[287]

Definitions of homelessness used in Journeys Home

Journeys Home adopt Chamberlain and Mackenzie's (1992) cultural definition of homelessness that demarcates circumstances of homelessness into primary, secondary and tertiary homelessness categories,[286] discussed in Chapter 1. However, the *Journeys Home* survey data additionally provides an opportunity to categorise homelessness within the Melbourne Institute Classification of Housing Status (MIHS). This extended definition retains the key homelessness classifications of primary homelessness, secondary homelessness, and tertiary homelessness, however, additionally includes domains for people who are housed, but remain at risk of homelessness or who are vulnerable to the circumstances of homelessness.

These additional classifications reflect housing stability separated by the severity of a person's current situation, specifically, *marginally housed*, where people may not consider themselves technically homeless, but experience housing instability, *short-term housing* where people have been in their accommodation for less than three months and have no prospect for staying there for the next three months, and *long-term rental* accommodation where accommodation rental is likely to exceed three months, providing the greatest level of housing stability, however, occupants are still considered vulnerable to homelessness.[10] Because of its wide-ranging classification to comprehensively stratify characteristics of homelessness and housing vulnerability, the MIHS categorisation is used for Part One of *The Lived Experience.*

How the Journeys Home data was used – including variables.

Inclusion and exclusion

All 1682 participants from the original *Journeys Home* longitudinal study sample were included for this study’s descriptive statistical analysis.

Variables

Variables of interest in this descriptive study were chosen based on the risk factors for dementia identified in Livingston et al (2020)[66] and those identified from the scoping review by Beard et al[179] discussed in Chapter 3. These risk factors are: low education, hearing loss, smoking, excessive alcohol use, social isolation, cardiovascular disease, traumatic brain injury, hypertension, depression, physical inactivity, air pollution, diabetes, and obesity. Two of the Livingston et al (2020) risk factors for dementia (low physical activity and exposure to air pollution) could not be measured in the *Journeys Home* data set, and therefore those risk factors were out of scope for this data analysis. However, as identified in the broader literature, there is strong evidence to show low levels of physical activity in people experiencing homelessness,[289, 290] and low levels of physical activity are associated with a 12% burden to developing dementia.[291] Furthermore, unsheltered homelessness exposes people to air pollution[292] and is linked to poverty and deprivation.[66]

Other risk factors for dementia that are not included in the modelling by Livingston et al (2020), have the potential to be identified from the *Journeys Home* as being relevant to dementia risk in homelessness. In Part One of this study, these risk factors are grouped according to (i) health conditions, (ii) mental health conditions, (iii) lifestyle factors, and (iv) socioeconomic lifestyle factors, and stratified by MIHS classification. These are explained further in the next section.

Health-related potentially modifiable dementia risk factors

Data on lifetime exposure to health conditions known for their association with dementia risk that was available in *Journeys Home* included stroke, heart disease (as a proxy for high blood pressure), diabetes, liver problems, epilepsy, kidney disease, Hepatitis C, intellectual disability, and acquired (traumatic) brain injury. At each of the six waves participants self-reported whether they had *ever* been diagnosed with any of these health conditions. Wave 6 data was used because it reflected a participants answer according to their last participating wave of *Journeys Home,* regardless of whether they reached Wave 6. Lifetime exposure was defined as a participant reporting a diagnosis prior to, or on any wave of the *Journeys Home* dataset.

Mental health-related potentially modifiable dementia risk factors

Data about lifetime exposure to mental health conditions known for their association with dementia risk available in *Journeys Home* included bipolar affective disorder, schizophrenia, depression, port-traumatic stress and anxiety disorder. The metric used was determined by participants answering ‘yes’ to whether they had ever been diagnosed with any of these mental health conditions prior to the survey or on any wave of the *Journeys Home* dataset. Wave 6 data was used because it reflected a participants answer according to their last participating wave of *Journeys Home,* regardless of whether they reached Wave 6.

Measurement of psychological distress

Psychological distress is indicated on a Kessler 6. This validated Kessler (K6) non-specific Psychological Distress Scale (Cronbach’s alpha = .83) measures psychological distress and risk for severe mental illness.[293-295] The original research posed six self-assessed questions that were summed to generate a number between 0 and 24, with the key cut-off point being ≥13 for serious mental illness or distress, and ≥6 for moderate mental illness or distress aligned that could accurately assess against the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV).[294, 295] Original survey participants were asked to rate whether, in the previous four weeks, they felt nervous, without hope, worthless, restless, that everything was an effort, or so sad that nothing could cheer them up, which they rated against a five-point scale according to whether this was experienced all of the time, most of the time, some of the time, a little of the time or none of the time.[286] The indicator was as follows: 1 = All of the time, 2 = Most of the time, 3 = Some of the time, 4 = A little of the time, and 5 = None of the time.

For the analysis, data was recoded into groups showing scores of ≥13, indicating high psychological distress, scores between 6 and 12 to indicate moderate psychological distress, scores below the threshold for psychological distress, and those who refused, opted out or unable to be determined.[286] Additionally, data was stratified according to the MIHS to show mean scores for each wave. The Kessler 6 score on a 0-24 scale calculated the sum less 6 and was inverted over the 0-24 range to show higher scores indicated higher levels of distress.[288]

Lifestyle-related potentially modifiable dementia risk factors

Lifestyle factors reported in *Journeys Home* known to contribute to cognitive impairment or for their association with dementia risk included regular use of cigarettes, marijuana or cannabis, use of illegal street drugs, intravenous drug use and high daily alcohol consumption. Where possible, measures associated with increased risk for dementia were aligned to those used in publications reporting on dementia risk factors. An exception is an update to the metric used for safe drinking Livingston et al (2020) referred to 21 standard drinks per week, with more than 21 units of alcohol used as an indicator for unsafe drinking and subsequent increased risk of dementia. However, in 2022, in Australia, new alcohol safe limit guidelines revised this measure to 10 standard drinks in a week, and no more than four standard drinks in any one day,[296] and this revised measure was used for this data analysis. Despite extensive searching, any measure of frequency or a dose-dependent metric to indicate increased risk for dementia in illegal drugs (i.e., methamphetamine, heroin, marijuana), or any specific number of cigarettes smoked could not be found. Therefore, they are measured in less specific terms, for example, whether a person had used drugs on a weekly basis, or smoked cigarettes daily. Data on intravenous drug use was included due to the risk of exposure to the human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS), hepatitis C virus, or other neurocognitively impacting infections, and risk for cardiovascular disease.[297]

For this study, lifestyle-related dementia risk factors are defined as follows:

1. Regular use of cigarettes was defined as people who had ever smoked daily by their last participating wave of *Journeys Home*.
2. Regular use of marijuana or cannabis was defined as people who had ever used marijuana or cannabis on a daily basis by their last participating wave of *Journeys Home.*
3. Regular use of illegal/street drugs was defined as people who had ever used illicit drugs on a weekly basis by their last participating wave of *Journeys Home.*

4. Injected illegal/street drugs were defined as people who had ever injected illicit drugs by their last participating wave of *Journeys Home.*
5. Daily alcohol >10 standard drinks per week (as per Australian safe drinking guidelines) was measured by calculating the reported daily number of standard drinks consumed by their last participating wave of *Journeys Home*.
6. Having a self-assessed problem with drugs or alcohol was defined by the participant as ‘yes’, ‘no’, ‘unknown/refused’ by their last participating wave of *Journeys Home.*

Socioeconomic-related potentially modifiable dementia risk factors

Socioeconomic factors known for their association with dementia risk included in the longitudinal study data analysis comprised of experiences of physical and emotional distress over the life course, institutionalisation and incarceration, and social isolation. Early life distress and trauma were defined using four *Journeys Home* variables (ever experienced childhood violence by someone at home, by someone else, sexual assault by someone at home, by someone else) that were aggregated into a single measure. Adult distress and trauma were defined by the *Journeys Home* variables of experiencing adult physical violence and experienced sexual assault, aggregated into a single measure. Childhood institutionalisation was defined by variables reporting on state care in childhood (foster care, kin care, residential care) that were recoded into a new variable to indicate people who had experienced childhood institutionalisation for 12 months or more. Incarceration was defined as being detained, in remand or in adult prison for 12 months or more. Childhood neglect and poverty was defined by *Journeys Home* data using of ‘left with no adequate food or shelter, and finally, to measure social isolation, the *Journeys Home* variable of ‘often feel lonely’ was applied for the longitudinal study data analysis. Where comparisons are made to the general population (Australia), data from the Australian Institute of Health and Welfare (AIHW), the Australian Bureau of Statistics (ABS) and the *Journeys Home* reports were used.

Scope of the data analysis

This analysis was restricted to a descriptive statistical analysis. Therefore, logistical regression and other advanced statistical analysis were beyond the scope of this study.

Data Analysis: Journeys Home longitudinal study data analysis

The IBM SPSS v.27 software package (IBM SPSS hereafter) was used to conduct this descriptive analysis. Descriptive statistics including means, standard deviations, and percentages were calculated to describe exposure to the risk factors for dementia, identified above, stratified by the MIHS categories of primary homelessness. secondary homelessness, tertiary homelessness, marginally housed, short-term rental, and long-term rental. Demographic characteristics, including homelessness status and category, were defined at Wave 1 (baseline). A 2-sided chi square analysis test with $\alpha<0.05$ was used to compare lifetime exposure to dementia risk factors between primary homelessness (most acute) and long-term rental groups (most stable). These groups were chosen to make comparisons between the least and most stably-housed participants.
However, it is acknowledged that some participants moved between housing status within the duration of the *Journeys Home* survey. Conclusions drawn from the *Journeys Home* research report indicate that one in ten participants from the long-term rental (housed) group were reclassified as being homeless at the following interview interval (approximately six months later).[286] In contrast to using Wave 1 data for demographics, Wave 6 data was used to assess if a participant had ‘ever been’ diagnosed with a health and/or mental health condition, lifestyle factors or life course event. This was to ensure any diagnosis for any health condition over the duration of the survey was captured.

Computing new variables

The following data adjustments were made in IBM SPSS to facilitate a chi square analysis:

1. All cases from two groups; primary homelessness (acute homelessness) and long-term rentals (most stably housed) groups were selected for chi square analysis.
2. Social isolation was determined by the number of *Journeys Home* participants who stated they felt lonely (ever felt lonely - yes/no).
3. Variables that had multiple options for participant answers, i.e., ‘yes’, ‘no’, ‘refused’, ‘no response’ were computed into categorical variables with a binary ‘yes’ or ‘no or other response’ answers.

4. New variables were created to show if a participant had a changed response or ‘yes’ at any wave.

Comparisons made to the general population.

Where possible, population data is presented alongside *Journeys Home* data for comparison. To match dates as closely as possible, data used for comparisons between *Journeys Home* and the general public were sourced from the Australian Bureau of Statistics Australian Demographic Statistics: June 2011, the Australian Bureau of Statistics Health Survey 2011-2012, the 2010 National Drug Strategy Household Survey, the Australian Institute of Health and Welfare Australia’s Health 2012, and Annual Reports 2015-2016, 2017-2018.

Results for Study One, Part One: The Lived Experience

Demographic Characteristics

Of the 1682 included participants, 54.5% (*n*=917) were male (Table 3). A total of 87.5% (*n*=1471) were born in Australia and 331 (19.7%) people were First Nations people (either Australian Aboriginal, Torres Strait Islander peoples, or both). Participants were aged 15 to 81 years, on average 31.9 years (SD = 12.8) and most (61.4%, *n*=1032) had never been married. However, 82.8% (1392) were either currently married or living in de-facto relationships at Wave 1. Whole sample education attainment showed 0.4 (*n*=7) had no schooling, 19.9% (*n*=334) had less than year 10 schooling, with 39.2 (*n*=659) reaching year 10 or year 11, or certificate I or II. Just 2.1% (*n*=35) reached year 12 education with (13.1% (*n*=221) gaining certificate III or IV. 14.7% (*n*=247) had trade certificates or apprenticeships, or higher tertiary education. In addition to their current housing status, almost 94% (*n*=1577) of all participants reported having a previous period of living with homelessness before participating in *Journeys Home*.

Primary Homelessness

Of people experiencing the most insecure homelessness (primary) at Wave 1, 48.8% (*n*=21) were of Australian First Nations people descent, demonstrating an over-representation of 6:1 (325.15%). People experiencing primary homelessness were aged 42.1 years on average (SD = 12.437) and the majority (81.4%, *n*=35) were male. More people experiencing primary homelessness were over the age of sixty years when compared to those in long-term rental (4.7% and 2.0%, respectively). 41.9% (*n*=18) of all participants experiencing primary homelessness were early school leavers, achieving an educational level of year eight or below (or equivalent) with 32.6% (*n*=14) achieving up to year 10. Only 23.3% (*n*=10) completed years education to year 12.

Whole sample demographic characteristics stratified by MIHS of the at Wave 1 are presented in Table 3.

Table 3: Demographic characteristics at Wave 1 stratified using the Melbourne Institute classification of Housing Status

Housing status at Wave 1 (*n*=1682)		Primary (*n*=43)	Secondary (*n*=185)	Tertiary (*n*=207)	Marginally Housed (*n*=366)	Short-term Rental (*n*=41)	Long-Term Rental (*n*=832)	Not determined (*n*=8)	Total
Gender	Male	35 (81.4%)	120 (64.9%)	143 (69.1%)	202 (55.2%)	21 (52.2%)	391 (47.0%)	5 (62.5%)	917 (54.5%)
	Female	8 (18.6%)	65 (35.1%)	64 (30.9%)	164 (44.8%)	20 (48.8%)	441 (53.0%)	3 (37.5%)	765 (45.4%)
First Nations people	Refused/non-response	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (2.0%)	1 (12.5%)	3 (0.2%)
	No	22 (51.2%)	141 (76.2%)	173 (83.6%)	294 (80.3%)	37 (90.2%)	673 (81.1%)	6 (75.0%)	1346 (80.0%)
	Aboriginal	21 (48.8%)	41 (22.2%)	30 (14.5%)	67 (18.3%)	4 (9.8%)	139 (16.7%)	1 (12.5%)	303 (18.0%)
	Torres Strait Islander	0 (0.0%)	2 (1.1%)	2 (1.0%)	3 (0.8%)	0 (0.0%)	10 (1.2%)	0 (0.0%)	17 (1.0%)
	Both	0 (0.0%)	1 (0.5%)	2 (1.0%)	2 (0.5%)	0 (0.0%)	6 (0.7%)	0 (0.0%)	11 (0.7%)
	Unknown/undetermined	0 (0.0%)	0 (0.0%)	1 (0.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.1%)
Country of Birth	Australia	39 (90.7%)	165 (89.2%)	172 (83.1%)	322 (88.0%)	40 (97.6%)	727 (87.4%)	6 (75.0%)	1471 (87.5%)
	Other English speaking	1 (2.3%)	7 (3.8%)	16 (7.7%)	20 (5.5%)	0 (0.0%)	53 (6.4%)	1 (12.5%)	98 (5.8%)
	Other non-English speaking	3 (7.0%)	13 (7.0%)	18 (8.7%)	24 (6.6%)	1 (2.4%)	52 (6.3%)	1 (12.5%)	112 (6.7%)
Age at Wave 1	20 years and under	2 (4.7%)	53 (28.7%)	22 (10.6%)	167 (45.6%)	12 (29.3%)	181 (21.8%)	3 (37.5%)	440 (26.2%)
	21 - 30 years	7 (16.3%)	44 (23.8%)	39 (18.8%)	93 (25.4%)	17 (41.5%)	229 (83%)	4 (50.0%)	433 (25.7%)
	31 – 40 years	10 (23.3%)	33 (17.8%)	51 (24.6%)	59 (16.1%)	7 (17.1%)	196 (23.6%)	0 (0.0%)	365 (21.2%)
	41 - 50 years	10 (23.3%)	39 (21.1%)	50 (24.2%)	37 (10.1%)	5 (12.2%)	156 (18.8%)	1 (12.5%)	297 (17.7%)
	51 - 60 years	12 (27.9%)	12 (6.5%)	35 (16.9%)	9 (2.5%)	0 (0.0%)	53 (6.4%)	0 (0.0%)	121 (7.2%)
	61 and older	2 (4.7%)	4 (2.2%)	10 (4.8%)	1 (0.3%)	0 (0.0%)	17 (2.0%)	0 (0.0%)	34 (2.0%)
Highest school level at Wave 1	Not applicable/unknown	1 (2.3%)	3 (1.6%)	1 (0/5%)	1 (0.3%)	0 (0.0%)	2 (0.2%)	0 (0.0%)	8 (0.5%)
	Refused	0 (0.0%)	20 (10.8%)	21 (10.1%)	0 (0.0%)	0 (0.0%)	55 (6.6%)	1 (12.5%)	97 (5.8%)
	Year 11 -12 or equivalent	10 (23.3%)	53 (28.7%)	74 (35.8%)	133 (36.3%)	10 (24.4%)	364 (43.8%)	3 (37.5%)	644 (38.3%)
	Year 9 -10 or equivalent	14 (32.6%)	76 (41.1%)	86 (41.6%)	200 (54.6%)	21 (51.2%)	392 (47.1%)	2 (25.0%)	791 (47.0%)
	Year 8 or below	18 (41.9%)	33 (17.8%)	25 (12.1%)	32 (8.7%)	10 (24.4%)	85 (10.2%)	2 (25.0%)	205 (12.19%)

Health-related potentially modifiable dementia risk factors

Of the whole survey sample (*n*=1682), nearly 38% (n=632) reported living with a long-term health condition or disability. Common health conditions reported at some time before their last completed survey are listed in Table 4.

Table 4. Common health conditions

% of Journeys Home participants **'Ever been diagnosed with health condition**	**Journeys Home** **Last available wave**	**General Australian Population (date matched to 2014)**
Stroke	4.0% (*n*=67)	2% (*n*=377,000)
Heart disease	18.1% (*n*=304)	5.0% (*n*=1.1million)
Diabetes	7.3%, (*n*=123)	4.6% (*n*=999,000)
Liver problems	13.7% (*n*=230)	N/A
Epilepsy	4.8% (*n*=81)	0.6% (*n*=147,540)
Kidney disease	5.8% (*n*=97)	9% (*n*=203,400)
Hepatitis C	9.2% (*n*=154)	1% (*n*=226,700)
Traumatic brain (head) injury	5.6% (*n*=95)	N/A
*Intellectual disability	6.1% (*n*=103)	2.9% (*n*=668,100)

***Note: some intellectual disability will be non-modifiable. For example, Down Syndrome.[298]**

The primary homelessness group reported a diagnosis of diabetes (*n*=7, 16.3%) which was more than 8% of any other group and above that seen in the general population. Tertiary homelessness had a lifetime diagnosis of Hepatitis C at 16.9%, which was more than 4.0% more than any other group. In primary and tertiary homelessness, a quarter (25%) reported diagnosis of heart disease. Intellectual disability was high among primary homelessness and short-term rental groups (11.6%

and 12.2% respectively), and incidence of head injury was consistent across the marginally housed (4.6%, *n*=17), short-term rental (4.9% *n*=2), and long-term rental (4.9%, *n*=41) groups. Lifetime exposure to physical health conditions known to be associated with increased risk for dementia, stratified by MIHS categories, is presented in Table 5.

Table 5: Health conditions by Melbourne Institute classification of Housing Status

Housing status total participants (*n*=1682)		**Health conditions at last available wave– n (%)** Ever been diagnosed with:								
		Stroke	Heart Disease	Diabetes	Liver Problems	Epilepsy	Kidney Disease	Hepatitis C	Intellectual Disability	Head Injury
Primary homeless (*n*=43)	Yes	2 (4.65%)	11 (25.6%)	7 (16.3%)	4 (9.3%)	4 (9.30%)	6 (14.0%)	0 (0.0%)	5 (11.6%)	3 (7.0%)
	Unknown or refused	12 (27.9%)	11 (25.6%)	10 (23.3%)	12 (27.9%)	11 (26.0%)	11 (25.6%)	12 (27.9%)	12 (27.9%)	10 (23.3%)
Secondary homeless (*n*=185)	Yes	8 (4.3%)	33 (17.8%)	13 (7.0%)	29 (15.7%)	7 (3.78%)	11 (6.0%)	22 (11.9%)	8 (4.3%)	14 (7.57%)
	Unknown or refused	34 (18.38%)	32 (17.3%)	32 (17.3%)	32 (17.30)	36 (19.46%)	35 (18.9%)	31 (16.8%)	35 (18.9%)	37 (20.0%)
Tertiary homeless (*n*=207)	Yes	16 (7.73%)	53 (25.6%)	17 (8.2%)	38 (18.4%)	12 (5.8%)	11 (5.3%)	35 (16.9%)	13 (6.3%)	18 (8.7%)
	Unknown or refused	36 (17.4%)	26 (12.6%)	32 (15.6%)	31 (15.0%)	34 (16.4%)	33 (15.9%)	32 (15.6%)	38 (18.4%)	35 (16.9%)
Marginally housed (*n*=366)	Yes	5 (1.37%)	43 (11.8%)	23 (6.3%)	36 (9.8%)	14 (3.83%)	16 (4.4%)	16 (4.4%)	22 (6.0%)	17 (4.6%)
	Unknown or refused	63 (17.2%)	58 (15.9%)	64 (17.5%)	58 (15.9%)	63 (17.21%)	62 (16.9%)	59 (16.1%)	63 (17.2%)	61 (16.7%)
Short-term rental (*n*=41)	Yes	0 (0.0%)	7 (17.1%)	2 (4.9%)	6 (14.6%)	1 (2.44%)	4 (9.8%)	6 (14.6%)	5 (12.2%)	2 (4.9%)
	Unknown or refused	9 (22.0%%)	9 (22.0%)	9 (22.0%)	8 (19.5%)	9 (21.95%)	9 (22.0%)	8 (19.5%)	7 (17.1%)	7 (17.1%)
Long-term rental (*n*=832)	Yes	34 (4.1%)	155 (18.6%)	61 (7.3%)	116 (14%)	41 (4.93%)	48 (5.8%)	75 (9.0%)	49 (5.9%)	41 (4.9%)
	Unknown or refused	119 (14.3%)	107 (12.7%)	119 (14.3%)	115 (13.8%)	117 (14.1%)	120 (14.4%)	114 (13.7%)	120 (14.4%)	119 (14.3%)
Not determined (*n*=8)	Yes	1 (12.5%)	2 (25.0%)	0 (0.0%)	1 (12.5%)	2 (25.0%)	1 (12.5%)	0 (0.0%)	1 (12.5%)	0 (0.0%)
	Unknown or refused	1 (12.5%)	1 (12.5%)	1 (12.5%)	1 (12.5%)	1 (12.5%)	1 (12.5%)	1 (12.5%)	1 (12.5%)	1 (12.5%)

Mental Health-related potentially modifiable dementia risk factors

Mean scores on the Kessler 6 were: 8.64 (SD 6.121) at Wave 1, 6.82 (SD 6.385) at Wave 2, 6.34 (SD 6.435) at Wave 3, 6.10 (SD 6.310) at Wave 4, 6.09 (SD 6.317) at Wave 5, and 5.74 (SD 6.287). Mean scores decreased by 2.9 points between Wave 1 and Wave 6. Results stratified by MIHS classification are shown in Table 6.

Table 6. Kessler 6 mean scores for psychological distress across all Waves, stratified by Melbourne Institute classification of Housing Status

Kessler 6 Mean Score

Housing status total participants (*n*=1682)		Wave 1	Wave 2	Wave 3	Wave 4	Wave 5	Wave 6
Primary homeless (*n*=43)	Mean	6.77	4.95	4.47	4.21	3.65	3.40
	Standard Deviation	6.665	6.743	6.356	5.638	5.940	5.504
Secondary homeless (*n*=185)	Mean	10.11	6.88	6.19	6.11	6.42	5.41
	Standard Deviation	6.600	6.460	6.797	6.815	6.522	6.355
Tertiary homeless (*n*=207)	Mean	9.03	6.58	5.93	5.90	6.12	5.98
	Standard Deviation	6.386	6.613	6.734	6.600	6.701	6.549
Marginally housed (*n*=366)	Mean	8.12	6.26	5.62	5.69	5.63	5.36
	Standard Deviation	5.620	5.967	5.856	6.075	6.050	6.124
Short-term rental (*n*=41)	Mean	10.02	6.63	7.24	6.68	6.05	5.49
	Standard Deviation	5.265	7.067	6.557	6.142	6.249	6.929
Long-term rental (*n*=832)	Mean	8.46	7.17	6.79	6.38	6.34	6.03
	Standard Deviation	6.091	6.407	6.466	6.240	6.286	6.262
Not determined (*n*=8)	Mean	10.88	12.00	11.88	7.00	7.00	8.75
	Standard Deviation	7.680	5.782	6.151	7.783	7.051	5.849

A total of 2,555 (151.9%) diagnoses of mental health conditions occurred across 1,682 participants at any time prior to the end of the survey. There were 15.2% (*n*=255) people diagnosed with bipolar affective disorder, 11.5% (*n*=193) with schizophrenia, 63.3% (*n*=1064) with depression, 26.1% (*n*=439) with post-traumatic stress disorder, and 51.1% (*n*=859) with anxiety disorder. Depression, the most prevalent of all mental health conditions in the *Journeys Home* sample at 63.3%, compares with 8.9% of the general Australian population in 2014-2015, and anxiety, the second most prevalent, at 51.1%, comparing with 11% of the general Australian population in 2014-2015.

Rates of self-reported schizophrenia (15.5%, *n*=32), depression (69.1%, *n*=143), and post-traumatic stress (31.9%, *n*=66) were highest in tertiary homelessness and compares to 1.5%, 8% and 12% respectively in the general population. Rates of bipolar affective disorder (26.8%, *n*=11) and anxiety disorder (61.0%, *n*= 25) were highest in short-term rental. Primary homelessness presented the lowest scores across bipolar disorder (7%, *n*= 3), schizophrenia (7%, *n*=3).

Mental health conditions stratified by MIHS categorisation are shown in Table 7.

Table 7: Mental health conditions stratified using the Melbourne Institute classification of Housing Status

Housing status total participants (*n*=1682)		**Mental Health Conditions at Wave 6 - *n* (%)**				
		Ever been diagnosed with:				
		Bipolar Affective Disorder	Schizophrenia	Depression	Post-traumatic stress	Anxiety Disorder
Primary homeless (*n*=43)	Yes	3 (7.0%)	3 (7.0%)	15 (34.9%)	4 (9.3%)	11 (25.58%)
	Unknown/refused	9 (20.9%)	11 (25.6%)	9 (20.9%)	12 (27.9%)	11 (25.6%)
Secondary homeless (*n*=185)	Yes	18 (9.7%)	26 (14.1%)	122 (65.9%)	51 (27.6%)	100 (54.1%)
	Unknown/refused	5 (2.7%)	35 (18.9%)	63 (34%)	32 (17.3%)	19 (10.3%)
Tertiary homeless (*n*=207)	Yes	42 (20.3%)	32 (15.5%)	143 (69.1%)	66 (31.9%)	107 (51.7%)
	Unknown/refused	32 (15.5%)	34 (16.4%)	11 (5.3%)	29 (14.0%)	23 (11.1%)
Marginally housed (n=366)	Yes	39 (10.7%)	35 (9.6%)	204 (55.7%)	77 (21.0%)	167 (45.6%)
	Unknown/refused	16 (16.7%)	65 (17.8%)	36 (9.8%)	58 (15.8%)	40 (11.0%)
Short-term rental (*n*=41)	Yes	11 (26.8%)	5 (12.2%)	28 (68.3%)	12 (29.3%)	25 (61.0%)
	Unknown/refused	6 (14.6%)	7 (17.1%)	4 (9.8%)	7 (17.1%)	6 (14.6%)
Long-term rental (*n*=832)	Yes	127 (15.3%)	90 (10.8%)	546 (65.6%)	227 (27.3%)	445 (53.5%)
	Unknown/refused	118 (14.2%)	127 (15.2%)	58 (7.0%)	106 (12.85)	73 (8.8%)
Not determined (*n*=8)	Yes	3 (37.5%)	2 (25.0%)	6 (75.0%)	2 (25.0%)	4 (50.0%)
	Unknown/refused	1 (12.5%)	1 (12.5%)	1 (12.5%)	1 (12.5%)	1 (12.5%)

Lifestyle-related potentially modifiable dementia risk factors

Cigarette smoking was the most frequent of all lifestyle factors across all categories with 1465 (87.1%) participants reporting current and past use. Only 6.6% (*n*=111)) had never tried smoking. The youngest age when first smoked a full cigarette was 2 years old (0.06%, *n*=1), and 178 (10.58%) by age of 10 years. Most people had their first full cigarette at age 13 years (12.13%, *n*=204) and 36.39% (*n*= 612) were smoking daily between the ages of 13 years and 16 years. Just 12.3% (*n*=207) of all participants had never smoked 100 cigarettes or more compared to 60% of the general population.

At Wave 6, of the whole sample, only 97 (5.8%) drank alcohol daily. Of those, 69 were male (71.1%) and 28 (28.9%) female. Most (*n*= 317, 18.8%) drank alcohol on 1 or 2 days each week. Of those who consumed any alcohol, 631 (37.5%) drank between 2 and 6 standard drinks each day (n=631) placing them above the safe drinking measure of <10 per week, and 69 (4.1%) people drank more than 20 standard drinks per day. In the last reporting month, a total of 538 (32%) people had consumed more than 5 standard drinks on up to 10 occasions, and 38 (2.26%) people on 30 or more occasions.

Almost half (49.4%, *n*=830) of the Journeys Home participants reported past or current illicit drug use, only slightly more than reported in the general population (43%). Short-term rental participants had the highest rates of ever using illicit drugs (34.1%, *n*=14), ever injecting illicit drugs (34.1% (*n*=14), and ever smoking marijuana (63.4%, *n*=26). This compares to 14% (*n*=6), 20.9% (*n*=9), and 32.6% (*n*=14) respectively in the primary homelessness group.

Despite the high prevalence of cigarette smoking and alcohol consumption across all groups, few answered ‘yes’ to a self-assessed ‘problem with drugs and alcohol’ (12.1%, *n*=203), however, 600 (35.7%) reported having treatment for drug and alcohol problems at some time in their life.

Lifetime exposure to lifestyle factors for increased dementia risk, stratified by MIHS classification are shown in Table 8.

Table 8. Lifestyle factors stratified by Melbourne Institute classification of Housing Standards

Housing status total participants (*n*=1682)		Lifestyle Factors					
		Daily use of cigarettes at Wave 6	Daily use of marijuana or cannabis at Wave 6	Weekly use of illegal/street drugs at Wave 6	Ever injected illegal/street drugs by Wave 6	Weekly alcohol = >10 standard drinks per week at Wave 6	Self-assessed problem with drugs/alcohol by Wave 6
Primary homeless (*n*=43)	Yes	24 (55.81)	0 (0.0%)	6 (14.0%)	9 (20.9%)	27 (62.79%)	4 (9.3%)
	Unknown/refused	11 (25.6%)	11 (25.6%)	9 (20.9%)	9 (20.9%)	11 (25.6%)	11 (25.6%)
Secondary homeless (*n*=185)	Yes	96 (51.9%)	23 (12.4%)	54 (29.19%)	51 (27.6%)	91 (6.0%)	25 (13.5%)
	Unknown/refused	35 (18.9%)	35 (18.9%)	27 (14.6%)	27 (14.6%)	35 (18.9%)	36 (19.4%)
Tertiary homeless (*n*=207)	Yes	124 (59.9%)	17 (8.2%)	51 (24.6%)	68 (32.9%)	105 (50.72%)	28 (13.5%)
	Unknown/refused	36 (17.4%)	36 (17.4%)	32 (15.5%)	24 (11.6%)	36 (17.4%)	36 (17.4%)
Marginally housed (*n*=366)	Yes	188 (51.4%)	25 (6.8%)	66 (18.0%)	64 (17.5%)	211 (57.7%)	39 (10.7%)
	Unknown/refused	64 (17.5%)	64 (17.5%)	54 (14.8%)	53 (14.6%)	65 (17.8%)	64 (17.5%)
Short-term rental (*n*=41)	Yes	25 (61.0%)	2 (4.9%)	14 (34.1%)	14 (34.1%)	24 (58.6%)	3 (7.3%)
	Unknown/refused	9 (22.0%)	9 (22.0%)	6 (14.6%)	4 (9.8%)	9 (22.0%)	9 (22.0%)
Long-term rental (*n*=832)	Yes	454 (54.6%)	57 (6.9%)	181 (21.8%)	172 (20.7%)	492 (59.1%)	102 (12.3%)
	Unknown/refused	121 (14.5%)	121 (14.5%)	100 (12.0%)	100 (12.0%)	122 (14.7%)	126 (15.1%)
Not determined (*n*=8)	Yes	8 (100%)	0 (0.0%)	0 (0.0%)	2 (25.0%)	0 (0.0%)	2 (4.7%)
	Unknown/refused	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Socioeconomic-related dementia risk factors

Indicators of childhood poverty were reported, including 258 (15.3%) who did not have adequate food or shelter as a child. 554 (32.9%) did not have schoolbooks or were unable to attend school excursions (*n*=619, 36.8%), and 528 (31.4%) could not afford school uniforms (Figure 25).

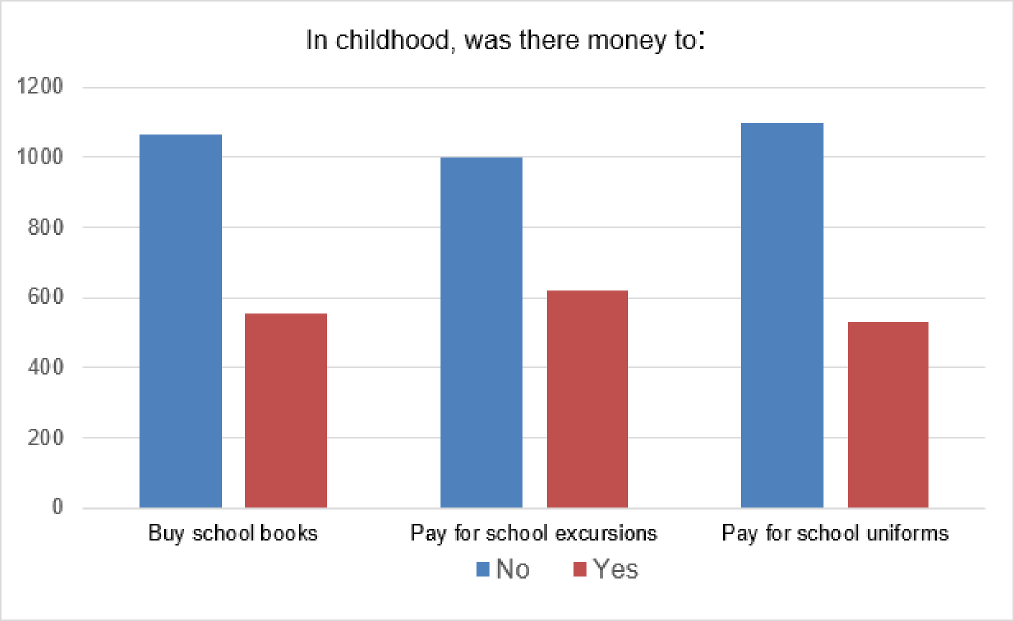


Figure 25. Childhood poverty

Among all participants, 97 (5.8%) reported having no caregiver at age 14 years. 112 (6.7%) were brought up by relatives rather than parents. A total of 351 (20.9%) lived only with their mother. Participants reported having parents who died (*n*=109, 6.5%), or who were unable to provide care due to ill health or other reasons (*n*=85, 5.1%), or experiencing relationship conflict with parents (*n*=122, 7.3%). Having more than one female caregiver as a child (*n*=560, 33.3%), with 47 participants having six or more female caregivers (2.8%). 435 (25.9%) had been placed into foster, residential or kin care with 378 (22.47%) having 10 or less placements and 25 (1.49%) having more than 11 or more placements.

When growing up, 148 (8.8%) said they had never felt loved, 163 (9.7%) hardly ever felt loved, and 310 (18.4%) sometimes felt loved. 62% (*n*=1,042) had family members who belittled or made hurtful or insulting statements to them. Half of participants (49.9%, *n*=840) said felt a family member hated them. Frequent observations of parents or caregivers physically fighting (*n*=397, 23.6%), or experiencing physical violence from a household member (*n*=702, 41.7%), or from someone else (*n*=750, 44.6%). Participants reported experiencing sexual assault as a child from someone living with them (13.2%, *n*= 222), and 336 (20%) from someone not living with them. Those in short-term rental experienced the highest rates of physical violence by a household member (53.7%, *n*= 22), and by someone else (46.3%, *n*=19).

Lifetime exposure to socioeconomic factors of institutionalisation, incarceration, adverse and traumatic events, stratified by MIHS classification of housing status is presented in Table 9.

Table 9. Socioeconomic factors stratified by Melbourne Institute classification of Housing Standards at Wave 6

Socioeconomic factors
Ever answered ‘yes’ at Wave 6 to:

Housing status total participants (*n*=1682)		Experienced childhood violence and/or sexual assault (Childhood trauma)	Experienced adult violence and/or sexual assault (adult trauma)	Experienced state care in childhood (>12 months)	Experienced detention, remand, or prison >12 months (Incarceration)	Left without adequate food or shelter as a child (childhood neglect/poverty)	Often felt lonely (at any age)
Primary homeless (*n*=43)	Yes	10 (23.3%)	11 (25.6%)	10 (23.3%)	10 (23.3%)	5 (11.6%)	12 (27.9%)
	Unknown/refused	15 (34.9%)	23 (53.5%)	0 (0.0%)	14 (32.6%)	9 (20.9%)	11 (25.6%)
Secondary homeless (*n*=185)	Yes	119 (64.3%)	83 (44.7%)	39 (21.15)	22 (11.9%)	28 (15.1%)	53 (28.7%)
	Unknown/refused	21 (11.4%)	79 (42.7%)	3 (1.62%)	38 (20.5%)	14 (7.6%)	37 (20.0%)
Tertiary homeless (*n*=207)	Yes	127 (61.4%)	104 (50.2%)	48 (23.2%)	26 (12.6%)	32 (15.5%)	73 (35.3%)
	Unknown/refused	26 (12.6%)	81 (39.1%)	7 (3.4%)	47 (22.7%)	15 (7.3%)	36 (17.4%)
Marginally housed (*n*=366)	Yes	200 (54.6%)	124 (33.9%)	49 (13.4%)	26 (7.1%)	46 (12.6%)	87 (23.8%)
	Unknown/refused	43 (11.8%)	191 (52.2%)	6 (1.6%)	72 (19.7%)	27 (7.4%)	64 (17.5%)
Short-term rental (*n*=41)	Yes	28 (68.3%)	18 (43.9%)	11 (26.8%)	4 (9.8%)	9 (22.0%)	13 (31.7%)
	Unknown/refused	6 (14.6%)	18 943.9%)	3 (7.3%)	9 (22.0%)	2 (4.9%)	9 (22.0%)
Long-term rental (*n*=832)	Yes	489 (58.8%)	420 (50.5%)	163 (19.6%)	103 (12.4%)	130 (15.6%)	268 (32.2%)
	Unknown/refused	108 (13.0%)	304 (36.5%)	11 (1.3%)	135 (16.2%)	63 (7.8%)	123 (14.8%)
Not determined (*n*=8)	Yes	5 (62.5%)	4 (50.0%)	3 (37.5%)	3 (37.5%)	2 (25.0%)	1 (12.5%)
	Unknown/refused	3 (37.5%)	4 (50.0%)	0 (0.0%)	1 (12.5%)	2 (25.0%)	0 (0.0%)

Group comparisons

The results of the chi square analysis undertaken to evaluate group comparisons between the least stably housed (primary homeless) and the most stably housed (long-term rental) are shown in Table 10. This univariate chi square analysis compared prevalence for risk factor exposure between those experiencing primary homelessness and those in long-term rentals in Wave 1 (“yes” at baseline) and across all waves (“yes” in any wave), mapped to risk factors in Livingston et al.[66] with significant differences observed for education, depression and diabetes.

Table 10. Results of Univariate chi square analysis

Risk Factor	Primary homeless *n*=43 (%)	Long-term rental *n*=832 (%)	X2	df	*p*
Low Education at Wave1	**18 (41.9%)**	**102 (12.3%)**	**30.275**	**1**	**<.001**
Low Education at any wave	**18 (41.9%)**	**102 (12.3%)**	**30.275**	**1**	**<.001**
Hearing Loss (prior 6 months) at Wave 1	4 (9.5%)	94 (11.3%)	0.164	1	.686
Hearing Loss (prior 6 months) at any wave	12 (27.9%)	202 (24.3%)	0.291	1	.589
Brain Injury at Wave 1	3 (7.0%)	29 (3.5%)	1.414	1	.234
Brain Injury at any wave	3 (7.0%)	41 (4.9%)	0.359	1	.549
Alcohol >10 units/week at Wave 1	30 (69.8%)	543 (65.3%)	0.367	1	.545
Alcohol >10 units/week at any wave	27 (97.7%)	492 (77.8%)	0.226	1	.634
Smoking daily/weekly at Wave 1	32 (74.4%)	594 (71.4%)	0.184	1	.668
Smoking daily/weekly any wave	39 (90.7%)	652 (78.4%)	3.744	1	.053
Depression at Wave 1	**13 (30.2%)**	**465 (55.9%)**	**10.859**	**1**	**<.001**
Depression at any wave	**15 (34.9%)**	**546 (65.6%)**	**16.794**	**1**	**<.001**
Social Isolation at Wave 1	23 (53.5%)	431 (51.8%)	0.047	1	.829
Social Isolation at any wave	36 (83.7%)	590 (70.9%)	3.294	1	.070
Diabetes at Wave 1	**7 (16.3%)**	**48 (5.8%)**	**7.667**	**1**	**.006**
Diabetes at any wave	**7 (16.3%)**	**61 (7.3%)**	**4.567**	**1**	**.033**
Cardiovascular (Inc High BP) at Wave 1	6 (13.6%)	111 (1.3%)	0.013	1	.908
Cardiovascular (Inc High BP) at any wave	11 (25.6%)	155 (18.6%)	1.285	1	.257

**P significant at 0.05 (highlighted in bold)*

Next, I will present Study One, Part Two methods and results.

Study One, Part Two: The Lived Experience

The study design for Study One, Part Two: *The Lived Experience* is presented in Figure 26.

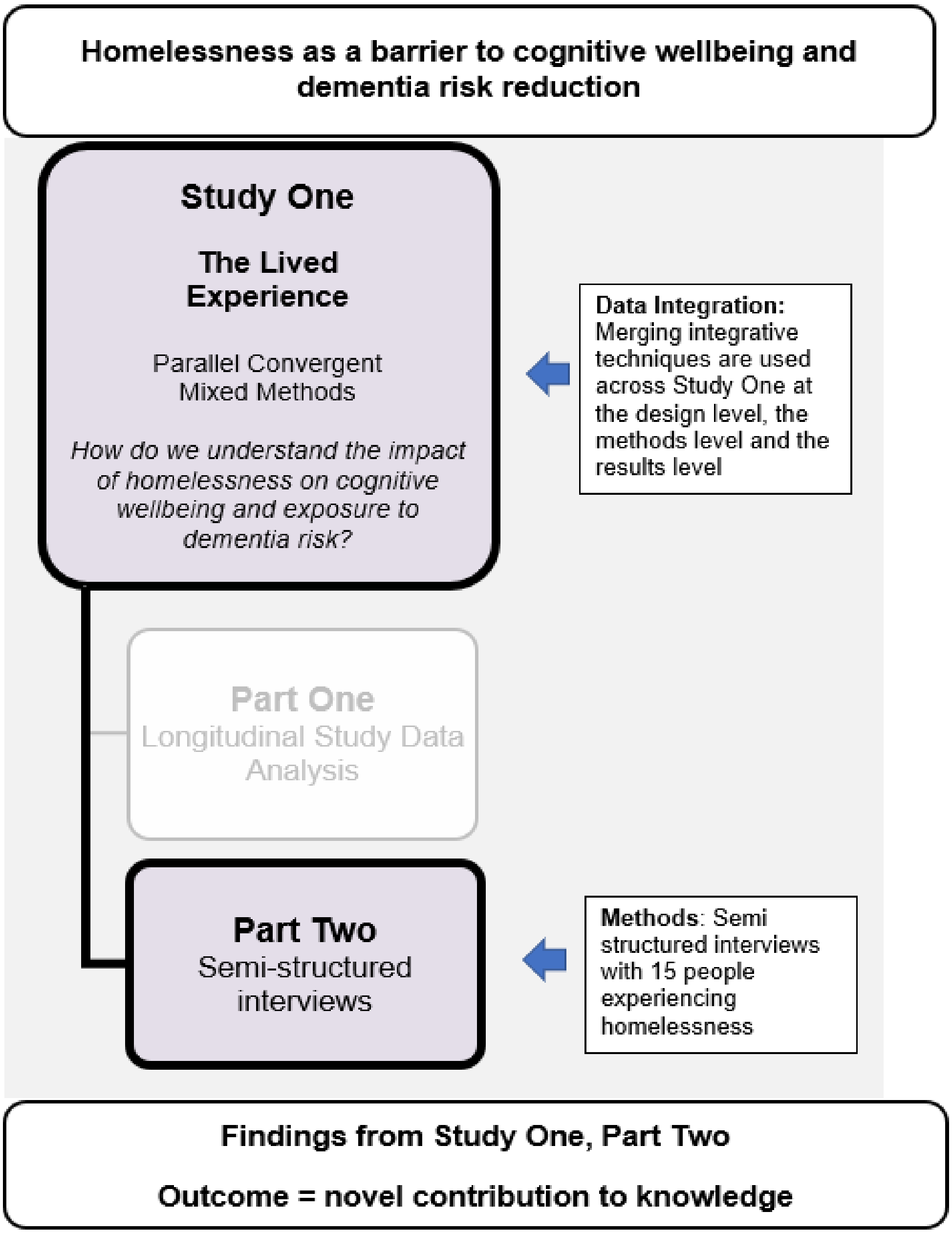


Figure 26. Study design for Study One, Part Two: *The Lived Experience*

Overview of Study One, Part Two: The Lived Experience

Part Two of *The Lived Experience* continues with the social determinants of health. It comprises of qualitative research, using semi-structured interviews with people experiencing homelessness, to illustrate a cross section of narratives on the experience of homelessness. This study gathers and analyses descriptive data related to cognitive wellbeing and potential exposure to dementia risk.

Methods for Study One, Part Two: The Lived Experience

Semi-structured interviews provide the basis of data collection for Study One, Part Two, and were chosen to elicit subjective responses from participants regarding a specific situation or phenomenon.[299] This mode of interview provided good flexibility and resourcefulness.[300] The use of semi-structured interviews allowed flexibility in questions based on the participant’s response, targeted towards ascertaining further detail specifically relevant to each participant. Additionally, semi-structured interviews can both encourage people to talk freely about their experiences, adding depth and vitality to the data, and provide a degree of reciprocity by hearing and active listening to peoples’ stories.[301] Whilst narratives stem from participants’ experiences, an analogy can exist between participant experiences and an exposure to dementia risk. When this occurred, participants were encouraged to provide further discussion.

This section discusses the methods for Study One, Part Two: *The Lived Experience* and are shown in Figure 27.

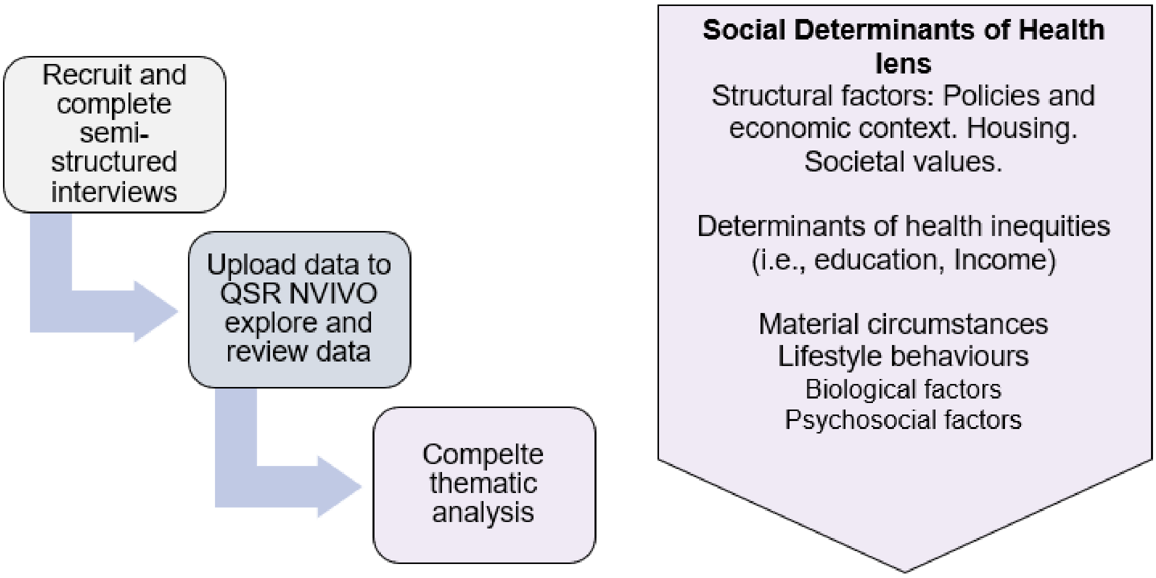


Figure 27. Methods for Study One, Part Two: *The Lived Experience*

Recruitment

Flyers inviting participation in face-to-face interviews were sent to key homelessness services in metropolitan Adelaide and regional areas in South Australia (Appendix 3). Homelessness service providers were asked to advertise the invitation to their clients or place flyers on notice boards. Potential participants were asked to contact the researcher to participate, and, if eligible, to arrange a day and time for interview. Interviews were conducted at homelessness service properties or at an allocated city central café. The café location was specifically chosen for its proximity to several homelessness services and its connection as a not-for-profit community amenity managed by people with a lived experience of homelessness. The café provided a room in which the interviews could confidentially be conducted. A donation was provided to the café's '*Pass it Forward'* program that aims to supply free nutritious meals for people experiencing homelessness in recognition for offering use of the room. Participants were renumerated with a gift card from two leading supermarket chains. Café interviewees were also provided with a refreshment at the time of interview.

Inclusion criteria for participation in an interview were stated in the flyer and at first contact with potential participant. These are characteristics that participants must have were:

Inclusion criteria

- Currently experiencing primary homelessness
- Be eighteen years of age or over
- Able to provide consent for interview that would be audio recorded (preferred) or scribed by note taking
- Able to read and understand the research information sheet
- Be willing to meet at a prearranged location, at a specific time and date
- Agreeable to discussing their experience of homelessness and how this affects their brain health (cognitive wellbeing)

Exclusion criteria comprise the characteristics that disqualify potential participants from participation. If any person met at least one of the exclusion criteria, then they did not participate in the interview. These criteria were:

Exclusion criteria

- Under eighteen years of age
- Not understand the purpose of the interview as provided in the information sheet
- Not willing, or unable to provide consent for participation
- Not currently experiencing homelessness
- Not willing to agree to other inclusion criteria

Data collection

Participants were assured of confidentiality, that their interview would be anonymous, with participants allocated to a number (1-15). Consent was sought for digital recording or detailed field notes. Participants were made aware that they did not have to answer any specific questions, elaborate on any details and that they could withdraw at any time.

Interview questions were structured using the interview guide (Appendix 1) and based on the study aims and objectives. The format of interviews allowed participants to discuss their experiences relating to a number of topics that were associated with potentially modifiable risk factors for dementia mapped to Livingston et al (2020)[66] and other seminal literature, including *Modifiable risk factors for dementia and dementia risk profiling*[166] and *The World Alzheimer Report 2014.*[35] Topics included diet, physical exercise, sleep quality, smoking, alcohol and other substance use, childhood trauma, traumatic head injury, chronic cardiovascular health conditions, including high blood pressure and stroke, hearing, and mental health conditions, and feeling safe. Each participant was asked the question: *what does brain health mean to you?* Demographics included age, if they identified as an Australian First Nations person, status of homelessness (rough sleeping, staying at hostel, couch surfing, etc), and educational history. Participant interviews were transcribed and uploaded in the QSR NVivo software package prior to data analysis.

Data saturation was achieved when interview data did not identify any new information. At this point, recruitment ceased. This measure of saturation was gauged against several articles where data saturation is defined as “the point in data collection and analysis where new information produces little or no change to the codebook”,[302 p.65] and by Braun and Clarke who discuss data saturation as “information redundancy”[303 p.201] before drawing discussion towards the pragmatic nature of sampling that can be “shaped and constrained by the time and resources available to the researcher.[303 p.211] Furthermore, Fusch and Ness argue that there is “no one-size fits all method to reach data saturation; moreover, more is not better than less and vice versa”.[304 p.1413] While these examples provided a variable platform from which to measure data saturation, all acknowledged the general tenet that a failure to achieve saturation impacts negatively on the validity of the study results.[302-304]

Data Analysis

Data analysis consisted of a thematic analysis using reflexive principles from Braun and Clarke (2019).[305] This analytical approach builds context from Braun and Clarke’s earlier 2006 thematic analysis model,[306] that remains relevant for processing this analysis.

Braun and Clarke's thematic analysis provides a rigorous and systemic model for dependable data analysis and additionally requires the researcher to take a reflexive approach.[305] As a central tenet of the qualitative analysis, I used a continuous process of self-appraisal and contemplation that ensured my engagement with the data remained thoughtful, analytical, respectful, and relevant to the research aims and the context of people experiencing homelessness.

Thematic analysis consisted of looking for patterns of shared meaning within the data rather than just grouping similar data themes. In accordance with the study methodological design, a SDoH lens applied meaning and guided the analysis using theory from Solar and Irwin’s 2007 conceptual framework for the CSHD.[307] This framework, previously discussed in Chapter 2, help to identify and organise data into sub-themes, themes and codes. The two principal Framework categories of structural determinants (social determinants of health inequities) and intermediary determinants (social determinants of health) were central to the analysis and allowed for reflexive thematic analysis of the impact that homelessness has on equitable cognitive health and wellbeing. For example, whether they were structural (governance-related, linked to policies and national strategies, housing), socioeconomic (education, occupation, childhood), intermediary (lifestyle behaviours, psychosocial, health) and in how health inequities arise within the Framework.[44] In this context, SDoH were used to examine and understand shared meanings and origins of cognitive concern or exposures to potentially modifiable risk factors for dementia that were revealed in the narratives.

Thematic analysis uses a six-phase iterative process to identify important themed data.[308] All data was analysed in QSR NVivo guided by the work of Braun and Clarke,[305, 306, 309, 310] illustrated in Table 11. Braun and Clarke's model for thematic analysis is compatible with pragmatist concepts related to trustworthiness and credibility in how thematic analyses identifies, organises, describes and reports qualitative data.[311]

Table 11. Thematic analysis adapted from Braun and Clarke (2006)

Phase	Task	Description of process for thematic analysis
1	Familiarising yourself with the data	Transcribing data, reading and rereading of data. Noting down initial ideas
2	Generating initial codes	Systematically coding features of the data across the entire data set and collating data relevant to each code
3	Searching for themes	Collating codes into potential themes, gathering relevant data to each potential theme
4	Reviewing themes	Checking if the themes work at level 1- coded extracts, and level 2 – entire data set. Generating thematic map
5	Defining and naming themes	Ongoing analysis. Refine specifics of each theme. Identify 'the story' of the analysis. Generation definitions, name themes
6	Producing the report	Final opportunity for analysis. Selection of vivid and compelling abstracts. Final analysis of abstracts. Relate back to research question and literature. Write up.

Anonymised interviews were transcribed verbatim prior to any identifying material being removed with subsequent data uploaded into QSR NVivo software. Participants were allocated a pseudonym for reporting. Braun and Clarke's approach to thematic analysis was used to analyse data through a series of transcript familiarisation, generating codes for the data, searching for themes organising data according to themes, reviewing, refining and naming themes[306]. The emerging framework of codes and themes was used to summarise the data and provide representative quotes supporting key elements of the analysis and which are illustrated in the data findings.

Results of Study One, Part Two

Participants

Nineteen people were initially recruited for interview. Fifteen participants completed interviews and four people did not attend and could not be subsequently contacted. Participants defined themselves as long-term, frequent rough sleepers or very short-term users of homelessness hostels (short-term emergency accommodation). All participants reported frequent moving from place to place, either on the streets, between hostels or intermittent couch surfing. Most participants were male (13 x male, 2 x female), which was unsurprising considering the over-representation of men in primary homelessness.

Narratives

Intergenerational homelessness

Participants talked about intergenerational homelessness. Several structural determinants were identified and regarded as an impediment to positive early childhood experiences, poverty and the lack of a stable address disrupted schooling, ability to form friendships, relationships and social interactions. Participants mostly saw these as contributing toward poor health and in having low health literacy (Jimmy, David, Tyson).

> *"I was brought up on the streets, I'm like a third generation of street people, you know what I mean? Like, my whole family's been on the streets, like, third-generation" (Tyson).*

The adversary associated with intergenerational homelessness extended to intermediary social determinants[44] that resulted in exposure to adverse weather conditions, ongoing hunger, personal injury, and a breakdown of social cohesion resulting from behavioural and psychosocial factors, including anxiety, stress, and social isolation (Jimmy, David, Tyson). Participants who experienced intergenerational homelessness spoke about having to implement survival techniques, with learnt behaviours passed down from family members or other people living on the street. This included begging, knowledge of how to access clothes, food and drink, and favoured places to shelter and sleep (Jimmy, David Carl, Tyson). Interactions with other people experiencing homelessness were generally guarded, and there was acknowledgement of social norms *“if someone’s using that particular space to sleep, well you move on”* (David) and behaviours that may include alcohol and drug use *“Yeah, some do that stuff, but me, well I’m too poor to even think about it*” (Tyson). Being judged and discriminated against by members of the general population were regarded commonplace.

Housing instability and education

The interactions of structural determinants on housing instability were invariable related to educational disruption (Jimmy, Rob, Sam, Chris, Carl, Ash, Michael), persistent truancy (Sam, Tyson) and school suspension (Carl, Michael), resulting in a trifactor that contributed to educational disengagement, and subsequently, in reduced opportunities for employment.

> *“I couldn’t…couldn’t handle it, didn’t have the skills as an eleven, twelve-year-old, um, to do that sort of stuff (school work)… Been to probably about thirteen different schools between 1980 and ’83, um, and so then the government gave me an ultimatum—or, my mother—um, that I go to the school for special needs, um, for developmental issues… which I didn’t have”* (Phil).

In addition to the loss of academic skills, persistent housing instability was seen to appreciably disrupt social engagement. Several participants identified their low school attendance and poor socialisation as a pathway to their future social and economic exclusion in later life:

> *“I never really spent any great time at one school, and I was bullied a lot because we was poor… and didn’t make friends because we moved about so much. I would skip school whenever I could. I was really lonely as a kid…. So, yeah… I left before I should’ve, but no one was interested in me anyways, not teachers or anyone, and then I had no skills or any job to go to… and it’s always been like this” (Fred).*

Few participants finished year ten at school or entered apprenticeships, however, for those that did, education and training did not equate to job security (Phil, Will, Jan, Ash). Housing instability and early life homelessness was seen to be the main distractor for job security.

Accommodation

Housing policies pose an obvious structural determinant of health that has denied housing security for all interview participants. As one participant said, *"I never catch a break, Just as I get some accommodation, I get chucked back out again and nothing prevents them from doing that*" (Damen). However, such social policies extend to available accommodation and participants frequently spoke about ongoing psychological stress associated with difficulties in securing any accommodation, including high competition for short-term hostel accommodation.

> *"(finding accommodation) it's really been horrible, mate, I tell you. You know… It's…it's like I…it feels to me similar to the, um, rats in a box environment, you know, where…where eventually, you know, where initially they sort of sniffing each other, at the end of it they're eating each other, you know?" (Michael).*

Several participant narratives revealed their distress of rental availability and affordability, and their incapacity to secure any tenue, which were regarded as significant contributors to personal stress, anxiety, and feelings of hopelessness.

> *"I went to a couple of, um, uh, shared accommodation joints this week, and I asked the people who are, um, are letting the rooms out, I said…I said, 'how many people have been…been and had a look at it?', 'Oh, about eighty'…" (David).*

Housing Policies

Resentment towards governance was evident, with some participants pointing to state and federal housing policies that were perceived to particularly fail single men experiencing homelessness (David, Rob, Sam, Mark, Will, Ash) resulting in some participants feeling systemically deprioritised in favour of homeless women, families, and people with specific needs or disabilities (David, Rob, Phil). For example, one participant stated, *"when you're a single guy of my age and you're homeless… you've got no chance"* (Ash). Nonetheless, one participant who had a disability continued to experience an accommodation crisis regardless of being a client of the National Disability Insurance Scheme (NDIS).

> *"Like, there's no help for people like me, like, you know, my last twelve months they've, um, they've finally come to the party and realised "Oh, he's got a disability that's never gonna go away", and I've been given the NDIS funding and that now and been able to get some community support now…. just need some housing"* (Carl).

This person regarded himself fortunate because he had the assistance needed to access the National Disability Insurance Scheme. He spoke about other people who had failed to navigate the complexities of the system. This was largely because of the need for records and opinions providing proof of disability and practicalities such as having no identification or a bank account, *"things like that get real hard when you don't have a permanent address, and all that they need… "* (Carl). Similar stories arose for the older participants trying to access the second national scheme, My Aged Care.

Securing short-term hostel accommodation was seen as daunting, and challenges presented in finding available rooms. Participants who were in short-term accommodation spoke about the pressure placed on them to vacate after a few days, regarding this normal, but a major reason for cyclical patterns of moving between a range of sheltered and unsheltered accommodation situation (Jimmy, David, Sam, Chris, Mark, Tyson, Fred, Michael).

> *"I've only been there (hostel) for one night, and the pressure's already on you to get out of there, you know what I mean? Like, what am I going to do? I go the next day, don't I? That's what I've been doing five years because all they do is put pressure on you in places like this… There's no such thing as an exit date for homeless" (Chris).*

State care and incarceration

A primary structural determinant perceived to contribute to future homelessness was the experience of state care. None of the participants who were in state care, either in state-run homes or the foster care system, had positive recollections of having a good childhood. Rather, participants spoke about feeling unseen or being devalued, and generally felt they were considered a problem to be managed. These feelings were described as feeling rejected or having a loss of identity and little self-worth.

A participant recalled that his time in a state children's home continued to impact him in middle age.

> *"(I was) chucked in and out of boys' homes and…. and then I find out that my last name isn't even really my last name…. Then me and my twin sister and ten other kids were invited to a party held by the minister of welfare; every kid got called up, got to shake the man's hand, got a present, got something…. I wasn't even mentioned… I've turned into such a negative person because of this whole… I'm forty-four years of age, and I'm still crying and holding on to the fact that he (the Minister) never acknowledged me…. they were responsible for me,*

> *and they didn't do a very good job. The only time when kids where actually being recognised, and they missed me out" (Rob).*

Foster care was equally connected with negative experiences. One participant stated:

> *"I wanted to be part of something, and I didn't feel like I was… and then you got the foster dad coming out with certain things like 'Your real dad's a bum, he didn't give a f*** about you. If he cared about you, he would've come and got you'… I didn't feel like I was (loved)…" (Damen).*

Some participants regarded prison as a highly negative and unhealthy experience (David, Fred), whilst others saw prison as a stable form of accommodation, preferable to rough sleeping, and somewhere basic needs could be met, including access health and dental services, and the provision of food (Sam, Phil, Chris, Fred, Will). An example of this was presented by a participant who said *"I won't lie to ya, this is the hardest time in my life [crying]. Ever since I got out of jail"* (Chris). Whilst participants who had experienced incarceration saw hazards for their physical and mental health, none had considered incarceration as a risk factor for dementia.

Violence and childhood trauma

Witnessing or experiencing family violence in childhood was frequently discussed and directly activated pathways into homelessness. Violence was largely seen as a pervasive and primary contributor to unhappy childhoods with some participants recognising it to be fundamentally instrumental to having poor mental health as an adult.

> *"I used to watch my dad beat up my mum, always. Time and time again... real bad... and then my mum would throw things at him… Umm, and all the shouting and screaming. It was so bad... Yeah… me and my brother would try and hide, and we would cry and cry…. real sobbing and all that. It used to go on for days at a time, and this happened for years… all of my childhood really. He often chucked us out. When he chucked us out that last time… Umm…. well, that was violent too. Literally picked us up off the ground and threw us straight out the door… I would have been about eleven or twelve by then and I was just a scrawny kid. I've never got over that" (Michael).*

Many participants spoke synonymously about their experience of childhood trauma, neglect and abandonment. Some linked their violent childhood experiences to late-life post-traumatic stress and adult homelessness, and admissions of childhood stress that extended into adulthood were commonplace (David, Rob, Phil, Tyson, Damen, Carl, Mark, Jan, Michael).

> *If I put all the time that I've spent with my father in my lifetime, it'd be about two and a half months… And so, um, she (mum) was doing…she'd do meditations and that sort of stuff and be in silence for, like, weeks, three weeks, four weeks at a time… I came back to Australia*

> *when I was ten, um, of my own accord … I stayed with friends…Um, and…in search of my father, actually. Um, and that didn't work… um, when my mother found out that… that ended violently."* (Phil).

For a few participants, family conflict and violence were combined with parentification (reverse parent-child relationships). In these situations, participants spoke about feeling burdened by having responsibility for a parent in an often-fractious relationship (Rob, Jan). One participant spoke about parentification as being a pivotal issue for their unhappy childhood, which was described as a primary reason for leaving home and favoured homelessness over home.

> *"(I was) surviving day to day. It was like I was the parent, and she was the child. She couldn't keep a home… always drunk or taking other stuff. I even had to change and clean up after her, and all I'd get was a load of abuse and her backhand" (Rob).*

Physical health

Early life accidents and illness were seen as being contributory to adult homelessness, and a barrier to employment, income and stable housing.

> *"I've had a brain injury. I had a brain injury at an early age… And, like, I was never destined to be on the streets, but after I had a brain injury I destined to be on the streets" (Carl).*

Participants who had severe childhood illness generally had low expectations of moving into older age in good health and pointed to friends and family who died young or who experienced chronic health issues from a young age.

> *"I was just really sick as a kid, always sick, no energy, not feeling good about anything. It's just the same now really… nothing's really changed except I've been told I've always had depression" (Jan).*

and

> *"I got asthma when I was a kid. It would get bad 'cos it was triggered by the cold, and we were always cold in winter, no heating or anything" (Ash).*

Participants indicated that health-related conditions were poorly managed in the setting of homelessness. Issues identified include the lack of a stable address or not being able to prove identity. There was often reluctance to visit a general practitioner, with participants pointing to an inability to safely store or self-administer prescribed medications. One participant explained that having medications on his person would likely make him a target for theft or *"attract trouble"*

(Jimmy). Many participants did not feel that their health was a priority and expressed opinions that it was *"best not to know about something that could not change"* (Fred).

Mental health conditions

Having a diagnosed mental health condition was common, with participants having a range of conditions that included depression, anxiety disorder, schizophrenia, attention deficit hyperactivity disorder (ADHD), dyslexia, or other undisclosed mental health concerns. Participants mostly recognised that they needed ongoing support, however, several had experienced barriers in accessing appropriate services.

> *"And there's not much help for mental health patients. Like, it isn't the homeless situation, like, it's the mental health situation in Australia, too, like… like not enough money being put into mental health (Jan).*

Socioeconomic factors

One participant spoke about poverty being a main barrier for him to access the mental health services that he wanted. First, he discussed the difficulties he had encountered if he had to pay to travel across town, and second, he identified that his appearance was an obstacle to sitting alongside others in a waiting room. He felt that the result of these barriers, in addition to his homelessness status, left him feeling very depressed.

> *"I got no purpose in life, I've got no reason to be here, really. You know what I mean, I've got no reason to be here, I've done what I had to do, I've reproduced, and the kids are adults. I'm ready to leave the world nearly, you know what I mean?" (Mark).*

Intermediary social determinants of health include material circumstances, and poverty was seen as a driving factor for poor diet. Participants generally recognised the value of having a balanced diet, however associated nutritionally rich food with high costs and an ability to provide for oneself. Commonly, participants wanted greater control over their diet to promote better general health outcomes, although they did not necessarily equate good diet to having better cognitive health. As one participant expressed; "*I've…look, if…if I had money, I'd cook for myself*" (Chris).

Several access barriers for obtaining nutritious food were acknowledged; in addition to high food costs, participants identified no refrigerated storage, having no means to cook, and not owning personal cooking and eating utensils as restricting opportunity to fresh food. Participants opined that access to food services were vital (Jimmy, David, Sam, Jan, Ash, Michael). Where access to food services were unavailable or limited, participants regularly associated poor nutrition as being a norm of living homeless. For example, one participant stated *"but, if…if you're living out there by yourself, you know, might be pretty much on a bad diet, you know what I mean?"* (David). Specifically, participants expressed that rough sleeping meant having a greater reliance on alternative methods in accessing food that did not consider its nutritional benefit, including bin searching (David, Rob, Sam, Jan), begging (Phil, Mark) and negotiating with other people:

> *"Well, on occasion I live for ten to fifteen days on bread, dry bread, and a packet of Woolworths rolled oats. Without sugar, without milk, uh, a little bit of water… Once… I shared (a doorway) with another chap who was in a similar position. He had two kebabs, you know those hot, yeah, so I said "Yes", he shared them with me and I shared my loaf of bread with him" (Sam).*

Participants who regularly engaged with homelessness services generally recognised that they fared better with access to foods with nutritional value, including access to fruit and vegetables. Engagement with homelessness services that provided meals was seen as a significant drawcard for participants and had encouraged some participants to relocate from rural areas (Jimmy, Rob, Phil, Chris, Will). Most participants spoke highly of the quality of the food accessed from established homelessness services, with statements such as *"It's good… mostly healthy food, but I tend to reward myself with junk food sometimes"* (Damen) and *"I manage to get some fruit that I can take away with me… bananas and that"* (Michael), being typical. Usual viewpoints were that healthy food was important as a way of getting vitamins, seen as essential to good health, although no participants were aware of the role of thiamine for brain health. Nonetheless, some participant experiences with homelessness food services were not so positive. One participant had been discouraged by a regional food service and questioned the quality of the food being offered, stating: *"they fill you up with cheap sausages or whatever… and white bread"* (Chris). This participant acknowledged that whilst this was preferable to hunger, he associated poor quality food with an exacerbation of his chronic health issues and poor wellbeing.

Participants identified having adequate sleep as being important to their health and overall ability to cope with life. Sleep deprivation was described as *"torture"* (Sam), and *"agony"* (Ash), with many participants framing sleep deprivation as being impactful on daytime brain functioning, escalating anxiety and ability to cope. As one participant said, *“yeah… having no sleep for days… makes me feel groggy all the time… everything feels like I’m climbing a mountain without oxygen”* (Fred). Reasons given for sleep deprivation included *“being moved on”* (Jimmy, Rob, Sam, Carl, Mark Fred), and difficulties in finding somewhere dry and warm in winter (Rob), but also an inability to ‘switch off’, from anxiety, as one participant stated: *“ I can’t get any sleep there and there’s sh** going through your head, in the back of your mind…”* (Jimmy). To manage sleep deprivation participants often compensating with daytime napping, whilst other participants capitalised on opportunities to oversleep. Oversleeping generally stemmed from participants feeling bored, needing to withdraw, or to escape intrusive thoughts: *“most people say the more sleep you get the more your brain doesn’t have to suffer from other things from the out world”* (Damen). Participants reported sleep deprivation often resulted from fear for personal safety and worrying about *“getting a kicking”* (Phil, Will), especially once nightclubs had closed and subject to the actions of others under the influence of alcohol or illicit drugs.

Behavioural factors associated with homelessness are intermediary determinants and resulted in both self-harming actions and becoming a victim to adverse behaviours of others. For example, many participants were concerned about personal safety and perceived dangers from socially interacting with other people experiencing homelessness. Participants reported incidences of theft, frequent fighting and described having physical altercations with peers or in witnessing violence.

> *“You get, like, people…mean, you get the drunk people around you, you get the druggies around ya….and, like, getting your stuff stolen, and you’ve always gotta have your stuff on ya….gotta keep ‘em on you 24/7, and when you keep your belongings on you 24/7 you’ve got a bag and that’s ya lot, and that starts affecting your physical health” (Sam).*

These experiences were seen to erode trust between other people experiencing homelessness and in building relationships with members of the general population. Participants described being suspicious of the motives of others. For example, one participant said *“you never know what’s going to happen…. It’s like they lure you in, just to give you a beating”* (Carl). Head injuries were regarded as a usual outcome of violent interactions:

> *"(I) feel, um, sort of like vulnerable, and you're letting yourself be vulnerable to community, you know what I mean, like there's some bad stuff happens to people on the streets. You can get your head kicked in, to put it quite bluntly… because violent things happen" (Tyson).*

Participants did link head injury to cognitive risk, with one participant connecting physical trauma to memory loss.

> *"Yeah… I know that, well, um… I got hit one time and hit my head on the ground… I was in the hospital for three months because there was a bleed… well yeah… my memories been awful since then. I always forget things I'm told to do or who I need to see" (Mark).*

Generally, participants thought head injuries were most likely to result in concussion, from which they viewed as temporary, or in the case of a severely violent attack, a permanent injury that could affect a person's thinking skills. Participants generally had a limited understanding of the risk between serious or accumulative concussive events, traumatic brain injury, chronic traumatic encephalopathy and dementia in later life.

> *"You know, my short-term memory's getting lost. I…I got picked up and put in hospital here the other day, and, um, when I woke up in hospital, they asked me where I was, and I told 'em I was in Brisbane"* (Carl).

Excessive alcohol, drug use and substance addiction were reported, although not commonplace. Alcohol and cigarettes were the most used substances among participants and were generally used as a distraction for boredom, rising stress and anxiety. For example, one participants said *"smoking helps keep me sane and calm. I avoid conflict if I smoke"* (Ash). There were many corroborating statements made among participants regarding smoking as a self-management tool for temporary relief of negative emotions, *"smoking helps to take away the mental pain and to deal with stress. It's a way to destress"* (Chris). Additionally, narratives identified that participants used cigarettes as informal currency, "*I'll give him a few cigarettes and he'll let me stay here, you know, put my head down for a couple of hours, like"* (Rob). For many participants, smoking and ownership of cigarettes appeared to have a value beyond habit or social smoking and was ingrained in the experience of homelessness.

The next section will provide a discussion of the data integration used in Study One: *The Lived Experience.*

Study One Data Integration

Integration processes used in Study One: The Lived Experience

Integration of data in the mixed methods is built into several stages of the study design and is based on Fetters et al [276] and Fetters and Molina-Azorin [278] Data integration is seen across three stages at the design level, methods level, and results level of Study One: *The Lived Experience.*

Design Level

The intention to integrate begins with the research purpose and research question: *How does homelessness impact cognitive wellbeing and exposure to dementia risk?* The structure of the research question is open and pragmatic, allowing for both quantitative and qualitative dimensions that can be brought together for the purpose of integration. The research question for Study One: *The Lived Experience* indicates the need for integration because it seeks an exploration of the relationship between homelessness and risk for dementia, and of mechanisms driving those relationships.[277, 278] The intent to integrate is also evident in the choice of the parallel convergent mixed methods design.[278] This concurrent data collection design is interactive in how one set of data collection exerts an influence on the focus of the second data being collected, and vice versa.[276] For example, childhood trauma was a frequent and distressing experience seen in the qualitative data, which placed attention on the quantitative data analysis to assess if further insight could be gained into the breadth and scope of comparable characteristics.

Methods Level

Linkages between methods of data collection and data analysis were designed to fit well and facilitate merging once the individual data sets have been analysed.[276] Study One: *The Lived Experience* integration examines how the quantitative and qualitative data relate to each other using core merging techniques. Integration by merging is used for this study and occurs when two databases are brought together.[276] Procedures are used to consider the linkages, intersections between the data, contrasts, and interpretations to identify common threads of information across the quantitative and qualitative data sets.[278] This allows the data to become meaningfully integrated rather than just combined. In Study One: *The Lived Experience* methods of data collection and analysis results were compatible for integration because the data was analogous between metrics and narratives that shared data points, and the integration weaves back and forth around comparable themes and concepts.[276]

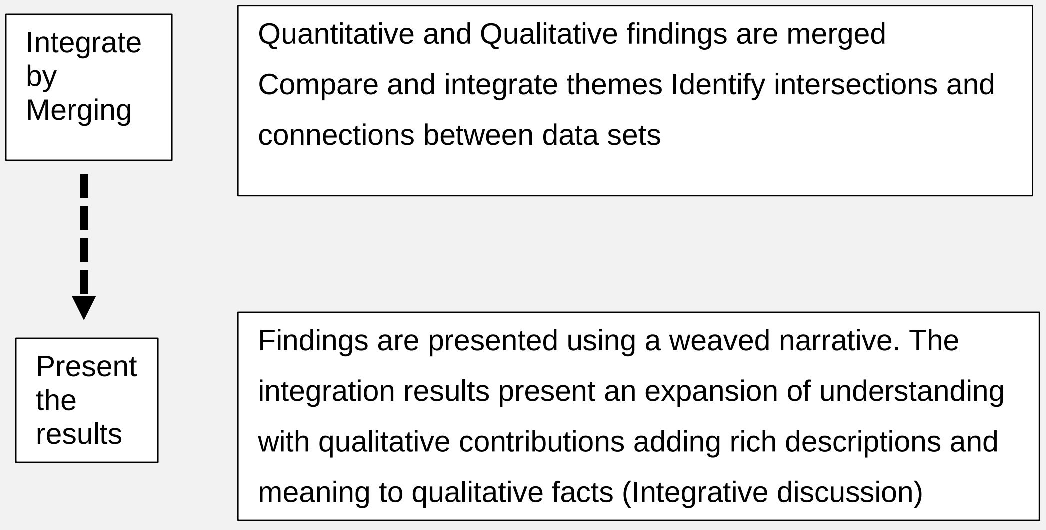
Results Level

The final integrated discussion presents a weaved narrative that describes the quantitative and qualitative results thematically.[276] In Study One: *The Lived Experience,* the quantitative and qualitative results are connected to each other through themes, described in the next section. Reflection is made on those themes to provide meaning for the interpretation used for the integrative discussion.

A summary model for data integration in Study One is shown in Figure 28.

Points of Data Integration (in bold text) in Study One : *The Lived Experience* based on Fetters et al. (2013, 2017)

1. **Design Level**: Intent to integrate through research question and choice of study design: Parallel Convergent Mixed Methods
2. **Methods Level**: Planned convergence of the Part One and Part Two data analysis results which are brought together for the purpose of integrating data
3. **Results Level**: Quantitative and Qualitative results first presented separately using descriptive statistics and narratives then brought together. Integration through merging processes, and integration through interpretation and reporting



Quantitative and Qualitative findings are merged
Compare and integrate themes Identify intersections and connections between data sets

Findings are presented using a weaved narrative. The integration results present an expansion of understanding with qualitative contributions adding rich descriptions and meaning to qualitative facts (Integrative discussion)

Outcome

Figure 28. Points of Integration for Study One

The Part One (quantitative) and Part Two (qualitative) results were combined using merging techniques based on the work of Fetters.[276]

Integration process for Study One: The Lived Experience

The process for integration by merging is complex and intricate. For Study One: *The Lived Experience* it involved two interrelated and continuous steps. First the quantitative and qualitative data findings were brought together and then the data detail was integrated. This process was completed by organising the data through a process of data charting to ensure the 'fit' of the data (the coherence of the quantitative and qualitative findings).[276]

To begin the data integration, I used an extensive 'pen and paper' mapping exercise to identify theme commonalities, points of intersection and connections linked across both data sets. The 'pen and paper' exercise was completed for all identified potentially modifiable risk factors for dementia mapped to Livingston et al (2020)[66] in the first instance, and the scoping review,[179] but also to other seminal literature, including *Modifiable Risk Factors for Dementia and Dementia Risk Profiling*[166] and *The World Alzheimer Report 2014.*[35]

Additionally, data coded in QSR NVivo was further assessed for frequency and precise content to provide an indication of the strength of a discussion point being articulated and whether it was positioned across more than one theme or sub-theme. An Excel spreadsheet was used to make comparisons in data themes and sub-themes. This process consolidated information from the 'pen and paper' exercise with each data theme and sub-theme allocated a cell within a table created in the Excel spreadsheet. The outcome of the Excel procedure is shown in Figure 29. This figure illustrates how the data from Part One and Part Two 'fit' together because of data integration using merging techniques.

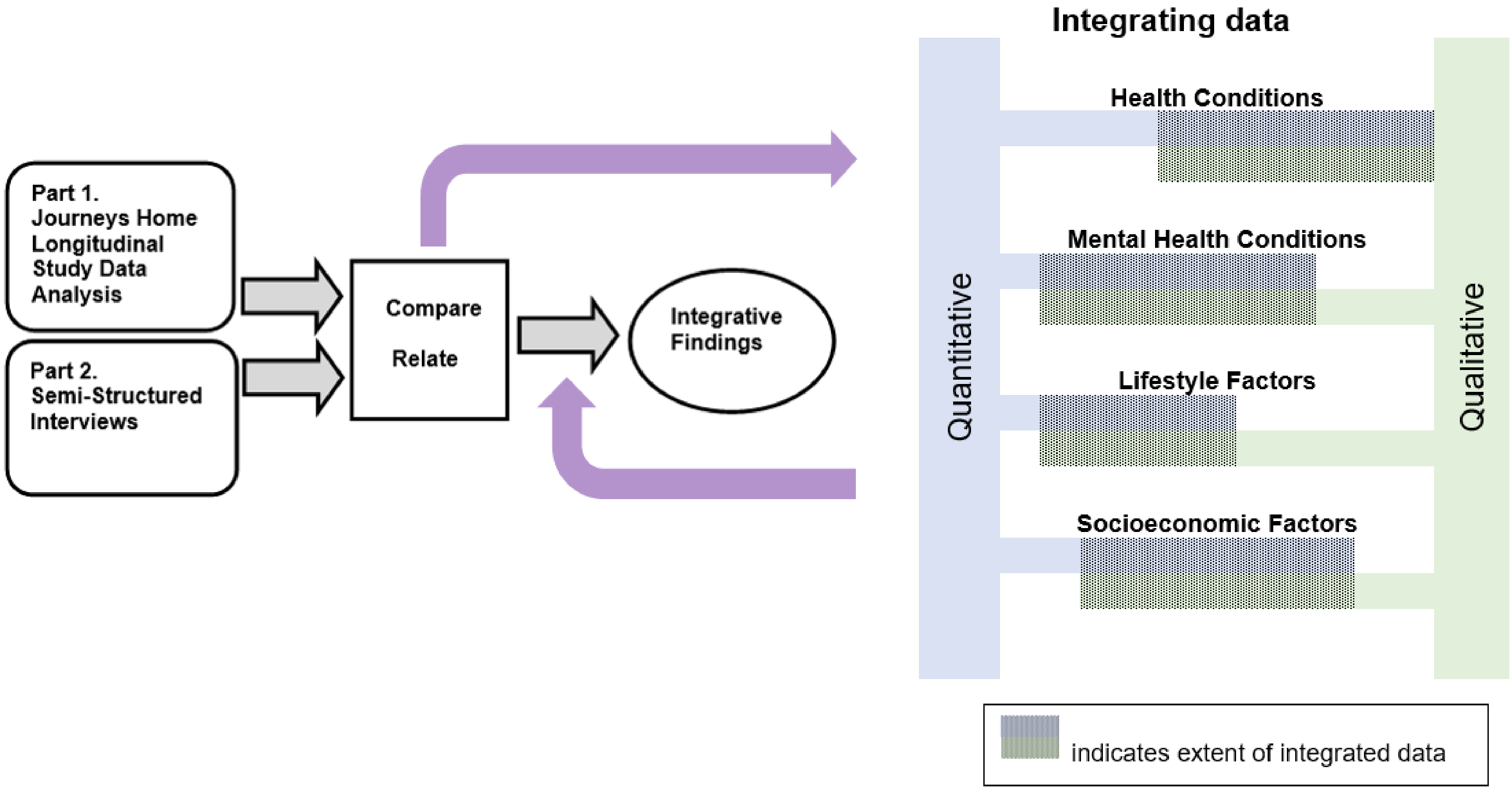


Figure 29. Data merging in Study One. Parallel Convergent Mixed Methods

Explaining Figure 29. Data integration by merging

In Figure 29, the left-hand side of the figure shows the parallel convergent mixed methods study design previously discussed in Chapter 4 (Methods section). The right hand side represent the extent of themes and sub-themes that were identified. For example, in *Health Conditions* the quantitative data provided more overall information than the qualitative data measured by volume of data. This is shown by the extent of the blue line (quantitative) that spans between the two data sets compared to the shorter green line (qualitative) that is seen below, and which does not span completely between the two data sets.

The shaded areas represent the degree in which the quantitative and qualitative data correlated and therefore, merged. Conversely, unshaded areas represent the extent of directly incomparable data (that could not be merged), however, this data is still important because it provides meaningful insights that contribute to the overall picture on dementia risk in homelessness.

Table of results of the integration

The following section presents the summary results of integrating the quantitative and qualitative data sets of Study One: *The Lived Experience*. The results are presented in a summary form in an integrative results table (Table 12). These results structure the evidence presented in the integrative discussion for Study One: *The Lived Experience* at the close of this chapter and contribute to the overall interpretation presented in Chapter 7. A direct comparison was made to determine how this data aligns to the known potentially modifiable risk factors for dementia evidenced in Livingston et al.[66] However, the data findings also extended beyond Livingston et al.[66] incorporate other factors that present a modifiable risk for dementia, for example, quality of sleep in people experiencing homelessness. These results expand on the potentially modifiable risk factors for dementia presented in Livingston et al.[66] because they combine the Study One findings, the Livingston et al risk factors and draws from evidence presented in the wider literature to link experiences associated with homelessness with exposures to dementia risk.

Table 12. Results of integrating the data

Highlighted results from data findings mapped to potentially modifiable risk factors for dementia (in bold) and other cognitive risk (in *Italics*)

✓ = merged data results, Insight = data that could not be directly compared in the quantitative or qualitative data, X= no data found in quantitative or qualitative sets but is evidenced in the literature.

Data Findings	Merged Quan/Qual	Data detail
Health Conditions	✓	**Heart disease** (including **hypertension**), *liver problems*, and **diabetes** had the highest representation of health conditions that are associated with risk for dementia. People did not manage chronic health well, including medication management and follow-up appointments.
	✓	*Intellectual disability* and **traumatic brain injury** were higher in homelessness than the general population. People expressed these as being reasons for unemployment and homelessness.
	X	No merged data available for *HIV* or other *neurologically impacting infections.* Literature sources only.
	Insight	General poor health was thought to be a direct consequence of homelessness. Contributes to *premature ageing***.** This was particularly so for primary homelessness exposed to weather and other environmental factors.
	Insight	Qualitative findings on *oral health* and *dental health* and decay showed there was very limited access to dental care. On occasions people had access to student dentists attending homelessness services or emergency dental services. Dental care was low and deprioritised.
	Insight	Quantitative findings include *stroke, epilepsy, kidney disease, hepatitis C.* All were experienced at higher rates than seen the general population, except for kidney disease.
	✓	**Traumatic brain injury** was seen considered a cause and a consequence of homelessness. Prevalence was well represented in homelessness. People aware that it affects brain health and potentially cognitive impairment.
	✓	*Epilepsy* was a characteristic of homelessness. In the interviews one person who had epilepsy spoke about the difficulties it presented for having good medication management and fear of having a seizure whilst in a vulnerable place. Also, stigma associated with epilepsy and had experienced a seizure whilst in a hostel and receiving little attention or support. The next morning, he had to leave with post-seizure confusion.
	✓	**Hearing loss** was noted in more than one quarter of participants. People found it difficult to obtain hearing aids and costs were prohibitive. Hearing was deprioritised. "just one of those things".
	Insight	Little data on **obesity**, however it was linked to diet and the difficulties in getting fresh food. Cheap foods are easily accessible. Don't need utensils or washing up. Help to keep warm in winter.
	X	No merged data available on **physical activity**. Literature sources only.
Mental health Conditions	✓	**Depression** was the most prevalent of all mental health conditions, and far exceeded rates seen in the general population. People felt that depression severely impacted life and ability to manage well. The effects of depression included withdrawing from social activities, participating in unhealthy activities such as excessive alcohol and smoking, and not wanting to live.
	✓	*Anxiety* was over-represented in homelessness. People linked anxiety to housing stress, finding immediate accommodation, coping with rough

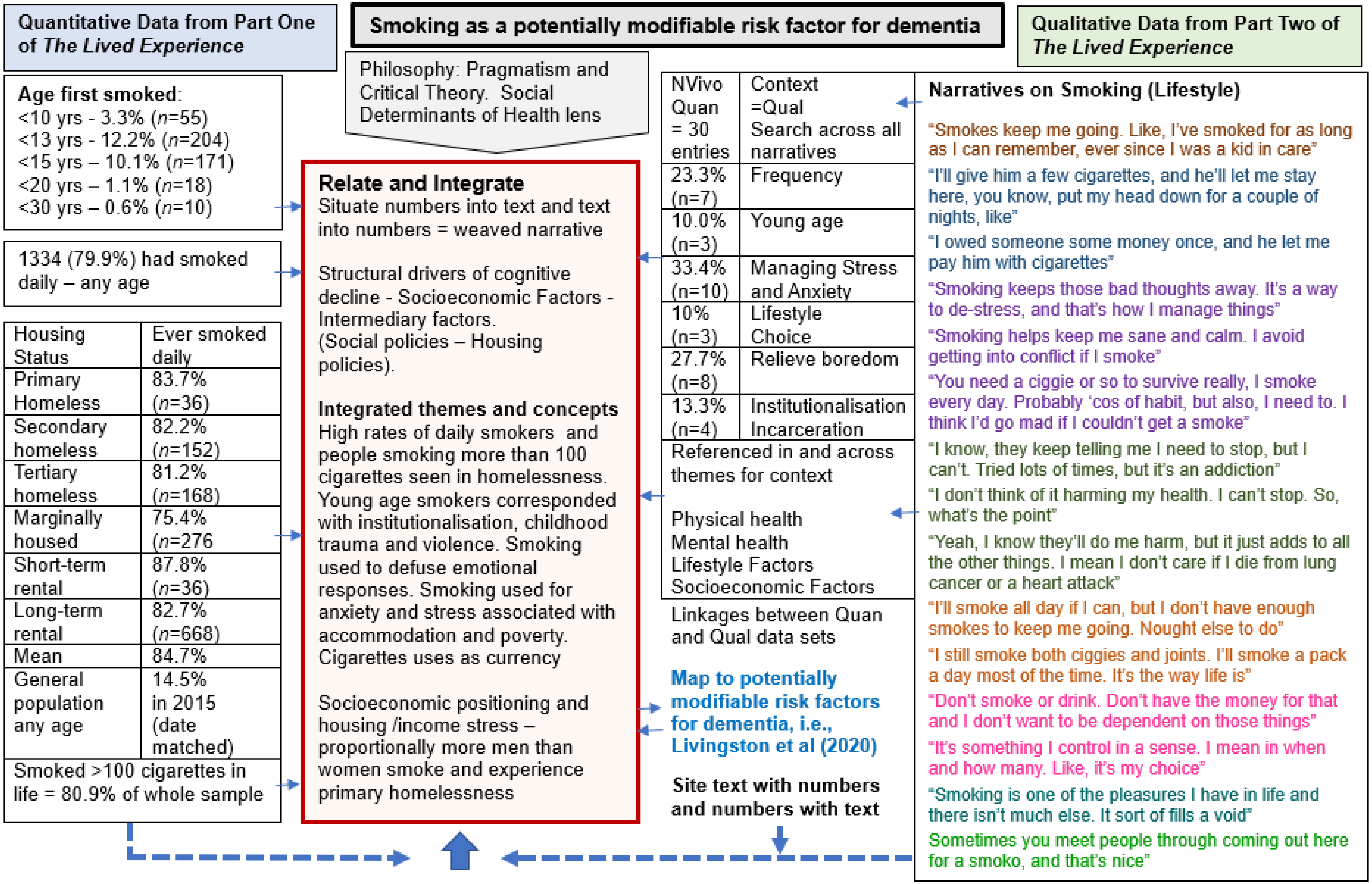
		sleeping or being in hostels and worried about violence. There was anxiety associated with finding food, keeping warm, finding somewhere safe to bed down, managing systems and applications (for example Centrelink)
	✓	*Post-traumatic stress disorder* was frequently reported in all data. People linked ongoing consequences of trauma stemming from childhood experiences that included severe neglect, violence
	Insight	*Bipolar affective disorder* and *schizophrenia* were reported in quantitative data but not qualitative data. More people reported Bipolar affective disorder than schizophrenia, but both had high prevalence in homelessness
	✓	*Mental health* distress measured by Kessler 6 validated indicator of mental health. People surveyed whether they felt nervous, without hope, restless, if everything felt an effort, that nothing could cheer them up, and if they felt worthless with a considerable number of people reporting scores indicating high levels of psychological distress >13 on Kessler 6. People spoke about feeling hopeless because of living homeless. They felt that they had no control of their circumstances. Caught in a spiral of adversity. Several spoke about feeling constantly nervous but could not pinpoint why. Feelings of worthlessness were common and linked to feelings of despondency. Described life as joyless and spoke about having no purpose, depression and sadness were confounded. The majority described feeling one or the other. i.e., this life makes me sad. Common statements include "I'm nothing", "there is no purpose in anything", "life is sh*t". No participants spoke about feeling happy or content, although one person was accepting of how life had panned out.
	✓	**Smoking** is highly prevalent and exceed that of the general population. Nearly all participants had tried smoking. Youngest age to smoke a cigarette was two years. Younger age was linked to state care, institutionalisation or with family violence. Large majority smoked daily. More men than women smoke. Cigarettes were used to help manage everyday stress. Majority of people smoked between 10 and 15 cigarettes daily. Majority of smokers started between ages 12 and 16 years old. Seen as a perceived lifeline to help emotions or other mental health. Smoking as a social norm and a way to connect. Something people have in common. Easier to talk with other smokers. Seen as a social activity but also as an addiction. Helps to manage anxiety associated with accommodation needs. Not concerned with long-term health outcomes. Smoking used as currency. Something to barter with. Used to pay off debt. Cigarettes have a value other than in monetary terms.
Lifestyle factors	✓	*Smoking marijuana* was common. Normalised behaviours for some with most users smoking marijuana daily if able to source. More than three quarters of people had smoked marijuana. The youngest age to first use marijuana was eight year old with the mean age seen around age16 years. People spoke about marijuana being a good regulator of mental health will most preferring marijuana to medication. Seen as being beneficial rather than detrimental to health as it is calming and enjoyable.
	✓	Interview participants were reasonable reserved about revealing *illicit drug use*. Some associated it with feelings of shame. Methamphetamine use was discussed and framed within brain health. Observed to be destructive, people spoke about the changes seen in other people to the point where they were "like zombies" and "changes people significantly". People associated methamphetamine use with poor brain health, making people volatile and abusive to others. Around one quarter of participants had injected illicit drugs, however, less than 10 per cent were currently doing so. The most common age for first trying illicit drugs were between 16 years and 18 years old. Of those still using illicit drugs,

		it was more frequently used on a monthly rather than weekly basis. Cost and sourcing were reasons for reduced illicit drug use.
	✓	**Alcohol** use was frequent and used to dull the “agonies” of the day. Common understandings of alcohol between participants who bartered alcohol. Collective and singular activity. Alcohol was frequently used over the recommended safe limits. Despite the high frequencies of drug and alcohol use, most people did not see it as being a problem. People considered drug and alcohol use as normal in their community.
	✓	*Poverty* in childhood had a direct influence of education and enjoyment of school. People felt that they stood apart from others regarding money for uniform, schoolbooks and excursions. Poverty made life miserable. Withdrawing from school linked to poverty. Poverty in later life affected accommodation, becoming “job ready”, access to food and healthcare.
	✓	*Unemployment* was linked to poverty and a reason for homelessness. People felt they were disadvantaged in applications, not address made it hard to apply for a job. Clothing and overall presentation was disadvantageous.
Socioeconomic	✓	**Social isolation** was seen to be connected to loneliness. People often felt lonely. Small social circle.
	✓	*Diet and nutrition* were generally poor, Low understandings of nutrition for brain health. Some access to fresh fruits.
	✓	**Education** and attainment were linked to poverty resulting in low educational attainment. Intellectual disability also linked to low educational attainment and unemployment.
	✓	*State care or Institutionalisation* in childhood was common. All narratives exposed bad experiences. More than one quarter were placed into foster care. Foster care usually erratic with frequent moves. Lack of stability. More than third having more than one female carer (some up to 10 placements). 20% experienced sexual assault from others, 13 % from family members. Nearly half experienced physical violence.
	✓	*Incarceration* was a cause of homelessness on release. Unable to secure employment or rentals. Some preferred incarceration to homelessness. Nearly one quarter of primary homelessness had experienced long-term prison sentences.
	✓	*Childhood trauma and neglect* featured in many narratives. Half of all participants said a family member hated them. Frequent violence between parents or violence directed at them. 15% left with inadequate food or shelter. Childhood violence a reason for homelessness.
	Insight	Qualitative only. *Loss of self-identify*. No Medicare card or reliable identification made claiming benefits and healthcare difficult. Not having a stable address affected self-identify.
	Insight	Qualitative only. *Sleep quality* was considered poor. Mostly due to environmental factors. Cold and damp, or fear of violence both outdoors and in hostels. Disturbed sleep is common. Affects daytime alertness. Need to sleep during day. Risk of oversleeping due to boredom.
Other Factors	Insight	Qualitative only. Asked about *brain health.* All participants felt that it was not as good as it should be. Direct result of homelessness, constant stress, poor living conditions, limited friendship groups on going effects of trauma and past experiences. Use of alcohol and drugs.
	✓	**Domestic violence** featured considerably in data sets. Particularly in childhood or witnessing violence between parents.
	✓	*Family breakdown* a common reason for homelessness. Cause of stress and poor psychological health.

Process used to integrate the data

The process for integrating the data included a cycle of extensive data charting which sited text with numbers and numbers with text to ensure that the data was unified or combined. The process of data charting is presented in Figure 30, using the example of smoking. This process was iterated for the range of health conditions, mental health conditions, lifestyle factors and socioeconomic factors mapped to potentially modifiable risk factors for dementia shown in the previous table (Table 12).

The summary results were used to create data charts that contributed to the integrated discussion, and an example using data on smoking is shown in Figure 30.



Quantitative Data from Part One of *The Lived Experience*

Smoking as a potentially modifiable risk factor for dementia

Qualitative Data from Part Two of *The Lived Experience*

Age first smoked:
<10 yrs - 3.3% (*n*=55)
<13 yrs - 12.2% (*n*=204)
<15 yrs – 10.1% (*n*=171)
<20 yrs – 1.1% (*n*=18)
<30 yrs – 0.6% (*n*=10)

1334 (79.9%) had smoked daily – any age

Housing Status	Ever smoked daily
Primary Homeless	83.7% (*n*=36)
Secondary homeless	82.2% (*n*=152)
Tertiary homeless	81.2% (*n*=168)
Marginally housed	75.4% (*n*=276
Short-term rental	87.8% (*n*=36)
Long-term rental	82.7% (*n*=668)
Mean	84.7%
General population any age	14.5% in 2015 (date matched)

Smoked >100 cigarettes in life = 80.9% of whole sample

Philosophy: Pragmatism and Critical Theory. Social Determinants of Health lens

Relate and Integrate
Situate numbers into text and text into numbers = weaved narrative

Structural drivers of cognitive decline - Socioeconomic Factors - Intermediary factors. (Social policies – Housing policies).

Integrated themes and concepts
High rates of daily smokers and people smoking more than 100 cigarettes seen in homelessness. Young age smokers corresponded with institutionalisation, childhood trauma and violence. Smoking used to defuse emotional responses. Smoking used for anxiety and stress associated with accommodation and poverty. Cigarettes uses as currency

Socioeconomic positioning and housing /income stress – proportionally more men than women smoke and experience primary homelessness

NVivo Quan = 30 entries	Context =Qual Search across all narratives
23.3% (n=7)	Frequency
10.0% (n=3)	Young age
33.4% (n=10)	Managing Stress and Anxiety
10% (n=3)	Lifestyle Choice
27.7% (n=8)	Relieve boredom
13.3% (n=4)	Institutionalisation Incarceration

Referenced in and across themes for context

Physical health
Mental health
Lifestyle Factors
Socioeconomic Factors

Linkages between Quan and Qual data sets

Map to potentially modifiable risk factors for dementia, i.e., Livingston et al (2020)

Site text with numbers and numbers with text

Narratives on Smoking (Lifestyle)

"Smokes keep me going. Like, I've smoked for as long as I can remember, ever since I was a kid in care"

"I'll give him a few cigarettes, and he'll let me stay here, you know, put my head down for a couple of nights, like"

"I owed someone some money once, and he let me pay him with cigarettes"

"Smoking keeps those bad thoughts away. It's a way to de-stress, and that's how I manage things"

"Smoking helps keep me sane and calm. I avoid getting into conflict if I smoke"

"You need a ciggie or so to survive really, I smoke every day. Probably 'cos of habit, but also, I need to. I think I'd go mad if I couldn't get a smoke"

"I know, they keep telling me I need to stop, but I can't. Tried lots of times, but it's an addiction"

"I don't think of it harming my health. I can't stop. So, what's the point"

"Yeah, I know they'll do me harm, but it just adds to all the other things. I mean I don't care if I die from lung cancer or a heart attack"

"I'll smoke all day if I can, but I don't have enough smokes to keep me going. Nought else to do"

"I still smoke both ciggies and joints. I'll smoke a pack a day most of the time. It's the way life is"

"Don't smoke or drink. Don't have the money for that and I don't want to be dependent on those things"

"It's something I control in a sense. I mean in when and how many. Like, it's my choice"

"Smoking is one of the pleasures I have in life and there isn't much else. It sort of fills a void"

Sometimes you meet people through coming out here for a smoko, and that's nice"

Figure 30. Data charting: Example of data integration for the dementia risk factor of smoking.

The final section of this chapter comprises of a discussion based on the integrated data which is presented as a narrative dialogue.

Integrative discussion on The Lived Experience

The data shows that the health and social profile of people experiencing homelessness is bleak and living homeless makes people vulnerable to a range of exposures for dementia risk, discussed in Chapter 3, Scoping the Literature. *The Lived Experience* shows the high adversarial impact that homelessness has on cognitive wellbeing. This is underpinned by a set of common characteristics that places people into homelessness and where persistent social vulnerabilities further increase the risk of exposure to modifiable risk factors for dementia. When viewed through a social determinants of health lens, homelessness is seen as a consequence of hostile social and economic factors that drives poor health outcomes.[99] The integrated data reinforces the need to consider social determinants of homelessness health because they are inextricably linked to poor cognitive and other health outcomes, interconnected with structural and societal factors, such as entrenched poverty, illicit drug use, and food insecurity.[125] This discussion is focused on the integrated data findings from *The Lived Experience,* presented in a life course perspective for exposure to dementia risk factors using a social determinants of health lens. The life course for dementia risk was previously discussed in Chapter 2.

Early-life and childhood

The data confirmed that homelessness is often preceded by childhood adversity and severe social exclusion[99]. Clear characteristics that disadvantage people from an early age are evident throughout *The Lived Experience,* and mostly emerge from disadvantageous and volatile childhoods, complicated by family breakdown and issues that impinge on stability, such as loss of household income and parental unemployment or ill health. Inefficacious parenting shifts responsibility onto children and adolescents to manage complex, adult situations, including the reversal of child-parent roles. For example, taking on domestic chores, being responsible for younger siblings, meeting the care needs of an incapacitated parent. Examples of structural and societal factors revealed in *The Lived Experience* shows that contributors to childhood adversity include personal experiences of emotional, physical and sexual abuse, trauma from high rates of state care, institutionalisation and distress from enduring unstable housing situations.

A childhood devoid of life satisfaction and recognised childhood norms can be enduringly stressful with consequences for socialisation, education and wellbeing, triggering a cortisol-stress response[312-314] and a physiological pathway to increasing risk of dementia in late-life.[315] Early-life stress-inducing circumstances result in poor physical, psychological and cognitive health that contribute to stress-mediated pathways affecting adult cognitive functioning[213] and present a twofold increase in risk for developing a major depressive disorder during childhood or adolescence.[316] Depression, a known risk factor for dementia, can occur anytime over the life course but having an adolescent major depressive disorder risk recurrent episodes of depression, suicide ideation, and psychiatric illness throughout late-life.[317]

Education

Education is a structural determinant of health and is closely connected to life expectancy, morbidity, and unfavourable health behaviours.[318] Early-life education provides a buffer against future socioeconomic disadvantage by influencing future wealth and improving socioeconomic positioning.[192] Education, a key life course factor that is advantageous for improved later-life cognitive function,[195] however, access to education can be severely disrupted by childhood socioeconomic disadvantage and homelessness.[319] Education is seen as a protective factor for dementia, drawing from the cognitive reserve theory of increasing brain resilience to structural brain changes.[320-322] However, the data from *The Lived Experience* demonstrates the difficulty in maintaining educational consistency when living homeless. Achieving good school attendance is hard to when living with disadvantage due to having extremely low socioeconomic means and unstable housing, revealing housing, including the economic ability to maintain housing, as a structural social determinant of health that affects education.

Furthermore, people experiencing homelessness face complex, unfair and inequitable psychosocial issues that directly result from being unstably housed, exposing childhood poverty that can emphasise difference.[323] Findings from *The Lived Experience* show that material deprivation when attending school becomes obvious when not able to afford school uniform, books and excursions, and which has an emotional bearing on educational continuance. *The Lived Experience* demonstrates the depth of distress experienced from standing apart from peer groups, which reinforces subjective and objective social marginalisation, for example, bullying at school is seen as a frequent, and serious consequences of childhood homelessness, although you don't have to be homeless to be bullied.

All these factors create a high risk for failure in schooling.[324] In *The Lived Experience* truancy was frequently reported, exacerbating disengagement with education, and interrupting opportunities for friendships. Under these circumstances shortcomings in reaching cognitive milestones and dysregulation of emotional and behavioural behaviours and high psychosocial risk are familiar and expected,[325] and elevates risk for late-life dementia through a life course association between low early-life educational performance and later-life reliance on cognitive reserve.[320]

Behaviours

There is a social milieu of health outcomes that descend from non-medical upstream social determinants, created from social, political and economic contexts that shape individual actions.[326] People who are socially and economically disadvantaged are more likely to present with behaviours that are harmful to long-term health outcomes, such as having low physical activity, high consumption of alcohol and cigarettes, poor diet, and low consideration for dental health.[53] These constitute health behaviours. The range of socially determined upstream factors that modulate health behaviours include the socioeconomic and political context in which policies are formed and enforced, which in turn influence education, employment, occupation and income opportunities, shaping behavioural factors that become socially patterned.[44]

The Lived Experience suggests that childhood homelessness establishes behavioural patterns that continue into adolescence. Early smoking, in one instance occurring at the age of two years old, sets in motion long term tobacco habits. Economic disadvantage, stress and depression seen in homelessness can reinforce smoking habits. People smoke to relieve tedium, to build social connections over a shared cigarette, or use cigarettes as an unofficial currency, to be exchanged for items, food, or shelter. However, smoking poses a serious health concern in an already vulnerable group,[327] and smokers interviewed in *The Lived Experience* had no knowledge that smoking is regarded a risk factor for dementia. Smoking, at a time of overall reduced smoking prevalence, remains stubbornly high in low socioeconomic groups.[328]

Tobacco use has long been thought as a gateway drug to alcohol and other substances mediated through neural pathways connected to the brain's reward system, particularly during adolescence when the brain is maturing and susceptible to chemical change.[329] *The Lived Experience* supports a relationship between smoking and alcohol use, although smoking is the more frequent activity, and unlike high alcohol consumption, is not known to directly contribute to homelessness. On the other hand, a strong relationship between homelessness and alcohol use exists,[330] and is evident across *The Lived Experience*. Alcohol, an established risk factor for dementia,[331] is generally used as a prop to cushion daily worries associated with homelessness and regarded as being a coping mechanism. Nonetheless, having an awareness of its addictive properties and a daily reliance on heavy alcohol consumption deepened a sense of despondency in the participants. Underlying high rates of heavy consumption of alcohol and other substances is a network of psychosocial factors that are hard for people to navigate without intensive professional support, such as psychological distress and addiction. However, this was not necessarily obvious to people experiencing homelessness, who did not always want to engage with substance use support services.

The data revealed that both alcohol, smoking and illicit drug use as a youth increased the likelihood of remaining homeless into adulthood, partly by augmenting and reinforcing stereotyping, but generally because of economic and social consequences associated with these health behaviours.

Illicit drug use

Social determinants contribute to discrepancies in problematic drug use behaviours with the health of people who use drugs is essentially connected to a person's social environment.[332, 333] Social determinants establish the circumstances in which drug use and drug associated risk behaviours become socially processed, and where poor health becomes the product of drug use behaviours and detrimental social determinants.[332] These determinants include complex cultural, economic and political spheres of socially defined influence.[333]

The Lived Experience provides insight into how substance misuse impact people at a community level and it was common to find substance users have a concurrent mental health condition or high stress. An assertion that post-traumatic stress was highly prevalent in people experiencing homelessness[334] was confirmed. Most people had an awareness of physical and mental health impacts of substance use, some of which were regarded as a positive. For example, many participants spoke about marijuana as being innocuous, having a calming and enjoyable effect and certainly preferable to tobacco use or the pharmacological management of stress and anxiety. Late-life consequences for brain health were generally unregarded other than with methamphetamine use, with good reason. Methamphetamine is known to fluctuate blood pressure, with an overall increase providing a risk for cerebral small vessel disease and increasing white matter hyperintensities and lacunes in the brain,[335] and can present a near five-fold risk for dementia.[336] As a psychostimulant, it also presents a concern for sleep quality, often causing sleep disruptions that undermines the relationship sleep has with emotions and memory function.[337] Its misuse contributes to impaired cognitive function, especially seen in executive functions, attention, social cognition, and working memory.[337] However, not all illicit drug use is problematic and in some circumstances can be functional and normative.[333]

Drug use and incarceration

Substance misuse can increase negative social interactions among peers and with the general population, that can lead to contact with the justice system. Illegality can lead to punitive fines that compound poverty and build resentment, or result in incarceration,[338] placing people at high risk of recidivism.[339] A history of incarceration then becomes a problem for securing reasonable post-release accommodation, work opportunities and reintegration into society.[340, 341] Whilst incarceration poses several risks for cognition, including social isolation, stress, opportunity of head trauma and infectious disease,[342] some regard it preferable to the hardships and solitude of homelessness, thus, presenting contributors to reoffending (intended recidivism).

Social isolation and loneliness

Literature points to homelessness as largely a socially isolating experience.[343] Social isolation is a determining factor in the health of people experiencing homelessness and connects structural housing issues to health outcomes.[344] Social isolation, as a social determinant of health, parallels with homelessness, and is compounded by the inability to secure accommodation, gain employment and build social networks[344] and is recognised to influence the risk for late-life dementia.[66, 345] However, *The Lived Experience* demonstrates that 'social isolation' was a confused term that conflated personal and meaningful friendships with having contact with the homelessness workforce. For example, meeting a key worker was regarded as being socially connected. Rather, people had more clarity around concepts of loneliness, linked to a sense of social loss, few social relationships, and limited opportunities to choose with whom you socially engage with, leading to social unfulfillment.[346, 347]

Social loss and loneliness extends to living in an impoverished area where living with disadvantage frames the inequitable access that people have to social and health enhancing resources, such as public transport, employment and green spaces.[346] However, loneliness has a subjective dimension, and no two people experience it in the same way,[348] yet it has a profound baring on a person's quality of life.[349, 350] Loneliness has consequences for a range of health adversity, including depression, high systolic blood pressure and heart disease.[346] This may, in part, explain why loneliness is thought to increase the risk of dementia.[66, 351-353]

Mental health conditions

Regardless of social connectedness, the experience of depression and anxiety, among a range of mental health conditions, remains common in homelessness.[354] Data shows clear relationships between homelessness and poor mental health, and *The Lived Experience* identified high rates of a range of mental health conditions. Understanding mental health conditions, and the consequences it has for resilience, behaviours and social engagement are an important target area for dementia risk reduction as programs because good management of mental health conditions may subsequently reduce risk for developing late-life dementia.[355] This was a connection that was, in part, recognised by stakeholder participants who linked mental health to brain health, but not necessarily to risk for dementia. Depression and anxiety are the most prevalent of mental health conditions identified in *The Lived Experience* and when amendable to treatment options, it may provide opportunity for dementia risk reduction and potential to delay abnormal build-up Amyloid-Beta, the protein primarily associated with Alzheimer's disease.[356]

Sleep

A lack of having a physical, safe and secure place to sleep well is a structural barrier for health that presents a range of difficulties for maintaining cognitive wellbeing. Socioenvironmental determinants and related psychosocial stressors emerge from structural and societal factors that determine a person's housing and socioeconomic security, contributing to poor sleep quality in homelessness.

Both youth and adults experiencing homelessness face structural, environmental and economic difficulties in obtaining quality sleep.[357, 358] Difficulties arise for those experiencing primary homelessness where weather conditions, harassment, fear of violence or theft of belongings, noise and a lack of a bed are barriers to sleep.[357] These circumstances subject people to a burden of sleep-related chronic health conditions, including metabolic disease such as diabetes, hypertension and emotional distress[359] which are known to be risk factors for dementia.[66] *The Lived Experience* suggests that these factors extend to accommodation at hostels where high noise levels, anxiety, harassment and violence can continue to disrupt sleep. As sleep patterns appear to be important in the diurnal production of amyloid-bata in the brain and its nightly cycle for clearance, disordered sleep promotes a risk for late-life dementia.[360, 361] As well as long-term consequences for cognition and risk for dementia, it has further consequences for daytime functionality, with l. This is because promoting a likely association between sleep deprivation and increased risk for dementia in later life.[360-364]

Food, nutrition and cognition

The Lived Experience indicated that just as quality sleep is hard to acquire, and similar challenges present for accessing quality food. Certainly, the lack of food is associated with hunger-driven anti-social activities, such as bin-raiding or shop theft, which exposes a wider societal problem of how hunger is managed across judicial and social services, a point made within this study. But also, dietary insufficiency is a concern for cognitive health, for example, nutritional deficiencies include that of thiamine (vitamin B1), long known for its effect on cognition, and brain health in general. Thiamine deficiency interferes with the glucose metabolism required by the brain,[365] and its deficiency is compounded by alcoholism which reduces absorption, placing some of the homeless population particularly at risk. In these situations parenteral administration is considered to prevent a neurological progression to Wernicke encephalopathy and Wernicke-Korsakoff syndrome [366] that presents with severe memory deficits, disorientation and confabulation.[365-367]

Premature ageing

What was missing in *The Lived Experience* was data regarding premature ageing due to allostatic load. Allostasis is the ability of the body to maintain stability of internal and external body environments and is generally regulated by stress hormones and neurotransmitters that adjust to day to day stressors. Allostatic load occurs when those stressors and challenges overload those stress hormones and other regulators, which places them in constant use.

The result of allostatic loading can manifest in physical conditions such as heart disease, chronic illness, cancer, thereby increasing morbidity.[368] Allostatic load can be regarded as an accelerated form of ‘wear and tear’ on the body that contributes to premature ageing, a well-known phenomenon of homelessness.[172, 369] Allostatic load incurs a cumulative risk that can originate from childhood stress and poverty,[212] and premature ageing exposes people risk to geriatric conditions,[370] including dementia. Similarly, no data in *The Lived Experience* exists for poor oral health and dental decay which also increases risk for dementia,[371, 372] and is a significant problem for people experiencing homelessness.[48]

Healthcare over the life course

The data identified many situations were access to healthcare and health support would assist in alleviating or managing health conditions. However, the heath system itself is social determinant of health, with barriers to equitable access in meeting individual needs for compounded health risks.[44]

Chapter summary

Study One: *The Lived Experience* has addressed the research question ‘*How does homelessness impact cognitive wellbeing and exposure to dementia risk?’* This chapter completes a parallel convergent mixed methods examination of common characteristics associated with people experiencing homelessness. It has presented detailed methods, results and a discussion for both parts of Study One. A quantitative analysis of data from a longitudinal study examined characteristics of homelessness mapped to potentially modifiable risk factors for dementia has been completed. A qualitative component consisting of semi-structured interviews with people experiencing homelessness provided rich detail to augment the statistical data. The findings from part one and part two were integrated using a merging technique. Integrated findings were presented to show close linkage between many characteristics of homelessness and exposure to risk for dementia.

A range of physical health and mental health conditions have been identified in this study as being a consequence of homelessness. Socioeconomic factors and lifestyle issues contribute to the milieu of exposure to dementia risk showing an increased burden of risk for people experiencing homelessness.

In the next chapter, I present Study Two: *Stakeholders in Homelessness*.

CHAPTER 6: STAKEHOLDERS IN HOMELESSNESS

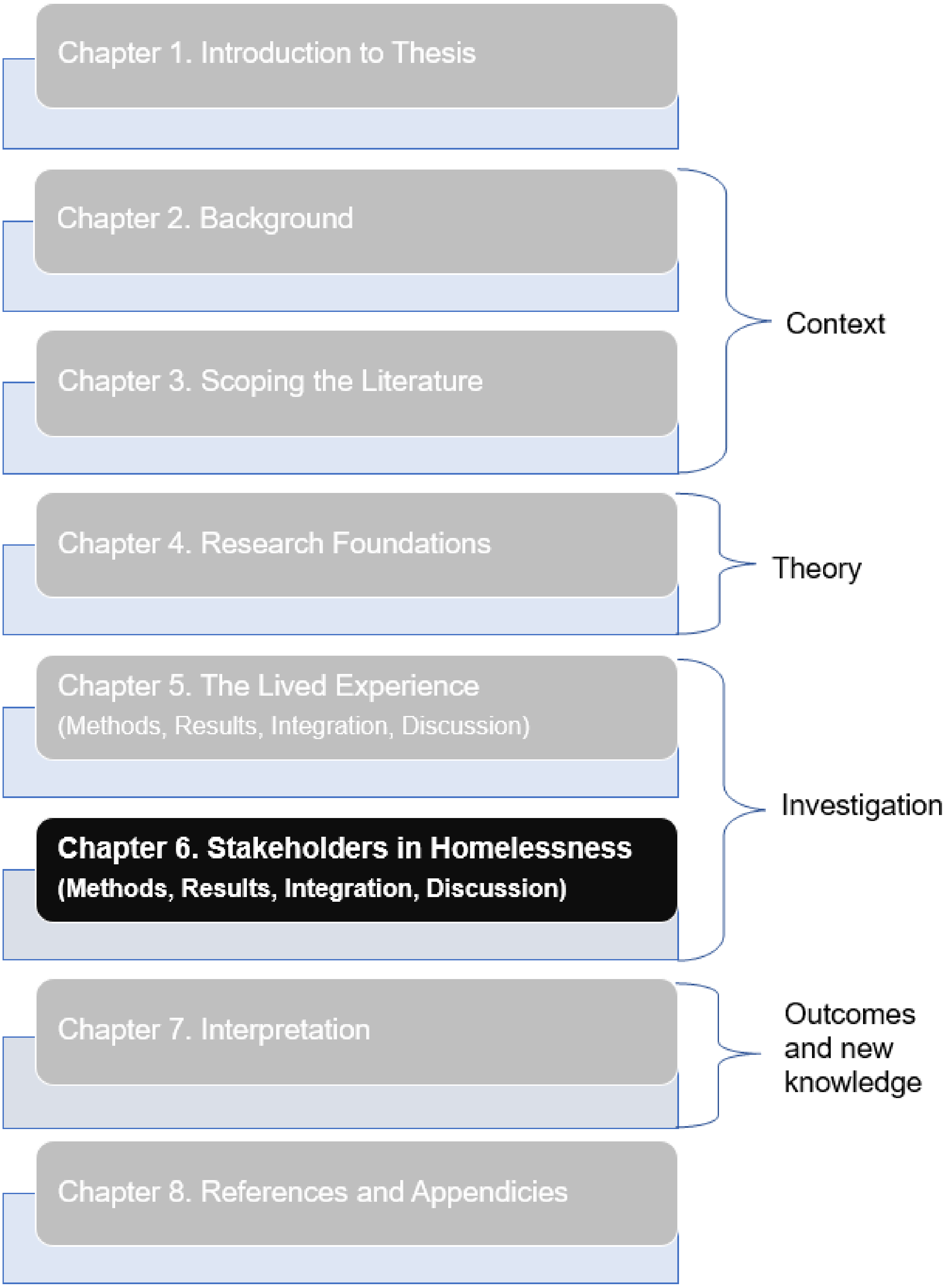


Figure 31. Thesis structure - Chapter 6

Introduction to Chapter

In this chapter, I present the second of two mixed methods studies. It is presented in four parts, as follows:

- **Study Two, Part One (Quantitative)**
    - Introduction
    - Methods
    - Results
- **Study Two, Part Two (Qualitative)**
    - Introduction
    - Methods
    - Results
- **The Data Integration**
- **Integrative Discussion**

This chapter describes an explanatory sequential mixed methods study focussed on key stakeholders in homelessness and is the second study in this thesis. The design for *Stakeholders in Homelessness* was previously described in Chapter 4. In this chapter I will reiterate the research question, aims and objectives of this study. I then present Study Two, Part One, methods and results followed by part Two methods and results. Following this, I discuss how sequential nature of Study Two determines a multi-level data integration. The data integration is particularly relevant in how Part One quantitative data informs the questions posed in the Part Two qualitative phase and integrates with the final study findings. Finally, I will describe the integrated findings.

Stakeholders in Homelessness will address the research question: *How can dementia risk reduction for people experiencing homelessness be improved?* It has the following research aims and objectives (as outlined in Chapter 1):

Aims

- To understand dementia knowledge in services to people experiencing homelessness.
- To describe how cognitive wellbeing and dementia risk reduction strategies may be supported and improved.

-

Objectives

- Quantify the level of dementia knowledge in a cohort of specialist homelessness services in South Australia.
- Synthesize data gathered from stakeholders to improve understanding of barriers and facilitators to dementia risk reduction.

In this explanatory sequential mixed methods design the quantitative data is collected first and then analysed. The findings from the quantitative analysis are used to frame the questions for the qualitative interviews which comprise the second data collection. Data integration is an integral part of this process and will be explained in detail later in the chapter.

Applying the methodological lens of the transformative approach

In Chapter 4, I introduced the transformative approach as the methodological lens engaged for Study Two: *Stakeholders in Homelessness*. This lens will help guide the study approach, the integration and interpretive discussion of the study findings. In line with social research and the methodological design of this explanatory mixed methods study, the transformative approach lens ensures that the methodology and methods are sensitive to the needs and outcomes of marginalised communities.[266] The explanatory sequential mixed methods suit the transformative approach lens applied to *Stakeholders in Homelessness* because it necessitates that the research follows a set of transformative principles including advocacy and concern for the human condition [50, 266]. It is this methodological perspective that edifies how the emphasis is placed upon data integration and how the research is conducted.

The aims of Study Two: *Stakeholders in Homelessness* are, in part, identifying a community needs assessment.[268] It identifies and evaluates gaps in dementia knowledge and dementia risk reduction in a cohort of stakeholders providing services to people experiencing homelessness and explores knowledge gaps to consider how dementia risk reduction interventions can be best communicated and encouraged. The study is action-orientated in seeking change where actions should be strengths-based, and not focussed on deficit, when meeting transformative axiological assumptions.[51] Therefore, to fully understand barriers to dementia risk reduction and where possible, generate workable actions to overcome them, the research must reference and reflect on the resilience and capabilities of people experiencing homelessness and stakeholders. To evaluate the dementia knowledge in the homelessness sector and subsequently negate or minimise barriers to improve the cognitive wellbeing of clients through pragmatic, transformative actions comply with the Study Two research aims. Study Two, Part One will be discussed in the following section and move through the methods, results and discussion.

Study Two, Part One: Stakeholders in Homelessness

The study design for Study Two, Part One: *Stakeholders in Homelessness* is presented in Figure 32. Part One comprises a quantitative, cross sectional study on dementia knowledge circulated to the South Australian homelessness workforce.

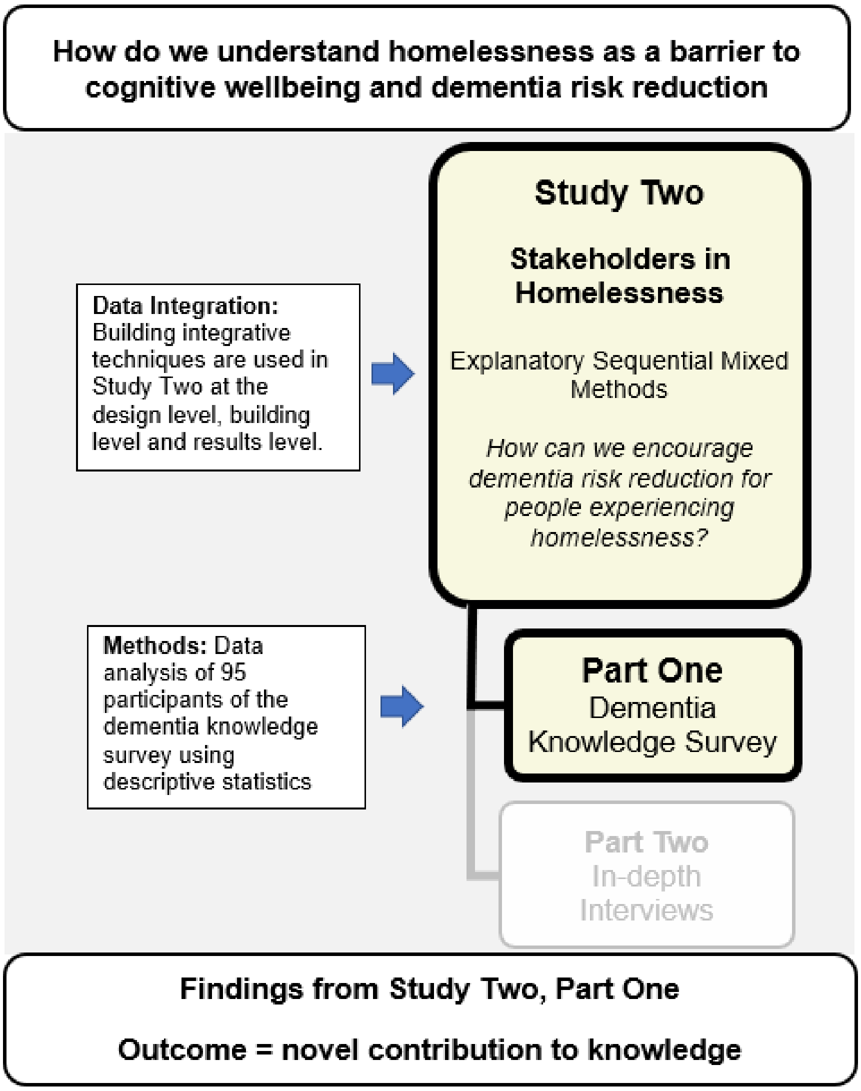


Figure 32. Study design for Study Two, Part One

I begin this section with a description of the Dementia Knowledge Assessment Survey (DKAS) used for the Study Two, Part One, data collection.

Dementia Knowledge Assessment Scale Survey

As a response to the World Health Organisation call for greater dementia awareness and education,[373] the Wicking Dementia Research and Education Centre at the University of Tasmania developed a reliable and validated survey as a tool for assessing dementia knowledge.[374] The DKAS survey addresses limitations of previous knowledge scales that were focussed on biomedical knowledge, support knowledge evaluation in diverse populations and to inform educational development.[374, 375] The DKAS survey was developed through a battery of stages including psychometric evaluation and a principal component analysis to provide a conceptually robust 25-item scale that supported the four domains of dementia causes and characteristics, communication and engagement, care needs, and risks and health promotion.[376] The DKAS validation process identified sound internal consistency (coefficient of reliability) as measured by Cronbach's Alpha ($\alpha = .85$) without redundancy. Sub-scale Cronbach Alpha scores ranging between .65 to .75, providing consistency with similar validated scales, again without redundancy or any duplication across themes.[374, 375] The survey was further validated across a sample of health care workers with low dementia understanding, and a group of medical students before and after an aged care placement, and was found to be sensitive to change in dementia knowledge.[374] In 2017, the DKAS was tested amongst 3649 volunteers attending a dementia Massive Open Online Course (MOOC), further confirming its reliability and sensitivity.[376]

The Dementia Knowledge Assessment Survey (DKAS survey) (Appendix 2) is a validated quantitative tool designed to elucidate dementia knowledge. It contains 25 statements about dementia that are verifiably correct or incorrect, presented on a 5-point Likert-type scale of 'false' (1), 'probably false' (2), 'probably true' (3), 'true' (4), and 'don't know' (5).[375] Dementia knowledge is measured across four distinct domains (causes and characteristics, communication and behaviour, care considerations, and risks and health promotion), and provides good discrimination between cohorts of survey participants who would likely have differing levels of dementia knowledge.[375]

Methods – Study Two, Part One: Stakeholders in Homelessness

The methods are in-line with explanatory sequential mixed methods. Study Two, Part One, explains the first data collection, which is quantitative. The methods for Study Two, Part One are shown in Figure 33.

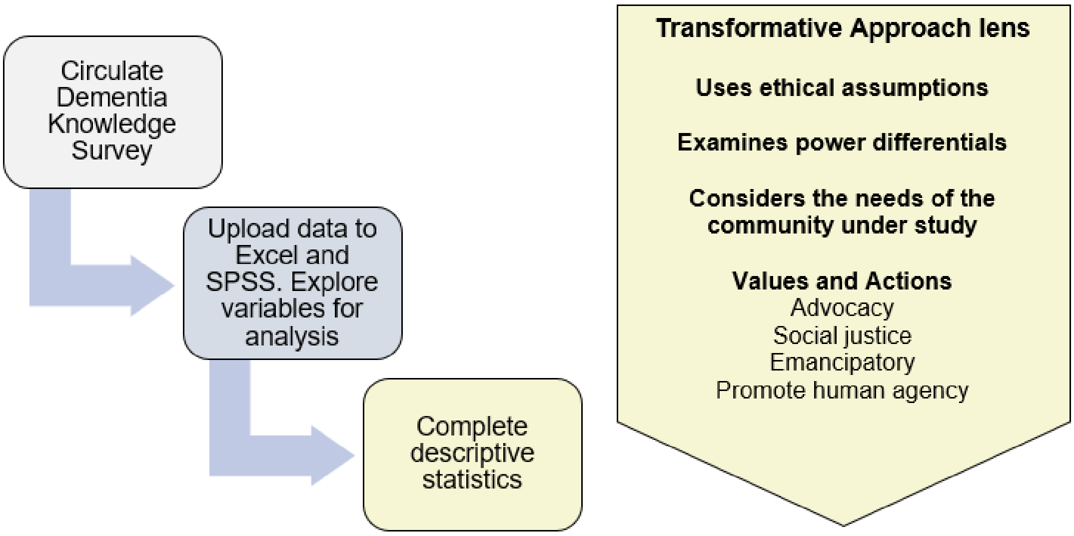


Figure 33. Methods for Study Two, Part One: *Stakeholders in Homelessness*

Participants and Recruitment

An email invitation for participation (Appendix 4) was sent to key homelessness services listed on the SA Government homelessness service provider directory in September 2020. Participation was voluntary and anonymous. Inclusion and exclusion criteria are now described.

Inclusion criteria

- All paid and unpaid staff working at homelessness services in South Australia.
- Stakeholders working with homelessness services and their client groups in South Australia.

Exclusion criteria

- Any person who did not understand the information about the purpose of the survey, supplied in the information sheet.

Data collection

Stakeholders completed the survey via an online link to a Qualtrics XM[377] survey or by using a hard-copy form at their workplace. A total of 60 hard-copy surveys were either mailed out or hand delivered to homelessness services depending on service location, requesting that completed hard copy forms containing no identifying information were placed in a universal envelope that was either collected by the researcher or returned by mail. In addition, eight emails were sent to regional homelessness services in South Australia containing the Qualtrics XM link with the request that it be circulated among staff. A four-week time frame was provided before the close of the survey, after which all hard-copy surveys were collected or received in the mail. Surveys that were completed using Qualtrics XM were exported into Microsoft Corporation Excel Spreadsheet (Excel hereafter) with hard-copy data manually added. All data was then uploaded into IBM SPSS analytical software.

Data management

Data were classified into three occupational groups for analysis: (i) social work (employed by homelessness service), (ii) allied health (employed by homelessness service), or (iii) volunteer or other service (working in the homelessness sector but not directly employed by a homelessness service). 'Other' represented those working in adjunct services, including drug and alcohol services, community mental health services, other visiting professional services, music and art therapy, and those who had a substantial presence within homelessness services or volunteered in homelessness services. Survey participants were asked to classify their service work environments. as (i) homelessness service with a short and medium-term residential capacity of up to six weeks, (ii) non-residential homelessness service (providing daytime services only with no accommodation), and (iii) other service. 'Other' provided an option for secondary environments linked to working directly with homelessness services including social housing services for people who would otherwise be homeless. Gender and age were not considered relevant demographics and were excluded from the survey.

Measure used for scoring the Dementia Knowledge Assessment Survey

The DKAS 25-item scale and scoring guide was used for reference (Appendix 2). Subscale and item scores were measured.[374, 375, 378, 379] Scoring responses to the DKAS involved recoding and calculation of subscales and item scores to provide a total individual score within a range of 1 to 50. First, answers were labelled as follows: 'False' = 1, 'Probably false' = 2, 'Probably true' = 3, ‘True’ = 4, and ‘I don’t know’ = 5. Second, once all answers were categorised, the data was then recoded using the syntax function of SPSS as follows:

- Score 2 points for an answer of ‘true’ to a truthful (true) statement.
- Score 2 points for an answer of ‘false’ to an untrue (false) statement.
- Score 1 point for an answer of ‘probably true’ to a truthful (true) statement.
- Score 1 point for an answer of ‘probably false’ to an untrue (false) statement.
- Score 0 points for an answer of ‘true’ or ‘probably true’ to an untrue (false) statement.
- Score 0 points for an answer of ‘false’ or ‘probably false’ to a truthful (true) statement.
- Score 0 points for an answer of ‘I don’t know’.

Once recoded, the sum items provided a total score out of a maximum score of 50 points. A score of 45/50 represents comprehensive dementia knowledge, typically accomplished by ten per cent of allied health professionals prior to undertaking an Understanding Dementia Massive Open Online Course.[380]

Data Analysis

Ninety-five stakeholders completed DKAS Surveys were received and entered into IBM SPSS for quantitative data analysis. Incomplete surveys (*n*=9) were excluded from data analysis due to being substantially incomplete (> 30% missing data and represented abandoned surveys). Descriptive statistics of survey data (frequencies, means, percentages, standard deviation) were calculated using Microsoft Excel spreadsheet (Excel version 2203) and IBM SPSS (version 27). Measures of centrality and dispersion were calculated, and an Analysis of Variance (ANOVA) test was undertaken to compare dementia knowledge between occupational groups. Outliers were defined as >2 standard deviations of variability from the mean using 1.5 multiplier in SPSS boxplot. Due to a marginal skew (.455 with std error of skewness .247), a non-parametric Kruskal-Wallis one-way analysis of variance was also completed. A Tukey honest significance post-hoc test was completed as a single-step multi-comparison test to compare difference between the group means.

Results of Study Two, Part One: Stakeholders in Homelessness

A total of 104 surveys were returned with 91.4% (*n*=95) fully completed and included for analysis. Of surveys included 49.5% (*n*=47) were returned electronically and 51.6% (*n*=48) returned as hard copy.

Sample characteristics

Respondents were asked their occupational role and work setting. 28.4% of respondents identified as Allied Health professionals (*n*=27), with 28.1% of this group working in non-residential homelessness settings (*n*=9), 14.8% in homelessness settings with a residential capacity (*n*=4), and 51.9% providing other services to homelessness (*n*=14). 41.1% of all respondents were in social work (*n*=39), with 35.9% of this group working in non-residential homelessness settings (*n*=14), 35.9% working in homelessness settings with a residential capacity (*n*=14), and 28.2% providing other (adjunct) services to homelessness. Finally, 30.5% of all respondents identified as volunteers/other (*n*=29), with 31.0% working in non-residential homelessness settings (*n*=11), another 31.0% working in homelessness settings with a residential capacity (*n*=11), and 37.9% providing other services to homelessness.

Across the whole sample, the DKAS mean score was 24.8 (standard deviation (SD): 10.1) with a range between 8 and 46, out of a possible score of 50. The items with the lowest mean scores across all sample were '*Blood vessel disease (vascular dementia) is the most common form of dementia*' with 66.3% (*n*=63) respondents providing an 'I don't know', or an incorrect answer; '*The sudden onset of cognitive problems is characteristic of common forms of dementia*' with 63.2% (*n*=60) respondents providing an 'I don't know', or an incorrect answer; '*Medications are the most effective way of treating behavioural symptoms of dementia*' with 63.2% (*n*=60) respondents providing an 'I don't know', or an incorrect answer; and '*having high blood pressure increases a person's risk of developing dementia*' with 54.7% (*n*=52) respondents providing an 'I don't know', or an incorrect answer.

Conversely, across all the sample, respondents performed best on the following survey statements *'Exercise is generally beneficial for people experiencing dementia'* with 89.7% (*n*=85) respondents provided an answer that was correct or ‘probably’ correct. For *‘People with advanced dementia may have difficulty speaking’,* 87.4% (*n*=83) respondents provided a correct or ‘probably’ correct answer. For *‘Symptoms of depression can be mistaken for symptoms of dementia’,* 84.2% (*n*=80) respondents provided a correct or ‘probably’ correct ‘answer; and finally, for *‘People experiencing dementia often have difficulties learning new skills’, 81.1% (n=77)* respondents provided a correct or ‘probably’ correct answer. The whole sample results showed a marginally right skew of .455 (Std error of skewness .247), bimodal distribution observed with no outliers. A statistically significant Shapiro-Wilk test of normality (p<0.001) indicated that the data deviated from a normal distribution.

Group comparisons

Comparisons were made of the mean scores stratified by occupational group which are presented in Table 12. Results of a one-way ANOVA demonstrated a statistically significant difference between group mean scores (F (2,92)=6.41, *p*=0.002, 95% confidence interval (CI): 22.81, 26.90), shown in Figure 34.

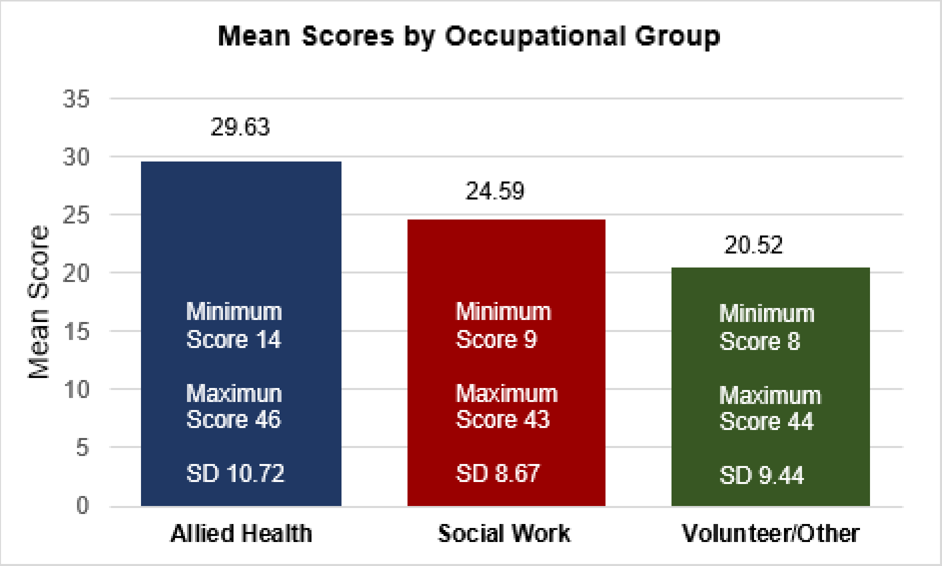


Figure 34. Mean, Standard Deviation, Minimum and Maximum scores by occupational group

Histograms were developed to show whole sample and occupational data distribution (Figure 35). A non-normally distributed pattern was observed in the whole sample (Figure 35.1). However, histograms for each occupational group showed a multimodal distribution seen in the allied health comprising three discrete peaks, with a centrally dominant kurtosis of -1.421 (std error 0.872)

(Figure 35.2). This compares with the unimodal distribution seen in both Social Work, (Figure 35.3) and volunteer/others (Figure 35.4), however, both observed a marginally right (positive) skew at 0.262 (std error 0.378) and 1.174 (std error 0.434) respectively. A narrower range of mean was observed in allied health at 32 (14 – 46) than in social work at 34 (9-43), with the widest dispersion of mean noted in volunteer/others at 36 (8-44).

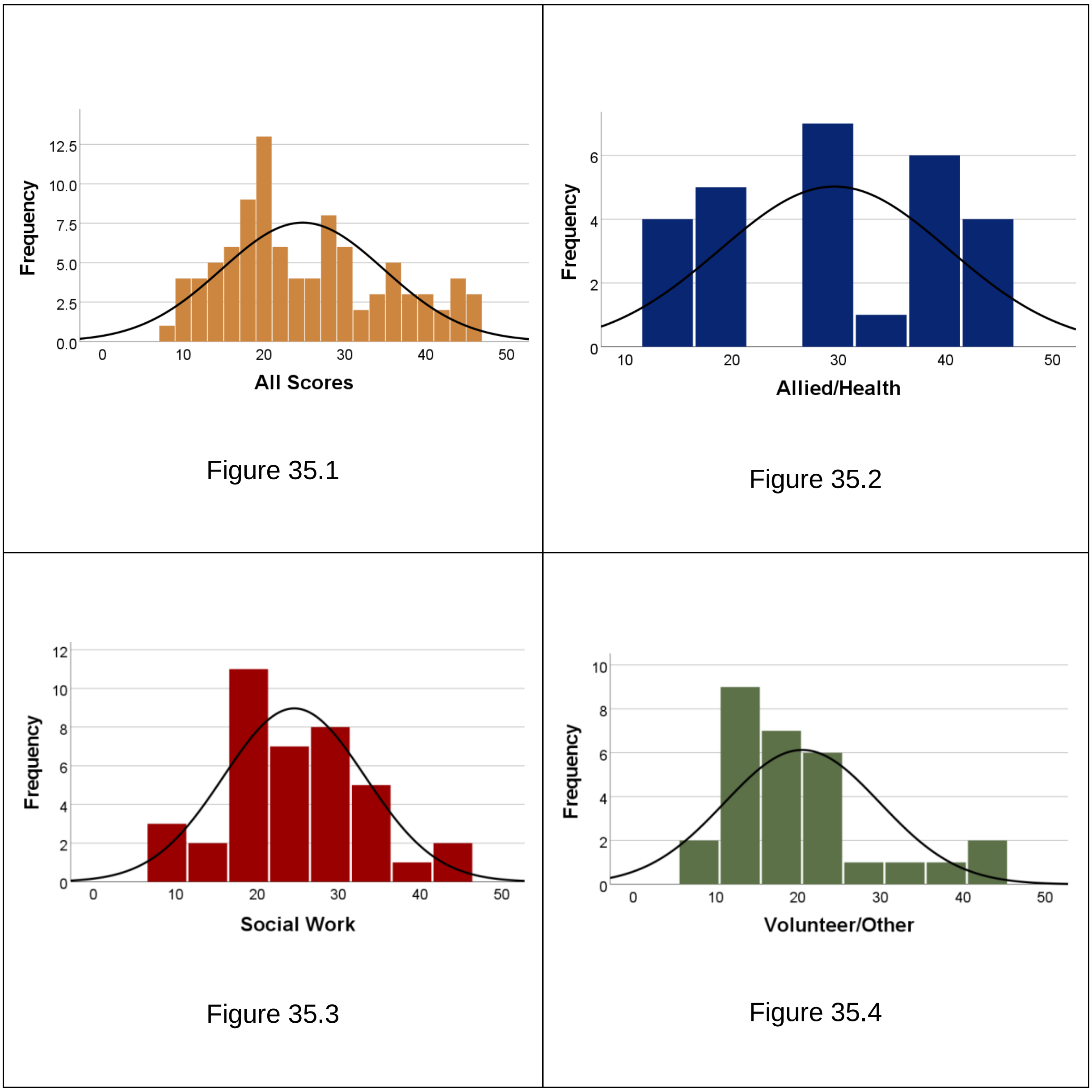


Figure 35.1

Figure 35.2

Figure 35.3

Figure 35.4

Figure 35. Histograms of data distribution

Due to the non-normally distributed data, a comparison between groups was conducted using the non-parametric Kruskal-Wallis test, which confirmed a statistical difference in the mean across the three occupational groups (H=10.523, X^2=5.991, *p*=0.005). A Bonferroni corrected post-hoc Tukey test indicated that there was no statistically significant difference between the mean of the allied health group and social work group or between the social work and volunteer/other group, suggesting mean score differences were unremarkable between these groups. However, there was a statistically significant difference between the mean of the Allied Health group and the Volunteer/Other groups (95% CI), with Allied Health professionals scoring significantly higher (indicating greater knowledge) than the volunteers and other professionals. A Tukey honest significance difference (HSD) post-hoc test was taken to confirm if this difference in mean exists within the groups, shown in Table 13.

Table 13. Tukey comparisons between occupational groups

Tukey Honest Significance Difference				95% Confidence Interval	
		Mean Difference	P (Significance)	Lower Bound	Upper Bound
Allied Health	Social Work	4.97	.096	-.68	10.63
Social Work	Allied Health	-4.97	.096	-10.63	.68
Volunteer/Other	Allied Health	-9.01	.002	-15.05	-2.97

The Allied Health group consistently recorded a higher percentage of correct or ‘probably’ correct scores across all four knowledge domains when compared to the social work and volunteer/other groups. The knowledge domain of *Communication and Behaviour* attracted the lowest percentages of correct or ‘probably’ correct responses across all groups, with allied health at 69%, social work at 59%, and volunteer/other at 48%, marking a 21% difference between the highest and lowest scores. Conversely, all occupational groups performed best across the knowledge domain of care considerations, with just 14% difference between the highest (allied health) and lowest (volunteer/other) scores. Combined scores for the four dementia knowledge domains, stratified by occupational group and shown in Table 14.

Table 14: Scores for dementia knowledge domains categorised by occupational group

n=number of questions x respondents		
Causes and Characteristics - 7 x *DKAS Survey questions		
Occupational role.	Combined correct or probably correct scores	Combined incorrect, ‘probably’ incorrect, or ‘did not know’ scores
Allied Health (*n*=189)	75% (*n*=142)	25% (*n*=47)
Social Work (*n*=273)	60% (*n*=164)	40% (*n*=109)
Volunteer/Other (*n*=203)	58% (*n*=117)	42% (*n*=86)
Risks and Health Promotion - 6 x *DKAS Survey questions		
Occupational role.	Combined correct or probably correct scores	Combined incorrect, ‘probably’ incorrect, or ‘did not know’ scores
Allied Health (*n*=162)	70% (*n*=114)	30% (*n*=48)
Social Work (*n*=234)	65% (*n*=152)	35% (*n*= 82)
Volunteer/Other (*n*=174)	56% (*n*=98)	44% (*n*= 76)
Communication and Behaviours - 6 x *DKAS Survey questions		
Occupational role.	Combined correct or probably correct scores	Combined incorrect, ‘probably’ incorrect, or ‘did not know’ scores
Allied Health (*n*=162)	69% (*n*=112)	31% (*n*=50)
Social Work (*n*=234)	59% (*n*=137)	41% (*n*=97)
Volunteer/Other (*n*=174)	48% (*n*=83)	52% (*n*=91)
Care Considerations - 6 x *DKAS Survey questions		
Occupational role.	Combined correct or probably correct scores	Combined incorrect, ‘probably’ incorrect, or ‘did not know’ scores
Allied Health (*n*=162)	89% (*n*=144)	11% (*n*=18)
Social Work (*n*=234)	78% (*n*=183)	22% (*n*=51)
Volunteer/Other (*n*=174)	75% (*n*=130)	25% (*n*=44)

*DKAS = Dementia Knowledge Assessment Scale

A focus on risk factors and health promotion

The domain of *Risk Factors and Health Promotion* hold specific relevance to the research question and the six DKAS questions provide an insight into the risk reduction knowledge of the South Australian homelessness sector. More than half (56.8%, *n*=54) of the whole sample did not recognise hypertension as a modifiable risk factor for dementia, with 17.9% (*n*=17) who definitively did. 36.8% (*n*=35) identified that they understood the importance of healthy lifestyles in reducing dementia risk, however, when combined with those who gave a partially correct answer, this rose to 71.6% (*n*=68). That symptoms of depression can be mistaken as symptoms of dementia was known by 45.3% (*n*=43), or, when combined with partially correct answers, by 88.42% of respondents. More than half understood exercise to be beneficial for those living with dementia

(50.5%, *n*=48), however, just over half (58.9%, *n*=56) understood the importance of an early diagnosis in improving quality of life. More than two thirds of the respondents (70.5% *n*=67) mistook sudden cognitive problems as being characteristic of dementia, with just less than a third of respondents (29.5%, *n*=28) providing a correct or partially correct answer. Risk and health promotion statistics are presented in Table 15.

Table 15. Risk Factors and Health Promotion domain

Risk Factors and Health Promotion	**Wrong answer**	**Partially correct**	**Correct**
Question			
Having high blood pressure increases a person's risk of developing dementia.	56.8% (*n*=54)	25.3% (*n*=24)	17.9% (*n*=17)
Maintaining a healthy lifestyle does NOT reduce the risk of developing the most common types of dementia.	28.4% (*n*=27)	34.7% (*n*=33)	36.8% (*n*=35)
Symptoms of depression can be mistaken for symptoms of dementia.	12.6% (*n*=12)	42.1% (*n*=40)	45.3% (*n*=43)
Exercise is generally beneficial for people experiencing dementia.	7.4% (*n*=7)	42.1% (*n*=40)	50.5% (*n*=48)
Early diagnosis of dementia does NOT generally improve quality of life for people experiencing the condition.	41.1% (*n*=39)	30.5% (*n*=29)	28.4% (*n*=27)
The sudden onset of cognitive problems is characteristic of common forms of dementia.	70.5% (*n*=67)	17.9% (*n*=17)	11.6% (*n*=11)

Of importance is how these quantitative data results inform the methods used in Study Two, Part Two. This is part of the data integration process that I discuss later in this chapter. First, I now move to Study Two, Part Two methods and results.

Study Two, Part Two: Stakeholders in Homelessness

Study design for Study Two, Part Two: *Stakeholders in Homelessness* is shown in Figure 36.

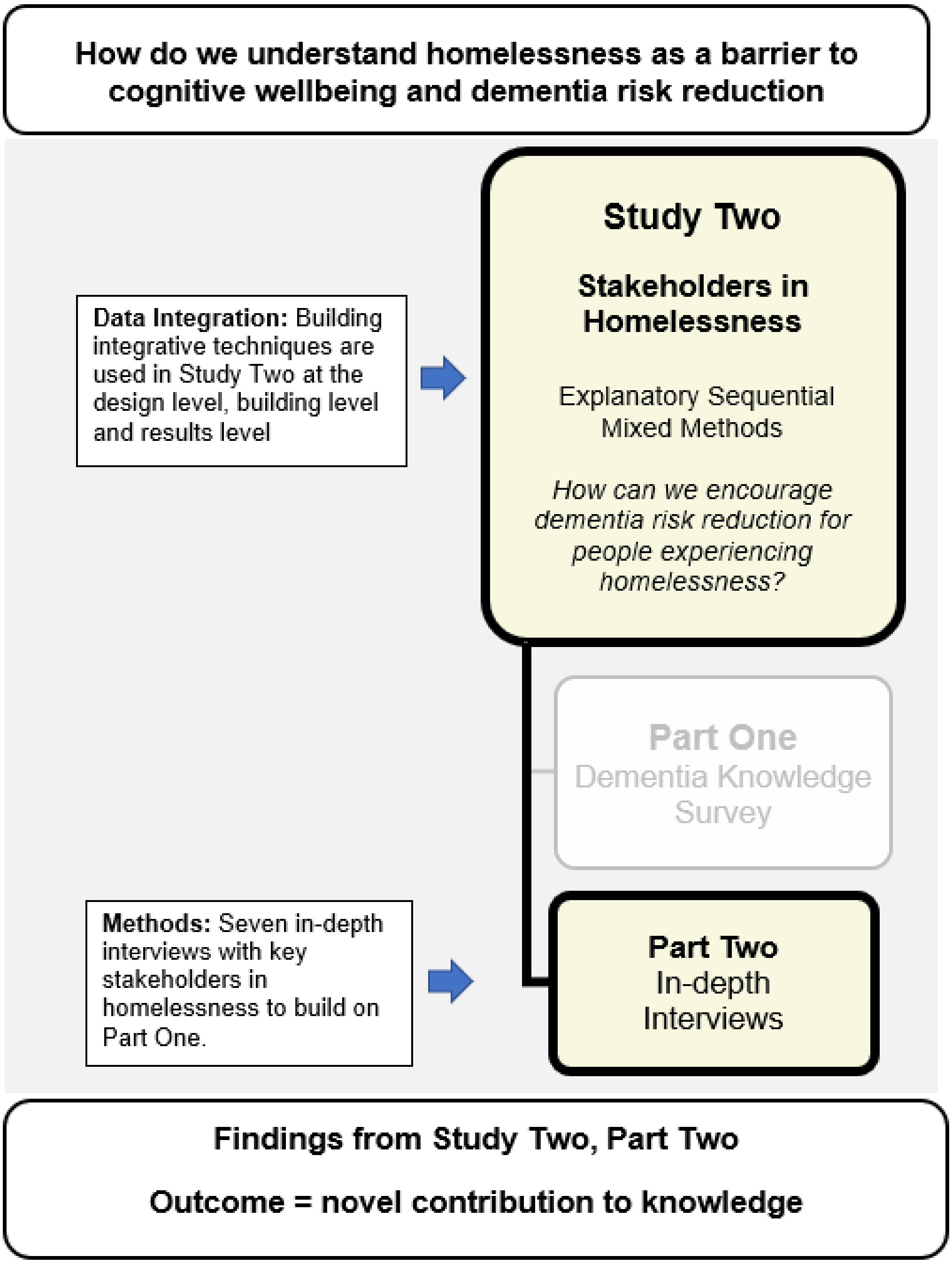


Figure 36. Study design for Study Two, Part Two

In line with the explanatory sequential mixed methods design for *Stakeholders in Homelessness,* Study Two, Part Two focusses upon qualitative data collection with the purpose of explaining the quantitative findings of part one.

Methods for Study Two, Part Two: Stakeholders in Homelessness

Methods for Study Two, Part Two: *Stakeholders in Homelessness* is shown in Figure 37.

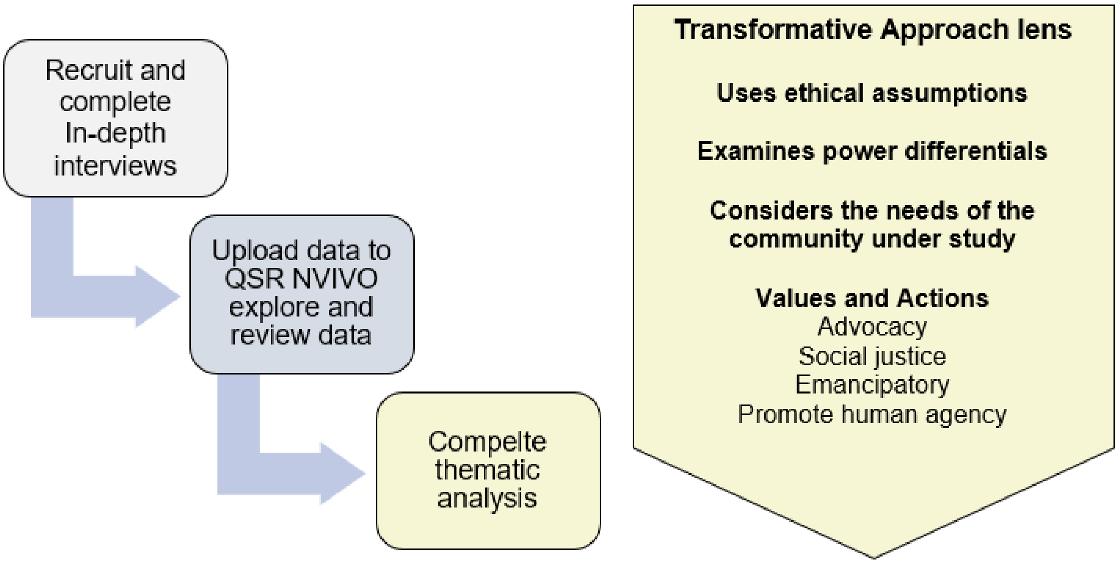


Figure 37. Methods for Study Two, Part Two: *Stakeholders in Homelessness*

Participants and Recruitment

Purposive participant recruitment targeted representation from key stakeholders. This was dependent on their position, willingness, and homelessness service type who agreed to participate in the in-depth interviews to build on the DKAS survey findings through discussion. In Study Two, Part One and Part Two data sets were likely connected through the sampling frame as participants had previously been invited to complete the anonymous dementia survey. However, survey content could not be linked to a potential interview participant due to the anonymous nature of the survey. Furthermore, agreement to participate in an interview was not contingent on having completed the dementia knowledge survey. Priority was instead placed on key stakeholders' who were in positions that could build on the quantitative findings and who could potentially implement transformative change.

Potential participants were approached and invited to participate directly, either by email or by telephone and asked for a follow-up interview following the DKAS survey invitation. An introduction to the research was provided in both written and verbal form. An overview of the study design was explained, and the purpose of the in-depth interviews to elucidate a deeper understanding on dementia knowledge within homelessness services and the perceived or known barriers and enablers to dementia risk reduction in the homelessness sector was explained. The benefits of contributing to the research were outlined, and potential participants were afforded time to consider if they wanted to contribute their expertise or ask questions related to participating. Once potential participants confirmed their willingness to participate in the in-depth interviews, arrangements for time and place were made, working around stakeholder preference for face-to-face or online interviews.

Inclusion criteria

- Key stakeholders in homelessness willing to participate in in-depth interviews.

Exclusion criteria

- Any person who did not understand the information about the purpose of the survey supplied in the information sheet.

Data collection

In-depth interviews were the chosen data collection method because they provide the flexibility of being unstructured, allowing free-flowing discussion on themes that need to be explored using follow-up questions to provide greater clarity, depth and understanding.[381] Discursive interviews provided an opportunity to explore topics and themes beyond a Likert-scale type answer and move discussion into an exploratory dialogue. For example, health promotion requires some knowledge of dementia types, and of mechanisms underpinning risk reduction in modifiable risk exposures.

Interviews followed an initial, broad question guide developed from the findings of part one. Questions posed were flexible and adjusted to the discussion. All interviews were carried out between January 2021 and April 2021, conducted face-to-face at a time and place convenient to interview participants, and completed over a 60-to-90-minute duration.

Data saturation

An arbitrary initial target was to have eight key stakeholders contributing to discussion in the in-depth interviews and then assess for data saturation to determine if a second wave of interviews was required. A total of seven key stakeholders agreed to participate, with one unable to commit to a time frame, therefore, data saturation was assessed at this point. The criteria for meeting data saturation was the same method used for Study One, Part Two in Chapter 5: *The Lived Experience*. This was measured through the coding process in QSR NVivo where data saturation was assessed as achieved because discussions added to the frequency of which a pre-existing topic or theme was discussed, rather than generating new themes and sub-themes.

Data management

Interviews were de-identified, transcribed verbatim and uploaded into QSR NVivo. Unlike Study One interview participants (where it was important to project the human condition), Study Two interview participants were not allocated pseudonyms. Instead, individual transcripts were allocated an identity number (1-7) and allocated initials to indicate the work environment with HR (homelessness service with residential capacity), NR (non-residential homelessness service, and OS (other service working substantially in homelessness, but not employed by homelessness services), specifically, a dementia educator who supported staff and other professionals working in the homelessness sector, and a community mental health provider whose work considerably linked them to various homelessness services. The work environment was required to help analyse where potential opportunities for improved dementia knowledge or risk reduction could be identified and initiative implemented. All parts of the stakeholder interview transcripts were coded in QSR NVivo.

Data Analysis

Data analysis was completed using QSR NVivo and largely followed the same process than that used in Study One, Part Two: *The Lived Experience.* The sequential nature of the mixed methods design meant initial themes were largely pre-determined from the integrative process, consisting of gaps, barriers, facilitators and opportunities. I used Braun and Clarke's (2006) thematic analysis[306] to identify additional themes and sub-themes that developed from the discussions. Braun and Clarke's (2006) thematic analysis is previously discussed in Chapter 5, and its use in *Stakeholders in Homelessness* was procedurally similar.

Analysis was conducted from a transformative lens, grounded in principles of social justice and advocacy for people experiencing homelessness. For example, stakeholders defined their roles as seeking to improve client circumstance, alleviate health inequities and emphasise client wellbeing through their individual actions and collective services. Emphasis was placed upon generating discussion to redress inequitable cognitive impact and promote opportunities for dementia risk reduction by diminishing barriers to dementia risk reduction. Data analysis using a transformative lens therefore examines the discourse for actions with transformative value. For example, inspecting a clients belongings for illicit substances holds no transformative value, but providing people the means to access peer learning for computer skills that can advance their re-engagement in society and build self-worth does have a transformative value.[382]

To assist with the data analysis, a concept map was developed in QSR NVivo and used to identify connections between themes and sub-themes in the transcripts. This provided a visualisation of the strength and frequency of discussion placed on a specific topic and their connections between those themes. The concept map (Figure 38) was also used to provide an indication of when data saturation was reached because information could be graphically mapped to show no new inclusions.

This section concludes the methods for Study Two, Part Two. Next, I will move to the qualitative results.

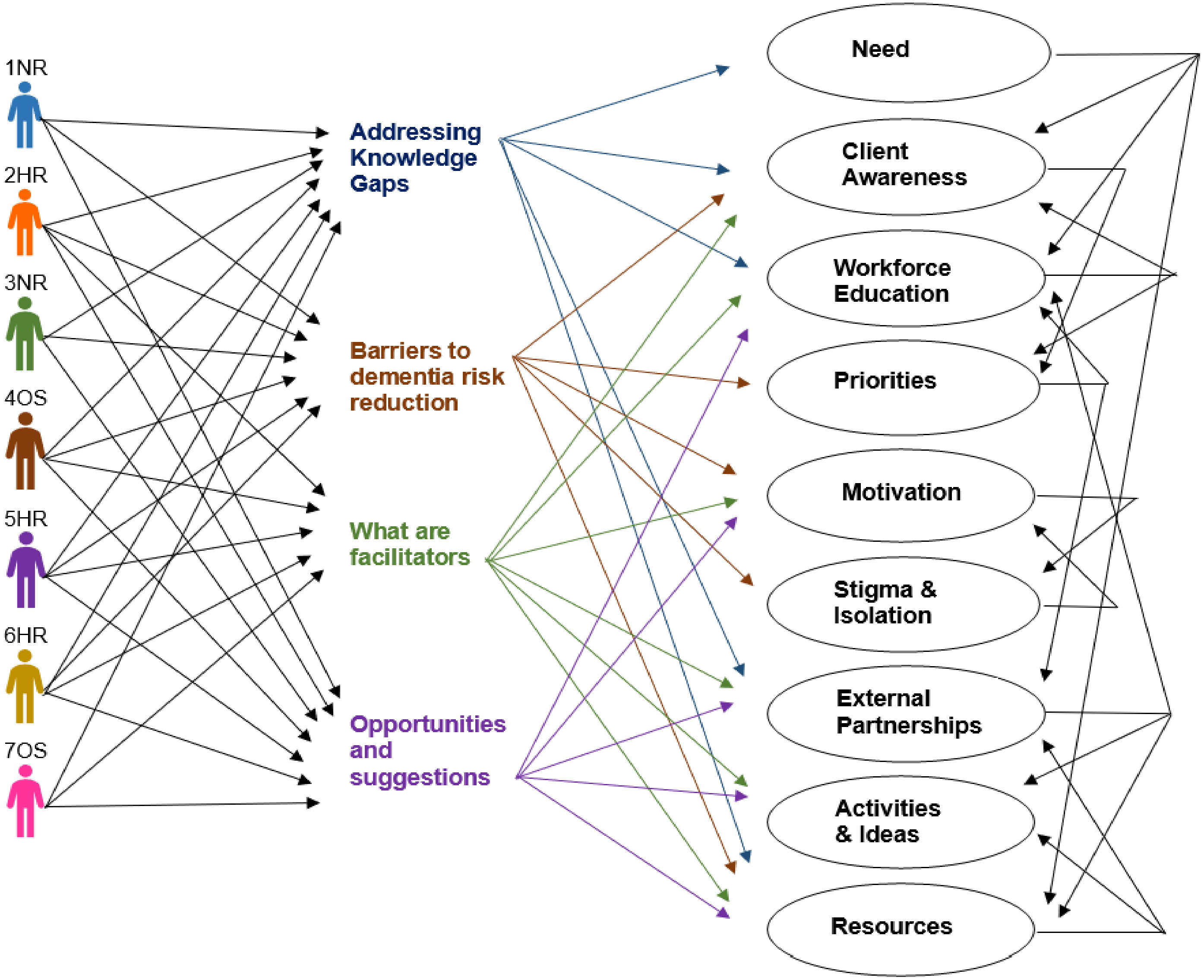


Figure 38. Concept map for data analysis developed in QSR NVivo

Results of Study Two Part Two: Stakeholders in Homelessness

Seven key stakeholders consented to being interviewed which were audio recorded and subsequently transcribed.

Characteristics of the participants

From the seven in-depth interviews, four stakeholders were from metropolitan homelessness services, one was from a regional South Australian homelessness service (non-residential homelessness service), and two stakeholders provided services within the homelessness sector but were not directly employed by them. The expertise of the stakeholders was high, with every participant having had more than ten years' experience in working in the sector or in a service delivery capacity. Skills and positions of stakeholders varied across executive, middle managerial positions, and team leaders or program managers.

Approach

All stakeholders were receptive to participating in an in-depth discussion situated within transformative principles of social justice and advocacy for people experiencing homelessness. For example, the question was posed as *"How will this improve agency for people experiencing homelessness…"* or "*What improvements for people experiencing homelessness could be made regarding…"* or "*How do we co-design this activity with people experiencing homelessness*…" Similarly, all stakeholders were agreeable towards exploring broad issues surrounding cognitive wellbeing and dementia risk reduction in the context of homelessness. Interview questions posed to stakeholders used to open discussion and followed the themes of gaps, barriers, facilitators and opportunities generated from the 'building' stage of data integration. Results are presented using these four themes; however, stakeholders' transcripts were analysed using Braun and Clarkes (2006) thematic analysis to further identify what sub-themes or additional themes emerged. The stepped process for stakeholder interviews is shown in Table 16 which presents the key points of the analysis using Braun and Clarke (2006).[306]

Table 16. Process for stakeholder Interviews

Questions	Themes from analysis	Discussion Summary	Transformative outcomes
How can dementia knowledge and risk reduction awareness be elevated across the workforce to benefit clients?	Gaps	Need to professional development to increase dementia awareness and understanding of dementia risk reduction. Understanding differences to mental health. Translating knowledge into brain healthy messaging and resources for clients.	Workforce development should target dementia knowledge and increase understanding of risk reduction. Need to have defined pathways to access information on behalf of clients.
Is there an identified need to implement dementia risk reduction in homelessness service supports?	Gaps	Workforce observations of cognitive difficulties in client groups. Understanding of early intervention when risk is modifiable. Ageing client group. Seeing the cognitive effects of drugs and alcohol misuse.	Need is identified – this is an ageing and cognitively vulnerable client group. Review programs to reflect brain health messaging and risk reduction.
What prevents discussions on dementia risk and risk reduction between workforce and clients, and how can they be addressed?	Barriers	Hard to engage clients on topic. Time pressures and priorities in other areas. Limited workforce understanding of dementia and risk reduction. Not been a focus for client programs. Deprioritised need. Clients being isolated, low education levels, not seen as a priority, not wanting to engage with topic. Access to services. Disconnect between client and service provider.	Added value for clients and encourage engagement. Risk reduction introduced built into social programs offered to engage clients. Need to normalise discussions with clients. Encourage clients to see value in brain health.
What barriers exist for clients to engage with dementia risk reduction strategies and how do we overcome them?	Barriers	Motivation to engage. Stigma and fear of labelling. Lack of awareness. Not recognising need. Brain health regarded unimportant in acute homelessness situations.	Need to destigmatise dementia and risk reduction. Need to reprioritise and emphasise brain health and with ageing clients.
What improvements for people experiencing homelessness could be made to raise their awareness of dementia risk and risk reduction?	Facilitators	Having more general knowledge of dementia and better workforce education. Working with external services who specialise in dementia. Have expert guest speakers (appropriately pitched for clients) and information to be meaningful.	Develop partnerships with external services. Gain upstream support for workforce learning. Advocate for funding for resources in partnership with external specialist organisations. Consider funding for ageing in place.

Continued

Questions	Themes from analysis	Discussion Summary	Transformative outcomes
How does this improve the agency of clients – what are the strengths of clients that can be built on?	Facilitators	Clients have resilience which is good for brain health. Given opportunity, clients can build on knowledge foundations to advance their understanding of dementia risk reduction	Increased understanding with practical strategies designed to promote an interest. Provides a platform from which clients can inform presents and external agencies
What are tangible and meaningful ways to introducing dementia risk reduction into your programs that will benefit clients?	Opportunities	Brain health programs linked to activities of interest. Information notes with tips and fun facts. Targeted information for specific clients. Risk reduction and brain healthy 'fun facts' communicated to clients.	Brain healthy, risk reduction messages in client newsletter. Increase social, activity and physical activity programs. Make brain health and risk reduction enjoyable for clients.
How do we co-design risk reductions activities so that clients feel participatory?	Opportunities	Seek expressions of interest from clients who would be willing to contribute to activity concept, design and implementation.	Encourage clients to feel invested in brain health and risk reduction activities

Gaps

Stakeholders generally perceived that limited dementia knowledge existed across the workforce and saw this as a professional development gap. There was a perception that improving dementia knowledge and having an accomplished understanding of dementia was not essential, however, recognising subtle changes in the cognition of clients would make stakeholders more watchful and likely to refer onwards to medical practitioners (1NR, 3NR, 5HR, 6HR). One stakeholder summarised as follows:

> *"I'm not sure if we have a role to formally assess changes in memory; however, we may notice if memory changes become evident, and should act on those changes"* (6HR).

Another stakeholder's viewpoint was that a stereotypical understanding of dementia existed across the workforce, mainly that *"dementia is something that happens to older people residing in aged care"* and this needed to be addressed (1NR). This emphasised the viewpoint that whilst homelessness offered a different sphere of service than aged care, and better integration of knowledge was required between homelessness services, dementia services and aged care services.

> *"If we are looking at providing a range of services, including getting the right information, to people, then we must expand our knowledge beyond housing applications, bond arrangements, and legal aid referrals" (1NR).*

Most stakeholders observed an upward swing in the average age of clients engaged with their service, and all stakeholders agreed that services would need to respond to an increasingly older homelessness client population. Some stakeholders immediately saw brain health and dementia risk reduction as part of a changed response to workforce dementia education (2HR, 3NR, 5HR-7HR). In noting the overall change in client age, and with seeing more clients demonstrating cognitive difficulties, stakeholders considered that an integral part of future service provision and planning required an appropriate response to ensure workforce preparedness. This included a focus on more traditionally geriatric conditions, especially dementia.

> *"a considerable number of our new clients are older people who have no formal supports. We need to look at the services they are likely to need" (5HR).*

Discussions on dementia risk reduction attracted similar statements with some stakeholders identifying their own knowledge deficits and having limited understanding of why risk for dementia may be elevated in homelessness. Most stakeholders felt that a degree of dementia knowledge was required to understand the need for dementia risk reduction activities, and one was required to support the other.

> *"I don't think that any activity we do is… or recommendation given… are communicated as dementia risk reduction. Maybe that should change. It could help orientate discussions toward cognitive benefits" (2HR).*

Understanding cognitive impairment in people experiencing homelessness was generally considered to a sector knowledge gap as well as an individual knowledge gap. Some stakeholders thought that early symptoms of dementia in older clients were commonplace but easily confused with other causes, such as intellectual disability or long-standing effects of medications, drugs use or head injuries, and a status quo was often accepted. This was because stakeholders mostly perceived brain health and cognitive wellbeing to be multifaceted and complex concepts, that had historically sat outside the immediate scope of homelessness services.

> *"Um, because people still don't fully, I think, understand, and neither do I. And I've worked in it (homelessness) for many years, and I still don't understand completely, because it (brain health) is so varied and huge, isn't it?" (5HR).*

However, once stakeholders thought about dementia risk for their clients, stakeholders demonstrated an understanding of links between some behaviours commonly seen in homelessness and exposure to dementia risk (1NR, 3NR, 4OS).

> *"I do worry about some of the reckless behaviours that we see in the young to mid age group. So many of them end up with head injuries or concussions. I think that may be a risk for getting dementia later on" (1NR).*

Commonly perceived risk factors for dementia included excessive alcohol consumption and drug use, which were recognised for their impact on cognition. For example, one stakeholder hypothesised that:

> *"Um, yeah, I know a little bit about that sort of stuff. Alcohol, specifically, um, can be a precursor for dementia later in life… Um, I'm not 100% sure about drug use, um, but I would think that anything that, um, interferes with, you know, brain function would be a…a risk*

> *factor for later in life and the onset of dementia, I would think, so you could…you could draw a parallel there" (2HR).*

One stakeholder stated that they had heard about Wernicke-Korsakoff syndrome which they understood to be a precursor to more protracted cognitive impairment and possibly resulting in dementia.

> *"Of course, there is Wernicke-Korsakoff's which I believe can turn into dementia, or at the very least, worsening cognition. We see that sometimes" (2HR).*

Another stakeholder saw dementia as primarily a condition affecting older people and connected both older client groups and premature ageing to geriatric conditions, and that homelessness services were underprepared in knowledge.

> *"…of course… well… now we are getting older clients and clients with long-term homelessness who have grown old very early, it should be expected that we will see more people with poor cognition" (3NR).*

Stakeholders were curious about the role of methamphetamine on brain health and desired further information. Overall, stakeholders expressed uncertainty if methamphetamine was a risk factor for dementia, however, broader discussions identified a range of negative associations with its use, which stakeholders observed to poor brain health outcomes with an assumed risk for dementia (1NR, 5HR, 6HR). For example, one stakeholder spoke about a commonly observable deterioration in the cognitive abilities of clients of regular methamphetamine users, including a cascade of impacts to their overall wellbeing.

> *"it's awful to see, you know, first-hand. You know, it just completely wrecks people, wrecks their…obviously their brain, their cognitive function, wellbeing, um, self-worth…" (5HR).*

Interestingly, one stakeholder suggested a theoretical link between homelessness and risk factors for dementia and the need for awareness of connections between the two problems.

> *"[I think] homelessness can be a risk factor of dementia…. So, I think the greater knowledge would, you know…greater knowledge would be better than no knowledge. So, yeah, it would be a…it would be a win-win, I would think, in respect of, um, gaining that extra knowledge" (4OS).*

Several stakeholders commented on the need for more workforce training to upskill dementia knowledge (1NR, 3HR, 4OS, 4HR, 7OS). However, tertiary education for some professional roles, particularly nurses and occupational therapists, would have a more nuanced understanding of dementia than what was expected from other roles across the workforce (1NR, 2NR 6HR). For example, one stakeholder observed:

> *"I guess Allied Health…it makes sense that there's a stronger sort of, um, knowledge set there… Social workers, I'm disappointed (we did not know more). But, there again, I'm a social worker… The volunteers and other makes sense in that they may not necessarily have, you know, that professional knowledge around things. Um, particularly if they're just volunteering" (5HR).*

Stakeholders reported favouring more in-service learning opportunities on brain health and dementia risk reduction to help shape their understanding of brain health in the context of homelessness (1NR, 2HR, 4OS, 5HR 6HR). Stakeholders considered this favourable for their clients.

> *"I think probably a lot more education in that space would be more beneficial. So, for me, if…if that's a factor that impacts on them being able to live their best life because, um, we don't know about it, therefore we're not able to, I guess, adjust our approach accordingly, or to make sure that they are getting what…what is needed to support, nurture, grow…" (2HR).*

The willingness for formal workforce education was enthusiastically considered by stakeholders as a mechanism for knowledge acquisition. Stakeholders wanted training to be contextual on factors associated with homelessness, with tangible, practical suggestions that could enhance their discussions and referrals for clients.

> *"Right, well I think more training. So, for instance…more of the core training that, workers should do within an organisation. Um, so, you know, yeah, we do have things like, you know, mental health core training, um, Aboriginal and Torres Strait Islanders, child safe… we're doing cultural awareness, that type of thing, so let's look at, you know, brain health awareness being part of that, right? Of…of our core training" (5HR).*

Workforce education was further seen to be a way of defining brain health from mental health. One stakeholder reported that the workforce was largely well trained to manage mental health referrals and support clients with a history of mental health conditions and that clients' cognitive wellbeing was mostly defined within this sphere (7OS). Poor cognitive wellbeing and dementia were not necessarily seen as separate entities to mental health conditions, and whilst mental health appeared extensively targeted for education, discussion on dementia was highly limited and unsatisfactory (2HR, 4OS, 7OS).

> *"It [dementia knowledge] is probably limited. I think a lot more information in that space would be beneficial. I think there has been one element of training that I can recall when someone came in and actually spoke to us about it. It (dementia) is touched on in mental health training, respect for capacity and consent, and things like that. It's not… nothing that is greatly explored in any great depth or anything" (2HR).*

Strengthening partnerships with external organisations to provide targeted workforce training was widely regarded as a good remedial measure to close the knowledge gap (1NR, 2HR, 3NR, 5HR, 6HR 7OS). Nonetheless, stakeholders separated the discussion into two distinct groups: upskilling the homelessness workforce and building dementia awareness and dementia risk reduction in clients. First, closer relationships between the homelessness and non-homelessness sectors were considered a primary conduit for cross-sectional knowledge that could both upskill the homelessness workforce and inform other services (1NR, 2HR, 3NR, 5HR). Second, stakeholders held mixed views regarding who best to deliver dementia risk reduction awareness for clients considering both the skill set and the time pressures already imposed on the homelessness workforce (1NR, 2HR, 6HR). When asked for solutions to managing time pressures, most stakeholders shared a similar sentiment that this was a role external specialists could fill.

> *"I think having guest speakers come in to talk to clients on this subject may help to get the conversations started' (2HR).*

A minority of stakeholders reported concerns that non-homelessness service providers may lack the sensitivity needed to reach out to client groups, which extended beyond empathetic engagement (1NR, 2HR). In this sense, stakeholders reported the need for external presenters to have unique understandings of factors related to homelessness, and which incorporated the expert contribution of the homelessness sector through collaboration (4OS, 5HR).

One stakeholder, who had specialist dementia knowledge, reported their unease that dementia services were primarily unable to meet the needs of clients living homeless. This largely was because dementia services catered to their core demographic and had limited funding to adjust programs towards specialist, minority groups.

> *"I remember flagging my concern that a lot of the clients that we were connecting with actually were coming from quite supportive family units, and that I wasn't seeing any representation from the homeless communities… I knew that people were out there, but mainstream services weren't set up in a way to be able to connect in the traditional sense" (7OS).*

As a result of dementia services not accommodating people experiencing homelessness was seen as being problematic. Stakeholders concurred that there was disengagement between the homelessness and the dementia sectors, with a need for bi-lateral training to bridge the disconnection.

Barriers

Perceived barriers to cognitive wellbeing and dementia risk reduction among people experiencing homelessness were diverse. The primary barrier identified by participants was poverty associated with entrenched homelessness. Poverty influenced exposure to several risk factors for dementia, including diet, sleep, access to services and social isolation.

Sleep deprivation associated with rough sleeping or sleeping in unsafe emergency hostels was seen as problematic to wellbeing, however most stakeholders did not consider sleep deprivation as increasing risk specifically for dementia (1NR, 2HR, 3NR, 6HR).

> *"I know that many clients do not sleep well for many different reasons. That makes their thinking skills worse than usual… and I can see it being a problem for their overall health and wellbeing, especially when it happens often and routinely" (5HR).*

Stakeholders reported their clients continuously consumed a poor diet or had very limited access to nutritious food due to poverty (1NR, 2HR, 3NR, 5HR). Stakeholders understood poor diet and nutritional deficiency as having potential to affect wellbeing, however, did not expand on the role thiamine or other nutrients have for good brain function.

> *"There is one guy I regularly see… he often buys fast food, hot chips mainly. I don't think he gets much in the way of vegetables or fruit because he wants warm food that will help stave off the cold, and his choices are limited by lack of money" (2HR)*

Traumatic brain injury was seen as both a contributor to homelessness and a cause of compromised brain health (2HR, 3NR, 5HR).

> *"Quite a few people have an existing brain injury from birth or childhood, and sometimes, because of that, they are of risk of homelessness… and I know that because of homelessness, some people acquire a brain injury" (4OS).*

Mental health conditions were viewed as a substantial concern for overall wellbeing, but especially cognitive wellbeing, and a driver of health compromising behaviours.

> *"I guess just, um, keeping your mental health in a place where you…you don't want to end your life is possibly higher (priority) …or, um, keeping you medication-stabilised so that your body can function…" (6HR).*

Stakeholders recognised that clients faced multiple barriers for improving cognitive wellbeing. Systemic barriers included policies that compound disadvantage, including social housing, welfare and access to health care. A stakeholder stated, "*We do what we can, we help them to engage with the system, to support their medical needs"* (3NR). Nonetheless, offering support did not always equate to uptake of support: "*they are afraid of outcomes that they feel will disempower or restrict them, like the public advocate*" (3NR). Stakeholders held a shared opinion that ongoing stress, past trauma, mental health and apathy for self-care were all obstacles to better cognitive wellbeing in their clients (1NR, 2HR, 3NR, 4OS, 5HR 6HR).

> *"I think it's lack of sleep, the substance abuse, um, the drinking, and also just not…not caring about yourself, as well, just not really respecting yourself, trauma and underlying youth issues, childhood trauma, um, and not caring (3NR).*

Stakeholders suggested that there would likely be resistance to changing behaviours and attitudes in homelessness. For example, one stakeholder emphasised that many clients *"would likely wavier any potentially adverse brain effects in favour of opportunities for enjoyment, survival, or self-medication against the stress of living homeless"* (6HR). Another stakeholder reported concerns that some clients *"would not be able to overcome alcohol and illicit drug addiction regardless of having increased awareness of brain health and dementia risk reduction"* (2HR). Stakeholders generally saw a conflict between clients using cognitively reckless lifestyle behaviours in managing their daily and immediate struggles and having any ability to apply proactive dementia risk reduction or have consideration for future cognitive outcomes (4OS, 5HR).

> *"…to, you know, consume something that may not be good for your immediate health that will give you, like…like a temporary sense of calm or peace or enjoyment or whatever…. is often far more attractive than not doing that because, you know, that maybe in ten, twenty years' time you have a less chance of having something that…um, like dementia or whatever else" (6HR).*

Other comments reinforced potential reticence to ask someone living with acute homelessness to refrain from certain behaviours or activities for what was perceived as an *"unguaranteed risk of not getting dementia in later life"* (6HR). Stakeholders opined that whilst those experiencing acute (primary) homelessness were far less likely to engage with dementia risk reduction for many reasons. *“Like, they (people experiencing primary homelessness) don’t really care about brain health”* (3NR), however, this did not necessarily mean that people in housing first models of accommodation would not engage (1NR, 2HR, 3NR, 4OS, 6HR). In this sense, some stakeholders posited that prioritising dementia risk reduction in acute and extreme homelessness would be viewed as a redundant activity.

> *“Quite often they’re (health promotion activities) about telling people how to live a better life… …and …you’re not living in a controlled environment, you’re…you’re in survival mode, wondering where your next meal’s going to come from” (7OS).*

Stigma associated with a health condition is known to be a significant barrier that severely compounds distress, and overcoming stigma associated with dementia is challenging. Negative attitudes to dementia are pervasive and can also extend to dementia risk reduction. Stakeholders were aware of the associations between dementia and stigma.

> *I think that the whole stigma associated with dementia is a barrier to discussing brain health and dementia risk. I ask myself if clients would want to go there…. and I am not sure of the answer. You only have to mention the word ‘dementia’ and you can see people clam up on that topic…. um, so while promoting brain health and dementia risk reduction is really important, I’m just not sure how we can overcome the stigma” (1NR).*

When asked further, stakeholders elaborated that stigma associated with dementia reinforces the fear that people experiencing homelessness are attracting yet another negatively associated label. Stakeholders unanimously thought this would be wholly detrimental to the cognitive wellbeing of their client group. Concerns for increasing stigma and labelling included a dementia focus based on lifestyle behaviours, *“it becomes hard when all that they hear is do this or don’t do that. The onus is placed on them to change*” (6HR). However, rather than evade dementia risk reduction, it was thought that stigma and labelling linked to dementia and exposure to dementia risk were compounded by a lack of easily accessible information. For example, one stakeholder considered the lack of resources in homelessness to be a factor for poor dementia and risk reduction literacy among clients. Another was concerned for people who feel stigmatised because of having cognitive symptoms of dementia.

> *"…there's a lot of stigma attached to…to dementia, so if there hasn't been anyone in that person's world to have helped bridge that gap and to have tried to navigate the stigma" (7OS).*

A suggestion to overcome stigma-related concern for brain health included surreptitiously introducing dementia risk reduction into client activities, or to insert subtle brain healthy messaging in general discussions.

Facilitators

Commonly described facilitators for dementia risk reduction included upskilling stakeholder and client dementia awareness, empowering client choice, improved access to appropriate resources, ensuring clients are engaged and supported by the workforce (3NR, 5HR, 7OS). However, stakeholders mostly perceived their role as a link between clients and specialist organisations able to address dementia-specific inquiries (3NR, 5HR, 6HR, 7OS). Some stakeholders reported that a dearth of funding prevented the facilitation of sector-specific brain health and dementia risk reduction activities and looked towards specialist organisations to 'step in' (3NR, 5HR).

> *"We need funding to run programs that work alongside expert organisations. It's incredibly sad that we are curtailed by funding constraints… we've lost so much funding … when that funding would create the opportunities need to support brain health and dementia risk reduction. Because they need it. They absolutely need it… you see their brain health deteriorating week by week" (5HR).*

Another stakeholder suggested a cross-service approach be considered, open to all clients across homelessness services that were closely located, i.e., in neighbouring metropolitan areas (4OS). Another stakeholder encouraged having identified staff who held enhanced knowledge of cognitive wellbeing and dementia awareness rather than a blanket approach across the workforce. This would extend to identified roles that helped clients navigate dementia awareness and risk reduction resources, access key programs, and advocate on their behalf (7OS).

> *"It's probably more about creating a role that almost stands next to the person… helping them to navigate everyday life and, again, maintaining their sense of purpose and dignity… it's very much about meeting people where they're at and on their terms, and in their timeframes…" (7OS).*

Stakeholders wanted clients to benefit from brain healthy activities and dementia risk reduction strategies. Whilst stakeholders were keen to explore how these activities could be facilitated within the sector, they were mindful of unintended harms generated through poor resources and programs that may lack sensitivity for their clients.

Opportunities

Stakeholders typically saw written information resources and targeted activity programs as the primary opportunity to increase brain health awareness and dementia risk reduction. Stakeholders, however, were cognisant that a paucity of appropriate resources and activities exist that are suitable and tailored for people experiencing homelessness (1NR, 2HR, 5HR). Stakeholders considered these resources as significantly different to those used by mainstream communities and offered examples that included: a safe education space that clients can access within homelessness services, introduction to basic computing skills, basic cooking classes, and guest talks (audiologists, diabetes educators, drug and alcohol workers and similar professions) where information would be pitched at a practical and supportive level for vulnerable clients (1NR, 2HR, 3NR, 4OS, 5HR). One stakeholder spoke about the need for specialist dementia services to be equally held to account in not providing appropriate resources for people experiencing homelessness. The suggestion was that resources should be cooperatively developed and co-designed with homelessness services and their clients to provide realistic solutions in educating people experiencing homelessness on dementia risk exposure and risk reduction (1NR).

One stakeholder championed an uncomplicated postcard-size infographic promoting a range of positive brain health and dementia risk reduction messages that could be placed strategically at various service access points. This included the food van, clothing opportunity shop, community room, or service reception desks where people did not feel pressure to take them. This participant argued that this approach could increase visibility and the normalisation of seeing supportive brain healthy information for the betterment of cognitive wellbeing. Other interview participants were generally enthusiastic about this suggestion, for example:

> *"Like I said, the thing is that you try a few different angles and…and, well, I guess the more different angles you try, the more people you reach" (6HR).*

Several stakeholders looked to their organisation's existing social programs and reported opportunities to include a range of brain challenging activities with brain-healthy messaging built in them (2HR, 3NR, 5HR). For example, one stakeholder suggested their walking group could promote the benefits of exercise as a brain-healthy initiative, promoting social and cardiovascular health improvements (3NR). Another suggestion was to place a brain-healthy message on a sign next to free books for clients to promote reading, which could encourage cognitive challenge and strengthening neural circuits (5HR). As one stakeholder said:

> *"There's no reason why we couldn't find ways to integrate looking after people's brain health in the way we do our programs…" (6HR).*

These interview discussions largely divided stakeholders between having subtle brain-healthy messaging discretely woven into existing social programs (1NR, 2HR, 6HR) or for more focussed dementia risk reduction activities (3NR, 5HR). For example, one stakeholder suggested interest in brain health through activities such as music, singing, sudoku or crossword group, or discussion groups would gain traction with clients (3NR).

> *"And…and maybe even having support groups, as well, where people knew, um, that they can do some small things to keep their brain health healthy, as well" (3NR).*

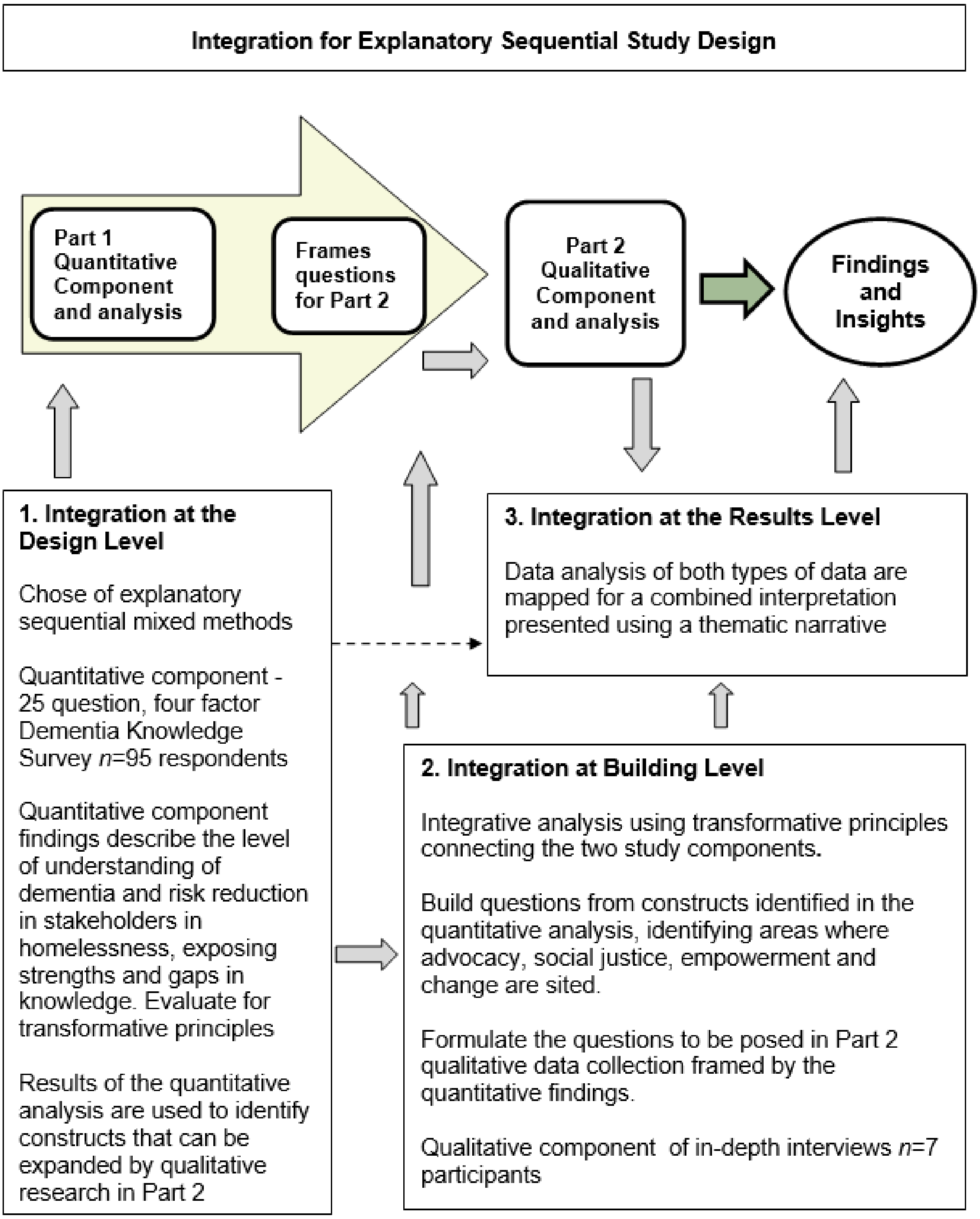
Stakeholders also suggested that their widely-circulated newsletters provided opportunities for brain health awareness. For example, it was proposed that regular snippets of 'fun facts or information' alongside puzzles would provide an inexpensive method of reaching people in housing first models of homelessness services (2HR, 5HR). In addition, organisational client newsletters were seen to be a reliable and culturally safe conduit of information. However, whilst this was a popular suggestion, stakeholders' routinely thought that newsletter content should be assisted by peak bodies such as Dementia Australia or Brain Injury SA (2HR, 3NR 4OS, 5HR).

The next section provides a discussion on how the data was integrated across Study Two.

Study Two Data Integration

Similar to Study One, Study Two employed a multi-level integration considerations, however these were suited to the explanatory sequential design. The intent to integrate data is considered in the study question and mixed methods design choice. The purpose of explanatory mixed methods for this thesis is to have qualitative data explain and build on the findings of the quantitative data results.[256] This process allows the qualitative data to add an interpretation and clarification of the quantitative findings.[383] The central integrative component occurs in the building phase where Part One's quantitative data findings (Dementia knowledge survey) are used to frame the questions in the Part Two qualitative data collection (in-depth interviews). This allows the qualitative component to 'build' the information further.[276] A third integrative process is reflected in the integrative outcomes, where results from the data sets are linked back and forth to subsequently support the development of concepts and new understandings.[266, 276] This process facilitates a deep dive into the data where the quantitative results may be explained from the qualitative findings.[277] The final point of integration is in the integrative discussion that provides a narrative based on the qualitative and quantitative findings and understanding the fit between the data sets that confirm, compliment, expand or discord each other.[278]

To explain the integrative procedures in *Stakeholders in Homelessness,* I revisit the study design presented in Chapter 4 and further develop the Explanatory Sequential Mixed Methods model, to illustrate the contact points where integration was applied (Figure 39).



1. Integration at the Design Level

Chose of explanatory sequential mixed methods

Quantitative component - 25 question, four factor Dementia Knowledge Survey *n*=95 respondents

Quantitative component findings describe the level of understanding of dementia and risk reduction in stakeholders in homelessness, exposing strengths and gaps in knowledge. Evaluate for transformative principles

Results of the quantitative analysis are used to identify constructs that can be expanded by qualitative research in Part 2

3. Integration at the Results Level

Data analysis of both types of data are mapped for a combined interpretation presented using a thematic narrative

2. Integration at Building Level

Integrative analysis using transformative principles connecting the two study components.

Build questions from constructs identified in the quantitative analysis, identifying areas where advocacy, social justice, empowerment and change are sited.

Formulate the questions to be posed in Part 2 qualitative data collection framed by the quantitative findings.

Qualitative component of in-depth interviews *n*=7 participants

Figure 39. Multi-level Integrative process design for *Stakeholders in Homelessness*

How Part One findings were linked to Part Two

Results of the quantitative data allowed for informed framing of the in-depth interview questions. This approach represents an imperative integrative stage of *Stakeholders in Homelessness*. It is a transitional stage that occurs between the collection of the quantitative and qualitative data. I began the data integration by using the mean score findings across the four domains contained within the survey. Next, I considered the strengths and weaknesses of the dementia knowledge level identified in the survey quantitative findings, after which I expanded the quantitative contribution from the broader quantitative results. Across the whole sample, the quantitative finding showed a DKAS mean score, of 24.8, which represents just under half a possible total score of 50. It was not expected that the homelessness workforce would meet mean score measures indicating comprehensive knowledge (measured at 45/50 (90%).[380] However, using information from a recent international DKAS validation study[384] co-authored by an original member of the survey development team, having a good level of dementia knowledge was subjectively benchmarked at 33.3/50 (66% or 2/3 of total possible score). This measure was included to identify where emphasis was needed during the process of framing the questions for the in-depth interviews (see Table 16).

The applied transformative lens led me to consider the meaning these findings have for dementia understanding and dementia risk reduction in the homelessness workforce, and the potential consequences for people experiencing homelessness. In recognising homelessness as a breach of human rights, striving for equitable access to dementia information and interventions for modifiable risk is a concern for social justice. Transformative considerations, therefore, examine the need for having a good level of dementia knowledge within the homelessness workforce and why it can benefit people experiencing homelessness and deliberate on power relationships between workforce and clients and the role of the homelessness workforce in encouraging dementia risk reduction with client groups. Other transformative considerations include ways to address inequitable barriers to dementia risk reduction. These considerations were developed further and evolved into interview questions organised in themes of (i) gaps, (ii) barriers, (iii) facilitators, (iv) opportunities guided by Braun and Clarke (2006). The integrative processes for the ‘building’ stage of *Stakeholders in Homelessness* are outlined in Table 17.

Table 17. Framing the qualitative questions from Quantitative results.

Mean score of whole sample by domain	Correct or partially correct answers	Analysis summary	Linking the data to qualitative questions
	Benchmarked at DKAS score of 66%	**Broader Quantitative findings**	
Causes and Characteristics 7 questions across 95 participants - Total number of answers *n*=663	64% (*n*=423) ⇨	Knowledge of causes and characteristics was <66%. Knowledge could be improved in this sample of the homelessness workforce. ⇨	Improving dementia knowledge in workforce. Why is it important and best to achieve it? What is the observed need for increased knowledge?
Risk Factors and Health Promotion 6 questions across 95 participants - Total number of answers *n*=570	63% (*n*=364) ⇨	Knowledge of risk factors and health promotion was <66%. workforce. Knowledge could be improved in this sample of the homelessness workforce. ⇨	Focus on brain health and cognitive wellbeing. Understand risk reduction in homelessness settings. How to make it meaningful for clients? Barriers to implementation.
Communication and Behaviours 6 questions across 95 participants - Total number of answers *n*=570	59% (*n*=332) ⇨	Knowledge of communication and behaviours was considerably low (less than <66%). Knowledge should be improved in this sample of the homelessness workforce. ⇨	Distinguish cognitive difficulties from mental health challenges. Understand why behaviours manifest and what to expect. Communication and resources for clients.
Care Considerations 6 questions across 95 participants - Total number of answers *n*=570	80% (*n*=457) ⇨	Knowledge for care considerations was >66%. A good level of knowledge exists in this sample of the homelessness workforce. ⇨	Importance of early support. Outline pathways for early onward referrals. Partnerships with other agencies.

***Quantitative findings frame questions developed for Part Two of Stakeholders in Homelessness*.**

The next section will provide an integrative discussion of the findings of Study Two, Part One and Part Two.

Integrative discussion on Stakeholders in Homelessness

> *“From an ethical perspective, researchers who do not consciously act to address inequities may be complicit in sustaining an oppressive status quo”*[51]

This section describes the integrative discussion between the two parts of Study Two: *Stakeholders in Homelessness*. It is presented under the transformative lens that places value on examining aspects of power and privilege,[268] and cognisant of the need for advocacy and change.[271] The data integration for this discussion continues to be guided by Fetters.[276]

Transformative values of advocacy

Pragmatically, transformative advocacy for people experiencing homelessness on dementia risk reduction will occur through actions based on the knowledge of homelessness stakeholders. The transformative lens incorporates an intent to provide advocacy to improve the interests of others and challenge issues of power and their ensuing social relationships that disbenefit them.[266] The data revealed that people experiencing homelessness have a different experience of life compared to the general population, and face inertia, discrimination and judgement in societies that are not homelessness-friendly, much less dementia friendly.

Findings from the data indicate that stakeholders were emphatic about their role as advocates for clients experiencing homelessness and this could extend to dementia risk reduction. Advocacy reflects workforce assumptions regarding structural power imbalances (the need for advocacy) and an understanding the social nature of need (what clients require to succeed), making advocacy a matter for social justice. Providing advocacy on behalf of people experiencing homelessness helps to safeguard grassroots representation and ensure services remain supportive, focussed, and address power differentials.[51] The data evidenced transformative advocacy in how stakeholders act in the best interests of their clients by placing client needs uppermost, filter out potentially harmful interferences, and present ideas from the viewpoint of clients. These transformative values are helpful to ensure people experiencing homelessness receive appropriate and equal access to brain health and dementia risk reduction activities, regardless of their minority representation within specialist dementia services.

Transformative attitudes of the workforce

Participant interviews revealed the homelessness workforce as protective gatekeepers who alternate between concern for their clients' brain health and the risk for clients to feel further labelled or blamed for having socially challenged behaviours. Points of concern raised included an increased pressure on clients to adopt brain healthy activities when coping with adversity, and questions that, regardless of the intent for improved cognitive wellbeing, there was limited funding scope to follow through with sufficient supports and services. Furthermore, study participants pointed to structural barriers that impede their clients cognitive wellbeing, highlighting multiple systemic disadvantages, including housing policies, welfare and access to health care, as concerns that must firstly be addressed.

The data provided many examples of transformative actions, including assisting clients at their medical appointments so that they felt supported and encouraged to speak for themselves. Advocacy and empowerment roles of the workforce extended to guiding clients to see medical professionals known to be particularly accessible and amiable to people experiencing homelessness and understanding of their circumstance. These transformative actions empower clients who are reluctant to attend medical appointments for memory difficulties and who are apprehensive of power differentials, fearing they may lead to institutionalised care or be placed under the guardianship of the public advocate. By supporting, advocating and empowering clients, these transformative actions that circumnavigate structural barriers to health care.

Transformative benefits of knowledge acquisition

Analysis identified a knowledge gap among a cross-sectional cohort of the South Australian homelessness workforce using a dementia knowledge survey. The workforce mean score of 24.8 out of 50 is below that seen in Australian studies in health professionals [379, 380]. It also fell below a mean of 29.8 out of 50 using DKAS of a recent study of Chinese healthcare providers that identified this score as a poor level of knowledge.[384] Given that the homelessness workforce sample comprised of just 28.4% of allied health workers, this result is unsurprising. Nonetheless, the ostensibly low DKAS survey mean score finding has implications for homelessness services, given their de facto carer role with such a vulnerable, ageing community who have a disproportionate risk for cognitive impairment.[185, 207, 385] The results identify an opportunity to improve shared dementia knowledge across the homelessness workforce because stakeholders have the potential to bridge the gap between Study One and Study Two, however, they lack the knowledge to do this.

A higher level of antecedent dementia knowledge would be expected in allied health roles compared to the non-medicalised roles of social work, volunteer or other roles in this cohort of the homelessness workforce. However, the reasonably narrow difference between the mean scores across occupational roles suggests that an advanced level of dementia knowledge in the allied health group should not be assumed. Instead, mean scores suggest that all cohorts may benefit from having dementia awareness education. This is an important finding for transformative change because it is relevant to clients' shifting cognitive needs and how that is recognised and managed, and increased education in the workforce helps toward problem solving and advancement of professional development.[386, 387]

The dementia knowledge gap of stakeholders

The data shows sporadic knowledge deficits in the cohort of the homelessness workforce. For example, whilst Alzheimer's disease is the most common type of dementia,[35, 66] more than half of all respondents attributed blood vessel disease (vascular dementia) as being the most prevalent. Implications mean that subtle cognitive differences may be missed, or their significance not understood. For example, most respondents mistook sudden changes in cognition as a potential symptom of dementia, potentially delaying consideration for acute and serious causes of unexpected cognitive change, including adverse (illicit) drug reactions, alcohol toxicity, delirium, head injuries, seizures, or other neurological events.[388, 389] In contrast, respondents broadly understood that symptoms of depression, frequently seen in people experiencing homelessness,[390] could be mistaken for symptoms of dementia.[391] These examples indicate the importance that dementia awareness has for implementing transformative actions to benefit clients with high rates of cognitive impairment. Whilst cognitive assessments for dementia sits outside the scope of the homelessness sector, greater awareness of cognitive anomalies helps direct need for referrals and the planning of housing and support needs.[206, 392]

The medicalisation of behaviours

Respondents mostly thought that a medicalised approach to managing behavioural symptoms of dementia was an effective way to control difficult behaviours. However, this approach largely disregards the valuable input the homelessness workforce can have in providing non-pharmaceutical support, including the client care environment, developing and maintaining individual support skills, and tailoring care options to suit the individual.[393] Transformative values would encourage a greater awareness of the underlying ethics, assumptions and power dynamics of systems (medical care) to instead chose to amend socially defined problems using only technical (pharmacological) solutions.[394] Whilst no easy solution exists, medicalised approaches to behaviour management present an array of challenges in homelessness. Cognitive impairment increases noncompliance to pharmacological routine,[395] including the ability to access affordable medications, maintain supply and the safekeeping of medications. People experiencing homelessness have increased vulnerability to theft or loss of medicines that are outside personal control.[138] These problems can increase a person’s dependence on the homelessness workforce to step-in and assist with systems for medication management.

Transformative values for health promotion in homelessness services

People experiencing homelessness experience wide-ranging health problems and are a highly marginalised, hard-to-reach population. The homelessness workforce is critically positioned to support and advocate for cognitive wellbeing and dementia risk reduction for clients, offered through a range of health promotion education, activities, and actions.[396, 397] However, the data uncovered challenges related to the homogenous nature of existing health promotion recommendations and resources. From this data, the dominant challenge is to appropriately situate brain health promotion initiatives in homelessness services. Currently identified generic approaches to health promotion lack insight and relevance for people experiencing homelessness, and require rethinking.[396] To be transformative, services must incorporate inclusive and impactful responses that are guided by stakeholders, formed by partnerships between clients and services.[51] This could include resources and programs established by an empathic, trauma-informed, and inclusive methodology to avoid further marginalising or preclude people.[398]

Data shows that stakeholders recognise important benefits for clients' cognitive wellbeing, and were keen for brain healthy activities, risk reduction programs that had client centric perspective. They advocated that clients should contribute to dementia risk reduction programs and brain health information. Nonetheless, the input of specialist dementia services is recognised and required, but for transformative and appropriate health promotion and dementia risk reduction, it must be tailored for people experiencing homelessness.[370, 399]

Structural barriers to transformative actions

Speculatively, there are several structural reasons, including funding, as to why specialist dementia services have maintained a low profile within the homelessness sector. This disconnection is a problem for transformative practice because client status, agency, power dynamics and prejudices result in one group (general population) being favoured over a marginalised group (people experiencing homelessness.[400] Remedy begins with strong advocacy for change, including funding arrangements that allow partnerships to prosper between the sectors, and by co-designed resources, programs and activities.

Within the data, apprehensions surfaced around exposing clients to the phenomenon of lifestyle drift, where a problem 'drifts' from its causative structural determinants toward behavioural lifestyle approaches that place culpability on individual behaviours that must be changed.[57, 59, 401] However, a health promotion approach focussed solely on proximal behavioural change rather than addressing distal root causes are unlikely to be sustainable.[58, 59] Lasting change requires a multi-level effort to support the cognitive wellbeing of people experiencing homelessness. This occurs when the approach to bettering health outcomes reorientates away from behavioural change alone,[58] an approach that benefits from transformative values of challenging power structures and imbalances.[51, 266]

Transformative actions of reciprocity and service partnerships

Findings in the data call for knowledge reciprocity and service partnerships established between homelessness and dementia sectors. Partnerships, promoting shared aims to improve cognitive wellbeing through and co-established programs and services, could add value and provide dignity to people experiencing homelessness. The stakeholder drive for reciprocity and service partnerships is transformative because these actions increase client confidence and improve self-worth.[52] Services framed by transformative values be client-centric, co-created with clients and practical of their needs.[402] Services would allow for community vulnerabilities and encourage client control and agency. They provide strengths-based programs recognising that clients will be disadvantaged in the expertise and understanding of service management decisions but have value in adding expertise and knowledge regarding the reach and quality of services that encompass their wellbeing needs.[402]

Transforming stigma and discrimination

Many unfavourable and stigmatising perceptions of dementia exist,[403, 404] often supported by deficit language that devalues or victimises people.[405] Stigma was a concern identified from the data. When people occupy positions that stigmatized in society it increased stress, depression and increases social isolation.[406] Stigma in homelessness is pervasive and an understood barrier for people accessing mainstream services, leading to service avoidance.[407] For these reasons, homelessness service providers are regarded safe places and service delivery offered within those providers help overcome both social and structural barriers to accessing much needed supports. This approach was posited because people experiencing homelessness are intensely aware of their stigmatised status and in-place services ameliorates the need to disclose their status.[406] The concern in this study is that stigma and labelling associated with dementia, albeit dementia risk, layers on top of the sigma and labelling associated with homelessness. Stigma is complex, and concerted efforts have been made to understand and address it,[156] including awareness of how it negatively influences health and wellbeing.[408] Transformative actions reduce stigma and labelling, but also present a complex challenge that stakeholders appear to be aware of.

Transformative values in homelessness services

Homelessness services are attuned to the sense of ‘place’ and provide a physical and non-judgemental space where people can engage with various programs and activities.[396] Brain health awareness and dementia risk reduction initiatives are most likely to be successful when delivered in this environment. However, health promotion for a heterogeneous population is unlikely to meet the consensus of all clients, and subject to the scrutiny of meeting needs.[396] The degree to which people experiencing homelessness are likely to engage with dementia risk reduction is unknown but will be best placed in homelessness services that provide familiar, enabling settings for their clients.

Empirical findings reveal the homelessness sector workforce as a specialism, providing professional wrap-around services that respond to a diverse range of challenges within a client-service design.[409] Competence in crisis management, understanding immediate social housing needs, case management skills, contemporary knowledge of available supports and problem solving are part of the workforce skill set,[386] indicating that they are practiced at applying transformative values in service delivery.

Transformative solutions

The data shows that stakeholders were focused on positive change for their clients, which is congruent with transformative values. However, the choice of having dedicated dementia brain health and dementia risk reduction programs or subtle was contested. An argument exists to introduce brain-healthy messaging linked to pre-existing social activities, such as walking groups or normalising brain health through community newsletters. However, this may not provide an explicit platform from which to provide direct information on dementia risk and risk reduction. To do this, transformative programs should be created based upon a social justice framework[268] to provide social change through transformative actions.[266] This approach does not prevent brain healthy messaging from being reinforced within other appropriate activities but provides a focus point and opportunity for clients who may have questions, to seek answers.

The increasing numbers of aged clients is an indication that service needs have changed and that the requirement for dementia awareness has been expanded. Proficient knowledge of brain health and dementia risk reduction requires careful attention because of the underlying mechanisms and association with dementia itself. This is likely onerous for the homelessness workforce who would look toward specialist organisations to support the delivery of dementia-related services. However, stakeholders have a perception that specialist dementia sector are, at present, hesitant in engaging in collaborative partnerships, making transformative actions more difficult to implement without this level of support.

Chapter summary

Study Two: *Stakeholders in Homelessness* has addressed the research question: *How can dementia risk reduction for people experiencing homelessness be improved?.* This chapter described the explanatory sequential mixed methods study *Stakeholders in Homelessness.* Part One described the quantitative component using the dementia knowledge survey distributed across specialist homelessness services in South Australia. Part Two describes the qualitative in-depth interviews that were generated from questions informed by Part One. The multilevel data integration was explained to demonstrate how data was linked across the study, and the integrative findings were presented, under a transformative lens. *Stakeholders in Homelessness* demonstrates both need for increased dementia knowledge and dementia risk reduction, showing that cognitive wellbeing in clients is an increasing concern for the homelessness workforce. Structural barriers to dementia risk reduction have been identified, such as limited secure housing, low workforce dementia knowledge, poor client engagement, and inappropriate dementia risk reduction resources, The limited collaboration or partnerships with specialist dementia services has been highlighted.

The next chapter will provide an interpretation of the research, its implications, recommendations, and summarise the original contribution to knowledge as part of the thesis conclusion.

CHAPTER 7: INTERPRETATION

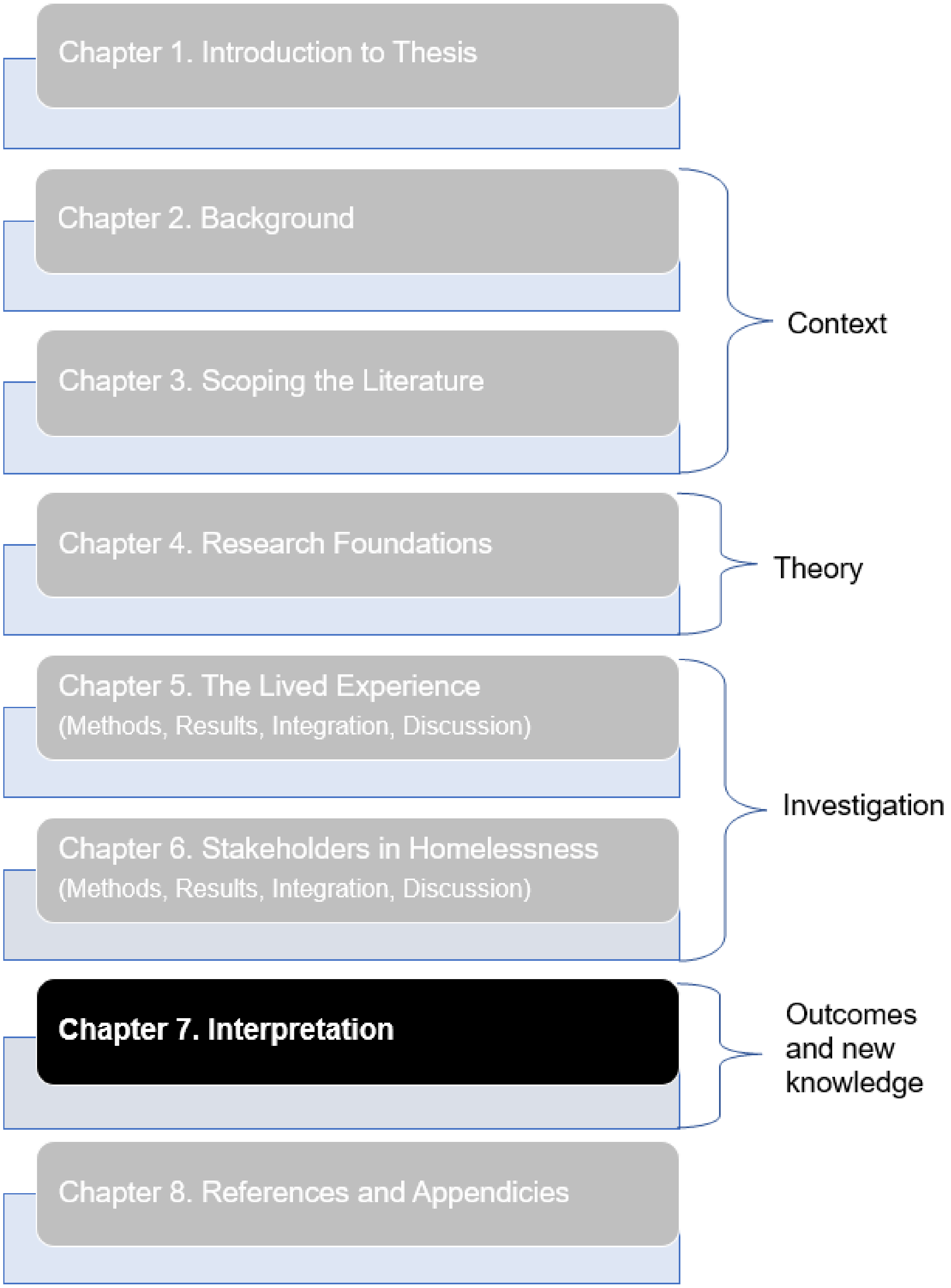


Figure 40. Thesis structure - Chapter 7.

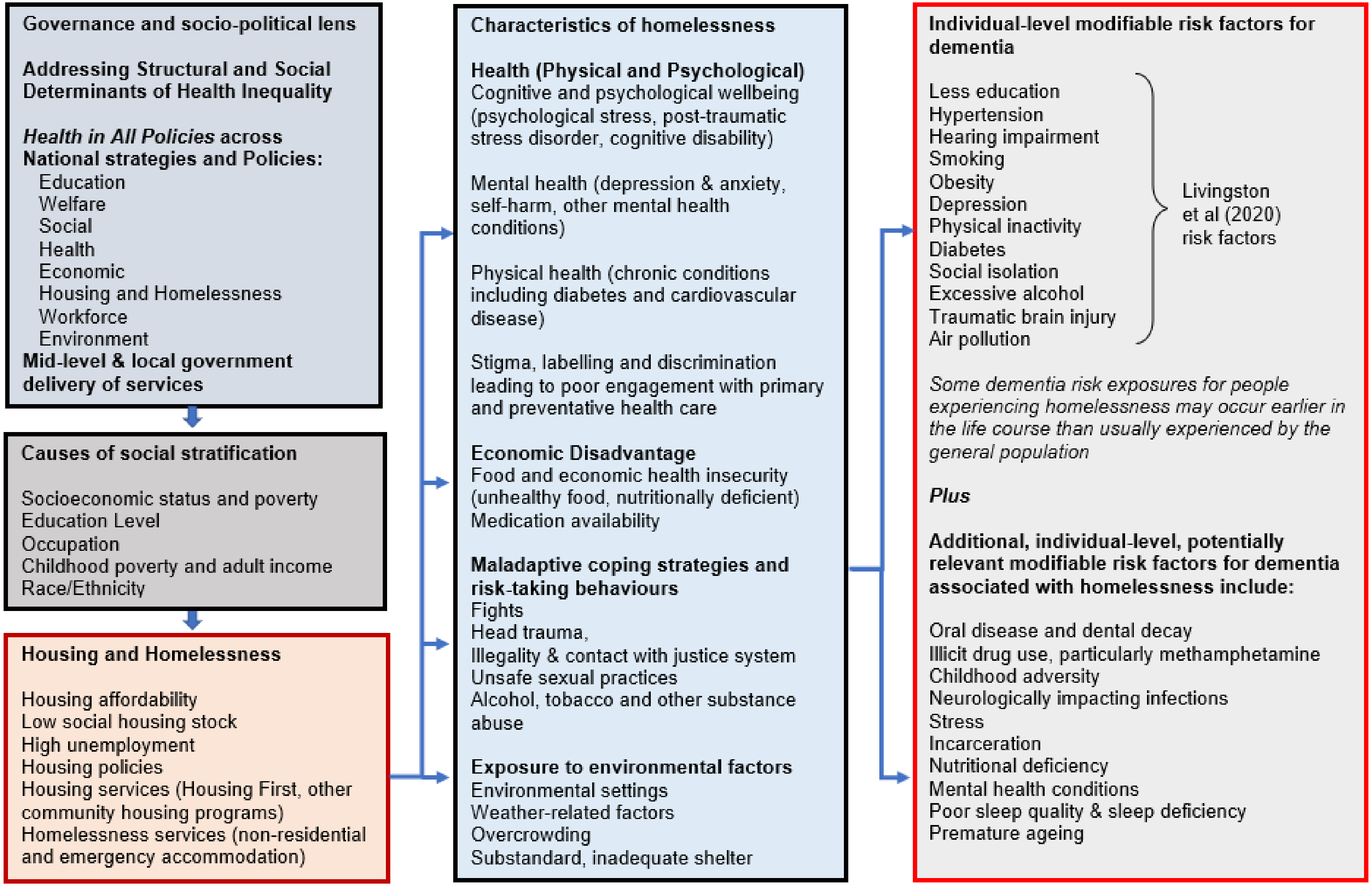
Introduction to Chapter

This interpretation collates new insights into potentially modifiable risk factors for dementia, their relationship with the experience of homelessness, and opportunities for reducing dementia risk exposure. I present this information as an interpretive discussion and explain how the two research questions: *How does homelessness impact cognitive wellbeing and dementia risk?* and *How can dementia risk reduction for people experiencing homelessness be improved?* are answered. This interpretation maintains its critical theory perspective by continuing the use of the social determinants of health and transformative lenses to summarise the socio-political and economic factors that generate exposures to dementia risk, and the actions needed to for dementia risk reduction.

I begin by presenting a multi-level pathways and mechanisms model showing exposures to dementia risk using findings from this thesis (Figure 41). This is presented as a gestalt of structural, societal and individual risk factors based on the CSDH Conceptual Framework for Action on the Social Determinants of Health.[44] I then discuss if the *Lancet Commission; dementia prevention, intervention and care* by Livingston et al (2020)[66] discussed in Chapter 2, is sufficient to provide a picture of potentially modifiable risk factors for dementia in homelessness. Based on the findings in this thesis and contextualised by the broader literature, I present (i) a new model of potentially modifiable risk factors for people experiencing homelessness, and (ii) a diagram of suggested multi-level opportunities to reduce exposure to dementia risk, based on transformative values including equity, social justice and advocacy using Mertens,[49] Blocker and Barrios,[52] Sweetman,[266] and other researchers in this field. Finally, I present recommendations arising from this thesis, its strengths and limitations, significance of this thesis, and I close with a conclusion.

Gestalt of pathways and mechanisms

The origins of exposures to dementia risk are compounding and challenging, and data from Chapter 5: *The Lived Experience* show that they cannot be considered in isolation. The gestalt of pathways and mechanisms underlying exposures to dementia risk are shown in Figure 41.



Governance and socio-political lens

Addressing Structural and Social Determinants of Health Inequality

***Health in All Policies* across National strategies and Policies:**
- Education
- Welfare
- Social
- Health
- Economic
- Housing and Homelessness
- Workforce
- Environment

Mid-level & local government delivery of services

Causes of social stratification

Socioeconomic status and poverty
Education Level
Occupation
Childhood poverty and adult income
Race/Ethnicity

Housing and Homelessness

Housing affordability
Low social housing stock
High unemployment
Housing policies
Housing services (Housing First, other community housing programs)
Homelessness services (non-residential and emergency accommodation)

Characteristics of homelessness

Health (Physical and Psychological)
Cognitive and psychological wellbeing (psychological stress, post-traumatic stress disorder, cognitive disability)

Mental health (depression & anxiety, self-harm, other mental health conditions)

Physical health (chronic conditions including diabetes and cardiovascular disease)

Stigma, labelling and discrimination leading to poor engagement with primary and preventative health care

Economic Disadvantage
Food and economic health insecurity (unhealthy food, nutritionally deficient)
Medication availability

Maladaptive coping strategies and risk-taking behaviours
Fights
Head trauma,
Illegality & contact with justice system
Unsafe sexual practices
Alcohol, tobacco and other substance abuse

Exposure to environmental factors
Environmental settings
Weather-related factors
Overcrowding
Substandard, inadequate shelter

Individual-level modifiable risk factors for dementia

Less education
Hypertension
Hearing impairment
Smoking
Obesity
Depression
Physical inactivity
Diabetes
Social isolation
Excessive alcohol
Traumatic brain injury
Air pollution

Livingston et al (2020) risk factors

Some dementia risk exposures for people experiencing homelessness may occur earlier in the life course than usually experienced by the general population

Plus

Additional, individual-level, potentially relevant modifiable risk factors for dementia associated with homelessness include:

Oral disease and dental decay
Illicit drug use, particularly methamphetamine
Childhood adversity
Neurologically impacting infections
Stress
Incarceration
Nutritional deficiency
Mental health conditions
Poor sleep quality & sleep deficiency
Premature ageing

Figure 41. Exposures for Dementia risk in homelessness. A Gestalt Model of Pathways and Mechanisms

Explaining the model of Pathways and Mechanisms (Figure 41)

Noticeable connections exist between structural, and societal causes of homelessness and potentially modifiable risk factors for dementia. Figure 41 illustrates findings from this thesis to show clear patterns of dementia risk associated with homelessness. The CSDH framework,[307] discussed in Chapter 4, captures the processes of socially determined dementia risk. Governance, the socio-political lens, causes of stratification, housing and homelessness policies and a range of intermediary and individual determinants indicate how exposures for dementia are generated. Data derived from Chapter 5: *The Lived Experience*, serves as the primary information source for Figure 41, supported by information contextualised from the broader literature and insights from Chapter 6: *Stakeholders in Homelessness*. The following sections discuss key points contained within this gestalt model of pathways and mechanisms for exposures to dementia risk.

Governance and socio-political lens

Applying critical theory and using the social determinants of health lens within the CSDH framework, it is possible to identify that a range of socio-political and economic factors emerge from power structures that contribute to health inequities. There are systemic factors that perpetuate poor cognitive health. They include inequitable distribution of financial and material resources, social stratification that access to healthcare and social marginalisation and discrimination.[99, 410, 411] Policies that are influential for health equity, and therefore cognitive health equity, include welfare, housing and homelessness policies. These policies, however, are structural determinants that create social stratification and for people whom they disadvantage they become barriers to cognitive wellbeing.

Health inequities persist regardless of the South Australian government’s commitment to ‘Health in all Policies’, an approach for integrating health considerations in policy making. Theoretically, policies such as ‘Health in All Policies’[56, 412, 413] should be remedial for the health of people experiencing homelessness, however, evidence from this data suggests that benefits have not translated into healthy outcomes as poor health continues to persist in homelessness.

‘Health in All Policies’ has its roots in the 1978 Alma-Ata declaration and the 1986 Ottawa Charter for Health Promotion and was developed to attain the highest level of health through the broad interactions of all policies to create a horizontal approach to health policy.[414] It commenced in South Australia in 2007 following a key ‘Thinker in Residence’ address, and recommendations made by Professor Ilona Kickbusch in Adelaide with the purpose of addressing the social determinants of health and health equity.[413] ‘Health in All Policies’ provides a framework of guidance, used as a tool for health-focussed policy decision making and the fostering of an intersectoral approach to produce population-level health benefits.[413, 415] As such, a ‘Health in All Policies’ approach should act as a principal tool towards addressing mechanisms for dementia risk exposure, levelling dementia risk for people experiencing homelessness.

However, some limitations of ‘Health in All Policies’ have been identified, primarily in its implementation, or lack thereof. Familiar and comfortable government systems, across and within long-defined government portfolios, create silos that ‘Health in All Policies’ has not always been able to transcend,[412] resulting in minor modifications to policies that remain insufficient. The central ‘Health in All Policies’ focus becomes lost regarding health equity and instead, governments shift attention toward different policy priorities.[413] Similarly, effecting change requires funding, and the lack of available budget can present a justification for the non-implementation of ‘Health in All Policies’.[413] The data indicates the continuing effects of social policies, such as homelessness, housing, welfare, and other socially defined concerns affecting people experiencing homelessness, for example, inaction on implementing a national *Housing First* approach, as discussed in Chapter 6. This represents a missed opportunity for improving housing outcomes that would benefit cognitive wellbeing and reduce exposure to dementia risk seen in primary and tertiary homelessness.

What are the structural barriers to cognitive wellbeing?

Structural barriers to homelessness and health outcomes have been identified in this thesis. An example is seen from the data in Chapter 5: *The Lived Experience* which discusses the accessibility of the Australian flagship disability agency, a gateway for all people seeking disability services. For people experiencing homeless, the process to access services can be difficult, protracted, and at times, impossible. The problem for the national disability agency is that disability is highly prevalent in homelessness, which is understandable in so far as disability is itself a risk factor for poor housing outcomes and a known entry point into homelessness.[416] It is reported that in Australia in 2022, 30% of all specialist homelessness service clients have a severe or profound disability, and just over half (51%) were provided some type of accommodation.[417] However, in many cases, people are being denied disability services because appropriate supports cannot be implemented in a homelessness context, and in the absence of safe, secure housing, disability service provision becomes unavailable.[418]

A difficulty arises when policies and strategies apply a ‘one-size-fits-all’ approach across all population groups and localities. As identified in *The Lived Experience,* and noted across the broader literature in general, homelessness is associated with high rates cognitive impairment, intellectual disability and attention deficit hyperactivity disorder, which are all distinct considerations for homeless youth.[121, 200, 419] Access to disability support for clinical management, and assistance to gain the skills and education needed to re-enter the workforce become imperative interventions for disrupting the cycle of homelessness and opening opportunity for having secure income and accommodation. The significance of this is twofold. First, cognitive impairment and intellectual disability likely increases the risk for dementia.[420-422] Second, and importantly, when a failure occurs in one social determinant, it creates unfavourable relationships across multiple determinants, resulting in a downward spiral of disadvantage, and the greater the socioeconomic disadvantage, the greater the risk for late-life dementia.[174, 192, 197]

Best practice approaches are always good to adopt, and *Housing First,* first discussed in Chapter 2, is an international leading example that, when implemented by its principles for rapid housing, consumer choice, separation of clinical and housing services, being recovery orientated, and focused on community integration, can make a demonstrable difference to chronic homelessness. *Stakeholders in Homelessness* identified many benefits from the *Housing First* model, with considerable benefits seen across other social determinants, for example, in improved health, social and justice outcomes.[94, 102] However, difficulties persist in entrenching *Housing First* as the preeminent Australian policy for homelessness. These difficulties endure because the distribution of funding for homelessness is pre-allocated to specific services and programs within homelessness providers and the *Housing First* model is expensive. It is hard for agencies to build extensive property portfolios due to costs and the shortage of available social housing, and especially so in the current environment of housing unaffordability, which majorly exacerbates the causes of homelessness in the first place, making part of the solution as part of the problem. Not least, implementing *Housing First* on a national scale is complicated by the highly complex homelessness system itself, making it hard to introduce the necessary reforms and adjustments.[102]

A noteworthy omission from the data, and important for both policy making and the aim of this thesis, is the lack of a register on homelessness mortality statistics in Australia.[114, 423] While increased morbidity suggests that people experiencing homelessness are more susceptible to premature and preventable death,[112, 116, 424] statistical evidence of this could not be confirmed in this thesis. There appears scant research on morbidity and specifically mortality among people experiencing homelessness in Australia, which may provide a better understanding around the impact of dementia in this community. The importance of gathering statistical data on homelessness morbidity and mortality (incidence and cause) cannot be understated. It is an imperative for recognising, highlighting, and addressing health and mortality inequity, and as a research gap, it is currently attracting interest.[425]

A statistical understanding of morbidity and mortality (incidence and cause) relative to homelessness would serve three important functions:

1. It would allow for a *Population Attributable Fraction* to be calculated. This would show the proportional reduction in dementia that would occur if exposure to a risk factor was eliminated.[426] Whilst the modelling of potentially modifiable risk factors for dementia by Livingston[66] applies a Population Attributable Fraction, this was not possible to calculate for risk factors in people experiencing homelessness. This is because of the *Population Attributable Fraction* formula reliance on statistics of the number of deaths or burden of disease, which is absent.

2. They would allow for a measure of *Disability Adjusted Life Years*. This is calculation made on the mortality and morbidity statistics to understand the burden of disease and measure lost health in years by making direct comparisons between different population groups.[427]
3. Reporting of statistics would illuminate the housing needs and health priorities of people experiencing homelessness, highlight mechanisms to reduce social stratification, and can be used to garner action for further funding allocation. Importantly, this could support the argument for a national implementation of the evidence -based *Housing First* approach as a standard approach within a Australian national homelessness strategy.[428]

Characteristics of homelessness

The characteristics of people experiencing homelessness investigated in Chapter 5: *The Lived Experience* provide a representation of factors that are unfavourable to cognitive wellbeing and brain health. The data from Chapter 5: *The Lived Experience* shows that antecedents to homelessness include a battery of characteristics that contribute to poor physical and mental health outcomes. These include personal histories of childhood trauma, state care or institutionalisation,[94] and other causes of childhood psychological stress have repercussions for late-life risk of dementia.[190, 429] Maladaptive responses to manage past trauma and the effects of homelessness can result in illegality, substance use, and self-destructive behaviours,[430] and adaptive techniques for stress may include the use of alcohol[431] and smoking.[188]

Whilst these individual risk factors may imply personal responsibility, they are, in fact, mechanisms that emerge from broader determinants, which in turn increase vulnerability to becoming or maintaining homeless.[74] Public perception of the causes of homelessness are often misplaced upon visible coping mechanisms of people. This is observed from Chapter 6: *Stakeholders in Homelessness* data which showed stakeholders to be concerned about labelling and stereotyping that increases discrimination and includes victim blaming that ignores systemic factors such as the enduring effects of poverty.[73, 406, 432]

Individual-level potentially modifiable risk factors for dementia

Potentially modifiable risk factors for dementia, by definition, suggests that risk can be amendable. However, action on reducing risk is profoundly more difficult in homelessness than across the general population, and targeted individual-level interventions are highly unlikely to succeed in people experiencing homelessness. Meeting basic healthcare needs is itself challenging when people are disengaged or distrusting with healthcare systems and people prioritise food and shelter over health concerns. As previously discussed in Chapter 6, stigma and discrimination create access barriers to health services,[137, 433] which is problematic for managing health conditions, and poorly managed conditions such as diabetes or heart disease can maintain risk for developing dementia. Data from Chapter 6 indicates that stakeholders support the belief that the multi-layered social factors shape exposure to dementia risk and must be addressed. Additionally, stakeholders perceived that risk exposures and management of their mechanisms will look differently in homelessness than seen in the general population.

Sufficiency of Livingston's model for twelve risk factors for dementia in homelessness

The Livingston et al. report to *The Lancet Commissions*[66] has had a seminal influence in identifying potentially modifiable risk factors for dementia. As discussed in Chapter 2, twelve potentially modifiable risk factors for dementia may reduce dementia prevalence by 40%. These risk factors (low education, traumatic head injury, excessive alcohol, social isolation, hypertension, physical inactivity, air pollution, diabetes, smoking, depression, obesity, and hearing loss) occur across a life course model for dementia risk exposure, presented in Chapter 2. However, this model was designed with a focus on the general population rather examining cognitive outcomes that emerge from experiencing homelessness. Livingston et al.[66] acknowledge that risk factors may cluster around inequities, including in vulnerable populations where "tacking these factors will involve not only health promotion, but also societal action to improve the circumstances in which people live their lives".[66 p.414] The findings from this thesis concur with this notion and provides the evidence to build on this concept. Without accounting for the different causes of risk for dementia, and the increased exposures people experiencing homelessness have to dementia risk, the Livingston et al.[66] model does not sufficiently present a picture of risk factors that can be contextualised in homelessness. Furthermore, people experiencing homelessness more likely to experience multiple exposures to dementia risk just as they experience multiple health adversities,[179] and do so at an earlier stage of the life course than that suggested by Livingston et al.[66] Data from this thesis suggests that many characteristics of homelessness parallel with risk factors for dementia and occur at an early age. These risk have been discussed in Chapter 5: *The Lived Experience*, however, examples explored in this thesis include very young age of smoking, educational disengagement, childhood trauma, and early illicit drug use.

That people experiencing homelessness are over-represented across known risk factors for dementia when compared with the general population is highlighted across this thesis. Data could not confirm exposure to air pollution or rates of obesity as this information was not available. However, the broader literature supports elevated rates of exposure to air pollution, especially when people are living alongside main traffic routes or near factories.[434, 435] Obesity presents in homelessness and is contrary to the stereotyping of being underweight.[436] A hunger-obesity paradox exists when people access low-cost, high calorific food because of high accessibility of fast food outlets and limited options to buy, store and cook their own food.[436] Low physical activity, poor sleep and stress are also reasons for obesity in homelessness.[436] Being either obese or appreciably underweight is a concern because diet can lack vital nutrients for brain health, such as thiamine, discussed in Chapter 5: *The Lived Experience*.

The Lived Experience integrative discussion presented evidence for many risk factors for dementia in the context of homelessness and compares findings against the Livingston et al. [66] as part of the Study One data integration. To complete an interpretation of the Study One and Study Two findings, an evaluation needs to be completed to assess sufficiency of the Livingston et al.[66] model in representing potentially modifiable risk for dementia in people experiencing homelessness. Table 18 provides a summary of how this assessment was made.

Table 18: Linking evidence between known potentially modifiable risk factors for dementia and homelessness

Risk factor identified by Livingston et al.[66]	**Common traits and characteristics of people experiencing homelessness – overview**	**Why those traits and characteristics are potentially modifiable risk factor for dementia - overview**	**Does the thesis data support the link?**
Low education	Low education levels are a risk factor for homelessness.[74] Adverse factors in child homelessness include disruption of education.[130]	Illiteracy is associated with an increased risk of incident dementia and poorer cognitive abilities.[437] However, this is disputed by Sala et al.[438] but higher levels of education are consistent with lower risk for late-life dementia.[174]	Yes. Data from Chapter 5:*The Lived Experience* show high rates of early school exits and low educational attainment.
Traumatic brain injury	The rate of traumatic brain injury is high among people experiencing homelessness when compared to the general population [187]. Traumatic brain injury is a common and underappreciated health problem in homelessness.[439]	Traumatic brain injury is associated with acute and long-term sequalae, and a risk factor for serious neurological illness.[439] Accumulating evidence suggests the traumatic brain injury is associated with risk for dementia.[440]	Yes. Data from Chapter 5:*The Lived Experience* showed 7% of survey participants had a traumatic brain injury.
Air pollution	People experiencing chronic, primary homelessness are exposed to a range of air polluting sources, including proximity to major roads.[435] People experiencing homelessness observe air-pollution and seek medical help for air pollution related health concerns, and negative health outcomes arise from air pollution.[434]	High levels of air pollution, specifically ozone, a factor for systemic inflammation that increases risk of Alzheimer's disease by 211% where people have been exposed to a 10.91 ppb increase in ozone over a 10-year period.[441] There are adverse effects resulting from air pollution on cognitive ageing and brain health.[442]	There was no data obtained in this thesis that could provide a measure of exposure to air pollution. Participants were unlikely to be cognisant of air pollution.
Excessive Alcohol use	Alcohol misuse has strong association with the initiation and persistence of homelessness.[119] Homeless men have an estimated prevalence rate of alcohol dependence 37.9% compared to 3 or 4 % of the general population.[443]	Robust evidence supports a relationship between excessive alcohol consumption and dementia risk [444]. Alcohol enhances neuroinflammation, with high levels of alcohol linked to an increase in dementia risk.[331]	Yes. Both Chapter 5:*The Lived Experience* and Chapter 6: *Stakeholders in Homelessness* show elevated rates of excessive alcohol use.
Smoking	Higher rates of smoking is observed in people experiencing homelessness.[119]	Current smoking increases dementia risk, which is more pronounced in people without APOE4 than with this genetic expression.[445]	Yes. Chapter 5:*The Lived Experience* demonstrated early and frequent use of cigarette smoking. Smoking was the most common coping mechanism used.
Hypertension	Rates of hypertension are similar to low-income groups, but more likely to poorly controlled than in the general population.[119]	Cognitive decline in late-life has a relationship with mid-life hypertension [446]. Hypertension is	Yes, when cardiovascular disease used as a proxy for metrics.

Risk factor identified by Livingston et al.[66]	Common traits and characteristics of people experiencing homelessness – overview	Why those traits and characteristics are potentially modifiable risk factor for dementia - overview	Does the thesis data support the link?
	Hypertension is a risk for cardiovascular disease, a major cause of death for people experiencing homelessness, with higher prevalence than seen in the general population.[124]	associated with a 19% increased risk for dementia.[447]	
Diabetes	Diabetes is more likely to be poorly managed in people experiencing homelessness, with the average HbA1c higher in homelessness than that seen in the general population.[448] However, Bernstein et al.[449] disagreed, finding no difference in diabetes rates between homelessness and general populations.[119]	A U-shaped dementia risk over time exists for people with diabetes.[450] Diabetes (Type 2) is associated with a 1.5 to 2.5 fold greater risk of dementia, it is a significant risk factor for not only vascular dementia, but also Alzheimer's disease.[451] Diabetes (Type 2) has a bi-directional relationship with Alzheimer's disease, involving modifications to vascular function & structure and other mechanisms contributing to neurodegeneration.[452]	Yes. The data indicated higher rates of diabetes in people experiencing primary homelessness compared with the general population.
Social isolation	Social isolation is a frequent characteristic of homelessness.[74] People experiencing homeless faced rejection from non-homeless, loss of critical networks, lack of companionship and low quality relationships with the homeless community.[343]	Social connectedness (social bridging and social bonding) has implications for cognitive ageing, affecting trajectories of cognitive decline, including dementia.[201] Social isolation is an important risk factor for dementia, with living alone associated with a greater risk than physical activity, hypertension, diabetes and obesity.[453]	Yes, when loneliness used as a proxy for metrics. There were high rates of loneliness evidenced in Chapter 5:*The Lived Experience* and Chapter 6: *Stakeholders in Homelessness*
Hearing loss	High rates of hearing loss in the homeless population are suggested, and barriers to access resources, such as hearing aids, could be reduced.[454] In one cohort study, more than a third (35.6%) of 350 older homeless people had a hearing impairment, yet only three had a hearing aid.[370]	Hearing loss has been shown to be strongly correlated with increased social isolation, reduced earning potential and higher rates of neurocognitive disease.[454] Elderly people with hearing loss have an increased rate of developing dementia with more rapid decline seen on a modified mini-mental state examination cognitive test compared to their hearing counterparts.[455]	Yes. Data from Chapter 5:*The Lived Experience* shows 27.9% of primary homelessness reported hearing loss over any wave of data collection. General populations rates of hearing loss are approximately 14.5%.
Physical inactivity	Limited data across studies suggest that the level of physical activity in people experiencing, or at risk of homelessness is low.[456] Physical activities, such as street	Greater physical activity is associated with reduced cognitive decline and lowered risk for developing dementia, and physical activity hold possibility of reverse causation with physical	There was no data obtained in this thesis that could provide a measure of physical activity.

Risk factor identified by Livingston et al.[66]	Common traits and characteristics of people experiencing homelessness – overview	Why those traits and characteristics are potentially modifiable risk factor for dementia - overview	Does the thesis data support the link?
	football improved postural balance, and bone mineral density.[457]	activity having a strong protective factor on dementia risk.[32]	
Obesity	Findings from one study showed that less than one-third of people experiencing homelessness ate vegetables daily; while almost two-thirds seldom ate fruit, salad, fruit juice or wholemeal products. For men and women diets were high in saturated fat and nonmilk extrinsic sugar.[458]	Obesity triggers vascular dementia through mechanisms of decreased cerebral blood supply causing cognitive decline, the role of adipocyte-secreted proteins and inflammatory cytokines, but also a leptin-driven reverse association is seen with elevated body mass in late-life.[459]	No data obtained in this thesis, however, risk factors for obesity are evidenced in Chapter 5: *The Lived Experience* as a socioeconomic risk and in narratives regarding high calorific foods that are affordable.
Depression	In a review of 17,215 participants, analysis showed that the prevalence of depressive symptoms was high among younger homeless people. Of all participants, nearly half, one-fourth, and one-tenth of people experiencing homelessness are suffering from depressive symptoms, dysthymia, and major depressive disorders respectively.[460] Comparative studies between homeless and non-homeless population showed rates of depressive symptoms are 5 to 14 times higher in the homeless population.[461]	Depression should be considered as being a risk factor for dementia, especially Alzheimer’s Disease.[452] Mid-life depression is associated with associated with approximately a two-fold increase in risk for Alzheimer’s Disease, with neurodegenerative damage and hippocampal atrophy causing the earlier attainment of clinical threshold for dementia.[32]	Yes. Data from Chapter 5:*The Lived Experience* evidenced high rates of depression associated with homelessness.

The Livingston et al. model[66] alone does not fully capture additional and relevant risk factors for dementia in homelessness. Using the data arising from this thesis, and contextualised from the broader literature, arguably an additional ten potentially modifiable risk factors for dementia must be included:

1. **Illicit drug use** (from the thesis data). Drugs such as amphetamine can have a direct effect on neurones and impair cognitive function.[337]
2. **Childhood adversity** (from the thesis data). Includes neglect, trauma, physical and sexual abuse, or institutionalisation. All present an increased risk for dementia.[190, 312, 429]
3. **Stress** (from the thesis data). Homelessness is associated with high levels of stress which are a risk factor for dementia.[315, 355, 462]
4. **Incarceration** (from the thesis data). Evidence is showing incarceration to be a risk factor for dementia, mediated through several pathways, including social isolation, and post-release factors.[342, 463, 464]
5. **Nutritional deficiency** (from the broader literature). Nutritionally deficient diet presents a risk to cognitive functioning.[465, 466]
6. **Mental health conditions** (from the thesis data). Major depressive disorders have been recognised for increased risk within the Livingston (2020) report, however, other mental health conditions are over-represented in homelessness, and present an increased risk, including schizophrenia[467, 468] and post-traumatic stress disorder.[469]
7. **Sleep** (from the thesis data). Sleep is often disordered in homelessness, and chronic sleep disturbance increases risk for dementia.[361, 470]
8. **Premature ageing** (from the thesis data). Multiple assaults on physical and mental health, and increased allostatic load is common in older people experiencing homelessness. Low socioeconomic status accelerates premature ageing and exposures people to geriatric conditions, including risk for dementia.[172, 369, 471]
9. **Poor oral care and dental decay** (from the broader literature). The risk for systemic infection through poor oral health is a factor recognised for increased risk for dementia.[371, 372, 472, 473]

10. **Neurologically impacting infection** (from the broader literature). People experiencing homelessness are at high risk of neurologically impacting infections, including human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS),[474] syphilis,[475] and herpes simplex virus.[476 477] Transmission risk is garnered through injecting illicit drugs,[299] (rates of drug use through injecting are presented in Chapter 5: *The Lived Experience*) or sex risk behaviours,[478] both frequently seen in homelessness.[479] However, people living with HIV/AIDS now face less risk for developing dementia when effectively managed by highly active anti-retroviral therapy.[480] Herpes simplex virus is also manageable using suppressive therapies, however, not all studies have supported its role in incident dementia.[481] Other considerations for potentially neurologically impacting infections include hepatitis C, now a curable disease with alfa interferons or directly acting antiviral therapies,[482] and syphilis, which has the potential to progress into neurosyphilis unless treated with antibiotics.[483]

A new model of potentially modifiable risk factors

The insufficiency of the Livingston et al.[66] model to fully illustrate potentially modifiable risk factors for dementia in people experiencing homelessness requires action, and a new model has been developed from the results of this research. (Figure 42). The new model combines dementia risk factors identified by Livingston et al.[66] with dementia risk exposures identified in this study and those supported by evidence seen across the broader literature. The new model is simplified to allow for future development. For example, it cannot show a population attributable fraction, discussed earlier in this chapter, because data on mortality and morbidity rates of people experiencing homelessness that are required to calculate this measure are not yet collected in Australian. The new model follows that of Livingston et al (2020) by providing a basic life course division over three specific time frames: early life – childhood and adolescence (youth), Mid-life – young adult to age 40 years, and later-life, over the age of 40 years. These age divisions have been adjusted to account for the shorter lifespan observed in people experiencing homelessness.[114]

The model for potentially modifiable risk factors for dementia in homelessness is presented in Figure 42.

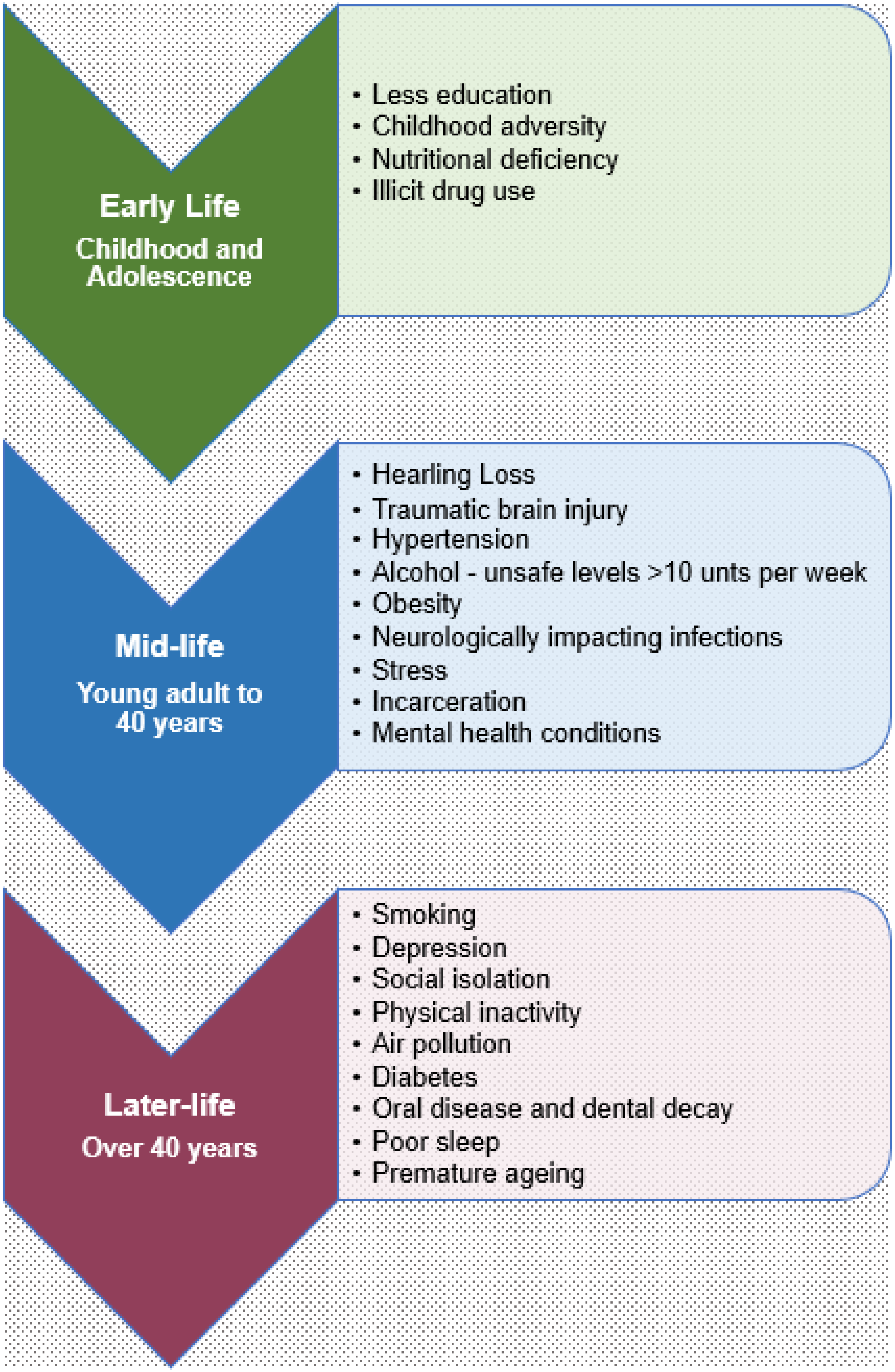


Figure 42. A new model for potentially modifiable risk factors for dementia in people experiencing homelessness

Using the epistemological position of critical theory applied to this thesis, there is a congruence in the use of the CSDH framework under a social determinants of health lens and actions under a transformative approach as both are grounded in principles of equity.[44, 266] Transformative actions direct focus on improving cognitive wellbeing based on values grounded in social justice and focussed on community need.[51, 266] They have been previously described in Chapter 4 of this thesis and discussed throughout Chapter 6, reducing the risk of dementia for people experiencing homelessness.

Regarding dementia risk reduction, these actions extend far beyond simplistic messaging to eat a Mediterranean diet, increase your physical activity, challenge your brain, and improve other familiar behavioural actions to reduce a personal risk of developing dementia. The current risk reduction messages are problematic will not resonate with people experiencing homelessness, who will feel further labelled and marginalised for not being able to action these messages. Unfair expectations to respond to these messages can be a harmful imposition and goes directly against the principles for transformative actions based on ethical and inclusive assumptions.[51]

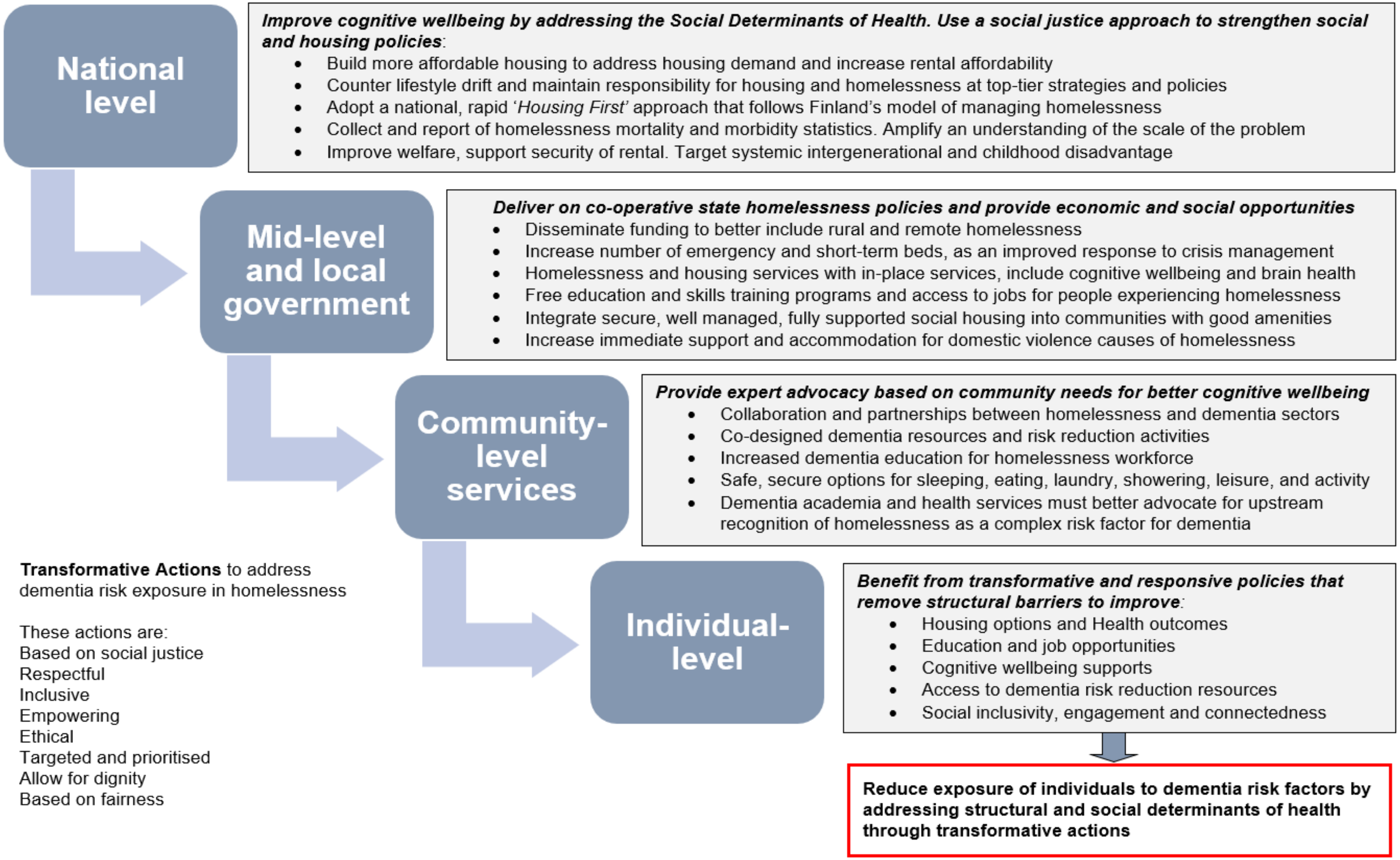
Transformative actions needed to address barriers to cognitive health and dementia risk reduction are complimentary and advance those proposed in the CSDH framework[44] given their focus on equity in health and wellbeing (discussed in Chapters 2 and 6). Nonetheless, stakeholders in homelessness did not necessarily relate dementia risk reduction to the socio-political climate, policy decisions or broader factors of the social determinants of health. Given that dementia risk reduction was not their focus of service support, and the low dementia knowledge across the workforce, this was to be expected.

When stakeholder participants were asked to consider ways in which dementia risk reduction could be implemented, their primary focus was placed upon individual behavioural factors of clients that could be supported through social engagement programs, such as weekly walking groups, music and art-based programs, cooking activities and a monthly newsletter. In addition, some suggestions were for activities based around skill acquisition, for example, acquiring computer skills, that are especially important for addressing the occupational needs of young people experiencing homelessness.[484] Whilst these are worthy and important suggestions, overarching and far-reaching recommendations for risk reduction begin with structural determinants at the national and mid-level government. Transformative actions at this level should include strong advocacy for health and housing policies to positively discriminate toward people experiencing homelessness, champion affordable housing and welfare to prevent people from becoming homeless and unify support for a nationally implemented *Housing First* policy to accommodate people experiencing homelessness. These actions target root causes of cognitive inequity because they recognise housing as a pivotal, although not only, influence on cognitive wellbeing. The establishment of a homelessness morbidity and mortality register, discussed earlier in this chapter, would provide a social justice approach to understanding the scope of health conditions and fatality linked to homelessness and provide foundations for in-place homelessness health services.

At a community-level, the thesis data showed that homelessness services providers are enthusiastic for partnerships that will bolster (i) dementia awareness and brain health for people experiencing homelessness, (ii) present a unified stance to advocate for funding, and (iii) provide a mechanism for reciprocal knowledge sharing. However, the greater transformative value relies on opportunities for client inclusiveness and co-design of programs and activities. The data provides evidence that homelessness is associated with high levels of trauma, and trauma-informed approaches to education, activities and programs is essential for clients and in supporting the workforce.[485]

At the individual level, improvements for cognitive wellbeing stemming from improvements to structural and societal determinants of health, and community-level interventions that engage people experiencing homelessness and involve them in decision-making processes may provide outcomes for implementing dementia risk reduction interventions.

Suggested opportunities for transformative actions to reduce dementia risk are shown in Figure 43.



National level

Improve cognitive wellbeing by addressing the Social Determinants of Health. Use a social justice approach to strengthen social and housing policies:

- Build more affordable housing to address housing demand and increase rental affordability
- Counter lifestyle drift and maintain responsibility for housing and homelessness at top-tier strategies and policies
- Adopt a national, rapid '*Housing First*' approach that follows Finland's model of managing homelessness
- Collect and report of homelessness mortality and morbidity statistics. Amplify an understanding of the scale of the problem
- Improve welfare, support security of rental. Target systemic intergenerational and childhood disadvantage

Mid-level and local government

Deliver on co-operative state homelessness policies and provide economic and social opportunities

- Disseminate funding to better include rural and remote homelessness
- Increase number of emergency and short-term beds, as an improved response to crisis management
- Homelessness and housing services with in-place services, include cognitive wellbeing and brain health
- Free education and skills training programs and access to jobs for people experiencing homelessness
- Integrate secure, well managed, fully supported social housing into communities with good amenities
- Increase immediate support and accommodation for domestic violence causes of homelessness

Community-level services

Provide expert advocacy based on community needs for better cognitive wellbeing

- Collaboration and partnerships between homelessness and dementia sectors
- Co-designed dementia resources and risk reduction activities
- Increased dementia education for homelessness workforce
- Safe, secure options for sleeping, eating, laundry, showering, leisure, and activity
- Dementia academia and health services must better advocate for upstream recognition of homelessness as a complex risk factor for dementia

Individual-level

Benefit from transformative and responsive policies that remove structural barriers to improve:

- Housing options and Health outcomes
- Education and job opportunities
- Cognitive wellbeing supports
- Access to dementia risk reduction resources
- Social inclusivity, engagement and connectedness

Reduce exposure of individuals to dementia risk factors by addressing structural and social determinants of health through transformative actions

Transformative Actions to address dementia risk exposure in homelessness

These actions are:
Based on social justice
Respectful
Inclusive
Empowering
Ethical
Targeted and prioritised
Allow for dignity
Based on fairness

Figure 43. Proposed opportunities for multi-level transformative actions

Recommendations moving forward

Recommendations for dementia risk reduction are hard to conceptualise if the core issue of homelessness has not been addressed. Homelessness is *the* significant barrier to cognitive wellbeing and dementia risk reduction and its absence would reduce exposure to dementia risk. Therefore, the ideal recommendation is for transformative advocacy, using a social justice perspective, to end homelessness. However, you cannot eradicate homelessness without addressing the social determinants of health and their upstream and downstream factors. National-level approaches should strengthen housing, health and welfare policies to reduce concerns and counter homelessness. In Australia, the State and Territory Governments hold primary responsibility for public and community housing and homelessness services. However, in the 2020 to 2021 period, the Australian Government allocated $8.4 billion to support housing and homelessness,[486] yet homelessness rates are increasing. This suggests that ending homelessness requires a different approach from current strategies to see any improvements, and it is not enough to accept the scarcity of social housing as a settled problem to be managed. However, if homeliness cannot be eradicated, what else can be done? Multisectoral working is essential when addressing structural causes of health inequity across housing and other socially defined factors[487] that expose people to dementia risk. Upskilling the homelessness workforce to focus on more tangible interventions and risk reduction activities can help.

Specialist dementia service providers have a vital role in meeting obligations for dementia awareness, services, programs and resources that reach marginalised groups. Consistent and dedicated funding is required for meaningful engagement with homelessness service providers beyond temporary, improvised or case-by-case interaction. There is exigent need to amend the ambivalence around cultural, social and economic drivers that disregard human rights and dementia in the aged care and community sectors.[488] This begins with purposeful dementia awareness for risk reduction, knowledge acquisition, and appropriate adjustments to service delivery.

A list of recommendations arising from this thesis is shown in Table 19.

Table 19. Recommendations arising from this thesis

Level	Recommended actions	Who
Structural	Housing: Provide advocacy for a nationally consistent approach to addressing homelessness. Be reflexive in approach. Evidence *Housing First* models as potential standard for best practice.	Management (homelessness sector)
	Data: Establish a national registry for mortality (cause and incidence) in homelessness. Consider the Homeless Mortality toolkit developed by the National Health Care for Homeless.	Management (homelessness sector) Broader health services. Coronial services
	Strategy: Work towards a stronger 'Health in All Policies' approach is needed, particularly across housing, health, social and welfare policies, to improve cognitive wellbeing and brain health outcomes.	Homelessness and community housing providers
Community	Risk factors for dementia in homelessness must be explained in the context of the structural and societal barriers rather than being focussed on individual factors alone. Advocacy must be robust and consistent community engagement maintained.	Specialist dementia services
	Both homelessness and specialist dementia sectors must establish collaborative working practices to benefit brain health and improved knowledge across sectors. Brain health should underpin programs and social activities provided for people experiencing homelessness. Service provision should use a trauma-informed approach.	Specialist dementia services to provide educational development for the homelessness workforce
	Consider in-place, culturally appropriate supports that provide a suite of services to benefit cognitive wellbeing (podiatry, hearing, dental, medical and cognition). Provide talks and suitable resources for people wanting to learn about brain healthy.	Specialist dementia services Homelessness and community housing providers
Individual	The onus of dementia risk reduction must not be placed upon individuals who do not have agency in policies and other structural determinants that unfavourably influence their cognitive wellbeing	Specialist dementia services Homelessness and community housing providers
	Encourage agency for resources co-design, activities and programs that benefit brain health. Aim to increase awareness of brain health and cognitive wellbeing through inclusive approaches.	Specialist dementia services Homelessness and community housing providers

Figure 44 shows the completed research design and findings of this this thesis.

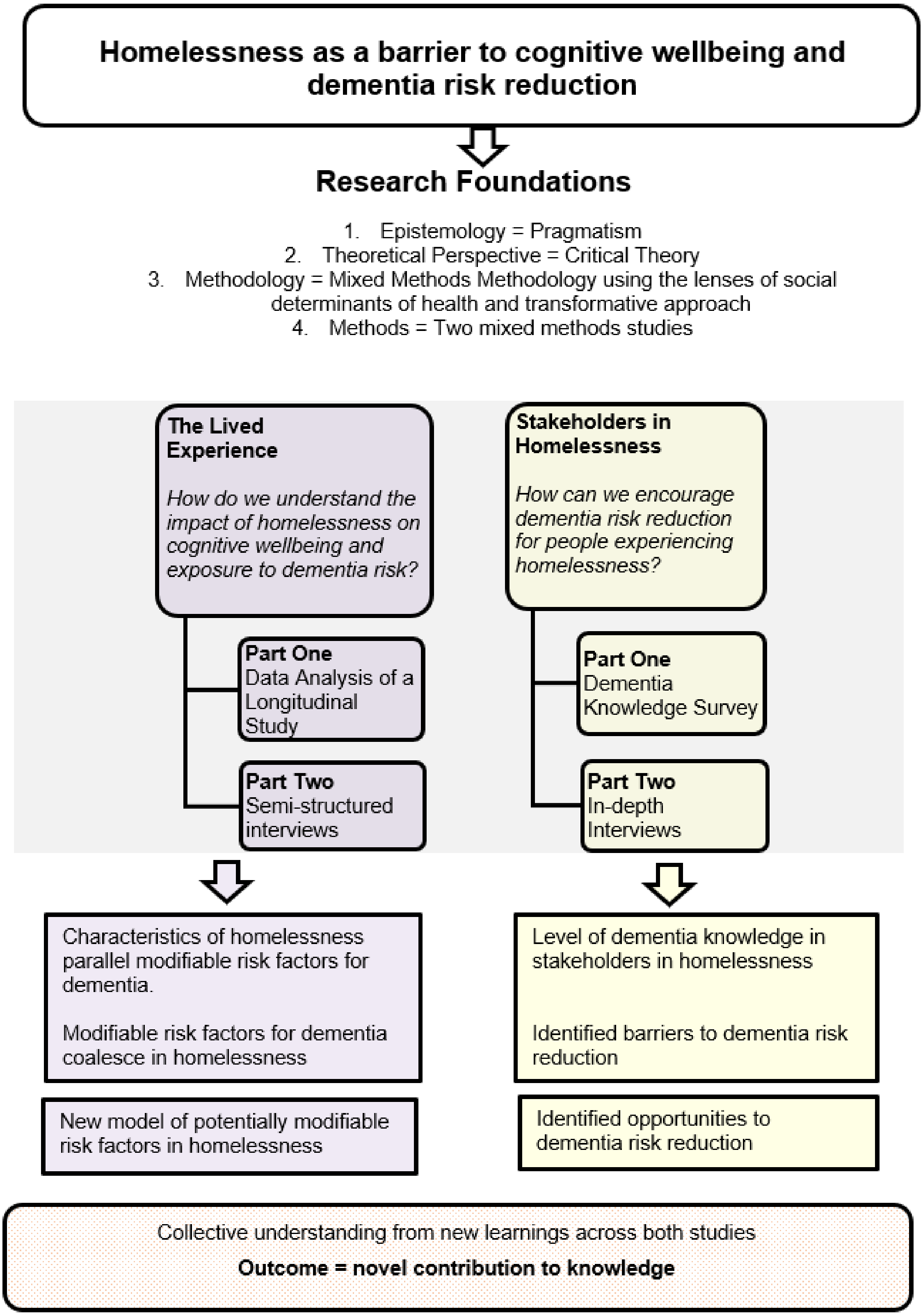


Figure 44. The completed research

Linking the research questions

The two research questions: *How does homelessness impact cognitive wellbeing and dementia risk?* and *How can dementia risk reduction for people experiencing homelessness be improved?* have been independently answered in this thesis across Study One and Study Two respectively. However, these questions are indivisibly linked to each other and the purpose of this inquiry. First, how the experience of homelessness affects cognitive wellbeing and dementia risk exposure is not well demonstrated as a social health issue nor understood from root structural and societal causes. The challenge for service providers is how to use this information to provide vigorous advocacy for change and assists the cognitive wellbeing of their clients. However, awareness of the social factors that influence cognitive wellbeing is insufficient without a practical knowledge of dementia risk. Second, mitigating potentially modifiable risk factors for dementia in homelessness is a challenge because, presently, homelessness service providers lack the dementia knowledge and skills required to implement risk reduction interventions and require support from specialist dementia service providers.

Original contribution to knowledge

This thesis presents the first detailed *mixed methods* study on understanding the juncture between the experience of homelessness, cognitive wellbeing, and exposure to potentially modifiable risk factors for dementia. Results identified analogous findings between characteristics of homelessness and exposures to dementia risk, presented in Study One: *The Lived Experience*. This thesis demonstrates the structural, societal and individual drivers from which cognitive risk emerges, and shows that risk factors for dementia coalesce because of the experience of homelessness. A novel contribution from these findings is a new life course model for potentially modifiable risk factors for dementia in homelessness (Figure 42).

Identifying barriers to cognitive wellbeing and dementia risk reduction in homelessness has previously been uncharted and provides a new contribution to knowledge. Based on the data contained in this thesis, a gestalt of pathways and mechanisms of dementia risk exposure in homelessness has been developed along with multi-level opportunities to reduce cognitive inequities. This provides a new understanding of barriers to cognitive wellbeing and dementia risk reduction. Study Two presents an opportunity exists for specialist dementia services to understand homelessness as a potentially modifiable risk factor for dementia and to subsequently introduce a program for dementia awareness, workforce training and co-design, collaborative supports.

Strengths and Limitations

A strength of this research lies with its comprehensive mixed methods and data integration approach to understanding cognitive wellbeing and dementia risk reduction in the context of homelessness. The approach to the research has remained respectful and productive. Another strength is with the scope of investigation, across both people experiencing homelessness and stakeholders in homelessness. A limitation of this thesis is that it could not directly examine all potentially modifiable risk factors for dementia, with some metrics unavailable in the *Journeys Home* data. This resulted in several risk factors being contextualised from the broader literature. A further limitation is that data has been drawn from a single state in Australia. However, containing the geographical boundary assisted in connecting the data sets across the two studies in this thesis. Regardless of geographic restriction, the findings are not limited to South Australia and will have applicability to broader national and international homeless communities. Additionally, there remains potential to develop the new model of potentially modifiable risk factors for dementia in homelessness further if it can be assisted by data to calculate a *Population Attributable Fraction.*

Implications of this research

Homelessness is increasing in Australia, and the socioeconomic gap is widening, meaning more people will be unfairly exposed to risk for dementia. Dementia still has no known cure and remains a primary cause of disability and death making risk reduction an important issue for improving cognitive wellbeing. Behavioural approaches to dementia risk reduction are not appropriate for people experiencing homelessness, and interventions must focus on distal factors that shape the circumstances for both homelessness and dementia risk exposure.

Homelessness Service providers and specialist dementia services have considerable responsibilities toward managing strategies that may negate or minimise dementia risk exposure.

Implications for service providers, be they homelessness or dementia sectors, lie in the findings and recommendations that come out of this research. Dementia and understanding of dementia risk reduction requires a trauma informed approach for people experiencing homelessness. Mainstream methods are both inappropriate and potentially harmful.

Thesis Conclusion

The thesis firstly presented the background for homelessness, dementia, and dementia risk reduction. The research gap is identified from a scoping review of potentially modifiable risk factors for dementia in people experiencing homelessness. The thesis then introduces the first of two mixed methods studies: *The Lived Experience.* Common characteristics of homelessness are identified from a descriptive statistical analysis. Findings are compared against known potentially modifiable risk factors and enriched by a concurrent narrative component. The second study, *Stakeholders in Homelessness,* examines the dementia knowledge within a cohort of the South Australian homelessness workforce and identifies barriers and facilitators to implementing dementia risk reduction. Both studies provide an integrated discussion of their findings which contribute to the overall interpretation of evidence. Finally, a list of recommendations is provided.

I began this thesis with a quote from Daniel Quinn, and now I end this thesis with another.

> **"Don't drive the homeless into places we find suitable.**
>
> **Help them survive in places they find suitable"**
>
> *Daniel Quinn (1999). "Beyond Civilisation: Humanity's Next Great Adventure" Harmony.*

CHAPTER 8: REFERENCES AND APPENDICIES

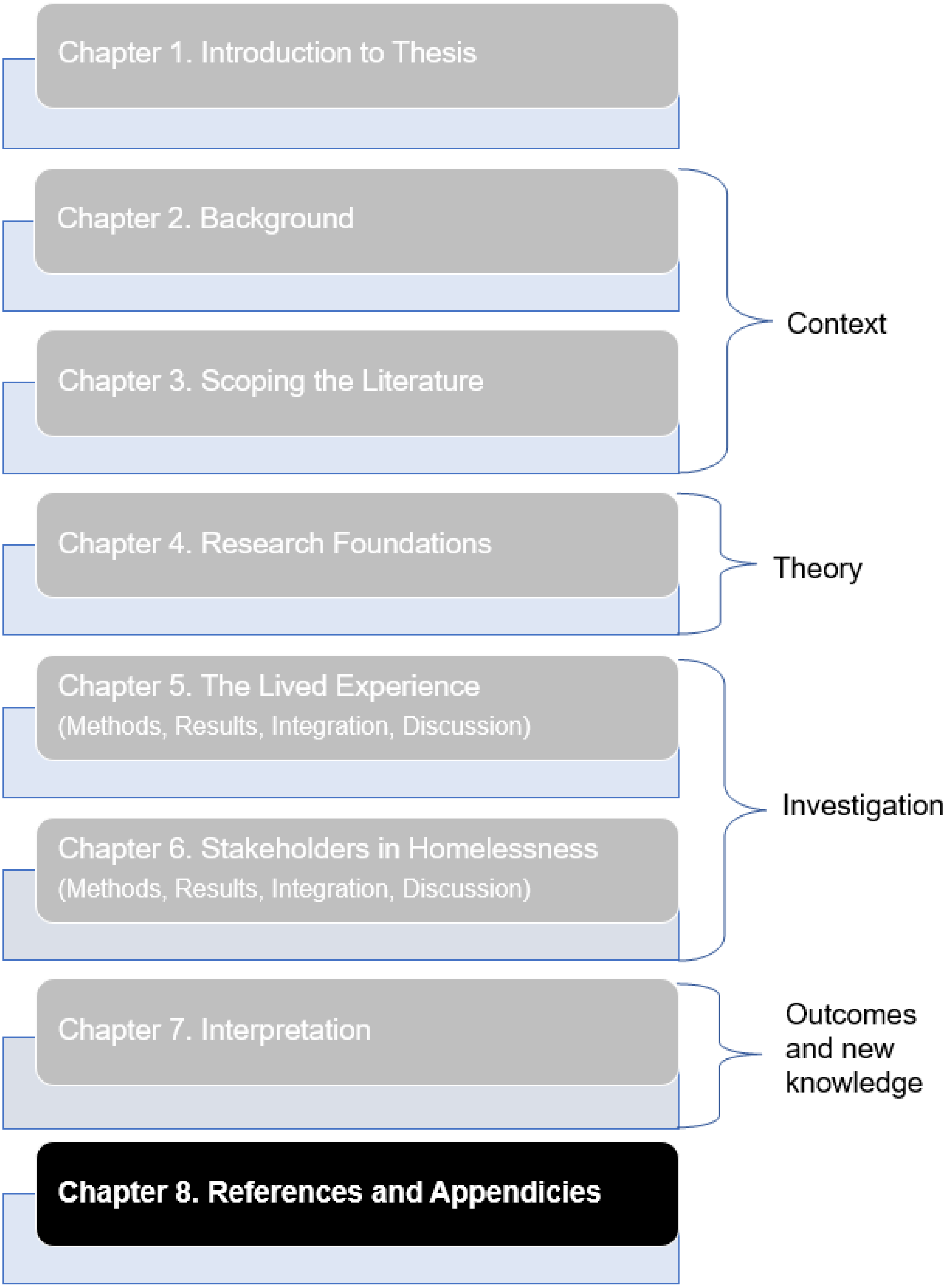


Figure 45. Thesis structure - Chapter 8

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Appendix 1. Interview Guide for semi-structured interviews

Interview Guide for semi-structured interviews.

Theis is a guide only and questions may be flexible to best suit the interview

Introduce yourself.

Remind participant that they can withdraw from the interview at any time, and that they can opt to not answer any question.

Discussion themes:

1. Housing situation
    - how long they are/have experienced housing stress.
    - Did they sleep in a bed last night?
    - Have they ever slept rough? Tell me about it
    - Do they feel safe in their housing situation?
2. Education and employment history
3. Social and physical activity
4. Typical diet – food quality/nutritional value/fresh fruit and vegetables?
5. How do they feel their physical and mental health is?
6. Their cognitive well-being – can explain as ‘brain health or thinking skills and memory for understanding – and what impacts on their cognitive well-being? Potential to identify:
    - Medication
    - Worry about housing or where to go to spend the night
    - Worry about others
    - Disability
    - Head injury
    - Stress
    - Mental health
    - Alcohol
    - Smoking
    - Other substance use
    - Sleep quality
    - Feeling happy or sad
    - Purposeful engagement
    - Social isolation
    - Mindfulness activities (music/reading/meditation/

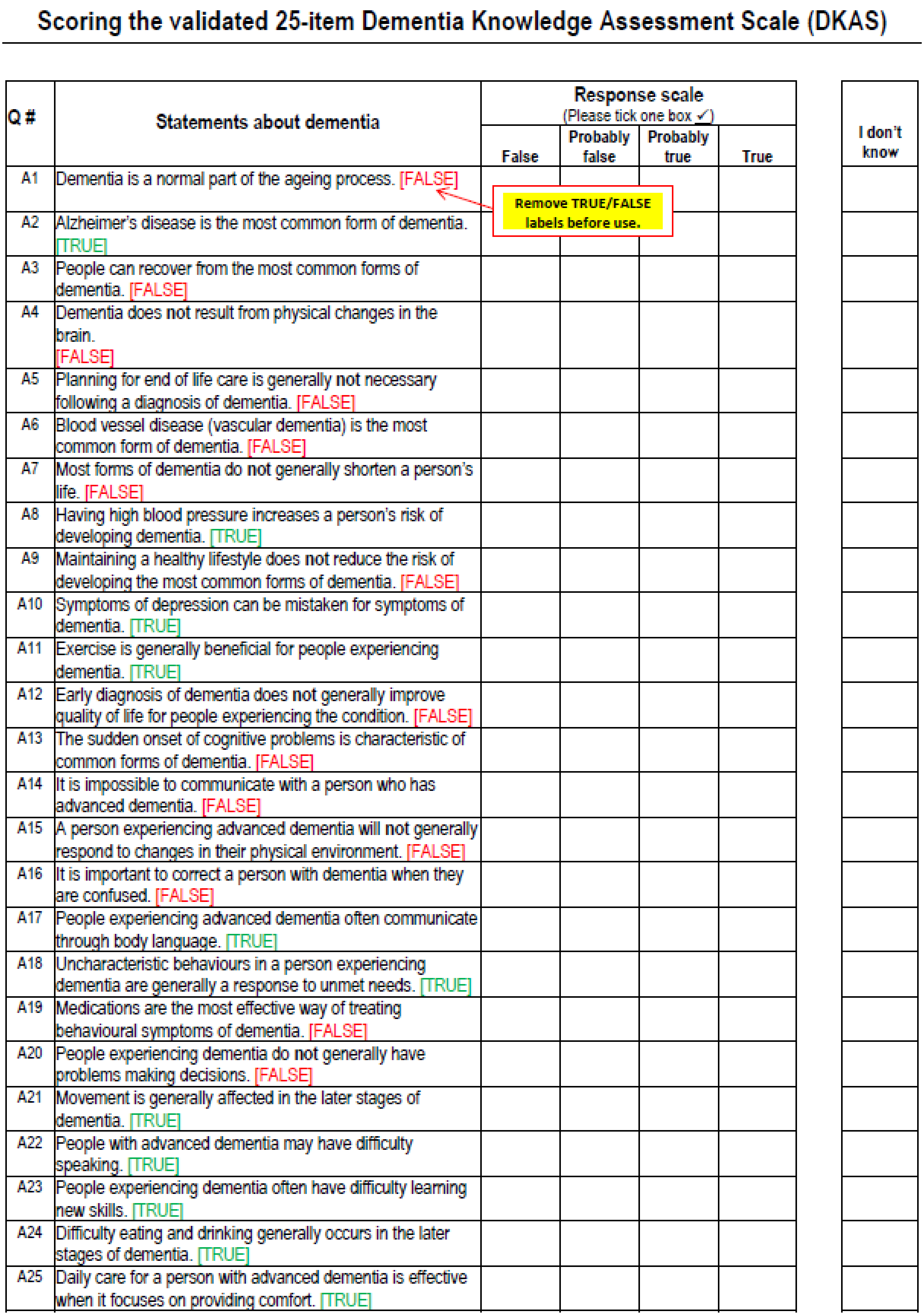
   - Other health condition
   - Concerns about cognition and memory.
   - Other things
7. Childhood and life experiences
8. What does ‘brain health’ mean to you? (How does being homelessness affect brain health? What would be good/bad brain health?) Anything else?

Ask the participant if they have anything further to contribute
Any questions?
Thank the participant for their contribution

Remind participant that they can review the transcript of the interview

Appendix 2. Dementia Knowledge Assessment Scale (DKAS) and scoring instructions

Credit: The Wicking Dementia Research and Education Centre. University of Tasmania. Australia.



Scoring the validated 25-item Dementia Knowledge Assessment Scale (DKAS)

Q #	Statements about dementia	Response scale (Please tick one box ✓)				I don't know
		False	Probably false	Probably true	True	
A1	Dementia is a normal part of the ageing process. [FALSE]					
A2	Alzheimer's disease is the most common form of dementia. [TRUE]					
A3	People can recover from the most common forms of dementia. [FALSE]					
A4	Dementia does **not** result from physical changes in the brain. [FALSE]					
A5	Planning for end of life care is generally **not** necessary following a diagnosis of dementia. [FALSE]					
A6	Blood vessel disease (vascular dementia) is the most common form of dementia. [FALSE]					
A7	Most forms of dementia do **not** generally shorten a person's life. [FALSE]					
A8	Having high blood pressure increases a person's risk of developing dementia. [TRUE]					
A9	Maintaining a healthy lifestyle does **not** reduce the risk of developing the most common forms of dementia. [FALSE]					
A10	Symptoms of depression can be mistaken for symptoms of dementia. [TRUE]					
A11	Exercise is generally beneficial for people experiencing dementia. [TRUE]					
A12	Early diagnosis of dementia does **not** generally improve quality of life for people experiencing the condition. [FALSE]					
A13	The sudden onset of cognitive problems is characteristic of common forms of dementia. [FALSE]					
A14	It is impossible to communicate with a person who has advanced dementia. [FALSE]					
A15	A person experiencing advanced dementia will **not** generally respond to changes in their physical environment. [FALSE]					
A16	It is important to correct a person with dementia when they are confused. [FALSE]					
A17	People experiencing advanced dementia often communicate through body language. [TRUE]					
A18	Uncharacteristic behaviours in a person experiencing dementia are generally a response to unmet needs. [TRUE]					
A19	Medications are the most effective way of treating behavioural symptoms of dementia. [FALSE]					
A20	People experiencing dementia do **not** generally have problems making decisions. [FALSE]					
A21	Movement is generally affected in the later stages of dementia. [TRUE]					
A22	People with advanced dementia may have difficulty speaking. [TRUE]					
A23	People experiencing dementia often have difficulty learning new skills. [TRUE]					
A24	Difficulty eating and drinking generally occurs in the later stages of dementia. [TRUE]					
A25	Daily care for a person with advanced dementia is effective when it focuses on providing comfort. [TRUE]					

Remove TRUE/FALSE labels before use.

The primary approach to scoring the valid and reliable 25-item version DKAS involves recoding responses and the calculation of a total, subscale and item scores using SPSS (or similar data analysis software).

Verified DKAS subscales

Subscale A: *Causes and Characteristics* (7 items scored out of 14): A1 + A2 + A3 + A4 + A5 + A6 + A7
This subscale describes fundamental information relating to the pathology and terminal course of dementia.

Subscale B: *Communication and Behaviour* (6 items scored out of 12): A14 + A15 + A16 + A17 + A18 + A19
This subscale describes information about how a person with dementia engages with the world.

Subscale C: *Care Considerations* (6 items scored out of 12): A20 + A21 + A22 + A23 + A24 + A25
This subscale describes symptoms that are relevant to the provision of care.

Subscale D: *Risk Factors and Health Promotion* (6 items scored out of 12): A8 + A9 + A10 + A11 + A12 + A13
This subscale describes information about risk factors and conditions that are associated with or mistaken for dementia.

DKAS scoring

Step one: in your database, DKAS response categories should be labelled as follows:

False	1
Probably false	2
Probably true	3
True	4
I don't know	5

Step two: recode results to reflect whether responses are correct (True) or incorrect (False) and apply the scoring system. *Examples of recoding in SPSS syntax:*

Insert name of item used in your database.

Insert desired name of recoded item.

```
RECODE [item_A1] (3,4,5=0) (1=2) (2=1)into [final_item_A1].
RECODE [item_A2] (1,2,5=0) (3=1) (4=2)into [final_item_A2].
```

The DKAS scoring system is as follows:

- Score 2 points for an answer of 'true' to a truthful (true) statement.
- Score 2 points for an answer of 'false' to an untrue (false) statement.
- Score 1 point for an answer of 'probably true' to a truthful (true) statement.
- Score 1 point for an answer of 'probably false' to an untrue (false) statement.
- Score 0 points for an answer of 'true' or 'probably true' to an untrue (false) statement.
- Score 0 points for an answer of 'false' or 'probably false' to a truthful (true) statement.
- Score 0 points for an answer of 'I don't know'.

Recoding of DKAS scores can be undertaken using the syntax function in SPSS. Note that the syntax below assumes that the order of items is the same as that presented in the scale.

Step four: sum items to provide a total score. The maximum total score on the DKAS is 50 points.

Step five: depict relative item scores and subscale scores. Subscales can be compared directly by creating a normalized score (that is – turning the score into a fractional score between 0 and 1).

Appendix 3. Flyer invitation and information sheet for people experiencing homelessness

People with a lived experience of homelessness

You are invited to participate in a Flinders University research study. The aim of the study is to:

1. Understand the experience of homelessness and how it may, or may not, affect brain health.

2. Examine how the experiences of homelessness may, or may not, affect the risk for developing dementia in later life.

I am interested in hearing your stories and experiences about:

- Your housing situation, now and in the past
- Education and employment
- How you socialise and keep physically active
- Your typical diet, and what influences your food choices
- General physical and mental health
- Your brain health and what you think affects this

Interviews are **confidential**. I need your name and how to contact you, but this information is kept private. Interviews will be audio recorded or I can take notes, but your identity is kept private.

Interviews may take up to an hour. They will take place at:

Insert place and time

People participating in the interview will receive a Woolworths or Coles voucher for $40.00.

For more information, please call or text Clare on **** **** ****

NOTE: Clare Beard has previously worked with people experiencing homelessness in a previous role with Dementia Australia and she may be known to potential participants. Should this be of concern, potential participants are advised not to apply for interview.

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Semi-structured interviews

Chief Investigator

Dr Annabelle Wilson

College of Medicine and Public Health

Flinders University

Co-Investigator

Ms Clare Beard

College of Medicine and Public Health

Flinders University

Supervisor

Dr Monica Cations

College of Education, Psychology and Social Work

Flinders University

My name is Clare Beard, and I am a Flinders University research student. I am undertaking this research as part of my degree. For further information, you are more than welcome to contact my supervisor. Her details are listed above.

Description of the study

This project will investigate homelessness as a barrier to cognitive wellbeing and dementia risk reduction. This project is supported by Flinders University, College of Medicine and Public Health.

Purpose of the study

This project aims to:

1. Understand the role of the social determinants of health in developing or contributing to social norms and behaviours that can lead to cognitive harm in homelessness
2. Examine how the experiences of homelessness build into a life trajectory risk for dementia
3. Better understand the cognitive impact of living homeless through a lived-experience narrative
4. Discover key themes relating to dementia risk through cognitively adverse behaviours in homelessness
5. Understand the level of dementia knowledge in homelessness services
6. Develop understanding of cognitive wellbeing supports in homelessness services across domains of social, physical, educational and mindfulness activities
7. Examine ways to embed dementia risk reduction into services and activities

Benefits of the study

The sharing of your experiences will help to significantly add depth to the understanding of the barriers that exist in homelessness to cognitive wellbeing dementia risk reduction. The interview will contribute to a list of recommendations in ways that dementia knowledge and risk reduction can be embedded into services and activities.

Participant involvement and potential risks

If you agree to participate in the research study, you will be asked to:

- attend a one-on-one interview with a researcher that will be audio recorded or written down
- respond to questions regarding your experience of homelessness and how this can impact on your cognitive wellbeing (keeping brain healthy).
- respond to questions regarding your personal circumstances such as housing history, social activities, general health, diet and physical activity.
- offer opinion on what impacts your cognitive wellbeing

The interview will take about 60 minutes and participation is entirely voluntary.

You may be exposed to some risk, including:

- participating in the research may cause you to recall unpleasant or distressing memories of your experience of homelessness.
- Participating in the research may cause you to consider, or have some concern, for your cognitive wellbeing, or brain health, and the risk for developing a dementia in later life.

The researchers do not expect the questions to cause any harm or discomfort to you. However, if you experience feelings of distress as a result of participation in this study, please let the research team know immediately. You can also contact the following services for support:

- Lifeline – 13 11 14, www.lifeline.org.au
- Beyond Blue – 1300 22 4636, www.beyondblue.org.au
- Dementia Australia Helpline – 1800 100 500

Withdrawal Rights

You may, without any penalty, decline to take part in this research study. If you decide to take part and later change your mind, you may, without any penalty, withdraw at any time without providing an explanation. To withdraw, please contact the Chief Investigator or you may just refuse to answer any questions. Any data collected up to the point of my withdrawal will be securely destroyed.

My decision not to participate or to withdraw from this research study will not affect my relationship with Flinders University and its staff and students.

Confidentiality and Privacy

Only researchers listed on this form have access to the individual information provided by me. Privacy and confidentiality will be assured at all times. The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will be protected at all times. I will not be named, and my individual information will not be identifiable in any research products without my explicit consent.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without my explicit consent.

Data Storage

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

Recognition of Contribution

If you would like to participate, in recognition of your contribution and participation time, you will be provided with a $40.00 voucher. This voucher will be provided to you face-to-face on completion of the interview.

How will I receive feedback?

On project completion, a short summary of the outcomes will be provided to all participants on request via email.

Ethics Committee Approval

The project has been approved by Flinders University’s Human Research Ethics Committee (HEG1861-1)

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University’s Research Ethics & Compliance Office team via telephone **** **** or email

NOTE: Clare Beard has previously worked with people experiencing homelessness in a previous role with Dementia Australia and she may be known to potential participants. Should this be of concern, potential participants are advised not to apply for interview.

Appendix 4. Emailed Information to Homelessness Service providers

Email text for Survey participation: sent to CEO or key person in homelessness organisation

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Flinders University logo

Dear………

Request for survey participation

My name is Clare Beard, and I am a Research Student at Flinders University. I am undertaking a study into homelessness as a barrier to cognitive wellbeing and dementia risk reduction. This research is being supervised by Dr Annabelle Wilson, College of Medicine and Public Health, Flinders University.

The aims of my study are to:

1. Understand the role of the social determinants of health in developing or contributing to social norms and behaviours that can lead to cognitive harm in homelessness

2. Examine how the experiences of homelessness build into a life trajectory risk for dementia

3. Better understand the cognitive impact of living homeless through a lived-experience narrative

4. Discover key themes relating to dementia risk through cognitively adverse behaviours in homelessness

5.Understand the level of dementia knowledge in homelessness services

6. Develop understanding of cognitive wellbeing supports in homelessness services across domains of social, physical, educational and mindfulness activities

7. Examine ways to embed dementia risk reduction into services and activities

I am contacting you to request if you can circulate this email for survey participation amongst your staff/colleagues/networks. The survey should take around 10-15 minutes to complete and is structured to be anonymous.

The survey can be accessed through this link:

https://qualtrics.flinders.edu.au/jfe/form/SV_6VitsOCwRNXkdmZ

A letter of introduction and an information sheet/consent form is attached to this email, although consent is implied through completion of the survey.

People are further invited to also register interest for a follow-up interview on the survey results and other aspects of this research, and particularly in discussing ways for dementia risk reduction for clients. For further information on this study, or to register interest for a follow-up interview please contact Clare Beard at ******** or phone: **** **** ****.

Regards

Clare Beard

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Homelessness as a barrier to cognitive wellbeing and dementia risk reduction: In-depth interviews

Chief Investigator

Dr Annabelle Wilson
College of Medicine and Public Health
Flinders University

Co-Investigator

Ms Clare Beard
College of Medicine and Public Health
Flinders University

Supervisor

Dr Monica Cations
College of Education, Psychology and Social Work
Flinders University

My name is Clare Beard, and I am a Flinders University higher degree by research student. I am undertaking this research as part of my degree. For further information, you are more than welcome to contact my supervisor. Her details are listed above.

Description of the study

This project will investigate homelessness as a barrier to cognitive wellbeing and dementia risk reduction. This project is supported by Flinders University, College of Medicine and Public Health.

Purpose of the study

This project aims to:

1. Understand the role of the social determinants of health in developing or contributing to social norms and behaviours that can lead to cognitive harm in homelessness
2. Examine how the experiences of homelessness build into a life trajectory risk for dementia
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5. Understand the level of dementia knowledge in homelessness services
6. Develop understanding of cognitive wellbeing supports in homelessness services across domains of social, physical, educational and mindfulness activities

7. Examine ways to embed dementia risk reduction into services and activities

Benefits of the study

The sharing of your expertise within homelessness services will help build a list of recommendations of ways in which dementia knowledge and dementia risk reduction can be embedded into services and activities. This is important as advancing age is a major risk factor for dementia and data from the Australian Institute for Health and Welfare indicates a trend for increasing numbers of older homeless people connecting to homelessness services, particularly women (AIHW, 2020). Having an increased understanding around barriers and facilitators to cognitive wellbeing and dementia risk reduction may benefit people experiencing homelessness and evidence suggests that in addressing modifiable dementia risk factors, delaying onset of dementia in some people may be possible (Livingston et al, 2017, Yaffe 2018).

Participant involvement and potential risks

If you agree to participate in the research study, you will be asked to:

- attend a one-on-one interview with a researcher that will be audio recorded
- discuss the results arising from the research
- discuss ways in which dementia risk reduction may be embedded into homelessness services

The interview will take about 60 minutes and participation is entirely voluntary.

Withdrawal Rights

You may, without any penalty, decline to take part in this research study. If you decide to take part and later change your mind, you may, without any penalty, withdraw at any time without providing an explanation. To withdraw, please contact the Chief Investigator or you may just refuse to answer any questions. Any data collected up to the point of my withdrawal will be securely destroyed.

My decision not to participate or to withdraw from this research study will not affect my relationship with Flinders University and its staff and students.

Confidentiality and Privacy

Only researchers listed on this form have access to the individual information provided by me. Privacy and confidentiality will be assured at all times. The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will be protected at all times. I will not be named, and my individual information will not be identifiable in any research products without my explicit consent.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without my explicit consent.

Data Storage

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

How will I receive feedback?

On project completion, a short summary of the outcomes will be provided to all participants on request via email.

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (HEG1861-1).

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet and if you accept our invitation to be involved, please sign the enclosed Consent Form.