

Investigating the acceptability and feasibility of a self-management care planning-based intervention: To improve cardiovascular health and quality of life of community-living adults with severe mental illness.

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THESIS SUMMARY

Globally, it has been well established that adults with severe mental illness (SMI) die 10-20 years earlier than the general population, mainly due to cardiovascular disease (CVD). To address this health inequity, the Flinders Chronic Condition Self-Management Program[™] (henceforth referred to as the Flinders Programme) was delivered from November 2017 to February 2021 among 120 South Australian community-living adults diagnosed with SMI and CVD risk factors in order to improve their cardiovascular health and quality of life. While there is ample evidence of the effectiveness of personcentred and recovery-oriented health interventions such as the Flinders Programme, their adoption and sustainability as part of routine care have been limited within the mental health system. This exploratory thesis aimed to investigate the underlying causes behind this systemic issue from a socio-cultural viewpoint by capturing and elevating key stakeholders' voices.

A longitudinal qualitative methodology underpinned by Roy Bhaskar's Critical Realism philosophy and ontology was employed for this research. The first research question examined how the delivery of the Flinders Programme was achieved. The second research question aimed to understand why, how, and in what context the Flinders Programme worked (or not). Qualitative data were collected from 48 key stakeholders involving 15 service users, 4 matched family caregivers, 10 matched health professionals, and 19 trial staff at multiple time points. Data were gathered through 61 interviews (31 service users, 7 caregivers, 13 health professionals, and 7 trial team member interviews), 2 focus group discussions (involving 4-8 trial team members), 10 series of meeting minutes (involving 8-12 trial team members), 5 trial team members' reflective journals (including the researcher's), and 8 service users' Flinders Programme care plans (7 service users dropped out of the larger trial after their initial interviews). Data analysis involved a four-step complex iterative process where findings from the different stakeholders were analysed and triangulated using the Critical Realist Analysis (CRA) and a longitudinal analytical approach.

The results found that service users' health-seeking behaviours were negatively impacted by their past experiences related to treatment coercion from the mental health system, and staff members' preconceptions regarding service users' ability to recover. Patriarchy in the service culture, funding issues, and resource mismanagement were identified as root causes resulting in a paucity of recovery-oriented care; they also triggered sectoral competition, internal political problems, and a barrage of top-down approaches with minimal positive impacts. Mental health staff reported change fatigue and job insecurity as factors that hampered the quality of care provided to service users. These structural issues negatively impacted the delivery of the Flinders Programme. There was also evidence of service users experiencing social injustice (e.g., stigma, and housing, food, and financial insecurity). However, the overall outcome suggested that when all key stakeholders were engaged in the care plan, the Flinders Programme could help service users achieve some of their health and social goals (e.g., preparation towards finding a job, improved social connections, healthy lifestyle).

A person-centred and family-inclusive approach, a written care plan, motivational interviewing techniques, regular follow-ups, feedback, and rapport with empathetic and respectful trial nurses were identified as central facilitators in the success of the programme.

Significant findings generated a novel middle-range model called Supported Self-management and Social Recovery (SSMSR) involving four domains: a) Service users: 'active citizens'; b) Caregivers: promote recovery; c) Positive health environment: deliver recovery-oriented and culturally safe care; and d) Community: promotes social justice and empowerment. The realist synthesis also generated 40 Initial Programme Theories (IPTs) to define key stakeholders' roles. Overall, the Flinders Programme demonstrated that given the opportunity and proper support, service users actively engaged in the self-management care plan, showed meaningful change, and generated hope, orienting them towards recovery.

DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and it does not contain any material previously published or written by another person except where due reference is made in the text. No professional editor was deployed in the preparation of this thesis. The editing remains the work of Dr. Robert Muller.

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LIST OF PUBLICATIONS AND CONFERENCES

Publications directly linked to this thesis

• Zabeen, S., Lawn, S., Venning, A., & Fairweather, K. (2021). Why Do People with Severe Mental Illness Have Poor Cardiovascular Health? — The Need for Implementing a Recovery-oriented Self-Management Approach. *International Journal of Environmental Research and Public Health*, 18(23), 12556.

(Some parts of the above paper have been modified and included in Chapter One: Background).

• **Zabeen, S.**, Phua, D., Mohammadi, L., & Lawn, S. (2020). Family involvement to support cardiovascular self-management care for people with severe mental illness: a systematic review. *Journal of Mental Health*, 1-17.

(The outcome of the above paper, a conceptual self-management framework identifying caregiver roles, has been used as a frame for analysis in Chapter Four: Experiences of caregivers, and further refined with the help of empirical data. The original framework has been added as an appendix).

Battersby, M., Kidd, M.R., Licinio, J., Aylward, P., Baker, A., Ratcliffe, J., Quinn, S., Castle, D.J., Zabeen, S., Fairweather A.K., & Lawn, S. (2018). Improving cardiovascular health and quality of life in people with severe mental illness: study protocol for a randomised controlled trial. *Trials*, 19 (1), pp.1-10.

(Some description of the trial intervention used in the above paper has been included in the appendix).

[Due citations were made when information from the above papers was included in this thesis].

Other relevant publications

- Muir-Cochrane, E., Lawn, S., Coveney, J., Zabeen, S., Kortman, B., & Oster, C. (2019).
 Recovery college as a transition space in the journey towards recovery: an Australian qualitative study. *Nursing & Health Sciences*, 21(4), 523-530.
- Lawn, S., Zabeen, S., Rowlands, N., & Picot, S. (2018). Hidden care: Revelations of a case-note audit of physical health care in a community mental health service. *International Journal of Mental Health Nursing*, 27(6), 1742-1755.

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- Lawn, S., McMahon, J., & **Zabeen, S.** (2017). Foundations for change: part 2 carers: experiences of carers supporting someone with the diagnosis of Borderline Personality Disorder (BPD) 2017 Update. Private Mental Health Consumer Carer Network (Australia) Ltd: Marden, South Australia, Australia.

Thesis-related conference presentations and other relevant engagements

- Zabeen, S.,* Lawn, S., Venning, A., & Fairweather, K. (2023, May 22-24). How to achieve delivery of a cardiovascular health intervention in community mental health settings: a process evaluation of Flinders Programme using RE-AIM framework [Conference Presentation]. 23rd International Conference on Integrated Care. Flanders Meeting & Convention Center Antwerp, Belgium.
- Zabeen, S*. (2023, May 11). Investigating the acceptability and feasibility of a self-management care planning-based intervention: To improve cardiovascular health and quality of life of community-living adults with severe mental illness [Symposium Presentation, virtual]. The FHMRI Healthy Communities Symposium. Tarntanyangga (Victoria Square), Adelaide, South Australia.
- Zabeen, S.,* Lawn, S., Venning, A., & Fairweather, K. (2022, November 29). Supported Selfmanagement and Social Recovery: A Critical Realism-informed middle-range theoretical model to improve cardiovascular health and quality of life of community-living adults with severe mental illness. Conference presentation by Slade, S.* in The Australian Experience in Social Prescribing [Breakout session oral presentation]. 1st Asia Pacific Social Prescribing Conference: Social Prescribing and its impact on population health. Ngee Ann Kongsi Auditorium, Academia, Singapore.
- COMPAR-EU (May-July, 2021). How to successfully implement self-management interventions in real life contexts? [A three round online Delphi survey participation of Zabeen, S. as an invited research expert]. https://self-management.eu/compar-eu-project-2/

- Zabeen, S.,* Lawn, S., Venning, A., Fairweather, K., & Smith, D. (2021, February 10). The
 Role of Family in Promoting Self-Management Support in Adults with Severe Mental Illness
 (SMI). [Conference Presentation, virtual]. *TheMHS Learning Network*. S29, Panel paper:
 Support and Recovery. Perth, Australia.
- Zabeen, S.* (2019). Improving cardiovascular health of those with severe mental illness:
 does self-management work for all? [Oral presentation]. Three-minute thesis (3MT)
 competition. Flinders University, Bedford Park, South Australia. First Round: 3 July 2019;
 Semi-final: 15 August 2019
- **Zabeen, S.,*** Lawn, S., Venning, A., Fairweather, K., & Smith, D. (2019, August 28). Engaging patients with serious mental illness (SMI) in self-management care planning-based physical health interventions: what works (or not) and why? [Conference Presentation]. *TheMHS Learning Network*. S49, Brisbane, Australia.
- **Zabeen, S.**, Hough, L.,* Rowlands, N.,* & Fairweather, K. (2019, October 30). Experiences of trial nurses delivering Flinders Programme: cardiovascular risk and quality of life among adults with severe mental illness. [Seminar Presentation]. *Chronic Condition Management Accredited Training Forum*. Flinders University, Bedford Park, South Australia.

^{*}Presenting author

ABBREVIATIONS

CALHN = Central Adelaide Local Health Network

CBT = Cognitive Behavioural Therapy

CCM = Chronic Care Model

CCSM = Chronic Condition Self-Management

CMHC = Community Mental Health Clinic

CMHS = Community Mental Health Setting

CMO = Context-Mechanism-Outcome

CR = Critical Realism

CRC = Community Rehabilitation Centre

CRW = Community Rehabilitation Worker

CTO = Community Treatment Order

CVD = Cardiovascular Disease

C&R = Cue & Response

FP = Flinders Programme

GP = General Practitioner

IPT = Initial Program Theory

MH = Mental Health

NDIS = The National Disability Insurance Scheme

NRT = Nicotine Replacement Therapy

PH = Physical Health

PT = Public Trustee

RE-AIM = Reach, Effectiveness, Adoption, Implementation, Maintenance

SALHN = Southern Adelaide Local Health Network

SMI = Severe Mental Illness

SRF = Supported Residential Facility

SSM = Supported Self-management

SU = Service User

[A = Answer, Q = Question]

THESIS OVERVIEW AND STRUCTURE

Background

The research literature highlights that people with severe mental illness (SMI) die 10-20 years earlier than the general population (matched for common demographic factors such as age and gender) (De Mooij et al., 2019); this is mainly related to experiencing physical morbidities such as cardiovascular disease (CVD) (Colton & Manderscheid, 2006; Walker, McGee, & Druss, 2015). There is evidence that this health inequity could be reduced by employing person-centred and recovery-oriented Chronic Condition Self-Management (CCSM)-based care (Ngamaba et al., 2023; Muir-Cochrane, Barkway, & Nizette, 2014). Nevertheless, despite four decades of translational research and implementation of these care approaches, there has been very poor uptake among people with SMI and their health care providers, and little integration of these approaches into routine health care practice (Zabeen et al., 2021).

Research problem and knowledge gaps

A summary of existing research on this health issue suggests that there remain multi-tiered problems impeding the successful adoption of CCSM-based physical health interventions among people with SMI and their mental health care support providers (Zabeen, Lawn, Venning, & Fairweather, 2021).

The four major gaps identified in the literature are:

- 1) Knowledge gaps in both health practice and implementation research regarding what approaches suit the complex needs of people with SMI and CVD risk factors and how to implement these approaches successfully into real-life settings where service users' and organisations' needs and preferences constantly change depending on their situations.
- 2) A paucity of interpretive or exploratory studies that discuss intertwined problems at the individual (service users' bio-psychological and lifestyle-related factors), community (family's roles, socio-environmental factors), and organisational (health policy, system, and service culture-related factors) levels by seeking feedback from adults with SMI and CVD risk factors and their matched stakeholders.
- 3) Limited studies addressing issues in Australian community-based mental health settings.
- 4) Further to these known gaps, to the researcher's best knowledge, there is no longitudinal qualitative study that has explored the above problems by seeking feedback from matched stakeholders at multiple time points.

Therefore, to date, while the research suggests that helping adults with SMI to support themselves works, questions remain about "what works, for whom, and in which context" (Zwar & Dennis, 2018, p. 66). This question becomes particularly convoluted for the population group (adults with SMI and CVD risk factors) constituting the participants in the current study. This group receives more intensive mental health case-management support due to their current and sometimes complex clinical and psychosocial support needs, and are often alienated from their family and community. It is apparent that further research is needed to simultaneously investigate the individual, community, and organisational factors potentiating the uptake of CCSM-based health approaches, such as the Flinders Programme, among relevant stakeholders. The current exploratory research (referred to hereafter as 'thesis'), has therefore aimed to identify the mechanisms (e.g., social constructs, culture, power, politics) in their different contexts and through time, involving all key stakeholders that have produced positive health outcomes for community-living adults with SMI and CVD risk factors who were exposed to the Flinders Programme.

Flinders Programme

The Flinders Programme is consistent with the principles of the Chronic Care Model (CCM) and mental health recovery-oriented care (Battersby et al., 2010; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Wagner et al., 2001), which promotes a partnership between the service user and their health professionals to foster the person's empowerment, and their capacity for self-determination and autonomy (Pulvirenti et al. 2014). The CCM coordinates chronic condition care, aiming to integrate the micro, meso, and macro aspects of health care delivery (Wagner et al., 2001). Recovery-oriented care, on the other hand, aims to ensure that mental health care is centred on holistic approaches primarily led by the person's identification of what recovery means to them (Leamy et al., 2011). During the period November 2017 to February 2021, the Flinders Programme was delivered among 120 South Australian community-living adults diagnosed with SMI and CVD risk factors. The programme involved a tailored one-to-one planning-based person-centred approach, which used motivational interviewing techniques and Cognitive Behavioural Therapy (CBT) (Battersby et al., 2018). Two initial assessments, six sessions, and three six-monthly follow-ups were delivered among Finders Programme participants (service users) by two trial nurses (further details provided in Chapter One).

Key research questions

Based on the knowledge gaps, the current thesis aimed to answer the following research questions:

a) How was the Flinders Programme delivered in South Australian community mental health clinics?

b) How and why did the Flinders Programme work (or not), for whom, and under what circumstances in these community mental health clinics?

Thesis aim and objectives

The broad aim of the thesis was to investigate the acceptability and feasibility of a chronic condition self-management care planning-based intervention (Flinders Programme) to improve cardiovascular health and quality of life among adults with severe mental illness in an Australian community mental health service setting.

This was achieved by pursuing the following objectives:

- a) Objective One: Exploring the experiences of community-living adults with SMI and CVD risk factors (objective 1.1), their matched family caregivers (objective 1.2), and matched health professionals (mental or physical health staff) (objective 1.3) as the participants undertook the Flinders Programme during November 2017 to September 2020.
- b) Objective Two: Exploring the experiences of the trial team to understand how the Flinders Programme was delivered.
- c) Objective Three: Data triangulation of objectives one and two to identify the contextual factors (social, political, and economic conditions of the community and health system where service users and other stakeholders live, work, and thrive) and underlying mechanisms (e.g., social constructs, culture, power, politics, connection, identity), which support (or inhibit) the delivery of self-management and recovery care (exemplified by the Flinders Programme) among adults with SMI and CVD risk factors.

The overall outcome of this thesis generated 40 Initial Programme Theories (IPTs) to identify all key stakeholders' roles in CCSM. IPTs are a set of assumptions that explain how a health intervention (in this case, the Flinders Programme) might work within a real world setting where stakeholders' experiences can vary based on their contexts and interactions with each other. A Context-Mechanism-Outcome (CMO) configuration was used to develop the IPTs (Mukumbang, Marchal, Van Belle, & van Wyk, 2020; Pawson, Greenhalgh, Harvey, & Walshe, 2004).

Methodology

The existing literature suggests that in order to address the research problem, any solutions would involve a detailed examination of key stakeholders' bio-psychosocial worlds and their interactions. Roy Bhaskar's *Critical Realism (CR)* was deemed the most suitable philosophy to support this notion because it acknowledges the strengths and necessity of both positivism and relativism (Bhaskar, 1989). Bhaskar (1989) argues that neither positivism nor relativism is sufficient to identify the underlying mechanisms generated in an open system (real world), such as a community mental

health service setting aiming to serve the psychological and physical health needs of people with SMI. The philosophy of CR, therefore, supports the complexity of the existing and perceived social constructs that impact relevant stakeholders' experiences and recognises the value of personal insights, which aligns with the aim of the thesis.

To implement CR in this exploratory thesis, the RE-AIM framework (Reach, Effectiveness, Adoption, Implementation, Maintenance) (Glasgow, Vogt, & Boles, 1999) was applied to answer the research question: How was the delivery of the Flinders Programme achieved in South Australian community mental health clinics? Complementing the RE-AIM framework, Realist Evaluation (Pawson & Tilley, 1997) was used to explore the dimensions between the CMO of the study, to assist with answering the second research question: How and why did the Flinders Programme work (or did not work), for whom, and under what circumstances? Combined examination of underlying context and related mechanisms at the macro (social), meso (health system), and micro (individual) levels involving all key stakeholders – people with SMI, their family members (who will be described as 'caregivers' from this point onwards), and health professionals – helped to answer the research questions.

This research produced an enormous quantity of data with diverse perspectives, requiring careful synthesis to focus on the key deciding contextual factors and mechanisms derived from the macro, meso, and micro levels. Therefore, to present the findings coherently, Laura Damschroder's *Clarity out of chaos* framework was used to guide the interpretation of these data (Damschroder, 2020).

Study significance

The thesis findings identified key stakeholders' roles and strategies to effectively deliver the Flinders Programme in community mental health settings. The thesis outcomes also assisted in understanding support providers' (health professionals' and caregivers') roles in helping people with SMI to adopt healthier lifestyle choices towards improved self-management of chronic conditions. In their recent systematic literature review, Zabeen, Phua, Mohammadi, and Lawn (2020) determined there was a paucity of research on caregivers' roles in improving heart health and the quality of life of community-living adults with SMI. Therefore, this thesis also focused on caregivers' roles and needs in supporting adults with SMI and CVD risk factors. This critical new knowledge will assist policy-makers, service managers, and service providers to comprehend how to improve the delivery of CCSM-based care to people with SMI and comorbid CVD risk factors. When provided as an early intervention, the Flinders Programme might also avert the development of further comorbidity in this population group.

Thesis structure

There are nine chapters in this thesis, as outlined below.

Chapter One collates and describes the current evidence around the poor physical health of those with severe mental illness, focusing mainly on CVD and related risk factors. This is presented as a narrative review of the existing international peer-reviewed and grey literature and provides a detailed rationale for the study and existing knowledge gaps.

Chapter Two provides a thorough description of the philosophical assumptions that underpin the overall study design. A rationale is provided for the chosen theoretical frameworks and how they are employed to attain the research programme's aim and objectives. Additionally, information is provided on the study participants, ethics approval, participant recruitment, data collection, and the data analysis.

Chapters Three to Six present the perceptions of the four key stakeholder groups recruited for this thesis: adults with SMI and CVD risk factors; their informal caregivers; health professionals; and the trial team members. All key stakeholders' insights and experiences of the intervention in a real-life setting were captured and used to identify contextual factors and the underlying mechanisms that impacted the overall delivery of the intervention and its uptake among the participants. These chapters fulfilled **objectives one and two** (see page xxii).

Chapter Seven reports on the triangulation of the outcomes for Chapters Three to Six, alongside examining the CCSM care plans for participants with SMI, the researcher's and trial nurses' reflective journals, and the trial team meeting minutes. This process was used to create a better understanding of the overall research problem – why people with SMI and their care providers struggle to adopt and sustain self-management-based physical health interventions (fulfilling **objective three**).

In **Chapter Eight**, the discussion chapter, these integrated findings were then used to identify new knowledge areas and to question or extend the existing knowledge on this topic. However, the chapter also identified some 'unknowns' which still remain, requiring further research and discussion.

Finally, **Chapter Nine** provides the thesis conclusions by identifying the potential ways in which service providers and family caregivers might better support people with SMI and CVD risk factors to address their self-management support needs to improve their overall quality of life.

CHAPTER ONE: BACKGROUND

1.1 Chapter purpose and structure

This introductory chapter provides the background to the issues being investigated and is presented in eight broad sections. First, evidence of cardiovascular disease (CVD)-related excess mortality in people with severe mental illness (SMI) is presented. The following section describes the methods of this chapter - a narrative review and synthesis of targeted literature on the topic. Based on the narrative synthesis, section three attempts to understand why this mortality gap has persisted despite its recognition decades ago. To unpack the causes behind this pervasive health crisis, this population group's bio-psychological features, surrounding environment, and the ways in which the current health system responds to this crisis are discussed. This third section also summarises the existing gaps in the evidence-based and implementation research regarding why people with SMI struggle to uptake and sustain healthy lifestyle choices. In section four, the dialogue then moves to identify why a Chronic Condition Self-management (CCSM) and recovery-oriented care model is needed to tackle this pervasive health issue. The fifth section summarises the existing evidence and identifies the research problems. Next, section six describes a CCSM and recovery-oriented health intervention trialled in South Australia among community-living adults with SMI to improve their cardiovascular health and quality of life. The seventh section describes the significance of the current thesis (an exploratory study) as it runs alongside the health intervention. Finally, the chapter concludes with a summary.

1.2 Physical health of people with severe mental illness (SMI)

SMI commonly refers to diagnoses such as psychotic disorders, bipolar disorder, major depression with psychotic symptoms or treatment-resistant depression. SMI can also include anxiety disorders, eating disorders, and personality disorders, if the degree of functional impairment is severe (Swinson et al., 2016). The same source mentions that SMIs are long-term illnesses involving substantial functional impairment, significantly impacting the individual's ability to maintain employment and social relationships. People with SMI can also experience repeated psychiatric hospitalisations, homelessness, incarceration, and coexisting substance use disorders. In Australia and internationally, adults with SMI, such as schizophrenia, schizo-affective disorder, and bipolar disorder, are at increased risk of early death due to physical health problems. Cardiovascular diseases (CVD), type 2 diabetes, nutritional and metabolic diseases, obesity, and smoking-related cancers are potentially preventable chronic conditions that are frequently observed and disproportionately found among people with SMI compared with non-SMI populations (Correll et al., 2017). This mental-physical health interface has multiple adverse impacts on the person's daily life and appears to generate greater difficulty in the person's health care management. It is particularly

challenging for community-living adults with SMI who rely on the overburdened, and often fragmented, public health and support service systems, resulting in poorer health outcomes (Novella, 2010). Overall, an estimated AUD 15 billion is spent across Australia and New Zealand each year on health care costs related to people with SMI experiencing comorbidities and resultant mortality (RANZCP, 2016), where a significant proportion of deaths involve CVD (Correll et al., 2017). Accordingly, the economic and social burden of SMI-related CVD on the health care system and the community is a high cost to all key stakeholders (e.g., adults with SMI, their families, health practitioners, and policy-makers) (RANZCP, 2016).

Despite a large body of research documenting the relationship between SMI and physical comorbidities, and efforts to meet the complex medical needs of the population with SMI, addressing this health inequity remains at the periphery of research and health care practice (Bartels & DiMilia, 2017). These physical health disparities in adults with SMI are observed across low-, middle-, and high-income countries, making it a multifaceted global health problem (Daré et al., 2019; Firth et al., 2019). Through a meta-analysis of 100 systematic review papers, Firth et al. (2019) showed that globally, people with SMI are 1.4–2.0 times more likely to have CVD.

The following section discusses the major drivers contributing to, and perpetuating, this chronic status quo over many decades. Synthesising the findings involving these key drivers will assist in fulfilling this chapter's objective: to propose a framework suitable to better understand and tackle this significant health problem. By identifying these critical issues, the reader may better understand the focal points at the individual, health system, and socio-environmental levels, with the potential to catalyse improvements in the cardiovascular health of those with SMI.

1.3 Methods

Perspectives on improving the cardiovascular health of those with SMI discussed in this chapter are drawn from various sources. Given that the literature on physical health and mental health is vast, a more targeted approach was undertaken to identify documents based on their perceived and reported reach, influence, and importance in this area of research. The phrase 'cardiovascular disease in people with severe mental illness' was searched in the Google Scholar search engine to identify systematic reviews and peer-reviewed articles that discussed the broader socio-environmental, cultural, and political factors impeding the cardiovascular health of those with SMI. The search was limited to papers published since 2000 because there was evidence of a clear shift from that time, with increasing calls to address this topic. In Australia, for example, the first national report on physical health and mental health (The Duty to Care Report), linking several national datasets for the first time, was released two decades ago, elevating the significance of this topic nationally (Coghlan, Lawrence, Holman, & Jablensky, 2001). Reports were also identified from government bodies and non-government organisations (e.g., The World Health Organisation), professional bodies (e.g., The Royal College of Psychiatrists), and advocacy organisations (e.g.,

The King's Fund) on this topic from Australia, the United Kingdom, the United States, and other jurisdictions that have been developed since 2000. These were identified similarly through Internet searching and drawing on the researcher and supervisory team's knowledge and expertise. Further papers were identified by cross-referencing of the systematic review articles. In total, the researcher screened 150 article abstracts and the full-text of 80 articles. Following discussions between the researcher and the supervisory team, 48 papers were included and synthesised in the following section to better understand the research problem – why community-living adults with SMI experience poor cardiovascular health and quality of life.

1.4 Chief contributors to CVD among people with SMI

Health research investigating the excess CVD-related mortality associated with SMI reveals multilevel factors exacerbating poor heart health. Existing evidence can be divided into five key areas linked to the marginalisation of people with SMI: (1) bio-psychological and lifestyle-related risk factors; (2) socio-environmental factors; (3) health system-related factors; (4) service culture and practice-related factors; and (5) research-related gaps on how to improve the cardiovascular health of people with SMI.

1.4.1 Bio-psychological and lifestyle-related factors impacting cardiovascular health of people with SMI

Coping mechanisms such as tobacco smoking, excessive alcohol consumption, poor diet, and physical inactivity are common behaviours among people with SMI; many consider these a consequence of trying to self-manage their mental illness (Firth et al., 2019). These risky behaviours contribute to the high rates of chronic physical diseases, the most common being CVD (Correll et al., 2017). A clear association between SMI and CVD identifies that the comorbidity of these chronic conditions has a shared biological (older age, male gender, family history), psychological (stress, major depression), and lifestyle (smoking, alcoholism, poor diet, lack of exercise) aetiology (De Hert, Detraux, & Vancampfort, 2018). Furthermore, a person with SMI typically experiences a combination of three main symptom types across the course of their illness: positive (delusions and hallucinations), negative (amotivation and anhedonia), and cognitive symptoms (poor concentration, reasoning, and memory) (NMHS, 2007). The influence of these symptoms and their interactions severely impact the day-to-day activities of people with SMI, making it difficult for them to effectively manage their mental and physical health issues.

1.4.2 Socio-environmental factors impacting cardiovascular health of people with SMI

Besides the bio-psychological and lifestyle-related risk factors linking SMI and CVD, common socioenvironmental factors such as financial hardship, lack of access to community resources, and social isolation appear to perpetuate the comorbidity of these conditions (Farrer, Walker, Harrison, & Banfield, 2018). Researchers have observed that the nature and complexity of SMI-related symptoms (disorganised behaviours, major depression and anxiety, cognitive impairment, problems with social skills) often lead to high rates of unemployment, underpinning the financial hardship experienced by many people with SMI (Piterman, Jones, & Castle, 2010). Financial hardship frequently impacts this group's capacity to access transportation and maintain consistent housing or accommodation (Hill, Francis, & Robinson, 2018). The unpredictability or absence of housing and transport can disengage individuals with SMI from their community, diminishing their overall quality of life.

Social support is a crucial protective factor known to improve the overall health of people, especially those living with mental—physical health comorbidity (Bartels & DiMilia, 2017). Due to the complexity of SMI and related positive symptoms (delusions, hallucinations), it is not unusual for this population to experience significant social stigma, self-stigma, social exclusion, and isolation (NMHS, 2017). Consequently, people with SMI may be more prone to living in unsafe environments that expose them to greater substance abuse such as heavy smoking, alcoholism, and drug misuse (Hill et al., 2018; Piterman et al., 2010), thereby contributing to the likelihood of CVD. Furthermore, the ongoing social stigma of mental illness results in service users struggling to fully engage and participate in, or gain equitable access to, meaningful community activities as citizens. The combination of the above factors, the debilitating nature of SMI, and potential low physical health literacy have created further challenges for this population in managing their health conditions (Kemp, Fisher, Lawn, Battersby, & Isaac, 2014). Ultimately, these circumstances are implicated in reducing self-esteem, negatively impacting their treatment-seeking, and delaying the delivery of effective prevention, early intervention, and treatment for their health conditions (Treichler & Lucksted, 2018).

1.4.3 Health system and practice-related factors impacting cardiovascular health of people with SMI

Health system-centric factors increasing the risk of CVD among those with SMI include the inconsistent provision of quality medical care tailored for this population group. For instance, General Practitioners (GPs) are well-positioned to promote healthy lifestyles in people with SMI (Piterman et al., 2010). However, the evidence suggests the existence of stigma in the primary health care setting coupled with a GP lacking in experience in managing people with SMI can undermine help-seeking behaviours and adherence to treatment plans recommended by GPs (NMHS, 2017). Consequently, some researchers have argued that physical health care should be the responsibility of mental health professionals (particularly psychiatrists and mental health nurses), owing to their existing expertise with this group (Šprah, Dernovšek, Wahlbeck, & Haaramo, 2017). However, the global shift of psychiatry towards 'deinstitutionalisation' in addition to ongoing reforms have overburdened the mental health system (Novella, 2010). Similarly, structural changes in primary and secondary care have led to increased levels of bureaucracy and increased pressure on already stretched health resources (insufficient skilled staff and time), creating further challenges for SMI populations to access GP services (Croxson, Ashdown, & Hobbs, 2017; Farrer et al., 2018). There are ongoing dilemmas regarding *who* is well-suited and responsible for managing the physical health needs of

people with SMI (Clancy et al., 2019). Furthermore, where there *are* clear guidelines for identifying and managing health risk factors among people with SMI, health policies and procedures are poorly implemented; in this regard, Australia is no exception (Clancy et al., 2019). Consequently, adults with SMI have limited access to preventative care, motivational interventions, and evidence-based guideline-adhering treatments that address lifestyle risk factors and illnesses such as CVD (Stanislaus, Bastiampillai, Harris, & Battersby, 2017).

Diagnostic overshadowing is another significant issue. Hallyburton (2022) discusses that often, due to the severity of service users' mental health symptoms, their physical health problems are largely overlooked and left untreated by the health staff.

1.4.4 Service culture and policy-related gaps on how to improve the cardiovascular health of people with SMI

Although there are strong signals identifying an association between CVD and SMI risk factors, person-centred evidence-based health care (EBHC) interventions relating to CVD risk reduction strategies are rare (Osborn et al., 2016). Recovery-oriented and self-management-based interventions, tailored information, and education and training incorporating community support are considered crucial for potentiating physical health for this population (Morgan et al., 2017). The research indicates that when such interventions are implemented, better health outcomes are observed owing to the approach enhancing individuals' abilities, knowledge, and confidence to manage their conditions (Signal et al., 2017). Providing a person-held medical record has been shown to improve the understanding of physical health risks among those with SMI (Kisely et al., 2013). A person-centred approach to health care acknowledges the critical contributions of the families of people with SMI to care decisions and support, and emphasises partnership and collaborative interventions. Peer support and clear and brief health promotion messages are well suited to this population (Kemp, Bates, & Isaac, 2009). In practice, however, most of these elements are overshadowed within predominantly hierarchical health care systems primarily interested in maintaining acute care, risk, and medication compliance, with the least focus on the long-term holistic psychosocial wellbeing and needs of this population (NMHCCF, 2017; Slade, 2009). This 'illness' focus is notably at odds with a recovery orientation (Muir-Cochrane et al., 2014; Rowe & Davidson, 2016).

Health service culture can also negatively impact the uptake of recovery-oriented and self-management-based physical health interventions specific to the SMI population (Muir-Cochrane et al., 2014). Broadly, among mental health organisations, there is a service culture perception that improving physical health behaviours among SMI persons is highly challenging (Kisely et al., 2013). This cultural inertia includes the acceptance of obesity as an *inevitable* side-effect of antipsychotic medications (Bartels, 2015). Similarly, smoking among people with SMI continues to be considered an embedded culture or group norm within mental health services (Ashton, Lawn, & Hosking, 2010). Thus, pervasive pessimism regarding the capacity of people with SMI to embrace health behaviour

change contributes to the failure to treat these common CVD risk factors among people with SMI (Happell, Platania-Phung, & Scott, 2014). Nevertheless, evidence shows that mental health organisational culture changes can be accomplished with targeted improvement strategies (Aarons et al., 2012). Such improvement strategies targeting culture can concentrate on the significant impeding factors, such as the absence of strong clinical leadership and engagement and a lack of coordination in inter-organisational partnerships and teamwork (Brooks, Pilgrim, & Rogers, 2011). However, implementing the abovementioned approaches meets consistent resistance from the mental health system, as novel strategies are often considered a threat to extant rules and regulations; thus, both fail to be initiated and subsequently sustained (Brooks et al., 2011).

Beyond health system-level culture issues, models of practice (e.g., individually based illness model vs recovery approach) also influence treatment methodologies and are seen as problematic by mental health researchers (Muir-Cochrane et al., 2014; Pilgrim, 2014). For instance, to date, psychiatry relies heavily on a medication-centric model, despite research repeatedly showing the adverse impacts of a variety of these drugs on people's overall health and wellbeing (Chang & Lu, 2012). It is also important to note that some CVD-related risk factors may be the 'iatrogenic (inadvertently induced and often harmful) consequences of antipsychotic medications' (Ashworth, Schofield, & Das-Munshi, 2017). These include, for instance, an amplified appetite driven by antipsychotic medications, resulting in negative impacts on metabolism and rapid weight gain (Chang & Lu, 2012). Some antipsychotic medications' (e.g. clozapine) side-effects are directly linked with myocarditis. Clozapine induced myocarditis is not prevented through health behaviours; rather, it is a dangerous side-effect induced by the drug itself. Sedation and other common side-effects of antipsychotic medications can also hinder the person's motivation and energy to make healthy lifestyle choices (NMHCCF, 2017). Adding further complexity, for some people with SMI, these antipsychotic medications are 'imposed coercively', with limited collaborative decision-making with the person about medication choice and dose, as part of them being detained for in-person treatment, or as part of compulsory Community Treatment Orders (CTOs) (Pilgrim, 2014, p. 80). As Laugharne and Priebe (2006) found, this power imbalance between persons and clinicians was identified as a contributor to people with SMI disengaging from mental health services. A Cochrane review found that CTOs did not result in improved service use, social functioning, or quality of life compared to voluntary care (Kisely, Campbell, & O'Reilly, 2017). However, the authors acknowledged that the findings were inconclusive due to the small number of articles. They also noted that the studies excluded service users with a history of violence which is a significant limitation considering that is one of the main reasons for CTOs in many contexts. More recent research suggests that Australia has one of the highest rates of CTOs worldwide (112.5 per 100,000 in South Australia) despite limited evidence of their effectiveness in improving mental health outcomes (Kisely, McMahon, & Siskind, 2023). Nevertheless, it is essential to note that coerced treatment inhibits active engagement by the person in their care (Kemp, 2011) and damages their trust in health care providers (Pilgrim, Tomasini, & Vassilev, 2010), known to be crucial for improving overall

health outcomes (Ward, 2017). Correct and sufficiently communicated information, treatment choice, continuity of care, and a consistent attending clinician are crucial components for enabling people to retain trust in mental health service systems (Laugharne & Priebe, 2006; Mechanic & Meyer, 2000).

1.4.5 Research-related gaps on how to improve cardiovascular health of people with SMI

The acknowledgement of the acceptability and potential clinical effectiveness of integrated general medical and psychiatric care interventions has led to policy-makers recently recalibrating their approach towards the adoption of recovery-oriented EBHC programmes within the mental health system (NMHS, 2017). However, Hannigan and Coffey (2011) noted a paradox: the act of such an implementation has created further challenges by initiating a variety of top-down interventions without considering how the delivery will be achieved in different contexts. Similarly, another significant disconnection is between the research sector and community health practices, resulting in the poor translation of EBHC within real-world settings (Whiteman, Naslund, DiNapoli, Bruce, & Bartels, 2016). To ensure effective physical health outcomes in people with SMI, research must align with policy priorities that are fully informed by the practice field. To achieve this alignment, research and policy-makers will need to understand the practical challenges faced by frontline clinicians such as psychiatrists, mental health nurses, and GPs (NMHS, 2017). Of further concern is that current EBHC research predominantly focuses on 'biomedical' self-management and related individualistic factors. Biomedical self-management involves both 'work' and 'cost' for persons, where the management burden is often shifted from the health care system to the person (Greenhalgh, 2017; Signal et al., 2017). This contrasts with 'lifeworld' self-management and related research, which additionally considers socio-environmental factors where the problems originate and are sustained (Greenhalgh, 2017).

The 'work' associated with chronic condition management increases significantly for service users with comorbidities, potentially exceeding their capacity to cope (Signal et al., 2017). Coping can be further undermined when service users' priorities do not align with their health professionals and vice-versa (Drennan et al., 2007), often disengaging service users from care due to coerced treatment, as explained earlier (Pilgrim, 2014). Furthermore, Zulman and colleagues found that this discordance increased with greater service user health complexity (Zulman, Kerr, Hofer, Heisler, & Zikmund-Fisher, 2010). In addition to this system-level problem, widespread disregard for influential socio-environmental factors may enable or hinder service users' capacities to enact and sustain self-management to address their chronic conditions (Hinder & Greenhalgh, 2012). As a result, CCSM is enabled or constrained by the individual's socio-economic and cultural conditions within the community; these factors need further attention in the research (Hinder & Greenhalgh, 2012; Morgan et al., 2017; Suetani, Scott, & McGrath, 2016).

Existing research also suggests that outcome evaluation alone is generally inadequate to address wicked problems (problems that are often resistant to change or improvement initiatives) (Signal et

al., 2012), as with those highlighted in this review. A naturalistic study investigating health settings from both 'inside' and 'outside' is needed to examine the lifeworld implementation of EBHC and self-management-based interventions in community mental health settings (Greenhalgh, 2017). Few studies have represented a holistic picture of the factors that impact and shape the uptake of chronic condition self-management (CCSM) behaviours and related health practices (Greenhalgh, 2017; Hinder & Greenhalgh, 2012). While progress may be made by employing person-centred physical health interventions (Whiteman et al., 2016), it often fails to achieve replicability and sustainability due to the poor understanding of underlying processes facilitating or impeding the delivery of these interventions in the first place (Kemp, Fisher, Lawn, Battersby, & Isaac, 2015). The status quo reflects the apparent paucity of research into successfully implementing person-centred physical health interventions among people with SMI.

1.5 Suitability of a CCSM and recovery-oriented approach

From the above-articulated concerns, it is apparent that there remain identifiable CVD risk factors for people with SMI at the individual, community, health system and culture, and research levels (Barber & Thornicroft, 2018). There is no doubt that this is a 'complex health problem', and therefore, needs a 'complex solution' (Ward, Meyer, Verity, Gill, & Luong, 2011). With 'no quick fix', systematic changes with long-term patient-centred interventions will be required for sustainable outcomes (Kemp et al., 2015; Slade, 2009). Globally, CCSM-based physical health interventions among people with SMI have shown promise in supporting a person's overall health and wellbeing (Kemp et al., 2015; Lawn et al., 2007; Ward, Cotes, & Bartels, 2019; Whiteman et al., 2016). The underlying mechanisms of CCSM aim to enhance the person's self-efficacy to better manage their health conditions with the help of their support network (Hinder & Greenhalgh, 2012). There is mixed evidence for CCSM-based tailored weight-loss programmes, smoking cessation, substance abuse, and risky sexual behaviour in this population (Barber & Thornicroft, 2018; Holt et al., 2018).

There is also evidence for recovery-oriented models improving the wellbeing of people with SMI (Muir-Cochrane et al., 2019; Ngamaba et al., 2023; Winsper, Crawford-Docherty, Weich, Fenton, & Singh, 2020). Learny's recovery framework, known as CHIME (Connectedness, Hope and optimism, Identity, Meaning, Empowerment), is one such model (Learny et al., 2011). However, recent research has argued that such models cannot address the structural disadvantages or social marginalisation that a person with SMI might face (Karadzhov, 2021). Current models also fail to capture the organisational barriers needed to promote recovery-oriented care. Furthermore, none of the existing models identify caregiver roles in fostering recovery and improved self-management behaviours in service users (Zabeen et al., 2020). Therefore, the following section proposes a new framework that has elements of different chronic disease models (Wagner et al., 2001; Wagner, Austin, & Von Korff, 1996), recovery (Learny et al., 2011) and social justice (Morrow & Malcoe, 2017)

models (Figure 1: A recovery-oriented self-management framework). This framework can promote recovery-oriented care in people with SMI and CVD (plus other similar chronic diseases such as type 2 diabetes) risk factors.

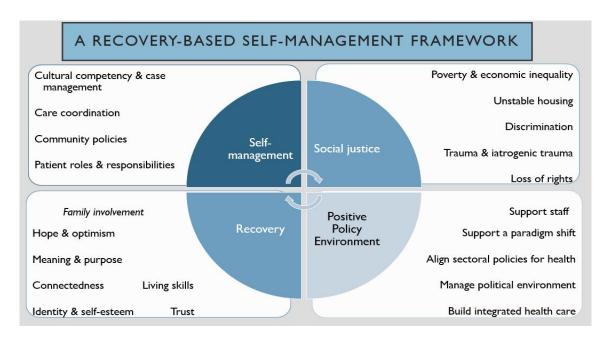


Figure 1. A recovery-oriented self-management framework (Zabeen et al., 2021, p. 6) (This image has been included in accordance with the Open Access Creative Commons Attribution: CC BY 4.0)

Based on the areas identified and discussed in this chapter, this framework identifies the key areas that require attention when applying CCSM and recovery-oriented care in a health setting.

1.5.1 Self-management

When the word self-management is used in this framework, it refers to the 'supported self-management (SSM) care where the person is actively supported by their care coordinator' (AHRQ, 2020). In SSM care, the service user is not only given information, but their care coordinator also helps them achieve their personalised goals through active follow-ups and by linking service users with community resources. It is also essential that the service user's cultural and religious beliefs are respected and considered when providing such care; this practice is necessary for a multicultural country such as Australia where people with SMI are even more vulnerable and often do not seek active care from the health system (Laugharne & Priebe, 2006; Mechanic & Meyer, 2000). Therefore, it is important to create a safe environment for this patient cohort where they can seek care and empower themselves. Above all, it is important that the person with SMI is encouraged to be more proactive in making decisions regarding their treatment. Current models overlook this aspect of SSM care, and hence, do not assert the clear roles service users should be playing in patient-centred care. Addressing these issues will improve the practice-related gaps in the health system by defining health professional and service user roles. Connecting service users with appropriate community resources will also enhance their psychosocial support to ensure healthy behaviour sustainability.

1.5.2 Recovery

Personal recovery is another crucial arm of this proposed new framework. There is no doubt that the elements of CHIME (Leamy et al., 2011) and other recovery models (Muir-Cochrane et al., 2019) play significant roles in motivating a person with SMI to initiate self-management and self-care. The exact reasons also help sustain improved health behaviours in people with SMI. However, the existing literature fails to justify the importance of families' roles in a person's recovery and selfmanagement journey in achieving improved heart health (Zabeen et al., 2020). Hence, we propose including this care dimension in the recovery-oriented self-management framework. Caregivers' inside knowledge about service users is helpful for the health system. Giving hope to service users, helping them build positive self-identities and promoting self-esteem are some expected outcomes of caregiver-supported recovery. However, it is also reported that caregivers might often need to accompany the person with SMI in adopting a new healthy behaviour such as exercising, giving up smoking or alcohol, and eating healthy (Zabeen et al., 2020). By acknowledging and optimising this crucial support in service users' lives, care coordinators can hope to achieve more meaningful physical health outcomes in people with SMI and CVD risk factors. The active involvement of caregivers in people's treatment plans can equip them with the necessary skills to support service users in addressing deteriorated mental and physical health symptoms, which are important steps that should be incorporated within current health practices. Efficient use of caregivers' experience, knowledge, and support can also reduce the burden on the health system. In addition, the changed health behaviours in service users can bring positivity into both parties' lives and can make their relationship stronger (Onwumere, Howes, Shiers, & Gaughran, 2018a; Onwumere, Howes, Shiers, & Gaughran, 2018b).

Another vital part of recovery is connectedness at the individual, social, and spiritual levels. Existing research suggests that the support of caregivers and community organisations can build connectedness at all three levels. An emerging concept called 'social prescribing' is deemed suitable here to promote connectedness. Social prescribing is a non-clinical approach in which health professionals refer service users to eligible community organisations for leisure and therapeutic activities (Marmot, 2022b; RACGP & CHF, 2020). Iwasaki, Messina, Shank, and Coyle (2015) explain how therapeutic and general leisure activities can help people with SMI to engage in meaningful community activities. The same study also showed the significance of people with SMI engaging in creative activities such as art, crafts, music, and reading because such engagement, in turn, activates positive emotions (Iwasaki et al., 2015). As part of the social prescribing-driven recovery process, researchers also emphasised the importance of activities such as bushwalking, camping, hiking, and individual and team-based sports that were identified as 'meaning-making' and as activities that 'heal connections' (Bickerdike, Booth, Wilson, Farley, & Wright, 2017; Drinkwater, Wildman, & Moffatt, 2019). The importance of religious institutions for fostering spiritual connection was also highlighted in the literature as it provided a sense of community for some individuals that

improved motivation towards recovery and self-care (Iwasaki et al., 2015). There was also evidence of how social prescribing reduced loneliness, anxiety, and depression in community-living adults with SMI (Haslam, 2022). These activities may create the conditions to support people with SMI to address CVD risk factors.

1.5.3 Positive policy environment

To date, psychiatry has heavily relied on an illness model through which the service user is treated for their illness with medications; this is argued to generate iatrogenic trauma for many patients (Pilgrim, 2014). According to health professionals, high workloads, frequent staff turnover and the resultant discontinued care, role ambiguities between mental and physical health staff, and a lack of resources are some of the other commonly identified barriers that hinder the provision of quality service and recovery-oriented care to service users (Clancy et al., 2019; Stanislaus et al., 2017). Recovery-oriented care demands time and is a risk-preferred model (Pilgrim, 2014), which often becomes difficult to adopt within a resource-scarce community mental health system. From a service culture viewpoint, coercive and controlling roles arising from CTOs might also need further consideration regarding how to make these practices more humane, less restrictive, and acceptable to service users. Hence, this proposed framework identifies some key areas that should be in place before promoting a self-management intervention to improve the cardiovascular health of those with SMI. These areas are: (a) support staff with training, job security, and emotional assistance (the emotional support is required to deal with vicarious trauma related to service users' illnesses), (b) changed paradigm (move towards a recovery-oriented model and away from an illness model where health professionals may hold negative preconceptions regarding the service users' scope of, and capacity for, recovery), (c) align sectoral policies (such as better coordination between mental health nurses, psychiatrists, and rehabilitation staff), (d) managing the political environment (to prevent topdown, unplanned interventions without staff consultation), and (e) better liaising with physical health staff by sharing real-time medical records through a shared database, where these areas are essential to promote effective self-management care to service users (Wagner et al., 2001). Effective leadership is also crucial here to promote and sustain the cultural shift needed within psychiatry to ensure service users' perspectives are maximised in decisions about treatment and care and recovery orientation (Greenhalgh, 2017). Most recently, in Australia, an extensive collaborative network of stakeholders, known as Equally Well, has formulated a detailed set of recommendations for policy to address the physical health of people with mental health issues (Morgan et al., 2021). Paying attention to these issues can improve psychiatry's service culture and health practices, and address the broader structures of health care delivery and shared care to create a positive health model that promotes wellbeing.

1.5.4 Social justice

Apart from the three elements of the framework outlined above, it is essential to identify and tackle the root causes that perpetuate poor health conditions in people with SMI, such as discrimination, social stigma and resultant isolation, unemployment-generated poverty, and social inequality. Recent research demonstrates *personal* recovery models do not reflect these broader social structural problems (Karadzhov, 2021; RITB, 2016; Winsper et al., 2020) and, as a result, fail to achieve sustainable outcomes. Trauma (and iatrogenic trauma) are other dismaying issues that require close attention if we want genuine change in service users' health behaviours (Pilgrim, 2017). Ensuring these fundamental rights can help service users be included as citizens who are able to actively contribute to society, with a broader focus on the social determinants of recovery.

The findings suggested that addressing the policy and health-system level factors, such as embracing a *social* recovery-oriented approach (alongside personal or clinical recovery), is the key to addressing the long-lasting health problem of CVD in people with SMI. Caregivers should also be engaged more actively and systematically in a person's treatment plan (where applicable and with the person's consent); this will be beneficial for all stakeholders and, as such, can reduce the burden on the resource-limited health system.

1.6 Summary of existing evidence and statement of the research problem

This chapter has presented evidence of the poor physical health of those with SMI, and has stated that, even after four decades of initiation of recovery-oriented and CCSM-based care (Muir-Cochrane et al., 2014), there is very poor uptake of such approaches among SMI patients and their health care providers. A summary of existing research on this health issue suggests that there remain multitiered problems at the individual, collective, and organisational levels that impede the successful adoption of CCSM-based physical health interventions among people with SMI. Moreover, there are gaps at both the practice and research levels regarding which approaches suit the complex needs of people with SMI and CVD risk factors and how to successfully implement them in real-life settings within contexts where needs constantly change depending on salient situations. Therefore, while the research suggests that helping patients help themselves works, questions persist about "what works, for whom, and in which context" (Zwar & Dennis, 2018, p. 66). This question is particularly pertinent for the current study's population group - people with SMI and CVD risk factors - already a vulnerable group with complex health and psychosocial needs. With this in mind, further research is needed in this area to simultaneously investigate the individual, sociocultural, and organisational factors potentiating the uptake of CCSM-based health approaches for this population among relevant stakeholders.

1.7 Trial of a CCSM and recovery-oriented intervention in South Australian community mental health settings: Flinders Programme

In 2016, the Flinders Human Behaviour and Health Research Unit (FHBHRU) used a comprehensive process to develop a CCSM-based intervention focusing on reducing CVD risk among people with SMI (Battersby et al., 2018). The intervention was positioned within a National Health and Medical Research Council (NHMRC) funded phase-III randomised controlled trial (RCT) within metropolitan South Australian (SA) community mental health services. With external collaborators, FHBHRU adopted principles from the UK's Medical Research Council (MRC) guide to developing this complex health intervention [NHMRC grant proposal: APP1121334, unpublished]. The intervention integrates components of the Flinders Programme of CCSM, a programme designed in South Australia during 1997-98 as part of a large coordinated care trial seeking to address the growing burden of chronic disease (FHBHRU, 2016). It is an overarching clinical, generic process underpinned by cognitive behavioural theory and motivational techniques. The Flinders Programme is consistent with the principles of the CCM and recovery-oriented care (Battersby et al., 2010; Leamy et al., 2011; Wagner et al., 2001). Notably, the Flinders Programme places patients at the *centre of their care* planning (FHBHRU, 2016; Galletly et al., 2012; van Hasselt, Krabbe, van Ittersum, Postma, & Loonen, 2013).

The Flinders Programme intervention started with two initial assessments. Through a collaborative approach, patients and trial nurses used the Flinders Programme tools (e.g., the *Partners in Health* Scale, *Cue & Response* Interview, and *Problems & Goals* Assessment) to identify all CVD risk factors, chronic conditions, and psychosocial issues and determined the best course of action. The common CVD risk factors considered for this intervention were smoking, poor diet, physical inactivity, heavy alcohol consumption, or sleep problems identified by health researchers (Baker et al., 2017; Bartels & DiMilia, 2017; De Hert et al., 2018). The Flinders Programme involved six face-to-face one-hour sessions over 20 weeks between the person and the trial nurse, with a further four follow-ups over 18 months (Battersby et al., 2018). Trial nurses delivered the programme in community mental health settings or in patients' homes as per patients' preferences and convenience. Appendix 1 provides details of the Flinders Programme tools, and the contents of the assessments and the six sessions.

Across a range of populations, including those with SMI and comorbid physical health problems, the evidence indicates that the Flinders Programme can produce better patient health outcomes when oriented in an organised system of care and patients are followed up regularly (Battersby et al., 2013; FHBHRU, 2016; Lawn et al., 2007). However, the successful implementation and sustainability of such interventions, particularly the integration into existing routine care, still need to be addressed for health care systems (Bovenkamp & Dwarswaard, 2017; Harris et al., 2015; Lawn, 2015). Accordingly, more research is required to understand what needs to be done at the system level to initiate a CCSM-based programme that can improve the cardiovascular health of those with SMI.

1.8 Purpose, rationale, and significance of the current thesis

The findings of this chapter suggest that for this current study, any solutions would involve a detailed examination of key stakeholders' bio-psychosocial worlds (and their interactions) to be able to identify the context, mechanism, outcome (CMO) patterns that triggered (or did not) patient activation in self-management-based practices. Combined examination of underlying context and related mechanisms at all three levels, involving all key stakeholders, is therefore warranted to better understand and address this health crisis.

To the researcher's best knowledge, there is no interpretive study on delivering a CCSM-based physical health intervention among people with SMI within the context of SA community-based mental health settings. Therefore, this exploratory study (thesis) considers the socio-environmental and organisational factors and all key stakeholders' attitudes and expectations that impact the overall delivery of the Flinders Programme. Outcomes will help to identify the contexts that generate mechanisms at different levels, producing positive health outcomes for patients exposed to the Flinders Programme. These study findings will also help to identify key stakeholders' crucial steps and strategies to effectively deliver the Flinders Programme in community mental health settings. The overall study outcomes will assist us in understanding support providers' (health professionals and caregivers) roles in helping patients to adopt healthier lifestyle choices. This essential new knowledge will help policy-makers, managers, and service providers to understand how to improve the delivery of CCSM-based care to people with SMI and comorbid CVD risk factors.

1.9 Chapter summary

This introductory chapter employed a narrative review to describe the critical research problems; the factors that relate to the poor cardiovascular health and quality of life of adults with SMI. The overall findings suggested that CCSM and a recovery-oriented approach would be suitable to resolve this comorbid health problem.

Between November 2017 and September 2020, a CCSM-based health intervention was delivered to 120 South Australian community-living adults with SMI and CVD risk factors. This thesis undertook a longitudinal qualitative study alongside the intervention to explore the perspectives of service users, their matched caregivers, health professionals, and the trial team members. The aim was to investigate ways that best support service users' Flinders Programme goals, and to identify the roles of all key stakeholders that enable self-management behaviours among service users to help them recover. The next chapter, methodology and methods, elaborates on the study design.

CHAPTER TWO: METHODOLOGY AND METHODS

2.1 Chapter purpose and structure

This chapter describes the overarching philosophy and theoretical frameworks underpinning the thesis design. This chapter also explains how these frameworks were used in answering the key research questions. Then, the methodologies and methods that fulfilled the three thesis objectives are outlined (see page xxi), followed by a description of how the data were analysed and details of the ethics approval process. The chapter contains four broad sections: 2.2) Philosophical and theoretical frameworks; 2.3) Study design; 2.4) Data analysis; and, 2.5) Ethics approval. Each section contains sub-sections to describe the step-by-step study design.

2.2 Philosophical and theoretical frameworks

The previous chapter revealed that we have known about the poor life expectancy of people with severe mental illness (SMI) for many decades, primarily due to physical conditions such as cardiovascular disease (CVD). Health researchers identified this problem decades ago (Maudsley, 1873), and efforts have been made by health care services and policy-makers to address this health crisis (Zabeen et al., 2021). However, this health problem still perpetuates despite global attempts, warranting a detailed examination of service users' bio-psychosocial worlds. The current exploratory study presents an opportunity to examine these factors simultaneously with a clinical trial that employed a chronic condition self-management (CCSM)-based intervention, the Flinders Programme. The Flinders Programme delivered between November 2017 and September 2020 in South Australian community mental health settings, sought to improve cardiovascular health and quality of life among adults with SMI. Chapter One provided information as to why people with SMI suffer from poor cardiovascular health and what more can be done at the research level to better understand this problem. Table 1 below highlights a number of assumptions made in the current study.

Table 1: Key study assumptions and concepts

Knowledge dimensions	Underlying assumptions
What is out there to know? (Ontology)	Why people with SMI have CVD risk factors and, to date, do not receive optimal health care?
	2. A range of bio-psychosocial factors need to be examined to understand this complex health problem and related health practices as 'complex problems requir[ing] complex solutions'. However, knowledge is 'deep', and it is not possible to know everything.
What/how can we know about it? (Epistemology)	It is essential to consider both subjective (study participants' experiences) and objective (medically/scientifically established facts) perspectives to better understand the research problem - why people with SMI are less likely to take up CCSM-based physical health interventions.
	Existing theories are 'fallible' (and hence, amenable) as reality continues to change due to the constant interaction of humans and society.
Underpinning values and morals (Axiology)	People with SMI suffer physical health inequity. Therefore, more must be done at the system and community levels to provide them with optimal health care.
	It is important to acknowledge SMI service users' human rights so that they are empowered.
How can we go about acquiring knowledge? (Methodology)	An exploratory research methodology must be employed to investigate the underlying contexts that generate mechanisms and ultimately produce outcomes.
Which procedures are used to acquire knowledge? (Methods)	Multiple methods must be used to unfold this complex, multifactorial, real-world health problems.
Which data can be collected? (Knowledge sources)	Multiple sources involving all key stakeholders must be employed to allow data triangulation, and thus, reach closer to the 'deep reality'.
sources;	Lived Experience perspectives are essential sources of knowledge to understand translation to real-world contexts.

Grounded on these above assumptions, this study has chosen *Critical Realism* as the underpinning philosophy and *RE-AIM*: **R**each, **E**ffectiveness, **A**doption, **I**mplementation, **M**aintenance (Glasgow et al., 1999) and *Realist Evaluation* (Pawson & Tilley, 1997) as theoretical frameworks to answer the key research questions:

- a) How was the Flinders Programme delivered in SA community mental health clinics?
- b) How and why did the Flinders Programme work (or not), for whom, and under what circumstances?

Both *RE-AIM* and *Realist Evaluation* are based on the philosophy of CR (Glasgow et al., 1999; Pawson & Tilley, 1997), and are thus deemed suitable to answer the current study's research questions. The following section describes these philosophical and theoretical frameworks and explains how they align with the overall study aim and objectives.

2.2.1 Critical Realism (CR) - the philosophy

CR - Background

CR is a philosophy of social science that originated from the work of British philosopher Roy Bhaskar in the 1970s. His combined works on 'transcendental realism': a general philosophy of science (Bhaskar, 1975) and 'critical naturalism': a philosophy of human science (Bhaskar, 1979), generated the idea of CR. Bhaskar and others further refined various aspects of CR over the following decades (Archer, Bhaskar, Collier, Lawson, & Norrie, 1998; Bhaskar, 1989; Collier, 1994). Bhaskar (1989) criticised the underpinning ontology (e.g., 'What's out there to know?') and epistemology (e.g., 'How do we know what we know?') of both positivism (that is, objective science) and relativism (or, subjective science). Positivism broadly locates causal relationships at the level of events, referring to a linear relationship between cause and effect (Creswell & Creswell, 2017). More precisely, positivism reflects a closed system (controlled situation/ideal world), implying that all findings are generalisable and knowledge is deducible within a given theoretical framework. On the contrary, relativism relies solely on human interpretation for understanding a phenomenon, often omitting the value of empirical evidence (Creswell & Creswell, 2017).

While Bhaskar acknowledged the strengths and necessity of both positivism and relativism, he argued that neither was sufficient to identify the underlying mechanisms generated in an open system (real world). Therefore, the philosophy of CR supports the reality of empirical knowledge but recognises the importance of individual insights. Thus, CR draws elements from both the natural (physical) and the social (human) worlds. However, Bhaskar argued that the existing theory is 'fallible' because human interaction ('agency') can change current social 'structures', resulting in different consequences within different contexts. Therefore, CR considers both macro-level issues (e.g., culture, history, power) and empirical evidence (medically/scientifically established facts), rather than relying solely on subjective meaning (e.g., how service users experience services and health outcomes). For instance, CR-informed health research will consider service users' objective medical diagnoses, treatment plans, and perceptions of their health care providers alongside their subjective interpretations of their illnesses. For the current study, triangulation of multiple data sources (Golafshani, 2003) was employed to better understand SMI service users' claims and perceptions of their illnesses, their relationships with their health care providers, and their related self-management practices.

CR primarily promotes social equity by acknowledging service users' treatment choices and stressing the importance of accessing quality care accordingly (Edwards, O'Mahoney, & Vincent, 2014). Hence, CR has been recognised as a practical philosophy for exploring complex issues involving marginalised populations (Clark, Lissel, & Davis, 2008; Fletcher, 2017). Overall, CR emerges as a robust philosophy for health research that combines ontological realism (accounting for empirical evidence) and epistemological relativism (recognising service users' subjective meanings of their illnesses).

Domains of CR

To better define the complex interaction of individual (agency) and context (structure), Bhaskar stratified reality into three domains (Archer, Bhaskar, Collier, Lawson, & Norrie, 1998; Bhaskar, 1989):

- 1) EMPIRICAL domain/Experience: This domain refers to observed and experienced (outcomes) events by participants; that is, knowledge of what is PERCEIVED to be happening. According to Bhaskar, events are understood through participants' 'interpretations', and that these are fallible.
- 2) ACTUAL domain/Actuality: This domain provides knowledge about what ACTUALLY happens; that is, events occur, whether observed or not.
- 3) REAL domain/Reality: This domain presents knowledge of WHAT and WHY (all) things are, and identifies causal mechanisms within objects or structures that cause events at an empirical level.

In brief, the REAL domain generates mechanisms that occur as events in the ACTUAL domain. These events may or may not be observed in the EMPIRICAL domain. Also, it is not always necessary that all elements of the REAL domain will influence the outcome in the ACTUAL domain. Thus, CR acknowledges the co-existence of agency (individuals' personal beliefs and attitudes) and structure (socio-environmental factors), regardless of human experience (Clark et al., 2008). Bhaskar (1975, 1979) also admits that reality is deep; thus, knowledge may never reach the bottom. Fletcher (2017, p. 183) compares this phenomenon to an 'iceberg,' arguing that the EMPIRICAL domain is only the visible tip; examining the ACTUAL and REAL domains and their interactions is necessary to understanding underlying mechanisms, but that these may not provide all the answers.

Adoption of CR

As mentioned earlier, CR adopts the strengths of both positivism and relativism and thus functions as a flexible methodology in dealing with reality (Creswell & Creswell, 2017). Consequently, CR is aptly suited to answering the key research question of this study – "How and why did the Flinders Programme work (or did not work), for whom, and under what circumstances?" That is to say, CR can answer the 'what' (positivism) and the 'why'/'how' (relativism) of respective research questions.

CR is a well-matched philosophy for health science research as it recognises the holistic approach to health and its dimensions: biological (e.g., genetics, neurology); psychological (e.g., resilience); and socio-environmental aspects (e.g., social isolation, financial issues, organisational practices) (Clark et al., 2008). The negative effects of any one of these three factors (or their combinations) can be of great concern for service users' physical health (e.g., reduced physical activity) and mental health (e.g., severe depression or anxiety). This is argued to be particularly important for people with SMI and CVD risk factors, the target population of this study, who are more at risk of being negatively affected by this mental-physical comorbidity (DiNapoli et al., 2016). By recognising these

interdependencies between the three dimensions (bio-psychosocial), CR can explain this complex world of mental health research (Pilgrim & Rogers, 1997; Rogers & Pilgrim, 2014).

While service users' bio-psychosocial factors will help us to understand the true meaning of their experiences at the micro-level, it is also crucial to examine both meso- (e.g., current mental health policies and practices within mental health services) and macro-level issues (e.g., community, geography). This process also identifies hidden influences such as power, politics, and culture that shape the current South Australian mental health system and its services. Investigating these factors jointly will aid us in understanding the meta-perspective of how service users with SMI attempt to undertake and sustain positive health behaviours in this bigger picture. For these reasons, CR's underpinning philosophy and methodology are suited to analysing these factors. Clark et al. (2008) mention that the application of CR can assist with interpreting complex health outcomes and optimising evidence-based interventions. Thus, CR will assist in guiding this thesis in which a detailed examination of the delivery of the Flinders Programme will be undertaken: to assess a self-management care planning-based intervention that aims to improve CVD risk factors in service users with SMI.

2.2.2 Guidelines and theoretical frameworks employed to evaluate a complex health intervention

While CR is well-accepted as a strong philosophy and methodology for understanding evidence-based health practices, more literature is still needed on implementing CR in exploratory research (Fletcher, 2017). A recent UK Medical Research Council (UK MRC) framework provides a set of comprehensive guidelines (Moore et al., 2015) suitable for undertaking process evaluations of health interventions, such as the Flinders Programme. These guidelines also incorporate the core principles of CR. The following sub-sections describe the general guidelines and relevant theories and explain their relevance for answering the research questions (see page 16).

UK MRC guideline: description and its suitability

A plethora of interventions in health research need to be translated into practice (Campbell et al., 2007; Greenhalgh, 2017). A leading reason for this lack of translation is the heavy reliance of the existing studies on objective-based outcome evaluation ('Does this work?') and the omission of process evaluation ('Why and how did it work or not?') (Craig et al., 2008). The paucity of process evaluation studies has resulted in an underwhelming and inconsistent uptake of evidence-based practices in real-life health settings (Greenhalgh, 2017). As a possible resolution to this problem, Moore et al. (2015) have developed a framework to help researchers examine complex health interventions that focus on the outcome and highlight the need to examine contextual factors and underlying mechanisms of impact. This framework can also answer research questions around implementation or delivery, thus serving as a comprehensive guideline for examining and optimising evidence-based health interventions (Figure 2).

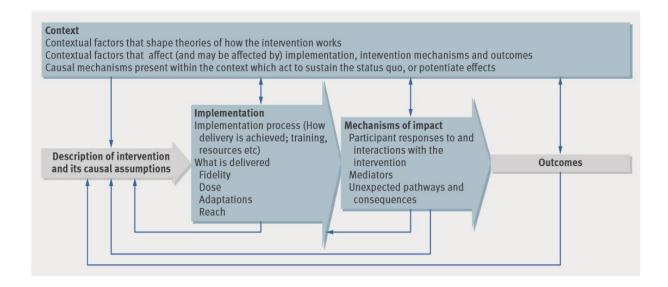


Figure 2: Key functions of UK-MRC guidelines for process evaluation and relations among them (Moore et al., 2015, p. 2) (This image has been included in accordance with the Open Access Creative Commons Attribution: CC BY 4.0).

RE-AIM: description and its suitability

To comply with the UK-MRC guideline, RE-AIM (Reach, Effectiveness, Adoption, Implementation, Maintenance) (Glasgow et al., 1999) will be applied to answer the research question: *How was the delivery of the Flinders Programme achieved in SA community mental health clinics?* The RE-AIM framework was developed in the late 1990s by Glasgow and his colleagues to evaluate the public health impact of health promotion interventions (Glasgow et al., 1999). Holtrop, Rabin, and Glasgow (2018) described the qualitative guidelines of RE-AIM, as used in this thesis. RE-AIM has five dimensions:

- Reach: whether the target population (people with SMI and CVD risk factors) was reached as intended
- 2. **Effectiveness**: of the intervention (CCSM and recovery-oriented care plan: Flinders Programme)
- 3. **Adoption** (acceptance): by target participants and institutions (SA community mental health settings and their staff)
- 4. **Implementation** (delivery): consistency, costs, and adaptations made during the delivery of the intervention
- 5. Maintenance: of an intervention's effects on individuals and settings through time

Here, it is important to clarify that the main research trial was not 'implemented' as the dominant day-to-day practice of service providers in mental health settings. Thus, for the present study, elements of RE-AIM were used to examine the challenges faced by the trial team and how they were resolved. In doing so, the study described the programme's acceptance levels among study

participants, and the *adaptations* (if any) made during the delivery process with an explanation of why they were needed. RE-AIM also helped to explain how the target population was *reached* (or not). The main trial examined 'What is delivered' (dose), and the programme's effectiveness and *maintenance* using a quantitative approach. Also, separate studies were conducted by the central trial team to investigate the *fidelity* and *cost-efficacy* of the Flinders Programme.

Realist evaluation: description and its suitability

Realist Evaluation (Pawson & Tilley, 1997) is used here to explore the dimensions between Context, Mechanism, and Outcome (CMO) of the study in answering the other research question: *How and why did the Flinders Programme work (or did not work), for whom, and under what circumstances?* Bhaskar (1989) argued that for events to occur, elements of underlying structures (contextual factors) and agency (individual) must act together under certain circumstances; the same philosophy underpins Realist Evaluation (Pawson & Tilley, 1997). The primary purpose of this exercise was to generate Initial Programme Theories (IPTs) that helped us understand when and how the Flinders Programme worked (or not). The following diagram (Figure 3) shows each aspect of the CMO parameters.

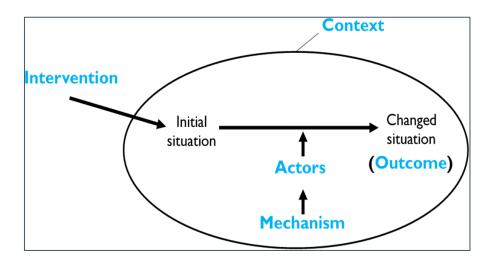


Figure 3: The conceptualised intervention-context-actor-mechanism-outcome analytic tool (Mukumbang et al., 2020, p. 494) (This image has been included in accordance with the Open Access Creative Commons Attribution: CC BY 4.0).

Realist Evaluation explains human behaviour in the context of open systems (the real world), recognising that any outcome is the result of the interaction of humans with their social world. That is, the effectiveness of any intervention (performance under a 'real-world' situation) is not inherent in the intervention, participants, or contexts alone; instead, they are shown in the ways the intervention works (mechanisms) for participants in different contexts (Archer et al., 1998; Moore et al., 2015).

Table 2 below provides further definitions of the intervention-context-actor-mechanism-outcome parameters.

Table 2: Definitions of the intervention-context-actor-mechanism-outcome parameters

Categories		Definition			
Intervention (including resources)		A novel input is inserted into the existing system to bring a positive change and outcome in behaviours.			
A	ctors	The target participants or institutions who experience the intervention.			
Co	ontext	Existing socio-environmental conditions, systems, norms, and practices where the health condition arises or perpetuates. Often, it is essential to prepare or change the context (environment) before initiating an intervention, or the change might not be meaningful or sustainable.			
Med	chanism	Mechanism refers to the step, or series of steps, that enables the changes in actors and their behaviours. Mechanisms are often hidden or invisible.			
	Immediate	The immediate effect of the intervention, e.g., knowledge, information			
Outcome	Intermediate	This refers to the behavioural changes that occur due to having knowledge or information.			
	Long-term	This results from a sustained behavioural practice that positively impacts the health system or community.			
Initial Prog	ramme Theory	A programme theory is described as a set of implicit or explicit assumptions of how the programme should be organised and why the programme is expected to work.			

Sources: (Mukumbang et al., 2020; Pawson et al., 2004)

Next, Figure 4 uses an example to unpack the intervention-context-mechanism-outcome configuration and generates an IPT.

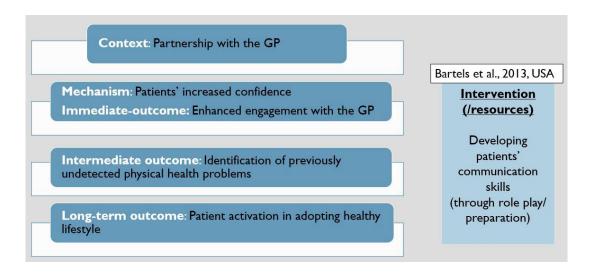


Figure 4: Context-Mechanism-Outcome (CMO) configuration example

Initial Program Theory (IPT): When a communication development initiative (Resource/R) is taken within a collaborative approach (Context/C), this can help increase the confidence (Mechanism/M) of a service user to better engage with their health professional (Immediate outcome/Imm-O). Thus,

effective communication can identify previously undetected health problems (Intermediate outcome/Int-O), activating a healthy lifestyle (Long-term outcome/L-O) in the service user (Figure 4).

The above procedure of identifying CMO configurations and relevant resources and developing an IPT has been used for each results chapter. The outcome identified each stakeholder's roles in CCSM and recovery-oriented care, focusing on stakeholders' perceptions of the Flinders Programme.

2.2.3 Chronic Care Model (CCM) based intervention - Flinders Programme

Whilst RE-AIM and Realist Evaluation provides practical guidelines to conduct a CR-informed process evaluation, a middle-range theory is needed to direct the overall study inquiry (Pawson, 2000; Smith, 2010). A middle-range theory is a topic-related theory based on established evidence, which guides study design, implementation, data collection, analysis, and interpretation. Middle-range theories are usually based on a systematic set of assumptions that explain interactions between micro-level organisations (social institutions, health clinics) and are amenable under interactions between new contexts (settings) and agents (humans) (Pinder & Moore, 2012). Such approaches are widely used to unfold systemic barriers within health organisations and link them to service user health outcomes (Greenhalgh, 2017).

For the current study, the Chronic Care Model (CCM) (Wagner et al., 2001) has been adopted to provide this middle-range guiding theory (an *a priori* theory). The CCM is a one-to-one chronic condition self-management (CCSM) model that acknowledges micro, meso, and macro system layers and is designed to be delivered within routine health care. It is a widely adopted (and often adapted) CCSM model. The model augments collaborative care between the service user and health care providers (in this case, both physical and mental), linking service users to community resources, and consequently, employs a holistic, lifelong approach to health and self-care (HealthyWA, 2015; Lorig & Holman, 2003). This CCM includes assessment, problem-solving, and decision-making strategies enhancing service user capacities and empowerment.

The CCM is ideally suited for this purpose, given that the Flinders Programme draws upon this theoretical framework. The key differences between the CCM and the Flinders Programme were that the latter was delivered outside routine care and used recovery-oriented motivational interviewing techniques and Cognitive Behavioural Therapy (CBT) to initiate a person-centred written care plan (Battersby et al., 2018). As part of the Flinders Programme, service users received two assessment sessions and six fortnightly (sometimes monthly, to accommodate their schedules and treatment preferences) follow-up sessions to motivate and engage them in their self-management care (see Appendix 1 for details). These additional characteristics of the Flinders Programme generated new ideas captured through an inductive approach to define service user and caregiver roles within self-management care. The inductive approach also generated sub-themes based on emerging data. Next, using CMO configurations, each of the results chapters proposed a set of IPTs that defined

the roles of four key stakeholders within self-management care: service users, caregivers, health professionals, and community members or organisations.

The CCM model asserts that improving chronic illness care requires collaboration between the service users and their health care providers. Service users also need access to a safe environment and sufficient resources (Fiandt, 2006). To determine the impact of the Flinders Programme on service users' health and how the programme achieved delivery, six interrelated critical components of the CCM have been matched with the current intervention, and subsequently, explored during this study: 1) organisation of health care; which must support 2) a redesigned delivery system, 3) clinical information system, and 4) systematic decision support; 5) self-management support for service users; and 6) links to available community resources (Wagner et al., 2001). In 2003, the CCM was further refined to incorporate five additional themes under the existing six tiers: 1) service user safety (in the health system), 2) cultural competency and 3) case management (in the delivery system); 4) care coordination (in the health system and clinical information system); and 5) community policies (in community resources and policies) (MCHCI, 2003). These additional themes were added to improve service user experience and promote person-centred care. The current thesis has considered these themes in analysing the data and interpreting the results. Figure 5 shows the key CCM domains.

The Chronic Care Model Community **Health Systems** Resources and Policies **Organization of Health Care** Self-Clinical **Delivery** Decision Management Information System Support Support Design Systems Prepared, Informed, Productive Proactive Activated Interactions Practice Team Patient

Figure 5: The Chronic Care Model (Wagner et al., 2001) (This image has been included in accordance with the Open Access Creative Commons Attribution: CC BY 4.0).

Improved Outcomes

Developed by The MacColl Institute

The current study considered all the CCM elements while developing the interview guide and collecting, analysing, and interpreting the data. However, it is essential to note that the CCM is usually operated as an 'implementation' theory (e.g., when an intervention is embedded as part of routine care) to study health settings-based programmes. Given the phase-III status of the larger trial of the Flinders Programme, this study used the CCM domains to consider the programme's feasibility, suitability, and implications for the future embedding of the programme into routine practice.

As highlighted in the previous chapter, mental health advocates highly value service user-centred and recovery-oriented strategies, as they can help people with SMI to live a meaningful life in their community (Muir-Cochrane et al., 2014; Pilgrim, 2017). Existing evidence suggests that people with SMI can play an essential role in managing their own health needs, especially when also suffering from preventable physical health problems (Battersby et al., 2010; Harris et al., 2015; Lawn et al., 2007). Researchers also acknowledge the importance of health professionals' roles in engaging SMI service users' families and friends in their self-management care plan, by involving them in the support and decision-making processes (McGovern, Miller, & Hughes-Cromwick, 2014; NMHC, 2014; Piterman et al., 2010). These strategies resonate with the CCM's core principles that emphasise service users' central role in self-management care (HealthyWA, 2015; Wagner et al., 2001).

This thesis, however, considered CCM as 'fallible' (and hence, amenable under new contexts or for new study populations) given that, globally, there remains a paucity of implementation research that has tested CCM theory within mental health contexts, particularly where the key target is improving service users' physical health outcomes (Zabeen et al., 2021). Moreover, this study may be of particular interest to researchers and policy-makers because it was undertaken during a period in which significant reforms were being attempted within the SA mental health system (SA-MHC, 2017). Therefore, this CR-informed thesis added new knowledge about how CCM-informed individual, sociological, and organisational factors influenced stakeholders to adopt the Flinders Programme and what more needs to be done for its successful implementation in the future. It may also inform other programmes with similar features and help build understanding of system inertia to new models of care, more broadly within mental health services.

2.2.4 CHIME – the recovery-oriented model

Alongside the self-management approach, Leamy's recovery model CHIME (Leamy et al., 2011) was also used as an analytical lens. CHIME stands for Connectedness, Hope & optimism, Identity, Meaning, and Empowerment (Figure 6). The model promotes the idea that all humans deserve these five elements in life to thrive. There has been extensive use of this model in improving the quality of life of those with SMI (Muir-Cochrane et al., 2019; RecoveryPlace, 2017). Resultantly, the Flinders Programme also drew elements from the CHIME model (Battersby et al., 2018), with trial nurses

prioritising social connections and other essential aspects of the model when delivering the intervention among service users.

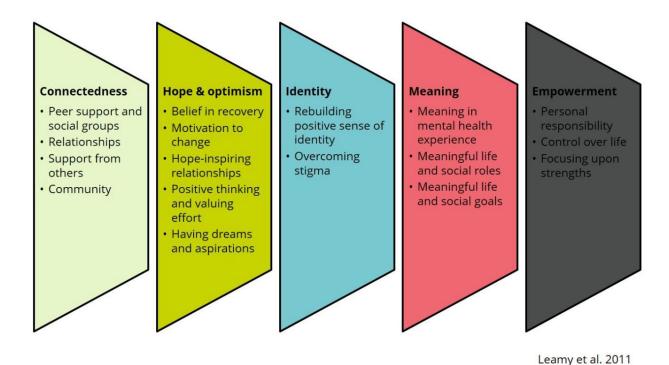


Figure 6: Leamy's recovery model: CHIME (RecoveryPlace, 2017) (This image has been included in accordance with the Open Access Creative Commons Attribution: CC BY 4.0).

2.3 Study design

2.3.1 Qualitative study - rationale

The methodological strength of CR resides in that either quantitative or qualitative approaches can be used to answer research questions based on the aim of the study (Clark et al., 2008). The current study employed a CR-directed qualitative methodology (Edwards et al., 2014; Fletcher, 2017) to fulfil the three thesis objectives (see page xxi). Qualitative approaches offer ideal methods for detecting, unfolding, and understanding health service delivery processes (Greenhalgh, 2017). Qualitative methods can provide valuable insights into how a new intervention is accepted and embedded in health care contexts. These research methods can focus on detailed experiential accounts of individual, collective, and organisational processes and practices. Thus, these study methods also align with the UK-MRC guidance on intervention examination that aims to understand the functioning of a complex health programme by examining implementation, mechanisms of impact, and contextual factors (Moore et al., 2015). To gain an in-depth understanding of the Flinders Programme's acceptability and feasibility, the roles of the representatives of all relevant stakeholder groups were explored by interviewing service users, caregivers, health professionals, and trial team members, and observing their interactions in the selected health settings.

2.3.2 Study settings

The South Australian mental health system is comprised of multiple interrelated services, including emergency departments, acute care in-patient hospital units, forensic services, rehabilitation services, intermediate care, short- and long-term accommodation including Supported Residential Facilities (SRFs), and Community Mental Health (CMH) clinics which offer longer-term case management in the community for people with more serious, complex, and enduring mental health disorders. These services are continuously supported by primary care (General Practice), allied health, and non-government organisations (NGOs), more recently referred to as Community Managed Organisations (CMOs), providing psychosocial support packages and peer support (NMHS, 2017). While all these organisations play a crucial role in managing the needs of service users with SMI, community mental health services (CMHS), in particular, have been placed at the centre of the broader health system (see Figure 7) to promote a recovery-oriented stepped care approach (SA-Health, 2010, 2020; SA-SIB, 2007).

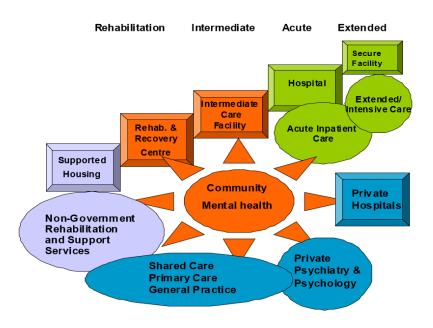


Figure 7: SA Community Mental Health Care at the centre of the system (SA-Health, 2010, p. 49) (This image has been reproduced with the publisher's permission).

Community mental health services

As per the current system, service users can be referred to community mental health services through any organisation highlighted in the above image (Figure 7). The person's family and friends may also play essential roles in supporting their engagement and communication of needs with service providers. Service users are assessed initially by the community mental health team, which involves an examination of service users' mental state and a 'risk assessment' (SA-Health, 2010). This comprehensive bio-psychosocial assessment and review process involves service users' clinical diagnosis in the context of their sociocultural setting, physical illness, and risky lifestyle behaviours (substance abuse, alcohol problems, and smoking) (SA-Health, 2010; White, Roy, & Hamilton, 1997). A service user with SMI usually requires team-based care involving input from

multiple health professionals, including psychiatrists, psychologists, mental health nurses, social workers, and occupational therapists, in collaboration with general practitioners (GPs). To ease the system navigation process and ensure continuity of quality care, each service user is assigned a dedicated 'care coordinator' (also known as a key worker/case manager) who is part of the multidisciplinary community mental health team (SA-Health, 2010).

Service users at risk of frequent relapse and rehospitalisation are closely monitored and managed by an acute care team involving mental health specialists. This 'high priority' with complex-needs group is called 'open episode' service users and requires frequent face-to-face services (daily to monthly) from the mental health team. Essential services include regular one-to-one contact to provide psychoeducation, psychosocial support, linkage to community resources that will promote recovery from mental illness, antipsychotic medications administration as applicable (such as depot injection) by mental health nurses, and review of medications and mental health and wellbeing by psychiatrists. Depot is preferable for those service users who have trouble remembering to take their medications daily; this slow-release intramuscular injection is usually administered fortnightly or monthly. For many service users, their mental illness can, at some point, impact their capacity to understand the need for treatment; this can change and loss of insight or capacity is not constant or irreversible, as insight can fluctuate (Rozalski & McKeegan, 2019) They might also be self-injurious or deemed dangerous to others. In such cases, the Mental Health Act of 2009 provides the legal basis for an involuntary treatment known as a Community Treatment Order/CTO (SA-Legislation, 2018).

Service users whose mental health is more stable and who do not require close monitoring are called 'shared care' service users. As part of the 'Better Access Programme', this group's mental health needs are largely managed by specially trained GPs (Department-of-Health, 2017) and only require six-monthly to yearly interactions with the community mental health team, facilitated by the service user's assigned care coordinator. Many service users supported within 'shared care' arrangements are prescribed 'clozapine', an antipsychotic oral medication that requires stringent medical monitoring through regular blood testing because it is associated with serious side-effects, including myocarditis (Ashworth et al., 2017; Pilgrim, 2017). Finally, service users who no longer need mental health services (as assessed by the mental health team) are discharged from the service and known as a 'closed episode'. They still receive ongoing support from NGOs, allied health, and primary care, as needed. Table 3 below summarises community-living mental health service users' usual clinical care path based on the course of their mental health conditions.

Table 3: Care path of community mental health service users

Open episod
•At risk of frequent ho
•On anti-psychotic m

- spitalisation
- edications
- Meets MH nurse daily/weekly/ monthly as needed
- Meets care coordinator monthly
- •Meets psychiatrist once every 6 month
- Meets psychologist as required
- •Meets GP as required for physical health conditions only
 - •Might have NGO psychosocial supports

Shared care (open episode)

- •Stable mental health no hospitalisation in a long time
- On anti-psychotic medications
- •Meets GP every month for Clozapine prescription
- •Meets MH nurse once a year
- Meets care coordinator once a year
 - •Meets psychiatrist once a year
 - •Might have NGO psychosocial supports

Closed episode

- •Stable mental health no hospitalisation in a long time
- May or may not be on antipsychotic medications
- •Meets GP as required for physical health conditions
 - •No (public) MH contact
 - •Might have NGO psychosocial supports

Source: Consultation with the core trial team, 2018

Local health networks and study sites

To improve the overall regional functionality and reach of the South Australian health system, three distinct Local Health Networks (LHNs) manage mental health services in the Adelaide metropolitan region: the Southern Adelaide Local Health Network (SALHN), the Central Adelaide Local Health Network (CALHN); and the Northern Adelaide Local Health Network (NALHN). These networks deliver clinical services and are complemented by the Adelaide Primary Health Network, which has responsibility for commissioning psychosocial support services as part of their role in overseeing better coordination and integration of services and support for the primary health care workforce across the metropolitan region. The latest data shows that 53,000 South Australians diagnosed with SMI are currently managed by these three LHNs in conjunction with non-government services commissioned by the Adelaide Primary Health Network (SA-MHC, 2017). For the current study, the study settings were community mental health services in southern (SALHN) and western Adelaide (CALHN). To ensure maximum participation, 'closed episode' service users discharged from the community mental health service within the past five years were also recruited.

Data were collected from the following four Adelaide community mental health sites:

- 1. An inner Southern community mental health clinic that manages approximately 800 communityliving adults with mental health problems.
- 2. A 20-unit (shared) outer southern community rehabilitation centre for adult service users who require intensive support to improve daily living skills and self-management of mental illness. Service users can reside for up to six months.

- 3. A western community mental health clinic that manages approximately 300 community-living adults with mental health problems.
- 4. A 12-bed inner southern Supported Residential Facility (SRF) that provides long-term community-based accommodation and support for adults with SMI. This SMI population sub-group is usually stable but lacks independent living skills. Most of them are on antipsychotic medications, and therefore, still require regular monitoring of their mental health by their GPs (usually monthly) and community mental health team (usually six-monthly to yearly) (SA-Health, 2010).

These four sites were purposively chosen because service users registered with them fulfilled the study inclusion criteria.

2.3.3 Study participants, eligibility, and sample size

For this qualitative study, different stakeholders' perceptions were explored to derive a sense of their personal perspectives: a) service users; b) caregivers; c) health professionals; and d) trial intervention providers. Data were collected at three different time points: the pre-, mid-, and post-trial periods (Figure 8).

Data collection timeline and methods



Figure 8: Data collection timeline and methods

<u>Service users</u>: A sub-sample of intervention service users was drawn from the larger RCT, where participants accessed mental health services from the southern (SALHN) and western (CALHN) Adelaide community mental health clinics (N=15 of 50 intervention service users with

the diagnosed psychotic condition and CVD risks). This sample size (N=15) was deemed to be within the acceptable range of 5–25 individuals for qualitative research, a group within a population who were exposed to the same intervention (in this case, the Flinders Programme) (Polkinghorne, 1988). Participants were purposefully selected to ensure they varied in gender, age, and living situation to reflect the heterogeneity of the community mental health service user population receiving care coordination. To do this, the list of 50 intervention service users was viewed with these criteria in mind, and potential 15 participants were then purposefully approached to seek their consent to participate. Hence, the thesis focused on gathering a diverse range of experiences rather than aiming for data saturation. Table 4 below provides recruitment eligibility inclusion and exclusion criteria.

Table 4: Participants' eligibility criteria

Inclusion criteria	Exclusion criteria		
Aged 30-65	Aged <30 or >65		
Psychotic Condition: Diagnosis of either schizophrenia, schizoaffective disorder, bipolar disorder, or depressive psychosis, and prescribed antipsychotic medication for that condition	Acute psychosis or suicidality at the time of recruitment		
At least one or more CVD risk factors: obesity, smoking, high blood pressure/blood lipids/glucose	No CVD risk factor		
Open or closed episode (last contact with MH no more than 12 months ago)	Closed episode (previous contact with MH more than 1-5 years ago)		
Community living service users (including community rehabilitation centres or supported residential facilities)	In-service users		
Ability to provide informed consent	Unable to provide informed consent due to limited English literacy or intellectual disability		
For qualitative study: RCT Intervention group participants	RCT Control group participants		

Source: Battersby et al. (2018) and core trial team

For this trial, adults aged 18-29 were excluded as they were less likely at risk of CVD. Service users were recruited after consulting their medical team. Those with more acute symptoms of distress from their mental health condition or current acute risk of suicidality were excluded, given ethical concerns for their ability to provide fully informed consent, safety concerns, and being mindful that we did not want to cause them any further distress or burden. By consenting to be involved in the trial,

participants agreed to long-term commitment to involvement in care planning with trial nurses and follow-up data collection. Due to a lack of funding for additional resources (e.g., interpreters or communication support staff), the trial was not able to include those with limited English literacy or intellectual disability. Fortunately, no such service users had to be excluded during the recruitment process.

- Caregivers: People with SMI often live alone or in SRFs, and thus, do not have any informal caregivers (family members). This group is often socially isolated and alienated from family and friends (Eglit, Palmer, A'verria, Tu, & Jeste, 2018; Linz & Sturm, 2013). Therefore, although this study aimed to conduct ten caregiver interviews at two time points (N=20), it was only possible to explore the views of four caregivers at two time points (at the middle and end of the trial, N=8). Data were collected from caregivers to assess the Flinders Programme for the person they cared for, including what worked (or did not), and why. Eliciting their perspective also identified the contextual factors (access to community resources, financial support) that facilitated or impeded the delivery of the Flinders Programme intervention. Furthermore, the CMO-based analysis highlighted caregivers' roles in CCSM and recovery-oriented care. Although a small sample size (N=4 caregivers), the detailed information collected from participants proved to be helpful in depicting a holistic picture of supported self-management care.
- Health professionals: Health professionals' perspectives were elicited, drawing from the clinical expertise and experience of providing mental health care and working within a mental health system, to illuminate the scope and effectiveness of the Flinders Programme. Ten mental and physical health professionals' (a psychiatrist, general practitioners, clozapine and depot nurses, and care coordinators) views were captured at two different time points (the middle and end of the trial). At mid-trial, seven health professionals were interviewed, and at post-trial, six. Of these two groups, only three health professionals participated in both phases. Trial team core members explained that low recruitment was a direct impact of the SA health reform, resulting in high staff turnover, job losses, and immense work pressure.

Some service providers delivered care for more than one service user who participated in the Flinders Programme. It is evident in the literature that implementing self-management-based interventions to improve the physical health of those with SMI is difficult for mental and physical health staff (Happell et al., 2014; Šprah et al., 2017). Therefore, health professionals' views on the potential rollout of the Flinders Programme and its sustainability in practice were also explored.

• <u>Trial Intervention providers:</u> This study also captured the experiences and reflections of the core trial team members throughout the study (N=7; trial nurses, the trial manager, and key

study investigators). It is essential to mention that the Flinders Programme was delivered as a phase-III trial from within the mental health clinical settings. The trial team therefore had close encounters with mental health staff throughout the establishment and delivery phases. This experience helped them to understand the trial's practical aspects, such as how the SA mental health system functioned, and the workforce and service priorities. Thus, exploring intervention providers' perspectives helped to gain an understanding of how to optimise the impact of the Flinders Programme among people with SMI (if proven suitable) and the scope of its future implications for routine health care practices.

Information collected from multiple stakeholders enabled the identification of the contextual issues and underlying mechanisms at the individual, organisational, and community levels that played critical roles in the effective delivery of the Flinders Programme within this community mental health setting and population. This also ensured the rigour and validity of the data through 'triangulation' (Golafshani, 2003), an essential requirement of CR-based research (Olsen, 2004). Triangulation is a research methodology in which examining multiple data sources (both within and between different stakeholders) can eliminate the risk of subjective bias (Flick, 2004). This was achieved by integrating/balancing the claims of the four stakeholders mentioned above: service users, informal caregivers, health professionals, and trial staff.

2.3.4 Recruitment process

Trial nurses recruited potential trial intervention participants by initially explaining the qualitative component of the study during their assessment interviews with participants for the larger RCT activities. Recruitment involved trial nurses providing the person with an information sheet specifically developed to explain the qualitative study and invite their participation. Upon receiving their initial verbal consent, trial nurses then notified the researcher of interested participants and provided their contact details, with permission from the person. The researcher then contacted each potential participant via telephone to arrange a mutually convenient meeting time. On the day of the qualitative interview, the researcher gave participants further explanations of the study and again checked their consent to proceed. Their written consent was then obtained before commencing each interview. Appendix 2 presents the master participant information sheet and consent form.

With the service user participants' approval, their matched caregivers and health professionals were contacted via telephone and email to invite them to participate in the study. They were given an information sheet outlining the study's purpose and expectations for their involvement. Interested participants were contacted again via telephone to organise a mutually convenient day and time to conduct a face-to-face interview. On the participants' nominated day of data collection, their written consent was obtained before commencing the interview process. All interviews with service users, caregivers, and health professionals took place at community mental health clinics in a private meeting room to ensure confidentiality and privacy to all participants and to satisfy safety concerns

established as part of the ethical conduct of this research. The clinics were deemed convenient and familiar locations for service user participants to come for interviews. It was also convenient for health professionals to minimise the time burden away from the demands of their clinical roles. However, due to commuting convenience, some caregivers and intervention providers were interviewed at the university office where the trial team was based.

2.3.5 Data collection methods

CR-informed data collection

CR requires the reconciling of both subjective (participants' perspectives) and objective values (empirical evidence) of data to obtain a holistic picture of the research problem (Bhaskar, 1989). However, Bhaskar was concerned that human social perceptions were 'fallible' (as they only capture the subjective meaning of a phenomenon), and therefore, underscored the importance of considering a research problem from all stakeholders' perspectives and judging their claims against each other to gain a better understanding of the overall problem. The present study addressed this issue by approaching participants' matched caregivers, health professionals, and trial staff to clarify service users' claims regarding their illness perceptions and related self-management practices.

With their consent, service users' care plans (collaboratively created by trial nurses and service users using the Flinders Programme care planning tools) were also examined for this study. Care plans helped to fill in any information gaps. They helped with understanding the steps service users took to reach their main identified goals as part of the trial intervention and as an additional component of data triangulation. A discussion with the relevant trial nurses clarified any confusion about the meaning and intention of the care plan content. Besides exploring all stakeholders' perceptions, trial staff's reflective journals, minutes, and participant observation-based field notes were also examined. Thus, this study was informed by the CR approach, which emphasises the value of triangulation from multiple data sources in reconciling all stakeholders' perspectives or any claims made against each other (Olsen, 2004).

Data collection process

Data were collected in three phases.

a) Pre-trial:

In-depth interviews with 15 service users were conducted during this phase, eliciting a vivid and rich picture of the participants' experiences (Boyce & Neale, 2006). This was particularly important for this population because the interview process gave them privacy and time to recount their experiences. Pre-trial interviews examined service users' lifestyles and psychosocial support factors and their relationship with their health care providers. This process helped with an understanding of how these factors impacted service users' decisions to engage with self-management-based interventions, such as the Flinders Programme. The information collected allowed us to explore how

service users reach a consensus with health professionals about their physical health goals, where their priorities lie, and their interpretations of physical health interventions. In addition to the above data sources, core trial team members involving two trial nurses, the manager, and the site coordinator were asked to keep periodic reflective journals (N=4) throughout the study period (November 2017 to September 2020) to record their perceptions of the intervention. The researcher also kept field notes throughout the study to reflect upon, and document, her passive observations (DeWalt, DeWalt, & Wayland, 2010). 'Passive participant observation' played a crucial role in gaining 'a feel' for the participants' Flinders Programme-related journey, as this process involved observation of participant expressions, body language and appearance during the in-depth interviews (DeWalt et al., 2010). Additionally, service users' interactions with their trial nurses, mental health staff, and informal caregivers were carefully observed where possible (conversations and interactions between stakeholders in clinic waiting rooms, clinic corridors, the rehabilitation centre, and the SRF). The researcher also carefully recorded observations of how different mental health settings oriented their spaces and used the Flinders Programme flyers and other health promotion materials to deliver recovery-oriented services. All these observations were thoroughly documented in the researcher's field notes and continually clarified with the trial team to ensure all interpretations were correct. Similarly, trial team members' interactions with each other during team meetings and how their positions influenced the overall team's decision-making processes were also observed, noted, and examined. These data sources (e.g., reflective journals) are precious when reviewing the delivery of any new intervention, but are often under-utilised (Mezirow, 1981). Alongside the service user pretrial interviews, trial staff's reflective journals, the researcher's field notes, and the trial team's meeting minutes were collected and examined as part of the process evaluation.

b) Mid-trial: After three months, follow-up interviews with the eight service users were undertaken. The researcher expected a 10 per cent drop-out rate for the follow-up interviews (the maximum anticipated from a previous experience with this service user group). Nevertheless, this study had a higher drop-out rate (almost 50 per cent). The SA structural reform was a key reason behind this high attrition rate. For instance, four of the five site D service users were discharged from the system after the initial assessment to become more 'independent'. These follow-up interviews investigated whether service users' self-management views and actions, and their relationship with their respective illnesses, had changed and further examined their experiences of the intervention. Data were also collected about the underlying motivations of this group to actively engage with the Flinders Programme. At this mid-trial stage, service users' care plans (N=8, administered by the trial nurses) were incorporated as an additional data source. In addition, four matched caregivers and seven health professionals were interviewed to investigate their perceptions of whether/how their service user was influenced by receiving the Flinders Programme intervention. In the mid-trial interviews, the participants' personal or social contextual changes were recorded and considered during data interpretation to better understand how these factors impacted their Flinders Programme

care plan and related self-management actions (e.g., hospitalisation, death in the family, bad weather, and job issues).

c) <u>Post-trial:</u> At the end of the trial, several methods were used to elucidate the experiences and perceptions of the stakeholders, particularly regarding barriers, facilitators, and implications for the delivery of the trial intervention. The eight intervention service users, four caregivers, and six health professionals were re-interviewed. Trial team members (N=7) were also interviewed at this post-trial stage.

An in-depth understanding of these data fulfilled **objective one:** exploring service users', caregivers', and health professionals' experiences, and objective two: exploring trial staff member's experiences. Triangulation (Golafshani, 2003) of the results of objectives one and two, along with a reflective approach, fulfilled the requirements of objective three: identifying the contextual factors that supported or impeded the delivery of the Flinders Programme. Thus, the study intended to achieve the overall aim - to investigate the acceptability and feasibility of a CCSM and recoveryoriented intervention (Flinders Programme) to improve cardiovascular health and quality of life of community-living adults with SMI. This overall process helped us to understand the underlying sociocultural structures better. For instance, contexts in REAL domains (structural reform in the mental health system) triggered the mechanisms in ACTUAL domains, whether observed or not (change fatigue in staff), which impacted the quality of care experienced by service users in the EMPIRICAL domain. Additionally, triangulation of these data sources minimised the risk of subjective bias that might confound information when capturing only service users' perspectives observed from EMPIRICAL domains. As a result of the current thesis, the trial team will have a greater understanding of the modifications required in these types of settings and within the Flinders Programme to optimise health outcomes for adults with SMI and CVD risk factors.

2.3.6 Interview guide

The Chronic Care Model (CCM) links beliefs and behaviours (Wagner et al., 2001), drawing on the understanding that attitudes towards a new CCSM-based intervention and perceived behavioural control mechanism (organisational structure) influence individuals' uptake of that intervention and individual actions (Fishbein & Ajzen, 2011; May, 2013). Thus, the domains within the Patient Assessment of Chronic Illness Care (PACIC) (Glasgow et al., 2005) and Assessment of Chronic Illness Care (ACIC) (Bonomi, Wagner, Glasgow, & VonKorff, 2002), which are measures developed by the creators of the CCM to seek service user and service staff feedback (respectively) on the six CCM domains, were used as frameworks to develop questions for the interviews, in addition to those arising from the literature review.

The interview guide constantly evolved as the study progressed, enabling the exploration of new themes emerging from the iterative data collection and analysis process. The key findings of the pre-trial interviews were further explored and verified in the mid-trial and post-trial interview phases by seeking feedback from relevant study participants and trial team members. For instance, the literature review showed the importance of peer support and group learning in delivering CCSM-based care (Zabeen et al., 2021); hence, service users' views were sought on that notion as the Flinders Programme lacked this aspect. While all service users affirmed the benefit of role-modelling associated with the peer-support approach, most preferred one-to-one engagement, saying it allowed for greater comfort and better rapport with the trial nurses. This process helped to refine the emerging IPTs of the realist synthesis process (Pawson, Greenhalgh, Harvey, & Walshe, 2005). Similarly, key themes that emerged from the service users' pre-trial interviews were further explored and validated by reconciling them with the views of their caregivers and health professionals. See Appendix3 for the different stakeholders' interview guides.

2.4 Data analysis

This thesis employed a complex four-step analysis approach involving step 1: a combination of thematic and framework analysis, step 2: a realist synthesis, step 3: a critical realist analysis (CRA), and step 4: a longitudinal analysis (see Figure 9).

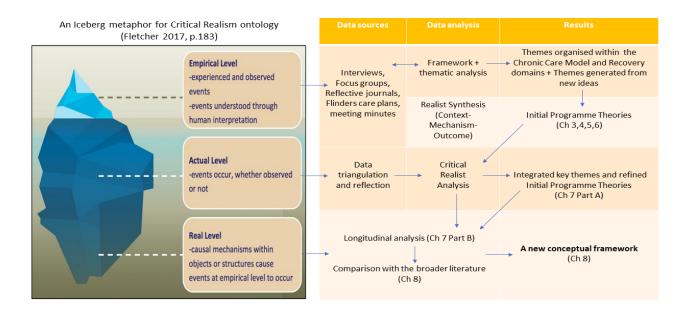


Figure 9: Critical Realist and Longitudinal analysis (The image 'Iceberg metaphor for Critical Realism ontology', Fletcher 2017, p.183 has been reproduced with the publisher's permission).

Each of the four steps has been described below in detail.

Step 1: A combination of framework and thematic analysis

Each results chapter (Chapters 3, 4, 5, and 6) explored perceptions of different stakeholders on the same topic: 'experiences of the Flinders Programme within the broader socio-environmental context'. Next, each chapter's data were analysed using a combination of the framework (Srivastava &

Thomson, 2009) and thematic analytic techniques (Braun & Clarke, 2006; Terry, Hayfield, Clarke, & Braun, 2017). Wagner's CCM was used as the structural framework of the underpinning model of the Flinders Programme. As part of the framework analysis, key findings were positioned within the six CCM domains, namely a) self-management support, b) organisational support, c) delivery system design, d) decision support, e) clinical information systems, and f) community resources and policies (Wagner et al., 2001). Elements of the CCM and related guidance assist health professionals in planning and implementing supported self-management care planning within routine health care. Thus, the intended outcome of the Flinders care plan was to collaborate with service users to set measurable goals for better management of chronic illnesses, including SMI and CVD. Combined with the CCM-guided framework analysis, thematic analysis was used to describe additional themes originating from these data; these sub-themes were positioned within the six existing CCM domains or key themes.

This overall process required each transcript to be systematically analysed to generate codes. An iterative comparison of coding was undertaken among all the transcripts as part of constructing and finalising the codes. Similar codes were gathered to develop the key themes. Then, the themes were positioned tentatively under the relevant CCM domains. Final positioning and themes were confirmed through discussion with the supervisory team, checking for parsimony and alignment with domains, with any convergent views resolved through further discussion.

Step 2: Realist Synthesis

Next, Realist Synthesis (Pawson et al., 2004) was used to identify the context-mechanism-outcome (CMO) configurations within the key themes and sub-themes. The Realist Synthesis method is appropriate here because it stresses the importance of causal mechanisms as crucial determinants of programme functionality rather than focusing on the outcomes (Rycroft-Malone et al., 2012). Overall, through this analytic method, the researcher identified the contexts that generated mechanisms in facilitating intervention functionality. The outcome developed 40 initial programme theories (IPTs) to define each stakeholder's role (e.g., service user, caregiver, health professional, and community organisations/members) in CCSM and recovery-oriented care. IPTs are a set of assumptions to explain how and why an intervention (in this case, the Flinders Programme) might work in natural settings; Context-Mechanism-Outcome (CMO) configurations of key findings helped to develop the IPTs (Mukumbang et al., 2020; Pawson et al., 2004). IPTs are generally tested through the broader literature and can be employed by researchers to develop, deliver, and evaluate similar interventions in natural settings. Identifying these underlying factors is crucial to intervention sustainability and replicability in the future (Moore et al., 2015; Pawson et al., 2004).

Step 3: Critical Realist Analysis (CRA) - description and its suitability

In step 3, data were processed involving a Critical Realist Analysis (CRA) that integrated the key themes, sub-themes, and IPTs, and refined them through data triangulation (Chapter Seven: Data

triangulation provides more detail on this analytical method). CRA is an iterative process in which data collection, analysis, and interpretation go hand-in-hand (Fletcher, 2017). Key themes emerging from one source are verified by further exploration of other sources, involving a continual comparative, iterative process. Thus, CRA takes the middle ground between inductive (observations to theory generation) and deductive (general to specific by theory testing) data analysis methods. CRA further employs 'abduction' (theoretical re-description by analysing data that did not fit original theoretical assumptions) and 'retroduction' (interpreting findings generated through the abduction process in the aspect of current social realities) in interpreting data (Archer et al., 1998; Danermark, Ekström, Jakobsen, & Karlsson, 1997). After the initial data coding, abduction was used to redescribe the results that used the CCM as an *a priori* framework.

As mentioned earlier, the CCM encapsulates some assumptions about reality, that interaction among all six tiers of the model is needed to implement CCM successfully (Wagner et al., 2001). This process assists with looking beyond the individual's perspectives of 'real', located in the EMPIRICAL domain, by investigating the underlying causes that triggered the events. These underlying causes/factors could be part of any of the six realms of CCM, interactions of multiple domains, or something completely new. The 'abduction' method helped to explain and interpret these 'new' causes and suggest modifications to the current CCM (if necessary). The final stage involved 'retroduction' in identifying the causal mechanisms in the ACTUAL domain and linking them back to the underlying conditions (in the REAL domain). This step required a reflective approach considering the impact of the socio-cultural and environmental factors of the participants and settings on the delivery of the Flinders Programme. 'Abduction' and 'retroduction' are complementary CRA tools that require constant movement between data collection (fieldwork) and theory-driven data analysis and interpretation (desk work), resulting in theory refinement and redevelopment if required (Belfrage & Hauf, 2017; Meyer & Lunnay, 2013).

The research personnel had a pivotal role in meaningfully linking all these domains based on related and seemingly unrelated social notions (such as service users' trust in health practices, and power practice within and between health professionals) that motivated (or not) stakeholders to adopt the Flinders Programme. As Belfrage and Hauf (2017, p. 260) mention: "the researcher is the acknowledged vehicle of producing knowledge in a research process which is carefully recorded, analysed and reflected upon. The researcher is subjective and socially positioned, yet reflexive". For this thesis, the researcher's academic background in Public Health played a pivotal role as it allowed them to investigate a health problem of Psychiatry with a fresh lens. The researcher's axiology supported health equity and social justice (see Table 1, p.40). Also, the researcher did not have a clinical mental health background and could therefore bring a level of independence and impartiality when considering organisational and cultural aspects. Thus, CRA-based analytical methods enabled the refining and redevelopment of the CCSM and recovery-oriented intervention of the Flinders Programme – given that it involved a new population (adults with SMI and CVD risk factors), a new

context (SA community mental health settings), and a new target health outcome (improving heart health and quality of life of the target population using self-management-based practices). Forty IPTs defined stakeholders' roles in supporting self-management and recovery care.

Step 4: Longitudinal analysis

In addition to CRA-based data triangulation, this thesis also reported on the researcher's conduct of longitudinal qualitative analysis, as data were often collected at multiple time points from the same stakeholder over 2.5 years (November 2017 to September 2020). Longitudinal qualitative research is an emerging methodology in health behaviour research that concedes that time and change are contextual (Tuthill, Maltby, DiClemente, & Pellowski, 2020). This unique analytical approach acknowledges that human situations and experiences are different at different time points, which can significantly impact one's behaviours and lifestyle depending on the situation. Participant experiences captured over an extended period allow a better understanding of the critical factors that facilitate or hinder one's engagement and adherence to a behavioural change intervention. A longitudinal qualitative data analysis approach achieves this by identifying the transition points (contexts) and related factors (mechanisms) that initiate changes, which are otherwise difficult to gather through single-point data collection. Additionally, longitudinal qualitative analysis incorporates a reflective approach where the researcher is an observer of change (reflective journal based on field observations and overall study experience), and thus, is considered a vehicle for understanding and interpreting the data (Tuthill et al., 2020). For this aspect of the analysis, Saldaña's (2003) set of guidelines was employed where a set of 18 questions helped to answer key questions such as: when changes occur through time, what increases or emerges through time, which changes interrelate through time, who are the change agents through time, and so on. Appendix 5 presents Saldana's longitudinal analytical framework and related questionnaires that guided this aspect of the data analysis process.

Throughout the data triangulation and the longitudinal analysis, the researcher's reflective journal and overall study experiences played a significant role in explaining the data. Critical Realism philosophy (Bhaskar, 1979, 2014) further pushed the researcher to delve into socio-political constructs that shape human behaviours and their interactions, and thus, to unpack the underlying mechanisms that triggered events or behaviours to generate outcomes. This complex and layered data analysis helped to identify broader socio-environmental factors that could improve the future implications of the Flinders Programme in improving the self-management behaviours of community-living adults with SMI and CVD risk factors.

CR-informed analysis of the study datasets fulfilled the thesis objectives using NVivo[™] software version 12 (QSR-International, 2018) to manage the vast amount of data for analysis. Additionally, datasets were compared and contrasted by triangulating the perspectives of all participant groups. This means that this study employed a holistic approach to understanding a complex health

intervention delivered among an even more complex population group (people with SMI and CVD risk factors). So, it is essential to acknowledge that this comprehensive study will use some existing knowledge and add new knowledge. Still, in the study's conclusion, some gaps in knowledge may remain about why people with SMI struggle to uptake and sustain CCSM-based physical health practices.

2.5 Ethics approval

Ethics approval for the original trial and this study was gained from the Southern Adelaide Clinical Human Research Ethics Committee (Study 469.16) (see Appendix 4 for the approval letter). Due to the deemed vulnerable nature of the population from which service user participants were drawn, a Vulnerable Person Related Screening was obtained for the researcher. The original trial was also registered (trial registration number: ACTRN12617000474358). The trial nurses initially sought verbal consent from the potential participant(s) in each setting once recruitment commenced. The researcher then contacted interested participants to organise an interview as per their convenience. The researcher then further explained the study and sought written consent from the participants on the scheduled day before commencing the interviews. All interviews took place in the community mental health settings to comply with the safety regulations of the ethics committee in conducting research involving people with SMI.

2.6 Chapter summary

In this chapter, the rationale for using the chosen theoretical frameworks has been provided, along with a detailed description of how they informed the methodology and methods. A report on the study participants, their eligibility and recruitment, and the study settings have also been presented. The complementary relationship of data collection tools with the analysis techniques has been illustrated, and a description of how they fulfil the study objectives has been provided. Thus, this chapter has justified the need to use CR in conducting the overall research. This thesis is a process evaluation in the broad sense. However, gathering perspectives of key stakeholders (service users, caregivers, health professionals and trial team members) on overall socio-environmental factors helped to depict a holistic picture of the research problem. The next chapter reports the findings involving service users' experiences and perspectives of the Flinders Programme.

CHAPTER THREE: EXPERIENCES OF SERVICE USERS

3.1 Chapter purpose and structure

This chapter explores service user participants' views to understand the Flinders Programme's acceptability, suitability, and effectiveness within the broader socio-environmental context. The study participants are adults diagnosed with severe mental illness (SMI) and possessing cardiovascular disease (CVD) risk factors and are associated with the South Australian community mental health settings (CMHS); they have been referred to as service users throughout this thesis. The six-month-long Flinders Programme aimed to improve participants' cardiovascular health by employing a behavioural change health intervention care plan involving motivational interview techniques. The present chapter sought to identify the underlying factors influencing service users' engagement and adherence to a motivational health behavioural change programme, in this case, the Flinders Programme.

Following this introductory section, the methods section (section 3.2) outlines the data collection and analysis process. Next, the key findings (section 3.3) explain the impact and role of different stakeholders in improving service users' self-management health behaviours. Section 3.4 summarises the results and presents Initial Programme Theories (IPTs). Finally, the chapter concludes with an overall summary of the findings (section 3.5) to fulfil study objective one: understanding the experiences of community-living adults with SMI and CVD risk factors in improving their cardiovascular health and quality of life.

3.2 Methods

Fifteen adults (aged 33-69) diagnosed with SMI and possessing CVD risk factors who participated in the Flinders Programme between 2018-2021 were interviewed. Participants were service users of the South Australian CMHS, and were recruited from four different sites. Sites A and D are urban Community Mental Health Clinics (CMHC), site B is a Community Rehabilitation Centre (CRC), and site C is a Supported Residential Facility (SRF).

Out of these 15 service users, 7 had an 'open episode' (primarily managed by the CMHS), 2 had a 'shared episode', meaning they were jointly managed by their general practitioners (GPs) and the community mental health practitioners, and the remaining 6 people were discharged from the CMHS ('closed episode'). Table 5 below provides further details on the participants' diagnoses, living situations, and access to informal (family) caregiving arrangements. Service users' diagnoses were collected by the trial nurses from the study settings' clinical record that followed the International Classification of Diseases (ICD)-10 codes (World Health Organization, 2019). All service users had codes of F20-39, F60.3 and/or F99.

Table 5: Socio-demographic details of 15 Flinders Programme participants (service users of South Australian Community Mental Health Settings)

Participants	Age					
(Pseudo names)	(as of 2021)	Primary MH diagnosis	CVD risk factors	Living situation	Caregivers	Episode

Ten service users (sites A, B, and C belonging to the Southern Adelaide Local Health Network/SALHN)

Suzy	59	Borderline Personality and Eating Disorders	Smoking	Lives with family	Caregiver herself to 9-year-old grand-daughter	Open
Steve	69	(Parkinson's) Medication-induced psychosis	Heart disease	Lives with family	Wife	Shared
Lorraine	33	Schizophrenia	Type 2 diabetes, Obesity	SRF	N/A	Open
Joe	65	Schizoaffective Thought Disorder	Low metabolism	SRF	N/A	Shared
Paul	41	Schizophrenia	Smoking, Obesity	Lives alone	Mother	Open
Damian	43	Schizoaffective, Bipolar	Smoking	Rehab Centre	Mother	Open
Peter	67	Major Depression, Delusional Disorder, Obsessive Compulsive Disorder	Type 1 diabetes	Lives alone	N/A	Closed
John	35	Schizophrenia	Smoking, Obesity	Rehab Centre	Elder sister	Open
Codi	52	Schizophrenia	Smoking, Obesity, Alcoholism	Lives with family	Wife	Closed
Matt	39	Schizophrenia	Smoking	Lives alone	Mother	Open

Five service users (site D belonging to the Central Adelaide Local Health Network/CALHN)

Brian	37	Schizoaffective, Borderline Personality Disorder	Smoking, Obesity	Lives with family	Girlfriend	Closed
Mark	57	Schizophrenia	Smoking	Lives alone	N/A	Closed
Eddie	41	Schizophrenia	Smoking, Type 2 diabetes	Lives alone	Parents	Open

Alice	56	Delusional Disorder	Smoking	Lives with family	Caregiver herself to her 21-year-old autistic son and her mother	Closed
Pam	52	Schizoaffective	Obesity	Lives with family	Caregiver herself to her new-born grand-daughter	Closed

^{*}Those highlighted in red (N=7 service users) dropped out of the clinical trial and/or the qualitative study after the pre-trial interview

Participants were interviewed at three time points: pre-Flinders Programme trial, mid-trial, and post-trial. Seven of the 15 participants dropped out of the trial and/or the qualitative study after completing their pre-trial interviews. Thus, 31 interviews took place. Out of the 7 participants who dropped out, 3 female and 2 male participants reported they were 'too busy' to participate in this longitudinal study. All 3 female participants were caregivers, and both men were working. In contrast, site D mental health professionals requested the withdrawal of 2 male participants from the Flinders Programme intervention so they could become more 'independent'.

Besides the face-to-face interviews, participants' Flinders Programme care plans were analysed to better understand their goals, actions, and steps. Furthermore, field notes were collected and analysed to observe service users' interactions with health staff, caregivers, and trial nurses. Notes were also taken of service users' socio-environmental factors that facilitated or hindered their overall health journey and experience towards improved self-management behaviours.

3.3 Key findings

The findings of this chapter present the ways in which different factors facilitated (or hindered) service users' self-management journey. Key themes and sub-themes were organised within the Chronic Care Model (CCM) framework (Wagner et al., 2001) (see Table 6).

Table 6: Perceptions of service users who took part in the Flinders Programme – key themes and sub-themes

	Chronic Care Model							
Service users and family		Community						
Self- management support	Organisational support	Delivery system design	Decision support	Clinical information systems	Community resources and policies			
Service user's roles	Coerced care, trauma, and mistrust	Need for better administration and skilled staff	Need for recovery- oriented care	Inadequate access to care plans and treatment results	Paucity of psychosocial support			
Family's roles	latrogenic trauma	Uncoordinated and discontinued care	Information and encouragement		Unstable housing and economic inequality			
Experiences of the Flinders Programme					Loss of financia control, power, and identity			
					Stigma and loneliness			

3.3.1 Self-management support

As per the CCM framework, 'self-management support' refers to the support provided to the service users by health professionals as part of a collaborative care approach. Service users are encouraged to set their own health goals, plan strategies to reach them, and monitor their health conditions (Wagner et al., 2001). On the other hand, health professionals provide self-management support by delivering assessment, psychoeducation, information, problem-solving, referral to other necessary resources and supports, monitoring, and follow-up. The Flinders Programme follows these same principles where service users and health professionals are proactive and form partnerships. This section explains the roles of service users and trial nurses in helping service users achieve their Flinders Programme care plan goals. In addition, this section identifies and elaborates upon how family caregivers facilitate self-management and recovery journeys. Notably, the original CCM framework does not explicitly discuss caregiver roles (Wagner, 1998; Wagner et al., 2001), so this section adds an original research contribution. Overall, three sub-sections are described below: i) service user's roles, ii) family roles, and iii) experiences of the Flinders Programme. The last section also focuses on the role of trial nurses to understand how they helped the participants achieve their goals.

Service user's roles

According to the findings, six factors largely impacted upon service users' ability to self-manage: a) cognitive skills, b) living skills, c) tools to remain organised, d) training and strategies, e) tackling addictive behaviours, and f) resilience.

a) Cognitive skills: Many service users reported that they struggled in their daily activities due to limited cognitive skills. Most participants complained of poor memory, inability to concentrate, difficulty staying focused, inability to communicate effectively to voice health problems, or general issues with reading and writing. Many participants, therefore, became more reliant on formal (support workers) or informal caregivers (family members) for practical tasks.

They (a laser clinic) got these forms that I need to fill out first, but I can't read and write properly. I'm gonna get her (support worker) to do it for me [Lorraine, pre-trial].

Limited cognitive skills often hindered participants' ability to seek out and fully understand health information, persist with health advice, or focus on healthy lifestyle behaviours and health goals, potentially hampering their recovery.

Q: So, have you ever been diagnosed with heart disease or diabetes, as per your knowledge? A: No. (long pause). Sometimes I have diarrhoea (often occurs due to the side-effects of antipsychotic medication). Q: So, did you mention that to your GP or anybody from here (SRF)? A: No, I don't think I did. (pause). I have poor eyesight. Q: Poor eyesight? Ok. So, when did you last check your eyes? A: (silence, thinking) a couple of years ago [Joe, pretrial].

- b) Living skills: Field notes suggested that female participants were generally better at self-care (better dressed and maintained hygiene); they were also better at managing finances. In contrast, most male participants reported difficulties with basic living skills such as cooking and cleaning, which affected their ability to self-care.
 - Q: Say, what does a good day look like to you? A: A good day? Getting food on the table would be a good day! But I struggle with that at the moment knowing what to cook and how to cook it, doing that every day, cooking and cleaning. A good day would be able to look after myself, that's the main thing, staying stress-free. I hope no-one is annoying me or anything like that [Matt, pre-trial].

c) Tools to keep organised: Some participants reported that a diary or reminders on their watch or phone helped improve their organisational skills, allowing them to better adhere to their treatment plans and self-management actions by providing them with an easily accessible visual prompt.

I write it (medical appointments) down on a card or something. Keep a date on my watch [Paul, pre-trial].

So, probably about 4 or 5 years ago, I was diagnosed with type 2 diabetes, so I forgot to tell you that earlier - but that's remained within reasonable limits, so yeah, for a while there, yeah, the GP had given me a diary, and I do the pin-prick check, and record what kind of level it was, so that was 4 or 5 times a day over 2 weeks, and yeah so I've kept that [Eddie, pre-trial].

Most participants did not recall seeing their mental or physical health care plans from their respective health care providers (GP/CMHS).

d) Training and strategies: The findings suggested that service users who were more educated and had access to sufficient health information better understood their health needs and were motivated to self-care. Service users used different strategies to cope with aggravated mental illness symptoms such as stress and anxiety. Some participants explained that sleeping, walking, and having healthy food helped them better manage these symptoms. Participants also appreciated enjoyable activities such as dancing, swimming, gardening, and painting as suitable coping mechanisms. Having pets was considered a protective factor that motivated service users towards physical activities. For some service users, smoking seemed to help them cope with stress.

If I feel myself becoming unwell, I eat more good food, or I make sure I take my medication, and I increase my medication. I have a hot shower; I go for a walk with my dogs or by myself. I smoke cigarettes because that helps; not supposed to [Codi, pre-trial].

Service users who had rehabilitation or self-management training at any point described these strategies as helpful. These service users were generally self-motivated and more proactive towards self-management.

Q: So, what keeps you motivated to get on with your daily activities and stuff?
A: I keep me motivated; that job is mine! Q: Can you think of any strategies for how you do that? A: I've actually done a bit of training myself in – it was neurolinguistics and understanding how the mind works, so I have coping strategies and lots of strategies that I learned through my training there and

as far as keeping motivated [Alice, pre-trial].

Q: And what helps you to stick to your goals (regarding a healthy lifestyle)?

A: I've done some rehabilitation in the past, so just with a government rehab group, so that was good building blocks, so yeah, sort of makes sense to be healthy, yeah [Eddie, pre-trial].

e) Tackling addictive behaviours: The participants also talked about tackling their addictive behaviours, such as alcohol or drug addiction, which are considered major CVD risk factors. Many said they could refrain from their addictions with the rehabilitation programme. Some participants also explained that being religious meant they were not supposed to drink or take drugs, which helped them stick to a healthy lifestyle. Participants who were smokers, however, admitted they used cigarettes as a coping mechanism when they felt mentally unwell, and that it was the hardest habit to tackle.

Q: So, you never want to give up smoking? A: No. (pause) I don't know what I would do without smoking! (sounds helpless). Smoking keeps my brain - I don't know, it affects my brain - keeps it clouded or opens it up a bit. I would be a mess without smoke and wouldn't know what to do! I might get a bit more money, but that doesn't help my life or wellbeing. Gotta get fed [Matt, pre-trial].

f) Resilience: Most participants tried their best to better manage their mental and physical illnesses despite suffering from both SMI and CVD risk factors-related health issues (e.g., obesity, poor metabolism), demonstrating their resilience.

When you're told, you try to do things, and you get put down all the time, and you're trying, you virtually, you get tired ... you get tired, tired trying [Mark, pre-trial].

I am ok with my physical health. I push through - what else can I do? [Damian, C&R of Flinders care plan].

Family's roles

It was evident that family played a crucial role in participants' self-management and recovery journey. Family members supported participants in every way possible. They fulfilled participants' emotional, practical, and financial needs as required. Remarkably, most female participants were caregivers themselves (to children or elderly family members), whereas male participants relied heavily on their female caregivers for psychosocial and practical support. Either way, all participants asserted the importance of family connections and relationships. The participants mostly desired essential emotional support such as love and care from their family members.

My mum supports me in everything I do. And she's lovely - She's a pillar of strength for me. I rang her every single day from my worst spot - she was there for me. And that mattered, that mattered, you know? And every single time she could pick up the phone, she did. And every time she didn't, I'd try ringing again and again and again and again. And mum never told me off about that, actually, because I sort of needed to hear from my mum. When we're like stones stuck together [Damian, pre-trial].

There were also reports of heavy reliance on caregivers regarding practical support such as accompanying them at appointments, support with cooking and cleaning, and ensuring medication intake. According to one participant, Codi, familial relationships and related activities (e.g., doing chores together, walking the dogs, attending social gatherings) also helped to maintain a sense of 'normalcy'. Codi's comment revealed that he might have experienced self-stigma and viewed family activities as fundamental to societal acceptance.

Jess (wife), she is a world of support. She does everything for me to support me. She monitors my medication, and she puts it in the dosette and makes sure that I've got enough every day to take. She encourages me to do a bit of housework and stuff. And she makes sure that I get a lot of social support. So, we go to the movies a lot — every second week or every week. When Jess goes away on trips overseas, she usually appoints personal carers to do the cooking for me and other jobs that I need them to do ... Jess, she keeps me balanced. I mean it — without her I would be quite chaotic. Like, I would end up being more psychotic, more ... than usual, and she keeps me balanced because we do normal things together. We do housework together sometimes. We walk the dogs together. We go to the movies together. We eat out together [Codi, pre-trial].

Those with stronger family and social connections reported that their social responsibilities provided meaning and purpose and motivated them towards recovery and self-care. For instance, it was evident that the female participants were generally more active in their daily lives as most of them were caregivers themselves ('mother', 'daughter', 'grandmother').

... well you just have to keep motivated and what I project is what my son sees, so I have to be very careful about what I put out and the kind of energy I put out there because I don't want him falling into a hole because Mum's not feeling great today. So very aware of what I, the mirroring type thing, what I reflect; I've got to be very careful [Alice, pre-trial].

Service users' social responsibilities motivated them to become more resilient and optimistic towards their recovery journeys, such as building personal and social identities beyond the mental illness labels and feeling self-worth and value. Strong family support and social connectedness worked as protective factors for all participants.

Q: Could you please tell me about yourself? A: I'm a foster kid. I've got paranoid schizophrenia. I got pregnant three times (silence, looks upset), but none of them made it. I love figure skating - mm - I used to be 50 kilos; then I went up to 150 (medication side-effects). Now I'm about 110. What else? I love music, and (laughs) I love food! What else? Let me think (trying to remember). I bought my mum and family birthday presents and Christmas presents, starting three years ago, for 12 people. Q: Okay, that's nice! How did you manage that? A: I've got money (giggles)! Since I don't have to pay rent (lives in an SRF), I've saved up heaps. Q: So, do you work? A: No. I'm paranoid schizophrenia (looks annoyed). Q: Yeah, of course. And what about studies and things like that? A: Nah (yawns) [Lorraine, pre-trial].

Childhood trauma seemed to play another significant role in participants' onset of illness and their ability to self-care. This chapter's results found that male participants were heavily influenced by their fathers' behaviours and actions – positively and negatively. Interview outcomes also suggested that participants' male family members (father, brother) were less engaged in participants' lives and recovery journeys.

When I was growing up, I didn't have a very good childhood, and that's probably why I've got depression, because my father used to belt my mother up. I came from a very rich family. We used to live in Springfield. Yeah, but he was a narcissist, yeah, and so is my brother, he's a narcissist. So, I love my mother dearly, and he used to belt her up, so one day I belted him up to fix him up ... I used to drink heavily, very heavily, because of my upbringing; everyone my family used to drink. My father was a drunk, he used to come home drunk, and as I said, belt my mum up. So, I used to drink as well, I used to drink a lot, and it had effects on my brain [Peter, mid-trial].

Experiences of the Flinders Programme

The Flinders Programme is a person-centred collaborative approach that employs motivational interviewing techniques to help participants set their health and/or social goals. The delivery person's role is to help participants achieve those goals through regular follow-ups, sharing necessary information and supporting them in navigating the related health and social channels as required. Out of the 15 participants, 8 completed their Flinders Programme and associated care plans to set health goals. Most participants focused on improved social connections. Lifestyle-wise,

participants mainly aimed at cutting down on smoking and increasing exercise. The younger unemployed male participants were keen to find suitable jobs, indicating their willingness to build or rebuild personal, communal, and social identities (Table 7).

Name	Problem statement	Goal statement	Sub-goals and steps
		Open epi	sode
Paul	I'm lazy plus I'd like to work as I'm bored with too much spare time	I will walk to Marion (instead of catching the bus) for fitness, i.e., every day for 15 minutes	Regularly walk to Marion rather than catch the bus Eat healthily, drink more water Quit cigarettes - slowly cut down and read the QUIT booklet Go to Centrelink and work dismantling radios (job found by his mother) Be nice to my family, be fitter and live longer, make friends
Matt	I am unable to look after myself with cooking, cleaning, and laundry. This makes me feel disorganised and worthless at times	In the next three months, I would like to develop a routine which includes cooking, cleaning, and laundry	 Regularly add something to an existing routine that includes cooking, cleaning, or laundry Having breakfast daily (he complains about not having enough energy) Working with the support worker to look at recipes, shopping lists, and meal preparation Specific work on motorbike
Damian	Smoking makes me do less activity due to the time I spend smoking, and I feel unhealthy	In the next six weeks, I will reduce the number of cigarettes smoked by half per week	Increase (rehab) group activities to distract from smoking; ask (rehab) staff about nicotine patches Increase fruit & vegetable intake and drink nosugar soft drinks Know more about MH condition and treatment
John	I don't have enough energy, and this means I miss out on groups and gym, and this makes me feel worthless	I will go to Noarlunga Anytime Fitness twice a week for half an hour	 Participating in all the groups at (rehab) Wanting a good & healthy body, i.e., build muscle, burn fat, and be lean Eat healthy food Gradually reduce smoking and eventually quit Learn more about conditions, i.e., metabolic syndrome and high triglycerides Find the right church to be able to meet kind people and make friends Improve on managing anxiety Investigating work experience/training and TAFE course options
		Shared o	care
Joe	I don't have many friends, so I miss out on social things - this makes me feel lonely	I will go to a community centre/social activity one afternoon per week	 To be busier and more active To have more friends To write letters to family members to be able to reconnect with them
Steve	I am not as fit as I would like, so I miss out on doing some things, plus this makes me feel sad and disappointed	I will play bowls one session per week with Shiloh (wife)	Go to GP for a care plan for Adelaide Exercise Physiology (I have heard about it from a friend) Also, get GP, Parkinson's, and mental health care plan too Look into bowling clubs that offer morning social groups

Name	Problem statement	Goal statement	Sub-goals and steps
		Closed e	pisode
Codi	As I smoke heavily, I am limited in what I can do at the gym - this makes me feel sad	I will go to the gym for an hour on Wednesdays with Jess (wife) and Fridays by myself	Improve breathing by cutting back on daily cigarettes Go to the gym more often so that I can be fit and healthy Finding more about Arthritis - especially in the knees Later added - continue eating healthy, drinking plenty of water and no sugar drinks, switching to artificial sweeteners for tea/coffee
Peter	I live in a disorganised state with papers everywhere (a hoarding environment), I don't have people over, and I feel overwhelmed by it. It makes me feel embarrassed	In the next two months, I will link in with the hoarding and clutter programme through Mitcham Council to help support me in sorting out my living environment	Meet GP to link in with the hoarding plus clutter programme Trial nurse to send GP a letter outlining trial and recommendation for referral to clutter programme
Alice	I get overwhelmed by the demands of my family. This means I get exhausted and makes me feel insignificant	I will allow myself one hour per day for nurturing (i.e., a book, exercise, massage)	I want to feel more serenity I want to go on yearly cruises I want to be healthier by cutting back on my smoking I want to exercise more

Participant comments suggested that the Flinders Programme's initial assessment questionnaires, one-to-one delivery process, and the easy language and structure of the written care plan encouraged them to pursue, and adhere to, their health goals. But most importantly, the rapport with the trial nurses, and the nurses' empathy and diligence in motivating the participants were identified as key facilitators in this process. Trial nurses regularly followed up with the participants and prompted them to stick to their goals. Notably, out of the two trial nurses, the one with a background in primary care (as opposed to mental health) received more positive feedback regarding their empathy, persistence, and ability to motivate the participants. These findings indicate that the delivery person's academic background, skills, and personality are important factors.

Regarding adherence to their health care goals, the participants went through a range of ups and downs depending on their individual contexts. For instance, Alice started to walk and made good progress for quite some time. Her case shows that it is easier to achieve health goals when family members actively accompany the person. However, Alice could not continue walking due to other physical health problems.

I am doing as much walking as I can when I can. I have taken my mother out too for a walk [Alice, session 2, Flinders Programme care plan].

My sore hip – (tendonitis) has prevented me from walking, but I have been active in the garden [Alice, session 3, Flinders Programme care plan].

I can start low-key walking soon [Alice, session 5, Flinders Programme care plan].

I still have knee pain; keeping my exercise light ATM (at the moment). However, I am seeing the GP today regarding the ongoing knee and hip pain [Alice, session 6, Flinders Programme care plan].

According to Saldana's (2003) longitudinal analytical approach (see Appendix 5 for details),

- 1. getting Alice's health goal (walking) on the Flinders Programme care plan was the **intervening condition** that initiated change,
- 2. having mum walk with her worked as a positive contextual condition,
- 3. but the hip and knee pain worked as the adverse **contextual condition** that stopped her from walking.

The following table accumulates the critical findings of all eight participants' Flinders Programme care plans and their views on the Flinders Programme experience collected through interviews to identify their health behaviour changes along the way. The factors that helped participants better manage their overall health and wellbeing are also unpacked using the CMO configuration (Table 8).

Table 8: Supported self-management (SSM) - perceptions of service users

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
	Living skills	Personal and social responsibilities	Female participants have naturally stronger living skills		
Service user's roles in self- management	Self-management tools (diary, planner, watch)	Weaken memory and cognitive abilities	Tools help to improve organising skills		With age and time, participants get better at self- management
	Awareness	Addictive behaviours	Motivation	Better self- management	J
	Rehab/training		Self-care skills development	and treatment adherence	
Family's roles in SSM and recovery	Psychosocial, practical, and financial support	Service users living with, or nearby to, their family members	Promoting recovery		Family relationships and the nature of dependency are mostly constant (either positive or negative)
Experiences of the Flinders Programme	Motivational interview techniques, care continuity	Phase-III trial (real-life health system does not offer consistency and lacks time)	Rapport with the trial nurse (social connection)		Enhanced trust and hope But achieving the goals is a volatile process

IPT 1: Social connectedness (C) and appropriate self-management tools (R) can promote recovery (M) in service users to help them uptake and sustain self-management behaviours (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

3.3.2 Organisational support

This domain of the CCM refers to the organisational culture within which it is safe to promote evidence-based care. Organisations should also consider resources and staff capacity to deliver quality care. Overall findings revealed that service users experienced i) coerced care, trauma, and mistrust, and ii) iatrogenic trauma.

Coerced care, trauma, and mistrust

Notably, most service user participants (N=11 of 15) were currently on, or had been subject to, a Community Treatment Order (CTO). A CTO allows enforced treatment under the Mental Health Act to comply with patient and community safety. Many participants became emotional, saying they opened up to their loved ones or health professionals about their mental health problems (e.g., suicidal thoughts, major depression, hearing voices) in the hope of getting help, but instead, those close people reported service users' 'delusional behaviours' to health authorities. During their CTO, some participants were separated from their children, lost financial control of their bank accounts, and lost driving or travelling rights. They faced restrictions through institutions such as the South Australian Civil and Administrative Tribunal (SACAT). This process often involved police and

paramedics removing the person from their house, making the experience traumatic and stigmatising.

I walked into the Flinders Medical Hospital of my own accord (due to depression), and what happened - I came out getting an order (Community Treatment Order) put on me, whereas they should have talked me through my problems. If I was sending money overseas (fell for a scam), they should have talked me through that process instead of just throwing me into an institutional place like SACAT, which is a tribunal. It's like going to court, really ... they only saw me for five minutes, and they came up and stamped me as being a, what do they call it? (raised voice with anger) delusional? In their little meetings, they had a doctor and psychiatric nurse, and they had about six in there, and you can't sort of talk to people individually with all those people there [Peter, mid-trial].

Service users who experienced these coercive treatments and had to endure the associated distress frequently mentioned being afraid of receiving similar treatment from the system. These experiences negatively affected service users' trust in the system and willingness to seek help from health professionals. Such acts isolated them from essential support and services and adversely impacted their health and wellbeing.

I'm not being completely honest with the suicidal thoughts and stuff like that. Because I don't trust anybody yet. The last time I did that, I got sectioned. So, you gotta be careful whom you tell stuff to. Because I sometimes feel like I'm up and moving around within half an hour. So, yeah, I haven't got that trust yet. Because I had a counsellor before, and I was really, really depressed and told her that I felt suicidal. So, I told her that, and she reported me to the Families SA. She said, I'm sorry, but I have to report you for (5 years old grand-daughter's) sake to the Families SA. And I just thought - oh what? So, yeah, I just freaked out, and then I didn't go back to see her again. (silence). And the next time I did it, I put something on Facebook, and that got me sectioned ... I often put stuff there, and then I delete it - kind of just makes you feel good, and then I delete it. But it was too late; my son was there. Ambos and cops came, and I got sectioned. I had an anxiety separation with (my grand-daughter). I'm still going through the trauma of that; I'm not the same person I was. But when I went in there (hospital) (silence, looks sad) ... I'm a totally different person now ... I'm worse. I'm heaps worse now that has happened. It was one of the most devastating things to be apart for (grand-daughter) because she never stayed in anyone's

house, and we have never been apart. So, I could only focus on that [Suzy, pre-trial].

latrogenic trauma

latrogenic trauma is the physical, emotional, or psychological harm caused unintentionally by the service or process of treatment (e.g., coerced care, medication side-effects, misbehaviour by health professionals, system-caused anxiety and stress) (Markham, 2018; Sweeney, Filson, Kennedy, Collinson, & Gillard, 2018).

To ensure compliance, the treatment often required receiving a regular intramuscular Depot injection of antipsychotic medication. But participants frequently complained about medication side-effects. The Depot injection often caused metabolism problems, obesity, and drowsiness. Participants also reported that Depot caused drooling, soreness, and numbness in the injected body part and made them feel like they were sedated. Field notes suggested that drooling and drowsiness caused social stigma as well. On the other hand, Clozapine was deemed a more effective medication, but was associated with myocarditis. The findings, however, noted that health professionals were fully aware of this complication and regularly monitored participants' heart health to comply with patient safety.

It (treatment) used to be good. In 2011, I had a heart attack because of Clozapine. They took me off (Clozapine), and ever since then, I've gone downhill. I'm on some Depot and some tablets, and none of them seems to work. Everything, everything's come back again. So, that's just the easiest way to explain it. So, when I was on the Clozapine, no voices, nothing. But then, I can't really turn around and say to a doctor, well, these are the voices because I don't know if they're voices or not because it's natural to me [Brian, pre-trial].

I feel like with myself that I was put on a drug (Depot) that basically made me a lot worse than I was, and my ability to think clearly, basically, I lost about eight or ten years of my life because I was on the Depot, and I felt like I had no options or choices and it was very scary. I used to get unwell more than if I was actually on nothing, so I feel like people with illnesses and stuff should have more power over what sort of medication they're going to be put on, to know if it's going to be a drowsy drug or if it's going to make you feel better, emotionally and stuff, or, yeah, I lost a lot of my life and a little bit upset about it because I could have been on Clozapine 10 years ago ... since I've been taking Clozapine and off the Depot that I'm actually improving and getting better, so it was horrible, yeah, it was really horrible. I don't know how it works, but the Depot, which was Zuclopenthixol, it's nasty, so maybe they should be more patient with their patients and not rush into a Depot because

that could ruin someone's life. It was very horrible, yeah. So, that's my thoughts about that [John, mid-trial].

Table 9 below summarises this section's key findings and CMO configuration to reflect how organisational support impacts service users' self-management behaviours.

Table 9: Organisational support - perceptions of service users

Sub-themes	Resources (/policies)	Context	Mechanism	Outcome	Change through time
Coerced care, trauma, and mistrust	MH Act allows enforced care	Lack of recovery- oriented care	Traumatic experience >	Lack of spontaneity in	The initial traumatic experience leaves a
latrogenic trauma	Lack of resources (including time)	Risk-averse illness model	mistrust of the system	accepting care	life-long scar

IPT 2: Due to a lack of sufficient resources and time (R), the mental health system heavily relies on the risk-averse (often enforced) illness model (C). Such traumatic experience generates mistrust (M) and hampers service users' health-seeking behaviours (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

3.3.3 Delivery system design

The CCM's third domain, 'delivery system design', focuses on defined teamwork and an expanded scope of practice for team members to support chronic care. Multidisciplinary teamwork, how team members collaborate with other service providers, how models of care are delivered, how care decisions are made and by whom are all part of the delivery system design. To ensure efficient resource utilisation, the system must ensure consistent and coordinated case management, planned interactions, and active follow-up. Theoretically, the model should be patient-centric and culturally appropriate. The results, however, found that the overall health system had some issues; there was i) a need for better administration and skilled staff, and ii) uncoordinated and discontinued care.

Need for better administration and skilled staff

The health system and related procedures significantly impacted service users' recovery journey and health outcomes. As part of the delivery system design, participants appreciated flexibility regarding appointments. They were frustrated when their appointments were cancelled, or emails were unanswered.

At the moment, I'm waiting for (the care coordinator) to find out what's going on with this OT (Occupational Therapy) worker. Still, it could be nine months before I find anything out because, as I said, there's no communication in this job. Well, I didn't even know she (the care coordinator) was on holidays, and I've been sending her an email! (gets upset). And then I find out she's on holidays, and it's like, you didn't – (raised voice) you could have told me,

you could have told me who's looking after me while you're gone! – nup – so [Brian, pre-trial].

Participant comments also suggested that many staff needed to prepare and be more skilled within the physical health services to work collaboratively with service users to understand and address their health needs.

Well, I had this same GP for over 36 years, and it's only when he left I had seen another one, and she said, that I think you have Bipolar, not depression. And I thought: oh! And I went to the psychologist, and it was Borderline Personality not, the Bipolar. Yeah. So, I was a bit zapped off that my GP didn't figure it out (ironic laughter) - considering we were together for ... since Sam, because he knew Sam (her son who took his own life at the age of 14). So, he just thought that it was depression! Yeah, I wish I was diagnosed a lot earlier. Cause Sam probably would have been here (becomes sad) ... because of all the crazy things I was doing. I was finding it hard; it was hard coping with the kids [Suzy, pre-trial].

It was also evident that some service users whose episodes were closed still required assistance with managing their mental illness. But due to the extreme pressure on the community mental health workforce, many of the service users could not be adequately supported even if they were *entirely* alienated from their families and other necessary psychosocial provisions. This showed the vulnerability of the system and the potential risks to service users if they relapsed during their recovery journey.

Q: Do you see anybody here? Like at (site A), any psychiatrists or mental health nurses? A: I'm not allowed to. My doctor (GP), he sent an application in to have me seen here – just every so often, but that was denied. Because they said I've got structures in place, but that's part of my structure to come here if I've got any problems, but I am just solving my own problems now [Peter, mid-trial].

It is notable that Peter was over 65 years of age, living alone, unemployed, did not have any connections with family members or friends, and was also diagnosed with type 1 diabetes, major depression (suicidal), delusional disorder, and obsessive-compulsive disorder.

Uncoordinated and discontinued care

Further insights gained through participants' comments suggested that the staff were not well-supported with necessary resources, including time. This resulted in a lack of coordination and continuity in care (critical components of effective delivery system design), which frustrated the

participants. The care discontinuity negatively impacted the much-needed rapport required between service users and their health professionals to achieve self-management goals.

Q: So, how many psychiatrists have you had over the past year and a half? A: I've had three, and I'm just about to come into my fourth. As I said, there's no continuity there, you're seeing different people all the time, and one says something like twelve months ago; the one I was seeing was hopeful that I would be off all medications last year. And then you see a new one, and they keep you on it, and they're all saying different things, and that's where I feel that I'd be better off going private as a private patient [Alice, pre-trial].

Table 10 shows how the system's delivery design impacts a person's overall health and wellbeing.

Table 10: Delivery system design - perceptions of service users

Sub-themes	Resources (/policies)	Context	Mechanism	Outcome	Change through time
Need for better administration and skilled staff	Lack of skills	Disjointed systems	Uncoordinated MH & PH systems	Poor quality of care	
Uncoordinated and discontinued care	Lack of resources	Systems	Q 1 11 Systems		

IPT 3: Due to the lack of sufficient resources and skilled staff (R) and disjointed health systems (C), there is a lack of coordination among health staff (M) - resulting in poor quality of care (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

3.3.4 Decision support

Decision support embeds the integration of evidence-based guidelines into daily clinical practice. It promotes patient-centred clinical care and actively encourages patients to participate in treatment plans. This CCM domain also ensures coordination between specialists (e.g., psychiatrists) and primary care providers (GPs). Two critical themes related to this CCM domain were identified: i) the need for recovery-oriented care, and ii) information and encouragement.

Need for recovery-oriented care

Participants expected empathy from staff saying it was disappointing as health professionals often did not listen, care, or value their opinions regarding treatment choices. Most participants also reported that neither their GPs nor the MH staff were proactive about their physical health issues or promoting healthy lifestyles. Participant comments revealed that the treatment relied heavily on medication. They wanted more self-management support and recovery-oriented strategies towards their overall health and wellbeing.

Q: So, you mentioned that you didn't feel very energetic, so did you ever discuss that with your GP? A: Mmm, I am not sure; I think I tell him that all the time, but I am not sure whether he listens or not (looking down, long pause) ... I get angry - not angry but stressed easily. (raised frustrated voice). It's hard! I tell him all the time, but I don't know if he takes that into account! [Matt, pre-trial].

Q: What about your physical health? Like, do they (site A staff) take care of that part? A: No. No, they don't, no. It is good to have (the trial nurse) onboard because she works at goals, and she's doing a good job with that. Yeah, I mean they're doing the fitness, the classes and stuff at [site A], but I feel, yeah, there should be more help regarding eating properly, and you know, given the discussion about how important it is to eat well, and take vitamins, and look after your body and stuff. They don't really do that; they just give you a tablet and say, 'There you go', you know – yeah [John, pre-trial].

Information and encouragement

The findings also revealed that the participants who were well-informed about their conditions showed more positive outcomes in self-care. Timely diagnosis of health issues and related self-management information from health professionals also encouraged participants to tackle addictive behaviours more effectively. The comments below reflect this notion.

And they gave me a list of all the things that were in my blood when I was over at ICC (Intermediate Care Centre). I found that useful [Damian, midtrial].

My neuropsychologist said to me if I stop drinking altogether, and I don't drink now at all, that my brain would regrow and bring itself back to normal. And I'm fine, you know [Peter, pre-trial].

Unfortunately, service users disclosed that they rarely got enough health information. Also, many service users did not seem to receive optimal care from the health system. For instance, an SRF-living older person with cognitive impairment reported not having eye check-ups in years; he also had metabolism issues, but said he never discussed the matter with the SRF staff. Another resident of the same SRF reported that she was diagnosed with type 2 diabetes once the Flinders Programme nurses tested her as part of the trial; she had never been tested before (she was obese, which is a common risk factor for type 2 diabetes). The diagnosis helped the young female service user adopt a healthier lifestyle, demonstrating the importance of timely diagnosis and health information.

Q: So, can you please tell me how you are managing that? A: What, diabetes? I've been only diagnosed last week (through the Flinders

Programme)! But before that, every week I used to go to Mcdonald's with my mum, and now I go to Subway [Lorraine, pre-trial].

Table 11 below shows this section's key themes and related CMO configuration.

Table 11: Decision support - perceptions of service users

Sub-themes	Resources (/policies)	Context	Mechanism	Outcome	Change through time
Need for recovery- oriented care	Lack of resources and time	Medical-based model		Poor health outcome	
Information and encouragement	Early diagnosis	Comorbidities	Awareness	Self-care and self- management	Adherence to practices when have positive results

IPT 4: Recovery-oriented care (C) requires time and quality care (R) that can enhance patient awareness and encouragement (M) to promote self-management (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

3.3.5 Clinical information systems

The CCM 'Clinical information systems' domain asserts that it is crucial to develop sound information systems for accurately recording, storing, and communicating service user data. This information system should be shared between relevant health professionals, allowing efficient recall and reminders for follow-up care. Participants, however, revealed that there was inadequate access to care plans and treatment results. Health professionals also seemed to have problems with information-sharing among themselves.

Inadequate access to care plans and treatment results

When participants were asked about their existing mental or physical health care plans, most of the 15 patients said they had never seen their care plan or did not have a copy. There were also comments regarding the lack of coordination between mental and physical health staff negatively impacting the health information system and service users' health-seeking behaviours.

I've also had a spec scan, and apparently, I haven't got enough blood on this side of the brain. They (MH staff) said they were going to get someone here to help with that, and now they're telling me to go to my GP and do it. So, that was last year. So, now I've got to get my GP to do it all, and that was a waste of time me getting it. They won't even give me the results so I can have a look myself – so ... he (GP) talks directly to these guys, but they won't tell him things he needs to know. Like the spec scan and that, he sent them an email asking them, six months now, and they still haven't replied. So, as I said, there's no communication here. They don't care! (shaking head in disappointment) [Brian, pre-trial].

Table 12 below shows this section's key theme and the related CMO configuration.

Table 12: Clinical information systems - perceptions of service users

Sub-themes	Resources (/policies)	Context	Mechanism	Outcome	Change through time
Inadequate access to care plans and treatment results	Not a patient- centred model	Lack of coordination between mental and physical health systems	Inadequate access to information	Poor health outcome	Service users lose hope, which hampers their health-seeking behaviours

IPT 5: As the patient-centred model is not followed in the health system (R), there needs to be more coordination between mental and physical health systems (C). Service users thus lack adequate health information (M) and experience poor health outcomes (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

3.3.6 Community resources and policies

'Community resources and policies' is about developing partnerships with community organisations that support and meet service users' needs. This is to ensure that resource allocation and funding of services are sustainable, equitable, and able to respond to the community's changing needs and the specific needs of more disadvantaged sub-groups (such as people with mental health issues). The findings showed that community-living adults with SMI usually experience social isolation and related disadvantages due to stigma. Four key themes were identified: i) stigma and loneliness, ii) paucity of psychosocial supports, iii) unstable housing and economic inequality, and iv) loss of financial control, power, and identity.

Stigma and loneliness

The findings revealed that participants experienced both self and social stigma. Social stigma refers to the public view that people with severe mental illness are often labelled as atypical and are unable to comply with societal norms and culture. Consequently, the stigmatised person can continually develop negative feelings due to societal alienation, leading to self-stigma.

Q: How about your sleep? Do you have trouble sleeping at night? A: Yeah little bit, if I go to bed late (silence, long pause). Q: Yeah same happens to me. I think I need about 7/8 hours of sleep, and if I don't get it, I feel ... A: grumpy? Q: Yeah! And not enough energy A: You too? (looks surprised). Q: Yeah! (laughs) isn't that true for everybody? A: Like people get agitated? Q: Yeah, yeah. Like when I don't get enough sleep, I feel low and get grumpy ... A: Bored? Q: Yeah! Bored and then eating all the wrong food like junk food and stuff. A: Hmmm [Matt, pre-trial].

Of the 15 patients, only two were married, and one was in a relationship after 18 years of being on their own. Others were either divorced or had never married; most participants reported no relationships.

... as soon as you turn around and tell them you've got a mental illness, no one wants to know, so [Brian, pre-trial].

The situation was particularly challenging for people with minimal or no contact with their families. This social stigma generated loneliness that might have seriously hampered participants' willingness to recover from their illness and adhere to self-management.

Not really (in touch with the family); no, they're scared of me; I didn't do anything wrong to them. I love to go out and be part of society or community, but (looking down, looks sad, talking to himself) ... if you don't conform, you don't conform to society, Mark, you've got problems. A lot of people lie to me, you know - they're lying in front of you. Other people saying things or assume things, assume something ... my father's 70th birthday, and they had a reunion, and they said they're having a reunion in the family, but really this is for his birthday. Mum's birthday, they didn't want me there. I'm very sad about that. Oh well, I would have loved to go to Christmas last year! Christmas gone, this year's gone, the year before, but ... this Christmas be less stressful for them, I would have liked to have been there (looks sad) [Mark, pre-trial].

Paucity of psychosocial supports

People with SMI needed intense and ongoing medical and psychosocial support to improve their overall wellbeing. Participants reported the benefits of having psychosocial support from support workers and different community and non-government organisations. For instance, some study participants were clients of Skylight, Anglicare, or Parkinsons SA, who organised day trips, and art and cooking classes. Being religious also protected many, as suicide, alcoholism, substance abuse, and gambling are forbidden in religion. Similarly, this study found that having pets was advantageous towards improved quality of life. These factors were deemed to be crucial forms of support, especially for those who were alienated from their family, or socially isolated due to stigma.

Unstable housing and economic inequality

Out of the 15 service user participants, only 6 who lived with their families had steady housing. The remainder primarily resided in government-provided subsidised houses or SRFs; some were forced to move houses multiple times over a short tenure. Reasons for this were prolonged hospitalisation, low or no income, and inability to adjust to the neighbourhood. This housing problem often caused stress and negatively impacted the person's recovery journey as service users felt unsettled due to

not having stable shelter. This housing problem and the fluctuating nature of participants' mental health and wellbeing also caused further stress to service users.

The results suggested that participants' inability to work affected their financial position, pushing them toward poverty. Although the Australian government provides economic support to people with severe mental illness (the disability pension and NDIS benefits for some), most participants reported financial hardship in fulfilling their day-to-day living and health care needs and adopting a healthy lifestyle (e.g., paying bills, buying quality nutritious food, attending gym sessions).

I just go looking for cans, and do all sorts of little bits and things, and looking after mum and dad and my sister. Go to the bank every day (to get his daily allowances); that's all I know. I work - I just ... (inaudible) messages one night a week (messenger: folding newspapers and delivering to peoples' houses). That's all I know. Q: Yeah, yeah. Do you enjoy that? A: Yeah, it's not bad, and the money is good. I make twenty bucks every week. That's good. I like it [Paul, pre-trial].

Paul and Matt also mentioned that they tried to work for recycling plants (peeling labels off bottles), but the net pay was poor due to the regulation of their finances (e.g., \$3/hour). This income inequality dampened their incentive to work, and they gave up.

Loss of financial control, power, and identity

Participants whose finances were administered by the Public Trustee (N=7 of 15, all males and living alone) faced more difficulties as they lost control over their finances because they were deemed unable to manage their finances independently. Their salaries were regulated under this system, negatively impacting their day-to-day living conditions.

Public Trustee - I just get through the day and sleep of a night ... Just you might chuck in to order a pizza if you've got enough money; it might be payday, it might be the day after payday, you might have saved \$10, get a burger from Hungry Jacks, something to eat ... and then some milk if I'm lucky enough [Damian, pre-trial].

Further to the regulation of finances, participants were often not allowed to drive or travel interstate or overseas for holidays due to the nature and volatility of their illness symptoms (psychosis, delusions, cognitive impairment). This control by the system created or reinforced a sense of disempowerment and a loss of identity and affected service users' confidence in the overall structure and policies.

I'm an intelligent man, I'm not stupid, and I don't think, probably, the Public Trustee should be controlling my money for me; I mean, I can control my own money. When I was doing architecture, I was controlling, you know, hundreds and thousands of dollars, you know? And stuff like that. I had my license taken away. And I'm treated like a little child, really (raised voice), and I'm not a child; I'm a sixty-five-year-old man! (becomes teary) [Peter, mid-trial].

So, it's like I want to go to London, but they won't let me. I can't go and get my passport anymore. I had it before mental health came into it; well, now I can't even apply for it, and they say I can. I applied for it, and they knocked it down because I'm under the State. But I said that to (care coordinator), and she goes, 'no, you're full of shit'. Why don't you do your research before you say I'm full of shit? So, I know they know more about me than what they tell me. Well, you have to because you're supposed to communicate with doctors and stuff like that, but don't lie to me. When you lie to me, I hate you, because you're lying about my health — so [Brian, pre-trial].

The table below (Table 13) shows the key themes and their CMO configurations related to community resources and policies that impact service users' self-management behaviours.

Table 13: Community resources and policies - perceptions of service users

Sub-themes	Resources (/policies)	Context	Mechanism	Outcome	Change through time
Stigma and loneliness	Lack of family support	Societal norms	Alienation from society	Poor recovery and negative impact on overall wellbeing	Increased loneliness due to continued
Paucity of psychosocial support	Lack of funding	Uncoordinated care	Decreased hope	Poor quality of life	social isolation
Unstable housing and economic inequality	Poor policy	Social stigma	Inequity and injustice	Poverty	Ups and downs as per their mental condition
Loss of financial control, power, and identity	Patriarchal system and policy	Lack of recovery- oriented care	Coerced care	Lack of spontaneity in treatment adherence and self-management	Decreased hope and optimism toward recovery

IPT 6: Lack of resources and recovery-oriented care (R) and stigma-related social isolation (C) perpetuates inequity and injustice that decrease hope in service users (M) towards poor adherence to self-management and recovery strategies (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

3.4 Summary findings and Initial Programme Theories (IPTs)

The key findings suggested that positive identity (self, communal, and social identities) and connectedness (with family, friends, and the broader community) were critical facilitators in

supporting service users in their recovery-oriented self-management journey. Most participants had not participated in work or study since they were diagnosed with their MH or severe PH conditions. For many, this meant they experienced a crisis of losing their self-identities (e.g., they had to give up work and shift family roles). Male service users seemed more frustrated about this issue, whereas female service users expressed less enthusiasm about returning to work or study as they prioritised familial relationships and responsibilities. The loss of self-identity was offset for those participants who grew or maintained their social identities.

IPT 1: Social connectedness (C) and appropriate self-management tools (R) can promote recovery (M) in service users to help them uptake and sustain self-management behaviours (O)

Participants' stories showed that the lack of a recovery orientation in the mental health system was the biggest challenge for them. Limited health promotional and psychosocial supports were available to service users, negatively impacting their motivation, hope, and optimism towards recovery. As well, the physical and mental health systems are disjointed, which causes uncoordinated care. The mental health system also lacks funding and resources, including time, which creates further problems resulting in poorer health outcomes.

IPT 2: Due to a lack of sufficient resources and time (R), the mental health system heavily relies on the risk-averse (often enforced) illness model (C). Such traumatic experience generates mistrust (M) and hampers service users' health-seeking behaviours (O)

IPT 3: Due to the lack of sufficient resources and skilled staff (R), and disjointed health systems (C), there is a lack of coordination among health staff (M), resulting in poor quality of care (O)

IPT 4: Recovery-oriented care (C) requires time and quality care (R) that can enhance patient awareness and encouragement (M) to promote self-management (O)

IPT 5: As the patient-centred model is not followed in the health system (R), there needs to be more coordination between mental and physical health systems (C). Service users thus lack adequate health information (M) and experience poor health outcomes (O)

At the community level, participants frequently faced social stigma that led to social isolation. There was also evidence of social inequity and injustice at different levels. All these factors lowered the quality of participants' lives and hampered their recovery journey.

IPT 6: Lack of resources and recovery-oriented care (R), and stigma-related social isolation (C), perpetuates inequity and injustice that decreases hope in service users (M). As a result, service users can demonstrate poor adherence to self-management and recovery strategies (O)

3.5 Chapter summary

The key findings of this chapter suggest that service users are willing and able to adhere to a healthy lifestyle if they get proper support from their family and the health system. Family played a crucial role by providing emotional, practical, and psychosocial support and normalcy. Thus, it was evident that family was the primary source of social Connectedness, Hope & optimism, Identity, Meaning, and Empowerment, which are all critical elements of the CHIME recovery model (Leamy et al., 2011). However, many service users were alienated from their families and friends. As the target participants were adults with SMI and CVD risk actors living in the community, they should receive community-integrated psychosocial support for a sustainable lifestyle change. A novel idea called 'social prescription' (Marmot, 2022b) might be helpful if implemented in collaboration with community partners. 'Social prescription' allows health professionals to refer the service user to a relevant community organisation that can alleviate their isolation and loneliness and improve their overall health and wellbeing through community engagement (e.g., sports, arts, music, bushwalking); the Flinders Programme's secondary aim of an 'improved quality of life' perfectly aligns with this notion. The positive impact of improved social capital is also evident in the latest research (Ngamaba et al., 2023).

The health system also has a significant role in supporting service users' recovery journey. Participants mentioned experiencing trauma (e.g., negative experiences involving the Public Trustee and Tribunal) and iatrogenic trauma (e.g., medication side-effects) from the enforced treatment. The regulation of service users' finances and general lifestyle were identified as significant barriers to their health-seeking attitudes and keeping trust in health and related community policies. In contrast, the Flinders Programme offered motivation, hope, rapport, and respected service users' health decisions. The overall result positively impacted participants' attitudes and self-management behaviours. Overall, this chapter's results showed that with genuine care, empathy, respect, and a supportive system, it is possible to improve cardiovascular health and quality of life in adults with SMI.

CHAPTER FOUR: EXPERIENCES OF CAREGIVERS

4.1 Chapter purpose and structure

The previous chapter presented service users' (N=15) experiences of the Flinders Programme. The service users were patients in SA community mental health settings'; in other words, community-living adults with severe mental illness (SMI) and cardiovascular disease (CVD) risk factors. The current chapter will present their matched family members' perceptions of the programme (family members will be referred to as 'caregivers' henceforth). Caregivers play an active and crucial part in supporting service users' recovery and self-management journeys. Yet, there is a paucity of research focusing on caregivers' roles and specific needs around supporting their family members with recovery and encouraging positive cardiovascular health-related self-management behaviours. Furthermore, a lack of understanding impedes how informal caregivers' 'lived experience' expertise could be effectively incorporated into the broader health system to improve the overall health of people with SMI. Accordingly, the current chapter investigates how caregivers support incorporating healthy behaviours and their perceptions of service users' Flinders Programme journey. The chapter also explores how the health system and community services can better support caregivers to improve the overall quality of life and cardiovascular health of people with SMI.

This chapter has four specific sections. Following this introduction, the methods utilised to access caregivers' perspectives are outlined in section 4.2. The key findings from family caregivers' interviews concerning their roles and how this care giving role impacts their daily lives are provided next in section 4.3. Section 4.3 also details caregivers' perceptions of the Flinders Programme. It explores the broader biological, psychosocial, and environmental factors that facilitate or hinder service users' recovery and self-management journeys. Throughout section 4.3, 'change through time' was also investigated; this results section also identified the Context-Mechanism-Outcome (CMO) configurations to gain insight into 'what works for whom and under what circumstances' from the family caregiver perspective. Section 4.4 summarises the key findings and compiles the Initial Programme Theories (IPTs). Finally, the chapter concludes with an overall summary of the results which links their significance to the broad objective of the thesis: understanding caregiver roles and experiences in improving the cardiovascular health and quality of life of adults with SMI (section 4.5).

4.2 Methods

The initial target was to interview 15 matched caregivers; however, most service users were alienated or estranged from their families. Only eight service users identified caregivers. Nevertheless, two of these eight caregivers refused to participate in the interviews. Two more caregivers could not be approached as the related study participant (an adult with SMI and CVD risk

factors) withdrew from the main trial after their initial interview. Seven in-depth interviews with four caregivers were conducted at two points: at mid-trial and post-trial, spanning 6-12 month periods. These seven interviews lasted between 40-60 minutes and took place in the caregivers' preferred nominated locations (e.g., study sites, trial team's office). One caregiver chose to provide email feedback during the follow-up interview. Although a small sample size, these feedbacks proved valuable given caregivers' lived experience and detailed knowledge about their family members.

Table 14 provides socio-demographic information about the interviewed caregivers. Pseudonyms have been used for both service users and their caregivers to maintain privacy and anonymity. It is noteworthy that all caregivers were female, and female service users were often caregivers to others (e.g., had dependent children, parents, or grand-children).

Table 14: Socio-demographics of caregivers interviewed

Participants	Approximate age	Living status	Employment and relationship status	Length of caregiving roles	
	(as of 2021)				
Paul's mother, Eileen	67	Does not live with Paul, but lets him stay at her house on weekends	Retired, Divorced	Over 30 years	
John's elder 42 sister, Marilyn		Does not live with John or near his residence	Part-time worker, Uni student (online), mother of three young children	Over 10 years	
Steve's wife, 68 Shiloh		Lives with Steve	Retired, looks after grand- children	Over 5 years	
Codi's wife, Jess 57		Lives with Codi	Full-time worker, mother of a teenage boy living with them	Over 15 years	

While preparing for this component of the study, it became apparent that the existing literature omitted a clear framework for defining caregivers' roles in supporting the service user's self-management journey. Such a framework is considered necessary in conducting the 'deductive' analysis part of the realist synthesis (Pawson et al., 2004). The deductive analysis involves a top-down approach that uses an existing framework to test already established theories. For the other results chapters, Wagner's Chronic Care Model (CCM) has been used for this purpose (Wagner et al., 2001). However, CCM does not explore caregivers' roles in self-management in detail. Therefore, the researcher developed a framework after conducting a systematic review of caregivers' roles in providing self-management support to improve the physical health of those with SMI (Zabeen et al., 2020). This framework was used as an *a priori* framework for the 'deductive' part of the current analysis (Appendix 6 presents the original framework). Elements of this framework were primarily informed by England-Kennedy and Horton (2011), and Siegloff and Aroni (2003), and further expanded based on the literature review outcomes (Zabeen et al., 2020). The framework provides a

lens that can be used to observe that caregivers play active roles in maintaining both the 'self' (e.g., identity, enhanced hope, optimism) and the 'management' (e.g., treatment adherence, voicing encouragement, promoting independence) aspects of 'self-management'.

Next, the 'inductive' analysis of the findings focused on caregivers' perceptions and experiences about the 'when, why, and how' of the service user's health-promotional behaviours, and the related outcomes, changed through time (or not). In this analysis process, the researcher used an open coding method to capture any emerging themes that were not captured by the Zabeen et al. (2020) literature review. This was undertaken in the context of existing socio-cultural constructs and environmental factors that influenced service users' and their caregivers' lives, drawn from the caregivers' perspective. Thus, the original framework developed by Zabeen et al. (2020) was further refined by new ideas emerging from the present chapter's empirical data and subsequent analysis.

During the realist synthesis process, as stipulated by Pawson et al. (2004), the underlying mechanisms that initiated and sustained these changes were further investigated by identifying the Context-Mechanism-Outcome (CMO) configuration. This CMO-based analytical step also generated a few Initial Programme Theories (IPTs). IPTs helped to propose a set of assumptions that described how caregivers' roles facilitated self-management behaviours in service users.

4.3 Key findings

The findings of this section are organised into two parts. Caregivers' roles in supporting the service user's recovery and self-management journey, including how these roles impacted the caregiver, are described in Part A. This section also examines the socio-political and environmental factors that facilitate or hinder care giving roles. In Part B, caregivers' perceptions of the service user's Flinders Programme journey are captured in addition to changes transpiring through time. This section's findings were further synthesised to identify the CMO configurations and to generate IPTs.

Part A

Caregiver's roles in the service user's recovery and self-management journey

These interviews showed that caregivers of people with SMI undertake an ongoing and challenging role in supporting the service user's recovery journey, and managing their mental and physical health. This section portrays how, by fulfilling a service user's complex needs, caregivers provide a range of emotional, psychological, and practical supports, usually involving both tangible (e.g., transportation) and intangible (e.g., nurturing) supports. Based on these findings, three key themes were arranged under two broad sections: a) Maintaining 'self' in self-management support, and b) Providing 'management' in self-management support (Figure 10). The three key themes were: 4.3.1) Passive intangible support, 4.3.2) Tangible support, and 4.3.3) Active intangible support. Figure 10 is a refined version of the framework published by Zabeen et al. (2020, p. 13) (see Appendix 6). The

themes identified in both the 2020 paper and the current chapter are in black font; the theme excluded from the recent findings is in red, and a new theme identified is in green font.

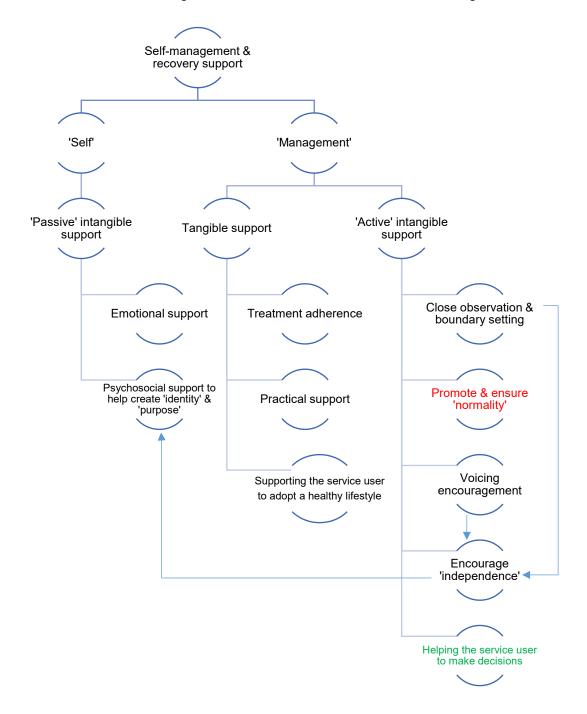


Figure 10: Caregiver role in providing self-management support in people with SMI, to promote recovery and adopt a healthy lifestyle (The image 'Caregiver role in providing self-management support in people with SMI, to promote recovery and adopt a healthy lifestyle' (Zabeen et al., 2020, p. 13) has been reproduced and refined with the publisher's permission).

MAINTAINING 'SELF' IN SELF-MANAGEMENT SUPPORT

The findings suggested that caregivers were vital in helping service users retain the 'self' in self-management, primarily representing a person's identity. Caregivers also helped boost service users' feelings of safety and comfort. Support of this kind is known as 'passive intangible support' (key

theme 1) that includes: 1) Emotional support, and 2) Psychosocial support to help create 'identity' and 'purpose'.

4.3.1 Passive intangible support

'Passive intangible support' refers to emotional and psychological support, such as showing love and care by caregivers during a crisis. Such acts of emotional support reassure service users, and thus, help them to deal with their ordeals. This is a crucial element of the 'recovery' process as such gestures by family can provide a sense of security, enhance service users' confidence, and give them 'hope' for a better future (Muir-Cochrane et al., 2019).

Emotional support

Family is the very first structure in the context of human society that is responsible for a service user's overall wellbeing (Collins, Jordan, & Coleman, 2012). The family also shapes and nurtures an individual's beliefs, values, attitudes, and behaviours and can hasten one's recovery process (Salehi, Ehrlich, Kendall, & Sav, 2019); this study reflects these observations. The findings suggest that positive (and extended) parenting and nurturing encourage positive thinking and boost confidence in service users, which strongly influences the recovery process. The analysis also indicates that as caregivers age, they gain more life experience and display a better understanding of the service user's emotional, practical, and overall wellbeing needs. The following comment from John's elder sister, Marilyn, supports these notions and shows how nurturing and positive social bonding can improve the overall health outcomes of a service user. Marilyn also showed regret that, being inexperienced, she could not help John when she was younger. As time passed and she had her children, her parenting skills improved to better help guide and support John. Overall, it appears that family functioning, mainly nurturing, can be an essential source of emotional support, which is difficult for the service user to source from anywhere else.

I have always talked to him about positive thinking and how he can achieve anything. Our Mum died when John was only 16, and we didn't really see our Dad at that time. This is when things went downhill for John, and as I was only 22, I tried everything to help him, but it was overwhelming for me. Now that I am 40, and have three children of my own, I kind of know better now what he needs. I actually treat him like one of my children more than my brother, and I think that this has had a very positive impact on him. I think John needed more parenting than he received earlier in life [John's sister Marilyn; post-trial interview].

Psychosocial support to help create 'identity' & 'purpose'

Given the volatile, complex, and chronic nature of SMI and the related negative personal and social life consequences, service users often lose hope of recovery (Slade, 2009). This negative emotionality can also affect their willingness to self-care and hinder their overall expectation of better

health outcomes. The comment below, by Codi's wife, Jess, revealed concern for Codi's wellbeing due to social isolation and explained how she tried to fill that void by expressing constant love. Consequently, Codi was motivated towards better self-management and recovery. Such situations identify family members as potentially playing a crucial role in providing hope and a sense of purpose for the service user, improving their quality of life.

Q: Codi actually made a very sweet comment (at the post-trial interview), something regarding, I think I asked him what motivated him towards recovery and self-management practices, and he said he looked forward to you (wife) coming back home every day and showing you something, that he had done something. A: (smiles and looks a little embarrassed). Well, he's, yeah so, he's, because the day can be, the day can be completely full of just sleeping ... the day can be full of empty, nothingness, nothing, can be full of nothing, no, so he'll always get hugs and non-judgemental and supportiveness [Codi's wife Jess; post-trial interview].

Family members can also help create or rebuild lost identities. These identities can be a) personal (that gives a sense of 'self'); b) relational (social roles and responsibilities that provide 'meaning' to life); or c) social identity (being part of the broader society that provides a sense of belonging and defines an individual beyond their 'self' identity) (Adams & Van De Vijver, 2017). In these ways, people with SMI can live meaningful lives within their community. Caregiver's knowledge about the service user is helpful here as this encourages the service user to uptake previous positive habits in restoring identities. For instance, John's sister Marilyn explained how revisiting a favourite church could help John rebuild friendships with like-minded people and, as a result, bring positivity to his life.

I actually had one last thought, I would love for John to find some friends. Not people who are a bad influence on him. I have encouraged him to go back to a church he went to years ago to meet new people, as he seems to have fond memories of this. I am also encouraging him to join a tennis team this summer - he used to be a very good tennis player when he was younger. I would love some help in him finding good friendships [John's sister Marilyn; post-trial interview].

The combined findings of the CMO configuration and longitudinal analysis (see <u>Appendix 5</u> for details) have generated Initial Program Theory 1 (IPT 1): Older caregivers' (C) better knowledge, nurturing habits, and understanding of the service user's needs (R) provide 'meaning' (M), improving their quality of life (O). Caregiver's emotional supportiveness (R) also motivates (M) the service user towards recovery (O) (Table 15).

Table 15: Role of caregiver in Passive intangible support

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
Emotional support	Companionship	Loneliness generated due to social isolation	Source of happiness, enthusiasm, and motivation	Positive impact	Constant emotional support (nurturing) from the caregivers and family > optimism towards
	Unconditional love and affection		'Meaningful' life	Motivation towards self- management	living a 'meaningful' life
			Empathy	Trust and reliance	
Psycho- social support to help create	Nurturing	Caregiver's knowledge about the service user's medical and behavioural histories	Assurance	Service user's better management of the mental illness symptoms	Older caregiver > More life experiences > Better
'identity' & 'purpose'			Encourages positive thinking Nurtured	Positive impact	understanding of the service user's needs
			Encouragement to uptake previous positive habits	Restored identities	

IPT 1: Older caregivers' (C) better knowledge, nurturing habits, and understanding of the service user's needs (R) provide 'meaning' (M), improving their quality of life (O). Caregiver's emotional supportiveness (R) also motivates the service user towards recovery (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Program Theory

PROVIDING 'MANAGEMENT' IN SELF-MANAGEMENT SUPPORT

As part of the 'management' aspect in self-management care, caregivers reported providing tangible and 'active intangible' support in managing the service user's physical and mental health. Thus, two key themes were under this section: 4.3.2. Tangible support; and 4.3.3. Active intangible support.

4.3.2 Tangible support

Tangible supports are visible and require the caregiver to help with the practical aspects of the self-management approach (e.g., helping with chores, transportation, and financial assistance). Based on these strategies, this section was divided into three sub-themes: 1) Treatment adherence, 2) Practical support, and 3) Supporting the service user to adopt a healthy lifestyle.

Treatment adherence

The results indicated that managing the service user's mental health was the caregivers' first and foremost priority. A service user's first psychotic episode and resultant anxiety made the caregiver

proactive towards managing their mental illness over the longer term. For example, Steve's wife Shiloh's comment made it apparent that the first psychotic episode was traumatic for her and, due to the ongoing volatile nature of the SMI and related actions (e.g., self-harm, posing a risk to others), Shiloh kept worrying about this happening again. Shiloh always ensured that Steve regularly took his antipsychotic medications and accompanied him to his appointments.

So, I'm very proactive in making sure that he does everything he needs to stay in good health, mental health place because it was an experience (husband's first psychotic episode) that I would never want to go through again (gets upset). And – it does worry me that, you know, as we go along, this could happen again. It has happened a couple of times and – but no, since he's been under the mental health regime (community mental health service, not a Community Treatment Order) – you know, hasn't ended up in the hospital and you know, wanting to harm people and stuff like that. So, yeah, I'm very proactive in that field. I make sure that he takes all his medication. That he keeps all his appointments [Steve's wife, Shiloh; post-trial interview].

Caregivers also reported promoting continuity by regularly prompting the person to follow through on advice and regular self-management actions (e.g., following up on advice from the GP, ensuring the service user has a flu vaccination, prompting nebuliser use).

Practical support

The findings also suggested that caregivers strived to ensure that service users led a healthy lifestyle by providing practical support. For instance, helping service users with household chores, gardening, driving them to appointments, and managing finances. During service users' psychotic episodes or any major physical illness, caregivers sometimes needed help with basic needs (e.g., helping with dressing or showering). It was also evident that caregivers often required financial assistance as most of the service users did not work (only 2 of the 15 service users/study participants were involved in part-time or casual work). However, while fulfilling these duties, caregivers said they often found themselves in financial hardship, especially elderly caregivers like Steve's wife, Shiloh, and Paul's mother, Eileen, who were retired. They further explained that doing labour-intensive work such as cleaning the house or gardening became challenging due to their age. They often struggled to afford professionals to complete these household tasks for service users.

(I) support teams to provide cleaning, washing, food shopping, delivering meals, and gardening. Because of my age (approx. 67), these daily needs are beyond my daily capabilities. Financially, I am paying for most of these services, so I am economically disadvantaged [Paul's mother, Eileen; midtrial interview].

Supporting the service user to adopt a healthy lifestyle

Caregivers reported using multiple overt and covert strategies to promote behavioural change in the service user. Caregivers said they encouraged the service user to do a range of outside activities (e.g., joining the gym) and often accompanied them to support the adoption of a healthier lifestyle. When caregivers could afford a healthy lifestyle or services and had enough time, both parties were motivated and experienced the greatest benefits as they worked towards the same goal together. Paul's mother, Eileen, revealed that she often took the financial responsibilities associated with Paul's health practices.

Strategies Paul and I use – Paul gets a daily allowance from the bank; therefore, a daily walk is needed to the bank. However, his lung damage (Paul has Asthma) is now constricting walking - his lunch meal is delivered by Meals on Wheels enabling a more balanced diet (organised and paid for by Eileen) [Paul's mother, Eileen; mid-trial interview].

However, when the service user was more mentally and physically unwell, caregivers explained they needed to provide more practical support as it was difficult for them to initiate and sustain self-management behaviours at these times.

Table 16 below shows four more IPTs generated from the CMO configuration and longitudinal analysis of the above section – caregivers' roles in *tangible support*.

Table 16: Role of caregiver in tangible support

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
Treatment adherence	Ensuring medications, taking to appointments	Service user's first psychotic episode	Caregiver's traumatic experience > anxiety	Caregiver proactive in managing MH symptoms	A service user's first psychotic episode leaves caregivers with an unforgettable traumatic experience

IPT 2: The service user's first psychotic episode (C) and resultant anxiety (M) keep the caregiver proactive (O) towards managing the service user's mental illness

Practical support	Home- delivered healthy food options arranged and paid for by the caregiver	Access to healthy meals	Positive, healthy food choices (eat fruit, quit sugar)	Weight loss	Service users regularly need financial and other practical support from their caregivers (e.g., chores)
	Gym membership and NDIS plan	Caregiver to arrange and finance facilities	Access to amenities	(theoretically) More physical exercise	

IPT 3: Caregivers ensure a healthy lifestyle (C) by making financial contributions (R), which ultimately helps the service user with SMI to achieve desired health outcomes (O)

	If has enough finances and time	Caregiver to 'walk alongside' the service user (accompanying the service user in their self- management journey)		The caregiver is also motivated to adopt a healthy lifestyle	Enhanced motivation for caregivers as they accompany the service user to adopt a healthy lifestyle		
	IPT 4: Given sufficient financing and time (R), both parties are motivated (M) and get the most benefits (O) when working towards the same goal together (C)						
Supporting the service user to adopt a healthy lifestyle		When mentally unwell	Lesser scope of initiating/ sustaining 'self- management'	Require more tangible support from the caregiver			
	Overt strategy	Relapses in mental health	Service user's challenges in sustaining changed behaviours	Caregiver's constant efforts in trying to restore healthy habits	People with mental illness mostly go through cycles of good and bad		
		When unwell	Financing and organising Meals on Wheels	More balanced diet	phases		
	Covert strategy	When physically and mentally well	Daily allowance from the bank	Forces the service user to walk			
		entally unwell (C), seenging to initiate an			actical support (O) as it nese times (M)		

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

4.3.3 Active intangible support

Unlike any materialistic supports, active intangible supports require caregivers' time and energy. This key theme subsumes four other sub-themes that were used as an *a priori* theory derived from the original framework (Zabeen et al., 2020): 1) Close observation & boundary setting; 2) Promoting & ensuring 'normality'; 3) Voicing encouragement; and 4) Encouraging independence. In contrast to the earlier study, the current study did not find any comments relevant to 'Promoting & ensuring normality'. Instead, a new sub-theme emerged: 5) Helping the service user to make decisions.

Close observation & boundary setting

To ensure the service user's safety and overall wellbeing, caregivers reported 'keeping an eye' on the service user's mental health-related symptoms, medication adherence, and general health behaviours. Caregivers with better knowledge, awareness, and understanding of mental illness symptoms could better relate to, and help, their family members respond positively to these symptoms. For instance, Codi's wife, Jess, empathised with how the cognitive impairment made it

difficult for Codi to comprehend and perform his usual social roles (e.g., helping with chores). Jess, therefore, took more decisive actions in setting boundaries to promote Codi's independence.

I tell him off every now and again and that I just draw the line and say, "Get off your bum and give us a hand (regarding house chores) - this is unfair, and this is not equitable." Yeah, well, you know — "no, you're sitting there or come and help me hang out the washing", and because otherwise, he's just — the brain and the thinking are not — because they're just not connecting, and he'll sit there and watch it. It's like watching a house burn down and say, 'oh, there's a fire' [Codi's wife Jess; post-trial interview].

Voicing encouragement

All caregivers reported encouraging the service user to adopt a healthier lifestyle; the most common was prompting them to exercise more. However, due to the service user experiencing medication-induced drowsiness and exhaustion, and often due to physical illnesses (e.g., back pain, Asthma, Parkinson's Disease), their caregiver perceived that service users were unable to do moderate to vigorous exercise. John's sister, Marilyn's comment, made this evident.

I try and encourage him to exercise, but he finds it hard as he is quite exhausted from the Clozapine most of the time [John's sister Marilyn; mid-trial interview].

This comment identifies a lack of exercise as the consequence of the side-effects of medication, which impacted the service user's energy levels. Hence, caregivers' encouragement alone is likely insufficient to help the service user engage in physical exercise.

Caregivers also reported how they helped the service user manage their mental health by providing 'active' emotional support.

John has suffered from anxiety his whole life, and he sometimes gets worried that he is going to become unwell when he starts feeling anxious. I remind him that he will only become unwell if he takes intoxicants and that he just needs to take some deep breaths to lessen the anxiety. He is a lot better these days at managing his anxiety and doing things to calm the nerves [John's sister Marilyn; mid-trial interview].

This section on voicing encouragement shows that the caregiver's knowledge about the service user's medical and behavioural histories helped them provide timely emotional support and assurance that matched their mental and physical health needs. As a result, the service user could better manage their mental illness symptoms.

Encourage 'independence'

Caregivers also recounted overseeing the routines of their family members and making conscious efforts to promote independence by stepping back from an active role. At the post-trial interview, Marilyn (John's elder sister) explained how nurturing John and monitoring his daily activities made him more accountable towards better self-management. Marilyn was relieved and proud to observe John's efforts to build independence.

I call John every day to make sure he has woken up at a good time and to see what he is doing for the day. I find this helps John a lot to know someone cares, but also someone he has to justify what he is doing too - if that makes sense? I make sure that he goes to all his appointments - and he is getting a lot better at that. This morning he had a psychologist appointment at 10 am, and he made sure that he was up and went to the appointment [John's sister Marilyn; post-trial interview].

Overall, it is evident that a caregiver needs to play an intricate part in managing both the 'self' and the 'management' aspects of the self-management of the physical, mental, and emotional aspects of health. This becomes particularly challenging when the service user goes through a difficult time. In such situations, caregivers simultaneously need to provide emotional, psychological, and practical support, as can be seen from the following comment by Jess.

(When mentally unwell) - it's like, "what do you need at the moment? Have you tried this (medication)? Do you think maybe if you ..." - and I've had times when he's been unwell where I physically take him by the hand, helped him get undressed, helped him get in the shower, or helped him get into a bed or actually helped him get to a quiet place because he hasn't thought "oh, I will get myself to a guiet place or I will do this or I will do that" - it's because it's yeah it's - so we've had an ongoing translating sort of dialogue around strategies and symptoms, and he's got good knowledge and plan, but even there are times when okay so – I'll get home, and he's obviously been having a rough day, and it's, "oh, so what have you tried and has that helped and have you thought maybe you do need to take some PRN (as needed additional medication). Give it - it might not work, but give it a try anyway, see how you feel and see how – give it half an hour and then see how you go, and then we can work out what we'll do from there", and so it's a process yeah? And it's like physically, "here you go" [Codi's wife Jess; midtrial interview].

These comments show that when mentally unwell, more tangible support is required from the caregiver. There is less scope and capacity for the service user to initiate or sustain 'self-

management' behaviours at such times. When the service user is mentally stable, more dialogue around strategies can be engaged in to manage the illness symptoms.

Helping the service user to 'make decisions'

The current study identified this new theme that was not captured in the initial systematic review (Zabeen et al., 2020). Caregivers suggested that the service user often made 'poor decisions' due to their cognitive impairment, lack of insight into reality, and poor judgement (e.g., being defrauded by scams, spending money on unnecessary luxury items beyond their financial means, inability to navigate and complete paperwork for health and administrative systems). Resultantly, caregivers often ended up making decisions for the service user and, when combined with other roles and responsibilities (e.g., work, looking after young children), caregivers often found it challenging to manage the added time required to perform these tasks.

... it became apparent when – because Codi – any appointments or anywhere where he needs to navigate a system he always – we will tag team. He always asks me to help explain and express the words, and I include him and ask him ... – and we plan – I ask him, "what do you want to do?" and then when we're out at the things, I say "does that make sense to you and here's what they're explaining and the options and which one of those do you think makes – fits with what" – so yeah, because when you're out doing that sort of thing, people instantly go – they look to you, and they treat the patient as if they're not even there, and you got to sort of stop that. Yeah, so, it's a busy time, particularly because I'm so – in a job where I'm working 50-60 hours a week sometimes [Codi's wife Jess; mid-trial interview].

This section also encapsulates examples demonstrating that the service user can often find it difficult to navigate systems. Thus, caregivers need to perform a range of roles here, supporting service users' health literacy, interpreting and explaining information provided by health professionals to help understand what is being said, and engaging with the care plan ideas in ways that can be easily understood and applied in life. However, these active actions made some caregivers say that unconsciously, they became the service user's voice in their treatment choice. The potential consequence of taking on the decision-making role was highlighted by Steve's wife, Shiloh, who expressed her concerns about how Steve might be losing his natural abilities and skills to deal with different situations due to Shiloh's active involvement in the decision-making process. Shiloh expressed concerns for Steve's autonomy, not wanting to reinforce dependency, and losing his capacity to self-manage inadvertently.

... you know, I really don't think he'd be able to manage his warning signs and use, you know, other strategies, because you know when he gets – you know if he gets like that; if he gets anxious, then his cognitive condition is not very good. He can't think, you know, he, yeah, I do all the thinking for him. I don't know, that could be all my fault – because, you know, when he was first diagnosed with Parkinson's, I just took over. And he used to do everything. And I – I used to work very long hours, and he would do everything, and once, you know, his condition started to deteriorate, I just took over, and maybe that was the wrong thing to do. I probably should have let him cope for himself, you know, a bit more than he does. But I just take it over, so hope it – hope I haven't made it worse [Steve's wife, Shiloh; post-trial interview].

Table 17 below summarises the findings and presents IPT 6 – IPT 9.

Table 17: Role of caregiver in active tangible support

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
Close observation & boundary setting		The service user has both physical and mental issues	Preventing deteriorating health	Caregivers are vigilant of the service user's risky health habits (e.g., heavy smoking and alcohol consumption)	The constant need for monitoring to prevent relapses
	Knowledgeable caregiver	A service user with SMI has cognitive impairment	Requires more direction	More assertive actions from the caregiver	With experience, caregivers get better at understanding the service user's needs

IPT 6: Experienced and knowledgeable caregivers (R) have a better understanding of the service user's needs (C) and can take more assertive actions (O)

	Caregiver's role: Despite voicing encouragement	Side-effects of medications	Exhaustion	Difficulties in exercise	Depending on the mental health
Voicing encouragem ent		When mentally stable	More dialogue between the service user and their caregiver around strategies	Improved self- management skills	'phases', caregivers must change their strategies for voicing encouragement

IPT 7: When mentally stable and not over-medicated (C), there are better opportunities for the caregiver to have dialogue (M) that encourages the service user towards improved health habits (O)

the	verseeing Accountability e service user's routine	Better self- management	
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Encouraging 'independen ce'	Caregiver to monitor the service user's daily routine	Service user's accountabilit y to a family member	Motivation towards self- management	Positive outcome	'Regular' monitoring decreases when the service user
		Regular follow-ups > structure/ routine	Encouragement and motivation (combined efforts of the trial nurse & the caregiver); engaged > good habit forming	Independent (small) actions	with SMI shows 'independence'
		The caregiver manages overall money, but the service user manages daily expenses	Increased hope & optimism	Increased financial responsibility	
		Over- reliance on the caregiver ('quick solution')	Caregiver's roles: boundary setting and guidance	Independence	
IDT 9: \\/\ba	n the correctiver eve	Cognitive impairment	Difficulties comprehending and performing social roles	Caregivers to set boundaries to promote independence	D) that make the

IPT 8: When the caregiver oversees the service user's daily routine and sets boundaries (R) that make the service user accountable (M) towards independent actions (O)

Helping the	Caregiver's time	Difficulties	Including the	A caregiver helps	Caregiver often
service user to make		navigating health/admin	service user's voice in their	the service user in the decision-	engages the service user in
decisions		systems	treatment choices	making	decision-making
					(when mentally
					stable)

IPT 9: Due to the difficulties in navigating health systems (C), caregivers help the service user in decision-making (O) - this is so the service user's opinion is included in the treatment choice (M)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

A further IPT (IPT 10) was generated following the above IPTs, as the findings suggest that, in most cases, caregivers use a mix of tangible and intangible strategies in supporting their family members to better manage their health behaviours (Table 18).

Table 18: A mix of tangible and intangible strategies

Resources	Context	Mechanism	Outcome	Change through time
	Knowledge: 'Passive smoking' could be harmful to the kitten	Awareness and responsibility	Service users quit smoking	
Caregiver bought a pet	The service user living alone	Companionship	Reduced loneliness	Knowledge enhances awareness
	Quit smoking	Service user proud of their achievements	Improved mental health and wellbeing	(cumulative change)
Access to amenities (e.g., gym membership)	Volatile nature of the mental illness	Amotivation	Caregiver supports with verbal encouragement (tools: motivational interviewing) and accompanying the service user in adopting a healthy lifestyle (e.g., swimming)	Caregiver adopts strategies based on the 'stages' of the service user's mental illness

IPT 10: A combination of tangible (access to amenities/resources) and intangible supports (information, encouragement, companionship) (R) can enhance awareness, responsibility, and motivation, and reduce loneliness (M), resulting in improved health and wellbeing (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

Part B

Caregivers' perceptions of the service user's Flinders Programme experience and 'change through time' – what worked (or not), why, and how

This section shows how the Flinders Programme influenced service users and their caregivers while service users took the self-management and recovery journey. This section also seeks to explain why (or why not) the Flinders Programme worked and how, from the caregivers' perspectives. In doing so, this section unpacks the underlying mechanisms of the Flinders Programme content, related tools, and the delivery process.

Codi: Codi had two primary goals - to reduce smoking and to increase exercise.

Initially, Codi's wife Jess reported that reducing smoking had always been challenging for Codi. Jess said that Codi 'externalises the solution' by experimenting with a range of different Nicotine Replacement Therapies (NRTs) with Jess's constant encouragement and support, but they last for

only a short period, 'rather than focusing on something more internal' (that is, making an active 'choice' to reduce smoking). At the post-trial interview, Jess confirmed that Codi was making conscious efforts to limit his smoking and sought Jess's help throughout that journey.

He's motivated to get back to using NRT again, because now and again I've said -I – "do you want to try patches again" and we've – we've done things where I'll put the patches on before he gets out of bed so that by the time he's up, he's not going to go straight out the back and have a – so we – we've been experimenting, trial and error with all sorts of – those sort of things. But yeah, invariably, he goes through cycles where I think he loses momentum for it, and it's just too easy to – yeah, he's not great at following through with things [Codi's wife Jess; mid-trial interview].

Q: ... (after interviewing Codi) I felt like he was more mindful, and he genuinely wanted to quit or reduce (smoking)? A: Absolutely, he, and that's the frustration. So, it's not that he doesn't want to; in fact, that's, it's because he's had a whole series of falls and more falls and more concern about his physical health, that's probably tipped him up with his mental health in the three months because he's had a couple of significant falls in July and then again in August, both of which required stitches in the head and he's had ongoing back pain for the last three months or more [Codi's wife Jess; post-trial interview].

The above comments assert that relapses in the service user's mental or physical health issues pose challenges in sustaining changed health behaviours. Caregivers have to make constant efforts to support the service user to restore healthy habits. In Codi's case, a positive change was demonstrated through time despite the falls and subsequent mental health challenges; he was more mindful and motivated to reduce smoking.

Regarding Codi's second goal (joining the gym and the swimming club), it was evident from Jess's experience that 'walking alongside' was the most effective way to increase Codi's exercise level.

It's often I'll get home and he – half the time he's saying, "Yep, I'm going" (to the swimming or the gym) and the other half he sort of – "oh I'll just – I'll stay in bed", and I say well, "why don't you just go anyway" and might as well get up. So, it's all the – "I'm coming, are you coming with me?" So yeah, but other than – if – we've left – it's too easy, "oh no, I won't be bothered", yeah [Codi's wife Jess; mid-trial interview].

Q: So, the second one (Flinders Programme goal) was about going to a gym or doing some light activities? A: So again, he wants to do, I think there's an element where there's so many things that it's all too hard. And he worries, he's, he's in this spiral sometimes where, "where do you start? There are so many things", but I've certainly, he does have a gym membership, and I have a gym membership, and it's a case of I get home, "Right where, how about we go to the?" - So, so the last two Monday nights, he's come along to the swimming pool with me, and I've said, "Well I'm going anyway, how about if you come along, you don't have to go in the pool, you can just sit and get out of the house, just come along." And then two seconds later, "Oh well, I might just get my shorts then" [Codi's wife Jess; post-trial interview].

The caregiver's ability to provide necessary resources and access amenities (e.g., gym membership) was crucial in this case. However, the varying nature of mental illness often meant the service user experienced significant problems with amotivation. In such cases, the caregiver had to support with verbal encouragement and accompany the service user in adopting a healthy lifestyle (e.g., swimming). One feature was consistent across time – the service user required constant encouragement, and being accompanied by their caregiver ensured further commitment to better health choices.

According to Codi's final care plan, some of his other sub-goals were to reduce weight (recommended by his GP to manage arthritis pain better), replace sugar with sweeteners, and drink more water. At the post-trial interview, Jess stated that Codi had successfully replaced sugar with sweeteners, drank 'maybe a little' more water, and had lost some weight. However, Jess revealed that losing weight was not a conscious decision, as can be seen in the following comment.

He doesn't, he doesn't use food to manage anxiety and stress, and in fact, when he's more unwell with his schizophrenia, it's actually more the case that he, because he'll be sleeping much more, that he won't have had, I'll come home in the evening, and he won't have had anything to eat at all. And possibly not have had much to drink either, and then the first thing I get is the comment, "Oh, I'm anxious." And one of his strategies for his managing the anxiety, which he has found to be helpful, is to actually have something in his stomach. So literally, so he may well lose a bit of weight over that period of time because his food intake is a bit lower [Codi's wife Jess; post-trial interview].

This comment showed that during a phase of deteriorating mental health (e.g., increased anxiety), Codi used some coping mechanisms (e.g., prolonged sleeping that led to having nothing to eat or drink for an extended period), which directly impacted his physical health (e.g., weight loss). In this

case, Jess later explained how she supported Codi by providing emotional (assurance, comfort) and practical support (giving medication and meals) to help him cope with anxiety.

Overall, Jess had a positive view of the Flinders Programme. She thought the person-centred program (without the caregiver's direct involvement) led Codi towards greater independence and engagement in his decision-making process. His sense of achievement appeared to build Codi's confidence, autonomy, and self-esteem.

I think it's useful that they've (the trial nurse and the GP) sat down with him individually because it's too easy for a caregiver to sit down, and it becomes — it then gives him permission to step back if the caregiver is always there. So, it's made him, on his terms, autonomously engage in thinking about his own health because I'm all the time — I'm railing against that because he — there's dependencies that — and he will slip into that dependency. So, it's good that it's been — he's done it on his own terms, independently, autonomously, and I think that he feels good about that too, yeah, yeah? Because otherwise I — "oh, Jess can do that, Jess can do that, Jess could do that" [Codi's wife Jess; mid-trial interview].

The trial nurse delivering the programme was also praised for the way she was able to motivate Codi. Jess explained that regular follow-ups and the structured programme helped towards this motivation. Besides, Jess acknowledged that the trial nurse maintained regular communication with her, which kept her updated about Codi's Flinders Programme goals and related plans. Overall, good habit formation led to Codi's independent (small) actions; this was possible due to the combined effort taken by the trial nurse and Jess.

Yeah, no, I think he's — he is definitely engaged with it (the Flinders Programme). He seems to — he talks — he doesn't talk a lot about it, but he clearly, he's — you can see that he — "yes, I've got this appointment. So yep, can you remind me" or — it's in his mind. So, it's given a structure for him. He is motivated. He — whatever that means. It's undoubtedly more motivation than what he was having. It's something that he's building — he's building into his habit process, so that's a good habit forming — yeah, and he's now moving to doing that Wednesday swim session on his own. It sounds like (the trial nurse) has really, really encouraged him as well, and so between her and me on the other side and him himself — yeah, no, he's — and I think there's small things where he is doing a little bit more things independently. So, there is something where — oh, just little things. I came home the other day, and he had actually pulled something out of the freezer to defrost without me having to sort of ask or leave a list, or he'd done something because normally he

wouldn't – things would just be left, and he'd sit or he'd sleep or yeah so, he was, and I sort of – I think I said "you need to help me. You need to do more here. I can't do everything and stuff", so he – I think he thought about that and having (the trial nurse) also doing that process has made him think, "yeah maybe I should try and do more". Yep, so they're small – they're small things, but they're noticeable because going from nothing to something is noticeable. So, that's been quite good, I think [Codi's wife Jess; mid-trial interview].

Jess also mentioned that the overall process was 'very easy' to follow. Also, the care plan was written in a language that was easy to 'read, understand and relate to', given the service user's mental illness-related cognitive impairment, it was also a significant positive factor.

<u>Steve</u>: Steve had one main goal – to get into lawn bowling, and his sub-goal was to get into Adelaide Exercise Physiology (AEP) – a tailored exercise programme suited for people with Parkinson's like him. The other secondary goals involved attending regular dance and art classes. Steve's wife, Shiloh, provided details about the positive outcomes of Steve joining the AEP programme.

We'd heard about it from friends that go, a friend of ours had a stroke, and he went. So, when we were discussing this with [the trial nurse] about what we wanted to do, well, that was one of the things that we said, "we would like to go to Adelaide Exercise Physiology". So, then she, no, she said, "Well, go back to your GP, get a care plan done and do it". So, we've done all that, and I suppose we've heard about that programme from a friend, and it's been very beneficial. It's very good; they treat you as a one-on-one service user, assess you, and then set up a programme specifically for you. And that, hopefully, in time, the programme will get a bit more involved, you know, so it should be good [Steve's wife Shiloh; mid-trial interview].

Testimonies about the linked programme (the tailored exercise programme for those with Parkinson's) helped Steve set a clear goal. This encouraged Steve and Shiloh to join the Flinders Programme to work towards Steve's goal (e.g., arranging a GP care plan to be referred to the tailored exercise programme). Shiloh reported that the Flinders Programme care plan also helped them to stick to their secondary goals of attending dance and art classes. Shiloh mostly acknowledged the exercise programme's benefits on Steve's health. Field notes also mentioned that at the mid-trial interview, Steve looked healthy and happy.

Well, the change obviously is going to exercises and getting the benefit of that. Just seeing that Steve's physical health – health has definitely improved and, and when people see him now, and go, "you're looking so good, Steve".

So, yeah, from that point of view, that's a, a very, yeah, that's what's changed the most. His physical wellbeing and being able to cope with life were a bit easier than he was. Yeah [Steve's wife, Shiloh; post-trial interview].

During the mid-trial interview, Shiloh was very enthusiastic and said that the couple's shared love for lawn bowls motivated them to work towards the goal. Returning to playing their favourite sport together restored their identities beyond the 'caregiver' and 'care recipient' identities. The findings suggested that the Flinders Programme and related goals improved Steve's physical health and wellbeing. This process also positively impacted him and Shiloh (his wife) in terms of strengthening relationships and daily activities, as sometimes they worked towards the same goal (e.g., lawn bowls).

I think if we do get to that goal (lawn bowls), too, it's good for our relationship as well. Doing something together that we both enjoy, because I did enjoy lawn bowls as well, but have found that I haven't been able to get out to do it. So, it will be good, be a positive thing for both of us ... Something we're doing together, yep, nice [Steve and his wife Shiloh; mid-trial interview].

However, at the post-trial interview, Shiloh reported that Steve could not continue bowling after a few sessions. It was physically quite challenging for him.

... his goal was to go out and have a game of bowls, and which we did get to do a few times, but then we realised that even that was getting a bit too difficult for him, and he realised that too. And so, the, the best result of that (Flinders) programme was to get him into the exercise programme and, you know, he felt, he felt as though that really improved his physical health and his mental health. And you know, we still say, we should go, you know, go out and try to have another shot at bowls. And we know that's always there if we want to [Steve's wife, Shiloh; post-trial interview].

Shiloh pointed out that the Flinders Programme care plan and related questionnaires ('how does the patient feel') helped Steve to open up. There was awareness in both parties due to the open discussions, which led them to make a better health plan ('what he needed to do').

Yeah, the (Flinders) programme has been good, in that it's made Steve think about, you know - how does he feel? And, so, I think that's good for me to hear how he feels. I don't think we sit down probably enough and really chat. You know, like that. Life is sort of, we just – robotic, I suppose, really. Yeah, so that was good in that respect, that he, he was able to say how he felt and what he needed to do to get around it. And, and we – you know, we both did,

you know. So, yeah, so the programme was good in that respect, that I, you know, we were able to, yeah, he was able to open up. And I was able to appreciate his views, so it was good [Steve's wife, Shiloh; post-trial interview].

Shiloh also acknowledged that getting the care plans from Steve's GP and the psychiatrist, and informing the neurologist (as part of being referred to the AEP) had other positive outcomes; all these health professionals were liaising with each other a bit more than they did in the beginning. The care plan also had plain language that was easy to follow.

<u>John</u>: John was staying at a rehab centre when enrolled in the Flinders Programme and had eight goals: 1. Participate in all the groups (e.g., art, writing) during his stay in the rehab centre; 2. Join the gym; 3. Eat healthily; 4. Gradually reduce smoking to quit; 5. Learn more about his metabolism-related conditions; 6. Increase his friendship circle – and find Christian friends (for positive influence); 7. Improve the management of his anxiety, and 8. Investigate work experience/ training and TAFE course options.

John's older sister, Marilyn, was unaware of the Flinders Programme at the mid-trial interview. However, she was still concerned about John's physical health problems, such as obesity and smoking, and was keen to address these issues. She also mentioned the rehab centre's positive impact on John in getting him into a healthy routine.

At the post-trial interview, Marilyn was far more aware of John's Flinders Programme goals. It was evident that she provided him with immense emotional (e.g., helping John manage anxiety) and practical support (e.g., organising healthy eating and encouraging John to quit smoking).

I have organised Lite and Easy for John to help him make healthy food choices. Since he has been on Lite and Easy, he has gone from 118kg to 106kg. John just likes to eat fruit for breakfast, so I have organised his Lite and Easy for lunch and dinner. He is on an 1800-calorie plan, and he only buys food out at the most once a week and often only once a fortnight. He has quit sugar except for only having it in his coffee. This is major as he was drinking a lot of soft drinks and eating a lot of chocolate [John's sister Marilyn; post-trial interview].

This example reaffirmed that caregivers' ability to arrange and supply necessary resources is vital in ensuring healthy lifestyles in service users in tackling CVD risk factors.

John's sister, Marilyn, also played an active role in helping him quit smoking. She encouraged John to quit and followed up regularly. She also bought a kitten for John and explained that passive smoking was bad for the kitten. Having a pet also reduced John's loneliness and made him more

responsible. Marilyn reported an overall positive impact on John's mental health and wellbeing. Thus, the findings showed that having a pet could positively impact a service user to adopt a healthier lifestyle.

In the past four weeks, I have been almost holding John's hand every step of the way to quit smoking. He has finally achieved that goal by not having any cigarettes or vapes since Sunday, 15th September. This has significantly impacted John's mental health and wellbeing, as he is proud of his achievements and is already noticing the positive health benefits. I also said that when he stops smoking, I will buy him a pet kitten or cat. I explained to him that it is very bad for pets to be passive smokers. This week, we went and bought him a pet kitten, and he is over the moon with him. It has given him a friend and companion around the house, and I also feel it has taken his mind off the need to smoke [John's sister Marilyn; post-trial interview].

Marilyn reported that quitting smoking had improved John's financial status. She also proudly shared how John was completing an online course, which was his ultimate target towards finding work.

(Looking at the Flinders Programme care plan). Yes, I think these goals are definitely achievable, and he has actually achieved some of them already. Quitting smoking has greatly affected his financial position. He was spending over \$100 a week on cigarettes! He has also enrolled in a Disability Support Worker course - Certificate 3 (online). This was organised through Maxima. He is really enjoying his study and is well on track to finish the certificate. I think he is doing wonderfully - I am very proud of him [John's sister Marilyn; post-trial interview].

Except for finding Christian friends, John indeed managed to fulfil all his goals. With time, there was a sense of increased hope and optimism, which was also displayed by Marilyn.

I manage John's overall money, but he manages his day-to-day expenses. He has been a lot better with his finances as he feels more positive for his future and has stopped spending money on random expensive things [John's sister Marilyn; post-trial interview].

<u>Paul</u>: Paul initially had three main goals - to increase exercise, reduce smoking, and to find work. His mother, Eileen, was not fully aware of the Flinders Programme when she was interviewed at the mid-trial point, but reported observing Paul's positive self-management behaviours. Eileen said that, with time, Paul had more knowledge about health issues, making him more focused on self-management. He was seeking and accepting help from others, not only from his mother.

Paul is more focused on self-management in recent times; for example, contacting his GP more often, getting hospital admittance more often, acceptance of Meals on Wheels and acceptance of others' help - not just me, more often - the realisation of his shortened life expectancy due to his health issues has made him more alarmed, he realises the futility of his life [Paul's mother, Eileen; mid-trial interview].

Eileen also appreciated how the trial nurse engaged with Paul during care delivery with empathy, care, and respect.

... thank you for dealing with Paul so kindly. He really did look forward to meeting up with you all. He doesn't get many opportunities to be valued, so this meant a lot to him [Paul's mother, Eileen; post-trial interview].

4.4 Summary findings and Initial Programme Theories (IPTs)

This chapter aimed to understand caregivers' roles in supporting self-management behaviours with, and for, service users diagnosed with SMI and CVD. The findings explored whether the Flinders Programme influenced caregivers (positively or negatively) while the service user participated in the programme. This section integrates the essential findings and identifies the CMO configuration, which is necessary to understand how different resources and contexts that enable the mechanisms helped service users to adopt a healthier lifestyle. This section also compiles the Initial Programme Theories (IPTs).

Caregivers reported that the Flinders Programme positively impacted them in multiple ways; it gave the service user a sense of ownership and autonomy, and consequently, lessened the burden on the caregiver. Caregivers confirmed that the service user's involvement in the Flinders Programme added no high cost or pressure on them as caregivers. Being a structured programme with regular follow-ups made by empathetic health professionals was a relief for the caregiver, knowing that someone else was keeping a consistent and regular 'eye on the service user'.

The emotional support and nurturing nature of caregivers generated hope and motivation within the service user towards recovery. Older caregivers were deemed to better understand the service user's needs due to their years of experience supporting the service user and developing more specific knowledge and understanding of the service user's expression of their needs.

IPT 1: Older caregivers' (C) better knowledge, nurturing habits, and understanding of the service user's needs (R) provide 'meaning' towards life (M), thereby improving their quality of life (O). Caregiver's emotional support (R) also motivates (M) the service user towards recovery (O)

IPT 6: Experienced and knowledgeable caregivers (R) have a better understanding of the service user's needs (C) and can take more assertive action (O)

Caregivers pointed out that managing the service user's mental illness symptoms was a clear priority for them due to the potential detrimental consequences of aggravated mental illness; this kept caregivers alert in managing the service users' mental illness symptoms.

IPT 2: The service user's first psychotic episode (C) and resultant anxiety (M) make the caregiver proactive (O) towards managing the service user's mental illness

Practical and tangible supports, including monetary help, were significant facilitators in helping the service user manage their day-to-day activities and a healthy lifestyle.

IPT 3: Caregivers ensure a healthy lifestyle (C) by making financial contributions (R), which ultimately help the service user to achieve desired health outcomes (O)

IPT 4: Given sufficient finance and time (R), both parties are motivated (M) and get the most benefits (O) when they work towards the same goal together (C)

There was a linear connection between the service user's mental health and 'self-management' behaviours. Caregivers explained that it was easier to encourage the service user to adhere to healthier lifestyle choices and actions when their mental health was stable. It was also an appropriate time to promote independence in service users by setting boundaries.

IPT 5: When mentally unwell (C), the service user needs more practical support (O) due to difficulties in initiating and sustaining self-management (M)

IPT 7: When mentally stable and not over-medicated (C), there are better opportunities for the caregiver to engage in dialogue (M) that encourages the service user towards improved health habits (O)

IPT 8: When the caregiver oversees the service user's daily routine and sets boundaries (R), this makes the service user accountable (M) towards independent actions (O)

Caregivers spend significant time and energy providing intangible support such as promoting hope, helping them build and rebuild their identity, and helping the service user make decisions in different situations. All these elements are integral parts of a service user's recovery journey.

IPT 9: Due to the difficulties in navigating health systems (C), caregivers help the service user in decision-making (O) so that the service user's opinion is included in the treatment choice (M)

Overall, it seemed necessary that caregivers employed a mix of tangible and intangible strategies as each situation demanded.

IPT 10: A combination of tangible (access to amenities or resources) and intangible supports (information, encouragement, companionship) (R) can enhance awareness, responsibility, and motivation, and can reduce loneliness (M), resulting in improved health and wellbeing (O)

4.5 Chapter summary

This chapter has shown that caregivers play a number of vital roles in the service users' recovery journey by maintaining and promoting the 'self' in 'self-management'. Caregivers' constant emotional support towards service users can motivate them to live meaningful lives. Caregivers also promote 'hope' and 'autonomy' in supporting the service user to create and retain 'individual' and 'social' identities. These qualities eventually encourage the service user towards self-care and to adopt healthy behaviours. Caregivers also helped to manage the service user's emotional, mental, and physical health care needs by employing different overt and covert strategies. Some critical aspects caregivers regularly managed were ensuring that adults with SMI and CVD adhered to their treatment, helping them make decisions, and supporting their day-to-day activities such as cleaning, shopping, cooking, and driving. Nevertheless, it was reported that caregivers' knowledge and expertise were often not valued by health professionals operating in the broader health system.

Caregivers who were aware of the Flinders Programme process acknowledged that the programme and its trial nurses motivated service users, as it sought and valued their decisions regarding their behavioural change goals. The trial team was recognised and appreciated for treating the service user with empathy and respect. Service users with SMI and CVD showed promising results when caregivers actively supported them, including accompanying them to the gym, eating healthily, or other health-related goals. Furthermore, it was beneficial when staff in the health organisations and community locations (e.g., gym instructors, bowling club managers) understood the service user's needs and treated them with respect and care.

The findings revealed that caregivers have to spend a lot of time, energy, and money due to the severity of the service user's comorbidities of SMI and CVD. Many aspects of the caregiver's role are emotionally and physically demanding, which requires patience, resilience, and skills to help the service user to manage the symptoms of both SMI and CVD illnesses. With age, caregivers had more experience supporting service users in self-management. However, some mentioned that their age-related physical limitations challenged their ability to provide practical support (e.g., doing household chores). Support workers were key in lessening this burden on caregivers. The findings of this chapter suggest that caregivers might benefit from receiving counselling and training on 'supported self-management and recovery'. Overall, the health system must better acknowledge the caregiving role, incorporate their experiences within the treatment plan, and provide them with necessary emotional and practical support.

CHAPTER FIVE: EXPERIENCES OF HEALTH PROFESSIONALS

5.1 Chapter purpose and structure

The previous two results chapters presented the experiences and views of adults with severe mental illness (SMI) and cardiovascular disease (CVD) risk factors (Chapter Three) and the experiences and views of family caregivers (Chapter Four), as their family members (adults with SMI and CVD risk factors; referred to as 'service users' hereafter) took part in the Flinders Programme. This chapter explores the views of health professionals (mental and physical health care providers) regarding service users' recovery-oriented self-management skills.

This chapter is presented in four broad sections. After the introductory section, the methods section (section 5.2) describes the processes undertaken in collecting data from the health professionals and how they were analysed. Next, section 5.3 presents the key findings organised through the domains of Wagner's Chronic Care Model (CCM) (Wagner et al., 2001). This section also generates a set of Initial Programme Theories (IPTs) to define the health system's and professionals' roles towards self-management and recovery-oriented care. Section 5.4 then summarises the key findings and collates the IPTs. Finally, the chapter concludes with a summary (section 5.5).

5.2 Methods

The researcher initially sought verbal consent from service users to approach their respective health professionals and then obtained written consent from the health professionals for in-depth face-to-face interviews. The South Australian (SA) community mental health service was transitioning through a significant staff restructure at the time. A high staff turnover resulted in re-defined job roles and increased workloads; this may have led to the low participation rate for the study. The pandemic also interrupted the follow-up face-to-face interviews. To address these issues, the relevant ethics committee approved additional data collection methods for gathering study participants' feedback. These methods involved telephone interviews, postal written feedback, video chats (e.g., Zoom, Google Meet, and Microsoft Teams meetings as per participant convenience), and getting written feedback through email; three health professionals employed these alternative mediums (telephone interviews and email feedback).

Sixteen health professionals were initially approached from site A, an urban community mental health clinic (CMHC); site B, a community rehabilitation centre (CRC); and site C, a supported Residential Facility (SRF). Ten agreed to take part in the mid-trial and post-trial interviews. Of these ten participants, there were four mental health nurses (MHNs), three psychiatrists, two community rehab workers (CRWs), and one supported residential facility (SRF) hostel manager. The researcher approached a social worker, two GPs, an NGO staff and five more mental health staff; however, they were not available for interview. No other allied health professionals (e.g., occupational therapists, physiotherapists, nutritionists) were approached for interviewing as neither any of the service users nor their care coordinators recommended names for allied health professionals.

Qualitative data were collected from seven participants at the mid-trial point and six at post-trial, generating thirteen responses. Three of these health professionals took part in both data collection phases. Interviews took place at health professionals' offices, with each interview lasting between 20 and 45 minutes. All face-to-face interviews were audio-recorded with consent and transcribed. It is noteworthy that some staff preferred to speak 'off the record', particularly about the organisational and interdisciplinary elements of their roles in providing treatment and care to service users, which revealed the internal conflicts, politics, tensions, and resultant mistrust towards the system. In such situations, these data were not used for analysis. Given that the mental health teams and some disciplines within those teams were potentially identifiable, the researcher chose not to reveal gender, age, qualifications/role level, or participants' details regarding who provided services to which service users. This process maintained participant anonymity and confidentiality.

It is also noteworthy that many of the 'closed episode' service users (those discharged from community mental health services) did not have any designated health care providers such as general practitioners (GPs) or private psychiatrists to provide follow-up care post-discharge from the community mental health team. For instance, all service users from site D (second urban CMHC) had their episodes 'closed' or dropped out of the trial. Consequently, no health professionals were available to provide feedback about the Flinders Programme journey for site D service users.

5.3 Key findings

The six domains of Wagner's CCM (Wagner et al., 2001) and how they relate to key findings are presented in Table 19 below.

Table 19: Perceptions of health professionals whose service users took part in the Flinders Programme

	Chronic Care Model						
Self- management support	Organisational support	Delivery system design	Decision support	Clinical information systems	Community resources and policies		
Service users' bio- psychosocial features	Paternalistic model of care	Uncoordinated care and role confusion	Vicarious trauma and change fatigue at work	Administrative work-related burden	Over-dependence on family caregivers		
Preconceptions regarding service user recovery	Power and politics	Regular monitoring of antipsychotic's side-effects		Lack of service user data and access to the database	The necessity of support workers		
Perceptions of the Flinders Programme							

5.3.1 Self-management support

As per the CCM framework, 'self-management support' refers to the support provided to service users by health professionals as part of a collaborative care approach. Service users are encouraged to set their own health goals, plan strategies to reach them, and monitor their health conditions (Wagner et al., 2001). On the other hand, health professionals provide self-management support by delivering assessment, psychoeducation, information, problem-solving, referral to other necessary resources and supports, monitoring, and follow-up. This chapter identified three major themes that impacted health professionals' ability to support service users' self-management: a) Service users' bio-psychosocial features, b) Health professionals' beliefs regarding service user recovery, and c) Health professionals' perceptions of the Flinders Programme.

Service users' bio-psychosocial features

Most health professionals in the current study expressed concerns regarding service users' negative symptoms (e.g., social withdrawal, flattened affect) and disorganised behaviours (e.g., problems with planning, memory and problem-solving), and how these symptoms affected a person's motivation and their ability to self-manage. Clinicians explained that most service users needed regular prompting regarding simple day-to-day activities such as maintaining hygiene and managing a healthy lifestyle. Also, smoking and drinking were commonly identified as risky health behaviours displayed by their service users.

Older age (65 and above) was determined as another significant barrier to service users' recovery and improved self-management skills. For instance, during the mid-trial interview, Joe's (65 year old SRF service user) MHN was not very hopeful of his active participation in the Flinders Programme, implying that he had maintained a fixed routine for many years, which would be difficult to change. However, his SRF hostel manager confirmed that, during the study period, Joe was highly motivated and wanted to get more out of his life. With his support worker's help, Joe fulfilled his goals of

increased social activities. Joe and his SRF hostel manager were happy with his Flinders Programme outcomes. His progress differs significantly from the view maintained by Joe's MHN:

Joe has a lot of negative symptoms. So, there's – lacks that motivation, and there's also that – not a lot of organisational skills. So, he needs support in giving him direction and prompting with personal hygiene care. Those sorts of things. But he's – he also gets a lot of – he gets some voices, but he tends to have a lot more delusional context about things … He used to smoke; he hasn't smoked for years. He's getting a bit frailer in his age as he's getting older. And he looks a little bit gaunt at times. But as we get older, things do increase so [MHN 2, CMHC, mid-trial].

Preconceptions regarding service user recovery

The findings of this study suggest that the risk-assessment system used by mental health services and the resultant treatment plans used by mental health professionals are based primarily on service users' history rather than their current status or their intentions, now and in the future. This past behaviour-based risk-assessment process made health professionals less hopeful of a service user's recovery. For example, John's psychiatrist lacked awareness about his lifestyle and efforts to improve it, claiming that John might still be involved in risky health behaviours (i.e., illicit drug and alcohol abuse). In contrast, John's family and the CRC staff confirmed that John had not taken drugs or alcohol for many years. John had also been using e-cigarettes for several weeks and was trying to quit smoking; again, the psychiatrist seemed unaware of this.

Look, I don't know (about John's lifestyle) because he's actually gone into 'site B' (community rehabilitation centre). Based on his historical presentation over the last few years, he's been using less illicit drugs anyway. I think he's still smoking, but he may have cut back somewhat. He was drinking a bit, and that is less than it was. Well, I think he's probably still drinking [Psychiatrist 2, mid-trial].

Most mental health staff were also reluctant to interrupt service users' routines, stating that service users were not interested in changing their health behaviours and that a changed routine could aggravate their mental illness symptoms. This demonstrated that health professionals tended to hold a paternalistic and simplistic view of service users' capacities to change, and assessed their capacities predominantly within a risk-averse community mental health model. This attitude adversely impacted health professionals' approach to supporting the adoption of self-management principles when interacting with service users.

The thing is with the mental health people – because I've worked in this industry for the last ten years with mental health people, roughly, if you count 100, you can do any Programme with them – maybe you can change the routine for only a couple of people, but the 98 per cent people – they – they're strict with their routines [SRF Manager, mid-trial].

However, not all mental health professionals were so pessimistic. For instance, it was apparent that health professionals working in the CRC were generally more hopeful about service user recovery than their colleagues in other parts of the mental health service.

I think everyone's always got scope (for recovery), and he's (Damian) certainly got potential; he just needs to keep working on it and stay off alcohol and things. That can be an issue for him at times. I think with support, yeah, he can get back to living by himself and doing really well in the community, but yeah, he has to keep on trying, yeah [MHN 3, CRC, mid-trial].

Perceptions of the Flinders Programme

Health professionals thought the Flinders Programme delivery process and the related care plans were suitable for their service users but identified a few barriers. First, they perceived the delivery process could be more time-consuming (up to an hour). Next, some health professionals thought it could be challenging to build the rapport consistency needed to follow through with care plan goals and actions with the service users due to high mental health staff turnover. One MHN also expressed concerns that the Flinders Programme care plan might need to be revised for some service users with too many ambitious goals.

(smirking, looking at John's Flinders Programme care plan). I think some of the goals on here might be a bit too far-fetched for him (John), and we need to kind of go back to basics and revisit them as far as just activities of daily living — getting up, having a shower, and committing to just some activities that he finds manageable. I think in his mind, he would love to be able to join a gym and be able to go on a daily basis and exercise, but physically, I think it's an unrealistic expectation that he would do that. I think he would be setting himself up for failure. In fact, I know he would, and then he would feel bad about himself, whereas sort of taking it back to basics is more realistic, and he feels that sense of accomplishment, and he feels proud of himself for having achieved the goals that he has set, rather than feeling as though he's failed [MHN 4, CRC, mid-trial].

MHN 4 no longer worked for the services and was not available for a post-trial interview. John, however, fulfilled most of his Flinders Programme targets, including completing coursework towards finding a job – details are available in Chapter Three: perceptions of service users.

The summary findings of this section (section 5.3.1) helped to generate IPT 1 (Table 20).

Table 20: Health professionals' perceptions and roles in service users' self-management support

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
Service users' bio-psychosocial features	Prompting and monitoring	Require formal or informal caregivers	Cognitive impairment	Look of hone in	Older patients > frailty and have set routine > lesser chance of recovery
Preconceptions regarding service user recovery	'Risk assessment' system/tool	History of consuming alcohol, cigarettes, or drugs	Lack of trust	Lack of hope in service users' recovery	In general, no change
Perceptions of the Flinders Programme	Requires much time	Phase-III trial	'unrealistic'	Service users might fail	With time, staff showed more positive attitudes towards FP

IPT 1: Given sufficient time and care continuation (C), staff providing quality care (R) and trusting in service users' goals (M) can enhance service users' chance of recovery (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

5.3.2 Organisational support

This domain of the CCM refers to the organisational culture within which it is safe to promote evidence-based care. The findings revealed three cultural barriers that impeded service users' recovery-oriented care: a) The paternalistic model of care, and b) Ineffective resource management, and c) Power and politics.

Paternalistic model of care

One MHN stated that there were only a few recovery-oriented services within the current system, expressing their regret that the whole mental health service was not recovery-oriented. The SA community mental health care system was described by participants as paternalistic and founded on coercive care practices involving institutions such as the tribunal and the public trustee. The tribunal is in place for making orders for compulsory mental health treatment and the public trustee for administrative control of service users' finances where these were deemed necessary. Within such systems of care, some health professionals described how service users often had to endure negative experiences such as enforced medication administration, losing control over their finances or having their driving licence suspended. They also expressed concerns about the person's capacity to benefit from community resources when subject to an Administrative Order, whereby a public trustee's control over a person's finances limits their hope and choices, and thus, negatively impacts

their recovery process. Health professionals acknowledged that this adversely affected service users' trust, health-seeking behaviours, and level of engagement with the service.

... they (service users) would have such a different side – such a different side. I mean, a bad experience in mental health can just (shaking head in sadness), and then you're dealing with public trustees and all that, it's so much determined by the person (health professional) who is on the other end of the phone or the person that's in front of you, and yeah, they're going to have bad experiences, and it's just, it's not a nice system ... I think it gets all back to that recovery-oriented services stuff, really. If you're really working from that approach where the highest priority is people's dignity and rights, and that we are here to offer a service as opposed to being paternalistic and telling people what to do, and offering people choice and hope and all that kind of stuff, then this wouldn't be such a problem, but our services aren't offering and public trustee, I think their philosophy is (pause), but you get the wrong person on a wrong day, and grumpy [MHN 1, CMHC, mid-trial].

The same staff member also mentioned that their service previously employed peer workers (people diagnosed with SMI who were now in recovery and using that lived experience expertise to support other service users). They described how this improved the service culture and addressed staff members' paternalistic attitudes towards service users; unfortunately, the service no longer included peer roles.

I'm not sure now how many peers – we had peer workers, but we haven't got them in the community anymore [MHN 1, CMHC, mid-trial].

Some health professionals acknowledged how antipsychotic medications negatively impacted a person's physical health and ability to adopt an active lifestyle. Some staff also expressed disappointment about the over-reliance on medications as the dominant treatment approach, while other psychosocial and quality of life needs were considered less important in decisions about care.

So, there have been times his (John's) family has reported to us that he's slept from the night before right through till 7:00 pm the next day, which then doesn't help his mental health because this is supposed to be an enjoyable time for him, and he wakes up, and it's night-time again. So, we're currently in the process of looking at medications; his team is interested in reducing the Clozapine gradually to see if he can, if he's still stable. And then eventually, if the Clozapine is no longer needed, then that's going to completely change his life in terms of the sleeping side of things and sleep hygiene. Clozapine also contributes to weight gain; it affects the metabolism,

so that obviously affects his self-esteem and his ability to be more energetic and things like that. In saying that, though, he was successful in having a reduction of medication not that long ago, and there has been an improvement [CRW 2, mid-trial].

Ineffective resource management

As mentioned earlier, many community mental health professionals expressed concerns regarding the amount of staff time (resources) required to deliver recovery-oriented care, such as the Flinders Programme. This was particularly concerning due to the significant restructuring of the SA community mental health system that resulted in cost-cutting, job losses, and subsequent work pressure on existing staff. However, one psychiatrist explained that the issue was not about resource scarcity, but rather, ineffective resource management. There was a sense that the settings experienced many unplanned top-down approaches, which caused unnecessary service duplications and wasted resources. The staff suggested that delivering the Flinders Programme within routine care was plausible if there were better policies and effective strategies to manage existing resources by providing more targeted care.

Q: ... do you reckon we have the resources staff wise, or the capacity to deliver the (Flinders CCSM) Programme within your current day-to-day practices? A: I think, I think it'd be, I think there should be a trial, I think it, I think the problem comes about when, when we start imposing goals, and we put a lot of effort into, into imposing goals on people. Do you know what I mean? So, I think there, there's potential efficiencies in the resources, I think there, there's not enough care planning going on in the service. So, there's a lot of activity that goes on for no clear reason and to some extent - turn your thing (voice recorder) off, turn it off [Psychiatrist 2, mid-trial].

Power and politics

While the above section suggested ineffective care management as an underlying perceived cause of poor resource allocation and poor service quality, staff revealed that internal rivalries towards securing funding and power struggles were two significant causes of unplanned services and ineffective resource management. Some staff explained the scenario well, shedding some light on how the current service still advocated for an illness-based rather than a recovery model as it secured them funding for offering a different treatment option. One participant's comment revealed that sectors like the CMHC, CRC, SRF, and NGO were eager to secure Commonwealth health funding. Resultantly, each sector tried different care models, even if these models overlapped and created duplication with other services and were often deemed unnecessary.

Ineffective resource management (within and between different MH-related sectors), that's the core, but underneath that is a story of money, politics, and power. So, you've got to understand mental health as a proxy battleground. It's a game of thrones, and the patient is part of the dramatic act and the power between social, bio, and psychosocial - three powerful paradigms. Instead of having two of me (psychiatrist), you need one of me, and then you need four of the NGO. But then you need to transfer the money, and then it becomes politics. No-one's going to transfer money. Once you've got the money, you hold it. So, we've converted to clinical (to ensure the funding and justify the existence of psychiatry). It's like – the NGOs – yes, that's sort of – the clinicians, the doctors, the nurses, the social workers, the internal rivalries. And these internal rivalries are almost unconscious and not fully acknowledged, but it's there. And then - and it's been played out unconsciously. And the patient subtly is aware of that, or more than subtly. They're probably aware of that. But ultimately, the conductor idea (more organised coordination between and within the sectors) has to be aligned with a mission. I don't think mental health has a vision like that [Psychiatrist 1, post-trial].

The summary findings of this section (section 5.3.2) helped to generate IPT 2 (Table 21).

Table 21: Health professionals' perceptions of 'organisational support'

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
Paternalistic model of care	Limited time and resources	Iliness model- based care	Lack of hope in service user recovery	Illness is managed, but service users are not actively supported towards recovery	Acknowledging the need for recovery-oriented care: a prolonged change in the philosophy and the system
Ineffective resource management	Lack of planning	Top-down approaches	Inefficiency in care management	Poor financial and health outcomes	Unnecessary service duplications and overlaps waste resources
Power and politics	Limited funding	Different paradigms and related services	Unhealthy competition between sectors for funding and authority	Tensions between different sectors of health professionals	Due to increased competition, politics, and related tensions also increased

IPT 2: Limited time and funding (R) is a challenge towards recovery-oriented care (C), resulting in politics within the system (M); this has generated tensions among staff, created resource mismanagement, and has hampered patient care (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

5.3.3 Delivery system design

The CCM's third domain, 'delivery system design', focuses on defined teamwork and an expanded scope of practice for team members to support chronic care. Multidisciplinary collaboration, how team members collaborate, how models of care are delivered, and how care decisions are made are all part of the delivery system design. To ensure efficient resource utilisation, the system must ensure consistent and coordinated case management, planned interactions, and active follow-up. Theoretically, the model should be person-centric and culturally appropriate. This study, however, found that the South Australian community mental health system required additional capacities and planning to provide such holistic care. Two major themes emerged from this section of the analysis that demonstrated this finding: a) uncoordinated care and role confusion, and b) regular monitoring of medication side-effects.

Uncoordinated care and role confusion

Mental health professionals conveyed that engaging with GPs was vital when working with service users with chronic physical health problems comorbid with mental health issues. One psychiatrist explained that GPs could help improve service users' health literacy by sharing information about self-management. But he acknowledged that service users often did not have a designated GP; this was a common scenario for users with closed community mental health service episodes. There were also significant role ambiguities between GPs and mental health professionals regarding who should monitor service users' CVD risk factors and promote a healthy lifestyle.

I guess the first question is, what's the role of the general practitioner? Oh, well, if you start with self-management and the role of the consumer and patient and to what extent they understand physical health issues – literacy this is the first question. Literacy – what are they informed about physical health issues at the system? And health education is broadly defined from a public health lens as well. Then I think the - do they have a general practitioner? The practical question - do they actually see a general practitioner? Like a practical access issue. And then, even if they do see a GP, what's the level of engagement, and what's the bi-directionality of that consult? And then the next phase is the role of community mental health and the interaction with general practice and the consumer in terms of a selfmanagement or a health education framework. And then there's a question about who is meant to do what? Role clarity. Is it – is the GP meant to check on cholesterol, or is it me (psychiatrist) if I'm in the clinic? Or is it the case manager? And then the data systems are not shared, so, I don't know – I'm not going to check the cholesterol if the GP's checked the cholesterol. And then it's not – I don't have a line of sight as to what the GP's doing, and they

don't know what I'm doing ... So, it gets really confusing. That's a governance question [Psychiatrist 1, post-trial].

In addition to GPs, study participants emphasised that other health professionals such as pathology staff, allied health workers, pharmacists, and NGO workers all played essential roles in supporting the service users' self-management and recovery journey. However, staff reported that it seemed challenging to coordinate with different health sectors and their staff. It was also evident that there needed to be more cohesive care and communication and better care coordination between, and within, other services and disciplines. Health professionals also needed better guidance, data sharing systems, and role clarity to provide an improved comprehensive health service to the service user.

Unfortunately, this story has developed down at (site B: CRC) that he's (John) got better, because the medication has been reduced, and therefore, the drug should be reduced even more, which, if that occurs, he will become unwell. This is a man with schizophrenia, he's had long-standing, quite severe symptoms and lots of anxiety. So, if he's not on the right medication, that will come back, but obesity's been a problem, smoking etc. So, he's a classic for these things; he might be on some lipid-lowering agent, I can't, can't quite remember; he's certainly got some reflux as well [Psychiatrist 2, mid-trial].

Unfortunately, his (John's) psychiatrist is reluctant to want to reduce his antipsychotics any further because he is so-called stable at the moment, and he did. Some residual symptoms did resurface when he ceased his morning medication, like the Clozapine, but that seems to have abated now. His anxiety remains a bit of an issue, but he does broach staff now and talks about his anxiety, and he will talk through that [MHN 4, CRC, mid-trial].

Regular monitoring of antipsychotic medication side-effects

Despite all the limitations in coordination and communication between the mental health and physical health systems, health professionals emphasised that the mental health system acknowledged and embraced the importance of regular monitoring of the side-effects of antipsychotic medications on patients' cardiovascular health.

Look, because people – not just with, on Clozapine, but I guess Clozapine and any antipsychotic medications, there's always, you're increasing physical health risks when you're putting someone on antipsychotic medications. So, then you're having schizophrenia and then also then being on antipsychotic medications, you're increasing the risks, especially with

Clozapine, so as you'd be aware of all the cardiac issues that can occur with Clozapine. So, we do our annual monitoring. So, we make sure that every – at least every 12 months – people have an ECG or an echocardiogram. We'll also do, every six months, we do full fasting blood, and in those blood – so we're checking cholesterol, but we'll also do a ... CRP, so we're just sort of getting more of a bit more around the cardiac, and we check Clozapine regularly, the levels. If we've got clientele that we've got concerns about, then we'll sort of follow them up a little bit more, and for those in shared care, it's important to keep in touch with the GPs and vice-versa. If they find something, then hopefully, they will keep us informed [MHN 2, CMHC, midtrial].

The summary findings of this section (section 5.3.3) helped to generate IPT 3 (Table 22).

Table 22: Health professionals' perceptions and roles in 'delivery system design'

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
Uncoordinat ed care and role confusion	Lack of access to a shared database	Disjointed PH and MH system	Lack of role clarity	Illness is managed, but service users are not actively supported towards recovery	Acknowledging the need for recovery-oriented care: a prolonged change in the philosophy and the system
Regular monitoring of antipsychotic 's side- effects	Proper guidelines	Antipsychotics increase the risk of CVD	Awareness	CVD risk management	The realisation for better coordination

IPT 3: Psychiatry still follows an illness model (C) that monitors symptoms and manages illness (O), as the system is not well-equipped for recovery-focused care (M)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

5.3.4 Decision support

Decision support embeds the integration of evidence-based guidelines into daily clinical practice. It promotes person-centred clinical care and encourages patients to participate actively in their treatment plans. This CCM domain also ensures coordination between specialists (e.g., psychiatrists) and primary care providers (GPs). The central key theme to emerge from this section was: Vicarious trauma and change fatigue at work.

Vicarious trauma and change fatigue at work

The mental health professional participants described how their profession's traumatic and demanding nature negatively impacted their mental health. Besides the role of providing mental health care being challenging, mental health professionals also revealed that an influx of top-down

bureaucratic management approaches, resource mismanagement, and job insecurity within the mental health system generated significant change fatigue. Older mental health staff were reported to have more difficulty dealing with all the restructures and changes within the South Australian mental health system, negatively impacting their behaviours towards the service users due to work stress. Positive leadership was identified as a facilitator for addressing these perceived problems within the system.

To tell you the truth, this is a real worry that the mental health nurses and the other allied health people coming through aren't so bad, but we're all old and grumpy ... I think that's – a lot of people are very burned out and, yeah, it's hard, it's hard for people working here now. So, I think if we had a compassion-based service where the clinicians were treated with compassion and care and given lots of support because this is hard work. We talk about burnout and stuff like that, and we talk about trauma-informed care, but this needs to happen with the staff as well. If there's a few really good managers that are, I think, doing as much as they can. Still, until we have really cared for staff, I don't think, yeah, I think that's what's really important because then, if you're compassionate with your staff, then I think that flows on to the people that they're working with and if they feel safe, because a lot of it's around them not feeling safe (job insecurity) [MHN 1, CMHC, mid-trial].

The participants also disclosed problems with leadership issues that involved top-down approaches that tended to impose change without precise planning and with limited consultation or input from staff. Staff felt that the top leaders might have a disconnection with routine care, and hence, needed to fully comprehend how to translate proposed improvement strategies effectively into real-world settings. The result of this disconnection generated unnecessary administrative work. The staff were now being asked to focus even more of their time on tracking and accounting for other paperwork processes that then limited the time available to see and spend with service users. Furthermore, the structural change within the community mental health setting caused job losses and increased work pressure, which only fuelled the staff's dissatisfaction towards the health system and any new interventions, such as the Flinders Programme.

The summary findings of this section (section 5.3.4) helped to generate IPT 4 (Table 23).

Table 23: Health professionals' perceptions of 'decision support'

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
Vicarious trauma and change fatigue at work	Limited resources and top-down approaches	Nature of job and restructure within the community mental health system	Demanding job	Negative impacts on staff's mental health > implications for quality of care	By post-trial interviews, some staff had lost their jobs, which impacted both on the usual care and the Flinders Programme

IPT 4: Limited resources and top-down approaches (R) have brought major restructures within the system (C), resulting in change fatigue (M), which negatively impacted patient care (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

5.3.5 Clinical information systems

An earlier section revealed that health professionals emphasised the importance of sharing service user information between health professionals to improve overall mental and physical health care for the service user. The CCM 'Clinical information systems' domain also asserts that it is crucial to develop sound information systems for accurately recording, storing, and communicating service user data. This information system should then be shared between relevant health professionals, minimising duplication, errors, and gaps in care and allowing efficient recall and reminders for follow-up care. Two key themes emerged from this analysis section: a) Administrative work-related burden; and b) Lack of service user data and access to the database.

Administrative work-related burden

Mental health nurses were overwhelmed with work, mainly administrative and clinical paperwork. There was a sense of frustration regarding how they could not deliver quality care due to the existing multi-layered service user assessment practices and related documentation.

... if clinicians felt safe and supported, they're far more – other than, I've got to run back and do my nights now or my risk assessment, rather than sitting with the person in front of them, there's so much pressure that if you changed that around and the main thing a clinician does is actually be with people instead of being a documenter and a risk assessment writer, yeah, I think that would probably help a lot more [MHN 1, CMHC, mid-trial].

Lack of service user data and access to the database

While health professionals reported having excessive paperwork to complete as part of service users' data management processes, further comments from another staff member revealed that a lot of these data were not helpful, as they were insufficient to deliver recovery-oriented care. Furthermore, physical (GP) and mental health professionals (MHNs, psychiatrists) did not have

access to a shared database across their two service systems, which was a significant barrier to delivering coordinated care across the primary, secondary, and tertiary care interface.

How do you do chronic disease management, self-management, recovery, rehab? You can't do rehab and recovery without data. And then the system doesn't collect data, but they say we believe in rehab and recovery. I think the rehab and recovery movement hasn't embraced the value of data. And then if they don't embrace the value of data – because they look at qualitative personalised medicine and say, no, no, we don't want state - we don't want a system to know stuff. They said each one is individual, unique. So, there's a kind of a perspective of uniqueness and personalisation and resistance to capturing holistic information. If you want to be holistic, you've got to capture the information ... if we converted that into a 6-monthly check-up for cholesterol, a 12-monthly check-up for mental health, a 12-monthly rehab plan, then you could just automate it ... then the allocation of roles. So, it's a governance issue. It's a roles and responsibility issue, it's a funding issue, and it's really a database issue [Psychiatrist 1, post-trial].

The summary findings of this section (section 5.3.5) helped to generate IPT 4 (Table 24).

Table 24: Perceptions and roles of health professionals in managing 'service user information system'

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
Administrative work-related burden	Paperwork	'Risk assessment' system	Time- consuming, yet guided by preconceptions > mistrust	Unable to provide actual quality care/consultation	More administrative work due to structural changes > change fatigue
Lack of service user data and access to the database	Lack of personalised holistic data	Illness-based model	Focuses on individual risks (as opposed to holistic social determinants)	Unable to provide recovery-oriented care	Staff acknowledged the need for change in paradigm

IPT 5: Illness-based model (C) is focused on managing risks (M), which does not collect holistic data for recoveryoriented care (O)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

5.3.6 Community resources and policies

'Community resources and policies' is about developing partnerships with community organisations (either formal or informal/voluntary) that support and meet service users' needs. This is to ensure that resource allocation and funding of services are sustainable, equitable, and able to respond to the community's changing needs and the specific needs of more disadvantaged sub-groups (such

as people with mental health issues). Analysis of the interviews with mental health professionals identified two themes that impacted their perceived ability to provide service users with self-management support: a) Perceived over-involvement of family caregivers; and b) the necessity of support workers.

Perceived over-involvement of family caregivers

Caregivers were often reported as key communicators, navigators, and coordinators between the MH and PH service systems. Although the CCM does not explicitly define the role of families within the self-management support framework, this study found that caregivers were actively involved in service users' recovery and self-management journey. Several staff participants mentioned how the family's extensive instrumental support helped the service user with daily activities, finances, and treatment adherence. However, a few staff participants expressed their concerns regarding service users' potential over-reliance on close family members, which could work as a barrier towards the person's independence and improved self-management skills. Staff members were also compassionate about the negative impacts of the caring role on caregivers' health and wellbeing due to their intensive roles in ensuring service users' overall wellbeing.

I think mum's quite supportive; she's been a few times while he's been here. And I think it often helps him with things like shopping, particularly when he doesn't have money for things if he spent on smoking or alcohol and things, and she will make sure he at least has food and those sorts of things. So, I think at times his mum — as a lot of people, families find they do get a bit burnt out and find they — she's rescuing him a lot, but she's as supportive as she can be given, yeah, how much she's been through I guess, yeah. Q: Yeah, and regarding changing his (self-management) behaviour, do you reckon she -? A: Oh, mum yeah, I don't know. I guess I don't know enough about their relationship. There may be a little bit of some co-dependence there, possibly which often becomes the case when you've had a child that becomes — having mental health conditions. Often, parents become a little bit over-involved as well. So, there might be an element of that between mum and Damian, but yeah, I don't know — don't know their relationship well enough [MHN 3, CRC, mid-trial].

The necessity of support workers

Aside from the family, NGOs were also identified as an essential community resource for this population group's improved connectedness and recovery. Some NGOs arrange support workers for service users' day-to-day activities, such as attending appointments, grocery shopping, exercising, etc. Staff from the CRC (site B) pointed out that in order to sustain the benefits of the

rehab centre, the service users needed support workers' assistance to ensure a smoother transition to the community.

I have recently put in an IPRSS [Individual Psychosocial Rehabilitation and Support Services] application for him to have a support worker to link him to mainstream supports in the community so that when he is at home, he's got stuff to do during the week without having to — I suppose in the ideal world, it would be great if he took responsibility for doing that on his own. Still, in the last six months, he hasn't been able to make those links or follow through on those commitments. So, we're now wanting to engage an IPRSS worker actually to support him whilst he is at home. I won't be putting him on transition during the week until that worker is in place, so that I know that that person is able to go around and take him out to do what he needs to do as far as cooking healthy meals maybe and linking into something that he is interested in the community [MHN 4, CRC, mid-trial].

The summary findings of this section (section 5.3.6) helped to generate IPT 4 (Table 25).

Table 25: Health professionals' perceptions of 'community resources and policies'

Sub-themes	Resources	Context	Mechanism	Outcome	Change through time
Over-involved family caregivers	Family support	Child's (service user/patient) illness	Co-dependence	A barrier towards recovery	Increased dependency with time
The necessity of support workers	NGO resources	Social isolation, Administration order	Improved connectedness	Recovery	Having a support worker had proven helpful

IPT 6: Having an informal (family member) or formal (support worker) (R) improves social connectedness (M) and work towards recovery (O), but there is also a chance of over-reliance on these supports (O), especially when the service user is an offspring (C)

R= Resources, C= Context, M= Mechanism, O= Outcome, IPT= Initial Programme Theory

5.4 Summary findings and Initial Programme Theories (IPTs)

This chapter found that, although SA community mental health settings, in theory, talk about adopting recovery-oriented practices, the system relies heavily on medications to treat mental illness. A key reason probably is the risk of relapse associated with the recovery model that allows service users to 'fail' at times as part of aiming to respect and build autonomy through the dignity of risk that underpins this approach (Pilgrim, 2014). The recovery model promotes supported self-management that requires care continuity, sufficient time, and service users' close inclusion and collaboration in decision-making with their care coordinators.

Given the context, most clinicians considered Flinders Programme time-consuming and unrealistic, given that the sector needed more resources and heavy staff turnover. With the existing unstable work atmosphere, care continuity for the long-term was deemed unattainable. Furthermore, due to high funding competition among mental health settings, there was competition and rivalries between sectors. An influx of top-down approaches also caused change fatigue and tensions among mental health staff. Overall, the stressed work atmosphere was deemed to have both direct and indirect negative impacts on the quality of care.

Rehabilitation centres strongly promote self-management and recovery models. Consequently, the rehabilitation staff showed more positivity towards the Flinders Programme adoption than in other clinical settings. This indicated that, with proper staff training and education, all community mental health settings could be prepared for delivery of the Flinders Programme and similar models, rather than relying heavily on medications as the only, or predominant, first-line intervention. This is particularly concerning given the potential iatrogenic impacts of long-term use of psychiatric medicines for service users (Ashworth et al., 2017; Pilgrim, 2017).

The above findings helped to generate IPT 1 through 5.

IPT 1: Given sufficient time and care continuation (C), quality care (R) and trusting in service users' goals (M) can enhance service users' chance of recovery (O)

IPT 2: Limited time and funding (R) is a challenge towards recovery-oriented care (C), resulting in politics within the system (M); this has generated tensions among staff, created resource mismanagement, and hampered patient care (O)

IPT 3: Psychiatry still follows an illness model (C) that monitors symptoms and manages illness (O), as the system is not well-equipped for recovery-focused care (M)

IPT 4: Limited resources and top-down approaches (R) have brought major restructures within the system (C), resulting in change fatigue (M), which negatively impacted patient care (O)

IPT 5: An Illness-based model (C) is focused on managing risks (M), which does not collect holistic data for recovery-oriented care (O)

IPT 1 through 5 demonstrate that SA community mental health settings face multiple challenges. The immediate effect of these challenges is limited time with service users and discontinuity of care due to high staff turnover, which directly impacts the quality of service that service users receive, and potentially, the ability to implement early intervention and mental health relapse prevention. So, even though the Flinders Programme trial saw success with service users, it could be challenging to make the Programme part of routine care where staff are already overwhelmed with work burden.

Outside the formal health settings, the challenge lies in building community connections. Family members or support workers were deemed to play a crucial role in this regard. However, staff expressed concerns about co-dependence with family members and how this could impede service users' independence and recovery.

IPT 6: Having an informal (family member) or formal (support worker) caregiver (R) improves social connectedness (M) and works towards recovery (O), but there is also a chance of over-reliance (O) on these supports, especially when the service user is an offspring (C)

5.5 Chapter summary

This chapter's findings indicate several structural issues related to the services in which mental health professionals work. For instance, attitudes towards service users held by mental health professionals can impede the delivery of adequate self-management support. This is therefore likely to have adverse impacts on the potential for any CCSM Programme (such as the Flinders Programme) to be embedded and sustained within these services.

The findings also reflected the pessimism of staff, and their lack of belief in service users' ability to change and improve their healthy lifestyle behaviours. This is most likely the impact of an illness-focused model of care, which is dominated by a focus on medication provision as the primary treatment option, coupled with an emphasis on treating risky health behaviours (e.g., heavy consumption of alcohol, substance abuse) as opposed to targeting root causes such as social isolation or trauma. This may explain why mental health professionals were less likely to deliver more holistic case management support focused on the psychosocial needs and goals identified as priorities by service users.

The other significant barrier is how a service user is diagnosed through the 'risk-assessment' process, where their previous histories and behaviours determine their treatment plan. This system is problematic as health professionals are reluctant to take risks because they fear that changed routines or health behaviours could aggravate service users' illnesses. For the same reason, the staff also seemed to lack trust that the service users could recover or show improved health behaviours. However, proper training and education might help health professionals embrace more recovery-oriented services within regular mental health services.

CHAPTER SIX: VIEWS OF THE TRIAL TEAM MEMBERS

6.1 Chapter purpose and structure

The previous results chapters presented the views of people with severe mental illness (SMI) and cardiovascular disease (CVD) risk factors as they took part in the Flinders Programme (Chapter Three), and the experiences of family caregivers (Chapter Four) and health professionals (Chapter Five). Qualitative data were collected at three time points: the pre-, mid-, and post-trial stages. The combined findings of Chapters Three, Four, and Five generated 49 in-depth interviews; the Critical Realism-informed analysis fulfilled study objective one: exploring the experiences of service users, caregivers, and health professionals to identify their roles through the Context-Mechanism-Outcome (CMO) configurations of the Flinders Programme and broader self-management experiences.

In addition to the important groups mentioned above, a key group whose experiences and insights can contribute further to understanding the Context-Mechanism-Outcome (CMO) configurations of the Flinders Programme was the trial team members who delivered the Flinders Programme to participants. Hence, this chapter describes the methods (section 6.2) and results (section 6.3) of the investigation of the roles and experiences of trial staff to understand how the programme was delivered in four South Australian community mental health settings. This process also helped to understand why the Flinders Programme worked (or not), how, for whom, and within which contexts. The outcomes of this chapter contribute to the fulfilment of thesis objective two: exploring trial staff members' experiences. The results of this chapter will help us understand the pre-existing challenges that often lie within the health system and health settings and which negatively impact programme delivery. The researcher also identifies the strategies taken by the Flinders Programme trial team to overcome some of these challenges. Other researchers and health professionals might find these strategies helpful in delivering and replicating similar programmes more efficiently in the future.

6.2 Methods

Over the three-year study period (November 2017 to September 2020), qualitative data were collected from nine core trial team members who managed and delivered the Flinders Programme. Data were also collected from ten project investigators. This latter team included psychiatrists, CVD specialists, researchers, mental health nurses, and admin officers. Multiple data sources and collection methods were used for this chapter, such as in-depth interviews, focus groups, reflective journals, and meeting minutes. Details are displayed in Table 26.

Table 26: Data collection methods and timeline used to extract data from trial team members

Period	Data collection methods	Number of participants
November 2017	1 Pre-trial focus group	7
	(Extended trial team involving 2 trial nurses, 1 manager, 2 research investigators and 2 administrative officers)	
October 2018	1 Mid-trial focus group	3
	(Core trial team: 2 trial nurses, and 1 manager)	
September - October 2019	Post-trial interviews	7
	(Extended trial team involving 2 trial nurses, 1 manager, 4 research investigators)	
August 2017 - August 2020	4 Reflective journals	4
	(Core trial team: 2 trial nurses, 1 manager, 1 research investigator)	
November 2017 - September 2020	Meeting minutes from 10 trial investigator meetings	10-20

The data were analysed in two steps per the realist synthesis method: deductive and inductive analysis (Pawson et al., 2005). First, under the deductive analysis process, the RE-AIM framework: Reach, Effectiveness, Adoption, Implementation, and Maintenance, was used to organise the data and related themes within RE-AIM's five domains (Glasgow et al., 1999). The RE-AIM-based process evaluation involved the perspective of the trial staff at three time points: pre-trial, mid-trial, and post-trial (Table 26). Trial staff were well positioned to see the trial being rolled out in practice and to reflect on the implementation process as part of their everyday interactions with service user participants, as well as their communications with the services and their staff.

Then, as part of the inductive step, the researcher used an open coding process towards 'thematic analysis' to search for new themes not captured by the RE-AIM framework (Braun & Clarke, 2006; Terry et al., 2017). Findings were collated from different data sources (interviews, focus groups, and meeting minutes), and integrated and interpreted to understand how the Flinders Programme was delivered in the four selected sites. All study participants whose data are reported in this chapter are referred to as T1, T2, T3, and so forth to ensure anonymity given the sensitivity of some of the data reported ('T' to represent 'trial' team members).

6.3 Key findings

The findings are presented within the five domains of the RE-AIM framework, which will be referred to here as key themes. Each of the five key themes and further sub-themes is summarised in Table

27. Direct de-identified quotes from the trial team support the description of each theme and subtheme.

Table 27: Perceptions of Flinders Programme trial team members: key themes and sub-themes

RE-AIM domains and related themes						
Reach	Effectiveness	Adoption	Implementation	Maintenance		
Low recruitment	Non-specific effects	Model of care	Preparation	Self- management capacity		
Strategies taken to increase recruitment	'Invisible change'	Work atmosphere	Pilot survey	Resources		
		The physical structure of the setting	Revising study design	Care continuit		
			Actual trial and adaptations			
			Fidelity			

6.3.1 Reach

'Reach' is about understanding what factors make participants accept or decline any new intervention and what can increase participation (Glasgow et al., 1999). Reach could be limited by the service user experiencing problems with transportation to the clinic, treatment choices, or mistrust in the health care system (Holtrop et al., 2018). This section reports on two aspects: (a) 'Low recruitment' into the Flinders Programme, and (b) Strategies taken to improve recruitment.

Low recruitment: Recruitment was reported to be a significant issue throughout the trial. The trial team struggled to fulfil the target number of 358 adults with SMI and CVD risk factors who were to participate in the six-month care planning intervention and 1.5 years of follow-up using the Flinders Programme. The recruitment began in mid-November 2017 and was carried out until February 2019. The total number of people approached (or referred) over this tenure amounted to 361. In total, only 120 people finally agreed to participate in the trial and completed at least the initial assessment.

The trial was initially designed to receive referrals from clinicians in community-based mental health settings (care coordinators and medical staff at sites A, B, and D), but this did not happen. The reasons for this were many, but the most prominent were the structural changes, such as proposed changes to allied health staff numbers and fulfilling Key Performance Indicator (KPI) requirements. KPIs are set parameters that seemingly indicate an institution's progress and which measure performance about formally established standards of care and internally focused targets. Due to time and resource limitations, no further data was collected on the KPIs. The trial team revealed that the service was in crisis at most sites due to high staff turnover; many staff were over-worked and unhappy with the restructuring process. This structural change within the community mental health

system coincided with the conduct of the trial and impacted the level of positivity around the Flinders Programme behavioural health intervention trial. The trial recruitment was perceived as another added responsibility that mental health staff needed to consider when they were already pushed to the limit to do the basic requirements of their roles. Trial staff comments suggested that staff were experiencing significant pressure due to these changes. So, unsurprisingly, recruiting for a research trial was described as the least of their priorities.

It (referral and recruitment) is one more thing on their (clinicians') plate [T4, reflective journal, October 2018].

The community mental health clinics are also predominantly set up for home visits by care coordinators; service users often find it challenging to be motivated to visit the clinic and sometimes forget their appointments, requiring clinicians to make a home visit to deliver support. Home visits also save service users' a journey to the clinics, which is favourable in scorching weather and may also save on transport costs. A limited number of service users attend the clinic, usually in the context of an appointment with a psychiatrist or for a regular appointment with the clinic's depot nurse to receive a legally imposed or voluntary injection of their psychiatric medication. Trial nurses could not home visit on their own for this trial, and were dependent on seeing people at the community mental health clinics (or rehabilitation centre or SRF), making it more challenging to see more people, see them regularly, or ensure that the work progressed promptly.

I think a drawback to the project may be that people with a lived experience of mental illness may not feel happy about making their own way into [the clinic] – especially when it is hot. It may even cost them money for bus fares [T4, reflective journal, November 2017].

Trial nurses also reported that since the target population were diagnosed with SMI, most struggled with amotivation and engagement with services and had problems organising their daily life and commitments, such as appointments. This impacted upon their ability to engage effectively and commit to regular Flinders Programme appointments. As previously highlighted in earlier chapters, this population commonly has little choice in receiving services due to many being on legally imposed treatment orders via the state's Mental Health Act. Hence, when offered an option to participate in an initiative provided by the "service", many chose to decline.

Another reason for low recruitment could be mental health staff members' scepticism and pessimism towards recovery-oriented care. Traditionally, psychiatry relies heavily on an illness model focused on treating mental health conditions through medications as the primary intervention. As a result, attention to comorbidity, lifestyle interventions, and physical health care needs are rarely focused on and addressed in mental health services. Because of this scepticism by some clinical staff, trial nurses fulfilled the task of recruiting themselves and delivering the intervention alone instead of

receiving referrals from clinical staff. This created enormous pressure on the trial nurses. One trial nurse reported that clinicians were less proactive in referring service users to the Flinders Programme trial and showed poor attitudes due to their potential lack of belief in self-management intervention and recovery.

There is a level of amusement that is coming from clinicians (medical staff) about the trial. When seen by the trial nurses, responses (from clinicians) have been to laugh and ask how it is all going. This is in the context of people not believing in the approach to the study (improving the physical health of service users). This, I feel, directly correlates with the number of referrals from clinicians we are receiving - very, very low [T2, reflective journal, March 2018].

Strategies taken to increase recruitment: To deal with the low recruitment numbers and problems discussed above, the trial team developed various problem-solving strategies to boost recruitment numbers during the trial. These included:

1. Promoting the Flinders Programme (November 2017): The initial intervention protocol did not consider advertising study participation to generate recruitment. However, the trial team proposed and piloted several strategies to promote the intervention. Active advertisement of the study by placing flyers in reception waiting areas at the clinics, presenting participants with a sample bag demonstrating healthy eating, and increasing the number of recruitment sites were some of the key strategies employed by the trial team.

So, we spent quite a lot of time developing referral sheets and referral post boxes and developing advertising stuff and flyers and making a presence at various locations. We tried that for a while and were looking at recruitment rate, but also declines, no shows [T3, post-trial interview].

I have noticed the trial nurses here on Wednesday come with fruit and drinks for people – I think that it's so important that both clinicians and patients see them – and that they remain visible. [trial nurse] is thinking of ways to recruit participants, such as going to SRFs. This means they do not have to travel to [the clinic] – there is an office in most of the SRFs that the research nurses can use [T4, reflective journal, November 2017].

2. Approaching Consumer Advisory Group leaders (January 2018): Site A had a 'consumer advisory group' where some service users came together to support each other as peers, discuss service-related issues, and provide systems-based advocacy and advice to the services. The trial team approached them in the hope of increasing participant numbers.

However, as the comment below demonstrates, this strategy did not result in any further service users participating in the trial.

I just had an email from the chair of the Consumer group. The group has small numbers, so they want the research nurses to come to the meeting in March instead of Feb. They are hoping to recruit more members by then. It seems the consumer groups are also having problems with recruitment [T4, reflective journal, February 2018].

3. Inclusion of an honorarium (February 2018): After three months into the commencement of the trial, the recruitment rate still needed to be higher. Given the disappointing results, the chief investigators decided to pay participants a small honorarium (AUD 20) to acknowledge their contributions.

The honorarium was a really important part in this population. It's very common that I guess the greater proportion of sufferers with this type of mental illness have very little means, and so having a food voucher, whatever they did with it, was a real advantage, and it perhaps got them over the line to do the guestionnaire, so that was really important [T3, post-trial interview].

- 4. Changed recruitment strategy (February 2018): The trial team acknowledged that talking to a service user and presenting them with a two-year study plan up-front (six-month intervention and 1.5 years follow-ups), which outlined multiple planned contacts, was overwhelming and off-putting to almost all the participants who were approached. Therefore, the team offered initial baseline measures to participants, hoping that this more temporal focus would be less overwhelming to them. Participants were then asked at each session if they would attend the following appointment as they completed each session.
- 5. Recruiting 'closed episodes' and more trial nurses (August 2018): An ethics amendment was sought to include participants with 'closed episodes' (no longer service users of the service, discharged within the past 1-5 years). These past service users now often accessed their psychosocial support from a Non-Government Organisation (NGO) (also known as a community-managed organisation), with the trial nurses approaching these organisations to recruit more participants. This strategy was somewhat successful.

The team also tried to recruit more trial nurses and community rehabilitation workers from different sites, hoping this would increase their capacity to approach more potential service users for recruitment. However, this strategy did not appear to improve recruitment, which was perceived to be for various reasons, including the cultural and political environment surrounding the trial.

I'm not sure exactly about the timeframes, but essentially, we went - we're just not going to get enough people through the open episode for a number of different reasons. And so, the next recruitment strategy we tried was to open it up to closed episodes, so people that were no longer receiving constant, I guess constant care, and were "well enough" to just have follow-ups at GPs, and I guess other non-government organisations that they could link into. We tried to recruit more trial nurses; we tried to recruit a community – what were they called? Community rehab worker? Q: Oh, yes. A: To try to be the conduit between the actual health centre or [the clinic] and those that had been discharged because the community rehab worker goes to all of the other NGOs. We had absolutely no luck with recruiting those people, so that was incredibly disappointing; we felt that was going to be, that would really work, and again, there was a comedy of errors of communication or lack of communication, I mean, how much of that was passive resistance, it's really difficult to say [T3, post-trial interview].

6. Expansion of recruitment site (August 2018): Adding closed episode participants could have proved more effective. The trial team organised letters to go out to service users with closed episodes and made phone calls, but the response rate remained low. The trial team also needed help with contacting and delivering the intervention to participants from NGOs due to the structural and financial reforms these organisations were undertaking at the time. Trial nurses explained that those services were transitioning to become National Disability Insurance Scheme (NDIS) providers during that time, and their workforce was very consumed with that focus. The failed recruitment target reached a critical point when, despite trying all these options and strategies, the trial needed more progress. Consequently, the research steering group expanded recruitment to the second trial service region (site D).

So, we had tried to hook into various NGOs to use that as potential places that we could go and recruit people; they were having a restructure because of the whole NDIS (National Disability Insurance Scheme), there's different funding that is going on, it was like the perfect storm and yeah, so in the end, I think that we were on the cusp of going okay, really where to next? We could go to the College of General Practice, try to send out letters to GPs and try to capture people like that, but we also knew that GPs are incredibly time-poor; we probably would've sent stuff out or had things in newsletters that realistically you'd probably get a five per cent participation rate from a lot of work, and we really needed something that was a little bit more effective than just waiting. I mean, if you think about your own response and you're

always receiving bits and pieces of communication in the mail or random newsletters, it doesn't engage me much and GPs they're just swamped. So, I thought whilst that is a strategy, it probably wasn't very time-efficient and for a very little return. And so, given that the initial ethics and site-specific agreements were inclusive of site B that was our last frontier [T3, post-trial interview].

6.3.2 Effectiveness

'Effectiveness' is about capturing the perceptions of different stakeholders to investigate if they found the intervention meaningful. This is also about understanding why the same intervention might have worked differently on different sub-groups or settings. Furthermore, 'effectiveness' also allows reporting on an intervention's unintended positive or negative consequences, and can explain the outcomes that are often not measurable; for example, enhanced hope and motivation (Holtrop et al. 2018). This study found that: (a) 'non-specific effects', and (b) 'invisible change' were attributed to the Flinders Programme.

'Non-specific effects': Trial nurses reported that most participants engaged well with the Flinders Programme and enjoyed the process. Surprisingly, a few control group participants also reported positive changes in their health behaviours and attributed that to their involvement in the study. However, control group participants could not explain why and how the study helped them change their heart health-related lifestyle. While discussing this matter at the team focus group, the trial team named this outcome 'non-specific effects'. The trial team explained that using the surveys at routine intervals to ask control group participants about their heart health-related behaviours (e.g., smoking, alcohol consumption, diet, exercise), undertaking routine physical measures, and the process of contact and engagement with the service users (given that their usual care coordinators were perceived as time-poor or otherwise less engaged with them), might have contributed to this unexpected positive consequence for the control group participants.

T2: I was just saying to [T1] this morning, one of the participants in an SRF, who has very poor cognitive functioning, who we actually placed in the control group from the intervention, because it, we just weren't getting anywhere, thanked me the other day at her twelfth month for helping her to stop smoking. Q: Oh, really? T2: So, there'd been no intervention, there'd been no Flinders Programme intervention, it had just been our control, but she attributed her stopping smoking to us going there. And so, even though the ... T3: So, what we would say then for that, that's a non-specific effect? T2: Yes. T3: So, it's actually just ... T2: Just the contact ... And I said to her, what have I done to help you do that? And she couldn't articulate that ... I actually think it was probably just by virtue of having a consistent touch base

with someone and actually feeling like that is of value, and they are valued, and they have ... T1: And we have smoking conversations, and the survey questions, and that, we didn't work together with the Flinders tool to address that, but through that ... T3: So, that really shows the power of just eliciting, you know, even in someone with such a cognitive impact, just putting the question is enough to actually get them thinking [Mid-trial Focus Group Discussion; October 2018].

There was also a report of a positive impact on some caregivers while they actively accompanied service users in achieving an improved lifestyle (e.g., exercise and healthy eating). In some instances, completing a goal together and succeeding improved the relationship between caregivers and service users.

'Invisible change': Findings in the earlier results chapters (Chapters Three-Five) demonstrated that many service users experienced amotivation and cognitive impairment, reducing their ability to change health behaviours for the better. Trial nurses, however, reported that most participants experienced positive changes with time, even if it was a small change in their overall attitudes, behaviours, or motivation towards improving their lifestyle. The nurses explained that for this seemingly 'difficult to engage' population group, this was a significant achievement and demonstrated that a person-centred self-management care planning approach that also involved consistent follow-up with the person, and which was delivered at their pace (such as used by the Flinders Programme), could help them to achieve positive changes to their cardiovascular health. The trial team called it an 'invisible change', as this process was difficult to measure quantitatively.

So, then even another one, who I think if someone looked at it in the cold hard light of day, would say, I know they haven't been successful, but actually, they've been making a point of walking more, and they are mindful about the whole cigarette smoking thing, and they had a moment where they said, "oh, I get it now; if I give up smoking, I'll have more money, and I'll live longer". Now, I don't think people involved with that service user would attribute that level of thinking and reflection to that service user, and it wouldn't be a permanent state, I believe, but at a point in time with interaction of the Programme, he actually said that, and I think I've actually got that on tape [T1, post-trial interview, October 2019].

T2: And you could say, just the contact has taken them from precontemplative to contemplative, just the contact. T3: You know what, I was thinking just as you were saying that, and just before you were saying that, that it would have been good to have some representation of the stages of change because that's a movement from not interested to maybe. T4: That's a big ... T1: It is, and you can't see it. T4: No. T1: But that's a shift in, a huge shift in the right way. T2: It's a shame. T3: Yeah, it is, sort of. You know, that was – I mean, that was never on the cards, more involvement, but maybe next time, you know, another similar trial, you know, if one should come up, maybe that's something that's worthwhile so that we can see the invisible change, you know [Mid-trial Focus Group Discussion; October 2018].

6.3.3 Adoption

This element of the RE-AIM framework focuses on the factors that facilitate or hinder the uptake of a new intervention within an organisation and its staff. Holtrop et al. (2018) suggest exploring the intervention's compatibility with the organisation's mission, current priorities, competing demands, policies, regulations, and staff turnover rate. A setting's location, layout, and space are also important in adopting a new intervention. Therefore, this section examines and reports on three areas relevant to adopting the intervention: a) the model of care, b) the work atmosphere, and c) the physical structure of the setting.

Model of care: A significant difference was observed between the site A and site D models of care, despite both being community mental health clinics. These two clinics were in different Local Health Network regions and had separate administrations, which might have influenced the service cultural variability of each clinic. One of the trial team members who had experience working for both networks suggested that the latter service region (site D) might have a more person-centred and family-oriented approach. This approach helped their staff and service users to be more accepting of the Flinders Programme, which is also underpinned by a person-centred model of care.

So, [suburb name] suburbs are migrants. [suburb name] is Anglo, [suburb name] North is Anglo. So, the — it's a migrant set-up, and it's Italian psychiatry. It's got a community mental health; it's all about migrants and family and looking after you for life. So, the idea is we look after you for life. Woodwork, art, beach. That's the philosophy which still is there, but it's going down over time. We become more individualised, but the core is Vietnamese, African, Greeks, Italians. So, it's infused by the social structure of the place, and that social structure was family. Site A is the care plan, individual, discharge, and GP. Site D model is Anglo. Site D model is family, life, Italy. Q: That's a good way to put it. A: So, it's sort of ... means that the patient gets a qualitatively different experience. And I don't know whether it's quantitatively better or not, but—yeah [T6, post-trial interview, October 2019].

The trial nurses perceived that, potentially, site A still managed a higher proportion of acutely unwell service users compared to site D. Consequently, site D had more stable service users. However, trial team members familiar with both settings admitted that site D linked with a broader range of

more established psychosocial supports such as employment, housing, community groups on cooking, etc. Service user experiences and field notes also supported this finding.

Work atmosphere: Before the trial began, site A staff were optimistic about the study. The trial's site coordinator, who was also a well-regarded site A clinician and had worked in the team for several years, reported that it was conducive to the trial.

I am very excited to be involved in a project of this scale! I believe that this kind of research can benefit both clinics and service users – I think that it helps clinicians feel part of a larger picture – that it helps morale – that it helps them understand research and the need for evidence-based practice. Great meeting this afternoon – I think [sector manager] is very on board which will be great [T4, reflective journal, August 2017].

However, within months, the picture changed completely. There was a significant structural change within the service that included leadership changes, a significant reform agenda, and a model of care reform within site A. Trial nurses wrote in their journals that there were a lot of adverse workplace and workload issues in the service teams. They explained that some of the changes were not in accord with what staff perceived was needed or wanted for the service or service users, which made staff feel "overworked and extremely unhappy". This conflicting situation within the mental health system and settings jeopardised the success of the trial intervention. Trial nurses expressed the belief that some of the other health networks did not appear to be at the same crisis stage as their service at the time of this intervention. Therefore, when the trial team approached staff in the second service region (site D) to flag their interest in being involved in the trial, the research and trial team were received quite positively.

The physical structure of the setting: Site D appeared to be more proactive about their service users' physical health. For instance, they had a better physical structure in terms of size and layout, and how they promoted physical health in their settings. Further to this, site D had a dedicated biometric measurement corner, and more health promotional posters in and around the service user waiting area, which were visually appealing and easy to understand. The place overall was also described as inviting in decoration and seating arrangements.

T1: And every couple of months, they (site D) have, they send out letters to every consumer – they come in and have their physical health checked, and they'll bring nurses down, and from one of their NGOs too – so, physical health is not an alien concept to their service users, you know, they seem more receptive, whereas there's not that focus [at site A region]. T2: There seemed to be a lot of information in the reception area that was updated and well-stocked ... T1: Around physical health. T3: Did you ever see anybody

looking at it? T1: Yeah. T2: Yeah, yeah, yeah. T1: Yep, and there was information about what someone would save if they gave up smoking, a big poster at the entrance to the Depot clinic, about yeah, if you smoked a packet a day, this is what you could save in a few months [Mid-trial FG; October 2018].

T1: The other thing that I think is noteworthy, the differences between site D and site A, is I think that the site D environment, reception, the space is much bigger and friendlier and open, as compared to site A. When you consider the space that site D has in the whole reception ... T2: Well, it's that they're the only standalone – it's just them ... T1: Yeah, that's right, so you get down to a bit, the building environment. And then, there was the middle biometric chronic disease monitoring area. Now, I didn't see many service users using it, but they were always reminded that they could come in and check their weight and do their blood pressure and that, so that might be noteworthy, given it's heart health and research [Mid-trial FG; October 2018].

Also, the suburbs covered by site D were in a favourable position regarding transportation and proximity to basic amenities and psychosocial supports. The following conversation among trial team members shed some light on this matter.

T1: It'd be interesting to look at the populations and the differences, but I mean, they are a very inner urban area that's old. My impression is that they have a lot of support and they have a lot of infrastructure and transport, whereas I think, the more you get, especially to the [outer suburbs of site A region] ... T2: Absolutely, there's not a lot of ... T1: You get less and less support — well you have to travel further for support. Whereas, I think probably, the people who access the [site D clinic] have got access to a lot of support, really close because the [hospital] is just up the road. T2: There seems to be more NGO input in there, whether it's because it's a smaller catchment, whereas the [inner and outer site A region] goes from [suburbs with large distances between them], to ... you know, there's a huge area it covers, and there's only so many NGOs within that space [Mid-trial FG; October 2018].

6.3.4 Implementation

'Implementation' is generally the stage where intervention is integrated into routine health care. However, being a phase-III trial, this section describes how the Flinders Programme was delivered outside of routine care, by whom, when and how. This section also focuses on the adaptations and modifications that the intervention required. Holtrop et al. (2018) explain that different settings may

require intervention adaptations depending on the context; this process indeed improves the fit and outcomes of an intervention. Therefore, the findings for this theme are organised and presented under five sub-themes: (a) preparation; (b) pilot survey; (c) revising study design; (d) actual trial and adaptations; and (e) fidelity.

Preparation (July 2017-February 2018)

Training: Two trial nurses were trained in the delivery of the Flinders Programme. They had access to online resources and guidance from clinicians who had previously used the tool in similar trials. As the trial was conducted by the university research unit where the nurses were stationed, they had constant support from the unit's chronic condition self-management (CCSM) postgraduate course and training coordinator. There was also training on biophysical readings and measurement equipment needed in the trial to measure height, weight, body mass index, and so forth. Training with the trial site coordinator was arranged to ensure both trial nurses understood the information presented in the biophysical readings the same way, achieving consistency and accuracy. It was noted early that the three weight scales and the height measuring equipment were not returning the same results when checked for parity. Consequently, the trial team arranged for a biomedical engineering technician to go to the site who calibrated each of these pieces of equipment before the commencement of the trial.

There was training on blood taking as well. The trial team organised necessary training for the primary health care trial nurse to ensure their skills were up to date, given that blood taking had not been a routine part of their role before involvement in the trial. SA Pathology (the state-based blood testing services) assisted with this training. The trial nurses were also trained to use Point of Care Testing (PoCT) machines. There had been concerns regarding who would be responsible for the results and any abnormalities detected. There were also discussions around whether participants would fast and if they needed to fast for an afternoon appointment. The trial nurses developed a template to send to GPs if an abnormal blood result was returned. Trial nurses also contacted the participants' care coordinator and the GP to flag these abnormalities to address their 'duty of care' responsibilities. Other concerns were resolved in group meetings involving core trial team members and senior study investigators with relevant expertise.

For this trial, it was important that the two trial nurses delivered the Flinders Programme intervention and also collected the biometric measures and other process and outcome measure data from the service user participants as part of their care planning interactions with them. The nature of the service users as individuals with SMI and the importance of building trust and maintaining continuity of trial contact person aligned with the needs of the population being researched.

Sourcing of equipment: The trial team spent much time investigating options for sourcing the equipment required for the trial and trying to source free equipment due to research budget

constraints; for instance, arranging free Blood Pressure (BP) and Blood Glucose Level (BGL) monitoring machines for testing. This strategy also included contacting a Nicotine Replacement Therapy (NRT) product manufacturer to enquire about free or reduced-cost products for the trial, although this request was unsuccessful.

Developing guidelines to collect data: The trial team also prepared scripts to approach service user participants to seek their involvement in the trial. The writings included information about the trial and making appointments. Another important aspect was to consider the potential pharmacological impacts and interactions of NRT with the metabolism of antipsychotic medications to avoid any possible complications regarding service users' physical health and mental health symptoms, particularly as many of the participants were identified as being prescribed to antipsychotic medications.

T1: I sort of did a bit of revision with Clozapine, and because the fact about the dangers in people cutting back on their cigarette smoking in relation ... Q: Oh yes, yeah. T1: ... to Clozapine and looking at what we could do about that because, again, there's been a bit of a difference of opinion about that. How much monitoring is done? We've had a lot of discussions about the practicalities of getting results, how hard that would be. Yeah, so, bit of mixture of practicality versus reading a lot and coming up, we've come up with some of our own stuff. Q: Okay. T2: Appointment sheets, measure sheets, follow-up sheets (Pre-trial FG; November 2017).

Data storage: The trial team also had to consider operational elements, such as arranging rooms to deliver the actual Flinders Programme intervention to service user participants. The trial team sought the help of the settings' leaders in sorting this requirement. Additionally, the team needed to acquire iPads for the trial nurses to use with service users to streamline data entry for surveys and other measures when they were with the service users, regardless of their location. There was also the need to find a cost-effective method to collect and store the data. After extensive search and discussion among the research team, 'Qualtrics' was selected to store the data. Despite being pressed for time and resources, the teamwork and collaboration with the site managers resolved all issues within a short time, and the trial team was prepared for the actual data collection within the deadline.

The trial starts next week, and the trial nurse is still not in position – still I am amazed at how quickly things finally came together – It must have taken such hard work and collegiality from all team members! There was so much to do - i.e., rooms for interviews, equipment for measures – iPads and the Programme Qualtrics that needs to be exactly right [T4, reflective journal, October 2017].

Other trial process adjustments: The trial team also made some changes to the original protocol to accommodate the unique needs of this population group which became more apparent in the early stages of the trial, such as reducing the number of questions and the overall length of the survey questionnaires. There were other problems regarding the collection of biometric measures from service users. For instance, blood collection forms needed to be signed by medical staff before trial nurses could approach service users. But the reduced ability for trial nurses to access medical staff at site B (community rehabilitation centre) caused an issue making the whole process very difficult, time-consuming, and cumbersome. Several participants in the site A region were recruited from the Dialectical Behaviour Therapy (DBT) group. These service users also needed access to medical staff who could approve the blood tests. Consequently, gaining the blood test results intrinsic to the research took much work. This issue was resolved by having a PoCT machine as part of the research equipment to ensure that the ability to get this vital information was smooth and consistent. The PoCT device allowed the trial nurses to recruit anyone into the study who was deemed eligible and had access to the necessary equipment (for lipids and glucose testing) without having to access GP clinical information, which saved time and made the process easier.

... so that's kind of what we did aside from the Point of Care machine which enabled – we had a lot of trouble with trying to get bloods initially through GPs – well no, it wasn't GPs, it was the psychiatrists signing the requests for the bloods to be done, or one, I guess, concept was that when they came in to have their Depots or their Clozapine, that they would have fairly regular bloods done which wasn't the case. So, we were running around after psychiatrists trying to get blood request forms signed and then not having the bloods line up with when we did questionnaires, and it was just an absolute pain in the neck. So yeah, so we went to [company name] and asked them to come to the party and provide whatever that they would suggest, but they provided us with some Point of Care machines which meant that we were mobile and could do blood tests wherever whenever; so that was actually a real boon, I think that helped the nurses a lot. So that's pretty much what we did [T3, post-trial interview].

Pilot survey (October-November 2017)

Trial team staff took care in selecting and discussing potential psychometric questionnaires that would be used for the trial, drawing on their diverse expertise as mental health clinicians and researchers. This was supplemented by one of the trial team members performing a mock interview with a service user. This practice session involved the initial baseline assessment in the piloting test of the Flinders Programme care plan's suitability and acceptability with service users. The feedback helped the team prepare for the first day of trial implementation. During this pilot session, the team

looked at each section of the survey and noted where there were difficulties explaining the questions to participants. Consequently, the trial nurses used visual props to describe the difficult sections. The trial nurses also realised that time would be a barrier, as SMI can impact participants' ability to think quickly. There was also a concern regarding the inability of some participants to sit still and concentrate for up to one hour. As a solution, the trial nurses decided to conduct the first few assessments together, then debrief each other and identify issues they had observed or noted while undertaking the assessments. Realising that this SMI population would likely struggle with long questionnaires, the trial team reduced the number and length of the questionnaires. The trial nurses also sourced several visual materials to accompany the survey questionnaires to make them as simple and easy to complete as possible.

Revising survey forms (November-December 2017)

As described above, it was noted during a pilot survey that there were issues with how some of the questions were worded, making them difficult to understand for service users. This needed further explanation and added to the time the participants required to complete the survey. There were also issues with changes to how the questions were answered (e.g., responding in numbers, percentages, and answering in word form). This needed to be clarified for some of the participants. The number of questions the participants were asked to complete was also significant. Some participants needed a break during their appointment to complete the survey. The trial team met to discuss these issues and then amended the surveys to reflect a shorter, more consistent way of answering the questions. The team had access to a pictorial Likert scale and other supporting images (e.g., a picture of a clock to explain 'sitting time' to answer questions regarding daily physical activities), which were used if necessary. There was also discussion around changes to the sleep survey to reduce the number of questions. It was noted that the next participant found the questions easy to understand and complete after the changes had been made to the survey questions to be more consistent. However, it was noted that the second participant had higher cognitive function than the first participant.

So yeah, we cut quite a lot out of the questionnaire, so from about probably the start, about the first third of this year, we cut it probably by about two-thirds, I guess. So now, we only have those measures that are absolutely crucial for hypotheses one and two, and maybe one or two extra measures [T3, post-trial interview].

Actual trial and adaptations (March 2018-September 2020)

The trial began in mid-November 2017, but had a slow start in terms of recruitment. After employing different strategies, data collection was smoother from March 2018. The trial nurses reported equipment being adequate for the needs of the study. The nurses reported being flexible about the

locations where, and how, they did baseline assessments, which was helpful. It was reported that several participants felt more comfortable taking their surveys home to complete. When documenting this information, the team had a 100% return rate on the postal surveys. During the group discussions and interviews, trial team members concurred that the paper version of the surveys was deemed more suitable for this population group than electronic versions.

The other thing that perhaps isn't important in what we changed, but for what we might do differently next time, is that we were intending to use electronic entry for our data, but what was — well not surprising in retrospect, but initially, we were being very pragmatic in trying to reduce error, trying to reduce or increase efficiency by doing direct entry on an iPad with Qualtrics, but the population, this population really didn't work well with a non-tactile questionnaire, they needed to feel it and see it and manipulate it and point to it, which it makes a lot of sense and I think that when there is a lot going on upstairs, that actually having and using a different sensory modality is a really important part of engaging with the process; so I think in the future, whilst paper questionnaires are somewhat poo poo-ed because it's old style and increases error in the transfer of data, at least you get some data, because otherwise, it's another barrier for engagement, so we've just got to go with what works best for those engaged [T3, post-trial interview].

To begin with, the study had one full-time and one part-time trial nurse. However, after the first few months, the study had stagnated somewhat with the reduction of the full-time trial nurse's working hours (they had some better work opportunities arise). Consequently, there was no capacity to actively recruit further service users while attending to reviews and intervention follow-ups. This resulted in the team looking at other avenues to gain participants, such as recruiting more staff to undertake more assertive recruitment. However, the team was unsuccessful at recruiting more staff. Furthermore, the perceived internal conflicts within the site A system, and the lack of physical space available at the service sites to sit down with service users to conduct the measures, caused obstacles for the trial.

There were a lot of political issues that were also happening simultaneously, so there were some awkward meetings at various sites. And there was reticence which is probably a diplomatic word, particularly down in one of the sites ... Aside from political aspects, there were just issues with trying to find space with doing the biometrics, sitting down somewhere that was private, somewhere that was safe for the nurses, something that could be booked and not reused or reconfigured, and the continual issues that we had with trying to actually get hold of someone to speak to confirm we had office space

or testing space; so that was another quite problematic thing. So, we went on for a while; we did our best to work around those issues [T3, post-trial interview].

Fidelity: Examining the fidelity of the Flinders Programme was beyond the capacity and aims of this thesis. This aspect will be studied and examined separately by the trial researchers. However, the trial nurses were requested to record some of their sessions with service user participants for later analysis. This process will enable the researchers involved in the larger trial to capture the perspectives of the trial nurses and other team members regarding what motivated them to adhere to the programme's core principles and how they did so. This process will also be able to capture their perceived concerns about the implementation generally, and how to manage these better moving forward.

There is some talk also around keeping the veracity/authenticity of the Model – I agree with that – but also believe that, because of the nature of our population, that there may be times when the Model, and the delivery of the Model, needs to be tailored to their unique needs. I am not sure how that will pan out [T4, reflective journal, October 2017].

The Flinders Programme meeting with [name of two clinicians who had experience using the Programme with a similar population group] was an extremely productive meeting allowing trial nurses to explore ways that the Flinders Programme can be used with participants without affecting the fidelity of the Programme itself. Initially, the Flinders Programme appeared to be a barrier for me as a clinician. The way I perceived it was as a structured Programme with no ability to be flexible around how the information/care plan was delivered. However, the programme can be used in any way that maintains the basis of it to fit the participant. This meeting energised me and the passion I have for this particular work – I believe the Flinders Programme is a sound framework for self-management, and the ability to use it in a person-centred way will enable this population of participants in the study to be able to engage with it also in a way that is meaningful to them [T2, reflective journal, December 2017].

6.3.5 Maintenance

Being a phase-III trial, consideration of the maintenance of the intervention beyond the trial process was outside the scope of this research. Hence, this section highlights the perceived potential for 'maintenance' of the intervention, according to the various participant groups.

Self-management capacity: This study found that while the Flinders Programme appeared to be an excellent programme designed to support people in self-managing their health and lifestyle, it requires a degree of organisational skills and cognitive functioning for the person to improve their self-management capabilities. The trial nurses thought a few service users lacked the skills to self-manage but could make small changes. They further explained that the input or support required to achieve these changes was significant, but worthwhile.

Resources: Another aspect of the intervention was to sustain participants' skills regarding improved heart health behaviours. The protocol intended to link participants with community-based programmes or institutions to maintain their changed behaviours during and after the intervention (e.g., Quitline, local gym, local clubs). This was achievable for some participants, but not all, mainly due to practical issues (e.g., lack of transportation, insufficient finances to join the gym or to buy healthier food items). Furthermore, the trial was not part of routine care; hence, it was challenging to ensure the follow-ups required to link people to these programmes and support them to maintain these links, if needed.

I think initially, there was perspective that there were going to be some group programmes or some sort of skill-based stuff that our nurses were going to deliver; at least, that was the sense that we had from the protocol, and that involved trying to increase quitting cigarettes and various other things to do with diets and blah, blah, blah. We just had no capacity to deliver things like that, and what's more, I felt that by providing something that was only very time-limited, not only in terms of how often it could be delivered, but once the trial was finished, it disappeared, it would be better to engage participants with services that were already out there so they would be able to continue with that. And the reality is even those are transient, so they start, and then they peter out, so must be so frustrating for patients or service users to be on a path and then suddenly they're not doing that anymore as funding is removed or there's a different focus on care or — it's just like the wind blows I think if you're in that situation [T3, post-trial interview].

Care continuity: The perceptions gained from the trial nurses were that mental health staff in the community mental health teams were highly overworked. They would therefore be unlikely to have the time to deliver a programme like this that would need one-to-one attention for up to one hour every fortnight or at least every month, and ideally by a consistent provider of contact and support. But, the rapport between the service user participants and trial nurses was identified as one of the critical mechanisms that helped attain some of the trial's success. MH staff might struggle to establish this much-needed rapport due to high staff turnover. As such, it might be not easy to fully implement the trial as part of the MH system's routine care or sustain the programme's benefits once delivered.

A: There are actually guidelines that actually talk about all of this now, there's more guidelines around physical health of people with mental illness in the mental health system, and it's ... talk about the GP's role and all that sort of stuff, so the College of GP's or, and the mental health service national guideline, national standards, there's a whole thing on physical health for the mental health service, so yeah, it's written down there, and there's always the government or College of Psychiatrists will be saying, this is one of our main priorities, and this is how you should do it, but we know that it's really hard to get our clinicians to actually do it. Q: And is it because of the time and ... A: Yeah, they'd say time and stuff like that. Yeah, that's really good, yep. I think that's correct ... So then you've got these other general issues for the staff if they're feeling insecure and all of that, and they're less focused on these other things like health promotion [T7, post-trial interview].

6.4 Trial team's perceptions of the Flinders Programme

This study found that with time, rapport, and quality care, service users with CVD risk factors engaged well in the Flinders Programme. The changes were often noted as small and therefore unacknowledged or seen by others as insignificant ('invisible'), such as changes in the person's motivation or awareness. But the trial staff suggested that even such small changes were noteworthy for this population group.

This study also underwent many adaptations, such as shortened questionnaires and flexibility in how and where trial nurses saw participants. The six-month-long care planning programme was also deemed insufficient for this target group. The trial nurses suggested regular follow-ups with the participants once the programme had finished. They perceived that adults with SMI might require longer time-frames to trust the 'service' and build rapport with its staff.

Some clinicians demonstrated preconceptions regarding the success of such self-management behavioural change programmes. This is most likely because psychiatry has historically followed the illness model up to the present day. The trial team, however, was hopeful that with proper resources, trained staff, and a healthy work atmosphere, it was possible to initiate and sustain the Flinders Programme within a community mental health clinic setting.

6.5 Chapter summary

This chapter described the delivery steps of the Flinders Programme within a few South Australian metropolitan mental health clinics between November 2017 and February 2021 from the perspectives of trial staff. The trial team needed help in fulfilling the recruitment target for the trial. A few critical reasons were identified: the South Australian community mental health system underwent

a significant restructuring at the time of the recruitment for the trial, resulting in enormous workload increases in an already resource-scarce sector. Work atmosphere and politics had a direct negative effect on the trial. Besides, *improving the cardiovascular health of SMI* was not deemed a priority in a system that needed help to deal with acute mentally-ill patients within a crisis-driven system. Most sites required more precise communication from the trial team both before recruitment and throughout the trial period. In future, more preparation, including information and education sessions among clinicians, will be required before delivering such physical health interventions within mental health settings.

CHAPTER SEVEN: DATA TRIANGULATION

7.1 Chapter purpose and structure

Chapter Seven, 'Data Triangulation', collates and synthesises the key findings of the previous results chapters where the perceptions of key stakeholders (service users – Chapter Three, caregivers – Chapter Four, health professionals – Chapter Five, and trial team members - Chapter Six) have been captured on the Flinders Programme, within the context of broader socio-environmental settings. Through a person-centred care plan, the Flinders Programme aimed to improve cardiovascular health and quality of life of community-living adults with severe mental illness (SMI). This chapter integrates the feedback of all key stakeholders to understand their respective roles within supported self-management care.

This chapter fulfilled study objective three: data triangulation of objective one (exploring service user, caregiver, and health professionals' views on the Flinders Programme), and objective two (exploring perspectives of trial team members to understand why and how the Flinders Programme worked or not). Triangulation enabled the revision of the key themes and sub-themes, proposing a refined set of Initial Programme Theories (IPTs) to identify stakeholders' roles in self-management that were initially generated from each result chapter's key findings.

The following sections first describe the chapter methods (7.2). The findings are presented in Part-A: data triangulation (7.3) and Part-B: a longitudinal analysis of key findings (7.4). Finally, the chapter ends with a summary of conclusions (7.5).

7.2 Methods

This thesis collected data from 15 service users (Chapter Three), 4 matched caregivers (Chapter Four), 10 matched health professionals (Chapter Five), and 19 trial team members (Chapter Six) at multiple time points (total study participants = 48). Data were gathered through 61 interviews (31 service users, 7 caregivers, 13 health professionals, and 7 trial team member interviews), 2 focus group discussions (involving 4-8 trial team members), 10 series of meeting minutes (involving 8-12 trial team members), 5 trial team members' reflective journals (including the researcher's), and 8 service users' Flinders Programme care plans (7 service users dropped out of the larger trial after their initial interviews).

As explained in Chapter Two: Methodology and methods, this thesis employed a four-step analysis approach. This current chapter employed step 3, which involved data triangulation, and part of step 4: longitudinal analysis (highlighted in red fonts within Figure 11).

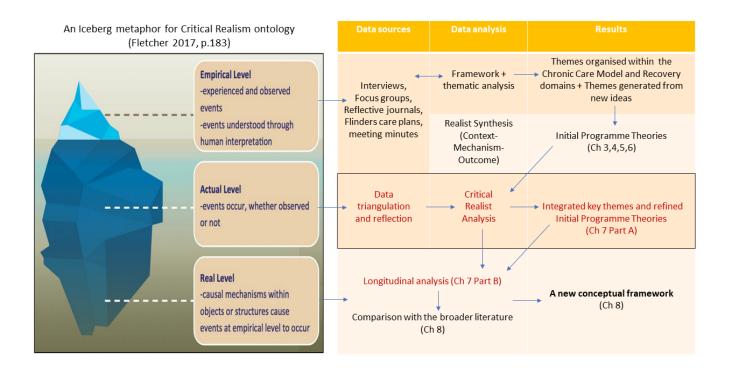


Figure 11: Data triangulation of key findings based on Critical Realist and Longitudinal analysis (The image 'Iceberg metaphor for Critical Realism ontology', Fletcher 2017, p.183 has been reproduced with the publisher's permission).

7.2.1 Data Triangulation

Earlier in the thesis, each results chapter (Chapters Three, Four, Five, and Six) explored perceptions of different stakeholders on the same topic: 'experiences of Flinders Programme within the broader socio-environmental context'. Each results chapter followed the same data analysis method, and related outcomes were presented similarly to maintain consistency (Figure 11), and to compile and compare them later. Consequently, this chapter used the qualitative data triangulation method, as described by Carter, Bryant-Lukosius, DiCenso, Blythe, and Neville (2014), to integrate and synthesise all the findings from the previous results chapters. The data triangulation process involved two significant steps: the first combined key themes and sub-themes and revised them, and the second refined the IPTs. The convergence of information gathered from different stakeholders using different methods helped with an understanding of the research problem and validating the key findings. This process also helped to identify the root causes of many issues (e.g., why service users

do not engage with the mental health system, and why mental health professionals do not deliver physical health care within their role).

Step 1 of data triangulation - Critical Realist Analysis: As part of the first step of the data triangulation method, a Critical Realist Analysis (CRA) approach was used (Archer et al., 1998; Danermark et al., 1997), which is underpinned by Roy Bhaskar's philosophy and ontology of Critical Realism (Bhaskar, 1989; Clark et al., 2008). Critical Realism asserts the importance of identifying factors within a broader socio-environmental context ('real' world) that trigger changes at the 'actual' level to generate outcomes at the 'empirical' level (see Figure 11).

As part of the CRA, two analytical tools were used towards developing a new conceptual framework - abduction (theoretical re-description by analysing data that did not fit original theoretical assumptions) and retroduction (interpreting findings generated through the abduction process, in the aspect of current social realities) (Fletcher, 2017; Meyer & Lunnay, 2013). Abduction and retroduction are complementary CRA tools that require constant movement between data collection (fieldwork) and theory-driven data analysis and interpretation (desk work), resulting in theory refinement and redevelopment if required (Belfrage & Hauf, 2017; Meyer & Lunnay, 2013). Under the abduction process, ideas not covered by the Chronic Care Model (CCM) premise in the previous results chapters were identified and further explored. The Wagner (1998) CCM is the underpinning model of the Flinders Programme and was used as the structure for the framework analysis (Figure 11, step 1). Next, retroduction helped to make sense of the overall outcomes by identifying the socioenvironmental factors that explained the additional ideas captured by the abduction process. This detailed analysis process intended to propose a new conceptual framework (presented in Chapter Eight) that would better suit the self-management and recovery needs of individuals living in the community with SMI and CVD risk factors.

Step 2 of data triangulation – Realist Synthesis: The earlier results chapters (Chapters Three, Four, Five, and Six) employed the Realist Synthesis analytical method to unpack the Context-Mechanism-Outcome (CMO) configurations of the key findings and proposed some Initial Programme Theories/IPTs (Pawson et al., 2004) (Figure 11, step 2). Realist Synthesis is also underpinned by the philosophy and ontology of Critical Realism (Bhaskar, 1989; Clark et al., 2008). In this chapter, the initially proposed IPTs in the earlier results chapters were first consolidated and then further synthesised and refined to present a holistic understanding of the problem. In the process, it was discovered that a final health intervention outcome could have gone through various stages of change (Mukumbang et al., 2020). As such, in the final IPTs presented in this chapter, the results are displayed as immediate (Imm-O), intermediate (Int-O), and long-term outcomes (L-O). These detailed IPTs will help future health professionals and researchers identify underlying causes that could be addressed through delivering the Flinders Programme or similar health interventions to produce intended outcomes by employing a more targeted approach.

7.2.2 Longitudinal analysis

In addition to CRA-based data triangulation, this chapter also reports on the researcher's conduct of the longitudinal qualitative analysis. Data were collected at multiple time points from the same stakeholder over 2.5 years (November 2017 to September 2020). Longitudinal qualitative research is an emerging methodology in health behaviour research that concedes that time and change are contextual (Tuthill et al., 2020). This unique analytical approach acknowledges that human situations and experiences are different at different times, which can significantly impact one's behaviours and lifestyle depending on the situation. Participant experiences captured over an extended period allow a better understanding of the critical factors that facilitate or hinder one's engagement and adherence to a behavioural change intervention. A longitudinal qualitative data analysis approach achieves this by identifying the transition points (contexts) and related factors (mechanisms) that initiate changes, which are otherwise difficult to gather through single-point data collection. Additionally, the longitudinal qualitative analysis incorporates a reflective approach where the researcher observes change (reflective journal based on field observations and overall study experience) and is considered a vehicle for understanding and interpreting data (Tuthill et al., 2020). For this chapter, Saldaña's (2003) guidelines were employed with a set of 16 questions helping to answer critical questions such as, when changes occur through time, what increases or emerges through time, which changes interrelate through time, who are change agents through time, and so on. The complete set of questions and the related findings are presented in section 7.4.

Throughout data triangulation and the longitudinal analysis, the researcher's reflective journal and overall study experience significantly explained these data. Critical realism philosophy (Bhaskar, 1979, 2014) further forced the researcher to delve into socio-political constructs that shape human behaviours and their interactions, and thus, to unpack the underlying mechanisms that triggered events or behaviours to generate outcomes. This complex and layered data analysis helped to identify broader socio-environmental factors that could improve the future outcomes of the Flinders Programme in improving the self-management behaviours of community-living adults with SMI and CVD risk factors.

Part A

7.3 Data Triangulation: Refined key themes and Initial Programme Theories (IPTs)

This chapter presents four key themes based on data triangulation: i) Service users as 'active citizens', ii) Caregivers: promote recovery, iii) Positive Health Environment: deliver respectful and recovery-oriented care, and iv) Community: promote socio-economic security and social justice. Next, integrated, synthesised, and refined sub-themes and IPTs from the previous results chapters

(Chapters Three, Four, Five, and Six) are presented within key themes and sub-themes. The findings helped define the roles of four key stakeholders within self-management and recovery care: service users, caregivers, health professionals, and community members or organisations.

7.3.1 Service users as 'active citizens'

The integrated and revised findings of the previous results chapters that focused on stakeholders' perceptions of service users' roles within self-management identified four key factors that helped to improve their self-management behaviours: a) Role acceptance in self-management, b) Preparation and sustainability, c) Resilience and positive attitude, and d) Pets promote companionship and a healthy lifestyle.

- a) Role acceptance in self-management: Overall, the findings of this thesis suggest that the SA health system (involving both mental and physical health services) for delivering care does not actively incorporate service users' treatment choices and health priorities in their care plans. Within this context, service users are more familiar with accepting care as 'passive' recipients, whereas health professionals employ a more directive approach. Consequently, service users of the larger Flinders Programme trial took time to fully engage in their care plans and embrace their active decision-making roles; the trial nurses also verified this finding. The integrated findings suggested that the one-to-one mentoring promoted service users' trust in the health system and boosted their confidence in self-management. The Flinders Programme also encouraged them to set their health and social goals. This personcentred approach and a written care plan provided a sense of commitment and ownership, and activated service users in self-management behaviours. Overall, this process of the Flinders Programme empowered service users by encouraging them to actively participate in their health care plan.
- b) Preparation and sustainability: Three factors were identified that helped service users to prepare better and sustain self-management behaviours. First, 'information and education: key findings' suggested that a well-informed and educated service user holds an advantageous position in discussing their health needs with their health professionals. They are generally more confident in their communication, which empowers them to engage in their care plan. Second, 'training and strategies': a common characteristic among service users who generally managed their health well was that most of them went through self-management or rehabilitation training at some stage in their lives. Third, 'tools to keep organised': adults with SMI and CVD risk factors were often dealing with cognitive impairments, memory loss, and poor organisational skills. The findings identified that simple self-management tools such as written care plans, appointment diaries, calendars, and

setting reminders on their phone could help service users improve their organisational skills. Self-care education, self-management training, and organising tools also sustain healthy lifestyles and behaviours. For instance, Flinders Programme written care plans and health education materials (e.g., on diet, smoking) provided by trial nurses were regarded as helpful by participants.

- c) Resilience and positive attitude: Due to self and social stigma, service users often endure social isolation and loneliness. The combination of two severe illnesses (SMI and CVD) made this situation even more challenging. But, despite experiencing such hardships in life, some service users demonstrated incredible resilience. They were self-motivated and held a positive outlook on life. Such encouraging attitudes helped them adhere to self-care and self-management behaviours within the Flinders Programme intervention.
- d) Pets promote companionship and a healthy lifestyle: Having a pet was regarded as another protective factor in maintaining a healthy lifestyle (e.g., dogs need walking). One caregiver bought a kitten for her younger brother (a service user) and explained that passive smoking harmed the kitten; the service user eventually quit smoking. Besides, many service users and caregivers revealed their pets were one of the critical sources of positivity and companionship, mainly when the service user lived alone. These findings confirmed the value of pets as providing unconditional positive regard and alleviating social isolation and loneliness. Thus, pets often helped Flinders Programme participants adhere to their health goals.

Table 28 summarises the above findings and highlights the mechanisms within IPTs that can help service users activate, engage, and adhere to their self-management journey.

Table 28: Role of service user in self-management and recovery

Service users as 'active citizens'

Integrated themes		Refined Initial Programme Theories		
Role acceptance in self- management			Access to an affordable one-to-one mentoring approach (R) can promote rapport (M) and resulting trust (Imm-O). This helps service users to better engage in their care plan (Int-O) towards self-management (L-O) A written care plan signed by participant (R) generates commitment (M) that gives a sense of ownership (Imm-O) and activates service users (Int-O) in self-care (L-O)	
Preparation & sustainability	Information and education	When the service user is motivated and wants to improve their self-management behaviours (C),	A well-informed and educated service user (R) has more awareness and confidence (M) to communicate more effectively with their health professionals (Imm-O). This empowers service user (Int-O) and helps them to contribute towards their treatment plan (L-O) actively	
	Training and strategies	gonavious (o),	Self-management training, strategies, and related study materials (R) can improve self-management skills (M) and self-efficacy (Imm-O) to initiate healthy lifestyles (Int-O). Revisiting the study materials as needed (R) can sustain self-management behaviours (L-O)	
	Tools to keep organised	When the service user experiences difficulty with cognitive, living or organisational skills in their daily life (C),	Access to self-management tools, such as a written care plan, diary, and calendar (R), can improve organisational skills (M). This can improve self-care (Imm-O) and self-management skills (Int-O) and help service users adhere to health goals (L-O)	
Resilience and positive attitude		In the context of	Resilience (R) enhances positivity (M) that motivates (Imm-O) service user to adhere (Int-O) in self-care and self-management (L-O)	
Pets promote companionship and a healthy lifestyle		social isolation and loneliness (C),	Having pets (R) provide companionship (M) that reduce loneliness (Imm-O). Pets also offer a sense of responsibility (Int-O) towards a healthier lifestyle (L-O)	

C=Context, R=Resource, M=Mechanism, Imm-O=Immediate Outcome, Int-O=Intermediate Outcome, L-O=Long-term Outcome

7.3.2 Caregivers: promote recovery

The findings revealed a family caregiver's vital role in the service user's self-management and recovery journey. All stakeholders, especially service users, acknowledged this aspect of care with the highest regard. Through data triangulation, this chapter identified five critical roles that caregivers play in supporting service users in managing their SMI and CVD risk factors: a) Promoting recovery, b) Positive and extended 'parenting' (nurturing), c) Promoting self-care, d) Practical support, and e) Negotiation with health professionals.

a) *Promoting recovery*: A family member can provide unique and inimitable emotional support. The familial connection is an essential source of crucial recovery elements such as connectedness, hope, identity, meaning, and empowerment (Leamy et al., 2011). Data triangulation revealed that caregivers' unconditional love and emotional support provided

these recovery elements in service users' lives. Service users' roles and identities as family members motivated and activated them in Flinders Programme's self-management behaviours. Data revealed that in some situations, caregivers helped service users make decisions towards their care plan and other social activities by helping create space and respect for the service user's contribution to discussions with others; this conscious caregiving act empowered service users as their opinions were counted.

b) Positive and extended 'parenting' (lifelong nurturing): It was also found that parenting significantly impacted how service users sought health care and adhered to self-management skills. Showing confidence in service users' recovery ability, initiating self-management skills, and voicing encouragement were crucial facilitators. All stakeholders asserted the importance of ongoing positive parenting, revealing that it generated hope and motivation and boosted confidence in service users. The critical finding was that 'parenting' could ensue from non-parent family members as well – for instance, this thesis found that a caring older sister or wife also often actively played the role of a 'parent' (that is, unconditional emotional support, nurturing, assurance, guidance, and practical and financial supports), which positively impacted service users' overall health and emotional wellbeing. The importance of parenting and extended parenting (lifelong nurturing) as a focus of wellbeing and recovery was also affirmed by other stakeholders such as health professionals and the trial nurses; the broader literature also supports this notion (Reupert, Price-Robertson, & Maybery, 2017; Sanders, Kirby, Tellegen, & Day, 2014).

While there is no doubt that having a supportive caregiver is highly beneficial for adults with SMI, a few health professionals were concerned that there was a potential for over-reliance on a caregiver. Health professionals explained that over-reliance could negatively impact the service user's recovery journey by creating a sense of co-dependence, especially when the service user was an offspring. The findings also suggested that the caregivers were sometimes challenged by the highly demanding nature of the role. For instance, caregivers were recorded as providing a combination of emotional (e.g., love, attention, encouragement), practical (e.g., helping with self-care, doing chores, taking to appointments), or financial support (paying for healthy food, gym membership, arranging formal caregiving support at times, private treatments). All caregivers said they sometimes felt overwhelmed by fulfilling all these constant needs. Hence, health professionals and Flinders Programme trial team members suggested that caregivers should set some boundaries from the risk of overburdening themselves and promote independence in service users. The health and community policies and related systems can also do more to support caregivers' emotional, psychosocial, and practical needs; Chapter Eight will discuss this further.

c) Promoting self-care: The results found that a good time to set boundaries was when service users were mentally stable (e.g., not going through any major crisis, relapses, or hospitalisations). The findings suggested that through close observation and being aware of service users' daily activities while at the same time encouraging independent actions, helped build self-care skills.

During the implementation of the Flinders Programme, it was evident that family members could provide healthy lifestyle support via multiple pathways. For instance, family caregivers voiced encouragement, supported and monitored lifestyle change progress (e.g., reducing smoking), and provided financial support to ensure access to health amenities (e.g., gym membership, healthy food, alternate treatment options). But the most effective strategy was when caregivers enthusiastically adopted healthier habits alongside service users. The Flinders Programme trial nurses also acknowledged caregivers' roles in the care plan, and where caregivers expressed interest, actively engaged service users in the process. This 'walking alongside' approach improved both parties' health outcomes (e.g., improved diet, more exercise). Service users' achievements generated hope in both parties and encouraged them to become more involved in achieving new health goals. This overall process and the positive health outcomes were deemed to have improved the mutual service user-caregiver relationship.

- d) *Practical support*: It was evident that dealing with two severe health conditions, SMI and CVD risk factors, was challenging for both service users and their caregivers, especially when service users experienced any significant setbacks (e.g., mental health deterioration, hospitalisation, injuries, or a personal or family crisis). The practical support that caregivers provided was crucial in such situations. For instance, caregivers helped with self-care and daily chores, took service users to medical appointments, ensured treatment adherence, or helped them navigate the health system by explaining health information. Receiving such support during a crisis helped service users better cope with the situation and prevented any significant relapses.
- e) Negotiating with the health professionals: A key finding of this thesis indicated that, to date, psychiatry implied medication-based care, often without considering the treatment choices of service users or their caregivers. All service users acknowledged the benefit of having medications, but requested a dose review every now and then due to their side-effects, such as feeling lethargic, problems with metabolism, obesity, and consequent inability to get on with a healthy lifestyle due to lack of energy and motivation. It was found that caregivers often played a crucial role in negotiating medication dose reviews and other treatment plans with health professionals. Service users commented that such positive outcomes helped them get on with life and motivated them to engage in a healthier lifestyle (e.g., the Flinders

Programme health goals). Table 29 below summarises these key findings and presents the related IPTs.

Table 29: Role of caregiver in self-management and recovery

Caregivers: source of recovery

Connectedness, identity, and meaning Under all circumstances (that is, whether the service user is mentally stable or not, and whether they possess sufficient self-management Skills or not) (C), Showing confidence and voicing encouragement Risk of co- Parents' (especially mothers') i	Refined Initial Programme Theories		
Connectedness, identity, and meaning Under all circumstances (that is, whether the service user is mentally stable or not, and whether they possess sufficient self-management skills or not) (C), Connectedness (M) that help communal, and social identity and purpose in life (Int-O) that not (L-O) Caregivers can help navigate the (R) by helping the person under the preferred health choices (Imm-0 activated within their treatment skills or not) (C), Parents' belief in children's ability and purpose in life (Int-O) that not not (L-O) Caregivers can help navigate the (R) by helping the person under the preferred health choices (Imm-0 activated within their treatment skills or not) (C),	ional support (R) provides hope and generates positivity (Imm-O) and d adhere to a healthy lifestyle (L-O)		
Empowerment Empowerment Showing mentally stable or not, and whether they possess sufficient self-management skills or not) (C), Parents' belief in children's ability for not in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices (Imm-to activated within their treatment in the preferred health choices).	ional support (R) provides essential is to build and maintain personal, (Imm-O). Identity creates meaning motivates towards a healthy lifestyle		
Showing The fater is belief in children's ability	ne health and administrative system derstand health information (M). rvice users make decisions towards O) and empower them (Int-O) to be plan (L-O)		
Risk of co-Parents' (especially mothers') i	ty to self-care (R) can promote self - nfidence (Imm-O) in service users. ionship enhances motivation (Int-O) plan (L-O)		
dependence and over-reliance practical support (R) can cre negatively impact the ability of independence (Int-O) and self-co	intense and ongoing emotional and eate over-reliance (M). This can f decision-making (Imm-O), hinder care skills (L-O)		
to set more explicit boundaries	outines and have more dialogue (R) (M). This will improve accountability endent actions (Int-O) towards self-		
	time (R), both parties are motivated ne goal together (M). Such actions) that increase hope and motivation s improve their relationship (L-O)		
organisational skills daily self-care needs (Imm-O)	(R) can help better cope (M) with the cope to prevent any severe ate the recovery process (L-O)		
health professionals coerced care (C), service users to have prefer improves service user's motive	with health professionals (R) allow red treatment options (M). This ation (Imm-O), engagement (Int-O) activation (L-O) in care		

C=Context, R=Resource, M=Mechanism, Imm-O=Immediate Outcome, Int-O=Intermediate Outcome, L-O=Long-term Outcome

7.3.3 Positive Health Environment: deliver respectful and recovery-oriented care

Based on data triangulation of stakeholder views on the health system and its ability to support workers' desired roles towards self-management and recovery care, this section proposes four revised key themes to initiate a positive health environment in community mental health settings: a) Organisational support towards person-centred care, b) Respectful, fair, and coordinated delivery system design, c) Decision support to promote recovery-oriented care, and d) Accessible and up-to-date clinical information systems. These four domains are the adapted and extended version of the CCM (Wagner, 1998), suitable for adults with SMI with other chronic conditions.

a) Organisational support towards person-centred care: Data triangulation indicated that the mental health system, especially psychiatry, held a paternalistic view on care where service users had a minimal voice in treatment choices. Service users disclosed that they were often not listened to, or not actively encouraged to achieve their health goals. Data triangulation revealed that mental health professionals relied heavily on a treatment approach known as 'risk assessment' that recorded service users' case histories and past health behaviours, which (consciously or unconsciously) might have influenced health professionals' present-day decisions and related actions. As such, most health professionals had some preconceived ideas regarding service users' ability to recover and self-manage. Being a person-centred approach, however, the Flinders Programme's written care plan encouraged service users to express their health needs and choose related lifestyle change actions. This process motivated, empowered, and activated service users in self-management behaviours. These findings suggest that the mental health system requires a paradigm shift from paternalistic care towards a person-centred approach to ensure service user empowerment.

The other key finding was that a significant funding crisis throughout the SA community mental health system caused multiple problems. First, the overall mental health system reluctantly shifted towards a risk-averse medical model (heavy reliance on medications) in contrast to recovery-oriented care and health promotion (focusing on behavioural change); staff perceived that the latter approach needed far more time and individualised attention. Many health staff confirmed the validity of the finding that cost-cutting health promotional programmes occurred as a consequence of the funding crisis and subsequent policy reforms. While service users highly valued the medications, they periodically requested dose reviews due to their side-effects. Service users explained that despite Clozapine (an oral anti-psychotic medication) being more effective than other anti-psychotic medications delivered via Depot (an injection), the heavier dosages of both anti-psychotic medications often caused drowsiness, drooling, soreness (in the Depot injected body part), numbness, constipation, and obesity due to slowed metabolism. Most importantly, Clozapine is recorded as a direct risk factor for myocarditis, as was also confirmed by the health professionals. Some service users also expressed discomfort and shame as Depot was injected in their buttocks (this location is preferred due to the muscularity of the area along with fewer blood vessels, making

it a safer place for injection). All these factors negatively impacted service users' motivation and ability to self-manage- while they took part in the Flinders Programme.

The mental health system funding crisis was also perceived as causing internal power and political tensions within the services. Data triangulation revealed professional 'competition' within and between different health sectors involving community mental health clinics of other regions. rehabilitation centres, Supported Residential Facilities (SRFs), primary health care providers, and Non-Government Organisations (NGOs) over securing funding. The current findings also suggested that some health professionals from some disciplines had more authority and 'voice' in the service user's overall health care plan (e.g., psychiatry), causing dissatisfaction and frustration among other stakeholders, including their colleagues in other disciplines (e.g., mental health nurses, community rehabilitation workers). Such exercise of power seemed to generate an influx of top-down approaches causing change fatigue among staff who were already constrained by limited time, resources, and job insecurity. Some team members and health professionals explained that there was also resource mismanagement among different health sectors that often (unwillingly) ended up 'double benefitting' those service users who showed better health outcomes (as positive results generated funding). The more vulnerable people fell through the gaps. These findings indicate the need to ensure a favourable political environment in the health system where staff within, and between, sectors will be more respectful towards each other, work collaboratively, and ensure that all service users receive the best treatment possible. Marmot (2022a) explains that the health system cannot escape politics if it wants to achieve health equity; in fact, constructive politics can assist to reform policies and initiate much-needed change. Table 30 below provides a snapshot of the findings, and presents the related IPTs.

Table 30: Role of health system in self-management and recovery: *Organisational support towards* person-centred care

Organisational support towards well-funded person-centred care			
Integrated themes	Refined Initial Programme Theories		
Discarding preconceived ideas		A commonly used approach in mental health treatment called 'Risk assessment' (R) is focused on the service user's case history (M), which often perpetuates preconceived ideas (Imm-O). Consequently, mental health staff hold minimum hope and enthusiasm (Int-O) that service users can change their past habits and adopt a healthier lifestyle (L-O)	
Ensuring service- user voice in treatment choice	In the context of a paternalistic model of care (C),	A person-centred written and flexible care plan (R) provides a sense of ownership (M) that empowers service users (Imm-O) towards treatment choices (Int-O) and activates them in self-management (L-O)	
Preventing iatrogenic trauma		The mental health system primarily relies on a risk-averse medical model (R) where service users often experience side-effects of antipsychotic medications (M) causing iatrogenic trauma (Imm-O), which can limit service users' ability to engage (Int-O) in self-management activities (L-O)	

Positive political environment	In the context of limited resources and time (C),	To secure funding (R), there was politics within and between different health sectors (M). This resulted in an influx of top-down approaches in the system (Imm-O) that caused change fatigue in staff (Int-O), hampering the quality of care (L-O)
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C=Context, R=Resource, M=Mechanism, Imm-O=Immediate Outcome, Int-O=Intermediate Outcome, L-O=Long-term Outcome

b) Respectful, fair, and coordinated delivery system design: Showing respect towards the service user's health priorities and choices is a positive step towards delivering person-centred care. As per the collated thesis findings, this aspect of providing respectful care seemed largely missing from the health settings. However, service users and caregivers acknowledged that the Flinders Programme trial nurses were empathetic and respectful, and diligently worked to support service users in achieving their health goals. Being a one-to-one programme helped to build rapport between service users and trial nurses, which promoted hope and trust. The initial assessments addressing psychosocial and environmental needs, motivational interview techniques, written care plans, and regular follow-ups further helped to motivate and activate service users in their care. Both service users and caregivers appreciated these aspects of care: respectful, empathetic, one-to-one, and active follow-ups, demonstrating their efficacy.

The other major drawback of the health system was a need for improved coordination and a more collaborative approach within and between the different health sectors. This situation negatively impacted service users' health-seeking experiences as they and their caregivers struggled to navigate the health system to get appropriate treatment on time. The Flinders Programme's written care plan was deemed to improve coordination among stakeholders such as the service user's mental health care coordinator, GP, and even their caregiver, which all stakeholders reported to be beneficial.

Discrimination and paternalistic care constitute other harmful attributes of the health system. Data triangulation identified that some service users experienced poor quality of care in different health sectors (e.g., support workers not following the care plan, GPs and psychiatrists not considering the health choices of service users and caregivers). Most service users, as such, were initially reluctant to share their Flinders care plans with their respective health professionals; the trial nurses also verified this finding. There was also evidence of some service users being excluded by the mental health system even though they expressed deterioration in their mental health and requested help. Service users diagnosed with Borderline Personality Disorder (BPD) and those vocal about their health needs were perceived to experience more care discrimination; health professionals often referred to them as 'difficult' or 'not a real service user'.

Regarding adopting a collaborative approach, support workers were crucial in providing practical support to service users. The process reached maximum health optimisation when the different

health sectors' care plans were amalgamated, and their priorities aligned with the Flinders Programme. The trial team, however, advised that the workforce required further training in developing their interpersonal skills towards implementing person-centred care. Overall, the findings of this thesis suggested that the mental health workforce would benefit from interpersonal and interprofessional training to improve their communication and care planning skills. Table 31 below presents the integrated themes and related IPTs on the topic.

Table 31: Role of health system in self-management and recovery: Respectful, fair, and coordinated delivery system design

Respectful, fair, and coordinated delivery system design			
Integrated themes		Refined Initial Programme Theories	
Empathetic and respectful care	In the context of mental health service culture and power (C),	Training to improve interpersonal skills (R) can enhance staff's empathy and respect towards all stakeholders (M). This will ensure all key stakeholders have a voice in the treatment plan (Imm-O), which will motivate them (Int-O) to engage in the self-management process (L-O)	
One-to-one programme to build rapport	In the context of service user's mistrust towards the health system (C),	One-to-one motivational interviewing (R) can promote rapport and trust (M) that can enhance motivation (Imm-O) and improves service user activation (Int-O) in self-management (L-O)	
	In the context of the side- effects of antipsychotics (C),	Clozapine (an oral medication) is highly regarded as an effective drug by service users and staff (R). However, it is a direct risk factor of cardiovascular disease (M) that compels (Imm-O) health professionals to actively monitor the side-effects of Clozapine. This system prevents death (L-O)	
Active (but flexible) follow-ups	In the context of acute illness and related intense health care needs (C),	Ongoing (but flexible) follow-ups through a written care plan (R) can promote accountability (M) and track the progress of the self-management journey (Imm-O). This process keeps service users engaged in their care plan (Int-O) and ensures adherence to self-management (L-O)	
	In the context of fragmented mental health	Clear guidelines are needed (R) to clarify health professionals' roles (M) in identifying (Imm-O) and addressing service users' physical health needs (Int-O). This will optimise health outcomes (L-O)	
Coordinated care	and physical health care systems (C),	A written care plan (R) can improve coordination within and between services (M). This will enhance service collaboration (Imm-O), meet service users' health needs (Int-O), and maximise health resources (L-O)	
Promote fairness	In the context of discrimination and	If a service user has been or is uncooperative (M) with the mental health system in complying with the treatment plan (R), they can often experience care discrimination (Imm-O). This can exclude them from the service (Int-O) and negatively impact their health outcomes (L-O)	
Trained workforce	patriarchal care (C),	When staff are well trained in recovery-oriented care (R), they can identify (M) and fulfil service user health needs (Imm-O). This process can enhance rapport (Int-O) and trust (L-O)	

C=Context, R=Resource, M=Mechanism, Imm-O=Immediate Outcome, Int-O=Intermediate Outcome, L-O=Long-term Outcome

c) Decision support to promote recovery-oriented care: The results showed that a significant issue with the mental health system was its lack of recovery-oriented care; even mental health professionals were disappointed. Mental health staff explained that they could not provide quality care due to time and resource constraints. All stakeholders desired more focus and time for health promotion and recovery-oriented maintenance from the mental health system.

Service users and caregivers also wanted mental health staff to actively promote healthy lifestyles towards improved physical health. The findings suggested that mental health staff were better trained, more confident, and more comfortable dealing with adults with SMI than GPs or primary care nurses. Hence, they were ideally situated to the promotion of lifestyle change in service users to improve their heart health. However, the trial nurses explained that mental health staff would need to consider the Flinders Programme (or similar health promotion interventions) to be effective and, more importantly, believe in service users' capacity to change their health behaviours.

The findings suggested that access to psychosocial supports such as healthy cooking classes, career support consultancy, and self-management skills training were essential for health promotion and recovery. Service users reported emotional, physical, and practical benefits from learning important self-care and living skills. Service users from site D (urban community mental health clinic, Central) seemed more connected with such services than site A (urban community mental health clinic, South). Data triangulation identified site D to be more proactive in health promotional interventions among their service users. Trial team members who had knowledge of both sites also advised that site D service users were better connected with psychosocial supports through the system, which helped them to uptake and sustain self-management behaviours beyond routine health care.

While most of the mental health staff interviewed as part of this thesis admitted that the mental health system should promote more recovery-oriented care, they were concerned about the potential added workload. It was evident from data triangulation that mental health staff were very overworked and were dealing with change fatigue and job insecurity. All these negatively impacted the way they delivered care. Some health staff reported that the higher authorities and management initiated new policies and services every now and then without considering or discussing them with the clinical care delivery teams (e.g., the 2018 structural reform of the SA community mental health system). According to the staff, most of these new policies only created more paperwork and had a minimal meaningful impact on change towards improved health services.

Additionally, staff had to deal with vicarious trauma when service users (adults with SMI) went through difficult phases. All these findings suggest that staff need a better, more supportive work

environment to provide quality care to service users. Table 32 below presents the integrated themes and related IPTs discussed in this section.

Table 32: Role of health system in self-management and recovery: *Decision support to promote recovery-oriented care*

Decision support to promote recovery-oriented care			
Integrated themes	Refined Initial Programme Theories		
Adopt recovery- oriented care		Mental health services should promote recovery-oriented care (R), underpinned by a person-centred approach (M), which focuses on socia inclusion (Imm-O) towards a meaningful life (Int-O). This process activates service users in their self-care (L-O)	
Active promotion of a healthy lifestyle	In the context of limited resources and time (C),	Mental health staff are well-trained to deal with people with SMI (R). So, they will likely be more comfortable and confident than other health practitioners (M) in promoting a healthy lifestyle (Imm-O). This whole-person approach can motivate service users towards recovery (Int-O) and improve their engagement in the treatment plan (L-O)	
Connect with psychosocial supports		Connecting service users with appropriate psychosocial supports (R) can motivate (M) them towards a meaningful life (M). Such services can improve social cohesion (Imm-O), reduce loneliness (Int-O), and improve self-management skills (L-O)	
Ensuring a positive work environment		An influx of top-down approaches (R) causes change fatigue in staff (M). Consequently, staff enthusiasm decreases (Imm-O) and work quality is negatively impacted (Int-O), hampering service users' health outcomes (L-O)	

C=Context, R=Resource, M=Mechanism, Imm-O=Immediate Outcome, Int-O=Intermediate Outcome, L-O=Long-term Outcome

d) Accessible and up-to-date clinical information systems: The overall findings indicated that adults with SMI and CVD risk factors had to undergo intense, ongoing treatments to manage their overall health and wellbeing. The severity of their illness and the related health management required them to access multiple health care providers across different health services. But many service users and their caregivers reported that they did not have an up-to-date copy of the service user's regular mental or physical health care plans. Some of them also requested treatment results and regular feedback to check progress and ensure care coordination occurred among different health sectors. The Flinders Programme trial nurses regularly provided feedback to service users. They described that some service users sought their updated MH or PH care plans from their regular service providers after some encouragement. Caregivers played a significant role here in liaising with the service providers.

Some caregivers also revealed that they often needed to fill in the gaps regarding medications or treatment plans, as some health professionals were required to be made aware of any changes in the care plans created by their colleagues. Even health staff often expressed frustration about problems with care communication between service providers, saying that a

lack of a comprehensive, up-to-date database hampered their decision-making processes and increased the risk of unintended treatment errors. The trial team participants suggested that only a real-time, up-to-date, comprehensive shared database among all key health care providers could resolve this critical information system problem.

Service users and caregivers also expressed concerns regarding the diagnostic criteria of SMI (primarily based on subjective questionnaires). They explained that once diagnosed with an SMI, the service user experienced stigmatisation and a range of other health and social problems (e.g., obesity, demotivation, and lack of energy caused due to medication side-effects; housing and unemployment problems leading towards poverty). Hence, service users demanded that it be essential to use more scientific and evidence-based approaches to diagnose SMI and provide treatment. They explained that this would also support them in improving their treatment (i.e., medication) adherence. The following table (Table 33) displays the revised themes and related IPTs discussed above.

Table 33: Role of health system in self-management and recovery: Accessible and up-to-date clinical information systems

Accessible and up-to-date clinical information systems			
Integrated themes	Refined Initial Programme Theories		
Access to care plans and treatment results	In the context of fragmented mental health and physical health care systems (C),	Access to health information and treatment results (R) can improve trust in the health system (M) and make service users aware of their self-management needs (Imm-O). This can motivate and encourage service users (Int-O) to adopt a healthier lifestyle (L-O)	
Shared database		A shared database between the mental and physical health systems (R) can improve care coordination (M). This will help identify service users' physical health needs (Imm-O) and encourage all stakeholders (Int-O) to undertake related actions (L-O)	
Evidence-based diagnostic criteria	In the context of subjective clinical measures and diagnostic criteria (C),	Subjective measures to diagnose illness (R) lacked scientific evidence (M) that lacked credibility (lmm-O). More evidence- based care can improve diagnosis acceptance (Int-O) and hence, compliance with the treatment	

C=Context, R=Resource, M=Mechanism, Imm-O=Immediate Outcome, Int-O=Intermediate Outcome, L-O=Long-term Outcome

7.3.4 Community: promote socioeconomic security and social justice

More broadly, supported self-management and recovery models aim to help the person gain a greater sense of autonomy and self-efficacy and enhance their ability to manage their health and wellbeing in their communities. Based on data triangulation of the previous results chapters, this section presents four revised themes towards creating an inclusive community for adults with SMI: a) Social inclusion and cohesion, b) Socioeconomic security, c) Policy towards social justice, and d) Aligning of sectoral policies.

- 1. Social inclusion and cohesion: This thesis identified social stigma as a critical barrier to service users' access to necessary psychosocial support. Therefore, service users and caregivers appreciated organisations that understood their health needs and respected their choices (e.g., a welcoming small gym that provided personalised yet affordable care and was free of stigmatisation). Access to community organisations also provided social cohesion. For instance, being part of a religious organisation was recorded as beneficial by some service users and caregivers as it provided communal and social connectedness that reduced loneliness. These study participants explained that being religious also helped them to refrain from risky health behaviours such as self-harm, alcohol, and drug abuse, which are forbidden in most religions. Service users also reported benefits by accessing art, dance, or lawn bowls clubs. These supports were particularly useful for 'closed episode' service users (i.e., where they were no longer receiving services from the mental health system) and those alienated from family and friends.
- 2. Socioeconomic security: Due to the severity of their illnesses, most service users could not work (only 3 of the 15 service user study participants were employed part-time or held casual positions). Consequently, most participants experienced financial hardship. It is well-known that people with lower socio-economic status experience poorer health outcomes and require additional support to achieve health equity (Marmot, 2022b; Marmot, Friel, Bell, Houweling, & Taylor, 2008) compared with individuals with higher socio-economic status. Therefore, it is vital to ensure that adults with SMI are also given the opportunity to live a dignified life that includes financial security to support them to also achieve a sense of actively contributing to society and the economy.
- 3. Policy towards social justice: Two service users said they lost motivation to work as the pay was very low. Further probing revealed that their salary was controlled by the Office of the Public Trustee, which allowed only a nominal amount for spending (more exploration is required to clarify this matter). While the intention of Public Trustee regulations is good (to administer finances for individuals who cannot do so independently), even some health professionals admitted that the policy needed a revision to ensure that it did not disempower service users and violate their fundamental human rights and dignity.

Service users expressed dissatisfaction and frustration with the mental health and community systems' coerced health care policies. Out of the 15 service users, at least 10 had experienced a Community Treatment Order (CTO), forced hospitalisation (under the SA Mental Health Act 2009), or Public Trustee involvement at different stages of their illnesses. These service users revealed that, in most cases, either their health professionals (e.g., GP, counsellor) or family members' involvement with the mental health system without the service user's knowledge, consent, or any explanation, breached their trust in the system and these support providers. They all said that the participation of police in the forced hospitalisation, facing a tribunal under Public Trustee policies, and their nature of controlling finances, or

facing a mental health team/committee during assessment and diagnosis, meant that everything felt demeaning, disempowering, and often stigmatising. Three female participants were separated from their young children for days during hospitalisation and treatment, which caused separation anxiety. All participants described their experiences as traumatising, which led them to no longer trust the health system for fear of repercussions (e.g., not revealing suicidal thoughts to their health professionals or not seeking help even if severely depressed).

4. Aligning of sectoral policies: Adults with SMI and CVD risk factors are deemed by care systems as service users with high health risks and needs. As such, they usually access care from several health and community sectors as required. Some of these sector organisations include mental health clinics, primary care GPs, rehabilitation centres, SRFs, allied health, private health care services, non-government organisations (NGO), and community clubs or other organisations (e.g., gyms, sports clubs, religious institutions). Key findings showed that all these settings often had their care plans and mainly collected service user data in a silo. There needs to be more coordination and collaboration among all these health care providers to ensure there is an integrated care plan. This process will not only improve service users' health outcomes but will also prevent over- or under-utilisation of health services. The trial team members and health professionals explained that the overall system requires a better resource management policy to ensure all service users have access to all available care per their needs. Still, at the same time, there were no overlaps by receiving similar services from multiple sectors. A single routinely updated care plan can resolve this issue, and caregivers' inputs could be sought in preparing this comprehensive care plan (ADHA, 2023).

Table 34 below summarises this section and presents the related IPTs.

Table 34: Role of community in self-management and recovery

Integrated themes	Refined Initial Programme Theories		
		Social acceptability within the broader community (R) can reduce social stigma (M), create a communal and social identity (Imm-O), positively impact service users' health-seeking behaviour (Int-O), and motivate them towards recovery and self-management behaviours (L-O)	
Social inclusion and cohesion	In the context of	Access to welcoming and affordable health care and housing (R) can ensure social inclusion and connectedness (M). This will enhance health and social security (Imm-O) and encourage service users (Int-O) to adopt a healthier lifestyle within the community (L-O)	
Socioeconomic security	social stigma, disempowerment, and economic inequality (C),	Due to illness severity (and income inequity) (R), service users experience poverty (M) and resultant disempowerment (Imm-O). This negatively impacts the capacity (Int-O) to adopt a healthier lifestyle (L-O)	
		Re-orienting policies (e.g., Mental Health Act, CTO, PT) (R) that often cause trauma , mistrust , and disempowerment (M) can improve service users' acceptance of services offered by mental health services (Imm-O).	

Policy towards social justice		This will help them better engage (Int-O) with self-management behaviours (L-O)
Aligning of sectoral policies	In the context of the collaborative care approach (C),	To maximise resources and ensure affordable care (M), it is essential to amalgamate different organisational care plans (R). This will better engage relevant organisations (Imm-O), improve coordination and collaboration (Int-O), and optimise health outcomes (L-O)

C=Context, R=Resource, M=Mechanism, Imm-O=Immediate Outcome, Int-O=Intermediate Outcome, L-O=Long-term Outcome

Part B

7.4 Longitudinal analysis of key findings

Saldaña (2003) proposed a set of 16 framing questions to guide the longitudinal analysis. Data triangulation of the four results chapters (Chapters Three-Six) presented in the previous section (Part A, section 7.3), and five trial team members' reflective journals gathered over time (November 2017 to September 2020) helped answer some of these questions. Each framing question is presented below with 'answer' statements (A), followed by brief explanations for each answer.

7.4.1 Framing questions

1. What is different from one pond or pool of data to the next?

A: INCREASED TRUST TOWARDS THE RESEARCHER, AND HENCE, MORE OPENNESS IN SHARING EXPERIENCES

With time, study participants became comfortable with the researcher and shared more personal information and experiences, demonstrating trust. Reflective journals suggested that the trial nurses also had similar experiences with service users. Service users and their caregivers also mentioned that the trial team's genuine interest in service users' wellbeing and their respectful attitude made them feel valued. These findings confirm the value of empathetic and respectful person-centred care that promotes trust and engagement.

2. When do changes occur through time?

A: WHEN THE SERVICE USER IS FULLY ENGAGED AND RECEIVES KEY STAKEHOLDERS' SUPPORT CONSISTENTLY OVER TIME

Trial nurses explained that, although most service users were motivated and enjoyed the Flinders Programme care process, it took a lot of groundwork, constant reinforcement, and education to fully activate service users in their care plans. Trial nurses suggested this happened because service

users were accustomed to following care plans and advice provided by their health professionals rather than coming up with their own goals and related action plans. As such, the Flinders Programme provided a fresh perspective on receiving person-centred, empowering care. Next, it also took significant effort to engage health professionals in most cases, as they were not interested in getting too involved in the care plan. The trial nurses believed that health professionals were too busy and concerned about the potential future workload if the Flinders Programme was rolled out and they had to deliver the programme (on top of their existing work). One of the trial team members described that the trial aimed to replace the mental health care plan with the Flinders Programme, but this intention was not explained clearly to the health settings and their staff. On the other hand, caregivers had a more positive response towards the Flinders Programme. In cases where key stakeholders showed genuine interest and actively supported the service user consistently over time, they demonstrated more success in helping the person to change their lifestyle.

3. What contextual and intervening conditions influence and affect participant changes through time?

A: SERVICE USERS' HEALTH CONDITIONS, ANY MAJOR CRISIS, WEATHER

It was observed that service users often had mental ill-health relapses or severe physical health problems due to CVD risk factors – sometimes, they were hospitalised. There were also injuries or significant crises (e.g., sickness or death of close family members or financial troubles). The weather was another barrier (e.g., during extreme heat or cold, people could not be involved in outdoor sports or physical activities). All these factors hampered service users' engagement and progress in the Flinders Programme. But, due to the flexible programme, service users could take time off anytime they wanted and modify goals as per their capacity, which helped them stay motivated and engaged in their care plan. The trial nurses explained that they were sensitive to service users' needs when such setbacks occurred and tried to promote positivity and encourage service users to problem-solve these hurdles.

4. What are the dynamics of participant changes through time?

A: RELATIONSHIPS WITH KEY STAKEHOLDERS

It was evident from data triangulation that service users' relationships with their caregivers and health professionals were crucial in terms of being motivated and engaged, and to maximise their health opportunities. Positive respectful relationships promoted these qualities. High staff turnover hindered service users' care continuity; caregivers confirmed this issue. Caregivers further explained that adults with SMI required good rapport with their health professionals as their illness generally made them reluctant to engage with someone they did not know or trust. The data also revealed that service users' positive relationship with their caregivers significantly impacted their motivation towards improved health behaviours and lifestyles. For instance, service users were better engaged

with the Flinders Programme care plan when they had encouragement and practical support from their caregivers. The outcomes were most fruitful when caregivers adopted a healthier lifestyle alongside the service user; this caregiving act promoted role modelling by 'walking alongside' the service user, providing significant support for psychosocial disability and cognitive issues.

5. What preliminary assertions (propositions, findings, results, conclusions, interpretations, and theories) about participant changes can be made as data analysis progresses?

A: RESPECTFUL AND EMPATHETIC HEALTH CARE DELIVERY PROCESS ALWAYS WORKS

As the larger trial and this study progressed side by side, it was evident that the fundamentals of good health care lie in its delivery process. All service users said they looked forward to attending the Flinders Programme sessions as they enjoyed the process and interactions with the trial nurses. Both trial nurses were well-trained and worked hard to deliver the best possible care; the service users and caregivers sincerely appreciated this aspect of the care. They explained that service users were treated respectfully, and their opinions were valued, which they said they usually did not receive from the health system and its staff. This generated hope in both parties and motivated them to engage in service users' health care plans actively. These findings show that respectful and empathetic delivery processes work.

7.4.2 Descriptive questions

6. What increases or emerges through time?

A: CONFIDENCE (of both service users and the programme delivery person), MOTIVATION, POSITIVE ATTITUDE

Service users were more motivated as the trial progressed due to positive health outcomes, which helped them better engage with the Flinders Programme. Caregivers also showed more positive attitudes and enthusiasm when service users demonstrated improved health behaviours. With time, service users and the trial nurses reported feeling more confident applying skills learnt during the delivery of the programme. Many service users were also more confident navigating the health system and voicing their opinions before health professionals.

7. What is cumulative through time?

A: INFORMATION, KNOWLEDGE, EVIDENCE

Significant findings suggested that as service users accumulated health information over time, their knowledge about CVD and related preventative measures improved. Caregivers confirmed this finding for the trial team members, including the researcher; their ideas and understandings of the research topic improved as they gathered more data and evidence from the study participants.

Evidence gathered through data collection and service user interactions helped the trial team members understand how to deliver the Flinders Programme more effectively.

8. What kinds of surges or epiphanies occur through time?

A: POSITIVE RESULTS, RECOVERY-ORIENTED MODEL OF CARE, HOPE

Data triangulation confirmed that there needed to be more recovery-oriented care throughout the mental health system. As a result, service users responded positively towards the Flinders Programme, which incorporated motivational interviewing techniques and encouraged personal and social recovery. Service users showed further engagement and activation as they experienced success in achieving their health goals and related steps in their Flinders Programme journey. Positive health results generated a sense of hope among all stakeholders, including the trial team members.

9. What decreases or ceases through time?

A: RESISTANCE, PRECONCEIVED IDEAS

When the Flinders Programme trial was initiated in late 2017, the trial team reported feeling resistance from the community mental health staff. Trial team members explained that mental health staff were likely under immense work pressures and did not have time to fully cooperate with the trial nurses in participant recruitment or to help with any administrative processes related to the trial. The trial nurses, service users, and caregivers also described how health professionals held preconceptions regarding service users' ability to recover, which resulted in a lack of enthusiasm by mental health staff towards the Flinders Programme. Data triangulation suggests that the 'risk assessment' system used in treatment provision might be responsible for this negative attitude as this approach records service users' past health behaviours, which forces staff to take a more conservative path when providing care (e.g., implying a risk-averse medical model). As the trial progressed and service users' small achievements were noted, some health professionals expressed surprise and showed more interest in the Flinders Programme.

Notably, the researcher herself had some preconceptions that were eliminated over time as the data collection progressed. For instance, the researcher assumed that group education on improved health behaviours might be more appealing and practical to adults with SMI as they promoted social connectedness and peer support and were deemed enjoyable (Lorig & Holman, 2003). However, the in-depth interviews revealed that most service users preferred one-to-one sessions as this allowed comfort and privacy. Being a public health student, the researcher also had limited knowledge of antipsychotic medications and assumed that drugs caused more harm than good to service users. While some medications have significant side-effects, all service users acknowledged their benefits.

10. What remains constant or consistent through time?

A: FAITH (religious), BELIEF (health), TRAUMA (both personal and health system related), NEED FOR EMOTIONAL SUPPORT AND SOCIAL CONNECTEDNESS

Data triangulation suggested that religious faith and beliefs regarding health were essential to some service users, which helped them to refrain from risky health behaviours (e.g., self-harm and alcohol and drug abuse are forbidden in most religions). As people usually learn these practices through their family or community connections, they try to comply with them to maintain social belonging, conformity, and identity. The importance of the emotional connections service users had with their caregivers was also crucial. The thesis findings suggested that family support was highly beneficial (and appreciated) in life, which motivated service users towards recovery.

11. What is idiosyncratic through time?

A: INTERPERSONAL and INTERPROFESSIONAL SKILLS, FAIRNESS (in delivering care)

Trial team members' reflective journals described that, while health professionals' attitudes and behaviours significantly varied according to their personalities and learned experiences, the entire health system might benefit from interpersonal (e.g., improved communication, empathy, trust, and respect towards service user and caregiver decisions) and interprofessional training (e.g., collaborative and coordinated approach, trust, and respect towards colleagues). Overall, health professionals with academic backgrounds in health prevention and health promotion (such as rehabilitation centre staff, primary health care nurses, and public health professionals) seemed to show more optimism and positive attitudes towards service users' recovery capacity.

There were some indications that service users with similar mental health needs received different health services. For instance, older and more educated service users seemed to be treated with more patience and respect. Service users who were more compliant with health staff and demonstrated improved health outcomes also seemed to receive more services from the overall system (from mental health clinics, rehabilitation centres). Comments by some trial team members supported these ideas; they explained that such discrimination could mean more vulnerable and 'high support needs' service users falling through the gaps. It also seemed there was a sense of service inconsistency based on the nature of compromised safety. For instance, the potential for self-harm due to a depressive disorder (compromised personal safety) seemed to be less prioritised by health professionals in comparison to the possibility of harming others due to an aggravated mental illness (compromised community safety); the latter group seemed to receive more attention from the mental health system. However, all these ideas require further exploration.

12. What is missing through time?

A: LEADERSHIP, CHAMPIONSHIP (within the regular mental health system), CONSISTENCY, SUSTAINABILITY

While the Flinders Programme was trialled within the selected SA community mental health settings between November 2017 and September 2020, it seemed that operational-level solid leadership was missing that could have ensured the complete adoption and effective delivery of the programme. Also, although service users and caregivers expressed positive views towards the Flinders Programme during the delivery stage, it was unclear if the programme's positive impacts could be sustained beyond completion of the trial, and what was required to ensure the programme's sustainability. There was also a lack of consistency in service users' health outcomes.

Health professionals and trial team members were requested to express their views on the suitability, sustainability, and potential routine delivery of the Flinders Programme within regular care. Their collective thoughts suggested that the programme could be sustainable with proper staff training, preparation, resource management, leadership, and ongoing follow-ups.

7.4.3 Analytical and interpretive questions

13. Which changes interrelate through time?

A: KNOWLEDGE, AWARENESS, MOTIVATION, ACTIVATION

As the trial progressed, it was evident that service users needed more information and understanding about CVD risk factors. The trial nurses took time to explain the matters and reinforced the information time and again. Trial nurses reported that working with adults with SMI's limited cognitive and organisational skills and poor memory made it challenging for them to deliver the CCSM intervention; hence, spending additional time with service users was necessary to cement essential health information. Caregivers acknowledged that the trial nurses' dedicated educational and motivational approach tailored to the needs of the service user helped improve service users' knowledge and awareness of CVD risk factors. Resultantly, service users were motivated and became active in their own care plan to improve their health behaviours; they could apply it more directly to their own life circumstances.

14. Which changes oppose or harmonise with natural human development or constructed social processes through time?

A: AGE, GENDER

It was evident that older and experienced caregivers better understood service user needs. But more senior caregivers needed help with providing practical support, and were financially more disadvantaged, as most were retired but still needed to support service users during any financial

crisis or in engaging a healthier lifestyle. One trial team member explained that older health staff needed more enthusiasm in providing care and adopting new approaches to care delivery.

Regarding gender, the findings suggested that female service users were better at self-care and financial management. They also had fewer problems with living skills (e.g., doing chores such as cooking and cleaning), which were often reported as significant challenges by male service users. Female participants demonstrated better everyday nurturing habits and resilience that enabled them to adhere to their caregiving role; this was true for both caregivers and service users. Notably, four female service users took part in this longitudinal qualitative study, three of whom were also caregivers for other family members, such as children or parents.

15. What are a participant or conceptual rhythm (phases, stages, cycles, and so on) through time?

A: SUCCESS AND FAILURES of the intervention coincided with the CONTEXTUAL CHANGES

A participant or conceptual rhythm refers to participant actions or contextual changes that follow a pattern (repetitive, serial, or cumulative); for instance, how seasonal change can impact one's mood and subsequent lifestyle behaviours. Throughout the trial period, most service users went through cycles of positive and negative health behavioural changes. The setbacks in achieving the Flinders Programme goals largely coincided with other contextual factors such as a sudden injury, hospitalisation, or family issues. Overall, there needed to be more consistency in programme sessions and follow-ups to help service users better cope with the changed situations. However, once the initial rapport was built with the trial nurses, service users remained engaged with the Flinders Programme. Despite these setbacks, the trial nurses explained that they constantly voiced encouragement, even over service users' smallest successes, and showed positive attitudes when service users were unable to adhere to their health goals. This empathetic care approach helped service users remain motivated and engaged with the Flinders Programme.

16. What is the through-line of the study?

A: HOPE

According to Saldana (2003, p. 151), "a through-line describes, connects, and summarises the researcher's primary observations of participant change". The overall findings suggest that, generally, adults with SMI are hard to engage in health care, especially in behavioural health interventions. Consequently, even small 'invisible changes' among service users, such as improved awareness or motivation, were deemed important achievements. The trial team explained that even such small changes were significant for this population group, given that amotivation is known to be a common feature for people living with SMI. The Flinders Programme, as such, generated hope in all stakeholders about the possible behavioural changes in adults with SMI. The importance of nurturing hope as a continuous underpinning 'through-line' was noted as a goal for service

interactions between service users and all those supporting them in their efforts to improve and manage their health.

7.4.4 Additional questions

In addition to the above 16 questions, two additional questions were answered in this chapter. They were originally omitted by Saldaña (2003) as he intended to focus more on human perceptions and actions through time rather than capturing their involvement in change. However, the researcher included them within this thesis' analytical methods, as they seemed appropriate to predict the possibility of implementing the Flinders Programme within routine care. These two questions were deemed relevant for this study to identify the change agents and those who resisted the change.

17. Who are change agents through time?

A: BELIEVERS

Key findings of this thesis showed that compassionate and humanistic staff and family members played crucial roles in motivating service users towards self-care activation. It was evident that stakeholders who believed in service users' ability to recover from mental illness were also able to generate confidence in service users. Their genuine caring nature gave service users hope and purpose, which resulted in positive health behaviours. When asked about the ideal health professionals suitable to deliver the Flinders Programme as part of possible routine care (e.g., mental health nurse, care coordinator), the trial nurses also said that anybody who believed in the programme and the person would be ideal.

18. Who resists change through time?

A: GATEKEEPERS AND POTENTIAL FUTURE PROGRAMME DELIVERY PERSON

Data triangulation revealed that at the initial stages of the Flinders Programme, the trial team faced resistance from mental health staff within the trial sites. The trial team explained that mental health staff were already under work stress and pressure that did not allow them to collaborate actively with trial nurses to help with participant recruitment or to perform administrative tasks. The trial nurses also thought that staff refrained from active participation out of fear of added workload if/when the Flinders Programme became part of routine care.

The overall findings suggest that if the Flinders Programme care plan is incorporated within the existing community mental health plan, and staff are included in the decision-making process and planning stages from the very beginning, it is possible to implement the Flinders Programme within routine care. However, this also requires effective leadership and organisational cultural work to bring staff along and build their trust in the change process.

7.5 Chapter summary

The current chapter integrated the critical findings of the previous results chapters (Chapters Three-Six), synthesised them through data triangulation, and refined the key themes, sub-themes, and proposed IPTs of the preceding chapters. The outcomes generated four key themes capturing conditions that seemed necessary to promote self-management and recovery towards improved heart health and quality of life in community-living adults with SMI and CVD risk factors: i) Service users as 'active citizens', ii) Caregivers: promote recovery, iii) Positive health environment: deliver respectful and recovery-oriented care, and iv) Community: promote socioeconomic security and social justice. The data triangulation process also produced 40 IPTs defining stakeholders' roles in self-management and recovery care.

The findings suggested that the Flinders Programme could initiate positive behavioural health changes in service users. However, improvements were often 'invisible' (minimal or non-clinical) and non-specific (e.g., unintended positive impact on caregivers and control group participants). The programme's success was attributed to its design, which adopted a person-centred, motivational care plan approach. The written care plan encouraged service users to set their health (e.g., improved diet, increased exercise, reduced smoking) or social (e.g., having more friends, engaging in social activities, preparing for jobs) goals that activated and empowered them in their care. These findings showed the importance and benefits of delivering person-centred care where service users' needs are identified and met. Furthermore, the engagement of caregivers and related health professionals (e.g., mental health nurse, care coordinator, psychiatrist, GP, support worker, hostel manager, or community rehabilitation worker) improved care coordination and collaboration that optimised service users' health outcomes by maximising resources.

While there was initial resistance from the health staff regarding accepting the programme, with time, many were surprised by some of the positive outcomes. These positive outcomes then challenged their preconceptions regarding service users' ability to self-care. In the future, it would be ideal if the study settings and their staff were better prepared to improve their communication and interpersonal skills before delivering such programmes. This must be part of the delivery module so all staff can upskill and work cohesively. Trial nurses communicated that, in their view, anybody who genuinely believed in the Flinders Programme (or similar recovery-oriented models) and was interested in improving service users' overall health and wellbeing could deliver this programme.

While the intervention (Flinders Programme) seemed to contain all the elements to successfully activate adults with SMI in their health care, many of the broader socio-environmental and service cultural factors required attention as they impacted service users' overall health and wellbeing experience and subsequent capacity to self-manage. For instance, social stigma caused unemployment, housing, and social networking problems; coerced health and community policies

caused mistrust towards the health system, disempowerment, and poverty. Therefore, creating a positive health environment and community space for health equity and social justice is essential.

A functionally integrated health system requires collaboration with communities and joint work towards ensuring destigmatisation, economic equity, and social justice so that adults with SMI feel socially included and connected. Adequate community-based psychosocial support will ensure that service users' newly adopted self-management practices are sustained long-term and prevent them from non-engagement after relapse (relapses are likely to attenuate, with consistent self-management practice). Caregivers play crucial roles in this regard, deserving acknowledgement, respectful engagement in the care, and simultaneous psychological support from the health system.

Support workers are another vital agent well positioned to provide practical support to service users, but the findings indicated that, in general, they might require more training to develop interpersonal skills. Interpersonal skills involve competence training where health professionals learn to communicate effectively and respectfully with key stakeholders (e.g., service users, caregivers, and colleagues) (O'Toole, 2016). Such training aims to provide care with empathy and make service users (and caregivers) feel safe. All these findings show the importance of embracing a collaborative approach where different stakeholders' ability to support service users is maximised by aligning sectoral policies and complementing each other's roles.

CHAPTER EIGHT: DISCUSSION

8.1 Chapter purpose and structure

This chapter discusses the key findings of this thesis within the context of the broader literature and global research evidence. This will be presented in five sections. First, the thesis objectives and related key findings are presented in section 8.2. This section describes the roles of key stakeholders to identify how they can support service users in achieving self-management and recovery goals. Next, in section 8.3, two thesis research questions are answered which relate to how the Flinders Programme was delivered and why it worked (or not). Section 8.4 explains Flinders Programme's acceptability, suitability, and potential sustainability. The outcomes also suggest ways to improve the content and delivery of the Flinders Programme, suitable for community-living adults with severe mental illness (SMI) and cardiovascular disease (CVD) risk factors. Based on the overall thesis findings, section 8.5 proposes a middle-range theoretical model – Supported Self-Management and Social Recovery (SSMSR) – suitable for improving the health behaviours and quality of life of community-living adults with SMI. The middle-range theory combines sociological and empirical research applicable in natural settings (Liehr & Smith, 2017). Lastly, the chapter concludes with some remarks about the overall study findings (section 8.6).

8.2 Thesis objectives and key findings: understanding stakeholder roles

This thesis aimed to investigate the acceptability and feasibility of a chronic condition self-management care planning-based intervention (Flinders Programme) to improve cardiovascular health and quality of life of South Australian community-living adults with SMI and CVD risk factors. This broad aim was achieved by pursuing the following three objectives:

- 1) Objective One: Exploring the experiences of community-living adults with SMI and CVD risk factors (objective 1.1), their matched family caregivers (objective 1.2), and matched health professionals (mental or physical health staff) (objective 1.3) as the participants undertook the Flinders Programme during November 2017 September 2020.
- 2) Objective Two: Exploring the experiences of the trial team to understand how the Flinders Programme was delivered.
- 3) Objective Three: Data triangulation of objectives one and two to identify the contextual factors (social, political, and economic conditions of the community and health system where service users and other stakeholders live, work, and thrive) and underlying mechanisms (e.g., social

construct, culture, power, politics, connection, identity), which support (or inhibit) the delivery of self-management and recovery care (exemplified by the Flinders Programme) among adults with SMI and CVD risk factors (data triangulation of objectives 1 and 2).

8.2.1 Objective 1.1: Experiences of service users within self-management and recovery care

Most chronic condition self-management models, including the CCM (Wagner, 1998), do not emphasise service users' active roles within their health care plans. In the CCM, Wagner (1998) describes that when informed and activated service users interact with prepared and proactive health professionals, improved health outcomes are achieved due to productive exchanges. However, the CCM does not explain how service users will be activated. Besides, the term 'activated' itself is a passive word suggesting that health professionals are responsible for initiating the action of service users' input. In contrast, the findings of this thesis indicated that adults with SMI, when not going through any significant health or social crisis, were fully capable of setting their health goals and related strategies that shifted the power within the care delivery approach to consider them as 'active citizens'. The idea of 'citizenship' is intertwined with social recovery, which suggests that adults with SMI can live beyond their illness, and the mental health service gaze, and thrive in the community like other citizens (Pelletier et al., 2015; Ramon, 2018).

The findings of this thesis pointed out a few factors that promoted 'active citizenship' in service users. First, the Flinders Programme trial nurses were respectful and empathetic, and this helped service users to open up and voice their opinions about their health choices (Leape et al., 2012). The thesis findings suggested that the one-to-one engagement with the trial nurse generated comfort, rapport, and consequent trust.

Next, a person-centred care plan approach encouraged service users to set their health or social goals and related strategies, which motivated them to engage in their care plan. Person-centred care is an extension of patient-centred care where an individual's socio-cultural needs are addressed (e.g., loneliness, unemployment, poverty) (Eklund et al., 2019). In doing so, a person-centred care plan can address the 'causes of the causes' that hinder self-management behaviours (Braveman & Gottlieb, 2014). For instance, as part of the Flinders Programme, service users often chose goals that were not directly related to health outcomes (e.g., 'make more friends', 'find a job'). This self-driven process empowered service users and activated them in their care.

This study found that the Flinders Programme written care plan, co-developed with and then signed by the service users, produced a sense of commitment and ownership. Consequently, the service users were motivated to improve their self-care and self-management behaviours towards achieving set goals. Taylor, Budge, Hansen, Mar, and Fai (2019) support this aspect of improved self-management skills and describe that a written care plan improves communication with health staff who provide care. Service users also seemed to receive better care from other health care practitioners (e.g., their GP). The Flinders Programme service users, their caregivers, and health

professionals regularly received an updated copy of the care plans. Being a tangible document, it allowed caregivers and health professionals to initiate dialogues around improving self-care practices (Zabeen et al., 2020). Updated copies of these care plans, shared with the service user and their family carer (where applicable), were beneficial for service users and caregivers; this was reported as not being a common practice in the regular mental health or physical health systems.

Like the benefits of a written care plan, self-management education is well-established in the global literature (Lorig & Holman, 2003; Sherifali et al., 2018). This thesis also confirmed that information and education enhanced awareness and confidence in service users. Some service users were selfmotivated to acquire health information independently, especially the young adults who had regular access to the health professionals who educated them about healthy lifestyles (e.g., staff of the rehabilitation centre, GPs, mental health nurses, and trial nurses). The benefits of receiving health education were immediate, with most service users or their caregivers reporting service users' improved awareness and related health actions (e.g., making healthier lifestyle choices, seeking help from health professionals towards improved self-management skills). Self-management training and strategies were also proven helpful in developing self-management skills. One rehabilitation centre's service user explained that staff members' visual demonstrations about diabetes and CVD risk factors (e.g., how many spoons of sugar are in a can of Coke) were very helpful and encouraged him to switch to a healthier drink option. The benefits of such practical sessions are also confirmed by Aschbrenner et al. (2016). The trial nurses also reported that service users who struggled with planning and organisational skills benefitted from using tools such as appointment diaries and phone reminders. A systematic literature review suggests that self-management education, training, and supporting tools (such as those that help to organise tasks) not only initiate improved self-care in service users, but also help sustain their changed behaviours (Dineen-Griffin, Garcia-Cardenas, Williams, & Benrimoj, 2019). Although this paper is focused on the general adult population in primary care with any conditions, as found by this thesis, these self-management support approaches and tools were equally beneficial for people with SMI.

In a recent webinar called 'Social Isolation and Social Prescribing', Professor Catherine Haslam described social isolation and loneliness as the critical risk factors of chronic conditions, and as more dangerous than smoking (Haslam, 2022). Researchers explain that social connectedness has multiple health benefits, such as reduced loneliness and social anxiety, and improved mental health and group belonging (Haslam et al., 2019; Wakefield et al., 2022). As a result, the Royal Australian College of General Practitioners (RACGP) and the Consumers Health Forum (CHF) of Australia have proposed the adoption of 'social prescribing' as part of regular care (RACGP & CHF, 2020). It is a practical way of bridging the gaps between clinical and non-clinical services (e.g., arts, sports, exercise clubs), and is deemed suitable for community-living adults with SMI who frequently experience loneliness. Kindred Clubhouse is one such group that promotes social prescribing through a 'walk and talk' programme for community-living adults with SMI (KindredClubhouse, 2023).

Hazeldine et al. (2021) describe that, with proper training, link workers (those who deliver social prescribing) can implement such interventions among people with SMI and there is potential for positive outcomes. Health professionals such as GPs, nurses, and other primary care professionals can prescribe social activities and link service users with local non-health facilities (RACGP & CHF, 2020). This approach acknowledges that various socio-environmental, economic, and political factors impact upon health. Social inclusion, connection, and cohesion are essential to improving health outcomes (Ward et al., 2011).

The findings of this thesis also highlighted the importance of service users' resilience and positive attitudes, especially in the context of social isolation and loneliness. Many service users demonstrated self-motivation and willingness to improve health behaviours despite lacking an ideal support system. A recent study found that many socially isolated mental health service users employed self-care to alleviate loneliness (Lawn & Kaine, 2022); this strategy demonstrates resilience. The emerging importance of resilience-based self-management frameworks is also highlighted in recent health research (Salerno & Margolies, 2022). For future delivery of the Flinders Programme and similar health interventions among adults with SMI, this aspect of resilience building in service users should be promoted. Resilience building is arguably of even greater importance for this population given they are likely to disproportionately experience issues of marginalisation, stigma and discrimination compared with other populations.

8.2.2 Objective 1.2: Experiences of caregivers in supporting service users' self-management and recovery

Service users' and caregivers' roles were not well-acknowledged or integrated into the CCM (Wagner, 1998). As this thesis employed a mix of framework and thematic analysis at the beginning (Figure 11, step 1), a relevant health model or framework was necessary to guide this study, absent from the existing literature. Hence, Zabeen et al. (2020) conducted a systematic literature review to identify and understand caregiver roles in self-management and recovery care to improve the cardiovascular health of adults with SMI. The outcome of the evaluation generated a conceptual framework defining the roles of caregivers in improving health behaviours and the quality of life of adults with SMI. This thesis tested and refined that framework based on stakeholder feedback (Chapter Four: caregiver experience). The key findings suggested that caregivers were an 'invisible workforce' who should be acknowledged for their ongoing contributions towards supported self-care. To maximise their expertise and knowledge as an insider (Zabeen et al., 2020), caregivers need to be better integrated into the health system.

This thesis found that caregivers' most vital role was in promoting the service user's personal recovery, such as helping to provide the person with connectedness, hope and optimism, identity, meaning and empowerment in life; these are also the elements of the CHIME personal recovery

model (Leamy et al., 2011). Caregivers were also able to promote self-care by teaching and nurturing living skills 'walking alongside' the person. Lawn (2015) explained that helping the person with boundary setting, close observation, and monitoring were good ways to encourage self-care in service users. This thesis also verified this position. This caregiving orientation also initiated and sustained independence in service users. Setting boundaries to promote service users' independence was particularly important in contexts where over-reliance on their caregivers (especially true for child-parent relationships) created co-dependency (Nordgren, Richert, Svensson, & Johnson, 2020). However, it is essential to implement these strategies within a context where service users do not feel abandoned (e.g., unsuitable for applying during a health or social crisis) (Zabeen et al., 2020).

The key findings also suggested that both service users and caregivers could optimise their health during the Flinders Programme delivery when caregivers adopted a healthier lifestyle and accompanied service users in their self-management journey. In accordance with Bailey et al. (2018), successful health outcomes generated hope and improved their mutual relationship. However, only a few papers have reported on these positive aspects of caregiving (Alqhtani, Barry, & King, 2021). Aschbrenner et al. (2016) further identified that practical group sessions on building self-management skills involving service user-caregiver pairs were more effective and more enjoyable for group participants than providing information alone. This aspect of group learning was also supported by this thesis, where a caregiver appreciated attending community group art and craft sessions designed for service user-caregiver pairs.

Another critical finding suggested that positive and extended parenting (lifelong nurturing) helped service users' self-efficacy and confidence towards self-management. Caregivers' unconditional love and emotional support were identified as the precursors of 'parenting'. According to this thesis, 'parenting' could be promoted by non-parent family members as well (e.g., elder sibling, partner); this finding was also affirmed by caregivers and health professionals, and they considered this nurturing aspect a necessary element of the caregiving role. Voicing encouragement and believing in service users' recovery capacity was crucial in achieving this health outcome. In some cases, service users' elder sister or wife played 'parental' roles (even though the person was an adult), which seemed necessary in supporting the wellbeing and recovery of some adults diagnosed with SMI. A recent systematic review advocates that positive parenting should be integrated within recovery-oriented approaches for better health and family outcomes (Reupert et al., 2017). Positive parenting in childhood can play a significant role in building resilience and forming good health habits in adulthood (Muller, Ward, Winefield, Tsourtos, & Lawn, 2009). As such, this thesis advocates for acknowledgement and better understanding of extended or lifelong parenting as part of the service user's recovery process.

The other critical understanding was how caregivers helped service users navigate the health system, sometimes even advocating for the service user through negotiating with the health professionals. It is well-noted that mental health services perpetuate paternalistic care, where service users have a limited voice in their treatment choice (Pilgrim, 2017; Zabeen et al., 2021). For instance, many service users were under the regime of a CTO (to ensure they complied with their treatment), the Public Trustee (to manage their finances), or prescribed heavy dosages of antipsychotic medications, often without service users' or their caregivers' full consent. Service users explained how these practices caused them iatrogenic trauma. Given this scenario, caregivers' active engagement proved to empower service users to receive preferred care, such as more recovery-oriented care.

The abovementioned strategies worked well when service users' mental and physical health was stable (e.g., no recent hospitalisation due to mental or physical illness, no family crisis, and no major crisis regarding finances or accommodation). But when they were experiencing significant life stressors, they needed more emotional and practical support from their caregivers, such as help with the chores, grocery shopping, and transportation to appointments. Widyowati, Murti, and Sudiyanto (2021) suggest that caregiving acts are essential during a crisis to support recovery.

Although this thesis focused on caregiver roles rather than caregiver burden, the findings suggested that this aspect could be addressed. In their systematic literature review, Zabeen et al. (2020) found that caregivers of people with severe mental illness could spend up to 104 hours/week providing crucial support, and that 82.7 per cent of caregivers were female. This thesis also supported these findings, as *all* caregivers in the current study (100 per cent female) reported feeling burnt out due to intensity and ongoing nature of their unpaid caregiving role. Caregivers are a vital source of support for personal recovery, a unique motivational resource unavailable to many service users (Zabeen et al., 2020). Hence, caregivers must also be supported in every way possible which, in return, might help service users avoid hospitalisation and thrive in the community. The findings recommend that caregivers should receive emotional (e.g., counselling to deal with vicarious trauma), practical (e.g., older caregivers require support in managing chores, gardening, driving service users to places etc.), and financial (e.g., especially those who are unemployed or retired) support. NGOs and community organisations can play a vital role in supporting caregivers. These findings are consistent with the broader literature (Alghtani et al., 2021; Sabo & Chin, 2021).

Global evidence suggests that caregivers would also benefit from training to promote recovery and support service users to sustain self-management behaviours (Aschbrenner et al., 2014; Bailey et al., 2018). Such training activities build confidence in helping service users manage their mental health and relapse symptoms at home. It will promote explicit boundary setting towards developing better independent self-care behaviours and lessening the burden on caregivers. Caregivers interviewed in this thesis disclosed that the Flinders Programme and its trial nurses were able to

provide them with some relief when service users demonstrated the ability to seek help from others (not only from caregivers) and initiated independent actions (often very small and subtle, but caregivers still appreciated service user efforts to be independent and explained that it ignited hope among all key stakeholders involved). Most importantly, health professionals need to acknowledge caregivers' roles, respect their decisions, and actively engage them in service users' care plans (where service users give their consent), given that both parties are willing to participate in this collaborative care approach.

8.2.3 Objective 1.3: Experiences of health professionals in supporting service users' self-management and recovery

While service users themselves and caregivers have essential roles to play in self-management and recovery, it is undeniable that the health system and its staff play a crucial role in supporting service users in their health journey (Whiteman et al., 2016). Globally and in Australia, however, physical and mental health services are disjointed, making it challenging for adults with SMI to receive holistic support and treatment to look after their cardiovascular health (Ashworth et al., 2017; NMHC, 2016; NMHS, 2017; RANZCP, 2016). The international literature on the topic (Zabeen et al., 2021) and the current thesis results suggest that limited coordination and collaboration between the sector's health staff and data-sharing systems hampers how service users understand, seek, and experience health care.

This thesis further highlighted that service users' health-seeking behaviours were negatively impacted by their past experiences with the mental health system. The paternalistic and coerced medical-model-based care and health professionals' preconceived ideas about service users' inability to recover caused trauma, iatrogenic trauma, mistrust, and demoralisation among service users and their caregivers. In their literature review, Zabeen et al. (2021) described that these findings were consistent with the Australian and international evidence. Further to these problems, service users experience discrimination, stigma and inconsistent care from the health system (Tyerman, Patovirta, & Celestini, 2021). Diagnostic overshadowing by health professionals is another significant barrier that likely has negative impacts for people with SMI, including whether health professional raise and encourage uptaking healthy lifestyles (Hallyburton, 2022).

Greenhalgh and Papoutsi (2018) explain that a complex system has fuzzy boundaries where staff often operate according to internal rules that cannot be predicted; staff interact with other stakeholders and co-evolve directives according to the system's needs. The SA community and mental health system seemed to suffer from these same issues that hindered how service users experienced being listened to, included in the decision-making process, and provided with the support they needed to manage their health. There is ample literature available acknowledging these problems (Morrow & Malcoe, 2017; Pilgrim, 2017; RITB, 2016), which advocates for an urgent

paradigm shift to achieve person-centred, recovery-oriented care and health equity within the mental health system where service users are treated with respect and empathy.

Overall, the participants' comments suggest there was a paucity of recovery-oriented care throughout the SA community mental health settings. Funding issues and resource mismanagement were identified as some of the root causes of this problem; they also triggered sectoral competition, professional rivalries, and related issues involving power and politics. For instance, the SA community mental health system underwent a major reform in 2018, resulting in an influx of top-down approaches. Mental health staff complained of change fatigue and job insecurity that caused them stress and which led to poor behaviours towards service users. Hence, Finklestein, Stein, Greene, Bronstein, and Solomon (2015) suggest that it is important for organisational leaders to look after staff wellbeing to ensure service users receive quality care.

Further to these issues, the negative attitudes and prejudices towards service users' ability to recover by health staff were also a concern. This thesis and the related global evidence (Zabeen et al., 2021) confirmed these findings. These factors negatively impacted the delivery of the Flinders Programme. Given this scenario, training staff in good interpersonal and interprofessional practice is important to promoting coordinated, collaborative, and respectful care.

In their recent research, Strong, Letts, Gillespie, Martin, and McNeely (2022) mentioned the importance of staff members' cultural competence (knowledge/education) in successfully delivering respectful care in mental health settings. The current findings suggest that cultural competence alone is insufficient to achieve health equity in adults with SMI, and that the entire health system should embrace cultural safety. Cultural safety refers to an empowering care approach where service users feel welcomed, respected, and most importantly, their voices are heard and views actioned (Karadzhov & Health, 2021; Mitchell, Wade, Haynes, Katzenellenbogen, & Bessarab, 2022). Although cultural safety is commonly advocated for in the health literature involving Culturally and Linguistically Diverse (CALD) population groups (e.g., Aboriginal and Torres Strait Islanders, immigrants), this thesis recommends embracing this approach among people with SMI and other marginalised patients. The extant literature underscores that marginalised service users face common challenges within the community and the health system, particularly social stigma and related social isolation, socio-economic disadvantage, disrespect, discrimination, disempowerment, and institutional and interpersonal prejudice. These negative experiences often cause mistrust among service users (including adults with SMI) and negatively impact their health-seeking behaviours and health outcomes (Pilgrim et al., 2010; Ward, 2017). A longitudinal qualitative study involving Human Immunodeficiency Virus (HIV) patients suggested that reassurance, encouraging service users to ask questions, sharing treatment results with explanations, avoiding judgemental behaviours, and prioritising patient goals promoted rapport and trust (Dang, Westbrook, Niue, & Giordano, 2017). These suggestions are deemed suitable for adults with SMI because they may also

experience discrimination and stigma, like HIV patients, that result in mistrust in the health system, and which then negatively impact their health seeking behaviours (Tyerman, Patovirta, & Celestini, 2021)

A 'cultural safety' framework aims to make health staff more competent in the delivery of care by promoting person-centred, respectful care that empowers service users by addressing stigma and structural disadvantages. A 'cultural safety' framework also addresses issues of low literacy levels and cognitive impairments. It uses family connections to overcome these barriers (Ristevski, Thompson, Kingaby, Nightingale, & Iddawela, 2020). These healthcare elements seem appropriate to support the self-management care of adults with SMI as well. Therefore, 'cultural safety' and its stepping stones such as cultural awareness (recognising that 'my culture is different'; in this caseshowing empathy to people with SMI), sensitivity (being respectful to others' culture; in this casebeing respectful to people with SMI and alleviating their voices), competence (educational phase/knowledge), and humility (self-reflection, commitment to lifelong learning, creating an environment that enables mutual trust and respect) (Cox & Simpson, 2020; Foronda, MacWilliams, & McArthur, 2016; Gollan & Stacey, 2021; Mitchell et al., 2022; Parisa, Reza, Afsaneh, & Sarieh, 2016), are suitable for addressing some of the issues discussed in this thesis. In summary, the following definition of 'cultural safety' justifies its suitability towards any marginalised patient group, not only for Aboriginal and Torres Strait Islander or Culturally and Linguistically Diverse (CALD) People:

Cultural Safety is more or less - an environment which is safe for people, where there is no assault, challenge, or denial of their identity, of who they are and what they need. It is about shared respect, meaning, knowledge, and experience, learning with dignity, and genuinely listening (CVIMS, 2021, p. 4).

8.2.4 Objective 2: Experiences of the trial team during the delivery of the Flinders Programme

As mentioned earlier, due to major structural reforms being implemented in the mental health services involved in the trial from 2018 onwards, the trial team faced multiple challenges in delivering the Flinders Programme in these settings. Due to the initial poor communication between the trial team and the target settings' health professionals, the Flinders Programme was seen as a coerced health intervention. Such enforced intervention is known as the 'top-down' approach (minimal communication or discussion with the host setting's staff), which is considered a significant barrier to successfully implementing any novel intervention in an organisational environment (Hannigan & Coffey, 2011). As well, the programme ran outside of routine care, which meant that staff were not proactive in helping the trial team with recruitment or other administrative work. As a result, the trial nurses had to put in extra effort to fulfil the recruitment target (N=358 adults with SMI and CVD risk factors). Their reflective journals suggested that this situation made them feel overwhelmed and

demotivated. This experience indicates that, in future, extensive groundwork should be undertaken in the proposed study settings to ensure the sites' leadership teams and their staff have sufficient buy-in and are well-prepared regarding resources, staffing, and infrastructure capacity (Greenhalgh, 2017; O'Cathain et al., 2019).

The service culture of delivering predominantly biomedical care might be a key reason why mental health staff were reluctant to adopt a behavioural change physical health intervention in mental health settings (Pilgrim, 2014; Slade, 2009). This issue can be addressed through reformed policies and training towards recovery, cultural safety, and more person-centred care (Buchanan-Barker & Barker, 2008; Kerrigan, Lewis, Cass, Hefler, & Ralph, 2020; Leape et al., 2012). The trial team also felt resistance from physical and mental health staff, as they were already busy managing acute mental health cases in a resource-scarce system (NMHCCF, 2017). Given the context, improving the cardiovascular health of adults with SMI through a behavioural health intervention was not seen as a priority by health staff at the study sites. However, the international research indicates that many health professionals want to implement more recovery-oriented quality care. These findings suggest the need for greater focus on managing the workload of frontline staff, such as mental health nurses, GPs, and support workers who have frequently reported work fatigue, stress, and burnout (Croxson et al., 2017; Judd, Dorozenko, & Breen, 2017; Ross, Rogers, & King, 2019).

The trial team employed multiple recruitment strategies and adaptations to address some of the above issues. The details are discussed in section 8.3.1, describing how the Flinders Programme was delivered in community mental health settings.

8.2.5 Objective 3: Identifying the critical contextual factors and underlying mechanisms that generated (or inhibited) self-management outcomes

The key findings suggested that service users had the best Flinders Programme outcomes when they had an encouraging caregiver, supportive health professionals, and good community engagement (Context). The vital mechanisms that triggered this outcome were hope, optimism, connectedness, and motivation from caregivers' unconditional emotional support. On the other hand, health professionals were considered supportive when they demonstrated empathy and respect. They could boost service users' awareness, confidence, and treatment adherence (Mechanisms) by sharing health information and acknowledging health priorities and needs (Resources/policies). Community engagement was also crucial because of community acceptance and social inclusion (mechanisms). Consequently, active community participation promotes social connectedness, cohesion, and identity (Outcomes). When service users did not have access to these supports, positivity, their own resilience, and spirituality (mechanisms) seemed to help them adhere to their self-management practices. This was a common scenario for 'closed episode' service users who no longer received care from the community mental health settings. The situation particularly worried those alienated from their friends and family who lived alone or who did not have a regular GP. The findings suggested that having a pet (responsibility and companionship), affiliation with an NGO

(guidance and practical support), and regular visits to religious institutions and maintaining connections with other community organisations and interests (social cohesion and connectedness) worked as protective factors for these 'closed episode', socially isolated service users. Alongside the broader socio-environmental factors, the Flinders Programme and related mechanisms also activated self-management behaviours in service users. One-to-one motivational interviewing techniques (rapport and trust), a written care plan (commitment and ownership), and regular follow-ups (accountability) were identified as the key facilitators. Appendix 7 presents a summary of the critical context-mechanism-outcome (CMO) configurations.

8.3 Research questions answered

This thesis answered two research questions in investigating the acceptability and feasibility of the Flinders Programme.

8.3.1 How was the Flinders Programme delivered in South Australian community mental health settings?

The Flinders Programme trial team experienced multiple barriers in fulfilling the recruitment target (recruited N=120 of targeted N=358). Chapter Six of this thesis undertook a process evaluation (of the trial processes) (Moore et al., 2015) of the Flinders Programme by capturing the experiences of the trial team members through interviews, field observations, and by analysing meeting minutes. The RE-AIM framework: Reach, Effectiveness, Adoption, Implementation, Maintenance (Glasgow et al., 1999) was used to understand how programme delivery was achieved in the South Australian metropolitan community mental health settings between November 2017 – September 2020. In relation to the aforementioned failure to reach the initial recruitment target, multiple strategies were taken to increase the recruitment rate (e.g., increased number of sites, the inclusion of discharged service users, attempt to hire additional trial nurses from other sites, reduced questionnaires to lessen the burden on the service users, flexibility regarding where to meet service users), but the outcomes were still unsatisfactory.

A few underlying reasons were identified for this low recruitment rate, (1) the South Australian community mental health system went through a significant restructuring at the time of the trial, resulting in an enormous workload in an already resource-scarce sector; (2) Health system-related politics and related change fatigue in mental health staff had a direct negative effect on the trial; and (3) *improving the cardiovascular health of SMI* was not deemed as a priority within a crisis-driven system that was struggling to deal with acute cases of mental illness. As already noted, there was a clear indication that most sites needed more or clearer communication from the senior trial team members before the recruitment and throughout the trial. However, it is evident that this is a very difficult population to recruit from (Peckham et al., 2018). O'Cathain et al. (2019) suggest that

aligning with the settings' organisational goals, involving key stakeholders in the decision-making process, co-producing the intervention, and regular consultation to resolve issues during the delivery of the intervention could be valuable strategies for tackling the problems above; these practices will ensure successful delivery of a complex new health intervention such as the Flinders Programme.

Besides the recruitment issues, some aspects of the trial needed modifications as well. These issues were revealed during the preparation period of the trial, which involved gathering self-management resources, trial equipment, nurse training on the Flinders Programme and other essential aspects of the trial (e.g., how to collect physical measures), practice with two service users, and multiple team meetings (July-October 2017). The outcomes of this preparatory phase led to several changes in the initially proposed grant application (NHMRC: APP1121334). Some were shorter versions of trial questionnaires, fewer questionnaires, modified ways of collecting physical measures, modified data collection and recording forms, and flexibility regarding how and where trial nurses saw the participants. The trial nurses underwent necessary training to comply with some modifications (e.g., training from SA pathology). While the primary trial-related materials needed significant adaptations, the actual Flinders Programme was well-accepted by all key stakeholders.

Service users said the care plan and delivery process were easy to understand. However, the trial nurses reported having to be flexible in the delivery process and methods to accommodate service users' emotional, health, and social needs; for instance, the trial nurses' hand-drawn care plans for two service users to make the plan clearer, easier, and visually appealing. They explained that due to many service users' limited cognitive skills or low literacy levels, they needed more time and constant reinforcement of self-care education. Many of these adaptations are recommended in the 'cultural safety' framework (Curtis et al., 2019; Parisa et al., 2016; Ristevski, Thompson, Kingaby, Nightingale, & Iddawela, 2020).

Recently, Strong et al. (2022) unpacked how they prepared a mental health setting before delivering a self-management intervention, which might be helpful for future physical health interventions. They mapped health providers' strengths and weaknesses on the elements of capability (C), opportunity (O), and motivation (M) that influenced behaviour (B) in the COM-B system (Michie, van Stralen, & West, 2011). Strong et al. (2022) identified some key facilitators that enhanced the delivery of a new self-management intervention within the targeted mental health setting. Championship among midlevel managers who were able to manage staff resistance and crisis, promotion of a recovery-oriented and person-centred approach, use of motivational interviewing techniques, employment of culturally competent staff, job satisfaction among staff, local adaptations, and rapport between staff and service users are some such facilitators. Given the time-intensive nature of any health interventions, having a dedicated workforce in the setting is also considered beneficial (Strong et al., 2022). On the other hand, service users' limited support networks, limited self-management capacities, disempowerment, staff members' negative beliefs about service users' ability to succeed,

and the lack of collaboration within and between different health sectors were described as barriers towards the successful delivery of the programme. The Flinders Programme care plan aimed to address some of these gaps by improving care coordination among health sector staff, particularly mental health staff, GPs, support workers, and SRF staff.

All stakeholders appreciated the Flinders Programme's one-to-one, recovery-oriented, flexible approach and said it was worth trialling the programme as part of routine mental health care. Many health staff also expressed interest in getting trained on the programme. However, as previously noted, the findings of this thesis suggested a considerable amount of prior groundwork should be undertaken to prepare anticipated health settings and their staff before making this attempt.

8.3.2 How and why did the Flinders Programme work (or not), for whom and under what circumstances in the selected community mental health settings?

While there were issues with the delivery of the Flinders Programme due to mental health service culture and system policies, most service users and their caregivers gave positive feedback about the Flinders Programme. The trial nurses also confirmed that all service users enjoyed the process of regular interactions and reported the overall experience as rewarding. Many stakeholders noted positive changes in service users' attitudes and health behaviours. Often these changes were coined as 'invisible changes' as they were non-clinical (e.g., enhanced awareness, motivation, hope, seeking help), but the trial team asserted that even such small changes were significant in this population group. The broader literature also supports and encourages habit formation towards such minor changes and affirms they have a higher chance of sustainability (Clear, 2018; Kemp et al., 2015; Muralidharan, Peeples, & Lucksted, 2021).

Alongside service users' 'invisible changes' (minor changes), there were other non-specific positive impacts of the programme on other stakeholders; all caregivers expressed a sense of hope and optimism as the trial progressed. Some caregivers made lifestyle changes as they accompanied the person cared for (e.g., more exercise). Bailey et al. (2018) also found positive health impacts on caregivers, including enhanced hope when they actively supported their family members diagnosed with SMI and CVD risk factors. Similarly, some control group patients also improved their health behaviours (e.g., they actively tried to tackle their nicotine addiction). Trial nurses' reflective journals and the trial team's focus group discussion revealed that control group service users attributed this positive result to the Flinders Programme's regular health monitoring system.

Further investigation suggested that during the programme, the trial nurses asked questions about health behaviours to both intervention and control group service users, collected clinical measures from both groups at pre-trial, 3-month, 6-month, 12-month, and 18-month time points, and conveyed back the results. To comply with the duty of care, the control group participants were also alerted about their CVD risk factors when flagged and were encouraged to adopt a healthier lifestyle. These

findings show the value of recovery-oriented care where the trial nurses showed genuine interest in service users' improved health and wellbeing and delivered care with respect and empathy (Leamy et al., 2011; Pilgrim, 2014). In their systematic review, Manojlovich, Lee, and Lauseng (2016) also reported positive unintended consequences and suggested further exploring the relations between the intervention and all other positive and negative outcomes. This will allow a fuller picture of the factors triggering change in human behaviours.

While the factors that facilitated positive outcomes were explored, this thesis found that the Flinders Programme's person-centred care approach (e.g., letting service users decide their health or social goals and related steps), cognitive behaviour therapy, and motivational interview techniques were identified as the key reasons that generated hope, trust, and motivation in service users and helped them activate their care plans. Additionally, stakeholders were highlighted as important facilitators for a one-to-one tailored delivery approach, an easy process involving a written care plan, regular follow-ups, and flexibility with appointments and goal setting. Also, the partnership between the service user and the programme delivery nurse allowed a straightforward way to discuss the person's needs and preferences and to identify strengths and barriers to self-management. Service users who had the active support of caregivers and their health professionals (e.g., care coordinators, mental health nurses, GPs, SRF hostel managers, support workers), or had a strong social support system, demonstrated more positive health outcomes. It is also essential to note that the Flinders Programme was delivered free of cost, considering the financial difficulties endured by service users due to their high levels of unemployment. All these elements are frequently highlighted in the literature as the fundamental principles of evidence-based and recovery-oriented selfmanagement interventions (Battersby et al., 2018; Battersby et al., 2010; Baum et al., 2014; SA-Health, 2023; Wagner et al., 2001). The Barker (2001) Tidal Model proposed for mental health settings seems to be the closest fit in explaining these outcomes. The Tidal Model is a philosophical approach that encourages the enhancement of the patient voice, respect for their decisions, and the implementation of a tailored care plan accordingly that celebrates the patient's story (Barker, 2001).

Another reason the Flinders Programme worked was its delivery outside of routine care, where the trial nurses had enough time to build rapport with the participants and deliver quality care (e.g., each session lasted between 45 and 80 mins). The trial nurses provided care with respect and empathy. They spent significant time in preparation, finding relevant and updated self-management study materials for each service user, and directing them towards the proper psychosocial and health supports. In natural real-world settings, this might be difficult to achieve within routine health care as mental and physical health care staff, including support workers, have reported feeling overworked, stressed, and fatigued (Croxson et al., 2017; Judd et al., 2017; Ross et al., 2019).

The overall thesis outcome suggested that when all key stakeholders fully engage in the care plan, the Flinders Programme could help service users achieve some of their health and social goals (e.g.,

preparation for a job, improved social connections, and healthy lifestyle). The programme was described as particularly beneficial for closed-episode male service users (discharged from the mental health system) who were alienated from their family and friends. While the service users were deemed to be satisfied with their progress, the primary care trial nurse noted that a few health staff members and caregivers often had unrealistic expectations regarding health change behaviours and related outcomes. For instance, if a service user decided to quit smoking, family members and health staff often expected quick, immediate, and sustained results. But according to the trial nurse, it is important to encourage and celebrate small achievements (e.g., reduction in cigarettes per day) and to expect gradual changes. One of the trial nurses also described that relapses during any health change intervention are expected, and other stakeholders need to understand this to be more patient with the service users. Global research supports these findings (Clear, 2018; Kemp et al., 2014, 2015; Lally, Van Jaarsveld, Potts, & Wardle, 2010).

8.4 Flinders Chronic Condition Self-Management Programme: 'A cog in the wheel'

The above findings suggested that the Flinders Programme is not an effective stand-alone programme, and instead, is effective only when coupled with a service user's current lifestyle, active support of key health staff, and when community resources are maximised. There was a clear indication that caregivers played a crucial role in promoting recovery in service users' lives and helped them achieve their health or social goals (e.g., improved eating and exercise habits and preparation towards employment). The outcomes were magnified when caregivers adopted the same health goals and accompanied service users in their health journey. It is also noteworthy that many service users were already involved in a healthy lifestyle unrelated to the Flinders Programme that was reported beneficial. For instance, some service users were receiving self-management training at the rehabilitation centre, were involved in gardening, dancing, sports, and art classes aside from their Flinders Programme goals, and they reported these activities as helpful.

The findings of this thesis suggest that it is important to fulfil service users' basic needs first, which are food, housing, and income security. In their care plans, most service users then prioritised having improved social connections. Some of these findings are consistent with 'Maslow's hierarchy of needs theory towards motivation' (McLeod, 2007). Once these basic needs were addressed, service users were automatically motivated and engaged in a healthy lifestyle. This outcome signifies the importance of a person-centred approach where service users identify their needs. Health professionals need to respect and prioritise those preferences and support service users in achieving those goals by employing a partnership approach (Eklund et al., 2019).

The above findings may explain why many service users at the study sites refused to participate in the Flinders Programme that targeted improved cardiovascular health, because they were overwhelmed in fulfilling their other basic needs such as housing, food, income, and social connectedness. As per the thesis findings, the figure below shows the hierarchy of perceived social and health needs of community-living adults with SMI and CVD risk factors. As such, during future delivery of the Flinders Programme or similar health interventions, it would be beneficial if service users' basic needs were identified and prioritised first, to the system's best capacity (Figure 12). Social prescription (Marmot, 2022b) can enhance this process while service users' mental and physical health problems are treated alongside. It should also be noted, however, that the order of priorities using such a hierarchy should not be overly prescriptive. This is because there is a danger in assuming that a range of social and psychological needs must be fully met prior to people with SMI being ready to address physical health concerns. Improving physical health first may positively impact earlier hierarchical levels; for example, quitting smoking can improve mental health and financial stability. Higher levels of support included in self-management programs are likely warranted for individuals with unmet hierarchical needs.

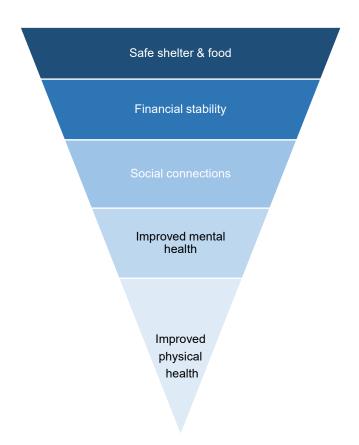


Figure 12: Hierarchy of needs of health and wellbeing of adults with severe mental illness and cardiovascular disease (or risk factors)

While the existing Flinders Programme was deemed suitable for adults with SMI and CVD risk factors, some aspects could be improved. For instance, one of the trial nurses made suggestions regarding drawing elements from treatment models suitable for an Aboriginal population, as both

groups endure similar socio-economic and environmental challenges (e.g., social stigma, low literacy levels, poverty, complex health and social needs, health care discrimination, disrespect, and resultant mistrust towards health and community policies and systems). The Flinders Programme care plan already has an Aboriginal version called 'My Health Story' for use in community primary care settings (Battersby et al., 2018) that could be considered for adaptation to the mental health setting. Some trial team members suggested that a similarly illustrated booklet would also be appropriate for adults with SMI. It would also be useful if there was greater and earlier focus on codesign of interventions with service users and/or Lived Experience advocates to inform how to establish the best possible intervention and trial conditions in the first place.

In earlier sections, it was evident that both physical and mental health care staff were under tremendous work pressures and might need more time to deliver the Flinders Programme, which is a time-intensive approach. To resolve this issue, peer educators (e.g., adults with lived experience of SMI who have recovered) could be introduced as a new workforce to deliver the Flinders Programme (or similar physical health interventions) as part of mental health routine care. Some of the trial team members also supported this idea. The benefits could be twofold; peer educators could promote hope, motivation, empathy, and role modelling (Muir-Cochrane et al., 2019), whereas the paid work would help peer educators thrive as 'active citizens', which is the ultimate goal of social recovery (Pelletier et al., 2015; Ramon, 2018; Rowe & Davidson, 2016). An earlier Flinders Programme pilot study also reported acceptance of peer educators by service users and overall positive health outcomes for peer educators (Lawn et al., 2007).

The six-month-long Flinders care planning programme was also deemed insufficient for this target group. The trial nurses perceived that people with SMI might need longer to trust the 'service' and build rapport with its staff, and suggested at least a 12-month programme with regular follow-ups with the participants once the programme had finished. These findings are supported by research showing that the formation of a new habit can take anywhere between 18 and 254 days, depending on a wide range of factors (Clear, 2014; Lally et al., 2010). This is particularly relatable to adults with SMI and CVD risk factors who may experience significant fluctuations in their health and social needs. In fact, Clear (2014) explains that it is normal to *veer off the track* now and again as habit formation is not an 'all-or-nothing' process. Therefore, all stakeholders must be patient with service users and health professionals should provide iterative feedback and support, given that people with SMI experience significant psychosocial disability. This idea was also strongly supported, and advocated for, by the trial team.

In summary, in Figure 13 below, six steps underpinning the systematic implementation of the Flinders Programme or similar health interventions among adults with SMI. The left-hand column in red font shows the potential barriers health staff might experience while delivering the health

intervention. The right-hand column in green font proposes some strategies to overcome those barriers.

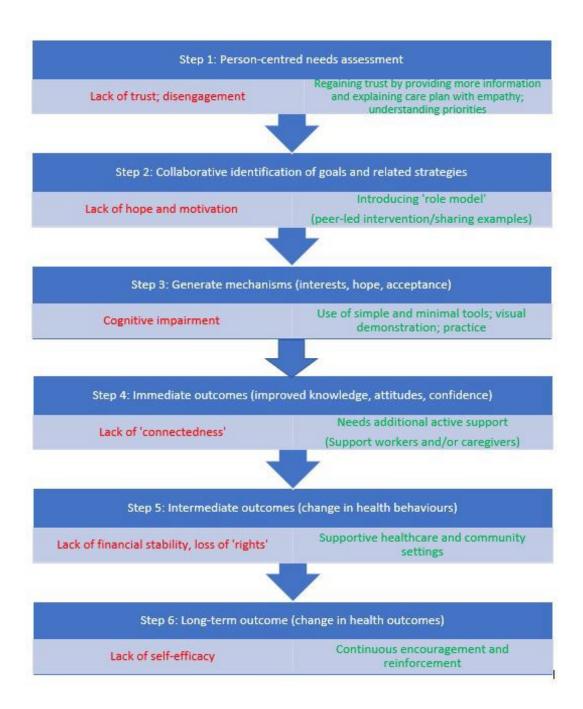


Figure 13: How to initiate and engage service users in self-management and recovery-oriented care

8.5 Supported Self-Management and Social Recovery (SSMSR): A novel middle-range theoretical model

As described in the previous chapter, the Chronic Care Model (CCM) (Wagner, 1998) underpins the Flinders Programme (Battersby et al., 2018). The CCM is a one-to-one self-management programme that acknowledges micro (individual), meso (health system), and macro level (community) factors, and is designed to be delivered within routine health care. CCM is a widely adopted (and often adapted) chronic condition self-management model that has six domains: i) self-management support, ii) organisational support, iii) delivery system design, iv) decision support, v) clinical information systems, and vi) community resources and policies.

The key differences between the CCM and the Flinders Programme are that the latter can be delivered outside routine care and uses recovery-oriented motivational interviewing techniques to initiate a person-centred written care plan. The delivery person (health professional) aims to empower the service user by encouraging them to set their own health goals, which often target the social determinants of health (e.g., improved social connections), rather than focusing on the direct health outcomes (e.g., improved eating habits or physical activities). The aim of the Flinders Programme is thus to target the 'causes of the causes that hinder self-management behaviours' (Braveman & Gottlieb, 2014). These additional features of the Flinders Programme and stakeholders' expressed needs regarding improving the cardiovascular health of community-living adults with SMI generated new ideas captured through thematic analysis in the earlier result chapters. In this chapter, the critical realism-based data triangulation helped to collaborate and synthesise those newly emergent ideas (Figure 11, step 2). As the data analysis progressed, it was evident that adults with SMI experienced significant health inequity and social injustice. Therefore, social recovery-oriented equitable care was needed for motivation and engagement to enable cardiovascular-related self-management behaviours (Pelletier et al., 2015; Ramon, 2018; Rowe & Davidson, 2016).

This thesis revealed that the original six CCM domains did not elaborate on service user roles within self-management. The CCM also failed to capture family caregivers' essential contributions in this process. This chapter also spotlighted the importance of incorporating elements of both personal (Leamy et al., 2011) and social justice (Morrow & Malcoe, 2017) models within the CCM when addressing health issues of community-living adults with SMI. Participant feedback suggested that the Flinders Programme contained critical elements of CCM (e.g., educated, activated patient, organisational support, connection with community resources) and personal recovery models (e.g., focusing on motivation and empowerment). However, a significant change within the health service culture is required to deliver the programme successfully within a community mental health setting. There is also the need to address the broader socio-cultural and policy-level issues, such as moving away from paternalistic psychiatry towards a recovery-oriented approach. This chapter reports that coerced care and community policies (e.g., the heavy reliance of the mental health system on the

risk-averse medical model, community treatment order, and public trustee involving the tribunal) were key reasons for service users to feel disempowered, and hence, unmotivated to engage in seeking, and adhering to, self-management behaviours. Service users and caregivers greatly appreciated the Flinders Programme trial nurses' respectful and empathetic attitude and were deemed the main facilitators of successful engagement with the Flinders Programme. The integrated stakeholder perceptions revealed 'invisible changes' in the Flinders Programme participants, such as enhanced hope, motivation, and awareness towards recovery; these changes were still highly valued by health professionals and researchers, saying that even such small changes were significant in adults with SMI.

The broader literature also acknowledges the importance of this concept of invisible changes and small steps in behavioural change interventions, especially when the target patient population is a high-risk, high-need group such as adults diagnosed with SMI and CVD risk factors (Kemp et al., 2015; Muralidharan et al., 2021). A holistic health approach involving social cohesion, inclusion, empowerment, and socioeconomic security (Ward et al., 2011) will ensure that service users beyond the health settings will sustain the programme's effect as part of their ongoing recovery and life in the community. As a result, this thesis proposed a new middle-range theoretical model called Supported Self-management and Social Recovery (SSMSR). Middle-range theoretical models create a bridge between theory and practice, propose an implementation framework suitable for the current context, and consider the broader socio-environmental factors in delivering the complex intervention in natural settings (Liehr & Smith, 2017). Figure 14 below presents the SSMSR model.

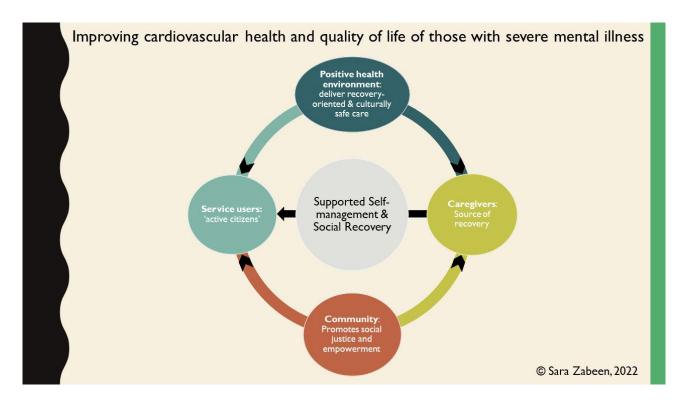


Figure 14: Supported self-management and social recovery (SSMSR) model

8.6 Chapter summary

With time, rapport, and quality care, this chapter presented evidence showing adults with SMI and CVD risk factors engaged well with the Flinders Programme and improved health behaviours. The changes were often perceived as insignificant ('invisible'), such as changes in the person's motivation, awareness, or hope. However, the trial team members and caregivers suggested that even such small changes were noteworthy for adults with SMI and CVD risk factors. Global research also suggests this notion (Kemp et al., 2015; Muralidharan et al., 2021). However, to ensure service users' full engagement and sustained positive health behaviours, it is important to fulfil their basic needs first: food, housing, and income security. Most service users then prioritised having improved social connections in their care plans. Once these concerns were addressed, service users were automatically motivated and engaged in a healthy lifestyle. A person-centred care approach (Eklund et al., 2019) seemed suitable as it actively involves the person and their preferences and needs. Overall, service users' active participation in care plans as 'citizens', caregivers' emotional support, the health system's respectful and recovery-oriented care, and greater social inclusion and community connection can improve the heart health and quality of life of community-living adults with SMI.

CHAPTER NINE: CONCLUSION

9.1 Chapter purpose and structure

This chapter concludes the thesis. Section 9.2 provides a summary of the thesis findings. Section 9.3 then demonstrates the significance of the study by highlighting its original contributions from a theoretical and methodological perspective and proposes policy-level and practical suggestions to orient the health system and professionals to improve their health practice so that adults with SMI and CVD risk factors achieve equitable health care while living in the community. Sections 9.4 and 9.5 then present the limitations of the research and potential future research, and Section 9.6 concludes the thesis with some final remarks.

9.2 Summary findings

The current research thesis found that service users' health-seeking behaviours were negatively impacted by their past experiences with the mental health system. The paternalistic and coerced medical-model-based care, and health professionals' preconceived ideas about service users' inability to recover caused trauma, mistrust, and demoralisation among service users and their caregivers. It was identified that recovery-oriented care rarely existed in "The System". Funding issues and resource mismanagement were identified as the root causes of this problem, triggering both sectoral competition and problems involving power and politics. All these factors negatively impacted the delivery of the Flinders Programme. The results suggest that future extensive groundwork should be undertaken to ensure that sites are well prepared with regards to resources and infrastructure capacity to undertake the Flinders Programme, with staff trained in good interpersonal and interprofessional practice to promote coordinated, collaborative, empathetic, and respectful care.

In relation to social recovery and community integration, it was evident that adults with SMI experienced social stigma and associated isolation and injustice (e.g., unemployment, housing problems, and disempowerment). Caregivers were a primary source of personal recovery as they provided hope, meaning, and purpose in service users' lives and initiated positive role modelling by adopting a healthier lifestyle alongside the service user.

The overall outcomes of the current thesis suggested that when all key stakeholders were fully engaged in the care plan, the Flinders Programme could help service users achieve some of their health and social goals (e.g., preparation towards finding a job, improved social connections, healthy lifestyle). The written care plan, motivational interviewing techniques, regular follow-ups, and rapport with empathetic and respectful nurses were identified as key facilitators to the programme's success.

9.3 Significance of the thesis in terms of original contributions

9.3.1 Theoretical original contributions

This thesis gathered perspectives from all key stakeholders involved in the Flinders Programme trial: service users, their family caregivers, health professionals, and trial team members. This holistic view helped better understand the research problem; how to improve cardiovascular health and quality of life of community-living adults with SMI. The outcomes identified significant gaps in the CCM (Wagner, 1998) (the underpinning model of the Flinders Programme) delivered among community-living adults with SMI and CVD risk factors. While the actual Flinders Programme demonstrated some elements of a person-centred care approach (Eklund et al., 2019), the CCM lacked in four aspects: limited consideration of service users as 'active citizens', lack of caregivers' roles within self-management care, lack of recovery-oriented care within the health system, and little consideration of socioeconomic security and social justice within the community. To address these gaps, this thesis proposed using a new middle-range theoretical model (Liehr & Smith, 2017; Merton, 1968) called Supported Self-Management and Social Recovery (SSMSR). This model is novel and valuable, as it blends principles of personal recovery (Leamy, 2011), self-management (Wagner, 1998) and social recovery (Karadzhov, 2021; RITB, 2019), while considering the practical challenges experienced by frontline health professionals and services. To the best of the researcher's knowledge, no such comprehensive chronic condition self-management model is available that highlights the roles of key stakeholders and is suitable for addressing the physical health needs of community-living adults with SMI while promoting health equity and social justice.

Further to the SSMSR model, the researcher also proposed a conceptual framework identifying the key roles caregivers play in supporting the self-management and recovery journey of service users, which was the outcome of a systematic literature review (Zabeen et al., 2020). It was deemed necessary to develop this new framework as the CCM (Wagner, 1998) did not incorporate caregivers' roles into the model. This thesis further tested and refined the framework with the support of empirical data (Chapter Four). No extant framework could be found that highlighted the importance of caregivers' roles in guiding and supporting the cardiovascular self-management and recovery journey of community-living adults with SMI.

Finally, this thesis has proposed 40 Initial Programme Theories (IPTs) defining stakeholders' roles within the newly proposed Supported Self-Management and Social Recovery (SSMSR) model (see Chapter Seven: Data Triangulation). IPTs are a set of assumptions that explain how a health intervention (in this case, Flinders Programme) might work within the real world where stakeholders' experiences can vary based on their contexts and interactions with each other. Here, the CMO configuration was used to develop IPTs (Mukumbang et al., 2020; Pawson et al., 2004). The researcher hopes that capturing the views and perceptions of all key stakeholders and observing their interactions within community mental health settings over an extended period (November 2017–

September 2020) will allow a more holistic understanding of the topic: how to improve cardiovascular health and quality of life of community-living adults with SMI. Again, to the best of the researcher's knowledge, no study has used this detailed methodology and fine-grained process of developing IPTs on this topic.

9.3.2 Original methodological contributions

In their review paper, (Zabeen et al., 2021) found that more research was needed to understand how physical health interventions were delivered in mental health settings to ensure replicability and sustainability. As such, this thesis employed a process evaluation (Chapter Six) defined by Moore et al. (2015) within the UK Medical Research Council guidelines. Further to this aspect, researchers found a significant gap in comprehensive outcome evaluation-based study design that considered socio-environmental factors of real world settings to understand the delivery of health interventions (Greenhalgh & Papoutsi, 2018). Real world settings-based studies help to investigate a health intervention from both the 'inside' (views of the trial team and health professionals) and the 'outside' lifeworld (views of the service users and caregivers) (Greenhalgh, 2017).

To address this methodological gap, this thesis has used the philosophical and ontological lens of CR (Bhaskar, 1979, 2014) to understand how to improve cardiovascular health and quality of life of community-living adults with SMI. The original aim of this thesis was not to propose any new models, but instead, to use a combination of process (RE-AIM) and outcome evaluation (Realist Evaluation) to investigate the acceptability and feasibility of the Flinders Programme. While RE-AIM (Glasgow et al., 1999) helped to gain an understanding of how the Flinders Programme was delivered in the South Australian community mental health settings, Realist Evaluation (Pawson & Tilley, 1997) explained how and why it worked (or not) and under which circumstances. The Realistic Evaluation framework unpacked the CMO configurations of all key stakeholder roles within their real-world settings. The overall outcome identified significant gaps in terms of theoretical aspects - lack of understanding and acknowledgement of roles and responsibilities of the service users and caregivers, and gaps in recovery-oriented health practices by service providers. Therefore, this thesis proposed a conceptual framework highlighting caregivers' roles in supported selfmanagement and recovery-oriented care that can improve the cardiovascular health and quality of life of community-living adults with SMI. The development of SSMSR and the caregiver frameworks resulted from the gaps identified while conducting this thesis. However, the further generation of 40 IPTs associating stakeholder roles was an objective of the view that helped to identify the underlying mechanisms within the natural world that produced (or inhibited) positive CVD health outcomes for service users. These 40 IPTs will be helpful to maximise the outcome of the Flinders Programme (or any similar health intervention) in the future. Overall, this thesis adhered closely to theory while considering the practical aspects of delivering a health intervention in the real world. From a

methodological point of view, this was a unique and comprehensive approach that took a fresh perspective on the research problem, that is, inequitable health outcomes experienced by community-living adults with SMI and CVD risk factors.

In terms of data sources, settings, and data collection methods, this thesis again took a holistic approach as it captured views of all key stakeholders – service users, their matched family caregivers, their matched health professionals (both mental and physical health staff), and the trial team including the Flinders Programme delivery nurses. Health professionals and the trial team helped to gain an understanding of the practical challenges faced by frontline staff, such as mental health nurses and community rehab workers. Data were gathered from two urban community mental health clinics within two different health networks, one rehabilitation centre, and one supported residential facility. Stakeholders' perceptions, interactions, and combined experiences within the real world helped identify the critical risk factors that initiated and perpetuated poor physical health outcomes in adults with SMI for decades. Inclusion of the trial team members' experiences illuminated how the Flinders Programme or a similar intervention can be implemented successfully within the current health system after some adaptations.

As part of this longitudinal qualitative evaluation (Tuthill et al., 2020), the perceptions of all key stakeholders captured through interviews and focus group discussions helped to depict a holistic picture of the problem. Further to these methods, the minutes from 10 trial team meetings and 5 reflective journals were analysed. The reflective journals captured the key understandings of 5 trial team members, including the researchers who employed a mix of participant and non-participant observations. The researcher herself acted like a 'fly on the wall' (Gkatzidou, Giacomin, & Skrypchuk, 2021) to observe the physical and service culture-related characteristics of the study sites and stakeholder behaviours over an extended period (July 2017 to November 2019). Stakeholders' interactions and power dynamics were also explored through this method. Recent research on implementation science (Greenhalgh & Papoutsi, 2018) and a narrative review (Zabeen et al., 2021) confirmed that researchers scarcely employ such a holistic research methodology. In contrast, this thesis demonstrated methodological comprehensiveness and rigour in process evaluation (Moore et al., 2015).

The use of Roy Bhaskar's CR (Bhaskar, 1979, 2014) in this thesis asserted the importance of identifying socio-environmental factors in the real world that impact human behaviours and initiate mechanisms towards health outcomes, which guided the approach to all the analyses. The four-step iterative and complex Critical Realist Analysis process (Fig 7.1) helped to identify the root causes integrated within the social fabric and constructs (e.g., power, politics, socioeconomic discrimination, stigma) that hindered community-living service users' health, wellbeing, and motivation towards recovery. CCM was used as part of the framework analysis (Srivastava & Thomson, 2009) to organise the key themes within CCM's existing six chronic condition self-management domains

(Wagner, 1998). Any new ideas or emerging themes were captured through thematic analysis (Braun & Clarke, 2006; Terry et al., 2017). Next, Realist Synthesis was used to identify the Context-Mechanism-Outcome/CMO configurations that helped to generate the Initial Programme Theories/IPTs (Pawson et al., 2005). Data triangulation (Carter et al., 2014) and longitudinal qualitative analytical approaches (Saldaña, 2003; Tuthill et al., 2020) were then used to revise and refine the key themes, sub-themes, and related IPTs while considering the different contexts and changes that occurred through time (Figure 11). The overall outcomes helped to develop the Supported Self-Management and Social Recovery (SSMSR) model and 40 IPTs, which have the potential for replication in other regions and among other behavioural health interventions, especially involving marginalised and stigmatised service users. The researcher's observations and reflections from public health and social science perspectives have added further novelty and uniqueness in examining the research topic that is deeply embedded within the field of Psychiatry (e.g., service culture-related issues, the underlying philosophy of the model of care). To the best of the researcher's knowledge, no other studies have adopted such a comprehensive methodological approach in exploring the research problem.

9.3.3 Policy-level contributions

The findings of this thesis strongly encourage the following policy-level changes to ensure the maximisation of health and community resources and the optimisation of service user health for people with SMI and CVD risk factors:

- a) The South Australian mental health system needs a *paradigm shift* towards more person-centred recovery-oriented care. There was clear evidence that existing mental health and community policies caused trauma, stigma, and disempowerment to service users, negatively impacting their trust and engagement towards the health system. This is particularly important as recent research suggests that there is limited scientific evidence that community treatment orders or similar enforced treatments have more benefits than voluntary treatment (Kisely, McMahon, & Siskind, 2023).
- b) More funding and more secure funding beyond short-term pilot programmes should be provided to community mental health settings. A CRA-based analysis suggested that lack of funding towards recovery-oriented care was the critical reason mental health moved more towards medication-based models. While the Flinders Programme was trialled within SA community mental health settings, sites A and D (urban community mental health clinics) underwent major structural reforms that saw significant budget cuts of recovery-oriented models and subsequent job losses. Health professionals reported that over the past five years, many excellent recovery-oriented health interventions had lost funding despite showing promising results. Some of the

trial team members mentioned that non-government organisations (NGOs) had been availed of more recovery-oriented funding as they could support more service users within the community at a lesser cost. However, there was a sense that NGO staff (e.g., support workers) were not well-trained and lacked consistency in delivering care to adults with SMI, a finding also supported by Moskos & Isherwood (2019).

- c) There is also a need for role clarity regarding who oversees the physical health problems of adults with SMI. Mental health professionals suggested that General Practitioners (GPs) and primary care nurses were well-positioned to deliver health promotion and self-management care among service users. However, this thesis and the global literature (Croxson et al., 2017) found that these two health professional groups were extremely time-poor and needed more skills to understand the overall health needs of adults with SMI. Consistent with the global literature, the findings of this thesis suggested that while primary care providers were highly valued, service users and caregivers wanted mental health staff to provide more recovery-oriented care as they were more skilled and confident in supporting adults with SMI (Šprah et al., 2017).
- d) The trial team proposed that it was also possible to deploy a new workforce involving peer educators with lived experience who would be able to understand service user health and wellbeing needs, and thus, be suitable to deliver the Flinders Programme or similar recovery-oriented self-management health interventions with proper training. Other research also supports the value of peer educators in fostering hope, motivation, and role modelling towards recovery (Muir-Cochrane et al., 2019). The benefits are two-fold: the peer educators would have the opportunity to thrive in the community as 'active citizens', and the delivery cost of the programme would likely be less than that of a mental health clinician.
- e) One of the significant findings was how caregivers played a pivotal role in supporting service users' self-management and recovery journey, but were largely overlooked by the health system and researchers. The earlier section of this chapter (section 9.3.1) already identified the current gaps in research and proposed new frameworks highlighting caregivers' roles within self-management and recovery care (Supported Self-Management and Social Recovery model, unpublished: Zabeen et al., 2020). This section recommends practical solutions regarding incorporating caregivers within the health system to optimise service users' health outcomes. For instance, caregivers' lived experience of service users' self-management capacities and inside knowledge about their health needs could be integrated within the care plan by employing a more systematic and family-inclusive approach. However, caregivers themselves need support as well; counselling, training regarding managing service users' mental health warning signs, and receiving practical support (e.g., NDIS and well-trained support workers) would be beneficial. This thesis found that most service users were alienated from their family and thus, did not have

a caregiver. But if potential caregivers receive the aforementioned supports from the health system and the communities, they might feel encouraged to assist their family member with SMI.

f) Stigmatisation was identified as another basis for adults with SMI developing and sustaining CVD risk factors, suggesting that stronger government policies to address stigma are needed. This thesis highlighted that social stigma was the underlying reason for social isolation, socioeconomic injustice, and the paucity of social cohesion (e.g., lack of employment, housing, and access to psychosocial support). This finding is consistent with those of other global researchers and could be resolved by effectively using media (TV, radio, billboards), social media, and public campaigns (Ma, 2017). In addition, there needs to be a stronger focus on addressing stigma within systems and their workforces, as emphasised by the soon to be released National Stigma and Discrimination Reduction Strategy (NMHC, 2023).

The ten principles of the 'Health in All Policies' approach seem to support many of the above ideas, which advocate that health is a fundamental human right. In order to resolve many of the 'wicked problems' of the overall health system, it is essential to shift our focus toward also including non-health social, political, cultural, and environmental factors into the equation so that the various stakeholders are enabled to work together rather than to operate and deliver support in silos (Baum et al., 2014; SA-Health, 2023).

9.3.4 Empirical contributions

The key findings of this thesis have generated some practical suggestions regarding improving cardiovascular health and quality of life of community-living adults with SMI. These suggestions would help provide more targeted solutions suitable to stakeholders and the systems that support and engage with these populations.

- The results of this thesis showed a poor adoption rate of the Flinders Programme within the study sites. CRA-based analysis suggested that mental health professionals saw the programme as a top-down approach in the context of a challenging time (e.g., funding issues that caused cost-cutting, job losses, work pressure in the community mental health settings). Therefore, in the future, researchers should ensure that the study sites are well-equipped in terms of resources, time, and capacity, and that their staff are well-informed and supportive of any new health interventions; these suggestions are also supported by the broader literature (O'Cathain et al., 2019; Strong et al., 2022).
- The need for improved workforce training in health promotion and communication is indicated by
 this thesis. Work pressures, change fatigue, job insecurity, and the vicarious trauma of dealing
 with adults with SMI were identified as key contributing factors to staff members' poor
 communication styles with service users, caregivers, and/or colleagues. The researchers

suggest that proper staff communication training can improve service users' trust in the health system, enhance rapport between service users and health professionals, and achieve better health outcomes (Kerrigan et al., 2020). The findings also show the importance of looking after staff to avoid burn-out and apathy towards service users and their colleagues (Finklestein et al., 2015).

- The findings stress the overall importance of health professionals having trust in any new health interventions involving populations with SMI. Health professionals should also demonstrate trust in service users' ability to change their health behaviours; proper cultural competency training can be helpful in this regard (Kerrigan et al., 2020).
- The importance of co-designing health interventions involving all key stakeholders is also highlighted by the findings. This process can ensure that the research aims are aligned with the target settings' organisational aims, that service users' health needs and preferences are prioritised, and health settings are ready to address any potential cultural barriers to change.

9.4 Thesis strengths and limitations

This thesis has a number of strengths:

- 1. It was a theory-driven process evaluation that identified major socio-cultural causes that effected and perpetuated poor uptake of recovery-oriented care in the community mental health settings (e.g., patriarchy in mental health, political tension between and within health sectors, internal sectoral rivalries to secure funding, change fatigue in staff).
- 2. The longitudinal qualitative research design enabled the capture of changes in real world settings over an extended period (July 2017-September 2020). The findings revealed crucial factors that promoted or inhibited changes in service users' self-management behaviours (e.g., improved social capital, active family support, death in the family, discharged from the health system). This process also helped to highlight some systemic issues and structural changes within the health system.
- 3. Feedback of matched stakeholders helped to investigate the research problem more intensely from multiple perspectives, and thus, depicted a more holistic picture of the situation.

4. Developing detailed IPTs using qualitative feedback also demonstrated novelty. This process unpacked the CMO configurations of stakeholder roles, thereby identifying the key mechanisms that generated outcomes (whether positive or negative).

All these characteristics make this research unique and valuable.

The limitations of this thesis also need to be acknowledged:

- 1. This research was conducted in South Australia, and thus, may not be replicable or generalisable to other Australian jurisdictions or other countries and their mental health service systems.
- 2. The sample size was very small for caregivers (only four caregivers were available for this longitudinal analysis that generated eight in-depth interviews). Most service users were alienated from their family, and most female service users (N= 3 of 4) were caregivers themselves to dependent children or parents. There were also insufficient follow-up data to gauge the progress of health professionals' experiences (mid-trial had nine interviews; post-trial had three follow-up interviews).
- 3. This research lacks comprehensiveness regarding longitudinal analysis, as suggested in Saldaña (2003). Due to the sheer volume of data, it was challenging to undertake detailed case-based and cross-case analysis that could have captured changes across key themes and sub-themes through time. Instead, the researcher took a reflexive approach based on the outcome of the data triangulation chapter and the reflective journal that integrated and refined the vital themes and sub-themes, and identified change through time.
- 4. Due to time constraints, it was not feasible for the researcher to undertake a realist review where 40 IPTs could be tested. A realist review is an extended version of a systematic literature review where IPTs are tested and refined through existing research evidence available on the topic (Pawson et al., 2004). The outcome would ensure the reliability of the IPTs that could help health professionals and researchers take a more targeted approach in delivering a health intervention, as IPTs identify the CMO configurations of any health intervention.
- 5. COVID-19-related public health measures and the researcher's relocation in late 2019 impacted a few post-trial interviews (the researcher left Adelaide and settled in Darwin for personal reasons). For instance, one service user's mid- and post-trial interviews were conducted by telephone instead of face-to-face. Furthermore, two health professionals could not be reached for the follow-up telephone interviews even after multiple attempts (e.g., were

offsite, on leave, travelling due to work). Both these alternate data collection methods occurred based on participant preferences and after the original ethics approval had been amended.

6. The researcher's close involvement in this longitudinal study produced additional contacts with service users (in addition to their Flinders Programme sessions). These other contacts occurred during in-depth interviews, which might have caused unintended positive outcomes. For instance, being a social science study (underpinned by Critical Realism), service users were encouraged to share personal experiences reflecting on broader socio-environmental factors that impacted their self-management behaviours. This process created rapport between the researcher and the service users, and consciously or sub-consciously, the researcher might have motivated service users to adopt and adhere to their health goals. This assumption should be considered during the quantitative analysis of the Flinders Programme.

9.5 Future research focus

This thesis has made three significant theoretical contributions: a) a conceptual framework has been developed and refined based on the literature review and empirical data that has identified caregiver roles in recovery and self-management care (Zabeen et al., 2020), b) A Supported Self-Management and Social Recovery (SSMSR) model has been developed based on the key findings, which suggests ways to improve overall health and quality of life of a marginalised patient group (community-living adults with SMI and CVD risk factors), and c) the development of 40 IPTs unpacking the Context-Mechanism-Outcome (CMO) configuration of the Flinders Programme and related stakeholders' roles in recovery and self-management care. Although the caregiver framework (Zabeen et al., 2020) has been tested through empirical data in Chapter Four (caregivers' experiences captured via in-depth interviews), the sample size was very small and should be tested with a larger sample. Similarly, the SSMSR model should be tested in future research. The researcher is preparing to test the 40 IPTs through a realist review (Pawson et al., 2005), which will be published at a later date. These frameworks and theories need to be further examined through replication in similar high-risk, high-needs, marginalised populations and in other regions. Furthermore, the 40 IPTs could also be used in quantitative studies to examine their validity and reliability.

Based on the overall thesis findings, the previous chapter made a few suggestions regarding the Flinders Programme (Chapter Eight, section 8.4) to improve its suitability, delivery, adoption, and potential sustainability in community mental health settings. Future research should assess these suggestions to determine whether the delivery and efficacy of the Flinders Programme improve. This

modified version of the programme might also be helpful when used with marginalised populations with analogous long-term conditions.

9.6 Concluding remarks

Globally, it has been established that adults with SMI die far earlier than the general population (GBD & Collaborators, 2022), and CVD is a key instigator in this health inequity (De Mooij et al., 2019). Although researchers identified this health problem many decades ago (Maudsley, 1873), the findings of this research revealed that adults with SMI continue to experience poor physical health mainly due to CVD risk factors (e.g., diabetes, obesity, major depression, severe stress and anxiety, a sedentary lifestyle, social isolation, and poverty). Undeniably, there remain identifiable CVD risk factors for adults with SMI spanning the individual, community, and health system levels (Barber & Thornicroft, 2018). Various interventions have been used to enhance preventative health management services through mental and physical health service integration and by supporting persons with SMI to change their health behaviours (Whiteman et al., 2016). However, few studies have measured outcomes directly relating to CVD risk using recovery and self-management-based approaches (Barber & Thornicroft, 2018; Whiteman et al., 2016).

The proposed SSMSR model has employed critical elements of different chronic disease, recovery, and social justice models to address this gap in the current integrated care and implementation research. The SSMSR model has the potential to address CVD risk factors in people with SMI. According to this framework, when all key stakeholders acknowledge their roles and actively engage in the health system and the community, there is a greater chance of achieving improved cardiovascular health among people with SMI. This thesis asserts that CCSM is not a singular pursuit, but is shared by a distributed network of formal and informal community support providers who require the information and skills to support people with SMI effectively. This support network provides the foundation for people with SMI to improve self-care and the capacity to live a meaningful life (Pilgrim, 2017; RITB, 2016). Similarly, at the health system level, more skilled staff and resources, collaborative and integrated care, addressing adversity across the life course as an environmental risk factor, and the provision of more tailored psychosocial supports are required to improve the cardiovascular health of people with SMI (Shrivastava & Shrivastava, 2019; van Hasselt et al., 2013). There is 'no quick fix' available to resolve this complex and wicked health problem; systematic changes with long-term person-centred interventions will be required for sustainable outcomes (Shrivastava & Shrivastava, 2019; Stein et al., 2019).

This longitudinal qualitative research found that 'hope' motivated all stakeholders who engaged with the Flinders Programme. The change agents consisted of those who truly believed in the programme and, more importantly, in service users' ability to change health behaviours and lifestyles. However, it is essential to fulfil service users' basic needs: food, housing, and income security (i.e., acknowledging a clear hierarchy of needs) alongside treating their SMI. Most service users then prioritised having improved social connections in their care plans. Once these problems had been addressed, service users were more motivated and engaged in a healthy lifestyle.

Overall, service users' active participation in care plans as 'citizens', caregivers' emotional support towards personal recovery, the health system's respectful and recovery-oriented care, and the community's social inclusion and cohesion towards social recovery can improve heart health and quality of life of community-living adults with SMI. The outcome of this thesis is the SSMSR model supporting these aspects of health care, which strongly advocates for health equity and social justice for adults with SMI and CVD risk factors. This thesis provides clear evidence for what is needed to be able to achieve these solutions, beginning with greater empathy, respect, and care. This calls for cultural change in the mental health service that promotes family-inclusive, respectful care where service users have a voice and an active role in their care plans.

APPENDICES

Appendix 1: The Flinders Programme Tools

Table 1.1: Flinders Programme components

Flinders Program component ^a	Planning and action for:			
	Condition management	CVD risk management		
Assessment 1 (week 1) Flinders tools: Partners in Health (PIH), Cue & Response	Patient and trial nurse use Flinders tools to identify all risk factors, chronic condition and psychosocial issues and decide which require action.	Using additional tools and resources: • NVDPA Guidelines for the Management of Absolute Cardiovascular Disease Risk • Flinders Program health behaviour assessment tools • Trial nurse database of resources, • Nurse and patient review CVD risk and lifestyle and agree		
Assessment 2 (week 2) Flinders tools: Problems & Goals (P&G), Flinders Care Plan		plan for behaviour change among: - Smoking cessation – details below - Diet and exercise – details below - Alcohol use – SA Alcohol and Drug Information Service (ADIS) resources - Lipid-lowering / BP medication via GP		
Flinders Care Plan for following 6–12	months shared by trial nurse, patient, psychiatrist, mental health care coordinator and genera	al practitioner (GP).		
Follow-up (week 1–4)	At flexible negotiated follow-up and review contacts (6 in total), the trial nurse: • Monitors outcomes of the care plan using PIH and P&G scores • Assists the patient to achieve goals using motivational and problem-solving approaches and informational and community-based resources • Uses the structured framework of the Flinders Program to coordinate care e.g.,: – as needed, assists access to identified disease specific services e.g. self- management education, home medication review, GP Management Plan and Team Care Arrangements, Chronic Disease Dental Scheme, as per care plan – as needed, assists access to services and coordinates communication between patient and services, social work, Occupational Therapist assessment, Patient Assistance Transport Scheme, financial counselling, local activity groups/courses, Disability Employment Services, Housing, other as per care plan • Reviews and updates Flinders Care Plan as required.			
Follow-up (week 6)				
Follow-up (week 8)				
Follow-up (week 12)				
Follow-up (week 16)				
Follow-up (week 20)				

 $^{{\}rm ^aAssessments\ face\text{--}to\text{--}face\ and\ follow\text{--}ups\ face\text{--}to\text{--}face/phone/email/SMS\ to\ suit\ patient\ needs}}$

Source: Battersby et al. (2018, p. 4)

Table 1.2: Flinders Programme tools

Component	Processes	Completion Time
1. Partners in Health Scale (PIH)	These are 12 questions where the patient rates their self-management capabilities. Each question is scored on a 9-point Likert-scale where 0=no self-management and 8=high self-management.	3-5 minutes
2. Cue and Response Interview	The health professional and the patient have an in-depth conversation about the abovementioned 12 PIH questions in order to establish what the patient knows, what they do well, and the potential enablers and barriers to effective self-management. Each question is then scored by the health professional on a 9-point Likert-scale where 0=no self-management and 8=high self-management. They then compare their score for each question with the patient's score. Discussion of any discrepancies between their views is undertaken. Problems to be addressed within the care plan are collaboratively determined by the patient and health professional; this step provides key detailed assessment information.	20-45 minutes
3. Problem and Goal Assessment	The patient's current priority issue affecting their life and a "SMART" goal, led by the patient are then determined.	10-20 minutes
4. Self-Management Care Plan	Developed with full collaboration and agreement with the patient, listing priority issues, what the patient wants to achieve, steps to get there, who is responsible and an agreed review date to monitor progress.	15-20 minutes

Source: Battersby et al. (2018, p. 5) (Additional file 2)

Appendix 2: Master Participant Information and Consent Form

FLINDERS UNIVERSITY

ADELAIDE • AUSTRALIA

Flinders Human Behaviour & Health Research Unit

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Participant Information Sheet

Project:

Improving cardiovascular health and quality of life in people with severe mental illness: a qualitative study to determine underlying facilitators and barriers of a 'partners in health' intervention

We are inviting you to participate in this research project, but whether you wish to or not is entirely up to you. Whether you take part or not, the services which you receive from SALHN mental health clinics or any other service will not be affected in any way.

Introduction

This study looks at whether the Flinders Program of care planning can improve heart health for people with mental illness. The study will involve two groups: one group will receive the usual care that they currently receive from services. The other group will also receive this usual care plus the Flinders Program of care planning to provide chronic condition self-management support.

We will aim to conduct qualitative interviews (approximately 30-60 minutes in length) with a sample of approximately 20 participants (at three points of times): at the start of the trial, at the middle stage and then again at the end of the trial. The purpose of the interviews is to hear your perspectives of self-management, the care plan, the care provided, any concerns about your physical health, and communication with service providers.

Why is this study being carried out?

The aim of this study is to improve the physical health of people with mental health conditions. We will evaluate the effectiveness of the Flinders Program to reduce risks linked to heart disease and improve quality of life for people with mental health conditions. We will also seek the views of trial and health service staff, and patients' carers.

Are there any direct benefits from my participation?

You will have the opportunity to contribute your feedback on the trial. Whilst you may not receive any direct benefit from your involvement in this study, this information you provide during interviews will inform how we might help to improve services to people with mental health and physical health conditions, generally. All participants will receive a small honorarium for their time and to cover any expenses incurred as part of attending interviews.

What does giving consent mean?

Giving consent means that you have signed a written consent form and read the information sheet. We are happy to answer any questions you may have. If you wish, you can discuss this with relatives, friends and your personal doctor. The

consent is to participate in the interviews and to allow us to use your de-identified comments when we write our research report and any publications.

You can withdraw your consent to participate at any time up until the final draft report of de-identified data is produced. You can do this by contacting the researcher either by phone or email (details provided at the top of this information sheet), or through a person (such as a friend or your usual mental health professional contact person) who you nominate to contact the researcher on your behalf.

What will you need to do?

- If you take part in the study we will ask you to participate in the interviews at the start, middle and at the end of the treatment.
- Interviews will occur at the community mental health clinic or another convenient location that you nominate, and at a time mutually agreed by you and the researcher.
- All interviews will be audio-recorded and transcribed to enable accurate recall by the researcher. If you do not wish
 this to occur, the research officer will take notes only of what is said in the interview. The audio-records and
 transcriptions will be stored in a secure password protected system for a period of fifteen years in accordance with
 the Flinders University requirements and later permanently erased from the system.

How will my privacy be protected?

The information we collect from you will not be seen or used by anyone except the research team. Your information will not be given to any other person without your permission. All data is stored on a secure password protected system. You will have the opportunity to view your typed comments from the interview and delete, change or add any further comments if you wish to.

Is taking part in the study voluntary?

Yes. You don't have to participate in this study if you do not want to. If you choose to participate and then want to withdraw without giving a reason, that is OK – this will not affect your current or future treatment in any way.

If you have any further questions

Any enquiries you may have concerning this project should be directed to me. The contact details are given above.

Thank you for your attention and assistance.

Yours sincerely,

Stann

Professor Sharon Lawn,

Director, Flinders Human Behaviour and Health Research Unit

Department of Psychiatry, School of Medicine

Flinders University, South Australia

CONSENT TO PARTICIPATION IN RESEARCH

1,			
(first or given names)	(last name)		
research project on Improving ca	rdiovascular health and q	pate as requested in the letter of intro quality of life in people with severe of d barriers of a 'partners in health' in	mental illness:
I acknowledge that the details of tinvolved; anticipation of length of ti	-	plained to me, including indications on which they will be performed:	f risks; any discomfort
I have had the opportunity to given to me.	ask questions about the stu	udy and am satisfied with the answers	s and the explanations
 I have been provided with a w I understand that my involven affecting my rights or the resp 	nent in this research to me	e and that I may withdraw my conseners in any respect.	nt at any stage without
I know I have the opportunity t decision to take part in this stu	-	vith another person and have had suff	icient time to make the
 I know that I may withdraw from participate, it will have no important. 	-	without affecting my usual care or tr receive.	reatment. If I refuse to
	ecure data storage area fo	ed, but my identity will be kept confider a period of fifteen years in accordance	
I agree to my interview being discussed in the interview. Yes		accurate recall by the researcher of w whichever applies)	hat we have
Signature of Research Participant:		Date:	
l,	have descri	bed to	
the research project and nature and has freely given his/her conse	•	volved. In my opinion he/she unders	stands the explanation
Researcher's Signature:		Date:	

Status in Project:

Appendix 3: Interview guide

Qualitative question guide

1. Intervention Participants

Initial interviews with patient participants will explore:

- Views of self-management
- Views of recovery
- · Experiences with care plans

Follow-up interviews with patients will explore:

- Whether care experiences have changed
- · Whether views of self-management and recovery have changed
- Whether actions and relationship with the illness have changed
- Their experiences with the intervention
 - O What is helpful to you with this programme?
 - o What are some of the challenges you have been encountering?

2. Carers of Intervention Participants

Initial interviews with intervention carers will explore:

- Perceptions of previous and current self-management by the person cared for
- Perceptions of the intervention
- Previous and current interaction, care and support provision with the person
- Concerns about the person's physical health
- Previous and current experiences of communication with service providers

Follow-up interviews with carers will explore:

- Perceptions of previous and current self-management by the person cared for
- Perceptions of the intervention
 - O What is helpful to you with this program?
 - o What are some of the challenges you have been encountering?
- Previous and current interaction, care and support provision with the person
- · Concerns about the person's physical health
- Previous and current experiences of communication with service providers

3. Health Professionals

Interviews with health workers from each role group (psychiatrist, general practitioners, clinic nurses, case managers) providing care to participants will explore:

- Perceptions of providing self-management to people with mental illness
- Perceptions of patient collaboration in care
- Perceptions of previous and current interaction with the patient's carer and other support providers
- Perceptions of the intervention
 - o What responses are you having from your clients?
 - Your experience so far with the Flinders Program?

- o Your understanding of this program?
- o Tell me how it compares to your previous practice?
- O What is helpful to you with this program?
- o What are some of the enablers you have been encountering?
- o What are some of the challenges you have been encountering?
- Implications for implementation of the trialled approach into current and future practice

Focus groups with mental health workers (psychiatrists, GPs, clinical nurses, and case managers) will explore similar questions to the individual interviews with staff. Group discussion will enable participants to reflect on the experience as a group. This is likely to prompt further reflections on practice and organisational considerations for the implementation and sustainability of these approaches to care.

Trial staff will be asked to keep reflective journals throughout the trial to record perceptions of the intervention and participants' responses to the intervention. They will also be interviewed at the end of the trial to explore their perceptions of the following:

- Uptake of the intervention
- Response of patients, carers, and health professionals to the intervention

Appendix 4: Ethics approval

Office for Research

Flinders Medical Centre Ward 6C, Room 6A219 Flinders Drive, Bedford Park SA 5042 Tel: (08) 8204 6453 E: Health.SALHNOfficeforResearch@sa.gov.au



Final approval for ethics application

You are reminded that this letter constitutes **ethical** approval only. **Ethics approval is one aspect of the research governance process.**

You must not commence this research project at any SA Health sites listed in the application until a Site Specific Assessment (SSA), or Access Request for data or tissue form has been authorised by the Chief Executive or delegate of each site.

28 February 2017

Professor Malcolm Battersby Department of Psychiatry Flinders University BEDFORD PARK SA 5042

Dear Professor Battersby

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188) have reviewed and provided ethical approval for this application which appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research*.

Application Number: OFR # 469.16 - HREC/16/SAC/484

Title: Improving cardiovascular health and quality of life in people with severe mental illness: a randomised trial of a partners in health intervention

Chief investigator: Professor Malcolm Battersby

Approval Period: 28 February 2017 to 28 February 2020

Public health sites approved under this application:

- Marion GP Plus (Mental Health Community Services)
- GP Plus Noarlunga (Mental Health Community Services)
- Trevor Parry Centre
- Cramond Clinic

The below documents have been reviewed and approved:

- NEAF dated 20 January 2017
- PICF Staff Qualitative CVD v3.0 dated 24 February 2017
- PICF Carers' Qualitative CVD v4.0 dated 24 February 2017
- PICF Patients' Qualitative CVD v4.0 dated 24 February 2017
- PICF RCT CVD v4.0 dated 24 February 2017
- Chronic Condition Management Care Plan dated March 2016
 Cue and Response Interview dated March 2016
- Description of Intervention v1.0 dated 8 February 2017
- Outcome Measures v1.0 dated 8 February 2017
 Partners in Health Scale dated March 2016
- Problem and Goals Assessment dated March 2016
- Qualitative Question Guide n.d

TERMS AND CONDITIONS OF ETHICAL APPROVAL

As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below and with the *National Statement chapter 5.5.*

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

- The approval only covers the science and ethics component of the application. A SSA will need to be submitted and authorised before this research project can commence at any of the approved sites identified in the application.
- If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
- Compliance with the National Statement on Ethical Conduct in Human Research (2007) & the Australian Code for the Responsible Conduct of Research (2007).
- To immediately report to SAC HREC anything that may change the ethical or scientific integrity of the project.
- 5. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.
- Submit an annual report on each anniversary of the date of final approval and in the correct template from the SAC HREC website.
- 7. Confidentiality of research participants MUST be maintained at all times.
- 8. A copy of the signed consent form must be given to the participant unless the project is an audit.
- Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
- All requests for access to medical records at any SALHN site must be accompanied by this approval email.
- To regularly review the SAC HREC website and comply with all submission requirements, as they
 change from time to time.
- 12. Once your research project has concluded, any new product/procedure/intervention cannot be conducted in the SALHN as standard practice without the approval of the SALHN New Medical Products and Standardisation Committee or the SALHN New Health Technology and Clinical Practice Innovation Committee (as applicable) Please refer to the relevant committee link on the SALHN intranet for further information.

Kind Regards

A/Professor Bernadette Richards

Chair, SAC HREC

Appendix 5: Johnny Saldana's longitudinal analytical framework

As part of the longitudinal analytical framework, Saldaña (2003) proposed a few questionnaires to guide the analysis process. The questionnaires are presented below.

Framing questions

The five questions in the first set are ways of framing the data (and must therefore be discussed first). Framing questions address and manage the contexts of the particular study's data by locating them in a processual, analytic ocean, if you will. The second set of questions is intended to generate descriptive answers. The third set encourages the researcher to 'rise above the data' to richer levels of analysis and interpretation.

Five framing questions are posed as data analysis progresses:

- 1 What is different from one pond or pool of data to the next?
- 2 When do changes occur through time?
- 3 What contextual and intervening conditions appear to influence and affect participant changes through time?
- 4 What are the dynamics of participant changes through time?
- 5 What preliminary assertions (propositions, findings, results, conclusions, interpretations, and theories) about participant changes can be made as data analysis progresses?

Descriptive questions

The second subset of questions generates descriptive information to help answer the five framing questions and the more complex analytic and interpretive questions that follow. The goal is to generate documented observations of meaningful human actions across time to extract processes (themes, trends, patterns, and so on). This is not necessarily a linear checklist to be answered in the order these questions appear, but an iterative subset of questions to consider on an 'as needed' basis as fieldwork progresses and data are reviewed:

- 6 What increases or emerges through time?
- 7 What is cumulative through time?
- 8 What kinds of surges or epiphanies occur through time?
- 9 What decreases or ceases through time?
- 10 What remains constant or consistent through time?
- 11 What is idiosyncratic through time?
- 12 What is missing through time?

Analytic and interpretive questions

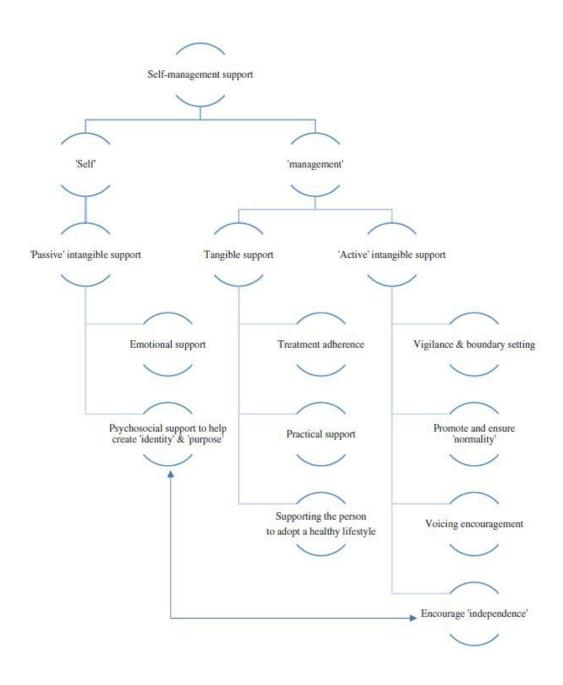
The third subset of questions integrates the descriptive information collected earlier to guide the researcher toward richer levels of analysis and interpretation. Like the second subset, these are iterative and their answers may appear during any moment (even during the framing questions review). More than likely, answers will tend to formulate toward the latter rhythms of data analysis. Answers to one particular question may also apply to other questions:

- 13 Which changes interrelate through time?
- 14 Which changes through time oppose or harmonise with natural human development or constructed social processes?
- 15 What are participant or conceptual rhythms (phases, stages, cycles and so on) through time?
- 16 What is the through-line of the study?

Additional questions

- 17 Who are change agents through time?
- 18 Who resists change through time?

Appendix 6: Zabeen et al. (2020) as an a priori framework to analyse caregivers' data (Chapter Four)



Source: Zabeen et al. (2020, p. 13) (The image 'Caregiver role in providing self-management support in people with SMI, to promote recovery and adopt a healthy lifestyle' has been reproduced with the publisher's permission)

Appendix 7: Summary Context-Mechanism-Outcome (CMO) table

Resource/ policy/action	Mechanisms	Immediate outcomes	Intermediate outcomes	Long-term outcomes	
Service user					
Information and education	Awareness and confidence	Effective communication (with health professionals)	Empowerment	Activation	
Self-management training, strategies, and related study materials	Self- management skills	Self-efficacy	Healthy lifestyles	Sustainability	
Access to self-management tools such as a written care plan, diary, and calendar	Organisational skills	Self-care	Self- management	Adherence	
Having pets	Companionship, responsibilities	Reduce Ioneliness	Responsibility	Healthier lifestyle	
Resilience	Positivity	Motivation	Adherence	Self-care and self- management	
Caregiver					
	Hope and optimism	Positivity	Encouragement	Adoption and adherence	
Caregiver's unconditional emotional support	Connectedness	Personal, communal, and social identity	Meaning and purpose in life	Motivation	
Caregivers help navigate the health and administrative system	Help understand health information	Help make decisions toward preferred health choices	Empowerment	Activation	
Parents' belief in children's ability to self-care	Resilience and self-efficacy	Confidence	Motivation	Adherence	
Caregiver can oversee daily routine and have more dialogues	Set boundaries	Accountability	Independent actions	Self-care	
Financing and time by caregivers	Same goal	Health benefits	Hope and motivation	Improved relationship	
Caregiver's practical support	Coping	Daily self-care needs	Prevent any severe relapses	Escalate recovery process	
Caregiver's ability to negotiate with health professionals	Preferred treatment options	Motivation	Engagement	Activation	
Health system					
Maximization of resources and ensuring affordable care	Amalgamation different organisational care plans	Engagement	Coordination and collaboration	Optimise health outcomes	

Access to health information and treatment results	Trust	Awareness	Motivation and encouragement	Healthier lifestyle adoption	
Shared database between mental health and physical health system	Care coordination	Identifying health needs	Encouragement	Activation	
Training to improve staff's interpersonal skills	Improved empathy and respect	Service user's empowerment	Motivation	Engagement	
Clear guidelines	Clarify health professionals' roles	Identifying health needs	Addressing health needs	Optimise health outcomes	
Written care plan	Coordination	Collaboration	Addressing health needs	Maximise health resources	
Treatment plan	Identification of health needs	Fulfilling health needs	Rapport	Trust	
Well trained	Comfortable and confident	Promote healthy lifestyle	Motivation	Engagement	
Recovery-oriented care	Person-centred approach	Social inclusion	Meaningful life	Activation	
Community					
Psychosocial supports	Motivation towards meaningful life	Reduce loneliness	Social cohesion	Self- management	
Social acceptability within the broader community	Reduce social stigma	Create social identity	Positivity	Motivation	
Access to welcoming and affordable health care and housing	Social inclusion and connectedness	Enhance health and social security	Encouragement	Adoption	
Re-orienting policies (e.g., mental health Act, CTO, PT)	Addressed trauma, mistrust, and disempowerment	Acceptance	Engagement	Self- management	
Flinders Programme					
Affordable one-to-one mentoring approach	Rapport	Trust	Engagement	Self- management	
A person-centred written and flexible care plan	Ownership	Empowerment	Preferred treatment choices	Activation	
Ongoing (but flexible) follow- ups	Accountability	Track progress	Engagement	Adherence	
One-to-one motivational interviewing	Rapport and trust	Motivation	Activation	Self- management	
Written care plan signed by service user	Commitment	A sense of ownership	Activation	Self-care	

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