

Health Literacy and Enduring and Severe Psychotic Disorders: The Development,
Implementation, and Evaluation of Cardiometabolic Health Literacy Interventions
in Outpatients, Inpatients, and Primary Health Care Settings

*A thesis submitted in fulfilment of the requirements
for the degree of*

Doctor of Philosophy

By

Philippa Boss

*Concord Clinical School
Faculty of Medicine and Health
University of Sydney*

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STATEMENT OF ORIGINALITY

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged. To the best of my knowledge and belief, this thesis contains no material previously published or written by another person except where due reference is made. This thesis contains no material that has been presented for a degree at the University of Sydney or any other higher educational institution.

Philippa Boss

10/12/2022

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ABSTRACT

Background

Premature mortality rates from natural causes are considerably higher in people with an enduring and severe psychotic disorder (ESPD) than those found in the general population. Low individual Health Literacy (HL) must be considered when addressing the physical health concerns and premature mortality rates in this population. HL focuses on the necessary individual skills required to obtain, process, and understand health information (Sorensen et al. 2012). Improving individual HL knowledge and skills in this population may empower the patient to self-manage their cardiometabolic comorbidities, and subsequently, help to reduce premature mortality rates.

Aim

The purpose of this thesis is to enhance the understanding of HL and HL interventions in people with an ESPD. The HL interventions in this thesis were feasibility studies designed to test, whether the HL interventions can be implemented in this population group to improve individual HL knowledge and skills.

Methods

Three studies were completed to evaluate the thesis objectives. The studies used a pre-post test study design. Two multi-component HL interventions were developed and were called: (1) Health Education Literacy Program (HELP); and (2) Wallet Prompt Card (WPC). The first two studies piloted the HELP to examine its feasibility in inpatients and outpatients with an ESPD. The third study piloted the WPC to examine its feasibility in outpatients with an ESPD. The Health Literacy Questionnaire (HLQ) was used to evaluate the participants individual HL at baseline and six weeks.

Results

The HL interventions were effective in improving individual HL knowledge and skills. The HELP showed significant ($P < 0.05$) improvements in mean scores for two HLQ domains, and the WPC showed improvements across three domains.

Conclusion

HL interventions are feasible and have the potential to improve individual HL, and thereby, improve health outcomes and reduce premature mortality in this population.

TABLE OF CONTENTS

Statement of Originality.....	2
Acknowledgements.....	3
Abstract.....	4
Table of Contents.....	6
List of Tables.....	15
List of Figures.....	16
List of Publications and Conference Presentations.....	17
Supervisor Confirmation.....	18
List of Common Abbreviations.....	19
Chapter 1: Introduction.....	22
1.1 Introduction.....	22
1.2 The Research Problem.....	23
1.3 General Aims of the Thesis.....	23
1.4 The Research Questions.....	24
1.5 Importance of this Research.....	24
1.6 Design.....	25
1.7 Word Definitions Used in Thesis.....	26
1.8 Structure of the Thesis.....	26
1.8.1 Chapter Two.....	26
1.8.2 Chapter Three.....	26

1.8.3 Chapter Four.....	27
1.8.4 Chapter Five.....	27
1.8.5 Chapter Six.....	27
1.8.6 Chapter Seven.....	28
Chapter 2: Literature Review.....	29
2.1 Introduction.....	29
2.2 Search Strategy.....	30
2.3 Psychotic Disorders and Multimorbidity.....	30
2.3.1 Overview of Psychotic Disorders.....	30
2.3.2 Medication Adherence, Psychotropic Medications, and Side Effects.....	31
2.3.3 Multimorbidity, Medical Biomarkers, and Mortality in Psychotic Disorders.....	33
2.4 Treatment Barriers and Determinants of Health in Psychotic Disorders.....	36
2.4.1 Treatment Barriers for Physical Health Care in Psychotic Disorders.....	36
2.4.2 Determinants of Health and Lifestyle Risk Factors in Psychotic Disorders.....	37
2.4.3 Modifiable Lifestyle Risk Factors - “It Makes SENSE” - (Sleep, Exercise, Nutrition, Substance Use, and Ethanol) – The SENSE Acronym.....	38
2.4.3.1 SENSE Acronym.....	38
2.4.3.2 Sleep.....	39
2.4.3.3 Exercise.....	39
2.4.3.4 Nutrition.....	40

2.4.3.5 Substance Use.....	41
2.4.3.6 Ethanol (alcohol).....	43
2.5 Foundation Skills, Health Literacy (HL), Health Promotion, and Psychotic Disorders.....	43
2.5.1 Foundation Skills and Health Literacy (HL).....	43
2.5.1.1 Literacy.....	44
2.5.1.2 Numeracy and Oral Literacy.....	46
2.5.1.3 Media, Digital or Technology Literacy.....	47
2.5.2 Health Literacy (HL).....	47
2.5.3 HL Definitions.....	49
2.5.4 HL Components.....	50
2.5.4.1 Individual HL.....	51
2.5.4.2 HL Environment or Organisational HL.....	51
2.5.5 Conceptual HL Models.....	52
2.5.6 HL Measures.....	53
2.5.7 Health Literacy Questionnaire (HLQ) and the OPTimising HEalth LiterAcy (Ophelia) Process.....	54
2.5.8 Health Promotion and HL Interventions for People with a Psychotic Disorder.....	55
2.5.8.1 Benefits of HL Interventions for People with a Psychotic Disorder.....	56
2.5.8.2 Limitations of HL Interventions.....	57
2.6 Health Care Utilisation and Chronic Disease Self-Management in Psychotic Disorders.....	58

2.6.1 General Practitioners (GPs).....	58
2.6.2 Integrated Health Care.....	59
2.6.3 Collaborative Centre for Cardiometabolic Health in Psychosis (ccCHiP) Clinic ...	59
2.6.4 Chronic Disease Self-Management.....	60
2.6.5 HL and Type 2 Diabetes Mellitus (T2DM) Self-management.....	61
Chapter 3: Research Design.....	63
3.1 Introduction.....	63
3.2 Planning the Study.....	64
3.3 Research Design and Paradigm.....	65
3.4 Participants.....	66
3.4.1 Eligibility Criteria.....	66
3.4.1.1 Inclusion Criteria.....	66
3.4.1.2 Exclusion Criteria.....	67
3.4.2 Data Collection Settings.....	67
3.4.2.1 HELP Intervention Studies.....	67
3.4.2.2 WPC Intervention Study.....	68
3.5 Sampling Technique.....	68
3.6 HELP Intervention.....	69
3.6.1 Theoretical Framework of HELP Intervention.....	69
3.6.2 Co-design of HELP Intervention.....	69
3.6.3 HELP Intervention.....	70

3.6.3.1 Modifiable Lifestyle Risk Factors - “It Makes SENSE” – (Sleep, Exercise, Nutrition, Substance Use, and Ethanol) - The SENSE Acronym.....	72
3.7 WPC Intervention.....	73
3.7.1 Theoretical Framework of WPC Intervention.....	73
3.7.2 Co-design of WPC Intervention.....	73
3.7.3 WPC Intervention.....	74
3.8 Outcome Measures.....	75
3.8.1 Primary Outcome Measures.....	76
3.8.1.1 Self-reported Individual HL.....	76
3.8.1.2 Self-reported GP Care.....	76
3.8.2 Secondary Outcome Measures.....	77
3.8.3 Exploratory Outcome Measures.....	77
3.8.4 Evaluation of HELP and WPC Interventions.....	77
3.9 Sample Size.....	78
3.10 Ethical Approval.....	78
3.10.1 Approvals.....	78
3.10.2 Consent Form.....	78
3.10.3 Statistical Analysis.....	79
Chapter 4: HELP Makes SENSE: Effects of a Health Literacy Intervention in Outpatients Living with an Enduring and Severe Psychotic Disorder with High Levels of Cardiometabolic Risk: A Pilot Study.....	80
4.1 Introduction.....	80
4.2 Methods.....	81

4.2.1 Participants.....	81
4.2.2 Procedure.....	81
4.2.3 Data Collection and Measures.....	82
4.2.4 Statistical Analysis.....	83
4.2.5 Ethics Approval.....	83
4.3 Results.....	83
4.3.1 Demographic Characteristics.....	83
4.3.2 Health Literacy (HL).....	85
4.3.3 HELP Evaluation Form.....	87
4.3.4 Follow-up Interviews.....	89
4.4 Discussion.....	93
4.4.1 Strengths and Limitations.....	98
4.5 Conclusions.....	99
Chapter 5: HELP Makes SENSE: Effects of a Health Literacy Intervention for Inpatients Living with an Enduring and Severe Psychotic Disorder with High Levels of Cardiometabolic Risk: A Pilot Study.....	100
5.1 Introduction.....	100
5.2 Methods.....	102
5.2.1 Participants.....	102
5.2.2 Procedure.....	103
5.2.3 Data Collection and Measures.....	104
5.2.4 Statistical Analysis.....	104
5.2.5 Ethics Approval.....	104

5.3 Results.....	105
5.3.1 Demographic Characteristics.....	105
5.3.2 Health Literacy (HL).....	106
5.3.3 HELP Evaluation Form.....	108
5.3.4 Follow-up Interviews.....	109
5.4 Discussion.....	110
5.4.1 Strengths and Limitations.....	112
5.5 Conclusions.....	113
Chapter 6: A Wallet Prompt Card (WPC) Intervention to Improve General Practitioner (GP) Care for the Prevention, Treatment, and Management, of Cardiometabolic Comorbidity in Outpatients Living with an Enduring and Severe Psychotic Disorder: A Pilot Study.....	115
6.1 Introduction.....	115
6.2 Methods.....	118
6.2.1 Participants.....	118
6.2.2 Procedure.....	119
6.2.3 Data Collection and Measures.....	119
6.2.4 Statistical Analysis.....	119
6.2.5 Ethics Approval.....	120
6.3 Results.....	120
6.3.1 Demographic Characteristics.....	120
6.3.2 Health Literacy (HL).....	122
6.3.3 WPC Evaluation Form.....	124
6.3.4 Follow-up Interviews.....	125

6.4 Discussion.....	125
6.4.1 Strengths and Limitations.....	127
6.5 Conclusions.....	128
Chapter 7: General Discussion and Conclusions.....	129
7.1 Introduction.....	129
7.2 Summary of Main Findings.....	130
7.3 Strengths and Limitations.....	135
7.4 Recommendations for Future Research.....	135
7.5 Conclusions.....	138
References.....	139
Appendix 1: Nutbeam’s Outcome Model for Health Promotion.....	163
Appendix 2: Health Literacy Definitions.....	164
Appendix 3: Multilevel Model of Risk for Excess Mortality in People Living with a SMI.....	166
Appendix 4: Comprehensive Initial Physical Health Assessment Checklist.....	167
Appendix 5: SHIP Study Results.....	170
Appendix 6: Proposed Neurobiological Targets of Physical Exercise in Bipolar Disorder.....	171
Appendix 7: Physiological and Psychological Mechanisms and Theories Explaining the Link Between Exercise and Improved Mental Health and Wellbeing.....	172
Appendix 8: Checklist for Easy to Understand Print Materials.....	175
Appendix 9: Examples of the Ten Attributes of a Health Literate Health Care Organisation Model.....	177
Appendix 10: Health Literacy Questionnaire (HLQ).....	179
Appendix 11: Steps in the Ophelia Process for the Development of HL Interventions.....	180

Appendix 12: The Health Literacy Questionnaire (HLQ) Scales With High and Low Descriptors of Each Construct.....	181
Appendix 13: Linkage Between the Nutbeam Matrix of Health Literacy (HL) and the Health Literacy Questionnaire (HLQ).....	183
Appendix 14: Effective Lifestyle Interventions to Improve T2DM Self-management in Psychotic Disorders.....	184
Appendix 15: HELP Focus Group Questions.....	185
Appendix 16: Personal Improvement Plan (PIP).....	186
Appendix 17: Structured Follow-up Interview Questionnaire for HELP and WPC Studies.....	187
Appendix 18: Evaluation Form for HELP and WPC Studies.....	192
Appendix 19: Ethics Approval for HELP and WPC Intervention Studies.....	194
Appendix 20: Participant Information Sheet and Consent Form for HELP and WPC Studies.....	196
Appendix 21: Outpatient HELP Participant Cartoon Script.....	214
Appendix 22: WPC Participant Experience with Receiving GP Care.....	219

LIST OF TABLES

Table 4.1	Demographic Data for Outpatient HELP Participants.....	84
Table 4.2	Health Literacy Questionnaire (HLQ) Domain Score Changes for Outpatient HELP Intervention.....	86
Table 4.3	Outpatient HELP Participant Feasibility and Acceptability Ratings.....	88
Table 4.4	Follow-up Interview Data for Outpatient HELP Participants.....	90
Table 5.1	Demographic Data for Inpatient HELP Participants.....	105
Table 5.2	Health Literacy Questionnaire (HLQ) Domain Score Changes for Inpatient HELP Intervention.....	107
Table 5.3	Inpatient HELP Participant Feasibility and Acceptability Ratings.....	109
Table 6.1	Demographic Data for WPC Participants.....	120
Table 6.2	Health Literacy Questionnaire (HLQ) Domain Score Changes for WPC Intervention.....	123
Table 6.3	WPC Participant Feasibility and Acceptability Ratings.....	124

LIST OF FIGURES

Figure 2.1	Complex Phenomenon of HL.....	44
Figure 2.2	Components of HL.....	50
Figure 2.3	HL as an Asset.....	51
Figure 2.4	Integrated HL Model.....	53
Figure 2.5	Nine HLQ Domains.....	55
Figure 2.6	Structure of ccCHiP Clinic and the Clinics External Relationships.....	60
Figure 3.1	HELP and WPC Study Process.....	65
Figure 3.2	Outline of HELP Intervention.....	71
Figure 3.3	Wallet Prompt Card (WPC).....	74
Figure 3.4	Outline of WPC Intervention.....	75
Figure 4.1	Study Profile for Outpatient HELP Intervention.....	82
Figure 4.2	Effect Sizes for the 9 HLQ Domain Scales for Outpatient HELP Intervention...87	
Figure 5.1	Study Profile for Inpatient HELP Intervention.....	103
Figure 5.2	Effect Sizes for the 9 HLQ Domain Scales for Inpatient HELP Intervention....108	
Figure 6.1	Study Profile for WPC Intervention.....	118
Figure 6.2	Effect Sizes for the 9 HLQ Domain Scales for WPC Intervention.....	122

LIST OF PUBLICATIONS AND CONFERENCE PRESENTATIONS

Peer-reviewed Abstracts

Boss, P., and Lambert, T. (2021) HELP Makes SENSE: A Health Literacy Intervention for People with an Enduring and Severe Psychotic Disorder with High Levels of Cardiometabolic Risk. *HLRP: Health Literacy Research and Practice*. 5 (2) 140-154.

Conference Presentations

Boss, P., and Lambert, T. HELP Makes SENSE: A Health Literacy Intervention for People with an Enduring and Severe Psychotic Disorder with High Levels of Cardiometabolic Risk. *Institute for Healthcare Advancement (IHA) 3rd Annual Health Literacy in Action (HLiA) Conference. Health Literacy Annual Research Conference (HARC)*, October 19th-21st 2020. (Virtual Poster presentation).

Boss, P. Health Literacy: A neglected intervention in mental health care?. *28th Annual The Mental Health Services Conference Inc. of Australia and New Zealand (TheMHS)*. Adelaide, August 28th-31st 2018. (Presentation Brief Paper – 10 minutes).

Boss, P. Impact of a health literacy intervention on cardiometabolic health, knowledge, and access to medical care, in people living with a psychotic illness: a feasibility study undertaken in three different NSW mental health service settings. *Sydney Innovation and Research Symposium*. Sydney, June 23rd 2017. (Poster presentation).

Boss, P. The impact of health literacy on the management of multi-morbidity in people with psychotic disorders: A review of the literature. *23rd Annual The Mental Health Services Conference Inc. of Australia and New Zealand (TheMHS)*. Melbourne, August 20th-23rd 2013. (Presentation – 20 minutes).

SUPERVISOR CONFIRMATION

As supervisor for the candidature upon which this thesis is based, I confirm that the author attribution statements above are correct.

Professor Tim Lambert

10/12/2022

LIST OF COMMON ABBREVIATIONS

ADLs	activities of daily living
AMI	Australian Medical Index
ANOVA	analysis of variance
AUDs	alcohol use disorders
BD	bipolar disorder
BDNF	brain-derived neurotrophic factor
BMI	body mass index
CALD	culturally and linguistically diverse
CATIE	Clinical Antipsychotic Trials of Intervention Effectiveness
CBT	cognitive behaviour therapy
ccCHiP	Collaborative Centre for Cardiometabolic Health in Psychosis
CCMH	Concord Centre for Mental Health
CDMP	Chronic Disease Management Plan
CDSM	chronic disease self-management
CFA	confirmatory factor analysis
CI _s	clinical indicators
CMHC	Community Mental Health Centre
CMO	community managed organisation
CMRF	cardiometabolic risk factors
CRGH	Concord Repatriation General Hospital
CVD	cardiovascular disease
DA	dopamine
D&A	drug and alcohol
DSME	Diabetes Self-Management Education
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, fourth edition

DSM-V	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
EIP	Early Intervention in Psychosis
EM	expectation maximisation
ES	effect sizes
ESPD	enduring and severe psychotic disorder
ESS	Epworth Sleepiness Scale
FCMHP	Family and Carer Mental Health Program
FEP	first-episode psychosis
FHL	functional health literacy
GP	General Practitioner
GPs	General Practitioners
GWAS	genome wide association study
HBM	Health Belief Model
HELP	Health Education Literacy Program
HL	health literacy
HLQ	Health Literacy Questionnaire
LHD	Local Health District
MeSH	Medical Subject Headings
MetS	metabolic syndrome
NE	noradrenaline
NGO	non-government organisation
NRT	nicotine replacement therapy
NSQHS	National Safety and Quality Health Service
NSW	New South Wales
ODMH	One Door Mental Health

Ophelia	OPTimising HEalth LIterAcy
OSAS	obstructive sleep apnoea syndrome
PBS	Pharmaceutical Benefits Scheme
PDSA	Plan-Do-Study-Act
PIP	Personal Improvement Plan
PSQI	Pittsburgh Sleep Quality Index
QoL	quality of life
RANZCP	Royal Australian and New Zealand College of Psychiatrists
RCT	randomised control trial
REALM	Rapid Estimate of Adult Literacy in Medicine
SDs	standard deviations
SENSE	Sleep, Exercise, Nutrition, Substance Use, and Ethanol
SHIP	Survey of High Impact Psychosis
SLHD	Sydney Local Health District
SMARTER	Specific, Measurable, Achievable, Relevant, Time-bound, Evaluate, and Revise or Reward
SMI	severe mental illness
SMS	Short Message Service
SPSS	Statistical Package for the Social Sciences
SUDs	substance use disorders
T2DM	type 2 diabetes mellitus
TOFHLA	Test of Functional Health Literacy in Adults
UNESCO	United Nations Educational, Scientific and Cultural Organisation
US	United States
WHO	World Health Organisation
WPC	Wallet Prompt Card

CHAPTER 1

Introduction

Abstract

This chapter presents a summary of the thesis. Firstly, it begins with a brief overview of the background to the research and the research problem. Secondly, the aims and questions that guided the research hypothesis are presented to justify the importance of the research. Thirdly, the design section outlines the methods used to conduct the research, followed by an overview of its scope and limitations. Finally, the structure of the remaining thesis chapters is delineated.

1.1 Introduction

Global research regarding the prevalence of health literacy (HL) levels among people living with an enduring and severe psychotic disorder (ESPD) is limited (Barry & Jenkins 2007; Galletly, Lincoln & Arford 2013). A review of the literature revealed a paucity of quality research in this area. The limited research that exists on HL in mental illnesses has primarily investigated depression and symptoms of depression (Galletly, Lincoln & Arford 2013). Low individual HL is an independent risk factor for poorer overall health and increased mortality (Australian Commission on Safety and Quality in Health Care 2014; Berkman, Sheridan, Donahue, Halpern & Crotty 2011; Brach, Keller & Hernandez 2012; Geboers et al. 2018). Therefore, low individual HL should be taken into account and managed in all psychiatric patients. Currently, cardiometabolic HL interventions are rare in mental health treatment settings. Early intervention to improve individual HL regarding cardiometabolic risk factors (CMRF) in this high-risk population may help to improve cardiometabolic health outcomes. Particularly, it may help reduce premature death through patient engagement, education, empowerment, and self-management of CMRF and chronic diseases (Bradshaw, Lovell & Harris 2005; Conn, Hafdahl & Brown 2009; Galletly, Lincoln & Arford 2013; Linde-Feucht 2007).

Evidence shows that the physical health disparities in this population are not improving. They are getting worse and the life expectancy gap is increasing not narrowing (Lambert et al. 2017).

This parlous state could be significantly reduced through the modification of biomedical and behavioural risk factors (Lambert, T & Chapman, LobotCWG 2004). Increased differential morbidity and mortality in this population is largely due to treatable medical conditions that are caused by modifiable risk factors. A number of factors account for the inequality in life expectancy and the excess rates of multiple chronic diseases in this population (Brown, P 2018). Limited HL is associated with poorer overall health, lower use of preventative healthcare services, increased risk of adverse health outcomes in many chronic diseases, increased health care expenditure costs, and premature death (Lee, E, Lee & Moon 2016; Visscher et al. 2018). Therefore, the self-management of CMRF and cardiometabolic health conditions in this high-risk population is of key relevance. To self-manage chronic health conditions an adequate individual HL level is required to make appropriate healthcare decisions for your individual needs and circumstances (Heide et al. 2018). Improving individual HL in people living with an ESPD may help to improve the health outcomes and health inequalities that are experienced by this vulnerable population.

1.2 The Research Problem

The primary aim of this thesis is to enhance the understanding of HL and the application of HL interventions in people living with an ESPD, to determine if HL interventions are a useful therapeutic intervention to support mental health consumers to self-manage their CMRF and cardiometabolic health conditions. HL interventions for this high-risk population are needed to support people living with an ESPD to self-manage cardiometabolic multimorbidity. To my knowledge HL interventions in mental health treatment settings for psychiatric patients are either non-existent or sub optimal. There is minimal published research on the topic both from a local and international perspective. Currently there is a gap in HL research in people living with an ESPD, and there is no evidence-based rationale or HL intervention specifically designed to target the CMRF and cardiometabolic health conditions that are highly prevalent in people living with an ESPD.

1.3 General Aims of the Thesis

The primary aim of the present research is to enhance the understanding of HL and HL interventions in people living with an ESPD. Two cardiometabolic HL interventions were

developed for the purposes of this thesis to directly test the feasibility and effectiveness of the multi-component HL interventions in people living with an ESPD. The HL interventions were feasibility studies designed to test, whether the HL interventions are able to be effectively implemented in this population group to improve individual HL knowledge and skills. The two HL interventions developed for this thesis are called: (1) Health Education Literacy Program (HELP); and (2) Wallet Prompt Card (WPC). The aims of this thesis are to:

1. Pilot the HELP intervention to examine its feasibility in inpatients and outpatients living with an ESPD. The HELP intervention will result in the development of an effective HL education program for people living with an ESPD.
2. Pilot the WPC to examine its feasibility in outpatients living with an ESPD. The WPC was developed to prompt outpatients to discuss their physical health care needs with a General Practitioner (GP), and thereby potentially improve the self-management of their cardiometabolic health.

1.4 The Research Questions

Three questions supported the research aims. Firstly, is it feasible and effective to implement the HELP in people living with an ESPD? Secondly, what is the impact of implementing the HELP in community mental health services and inpatient facilities? To answer these questions the HELP was implemented and evaluated in both mental health treatment settings. Finally, can a WPC assist this population to have a comprehensive physical health check-up with their GP? To answer this question a WPC was designed specifically for this high-risk population to use with a GP, to prompt and engage the patient and GP to have a discussion about CMRF and regular physical health check-ups.

1.5 Importance of this Research

The present research was necessary to determine, if people living with an ESPD are an appropriate group to receive HL interventions. This research was needed to establish if HL interventions can assist mental health consumers to develop their cardiometabolic health knowledge and skills, and to self-manage their health. Currently there is a gap in the existing research regarding HL, psychotic disorders, and cardiometabolic health. The current research

hopes to contribute towards filling the gap in knowledge that exists in HL and people living with an ESPD.

1.6 Design

The Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) was used to classify the participants' diagnosed psychotic disorder for all the studies presented in chapters 4-6. The overall methodology underpinning the present research was based on a pragmatic paradigm. Therefore, a mixed methods methodology was used for the overall research design. A quasi-experimental single subject design (A/B design) was chosen for the purpose of implementing the pilot HELP and WPC intervention studies. The HELP and WPC interventions use a pre-post test study design to evaluate the interventions, with only two time points and a single group. The HELP and WPC interventions were feasibility studies designed to test whether the HL intervention can be implemented in this population group in order to improve individual HL knowledge and skills.¹

Multiple models of HL exist within the literature. The HL model being used for this thesis is Nutbeam's Outcome Model for Health Promotion, which incorporates both medical and public health perspectives, see Appendix 1 (Nutbeam 2000). This model was used to develop the underlying theoretical framework for the HELP and WPC interventions.

Within the literature there are multiple definitions of HL, see section 2.5.3 and Appendix 2. The following HL definition developed by Nutbeam is being used for the purposes of this thesis:

“the ability to gain access to, understand, and use information in ways which promote and maintain good health” (Nutbeam 1998, p. 3).

This HL definition has similarities with the principles that guide an individual's mental health recovery and treatment outcomes (Gagne, White & Anthony 2007; Hutchinson et al. 2006).

¹The studies are not designed to measure effectiveness as the original plan was to measure this in the future using a randomised control trial (RCT).

1.7 Word Definitions Used in Thesis

There is an ongoing debate within the field of HL regarding the correct use of the words “low” and “limited” to describe an individual’s HL level. Due to people’s changing opinions on the topic of HL and the socially dynamic aspects of language and culture, HL definitions are always changing, which results in further complicating the concept of HL. As the underlying science behind the concept of HL has not appreciably changed, I chose to use the words “low” and “limited” interchangeably in this thesis to describe an individual’s HL level. In addition, the words “healthcare” or “health care” also cause confusion for people as they need to know conventions for how to use and spell the word. Depending on the setting these words have different meanings and purposes (Arcadia 2020). In this thesis *health care* spelt with two words refers to provider actions and *healthcare* spelt as one word refers to a healthcare system.

1.8 Structure of the Thesis

Beyond this introduction, the thesis comprises six chapters that follow a logical sequence in presenting the research.

1.8.1 Chapter Two

Chapter two presents a review of the relevant literature on HL in the context of CMRF and chronic disease self-management in people living with an ESPD. The literature review creates support for the present research and synthesizes the existing evidence on novel HL strategies for psychotic disorders. The literature review highlights that existing research has yet to reveal the role that HL interventions may play in assisting individuals with an ESPD to self-manage their CMRF and cardiometabolic health conditions.

1.8.2 Chapter Three

Chapter three details how the research studies presented in chapters 4-6 were designed to address the research aims of the thesis. The first section of the chapter provides an overview of how the HL interventions were planned and the mixed methods approach used to preference its design components. The second section of the chapter describes how the HELP and WPC interventions were developed and the outcome measures used to evaluate the interventions.

1.8.3 Chapter Four

Chapter four evaluates the feasibility of the pilot HELP intervention in outpatients living with an ESPD. The outpatient HELP intervention was implemented in community mental health settings. The hypothesis tested was that the tailored cardiometabolic HL intervention would improve participant's individual HL knowledge and skills. The HELP intervention resulted in the development of an effective HL education program for participants. The study highlights that cardiometabolic HL interventions to improve individual HL in this population are feasible and can be implemented in community mental health services.

1.8.4 Chapter Five

Chapter five evaluates the feasibility of the pilot HELP intervention for inpatients receiving acute or sub-acute treatment for an ESPD. The inpatient HELP intervention was implemented in two mental health inpatient units at the Concord Centre for Mental Health (CCMH) in Sydney, Australia. The study procedure for the inpatient HELP intervention is exactly the same as the outpatient HELP intervention presented in Chapter 4. The hypothesis tested was that the tailored cardiometabolic HL intervention would improve participant's individual HL knowledge and skills. The study highlights that the HELP intervention is feasible and has the potential to be implemented in acute and sub-acute mental health inpatient settings.

1.8.5 Chapter Six

Chapter six evaluates the feasibility of the pilot WPC intervention in outpatients living with an ESPD. The outpatient WPC intervention was implemented in primary healthcare services. The hypothesis tested was that the tailored cardiometabolic WPC intervention would improve participant's individual HL knowledge and skills. The WPC intervention resulted in the development of an effective cardiometabolic HL prompt for participants to discuss their physical health with their GP. The study highlights that a WPC intervention to improve individual HL in this population is feasible and can be implemented in primary healthcare settings.

1.8.6 Chapter Seven

Chapter seven is the final chapter of the thesis. The chapter summarises the findings of the HELP and WPC intervention studies as they relate to the research questions of the thesis. The chapter includes research contribution, strengths and limitations, and recommendations for future research. The chapter highlights that the HL studies in this thesis have advanced knowledge on the role of HL and the multidimensional benefits that occur when addressing HL in this high-risk population.

Each chapter in this thesis begins with an overview and concludes with a summary that provides the link to the proceeding chapter. Therefore, the chapters are interlinked to reflect the research process and provide the reader with a logical progression of thoughts and ideas that are driven by the aim of the research studies. The next chapter presents a review of the relevant literature and synthesises the existing literature on novel HL strategies for psychotic disorders to create support for the present research.

CHAPTER 2

Literature Review

Abstract

This chapter seeks to build knowledge and understanding of HL in the context of cardiometabolic health, chronic disease self-management, health care utilisation, and medical treatment for people living with an ESPD. This chapter presents a review of the relevant literature obtained through the search strategy in section 2.2. This review creates support for the present research and synthesises the existing literature on novel HL strategies for psychotic disorders.

2.1 Introduction

Worldwide premature mortality rates from natural causes are considerably higher in people with a psychotic disorder than the general population. Individuals with a psychotic disorder are dying from similar causes as found in the general population. However, the standardised mortality rates in psychotic disorders are higher than those of the general population. The life expectancy of individuals with a psychotic disorder is between 10-30 years less than that of the general population (Hjorthoj et al. 2017; Muir-Cochrane 2006; Oakley et al. 2018; Smith, S 2008). Physical health problems are highly prevalent in people with a psychotic disorder due to a number of complex interactions and associations between multiple causes.

Various factors including: (1) Genetic; (2) Environmental; (3) Personal; (4) Medical; (5) Pathophysiological; and (6) Behavioural are fundamental drivers for the high prevalence of CMRF leading to metabolic problems, cardiovascular disease (CVD), and mortality in this population (Lambert & Newcomer 2009; Lambert et al. 2017; Lambert & Sureshkumar 2019; Sowden & Huffman 2008). Low individual HL and numeracy must be considered when addressing the physical health concerns and premature mortality rates in this population, as discussed in section 2.3. Psychiatric patients need to have an adequate level of understanding numerical processes when discussing cardiometabolic risk (Webster & Heeley 2010). HL, health education, and health promotion, interventions in this population are unsatisfactory and scarce (Galletly, Lincoln &

Arford 2013). HL interventions should begin as early as possible in the treatment process for psychiatric patients, ideally when first diagnosed and commencing treatment on psychotropic medication. HL interventions need to be implemented in both acute and non-acute psychiatric wards and community health centres to promote and encourage a holistic recovery (Coughlan et al. 2001).

2.2 Search Strategy

A literature search was conducted using the Medical Subject Headings (MeSH) terms ‘health literacy’, ‘health promotion’, ‘health intervention’, ‘lifestyle intervention’, ‘primary health care’, ‘weight management’, ‘physical health’, ‘intervention’, ‘health education’, ‘psychoeducation’, ‘cardiometabolic health’, ‘diabetes’ ‘psychotic disorders’, ‘schizophrenia’, ‘psychosis’, ‘severe mental illness’, and ‘mental illness’ in addition to combinations of these terms. The search was conducted in Ovid MEDLINE, PsycInfo, PubMed and the Cochrane Library with no restrictions on time period and concluded in October 2022. Reference lists of relevant studies and reviews were also scanned for additional publications not identified by the search strategy.

2.3 Psychotic Disorders and Multimorbidity

2.3.1 Overview of Psychotic Disorders

Psychotic disorders are a group of severe psychiatric illnesses that impact on aspects of brain function that are involved in thinking, communication, emotions, perceptions, and behaviour (Association 2000). The most common psychotic disorders managed in health care settings in Australia are schizophrenia, schizoaffective disorder, and bipolar disorder (BD) (Perala 2013; The Department of Health & 2011). Psychotic symptoms can occur in an isolated episode or as part of an ongoing diagnosed psychiatric illness such as schizophrenia or BD. Intervening early assists to improve treatment outcomes for psychiatric patients (McGorry et al. 2004). Individuals with a psychotic disorder are a marginalised group in today’s society, their illness affects all aspects of their life, and a significant number of people experience undesirable outcomes, including: (1) Unemployment; (2) Lack of secondary and tertiary education; (3) Social isolation; (4) Poverty; (5) Homelessness; (6) Repeated hospital admissions; (7) Imprisonment; (8) Stigma; (9) Poor physical health; and (10) Increased premature mortality (Coughlan et al. 2001).

The population prevalence of psychotic disorders is about 3.5% (Lambert 2018). In Australia the annual cost of psychotic disorders to society is \$4.91 billion per annum, and approximately \$3.52 billion per annum for the Australian government (Neil et al. 2014). Worldwide psychotic disorders contribute significantly to the burden of disease in many countries due to their substantial effect on disability and functional impairment (Correll, CU et al. 2017). The multimorbidity of physical health problems in this population along with multiple biomedical and behavioural risk factors contributes to the premature mortality rate (Correll, CU et al. 2017; Mental Health Commission of NSW 2016). A bidirectional effect on disease trajectory occurs with the high presence of unmet physical health needs in psychiatric patients, resulting in more severe psychosis and depression which leads to more complex health needs (Dixon et al. 1999; Kraus et al. 2019).

2.3.2 Medication Adherence, Psychotropic Medications, and Side Effects

Medication adherence² deserves special attention as low HL, is a barrier to medication adherence (Krueger, Berger & Felkey 2005). Evidence shows low individual HL levels are associated with poor medication adherence (Australian Commission on Safety and Quality in Health Care 2014; Willis 2018). Medication adherence is a complex multifactorial behaviour (AlGhurair et al. 2012; Lam & Fresco 2015). Multifaceted medication adherence interventions using the Health Belief Model (HBM) to target a patient's specific barriers to adhering to medication, have shown to be effective in psychiatric outpatients (Kelly, G, Mamon & Scott 1987; Krueger, Berger & Felkey 2005). Improving individual HL levels and health beliefs in this population may assist to improve medication adherence.

Individuals with a psychotic disorder do not adhere with their medication due to: (1) Medication side effects; (2) Psychotic disorganisation; (3) Patient is in denial about the illness and has a lack of insight; (4) Patient wants to maintain ego-syntonic grandiose delusions; (5) Delusional beliefs about taking the psychotropic medication (e.g., patient believes the medication is poisoning them); (6) Patient believes they can heal themselves without the use of medication; (7) The health care team or doctor has not provided the necessary psychoeducation to the patient, to enable the patient to be informed about their illness and self-manage the condition; (8) The patient has been treated

²Adherence is used in this thesis to refer to the patient voluntarily taking their prescribed psychiatric medication, as the patient is actively engaged in their treatment and recovery goals.

in an authoritarian manner by the doctor or health care team resulting in the cooperation and therapeutic relationship not being maintained; (9) Health information is written at high literacy levels; (10) Cognitive impairment; (11) Motivation; (12) Stigma associated with the disorder and medications; (13) Depression, anxiety, psychosocial stress or anger; and (14) Substance dependence (Bardwell & Taylor 2009; Davies 2003; Vermiere, Hearnshaw & Van Royen 2001). In addition, many cultures across the world believe that the underlying signs and causes of a psychiatric illness are related to their culture, superstitions, spiritual causes or personal beliefs, these sociocultural influences impact on medication adherence (Fricchione et al. 2012; Lambert 2007). A barrier to medication adherence is created when migrant psychiatric patients are not familiar with modern medicine procedures and treatments, particularly regarding psychiatric treatment and pharmacotherapy, as it is different to their traditional culture methods of healing (Lambert 2007).

Psychotropic medication is essential for treating psychotic disorders. A common clinical problem is side effects of psychotropic medications (Bardwell & Taylor 2009; Lambert 2011). The side effects from first and second generation antipsychotics impact on the general physical health of patients and contribute to iatrogenic physical health problems (Lang, Barr & Procyshyn 2013; Malhi, Mitchell & Caterson 2001; Osborn 2001). Numerous randomised control trial (RCT) studies demonstrate that the majority of antipsychotics used today are associated with weight gain (Correll, C et al. 2015; Goncalves, Araujo & Martel 2014). The psychotropic medications clozapine and olanzapine have the greatest potential to cause weight gain, dyslipidaemia, and impaired glucose control (Lambert, TJR & Chapman, LH 2004; Lieberman et al. 2005; Malhi, Mitchell & Caterson 2001; Wand & Murray 2008). Weight gain in the long term is highly related to behavioural and lifestyle factors rather than to psychotropic medication alone (Lambert, TJR & Chapman, LH 2004). Doctors who prescribe antipsychotic medications need to consistently and regularly monitor for the development of potentially debilitating side effects, metabolic syndrome (MetS) and CMRF in patients (Byrne et al. 2010; Royal Australian and New Zealand College of Psychiatrists 2015).

2.3.3 Multimorbidity, Medical Biomarkers, and Mortality in Psychotic Disorders

In Australia, the cost of premature mortality in severe mental illness (SMI) due to preventable physical health conditions is estimated to be \$15 billion annually (Brown, P 2018). The inadequate physical health conditions highly prevalent in people living with a SMI is one of the biggest public health challenges facing health care services across Australia in the 21st century. Unfortunately, the physical health concerns in this population are not improving, they are getting worse and the life expectancy gap is increasing not narrowing (Lambert et al. 2017; World Health Organization 2015). A number of factors account for the inequality in life expectancy and the excess rates of multiple chronic diseases in this population. These factors don't act in isolation they are synergistic to the: (1) Individual; (2) Social environment; (3) Health system³; and (4) Psychiatric illness (Brown, P 2018).

Numerous studies have reported that people with a SMI have higher prevalence rates of physical health comorbidities (Correll, CU et al. 2017; Oakley et al. 2018). Multiple causes are associated with the inferior physical health conditions and the excess mortality that exists in this population, see Appendix 3 (Bonfioli et al. 2012). The most common comorbid physical illnesses experienced by people with a psychotic disorder include: (1) CVD; (2) MetS; (3) Type 2 diabetes mellitus (T2DM); (4) Hypertension; (5) High cholesterol/lipids; (6) Respiratory diseases; and (7) Obesity (Kelly, D, Boggs & Conley 2007; O'Sullivan, Gilbert & Ward 2006). Increased morbidity and mortality in psychotic disorders is largely due to treatable medical conditions caused by the following modifiable risk factors: (1) High levels of cigarette smoking; (2) Obesity; (3) Physical inactivity, sedentary lifestyle, and prolonged daily sitting rates; (4) A poor diet that is high in sugar and saturated fat; (5) Excessive substance use; and (6) Inadequate access to medical care (Lambert 2009; Linde-Feucht 2007; Skrinar & Hutchinson 2009). The primary causative CVD risk factors that are modifiable and treatable include: (1) Smoking cigarettes; (2) Dyslipidaemia; (3) Hypertension; (4) Physical inactivity, sedentary lifestyle, and prolonged daily sitting; (5) Diet; (6)

³Systemic problems within the mental health system in conjunction with health care professionals displaying the 2N's: (1) Neglect; and (2) Nihilism, towards the physical health of individuals with a psychotic disorder, synergistically contributes to the multiple causes of multimorbidity in this population.

Obesity; and (7) T2DM (Lambert 2009; Webster & Heeley 2010). These modifiable risk factors increase the risk of a stroke and acute myocardial infarctions (Webster & Heeley 2010).

A higher prevalence of T2DM and CVD exists in the family history of individuals with schizophrenia, it is not known if the increased risk is due to genetics, the environment or the pathophysiology of schizophrenia (Lambert & Newcomer 2009). A genome wide association study (GWAS) exploring the relationship between schizophrenia and CVD showed that genetic correlations between schizophrenia and CVD were minimal (Veeneman et al. 2022). Therefore, shared genetics are not likely to be the cause underlying associations between schizophrenia and CVD. However, the study reported that schizophrenia causally increases the risk of heart failure (Veeneman et al. 2022). The impact of CVD which leads to premature mortality in this population can be significantly reduced through changes to biomedical and behavioural risk factors (Bonfioli et al. 2012; Park et al. 2013). It is now recognised that a wider holistic view of health is needed for this population to prevent, screen, and monitor for cardiometabolic risk (Lambert et al. 2017).

The Framingham Heart Study clearly highlights CVD risk factors are interrelated and influence one another synergistically (Webster & Heeley 2010). Looking at each individual risk factor on its own is pointless, the study highlights “that minor abnormalities in several risk factors combine to produce a high absolute risk of disease” (Webster & Heeley 2010, p. 49). An individual’s overall CVD risk factors need to be screened for and managed, in order to know their overall total risk of having a cardiovascular incident, see Appendix 4 (Lambert et al. 2017; Webster & Heeley 2010). Results from the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study report that psychiatric patients were not receiving medications to help control and self-manage the following MetS conditions: (1) Dyslipidaemia (88% of patients); (2) T2DM (30% of patients); and (3) Hypertension (62% of patients) (Newcomer & Hennekens 2007).

The factors contributing to multimorbidity and CVD in this population are complex and have multifactorial connections (De Hert et al. 2011; World Health Organization 2015). A direct causal pathway between CMRF and the prevalence of a chronic disease cannot be implied (Royal Australian and New Zealand College of Psychiatrists 2015). There are multiple causal pathways interacting and interrelating synergistically on an individual level due to: (1) Genetic; (2) Biological; (3) Behavioural; (4) Psychological; (5) Sociocultural; (6) Economic; (7)

Environmental; and (8) Patient demographic characteristics (Kazdin & Kagan 1994). Single risk factors have a minimal effect on their own but combine to have a strong interactive or even synergistic effect. Exposure to multiple risk factors over time has a cumulative effect (Kazdin & Kagan 1994). Reducing as many risk factors as possible helps lower the risk of developing CVD (Piepoli et al. 2016).

Psychotic disorders are an independent risk factor for developing metabolic dysregulation (Lambert 2009). The relationship between psychotic disorders and MetS is not a new phenomenon. In the late 19th century and prior to the development of psychotropic medications, studies reported a link between psychotic disorders and glucose abnormalities. The pathophysiology of a psychotic disorder may be associated with diabetes independently of psychotropic medications (Foley et al. 2013; Lambert, TJR & Chapman, LH 2004). In 1895 Maudsley reported that “diabetes is a disease which often shows itself in families in which insanity prevails” (Lambert 2009, p. 171). Shared genes for T2DM and schizophrenia have been identified in gene association studies this demonstrates that these two diseases share common susceptibility genes (Ding et al. 2023; Ferentinos & Dikeos 2012; Hackinger et al. 2018; Perry et al. 2020). Globally T2DM is a major health priority as approximately 85% of individuals diagnosed with diabetes have multimorbidity (Chiang et al. 2018).

Worldwide MetS contributes to mortality and morbidity in CVD, it is considered an epidemic in the general population, due to genetic factors and the universal obesity epidemic that is highly prevalent in western societies (Ferentinos & Dikeos 2012; John et al. 2009; Kassi et al. 2011; Patt Franciosi & Kasper 2005). MetS is a multifaceted disorder defined by a group of interrelated factors that increase the risk of heart disease, stroke and T2DM (Kassi et al. 2011). Its main components are: (1) Abdominal obesity; (2) Insulin resistance; (3) Dyslipidaemia; (4) Hypertension; and (5) Hyperglycaemia (Kassi et al. 2011). Numerous consensus statements exist for detecting and treating MetS in psychiatric patients (Lambert, T & Chapman, L 2004; Lambert et al. 2017). The recommended treatment approach for treating MetS is lifestyle modification and pharmacotherapy (Patt Franciosi & Kasper 2005).

Comprehensive data from the Australian Survey of High Impact Psychosis (SHIP) study, reports high incidences of metabolic comorbidities, in people with psychosis. SHIP was a population

based cross sectional study of psychosis in people aged 18-64. The SHIP results are comparable to other countries and show a 61% prevalence of MetS, irrespective of diagnostic group (Morgan, V, McGrath & Jablensky 2014). SHIP data was studied to explore the age that significant clinical cardiometabolic risk indicators start to diverge from the general population in people with psychosis. The study was not able to determine the age at which significant clinical cardiometabolic risk indicators first diverge from the general population, in people with psychosis, as the distinctive cardiometabolic profile that distinguished psychosis was already present at age 25 (Foley et al. 2013). The study reported that the same clinical cardiometabolic risk indicators are prominent across all ages in adulthood in people with psychosis, see Appendix 5 (Foley et al. 2013).

2.4 Treatment Barriers and Determinants of Health in Psychotic Disorders

2.4.1 Treatment Barriers for Physical Health Care in Psychotic Disorders

Psychiatric patients have multiple barriers when accessing medical treatment for their physical health which include: (1) The patient's HL level, knowledge, and skills; (2) Stigma; (3) Patient factors; and (4) Provider and system factors (Collins, Drake & Deacon 2013b; Dombrowski & Rosenstock 2004; Lambert, TJR & Chapman, LH 2004; Lambert & Newcomer 2009; Muir-Cochrane 2006; Vandiver 2007). Worldwide there are still high levels of stigma towards people with a psychiatric illness amongst the general population and health workers (Hugo, Boshoff & Traut 2003). Social rejection and discrimination associated with stigma, can negatively impact on people's recovery, making them feel more disadvantaged and disempowered (Ghuloum, Bener & Burgut 2010; Link et al. 1997). Stigma associated with psychotic disorders is a barrier to health treatment and discourages individuals and their families from seeking advice and treatment early.

The acculturative alignment between health systems and an individual's cultural beliefs may be a barrier to medical treatment that impacts the health care provided to an individual. The extent to which a patient will benefit from a health care experience is influenced by their culture, knowledge, and belief systems (Fricchione et al. 2012; Ganasen et al. 2008). Delivering health care in a culturally sensitive way is important, to engage culturally and linguistically diverse (CALD) populations in treatment (Purdie, Dudgeon & Walker 2010; Welfare 2009). Delivering culturally and linguistically appropriate health care services involves intertwining HL, literacy, language,

and culture (Andrulis & Brach 2007; Brach, Keller & Hernandez 2012). People born overseas and individuals with low English proficiency are at greater risk of having low HL levels (Cross 1998). CALD individuals and communities may have low HL levels due to multiple factors including: (1) Language barriers; (2) Lack of familiarity with the healthcare system; (3) Reduced access to culturally appropriate health care services and health information; (4) Socioeconomic factors; (5) Alternate ways of learning; (6) Beliefs about medical illnesses and treatment; and (7) Patterns of communications (Zanchetta & Poureslami 2006). When necessary health care services should involve interpreting services or bilingual health workers in health consultations for psychiatric patients and their carers (Lambert et al. 2017). Addressing cultural barriers to HL is important. An individual's culture and social identity plays an important role in patients understanding, interpreting, and acting on health information (Australian Commission on Safety and Quality in Health Care 2014).

2.4.2 Determinants of Health and Lifestyle Risk Factors in Psychotic Disorders

This section focuses on determinants of health and modifiable lifestyle risk factors that contribute to multimorbidity in psychotic disorders. People with a psychotic disorder are more at risk of multimorbidity, due to health inequalities and a higher prevalence of lifestyle related harm (Fiscella & Franks 1997; Foster et al. 2018). Many factors are involved in changing individual determinants of health and lifestyle behaviours. Multiple risk factors accumulate to contribute to the higher prevalence of increased morbidity and mortality in people with a SMI (De Hert et al. 2011). The increased morbidity and mortality in psychotic disorders is largely due to treatable medical conditions caused by the following modifiable risk factors: (1) Cigarette smoking; (2) Obesity; (3) Physical inactivity; (4) A poor diet; and (5) Excessive substance use (Lambert 2009; Linde-Feucht 2007; Skrinar & Hutchinson 2009). These modifiable CVD risk factors can be prevented or modified through lifestyle behaviour changes (Bonfioli et al. 2012; Lambert 2009; Webster & Heeley 2010). Mortality rates in this population are 40% related to an individual's lifestyle risk factors (Linde-Feucht 2007). To reduce comorbidity and increase a person's longevity targeted individualised health promotion interventions should be integrated as part of standard care for people living with a SMI (Bonfioli et al. 2012; Curtis et al. 2015). The National Mental Health Commission recommends focussing on early intervention to decrease CVD lifestyle risk factors

to help reduce cardiometabolic risk in people with a SMI (National Mental Health Commission 2012).

An individual's HL influences their choices and actions regarding lifestyle behaviours (Taggart et al. 2012). HL is a determinant of health that interacts with many factors contributing to health disparities (Keleher & Hagger 2007; Simich 2009; Wills 2009). Low individual HL levels are associated with reduced uptake and engagement in health promoting behaviours and lifestyle changes (Keleher & Hagger 2007; Nutbeam 2000). Implementing HL interventions may help improve cardiometabolic health outcomes and health inequalities in people living with a SMI.

2.4.3 Modifiable Lifestyle Risk Factors - “It Makes SENSE” - (Sleep, Exercise, Nutrition, Substance Use, and Ethanol) – The SENSE Acronym

This section aims to give support for the principles of the acronym SENSE which stands for: (1) Sleep; (2) Exercise; (3) Nutrition; (4) Substance Use; and (5) Ethanol. These lifestyle risk factors interact synergistically to raise multimorbidity and premature mortality rates in people with an ESPD (Foster et al. 2018).

2.4.3.1 SENSE Acronym

The acronym SENSE was developed by the thesis author as a specific tool to help facilitate the HL intervention studies presented in chapters 4-6 of this thesis. The idea behind the SENSE acronym was to educate and inform psychiatric patients about the modifiable lifestyle risk factors and lifestyle behaviours that impact on their cardiometabolic risk, and overall cardiometabolic health. The SENSE acronym was designed in clear and concise plain language, to ensure the health information was easy for participants to understand. A universal precautions approach was used to design the acronym. A universal precautions approach works by assuming every patient has low HL knowledge and skills (DeWalt, D, Berkman & Sheridan 2004). The teach-back technique was used throughout the HL intervention sessions, to reinforce the key messages and principles of the SENSE acronym. The concept of teach-back is to evaluate how well patients understand the health information you have provided to them by asking the patient to explain in their own words the information you provided (Agency for Healthcare Research and Quality 2018). If the patient

doesn't teach-back the information correctly, the healthcare worker has the opportunity to address misinformation and confusion.

2.4.3.2 Sleep

A bi-directional relationship exists between sleep and psychotic disorders, due to the pathophysiology of the disorder and symptoms affecting sleep-wake and circadian rhythms (Monti & Monti 2004). Sleep disturbance is associated with more severe psychotic symptoms, treating co-morbid obstructive sleep apnoea syndrome (OSAS) should improve psychotic symptoms (Kalucy et al. 2013; Monti & Monti 2004; Reeve, Sheaves & Freeman 2019). Individuals diagnosed with OSAS often experience daytime sleepiness, cognitive impairment, have trouble concentrating, are more likely to have heart failure, stroke, depression, anxiety, motor accidents, and increased morbidity and mortality in the long term (Kalucy et al. 2013; Marshall 2015). OSAS increases the risk of cardiovascular conditions and mortality (Kalucy et al. 2013; Piepoli et al. 2016). Individuals with OSAS present with very similar core component abnormalities as MetS (Gami & Somers 2004). The main components of MetS are: (1) Abdominal obesity; (2) Insulin resistance; (3) Dyslipidaemia; (4) Hypertension; and (5) Hyperglycaemia (Kassi et al. 2011). Evidence suggests that sleep disordered breathing is its own independent risk factor that synergistically acts with the core components of MetS, this has been termed syndrome Z. Syndrome Z includes sleep disturbance in addition to the standard MetS criteria, this helps to understand an individual's overall CVD risk (Nock et al. 2009).

2.4.3.3 Exercise

Exercise is a feasible adjunct intervention that may help target sedentary behaviour and physical inactivity in people with an ESPD (Callaghan 2004; Morgan, A, Parker, Alvarez Jimenez, et al. 2013; Rosenbaum et al. 2014; Skrinar & Hutchinson 2009; Wand & Murray 2008). Strong evidence reports the multi-dimensional benefits of exercise and physical activity on a person's physical and mental health (Dogan & Dogan 2008; Stubbs et al. 2018; Way et al. 2018). Undertaking regular exercise and physical activity helps to improve psychiatric symptoms, treatment outcomes, CMRF, and social networks in this population (Glowacki, Weatherson & Faulkner 2019; Skrinar & Hutchinson 2009; Way et al. 2018). Beneficial effects occur to CMRF and cognition independent of changes to body mass index (BMI) (Stubbs et al. 2018). Clear

evidence supports the health benefits of regular exercise to reduce the incidence of chronic disease and premature death (National Centre for Chronic Disease Prevention and Health Promotion 1999; Pedersen & Saltin 2006; Piepoli et al. 2016; Vancampfort et al. 2015; Warburton, Nicol & Bredin 2006).

The literature clearly shows that exercise is associated with: (1) Reduced anxiety and depression; (2) Improved mood, self-worth, and body image; and (3) Improved cognitive functioning (Callaghan 2004; Dogan & Dogan 2008; Morgan, A, Parker, Alvarez-Jimenez, et al. 2013). Exercise as an adjunct intervention for people with a mental illness is popular, cost effective, accessible, flexible, sustainable, and normalising (Dogan & Dogan 2008; Richardson et al. 2005; Wand & Murray 2008). A review of 80 studies shows robust evidence reporting an association between depression and exercise (Scully et al. 1998). Individuals with a clinical diagnosis of depression experience antidepressant effects from exercise (Scully et al. 1998). In people with BD neuroprotectant characteristics occur in response to exercise, see Appendix 6 (Alsuwaidan et al. 2009; Skrinar & Hutchinson 2009).

There is no specific explanation to explain the beneficial link between exercise and mental health. A number of multifaceted physiological and psychological mechanisms and theories are identified in the literature to explain this link, see Appendix 7 (Daley 2002; Pedersen & Saltin 2006; Pickett, Kendrick & Yardley 2017). The theories are likely to have a multifactorial and bidirectional effect with each other to improve health. Mental health treatment settings should prescribe exercise and physical activity as a therapeutic intervention in conjunction to other forms of treatment for psychiatric patients. This is endorsed and recommended by international associations and the Royal Australian and New Zealand College of Psychiatrists (RANZCP) (Craft & Perna 2004; Lambert et al. 2017; Lederman et al. 2016; Morgan, A, Parker, Alvarez-Jimenez, et al. 2013; Royal Australian and New Zealand College of Psychiatrists 2015). Despite the endorsement and recommendations exercise and physical activity interventions are underutilised in psychiatry and mental health treatment settings (Callaghan 2004; Crone & Guy 2008).

2.4.3.4 Nutrition

A bidirectional relationship exists between nutrition and psychiatric illnesses (Teasdale et al. 2016). Nutrition plays a part in the development, prevention, and management of metabolic

conditions and CMRF (Alcock, Maley & Aktipis 2014; Teasdale et al. 2016). Individuals with a psychotic disorder have unhealthy eating routines and behaviours that are difficult to change and may lead to poor nutritional status (Agency for Clinical Innovation 2013; Pignone et al. 2005). Many people with schizophrenia report the following unhealthy eating behaviours and routines: (1) Skipping breakfast; (2) Having a cup of tea with six tablespoons of sugar added; (3) Drinking excessive amounts of caffeine and carbonated drinks daily; (4) Eating a high saturated fat diet; (5) Eating a low fibre diet; (6) Low intake of vegetables and fruit; and (7) Hoarding food (McCreadie 2003).

2.4.3.5 Substance Use

Substance use disorders (SUDs), alcohol use disorders (AUDs), nicotine dependence, and caffeine consumption are highly prevalent in people with an ESPD compared to the general population (Association 2013; Kraus et al. 2019; McGorry et al. 2004). Studies report that 62% of people with a psychotic disorder smoke tobacco and use drugs and alcohol (Coughlan et al. 2001b; Leucht et al. 2007). The SHIP study reported a high prevalence of diagnosed lifetime SUDs for: (1) Alcohol (51%); (2) Cannabis (51%); and (3) Other illicit drugs (32%) (Lambert et al. 2017; Morgan, V, McGrath & Jablensky 2014). Individuals with a psychotic disorder smoke more cigarettes daily, compared to the general population (Ashton, Rigby & Galletly 2013; Association 2013; Bowden, Miler & Hiller 2011; Cooper et al. 2012; Morgan, V et al. 2011). Alcohol is not included in this substance use section of the review it is referred to after this section under the term ethanol.

Legal substances such as cigarettes and caffeinated drinks (e.g., coffee, soft drinks, and energy drinks), increase cardiometabolic risk and are highly consumed by people with a SMI (Agency for Clinical Innovation 2013; McCreadie 2003). Caffeine is the most highly used stimulant drug across the world. Compared to the general population, people with a psychotic disorder have higher daily caffeine consumption rates ($\geq 200\text{mg}$) (Agency for Clinical Innovation 2013). Large intakes of caffeine ($> 600\text{mg/day}$ or $> 6\text{-}8$ cups of coffee/day) may impact on psychiatric disorders, increasing symptoms including: (1) Insomnia; (2) Anxiety; (3) Psychosis; (4) Psychomotor agitation; and (5) Increased plasma clozapine levels (Agency for Clinical Innovation 2013). Therefore, the routine psychiatric assessment of patients should include caffeine intake, to help manage patients daily caffeine consumption (Agency for Clinical Innovation 2013).

Due to the traditional way of treating patients in mental health and drug and alcohol (D&A) services common experiences exist across these treatment settings (Gagne, White & Anthony 2007). Individuals accessing either service (psychiatric or D&A), often receive ineffective institutionalised treatment for their disorder or receive no treatment at all (Coghlan et al. 2001a). SUDs play a major role in: (1) The onset of psychotic disorder symptoms and the severity of the psychiatric illness; (2) Cardiometabolic risk; (3) Suicide; (4) Hospital readmission; (5) Poor medication adherence; (6) Homelessness; and (7) Poor social outcomes (Collins, Drake & Deacon 2013a; McGorry et al. 2004). Psychiatric patients use substances to self-medicate, socialise, and cope with social inequities such as poverty, unemployment, and social isolation (Smith, J & Hucker 1994). Numerous studies report that individuals with a SMI want support and assistance from health care workers to live a life free from D&A (Wright et al. 2011). Targeted programs and innovative interventions to reduce tobacco and substance use are needed in this population to improve cardiometabolic health outcomes and mortality rates from natural causes (Coghlan et al. 2001b).

Major progress in tobacco control has occurred in Australia since the 1960s in the general population. Population wide tobacco control approaches are less effective in vulnerable population groups, including people with an ESPD (Ashton, Rigby & Galletly 2013). Tobacco cessation treatment options, support, and encouragement to quit are rarely offered to people with a psychiatric illness (Coghlan et al. 2001b; Lambert et al. 2017). Numerous guidelines and consensus statements recommend supporting and encouraging smoking cessation and tailored tobacco reduction programs in this population (Lambert, TJR & Chapman, LH 2004; Mendelsohn & Montebello 2013; Tam, Warner & Meza 2016). For people with an ESPD to have successful quit attempts, they need to be offered access to free: (1) Behavioural and pharmacological approaches to smoking cessation; and (2) Individualised and tailored support for smoking cessation (National Preventative Health Taskforce 2009).

The connection between tobacco dependence and individuals with an ESPD is complicated. The Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V) recognises nicotine dependence as an addiction disorder (Hughes 2007). Mental health services throughout Australia fail to treat nicotine dependence in this population (Hughes 2007). It is recommended to treat nicotine dependence in conjunction with other SUDs, using a combination of behavioural

interventions and pharmacotherapy (Baird, Segan & White 2018). Strong evidence exists reporting all types of brief interventions for smoking cessation are effective in psychotic disorders including: (1) Education to stop smoking; and (2) Pharmacotherapy approaches such as bupropion, varenicline, and nicotine replacement therapy (NRT) (Piepoli et al. 2016). There is evidence that with support smoking cessation interventions are highly successful in psychiatric patients and positive quit results are achieved (Prochaska, J, Delucchi & Hall 2004).

2.4.3.6 Ethanol (alcohol)

In Australia, more than half of new psychiatric presentations to mental health services have substance use problems in conjunction with a psychiatric illness (NSW Mental Health Commission 2014). Health care professionals refer to this as a dual diagnosis (NSW Mental Health Commission 2014). There are limited integrated care services available for treating individuals with a dual diagnosis (Kuehn 2010). Research shows that when treatment services are integrated for individuals with a dual diagnosis the detection, assessment, and management of these comorbidities are improved (Siegfried 1998). Studies report that alcohol and other SUDs co-occur in 40-70% of people with a psychotic disorder (Coghlan et al. 2001a; Davies 2000; National Mental Health Commission 2016; Smith, J & Hucker 1994). This population may use alcohol for its pleasurable effects to overcome sedative side effects of psychotropic medication, or to self-medicate to cope with psychiatric symptoms (Davies 2000). Alcohol is the main substance individuals have used when a substance-induced psychotic disorder is diagnosed (Perala 2013).

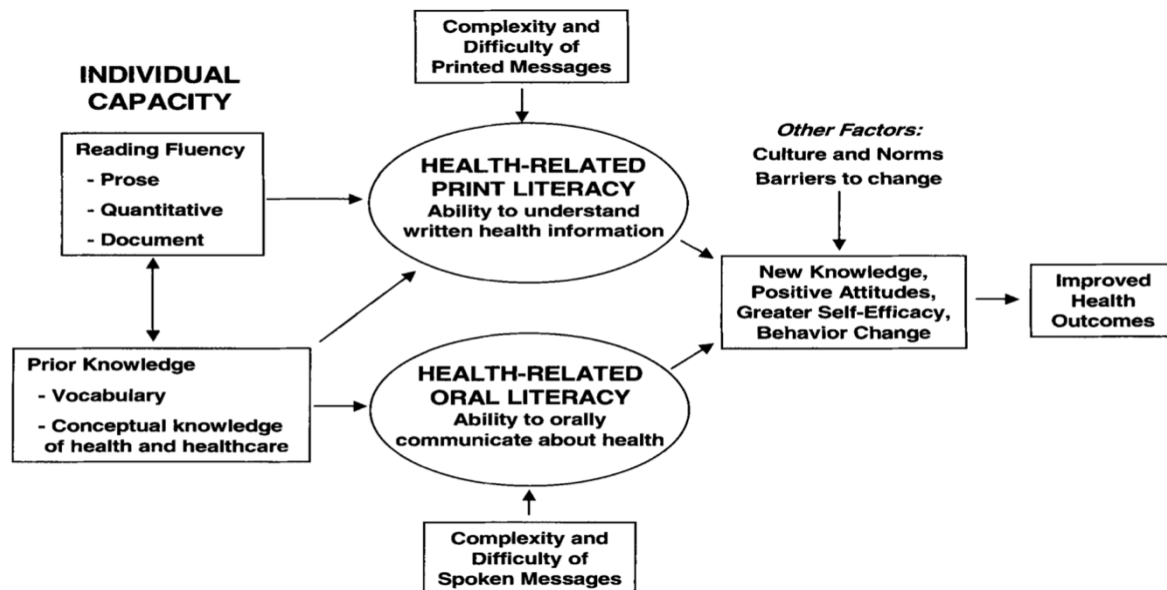
2.5 Foundation Skills, Health Literacy (HL), Health Promotion, and Psychotic Disorders

2.5.1 Foundation Skills and Health Literacy (HL)

Foundation skills include: (1) Literacy; (2) Numeracy; and (3) Critical thinking. Together they are fundamental to HL (Australian Commission on Safety and Quality in Health Care 2014). An individual's literacy and numeracy skills related to health is referred to as functional health literacy (FHL) (Nutbeam 2008). HL is a multifaceted phenomenon involving individuals, families, communities, and systems interacting differently, see Figure 2.1. In Australia HL needs to be addressed in a coordinated approach using these strategies: (1) Embed HL into healthcare systems, policies, and organisational practices; (2) Design health information so it is clear, specific, and

useable, for health care consumers, see Appendix 8; and (3) Ensure HL is incorporated into education for health care workers and patients.

Figure 2.1 Complex Phenomenon of HL



Reproduced from Baker, D 2006, 'The Meaning and the Measure of Health Literacy', *Journal of General Internal Medicine*, vol. 21, no. 8, p. 879.

In the United States (US) limited literacy and mental illness commonly co-occur (Lincoln et al. 2008). Social disadvantage often coexists with low HL exacerbating its effects and putting vulnerable populations at risk (Hichler, Wieser & Brugger 2009). HL needs to be on the agenda as a public health priority to reduce adverse health outcomes and inequities in vulnerable and marginalised individuals (U.S Department of Health and Human Services 2010).

2.5.1.1 Literacy

A complex association between literacy and health exists, it is important to differentiate between the terms 'literacy' and 'HL' (Australian Commission on Safety and Quality in Health Care 2014). Literacy is the term used to refer to the ability to read and write. Literacy is defined by the United Nations Educational, Scientific and Cultural Organisation (UNESCO) as "the ability to identify, understand, interpret, create, communicate, and compute, using printed and written materials associated with varying contexts" (Ganasen et al. 2008, p. 24). The inability to read, write, and use

numbers effectively is defined as low literacy, and is associated with a wide range of adverse health outcomes (Pignone et al. 2005). One in five Australians do not have an adequate level of literacy to successfully participate in daily life (Keleher & Hagger 2007).

A variety of interrelated literacies are integrated into healthcare systems and services (Australian Commission on Safety and Quality in Health Care 2014). The ability to read and comprehend written health information involves a variety of subject specific literacies, tasks, and foundation skills which include: (1) Visual literacy (understanding visual information and images); (2) Digital or technology literacy (ability to use technology, operate a computer, and navigate the internet); (3) Information literacy (ability to obtain and apply relevant information); (4) Print literacy (ability to read and comprehend written print); (5) Oral literacy (understanding verbal communication messages and the ability to speak and listen effectively); (6) Numerical literacy (the ability to use quantitative information, calculate, and understand numbers); (7) Cultural literacy (understanding different cultures and having cultural awareness); (8) Media literacy (understanding media messages and broadcasts); (9) Evidence-based and scientific literacy (understanding evidence-based reports, information, and scientific studies); (10) Nutrition literacy (reading and understanding nutrition information and food labels); and (11) Mental health literacy (Australian Commission on Safety and Quality in Health Care 2014; Institute of Medicine 2004; Nutbeam 1998; Sorensen et al. 2012).

Literacy is an important determining factor involved in population, community, and individual health outcomes (Australian Commission on Safety and Quality in Health Care 2014; Cavanaugh et al. 2009). Poor literacy contributes significantly to the burden of disease in illiterate individuals and is a barrier to providing adequate health care (Hauser & Edwards 2006; Kickbusch 2001). Functional literacy is considered to be a social determinant of health, due to its effect on an individual's: (1) Socioeconomic status; (2) Ability to access services; and (3) Employment (Wills 2009). Individuals with limited literacy tend to not ask questions during health consultations, they may have learnt to mask their illiteracy by using other communication methods (DeWalt, D, Berkman & Sheridan 2004). It is hard to identify low literacy in people by having a conversation with them, they feel highly stigmatised and ashamed to reveal their reading ability (DeWalt, DA et al. 2010; Lincoln et al. 2017).

Low literacy is highly prevalent in the following population groups: (1) The elderly; (2) People with lower education levels and fewer years of education; (3) Individuals with low socioeconomic levels; (4) Minority populations; (5) Certain ethnic groups; (6) Individuals with lower cognitive ability or problems with cognition; and (7) People with limited English skills (DeWalt, D, Berkman & Sheridan 2004; Hauser & Edwards 2006; Krueger, Berger & Felkey 2005). Other factors linked to low literacy include: (1) Being in prison; (2) Female gender; (3) Low income status; (4) Personal ability; (5) Early Childhood Development; and (6) Aging (DeWalt, D, Berkman & Sheridan 2004; Hauser & Edwards 2006; Sorensen et al. 2012).

Research regarding the impact of low literacy levels in people with a psychiatric illness is scarce (Lincoln et al. 2017). Low literacy skills in psychiatric patients may impact on: (1) Patient care; (2) Numerous health outcomes; (3) Medication adherence; and (4) Recovery (Ganaseen et al. 2008; Lincoln et al. 2017). “HL is clearly dependent upon levels of fundamental literacy and associated cognitive development. Individuals with undeveloped skills in reading and writing will not only have less exposure to traditional health education, but also less developed skills to act upon the information received” (Nutbeam 2000, p. 264). Furthermore, individuals with low literacy knowledge and skills rarely engage in health interventions, health services, and chronic disease self-management, due to their insufficient literacy skills impacting on their self-efficacy, to undertake and engage in these activities (Keleher & Hagger 2007).

2.5.1.2 Numeracy and Oral Literacy

Numeracy and oral literacy are fundamental skills required to interact effectively within the health care environment (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011; DeWalt, D, Berkman & Sheridan 2004). Numeracy is the ability to understand and use numbers, it is independently linked to health outcomes and is understudied as a necessary part of literacy and HL (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011; Cavanaugh et al. 2009). Oral literacy is the ability to speak and listen (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011). Patients have trouble understanding oral communication messages during health consultations, approximately 50% of the information discussed is remembered (DeWalt, DA et al. 2010). Numerical and oral skills are needed to understand health information and follow recommended treatment procedures (Hauser & Edwards 2006). Numerical information in health care is often displayed as fractions,

percentages, and in digit form (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011). Some health care tasks require mathematical concepts and skills, for example, following instructions and measures for prescribed medications (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011; DeWalt, D, Berkman & Sheridan 2004).

2.5.1.3 Media, Digital or Technology Literacy

In today's society technology is rapidly being integrated into healthcare systems. A patient's journey and medical records are becoming digitalised with initiatives such as My Health Record. Media and digital literacy skills are required to access, navigate, and evaluate health information and media messages, distributed through technology (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011). "Digital HL is an extension of HL and uses the same operational definition, but in the context of technology" (Dunn & Hazzard 2019, p. 1). Digital environments are being created as spaces for online health care treatment, to improve health outcomes and engage people through online options (Conard 2019). Individuals must have technology skills to work their way through the digital environment to have success with online health care. Navigating digital environments, irrespective of your literacy or HL level, requires technology skills that some individuals may not have (Bickmore & Paasche-Orlow 2012).

2.5.2 Health Literacy (HL)

Worldwide, HL is a significant issue in many developed countries (Geboers et al. 2018). Universally HL is identified by people as an issue that requires attention and a national focus (Australian Commission on Safety and Quality in Health Care 2014; Visscher et al. 2018). HL research in Australia is currently a small and growing field with many projects being undertaken to address HL within and outside the health system. Unfortunately, these projects have limited learning opportunities as they are disconnected (Australian Commission on Safety and Quality in Health Care 2014). Adequate to high levels of HL are found in 41% of Australians, this suggests that around 60% of Australians have insufficient HL levels (Australian Commission on Safety and Quality in Health Care 2014).

In Australia a pilot study exploring HL in people with schizophrenia and a comparison group with depression reported good HL in both groups, lower HL was associated with level of educational

attainment and cognitive impairment (Galletly et al. 2012). A review of 14 studies shows evidence that higher rates of low HL exist in people with a mental illness compared to the general population (Degan et al. 2021). To help improve treatment and health outcomes in this population further research is required to improve our knowledge and understanding of the associations between HL and people with an ESPD (Lincoln et al. 2008).

HL plays an important role in the safety and quality of health care provided to patients (Australian Commission on Safety and Quality in Health Care 2014). Low HL is an independent risk factor for poor health and a health status predictor, that has an impact on mortality similar to the effect of chronic disease (Australian Commission on Safety and Quality in Health Care 2014; Keleher & Hagger 2007). Individuals with low HL are 1.5 to 3 times more likely to experience an adverse health outcome (Australian Commission on Safety and Quality in Health Care 2014). Canadian and American HL studies report an independent association between low HL and increased use of health care services and emergency care services, a reduced use of preventative health services, higher mortality rates, and health care costs (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011; Keleher & Hagger 2007). Individuals with low HL skills have limited ability to understand health messages and medication labels, they experience shame and mask their HL knowledge and skills (Australian Commission on Safety and Quality in Health Care 2014; Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011).

The quality and care of health care provided to patients is affected by the way health care providers work, communicate, and interact together (Rosenberg & Hickie 2013). Health care professionals create barriers to individual HL, by using technical medical terminology and health jargon, when communicating health care messages to patients (Parker & Ratzan 2010). Health care professionals must remember patients play an integral role in the management of their health (Harris et al. 2008; Keleher & Hagger 2007). Communicating health care messages in plain language to patients is important for optimal health outcomes and to self-manage chronic health conditions (Adams et al. 2009; DeWalt, DA et al. 2010; Institute of Medicine 2004). Health professionals should: (1) Speak slowly; (2) Use the teach-back technique; (3) Encourage questions; (4) Use plain language; and (5) Show examples when communicating health care information to patients (DeWalt, DA et al. 2010; Institute of Medicine 2004).

2.5.3 HL Definitions

Within the literature HL first appeared in 1974, as a concept around health education and the development of HL standards in schools (Baker et al. 1997). HL as a concept was not incorporated into health education or other fields until two decades later in the 1990's (Baker et al. 1997). Today HL is considered an important concept among health care professionals and the health promotion field (Nutbeam 2000). Many definitions and models of HL have evolved and expanded overtime, this has now created complexity, barriers, confusion, and controversy in the field of HL (Baker 2006). As a result, the concept and definition of HL is not always clear for individuals and health care workers to understand. HL now means different things to individuals and health professionals. Unfortunately, HL has become so complicated individuals do not know why it is important to address (Australian Commission on Safety and Quality in Health Care 2014).

Seventeen HL definitions exist within the literature, see Appendix 2. The most cited HL definitions include: (1) World Health Organisation (WHO); (2) Institute of Medicine; and (3) American Medical Association (Sorensen et al. 2012). These definitions all include a focus on the necessary individual skills required to obtain, process, and understand health information (Sorensen et al. 2012). A content analysis was undertaken on the seventeen HL definitions to examine the key components of each definition. The following HL definition was developed from the content analysis examining the seventeen HL definitions: "HL is linked to literacy and entails people's knowledge, motivation, and competencies to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention, and health promotion to maintain or improve quality of life during the life course" (Sorensen et al. 2012, p. 3).

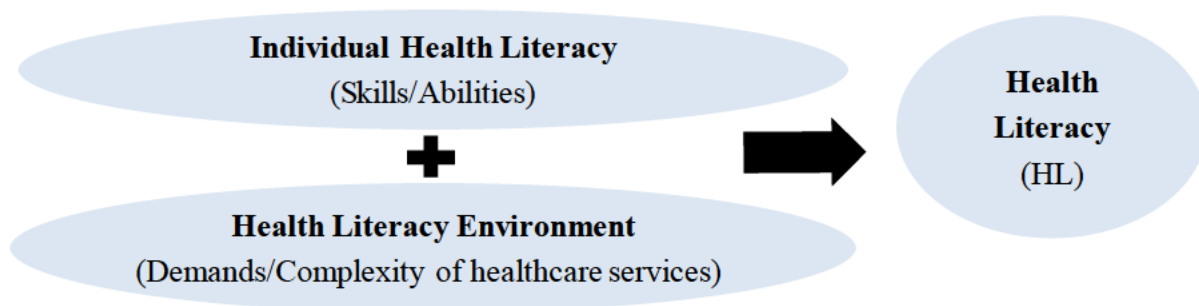
HL definitions now include factors that influence health making decisions and health related behaviour changes (Nutbeam 2008). However, many HL definitions have not considered that individuals with high HL levels and good FHL, may choose not to use their HL skills in health promoting ways (Peersons & Saunders 2009). It is acknowledged that HL definitions would be more useful if they took into account and distinguished the following: (1) Possessing information; (2) Understanding information; and (3) Applying appropriate action (Nutbeam 2008; Peersons & Saunders 2009). Within the literature, the definition and concept of HL has no consensus, this

impacts the ability to measure and compare HL interventions and creates a barrier to achieving HL outcomes (Sorensen et al. 2012).

2.5.4 HL Components

HL components affect how people interact and function in health care settings. The two HL components are: (1) Individual HL; and (2) HL environment or organisational HL (e.g., healthcare system or health organisation), see Figure 2.2 (Australian Commission on Safety and Quality in Health Care 2014; Institute of Medicine 2004). Individual HL, the HL environment, and contextual factors influence health outcomes (Australian Commission on Safety and Quality in Health Care 2014). The main causal pathways associated with HL and health outcomes are related to the influence of individual HL, the HL environment, and contextual factors on the following: (1) Individuals accessing and using health care services; (2) Health care interactions and experiences; and (3) How individuals manage their own health and lifestyle behaviours (Australian Commission on Safety and Quality in Health Care 2014). Numerous personal characteristics and contextual factors determine HL: (1) Age; (2) Education; (3) Health status; (4) Ethnicity; (5) Socioeconomic status; (6) Poverty; (7) Social supports; (8) Prior health care experiences; and (9) the media, are involved in a person's ability to make decisions and take action to improve their health (Australian Commission on Safety and Quality in Health Care 2014; Hichler, Wieser & Brugger 2009). A predictably strong association exists between: (1) HL; (2) Age; (3) Race; (4) Ethnicity; and (5) Educational achievement (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011; Leger 2001).

Figure 2.2 Components of HL

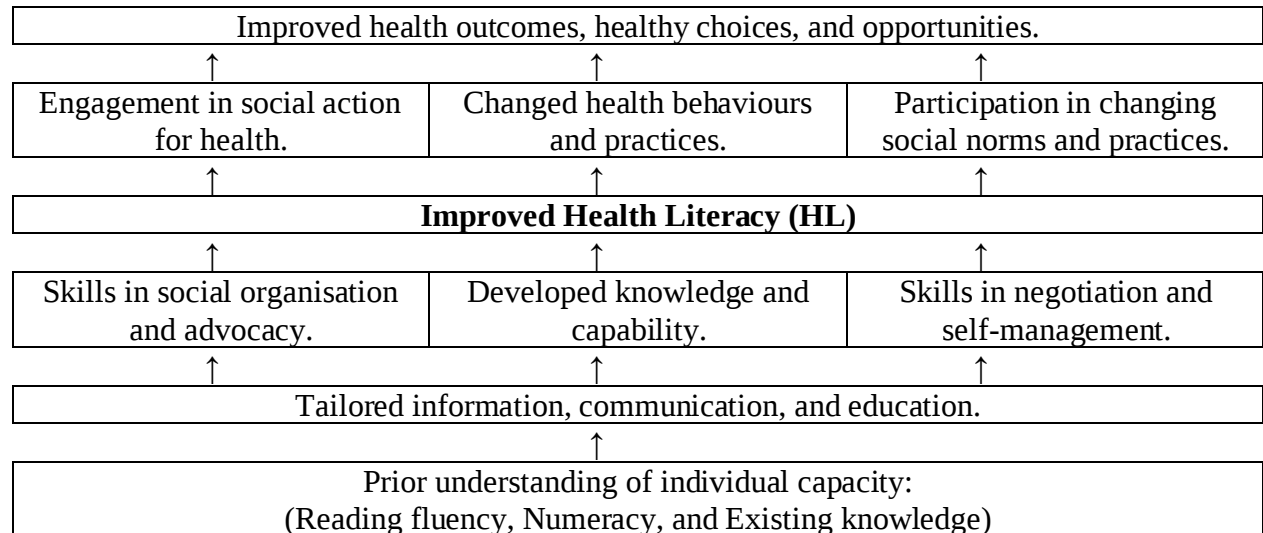


Reproduced from Australian Commission on Safety and Quality in Health Care 2014, 'Health literacy: Taking action to improve safety and quality', p. 10, viewed 15 August 2015, <<https://www.safetyandquality.gov.au/publications-and-resources/resource-library/health-literacy-taking-action-improve-safety-and-quality>>.

2.5.4.1 Individual HL

Individual HL involves a range of skills to function effectively in health care environments. Individual HL skills are necessary to navigate, access, use, process, and comprehend health information to make informed health decisions (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011; Sorensen et al. 2012). Individual HL skills include: (1) All the subject specific literacies, tasks, and foundation skills previously listed in this chapter; (2) Motivation for action regarding health issues; and (3) Self-efficacy (Australian Commission on Safety and Quality in Health Care 2014; Institute of Medicine 2004; Nutbeam 1998; Sorensen et al. 2012). Nutbeam identifies HL levels on a matrix to support individual empowerment to make informed health choices that benefit the individual and the community (Keleher & Hagger 2007; Nutbeam 2008; Nutbeam & Bauman 1993). Nutbeam also highlights HL as an asset and uses an empowerment approach to encourage and motivate people to understand and act on health information and change health behaviours, see Figure 2.3 (Nutbeam 2008).

Figure 2.3 HL as an Asset



Reproduced from Nutbeam, D 2008, 'The evolving concept of health literacy', *Social Sciences and Medicine*, vol. 67, p. 2074.

2.5.4.2 HL Environment or Organisational HL

The primary responsibility of HL falls on the health care system – it does not depend on a person's individual HL skills. Health care services are required to have accessible, person-centred, and health promoting facilities (Adams et al. 2009; Brach, Keller & Hernandez 2012). The HL

environment is also known as organisational HL it includes: (1) Health care infrastructure; (2) Policies and procedures; and (3) Understanding health care facility signage (Australian Commission on Safety and Quality in Health Care 2014; Brach, Keller & Hernandez 2012). In Australia, HL is a key focus area across the National Safety and Quality Health Service (NSQHS) standards for accreditation (Australian Commission on Safety and Quality in Health Care 2014). Therefore, health care services are required to provide evidence for implementing HL strategies to meet the NSQHS standards for accreditation. Health systems and health care environments have become hard to access and navigate, this can impact on patient safety and quality of health care (Australian Commission on Safety and Quality in Health Care 2014). Health literate health care organisations take action to make it easier for individuals to navigate and use health care services and understand health information, see Appendix 9 (Australian Commission on Safety and Quality in Health Care 2014; Brach, Keller & Hernandez 2012).

The Consumers Health Forum of Australia advocated for health care organisations to use the Ten Attributes of a Health Literate Health Care Organisation model when designing and implementing HL programs (Brach, Keller & Hernandez 2012; Consumers Health Forum of Australia 2013). Health care professionals should use a universal precautions approach with every patient. Using plain language and easy to understand health information with every patient helps to reduce HL barriers and makes health care services easier to navigate and understand (DeWalt, D, Berkman & Sheridan 2004). In America the Agency for Health Care Research and Quality, designed the Health Literacy Universal Precautions Toolkit, to assist health care organisations to take action towards addressing HL (DeWalt, DA et al. 2010). The toolkit can be found at the following web page⁴.

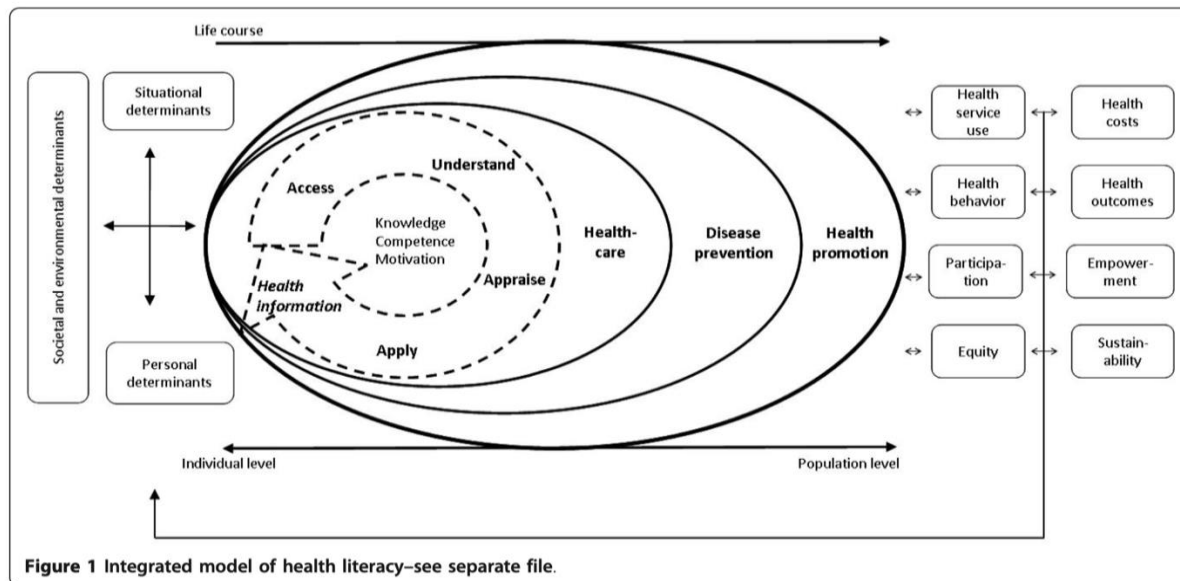
2.5.5 Conceptual HL Models

There is limited data to support the factors, relationships, and interactions that exist in conceptual HL models (Australian Commission on Safety and Quality in Health Care 2014). This may underestimate the complexity of HL and further adds to HL problems. Within the literature twelve conceptual HL models exist, only a few models incorporate views from medical and public health perspectives (Sorensen et al. 2012). HL models can be used as a foundation to design and develop HL interventions across various health settings (Nutbeam 2000; Sorensen et al. 2012). An

⁴www.ahrq.gov/legacy/qual/literacy/healthliteracytoolkit.pdf

integrated HL model was developed after reviewing the existing HL definitions and models, see Figure 2.4.

Figure 2.4 Integrated HL Model



Reproduced from Sorensen, K, Broucke, S, Fullam, J, Doyle, G, Pelikan, J, Slonska, Z, Brand, H & European, fH-ECHLP 2012, 'Health literacy and public health: A systematic review and integration of definitions and models', *BMC Public Health*, vol. 12, no. 80, p. 9.

2.5.6 HL Measures

HL measures are designed to assess individual HL and mainly focus on FHL skills (Visscher et al. 2018). HL studies mainly investigate health knowledge and the most common HL measures used are: (1) Rapid Estimate of Adult Literacy in Medicine (REALM); and (2) Test of Functional Health Literacy in Adults (TOFHLA) (Baker 2006). Health behaviours, measures of disease prevalence or severity, and intermediate markers, are studied less frequently (Pignone et al. 2005). Many HL studies do not describe the details about the background of the materials used in the HL intervention or about how assessments in patient outcomes were implemented (Visscher et al. 2018).

2.5.7 Health Literacy Questionnaire (HLQ) and the OPTimising HEalth LIterAcy (Ophelia) Process

A more recent HL measure is the Health Literacy Questionnaire (HLQ), which is used to design and evaluate HL interventions, see Appendix 10 (Batterham et al. 2014; Osborne et al. 2013). The HLQ was developed in Australia by researchers at the Deakin and Monash universities (Osborne et al. 2013). The HLQ captures a broad range of components contributing to individual HL (Australian Commission on Safety and Quality in Health Care 2014; Osborne et al. 2013). The HLQ provides detailed information about what needs to be done to improve systems and services. The HLQ can be used to identify the HL needs of service users to develop appropriate and targeted HL interventions using the OPTimising HEalth LIterAcy (Ophelia) process, see Appendix 11 (Batterham et al. 2014). The Ophelia process is a model used to develop tailored HL interventions for services and their service users. Instead of implementing standardised interventions services use feedback from a needs assessment of individual service users to develop tailored HL interventions (Batterham et al. 2014).

The HLQ consists of 44 questions across 9 domains, 4 to 6 questions are in each domain to give a graded response score. The HLQ provides demographic information and measures an individual's HL across nine domains, to identify their strengths and limitations, see Appendix 12 (Osborne et al. 2013). Domains 1 to 5 measure the participant's agreement with a question using a 4-point ordinal scale (1 = "strongly disagree" to "strongly agree" = 4). Domains 6 to 9 measure the participant's perceived ease in completing a task using a 5-point ordinal scale (1 = "cannot do or always difficult" to "always easy" = 5), see Figure 2.5. The domain scale score is formulated by adding the item scores within each scale, then dividing the number of items in the scale. A priori, confirmatory factor analysis (CFA) was used to determine the median reliability of the HLQ domains to be 0.88, with a range from 0.77 to 0.90 (Osborne et al. 2013). Each HL score can be looked at independently, however the scores are more useful and informative when looked at collectively across the 9 domains, to identify and understand an individual's HL profile (Osborne et al. 2013). Nutbeam's HL matrix can be linked to the 9 HLQ domains to further capture an individual's HL profile, see Appendix 13. The HLQ is provided in many languages, it can be self-administrated using pen and paper or by interview, to assist individuals with completing the questionnaire (Batterham et al. 2014).

Figure 2.5 Nine HLQ Domains

1	Strongly Agree – Strongly Disagree (Ordinal Scale 1-4) Feeling understood and supported by healthcare providers
2	Having sufficient information to manage my health
3	Actively managing my health
4	Social support for health
5	Appraisal of health information
6	Cannot Do – Very Easy (Ordinal Scale 1-5) Ability to actively engage with healthcare providers
7	Navigating the healthcare system
8	Ability to find good health information
9	Understand health information well enough to know what to do

Reproduced from Osborne, R, Batterham, R, Elsworth, G, Hawkins, M & Buchbinder, R 2013, 'The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ)', *BioMed Central Public Health*, vol. 13, no. 658, p. 8.

2.5.8 Health Promotion and HL Interventions for People with a Psychotic Disorder

HL is a concept of health promotion that is an essential part of health education (Nutbeam 2000). Collaboration between health and education departments can improve public health outcomes for the local community (Leger 2001). Health education aims to empower and improve individual HL in communities through education and communication approaches (Vandiver 2007). “Health promotion has come to be understood as public health action which is directed towards improving people’s control over all modifiable determinants of health. Health promotion outcomes represent those personal, social, and structural factors that can be modified in order to change the determinants of health” (Nutbeam 2000, p. 261). HL is a fundamental outcome of health education which should be integrated into the broader concept of health promotion (Nutbeam 1998).

Health promotion strategies are essential to improve individual and population HL outcomes in people with a psychotic disorder (Green & Kreuter 1991; Hutchinson et al. 2006; Nutbeam 2008; Sorensen et al. 2012; Vandiver 2007). HL and health promotion interventions should start as early as possible as an adjunct intervention for psychiatric patients to minimise weight gain and health problems. Studies report that brief eight-week education programs in people with schizophrenia

are beneficial (Bauml, Pitschel-Walz & Volz 2007). HL and healthy lifestyle interventions are worth implementing in psychiatric patients to prevent and manage CMRF (Bradshaw, Lovell & Harris 2005; Cimo et al. 2012; O'Sullivan, Gilbert & Ward 2006; Wand & Murray 2008; Yatham et al. 2018). Health promotion and HL are vital for improving health outcomes in people with a psychotic disorder due to: (1) Large numbers of individuals affected by low HL levels; (2) Poor health outcomes; (3) Increasing rates of chronic disease; (4) Health care costs; (5) Health information demands; and (6) Equity (Kickbusch 2001). Outcomes from health promotion interventions implemented in this population are multifaceted and aim to improve the functional health and quality of life (QoL) for individuals with a SMI (Hutchinson et al. 2006).

Population health campaigns aimed at the general population have not been successful in people with a psychotic disorder (Coghlan et al. 2001b). HL interventions implemented in psychiatric treatment settings have small participant numbers and high dropout rates, which impacts on justifying the success of the intervention (Brown, S & Chan 2006). Most interventions for psychiatric patients are implemented in outpatient settings (Bonfioli et al. 2012). Group education programs and interventions for people with a SMI are more successful and beneficial in community settings, due to barriers engendered by psychiatric symptoms experienced by inpatients (Rummel-Kluge & Kissling 2008b). Health promotion interventions targeted at psychiatric patients should include a follow-up period and offer booster sessions to support lifestyle behaviour changes (Bonfioli et al. 2012).

2.5.8.1 Benefits of HL Interventions for People with a Psychotic Disorder

HL interventions have added benefits to individuals with a psychiatric illness which include: (1) Improved QoL; (2) Increased opportunities to socialise, build self-esteem, and confidence; (3) Decrease loneliness; and (4) Build support networks (McGorry et al. 2004). The accountability of the group helps to improve adherence to the intervention and assists in normalising their psychiatric illness symptoms and experiences (Rummel-Kluge & Kissling 2008b). The exchange of information with peers that have a SMI within a group education program is highlighted in the literature, as a very important factor, to the success of the program outcomes and adherence to the group (Sibitz et al. 2007).

2.5.8.2 Limitations of HL Interventions

Limited RCT HL studies exist. The majority of HL interventions exploring health outcomes investigate FHL improvements in knowledge, with the studies generally reporting improvements in the participant's knowledge after they have received the intervention (Pignone et al. 2005; Visscher et al. 2018). HL studies fail to evaluate the costs associated with implementing HL interventions in regards to the health economics (Pignone et al. 2005; Rummel-Kluge & Kissling 2008b). HL interventions are often reported poorly and described ineffectively. This limits the use of the intervention in future studies, as the intervention cannot be replicated (Pignone et al. 2005). In multimodal HL interventions it is difficult to determine which components of the intervention produced positive effects (Visscher et al. 2018). The reporting of how health outcomes are measured in HL interventions is also poor. Many studies do not stratify results by literacy level, making it hard to decide if the intervention did help to improve the study outcomes due to the participant's existing literacy skills (Pignone et al. 2005). Future HL interventions need to improve the reporting of the following aspects of the study: (1) Intervention design; (2) Statistics used to analyse the intervention; and (3) Study results (Pignone et al. 2005).

The most researched area in HL is individual HL and the role of HL in relation to medication safety risks, mainly in relation to dosing and administration risks (Australian Commission on Safety and Quality in Health Care 2014; Pignone et al. 2005). Many HL studies do not describe the details about the materials used in the HL intervention or how assessments in participant outcomes were implemented (Pignone et al. 2005). A significant amount of research has been done on HL interventions in different diseases (e.g., diabetes, cancer, and cardiovascular disease) across a variety of population groups and health care settings (Visscher et al. 2018). However, limited research exists on HL interventions in mental illnesses (Galletly, Lincoln & Arford 2013). Existing studies on HL in mental illness have limitations as the majority of studies used a FHL measure and only a few studies used a multidimensional HL measure (Degan et al. 2021). Furthermore, existing studies have methodological shortcomings which include small participant numbers, lack of follow-up, heterogeneity of study designs, and limited RCT studies exist.

2.6 Health Care Utilisation and Chronic Disease Self-Management in Psychotic Disorders

A person's ability to learn and develop self-management practices and skills depends on their FHL. Studies report that FHL is interrelated with achieving self-efficacy in chronic disease self-management (Ishikawa, Takeuchi & Yano 2008). A chronic disease is defined as, any enduring or reoccurring health condition that significantly impacts on a person's life (World Health Organisation 2006). Chronic diseases include: (1) Asthma; (2) Chronic pain; (3) Arthritis; (4) Coronary vascular disease; (5) Cancer; (6) Anxiety; (7) Depression; and (8) T2DM (World Health Organisation 2006). HL and chronic disease self-management are a fundamental part of the treatment process for any chronic disease (Heide et al. 2018; Linder et al. 2003). Many aspects of HL are involved in chronic disease self-management (Heide et al. 2018). The benefits of knowledge, education, teaching of chronic disease self-management skills, screening, and early intervention to prevent chronic diseases in people with a psychotic disorder is well documented and recommended in Australia and other countries (Lambert, TJR & Chapman, LH 2004).

Chronic diseases in the Australian population are increasing in prevalence (Muscat et al. 2020). In the general population individuals with a chronic disease are being diagnosed earlier and living longer, unfortunately this has not transferred to psychiatric patients (Britt 2013). General Practitioners (GPs) have a central role to play in the management of a psychiatric patient's physical health and should always be closely involved in the patients overall medical treatment through shared care partnerships with the patient's psychiatrist, this is considered best practice (Berardi et al. 2007; Fredheim et al. 2011; McGorry et al. 2004; Waterreus & Laugharne 2009). Evidence clearly shows that a highly accessible, integrated specialised multi-disciplinary model of care is needed to target the primary health care needs of psychiatric patients (Berardi et al. 2007; Lambert 2018; Lambert et al. 2017; McGorry et al. 2007; Piane & Smith 2014).

2.6.1 General Practitioners (GPs)

Globally primary health care is the most affordable and sustainable way to deliver health care to a population (Britt et al. 2014). GP services are a lot more cost effective than other medical services, and so too for psychiatric patients. GPs are the main health care provider for individuals with a SMI, 70.8% of people with a mental illness consult a GP, 22.7% consult a psychiatrist and 37.7% consult a psychologist (Australian Institute of Health and Welfare 2014). GPs play a vital role in

organising all aspects of clinical care and care coordination in a normalising health care setting for psychiatric patients (Kiraly, Gunning & Leiser 2008; Mercer et al. 2012; Rosen, Newton & Barfoot 2003). GPs are the gate-keepers to individualised and specialised health care, they play a fundamental role in the referral process for psychiatric patients to receive: (1) Medicare subsidised mental health care; (2) Mental Health Treatment Plan; and (3) Chronic Disease Management Plan (CDMP) (Mercer et al. 2012). GPs are in the best position to assist psychiatric patients with their physical health, regular physical health check-ups, and smoking cessation advice and treatment (Hall et al. 2010). To improve health outcomes for psychiatric patients mental health services and GPs should provide shared care (Berardi et al. 2007; Waterreus & Laugharne 2009).

2.6.2 Integrated Health Care

Primary health care services provide the ideal health care setting for integrated clinical care to identify and address CMRF and multimorbidity in psychiatric patients (Fricchione et al. 2012). Integration is defined as the “development of more comprehensive approaches to care provision that depend on formal relationships or structural arrangements to organise and deliver that care” (Tieman, Mitchell & Shelby-James 2007, p. 57). Worldwide and in Australia numerous studies show that the most effective approach to address and improve the physical and mental health outcomes of psychiatric patients is through collaborative integrated care, despite the higher costs (Lambert & Newcomer 2009; Lunnay & Bywood 2011; Randolph, Blasinsky & Leginski 1997). For decades studies and reports have reported “that mental health is inextricably intertwined with general medical health and high quality mental health systems must integrate medical care with psychiatric treatment” (Newcomer & Hennekens 2007, p. 1795).

2.6.3 Collaborative Centre for Cardiometabolic Health in Psychosis (ccCHiP) Clinic

There is a need to develop and sustain interdisciplinary models of care for individuals with a psychotic disorder. In 2008 the Collaborative Centre for Cardiometabolic Health in Psychosis (ccCHiP) clinic was developed. The clinic is a one stop shop, integrated service model to screen, detect, manage, and follow-up on CMRF and metabolic conditions in this population (Lambert 2018), see Figure 2.6. When a patient attends the ccCHiP clinic they see the following health care professionals in the one visit: (1) Psychiatrist; (2) Cardiologist; (3) Endocrinologist; (4) Oral Health Team; (5) Dietitian; (6) Exercise Physiologist; (7) Nurse and (8) Sleep clinician (Lambert

2018). Following the visit to the ccCHiP clinic a comprehensive treatment plan is devised for the patient and their health care team incorporating recommendations from all the health care professionals. The recommendations are provided to assist the patient and their health care team in the ongoing management of CMRF and metabolic conditions to improve the holistic health of the patient (Lambert 2018).

Figure 2.6 Structure of ccCHiP Clinic and the Clinics External Relationships



Reproduced from Lambert, T 2018, 'There is no mental health. There is no physical health. There is ... health. ', *The Australian Journal on Psychosocial Rehabilitation*, no. Winter 2018 p. 16.

2.6.4 Chronic Disease Self-Management

Most people that have a diagnosed chronic disease manage their condition with irregular visits to health professionals. With the help of a health care practitioner people with a chronic disease can develop skills to learn how to self-manage their chronic disease (Coleman & Newton 2005). “The National Chronic Disease Strategy defines self-management as active participation by people in their own health care” (Harris et al. 2008, p. 17). Successful chronic disease self-management

interventions use a coordinated multidisciplinary care team approach, to empower and motivate individuals to effectively use self-management techniques (Bodenheimer et al. 2002; Von Korff et al. 1997; Wagner 2000). Self-efficacy is consistently reported as the most positive outcome for interventions designed to improve chronic disease self-management (Farrell, Wicks & Martin 2004).

2.6.5 HL and Type 2 Diabetes Mellitus (T2DM) Self-management

Research regarding HL and cardiometabolic health conditions in people with an ESPD is limited (Galletly, Lincoln & Arford 2013). The research that exists has primarily investigated HL and T2DM (Cimo et al. 2012). Therefore, a brief review of the literature on HL and T2DM is necessary to see if there are any research findings that can be replicated in psychiatric patients. Currently, there is a gap in the existing research regarding HL, psychotic disorders, and cardiometabolic health (Degan et al. 2021). The current research in this thesis hopes to contribute towards filling the gap in knowledge that exists in HL and people living with an ESPD.

Low individual HL levels impact on the ability to self-manage T2DM and is linked to diabetes complications (Cimo et al. 2012; White et al. 2010). Studies report that self-care activities involved in T2DM self-management are proximal outcomes of HL (Lee, E, Lee & Moon 2016). To achieve optimal diabetes care good HL knowledge and skills are important to effectively self-manage all the tasks associated with T2DM (Gibbs 2012). Studies report that T2DM patients are required to comprehend complexed health information (Gibbs 2012). T2DM education and health information on T2DM are written at high HL levels (Keleher & Hagger 2007). There is significant and accumulating evidence to show that people with T2DM and low HL levels find it difficult to self-manage T2DM (Powell, Hill & Clancy 2007).

In the general population Diabetes Self-Management Education (DSME) is recommended for individuals with T2DM, to support them to develop knowledge and skills to self-manage T2DM. The DSME program and optimal health care for T2DM is infrequently and less likely to be provided to psychiatric patients with T2DM (Cimo et al. 2012). Consequently, psychiatric patients experience “higher rates of hospitalisation for hyper or hypoglycaemic episodes and for infections” (Cimo et al. 2012, p. 2). A systematic review undertaken in psychotic disorders evaluating the effectiveness of lifestyle interventions to improve T2DM self-management in this population,

showed that diabetes education in conjunction with information on diet and exercise is effective, see Appendix 14 (Cimo et al. 2012).

In summary, physical health problems are highly prevalent in people with an ESPD due to a number of complex interactions and associations between multiple causes. Low individual HL and numeracy must be considered when addressing the physical health concerns and premature mortality rates in this population. Existing research has yet to reveal the role that HL may play in assisting individuals with an ESPD to self-manage their CMRF and cardiometabolic health conditions, which contribute to multiple chronic diseases and premature death in this population. Improving individual HL in people living with an ESPD may help to improve the health outcomes and health inequalities that are experienced by this vulnerable population. The next chapter details how the research studies presented in chapters 4-6 were designed to address the research aims of the thesis.

CHAPTER 3

Research Design

Abstract

This chapter details how the research studies presented in chapters 4-6 were designed to address the research aims of the thesis. Three questions were structured to guide the studies for the thesis. Firstly, is it feasible to implement the HELP in people living with an ESPD? Secondly, what is the impact of implementing the HELP in community mental health services and inpatient facilities? Finally, can a WPC assist this population to have a comprehensive physical health check-up with their GP? Details of the design include the methodology underpinning the research process together with the methods used to conduct the HL interventions. The first section of the chapter provides an overview of how the HL interventions were planned and the mixed methods approach used to preference its design components. The second section of the chapter describes how the HELP and WPC interventions were developed and the outcome measures used to evaluate the interventions.

3.1 Introduction

The primary aim driving the development of the two HL interventions presented in this thesis was to determine if cardiometabolic HL interventions are a useful therapeutic strategy for supporting self-management of CMRF and cardiometabolic health in this population. Existing research has yet to reveal the role that HL interventions may play in assisting individuals with an ESPD to self-manage their CMRF and cardiometabolic health conditions. An adequate level of HL is required to manage a psychotic disorder in conjunction with CMRF and cardiometabolic health conditions (Galletly et al. 2012). Therefore, specifically targeted HL interventions are needed in this population. HL interventions for people living with an ESPD, need to focus on the major lifestyle and CMRF that are highly prevalent in this population (Coughlan et al. 2001a; Conn, Hafdahl & Brown 2009). The present research was necessary to determine if people living with an ESPD are an appropriate group to receive HL interventions. This research was needed to establish if HL interventions can assist mental health consumers to develop their cardiometabolic health

knowledge and skills to support them to self-manage their cardiometabolic health. The present research provides insights into individual HL in adults living with an ESPD in Sydney, Australia.

3.2 Planning the Study

Existing research has yet to reveal the role that HL interventions may play in assisting individuals with an ESPD to self-manage their CMRF and cardiometabolic health conditions. The current research hopes to contribute towards filling the gap in knowledge that exists in HL and psychotic disorders. The plan was to develop and pilot two cardiometabolic HL interventions in the target population. The two HL interventions developed for the purposes of this thesis are called: (1) HELP; and (2) WPC. A flow chart of the HELP and WPC study implementation process is presented in Figure 3.1.

The HELP is a structured six topic cardiometabolic HL education program. The HELP was specifically designed to target CMRF and cardiometabolic health conditions that are highly prevalent in this population. The HELP is designed to educate and support individuals living with an ESPD to improve their individual HL knowledge and skills to self-manage their CMRF and cardiometabolic health conditions.

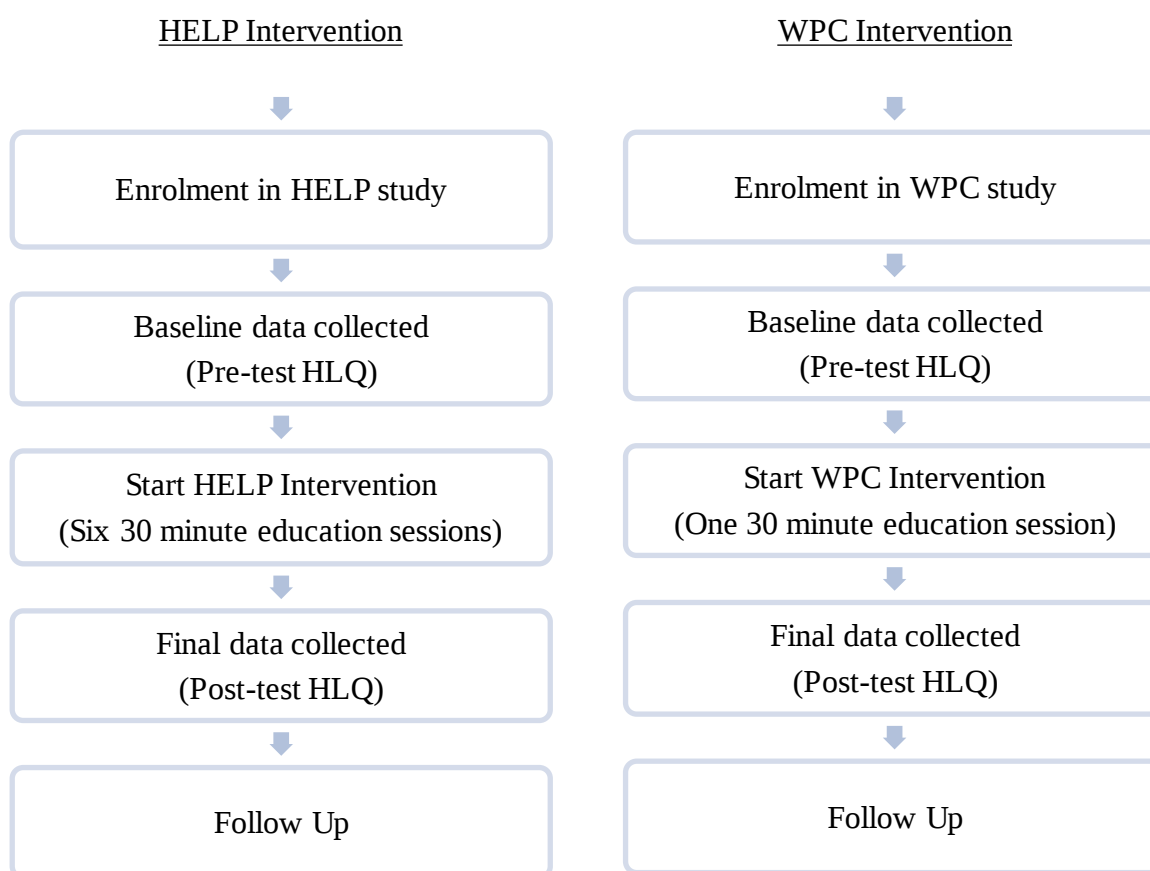
The WPC is a practical tool for outpatients living with an ESPD to use in a GP consultation. The WPC was developed to prompt outpatients to discuss their physical health care needs with a GP, and thereby potentially improve self-management of their cardiometabolic health. The WPC is specifically designed for use in a primary healthcare setting.

The HELP and WPC were developed to test the feasibility of the multi-component HL interventions in this population. Testable goals comprised:

- (1) Improved individual HL knowledge and skills (Primary Outcome);
- (2) Improved GP care for regular physical health check-ups (Primary Outcome);
- (3) Lifestyle modifications related to SENSE, see section 2.4.3 (Secondary Outcome);
- (4) Recall of the SENSE acronym (Exploratory Outcome); and
- (5) Booster session interest (Exploratory Outcome).

If feasibility of the HELP and/or WPC interventions are demonstrated in this population, the interventions could be used in mental health treatment settings in the future to: (1) Improve individual HL knowledge and skills; (2) Improve organisational HL outcomes; (3) Support and educate individuals living with an ESPD to self-manage their CMRF and cardiometabolic health conditions; and (4) Promote and improve GP care for CMRF screening and management of cardiometabolic comorbidity.

Figure 3.1 HELP and WPC Study Process



3.3 Research Design and Paradigm

A quasi-experimental single subject design (A/B design) was chosen for the purpose of implementing the pilot HELP and WPC intervention studies presented in chapters 4-6. A quasi-experimental design was used for the following practical reasons: (1) It was not reasonable to randomise study participants to the treatment conditions as the HELP and WPC interventions were not designed to measure effectiveness, the objective was to measure the effect sizes (ES)

achieved and only secondarily to show a significant change; (2) The HELP and WPC interventions were feasibility studies designed to test, whether the HL interventions can be implemented in this population group to improve individual HL knowledge and skills; and (3) Fewer resources were required to implement and evaluate the real world impact of the HL interventions. The HELP and WPC interventions use a pre-post test study design, to evaluate the interventions, with only two time points and a single group.

The overall methodology underpinning the present research, was based on a pragmatic paradigm. Therefore, a mixed methods methodology was used for the overall research design. A mixed methods research approach is defined by the use of both quantitative and qualitative research methods in the same study (Kivunja & Kuyini 2017). The HELP and WPC intervention studies were evaluated using both a quantitative and qualitative approach.

Quantitative evaluation gives an indication of the outcomes of the HELP and WPC interventions in terms of improving the participant's individual HL knowledge and skills, and thus the success of the intervention in achieving its objectives.

Qualitative evaluation of the HELP and WPC is based on participant feedback and assesses the HL interventions with regards to its suitability and relevance for this population group. Feedback obtained as a result of this evaluation was used to identify whether the HELP and WPC interventions met the needs of the target population, and whether components of the multi-layered HL interventions need to be modified or included to better suit the needs of the target population.

3.4 Participants

3.4.1 Eligibility Criteria

People with a diagnosed psychotic disorder aged 18-65 were eligible to participate in the HELP and WPC intervention studies. All study participants were screened for their suitability to participate in the HELP and WPC studies using the inclusion and exclusion criteria listed below.

3.4.1.1 Inclusion Criteria

Study participants were screened to determine their suitability for participation in the HELP and WPC intervention studies using the following inclusion criteria:

- (1) Having a Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) diagnosis of schizophrenia, schizoaffective disorder, other psychotic disorder, or major mood disorder with psychotic features;
- (2) Aged 18 to 65;
- (3) Currently receiving treatment in the community by a Community Mental Health Centre (CMHC), or a current inpatient at the Concord Centre for Mental Health (CCMH); and
- (4) Be able to give written informed consent to participate in the study.

3.4.1.2 Exclusion Criteria

To determine if study participants were ineligible to participate in the HELP and WPC intervention studies, the exclusion criteria included:

- (1) Participant not able to give informed consent due to diminished understanding or comprehension, or a language other than English is spoken, and a trained interpreter is not available; and
- (2) Participant has an organic brain disorder.

3.4.2 Data Collection Settings

3.4.2.1 HELP Intervention Studies

The HELP was piloted in outpatient and inpatient mental health service settings, to determine the most appropriate and feasible setting for the intervention in the future. The outpatient HELP study was implemented in a community setting to further adapt and refine components of the HELP in this population, to prepare for a larger pilot study to investigate the potential efficacy of the HELP in the future.

The outpatient HELP study was a multi-centre study conducted across two community mental health service settings in Sydney, Australia. The outpatient HELP was piloted in: (1) Physical health services run under the auspices of a Community Managed Organisation (CMO) called One Door Mental Health (ODMH), which was originally called Schizophrenia Fellowship of NSW; and (2) Three of the four Sydney Local Health District (SLHD) Community Mental Health Centres.

In Australia, a CMO is also known as a non-government organisation (NGO); a CMO is a not-for-profit organisation managed by a board of elected community members (Mental Health Coordinating Council 2010). ODMH⁵ is a mental health CMO that provides community-based services, psychosocial services, and advocacy support to people living with a mental illness and their families to help keep people well in the community. The SLHD⁶ has considerable diversity across the local health district (LHD) region in population structure, socioeconomic advantage and disadvantage, culture, and health status (Central and Eastern Sydney Primary Health Network 2017). The LHD⁷ provides public hospitals and health services to promote, protect and maintain the health of individuals, families, and communities that live within the LHD region. The inpatient HELP study was conducted across two mental health inpatient units in the SLHD in Sydney, Australia. The inpatient HELP was piloted in the Kirkbride and Broughton units at the CCMH. The Kirkbride unit is a sub-acute inpatient mental health facility that provides voluntary and involuntary short term mental health treatment. The Broughton unit focuses on the rehabilitation and extended mental health recovery of psychiatric patients that require extended hospital stays.

3.4.2.2 WPC Intervention Study

The WPC was piloted in primary healthcare settings to examine its feasibility in outpatients living with an ESPD. The WPC is designed to improve GP care for the prevention, treatment, and management, of cardiometabolic comorbidity in this population. GPs are the main health care provider for individuals with a SMI, whereby 70.8% of people with a mental illness consult a GP and 22.7% consult a psychiatrist (Australian Institute of Health and Welfare 2014). The WPC is specifically designed for use in a primary healthcare setting, as a tool to prompt the patient and GP to discuss the patient's physical health needs.

3.5 Sampling Technique

A non-probability sampling technique by means of convenience sampling was used. The HELP and WPC participants were mainly recruited through opportunistic sampling, which involved

⁵www.onedoor.org.au

⁶www.slhd.nsw.gov.au

⁷www.health.nsw.gov.au

promoting the HELP and WPC studies verbally at all study sites, during specialised health clinics (e.g., clozapine or olanzapine clinics) and group programs (e.g., healthy lifestyle, smoking cessation, and Hearing Voices). Multiple recruitment strategies were used, the study flyer was advertised at all study sites, and mental health workers at the study sites promoted the study using the study flyer.

3.6 HELP Intervention

3.6.1 Theoretical Framework of HELP Intervention

The HELP was co-designed⁸ using a solid foundation of evidence-based models of HL and behaviour change theories, to create a strong flexible mixed method interventional framework. Nutbeam's Outcome Model for Health Promotion was used to develop the theoretical framework for the HELP, see Appendix 1 (Nutbeam 2000). Two behaviour change models were used in conjunction with the theoretical framework, to facilitate behaviour change and improve individual HL skills. The two behaviour change models used were the: (1) Health Belief Model (HBM) (Becker 1974; Rosenstock 1974); and (2) Stages of Change Model (DiClemente & Prochaska 1982; Prochaska, JO & DiClemente 1983).

3.6.2 Co-design of HELP Intervention

The HELP was co-designed in a community setting to further adapt and refine the components of the HELP in this population. Two focus groups were conducted to review the six HELP topics prior to the final development of the intervention, see Appendix 15. The first focus group was undertaken with the health care professionals from the ccCHiP clinic. The ccCHiP clinic is a one stop shop, integrated service model to screen, detect, manage, and follow-up on CMRF and metabolic conditions in this population (Lambert 2018). The ccCHiP clinic focus group comprised the following health care professionals: (1) Psychiatrist; (2) Cardiologist; (3) Endocrinologist; (4) Mental Health Nurse Consultant; (5) Dietitian; and (6) Exercise Physiologist.

⁸Co-design means the researcher designs the intervention collaboratively with people that have lived experience of an ESPD. The intervention content and resources are reviewed from the perspectives of people with lived experience.

The second focus group was undertaken to review the HELP and WPC content and participant resources, from the perspectives of people with lived experience. The focus group included four people (3 men, 1 female) living with and ESPD. The focus group participants were recruited from ODMH physical health services. The participants in this focus group had a diagnosis of schizophrenia and were 38-45 years old. All participants were currently receiving treatment in the community by a CMHC. The participants had lived with their psychiatric illness for over ten years. All participants had completed high school. Two participants were permanently unable to work due to their psychiatric illness and two participants were employed part-time. All participants were born in Australia and spoke English at home as their main language.

One sixty minute focus group discussion was facilitated by the thesis author. The focus group was conducted at the ODMH physical health service in Sydney, Australia. The focus group discussion content was collected by the facilitator throughout the focus group using notetaking. Key words, phrases, and quotes from participants were written down to emphasise their main points. The participant's feedback and main points were then facilitated back to the focus group participants to create ideas to inform final changes to the HELP and WPC.

3.6.3 HELP Intervention

The HELP is a structured six topic cardiometabolic HL intervention for individuals living with an ESPD, see Figure 3.2. The HELP was specifically co-designed to target the CMRF and cardiometabolic health conditions that are highly prevalent in this population. The HELP is designed to support and educate individuals living with an ESPD to self-manage their CMRF and cardiometabolic health conditions by improving individual HL.

The HELP sessions involve: (1) Education about a cardiometabolic health topic; and (2) A discussion about the SENSE acronym modifiable lifestyle risk factors. The HELP topics are designed to educate this population about the medical terminology and numeracy used for each cardiometabolic health condition. The HELP content was developed to assist this population with understanding medical terminology and cardiometabolic health conditions that may be used in a consultation with a health care professional. Through the provision of support and education, participants learn to manage their health and make healthy lifestyle choices.

Figure 3.2 Outline of HELP Intervention

Session	Topic
1	Lifestyle Risk Factors (1) Non-modifiable risk factors (GAS): Genetics, Age, and Sex (2) Modifiable risk factors (SENSE): Sleep, Exercise, Nutrition, Substance use, and Ethanol
2	Wallet Prompt Card (WPC)
3	High Blood Pressure
4	High Cholesterol
5	Type 2 Diabetes Mellitus (T2DM)
6	Metabolic Syndrome (MetS)

The HELP intervention was flexible in its implementation approach, to allow for the needs of participants and service settings. The discussion topics are designed to be educational and empowering to promote: (1) Discussion; (2) Motivation; and (3) Behaviour change. The participants received six, thirty minute, health education sessions facilitated by the thesis author. The outpatient HELP participants received the intervention in a group format and the inpatient participants received the intervention individually. The HELP sessions were thirty minutes in duration, divided into twenty minutes for presentation of the cardiometabolic health topic, and then ten minutes for the Personal Improvement Plan (PIP) and SENSE acronym. The PIP is a

tool developed to support participants to set individual weekly goals related to SENSE to self-monitor lifestyle behaviour changes, see Appendix 16.

The HELP participant book was used to implement the intervention. The HELP participant book contains plain language health information for the six cardiometabolic health topics in the intervention, and key health messages. At the beginning of the intervention each participant received the following HELP resources to keep: (1) HELP participant book; (2) WPC; and (3) PIP.

3.6.3.1 Modifiable Lifestyle Risk Factors - “It Makes SENSE” – (Sleep, Exercise, Nutrition, Substance Use, and Ethanol) - The SENSE Acronym

The SENSE acronym was a specific tool developed to help facilitate the HL studies presented in chapters 4-6, see section 2.4.3. The SENSE acronym stands for: (1) Sleep; (2) Exercise; (3) Nutrition; (4) Substance Use; and (5) Ethanol. These lifestyle risk factors interact synergistically to raise multimorbidity and premature mortality rates in people living with an ESPD (Foster et al. 2018). The idea behind the SENSE acronym was to educate and inform psychiatric patients about the modifiable lifestyle risk factors and lifestyle behaviours, that impact on their cardiometabolic risk and overall cardiometabolic health, to empower them to learn to have some agency.

The SENSE acronym was designed in clear and concise plain language, to ensure the health information was easy for participants to understand. A universal precautions approach was used to design the acronym. A universal precautions approach works by assuming every patient has low HL knowledge and skills (DeWalt, D, Berkman & Sheridan 2004). The teach-back technique was used throughout the HELP and WPC intervention sessions, to reinforce the key messages and principles of the SENSE acronym.

The acronym provided goal-oriented discussion around modifiable lifestyle risk factors related to SENSE that are important and meaningful for the participant to achieve. Participants were encouraged to set SMARTER goals related to SENSE throughout the HELP. The SMARTER acronym, used to facilitate participant goal-setting stands for: (1) Specific; (2) Measurable; (3) Achievable; (4) Relevant; (5) Time-bound; (6) Evaluate; and (7) Revise or Reward (Bovend'Eerd, Botell & Wade 2009; Bowman et al. 2015).

3.7 WPC Intervention

In the general population individuals with a chronic disease are being diagnosed earlier and living longer, unfortunately this has not transferred to psychiatric patients (Britt 2013). To improve health outcomes for psychiatric patient's mental health services and GPs could provide shared care (Berardi et al. 2007). Primary healthcare services provide the ideal healthcare setting for integrated clinical care to identify and address CMRF and multimorbidity in psychiatric patients (Fricchione et al. 2012). GPs have a central role to play in the management of a psychiatric patients' physical health and should always be closely involved in the patients' overall medical treatment through shared care partnerships with the patient's psychiatrist, this is considered best practice (Berardi et al. 2007; Fredheim et al. 2011; McGorry et al. 2004; Waterreus & Laugharne 2009).

3.7.1 Theoretical Framework of WPC Intervention

The WPC intervention was co-designed using the same solid foundation of evidence-based models of HL and behaviour change theories that were used to develop the theoretical framework for the HELP, see section 3.6.1.

3.7.2 Co-design of WPC Intervention

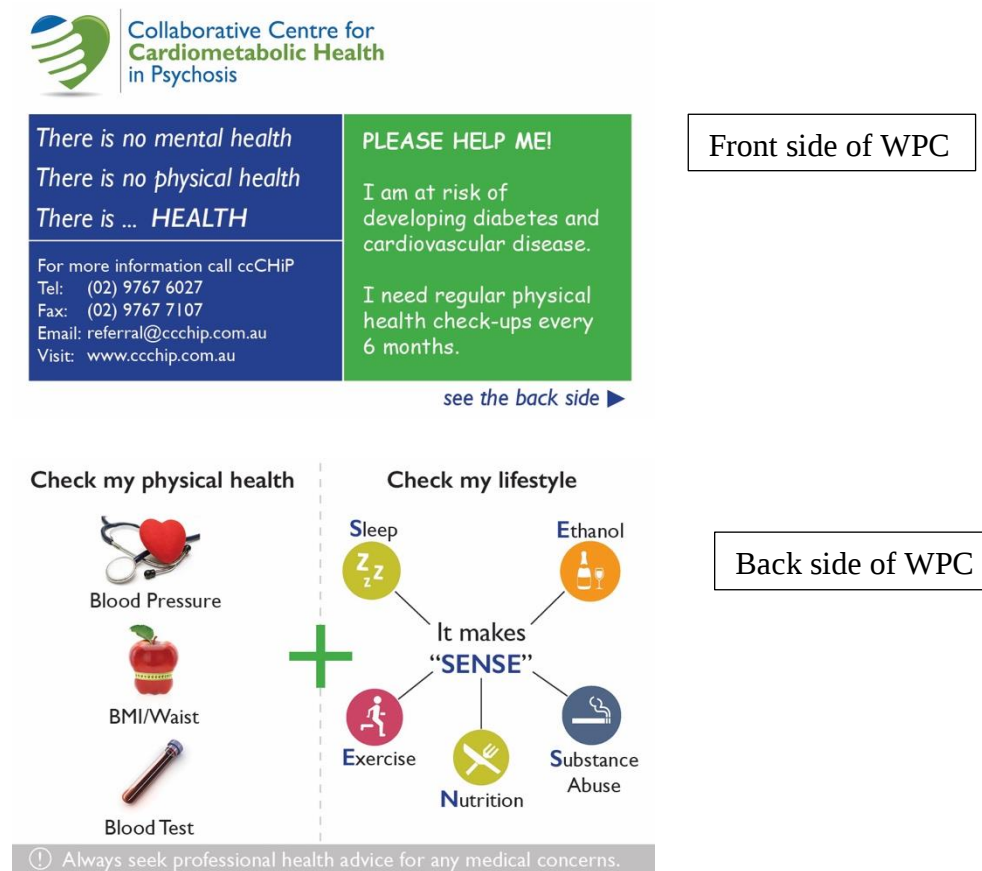
The WPC was developed to assist outpatients living with an ESPD to start a conversation with the GP about their physical health. The WPC was specifically designed to use in a primary healthcare setting, as a tool to prompt the patient and GP to discuss the patient's physical health and undertake regular physical health check-ups. GPs are in the best position to assist psychiatric patients with their physical health, regular physical health check-ups, and healthy lifestyle advice (Hall et al. 2010). Therefore, the WPC was designed to improve GP care for CMRF screening, detection, treatment, and management, of cardiometabolic health conditions that are highly prevalent in this population. In addition, the WPC was also designed to be used as a cue to improve preventative health care and health promoting lifestyle behaviours related to SENSE. The final design of the WPC included the necessary images for a comprehensive physical health check-up and a lifestyle check-up using the SENSE acronym, see Figure 3.3.

Three focus groups were conducted to co-design and review the components of the WPC in this population prior to the final development of the intervention. The WPC was co-designed in a

primary healthcare setting with a GP that had a special interest in mental health. Two focus sessions were conducted with the GP to help co-design and refine the components of the WPC concept. During the co-design focus sessions a draft design concept of the WPC was used to ask the GP “how the WPC could be designed to be useful and meaningful for the patient and GP in a health care consultation?”

The third focus group was undertaken to review the WPC content and participant resources, from the perspectives of people with lived experience. The lived experience focus group was described previously, see section 3.6.2.

Figure 3.3 Wallet Prompt Card (WPC)



3.7.3 WPC Intervention

The WPC intervention is a structured thirty minute cardiometabolic HL intervention for individuals living with an ESPD, see Figure 3.4. The WPC intervention involves one thirty

minute education session, divided into twenty minutes for presentation on how to use the WPC and normal range CMRF targets, then ten minutes for the PIP and SENSE acronym. The PIP is a tool developed to support participants to set individual weekly goals related to SENSE to self-monitor lifestyle behaviour changes. Following the education session participants had six weeks to attend a GP for a physical health check-up using the WPC.

Figure 3.4 Outline of WPC Intervention

Session	Topic
1	1. How to use the WPC with a GP. 2. Normal range targets (e.g., healthy range) for blood pressure, waist circumference, cholesterol, and blood glucose levels. 3. Modifiable Lifestyle Risk Factors (SENSE): Sleep, Exercise, Nutrition, Substance use, and Ethanol.

3.8 Outcome Measures

The HLQ was used to evaluate the participants individual HL at baseline (before starting the intervention) and at completion of the HL intervention (final week of the intervention). Primary outcomes across the HELP and WPC intervention studies included: (1) Self-reported individual HL changes measured using the HLQ; and (2) Self-reported GP care for CMRF screening and cardiometabolic health conditions, evaluated using the structured follow-up interview questionnaire.

Lifestyle modifications related to SENSE might be expected to improve (a secondary outcome) across the HELP and WPC intervention studies. Consequently, lifestyle modifications related to SENSE were positively promoted as secondary outcomes and evaluated using the structured follow-up interview questionnaire that was developed for the HELP and WPC intervention studies, see Appendix 17. Additionally, recall of the SENSE acronym and booster session

interest are exploratory outcomes being evaluated using the structured follow-up interview questionnaire.

Finally, quantitative measures of feasibility included program completion, individual HL changes on subscales of the HLQ, and participant satisfaction. An evaluation form was developed for the HELP and WPC interventions to evaluate the impact of the HL interventions to meet the needs of participants in terms of providing support and education, see Appendix 18. By providing tailored cardiometabolic health education to this vulnerable population it is hypothesised that individual HL will improve.

3.8.1 Primary Outcome Measures

3.8.1.1 Self-reported Individual HL

The HLQ was used to evaluate the HELP and WPC interventions to capture a broad range of components that contribute to individual HL, see section 2.5.7. The HLQ is a multi-dimensional tool that measures individual HL, it can be self-administered using pen and paper or orally administered by interview to assist individuals with completing the questionnaire (Batterham et al. 2014). Participants self-completed a paper-based HLQ upon commencement (pre-intervention) and completion (post-intervention) of the HELP or WPC intervention. Participants needing assistance to complete the HLQ received verbal support, from the thesis author, a family member, or a bilingual Vietnamese mental health worker. The HLQ takes approximately 7 to 40 minutes to complete (Muscat et al. 2020). In our study participants completed the HLQ in approximately 15 to 20 minutes. Participants with English as a second language took longer to complete the HLQ, and needed an interpreter or assistance to complete the HLQ.

3.8.1.2 Self-reported GP Care

A structured follow-up interview questionnaire was used to evaluate participants GP attendance and WPC use, see Appendix 17. The structured follow-up interview questionnaire was developed using the Survey Designs chapter (Creswell 2008). It is comprised of four parts: (1) HL questions; (2) Medical appointment (GP) questions; (3) Behaviour/Lifestyle change questions; and (4) Booster session interest. The HL part included questions about the information retained from the HELP and WPC intervention. The medical appointment section asked about GP attendance for a physical health check-up and use of the WPC. The behaviour/lifestyle change

questions focused on recall of the SENSE acronym and SENSE lifestyle modifications. The final part asked about future booster session interest. The structured follow-up interviews were conducted at 3 and 6 months after completion of the HELP or WPC intervention. The thesis author conducted the 15 minute structured follow-up interviews. Most interviews were done over the phone. However, some participants preferred to conduct the interview face to face, as they preferred this method of communication.

3.8.2 Secondary Outcome Measures

Lifestyle modifications related to SENSE were positively promoted as secondary outcomes and evaluated using the structured follow-up interview.

3.8.3 Exploratory Outcome Measures

Recall of the SENSE acronym and booster session interest were exploratory outcomes being evaluated using the structured follow-up interview.

3.8.4 Evaluation of HELP and WPC Interventions

An evaluation form was developed for the HELP and WPC interventions to determine the impact the intervention has had on participants in terms of meeting specific needs, and providing support and education, see Appendix 18. The evaluation form was developed from the NSW Family and Carer Mental Health Program (FCMHP) - education and training evaluation form, which was designed to measure perceived satisfaction and usefulness of the FCMHP⁹ - education and training programs.

At the end of the final HELP or WPC intervention session participants completed a written evaluation form for the intervention. The evaluation form could be completed anonymously. Participants were asked to answer four questions related to different components of the intervention. Participants rated their level of satisfaction with the intervention using a 5-point ordinal scale (1 = “unsatisfactory” to “excellent” = 5). Participants were then asked to provide feedback about: (1) Their expectations of the intervention; (2) What they liked most about the intervention; and (3) What changes should be made to the intervention.

⁹www.onedoor.org.au/services/carer-services/nsw-family-carer-mental-health-program

Qualitative evaluation of the HELP and WPC interventions is based on participant feedback and evaluates the intervention with regards to its suitability and relevance for this population. Participant feedback obtained from the evaluation form was used to identify whether the HELP and WPC interventions met the needs of the target population, and whether components of the multi-layered HL interventions need to be modified or included to better suit the needs of the target population. Specific changes can then be made to the intervention or its implementation where required.

3.9 Sample Size

To determine the appropriate sample size to produce a statistical significance a statistician was consulted and a power calculation was performed. A study sample of 20 participants completing the HELP or WPC intervention allows a within-subject effect size of 0.7 standard deviations (SDs) to be statistically significant using a paired t-test. The objective was to measure the effect size achieved and only secondarily to show a significant change. Previous studies examining healthy lifestyle interventions in people with a psychotic disorder report a 17-40% drop-out rate (Brown, S & Chan 2006). Therefore, a 40% drop-out rate was expected for the HELP and WPC interventions. To allow for the expected drop-out rate in the HELP and WPC interventions the aim was to recruit: (1) 28 participants to the inpatient HELP study and WPC study for the required sample size of $n = 20$; and (2) 56 participants to the outpatient HELP study for a sample size of $n = 40$.

3.10 Ethical Approval

3.10.1 Approvals

Ethical approval was obtained from the SLHD Human Research Ethics Committee - Concord Repatriation General Hospital (CRGH) (Protocol number: CH62/6/2014-174), see Appendix 19.

3.10.2 Consent Form

Multiple recruitment strategies were used to recruit participants to the HELP and WPC intervention studies. Potential participants received a verbal explanation describing the HELP or WPC study prior to receiving the written Participant Information Sheet and Consent Form for the

study, see Appendix 20. Once the participant's eligibility was ensured and they had decided to participate in the HELP or WPC study, informed written consent was obtained.

3.10.3 Statistical Analysis

All statistical analyses were conducted using the Statistical Package for the Social Sciences (SPSS) software, version 27.0 (IBM Corporation 2020). Descriptive statistics were used to summarise demographic characteristics and the pre-and post-test intervention HLQ scores. Paired sample *t*-tests were used in chapter four to compare the mean change in HLQ domain scores before and after the outpatient HELP intervention. Non-parametric statistics were used in chapters five and six due to the small sample size. The Wilcoxon signed-rank test was used to report the *p*-value to compare the mean change in HLQ domain scores pre-and post-intervention for the inpatient HELP intervention and WPC intervention. The expectation maximisation (EM) algorithm was used to impute missing HLQ item scores.

To determine whether the magnitude of change in the: (1) HLQ domain scores; and (2) HELP evaluation form participant feedback was due to sociodemographic factors. One-way between groups analysis of variance (ANOVA) with post-hoc tests using the Welch method were used in chapter four; chapters five and six used the Kruskal-Wallis test. Effect sizes (ES) for standardised differences in mean domain score changes between the pre-and post-intervention HLQ domain scores were calculated using Hedge's *g* (calculated using a sample size weighted pooled standard deviation) with interpretation of ES as follows: 'small' ES >0.20-0.50, 'medium' ES 0.50-0.80, and 'large' ES >0.80. The significance level was set at $p < 0.05$ (two tailed).

In summary, to address the cardiometabolic health needs and multimorbidity experienced by people living with an ESPD. Specific and tailored multi-layered HL interventions should be developed for this population. HL interventions should be implemented across the spectrum of mental health treatment settings (e.g., private and public mental health hospitals, and community mental health services). The next chapter examines the feasibility of the pilot HELP in outpatients living with an ESPD that are receiving treatment in the community.

CHAPTER 4

HELP Makes SENSE: Effects of a Health Literacy Intervention in Outpatients Living with an Enduring and Severe Psychotic Disorder with High Levels of Cardiometabolic Risk: A Pilot Study

This chapter evaluates the feasibility of the pilot HELP intervention in outpatients living with an ESPD. The outpatient HELP intervention was implemented in community mental health settings. The HLQ was used to evaluate participants individual HL at baseline and at completion of the intervention. The hypothesis tested was that the tailored cardiometabolic HL intervention will improve participant's individual HL knowledge and skills. The HELP intervention resulted in the development of an effective HL education program for participants. The study highlights that cardiometabolic HL interventions to improve individual HL in this population are feasible and can be implemented in community mental health services.

4.1 Introduction

Currently, cardiometabolic HL interventions are rare in mental health treatment settings (Galletly, Lincoln & Arford 2013; Lincoln et al. 2017). Low individual HL and numeracy must be considered when addressing the physical health concerns and premature mortality rates in this population (Webster & Heeley 2010). Psychiatric patients need to have an adequate level of understanding numerical processes when discussing cardiometabolic risk (Webster & Heeley 2010). The self-management of CMRF is of key relevance, as inadequate individual HL knowledge and skills affect a person's ability to self-manage their CMRF and chronic diseases, leading to poor health outcomes (Royal Australian and New Zealand College of Psychiatrists 2015). Educating the patient about self-management of CMRF and cardiometabolic health conditions to improve their individual HL may help to improve cardiometabolic health outcomes in this population (Bradshaw, Lovell & Harris 2005; Conn, Hafdahl & Brown 2009; Galletly, Lincoln & Arford 2013; Linde-Feucht 2007).

The benefits of knowledge, education, teaching of illness self-management skills, screening, and intervention to prevent cardiometabolic health conditions in this population, is well documented in numerous studies and clinical practice guidelines in Australia and worldwide (Coughlan et al. 2001b; McGorry et al. 2004; Royal Australian and New Zealand College of Psychiatrists 2015).

Patients report that they find the educational components of an intervention most beneficial to improve self-management of their comorbidities (Nover & Jackson 2013). Early intervention and improving individual HL regarding CMRF in this vulnerable population, may help improve cardiometabolic health outcomes and reduce premature death, through patient engagement, education, empowerment, and self-management of CMRF (Galletly, Lincoln & Arford 2013).

Existing research has yet to reveal the role that HL may play in assisting individuals with an ESPD to self-manage their CMRF and cardiometabolic health conditions, which contribute to multiple chronic diseases and premature death in this population. To date, no published study has investigated the impact of cardiometabolic HL interventions in people living with an ESPD. Therefore, the present study was necessary to determine, if people living with an ESPD are an appropriate group to receive cardiometabolic HL interventions. This pilot study examined the feasibility of the HELP intervention. The overall goal of this pilot study was to test whether the HELP can be implemented in outpatients living with an ESPD to improve individual HL knowledge and skills.

4.2 Methods

4.2.1 Participants

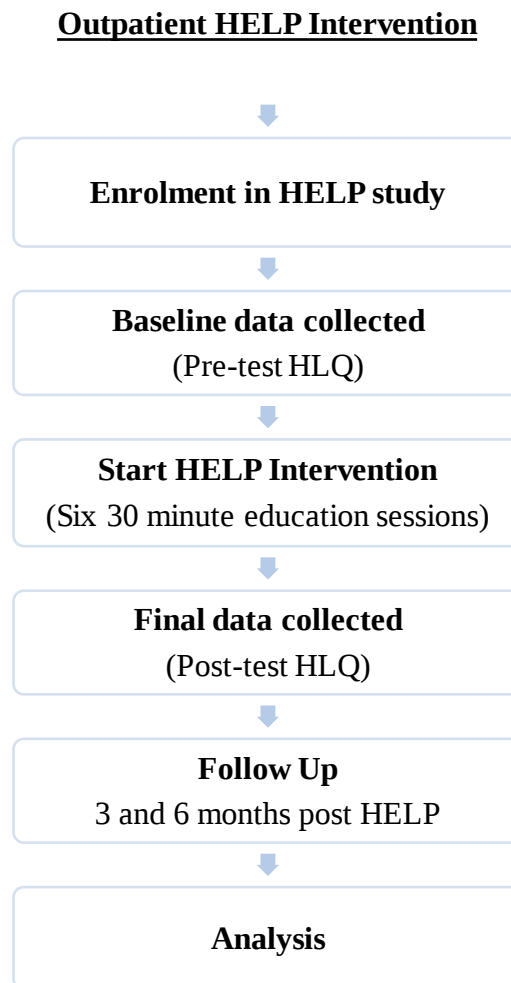
Figure 4.1 shows the enrolment process. A total of 43 outpatients with an ESPD receiving treatment in the community by a CMHC consented to participate. They were recruited between February 2017 and December 2018 from: (1) ODMH physical health services; and (2) Three of the four SLHD Community Mental Health Centers. The inclusion criteria and exclusion criteria were explained in greater detail earlier, see sections 3.4.1.1 and 3.4.1.2.

4.2.2 Procedure

The HELP is a structured, six topic cardiometabolic HL intervention for individuals living with an ESPD. The theoretical framework, co-design, and implementation of the HELP intervention was explained in greater detail above, see section 3.6. The participants received six, thirty-minute, group health education sessions facilitated by the thesis author. The outpatient HELP participants received the intervention in a group format that consisted of six group health education sessions. The HELP sessions were thirty minutes in duration each divided into twenty

minutes for presentation of the cardiometabolic health topic, and then ten minutes for the PIP and SENSE acronym discussion.

Figure 4.1 Study Profile for Outpatient HELP Intervention¹⁰



4.2.3 Data Collection and Measures

Participants self-completed a paper-based HLQ upon commencement (pre-intervention) and completion (post-intervention) of the HELP. The HLQ provided demographic information and measured individual HL across nine domains, see section 2.5.7. Participants needing assistance to complete the HLQ received verbal support from the study investigator, a family member, or a Bilingual Vietnamese Mental Health Care Coordinator. The HLQ takes approximately 7 to 40

¹⁰The numbers for each section of the outpatient HELP intervention are discussed in the text.

minutes to complete (Muscat et al. 2020). The instrumentations and the methods used for assessments were explained in greater detail above, see section 3.8.

After completing the intervention participants self-completed the HELP evaluation form to evaluate participant satisfaction with the intervention. Phone interviews were conducted at 3 and 6 months follow-up. The phone interviews evaluated the participants' (1) GP attendance; (2) WPC use; (3) Lifestyle modifications related to SENSE; (4) Recall of the SENSE acronym; and (5) Booster session interest. The study investigator conducted the fifteen-minute follow-up phone interviews. Most interviews were completed over the phone, although four interviews were conducted face to face as the participants preferred this method of communication.

4.2.4 Statistical Analysis

The statistical analysis was explained in greater detail above, see section 3.10.3.

4.2.5 Ethics Approval

This study was approved by the SLHD Human Research Ethics Committee – CRGH (Protocol number CH62/6/2014-174) and written informed consent was obtained from all participants.

4.3 Results

4.3.1 Demographic Characteristics

The sample consisted of 43 participants (22 men, 21 females) with a mean age of 45.8 years (SD = 12.0, range 24-65). The psychiatric diagnoses of study participants included schizophrenia, schizoaffective disorder, and bipolar disorder. The demographic characteristics of the sample are shown in Table 4.1. The majority of participants had a Health Care Card, issued by Services Australia. These cards are given to people in Australia that receive government payments or supplements from the Australian Government¹¹.

¹¹The Australian Government issues a Health Care Card to people in Australia that receive government payments. A Health Care Card assists people to receive cheaper health care products and services such as Pharmaceutical Benefits Scheme (PBS) prescription medicines, medical services, ambulance transportation, dental care, eye care, and other government concessions.
www.servicesaustralia.gov.au/health-care-card

Table 4.1 Demographic Data for Outpatient HELP Participants (*n* = 43)

Characteristics	n (%)
Study site	
ODMH	21 (48.8%)
SLHD Canterbury CMHC	13 (30.2%)
SLHD Marrickville CMHC	6 (14%)
SLHD Croydon CMHC	3 (7%)
Psychiatric diagnosis	
Schizophrenia	29 (67.4%)
Schizoaffective disorder	3 (7%)
Bipolar disorder	11 (25.6%)
Gender	
Male	22 (51.2%)
Female	21 (48.8%)
Age	
18-24	2 (4.7%)
25-34	5 (11.7%)
35-44	15 (34.9%)
45-59	14 (32.4%)
60-65	7 (16.3%)
Lives alone	
Yes	17 (39.5%)
No	26 (60.5%)
Country of Birth	
Australia	23 (53.5%)
Pacific Islands	4 (9.3%)
Anglo - other	4 (9.3%)
Asian	8 (18.6%)
African	4 (9.3%)
English spoken at home	
Yes	37 (86%)
No	6 (14%)
Identifies as Indigenous/Torres Strait Islander	
Yes	0 (0%)
No	43 (100%)
Educational attainment	
High school (not completed)	2 (4.7%)
High school (completed)	12 (27.9%)
TAFE/Trade	23 (53.5%)
Undergraduate degree	5 (11.6%)
Postgraduate degree	1 (2.3%)
Employment status	
Working (full time)	1 (2.3%)
Working (part time)	8 (18.6%)
Home duties	12 (27.9%)
Student (full time)	1 (2.3%)

Student (part time)	1 (2.3%)
Retired	5 (11.6%)
Permanently unable to work/ill	9 (20.9%)
Other	6 (14%)
Chronic Health Condition	
Arthritis	5 (11.6%)
Back pain	11 (25.6%)
Heart problems	2 (4.7%)
Asthma/lung condition	2 (4.7%)
Cancer	0 (0%)
Depression/Anxiety	27 (62.8%)
Diabetes	8 (18.6%)
Stroke	0 (0%)
Other	14 (32.6%)
≥ 4 Chronic conditions	4 (9.3%)
Reports no health condition (None)	5 (11.6%)
Private Health Insurance	
Yes	9 (20.9%)
No	34 (79.1%)
Have Health Care Card	
Yes	40 (93%)
No	3 (7%)
Attended hospital emergency in the past 12 months	
Yes	14 (32.6%)
No	29 (67.4%)
Assistance required to complete HLQ	
Yes	16 (37.2%)
No	27 (62.8%)
Type of assistance required to complete HLQ	
Interpreter used (e.g., Bilingual Mental Health Care Worker)	3 (7%)
Researcher explained HLQ statements to participant	12 (27.9%)
Researcher administered HLQ for participant	1 (2.3%)

4.3.2 Health Literacy (HL)

The sample consisted of 43 participants, 41 of whom completed the HELP in its entirety. Two participants dropped out of the intervention, one participant dropped out at week 3 and the other participant dropped out at week 4. The participants mean pre-and post-intervention HLQ domain scores and the mean domain score changes are shown in Table 4.2. There were statistically significant ($P < 0.05$) improvements in mean scores for two HLQ domains (Domain 2: Having sufficient information to manage my health and Domain 6: Ability to actively engage with healthcare providers). There was no significant change in the other seven HLQ domains. The

effect sizes (ES) (Hedge's *g*) were small for eight HLQ domains and ranged between 0.05 (Domain 5: Appraisal of health information) and 0.42 (Domain 2: Having sufficient information to manage my health). Domain 7: Navigating the healthcare system had no ES, see Figure 4.2.

Table 4.2 Health Literacy Questionnaire (HLQ) Domain Score Changes for Outpatient HELP Intervention (*n* = 41). Higher values indicate greater understanding or ability.

HLQ Domain Scale ¹²	Pre-intervention Mean (SD)	Post-intervention Mean (SD)	<i>t</i> -test	<i>P</i> -value
1. Feeling understood and supported by healthcare providers	3.26 ± 0.49	3.18 ± 0.63	0.91	<0.366
2. Having sufficient information to manage my health	2.77 ± 0.72	3.06 ± 0.67	-2.64	<0.012
3. Actively managing my health	3.04 ± 0.62	3.03 ± 0.71	0.05	<0.955
4. Social support for health	2.83 ± 0.63	2.93 ± 0.77	-1.23	<0.224
5. Appraisal of health information	2.79 ± 0.65	2.82 ± 0.68	-0.35	<0.727
6. Ability to actively engage with healthcare providers	3.55 ± 0.89	3.80 ± 0.89	-2.71	<0.010
7. Navigating the healthcare system	3.76 ± 1.74	3.76 ± 0.87	0.03	<0.973
8. Ability to find good health information	3.48 ± 0.92	3.67 ± 0.89	-1.88	<0.067
9. Understand health information well enough to know what to do	3.71 ± 0.84	3.85 ± 0.82	-1.27	<0.210

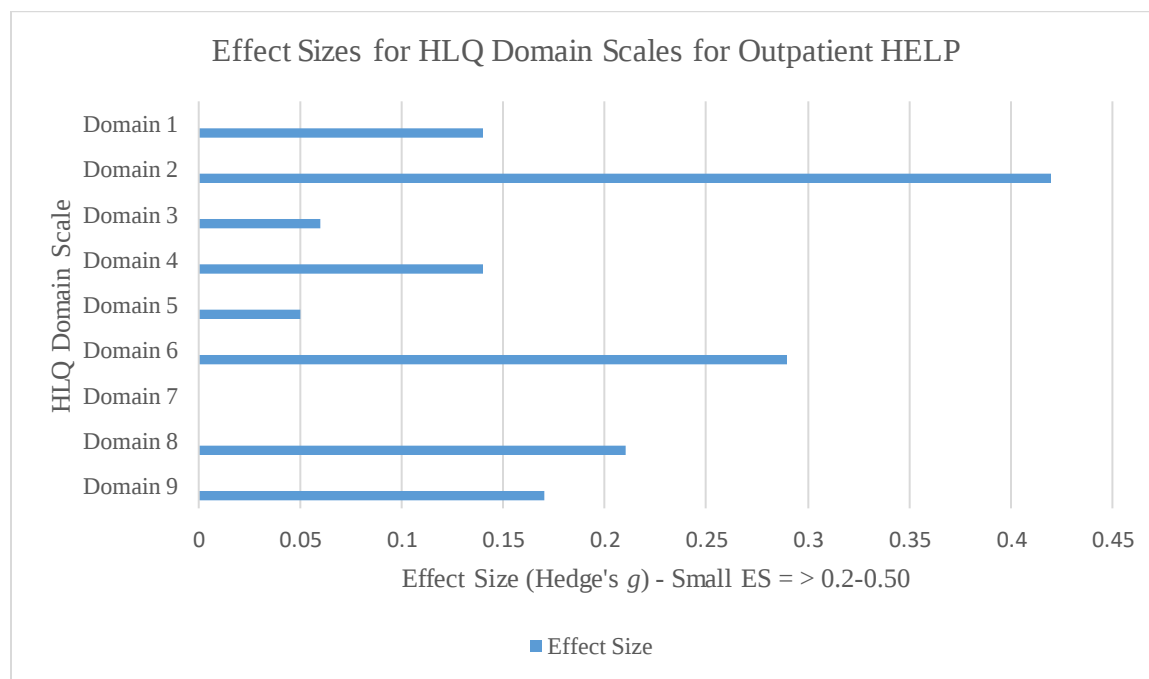
Results in bold have *p*-value <0.05 for difference in means.

All nine pre-and post-intervention HLQ mean domain scores were individually analysed using one-way between groups ANOVA to determine whether the magnitude of change in the HLQ domain scores changed due to sociodemographic factors regarding age, gender, psychiatric

¹²The first 5 HLQ domain scales (e.g., HLQ domain scales 1-5) are answered using response options ranging from strongly disagree to strongly agree (range 1 to 4). The last 4 HLQ domain scales (e.g., HLQ domain scales 6-9) are answered using response options ranging from cannot do to very easy (range 1 to 5).

diagnosis, education level, and study site. The outcomes of the one-way ANOVA between groups analysis indicated a statistically significant difference between psychiatric diagnosis and pre-intervention mean score changes for Domain 4: Social support for health ($F(2,40) = 3.459, p = .041$). Despite reaching statistical significance, the actual difference in mean score changes between the groups was quite small. The pre-intervention ES, calculated using eta squared, was 0.15. Post-hoc comparisons using the Tukey HSD test indicated that the pre-intervention mean score for participants with BD ($M = 2.51, SD = 0.82$) was significantly different from participants with schizophrenia ($M = 3.03, SD = 0.52$). The pre-intervention mean score for participants with schizoaffective disorder ($M = 2.53, SD = 0.50$) did not differ significantly from participants diagnosed with BD or schizophrenia. The one-way ANOVA between groups analysis indicated that there were no significant differences between HLQ domain score changes and age, gender, education level, and study site.

Figure 4.2 Effect Sizes for the 9 HLQ Domain Scales for Outpatient HELP Intervention



4.3.3 HELP Evaluation Form

The sample consisted of 43 participants, 41 of whom completed the HELP evaluation form. The feedback is shown in Table 4.3. Participants reported satisfaction with the HELP and agreed that the program was useful. Participants were satisfied with the HELP resources. One-way between

groups ANOVA was undertaken to determine whether any sociodemographic factors were associated with the HELP evaluation form participant feedback. There were no significant differences between participant feedback and age, gender, psychiatric diagnosis, education level, and study site. Participants commented that they liked that the program was practical, interactive, inclusive, fun, and could provide access to the ccCHiP clinic. Participants suggested future changes to the HELP could include: (1) Making the intervention longer to cover more health topics; and (2) Having a person with a lived experience of a psychotic disorder involved in facilitating the program.

Table 4.3 Outpatient HELP Participant Feasibility and Acceptability Ratings ($n = 41$)

HELP Evaluation Form Questions	Unsatisfactory	Average	Good	Very Good	Excellent
<u>Feasibility</u> : How useful was the HELP for you?	0 (0%)	3 (7.3%)	14 (34.1%)	9 (22%)	15 (36.6%)
<u>Satisfaction</u> Education materials (handouts, powerpoint slides, ect.)?	0 (0%)	2 (4.9%)	15 (36.6%)	8 (19.5%)	16 (39%)
Overall, how do you rate the HELP?	0 (0%)	1 (2.4%)	20 (48.8%)	7 (17.1%)	13 (31.7%)
Overall, how do you rate the session presenters?	0 (0%)	0 (0%)	13 (31.7%)	7 (17.1%)	21 (51.2%)

Perceived intervention benefits were extracted from the participants' written comments provided in their responses to the questions in the HELP evaluation form. The themes from the participants' written comments in the HELP evaluation form included: (1) Informative cardiometabolic health education was provided in each session; (2) The HELP resources had easy to understand language and images; (3) Health information was in plain language; (4) Tools were provided to assist with getting healthy (e.g., PIP for modifiable lifestyle risk factors related to SENSE); (5) Specific health information on health issues related to people living with an ESPD (e.g., education on CMRF, blood pressure, diabetes, and cholesterol); and (6) Discussing physical health concerns, and improved understanding of healthy targets to achieve for CMRF (e.g., normal range for blood sugar levels and cholesterol levels). One participant drew a cartoon script highlighting how the HELP benefitted them, see Appendix 21. Participant testimonials are reported below

Outpatient HELP Participant Testimonials

1. “The HELP participant book is clear to read and understand. It gives you vision to run with what you have learnt in the study.”
2. “The HELP participant booklet contains relevant easy to understand information.”
3. “The very clear and easy to understand explanations of everything in the HELP participant booklet.”
4. “The HELP content was excellent.”
5. “I liked the SENSE acronym the best. Who thought of the acronym? It’s great.”
6. “The relaxing, open and frank discussions during the HELP sessions, which I have found fun and beneficial.”
7. “They don’t tell you about the weight gain when you start these medications or the side effects.”
8. “This was very helpful. I now understand cholesterol and blood sugar levels.”
9. “The HELP has very useful content to assist with my exercise program and diabetes self-management.”
10. “Gratefully appreciated to have the opportunity to be involved in such a helpful program.”

4.3.4 Follow-up Interviews

The sample consisted of 43 participants. At 3 months follow-up 27 participants completed the follow-up interview, and at 6 months follow-up 16 participants completed the follow-up interview. Responses to the questions in the follow-up interview are shown in Table 4.4. At follow-up participants reported feeling more confident in understanding health information. They also reported that they want more help with HL and are interested in attending a HL refresher session in the future. In addition, most participants reported lifestyle modifications related to SENSE and that they will make future lifestyle changes.

Table 4.4 Follow-up Interview Data for Outpatient HELP Participants
(3 months $n = 27$, 6 months $n = 16$)

Follow-up Interview Questions	3 months n (%)	6 months n (%)
Health Literacy Questions		
1. Have you retained most of the information you learnt in the HELP?		
Yes	18 (66.7%)	9 (56.2%)
No	5 (18.5%)	3 (18.8%)
Uncertain	4 (14.8%)	4 (25%)
2. Do you feel more confident in understanding health information?		
Yes	22 (81.5%)	14 (87.5%)
No	2 (7.4%)	0 (0%)
Uncertain	3 (11.1%)	2 (12.5%)
3. Do you need more help with anything related to health literacy?		
Yes	15 (55.6%)	7 (43.8%)
No	11 (40.7%)	9 (56.2%)
Uncertain	1 (3.7%)	0 (0%)
4. Have your health literacy knowledge, skills & behaviours changed?		
Yes	20 (74.1%)	13 (81.2%)
No	4 (14.8%)	1 (6.3%)
Uncertain	3 (11.1%)	2 (12.5%)
Medical Appointment (GP) Questions		
5. Have you been to a GP for a physical health check-up since participating in the HELP?		
Yes	16 (59.3%)	11 (68.8%)
No	11 (40.7%)	5 (31.2%)
5a. Did you use the WPC given to you at the end of the HELP?		
Yes	2 (7.4%)	2 (16.7%)
No	25 (92.6%)	14 (83.3%)
If yes, did you find the WPC useful on your visit to the GP?		
Yes	2 (100%)	2 (100%)
No	0 (0%)	0 (0%)
Uncertain	0 (0%)	0 (0%)
5b. If no, why did you not use the WPC when you went to see the GP?		
Forgot I had the card in my wallet	7 (35%)	3 (25%)
Have lost the wallet card	3 (15%)	0 (0%)
Left the card at home	1 (5%)	1 (8.3%)
Other	16 (45%)	12 (66.7%)
6. Is there a reason why you have not been to the GP for a physical health check-up?		
Yes	6 (54.5%)	3 (50%)
No	5 (45.5%)	2 (33.3%)
Uncertain	0 (0%)	1 (16.7%)

7. How many times have you been to the GP since participating in the HELP?		
None	6 (19.2%)	2 (12.5%)
1 visit	8 (30.8%)	4 (25%)
2 visits	4 (15.4%)	3 (18.7%)
3 visits	4 (15.4%)	1 (6.3%)
4 visits	2 (7.7%)	0 (0%)
≥ 4 visits	3 (11.5%)	6 (37.5%)
Behaviour/Lifestyle Change Questions (e.g., SENSE Acronym)		
8. Do you remember the SENSE acronym used in the HELP?		
Yes	11 (40.7%)	8 (50%)
No	14 (51.9%)	7 (43.7%)
Uncertain	2 (7.4%)	1 (6.3%)
9. Do you remember what the SENSE acronym letters stand for/mean?		
Yes	12 (48%)	9 (56.2%)
No	15 (52%)	5 (31.3%)
Uncertain	0 (0%)	2 (12.5%)
9a. SENSE acronym letters remembered:		
Sleep		
Yes	20 (66.7%)	9 (56.2%)
No	7 (33.3%)	7 (43.8%)
Exercise		
Yes	16 (53.3%)	8 (50%)
No	11 (46.7%)	8 (50%)
Nutrition		
Yes	15 (52%)	9 (56.2%)
No	12 (48%)	7 (43.8%)
Substance use		
Yes	15 (52%)	7 (43.8%)
No	12 (48%)	9 (56.2%)
Ethanol		
Yes	10 (43.3%)	7 (43.8%)
No	17 (56.7%)	9 (56.2%)
9b. Why do you remember these SENSE acronym letters/words?		
• I am making changes to these lifestyle behaviours	1 (3.7%)	0 (0%)
• The SENSE acronym is really clear	4 (14.8%)	3 (18.7%)
• Repetition of the SENSE acronym in each topic of the HELP	3 (11.1%)	2 (12.5%)
• Revised the HELP participant book regularly	1 (3.7%)	0 (0%)
• I remember the alcohol one as it was a funny way of saying it	1 (3.7%)	0 (0%)
• The acronym applies to me and my health	6 (22.2%)	6 (40.5%)
• I didn't remember any of the SENSE acronym letters	11 (40.8%)	5 (28.3%)

10. Have you made any changes to your lifestyle in regards to the SENSE acronym used in the HELP?		
Yes	24 (90.6%)	14 (87.5%)
No	3 (9.4%)	2 (12.5%)
10a. If yes, what SENSE lifestyle factors have you made changes too?		
Sleep		
Yes	17 (56.7%)	11 (68.8%)
No	10 (43.3%)	5 (31.2%)
Exercise		
Yes	20 (66.7%)	12 (75%)
No	7 (33.3%)	4 (25%)
Nutrition		
Yes	24 (90.6%)	14 (87.5%)
No	3 (9.4%)	2 (12.5%)
Substance use		
Yes	17 (56.7%)	2 (12.5%)
No	10 (43.3%)	14 (87.5%)
Ethanol		
Yes	15 (52%)	2 (12.5%)
No	12 (48%)	14 (87.5%)
Other		
Yes	3 (9.4%)	0 (0%)
No	24 (90.6%)	16 (100%)
10b. What motivated you to make changes in regards to your lifestyle?		
HELP study		
Yes	15 (52%)	8 (50%)
No	12 (48%)	8 (50%)
GP/Doctor		
Yes	10 (43.3%)	7 (43.7%)
No	17 (56.7%)	9 (56.3%)
Psychiatrist		
Yes	7 (33.3%)	4 (25%)
No	20 (66.7%)	12 (75%)
Case manager		
Yes	3 (9.4%)	2 (12.5%)
No	24 (90.6%)	14 (87.5%)
Primary carer		
Yes	11 (40.7%)	2 (12.5%)
No	16 (59.3%)	14 (87.5%)
Friend		
Yes	5 (18.5%)	4 (25%)
No	22 (81.5%)	12 (75%)
Myself		
Yes	14 (51.9%)	10 (62.5%)
No	13 (48.1%)	6 (37.5%)

11. If no, is there a reason why you have not made any changes to your lifestyle?		
Yes	1 (33.3%)	0 (0%)
No	2 (66.7%)	2 (100%)
12. Do you think you will make changes to your lifestyle in the future?		
Yes	25 (92.6%)	14 (87.5%)
No	2 (7.4%)	1 (6.3%)
Uncertain	0 (0%)	1 (6.3%)
Booster Session Interest		
13. Are you interested in attending a health literacy refresher session in the future?		
Yes	25 (92.6%)	14 (87.5%)
No	2 (7.4%)	2 (12.5%)

4.4 Discussion

The objective of this pilot study was to evaluate the feasibility of the HELP in outpatients living with an ESPD. This is the first study to evaluate the impact of the HELP on individual HL using the multi-dimensional HLQ. Analyses showed that the HELP was effective in improving two HLQ domains. There were statistically significant ($P < 0.05$) improvements in mean scores for Domain 2: Having sufficient information to manage my health, and Domain 6: Ability to actively engage with healthcare providers. There were no significant changes in the other seven HLQ domains.

Statistically significant improvements (corresponding to small ES) were observed across domains 2 and 6 of the HLQ. Individuals that score high for Domain 2 feel confident that they have all the information that they need to live with and manage their condition and to make decisions, see Appendix 12 (Osborne et al. 2013). Individuals that score high for Domain 6 are proactive about their health and feel in control in relationships with healthcare providers. They are able to seek advice from additional healthcare providers when necessary and are empowered to keep going until they get what they want (Osborne et al. 2013). This pilot study shows evidence that implementing the outpatient HELP is feasible from a participant's perspective and can be effective in improving aspects of individual HL in outpatients living with an ESPD.

According to Nutbeam's schema of HL, the two HLQ domains that showed significant improvements in mean scores post-intervention, are important basic and communicative HL

domains, see Appendix 13 (Osborne et al. 2013). Firstly, the results for Domain 2 show that participants had basic HL and sufficient skills in reading and writing to be able to function effectively in everyday situations - this relates to Nutbeam's 1st level of HL (Osborne et al. 2013). Secondly, the results for Domain 6 demonstrate that participants had communicative HL skills and more advanced literacy skills, which together with social skills can be used to actively participate in everyday activities to extract information, this relates to Nutbeam's 2nd level of HL (Osborne et al. 2013). Therefore, people can derive meaning from different forms of communication to be able to apply new information to changing circumstances this is often needed to navigate and function in mental health services, and is important for improving health outcomes in this population.

One-way between groups ANOVA analysis indicated that the differences in HL mean score changes according to sociodemographic factors were domain-specific. This study showed small differences between psychiatric diagnosis and pre-intervention mean score changes for Domain 4: Social support for health. Individuals that score low for Domain 4 are completely alone and unsupported, a high score shows a person's social system provides them with all the support they want or need. There were small differences between participants diagnosed with BD and schizophrenia. This suggests that specific psychiatric symptoms (e.g., positive and negative symptoms) and past health care experiences may have impacted on the participants responses to the HLQ statements for this HLQ domain.

The present study had multiple challenges related to implementing and sustaining the HELP in community mental health services. Firstly, to facilitate staff engagement in the study a senior clinical manager from one of the community mental health services invited the thesis author to provide an in-service education session to staff about the HELP study. During the in-service education session information was provided to staff on the evidence supporting HL interventions in people living with an ESPD. Secondly, the thesis author found that educating mental health staff through in-service education opportunities was necessary and well received by staff and service managers. Finally, we found that when we embedded the HELP into specialised mental health teams and services (e.g., clozapine and olanzapine clinics) the intervention was successful and sustainable.

As hypothesised for the primary outcome the tailored cardiometabolic HELP significantly improved participant's individual HL knowledge and skills for Domains 2 and 6. Overall, the HELP was successful in improving: (1) Individual HL; and (2) Lifestyle modifications related to SENSE, see Table 4.2 and Table 4.4. These results demonstrate that the HELP can assist mental health consumers to develop their cardiometabolic health knowledge and skills to self-manage their health. The results indicate that a tailored multi-layered cardiometabolic HL intervention has the potential to improve individual HL and lifestyle behaviours in outpatients living with an ESPD. This study adds to the body of evidence supporting the potential effectiveness and benefits of HL interventions for people with a psychotic disorder, see section 2.5.8.1. Those benefits include improved individual HL and group support which helped participants with their health promoting lifestyle behaviour changes.

In this study participants achieved a high rate of program completion. This could be due to participants appreciating the support that developed through open and frank conversations with program participants. Participants liked that the HELP provided solid and easily digested facts followed by opportunities to have open discussions about cardiometabolic health conditions and risk factors. The social participation and group format of the HELP benefited participants this may be a promising strategy for future HL interventions. Existing studies amongst socioeconomically disadvantaged groups report similar benefits with group based interventions and social participation (Lee, S, Arozullah & Choc 2004; Rummel-Kluge & Kissling 2008a). Group formats help to create opportunities to receive and enhance health information sharing amongst participants (Lee, HY et al. 2008; Lori, Munro & Chuey 2016). Groups tend to make people accountable and assist to support individuals with their life circumstances by sharing stories and strategies (Rummel-Kluge & Kissling 2008a).

In this study a Bilingual Vietnamese Care Coordinator from one of the community mental health services referred two Vietnamese participants to the HELP. Bilingual Care Coordinators provide: (1) Case management services; (2) Support; and (3) Education to CMHC outpatients and their families. The Bilingual Care Coordinator provided weekly support and translated the HELP resources to the Vietnamese participants. The study participants completed the HLQ in approximately 15 to 20 minutes. Participants with English as a second language took longer to complete the HLQ and needed an interpreter or assistance to complete the HLQ. CALD

participant testimonials and recommendations are reported below. In the future culturally appropriate HL interventions should be developed as they are needed to create equity and access for CALD individuals living with an ESPD.

Outpatient HELP CALD Vietnamese Participant Testimonials and Recommendations

1. “Thank you so much. You help me.”
2. “Produce the HELP intervention resources in different CALD languages, such as Vietnamese to assist CALD clients in understanding the HL information that is provided in the HELP participant booklet. Translate the HELP participant book into other languages and have English words as well and simple images.”

This pilot study does provide evidence that individuals with an ESPD do want to make lifestyle behaviour changes. Participants reported that the HELP assisted them to make lifestyle modifications. The results demonstrate that prompting participants about modifiable lifestyle behaviours using the SENSE acronym was helpful to support participants in achieving their goals. Participants reported making lifestyle modifications related to SENSE and recorded their weekly progress using the PIP. In this study participants used the PIP to set weekly goals for sleep, exercise, and nutrition. Participants reported leading healthier lifestyles post-intervention, exercising on a regular basis, eating a more balanced diet, and improved sleep hygiene. Furthermore, at 6 months follow-up most participants reported that they will make future lifestyle changes.

Interestingly, the results highlight that at 6 months follow-up participants choose not to persist with the lifestyle modifications made at 3 months follow-up regarding substance use and ethanol. The findings suggest that participants may not have the motivation or ability to persist with lifestyle modifications regarding substance use and ethanol use. This population may use addictive substances (e.g., caffeine, energy drinks, soft drinks, cigarettes, illegal substances, and ethanol) for their pleasurable effects to overcome sedative effects of psychotropic medication, or to self-medicate to cope with psychiatric symptoms, and socialise (Davies 2000; Smith, J & Hucker 1994). Legal substances such as cigarettes and caffeinated drinks increase cardiometabolic risk and may worsen psychiatric symptoms (Agency for Clinical Innovation 2013; McCreadie 2003). It is important to reduce the use of these substances in psychiatric

patients to help maintain good overall health outcomes (e.g., mental and physical health). The study results clearly demonstrate the need for cost effective and sustainable targeted programs and innovative interventions to reduce substance use (e.g., legal and illegal substances) and ethanol use in this population.

These findings highlight the importance of prompting, discussing, and supporting individuals with an ESPD to identify small modifiable lifestyle changes they can achieve and review regularly. The majority of participants in this study reported that they did not smoke cigarettes, use illegal substances or drink high amounts of alcohol regularly. Participants reported having 1-2 alcoholic drinks per occasion on a special event (e.g., birthday). In this study the overall components of the SENSE acronym (e.g., substance use and ethanol) did not apply to most participants. The generalisability of these findings is limited as the majority of participants in this study did not smoke cigarettes, use illegal substances or regularly drink alcohol. This is not a true representation of the clinical population.

Although most participants went to the GP for a physical health check-up after receiving the WPC. The results demonstrate that the WPC component of the HELP was insufficient due to only two participants using the WPC during their GP consultation. Therefore, any analysis of the functionality of the WPC was not practical. To further examine the functionality and feasibility of the WPC future research should focus on developing a scheme that prompts and supports this population to remember to use the WPC during a GP consultation. Anecdotal reports from participants indicate that participants liked the idea of the WPC and used it as a visual prompt to remind them of lifestyle modifications related to SENSE. At 6 months follow-up 56.2% ($n = 9$) of participants remembered what the SENSE acronym letters signified. Most participants reported that they could remember the SENSE acronym letters as the acronym applied to their health. At 6 months follow-up 87.5% ($n = 14$) of participants were interested in attending HL booster sessions in the future to refresh their HL knowledge and skills. The results show that individuals living with an ESPD do want to receive ongoing HL education and participate in HL interventions regularly. Future HL interventions should offer regular booster sessions to participants to help maintain the effects of the intervention.

In this study we did not measure the participants HL knowledge or skills regarding their primary psychiatric diagnosis. However, anecdotally we observed approximately three quarters (75%) of

participants having trouble spelling their psychiatric diagnosis on the HLQ. When the participants were prompted about the spelling of their psychiatric diagnosis, they reported that they do not know how to spell their psychiatric diagnosis. Primarily this occurred with participants that had a diagnosis of schizophrenia or schizoaffective disorder. Most of these participants have been living with the diagnosis for over ten years. This could suggest that these participants do have poor literacy skills which may affect their individual HL knowledge and skills and self-management of their health conditions. We did not measure this in the study or think of it as an outcome for the study. However, future HL studies in this population should explore this in more detail to determine the extent of the problem. Furthermore, future HL interventions being designed for this population should include a specific module on the terminology of psychiatric diagnoses.

4.4.1 Strengths and Limitations

There are a number of limitations associated with the current study that weaken the generalisability of the results. The main limitations of the study were the lack of a control group and participant bias due to the single-arm-pre-post study design with non-random selection of participants. Given the use of convenience sampling the study sample was biased. The study was unable to account for concurrent programs that could have contributed to the change in participants HL during the intervention period and the possibility of recruiting participants who were highly motivated to improve their health. The study participants were already involved in physical health programs at ODMH or a CMHC in SLHD prior to recruitment for the HELP. There are also limitations regarding the self-reported HLQ used in the study. The HLQ relies on self-reported information about the participant's individual HL skills and confidence. Therefore, social desirability bias was a source of bias in the participant's HLQ responses. This can lead to some uncertainty as self-reported information may not provide a true representation of the actual extent of an individual's HL due to the participants selective reporting of their HL. Post-hoc analyses should be interpreted with caution due to the potential for Type I error.

The primary purpose of this pilot study was to examine the feasibility of implementing the HELP in outpatients living with an ESPD. Therefore, the study was not designed or statistically powered to evaluate the effectiveness of the HELP intervention. The results suggest that the HELP is feasible in this population. Further research is needed to replicate these results with a

larger sample in a RCT to evaluate the effectiveness of the HELP in improving individual HL knowledge and skills in outpatients living with an ESPD.

Despite these limitations a major strength of this study was the high retention rate of participants. Another major strength was the examination of feasibility of the intervention from the perspective of participants which allowed us to explore participant recommendations to improve the HELP in the future. The findings may not be generalisable to individuals living with an ESPD in other community mental health services as the majority of participants in the study did not smoke cigarettes, use illegal substances or regularly drink alcohol. This is not a true representation of the clinical population.

4.5 Conclusions

Individuals living with an ESPD are interested in participating in HL interventions to improve their health. Educating, supporting, and empowering this population to develop individual HL knowledge, skills, and confidence in self-managing their cardiometabolic health conditions and CMRF, may assist to reduce the health disparities that currently exist in this disadvantaged high-risk population. Implementing and embedding HL interventions in this population is feasible and should be considered as a therapeutic intervention in conjunction with their overall treatment plan to help achieve optimal health outcomes.

In summary, the results presented in this chapter show that the HELP is feasible for outpatients living with an ESPD. The evaluation of the HELP demonstrates that HL programs can be effectively designed and implemented in community mental health settings. Implementing HL interventions in mental health hospitals may help to address the overall health needs of this population. The next chapter examines the feasibility of the pilot HELP in mental health inpatients receiving treatment at the CCMH, located in Sydney, Australia.

CHAPTER 5

HELP Makes SENSE: Effects of a Health Literacy Intervention for Inpatients Living with an Enduring and Severe Psychotic Disorder with High Levels of Cardiometabolic Risk: A Pilot Study

Abstract

This chapter aims to evaluate the feasibility of the pilot HELP intervention for inpatients receiving acute or sub-acute treatment for an ESPD. The inpatient HELP intervention was implemented in two mental health inpatient units at the CCMH in Sydney, Australia. The study procedure for the inpatient HELP intervention is exactly the same as the outpatient HELP intervention presented in Chapter 4. The HLQ was used to evaluate participants individual HL at baseline and at completion of the intervention. The hypothesis tested was that the tailored cardiometabolic HL intervention will improve participant's individual HL knowledge and skills. The inpatient HELP intervention was sufficient in improving the individual HL of mental health inpatients. This study highlights that the HELP intervention is feasible and has the potential to be implemented in acute and sub-acute mental health inpatient settings.

5.1 Introduction

Individual HL knowledge and skills are important for improving health outcomes in mental health inpatients as individuals living with an ESPD have a high level of cardiometabolic risk (Bradshaw, Lovell & Harris 2005; Galletly, Lincoln & Arford 2013; Lambert 2018). With the recognition of the link between individual HL and health outcomes there is a need for cardiometabolic HL interventions to be co-designed and implemented in mental health inpatient treatment facilities. Teaching self-management strategies for CMRF and cardiometabolic health conditions to improve individual HL in psychiatric patients may help to improve their cardiometabolic health outcomes (Bradshaw, Lovell & Harris 2005; Conn, Hafdahl & Brown 2009; Galletly, Lincoln & Arford 2013; Linde-Feucht 2007; Pignone et al. 2005). Studies in people with limited literacy skills report that appropriate self-care tasks can be learnt, if the self-care tasks are organised and demonstrated in a way that assists them to integrate the tasks into their activities of daily living (ADLs) (Pignone et al. 2005). HL interventions have an important role to play in supporting people with a psychotic

disorder to develop the necessary skills to self-manage their health, co-morbidities, and mental health recovery.

In today's complex healthcare environments it is important for healthcare services to implement HL practices to help patient's navigate healthcare services and improve individual health outcomes (Haun et al. 2015; Lee, E, Lee & Moon 2016). For patients to self-manage a chronic illness they need to have an adequate level of individual HL to: (1) Function effectively in healthcare environments; (2) Undertake health care tasks; and (3) Understand written and oral health information (Batterham et al. 2014; Cavanaugh et al. 2009). An adequate HL level is required to participate in health care decisions and to select the most appropriate health care for the patient's individual needs and circumstances (Batterham et al. 2014). Individuals with limited levels of HL are faced with more obstacles when accessing and using health services, they have higher rates of admissions to emergency and hospital, more medication errors, poorer overall health and lower use of preventative healthcare services, are more non-compliant to prescribed treatments and care plans, have increased risk of adverse health outcomes in many chronic diseases, experience increased health care expenditure costs, and have increased mortality rates (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011; Brach, Keller & Hernandez 2012; Geboers et al. 2018; Lee, E, Lee & Moon 2016; Visscher et al. 2018). It is predicted that an adverse health outcome is one and a half to three times more likely to be experienced by people with limited HL (Australian Commission on Safety and Quality in Health Care 2014). Improving individual HL knowledge and skills in psychiatric patient's is important for tackling health inequalities (Batterham et al. 2014; Berkman, Sheridan, Donahue, Halpern & Crotty 2011).

The concept of optimising HL should be integrated into the patient's mental health treatment plan from the acute stage of treatment. Individual and organisational HL is fundamental in improving a patient's engagement with healthcare services and impacts on the safety and quality of care (Australian Commission on Safety and Quality in Health Care 2014; Pignone, DeWalt & Sheridan 2005). There is an association between patients with higher HL levels and enhanced levels of empowerment and decision making skills (Visscher et al. 2018). Patients with higher HL levels are more engaged and have an active role in their treatment (Visscher et al. 2018). A small observational study in people with depression found that the participants' depression symptoms improved when they received literacy education as the latter increased the participants' self-

efficacy (Francis et al. 2007). This study provides evidence that self-efficacy may be a mediating factor involved in improving depression symptoms in depressed patients that have low literacy (Francis et al. 2007).

Studies in patients with schizophrenia have reported that the management of weight gain and improvements in patient's metabolic health profiles are possible when psychoeducation behavioural interventions are implemented in this population (Littrell et al. 2003). Furthermore, lifestyle interventions implemented in inpatients with schizophrenia or schizoaffective disorder incorporating diabetes education, with diet, and exercise, are shown to be effective and have a positive impact on weight, BMI, and blood glucose measurements (Cimo et al. 2012). Finally, numerous studies have focused on improving lifestyle habits (e.g., physical activity and diet) in people living with a SMI, positive effects were reported showing improvements in their physical health (Rosenbaum et al. 2014; Teasdale et al. 2017; Vera-Garcia et al. 2015). However, most of these studies have been conducted in outpatient settings. Studies on how to improve cardiometabolic HL in inpatients living with an ESPD are to my knowledge non-existent. Therefore, the present study was conceived so as to determine if inpatients receiving acute or sub-acute treatment in a mental health facility are an appropriate group to receive cardiometabolic HL interventions.

To date, no published study has investigated the impact of cardiometabolic HL interventions in mental health inpatients receiving acute or sub-acute treatment for an ESPD. In response, this pilot study examined the feasibility of employing the HELP intervention in mental health inpatient services in the SLHD in Sydney, Australia. The overall goal of this pilot study was to test whether the HELP can be implemented in psychiatric inpatients receiving treatment for an ESPD to improve individual HL knowledge and skills.

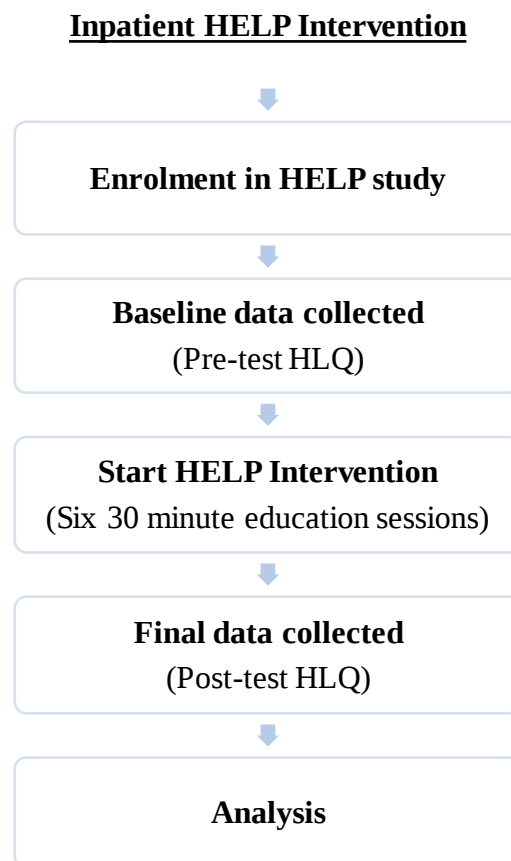
5.2 Methods

5.2.1 Participants

Figure 5.1 shows the enrolment process. A total of 11 inpatients with an ESPD receiving acute or sub-acute treatment in the CCMH consented to participate. They were recruited between November 2016 and October 2018 from: (1) Kirkbride unit; and (2) Broughton unit at the

CCMH in Sydney, Australia. The inclusion criteria and exclusion criteria were explained in greater detail earlier, see sections 3.4.1.1 and 3.4.1.2.

Figure 5.1 Study Profile for Inpatient HELP Intervention¹³



5.2.2 Procedure

The HELP is a structured, six topic cardiometabolic HL intervention for individuals living with an ESPD. The theoretical framework, co-design, and implementation of the HELP intervention was explained in greater detail earlier, see section 3.6. The participants received six, thirty-minute, individual health education sessions facilitated by the thesis author. The inpatient HELP participants received the intervention in an individual format that consisted of six one-to-one

¹³The numbers for each section of the inpatient HELP intervention are discussed in the text.

health education sessions. The HELP sessions were thirty minutes in duration each divided into twenty minutes for presentation of the cardiometabolic health topic, and then ten minutes for the PIP and SENSE acronym discussion.

5.2.3 Data Collection and Measures

Participants self-completed a paper based HLQ upon commencement (pre-intervention) and completion (post-intervention) of the HELP. The HLQ provided demographic information and measured individual HL across nine domains, see section 2.5.7. Participants needing assistance to complete the HLQ received verbal support from the study investigator. The instrumentations and the methods used for assessments were explained in greater detail above, see section 3.8. After completing the intervention participants self-completed the HELP evaluation form to evaluate participant satisfaction with the intervention. Phone interviews were conducted at 3 and 6 months follow-up. The study investigator conducted the fifteen-minute follow-up phone interviews.

5.2.4 Statistical Analysis

Statistical analyses were conducted using the SPSS software, version 27.0 (IBM Corporation 2020). Descriptive statistics were used to summarise demographic characteristics and the pre- and post-test intervention HLQ scores. Non-parametric statistics were used due to the small sample size. The Wilcoxon signed-rank test was used to report the *p*-value to compare the mean change in HLQ domain scores pre-and post-intervention. The EM algorithm was used to impute missing HLQ item scores, as explained earlier in section 3.10.3. The Kruskal-Wallis test was used to determine whether the magnitude of change in the: (1) HLQ domain scores; and (2) HELP evaluation form participant feedback was due to sociodemographic factors. ES for standardised differences in mean domain score changes between the pre-and post-intervention HLQ domain scores were calculated using Hedge's *g* (calculated using a sample size weighted pooled standard deviation) with interpretation of ES as follows: 'small' ES 0.20-0.50, 'medium' ES 0.50-0.80, and 'large' ES >0.80. The significance level was set at $p < 0.05$ (two tailed).

5.2.5 Ethics Approval

This study was approved by the SLHD Human Research Ethics Committee – CRGH (Protocol number CH62/6/2014-174) and written informed consent was obtained from all participants.

5.3 Results

5.3.1 Demographic Characteristics

The sample consisted of 11 participants (7 men, 4 females) with a mean age of 52 years (SD = 7.28, range 41-64). The psychiatric diagnoses of study participants included schizophrenia and bipolar disorder. The demographic characteristics of the sample are shown in Table 5.1.

Table 5.1 Demographic Data for Inpatient HELP Participants ($n = 11$)

Characteristics	n (%)
Study site	
Kirkbride unit CCMH	3 (27.3%)
Broughton unit CCMH	8 (72.7%)
Psychiatric diagnosis	
Schizophrenia	10 (90.9%)
Bipolar disorder	1 (9.1%)
Gender	
Male	7 (63.6%)
Female	4 (36.4%)
Age	
18-24	0 (0%)
25-34	0 (0%)
35-44	2 (18.2%)
45-59	6 (54.5%)
60-65	3 (27.3%)
Lives alone	
Yes	6 (54.5%)
No	5 (45.5%)
Country of Birth	
Australia	7 (63.6%)
Pacific Islands	1 (9.1%)
Anglo - other	0 (0%)
Asian	2 (18.2%)
African	1 (9.1%)
English spoken at home	
Yes	9 (81.8%)
No	2 (18.2%)
Identifies as Indigenous/Torres Strait Islander	
Yes	0 (0%)
No	11 (100%)
Educational attainment	
High school (not completed)	4 (36.4%)
High school (completed)	1 (9.1%)
TAFE/Trade	4 (36.4%)

Undergraduate degree	2 (18.2%)
Postgraduate degree	0 (0%)
Employment status	
Working (full time)	0 (0%)
Working (part time)	0 (0%)
Home duties	2 (18.2%)
Student (full time)	0 (0%)
Student (part time)	1 (9.1%)
Retired	2 (18.2%)
Permanently unable to work/ill	2 (18.2%)
Other	4 (36.4%)
Chronic Health Condition	
Arthritis	5 (45.5%)
Back pain	6 (54.5%)
Heart problems	1 (9.1%)
Asthma/lung condition	4 (36.4%)
Cancer	0 (0%)
Depression/Anxiety	7 (63.6%)
Diabetes	3 (27.3%)
Stroke	0 (0%)
Other	2 (18.2%)
≥ 4 Chronic conditions	3 (27.3%)
Reports no health condition (None)	1 (9.1%)
Private Health Insurance	
Yes	2 (18.2%)
No	9 (81.8%)
Have Health Care Card	
Yes	9 (81.8%)
No	2 (18.2%)
Attended hospital emergency in the past 12 months	
Yes	7 (63.6%)
No	4 (36.4%)
Assistance required to complete HLQ	
Yes	7 (63.6%)
No	4 (36.4%)
Type of assistance required to complete HLQ	
Interpreter used (e.g., bilingual mental health care worker)	0 (0%)
Researcher explained HLQ statements to participant	5 (45.5%)
Researcher administered HLQ for participant	2 (18.2%)

5.3.2 Health Literacy (HL)

The sample consisted of 11 participants, 9 of whom completed the HELP in its entirety. Two participants dropped out of the intervention, one participant dropped out at week 2 due to

scheduling conflicts with study obligations, and the other participant dropped out at week 5 due to being discharged from hospital. The participants mean pre-and post-intervention HLQ domain scores and the mean domain score changes are shown in Table 5.2. There were statistically significant ($P < 0.05$) improvements in mean scores for two HLQ domains (Domain 6: Ability to actively engage with healthcare providers and Domain 9: Understand health information well enough to know what to do). There was no significant change in the other seven HLQ domains. The ES (Hedge's g) were large for four HLQ domains and ranged between 0.09 (Domain 3: Actively managing my health) and 1.31 (Domain 9: Understand health information well enough to know what to do), see Figure 5.2.

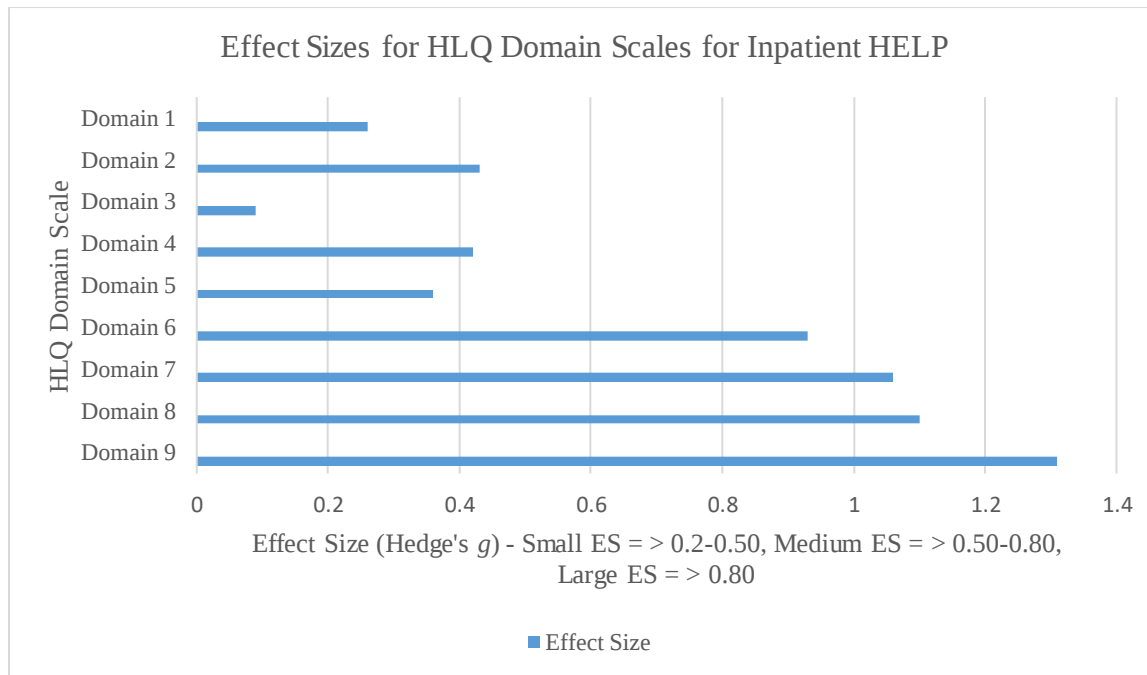
Table 5.2 Health Literacy Questionnaire (HLQ) Domain Score Changes for Inpatient HELP Intervention ($n = 9$). Higher values indicate greater understanding or ability.

HLQ Domain Scale ¹⁴	Pre-intervention Mean (SD)	Post-intervention Mean (SD)	z	P -value
1. Feeling understood and supported by healthcare providers	3.23 ± 0.39	3.33 ± 0.38	-1.511	<0.131
2. Having sufficient information to manage my health	3.02 ± 0.54	3.25 ± 0.52	-1.163	<0.245
3. Actively managing my health	3.25 ± 0.47	3.29 ± 0.41	-0.680	<0.496
4. Social support for health	2.95 ± 0.66	3.18 ± 0.42	-1.055	<0.291
5. Appraisal of health information	2.98 ± 0.46	3.16 ± 0.55	-0.530	<0.596
6. Ability to actively engage with healthcare providers	3.82 ± 0.56	4.38 ± 0.64	-1.965	<0.049
7. Navigating the healthcare system	3.76 ± 0.49	4.30 ± 0.53	-1.895	<0.058
8. Ability to find good health information	3.51 ± 0.55	4.16 ± 0.63	-1.866	<0.062
9. Understand health information well enough to know what to do	3.55 ± 0.58	4.27 ± 0.52	-2.035	<0.042

Results in bold have p -value <0.05 for difference in means.

¹⁴The first 5 HLQ domain scales (e.g., HLQ domain scales 1-5) are answered using response options ranging from strongly disagree to strongly agree (range 1 to 4). The last 4 HLQ domain scales (e.g., HLQ domain scales 6-9) are answered using response options ranging from cannot do to very easy (range 1 to 5).

Figure 5.2 Effect Sizes for the 9 HLQ Domain Scales for Inpatient HELP Intervention



The Kruskal-Wallis test was used to individually analyse all nine pre-and post-intervention HLQ mean domain scores to determine whether the magnitude of change in the HLQ domain scores changed due to sociodemographic factors regarding age, gender, psychiatric diagnosis, education level, and study site. The Kruskal-Wallis test analysis indicated that there were no significant differences between HLQ domain score changes and age, gender, psychiatric diagnosis, education level, and study site.

5.3.3 HELP Evaluation Form

The sample consisted of 11 participants, 7 of whom completed the HELP evaluation form. The feedback is shown in Table 5.3. Participants were satisfied with the HELP and reported that the program was useful. The Kruskal-Wallis test was undertaken to determine whether any sociodemographic factors were associated with the HELP evaluation form participant feedback. There were no significant differences between participant feedback and age, gender, psychiatric diagnosis, education level, and study site. Participants commented that they liked that the program was informative and provided diabetes education. Participants suggested future changes to the HELP could include: (1) Making the intervention longer to cover more health topics; and (2) Include information about mental health conditions (e.g., schizophrenia).

Table 5.3 Inpatient HELP Participant Feasibility and Acceptability Ratings ($n = 7$)

HELP Evaluation Form Questions	Unsatisfactory	Average	Good	Very Good	Excellent
<u>Feasibility</u> : How useful was the HELP for you?	0 (0%)	2 (28.6%)	1 (14.3%)	2 (28.6%)	2 (28.6%)
<u>Satisfaction</u> Education materials (handouts, powerpoint slides, ect.)?	0 (0%)	1 (14.3%)	2 (28.6%)	2 (28.6%)	2 (28.6%)
Overall, how do you rate the HELP?	0 (0%)	1 (14.3%)	2 (28.6%)	1 (14.3%)	3 (42.9%)
Overall, how do you rate the session presenters?	0 (0%)	1 (14.3%)	2 (28.6%)	1 (14.3%)	3 (42.9%)

Perceived intervention benefits were extracted from the participants' written comments provided in their responses to the questions in the HELP evaluation form. The themes from the participants' written comments in the HELP evaluation form included: (1) Informative health education was provided specifically on diabetes; and (2) The HELP resources had easy to understand health information, simple language, and explanations (e.g., medical terminology such as hypertension was provided using plain language and reworded as high blood pressure). Participant testimonials are reported below.

Inpatient HELP Participant Testimonials

1. "It is very enlightening and helpful to understand about medical factors."
2. "The HELP was very good."
3. "The HELP provided a lot of information and a good participant book to refer to."
4. "The HELP taught me more about health problems."

5.3.4 Follow-up Interviews

The sample consisted of 11 participants. At 3 months follow-up 2 participants completed the follow-up interview, and at 6 months follow-up no participants completed the follow-up interview. At 3 months follow-up 90% ($n = 9$) of participants were not able to be contacted by phone and were lost to contact. The study results demonstrate that the follow-up interview

component of the inpatient HELP was insufficient due to only two participants completing the 3-month follow-up interview and nine participants lost to contact. Therefore, any analysis of the inpatient 3 and 6 month follow-up interviews was not practical.

5.4 Discussion

The objective of this pilot study was to evaluate the feasibility of the HELP in mental health inpatients living with an ESPD. This is the first study to evaluate the impact of the HELP on individual HL using the multi-dimensional HLQ in psychiatric inpatients. Analyses showed that the inpatient HELP was effective in improving two HLQ domains. There were statistically significant ($P < 0.05$) improvements in mean scores for Domain 6: Ability to actively engage with healthcare providers, and Domain 9: Understand health information well enough to know what to do. There were no significant changes in the other seven HLQ domains. However, the p -value for Domain 7: Navigating the healthcare system was $p < 0.058$, and Domain 8: Ability to find good health information was $p < 0.062$. Given the apparent ES for these two domains (Domain 7 ES: 1.06 and Domain 8 ES: 1.10) with a larger sample size these domains may reach statistical significance.

Statistically significant improvements (corresponding to large ES) were observed across domains 6 and 9 of the HLQ. Individuals that score high for Domain 6 are proactive about their health and feel in control in relationships with healthcare providers. They are able to seek advice from additional healthcare providers when necessary and are empowered to keep going until they get what they want, see Appendix 12 (Osborne et al. 2013). Individuals that score high for Domain 9 are able to understand all written information (including numerical information) in relation to their health, and are able to write appropriately on forms where required (Osborne et al. 2013). This pilot study shows evidence that implementing the inpatient HELP is feasible from a participant's perspective and can be effective in improving aspects of individual HL in psychiatric inpatients living with an ESPD.

According to Nutbeam's schema of HL, the two HLQ domains that showed significant improvements in mean scores post-intervention are important basic and communicative HL domains, see Appendix 13 (Osborne et al. 2013). Firstly, the results for Domain 9 show that participants had basic HL and sufficient skills in reading and writing to be able to function effectively in everyday situations – this relates to Nutbeam's 1st level of HL (Osborne et al.

2013). Secondly, the results for Domain 6 demonstrate that participants had communicative HL skills and more advanced literacy skills which, together with social skills, can be used to actively participate in everyday activities to extract information, this relates to Nutbeam's 2nd level of HL (Osborne et al. 2013). Therefore, people can derive meaning from different forms of communication to be able to apply new information to changing circumstances this is often needed to navigate and function in mental health services, and is important for improving health outcomes in this population.

The Kruskal-Wallis test analysis indicated that there were no significant differences between HLQ domain score changes and age, gender, psychiatric diagnosis, education level, and study site. Due to the small sample size it was not expected that these post hoc tests would show any significant differences. As hypothesised for the primary outcome the tailored cardiometabolic inpatient HELP significantly improved participant's individual HL knowledge and skills for Domains 6 and 9. Overall, the inpatient HELP was successful in improving individual HL, see Table 5.2. These results demonstrate that the inpatient HELP can assist psychiatric inpatients to develop their cardiometabolic health knowledge and skills to self-manage their health. The results indicate that a tailored multi-layered cardiometabolic HL intervention has the potential to improve individual HL in acute and sub-acute mental health inpatients receiving treatment for an ESPD.

This study adds to the body of evidence supporting the potential effectiveness and benefits of HL interventions for people with a psychotic disorder. Those benefits include improved individual HL and individual support which helped participants to understand cardiometabolic health information. Participants liked that the inpatient HELP was informative and provided diabetes education. Participants would have liked the HELP intervention to include more health topics and information about mental health conditions (e.g., schizophrenia). This pilot study does provide evidence that mental health inpatients do want to improve their individual HL knowledge and skills.

Although our target sample size was 20, we were able to recruit only 11 participants from acute and sub-acute mental health units at the CCMH through the use of recruitment flyers. Involving health care workers in participant recruitment activities in mental health inpatient facilities may be an important strategy to ensure targeted enrolment rates (Lee, H & Schepp 2013). After

participants were discharged from the CCMH most participants dropped out of the study and were lost at 3 months follow-up. Therefore, the 3 and 6 months follow-up data for the inpatient HELP study was not able to be obtained. Evidence shows that post discharge from hospital, patients tend to disengage in treatment programs and prevention interventions, and over time, the patient's participation in therapy activities further declines (Piepoli et al. 2016). Hospital discharge planning¹⁵ meetings may be an optimal time for health care workers to discuss linking mental health inpatients with HL interventions in the community post discharge. Supporting mental health inpatients to develop the necessary knowledge and skills to self-manage their CMRF and cardiometabolic health conditions may help to improve cardiometabolic health outcomes in this high-risk population (Bradshaw, Lovell & Harris 2005; Conn, Hafdahl & Brown 2009; Galletly, Lincoln & Arford 2013).

The inpatient HELP intervention was delivered to participants in an individual format that consisted of six one-to-one health education sessions. Therefore, the format of the inpatient HELP was adapted for the mental health inpatient treatment setting so the intervention could be implemented successfully. The participants preferred to receive the intervention individually rather than in a group due to their individual daily schedule of activities. As a result, the inpatient HELP format was more flexible and individualised to the needs of mental health inpatients (e.g., inpatient preferences, habits, and cognitive processes). The WPC component of the inpatient HELP was not relevant as the study was implemented in mental health inpatient settings. To further examine the functionality and feasibility of the WPC future research should focus on developing a scheme that prompts and supports mental health inpatients to go to the GP during their inpatient admission.

5.4.1 Strengths and Limitations

Limitations were the small number of participants in the study and the self-reported HLQ used to report individual HL skills and confidence. The present study had multiple challenges related to implementing and sustaining the HELP intervention in acute and sub-acute mental health

¹⁵Hospital discharge planning is the development of a personalised plan for the patient to ensure all the services the patient needs post discharge from hospital are in place for them in the community, so the patient is supported once they leave hospital.

www.healthdirect.gov.au/hospital-discharge-planning

inpatient services. Recruitment and retention of inpatients with an ESPD was challenging. Participant recruitment and enrolment in the study was lower than expected. The small sample size can be explained in part by clinical characteristics of the sample (e.g., mental health inpatients are severely ill and are experiencing positive and negative psychiatric symptoms that affect their daily cognitive and physical functioning). Therefore, participants with lower functioning levels were more inclined to abandon the study or offer poorer participation. Furthermore, the Broughton unit focuses on the rehabilitation and extended mental health recovery of psychiatric patients that require extended hospital stays. Patients admitted to the Broughton unit are inpatients for a very long time (e.g., minimum twelve months to two years). Therefore, the admission of new patients into the Broughton unit is slow, this impacted on the recruitment of participants into the inpatient HELP and can assist in interpreting why the sample size for the study was small. The inpatient HELP study further demonstrates how hard it is to recruit participants living with an ESPD into studies implemented in mental health inpatient settings. However, participant retention in the inpatient HELP study was comparable with other studies (Cabassa, Ezell & Lewis-Fernandez 2010). Existing studies on HL interventions implemented in psychiatric treatment settings report small participant numbers and high dropout rates that impact on justifying the success of the intervention (Brown, S & Chan 2006). Therefore, most interventions for people living with an ESPD are implemented in outpatient settings (Bonfioli et al. 2012).

Despite these limitations a major strength of this study was examining the feasibility of implementing the HELP in inpatients receiving acute or sub-acute mental health treatment for an ESPD. The study findings may not be generalisable to individuals receiving acute or sub-acute mental health treatment for an ESPD in other mental health inpatient services, as the thesis author probably put more effort into engagement and retention than would be possible in an inpatient mental health setting.

5.5 Conclusions

HL interventions are a valuable health promotion strategy that may help to improve CMRF and cardiometabolic health outcomes in this high-risk population. It is recommended and important to start appropriate health prevention programs in hospital prior to mental health inpatients being discharged. Inpatient mental health treatment facilities and health care workers may potentially

play an important role in encouraging, motivating, and supporting, psychiatric inpatients to be involved in HL interventions, by implementing and embedding HL practices as part of routine care. Implementing HL interventions in acute and sub-acute mental health treatment services is feasible and should be considered as a therapeutic intervention in the patient's mental health treatment plan. HL interventions may have positive effects in improving CMRF and cardiometabolic health outcomes to help reduce the life expectancy gap in this population.

In summary, the results presented in this chapter show that the inpatient HELP is feasible for mental health inpatients receiving treatment for an ESPD. The evaluation of the inpatient HELP demonstrates that HL interventions can be effectively designed and implemented in acute and sub-acute mental health inpatient treatment settings. The next chapter pilots the WPC intervention in primary healthcare settings to examine its feasibility in outpatients living with an ESPD.

CHAPTER 6

A Wallet Prompt Card (WPC) Intervention to Improve General Practitioner (GP) Care for the Prevention, Treatment, and Management, of Cardiometabolic Comorbidity in Outpatients Living with an Enduring and Severe Psychotic Disorder: A Pilot Study

Abstract

This chapter aims to evaluate the feasibility of the WPC intervention in outpatients living with an ESPD. The outpatient WPC intervention was implemented in primary health care services. The HLQ was used to evaluate participants' individual HL at baseline and at completion of the intervention. The hypothesis tested was that the tailored cardiometabolic WPC intervention would improve participant's individual HL knowledge and skills. The WPC was designed to help prompt GPs with respect to their care for the prevention, treatment, and management, of cardiometabolic comorbidity in people living with an ESPD. The WPC intervention resulted in the development of an effective cardiometabolic HL prompt for participants to discuss their physical health with their GP. This study highlights that a WPC intervention to improve individual HL in this population is feasible and can be implemented in primary health care settings.

6.1 Introduction

Globally HL is identified as a major 21st century health challenge and is an issue that requires attention and a national focus (Geboers et al. 2018). In Australia the healthcare system and healthcare information is becoming more complex and harder to understand (Australian Commission on Safety and Quality in Health Care 2014; Berkman, Sheridan, Donahue, Halpern & Crotty 2011). From a public health perspective an adequate individual HL level is important for finding and understanding healthcare information to manage and make decisions about health (Berkman, Sheridan, Donahue, Halpern & Crotty 2011; Nielsen-Bohlman, Panzer & Kindig 2004). Creating opportunities for individuals living with an ESPD to be active participants in self-managing their CMRF and cardiometabolic health conditions may help this population to make informed health care decisions that could improve cardiometabolic health outcomes and reduce premature death (Galletly, Lincoln & Arford 2013). Individuals with higher HL levels are more empowered to self-manage their health and play a more active role in their treatment as they have

better decision making skills (Visscher et al. 2018). Improving individual HL knowledge and skills in this high-risk population may help to increase the uptake and use of preventative health care services and health promotion initiatives (Von Wagner et al. 2007).

In the general population, individuals with a chronic disease are being diagnosed earlier and living longer. Unfortunately, this has not transferred to psychiatric patients (Britt 2013). Psychiatric patients have multiple barriers when accessing medical treatment for their physical health which include: (1) The patient's HL level, knowledge, and skills; (2) Stigma; (3) Patient factors; and (4) Provider and system factors (Collins, Drake & Deacon 2013a; Dombrowski & Rosenstock 2004; Lambert, TJR & Chapman, LH 2004; Lambert & Newcomer 2009; Muir-Cochrane 2006; Vandiver 2007). The impact of CVD which leads to premature mortality in this population can be significantly reduced through changes to biomedical and behavioural risk factors. It is now recognised that a wider integrated holistic approach to health is needed for this population to prevent, screen, and monitor for cardiometabolic risk (Lambert et al. 2017).

Primary health care services provide the ideal health care setting for integrated clinical care to identify and address CMRF and multimorbidity in psychiatric patients (Australian Institute of Health and Welfare 2014; Fricchione et al. 2012). GPs have a central role to play in the management of a psychiatric patient's physical health, as early detection of CMRF and cardiometabolic health conditions may help to improve access to medical treatment and management of the condition (Anderson et al. 2015). A GP should always be closely involved in the patient's overall medical treatment through shared care partnerships with the patient's psychiatrist, this is considered best practice (Berardi et al. 2007; Fredheim et al. 2011; McGorry et al. 2004; Waterreus & Laugharne 2009). People living with an ESPD should be encouraged to have their own GP that they see regularly for the management, detection, and treatment of physical illnesses (Lambert, TJR & Chapman, LH 2004).

HL and chronic disease self-management are a fundamental part of the treatment process for any chronic disease (Heide et al. 2018; Linder et al. 2003). Many aspects of HL are involved in chronic disease self-management (Heide et al. 2018). The benefits of knowledge, education, teaching of chronic disease self-management skills, screening, and early intervention, to prevent chronic diseases in people living with an ESPD is well documented and recommended in Australia and other countries (Lambert, TJR & Chapman, LH 2004; Lunnay & Bywood 2011; Newcomer &

Hennekens 2007; Randolph, Blasinsky & Leginski 1997). It is recommended that GPs have a role to play in HL by being proactive in providing patients with simple and easy to understand health information that is targeted towards and mindful of the motivation and needs of the patient (Keleher & Hagger 2007). Interestingly, GPs are concerned about their patients individual HL level, particularly when a patient has limited literacy as this impacts on the patient's self-management of a chronic disease and health outcomes (Keleher & Hagger 2007). GPs are the main health care provider for individuals with a SMI and are increasingly treating the overall health (e.g., mental and physical health) of individuals living with an ESPD (Australian Institute of Health and Welfare 2014; Nover & Jackson 2013). A GP is in the best position to assist psychiatric patients with their physical health, regular physical health check-ups, healthy lifestyle advice, and smoking cessation advice and treatment (Hall et al. 2010).

Comprehensive treatment of patients with a SMI needs to involve primary health care approaches and prevention strategies to strengthen early detection and timely treatment for physical health conditions (Dombrowski & Rosenstock 2004). Increased morbidity and mortality in people living with a SMI is largely due to inadequate access to medical care for treatable medical conditions, caused by modifiable risk factors (Lambert, TJR & Chapman, LH 2004). Medications prescribed in general practice such as statins, hypoglycaemics, and antihypertensives are relatively less frequently prescribed to psychiatric patients receiving treatment in a mental health care service despite their effectiveness for treating and managing high cholesterol, hypertension, and T2DM (Lambert & Newcomer 2009). Primary health care services can help support this population to develop individual HL knowledge and skills to improve their self-efficacy to undertake regular physical health check-ups, self-manage CMRF and cardiometabolic health conditions, and discuss their CVD risk with health care professionals (Keleher & Hagger 2007).

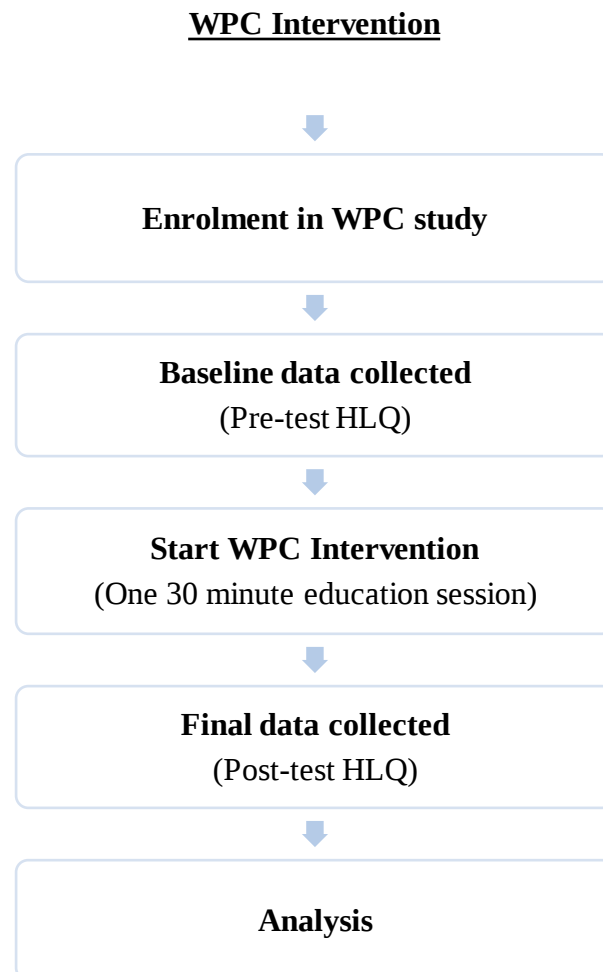
To date, no published study has investigated the impact of the use of a WPC as a tool to prompt the patient and GP to discuss the patient's physical health needs. In response, this pilot study examined the feasibility of the WPC intervention. The overall goal of this pilot study was to test whether the WPC can be implemented in a primary healthcare setting as a tool to prompt the patient and GP to discuss the patient's physical health.

6.2 Methods

6.2.1 Participants

Figure 6.1 shows the enrolment process. A total of 20 outpatients with an ESPD receiving health care from a GP in a primary healthcare setting consented to participate. They were recruited between April 2018 and May 2019 from: (1) ODMH physical health services; and (2) Three of the four SLHD Community Mental Health Centers. The inclusion criteria and exclusion criteria were explained in greater detail earlier, see sections 3.4.1.1 and 3.4.1.2.

Figure 6.1 Study Profile for WPC Intervention¹⁶



¹⁶The numbers for each section of the WPC intervention are discussed in the text.

6.2.2 Procedure

The WPC intervention is a structured thirty minute cardiometabolic HL intervention for individuals living with an ESPD. The theoretical framework and implementation of the WPC intervention was explained in greater detail above, see sections 3.7.1 and 3.7.3. The participants received one thirty-minute health education session facilitated by the thesis author. The WPC participants received the intervention in an individual format that consisted of one health education session. The WPC session was thirty minutes in duration divided into twenty minutes for presentation on how to use the WPC and normal range CMRF targets, and then ten minutes for the PIP and SENSE acronym discussion. Following the education session participants had six weeks to attend a GP for a physical health check-up using the WPC. Participants completed the post-intervention HLQ and WPC evaluation form after the GP visit.

6.2.3 Data Collection and Measures

Participants self-completed a paper-based HLQ upon commencement (pre-intervention) and on completion (post-intervention) of the WPC intervention. The HLQ provided demographic information and measured individual HL across nine domains, see section 2.5.7. Participants needing assistance to complete the HLQ received verbal support from the study investigator. The instrumentations and the methods used for assessments were explained in greater detail above, see section 3.8. After completing the intervention participants self-completed the WPC evaluation form to evaluate participant satisfaction with the intervention. Phone interviews were conducted at 3 and 6 months follow-up. The study investigator conducted the fifteen-minute follow-up phone interviews.

6.2.4 Statistical Analysis

Statistical analyses were conducted using the SPSS software, version 27.0 (IBM Corporation 2020). Descriptive statistics were used to summarise demographic characteristics and the pre- and post-test intervention HLQ scores. Non-parametric statistics were used due to the small sample size. The Wilcoxon signed-rank test was used to report the *p*-value to compare the mean change in HLQ domain scores pre-and post-intervention. The EM algorithm was used to impute missing HLQ item scores. The Kruskal-Wallis test was used to determine whether the magnitude of change in the: (1) HLQ domain scores; and (2) WPC evaluation form participant feedback

was due to sociodemographic factors. ES for standardised differences in mean domain score changes between the pre-and post-intervention HLQ domain scores were calculated using Hedge's *g* (calculated using a sample size weighted pooled standard deviation) with interpretation of ES as follows: 'small' ES >0.20-0.50, 'medium' ES 0.50-0.80, and 'large' ES >0.80. The significance level was set at $p < 0.05$ (two tailed).

6.2.5 Ethics Approval

This study was approved by the SLHD Human Research Ethics Committee – CRGH (Protocol number CH62/6/2014-174) and written informed consent was obtained from all participants.

6.3 Results

6.3.1 Demographic Characteristics

The sample consisted of 20 participants (12 men, 8 females) with a mean age of 51.35 years (SD = 8.50, range 32-63). The psychiatric diagnoses of study participants included schizophrenia, schizoaffective disorder, and bipolar disorder. The demographic characteristics of the sample are shown in Table 6.1. Every participant had a Health Care Card, issued by Services Australia.

Table 6.1 Demographic Data for WPC Participants ($n = 20$)

Characteristics	n (%)
Study site	
ODMH	13 (65%)
SLHD Canterbury CMHC	2 (10%)
SLHD Marrickville CMHC	3 (15%)
SLHD Croydon CMHC	2 (10%)
Psychiatric diagnosis	
Schizophrenia	10 (50%)
Schizoaffective disorder	3 (15%)
Bipolar disorder	7 (35%)
Gender	
Male	12 (60%)
Female	8 (40%)
Age	
18-24	0 (0%)
25-34	1 (5%)
35-44	5 (25%)
45-59	10 (50%)
60-65	4 (20%)

Lives alone	
Yes	13 (65%)
No	7 (35%)
Country of Birth	
Australia	18 (90%)
Asian	2 (10%)
English spoken at home	
Yes	19 (95%)
No	1 (5%)
Identifies as Indigenous/Torres Strait Islander	
Yes	1 (5%)
No	19 (95%)
Educational attainment	
High school (not completed)	6 (30%)
TAFE/Trade	13 (65%)
Undergraduate degree	1 (5%)
Employment status	
Working (full time)	0 (0%)
Working (part time)	2 (10%)
Home duties	4 (20%)
Student (full time)	0 (0%)
Student (part time)	0 (0%)
Retired	0 (0%)
Permanently unable to work/ill	7 (35%)
Other	6 (30%)
Chronic Health Condition	
Arthritis	4 (20%)
Back pain	4 (20%)
Heart problems	4 (20%)
Asthma/lung condition	4 (20%)
Cancer	1 (5%)
Depression/Anxiety	15 (75%)
Diabetes	3 (15%)
Stroke	2 (10%)
Other	7 (35%)
≥ 4 Chronic conditions	3 (15%)
Reports no health condition (None)	3 (15%)
Private Health Insurance	
Yes	6 (30%)
No	14 (70%)
Have Health Care Card	
Yes	20 (100%)
No	0 (0%)
Attended hospital emergency in the past 12 months	
Yes	9 (45%)
No	11 (55%)

Assistance required to complete HLQ	
Yes	6 (30%)
No	14 (70%)
Type of assistance required to complete HLQ	
Interpreter used (e.g., Bilingual Mental Health Care Worker)	0 (0%)
Researcher explained HLQ statements to participant	4 (20%)
Researcher administered HLQ for participant	2 (10%)

6.3.2 Health Literacy (HL)

The sample consisted of 20 participants, 14 of whom completed the HELP in its entirety. Six participants dropped out of the intervention. The participants mean pre-and post-intervention HLQ domain scores and the mean domain score changes are shown in Table 6.2. There were statistically significant ($P < 0.05$) improvements in mean scores for three HLQ domains (Domain 2: Having sufficient information to manage my health; Domain 3: Actively managing my health; and Domain 8: Ability to find good health information). There was no significant change in the other six HLQ domains. The ES (Hedge's g) ranged between 0.02 (Domain 4: Social support for health) and 0.61 (Domain 8: Ability to find good health information), see Figure 6.2.

Figure 6.2 Effect Sizes for the 9 HLQ Domain Scales for WPC Intervention

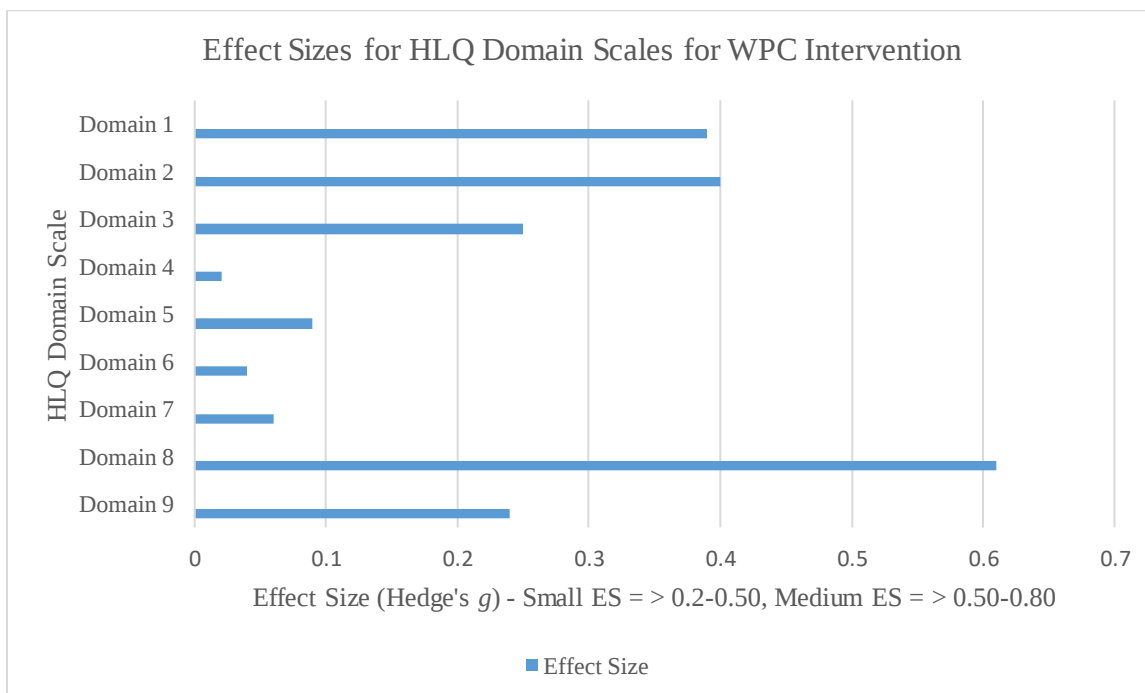


Table 6.2 Health Literacy Questionnaire (HLQ) Domain Score Changes for WPC Intervention ($n = 14$). Higher values indicate greater understanding or ability.

HLQ Domain Scale ¹⁷	Pre-intervention Mean (SD)	Post-intervention Mean (SD)	Z	P-value
1. Feeling understood and supported by healthcare providers	3.25 ± 0.39	3.25 ± 0.38	-1.027	<0.305
2. Having sufficient information to manage my health	2.83 ± 0.56	3.05 ± 0.54	-2.169	<0.030
3. Actively managing my health	2.98 ± 0.57	3.11 ± 0.46	-2.430	<0.015
4. Social support for health	2.85 ± 0.54	2.86 ± 0.68	-0.998	<0.318
5. Appraisal of health information	2.75 ± 0.65	2.81 ± 0.64	-0.414	<0.679
6. Ability to actively engage with healthcare providers	3.48 ± 0.79	3.51 ± 0.77	-0.476	<0.634
7. Navigating the healthcare system	3.44 ± 0.80	3.39 ± 0.75	-0.595	<0.552
8. Ability to find good health information	3.05 ± 0.88	3.54 ± 0.73	-2.744	<0.006
9. Understand health information well enough to know what to do	3.66 ± 0.63	3.81 ± 0.62	-0.892	<0.372

Results in bold have p -value <0.05 for difference in means.

The Kruskal-Wallis test was used to individually analyse all nine pre-and post-intervention HLQ mean domain scores to determine whether the magnitude of change in the HLQ domain scores changed due to sociodemographic factors regarding age, gender, psychiatric diagnosis, education level, and study site. The Kruskal-Wallis test analysis indicated that there were no significant differences between HLQ domain score changes and age, gender, psychiatric diagnosis, education level, and study site.

¹⁷The first 5 HLQ domain scales (e.g., HLQ domain scales 1-5) are answered using response options ranging from strongly disagree to strongly agree (range 1 to 4). The last 4 HLQ domain scales (e.g., HLQ domain scales 6-9) are answered using response options ranging from cannot do to very easy (range 1 to 5).

6.3.3 WPC Evaluation Form

The sample consisted of 20 participants, 13 of whom completed the WPC evaluation form. The feedback is shown in Table 6.3. Participants reported that the intervention was useful. The Kruskal-Wallis test was undertaken to determine whether any sociodemographic factors were associated with the WPC evaluation form participant feedback. There were no significant differences between participant feedback and age, gender, psychiatric diagnosis, education level, and study site.

Table 6.3 WPC Participant Feasibility and Acceptability Ratings ($n = 13$)

WPC Evaluation Form Questions	Unsatisfactory	Average	Good	Very Good	Excellent
<u>Feasibility</u> : How useful was the WPC for you?	0 (0%)	1 (7.7%)	8 (61.5%)	1 (7.7%)	3 (23.1%)
<u>Satisfaction</u> Education materials (handouts, powerpoint slides, ect.)?	0 (0%)	1 (7.7%)	8 (61.5%)	1 (7.7%)	3 (23.1%)
Overall, how do you rate the WPC?	0 (0%)	1 (7.7%)	8 (61.5%)	0 (0%)	4 (30.8%)
Overall, how do you rate the session presenter?	0 (0%)	0 (0%)	4 (30.8%)	0 (0%)	9 (69.2%)

Participants commented that they liked learning about how to improve their general health in order to improve their mental health. Participants reported that they can see how people living with an ESPD will benefit from the WPC intervention in the future. Participants suggested future changes need to include consulting people with a lived experience of a psychotic disorder in all aspects of conducting the research study (e.g., study design, implementation, and evaluation). In the future the intervention could include more strategies and information about how to be healthier (e.g., simple daily health tips to achieve). Participants liked that the WPC intervention provided a useful prompt for the patient and GP to use to screen for and discuss the patient's CMRF and cardiometabolic health. One participant reported that the WPC prompted their GP to undertake a more extensive assessment of their health. Another participant reported that the WPC helped them to feel personal empowerment. Participants liked talking to the GP about their physical health concerns and lifestyle behaviours regarding the SENSE acronym. Participants wanted to learn more about CMRF that can be changed to improve their health outcomes. One

participant reported that they liked the WPC intervention as it prompted them to make changes to how they self-manage their health.

Perceived intervention benefits were extracted from the participants' written comments provided in their responses to the questions in the WPC evaluation form. The themes from the participants' written comments in the WPC evaluation form included: (1) Informative cardiometabolic health information about how to manage health; (2) The WPC intervention helped to explain health concepts more clearly; (3) The intervention provided awareness about CMRF and screening for cardiometabolic health conditions; and (4) The WPC was very helpful. Participant testimonials are reported below.

WPC Participant Testimonials

1. "The WPC intervention helped me to better understand my health problems (e.g., healthy targets for diabetes, cholesterol, and high blood pressure.)"
2. "I learned new things on health."
3. "It's all on the card (e.g., WPC) to show you what you need to do."
4. "The thing I liked most about the intervention was the Health Card (e.g., WPC)."

6.3.4 Follow-up Interviews

The sample consisted of 20 participants. At 3 months follow-up 2 participants completed the follow-up interview, and at 6 months follow-up no participants completed the follow-up interview. At 3 months follow-up 90% ($n = 18$) of participants were not able to be contacted by phone and were lost to contact. The study results demonstrate that the follow-up interview component of the WPC intervention was insufficient due to only two participants completing the 3 month follow-up interview and 18 participants lost to contact. Therefore, any analysis of the WPC intervention 3 and 6 month follow-up interviews was not practicable.

6.4 Discussion

The current study evaluated the feasibility of the WPC intervention in outpatients living with an ESPD in primary health care services. This study examined the impact of the WPC intervention on individual HL using the multi-dimensional HLQ. The WPC intervention was effective in improving three HLQ domains. There were statistically significant ($P < 0.05$) improvements in

mean scores for Domain 2: Having sufficient information to manage my health, Domain 3: Actively managing my health, and Domain 8: Ability to find good health information. There were no significant changes in the other six HLQ domains.

Statistically significant improvements (corresponding to small and medium ES) were observed across domains 2, 3 and 8 of the HLQ, see Table 6.2. Individuals that score high for Domain 2 feel confident that they have all the information that they need to manage their health condition and make decisions about their health, see Appendix 12 (Osborne et al. 2013). Individuals that score high for Domain 3 recognise the importance and are able to take responsibility for their own health, they make health a priority, and proactively engage in their own health care and make their own decisions about their health (Osborne et al. 2013). Individuals that score high for Domain 8 actively use a diverse range of sources to find health information (Osborne et al. 2013). The results suggest that the WPC intervention is feasible and has the potential to help improve individual HL in outpatients living with an ESPD.

The three HLQ domains that showed significant improvements in mean scores post-intervention are important basic, communicative, and critical HL domains, see Appendix 13 (Osborne et al. 2013). The results for Domain 3 show that participants had critical HL and more advanced cognitive skills, which together with social skills, can be applied to critically analyse information and use this information to exert greater control over their life events and situations (Osborne et al. 2013). The Kruskal-Wallis test analysis indicated that there were no significant differences between HLQ domain score changes and age, gender, psychiatric diagnosis, education level, and study site. It was not expected that these post hoc tests would show any significant differences given the small sample size. The 3 and 6 months follow-up data for the WPC study was not able to be obtained as most participants were lost at 3 months follow-up.

It is important to support and educate this high-risk population to develop the necessary knowledge and skills to understand CMRF and cardiometabolic health conditions, so they can make informed health care decisions about their cardiometabolic health. Participants reported that using the WPC with their GP assisted them to be self-empowered to have a discussion with their GP around their cardiometabolic health concerns. However, one participant wrote about their experience with receiving GP care and the associated stigma they felt as a psychiatric patient, see Appendix 22. The literature clearly shows that stigma is associated with psychiatric

patients accessing medical treatment for their physical health, see section 2.4.1 (Collins, Drake & Deacon 2013a, 2013b; Lambert, TJR & Chapman, LH 2004; Lambert & Newcomer 2009; Muir-Cochrane 2006; Vandiver 2007). Stigma associated with psychotic disorders is a barrier to health treatment and discourages individuals and their families from seeking advice and treatment early. This reinforces the need to educate individuals living with an ESPD about CMRF and cardiometabolic health conditions that are highly prevalent in this population.

The WPC was designed to enhance GP awareness of the need for prevention, treatment, and management, of cardiometabolic comorbidity in this high-risk population. The WPC intervention was delivered to participants in an individual format that consisted of one thirty minute one-to-one health education session. The individual format of the WPC intervention was used so the intervention could be implemented successfully in primary health care services. Primary health care services are in the best position to implement national and state health policy initiatives for patients living with an ESPD to: (1) Screen, prevent, and treat, cardiometabolic health conditions; and (2) Provide chronic disease self-management (CDSM) education (Fricchione et al. 2012; Lambert, TJR & Chapman, LH 2004; Lambert & Newcomer 2009; Lunnay & Bywood 2011). This study highlights the need for primary health care services to support individuals with an ESPD to access, use, and act, on health care information and advice regarding their CMRF and cardiometabolic health conditions. To further examine the functionality and feasibility of the WPC future research should focus on GP's attitudes towards patients with an ESPD using the WPC as a practical tool in a consultation to discuss their physical health care needs.

6.4.1 Strengths and Limitations

Limitations of the study were the small sample size and participants chose to participate in the WPC intervention, this suggests that participants may have been more motivated to make changes to improve their health. A major strength of the study was that it provides evidence to support the potential benefits and feasibility of HL interventions in this population. The study showed that the WPC intervention can assist individuals living with an ESPD to develop their cardiometabolic health knowledge and skills to self-manage their health. The study also demonstrated that psychiatric outpatients in primary health care services are interested in improving their individual HL knowledge and skills. However, the study findings may not be generalisable to individuals living with an ESPD in other primary health care services as the

majority of participants in our study did not use illegal substances or regularly drink alcohol. This is not a true representation of the clinical population.

6.5 Conclusions

Improving individual HL may help individuals living with an ESPD to engage in health promoting behaviours and preventative health care to improve their cardiometabolic health outcomes. The results of this study suggest that the WPC intervention is feasible and beneficial beyond usual care in terms of improved individual HL, and GP care for the prevention of cardiometabolic comorbidity. Integration of the WPC intervention with usual care at the onset of a psychotic disorder diagnosis would further enhance preventative approaches to CMRF and cardiometabolic health care in this high-risk population.

In summary, the results presented in this chapter show that the WPC intervention is feasible for outpatients living with an ESPD. The evaluation of the WPC intervention demonstrates that HL interventions can be effectively designed and implemented in primary health care settings. Implementing HL interventions in primary health care services may help to address GP care for the prevention, treatment, and management, of cardiometabolic comorbidity to improve health outcomes in this population. The next chapter is the final chapter of the thesis. The chapter summarises the findings of the HL studies as they relate to the thesis research questions. The chapter includes research contribution, strengths and limitations, and will discuss the implications for future research.

CHAPTER 7

General Discussion and Conclusions

This final chapter summarises the findings of the HELP and WPC intervention studies as they relate to the research questions of the thesis. The primary aim of this thesis was to further enhance the understanding of HL and HL interventions in people living with an ESPD, to determine if HL interventions are a useful therapeutic intervention for this population. This chapter will include research contribution, strengths and limitations, and recommendations for future research.

7.1 Introduction

Worldwide the deficits of HL is a silent epidemic many individuals, policy makers, and health care professionals, have a poor understanding of how limited individual HL levels impact on: (1) Individual and population health outcomes; (2) The healthcare system and health care settings; and (3) Recommended public health guidelines and population health goals (Australian Commission on Safety and Quality in Health Care 2014; Parker & Ratzan 2010). Limited individual HL is a healthcare system issue, that reflects the complexity and difficulty experienced by individuals accessing and utilising health care services (Parker & Ratzan 2010). Literacy and HL plays a big part of being able to access, navigate, and utilise, the multiple health care services that are needed for this high-risk population (Whiteford et al. 2013). HL is a multidimensional concept that incorporates various individual characteristics including cognitive, social, and personal skills, in conjunction with many different aspects on an individual and organisational level (Batterham et al. 2014; Sorensen et al. 2012).

Limited HL is associated with poorer overall health, lower use of preventative health care services, increased risk of adverse health outcomes in many chronic diseases, premature death, and increased health care expenditure costs (Lee, E, Lee & Moon 2016; Visscher et al. 2018). From a public health perspective an adequate individual HL level is required to obtain and understand health care information, to manage and make decisions about your health (Berkman, Sheridan, Donahue, Halpern & Crotty 2011). Healthcare systems continue to become more complexed and create more demands on patients (e.g., patients are expected to understand more

about health conditions) (Berkman, Sheridan, Donahue, Halpern & Crotty 2011; Nielsen-Bohlman, Panzer & Kindig 2004). To self-manage chronic health conditions an adequate individual HL level is required to make appropriate health care decisions for your individual needs and circumstances (Heide et al. 2018).

There is a strong and complex link between physical health conditions and psychiatric disorders. With the recognition of this link there is an urgent need for HL interventions using health promotion approaches to be co-designed and implemented in mental health treatment facilities, community mental health services, and primary health care settings. In today's complex health care environments HL is a fundamental skill needed to access and use healthcare systems due to its ability to reduce health inequalities, predict health outcomes (e.g., health complications), and navigate health care services (Haun et al. 2015; Lee, E, Lee & Moon 2016). Therefore, improving individual HL in people living with an ESPD may help to improve the health outcomes and health inequalities that are experienced by this vulnerable population.

Population health campaigns aimed at the general population have not been successful in people with a psychotic disorder (Coughlan et al. 2001b). Therefore, this research was needed to establish if HL interventions can assist mental health consumers to develop their cardiometabolic health knowledge and skills to support them to self-manage their cardiometabolic health. The primary aim driving the development of the HELP and WPC interventions presented in this thesis was to determine if cardiometabolic HL interventions are a useful therapeutic strategy for supporting self-management of CMRF and cardiometabolic health in this population. To address this aim, three HL intervention studies were conducted using a pre-post test study design, with only two time points and a single group, to evaluate the outcome and impact of the HELP and WPC interventions. The three HL intervention studies were feasibility studies designed to test whether the HELP and WPC interventions can be implemented in this population in order to improve individual HL knowledge and skills.

7.2 Summary of Main Findings

The results of the HL intervention studies in this thesis are promising for people living with an ESPD. Based on the results of this thesis, tailored HL interventions that are co-designed and multi-layered can assist mental health consumers to develop their cardiometabolic health

knowledge and skills so as to self-manage their chronic health conditions. This current research demonstrates that people living with an ESPD are an appropriate target group for HL interventions. The present research showed that the outpatient and inpatient HELP and WPC interventions were successful in improving individual HL knowledge and skills in this population. The HELP and WPC study results add to the minimal published research that exists regarding the benefits of HL interventions in people living with an ESPD. Therefore, the results from the feasibility studies in this thesis further show suggestive benefits of HL interventions in this population, and to a small extent adds to the body of knowledge in the area.

The HELP and WPC studies highlight that cardiometabolic HL interventions to improve individual HL in this population are feasible and can be implemented successfully in community mental health services and primary health care services. However, the acute and sub-acute mental health inpatient setting did have implementation challenges. The HELP was piloted in outpatient and inpatient mental health service settings, to determine the most appropriate and feasible setting for the intervention in the future. The outpatient HELP was effective in improving individual HL and lifestyle modifications related to SENSE. Participants in the outpatient HELP achieved a high rate of program completion.

The inpatient HELP improved individual HL but was not successful in improving lifestyle modifications related to SENSE. The inpatient HELP also had limitations due to a small sample size, this is consistent with previous studies undertaken in psychiatric treatment settings that report small participant numbers and high dropout rates (Brown, S & Chan 2006). Therefore, most interventions for psychiatric patients are implemented in outpatient settings (Bonfioli et al. 2012). Previous research shows that group education programs and interventions for people with a SMI are more successful and beneficial in community settings, due to barriers engendered by psychiatric symptoms experienced by inpatients (Rummel-Kluge & Kissling 2008b). The outpatient and inpatient HELP study results are similar to previous studies examining health promotion and health education interventions in this population (Lee, S, Arozullah & Choc 2004; Rummel-Kluge & Kissling 2008b).

The inpatient HELP study provides evidence that mental health inpatients do want to improve their individual HL knowledge and skills. However, after participants were discharged from the

mental health hospital most participants dropped out of the inpatient HELP study and were lost at 3 months follow-up. Evidence shows that post discharge from hospital, patients tend to disengage in treatment programs and prevention interventions, and over time, the patients' participation in therapy activities further declines (Piepoli et al. 2016). Future inpatient HELP studies should include strategies to engage and retain participants in the long term by using regular text messages (e.g., SMS - Short Message Service), to encourage and remind participants to maintain lifestyle modifications related to SENSE. Previous studies report that text message reminders are encouraging and beneficial in supporting people with a SMI to maintain healthy lifestyle modifications (Aschbrenner et al. 2016).

The inpatient HELP intervention has the potential to be implemented and integrated into acute and sub-acute mental health inpatient settings. The HELP intervention was adapted for the mental health inpatient treatment setting so the intervention could be implemented successfully. The participants preferred to receive the intervention individually rather than in a group due to their individual daily schedule of activities and psychiatric symptoms. One participant was experiencing psychotic symptoms whilst completing the baseline HLQ statements. Therefore, when implementing HL interventions in acute and sub-acute mental health inpatient settings, patients' cognitive limitations (e.g., cognitive impairment), clinical characteristics, and mental health symptoms (e.g., positive and negative symptoms such as amotivation) should be considered (Galletly et al. 2012; Nover & Jackson 2013; Rummel-Kluge & Kissling 2008b).

The HELP and WPC studies showed statistically significant changes on some subscales of the HLQ. The subscale differences were slightly different for each study. The findings suggest that population sub-groups living with an ESPD may be disadvantaged in terms of the chronicity of their mental illness, severity of their mental health symptoms, and their level of functional independence. The subscale HLQ domains that changed in the HELP intervention shows evidence to support that the participants were empowered by the intervention. The subscale HLQ domains that changed in the WPC intervention shows evidence that the WPC participants were more independent in actively managing their health. The findings provide insight into the type of approach that may need to be taken in the future when implementing HL interventions in this population.

Among different contexts and population groups substantial evidence exists showing a positive association between HL and health outcomes (Berkman, Sheridan, Donahue, Halpern, Viera, et al. 2011). A person's ability to learn and develop self-management practices and skills will depend on the person's level of HL and their FHL. Evidence demonstrates that FHL is interrelated with achieving self-efficacy in the self-management of a chronic disease (Ishikawa, Takeuchi & Yano 2008). The WPC intervention was a useful strategy for improving individual HL and self-efficacy to support this population to engage in preventative health care. The HELP and WPC interventions created opportunities for individuals with a psychotic disorder to be active participants in self-managing their health conditions, this allowed participants to be independent, and make informed health care decisions to improve their overall health and wellbeing. Improving individual HL knowledge and skills in this population may help to increase the uptake and use of preventative health care services and health promotion initiatives (Von Wagner et al. 2007).

The HL intervention studies in this thesis further confirm that multicomponent strategies work best for HL interventions and are well-received by people with an ESPD. In the future, strategies for improving individual HL in this population need to be innovative, comprehensive, opportunistic, and adaptable. The HELP and WPC interventions could be used in mental health treatment settings in the future to: (1) Improve individual HL knowledge and skills; (2) Improve organisational HL outcomes; (3) Support, educate, and empower, individuals with a psychotic disorder to self-manage their CMRF and cardiometabolic health conditions; and (4) Promote and improve GP care for CMRF screening and management of cardiometabolic comorbidity.

The SLHD has made a strong commitment to addressing the physical health of people living with a SMI through the Living Well, Living Longer (LWLL) program¹⁸. The LWLL program is an initiative to ensure mental health services across the SLHD are supporting psychiatric patients to look after their physical health. Existing resources within the LWLL program steering committee could be used to lead, develop, and coordinate, strategies and actions to implement a HL framework to help embed HL into high level systems across SLHD mental health services. The primary responsibility for HL falls on the healthcare system (Adams et al. 2009). Therefore,

¹⁸www.slhd.nsw.gov.au/mentalhealth/services_liv.html

it is the responsibility of the healthcare system to ensure that health care services are accessible, person centred, and health promoting.

Interestingly, an employee of SLHD recommended educating staff about the concept of HL and suggested “clinical staff should continue to get exposed to the language and culture of HL.” In addition, mental health peer workers perform various HL tasks with people living with a SMI as part of their job role. Therefore, mental health peer workers would benefit from being educated about the overall concept of HL. It is important for mental health staff to receive ongoing education about the benefits and concept of HL through staff training opportunities that are integrated into organisational practices (Australian Commission on Safety and Quality in Health Care 2014).

Furthermore, HL interventions should begin as early as possible in the treatment process for this population. Ideally, HL interventions should be implemented in the Early Intervention in Psychosis (EIP) teams, as younger people with an ESPD present with significant clinical cardiometabolic risk indicators prior to age 25 (Foley et al. 2013; Morgan, V, McGrath & Jablensky 2014). Improving an individual’s HL knowledge and skills in the first-episode psychosis (FEP) setting has many benefits for people living with a SMI and the healthcare system in the long term. Integrating HL interventions with usual care at the outset of a psychotic disorder diagnosis would further enhance the benefits and recovery outcomes for this population. Initiating targeted cardiometabolic HL interventions as an early intervention in the recovery of a SMI may potentially help to improve CMRF and cardiometabolic health outcomes in this high-risk population.

In Australia, a large number of people that access the public mental health system to receive psychiatric treatment are from CALD backgrounds (Lambert & Newcomer 2009). Addressing cultural barriers to HL and medical treatment is important (Fricchione et al. 2012). Therefore, culturally and linguistically appropriate HL interventions are needed to create equity and access for CALD individuals living with an ESPD. Current best practice to improve HL in CALD patients involves health promotion strategies (e.g., community based interventions with direct inter-personal communication undertaken by a culturally appropriate bilingual health educator) (Simich 2009). A Bilingual Vietnamese Care Coordinator referred two Vietnamese participants

to the outpatient HELP. Consequently, the Bilingual Care Coordinator needed to provide weekly support and translate the HELP resources to the Vietnamese participants.

The most socioeconomically disadvantaged area in the SLHD is Canterbury. Sixty-seven percent of the population that live in Canterbury are from CALD backgrounds, and do not speak English at home. In addition, poor English proficiency is reported by 16.6% of these people (Central and Eastern Sydney Primary Health Network 2017). Mental health professionals working in the SLHD recommended translating the HELP study resources into Vietnamese, Chinese, Greek, and Arabic, to benefit and engage CALD service users in the study. In the future, culturally and linguistically appropriate HL interventions should be developed for CALD population groups that are living with an ESPD as they may have English as a second language. Studies show that effective methods to improve individual HL in CALD patients involves working with established cultural networks to provide interactive, highly visible health information, in both English and the patients' preferred language (Simich 2009).

7.3 Strengths and Limitations

Strengths of the present research were: (1) To my knowledge this is the first time cardiometabolic HL interventions examining individual HL in people living with an ESPD have been undertaken in Sydney, Australia; and (2) The relatively high participation rates in the outpatient HELP intervention (e.g., sample size wanted for the study was 40 participants, the final sample size for the study was 43 participants). There were limitations regarding the small sample size of the inpatient HELP and WPC interventions, and the self-reported HLQ used in the studies. There were also limitations regarding increasing the number of sites to implement the HELP and WPC interventions due to the limited time and a single researcher. This also had an impact on the low recruitment and follow-up rates due to the specific healthcare setting where the HELP or WPC intervention was being implemented. The study results demonstrate that the HELP and WPC interventions are feasible, and beneficial beyond usual care in terms of improved HL in people living with an ESPD.

7.4 Recommendations for Future Research

HL interventions have an important role to play in helping people with an ESPD to access, engage, and be empowered to self-manage their health and co-morbidities. To help embed HL into mental

health treatment settings further research is warranted to demonstrate the effectiveness of HL interventions in assisting this population to self-manage their CMRF and cardiometabolic health conditions.

The preliminary findings of the HELP and WPC intervention studies suggest that HL interventions may improve individual HL knowledge and skills in people with an ESPD. The HELP and WPC intervention studies provide evidence that HL interventions are feasible in this population. However, the HELP and WPC intervention studies were of limited effectiveness and resource intensive. The success or failure of the HELP and WPC interventions were very context specific suggesting that future HL interventions should be examined in more settings to report outcomes. Therefore, future research is needed to develop alternative strategies to examine the effectiveness of HL interventions in this population across a variety of settings.

Further research is needed to explore the feasibility of online HL interventions to examine the efficacy, cost-effectiveness, and sustainability of internet-delivered HL interventions in people living with an ESPD. Future research exploring the development of the HELP and WPC intervention using the internet to deliver the intervention online may help to improve the low recruitment and follow-up rates. Furthermore, investigating whether online HL interventions are more effective, less resource intensive, cost-effective, and sustainable is important research to undertake in the future. Further research also needs to examine the cost-effectiveness of different HL interventions targeting CMRF, cardiometabolic health conditions, and cardiometabolic health outcomes, to assist in the development of innovative health promotion interventions for this high-risk population.

Population health campaigns aimed at the general population have not been successful in people with a psychotic disorder due to small participant numbers and high dropout rates (Coghlan et al. 2001b). Motivation and individual HL are important factors involved in making lifestyle changes (Aschbrenner et al. 2016; Australian Commission on Safety and Quality in Health Care 2014). To assist people living with an ESPD to engage in health promotion interventions it is important to understand that a person's psychiatric disorder and the symptoms of their disorder (e.g., apathy and withdrawal) may affect their motivation to undertake and sustain health promotion interventions (Archie et al. 2007; Aschbrenner et al. 2016). Furthermore, people with schizophrenia have desires and goals like everyone else but have trouble selecting the right course

of action to achieve their goals (Morris et al. 2015). Therefore, turning goals into actions for people living with schizophrenia is hard, as the illness impacts on brain structures that are important for desire and emotion (Morris et al. 2015). Brain structures are less active and fail to transmit goal directed messages to cortical regions affecting human decision making. (Morris et al. 2015). Consequently, people with schizophrenia have an inability to initiate goal directed behaviour to achieve real world goals such as lifestyle modifications (Morris et al. 2015). It is clear that more research is needed to develop innovative HL interventions that address the motivational factors for people with an ESPD to participate in HL interventions.

Future research in mental health inpatient settings should focus on the co-design and implementation of HL interventions that incorporate a stepped care model¹⁹. A stepped care model would assist people living with a SMI to move easily between HL interventions and health promotion programs as their support and treatment needs change. A stepped care model approach to HL interventions in acute and sub-acute mental health settings may assist with treatment and discharge planning. The design and implementation of HL interventions for mental health inpatient settings should take into account the patients psychiatric symptoms and cognitive skills. A stepped care model approach would help to provide appropriate targeted HL interventions that are more personalised. It may also help psychiatric patients to sustain, and engage in HL practices and interventions after they are discharged from hospital.

Australian research focusing on HL interventions in the context of psychiatric patients and treatment outcomes is yet to be realised. HL interventions are currently not implemented as standard practice or offered as a therapeutic adjunct treatment. Further research is warranted to examine the barriers related to implementing and sustaining evidence-based HL interventions in mental health services. Implementation research is needed to explore models for implementation and the cost-effectiveness of HL interventions in mental health service settings. Implementation research may help to embed HL interventions as part of standard practice in mental health services in the future. Implementing targeted HL interventions as an early intervention in the

¹⁹The stepped care model is evidence based, and integrates a hierarchy of interventions that are provided across a continuum on a population level, from low to moderate, to high intensive. The intervention provided in the stepped care model is matched to the individuals needs using a population health framework, to create an integrated mental health system that provides efficient streamlined access to the most appropriate level and type of treatment for the mental health service user.

treatment process for people living with an ESPD may assist in preventing a number of CMRF, cardiometabolic health problems, and premature mortality in this population.

7.5 Conclusions

The current research suggests that HL interventions are warranted in this population and have the potential to support and empower mental health consumers to self-manage their CMRF and cardiometabolic health conditions. Implementing and embedding HL interventions in this population is feasible and should be considered as a therapeutic intervention in conjunction with their overall treatment plan to help achieve optimal health outcomes. HL interventions are promising and should be further examined to help embed HL into mental health treatment settings and primary health care services. HL interventions are a valuable health promotion strategy that may help to improve health outcomes and premature mortality in this high-risk population.

In summary, the importance of HL interventions are not to be underestimated in the recovery journeys of people living with an ESPD. This population may actively seek HL education programs as an opportunity to engage in psychosocial activities to assist them to self-manage and maintain their physical health. The HL studies in this thesis have extended the literature on HL in people living with an ESPD in Sydney, Australia. The studies have advanced knowledge on the role of HL and the multidimensional benefits that occur when addressing HL in this high-risk population. Improving individual HL knowledge and skills, and organisational HL practices may help to prevent, treat, and manage, cardiometabolic health complications in this population.

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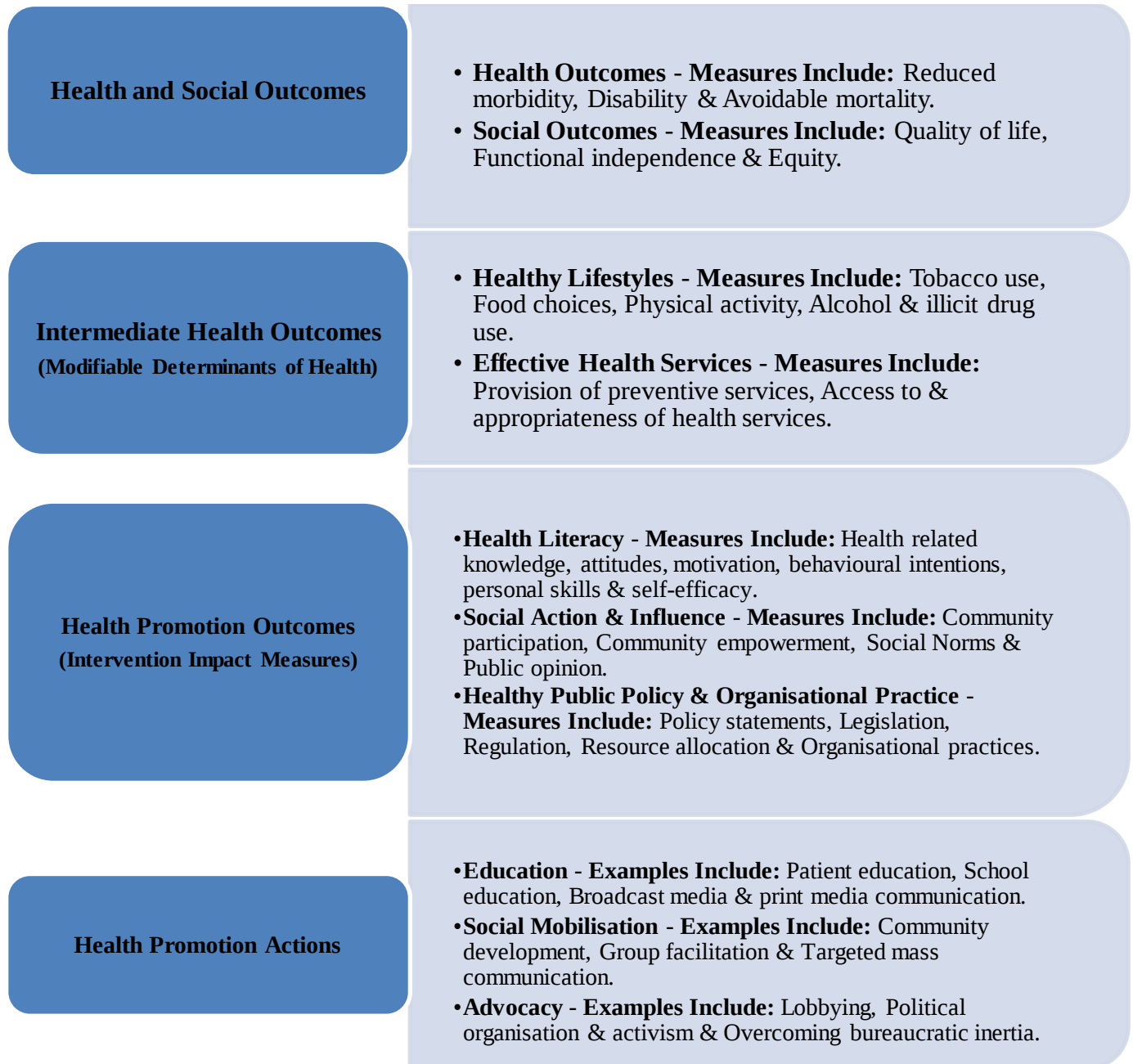
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APPENDIX 1

Nutbeam's Outcome Model for Health Promotion



Reproduced from Nutbeam, D 2000, 'Health literacy as a public goal: a challenge for contemporary health education and communication strategies into the 21st century', *Health Promotion International*, vol. 15, no. 3, p. 262.

APPENDIX 2

Health Literacy Definitions

<u>Author</u>	<u>Definition</u>
1. WHO (1998)	“The cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health.”
2. American Medical Association	“The constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment.”
3. Nutbeam (2000)	“The personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health.”
4. Institute of Medicine (2004)	“The individual’s capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”
5. Kickbusch, Wait & Maag (2006)	“The ability to make sound health decision (s) in the context of everyday life at home, in the community, at the workplace, the healthcare system, the market place and the political arena. It is a critical empowerment strategy to increase people’s control over their health, their ability to seek out information and their ability to take responsibility.”
6. Zarcadoolas, Pleasant & Greer (2003)	“The wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life.”
7. Paasche-Orlow & Wolf (2007)	“An individual’s possession of requisite skills for making health related decisions, which means that health literacy, must always be examined in the context of the specific tasks that need to be accomplished. The importance of a contextual appreciation of health literacy must be underscored.”
8. EU (2007)	“The ability to read, filter and understand health information in order to form sound judgements.”
9. Pavlekovic (2008)	“The capacity to obtain, interpret and understand basic health information and services and the competence to use such information to enhance health.”

10. Rootman & Gordon-Elbihbety (2008)	“The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course.”
11. Ishikawa & Yano (2008)	“The knowledge, skills and abilities that pertain to interactions with the health care system.”
12. Mancuso (2008)	“A process that evolves over one’s lifetime and encompasses the attributes of capacity, comprehension and communication. The attributes of health literacy are integrated within and preceded by the skills, strategies and abilities embedded within the competencies needed to attain health literacy.”
13. Australian Bureau of Statistics (2008)	“The knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies and staying healthy.”
14. Yost et al. (2009)	“The degree to which individuals have the capacity to read and comprehend health related print material, identify and interpret information presented in graphical format (charts, graphs and tables) and perform arithmetic operations in order to make appropriate health and care decisions.”
15. Adams et al. (2009)	“The ability to understand and interpret the meaning of health information in written, spoken or digital form and how this motivates people to embrace or disregard actions relating to health.”
16. Adkins et al. (2009)	“The ability to derive meaning from different forms of communication by using a variety of skills to accomplish health related objectives.”
17. Freedman et al. (2009)	“The degree to which individuals and groups can obtain, process, understand, evaluate and act upon information needed to make public health decisions that benefit the community.”

Reproduced from Sorensen, K, Broucke, S, Fullam, J, Doyle, G, Pelikan, J, Slonska, Z, Brand, H & European, fH-ECHLP 2012, 'Health literacy and public health: A systematic review and integration of definitions and models', *BMC Public Health*, vol. 12, no. 80, p. 4.

APPENDIX 3

Multilevel Model of Risk for Excess Mortality in People Living with a SMI

Individual Factors	Health System Factors	Social Determinants of Health
Disorder-specific: 1. Severity of disorder 2. Family history 3. Symptoms and pathophysiology 4. Amotivation or low motivation 5. Early age of onset 6. Recency of diagnosis 7. Stigma Behaviour-specific: 1. Lifestyle choices 2. Smoking/tobacco use 3. Substance use (alcohol/drugs) 4. Food insecurity/poor diet 5. Inadequate physical activity 6. Sexual and other risk behaviours	Leadership: Absence of relevant policies and guidelines Financing: Low investment in quality care Information: Limited health information systems Service delivery: 1. Verticalization and fragmentation of health services 2. Lack of care coordination and management 3. Limited access to services 4. Lack of whole of person care 5. Lack of supportive relationships 6. Limited organisational health literacy Human resources: 1. Poor quality service provision 2. Negative beliefs and attitudes of workforce 3. Poor communication Medications: Antipsychotic medications (no treatment, polypharmacy, higher than recommended dosages)	Public policies: 1. Discriminating policies 2. Low financial protection and limited coverage in health packages Socio-economic position: 1. Unemployment 2. Homelessness 3. Low health literacy Culture and societal values: 1. Stigma and discrimination in society 2. Negative perceptions about people living with a SMI Environmental vulnerabilities: 1. Infections, malnutrition 2. Access to means of suicide 3. Impoverished or unsafe neighbourhoods Social support: 1. Limited family, social and community resources Other: 1. Lack of education 2. Social exclusion 3. Low income and poverty 4. Inadequate housing 5. Intergenerational trauma 6. Exposure to violence and abuse

Reproduced from Organization, WH 2015, *Meeting Report On Excess Mortality in Persons with Severe Mental Disorders*, World Health Organization, WHO Headquarters, Geneva, p.7.

APPENDIX 4

Comprehensive Initial Physical Health Assessment Checklist

<u>Direct Clinical Measurements</u>	
☐ Waist circumference	☐ Blood pressure
☐ Height	☐ ECG (or review recent, if available)
☐ Weight	
<u>Biochemical Assessment</u>	
☐ Fasting blood sugar levels	☐ Triglyceride levels
☐ Two random blood sugar levels (if fasting not available)	☐ Hepatitis and HIV serology
☐ Total cholesterol	☐ Full blood examination
☐ Low density lipoprotein (LDL-C)	☐ Liver function tests
☐ High density lipoprotein (HDL-Cholesterol)	☐ Urea, electrolyte and creatinine levels
☐ Non-HDL cholesterol	☐ Estimated glomerular filtration rate
☐ TG/HDL-C or Log (TG/HDL-C)	☐ Thyroid function tests (including thyroid stimulating hormone levels and T4)
<u>Past or Current History</u>	
☐ A complete medication history for the last 6 months Also note the following: • Orexigenic psychotropic medications • Presence of polypsychotropic prescribing • Other orexigenic medications (e.g., insulin, steroids, etc.)	
☐ Obesity	☐ Gestational diabetes (in patient or close relative, see below)
☐ Diabetes	☐ Cancer
☐ Hypertension	☐ Polycystic ovarian disease
☐ Cardiovascular disease ☐ Ischaemic heart disease ☐ Peripheral vascular disease	☐ Sexually transmitted infections

☐ Stroke	
☐ Dyslipidemia	☐ Hepatitis and HIV related

<u>Lifestyle Factors</u>	
☐ Smoking history	☐ Sleep disturbance (chronic)
☐ Diet (either/both QuickScreen or dietitian)	☐ Sleep apnoea
☐ Exercise history	☐ Dentist
☐ Substance Use Disorder (alcohol or amphetamines at least)	☐ Fitness
<u>Sociodemographic Factors</u>	
☐ Age	☐ Source of income
☐ Gender	☐ Who they are living with
☐ Ethnicity (both parents)	☐ Type of accommodation
☐ Education level	☐ Marital status
☐ Occupational status	
<u>Family History</u>	
☐ Diabetes	☐ Obesity
☐ Hypertension	☐ Psychosis
☐ Hyperlipidemia	☐ Cancer
☐ Cardiovascular disease	
<u>Services Received</u>	
☐ Psychiatrist	☐ Exercise physiologist (status differs by state)
☐ Medical specialist	☐ Clinical psychologist
☐ General practitioner	☐ Disability support providers
☐ Case manager	☐ Public community rehabilitation
☐ Dietitian	☐ NGO specialising in psychiatric disability and community rehabilitation services

Notes:

1. Include assessment of (1) When diagnosed (2) Whether receiving treatment past/present (3) Current prescriptions and off label consumption with respect to cardiometabolic health, e.g., Omega-3 fish oils, ect.
2. Use of structured brief clinical tools is recommended, e.g., Pittsburgh Sleep Quality Index (PSQI), Epworth Sleepiness Scale (ESS) ect.
3. Age of onset for cardiovascular disease (CVD) should be recorded, e.g., Father, Australian Medical Index (AMI) age 54. This may help with considering treatment eligibility as well as determining risk using a variety of calculators.
4. This information serves both history and communication. As multidisciplinary care is essential in integrated health systems, it is recommended to communicate with all service providers after clinical reviews.
5. The above list is one that would be undertaken in a dedicated cardiometabolic service for those with psychotic disorders. Where available resources are limited, services might implement their own service guidelines using subsets of the items.

Reproduced from Lambert, T, Reavley, N, Jorm, A & Oakley Browne, M 2017, 'Royal Australian and New Zealand College of Psychiatrists expert consensus statement for the treatment, management and monitoring of the physical health of people with an enduring psychotic illness', *Australian and New Zealand Journal of Psychiatry*, vol. 51, no. 4, p. 333.

APPENDIX 5

SHIP Study Results

The age or age range when cardiometabolic risk indicators were significantly different in those with psychosis compared with general population controls.

<u>Domain</u>	<u>Risk Indicator</u>	<u>Males with Psychosis</u> <u>25-64 years</u>	<u>Females with Psychosis</u> <u>25-64 years</u>
Obesity	Waist Circumference	Always worse	Always worse
	BMI	Always worse	Always worse
Dyslipidemia	Cholesterol Total	Better after age 35 ¹	Better after age 45 ²
	Cholesterol LDL	Always better ³	Comparable to ~ age 40 ⁴
	Cholesterol HDL	Always worse	Always worse
	Triglycerides	Worse until ~ age 60 ⁵	Always worse
Hypertension	Systolic BP ⁶	Generally slightly better ⁷	Generally slightly better ⁸
	Diastolic BP	Always worse	Always worse
Diabetes	Glucose	Generally comparable ⁹	Generally comparable ¹⁰

Key to Table:

1. Mean is lower after age 33 but clinical indicators (CIs) do not overlap after age 35.
2. Lower at all ages although between age 38 and 42 the difference is less than .05 – lower than the accuracy of the assay. Before 33 and after 45 CIs do not overlap.
3. CIs never actually coincide, but from 27-31 the gap between the lower bound of the general population sample and the upper bound of the psychosis sample is 0.0 to one decimal place.
4. After age 46 the CIs do not overlap. The psychosis sample mean is lower from age 40.
5. Means for triglycerides in males from the psychosis and general population samples meet at 60. CIs overlap from age 57.
6. Men from the general population sample have higher mean systolic blood pressure (BP) only between age 34 and 41. CIs always overlap, so the difference is not significant.
7. Lower mean systolic blood pressure only between age 32 and 40 but CIs always overlap.
8. Blood glucose means are higher from age 31 to 56 although CIs overlap during this period.
9. Blood glucose means are higher up to age 60. CIs sometimes overlap, sometimes don't during this period.

Reproduced from Foley, D, Mackinnon, A, Watts, G, Shaw, J, Magliano, D, Castle, D, McGrath, J, Waterreus, A, Morgan, V & Galletly, C 2013, 'Cardiometabolic Risk Indicators That Distinguish Adults with Psychosis from the General Population, by Age and Gender', *PLOS ONE*, vol. 8, no. 2, p. 6.

APPENDIX 6

Proposed Neurobiological Targets of Physical Exercise in Bipolar Disorder

<u>Neurobiological Mediator</u>	<u>Bipolar Disorder</u>	<u>Effect of Physical Exercise</u>
Noradrenaline (NE)	Lower plasma levels in depression and higher in mania.	Acutely increases plasma (NE). Chronically may increase NE in locus coeruleus and dorsal raphe.
Serotonin (5HT)	Abundant evidence for altered neurotransmission. Decreased 5HT _{1A} binding potential.	Elevated peripheral tryptophan levels. Elevated central 5HT and 5-HIAA.
Dopamine (DA)	Lower CSF homovanillic acid (major DA metabolite) in depression.	Mouse models demonstrate increased DA synthesis.
Phenylethylamine	Low urinary phenylacetic acid (major phenylethylamine metabolite) in depression.	Increase in urinary phenylacetic acid levels.
Endocannabinoids	Decreased CB ₁ receptor density in anterior cingulate cortex in depression.	Increased plasma anandamide.
Inflammation	Higher levels of pro-inflammatory cytokines and lower levels of anti-inflammatory cytokines than normal controls for both manic and depressive phases.	Acute inflammatory response (e.g., IL-6) leads chronically to robust anti-inflammatory response.
Oxidative stress	Alterations in mitochondrial respiration are reported in depressive syndromes.	Induction of the anti-oxidant system through adaptation to increased reactive oxygen species (e.g., increased activity of superoxide dismutase and glutathione peroxidase in brain).
Neuroplasticity	Chronic antidepressant administration increases new neurons in hippocampus, chronic treatment with lithium and valproic acid activates mitogen-activated protein kinase cascade in human neuronal cells and rat frontal cortex and hippocampus.	Enhanced hippocampal neurogenesis, growth of blood vessels in the hippocampus, cortex and cerebellum, increased brain-derived neurotrophic factor (BDNF) in multiple brain regions, increased BDNF gene and product proteins in hippocampus.

Reproduced from Alsuwaidan, M, Kucyi, A, Law, C & McIntyre, R 2009, 'Exercise and Bipolar Disorder: A Review of Neurobiological Mediators', *Neuromol Med*, vol. 11, p. 333.

APPENDIX 7

Physiological and Psychological Mechanisms and Theories

Explaining the Link Between Exercise and Improved Mental Health and Wellbeing

Physiological Mechanisms

1. Hyperthermic Model or Thermogenic Hypothesis

Proposes the main stimulus for helping affective change is the rise in body temperature that occurs from exercise and physical activity. Therefore, the body warming is associated with wellbeing as it increases maximal oxygen consumption and delivery of oxygen to cerebral tissues which helps to reduce muscle tension. Sustained body heating that leads to increased core temperature via exercise triggers slow wave brain pattern associated with sleep response.

2. Endorphin Hypothesis

Suggests the effects of exercise on psychological well-being are produced by the release and subsequent binding of endogenous opioids. Consequently, exercise produces an increase release of endorphins and enkephalins that can give the exerciser a ‘natural high’ and promotes feelings of wellbeing and pain relief.

3. Monoamine Hypothesis

Studies show that changes in brain neurotransmitters such as serotonin, dopamine, and norepinephrine occur during exercise and have an effect on a person’s mood, stress levels, and feelings of wellbeing and happiness following an exercise session.

4. Brain Derived Neurofactor (BDNF) Effect of Exercise

Exercise induces BDNF which promotes a beneficial response in the brain associated with cognitive improvement and the alleviation of depression and anxiety.

Psychological Mechanisms

1. Self-esteem and Self-concept

Participating in exercise increases physical ability, this positively impacts on a person's self-estimation and assists in promoting higher levels of self-esteem.

2. Enhanced Self-efficacy and Self-mastery

Exercise involves learning new skills and achieving goals. Mastering attainment of new skills can improve self-worth, body image, and confidence. Studies demonstrate that participants report the perceived benefit of feeling like they have accomplished something and that the exercise has enhanced their wellbeing.

3. Distraction Hypothesis

Physical activity can be useful as a distraction from the preoccupation with stressful and negative thoughts and feelings that are a characteristic in many mental illnesses. Physical activity assists to deal with everyday life stresses and can lead to improved psychological wellbeing.

4. Flow Experience

Exercise creates within a person a flow experience which is the state in which people are so involved in an activity that nothing else seems to matter.

5. Enhanced Feeling of Control

Exercise is seen as a normal activity in which people engage in.

6. Positive Social Interactions

Exercise enables people to build new positive social networks and relationships. These relationships may help combat and prevent depression through positive social contact and social experiences.

7. Enhanced Recovery and Rehabilitation Outcomes

Exercise can reverse the risks of associated cardiometabolic diseases (e.g., diabetes, high cholesterol, and MetS) that are prevalent among mental health patients. Exercise helps people with an ESPD in their recovery journey and rehabilitation by improving fitness and muscular strength. This can lead to improved health and wellbeing, and may have flow on effects to reduce medication related side effects such as lethargy.

8. Opponent-Process Model

Exercise equals stress and activates all of the systems in the body. The nervous system responds and the sympathetic nervous system is activated to maintain homeostasis in the body. Consequently, the opposing parasympathetic nervous system is conditioned to associate exercise with relaxation.

9. Green Exercise

Exercising and participating in exercise outdoors in nature and natural environmental settings results in greater mental health benefits. However, the evidence on 'green exercise' is limited. Biophilia benefits of nature occur when exercise is undertaken in green open spaces outdoors. Biophilia is an instinctive and genetically determined attraction of human beings with the natural world. Biophilic experiences help to reduce stress, improve cognitive function, and enhances mood and creativity, which assists to improve health and wellbeing.

Adapted from Daley, A 2002, 'Exercise therapy and mental health in clinical populations: Is exercise therapy a worthwhile intervention?', *Advances in Psychiatric Treatment*, vol. 8, pp. 262-270.

Adapted from Pedersen, B & Saltin, B 2006, 'Evidence for Prescribing Exercise as Therapy in Chronic Disease', *Scandinavian Journal of Science and Medicine in Sports*, vol. 16, no. 1, pp. 3-63.

Adapted from Pickett, K, Kendrick, T & Yardley, L 2017, "'A forward movement into life': A qualitative study of how, why and when physical activity may benefit depression", *Mental Health and Physical Activity*, vol. 12, pp. 100-109.

APPENDIX 8

Checklist for Easy to Understand Print Materials

A Checklist for Easy to Understand Print Materials designed as a guide for creating easy to understand HL materials, to communicate complicated scientific medical and health information.

<u>Message Content</u> ☐ Have you limited your messages to three or four messages per document (or section)? ☐ Have you taken out information that is “nice to know” but not necessary? ☐ Is the most important information at the beginning of the document? ☐ Is it repeated at the end? ☐ Have you identified action steps or desired behaviours for your audience? ☐ Have you post-tested your materials?	<u>Layout and Design</u> ☐ Is information presented in an order that is logical to your audience? ☐ Is information chunked, using headings and subheadings? ☐ Do lists include bullets? ☐ Have you eliminated as much jargon and technical language as possible? ☐ Is technical or scientific language explained? ☐ Have you used concrete nouns, an active voice, and short words and sentences? ☐ Is the style conversational? ☐ Have you post-tested your materials?
<u>Text Appearance</u> ☐ Does your document have lots of white space? ☐ Are margins at least 1/2 inch? ☐ Is the print large enough (at least 12 points)? ☐ Is a specific font style used? ☐ Have you used bold, italics, and text boxes to highlight information? ☐ Have you avoided using all capital letters? ☐ Is text justified on the left only? ☐ Did you use columns with a line length of 40 to 50 characters of space? ☐ Have you post tested your materials?	<u>Translation</u> ☐ Are the language and content culturally appropriate? ☐ Are the visuals culturally appropriate? ☐ Have you had the piece back translated? ☐ Is the translator fluent in the same linguistic variation as the intended audience? ☐ Have you post tested your materials?

Visuals

- ☐ Is the cover attractive to your intended audience?
- ☐ Does the cover include your main message and show who the audience is?
- ☐ Are the visuals simple and instructive rather than decorative?
- ☐ Do visuals help explain the messages found in the text?
- ☐ Are your visuals placed near related text?
- ☐ Do they include captions?

Understandability

- ☐ Have you tested the complexity of the language used in your material for comprehension?
- ☐ Have you pre-tested your materials with members of your intended audience?
- ☐ Have you post tested your materials with members of your intended audience?

Reproduced from US Department of Health and Human Services. (2009). *Simply Put: a Guide for Creating Easy to Understand Materials*. Washington DC: Centers for Disease Control and Prevention, p. 29.

APPENDIX 9

Examples of the Ten Attributes of a Health Literate Health Care Organisation Model

Ten Attributes of a Health Literate Organisation	Example of Actions That Can Be Taken
1. Has leadership that makes health literacy integral to its mission, structure, and operations.	• Assign responsibility to an individual or group for actions to improve the health literacy environment. • Design the physical environment to support effective communication and navigation. • Make clear and effective communication a priority across all levels of the organisation and all communication channels.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.	• Audit the health literacy environment in the annual audit program of the healthcare organisation. • Ensure safety and quality and other improvement initiatives reflect health literacy principles and are evaluated to ensure they improve the health literacy environment. • Align a focus on health literacy with other organisational priorities reducing health disparities and providing patient centred care.
3. Prepares the workforce to be health literate and monitors progress.	• Incorporate health literacy into orientation sessions and other training. • Provide training to administrative and reception staff.
4. Includes populations served by the organisation in the design, implementation, and evaluation of health information and services.	• Involve consumers in governance processes. • Collaborate with members of the target community in the design and testing of interventions.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatisation.	• Adopt an approach to health literacy that does not make assumptions about levels of individual health literacy (a ‘universal precautions’ approach).

	• Provide alternatives to written information where possible, and create an environment that does not impose high literacy demands (such as walls and bulletin boards that are not covered with a lot of print information).
6. Uses health literacy strategies in interpersonal communication, and confirms understanding at all points of contact.	• Foster a culture that emphasises verification of understanding of every communication (clinical and non-clinical). • Plan for and provide language assistance where needed, and treat communication failures as patient safety issues.
7. Provides easy access to health information, services and navigation assistance.	• Design healthcare facilities with features that help people find their way. • Use easily understood language and symbols on signs. • Ensure information about local resources and services can be understood by consumers with low literacy levels.
8. Designs and distributes print, audio-visual, and social media content that is easy to understand and act on.	• Stock high quality educational materials appropriate for consumers with low health literacy. • Choose materials that reflect health literacy principles. • Test consumer information publications with the target audience as part of the development process.
9. Addresses health literacy in high risk situations, including care transitions and communications about medicines.	• Identify high risk situations and make plans to ensure safe communication in areas such as clinical handover, use of medicines, informed consent, and end of life care.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.	• Provide easy to understand descriptions of health insurance policies and communicate the out of pocket costs for healthcare services before they are delivered.

Reproduced from Australian Commission on Safety and Quality in Health Care 2014, 'Health literacy: Taking action to improve safety and quality', pp. 39-40, viewed 15 August 2015, <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/health-literacy-taking-action-improve-safety-and-quality>.

APPENDIX 10

Health Literacy Questionnaire (HLQ)

The authors of the HLQ²⁰ have requested that the instrument not be reproduced as an Appendix as part of this PhD thesis.

²⁰<https://healthliteracy.bu.edu/hlq>

APPENDIX 11

Steps in the Ophelia Process for the Development of HL Interventions

1. Needs assessment

The HLQ and semi-structured interviews assess health literacy needs, and organisational assessments determine contextual enablers and barriers.



2. Identify performance objectives, determinants, and change objectives

Use a structured workshop format to engage key stakeholders from participating sites in interpretation of HLQ data and generate a broad range of ideas about what is needed locally to meet the needs of clients and to support the organisation to meet the needs of clients.



3. Selection of interventions, methods, and strategies

The project management team at each site considers needs assessment data, intervention ideas, develops program logic models and selects appropriate interventions to test. Promotion of communities of practice.



4. Detailed design and planning of interventions

The research team will work with the sites to co-create and pre-test interventions, resources, and specify evaluation activities in Plan-Do-Study-Act (PDSA) cycles.



5. Adoption and implementation of interventions

PDSA cycles are implemented and results considered by project management group.



6. Implementation trial

For those pilot interventions demonstrating potential to improve health literacy and health outcomes, implementation and evaluation plans are determined and trials are conducted.

Reproduced from Batterham, R, Buchbinder, R, Beauchamp, A, Dodson, S, Elsworth, G & Osborne, R 2014, 'The OPTimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform', *BMC Public Health*, vol. 14, p. 698.

APPENDIX 12

The Health Literacy Questionnaire (HLQ) Scales With High and Low Descriptors of Each Construct

Low Level of the Construct	High Level of the Construct
1. Feeling understood and supported by healthcare providers. People who are low on this domain are unable to engage with doctors and other healthcare providers. They don't have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice.	1. Feeling understood and supported by healthcare providers. Has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.
2. Having sufficient information to manage my health. Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns.	2. Having sufficient information to manage my health. Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.
3. Actively managing my health. People with low levels don't see their health as their responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them.	3. Actively managing my health. Recognise the importance and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health. They make health a priority.
4. Social support for health. Completely alone and unsupported for health.	4. Social support for health. A person's social system provides them with all the support they want or need for health.
5. Appraisal of health information. No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information.	5. Appraisal of health information. Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others.

6. Ability to actively engage with healthcare providers. Are passive in their approach to healthcare, inactive, for example, they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they do not understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns. They do not have a sense of agency in interactions with providers.	6. Ability to actively engage with healthcare providers. Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional healthcare providers when necessary. They keep going until they get what they want. Empowered.
7. Navigating the healthcare system. Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.	7. Navigating the healthcare system. Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level.
8. Ability to find good health information. Cannot access health information when required. Is dependent on others to offer information.	8. Ability to find good health information. Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date.
9. Understanding health information well enough to know what to do. Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms.	9. Understanding health information well enough to know what to do. Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required.

Reproduced from Osborne, R, Batterham, R, Elsworth, G, Hawkins, M & Buchbinder, R 2013, 'The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ)', *BioMed Central Public Health*, vol. 13, no. 658, p. 8.

APPENDIX 13

Linkage Between the Nutbeam Matrix of Health Literacy (HL) and the Health Literacy Questionnaire (HLQ)

Nutbeam Matrix	Broad Matching HLQ Domains
1. Basic/Functional HL Sufficient basic skills in reading and writing to be able to function effectively in everyday situations.	9. Understanding health information well enough to know what to do 2. Having sufficient information to manage my health 8. Ability to find good quality health information
2. Communicative/Interactive HL More advanced cognitive and literacy skills which, together with social skills can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances.	1. Feeling understood and supported by healthcare providers 3. Actively managing my health 4. Social support for health 6. Ability to actively engage with healthcare providers 7. Navigating the health system 8. Ability to find good quality health information
3. Critical Literacy More advanced cognitive skills, which together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations.	5. Appraisal of health information 3. Actively managing my health 4. Social support for health

Reproduced from Osborne, R, Batterham, R, Elsworth, G, Hawkins, M & Buchbinder, R 2013, 'The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ)', *BioMed Central Public Health*, vol. 13, no. 658, p. 15.

APPENDIX 14

Effective Lifestyle Interventions to Improve T2DM Self-management in Psychotic Disorders

Author	Year	Location	Study Design	Length of Intervention	Sample Size	Mean Participant Characteristics	Location	Type of Intervention
Lindenmayer et al.	2009	US	Retrospective No control group	12 months	275 (72 diabetes)	Mean age: 44.25 78.5% had a psychotic disorder	Inpatient	Psycho-education
Teachout et al.	2011	US	Pre-test Post-test No control group	6 months	13	Mean age: 45 85% had a psychotic disorder	Inpatient	Diabetes Education
McKibbin et al.	2006	US	RCT	6 months	64	Mean age: 53 All had a psychotic disorder	Outpatient	Psycho-education
McKibbin et al.	2010	US	RCT	12 month Follow-up	52	Mean age: 52.4 All had a psychotic disorder	Outpatient	Psycho-education

Reproduced from Cimo, A, Stergiopoulos, E, Cheng, C, Bonato, S & Dewa, C 2012, 'Effective lifestyle interventions to improve type II diabetes self-management for those with schizophrenia or schizoaffective disorder: a systematic review', *BioMed Central Psychiatry*, vol. 12, no. 24, p. 4.

APPENDIX 15

HELP Focus Group Questions

1. Should the lifestyle risk factor weeks be put into one week?
2. Should week six be on the WPC and that is the topic for the week?
3. What pictures do you like and not like throughout the HELP participant book?
4. Should we include a page on group rules or call it something else?
5. Should we talk about the allied health professionals that can assist with the SENSE acronym risk factors (e.g., Exercise Physiologist, Dietitian, etc.)?
6. In the smoking section should we talk about a smokerlyser and Tobacco Treatment Specialists?
7. What is the most important information to know about blood pressure?
8. What is the most important information to know about cholesterol?
9. What is the most important information to know about T2DM?
10. What is the most important information to know about MetS?
11. Should we include questions to ask your GP?
12. Do you want to know about type 1 diabetes?
13. What do you want to know about managing T2DM?

APPENDIX 16

Personal Improvement Plan (PIP)

“It makes SENSE” to Record Changes

Use this chart to improve your lifestyle risk factors.

Circle the lifestyle risk factor you can change this week.

“It makes SENSE” = Sleep, Exercise, Nutrition, Substance Use, Ethanol
--

Record your changes using this chart.

<u>Week</u>	<u>Weekly Risk Factor Change</u>	<u>Mon</u>	<u>Tue</u>	<u>Wed</u>	<u>Thur</u>	<u>Fri</u>	<u>Sat</u>	<u>Sun</u>
1								
2								
3								
4								
5								
6								
7								

☺ “It makes SENSE” to make lifestyle changes to improve your health ☺

APPENDIX 17

Structured Follow-up Interview Questionnaire for HELP and WPC Studies

Documented Attempts to Contact

<u>Attempt Number</u>	<u>Method</u>	<u>Date/Time</u>	<u>Interviewer</u>
1	Phone		
2	Phone		
3	Phone		
4	Phone		

Pre-Interview Information

Interviewer's ID: _____ Date of Interview: _____

Interviewer's Introduction

"Hello, my name is _____ I am calling from the University of Sydney and would like to speak with (study participants name) _____ about their health literacy, medical appointments and lifestyle behaviours since participating in the Health Education Literacy Program (HELP study) 3 months ago."

"May I please speak with (study participants name) _____?"

NOTE TO INTERVIEWER: As needed, ensure the person answering the phone that you are not trying to sell anything or asking for money. Leave a similar message if your call is answered by voice mail or an answering machine, leaving a return phone number.

____ Yes, study participant is available. (Interviewer: if checked, proceed to survey).

____ No, study participant is not available, but will be at another time. Set appointment, if possible: Date: _____ Time: _____.

____ Study participant declined to participate.

____ Do you not want to participant in a follow-up telephone interview at all?

____ Can I call you back in 2 weeks to do a follow-up telephone interview?

____ Would you like to do this telephone interview at another time that is convenient to you.

Set appointment, if possible: Date: _____ Time: _____.

HELP Study 3 Month Follow-up Survey

We appreciate your willingness to be interviewed today. As we indicated earlier, the purpose of this phone call is to follow-up on your health literacy, recent visits to medical appointments and to see if you have made any changes to your lifestyle since participating in the Health Education Literacy Program (HELP study) 3 months ago. This telephone interview should take 15 minutes to complete.

NOTE TO INTERVIEWER

Circle the study participants answer to the question.

Health Literacy Questions

1. Have you retained most of the information you learnt in the Health Literacy Program?

Yes No Uncertain Comment: _____

2. Do you feel more confident in understanding health information?

Yes No Uncertain Comment: _____

3. Do you need more help with anything related to health literacy?

Yes No Uncertain Comment: _____

4. Have your health literacy knowledge, skills & behaviours changed?

Yes No Uncertain Comment: _____

Medical Appointment (GP) Questions

Since participating in the Health Literacy Program:

5. Have you been to a GP/doctor for a physical health check-up?

Yes No (go to question 5b) Comment: _____

(a) Did you use the GP wallet card given to you at the end of the Health Literacy Program?

Yes No Comment: _____

If yes, did you find the GP wallet card useful on your visit to the GP/doctor?

Yes No Uncertain Comment: _____

(b) If no, why did you not use the GP wallet card when you went to see the GP/doctor?

Forgot I had the card in my wallet

Left the card at home

Have lost the wallet card

Other: _____

6. Is there a reason why you have not been to the GP/doctor for a physical health check-up?

Yes No Uncertain Reason: _____

7. How many times have you been to the GP since participating in the Health Literacy Program?

None 1 visit 2 visits 3 visits 4 visits No. visits: _____

Behaviour/Lifestyle Change Questions

In regards to the SENSE (Sleep, Exercise, Nutrition, Substance Abuse, Ethanol) acronym

8. Do you remember the SENSE acronym used in the Health Literacy Program?

Yes No Uncertain Comment: _____

9. Do you remember what the SENSE acronym letters stand for/mean?

Yes No Uncertain Comment: _____

Letters remembered: _____

(b) Why do you remember these SENSE acronym letters/words?

10. Have you made any changes to your lifestyle in regards to the SENSE acronym used in the Health Literacy Program?

Yes No (go to question 11) Uncertain Comment: _____

(a) If yes, what SENSE lifestyle factors have you made changes to?

Sleep: _____

Exercise: _____

Nutrition: _____

(a) If yes, what SENSE lifestyle factors have you made changes to?

Substance Abuse: _____

Ethanol: _____

Other: _____

(b) What motivated you to make changes in regards to your lifestyle?

HELP Study

GP/Doctor

Psychiatrist

Case Manager

Primary Carer

Friend

Myself

Other: _____

11. If no, is there a reason why you have not made any changes to your lifestyle?

Yes

No

Uncertain

Reason: _____

12. Do you think you will make changes to your lifestyle in the future?

Yes

No

Uncertain

Reason: _____

13. Are you interested in attending a health literacy refresher session in the future?

Yes

No

Uncertain

Reason: _____

Thank you for your time

APPENDIX 18

Evaluation Form for HELP and WPC Studies

Health Education Literacy Program (HELP) Evaluation

Participant's Name: (optional) _____

- 1. The main things I wanted to get out of this health literacy education program were (list your expectations):**

- 2. Did this health literacy education program achieve these expectations?
(Please explain or list your reasons)**

- 3. Please circle the box to rate the following aspects of the health literacy education program:**

- **How useful was the health literacy education program for you?**

Unsatisfactory	Average	Good	Very Good	Excellent
----------------	---------	------	-----------	-----------

- **Education materials (handouts, powerpoint slides, ect.)?**

Unsatisfactory	Average	Good	Very Good	Excellent
----------------	---------	------	-----------	-----------

➤ Overall, how do you rate the health literacy education program?

Unsatisfactory	Average	Good	Very Good	Excellent
----------------	---------	------	-----------	-----------

➤ Overall, how do you rate the session presenters?

Unsatisfactory	Average	Good	Very Good	Excellent
----------------	---------	------	-----------	-----------

4. What did you like most about the health literacy education program?

5. What would you change in regards to the health literacy education program?

6. Please write any other comments and suggestions:

😊 THANK YOU FOR PROVIDING THIS FEEDBACK 😊

APPENDIX 19

Ethics Approval for HELP and WPC Intervention Studies

Contact: Sydney Local Health District (SLHD)
Research Office
Concord Repatriation General Hospital (CRGH)
Building 20, Hospital Road
Concord NSW 2139
Telephone: (02) 9767 5622
Email: Virginia.Turner@sswahs.nsw.gov.au
Our Ref: (SSA Authorisation)



CONCORD
REPATRIATION GENERAL
HOSPITAL

23 March, 2015

Professor Tim Lambert
Concord Medical School
Building 20
CONCORD RGH

Dear Professor Lambert,

HREC reference number: HREC/14/CRGH/238

SSA reference number: SSA/15/CRGH/25

Project title: *Impact of a health literacy intervention on cardiometabolic health, knowledge and access to medical care, in people living with a psychotic illness: a feasibility study. (HELP)*

Thank you for submitting an application for authorisation of this project.

I am pleased to inform you that the delegate of the Chief Executive has granted authorisation for this study to take place at the following site:

Concord Repatriation General Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to this office.
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to this office.
3. Please note that you are responsible for making the necessary arrangements (eg identity pass) for any researcher who is not employed by the Sydney Local Health District and is conducting the research on-site at CRGH.
4. Where appropriate, I recommend that you consult with your Medical Defence Union to ensure that you are adequately covered for the purposes of conducting this study.
5. Site approval is granted on the assumption that all students and early career researchers are adequately supervised by the principal and senior

investigators on a project. This supervision would ensure that all privacy concerns are met (including the completion of confidentiality agreements by participating students) and that both students and participants are supported in the conduct of the study in line with the approved research protocol.

Yours sincerely,

[REDACTION]

p.p.

Virginia Turner
Research Governance Officer
Concord Repatriation General Hospital

APPENDIX 20

Participant Information Sheet and Consent Form for HELP and WPC Studies



HELP Study

Health Education Literacy Program

INFORMATION FOR PARTICIPANTS

(Version 3.0 (23/8/2015))

STUDY TITLE: Impact of a health literacy intervention on cardiometabolic health, knowledge and access to medical care, in people living with a mental illness: a feasibility study undertaken in three different NSW Mental Health Service settings.

INVESTIGATORS: Professor Tim Lambert (Professor of Psychiatry, Concord Medical School, University of Sydney), Philippa Boss (Higher Degree Research Candidate)

INTRODUCTION:

You are invited to take part in a research study conducted by the University of Sydney to see if learning more about heart disease and other metabolic diseases such as diabetes can improve the health of people with mental illnesses.

This Participant Information Sheet will tell you about what is involved in the study and help you decide whether or not you wish to take part. Please read this information carefully. If there is anything you do not understand or if you feel you need more information about anything, please ask one of the members of our research team. Before you make a decision, please feel free to talk things over with a relative, a friend or your own doctor.

WHY HAVE I BEEN ASKED TO TAKE PART?

You have been invited to take part in this research study because you have been diagnosed with a mental illness and previous studies have shown that education is a key component in the recovery journey for people with a diagnosed mental illness.

WHAT IS THE PURPOSE OF THIS RESEARCH?

The purpose of this study is to see if the Health Education Literacy Program (HELP) will assist participants in understanding the cardiometabolic health conditions associated with mental illness. These include high blood pressure, type II diabetes, high cholesterol and cardiovascular disease. Previous research studies have shown that if people learn more about health issues they are better able to manage their mental illness and any associated cardiometabolic disorders.

DO I HAVE TO TAKE PART IN THE STUDY?

Taking part in any research is entirely voluntary. If you do decide to take part you can withdraw at any time without having to give a reason. Please be assured that, whatever your decision, it will not affect your medical treatment or your relationship with medical staff in the Sydney Local Health District.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

To start with, we would like you to sign the participant consent form. The study procedures outlined below will then be implemented:

1. A week prior to starting the HELP intervention you will need to attend the ccCHIP clinic to fill out the baseline data questionnaires with the assistance of one of the primary investigators (Philippa Boss or Professor Tim Lambert). We would like you to repeat this process again in week six of the HELP intervention. The questionnaires will ask you specific questions about your lifestyle, your experiences with mental illness, the current medications you are taking, and your health literacy. You will also be asked about your readiness to change lifestyle behaviours around sleep, exercise, nutrition and cigarette and alcohol consumption. The following information will also be collected and recorded about you during this visit:

- A detailed history of your risk factors for diabetes;
- Your key demographics;
- Current medications you are taking;
- Questions about your mental illness diagnosis;
- Previous treatments you have had for your mental illness;
- Previous diagnosis of your relevant risk factors;
- Your smoking status;
- Your diet and exercise behaviours;
- Your substance abuse history;
- Your blood results will be reviewed;
- Your blood sugar;
- Blood pressure;
- Dental hygiene status;
- Body mass index (BMI); and
- Waist circumference.

Your blood sugar (glucose) will be tested by a quick finger prick test. This test is preferred as it minimises any potential discomfort. Your cholesterol levels, vitamin D levels and dental hygiene status will be tested using the standard ccCHIP clinic procedures. Your blood pressure will be

measured using a blood pressure machine (sphygmomanometer). This will involve wrapping an inflatable pressure cuff around your upper arm. A member of the research team will administer these tests.

The results of these tests will be recorded against your unique participant number that has been allocated to you for the study. No personally identifying information will be linked with this number. The samples you provide for the metabolic health tests will not be stored or used for any other purpose than the HELP study. These samples will be disposed of immediately following interpretation of the results of the tests.

2. The week after your baseline data is collected you will start the HELP intervention. The HELP intervention involves six, forty-five minute education sessions delivered over six consecutive weeks. Each education session will be delivered in a group format, with 8-12 participants. You will be given homework and the following week the homework task will be discussed. The homework will be cognitive behaviour therapy (CBT) based. A text message will be sent to remind you to attend the HELP intervention.

3. In week six you will fill out the data questionnaires that you completed the week prior to starting the HELP intervention. The primary investigators (Philippa Boss or Professor Tim Lambert) will assist you with completing these questionnaires.

4. Your consent will be sought for follow-up phone calls at three months and six months following completion of the HELP intervention (we will ask you to provide the name, address and telephone number of someone who will be able to tell us your new contact details if you should move). These follow-up phone calls will take up twenty minutes of your time. The purpose of the calls is to offer you refresher education sessions and to re-evaluate your health literacy and adherence to medical treatment.

You will be involved in the HELP study for approximately 7 ½ months (six weeks for the HELP intervention and two follow-up phone calls: one at three months and the other at six months after completion of the HELP intervention).

The HELP intervention will be delivered at the Marrickville Community Mental Health Centre, Croydon Community Mental Health Centre and the Canterbury Community Mental Health Centre in the Sydney Local Health District. You will have to travel to the Community Mental Health Centre once a week, during the six week period, in which you are participating in the HELP intervention. You will decide which Community Mental Health Centre you will attend whilst participating in the study. There are no costs involved in this study. All education sessions and medical care related to the study will be provided to you free of charge.

WHAT DO I HAVE TO DO?

If you agree to take part in the HELP study we will ask you to make a commitment to the six consecutive forty-five minute weekly education sessions. You will also have to get yourself to the Community Mental Health Centre where the education sessions are held. Apart from you having to attend the education sessions, participation in the study will not affect your daily routines and you can still undertake your normal everyday activities.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

While we intend that this research study will further medical knowledge and may improve health promotion and health literacy interventions for people with a mental illness in the future we cannot and do not promise that you will personally receive any benefits from this study.

However, with your permission, if we detect any problems with your physical health we will inform your doctor. Your doctor will advise you on how to treat any physical illness that is of concern to you or the research team.

WHAT ARE THE RISKS OF TAKING PART?

In an effort to avoid any worsening of your mental illness symptoms, we will monitor your mental health during the study. We would like your consent to inform your psychiatrist, case manager, rehabilitation team, clinical team, general practitioner or other relevant health professional of your participation in the HELP study. We would like to pass on relevant information, such as, the results of your initial assessment, to those people involved in your health care. We believe it is important for you to maintain contact with these health professionals throughout the HELP study and we encourage you to do so.

At the conclusion of each of the HELP intervention education sessions, we will talk briefly with you to assess your mental illness symptoms. We will also talk briefly with you about any behavioural changes or improvements and how these are affecting you. If you feel your mental illness symptoms are increasing, we would like permission to contact the relevant health professional involved in your health care to arrange a medical appointment and/or emergency assistance.

In addition, it is possible that when you complete the questionnaires you are at risk of being confronted by questions about your mental, physical and emotional health that may lead to some discomfort. There is also, the additional minor discomfort associated with the usual clinical risks of physical health tests.

WHAT IF NEW INFORMATION BECOMES AVAILABLE?

Sometimes during the course of a study new information becomes available about the treatment that is being studied. While you are participating in the study you will be kept informed of any significant new findings that may affect your willingness to continue in the study.

CONFIDENTIALITY

If you consent to take part in this study your hospital medical records may be inspected by the researchers or by the Human Research Ethics Committee. By signing the consent form you are giving permission for this to be done. All details obtained by those named will remain confidential. A report of this study may be submitted for publication but individual participants will not be identifiable, only summarised data will be made available from this study.

Any information that is collected for this study and that can be identified with you will remain confidential. This information will be disclosed only with your permission except as required by law.

The person interviewing you and the research team involving people from the ccCHIP clinic will have access to your information. At the start of the study, you will be given a numeric participant number. All information you provide for this study will only be identified by this number. Your name, address and personal details and information will be removed from this information.

COMPENSATION

Every reasonable precaution will be taken to ensure your safety during the course of the study. In the event that you suffer any injury as a result of participating in this research project, hospital care and treatment will be provided at no extra cost to you.

FURTHER INFORMATION

When you have read this information, Philippa Boss or Professor Tim Lambert will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Philippa Boss, the primary study investigator, on

[REDACTION]. This information sheet is for you to keep.

This study has been approved by the Human Research Ethics Committee - CRGH of the Sydney Local Health District. If you have any concerns or complaints about the conduct of the research study, you may contact the Executive Officer of the Ethics Committee, on (02) 9767 6027.

In addition, if you wish to speak to someone about any problems or queries you may have about the conduct of the study at the Marrickville Community Mental Health Centre, Croydon Community Mental Health Centre or the Canterbury Community Mental Health Centre, you can contact the Research Governance Officer, on (02) 9515 7899.

Study Title: Impact of a health literacy intervention on cardiometabolic health, knowledge and access to medical care, in people living with a mental illness: a feasibility study undertaken in three different NSW Mental Health Service settings.

PARTICIPANT CONSENT FORM

I,[name]
of.....[address]

have read and understood the Information for Participants for the above named research study and have discussed the study with

.....

- I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.
- I understand that, during the course of this study, my medical records may be accessed by the researchers, by regulatory authorities or by the Ethics Committee approving the research in order to verify results and determine that the study is being carried out correctly.
- I give the primary research investigators permission to collect information from my medical records. I have been told that my medical records will be accessed to collect information about my medical history as part of this study.
- I give the primary research investigators permission to contact, inform and pass on relevant information, such as, the results of my initial assessment to my psychiatrist, case manager, rehabilitation team, clinical team, general practitioner or other relevant health professional involved in my health care.
- I freely choose to participate in this study and understand that I can withdraw at any time.
- I also understand that the research study is strictly confidential.
- I hereby agree to participate in this research study.

Name (Please Print):

Signature:..... **Date:**

Name of Person who conducted informed consent discussion (Please Print):

.....

Signature of Person who conducted informed consent discussion:

Signature:..... **Date:**



HELP

Health Education Literacy Program

INFORMATION FOR PARTICIPANTS

(Version 3.0 (28/9/2015))

STUDY TITLE: Impact of a health literacy intervention on cardiometabolic health, knowledge and access to medical care, in people living with a mental illness: a feasibility study undertaken in three different NSW Mental Health Service settings.

INVESTIGATORS: Professor Tim Lambert (Professor of Psychiatry, Concord Medical School, University of Sydney), Philippa Boss (Higher Degree Research Student).

INTRODUCTION:

You are invited to take part in a research study conducted by the University of Sydney to see if learning more about heart disease and other metabolic diseases such as diabetes can improve the health of people with a mental illness.

This Participant Information Sheet will tell you about what is involved in the study and help you decide whether or not you wish to take part. Please read this information carefully. If there is anything you do not understand or if you feel you need more information about anything, please ask one of the members of our research team. Before you make a decision, please feel free to talk things over with a relative, a friend or your own doctor.

WHY HAVE I BEEN ASKED TO TAKE PART?

You have been invited to take part in this research study because you have been diagnosed with a mental illness and previous studies have shown that education is a key component in the recovery journey for people with a diagnosed mental illness.

WHAT IS THE PURPOSE OF THIS RESEARCH?

The purpose of this study is to see if the Health Education Literacy Program (HELP) will assist participants in understanding the cardiometabolic health conditions associated with mental illness. These include high blood pressure, type II diabetes, high cholesterol and cardiovascular disease.

Previous research studies have shown that if people learn more about health issues they are better able to manage their mental illness and any associated cardiometabolic disorders.

DO I HAVE TO TAKE PART IN THE STUDY?

Taking part in any research is entirely voluntary. If you do decide to take part you can withdraw at any time without having to give a reason. Please be assured that, whatever your decision, it will not affect your medical treatment or your relationship with medical staff in the Sydney Local Health District.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

To start with, we would like you to sign the participant consent form. The study procedures outlined below will then be implemented:

1. A week prior to starting the HELP intervention you will need to attend the ccCHIP clinic to fill out the baseline data questionnaires with the assistance of one of the primary investigators (Philippa Boss or Professor Tim Lambert). We would like you to repeat this process again in week six of the HELP intervention. The questionnaires will ask you specific questions about your lifestyle, your experiences with mental illness, the current medications you are taking, and your health literacy. You will also be asked about your readiness to change lifestyle behaviours around sleep, exercise, nutrition and cigarette and alcohol consumption. The following information will also be collected and recorded about you during this visit:
 - A detailed history of your risk factors for diabetes;
 - Your key demographics;
 - Current medications you are taking;
 - Questions about your mental illness diagnosis;
 - Previous treatments you have had for your mental illness;
 - Previous diagnosis of your relevant risk factors;
 - Your smoking status;
 - Your diet and exercise behaviours;
 - Your substance abuse history;
 - Your blood results will be reviewed;
 - Your blood sugar;
 - Blood pressure;
 - Dental hygiene status;
 - Body mass index (BMI); and
 - Waist circumference.

Your blood sugar (glucose) will be tested by a quick finger prick test. This test is preferred as it minimises any potential discomfort. Your cholesterol levels, vitamin D levels and dental hygiene status will be tested using the standard ccCHIP clinic procedures. Your blood pressure will be measured using a blood pressure machine (sphygmomanometer). This will involve wrapping an inflatable pressure cuff around your upper arm. A member of the research team will administer these tests.

The results of these tests will be recorded against your unique participant number that has been allocated to you for the study. No personally identifying information will be linked with this number. The samples you provide for the metabolic health tests will not be stored or

used for any other purpose than the HELP study. These samples will be disposed of immediately following interpretation of the results of the tests.

2. The week after your baseline data is collected you will start the HELP intervention. The HELP intervention involves six, forty-five minute education sessions delivered over six consecutive weeks. Each education session will be delivered in a group format, with 8-12 participants. You will be given weekly activities and the following week the weekly activity will be discussed. The weekly activity will be cognitive behaviour therapy (CBT) based. A text message will be sent to remind you to attend the HELP intervention.
3. In week six you will fill out the data questionnaires that you completed the week prior to starting the HELP intervention. The primary investigators (Philippa Boss or Professor Tim Lambert) will assist you with completing these questionnaires.
4. Your consent will be sought for follow-up phone calls at three months and six months following completion of the HELP intervention (we will ask you to provide the name, address and telephone number of someone who will be able to tell us your new contact details if you should move). These follow-up phone calls will take twenty minutes to complete. The purpose of the calls is to offer you refresher education sessions and to re-evaluate your health literacy and adherence to medical treatment.
5. You will be involved in the HELP study for approximately 7 ½ months (six weeks for the HELP intervention and two follow-up phone calls: one at three months and the other at six months after completion of the HELP intervention).
6. The HELP intervention will be delivered in the Kirkbride Unit and Broughton Unit at the Concord Centre for Mental Health in the Sydney Local Health District. You will be required to attend the education sessions once a week, during the six week period, in which you are participating in the HELP intervention. There are no costs involved in this study. All education sessions and medical care related to the study will be provided to you free of charge.

WHAT DO I HAVE TO DO?

If you agree to take part in the HELP study we will ask you to make a commitment to the six consecutive forty-five minute weekly education sessions that are held in the Kirkbride Unit and Broughton Unit. Apart from you having to attend the education sessions, participation in the study will not affect your daily routines and you can still undertake your normal everyday activities.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

While we intend that this research study will further medical knowledge and may improve health promotion and health literacy interventions for people with a mental illness in the future we cannot and do not promise that you will personally receive any benefits from this study.

However, with your permission, if we detect any problems with your physical health we will inform your doctor. Your doctor will advise you on how to treat any physical illness that is of concern to you or the research team.

WHAT ARE THE RISKS OF TAKING PART?

In an effort to avoid any worsening of your mental illness symptoms, we will monitor your mental health during the study. We would like your consent to inform your psychiatrist, case manager, rehabilitation team, clinical team, general practitioner or other relevant health professional of your participation in the HELP study. We would like to pass on relevant information, such as, the results of your initial assessment, to those people involved in your health care. We believe it is important for you to maintain contact with these health professionals throughout the HELP study and we encourage you to do so.

At the conclusion of each of the HELP intervention education sessions, we will talk briefly with you to assess your mental illness symptoms. We will also talk briefly with you about any behavioural changes or improvements and how these are affecting you. If you feel your mental illness symptoms are increasing, we would like permission to contact the relevant health professional involved in your health care to arrange a medical appointment and/or emergency assistance.

In addition, it is possible that when you complete the questionnaires you are at risk of being confronted by questions about your mental, physical and emotional health that may lead to some discomfort. There is also, the additional minor discomfort associated with the usual clinical risks of physical health tests.

WHAT IF NEW INFORMATION BECOMES AVAILABLE?

Sometimes during the course of a study new information becomes available about the treatment that is being studied. While you are participating in the study you will be kept informed of any significant new findings that may affect your willingness to continue in the study.

CONFIDENTIALITY

If you consent to take part in this study your hospital medical records may be inspected by the researchers or by the Human Research Ethics Committee. By signing the consent form you are giving permission for this to be done. All details obtained by those named will remain confidential. A report of this study may be submitted for publication but individual participants will not be identifiable, only summarised data will be made available from this study.

Any information that is collected for this study and that can be identified with you will remain confidential. This information will be disclosed only with your permission except as required by law.

The person interviewing you and the research team involving people from the ccCHIP clinic will have access to your information. At the start of the study, you will be given a numeric participant number. All information you provide for this study will only be identified by this number. Your name, address and personal details and information will be removed from this information.

COMPENSATION

Every reasonable precaution will be taken to ensure your safety during the course of the study. In the event that you suffer any injury as a result of participating in this research project, hospital care and treatment will be provided at no extra cost to you.

FURTHER INFORMATION

When you have read this information, Philippa Boss or Professor Tim Lambert will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Philippa Boss, the primary study investigator, on

[REDACTION]. This information sheet is for you to keep.

This study has been approved by the Human Research Ethics Committee - CRGH of the Sydney Local Health District. If you have any concerns or complaints about the conduct of the research study, you may contact the Executive Officer of the Ethics Committee, on (02) 9767 5622.

Study Title: Impact of a health literacy intervention on cardiometabolic health, knowledge and access to medical care, in people living with a mental illness: a feasibility study undertaken in three different NSW Mental Health Service settings.

PARTICIPANT CONSENT FORM

I,[name]
of.....[address]

have read and understood the Information for Participants for the above named research study and have discussed the study with

.....

- I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.
- I understand that, during the course of this study, my medical records may be accessed by the researchers, by regulatory authorities or by the Ethics Committee approving the research in order to verify results and determine that the study is being carried out correctly.
- I give the primary research investigators permission to collect information from my medical records. I have been told that my medical records will be accessed to collect information about my medical history as part of this study.
- I give the primary research investigators permission to contact, inform and pass on relevant information, such as, the results of my initial assessment to my psychiatrist, case manager, rehabilitation team, clinical team, general practitioner or other relevant health professional involved in my health care.
- I freely choose to participate in this study and understand that I can withdraw at any time.
- I also understand that the research study is strictly confidential.
- I hereby agree to participate in this research study.

Name (Please Print):

.....

Signature: **Date:**

Name of Person who conducted informed consent discussion (Please Print):

.....

Signature of Person who conducted informed consent discussion:

Signature: **Date:**



HELP Study

INFORMATION FOR PARTICIPANTS

(Version 2.0 (28/6/2016))

STUDY TITLE: Impact of a health literacy intervention on cardiometabolic health, knowledge and access to medical care, in people living with a mental illness: a feasibility study undertaken in three different NSW Mental Health Service settings.

INVESTIGATORS: Professor Tim Lambert (Professor of Psychiatry, Concord Medical School, University of Sydney), Philippa Boss (Higher Degree Research Candidate)

INTRODUCTION:

You are invited to take part in a research study conducted by the University of Sydney to see if learning more about heart disease and other metabolic diseases such as diabetes can improve the health of people with mental illnesses.

This Participant Information Sheet will tell you about what is involved in the study and help you decide whether or not you wish to take part. Please read this information carefully. If there is anything you do not understand or if you feel you need more information about anything, please ask one of the members of our research team. Before you make a decision, please feel free to talk things over with a relative, a friend or your own doctor.

WHY HAVE I BEEN ASKED TO TAKE PART?

You have been invited to take part in this research study because you have been diagnosed with a mental illness and previous studies have shown that education is a key component in the recovery journey for people with a diagnosed mental illness.

WHAT IS THE PURPOSE OF THIS RESEARCH?

The purpose of this study is to see if the GP Wallet Prompt Card will assist participants in accessing medical care for physical health check-ups to help participants to understand the cardiometabolic health conditions associated with mental illness. These include high blood pressure, type II diabetes, high cholesterol and cardiovascular disease.

Previous research studies have shown that if people learn more about health issues they are better able to manage their mental illness and any associated cardiometabolic disorders. Research also shows that physical health check-ups are not routinely performed in people living with a psychotic disorder.

DO I HAVE TO TAKE PART IN THE STUDY?

Taking part in any research is entirely voluntary. If you do decide to take part you can withdraw at any time without having to give a reason. Please be assured that, whatever your decision, it will not affect your medical treatment or your relationship with medical staff or health workers at the University of Sydney, Sydney Local Health District or Day to Day Living (D2DL) program sites.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

To start with, we would like you to sign the participant consent form. The study procedures outlined below will then be implemented:

1. A week prior to starting the HELP study you will need to attend the ccCHIP clinic or another study site you select to fill out the baseline data questionnaires with the assistance of one of the primary investigators (Philippa Boss or Professor Tim Lambert). We would like you to repeat this process again in week six of the HELP study over the phone using a Telephone Interview Script which has been designed for this study. The questionnaires will ask you specific questions about your lifestyle, your experiences with mental illness, the current medications you are taking, and your health literacy. You will also be asked about your readiness to change lifestyle behaviours around sleep, exercise, nutrition and cigarette and alcohol consumption. The following information will also be collected and recorded about you during this visit:

- A detailed history of your risk factors for diabetes;
- Your key demographics;
- Current medications you are taking;
- Questions about your mental illness diagnosis;
- Previous treatments you have had for your mental illness;
- Previous diagnosis of your relevant risk factors;
- Your smoking status;
- Your diet and exercise behaviours;
- Your substance abuse history;
- Your blood results will be reviewed;
- Your blood sugar;
- Blood pressure;
- Dental hygiene status;
- Body mass index (BMI); and
- Waist circumference.

Your blood sugar (glucose) will be tested by a quick finger prick test. This test is preferred as it minimises any potential discomfort. Your cholesterol levels, vitamin D levels and dental hygiene status will be tested using the standard ccCHIP clinic procedures. Your blood pressure will be measured using a blood pressure machine (sphygmomanometer). This will involve wrapping an

inflatable pressure cuff around your upper arm. A member of the research team will administer these tests.

The results of these tests will be recorded against your unique participant number that has been allocated to you for the study. No personally identifying information will be linked with this number. The samples you provide for the metabolic health tests will not be stored or used for any other purpose than the HELP study. These samples will be disposed of immediately following interpretation of the results of the tests.

2. The week after your baseline data is collected you will start the HELP study. The HELP study involves you going to a GP for a physical health check-up in the six weeks after you have received the GP Wallet Prompt Card. A text message will be sent to remind you to attend the GP for a physical health check-up.

3. In week six you will fill out the data questionnaires that you completed the week prior to starting the HELP study over the phone. You will also complete a Telephone Interview Script asking you questions about how you used the GP Wallet Prompt Card when you went to the GP for a physical health check-up. The primary investigators (Philippa Boss or Professor Tim Lambert) will assist you with completing these questionnaires.

4. Your consent will be sought for follow-up phone calls at three months and six months following completion of the HELP study (we will ask you to provide the name, address and telephone number of someone who will be able to tell us your new contact details if you should move). These follow-up phone calls will take up twenty minutes of your time. The purpose of the calls is to offer you refresher education sessions and to re-evaluate your health literacy and adherence to medical treatment.

You will be involved in the HELP study for approximately 7 ½ months (six weeks for the HELP study GP Wallet Prompt Card intervention and two follow-up phone calls: one at three months and the other at six months after completion of the GP Wallet Prompt Card intervention).

The HELP study GP Wallet Prompt Card intervention will be delivered at the Kirkbride Unit and Broughton Unit at the Concord Centre for Mental Health, Sydney Local Health District Community Mental Health Centres (Marrickville, Croydon and Canterbury), ccCHIP clinics at Concord Hospital and the Charles Perkins Centre at the University of Sydney and at the Schizophrenia Fellowship of NSW Inc. Day to Day Living (D2DL) program sites at Parramatta (Frangipani House) and Chatswood (Hercules House). There are no costs involved in this study. All education sessions and medical care related to the study will be provided to you free of charge.

WHAT DO I HAVE TO DO?

If you agree to take part in the HELP study we will ask you to make a commitment accessing a GP within six weeks of receiving the GP Wallet Prompt Card. Apart from you having to attend the initial education session about the use of the GP Wallet Prompt Card at a research site you choose from the ones listed above, participation in the study will not affect your daily routines and you can still undertake your normal everyday activities.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

While we intend that this research study will further medical knowledge and may improve health promotion and health literacy interventions for people with a mental illness in the future we cannot and do not promise that you will personally receive any benefits from this study.

However, with your permission, if we detect any problems with your physical health we will inform your doctor. Your doctor will advise you on how to treat any physical illness that is of concern to you or the research team.

WHAT ARE THE RISKS OF TAKING PART?

In an effort to avoid any worsening of your mental illness symptoms, we will monitor your mental health during the study. We would like your consent to inform your psychiatrist, case manager, rehabilitation team, clinical team, general practitioner or other relevant health professional of your participation in the HELP study. We would like to pass on relevant information, such as, the results of your initial assessment, to those people involved in your health care. We believe it is important for you to maintain contact with these health professionals throughout the HELP study and we encourage you to do so.

At the conclusion of each of the telephone interviews, we will talk briefly with you to assess your mental illness symptoms. We will also talk briefly with you about any behavioural changes or improvements and how these are affecting you. If you feel your mental illness symptoms are increasing, we would like permission to contact the relevant health professional involved in your health care to arrange a medical appointment and/or emergency assistance.

In addition, it is possible that when you complete the questionnaires you are at risk of being confronted by questions about your mental, physical and emotional health that may lead to some discomfort. There is also, the additional minor discomfort associated with the usual clinical risks of physical health tests.

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Any information that is collected for this study and that can be identified with you will remain confidential. This information will be disclosed only with your permission except as required by law.

The person interviewing you and the research team involving people from the ccCHIP clinic will have access to your information. At the start of the study, you will be given a numeric participant

number. All information you provide for this study will only be identified by this number. Your name, address and personal details and information will be removed from this information.

COMPENSATION

Every reasonable precaution will be taken to ensure your safety during the course of the study. In the event that you suffer any injury as a result of participating in this research project, hospital care and treatment will be provided at no extra cost to you.

FURTHER INFORMATION

When you have read this information, Philippa Boss or Professor Tim Lambert will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Philippa Boss, the primary study investigator, on [REDACTION]. This information sheet is for you to keep.

This study has been approved by the Human Research Ethics Committee - RPAH of the Sydney Local Health District. If you have any concerns or complaints about the conduct of the research study, you may contact the Executive Officer of the Ethics Committee, on (02) 9515 6766.

Study Title: Impact of a health literacy intervention on cardiometabolic health, knowledge and access to medical care, in people living with a mental illness: a feasibility study undertaken in three different NSW Mental Health Service settings.

PARTICIPANT CONSENT FORM

I,[name]
of.....[address]

have read and understood the Information for Participants for the above named research study and have discussed the study with

.....

- I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.
- I understand that, during the course of this study, my medical records may be accessed by the researchers, by regulatory authorities or by the Ethics Committee approving the research in order to verify results and determine that the study is being carried out correctly.
- I give the primary research investigators permission to collect information from my medical records. I have been told that my medical records will be accessed to collect information about my medical history as part of this study.
- I give the primary research investigators permission to contact, inform and pass on relevant information, such as, the results of my initial assessment to my psychiatrist, case manager, rehabilitation team, clinical team, general practitioner or other relevant health professional involved in my health care.
- I freely choose to participate in this study and understand that I can withdraw at any time.
- I also understand that the research study is strictly confidential.
- I hereby agree to participate in this research study.

Name (Please Print):

Signature:..... **Date:**

Name of Person who conducted informed consent discussion (Please Print):

.....

Signature of Person who conducted informed consent discussion:

Signature:..... **Date:**

APPENDIX 21

Outpatient HELP Participant Cartoon Script²¹



²¹The author of the cartoon script pictures has given written approval to use these pictures as part of this PhD thesis.

2.

I HAD A PHYSICAL
HEALTH CHECKUP
WITH GP



I showed
him the
sense
card

had blood test

3.

I STUDIED THE SENSE
Anagninum?
at camp



4.

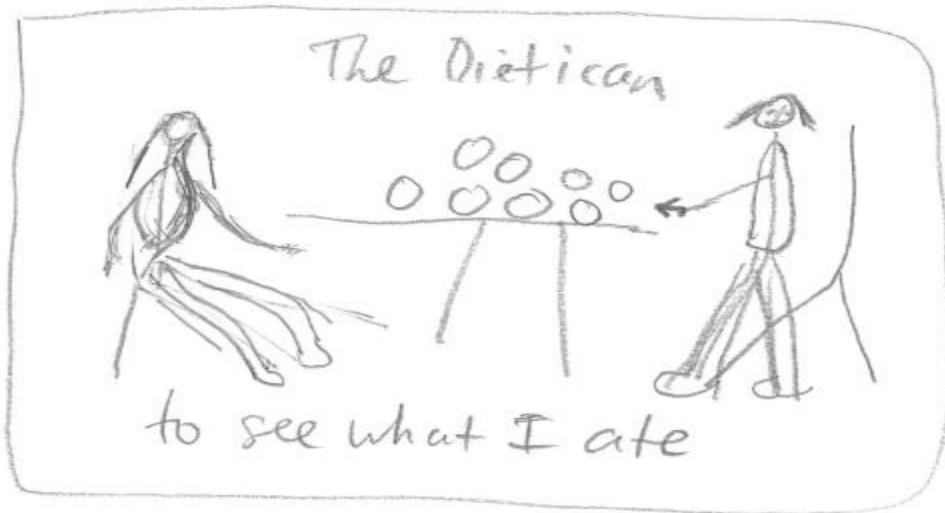
I SAW THE
CARDIOLOGIST

AT the CCChip
Clinic

howls your pressure?



5.



6.

I learned more about lifestyle
using the SENSE Anagninum?

SLEEP - I slept

EXERCISE - I walked + swam

NUTRITION - tried to eat well

SUBSTANCE ABUSE X - ~~didn't~~ didn't smoke

ETHANOL X - drank less



APPENDIX 22

WPC Participant Experience with Receiving GP Care

My own time with a usual GP doctor is if you are usually not in a private health fund you see a GP. While being on welfare Centrelink you will usually be treated as a basic number statistic if you present as a mental health illness challenge. Some GPs may want to check your blood pressure and other GPs may not think about checking your own blood pressure in a GP appointment. So the reality is that I may come across to a GP as another mental health challenge and get treated at a different level of care by the GP in the appointment. I say it is all **STIGMA**. Mental health is a problem to GP.

Thank you for your time.

WPC Participant