

# Northumbria Research Link

Citation: Brown, Sarah (2019) Care and support planning for people with long term conditions: a realist evaluation. Doctoral thesis, Northumbria University.

This version was downloaded from Northumbria Research Link:  
<https://nrl.northumbria.ac.uk/id/eprint/41880/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

# Northumbria Research Link

Citation: Brown, Sarah (2019) Care and support planning for people with long term conditions: a realist evaluation. Doctoral thesis, Northumbria University.

This version was downloaded from Northumbria Research Link:  
<http://nrl.northumbria.ac.uk/id/eprint/41880/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>



**Northumbria  
University**  
NEWCASTLE



**UniversityLibrary**

**Care and support planning for people  
with long term conditions: a realist  
evaluation**

Sarah Brown

PhD

2019

**Care and support planning for people  
with long term conditions: a realist  
evaluation**

Sarah Brown

A thesis submitted in partial fulfilment of  
the requirements of the University of  
Northumbria at Newcastle for the award of  
Doctor of Philosophy

Research undertaken in the Faculty of  
Health and Life Sciences

March 2019

## Abstract

**Background:** An increasing prevalence of long term conditions (LTCs) and multimorbidity is challenging the sustainability of the National Health Service. There is a major focus in policy to change the dynamics in healthcare systems so that people with LTCs are recognised as equal experts in the consultation. Care and support planning (CSP) has been described as a “better conversation” that supports this and promotes self-management, however, evidence suggests that CSP implementation and impacts are inconsistent. The purpose of this research is to close the gap in knowledge regarding the specific underlying mechanisms and related contexts needed for the effective operationalisation of CSP.

**Methods:** This study used realist evaluation, which contends that underpinning mechanisms of action are triggered under key conditions, leading to observable outcomes. Context-Mechanism-Outcome configurations provide explanatory statements, which are developed, refined and empirically tested. This was operationalised in three overlapping phases:

1) Programme theories were developed through a rapid realist review of 51 peer reviewed articles. 2) These were refined through a focus group with 5 CSP leaders. 3) They were tested through interviews with 9 CSP implementers and 11 people with LTCs.

**Data analysis:** Mind maps were used to decipher between contexts and mechanisms and formulate explanatory theories.

**Findings:** CSP is detailed and explained through 6 programme theories, articulated around preparation, quality conversations, goal setting, shared decision-making, conversation summaries, and communication. Together these explain how, for whom and in what circumstances CSP works best.

**Discussion:** This study challenges the idea of CSP being a healthcare practice taking place in statutory organisations only. It highlights how people with LTCs are an inherent part of the CSP team, who implement and normalise changes within their own contexts, and therefore inherently challenges the boundaries of what is considered “practice”, and where it is operationalised. In a context of ageing demographics, rising multimorbidity, and strained public finances, the potential relevance and application of this understanding is wide ranging.

## Contents

Abstract .....	iii
Contents .....	iv
List of tables and figures .....	viii
Glossary of abbreviations .....	ix
Acknowledgements .....	x
Declaration .....	xi
Introduction .....	xii
Background .....	xii
Publication .....	xiv
Flow of the thesis .....	xiv
Chapter 1: Long term conditions .....	1
Defining long term conditions .....	1
Terminology: person over patient .....	3
Impact and burden of long term conditions .....	4
Incidence and prevalence .....	10
Inequalities in health .....	11
Inequalities in access to healthcare .....	15
Long term condition management in general practice .....	18
The importance of self-management .....	25
Support for self-management .....	30
Chapter Summary .....	32
Chapter 2: Care and support planning .....	34
Care plans, care planning and care and support planning .....	34
Why is CSP important? .....	36
The philosophy underpinning CSP .....	37
The role of the healthcare professional .....	38
Care and support planning: a model for people with LTCs .....	39
Introducing the House of Care .....	40
Prepare – information gathering/sharing .....	43
Discuss – the CSP consultation .....	44
Document – summarising the discussion .....	45
Review – follow up appointment .....	45
Evaluation of CSP .....	46
Chapter Summary .....	51

Chapter 3: Methodology .....	53
Realism .....	53
Realism and causality .....	54
Realism and complexity .....	57
Social programmes .....	59
Unpacking black boxes .....	60
Mechanisms, context and outcomes .....	61
How are social programmes evaluated? .....	63
Why have I chosen to use realist evaluation? .....	64
Research questions .....	68
Study design: rapid realist review and realist evaluation .....	68
Operationalisation of the study design .....	69
Data collection .....	71
Data analysis .....	71
Methods .....	76
Phase 1: Developing the programme theories .....	76
Phase 2: Refining the programme theories .....	84
Phase 3: Testing the programme theories .....	89
Integration of the data across the three phases .....	93
Ethical approval .....	99
Chapter Summary .....	99
Chapter 4: Findings .....	101
<b>4.1 Preparation</b> .....	106
<b>4.1.1 Developing the programme theory</b> .....	106
<b>4.1.2 Refining the programme theory</b> .....	109
<b>4.1.3 Testing the programme theory</b> .....	114
4.1.4 Summary .....	129
<b>4.2 Quality conversations</b> .....	131
<b>4.2.1 Developing the programme theory</b> .....	131
<b>4.2.2 Refining the programme theory</b> .....	134
<b>4.2.3 Testing the programme theory</b> .....	139
4.2.4 Summary .....	148
<b>4.3 Goal Setting</b> .....	150
<b>4.3.1 Developing the programme theory</b> .....	150
<b>4.3.2 Refining the programme theory</b> .....	154

<b>4.3.3 Testing the programme theory</b> .....	157
4.3.4 Summary .....	166
4.4 Shared Decision Making .....	168
<b>4.4.1 Developing the programme theory</b> .....	169
<b>4.4.2 Refining the programme theory</b> .....	175
<b>4.4.3 Testing the programme theory</b> .....	177
4.4.4 Summary .....	188
<b>4.5 Conversation summary</b> .....	191
<b>4.5.1 Developing the programme theory</b> .....	192
<b>4.5.2 Refining the programme theory</b> .....	196
<b>4.5.3 Testing the programme theory</b> .....	200
4.5.4 Summary .....	209
<b>4.6 Communication</b> .....	212
<b>4.6.1 Developing the programme theory</b> .....	212
<b>4.6.2 Refining the programme theory</b> .....	217
<b>4.6.3 Testing the programme theory</b> .....	218
4.6.4 Summary .....	227
Chapter 5: Summary Chapter .....	230
An adapted person-led CSP model: the “ideal” .....	230
Barriers to person-led CSP .....	236
Chapter 6: Discussion .....	240
Personal contribution to study findings .....	240
Normalisation Process Theory .....	243
Coherence: sense-making work .....	246
Cognitive Participation: relational work .....	257
Collective action: operational work .....	263
Reflexive Monitoring: appraisal work .....	270
Reflection on terminology .....	275
Implications for practice .....	278
Multimorbidity: where does this fit? .....	278
Challenges .....	280
Limitations .....	283
Future research .....	284
Conclusion .....	287
Appendices .....	288

Appendix 1: Notes from Year of Care training event - June 2015 .....	288
Appendix 2: Observations of CSP at a North East medical centre on 6 <sup>th</sup> October 2015.....	291
Appendix 3: Example of the formulation of an IPT .....	294
Appendix 4: Search strategy .....	296
Appendix 5: Data extraction form.....	298
Appendix 6: Recruitment email and information sheet for leaders .....	300
Appendix 7: Focus group pre-reading.....	303
Appendix 8: Example of programme theory refinement process.....	305
Appendix 9: Refined programme theories after focus group .....	306
Appendix 10: Informed consent form .....	310
Appendix 11: Recruitment email and information sheet for implementers .....	311
Appendix 12: Recruitment poster .....	314
Appendix 13: Information sheet for people with LTCs.....	315
Appendix 14: Interview schedule for people with LTCs.....	317
Appendix 15: Ethical approval letter phase 2 .....	319
Appendix 16: Ethical approval letter phase 3 .....	320
Appendix 17: HRA approval letter .....	321
Appendix 18: NHS research passport approval letter .....	329
Appendix 19: RRR article information .....	331
References.....	340

## List of tables and figures

<i>Figure 1: Web of Care example (National Voices, 2011)</i> .....	20
<i>Figure 2: Interaction with healthcare professionals (Year of Care, 2016)</i> .....	26
<i>Figure 3: The House of Care (Year of Care, 2011)</i> .....	41
<i>Figure 4: CSP – a cyclical process (Coulter et al., 2013)</i> .....	48
<i>Figure 5: The operationalisation of the method</i> .....	75
<i>Figure 6: Email response showing the development of a potential IPT around communication</i> .....	94
<i>Figure 7: 18<sup>th</sup> July 2015. Email response showing the development of a potential IPT around psychological support</i> .....	95
<i>Figure 8: Extract from working document</i> .....	96
<i>Figure 9: Outcome of the focus group (changes to the programme theories)</i> .....	97
<i>Figure 10: Some of the coded data after the phase three interviews</i> .....	98
<i>Figure 11: The programme theory trail</i> .....	101
<i>Figure 12: Flow chart of the screening process</i> .....	102
<i>Figure 13: Depiction showing how the programme theories may be linked</i> .....	104
<i>Figure 14: Preparation as a component of CSP</i> .....	106
<i>Figure 15: Quality conversations as a component of CSP</i> .....	131
<i>Figure 16: Goal setting as a component of care and support planning</i> .....	150
<i>Figure 17: Shared decision making as a component of care and support planning</i>	168
<i>Figure 18: A concept map of shared decision making (Lhussier et al., 2013)</i> .....	172
<i>Figure 19: Conversation summary as a component of care and support planning</i> .	191
<i>Figure 20: Communication as a component of care and support planning</i> .....	212
<i>Figure 21: Division of tasks and responsibilities throughout the CSP process</i> .....	235
<i>Table 1: Components of coherence and related questions considered</i> .....	247
<i>Table 2: Components of cognitive participation and related questions considered</i>	257
<i>Table 3: Components of collective action and related questions considered</i> .....	264
<i>Table 4: Components of reflexive monitoring and related questions considered</i> ...	271

## Glossary of abbreviations

CSP: Care and support planning

IPT: Initial programme theory

LTC: Long term condition

RRR: Rapid realist review

## Acknowledgements

Firstly, I would like to thank Northumbria University for giving me the opportunity and funding to embark on this journey and enhance my learning.

I extend my sincere thanks to the people who participated in this research. Your enthusiasm in sharing your personal and practice experiences and your dedication to improvement in the realm of long term condition management is admirable. I would also like to thank the Year of Care Partnerships for your continuous support, information and learning opportunities.

I owe my deepest gratitude to my supervisors, Dr Monique Lhussier, Dr Sonia Dalkin and Dr Simon Eaton. This journey has been challenging, exciting, and at times overwhelmingly difficult. Your positivity and unrelenting support as a supervisory team kept me going even when the task ahead seemed insurmountable. Monique and Sonia, your knowledge of realist methodology and your dedication to sharing it is inspiring. Simon, your support in my integration into practice settings has been invaluable. I am honoured to have had the pleasure of working with such wonderful people.

Finally, I extend my everlasting appreciation to my family. Thank you Mum and Dad for always believing in me. Thank you Jamie, my wonderful husband, for supporting me emotionally (and financially) throughout this journey. Thank you Lewis, my darling son. You came into this world at exactly the right time and you taught me resilience. You are my rock; I love you "to the moon and back".

## Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by Northumbria University Faculty of Health and Life Sciences Research Ethics Committee on 15/05/2015 and 12/04/2017. The NHS local ethics committee approved the study and HRA approval was granted on 23/08/2017.

**I declare that the Word Count of this Thesis is 74,837 words**

Name: Sarah Brown

Signature:

Date: 29/07/2019

# Introduction

## Background

When I began this journey into the depths of care and support planning (CSP), my initial feeling was that surely, this was the standard of care that anybody with a long term condition (LTC) should be experiencing. My background was in social sciences (BSc Psychology and MSc Social Research Methods) and following the completion of my master's degree, I spent two years working in several roles within mental health services. This included providing nursing assistance on an acute adult inpatient ward, helping to deliver psychological interventions for elderly people with dementia, auditing health promotion interventions in community teams, and working as an Assistant Psychologist in children and adolescent mental health services. I quickly gained insight into the roles and interactions between different services within the NHS, and although CSP was not being implemented across the Trust, elements of it were being incorporated into each individual service.

Although I had gained an awareness of different services within secondary care locally, the transition to research within primary care was enlightening as I had had no formal training or expertise in the workings of general practice, or in CSP. I found this to be an advantage as I had no biases and I could begin to unpick the layers of complexity within CSP, from different levels of the healthcare system. It was not until I experienced my own deterioration of health, which led to a major surgical procedure during the second year of my PhD programme, that I truly began to understand healthcare needs through the eyes of a person with LTCs. Although I received the traditional standard care, my research on CSP led me to have expectations throughout

all of my primary care appointments and consultations with specialists. In my third year of studying, I gave birth to a baby boy, who also has a rare LTC. In my search for his diagnosis and treatment, we hit a number of barriers, which ultimately had a negative impact on him, and also on me as I was desperately and unsuccessfully seeking answers from a support system that did not exist. I will discuss this further in Chapter 6, p. 241 and will explore how it relates to my findings. My research has shown that CSP enables people to trust and to feel valued, more informed, and more supported to engage in every aspect of their care and to become experts in their own condition(s). I believe, as a person with a LTC, as a mother, and as a researcher, that CSP is a universal change that could transform the lives of many.

With a background in social sciences, I have always found myself asking the question “why?” Why do some interventions work, why do some fail, and why do some work for some people and not others? Why do some people enact certain behaviours and others do not? Those questions drew me to realist methodology, along with its recognition of the unique human mind and individual differences. I was delighted to see that a combination of social, medical and environmental factors can be embraced in a methodology that seeks explanation of data. In summary, when I began this PhD journey, I faced two new learning challenges: CSP and realist methodology. Emerging myself into both areas has been an enjoyable experience and I look forward to continuing in this field of research in the future.

## Publication

In 2018, my rapid realist review (RRR) paper, which was co-authored by members of my supervision team (Brown et al., 2018), was published in the journal *Qualitative Health Research*. It describes the empirical testing of the specific mechanisms through which CSP may lead to outcomes such as improvement in health. The RRR forms a critical and comprehensive part of this PhD research, as it illustrates the development of realist programme theories, which were then refined and tested in the later phases of this realist evaluation.

## Flow of the thesis

The thesis is divided into six chapters. Chapters one and two introduce and use existing literature to contextualise the research in terms of CSP and LTCs. Chapter three introduces realism, RRR and realist evaluation. It also details how the findings of the research will be presented, describes the methods used for data collection, and provides the research questions and initial programme theories (IPTs) that were developed using various sources. Chapter four provides the findings from the three phases of the study. At each phase the programme theories become more refined. Each of the sub-sections outline the programme theories, followed by supporting or refuting data, and developed/refined/tested programme theories are then presented. A summary is provided at the end of each sub-section, and an overall summary is provided in chapter five. Chapter six presents a comprehensive discussion of the study findings, challenges faced during the research process, limitations of the study and implications for future research.

## Chapter 1: Long term conditions

This chapter examines some of the key issues that many people with LTCs face and it explores the implications these issues have on the individual, their carers, and on the healthcare system. A description of the care and management for people with LTCs over the past decade is provided, with implications for practice. Key health policies and their underlying philosophies will be explored and practicalities of using these philosophies in LTC care will be addressed. The current role of primary care practitioners and of the person with LTCs will be described, as well as the effectiveness of particular models of care that have been implemented in the UK and internationally.

### Defining long term conditions

Disease and illness can be understood as “modes of unhealth” (Marinker, 1975). Although the terms disease and illness are used interchangeably by healthcare professionals, there is a distinguishable difference between them. Disease has been characterised a pathological process which is most often physical, such as tonsillitis, and sometimes undetermined in origin, such as dementia (Boyd, 2000). There is an objectivity about disease which healthcare professionals are able to see, touch, measure, or smell. Conversely, illness is a feeling or an experience of unhealth which is entirely individual (Lee, 2018, Carel, 2019). Illness often accompanies disease; however, it sometimes exists where no disease can be found (Marinker, 1975). Two people with the same disease can have very different illness experiences. Although it is important to recognise the pathological process of a chronic disease, understanding

the illness experience is essential to providing holistic care (Larsen, 2017, Carel, 2019).

When an individual develops an acute disease, there is typically a sudden onset with signs and symptoms which last for a relatively short time and it ends with either recovery or death (Liang et al., 2016, Karvellas et al., 2016, Prescott and Angus, 2018). A chronic disease, on the other hand, can appear suddenly or over time (Bernell and Howard, 2016). It can present as flare-ups or exacerbations, or remain in remission for long periods. A chronic disease often continues indefinitely and becomes part of a person's identity (Larsen, 2017, Oris et al., 2018). There is a degree of variation in classifying the term chronic disease within the medical, public health, academic and policy fields (Bernell and Howard, 2016). The Centres for Disease Control identify the following as chronic diseases: heart disease, stroke, cancer, type 2 diabetes, obesity, and arthritis (CDC., 2016). The Centers for Medicare and Medicaid Services propose a more extensive list of 19 chronic conditions that includes Alzheimer's disease, depression, and HIV (Centers for Medicare and Medicaid Services, 2015). This ambiguity will be considered throughout this study and specific chronic diseases will be referred to where possible, to ensure clarity is maintained.

The "chronic" of chronic disease refers to all impairments or deviations from normal that include one or more of the following: permanency; residual disability; non-pathologic alteration; required rehabilitation; or a long period of supervision, observation and care (Mayo, 1956). Other sources have added a time dimension to these characteristics: the U.S. National Centre for Health Statistics defines chronic

conditions as those lasting three months or more (MedicineNet., 2016) whilst the National Centre for Chronic Disease Prevention and Health Promotion state that chronic diseases last one year or more and require ongoing medical attention (CDC., 2018). The World Health Organisation do not specify a particular time dimension but state that chronic diseases are “of long duration” (WHO., 2016). Despite these differences, most sources agree that chronic diseases can be controlled, but not cured by, medical interventions, meaning the life of a person with a chronic condition is forever altered (Department of Health, 2004). LTC is therefore a more suitable term and is now increasingly favoured as an alternative to “chronic illness” and “chronic disease”. The term LTC will be used throughout this thesis, unless research participants state otherwise.

#### Terminology: person over patient

Semantics are vitally important in the literature around the care and management of LTCs, particularly when considering the people involved. Whilst we generally perceive ourselves as patients when we access healthcare, we are unlikely to define ourselves in this way, because the word “patient” has specific negative connotations (Neuberger, 1999, Scott, 2010, Brinkmann, 2018). When we think of “patients” rather than “people”, there is a mental shift in the balance of power from equal people, to “helper” (with knowledge, skills and experience) and “person needing help” (seeking knowledge, skills and experience) (Barnett, 2018). Barnett (2018) suggests that when healthcare professionals talk about “patients”, this unconsciously encourages a more paternalistic attitude to the person being treated, thus reinforcing an unequal balance of power. It is thus best suited for use within a paternalistic model of healthcare relationships

focusing on the acute recognition of disease and its management (Shevell, 2009, Brinkmann, 2018).

When searching for literature on the care and management of LTCs, I noted that there is a shift in preference towards the term “person-centred care” rather than “patient-centred care” in relation to health. Person-centred care is now used by the World Health Organisation (World Health Organisation, 2007, World Health Organisation, 2017) and is internationally accepted. It focuses on the individual receiving healthcare (the patient) yet refers to the “whole person” who is living with their LTC, in the context of their life (The Health Foundation, 2016). Although some of the literature reviewed in this research adopts the term “patient” when referring to a person with LTCs in a healthcare setting, this research focuses on the experiences, needs, values and preferences of people in relation to health and healthcare. Thus, I will refer to “people” rather than “patients” throughout this thesis, unless research participants or quotes from the literature state otherwise.

### Impact and burden of long term conditions

Supporting people with LTCs is a major challenge to the sustainability of health services globally (UN Secretary General, 2011). In the UK, LTCs account for 70% of inpatient bed days (Department of Health, 2012a), 78% of General Practice (GP) appointments (Salisbury et al., 2011), and around 70% of health and social care spending (Department of Health and Social Care, 2015a). In addition to putting strain on health and social care services, LTCs can have a negative physical, psychological and psychosocial impact on individuals and their families. This goes beyond initial

diagnosis and stays with the individual and their family as the condition progresses (Nicol, 2011). Although physical effects tend to be condition specific, common symptoms include pain, disability, and change in the condition itself that can result in hospitalisation or more intensive care requirements, in addition to the potential development of both short and long term complications (Carrier, 2009).

In a review of the psychological consequences of stroke, Thompson and Ryan (2008) proposed several key issues that impact on both individuals and their families. These include: dependency; loss of work; fatigue; decline in sexual activity; depressive mood; loneliness; cognitive difficulties and lack of autonomy. COPD has been linked with depression and anxiety (Halpin, 2008) as many people with this condition become self-conscious about coughing, do not feel in control of their health and are unable to participate in activities they had previously enjoyed (Carrier, 2009). In addition, individuals living with a LTC such as diabetes, COPD or cardiovascular disease are two to three times more likely to develop depression than people who are considered in good physical health (Haddad, 2010). Furthermore, depression is thought to affect about half of all people with Parkinson's disease (National Collaborating Centre for Chronic Conditions, 2006) and is three times more likely in people who have rheumatoid arthritis (Sheehy et al., 2006). There is also evidence to suggest that depression can increase the likelihood of a person developing a LTC such as heart disease or type 2 diabetes (Mezuk et al., 2008). Whether it is a cause or a consequence of a physical condition, depression can exacerbate the perceived severity of symptoms of a co-morbidity, thus resulting in an increased utilisation of healthcare services (Lyons, 2006). For people living with a LTC, identifying depression can be challenging as many of the symptoms (such as fatigue, insomnia and reduced

appetite) may also be related to the LTC and/or its treatment (Nicol, 2011). Moreover, discussing mental health issues can feel uncomfortable for both people with LTCs and the healthcare professionals involved in their care. Developing effective therapeutic relationships that are open and non-judgemental can increase trust and thus encourage people with LTCs to communicate their hopes and fears, which in turn may assist healthcare professionals in recognising changes in a person's mental health (Nicol, 2011).

The impact of multimorbidity can be profound and multi-faceted. A report that was produced for the Richmond Group of Charities, a coalition of 14 of the leading health and social care organisations in the voluntary sector, highlighted that people with multimorbidity tend to have poorer quality of life and poorer clinical outcomes. In addition, they are more likely to have longer hospital stays and more post-operative complications, and are costlier to healthcare services (Aiden, 2018). Some studies have found that people with multimorbidity may experience difficulties in interacting with the healthcare system due to disagreements with healthcare professionals regarding what they perceive to be priority (Kenning et al., 2015, Aiden, 2018, Neuner-Jehle et al., 2017). Other people with multimorbidity have reported that consultation times are not always sufficient to allow their multiple LTCs to be discussed (Aiden, 2018).

Managing multimorbidity with the existing NHS payment structures, measurement systems and incentives is a major challenge for healthcare professionals in primary care services. Although new recommendations have emerged from the NICE Clinical

Knowledge Summaries (2018) on multimorbidity, which are based on the guideline, *Multimorbidity: clinical assessment and management* (NICE, 2016), current healthcare interventions have been developed based on previous clinical guidelines, which generally focus on single LTCs. This is partly because NICE guidelines are designed to be based on evidence from randomised controlled trials, and it is impossible to have evidence for every possible combination of conditions (Guthrie et al., 2012). There are growing concerns that by financially rewarding General Practices for carrying out specific activities in relation to individual conditions, such as monitoring HBA1c in people with diabetes, healthcare professionals are less likely to consider the whole person, and how non-medical interventions, such as social prescribing, might improve long term outcomes (Gillam and Steel, 2013).

For people with multimorbidity seeking help from healthcare services, utilising all clinical recommendations for one individual could be risky and would likely result in polypharmacy (i.e. the concurrent use of multiple medications) (Aiden, 2018). Hypothetically, a 78-year-old woman with previous myocardial infarction, type 2 diabetes, osteoarthritis, chronic obstructive pulmonary disease, and depression would potentially fall under the recommendation of five UK clinical guidelines (Hughes et al., 2013). If each of the recommended guidelines were followed, she would be prescribed a minimum of 11 drugs, with potentially up to 10 others recommended depending on her symptoms and progression of disease; she would also be advised to engage in at least nine lifestyle modifications. In addition to any unplanned appointments, she would be expected to attend between eight and ten routine primary care appointments annually for her physical conditions and between eight and thirty psychosocial intervention appointments for depression. She would also be advised to attend

multiple appointments for smoking cessation support and pulmonary rehabilitation (Hughes et al., 2013). This would have a huge impact on the individual, her family, and on her healthcare providers, and it would not be sustainable long term.

The prevalence of polypharmacy is rising in relation to the increasing prevalence of multimorbidity. A longitudinal study in Scotland found that the proportion of adults who were prescribed at least five repeat medications doubled to 20.8% between 1995 and 2010, and the proportion of adults who were prescribed more than ten medications tripled to 5.8%. Receipt of more than ten drugs was strongly associated with increasing age, level of deprivation, and was more common in care home residents (Guthrie et al., 2015). Furthermore, polypharmacy is associated with numerous negative outcomes including adverse drug reactions, medication errors, reduced adherence, increased cost and increased morbidity and mortality (Guthrie et al., 2011, Wallace and Paauw, 2015, Hanlon et al., 2018). Adverse drug reactions are a significant burden to the healthcare system and it is estimated that they may be the cause of over 10% of emergency hospital admissions in older people (Kongkaew et al., 2008). Although polypharmacy is often an appropriate treatment option for people with multimorbidity (Masnoon et al., 2017), adverse drug reactions sometimes result in a prescribing cascade, where additional medication is used to treat or prevent the side effects of another (Nguyen and Spinelli, 2016). In these complex situations, the use of polypharmacy may reflect suboptimal prescribing practices where the risks of treatment outweigh the benefits (Cahir et al., 2014).

People with LTCs, in particular multimorbidity, must therefore deal with not only the burden of illness but also the burden of treatment. Treatment burden is defined as the workload imposed by healthcare systems on people and the impact this has on their quality of life (Eton et al., 2012). There is growing interest in this emerging concept. Much of the relevant literature focuses on biological side effects of treatment, such as weight gain and hypoglycaemia (Wang et al., 2017, Eng et al., 2014). Some studies have focused on the workload for people with single LTCs, such as diabetes (Russell et al., 2005) whilst others have focused mainly on the time spent by people with LTCs participating in health-related activities, i.e. attending GP appointments, rather than the impact on different aspects of their lives (Jowsey et al., 2013, Buffel du Vaure et al., 2016). Gallacher et al. (2011) highlighted the steps people with LTCs take to embed treatments into their daily lives. They proposed that treatment burden includes the work people do to understand treatments, interact with others to organise care, attend appointments, take medications, alter lifestyle, and appraise treatments. People with LTCs have reported several factors which can increase treatment burden, including too many medications and appointments, barriers to accessing services, fragmented and poorly organised care, lack of continuity, and inadequate communication between healthcare professionals (Gallacher et al., 2011).

A study by Demain et al. (2015) indicated that treatments often had much worse psychological and biographical consequences than initially considered in this field of research. For instance, they found that treatments had effects on identity, interaction with others, and in many cases were associated with anxiety, fear, anger, and frustration. In some cases, these symptoms were severe and debilitating and impacted on independence, relationships and ultimately, adherence to treatment regimens.

Research that focuses on the perspectives of people with LTCs is thus beginning to uncover the range of complex factors that impact their daily lives.

### Incidence and prevalence

In 1948 when the National Health Service was founded, life expectancy was 66 years for men and 71 years for women (Department of Health, 2000). The Office for National Statistics now place life expectancy in the UK at 79 years for men and 82 years for women (Office for National Statistics, 2018b). This ageing population is a result of public health improvements over the past fifty years (Lunenfield et al., 2013), including the development of preventative measures, i.e. vaccinations, meaning people are less susceptible to serious infections that would have previously been fatal (Andre et al., 2008, Greenwood, 2014). This development has resulted in a decrease in mortality, however, it has indirectly contributed to an increase in the incidence and prevalence of LTCs, including type 2 diabetes, coronary heart disease and chronic liver disease (Office for National Statistics, 2018a, Department of Health, 2008). It is estimated that there are more than fifteen million people living with a LTC in the UK (Department of Health and Social Care, 2015a). Multimorbidity, commonly defined as the presence of two or more LTCs, is also increasingly common (Barnett et al., 2012, Aiden, 2018). Estimates for the percentage of people living with multimorbidity in England vary from 15% to 30%, according to different sources (Aiden, 2018). With the population of people aged 65 years and over projected to grow by around fifty percent between 2016 and 2039 (Office for National Statistics, 2018a), these figures are expected to rise (Department of Health, 2012a).

## Inequalities in health

There are many individual, lifestyle and environmental factors that can determine the health of a person at present and in the future (Bircher and Kuruvilla, 2014). For example, smoking is a key driver of poor health and premature mortality (Connolly et al., 2017). Research shows that people who smoke are more likely to suffer from a LTC. According to the Office for National Statistics, 44% of people who smoke heavily reported living with a LTC, compared to 32% of people who have never smoked (Office for National Statistics, 2015). Furthermore, smoking also exacerbates existing LTCs. To put this into perspective, COPD causes over 24,000 deaths in England every year (NHS England, 2014b) and smoking accounts for as many as 90% of COPD related deaths (Public Health England, 2015a). People suffering from asthma who smoke experience higher rates of hospitalisation, worse symptoms and more rapid decline in lung function than those with asthma who do not smoke (Action on Smoking and Health, 2015). In addition, exposure to second-hand smoke increases the risk of childhood asthma by up to 85% (Burke et al., 2012). Furthermore, smoking significantly increases the risk of heart disease and stroke (Shah and Cole, 2010) and increases the risk of complications and premature death in people with diabetes (Sliwinska-Mosson and Milnerowicz, 2017).

There is currently a particular focus on the health inequalities of different ethnic groups in England. In 2017, Public Health England released a report that described considerable inequality in smoking prevalence in ethnic groups. Moreover, this inequality was even more prominent when groups were broken down by gender (Connolly et al., 2017). The 'smoking double standard' (Triandafilidis et al., 2016, p. 1450) relates to the stigma of smoking in relation to gender identity, as well as the

intersection between gender and culture. In most cultures, men's smoking practices are seen as more acceptable, or desirable, and women's smoking as less acceptable or desirable. Triandafilidis et al. (2016) reported that women therefore face compounding stigma due to their gender and cultural identities, which has implications for their subjectivities and practices. For example, they might hide their smoking habits from family, friends, and healthcare providers, or in this case, perhaps not place themselves in the smoking category in public health surveys, thus reinforcing the inequality. Such people may therefore not receive appropriate healthcare services, such as Nicotine Replacement Therapy. This is particularly concerning given the link between smoking and the development or exacerbation of LTCs.

Health status is also largely determined by a person's socioeconomic environment. Those in lower socioeconomic groups are significantly more likely to have LTCs and higher rates of smoking, which has significant implications for their health and wellbeing (Action on Smoking and Health, 2015). Higher education levels, income and social status are linked to better health, with those in the higher social classes (bank managers, doctors) living on average eight years more than those in lower social classes (cleaners, manual labourers) (Office for National Statistics, 2017). Income, or a lack of, can determine many lifestyle factors, including housing and dietary choices, which can influence health status. For example, cold and damp living conditions are strongly associated with respiratory conditions and thousands of people in the UK die every year from "excess winter deaths" as a result of not being able to afford to heat their homes (Carrier, 2009). Currently, in England, people living in the least deprived areas of the country live around twenty years longer in good health than people in the most deprived areas (Connolly et al., 2017, Churchill, 2018). Furthermore, the

prevalence of multimorbidity is much higher in areas of low socioeconomic status (Barnett et al., 2012, Arokiasamy et al., 2015).

Adding to these potential determinants of health status is health literacy (Osborne, 2014), which describes “the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health” (Dodson et al., 2015). There is consistent evidence that people with low health literacy have poorer health status, higher rates of hospital admission, are less likely to adhere to prescribed treatments and self-care plans, experience more drug and treatment errors, and make less use of preventive services (Coulter, 2007, The Marmot Review Team, 2010, World Health Organisation, 2013). Addressing health literacy is thus increasingly seen as integral to reducing health inequalities and improving health outcomes, especially for those with LTCs (Batterham, 2014).

In England, 42% of adults are unable to understand and make use of everyday health information. This figure rises to 61% when numeracy skills are also required for comprehension (Public Health England, 2015b). People with LTCs (amongst several other population groups) are more likely to have limited health literacy than the general public (World Health Organisation, 2013) and are thus more closely linked to poor diet, smoking, lack of physical activity, reduced use of preventative services, and an increased risk of morbidity and premature death (Berkman et al., 2011). In addition, people with low health literacy are less likely to adhere to medical instructions and treatment plans; make more use of accident and emergency services; have less

effective communication with healthcare professionals and are less likely to engage in active discussions about their treatment options (Berkman et al., 2011). For people with LTCs, particularly those who are at risk of life-threatening exacerbations, for example, those who suffer from asthma or COPD, this could be detrimental. Improving health literacy is thus crucial to empowering people to effectively manage their LTCs, thereby reducing health inequalities (World Health Organisation, 2013).

Health and social care systems have the complex task of delivering services that target these inequalities. However, it is widely recognised that the relationship between healthcare need and access is inversely proportional (Willis and Dalrymple, 2015). For example, a low-paid factory operative may not be allocated paid leave for GP appointments and thus may need to take time off work. However, the reality is that they probably cannot afford to lose pay. Moreover, the GP surgery may be a bus ride away, which will cost additional time and money. In contrast, the high-earning executive may be able to schedule meetings around GP appointments and drive there in a company vehicle, thereby incurring minimal costs. In this example, it is easy to see how encounters with healthcare professionals may be reduced to only those that people deem absolutely necessary, i.e. emergency situations, thus, inequalities in access to healthcare contribute to the high incidence of emergency hospital admissions for people with LTCs. Indeed, what policy makers consider to be accessible healthcare may not be accessible to all people in all situations. This notion is developed further in the following pages.

## Inequalities in access to healthcare

In 1971, Julian Tudor Hart, a visionary general practitioner in South Wales, described the inverse care law, which he defined: “The availability of good medical care tends to vary inversely with the need for the population served” (Tudor Hart, 1971). In other words, those who require services most have least access, and vice versa. This can be seen in the example on page 14. In order to tackle health inequalities, more attention must be given to those who are at greatest risk of poor health (Connolly et al., 2017). Policy makers have developed many strategies to target this population, including increasing numbers of GPs in disadvantaged communities, removing financial disincentives to longer consultations, and strengthening health promotion and community health services in disadvantaged areas (The Marmot Review Team, 2010). Initiatives such as Sure Start, Health Action Zone and the Healthy Places Programme have been implemented throughout the UK as part of this provision. Additionally, Public Health England’s national marketing campaigns, such as the successful “Stoptober” mass quit month and the “One You” campaign are specifically focused on the socio-economic groups most likely to have the poorest health (Connolly et al., 2017).

Ensuring every individual has equal access to health and social care services is a key priority for the NHS. One of the seven core requirements for implementing improved access, as set out in the NHS Operational Planning and Contracting Guidance 2017-19 (NHS England and NHS Improvement, 2016), is to address issues of inequality in people’s experience of accessing general practice, as identified by local research. Ford et al. (2016) developed a seven-stage pathway to illustrate these issues and explore the capacity of local GP services to respond accordingly. NHS England and

NHS Improvement (2016) used the pathway as a practical resource to support commissioners and providers of general practice services to address inequalities in access to healthcare. They suggested that people who struggle to recognise health issues, for reasons such as low health literacy or social isolation, may be helped by GP advertising services and health campaigns which educate people about the symptoms of ill health and when to seek help. For those who fail to access healthcare services because they are unsure whether they need to seek help, feel like a burden, or are uncertain of their entitlements (for example, residential status), help and advice is available from pharmacists, care navigators, NHS 111, NHS Choices, GP practice websites, and other online services.

When people with LTCs face barriers to seeking help (for example, not knowing where to access care, lack of internet access, not being registered with a GP, confusion about how the NHS works), active signposting and care navigators can help streamline the process of getting the right care from the right service. Improved training for receptionists can also help people to access the right type of appointment, and offering appointments at different times and locations can help those who cannot take time off work or have care duties. Transport services have been put in place nationally to help those who rely on public transport and struggle to get to their appointments. Similarly, telephone and video/online consultations mean that travelling to appointments is not always necessary, particularly for people with mobility issues or low income.

Inequalities in health and inequalities in access to healthcare are key concerns which animated the vision that Nye Bevan, founder of the NHS, had. His core founding

principles were that people should receive: comprehensive treatment within available resources; universal access based on need; and services delivered free at the point of delivery. However, inverse care law is still evident from when it was first described, and ingrained health inequalities must be addressed for an NHS based on Bevan's principles to be sustained. McLean et al. (2015) explored relationships between multimorbidity, general practice funding, and workload by deprivation across 956 General Practices in Scotland. They found no evidence that funding matches clinical need. Similarly, Mercer et al. (2018) found that in deprived areas, the greater need of people with multimorbidity is not reflected in the longer consultation length, higher General Practitioner (GP) person-centeredness, and higher perceived GP empathy found in affluent areas. Multimorbidity is a relatively new research interest, and the needs of people with multimorbidity are only just beginning to be explored (Aiden, 2018), which may account for these findings.

Graham Watt, a professor of general practice at the University of Glasgow, suggests that inverse care law is not a pre-existing law ingrained in society, but rather a "man-made policy" because since the beginning of the NHS, access to the frontline has been rationed in the same way milk, butter and eggs were in World War 2 – everybody gets the same (Watt, 2013). Watt adds that although strategies have been put in place to address health inequalities, they are not distributed according to need, thus, tackling inverse care law in practice is "important unfinished business" (Brindley, 2011). Action is required to address the mismatch of need and service provision for people with LTCs if health inequalities are to be narrowed rather than widened by primary care (Mercer et al., 2018). Barnett et al. (2012) proposed that in order to achieve this, healthcare professionals should be generalist in their approach to LTC care, and they

should provide personalised, person-centred, comprehensive continuity of care, especially in socioeconomically deprived areas.

### Long term condition management in general practice

LTCs gained prominence in public health policy in 2006, when Lord Darzi published the Next Stage Review. This report focused on changing public expectations of healthcare services and developing a vision for the next decade that involved making primary and secondary care more convenient, more integrated, and easier to access. Lord Darzi wanted to build a service that is based around the person being in control and having choice and local accountability. He recommended one hundred new general practices in the 25% of primary care trusts with the greatest need, and one hundred and fifty new health centres throughout the country that would provide a range of services, such as minor surgery, from 8am-8pm, seven days per week. In 2008, the final report of the Next Stage Review was published, entitled High Quality Care for All (Department of Health, 2008). Lord Darzi and the Department of Health considered the best available clinical evidence, worked in partnership with thousands of people, listened to the needs and aspirations of the public and set out comprehensive visions for the future based on prevention, improved quality and innovation. The LTC group involved in their review proposed the need for true partnerships between people and professionals, better information and care plans (Department of Health, 2008).

Healthcare policy began to reflect this and in 2009, the first NHS Constitution in England proposed a framework based on policy statements, which informed people what they could expect the NHS to deliver. It stated that “NHS services must reflect

the needs and preferences of patients, their families and their carers. Patients, with their families and carers where appropriate, will be involved in and consulted on all decisions about their care and treatment” (NHS England, 2009, p. 4). The framework has been further strengthened in subsequent versions (Department of Health and Social Care, 2015b). Since 2010, the Francis inquiries into failings in care at Mid Staffordshire NHS Foundation Trust between 2005 and 2009 drove person-centred care into the spotlight, focusing on compassion, dignity and respect (Francis, 2013) and in 2013, the Berwick Advisory Group argued for “greater involvement of patients and their carers at every level of the health service in order to deliver safe, meaningful and appropriate health care” (Berwick, 2013).

Giving a voice to people with LTCs in health research is now recognised as essential to making sure their interests and needs are heard and reflected in clinical practice. National Voices is a coalition of health and social care charities which was formed in the UK in 2008. It has a prominent role in representing and strengthening the voices of people with LTCs. In 2011, National Voices published *Webs of Care: what does care look like from the individual’s perspective?* (National Voices, 2011). These webs represented the illustrative perspectives of people with LTCs, carers and charities on their interactions with health and social care services. Figure 1 demonstrates the complexity of one couple’s web.

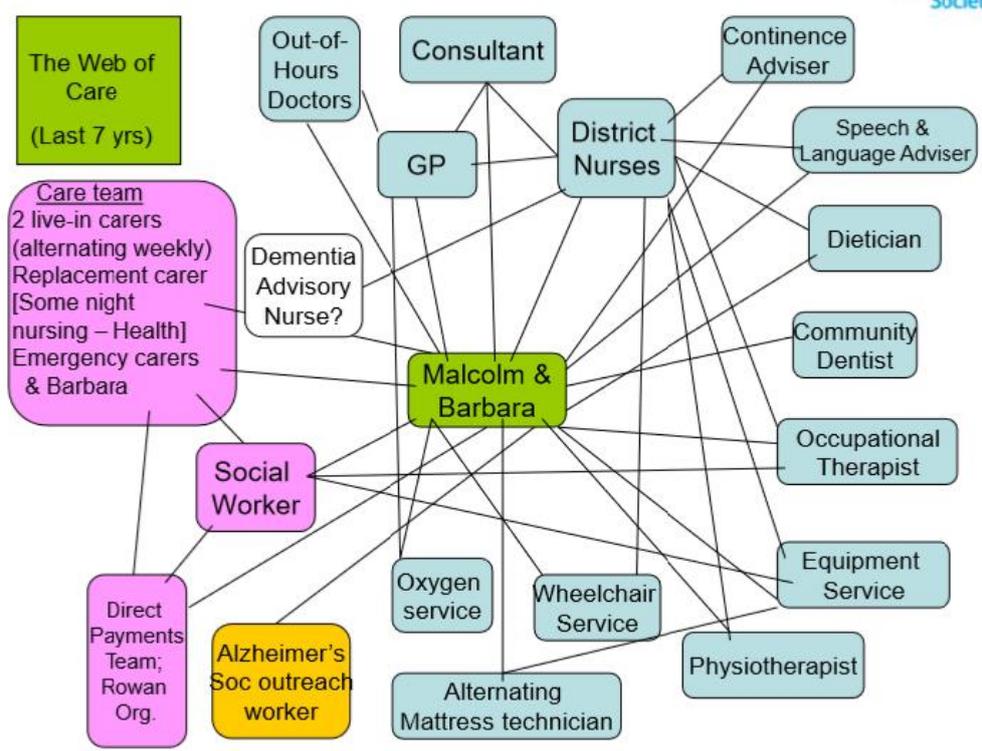


Figure 1: Web of Care example (National Voices, 2011)

National Voices invited its patient advocacy groups to tell them what they wanted with regards to their LTC care. They devised a series of “I statements” which challenged the complexity of the model described above (Figure 1). Generally, what people described was personalised, coordinated care, led by them and supported by professionals (National Voices, 2013).

Person-centred care provides a coordinated system of care that is tailored to the needs of the individual (The Health Foundation, 2016). It can facilitate an understanding of the person’s health and wellbeing, enable them to make choices and offer solutions beyond medical interventions (The Health Foundation, 2014). In

person-centred care, health and social care professionals work collaboratively with people who use services and support them to develop the knowledge, skills and confidence they need to effectively manage and make informed decisions about their own health. Additionally, implementing these principles ensures that people are always treated with dignity, compassion and respect (The Health Foundation, 2016).

Embedding person-centred care into practice requires a fundamental shift in service delivery, the roles of both healthcare professionals and people with LTCs, and the relationships between them. It is an evolving area in healthcare, and how it looks depends on the needs, circumstances and preferences of the individual receiving care. Thus, the term “person-centred care” is an umbrella term used to refer to whichever combination of interventions is adopted for an individual, with these underpinning principles: care is personalised, coordinated, and enabling, and the person is treated with dignity, compassion and respect (National Voices, 2017).

Shared decision making describes “involving [people] fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone” (Department of Health, 2010, p. 13). It has been exalted as the “pinnacle of patient-centred care” (Barry and Edgman-Levitan, 2012). In 2011, The King’s Fund published *Making shared decision-making a reality: no decision about me, without me* (Coulter, 2011), which outlined the skills and resources healthcare professionals needed to implement shared decision making in practice. Since then, guidelines have continued to emphasise the need for healthcare professionals to take into consideration peoples’ needs, wishes and preferences and to involve them in decisions about their care at

the level they wish, through shared decision making. It is widely recognised that one person's preferences may not be the same as another, and similarly, a person's healthcare needs may change from one day to the next (The Health Foundation, 2016). In 2011, The Health Foundation, in partnership with the Royal College of General Practitioners, commissioned a report that encourages doctors to be generalists rather than specialists and to treat the whole person rather than individual conditions, in order to meet their changing health needs (The Health Foundation, 2011).

In 2013, The Royal Pharmaceutical Society published the *Now or never* report (Smith et al., 2013), which highlights how pharmacists can support people with LTCs, and the *Medicines optimisation guidance* (Picton and Wright, 2013) lists "patient experience" as the first of four key principles of medicines optimisation. Medicines optimisation (formerly termed "medicines management") is a key component of LTC management that is considered a person-centred approach to safe and effective medicines use, which applies to people who may or may not take their medicines effectively. An estimated 30-50% of medicines prescribed for LTCs are not taken as intended (NICE, 2009). As life expectancy and the number of people living with multimorbidity increase, polypharmacy is becoming a critical factor to consider in the care and management of people with LTCs. Optimising a person's medicines is vital to ensuring they are taking their medicine as intended. In 2013, the King's Fund published *Polypharmacy and medicines optimisation – making it safe and sound* (Duerden et al., 2013). This paper outlined the view that polypharmacy may in fact have positive or negative potential. For instance, "prescribing for an individual for complex conditions or for multiple conditions in circumstances where medicines use has been optimised and where the

medicines are prescribed according to best evidence” (Duerden et al., 2013) is considered appropriate polypharmacy. Alternatively, “the prescribing of multiple [medicines] inappropriately, or where the intended benefit of the [medicines are] not realised” (Duerden et al., 2013) is considered problematic polypharmacy. Where medicines management was primarily led by pharmaceutical teams, medicines optimisation focuses on actions taken by all health and social care professionals and requires greater engagement from people, including shared decision making, and greater professional collaboration across teams (NICE, 2015).

In a study by Reeve et al. (2012), people with LTCs felt their care was personal, but not personalised, because practitioners had not used a whole-person approach to help them make decisions about their care. As a result, they described feeling “trapped on a conveyor belt” with healthcare becoming an additional burden on, rather than a resource for, living (Reeve et al., 2012, p. 3). Giving personalised information to people, for instance, about their parameters and treatment options, enables them to take an active role in LTC management because increased knowledge promotes engagement and empowerment (Rijken et al., 2014). Research into the effectiveness of various patient engagement strategies has shown that outcomes include improved knowledge and understanding, more accurate risk perceptions, greater comfort with decisions, fewer people choosing major surgery, better treatment adherence, improved confidence and coping skills, improved health behaviours and more appropriate service use (O’Connor et al., 2009, Winterbottom et al., 2010).

Implementing a whole-person approach requires consideration of the emotional and social aspects of a person's health. This is intensive and means that practitioners need to know which community services are available so that they can signpost people to them. For some healthcare professionals, this is the most difficult aspect of their job (Fuller et al., 2004). Not knowing which resources are available can be a barrier to supporting people with LTCs to self-manage. In a study by Ross et al. (2014), people with LTCs expressed their keenness to be given support from services other than the one provided by their GP. Their suggestions for how care for LTCs could be improved focused on helping people to help themselves by providing information about services available, listening, and helping them to feel safe and supported. The Department of Health's (2012b) vision for greater online access has facilitated recent developments, including the NHS Choices, Patient Opinion and IWantGreatCare websites, which provide the public with access to a wide range of information about health and healthcare choices. Since people with LTCs spend less than 1% of their time in contact with healthcare professionals and are otherwise self-managing their condition(s), these developments were a step in the right direction to promote independence, enable people to do their own research into their condition(s) and empower them to take control over their care and treatment. In order to make this vision the "norm", the NHS Five Year Forward View described the need for a profound shift in the way that healthcare is organised and perceived in the UK. It stated:

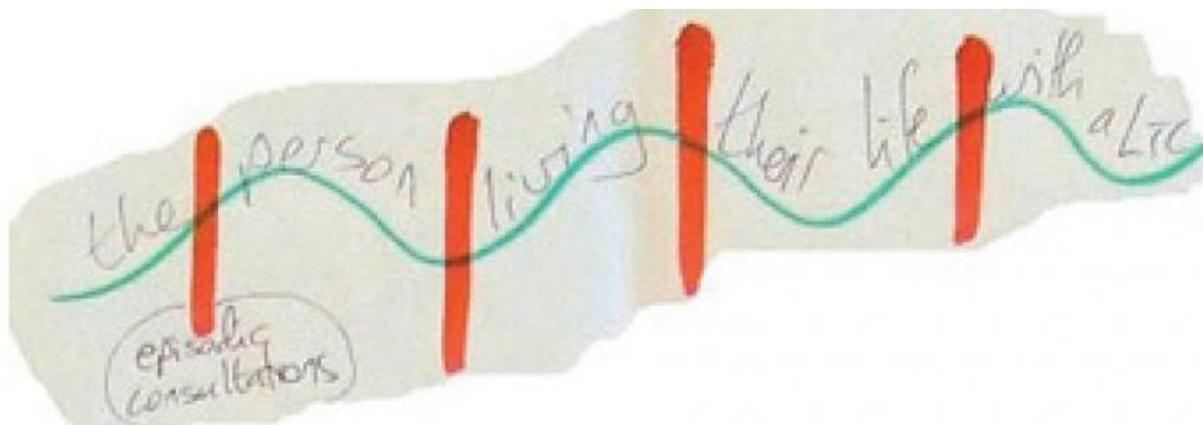
"Personalised care will only happen when statutory services recognise that patients' own life goals are what count; that services need to support families, carers and communities; that promoting well-being and independence need to be the key outcomes of care; and that patients, their families and carers are often 'experts by experience'" (NHS England et al., 2014).

To paraphrase, culture and systems must change to support this way of working. People with LTCs should be in the driving seats of their care and should be recognised as “experts” in their condition and how it impacts on their lives.

### The importance of self-management

Self-management is a term used to describe the actions taken by people to recognise, treat and manage their own health. They may do this independently or in partnership with the healthcare system. In reality, people with LTCs spend just a few hours a year interacting with health care services and are otherwise self-managing their conditions (Eaton et al., 2015), successfully or not, yet definitions of LTCs such as “health problems that require ongoing management over a period of years or decades” (World Health Organisation, 2005, p. 13) fail to acknowledge the person in the driving seat of their health. Despite people with LTCs spending most of their time self-managing their condition(s), research has shown that most are not involved in their care as much as they would like to be. In a survey by the Institute for Public Policy Research (McDonald, 2014) with over 2,500 people living with LTCs, over three quarters of respondents (77%) felt that more of their healthcare could and should be managed independently at home, and that a lack of support and information was holding them back from doing so. Over half of the respondents (56%) thought that a healthcare plan would be useful, and people who were offered healthcare plans were much more likely to report satisfaction with the management of their condition (91% compared to 63% of all respondents).

As previously discussed, the challenges people face with self-management vary depending on their personal circumstances; the number, nature, and stages of their conditions; the need for lifestyle, specialist and technical interventions; and their capacity to self-manage effectively (Eaton et al., 2015). The illustration below (Figure 2) was created by a person with LTCs at a world café event. It depicts what life is like with a LTC. The green wavy line represents day-to-day life managing their conditions and the vertical orange lines represent the time spent interacting with healthcare professionals. The image highlights not only the fact that time with healthcare professionals is limited, but also that contact occurs episodically and is often unrelated to life events or the needs of the person involved. It is therefore critically important for interactions with healthcare professionals to be meaningful and supportive in order to encourage self-management throughout the “ups and downs” of life.



*Figure 2: Interaction with healthcare professionals (Year of Care, 2016).*

Self-management support services were introduced in the NHS via a telephone helpline in the early 1990s. Over the next decade, the demand for these services grew as public expectations began to mirror other service industries and people became

willing to do more for themselves and interact with services via technology, and the NHS extended its self-management support to online and interactive digital television services. In response to the growing trend, in 2000 the NHS Plan set out to include self-management as one of its five building blocks (Department of Health, 2000) and shortly afterwards, in 2001, the Expert Patients Programme was initiated to provide self-management skills training to people with LTCs, to support them becoming experts in their own condition(s) (Department of Health, 2004). The aim of the programme is for people to share their skills and experiences and to develop the confidence to take responsibility for their own care, and to work in equal partnership with health and social care professionals (Department of Health, 2001a). Although the Expert Patients Programme is the most well-known programme of its kind, with around 12,000 course places per year, there are many other well attended self-management initiatives, however, most are specific to individual conditions. These include: DAFNE (Dose Adjustment for Normal Eating); DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed Diabetes); Challenge Arthritis; and Self-Management for IBS (Irritable Bowel Syndrome). The very fact that these programmes are so well attended highlights people's views on the importance of self-management.

In terms of outcomes, The Health Foundation reported that self-management can improve people's motivation, diet and exercise regime, symptoms and clinical outcomes, and can have a positive impact on how they utilise healthcare services (De Silva, 2011). In addition, it can lead to reduced accident and emergency admissions, for instance, in those with COPD and asthma (Purdy et al., 2011). Nevertheless, there are commonly reported barriers to self-management. People may be unaware that

self-management support, for example, the Expert Patients Programme, is often free of charge. Others may lack motivation to self-manage, so even if they are generally interested in the prospect, it may not be a priority for them. Other barriers to self-management include lack of knowledge of health issues; lack of health or treatment information, and inability to understand the complex information received or how to utilise it. Supporting and encouraging people to utilise education and other resources is therefore a key function of general practice, and is likely to increase motivation, as well as people's ability and skills to self-manage their condition(s) (Beebe and Schmitt, 2011).

In 2018, The Richmond Group published a report on an ethnographic study that gives a voice to people living with multimorbidity and aims to share an understanding of their lived experiences (Aiden, 2018). Some respondents reported taking greater ownership of their health and developing self-management strategies that felt relevant to them. Age was a major factor that influenced the extent to which people felt able to take control of their health. The youngest participant was diagnosed with type 1 diabetes at a young age and had experienced "excellent" paediatric care, had high expectations from her care providers and felt very much like she was the expert in her condition. In contrast, the oldest participant expressed disapproval of the notion that people would not take advice from their doctor. One participant, who lives with schizoaffective disorder, sciatica and asthma, had developed an intricate and personalised self-management system, involving reminders of the things that make her happy, and the triggers that may impact on her mental wellbeing, pinned to the walls around her house. She also completes a symptom spreadsheet every day, and if the total number recorded exceeds five, she will seek help from her friends and family in the first

instance. However, even the most structured, successful self-management strategies can be rendered less effective when health issues build up or develop. The same participant was confronted with this challenge after she was involved in a car crash, which caused her serious back pain and leg weakness, and later suffered a fall, leaving her with a broken elbow, wrist, and several ribs. The physical disability she endured meant that she was less able to get outside for 30 minutes per day, which was one of her strategies to maintain her mental wellbeing. Furthermore, living with constant pain meant that sleep became an issue, which consequently affected her mental health. Although the participant described previously being able to adapt her coping strategies to suit her needs, at this particular point in time, she was vulnerable and had to rely much more on her support system, including healthcare services (Aiden, 2018).

This example highlights a key message for health and social care providers, and for people with LTCs, in just how critical it is to reassess needs when circumstances change, which can happen unexpectedly. It also highlights the fact that people flow in and out of healthcare services at different points in their journey with their LTC(s) and although they should be encouraged and empowered to find personalised ways of managing their conditions, it may not always be appropriate at every single point of contact. Thus, the best care for people with LTCs is when health and social care teams, care givers, and support groups work in partnership with the person and with each other, to support self-management, minimise disruptions, and provide care and guidance when self-management strategies are less effective.

## Support for self-management

Research suggests that as many as 80-90% of people with LTCs, as well as their carers, can be supported to actively manage their own health and wellbeing (De Silva, 2011). It is the responsibility of the practitioner to gauge the extent of the person's knowledge, skills, and confidence to self-manage their health, to strengthen this where necessary, and to ensure that relevant interventions and support services are available (Coulter et al., 2015, Ross et al., 2014, Year of Care, 2011). Not only should practitioners recognize and suggest relevant support services, but also, they should do so using a whole-person approach, treating people as individuals who are active in their own care (Ross et al., 2014).

Several self-management initiatives have become well established in the UK, however, the provision of self-management support is inconsistent, with very little choice. For example, research has shown that only 42% of people in England who had either a heart attack, bypass surgery, or an angioplasty participated in cardiac rehabilitation, despite evidence that it can reduce mortality and improve quality of care (British Heart Foundation, 2011). In addition, less than 50% of people with diabetes were given the opportunity to discuss their own goals for self-management (Healthcare Commission, 2007). Although self-management initiatives will vary in terms of delivery and effectiveness, there are key elements of self-management support that contribute to its successful implementation. These include: offering personalised information, including action plans, education, and access to specialist support when needed (Wagner et al., 1996). Furthermore, self-management strategies should include psychological and social care components to support people through the many dimensions of living with a LTC (Ham et al., 2012).

When self-management support is effective, the outcome is a person with increased confidence and problem-solving skills (Ryan and Deci, 2000). Various terms have been used for this, including “engagement,” “empowerment,” and “activation.” Whichever term is used, the focus moves from the healthcare professional doing things to the person, to supporting them to gain confidence and competence to manage the challenges of living with their condition(s). The person with LTCs should also be willing to engage in the process, and research shows that “activated” people are more likely to engage in self-management than people who simply attend their appointments because they feel they must (Hibbard and Gilbert, 2014).

Activation and empowerment of a person with LTCs begins with increasing their knowledge and enabling them to play their part in disease management (Rijken et al., 2014). In a systematic review by Boger (2015), there was evidence that people felt gaining knowledge was key to enabling self-management. They also viewed independence as a key factor, which may be achieved through becoming more knowledgeable about their condition(s). The review also highlighted that the relationship between people with LTCs and healthcare professionals is fundamental to ensuring support for self-management is effective. People expressed a need to be treated as individuals by healthcare professionals: *“I need to feel my doctor is interested in my health, I need to feel I can talk to him and he is trying to understand me”* (Boger, 2015, p. 14-15).

In response to demographic changes, the shifting burden of disease and rising public expectations, CSP (termed care planning in earlier literature) was developed within the Year of Care pilots in 2008 as a means to improve care for people with single and multiple LTCs. It promotes people with LTCs being in control of their care and supports them to self-manage. It promises to transform annual reviews into constructive, meaningful dialogues between two equals. Year of Care set out to demonstrate how routine care can be redesigned and commissioned to provide a personalised approach for people with LTCs. Evaluation of CSP in three UK pilot sites (Calderdale and Kirklees PCTs; NHS North of Tyne; and Tower Hamlets PCT) has shown that implementation was a success and healthcare providers are now in the process of implementing the programme nationally. CSP will be discussed in more detail in Chapter 2.

### Chapter Summary

An ageing population is seeing an increase in the incidence and prevalence of LTCs and in particular, multimorbidity (Department of Health, 2008, Barnett et al., 2012, Aiden, 2018). Due to rising prevalence and costs, supporting people with LTCs is a major challenge to the sustainability of healthcare services (UN Secretary General, 2011). In addition to the impact LTCs have on the healthcare system, they can have a negative physical, psychological and psychosocial long-lasting impact on people and their families (Nicol, 2011). Over the past decade, healthcare policy and national clinical guidelines have been refined to reflect key research findings. Several different initiatives have been trialled in an attempt to proactively manage the soaring costs of LTC management, including education, shared decision making, person-centred care and support for self-management. However, it is only recently that people with LTCs

and multimorbidity have been given a voice to share their lived experiences, preferences and healthcare needs. In response, general practice has become more generalist in orientation to account for people's changing needs, and practitioners are being encouraged to focus on the emotional and social aspects of health, as well as helping people to become activated and to utilise education and other resources in order to become better at self-managing their LTCs. CSP puts people in the driving seat of their care and supports self-management. It is a personalised approach for people with any amount of LTCs. The next chapter explores in detail the fundamentals of CSP in the management of LTCs. It describes its underpinning philosophy and its strengths as a model of care. A detailed description of the CSP process is provided, in order to contextualise the subsequent chapters.

## Chapter 2: Care and support planning

This chapter distinguishes between care plans, care planning and CSP, in terms of how they are defined and described in the literature. Following this, the rationale underpinning the development of CSP as a model for supporting people with LTCs will be described, and its implementation processes will be explained. Published research will then be drawn on to highlight what is known about CSP for people with LTCs in current practice, and to identify a clear gap in the literature regarding underlying mechanisms.

### Care plans, care planning and care and support planning

To contextualise this chapter, it is essential to distinguish between care plans, care planning and CSP. Traditionally, a care plan is a written document made for a person who is unable to care for themselves in some way. It provides didactic instructions about what to do, i.e. after an operation or during a period of severe illness. For example, discharge plans are utilised after people are discharged from hospital and advance care plans specify a person's preferences for end of life care. They provide healthcare professionals with information about the medical and personal needs of the individual and outline their care and treatment. A care plan developed for this purpose may not involve the person it is aimed for in discussion or delivery, depending on their situation (Walker, 2014). It is a medical model of care for acute and/or short-term periods that depicts people as passive recipients of care.

“Care planning” originated from the Diabetes National Service Framework (Department of Health, 2001b), which describes people having care plans and the National Service Framework Delivery strategy (Department of Health, 2003), which describes the process of agreeing, owning and sharing the plan in the clinical encounter. In 2015, policy makers, service directors and healthcare professionals moved away from using the term “care planning” when describing the clinical encounter for people with LTCs to highlight that it is different from traditional treatment planning. Terms such as “collaborative”, “person-centred”, “individualised” and “holistic” could similarly be used to reflect that interactions between individuals and healthcare professionals rely on equal input and consider the individual’s health and care needs within the wider context of their lives. “Care and support” indicates that people generally need more than medicines or clinical treatments; they may require social and psychological support to do things for themselves, and links to community-based support are equally important. CSP focuses on the interaction between the individual, their carer, and the health or social care practitioner(s) involved in their care. The key points of these conversations are recorded as the person’s agreed care plan. The aim is for a plan to be developed that includes all aspects of an individual’s health, wellbeing and life. Burt et al. (2012) described the presence of a care plan within a CSP consultation as the “gold standard”, and the absence of both as poor quality of care. It is evident within general practice that routine care often contains elements of the CSP process without the written plan, just as developing a written plan may occur outside of a CSP consultation, for example, if it is incentivised. Care plans and CSP consultations have been implemented worldwide, and in the UK, have been proposed for all people with LTCs (Department of Health, 2008).

Several organisations have focused on developing, improving and rolling out CSP in the UK, including National Voices, Royal College of General Practitioners, and the Year of Care Partnerships, who have developed and extensively tested models of CSP and provided practice guidance for successful implementation. With a lack of singular defined approaches, CSP is currently delivered in many different ways depending on local interests, incentives and demographics. This thesis explores CSP through a broad lens but draws strongly on the experiences and expertise of the Year of Care Partnerships, who have supported numerous health communities to implement CSP over the past ten years.

### Why is CSP important?

In 2013, National Voices released “A Narrative for person centred coordinated care (the “I” statements)”, which set out what matters most to people with LTCs, from their perspective. Statements relating to CSP, communication, information, decision making, and transitions were voiced. Those relating to CSP were focused around the person being in control of their health and healthcare and meeting with professionals regularly to review their treatment, having the information that they need in order to live well, with a plan in place for whenever their health deteriorates. People also reflected that communication is an important part of the CSP consultation. They want to feel listened to and informed about their options and be part of a team with professionals who communicate with each other. In terms of information sharing, people described the importance of having access to appropriate information that they can understand and use to make decisions about their health and healthcare, in collaboration with professionals if needed. People described wanting to be involved in discussions and decisions about their care (as much/as little as they wanted), and to

receive skilled advice on how to make the best use of their healthcare budget (whether that is their own money, direct payment, or a “personal budget” from the council or NHS). Finally, people wanted better coordination of care, so that transitions between services were smooth and each professional contact had knowledge of the person’s plan. A new definition of person-centred, coordinated care, from the person’s perspective, was subsequently developed from this piece of work:

“I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me” (National Voices, 2013)

This provides the basis for CSP and emphasises the importance of the person being in control of their care and working in partnership with coordinated professionals who enable and encourage self-efficacy and self-management.

### The philosophy underpinning CSP

The main drivers for change came from evidence that questioned the efficacy of traditional methods, service user surveys and national policy in LTC care (Doherty et al., 2012). Evidence suggests that better outcomes come from a proactive and systematic service working in partnership with an empowered and activated individual, i.e. someone who has gained the knowledge and skills required to manage their condition and is ready to do so (Doherty et al., 2012). CSP places the person with LTCs in charge of their decisions about the actions they take in relation to their LTC management. Healthcare professionals therefore have a new role. Instead of doing things ‘to’ or ‘for’ *patients*, CSP promotes doing things ‘with’ *people* and enabling them to identify their own needs, goals and action plans. This is now supported in the General Medical Services (GMS) contract, which emphasises the importance of

continuity built on strong therapeutic relationships, and the need to move to conversations which are focused on what matters to the person with LTCs. The GMS Contract (NHS England, 2018) states that many healthcare professionals felt previous review systems, including the Quality and Outcomes Framework (QOF), which uses a points-based system to reward general practices for excellence in specific areas, were too disease-specific. In addition, they felt that these systems greatly increased bureaucratic workload and were supportive of structured “box ticking”, rather than holistic and person-centred conversations.

### The role of the healthcare professional

In CSP, although people with LTCs are encouraged to take control of their health and healthcare, the role of the healthcare professional depends on how much support the person with LTCs wants and needs, and how much they feel able to do themselves. Key responsibilities of the practitioner include: seeing patients as people in the context of their lives; valuing their expertise and encouraging them to share information in order to facilitate the best shared decisions; building a trusting and supportive relationship through effective communication; working as part of a team to coordinate care and ensure it fits into the person’s life; and signposting to local community support services. Implementing CSP creates opportunities for healthcare teams to expand and create roles, for example, Healthcare Assistants (HCAs) may be offered training so that they can complete tasks that would otherwise be undertaken by nurses. Many of the practices that are implementing CSP have adopted a system whereby HCAs complete the initial information gathering, including routine biomedical tests, thus freeing up nurses to support people in CSP consultations. GPs often take an oversight role and support the skills development of other team members. These skill mix

changes are an effective use of resources. Furthermore, every role is crucial and gives team members a feeling of purpose, thus enhancing job satisfaction (Year of Care, 2011).

### Care and support planning: a model for people with LTCs

It is widely accepted that people with LTCs benefit from proactively planning their care over time, in partnership with support systems, rather than seeking episodic, reactive treatment (Coulter et al., 2013, Graffy et al., 2009). Two people who have the same diagnosis will experience the condition differently and will have a different outlook on what they wish to achieve and how to get there. CSP is a systematic process which helps people to set their own aims, and then secures the support and care that is needed to achieve them. It is the epitome of person-centred, coordinated care that focuses on what is important to the person with LTCs, and the care and support they might need to live well and stay well with their condition(s) (National Voices, 2013).

The Year of Care Partnerships Programme combines the routine biomedical disease surveillance with a collaborative consultation. It promotes shared decision making and self-management support and facilitates implementation of these strategies through interactions between people with LTCs and the health and social care professionals supporting them. It also ensures there is a choice of local support services for people to attend to improve their health and wellbeing. CSP recognises that both the healthcare professional and the person with LTCs bring different expertise and experience to a consultation (Eaton et al., 2015). Although healthcare professionals have knowledge and expertise about the clinical care of particular LTCs, only the

person with the condition knows how it impacts on their life. CSP aims to transform the annual review from ticking boxes into a collaborative consultation, providing opportunities for people to share information with their healthcare team and openly discuss issues and concerns, as well as receive help with accessing the services and support that they require to self-manage their condition. Year of Care (2011) initially proposed two key components of CSP that enable this change. These are:

1. Sending out test results with a short explanation and agenda setting prompts in easily understood language ahead of the annual CSP consultation (enabling people to think about their condition, talk about it with their family and carers and decide on specific goals)
2. A person-centred consultation delivered by a healthcare professional who is committed to partnership working, which explores and discusses agendas and helps individuals develop their own goals and actions

These key components are embedded within the CSP process, which is explored further below.

### Introducing the House of Care

A pilot study was carried out with the aim of developing a systematic CSP approach in diabetes that could be embedded into routine practice as the normal way to deliver care, so that people could have active involvement in deciding, agreeing and owning how their diabetes is managed (Year of Care, 2011). There were three pilot sites: Tower Hamlets (TH), Calderdale and Kirklees and North of Tyne – North Tyneside (NT) and West Northumberland (WN). These sites were chosen because of their spread of demographics, standards of existing care and geography (Year of Care,

2011). All of the sites were able to implement CSP as the normal method of delivering care and have rolled out this approach beyond the pilot practices. Whilst reviewing the evidence base for CSP (Graffy et al., 2009), and exploring the support required in the pilot sites it became clear that the key implementation components suggested by Year of Care are not enough and several other changes at the organisational level are required to embed CSP into practice (Year of Care, 2011). The House of Care Model (Figure 3) was developed to reflect this.

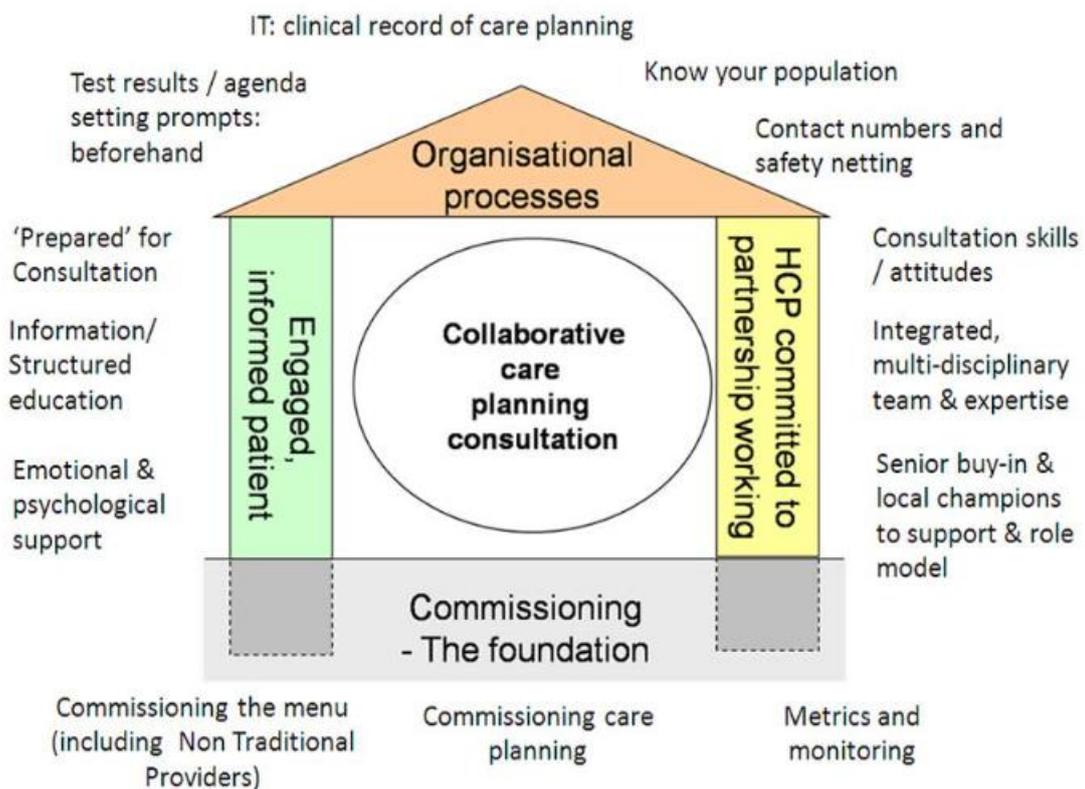


Figure 3: The House of Care (Year of Care, 2011)

The House of Care is a visual representation of the elements that must be in place to deliver person-centred, coordinated care through CSP. It proposes four key

components working together in the healthcare system: engaged, informed people working with healthcare professionals committed to partnership working, supported by appropriate and robust organisational processes and underpinned by responsive whole-system commissioning (Year of Care, 2011). At its heart is the CSP consultation, which has been described as a “better conversation” that meets the needs of people with LTCs and supports them to be in control of planning their care, alongside professionals who understand them and bring together services to achieve desired outcomes (National Voices, 2013). CSP is an ongoing, often annual process which aims to transform annual reviews into meaningful and useful discussions. These consultations focus on looking forward, identifying personal needs and goals, discussing and exploring issues and priorities, and supporting people to develop the tools they need to live well with their LTC (Eaton et al., 2015). CSP encourages a collaborative, whole-team approach and works well when there is a variety of special interests across teams, so that people experience a single CSP consultation, whether they have one LTC or three. People with LTCs may require encouragement to participate in a more active way than they used to, and healthcare professionals must consider how they will prepare them for this new role and value their contribution to the discussion. The CSP consultation can facilitate this through person-centred, coordinated care. The roof of the house represents the robust organisational processes that are essential to ensuring efficiency, including reliable systems for identifying and contacting people with LTCs, flexible appointment systems that allow for longer consultations when necessary, and record systems that can be used to document and share care and support plans, and for monitoring outcomes. All of this requires the firm foundation of a responsive local commissioning system (Year of Care, 2011).

The Figure illustrates how the house is a flexible set of principles which can be adapted to different conditions and different sites of care, yet without all of the components, the metaphorical house would collapse (Year of Care, 2011). Some of the components are organised within practices, such as blood tests; and others, for example, education, are commissioned by community health and social care services. The House of Care has three main functions. It acts as a checklist which highlights what needs to be in place for CSP to be effective, a metaphor that emphasises the complexity and interdependency of the components, and a flexible framework that may be adapted and reproduced depending on the needs of people in particular localities (Eaton et al., 2015). The House of Care has received prominence in the UK as a practical framework for a whole-system approach that can deliver a unique and coordinated response for each individual involved (Coulter et al., 2013, NHS England, 2014a, The Health and Social Care Alliance Scotland, 2016). In 2013, National Voices worked in collaboration with a wide range of people who utilise services to develop a better understanding of the CSP process. They highlighted four main steps, namely: prepare, discuss, document and review (National Voices, 2013). Each of these will be discussed further below.

#### Prepare – information gathering/sharing

The CSP process begins with an information gathering appointment, in which tasks and tests are completed ahead of the CSP conversation. Between the two appointments, which are usually two weeks apart, test results, reflective prompts, education opportunities and condition-specific information are sent to the person with

LTCs. Year of Care (2011) proposes that the results letter should be accompanied by an explanation of what it means, so that people have an opportunity to think about their results and consider what they would like to discuss in their CSP consultation. The person with LTCs is encouraged to think about different aspects of their health and wellbeing, including their physical and mental health needs, as well as social requirements.

### Discuss – the CSP consultation

People with LTCs experience living with their condition(s) and have knowledge on how they impact on their lives, whereas healthcare professionals have medical knowledge and expertise, and readily available resources to help people access support from other services. The CSP consultation brings people with LTCs and healthcare professionals together to share this information and expertise (Coulter et al., 2013). The CSP discussions should be focused around the individual and their LTC(s) in the context of their life, and how they can stay as well as possible and achieve their goals, using a proactive, solution-focused approach. They should include healthcare professionals communicating in a way that focuses on what is most important to the person with LTCs, supporting them to develop the confidence, skills and knowledge to take control of their health and healthcare and outlining the treatment and support that is available to them. From these discussions, agreed care and support plans, reached through shared decision making, should be drawn up for each person with LTCs (National Voices, 2013).

### Document – summarising the discussion

The care and support plan is a record of the key points discussed in the CSP consultation, and is owned by the person with LTCs to do with as they wish. It is therefore vitally important that the plan is written in a way that is understood by its owner and encompasses information that they may need to live well and stay well with their LTC. This may include a summary of the actions proposed by the person with LTCs, for example, a diet and exercise regime, in addition to a summary of the care and support that is available from other services. The care and support plan may be written by the person with LTCs, or by the healthcare professional if the individual prefers. A summary of the discussion should also be recorded on the NHS electronic system to ensure better coordination of care and transition between services and/or professionals (National Voices, 2013).

### Review – follow up appointment

The purpose of the review appointment is to discuss and track progress, highlight any changes or barriers to self-management and share ways to overcome them. The content of a review may be different for each person, and for one person each review may be different depending on changing needs. Nevertheless, it may include discussions around mental and physical wellbeing, life events, unplanned or emergency care, confidence to self-manage, and support services. Further regular follow up appointments should be offered at least once a year, however, the person with LTCs may decide how regularly they would like to receive support from the healthcare professional, and in which format, for example, via telephone, email, or face-to-face. Flexibility is vitally important in order to support peoples' changing healthcare needs (National Voices, 2013).

## Evaluation of CSP

CSP aims to provide high quality, person-centred care to people with LTCs. Year of Care (2011) proposed that in particular, it will:

- Make better use of skill mix and combine LTC monitoring into a single appointment, no matter how many conditions a person is living with.
- Ensure people with LTCs receive results and agenda setting prompts to enable them to be prepared, more informed, involved and in a better position to make decisions about their care.
- Facilitate holistic, person-centred conversations with expert generalists and provide longer appointments for those with complex issues.
- Provide a single administrative process and a recall system.
- Focus on multimorbidity and on 'people not conditions', which will free up appointments and save time.
- Signpost to community support teams, care navigators and social prescribers.

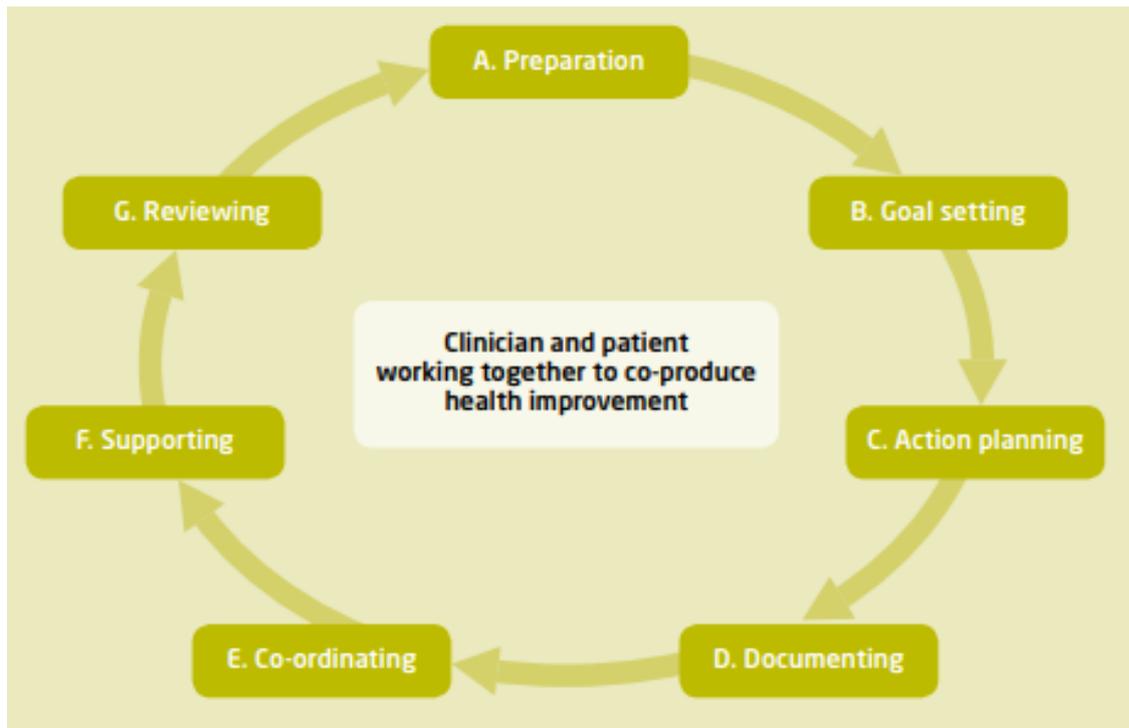
However, some healthcare professionals have expressed concerns over its effectiveness. Many have claimed that they are already implementing CSP, or they do not have enough time to implement CSP in a way that would be meaningful for all people with LTCs, or that people with LTCs are uninterested in its philosophy (Coulter et al., 2013). This finding reflects the ambiguity, in the current literature and in practice settings, around the efficacy of CSP as a tool for supporting self-management.

Evaluating CSP in terms of specific outcomes for people with LTCs has proven difficult because interactions are generally focused on what the person wishes to achieve.

Goals and actions may include self-management strategies such as: using medicine, giving up smoking, and managing nutrition, diet and exercise. However, since every person living with a LTC experiences different symptoms and has different values and levels of motivation, goals and actions will vary from person to person and will therefore be difficult to measure. Despite this challenge, the Year of Care pilots have provided some understanding and guidance around the implementation of CSP. The initial focus was on care for people with diabetes, but it has subsequently been applied to other LTCs and multimorbidity. The pilot programme has uncovered several key improvements for people with LTCs, healthcare professionals and practices, including improved experience of care and changes in self-care behaviour for people with LTCs, and improved knowledge and skills and greater job satisfaction for healthcare professionals. Practices have reported better organisation and team work, and greater value for money. The evaluation has also suggested that although CSP takes time to embed into practice and improvement in clinical outcomes may be seen after two or three CSP cycles, it is a long term, sustainable solution to reducing the burden of LTCs on local resources (Year of Care, 2011). Perhaps the fact that outcomes may not be seen immediately has influenced some healthcare professionals' perceptions of the programme's effectiveness.

Further attempts to evaluate CSP in general practice have been made over the past decade. Coulter et al. (2015) carried out a Cochrane review which aimed to assess the effects of CSP for people with LTCs compared to usual care. A patient advisory group suggested four key outcomes to look for in the literature. These were physical health, psychological health, subjective health status (i.e. quality of life) and self-management capabilities. Other areas considered were health-related behaviours,

resource use, adverse effects and type of intervention. The review highlighted the fact that CSP is a cyclical process and not a one-off event. The process includes seven steps as opposed to the four proposed by National Voices (2013). These are: preparation, goal setting, action planning, documenting, coordinating, supporting and reviewing (Coulter et al., 2013). This process is shown below in Figure 4.



*Figure 4: CSP – a cyclical process (Coulter et al., 2013)*

Coulter et al. (2013) proposed that the CSP process involves:

A. Preparation: People with LTCs may be invited to attend a preliminary appointment to check progress and undergo relevant tests, or they may be sent information by post or email to reflect on prior to a CSP appointment.

B. Goal setting: People with LTCs are encouraged to talk about their experience of living with the condition, their beliefs and concerns, their comprehension of and

reactions to the information provided, and their values and priorities. They then work with the clinician to articulate their own goals for the future.

C. Action planning: A plan is jointly developed for achieving these goals, including specific behavioural changes if relevant, what to do if new issues arise and identification of appropriate sources of support.

D. Documenting: These actions are documented for use by professionals and people with LTCs, either as a single shared record or two separate records containing appropriate detail for both.

E. Co-ordinating: The professional is responsible for ensuring that all agreed tests, treatments, education or support packages are available to the person with LTCs and provided in a timely and co-ordinated fashion.

F. Supporting: The person with LTCs and the professional agree a schedule for regular, systematic follow-up to maintain progress and contact arrangements should any problems occur.

G. Reviewing: A meeting (face-to-face or remote) during which the person with LTCs and professional jointly review progress and plan next steps.

Although goal setting, action planning, coordinating and supporting were mentioned within the four processes identified by National Voices (2013), Coulter et al. (2013) positioned them as processes in and of themselves. Coulter et al. (2015) found that in 19 randomised controlled trials involving 10,856 participants, CSP has led to better physical health (including blood glucose and blood pressure), better emotional health (including depression scores) and better capabilities for self-management (self-

efficacy). They also found that there was no difference in subjective health status (quality of life), however, no two studies used the same measure to assess quality of life and most of them were not designed for people with multimorbidity, and thus were not fit for purpose. Another key finding of the systematic review was that CSP works best when it is comprehensive, i.e. the whole seven-step process is completed, and not just elements of it. In addition, Coulter et al. (2015) found that CSP is most effective when it is integrated with routine practice, there are more contacts between people with LTCs and healthcare professionals over longer periods and both parties are well supported.

Despite the policy messages and growing evidence, both nationally and internationally, of the benefits of CSP for people with LTCs, National Voices published a report in 2017 stating that there are mixed findings which are consistent with person-centred care, including CSP, being an ambition but not yet a priority for service leaders. In addition, evidence about the extent and quality of CSP is inconsistent (National Voices, 2017) and suggests that in most mainstream NHS settings, it is largely absent. Although evaluation of the Year of Care pilot programme suggested challenges and barriers that may be faced by those involved with its implementation, and proposed solutions to these problems, there are significant gaps in knowledge regarding how, why, for whom and in what circumstances CSP works best. National Voices (2017) proposed that the current measures for person-centred care must evolve in order to achieve the goal of it becoming the “norm” in mainstream practice. Little is known about the most favourable contexts for CSP interventions, and the mechanisms they trigger, thus, increased detailed knowledge is required in order to maximize the translational potential of any future research on CSP. This knowledge

will also provide those who deliver CSP with the information they need to: roll out CSP within clinical practice effectively; adapt CSP to suit the needs of practice demographics; and make CSP the “norm” for treating people with LTCs. This research therefore focuses on gaining a greater understanding of how, why, for whom and in what circumstances CSP works best.

### Chapter Summary

Whilst I have explored CSP through a broad lens for the purpose of contextualising where and how it fits into current practice, I have drawn largely on the experiences and expertise of the Year of Care Partnerships, who have supported numerous health communities to implement CSP over the past 10 years. National Voices (2013) set out to give people with LTCs a voice, and to find out what matters most to them. They found that people want to be in the driving seat of their health and healthcare, and to work in partnership with professionals who provide access to information and support, and respect the person making decisions about their care. These principles provide the basis for CSP. A pilot study was undertaken across three pilot sites; all of which were able to implement CSP as the normal method of delivering care. Evaluation of the pilot project has suggested that key components forming the House of Care, with the “better conversation” at the centre, must work together in order for person-centred, coordinated care to be achieved (Year of Care, 2011).

Further research in this area has suggested a number of key processes that must occur for CSP to work (Coulter et al., 2013). Despite growing evidence of the benefits of CSP for people with LTCs, recent evidence suggests that the extent and quality of

CSP is inconsistent (National Voices, 2017) and in most mainstream NHS settings, it is largely absent. There are significant gaps in knowledge around the specific underlying mechanisms of CSP. This research uses realist methodology to gain a greater understanding of how, why, for whom and in what circumstances CSP works best. Realist methodology will be explored further in Chapter 3.

## Chapter 3: Methodology

This chapter will begin with an exploration of the philosophy and principles of realism and an explanation of social programmes. This will be followed with a discussion of the differences between critical realism and scientific realism, and justification for scientific realism being applied to this research project. Realist review and realist evaluation will then be discussed, with an explanation of realist logic of inquiry, to show how CSP will be evaluated in terms of Context-Mechanism-Outcome Configurations (CMOCs). The research questions will be stated, followed by an explanation of the development of eleven IPTs. A study design using RRR and realist evaluation has been developed to answer the research questions and test the programme theories through the literature and in clinical practice.

### Realism

Realism is a methodological orientation that is grounded in the philosophy of science and social science (Bhaskar, 1978, 1979, Putnam and Conant, 1990, Collier, 1994). It has been labelled the principal post-positivist perspective as it provides an explanation of phenomena that sits between the positivist and constructivist accounts of scientific explanation (Pawson, 2006). Realism's key premise is its focus on the mechanics of explanation (Pawson and Tilley, 1997) and it values both qualitative and quantitative research methods to aid this explanation (Sayer, 1992, Archer, 1995, Sayer, 2000). Realism regards social change as transformational, and it holds specific ontological and epistemological beliefs about causation, the constitution of the social world, and the stratification of social reality (Pawson, 2006), all of which are explored further in this chapter.

## Realism and causality

(Pawson, 2008) describes three models of causal explanation in natural and social science: successionist causation, configurational causation and generative causation. I will outline each of these models below in relation to CSP.

Successionist (Empiricist) causation is a model used to describe variables and correlation. We often see this kind of causal explanation in experimental research, which produces test results, large data sets and variables. The dependent variable is the outcome, and the other variables, the causal powers, are independent variables. A change in the independent variable X is said to bring about change in the dependent variable Y, and thus we see the familiar  $X \rightarrow Y$  linear model of correlation. However, correlation does not imply causation. In an attempt to strengthen the causal inference described by this model, experimental researchers try to manipulate experiments by isolating one variable from all potential confounding variables. They randomly assign participants to experimental and control groups, and only perform the treatment to the former. Since the only difference between the groups is the application of the treatment, the relationship between X and Y can thus be measured and observed directly (Pawson, 2008). According to the philosophies underpinning this model (positivism and empiricism), there is no standard technique for experimentalists in choosing variables to investigate. Positivism proposes that causes are not real; we cannot observe them. Rather, we should make causal inferences based on the phenomena we can observe, i.e. objects and their properties and their mutual occurrence (Hume, 1902). Empiricism advocates that there is no reason to assume

that one variable will have explanatory power over another, and thus all inquiry is a matter of trial and error. Experimental researchers tend to build hypotheses with chosen variables, which reflect their nous and experience, and they justify the patterns of variables described by concluding with logical reasoning, “what we have discovered makes sense”. However, that is as far as it can go, because the structure of the theories remains the X leads to Y statement (Pawson, 2008) and isolating and manipulating the variables “effectively *strips away the context* and yields results that are valid only in other contextless situations” (Guba and Lincoln, 1989, p. 60). Applied to CSP, this model of causal explanation would identify one key CSP component and seek to link this causally to set clinical outcomes by eliminating confounding variables, such as the person’s socioeconomic background or education.

Configurational causation introduces “attributes” or “conditions” to causal explanation. Attributes have the power to condition what follows, for example, weather conditions influence the growth of crops. They are identifiable, observable parts of the social world. Variables are considered entities in their own right, whereas attributes are regarded as features of larger systems (Pawson, 2008). A configuration of attributes within a system facilitates change, and it is the connection between this configuration that social scientists are interested in. If one essential ingredient in the connection is absent, change will not occur. Thus, configurationism is able to show that small similarities and differences within a connection of attributes can lead to quite different outcomes. It can, however, only describe simple binary outcome patterns (Pawson, 2008). Hypotheses are developed in the same way as in the successionist model; theories begin as common-sense hunches linking attributes and outcomes and become more sophisticated as the interplay between attributes is unravelled (Pawson,

2008). Applied to CSP, this model of causal explanation would identify different attributes that act in packages and make a difference, for example, a person who is motivated and has time to spare (attributes) may attend the gym (outcome). In contrast, if the person is motivated but has no time to spare, they would not attend the gym. Similarly, if they had time but lacked motivation, they would not attend the gym.

Generative causation (realism) introduces contexts and mechanisms to causal explanation. It assumes that events and outcomes are connected at a deeper level and that there is some kind of necessity in their connection. Realism shares the positivist view that “entities exist independently of being perceived, or independently of our theories about them” (Phillips, 1987, p. 205). Positivist science is grounded in a linear, observable model of causation: if we see A and then we see B, we always see B after A, and without A we do not see B, then A causes B (Westhorp, 2013). However, realism is not concerned with documenting or describing the world, it seeks to go deeper than what successionist and configurational accounts of causation can offer. Realism delves beyond the observable by going beneath the surface of objects to explain their “inner workings” (“generative mechanisms”, “underlying mechanisms”) to really understand causation (Pawson and Tilley, 1997). Applied to CSP, this model of causal explanation would identify what it is about the programme that works, for whom and in what circumstances. For example, when a decision needs to be made about a person with LTCs’ treatment (context), and a full menu of options is shared by a healthcare professional, the person fully understands the pros and cons of each option and feels able to express their preference (mechanism) and a collaborative agreement on the course of action is reached (outcome).

## Realism and complexity

The exploration of mechanisms in understanding causation requires consideration of a complex social world. According to Clark (2015), some entities are “simple” and can be described using the positivist approach to causation; in situation *a*, do *b* and *c* will happen, whilst other entities are “complicated”, such as empirical investigations including randomised controlled trials. However, the social world is neither a simple nor a complicated place; it is complex and everything in it is unique (Clark, 2015). (Westhorp, 2013) describes a layered reality in which the world is made up of open systems. People, information and resources flow in and out of them, and social systems themselves interact with and affect each other. Social systems may change over time, in complex and interactive ways, and any outcome that occurs may be a result of many causes, including interactions within and across systems. CSP is considered a social system. An individual may effectively self-manage their LTC(s) in response to a mechanism introduced by CSP, for example, test results being sent prior to the CSP consultation. As the programme evolves over time at the organisational level, in line with advancing technology, it may be possible to access test results online. Individuals who have no access to the internet may consequently disengage from the programme and have poorer health outcomes. In keeping with Clark’s (2015) notion, realists inherently consider the world a complex place, and realist approaches to research, namely critical realism and scientific realism, have been developed to make sense of that complexity.

Critical realism was founded by Bhaskar in 1978 and was explored further by (Archer, 1995) and (Sayer, 1992) amongst others. Bhaskar (1978) proposed that we explain patterns in the social world by unearthing the underlying mechanisms that influence or constrain them. To achieve this requires theory and Bhaskar believed it is generative theories that allow us to know how to manipulate the experiment and explain the results we then observe. Bhaskar assumes that in this complex social world there will always be several explanatory possibilities, some of which will be mistaken (Pawson, 2006). It is therefore the primary task of the critical realist to be critical of the ideas behind false explanations (Bhaskar, 2002). Scientific realism (Pawson and Tilley, 1997, Pawson, 2006, 2013, Wong et al., 2013) was influenced by critical realism. It assumes that a decision should be made between alternative explanations, despite the knowledge that further explanatory possibilities exist in the open systems in which people live (Pawson, 2006). It seeks to adopt the most plausible explanation, using evidence (data) and theory together to understand causation.

Another crucial difference between critical and scientific realism is how they deal with complexity. According to Bhaskar, complexity is managed by empirical researchers in the physical sciences by controlling all confounding variables, thus creating closed experimental systems so that physical law can unfold (Bhaskar, 1986). In social science, due to the ever-changing nature of the social world, empirical researchers can only ever describe the surface, fleeting phenomena that manifest themselves in open systems, which Bhaskar says “is literally useless” (Bhaskar, 1979, p. 27). We cannot control and isolate the underlying mechanisms because they are transforming under human agency. Bhaskar proposed that redemption of the complex underlying

mechanisms requires a great deal of intense, abstract, theoretical work, and this work needs to come first (Collier, 1994) thus, “in social science, attempts at real definitions will in general precede rather than follow successful causal hypotheses” (Bhaskar, 1979, p. 63). The answer for dealing with complexity in the social world is therefore to produce *a priori* reasoning through which to critically evaluate human actions (Bhaskar, 1986). Although Pawson (2013) agrees with many of Bhaskar’s ideas, he disagrees with his notion of closed systems. He argues that neither physical science nor social science investigation depends on the achievement of closed systems. There are no crucial experiments that provide us with social laws, and there is no need for social scientists to seek alternative strategies because of the impossibility of achieving closure. Instead, Pawson argues, we should accept that accounts of progressive, unfinished closure are entirely consistent with the logic of scientific discovery (Pawson, 2013, Popper, 1963, Lakatos, 1978) and it is this notion that he builds upon in scientific realism.

### Social programmes

Most realists perceive social programmes as products of human imagination; they are hypotheses about social betterment (Pawson and Tilley, 2004). They attempt to address existing social problems – that is, to create some level of social change. They “work” by enabling participants to make different choices, although choice-making is always influenced by participants’ previous experiences, beliefs and attitudes, opportunities and access to resources, and they also “work” in different ways for different people (Pawson and Tilley, 1997). Programmes are thus shaped by a vision of change and they succeed or fail according to the accuracy of that vision. According to Pawson and Tilley (2004), programmes are theories developed by policy makers,

that get passed onto practitioners and sometimes onto programme participants. As they are delivered, they become embedded in social systems and any changes in behaviours, events and social conditions are generated by bringing new ideas to the system in the hope of disturbing and re-balancing it.

### Unpacking black boxes

The black box “problem” in social research refers to the practice of viewing social programmes primarily in terms of effects, whilst paying little or no attention to how those effects are produced. Experimental evaluators who treat programmes as “black boxes”, investigate observable effects such as light switches that can be turned on and off (Astbury and Leeuw, 2010). Realists, however, believe reality is complex, and behaviours are not necessarily switched “on” and “off”; we need to “unpack the black box” (Astbury and Leeuw, 2010). In doing so, we can find that a person might feel disempowered, slightly empowered, through to extremely empowered, etc. Over the years, there have been several attempts to “unpack” the black box in evaluation research, so that the inner components of a programme can be inspected (Scriven, 1994). This kind of evaluation is commonly named theory-driven evaluation and was first explored by Edward Suchman in 1967. Suchman highlighted the importance of opening up and empirically testing the ‘black box’ of social programmes (Suchman, 1967). Weiss (1997), Wholey (1979), (1983) and Chen and Chen (2005), among others, have also contributed to the development and establishment of theory-driven evaluation in social research. In contemporary theory-driven evaluation, theories about a programme are developed in many different ways and used for a variety of purposes (Birckmayer and Weiss, 2000, Donaldson, 2007). A key premise of realist

inquiry is to seek out the mechanisms, contexts and outcomes in order to unpack the black box of a social programme. These key concepts are explored further below.

### Mechanisms, context and outcomes

There have been a number of different conceptualisations of the term “mechanism”. It was first used by Chen and Rossi (1987), who argued that “the theory driven approach avoids the pitfalls of black-box evaluation and provides better understanding of the *causal mechanisms* underlying the relationship between treatment and effects” (p.102). Indeed, the term mechanism relates to causation, and is the pivot around which realist research revolves (Pawson and Tilley, 2004). Mechanisms are usually hidden, they are sensitive to variations in context, and they generate outcomes (Astbury and Leeuw, 2010). For Archer (1995), a critical realist, all social outcomes are created by collective, constrained decision making (mechanism). Peoples’ choices are conditioned by pre-existing social structures and therefore we are always constrained in our actions. We can, however, choose to attempt to change these initial conditions. Over time, these choices mould changed systems, and in turn, these systems constrain and enable the choices of the next generation, and so on (Dalkin et al., 2015). This representation of mechanisms of social change is accepted by most realists, however, there are some differences in where realists believe that change occurs. For Bhaskar (1978), mechanisms reside in the power and resources that lie within institution structures. For Pawson and Tilley (1997), mechanisms are identified within human reasoning. Thus, within realism, mechanisms can either be structural or hidden within the human mind, depending on the scope of the intended explanation (Dalkin et al., 2015). Physical, structural mechanisms are generally easier to understand. In trying to understand the mechanisms of a clock, we must go beneath

the “surface (observable) appearance” and delve into the ‘inner (hidden) workings’ (Pawson and Tilley, 1997). However, human behaviour is much more complex than mechanics and thus requires deeper explanation. If I were to look at the structural mechanisms of CSP, I might explore staffing or training issues, for example. Seeking explanation for how and why people with LTCs and healthcare professionals behave in certain ways during the CSP consultation requires deeper consideration and explanation.

Within scientific realism, Pawson and Tilley (1997) have conceptualised mechanisms as a way that offers a deeper explanation of human behaviour. They propose that mechanisms are made up of programme resources and reasoning of the stakeholders (Pawson and Tilley, 1997, Pawson, 2006) and they will only activate in the right context. Within CSP, a mechanism may consist of preparation (resource) and permission to engage (reasoning). The context is made up of pre-existing circumstances within which an intervention is implemented. It includes the organisational, institutional, social, cultural and political conditions that sometimes enable and sometimes constrain peoples’ choices (Giddens, 1984), for example, an existing understanding and belief in the philosophy of CSP. Realist methodology uses contextual thinking to answer the questions, “for whom” and “in what circumstances” does a programme work? Context can influence the way in which, or the extent to which, a programme is implemented, who it targets, who it reaches, etc. It can also influence the way in which stakeholders respond, or indeed do not respond, by constraining their choices (Pawson and Tilley, 1997).

The “evidence” in social research is presented as outcomes or regularities. In realist inquiry, explaining causality requires a deep investigation of demi-regularities (Lawson, 1997) or outcome patterns (Pawson, 2008). I will use the term outcome patterns throughout this thesis. Outcome patterns comprise the intended and unintended consequences of programmes, resulting from the activation of mechanisms in particular contexts (Pawson and Tilley, 2004). They may take the form of a simple correlation, but they can also describe more complex trends (Pawson, 2013). Deciphering the reasons for such varied patterns can give vital clues to the workings of programmes, and to do this, we need to ask “why” or “how”. We need to seek an understanding of what the programme actually does to change behaviours and why not every situation is conducive to that particular process (Pawson and Tilley, 1997). For instance, programme evaluators may find that CCTV installation increases car park “turnover” (outcome 1) and causes a fall in crime rates (outcome 2), which may prompt the hunch that public presence, as well as deterrence or detection, is causing the change. Evaluators may then explore this hunch further, by comparing crime rates at busy and quiet times of the day (Pawson and Tilley, 2004). Thus, we can see that exploring plausible reasons for such outcome patterns can provide more clues about the underlying mechanisms and contexts that enable or constrain the programme.

### [How are social programmes evaluated?](#)

Outcome patterns are found within most social programmes (Pawson and Tilley, 2004) and realist evaluation focuses on exploring these observed differences. This is done by identifying Context-Mechanism-Outcome configurations (CMOCs), which are developed using the formula: context (C) + mechanism (M) = outcome (O) (Pawson

and Tilley, 1997). As aforementioned, mechanisms are made up of resources and reasoning. Social programmes provide resources (such as the test results letter, communication techniques, and longer consultations) which activate peoples' reasoning (for example, increased confidence). Although resource and reasoning are made explicit in the seminal work of Pawson and Tilley (1997), this disaggregation has not been referred to in subsequent research. Dalkin et al. (2015) highlighted the need to separate mechanisms into resources and reasoning within the CMOC and proposed the following adaptation to the C+M=O formula: Intervention resources (M) are introduced in a context (C), in a way that enhances a change in reasoning (M). This alters the behaviour of participants, which leads to outcomes (O). This adapted formula will be used throughout this study. I have found that it helps to identify and understand the mechanisms of CSP by unpacking them in terms of resources and reasoning.

### Why have I chosen to use realist evaluation?

I will begin by highlighting why I am not using a successionist or configurational model of causation. Stakeholder reasoning is needed to complete causal accounts (Pawson and Tilley, 1997, Westhorp, 2013). Successionist and configurational researchers believe that the explanatory role of two specific types of variable, namely mediators and moderators within causal accounts, offer the same explanatory function. However, these are intervening variables, which are not the same as mechanisms. Successionist and configurational models thus provide incomplete explanations (Pawson, 2008). To date, CSP has been studied using successionist and configurational understandings of causation (Coulter et al., 2015, Care Quality Commission, 2016). Coulter et al. (2015) identified moderator variables, i.e. those that

influence the strength of a relationship between two other variables, in a systematic review of CSP. They found that in 19 randomised controlled trials, people with LTCs who received CSP had better physical health (including blood glucose and blood pressure), better emotional health (including depression scores), and better capabilities for self-management (self-efficacy scores). Additionally, they found no difference in subjective health status (quality of life). In 2016, the Care Quality Commission published a thematic review on peoples' involvement in their care. The review identified mediator variables, i.e. those that explain the relationship between two other variables. One of its key findings was that adults and young people with LTCs, mental health conditions and learning disabilities, and people over 75 are less likely to be involved in their care than other groups. They explained these relationships by stating that GPs said they did not have enough time to implement tools and undertake CSP in a way that would be meaningful for all groups of people (Care Quality Commission, 2016, National Voices, 2017). However, these models fail to acknowledge stakeholder reasoning. Realist research, which uses a generative model of causation, grabs hold of parts that the other models cannot reach and will therefore help to close this gap in knowledge.

Realism argues that it is possible to work towards a closer understanding of the nature of reality, through asking the question "why?" It is through asking "why?" that mechanisms and influencing and constraining contexts are uncovered, however, they only help to understand one level of reality. Realism acknowledges that within complex interventions there are many dimensions and layers that warrant exploration, for example, in this study there are behaviours of people with LTCs and practitioners, as well as multiple interactions between the numerous components of CSP. Realist

evaluation does not seek to explain all of these layers; it is specifically focused on the outcome patterns in the social world which create preconditions for particular human behaviours (Pawson, 2006). Whilst I acknowledge the existence of critical realism, I have chosen to follow the methods of scientific realism throughout this study. I am drawn to Pawson and Tilley's realist evaluation approach (1997) because of its appealing practical framework for making sense of complex programmes and its emphasis on combining theory with empirical data.

The aim of this study is to develop and test, through an iterative process combining primary and secondary data, theories that carry the greatest possible explanatory potential for CSP. This comprehensive study will offer a deep understanding of the causal link between CSP outcomes and explanations, whilst embracing human volition and the complex social systems in which people reside. It will therefore provide unique insight into the "inner workings" of CSP.

Furthermore, theories derived from realist evaluation contribute to "Theories of the Middle Range" (Merton, 1968), which situate at a level of abstraction that is "useful" as they are specific enough to generate and test particular explanations and general enough to apply across different settings (Pawson and Tilley, 1997). In order to maximise the translational potential of this new information, a middle range theory, specifically Normalisation Process Theory (NPT), will be used to explain the programme theories at a higher level of abstraction. NPT is a theory of implementation that focuses on what people – individuals and groups – do rather than what they believe or intend, and it has been developed and adapted in studies of practice across many different healthcare systems.

NPT and realist evaluation are theoretically informed approaches that share similarities in that they both use generative conceptions of causality in order to explain how interventions work (Wilson et al., 2015). NPT can be used with and alongside other epistemological and theoretical perspectives that are qualitative in nature. It can complement qualitative research by informing, guiding and structuring one or all of the following: the initial research focus and questions; the initial research design, sampling and data collection; the way the data is coded and analysed; or the emerging interpretations, conclusions and recommendations. Furthermore, NPT can be used at different points in qualitative research. For instance, it can be used throughout the life of an ongoing research project; at one of the stages in an ongoing research project; or to re-analyse qualitative data from a completed research project (May et al., 2015).

I will use NPT as an explanatory theory to complement and enhance the findings of this study. This study explores CSP implementation, and in doing so it highlights key barriers and enablers to effective CSP. Often in realist evaluation, researchers explain what works, for whom and in what circumstances by evidencing the opposite (what does not work, for whom and in what circumstances). This is achieved by identifying the association of the failed outcomes with “missing mechanisms” and “negative contexts”. This process requires the application of counter-factual thinking (testing possible alternative explanations) to argue towards *transfactual* (mechanism-centred) conditions (Eastwood et al., 2014).

Similarly, NPT identifies, characterises and explains key mechanisms that promote and inhibit the implementation, embedding and integration of complex interventions (May et al., 2018), but at a higher level of abstraction than the programme theories. Thus, NPT will be used to examine the programme theories more broadly and elaborate explanation of the findings. Whilst the programme theories describe the inner workings of the CSP conversation, NPT can lift them up on another explanatory level outside of the structure of the programme theories. Used together, realist evaluation and NPT will provide unique insight and practical recommendations which will have the potential to make a significant impact on the effective implementation of CSP in practice.

### Research questions

The initial research questions were: How does CSP work? For whom and in what circumstances does it work best?

These questions were purposely broad to allow the formulation of calculated hunches (set out as CMOCs), referred to as initial programme theories (IPTs). These IPTs are the underlying assumptions about how a programme is supposed to work, and what impacts it is expected to have (Pawson et al., 2005). Thus, they are a crucial starting point for realist evaluation. Typically, there are multiple programme theories per intervention. This study began with eleven IPTs. They are presented and discussed in more detail on page 78.

### Study design: rapid realist review and realist evaluation

Eleven IPTs were developed through: scoping policy documents, protocols and key research papers; mind mapping sessions; attending CSP training events (Appendix 1)

and observing CSP consultations (Appendix 2). Appendix 3 shows how an IPT was formulated using these methods. A RRR was used to develop these IPTs into testable programme theories, which were then discussed and refined during a focus group with expert stakeholders. The programme theories were tested in practice in a realist evaluation, which for this particular study embraces qualitative data. Analysis of the data provides an understanding of how CSP resources interact with contexts and trigger the necessary mechanisms to cause desired outcomes.

### Operationalisation of the study design

Realist approaches are method neutral and can employ quantitative and qualitative methods (Manzano, 2016, Pawson and Tilley, 1997). Pawson and Tilley (1997) propose that realist evaluation employs no one standard formula; the choice of data collection and analysis should be guided by the types of data that are needed to answer the research questions, or more specifically, to test the IPT in all its dimensions. Marchal et al. (2012) reviewed 40 realist studies that followed Pawson and Tilley's approach between 2004 and 2010. Of those studies, 5 used interviews as their only method of investigation and 27 used interviews combined with other methods. Eight out of the 40 studies mixed quantitative and qualitative primary data. For example, in their realist evaluation of a large-scale healthcare intervention, Greenhalgh et al. (2009) conducted 100 interviews and these were also accompanied by observations, group interviews, informal discussions, documentary analysis and secondary analysis of quantitative and qualitative documentation. Rycroft-Malone et al. (2008) on the other hand, primarily used qualitative methods (observation of nursing and multi-disciplinary activities; interviews with practitioners, patients and other stakeholders; tracking patient journeys; field notes and the review of relevant

documentation, e.g. copies of pathways and guidelines). The realist evaluation undertaken for this thesis uses qualitative methods to develop, test and iteratively refine programme theories through analysis of secondary data, observations, field notes, focus groups and interviews, using a realist “lens” (Pawson and Tilley, 1997). As this research is related to the personal views and experiences of the different stakeholders, this combination of qualitative methods will best answer the research questions.

This study is a three-phase realist evaluation, comprising:

1. Developing the programme theories: RRR to develop programme theories through existing literature
2. Refining the programme theories: focus group with experts who are involved with leading the implementation of CSP (leaders)
3. Testing the programme theories: interviews with healthcare professionals who are implementing CSP in practice (implementers), and people with LTCs who attend CSP consultations (experts by experience)

Operationalisation of the methods used can be seen in Figure 5 (page 75). The programme theories became more refined at each phase of the study as they were tested with a broad range of programme stakeholders to reflect different perspectives. The diagram shows how the three phases had a range of data strands feeding into them, which reflects the iterative nature of realist evaluation (Pawson and Tilley, 1997).

## Data collection

Practitioners tend to have specific ideas on what works within CSP (mechanisms) because they are likely to have experienced successes and failures (outcomes) and they are likely to have some awareness of people and places for whom and in which CSP works (context). Conversely, people who use services are more likely to be aware of mechanisms, such as changes in the way they feel, than contextual constraints and outcome patterns (Pawson and Tilley, 1997). According to Manzano (2016) it is best to begin by interviewing people who a) know the programme well and b) monitor what goes on, for example, ward managers. This enables programme theories to quickly take shape so that they can be tested in future interviews with other stakeholders. Manzano (2016) suggests interviewing practitioners next, because they frequently see themselves as “picking up the pieces” following programme implementation and tend to know about programme barriers and unintended consequences. Manzano states that interviews with people who use services (in this case, people with LTCs) may follow, as they tend to be experts on how some of the programme mechanisms may have influenced some of their outcomes. The three phases of this study follow Manzano’s “top-down” approach to data collection, so that all aspects of the programme theory (context, mechanism and outcome) are explored in depth. Ensuring close collaboration with stakeholders throughout this three-phase study will be key to the successful translation of knowledge into clinical practice.

## Data analysis

The purpose of realist analysis is to see if the proposed programme theories will explain the complex outcome patterns triggered by the CSP intervention (Pawson and Tilley, 2004). Realist analysis is not a defined separate stage of the research process;

it is an ongoing iterative process of placing nuggets of information (Pawson, 2006) within wider configurational explanations (CMOCs). Realism assumes that there will be a nuanced outcome pattern of successes and failures within and across interventions, because of mechanism-variation and relevant context-variation (Pawson and Tilley, 2004). Thus, the task at hand is to pinpoint the configuration of features needed to sustain the CSP process. Analysis which explores data through a realist “lens” was applied to the three phases of data collection.

In addition to the three data collection phases, I took brief notes during observations of CSP consultations (n = 5) and Year of Care training events (n = 3). Consultations were selected opportunistically after a gate keeper introduced me to Year of Care trainers, who invited me to the training events and suggested practices who were keen to be involved in the study. Manzano (2016) highlights the value of maintaining a flexible approach to developing, refining and testing programme theories, and suggests that this can involve asking different or additional questions in future interviews with different respondents, going back to the literature, or observing key processes, and so on. This flexibility was emphasised in my ethical approval applications as I reinforced the iterative nature of realist evaluation and the potential to go back and forth between data strands.

I attended the Year of Care training events with existing ideas about what I might expect to see, whilst keeping an open mind for new explanation of how CSP worked. The three events were spread over the duration of the study and served different purposes for me: one took place in the first few weeks of me commencing the project

and was focused around setting up the House of Care model in practice. Along with my initial scoping of the literature, mind mapping sessions with my supervision team, and observations of CSP consultations, it helped me to understand the CSP process and what it “should” look like in practice. In particular, it gave me a clearer understanding of the resources that CSP offers. Another training event took place around halfway through my study and included video footage of “good” and “bad” exemplar CSP consultations. Whilst I did not take any direct quotes from people at the training event, my notes became data in that they helped to shape some of the programme theories. The third training event occurred when I was writing up my thesis and was focused around the CSP conversation. It enabled me to reflect on my findings and how far policy and practice had come since the study commenced; thus helping me to shape sections of my discussion chapter.

The five consultations I observed were carried out across two practices by two nurse practitioners (one in each practice) and one Healthcare Assistant. The first two observations occurred early in the data collection process and helped with IPT development as I tried to understand a) what practitioners did in practice, in terms of phrases or tone of voice used to engage people with LTCs; b) how much people with LTCs took the lead in the interactions; c) whether people with LTCs received preparation prompts and whether they were using them in the consultation; d) whether specific CSP resources were being implemented and what effect they had on the conversation; e) any contextual differences. The observations also helped with the analytical process in phase one as they added substance to the literature. The following three CSP consultations I observed occurred later in the data collection process. They were useful for guiding and informing the interviews and highlighting

different and/or additional questions to ask. My notes from each observation were typed (there were 2 pages of notes per observation) and sections were colour coded and mapped onto the relevant programme theory mind map. There were no direct quotes taken from the consultations in terms of what people with LTCs and healthcare professionals said, however, my notes and observation of the events did end up being data in that they helped shape the programme theories and therefore contributed to the realist analytical process. The methods used in phase one are detailed on page 76.

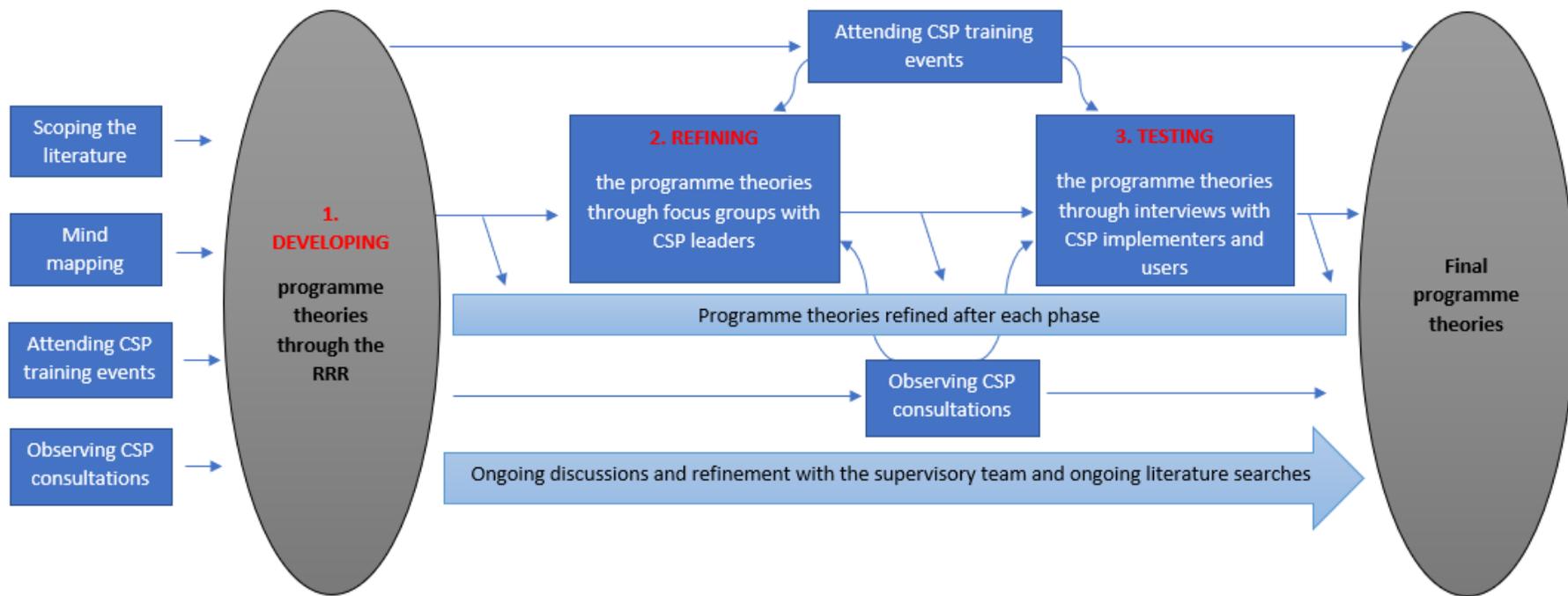


Figure 5: The operationalisation of the method

## Methods

### Phase 1: Developing the programme theories

The methods used for this phase of the study are described below following the realist and meta-narrative evidence synthesis (RAMESES) publication standards (Wong et al., 2013). There was an iterative relationship between theory development, refinement and testing, within and across the three phases of the study, which is core to realist sense-making processes, however, they are presented as distinct phases for the sake of clarity.

### *Changes in the review process*

This study explores the strategies/interventions, contextual factors and mechanisms that work in configuration to influence how CSP works in practice. Some other initiatives are thought to support CSP, including peer support groups and education programmes, and there are many organisational and structural processes that must be in place before CSP can work. However, after much consideration through scoping the literature, and discussing the scope of the project and developing mind maps with my PhD supervision team, I decided to focus this study on the CSP consultation itself and the interactions that take place within it to achieve person-centred, coordinated care.

### *Rationale for using a rapid realist review*

The purpose of a realist review is to develop and test, through an iterative process of literature searching and analysis, programme theories that carry the greatest possible explanatory potential for the inner workings of an intervention (Pawson and Tilley, 1997). Saul et al. (2013) developed rapid realist review (RRR) following the principles outlined in realist and meta-narrative evidence synthesis (RAMESES) publication standards (Wong et al., 2013), so that a realist approach can be applied to a knowledge synthesis process in order to produce a product that is useful to policy makers where there are time limitations. RRR is explicitly designed to engage knowledge users and stakeholders to define the research questions and streamline the review process (Saul et al., 2013). In addition, results are presented with a focus on context-specific explanations for what works within a particular set of parameters rather than producing explanations that are potentially transferrable across contexts and populations (Saul et al., 2013).

I used methods consistent with RRR to explore how, why, for whom and in what circumstances CSP is effective for people with LTCs, whilst keeping within the time and resource parameters of this study. Saul et al.'s protocol (2013) suggests the following essential team members for a RRR: project manager; local reference group and expert panel; librarian; review team; synthesis lead and academic or research lead. In this particular study, I undertook the role of the project manager and received guidance from Northumbria University's Library Information Specialist regarding optimising

the literature search. Since the RRR forms part of the wider PhD research project, the expertise usually provided by the local reference group and expert panel was instead provided by the PhD supervision team who have a breadth of knowledge in both CSP and realist methodology. The remaining roles, namely, the review team and academic lead were also fulfilled by members of the PhD supervision team.

### *Scoping the literature*

A key element in realist review is the scoping phase, which involves exploring the presence of “educated guess” theories, or IPTs, about how a particular programme works and testing their explanatory value; they are not considered definitive until they have been tested (Saul et al., 2013). The initial research questions were broad to allow the formulation of IPTs. They were: what is CSP and what does it look like in practice? How does CSP work for people with LTCs? In what circumstances does it work best? Eleven IPTs were developed through: scoping policy documents, protocols and key research papers using the Google and Google Scholar search engines; mind mapping sessions with the supervision team; attending CSP training events and observing CSP consultations. These IPTs are presented below and formed the basis for the more formal literature searches described from page 81 onwards.

1. When results are sent to people with LTCs ahead of their CSP consultation (resource) following an information gathering appointment (context), they have chance to think about and accept their current

health status (reasoning) and consultation time can be used as purposefully as possible (outcome).

2. When results are sent to people with LTCs ahead of their CSP consultation (resource), time-pressured practitioners (context) are able to spend consultation time focusing on the needs of the person with LTCs rather than reporting results (reasoning), giving them better job satisfaction (outcome).
3. When question prompt sheets are sent to people with LTCs ahead of their CSP consultation (resource), the pre-existing conception of the consultation being doctor-led (context) shifts; people with LTCs feel like permission has been given to ask for information specific to their individual needs and their confidence to ask questions increases (reasoning), so they become more engaged and ask more questions (outcome).
4. When question prompt sheets are sent to people with LTCs ahead of their CSP consultation (resource), practitioners who are open to people actively participating in the consultation (context) spend time focusing on what is important to the person (reasoning), which gives the practitioner better job satisfaction (outcome).
5. When practitioners give evidence-based information and support people with LTCs to set goals (resource) in the context of both parties being engaged in the CSP process, improved knowledge of the person leads to increased confidence (reasoning) to make informed decisions about their health care goals (outcome).

6. When a written care plan is shared within and across teams (resource) for people with multimorbidity who require care from different providers at once (context), they receive one coherent message which enables them to feel more engaged in the CSP process (reasoning), so they adjust their lifestyle appropriately (outcome).
7. When practitioners simplify explanations by using non-medical language (resource) for newly diagnosed people who may not know much about their condition(s) (context), the newly diagnosed person feels more confident to ask questions (reasoning), resulting in improved compliance with treatment or lifestyle improvement approaches (outcome).
8. Practitioners who have had communication training (resource) and are committed to partnership working (context) can interpret the needs of people with LTCs and modify their communication style to suit them (reasoning), which results in engaged, informed people (outcome).
9. People with multimorbidity engage in discussions around sensitive topics (resource) when they are engaged and informed (context) because they feel able to contribute to the conversation and mention anything that is of importance to them (reasoning), leading to a better relationship and shared decision making (outcome).
10. When support services are offered (resource) to people with multimorbidity who are experiencing psychological/emotional distress (context), they feel reassured that their practitioners care about their personal wellbeing (reasoning), leading to increased trust and reduced stress and anxiety (outcome).

11. When practitioners ask lifestyle questions (resource) to people with LTCs, whom they have a longstanding relationship with (context), people with LTCs understand that this will affect the way they lead their life (reasoning), therefore they initiate healthier behaviours (outcome).

As the study progressed, some of the IPTs were discarded because they were not sufficiently substantiated by the data, and others were merged (see Figure 11 on page 101 for a flow diagram explaining this process). The methods used to progress these eleven IPTs into seven developed programme theories are described in detail below.

### *Searching processes*

Systematic searches were undertaken in two electronic databases; CINAHL and ProQuest Hospital Collection (comprising 5 sub-collections: Family Health Database; Health & Medical Collection; Health Management Database; Nursing & Allied Health Database; Psychology Database). Searches were initially restricted to these databases because they provided a broad collection of healthcare journals, evidence-based resources and full-text dissertations to begin the RRR. The supervision team helped to streamline the searching by suggesting key papers and reference lists (Saul et al., 2013) to keep within the time parameters of the study. The databases were searched from their inception dates to December 2015, using an adaption of the Population Intervention Comparison Outcome (PICO) search strategy (Sayers, 2008). The search strategy can be seen at Appendix 4. Language restrictions were applied (English only) due to the cost and inconsistency of translations, and

publications of any type were included. Details of the search strategy are described below.

The search terms were created according to how CSP has been conceptualised as combinations of process resources, including preparedness, goal setting, communication, shared decision making and support for self-management (Lhussier et al., 2013). Furthermore, the searches were adapted to reflect the shift in terminology described in Chapter 1. For each database, searches were undertaken using these resources as subject headings where possible. For example, “shared decision making” and related free text terms (with truncations), “AND communication”. The search terms were broad and covered *participants*, *intervention resources* and *outcomes* and these were combined with the AND/OR Boolean operators. For each search strategy the first 100 titles and abstracts were screened against inclusion and exclusion criteria to ensure a manageable number of papers. In total, 165 potentially eligible studies were obtained in full text and were re-screened. 22 of those studies were acquired from reference lists of key papers, and through forwards and backwards citation searching (see figure 12 on page 102 for a flow chart of the screening process).

### *Selection and appraisal of documents*

Although the initial focus of the study was around CSP for people with multimorbidity, literature on CSP and multimorbidity is limited, therefore, studies were included if they considered managing single or multiple LTCs

through CSP conversations and/or shared decision making and/or support for self-management. If a relevant study focused on single LTCs, this was considered during analysis. Studies were excluded if they were not about the interaction between people with LTCs and healthcare professionals or if they did not contain any of the key concepts outlined above.

### *Data extraction*

51 full text articles that were included after screening were reviewed in more depth and assessed for relevance and rigor, as per realist approaches (Pawson, 2006). Key information (including aims, findings and links to theory) was recorded on a data extraction form (Appendix 5). In order to identify key elements of importance to the success or failure of CSP for people with LTCs using a realist perspective, information was also gathered on context, mechanisms and outcomes.

### *Analysis and synthesis processes*

Although I carried out the realist synthesis alone, my findings were regularly shared and discussed within the supervision team to ensure validity and consistency in the inferences made. In particular, I attempted to identify prominent recurrent outcomes patterns in the data and then sought to explain these through the means (mechanisms) by which they occurred and under which conditions (context). For example, I noted that in the included studies, people with LTCs may be more engaged during the CSP consultation when they had been sent their latest test results prior to their appointment (Hong et

al., 2010, Mathers et al., 2011, Tribal Consulting, 2009). During data synthesis I then aimed to provide an explanation of this outcome pattern through the identification of mechanism(s) and further exploration of the role of context. As I delved further into the included studies for an explanation, data emerged that people who were prepared in this way felt they could spend time reflecting on their current health status and preparing questions to ask (mechanism), but only when they understood their role in self-management (context). I developed this into a programme theory to be refined and tested throughout the rest of the study. This process was supported by using mind maps to link relevant sections of text to capture themes that might contribute to theory testing. I acknowledge that I could have used “framework” analysis (Srivastava and Thomson, 2009) on an excel spreadsheet, or constant comparative analysis (Glaser, 1965) using NVivo, but I preferred the colourful, visual nature of mind mapping. The coded sections of text were used to either confirm, refute or refine the programme theories.

## Phase 2: Refining the programme theories

Only a small proportion of practice initiative actually make it to the published literature and in acknowledgement of this, I wanted my programme theories to reflect strategic practice thinking on CSP. Therefore, I facilitated a focus group involving five CSP leaders, and realist interviewing techniques (Manzano, 2016) were employed in order to explore the programme theories that were developed in phase 1. The RAMESES II reporting standards for realist evaluations (Wong et al., 2016) state that different processes can be used for developing IPTs, including literature reviews (as has been done here through

the RRR), programme documentation reviews, and interviews and/or focus groups with key informants. In the focus group, leaders either agreed with, disagreed with or changed elements of the programme theories, thus adding their experiential knowledge to the programme theories drawn from the literature.

### *Recruitment and location*

Thirteen people who are involved in commissioning or leading the implementation of CSP were highlighted as potential participants. They were purposely sampled based on their locality (North East region) and their role in CSP. They were contacted via email and information was given about the study (Appendix 6). Eleven of those people expressed interest, and potential dates for the focus group were sent to all eleven. The most popular date was chosen, with seven participants confirming attendance. I developed an information sheet stating the programme theories (Appendix 7) and sent it via email to all seven confirmed participants two weeks before the focus group was scheduled to take place. I asked them to read through the information, essentially so they would be familiar with the theories we would be discussing, which would save time during the focus group (Pawson, 2006). Five out of seven leaders attended on the day (four females and one male). The focus group took place at a central meeting place for all of the participants. A large meeting room off a quiet staff corridor at Northumbria University was pre-booked for the event, and only two co-facilitators and the five participants were present during the discussions. Refreshments were provided for a gesture of appreciation for their time.

### *Data collection and analysis*

Leaders were presented with seven programme theories which were formulated during the RRR in phase one, and which they had already been sent via email. Each programme theory was presented as a CMOC on a large piece of flip chart paper, with four coloured cards stating the resource, context, reasoning and outcome. It was set out in non-technical terms, like such: *when X happens... in A context... it leads to Y (change in reasoning) ... which leads to Z outcome*. The thinking behind this was to help participants to quickly understand the realist focus on theory, without getting into the technicalities of realist methodology and its particular language, and whilst keeping me focused on theory refinement. The coloured cards were stuck with blue tack, so that they could be moved around. The programme theories were placed in the middle of the table with coloured pens and stationary for making changes, and there was also an identical set of programme theories on the wall for them to see. This was so that participants had a choice of writing down their ideas and moving the cards around or discussing their opinions and a co-facilitator would write them down. The programme theories were ordered in a specific way, to follow an implementation chain which leaders were likely to be familiar with, as well as to reflect the amount of literature substantiation for each. *Preparation* was least supported by the literature; thus, it was first on the agenda. *Shared decision making* and *support for self-management* (programme theory 7, which was removed after this phase) were most supported by the literature, so they were discussed last. This meant that if we ran out of time before

discussing the final programme theories, they would still be substantiated by the literature.

Ten minutes were allocated to discuss each of the programme theories. The first two programme theories were allocated an extra five minutes each to allow for leaders working out what was being asked of them. The session lasted for two hours and the outcome was a list of refined theories about how CSP “should” look, from the perspective of leaders. This can be seen in Appendix 8. The programme theories were the framework for data collection as well as the outcome of the discussions. One month after the focus group, the list of refined programme theories, along with an algorithm depicting how the key concepts of CSP may be linked, were sent via email to the leaders, and feedback was obtained from each leader. The programme theories were further refined to incorporate this feedback, and the refined list was re-sent via email to all leaders. This cycle was repeated (twice) until all leaders were satisfied with the refined programme theories. The list of refined programme theories, with an explanation of how they may be linked, is presented in Appendix 9.

### *Ethical considerations*

All five leaders had worked within a close-knit Year of Care team for some years and were driven by the same vision to make CSP a reality in practice. The use of a gatekeeper, within this context where anonymity within the group is impossible was carefully considered from an ethics perspective. Potential

for coercion was avoided as much as possible as I made it clear on the information sheet that participation was entirely voluntary. Leaders were contacted twice, via email and the second email stated that if they did not respond within three weeks it was assumed that they did not wish to participate. It reminded them that if they chose not to participate, they would not be affected in any way. Informed consent was obtained (Appendix 10) from each leader when they entered the research room, and participants were informed of their right to withdraw themselves or any data they gave, from the study within one month after their participation. A digital recorder was used to record the discussion as support for the analysis. The recordings were transcribed in order to lift illustrative quotes for the purpose of reporting and publication. All leaders were made aware of this and consent was obtained before the discussion commenced.

All data, including the digital tape recordings that were produced, were stored on the secure university U drive, which is password protected. All corresponding emails in relation to this research were sent and received via a Northumbria University email account, which is also password protected. All data will be destroyed in line with The Data Protection Act (1998) one year after the completion of the study, i.e. the secure U drive and digital tape recordings will be destroyed, emails will be deleted, and any paper files will be shredded. All information obtained will continue to remain anonymous and confidential and will be used for the purposes of this research project only.

## Phase 3: Testing the programme theories

### *Recruitment and location*

There is widespread agreement among qualitative researchers that there is no set number of interviews that can be assumed to achieve saturation (Morse, 1995, Saumure and Given, 2008). In realist evaluation, “the sample can only be weakly elaborated beforehand” (Emmel, 2013, p. 154) because “fragments” of evidence (Emmel, 2013, p. 141) are obtained using different methods of investigation, and they are pieced together to build up theories from relevance to rigour (Pawson, 2013). Thus, the precise number of participants needed for phase three could not be decided *a priori*, and recruitment therefore continued until the data reached completeness and saturation (Guest et al., 2006, Corbin and Strauss, 2008). With this in mind, 17 implementers of CSP were approached via email and informed about the study (Appendix 11). They were purposely sampled from GP practices in the North East of England that are implementing CSP. Nine of the 17 implementers agreed to take part in the study (5 nurses and 4 GPs). Interviews were arranged at their places of work, at a time that would cause them minimal disruption. This allowed for knowledge to be built on what happens in natural settings, rather than an unfamiliar room, and this knowledge contributed to building, testing and refining the programme theories.

A recruitment poster (Appendix 12) was displayed in the waiting room of five participating GP practices in the North East of England. Twenty copies of the participant information sheet (Appendix 13) were sent to each of the five

practices. The recruitment poster informed any person with LTCs who was interested in taking part to obtain an information sheet from a healthcare professional, and if, after considering the information, they still wanted to participate, they were advised to contact me via telephone or email. Eleven people who receive CSP at one of the participating GP practices, for one or more LTC, volunteered to take part in the study. Interviews were arranged at a time and place of their choice, to maximise participation.

### *Data collection and analysis*

Realist interviews (Appendix 14) were used to test the programme theories that were developed and refined in phases 1 and 2. Realist interviews differ from typical qualitative interviews in that the subject matter of the interview is the programme theory. Participants' (implementers and experts by experience) accounts confirm or falsify, and subsequently test the theory. Pawson and Tilley (1997) propose that realists should interview differently from constructivist researchers, i.e. they should ask questions like a realist. The objective is not to elicit participant narratives; it is to unearth the inner workings of the programme by capturing the participant's stories (Patton, 2003), because those experiences of the programme can help identify key contextual differences in the construction of the outcome patterns.

Implementers and people with LTCs have different experiences of the programme (Pawson and Tilley, 1997), thus there were separate interview schedules for each, with questions that were constructed to reflect their awareness and experiences of CSP (Dalkin et al., 2015). The questions were

semi-structured to allow for qualitative views to be explored through conversations, and flexible because interviews should plan for the unplanned and be ready for the exploration of unexpected contexts, mechanisms and outcomes emerging (Pawson, 2013). To encourage implementers and people with LTCs to tell me their stories, I abandoned the traditional insider/outsider approach and arrived at the interviews with some knowledge of what happens in the natural setting (Manzano, 2016), which I had obtained through observing CSP consultations.

### *Ethical considerations*

Many of the CSP implementers I contacted regarding the study had worked within close-knit teams for several years, therefore, maintaining anonymity of potential participants at the recruitment stage was a challenge. To manage this, I sent separate personalised recruitment emails, rather than a generic “one-for-all”. I also had to consider ways to ensure implementers and people with LTCs were not coerced to take part in the study, whilst at the same time maximising participation so as not to jeopardise my study. This was not always an easy balance to reach. Recruitment of implementers took much longer than I had anticipated because of their busy schedules and time limitations, and I found maintaining contact without coercing them very challenging. For example, I had received email responses from several implementers stating that they were interested in participating in the study, however, my attempts to arrange an interview were sometimes overlooked and I would not receive a response until months later when those implementers would resume contact with me to make an arrangement, with apologies for the delayed response.

Potential for coercion was avoided as much as possible as I made it clear on the information sheet that participation was entirely voluntary, and if they chose not to participate, they would not be affected in any way.

Informed consent was obtained via a consent form (Appendix 10) which was issued to implementers and people with LTCs when they entered the interview room. A digital recorder was used to record the interviews as support for the analysis. The recordings were transcribed in order to lift illustrative quotes for the purpose of reporting and publication. All implementers and people with LTCs were made aware of this before the interviews commenced. Anonymised data was stored on the secure university U drive, which is password protected. The digital tape recordings that were produced were stored securely at Northumbria University until the research was completed. Confidentiality was maintained as much as possible within the small world of CSP implementation and use. Participants were informed of their right to withdraw themselves or any data they gave, from the study within one month after their participation.

All data, including the digital tape recordings that were produced, was stored on the secure University U drive, which is password protected. All corresponding emails in relation to this research were sent and received via a Northumbria University email account, which is also password protected. All data will be destroyed in line with The Data Protection Act (Great Britain, 1998) one year after the completion of the study, i.e. the secure U drive and digital tape recordings will be destroyed, emails will be deleted, and any paper files

will be shredded. All information obtained will continue to remain anonymous and will be used for the purposes of this research project only.

### Integration of the data across the three phases

The methods used in this study produced large amounts of qualitative data: interviews ranged from 24 minutes to 2 hours and 12 minutes; observations produced a total of 10 pages of typed notes; training events produced a total of 13 pages of typed notes; the focus group led to 36 pages of transcription, interviews led to 331 pages of transcription. This data was challenging to organise at times. When I was familiarising myself with realist methodology, I learned that this messiness had been given a unique term: “CMO soup”, which fellow realists often described “drowning” in. As I progressed through the analysis, it became apparent that this metaphor was entirely suited to the process, and I felt that I needed to embrace the mess in order to make sense of the data. Whilst I have presented the findings as six clear and succinct sub-chapters with three distinct data collection phases, in reality, the process of getting to this point was lengthy and complex. Initially, I used mind maps to draw out potential CMOCs and sent ideas back and forth to my supervision team for discussion and deliberation; this often took the shape of email exchanges, two of which are shown as examples below.

12/05/2015 email discussion around this CMOc. ML responded:

Resource:

A healthcare professional with a flexible approach to communication in the care planning consultation... (or is the resource the communication skills training that they have received?) I WOULD ERR ON THE SIDE OF THE TRAINING – BUT SEE WHAT YOU MIGHT FIND EVIDENCE FOR – the paper does say communication skills training can lead to better patient-doctor relationships, but I think the resource here in this context is the healthcare professional with a flexible approach to communication.

Context:

The patient is elderly or has a poor education and is less likely to ask questions or engage in the consultation

Reasoning:

The healthcare professional recognises that the patient may need some guidance (PERHAPS BETTER PHRASED AS THE PROF RECOGNISES THAT STANDARD COMMUNICATION IS INSUFFICIENT) and modifies their communication style WOULD BE GOOD TO KNOW HOW (THIS COULD BECOME A RESOURCE THAT TRIGGERS A CHANGE OF REASONING IN THE PATIENT), the patient engages in the conversation I THINK THIS IS PART OF THE OUTCOME?

Outcome:

Collaborative communication between healthcare professional and patient in the care planning consultation

*Figure 6: Email response showing the development of a potential IPT around communication*

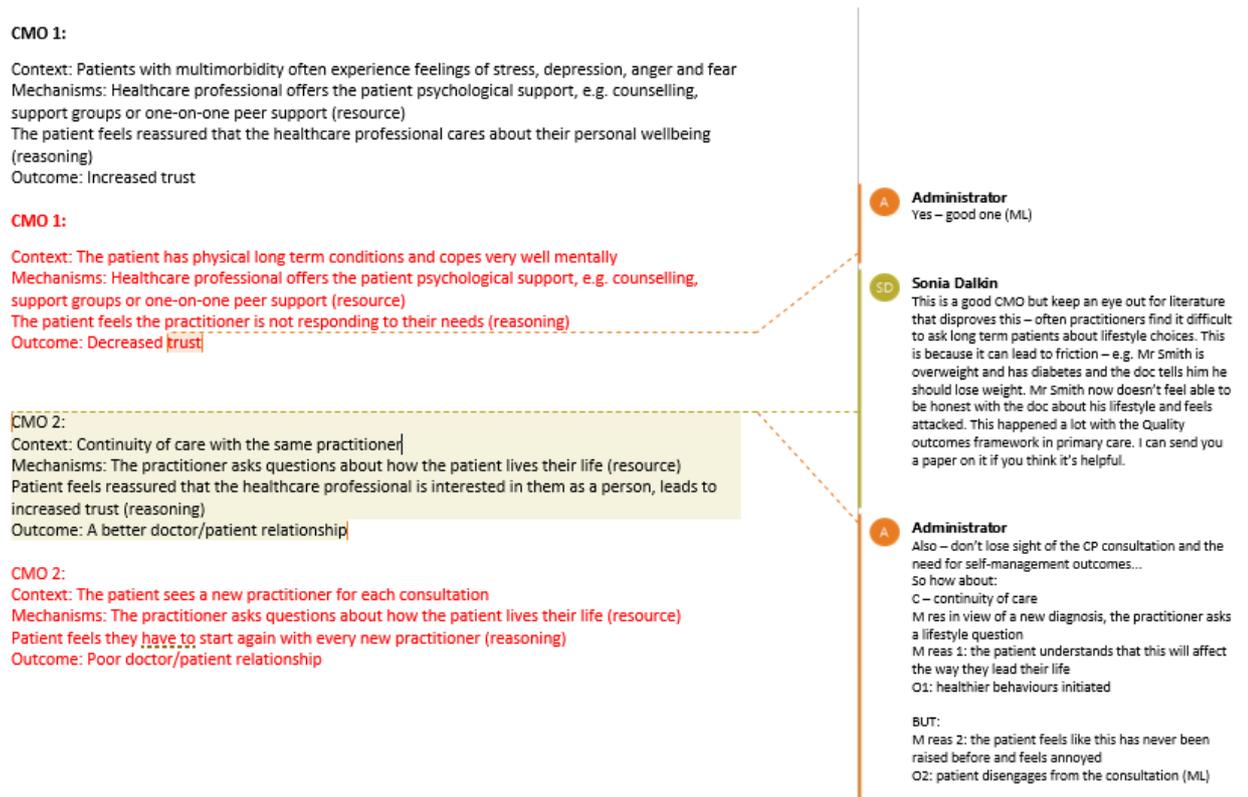


Figure 7: 18<sup>th</sup> July 2015. Email response showing the development of a potential IPT around psychological support

In Figure 7, the supervision team can be seen fulfilling the stakeholder role in the RRR process; guiding me towards relevant research papers so that key information was not missed. As aforementioned, when searching for evidence to prove a programme theory, in realist evaluation we also look for failed outcomes and the associated “missing mechanisms” and “negative contexts” (Mukumbang et al., 2018). The red text shows the opposite of the potential IPT. In order to maintain transparency, I created working documents for each potential programme theory using Microsoft Word and updated them whenever supporting/refuting evidence emerged and/or a decision was made to amend/keep/set aside an IPT. This included notes from CSP observations, training events, conversations with stakeholders, and my thoughts during each

phase. Below are some extracts taken from these working documents, highlighting my ideas particularly around context.

***“The True Blue model was successful in its primary aim that patients using its model of care showed a clinically significant improvement in depression. Improved 10-year cardiovascular risk, exercise rates, and referrals to exercise programmes and mental-health workers were also observed. Personal lifestyle goals were set by almost all (96 per cent) of intervention patients. Nurses, GPs, and patients found that the care plan provided a structure for teamwork and communication between the healthcare providers and patients, and the information and prompts within it ensured a comprehensive approach to care.” (Morgan et al., 2015)***

Explanation: A care plan has a clear benefit to clinical outcomes and the patient’s likelihood of setting goals, however it is difficult to say from this text whether this was directly related to the presence of a care plan. The care plans used here are specific for multimorbidity, however they are used in Australia and therefore may be different to the NHS standard care plans for multimorbidity. It does support CMOC 5 in that written documentation can be used as a tool for communication between providers. This text prompted me to add in to the CMOC that the patient also experiences benefits of having a copy of the care plan – it helps them to remember the goals they set and emergency plans, etc.

***“Asked if they wished to discuss anything else concerning their healthcare, they said: John: No I don’t think so, no. No, we’re alright aren’t we? Sheila: Yes, we’re alright as long as I can keep going. John: Aye and I can keep going. Sheila: And you can keep going. You can keep breathing yes.” (Newbould et al, 2012)***

Explanation: Note how they were asked if there was anything else they wanted to discuss concerning their *healthcare*. This is quite a closed question and is possibly the reason why they answered no, despite the text saying they were confused about some aspects of the patient’s medication. In this example the patient did not have continuity of care, up-to-date information was not sent between the teams involved, the patient did not receive one coherent message and therefore did not adjust his life appropriately. Instead, he and his wife just accepted their existence, for now.

***“Written documentation may be useful if care planning is to be sustained over a period of time with a number of professionals, or when continuity is more difficult to achieve. It may also function to maximise the impact of care planning, enhancing behaviour change by providing a record which can be used to self-monitor progress, and to specify agreements between patients and professionals.” (Newbould et al, 2012)***

Explanation: This text supports CMOC 5 in that having a written care plan for people who require complex care from different providers is useful for both practitioners and people with LTCs. For practitioners it may enable better coordination of care and for people with LTCs it may promote behaviour change.

Figure 8: Extract from working document

Once the programme theories were developed and then further refined in the focus group with leaders (see Figure 9), I went back to mind maps to draw out the refinements, with help from my supervision team, adding to the working documents whenever changes were made (or not).



*Figure 9: Outcome of the focus group (changes to the programme theories)*

Interview transcriptions were particularly difficult to code and map onto relevant programme theories because much of the data could be seen to support several programme theories, given their interrelatedness. In Figure 10, I had originally coded some data under the “preparation” theme (yellow), however, after closer scrutiny I moved it to “conversation summary” (green) as it was more supportive of programme theory 5. This emphasises the value of manually coding and physically being able to move data around to make sense of it.

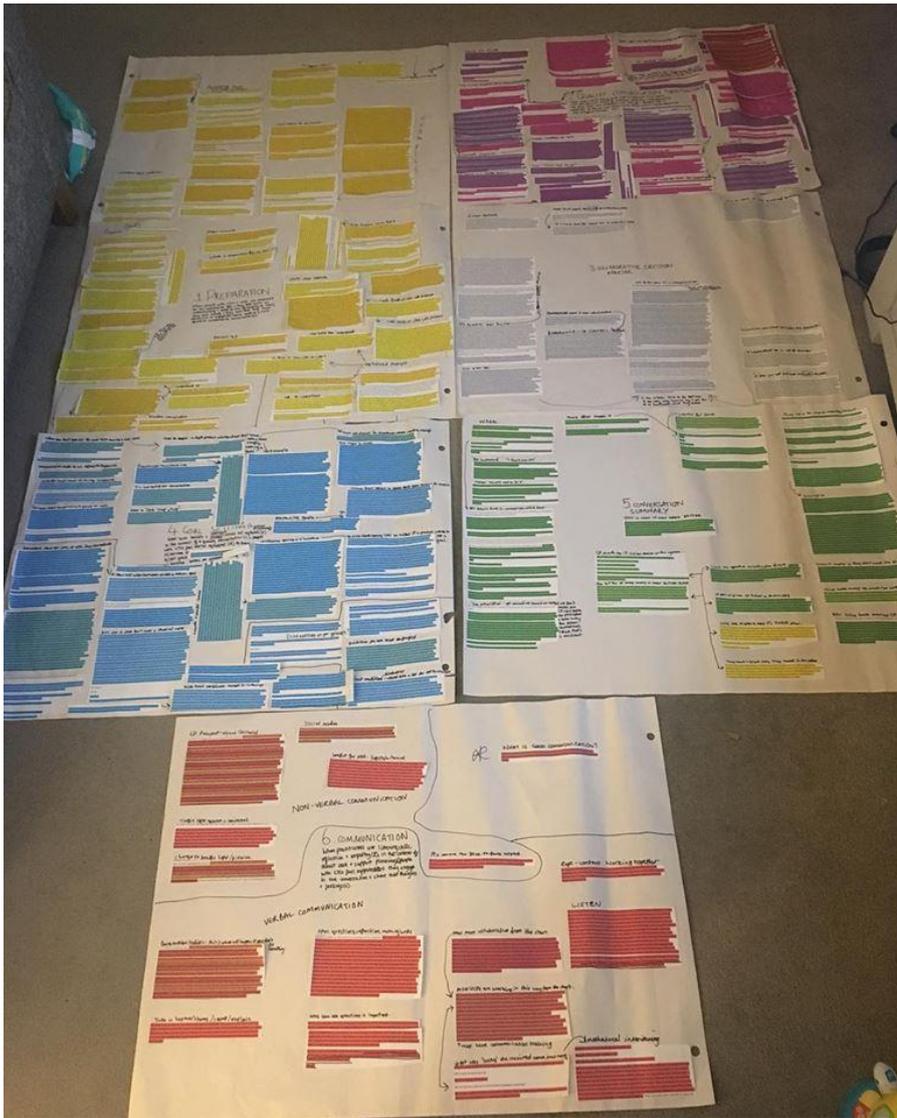


Figure 10: Some of the coded data after the phase three interviews

These figures highlight the iterative nature of realist evaluation. The methods used to analyse the data, particularly mind maps and working documents, were key to ensuring that data was integrated across the three phases and that transparency was maintained as much as possible.

## Ethical approval

I applied for ethical approval for phase two and phase three separately, because data collection at phase three would depend on findings from the previous phases. Ethical approval for phase two was granted from Northumbria University Faculty of Health and Life Sciences Research Ethics Committee on 15/05/2015 (Appendix 15). Following completion of phase two, I applied for ethical approval for phase three, which was granted on 12/04/2017 (Appendix 16). The NHS local ethics committee approved the study and HRA approval was granted (REC reference number: 17/SC/0301) on 23/08/2017 (Appendix 17). Following further checks, I obtained Research & Development approval in the form of an NHS Research Passport from The North of England Commissioning Support Unit (NECS) on 06/03/2018 (Appendix 18).

## Chapter Summary

This chapter has explored and outlined the research philosophically and methodologically, so that the complexities of CSP can be acknowledged throughout the evaluation. The RRR has generated specific, testable programme theories, and two subsequent data collection phases have been designed in order to generate data that is capable of refining and testing the programme theories.

The next chapter is presented as six distinct sub-chapters matching the programme theories that have been developed, refined and tested through this research. They are: preparation; quality conversations; goal setting; shared

decision making; conversation summaries; and communication. Although three separate phases have been described in this chapter, data has been collated into one Findings sub-chapter per programme theory to reflect the iterative nature of realist evaluation and the fact that all methods have a “conceptual refinement function” (Pawson and Tilley, 1997, p. 167). Although the sub-chapters are presented separately, they are interlinked, i.e. some discuss the same tools or concepts but in different aspects. The significance of the links will be discussed in depth in Chapter 6.

## Chapter 4: Findings

This chapter will explore six programme theories, titled preparation, quality conversations, goal setting, shared decision making, conversation summaries, and communication. The seventh programme theory, which was about support for self-management, was developed in the RRR phase and was explored in my publication (Brown et al., 2018). However, it was set aside at phase two because leaders agreed that support for self-management is the whole premise of CSP; not just one element of it. It is therefore integrated into a middle range theory in Chapter 6. Figure 11 shows why and at what stages the eleven initial programme theories were reduced to six.

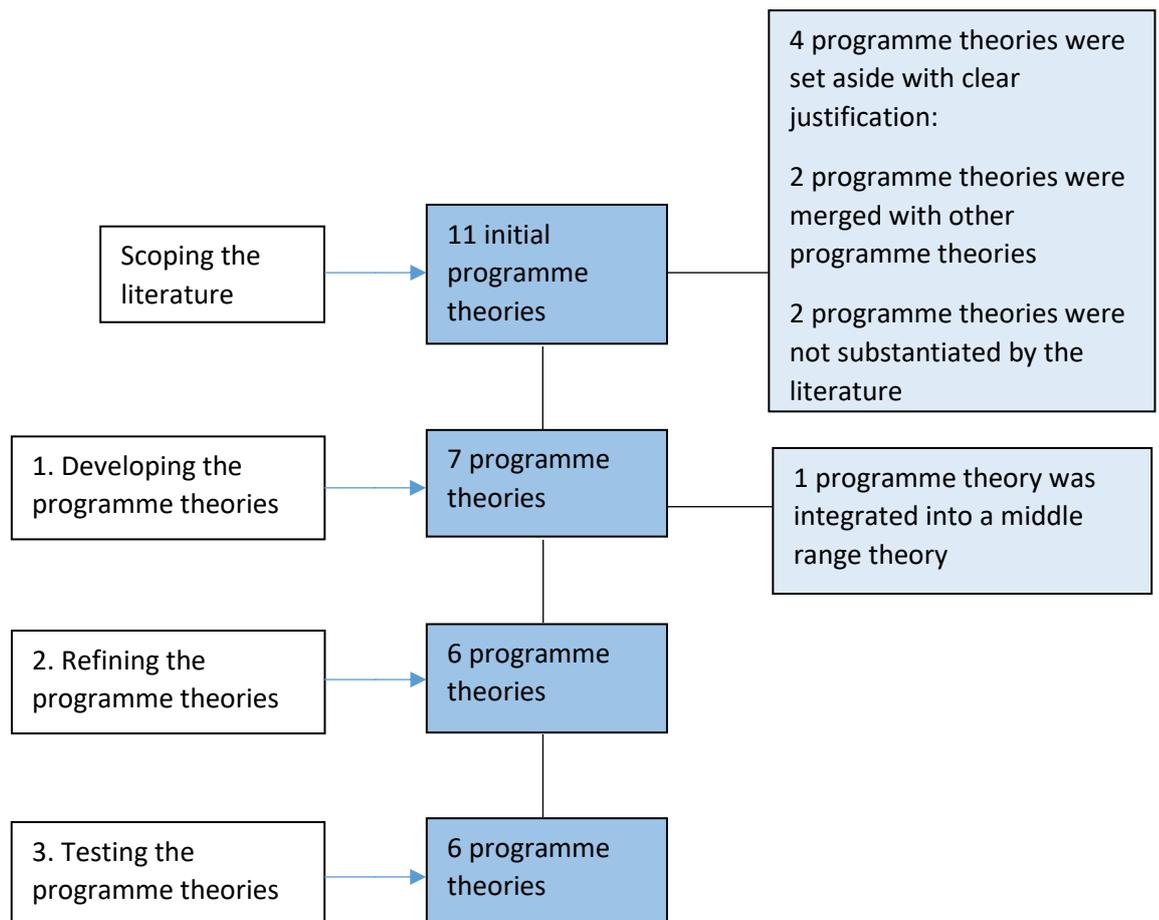


Figure 11: The programme theory trail

## Key details for this chapter

### Phase 1: studies included

Figure 12 shows the number of studies included at each stage of the RRR in phase 1 of this study. It outlines how I arrived at the 51 full text articles that formed the core of the review. Further information about each article can be found in appendix 19.

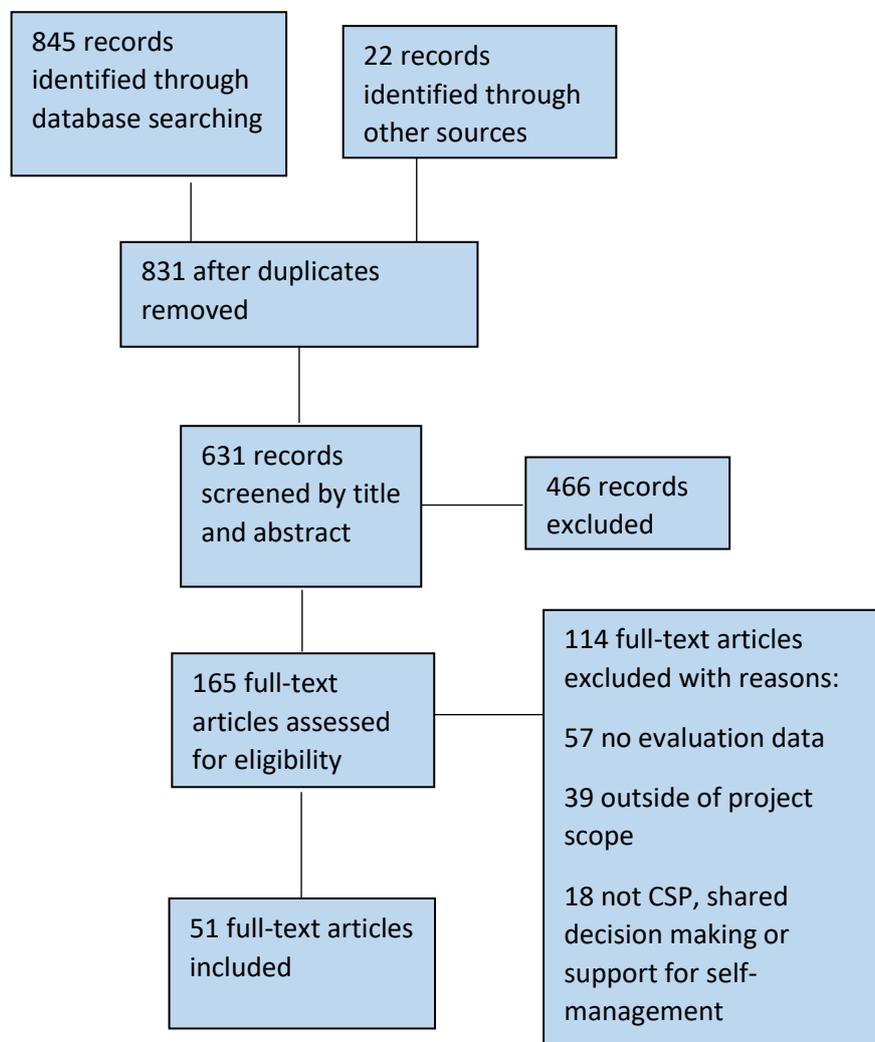


Figure 12: Flow chart of the screening process

### *Phase 2: discovery - programme theories are linked*

After phase 2 of the study, with the help of the leaders involved, I developed a depiction that shows how the programme theories may be linked (see Figure 13). Briefly, it shows that preparation is key to effective CSP. Better prepared healthcare professionals and people with LTCs have more time during the CSP conversation to focus on the person's agenda. During the conversation, the person with LTCs and the healthcare professional may collaboratively make a decision (when a decision needs to be made) and/or set goals. The CSP conversation may be summarised and owned by the person with LTCs. Throughout the whole process, effective communication is vital. If all of this is done well, support for self-management is achieved. The depiction will be displayed at the start of each sub-chapter, to remind readers that the programme theories are interlinked. It will be drawn on and developed further in Chapter 5 and Chapter 6.

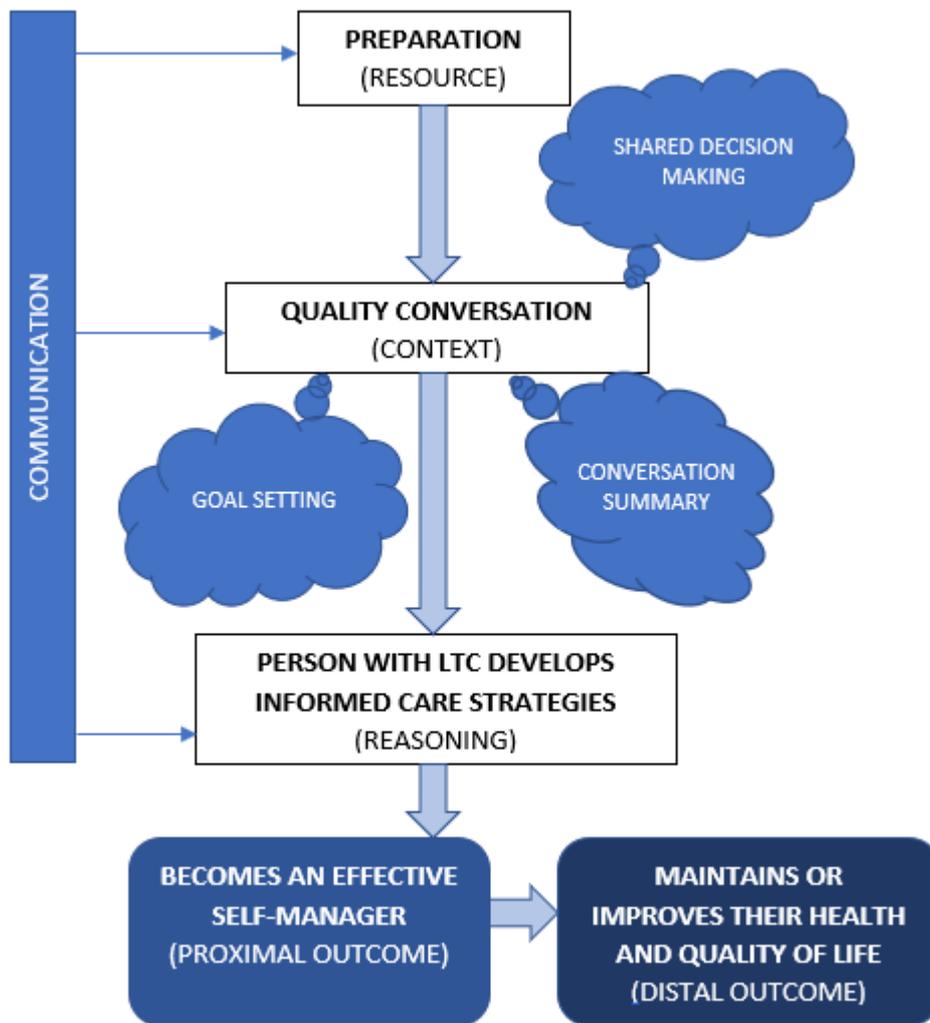


Figure 13: Depiction showing how the programme theories may be linked

### Terminology

Throughout my narrative of the chapter, I will use the term CSP, however, some of the literature reviewed in the RRR refers to care planning. In order to avoid unnecessary complications, I will only refer to care planning when participants use this terminology, or when quoting the literature.

Throughout the six sub-chapters, quotations from participants are either from leaders (L), implementers (I) or experts by experience (EbE). Some quotations from facilitators of the focus group (F) are also included. I will refer to healthcare professionals and people with LTCs when discussing them in the wider CSP context, and leaders, implementers and experts by experience when quoting participants of this study.

## 4.1 Preparation

Figure 14 below shows how preparation may relate to other CSP components, to form a tool that supports the self-management of LTCs.

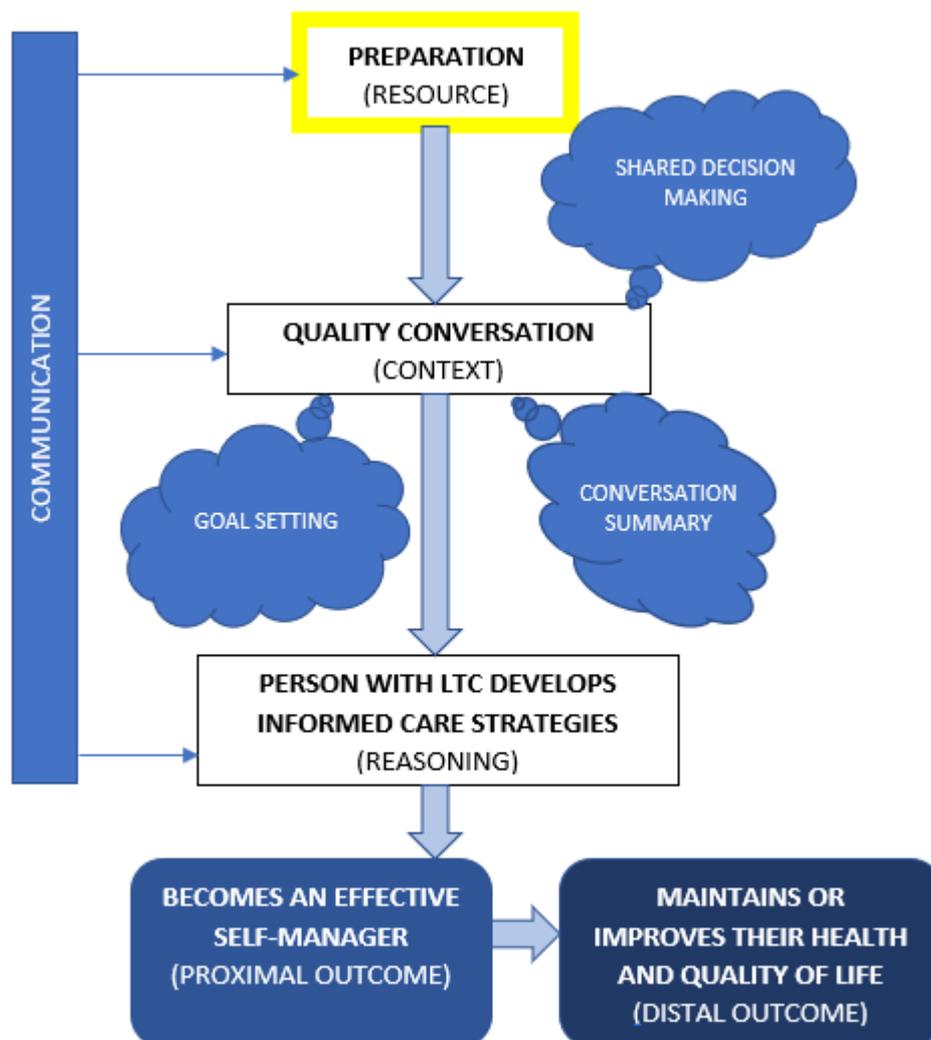


Figure 14: Preparation as a component of CSP

### 4.1.1 Developing the programme theory

The literature reviewed suggests that people with LTCs find it useful to receive their clinical results prior to their consultation (Doherty et al., 2012, Hong et al.,

2010, Lhussier et al., 2013, Mathers et al., 2011, Year of Care, 2011) and this information sharing is considered vital to effective CSP (Coulter, 2009, Year of Care, 2011). Many people have reported feeling more informed and better prepared for their appointment after receiving their results because it gives them time to think about their health status and prepare questions (Doherty et al., 2012, Mathers et al., 2011, Year of Care, 2011). Morton and Morgan (2009) suggested that this preparation enables people with LTCs to get the most out of the CSP consultation.

As part of the Year of Care pilot programme, Doherty et al. (2012) produced a paper describing the key drivers, theoretical underpinnings, and supporting evidence for the development of the programme. One of the fundamental stages to Year of Care CSP is the sharing of a person's biomedical results, usually by mail, prior to the consultation, with a reflection tool to use to prepare for the consultation. This step is considered the heart of the "informed, engaged patient" (Doherty et al., 2012). Upon evaluation of the pilot study, a person with diabetes stated that being prepared for the consultation works "really well" as there are "no surprises when you come" (Doherty et al., 2012, p. 186). Other people with diabetes reported feeling less nervous when they received their test results in advance (Year of Care, 2011). However, some healthcare professionals were concerned about the suitability of the results letters for all, suggesting that receiving their test results in advance of the consultation may scare some people off, as "health is one of those things some people would rather not know" (Doherty et al., 2012, p. 186). Despite this speculation, other reports have suggested that there is very little evidence that

people become anxious after receiving their results, stating that it is simply “a perception in some practices” (Tribal Consulting, 2009, p. 51).

Hong et al. (2010) facilitated a nonrandomised controlled trial with 106 participants attending diabetes outpatient clinics in Ireland. They explored the impact of sharing personalised clinical information, including recent test results, on the interaction between people with diabetes and health care professionals in clinical consultations. They found that people in the intervention group were more likely to initiate conversation during the consultation than those in the control group, and the mean time in which the person with diabetes was involved in the conversation was significantly longer for the intervention group than the control group (6.34 vs. 3.34 minutes,  $p < .01$ ). This suggests that receiving information and test results prior to the consultation significantly affects a person’s likelihood to engage during the consultation.

The study only explored people’s involvement in the consultation and did not take into consideration if or how the letter was utilised differently by different people in the intervention group. Some people compare their current results with previous tests (Year of Care, 2011), whereas others choose not to read their results at all (Mathers et al., 2011). Mathers et al. (2011) suggested that people who choose not to read their results may simply need time to adapt to the CSP process. They produced a report on the evaluation of the Year of Care project across three pilot sites. A practitioner in the North East of England described a person who brought her unopened letter containing her test results

to her first CSP consultation. The second time she had opened the letter and understood parts of it. The third time she had read the letter and generated some ideas to discuss (Mathers et al., 2011). This suggests that people need to have some understanding of CSP and their role in self-management, for the sending of test results in advance of the consultation to trigger positive mechanisms, which is an idea supported by others: “patients will not be engaged in the process of care planning without an understanding of what it constitutes” (Tribal Consulting, 2009, p. 60).

By taking into consideration all of the literature reviewed in this section, programme theory 1 was developed. It is stated below.

#### ***Developed programme theory 1***

When test results and question prompts are sent before the consultation (resource), to people who have an understanding of their role in self-management (context), they spend time reflecting on their current health status and preparing questions to ask (reasoning) which leads to greater engagement in the consultation (outcome).

#### **4.1.2 Refining the programme theory**

CSP leaders agreed that sending test results is a “manifestation of preparing the person for the consultation” (L3). Preparation occurs through other means, such as question prompts, signposting and education. One leader felt that the process of preparing the person with LTCs, either verbally or physically, is a

way of saying, “we’d like you to come and say what you think” (L3). It “gives permission to have that wider conversation” (L1) and “supports them to feel that they are valued, and their opinion is valued” (L3). Preparing the person using various resources can help them to think about different dimensions of their health care. One leader reflected:

“I think what people have said is that there are various dimensions of things that will help people, probably to be prepared. So there’s stuff about me, my health, where I am with my health, the rest of my life, and the things that stimulate me to think about all of those sorts of things. But there’s also stuff about knowing what the purpose of the consultation is, so, what am I going to? What are the things that I might need to take into that consultation? As well as, which might be about me and my health but they might be about other stuff, they might be about what the system can offer me or how I navigate it, or what my options are and things like that. The better prepared people are for those sorts of conversations the more likely the conversation is to be fruitful, I guess that’s what we’re saying” (L2).

All leaders (n = 5) agreed that the better prepared people are for CSP conversations, the more likely the conversations are to be fruitful and collaborative. One leader elaborated on this outcome and how it may be beneficial in the longer term, not just for the immediate consultation: “the people end up more confident and more skilful, and more successful in the management of their health, but also in relation to the rest of their lives” (L5).

One leader identified how, in a circumstance where this programme theory would not occur because the person with LTCs either disengaged from the conversation or disregarded their results letter, new resources could be introduced to achieve the desired outcome. The leader identified these resources as a “skills toolkit” (L2) which could be introduced when a person

with LTCs has disregarded their results letter (context), which would prompt the leader to think about why this has happened and ask different questions (reasoning) to try to gain an understanding of what they need to do to support the person to engage (outcome). This prompted a discussion about assuming people always want to be involved in an active way with every part of their health. Indeed, “we might not be being completely realistic because people feel ambivalent about some parts and they feel negative about others, and other bits feel important” (L5). However, leaders agreed that if a person had not engaged with the results letter that would be a good place to start the conversation:

“So if you know when the person has come in, that the work that you’ve done in terms of supporting them to get ready has not been something they’ve engaged with, then actually it allows you to get inside the underlying reasons why, at that moment they’re not engaged, rather than assuming, which, it happens in current consultations, that someone that comes into my heart clinic will want me to do things to them to make their left ventricular end-diastolic function better” (L5)

[Laughter in background]

“And they might not have a clue what that is or why it matters” (L5)

“Health is their number one priority” (F)

“Yeah, or it could be that it isn’t” (L1)

“It’s paying their mortgage that’s their priority” (F)

“Absolutely” (L1)

Rather than assuming every person wants to improve aspects of their health, it is more useful for healthcare professionals to try and find out the underlying reasons why, at that moment they are not engaging. In the extract above, the facilitator suggests that financial difficulties could be the reason for a person

disengaging with their health needs. A leader then goes on to describe what they would do if this situation were to arise:

“What sometimes can also happen is if you provide people with lots of support and resources around their life and their health, and they’re actually disengaged, it actually is a really good starting point. When you start having a conversation with somebody if they haven’t brought results back or if they’ve disengaged, or if they’ve thrown everything in the bin, it’s a really useful place to start to have an effective and meaningful conversation” (L2)

“Why?” (F)

“Because you know straight away where that person’s at, regarding their health, so you know, if that person’s thrown the results in the bin or hands them back to you, straight away as a health care professional you can hone in to your skills toolkit and think ok, now I know where this patient’s at” (L2)

“What do you do?” (F)

“I think one of the first things to ask is why? Why did you not look at your results? What does that mean about the results and their health? So I think it would just give you an opportunity to ask different questions” (L2)

This reiterates the idea that whether people engage with their results letter or not, the desired outcome is a better conversation, and this can be achieved in most circumstances: “...ultimately whether it’s Bob who doesn’t bring his results back or Bob who brings his results back and is highly motivated, it’s just a better conversation” (L1). However, leaders suggested that a better conversation is not necessarily the outcome policy makers are looking for. Their desired long term outcome is that people are “more successful in the management of their conditions” (L5) which would lead to better health outcomes and thus have a positive impact on healthcare resources. The discussion further highlighted how preparation can help in achieving this outcome, as “prior reflection and greater understanding enables patients to be

more involved in a conversation, and this will ultimately lead to better health outcomes” (L3).

Leaders disliked the fact that the programme theory was focused solely on the person with LTCs: “for me the degree to which it affects the practitioner in care planning has to be within scope” (L3). In order for professionals to recognise that a person is engaging, or not, they have to be prepared. One leader stated, “one of the things that I would say is equally important is professional or practitioner preparedness” (L3). This includes training in the CSP process, and also a belief in the philosophy of CSP. The discussion continued:

“And when, I think our experience would be, working with other projects, for instance the MAGIC project on shared decision making was a very important one. They concentrated on skills and tools and this sort of thing and didn’t get engagement initially because they hadn’t addressed attitudes and philosophy. So, in fact, people’s beliefs affect what they do. To get the practitioner to work in a collaborative way, and believe, the trendy word and I’m trying not to say it is, assets” (L3)

“Or capabilities” (L5)

“But recognising that people are problem solvers and all the philosophy stuff that we have in, is about preparing the professional. I think it’s as important for care planning as preparing the patient” (L3)

[Agreement in background]

Practitioners have to believe in the philosophy of CSP, and transfer this belief to practice, because “if somebody brings their results back and they are excited to talk about something, and the healthcare professional says, that’s interesting but I’m going to talk about this... then the patient will never bring their results back again” (L2).

Programme theory 1 was refined to incorporate data from leaders of CSP. It is stated below.

### ***Refined programme theory 1***

When people with LTCs and healthcare professionals are prepared for the consultation (resource) and they both have an understanding and belief of the philosophy of CSP (context), they feel valued and they feel that they have permission to engage (reasoning) which leads to a more fruitful collaborative conversation (outcome).

### **4.1.3 Testing the programme theory**

All nine implementers agreed that preparation is essential for effective CSP. They were also in agreement with the leaders, that in practice, much of the focus around preparation has been on the results letter and the information gathering appointment, however, one leader explained that it encompasses much more than that:

“I mean the Year of Care do say it’s not Year of Care if you haven’t been prepared, but preparation can take more than one form. I wouldn’t say this is a fault with the Year of Care team, but I think that was very much the focus of it, that they have to have had this letter and this preparation and the first information gathering thing had to occur. I think sometimes the preparation is about discussing – please have a think about how your breathing is affecting you” (I6)

Implementers agreed that organisation is a vital component of preparation. An implementer stated that if there is poor organisation within administration teams, with regards to allocating people the “right slots” (I2), practitioners “won’t have a chance” (I2) in the consultation. Although there are bound to be “teething problems” (I2) with administrative tasks, providing an understanding of the organisational processes of CSP to whole teams through training could aid in minimising this problem. An implementer stated that for diabetes CSP, their whole team receive training twice yearly to ensure everybody is on board with it, and this helps towards the smooth running of CSP.

“I think that’s when it doesn’t work, if you’ve got people that don’t really want to engage in it or feel that it’s not a worthwhile thing. We’re lucky that everybody feels the same with it, they feel it’s a worthwhile piece of work to do, and I think that really helps. Because I think it’s difficult if you’ve got somebody that’s doing it but maybe just doing it as a tick box exercise. And then it’s a bit meaningless, isn’t it?” (I5).

Another implementer summarised what aspects need to be in place to ensure a prepared healthcare professional, from the initial organisational processes, including setting up IT systems and administrative tasks, to ongoing staff training.

“When we started there were various – there was the practical IT side of it... Preparation for the admin staff, for the way of doing the call and recall, training – we had to upskill not just the nurses but also the doctors because we’d got quite entrenched in our own little specialities, so we all went off and did training in the other long term conditions so we can do more multimorbidity patients. And then time for preparation before we see each patient as well. There’s the preparation as in, review results and allocate an appointment, but then before a patient walks in the door I think it’s really important that we have a look at their results and their history and what’s been going on with their lives on the medical notes so that when they walk in the room we have an idea of their background as well as them having that” (I3)

The team described above had an IT expert on board with designing their CSP templates. Not all GP practices will have access to somebody with this level of knowledge in IT, so although Year of Care encourage practices to utilise their templates, there will be some differences in documentation due to factors like practice preferences. These differences between practices were discussed by some of the implementers. One implementer worked across two practices, both of which are offering CSP to people with LTCs. She stated that the results letters being sent to people with LTCs are different in both practices. In one practice, the results letter is very visual with pictures and instructions to circle any areas of concern, whereas in the other practice, people receive a leaflet with their results, an explanation of their results, and a small blank section for them to write down any issues.

Implementers agreed that the wording and presentation of the information on the results letter makes a difference to the CSP conversation. An implementer described a common occurrence in a previous clinic, where people who had lived with diabetes for years did not know what HBA1c meant, despite reading it on every clinic letter they had received and hearing it in every clinical discussion.

“I don’t think the forms, certainly the ones we are using - they were written quite a long time ago – are written in a way that all patients can understand... They might have had diabetes for 20 years, but it doesn’t mean they understand it... You could talk about HBA1c and they would be nodding, but they don’t understand it. If you don’t directly say, what does HBA1c mean to you or do you understand what that means? So I think we need to make less assumptions, and we need to be clearer on

our letters... And then making it a bit clearer, a bit more visually pretty” (I8)

The idea that people with LTCs do not usually disclose that they cannot understand their results was explored further in the interviews and the findings were mixed. One person with LTCs stated the wording was “Double Dutch” (EbE1) to him, whilst another said her results are never fully explained to her during her CSP appointments, however, she did go on to say “I suppose if I asked, they would tell me” (EbE3), suggesting the implementers were correct in saying people would not usually take it upon themselves to ask the meaning of medical terminology. Furthermore, one person with LTCs stated, “I don’t have a problem with it [results letter] at all” (EbE10), however, he described himself as the kind of person that likes to “ask why and what for” (EbE10). Another person had “no problems at all” with the results letter, and similarly, he described himself as “one of those types of people who likes to know what’s going on” (EbE8). Thus, a person’s characteristics are important, in that they can influence whether they are more (or less) likely to engage with the preparation involved with CSP.

Implementers explored individual characteristics further and four agreed that motivation and “activation” (I1) are major factors that contribute to a person’s level of engagement with CSP.

“They’re often a bit more proactive [people who utilise their results letter], they want to get their HBA1c’s down. I had one recently, he obviously kept every single letter that we sent out. And got his HBA1c down to 35, it was ridiculously low, and because he had been so keen on it, he changed his entire life. He is way outside of the diabetic range now... I’ve only had that

a handful of times. It's just because he gets it all there and keeps it and uses it to track" (18)

"There are some patients who think, I'm not bothered about my results, I don't have any questions, but then there is a group of patients who are motivated and are happy to have their results, and I feel it does work well for them" (19)

"We do get some people who say, "my care plan's due a review or is overdue", so it depends how motivated they are I think, and how involved they are in their health" (15)

Furthermore, implementers described differences between groups of people. They identified newly diagnosed people as those who tend to engage with CSP more, and people who are housebound as those who tend to engage with it less.

"In a way I guess with them [newly diagnosed people], it's almost easier because they've not known anything else. So we explain to them that for their annual review they'll get their results beforehand to look at so I guess they tend to be more engaged because that's a system that they're entering into at the beginning and I think that's quite helpful ... Perhaps that is one group that, for us in particular, it's not working quite as well – the housebound – because the preparation with the housebound patients is done via the district nurses and the district nurses don't belong to the practice. They're more general and they are not as engaged in the process. Yes, they will do their bloods and they will check their urine and do their blood pressure, but even though we've asked them to, I don't believe they do any promotion of the system or explanation. So I think, possibly in the first year, some of the housebound patients are a bit more – hadn't really looked at the yellow form. But again, once we've been out once and explained to them that that's what it's for, the next year they are engaging a bit better in that process" (13)

Housebound individuals might be engaging less with the letter (referred to here as the "yellow form"), however, the underlying reason described here was the initial lack of explanation from district nurses. Thus, understanding CSP and their role within it is a key context for both people with LTCs and healthcare

professionals. As one implementer stated, there is often a “misunderstanding as to what it’s all about and what purpose it’s for... did they fully grasp that, or was it just a piece of paper?” (I5). Newly diagnosed people tend to engage more from the outset, and this may be because CSP is explained to them, so they have a good level of understanding of their role within it, thus confirming the context in this programme theory.

Implementers agreed with the idea that explaining the process and purpose of CSP contributes to people engaging with it. One implementer stated, “the more successful ones are the ones where the patient has been really explained to about the process” (I5), whilst another implementer outlined the resources that her practice uses to do this:

“One of the first things is we try and prepare them by advertising that we do care and support planning. We have a good website and we have a page on there about care and support planning, and a page on our TV screen in the waiting room. When patients are first diagnosed with a condition that will be part of the initial conversation – to explain what care and support planning is. When they’re at their preparation appointment the HCA role is really key because, verbally, they are reinforcing to patients what’s going to happen next, about the paperwork, we have laminated copies of our care and support planning sheets so that patients can actually see it. Now of course, most patients are now onto their second, if not third cycle so they have seen it but especially at first, it was invaluable to show them what they would be getting, so that a) they would recognise it when it came in the post and ours is yellow to make it quite recognisable, but also so that they weren’t afraid of it when it came and they saw a load of numbers and panicked, you know, they can read and understand and just take time to look at that. We also explain to patients quite clearly that if there were any worrying results that we were concerned about we would not just send that out, we would contact them by phone, and we try and really reinforce that. We very rarely have patients who phone up worried, because they know that if we were concerned we would have contacted them in a more urgent manner. The HCAs also offer to patients the

Year of Care bubble information sheets that they have, which are condition specific, which tell patients things that they can do to improve results or to modify their lifestyle, so they're offered those as well at the HCA appointment. And obviously we give them time, it's usually about two weeks between that appointment and the care planning appointment. I think that time is important as well, long enough for them to read – (I3)

An expert by experience who attends this GP practice spoke highly of the service she receives. She understands the CSP process and her role within it. She states that she finds it helpful to write down any concerns or questions on her results letter so that she can bring it to her appointment and discuss them with the healthcare professional, and says that if she didn't write them down, she would forget what she wanted to discuss. She also compares her current results with previous results and says this allows her to reflect on why her HBA1c level has increased or decreased.

“It's very, very understandable. And as I say, when you go in and you discuss it with the doctor again, you know when you go for your next appointment for the clinic, they ask you to bring that in, and you've got the chance to put questions on it, which normally, if you go for another doctor's appointment, you don't think - pre-empt anything, whereas if you put it on there, you know it's there in writing and I write it as I think it then, rather than sort of, oh I'll put it down later, because later, you forget ... When that review has gone through, you get the next one and you can compare, and you think whether you've done bad or you've done good. And again, you can make your comments about it and think, oh yes, well that's the reason why that's happened. A couple of times when I've been on holiday, when the reviews – my blood levels have gone up, for my diabetes, but you can understand, when you're on holiday you let yourself go a little bit” (EbE4)

This lady pertains her effective self-management and improvement in her health to CSP. She says that her diabetes began to improve “when [GP] decided to do this leaflet thing that she had, you know, where you filled out your information and everything” (EbE4). In accordance with findings from

phase one and phase two, several people emphasised the importance of having something physical, “in black and white” (EbE4), “something I can hold in my hand” (EbE5), to have ownership and responsibility of. Two people with LTCs explained how the preparation process enabled them to become more self-aware, and this newfound self-awareness prompted them to make healthier lifestyle choices.

“When you see it on the piece of paper, you sort of look at it and think oh, it’s time to do something. So it made me very aware of my situation [...] Looking at the figures in front of you and having them to refer back to from year to year and then seeing the difference – that incited me to start going to Slimming World [...] I’ve certainly got a healthier lifestyle. I’ve managed to lose up to 5 stone. I would say that I’m at the stage where you can say I’ve practically reversed it [diabetes]” (EbE4)

‘...because you’ve got it written in front of you... I knew why they were up to 90, because I had a very sweet tooth... I said, I know, I know what I’m supposed to eat... And [at the next review] she said, they’re 60, and Dr [name] said I have to ask you how you’re getting them to drop so much? I said well, I’ve never had any crisps and I’ve had no sweet stuff at all, and I don’t eat after a certain time at night. Well I don’t eat any carbohydrates after a certain time. And I never used to take my blood sugars because I used to know, but I take them in a morning now, and they’re good in the morning, well they used to be dead high. So, I’m proud of myself that I’ve done that’ (EbE11)

Conversely, I observed a CSP consultation where a person, who had recently been diagnosed with diabetes, was not prepared. He had not received a results letter and was not aware that he should have received one through the post. He was not aware of the process and philosophy of CSP or of any difference in the length of the consultation he should be expecting. During the consultation, I had noted that the person was quite proactive and frequently asked questions. His wife works in a pharmacy and he appeared to have a good grasp of medical terminology. When I interviewed this gentleman, it

became apparent that he was disappointed in the service he had received. He stated:

“You know when I was speaking to [nurse], really I got the feeling that [nurse] wasn’t 100% sure what had been done because when she looked, I had to say, what’s my cholesterol. I’d have thought automatically they’d look at the bloods and the results and say right, this is the situation, your bloods are back, it’s X, Y and Z. Go through all the bloods so it’s quite a thorough explanation, if you like, and then say this is what we need to do, or where we go from here... I just felt as though in that appointment I had to sort of ask what the results were, what was tested for, and she said well your kidney results are fine. I said fine, what do you mean by fine? What’s the levels? That’s what I would like to know” (EbE2)

During the interview, it became apparent that this person had certain expectations about how he wanted the conversation to go. In the past, he has requested a copy of his blood test results because he “would like to know exactly what the reading or what the levels are” (EbE2) and he said he tends to ask questions until he understands. In his future CSP appointments, he would like to be able to say, “I’ve got the printout and I think that’s a little bit high. Where do we go from here? What do you think?” (EbE2). He described his ideal appointment, where five minutes would be spent going through the results because he had already seen them, then he could ask questions, the healthcare professional could ask questions, they could discuss lifestyle factors, and then together they could come up with a plan of action. This scenario highlights how important preparation is for CSP and how it can help a person with LTCs to feel ownership of the process. Even for a proactive individual who is motivated to manage his condition, without preparation, the conversation felt unproductive and practitioner-led. An implementer stated that when a person has not seen their test results prior to the CSP consultation,

and she has to read them from the computer, “it feels more like I’m leading it, and I don’t like that” (18). If the person had been given the opportunity to prepare for his CSP consultation, through receiving and reading his results letter and having the CSP philosophy, processes, and expectations explained to him, the outcome would most likely have been much more positive for both the him and the healthcare professional.

Another person with COPD attended the same GP practice, and had a CSP consultation with the same healthcare professional. I was able to observe this consultation and interview him the following week. During the interview, he said that he does usually receive his test results through the post, however, on this occasion he had received his latest results letter the day after his CSP consultation. He had found parts of the consultation helpful, for example, he was shown the correct way to use his inhaler.

“She told me all about the – well you’ve seen for yourself – how I’ve picked up a bad habit when I was using the inhaler” (EbE1)

However, I had noted that most of the 30-minute consultation was spent going through documents on the computer, ticking boxes and going through his results letter, which the practitioner printed out for him, since he had not received it. The practitioner informed the person that there had been a drop in his potassium level, and that he needed to give a urine sample two weeks from the original blood test. He stated that nobody had telephoned him with this information. In the final few minutes of the consultation, the person was able to discuss his agenda, which included concerns about spontaneous bruising

on his arms. If the person had received his results letter in the post prior to the consultation, perhaps he could have brought a urine sample with him to the consultation and prepared an agenda with his concerns. Consequently, the consultation may have been more two-way and more productive. This expert by experience recognised that preparation is important for him and stated:

“You might forget, so there’s a questionnaire that you fill in and take with you. So, you’ve got a prompt for the questions you want answered. Which I think is a big help” (EbE1)

In both of these scenarios where preparation had not occurred, the result was an “old-style” conversation where “the patient walks into the room, having no idea of what all the blood tests that they had recently, had shown” (I3). A healthcare professional working in a GP practice where preparation for both people with LTCs and practitioners is comprehensive stated that in her practice “this doesn’t happen anymore, so that’s a lot of time saved” (I3). She said, “the absolute majority of patients bring their yellow form in with them” (I3). This results in a more person-led “conversation” (I4).

“They tend to start off by saying what results had worried them or what they had been pleased about, so it’s definitely more patient-led and less reeling off information. Also, often if it’s worked well, the patients have already thought about changes they want to make, or already started making changes very often, from having the information and from having some preparation and information about what they can do to help themselves, they’ve perhaps already put things into place, and that’s a really great conversation then, because they’ve done all the work already” (I3)

An expert by experience described in his interview, an instance where he had an issue with his blood pressure. In the initial information gathering appointment, he thought he had misunderstood the Healthcare Assistant when

she informed him of the result. When he received his results letter, it confirmed the blood pressure result, and he was able to discuss his concerns with the practitioner in his CSP consultation. He stated, “it was quite handy to have it before I came, so that I had an idea what I was talking about” (EbE10). The preparation process enabled him to feel like he had permission to engage, thus resulting in a more collaborative conversation. An implementer gave an example of how, when people with LTCs prepare for their CSP consultations using their test results and question prompts, they tend to engage more in the conversation. A person she had seen for several years prior to the implementation of CSP for his diabetes, would attend his diabetes clinic once a year and his results were always “impeccable”. However, he was never very engaged and came across as “a little bit rude”, despite her trying to be as friendly as she could be.

“He was one of the first patients when we started doing care and support planning and he came in with his form, sat down, and he literally just slapped his yellow form on the desk. Across the front, where it says, “what’s important to you?” he had written in big capital letters “PAIN” and underlined it twice. And I just looked at this and said, “ok, you want to talk about pain today” and he came out with “oh, well, I’m sure you won’t want to talk about it... 20 years ago doctor so-and-so told me there was nothing that could be done about it so I’ve just suffered since then but I’m in agony every day”. All this stuff came out about this pain and that, twenty years ago a doctor told him that nothing could be done, and he’d been in agony since with his knees and his back. We spent the whole conversation talking about his pain, what could be done about it, how he could be helped to manage that better. I didn’t wave a magic wand, I don’t think I have a huge amount to make his pain better but by the end of that conversation he was like a changed man and the following year he came back, and he was so much more engaged and friendly. I saw him between then because I deliberately brought him back after about a month because actually, I think there were some issues with his mood as well. But for him, for twenty years he’d kept all that buried in, came along to his diabetic checks and not ever mentioned it. But the care plan and the agenda setting prompts gave him

permission that he could talk about what he wanted to talk about”  
(I3)

The opportunity that preparation presented for this individual, and the effect it had on him was immensely powerful. Being able to prepare his own agenda and bring it to his CSP consultation to discuss meant that he had permission to talk about whatever was important to him, and reassurance that he would be listened to. An implementer described how this might feel for people with LTCs: “they just feel a lot more valued and that someone is listening” (I2). Furthermore, an implementer described a situation where a lady, who had struggled with her diabetes and was in 24hr care, attended an appointment with her carer for something other than her diabetes, and she brought her diabetes results letter to discuss. She had said she was about to go on an all-inclusive holiday. She had received her results letter, which her carer had explained to her, and she was worried about her HBA1c level and wanted some dietary advice for whilst she was away. Her CSP appointment was already scheduled for two weeks after she returned, but she was proactive in seeking support, rather than waiting until after her holiday “when there would be even more damage done” (I4).

Although most implementers agreed that “you definitely get more out of a care planning session with people that are engaged in it” (I5), that is not to say you cannot have a CSP consultation with a person who is not engaging initially. This idea was initiated by leaders, who referred to resources that can be introduced when people do not engage with their results letter, to achieve a

more purposeful, collaborative conversation. In agreement with the leaders, an implementer explained:

“It doesn’t really matter if a patient is not engaging with their care planning consultation as such, because they are just by turning up. So, I don’t think if someone comes and says, well I haven’t brought the paper because I don’t think there was anything interesting on it – it’s always a starting point – the fact that they haven’t brought it, you’re maybe then thinking about confidence and importance scoring straight away. Oh, why is that, is it just that you don’t do paper? Or did you have trouble reading it, or was that an issue? Or were you really happy with the results that you had, and you didn’t have anything to add? So, you’re still doing a care planning consultation regardless of whether they bring them or not. And we’ve got a copy anyway, so whatever you’ve sent them, you just print it off and then we sit down and, I think the good thing is it brings you physically together” (I6)

This idea was tested with experts by experience. An 83-year-old gentleman who has lived with diabetes for over twenty-five years said he rarely attends his GP surgery “because it’s not often I’m bad” (EbE6). He manages his condition by keeping an active lifestyle and swimming six days per week. His son lives next door to him, which he finds comforting as “he keeps an eye on [him]” (EbE6). When I asked whether he finds the test results letters useful, he stated, “I don’t ever read them” (EbE6), because he feels well in himself and knows that if there were any issues, the surgery would contact him by telephone. He attends a review appointment only if the practice contacts him to say there is an issue with his results, and he describes the CSP consultation as a quick, simple process, which, judging by his speedy interview for this study, appears to be the way he prefers it.

“She never goes through the whole rigmarole... I hardly see them. I get my prescription, I get my tablets, and that’s it” (EbE6)

Similarly, a person who was diagnosed with diabetes three years ago has access to his test results on an online system, however, he does not read them because he has forgotten his password to sign in. He attends his CSP consultations but said “if they [results] look alright, I don’t get an appointment” (EbE5). He described the CSP consultation as “two people having a conversation” (EbE5) where he feels comfortable openly discussing personal issues. He stated, “I open up to her, we talk as if we’re two buddies” (EbE5). Neither of these people review their test results prior to the CSP consultation, yet they both attend and engage with CSP in their own ways. Although there are differences in the level of engagement with CSP, the long term outcome is the same, in that both of these people are effectively self-managing their conditions.

Programme theory 1 was further refined to incorporate the data from implementers and experts by experience in this testing phase. It is stated below.

### ***Tested programme theory 1***

When people with LTCs and healthcare professionals are prepared for the consultation (resource) and they both have an understanding and belief of the philosophy of CSP (context), they feel valued and they feel that they have permission to engage and take action (reasoning) leading to a more purposeful collaborative conversation (outcome)

#### 4.1.4 Summary

In all three phases, the idea that preparation is essential for effective CSP has been well established. However, there are variations in what preparation constitutes. The Year of Care literature depicts preparation through sending test results as the heart of the informed, engaged person. For it to work effectively, people with LTCs need to have an implicit understanding of CSP and their role in self-management. Leaders and implementers argued that the results letter is a manifestation of preparation, but that there are several other components involved, including question prompts, signposting and education, in addition to staff training, setting up IT systems, and reading a person's results and history prior to the consultation. Leaders felt that preparation gives people permission to have a wider conversation and supports them to feel valued, and when more preparation is done, the outcome is a more purposeful, collaborative conversation. They also proposed that people then become more confident and more skilful, and more successful in self-management. They explained that if an individual has not engaged with the letter, finding out why is a useful place to begin the conversation. However, whether the person has engaged with their results or not, leaders say the desired outcome is always a better conversation, and they can usually achieve this by using CSP resources as a "skills toolkit". Examples were given from interviews involving experts by experience to support these ideas.

In addition to the context around people with LTCs having an understanding of CSP, which was described in the literature, leaders felt that practitioners should also have an understanding and belief in the philosophy of CSP for it

to be effective. This was explored further by implementers, who suggested that organisation, training and a whole-team approach are essential preparation tasks for practitioners. Implementers stated that the wording and presentation of the results letter, level of motivation and activation of people with LTCs are also important contexts affecting engagement. They will be explored further throughout this chapter.

## 4.2 Quality conversations

Figure 15 below shows how quality conversations may relate to other CSP components, to form a tool that supports the self-management of LTCs.

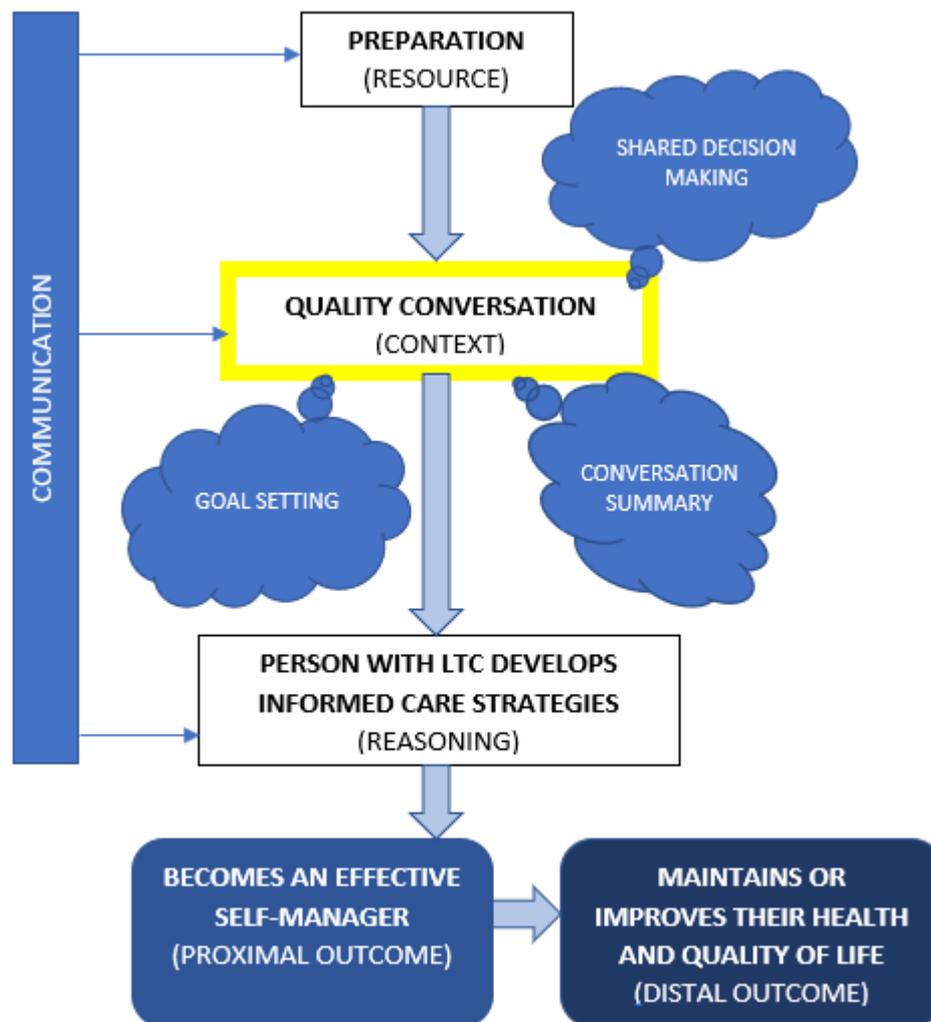


Figure 15: Quality conversations as a component of CSP

### 4.2.1 Developing the programme theory

Lack of time in consultations has been identified by people with LTCs and by healthcare professionals as a key barrier to CSP (Blakeman, 2006, Newbould

et al., 2012, Bower, 2013). This notion is discussed by Noël et al. (2007) who carried out focus groups to explore the collaborative care needs and preferences of people with multimorbidity. Participants in their study indicated that the amount of time allocated for a typical appointment was insufficient to address their multiple concerns, as one participant stated, there were “too many things to talk to the doctor about in such a short time and keep your mind in gear” (Noël et al., 2007, p. 58).

With regard to perceived length of time in consultations, there is a clear difference in responses between people who receive standard care and people who attend CSP consultations. Doherty et al. (2012) reported that most of the people involved in the Year of Care pilot study reacted positively to longer consultations. They reflected upon their experiences, stating “[healthcare professional] seems to have more time to deal with you personally, it’s more personal” and “you feel more at ease and able to discuss things because you know [healthcare professional] is not in a hurry to palm you off and see the next person” (Doherty et al., 2012, p. 186). Healthcare professionals have also identified longer consultations having a positive impact on care for people with LTCs, as people are utilising the consultation time to “deal with small things so they’re needing to come back in to see GPs less” (Year of Care, 2011, p. 74).

Longer CSP appointments allow more time to motivate people with LTCs to make changes, where changes need to be made (Year of Care, 2011). However, this time is not always used in the intended way. Healthcare professionals have reported that having more time to engage people in the

consultation is only conducive if staff are receptive to building on peoples' own ideas and agendas through partnership working (Coulter, 2007, Tribal Consulting, 2009) in an environment where there are enough time and resources to do so (Year of Care, 2011).

In practices where CSP was working well, practitioners reported feeling positively about partnership working, stating, "It's more rewarding" . . . "working with them rather than at them" . . . "[it's] more a two-way discussion" . . . "it focuses your mind on their motivation to make changes" (Year of Care, 2011, p. 87). When practitioners are committed to partnership working, people with LTCs have indicated that they recognise positive changes in their health care. One person with diabetes stated, "I thought about the negatives and positives and how we could take things forward. There was an improvement after one week. She helped me identify what was important to me" (Year of Care, 2011, p. 88). Other people reported, "It is a two-way thing" and is "a good mixture of professionalism and time" (Year of Care, 2011, p. 88). This suggests that a combination of time and a change in attitude of healthcare professionals can influence a change in behaviour (greater engagement with CSP) of people with LTCs.

The work of Hong et al. (2010) suggests that consultations do not have to be longer for people with LTCs to be more engaged in the conversation. Their study shows that although participants who had been given personalised clinical information prior to their consultation were involved in the conversation for a significantly longer period than those who had not been given information,

the overall consultation length for the intervention group was not significantly different to the overall consultation length for the control group (18.3 vs. 16.7 minutes,  $p = .35$ ). This suggests that pre-clinic information increases involvement without lengthening the consultation. If an appropriate length of time is allocated for the consultation, to people who are prepared (Hong et al., 2010) and in the context of partnership working (Coulter, 2007, Tribal Consulting, 2009), positive mechanisms are triggered which lead to greater engagement with CSP (Doherty et al., 2012, Hong et al., 2010, Year of Care, 2011) and improvements in health (Year of Care, 2011).

By taking into consideration all of the literature reviewed in this section, programme theory 2 was developed. It is stated below.

### ***Developed programme theory 2***

Longer consultations (resource) in the context of partnership working and preparedness (context) means that practitioners can spend time discussing what is important to the person with LTCs (reasoning), which enables the person to engage in the conversation (outcome) and take ownership of their health (outcome).

### **4.2.2 Refining the programme theory**

The key idea arising from the discussion in the focus group was that it is not about CSP consultations being longer, but rather, each one is an appropriate length of time for the needs of each person with LTCs. It could be “one minute

or five minutes, or ten minutes, but it's getting to that point where you're actually talking about what's important to the patient" (L1). These conversations often include discussions about "housing or benefits or social isolation" (L1) which are areas that practitioners are not typically specialised in. Thus, often their role moves towards being able to "help people to find a place where they can get the solutions" (L5). One leader described this process as "becoming a generalist again" (L3) whilst another said it feels like "putting the G back into general practice" (L5). Leaders felt that by moving to holistic care and talking about what is important to the whole person, even if it means signposting to "a man that can" (L5), the person is likely to feel more informed and therefore more in control, and so will be more likely to take positive actions, even if this is just a change in attitude.

In addition, the consultation length is dependent on the amount of preparation that has (or has not) been done. One leader highlighted findings from a series of studies looking at enablement of people with multimorbidity and practitioner empathy in GP practices across the west of Scotland (Mercer et al., 2012, Mercer et al., 2016). The studies promote longer consultations and relational continuity for people with multimorbidity. The leader stated that although GPs were given 40 or 50-minute slots for these consultations, they are perhaps not as effective as they might seem "because there's been no preparation, they're having to unpack everything. They're having to prepare, give permission, reflect, whatever, in 50 minutes" (L3).

The understanding that consultations can be longer or shorter depending on the amount of preparation done by both the practitioner and the person with LTCs, was shared by several leaders. One leader stated that practitioners can have excellent consultation skills, but if there is little or no preparation prior to the appointment, the outcome will be “an old-style conversation with good consulting skills” (L2). This is true of the consultations in the studies by Mercer et al. (2012), (2016). Preparation is therefore key to determining the length of a CSP consultation; if it is done well, then most of the information gathering is already completed and the consultation is generally shorter:

“The bigger this is [patient preparedness] the smaller this is [consultation length]” (F)

[Agreement]

This could be due to time being freed up to focus on the person’s agenda, rather than having to go through tests, results and condition-specific information, as one leader explains:

“If you do the preparation well, the person’s done a lot of the work already ... having a patient who is in some measure prepared, helps massively in freeing time in the subsequent consultation to focus on the things that actually become important. So that teasing out what’s really important becomes much easier if there’s preparation. You can’t do it, officially, otherwise. In fact, it’s really, really hard for someone to come in from cold, even with an hour I guess, and try to work out what really, really matters to them if they haven’t thought about it before they come in. It’s actually quite difficult for people to do” (L5)

Furthermore, one leader emphasised the importance of a person knowing how long their appointment is going to be. By relating to personal experiences, the

leader identified that this is also a crucial part of preparing the person with LTCs, which is an important context in this programme theory:

“But surely, it’s about having a defined time and as a person going for that appointment you know what that defined time is, so then you’ve had your prompts and you know what your agenda is, so you then know what to get out of your 15/20/30 minutes. So if that’s part of the preparation, so you know what time you’ve already got, then you can start to prioritise what you want to get out of that consultation as opposed to turning up and, just thinking from recent experience from hospital appointments I had a 10 minute appointment and then I had two consultations for half an hour and that was a real shock. And I got distracted. But it would have been nice to know before I’d gone in that this was going to be a 10 minute or -” (L1)

“Oh, you didn’t know?” (L5)

“No. I didn’t know until I went in, so then my first thought was panic, what am I going to do, or what are they going to do to me for half an hour?” (L1)

“So, understanding what this is about is critical, you’ve put it on there, but this is reinforcing that that’s critical preparation.” (L3)

Whilst awareness of the length of an appointment was identified as important for people with LTCs, for practitioners, focusing on time is perhaps not as helpful, particularly during consultations for people with multimorbidity because it encourages a single disease treatment approach, which CSP aims to move away from. Instead, maintaining a holistic approach and focusing on the conversation itself is suggested to be more effective:

“And also I think sometimes there’s healthcare professional anxiety, if you’re having a consultation with somebody with multimorbidity, then the healthcare professional when they’re setting their clinics up will think ‘I’ll see that patient for 20 minutes for their diabetes review and then 20 minutes for their respiratory review and their heart failure or whatever, and then all of a sudden you’ve got 40 minutes and that’s where they start because they think that’s where they should start. But I suppose what you forget is that you’re going to have a different conversation, it’s going to be about the whole person, and the

chances are there'll be one or two goals which will be a mish mash of all of that. All of those conditions, as we are talking as a holistic nature" (L2)

In this extract, it becomes clear that the content of the conversation is more important than the length of the conversation, indeed, "we've moved from a consultation to a conversation" (F). This shift in focus prompted a change in the subtitle for this programme theory, from Appropriate Consultation Length to Quality Conversations. Another leader stated, "it doesn't need to be 40 minutes if you just need 20 minutes of good conversation and they've had all the other boxes ticked" (L4), suggesting that allocating time for appointments is much more individualised than simply giving twenty minutes for all diabetes appointments and forty minutes for all people with multimorbidity, for example. This discussion also highlighted the possibility that as people go through the CSP process, they may become better at managing their condition(s) themselves and thus require shorter review appointments, or they may request to not come back at all unless an issue emerges. People who have had CSP for two or three years often ask, "can I just ring up, or do I have to come back? Or [they will say] everything's fine, thank you" (L3). Some flexibility would therefore be beneficial to people with LTCs, in order to avoid unnecessarily "putting them through a process because the process is there to put them through" (L5).

Programme theory 2 was refined to incorporate data from leaders of CSP. It is reported below:

## ***Refined programme theory 2***

When time is spent talking about what is important to the person with LTCs (resource) in the context of relational continuity and preparedness (context), the person feels more comfortable, more informed and therefore more in control (reasoning), so they are more likely to take positive actions (health behaviours, self-management, attitude) (outcome).

### **4.2.3 Testing the programme theory**

There was some variation across GP practices in the length of time people with LTCs are allocated for CSP consultations. Implementers stated they can last anywhere from twenty minutes to one hour. This is dependent on several factors, including the amount of LTCs a person has (implementers say generally, people with multimorbidity are allocated more time), mental health status and learning disabilities. Interestingly, three of the eleven experts by experience interviewed believed they are allocated a standard ten-minute slot for their CSP consultation. I had observed one of those CSP consultations and it was thirty minutes long. Five other experts by experience were unaware of the length of time they were allocated. This was not an issue, as they made comments like, “we’re done when we’ve finished the conversation” (EbE5), and “I know nothing about the time. I just take what time I need. They’ll [healthcare professionals] always say, “don’t hurry”” (EbE9). Implementers and experts by experience suggested that the conversation content is more important than the length.

“We are setting aside some special time for them, uncluttered with other things within the care planning consultation... it gets rid of all the extraneous things so you have the time to concentrate on the patient in front of you” (I1)

Implementers are encouraged to use open questions such as “how are things? ... What is (not) going well? ... Is there anything in particular you want to talk about today?” at the beginning of every CSP consultation to give permission and empower people to talk about their concerns. This may be, for example, with regards to “exercise, smoking, food choices” (I5), “mental health issues” (I2), or “bereavements” and “social support” (I6). An implementer stated:

“Where I work it’s a very deprived area. A lot of people, the most important thing to them at the moment is actually financial or benefits, and that question “what’s important to you?” is pretty much always asked towards the beginning of the conversation, it’s not obvious from their care planning agenda setting prompts. I would say much more than previously we spend time talking about non long term condition related – well, they are related of course but not directly, and if that’s what they want to talk about then we’ll go with that” (I3)

Another implementer stated that sometimes, you do not need to ask these questions because if a person has come to the CSP consultation prepared, with a list of questions, “that’s it. We’re away... I hardly get chance to say anything, which is a good thing” (I7). In a CSP consultation I observed, the person with LTCs had received her results letter through the post and read through it. She had brought it with her to the CSP consultation, and when the practitioner asked, how are you? she started to talk about her results. Below is an extract from my observation notes.

*The person with diabetes sat down, and the practitioner asked, how are you? She began talking about her results that she had received in the post. The practitioner asked if she would like to*

*go through the results and then asked if there was anything in particular that she had seen on the sheet and wanted to talk about. They went through the results together, although it was the person with diabetes talking mostly.*

*The practitioner asked if she had been able to attend the DESMOND education programme, which triggered her to talk in great detail about what a valuable experience it was. They continued going through the results and the practitioner asked, if she was ok with a certain tablet. Brief discussion about medication and she said she had no problems with any of the tablets. She confirmed she had had her foot check last week as part of the HCA appointment. The practitioner went back to the leaflet where the person with diabetes could have written any concerns etc. and she asked if there was anything in particular she wanted to talk about (she hadn't written anything down). The person then went on to say she was reading about how walking can change things, so she has started walking 3 laps instead of 2, and she has stopped buying chocolate biscuits.*

In this CSP consultation, the practitioner used open questions to invite the person with diabetes to talk about what was important to her. The person with LTCs had arrived at the CSP consultation prepared, so she was able to take the lead and talk about her results and how she had already made lifestyle changes. An implementer described a similar occurrence with a person who arrived at his CSP consultation with his test results, which he was unhappy with, and he had already made significant lifestyle changes to try and improve his HBA1c. The outcome was a much shorter, person-led conversation, in which the individual was in control.

*“So really, that was a conversation where normally, I would spend 20-30 minutes with him trying to encourage him to take his tablets and look at his lifestyle and that would never happen whereas this time, it was actually quite a short conversation, because really, I just said to him that is absolutely brilliant, fantastic, good luck. You know, keep up the good work” (13)*

In contrast, I observed three CSP consultations where two of the individuals had not received their results letters and one had received it but did not

understand it and did not bring it with her to the consultation. These conversations were notably different and were more practitioner-led. I asked the practitioner after the consultations whether this was common and she stated that 95% of her CSP consultations are like that; most people do not read their results letters and she usually ends up taking the lead. She stated:

“I would say though on the whole, I’m talking about their results mostly. Because like I said, most people come in and you say have you got any problems? No, I’m fine, doing really well. So where can you go with that? You start talking about results, and then something might come back from the patient, but the results are an important part of it. A lot of the time I think it’s just reassurance” (I2)

A key consideration here is whether this really is a reflection of the people she refers to, or whether it is a reflection of her style, and, possibly, the previous experiences they may have had with her or other healthcare professionals. The extract above suggests that the latter two are most likely. The practitioner describes asking people with LTCs a closed question and when they give a closed response, she apparently sees no other option but to discuss biomedical results. If this style of working became usual practice, it would inform peoples’ expectations of CSP consultations, and might explain why 95% of her CSP consultations are practitioner-led.

These scenarios support the notion that preparation is a key context in this programme theory. When time is spent talking about what is important to the person with LTCs (enabled by healthcare professionals asking open questions) in the context of preparedness, they are more likely to take the lead, reflect on their results and their actions to improve them (if appropriate).

Furthermore, people with LTCs and healthcare professionals also highlighted the importance of relational continuity. A CSP consultation I observed was with a person who had been newly diagnosed with diabetes and had not seen the practitioner before. This combined with lack of preparation may have been why the consultation did not feel as collaborative and productive. The person stated:

“She doesn’t know me, I don’t know her, and she’s having to look at the screen so I can understand – she can’t look at me and look at the screen at the same time but I just think it could be done where if I’ve got the printout, then [nurse] doesn’t have to look at the screen because she can just go off my printout [...] Possibly a little bit more organisation on both my account and maybe the Healthcare [Assistant] or [nurse]’s behalf would speed things up” (EbE2)

Experts by experience described talking about “mood” (EbE1), “diet” (EbE8) and “everything from sex to alcohol” (EbE1) during their CSP consultations. One individual described an instance where he told the practitioner during his CSP consultation about a swelling in his testicle. He said that he would have possibly not mentioned it in a standard GP appointment, and that he knew he could discuss anything during his CSP consultations, “I know, from speaking to [name] over the years, I can speak to her about anything else” (EbE1). This person attributed feeling comfortable discussing personal issues with the practitioner to having “built up a rapport” (EbE1) over the years. This was seconded by another expert by experience, who said:

“I think because I’ve been with [name] for such a long time, I can say anything to her. We don’t have any problems. Going back a few years ago, I had problems in that I lost my sex drive, if you like. And that was due to the medication that I had been taking, and I discussed that with her quite happily, and everything else” (EbE8)

“Is that something that you brought up to [name]?” (F)

“Absolutely. To be honest, she puts my mind at ease, because I was a little concerned that, was I spoiling my marriage with my wife, and what have you, because I couldn’t perform, and she gave me lots of reassurance and stuff like that, which was great” (EbE8)

“That’s great. Is that something that’s quite important to you, to see the same practitioner all of the time?” (F)

“I would say yes, I’ve got a good relationship with [name]” (EbE8)

Relational continuity was favoured by all of the experts by experience who were interviewed, because “you get used to them [healthcare professionals]” (EbE9) and “it saves you explaining everything every time” (EbE10). One person stated that he could easily fall into a cycle of sitting in his chair and wondering if his COPD is going to get worse, and he could become depressed. However, he said “because I’m seeing [name] every year, I’m much more relaxed. She’s on the ball and she’s used to me now, and I’m used to [name], which I think is a big thing” (EbE1). He continued:

“And actually, I got a lot of comfort from speaking to [nurse] about it. Because you know what you do? You go home, you’ve got COPD, you go on the internet and you google it straight away, and you see poor people going about with oxygen bottles” (EbE1)

“Yes, of course” (F)

“So you start to imagine all of this, oh shit, what’s going to happen, and all of this. It’s through speaking to [name] and speaking to [name], I feel as if I’m in some sort of control of it. And I can ask [name] the best ways to do things. You might have heard me – well, she asked me, she sent me on a course last year with British Oxygen to do – see, the one thing I learnt on that course was that a healthy muscle doesn’t need as much oxygen as a weak muscle” (EbE1)

This person stated that because of the ongoing support and education he receives with CSP, he now has the “confidence to go on” (EbE1).

An implementer suggested that usually, it is people with COPD who are most likely to require relational continuity and trust in the CSP practitioner. She explained that this is probably because of the sensitive nature of the discussions with this group of people.

“With everybody else it’s just really around what they’re doing, maybe a little bit around mental health and a little tiny bit about medication but I’m not a nurse prescriber so I can only go so far with that. Then it’s just looking at the results and explaining things better... With the COPDs, I think that’s a lot more relationship-wise. Because you’re empathising with them, you’re talking more in depth, they’re talking about their symptoms, where most of the others don’t really have symptoms of high blood pressure, kidneys. Do you know what I mean? We’re talking about, even if you’re trying to get them into something like pulmonary rehab at least they know you’re trying, even if they don’t want it. Then you look at their inhalers and if this inhaler doesn’t work then we’re going to try another one. You’re constantly trying, even if you get nowhere. A lot of the time you do. I think they know that you’re on their side, whereas the other ones it’s maybe not quite so obvious. I think COPD ones really can love you, do you know what I mean?” (I2)

The majority of implementers emphasised the importance of relational continuity and one said it is not uncommon for people with LTCs to walk into their CSP consultation and say, “thank God it’s you” (I2). Another implementer stated that ideally, practitioners should be able to “get to know them [people with LTCs] and see how things have changed” (I5). Two implementers suggested that this is easiest in smaller practices. One of the two implementers works across two practices; one with around four and a half thousand patients, and the other with around fourteen thousand patients. She stated that in the smaller practice, people know the healthcare professionals much more personally, and therefore “they all want to see who they want to see” (I4),

whereas, in the larger practice, “the majority of patients say it makes no difference [who they see]” (I4) as long as they can be seen on a Tuesday, for example. Even though “continuity with somebody they’ve developed rapport with is likely to produce better outcomes” (I1), sometimes, in practice this is not possible and “in some respects it shouldn’t matter, if everybody is taking the same approach” (I1). Another implementer explained how a person with diabetes and COPD might benefit most from seeing a practitioner who specialises in COPD if that is the main cause for concern at the time, and also seeing their usual CSP practitioner for their diabetes management, separately. In this common scenario, information sharing between healthcare professionals is key to preserving continuity for the individual.

Some people only want to know their results; however, this is their agenda and it is what matters to them. An implementer reflected:

“And that’s why, I think it’s important to remember that it’s not about this form and it’s not about doing the care planning consultation in the way we think it should be done – it is really about them setting their agenda and it being about what’s right for them” (I7)

“So if they want to focus on medication or their condition then you go with that?” (F)

“Absolutely. And they may well come in and say, I haven’t even looked at that form. Just tell me my results and tell me what you want me to do. And that’s fine. It’s about what’s right for them, because we are all different” (I7)

Others may not be mentally or emotionally stable enough to discuss their results or their current state of physical health. An implementer described two

scenarios where people arrived at their CSP consultations distressed, and this had a direct impact on the whole consultation. The implementer stated:

“She came in, spoke for 10 minutes about her dog, who had been for an operation, she was really distressed. I knew at that moment, from about a few minutes in, with her crying like mad about the dog, now is not the time. It’s not the time. So, I had to then make another consultation and said next time, we need to concentrate on this. But I understand today, we had to talk about your dog” (18)

“I saw that she had had a terrible delivery, she had had post-natal depression, loads of things had happened, and I knew when she walked in to me, I knew nothing was going to happen about diabetes, before she walked in. and she came in, she sat down, and she looked very down. I said, you’ve had a terrible few months, haven’t you? And she burst into tears. So, it’s about hierarchy of needs. Why would diabetes be anywhere up there? If I said I’m really sorry that you’ve had this, this and this, but actually we need to talk about your terrible HBA1c – I can tell them exactly how to get it down, but it’s not going to happen” (18)

If the implementer had continued to try and discuss test results with either of these two people, it is likely that the relationship would have been damaged and trust would be lost, which would affect future engagement with CSP and perhaps with self-management. What was important to those people was seemingly unrelated to their LTCs, but it was their agenda that they needed to discuss in order to move forwards. This was explained by an implementer:

“We might think that those things don’t matter but everything in life impacts on their health and their wellbeing and their condition, so even though we might not necessarily think that that’s related, it will be” (17)

Programme theory 2 was further refined to incorporate the data from implementers and experts by experience in this testing phase. It is stated below.

## ***Tested programme theory 2***

When time is spent talking about what is important to the person with LTCs (resource) in the context of relational continuity and preparedness (context), the person feels more comfortable, more informed and therefore more in control (reasoning), so they are more likely to take positive actions (health behaviours, self-management, attitude) (outcome).

### 4.2.4 Summary

In the literature reviewed, studies showed that people's perceptions of longer CSP consultations were that healthcare professionals had more time for them, which made them feel comfortable enough to discuss personal issues. Leaders in phase two emphasised the importance of people with LTCs knowing how long their appointment is going to be, however, eight of the eleven experts by experience who were interviewed in phase three of this study were unaware that they were allocated longer CSP consultations than the standard ten-minutes. Interestingly, they did not consider this an issue as they felt that the content of the conversation was more important than the length. Healthcare professionals agreed with this and felt that by asking open questions at the beginning of CSP consultations, they give people permission, which empowers them to discuss their agenda. This notion was seconded by leaders in the focus group, who suggested that each CSP consultation is an appropriate length of time for the needs of each individual.

All five leaders agreed that CSP consultations are generally shorter if preparation is done well. Leaders suggested that people who are effectively self-managing their LTC(s) also tend to require shorter CSP consultations, and some of those people prefer to be brought back for a review appointment only if there is something wrong with their results. This was reflected in the accounts from experts by experience. All four CSP consultations I had observed in phase three of this study were around thirty minutes long. Two of the individuals had not received their results letters, one did not understand her results letter, and another had read her results letter and brought it to her consultation. I observed a much more person-led, productive conversation when the person had prepared and brought her results letter to the CSP consultation, compared to the three people who had not. Leaders, implementers and experts by experience largely agreed that preparation and relational continuity are both key contexts in this programme theory. Extracts from experts by experience show that when those components are in place, they feel more comfortable and in control, and able to take positive actions. Furthermore, my observations of CSP conversations also support the tested programme theory.

### 4.3 Goal Setting

Figure 16 below shows how goal setting may relate to other CSP components, to form a tool that supports the self-management of LTCs.

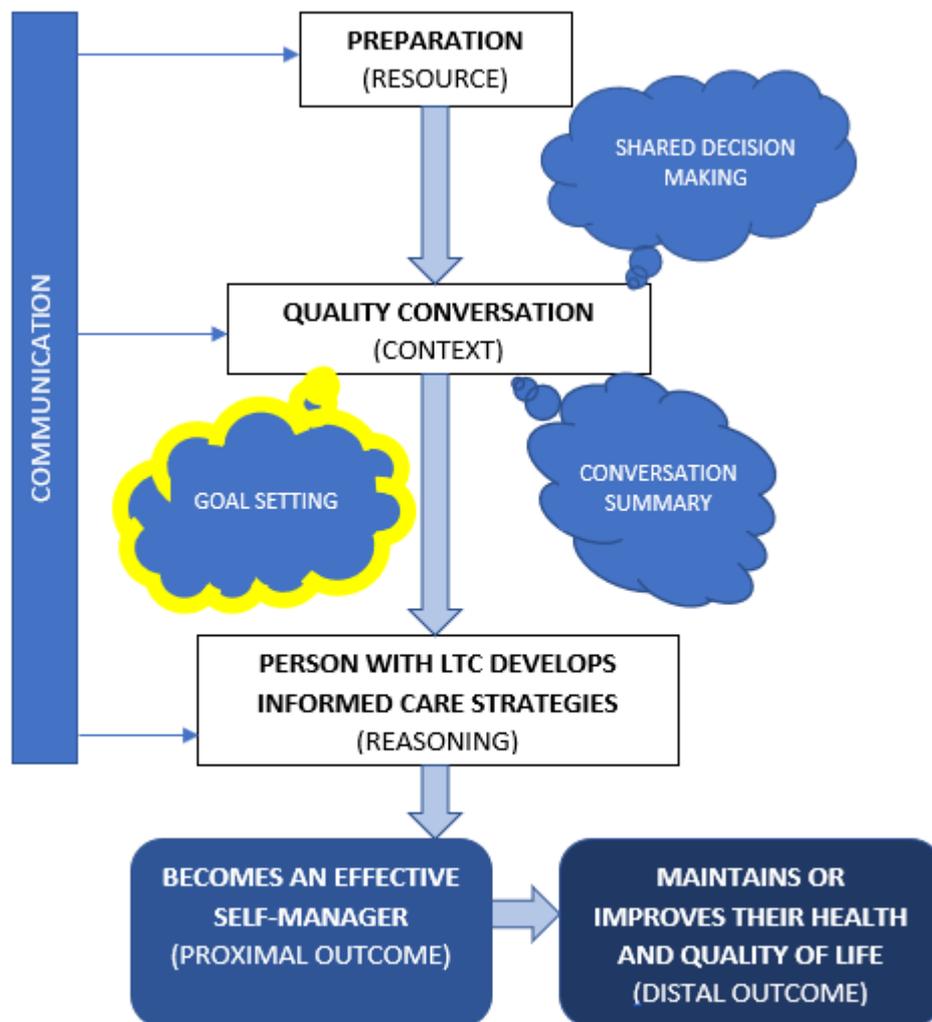


Figure 16: Goal setting as a component of care and support planning

#### 4.3.1 Developing the programme theory

The literature reviewed suggests that goal setting and action planning may make someone with a LTC feel respected, cared about, encouraged, and

capable of making a meaningful contribution to their state of health (Entwistle and Cribb, 2013). Evidence suggests that people are much more likely to take action in relation to the decisions they make themselves than decisions that are made for them (Year of Care, 2011). People with diabetes articulated how setting their own goals helped them to take ownership of their care and this made it more feasible for them to take action to manage their diabetes (Year of Care, 2011). Four of the studies reviewed reported on whether people felt they had achieved the goals they had set for themselves, and all four gave positive results. Battersby (2007) reported a 60% improvement in problem and goals measurement scores; Glasgow et al. (2005) found improvements in achievement of goals related to healthy eating and physical activity; Hart (1978) found a twofold improvement in goal attainment among the intervention group compared with controls; and Schillinger et al. (2009) reported that 88% of participants in the intervention group had succeeded in developing their own goals and action plans, leading to partial or complete success in goal achievement for an average of 2.5 plans per participant.

Other researchers have uncovered factors that might hinder or help people to achieve their goals. For example, a theme throughout the literature is that goals should be attainable for people to succeed in achieving them (Bower, 2013, Langford et al., 2007, Mathers et al., 2011, Year of Care, 2011). Langford et al. (2007) described a case study whereby a young woman was diagnosed with diabetes following pregnancy. Initially, she managed her symptoms well in a model that was largely provider driven and based on her medical conditions. However, following lifestyle changes (becoming a single

parent, battling depression, gaining weight, and taking up smoking), she stopped taking her medication and attending medical visits, resulting in a poorly controlled condition. When she took part in a diabetes self-management programme, the ongoing support she received in and between appointments helped to improve her problem-solving skills. She was empowered to set small, attainable goals which were feasible as part of her everyday life. The goals later became more specific, for example, around physical activity and diet. As a result of achieving these goals, her patient health questionnaire (PHQ-9) depression score and her HbA1c diabetes level returned to normal (Langford et al., 2007). Although this is just one case study, it is a prime example of how CSP resources (specifically personalised goal setting) can trigger positive mechanisms which lead to positive health outcomes.

Another case study illustrates how goal setting can lead to positive health outcomes (Battersby, 2007). A man with COPD and other complex health problems, whose symptoms had been worsening over the last 5 years, was supported to identify his problems and set a goal. His engagement in the process meant that his goal was realistic and important to him, so he was fully committed to achieving it. He was also very involved in the CSP process, which made him think about what was happening to his health and why. This led to recognition of his priorities and increased his motivation. As a result, he was able to reduce the impact of the problem on his daily activities from 8 to 4 (8 = *severe interference*, 0 = *no interference*) and completely achieved his goal (he scored an 8 on progress toward achieving his goal at the outset and scored 0 by the end of the trial: 8 = *no progress*, 0 = *complete success*). These

outcomes also appear to have contributed to his overall wellbeing, as his Mental Component Summary Score improved by 21 points over time.

In the Year of Care pilot study (Year of Care, 2011), people with diabetes identified the importance of considering advice from their clinicians but ultimately identified their own goals, which encouraged ownership and responsibility and enabled them to achieve their goals (Year of Care, 2011). Positive health outcomes were also reported as a result of goal setting. One person reflected on setting goals and stated, “I achieve a lot - I have become very conscious of what I eat and do more exercise. I started going to the gym to lose weight.” Another person reported, “as a result [of goal setting] . . . I walk more and have lost weight. I have also changed my diet” (Year of Care, 2011, p. 86). Not only do these quotes reflect positive lifestyle changes from the process of goal setting and action planning, but for some people, outcomes were becoming long term (Year of Care, 2011).

By taking into consideration all of the literature reviewed in this section, programme theory 3 was developed. It has two parts as the outcome in 3a becomes a mechanism (resource) in 3b. It is stated below.

### ***Developed programme theory 3***

**a.** When people with LTCs receive support in identifying priorities/goals (resource) and they want to improve aspects of their health (context), they feel empowered that they are better equipped (reasoning) so they set meaningful, achievable goals (outcome).

**b.** When achievable goals are set by people (resource) who understand how their behaviours and lifestyle affect their condition(s) (context), they feel they have ownership of their plan and their self-efficacy improves (reasoning), so they make healthier lifestyle choices (outcome) and their health improves (outcome).

#### **4.3.2 Refining the programme theory**

Leaders initially disagreed with the resource in programme theory 3a, because they felt that practitioners do not necessarily help people with LTCs to identify their goals; they begin by asking “what is important to you?” (L3). People might respond to this question with a goal, however, they may answer in a less obvious way with responses such as “family” or “money”. Practitioners would then need to explore these areas further to uncover any issues and agree a plan. On reflection, leaders thought that by beginning a conversation like this, goals may actually be unearthed early on, and they may encompass both health and social issues. The process of saying “let’s think about where you want to be” (L5) and “let’s think about how you’re going to get there” (L5) encourages people to think about their lifestyle and make decisions for themselves. Thus, the exploration of health and social issues is a key resource that may lead to goal setting. The context sparked a debate about the purpose of goal setting. One leader stated that “some people are not particularly helped by goals” (L3), perhaps because they cannot or do not want to achieve them. Others may be happy with their health and thus do not want to make any changes. Some might struggle to see how their condition impacts on their life. This is especially common with diabetes:

“Half the people would be ambivalent as to whether they wanted to do anything about their diabetes. Maybe because they don’t see the connection between the diabetes and their life” (L3).

This sparked a discussion about the role of CSP. One leader questioned whether the purpose of CSP is to support people to manage their LTC, or to help them to manage their life, with their LTC as part of it. The other leaders agreed with the latter, despite most of the literature being focused around the former. As leader 3 suggests, managing your condition well will help you to live well with your condition, therefore, practitioners can help people to make links between the two:

“Part of the role of the practitioner is to help people make the links between living well and being able to manage your long term condition well. But sometimes there aren’t any obvious links and they’ve got to be upfront with people about that” (L5).

Another leader added that even if a person does see the connection, it may not be important enough for them at that particular time to initiate a change:

“But the connection may not be important enough. But at least you have it, at least some of us see what the connection might be, and you might decide to be honest, it doesn’t matter enough” (L5).

Hypothetically, an obese person who is living with diabetes and has a rising HBA1c is told that within the next year they are probably going to need insulin treatment, unless they make some lifestyle changes. This person is happy with their lifestyle and does not see how changing their diet would make them any happier. For this person, suggesting a goal is unlikely to make a difference to their attitude or behaviour. The leader says that these occurrences are a “reality check” (15), in that no matter how terrible the situation might appear, it

if is not what is important to the person with LTCs at that particular time, they are unlikely to change it. For some people, “just beginning a conversation might be the outcome that you’re desiring” (L5) because it lays the foundations for potential future engagement with CSP conversations.

On exploration of the reasoning in this programme theory, leaders refuted the word “empowered” because it implies that the person was previously disempowered. Instead, they suggested that people “feel better equipped” (L5) to “set goals or to solve problems or to engage” (L5). A leader had recently spoken to a person with LTCs who had engaged with CSP. She described how he had become better at problem solving:

“At the end, he said things like, ‘I have a spring in my step’ and he said ‘I feel in control of things and that’s a big plus’... And it was a combination of: he now understood how the system worked, he also now understood what his condition was so it all made sense to him, so he could now start problem solving in his life. Which is different from the goal setting because it meant that now when a problem came up he could just work it out” (L3)

The person in this scenario had achieved something that leaders felt was greater than setting goals. This person went through a process that enabled him to become better at solving problems in his life whenever they emerged, which means “they don’t have to wait for you; they know they can do it” (L3). Although goal setting is “great when you can” (L5), other outcomes such as becoming engaged and better at problem solving are just as important as setting goals. One leader stated, “people have convinced me we ought to downplay goals but not to throw them out” (L3). This notion was explored further in phase three.

Programme theory 3a and 3b were refined and merged into one to incorporate data from leaders of CSP. It is reported below:

### ***Refined programme theory 3***

When both health and social issues are explored (resource) in the context of a quality conversation (context), people with LTCs feel better equipped (reasoning) so they: (a) become engaged, (b) set goals and/or (c) become better at problem solving (outcome).

#### **4.3.3 Testing the programme theory**

Most implementers agreed that goal setting is an effective tool that supports self-management. People who are motivated and want to make changes may set goals ahead of their CSP consultations. An implementer described a gentleman whose diabetes had been poorly controlled for many years. He rarely engaged with CSP and had a very busy lifestyle. At his most recent CSP review, he arrived having received and read his test results. He had already written his own goals on his care and support plan and was working towards achieving them.

“When he sat down he said straight away, I’ve got my results and I realise they really are terrible, or something like that, and I thought, oh well, let’s have a chat about it. He said well, it’s fine because I’ve already decided what I’m going to do. I said that’s great, what have you decided? Basically, he’d got his care plan, he’d seen how poorly his diabetes was controlled and, pretty much everything else was controlled, and he had talked to his wife about it; she wasn’t very happy with her weight. They both decided to make some changes. They’d

gone out and converted their garage into a gym. They'd bought gym equipment and they'd set aside half an hour every day to both go and spend time in their little gym together. Also, they'd decided to eat more healthily, so they'd got this whole menu plan written out. I think he'd had his results for about a month before I'd seen him, and he was up and running with this and they were both so excited, they were both proud to explain what they'd done, and so positive about the changes they'd made" (I3)

Other practitioners stated that this is not uncommon, and that they often see people who have set and are already achieving their own goals prior to the CSP consultation. An expert by experience, who was living with diabetes, described herself in a similar situation. Her HBA1c had spiked to 90 and a practitioner had suggested she begin insulin injections. This lady was a retired nurse and she said seeing those results made her realise that this was serious. Previously, when she had been for her CSP consultations, she would set goals with the intention to achieve them, but rarely acted on them. In the interview, she described the goal setting process as practitioner-led, which may have affected the likelihood of her achieving them, as implementers suggested, "they are more likely to make a change if they come up with the idea themselves" (I8). She stated:

"Every time I see her she goes through your goals and what you're going to do. As I say, I knew what to do, but you come out and you're full of – yes, I'm going to do that. And then after a few days it just goes out the window" (EbE11)

On this particular occasion, when she became aware that her HBA1c had spiked, she immediately made some lifestyle and diet changes, including cutting out crisps and sugar, avoiding carbohydrates on an evening, and checking her blood sugars every morning. She attributed her increased

motivation to make these changes to two things: her fear of insulin injections and the birth of her granddaughter.

“I think it was the fear of the insulin, that’s what did it for me, and I thought, I’m not sticking needles in me. Not that I’m frightened of needles, because I’m not. I just thought oh, I couldn’t! It just came, I thought, oh hey, howay, this is your life, it’s only you that can do anything about it... The other thing was with the baby being born, I thought, oh I want to see the baby and I want to be alive for this baby. That spurred me on” (EbE11)

Implementers proposed that life-changing events can have this impact on people’s motivation to make changes. This may be in relation to their health, as one implementer suggests, “if they’ve had a heart attack or something, they are usually quite motivated” (I8) or family events, as described in the above extract. There were varied responses when I asked implementers whether motivation to set goals and achieve them was dependent on any other factors. One implementer stated that with diabetes, people who are newly diagnosed “usually make big changes” (I8) because they do not want to have to take medication. Another implementer had found that some elderly people with diabetes made extreme changes to their diets, whilst another stated that all people with diabetes set goals in their CSP consultations. The last implementer worked in a practice which has a diabetic lead GP who is keen to set HBA1c targets, and the practitioners are used to negotiating realistic goals with people, for example, “your HBA1c is 100, let’s try and get it down to...” (I4). Conversely, an implementer explained that she knew of diabetic people who had had amputations due to diabetes complications, and even that was not enough to motivate them to make changes. She had also heard others say that if they got to that point, perhaps that may be enough to motivate them to

change. She explained that many people with diabetes have no symptoms; “it’s a silent condition” (I8), thus, people often do not take it seriously until it is in its later stages and symptoms begin to appear.

The above examples highlight the fact that there are several factors which may affect goal setting. Lifestyle also has a huge impact on a person’s likelihood to prioritise their health. For example, an implementer suggests that if a person travels around for their work and they stay in hotels and buy food on-the-go, they might “really struggle” (I8). Although, if their job requires a high level of motivation, perhaps they are the type of person to not let their lifestyle affect their health. Thus, “personality types” (I8) are also an influencing factor in this programme theory. I interviewed a person with LTCs whom, before he retired, worked as a mobile gas engineer travelling up and down the country. He said that when he was working he would not have time for breakfast, so he would often stop at service stations for fast food. He explained:

“You’re on the clock all the time, so you tend to eat when you can eat. And yeah, I was overdoing it. What brought it home – I retired, and it was just nice to be able to not eat to the clock. And then I had my heart attack and to be honest that frightened the crap out of me. I was fortunate, I’m alright, I was took into hospital and given a quadruple bypass, and I swore then I would change my life, and I have” (EbE5)

This individual described how his working conditions not only affected his diabetes, but also his ability to change his lifestyle. It took a heart attack to make him realise that his condition was serious, and at that point he became motivated to make changes. He and his wife, who is “100% on it” (EbE5) have changed their lifestyle together. He now runs 5km once a week, swims, plays

hockey, and walks for miles with his wife. His life events have contributed to him becoming an extremely motivated individual, and he sets himself goals to keep on track.

“My goal is – I set a goal – Great North Run, I’m going to do it. And that’s what I’m doing all of this running for, Great North Run. To prove to myself that I’m fit enough. After that, we’ll have to have a look, because you’ve got to have goals” (EbE5)

“Is that something that you” – (F)

“She [referring to a GP] mentioned that a few times. When I started telling her what I was doing, well, carry on” (EbE5)

This individual describes a CSP conversation where he is very much in control. The practitioner tells him to keep doing what he is doing, as he has clearly made, and is maintaining, major lifestyle changes, which will likely have a positive impact on his health and quality of life.

Another implementer suggested that although individuals setting their own goals is considered most effective, collaborative discussions around goals “can be a really helpful process” (I3) whereby a discussion takes place and entrenched issues, such as low confidence, can be explored. If a person has set their own goals prior to the consultation, this discussion might never take place and practitioners may never be aware of issues that they could potentially help with. Two implementers discussed importance scoring and confidence scoring. When a goal is set by a person with LTCs, during the consultation the practitioner asks, on a scale of 1-10, how important this goal is to them (1 is not important, 10 is very important). They also ask how confident the individual feels (on the same scale) that they will be able to

achieve this goal in an agreed timescale. Both implementers emphasised how helpful this process can be, as it reinforces whether an action plan is achievable and enables practitioners and people with LTCs to discuss resources and support that might be helpful, as well as stumbling blocks that might get in the way, and ways to overcome them.

“A good [confidence] score with a person who is very motivated and has read their results and decided what they’re going to do, is brilliant, all you need to do is get them to a point where they make a plan with a follow up, or not, they might say I don’t need any follow up, thank you, I’m quite confident that I can do that, I’ve done it before. It might be that this guy who you’re trying to get to drink 3 bottles of wine a week less is just, he’s saying that to get out of the door. And when you drill down a bit further, and put timescales on it, you might find that [confidence score] drops to a 5. Anything less than 7 is a waste of time, they think. Or, a point where you would say, well what might make that an 8? If you’re on a 4 now, what might make you more confident about doing that? It might be that you get your wife to give up drinking as well, or it might be any number of things, I suppose” (I6)

The agreeing implementer suggested that confidence scoring ensures that a person does not go away from the CSP consultation with an apparently great action plan but no confidence to achieve it. It also encourages discussions about potential barriers and ways to overcome them. For example, if a person’s goal was to swim five days per week, and initially they gave a confidence score of 8 for this goal, they may leave the consultation feeling confident that they would achieve it. However, once they are outside of the consultation, challenges may arise, thus preventing them from achieving their goal. An example might be anxiety around busy periods in the swimming pool. The person may suddenly realise that this anxiety is too much, and therefore choose not to act on the goal. If the practitioner had asked the person during the consultation to identify any potential barriers to achieving the goal, anxiety

around busy periods may have been acknowledged. The practitioner may have encouraged the person to think about ways to overcome this issue, for example, they could have planned a swimming timetable around quieter swimming sessions. If EbE11, who described setting goals with every intention to attain them, but then “after a few days it just goes out the window”, had been coached through how to overcome barriers, she may have had a different outcome. Discussions around problem-solving as part of the goal setting process are therefore key in helping people to achieve their goals.

I observed a CSP consultation where the practitioner guided the person with LTCs through this process. An extract from my observation notes describes the individual setting a goal around becoming more active. She identified a potential barrier and made a back-up plan.

*The practitioner asked if exercise was something they could look at.*

*This triggered the person to think about how it could benefit her and she replied that it is also important for her joints.*

*The practitioner then asked if she would like to make a plan around that and whether that would be helpful.*

*The person responded that she has found walking works for her, not the gym. She came up with a back-up plan for when the weather is bad – she will do indoor activities with her grandchildren instead.*

Initially, the person with LTCs had said that her goal was to maintain her current health status. This is a distal or long term goal. The practitioner helped her to think about how she could achieve this, which resulted in a proximal goal (short term goal to be achieved whilst working towards the distal goal) being set around becoming more active. An implementer suggested that it is

common for people to say that they are happy as they are, but once they enter into a conversation around lifestyle, there are usually several changes that they want to make and they had not realised it until the conversation. The implementer stated that the process of goal setting empowers people to want to make changes, and they tend to leave the consultation feeling positive. When they return for their next CSP review, if there has been any amount of improvement in their results, “that motivates them” (I5) to continue making healthier choices. Another implementer agreed that most people have something that they want to change. She stated:

“Very few people have got nothing they want to change, and if someone was genuinely sitting there saying, “I’m not interested”, there would be a massive red flag about mood, about depression, CBT, so there would always be something that we could do to help in some way” (I4)

The difference in perceptions around whether there is always a goal to set may be due to implementers having different beliefs in what constitutes a goal. Those implementers who suggested that some people will come in and say, “there’s nothing I want to ask, there’s no goals I want to set because everything is smashing” (I7) may perceive goals to be around behaviour or lifestyle, in which case, there may not be a specific goal to set. One implementer suggested that goals do not necessarily need to involve a behaviour change, particularly for people with multimorbidity. A goal might be “I want to write a DNAR, or I want to speak to my son about power of attorney” (I1) or it might be “ask my sister if she can come with me to the swimming baths next week” (I6). An expert by experience reflected, “there’s always something that you can put down that you want to do” (EbE4).

Conversely, an implementer suggested that often goal setting does not happen in practice like the literature says it does, and like most of the other implementers and people with LTCs have described.

“I think there’s some theory that it’s much better if you do – the patient does it themselves and you support the patient to develop specific goals. I think actually, what we don’t do is that. In reality, I think there’s very much a collaborative, good quality conversation about decisions to be made and how they’re looking after themselves and bring them on board, deciding what to do next. I think goal setting is a bit clumsy” (I1)

“Why?” (F)

“Because often you don’t goal set. It’s about supporting the person to be in the right place to look after themselves. And that’s sometimes not about a specific goal. I think clinically my experience is probably more about the coaching problem-solving part of it, rather than specific goals. Specific goals are easy – well I want to lose half a stone before my daughter’s wedding, and these are the steps I’m going to take. In a way, anybody can do that, but actually, real in-depth problem solving about the issues they’ve got around their exercise or depression or whatever it is. It’s sometimes harder to capture but it’s just as important” (I1)

The implementer felt that coaching problem-solving skills is as important as setting individual goals as it enables people to find solutions whenever problems arise. However, most of the other implementers and experts by experience have described this within the process of goal setting. I would therefore argue that coaching problem-solving skills is a natural part of goal setting and the care and support plan sets practitioners up to be able to ask the right questions to teach those skills. Another implementer agreed with the idea that goal setting (with coaching problem-solving skills as part of that) is not a separate process in the CSP consultation; it is part of the conversation and usually transpires naturally.

Programme theory 3 has remained unchanged since phase 2 as it is substantiated by the data collected in phase 3. It is stated again below.

### **Tested programme theory 3**

When both health and social issues are explored (resource) in the context of a quality conversation (context), people with LTCs feel better equipped (reasoning) so they: (a) become engaged, (b) set goals and/or (c) become better at problem solving (outcome).

#### 4.3.4 Summary

Across all three phases of this study, there was consensus that the process of goal setting and action planning is an effective tool to support self-management, and that people are most likely to achieve attainable goals they set for themselves. Leaders suggested that practitioners can help people with LTCs to identify goals early in the CSP consultation by asking open questions that might encourage people to think about their lifestyle and any health and social issues that they might have. This helps to shape the conversation around what is important to the person with LTCs. Examples were given by implementers and people with LTCs, of situations where people who were motivated had set their own goals ahead of their CSP consultations. Various factors can increase a person's motivation to make changes (where there is a change to be made), including lifestyle, personality types, the occurrence of a major life event, and support from a practitioner who motivates and encourages.

There was some variation in phase two and phase three about what goal setting constitutes. Some implementers maintained that goal setting empowers people to want to make changes, whereas others believed that goal setting does not have to involve a behaviour change. For those people, beginning a conversation or giving a discussion some thought might be the desired goal at that particular time. Others saw great value in discussing people's confidence to achieve goals and providing support around stumbling blocks they might face. This was observed in a CSP consultation, where an individual set herself a goal to become more active, recognised a potential barrier that could affect her achieving this goal, and was supported through creating a back-up plan to use if this situation were to arise.

Whilst the literature reviewed portrayed goal setting as a systematic process within the CSP consultation, with very little variance, in practice, the person's particular context may not always be the same. Goal setting is therefore described in phase two and phase three as a flexible process that happens naturally during a CSP conversation, and its usability is individual to the person and the context of their lives at that particular time.

#### 4.4 Shared Decision Making

Figure 17 below shows how shared decision making may relate to other CSP components, to form a tool that supports the self-management of LTCs.

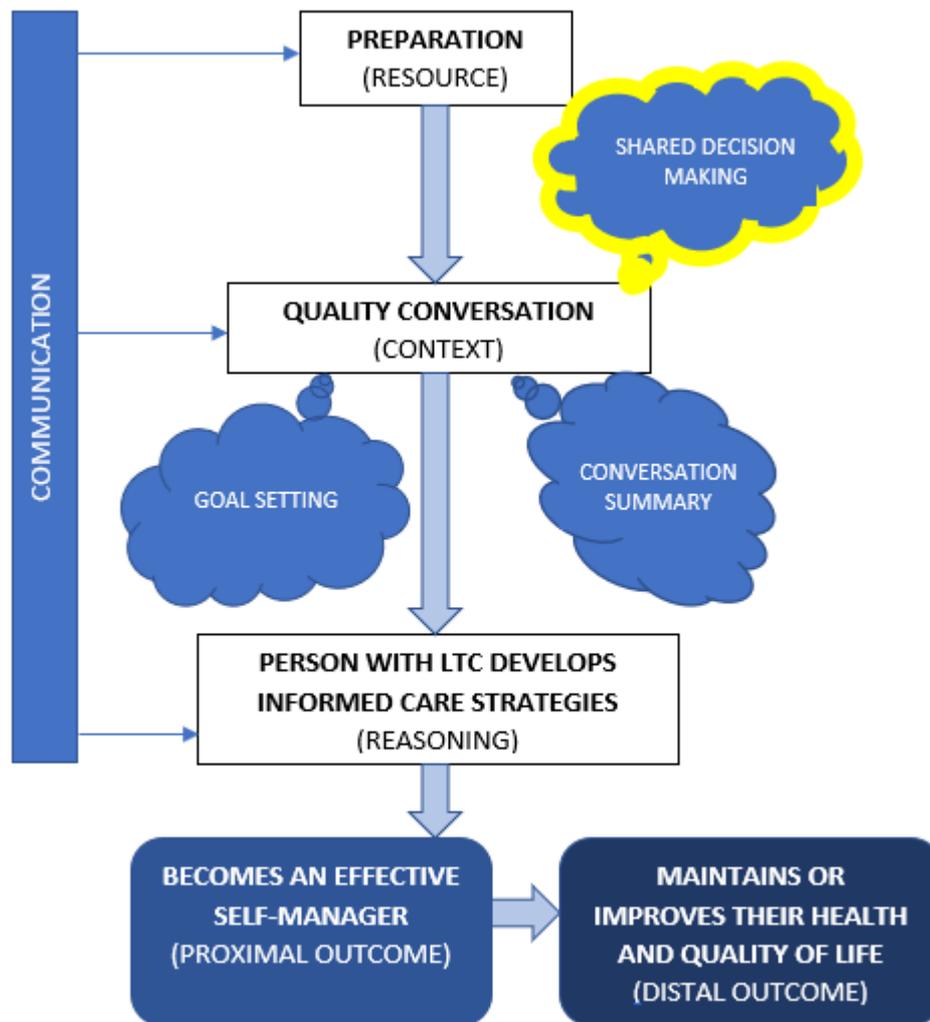


Figure 17: Shared decision making as a component of care and support planning

#### 4.4.1 Developing the programme theory

Shared decision making builds upon the principles of person-centeredness, but specifically considers what is needed in the context of making decisions in healthcare (Lhussier et al., 2013). It has been defined as “a meeting between two equals” (Makoul and Clayman, 2006) where practitioners and people with LTCs work together to select tests, treatments, management, or support packages, based on clinical evidence and people’s informed preferences. It involves the provision of evidence-based information about options, outcomes, and uncertainties, together with decision support counselling and systems for recording and implementing people’s treatment preferences (Coulter, 2011). Shared decision making is unlikely to be achieved if practitioners do not agree with its guiding ethical principles (Elwyn et al., 2012). At its core, shared decision making accepts that individual self-determination is a desirable goal and that clinicians need to support people to achieve this goal, while achieving autonomy by building good relationships and respecting individual competence and interdependence of others.

However, some healthcare professionals argue that some people do not *want* to be involved in decisions, lack the capacity or ability, might make “bad” decisions, or worry that shared decision making is just not practical, given constraints such as time pressure (Elwyn et al., 2012). Others claim they are “already doing it,” though data from patient experience surveys indicate that this is generally not the case (Elwyn et al., 2012). It is therefore clear that the first step for successful shared decision making is to ensure that practitioners support the underlying rationale. Nevertheless, even when this step is in place,

practitioners are likely to face implementation challenges. Low health literacy or low numeracy are barriers to shared decision making and some people come from cultural backgrounds that lack a tradition of individuals making autonomous decisions. Therefore, although good clinical communication skills, including building rapport and structuring the consultations, are key to effective shared decision making, there are other barriers and enablers to take into consideration.

Research shows that for the relationship between a practitioner and a person with LTCs to enable the desired outcome (shared decision making), both should be motivated to invest in better quality relationships and improved outcomes (Elwyn et al., 2012). For people with LTCs, this means working in partnership with healthcare professionals, to be better informed and involved in their care, to share decisions, and to contribute to health management (Ahmad, 2014). However, some practitioners believe this view of the person's role is unrealistic as they are not capable of engaging in decisions about their health and healthcare (Russell et al., 2008). Blakeman (2006) interviewed 16 GPs who were working in practices involved in the Expert Patients Programme: a lay-led self-management programme for people with LTCs. They found that GPs expressed the need to feel in control to fulfil their professional responsibility, and most had concerns about giving people too much responsibility without sufficient support or guidance.

Ensuring shared understanding within teams concerning the purpose of shared decision making is a vital component of programme implementation

(Lloyd et al., 2013). A mixed-methods study by Kennedy et al. (2014) describing a failed attempt at the implementation of Whole System Informing Self-Management Engagement (WISE) illustrates this concept. The implementation of WISE was met with issues at each level of the system, beginning at the organisational level. It was not prioritised by practices, and so little effort was invested in WISE techniques. This had a negative effect on healthcare professionals' perceptions of the programme and the way in which they implemented it, which ultimately affected the care of people with LTCs.

Lhussier et al. (2013) stated that the practitioner's role is to provide information to, and clarify and understand the preferences of, the person aiming to "share" the decision. The process involves an exchange of information about the treatment options available, clarifying the issue(s) and making decisions. To achieve this, healthcare professionals need to not only demonstrate core person-centred communication skills and empathy, but they must also be able to model and support the individual making the decision that is right for them without unduly leading or influencing them, which can involve considerable skills in deliberation and negotiation. It also requires people with LTCs to take ownership and responsibility for those decisions and to follow up with healthcare professionals within an agreed timeframe. Figure 18 below shows the operationalisation of this process, proposed by Lhussier et al. (2013).

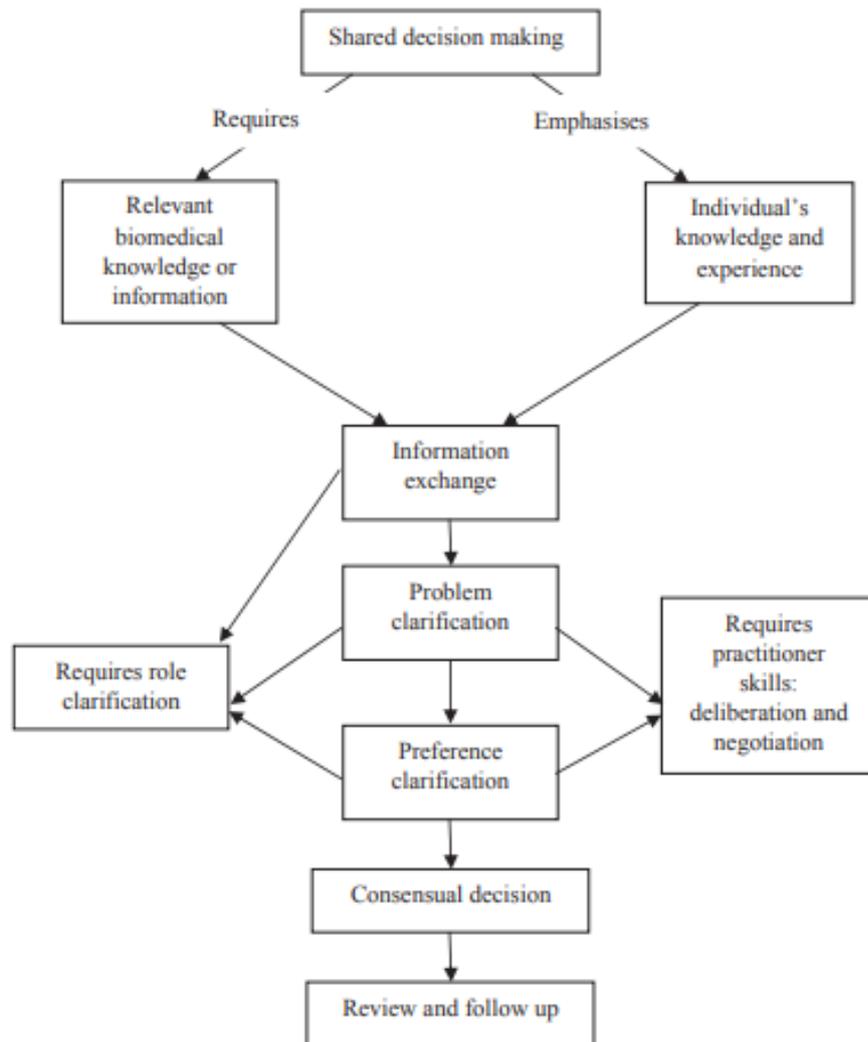


Figure 18: A concept map of shared decision making (Lhussier et al., 2013)

A study by Lawn et al. (2013) provides evidence that when the requirement of relevant biomedical knowledge or information is fulfilled (see figure 18), but no emphasis is placed on the individual's knowledge and experience, shared decision making does not occur. Lawn et al. (2013) describe occasions where practitioners dismissed input from people with LTCs, making decisions for them instead of supporting and encouraging them to become active communicators in an equal partnership.

In addition, studies have highlighted lack of health education for people with LTCs as a barrier to shared decision making. Bower (2013) felt that the process of shared decision making should be focused on educating people to make informed decisions. Bower (2013) described, through the responses of a healthcare professional research participant, the fine line between educating people to make informed decisions and telling them what to do. They reported that healthcare professionals did not want to come across as telling people what to do because enabling choice was considered central to maintaining good relationships with people with LTCs (Bower, 2013). Again, this reflects the importance of practitioners supporting people to make the decision that is right for them (Lhussier et al., 2013).

In a study by Lown et al. (2009), principles of appreciative inquiry were used to encourage participants (experienced practitioners and people with LTCs) to discuss examples and share stories of their own experiences in which shared decision making went well. One participant reflected, “[shared decision making] really does require a really kind of intimate attachment between the patient and the doctor...” (Lown et al., 2009, p. 165). However, sometimes, people may find it difficult to understand and express their feelings and values. The inability to share certain feelings is often due to a lack of trust in the healthcare professional, as discussed by participants, one of whom reflected, “. . . [It helps] having an open and candid dialogue and relationship so that pretty much anything can be discussed.” The participant went on to say, “if you have the trust, then you find that you are . . . more willing to put those things out on the table” (Lown et al., 2009, p. 165).

In a qualitative study of ethnographic observations and audio-taped consultations, Lawn et al. (2013) describe the healthcare professional's "battle for control of consultations appearing to have the goal of forcing peoples' submission and dependence" (Lawn et al., 2013, p. 391). They stated that in these circumstances, people with LTCs might become dependent or withdraw contact from healthcare professionals altogether, which would have a negative impact on the relationship and on the person's wellbeing. They found that engaging people with LTCs in the consultation appeared to build trust in the relationship and people became more confident in sharing their experiences, enabling more collaborative, power-sharing dialogues.

Shared decision making is based on the idea of an equal power relationship, and in the example above, this was not evident. CSP aims to balance this power and remove these associations as soon as the person walks through the door. Although the majority of these examples of shared decision making occurring (or not) are outside of the CSP setting due to limited evidence base, shared decision making is a core component of CSP conversations (Lhussier et al., 2013) and will be explored further in phase two and phase three.

By taking into consideration all of the literature reviewed in this section, programme theory 4 was developed. It is stated below.

#### ***Developed programme theory 4***

When healthcare professionals and people with LTCs effectively communicate their knowledge and expertise (resource) in the context of a relationship built on trust and respect (context), people feel well informed and well supported (reasoning) which leads to shared decision making (outcome) and a decision that fits with their values (outcome).

#### **4.4.2 Refining the programme theory**

During the focus group it became clear that leaders felt the way shared decision making is portrayed in the literature is not the same as shared decision making within a CSP conversation. A leader described the distinction:

“I think shared decision making is not exclusive of patient preparedness, consultations, collaboration on goals, or summarising. It’s a label that’s been attached to something that is generally a decision at a particular point in which you could go in one of several directions. But there’s a clear choice, whereas care planning is a much more iterative, open process where people make decisions across a range of behaviours rather than, am I going to have an operation vs a tablet for pain. So, I think shared decision making feels much too narrow to me” (L5)

The leader continued by saying that often, shared decision making that occurs outside of a CSP context is biomedically focused, whereas, in a CSP conversation, when a decision needs to be made about a person’s treatment, it tends to be biopsychosocial in nature. There are often a variety of legitimate options “which are patient sensitive” (L3). These may include biomedical options (surgery, medication, etc.) and lifestyle and behavioural choices (diet change, exercise, social groups, etc.).

Leaders agreed that within the CSP conversation, decisions should not be shared; they should be made by the person with LTCs. If a decision needs to be made, it should be “the right decision for the person” (L3). This idea was explored further:

“Unless it’s something that the doctor has to do, like prescribing, or you’re unconscious and the doctor is going to do a procedure on you, it shouldn’t be a shared decision, it should be your [referring to the person with LTCs] decision. And you [person with LTCs] should be able to override everything” (L3)

Leaders reinforced that although the final decision is always the person’s, the process before the decision is made is collaborative. Both practitioners and people with LTCs are “ignorant about key things” (L3) they need to know for a decision to be made. For instance, “the professional is unaware of what really matters to the patient and their personal and social context, and the patient is unaware of the science” (L3). Good decisions are made “when both of those things are pulled together” (L5) so that the practitioner is aware of the person’s preferences and values and the person is aware of the medical benefits and risks of their choices and can make an informed decision. This process often results in mutual satisfaction:

“I’ve certainly heard people say it means that health professionals feel much less burdened by the weight of have I got it right? Have I got it wrong? Because actually, we shared this decision and it was what you wanted to do. There’s also areas that patients have less decisional conflict, they’re more confident that the decision is the right one for them too” (L5)

It was decided during the focus group that there should be two separate CMOCs for programme theory 4: one for the professional and one for the

person with LTCs, however, the context and the outcome are the same for both. They are reported below.

#### **Refined programme theory 4**

##### a) Professional's perspective

When unbiased information (pros/cons of treatment options or no treatment) is shared (resource) in a context where a decision needs to be made (context), the person with LTCs has a better understanding of the options (reasoning), so a two-way conversation happens and the professional and person with LTCs agree on the course of action (outcome).

##### b) Person's perspective

When questions are prepared by the person with LTCs (resource) in a context where a decision needs to be made (context), the professional understands what the person with LTCs knows/wants to know and can cater for their needs (reasoning). A two-way conversation happens and the professional and person with LTCs agree on the course of action (outcome).

#### **4.4.3 Testing the programme theory**

Implementers described shared decision making as discussing options, risks, and supporting people to make a decision “that’s good for them, and not led by you” (I1). One implementer explained that there is always the option for a person to say how they feel about something, and sometimes, this might differ

to how a practitioner feels about it. She described what would happen in this circumstance:

“Even if we think someone is very poorly and needs to start on – they’ve got very high blood pressure and I would recommend that they started it today, it’s still their decision. This is what the NICE guidance says, this is what I think could be good for you, this is what I think the disadvantages of not being treated are. So, it’s giving them that and they’ll make their own decision” (I6)

The implementer stated that even in life-threatening circumstances, for example, if an individual does not want to be admitted to hospital and a practitioner feels they need urgent care, “there is always an alternative” (I6). As long as the person understands the risks and has capacity to make that decision, their decision is paramount. Another implementer felt that in this kind of circumstance, she would “push a little bit harder” (I2) and provide written information for them to take home and read, so that they can digest it and understand the risks in their decision.

Three implementers described how shared decision making can be affected when people with LTCs lack capacity to highlight their preferences and make decisions. One of them suggested that learning difficulties and early onset dementia are two conditions that may prevent people from making decisions about their health. She explained that if a person with learning difficulties cannot understand the implications of a decision, a carer is not able to make it on their behalf. In this situation, there would be a collaborative discussion with the individual’s carer about options and risks, but the implementer would make the final decision herself. She described a relatively independent young man with learning difficulties who lives in residential support housing, and for one

meal per day he makes himself whatever he wants to eat. The implementer stated that this is usually “a jar of peanut butter and some toast” (I4). Instead of removing his independence further and asking the carers to prepare all of his meals, a discussion took place between the implementer and the carer, and they agreed that it would be in the person’s best interest if he was given healthy food choices, which he could then prepare himself. Arguably, that is not the case. Restricting his diet (and what he enjoys) for the medical agenda may not truly represent his best interests or what might have been his decision on this matter. Although those involved maintained that this was a shared decision making process, the individual concerned was not involved. Furthermore, the implementer stated “there will always be people who can’t. And there’s nothing you can do about that” (I4). Similarly, people with early onset dementia usually cannot make decisions for themselves, and often, relatives become involved.

“I could sit and have a wonderful conversation with somebody who has got diabetes and early onset dementia. But they can’t make a shared decision with myself about their medication, because they’ll forget to take it. So, there will always be some elements that have to be enforced. You’ll tell them that’s what you’re doing and the husband’s sitting there saying, ‘I do her medication and it’s locked away and I give her it or else she would take the lot or wouldn’t take any’” (I4)

In addition to particular conditions affecting the likelihood of shared decision making occurring, some implementers emphasised the fact that individual characteristics can be enabling or disabling. One implementer suggested that some people would rather not make decisions for themselves. This may be due to lack of confidence or because the person has adopted a more traditional approach and “they feel the doctor knows best” (I5). They suggested that

others may want the responsibility taking away from them, particularly if they are struggling with their mental health. An implementer proposed that sometimes, she finds that negotiating with these people is supportive of shared decision making.

“You would never really make the decision for them because there’s always that negotiable part of the consultation, they’d say, what would you do? Well, you know, you never would say, well I would do this. You’d say well, let’s think about that a bit more. You could do this, that would be the benefits of that, or this might be better for you because... but that doesn’t mean you have to do that. You could say which do you find the most acceptable, because we could try that and if that doesn’t work, we can go to that or if you don’t find that you can manage that one, we can resort to the drug therapy” (I6)

In contrast, another implementer felt that in a situation where a person is asking for a decision to be made for them, sometimes it is best to “step into that role if that’s what they want” (I5). She would say to them, “I think this is probably what’s best for you” (I5). Similarly, an implementer explained that if a person with uncontrolled diabetes is resistant to treatment which she feels is necessary, the CSP conversation is very different because she “can’t let somebody walk out with a HBA1c of 150 and do nothing about it” (I4). In these cases, the conversation starts off the same, with the person arriving at the CSP consultation with their results letter and their agenda, but after this has been discussed, the practitioner would say:

“Now that we’ve dealt with that, how do you feel? Is there anything else you want to talk about? No? I feel I just need to mention...” (I4)

She suggested that if the person was still uninterested in her recommendation, she would initially try and motivate them to become interested. If she did not succeed, she would fall into a more traditional role. Despite her GP practice

having transitioned to CSP, she felt that there is still a place in some consultations where she has to take control and say something to the effect of:

“I’m sorry, but we’re going to have to increase your medication. You may not want to take any more medication but we’re going to have to pop you on insulin” (I4)

This outlook is not reflective of the philosophy behind shared decision making or CSP. An individual with a HBA1c of 150 is likely to have significant social or psychological stresses preventing them from engaging with diabetes self-management. Telling the person what to do, or “telling them off” is likely to be ignored and have a detrimental impact on the healthcare relationship. A practitioner who understood and believed in the philosophy of shared decision making and CSP would recognise that attempting to address these underlying stressors first, i.e. removing the barrier to self-management, would help the person far more.

Three experts by experience explained that decisions about their medication are usually made by the practitioner in their CSP appointment, and all three felt that they would like to have more input into these decisions. One of them stated that he has expressed to practitioners in his CSP consultations that he would prefer to try and control his diabetes with diet, but that he is always told “stick to two tablets and don’t knock it down to 1” (EbE7). He said that because the healthcare professional is the person with the knowledge, he obliges. He explained that he has already decided to reduce his blood pressure tablet himself because it is having an adverse effect, leaving him feeling “dizzy on

occasions” (EbE7). This supports the notion that if practitioners make decisions for people with LTCs, those who feel they would like more input into their healthcare are less likely to engage with the decisions being made for them.

Implementers generally agreed that if results were borderline and people wanted to try alternative treatments first, that would be acceptable. An implementer gave an example of when this might happen:

“Sometimes, they decide they don’t want the treatment. “Yeah, I hear what you’re saying, I understand that, but I want to try this first, I want to try beetroot juice from Holland and Barrett. Can I come back in a month? Or, can I check my own blood pressure at home?” You can’t make people take treatment either. So, I think it’s much better to let them do that” (I6)

A newly diagnosed person with uncontrolled diabetes described similar circumstances when he attended his first CSP consultation (which I had observed) and his HBA1c was 86. The practitioner explained the pros and cons of commencing a medication to bring it down quickly and explained that there would be a risk that the drug could cause his blood glucose level to drop too low (hypoglycaemia). The individual decided that he wanted to try and take control of his health himself via diet and revisit his results in six months’ time. I noted during his CSP consultation that the practitioner also offered another medication for his high cholesterol, and he declined. The risks of not treating high cholesterol were then explained to him, and he responded that the same medication had previously caused him serious side effects. He explained during the interview:

“At the moment, from taking no tablets to taking 3, and then maybe go onto a statin, and then maybe a blood pressure – it can be a lot of tablets, and ones that you haven’t been used to. I’m the type of person to say, well look, I’ll try and manage these tablets first, let’s get used to these and then see where we go, maybe down the line, I may have to go on them but at the moment, I’ll try not to. I’m not trying to be pedantic by any means and overrule anybody, but I just think it’s personal choice. I’m quite happy just to take 1 lot of tablets first and see where whether we can get it under control before we start trying to control everything at the same time” (EbE2)

I asked this person whether he felt that his opinion was respected by the practitioner, or whether he felt that there was any resistance. He stated that he felt his choice was respected, however, the outcome of the discussion was that he would instead speak to a GP about the suggested medication, as opposed to the nurse implementing CSP.

“She [referring to the nurse] said look, would you rather I put you on Glycoside or would you rather see the GP? I said well I would rather see the GP, you know, a GP that has been dealing with this, and explain my reasoning to them rather than somebody that I’m seeing for the first time” (EbE2)

The practitioner clearly gave the person two options, and neither were for him to go away and try to manage his diabetes and cholesterol by making lifestyle changes. Despite him being an average weight for his height, and claiming he eats a healthy diet, this was not investigated further. He was not given any dietary guidance, nor was he referred to a dietician. Instead, it appeared the practitioner either wanted him to accept the medication from her or speak to a GP who may be able to persuade him to take it. Another expert by experience confirmed that this is also a common occurrence for him in his CSP consultations. He suggested that if he told the nurse that because his blood pressure had dropped, he wanted to reduce his medication as it was making

him feel unwell, the nurse would tell him to discuss this with a GP, because “she wouldn’t get into that sort of area of ‘I don’t think that’s a good idea, or I think that’s a good idea” (EbE7). The act of one practitioner referring an individual to another to discuss medication, without exploring other options, reinforces the notion that some practitioners perhaps do not feel comfortable discussing lifestyle factors and/or allowing people to leave the CSP consultation with an unhealthy test result and no medical plan in place. They may be worried that poor diabetes control, or high cardiovascular risk, will lead to avoidable health problems. Thus, out of fear of litigation, or guilt for not helping in the way they feel they should, they refer them to a practitioner of higher status. An implementer stated:

“They don’t expect the nurses to make the decisions. A line we get all the time is, I don’t know, you’re the doctor. Whereas, I’ve never heard anyone say, I don’t know, you’re the nurse” (I8)

This implies that in practice, the roles of doctors and nurses are still perceived very differently, despite a lot of work having been done in recent years to upskill nurses and put them in control of LTC management. This power dynamic could influence a person’s opinion or decision. An expert by experience described exactly this:

“I did see the nurse and she couldn’t convince me of what I thought the problem was, but [GP] did” (EbE10)

“Can you think of any reason why [GP] could convince you?” (F)

“I think it is her level of expertise and knowledge” (EbE10)

One of the people who declined medication in the above example was one of three interviewed in this phase who stated that they make the decisions about

their health and wellbeing within and outside of the CSP conversation. They explained:

“The practitioner can only give me advice. She can only suggest that we do this, and we do that. It’s up to me” (EbE5)

“She has said different things over the years, she respects my decision because I keep going ‘no I’m alright, I’ll do this, I’ll do that’, so she doesn’t really push it because she knows it’s up to me anyway, if I don’t want to take this insulin I don’t want to” (EbE11)

This way of thinking involves a huge shift in the expectations and constructions people hold of the healthcare relationship. One expert by experience who has made that transition said that when she was younger, “you never questioned a doctor... had the highest respect [for them]” (EbE11). She described a GP who treated her whilst she was pregnant as “horrible” but “an excellent doctor” (EbE11). She had missed an antenatal class because her mother had recently passed away, and she said that when she saw him again, he said to her:

“Your mam’s dead, you’ve waited so long for this baby. Do you think your mam would want something to happen to the baby?” (EbE11)

This individual stated that although the GP was “brutal” (EbE11) in the way that he came across, and she felt that she could not question his authority, he did make her think about the implications of her actions. When her GP practice transitioned to CSP, she believed this was a major transition and suddenly, “it was like, oh, they will sit and talk to you and they ask for your opinion” (EbE11). She explained how being encouraged to participate on an equal level with practitioners has changed her expectations of contact with all healthcare services outside of CSP. She described a situation when her husband, who has vascular dementia, was unwell with a chest infection. A locum doctor

visited their home to treat him, and he asked her if she had thought about a DNAR (Do Not Attempt Resuscitation) order. She stated:

“I looked at him and thought, it’s not the time to think of a DNAR. And he went, well, you know, this is going to go on and he will just die. And I went, you are not the person I’ll discuss a DNAR with. And I said, he’s nowhere near a DNAR. I was quite taken aback” (EbE11)

In these emotionally charged situations that the person describes (regarding the antenatal appointment and the DNAR discussion), she reacted differently (mechanism) to the questions posed by the GPs because the context was different. In the first extract, which relates to traditional practitioner-led models of care, it was not the norm to question or disagree with a doctor’s authority. In the second extract, the person with LTCs had been actively encouraged to take the lead in CSP consultations and voice her opinions, thus her expectations of interactions with healthcare professionals were altered. In the circumstances described, a discussion about CPR was entirely appropriate, given its likelihood to be unsuccessful and traumatic. However, if such a sensitive discussion is unexpected or handled poorly, shared decision making does not typically occur. For example, in this context where an acute condition was being treated, a full range of potential actions was not shared with the person nor with his carer (resource), which resulted in the carer feeling upset and defensive (reasoning). A shared agreement on the course of action with regards to a DNAR was therefore not reached (outcome). If the doctor had prepared EbE11 by sharing information about different options and the pros and cons of each, and given her some information about DNAR to digest and understand, the outcome might have been a much more collaborative and

open discussion. Preparation can therefore be seen as an invitation to partake in collaborative discussions and shared decision making.

An implementer explored the idea that shared decision making is supported by preparation, and before CSP, it was difficult to achieve. She stated:

“I’d like to think it’s always shared and collaborative, but until we were preparing patients it probably wasn’t [pre CSP consultations]. Because they had just been told two minutes ago that their diabetes control was horrendous, so I then tell them they need a new tablet, they’re like ‘ok, fine’, walk out and it’s all a bit up in the air. Whereas now, they come prepared, it just feels like they are more open to discussing the different options and quite often patients will say to me, ‘let’s set some goals looking at diet or exercise or both, but then next time if we’ve tried that and it doesn’t work, perhaps next time we can think about their tablets. I’m always really happy to do that because if you’re showing them that you’re quite happy to let them try and take control – well, they should always be taking control – and make changes, but then there’s a back-up plan there that if it doesn’t work, then we’ll think about the tablets”  
(12)

For this implementer, these discussions occur daily, and often, people with diabetes who have been prepared and participated in shared decision making will return having lost weight and improved their diabetes. She suggested that even those who return with higher HBA1c levels will have a collaborative discussion about it and will either suggest or be open to other options.

Programme theory 4 was further refined to incorporate the data from implementers and experts by experience in this testing phase. It was merged back into one CMOC because the two CMOCs shared the same context and outcome, and the resources discussed in phase two and three were focused around the person with LTCs. It is stated below.

#### ***Tested programme theory 4***

When a full range of potential actions are shared (resource) in a context of equal power dynamics (context), there is an open discussion of the pros and cons of each option (reasoning), and professionals and people with LTCs reach a shared agreement on the course of action (outcome).

#### **4.4.4 Summary**

The literature utilises the term “shared decision making” when referring to practitioners and people with LTCs working together to select health and social care packages most suited to their preferences. Leaders, however, suggested that shared decision making is a label attached to a decision where there is a clear choice, for example, drugs vs physiotherapy. CSP is a much more iterative, open process where people make decisions across a range of behaviours, yet there is a place within the CSP conversation for shared decision making. The literature describes self-determination as the desirable outcome for people with LTCs and suggests that practitioners must agree with this principle and actively seek to achieve it through building positive, trusting relationships and respecting competence and interdependence. Leaders added that decisions should not be shared; people with LTCs should always be encouraged to make their own decisions about their healthcare, and the process of coming to those decisions should be collaborative.

In the testing phase, there were inconsistencies in the way that shared decision making is being implemented. Although some practitioners maintained that decisions should always be made by individuals themselves, unless they lack capacity, instances were described where practitioners would take control and enforce a plan or refer people to practitioners of higher status who may be able to influence their decisions. The literature described similar instances, where practitioners' "battle for control" of the consultation appeared to have the effect of forcing people's submission and dependence. Those encounters resulted in people disengaging from CSP. Reasons for this control-seeking behaviour in practitioners include the need to fulfil their professional responsibility, or their perceptions of it, and concerns about people having too much responsibility without sufficient guidance. In contrast, other studies in the literature suggest that engaging people in conversations builds trust (which people with LTCs have expressed is key), which enables them to be more confident in sharing their preferences, resulting in more collaborative, power-sharing dialogues. This requires a shift in the expectations and constructions people hold of the healthcare relationship, thus, shared decision making works best when preparation is done by both parties, so that each has an understanding of the underlying rationale of CSP and the components within it.

Ambiguous use of the term "shared decision making" throughout the three phases has resulted in confusion around its process and its effectiveness. There were some studies outlined in the literature where practitioners suggested they were doing "shared decision making", when in fact they were not. This was reflected in phase three, where some implementers stated that

some people are comfortable to make decisions about their health, yet if a person does not wish to do this, they would step back into a more traditional role and tell the person what they feel is best for them. Instead of resorting to this role, which disempowers people with LTCs, the literature suggests that practitioners should support people to work on areas that might boost engagement, for example, education, confidence or mental health. Studies suggested that when practitioners spend time working on implementation challenges, people with LTCs are more likely to engage in collaborative discussions and decisions about their health and/or become better at problem solving.

## 4.5 Conversation summary

Figure 19 below shows how a conversation summary may relate to other CSP components, to form a tool that supports the self-management of LTCs.

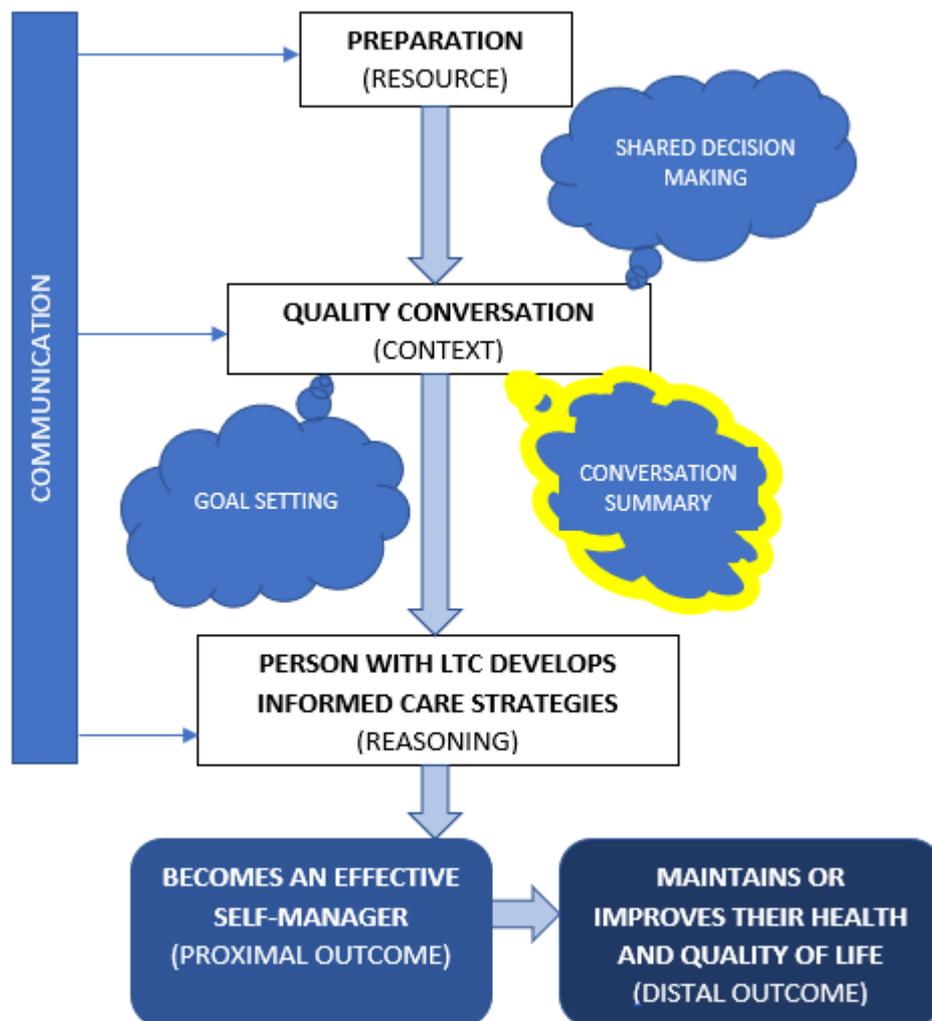


Figure 19: Conversation summary as a component of care and support planning

#### **4.5.1 Developing the programme theory**

The physical care and support plan has two main roles: one is to provide information for clinical teams, and the other is to provide support for the person's self-management. The traditional care plan was more about the former. In CSP, it is more about the latter, or both. The care and support plan contains attainable goals identified by the person, to enable progress tracking, reflection on daily habits, and levels of activity, and it identifies actions they will take to ensure they achieve their goals, and key barriers preventing them from doing so (Bower, 2013, Coulter et al., 2015). Bower (2013) suggested that only proactive people use care and support plans; care and support plans do not make people proactive, and they work most effectively for people who have an exceptionally strong motivation to make changes and divert physical and emotional energy from other aspects of their day to day lives to make those changes.

In CSP, one of the main roles of the care and support plan is to support self-management; therefore, it is most effective if the person whom it refers to has ownership and responsibility (Lhussier et al., 2013). Bower (2013) conducted a large scale mixed-methods study exploring the process and outcomes of care and support plans and elements of CSP. In their report, they stated that people with LTCs had at least some input into the plans and "they were used, and found useful, by the majority of patients" (p. 160). One person was uninterested in a care and support plan he described the nurse as making on his behalf, instead, putting it out of sight. His plan was used to record test results; the sections on goals and action plans remained blank (Bower, 2013).

This suggests that ownership of the plan was with the practitioner rather than the person with LTCs; therefore, it was more likely to be viewed as an information leaflet to be read by the clinical teams rather than to be used, reviewed, and amended by the person themselves.

Gibson and Powell (2004) explored the process and outcomes of written care and support plans for people with asthma. They reported that optimal self-management involving a written plan led to significant reductions in asthma related hospitalisations and reduction in emergency room use. This may be because a written care plan including goals and action plans for asthma facilitates the early detection and treatment of an exacerbation (Gibson et al., 2003). Gibson et al. (2003) found, in a systematic review of asthma self-management education, that when a person had ownership of a written action plan and was instructed in its use in the context of self-monitoring and asthma reviews, there were highly significant improvements in asthma outcomes. The risk of being admitted to hospital fell by over 40% and presentations to the emergency department with asthma fell by over 20%. Gibson and Powell (2004) found, in a review of randomised controlled trials evaluating asthma action plans, that written action plans specifying when and how to increase treatment, based on personal best peak expiratory flow, using two to four action points, and recommending both inhaled and oral corticosteroid consistently improved health outcomes. This suggests that for people with asthma, action plans that contain specific, pre-prepared information have the most impact.

Similarly, in a meta-analysis of COPD and self-management, Effing et al. (2007) reported that there were significant reductions in hospital admissions for people utilising a written care and support plan. In these cases involving COPD and asthma, self-management was about managing exacerbations and the care and support plan was kept in reserve and used and followed in specific situations. In day-to-day living with LTCs where self-management relates to lifestyle, the impact of adhering (or not) to a plan is perhaps less immediate and therefore may require people to have more motivation. The condition, setting, and personal circumstances are thus key contexts which may affect engagement with care and support plans. This means that for people with multimorbidity, where personal, social, and lifestyle factors are often key areas of focus, care and support plans need to reflect this and be used in a way that enhances engagement and motivation.

Bower (2013) explored the mechanisms that may explain how and why a care and support plan helps certain people to self-manage. They described a person in her mid-50s, who had diabetes since childhood and was “exceptionally engaged and informed about her condition” (Bower, 2013, p. 207). During her interview, she described an open and positive long term relationship with her diabetic nurse, with whom she had originally discussed and created her care and support plan. She had been living with diabetes for decades, and therefore was an “expert” in her own condition. Her wealth of knowledge and experience, combined with her practitioner’s medical knowledge and their positive long term relationship, might have promoted an equal power relationship between them, which may have empowered her to

set goals, and as she is an “exceptionally engaged” individual, she utilises her care and support plan to monitor her progress. She described it as a “thing that I’d written at one stage and it reminds me that I do need to just keep an eye on what’s going on with me in general” (Bower, 2013, P. 207).

Bower (2013) also explored healthcare professionals’ views on the impact of the written care and support plan for people with LTCs. A practice nurse who used them for weight management said the plans helped people to reflect on daily eating habits and levels of activity, and to identify the key barriers preventing them from achieving their goals. Thus, the nurse believed that having a written care and support plan was a vital tool for self-management: “I thought it was good for the patients to have written information, because they can compare” (Bower, 2013, p. 259).

By taking into consideration all of the literature reviewed in this section, programme theory 5 was developed. It is stated below.

#### ***Developed programme theory 5***

When individualised written care and support plans are shared (resource) with people who are proactive and motivated to change or continue to self-manage (context), their self-efficacy to perform self-care behaviours increases (reasoning), so they make healthy lifestyle choices (outcome).

#### 4.5.2 Refining the programme theory

In the focus group, leaders entered into a discussion about the semantics of sharing written care and support plans, agreeing that “they’re owned by the person and they’re developed by the person,” (L2) not shared by the practitioners like much of the literature suggests. This confusion has arisen because, as outlined in Chapter 2, “care plans” are widely used in primary and secondary care, though there are several different types (e.g. Emergency Care Plans, Treatment Plans, Acute Care Plans, etc.) and they are generally practitioner-led. Leaders commented that practitioners often ask them “what do we need to record?” (L4) and fail to see the distinction between writing a care and support plan and actually having a CSP conversation, in which the written document becomes a component:

“I think it’s something that people when they first hear about, they can’t see how the rest is different, they’re so used to writing the care plan that when they see care plan within this they don’t see the distinction and then they could slip into, I’m just doing you a care plan that’s all it needed” (L4).

“Is that why, you’ve just made me realise, it nearly always reverts to this template, so that instead of people building it up like this which would happen in training, when in fact they get to there, it sort of allows them to breathe a sigh of relief – I know what a plan is I have the template for that – and then it’ll all fit in. Because that’s what we observe a lot isn’t it?” (L3).

[Agreement]

“People default... so it’s still part of a conversation” (L5).

“Or they feel that if people haven’t set a goal then they’ve failed at their concentration because they’ve been incentivised to do lots of care plans and this is not doing that, it’s that culture shift and adjusting to it. And I think calling it a formal care plan would reinforce that misconception rather than anything else” (L4)

If too much emphasis is placed on a written care and support plan, leaders worry that practitioners may revert back to “I’m just doing you a care plan, that’s

all that is needed” (L4). They suggested that more emphasis should be placed on the conversation itself.

Leaders described the written document as a summary of the conversation, which is retained by both practitioners and people with LTCs. For the latter, it acts as a record “which the person [with LTCs] generates around what they perceive is important, in relation to things that matter to them” (L5). Thus, leaders agreed that the subtitle for programme theory 5 should be Conversation Summary, rather than Formal Care and Support Plan as it was initially, because the formal care and support plan is being confused with other multidisciplinary care plans which are more document focused. They noted that in an “ideal world” (L2), the person would “write down a plan in their own words that articulates where they want to be and how they want to get there” (L5). However, there are many factors to take into consideration that could prevent this from happening, for example, age, literacy issues, and learning difficulties. Practitioners would similarly record a summary of the conversation in their electronic notes, “as they would with any consultation. They’d write a summary that they needed to have for next time” (L4), which would provide them with “a lovely place to start when they next see the patient” (L2), so they do not have to start the whole information gathering process again. For both practitioners and people with LTCs, this continuity is “relationship building” (L2).

For people with LTCs, the process of writing down the conversation “makes them concentrate a little bit more” (L3) and gives them the opportunity to check that they have in fact discussed what they wanted to. It also acts as a tool for reminding them what was agreed, which can be particularly helpful in longer consultations facilitating more complex discussions, for example, for people with multimorbidity. One leader stated:

“Some of the patients have between an hour and an hour and a half consultation with a healthcare professional, lots of stuff happening, I think it’s when they’re left on their own and they’re sitting there thinking gosh, what did we agree ... I think it’s nice that they’ve got something tangible that they can go back to and remind themselves what they were going to do or what the healthcare professional is going to do ... It’s the same with my mum who’s 85, she goes and sees her GP, “what happened?” “Don’t know, can’t remember.” As a family member I get frustrated. She’s 85, she’s spritely as anything but she still doesn’t quite grasp everything that’s gone on in that conversation. So, I think it’s good for them to go back and reflect” (L2).

This leader describes how a physical copy of the conversation summary can also be beneficial to a person’s family. People who attend CSP consultations alone may not remember everything that was discussed. Thus, having a physical copy of the conversation enables them to share information with their family and/or friends, if they wish to.

In a discussion about context, leaders stated that not all people are proactive or motivated, but it does not mean that the plan isn’t theirs. The plan may be to go away and think about something, or it may be the discussion they just had. Despite this, they agreed that a conversation summary may be most helpful to those who are more involved in their care, because if people are

involved and they have documentation that shows this, they are more likely to become self-efficacious than somebody who has not been involved:

“I think people reflect on things, on health, on circumstances, in healthcare consultations and you do reflect endlessly after you’ve been in. You’ve had that 20 minutes or whatever and you’ve come away and you reflect, you think about things” (L2).

“Does everybody do that though or is it something about those people – are they more proactive and motivated?” (C1).

“I wonder whether the context is ‘with people who are more involved in discussions and plans about their care’. So, if people are involved and they’ve got this documentation that supports how involved they’ve been, they’re more likely to – they may not necessarily become more self-efficacious but they’re more likely to become self-efficacious. But giving it to people who haven’t been involved probably doesn’t make much difference” (L5).

“So, it’s not an adjunct, it’s actually a compounding, isn’t it? It’s the degree of involvement in the previous process makes the document more useful” (L3).

[Agreement]

As the discussion continued, I asked leaders why they thought people who are more involved in discussions and plans about their care might use the plan more than somebody who is not as involved in their health care. They came to the conclusion that having ownership of something physical that they have generated themselves with their own ideas and decisions “is really powerful” (L5) and “empowering” (L4).

It was decided during the focus group that there should be two separate CMOCs for programme theory 5: one for the professional and one for the person with LTCs. They are reported below.

### **Refined programme theory 5**

#### a) Person's perspective

When a summary of the conversation is owned by the person with LTCs (resource) and they are more involved in discussions and plans about their care (context), they utilise the summary to check/remind/reflect (reasoning) which leads to better self-management (outcome).

#### b) Professional's perspective

When a copy of the conversation summary is retained by the healthcare professional (resource) in the context of a quality conversation (context), it reminds and informs the healthcare professional (reasoning) which leads to transactional and relational continuity, and better job satisfaction (outcome).

### **4.5.3 Testing the programme theory**

Despite leaders adjudicating between document-focused care plans which are used in some healthcare programmes, and informal conversation summaries which are utilised in CSP, implementers used the term care plan throughout this phase to describe the results letter that people with LTCs bring to the consultation, with any added goals, action plans, and notes.

“Basically, they bring their care plan to the conversation, and then we complete the back of it, which is where we put goal setting, or we just write a summary if they prefer. They take that away with them” (I3)

As this implementer describes, often, practitioners write the care and support plan themselves, especially when an action plan or summary is devised. This

was observed in an exemplar CSP consultation at a Year of Care training event. My brief notes are below.

*The practitioner writes down the person's goals and their importance, but he does check with her first.*

Another implementer stated that the task of writing on the care and support plan is shared between herself and the person with LTCs (I7). One implementer disagreed with this and claimed that “no one [referring to people with LTCs] makes notes” (I8), although she “usually scribbles on [the care and support plans]” (I8) herself. Interestingly, three implementers disclosed that they do not write a conversation summary at all. One of them stated that at her previous GP practice, she would write notes during the conversation, and then update her electronic notes afterwards. In her current practice, she works differently and the CSP consultation is “just a verbal thing” (I4). Another of the three implementers suggested that she is not consistent in her recording of CSP conversations. She stated:

“I’m really, really bad at doing that. We do it verbally. Sometimes we’ll scribble together on the care planning information sheet, sometimes we just talk about it, sometimes we document it in their notes to remind us both for when we meet again. Bit haphazard. But you’re quite right, that’s what should happen. I don’t like care plans” (I1)

When asked why she often does not record CSP summaries, this implementer stated that “it’s another job to do at the end of quite a lengthy conversation” (I1). One of the agreeing implementers expressed, “it’s twice the amount of work” (I4). Both of these implementers felt that a good conversation outweighs any formal documentation, and one of them went on to explain that it is difficult

to capture the whole CSP conversation and choosing certain parts to record can feel artificial. For example:

“You tend to pick out some very specific things, so if it is about stopping smoking or something like that, you might put that down, but you both know that, you’re not going to forget about it. There may be a discreet thing about a specific exercise goal or a weight goal, ‘I’m going to lose X amount by three months’ time’, but there’s a little bit of patient autonomy there, and I sometimes think writing it down is a little bit like the teacher telling the pupil what to do. That’s your prep, rather than that’s your adult reminder. And I’m not a fan, but that’s probably just me, and I’d be prepared to be held to account that that makes me slightly less effective because people forget or – but I do think it brings in a bit of a, you know this is your agreed, this is what you will do, it just sounds a bit prescriptive” (I1)

This implementer admitted that she is “hopeless at recording things” (I1), and she is not alone in her approach. A key finding throughout this chapter is that people are more likely to achieve what they want to achieve, not what somebody instructs them to. This implementer suggests that recording a conversation and giving it to the person with LTCs puts the practitioner in an authoritarian position (if it is the practitioner who does the recording). CSP is about empowering people to be in control of their health, and for this implementer, a “teacher telling the pupil what to do” (I1) feels far away from what CSP sets out to do. However, the premise of the conversation summary is that it is not an instruction, but it could act as a reminder for subsequent meetings or as a reflection tool for the person who owns it. Implementer 1 states that she does sometimes write conversation summaries, but is not consistent and is instead rather “haphazard”. It seems that if she really did not agree with them, she would not do them at all. This suggests that when she describes conversation summaries as instructions, which is not their purpose,

she is trying to provide justification for not doing this “extra”, but important piece of work consistently.

Some of the implementers who document a conversation summary stated that they also record it electronically after the consultation has ended. Some “take a photocopy” (15) of the care and support plan for their notes. Two implementers suggested that recording conversations in this way is helpful for effective coordination of care, as it acts as a reminder for practitioners who have not seen people since their previous CSP consultation, and it enables other treating practitioners to explore their history.

“We’ll document the care plan and what we’ve discussed, so if somebody else sees that patient in six months, they can see that [name] discussed the granddaughter. So they can say ‘how’s your granddaughter?’ when they come in, and that’s documented, so someone can pick the threads up. So it’s not dependent on them seeing the same person all of the time because that cannot always happen” (14)

Another implementer described the electronic template for recording conversation summaries very differently. She described it as a tool to guide the consultation. She stated, “[it is a] tick box thing – have you discussed diet, have you checked for erectile dysfunction in men, have you checked for memory if over 70” (18) although she added that it does have a small textbox for her to add a summary of the CSP conversation. She explained that this acts as “a reminder... have we discussed those?” (18) which implies that she has to look at the computer screen often to use this function. This feels like a move away from the CSP philosophy which is about two people sitting together and having a conversation.

Other implementers suggested that the conversation summary leaves with the person and they do not need to take a copy of it for their records. One implementer explained that there is no need to question people on whether or not they did what they said they were going to do, because they have ownership of their health and they are not accountable to anybody. By not recording a summary, the care and support plan is truly owned by the person with LTCs, for them to do with as they wish.

“There’s lots of talk about whether we should photocopy or scan in the care plan to get the details but my personal point of view, and my nurse practitioner agrees with me – that care plan and the very detailed specifics of it does belong to the patient, they should own that, and when you see them next time, I think if you pull that up on your screen and say, ‘how have you done with this?’ then that becomes a bit accusatory. It might be that a week after they walked out of the door, their goals may totally change. Their spouse may become unwell or they might lose their job, and so what they set might become completely irrelevant” (I3)

This implementer likened the care and support plan to her own personal development plan. She explained that when she has her yearly appraisal in her practitioner role, she sets goals for the forthcoming year. If in one month’s time, she has to attend training to fill in for another practitioner who specialised in a particular area, she would amend her personal development plan accordingly. The written care and support plan is therefore a working document, to be used and reviewed and refined throughout a person’s life. The implementer thus stated that the plan “belongs to the patient” (I3) and she has no concerns about not “having the absolute finite details” of that plan” (I3).

The CSP consultation can be viewed as an information gathering appointment for people with LTCs. An implementer explains:

“They’ve obviously got their results, which we hope that they’ve brought back, but they’ve also got their goal setting and action planning thing as well, and any extra leaflets we might give them as well, say about COPD or diabetes or that kind of thing. So they would take away as much or as little as they want from the appointment, and that’s up to them” (I9)

All of the information that the individual gathers about their condition and the support that is available to them can be added to their care and support plan and can be used as a “LTC toolkit” so that if, for example, they receive their test results and see that their HbA1c has spiked, they could look in their “LTC toolkit” and view previous results, along with food diaries and conversation summaries and perhaps work out for themselves what they could do to reduce their HbA1c. As the implementer stated above, the care and support plan is personalised depending upon the information that the individual chooses to take away from the CSP consultation, and anything else they choose to add to it. This kind of resource would be most useful for people who are engaged and proactive in their care.

A person with LTCs described utilising her care and support plan as a working document in this way. She explained how she kept each document and compared results from previous years.

“Or is it that piece of paper [results letter] that you have all along, is that what you take away?” (F)

“That’s what I take away with me, yes. And then as I say, I can look at it at home again, and then I can reflect on what the doctor has talked about with me, and I tend to make little notes myself against it, so that I

can think, that's what we talked about last year, and I can reflect on it the year after" (EbE4)

This undeniably requires some level of proactivity and motivation, and the person with LTCs must remember to bring the document with them to their CSP consultation. It also requires administrative tasks to be completed so that people receive their letters. As aforementioned in previous sub-chapters, some people had not received their results letters through the post, therefore for them, different mechanisms would be activated, and this programme theory would have a different outcome. An implementer explained how the process of reflecting back on previous results can help people with LTCs to make more informed decisions about their care.

"They'll say, I've got my own care plan. And they'll look back at what was on the last one and that helps them make decisions for the next one. So, when it works like that, it works really well" (I5)

Another implementer suggested that some people find the conversation summary aspect of their care and support plan helpful, as it enables them to read it again after the CSP consultation and it reminds them what was discussed.

"I think it helps them because sometimes in a consultation, there's a lot of things discussed, people don't always take it all in, and they can go back to it and look it at again and digest it. And then if anything is not clear they've got the chance to ring and clarify it or check it again" (I5)

It is also a useful tool for people who wish to share information with family or friends, particularly those who are elderly and may struggle to remember the intricate details of a conversation.

“If they want to discuss things with relatives or people that are involved in their care, they can then share it and say this is my care plan. Sometimes, relatives like sons and daughters like to check what’s on an elderly parent’s care plan” (15)

An implementer suggested that around 50% of people with LTCs bring their previous care and support plan to their next CSP consultation (13). Another implementer stated, “not everybody wants it, but generally, patients respond quite well to it” (19) and this notion was shared by most of the implementers. I asked an implementer to explain why some people take a written conversation summary away with them and others do not. She responded:

“Because they just don’t want one. They don’t think they need to have it written down. So that’s fine, they’ll say yeah, yeah, no I don’t really need to have it written down, no, I know what I’m doing” (16)

Four experts by experience who were interviewed described not receiving conversation summaries in their CSP consultations, and all four stated that they usually remember what was said, even if it is just “the important things” (EbE9). An implementer confirmed that people can often recall their previous results and goals that they had set for themselves, without the presence of a written conversation summary from the previous CSP consultation. However, some cannot. Others require prompts to help them remember. Another implementer explained that in her previous GP practice, she would print the previous conversation summary off for people who had not brought it with them.

“Well what I used to do there was, because the templates were good, I used to just print it off and say can you remember, that’s what we discussed. And they’ll say, oh yeah, I remember now. Well let’s see how you’ve done” (14)

Whilst prompting people during CSP conversations by showing them previous summaries helps to remind them what they had discussed, this is a seemingly purposeless task. If they cannot remember goals that they had previously set for themselves, the chances of them having worked towards those goals is low. In addition, life may change drastically in six months or a year, and as aforementioned, goals may change. Thus, it seems it may be better for practitioners to simply ask where a person is at now, rather than spending time reminding them what they said they were going to do.

Programme theory 5 was further refined to incorporate the data from implementers and experts by experience in this testing phase. Part 5b was set aside because: the literature says that traditional biomedical care plans provide information for clinical teams, whereas the care and support plan within the CSP conversation is more for providing support to the person with LTC. Some implementers are not recording them, and are still facilitating effective CSP conversations. Therefore, it seems that whilst some practitioners do retain conversation summaries, and find them helpful for coordination of care, it is not essential for CSP conversations and they can be just as effective without it. Thus, there is no need for a separate programme theory. The tested programme theory is reported below.

### ***Tested programme theory 5***

When a summary of the conversation is owned by the person with LTCs (resource) and they are involved in discussions and plans about their care (context), they utilise the summary to check/remind/reflect (reasoning) which leads to better self-management (outcome).

#### 4.5.4 Summary

In all three phases of the study, it became apparent that the initial programme theory did not reflect the multiple functions of the care and support plan. It does in fact have two roles: to provide information for clinical teams and to provide support for self-management. Leaders suggested that there is some confusion in the literature around care plans and care and support plans as the former are widely used and are generally practitioner-led. Within the CSP context, leaders agreed that there is a distinction between writing a care and support plan, or conversation summary as they chose to call it, and having a CSP conversation. The conversation summary is a component of CSP, and leaders proposed that it should be owned by and shared by the person with LTCs, not by the practitioner as some of the literature suggests.

There were multiple studies referred to in the literature that suggested care and support plans were used and found useful by the majority of people with LTCs, especially when they had some input into the plan, and there was a link between the use of care and support plans and positive health outcomes. There was some variation in accounts from leaders and implementers around

who writes the care and support plan. However, four experts by experience claimed they do not receive any written information at all during their CSP consultations. Only one expert by experience described utilising her written care and support plan in the way that the literature suggests.

The literature states that healthcare professionals who record conversation summaries for people with LTCs are contributing to effective coordination of care within clinical teams. They are also providing a starting point for future CSP consultations and this continuity is relationship building. Some implementers, however, proposed that by not taking a copy for themselves, they are supporting the philosophy that the person with LTCs truly has ownership of their care and support plan.

Leaders agreed with the literature in that having ownership of something physical that a person has generated themselves with their own ideas and decisions is powerful and empowering. In phase three, none of the people with LTCs described generating their own care and support plans. The individual who did utilise her care and support plan as a working document to reflect and compare results was a proactive and motivated individual. The literature suggests that only proactive people will utilise a care and support plan, however, leaders proposed that not all people are proactive or motivated, but the plan can still be theirs. The plan may simply be to go away and think, or to have a discussion with a practitioner.

Interestingly, three implementers explained that they do not write conversation summaries at all, and only provide them in verbal format. They felt that it is an unnecessary piece of work that adds to an already lengthy conversation, and that good conversation can benefit people with LTCs more than any form of documentation. The findings in this sub-section varied across the three phases. In the Year of Care exemplar CSP consultation that I observed, the practitioner documented a conversation summary on the individual's care and support plan. This did not occur in any of the four CSP consultations I observed in two different practices. Leaders felt that although the written care and support plan is a component of CSP, more emphasis should be placed on the conversation itself. This notion was shared by three of the implementers in phase three, and many of those who did not receive written care and support plans were still effectively self-managing their conditions, suggesting that the conversation summary is a component of, but not essential to, CSP.

## 4.6 Communication

Figure 20 below shows how communication may relate to other CSP components, to form a tool that supports the self-management of LTCs.

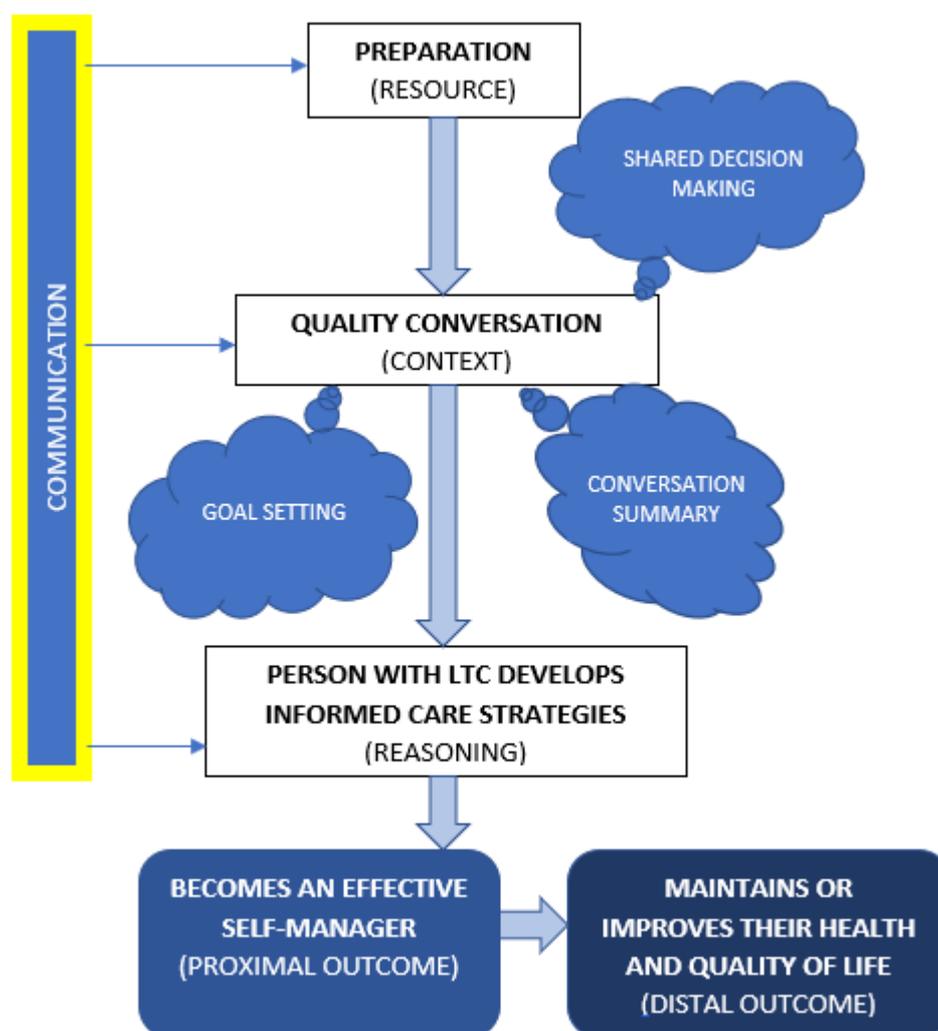


Figure 20: Communication as a component of care and support planning

### 4.6.1 Developing the programme theory

In the literature reviewed, effective communication between people with LTCs and healthcare professionals is defined as encompassing: the exchange of

information; the management of uncertainty and emotions; and the building of relationships between people and professionals (Street et al., 2009). It has also been defined as a tool for supporting self-management and shared decision making (Street et al., 2009). How one person communicates will affect the communication of the other; it is a “process of mutual influence” (Epstein and Street, 2007). Research suggests that some practitioners routinely provide more information, engage in partnership working, use supportive communication including reassurance and encouragement, and are more willing than others to talk about psychosocial topics. The conversations they have tend to be the most effective (Coulter, 2009, Harding et al., 2015).

People feeling listened to, and their perspectives understood and valued, is essential to enabling genuine coproduction and “shared mind” with healthcare professionals (Harding et al., 2015). In a qualitative study exploring the effective self-management of asthma, participants highlighted the importance of being listened to by healthcare professionals (Deacon and Rickards, 2013). Those who feel listened to experience positive outcomes, such as a reduction in the need for additional appointments (Macdonald, 2007). Conversely, those who do not feel listened to describe detrimental effects: “I’ll plummet fast . . . ended up in hospital” (Deacon and Rickards, 2013, p. 83). When healthcare professionals actively encourage engagement by asking people with LTCs to tell their stories, listening to their views, and acknowledging their experiences, this appears to build trust in the relationship. People’s confidence in sharing their experiences also improves, enabling more collaborative, power-sharing dialogues (Lawn et al., 2013).

Noël et al. (2007) reported that some people with multimorbidity felt their concerns were sometimes overlooked or ignored, and they were most likely to attribute this to their physicians lacking empathy. In a quantitative study by Mercer et al. (2012), examination of the relationship between GP empathy and enablement of people with LTCs showed that although high empathy did not guarantee high enablement (presumably due to other factors that negatively influence enablement such as emotional distress, multimorbidity, etc.), enablement never occurred with low empathy. This suggests that practitioner empathy is a basic pre-requisite for enablement of people with LTCs (Mercer et al., 2012).

One of the biggest barriers to effective communication with respect to people with LTCs is related to health literacy. Coulter (2007) suggested that well-designed written information, such as leaflets, combined with oral information, can improve health literacy. Research on people living with cancer has shown that having an understanding of medical terminology enables them to better participate in consultations (Luxford and Newell, 2015). This then increases the likelihood that they can contribute to shared decision making (Luxford and Newell, 2015).

Another barrier to achieving focused communication is the combination of the complexity of the illness weighed against the limited consultation time, and resistance and reluctance to address difficult issues. In a longitudinal qualitative study by Chew-Graham (2013), several instances were explored

where health care professionals' own agendas of ensuring compliance took prominence over people with LTCs' explanations and concerns. For example, a person in the midst of a divorce recognised in the consultation that the management of her asthma had been impaired by recent stressors. The healthcare professional did not empathise or explore the issue beyond acknowledgment. Instead, she used the person's fear of further exacerbations to encourage compliance with medication and the review process itself. As a result, the person's expectations of the review were changed, trust was lost, and the relationship was damaged.

Effective communication is central to CSP. This means providing current information, risks and benefits, eliciting questions, and adjusting information to suit the needs of people with LTCs, that is, using "language that is understandable by the patient" and checking that the person understood what was communicated (Lown et al., 2009, p. 167). Bower (2013) reported that some people described a frustrating lack of information sharing, with two people stating that health care professionals appeared unsure about their condition or appropriate treatment (Bower, 2013). The perceived lack of information may have been attributed to the fact that communication skills are reported to be a major challenge for healthcare professionals due to lack of specific training and the complexity of having to consider social values and circumstances (Harding et al., 2015).

People with LTCs who are "active" communicators put their perspective into the conversation and have the potential to influence the healthcare

professional's behaviour and decision making (Harding et al., 2015). An example of this is given by Lawn et al. (2013), who examined interactions during CSP to understand processes that foster empowerment and disempowerment. In their study, high levels of guidance, ranging from persuasion to dominance, were provided. The use of "we," rather than referring to people as individuals, was common across consultations. When a practitioner said, "There've been lots of habits we've had to get into" (Lawn et al., 2013, p. 389), her language inferred that healthcare professionals and people with LTCs were one and the same, with "we" used to express what people could and should be doing, often confusing and disempowering them, by creating a sense that they could/should not be responsible or trusted with ownership of the process.

By taking into consideration all of the literature reviewed in this section, programme theory 6 was developed. It is stated below.

#### ***Developed programme theory 6***

When practitioners use communication techniques (listening, empathy, reflecting) (resource) in an environment with a facilitative level of knowledge, skills, and motivation of both practitioners and people with LTCs (context), people with LTCs feel supported and their self-motivation increases (reasoning), so they engage in shared decision making and self-management (outcome).

#### 4.6.2 Refining the programme theory

All leaders agreed that good communication skills are critical to effective CSP, and they acknowledged the fact that to achieve empowerment, practitioners must have empathy. One leader mentioned the series of qualitative studies which were previously discussed in the focus group (Mercer et al., 2012, Mercer et al., 2016). These studies explored practitioner empathy in different socioeconomic areas. The researchers found that the perceived level of practitioner empathy (in terms of body language, listening skills, etc.) varies according to deprivation rights. To clarify, people with LTCs perceive GPs to be less empathic in areas of low deprivation, and more empathic in areas of high deprivation, despite the more deprived group reporting knowing the GPs better (Mercer et al., 2016). Another leader added that empathy alone does not lead to empowerment, but it is a vital part of the equation that results in empowerment. He stated:

“There are lots of us who care lots but can’t empower people. But you have to have it for empowerment to be a possibility. If you don’t have it, you can apply all of the technical skills you want but you won’t be able to empower people” (L5).

They reinforced that a practitioner can have excellent conversation skills but would have a very different conversation with a person who is prepared than someone who is not. Preparation and a robust CSP consultation are therefore key contexts for good communication skills to produce the desired outcome.

One leader stated:

“You could do it outside of care and support planning, but it doesn’t achieve that outcome. If you do it within the care planning consultation and you have those skills, it is a necessary ingredient” (L5).

Leaders disagreed with the outcome in programme theory 6 and said, “it’s not shared decision making” (L3). When asked directly, what is the outcome when the practitioner is empathic in the CSP consultation, one leader responded, “empowerment. We don’t like the word, but they feel supported to manage their wellbeing” (L3) and “if there is good communication [in the context of patient preparedness – L2], they feel they can engage in the conversation” (F). Another leader added that being engaged in the conversation felt “too cold” (L1) and questioned, “is it more about people sharing their views and feelings?” (L1) and there was an overall agreement.

Programme theory 6 was refined to incorporate the ideas discussed in the focus group. The refined programme theory is reported below.

#### ***Refined programme theory 4***

When practitioners use effective communication (resource) in the context of robust care and support planning (context), people with LTCs feel supported (reasoning) so they emotionally invest in the conversation, sharing their thoughts and feelings (outcome).

#### **4.6.3 Testing the programme theory**

At a Year of Care training event I attended, I watched a recording of an example CSP consultation. During the session, I noted different communication techniques used by the practitioner to aid the conversation. They included: asking open-ended questions; using non-medical language;

reflecting back and checking the person's understanding; motivating people by asking questions like, "how would you feel if you were able to do that?" In the testing phase, an implementer summarised good communication within the CSP consultation:

"It's open questions, empathy, value base, respecting their opinion, giving them time, ask not tell, sharing views, non-judgemental, it's all of that" (I1)

All of the implementers I interviewed agreed that effective communication between healthcare professionals and people with LTCs is critical for CSP. They gave examples of how using these skills can aid the conversation. One implementer described making a "conscious shift" (I6) in the way she communicates with people in CSP consultations, so that although she may be working from a template, she is flexible in her approach to ticking the necessary boxes.

"You work from a template and you start at number one and you've got to get to number 20. You can do the same work but in a different way. It's those open questions at the beginning. It's knowing those questions that are going to elicit the response that you want" (I6)

The implementer emphasised the importance of using open questions and listening skills at the beginning of a CSP conversation to identify the person's agenda and to avoid getting to the end of the consultation and then disclosing, for example, that they have chest pain, which would require immediate action. This kind of situation would cause the practitioner to run late and would potentially have a domino effect on the rest of their consultations that day. I observed a CSP consultation where, as the individual was about to leave, she

started a discussion about her daughter's mental health issues and how difficult things had been recently. Below are my notes from the consultation:

*It appeared that the care planning consultation had come to an end, when the person with LTCs began talking about her daughter's mental health issues and how difficult it is to have death threats coming through her letterbox. The practitioner continued to listen and her body language – sitting facing the person, nodding, and eye contact – showed that she was listening. It was clear that the person felt comfortable enough to discuss this private issue. It would seem as though she trusted the practitioner enough to discuss it.*

Although the person with LTCs led the conversation by discussing her agenda from the beginning, she decided to tell the practitioner about her family issues at the very end of the conversation. This problem may not have been high up on her agenda, or it may not have been something that she believed was relevant to her health and therefore not something to discuss within the main CSP conversation. Nevertheless, she chose to disclose something personal, which shows she felt comfortable with the practitioner and was supported to do so. The practitioner's open body language showed that she was still engaged in the conversation and was listening.

*The practitioner's body language seemed to make the person aware that she was listening. The practitioner often said 'yes' to confirm she was listening, and she understood. The person with LTCs was engaged and appeared comfortable taking the lead in the appointment as she did most of the talking.*

The practitioner's listening skills throughout the conversation had an impact on the individual's behaviour. She was not only engaged but she led the conversation and shared her feelings about private circumstances, which requires the presence of a trusting relationship. An implementer suggested

that listening is one of the most beneficial things they can do during a CSP consultation. She stated:

“I think it’s a much more satisfying way of working, because even if you do nothing else but listen, then you’ve kind of done something, I think. Which is more useful for someone than banging on about their cholesterol results” (I6)

Listening and empowering a person to take the lead in a conversation also enables practitioners to gain insight into many key factors which might impact on their self-management, including how motivated they are, whether they want to change, what they like and dislike, etc. Practitioners may be able to pick out those things from a person-led conversation, without having to directly ask. An expert by experience said the fact that the practitioner listens to him during the CSP consultation makes him feel like “she cares”, (EbE5) which helps him to open up to her. He stated, “it gives her an insight into who I am and what she can do” (EbE5).

Not only is listening important, the way in which practitioners show people they are listening is key. An implementer explained that the introduction of computers into healthcare was “one of the things that removed the face to face experience for the patient” (I6), however, CSP requires a physical shift in communication. It goes back to “sitting opposite each other” (EbE5) and having a conversation rather than the practitioner looking at the computer screen and reading results. An implementer elaborated:

“I wouldn’t be sitting here, I’d be sitting here [moves seat closer to me], and we’d be looking at it like this [places results letter between us], and I’d be explaining this, so I think that’s the difference, if nothing else. You don’t get a culture shift, you get a physical shift. It’s about, we are

actually looking at this together, at the same time, and trying to make some sense of it” (I6)

Experts by experience reflected on how this physical shift makes them feel. One person stated, “they look at you. They take notice of you, and I think that makes you feel relaxed” (EbE4). Another had had a less effective CSP consultation, where the practitioner “was having to turn around and look at the computer... which was time consuming” (EbE2). He agreed that having one printed copy of his results and looking at it together with the practitioner would be beneficial. He stated that this would “speed things up” (EbE2). He had recently been diagnosed with diabetes, this was his first CSP consultation and his first meeting with the practitioner and he stated, “she doesn’t know me, I don’t know her” (EbE2). Therefore, in his case there were no pre-existing contexts around relational continuity or preparation. It is therefore not surprising that the outcome he focused on was something as generic as time, rather than something personal like sharing his thoughts and feelings.

Whilst core communication skills, including those aforementioned, are key in any approach within primary care, including shared decision making and motivational interviewing, there was some ambiguity around communication training and whether practitioners receive any that is specific to CSP. One implementer suggested that communication is not particularly different in CSP.

She stated:

“The care planning trainers might say there’s still a lot of sub-optimal practice out there. But I think probably people have moved on a pace and are far more – you know all the graduates now come out with an understanding of Calgary Cambridge communication skills. Certainly,

GPs have embedded in them Calgary Cambridge even at post-graduate level. A person-centred approach – I mean you will always get those that think they do it and don't, but I think the knowledge base around good communication skills is much better now than it ever used to be. The core communication skills are key. I don't think it's particularly different in care planning" (I1)

Conversely, another implementer stated that there is some communication training that is specific to CSP, and she was lucky to receive it.

"Do you have special communication training or anything?" (F)

"Luckily, around the same time in general practice, I did get some, but that was just by chance, and I found it very hard to change because I had never done it before" (I8)

The implementer was a trainee GP, which might explain why these communication techniques were new to her. She went on to say that she uses motivational interviewing and suggested that framing questions in a specific way increases engagement. She described a person who "was so desperate for a circumcision, and he was so motivated to get his HBA1c down" (I8). She gave an example of how she would elicit thoughts about self-management by asking how the person feels:

"I'm waiting to have an operation. Ok, you know you have to have a certain HBA1c, how does that make you feel? Well, I really want to get it down because if it's not below a certain number, they won't do an operation and I'm desperate to have it" (I8)

Another implementer experienced a similar situation, however, she described dealing with it in a completely different way. She talked about a disengaged individual who attended his CSP consultation and who said something to the effect of:

“My mum had diabetes, my dad had diabetes, my brothers and sisters have got diabetes, so I was obviously going to get diabetes. There’s nothing I can do about it, this is the way it is. All of our family end up dying because of it” (I4)

The gentleman being referred to wrote on his care and support plan that he wanted to be more active because his daughter had just had a child, and she would not leave the child with him as he was so unwell. The implementer stated that this was the only thing he wanted to discuss. He was not taking his medication or checking his blood sugar levels. The implementer described how she tried to motivate the individual to make some lifestyle changes:

“I used the “well you’ve got a grandchild, do you want to run around the park with them for a couple of months or for a few years, because that’s going to be the difference, and your activity is being held back by the fact your diabetes is way out of control. So, we need to get your tablets taken, protect your heart, so that you’re here for longer for your granddaughter”. That eventually just makes them think – maybe doesn’t change their mind straight away, because everyone’s got their own health beliefs, but it’s enough to plant a seed” (I4)

These two implementers tried to achieve the same outcome using entirely different resources. The first implementer asked open questions to encourage the person to think about how something would make them feel. She believed the individual had succeeded in lowering his HBA1c and was able to have his operation. The second implementer spoke to the person in quite a derogatory way, as though she was “telling him off”. She used the pronoun, “we” rather than “you” when talking about something that the person with LTCs needed to do. If she had used the same tone when speaking directly to the person, this would likely have had a disempowering effect on him. She suggested that whilst this approach “plants a seed”, there is rarely an immediate reaction and people tend to continue doing what they are doing. These two cases highlight

differences in approach and suggest that the way the first implementer motivated the person and addressed lifestyle issues was far more effective.

These examples support the notion that communication within CSP interactions tends to differ from communication in other healthcare encounters. An implementer explained that even for newly diagnosed people, and those who have not prepared for their CSP consultation or seem disengaged with CSP, she “consults differently” (I3). She stated that the biggest change for her is focusing on what is important to the person and working more collaboratively from the beginning. When communication techniques are used as resources in a CSP consultation, practitioners can almost always achieve a desirable outcome.

“So, in a sense, no matter what the situation is, if a person isn’t really engaged, hasn’t done the preparation, doesn’t really want to open up to you, you can almost always get to where you want to be by the way that you communicate?” (F)

“Yes” (I6)

One implementer touched on the importance of communicating information to people with LTCs in language that they can understand. This is also true for non-verbal communication, such as leaflets, text messages and posts on social media. She stated that currently, people who have learning difficulties are allocated longer CSP consultations, and they are required to complete a lengthy questionnaire with their carers and bring it to their consultation. The questionnaire is “not user friendly” (I4), so the practice is looking at making it more visual. She explained:

“I am looking at an LD passport. It’s a very visual pack and I’d probably liken it to when you’re pregnant and you have a maternity pack and that goes everywhere that you go. It is big, it’s A4 pieces of paper, there’s lots of them, and they’re brightly coloured. So it’s, how do you feel today, there’s a smiley face. You know, who is your appointment with today? If it was [name] there would be a nurse with a hat on, if it was me it would be cardigan, or, you know whatever, because I don’t wear a uniform. That sort of thing. If it was a doctor there would be a stethoscope around his neck. What do you like to do? Who cares for you? What their numbers are, because that can change. And it would be a working document” (I4)

Another implementer suggested that using open questions in leaflets feels less disease-specific and more appropriate to CSP, especially for people with multimorbidity.

“There’s a nice leaflet here, which works really well for people with multimorbidity. The questions are what’s working well? What isn’t working well? What sort of things need to change? I think that lends itself much better to social issues, like, my health really isn’t my number 1 priority because I’ve got all these other problems going on – I’m going through a messy divorce or my mam’s just died and I’ve got to clean the house out and it’s all very miserable. It’s a little less clinical, I think. And I think that fits well with what you’re trying to achieve. There’s nothing about results on there, it’s all about things that you do – feeling hopeless, alcohol, lack of control, feeling scared, [inaudible], we’re talking more about activities of living rather than diseases and numbers and what your blood pressure is like” (I6)

In both of these examples, the goal is to find out about the individual. Not just about their physical health, but their lifestyle, their mental health, and anything else that could be impacting on their overall wellbeing. This shift in focus gives people permission to discuss social and lifestyle factors, as well as their thoughts and feelings, during the CSP consultation.

Programme theory 6 was further refined to incorporate the data from implementers and experts by experience in this testing phase. It is reported below.

### ***Tested programme theory 6***

When practitioners use active and open listening, considering holistically the person with LTCs and their social environment (resource), in the context of robust CSP (context), the person feels supported (reasoning) so they engage in the conversation and share their thoughts and feelings (outcome).

#### **4.6.4 Summary**

There was consistency across the three phases in the notion that effective communication between healthcare professionals and people with LTCs is critical for CSP to work well. The literature describes good communication within the CSP consultation as the exchange of information, management of uncertainty and emotions, and the building of relationships. Leaders added that empathy is an important component of good communication in CSP and they agreed with the literature in that high empathy does not guarantee high enablement but enablement does not occur with low empathy. Implementers explored different communication techniques that are frequently used within CSP consultations, including the use of open-ended questions and motivational interviewing. Studies have shown that some practitioners routinely provide more information, engage in partnership working, use supportive communication including reassurance and encouragement, and

are more willing to discuss psychosocial topics. These CSP conversations are considered the most effective. One study described a situation where a practitioner's own agenda of ensuring compliance took prominence over the individual's wishes. The practitioner used the person's fear of further exacerbations to encourage compliance with treatment. As a result, their expectations of the CSP consultation changed, trust was lost, and the relationship was damaged. An implementer described a similar occurrence in the testing phase. She used negative reinforcement of a person's current lifestyle to try and make him see that he was causing detriment to his own health. The outcome was that there was no immediate change in his self-care behaviour, but the practitioner believed she had "planted a seed". More motivational tactics may have made a more imminent impact on this person, as other implementers suggested in their case study examples.

There was agreement across the phases that people with LTCs feeling listened to is an essential ingredient in the CSP consultation. Implementers added that this requires a physical shift in the consultation, so that they are sitting opposite people with LTCs, reading through results together, using open body language and having a conversation. This physical shift makes people with LTCs feel relaxed and supported to discuss their thoughts and feelings. In the literature, studies showed that when practitioners use communication techniques to encourage engagement, this helps to build trust in the relationship, which increases confidence and results in a more collaborative dialogue. Other studies found that the disempowering use of "we" was common in consultations, and this was seen with one implementer in the

testing phase. The outcome for these practitioners is a person who feels they should not be responsible for or trusted with the ownership of the self-management process, thus they disengage.

Leaders suggested that a healthcare professional can have excellent communication skills, but they will have a very different conversation with a person who is prepared. Low health literacy was identified in the literature as a potential barrier to preparation, and implementers suggested that the distribution of well-designed written information, including leaflets, text messaging and social media posts, can enable people with LTCs to improve their health literacy and thus become more engaged with CSP and the self-management of their condition(s). The literature suggested that some healthcare professionals find the communication style within the CSP consultation a major challenge due to lack of training. There was some ambiguity around this. One leader stated that she found the transition to CSP difficult for this reason. Another believed there was no difference in the communication style compared to other healthcare programmes, whilst others had no issues with the transition and found that as a result of doing it for so long, they apply it naturally to all consultations. One of the most thought-provoking suggestions made by one of the implementers was that you can almost always achieve desirable outcomes if you communicate effectively in the CSP process. This notion is reflected in Figure 20 where good communication is key to CSP, from preparation right through to the conversation summary. Without this, support for self-management would not be achieved.

## Chapter 5: Summary Chapter

In this chapter, a summary of the study findings will be provided. An adapted CSP model will be presented and barriers to effective CSP will be summarised along with an explanation of how to overcome these barriers.

### *An adapted person-led CSP model: the “ideal”*

Chapter 2 of this thesis highlights a significant gap in knowledge in relation to how, why, for whom and in what circumstances CSP works best (National Voices, 2013, National Voices, 2017). The aim of this study was to develop, refine and test, through an iterative process combining primary and secondary data, realist programme theories that carry the greatest possible explanatory potential for CSP. Seven programme theories were developed from the literature reviewed. They were based on seven key elements of CSP, namely, preparation, quality conversations, goal setting, shared decision making, conversation summaries, communication and support for self-management. Each Findings sub-chapter begins with a diagram showing how CSP is expected to work; this is the ideal. The diagram was developed during phase two of the study as I considered leaders' expectations of CSP and how its core components may be linked. As I delved deeper into investigating the interaction between contexts, mechanisms, and outcomes, I began to see patterns in the data which enabled me to refine and test the programme theories. Six of the programme theories were refined using data from a focus group with CSP leaders in the second phase of this study. The seventh programme theory, which was about support for self-management, was set

aside at phase two because leaders agreed that support for self-management is the whole premise of CSP; not just one element of it. It happens “in the pre-thinking, in the work done in the consultation room, the summarising that into a plan, the communication and the decision making” (L5) and is thus already integrated in the first six programme theories. The six refined programme theories were tested in practice during the third phase of this study. Detailed qualitative accounts were attained from healthcare professionals and people with LTCs. This was a fundamental part of the study, as stakeholder reasoning is needed to complete causal accounts (Pawson and Tilley, 1997, Westhorp, 2013). This iterative process of developing, testing and refining programme theories has uncovered similarities and differences in literature ideals and practice realities in relation to the operationalisation of CSP. By going through this process of investigating the contexts needed for effective CSP, as well as highlighting common barriers to successful implementation, a better understanding of how CSP works in the real world has been achieved. The six tested programme theories are listed below:

1. When people with LTCs and healthcare professionals are prepared for the consultation (resource) and they both have an understanding and belief of the philosophy of CSP (context), they feel valued and they feel that they have permission to engage and take action (reasoning) leading to a more purposeful collaborative conversation (outcome).
2. When time is spent talking about what is important to the person with LTCs (resource) in the context of relational continuity and preparedness

(context), the person feels more comfortable, more informed and therefore more in control (reasoning), so they are more likely to take positive actions (health behaviours, self-management, attitude) (outcome).

3. When both health and social issues are explored (resource) in the context of a quality conversation (context), people with LTCs feel better equipped (reasoning) so they: (a) become engaged, (b) set goals and/or (c) become better at problem solving (outcome).
4. When a full range of potential actions are shared (resource) in a context of equal power dynamics (context), there is an open discussion of the pros and cons of each option (reasoning), and professionals and people with LTCs reach a shared agreement on the course of action (outcome).
5. When a summary of the conversation is owned by the person with LTCs (resource) and they are involved in discussions and plans about their care (context), they utilise the summary to check/remind/reflect (reasoning) which leads to better self-management (outcome).
6. When practitioners use active and open listening, considering holistically the person with LTCs and their social environment (resource), in the context of robust CSP (context), the person feels supported (reasoning) so they engage in the conversation and share their thoughts and feelings (outcome).

These programme theories provide clarity in terms of the most desired outcomes of CSP and the most favourable contexts for mechanisms to become activated, leading to these outcomes. The bedrock of realist evaluation is the CMO configuration and this is what the findings chapter has focussed on. Below I list the separate contexts, mechanisms and outcomes, mostly for the sake of clarity for practitioners (e.g. it is useful to see the list of resources that make CSP work), though of course it comes with the understanding that resources are only activated in the right context to lead to the most desirable outcome.

The most desired outcomes are greater engagement with CSP, shared decision making, better self-management, and health improvements. The most favourable contexts for these outcomes are when people with LTCs are motivated and involved in their care, and they understand their role in self-management. In addition, greater outcomes occur when healthcare professionals and people with LTCs are prepared for the CSP consultation, and when the healthcare relationship is enhanced by relational continuity and equal power dynamics. This study also highlights six key resources introduced by CSP. These are preparation, time spent discussing the person's agenda, exploration of their health and social issues, consideration of a full range of potential options, conversation summaries and communication techniques. These resources were highlighted as key components of CSP in articles accessed during the first phase of this study, including the work of Coulter et al. (2015), Lhussier et al. (2013), and Year of Care (2011). Coulter et al. (2015)

described a seven-step CSP process, involving strategies that take place both inside and outside of the consultation. Lhussier et al. (2013) and Year of Care (2011) placed more emphasis on the resources implemented during the CSP consultation. Although there are many dimensions of CSP, within and outside of the consultation, the scope of this study meant that I focused on the strategies used to support and enhance the interactions that take place within the CSP consultation.

The six programme theories are presented as separate sub-chapters in order of the CSP process, however, they are incremental and form part of a bigger picture with greater outcomes. They push the CSP ethos into the limelight and highlight the importance of recognising the person in the context of their life, and their health as part of that. Every person with a LTC is a self-manager; they are “experts by experience”, in their own bodies and in their own lives. The way in which they self-manage depends on various social, psychological and environmental factors. CSP conversations facilitate and promote better self-management by embracing the biopsychosocial aspects of peoples’ lives; helping them to manage life with their LTC, as opposed to just helping them to manage their LTC. This study highlights CSP as a practice which is implemented in three different settings: the life of the person with LTCs, the professional’s practice and the conversation they have in common. The division of tasks and responsibilities per setting, which includes the person’s life, has never been highlighted before as an explicit part of the care and management of LTCs, and pushes boundaries in relation to what we understand as effective practice. Figure 21 below illustrates this concept.

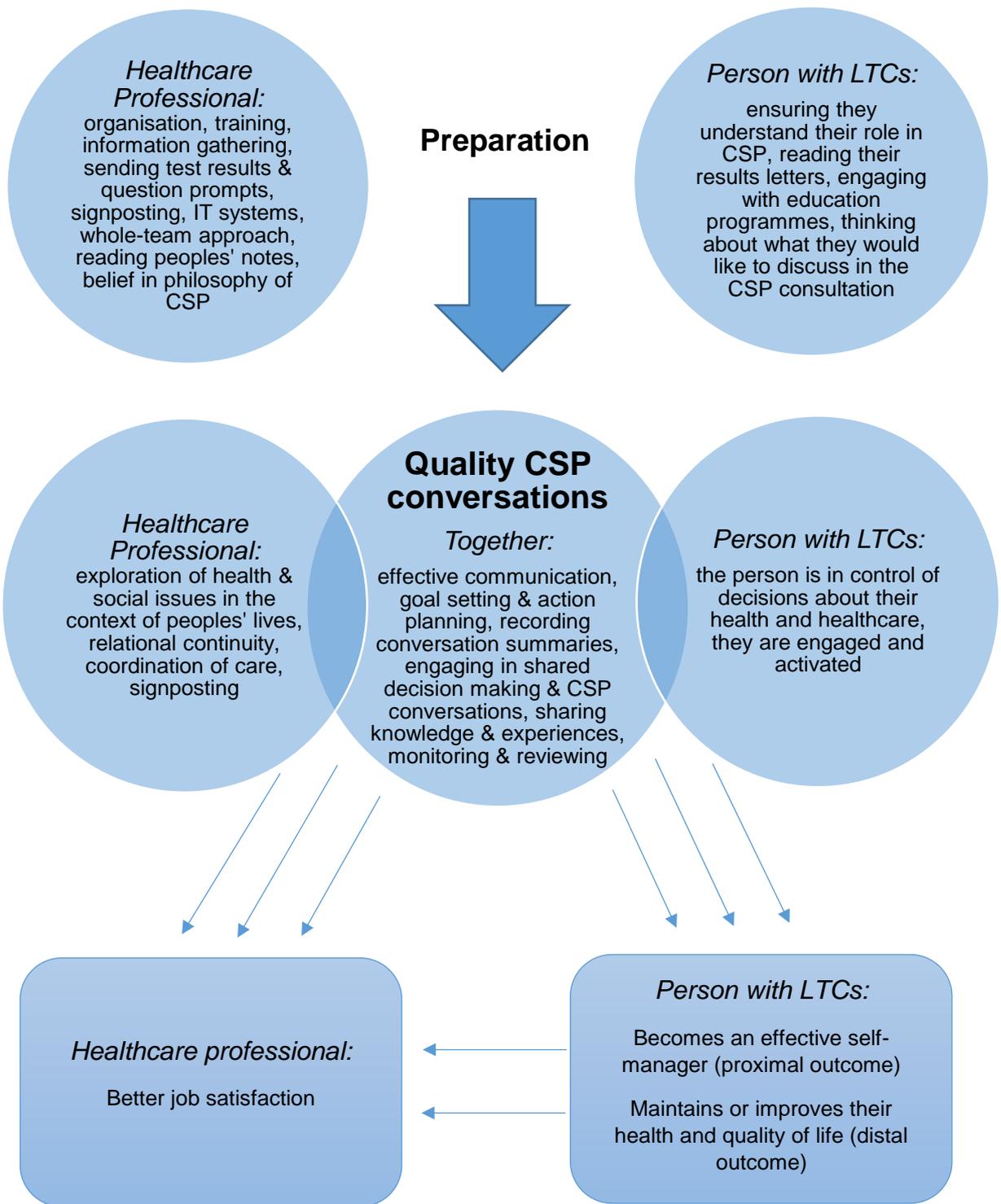


Figure 21: Division of tasks and responsibilities throughout the CSP process

Figure 21 highlights the interrelatedness between the six programme theories. The key contexts, mechanisms and outcomes in the tested programme theories are mapped onto this diagram to show how people with LTCs and healthcare professionals can get the most out of CSP conversations. It illustrates how preparation is a fundamental component of CSP and can impact the effectiveness of other CSP resources. For example, without preparation, shared decision making would not occur in the way that programme theory 4 proposes. In addition, CSP conversations would not be as purposeful and collaborative. Furthermore, Figure 21 shows the person with LTCs and healthcare professionals becoming a team; philosophically challenging traditional models of care where patients are users of healthcare services. This model proposes that people with LTCs are leaders of their own CSP journeys, using professional knowledge and resources as and when they feel they are needed. One fundamental concept that is consistent across the three phases of this study is that CSP begins by changing attitudes at all levels of the healthcare system (Joseph-Williams et al., 2017, Year of Care, 2011). This whole-system attitudinal change enables the person with LTCs to make the transition to “owning” the process.

### Barriers to person-led CSP

Although people with LTCs owning the CSP process is the ideal, the extent to which this is translated in practice varies. As this study has highlighted, there are several barriers to effective, person-led CSP. Organisational barriers include an inability to access or interpret test results prior to CSP conversations. This study shows how, when people with LTCs cannot access

or understand their test results, CSP conversations are affected. In the examples where this was evident, health literacy and administrative failings were clear issues. CSP resources, including whole-team training, efficient IT systems, signposting to education programmes, and sharing of clear information can help to minimise this issue. In terms of individual expectations of CSP, there are several potential barriers to engagement with the programme. This study has shown that if the person with LTCs or the healthcare professional disagrees with the underpinning philosophy of CSP, this has a major impact on the CSP conversation. There are several examples referred to throughout the findings chapter where perception of power relations did not sit within the CSP ethos. In some cases this had a detrimental effect on the healthcare relationship. CSP brings two experts together and promotes sharing of knowledge and experiences, therefore it is essential for both parties to have confidence in this underpinning ethos. Training/education programmes (for healthcare professionals and people with LTCs) and information sharing are thus key resources that can support this change in attitude and subsequently the implementation and normalisation of person-led CSP conversations in general practice.

Social, psychological and environmental factors can also be seen as barriers to engagement with CSP. In this study there were a number of instances described where CSP conversations did not occur because people with LTCs had arrived at their appointments distressed about financial difficulties, sick relatives or pets, and their mental health. Thus, their LTC was not their number one priority at that time. One of the implementers described the importance of

dealing with these underlying issues first, before talking about the LTCs in question. The philosophy of CSP is that it considers the whole person in the context of their lives, and so arguably, an agenda that is psychosocial in nature is very much part of, not separate to, CSP conversations. It is therefore imperative that people with LTCs are made aware of CSP and the expectations and responsibilities involved, individually and as a team. It was clear in this study that this was happening in some practices and not others. One implementer described thorough, transparent information sharing services provided by her practice to people with LTCs. This included advertising CSP on the practice website and on the television screen in the waiting room, and explaining and reinforcing the CSP process at each contact. The person with LTCs who engages with CSP at this particular practice and interviewed for this study was able to describe the CSP process she experiences and she was aware of her role within it. She had achieved her distal outcome of reversing her diabetes and pertained her ability to do this to the fact that CSP had made her much more aware of her diabetes and how her lifestyle choices were facilitating its progression. In contrast, other people with LTCs who attended practices that did not use the term CSP or advertise it, were unaware of any difference in their care and any change in roles and responsibilities.

To summarise, the resources that have been explored in this study and are illustrated in Figure 21 are crucial for successful operationalisation of CSP. When they are introduced in the contexts stipulated in the tested programme theories, they activate mechanisms that lead to greater engagement with CSP, shared decision making, better self-management and health improvements. In

addition, they can be introduced in different contexts to address underlying barriers to engagement. It is therefore a key finding that CSP works best when healthcare professionals and people with LTCs complete their individual tasks and responsibilities ahead of and during CSP conversations. This then enables them to come together as a team and engage in purposeful, collaborative, power-sharing CSP conversations which are led by people with LTCs. The ultimate goal of people becoming effective self-managers (proximal outcome) and maintaining or improving their health and quality of life (distal outcome) is then achieved. In the following chapter I will use NPT as a theoretical framework to help understand the shift from a position of using the CSP process to owning and leading it and becoming part of a team. I will also explain, through the domains of NPT, when, how, for whom and in what circumstances CSP becomes normalised within professional and personal contexts.

## Chapter 6: Discussion

In this chapter, I will offer a personal contribution to the study findings to introduce the idea that people have healthcare practices too (for people with LTCs these are the things they do to manage their condition; in my case it was the things I did to learn and seek a diagnosis). A middle range theory, specifically NPT, will be used to generate implications and recommendations about how to adapt and implement CSP in professional and personal contexts. These recommendations will be structured around the four domains of NPT. I will provide a reflection on some of the terminology used throughout this thesis and in practice. Implications for practice, challenges, limitations and future research will also be considered.

### Personal contribution to study findings

Throughout the latter part of my PhD journey I have had several encounters with general practitioners and specialist consultants to discuss my son's diagnosis and treatment for a vascular malformation. In the most recent hospital appointment, we received my son's MRI results. Eight months prior, the consultant had given me one website link for the Vascular Birthmarks Foundation and advised me not to seek out information from any other sources as they may be unreliable. In between the two appointments, I was unable to contact the consultant with questions and concerns that I had and instead, I was invited to email his (non-medical) secretary and she would try to answer as best she could. I attended my son's GP surgery several times but due to

this being a rare and complex condition, they were unable to answer my questions.

With very little support available to us and a long wait to receive my son's results, I accessed his MRI images and sent them to a diagnostician in Italy who specialises in vascular malformations. The traditional practice offered by my primary and secondary care systems did not meet my needs, therefore I took it upon myself as a carer to learn and act. I accessed the resources at my disposal (beyond what was naturally on offer) in order to feel like I was fulfilling my caring role as best as possible. It is important to highlight here that this does not differ vastly from healthcare professionals' practice.

The specialist gave my son a definitive diagnosis and outlined different treatment options. I took all of this information to the appointment on a piece of paper, confident in my efforts to educate myself about the condition, and still found myself asking my husband, "how will I tell the consultant about my research without undermining his expertise and knowledge?" This suggests that unless resources are put in place to shift our mind-sets from traditional to person-led care, a consultation will always be innately imbued with power, which is difficult to resist.

Although the consultant was open to me sharing my knowledge, I felt an innate awkwardness about doing so. He had initially given me information but actively discouraged me from doing my own research, suggesting that he believed I

was incapable to critically review different sources of knowledge. He was unavailable for support outside of the consultation and was unable to give me the results from my son's MRI for six months because of his busy schedule. This was an issue. I knew my son and the discomfort he was experiencing, therefore, by proxy, I was the expert by experience here. In addition, the consultant answered one of my questions about genetics with 'probably not' without further explanation or exploration. This question was important to me, and I felt devalued and disempowered by his response. Consequently, the initial trust that I had for the consultant was damaged. As a result of this response, I might have been less likely to follow his advice uncritically in the future, being labelled as non-compliant. The issue was of course complicated by the fact that we were talking about a baby, and that I was not the person receiving treatment, but nevertheless the same principles as CSP might have applied.

Although I had educated myself about my son's condition prior to the consultation, my role as an informed, health literate carer was not legitimised in collaboration with the consultant, meaning that an equal partnership becomes very difficult to implement. Lorig, who did a substantial amount of work on "expert patients", believed in a popular quote by Dr Thomas Ferguson MD, editor of Medical Self-Care Magazine, that "doctors would get off their pedestals when patients got off their knees" (Lorig, 2009). This insinuates that people need to make the first step in forming equal partnerships with healthcare professionals. However, in my experience, people need resources, such as education programmes (for practitioners and people) to pave the way

for these partnerships. People need to be taught specific strategies/tools for initiating partnerships, building trust, identifying expectations for each role, and developing plans to follow through on those expectations. That is why preparation is so important for effective CSP. Once this kind of new practice is initiated, it might become normalised, in professional and personal healthcare practices.

### Normalisation Process Theory

It is well established that complex interventions can only have a significant impact on health and healthcare if they are shown to be effective when tested, are capable of being widely implemented and can be normalised into routine practice (Murray et al., 2010). NPT is a middle range theory concerned with the work that people do individually and collectively to perform certain acts and achieve specific outcomes (May et al., 2009, May and Finch, 2009). This study presents key findings in relation to the effective implementation of CSP in the form of six tested programme theories. To enhance transferability of this knowledge into practice, I will use NPT as a theoretical framework to discuss the contexts and mechanisms required for successful implementation (referring to the social organisation of the work), embedding (making practices routine elements of everyday life), and integration (sustaining embedded practices in their social contexts) of CSP in professional and personal contexts. NPT not only explores early implementation of an intervention, it looks beyond this to the point where an intervention becomes so embedded into routine practice that it “disappears” from view (i.e. it is normalised) (May and Finch, 2009). Normalisation is not irrevocable: practices can be denormalised; for

example, electroconvulsive therapy is no longer a first-line treatment for schizophrenia (Leiknes et al., 2012). Neither is normalisation necessarily desirable: plenty of ineffective or inefficient practices are widely normalised, for example, polypharmacy in people with multimorbidity (Guthrie et al., 2015). I will refer back to these concepts throughout this chapter.

May and Finch (2009) propose that the work people do as they engage with activities can only become normalised in the matrices of existing knowledge and practices, thus, NPT can only be applied to formal organisational settings (e.g. primary care). Furthermore, this work is promoted or inhibited by generative mechanisms (coherence, cognitive participation, collective action, reflexive monitoring) through which human agency is expressed (May et al., 2009). These mechanisms are in dynamic relationships with each other and with the wider context of the intervention. In this chapter I will discuss these relationships in more depth to bring clarity to how the components of CSP are interlinked; so that, for example, when preparation does not occur within the CSP process (programme theory 1), it is unlikely that shared decision making (programme theory 4) will occur within the CSP consultation.

CSP is implemented within practice by professionals who have received specific training and are part of a whole-system change, but it is also adopted by people with LTCs who are expected to change their approach to the consultation and to self-management. A tried and tested intervention such as CSP can be embedded within practice, but unless the individual level of the

system is recognised and is supported by research that gives a voice to those people (National Voices, 2011), interventions are more likely to be applied *to* people rather than representing work undertaken *with* them. I have used NPT to describe the steps undertaken by practitioners and people with LTCs in making sense of CSP and adapting it to their particular contexts, so that it becomes normalised in practice.

This realist evaluation uses specific qualitative design and analysis techniques to answer questions around how, why, for whom and in what circumstances CSP works best. It demonstrates that CSP is a practice which is implemented in three different settings: the life of the person with LTCs, the professional's practice and the conversation they have in common. Each of these contexts are systems imbued with existing knowledge and practices. Mechanisms which embrace human agency have been established, in addition to the contexts in which they are activated, not only in primary care, but also in peoples' lives. The interactions between these contexts and mechanisms have been systematically and substantially tested in this realist evaluation. In this chapter, the six tested programme theories will be discussed using NPT to lift them up in a conceptual framework which can explain the work that healthcare professionals and people with LTCs do individually and collectively in order for CSP to become normalised in professional contexts (referring to the work that healthcare professionals do and the work that is done together in CSP conversations) and personal contexts (referring to the work that people with LTCs do). The four key constructs of NPT (coherence, cognitive participation, collective action and reflexive monitoring) are described below using examples

from the findings of this study to address the factors needed for successful implementation and integration of CSP into routine practice (normalisation). I have often alluded to one or two specific examples where I had been able to interview a healthcare professional and a person with LTCs, and observe their CSP conversation. They provided the most comprehensive understanding of CSP in all three contexts, i.e. in the healthcare professionals' practice, in the lives of people with LTCs, and in the CSP conversations.

### Coherence: sense-making work

Coherence refers to an understanding that individuals and organisations must achieve in order to promote or inhibit the routine embedding of CSP. Under this NPT construct are four components: differentiation, communal specification, individual specification and internalisation (May et al., 2015). These components are outlined in Table 1 below, in addition to related questions that I have considered of the study findings, and whom and which tested programme theories these questions apply to.

<b>Components of coherence</b>	<b>Questions considered within the NPT framework</b>	<b>Context this applies to</b>	<b>Tested programme theory this relates to</b>
Differentiation	How is CSP different from what you were previously doing?	Lives of people with LTCs, healthcare professionals' practice	1: preparation
Communal specification	Are the aims and benefits of the different roles within CSP understood?	CSP consultations	2: quality conversations
Individual specification	Do you understand your specific roles, tasks and	Lives of people with LTCs, healthcare professionals' practice	3: goal setting

	responsibilities in CSP?		
Internalisation	What do you understand to be the value, benefits and importance of CSP?	Lives of people with LTCs, healthcare professionals' practice	All

*Table 1: Components of coherence and related questions considered*

### *Differentiation*

A key element of sense-making work is to understand how a set of practices and their objects are different from each other. For healthcare professionals, this is the work that they do to understand and organise the differences between CSP consultations and standard appointments. For people with LTCs, this is the work that they do to understand and organise their role within the CSP process and how this differs from their previous self-management strategies or attitude and role in the CSP conversation (so they might not change much at home but they might change how they communicate with the healthcare professional).

This study has shown that preparation (programme theory 1) for CSP includes inviting people with LTCs to take on a new role which involves a fundamental shift in how they approach the consultation. In contrast to traditional doctor-led consultations where the person simply “turns up”, in a CSP consultation, people are required to have a certain knowledge and understanding of the process and underpinning philosophy (Tribal Consulting, 2009, Mathers et al., 2011). One of the key functions of CSP is therefore to equip healthcare professionals so that they can provide this information. Indeed, this study found that people with LTCs engage with CSP and self-management more

when its processes and expectations of roles are explained to them, allowing them to make sense of what CSP is and how it differs from their prior practice. In this study, I interviewed a person who attended a GP practice which provides extensive information about CSP to people with LTCs via social media, websites, advertisements in the practice waiting room, and in the initial conversations when people are diagnosed with a LTC. She was able to differentiate between CSP and standard care and confirmed that she had a good understanding of the CSP process and her role within it. Having this understanding enabled her to use her test results as question prompts and reflection tools to guide the CSP conversation, and ultimately this whole process led to her managing her life, and consequently her health, more effectively. As a result, she was no longer within the diabetic range. The act of being able to differentiate between two practices (CSP and standard care) enables people to see change, which, in the context described here (the person with LTCs had an understanding and belief in the philosophy of CSP), translated into the view that there was a need for a change in roles within the CSP process. This person had used the resources available to her and incorporated CSP practices into her life, not just within the consultation, and as a result, she improved her health and quality of life.

Although all of the implementers who participated in this study agreed that the preparation involved in CSP is different to practices involved in previous models of LTC care, their ideas about what preparation constitutes varied. New practices that were mentioned included organisation, administrative tasks, IT systems, ongoing staff training and reviewing test results and

histories. Whilst many of these practices exist in traditional models of care, there was agreement in that sending test results to people ahead of their CSP consultations differentiates CSP from other LTC management programmes. Although the other components of preparation were alluded to by leaders, implementers, experts by experience, and the literature reviewed, the act of sending test results prior to CSP conversations became the main focus of the preparation sub-chapter. This sense-making work relating to what constitutes preparation greatly impacts the effectiveness of the CSP conversation.

This study found that when preparation is comprehensive, the majority of people with LTCs read and reflect on their results and bring their results letters to the CSP consultation with ideas to discuss. Leaders, implementers and people with LTCs agreed that this results in a more person-led CSP conversation. In contrast, I observed a CSP consultation where a nurse (I2) spent thirty minutes going through a newly diagnosed person's documents on the computer, ticking boxes and reading biomedical results which he had not received prior to the consultation. The person was unable to differentiate between CSP and standard care because he had not been informed of a change in practice since he learned of his diagnosis. The implementer explained during her interview for this study that 95% of people who attend her CSP consultations do not read their results letters (that is assuming they have received them), which results in her taking the lead in the conversation. I concluded that this was a reflection on her style of working; she did not appear to fully understand and/or believe in the philosophy of CSP and during her interview she described using closed questions, leading the conversation and

trying to get people to agree to decisions about their healthcare. Being unable to differentiate between CSP and her usual style of practice therefore impacted on the experience of the person with LTCs, the effectiveness of the CSP conversation and the person's expectations of future CSP encounters.

### *Communal specification*

Sense-making also relies on people working together to build a shared understanding of the aims, objectives, and expected benefits of a set of practices. This is exemplified most particularly in programme theory 2: quality conversations, as healthcare professionals and people with LTCs come together in CSP conversations and build a shared understanding.

This study shows that effective CSP occurs when a person with LTCs and healthcare professionals become a team, with the person leading their care. The majority of healthcare professionals described using specific resources during CSP conversations, such as sending test results and question prompts, and using open questions to give permission for people with LTCs to discuss biopsychosocial aspects of their life. This acts as an invitation for them to become equal partners in the process and enables them to lead the CSP conversation. Much of the power traditionally has been held by healthcare professionals; they have the biomedical knowledge and people come to them to find out about their health. CSP resources, specifically preparation, enable healthcare professionals to deliver the message, "we may have different experiences but we have the same information, let's work on that together";

thus emphasising the lived experience of the person, whilst also recognising the practitioner's depth of medical knowledge. Both have to recognise each other's potential for (with)holding power, and they can do this by building a shared understanding about the aims, objectives and intended benefits of CSP (through preparation). CSP is thus an invitation to start to change the unequal power dynamics that are entrenched within the traditional healthcare encounter.

When an implementer (I2) who participated in this study stated that 95% of her CSP consultations are practitioner-led, the context was that people with LTCs were not prepared. The process and philosophy of CSP was not being explained to them and the term CSP was avoided in these interactions. In an initial CSP conversation for a newly diagnosed person which I observed, this lack of differentiation between CSP and usual practice had a domino effect on the communal specification of sense-making. There was no shared understanding of the aims and objectives of CSP as these appeared unclear to both the healthcare professional and the person with LTCs. The person was therefore left unsure of his role and was unable to see the intended benefits of CSP (inhibiting internalisation), as the "CSP" he experienced was *received*, rather than *led* by him.

### *Individual component*

Coherence work also requires that people understand their specific tasks and responsibilities around a set of practices. This applies to both healthcare

professionals and people with LTCs and is relevant to all six programme theories. It is relevant in the work that is done before CSP consultations, in the work that is done during CSP consultations, and in the work that people with LTCs do to embed CSP practices into their lives. One of the most evident links is to programme theory 3: goal setting. I will explain its relevance to the individual specification of coherence work below.

This study supports the idea that people are much more likely to take action in relation to the decisions they make themselves than decisions that are made for them (Year of Care, 2011). The operationalisation of goal setting is therefore dependent on healthcare professionals and people with LTCs having an understanding of their specific individual and communal tasks and responsibilities which enable this process. In this study, two people with LTCs (EbE11 and EbE5) described goal setting as a process which begins in the CSP consultation but has a much greater purpose in the wider context of their lives. They understood that they have full responsibility and ownership of the goals they set for themselves and that there must usually be some sort of motivation to attain them.

The person who set himself the goal of running the Great North Run (EbE5) stated that his motivation was to prove to himself that he was fit enough following a heart attack and subsequent quadruple heart bypass surgery. His goal had true meaning in the context of his life. He therefore committed himself to achieving proximal goals relating to sport and exercise and the routine

recording and monitoring of his blood sugar levels and diet, in order to achieve his distal goal of completing the Great North Run.

EbE11 initially perceived goal setting as an arbitrary task which was soon forgotten about after leaving the context of the CSP conversation. Her goal was not of immediate interest to her. It became a priority after her health deteriorated and she had a new grandchild. The work that she had done around goal setting may not have been a priority at the time of her CSP consultation (referring back to the green wavy line showing the ups and downs of life with a LTC and the points of contact with healthcare professionals – Figure 2, p. 26), however, it was an effective way to put in a safety net so that she could address her goal at such a time that it became more relevant to her in the context of her life (which she was able to do).

A key role of healthcare professionals within the CSP consultation is to provide such resources (e.g. exploration of both health and social issues). People with LTCs decide how much they wish to engage with self-management, how much (or how little) support they require, and the resources that may (or may not) be helpful to them at that particular time. CSP therefore facilitates people with LTCs being owners of their own CSP journeys and taking knowledge from healthcare professionals as and when it is needed. A core sense-making task for healthcare professionals is therefore to embrace this shift in responsibilities and recognise their role in providing resources to help the person manage their life more effectively with their LTC.

### *Internalisation*

Sense-making also involves people understanding the value, benefits and importance of a set of practices. This applies to both healthcare professionals and people with LTCs and is relevant to all six programme theories. Below I will explain the particular relevance to programme theory 4: shared decision making.

Whilst shared decision making is a collaborative process, it requires that healthcare professionals and people with LTCs individually adopt a belief in its value, benefits and importance before a shared agreement can be reached. For healthcare professionals, this includes the idea that people with LTCs should be supported to make decisions that are right for them without being unduly influenced (Lhussier et al., 2013, Elwyn et al., 2012). For people with LTCs, this means placing value on being more informed and involved in their care and understanding the importance of taking ownership and responsibility for decisions they make (Ahmad, 2014).

Phase three of this study found that implementers and people with LTCs had mixed views in relation to the value of shared decision making. One implementer stated that there are some circumstances where she feels she has to take control and make decisions about a person's care. In contrast, other healthcare professionals believed that people with LTCs should always make decisions about their health and healthcare. Similarly, people with LTCs

differed in their shared decision making practices. Some stated that healthcare professionals make the decisions about their care, yet they would like to be more involved in these decisions, whilst others were leading their care and felt that their decisions were respected by healthcare professionals.

This diversity in views is consistent with the literature reviewed in phase one, which leaders suggested portrays shared decision making as a biomedical task because it is mostly outside of the CSP context (due to limited research around the components of CSP). In the CSP context, however, where two power-sharing people come together and discuss all aspects of a person's life, shared decision making is biopsychosocial in nature. Internalisation refers to the work that healthcare professionals and people with LTCs do to attribute worth to this way of working.

People with LTCs who were making decisions about their care had made a shift in their expectations and constructions of the healthcare relationship, and were able to see the value, benefits and importance of their role in CSP. Those who were not making decisions about their care were perhaps influenced by healthcare professionals' belief systems. For example, the implementer (I2) who believed that in certain contexts she has to take control and make a decision for an individual to commence insulin therapy was the same implementer who described "pushing" people to make the "right" decision. This was also the same implementer who referred an individual to a GP when he disagreed with her preferred course of action. This implementer placed

emphasis on reading the results and offering reassurance around that, as opposed to valuing the person's role in the CSP process. She had been unable to differentiate between CSP and previous practice and had been unable to contribute to communal sense-making of CSP (discussed on page 250). Thus, her understanding of her specific tasks and responsibilities around CSP were biomedical (traditional practice) in nature which shaped her style of practice (individual sense-making). People with LTCs who attend CSP consultations with this implementer would therefore never experience effective CSP in the way that this study describes. The lack of communal sense-making would impact on their individual sense-making of CSP, which would ultimately inhibit internalisation of CSP. This explains why "95%" of them do not engage with their results letters; this style of working was normalised in their lives.

For the person who had recently been diagnosed with diabetes (EbE2), these ineffective CSP practices were not normalised in his life and he had pre-existing expectations of healthcare, hence he emphasised the importance of playing a more active role in his care. Programme theory 4 depends on healthcare professionals and people with LTCs understanding the value, benefits and importance of their roles and responsibilities in CSP (internalisation), particularly in relation to equal power dynamics (context) and achieving this understanding through differentiation and communal sense-making.

## Cognitive Participation: relational work

Cognitive Participation is the work that people do to build and sustain a community of practice around CSP. Under this NPT construct are four components: initiation, enrolment, legitimation and activation (May et al., 2015). These components are outlined in Table 2 below, in addition to related questions that I have considered of the study findings, and whom and which tested programme theories these questions apply to.

<b>Components of cognitive participation</b>	<b>Questions considered within the NPT framework</b>	<b>Context this applies to</b>	<b>Tested programme theory this relates to</b>
Initiation	Is CSP being driven forward?	Healthcare professionals' practice	1: preparation
Enrolment	How do relationships affect collective contribution to CSP?	CSP consultations	4: shared decision making
Legitimation	How do others define your contribution to CSP?	Lives of people with LTCs	All
Activation	How do you sustain CSP and stay involved?	Lives of people with LTCs	5: conversation summary

*Table 2: Components of cognitive participation and related questions considered*

### *Initiation*

When a set of practices is new or modified, a core problem is whether or not key participants are working to drive them forward (May et al., 2015). For healthcare professionals, this relates to offering resources that people with LTCs can use to prepare themselves before their CSP consultations (programme theory 1). This study suggests that offering these resources in

this way is a new practice that differentiates CSP from other LTC management programmes. Preparation is also arguably the most important component of CSP as it is a required context for quality conversations - and the goal setting, shared decision making, and conversation summaries that occur within them - to take place. For recently diagnosed people, since this differs from care that they would have been used to, healthcare professionals need to drive it forward to ensure that it becomes normalised in practice and in peoples' lives.

All healthcare professionals who participated in this study were on board with preparation, however, the extent to which people with LTCs were prepared differed across practices. CSP was most normalised in practices where people with LTCs received information about its processes via social media, websites, advertisements in the practice waiting room, and during interactions with staff. People who were prepared in this way had the best outcomes across all six programme theories. Practices that support a whole-team approach can share this workload between staff, thus maximising efficiency.

In contrast, housebound people who received care from district nurses were not prepared and thus did not engage with CSP. The district nurses had no affiliation with the GP practice or CSP and therefore had no interest in explaining its benefits and driving it forward. However, an implementer stated that once a member of her team had visited and explained the process whilst differentiating between CSP and usual practice and attributing worth to this

new way of working (internalisation), this facilitated future engagement with CSP.

### *Enrolment*

People may need to organise and reorganise themselves and others in order to collectively contribute to the work involved in new practices (May et al., 2015). Enrolment is particularly relevant to shared decision making (programme theory 4) as healthcare professionals and people with LTCs come together in CSP consultations and work out how their roles fit in the dynamic.

A crucial context for shared decision making is an equal power dynamic between healthcare professionals and people with LTCs. Through its use of specific resources (e.g. sending test results ahead of consultations), CSP invites people to share power. It acknowledges that people are experts in their own bodies and in their own lives, with their LTC as part of that. This study found that the majority of healthcare professionals had bought-in to a power-sharing role, however, one implementer (I2) did not appear to have adopted this ethos in her recollection of a CSP consultation. When she referred a person with diabetes to a GP because he was uninterested in taking a particular medication, she was affirming her belief that a GP could perhaps be perceived as more authoritarian and impact his decision making. The implementer had reorganised (or failed to organise) the power dynamic so that it was not facilitative of CSP conversations, which meant that neither she nor the person with LTCs collectively contributed to the work involved in shared

decision making. The implementer appeared to believe in the traditional view that nurses are generally perceived as less authoritarian than doctors (Marks et al., 2005; Richardson and Glasper, 2010). However, in this study, CSP was sometimes implemented by GPs, and sometimes by nurses and nurse practitioners. None of the people with LTCs who were involved in this study suggested that CSP was any more or less effective based on roles, which suggests that perception of authority is not as relevant within the context of CSP consultations. It is more about organising relationships between healthcare professionals and people with LTCs in the consultation so that power is shared and both can collectively contribute to CSP.

### *Legitimation*

An important component of relational work in the participation of CSP is ensuring that people with LTCs believe it is right for them to be involved and that they can make a valid contribution to it. This study has shown that the ultimate goal is that people with LTCs own the CSP process and use it in the context of their lives with their LTC, rather than merely believing they have a valid contribution to an existing practice. Legitimation refers to goal setting (programme theory 3).

A key role of healthcare professionals in the context of the CSP consultation is to encourage and enable people with LTCs to take control, with as much or as little support as they want and need, so that they feel legitimised as equals in the process. If the elderly lady with multimorbidity who did not understand

her test results (EbE3) had been encouraged to discuss biopsychosocial aspects of her life, reasons why she consistently did not prepare for CSP conversations (in this case it was health literacy) might have emerged and been addressed through the use of other CSP resources (e.g. education and clearer information). Additionally, the importance of her role in CSP may have been highlighted, resulting in her feeling legitimised as an equal partner in the process. This might have affected her future engagement with results letters.

Some other people who read their test results letters described a sudden realisation that their condition was serious and that this knowledge, often in addition to major life events, sparked an awareness that they had a legitimate role in managing their life with their LTC. This is the point where they truly took ownership of the CSP process and most importantly, of their lives. This resulted in goals being set and ultimately achieved. Sending test results ahead of the CSP consultation therefore helps to clarify and strengthen their crucial role through legitimation and CSP can be owned and embraced by the person with LTCs from the earliest point. This shift in responsibility could make a huge impact on the sustainability of healthcare services.

### *Activation*

Once a practice is underway, participants need to collectively define the actions and procedures needed to sustain it and to stay involved (May et al., 2015). This means keeping the new practices in view and connecting them with the people who need to be doing them. Even when people with LTCs

engage with CSP from the outset, sustaining involvement can be a challenge. When people with LTCs continue to attend CSP consultations, their role is reinforced and it becomes normalised in practice and also in the context of their lives. However, in reality, peoples' health (and motivation) tends to fluctuate, thus consistency in level of engagement with CSP and self-management is difficult to achieve. There might therefore be a need for continuous work in coherence so that their practices evolve with the changing contexts of their lives and health.

The conversation summary (programme theory 5) is a key resource which can act as a personalised reminder for subsequent CSP conversations and as a reflection tool for the person who owns it. This requires that the person with LTCs understands the value, benefits and importance of the conversation summary (internalisation) and their specific role and responsibilities in taking ownership of it (individual sense-making). Healthcare professionals can therefore facilitate this by reinforcing the value of the person becoming the leader in their care (legitimation).

This study shows that when a conversation summary is owned by a person with LTCs (resource), it can have several different functions depending on their individual sense-making of it. For example, some people described using the conversation summary as a toolkit to add information to (e.g. previous test results, food diaries, information about their LTC, etc.). It is therefore personalised with the information that they choose to take away from the CSP

consultation, assuming they have been involved in discussions and plans about their care (context), and anything else they might wish to add to it. People can use it to remind themselves about CSP conversations, reflect on previous results and share information with family, if they wish (reasoning). This can therefore help people with LTCs to sustain their self-management practices (outcome).

### Collective action: operational work

Collective Action is the operational work that people do to enact CSP. Under this NPT construct are four components: interactional workability, relational integration, skill set workability and contextual integration. These components are outlined in Table 3 below, in addition to related questions that I have considered of the study findings, and whom and which tested programme theories these questions apply to.

<b>Components of collective action</b>	<b>Questions considered within the NPT framework</b>	<b>Context this applies to</b>	<b>Tested programme theory this relates to</b>
Interactional workability	What impact does CSP have on interactions?	CSP consultations	2: quality conversations 6: communication
Relational integration	What is the knowledge work people do to maintain confidence in CSP?	Lives of people with LTCs, healthcare professionals' practice, CSP consultations	All
Skill set workability	Who does which aspects of the work?	Lives of people with LTCs, healthcare professionals' practice, CSP consultations	All
Contextual integration	How does CSP fit with the overall organisational context?	Healthcare professionals' practice, CSP consultations	All

*Table 3: Components of collective action and related questions considered*

### *Interactional workability*

This refers to the interactional work that people do with each other, with artefacts, and with other elements of a set of practices when they seek to operationalise them in everyday settings. In this study, interactional workability therefore relates mostly to the communication that takes place between healthcare professionals and people with LTCs within CSP consultations (programme theory 6), but it is also relevant in conversation summaries, preparation and goal setting as people interact (or not) with CSP resources.

I have established that the ethos of CSP is the person with LTCs being in control of their health and healthcare. This therefore has an impact on the interactional work that takes place within the context of the CSP consultation. Open ended-questions, non-medicalised language, empathy, reflecting, checking, and motivating people were identified by implementers as key communication strategies that facilitate and encourage the person with LTCs to lead the CSP process. A crucial communication practice which differentiates CSP from other models of care is the physical shift that people described. A person with LTCs described sitting down together with a healthcare professional and having an open, two-way conversation. This is different to the practitioner reading results from a computer screen, which often occurs in standard care (this did happen in a CSP consultation I observed, but preparation had not occurred). This physical shift reinforces the idea that CSP resources (including active and open listening and considering holistically the

person with LTCs and their social environment) invite the person to lead a conversation that focuses on their agenda.

In this study, when the person who was newly diagnosed with diabetes (EbE2) attended his first CSP appointment, this physical shift in communication was not present because the person had not been enabled to prepare, the practitioner had different ideas about effective CSP practices, and the coherence work that enables CSP to occur in the way that this study presents as ideal had not taken place. This therefore reinforces the interconnectedness of the components of NPT and of the six programme theories. For example, if the coherence work that enables preparation to occur is not done, this affects the interactions between people (and between resources and people) within the CSP consultation (collective action).

### *Relational integration*

This refers to the knowledge work that people do to build accountability and maintain confidence in a set of practices and in each other as they use them. A lack of relational integration (and coherence) may explain why some healthcare professionals disengaged with the conversation summary element of CSP. Throughout the findings chapter there were several examples where mechanisms were activated initially but became dormant until the context changed and reactivated them at different time points, when they were needed. In this study, major life events were seen to reactivate mechanisms relating to CSP in a number of people with LTCs. One person (EbE11) had

been attending CSP consultations for a few years and described a fluctuation in her diabetes control when she was going through a difficult time with her husband. At that time, self-management and CSP were not relevant to her. She told the healthcare professional during a CSP conversation that she knew what to do to lower her HBA1c, but she lacked motivation to do it at that time.

At a later date, the context changed and the combination of seeing a high figure on paper (resource) and the birth of her granddaughter (change in context) motivated her to make some lifestyle changes (reasoning). Consequently, she successfully lowered her HBA1c within three months (outcome). This person had described engaging with CSP from the outset, thus mechanisms were activated initially, however, due to changing needs and life events (her sick husband became her priority), which can be visualised on the “wavy line” illustration (Figure 2, p. 26), her engagement with self-management also fluctuated. Engagement with self-management may therefore run parallel to the wavy line, becoming dormant at particular times and reactivating when the context changes.

In this circumstance, there would have been regular reappraisal (reflexive monitoring) in light of changing contexts (will CSP practices be effective/useful to me now? What affect will it have on my life as it is now?), which would have given the person a revised sense of coherence about the value, benefits and importance of CSP (internalisation), enabling or inhibiting it from becoming

normalised in their life at that particular time. This explains how some people reengage with CSP and self-management after a period of disengagement.

### *Skill set workability*

This refers to the allocation work that underpins the division of labour that is built up around a set of practices as they are operationalised in the real world. This applies to all six programme theories and is relevant to the lives of people with LTCs, healthcare professionals' practice and CSP consultations. Traditionally, the majority of LTC management would be seen to take place in a healthcare setting, with practitioners adopting a paternalistic approach and taking the lead in terms of researching LTCs and distributing biomedical care plans. CSP happens in three different settings: the life of the person with LTCs, the professional's practice and the conversation they have in common. The division of labour per setting that includes the person's life has never been established in prior research.

CSP brings about a shift in roles for both healthcare professionals and people with LTCs. Primary care nurses (and doctors) are skilled in the management of different LTCs so that they can operate on a more generalist level than specialist services, which fits with the ethos of CSP (Barnett et al., 2012, The Health Foundation, 2011). I found that in the seven GP practices involved in this study, GPs were far more involved with the day-to-day operationalisation of CSP in some practices than others. I did not find any differences in the effectiveness of CSP based on level of seniority.

CSP enables and encourages people with LTCs to own their self-management journeys. This requires a substantial amount of work to be done and costs people their time (to read test results, attend education courses and prepare an agenda for the CSP consultation). Interestingly, people with LTCs who participated in this study did not highlight this as a barrier to engagement with CSP, suggesting that they understood the importance of this work (internalisation) and their role in CSP (legitimation). This finding supports the idea that people want to manage their LTCs more independently at home (National Voices, 2013, McDonald, 2014). A survey by the Institute for Public Policy Research, involving over 2,500 people living with LTCs, found that a lack of support and information was holding them back from doing so (McDonald, 2014). CSP enables and encourages this shift in roles through specific resources and related contexts which facilitate effective self-management (shown in all six programme theories).

### *Contextual integration*

This refers to the work that involves managing a set of practices through the allocation of different kinds of resources and the execution of protocols, policies and procedures (May et al., 2015). It applies to healthcare professionals' practice (particularly the initiation of preparation) and also to the lives of people with LTCs who might integrate CSP differently depending on their context at the time.

Some implementers described developing their own preparation prompts, depending on their practice population and practice systems. One implementer (I3) stated that their CSP templates were designed in collaboration with an IT lead (who is also a partner in the practice). He set up an intelligent template system for information gathering (preparation), efficient call and recall, and for the CSP consultation. This was working well for this particular practice which had a full-time administrator whose role was to carry out the pre-consultation tasks. Another implementer (I6) explained that her GP practice had outsourced some of the administrative work to an external agency (particularly the call and recall tasks) due to limited staffing resources. The two people with LTCs who did not receive their test results letters prior to their CSP consultations (EbE1 and EbE2) attended this practice. This therefore suggests that CSP is more effective when organisational and supporting processes are performed in-house (context).

It is likely that contextual integration happens at a number of levels, thus it is important to take into consideration the wider context of CSP in primary care. With an increasing prevalence of LTCs and multimorbidity challenging the sustainability of the NHS (Department of Health and Social Care, 2015a, Barnett et al., 2012, Aiden, 2018), policy makers have deemed self-management a key solution to soaring care costs. Self-management, supported by personalised and coordinated care from professionals, is also desired by people with LTCs (National Voices, 2013). In order to make this vision a reality that becomes normalised, the NHS Five Year Forward View described the need for a profound shift in the way that healthcare is organised

and perceived in the UK (NHS England et al., 2014). It stated that culture and systems must change to support this way of working, so that people with LTCs are in the driving seats of their care and are recognised as “experts” in their conditions in the context of their lives.

The six programme theories were developed, refined and tested using a systematic and comprehensive realist evaluation process. This realist evaluation considered a large body of evidence including policy and empirical research in the literature (phase one), accounts from CSP leaders (phase two) and experiences of CSP from the perspectives of healthcare professionals and people with LTCs (phase three). The outcome is six tested programme theories that show how CSP, through the use of specific resources, enables and encourages self-management for people with LTCs, thus confirming the contextual integration of CSP.

#### Reflexive Monitoring: appraisal work

Reflexive Monitoring is the appraisal work that people do to assess and understand how CSP affects them and others around them (May et al., 2015). Under this NPT construct are four components: systematisation, communal appraisal, individual appraisal and reconfiguration. These components are outlined in Table 4 below, in addition to related questions that I have considered of the study findings, and whom and which tested programme theories these questions apply to.

<b>Components of reflexive monitoring</b>	<b>Questions considered within the NPT framework</b>	<b>Context this applies to</b>	<b>Tested programme theory this relates to</b>
Systematisation	Is CSP working for you and others?	CSP consultations, lives of people with LTCs	1: preparation
Communal appraisal	How do you maintain confidence in CSP?	CSP consultations	2: quality conversations
Individual appraisal	What effect is CSP having on your life?	Lives of people with LTCs, healthcare professionals' practice	All
Reconfiguration	Does CSP need to be modified to suit you?	Lives of people with LTCs, healthcare professionals' practice	1: preparation

*Table 4: Components of reflexive monitoring and related questions considered*

### *Systematisation*

Participants in any set of practices may seek to determine how effective and useful it is for them and for others, and this involves the work of collecting information in a variety of formal and informal ways (May et al., 2015). Preparation (programme theory 1) involves sending question prompts to people with LTCs. This can be a helpful process as it allows healthcare professionals to see areas that people perhaps do not fully understand. For example, if several individuals circle their HBA1c level and write on the question prompt sheet that they do not know what this means, this is key information about the clarity of the results letter and would indicate that either it is not an explanatory resource or people do not have enough access to education. It is important to collect such information because this could clearly have an impact on peoples' self-management practices. Several people who participated in this study (healthcare professionals and people with LTCs) explained that test results letters were often not understood and work was being done to make them more visual and easily interpreted.

### *Communal appraisal*

Communal appraisal refers to participants working together in formal collaboratives or informal groups to evaluate the worth of a set of practices. This relates to reviewing progress in the context of CSP consultations (programme theory 2). Two people in this study who were self-managing their LTCs effectively described only attending CSP consultations if their results were problematic. NPT proposes that a crucial part of embedding CSP in practice is the individual and collective evaluation of its set of practices by people who are involved in it. Repeating the CSP cycle every six months to one year provides opportunities for healthcare professionals and people with LTCs to come together and discuss progress and underlying issues, but also to adjust the frequency of the meetings to the context of the person's health and life.

A person with LTCs who participated in this study (EbE5) described attending a CSP consultation in which he took the lead. The practitioner told him to continue doing what he was doing, as he had made and was maintaining major lifestyle changes. This communal appraisal is key to reinforcing the worth of a practice. The person may have been experiencing a dip in his "wavy line" experience (Figure 2, p. 26) and been struggling with the repeated coherence work he had to do for his effective self-management to remain normalised in his life. The healthcare professional reinforced the value and benefits of his actions during the CSP consultation (communal appraisal), thus reducing the

need for individual coherence work to be redone until another change in context in his life. The people who do not attend, or are not invited to CSP consultations, must therefore undertake individual sense-making and appraisal more often; without the reassurance of communal work, their self-management practices may become denormalised.

### *Individual appraisal*

Participants in a new set of practices also work experientially as individuals to appraise its effects on them and the contexts in which they are set. All people with LTCs who participated in this study reflected positively on CSP and the impact it had on their lives. People spoke about the convenience of receiving care for all of their conditions in one single appointment and the importance of continuity in the CSP relationship. Others reflected on taking responsibility for their own health and how CSP resources can help them do this. One person spoke about a referral to a lifestyle course and a gym, both of which initially helped her to lose weight, however, due to a lack of motivation to continue progressing and perhaps individual appraisal which led her to think that losing weight was no longer a priority after a while, she put the weight back on.

All of the people in this study described CSP conversations which focus on identifying personal needs and goals (where appropriate), discussing and exploring issues and priorities and supporting people to develop the tools they need to live well. Furthermore, they were all managing their conditions themselves, to an extent that was relevant within the context of their lives. This

finding supports the work of De Silva (2011), who found that as many as 80-90% of people with LTCs can be supported to actively manage their own health. This study explores this idea further and explains why people may engage or reengage with CSP at one particular time and disengage at another, depending on various factors within the context of their lives.

### *Reconfiguration*

Reconfiguration refers to the appraisal work by individuals or groups that leads to attempts to redefine or modify CSP practices. This happens in practice during team meetings and audit. For people with LTCs, CSP practices may be modified to fit within the context of their lives. An example of this can be seen in the Findings sub-section on preparation (page 128), where a person with LTCs (EbE5) could no longer access his test results because they were now online (differentiation) and he had forgotten his password to log onto the system. He explained that he prefers to receive a letter through the post. He could not attribute worth to the online system, therefore it was not internalised. However, this was not something he had discussed with a healthcare professional because he was only invited to CSP consultations if there was an issue with his results (no communal appraisal). This appears to be a modified practice (reconfiguration) that some GP surgeries have adopted.

Since he could not access his results, he would not know what the issue was until he was told in the CSP appointment, thus the focus would be on his results and it would be unlikely that the technological issue he was experiencing would be raised. This person was an extremely motivated individual at the time when

I interviewed him. He was keeping a diary where he recorded his blood sugars every morning and evening, in addition to the food that he was consuming, so that if there was a blood sugar spike, he could attribute it to something lifestyle related and learn from his actions. He had modified self-management practices to suit his lifestyle.

Somebody with less motivation, organisation or poorer literacy skills may struggle to do this and therefore without regular CSP conversations, would be at risk of a deterioration in health. Indeed, this same person may at some point in the future lose motivation to keep himself well (denormalisation). Maintaining regular contact and having permission to discuss anything that is important is therefore crucial for people with LTCs to sustain self-management. Telling people that they will receive a CSP review appointment only if there is an issue with their test results (like this person described) feels much too biomedically focused than CSP is considered to be and feels more like doing 'to' rather than 'with' the person. It removes permission for people to come and discuss whatever is important to them. It seems much more acceptable and in keeping with the person owning their own CSP journey, for them to decide if/when/how they would like to review their progress.

### Reflection on terminology

As this research progressed, so did my thinking about language and the way that it can reflect practice. In Chapter 1 (p. 3) I introduced the idea that semantics are vitally important in the literature around the care and

management of LTCs, particularly when considering the people involved. This idea also transfers to practice. When we think of “patients” rather than “people”, there is a mental shift in the balance of power from equal people, to “helper” (with knowledge, skills and experience) and “person needing help” (seeking knowledge, skills and experience) (Barnett, 2018). Leaders in phase two were understandably keen to change the wording in my developed programme theories, from “patients” to “people”, however, the quotations throughout phase two of the findings show that leaders defaulted back to using the term “patients” in their discussions. People were also referred to as “patients” by implementers in phase three of this study. Barnett (2018) suggests that when healthcare professionals talk about “patients”, this unconsciously encourages a more paternalistic attitude to the person being treated, thus reinforcing an unequal balance of power. Interestingly, people with LTCs also referred to themselves as “patients”. One stated, “she takes her time with me so she’s obviously taking her time with other patients” (EbE11). The position of the patient as a recipient of expert care is so ingrained in all of us that my supervisors and I had many deliberations as a whole PhD team about which terms to use, and ensuring they were used consistently. In the findings chapter, I used phrases like, “if the doctor had prepared EbE11” (p. 186). After careful consideration, I realised that this reflects the idea of a person being treated, thus reinforcing an unequal balance of power and affirming the practitioner-led philosophy that CSP moves away from. It is very easy to fall back into a default position, even in this thesis, and this highlights the challenges faced in both professional and personal practice.

However, our debates went much further than “patient” versus “people”. Another debate focussed on the term “service user” for people with LTCs who participated in this study. We thought this would no longer be appropriate as the connotation would be of someone using, and someone providing a service, which reproduces the power imbalances above. We settled for “Expert by Experience” to highlight people’s expertise and the fact that CSP is often described as a “meeting of experts”. In addition, we deliberated over “implementers” vs “biomedical experts” when referring to the healthcare professionals who participated in this study. They are biomedical experts in the context of the CSP conversation, but they are also people who have had to work around their practice systems and work with colleagues to implement CSP as a new intervention and then normalise it. This reflects the different levels of the CSP system. At the individual level, and in the context of the conversation, there are two “experts”. At the next system level (practice and life contexts) there are “implementers”. NPT helps to explain how we need the connection at the individual level (sense-making) in order for this to translate into implementation.

Furthermore, during phase two of this study, leaders of CSP deliberated over the terms “consultation” vs “conversation” and felt that the latter fit more with the ethos of CSP and in particular, the six programme theories which are focused around the content of the conversation. Whilst the Year of Care leaders have largely operationalised the shifts between “consultation” to “conversation”, “patient” to “person”, and “care planning” to “CSP”, by introducing “Experts by Experience” and questioning the use of service users

I am pushing these linguistic barriers further. The regularity and frequency of such debates suggests that there is still some way to go in fully embedding the CSP ethos into twenty-first century care and societal systems in the UK.

### Implications for practice

The aim of this study was to address the gap in knowledge regarding how, why, for whom and in what circumstances CSP works best. The House of Care model proposes that whole-system approaches and improvements are needed for “better conversations” to occur, in order to achieve person-centred, coordinated care (Year of Care, 2011). This realist evaluation comprehensively explores the most favourable contexts, and the mechanisms that are triggered, in order for “better conversations” to occur. It also highlights the fact that CSP requires active implementation strategies to become embedded into practice and indicates the importance of context and how this can affect its implementation and effectiveness. This, for many healthcare professionals, presents a departure from either a descriptive approach (detailing the intervention) or a focus on effectiveness (does CSP work better than other interventions). Thus, in generating evidence-based understandings of the effective implementation of CSP and using NPT to show how it becomes normalised in professional and personal contexts, this study has the potential to inform the working practices of many healthcare settings.

### Multimorbidity: where does this fit?

Initially, this study set out to focus on CSP for people with multimorbidity. During the rapid realist review phase, however, it became clear that there was

very little evidence in the literature around CSP for people with multimorbidity. Despite this lack of evidence, CSP is now being implemented for people with multimorbidity in GP practices nationally. In my experience of speaking to healthcare professionals and people with LTCs, there did not appear to be any distinction about whether this was an approach specifically suited to single or multiple conditions. The CSP ethos moves away from a biomedical model of thinking about care. When we distinguish between approaches for single and multiple conditions, we are still being driven by a biomedical perspective. The lived experience of multimorbidity is indeed far more complex than a count of clinical diagnoses alone; people understand illness not simply as the presence of disease, but the extent to which impairment affects their everyday lives (Porter et al., 2019). Porter et al. (2019) describe the lived experience of concurrency (the synchronous presence of multiple conditions) as characterised by fluctuating symptoms, meaning that a single symptom or condition may dominate experience at any one time. Normality is much more individualised and dependent on the context of people's lives. The practical efforts to monitor and affect the course of an illness, is vital to maintain a vision of normality. McClean and Shaw (2005) proposed that people with LTCs regularly use biomedical knowledge within their own sense-making practices, and interactions with clinicians are thus key to giving meaning to illness. Porter et al. (2019), however, suggested that multimorbidity radically truncates these sense-making practices as the biomedically informed concept obscures lived experience and distorts people's understanding of their bodies in line with biomedical presumptions. The priorities of people with multimorbidity were not associated with illness; instead, they were associated with selfhood (e.g.

maintaining roles, relationships and valued activities). Such priorities were achieved through control and normality. Porter et al. (2019) concluded that people do not understand their health in terms of the diagnosis and concurrence of multiple LTCs, therefore the notion that people prioritise the self-management of certain conditions over others seems somewhat erroneous. This therefore confirms that clinical encounters need to lay the foundations for different sense-making processes to happen, i.e. they consider the biopsychosocial aspects of a person's life. CSP, with its focus on the importance of the person's agenda and supporting them to manage their lives with whatever challenges come their way, has the potential to offer a way to operationalise control and normalcy in peoples' lives, regardless of their condition(s).

### Challenges

Realist conclusions about the generative causality of complex programmes can only be achieved through much negotiation and contestation (Greenhalgh et al., 2004). Developing, refining and testing the programme theories in this study has been a time consuming and demanding process, and although the findings are presented as three distinct phases for the sake of clarity, in reality the data collection and analysis process was much more iterative. This was due to the collective and concurrent use of many data strands feeding into each programme theory. This in itself was a challenge because the overlapping nature of the components of CSP meant that some of the data could have been coded into more than one programme theory. To avoid repetition, I tried to use different examples where possible.

Developing an understanding of contexts, mechanisms and outcomes, through attending realist workshops and summer schools, enabled me to collect, analyse and synthesise data through a “realist lens”. This understanding became clearer as the study progressed. Initially though, and in accordance with other realists (Jagosh et al., 2014), I found it especially difficult to decipher between contexts and mechanisms. In CSP, a variety of resources can be offered in array of contexts, so “choosing” one plausible causal explanation was challenging. I found that drawing out several versions of a programme theory using mind maps helped me to decipher between contexts and mechanisms and formulate an explanatory theory. In addition, unpacking mechanisms in terms of resources and reasoning using the adapted CMOC formula proposed by Dalkin et al. (2015) was extremely helpful because it allowed me to decipher from the data which CSP tool was being offered (resource) and whose decision-making process it was affecting (reasoning). Disaggregating between resources and reasoning in this way made the difference between contexts and mechanisms easier to comprehend. This method was also helpful during data collection, particularly with leaders of CSP who fed back that this was a useful process to go through and enhanced their thinking about CSP. Additionally, understanding mechanisms in this way enabled me to ensure I captured all of the data needed to develop, refine and test the programme theories without missing key elements of the CMOCs.

Another challenge I faced during this study was that I was unsure how to seek ethical approval for a three-phase realist evaluation. Initially, I thought that applying for approval for each phase separately would be most logical, because data collection at each phase would depend on the findings from the previous phase. However, in hindsight, filling in separate application forms and waiting for outcomes was incredibly time consuming and at times, frustrating. This could have been overcome if I had explained more about the nature of realist research in the ethics application, and been as transparent as possible in terms of what would be asked of participants, whilst maintaining some flexibility in the interview questions. The benefit of going through this learning process, however, is that I feel I would be able to apply this acquired knowledge to any future realist evaluations that I undertake, with confidence that it would help to streamline the ethics process.

Furthermore, recruitment of participants for phase two and phase three was a major challenge that was much more time consuming than I had envisaged. Initially, I sought ethical approval to facilitate a focus group with implementers, however, they were so busy in their daily practices that finding a time and location to suit multiple implementers proved problematic. After two attempts at trying to arrange a focus group, I amended my ethics application and interviewed implementers one to one. Although it was much easier to organise individual interviews, the response rate was still slower than I had anticipated, meaning data collection was ongoing for longer. However, this did come with benefits as it meant that I could spend time transcribing and coding each interview whilst recruiting for more participants, and this aided the iterative

nature of realist evaluation. Realist evaluation is undoubtedly time consuming and data analysis can be messy. Yet these negatives are overcome by the satisfaction derived from developing, refining and testing robust programme theories that provide credible explanations for observed outcomes.

### Limitations

Whilst recruitment for this realist evaluation followed recommendations from Corbin and Strauss (2008) and Guest et al. (2006), the study sample is small, which comes with implications. However, in keeping with realist research, recruitment of participants only ceased once the data had reached completeness and saturation. In addition, CSP leaders were Year of Care trainers, which meant that they were already fully committed to CSP and its underpinning philosophies and processes. They were, however, very honest about how the literature around care planning does not fully reflect CSP ethos and practice. All participants volunteered their time to participate in the study, therefore they were somewhat motivated. Since motivation is portrayed an important factor throughout the findings chapter, with reference to people with LTCs, there is a small risk that the sample may have influenced the findings. However, people with LTCs talked about having different levels of motivation, and all participants were candid in their discussions and often commented on negative issues that they had experienced, thus providing a balanced view of CSP.

A major limitation that I encountered during the RRR phase of this realist evaluation was a lack of clarity and limited background to CSP as a term,

particularly in academic literature. This made searching for key papers through complex literature difficult; however, by using the RRR protocol proposed by Saul et al. (2013), I was able to rely upon knowledge users to help streamline the searching by suggesting key papers and reference lists. Arguably, experts by experience could have also helped with tasks such as this. Evaluation is best undertaken when the philosophy of an intervention (in this case, CSP) is mostly aligned with that of the evaluation. A greater input of experts by experience in this study, not only as research participants, but as active advisors (helping with data analysis, for example) would have further enhanced the process. Although maximal transparency has been attempted in describing the realist evaluation process, it must be acknowledged that this is an inherently interpretive and subjective process. The use of NPT as a middle range theory complements and enhances the study findings by addressing the factors needed for successful implementation and integration of CSP into routine practice, and placing them within a theoretical framework.

### Future research

This study highlights how CSP operates at different levels and at each level, the roles of healthcare professionals and people with LTCs can be perceived differently. At the individual level, and in the context of the conversation, there are two “experts”. At the next system level (practice and life contexts) there are “implementers”. This initiates thinking about what extent we may want to consider people with LTCs as implementers. Applying NPT to the study findings has clarified that the role of the person with LTCs in the context of their life is key to the successful implementation of CSP. Therefore, a

recommendation for future research would be to study implementation processes in peoples' lives as they learn to live, and normalise life with, a LTC, using CSP as a key resource. Only once the linguistics barriers are fully understood can the CSP ethos be fully embedded into twenty-first century care and societal systems in the UK.

In addition, synthesising all of the data from different levels of the healthcare system, across six interrelated programme theories, was a major challenge. For example, one person with LTCs attributed her improved health outcomes to the opportunities that preparation brought about, however, preparation happens in the context of the person's life, in the healthcare professionals' practice, and in the CSP conversation. It was therefore difficult to attribute findings to one particular programme theory as often there were crossovers. This was difficult to articulate in the findings chapter and is therefore a rationale for further research to establish the impact of specific CSP components individually. This study found that preparation is the foundation of effective CSP, thus, further research that focuses on the specific mechanisms and impact of preparation, is warranted.

Furthermore, five of the nine implementers highlighted the importance of an additional role that is key to the effectiveness CSP. This role is the social prescriber or care navigator. It seems that the two names are used interchangeably in healthcare settings, but they offer similar services. I will refer to them as social prescribers. Their role is to be a point of contact for

support with any of the psychosocial issues that people with LTCs might raise during CSP conversations. This could be anything from court appeals to housing and childcare. Implementers suggested that the social prescribing role is vitally important for CSP and that it would be very dissatisfying to open a can of worms and then put the lid back on, which, in effect, is what they would be doing by conversing about lifestyle issues and not offering any further support (signposting within CSP conversations aims to address this). Social prescribers take on the responsibility of dealing with the issues in the context of the person's life. It was out of the scope of this research to focus on this broader aspect of CSP, and further research would establish the scope of this role in the care and support for people with LTCs, and its relationship to social care.

I had initially planned to carry out a mixed methods study, comprising both qualitative and quantitative data. However, in the initial scoping phase the IPTs became focused around specific CSP resources and the impact they had on peoples' lives. Outcomes were thus difficult to measure quantitatively, and the study design was adapted to reflect this. Additionally, long-term outcomes are especially difficult to capture through qualitative interviewing as they manifest over a period of time and are tricky to attribute back to the programme. Therefore, a longer term project which uses a longitudinal mixed methods design and follows specific people over time is warranted.

## Conclusion

With an increasing prevalence of LTCs and multimorbidity challenging the sustainability of the NHS (Department of Health and Social Care, 2015a, Barnett et al., 2012, Aiden, 2018), self-management strategies are becoming a major focus in health research. This thesis makes a number of key contributions to knowledge, some of which have clear practice impact potential. It provides rigorously developed, refined and tested explanatory theories of key elements of CSP, around preparation, quality conversations, goal setting, shared decision making, conversation summaries, and communication. Together these explain how, for whom and in what circumstances CSP works best. This is the first realist evaluation of CSP and it has the potential to inform future evaluations of complex and tailored interventions. This is also the first time that, to my knowledge, NPT has been used to make sense of normalisation processes not only in practice, but also in peoples' lives. Applying NPT in this way challenges the idea of CSP being a healthcare practice that belongs to statutory organisations only. It also highlights how people with LTCs are an inherent part of the CSP team who operate within their own contexts. This unique study therefore inherently challenges the boundaries of what is considered "practice", and where it is operationalised. The thesis thus provides a key contribution to NPT, and pushes the boundaries of our conceptual and practice understanding of CSP. In a context of aging demographics, rising multimorbidity, and strained public finances, the potential relevance and application of this understanding cannot be underestimated.

# Appendices

## Appendix 1: Notes from Year of Care training event - June 2015

CSP improves:

- Experience of care and self-care behaviours
- Support for self-management and job satisfaction
- Practice organisation and team work
- Productivity – cost outcomes
- Clinical outcomes

At Tower Hamlets, the diabetes care was the worst in England, until CSP was implemented. It then became the best diabetes care in England and patients liked it (Eaton et al., 2015).

### **Written care plan:**

For patients, it reminds them of the details discussed in the consultation.

For practitioners, it helps with their coordination of care.

There is a master template for the multimorbidity care plan available to all practices.

Administrative teething troubles – wording of things can mean patients get upset.

### **Patient education**

How is the patient educated? This will affect self-care behaviours.

EMIS web (app) is available for anybody to access. Practitioners can tell them about it.

NHS decision aids (app for android/apple) are available for anybody to access. Practitioners can tell them about the apps. There is also an NHS shared decision website.

### **Preparing the patient**

There is an emotional response when hearing negative information. When test results are sent out prior to the CSP review, they have time to think, reflect and set goals.

There is a space at the bottom of the information sheet that is sent out prior to the review, for patients to write any questions they may have. This affects the power balance between practitioner/patient and empowers the patient to take the lead.

The patient is prepared for the transition to CSP by the practice staff. The practitioner informs them what will happen next time, and explains how and why, and gives information to support the transition.

Questions around what information to send and will they be anxious about it? Most patients would be less anxious having their results soon after their blood test than they would if they had to wait 4 weeks for them. If something key has shown up in the results, practitioners would want the patient to know about it.

Appointment reminders are sent out the day before, also stating how long the appointment is for.

### **In the consultation**

The practitioner uses non-medical language and has the patient's previous results to compare. They present the information in a way that the patient doesn't panic.

If the patient didn't understand the information sent out to them, it's still a good outcome because it has prompted them to have a conversation about it and get some clarity.

Some patients will have many questions and concerns to ask in the consultation. Practitioners will need to help the patient to prioritise their main issues.

Practitioner will have to have good time management skills.

### **Cost to the practice**

Practices will actually save money on sending out multiple appointment letters throughout the year.

There is some level 3 funding to help develop practices, it is £5 a head and covers stamps, envelopes and HCA training, etc. There is no limit to the number of practices applying for/being granted this funding.

In theory, practices will use less appointments and will be less busy.

Efficient IT systems are key.

HCA roles expand so they need extra training. This will save a lot of expensive GP time.

## **Goal setting**

The practitioner and patient should come up with goals together or the practitioner should encourage the patient to think about their own goals.

Goals should be clear and concrete, and achievable.

A time frame is useful. How important is the goal (out of 10)?

Think about what could go wrong and what could you do if that happened?

How confident are you that you can make a change?

The practitioner should acknowledge and explore how the patient feels.

The practitioner should empower the patient.

The practitioner should signpost to local support groups. Staff resources will build up over time.

## **CSP consultation skills**

- Listen and use non-verbal communication and body language
- Use open questions
- Let the patient take the lead
- Reflect back on what the patient has said and check their understanding
- Summarise

By reflecting back exactly the words that the person says, the practitioner is giving them the opportunity to expand on and open up. This lets them know the practitioner is listening and not dismissing anything they've said.

The practitioner may be able to unearth certain lifestyle factors that explain things, for example medication adherence.

Practitioners need to work in a generalised way. In order to be able to do this they need training from specialists.

## Appendix 2: Observations of CSP at a North East medical centre on 6<sup>th</sup> October 2015.

### **Background**

The practice is a busy 10,000 patient medical centre. There are 6 partners, all of whom work on a part-time basis. They are all quite specialised.

### **Observations of a HCA appointment**

Below are my observations of a HCA appointment for a patient with diabetes and asthma:

1/ Patient brings the urine sample to the appointment, the HCA tests it straight away and then goes through any immediate results with the patient.

2/ The patient is weighed on the scales and the HCA goes through her weight and BMI, and any changes since last time.

3/ BP is taken and is too high so the HCA asks some lifestyle questions, e.g. about smoking, drinking and exercise. She then gives some diet advice and a leaflet on Live Well Gateshead, a 12 week healthy eating support group.

4/ BP is taken again.

5/ Blood samples taken.

6/ Peak flow is done.

7/ Feet are checked (pulses, sensations).

8/ HCA explained that information and blood test results will be sent with the appointment letter, and reminded the patient it's so that she can be more involved in her health care.

The appointment took about 30 minutes and appeared quite traditional in that it was practitioner-led and more about doing tests and gathering information.

### **Observations of a doctor's CSP review appointment**

Below are my observations of a review appointment with a doctor. The patient was a 70 year-old diabetic lady.

The patient sat down and initiated a conversation about her results that she had received in the post. The doctor asked if she would like to go through the results and then asked if there was anything in particular that she had seen on the sheet and wanted to talk about. The doctor and the patient went through the results together although it was the patient talking mostly.

The doctor asked if the patient had been able to attend the DESMOND clinic, which triggered her to talk in great detail about what a valuable experience it was. They continued going through the results and the doctor asked if she was ok with a certain tablet. Brief discussion about medication and the patient said she had no problems with any of the tablets. She confirmed she had had her foot check last week as part of the HCA appointment. The doctor went back to the leaflet where the patient could have written any concerns etc. and she asked if there was anything in particular she wanted to talk about (the patient hadn't written anything down). The patient then went on to say she was reading about how walking can change things so she had started walking 3 laps instead of 2, and she has stopped buying chocolate biscuits.

The patient hadn't filled out the goals section on the leaflet. I asked the doctor whether this was common and she said it varies, some people write lots and others forget to bring the form with them to the appointment. The doctor went through it with her and asked what would be her goal, and she said to stay the same. The doctor's use of open questions here prompted the patient to think about her goals and what is important to her:

The doctor asked if exercise was something they could look at.

This triggered the patient to think about how it could benefit her and she replied that it is also important for her joints.

The doctor then asked if she would like to make a plan around that and whether that would be helpful.

The patient replied that she has found walking works for her, not the gym. She came up with a back-up plan for when the weather is bad – she will do indoor activities with her grandchildren.

The doctor said her next routine diabetic review would be in 6 months' time and then asked if that was ok, or if she would like to come sooner. The patient responded that 6 months was fine and she would come back sooner if she had any concerns.

The doctor asked if there was anything else she would like to talk about and the patient responded that having the test results sent to her before the appointment was very useful.

It appeared that the CSP consultation had come to an end when the patient began talking about her daughter's mental health issues and how difficult it is to have death threats coming through her letterbox. The doctor continued to

listen and her body language – sitting facing the patient, nodding, eye contact, showed that she was listening. It was clear that the patient felt comfortable enough to discuss this private issue, it would seem as though she TRUSTED the doctor enough to discuss it.

## **Summary**

The doctor's body language seemed to make the patient aware that she was listening. The doctor often said "yes" to confirm she was listening and understood. The patient was engaged and appeared comfortable taking the lead on the appointment as she was the one that did most of the talking. She spoke positively about having her results sent to her prior to the appointment. There seemed to be a good doctor/patient relationship – the doctor encouraged her to think about what was important to her and come up with her own goals. More time was spent on talking about lifestyle factors, i.e. exercise, than the diabetes itself. It was evident that that was what the patient wanted to focus on as, when the doctor asked open ended questions, the patient continued to be focused on that. The patient seemed happy/confident to self-manage her condition. When the doctor asked if she would like to come back sooner than the 6 month review appointment, the patient said something like "I take all my pills and do my exercise and I'm fine". She seemed to know what works best for her, and seemed happy to continue self-managing in between appointments.

## Appendix 3: Example of the formulation of an IPT

### Developing IPT 1

#### Relevant notes from Year of Care training event (September 2015)

There is an emotional response when hearing negative information. When test results are sent out prior to the CSP review, they have time to think, reflect and set goals.

There is a space at the bottom of the information sheet that is sent out prior to the review, for patients to write any questions they may have. This affects the power balance between practitioner/patient and empowers the patient to take the lead.

Questions around what information to send and will they be anxious about it? Most patients would be less anxious having their results soon after their blood test than they would if they had to wait 4 weeks for them. If something key has shown up in the results, practitioners would want the patient to know about it.

At the Year of Care training event I had the opportunity to watch a video of an example CSP consultation. What was the impact of having the results letter?

- The patient had the chance to think about and take in their results and think of questions to ask

#### Relevant notes from my observations of a CSP consultation at a North East GP surgery on 6<sup>th</sup> October 2015:

The patient sat down and initiated a conversation about her results that she had received in the post. The doctor asked if she would like to go through the results and then asked if there was anything in particular that she had seen on the sheet and wanted to talk about. The doctor and the patient went through the results together although it was the patient talking mostly.

The doctor asked if the patient had been able to attend the DESMOND clinic, which triggered her to talk in detail about what a valuable experience it was. They continued going through the results and the doctor asked whether the person was ok with that tablet. Brief discussion about medication and the patient said she had no problems with any of the tablets. She confirmed she had had her foot check last week as part of the HCA appointment. The doctor went back to the leaflet where the patient could have written any concerns etc. and she asked if there was anything in particular she wanted to talk about (she hadn't written anything down). The patient then went on to say she was reading about how walking can change things, so she started walking 3 laps instead of 2, and she has stopped buying chocolate biscuits.

#### Early ideas for a possible IPT (01/07/2015)

1:

Resource: Information in the form of summary letters and leaflets is provided to the patient outside of the CSP consultation

Context: Patient is allotted a set amount of time for their CSP consultation

Reasoning: The patient feels encouraged to engage in thinking about their treatment options outside of the clinical encounter

Outcome: Time with the physician can be used as effectively as possible

**2:**

Resource: Written encouragement to ask questions and question prompt sheets are sent to the patient ahead of the CSP consultation

Context: The patient is allotted a set amount of time for the CSP consultation

Reasoning: The patient feels encouraged to engage in thinking about their treatment options outside of the CSP consultation

Outcome: Time with the healthcare professional can be used as effectively as possible

**3:**

Resource: Information is sent to the patient ahead of the consultation

Context: The patient (with multimorbidity) is too overwhelmed emotionally to process a large amount of information about their health at once

Reasoning: The patient has the opportunity to read and reflect on important information when they are ready to do so, which enables them to come to terms with things and formulate questions to ask in the consultation

Outcome: Time with the healthcare professional can be used as effectively as possible

**Feedback received from supervision team. Supervisors suggested I have one IPT for the patient's perspective and one IPT for the practitioner's perspective. They were refined to incorporate this suggestion on 23/07/2015:**

**IPT 1: Patient's perspective**

Resource: Written encouragement to ask questions and question prompt sheets are sent to the patient ahead of the CSP consultation

Context: In the traditional doctor-led consultation disease-specific information is given

Reasoning: The patient feels like permission has been given to ask for information specific to their individual needs and their confidence to ask questions increases

Outcome: Person-specific information is received

**IPT 2: Professional's perspective**

Resource: Written encouragement to ask questions and question prompt sheets are sent to the patient ahead of the CSP consultation

Context: The practitioner is open to the patient actively participating in the consultation

Reasoning: During the consultation the practitioner can focus on what they know to be important to the patient

Outcome: Better job satisfaction

**Feedback received from supervision team: Outcome in IPT 1 could be formulated better i.e. is it patient activation or patient engagement?**

## Appendix 4: Search strategy

Population	Intervention	Context	Outcome
multi?morbidity long term condition* chronic disease* chronic illness*	results test* informed	health AND physical OR check* OR monitor*  “health?care assistant”  physical AND observation*  <b>Uncomfortable</b>  <b>Anxious OR anxiety</b>  <b>Worry OR worrie*</b>  Time AND pressure  Rush*  Target*	Time AND “care planning”  purposeful*  accept OR accepting  understand*  <b>Panic*</b>  <b>Time AND “care planning”</b>  Focus AND patient  Time AND “care planning”
multi?morbidity long term condition* chronic disease* chronic illness*	question AND prompt AND sent OR send  encourage* AND question* AND sent OR send  plan OR prepare*	Information AND specific        <b>Flexible</b>	Confidence OR confident  Question*  Personalised  “job satisfaction”
multi?morbidity long term condition* chronic disease* chronic illness*	Communication AND training	Improve* AND communication	Engage*  Understand*
multi?morbidity long term condition* chronic disease* chronic illness*	Sensitive OR difficult	Engage*  Understand*	Relationship  “shared decision making”
multi?morbidity long term condition* chronic disease* chronic illness*	“Lay language”  Simple AND language  Simplify  Familiar AND language  Check AND understand*	Diagnosed OR diagnosis	Compliance  Lifestyle AND improve* OR change*
multi?morbidity long term condition* chronic disease*	Psychological OR emotional AND support  Counselling	Stress* OR depress* OR anger OR fear  Emotion*	Trust

chronic illness*	“Support group” “Peer support”	Physical AND condition* or illness	
multi?morbidity long term condition* chronic disease* chronic illness*	Lifestyle OR life AND question	Relationship “continuity of care”	Health AND behaviour* Self?manage* OR self?care Disengage*
multi?morbidity long term condition* chronic disease* chronic illness*	MDT Multidisciplinary AND meeting	Provider* AND care Multiple AND provider*	“Coordination of care” Informed
multi?morbidity long term condition* chronic disease* chronic illness*	Information AND sent OR shared	Communication AND team* OR provider*	Proactive Risk Engage*
multi?morbidity long term condition* chronic disease* chronic illness*	Home AND care OR support	Deteriorat* AND home OR hospital	“Quality of life”

**Key**

Black = patient’s perspective

Red = how the intervention might *not* work

Blue = practitioner’s perspective

## Appendix 5: Data extraction form

### **Title**

Langford, A., Sawyer, D., Gioimo, S., Brownson, C., and O'Toole, M. (2007). Patient-centered goal setting as a tool to improve diabetes self-management.

### **Aims**

This article describes the process of collaborative goal setting as a means to improve diabetes self-management in primary care.

### **Characteristics of the paper**

This article describes the process of collaborative goal setting as a means to improve diabetes self-management in primary care. In 2003, the St. Peter Family Medicine Residency Program was chosen as 1 of 6 Advancing Diabetes Self-management projects funded by the Robert Wood Johnson Foundation Diabetes Initiative. The goal of the project was to improve diabetes self-management by introducing systematic changes to improve the quality and delivery of primary care. This paper was developed in collaboration with representatives from the Department of Community Health, Saint Louis University; St. Peter Family Medicine Residency Program; and the National Program Office of the Diabetes Initiative of The Robert Wood Johnson Foundation, Division of Health Behaviour Research, Washington University School of Medicine

### **Methodology and quality assessment**

In 2003, the St. Peter Family Medicine Residency Program developed the Self-Management Goal Cycle to illustrate the process of care they wanted all diabetic patients to receive. Each step of the cycle directly supports the patient's goal setting process. They also developed The Big Bad Sugar War (BBSWAR) technique, which is modelled after Kate Lorig's work with self-management to aid providers in the goal setting process. The BBSWAR is an abbreviation for a set of steps that serve as a reminder for providers to follow at each patient visit.

One part of the paper is particularly relevant to this review; the case study. Findings are reported below. Although it is just one case study, it is a prime example of the differences between standard care and CSP, and how CSP process resources (specifically goal setting) can trigger positive mechanisms which lead to positive health outcomes.

### **Findings**

Case study: A young lady was diagnosed with diabetes following a pregnancy and was overwhelmed with managing her multiple long term conditions. Initially, she managed her symptoms well in the care of a traditional primary care model which was largely provider driven and based on her medical conditions. However, following lifestyle changes (becoming a single parent, battling depression, gaining weight and taking up smoking) she stopped taking her medication and attending medical visits, causing her diabetes to become poorly controlled. When she became part of a diabetes self-management programme, the ongoing support she received in and between appointments

helped to improve her problem-solving skills. Through collaborative goal setting, she was able to share with the practitioner what was going on in her life. Consequently, she felt empowered to set small, attainable goals, which later became more specific e.g. around physical activity and diet. As a result of achieving her goals, her PHQ-9 depression score and her HbA1c diabetes level returned to normal. She also shared her successful self-management behaviours with her father who also had diabetes (Langford et al., 2007).

### **Links to theory**

Goal setting techniques in the Self-Management Goal Cycle are based on the stages of change constructs of the Transtheoretical Model, self-efficacy scales, and nondirective support.

## Appendix 6: Recruitment email and information sheet for leaders

Dear all,

As part of my PhD at Northumbria University I am exploring the practicalities of CSP for people with multimorbidity. I have completed a systematic literature review and have developed some ideas about how CSP works best.

The next step is to test and refine these assertions with people that understand CSP and have been involved in the leading, influencing or delivery of CSP. I obtained your email via Year of Care leads/trainers as you were identified as CSP deliverers in the North East.

***I would like to invite you to participate in a 2-hour focus group on Thursday 26th May 10am-12pm at Northumbria University's Coach Lane Campus to help me test and improve the assertions about the important components of CSP.***

This will then be tested further in a national Delphi process, and then tested practically in clinical settings. This research will be vitally important to our understanding of the core components of CSP and which components make the most crucial differences – vitally important questions for the commissioning and delivery of CSP.

I have attached an information sheet, but I would be delighted to discuss it further if you have any questions. **I would be grateful if you could assist in identifying other potential participants by sharing this invitation with colleagues who are implementing CSP in practice.** There are limited places so could those who are interested in participating please respond as soon as possible to: sarah.wilmot@northumbria.ac.uk

Thank you in advance

**Sarah Wilmot**  
**Postgraduate researcher**  
Faculty of Health and Life sciences  
Northumbria University  
Coach Lane Campus West  
Benton  
NE7 7XA

## PARTICIPANT INFORMATION FOR FOCUS GROUPS

You are being invited to take part in this research study. Before you decide whether you wish to participate it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

**Name of Researcher:** Sarah Wilmot

**Name of Supervisor:** Dr Monique Lhussier

**Project Title:** A realist evaluation of care planning for people with multimorbidity; what works, for whom and in what circumstances?

### 1. What is the purpose of this study?

With increasing concerns around the expected rise in the prevalence of multimorbidity and costs for the NHS, it is essential to gain a greater understanding of the impact of care planning for people with long term conditions. The aim of this part of the research project is to establish an understanding of how, for whom and in which circumstances care planning works best.

### 2. Why have I been invited?

You have been invited to participate because it has been highlighted that you are either involved in commissioning or leading the implementation of care planning, or you are involved in the practical implementation of care planning.

### 3. Do I have to take part?

No. It is up to you whether you would like to take part in the study. I am giving you this information sheet to help you make that decision. If you do decide to take part, remember that you can stop being involved in the study whenever you choose, without telling me why. Deciding not to take part or leaving the study at any point will not affect you in any way.

### 4. What will happen if I take part?

You will be invited to attend a focus group with between five and ten other professionals, all of whom have similar roles to yourself and some of whom you may already know. I will try to organise the date and time of the focus group so that it causes minimal disruption to your work. During the focus group you will be presented with a series of proposed theories around care planning. These theories have been developed during a comprehensive literature review. There will be an open-ended discussion around each of these theories and you will have the opportunity to discard or add to them depending on how you think care planning works best. For example, one theory might suggest that an important element of care planning is that patients receive peer support during peer-led self-management groups, whereas another theory might suggest that emotional support is important, whether from peers, healthcare professionals, or family. You will be asked to share your viewpoint and may add to or improve any of the statements. With your permission, the discussion will be recorded digitally in order to support the analysis process.

**5. What are the possible disadvantages of taking part?**

You will be asked to give up some of your time to participate in the focus group. This will be approximately two hours. You will be required to sit for this period, however, there will be an opportunity to take a break and as it is an informal event you may stand and walk around the room as you wish.

**6. How will confidentiality be assured, who will have access to the information that I provide and how will it be stored?**

The data collected in this study will be used for a PhD thesis.

Your name or other personal details will not be associated with your data, for example the consent form that you sign will be kept separate from any other information you provide. Only the research team will have access to any identifiable information; paper records will be stored in a locked filing cabinet and electronic information will be stored on a password-protected computer. This will be kept separate from any data.

All information and data gathered during this research will be stored in line with university guidelines and the Data Protection Act (1998) and will be destroyed 1 year following the conclusion of the study. If the research is published in a scientific journal or presented at conferences it may be kept for longer before being destroyed. During that time the data may be used by members of the research team for purposes appropriate to the research question, but at no point will your personal information or data be revealed.

**7. What will happen to the results of the study?**

We will share the findings from this study with:

- Yourself as participants in this study
- Northumbria University, in the form of the PhD thesis
- Local and national NHS trusts for information purposes
- Other GP practices who might find the results helpful in developing care planning in their own practice

**8. How can I withdraw from the project?**

If, for any reason, you wish to withdraw your data please contact the researcher within one month of your participation and this can be done without prejudice. After this date, it may not be possible to withdraw your individual data as the results may already have been published. As all data are anonymised, your individual data will not be identifiable in any way.

**9. If I require further information who should I contact and how?**

Sarah Wilmot (researcher) – [sarah.wilmot@northumbria.ac.uk](mailto:sarah.wilmot@northumbria.ac.uk)

Dr Monique Lhussier (principal supervisor) – [monique.lhussier@northumbria.ac.uk](mailto:monique.lhussier@northumbria.ac.uk)

**10. Who has reviewed this study?**

This study and its protocol has received full ethical approval from the Faculty of Health and Life Sciences Research Ethics Committee at Northumbria University.

### Focus group pre-reading

I have recently completed a systematic literature review looking at the literature on the interaction between healthcare professionals and patients during care planning consultations, which I know most of you have experience of. Seven themes have emerged from this literature review, including; patient preparedness, longer consultations, collaborative goal setting, formal care plan, communication, shared decision making and support for self-management. Based on these themes and the research methodology I am using, I have developed statements that explain how, why, for whom and in what circumstances care planning works best. This has been a discovery process; I know the statements are not right yet and I would like to draw on your experiential knowledge to develop each one further.

The statements explain how/if outcomes occur. We are interested in the mechanisms that lead to the occurrence of outcomes. Below are the seven statements that I have developed to explain how care planning should work. We will be discussing them in the focus group, so it would be excellent if you could read them and note down your thoughts prior to this. Any suggested change will be valuable, so please don't hesitate to amend/add to/refute the statements. Once we have a refined list of statements, they will be tested in clinical practice (this will be the next phase of my study).

#### **Patient preparedness:**

1. When test results and question prompts are sent to patients who have an understanding of the concept of care planning and an understanding of their condition(s), they spend time reflecting on their current health status and preparing questions to ask, which leads to greater patient engagement in the consultation.

Notes:
--------

#### **Longer consultations**

2. Longer consultations mean that practitioners who are committed to partnership working can spend time discussing what is important to the patient, which empowers the patient to engage with the care planning process and make healthy lifestyle changes.

Notes:
--------

#### **Collaborative goal setting**

3a. When patients receive support in identifying priorities/goals and they want to improve aspects of their health, they feel empowered that they are better equipped so they set meaningful, achievable goals.

**3b.** When achievable goals are set by patients who understand how their condition(s) impact on their lifestyle, they feel they have ownership of their plan and their self-efficacy improves, so they make healthier lifestyle choices.

Notes:

#### **Formal care plan**

**4.** When individualised written care plans are shared with patients who are proactive and motivated to change or who continue to self-manage, they utilise the plans to monitor their health and make healthy lifestyle choices.

Notes:

#### **Communication**

**5a.** Practitioners use communication techniques for patients who tend to be passive to encourage them to open up and express their concerns; practitioners listen and offer support and guidance.

**5b.** Practitioners offer guidance and personalised information to patients who actively communicate, they feel supported and their self-motivation increases so they engage in shared decision making and self-management.

Notes:

#### **Shared decision making**

**6.** When clinicians and patients effectively communicate their knowledge and expertise in the context of a relationship built on trust and respect, patients feel well informed and well supported, which leads to shared decision making.

Notes:

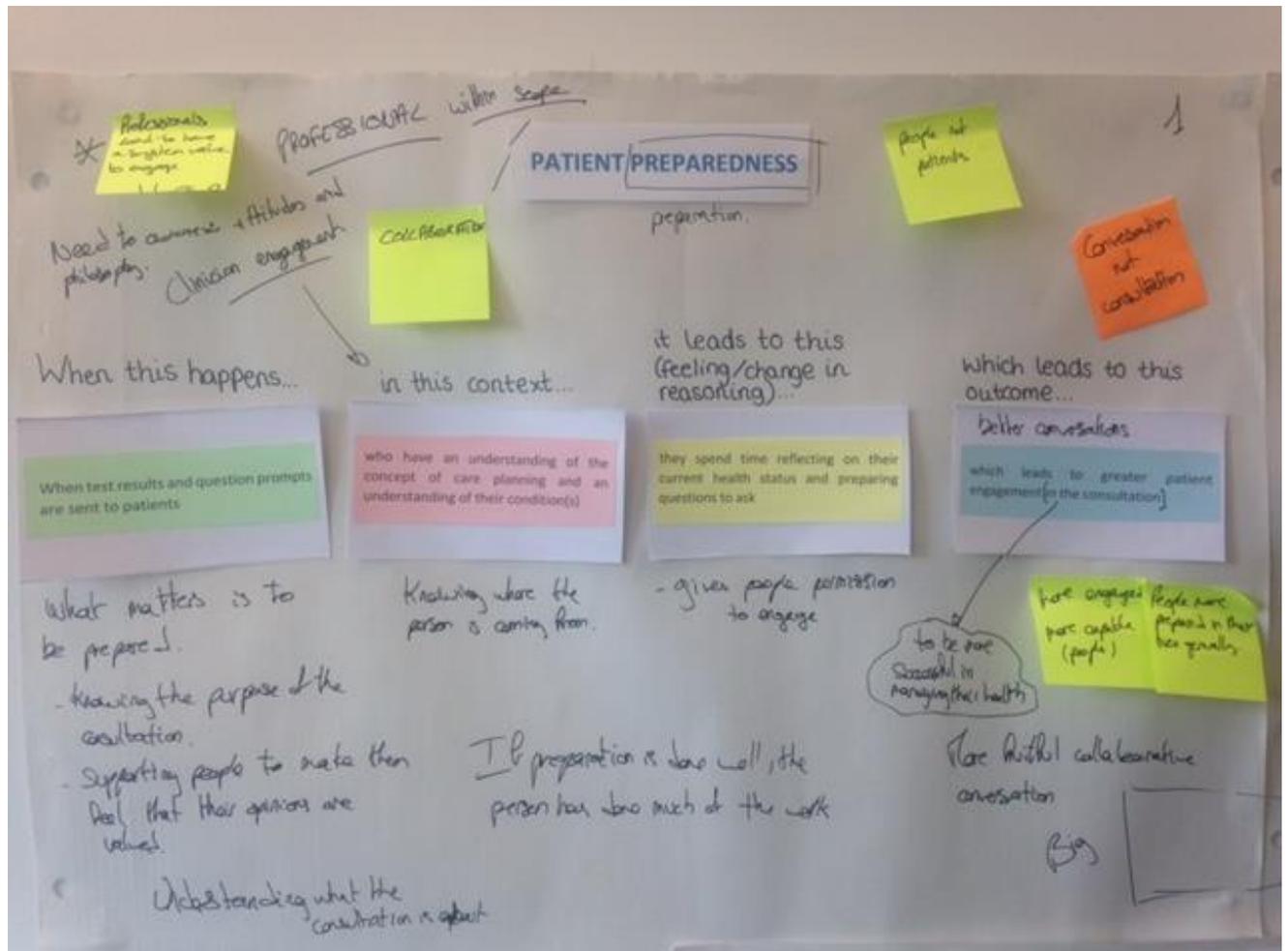
#### **Support for self-management**

**7.** Accessible support services for people with long term conditions who require holistic, personalised support provide them with the knowledge, skills and increased confidence to manage their own health and healthcare.

Notes:

Appendix 8: Example of programme theory refinement process

Example of the refining process of programme theory 1 in the focus group



## Appendix 9: Refined programme theories after focus group

### Refined Statements

Below (Figure 22) is a diagrammatic representation of care planning which was developed from your insightful discussions in the focus group. This is a proposed model of how care planning works best. We have tried to capture how all of our statements about care planning are linked together and we have set aside statement 7, which was about support for self-management, because we all agreed that support for self-management happens throughout the whole of care planning and is not just one part of it. I have thus incorporated it into my overarching programme theory about care planning, which is reported at the end of this document. The middle range theory was developed from the literature, but I feel it works well within this model. Happy to hear your views.

We said that preparation is key to care planning and the more preparation that is done (by both healthcare professional and person with long term conditions) the less work there is to do during the consultation. We said that the conversation is more about the content than the length, so the statement about 'length of the consultation' was changed to 'quality consultation'. During or after the quality conversation the person with long term conditions and the healthcare professional may collaboratively make a decision (when a decision needs to be made) and/or set goals. We agreed that for some people with long term conditions, the goal is simply to have that quality conversation. The conversation is summarised and is owned by the patient. Throughout the whole process, good communication skills are vital. If all of this is done well, support for self-management is achieved.

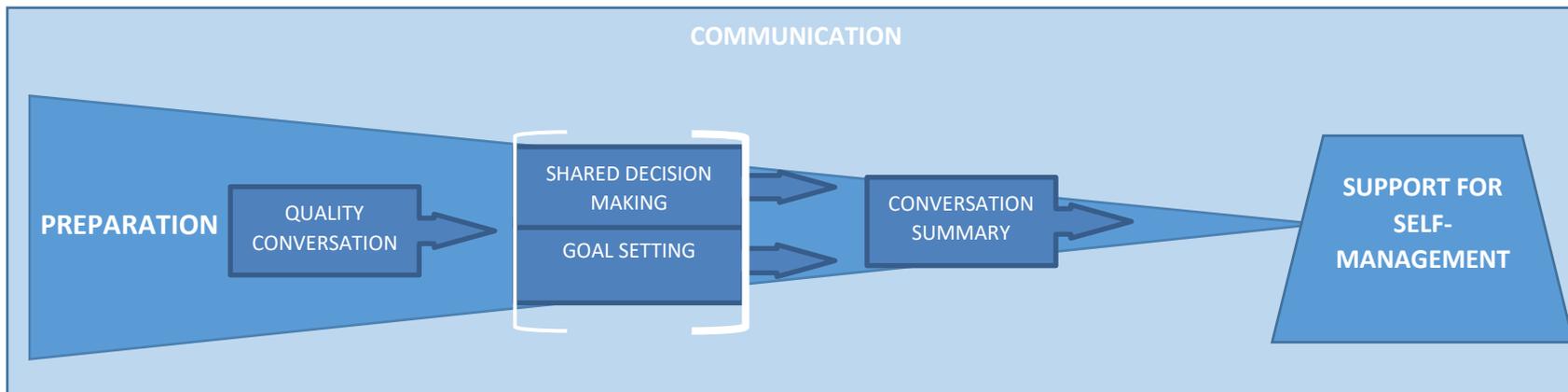
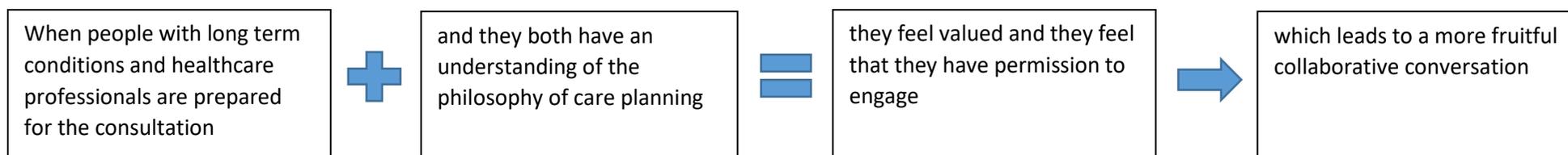


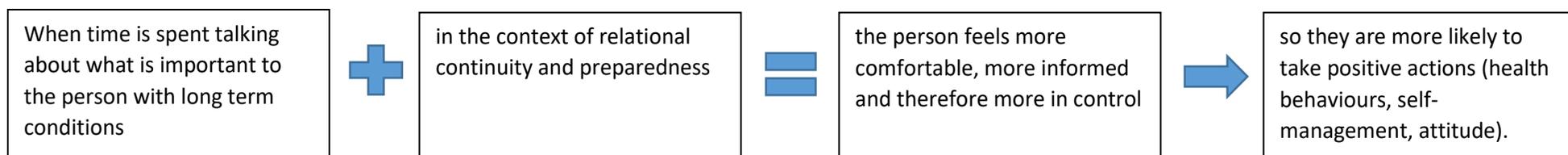
Figure 22: Diagrammatic representation of care planning

Below are the refined statements. They each follow the same structure as the coloured cards we used in the focus group: When this happens (resource)... in this context... it triggers this change in behaviour/reasoning... which leads to this outcome.

### Statement 1: Preparation

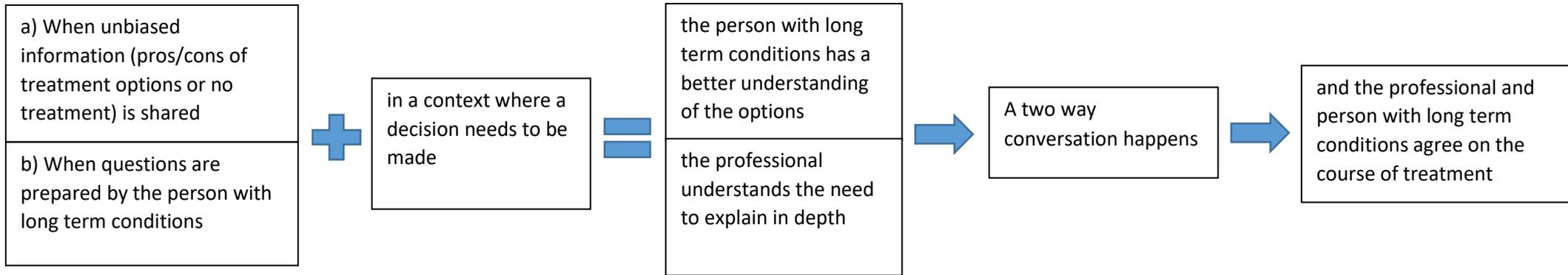


### Statement 2: Quality Conversation

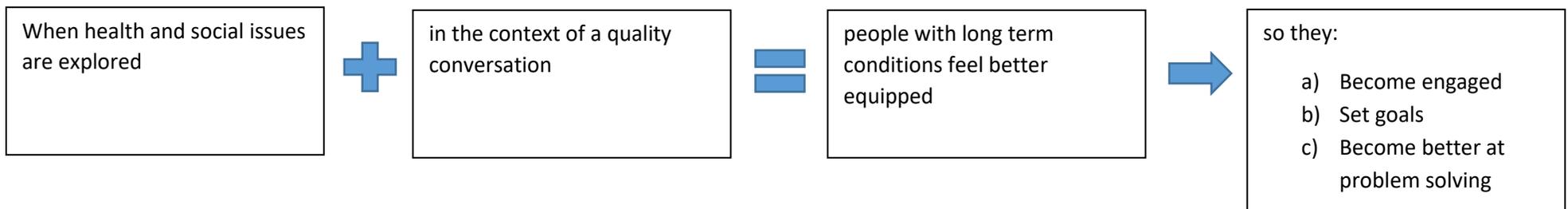


### Statement 3: Shared decision making

- a) Professional's perspective
- b) Patient's perspective

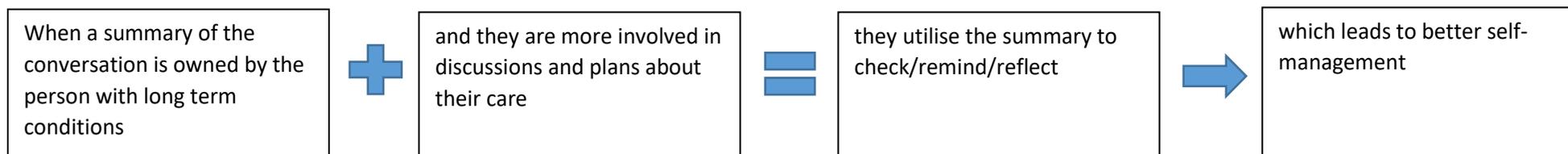


### Statement 4: Goal setting

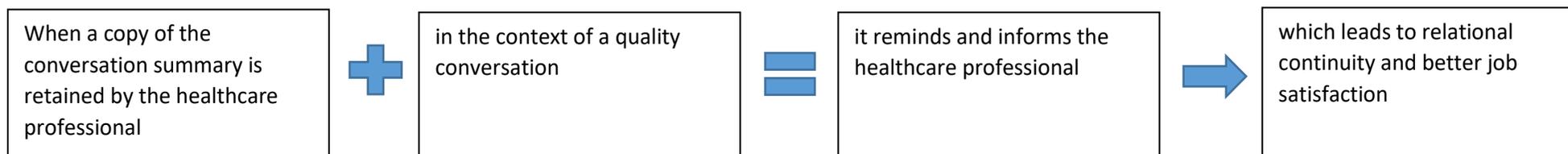


### Statement 5: Conversation summary

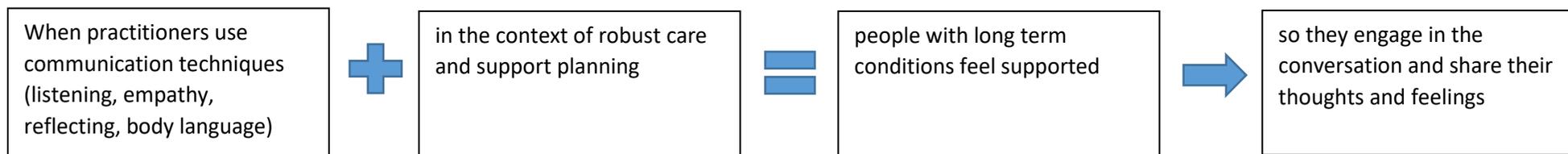
#### a) Patient's perspective



#### b) Professional's perspective



### Statement 6: Communication



### Overarching programme theory: Care planning as a tool for support for self-management

When interactions between practitioners and patients (resource) occur in an environment that is person centred, encouraging, supportive and respectful (context), patients can learn how to develop effective coping strategies and make informed decisions about their care (reasoning) in order to become effective self-managers (proximal outcome) and maintain their health (distal outcome).

## INFORMED CONSENT FORM

**Project Title:** A realist evaluation of care planning: what works, for whom, and in what circumstances?

**Principal Investigator:** Sarah Wilmot

	<i>Please tick</i>		<i>Yes</i>	<i>No</i>
I have carefully read and understood the Participant Information Sheet (version 4 dated 17/07/2017).	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
I have had an opportunity to ask questions and discuss this study and I have received satisfactory answers.	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
I understand I am free to withdraw from the study at any time, without having to give a reason for withdrawing, and without prejudice.	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
I understand that any data I provide can be withdrawn up until one month after the interview.	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in this study.	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
I agree for my interview to be recorded and for anonymised quotes to be used in the research.	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>

Signature of participant..... Date.....  (NAME IN BLOCK LETTERS).....
Signature of researcher..... Date.....  (NAME IN BLOCK LETTERS).....

## Appendix 11: Recruitment email and information sheet for implementers

Dear .....

My name is Sarah Wilmot and I am a 3rd year PhD student at Northumbria University. I am working with Dr Simon Eaton on an evaluation of care planning for people with long term conditions, and I am currently trying to articulate what the key components are. To date, I have done a detailed literature review (under review for publication), a focus group with people involved in championing care planning and have begun to test what I have learned with practitioners who implement care planning in practice. I would like to speak to 10 healthcare professionals to complete this phase of data collection and I am also hoping to observe some more care planning appointments (for theory verification rather than data collection). I would be really keen to hear your experiences of care planning. **Would you be interested in chatting to me and/or allowing me to observe a care planning consultation? (The interview would take approximately one hour, and I can come to your practice whenever is convenient for you).** I have attached an information sheet and would also be happy for you to share this email with any colleagues who may be interested.

This project will be key to helping us understand the key components and context of care planning and will support the continued and effective roll out. Ethical approval for this phase has been obtained.

Many thanks,

**Sarah Wilmot**  
**Postgraduate researcher**  
Faculty of Health and Life sciences  
Northumbria University  
Coach Lane Campus West  
Benton  
NE7 7XA

## Information Sheet for Implementers

**Study Title:** A realist evaluation of care planning: what works, for whom, and in what circumstances?

**Investigator:** Sarah Wilmot

You are being invited to take part in this research study. Before you decide it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

### What is the Purpose of the Study?

The number of people with multiple long term conditions is increasing. Care planning is being implemented in GP practices nationwide, to support people with long term conditions to effectively self-manage their condition(s). This research will provide invaluable knowledge and insight into how and why care planning works, for whom and in what circumstances.

### Why have I been invited?

You have been invited because it has been highlighted that you are implementing care planning in practice, and it would be very helpful to hear about your experiences.

### Do I have to take part?

No. It is up to you whether you would like to take part in the study. I am giving you this information sheet to help you make that decision. If you do decide to take part, remember that you can stop being involved in the study whenever you choose, without telling me why, and you can withdraw any data you provide up until one month after your interview. Deciding not to take part, or leaving the study at any point will not affect you in any way.

### What will happen if I take part?

You will be invited to attend an informal interview. I will be the interviewer and I will work with you to organise it for a suitable date and time, so that it causes minimal disruption to your work. The interview will take place at a location that is local to your workplace (to be confirmed). During the interview, you will be asked some questions about care planning. You may share your own experiences and your viewpoint and there are no right or wrong answers. With your permission, the discussions will be recorded so that I can use some quotations in my thesis.

### **What are the possible disadvantages of taking part?**

You will be asked to give up around one hour of your time.

### **What are the possible benefits of taking part?**

Your input could help healthcare professionals to provide the best support for people with long term conditions.

### **Will my taking part in this study be kept confidential and anonymous?**

Yes. The data collected in this study will be used for a PhD thesis and peer reviewed journals, but your name or any other identifying information will not be used in any publication. The consent form that you sign will be kept separate from any other information you provide. Only the research team will have access to any identifiable information.

### **How will my data be stored?**

Paper records, for example the consent forms, will be stored in a locked filing cabinet and electronic information will be stored on a password-protected computer. All information and data gathered during this research will be stored in line with university guidelines and the Data Protection Act (1998) and will be destroyed five years following the conclusion of the study. If the research is published in a scientific journal or presented at conferences it may be kept for longer before being destroyed, but at no point will your personal information or data be revealed.

### **What will happen to the results of the study?**

We will share a summary of the anonymised findings from this study with:

- Northumbria University, in the form of the PhD thesis
- Local and national NHS trusts for information purposes
- Other GP practices who might find the results helpful in developing care planning in their own practice
- Yourself; please contact me if you would like a copy of the summary.

### **Who is Organising and Funding the Study?**

I, Sarah Wilmot, am organising the study as part of my PhD. The study is being funded by Northumbria University. Should you have any queries or concern, please don't hesitate to contact myself or my academic supervisor (emails and phone numbers below).

### **Who has reviewed this study?**

This study and its protocol has received full ethical approval from the Faculty of Health and Life Sciences Research Ethics Committee, and local R&D permissions.

### **Contact for further information:**

**Researcher:** [sarah.wilmot@northumbria.ac.uk](mailto:sarah.wilmot@northumbria.ac.uk) / 07474904773

**Supervisor:** [monique.lhussier@northumbria.ac.uk](mailto:monique.lhussier@northumbria.ac.uk) / 0191 2156036

A long term condition is a condition for which there is no cure (e.g. diabetes, COPD, arthritis, hypertension, depression, dementia, asthma). It may be managed with drugs and other treatments.

Do you have a long term condition? How is your health care?

**Are you interested in sharing your views? A research study funded by Northumbria University is looking for participants.**

### **What is the focus of the research?**

The research will provide an understanding of health care for people with one or more long term condition(s).

### **Who can participate?**

Anybody that has been diagnosed with one or more long term condition(s) can participate.

### **What will I be asked to do?**

You will be required to give up around one hour of your time to meet the researcher at a location and time most convenient to you. You will be asked some questions about your health care experiences.

### **When is the research taking place?**

The research will take place between March - May 2018.

### **I want to know more, who do I contact?**

If you are interested in participating in this research study, **please contact Sarah Wilmot (researcher) on 07577461486 or [sarah.wilmot@northumbria.ac.uk](mailto:sarah.wilmot@northumbria.ac.uk)**

This study and its protocol has received full ethical approval from the Faculty of Health and Life Sciences Research Ethics Committee, and the NHS Research Ethics Committee.

**Study Title:** A realist evaluation of care planning: what works, for whom, and in what circumstances?

**Researcher:** Sarah Wilmot

## **Participant Information Sheet**

You are being invited to take part in this research study. Before you decide it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

### **What is the Purpose of the Study**

The number of people with multiple long term conditions is increasing. Care planning is being implemented in GP practices nationwide, to support people with long term conditions to effectively self-manage their condition(s). This research will provide an understanding of how and why care planning works best, for whom and in what circumstances. This knowledge will help healthcare professionals to adapt care planning, so that it works better for you.

### **Why have I been invited?**

You have been invited because it has been highlighted that you are living with one or more long term conditions, and it would be very helpful to hear about your experiences of healthcare.

### **Do I have to take part?**

No. It is up to you whether you would like to take part in the study. I am giving you this information sheet to help you make that decision. If you do decide to take part, remember that you can stop being involved in the study whenever you choose, without telling me why, and you can withdraw any data you provide up until one month after your interview. Deciding not to take part or leaving the study at any point will not affect your care in any way.

### **What will happen if I take part?**

If you decide you would like to take part, you can contact the researcher using the telephone number or email address provided at the bottom of this form. You will be invited to attend an informal interview. I will be the interviewer and I will work with you to organise it for a suitable date, and time, so that it causes minimal disruption to you. The interview will take place either at your GP surgery, at Northumbria university (coach lane campus), or at your home if you prefer. Before the interview begins, I will ask you to sign an informed consent form if you are happy to continue. During the interview, you will be asked what aspects of health care help you most in managing your long-term condition(s). You may share your own experiences and your viewpoint and there are no right or wrong answers. With your permission, the discussion will be recorded so that I can use some quotations in my thesis.

### **What are the possible disadvantages of taking part?**

You will be asked to give up around one hour of your time.

### **What are the possible benefits of taking part?**

Your input could help healthcare professionals to provide the best support for people with long term conditions.

### **Will my taking part in this study be kept confidential and anonymous?**

Yes. The data collected in this study will be used for a PhD thesis and peer reviewed journals, but your name or any other identifying information will not be used in any publication. The consent form that you sign will be kept separate from any other information you provide. Only the research team will have access to any identifiable information. The only exception to this is that I may have to share information with third parties if you tell me about harm to yourself or someone else.

### **How will my data be stored?**

Paper records, for example the consent forms, will be stored in a locked filing cabinet and electronic information will be stored on a password-protected computer. All information and data gathered during this research will be stored in line with university guidelines and the Data Protection Act (1998) and will be destroyed five years following the conclusion of the study. If the research is published in a scientific journal or presented at conferences it may be kept for longer before being destroyed, but at no point will your personal information or data be revealed.

### **What will happen to the results of the study?**

We will share a summary of the anonymised findings from this study with:

- Northumbria University, in the form of the PhD thesis
- Local and national NHS trusts for information purposes
- Other GP practices who might find the results helpful in developing care planning in their own practice
- Yourself; please contact me if you would like a copy of the summary.

### **Who is organising and funding the study?**

I, Sarah Wilmot, am organising the study as part of my PhD. The study is being funded by Northumbria University. Should you have any queries or concern, please don't hesitate to contact myself or my supervisor (emails and phone numbers below)

### **Who has reviewed this study?**

This study and its protocol has received full ethical approval from the Faculty of Health and Life Sciences Research Ethics Committee, and the NHS Research Ethics Committee.

### **Contact for further information:**

**Researcher:** [sarah.wilmot@northumbria.ac.uk](mailto:sarah.wilmot@northumbria.ac.uk) / 07577461486

**Supervisor:** [monique.lhussier@northumbria.ac.uk](mailto:monique.lhussier@northumbria.ac.uk) / 0191 2156036

**If you have any questions or concerns regarding your health care, please contact your GP.**

## Appendix 14: Interview schedule for people with LTCs

1. When you are going to an appointment about your long-term condition(s), do you prepare for it? How? Does the practice help you prepare (by sending results in advance for example)?
2. How does being prepared for your care planning appointment affect you? How does it affect the conversation?
3. Do you feel that both you and your healthcare professionals have the same understanding of how you should manage your condition(s)? Can you describe how you feel about managing your long-term condition(s)?
4. Are you sometimes given time to talk about things that might be important to you but not directly related to your condition(s) in consultations? How do you feel about this?
5. Sometimes stressful events in life can impact on how we feel about being able to look after our health. Do you feel able / are you willing to share what happens in your life with your healthcare professional?
6. Could you describe to me one healthcare professional who you really like? What do they do in the consultation that is different from others? What makes you like them?
7. Is knowing the healthcare professional well / seeing the same person every time important to you? Why?
8. Thinking about a (LTC) appointment that in your opinion went 'well', what was it like? How did it affect you? Were you able to set goals and stick to them?
9. Do you find that the way the healthcare professional communicates with you affects how you interact with them? Can you think of a time when you felt comfortable to share your thoughts and feelings with a healthcare professional? What was it that enabled you to do so?
10. Can you think about a time when you needed to come to a decision about your treatment plan? What happened in the appointment? How was a decision made?
11. After your (LTC) appointment are you given a summary of the conversation? If yes, what do you do with it?
12. Do you find that having a physical copy of the conversation helps? How? Why?

## Interview schedule for healthcare professionals

1. Do you help people with long term conditions to prepare for their care planning consultation? How?
2. Do most people prepare? What is it about those who don't prepare, compared to those who do?
3. How does preparation affect the person with long term conditions, and how does it affect you? How does it affect the conversation?
4. Do you spend time talking about things that might be important to the patient but not directly related to their condition(s)? How do you feel about this? How do you think this could affect the patient's health outcomes?
5. If you are seeing a patient for the first time, is the conversation different to conversations you have with patients you have known for a longer period of time? How? Why do you think this is?
6. Thinking about a (LTC) appointment that in your opinion went 'well', what was it like? How did it affect you and how did it affect the patient? Was the patient able to set goals and stick to them?
7. Do you find that the way you communicate with patients affects how they interact with you? Can you think of a time when a patient shared their thoughts and feelings with you - what was it that enabled them to do so?
8. Can you think about a time when a decision needed to be made about a person's treatment plan? What happened in the appointment? How was a decision made?
9. After a patient's (LTC) appointment are they given a summary of the conversation? Do you think having a physical copy of the conversation helps the person? How? Why?

## Appendix 15: Ethical approval letter phase 2



*Professor Kathleen McCourt, CBE FRCN  
Executive Dean*

This matter is being dealt with by:

*Dr Nick Neave  
Director of Ethics  
Faculty of Health & Life Sciences  
Northumberland Building  
Newcastle upon Tyne  
NE1 8ST*

15<sup>th</sup> May 2015

Dear Sarah

**Faculty of Health and Life Sciences Research Ethics Committee**

**Submission Code: HLS-PHW141523**

**Title: A realist evaluation of care planning in multimorbidities: what works, for whom and in what circumstances?**

Following independent peer review of the above proposal, I am pleased to inform you that Faculty approval has been granted on the basis of this proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent Disclosure & Barring Service (DBS) if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available on the ELP; Organisation name: HLS0002: Research Ethics and Governance

You may now also proceed with your application (if applicable) to:

- NHS R&D organisations for approval. Please check with the NHS Trust whether you require a Research Passport, Letter(s) of Access or Honorary contract(s).
- NHS or Social Care Research Ethics Committee (REC). [They will require a copy of this letter plus the ethics panel comments and your response to those comments].

You must not commence your research until you have obtained all necessary external approvals.

The University strongly advises that the supervisor accompany the student when attending an external REC.

All researchers must also notify this office of the following:

- Any significant changes to the study design, by submitting an 'Ethics Amendment Form'
- Any incidents which have an adverse effect on participants, researchers or study outcomes, by submitting an 'Ethical incident Form'
- Any suspension or abandonment of the study;

We wish you well in your research endeavours.

Yours sincerely

Dr Joanna Reynolds  
Faculty Ethics Coordinator: Department of Public Health and Wellbeing

*Vice-Chancellor and Chief Executive  
Professor Andrew Wathey*

Northumbria University is the trading name of the University of Northumbria at Newcastle

## Appendix 16: Ethical approval letter phase 3



**Professor Dianne Ford, BSc, PhD, FRSB**  
Executive Dean, Health and Life Sciences

This matter is being dealt with by:

**Dr Nick Heave**  
Director of Ethics  
Faculty of Health and Life Sciences  
Northumbria University  
Newcastle upon Tyne  
NE1 8ST, UK

E: [eth@northumbria.ac.uk](mailto:eth@northumbria.ac.uk)

W: [northumbria.ac.uk](http://northumbria.ac.uk)

12<sup>th</sup> April 2017

Dear Sarah Wilmot

Faculty of Health and Life Sciences Research Ethics Committee

Submission Code: HLSCW161707

Title: A realist evaluation of care planning: what works, for whom and in what circumstances?

Following independent peer review of the above proposal, I am pleased to inform you that Faculty approval has been granted on the basis of this proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent Disclosure & Barring Service (DBS) if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available on the ELP; Organisation name: HLS0002: Research Ethics and Governance

You may now also proceed with your application (if applicable) to:

- NHS R&D organisations for approval. Please check with the NHS Trust whether you require a Research Passport, Letter(s) of Access or Honorary contract(s).
- NHS or Social Care Research Ethics Committee (REC). (They will require a copy of this letter plus the ethics panel comments and your response to those comments).
- National Offender Management Service (NOMS) for relevant permissions.

You must not commence your research until you have obtained all necessary external approvals.

The University strongly advises that the supervisor accompany the student when attending an external REC.

All researchers must also notify this office of the following:

- Any significant changes to the study design, by submitting an 'Ethics Amendment Form'
- Any incidents which have an adverse effect on participants, researchers or study outcomes, by submitting an 'Ethical Incident Form'
- Any suspension or abandonment of the study;

We wish you well in your research endeavours.

Yours sincerely

Dr Joanna Reynolds

Faculty Ethics Coordinator: Department of Social Work, Education and Community Wellbeing

**Professor Andrew Wathey**

Vice-Chancellor and Chief Executive

Northumbria University is the trading name of the University of Northumbria at Newcastle



Health Research Authority

Miss Sarah Wilmot  
Postgraduate Researcher  
University of Northumbria at Newcastle  
Coach Lane Campus  
Benton  
Newcastle-upon-Tyne  
NE7 7XA

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

23 August 2017

Dear Miss Wilmot

**Letter of HRA Approval**

Study title:	A realist evaluation of care planning for people with long term conditions: what works, for whom and in what circumstances?
IRAS project ID:	183062
Protocol number:	N/A
REC reference:	17/SC/0301
Sponsor	University of Northumbria at Newcastle

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

**Participation of NHS Organisations In England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read Appendix B carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

#### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

#### After HRA Approval

The document ‘*After Ethical Review – guidance for sponsors and investigators*’, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

#### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

IRAS project ID	183062
-----------------	--------

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

#### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 183062. Please quote this on all correspondence.

Yours sincerely

Catherine Adams  
Senior Assessor  
Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Ms Samantha King, Sponsor's Representative*  
*Dr Shona Haining, North of England Commissioning Support (NECS)*

## Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Copies of advertisement materials for research participants [Participant recruitment poster]	3	03 July 2017
Evidence of Sponsor Insurance or indemnity (non NHS Sponsors only) [Sponsor insurance certificate]	1	30 May 2017
HRA Schedule of Events [Schedule of Events]	1.0	13 July 2017
HRA Statement of Activities [Statement of Activities]	1.0	13 July 2017
Interview schedules or topic guides for participants [Interview schedule]	2	30 May 2017
Letter from sponsor [Letter from sponsor]	1	18 July 2016
Other [NU ethics approval letter]	1	12 April 2017
Other [NU ethics amendment approval]	1	16 March 2017
Other [NU ethics amendment approval 2]	1	03 May 2017
Other [NU reviewer responses]	1	01 March 2017
Other [NU reviewer 2 responses]	1	18 February 2017
Participant consent form [Consent form]	3	17 July 2017
Participant Information sheet (PIS) [PIS]	4	17 July 2017
REC Application Form [REC_Form_31052017]		31 May 2017
Research protocol or project proposal [Research protocol]	2	30 May 2017
Summary CV for Chief Investigator (CI) [CV for CI]	1	30 May 2017
Summary CV for student [CV for student]	1	30 May 2017
Summary CV for supervisor (student research) [CV for supervisor]	1	30 May 2017

## Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS In England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.*

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Ms Samantha King  
 E-mail [samantha.king@northumbria.ac.uk](mailto:samantha.king@northumbria.ac.uk)  
 Telephone 01912437108

### HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	This application applies to Phase 4 only. Phase 3 has been confirmed as audit.
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A statement of activities will act as agreement of an NHS organisation to participate. The sponsor is not requesting and does not expect any other site agreement.  Although formal confirmation of capacity and capability is not expected of all or some organisations participating in this study (see Confirmation of Capacity and Capability section for full details), and such

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			organisations would therefore be assumed to have confirmed their capacity and capability should they not respond to the contrary, we would ask that these organisations pro-actively engage with the sponsor in order to confirm at as early a date as possible. Confirmation in such cases should be by email to the CI and Sponsor confirming participation based on the relevant Statement of Activities and Information within this Appendix B.
4.2	Insurance/Indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No funding is to be provided as confirmed in the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments

Section	HRA Assessment Criteria	Compliant with Standards	Comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

### Participating NHS Organisations in England

<p><i>This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.</i></p> <p>All organisations will be undertaking the same activity (i.e. there is only one 'site-type') as detailed in the protocol. Activity includes practice managers raising awareness about the study with team members to signpost to the study and display a poster</p> <p>The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.</p> <p>If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at <a href="mailto:hra.approval@nhs.net">hra.approval@nhs.net</a>. The HRA will work with these organisations to achieve a consistent approach to information provision.</p>
--

### Confirmation of Capacity and Capability

<p><i>This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.</i></p> <p>The HRA has determined that participating NHS organisations in England are <b>not expected to formally confirm their capacity and capability to host this research</b>, because study involvement is limited to sign-posting.</p> <ul style="list-style-type: none"> <li>• The HRA has informed the relevant research management offices that you intend to undertake the research at their organisation. However, you should still support and liaise with these organisations as necessary.</li> <li>• Following issue of the HRA Approval letter, and subject to the two conditions below, it is expected that these organisations will become participating NHS organisations 35 days after issue of this Letter of HRA Approval (no later than 27<sup>th</sup> September 2017):             <ul style="list-style-type: none"> <li>○ You may not include the NHS organisation if they provide justification to the sponsor and the HRA as to why the organisation cannot participate</li> <li>○ You may not include the NHS organisation if they request additional time to confirm,</li> </ul> </li> </ul>
--

until they notify you that the considerations have been satisfactorily completed.

- You may include NHS organisations in this study in advance of the deadline above where the organisation confirms by email to the CI and sponsor that the research may proceed.
- The document "[Collaborative working between sponsors and NHS organisations in England for HRA Approval studies, where no formal confirmation of capacity and capability is expected](#)" provides further information for the sponsor and NHS organisations on working with NHS organisations in England where no formal confirmation of capacity and capability is expected, and the processes involved in adding new organisations. Further study specific details are provided the *Participating NHS Organisations and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this Appendix.

**Principal Investigator Suitability**

*This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).*

A local PI is expected at participating organisations to co-ordinate the signposting activity. GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

**HR Good Practice Resource Pack Expectations**

*This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken*

Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to contact the local primary care research management function to follow local processes in obtaining a Letter of Access based on standard DBS checks and occupational health clearance.

**Other Information to Aid Study Set-up**

*This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.*

The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.

## Appendix 18: NHS research passport approval letter

NECS Researcher Access Assurance Letter (version 4.0, February 2017)



### North of England Commissioning Support Unit

Tuesday 6<sup>th</sup> March 2018

Sarah Wilmot  
214 Kings Close  
Lazenby  
Middlesborough  
TS6 8FA

NECS Research and Evidence Team  
2<sup>nd</sup> Floor  
Riverside House  
Goldcrest Way  
Newburn Riverside  
Newcastle upon Tyne  
NE15 8NY

Tel: (0191) 217 2586  
E-mail: [NECSU.researchanddevelopment@nhs.net](mailto:NECSU.researchanddevelopment@nhs.net)

Dear Sarah

**Study Title:** A realist evaluation of care planning: what works for whom, and in what circumstances?

**Ref:** 183062

The information supplied about your role in the above research has been reviewed by the North of England Commissioning Support Unit. We provide research assurance to Primary Care Providers in Northumberland Tyne and Wear, County Durham and Tees Valley and North Cumbria.

I can confirm that evidence of checks, as deemed commensurate with your research activity, has been provided and deemed acceptable.

This letter provides assurance that the necessary checks and clearances as required for your research activity in the following CCGs are in place:

**NHS Newcastle Gateshead CCG**  
**NHS North Tyneside CCG**

This assurance is valid for the duration of the research or until expiry of any Occupational Health or DBS clearance (duration 3 years), whichever is earlier. Evidence of updated clearances should be provided to Research and Evidence to ensure your assurance continues.

Should your role in the research change, it may be necessary to review these checks and assurances.

Hosted by NHS England



You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act and any local or regulatory requirements whilst on GP Practice premises.

Your substantive employer remains responsible for your conduct during this research project.

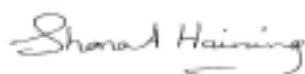
**NB: NECS/Health Research Authority assurance for the research study must be in place prior to commencement of your role.**

**This letter does not place any obligations on Primary Care Providers to allow you access to staff, patients, information or premises.**

If you require advice in relation to the conduct of the research within the above organisations please contact the NECS Research and Evidence Office.

May I take this opportunity to wish you well in your research role.

Yours sincerely



Shona A Haining BSc PhD  
Head of Research & Evidence  
North of England Commissioning Support



Appendix 19: RRR article information

**Table 5: Information about empirical research studies included in the review**

<b>Authors</b>	<b>Title</b>	<b>Type of paper</b>	<b>Sample</b>	<b>LTCs</b>	<b>Methods</b>	<b>Outcome measures</b>	<b>PT</b>
Battersby et al.	SA HealthPlus: a controlled trial of a statewide application of a generic model of chronic illness care.	Original research	3,115 intervention patients, 1,448 controls	Not specified	Quantitative analysis, interviews and focus groups with patients, GPs and service coordinators, document analysis and case studies	Health status, resource use, personal outcomes	3
Blakeman et al.	A qualitative study of GPs' attitudes to self-management of chronic disease.	Original research	16 GPs	N/A	Semi-structured interviews	Personal outcomes/ knowledge of the facilitation and barriers to self-management, knowledge and attitudes of the General Medical Services contract and the Expert Patients Program	2, 6
Bower et al.	Care planning in the treatment of long term conditions – final report of the CAPITOL project.	Original research	2439 patients	Multimorbidity	Review of care plans and care planning, exploratory qualitative work, secondary analysis	Self-reported vitality, QoF scores, health status, quality of life, condition specific outcomes	2, 3, 4, 5, 6

					of data, quantitative and qualitative studies to examine outcomes of care plans and care planning	(HbA1c control), self-efficacy, self-management behaviours, resource use	
Chew-Graham et al.	How QOF is shaping primary care review consultations: a longitudinal qualitative study.	Original research	34 patients,	Asthma, COPD, CHD, diabetes	Audio recordings of consultations, semi-structured interviews	Patient/healthcare professional interactions	4
Deacon & Rickards.	A job description for the effective self-management of a long-term condition: experiences of living with difficult asthma.	Study report	4	Asthma	Secondary analysis of focus group data	Experiences of physical, emotional and social being	4
Entwistle & Cribb.	Enabling People to Live Well.	Original research	Not specified	Not specified	Knowledge exchange events	Personal experiences of 'collaborative' approaches in the management of long-term conditions	3
Fuller et al.	Is client-centered care planning for chronic disease sustainable?	Original research	40	Not specified	Semi-structured interviews and focus groups	Satisfaction with the client-centred care planning and	7

	Experience from rural South Australia.					self-management approach used	
Glasgow et al.	Randomized effectiveness trial of a computer-assisted intervention to improve diabetes care.	Randomized effectiveness trial	886 patients, 52 primary care physicians	Diabetes	Implementation of the Diabetes Priority Program	Number of recommended lab screenings, recommended patient-centred care activities, lipids, HbA1c levels, quality of life, depression score	3
Hart.	Therapeutic effectiveness of setting and monitoring goals.	Original research	32 patients	Not specified	Implementation of a goal attainment model	Behaviour change, goal attainment scores	3
Hong et al.	Providing diabetes patients with personalized written clinical information in the diabetes outpatient clinic: a pilot study.	Original research	106 patients	Diabetes	Personalized clinical information was given to one group prior to their consultations. Controls were not given any information.	Conversation time, overall consultation time, number of topics raised by the patient	1, 2
Kennedy et al.	Implementing, embedding and integrating self-management support tools for people with long term conditions in	Original research	37 healthcare professionals	N/A	Semi-structured interviews	Experiences of the implementation of a self-management support approach	6

	primary care nursing: A qualitative study.						
Lawn et al.	Control in chronic condition self-care management: how it occurs in the health worker-client relationship and implications for client empowerment.	Original research	19 consultations from 2 GP surgeries	Not specified	Ethnographic observations and audio recordings of consultations	Body language, overall impression of the interactions	4
Lloyd et al.	Patchy 'coherence': using normalization process theory to evaluate a multi-faceted shared decision making implementation program (MAGIC).	Original research	31 healthcare professionals	N/A	Semi-structured interviews	Attitudes towards shared decision making	6
Lown et al.	Mutual influence in shared decision making: a collaborative study of patients and physicians.	Original research	85 patients and healthcare professionals	Not specified	Research work groups	Attitudes and behaviors that facilitate shared decision making	4, 6
Macdonald.	Origins of difficulty in the nurse-patient encounter.	Original research	12 patients and 10 nurses	Not specified	Observation and semi-structured interviews	Personal experiences of nurse-patient encounters	4

Mercer et al.	Patient enablement requires physician empathy: a cross-sectional study of general practice consultations in areas of high and low socioeconomic deprivation in Scotland.	Original research	3,044	Multimorbidity	Questionnaire	Patient enablement, GP empathy	4
Newbould et al.	Experiences of care planning in England: interviews with patients with long term conditions.	Original research	23 patients	Multimorbidity	Semi-structured interviews	Personal experiences of care planning	2
Noël et al.	The Challenges of Multimorbidity from the Patient Perspective.	Original research	720 patients	Single and multiple LTCs	Cross-sectional survey	Number of contacts with healthcare providers, self-management learning needs, willingness to see non-physician providers	2, 4
Reeve et al.	From personal challenge to technical fix: the risks of depersonalized care.	Original research	27 patients	Advanced cancer	Semi-structured interviews	Personal experiences of living with illness and related distress	7

Ross et al.	Learning from people with long-term conditions: new insights for governance in primary healthcare.	Original research	32 patients, 56 healthcare professionals	Not specified	Documentary analysis, semi-structured interviews	Patients' experiences of receiving care, professionals' experiences of governance and incentives	7
Russell et al.	Beyond fighting fires and chasing tails? Chronic illness care plans in Ontario, Canada.	Original research	20 patients, 13 healthcare professionals	Not specified	Semi-structured interviews	Experiences of a LTC management initiative	6
Schillinger et al.	Effects of self-management support on structure, process, and outcomes among vulnerable patients with diabetes: a threearm practical clinical trial.	Original research	339 patients	Diabetes	Implementation of two self-management support strategies	Structure, communication processes, and behavioural, functional and metabolic changes	3
Tribal Consulting.	Evaluating the Delivery and Impact of the 'Year of Care for Diabetes': Project Interim Report.	Original research	1,900+ patient responses, 51 GP practice responses, 3 case studies	Diabetes	Site visits, case studies, quantitative data collection	Overall satisfaction with the service, empathy and enablement, quality of life, number of visits to GP surgery	1, 2

Year of Care.	Report of findings from the pilot program.	Original research	3 pilot sites	Diabetes	Semi-structured interviews, group discussions, working groups, focus groups, learning events, email correspondence, document analysis, case studies, questionnaires	Personal experiences and satisfaction with the service, health status, change in key indicators across time	1, 2, 3, 7
---------------	--	-------------------	---------------	----------	---	---	------------

**Table 6: Information about other papers included in the review**

<b>Authors</b>	<b>Title</b>	<b>Type of paper</b>	<b>PT</b>
Ahmad et al.	Person-centred care: from ideas to action.	Systematic review	6
Batterham et al.	The OPTimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform.	Research protocol	4
Bodenheimer et al.	Helping patients manage their chronic conditions.	Information piece	7
Boger et al.	Self-management and self-management support outcomes: A systematic review and mixed research synthesis of stakeholder views.	Systematic review	7

Coulter et al.	'Effectiveness of strategies for informing, educating, and involving patients'.	Policy overview	2, 4
Coulter.	Implementing shared decision making in the UK. A report for the Health Foundation.	Scoping paper	1, 4
Coulter & Collins.	Making shared decision-making a reality: No decision about me, without me.	Information piece	6
Coulter et al.	Personalized care planning for adults with chronic or long-term health conditions.	Systematic review	5, 7
Doherty et al.	Diabetes Year of Care: The Key Drivers and Theoretical Basis for a Shift in Diabetes Care.	Theoretical paper	1, 2
Effing et al.	Self-management education for patients with chronic obstructive pulmonary disease.	Systematic review	5
Elwyn et al.	Shared decision making: a model for clinical practice.	Guidance for healthcare professionals	6
Epstein & Street.	Patient-centred Communication in Cancer Care: Promoting Healing and Reducing Suffering.	Monograph	4
Gibson et al.	<i>Self-management education and regular practitioner review for adults with asthma (Cochrane review).</i>	Systematic review	5
Gibson & Powell.	Written action plans for asthma: an evidence-based review of the key components.	Evidence-based review	5
Harding et al.	The state of play in person-centred care: A pragmatic review of how	Pragmatic review	4

	person-centred care is defined, applied and measured.		
Hibbard & Gilbert.	Supporting people to manage their health – an introduction to patient activation.	Information piece	7
Langford et al.	Patient-centred goal setting as a tool to improve diabetes self-management.	Information piece	3
Lhussier et al.	Care planning for long-term conditions – a concept mapping.	Systematic review	1, 5, 6
Luxford & Newell.	New South Wales mounts “patient based care” challenge.	Information piece	4
Makoul & Clayman.	An Integrative model of shared decision making in medical encounters.	Systematic review	6
Mathers et al.	Care Planning: Improving the lives of people with long term conditions.	Guidance for healthcare professionals	1, 3
Morton & Morgan.	Examining how personalized care planning can help patients with long term conditions.	Information piece	1
Rijken et al.	Chronic Disease Management Programmes: an adequate response to patients' needs?	Reflection paper	7
Ryan & Deci.	Self-Determination Theory and the facilitation of intrinsic motivation, social development and wellbeing.	Theoretical paper	7
Street et al.	How does communication heal? Pathways linking clinician-patient communication to health outcomes.	Information piece	4
WHO.	Preventing chronic diseases. Preparing a health care workforce.	Information piece	7

## References

- ACTION ON SMOKING AND HEALTH. 2015. *Smoking: Long term conditions* [Online]. Available: <http://ash.org.uk/information-and-resources/health-inequalities/health-inequalities-resources/smoking-and-long-term-conditions/> [Accessed 4 November 2018].
- AHMAD, N., ELLINS, J., KRELLE, H., LAWRIE, M. 2014. Person-centred care: from ideas to action. *The Health Foundation*. October ed.
- AIDEN, H. 2018. Multimorbidity: Understanding the challenge. The Richmond Group of Charities.
- ANDRE, F. E., BOOY, R., BOCK, H. L., CLEMENS, J., DATTA, S. K., JOHN, T. J., LEE, B. W., LOLEKHA, S., PELTOLA, H., RUFF, T. A., SANTOSHAM, M. & SCHMITT, H. J. 2008. Vaccination greatly reduces disease, disability, death and inequity worldwide. *Bulletin of the World Health Organization* [Online], 86. Available: <https://www.who.int/bulletin/volumes/86/2/07-040089/en/> [Accessed 17 February 2019].
- ARCHER, M. 1995. *Realist Social Theory: the Morphogenic Approach*, Cambridge, Cambridge University Press.
- AROKIASAMY, P., UTTAMACHARYA, U., JAIN, K., BIRITWUM, R. B., YAWSON, A. E., WU, F., GUO, Y., MAXIMOVA, T., ESPINOZA, B. M., SALINAS RODRÍGUEZ, A., AFSHAR, S., PATI, S., ICE, G., BANERJEE, S., LIEBERT, M. A., SNODGRASS, J. J., NAIDOO, N., CHATTERJI, S. & KOWAL, P. 2015. The impact of multimorbidity on adult physical and mental health in low- and middle-income countries: what does the study on global ageing and adult health (SAGE) reveal? *BMC Medicine*, 13, 178.
- ASTBURY, B. & LEEUW, F. L. 2010. Unpacking black boxes: mechanisms and theory building in evaluation. *Am J Eval*, 31.
- BARNETT 2018. Person-centred over patient-centred care: not just semantics. *The Pharmaceutical Journal*, 10.
- BARNETT, K., MERCER, S. W., NORBURY, M., WATT, G., WYKE, S. & GUTHRIE, B. 2012. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet*, 380, 37-43.
- BARRY, M. J. & EDGMAN-LEVITAN, S. 2012. Shared decision making--pinnacle of patient-centered care. *N Engl J Med*, 366, 780-1.
- BATTERHAM, R. W., BUCHBINDER, R., BEAUCHAMP, A., DODSON, S., ELSWORTH, G.R., OSBORNE, R.H. 2014. The Optimising HEalth LterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health*, 14.
- BATTERSBY, M., HARVEY, P., MILLS, P.D., KALUCY, E., POLS, R.G., FRITH, P.A. 2007. SA HealthPlus: a controlled trial of a statewide application of a generic model of chronic illness care. *The Millbank Quarterly*, 85, 37-67.
- BEEBE, C. A. & SCHMITT, S. 2011. Engaging Patients in Education for Self-Management in an Accountable Care Environment. *Clinical Diabetes*, 29, 123-126.
- BERKMAN, N. D., SHERIDAN, S. L., DONAHUE, K. E., HALPERN, D. J. & CROTTY, K. 2011. Low health literacy and health outcomes: an updated systematic review. *Annals of internal medicine*, 155, 97-107.
- BERNELL, S. & HOWARD, S. W. 2016. Use Your Words Carefully: What Is a Chronic Disease? *Frontiers in public health*, 4, 159-159.
- BERWICK, D. 2013. A promise to learn – a commitment to act: Improving the safety of patients in England. London: Williams Lea.
- BHASKAR, R. 1978. *A realist theory of science*, Brighton, Harvester Press.
- BHASKAR, R. 1979. *The Possibility of Naturalism: A philosophical Critique of the Contemporary Human Sciences*, Brighton, Harvester Press.
- BHASKAR, R. 1986. *Scientific Realism and Human Emancipation*, London, Verso.

- BHASKAR, R. 2002. *From Science to Emancipation: Alienation and the Actuality of Enlightenment*, Thousand Oaks, CA, Sage.
- BIRCHER, J. & KURUVILLA, S. 2014. Defining health by addressing individual, social, and environmental determinants: new opportunities for health care and public health. *Journal of public health policy*, 35, 363-386.
- BIRCKMAYER, J. D. & WEISS, C. H. 2000. Theory-based evaluation in practice: what do we learn? *Evaluation review*, 24, 407-431.
- BLAKEMAN, T., MACDONALD, W., BOWER, P., GATELY, C., CHEW-GRAHAM, G. 2006. A qualitative study of GPs' attitudes to self-management of chronic disease. *British Journal of General Practice*, 56, 407-414.
- BOGER, E., ELLIS, J., LATTER, S., FOSTER, C., KENNEDY, A., JONES, F., FENERTY, V., KELLAR, I., DEMAIN, S. 2015. Self-management and self-management support outcomes: A systematic review and mixed research synthesis of stakeholder views. *PLoS ONE*, 10.
- BOWER, P., REEVES, D., ROLAND, M., BLAKEMAN, T., PROTHEROE, J., ROGERS, A., KENNEDY, A., SIBBALD, B., RICHARDSON, G. 2013. Care planning in the treatment of long term conditions – final report of the CAPITOL project.
- BOYD, K. M. 2000. Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts. *Medical Humanities*, 26, 9-17.
- BRINDLEY, M. 2011. Are Aneurin Bevan's principles still relevant in today's NHS? *Wales Online*.
- BRINKMANN, J. T. 2018. Patient, Client, or Customer: What Should We Call the People We Work With? *The O&P Edge*. Northglenn, CO: Western Media LLC.
- BRITISH HEART FOUNDATION 2011. *The National Audit of Cardiac Rehabilitation. Annual Statistical Report*, London, British Heart Foundation.
- BROWN, S., LHUSSIER, M., DALKIN, S. & EATON, S. 2018. Care Planning: What Works, for Whom and in What Circumstances? A Rapid Realist Review. *Qualitative Health Research*, 28, 2250-2266.
- BUFFEL DU VAURE, C., RAVAUD, P., BARON, G., RAVAUD, P., BARON, G., BARNES, C., GILBERG, S. & BOUTRON, I. 2016. Potential workload in applying clinical practice guidelines for patients with chronic conditions and multimorbidity: a systematic analysis. *BMJ Open*, 6.
- BURKE, H., LEONARDI-BEE, J., HASHIM, A., PINE-ABATA, H., CHEN, Y., COOK, D. G., BRITTON, J. R. & MCKEEVER, T. M. 2012. Prenatal and passive smoke exposure and incidence of asthma and wheeze: systematic review and meta-analysis. *Pediatrics*, 129, 735-44.
- BURT, J., ROLAND, M., PADDISON, C., REEVES, D., CAMPBELL, J., ABEL, G. & BOWER, P. 2012. Prevalence and benefits of care plans and care planning for people with long-term conditions in England. *Journal of health services research & policy*, 17, 64-71.
- CAHIR, C., BENNETT, K., TELJEUR, C. & FAHEY, T. 2014. Potentially inappropriate prescribing and adverse health outcomes in community dwelling older patients. *British Journal of Clinical Pharmacology*, 77, 201-210.
- CARE QUALITY COMMISSION 2016. Better care in my hands: A review of how people are involved in their care.
- CAREL, H. 2019. *Illness: The cry of the flesh (3rd ed.)*, London, Routledge.
- CARRIER, J. 2009. *Managing Long-term Conditions and Chronic Illness in Primary Care: A guide to good practice*, Oxon, Routledge.
- CDC. 2016. *Chronic Disease Overview* [Online]. Available: <http://www.cdc.gov/chronicdisease/overview/index.htm> [Accessed 15 February 2019].
- CDC. 2018. *About Chronic Diseases* [Online]. Available: <https://www.cdc.gov/chronicdisease/about/index.htm> [Accessed 16 February 2019].
- CENTERS FOR MEDICARE AND MEDICAID SERVICES. 2015. *Multiple Chronic Conditions* [Online]. Available: [https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-reports/Chronic-Conditions/MCC\\_Main.html](https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-reports/Chronic-Conditions/MCC_Main.html) [Accessed 14 October 2018].
- CHEN, H.-T. & ROSSI, P. H. 1987. The theory-driven approach to validity. *Evaluation and program planning*, 10, 95-103.

- CHEN, H. T. & CHEN, H.-T. 2005. *Practical program evaluation: Assessing and improving planning, implementation, and effectiveness*, Sage.
- CHEW-GRAHAM, C., HUNTER, C., LANGER, S., STENHOFF, A., DRINKWATER, J., GUTHRIE, E.A., SALMON, P. 2013. How QOF is shaping primary care review consultations: a longitudinal qualitative study. *BMC Family Practice*, 14.
- CHURCHILL, N. 2018. The Long Term Plan for tackling health inequalities. NHS England.
- CLARK, A. 2015. *Critical realism and realist evaluation: An overview for everyone [webinar]* [Online]. Available: <https://www.youtube.com/watch?v=8Y3oVV5KxeU&feature=youtu.be> [Accessed 17 July 2015].
- COLLIER, A. 1994. *Critical Realism: an Introduction to Roy Bhaskar's Philosophy*, London, Verso.
- CONNOLLY, A. M., BAKER, A. & FELLOWS, C. 2017. Understanding health inequalities in England. Public Health Matters Public Health England.
- CORBIN, J. & STRAUSS, A. 2008. Basics of qualitative research: Techniques and procedures for developing grounded theory, 3rd ed. *Basics of qualitative research: Techniques and procedures for developing grounded theory, 3rd ed.* Thousand Oaks, CA, US: Sage Publications, Inc.
- COULTER, A. 2009. Implementing shared decision making in the UK. A report for the Health Foundation.
- COULTER, A., & COLLINS, A. 2011. *Making shared decision-making a reality: No decision about me, without me*, London, The King's Fund.
- COULTER, A., ELLINS, J. 2007. 'Effectiveness of strategies for informing, educating, and involving patients'. *British Medical Journal*, 335, 24-27.
- COULTER, A., ENTWISTLE, V. A., ECCLES, A., RYAN, S., SHEPPERD, S. & PERERA, R. 2015. Personalised care planning for adults with chronic or long-term health conditions. *Cochrane Database of Systematic Reviews*.
- COULTER, A., ROBERTS, S. & DIXON, A. 2013. Delivering better services for people with long-term conditions: building the house of care. London: The King's Fund.
- DALKIN, S. M., GREENHALGH, J., JONES, D., CUNNINGHAM, B. & LHUSSIER, M. 2015. What's in a mechanism? Development of a key concept in realist evaluation. *Implementation Science*, 10.
- DE SILVA, D. 2011. *Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management*, Health Foundation.
- DEACON, M. & RICKARDS, E. 2013. A job description for the effective self-management of a long-term condition: experiences of living with difficult asthma. *Contemporary Nurse*, 44, 76-86.
- DEMAIN, S., GONÇALVES, A.-C., AREIA, C., OLIVEIRA, R., MARCOS, A. J., MARQUES, A., PARMAR, R. & HUNT, K. 2015. Living With, Managing and Minimising Treatment Burden in Long Term Conditions: A Systematic Review of Qualitative Research. *PLOS ONE*, 10, e0125457.
- DEPARTMENT OF HEALTH 2000. The NHS Plan: a plan for investment, a plan for reform. Norwich: HMSO.
- DEPARTMENT OF HEALTH. 2001a. *The expert patient: a new approach to chronic disease management for the 21st century* [Online]. London: Department of Health. Available: [www.doh.gov.uk/healthinequalities/ep\\_report.pdf](http://www.doh.gov.uk/healthinequalities/ep_report.pdf) [Accessed].
- DEPARTMENT OF HEALTH 2001b. National Service Framework for Diabetes: Standards. London: Department of Health.
- DEPARTMENT OF HEALTH 2003. National Service Framework for Diabetes: Delivery Strategy.
- DEPARTMENT OF HEALTH 2004. *Chronic Disease Management – A compendium of information*, London, Department of Health.
- DEPARTMENT OF HEALTH 2008. *High Quality Care For All: NHS Next Stage Review final report*, London, The Stationery Office.
- DEPARTMENT OF HEALTH 2010. Equity and excellence: Liberating the NHS.
- DEPARTMENT OF HEALTH 2012a. Long Term Conditions Compendium of Information, Third Edition.

- DEPARTMENT OF HEALTH 2012b. *The Power of Information: Putting all of us in control of the health and care information we need*, London, Department of Health.
- DEPARTMENT OF HEALTH AND SOCIAL CARE 2015a. 2010 to 2015 government policy: long term health conditions
- DEPARTMENT OF HEALTH AND SOCIAL CARE. 2015b. *The NHS Constitution for England* [Online]. Available: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england> [Accessed 21 December 2018].
- DODSON, S., GOOD, S. & OSBORNE, R. 2015. *Health literacy toolkit for low and middle-income countries: a series of information sheets to empower communities and strengthen health systems*, New Dehli, India, World Health Organisation, Regional Office for South-East Asia.
- DOHERTY, Y., LUDBROOK, S., TURNBULL, R. & LEWIS-BARNED, N. 2012. Diabetes Year of Care: The Key Drivers and Theoretical Basis for a Shift in Diabetes Care. *Practical Diabetes*, 29.
- DONALDSON, S. 2007. *Donaldson, S. I. (2007). Program theory-driven evaluation science: Strategies and applications. Mahwah, NJ: Erlbaum.*
- DUERDEN, M., AVERY, T. & PAYNE, R. 2013. Polypharmacy and medicines optimisation – making it safe and sound.
- EASTWOOD, J. G., JALALUDIN, B. B. & KEMP, L. A. 2014. Realist explanatory theory building method for social epidemiology: a protocol for a mixed method multilevel study of neighbourhood context and postnatal depression. *Springerplus*, 3, 12.
- EATON, S., ROBERTS, S. & TURNER, B. 2015. Delivering person centred care in long term conditions. *BMJ*, 350.
- EFFING, T., MONNINKHOF, E. M., VAN DER VALK, P. D., VAN DER PALEN, J., VAN HERWAARDEN, C. L., PARTRIDGE, M. R., WALTERS, E. H. & ZIELHUIS, G. A. 2007. Self-management education for patients with chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, 17.
- ELWYN, G., FROSCHE, D., THOMPSON, R., JOSEPH-WILLIAMS, N., LLOYD, A., KINNERSLEY, P., CORDING, E., TOMSON, D., DODD, C., ROLLNICK, S., EDWARDS, A. & BARRY, M. 2012. Shared decision making: a model for clinical practice. *Journal of General Internal Medicine* 27.
- EMMEL, N. 2013. *Sampling and choosing cases in qualitative research: A realist approach*, London, Sage.
- ENG, C., KRAMER, C. K., ZINMAN, B. & RETNAKARAN, R. 2014. Glucagon-like peptide-1 receptor agonist and basal insulin combination treatment for the management of type 2 diabetes: a systematic review and meta-analysis. *The Lancet*, 384, 2228-2234.
- ENTWISTLE, V. A. & CRIBB, A. 2013. *Enabling People to Live Well*. The Health Foundation.
- EPSTEIN, R. & STREET, L. 2007. *Patient-centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. Bethesda, MD: National Cancer Institute.
- ETON, D. T., RAMALHO DE OLIVEIRA, D., EGGINTON, J., RIDGEWAY, J., ODELL, L., MAY, C. & MONTORI, V. 2012. Building a measurement framework of burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient Related Outcome Measures*, 3, 39-49.
- FORD, J. A., WONG, G., JONES, A. P. & STEEL, N. 2016. Access to primary care for socioeconomically disadvantaged older people in rural areas: a realist review. *BMJ Open*, 6, e010652.
- FRANCIS, R. 2013. *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. London: TSO.
- FULLER, J., HARVEY, P. & MISAN, G. 2004. Is client-centred care planning for chronic disease sustainable? Experience from rural South Australia. *Health & Social Care in the Community*, 12, 318-326.
- GALLACHER, K., MAY, C. R., MONTORI, V. M. & MAIR, F. S. 2011. Understanding patients' experiences of treatment burden in chronic heart failure using normalization process theory. *Annals of family medicine*, 9, 235-243.

- GIBSON, P. G. & POWELL, H. 2004. Written action plans for asthma: an evidence-based review of the key components. *Thorax*, 59, 94-99.
- GIBSON, P. G., POWELL, H., COUGHLIN, J., WILSON, A. J., ABRAMSON, M., HAYWOOD, P., BAUMAN, A., HENSLEY, M. J. & WALTERS, E. H. 2003. Self-management education and regular practitioner review for adults with asthma (Cochrane review). *Cochrane Database of Systematic Reviews*.
- GIDDENS, A. 1984. *The Constitution of Society*, Berkeley, University of California Press.
- GILLAM, S. & STEEL, N. 2013. QOF points: valuable to whom? *BMJ*, 346, 21-23.
- GLASER, B. G. 1965. The constant comparative method of qualitative analysis. *Social problems*, 12, 436-445.
- GLASGOW, R. E., NUTTING, P. A., KING, D. K., NELSON, C. C., CUTTER, G. & GAGLIO, B. 2005. Randomized effectiveness trial of a computer-assisted intervention to improve diabetes care. *Diabetes Care*, 28, 33-39.
- GRAFFY, J., EATON, S., STURT, J. & CHADWICK, P. 2009. Personalized care planning for diabetes: policy lessons from systematic reviews of consultation and self-management interventions. *Primary Health Care Research & Development*, 10, 210-222.
- GREAT BRITAIN 1998. Data Protection Act. London: Stationary Office.
- GREENHALGH, T., HUMPHREY, C., HUGHES, J., MACFARLANE, F., BUTLER, C. & PAWSON, R. 2009. How do you modernize a health service? A realist evaluation of whole-scale transformation in London. *The Milbank Quarterly*, 87, 391-416.
- GREENHALGH, T., ROBERT, G., BATE, P., KYRIAKIDOU, O., MACFARLANE, F. & PEACOCK, R. 2004. How to Spread Good Ideas: A systematic review of the literature on diffusion, dissemination and sustainability of innovations in health service delivery and organisation. National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO).
- GREENWOOD, B. 2014. The contribution of vaccination to global health: past, present and future. *Philosophical transactions of the Royal Society of London. Series B, Biological sciences*, 369, 20130433.
- GUBA, E. & LINCOLN, Y. 1989. *Fourth generation evaluation*, Newbury Park, CA, Sage.
- GUEST, G., BUNCE, A. & JOHNSON, L. 2006. How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field Methods*, 18, 59-82.
- GUTHRIE, B., MAKUBATE, B., HERNANDEZ-SANTIAGO, V. & DREISCHULTE, T. 2015. The rising tide of polypharmacy and drug-drug interactions: population database analysis 1995–2010. *BMC Medicine*, 13.
- GUTHRIE, B., MCCOWAN, C., DAVEY, P., SIMPSON, C. R., DREISCHULTE, T. & BARNETT, K. 2011. High risk prescribing in primary care patients particularly vulnerable to adverse drug events: cross sectional population database analysis in Scottish general practice. *BMJ*, 342, 3514.
- GUTHRIE, B., PAYNE, K., ALDERSON, P., MCMURDO, M. & MERCER, S. 2012. 'Adapting clinical guidelines to take account of multimorbidity'. *BMJ*, 345, 6341-6341.
- HADDAD, M. 2010. Caring for patients with long-term conditions and depression. *Nursing Standard*, 24, 40-49.
- HALPIN, D. 2008. COPD. *Journal of Chronic Obstructive Pulmonary Disease*, 5, 187-200.
- HAM, C., DIXON, A. & BROOKE, B. 2012. Transforming the delivery of health and social care: the case for fundamental change. The King's Fund.
- HANLON, P., NICHOLL, B. I., JANI, B. D., MCQUEENIE, R., LEE, D., GALLACHER, K. I. & MAIR, F. S. 2018. Examining patterns of multimorbidity, polypharmacy and risk of adverse drug reactions in chronic obstructive pulmonary disease: a cross-sectional UK Biobank study. *BMJ Open*, 8, e018404.
- HARDING, E., WAIT, S. & SCRUTTON, J. 2015. The state of play in person-centred care: A pragmatic review of how person-centred care is defined, applied and measured. The Health Foundation.

- HART, R. R. 1978. Therapeutic effectiveness of setting and monitoring goals. *Journal of Consulting and Clinical Psychology*, 46, 1242-1245.
- HEALTHCARE COMMISSION. 2007. *Managing Diabetes: Improving services for people with diabetes. Service review*. [Online]. Available: <https://www.yearofcare.co.uk/sites/default/files/pdfs/Managing%20Diabetes%20Improving%20services%20for%20people%20with%20diabetes.%20Service%20review.%20Healthcare%20Commission%202007.pdf> [Accessed 3 November 2018].
- HIBBARD, J. & GILBERT, H. 2014. *Supporting people to manage their health – an introduction to patient activation*, London, The King's Fund.
- HONG, Y. Y., LIM, Y. Y., LIM, S. Y. A., DONNELL, M. T. O. & DINNEEN, S. F. 2010. Providing diabetes patients with personalized written clinical information in the diabetes outpatient clinic: a pilot study. *Diabetic Medicine*, 27, 685-690.
- HUGHES, L., MCMURDO, M. & GUTHRIE, B. 2013. Guidelines for people not for diseases: the challenges of applying UK clinical guidelines to people with multimorbidity. *Age and Ageing*, 42, 62-69.
- HUME, D. 1902. *Enquiries Concerning the Human Understanding and Concerning the Principles of Morals by David Hume*, ed. L. A. Selby-Bigge, M.A. 2nd ed, Oxford, Clarendon Press.
- JAGOSH, J., PLUYE, P., WONG, G., CARGO, M., SALSBERG, J., BUSH, P. L., HERBERT, C. P., GREEN, L. W., GREENHALGH, T. & MACAULAY, A. C. 2014. Critical reflections on realist review: insights from customizing the methodology to the needs of participatory research assessment. *Research Synthesis Methods*, 5, 131-141.
- JOSEPH-WILLIAMS, N., LLOYD, A., EDWARDS, A., STOBART, L., TOMSON, D., MACPHAIL, S., DODD, C., BRAIN, K., ELWYN, G. & THOMSON, R. 2017. Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ*, 357.
- JOWSEY, T., MCRAE, I. S., VALDERAS, J. M., DUGDALE, P., PHILLIPS, R., BUNTON, R., GILLESPIE, J., BANFIELD, M., JONES, L., KLJAKOVIC, M. & YEN, L. 2013. Time's Up. Descriptive Epidemiology of Multi-Morbidity and Time Spent on Health Related Activity by Older Australians: A Time Use Survey. *PLOS ONE*, 8, e59379.
- KARVELLAS, C. J., TILLMAN, H., LEUNG, A. A., LEE, W. M., SCHILSKY, M. L., HAMEED, B., STRAVITZ, R. T., MCGUIRE, B. M., FIX, O. K. & THE UNITED STATES ACUTE LIVER FAILURE STUDY GROUP 2016. Acute liver injury and acute liver failure from mushroom poisoning in North America. *Liver International*, 36, 1043-1050.
- KENNEDY, A., ROGERS, A., BOWEN, R., LEE, V., BLAKEMAN, T., GARDNER, C., MORRIS, R., PROTHEROE, J. & CHEW-GRAHAM, C. 2014. Implementing, embedding and integrating self-management support tools for people with long term conditions in primary care nursing: A qualitative study. *International Journal of Nursing Studies*, 51, 1103-1113.
- KENNING, C., COVENTRY, P. A., GIBBONS, C., BEE, P., FISHER, L. & BOWER, P. 2015. Does patient experience of multimorbidity predict self-management and health outcomes in a prospective study in primary care? *Family practice*, 32, 311-316.
- KONGKAEW, C., NOYCE, P. R. & ASHCROFT, D. M. 2008. Hospital admissions associated with adverse drug reactions: a systematic review of prospective observational studies. *Ann Pharmacother*, 42, 1017-1025.
- LAKATOS, I. 1978. *The Methodology of Scientific Research Programmes*, Cambridge University Press.
- LANGFORD, A., SAWYER, D., GIOIMO, S., BROWNSON, C. & O'TOOLE, M. 2007. Patient-centered goal setting as a tool to improve diabetes self-management. *Diabetes Educator*, 15, 139-144.
- LARSEN, P. D. 2017. *Lubkin's Chronic Illness: Impact and Intervention (10th ed)*, Jones and Bartlett Publishers.
- LAWN, S., DELANY, T., SWEET, L., BATTERSBY, M. C. & SKINNER, T. 2013. Control in chronic condition self-care management: how it occurs in the health worker-client relationship and implications for client empowerment. *Journal of Advanced Nursing*, 70, 383-394.
- LAWSON, T. 1997. Economics and reality.

- LEE, M. J. H. 2018. Why Naming Disease Differs From Naming Illness. *AMA Journal of Ethics*, 20, 1195-1200.
- LEIKNES, K. A., SCHWEDER, L. J.-V. & HØIE, B. 2012. Contemporary use and practice of electroconvulsive therapy worldwide. *Brain and Behavior*, 2, 283-344.
- LHUSSIER, M., EATON, S., FORSTER, N., THOMAS, M., ROBERTS, S. & CARR, S. M. 2013. Care planning for long-term conditions – a concept mapping. *Health Expectations*, 18, 605-624.
- LIANG, K. V., SILEANU, F. E., CLERMONT, G., MURUGAN, R., PIKE, F., PALEVSKY, P. M. & KELLUM, J. A. 2016. Modality of RRT and Recovery of Kidney Function after AKI in Patients Surviving to Hospital Discharge. *Clinical Journal of the American Society of Nephrology*, 11, 30-38.
- LLOYD, A., JOSEPH-WILLIAMS, N., EDWARDS, A., RIX, A. & ELWYN, G. 2013. Patchy ‘coherence’: using normalization process theory to evaluate a multi-faceted shared decision making implementation programme (MAGIC). *Implementation Science*, 8, 102.
- LORIG, K. 2009. What it will take to embrace participatory medicine: one patient’s view. *Journal of Participatory Medicine*, 1.
- LOWN, B. A., HANSON, J. L. & CLARK, W. D. 2009. Mutual influence in shared decision making: a collaborative study of patients and physicians. *Health Expectations*, 12, 160-174.
- LUNENFELD, B., & STRATTON, P. 2013. The clinical consequences of an ageing world and preventive strategies. Best practice & research. *Clinical obstetrics & gynaecology*, 27, 643-659.
- LUXFORD, K. & NEWELL, S. 2015. New South Wales mounts “patient based care” challenge. *BMJ*, 350.
- LYONS, C., NIXON, D., COREN, A. 2006. *Long-term Conditions and Depression*, London, Care Services Improvement Partnership (CSIP).
- MACDONALD, M. 2007. Origins of difficulty in the nurse-patient encounter. *Nurse Ethics*, 14, 510-521.
- MAKOUL, G. & CLAYMAN, M. 2006. An Integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60, 301-312.
- MANZANO, A. 2016. The craft of interviewing in realist evaluation. *Evaluation*, 22, 342-360.
- MARCHAL, B., VAN BELLE, S., VAN OLMEN, J., HOERÉE, T. & KEGELS, G. 2012. Is realist evaluation keeping its promise? A review of published empirical studies in the field of health systems research. *Evaluation*, 18, 192-212.
- MARINKER, M. 1975. Why make people patients? *Journal of medical ethics*, 1, 81-84.
- MASNOON, N., SHAKIB, S., KALISCH-ELLETT, L. & CAUGHEY, G. E. 2017. What is polypharmacy? A systematic review of definitions. *BMC geriatrics*, 17, 230.
- MATHERS, N., ROBERTS, S., HODKINSON, I. & KARET, B. 2011. Care Planning: Improving the lives of people with long term conditions. London: Clinical Innovation and Research Centre.
- MAY, C. & FINCH, T. 2009. Implementing, Embedding, and Integrating Practices: An Outline of Normalization Process Theory. *Sociology*, 43, 535-554.
- MAY, C., RAPLEY, T., MAIR, F. S., TREWEEK, S., MURRAY, E., BALLINI, L., MACFARLANE, A., GIRLING, M. & FINCH, T. L. 2015. *Normalization Process Theory On-line Users’ Manual, Toolkit and NoMAD instrument*. [Online]. Available: <http://www.normalizationprocess.org> [Accessed 4 February 2019].
- MAY, C. R., CUMMINGS, A., GIRLING, M., BRACHER, M., MAIR, F. S., MAY, C. M., MURRAY, E., MYALL, M., RAPLEY, T. & FINCH, T. 2018. Using Normalization Process Theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. *Implementation Science*, 13, 80.
- MAY, C. R., MAIR, F., FINCH, T., MACFARLANE, A., DOWRICK, C., TREWEEK, S., RAPLEY, T., BALLINI, L., ONG, B. N., ROGERS, A., MURRAY, E., ELWYN, G., LÉGARÉ, F., GUNN, J. & MONTORI, V. M. 2009. Development of a theory of implementation and integration: Normalization Process Theory. *Implementation science : IS*, 4, 29-29.
- MAYO, L. 1956. *Guides to action on chronic illness*, New York, National Health Council.

- MCCLEAN, S. & SHAW, A. 2005. From schism to continuum? The problematic relationship between expert and lay knowledge – An exploratory conceptual synthesis of two qualitative studies. *Qualitative Health Research*, 15, 729-749.
- MCDONALD, C. 2014. Patients in control: why people with long-term conditions must be empowered. Institute for Public Policy Research.
- MCLEAN, G., GUTHRIE, B., MERCER, S. W. & WATT, G. C. M. 2015. General practice funding underpins the persistence of the inverse care law: cross-sectional study in Scotland. *British Journal of General Practice*, 65, e799-e805.
- MEDICINENET. 2016. *Medical Definition of Chronic Disease* [Online]. Available: <http://www.medicinenet.com/script/main/art.asp?articlekey=33490> [Accessed 16 February 2019].
- MERCER, S. W., HIGGINS, M., BIKKER, A. M., FITZPATRICK, B., MCCONNACHIE, A., LLOYD, S. M., LITTLE, P. & WATT, G. C. 2016. General Practitioners' Empathy and Health Outcomes: A Prospective Observational Study of Consultations in Areas of High and Low Deprivation. *Ann Fam Med*, 14, 117-24.
- MERCER, S. W., JANI, B. D., MAXWELL, M., WONG, S. Y. S. & WATT, G. C. M. 2012. Patient enablement requires physician empathy: a cross-sectional study of general practice consultations in areas of high and low socioeconomic deprivation in Scotland. *BMC Family Practice*, 13.
- MERCER, S. W., ZHOU, Y., HUMPHRIS, G. M., MCCONNACHIE, A., BAKHSHI, A., BIKKER, A., HIGGINS, M., LITTLE, P., FITZPATRICK, B. & WATT, G. C. M. 2018. Multimorbidity and Socioeconomic Deprivation in Primary Care Consultations. *The Annals of Family Medicine*, 16, 127-131.
- MERTON, R. 1968. *Social theory and social structure*, New York, Free Press.
- MEZUK, B., EATON, W.W., ALBRECHT, S., GOLDEN, S.H. 2008. Depression and Type 2 diabetes over the lifespan: a meta analysis. *Diabetes Care*, 31, 2383-2390.
- MORSE, J. M. 1995. The significance of saturation. Sage Publications Sage CA: Thousand Oaks, CA.
- MORTON, T. & MORGAN, M. 2009. Examining how personalised care planning can help patients with long term conditions. *Nursing Times*, 105, 13-15.
- MUKUMBANG, F. C., MARCHAL, B., VAN BELLE, S. & VAN WYK, B. 2018. Unearthing how, why, for whom and under what health system conditions the antiretroviral treatment adherence club intervention in South Africa works: A realist theory refining approach. *BMC Health Serv Res*, 18, 343.
- MURRAY, E., TREWEEK, S., POPE, C., MACFARLANE, A., BALLINI, L., DOWRICK, C., FINCH, T., KENNEDY, A., MAIR, F., O'DONNELL, C., ONG, B. N., RAPLEY, T., ROGERS, A. & MAY, C. 2010. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. *BMC medicine*, 8, 63-63.
- NATIONAL COLLABORATING CENTRE FOR CHRONIC CONDITIONS 2006. *Parkinson's: National Clinical Guidelines for Care and Management in Adults*, London, Royal College of Physicians.
- NATIONAL VOICES. 2011. *Webs of Care: What does care look like from the individual's perspective?* [Online]. Available: [https://www.nationalvoices.org.uk/sites/default/files/public/publications/webs\\_of\\_care.pdf](https://www.nationalvoices.org.uk/sites/default/files/public/publications/webs_of_care.pdf) [Accessed 14 November 2018].
- NATIONAL VOICES 2013. Principles of care and support planning.
- NATIONAL VOICES 2017. Person-centred care in 2017: Evidence from service users.
- NEUBERGER, J. 1999. Do we need a new word for patients? Lets do away with "patients". *BMJ (Clinical research ed.)*, 318, 1756-1757.
- NEUNER-JEHLE, S., ZECHMANN, S., GRUNDMANN MAISSEN, D., ROSEMANN, T. & SENN, O. 2017. Patient-provider concordance in the perception of illness and disease: a cross-sectional study among multimorbid patients and their general practitioners in Switzerland. *Patient preference and adherence*, 11, 1451-1458.

- NEWBOULD, J., BURT, J., BOWER, P., BLAKEMAN, T., KENNEDY, A., ROGERS, A. & ROLAND, M. 2012. Experiences of care planning in England: interviews with patients with long term conditions. *BMC Family Practice*, 13, 1-9.
- NGUYEN, P. V. & SPINELLI, C. 2016. Prescribing cascade in an elderly woman. *Canadian pharmacists journal* 149, 122-124.
- NHS ENGLAND 2009. The NHS Constitution: the NHS belongs to us all.
- NHS ENGLAND. 2014a. *Enhancing the quality of life for people living with long term conditions - the house of care*. [Online]. Available: <https://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/house-of-care/> [Accessed 2 October 2015].
- NHS ENGLAND. 2014b. *A resource to support commissioners in setting a level of ambition on reducing premature mortality* [Online]. Available: <https://www.england.nhs.uk/wp-content/uploads/2014/02/rm-fs-6.pdf> [Accessed 27 September 2018].
- NHS ENGLAND. 2018. *NHS England Standard General Medical Services Contract 2017/18* [Online]. Available: <https://www.england.nhs.uk/wp-content/uploads/2018/01/17-18-gms-contract.pdf> [Accessed 20 December 2018].
- NHS ENGLAND, PUBLIC HEALTH ENGLAND, HEALTH EDUCATION ENGLAND, MONITOR, CARE QUALITY COMMISSION & NHS TRUST DEVELOPMENT AUTHORITY. 2014. *Five Year Forward View* [Online]. Available: <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf> [Accessed 5 July 2018].
- NHS ENGLAND AND NHS IMPROVEMENT 2016. *NHS Operational Planning and Contracting Guidance 2017-2019*.
- NICE 2009. Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence. Clinical guideline [CG76].
- NICE 2015. Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes. NICE guideline [NG5].
- NICE 2016. Multimorbidity: clinical assessment and management. National Institute for Health and Care Excellence.
- NICE CLINICAL KNOWLEDGE SUMMARIES. 2018. *Multimorbidity* [Online]. Available: <https://cks.nice.org.uk/multimorbidity#!scenario:1> [Accessed December 2018].
- NICOL, J. 2011. *Nursing Adults with Long Term Conditions*, Exeter, Learning Matters Ltd.
- NOËL, P. H., PARCHMAN, M. L., WILLIAMS, J. W., CORNELL, J. E., SHUKO, L., ZEBER, J. E., KAZIS, L. E., LEE, A. F. S. & PUGH, J. A. 2007. The Challenges of Multimorbidity from the Patient Perspective. *Journal of General Internal Medicine*, 22, 419-424.
- O'CONNOR, A. M., STACEY, D., ENTWISTLE, V., LLEWELLYN-THOMAS, H., ROVNER, D., HOLMES-ROVNER, M., TAIT, V., TETROE, J., Fiset, V., BARRY, M. & JONES, J. 2009. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*.
- OFFICE FOR NATIONAL STATISTICS. 2015. *Adult Health in Great Britain, 2013* [Online]. Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/compendium/opinionsandlifestylesurvey/2015-03-19/adulthealthingreatbritain2013> [Accessed 1 October 2018].
- OFFICE FOR NATIONAL STATISTICS. 2017. *Most common age at death, by socio-economic position in England and Wales: a 30 years comparison* [Online]. Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/articles/mostcommonageatdeathbysocioeconomicpositionsinenglandandwales/a30yearscomparison> [Accessed 07/01/2019].
- OFFICE FOR NATIONAL STATISTICS. 2018a. *Living longer: how our population is changing and why it matters* [Online]. Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/agein>

- [g/articles/livinglongerhowourpopulationischangingandwhyitmatters/2018-08-13](https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2015to2017) [Accessed 17 February 2019].
- OFFICE FOR NATIONAL STATISTICS. 2018b. *National life tables, UK: 2015 to 2017* [Online]. Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2015to2017> [Accessed].
- ORIS, L., LUYCKX, K., RASSART, J., GOUBERT, L., GOOSSENS, E., APERS, S., ARAT, S., VANDENBERGHE, J., WESTHOVENS, R. & MOONS, P. 2018. Illness Identity in Adults with a Chronic Illness. *J Clin Psychol Med Settings*, 25, 429-440.
- OSBORNE, R. 2014. *Transforming health services: does health literacy provide the key?* London: The Health Foundation.
- PATTON, M. Q. 2003. Qualitative evaluation checklist. *Evaluation Checklists Project*, 21.
- PAWSON, R. 2006. *"Evidence-based Policy: A Realist Perspective"*, London, Sage.
- PAWSON, R. 2008. *Causality for Beginners* [Online]. Available: [eprints.ncrm.ac.uk/245/1/Causality\\_for\\_Beginners\\_Dec\\_07.doc](http://eprints.ncrm.ac.uk/245/1/Causality_for_Beginners_Dec_07.doc) [Accessed 28 November 2018].
- PAWSON, R. 2013. *The Science of Evaluation: A Realist Manifesto*, London, Sage.
- PAWSON, R., GREENHALGH, T., HARVEY, G. & WALSHE, K. 2005. Realist review-a new method of systematic review designed for complex policy interventions. *J Health Serv Res Policy*, 10.
- PAWSON, R. & TILLEY, N. 1997. *Realistic Evaluation*, London, Sage.
- PAWSON, R. & TILLEY, N. 2004. *Realist Evaluation* [Online]. British Cabinet Office. Available: [http://www.communitymatters.com.au/RE\\_chapter.pdf](http://www.communitymatters.com.au/RE_chapter.pdf) [Accessed 4 August 2018].
- PHILLIPS, D. C. 1987. *Philosophy, science and social inquiry: Contemporary methodological controversies in social science and related applied fields of research*, Pergamon Press.
- PICTON, C. & WRIGHT, H. 2013. *Medicines Optimisation: Helping patients to make the most of medicines*. The Royal Pharmaceutical Society.
- POPPER, K. 1963. *Conjectures and Refutations: The Growth of Scientific Knowledges*, London, Routledge.
- PORTER, T., ONG, B. N. & SANDERS, T. 2019. Living with multimorbidity? The lived experience of multiple chronic conditions in later life. *Health*, 0, 1363459319834997.
- PRESCOTT, H. C. & ANGUS, D. C. 2018. Enhancing Recovery From Sepsis: A Review Sepsis Recovery: Recognition and Management of Long-term Sequelae Sepsis Recovery: Recognition and Management of Long-term Sequelae. *JAMA*, 319, 62-75.
- PUBLIC HEALTH ENGLAND 2015a. Chronic smoking-related lung disease blights over 1 million lives in England. *Around 25,000 deaths each year in England are attributable to chronic obstructive pulmonary disease (COPD)*.
- PUBLIC HEALTH ENGLAND 2015b. *Local action on health inequalities: Improving health literacy to reduce health inequalities*. UCL Institute of Health Equity.
- PURDY, S., GRIFFIN, T., SALISBURY, C. & SHARP, D. 2011. Emergency admissions for coronary heart disease: a cross-sectional study of general practice, population and hospital factors in England. *Public Health*, 125, 46-54.
- PUTNAM, H. & CONANT, J. 1990. *Realism with a Human Face*, Cambridge, MA, Harvard University Press.
- REEVE, J., LYNCH, T., LLOYD-WILLIAMS, M. & PAYNE, S. 2012. From personal challenge to technical fix: the risks of depersonalised care. *Health and Social Care in the Community*, 20, 145-154.
- RIJKEN, M., BEKKEMA, N., BOECKXSTAENS, P., SCHELLEVIS, F. G., DE MAESENEER, J. M. & GROENEWEGEN, P. P. 2014. Chronic Disease Management Programmes: an adequate response to patients' needs? *Health Expectations*, 17, 608-621.
- ROSS, F., SMITH, P., BYNG, R., CHRISTIAN, S., ALLAN, H., PRICE, L. & BREARLEY, S. 2014. Learning from people with long-term conditions: new insights for governance in primary healthcare. *Health and Social Care in the Community*, 22, 405-416.

- RUSSELL, G., THILLE, P., HOGG, W. & LEMELIN, J. 2008. Beyond fighting fires and chasing tails? Chronic illness care plans in Ontario, Canada. *Annals of Family Medicine*, 6, 146-153.
- RUSSELL, L. B., SUH, D. C. & SAFFORD, M. A. 2005. Time requirements for diabetes self-management: too much for many? *J Fam Pract*, 54, 52-56.
- RYAN, R. M. & DECI, E. L. 2000. Self-Determination Theory and the facilitation of intrinsic motivation, social development and well being. *American Psychologist*, 55, 68-78.
- RYCROFT-MALONE, J., FONTENLA, M., BICK, D. & SEERS, K. 2008. Protocol-based care: impact on roles and service delivery. *Journal of evaluation in clinical practice*, 14, 867-873.
- SALISBURY, C., JOHNSON, L., PURDY, S., VALDERAS, J. M. & MONTGOMERY, A. A. 2011. Epidemiology and impact of multimorbidity in primary care: a retrospective cohort study. *British Journal of General Practice*, 61, 12-21.
- SAUL, J. E., WILLIS, C. D., BITZ, J. & BEST, A. 2013. A time-responsive tool for informing policy making: rapid realist review. *Implementation Science*, 8.
- SAUMURE, K. & GIVEN, L. M. 2008. "Data saturation." In *The Sage Encyclopedia of Qualitative Research Methods*, edited by Lisa M. Given, Thousand Oaks, CA, Sage.
- SAYER, A. 1992. *Method in Social Science: a Realist Approach*, London, Routledge.
- SAYER, A. 2000. *Realism and Social Science*, London, Sage.
- SAYERS, A. 2008. Tips and tricks in performing a systematic review. *The British Journal of General Practice*, 58, 136.
- SCHILLINGER, D., HANDLEY, M., WANG, F. & HAMMER, H. 2009. Effects of self-management support on structure, process, and outcomes among vulnerable patients with diabetes: a three-arm practical clinical trial. *Diabetes Care*, 32, 559-566.
- SCOTT, E. M. D. 2010. The term "patient" may describe me...but it does not define me. *J Participat Med*, 2, 22.
- SCRIVEN, M. 1994. Product Evaluation—The State of the Art. *Evaluation Practice*, 15, 45-62.
- SHAH, R. S. & COLE, J. W. 2010. Smoking and stroke: the more you smoke the more you stroke. *Expert review of cardiovascular therapy*, 8, 917-932.
- SHEEHY, C., MURPHY, E., BARRY, M. 2006. Depression in rheumatoid arthritis: underscoring the problem. *Rheumatology*, 45, 1325-1327.
- SHEVELL, M. I. 2009. What do we call 'them'? The 'patient' versus 'client' dichotomy. *Developmental Medicine & Child Neurology*, 51, 770-772.
- SLIWINSKA-MOSSON, M. & MILNEROWICZ, H. 2017. The impact of smoking on the development of diabetes and its complications. *Diab Vasc Dis Res*, 14, 265-276.
- SMITH, J., PICTON, C. & DAYAN, M. 2013. Now or never: shaping pharmacy for the future. Royal Pharmaceutical Society.
- SRIVASTAVA, A. & THOMSON, S. B. 2009. Framework analysis: a qualitative methodology for applied policy research.
- STREET, R. L. J., MAKOUL, G., ARORA, N. K. & EPSTEIN, R. M. 2009. How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling*, 74, 295-301.
- SUCHMAN, E. A. 1967. *Evaluative Research Principles and Practice in Public Service and Social Action Progr*, Russell Sage Foundation.
- THE HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND. 2016. *Scotland's House of Care: Learning Report. Developing a Compelling Narrative* [Online]. Available: <https://www.alliance-scotland.org.uk/wp-content/uploads/2017/10/ALLIANCE-HOC-LearningReport-2016.pdf> [Accessed 17 January 2019].
- THE HEALTH FOUNDATION 2011. Guiding patients through complexity: Modern medical generalism
- THE HEALTH FOUNDATION 2014. Ideas into action: person-centred care in practice.
- THE HEALTH FOUNDATION. 2016. *Person-centred care made simple: What everyone should know about person-centred care* [Online]. Available:

- <https://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple.pdf>  
[Accessed].
- THE MARMOT REVIEW TEAM 2010. *Fair Society, Healthy Lives: Strategic review of health inequalities in England post-2010.*, London, Marmot Review Team.
- THOMPSON, H. & RYAN, A. 2008. A review of the psychological consequences of stroke and their impact on spousal relationships. *British Journal of Neuroscience Nursing*, 4, 177-184.
- TRIANDAFILIDIS, Z., USSHER, J., PERZ, J. & HUPPATZ, K. 2016. *An Intersectional Analysis of Women's Experiences of Smoking-Related Stigma*.
- TRIBAL CONSULTING 2009. Evaluating the Delivery and Impact of the 'Year of Care for Diabetes': Project Interim Report. November.
- TUDOR HART, J. 1971. THE INVERSE CARE LAW. *The Lancet*, 297, 405-412.
- UN SECRETARY GENERAL 2011. Prevention and control of non-communicable diseases. . UN General Assembly.
- WAGNER, E. H., AUSTIN, B. T. & VON KORFF, M. 1996. Improving outcomes in chronic illness. *Manag Care Q*, 4, 12-25.
- WALKER, R. 2014. *Care planning for long-term conditions: part one* [Online]. Nursing in Practice. Available: <https://www.nursinginpractice.com/article/care-planning-long-term-conditions-part-one> [Accessed 16 August 2018].
- WALLACE, J. & PAAUW, D. S. 2015. Appropriate prescribing and important drug interactions in older adults. *Med Clin North Am*, 99, 295-310.
- WANG, W., LIU, H., XIAO, S., LIU, S., LI, X. & YU, P. 2017. Effects of Insulin Plus Glucagon-Like Peptide-1 Receptor Agonists (GLP-1RAs) in Treating Type 1 Diabetes Mellitus: A Systematic Review and Meta-Analysis. *Diabetes Therapy*, 8, 727-738.
- WATT, G. 2013. What can the NHS do to prevent and reduce health inequalities? *British Journal of General Practice*, 63, 494-495.
- WEISS, C. H. 1997. How can theory-based evaluation make greater headway? *Evaluation review*, 21, 501-524.
- WESTHORP, G. 2013. Developing complexity-consistent theory in a realist investigation. *Evaluation*, 19, 364-382.
- WHO. 2016. *Noncommunicable Diseases* [Online]. Available: [http://www.who.int/topics/noncommunicable\\_diseases/en/](http://www.who.int/topics/noncommunicable_diseases/en/) [Accessed 16 February 2019].
- WHOLEY, J. S. 1979. *Evaluation: Promise and performance*, Urban Institute Washington, DC.
- WHOLEY, J. S. 1983. *Evaluation and effective public management*, Little, Brown.
- WILLIS, S. & DALRYMPLE, R. 2015. *Fundamentals of Paramedic Practice: A Systems Approach*, Blackwell, Wiley.
- WILSON, P., MATHIE, E., KEENAN, J., MCNEILLY, E., GOODMAN, C., HOWE, A., POLAND, F., STANISZEWSKA, S., KENDALL, S., MUNDAY, D., COWE, M. & PECKHAM, S. 2015. ReseArch with Patient and Public involvement: a Realist evaluation – the RAPPORT study. *Health Services and Delivery Research*, 3.
- WINTERBOTTOM, A., CROSS, P. & REDDING, D. 2010. The quality of patient engagement and involvement in primary care. *The King's Fund*.
- WONG, G., GREENHALGH, T., WESTHORP, G., BUCKINGHAM, J. & PAWSON, R. 2013. RAMESES publication standards: realist syntheses. *BMC Medicine*, 11, 21.
- WONG, G., WESTHORP, G., MANZANO, A., GREENHALGH, J., JAGOSH, J. & GREENHALGH, T. 2016. RAMESES II reporting standards for realist evaluations. *BMC medicine*, 14, 96.
- WORLD HEALTH ORGANISATION 2005. Preparing a health care workforce for the 21st century: the challenge of chronic conditions.
- WORLD HEALTH ORGANISATION 2007. *People-centred health care : a policy framework*, Manila, WHO Regional Office for the Western Pacific.
- WORLD HEALTH ORGANISATION 2013. Health literacy: The solid facts.

- WORLD HEALTH ORGANISATION. 2017. *Reforming Health Service Delivery for UHC* [Online]. Available: <https://apps.who.int/iris/bitstream/handle/10665/255311/WHO-HIS-SDS-2017.9-eng.pdf;jsessionid=266BBF240EFDDCE2BC9C8DCF1BFB66E1?sequence=1> [Accessed 16 February 2019].
- YEAR OF CARE 2011. Report of findings from the pilot programme. London: Diabetes UK, NHS Diabetes, the Health Foundation, Department of Health.
- YEAR OF CARE. 2016. *'The challenge' (drawn by people with long-term conditions at a world café event)* [Online]. Available: [www.yearofcare.co.uk/challenge](http://www.yearofcare.co.uk/challenge) [Accessed 26 August 2018].