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Engagement in group-based self-management support
programmes for people living with long-term conditions:
a realist evaluation

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Abstract

Group-based self-management support (SMS) interventions are advocated to help individuals to manage long-term health conditions, which are a growing health concern. Engagement with group-based SMS programmes is a frequently cited challenge to programme success yet the concept is often ill-defined and focuses on individual states and behaviours.

A realist evaluation, a type of theory-driven evaluation, was adopted to generate explanatory theory of how engagement occurs in group-based SMS programmes. Programme theories, which explain how informal and formal elements of interventions work, were developed and tested using a suite of person-centred health and wellbeing programmes provided by a university in partnership with local healthcare organisations in the Southwest of England. Programme theories were developed using realist interviews with programme architects and practitioners, historic patient feedback from programmes delivered by the health and wellbeing (H&W) team, and data from a concurrent study. Programme theories were refined and verified using a multi-case study design which adopted non-participant observations of three types of group-based SMS programmes, and realist interviews with programme practitioners and participants. The three programmes were a Back Wellbeing Programme, a Living Well With and Beyond Cancer Programme, both of which were delivered at the university campus, and a Leg Wellbeing Programme, which was delivered at the university campus and three other sites in and around the city.

The output of this realist evaluation comprises a conceptual framework for engagement in group-based SMS programmes within which seven programme theories explain how various aspects of programme architecture impact engagement,

for whom, in which circumstances and why. The choice afforded to participants when participating in programmes, feedback and differentiation of activities, the emotional and physical environment, informal space for connection and time to develop relationships, helping individuals to identify how programmes may support their individual needs, the active involvement of students in programme delivery, and co-constructed engagement between practitioners and participants were all identified to support engagement in programmes. Key contexts influencing these mechanisms and their outcomes were also identified. The generation and empirical confirmation of these programme theories support a wider argument for expanding the focus of engagement beyond individuals and to shift away from viewing non-engagement as a patient problem, which has dominated the literature to date.

The portable theories presented in this work can be used to guide the support and evaluation of engagement in group-based SMS programmes and offer a platform for further testing and refinement of engagement theory in similar programmes in different contexts. Further, the theories may be used to inform programme design and support the training of practitioners delivering group-based SMS programmes to improve the success of these complex interventions.

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Abbreviations

CDSMP	The Stanford Chronic Disease Self-Management Program
CMO-C	Context-mechanism-outcome configuration
DoH	Department of Health
DSME	Diabetes self-management education
GP	General practitioner
HCP	Healthcare practitioner
LTC	Long-term condition
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
SDT	Self-Determination Theory
UK	United Kingdom
WHO	World Health Organization

Declaration

I declare that the work contained in this thesis is my own, except where otherwise stated. I confirm that this thesis has not been submitted for any other award.

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Chapter 1 Introduction

1.1 Chapter overview

This chapter provides an introduction to, and outline of this thesis, which explores engagement in group-based self-management interventions for people living with long-term health conditions. First, an overview of the discourse on the nature and causes of long-term health conditions is given. The ‘causes of the causes’ of long-term conditions are then discussed through an exploration of the determinants of health. The impact of long-term health conditions is presented, followed by a critical discussion of how healthcare models and their delivery have adapted to respond to the increasing challenges of long-term health conditions. The concepts of person-centred care and supported self-management, as key principles of supporting people living with long-term health conditions, are then introduced. The myriad self-management support interventions are described, with the focus narrowing to group-based self-management interventions. The inherent complexity of group-based self-management programmes is illustrated, leading to a discussion of the challenges faced in developing an evidence base for their use and best practice. The policy-practice gap in the delivery of person-centred group-based self-management support programmes is then presented. The chapter concludes with an outline of the structure of this thesis.

1.2 Defining long-term conditions

Long-term or chronic conditions are generally defined as conditions that require treatment and management over many years. The Department of Health (DoH, 2012) define a long-term condition as: “a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies.”

The terms long-term condition (LTC) and non-communicable disease (NCD) are often used synonymously (Adjaye-Gbewonyo & Vaughan, 2019). Although many LTCs are also NCDs, some communicable diseases result in clinical sequelae that persist long-term, such as HIV/AIDS (The World Health Organization [WHO], 2002), and more recently, Long COVID (Leung et al., 2020). Some NCDs are acute in nature (Unwin et al., 2004), rather than long-term. Dichotomising disease into communicable and non-communicable can be problematic for public health initiatives, not least because the two classifications are inextricably and complexly linked (Oni & Unwin, 2015). Further complicating the NCD discourse are calls to reframe and rename the classification based on the argument that NCDs are socially communicable (Zuccala & Horton, 2020). This idea is reflected around the discourses of chronic disease ‘epidemics’ (Green & Lynch, 2022), to be discussed in section 1.4 of this chapter.

Currently, NCDs are framed as diseases resulting from poor lifestyle choices, perpetuating individual blame narratives (Manderson & Jewett, 2023). Portraying chronic diseases as a consequence of problematic lifestyles constrains attempts to manage living with these conditions because it fails to appreciate the wider contexts in which health-behaviours and behaviour-change occur (Green & Lynch, 2022). The term disease implies a strictly physiological basis, which may not account for a lack of subjective experience of ill health in the presence of disease, or conversely, the experience of illness in the absence of identifiable underlying disease (Farre & Rapley, 2017).

The terminology adopted for general discussion in this thesis is long-term conditions (LTCs), as the term affords the flexibility to incorporate multiple causal explanations and experiences of conditions beyond the biomedical model which prevails in NCD

discourses (Adjaye-Gbewonyo & Vaughan, 2019; Green & Lynch, 2022). A wider lens through which to consider individual, social, and commercial determinants of health, aligns with the realist approach to inquiry adopted for this research and will be discussed in detail in Chapter 4. Sources from research and policy literature specific to NCDs will be made clear in the thesis.

There is no definitive list of LTCs (Taylor et al., 2014). Specific definitions of LTCs vary, as does the length of time a condition must be experienced for it be considered chronic (Bernell & Howard, 2016). The chronicity and lived experience of diseases also changes over time due to advancements or changes in treatment. For example, developments in HIV treatment have reduced mortality; however, the increased life expectancy is often burdened by pain and physical symptoms (Nkhoma et al., 2018). The long-term management of HIV has resulted in the disease becoming a risk factor for a number of other chronic health conditions, such as cardiovascular disease and type 2 diabetes (Bernell & Howard, 2016). This progression from fatality to chronicity is also occurring in the treatment of a number of cancers (Howell et al., 2021). Therefore, the health conditions considered under any agreed definition of LTCs is unlikely to remain static over time. As the nature and prevalence of LTCs change, so too will policy directives and resource allocation.

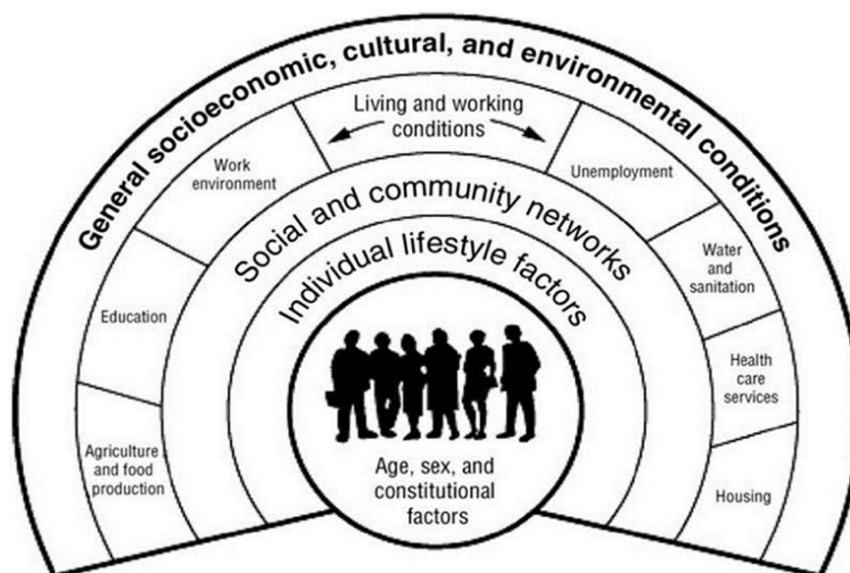
1.3 The determinants of health in the context of long-term conditions

The aetiology of long-term conditions is multifactorial, involving the complex interaction of individual, social and wider determinants of health. The Dahlgreen and Whitehead model, developed in 1991, provides one of the most widely used frameworks of the determinants of health, which recognises the interconnected layers of influence on

health determinants (Dahlgren & Whitehead, 2021). At the centre, or under the 'rainbow' of the model (Figure 1.1) are individuals' biological and genetic characteristics. The subsequent layers of the rainbow-shaped model are individual lifestyle factors, social and community networks, living and working conditions, and general socio-economic, cultural and environmental conditions. The model offers a holistic lens through which to view health, departing from the disease-focused models prevailing in healthcare (Dahlgren & Whitehead, 2021). Further, the model highlights that the determinants of health can be viewed as health promoting and protective as well as health-damaging, the latter being the most prominent in other health models (Dahlgren & Whitehead, 2021).

Figure 1.1

Dahlgren and Whitehead's model of the determinants of health (1991)



The lifestyle factors at the innermost level of Dahlgreen and Whitehead's model, referred to as health behaviours, influence the development, progression and experience of most LTCs (Marmot & Bell, 2019). Numerous models of health

behaviour have been proposed, with behaviours themselves having determinants at individual, interpersonal, environmental and policy levels (Condello et al., 2017). Michie et al.'s (2011) COM-B model posits that volitional behaviours (B) require capability (C), opportunity (O), and motivation (M). Individual capability may be influenced by a person's knowledge, skills and beliefs about their capabilities (Cane et al., 2012; Michie et al., 2005) and the symptoms of LCTs can impact whether people are, or feel, physically capable of carrying out health behaviours (Barhorst et al., 2022; Selzler et al., 2020).

Individuals' motivation for behaviours may be determined by beliefs and attitudes about the outcomes of behaviours, as well as their perception of disease susceptibility and severity (Conner & Norman, 2017; Michie et al., 2005). The regulation of behaviours related to diet and physical activity levels are affected as early as in childhood (Marmot & Bell, 2019). People's motivation and capacity to be physically active, for example, are affected over the course of their lifetime by individual beliefs; social support; cultural norms; their social, built and natural environment; and regional and national policy (Bauman et al., 2012; Condello et al., 2017), as recognised in Dahlgren and Whitehead's model (Dahlgren & Whitehead, 2021). In addition to individuals' motivation, psychological influences on health behaviours include basic psychological needs, emotions and feelings, personal dispositions, personality traits and psychological distress and disorder (Cortis et al., 2017; Górná et al., 2023).

Opportunities for health behaviour can be shaped by people's environment (Cane et al., 2012), providing an example of the interconnectedness of the layers of Dahlgren and Whitehead's model. Health-constraining and health-promoting environments have been shown to impact health behaviours as well as physical and mental health

outcomes even when controlling for age, gender, ethnicity and socioeconomic status (Hobbs et al., 2022). The availability of outdoor space, toys and equipment at home, and availability of activity programmes and equipment at school impact physical activity levels for youths; and neighbourhood features, such as pedestrian accessibility and safety impact youths and adults alike (Carlin et al., 2017). Food choice and eating behaviour are impacted by home, school and neighbourhood environments (Enriquez & Archila-Godinez, 2022; Wordell et al., 2012) with some people having poor access to affordable, healthy food, typically in low-income and low-access communities (Beaulac et al., 2009; Thomas & Cankurt, 2024).

There is a stark social gradient of health, showing that the more deprived a neighbourhood is, the worse the health is of that community (Marmot, 2017). Social determinants of health contribute significantly to the distribution of behavioural risk factors for NCDs as well as disability and mortality from NCDs, leading to this social gradient (Marmot & Bell, 2019). In 2018 to 2020 life expectancy was 9.7 years fewer for males and 7.9 years fewer for females, and healthy life expectancy, the years lived in good health over the lifespan, was 18.6 years fewer for males and 19.3 years fewer for females in the most deprived areas than in the least deprived areas of England (Office for National Statistics [ONS], 2022). Social determinants of health are not simply risk factors acting at a single point in time to influence the chances of poor health but are ongoing and accumulative factors which shape the possibilities and future of individuals' health (Green & Lynch, 2022; Schrecker, 2016). Further, risk factors for LTCs co-occur and interact with each other (Tazzeo et al., 2023).

Not only are people with lower socio-economic status (SES) more likely to develop LTCs, those living in deprived areas have fewer shops, green spaces and community

centres, all of which create barriers to adopting and maintaining health behaviours (Estechea Querol et al., 2020). Eating healthily is unaffordable for many and in the UK 9-10% of households were food insecure, which is reflected in the increase in the number of foodbanks (Marmot et al., 2020). The number of Trussell Trust foodbanks, representing 61% of UK foodbanks, rose from 65 in 2011 to 1,200 in 2019 (Marmot et al., 2020).

Low SES can more directly impact health, as well as impact behaviour through increased exposure to higher levels of indoor and outdoor air pollution; and damp, cold, mould and noise in poor housing (Ferguson et al., 2021; Marmot et al., 2020). Household debt, fuel poverty and increased fear and being victim to crime all directly harm physical and mental health of those living in more deprived areas (Marmot et al., 2020).

The access to and experience of healthcare also follows a social gradient. People living in more deprived areas in England are more likely to feel less supported by their GPs in managing their condition (Cookson et al., 2016). People with low SES tend to use healthcare differently as they are less likely to attend GP appointments for preventative care, are more likely to be admitted for emergency care and tend to present at a later stage for cancer (Cookson et al., 2016). Further, marginalised groups often use Emergency Departments for routine care due to difficulties accessing General Practice and community services (Coronini-Cronberg et al., 2020). These differences in healthcare experience and access are therefore likely to compound the negative impact of LTCs on people with lower SES.

It is feared that the COVID-19 pandemic may have led to an increased prevalence and worsening progression of LTCs (Palmer et al., 2020) and further exacerbated health

inequalities (Coronini-Cronberg et al., 2020). Lockdown and social isolation lead to reduced physical activity, worse dietary habits and a reduction in psychological wellbeing (Cavallo et al., 2023) as well as reduced access to healthcare services for non-COVID-19 reasons (Bambra et al., 2020; Coronini-Cronberg et al., 2020). Lockdown measures were more constraining for those living with existing LTCs due to their increased vulnerability to COVID-19 (Palmer et al., 2020) making health-promoting behaviours especially difficult to maintain. Bambra et al. (2020) argued that for those in lower SES groups, COVID-19 is experienced as a *syndemic*, where there is interaction with and exacerbation of existing ill health and social conditions. Further, reduced attendance at Emergency Departments and the restriction of non-urgent clinical services is feared to have impacted marginalised groups during the pandemic disproportionately (Coronini-Cronberg et al., 2020). In the wake of the pandemic, it is now more important than ever to mobilise efforts to support people with LTCs in a holistic way (Palmer et al., 2020) and to be cognisant of the social gradient in health. Research is needed to inform the complex delivery of person-centred support for those with LTCs who may have experienced exceptional challenges during this time.

The role that the social determinants of health play is recognised in global policy. The WHO Global Action Plan 2013 outlines the need to reduce modifiable risk factors for NCDs and their underlying social determinants and for healthcare systems to address the prevention and management of NCDs through people-centred care (WHO, 2013). However, there is a disproportionate focus of policies on individual responsibility, hampering opportunities to address wider determinants of health (Godziewski, 2021), despite evidence for risks to health outcomes from income inequality and large areas of deprivation (Naik et al., 2019). England led the way in systematically focusing on addressing social inequalities in health by shifting policy focus from individual lifestyle

to include the social determinants of health (Mackenbach, 2011). The 2004 white paper, “Choosing Health: Making healthy choices easier”, committed to supporting individuals to make better health choices through the provision of information and by shaping commercial and cultural environments to make healthy choices easier. However, even when policy rhetoric promises a more encompassing view on health, policy documents and implementation often drift in to focusing on individual lifestyle-factors and behaviour change, a concept known as lifestyle drift (Mead et al., 2022).

Wider influences still, come from commercial determinants of health, defined as the strategies and approaches used by the private sector to promote products and choices that are detrimental to health (Kickbusch et al., 2016). Individuals’ health can be impacted not just through the consumption of corporations’ products, such as alcohol and ultra-processed food, but via exposure to chemicals and pollution generated by their production, and health-harming business practices (Mialon, 2020). Corporations exert power to influence the blame-laden narrative of LTCs through the ownership of mass media and by framing LTCs as individual or societal choices and responsibilities (McKee & Stuckler, 2018). Corporations also impede public health policy to protect their profit interests by building alliances with health organisations; shaping knowledge through selective research funding; lobbying; and legal strategies (Mialon, 2020). Such conflicts of interest are also seen in the use of ‘Corporate Social Responsibility’ strategies to improve brand awareness and increase profit. For example, Coca-Cola GB funded the physical activity enhancing initiative ParkLives which provided a brand-promoting opportunity to children and young people (Jane & Gibson, 2018). Kickbusch et al. (2016) argue that the prioritisation of wealth creation over health creation in our global economic system has manifested in the rise of NCDs.

1.4 The impact of long-term conditions

The headline impact of focus for LTCs tends to be mortality (Institute for Health Metrics and Evaluation [IHME], 2024). LTCs are responsible for 41 million deaths per year, accounting for 74% of deaths globally (WHO, 2023). An estimated 89% of deaths in the UK were attributable to LTCs in 2016, and LTCs also resulted in an 11% risk of premature death (30 - 70 years of age) (WHO, 2018). The predominant global focus of policy and interventions is therefore on reducing mortality (Pearce et al., 2015), which is reflected in the WHO Sustainable Development Goal target 3.4 of reducing premature mortality from LTCs (referred to as NCDs in the policy) (WHO, 2017).

Particular focus has been directed on four LTCs, which have high mortality rates globally: cardiovascular disease, cancer, respiratory disease and diabetes, and share four modifiable risk behaviours: tobacco use, physical inactivity, harmful use of alcohol and unhealthy diet (WHO, 2018). This four-by-four framework has evolved over recent years by expanding to five-by-five with the inclusion of mental ill health as a health condition and air pollution as an additional risk factor (Tan et al., 2021), and with a call to further expand to six-by-six by including oral health and sugar consumption (Benzian et al., 2023). These simple frameworks have allowed for powerful messages regarding causation and burden to drive action and attract funding for these LTCs (Herrick, 2022), however, they lack explanatory power (Schwartz et al., 2021). By simplifying the complex causes of LTCs, as discussed in section 1.3, other LTCs and risk factors have arguably been side-lined (Benzian et al., 2023; Boudreaux et al., 2020; Schwartz et al., 2021). The oversimplification of risk factors for LTCs has resulted in the underestimation of the impact of environmental and genetic influences, and a lack of attention on multimorbidities (Boudreaux et al., 2020). Further, the focus of these powerful risk factor messages focuses on individual behaviours, resulting in

an emphasis on interventions to target behaviour change and less emphasis being placed on wider determinants of health (Mackert & Schorb, 2022). The simplified framework focuses on vertical disease control (Schwartz et al., 2021). For example, neoliberal economic policy dependent on economic growth mobilises indirect techniques to influence individuals' behaviour without being responsible for them (Viens, 2019), ultimately perpetuating the individual responsibility and blame narrative of LTCs.

In addition to the primary concern of LTC mortality (WHO, 2023) is the economic cost of these conditions. Austerity in the UK has led to pressures on health services and shaped how they are delivered with much of the focus now being on the efficiencies of health services (Viens, 2019). In 2012, the DoH reported that LTCs accounted for 50% of all GP appointments; 64% of outpatient appointments; 70% of all inpatient bed days; and 70% of NHS care spend in England (DoH, 2012). Average annual costs of a selection of LTCs between 2011 and 2015 (Table 1.1) were reported by Public Health England (PHE) (Blawat et al., 2020). The dataset analysed for this PHE report was from an affluent part of England, making the costs appear relatively low due to the likelihood of better health in this population.

Table 1.1

Average primary, secondary, and prescription cost per case for people who had contact with the health system due to their condition between 2012 and 2015 (Blawat et al., 2020)

Health condition	Male	Female
Coronary Heart Disease (CHD)	£1993	£1961
Hypertension	£1677	£1641

Chronic Obstructive Pulmonary Disease (COPD)	£3022	£2735
Diabetes	£1606	£1692
Colorectal cancer	£3582	£2955
Lung cancer	£3297	£2926
Breast cancer		£3136

The costs associated with treating multimorbidity is estimated to be 55% of NHS costs for secondary care and 75% of the costs of primary care prescriptions, with a projected increase in hospital costs of £4bn over the next 5 years (Stafford et al., 2018). Although to the researcher's knowledge more recent data on NHS expenditure on LTCs has not been published, it is likely that these figures are at the very least similar but more likely increased due to the rising prevalence of LTCs.

The number of people economically inactive due to LTCs in the UK is now over 2.5 million, of which 38% have 5 or more health conditions, up from 34% in 2019 (ONS, 2023a). The economic and healthcare costs of LTCs are of great concern, and increasingly so, with the rising prevalence of LTCs and multimorbidity in already stretched healthcare systems. However, there is a danger that a focus on the economic and healthcare system burden of LTCs may further contribute to the blame narrative of LTCs as neoliberal healthcare places responsibility on individuals for managing their health (Viens, 2019). An understanding of the impact of LTCs and their management on the individuals living with them is therefore essential in countering this view.

It is estimated that 26 million people in the UK live with at least one LTC (Stagg et al., 2022). The prevalence of LTCs is rising with aging populations and, as advancements in medicine reduces the mortality from many diseases, there is an increasing need to focus on reducing morbidity and improving the quality of life of people surviving illness and living with the long-term effects (Bernell & Howard, 2016). Further to this challenge is the prevalence of multimorbidity, which in the UK is between 23% and 27% (Barnett et al., 2012; Cassell et al., 2018) and globally, 33% (Nguyen et al., 2019). The prevalence of multimorbidity is projected to increase between 2015 and 2035, with the number of older adults with four or more conditions estimated to double during that time (Kingston et al., 2018).

LTCs can pose substantial challenges to the individual living with disease and their friends, families and communities (WHO, 2002) and can have an impact on all aspects of people's physical and mental wellbeing (DoH, 2012). Burden is associated with both illness and treatment and varies across and within conditions. The burden of illness includes the various symptoms experienced by individuals on a day-to-day basis (Nkhoma et al., 2018). Pain is highly prevalent in many LTCs and in some conditions pain is reported more frequently than symptoms of the primary disease, for example in chronic heart failure and chronic obstructive pulmonary disease (Viderman et al., 2023). Pain is a particularly impactful symptom for reduced quality of life with almost half of people with LTCs reporting moderate to extreme pain (DoH, 2012). Fatigue is experienced by many individuals across most LTCs, particularly post-stroke and cancer, and can be distressing and significantly impact an individual's daily life (Whitehead et al., 2016).

Individuals with LTCs are more likely to have depression and have worse health outcomes compared with depression or other LTC alone (Moussavi et al., 2007). In people's quests to live a life free of disease they face significant psychological and emotional challenges in relation to needing feelings of empowerment, capability and a sense of belonging (Eassey et al., 2020). People living with LTCs experience stigmatisation and blame as well as feelings of guilt, hopelessness and fear (Hajdarevic et al., 2024). Further, health stigma can co-occur with other stigmas such as gender, race, sexual orientation and socio-economic position (Stangl et al., 2019). Chronic illness can disrupt people's life narrative in numerous ways and challenge self- concepts (Estechea Querol et al., 2020; Hajdarevic et al., 2024). For example, people with LTCs, especially those with multimorbidity, are more likely to be limited in the type and amount of work they can do, which in itself can be detrimental to health (DoH, 2012). Perpetuating issues of financial instability and poor mental health due to their condition can further negatively impact their health (Estechea Querol et al., 2020).

The experience of LTC symptoms is compounded by the burden of their treatment. Treatment can involve taking medications, arranging and attending appointments, monitoring health, using medical devices, exercise and diet, and maintaining healthy bodyweight (Anderson et al., 2021; Eton et al., 2013). Dedicating time to these health-related activities is onerous for individuals and their families (Buffel du Vaure et al., 2016) and can incur financial cost (Sav et al., 2015). The side-effects of medications are also burdensome (Sav et al., 2015). For the increasing number of individuals with multimorbidities, there is the added encumbrance of needing to access multiple services (Barnett et al., 2012) and an increased risk of adverse events related to medication interactions in polypharmacy (Lleal et al., 2022). Further, complying with all clinical practice guidelines for people with three or more LTCs is unrealistic

according to Buffel du Vaure et al.'s (2016) model, which estimates that individuals may be required to take 3 – 13 medications per day, have 1.2 – 5.9 health visits per month, and spend 49.6 to 71 hours per month taking part in health-related activities. Individuals may have biomedical markers of disease without experiencing troublesome symptoms. In these circumstances, individuals' burden of disease may for a time, come solely from their management.

1.5 Management of long-term conditions

Health systems were originally developed to deal with acute and episodic care (Reynolds et al., 2018; Wagner, 1998) but since the second half of the 20th century, chronic disease has prevailed (Lorig & Holman, 2003). The management of chronic conditions is moving from the traditional provider-patient relationship to a model where individuals with LTCs work in partnership with HCPs to guide their care (Grady & Gough, 2014) and there is a commitment to shift care delivery from hospitals out into community settings (P. Ryan & Sawin, 2009). The Chronic Care Model (Wagner, 1998) outlined the need for decision support, clinical information systems, community resources, delivery system design, health system organisation, and SMS for improving care for people living with LTCs. The Chronic Care Model has been adapted for use in primary care in the UK and uses the analogy of a house to demonstrate the interdependence of the components necessary for the implementation of coordinated personalised care (Coulter et al., 2013). The House of Care model and the Diabetes UK Year of Care model include recommendations to support individuals to be more engaged and informed, and therefore better able to self-manage their conditions (Coulter et al., 2013). Despite the evolution of health systems in response to chronic care needs, the biomedical disease concepts which underpinned the 'old medical model' still persist (Fuller, 2017).

Long-term conditions fail to fit within the biomedical model which has dominated healthcare, partly due to the disconnection between lived-experience and the biomedical goal of curing disease (Green & Lynch, 2022). The biomedical model is reductionist in the context of LTCs because by definition it focuses on biomedical causes and solutions to illness (Fuller, 2017; Rocca & Anjum, 2020) failing to fully consider the complex determinants of health discussed in section 1.4. The biomedical model has been criticised for contributing to people becoming over-medicalised, over-diagnosed and not feeling as though they are seen as a whole person in medical systems (Rocca & Anjum, 2020). Biomedical paradigms frequently overlook individuals' self-perceptions and experiences living with LTCs (Hajdarevic et al., 2024). On one hand biomedical symptoms can co-exist with subjective perceptions of good health, while on the other, individuals can experience illness without an identified physiological cause (Bircher & Kuruvilla, 2014; Farre & Rapley, 2017). The biomedical model privileges professional knowledge, leading to a power differential between practitioner and 'patient' as illness is only legitimised following practitioner diagnosis (Green & Lynch, 2022). In the context of subjective good health, a biomedical focus on LTCs may in fact be detrimental to someone's experience of a good life due to the burden of treatment and following health guidelines described in section 1.5.

The limitations of the biomedical approach have been widely acknowledged, leading to an attempt to transition toward more collaborative approaches to healthcare and models which recognise the complex factors impacting health described in section 1.4. For example, Engel (1977) directly challenged the biomedical model, proposing the adoption of a biopsychosocial model to account for the reality of LTCs as human experiences. Numerous other models have steered healthcare practice, such as elements of the Chronic Care Model (Davy et al., 2015) discussed prior, the Narrative

Medicine model (Palla et al., 2024), and Cultural Competence Model (Henderson et al., 2018), but all should be underpinned by principles of person-centred care (McCormack et al., 2021).

1.6 Person-centred care

Person-centred care diverges from the biomedical model with its focus on personhood, anti-reductionism, partnership, mutualism and co-production (Harding et al., 2015). In contrast to the biomedical model, person-centredness is underpinned by principles of humanistic care (McCormack et al., 2021) focusing on the person as a whole (Downey et al., 2021). A person-centred approach sees a person as a capable and resourceful being, despite their health problems, the notion of capability being based on the philosophy of the person, rather than a neoliberal strategy to shift responsibility (Britten et al., 2017). Person-centred care is a practice which aims to move from the biomedical view of patients being passive recipients of care to supporting people to become active partners in their health (Britten et al., 2017). No single definition of person-centred care exists, and it is widely accepted as a multidimensional concept that has been applied in different ways in different contexts (Burton et al., 2017). However, all models of person-centredness include principles of mutual respect and individuality (Harding et al., 2015) and countering the power differential inherent in biomedical approaches (Green & Lynch, 2022). A person-centred approach involves shared decision-making, respect, a holistic approach and robust communication (Grover et al., 2022). Person-centred care is now central to various health policies (NHS, 2019; NHS England, 2017), particularly for the self-management of LTCs (Coulter et al., 2013; NHS England, 2015).

Central to this thesis is the focus on personhood and the eschewing of the biomedical 'patient' narrative of people living with LTCs. Where possible, the terms 'person', 'individual', or 'participant' will be used to align with this view. However, there are times where the term 'patient' may enhance clarity when distinguishing between multiple actors in discussions and findings. The term 'patient', unless stated otherwise, should therefore be understood as underpinned by the principles of personhood outlined in this section.

1.7 Self-management

Supporting self-management is central to person-centred care (Harding et al., 2015). Self-management is an inevitable part of living with an LTC and will be defined differently by each individual (Jones et al., 2011; Lawn et al., 2011). The term "self-management" has been used as early as the 1960s, when Thomas Creer used it to recognise that patients were active participants in their care (Lorig & Holman, 2003). Self-management can broadly be defined as an individual's day-to-day management of a LTC throughout its course, which for many will be a life-long endeavour (Lorig & Holman, 2003). As such, self-management is viewed as a process, rather than an event or outcome (Lawn et al., 2011).

The process of self-managing a LTC pertains to the activities individuals undertake to control their illness and limit or accommodate its physical and psychological consequences (Jones et al., 2011). These self-managing activities have been recognised to involve three key sets of tasks: medical and behaviour management; role management; and emotional management (Corbin & Strauss, 1985). Lorig & Holman (2003) expanded this set of tasks to five core self-management skills for people living with LTCs: problem-solving, decision making, finding and utilising

resources, forming partnerships with their HCPs, and planning and taking action to support their health. The original impetus for supporting people's ability to self-manage their LTCs was to improve patient care and was positioned as a key pillar of the Chronic Care Model (Wagner, 1998). Self-management support was intended to focus on individuals' concerns and problems, supporting people in applying knowledge and skills in the context of outcomes which are important to them (Lorig & Holman, 2003), in line with person-centred practices.

1.8 Self-management support interventions

This section presents the family of interventions which aim to support people with LTCs, namely self-management support (SMS) interventions. SMS interventions are broadly defined, followed by an overview of their modes of delivery. A critical discussion of person-centred practice and the conceptualisation of SMS is then presented, with a focus on group-based SMS interventions, which are the focus of this thesis.

1.8.1 Defining self-management support interventions

What constitutes a SMS intervention varies greatly across the literature (Jonkman et al., 2016). Some are described as behaviour-change interventions, education programmes, and some are referred to by their outcome, such as physical activity interventions. However, it is the multi-componential aspect of SMS interventions that set them apart from more focused exercise or psychosocial therapies (Jonkman, 2016). What should distinguish SMS from more traditional health promotion and patient education is the self-tailoring of the self-management skills and knowledge acquired (Lorig & Holman, 2003).

An operational definition of SMS interventions by Jonkman et al., (2016) proposes that support should aim to equip patients with skills to actively participate and take responsibility in the management of their chronic condition to function optimally. They propose that these self-management skills should be acquired through knowledge acquisition and at least two other supporting components: stimulation of independent sign/symptom monitoring, medication management, enhancing problem-solving and decision-making skills for medical treatment management, and changing their physical activity, dietary and/or smoking behaviour. Taylor et al. (2014) outline additional components in their taxonomy of SMS, which include psychological strategies to support adjusting to life with a LTC; practical support for physical care tailored to the specific LTC; creating action plans for LTCs that may deteriorate; and social support as appropriate. SMS programmes can therefore comprise varying combinations of supportive activities and strategies, making them complex interventions (Craig et al., 2008; Trappenburg et al., 2013).

1.8.2 Modes of delivery of self-management support interventions

The complexity of SMS interventions is evident in the multitude of formats in which they are delivered. SMS interventions are offered for specific LTCs and LTCs more generally, for example, DESMOND for diabetes in the UK (Skinner et al., 2008) and the Stanford Chronic Disease Self-Management Program respectively (Foster et al., 2007). Support may be delivered via booklets and DVDs; face-to-face, or remotely via online or telephone; in group settings or one-to-one; and delivered in a range of primary care, secondary care and community settings by a variety of healthcare providers and/or lay persons (de Silva, 2011; Timmermans et al., 2023). SMS interventions adopt different approaches and are underpinned by differing theories and assumptions (Mulligan et al., 2019). For example, SMS approaches may be

passive or active by providing information only or more actively supporting behaviour change by including strategies for self-monitoring with feedback and practical support with adherence (de Silva, 2011; Taylor et al., 2014).

This thesis focuses on face-to-face group-based SMS interventions, which have been demonstrated to provide opportunities for peer support and mutual learning, and may build confidence, increase social interaction and integration into society (Carnes et al., 2012; Hughes et al., 2017; Stenberg et al., 2016). Group-based SMS programmes have also been shown to support improved awareness of participants' condition and self-management strategies, help reduce symptom distress, and increase hope for the future (Stenberg et al., 2016). Systematic reviews have shown group interventions to be beneficial in improving pain, psychological symptoms, self-efficacy, self-care, quality of life and health service use (de Silva, 2011; Jackson et al., 2019). Group-based interventions may also be more effective than individual approaches for improving outcomes such as pain intensity and self-efficacy in chronic musculoskeletal pain (Carnes et al., 2012) and management of blood glucose by people living with diabetes (Mannucci et al., 2022). However, the comparison of the effectiveness of individual and group-based self-management interventions is challenging due to the heterogeneity within both approaches, as well as the limited number of RCTs available for analysis (Mannucci et al., 2022; Odgers-Jewell et al., 2017).

1.8.3 Person-centredness in self-management support interventions

Self-managing is complex and highly context dependent as it involves individuals managing their condition within a system or environment (Miller et al., 2015). The way that someone manages their LTC is dependent on their view of what a good life is, as well as their symptoms (van de Bovenkamp & Dwarswaard, 2017). Effective SMS

must therefore be person-centred, making the two concepts inextricably linked. Although SMS is central to person-centred care (Harding et al., 2015), approaches to SMS can drift back towards a more biomedical paradigm. For example, SMS interventions often aim to improve individuals' self-efficacy, focusing on their condition and on 'expert disease-management' rather than living well with their condition (Heggdal et al., 2021; Morgan et al., 2017).

SMS can be rooted in the idea that people living with LTCs require education on how to live their lives and should take greater responsibility for their actions and health (Harvey & Docherty, 2007; Kendall et al., 2011). SMS which assumes health to be an outcome of responsible behaviour and effective self-management can lead to health inequity through blaming individuals for their health outcomes (Kendall et al., 2011) and is arguably futile within systems that shape and constrain health behaviours (Harvey & Docherty, 2007). As has previously been discussed, health behaviours are complex and many of their determinants are beyond individual control. Individuals who do not self-manage their condition as expected and accepted by practitioners and health systems may be perceived as non-compliant and problematic, perpetuating individual blame (Franklin et al., 2018, 2021; Kendall & Rogers, 2007).

Just as a person's LTC self-management will depend on their views, the way in which LTCs and SMS are conceptualised will impact how SMS interventions are designed and delivered because fields of practice are shaped by the perceptions and beliefs of those working within them (Rocca & Anjum, 2020). The notions of what SMS interventions should do are partly reflected in the outcomes measured in programmes, with many interventions using biomedical outcomes to determine success (Franklin et al., 2021; Morgan et al., 2017); for example, HbA1c, body weight, BMI, waist

circumference, blood pressure, total cholesterol, LDL- and HDL-cholesterol, and triglycerides (Odgers-Jewell et al., 2017). Punna et al. (2019) measured the success of SMS interventions using physical activity and nutrition behaviour outcomes, reflecting their conceptualisation of self-management as an important means to change behaviour.

Individuals' health service utilisation is also a key outcome measure of SMS interventions (Allegrante et al., 2019; Allen et al., 2016; de Silva, 2011; Kendall et al., 2011; Schrijver et al., 2022; Trappenburg et al., 2013) due to the view that SMS is necessary to reduce health care costs. However, Harvey & Docherty (2007) liken the focus on cost-saving in the context of persistent upward pressure from demand for health services to Sisyphus rolling a rock uphill. They argue against hoping for supporting self-management to reduce healthcare costs and advocate for a focus on improving outcomes for people with LTCs. Cautions against a cost-reduction focus, in favour of quality improvement have been made since the outset of SMS. Wagner (1998) expressed concerns that cost-focus may reduce access to effective services. Viewing SMS as a cost-saving initiative further steers the SMS approach toward neoliberal and further away from person-centred aims and may also contribute to the blame-laden discourse of NCDs discussed throughout this chapter.

Despite the drive from policy, there is a demonstratable policy-practice gap in delivering person-centred care, particularly in the field of self-management for LTCs (Franklin et al., 2021; Kane et al., 2015). Studies of SMS interventions often fail to elucidate their incorporation of person-centred elements (Lafontaine et al., 2020). Incorporating person-centred practices in group-settings is particularly challenging. Group-based SMS programmes are generally considered and encouraged as a cost-

effective approach to supporting people living with LTCs (Hughes et al., 2017; Mensing & Norris, 2003), and as stated previously, have the important benefit of peer-support and mutual learning (Carnes et al., 2012; Stenberg et al., 2016). However, group interventions can be teacher-centred which undermines person-centredness (Stenov et al., 2018) and the degree to which individual needs are incorporated in group settings varies (Mensing et al., 2003). A significant challenge exists in the conflict between group-based programmes being curriculum-based to promote quality and efficiency, and working flexibly with patients to meet their individual needs (Horigan et al., 2017).

Person-centred care is often absent in practice, despite there being numerous supportive conceptual framework and training to support its implementation (Downey et al., 2021). Although practitioners aspire to be more person-centred, they can have an inveterate tendency toward a medical approach due to tensions between what practitioners view as a healthier lifestyle versus what individuals see as a better life (Bossy et al., 2019; Morgan et al., 2017). Practitioners may perceive their practice to be person-centred but patient feedback can be contradictory (Eaton et al., 2015), resulting in person-centred approaches to SMS being more evident in aspirational accounts rather than accounts of practice (Morgan et al., 2017). Achieving person-centred care requires an understanding of real-world necessary conditions and practices for its implementation, which are currently underexplored (Downey et al., 2021).

1.10 Chapter summary

This chapter has outlined the landscape of long-term health conditions by discussing how they are defined and conceptualised; their complex individual, social and

commercial determinants; and their impact on individuals and their families, health services and society. This chapter has discussed the changing models of healthcare within the context of the increasing prevalence of LTCs and multimorbidity. The needs and lived experiences of people with LTCs necessitate a shift from reliance on biomedical and paternalistic approaches to healthcare towards person-centred care. Central to person-centred care is supporting self-management of LTCs and support interventions must be person-centred. Although these concepts are interdependent, the two often fail to merge in practice. SMS interventions can have a tendency to drift back towards biomedical foci and neoliberal aims by focusing on cost-saving and disease control. A plethora of SMS interventions exist and group interventions have particular value as they offer opportunities for peer learning and support. However, the inevitable and necessary complexity of SMS interventions, particularly those that are group-based, creates a challenge in developing an evidence base to effectively support their use, especially in a person-centred way.

1.11 Thesis structure

This PhD thesis comprises seven chapters. The current chapter has presented an overview of long-term health conditions and their management, culminating in the rationale for this research project.

Chapter two presents the scoping phase, from which the aims of this thesis were further refined to focus on engagement with group-based SMS programmes.

Chapter three of this thesis presents a narrative review of the literature on engagement with group-based SMS programmes. The chapter begins with a description of the

methods used for the literature review and subsequently presents and discusses the findings of the review. The chapter concludes by setting out the aims and objectives of the empirical work undertaken for this thesis.

Chapter four details the methodological approach employed for this research. The chapter begins with an overview of my identity as a researcher and continues to set out the philosophical underpinnings and key tenets of realist inquiry. An explanation of realist evaluation and why it was used for this research is provided, followed by a discussion of quality in realist research and reflexivity.

Chapter five presents the specific methods of the realist evaluation. The methods used for theory development are discussed and justified in this chapter. The theory development methods include the choice and use of conceptual frameworks, a description of the data sources and collection methods used, and how initial programme theories, in the form of 'if...then...' statements, were consolidated. The process of triangulating data and further consolidating the initial programme theories into testable programme theories is also described in this chapter. The chapter continues with detailed descriptions of the verification and refinement of the proposed programme theories and their context-mechanism-outcome configurations.

Chapter six presents the programme theories via seven mini-chapters. Each mini-chapter presents a programme theory from its initial to its refined form, supported by empirical findings and substantive middle-range theory.

Chapter seven discusses the findings from this research in the context of wider debates in the self-management and engagement literature. Following this discussion, recommendations for practice and future work are presented. The final section of the chapter provides a critical reflection of the research undertaken.

Chapter 2 Scoping phase

2.1 Chapter overview

This chapter will introduce the researcher, the project and the suite of person-centred group-based SMS programmes which are the subject of enquiry for this thesis. These SMS programmes were developed in response to the persisting creep of biomedical ideals into the support for people with LTCs. The underpinning philosophies which drove the development of the programmes will be discussed and their components and content will be outlined. The evaluation of the programmes conducted to date will be presented, followed by a critical discussion of approaches to evaluating complex interventions. The chapter then presents the rationale for the use of realist evaluation to investigate these group-based SMS programmes. The chapter moves on to describe the preparatory work and scoping exercises undertaken to determine the specific focus of the realist evaluation: engagement. The chapter concludes with the thesis aims and objectives.

2.2 Introducing the project and researcher

The PhD project undertaken for this thesis was a fully funded studentship, offered as part of a package of PhD bursaries across numerous schools within the university. This PhD studentship was offered within the School of Health and Wellbeing to build on work previously undertaken in the delivery of student-led health and wellbeing (H&W) services. The H&W services and their evaluation to date are discussed in more detail in the following section 2.3. Following the recognition of the complexities of the H&W programmes, and the desire to support their spread and scale-up, the PhD studentship aimed to fund a more complex enquiry into how the programmes worked. A realist enquiry to explore how the H&W services work, for whom, why and which

circumstances was subsequently advertised as a fully funded PhD studentship, for which I applied.

At the time of applying for the studentship, I was working as a full-time lecturer at another institution and looking to develop the research strand of my career pathway. I am an osteopath by background, having completed my integrated Masters in the UK. Although I enjoyed some time in clinical practice, I have focused on shaping my career pathway in research and teaching and learning. Alongside my clinical practice, I held an associate lecturer position in osteopathy and a part-time position as a research assistant, working in a centre for primary care and public health where much of the work being undertaken was in translational research and complex interventions. During this time I gained some understanding of the need for research approaches which were consistent with the complexities of health interventions, which planted the initial seed for my research interests.

After my research assistant post I took a break from research and clinical practice to complete my teacher training in secondary science, and subsequently returned to teaching full-time in higher education with Qualified Teacher Status. My career journey may be described as a portfolio career, with my work in clinical practice, education and research. Although on the surface these areas may appear disparate, my experience in these disciplines were what led me to apply for this PhD studentship which offered an opportunity to develop my research skills through the exploration of complex health interventions in an educational setting, which themselves included an element of education. The way in which my background influenced the undertaking of this research is discussed in more detail in Chapter 4.

2.3 Introducing the H&W group-based self-management support programmes

The interventions under inquiry for this thesis are a suite of group-based SMS programmes, rooted in person-centred principles, supporting people living with LTCs in a local region in the Southwest of England, UK. The group of interventions are generally referred to as Health and Wellbeing (H&W) programmes by the programme team and their stakeholders so, the prefix H&W will be used throughout the thesis when referring to the team, approach and programmes overall. The H&W team responsible for the inception of these programmes recognised the limitations of the prevailing biomedical model, critiqued in the previous Chapter 1. The H&W teams sought to deliver multi-component SMS programmes, which maintain a holistic approach, to support the health and wellbeing of people living with LTCs (Bloxham et al., 2016; Bloxham et al., 2020; Downey et al., 2021). The SMS components of these programmes are described in section 2.2.3. The members of the H&W team who developed and delivered the first iterations of the H&W programmes were lecturer-practitioners based within a Higher Education institution. Alongside the goal of delivering person-centred support for people with LTCs was the aim to provide real-world learning for students aspiring to work in health and health promotion settings. Therefore, in addition to the programmes' alignment with person-centred values, the programmes are also underpinned by aims of experiential learning and knowledge exchange. The following two sections of this chapter explain these principles and how they form the foundation of the H&W programmes.

2.3.1 Person-centred underpinnings of the H&W programmes

Evaluation of the earliest iterations of the H&W programmes identified the value of a holistic and gentle approach to supporting individuals in managing their low back pain

and improving their physical activity levels (Gordon & Bloxham, 2017). Two ethnographic studies conducted by the H&W team elucidated the need to consider social contexts and interactions for exercise interventions to be successful (Williams & Gibson, 2018), further shaping the person-centred philosophy underpinning the H&W programmes. Williams & Gibson (2018) illustrated their findings through creative non-fiction stories, bringing to life the social determinants of health behaviours and the consequences of lifestyle drift in interventions discussed in Chapter 1. The H&W team became committed to providing support which moved beyond simply “educating” people about the benefits of physical activity and other positive health behaviours by seeking to understand individual barriers to changes in behaviour (Gibson & Malcolm, 2020; Williams & Gibson, 2018). The H&W team sought to prioritise the prevention of lifestyle drift and blame-laden approaches in their group-based SMS programmes by focusing on supporting individuals to become more empowered (Downey et al., 2021).

The prevailing culture of the H&W team, programmes and the organisation within which they were developed, is founded in humanistic practice, realised through unconditional positive regard for individuals using the H&W services (Downey et al., 2021). As such, the use of group-based approaches to supporting individuals is based on the value to the individuals in need of support, rather than as a cost-effective and convenient initiative for healthcare providers, which is a common impetus for designing this mode of support (Hughes et al., 2020). Group-based programmes were adopted by the H&W team for their use in generating intrapersonal behaviour change (Borek et al., 2019) and encouraging social integration (Queen et al., 2017). By delivering support in groups, the H&W programmes are proposed to help shape attitudes and behaviours through social connectiveness and to enhance wellbeing through valued membership and group belonging (Downey et al., 2021). The ways in which person-

centred practices are operationalised in the H&W programmes are discussed in detail in a separate publication (Downey et al., 2021) but can be summarised as being achieved through connecting with people, through groups and with self. Group work was posited to reduce power-differentials, thus supporting person-centred practice, which is in some contrast with the critique that group interventions can fail to be person-centred (Stenov et al., 2018). Downey et al. (2021) identified the need for organisational commitment to person-centred care and facilitator approaches to realise a person-centred practices in these group settings.

2.3.2 Student-led knowledge exchange in the H&W programmes

The H&W programmes were initially developed in a Higher Education setting, referred to as University from here in, as an opportunity for students to gain experience in working with people with LTCs and to support the development of their person-centred practice. Consequently, the group-programmes are often co-facilitated by students, providing a setting for mutual learning between programme participants and students. Running concurrently to this PhD research was a Research England and Office for Students funded project, undertaken to explore student-led knowledge exchange (SKLE) in Higher Education. The SKLE project identified that knowledge was viewed as socially constructed, where the knowledge of students, educators and programme participants are viewed as equally important, facilitating knowledge exchange, rather than simply experiential learning (Cotton et al., 2024). Valuing the knowledge of programme participants equally and the presence of students were deemed to be important in reducing power differentials, which combined with a de-medicalised approach and setting, supported the operationalisation of person-centred practices (Cotton et al., 2024; Downey et al., 2021).

2.3.3 Programme descriptions

Several services have been designed and delivered by the H&W team over the past 10 years, most of which have been group-based SMS programmes, though some focus more on supporting physical activity or are delivered one-to-one. The H&W group-based programmes are also part of a wider portfolio of health and wellbeing-related services delivered at the university. Some of the institution's degree programmes require students to gain experience in practice settings, for example, for qualifications in osteopathy, sports therapy and psychotherapy and counselling, and acquire this experience through placements in student-led clinics within the university. Further, the university has provided a location for external partners to deliver services, such as pain management programmes and interventions for people living with Long-COVID.

The services delivered at the university by the H&W team, and indeed by external providers, have a range of funding sources which are influenced by various contexts, which in-turn shape the way programmes are implemented. The changeable nature of service funding and priorities have led to continuous changes to the types of services and programmes delivered, programme components and their delivery over time, epitomising the complexity of these types of programmes. The number and types of programmes offered changed throughout the course of this PhD.

Although the group-based SMS H&W programmes, referred to as H&W programmes from here on, were developed within and delivered at the University, many are now delivered in various locations within a 16-mile radius of the University campus. H&W programmes have been developed for various groups over the past decade, including people with low back pain, leg ulcers and cancer; as well as groups with mixed LTCs.

Programmes have typically been delivered over 6 – 8 weekly as 1-2 hour-long small group sessions by exercise or sport therapy professionals, aided by students studying on various sport and health related degree programmes, for example, sport and exercise science, sports therapy, and sports rehabilitation. These students support participants in engaging with physical activity, sleep hygiene, healthy eating and mindfulness (Bloxham et al., 2016; Bloxham et al., 2020; Queen et al., 2017).

2.3.4 Evaluations of the H&W programmes

Early evaluations of the H&W programmes have shown improvements in various outcomes. The first H&W programme to be evaluated was for individuals with low back pain. The Local Health Authority commissioned a multidisciplinary subacute low back pain service, of which H&W was invited to deliver the exercise component. The primary aim of the programme was to support people with low back pain to better self-manage their pain and improve their physical activity levels. Although biomedical outcomes were not the primary focus of the programme, biomedical outcome measures were used to facilitate optional self-exploration activities during the programme (Downey et al 2021). Analysis of pre- and post-programme outcome measures demonstrated improvements in low back pain disability, strength, mobility, aerobic capacity, and body composition following a pilot of the programme (Bloxham et al., 2016). Outcomes also improved in a subsequent larger evaluation of 181 participants where there were statistically significant improvements in physical activity, aerobic capacity, muscle strength and LBP disability (Bloxham et al., 2020).

A qualitative evaluation of a H&W programme to support people recovering from cancer showed that patients' physical activity improved over the 6-month data collection period (Queen et al., 2017). Most patients attributed their motivation to take

part in the programme to come from the exercise professionals and the peer support network that was developed, with the latter highlighting the specific value of the group setting. Participants reported improvements in quality-of-life indicators relating to self-management, self-efficacy and chronic fatigue, with many feeling that they had taken control of their cancer recovery.

Unpublished data from a H&W programme supporting people with leg ulcers showed improvements from pre- to post programme in leg ulcer healing (80%), aerobic fitness (15% - 6-minute walk), ankle mobility (53%), timed up and go (11%), balance (Berg - 10%), wellbeing (11% - Warwick and Edinburg), pain (VAS - 20%), and flexibility (59% - Chair sit and reach). The value of the H&W programmes has also been captured in testimonies from stakeholder partners and people who had attended H&W programmes in a Research Excellence Framework impact case study (Bloxham et al., 2021); qualitative feedback from participants on H&W programmes spanning 10 years; and stakeholder partner interview transcripts from the SKLE project introduced in section 2.2.2.

The evaluations conducted for the H&W programmes so far have captured improvements in various biomedical, functional, and psychological outcomes for programme participants as well as the positive regard held for the H&W approach by participants and stakeholder partners. As with all complex interventions, a challenge lies in establishing how these outcomes are generated. Elucidating this further is an important step in generating a useful evidence-base which could support further spread and scale-up of this valued person-centred approach.

2.3.5 Delivering new self-management support services and learning from practice

In the local and wider context of needing to increase and improve services for people with LTCs, the positive results from the H&W evaluations have shown the potential of the H&W delivery model to support a wide range of local healthcare services. As a result of the positive impact of programmes to-date, local healthcare services have supported and requested H&W involvement in fibromyalgia, falls-prevention and other new LTC services. More recently, following the COVID-19 pandemic, there may also be emerging opportunities to support people with Long COVID (Leung et al., 2020). Public service organisations in the local area have also shown keen interest in the role that H&W can play in health and wellbeing promotion initiatives for their workforce.

Chapter 1 highlighted some of the complexities of delivering SMS, particularly in a person-centred way. The complexity of SMS interventions stems not only from the number of components and variety of settings but also from the expertise and skill required of those delivering and receiving the intervention (Skivington et al., 2021). Complex interventions are context dependent (Minary et al., 2019) and their interacting components are inseparable and dynamic (Cohn et al., 2013). Moreover, individuals are not passive in their receipt of SMS interventions as they interact with and interpret what interventions have to offer (Pawson, 2013). Individual circumstances and the determinants of health already discussed will therefore contribute to how interventions impact people with LTCs. In the case of this thesis, understanding how a person-centred approach is operationalised in the H&W programmes, and how the programmes help support people in self-managing their LTCs is not currently well understood.

The replication, scale-up and integration of complex interventions, such as SMS programmes, is often poor (Cuthbert et al., 2019) even when evidence for their benefits is strong (T. Greenhalgh & Papoutsis, 2019). Interventions that are scaled-up often do not achieve the same effect size; a phenomenon known as “scale-up penalty” (Lane et al., 2021; McCrabb et al., 2019). The substantial variability in all aspects of SMS interventions, described in the previous chapter, may account for some of the challenges in replication, scale-up and integration into practice (Cuthbert et al., 2019). Scaled-up H&W programmes will be delivered in different ways, and in different contexts, irrespective of their shared person-centred underpinning and philosophy. Each new, scaled-up programme will need to adapt to their specific contexts, which may include changes to the mode of delivery, for example, number of intervention elements, frequency and duration of delivery, and training and resources for those delivering the services; service setting; target audience; culture (e.g. language); and infrastructure (Lane et al., 2021; McCrabb et al., 2019). Programmes comprise formal components and strategies, such as the aforementioned intervention elements, but they also include informal aspects, such as the attitudes of HCPs and spontaneous collaboration between HCPs (Jagosh et al., 2022). The informal aspects of programme delivery are less well documented in policy than the formal aspects, yet they are essential components of how programmes work and are sustained through evolving models of health service delivery (Jagosh et al., 2022).

One of the most valued aspects of the H&W programmes is the person-centred, multi-component approach to supporting the empowerment of people with LTCs to improve their lives and health outcomes. Partner stakeholders reported that the H&W approach addressed the gap in previous service provision by supporting people to self-manage and adopt health behaviours within their own circumstances, leading to longer-term

behaviour change (Bloxham et al., 2021). Much of what is necessary for the person-centred delivery of the H&W programmes may reside in their informal architecture. Challenges in the translation of person-centred care principles into practice have led to calls to explicate the necessary components and conditions from successful examples in practice (Downey et al., 2021).

Medical Research Council guidance on evaluating complex interventions recommends moving beyond investigating the design of programmes to exploring mechanisms for change and their necessary conditions in real world implementation (Skivington et al., 2021). The guidance also moves its focus of evaluation beyond simply evaluating effectiveness and places more emphasis on asking broader questions, such as theorising how interventions work, how they interact with their implementation context, their additional impact, their contribution to system change and how evaluation efforts can support real world decision making. The challenges faced in the real-world delivery of person-centred, group-based SMS programmes, discussed thus far, require explanation for how programmes work in their given contexts to support implementation of these types of programmes. Developing an understanding of how both the informal and formal H&W programme architecture contribute to their person-centred approach can help to answer this call. A complexity consistent approach to enquiry is therefore necessary to develop the evidence base for person-centred SMS interventions and improve the translation of evidence into practice.

2.3.6 A scientific realist approach to evaluating the H&W programmes

Realist evaluation has gained considerable momentum in the research community due to its value in investigating complex interventions. The realist underpinnings of the

research in this thesis will be discussed in detail in the methodology chapter, Chapter 4. An overview is given in this current section to provide context and to support understanding of the scoping phase, which is reported later in this chapter.

Scientific realism embraces the social complexity in complex interventions in its key assumptions about how programmes work. Pawson and Tilley (1997) assert that programmes do not directly cause outcomes, rather it is the reasoning and responses of individuals that lead to change. They explain that outcomes are produced via generative causal mechanisms. These, most often invisible, mechanisms can be found in the choices and decision-making of individuals, and interactions between individuals. Mechanisms are considered to be activated, hindered or shaped by individual, inter-personal or organisational contexts meaning that programmes will not work in the same way for all people in all circumstances. Based on this understanding of how programmes work, observing what programmes do only provides information about the resources provided, not the underlying responses of individuals, and so fails explicate how programmes achieve their outcomes (Astbury & Leeuw, 2010; Westhorp, 2014). To develop our understanding of how programmes so reliant on social factors work, it is necessary to explore beyond the empirically observable components of programmes and investigate the underlying causal links between them (Jagosh, 2019).

A realist evaluation is a type of theory-driven evaluation underpinned by the philosophy of scientific realism (Westhorp, 2014) and is relevant when evaluating human services and health programmes where interventions involve the cognitive and emotional responses of stakeholders (Jagosh, 2020). A realist approach is particularly useful for programmes that appear to be effective, but it is unclear how or why; are due to be

scaled out; and have mixed patterns of outcomes (Westthorp, 2014). Realist inquiry seeks to move beyond simply describing processes and outcomes of interventions to developing an understanding of how and why interventions work, or indeed fail (Pawson & Tilley, 1997). The approach is epitomised by the typical realist questions “what works for whom, in which circumstances and why?”. The premise is that outcomes of programmes, both intended and unintended, come about via generative causal mechanisms that are activated in specific contexts. Realist approaches build nuanced explanations about how programmes work to transfer learning to and from similar types of programme (Punton et al., 2016). The realist approach adopted for this doctoral research specifically sought to produce explanatory theory for how person-centred group-based SMS programmes work to contribute to addressing the challenge of delivering person-centred care in SMS, as discussed in the previous Chapter 1.

2.3.7 Section summary

This chapter section has introduced the H&W programmes and their underpinning principles. The evaluative work undertaken to date (section 2.2.4) has been summarised and supports the opportunities for developing further services using the much-valued H&W approach. The need for a complexity consistent approach to evaluating the H&W programmes has been outlined (section 2.2.5). Realist evaluation has been introduced as the optimal research approach chosen to meet these complex needs when evaluating group-based person-centred SMS programmes (section 2.2.6). A realist approach will inform scale-up and spread of the programmes and contribute to addressing the policy-practice gap in person-centred care. The following section presents the preparatory work undertaken to define the scope of the realist evaluation undertaken for this thesis.

2.4 Defining the scope of the realist evaluation

Due to the depth of, and search for, nuanced explanations in realist inquiry, it is not possible to answer all questions or issues relating to a programme in a single realist evaluation. Therefore, the scope of the evaluation must be clarified, and questions prioritised in advance (Westhorp, 2014; Wong et al., 2016). Involving stakeholders in this process can make the findings of the evaluation more useful (Westhorp, 2014), which is a key criterion of quality in realist research (Wong et al., 2016) and essential for research impact. Including patient and public stakeholders in this discussion improves the relevance and overall quality of research by making sure the foci are important to patients (Staniszewska et al., 2017). Stakeholder and patient consultation are arguably of additional importance in realist evaluation as mechanisms can be found along extensive causal chains and at different levels of zoom. Identifying these mechanisms necessitates a choice being made about the points at which they will be examined (Westhorp, 2014).

This doctoral research began with a scoping phase to identify priority foci for the work undertaken. The following section outlines the methods and findings of the scoping activities and how they informed the focus for the literature review (Chapter 3) and the realist evaluation (Chapters 5 and 6). Focus groups were facilitated with stakeholder groups in June and July 2021. Consultations were undertaken with three separate stakeholder groups to allow the clear delineation of patient and public, and stakeholder partner contributions. The three stakeholder groups were the H&W partner stakeholders; previous attendees of H&W programmes; and members of the public with LTCs who had no experience of or connection the H&W programmes.

2.4.1 Ethical considerations

Involving patients and the public in the research process is important for carrying out more meaningful and relevant research (Preston et al., 2019). Ensuring the views of patients and people with LTCs were equally accounted for in directing the focus of this research was a key ethical consideration and the process is described in the following sections. Providing each group of contributors a separate forum to discuss their ideas for the evaluation aimed to give people with LTCs the opportunity to discuss their hopes and concerns with someone who was not a medical expert. Power differentials may come about in the way that conflicting stakeholder views are prioritised (Lander et al., 2019). The collection of separate views, rather than consulting with a mixed group of contributors, helped to ensure that the stakeholder views were not prioritised over the groups with LTCs.

Power in research often remains with the researcher, even within patient and public involvement activities to support the research process (Brand et al., 2020). Researcher power was explored through a reflexive account of the triangulation and decision-making process. Reflexivity and my position as a researcher will be discussed in detail in the methodology Chapter 4. The ethical implications for this work are further considered in Chapter 5. The triangulation process will be described in the following sections.

Although ethical approval is not typically required for patient and public involvement (PPI) activities, the iterative and emergent nature of realist evaluation methodology can blur the lines between PPI activities and data used for theory development, therefore an ethics application for Phase 0 was submitted to the University Ethics Panel and received a favourable ethical opinion (Appendix A and B).

2.4.2 Partner stakeholder consultation

The partner stakeholder consultation took place during a stakeholder event at the University campus where the H&W team are based. Partner stakeholders were invited to network and take part in a wider discussion about the development of Health and Wellbeing Services in the local region. Due to the COVID-19 pandemic, the event was held in a hybrid fashion so that delegates could attend in-person or online, via Microsoft Teams. Prior to the scoping consultation for the realist evaluation, partner stakeholders were provided with an overview of the H&W programmes and the PhD project during the introductory keynote presentations at the start of the stakeholder event. The stakeholder consultation was facilitated by the researcher and a member of the H&W programme team using the online platform: *Padlet*, to collate views and feedback from in-person and online delegates in one place. Stakeholders were encouraged to add to their feedback up to one week after the event. The verbal discussion was recorded using MS Teams and manually transcribed for analysis along with the *Padlet* feedback.

The questions presented for consultation were developed from Westhorp's (2014) list of potential questions for realist evaluation and adapted following discussion with members of the H&W programme team (Figure 2.1). Providing possible evaluation questions and topics for stakeholders to comment on rather than offering a completely open forum for suggestions, helped to ensure that feedback was useful and appropriate for realist evaluation.

Figure 2.1

Potential realist evaluation questions. Adapted from Westthorp (2014)

1. Where do you want to go?

What is your/your organisation's vision for self-management support?

2. Getting there...

What are the issues relating to self-management programmes like the ones that H&W deliver?

3. Focusing the evaluation

Do you think any of the following evaluation questions/topics might help to address any of the issues you identified and achieve your vision? If not, how could they be altered to be more useful? Please give each topic a star rating to indicate which are of highest priority.

- **Successful programmes**
*What matters about how the programmes are run for them to work?
When it works/doesn't work, why?*
- **Contexts**
How do programmes work in different contexts?
- **Uptake and attendance**
*Why do people continue/discontinue attendance of the programmes?
What impacts uptake on programmes?*
- **Understanding sub-groups**
*Which subgroups do the programmes reach/not reach and why?
Do outcomes vary across subgroups and if so, why?*
- **Long-term outcomes**
What works for whom, in which circumstances and why?
- **Commissioning**
What impacts the successful commissioning of these programmes, how and why?

2.4.3 Patient and public consultations

People with LTCs were consulted to contribute to the refinement of the focus for this PhD research during two separate focus groups, independent of the partner stakeholder event. The focus groups for people with LTCs, with and without

experience of the H&W programmes, were guided through a discussion on the following areas:

- Views on services for people with LTCs (brief)
- Views on self-management support programmes for people with LTCs
- Barriers and specific issues relating to self-management support programmes

Six people attended the H&W participant focus-group, which were a group of individuals who had previously attended a H&W programme. All participants were white and over the age of 60; four were male and two were female. Recruitment for the LTC focus group who had no experience of H&W programmes proved challenging. Despite approximately 15 people initially agreeing to participate; and efforts to arrange two groups to provide a choice of time, only two people attended. Such poor attendance was considered a finding in itself as some people explained that symptoms of their condition prevented them from attending, while others made apologies explaining that last-minute family commitments had prevented them from attending. Recruitment was aimed at people with a range of demographics by promoting the focus group opportunity through community Facebook groups, LTC charities, and GP practices. The two non-H&W participants were both white females under the age of 40. After 20 minutes, the internet connection for one of the participants failed so the discussion continued with the remaining participant.

2.4.3 Determining the focus of engagement

Transcriptions, follow-up emails and Padlet contributions were collated from all events and were analysed using thematic analysis (Braun & Clarke, 2006). The aim of triangulating the data was to identify which themes (Table 2.1) were common across

all stakeholders, giving more equal voice to all contributors and to enhance the quality of this phase of the research. All contributors expressed concerns and described challenges relating to awareness of programmes, referral, and attendance. The term “engagement” was frequently used by partner stakeholders when describing these challenges. For example, one stakeholder commented via MS Teams “interesting is early middle and late stage engagement in these type of interventions and impact on individual”. Other stakeholders provided comments on Padlet suggesting that the evaluation could seek to establish “why people don’t engage”, “what people want”, and “what people feel they can engage with”.

Previous and current participants on H&W programmes were concerned about why the programmes were not attended by more people who could benefit, and proposed reasons for why the problem existed: “so personally, I think it’s brilliant, but why aren’t people doing it?”, “they’re not being told about it”, and “it’s not advertised enough”.

Members of the public with LTCs echoed the concern regarding the lack of awareness and promotion. One individual said “I think things have got to be more advertised in the likes of the clinics you go to or by the doctors, GPs and things like that, you know, I think it would make a big difference”. Focus group participants also recognised more nuanced factors influencing engagement with programmes, showing an awareness of the complexity of the challenge of engagement.

There was a couple people in that group who had said they weren't going to go because they were too embarrassed. So, they were too shy or, you know, things like that, but they said was the best thing we ever did, because they got to meet, we have a group chat and all now, you know, we kept in touch with each other. (LTC public focus group)

Some contributors described engagement as a process occurring (or not) within programmes rather than simply whether people attend, as shown in an earlier quote where the process is described as early, middle and late. The low attendance for the non-H&W focus group further exemplified engagement as an issue. Challenges in recruiting patients and the public for research participation are noted in the literature, particularly non-attenders to healthcare services and people from ethnic minority groups and with lower SES (Bonevski et al., 2014; Gilfoyle et al., 2023).

Table 2.1

PPI themes for focusing this evaluation

Focus area	Members of public with LTC	Previous H&W participants	Stakeholder partners
Successful programmes			
Value of face-to-face vs online	x	x	x
HCP/LTC expert facilitator	x		
Individualised guidance and goal setting	x	x	x
Uptake & attendance			
Uptake & engagement	x	x	x
Referral	x	x	x
Promotion	x	x	x
Patient understanding of self-management	x		x
Contexts			
Isolation & loneliness	x	x	x
Peer & family support	x		x
Capacity of health services and staff	x		x

Long-term outcomes	x	x
Commissioning		x

Following the triangulation of data and identifying themes prioritised by all stakeholders. Engagement was considered to represent the most pressing concern shared by stakeholders and the term engagement incorporated ideas that were discussed in more depth during the consultations. Consequently, engagement with group-based SMS programmes was determined as the focus of this realist evaluation. The next section briefly introduces the concept of engagement and will be considered more critically in the context of group-based SMS programmes in the following chapter.

2.5 Engagement

Engagement is an essential person-centred process as it reflects the connectedness between patient and practitioner (McCormack & McCance, 2016). Engagement, or a person's responsiveness to an intervention, is also considered to be a key aspect of intervention fidelity (Carroll et al., 2007) and therefore, in part, determines whether a programme is likely to result in positive patient outcomes and satisfaction (Graffigna et al., 2015; Rookes et al., 2022). Engagement is a salient issue to tackle in the context of person-centred SMS, which was reflected in the unanimous concern expressed by contributors to the scoping phase of this research. However, what is meant by patient engagement is often unclear.

The term engagement is ubiquitous in healthcare policy and literature. Engagement in the field of healthcare is discussed in the context of patient engagement with their

healthcare in general (Parsons et al., 2010); patient and public engagement with healthcare research (Domecq et al., 2014); practitioner engagement with healthcare policy (Keyworth et al., 2018); patient engagement with self-management behaviours (Simmons et al., 2014); and patient engagement with interventions (Jahandideh et al., 2018). As well as patient engagement playing a key role across multiple aspects of healthcare, the concept itself is complex. Although no single definition exists, many authors agree that it involves cognitive, emotional and behavioural processes (Bright et al., 2015; Graffigna et al., 2015; Mittler et al., 2013).

The complexity of engagement and its importance in healthcare has led to calls to explore the concept in more depth. Particularly lacking in the literature is an understanding of whether particular components of the process of engagement are essential; an exploration of the temporal aspects of engagement; the identification of whether aspects of engagement differ for different groups of people; and exploration of the patient/clinician relationship (Bright et al., 2015). A realist evaluation of the person-centred H&W programmes provides the opportunity to address these knowledge deficits in a way that captures and explains the complexity of engagement rather than attempting to control or eliminate it.

2.6 Thesis aims and objectives

The overarching purpose of this thesis is to explore how people with LTCs engage with group-based SMS programmes, in which circumstances and why.

2.6.1 Aim

To produce portable, nuanced theory-informed insights which explain how group-based SMS programmes may be delivered in a way which supports participant engagement.

2.6.2 Objectives

- To identify key features of programme architecture and their mechanisms which may enhance or inhibit engagement.
- To explore how specific contexts shape mechanisms impacting engagement.
- To verify and refine the theory-informed explanations of how people with LTCs engage with group-based SMS programmes.

2.7 Chapter summary

This chapter has introduced the H&W programmes which provide the foundation for knowledge building for this PhD. The programmes provide real-world examples of person-centred group-based SMS programmes for people living with LTCs. Early evaluative work has demonstrated that the H&W programmes are effective in improving various health and wellbeing outcomes; that the programmes are valued by participants and stakeholder partners; and have been impactful in the local region. Challenges in evaluating, delivering and scaling up effective person-centred SMS in groups has led to calls to generate examples from practice that are evaluated in complexity consistent ways. A realist evaluation aims to contribute knowledge to this field by explicating what works, for whom, why, and in which circumstances. The preparatory work in determining the focus of the evaluation has been presented, with details of how patient, public and stakeholder contributions have been accounted for. Contributors were unanimous in their concerns regarding engagement with SMS.

Engagement is essential to person-centred care and is a key determinant of whether programmes work and is therefore a salient issue on which to focus this research. Developing an understanding of how individuals engage with programmes through realist evaluation can contribute nuanced and actionable insights to support programme commissioners, architects and practitioners in designing and delivering effective programmes. This chapter concludes with the overall purpose of this thesis, its aim and objectives. The narrative review in the following chapter aims to provide a critical overview of what is already known about engagement with group-based SMS programmes within which to situate this thesis.

Chapter 3 A narrative review of engagement with group-based self-management support programmes

3.1 Chapter overview

This chapter will explore patient engagement with group-based self-management support (SMS) programmes through an integrative narrative review of the literature. The justification for the literature review method and the search strategy are detailed, followed by an overview of the included studies. The chapter moves on to present the factors reported to relate to engagement in the reviewed body of literature. Next, some key points of critique for the body of research are discussed, identifying salient gaps in the research and challenges in the field. Limitations of this integrative review are then presented, followed by a summary of the chapter. The chapter concludes with the research questions for the realist evaluation undertaken for this thesis.

3.2 Chapter introduction

The focus of engagement for the realist evaluation undertaken for this thesis was determined following consultation with a range of stakeholders, the process of which was described in the previous Chapter 2. Engagement is essential in the delivery of person-centred care (McCormack & McCance, 2016) and plays a key role in intervention fidelity (Carroll et al., 2007) and positive patient outcomes and satisfaction (Graffigna et al., 2015; Rookes et al., 2022). Moreover, engagement with group-based SMS programmes was considered a key area requiring investigation and improvement amongst the stakeholder contributors to the scoping phase. As described in the previous chapter, engagement is a complex phenomenon, discussed in various healthcare contexts. The aim of the narrative review in this chapter is to provide a critical overview and synthesis of the published literature (Ferrari, 2015) which has

focused specifically on engagement in group-based SMS programmes. A critical overview and synthesis of the literature sought to identify areas of engagement to which this realist enquiry could contribute knowledge. The review was undertaken toward the end of the scoping phase and prior to developing programme theory, which will be discussed in Chapter 5.

3.3 Narrative literature review

A narrative review of engagement with group-based SMS programmes was undertaken to inform the realist evaluation for this thesis (Furley & Goldschmied, 2021). Rather than reviewing the literature to develop programme theory, this review sought to gain insight into the work already undertaken in the field of engagement in group-based SMS programmes to further orient the realist evaluation. A realist review could have been undertaken for theory development (Booth et al., 2019; Emmel et al., 2018). However, at the early stage of the project when this review was conducted, the theoretical stance and parameters for exploring engagement were not yet clear due to the breadth and diversity of engagement literature across multiple disciplines. Further, realist reviews are lengthy endeavours and given the opportunity to develop realist theory from H&W data, discussed in more detail in Chapter 5, section 5.2.1, a narrative review was considered a more pragmatic choice. Narrative approaches aim to deepen understanding through interpretation and critique of literature in the field (T. Greenhalgh et al., 2018) and by providing a broad perspective on a subject (Noble & Smith, 2018). Narrative reviews therefore have an important role in orienting research in broad fields (Sutton et al., 2019), such as engagement, which was considered a priority at this early stage in the project. Engagement is a complex and multi-dimensional construct (Bright et al., 2015) and a narrative review can encompass the heterogeneity and varied use of terminology used to refer to self-management

interventions in the literature (Jonkman et al., 2016). Given that this literature review is a precursor to realist inquiry, a narrative approach was particularly valuable due to its acknowledgment of context in qualitative research (Booth et al., 2016). “Systematic” reviews are more concerned with “what works?” and may be devoid of the context so fundamental to realist assumptions about causality (Pawson, 2004) and thus the aims of this research. Narrative reviews, on the other hand, can accommodate variations between research questions, designs and contexts (Booth et al., 2016).

The methodological approach used in this narrative review combined principles of both integrative and meta-narrative review. Initial scoping of the empirical work conducted in relation to engagement with SMS programmes revealed a range of quantitative and qualitative approaches to investigating the phenomenon. An integrative approach allows the synthesis of different ‘conversations’ rooted in different paradigms and the bringing together of knowledge created from different research approaches in a somewhat fragmented field (Booth et al., 2022; Cronin & George, 2023). An integrative approach to review is therefore useful for portraying complex concepts and healthcare problems (Whittemore & Knafl, 2005), such as patient engagement, and aimed to synthesise knowledge regarding engagement with SMS programmes. Guiding principles for meta-narrative reviews were adopted to also understand *how* engagement has been conceptualised and investigated in the context of group-based SMS programmes. Meta-narrative reviews are useful in examining topics that have been conceptualised and researched differently by different groups (Paparini et al., 2021; Wong et al., 2013a). A meta-narrative review approaches sense-making of diverse literature using key principles based on narrative-interpretive reasoning (T. Greenhalgh et al., 2005). The principles underpinning the goals of this review were particularly those of pragmatism, pluralism, contestation and reflexivity (Table 3.1).

Table 3.1

Four of the six principles guiding meta-narrative review. Adapted from Wong et al. (2013)

Principle	Explanation	Application in this review
Pragmatism	Evidence inclusion is guided by what will be most useful to the intended audience and most likely to promote sense making.	Focus on research which has specifically sought to understand engagement with programmes so that research approaches on this topic may be mapped and critiqued.
Pluralism	The topic should be illuminated from multiple angles and perspectives	Wide inclusion criteria and comprehensive list of search terms to capture a range of approaches to examining engagement in SMS programmes
Contestation	'Conflicting data' should be examined to generate higher-order insights	Exploration of conflicting findings regarding associated factors with engagement to develop over-arching narratives, guided by engagement theory and frameworks.
Reflexivity	Reviewers should continually reflect on the emerging findings	Writing a reflexive and reflective account of the different stages of this literature review, and throughout the PhD. Use of engagement theory to understand different approaches.

Searching across two such diverse and complex subjects as 'patient engagement' and 'self-management support' required a comprehensive yet pragmatic approach to capture a balance of relevant yet manageable body of literature. This trade-off between the two opposing goals of retrieving all relevant results and minimising the number of unwanted results is inherent in all literature searches (Booth et al., 2022).

The focus of the search strategy was to identify literature which had primarily and specifically explored engagement, rather than identify all available literature on the topic, as would be necessary with an aggregative review approach. As such, a selective approach to the search strategy, typical of narrative reviews (Paré et al., 2015) was adopted. This chapter continues with details of and justification for the narrative review search strategy and study selection, to offer transparency on how literature was searched and selected (Ferrari, 2015).

3.4 Search strategy

Pubmed and SCOPUS were searched directly using the advanced search functions on their interfaces. A list of search terms used for each topic area are listed below (Table 3.2). The search terms were determined by examining notes taken during informal discussions with the H&W team and the stakeholder event described in the previous chapter. The words used by stakeholders and practitioners to describe the points of engagement at which problems occurred were informally searched to identify synonyms. In the first instance, these terms were entered into the “Title”, “Abstract” and “Keyword” fields, however, this led to over 5,000 papers being identified in each database. After reviewing the titles, and in some cases abstracts of the first 100 papers, it was clear that many of the manuscripts were not relevant, despite the use of Boolean operators for limiting as well as expanding the searches. For example, the majority of papers returned related to experimental studies of interventions, which were not group-based SMS programmes and/or did not specifically discuss engagement or any of its constructs. This problem arose as terms such as participate, complete, enrol and attend are omnipresent in research literature as they are used in the description of most human studies. A similar issue was found when attempting to limit results to group-based interventions because the term group is used when

describing comparisons in studies. Limiting the search to studies using the term 'group' or 'group-based' also failed to identify group-based interventions that are described in separate papers, for example the Stanford Chronic Disease Self-Management Program (CDSMP). The term 'group' was therefore omitted from the search strategy but incorporated into the inclusion and exclusion criteria described in the following section 3.5. Searches were subsequently limited to Medical Subject Headings, however, this failed to return key papers that had already been identified as relevant in preliminary searches. The challenges faced during the searches highlights the need for more consistency in the use of terminology and to improve the indexing of literature in these fields.

Literature searches require a balance between the ability to locate all records of interest and the relevance of the search strategy to identify records of interest, referred to as sensitivity and precision, or specificity, respectively (Booth et al., 2022; Gough et al., 2017). Achieving this balance can be especially difficult and time-consuming in areas where concepts are ill-defined and/or used interchangeably in different contexts (Heath et al., 2022). Given that the aim of the review was to identify research that has focused specifically on gaining an understanding of engagement, search terms were finally entered into the '*Title*' field only. Although this may have excluded studies potentially relevant for the review, it was deemed an appropriate and pragmatic compromise considering the time-constraints of this work and the remit of the review. A title-only search returned fewer and more relevant papers, allowing time to examine abstracts and full-texts for inclusion and exclusion criteria, particularly the identification of group-based interventions, which could not be filtered at the search stage.

Table 3.2*Search terms for the narrative review*

Topic area	Search terms
Engagement	engage*, attend*, complet*, enrol*, participat*, reach, attrition, retention, retain, refer*, uptake, dropout, drop out, non-attend*, no show
Long-term conditions	long-term condition*, long-term illness*, chronic condition*, chronic disease*, chronic illness*, diabetes, chronic pain, arthritis, fibromyalgia, hypertension, cardiovascular disease*, heart disease*, respiratory disease*, chronic lung disease*, asthma, chronic obstructive pulmonary disease, cancer
Self-management	self-management education, self-management intervention, self-management program*, self-management class, education program*, education intervention, therapeutic education, support program*, support intervention, behaviour change program*, behaviour change intervention, lifestyle education, lifestyle intervention, lifestyle class, self-care program*, self-care education, self-care intervention, self-care class, physical activity intervention, physical activity program*

3.5 Inclusion and exclusion criteria

Self-management intervention components for inclusion were adopted from Jonkman et al.'s (2016) operational definition of self-management and Taylor et al.'s (2014) taxonomy of SMS, discussed in Chapter 1. The combined components are presented in Table 3.3. Group interventions describing themselves as self-management or education programmes, and education interventions incorporating at least two other self-management components were included in the review.

Table 3.3*Criteria chosen for inclusion of self-management support interventions*

Authors	Self-management support components
Jonkman et al. (2016)	“Self-management interventions aim to equip patients with skills to actively participate and take responsibility in the management of their chronic condition in order to function optimally through at least knowledge acquisition and a combination of at least two of the following: stimulation of independent sign/symptom monitoring, medication management, enhancing problem-solving and decision-making skills for medical treatment management, and changing their physical activity, dietary, and/or smoking behavior.”
Taylor et al. (2014)	Provision of knowledge and information about the LTC Psychological strategies to support people adjusting to life with a LTC Practical support for physical care tailored to the specific LTC. Social support as appropriate Other potentially effective components including self-monitoring with feedback and practical support with adherence strategies.

Studies, of all designs, that investigated aspects of engagement, either from a HCP, facilitator or patient perspective, were included due to their recognised roles in engagement theory (Bright et al., 2015; Graffigna & Barelo, 2018; Higgins et al., 2017).

Study protocols were excluded, as were studies where the main focus was patient engagement in research, for example patient involvement in developing an intervention or increasing patient engagement with research participation, rather than

specifically with a SMS programme. The process of excluding manuscripts was recorded in Excel, with accompanying notes for papers where exclusion was determined following more detailed screening of the content.

Further inclusion and exclusion criteria are detailed in Table 3.4

Table 3.4

Inclusion and exclusion criteria for papers in the narrative review

Inclusion criteria	Exclusion criteria
Community- and group-based interventions	Papers only reporting on non-community-based interventions e.g. home-based or hospital-based programmes, digital or web-based
Face-to-face interventions	Unstructured interventions or those not led by a trained facilitator
Interventions with self-management elements specified.	Interventions that are solely exercise or physical activity with no specific mention of other self-management elements
	Interventions for children
	Study protocols

3.6 Analysis of literature

Descriptive data from each paper were extracted and collated in an Excel file, which included authors and year, title, country of study, study design, cohort and type of SMS programme. Quantitative and qualitative papers were first analysed and synthesised separately and then brought together in a final synthesis (Booth et al., 2022).

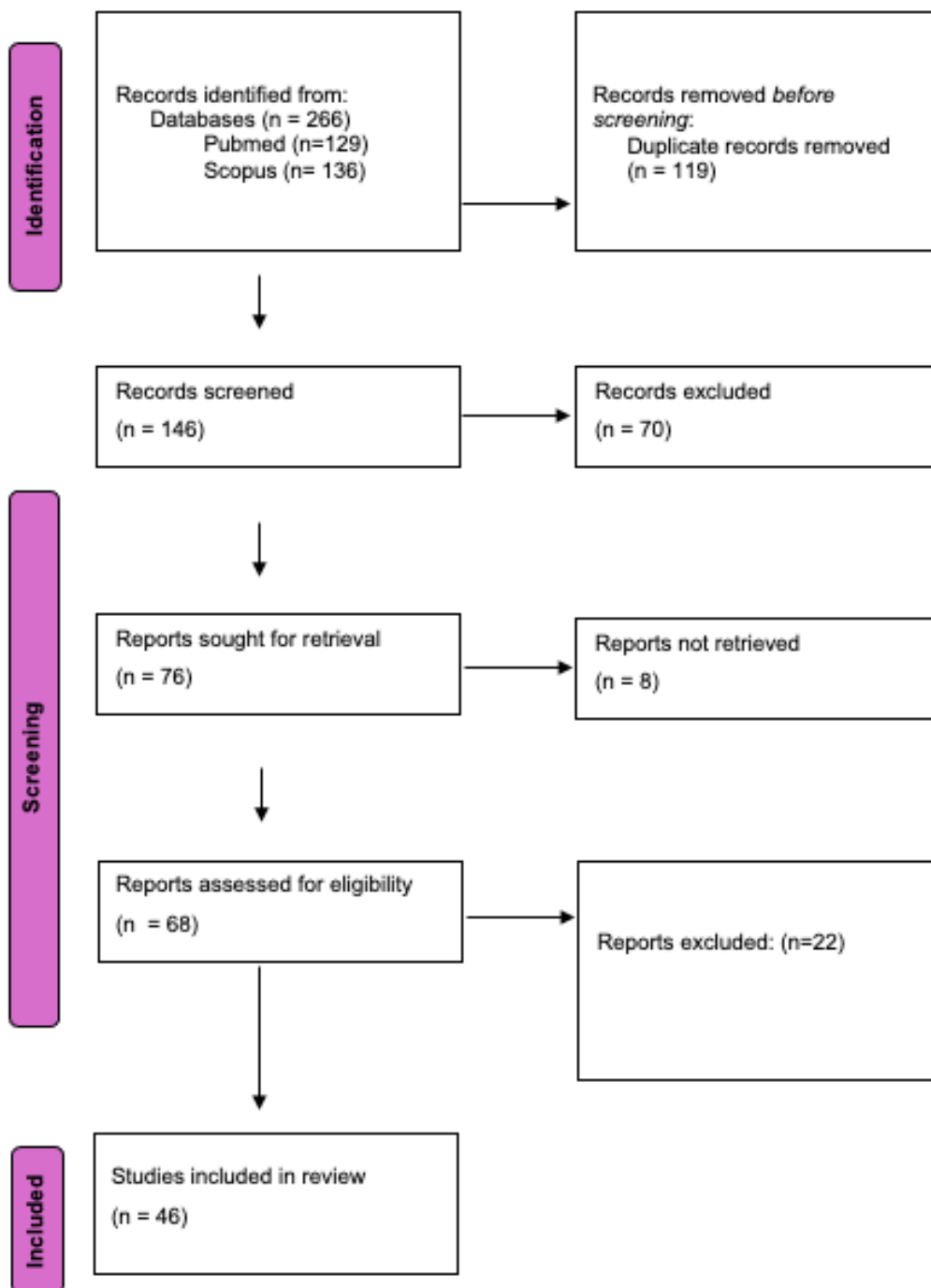
Manuscripts were analysed and interpreted in the context of established theory and frameworks, similar to other meta-narrative reviews (Barry et al., 2018). Two engagement models were selected following their identification in a concurrent search for patient engagement theory and frameworks. Nobles et al.'s (2018) engagement pathway and Bright et al.'s (2015) conceptual framework of engagement, which will be discussed further in Chapter 5, served as frameworks to support the organisation of extracted data by conceptual classification (Whittemore & Knafl, 2005) and to synthesise knowledge from this diverse field of study (Cronin & George, 2023). Data coding and analysis were iterative as manuscripts were continuously re-examined following the development of new themes throughout the constant comparison method adopted for analysis (Whittemore & Knafl, 2005).

3.7 Literature search results

A total of 266 papers were identified from Pubmed and Scopus. The search results were exported from the Pubmed and Scopus databases as csv. files and collated in an Excel spreadsheet. Prior to initial screening, duplicate papers were removed (n=119). A total of 146 titles and abstracts were screened, 70 of which were excluded as it was clear from the abstracts that they did not meet the inclusion criteria. Following the first round of exclusion, 76 papers were sought for retrieval and 68 were successfully sourced, which were assessed for inclusion. Exclusion decisions were recorded in the Excel spreadsheet for transparency and where it was not immediately obvious why a paper had been included, a statement of the reason for inclusion was recorded. The final assessment for inclusion resulted in 22 papers being excluded, leaving 46 to be included in this review (Figure 3.1).

Figure 3.1

PRISMA flow diagram for selection of papers



3.8 Overview of papers reviewed

The papers included in the review and their characteristics are summarised in Table 3.5. Three of the 46 included papers were reviews. One review focused on recruitment

to the Stanford Chronic Disease Self-Management Program (CDSMP) (Horrell & Kneipp, 2017); another review investigated reasons for non-attendance to diabetes education programmes (Horigan et al., 2017); and another sought to understand benefits and challenges of participating in all types of patient education programmes for chronic illness (Stenberg et al., 2016).

Most of the non-review papers were from the USA (n=30). The remaining non-review studies were from the UK (n=4), Canada (n=3), Australia (n=2), Ireland (n=1), Denmark (n=1), Germany (n=1) and France (n=1).

Almost half (48%) of the papers focused solely on programmes for diabetes (n=22), namely type 2 diabetes (T2D). This is unsurprising as diabetes mellitus is often described as the hallmark example of a LTC due to the degree of daily self-care required by individuals with the condition (Harris et al., 2019). Sixteen papers focused on programmes for chronic disease in general, and the remaining papers addressed programmes for individuals with arthritis (n=3), lupus (n=1), asthma (n=1), and cancer (n=3). Nineteen of the studies specifically investigated engagement with the Stanford University Chronic Disease Self-Management Programmes (CDSMP), and derivatives of. Few papers focused on other named and established programmes: Dose Adjustment for Normal Eating (DAFNE) (n=2) and Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) (n=1).

Quantitative cross-sectional surveys and/or programme administrative data, for example attendance and demographic data, analyses made up 63% of the studies (n=29). Qualitative studies contributed 20% of the included papers (n=9). Five studies used mixed-methods and five studies had longitudinal designs.

The reviewed manuscripts explored engagement at various points with self-management interventions. Engagement points include referral or recruitment, decision to attend, initial attendance, attendance throughout a programme and completion (Nobles et al., 2018).

Table 3.5*Overview of included papers in the narrative review*

Author and date	Title	Country	Design	Population	Named programme
Ackerman et al., (2013)	Factors limiting participation in arthritis self-management programmes: An exploration of barriers and patient preferences within a randomized controlled trial	Australia	Mixed methods	Osteoarthritis	
Ahn et al., (2015)	Factors associated with successful completion of the Chronic Disease Self-Management Program among middle-aged and older Asian-American participants: A national study	USA	Retrospective, quantitative, cross sectional study	Chronic disease, Asian-American	CDSMP
Allory et al., (2021)	Perspectives of deprived patients on diabetes self-management programmes delivered by the local primary care team: A qualitative study on facilitators and barriers for participation, in France	France	Qualitative, semi-structured interviews	Diabetes	
Alsayad Hassan et al., (2020)	Diabetes Self-Management Education and Support: Referral and Attendance at a Patient-Centered Medical Home	USA	Retrospective, secondary analysis of pre-post health records	Diabetes	

Author and date	Title	Country	Design	Population	Named programme
Ashtarian et al., (2012)	Factors influencing attendance at structured self-management education programs for diabetes	UK	Mixed method	Diabetes	
Atmann et al., (2020)	Participation factors for asthma education programs - A cross sectional survey	Germany	Cross-sectional survey, mixed quantitative and qualitative	Asthma	German Disease Management Program for Asthma
Boakye et al., (2018)	Sociodemographic factors associated with engagement in diabetes self-management education among people with diabetes in the United States	USA	Cross-sectional self-reported survey	Diabetes	
Bobitt et al., (2019)	Geographic and social factors associated with Chronic Disease Self-Management Program participation: Going the "extra-mile" for disease prevention	USA	Quantitative, observational study	Chronic disease, diabetes	CDSMP, DSMP
Brown-Podgorski et al., (2021)	Geographic and social factors associated with Chronic Disease Self-Management Program participation: Going the "extra-mile" for disease prevention	USA	Repeated cross-sectional analysis	Diabetes	

Author and date	Title	Country	Design	Population	Named programme
Cauch-Dudek et al., (2013)	Disparities in attendance at diabetes self-management education programs after diagnosis in Ontario, Canada: A cohort study	Canada	Retrospective population-based cohort study	Diabetes	
Davies et al., (2020)	Increasing uptake of structured self-management education programmes for type 2 diabetes in a primary care setting: A feasibility study	UK	Mixed methods	Type II diabetes	
Duca et al., (2021)	Self-Management Education Class Attendance and Health Care Provider Counselling for Physical Activity among Adults with Arthritis — United States, 2019	USA	Cross-sectional, observational study	Arthritis	
Erdem et al., (2014)	Self-management program participation by older adults with diabetes: Chronic disease self-management program and diabetes self-management program	USA	Retrospective observational study, administrative data	Diabetes	CDSMP, DSMP
Falasinnu et al., (2021)	Factors Associated with the Initiation and Retention of Patients with Lupus in the Chronic Disease Self-Management Program	USA	Longitudinal cohort study	Lupus	CDSMP

Author and date	Title	Country	Design	Population	Named programme
Faro et al., (2021)	Experiences and perceptions of referrals to a community-based physical activity program for cancer survivors: a qualitative exploration	USA	Qualitative study	Cancer	LIVESTRONG
Harris et al., (2019)	Characterization of Adults With Type 1 Diabetes Not Attending Self-Management Education Courses: The Barriers to Uptake of Type 1 Diabetes Education (BUD1E) Study	UK	Qualitative study, semi-structured interviews	Type I diabetes	DAFNE
Harris et al., (2018)	The attitude of healthcare professionals plays an important role in the uptake of diabetes self-management education: analysis of the Barriers to Uptake of Type 1 Diabetes Education (BUD1E) study survey	UK	Mixed methods	Type I diabetes	DAFNE
Helduser et al., (2013)	Factors associated with successful completion of the chronic disease self-management program by adults with type 2 diabetes	USA	Quantitative, prospective observational study	Type II diabetes	CDSMP
Horigan et al., (2017)	Reasons why patients referred to diabetes education programmes choose not to attend: a systematic review	UK	Systematic review – quantitative and qualitative studies	Diabetes	

Author and date	Title	Country	Design	Population	Named programme
Horrell et al., (2020)	Communication Cues and Engagement Behavior: Identifying Advertisement Strategies to Attract Middle-Aged Adults to a Study of the Chronic Disease Self-Management Program	USA	Theory-based evaluation - survey	Chronic disease	CDSMP
Horrell et al., (2017)	Strategies for recruiting populations to participate in the chronic disease self-management program (CDSMP): A systematic review	USA	Scoping review	Chronic disease	CDSMP
James (2021)	Improving Referrals to Diabetes Self-Management Education in Medically Underserved Adults	USA	Retrospective evaluation	Diabetes	
Jiang et al., (2015)	The role of Session Zero in successful completion of Chronic Disease Self-Management Program workshops	USA	Quantitative	Chronic disease	CDSMP
Khan et al., (2021)	Geographic disparities and temporal changes of diabetes prevalence and diabetes self-management education program participation in Florida	USA	Quantitative, retrospective ecological study	Diabetes	

Author and date	Title	Country	Design	Population	Named programme
Kneipp et al., (2019)	Participation of lower-to-middle wage workers in a study of Chronic Disease Self-Management Program (CDSMP) effectiveness: Implications for reducing chronic disease burden among racial and ethnic minority populations	USA	Descriptive, correlational design within an RCT	Chronic disease	CDSMP
Lin et al., (2020)	Factors Associated with Participation in the Chronic Disease Self-Management Program: Findings from the SUCCEED Trial	USA	Quantitative, part of an RCT	Stroke/chronic disease	CDSMP
Luo et al., (2021)	Rural-urban differences in uptake of diabetes self-management education among Medicare beneficiaries: Results from the 2016 to 2018 Medicare Current Beneficiary Survey	USA	Quantitative, cross-sectional design	Diabetes	
Lyonnais et al., (2020)	Potential Effect of Vouchers on the Completion of Self-management Education among Patients with Diabetes	USA	Quantitative, survey	Diabetes	
Mc Sharry et al., (2019)	Barriers and facilitators to attendance at Type 2 diabetes structured education programmes: a qualitative study of educators and attendees	Ireland	Qualitative study, thematic analysis	Type II diabetes	CODE, DESMOND, X-PERT

Author and date	Title	Country	Design	Population	Named programme
Mendez-Luck et al., (2020)	Participation of Latinos in the Diabetes Self-Management Program and Programa de Manejo Personal de la Diabetes	USA	Quantitative, cross-sectional study	Diabetes, Latino population	CDSMP
Mingo et al., (2015)	Chronic Disease Self-Management Education (CDSME) program delivery and attendance among urban-dwelling African Americans	USA	Quantitative, cross-sectional analysis of programme data	Chronic disease, African-American	CDSMP
Murphy et al., (2017)	Self-Management Education Participation Among US Adults With Arthritis: Who's Attending?	USA	Quantitative, cross-sectional, self-reported participation	Arthritis	CDSMP and Arthritis Self-Management Program
Parmenter et al., (2020)	Chronic disease self-management programs for Aboriginal and Torres Strait Islander people: Factors influencing participation in an urban setting	Australia	Qualitative	Chronic disease, Aboriginal and Torres Strait Islander people	Work it Out program
Santorelli et al., (2017)	Participation in a diabetes self- management class among adults with diabetes, New Jersey 2013-2015	USA	Quantitative, cross-sectional survey	Diabetes	

Author and date	Title	Country	Design	Population	Named programme
Schwennesen et al., (2016)	Patient explanations for non-attendance at type 2 diabetes self-management education: A qualitative study	Denmark	Qualitative	Type II diabetes	
Shi et al., (2021)	Attending with family members, completion rate and benefits accrued from chronic disease self-management program	USA	Quantitative, pre-post questionnaire	Chronic disease	CDSMP
Shi et al., (2017)	Understanding differences between caregivers and non-caregivers in completion rates of Chronic Disease Self-Management Program	USA	Quantitative, cross-sectional programme data, some self-reported	Chronic disease	CDSMP
Smith et al., (2018)	Engaging the Underrepresented Sex: Male Participation in Chronic Disease Self-Management Education (CDSME) Programs	USA	Quantitative, self-reported	Chronic disease, analysis of male participants only	CDSMP
Smith et al., (2015)	Workshop characteristics related to Chronic Disease Self-Management Education program attendance	USA	Quantitative, cross-sectional design, analysis of programme data	Chronic disease, urban-dwelling African-Americans	CDSMP

Author and date	Title	Country	Design	Population	Named programme
Stenberg et al., (2017)	A scoping review of the literature on benefits and challenges of participating in patient education programs aimed at promoting self-management for people living with chronic illness	Norway	Scoping review	Chronic disease	
Testerman et al., (2018)	Influences on diabetes self-management education participation in a low-income, Spanish-speaking, Latino population	USA	Qualitative	Diabetes, low income, Spanish-speaking Latino population	
Towne et al., (2015)	The reach of chronic-disease self-management education programs to rural populations	USA	Quantitative, cross-sectional design	Chronic disease, rural populations	CDSMP
Verevkina et al., (2015)	Attrition in Chronic Disease Self-Management Programs and Self-Efficacy at Enrolment	USA	Quantitative, cross-sectional design	Chronic disease	CDSMP
White Perkins et al., (2021)	Identifying factors affecting diabetes education program participation within a metro Detroit integrated health system	USA	Quantitative, retrospective observational study	Type II diabetes	
Wurz et al., (2015)	Breast cancer survivors' barriers and motives for participating in a group-based physical activity program offered in the community	Canada	Qualitative	Breast cancer	

Author and date	Title	Country	Design	Population	Named programme
Yufe et al., (2021)	Storying My Lifestyle Change: How Breast Cancer Survivors Experience and Reflect on Their Participation in a Pilot Healthy Lifestyle Intervention	Canada	Qualitative	Breast cancer	Healthy Lifestyle Modification After Breast Cancer (HLM-ABC) program

3.9 Narrative analysis of factors relating to engagement

The following sections present the findings of the analysis undertaken for this narrative review. The factors relating to engagement are categorised by individual factors, practitioner factors, and programme factors. The majority of studies investigated individual factors relating to engagement.

3.9.1 Individual factors for engagement in self-management programmes

Both quantitative and qualitative studies have explored individual factors relating to engagement, with some factors being identified through both quantitative and qualitative enquiry. Nobles et al. (2018) outlines the main stages of engagement with services: enrolment (recruitment and initiation); intervention (attendance, adherence, completion, retention, dropout and attrition); and maintenance stages, the last of which was not included in this review. Engagement was measured at different points along this engagement pathway in the reviewed studies. Much of the quantitative literature analysed data from programme administrative records, which include demographic and attendance data, as well as self-reported surveys of people with a range of LTCs. Some qualitative studies categorise individual factors influencing engagement as 'can't go' and 'won't go' (Harris et al., 2019; Horigan et al., 2017). The following sections attempt to synthesise these factors reported in the literature where possible.

Gender

Numerous studies cited the overrepresentation of females attending group-based self-management programmes (Alsayed Hassan et al., 2020; Boakye et al., 2018; Duca et al., 2021; Erdem & Korda, 2014; Harris et al., 2018; Horigan et al., 2017; Kneipp et al., 2019; Luo et al., 2021; Smith et al., 2015; Towne et al., 2015). Harris et al. (2018)

cited findings from their previous study (Harris et al., 2017), not reviewed in this work, that machoism may affect men's health-seeking behaviour and women may have more opportunistic interactions with HCPs during sexual health consultations, leading to more referrals generated for women than men. The authors recognised that more opportunistic encounters for women were less likely to be impactful in the context of type 1 diabetes programmes due to all individuals with diagnosed diabetes being offered annual appointments with an HCP. In addition to higher initial attendance rates, some studies have reported females to have higher completion rates (Alsayed Hassan et al., 2020; Erdem & Korda, 2014; Towne et al., 2015), but others have not (Cauch-Dudek et al., 2013; Helduser et al., 2013; Verevkina et al., 2014). The reasons for these differences in completion rate have yet to be explored.

Age

Age as a factor relating to engagement with SMS programmes was inconsistent in the literature, with some studies finding a higher likelihood of attendance in older adults (Boakye et al., 2018; Falasinnu et al., 2021; Shi et al., 2021; Verevkina et al., 2014; White Perkins et al., 2021) and others reporting that increasing age was associated with lower attendance (Cauch-Dudek et al., 2013; Luo et al., 2021; Mingo et al., 2015). Conflicting findings in these studies may be due to the variations in the study populations. For example, the typical age of onset of specific conditions (Cauch-Dudek et al., 2013) and differences in age of disease onset for different ethnic groups (Mingo et al., 2015) may have contributed to differing results. Other studies found no age differences between attenders and non-attenders of programmes (Atmann et al., 2019; Harris et al., 2018).

Whether increasing age was found to be associated with engagement in programmes may also have been dependent on the points at which they were analysed along the engagement pathway. Kneipp et al. (2019) conducted one of the few studies looking at participation at multiple points throughout the Stanford CDSMP. The authors reported that although increasing age was associated with lower enrolment, once enrolled, older individuals were more likely to attend and complete the programmes than those in younger age categories. A similar pattern of lower enrolment but higher completion was identified in other literature. Older individuals in outpatient settings were less likely to be referred to diabetes self-management education (DSME) in one study (Brown-Podgorski et al., 2021), which could contribute to lower enrolment. Verevkina et al. (2014) reported that individuals aged between 50 and 64 years of age were less likely to drop out of a CDSMP compared with younger individuals and that retired individuals were less likely to drop out. However, whether age and retirement were related or had independent impacts is unclear. The authors posited that retired individuals may have fewer commitments, allowing more time to attend the programme, however, this was not explored and confirmed in their study.

Race and ethnicity

Non-participation in SMS programmes has been shown to be associated with race and ethnicity in some studies; however, results are inconsistent. Participation has been shown to be lower amongst black, Hispanic and other ethnic minority groups in several studies (Boakye et al., 2018; Horigan et al., 2017; Khan et al., 2021; Santorelli et al., 2017). Conversely, Kneipp et al. (2019) found that the proportion of black participants was higher across all engagement points in their study and increased at each stage of attendance on their programme, whereas the proportion of white participants decreased. This finding is consistent with other studies who have found

that African-American or Black participants were more likely to complete programmes (Erdem & Korda, 2014; Shi et al., 2021; Towne et al., 2015). However, some studies found no association between race and engagement with programmes (Lin et al., 2020; Verevkina et al., 2014).

Inconsistent findings regarding race, ethnicity and engagement were reported within studies as well as between studies, highlighting that differences exist not simply due to variations in study design. Erdem and Korda (2014) compared completion rates in two different programmes: The Stanford Diabetes Self-Management Program (DSMP) and CDSMP. The authors found that completion of CDSMP was higher among African-American participants but not in the DSMP. It is not possible to determine whether higher completion rates for CDSMP compared with DSMP was due to differences in the way that programmes themselves were delivered because participants were not randomised to DSMP or CDSMP. Contextual factors at earlier points in the engagement pathway may have impacted whether participants completed the programme. For example, the authors postulated that attendance at one type of programme or the other may not reflect patients' choice as only one programme may have been available and different recruitment methods may have been used.

Testerman and Chase (2018) explored influences on DSME participation amongst low-income, Spanish-speaking Latino participants and elucidated specific cultural influences on willingness to attend DSME. They found that Latino male participants may be deterred by feelings of shame and lack of interest in their health due to a *machismo* culture where men are expected to be strong and masculine. Conversely, the authors reported that this culture can also serve as a motivator for participation

due to men being expected to provide for their family and therefore motivated to be healthy to support them.

The influence of family on motivation was also described in another study but more from the point of view of wanting to please others (Harris et al., 2019). Understanding what shapes these differing responses could be helpful in supporting individuals to participate. Parmenter et al. (2020) explored what participants perceived as particularly influential on their attendance on a self-management programme specifically designed for Aboriginal and Torres Strait Islanders in Australia. The group setting and approach of programme staff were highly valued for the support and relationships they provided, which helped participants to overcome barriers to attendance such as mental health issues and social isolation. Practitioner attitudes and support may therefore be particularly important in supporting engagement with programmes for more marginalised groups but there is a lack of data to support these suggestions.

Socioeconomic status

Socioeconomic status and numerous related factors were found to correlate with engagement in SMS programmes in the reviewed literature. (Allory et al., 2020; Ashtarian et al., 2012; Boakye et al., 2018; Bobitt et al., 2019; Cauch-Dudek et al., 2013; Duca et al., 2021; Harris et al., 2018; Kneipp et al., 2019; Lin et al., 2020; Luo et al., 2021; Murphy et al., 2017; Santorelli et al., 2017; White Perkins et al., 2021). These related factors included unemployment, language and cultural congruence, recent immigration, life chaos, household income, employment status, educational attainment, and type of medical insurance as a proxy indicator for low SES

Two studies found lower engagement with self-management programmes in individuals with lower household incomes (Boakye et al., 2018; Kneipp et al., 2019). Additionally, Kneipp et al. (2019) found that fewer individuals with a household income above the bracket of \$40,000 to \$79,000 engaged. Lower engagement in this higher income bracket may in part be due to the lower prevalence of LTCs in this group. However, this trend was also seen in continued participation, suggesting there may be other explanations for their lower engagement, which have not been explored. Lin et al. (2020) reported that unemployment was related to higher attendance, which they posited could be due to fewer work-related time restraints. However, unemployment has also been found to relate to non-attendance (Ashtarian et al., 2012; Harris et al., 2018), highlighting that the relationship between employment and non-attendance is complex.

Low educational attainment was associated with lower attendance in several studies (Boakye et al., 2018; Bobitt et al., 2019; Duca et al., 2021; Harris et al., 2018; Luo et al., 2021; Mendez-Luck et al., 2020; Murphy et al., 2017; Santorelli et al., 2017; Shi et al., 2021; Verevkina et al., 2014). The authors suggested various reasons why low educational attainment may impact engagement, including lack of time; competing demands, for example multiple jobs; not viewing education to be helpful for their condition; and lack of awareness of the programmes and the potential benefits of attending them. However, these postulations were not explored directly with the participants in these studies, preventing the identification of context-specific patterns and evidencing causal explanations.

Lower numerical capability, education confidence and baseline self-efficacy were identified as factors negatively influencing engagement (Harris et al., 2019; Verevkina

et al., 2014). Numeracy and education confidence shape individuals' perceived ability to cope with the numerical skills required for managing calorie intake and insulin use in a diabetes self-management programme (Harris et al., 2019). Improving self-efficacy is a key aim of self-management programmes, as it is an essential mediator of self-management behaviours (Taylor et al., 2014). Consequently, there is a potential for self-management programmes to inadvertently exacerbate health inequality by widening the self-efficacy gap between those in lower socioeconomic groups, with already lower self-efficacy, and more affluent groups, via a phenomenon known as the Inequality Paradox (Frohlich & Potvin, 2008).

Low educational attainment may also relate to negative attitudes towards education, further impacting engagement with programmes (Horigan et al., 2017). The theory that low educational attainment may influence engagement via mechanisms other than education confidence is consistent with reports of lower attendance in more general chronic disease SMS programmes, which likely require less proficiency in maths (Murphy et al., 2017; Junrong Shi et al., 2021). Murphy et al. (2017) offer suggestions of how to improve participation of those with lower educational attainment. They recommended that HCPs encourage people to participate in programmes, the use of community-based ambassadors, and delivering interventions to groups more likely to have lower education attainment, such as Medicaid beneficiaries, and lower-paid workforces. However, a more detailed exploration of how these recommendations should be implemented is necessary to effectively support engagement.

Urbanicity

The relationship between engagement with programmes and whether people live in rural or urban locations is inconsistent in the reviewed literature, and causative

explanations are lacking. Towne et al. (2015) investigated the geographic distribution of CDSMP participation. They reported that there were almost double the number of participants attending from urban areas as rural areas, although it is not clear how much of this is due to population sizes of the urban versus rural towns. The same trend has been identified in arthritis self-management programmes (Duca et al., 2021) and diabetes self-management programmes (Khan et al., 2021; Luo et al., 2021). Additionally, Khan et al. (2021) found that areas with high DSME attendance rarely overlapped with areas with high diabetes prevalence, demonstrating that there are inequities in the distribution of DSME. Cauch-Dudek et al.'s (2013) findings are contradicting as they found those living in rural areas were more likely to attend a diabetes self-management programme. They propose that this may be due to the difficulty in accessing other types of healthcare in rural areas. Mingo et al. (2015) investigated CDSMP delivery and attendance among urban-dwelling African Americans and found reduced odds of programme completion amongst individuals living in impoverished neighbourhoods. Conflicting results in relation to urbanicity may therefore be partly explained by the deprivation of areas rather than urbanicity alone.

Although low initial participation has been shown in those living in rural areas, some studies have found that completion rates are higher in rural compared with urban areas (Ahn et al., 2015; Bobitt et al., 2019; Towne et al., 2015). The significant difference in completion between rural and urban residents in Towne et al.'s (2015) study was small: 77.9% and 77.1% respectively; and therefore arguably unimportant. However, Bobitt et al. (2019) reported a larger difference in completion rates of 89.4% in rural dwellers compared with 75.6% in urban dwellers. Similarly, this pattern was demonstrated amongst Asian-Americans in CDSMP with 79% of urban participants completing compared with 86% of rural participants (Ahn et al., 2015). Urbanicity is

therefore another example of a factor that may influence engagement in different ways at different points on an individual's engagement journey. Exploring the underlying mechanisms of engagement at various points may be helpful to inform the promotion and initial access to programmes for people living in more rural areas.

Perceived benefit

Engagement with SMS programmes may be influenced by individuals' perception of the benefit they may receive from programmes. The perception of benefit is multifaceted with knowledge appearing to be an important feature. Some people have reported having sufficient knowledge regarding the self-management of their condition already and/or being satisfied with the rest of their care (Ackerman et al., 2013; Ashtarian et al., 2012; Harris et al., 2019; Horigan et al., 2017). Some individuals decline to attend programmes due to feeling that they would be more advanced in their skill and/or knowledge than other attendees, having acquired knowledge from previous attendance at other, similar programmes (Harris et al., 2019). Perceived benefit may also change over time as some participants feel that a programme may be more beneficial soon after diagnosis and that the benefits reduce as they gain knowledge from elsewhere and find their own ways to manage (Schwennesen et al., 2016).

Specific programme content may also contribute to perceived benefit as different content will have varying levels of appeal to potential participants. A supermarket visit as part of one diabetes programme was viewed as pointless by some and as attractive by others (Schwennesen et al., 2016), highlighting the influence of individuals' personal experience on engagement with programme content. Although lack of perceived benefit has generally been cited as a reason for non-engagement, the

underlying emotional and cognitive processes for this differ. In Harris et al.'s (2019) study, lack of perceived benefit was described akin to a waste of time, whereas a participant in Schwennesen et al.'s (2016) study described more of an altruistic act of declining attendance. They perceived that others who were worse off and in greater need of support would benefit more from attending. Prior experience and beliefs about what individuals can and cannot achieve, for example in relation to diet and weight-loss, and feelings of futility have been reported to contribute to disengagement with elements of programmes that feel too difficult or intense (Yufe et al., 2021). Differing emotional and cognitive processes require different approaches to appease individuals' concerns, even though they may be broadly considered similar factors. It is therefore necessary to understand how different contexts influence people's reasoning and responses to more effectively target efforts to improve engagement.

Health status and acceptance of condition

Numerous studies have included measures of health status and symptom experience in their analysis of factors associated with engagement with SMS programmes, but findings are inconsistent. Alsayed Hassan et al. (2020) reported slightly higher baseline A1c values, a commonly used biomedical marker for diabetes, in those who were referred to DSME. They proposed that this correlation may be due to clinicians being more likely to refer individuals with poorly controlled A1c levels. However, White Perkins et al. (2021) reported a higher proportion of no-shows and non-completers at DSME in people with higher baseline A1c values. Those who use insulin were found to be more likely to attend DSME than those who do not in one study (Boakye et al., 2018). The authors did not collect referral data so whether higher attendance amongst insulin users was due to them being more likely to have been referred could not be determined. Khan et al. (2021) found no significant difference between the proportion

of insulin and non-insulin in relation to DSME attendance. However, the authors analysed county characteristics rather than individuals. Therefore, attendance data could not be disaggregated to establish a relationship between insulin use and DSME attendance.

People's experience of their condition also impacts their perception of the benefit they may receive from programmes, so is interlinked with the perceived benefit discussed earlier. Those who are asymptomatic can feel that they do not need any intervention (Ackerman et al., 2013; Allory et al., 2020; Atmann et al., 2019). A third of respondents who had not attended a diabetes self-management programme in one study reported their diabetes being 'mild' as a reason not to attend, with some explaining that they did not believe that they were at risk of developing complications of diabetes (Ashtarian et al., 2012). Not engaging with SMS in the early stages of disease may pose a significant problem, particularly with diabetes, as complications develop over time. Individuals may miss the opportunity to prevent the onset of complications or minimise their impact.

Atmann et al. (2019) found that smoking status differed between previous attendees and non-attendees of an asthma education programme. Only 2% of previous attendees stated that they smoked compared with 17% of non-attendees. Due to the cross-sectional survey design of the study, it was not possible to establish whether these figures preceded attendance on a programme and therefore whether their smoking status was a result of the asthma education programme. Furthermore, reporting bias may have led to a greater difference in smoking prevalence in the data.

Some studies identified higher participation and lower drop-out rates in people who are more symptomatic (Duca et al., 2021; Murphy et al., 2017; Verevkina et al., 2014),

which may be due to higher levels of motivation to improve symptoms (Verevkina et al., 2014). However, condition-related or un-related symptoms, and treatment fatigue also pose barriers to engagement (Allory et al., 2020; Horigan et al., 2017; Schwennesen et al., 2016). For example, cancer-specific limitations such as sickness (Wurz et al., 2015), physical limitations, lack of energy and feeling unwell (Ackerman et al., 2013) have been reported to limit people's ability to attend programmes.

Psychological capability, which relates to the level of acceptance of individuals' diagnosis, can also impact engagement with SMS programmes (Harris et al., 2019; Horigan et al., 2017; Schwennesen et al., 2016). Diagnosis acceptance appeared to present on a continuum, with some participants accepting their condition and taking control through increased awareness; some not having accepted their diagnosis or the role of patient due to a lack of symptoms or interference with daily life; some actively avoiding their diagnosis; and some feeling anger and hatred towards their diagnosis (Harris et al., 2019; Schwennesen et al., 2016). The level of acceptance of individuals' diagnosis was deemed to be a key factor in optimal timing for referral in one study (Schwennesen et al., 2016). Some participants in the study explained that they chose not to attend because they had been offered diabetes education too close to their diagnosis when they had not yet come to terms with their diabetes.

Practical barriers

Several practical barriers to engaging with self-management programmes were reported in the literature, which were broadly categorised in one systematic review as logistical, medical and financial (Horigan et al., 2017). Logistical factors reported by people with LTCs in the reviewed literature included lack of time; transport issues; distance of the programme from their home; the duration or scheduling of the

programme being unsuitable; and competing family commitments (Harris et al., 2019; Horigan et al., 2017; Mc Sharry et al., 2019; Testerman & Chase, 2018; Wurz et al., 2015). One quantitative study identified further travel distance from home as a factor relating to worse attendance (Bobitt et al., 2019). Following disaggregation of travel distance data by urbanicity, the authors identified this only to be true for urban dwellers. The authors suggested that this may be due to rural dwellers being more equipped and used to traveling longer distances, highlighting an interaction between these factors relating to engagement.

Understanding the practical barriers to attending programmes may be helpful in adjusting programme schedules and access. Lin et al. (2020) reported an improvement in engagement when free transportation was introduced for all participants. Participants in another study also highlighted free, arranged transport as an important facilitator of attendance (Parmenter et al., 2020). However, Harris et al. (2019) identified the combination of both practical and emotional barriers to attending programmes, reporting that for some people, overwhelming psychological factors prevent engagement. For example, participants initially reported logistical explanations for not attending, yet when this barrier was removed and study participants were pressed for further explanation, they revealed fears of judgement from work colleagues and health professionals as deterrents for attending. The identification of emotional, cognitive and behavioural patterns of engagement in this study highlights that focusing on the removal of physical barriers to improve engagement will not suffice.

3.9.2 Practitioner factors for engagement in self-management programmes

In the reviewed literature, practitioners were found to play a role in engagement at various points along the engagement pathway, beginning with the referral process. The most common route of entry into SMS programmes is referral from a HCP. In the USA, National Standards for Diabetes Self-Management Education Delivery recommend that patients are referred to a programme if they have one of the following needs identified during a health consultation: initial diagnosis of diabetes; their condition is not being properly managed, as identified during an annual assessment; presence of a complicating factor such as the diagnosis of a new comorbidity; or the transition of care or insurance (Powers et al., 2016). In the UK, guidance from the National Institute for Health and Care Excellence (NICE) state that individuals with diabetes, asthma and chronic pain should be offered structured education and/or physical activity intervention (NICE, 2015b, 2015a, 2017, 2021). Despite these guidelines, several authors found that referral rates are consistently low and highlight that little research has been conducted to examine the underpinning reasons for why low referral rates persist (Alsayed Hassan et al., 2020; Brown-Podgorski et al., 2021; Faro et al., 2021).

Brown-Podgorski et al. (2021) examined how patient need, as categorised by the aforementioned Algorithm of Care for Diabetes Self-Management Education (DSME) (Powers et al., 2016) affected referral in their study. Their analysis of 356,631 patient-health provider encounters established that at least one need was identified in nearly two thirds of encounters but only 7% resulted in referral. The highest proportion of referrals were associated with an individual having multiple needs (13.1%) or not meeting glucose level targets (12.1%), with the smallest proportion being associated

with transition in care or insurance (3.1%) or a new diagnosis of diabetes (7.7%). The effect size of need on referral was relatively small, which the authors recognise as an indicator of numerous factors involved in decision-making regarding referral.

Faro et al. (2021) suggested that for some programmes, referral rates may be negatively impacted by a lack of understanding amongst HCPs of the availability of programmes to which they can refer patients. A greater number of available programmes was linked to increased referrals in one study, however, it was not established whether this was related to increased awareness of programmes (Brown-Podgorski et al., 2021).

The administrative burden of the referral process, poor system flow such as a lack of administrative support, and education programmes not being embedded in standard care have been identified as potential barriers to referral to SMS programmes (Faro et al., 2021; Mc Sharry et al., 2019). One study implemented changes to an electronic referral protocol by adding a question prompt about whether patients had attended DSME before; and an algorithm form to determine whether the patient should be referred based on need (James, 2021). The intervention was reported to increase the number of referrals, however, the author reflected that the increase may have been overestimated due to an informal referral system being used prior to the intervention.

The role of HCPs in patient enrolment, or initial attendance, on a programme following referral has been investigated in some studies. HCPs have been shown to have a role in increasing awareness of programmes, helping individuals to understand what a programme entails, and encouraging and promoting the benefits of attendance using positive messages (Faro et al., 2021; Harris et al., 2018; Mc Sharry et al., 2019), all of which may support decisions to attend programmes following referral. Having an

existing relationship with HCPs, and promotion of programmes by a multidisciplinary team have also been highlighted by attendees as important to facilitate motivation to partake in programmes (Allory et al., 2020; Faro et al., 2021), which is consistent with Bright et al.'s (2015) assertion that a prior therapeutic relationship is important for engagement. The perceived attitude of HCPs is also important in shaping individuals' engagement as a feeling of being judged by HCPs, and not being listened to, can result in individuals feeling that they are managing their disease to satisfy others (Harris et al., 2019). Participants in a study of participation in arthritis SMS programmes reported a lack of support from their GP (Ackerman et al., 2013). Participants in the study reported being told that a SMS programme would not help them or that they were not a suitable candidate for the programme. Given the impact that HCP-patient interactions can have on attendance, and engagement more generally through therapeutic alliance (Higgins et al., 2017), it is important to consider not only patients' attitudes towards SMS programmes but also those of HCPs involved in referral. Due consideration of the attitudes of both patient and practitioner is needed to understand engagement (Bright et al., 2015).

3.9.3 Programme factors for engagement in self-management programmes

SMS programmes are delivered in a plethora of ways, as was outlined in Chapter 1 and is evident in the diversity of programmes in this review, which will be discussed in section 3.10. The following section presents the relationship between programme factors and engagement reported in the literature.

Group setting and size

The group setting was found to have opposing influences on engagement in the reviewed literature. Being amongst people with similar conditions and sharing

experiences was cited as a positive aspect of group-based interventions (Parmenter et al., 2020; Stenberg et al., 2016) and can be a key motivator for people to attend programmes (Wurz et al., 2015; Yufe et al., 2021). However, group-settings have also been cited as a deterring factor for engagement. Participants report concerns that they may become depressed attending a group programme due to an increased focus on their condition or being irritated by others complaining about their condition (Ackerman et al., 2013; Harris et al., 2019). Educational confidence was highlighted as a factor in section 3.9.1 and group settings may compound this factor through concerns about *“being put on the spot and being made to feel like a fool”* (Harris et al., 2019).

Some individuals find expressing themselves in a group setting challenging, which in some cases may be due to mental health issues (Allory et al., 2020; Parmenter et al., 2020). A supportive environment in programmes can mitigate these challenges and encourage individuals to continue attending (Parmenter et al., 2020). Conversely, some report it being easier to express themselves in group settings compared with their friends and family because they feel less like they are burdening others in that environment (Stenberg et al., 2016).

Group sizes for interventions vary across programmes and contexts. Group sizes can be informed by programme standards, as is the case with The Stanford CDSMP which stipulates a group size of 10-15 (Smith et al., 2018). Smith et al. (2015) and Erdem and Korda (2014) reported higher rates of session completion with groups of 8 participants or fewer; and 6 participants or fewer respectively, whereas Bobitt et al. (2019) found no significant difference in mean attendance between large and small sized workshops. Group size was found to be influential in male participants in one study as they were more likely to complete a CDSMP when in smaller groups (Smith

et al., 2018). However, a comparison with females was not reported so it is not clear if group size affects males more than females.

Participant homogeneity in group settings

Group homogeneity appears to support engagement with self-management programmes, which may be linked to the valued opportunity to connect with others in similar situations and share experiences, as cited in several studies (Parmenter et al., 2020; Stenberg et al., 2016; Wurz et al., 2015; Yufe et al., 2021). Men were more likely to complete a CDSMP when there was a higher proportion of males in the group in one study (Smith et al., 2018). Asian-Americans were also reported to have higher rates of completion of CDSMP when groups comprised higher proportions of Asian-American participants (Ahn et al., 2015). An important next step would be to establish what it is about attending groups with individuals of the same gender and/or race or ethnicity that leads to better engagement. Understanding whether this is a more pertinent issue in males or females, or in specific ethnic and racial groups would also better inform efforts to recruit participants with homogeneity in mind.

Programme setting and location

Programme location was cited as influential for engagement in several studies, mostly in relation to the practical barriers cited by potential participants described in section 3.9.1. Only one study focused specifically on investigating the relationship between programme setting and engagement (Smith et al., 2015). Programmes in the study were delivered in a range of community and multi-purpose centres, faith-based organisations, educational institutions, county health departments, tribal centres and workplaces. The authors found no relationship between the programme setting and attendance. Studies reporting on programme engagement in relation to urbanicity (section 3.9.1), analysed the factor in terms of where individuals lived rather than the

location of the intervention. Smith et al. (2015), looked at the location of the interventions and found no relationship between the urbanicity or rurality of programme location and attendance. The authors did however note that different programme locations correlated with other factors. For example, programmes delivered at senior centres, residential facilities and tribal centres had attendees with higher-than-average co-morbidities; and workplaces and residential facilities had larger than average group sizes. This interaction between factors poses a challenge in identifying and evidencing causality regarding programme setting factors influencing engagement.

Programme schedule

Many individuals find it challenging to fit attending a programme into daily life. As previously discussed, employment is frequently cited as a barrier to attendance (Allory et al., 2020) so some programmes offer sessions outside typical working hours. Verevkina et al. (2014) reported that individuals who attended programmes at weekends were less likely to drop out than those who attended programmes during the week. Although this is promising, it may not be enough to encourage participation in some individuals. As discussed in section 3.9.1, participants may cite practical barriers but also have other reasons for not attending. A proportion of participants in Harris et al.'s (2019) study stated work commitments as a reason not to attend DSME. However, some participants had been granted time off work to allow them to attend. Further questioning of these participants revealed that they were concerned about judgement from their work peers for taking time off, being judged by education providers for putting education off for so long or being judged by peers on the programme.

Awareness and promotion of programmes

There was a paucity of literature exploring strategies to improve engagement with SMS programmes, and most authors who did focused on initial recruitment. Awareness and promotion of programmes was found to impact engagement in the reviewed literature. Referral pathways into programmes may be active or passive, where participants are identified and referred to interventions or self-refer (Nobles et al., 2018) and therefore different engagement strategies are required. Recruitment strategies were the focus of two studies in this review (Horrell & Kneipp, 2017; Lonnais et al., 2020). Programmes with a self-referral entry option, for example, the Stanford CDSMP, need to focus recruitment efforts beyond healthcare settings and reach people in their daily lives. Advertising cue preferences for CDSMP were explored by Horrell and Kneipp (2017), which were: *financial security, reduced stress, better health, self-management – the real magic pill, work stability and take control*. The authors found that cue preference was not positively associated with enrolment on the programme. Further, of the 407 sample, only 107 enrolled in the study, 53 were then assigned to the CDSMP and only 8 people completed the programme. Poor engagement at multiple points of the programme illustrates the potential limitation of supporting engagement at a single point on the engagement pathway. Further, this isolated engagement support intervention is incongruent with the conceptualisation of engagement being a fluid on-going process that can wax and wane (Bright et al., 2015).

3.9.4 Section summary

This section has synthesised and critically discussed the myriad factors associated with engagement in group-based SMS programmes in the literature reviewed. Individual factors include age, gender, race and ethnicity, socio-economic status and

related factors, urbanicity, perceived benefit, health status and acceptance of their condition, and practical barriers. In addition to individual factors, some studies identified factors relating to practitioners' roles, particularly in referring individuals to programmes. Finally, programme factors relating to engagement were discussed, which included the group setting generally, participant homogeneity in groups, programme setting, programme schedule, and promotion of programmes. The next section will present a narrative analysis of the approaches to investigating engagement with group-based self-management programmes.

3.10 Narrative analysis of the approaches to investigating engagement with group-based self-management programmes

The following section provides a critique of the approaches adopted to investigate engagement with self-management programmes in the literature reviewed. Authors appear to have conceptualised engagement in different ways and thus investigated it through varying lenses. Numerous challenges in engagement inquiry were identified: the conflation of engagement constructs, individualisation of engagement, the diversity of self-management programmes, the complexity and interlinking nature of factors, and the problem of drawing conclusions about engagement from trial interventions rather than real-world delivery of programmes. Each of these challenges will now be discussed in turn.

3.10.1 Engagement constructs and consideration for temporality

Engagement is a complex phenomenon, defined in various ways in the health literature. Authors who have explored engagement conceptually agree that it is multi-componential (Bright et al., 2015; Clavel et al., 2021; Dewing & McCormack, 2015;

Graffigna, 2017; Graffigna et al., 2015; Hickmann et al., 2022; Higgins et al., 2017; Jahandideh et al., 2018; Kimerling et al., 2020; Mittler et al., 2013). Yet, much of the literature reviewed isolated constructs and focused on observable participation in self-management programmes. Engagement comprises both observable and internal processes (Bright et al., 2015; Graffigna et al., 2015). The overreliance of observable measures of engagement has been criticised and calls have been made to undertake research to explore the emotional and cognitive aspects of engagement (Bright et al., 2015; Graffigna & Barelo, 2018). The findings of this review confirm that the focus on observable measures of engagement persist, and when participants' internal processes are explored, studies can fall short of adequately exploring the emotional aspects of engagement.

Interactions between practitioners and patients, or perspectives from both, were seldom explored in the literature examined in this review. The relational aspect of engagement is recognised in conceptualisations, to varying degrees (Bright et al., 2015; Clavel et al., 2021; Graffigna, 2017; Graffigna et al., 2020; Hickmann et al., 2022; Higgins et al., 2017; Kimerling et al., 2020). Yet only two studies explored both (Faro et al., 2021; Mc Sharry et al., 2019) and rarely is the need to examine both together acknowledged.

The oversimplification of engagement was also identified in relation to temporality. Engagement with programmes is an ongoing and fluctuating process (Bright et al., 2015; Clavel et al., 2021; Jahandideh et al., 2018; Nobles et al., 2018), meaning that engagement cannot be determined by investigating single points on the engagement pathway, nor can engagement at one point be used to infer engagement at another. Engagement was examined at referral, enrolment, initial attendance, participation and

drop-out, and completion across the studies. Many studies failed to convey their findings with the caveat that engagement at one time point may not result in sustained engagement or improved patient outcomes. Some of the few studies that investigated engagement at multiple time points demonstrated the limitations of not considering how engagement can change over time. Almost half of the 3,769 patients referred to DSME in White Perkins et al. (2021) study were not successfully reached to make an appointment, and of those who were, a further 15% did not attend their scheduled intake appointment. One study also reported that only half of participants referred to a diabetes self-management programme attended any sessions and of those that did attend, almost half only attended the assessment session (Alsayed Hassan et al., 2020).

This conflation of engagement at different pathway points is problematic when interpreting and comparing results from studies of engagement, especially if engagement is considered a determinant of programme success. Low attendance and completion of programmes was commonly reported in the papers in this literature review (Boakye et al., 2018; Duca et al., 2021; Kneipp et al., 2019; Murphy et al., 2017; White Perkins et al., 2021). However, some report completion rates that appear quite positive. For example, one study reported a 75% completion rate based on individuals who started a programme (Helduser et al., 2013), which is considered successful in terms of engagement. However, if non-starters had been included in their analysis, the completion rate would have been 55% which is more representative of the problem of poor engagement with these types of programmes. Completion rates were also higher than 70% in a number of other studies (Ahn et al., 2015; Bobitt et al., 2019; Mingo et al., 2015; Towne et al., 2015). The participant samples for these studies were all programme attendees and no enrolment data were analysed to calculate

completion rates based on individuals who had been referred or enrolled. If successful engagement with programmes is based on analyses which fail to account for the temporality of engagement, it will not be possible to accurately identify groups with poor engagement, which could lead to interventions inadvertently increasing health inequities (Fleming et al., 2017).

3.10.2 Individualisation of engagement

A large proportion of the research reviewed explored individual factors relating to engagement with SMS programmes, with comparatively little focusing on factors relating to practitioners and the way in which programmes are delivered. Further, components of a system, in this case participants, practitioners, the programmes and their delivery, and engagement outcomes, are often secondary to the relationships among them (Braithwaite et al., 2018). The relational aspect of engagement was underexplored in the literature and few studies investigated engagement from more than a single stakeholder perspective. Multiple stakeholder considerations are necessary in complex intervention research to allow for the co-production of explanations for how interventions work (Skivington et al., 2021). An individualistic conceptualisation of engagement therefore, thwarts attempts to understand its challenges in interventions.

An individualistic conceptualisation of engagement may also contribute to blame laden narratives of LTCs. Horigan et al. (2017) and Mc Sharry et al. (2019) broadly presented individual engagement factors as an inability to attend and an unwillingness to attend. Describing individuals as being unwilling to attend may compound and perpetuate the individualisation and lifestyle drift of LTCs described in Chapter 1, by placing further responsibility and blame on individuals who are deemed unwilling to ‘help themselves’

through engagement with SMS interventions. Exploration of the delivery of programmes and other agents in engagement, such as referring practitioners and programme facilitators, is therefore paramount in aligning research efforts with existing theories of engagement and avoiding a blame-laden narrative of patient engagement.

3.10.3 Diversity of group-based self-management programmes and engagement factors

The literature examined in this review demonstrated the diversity of group-based SMS programmes, and the subsequent challenges posed in identifying patterns of factors impacting engagement. No single factor was shown to have consistent associations with engagement outcomes across the literature. As described in section 3.8, interventions were delivered for specific and general LTCs (Table 3.5) delivered specifically to marginalised and/or underrepresented groups (James, 2021; Parmenter et al., 2020; Smith et al., 2018; Testerman & Chase, 2018) and in one manuscript specifically included delivery to care givers or family members (Shi et al., 2017). Programmes also varied in their session and overall programmes duration, contact point frequency, setting and group size.

Programmes were delivered by a range of facilitators, including dietitians (Harris et al., 2018; Mc Sharry et al., 2019; White Perkins et al., 2021); nurses (Ashtarian et al., 2012; Atmann et al., 2019; Harris et al., 2018; Mc Sharry et al., 2019; White Perkins et al., 2021); physicians (Atmann et al., 2019); psychologists and counsellors (Stenberg et al., 2016; Yufe et al., 2021); trained or certified individuals (Allory et al., 2020; Bobitt et al., 2019; Faro et al., 2021; Horigan et al., 2017; Testerman & Chase, 2018; White Perkins et al., 2021); trained peers (Atmann et al., 2019; Erdem & Korda, 2014; Falasinnu et al., 2021; Helduser et al., 2013; Kneipp et al., 2019; Mingo et al., 2015; Shi et al., 2017, 2021; Smith et al., 2015, 2018; Stenberg et al., 2016; Towne et

al., 2015; Verevkina et al., 2014); health care professionals (Alsayed Hassan et al., 2020; Duca et al., 2021; Harris et al., 2019); trained exercise specialists (Wurz et al., 2015) and community health workers (Lin et al., 2020).

Not all papers specified who delivered the interventions (Ackerman et al., 2013; Boakye et al., 2018; Jiang et al., 2015; Luo et al., 2021; Mendez-Luck et al., 2020; Murphy et al., 2017; Santorelli et al., 2017; Schwennesen et al., 2016), however, it was assumed that if they were CDSMP that they were led by trained peers, which is standard for CDSMP. Some interventions were delivered by a combination of facilitator types, either within programmes or across different programmes within the same study (Mc Sharry et al., 2019; Stenberg et al., 2016; White Perkins et al., 2021).

CDSMP facilitators all undergo specific training and are expected to adhere to the CDSMP implementation and fidelity manual (Self-Management Resource Centre, 2022) but of the manuscripts reporting other programmes, only one provided additional information about the facilitators and the training they received (Parmenter et al. 2020). Given that self-management programmes are social in nature, involving the interactions between practitioners and participants in group settings, detail regarding delivery approaches of practitioners is necessary to develop an understanding of engagement in these programmes. The lack of detail describing programme components and theory can create difficulty in making comparisons, and transferring meaningful lessons from programmes (Keogh et al., 2015; Mulligan et al., 2019; Punna et al., 2019). The lack of detail may be in part due to constraints regarding communicating the complexity of these programmes, particularly in peer-reviewed literature limited by journal word-count stipulations (Manzano, 2016).

Engagement is recognised to involve interactions and relationships between patients and practitioners in various models (Bright et al., 2015; Graffigna, 2017; Higgins et al., 2017) so it is difficult to discern patterns of engagement when there is a lack of information about practitioners delivering interventions. Some studies specifically focused on the role of practitioners in engagement (Harris et al., 2018) but focused less on participant variables, limiting further exploration of how factors impacting practitioner engagement may interact with participant factors, for example. The current body of research is diverse and lacks consistent reporting on programme delivery and contextual detail to allow conclusions to be made about factors impacting engagement.

3.10.4 The complexity of factors influencing engagement

As discussed in the previous section, conflicting findings regarding factors impacting engagement were ubiquitous in the literature reviewed. These conflicting findings demonstrate the complexity of factors influencing engagement and a lack of causal explanation compounds the challenge of understanding why associations differ. Although several authors postulated reasons for associations identified in their studies and/or inconsistencies, most did not verify their ideas within the cohorts or contexts they investigated. Given the diversity of programmes and the myriad factors influencing engagement, there is a need for complexity-consistent methods to attempt to identify engagement patterns.

In Chapter 1, the inter-relational nature of the social determinants of health and the experience of living with LTCs were highlighted. These inseparable relationships between factors were also evident with regard to engagement with self-management programmes in the reviewed literature. Various individual factors relating to

engagement with self-management programmes were identified; gender, age, race and ethnicity, socioeconomic factors, perceived benefit, urbanicity, health status and symptoms, and practical barriers were all highlighted as important in the reviewed literature. Many of these factors appeared to be inter-related and further interacted with factors related to practitioners and programme delivery. Some authors called for further exploration of these interactions and the influence of wider systems (Harris et al., 2019; Kneipp et al., 2019; Mc Sharry et al., 2019).

The interaction between factors poses further challenges in interpreting which factors are more salient in engagement in different contexts and so do the opposing ways in which influencing factors operate. For example, commonly cited physical and logistical barriers to engaging with programmes also acted as motivating factors, in particular in cases of condition-specific symptoms (Duca et al., 2021; Murphy et al., 2017; Verevkina et al., 2014) and caregiving (Shi et al., 2017).

A paucity of more nuanced causal explanations of factors influencing engagement in the reviewed literature may be due to the predominance of quantitative and retrospective study designs used to date (see Table 3.5). The complexity of both engagement and group-based self-management programmes necessitate a complexity-consistent approach to their investigation. Complex intervention research requires the consideration of context and programme theory, i.e. how change comes about and under which circumstances, and must prioritise the use of mixed-methods, theory-based or systems evaluation to do so (Skivington et al., 2021). Yet, very few papers reviewed adopted mixed-methods approaches and no theory-based approaches were identified.

3.10.5 Engagement research in real-world settings

Seven manuscripts explored issues relating to engagement with programmes that were trial interventions rather than real-world implementations of programmes (Ackerman et al., 2013; Davies et al., 2019; Falasinnu et al., 2021; Harris et al., 2019; Horrell et al., 2020; Kneipp et al., 2019; Lin et al., 2020). It is important to consider the differences between engagement with research of self-management programmes and existing programmes that are independent of research projects. Participants may have different attitudes towards participating in research and participating in self-management programmes. For example, a systematic review reported that some participants' unwillingness to engage with a SMS intervention was due to a historical mistrust of unfamiliar research among African-American and Chinese populations in the USA (Horrell & Kneipp, 2017). Some studies also offer incentives to participants taking part and/or participating in a certain number of sessions (Lin et al., 2020) or make additional efforts to recruit and retain participants that are not typical of real-life implementation of programmes. For example, Falasinnu et al. (2021) sent appointment reminders, conducted weekly phone calls to assess class attendance, and offered transport support for their participants. More research on programmes delivered beyond trials is necessary to develop an understanding of engagement with programmes in practice to support their future implementation and health and wellbeing outcomes.

3.10.6 Section summary

There is a clear incongruency of research approaches and the complexity of the phenomena under investigation in the literature reviewed. Engagement and group-based SMS interventions are complex, requiring complexity-consistent approaches to

investigating them. Yet, engagement has been over-simplified and individualised, and the vast majority of approaches to evaluating engagement with these complex interventions have not explored interactions with contexts or considered *how* engagement works, or not, in practice. A theory-based approach to researching engagement with self-management programmes, which considers engagement beyond the individual, is necessary to generate transferrable explanations to support the development and implementation of interventions.

3.11 Limitations of this narrative review

The aim of this narrative review was to synthesise and critically discuss the existing literature which has specifically explored engagement with group-based SMS programmes. However, the complexity of both engagement and SMS programmes posed challenges in identifying a manageable yet relevant set of manuscripts to review. The approach taken to searching for literature in the field was pragmatic but inevitably has limitations. Searching the title field only may have led to a suboptimal identification of additional studies that focused on engagement with programmes where this was not clear in the title, or where authors used alternative terms to describe their work.

The search strategy may also have been limited by using only two databases. This review and others (Timmermans et al., 2023) have identified the plethora of professionals delivering SMS meaning that further literature may have been identified in other databases specifically indexing literature in nursing and allied health, for example CINAHL.

Although the search terms adopted for the search were comprehensive, further search terms, particularly for LTCs, may have identified additional papers focusing on

engagement in group-based SMS programmes. The choice of search terms was mainly informed by the 4x4 NCD framework. Focusing on conditions in the 4x4 NCD framework has since been critiqued by the researcher while undertaking the work presented in this thesis and has been discussed in Chapter 1. Including search terms for all LTCs would not have been feasible, due to their changeable definitions, as discussed in Chapter 1. However, additional terms may have returned further useful literature.

In section 3.10, the lack of detailed causal explanation for issues relating to engagement was discussed and the lower proportion of qualitative research was proposed as a contributing factor. Qualitative studies contributed 19% of the included papers in this review. The low number of qualitative studies identified may, in part, be due to the search terms being entered into the Title field alone. Qualitative study titles are often descriptive and may not incorporate the precise terminology typically used in quantitative study titles (Booth, 2016; Evans, 2002). Searching qualitative study titles is further compounded by the fact that conceptualisations of topics can differ, which is certainly the case in the fields searched for this review.

The documentation of the decision-making process involved in this narrative review was detailed and transparent. Whilst only one researcher determined the inclusion and exclusion of papers and reviewed them, decisions were discussed in PhD supervision meetings and reflexivity was practiced throughout. Although it is best practice for a second reviewer to be involved in literature reviews, it is not uncommon for them to be a solo endeavour for PhD students.

3.12 Conclusion of narrative review findings

The findings of this narrative review elucidate a myriad of factors associated with engagement with group-based self-management programmes, confirming the complexity of the challenge of effectively supporting self-management in group settings. Factors which have been associated with different levels of engagement include personal characteristics such as gender; age; race and ethnicity; socioeconomic status and related factors, and individuals' health status. Inextricably related emotional barriers, including fear of judgement and lack of perceived benefit; and practical barriers such as transport issues, work and family commitments, and physical challenges due to disability and condition-related symptoms were also found to influence engagement. The role and perceptions of referring practitioners and facilitators is recognised in some of the literature yet remains under explored. Programme characteristics such as group size, location and scheduling have been shown to be related to engagement but the consideration of how the delivery of programmes influence engagement is largely absent in the literature. The diversity of group-based self-management programmes, and the lack of detailed information regarding their delivery, compounds this blind spot relating to how the delivery of programmes may influence engagement in the literature.

Overall, the body of literature investigating engagement with self-management programmes does not align with the overarching theories of engagement, which has led to conflation and omission of engagement constructs, oversimplification of engagement in this field, a lack of explanatory focus in the work undertaken, and a potential for perpetuating the individualisation and blame-laden narrative already dominating the LTC discourse.

The factors impacting engagement interact with each other, and understanding these interactions has been highlighted as an area in need of further exploration (Kneipp et al., 2019) as well as the influence of wider systems (Harris et al., 2019). Strategies to improve attendance can be targeted at multiple issues as barriers to engagement lie not just within individuals but within systems and other stakeholders (Mc Sharry et al., 2019). A thorough exploration of different perspectives and contexts are necessary to make progress towards developing interventions and policy to improve engagement. A realist approach explicitly recognises the numerous stakeholder and system influences on causal mechanisms and utilises methods to explore and test them empirically. There is currently a lack of adoption of theoretical frameworks to guide efforts to improve engagement (Horrell & Kneipp, 2017). The realist evaluation process not only allows the development of explanatory theory, but also affords the opportunity to test theory, which to date has not been addressed in the engagement literature in the field of group-based self-management interventions.

3.13 Research questions

The lack of explanatory theory linking the various contextual factors and underlying responses of individuals to generate outcomes of engagement in group-based self-management programmes is evident in this narrative review. Further, there is a distinct lack of research considering how engagement might be influenced by the way in which programmes are delivered. Finally, the lack of theoretical and complexity consistent approaches used to research engagement in these complex interventions has led to a disconnect between engagement as a concept and its exploration in the field. The aim of this PhD thesis, therefore, is to develop and test theories about how engagement works in group-based self-management programmes, for whom, in which

circumstances and why. Specifically, building on the overall aim and objectives of this thesis presented in the previous chapter, the current research seeks to answer the following questions:

1. How and in which circumstances do practitioners and people with LTCs engage with the H&W programmes and each other?
2. What is it about the way in which H&W programmes are delivered that influences how individuals engage?
3. What are the contexts that shape how individuals interact with and respond to the way that programmes are delivered?

The following chapter will discuss the philosophical underpinnings of scientific realism and realist methodology, and the methods used to address these questions for this research project.

Chapter 4 Methodology

4.1 Chapter overview

This chapter presents the underpinning philosophy of the methodological approach to this research. The chapter begins with a critical exploration of realism, its fundamental principles and how a scientific realist approach to evaluation can contribute to developing knowledge in the field of engagement in self-management programmes. This chapter will provide an overview of the philosophical underpinnings of scientific realism, its key tenets and definitions, and assumptions about how programmes work. This chapter will conclude with an introduction to my identity as a researcher and how this has shaped my understanding and approach to this work.

4.2 Realism

Realism is a model of scientific explanation that places itself between positivist and constructivist paradigms of research (Pawson & Tilley, 1997) and attempts to balance the understanding that we can both observe and construct a proportion of reality. Realism recognises that there is both a material and social reality with which we, as researchers, interact (Westthorp, 2014). There are many versions of realism and the range of terminologies adopted to represent them are vast. Many are listed by Maxwell (2012) who highlights that the main point of agreement among the different conceptualisations of realism is that finding one, single “correct” understanding of the world is not possible. The philosophical foundation for the research undertaken in this thesis is scientific realism, the key principles of which have been borrowed from various realist scholars (Pawson, 2013).

Scientific realism is underpinned by some of the key principles of Roy Bhaskar's realist theory of science (Bhaskar, 1978). Both Pawson's scientific realism and Bhaskar's critical realism are underpinned by principles of ontological depth and share the position that it is necessary to unearth underlying mechanisms to appreciate generative causation with the use of theory (Pawson, 2013) both of which will be discussed in section 4.3. The similarities and differences between scientific and critical realism have been debated and contested (Pawson, 2016b, 2016a; Porter, 2015b, 2015a), the details of which are considered beyond the scope of this thesis. Of particular relevance to this PhD is where scientific and critical realist perspectives diverge in the assumptions about what can be empirically tested given the complexity of social systems. Closed systems are considered to contain stable, empirically identifiable causal relationships, whereas the causal relationships in open systems are fleeting and impermanent (Pawson, 2024). Bhaskar's belief, from a critical realism perspective, is that physical science may be tested in constrained environments and that social science cannot, due to the impossibility of creating closed systems for empirical testing. As self-management programmes cannot be reduced to fit the experimental framework of gold standard randomised controlled trials (RCTs) (Minary et al., 2019) there lies a conundrum regarding developing an evidence base for how self-management programmes work, given their social nature. Although critical realism affords a freedom to theorise in the domains which evade empirical testing (Mukumbang et al., 2021) a critical realist approach may encourage a nihilistic view of empirically investigating and establishing patterns of causation in self-management programmes. As these programmes operate in open social systems, a critical realist view may consider it impossible to capture the causal relationships therein. However, Sayer (2010) asserts that the social world is not immune to empirical check. Further,

Pawson (2013) argues that in physical science there are no fully understood closed systems within which to test theories either, rather, numerous experiments are conducted to develop understanding over time. Pawson (2024) promotes the role of the researcher in building partially closed systems within which to undertake inquiry

Scientific realism focuses on an approach to theorising which can be corroborated with the best available evidence (Mukumbang et al., 2021). Pawson (2018) highlights the lessons that can be learned from evidence-based medicine, or physical science, by developing an understanding of mechanisms of action and working through the multiple contingencies by building and drawing on a multi-method evidence base, whilst adapting to the changes to programmes over time. For example, the effects of pharmaceutical drugs on different populations are not fully understood in a single RCT. Knowledge and understanding of the effects of pharmacological interventions are developed through multiple trial phases, ongoing data collection of less common side-effects, evidence syntheses and collective interpretation. Pawson (2013) drew on the work of Campbell (1988) to assert the need to utilise hypothesis-driven mixed methods to continually and empirically test theories of how social programmes work. Accumulating and refining knowledge over time underpins the pragmatic perspective of scientific realism that all knowledge generated through realist inquiry is partial and fallible (Astbury & Leeuw, 2010), just as in the case of evidence-based medicine (Pawson, 2018). A scientific realist approach to investigating engagement with self-management programmes in this thesis aims to address the shortfalls of both RCTs at one end of the spectrum and critical realist theorising at the other. The aim of this work is to build layers of knowledge and understanding which may be used to make incremental improvements to programmes and policy whilst recognising the limitations of what can be known and how we go about knowing it.

4.3 Ontological and epistemological underpinnings of realist inquiry

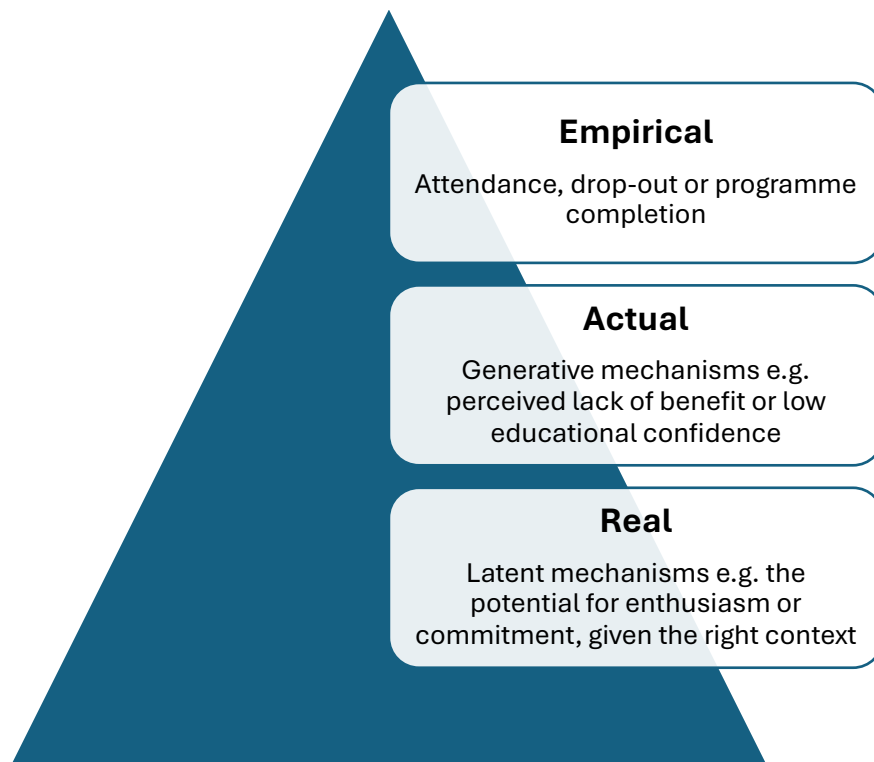
Realism is positioned between positivism and constructivism, however, it does not simply exist between the two on a continuum. Unlike positivism and constructivism, realism separates ontology and epistemology (Maxwell, 2012). Ontologically, realism shares the positivist assumption that there is a reality that exists independently of our ability to perceive it (Jagosh, 2019). Realists believe there to be both a material and social reality (Westhorp et al., 2011), meaning that social programmes, such as SMS programmes, have real effects, whether we see them or not. In some contrast with positivism however, realism adopts a more interpretive lens epistemologically (Easton, 2010), appreciating that knowledge is socially constructed, making it impossible to discover a definitive truth. Realism appreciates that there are multiple perceptions of reality, rather than multiple realities (A. J. Fletcher, 2017) but does not go as far as constructivism to assert that there is no way to choose interpretations at all (Westhorp et al., 2011). Realism aims to align what is real with our construction of reality, rather than assuming the constructivist stance that reality is only what we construct it to be. These ontological and epistemological assumptions underpin the realist position that knowledge will always be incomplete and fallible but that it is possible, and useful, to accumulate knowledge through multiple empirical research cycles. *'Fragmental, incremental understanding is the very nature of enlightenment'* (Pawson, 2024, p.58).

Realist philosophy embraces the concept of ontological depth where reality is stratified in layers (Jagosh, 2019), described by Bhaskar as "Stratified Ontology". These layers are *the empirical*, an observable reality; *the actual*, reality which manifests regardless of our perception of it; and *the real*, a reality of latent and dormant possibility (Sayer, 2010) (Figure 4.1). Much of the engagement literature has focused on the observable

features of engagement at the empirical level, with little investigation into mechanisms in the actual layer, generating this observable reality.

Figure 4.1

Stratified layers of reality in engagement



Realism understands causation to be a result of generative mechanisms that operate in different ways in different contexts rather than the more positivist linear depiction of programmes directly causing outcomes (Westhorp et al., 2011). Pawson and Tilley (1997) explain that causal connections are not established simply through repeated observation nor are they the construction of the human mind. Generative mechanisms, which will be discussed in more detail in section 4.6.1, have been conceptualised in numerous ways by realist scholars. Mechanisms in Pawson and Tilley's (1997) realist evaluation are the reasoning and responses of stakeholders which lead to change. Therefore, according to Pawson and Tilley, participants in SMS programmes are not

considered passive recipients of the interventions they attend but active agents responding to resources the programmes provide. Programmes are assumed to be introduced into complex systems, which influence the ways in which they are implemented and how individuals respond. Appreciating that human responses and interactions in different contexts lead to change is important for understanding complex interventions, like SMS programmes which are delivered in a multitude of ways (Timmermans et al., 2023). Most complex intervention research has focused on efficacy and effectiveness (Skivington et al., 2021), whereas realist inquiry seeks to answer questions about how, why and for whom interventions work and in which circumstances.

4.4 Realist evaluation

Realist evaluation is a form of theory driven evaluation which is underpinned by scientific realism. The aims of scientific realist evaluation are pragmatic in nature (Pawson, 2013). Realist evaluation aims to generate explanatory theories of causation that may help to inform the development and implementation of complex interventions (Jagosh et al., 2022). By developing a greater understanding of how and why people engage to different extents in different circumstances, programme implementers and practitioners can make better informed decisions about how to tailor interventions for better engagement and avoid unintended outcomes.

The two predominant approaches of realist inquiry are realist evaluation and realist synthesis. Both approaches are used to develop and test programme theories. Realist evaluation can be adopted when the researcher has direct access to a programme or family of programmes, where theory may be developed from primary data from a specific intervention. Realist evaluation can have an important role in rapidly changing

health services because programme theory can be developed in real time and subsequently inform future iterations of interventions as their implementation adapts to changing priorities, needs and funding constraints (Jagosh et al., 2022). Realist synthesis, on the other hand, may be used when developing theory for a wider family of programmes, where there is minimal access to primary data, by using secondary data for theory development. It is not uncommon for the two approaches to be used together. Juxtaposing primary data from programme stakeholders with published literature can strengthen a realist inquiry (Emmel et al., 2018). Some studies have used realist synthesis to develop programme theory and then tested these theories using realist evaluation, however, it is not necessary to use both in their entirety to benefit from using these complementary approaches. In fact, the RAMESES Quality Standards for Realist Evaluation explicitly include recommendations to use a wide range of primary and secondary data for developing programme theory (Greenhalgh, T. et al., 2017a) as well as to compare the findings of the realist evaluation with existing literature relating to how similar programmes work in different contexts (Wong et al., 2016).

The H&W programmes, introduced in Chapter 2, have undergone various iterations since their inception and continued to change throughout the course of this research. Therefore, it was necessary to adopt a methodology that can generate theory in these changing circumstances. Realist evaluation was chosen for this research due to the availability of existing primary data from a range of stakeholder sources and the opportunity to conduct interviews with programme architects and practitioners for theory development. Secondly, given the diverse conceptualisations of engagement and heterogeneity of self-management programmes highlighted in the narrative literature review, building programme theory from practice offered boundaries and a

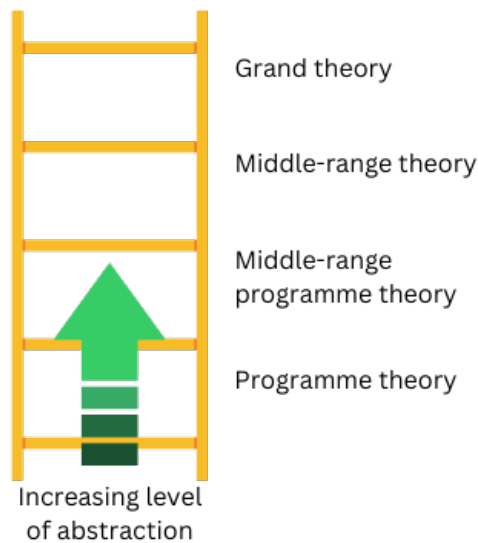
more navigable landscape to work in which was challenging to construct within the literature. Thirdly, given that a desired outcome of this research was to support the sustainability, spread and scale-up of H&W programmes, building theory primarily from the real-world implementation of these programmes was deemed more likely to produce relevant and directly actionable findings.

4.5 Theory in realist inquiry

Numerous engagement theories exist but most focus on describing its components with very few adequately explaining the relationship between them (Graffigna, 2017). Further, the findings of the narrative review in Chapter 3 highlighted the lack of theory-informed approaches to investigating engagement, leading to a dearth of explanatory accounts of engagement in the literature. The adoption of theory-driven realist inquiry for this research seeks to address this gap in the research by answering *how* engagement develops, or not, in group-based SMS programmes. It is therefore necessary to understand how theory is used and understood in the realist approach. Realist inquiry uses, generates and refines theory at various levels of abstraction during its iterative process, which has been illustrated as a ladder of abstraction by Punton et al. (2020) (Figure 4.2). Theory development and testing moves up and down this ladder, to and from programme theory, middle-range programme theory and middle-range theory (Mirzoev et al., 2020). The definitions and conceptualisations of these levels of theory in relation to this research will now be presented for clarity.

Figure 4.2

Ladder of abstraction, adapted from Punton et al. (2020)



4.5.1 Programme theory

Realist programme theories are the subject of analysis in realist evaluation and are the explanations of how a given programme is proposed to work, for whom, in which circumstances and why (Pawson & Tilley, 1997; Punton et al., 2016). Realist evaluation follows best practice for evaluating complex interventions by beginning with the development of programme theory and refining it during successive phases (Skivington et al., 2021). Programme theories are specific causal statements which explain how different outcomes are generated in different contexts (The RAMESES II Project, 2017). These causal explanations specifically articulate contexts and how they influence mechanisms to generate outcomes (Pawson & Tilley, 1997); each of these programme theory components will be discussed in sections 4.6.1 and 4.6.2. In the literature reviewed in Chapter 3, numerous contexts for engagement with SMS programmes were identified. However, empirically evidenced explanations for how contexts influenced mechanisms, and therefore outcomes, were scarce. Programme

theories in this thesis will seek to address this gap in the literature by explaining how various contexts shape how individuals respond to and engage with SMS programmes. These causal explanations may begin as incomplete statements at the initial theory development stage and develop into more complete configurations of mechanism, context and outcome in the latter stages of development (Jackson & Kolla, 2012).

4.5.2 Middle-range theory

Middle-range theories serve as an intermediary between grand social theory, which aims to provide encompassing explanations for general social uniformities, and the highly specific explanations relating to particular examples of social behaviour or change (Merton, 1968). By bridging the chasm between grand-theory and the much less generalisable explanations of how individual programmes work, i.e. programme theory, middle-range theory can facilitate empirical testing of social phenomena (Davidoff et al., 2015). Middle-range theories can be used both as a framework to begin programme theory development and/or to refine programme theory in the later stages of theory development (The RAMESES II Project, 2017). Theory abstraction can provide a common language with which to share learning between interventions (Pawson, 2013), making it possible to accumulate knowledge through multiple evaluations. For example, Self-Determination Theory provides overarching explanations for how biological, social and cultural conditions influence human capacity for psychological growth, engagement and wellness but also has specific applications in healthcare, education, sport and work demonstrated in empirical research (Ryan & Deci 2018). Theory developed in this realist evaluation of engagement in group-based SMS interventions may therefore be abstracted to

provide a framework to support the investigation and explanation of engagement in other, similar programmes.

In theory development, middle range theory can be used to facilitate the identification of complex, hidden or obscured outcomes by supporting the conceptualisation of the phenomenon (Jagosh et al., 2014). The use of theory to help identify outcomes of engagement is prudent due to the lack of a consensual definition in the literature (Graffigna, 2017). Further, engagement is not simply a static state and not all of its outcomes are observable (Bright et al., 2015). Therefore, a qualitative exploration of engagement outcomes is necessary. Middle range theory can be used to inform the choice of methods of identifying outcomes of engagement in this research and will be discussed in the next chapter. The use of middle range theory in realist evaluation can therefore support two-fold. Middle range theory can provide a delimiting lens through which to explore engagement in the H&W programmes, as explained above. Middle range theory can also offer a means to transfer specific learning from the programmes under investigation to support an understanding of engagement with similar programmes (Punton et al., 2020).

4.5.3 Retroductive theorising

The development of theory in realist enquiry utilises a retroductive approach, which is a form of retrospective theorising and overarching logical approach (Mukumbang et al., 2021). Retroductive theorising is necessary to move from understanding events from a successional view of causation, to unearthing generative causation (Sayer, 2010). Retroduction incorporates induction, deduction and abduction reasoning (Mukumbang et al., 2021) allowing researchers to search behind, below and back from observed patterns or regularities for causal explanations (Lewis-Beck et al., 2004).

Emmel et al. (2018) describe the process of identifying mechanisms as a simultaneous upward working from local programme data and downward working from formal theory, as described in the previous section. Abductive reasoning complements these inductive and deductive approaches as it involves creativity and reconceptualisation, providing a way to theorise otherwise elusive generative mechanisms (Jagosh, 2020). Retroduction therefore requires the use of common sense, intelligence, expertise and informed imagination to build and test theory (T. Greenhalgh, Pawson, Wong, Westhorp, Greenhalgh, Manzano, et al., 2017b). A retroductive approach to theorising allows the researcher to elicit configurations of contexts, mechanisms and outcomes, which make up realist programme theory (Gilmore, 2019) and will now be discussed in more detail.

4.6 Components of realist programme theory

The heuristic used to develop realist programme theory is a configuration of context-mechanism and outcome (CMO), often referred to as context mechanism outcome configurations (CMO-Cs). The following paragraphs explain the concept of each of these components, from a realist evaluation perspective.

4.6.1 Mechanisms

Mechanisms are the key to understanding causation in realist inquiry. Pawson and Tilley (1997) avoid providing a single definition of mechanisms, preferring to describe them in terms of their crucial characteristics, which are that they are the underlying inner workings of programmes and exist in layers of social strata. Mechanisms explain the relationship between variables of a programme rather than being programme activities or variables themselves (Astbury & Leeuw, 2010); they are not simply associations, they are generative (Pawson & Tilley, 1997). Variables associated with

engagement in self-management programmes interact and the relationships between them need exploring (Kneipp et al., 2019). Much of the literature describing engagement with SMS programmes (Chapter 3) identified programme and individual variables associated with engagement, such as gender, socioeconomic status and programme features, yet lacked these explanatory mechanisms.

Mechanisms are invisible, often due to their existence at a level of the system that is different to the one at which they generate outcomes; the time period over which they act; and their dependence on interactions and relationships (Emmel et al., 2018). Both temporal and relational aspects of engagement are underexplored (Bright et al., 2015), contributing to our lack of understanding of causal mechanisms. Mechanisms can be found at numerous points along a behaviour change process, for example, at various points related to an intervention, such as the waiting list, interactions during the intervention, and right through to the exit strategy (Pawson, 2013). Mechanisms of engagement must therefore be explored at multiple points along the engagement pathway, which is so far limited in existing literature. Mechanisms may also be elusive due to their latent or dormant existence in the 'real' level of stratified reality; they exist as part of a whole system and are latent until they are activated by given contexts (Westhorp, 2014), when they may be discovered at the 'actual' level of stratified reality. Generating an understanding of engagement mechanisms in the H&W programmes may facilitate the consideration of unrealised mechanisms in other, similar programmes. Understanding how mechanisms may be shaped and activated can inform where to target resources and how to maximise impact (Wong, 2015), supporting the spread and scale-up of interventions discussed in Chapter 2. Strategies to improve engagement with SMS programmes were tentatively suggested by studies reviewed in Chapter 3, but as previously discussed, these recommendations are not

based on an understanding of generative causation gained through empirical testing. The use of realist evaluation to develop and test explanatory theories of engagement seeks to provide some of this necessary insight required to effectively target resources to improve engagement.

The classic constructs of mechanisms in realist evaluation are reasoning and resources (Pawson & Tilley, 1997) which are particularly useful when considering mechanisms at an individual level. Mechanisms can operate at various levels of systems as different levels of systems have powers and properties that cannot be reduced to individual parts (Emmel et al., 2018). For example, mechanisms may be found in policy development and government decision making in relation to LTCs and supporting people living with them. The focus of the current research is to explore how programmes can be delivered in a way to support engagement. Conceptualisation of mechanisms at the individual level may help to explain how participants' engagement is affected by particular programme resources. However, mechanisms have also been conceptualised as forces, interactions and feedback/feedforward processes (Emmel et al., 2018). Mechanisms as interactions and feedback/feedforward process may help provide explanation for the interactional aspects of engagement largely absent from the literature (Kneipp et al., 2019). Emmel et al. (2018) list the key criteria for mechanisms, which regardless of their constructs, are that:

- they are causal and operate at a different level of a system than the outcome they generate;
- they are not observable using the same methods to measure that work at the level of the outcome they generate; and
- they describe the following 3 things:

- Necessary **components** of a system, for example, essential competencies and attitudes for delivering person-centred care (McCormack et al., 2021).
- Necessary **relationships** between components, such as the relationship between socioeconomic status and engagement with programmes (Boakye et al., 2018; Cauch-Dudek et al., 2013).
- **Processes** through which components generate their outcomes, for instance the psychological and emotional processes of engagement (Graffigna et al., 2020).

Conceptualising mechanisms according to the above criteria can facilitate unearthing causal explanations by recognising the need to look for mechanisms in different layers of systems from the outcomes they generate. In the case of engagement this may involve observing engagement constructs, such as participation, at an interpersonal level, but exploring their reasoning at an individual level. Outcome behaviours may be observable but individuals' reasoning may only be accessible through methods which can elicit these inner thought processes.

4.6.2 Contexts

Pawson and Tilley (1997) describe context as mechanisms' partner concept because whether the causal potential of a mechanism is realised, is dependent on its context. Programmes and their mechanism resources are introduced into pre-existing contexts (Dalkin et al., 2015). Contexts operate by constraining choices of stakeholders of programmes because although participants always have choices, they are shaped by the characteristics and circumstances of the individual (Pawson, 2004). Context may be found at different levels of social strata: individual, interpersonal relationships,

institutional settings and infrastructure (Pawson, 2013). Contexts may be conceptualised as observable features or as relational and dynamic features or forces (J. Greenhalgh & Manzano, 2021). For example, individual contexts such as low SES, low educational attainment and symptom severity have been found to impact engagement with SMS programmes (Boakye et al., 2018; Duca et al., 2021; Santorelli et al., 2017), as have inter-personal level contexts such as interactions with HCPs (Allory et al., 2020; Faro et al., 2021) and fellow participants on the programmes (Parmenter et al., 2020; Stenberg et al., 2016; Wurz et al., 2015; Yufe et al., 2021). The realist consideration of contexts at institutional and infrastructural levels is relevant in engagement because individual engagement is shaped by wider systems (Harris 2019; McSharry 2019). Contexts should therefore be conceptualised not as back drops, which has often been the case so far, but rather in relational terms, i.e. what a context does rather than what it is (J. Greenhalgh & Manzano, 2021). The contexts relating to engagement in Chapter 3 lacked these explanations of how contexts shaped mechanisms and therefore outcomes. Understanding how and why contexts shape mechanisms to produce outcomes is key to understanding how programmes work (J. Greenhalgh & Manzano, 2021).

Contexts can be conceptualised as tangible triggers of mechanisms but they can also be considered as having more of a shaping or modifying influence on mechanisms (J. Greenhalgh & Manzano, 2021). Dalkin et al. (2015) describe them as akin to an on/off switch in the former and a dimmer switch in the latter. As engagement is an ongoing process where engagement levels may ebb and flow (Bright et al., 2015), the dimmer switch analogy is helpful for exploring contextual factors of engagement.

Recognising that context matters does not necessarily mean that an intervention is context-bound (Emmel et al., 2018). Contexts may be identified that can amplify mechanisms of engagement within programmes, providing useful direction for leveraging opportunities to improve engagement. In realist inquiry, context and mechanism are inextricably linked; any attempt to separate them would be to move away from the realist goal of aligning reality and our construction of that reality. This is in stark contrast with the positivist approach and its common application in medical research where context is stripped as a confounding factor in experimental design.

4.6.3 Outcomes

There are numerous possible outcomes of programmes and realist inquiry is concerned with both intended and unintended outcomes. Outcomes can be found at the empirical level of reality and measuring them in realist evaluation therefore tends to be a quantitative endeavour (Pawson, 2013), for example, attendance or participation in programme activities. Appreciating that programmes can have unintended outcomes is particularly useful when considering the application of findings of a realist evaluation. Understanding how contexts and mechanisms interact to produce diametrically opposing outcomes can inform the tailoring of programmes to avoid inadvertently generating unwanted outcomes for some individuals or for an intervention overall. Examples of opposite outcomes were highlighted in the narrative review. For example, the experience of a person's condition may be a motivating factor as well as a deterring factor to engage with programmes (mechanism), depending on an individual's level of acceptance of their condition (context). Understanding how these differences come about in more detail may help to inform when and how programmes are recommended to potential participants in different circumstances.

4.7 Quality in realist inquiry

As realist evaluation increased in popularity following Pawson and Tilley's (1997) seminal work, it became apparent that robust quality standards were needed to support the appropriate use of the approach following the identification of various shortcomings of published realist evaluations (Marchal et al., 2012; Pawson & Manzano-Santaella, 2012). In response to calls for the development of guidance and standards to support realist researchers, the Realist and Meta-narrative Evidence Syntheses: Evolving Standards II (RAMESES II) project produced quality standards and training materials to support evaluators, researchers, peer reviewers and trainers (Wong et al., 2017). The quality standards outline features of quality in relation to the reporting of realist evaluations and demonstrating the alignment of the evaluation purpose, design, data collection methods, recruitment, analysis, and reporting align with realist philosophy and assumptions, including realist principles of causation and programme theory. The RAMESES Quality Standards for Realist Evaluation (T. Greenhalgh et al., 2017a) were used to inform quality enhancing practices and the reporting in this realist evaluation.

The judgement of quality in realist research is based on relevance and rigour (Wong et al., 2013). In research underpinned by positivist and constructivist stances, validity tends to be determined by the methods used to collect data because both positions view knowledge to be limited to what can be measured or constructed (Maxwell 2012). However, due to the realist separation of ontology and epistemology, validity in realist research focuses on the interpretations and conclusions made following the contextual use of specific methods for a specific purpose (Maxwell 2012). Theories are more than data and, as such, limiting judgements about quality to only data is not sufficient

(Emmel et al. 2018). Key considerations for quality in realist evaluation are based on whether the methods used align with underpinning realist philosophy and so include the explanatory focus of the work; the use of multi-methods and the investigation of contexts, mechanisms and outcomes in configuration (Pawson & Manzano-Santaella, 2012). The use of multi methods aims to increase researchers' confidence that they have collected adequate data to support their claims (Ronkainen & Wiltshire, 2021). Prolonged engagement with the environment and involving the most suitable participants in a study are also necessary for ensuring sufficient data is collected (Ronkainen & Wiltshire, 2021). Choosing the most suitable participants in this research will be discussed as part of the sampling strategy in Chapter 5.

The validity of research, through a realist lens, can also be considered in terms of its practical utility, meaning to what extent do the research findings provide actionable knowledge (Ronkainen & Wiltshire, 2021). The aim of programme theories in this research is to provide practical considerations for programme architects and practitioners to deliver group-based SMS programmes in a way that supports engagement. By focusing on mechanisms at the individual level and conceptualising them as reasoning and resources, as discussed in section 4.6.1, it is hoped that learnings from the programme theories will be more readily actionable by practitioners and more directly impact participants.

As realism spans both physical and social sciences, it shares several post-empiricist principles of objectivity (Pawson, 2024). Objectivity is founded on theory informed data generation; adjudicating between theories; accumulating evidence to extend existing explanatory networks; and collective level approaches, such as peer-review, attempted replication and testing or rival explanations (Pawson, 2024). The current

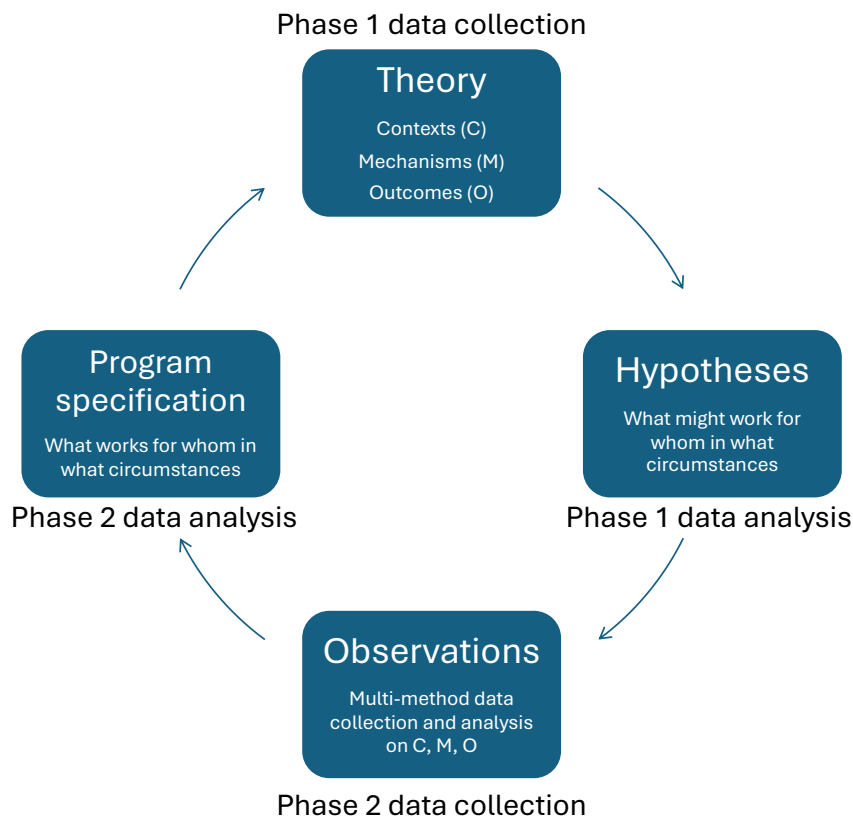
research has been aligned with these four concepts through its overall design and specific data collection methods, which will be described in detail in the next chapter. The accumulation of evidence is now introduced in the context of the realist evaluation cycle.

4.8 The realist evaluation cycle

In realist inquiry, knowledge is accumulated over time through cycles of theory development and testing of theories in subsequent phases of research (Jagosh, 2020). Each cycle begins and ends with theory (Marchal et al. 2012), as presented in Figure 4.3. The realist evaluation for this research therefore comprised two main phases which have been mapped onto this cycle in Figure 4.3: a theory development phase and a theory testing and refinement phase. The design, and data collection and analysis methods for these two phases are discussed in detail in Chapter 5.

Figure 4.3

The realist evaluation cycle for this research, adapted from Pawson and Tilley (1997)



Beyond a single realist evaluation, realist knowledge can be accumulated by abstracting the programme theories developed and tested to the middle range so that they may be useful to underpin the development of a range of programme types (Pawson & Tilley, 1997), as described in section 4.5.2. The aim of realist evaluation is continual betterment of practice rather than secure transferability of knowledge (Pawson & Tilley, 1997).

4.9 Reflexivity

Reflexivity is generally agreed to be the ongoing process of critical self-evaluation of a researcher's positionality and explicitly acknowledging how this impacts research processes and outcomes (Berger, 2015). Epistemologically, reflexivity understands

knowledge to be constructivist (Reid et al., 2018), which aligns with realist assumptions. It is therefore not possible to separate researcher from the researched. Researchers interact with gatekeepers and participants in qualitative research and will influence and be influenced by the social world being studied (Maxwell, 2012).

In realist research, the evaluator is recognised, along with subjects and practitioners, as key informants for programme theory development by bringing hypotheses from similar or previous programmes and from wider, more abstract theory (Pawson & Tilley, 1997). Researchers' prior experiences, beliefs, values and assumptions shape how a study is conceptualised and engaged with (Maxwell, 2012). The researcher's background is central to the process of retroductive theorising used in realist inquiry because of the creative interpretation of data required (Downey et al., 2024). Sampling is dependent on the decisions made by the researcher about whether samples will provide meaningful data to the research (Emmel, 2013). This researcher subjectivity is embraced in realist approaches, rather than treated as bias to be eliminated, provided it does not go unexplored and unchecked (Maxwell, 2012). Reflexive researchers are better able to genuinely involve other perspectives in their work and unearth the generative mechanisms at the root of realist inquiry (Downey et al., 2024). Although it is not possible to fully know ourselves or the full impact that we have on our research (Emmel, 2013), a self-audit trail of reflexivity can support transparency, articulate hunches and direct considerations for future research (Layder, 1998). The approach taken to systematically and transparently undertake reflexivity in this research is discussed in the method details in Chapter 5, and the following section of this chapter presents an examination of my own identity and perspective in relation to this research.

4.10 Researcher identity

I am a white female who grew up in a relatively affluent area, who enjoyed the privileges of a financially stable home environment, access to a good education, healthy food and opportunities to be physically active. I had some awareness of the need to not take these comforts for granted as my parents overcame great adversity to afford me the opportunities I had growing up. My mother is from former Yugoslavia, so we also had close friends and family who were directly impacted by the Yugoslav Wars. Knowing my parents' journeys and being close to people displaced by war heightened my awareness of some of the social determinants of health and wellbeing from a young age. However, my understanding was shaped by seeing the impact of these factors in the context of adverse situations being overcome. I held the belief that if you work hard and are a good citizen, you can overcome, which was accompanied by an implicit belief that a failure to overcome is a consequence of poor control, effort and/or morals. These beliefs shaped my attitude toward health behaviours for much of my teenage years and early twenties, and were reinforced by having generally good health and my being able to change my own behaviours relatively easily when I felt it was necessary. These blame-laden beliefs have slowly eroded over time and have been replaced with an increasing understanding of the complexities of the lived experience of health through listening to friends, family, patients and students, and experiencing my own challenges. The extensive reading I undertook for this PhD and learning from the H&W team and my supervisors allowed me to accelerate this change in my thinking and actively search for more humanistic ways of supporting people with LTCs. The departure from my earlier beliefs has allowed me to seek causal explanations for engagement with SMS programmes that do not place further blame, burden and responsibility on individuals.

My beliefs about how interventions work and my conceptualisation of engagement have been heavily influenced by my training and experience as an osteopath and teacher. One of A.T. Still's, the founder of osteopathy, key beliefs was that a physician does not cure disease. He asserted that the body is capable of self-regulation and self-healing and that an osteopath's role was to work with the individual to create the right conditions for this self-healing to occur. Many of my beliefs and attitudes have diverged somewhat from traditional osteopathic philosophy but this is a principle that still forms part of my foundation of practice. Although there are many differences between the manual therapy approach of osteopathy and SMS programmes, Pawson and Tilley's (1997) proposition that what makes a programme work lies within the participants themselves resonates strongly with me. I have a similar view of the role of the teacher-learner relationship. My role as an educator is to support students in developing and applying their own knowledge through facilitating their learning, rather than imparting facts and information; learning and development comes from within the learner as an active agent.

I applied for the opportunity to undertake this PhD as a full-time bursaried position, with the overall realist evaluation approach to investigating the H&W programmes pre-determined. My appreciation for the nuances of my clinical and educational practice resulted in my desire to learn methods of enquiry to explicate the underlying processes of complex interventions. As such my existing beliefs influenced my research from the point of applying for the studentship. My training as an osteopath was through an integrated Masters degree, during which the majority of my peers and lecturers criticised RCTs and other reductionist approaches to research for crudely oversimplifying and under-valuing osteopathy as a form of healthcare. Consequently, unlike many other researchers I attended realist training with throughout my PhD, I did

not have to 'unlearn' or contend with engrained positivist or constructivist assumptions. My more natural tendency toward realist thinking provided motivation to seek out alternative modes of enquiry for my PhD, but also made my realist learning journey seemingly easier than it was for some of my peers. However, through less resistance, I may have missed important opportunities to challenge some realist assumptions in my work. I have attempted to consider opposing views through reflexive writing and by seeking out alternative positions and arguments, both of which have helped me to understand where realist evaluation can be of great use and where it may be less so.

My experience in osteopathy and teaching has also shaped my conceptualisation of engagement. Particularly during my time training and teaching in secondary education, an enormous emphasis was placed on the teacher's responsibility for student engagement. It was simply unacceptable to label an individual as a 'difficult' pupil and to attribute low attainment to *their* poor engagement. This is not a message I have experienced to the same degree in healthcare; my impression has been that the "hard-to-reach" are portrayed as evasive and there is very little emphasis on reflecting on our role as healthcare professionals to engage individuals. Seeking to understand students' individual circumstances and adapt teaching accordingly was always the expectation of me, as a teacher. So, for me, there can be no model of engagement which ignores the relationship between teacher and learner or practitioner and patient; or which fails to consider its complexities. My beliefs about the relational and complex nature of engagement inevitably influenced my choice of conceptual framework for this thesis, the process of which will be described in the following Chapter 5. We can never fully know all of the theory that we bring to research (Emmel, 2013), however, by reflecting on my journey and experiences prior to

undertaking this research, I can offer some transparency regarding the choices I have made throughout this work.

My experiences and interaction with healthcare and education have influenced my beliefs and actions over time. Like context, in realist terms, the inevitability of subjectivity in human-led research is not seen as an affliction to be controlled and eliminated but as an essential part of the process of understanding (Maxwell, 2012). Bringing my ideas and experiences from education and working with groups outside of healthcare may even be advantageous in the complex problem-solving necessary for this research. Syed (2021) advocates both conceptual distance and conceptual depth for approaching complex problems so that they can be examined through different lenses, contributing to the development of recombinant solutions. Cognitive diversity, i.e. viewing challenges through different lenses, is an important tool in solving complex problems (Braithwaite et al., 2018). The practice of using ideas from other fields is also consistent with the pragmatic realist approach to reusing theory from other fields rather than starting from scratch for each problem (Pawson, 2013).

4.11 Chapter summary

This chapter has presented the underpinning philosophical assumptions for this thesis. The relevance of realist ontology and epistemology, and a realist understanding of causation to the investigation of engagement in SMS programmes has been outlined. Realist evaluation as a methodology has been justified and its use of terminology and principles in relation to theory have been described. The components of realist programme theory have been presented, using examples of factors relating to engagement identified in Chapter 3, which illustrated the shortcomings of the existing body of literature and how realist inquiry can contribute to resolving these issues.

The principles of quality in realist evaluation have been presented, followed by an overview of the realist evaluation phases in this work. Finally, a reflexive account of my identity as a researcher has been presented to enhance the transparency of how my assumptions, experiences and beliefs have shaped this research.

The following Chapter 5 details the research design and specific methods for data collection and analyses for this realist evaluation.

Chapter 5 Realist evaluation design and methods

5.1 Chapter overview

This chapter details the research design and methods used for this realist evaluation. The chapter builds on the previous chapter 4, which focused on the methodology for this thesis. This chapter begins by presenting the case study design for the evaluation and its two broad phases of theory development, and theory verification and refinement. Next, the conceptual framework used to guide data collection and analysis is articulated, along with the methods for identifying and layering middle-range theory to support programme theories. Ethical considerations for the work are then discussed. The sampling strategy is then presented, followed by the data collection methods, and study recruitment processes. Finally, the chapter presents the data analysis undertaken to develop and test the programme theories of engagement.

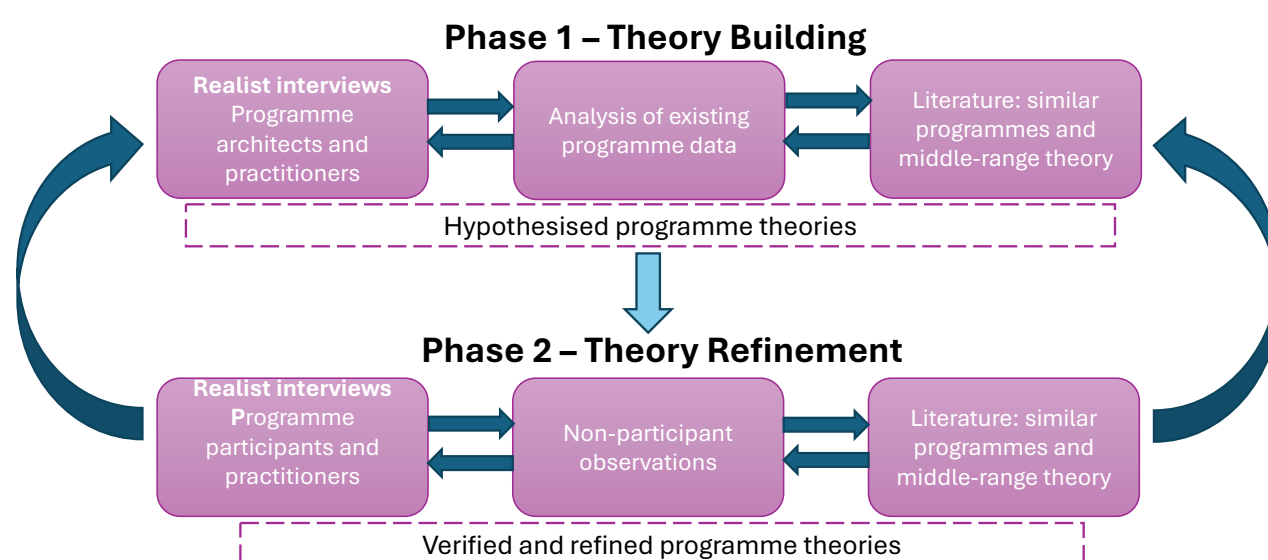
5.2 Research design

Although realist evaluation is method neutral, it most commonly employs a case-based approach (Gilmore et al., 2019; Renmans & Castellano Pleguezuelo, 2023). A case study describes what is going on in a specific setting and is both the process of inquiry about a case, and a product of that inquiry (Emmel, 2013). Case study designs can help to examine and explain causal links in real-world interventions (Yin, 2018) and develop an understanding of how and why outcomes vary across different contexts (Paparini et al., 2020). A case study design was used for this realist evaluation and comprised two broad phases: Phase 1 theory development; and Phase 2 theory verification and refinement, which are presented in Figure 5.1. These phases have been mapped to the realist evaluation cycle, which was described in more detail in Chapter 4, in section 4.8.

Phase 1 used the H&W approach overall as a case representing person-centred delivery of group-based SMS programmes from which to develop programme theories. Phase 2 involved a more focused and in-depth multi-case study of different H&W programmes delivered in different locations, to verify and refine programme theories. The process of theory development and testing is iterative (Pawson, 2006) so although the research phases in Figure 5.1 are presented in succession, the iterative process is implied by multi-directional arrows connecting the phases as well as data collection within each phase.

Figure 5.1

Outline of the research design for this realist evaluation



5.2.1 Phase 1 theory development

Programme theories for engagement with the H&W programmes were developed from realist interviews and secondary analysis of historical and concurrent research project data collected independent of this realist evaluation, which will be discussed in detail in sections 5.5.1 and 5.5.3. There is no single accepted way to develop programme

theory for realist evaluation (Pawson & Tilley, 1997). The choice of approach is determined by the data available and the nature of the evaluand. Group-based SMS programmes are conceptualised and delivered in a plethora of ways. Further, many SMS programmes have not reported theoretical underpinnings and those that have, vary greatly (Mulligan et al., 2019; Punna et al., 2019; Timmermans et al., 2023). Person-centred components of programmes are also infrequently reported (Lafontaine et al., 2020). The variation and complexity of person-centred SMS programmes, and therefore engagement with them, can therefore create an unmanageable abundance of candidate theories and elements of theory to explore (Shearn et al., 2017). Although theory of how programmes work can be developed from existing literature (Booth et al., 2019; Emmel et al., 2018), significant challenge was anticipated in identifying information relevant to the conceptual framework of engagement (discussed in section 5.2.3) and person-centred group-based SMS programmes specifically. Therefore, a case study approach was chosen to make use of the direct access to H&W programme architects and practitioners, and existing relevant H&W data, to build programme theories from rich and directly relevant data. Tacit knowledge evoked by a case study allow the researcher to vicariously experience the phenomenon through rich and holistic representations of the programmes (Emmel, 2013). Case studies therefore have an important role to play in developing causal claims in complex systems as they can elucidate multiple interacting components and resultant outcomes (Paparini et al., 2020).

5.2.2 Phase 2 theory verification and refinement

Realist evaluation seeks to test explanatory theories of causation, not simply through hypothetico-deductive reasoning, where theories are confirmed through observed instances, but also through seeking to refute theory (Haig & Evers, 2016). The

cumulative nature of realist inquiry allows researchers to identify which theories stand the test of time, with the aim to generate 'better' theories, rather than 'correct' theories (Pawson, 2013). Empirical testing of theories therefore requires seeking alternative plausible explanations for predicted patterns (Elster, 2007). Programme theory testing is consequently perpetual, taking place over multiple empirical evaluations (Pawson, 2013). To support this repeated search for alternative explanations, a more in-depth multiple-case study design was adopted. Theory development (Phase 1) was conducted using multiple H&W data sources collected at different time points, for example, historical data from previous participants and practitioners' prior experience. Theory testing (Phase 2), on the other hand, involved examining a selection of H&W programmes as they were delivered to allow a more detailed analysis of directly linked data sources. Contexts, mechanisms and outcomes must be tested in configuration (Pawson & Manzano-Santaella, 2012). The in-depth multi-case study approach in Phase 2 made testing theory configurations possible due to the exploration of contexts in which specific programmes were delivered (Reddy et al., 2016) and how or why things work in real life situations (Yin, 2018). Examining and analysing data within specific settings and delivery of individual programmes retains the unique context of each case (Maxwell, 2012).

5.2.3 Middle-range theory and a conceptual framework of engagement

Realist methodology aims to uncover explanatory theory for concepts, meaning that concepts must first be articulated (Shearn et al., 2017). Multiple substantive, middle-range theories of engagement were explored to enhance the development and explanatory power of the programme theories. The use of middle-range theory in realist approaches was also discussed in Chapter 4. First, general theories of

engagement were identified by searching Google Scholar and Scopus using principles from a search strategy outlined by Booth & Carroll (2015). They propose that a search can be constructed using search terms for a combination of behaviour (Be), health context (H), exclusions (E) and models or theories (MoTH) to attempt to systematically identify potentially relevant theories. In addition, discussions with the supervisory team, H&W team and colleagues in both secondary and higher education further aided the identification of potentially useful substantive theories.

Theories were reviewed for their usefulness in developing programme theory by establishing whether they explained engagement at the level of social strata (individual, interpersonal, institutional, and infrastructural (Pawson, 2006)) of interest for this research and were capable of integrating with depth ontology and realist explanation (Shearn et al., 2017). This realist evaluation sought to explore engagement at the individual and interpersonal level by exploring how programme participants responded to aspects of programme architecture, conceptualising mechanisms as reasoning and responses to resources, as described in the previous Chapter 4.

Prior to data collection and analysis, two complexity-consistent frameworks were selected and combined, following the engagement theory search, to help draw conceptual system boundaries around and identify the conceptual elements of engagement that may be relevant to group-based self-management programmes (Westthorp, 2012). A conceptual framework can provide a structure within which to situate the detailed analysis and identification of relationships between concepts required for realist programme theory development (Shearn et al., 2017). No single conceptual framework or theory is able to capture everything about a phenomenon to

be investigated; each theory can reveal, distort or conceal aspects of interest (Maxwell, 2012). Combining two frameworks aimed to utilise complementary lenses through which to make sense of engagement.

The choice of frameworks was informed by the literature review (Chapter 3); initial discussions with the PhD supervisory team regarding experiences relating to engagement; and conversations with contributors to the Phase 0 scoping phase (Chapter 2). Informal observations of the programmes; discussions with members of the H&W team; attending H&W team meetings; reviewing programme leaflets and documents; and reading published literature relating to the programmes were all undertaken in Phase 0, prior to the start of this realist evaluation. Informal observations in Phase 0 were overt but non-participatory. These observations included two sessions of one online group programme and one in-person group programme for people with a range of LTCs, and a single session of an in-person group programme to support individuals living with chronic back pain. Early reflections on how programmes were delivered and ideas about how people engaged with programmes were recorded in a research journal and facilitated ‘theory sensitization’ (Jagosh et al., 2022), further informing the choice of conceptual frameworks used for theory development. This early purposive work and theory sensitisation was important for informing sampling strategies (Emmel, 2013), which will be discussed in section 5.5.

The first of the two frameworks (Bright et al., 2015) provides a summary of constructs of engagement in relation to rehabilitation and highlights common features and relations which were deemed likely to play a role in programme theory for the H&W programmes (Shearn et al., 2017). Bright et al.’s (2015) depiction of both the *process* and *state* of engagement (Table 5.1) aligned with the programme team’s ideas about

how the programmes resulted in positive outcomes (Downey et al., 2021). Downey et al. (2021) describe the person-centred practices of connecting with people, through groups and with self, which align with the connectivity, and clinician attitudes and behaviours presented by Bright et al. (2015). These processes of engagement provide guidance for exploring realist notions of causation at the level of the system of interest for this work and recognises the interpersonal interactions, and internal reasoning and responses necessary for engagement (Shearn et al., 2017).

Table 5.1

Engagement constructs (Bright et al. 2015)

Engaging with (process)	Engaging in (state)
Process of connecting with activity or person	Being with what you're doing, participation beyond talk
Clinician's attitudes and behaviours crucial	Internal state: commitment, enthusiasm, effort and investment
Establishment of therapeutic relationship may precede state of engagement	Observable behaviours: participation, contribution, persistence
Fluid on-going process, may lead to state of engagement or disengagement	State of engagement: both internal state and observable behaviours present

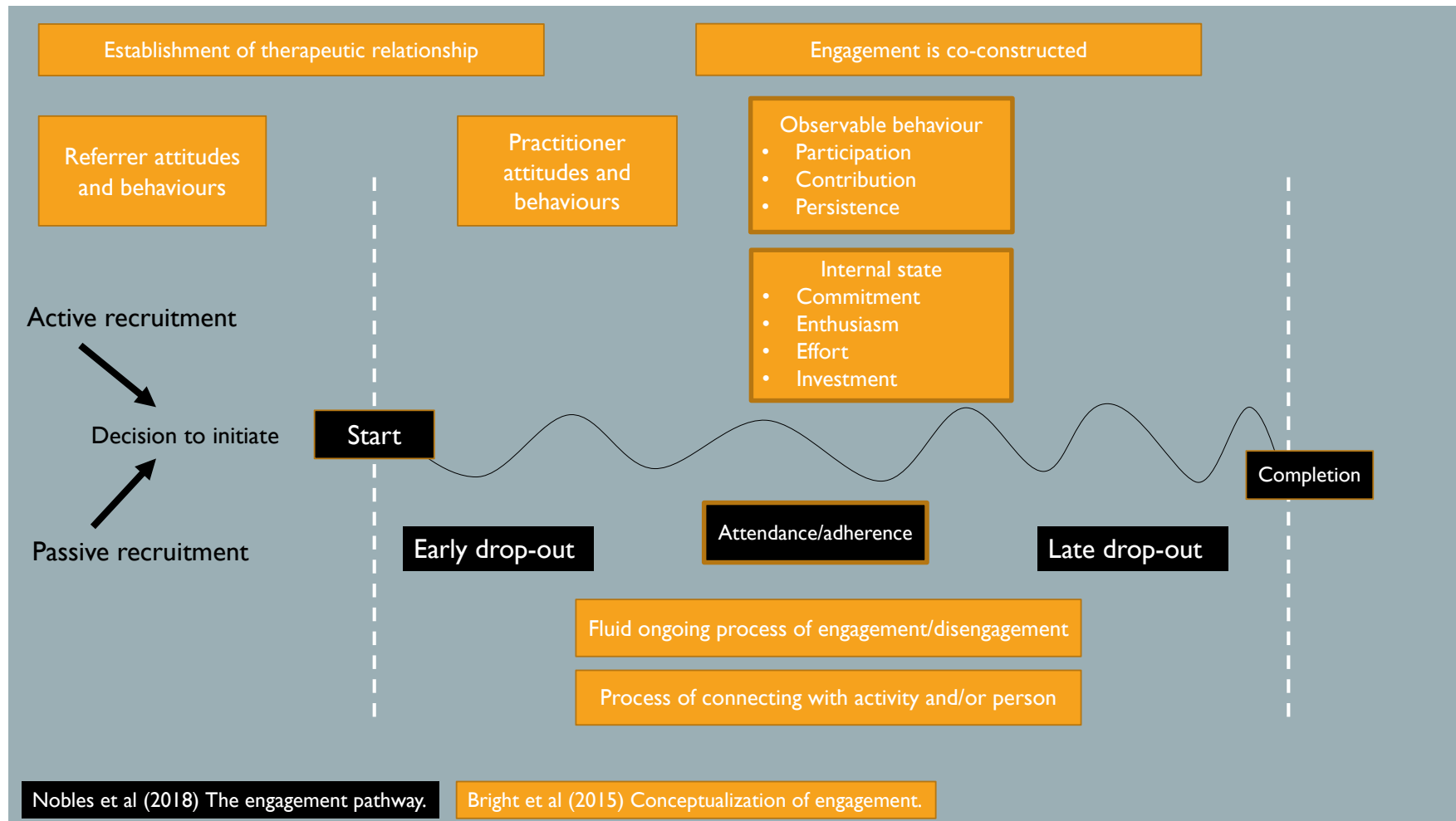
In addition to supporting the identification of mechanisms, conceptual frameworks can help to identify outcomes (Jagosh et al., 2014). Collecting outcome data is recommended to be a quantitative endeavour in realist evaluation, however Pawson and Tilley (1997) allude to instances where this is not possible due to the nature of the theory being tested. Quantitative measures currently available for engagement tend to focus on observable states of engagement (Bright et al., 2015) so do not entirely align with the conceptualisation of engagement adopted in this realist evaluation. The

interactional nature of engagement makes it a social phenomenon (Bright et al., 2015) and reducing social phenomena to their constituent parts is arguably impossible as properties of key interactions are emergent and contingent upon one another (Cohn et al., 2013). Bright et al.'s (2015) conceptualisation of the state of engagement, highlighted in bold in Table 5.1, provided a framework to identify qualitative engagement outcomes/labels in this realist evaluation. Data were then disaggregated by the contexts proposed to influence these outcomes to align with realist assumptions for analysis (Westthorp, 2014).

The second conceptual framework (Nobles et al., 2018) selected for theory development facilitated the exploration of the temporality of engagement. Temporality is an important consideration in the complexity of programmes (Pawson, 2013; Skivington et al., 2021) yet is currently under explored in engagement with SMS programmes, as discussed in Chapter 3, and in conceptualisations of engagement more generally (Bright et al., 2015). In the scoping phase (Chapter 2), contributors expressed concerns about engagement with programmes at the point of referral as well as at varying points during the programmes themselves. Nobles et al.'s (2018) engagement pathway framework in weight management represents the temporality of engagement with the H&W programmes, including the engagement points of concern for stakeholders. Nobles et al.'s engagement pathway framework was combined with Bright et al.'s (2015) conceptualisation of engagement to help determine which points along the service pathway engagement could be explored. The combined frameworks (Figure 5.2) were simple and an appropriate fit with the services and the phenomenon of engagement under investigation (Shearn et al., 2017). The frameworks' utility supported initial sense making, and informed the sampling strategies and data collection methods described later in this chapter.

Figure 5.2

Conceptual framework for programme theory development: based on Nobles et al. (2018) and Bright et al. (2015)



In addition to choosing and combining the two conceptual frameworks for data collection and analysis, substantive middle-range theories were identified, explored and layered onto the frameworks iteratively throughout the realist evaluation. The middle-range theories helped to further explain concepts, and relationships between concepts as theories developed. Some middle-range theories had been proposed by the H&W programme team to explain how the H&W model of practice was considered to achieve positive outcomes (Downey et al., 2021) and contributed to the development and refinement of some of the programme theories, namely Self-Determination Theory (SDT). Further, learning from other fields is encouraged in realist research (Pawson, 2013) and given the background of H&W practitioners as educators, learner engagement was considered a potentially valuable field for exploration. Employee engagement was also considered a field worthy of exploration due to the role of practitioners in engagement and how workplace contexts may influence how they engaged with their working roles on the programmes.

Additional substantive theories, at different levels of abstraction, were identified at various points during data collection and analysis, which further supported explanations within specific programme theories. A layering approach, similar to that described by Dalkin et al. (2016), was used to build and refine the explanatory theories from the conceptual framework, SDT, additional substantive middle-range theories and the programme theories, and will be presented in the following Chapter 6.

5.3 Ethics

Due to the iterative and emergent nature of realist inquiry, it is not always possible to specify all details of a realist evaluation at its outset, and legitimate changes to sampling and methods may be required as the project progresses (T. Greenhalgh et

al., 2017c). Ethics applications were therefore made separately for the theory development and theory testing phases. Points at which further decisions about data collection would be made were highlighted in each application, requesting that further detail be clarified via an ethics amendment. For example, providing an observation schedule for Phase 2 was only possible once theories had been developed in Phase 1 to determine which aspects of programmes required examining. Specifying points at which ethics amendments would be required, and submitting separate applications for each phase provided a road map for considering ethical issues in relation to the project, mitigating the potential for ethically unchecked changes to the project being made. The Plymouth Marjon University Ethics Panel granted a favourable ethical opinion for the research to be undertaken for Phase 1 (15th May 2021, 16th June 2021) and Phase 2 (17th November 2022, 18th January 2023) following consideration of the proposed research activities and steps to protect research participants from harm.

As a key requirement for testing realist programme theory is to test and analyse contexts, mechanisms and outcomes in configuration (Pawson & Manzano-Santaella, 2012), it is often necessary to link different data types to the same participant and data must be stored in way that allows these linkages to be made (T. Greenhalgh et al., 2017c). Therefore, all participants, practitioners and students were assigned a code or pseudonym to preserve anonymity in field notes and interview transcripts, which allowed the linking of the different data sources. Names, corresponding codes and pseudo names, and personal information were stored in an encrypted password protected Excel file, in a further password protected area of the University secure server, accessible only by me. Original interview recordings were deleted following manual interview transcription, and de-identification of the interviewee and any individuals or places named in the interview.

Anonymity can pose a particular challenge where linking data is necessary in small sample sizes (T. Greenhalgh et al., 2017c), which was the case in this research due to the small team of H&W programme architects and practitioners. The challenge of anonymity was compounded by the close relationship between the H&W team and supervisory team for this PhD. There was a possibility that programme team members on the supervisory team would be able to deduce which individuals had contributed specific views and information during interviews, creating a potential power differential and perceived risk of repercussion. Time was allocated prior to each interview to discuss this eventuality and its possible implications. Participants were also given the option to redact any sections, or all of their interview data if in hindsight they were uncomfortable with any information they had shared.

Additional ethical considerations relating to power were introduced in the scoping phase of this research in Chapter 2, section 2.3.1, and are further discussed in the following sections describing the specific methods of this research. Procedures for gaining informed consent are also included in the following sections.

5.4 Sampling strategy

Realist sampling strategies are driven by our theories about the social phenomena subject to our investigation and therefore frame the choices we make in relation to sampling (Emmel, 2013). Because data collection priorities are determined by theories of programmes which are social in nature, knowledge and expertise will be distributed between different actors in the programme (Pawson & Tilley, 1997). Part of the sampling strategy was therefore to determine key informants, through purposive work (described in section 5.2.3), for different aspects of programme theory at different phases of the evaluation. Programme architects and practitioners are useful

informants for theory development due to their broad experience of successes and failures, and of circumstances in which programmes succeed or fail (Pawson & Tilley, 1997). In the case of this research, programme architects and practitioners were able to describe instances when individuals engaged, or not, and postulate possible reasons why and how programme delivery may have contributed. Many of the H&W practitioners helped to design and deliver health and wellbeing programmes; in varying locations; and in partnership with different stakeholders. The H&W programmes have changed over time, so longstanding delivery staff understand how and why changes were made, and if and how this may have influenced engagement.

Data collection and analysis are often iterative in realist research, in part due to the theoretical approach to sampling required. Early analysis of programme architect and practitioner interviews in Phase 1 played a role in developing rough programme theories, consequently informing subsequent data collection through purposeful sampling (Emmel, 2013). For example, the architects and practitioners discussed the importance of the role of students in participant engagement with the programmes. These initial purposive ideas about student involvement revealed student practitioners as valuable informants, so student practitioners were purposefully sampled and invited for interview to explore their understanding and experience of engagement with the programmes.

The sampling process for Phase 2 began with prior developed theory, in line with realist sampling approaches (Emmel, 2013), aiming to select participants, activities, or incidents based on their relevance to the theory under scrutiny (Maxwell, 2012). Phase 2 cases were defined as individual programmes delivered from start to finish. A combination of critical, typical and deviant cases can be sampled to help adjudicate

theories in realist research; critical cases are crucial to understanding of; typical cases are most representative of; and deviant cases are most likely to be negative in relation to the phenomenon under investigation (Mukumbang et al., 2020). The programmes will be described in relation to these case classifications in the following section. The multiple case-study design allowed for the constant comparison necessary in theoretical sampling, which aims to identify categories under investigation in different situations (Emmel, 2013).

The approach to sampling individuals for interviewing in Phase 2 was based on the same principles of identifying 'who knows what' (Pawson & Tilley, 1997), previously outlined. As mechanisms work through individual agents and depend on their reasoning and volition (Astbury & Leeuw, 2010), they are best explored with programme participants themselves, whereas participants may be less sensitive to contextual restraints and outcome patterns (Pawson & Tilley, 1997). Contexts at various levels of the system were posited to shape mechanisms of engagement in this research. When testing programme theory, practitioners were considered more knowledgeable about contexts shaping their own practice and contexts impacting the delivery of programmes, whereas programme participants were able to provide information regarding their own individual circumstances. Further, ripple effects of CMO-Cs and the co-constructed engagement outlined in the conceptual framework (Bright et al., 2015) necessitated the empirical validation of mechanism responses of both participants and practitioners.

5.5 Study recruitment

5.5.1 Phase 1 recruitment

Attendance at H&W meetings as part of the familiarisation work conducted prior to the start of the realist evaluation, discussed in section 5.2.3, provided an opportunity to meet programme team members, and inform them of this realist evaluation and the opportunity to take part in interviews. As the researcher was a full-time PhD student at the same institution as the H&W team, interpersonal relationships were developed over the months leading up to and during the study, which may have facilitated interviewee recruitment and ease of communication in interviews. H&W architects and practitioners were invited by email, which included a participant information sheet. H&W team members, who expressed interest to take part, were given an opportunity to discuss the study procedures and any questions or concerns they had about the study. In particular, issues relating to a perceived pressure to participate, anonymity and the relationship of the research team to the H&W team were discussed in advance and as part of the consent process. For online interviews, participants were requested to email a signed consent form prior to the interview and physical forms were completed for in-person interviews. All participants were asked for verbal consent at the start of each interview and at the end of the interview to proceed with analysing the data collected.

5.5.2 Phase 2 case study selection

Various student-led health and wellbeing clinics and interventions were run at the University during this PhD; in addition to the group-based programmes these including one-to-one interventions and health assessments. The availability of programmes also changed between Phase 1 and Phase 2 due to changes in funding and partner

organisations' priorities. The interventions purposefully selected for Phase 2 were all group-based, delivered face-to-face over multiple sessions and included self-management and other physical activity, health or wellbeing component(s) (Table 5.2).

The group-based self-management programmes investigated were the Back Wellbeing Programme; the Leg Wellbeing Club; and Living Well With and Beyond Cancer. The programme names will be abbreviated to Back Programme, Leg Programme and Cancer Programme respectively to aid ease of reading for the remainder of this thesis. The shared aim of all the programmes is to support individuals to live well, with and beyond their long-term health conditions. Although it was anticipated that all programmes would have some of the causal mechanisms for engagement theorised in Phase 1, it was perceived that it would be possible to identify and test more of these mechanisms in some programmes compared with others due to some of the contextual variations between the programmes. Consequently, rather than determining whole programmes as critical, typical or deviant cases, they were postulated to exist on a spectrum, with some providing better opportunity to test specific elements of programme theory than others.

Discussions with programme practitioners, prior to observations revealed the characteristics of programme content and structure. For example, the Back Programme was anticipated to be a critical case for testing programme theories PT1: Choice and Variety and PT2: Space and Time due to its longer duration, wider variety of activities and location within the University Campus. The Leg Programme, on the other hand was particularly important for testing programme theory PT4: Environment due to its delivery in different physical locations, allowing comparison of the same programme being delivered in different locations, often by the same practitioner. The

Back and Cancer Programmes were delivered from a single location: the University Campus. The Leg Programmes were delivered from multiple sites, including the University Campus, which were all within a 16-mile radius. The University Campus and all but one of the Leg Programme delivery sites (Telsford) were located in a city where 95.3 per cent of residents identified their ethnic group as white (ONS, 2023b) and which ranked 64th, where 1 is the most and 317 is the least deprived, of the 317 local authority districts in England (Ministry of Housing, Communities & Local Government, 2019). Each of the Leg Programme sites have been given pseudo names to preserve anonymity of the locations. Telsford Leg Programme (Table 5.2) was delivered in a local authority district which is ranked 162nd. Index of Multiple Deprivation scores for specific neighbourhoods, calculated by the city's local authority, ranked the locations of the University Campus, Hilford and Corrington as 27th, 20th and 2nd most deprived of the 39 neighbourhoods in the city respectively.

The practitioners delivering the programmes had different backgrounds: one had a sports science degree and additional training in cardiac exercise, one had a degree in sports therapy and the other had a degree in health and wellbeing. All three practitioners had trained to deliver the programmes by observing and working alongside previous practitioners and had received informal mentorship. No other programme-specific training was provided. However, general mandatory healthcare practitioner training was undertaken via the NHS eLearning for health platform. The background of each practitioner has purposely not been detailed in relation to each programme to maintain a level of anonymity. Likewise, student practitioners had received general training for healthcare practitioners via NHS eLearning for health, but no formal training in delivering programmes. Students were briefed at the start of sessions about the programme aims and how they could be involved.

Table 5.2*H&W programme characteristics**All interventions were delivered in a group-format, face-to-face.*

Programme	Location	Referral and funding	Programme duration	Delivered by	Main programme activities	Modifications
Back Programme	University Campus – teaching room, public gymnasium and multi-purpose exercise/dance studio	Opt-in via recommendation from physiotherapy service at a local hospital. Previously funded by a local healthcare organisation but funding has recently ceased. The programme observed was financially supported by the university	6 x weekly 2-hour sessions with an optional 7th session in the swimming pool	Health and wellbeing practitioner, supported by four 2 nd year student practitioners	Pain education, physical activity, healthy eating, cardiovascular and resistance exercise, core stability, Nordic walking, goal setting, problem-solving, swimming and pool exercise, sleep hygiene, mindfulness	N/A

Leg Programme	University Campus – multi-purpose exercise/dance studio	Opt-out – participants automatically enrolled as part of overall service for leg wounds. Programmes are funded by another local healthcare organisation	4 x weekly 1-hour sessions	Health and wellbeing practitioner, with two 2 nd year student observers	Information about the condition, introductory and more advanced exercises, sleep and nutrition	Condensed to 3 x weekly 1-hour sessions due to staff illness
	Hilford – prayer room within a hospital	As above	4 x weekly 1-hour sessions	Health and wellbeing practitioner		Condensed to 3 x weekly 1-hour sessions due to staff illness
	Telsford – a room used for chemotherapy in an NHS clinic	As above	4 x weekly 1-hour sessions	Health and wellbeing practitioner		

	Corrington - a small clinical room within an NHS clinic	As above	4 x weekly 1-hour sessions	Health and wellbeing practitioner		
Cancer Programme	University Campus - teaching room, public gymnasium and multi-purpose exercise/dance studio	Opt-in via advertisement by a local cancer charity. The programme is funded by the cancer charity	4 x weekly 90-minute sessions	Health and wellbeing practitioner, supported by two 2 nd year student practitioners	Facility tour, stretching, cardiovascular exercise, resistance exercise, review of food diary and step count	N/A

5.5.3 Phase 2 sampling and recruitment

For Phase 2, all programme architects and practitioners were approached in advance of programmes commencing to first gain consent to observe the programmes. Practitioners were initially approached via email, which included a study information sheet, and option to be contacted for a follow-up interview if they were happy to be observed. Practitioners were invited to discuss the study, nature of observation and the interview, if they had expressed interest, in person before signing a consent form.

Once practitioners agreed to be observed, individuals with LTCs who were invited to a H&W programme were sent an information sheet providing a background to the study. The information sheet included a tick box to opt-out of programme observation as well as a tick box and space for providing contact details to indicate whether they would be happy to be contacted for an interview invitation. Participants had the option to return their completed sheet to the researcher by post in a pre-paid envelope so that non-attenders could be contacted for an interview if they wished. Alternatively, participants could return their sheet or verbally opt-out of observations or consent to being contacted for interview upon arrival to the programmes, when participants were briefed on the presence and role of the researcher.

All programme participants were provided with an option to be invited for interview, rather than select individuals, because our understanding of cases develops throughout the research process and is never finite; the question “what is this a case of?” is asked repeatedly (Emmel, 2013).

Study information was sent to programme participants either directly by the H&W team, which was the case for the Back and Cancer Programmes as patients consented to their contact details being provided to the H&W team to arrange

programme attendance, or by the partner staff member responsible for booking individuals onto programmes, in the case of the Leg Programmes. Referral of participants to the Leg Programmes was undertaken via an NHS service pathway, meaning patient data was held within NHS databases, which the ethical framework for this research did not permit access to. Leg Programme participants could therefore only be invited for interview if they consented to be contacted using the returned participant information sheet or in person during a programme. The ethical framework restrictions subsequently limited opportunities to recruit individuals who did not attend programmes and did not return their information form, the consequences of which will be discussed in Chapter 7.

Practitioners and programme participants who expressed an interest in being invited for interview were provided with an interview participant information sheet and then contacted by their preferred communication method once the programme has finished to arrange either an in-person or online interview. Personal and contact details were stored in a password-protected encrypted document, separate from any research data.

5.6 Data collection

As discussed in Chapter 4, realist evaluation advocates the use of multiple methods, the incorporation of numerous stakeholder voices, and data triangulation to develop high quality programme theories and strengthen their claims (J. Greenhalgh & Emmel, 2018; T. Greenhalgh et al., 2017b; Renmans & Castellano Pleguezuelo, 2023). Triangulation of data is particularly important in realist theory development because contexts, mechanisms and outcomes exist at different levels of a system to one another and therefore generally cannot be identified using the same tools (Pawson &

Tilley, 1997). This section presents the data sources and collection methods used in this evaluation. The data sources are first summarised in Table 5.3, with an indication of the stakeholder voice they represent, and are then presented in greater detail in subsequent sections. Primary data collection took place between October 2021 and December 2021 for Phase 1 and between February 2023 and May 2023 for Phase 2.

Table 5.3

Data sources for this realist evaluation. SP = stakeholder partner; P Arch = programme architect; P Prac = programme practitioner; S Prac = student practitioner; Part = Participant

Data Source	Stakeholder				
Phase 1	SP	P Arch	P Prac	S Prac	Part
Theory gleaned realist interviews		x	x	x	
Programme documentation and published articles	x	x	x		
Impact case study reports	x				
Concurrent study semi-structured interviews	x	x	x	x	
Concurrent study transformative evaluation stories				x	
H&W service evaluation responses					x
Phase 2					
Theory refining realist interviews			x	x	x
Non-participant observations			x	x	x

5.6.1 Realist interviews

Realist interviews overview

Realist interviews are a form of theory-driven qualitative interview (Manzano, 2016), which can be used to both predict and identify generative mechanisms in specific contexts (Connelly, 2001). As such, realist interviews can be useful for programme theory development, refinement and/or testing (Manzano, 2016; Rees et al., 2024). A key feature of the realist approach to interviewing is that the subject and focus of the interview is theory, not the interview participant themselves (Pawson, 1996). The aim of the interviews was to explore what works in engaging participants, for whom, why and which circumstances, with a commitment to ontological depth in seeking explanations for how participants engage with the programmes.

Manzano (2016) outlines phases of realist interviewing: theory gleaning, theory refining, and theory consolidation. Theory gleaning and theory refining realist interview approaches were used in phases 1 and 2 of this realist evaluation respectively. During theory development in Phase 1, five male practitioners, two of which were also programme architects; and one female student practitioner were purposefully sampled and interviewed. Three of the practitioners, including the programme architects, had a background in sport and exercise science, and exercise referral and taught on various degree programmes at the university; and two practitioners were sports therapists, who had completed their degrees at the university. The student practitioner was a final year student undertaking a BSc in Health and Wellbeing. Four of the interviews were conducted in-person and two were conducted via Microsoft Teams. The interviews

lasted between 52 and 64 minutes, totalling 345 minutes with a mean duration of 58 minutes per interview.

Phase 2 interviews were conducted with three male practitioners, one of whom was interviewed twice due to their delivery of two different programmes; seven programme participants (four male and three female); and two student practitioners (one male and one female). One practitioner held qualifications in exercise referral and cardiac exercise, and taught on various degree programmes at the university; one practitioner was a sports therapist, and one practitioner was a health and wellbeing practitioner. The latter two practitioners had gained their qualifications and experience delivering the H&W programmes as students at the university. Interviews were conducted in-person with all but two programme participants, who were interviewed via Microsoft Teams. Programme participant interviews lasted between 35 minutes and 63 minutes, totalling 354 minutes (mean duration: 51 minutes); practitioner interviews lasted between 36 and 44 minutes, totalling 157 minutes (mean duration: 39 minutes); and the two student practitioner interviews lasted 20 minutes and 25 minutes, totalling 45 minutes.

Phase 1 interviews

The Phase 1, theory gleaning interview were semi-structured and the questions were based on example starter questions developed as part of the RAMESES II project (Westhorp & Manzano, 2017). The questions were further informed by the early purposive work described in section 5.2.3. The questions (Appendix C) were exploratory, aiming to encourage interviewees to consider and compare the different programmes in general as well as their own experiences of successful or unsuccessful engagement with or of participants. Example questions are presented in Table 5.4.

Table 5.4*Realist interview question examples for theory-gleaning and theory-testing*

Theory-gleaning question examples	Theory-testing question examples
<p>Opening question:</p> <p>As an opener can you give me a background of what your involvement is and has been with the clinics please?</p>	<p>Opening question:</p> <p>So, perhaps then to begin with could you tell me a little bit about how you were referred on to the programme? I'm interested in how you ended up attending, who recommended that you go, for example.</p>
<p>Open question related to overall phenomenon of interest:</p> <p>I'm interested in what your view of participant engagement is. What does it look like, how do you conceptualise it with participants?</p>	<p>Open question related to programme theory of interest:</p> <p>I was wondering if you thought that there was anything about the emotional environment that was important.</p>
<p>Follow-up question to begin identifying a causal explanation:</p> <p>So, you started talking about choice for the participants and that it wasn't a prescription type of approach. What made you decide to go down that route when you were developing the programmes? What was your rationale behind it, what did you hope to achieve?</p>	<p>Follow-up question to check mechanism response and encourage refinement:</p> <p>We wonder if that this non-medical type of environment (you describe) might help people to feel less defined by their conditions, and perhaps that helps them to feel more positive and they might engage better. Do you think there's something in that or do you think, like you say, it's much more about creating a learning environment where people can speak more freely to each other?</p>

The Phase 1 architect and practitioner interviews played a role in developing rough programme theories but also served to inform subsequent data collection, as discussed in section 5.4. Following the gleaning of purposive ideas about the role of students in engagement, student practitioners were purposefully sampled for further data collection. Further, the interview schedule was subtly adapted following analysis of the first two practitioner interviews to follow emerging lines of enquiry regarding student involvement in more depth in interviews with both students and subsequent practitioners. Although some of the interview still focused on theory gleaning of engagement, some of the interview was tailored to theory refinement, which Manzano (2016) describes as an opportunity to begin testing candidate theories. The approach taken for the student interview was in between theory gleaning and refinement as no initial programme theories were presented to the student practitioner. Instead, they were encouraged to discuss their own ideas and experiences around topics identified in the earlier practitioner interviews. Providing a rough framework of ideas allowed for further development of the initial programme theories without losing an opportunity to glean alternative theories. Using a framework for discussion rather than directly asking students to agree or disagree with the perceptions of practitioners aimed to mitigate students being unduly influenced by the power differential between them and the practitioners, whilst still progressing towards theory refinement.

Phase 2 interviews

A 'Teacher-Learner' interview approach was used to corroborate, refute and refine the proposed theories (Manzano, 2016; Pawson, 1996) in Phase 2 of this realist evaluation. In contrast with the inductive approach for theory gleaning in Phase 1, a more deductive, hypothesis-focused approach for questioning was used (Table 5.4). Indicative questions are outlined in Appendix D. This 'teacher-learner' approach is

named so because the researcher transparently shares their theories with the interviewee, avoiding the criticised process of piecemealing fragments of interviews into the researcher's preferred explanatory framework post-interview, without the participant's involvement (Pawson & Tilley, 1997). Programme participants, practitioners and student practitioners were presented with tentative theories (Manzano, 2016), framed relative to the programme they were part of, and asked whether they agreed with the theories and to elaborate on why they did or if they had alternative explanations. Interviewee responses to the 'taught' theories allow the researcher to learn from them and refine programme theories accordingly.

It was deemed impossible and inappropriate to attempt to test all aspects of all programme theories with each participant due to the time required to explore programme theories in sufficient depth. Programme theories were chosen for discussion based on observations, individuals' characteristics, and features of the programmes and therefore which aspects of programme theories each respondent was best able to verify, refine or refute. Namely, the absence of student involvement in some programmes meant that this programme theory was not discussed with interviewees who attended programmes without students. Observed actions and interactions, which will be discussed in section 5.5.2, served as prompts for the realist interviews (Handley et al., 2020). Interviews were orientated primarily around semi-predictable patterns, known as demi-regularities in realist evaluation, of contexts mechanisms and outcomes identified during the observations. Prompts from observations were followed by an overview of the programme theory to which the demi-regularity belonged, to provide interviewees with the conceptual framework of the programme theories and an opportunity to discuss their experience within those parameters, termed 'conceptual focusing' by Pawson (1996).

Power imbalances are a known challenge in qualitative research and can undermine the aim of theory refinement when interviewees avoid disagreement with researchers' theory (Gilmore, 2019; Mukumbang et al., 2020). An attempt to mitigate the potential power imbalance was made by beginning the interviews with more open questions before venturing into theory testing (Gilmore, 2019), and more open questions about theory areas were asked before asking more specific questions (Table 5.4). Entire CMO-Cs were rarely presented at once, to allow interviewees to ponder different elements of programme theory and offer refinements. Further, interviewees were actively encouraged to consider alternative explanations, and theory was often presented in such a way to convey uncertainty, with the aim to encourage interviewees to offer their perspective, for example, beginning questions with "we wonder" rather than "we believe".

5.6.2 Non-participant observations

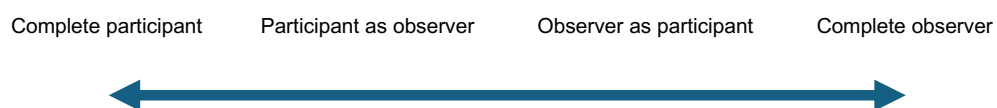
Non-participant observations were undertaken in Phase 2 during a 3-month period (February 2023 – May 2023), totalling 36.5 hours of observation. Details of the programmes were presented in Table 5.2, in section 5.5.2. These non-participant observations were undertaken for theory verification and refinement, to gain insights into interactions and activities during the programmes (Mukumbang et al., 2020), particularly as participants may not always be aware of, or able to articulate the nuances of their interactions with others (Corbin & Strauss, 2015). Non-participant observations therefore help to mitigate the criticism of privileging realist interviews for both theory development and testing given that individuals are only partly aware of their reality, leading to a potential social scientific interpretation of the already incomplete interpretation made by the participant (Connelly, 2001). Observations were considered complementary to the interviews by allowing the identification of

behaviours, actions and interactions not fully captured in the realist interviews (Handley et al., 2020).

In relation to programme participants, my role as a researcher was that of an outsider observing due to my having no established connection with the group being observed (Atkinson & Hammersley, 1998). However, my position as an observer varied along (Gold, 1958) spectrum (Figure 5.3) depending on the programme being observed. My role was that of a participant as an observer for the Back and Cancer Programme participants but more as observer as a participant for the Leg Programmes. This adoption of different roles was a result of moderating the obtrusiveness of researcher presence (Punch, 2014). The Back and Cancer Programmes were much more interactive and actively involved students compared with the Leg Programmes where there was little opportunity to interact with participants, therefore my observer role was moderated to match the environment.

Figure 5.3

Gold's (1958) observer spectrum



In relation to the programme practitioners, I adopted more of a participant role due to the working relationships I had developed with them over the previous 18 months. I navigated these differing roles by establishing boundaries myself, prior to observations regarding how I would take part in the programmes. For example, I did not contribute to the delivery of programme content, but I supported practitioners by helping them

set up the room. Explaining these boundaries but supporting where I could, helped practitioners understand my behaviour during the programme and facilitated open conversations about the delivery of the programmes.

At the start of each programme I introduced myself to programme participants at the earliest opportunity, to avoid any potential concern relating to my unexplained presence. For the Back and Cancer Programmes I was able to approach participants as they waited together in the University Sports Centre café to explain that I had been the person to provide the research information sheets they should have received prior to attending. I introduced myself more formally and provided some more information about the purpose of the study during the practitioner and student introductions and reiterated the option for participants to opt out of having notes taken about them during the programme sessions. Only one Back Programme and one Leg Programme participant opted out of the observations and had indicated this on the participant information form. I explained that I was observing practitioners, students and the way that the programmes operated and were delivered, as well the participants, to try to put them at ease.

The field note taking approach for the observations was determined in advance to ensure alignment with the realist methodological approach and theories under investigation (Phillippi & Lauderdale, 2018). An observation schedule (Appendix E) was created using Phase 1 programme theories to support a systematic approach to identifying contextual elements, mechanism and outcome patterns of engagement that had been hypothesised. The observation schedule served the purpose of focusing the taking of field notes to help adjudicate programme theories yet provided flexibility to identify alternative explanations for programme theory refinement (Handley et al.,

2020). Detailed field notes were taken under the sub-headings for each programme theory, some during and some after the session, to provide rich information and subsequent researcher reflections. Field notes comprised descriptions relating to contexts; mechanism resources of programmes and processes of engagement; interactions between participants practitioners and students; and the observable states of engagement.

5.6.3 Additional data sources

Numerous existing H&W data, representing patient, stakeholder partner, student practitioner and practitioners voices, were available to develop theory in this realist evaluation.

Service user feedback

As part of the ongoing evaluation of the H&W programmes, post-programme feedback from participants had been recorded by the H&W team over a 10-year period for the Back Pain and Cancer programmes. Data had been collected for 965 and 306 participants for the Back Pain and Cancer programmes respectively. Access to these data was provided by a data custodian in the H&W programme team, who had analysed the service evaluation data for previous research projects (Bloxham et al., 2020; Downey et al., 2021). The data set included patient demographic data, patient recorded outcomes, biomedical outcomes and service user feedback. Anonymised data were stored in encrypted, password protected, excel spread sheets. Use of these data for research purposes had been reviewed as part of a previous application to the University ethics panel for previous evaluation of the programmes and received a favourable opinion. Secondary analysis of the qualitative data only was undertaken, for the purposes of theory development in phase 1, by extracting qualitative responses

from the data set, and disaggregating responses by programme type (Back n=190, Cancer n=186). The qualitative data comprised participant responses to the questions and headings: “How was the programme helpful?”; “How could the programme be improved?”; and “Other thoughts”. Programme participants are important informants regarding mechanisms as they can articulate the reasoning and responses to resources provided by programmes and the resultant outcomes (Pawson, 2013).

Student-led knowledge exchange project

The concurrent project exploring student-led knowledge exchange (SLKE) in the H&W programmes and clinics, described in Chapter 2, provided further data for theory development. As part of the SLKE project, 34 semi-structured interviews with programme architects, practitioners, student practitioners and stakeholder partners had been conducted to explore and develop a model for SKLE (Cotton et al., 2024). The SLKE interviews explored programme architect, practitioner and stakeholder partner involvement with the programmes; the benefits of the programmes to stakeholder partners and patients; and the processes and outcomes, including barriers and facilitators, to knowledge exchange. In addition to the semi-structured interviews, story generation with student practitioners was undertaken as part of a Transformative Evaluation (TE) aspect of the project. TE is a qualitative evaluation method that examines practice in its natural settings to explore processes and outcomes (Cooper, 2017).

Engagement plays a central role in knowledge exchange in Higher Education, evidenced by a wide range of activities involving co-design and collaborative working across a range of stakeholders (Johnson, 2022). It was therefore anticipated that information gleaned from the SLKE project data would be a useful source of additional

information regarding contexts and mechanisms relevant to engagement from the perspective of stakeholder partners and other programme practitioners. The focus on processes and outcomes of knowledge exchange in real-life settings offered potential for causal insights to be gleaned for realist programme theory development.

As with the service user feedback data, the secondary analysis of the SLKE project data had been reviewed and agreed by the University ethics panel prior to the commencement of the SLKE project. Permission for the use of these data for this PhD was obtained from the Principle Investigator of the project and subsequently provided by the Research Fellow and TE project lead who had conducted the interviews and led the TE project respectively. All data, bar two SLKE interview transcripts, were obtained already anonymised. I transcribed two audio recordings of interviews to support the SLKE project, and to gain experience in the process of preparing the transcripts from a more experienced researcher.

Surveys

Pre- and post-programme surveys (Appendix F) were developed to identify aspects of context and engagement outcomes that had been theorised to be important in the theory development phase. A convenience sample of individuals with long-term health conditions provided feedback on the participant information and surveys to assess the readability and comprehension of the questions. Feedback from those who reviewed the surveys informed some minor changes to the phrasing of questions and the addition of examples to assist participants.

Not all aspects of programme theory were included in the surveys to reduce their burden on participants completing them. Contexts and mechanisms that related to

initial attendance, or lack thereof were prioritised as other contexts and mechanisms were considered accessible through observation and interviews. Survey questions intending to measure engagement outcomes and processes were based on the engagement constructs described by Bright et al (2015) (highlighted in the appendices for clarity) as no other suitable engagement measure was identified. Administering the survey pre- and post- attendance aimed to identify changes in engagement over time.

Following the poor return of surveys from individuals who did not attend programmes or participate in an interview, these data were not included for analysis, rather they were used to facilitate discussions about engagement during the realist interviews with programme participants. Using their completed surveys, participants confirmed whether they agreed that engagement comprised the constructs depicted in the survey and how they related to CMO-Cs discussed during the interviews.

5.7 Data analysis

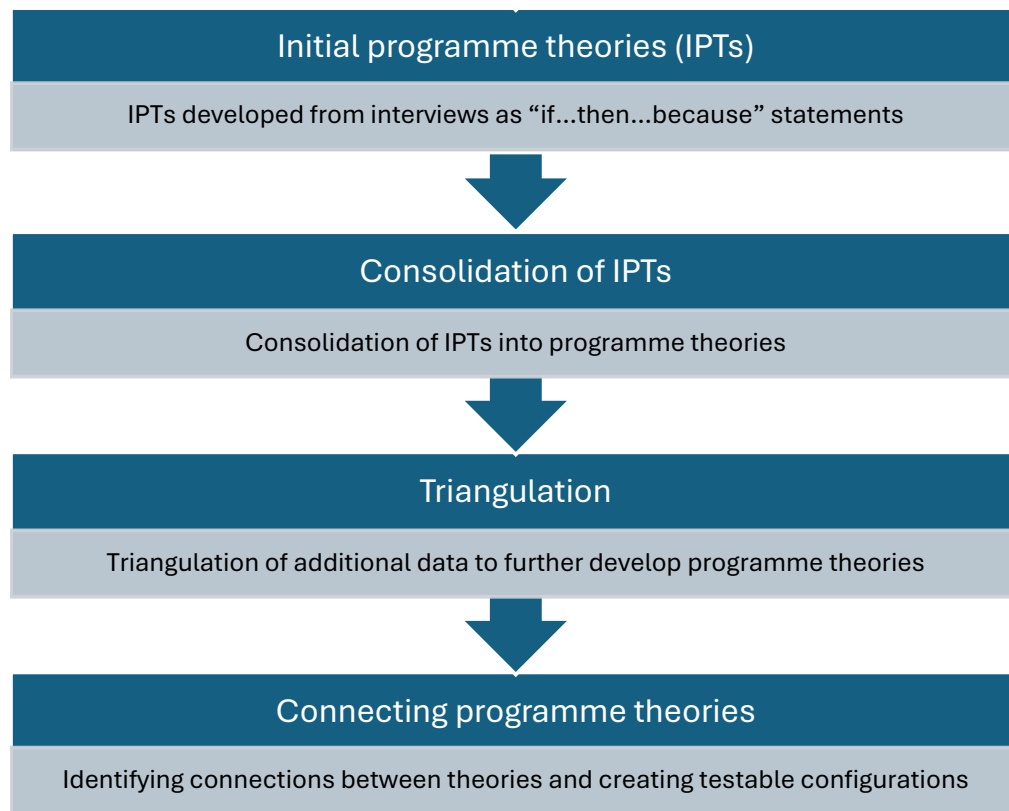
This section details the data analysis undertaken for theory development (Phase 1) and theory verification and refinement (Phase 2) of this realist evaluation. As is most often the case in realist inquiry, data collection and analysis were carried out iteratively but will be presented linearly for clarity. Data collection and analyses were guided by the use of a conceptual framework discussed in section 5.2.3.

5.7.1 Data analysis for theory development

The analysis for theory development comprised several iterative stages which have been depicted in a linear fashion for ease of comprehension (Figure 5.4)

Figure 5.4

Programme theory development analysis stages



If...then...because... statements

The theory development interviews with practitioners (n=3), programme architects (n=2) and student (n=1) were manually transcribed and anonymised. Printed copies of transcripts were reviewed in full and initial thoughts and reflections were recorded for each in a linked memo to a digital version of the transcript in NVivo 12. Theoretical memos function as an ongoing account of the analytical thought process of the researcher (Layder, 1998) and supported the self-audit trail of reflexive activity, as discussed in section 4.9 in the previous Chapter 4. Reviewing each full transcript prior to coding provided an overall contextualisation of the data that might otherwise have been more difficult to capture, even with coding large excerpts within interview

transcripts. Following the recording of overall reflections and initial familiarisation with the data (Braun & Clarke, 2006), a blend of thematic and content analysis was used to examine the data (Bowen 2009). Interview transcripts were annotated with initial codes and memos as a means of categorising areas discussed in each document. The code names were purposely broad and applied to large excerpts of the interviews to avoid decontextualising the data and potentially restricting the process of initial rough programme theory (IPT) development. This organisational categorisation of data describes the subject matter without exploring its meaning, serving the purpose of sorting data for further analysis (Maxwell, 2012). Coding in qualitative research has been criticised for neglecting context, which is essential, in realist terms, for developing causal explanation (Maxwell, 2012). To preserve contextual threads as much as possible, coding was used as a way of classifying data, to allow for comparison and a view of how elements related to one another, rather than as a process of re-ordering the data based on similarity (Maxwell, 2012).

Following the initial sensitisation and coding process, initial programme theories (IPTs) were generated from each of the interview transcripts, in the form of *“If...then...because...”* statements (Jagosh et al., 2022; Pearson et al., 2015). If...then...because statements communicate both the constituent and interconnected parts of realist programme theory (Pawson & Manzano-Santaella, 2012) and were used to facilitate retroductive theorising (Jagosh et al., 2022). Retroduction is a form of retrospective theorising and overarching logical approach (Mukumbang et al., 2021) which is described in more detail in the previous chapter (Chapter 4). Retroduction enabled the positing of mechanisms necessary for explanatory theory which may otherwise be elusive. *“If...then...because statements”* were written for any section of dialogue containing statements that appeared to relate to context or provide some

explanation for outcomes and were then labelled as initial programme theories (IPT). These IPT statements were often incomplete and captured dyads of context and mechanisms or contexts and outcomes (Jackson & Kolla, 2012). Partial and complete IPT statements were recorded in an Excel spreadsheet and labelled with individual IPT number codes (Figure 5.5). NVivo nodes were created and labelled with the IPT number to code the data excerpts from which each statement was generated. Coding by whole IPT, which could later be organised into conceptual buckets, rather than by context, mechanisms or outcomes was used because in one theory an element can be an outcome but may act contextually in another (Jagosh et al., 2015). Further, J.Jagosh (personal communication, April 25, 2022) cautions against focusing too much on CMOs in the early stages of analysis to avoid losing causative explanations.

Figure 5.5

IPT "If...then...because" statements in Excel

1	IRPT number ▼	IRPT content ▼
2	1	If participants are given the opportunity to develop empathy for student practitioners through activities that expose shared vulnerability, then they are more likely to develop altruistic motivation and higher levels of engagement with the programme.
3	2	If participants don't feel judged then they are more likely to engage with the programme...because...
4	3	If practitioners are more focused on supporting the process of behaviour change rather than outcomes then participants are more likely to engage with the programme. Due to less pressure?
5	4	If practitioners are not able to suspend their own judgement of a person's situation, they will be less able to listen and understand the person in order to create an appropriate foundation on which to support behaviour change.
6	5	If practitioners have space, time and support to reflect on their practice they will be better able to address their own biases and suspend judgement to improve engagement with participants
7	6	If practitioners have the knowledge and skills to foster engagement and this is reinforced by a wider culture of fostering engagement, then they will be better able to adopt this approach.
8	7	If supporting engagement and process are made to be the highest priority, rather than outcomes, practitioners are more likely to focus on and therefore improve engagement.
9	8	If practitioners focus on engagement rather than wanting to be seen as an expert participants may feel they have a genuine interest in them as an individual and therefore engage more with the programme.
10	9	If participants attend the programme via a passive approach to referral where they are not fully prepared for what to expect or how they might benefit, they are less likely to engage beyond simply attending in the first instance
11	10	If outcomes of engagement are not used then practitioners will focus less on fostering engagement.
12	11	If patients have negative core beliefs about their condition that have been reinforced by a healthcare practitioner, then it will be more difficult/take longer for them to challenge and change these beliefs and hinder their engagement.
13	12	If a participant's culture does not value other HCPs and/or an active approach to managing health then they are less likely to reach a level of engagement beyond participation.

Theoretical memos were recorded using linked memos in NVivo 12 for many of the IPTs. Using these memos allowed further development of IPTs with a clearer understanding of the thought process from its inception. Rather than coding sections of interviews to existing IPTs, new IPTs were formulated for each interview excerpt. Creating new IPTs for each excerpt resulted in the generation of a total of 126 IPTs, many of which were similar but ultimately unique. This abundance of unique IPTs impeded the pattern recognition necessary for generating context-mechanism-outcomes configurations. Identifying patterns in an abundance of incomplete theories has been highlighted as a challenge in realist programme theory development, and

requires a subsequent stage of analysis to link these fragments together (Jackson & Kolla, 2012) and will be discussed in the following section.

Consolidation of initial programme theories (IPTs)

The refinement and consolidation of IPTs to more complete programme theories was achieved using a combination of categorising and connecting analytical approaches (Maxwell, 2012). Consolidation began with coding the IPTs by general concept and were labelled by whether they related to participant, practitioner or group outcomes of engagement. This organisation categorisation, where the subject matter is described without exploring what is said, served the purpose of sorting data for further analysis (Maxwell, 2012). This conceptual grouping of data, sometimes referred to as “*conceptual buckets*” by realist researchers, can help avoid the overwhelm of coding context, mechanisms and outcomes in these early stages (Wong, 2015). Similar to Byng et al. (2005) analysis approach, IPTs could be coded into more than one conceptual bucket to allow for the identification of common contexts, mechanisms and outcomes across programme theories in subsequent analysis stages. The coding of IPTs into conceptual buckets was carried out using Excel (Figure 5.6). The table sort and filter function in Excel was used to view IPTs in each conceptual bucket in a single worksheet. Viewing similar IPTs together, in one place, reduced the cognitive demand of synthesising large numbers of IPTs and developing them into fewer, yet more refined programme theories.

Figure 5.6

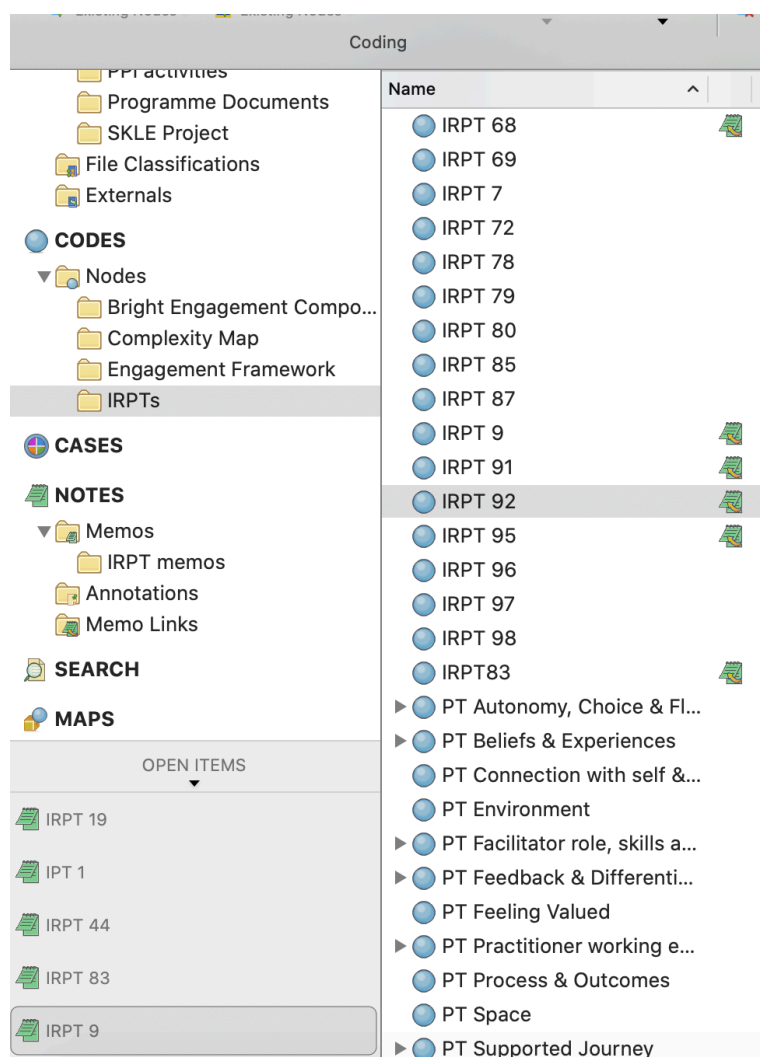
Coding IPTs into conceptual buckets using Excel

	A	B	D	E	F	G	H	I	J
	IRPT number	IRPT content	Stakeholder	Judgement	Outcomes	Process	Altruism/reciprocity	Feedback	Choice
1	13	If the group work in a way to encourage each other and provide feedback, then participants are more likely to engage with the programme.	Participant; Group					x	
2	27	If participants are more introvert, practitioners may find it harder to monitor their 'learning and experience' during a session and subsequently be less equipped to support their engagement and development through the programme.	Participant; practitioner					x	
3	28	If practitioners feel that they are giving up a lot of personal energy and time to an individual without them ultimately engaging with the programme, i.e. it feeling like a one-way effort, then practitioners may be less inclined to put their efforts into supporting individuals to such a high level.	Practitioner					x	
4	54	If participants don't perceive the practitioner or other members of the group to be engaged with the programme then they may become less engaged because....	Participant; group; practitioner					x	
5	65	If programme outcome measures are chosen whilst considering their use as differentiation tools, self-reflection tools and their use in a group setting then this will improve engagement because they will provide meaningful feedback to participants and practitioners, upon which they can act.	Participant		x			x	
6	100	If practitioners don't speak the same language as participants then they may find it harder to engage with participants because they are unable to gain feedback required for differentiation.	Participant; practitioner					x	
7	123	If practitioners focus on engaging with outwardly motivated individuals then this may reduce engagement in other participants because they may feel less important or misunderstood so that their efforts may go unrecognised.	Participant; practitioner					x	
8	127	If practitioners receive timely feedback about participants' progress then they will be more engaged when working with participants because they will feel a sense of satisfaction and capability.	Practitioner					x	
9									
10									
11	Appropriate level of challenge								
12	IRPT number IRPT content		Stakeholder	Judgement	Outcomes	Process	Altruism/reciprocity	Feedback	Choice
	Facilitator roles & skills	Environment	Connection with self and others	Space	Outcomes & process	Feedback & Differentiation			

Parent nodes for each conceptual bucket were created in NVivo 12 to facilitate the start of developing the more complete programme theories, so were labelled with a PT prefix. IPT nodes were moved into their respective parent PT node (Figure 5.7). As many IPTs were coded into more than one PT, copies were made to allow them to be viewed clearly in each category.

Figure 5.7

IPTs and programme theory conceptual buckets in NVivo 12



Triangulating data from other sources for theory development

Following the grouping of IPTs together, data were triangulated from the additional sources, described in section 5.6.3, to further refine the programme theories. The SLKE interviews, TE stories, feedback data from programme participants and programme documentation were all imported into NVivo 12. These additional data sources were scrutinised to determine the plausibility of the initial theories and to fill gaps relating to mechanisms. Rather than creating conceptual codes for each additional data set independently, the existing conceptual buckets were used as a

framework of pre-defined codes (Bowen 2009). This approach to coding and analysis was used because theory development in realist evaluation is recommended to begin with the knowledge of programme architects and practitioners (Pawson, 2013a).

Linked memos were created in NVivo 12 for the new overarching programme theory nodes to document the process of combining the IPTs, triangulating data and generating more detailed and refined programme theories. The approach taken for documenting this process was based on the methods reported by Dalkin et al. (2021), which included recording times and dates of changes, and the rationale for changes, in NVivo. This allowed an audit trail of iterations and rationales for changes to the theories to be documented, as recommended by the RAMESES II Reporting Standards for Realist Evaluations (Wong et al., 2016) to enhance the transparency of this process.

Once the IPT statements had been consolidated and triangulated with the additional data, and more detailed programme theories had been generated, they were written as context-mechanism-outcome (CMO) configurations for the final stage of development. CMO configurations clearly identified the constituent parts of the programme theories making it easier to analyse them as a collection of theories.

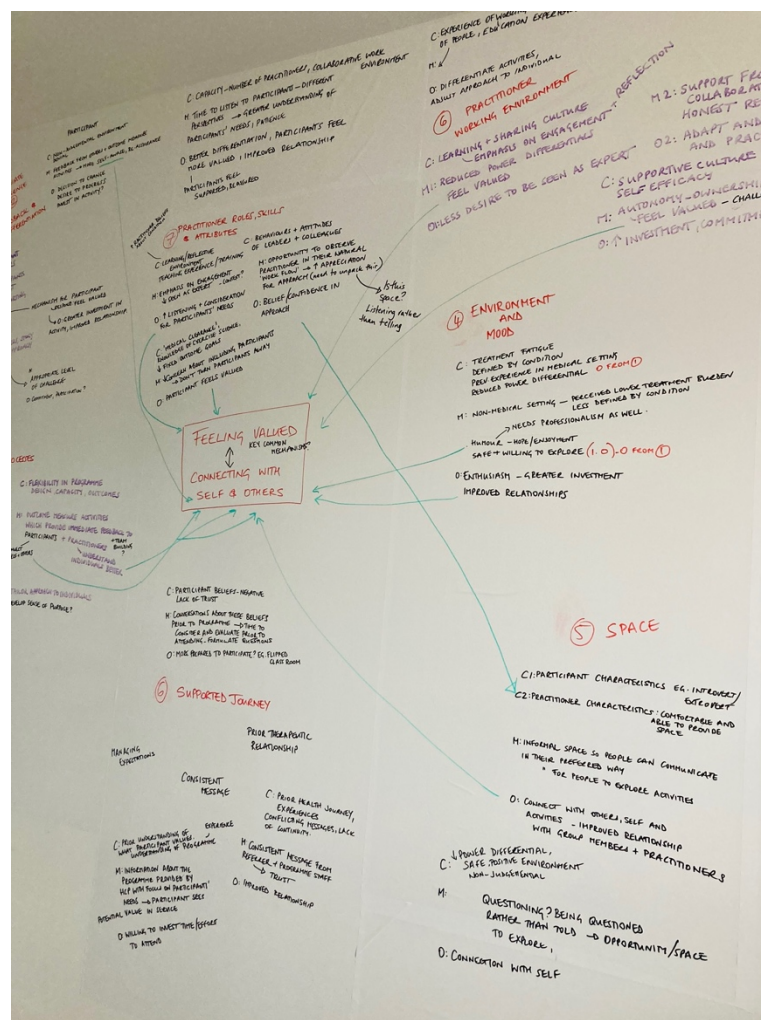
Connecting programme theories and final CMO configurations

CMO configurations may be presented in isolation to explain individual elements of programmes but may also be embedded within one another and/or presented in series to demonstrate a ripple effect (Jagosh et al., 2015). Given that engagement was conceptualised to be co-constructed; and both a process and a state (Bright et al., 2015), connections between CMO configurations were explored by creating a working map of programme theories on a whiteboard (Figure 5.8). Creating a physical map to

view the complex set of theories in one place, enabled the identification of common contexts, mechanisms and outcomes; ripple effects (where outcomes or mechanisms of one CMO behave contextually in another); and relationships between programme theories. Visualising programme theories through the mapping exercise also assisted in further refinement and consolidation of theories.

Figure 5.8

Working wall map of links between theories and their constructs



The programme theories provided causal explanations mainly for the informal components of programme architecture, as opposed to the more formal components, such as programme length or content (Jagosh et al., 2022).

Throughout Phase 1, developing theories were discussed with H&W team members and the supervisory team

5.7.2 Data analysis for theory verification and refinement

Observation field notes were analysed shortly after each observation to identify the presence or absence of programme architecture elements described in the programme theories thus far. Observations of interactions and behaviours relating to the programme theories helped to inform interview schedules (see section 5.5.1) so that interviewees could be prompted to discuss programme theory playing out in relation to specific observed events and features of the programmes.

Interview transcripts were manually transcribed and uploaded to NVivo 12. The interview transcripts were initially analysed similarly to those in Phase 1 where whole transcripts were read prior to coding to enable reflections on the overall context of the interview. Transcripts were then coded in two phases. The Programme Theory nodes created in NVivo 12 during theory development (5.7.1) served as a deductive framework to guide data analysis in this phase. First, interview excerpts were coded to relevant Programme Theory (PT) nodes. Similar to the approach for programme theory development, large excerpts were coded rather than individual contexts (C), mechanisms (M) and outcomes (O) in the first round of coding to avoid losing important aspects of context and meaning. Interviewees often discussed ideas and experiences at length, making it difficult to directly code Cs, Ms and Os without losing the meaning of what was being discussed.

Once data collection and the first round of coding to PT nodes were complete, interview transcripts and observation field notes were analysed in more depth to identify Cs, Ms and Os for each programme theory; an example is provided in Figure

5.9. Data excerpts were also coded by context, mechanism and outcome in NVivo 12, making it possible to create an audit trail of which data sources had contributed to theory verification and refinement (Appendix G). Linked memos were used to record whether the data verified, refuted or refined the CMO-Cs. Decisions regarding changes to programme theories and retroductive thinking were also recorded to support reflexivity and transparency.

Figure 5.9

CMO-C analysis table

Context – Mechanism - Outcome configuration	Observations	Example quotes
Communication	Back – Round of introductions, including practitioner and students. Choice to share Circle formation All participants shared stories and related with each other's experiences – discussed across the room	...that formality is where I have problems, that formal introduce yourself, I think you're put in a position where you have little choice and that would put me on the back foot... There's no follow-up, there's no banter, it's just so formal and sterile and I've not really found that easy to engage with. (P)
	Leg – Round of introductions. Practitioner introduced students. Cancer	It's the person in control that it is their responsibility basically to make sure that there is equal participation rather than all on one. (P)
Extent of participation	Back – Outcome measures and all activities optional. Some participants did not take part in the chester step test or body composition measurement	...if you don't turn up twice for a dentist, you're off the call, you're out of the dentist, you're off the NHS list... it's so important that you have to make those sessions otherwise you're gone. Whereas here, the freedom of, like for me, I got half way through and I started feeling embarrassed that I've got to come off and I stepped to one side and people just carried on, nobody questioned why I stopped, no one was like oh you're out of breath is it too hard for you, not even a question, it was just acceptance, and that was great. It's like an encouragement that you're not judged on things. (P)

Programme theory CMO-Cs were verified if they were supported by data and considered practically useful. Realist programme theory is not verified based on determining generalisability in larger populations, rather, the aim is to generalise across distinct cases and determining whether the theory holds in each case (Pawson, 2024). Empirical observations cannot establish the truth of theories but do have the ability to falsify them (Pawson, 2013). Programme theories were therefore verified if data supported them and they were not refuted.

Large numbers of programme theories and CMO-Cs can dilute their usefulness and stakeholders benefit from theories which are actionable and practical (Punton et al.

2015). Therefore, if CMO-Cs could be combined without losing essential explanatory components, they were not verified as separate theories but absorbed into other programme theories to assist the readability and practical utility of explanations.

5.8 Chapter summary

This chapter has detailed the two-phase case study research design for this realist evaluation and how it aligns with the realist evaluation cycle. Ethical considerations, data collection and analysis processes have been articulated in detail to enhance the transparency of this work. The following chapters present the findings of this realist evaluation.

Chapter 6 Programme theories

6.1 Chapter overview

This chapter presents the programme theories developed, verified and refined in this realist evaluation. The chapter begins with an overview of the programme theories, their position within the conceptual framework for engagement presented in the previous Chapter 5, and their abstraction to the overarching middle-range theory: Self Determination Theory. Each programme theory is then presented in individual sections, which are mini-chapters. Each mini-chapter presents the first iteration of the programme theory developed in Phase 1 in the form of context-mechanism-outcome configurations (CMO-Cs), which were introduced as heuristic for programme theorising in Chapter 4. CMO-Cs are presented in narrative form with contexts (C), mechanisms (M) and outcomes (O) labelled in the text, along with supporting Phase 1 data. Mechanisms are further differentiated into mechanism resource (M resource) and mechanism response (M response) to clearly identify the contributions of the programme architecture and how individuals respond to them in the explanatory accounts of engagement (Dalkin et al., 2015). Distinguishing between resources and responses was deemed appropriate to enhance the utility of programme theories. Clearly articulating programme resources was anticipated to help the introduction of mechanisms to support engagement in programmes. Each mini programme theory chapter continues with the findings of Phase 2 and how these helped to verify and refine theory. Each programme theory is discussed in relation to Self-Determination Theory and additional substantive theories, which will be introduced in section 6.3, to facilitate the abstraction and transferability of the findings of this realist evaluation.

Many of the CMO-Cs in the programme theories comprise multiple contexts. Contexts were identified at various system levels, for example, individual, interpersonal, institutional and infrastructural (Pawson, 2013), and were found to interact with each other in a dynamic way (J. Greenhalgh & Manzano, 2021). Contexts were identified to operate as both ‘triggers’ and ‘dimmer switches’, as described by Dalkin et al. (2015). Mechanisms, in some instances were contingent on certain contexts, however many mechanisms were intrinsically entangled with contexts and shaped by them in a more relational manner (J. Greenhalgh & Manzano, 2021). The relationships between contexts at different levels and their relationships with mechanisms are explained in the narrative section of each mini-chapter and are finally presented in table form at the end of each mini-chapter to provide a summary of the CMO-Cs discussed.

The forthcoming mini-chapters take an explanatory theoretical perspective and as such do not include the discussion of the theories in context of wider literature; this wider discussion takes place in the following Chapter 7. The next section provides an overview of the programme theories of this thesis.

6.2 Overview of programme theories of engagement in group-based self-management programmes

The programme theories presented in this chapter provide explanatory theories for how specific aspects of programme architecture influence engagement and the key contexts which shape how they generate outcomes. The conceptualisation of engagement (Bright et al. 2015) that contributed to the conceptual framework for theory development in this work define engagement as: “...a co-constructed process and state. It incorporates a process of gradually connecting with each other and/or a

therapeutic program, which enables the individual to become an active, committed and invested collaborator in healthcare”.

The engagement process has also been described as invisible (Bright et al., 2015). By examining engagement through realist enquiry, this research has unearthed six of these invisible mechanisms in the programme architecture of group-based self-management programmes. These mechanisms are: choice and variety; feedback and differentiation; the environment; space and time; alignment of needs; and student involvement, and were all found to contribute to participant and practitioner engagement in a central, seventh programme theory of co-constructed engagement (Figure 6.1). The seven explanatory theories are closely and inextricably linked, as are the many factors already known to relate to engagement, as discussed in Chapter 3. The processes involved in engagement depicted in wider engagement theory are also complexly interlinked (Bright et al., 2015; Graffigna et al., 2020). Therefore, consistent with wider theory and empirical study, no single aspect of programme architecture was found to be more important for engagement in this research. Similarly, engagement as a state, or outcome, comprises numerous inseparable internal and observable elements (Bright et al., 2015). Therefore, each CMO-C outcome is depicted as the consolidated term ‘engagement’ to enhance the accessibility of the theories presented in this work.

Figure 6.1

Overview of the seven programme theories



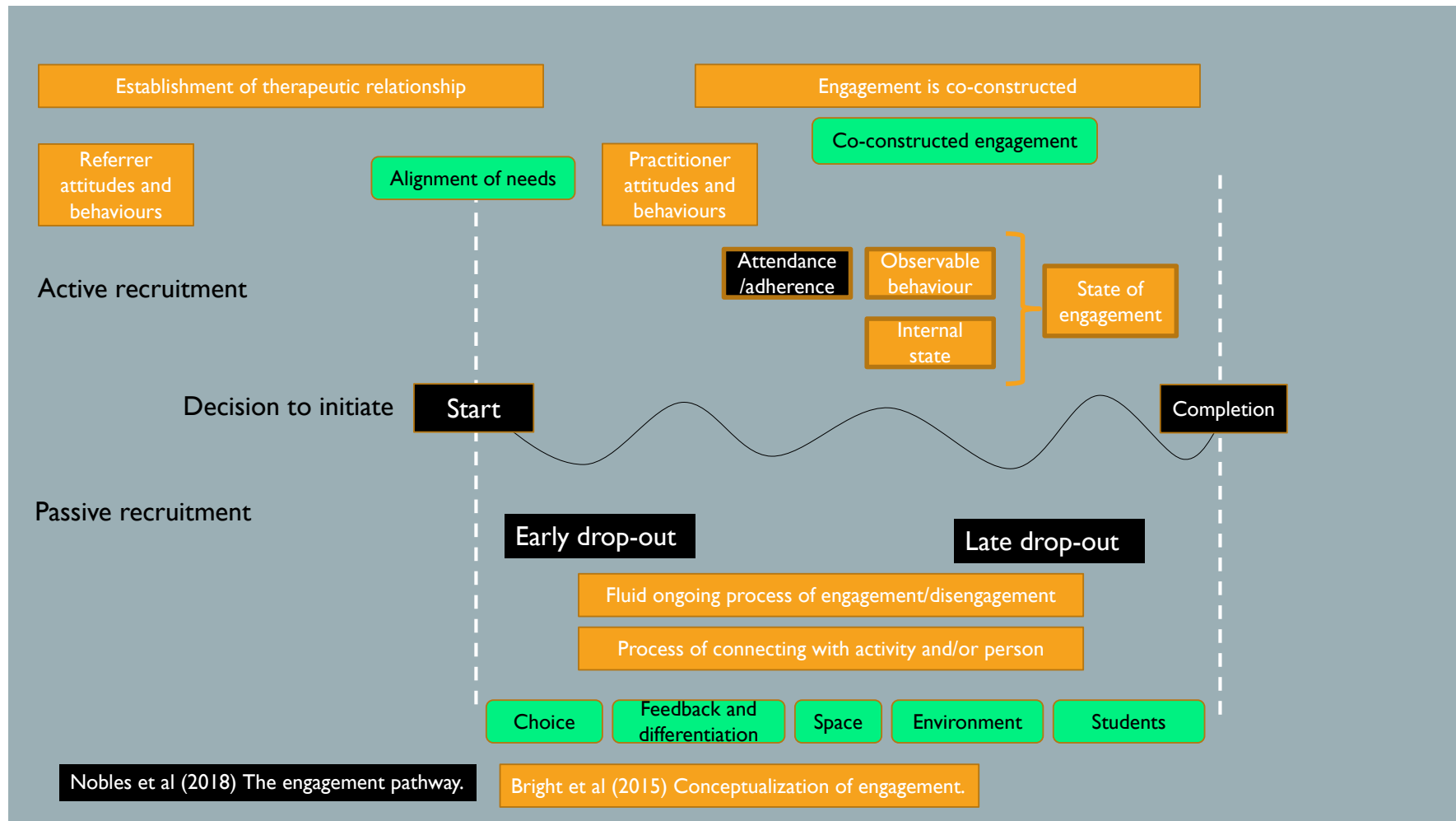
The following section positions the above programme theories within the aforementioned conceptual framework and in relation to substantive middle-range theory.

6.3 Positioning the programme theories within a conceptual framework and enhancing explanatory power with substantive middle-range theories

The programme theories produced in this research are presented below, in Figure 6.2, within the conceptual framework introduced in Chapter 5.

Figure 6.2

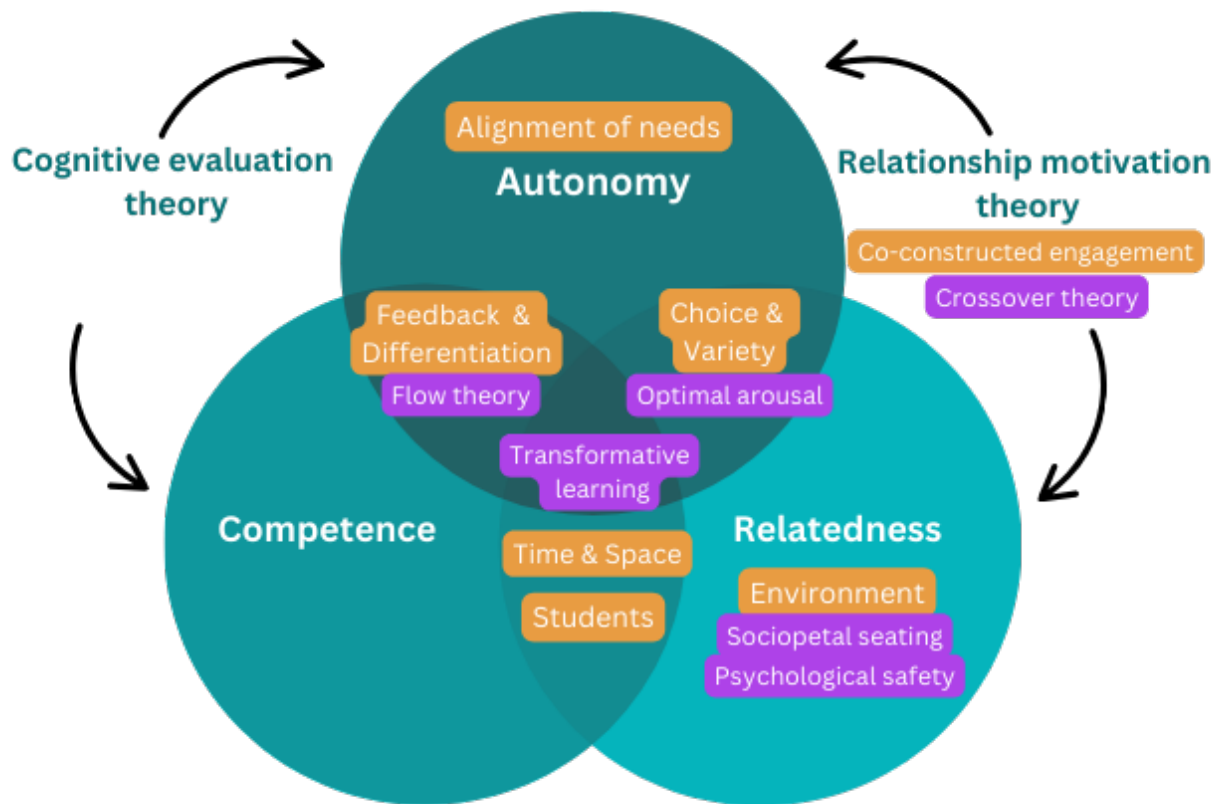
The programme theories situated within the conceptual framework, described in Chapter 5



The role of the conceptual framework was to provide a structure to support the identification of concepts and their analysis for realist programme theory development (Shearn et al., 2017). Substantive middle-range theories were explored, as described in Chapter 5, to enhance the explanatory power of the programme theories. No single theory is able to explain all aspects of a phenomenon (Maxwell, 2012; Westthorp, 2012). In some cases, Self-Determination Theory (SDT) did not fully explain programme theories, therefore additional middle range theories were identified and layered with SDT within the conceptual framework. The layering of the programme theories, SDT and additional middle-range theories is depicted in the summary diagram below (Figure 6.3) and each will be discussed in the context of programme theory in the relevant mini-chapter.

Figure 6.3

Programme theories of engagement mapped to self-determination theory



Note: Self-determination theory, cognitive evaluation theory, and relationship motivation theory are presented in blue, which represents substantive theory at the highest level of abstraction in this group of theories. Theories in purple represent substantive theory at a lower level of abstraction. Programme theories are presented in orange and are placed within and adjacent to the substantive theories which support them.

SDT was used as an overarching substantive middle-range theory to support the abstraction and explanatory power of the programme theories in this realist evaluation (Pawson, 2024) due to its explanatory role in engagement enhancement across a range of disciplines (Chiu, 2022; Goldman et al., 2017; Gu & Duan, 2024; Kosmala-Anderson et al., 2010; Shen et al., 2024). Further, SDT may have practical relevance in the delivery of person-centred interventions due to their similar perspectives at a metatheoretical level (Patterson & Joseph, 2007). SDT is a theory of human behaviour which explains how social-contextual factors support or hinder individuals' thriving

through satisfaction of their basic psychological needs for competency, relatedness and autonomy (R. M. Ryan & Deci, 2017).

Autonomy concerns a sense of initiative and ownership of one's actions; competence relates to feelings of mastery and sense of one's potential to succeed and grow; and relatedness concerns feelings of belonging and connection with others (R. M. Ryan & Deci, 2020). SDT explains the development of internal and external motivations preceding action through the satisfaction of these basic psychological needs. Although motivation is not in itself engagement, it is an important precursor to and quality enhancer of engagement (Martin et al., 2017). SDT therefore supports the programme theories by strengthening the explanations of how programme architecture impacts engagement by satisfying needs for autonomy, competence and relatedness. SDT was also considered to have particular explanatory utility due to its use of mini-theories. The SD mini-theories explain the relationship between the needs of competency, relatedness and autonomy, mirroring and supporting the explanation of inter-related programme theories in this research. Cognitive evaluation theory and relationship motivation theory, two of the six mini-theories of SDT, were used to support the articulation of the interlinking of the programme theories (Figure 6.3).

All of the programme theories aligned with more than one psychological need in SDT. Choice and variety, and feedback and differentiation shared the foundations of autonomy. However, choice and variety also relied upon, and impacted relatedness, whereas feedback and differentiation had closer links with competence. Time and space, and student involvement both shared principles of competence and relatedness. Alignment of needs and environment were considered to be predominantly associated with autonomy and relatedness respectively, however, in

reality they were not isolated from other needs. The relationships between programme theories will be discussed further throughout this chapter.

6.4 Programme theory 1: Choice and variety

Programme theory 1 provided an explanatory account of how choice and variety contributed to engagement in the H&W programmes. Choice can be divided into two distinct types: *option* and *action* choice (Reeve et al., 2003); option choice pertains to the ability to choose between numerous options, whereas action choice refers to the choice in how an activity may be carried out during the activity itself. These key mechanisms of choice were instrumental in achieving an autonomy-supportive approach to supporting participant engagement on the programmes. Autonomy-supportive approaches begin with understanding an individual's perspective and working with them to identify and create solutions as opposed to a more controlling approach of working toward imposed outcome goals (R. M. Ryan & Deci, 2017). Four CMO-Cs were developed during Phase 1 for this programme theory: communication; extent of participation; variety of activities; and choice of goals. Following verification and refinement in Phase 2, the first CMO-C: communication was absorbed into other programme theories; hence it has been labelled as CMO-C 0. The other three CMO-Cs were verified with some refinements, the details of which are presented in the following sub-sections.

CMO-C 0: Communication

During Phase 1, programme architects and practitioners described various types of interaction during programmes: programme participants could speak to the whole group, communicate in smaller groups, and have one-to-one discussions with the practitioners and student practitioners. They also recognised a variety of participant

preferences and personalities (C) which ranged from people who appeared more secure in communicating as part of a group and those who felt overwhelmed by speaking more openly in front of other people.

I just think it's down to personality types.... She [a programme participant] found it so overwhelming to speak to a group whereas it seems like some people, you know, when you get them into a smaller group, they wouldn't interact as much, you'd find they'd speak more in open groups. So, it's just an observation really, I think it's just the different ways people communicate.

(Phase 1 Programme Practitioner)

The choice participants had in the way that they communicated (M resource) was seen to play an important role in ensuring that everyone could share their stories and experiences in a way that was comfortable for them (M response) leading to better engagement (O).

And I think that that also really builds that engagement [having the option to speak to students], particularly with people that are a bit more nervous in the groups, people that are not quite so social and don't work well in those kind of groups. If they have somebody that they can kind of go over to at the side of the room and say, oh, I'm having a bit of problem with this, they feel that it's easier to do that than it is to come out in the middle of the room in front of everybody and talk to me. (Phase 1 Programme Practitioner)

During Phase 2, choice regarding communication was observed in all programmes to varying degrees but when this mechanism was discussed in programme participant interviews, they related their experience to informal space (programme theory 4) and a safe emotional environment (programme theory 3). The communication CMO-C was

therefore absorbed into programme theories 3 and 4 as no distinct choice elements were identified to warrant a separate CMO-C.

CMO-C 1: Extent of participation

A non-prescriptive approach to facilitating activities in the H&W programmes was proposed as an important factor in improving engagement with programmes during the Phase 1 interviews.

It's not a physio programme with set exercises, it is about engagement and it's about finding things that people can try out and potentially feel comfortable doing, or potentially have a touch of mastery over, thinking "oh I can do that and I couldn't do that before". (Phase 1 Programme Architect)

Participants were afforded action choice by being encouraged to do what they felt they were able to without pressure to take part in each of the activities (M resource). Not being required to take part may help satisfy participants' need for autonomy (M response), resulting in better engagement (O).

Yeah, I tell [them], "even if you don't want to do anything, please just come and join the session and just be part of the conversation. If you don't feel like you wanna do or move at all 'cause you're having a bad day 'cause your pain is through the roof then there's still a value of you being there because you're still a part of our group". So that, again, shows what we were driving through or what is our philosophy with our approach. (Phase 1 Programme Architect)

The development of this theory was supported by participants in programme feedback. A participant on the Back Programme provided feedback on the positive aspects of

the programme: “not requiring me to do things I felt I couldn’t. Using positive encouragement to get the best for me”.

The lack of pressure or being told what to do was perceived to be a particularly important approach on programmes that were run in the more deprived areas of the city (C).

At our kind of slightly more deprived areas in (City) where I think they don't necessarily know or have the skills to manage their health themselves quite so well, and but they also don't engage because they don't want to be told what to do. (Phase 1 Programme Practitioner)

The provision of action choice was confirmed as a mechanism of engagement in Phase 2. Choice was evident in the participant observations and corroborated as a factor in engagement with the programmes in participant interviews. Although practitioners on all programmes used phrases such as: “just do whatever you can” and “you are in charge/control”, choice was more frequently afforded during the Back Programme, partly due to the wider range of activities and exercises offered to participants. For example, there were numerous exercises and activities that some participants did not take part in at all. The Leg Programmes comparatively had more prescriptive exercises to demonstrate so, although participants were given control over how much they did, for example, “stop if it gets too much”, there was less emphasis on the option to avoid exercises altogether. Participants agreed that choice whether to participate was important for engagement. One participant described an example of being excluded from another service for not attending, corroborating the idea that being allowed to ease back or drop out of an activity helped them to feel accepted, and less judged, and subsequently more engaged.

...if you don't turn up twice for a dentist, you're off the call, you're out of the dentist, you're off the NHS list... it's so important that you have to make those sessions otherwise you're gone. Whereas here, the freedom of, like for me, I got half way through and I started feeling embarrassed that I've got to come off and I stepped to one side and people just carried on, nobody questioned why I stopped, no one was like oh you're out of breath is it too hard for you, not even a question, it was just acceptance, and that was great. It's like an encouragement that you're not judged on things. (Phase 2 Back Programme Participant H6)

Although action choice was initially theorised to be particularly important for those with lower SES, participants with a range of SES generally agreed that it was key for engagement. An important context discussed by participants was their previous experience of healthcare, feeling judged in healthcare settings and by society overall (C). These prior experiences were more pertinent contexts affecting how they felt about the programme and why choice was an especially valuable component of the service. Participants on the Back Programme in particular, felt that in contrast to previous experiences, they felt un-judged during the programme: "I haven't felt this sort of judgemental, you know, 'I'm old, I'm overweight, I'm not fit enough' You know, none of that has come to the fore at all. I thought it was very inclusive" (Phase 2 Back Programme Participant H1).

Entirely volitional and self-regulated behaviour is a key tenet of autonomy in SDT (R. M. Ryan & Deci, 2017). In the current research, choice as a mechanism was free from coercion and judgement and offered in the context of reduced power differentials, aligning with the SDT conceptualisation of autonomy.

CMO-C 2: Variety of activities

Programme architects and practitioners believed activity variety, or option choice, to be important for engagement. For example, some of the programmes included Nordic walking, various gym-based exercise, and swimming. Participants were recognised to have a range of knowledge and experience of these activities prior to attending programmes (C). The 'taster' nature of activities was proposed to allow participants to explore, without obligation to continue (M resource), activities they had never been exposed to, had wanted to try but never been able to, or had believed they would not have enjoyed. It was proposed that participants would be more likely to find an activity which met their needs and interests (M response), leading to better engagement (O).

It's not about going in the gym, it's about doing activity and doing exercise.

Because the Nordic walking's like 20 minutes, generally I'd say it's fun for everyone in terms of distracting and different, so for everyone it's engaging because they're doing something they haven't done before and weighing it up but it doesn't matter if it's not the thing they're gonna do because we're done then and we move on to something else as a group, back to the common themes that we include in our programmes. (Phase 1 Programme

Practitioner)

This CMO-C of option choice is consistent with other authors' assertions, including SDT theorists, that it is not the choosing itself that is beneficial, but the extent to which the available options are relevant to an individual's personal values and goals (M. Evans & Boucher, 2015; R. M. Ryan & Deci, 2017). The H&W team also proposed that option choice contributed to participants exploring activities and challenging their beliefs to work towards a new frame of reference through transformative learning

(Downey et al., 2021). Transformative learning theory explains the process by which people move away from rejecting ideas that are limited by their experiences and pre-conceptions and toward a new frame of reference with new habits of mind and points of view (Mezirow, 1997).

Participant feedback supported the idea that a taster of a variety of activities offered in an autonomy-supportive manner helped to facilitate this change in self-concept. Participants commented “surprisingly I actually really enjoyed the gym”, “encouraged me to try exercises which I never would before, without feeling pressured”, “inspiration to become more active, opportunity to try a variety of activities, support/assistance of staff”, and “gave me the opportunity to use the gym for the first time which I’ve wanted to for years”.

A rival theory for this CMO-C was considered as participant feedback in phase 1 revealed that some participants wished to develop a greater sense of mastery, possibly based on their beliefs and self-efficacy (*CR*). A taster approach (*M* resource) may have been perceived as less valuable due to a lack of opportunity to develop self-efficacy (*M* response *R*) resulting in reduced engagement (*OR*). The potential response to this mechanism is illustrated in this feedback comment: “we did tasters on some activities, I would like to have spent more time really getting the exercises right so I felt more confident in doing them myself”.

Option choice through the provision of a variety of programme activities was confirmed to impact engagement in the evaluated programmes in Phase 2. Engagement was highest in the Back Programme, which included the greatest variety of activities and the Leg Programmes had lower engagement along with the least variety. The Back Programme incorporated various forms of physical and learning activities whereas the

Leg Programmes were delivered more didactically through the delivery of information and demonstration of specific leg exercises. A variety of activities (M resource) was shown to impact engagement via two different mechanism responses. Firstly, by allowing people to try new activities and increase opportunities to take something meaningful from the programme (M response 1), and secondly, by preventing boredom (M response 2), which had not previously been considered in the programme theory. A Back Programme participant articulated the option choice mechanism response (M response 1):

I could see there are things there that I wouldn't take away but I was taking away so much from the other things90-95% of the things I was getting a huge amount out of...I think everyone got different things from it, which is absolutely brilliant. How can you put on a programme and not be happy with it when everyone's taking away something positive but different things from it?
(Phase 2 Back Programme Participant H1)

The proposed mechanism of a variety of activity tasters was supported by a participant who felt he had an opportunity to try things he would not have considered before, as well as challenge preconceptions he held about the activities.

I really wanted to try everything because you never know, there could be one thing you think "nah that ain't gonna do it for me" but you think "you know what that was a good thing". To me the whole Jane Fonda workout [referring to the Step Test], stepping up, you know I was laughing in my head continuously, thinking "what the hell am I doing?" but by stage four I'm like [panting heavily] woah this is hurting and I couldn't get past that last stage.

But you find that something like that, if there was a step aerobics class, I might even go for one. (Phase 2 Back Programme Participant H6)

The rival theory was put to participants during interviews in Phase 2 and was partly verified.

...it's like someone's dangling a carrot, you grabbed it and they pulled it back away from you, ah I've got it but I quite enjoyed the fact that we did three kinds of gym sessions.... So yeah, there is like quite a lot of positives, there might be a little bit of negative that it's not long enough... (Phase 2 Back Programme Participant H6)

Longer programmes were perceived to mitigate the issue of a lack of practise and skill development opportunity, and in this case, other engagement supporting mechanisms outweighed the disengaging aspect of not being able to pursue activities further.

The additional mechanism of variety (M resource) to reduce boredom (M response 2) and stimulate and maintain interest was discussed by participants on both the Back and Leg Programmes. Variety reduced boredom, enhancing engagement (O) in the Back Programme: "...it's got just the right amount in everything so you've got that right amount of talking time, then straight into exercise... It breaks it up so you don't become too involved but again you don't become bored" (Back Programme participant H6). Whereas the absence of variety was identified as a mechanism for disengagement in the Leg Programmes:

I think all the things that he was spouting out, the narration bit of it, was a bit too long. He could have cut it into 3 bits really, say one paragraph or two paragraphs at a time and then either gone out or done something else, he

could have made us do something and then came back and sat down and made a nice relaxing comment, which I would have done, and then do another bit to it. Don't go through the whole lot all at once. It's like being at school and you're like "oh the teacher's gonna go on and on". Half of it you don't listen to, you know what I'm saying? (Phase 2 Leg Programme Participant A1)

Variety to ameliorate boredom was not explained by SDT. Optimal arousal theory was drawn on to explain this additional response. A variety of activities and delivery methods may prevent boredom through creating optimal arousal and enhancing attentional engagement. Boredom is a state of non-optimal arousal (Tam et al., 2021) and can have a detrimental impact on internal and external motivation, leading to the avoidance of the activity (Tam et al., 2020). This optimal arousal appeared to impact practitioner engagement as well:

...it can be monotonous even when updating content and it still being similar is quite monotonous, constantly delivering the same content, even when you update it if new evidence emerges and things and we update it, like we are at the moment, it's still quite monotonous delivering the same. I like to think a lot of practitioners have their style and they sort of deviate within that ever so slightly, so I like to think most of my sessions aren't necessarily the same and that I'll try and vary it a little bit for me as much for the patients as well. (Phase 2 Leg Programme Practitioner)

The ability to try various activities and finding ones that they enjoyed and met their needs, led some participants to consider continuing with some of the activities in future, beyond the programme. In contrast, variety to prevent boredom was only

identified as a mechanism for enhanced engagement during the programme itself, suggesting that variety has a role to play in both short and longer-term engagement through these two mechanisms.

Numerous contexts at different levels were identified to interact in this CMO-C. The contexts shaping variety on the programmes included session length and programme duration (C). The Back Programme had the longest sessions and course duration and the Leg Programmes had the shortest in both respects. The access to a range of equipment and facilities (C) was an important context for providing a variety of physical activities for individuals to explore, however, it was not sufficient alone. One of the Leg Programmes was delivered in the same location as the Back Programme, yet did not offer more choice in activities, demonstrating that a lack of variety is not solely due to lack of facilities and/or equipment. The contextual influence of programme duration on variety in the programmes was supported by practitioners who explained that the Leg Programmes had shortened over time, reducing what could be included in programmes. Practitioners described the need to condense material and activities into a shorter programme, leaving less time to vary activities and to revisit content throughout the programme: “It’s different iterations so, from twelve weeks down to eight, six, ten whatever, and now being a four... the previous outcome measures and things like that just aren’t realistic to take because we don’t have the time” (Leg Programme Practitioner). An attempt to abridge the programme to help meet demands for the service (C) was shown to inadvertently limit this valuable choice mechanism for engagement, and therefore reducing engagement on the Leg Programmes.

CMO-C 3: Choice of goals

In Phase 1, practitioners hypothesised that giving participants a choice of goals to aim for improved engagement, and programmes often started with a conversation with participants about what they wanted to gain from taking part.

Okay, let me talk to this patient. I mean, listen to them and see what they actually want, and how I can help them and then I'll use my knowledge and my education that I've been presented with, deliver what I think is best for that patient. (Phase 1 Programme Architect)

The importance of individualised goals was supported when triangulating participant feedback. For example, a participant commented that “the program achieved my goal of being able to explore what I am able to do in a supported environment”. The choice in goals (M resource) was considered to make goals feel more achievable (M response 1) and/or make participants feel more valued (M response 2), resulting in better engagement (O). More achievable goals were proposed to be particularly important for individuals with low self-esteem, self-confidence or self-efficacy (C).

What they can feel they could set in terms of a realistic goal and removing any pre-set, I don't know, so for example a pre-set goal like the 10,000 step thing. “I've got to do....” It's everyone's gotta do 10,000 steps, that was just binned. You know, it's very much about what do you think you could do. (Phase 1 Programme Architect)

The choice in goal setting was verified as important for individuals to engage with programmes in Phase 2. The mechanism of goal choice was more impactful in the Back Programme which incorporated a specific goal-setting activity, which

emphasised that goal setting was within individuals' control. Further, continuous relating of activities and information to individuals' goals provided ongoing nurturing of engagement through an alignment of needs (programme theory 5), which will be discussed in section 6.8. The mechanism response 1 of goals being more achievable was not supported by programme participants during testing. Interviewees referred to the importance of the personalisation of goals and how that supported their activity choices throughout the programme. This aspect of choice offered in programmes aligned more with the basic need for autonomy, hallmarked by individuals' behaviours being self-endorsed or congruent with their authentic interests and values (R. M. Ryan & Deci, 2017).

...my aim was the gym 'cause I miss it. I used to gym quite regularly and I was getting to the point where I was getting quite big but then I dropped off, my back went...I'm quite looking forward to finding me again. (Phase 2 Back Programme Participant H6)

Ripple effects

Providing individuals with choice regarding their goals (CMO-C 3) and extent of participation (CMO-C 1) was believed to be made possible by the flexibility of the programmes (C). Some of the H&W programmes were not required to demonstrate changes in particular outcomes or required to use specific outcome measures by stakeholder partners funding the programmes (C). A lack of pressure to meet pre-determined targets and use prescribed outcome measures (M resource) meant that programme architects and practitioners were not concerned with ensuring participants met specific targets (M response). Subsequently, practitioners could support participants in working toward goals of their choosing in a more flexible way (O).

I'll give you an example. So one of our programmes, a gentleman on one of the programmes had some hip pain and he'd had it through the length of and it was associated with his treatment and one of the sessions, penultimate sessions, it might have been the last of second to last session, we didn't end up doing any exercise at all but we planned to do that, we just sat and had a chat with the students and he found more benefit from that than going in and trying to loosen up his hip. 'Cause at the start I was keen to try and do something to alleviate the discomfort, trying to do something physically active but in the end he was just like, "shall we just have a chat?" and I was like, "well yeah, if you'd find more value in that then yeah, absolutely". Like there's no, that's what I mean about the flexibility of the programmes, they're not rigid, that "right we've got to do an exercise even if people don't wanna do it".

(Phase 1 Programme Practitioner)

Practitioners confirmed during Phase 2 that they felt free from external pressures to achieve biomedical outcomes, allowing them to work with participants in an autonomy-supporting, rather than autonomy-controlling way (Downey et al., 2024; Silva et al., 2017). The lack of pressure, combined with those in leadership and practitioners sharing person-centred values were viewed as necessary contexts for practitioners to deliver autonomy-supportive flexible programmes.

I see it more positive that I can, I have freedom just to support things that I think are important, so give people genuine care, give them a range of options that tailor to them, give them the space to trial things out and in a safe manner. So I don't sit there and go "this is brilliant because I don't feel like I'm gonna fail" or funding's going to be cut, I see it more as "isn't that brilliant

that's not being pushed on me, which is person-centred and now I can be person-centred with other people. (Phase 2 Back Programme Practitioner)

Practitioners recognised that the flexibility afforded to them regarding individualising participants' experience was not the norm. Practitioners postulated that on other programmes participants may experience imposed goals, due to external pressures on practitioners to demonstrate specific biomedical programme outcomes.

I actually think that lack of pressure to prove something or even collect anything it's important for me as the practitioner. 'Cause I feel like then I can give the, I can go in different ways depending on what the person needs. (Phase 2 Leg Programme Practitioner)

A practitioner delivering the Cancer Programme held a similar view: "But yeah, I think it's somewhat frustrating that almost their experience is compromised at the expense of outcome measures".

These contexts and mechanisms at varying levels of social strata were conceived to operate in a ripple effect of CMO-Cs, as described by Jagosh et al. (2015). Figure 6.4 demonstrates how the outcome of one CMO-C, became the context for a subsequent CMO-C within this programme theory. Further, more than one context was identified as potentially important in the provision of choice in the programmes, creating a CCCMO-C.

Figure 6.4

Ripple effect of CMO-Cs based on Jagosh et al. (2015)



The context of organisational culture and leadership was highlighted by practitioners in Phase 2.

...if we were out in the community that becomes really important, doesn't it? If you are not proving these metrics, your service might be slashed. Whereas I don't feel that pressure in the environment we're in. It's not about a risk of failure. It's about he's [person in leadership] given me the space to do things which are important beyond just the outcomes....I definitely don't feel it's a fear of failure. It's more of a, you know, this person recognises, it's sort of the Commissioners, or whoever's putting this in front of them are recognising the importance of the processes not just the outcomes. (Phase 2 Back Programme Practitioner)

In addition, participants described the importance of practitioners' skill in being able to deliver a flexible programme that had elements of variety and choice: "...you have to have people who've got the confidence and skills to run it in that way. Sorry, you have and you've quite clearly got that" (Back Programme Participant H1).

The refined CMO-Cs for Programme Theory 1: Choice and variety, are presented in Table 6-1

Table 6.1

Refined programme theory 1: Choice and variety

	Context	Mechanism	Outcome
CMO-C 1	Previous experience of healthcare and feeling judged.	Action choice in participation making people feel more valued and less judged.	Engagement
CMO-C 2	Practitioner skill in facilitating varied sessions. Programme facilities. Programme duration. (Meeting service demands).	Option choice of activities to increase chance of participants experiencing personally valuable activities. Variety to hold interest and prevent boredom.	Engagement
CMO-C 3	Practitioner skill and programme flexibility.	Option choice of goals to make the programme feel more personalised and individuals feel valued.	Engagement

Programme theory 1 summary

The programme theory proposed in phase 1 presented four CMO-Cs which explained how different types of choice could support engagement in programmes: communication, extent of participation, variety of activities and choice of goals. Phase 2 led to the absorption of CMO-C 0 into programme theories 3 (environment) and 4 (informal space), and the verification and refinement of CMO-Cs 1-3. Numerous contexts at different levels of the system were identified and shown to interact with one another as depicted in all CMO-Cs and described in the section: ripple effects.

6.5 Programme theory 2: The role of feedback and differentiation in engagement

Programme theory 2 provides an explanation of how feedback and differentiation can support engagement in group-based programmes. Feedback and differentiation are key concepts in teaching and learning. According to the SDT mini theory: cognitive evaluation theory, positive, efficacy-enhancing feedback can enhance intrinsic motivation provided that it is delivered in a non-controlling way i.e. with the aim to inform and acknowledge rather than to motivate or control (R. M. Ryan & Deci, 2017). Cognitive evaluation theory therefor helps to explain the link between this theory of feedback and differentiation with the previous theory of choice in section 6.4. Providing positive feedback along with ongoing information exchange was considered key to enhancing intrinsic motivation in the H&W programmes by helping individuals challenge their identity and achieve a shift in self-concept through transformative learning (Downey et al., 2021).

As well as feedback providing a direct impact on participant engagement, it was also identified as an important way of supporting effective differentiation. Differentiation is

a pedagogical approach rooted in the respect for learners and their differences. Differentiation involves educators purposely adapting their teaching to meet the diverse needs of individual students in relation to their levels of readiness, as well as their interests and learning preferences (Smale-Jacobse et al., 2019; Tomlinson et al., 2003). Differentiation can therefore help to satisfy needs of both competence and autonomy in SDT. Feedback *from* participants on the H&W programmes provided a means to assess their knowledge, skills and needs, which can allow staff to provide optimally challenging learning (M. Evans & Boucher, 2015). Perceived competence in cognitive evaluation theory can be supported through optimal challenge and informational feedback (R. M. Ryan & Deci, 2017), both of which were identified in this research and are discussed in detail in the following two CMO-Cs: feedback, and differentiation.

CMOC 1 Feedback

During Phase 1, programme practitioners and architects described the use of feedback throughout the programmes, which appeared to have multiple roles. Practitioners explained that participants were provided verbal feedback, and feedback directly from outcome measure activities, referred to as other-mediated feedback and task-inherent feedback respectively, in cognitive evaluation theory (R. M. Ryan & Deci, 2017). Examples of practitioner and student-practitioner feedback included checking that exercises were being performed correctly; and task-inherent feedback through outcome measures included measuring step count using pedometers, body composition measurement, and various strength and fitness tests (M resource). Both verbal and outcome measure feedback were considered useful in building self-awareness and changing participants' frames of reference through Transformative Learning (Mezirow, 1997) (M response) to enhance engagement (O).

So, say, for example, one of the outcomes we usually take with the patients is body composition. Now, sometimes, we don't find any difference in the body composition, because it's a very short time that we're working with the patient. But patients really appreciate it because they get a bit of an insight into what their body is actually made up of. And they find that really interesting, you know, that they're provided with something that they're not provided anywhere else. (Phase 1 Programme Architect)

The development of this theory was supported by triangulating Phase 1 participant feedback data from programmes:

The program was really informative, it helped me understand my body and what it is capable of and the ways it is safe to move. Monitoring the body composition was very useful and been given the pedometer was motivating. I feel more in control and it has had a positive effect on my mental health. (Phase 1 Programme Participant Feedback)

Practitioners highlighted that outcome measure feedback should be provided in a supportive manner, alongside peers in some instances (C) for feedback to support engagement. The shared vulnerability of participants when taking part in baseline testing, and the fact that participants were afforded choice in whether they took part in each measuring activity (see previous Programme Theory 1) were seen as essential to developing this safe and supportive environment.

A context was identified which could negatively shape the mechanism resource of task-inherent feedback from patient reported outcome measures (PROMs). In the case of high condition severity or poor prognosis (C), participants may feel that attempts to change would be futile (M response) and feel less engaged (O). Potential

disengagement was identified in this poignant quote from Phase 1 participant feedback on the Cancer Programme where the EORTC QLQ-C30 was used as an outcome measure for assessing quality of life pre and post participating in the Cancer Programme:

I'm not sure how accurate the questions on well-being are as this all depends on the moment in time because of the need to make a claim under special rules I've been reminded that I have a chance of living less than six months. It's made me think about death and end of life arrangements more than I would have. (Phase 1 Programme Participant Feedback)

Phase 2 data supported the theory that feedback could impact engagement with the programmes. Participants were observed being provided feedback during all programmes. The positive impact of feedback on engagement was most notable in the Back and Cancer programmes where feedback was more abundant, informative, supportive and delivered one-to-one. Feedback on the Leg Programmes tended to be limited to brief encouraging verbal feedback and confirmation of correct exercise performance. Participants on the Leg Programmes did not highlight these kinds of feedback as particularly important for increasing self-reflection or engagement. In contrast, feedback mechanisms were confirmed as important for engagement in the Back and Cancer Programmes. The regular individualised feedback (M resource) provided on these programmes was deemed possible due to the additional one-to-one support from students and the length of programme sessions (C). Longer session duration allowed participants the time to practise activities long enough to receive and act on personalised feedback (M response). Participants were observed receiving

feedback and engaging by adjusting what they were doing and/or continuing with greater engagement (O).

H1 looked nervous and apprehensive about doing some of the exercises with his knee - moved very gingerly. The student talked it through with me and then coached him through a new version [of the exercise]. H1 moved more confidently second time around and looked more determined, very appreciative too. (Phase 2 Back Programme field note)

This was corroborated in participant interviews as some explained a need to be reassured that they were carrying out activities safely and correctly in order to engage with the activities fully.

I made sure I had an instructor that showed me what to do and how to do it. Because I didn't want to go into the gym naively, start pulling weights and potentially do more damage to my body, which I feel if you don't know how to do it properly you could do that. (Phase 2 Back Programme Participant H4)

In terms of the role of outcome measures as a form of task-inherent feedback, some participants felt they already had a level awareness that they did not need to confirm with feedback, for example, body composition. No individuals with severe disease or very poor prognosis were interviewed so it was not possible to verify whether this context may lead to the outcome measure feedback negatively impacting engagement. However, interview and observation data revealed that PROMs did not necessarily capture and reflect people's experience of their condition.

...actually that's not fully describing how I actually feel about it...it probably made me feel that I'm making a big thing out of something that could be trivial

and it isn't trivial to me and I had to stick with that, that it isn't trivial to me even though I'm coming fairly high or low on the score. (Phase 2 Back Programme Participant H1)

The failure of PROMs to capture individuals' experiences accurately, and their concerns being trivialised, has been identified in other realist research (J. Greenhalgh et al., 2018). This trivialisation of concerns may undermine the acknowledging approach needed for feedback provision to enhance intrinsic motivation, as described in cognitive evaluation theory (R. M. Ryan & Deci, 2017). The potentially detrimental impact of PROMs in this regard was mitigated in this research by the other-mediated feedback of ongoing and supportive discussions with programme practitioners (C). Practitioners acknowledged participants' experiences and prioritised this information over PROM scores.

CMOC 2 Differentiation

Practitioners interviewed in Phase 1 viewed differentiation of activities by interest and capabilities as an essential mechanism for supporting engagement, and key component of their person-centred approach. Due to the wide range of experiences and physical capabilities of participants on programmes, it was not deemed appropriate to encourage them all to perform activities in the same way or aim for similar targets. Too much challenge was perceived by practitioners to discourage people from returning to the programmes due to worsening of symptoms and/or low self-efficacy, which was one of the drivers for allowing participants choice in how they participated in activities (Programme Theory 1). However, too little challenge was identified by practitioners and in participant feedback to result in participants having low confidence in the value of the programme for meeting their needs.

I remember ... we had a lady who came along to one of the groups and didn't want to do any nutrition stuff because she said she had never eaten a hamburger in her life, and she basically was convinced that we couldn't tell her anything about healthy eating and so didn't want to engage because she thought she knew better or that there was nothing that we could let her know that she didn't already know. (Phase 1 Programme Practitioner)

The disengaging impact of too little challenge was supported by a feedback comment from one participant: "It is mainly aimed at those with no gym or exercise background. I found it tedious and boring and it needs to be modified to make it more interesting for people who are already active and have good knowledge". Engagement was therefore posited to be enhanced (O) by differentiating activities (M resource) to provide optimal challenge (M response) and a personalised experience (M response). Practitioners identified the flexible use of outcome measures as an important context (C) to support the differentiation of activities, as some measures were more suitable for assessing the needs of participants in a group situation.

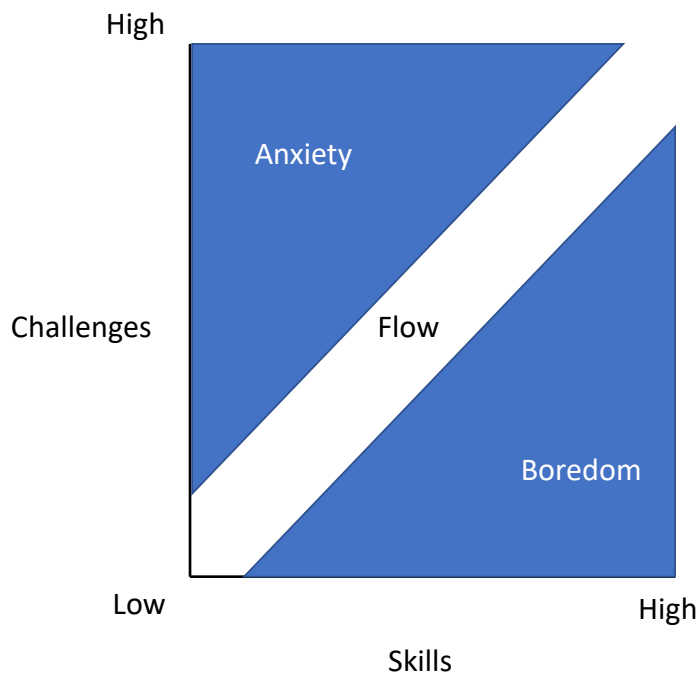
So, week one has always been really good because it is a learning experience for the individuals, it does allow us to look at the group and see what they're capable of. So, like step test, for example, not the best physiological test but is the easiest one we can run in the whole group and also it's a very good way of looking at what people are capable of, in terms of the physical nature of stepping up and their cardiovascular fitness and so it's always information for how we can then plan the group. (Phase 1 Programme Architect and Practitioner)

The impact of optimal challenge on engagement enhancement was supported further by other participant feedback comments. For example, “I believe it is well balanced considering the different levels of participants”, and “when an exercise was difficult to do instructors able to give variation on it so can still try it in another safe way”.

Numerous theories support the notion that challenge which is neither too low nor too high can support engagement (Csikszentmihalyi, 2002; Katz & Assor, 2007; Vygotsky, 1978). As an example, Figure 6.5 below illustrates the skill-demand balance depicted in Csikszentmihaly's (2002) flow theory. However, cognitive evaluation theory emphasises the requirement of a degree of felt autonomy for there to be a positive effect of optimal challenge on intrinsic motivation (R. M. Ryan & Deci, 2017), supporting the link between the current theory and choice described in Programme Theory One, section 6.4.

Figure 6.5

Csikszentmihalyi's Flow Theory (1990)



The differentiation of programme activities by level of challenge, personal interest and circumstances (M resource) were verified to impact engagement in Phase 2. Consistent with proposed theory, too high or too low challenge were confirmed as mechanisms of disengagement. Optimal challenge, both physically and intellectually seemed to be necessary to hold participants' interest and satisfy their need for competence and autonomy (M response) and therefore engage with the programme (O). A participant on one of the Leg Programmes stated, "I found the programme sufficiently interesting to stick at it for three weeks".

Reassurance and the management of expectations regarding the level of challenge on the programmes ameliorated the disengaging impact of concerns regarding inappropriate levels of challenge. This was particularly important for initial attendance on the programmes.

Don't forget, I've come with an injury, I'm really worried, I emailed in and said look if you don't want me here I understand that because you know I am going to be struggling. At the beginning of the programme I was about 3 weeks after I'd messed my knee up and therefore to be told "no, no come along" and I'm thinking "oh my god, what am I gonna be doing with these physical things" and again, right from the start, "either step back out of it" or I think yourself, you were suggesting other things that I could do that had similar things. Now you're tailoring that to the individual, wow, you know, where can we get that?

(Phase 2 Back Programme Participant H1)

An additional pertinent context, identified in Phase 2, for differentiating programme activities and making them appropriately challenging was the increasing level of complexity of participants' health needs (C). One practitioner explained that it was difficult to manage so many different needs in a single group, leading to a tendency to reduce the overall level of challenge for the group, to reduce risk of adverse events. The feeling of needing to 'play it safe' may contribute to some participants feeling unchallenged and bored, which was the case with one participant:

and I thought "oh god it's so boring this".....The only thing he did was doing your feet like, which I do every night anyway in bed. (Phase 2 Leg Programme Participant A1)

The admission of low engagement by this participant provided an empirical example of the measure of attendance being a poor indicator of engagement. This participant attended all available sessions and contributed verbally and actively during the sessions, demonstrating observable signs of engagement, yet did not feel engaged during the programme.

As discussed in Programme Theory 1, practitioner skill was also highlighted as necessary (C) for delivering flexible programmes that met individuals' needs. Further, in addition to assessing individuals' needs through outcome measures at the start of programmes, it was clear during observations that information regarding their needs was gathered continuously throughout the programmes and recognised as necessary by participants. For example, one of the Leg Programme participants stressed the "need to find out what each person in the group is like".

During interviews, practitioners recognised the role that students played in increasing capacity (C) to gather information about participants during the programme.

I think it basically just scales up the one-to-one approach obviously because generally we have quite a lot of students on the programmes. We try and go for one-to-one. So, if there are more patients, and obviously we would therefore have more students, and that kind of person-centredness hopefully shines through...In terms of the information that can be found from them, from the students, about the patients, the more patients are on the programme, that one to one ratio is really important. (Phase 2 Cancer Programme Practitioner)

Although there was some agreement that this information could be useful in differentiating activities for participants, practitioners emphasised the role it played in developing therapeutic alliance, which will be discussed in section 6.9: Programme Theory 6 Student Involvement.

The refined CMO-Cs for the programme theory of feedback and differentiation is presented in Table 6.2.

Table 6.2*Refined programme theory 2: Feedback and differentiation*

	Context	Mechanism	Outcome
CMO-C 1	Time capacity of practitioners to provide personal feedback – provided by student support and longer programme sessions. PROMs ability to capture participant experience of condition.	Feedback	Engagement
CMO-C 2	Practitioner skill in facilitating varied sessions. Practitioner communication about programme content. Flexibility of outcome measures to assess participants' capability in a group setting. Complexity and multi-morbidity of conditions. Staff capacity to gain information about participants' needs enhanced by student involvement.	Differentiated activities by interest and level of challenge.	Engagement

Programme theory 2 summary

Feedback and differentiation were proposed to enhance engagement in programmes in a way consistent with the pedagogical conceptualisation of feedback and differentiation. Through this pedagogical lens, feedback which is delivered in an autonomy-supportive way can support shifts in individuals' frame of reference through transformative learning. Feedback in this context also provides information for

practitioners to differentiate programme activities appropriately. Differentiation of activities by interest linked this programme theory to the previous theory of choice and variety and differentiating by capability helped participants participate with an optimal level of challenge. Both feedback and differentiation were verified to impact engagement in the ways proposed by this programme theory in Phase 2. Concerns were raised in Phase 1 regarding the negative impact of PROMs on engagement for individuals with a very poor prognosis for their condition, yet it was not possible to verify the impact of this context. However, the use of PROMs was identified as potentially disengaging if they did not capture individuals' experiences of their condition.

6.6 Programme theory 3: The role of the environment in engagement

Programme theory 3 sought to explain how the physical and emotional environments within which programmes were delivered could modulate engagement. Both the physical and emotional care environment are important considerations for supporting person-centred care (McCormack et al., 2021). Some of the H&W programmes, as outlined in Chapter 5, are delivered in the University Campus Sports Centre, which was theorised to support engagement with the programmes. The first initial CMO-C of this programme theory sought to explain how this physically non-medical environment supports engagement. In addition to the non-medical setting, the H&W team proposed that a positive emotional environment was an essential facilitating mechanism for engagement with programmes, which was theorised in two emotional environment CMO-Cs. The CMO-Cs of the physical non-medical environment and the positive emotional environment were expanded to include two CMO-Cs in each following verification and refinement during Phase 2.

CMO-C 1a Physical environment -

The Sports Centre at the University Campus had a practical role to play in the programme theory of choice (section 6.4, Programme Theory 1) as the campus facilities made it possible to offer participants a range of activities to try in a single location. During Phase 1 theory development, practitioners and stakeholders proposed that the University Sports Centre also contributed to engagement due to its non-medical environment.

But I think it's also the environment... I think a lot of our clients have kind of come in and said, it's nice to be in a non-clinical environment. It's like community environment where they come in, there are people playing sport, there are people having a coffee, you know, it's just, oh, this is normal life, as opposed to, oh, I've got an appointment at the hospital again, or I'm going to go and see my GP. (Phase 1 Stakeholder Partner)

The non-medical setting was postulated to enhance engagement (O) through a lack of associations with passive medical treatment (M resource), and being surrounded by healthy people as opposed to ill people (M resource). The University Sports Centre was viewed as a community setting and that it may contribute to individuals feeling less defined by their condition (M response). Detracting from perceptions of illness may be particularly important for those who have a poor and/or lengthy experience of traditional healthcare settings (C), or as identified in the literature reviewed in Chapter 3, those who have not yet accepted their condition or have negative feelings toward their diagnosis.

The findings from Phase 2 led to considerable refinement of this CMO-C. Although some participants agreed that a non-medical environment was a positive factor for

engagement (O), this was mostly attributed to the relaxed atmosphere in the University Campus Sports Centre (M resource), not often afforded in medical settings, allowing for social connection with other participants on the programme (M response). A participant on one of the Leg Programmes explained that when “you go to a doctor's waiting room you don't know what people have got or if they're suffering or whatever. So, you tend not to talk to anyone unless it's, you know, somebody's sat beside sort of thing” (Phase 2 Leg Programme Participant D1).

The value of the physical environment for offering opportunities for social connection and influencing the extent to which people can value and enjoy relationships is recognised as a key aspect of person-centred care (McCormack et al., 2021). The principle of the physical environment influencing possibilities for social interaction was also identified in the specific rooms in which programmes are delivered, and is discussed in CMOC-C1b in the next sub-section.

The benefits of a non-medical setting were also supported in Phase 2 by a disengaging aspect of one of the Leg Programmes delivered in a medical centre. An unpleasant waiting environment was observed in this location where there was less engagement with the programme; the ‘awful’ smell in an enclosed waiting area, with no one on reception was considered very off putting by a participant:

It's just that initial reception with nobody on the desk, no way of getting in.
When I first went I thought what's going on here? And the smell was awful
and I just thought god I could do without this. (Phase 2 Leg Programme
Participant G1)

Although the non-medical environment was verified to be positive for engagement to some degree, some participants found the University Campus setting a negative

influence on engagement (O). Some participants felt self-conscious in this setting (M resource), providing examples relating to feeling judged or simply not belonging (M response). A participant on the Back Programme explained that they “suffer with quite bad paranoia at certain times” and that during the Nordic walking activity they were “always looking around at students looking at us so I was thinking people were judging”. A Leg Programme participant felt judged because of her age: “They were all young, and they’re thinking ‘well what’s she doing in here?’ ‘What’s that old girl going in there for?’ you know?”.

Negative responses to the Campus Sports Centre were shaped by age and capability differences between participants and other people using the facilities, as well as participants’ existing experiences of anxiety (C). Humans have a basic need for belongingness, which is to be accepted by others, and can influence both emotional patterns and cognitive processes fundamental to motivation (Baumeister & Leary, 1995). Reception staff helped to alleviate some of the anxiety experienced by an elderly participant, by helping the participant feel known, addressing the need for a sense of ongoing relational interaction.

Any way this other lad, he was on the thing there [reception] he said “well, you’re trouble then aren’t you, chatting all the boys up”. Once he started doing that I interacted with him and every time he saw me “trouble’s coming” he’d go. You see what I mean? And that’s the way to make people feel relaxed. And if he saw me today he’d go “oh god, you’re not here” you know? He would, I know he would. I don’t even know him! It was nice to think that I walked into a building, somebody knew me, only by sight, and because of a simple [inter]action. (Phase 2 Leg Programme participant A1)

CMO-C1 b Sociopetal seating arrangements

In Phase 2, interview and observation data lead to the inclusion of seating arrangements conducive to open communication and social connection as a mechanism for engagement in this programme theory. Osmond (1957) introduced the concepts of sociopetality and sociofugality to describe physical environments which promote or hinder social interaction respectively. A participant on one of the Leg Programmes highlighted that the room in which the programme was delivered was not optimal for facilitating discussion and connection:

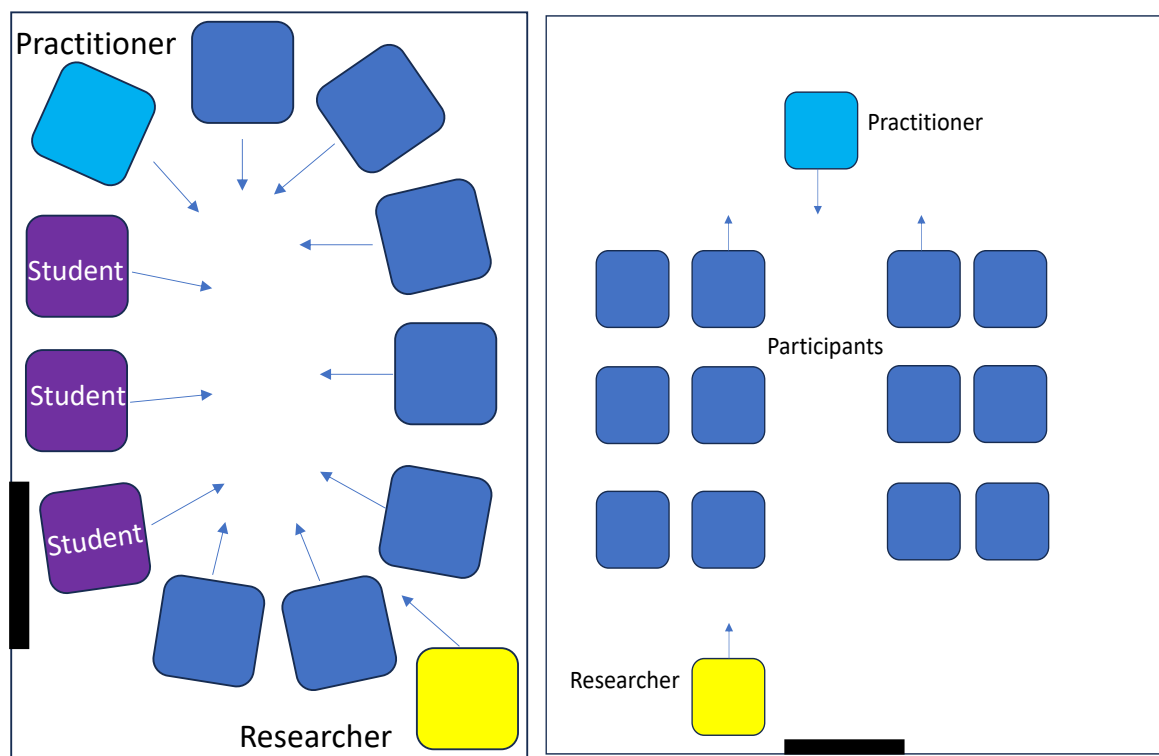
I don't think the prayer room is ideal. It's not set up to be intimate. You know, in any sort of way. It would be better done in a sort of café, you know, sitting round in the circle with a cup of coffee, but obviously you couldn't do in a public coffee, in a public cafe. The Chapel wasn't ideal in my opinion....

because it was set up like a lecture. (Phase 2 Leg Programme Participant D1)

During participant observations participants were seen to communicate with each other more easily and frequently (M response) if they were sat closer together and angled toward each other (M resources), leading to better engagement (O), as was the case in the Back Programme (Figure 6.6). In some instances, practitioners were constrained by room size and by multi-use rooms (C) and therefore not able to rearrange the room to make use of this mechanism, for example as was the case in The Chapel room in Hilford (pseudonym). In some programme locations, ten to fifteen minutes were needed at the start and end of each block of programmes to move medical equipment out of the way, which was a frustration for practitioners who were busy and time-constrained (C).

Figure 6.6

Typical seating configuration in the Back Programme (Left) compared with typical seating configuration in Hilford (Right)



CMO-C 2a Emotional environment – fun and humour

During theory development, programme architects and practitioners emphasised the importance of fostering a positive emotional environment to support engagement. The programmes were described as fun and enjoyable by programme staff and participants alike. Play and humour (M resource) were proposed as mechanisms for creating an enjoyable atmosphere to connect with others (M response) and enhancing engagement (O). Relatedness may be stimulated through fun and humour by creating social closeness through fostering harmony, collegiality, and trust (Scharp et al., 2022), as illustrated by a programme architect, "...they're quite fun. You know.... they're not approached in a serious sort of way. As a consequence, people tend to be quite friendly and quite open. The value of fun was also evident in participant feedback:

“Overall it's been fun informative and very helpful which has led to me being able to keep a positive attitude and realise that I don't have to push myself to the limit every time I exercise.”

The involvement of students in the delivery of programmes was proposed to support the fun and enjoyable atmosphere (C).

Yeah, it was all lads that were involved, and they just really brought some fun to the clinics. And I thought, professionally maybe that's not the right thing to say? But I think it helped the patients a lot, to have that level of fun and excitement that they brought. And obviously they were professional and they were helpful in those respects as well but I just saw that they made the clinics really enjoyable and fun. (Phase 1 Student Practitioner)

Practitioners, participants and students all alluded to the caveat that a level of professionalism was also important in creating an optimum environment by preventing an unprofessional and non-therapeutic setting (C). For example, a participant appreciated being “within a sports centre with a group of people” and “felt it was very supportive and friendly, and professional too”. (Phase 1 Programme Participant feedback)

The balance between a fun and relaxed environment, and professionalism was confirmed to have a positive impact on engagement during theory testing in Phase 2. During an observation of the Back Programme a participant commented on the balance between a relaxed (M resource) yet professional atmosphere (C) contributing to the perception of a positive atmosphere (M response), corroborating the proposition that professionalism is necessary for a relaxed environment to enhance engagement (O).

H1 commented that programme was “relaxed, but not pointless”. I felt they were referring to the fact that there was still professional direction and guidance, which H1 has commented on before. (Phase 2 Back Programme field note)

The use of humour and the relaxed atmosphere was verified to support the process of connecting with others on the programme.

I wouldn't say any of us are in the same boat, everyone is very different, but all positive, trying to do something about it, quite open, and more than happy to laugh about the condition that we call humanity, and I think that's really been nice actually, people are just sort of happy to engage with others and you know throw-away comments and be part of what's going on. And not feel constrained by anything. (Phase 2 Back Programme Participant H1)

Practitioners were deliberate in their use of humour to support engagement:

So, like I'm always, my delivery style is quite informal, definitely, and we always try and have a laugh and a bit of a joke and take things to the line, but not over the line with jokes to try and make people feel more comfortable. (Phase 2 Cancer Programme Practitioner)

One student highlighted that being a student may be what makes it possible for them to be more relaxed during interactions due to a reduced expectation on them to act as the lead professional (C).

I thought, I might not have been the most professional sometimes but I managed to have conversations, made jokes that probably made them feel a bit more easy and a bit more laid back, I think that's sort of quite crucial in

building up a rapport..... I feel like as a student maybe you can get away with that more, have a laugh about that, whereas somebody like Simon leading on it maybe not got away with it but having someone a bit more laid back and there more to observe sort of gives you a bit more options to sort of build more rapport and make them more comfortable. (Phase 2 Back Programme Student Practitioner)

The context of the practitioner's ability to manage a positive atmosphere (C) was theorised in phase 1 from participant feedback:

I hate to say it but people need to stop moaning about their backs. It is a given that everyone attending has varying degrees of pain but I feel that there needs to be some jointly agreed ground rules at the beginning of the program. Talking about backpain feels fine but sometimes it can feel too central. (Phase 1 Programme Participant feedback)

Practitioners were perceived to play an important role by balancing giving participants a voice and opportunity to share their stories whilst maintaining an overall positive mood. A focus on negative experiences may be more disengaging for people who do not want to associate themselves with a condition (C), which was highlighted as a barrier to engaging with programmes in the literature review, Chapter 3.

The practitioner role in balancing the mood of the programme was supported in Phase 2, with one participant highlighting the lack of dwelling on things yet allowing individuals to share their stories: "I think probably the pace of it was really quite well-measured, so we weren't dwelling on anything and people were then able to talk" (Phase 2 Back Programme Participant H6).

CMO-C 2b Emotional environment - psychological safety

When discussing the emotional environment in Phase 2 interviews, participants described a lack of judgement as an important aspect of the programmes, particularly for those who had previously felt judged in other situations, which led to the generation of an additional CMO-C within this programme theory.

Because I think sometimes society makes it feel like oh you've gone out to work one day, you've done your garden, you've done your shopping, you just woke up the next morning and thought "you know what, I can't be bothered with life anymore" when that's not how it goes. But I think society and medical professions have got this way of making us feel like we've chosen this and I find that really frustrating. (Phase 2 Back Programme Participant H4)

The psychological safety created by a lack of judgement (M resource) was important in satisfying needs for relatedness (M response) to enable engagement with others and the programme (O), particularly for a participant with mental health challenges (C).

And here, I've said, like I went round the first time and like describing your injuries to people and I've had a car accident and stuff like that and you're thinking jee-whizz and obviously when I said I'd broken my back people were like "woah". And it's like no-one really questions it, it's almost like an acceptance straight away and you carry on. And it was really, that comforting thing is huge, especially for people like me, I suffer with quite bad mental health so to be in an environment, especially a new environment and to link that quickly is quite strange. (Phase 2 Back Programme Participant H6)

Psychological safety refers to the perception of the lack of negative consequences of taking interpersonal risks in a given context and has been shown to improve engagement in workplace settings (Edmondson & Lei, 2014) and enhance learning in educational settings (Torralba et al., 2020). In the case of the H&W programmes, participants felt free from anticipated consequences of being judged. In healthcare settings, psychological safety has been highlighted as being important in effective collaboration and communication between healthcare professionals and patients for shared-decision making (Fukami, 2023).

Participants felt that the non-judgemental environment was partly achieved by the time taken by practitioners to listen (C).

So, the teachers and the students, every individual just gave you that time, that space and there was no judgement, so you sit back and you think everybody's of the understanding that we're all hurting as much as each other. (Phase 2 Back Programme Participant H6)

Participants remarked that this time is not always afforded in healthcare interactions.

You know, it was nice. I think we all felt secure coming here and being able to talk about how we felt and what we felt because I think you all made us feel like we're able to do that. Because again it's not like going to your GP or somewhere else where you've only got 5 or 10 minutes and you know, you're feeling rushed out because they wanna get onto the next person. (Phase 2 Back Programme Participant H4)

One participant recognised that many health professionals are constrained by time and rigid guidelines (C), preventing this opportunity for listening, whereas the flexibility

of programmes described in Programme Theory 1 (section 6.4) made listening possible.

If I can be fair most of the people I've met through a medical setting have been absolutely first class people trying to do an impossible job. Where we were talking about earlier about being able to be flexible within the programme I don't think that flexibility is there, they're held with various different guidelines, the guidelines say you've got this there and you ought to be pushing them onto statins, you ought to be doing this, you ought to be doing that, they're working within very very close guidelines and when you actually say stop, I want to know a bit more about this or whatever, time is very quickly up. I'm struck by an occasion where I went and they were happy to talk to me about one of the issues but the whole thought of interconnectivity was beyond because it couldn't fit into their box, and I was quite sore about that. It's a long time but I'm still talking about it. (Phase 2 Back Programme Participant H1)

Practitioners on all programmes were observed taking the individuals' internal frame of reference (R. M. Ryan & Deci, 2017) when conversing with participants and demonstrating an attitude of unconditional positive regard (Wilkins, 2000), creating an autonomy-supportive environment. Practitioners and students also shared some of their own experiences in a way that conveyed understanding rather than superiority (M resource), which appeared to encourage participants to feel safe when sharing (M response).

The refined CMO-Cs for the programme theory of environment are presented in Table 6.3.

Table 6.3*Refined programme theory 3: Environment*

	Context	Mechanism	Outcome
CMO-C 1a	Location building layout	Pleasant non-medical physical environment to allow relaxed communication with others.	Engagement
CMO-C 1b	Multi-purpose rooms	Sociopetal seating to allow natural conversation and reduce power-imbalance	Engagement
CMO-C 2 a	Level of professionalism and purpose for the programmes. Student involvement. Practitioner skill in balancing mood. People with negative feelings toward their condition	Fun and enjoyable environment to support building rapport.	Engagement
CMO-C 2b	Poor mental health, previous experience of being judged in healthcare settings and in society. Time and space (PT4) in programmes for practitioners to listen.	Emotionally safe environment to share experiences	Engagement

Programme theory 3 summary

The initial programme theory of environment was broadly developed as three CMO-Cs, one relating to the physical non-medical environment and two relating to the emotional environment. Following Phase 2 the physical environment CMO-C was refined to capture the opportunities for social interaction being the key generative mechanism at play, and a further CMO-C was added to explain how the room layout where programmes were delivered could support social interaction and engagement. The emotional environment CMO-C was confirmed through testing and a further CMO-C was developed. The additional CMO-C explained the necessity of not just a positive and fun environment, but a psychologically safe, non-judgemental environment for engagement.

6.7 Programme theory 4: The role of time and space in engagement

Programme theory 4 provided an explanatory account of how informal space and time play a role in supporting engagement with group-based self-management programmes. Both programme duration and non-practitioner-led moments during programmes were identified as potential mechanisms for engagement. Informal opportunities for participants to interact with each other were viewed to support relatedness (CMO-C1) and the duration of programmes was considered important in supporting the development of both relationships and mastery of activities (CMO-C2), supporting needs of relatedness and competence respectively.

CMO-C 1 Informal space

During theory development interviews, programme practitioners and architects used the term “space” to describe some aspects of the programme that facilitated

engagement. The conceptualisation of space focused around informal and less structured time points within the programmes (M resource) where participants could converse more socially, satisfying needs for relatedness (M response), therefore enhancing engagement (O).

Programme architects and practitioners described the facilitation of catch-up sessions at the start of sessions to allow social connection through catch-up chats. More informal space was also intentionally incorporated into programme activities, such as during walking, providing opportunities for participants to chat to one another, and with the students.

I think they feel valued. I think it's a value thing, isn't it? Like OK, you want to hear? You want to listen to my story and my challenges, they'll all try and tell you their story. And there's space in the programme I designed for that to happen multiple times through the session. So, they chatted at the start, they're together or separately, it was all about hearing and listening and sharing among things we knew were going to be therapeutically beneficial, like walking or flexing particular muscle groups we knew were always likely to be tight for people with that kind of pain. (Phase 1 Programme Architect)

Informal space was not always planned but identified and valued in other moments during the programme and subsequently allowed to remain as part of the programme. Allowing informal space in the programmes appeared to rely on practitioners' willingness to relinquish control over this aspect of programme delivery due to valuing it as a programme asset (C).

And then I used to feel bad that there'd be three people over there not doing anything and like the timing of all the assessments leaves someone sat there

and twiddling their thumbs but actually over the years we realised that that space was part of the process. So, they'd be sat next to someone. So, I'd look over and I'd be doing something over there and you look over and you'd see a couple of people just chatting. So, it's not forced or encouraged, sorry forced, but that space is part of the programme. So, we stopped feeling bad about.

We didn't build it in but it was ok to have space. (Phase 1 Programme Architect and Practitioner)

The informal space was also considered to be an opportunity for participants to converse about topics unrelated to their condition, which may be another mechanism particularly important for those who have negative feelings toward their diagnosis (C) (see Programme Theories 1 and 3).

And that's why walking is really good, that's why any of the exercises are good and again, I talked about this space that I was thinking about that particular testing week, but even throughout all the weeks, definitely just about giving people space so that's why the walk is, you know, we're gonna walk up there and that's it but I can turn around and I can see people just chatting away about stuff and sometimes I give them something to talk about but often I won't but we're getting from one place to the next but you actually just listening. And I know that there are some of them aren't even talking about their backs sometimes or their condition but that's obviously a good thing because they're spending time not being defined by it. (Phase 1 Programme Architect and Practitioner)

The opportunities for conversing with others was identified as a valuable part of the programmes in participant feedback both for social connection as well as sharing

experiences and solutions relating to their health conditions: “My group was good fun. Lots of chattering and useful to hear other people's health worries/solutions”. (Phase 1 Programme Participant feedback)

Data from Phase 2 verified the role of informal space in engagement and supported the refinement of this CMO-C by revealing additional contexts shaping the opportunities for informal opportunities for social connection. The Back and Cancer Programmes were observed to incorporate informal space within programme activities themselves (M resource), for example, during walks outside around the University Campus; during the collection of baseline and post-programme outcome measures; and in the Back Programme there were designated experience sharing sessions each week (M resource). Sharing in these short ‘catch-up’ activities, in many instances, involved talking in groups of three or four as students supported the programme. These smaller group talks, and referring to the sessions as a ‘catch-up’, seemed to provide a more informal and relaxed atmosphere for talking compared with talking in a larger group and taking turns (C). These more intimate conversations were confirmed as being important for engagement (O).

Interviewer: We think that those kind of informal chats are really important to help you to comfortably connect with other people, do you think that’s an important part of the programme? The space bits I mean.

Yeah, ‘cause I mean, that’s what it did, that’s why I came every week, because I felt connected with the other people. (Phase 2 Back Programme Participant H4)

Informal space was scarce during the Leg Programme sessions, where engagement was also lower overall (O). Less informal space appeared to be due to the amount of

content practitioners needed to deliver in the four weeks available to them (C). However, on the few occasions across programmes, when the practitioner momentarily left the room, conversations were quickly struck between participants and students. One participant highlighted one of these conversation opportunities (M resources) as a moment that he connected briefly with another participant (M response), who otherwise did not speak with others in the group.

Funny enough, I mean, I did feel a certain connection with yeah, even with D2 because his wife was talking about putting the stockings on and getting swollen feet at the, swollen toes at the end and I was just able to say, listen, that's what happens when I put them on too. (Phase 2 Leg Programme Participant D3)

Informal space was also identified in some of the waiting areas but these opportunities were dependent on a pleasant environment (C) as discussed in Programme Theory 3: Environment (section 6.6).

Participants who reported anxiety and discomfort in group-situations (C) who engaged with the programme agreed that space for informal conversation was important for connecting with practitioners and other participants. Some participants compared this experience with another programme they had attended where there was a lack of space to connect, further supporting this theory.

The context of long health journey narratives (C) was added to the programme theory as one participant highlighted the informal space and time needed to share this information with the practitioners and participants, without dominating wider group conversations.

This is where my anxiety comes in, it's not easy to open up and talk sometimes about yourself, you know, it's not just one thing that's happened, there is an accumulation and a combination of things that have gone on over the decades to get to this very place. So, when there's a big group, you can't just be the only one going right hang on let me explain from so many years ago this all started and where I got to now, you know? (Phase 2 Back Programme Participant H4)

CMO-C 2 Programme length

During informal discussions and interviews with practitioners in Phase 1, it was posited that programme duration was important for engagement with some practitioners expressing frustration at external pressures to shorten programmes (C). Practitioners argued that although content may feasibly be condensed into fewer sessions, it takes time (M resources) for participants to connect with practitioners and each other (M response), which is necessary for relatedness and developing therapeutic alliance in engagement (Bright et al., 2015; Higgins et al., 2017).

I think the more people attend it, it's just like anything isn't it, the more you get to know somebody, the more comfortable you feel with them. So, I think as you go on you notice an increase in the level of engagement in terms of people's level of comfort, so I think that's probably an important point. (Phase 1 Programme Practitioner)

The value of time for connecting with others was supported by participant feedback, but also as necessary for developing confidence and mastery, satisfying needs of competence (M response). Feedback included suggestions to make the programmes longer "as it takes a few weeks for the group to gel" and so that participants could

“practice what we have been shown and learnt”. (Phase 1 Programme Participant feedback)

Data from interviews and observations in Phase 2 verified the importance of programme length and contributed to the refinement of this CMO-C. Participants specifically valued the way that relationships built up over time and stressed the importance of practitioner continuity (C) and building an understanding of participants.

I think continuity is hugely important in all of these things, it comes back to that open moaning session about the NHS we had. But that, yes continuity, continuity of care in terms of making you feel like an individual I think is really, really important. If you go along and this week your counsellor is, I haven't gone for counselling but I know a lot of my family have, and this week I got so and so, and this week I got so and so, and this week and the second week they've only been drafted in with 20 minutes time so you're back to square one and they've taken a different line on this completely and then, so you're not getting that level of relationship and understanding and the feeling that there's actually someone there who's looking out for you, someone who will actually put their hand up and say yeah, that's my responsibility, I'll do it....

[referring to the Back Programme]...we'll have a conversation, you know how's your week been, how's this and oh I remember last week you were, you know. People are then acknowledging each other's worth almost. And you felt, oh someone actually took notice of what I said last week, and you say something back and hopefully they're feeling the same sort of acknowledgement of being human. You can look at it as being engaged but

actually making you feel like you've got some sort of importance and that you are a human being. (Phase 2 Back Programme Participant H1)

Practitioners also valued consistent opportunities to work with participants and build relationships over time. One practitioner reflected on their engagement lowering when a participant did not attend some of the sessions: "...when he came back, he almost like, was needing catching up. If you like, not on content, within relationships and connections and all those things" (Phase 2 Back Programme Practitioner).

The refined CMO-Cs for the programme theory of space and time are presented in Table 6.4.

Table 6.4

Refined programme theory 4: Space and time

	Context	Mechanism	Outcome
CMO-C 1	Discomfort in group situations. Anxiety. Long health journey. Pressure to deliver programmes in fewer sessions due to long waiting lists and cost-saving pressures. Environment in waiting areas (PT3).	Informal space for participants to share experiences openly.	Engagement Positive emotional environment (PT3)

CMO-C 2	Key performance indicators of funding organisation based on number of participants attending programmes; long waiting lists. Continuity of practitioners and participants.	Length of programme.	Engagement
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Programme theory 4 summary

The two CMO-Cs initially developed for this programme theory were explanatory theories of how informal space, and programme duration could support engagement. The two CMO-Cs were verified during testing and refined with the addition of contexts of external pressures to shorten programmes, and the need for practitioner continuity. The informal space featured in this theory was also confirmed to be inter-related with the positive emotional environment discussed in section 6.6.

6.8 Programme theory 5: The role of aligning needs

Programme theory 5 explains how participants may be supported in aligning what programmes have to offer with their personal needs. Aligning needs was deemed to play a continuous role in supporting engagement throughout programmes as part of differentiation, which was discussed in Programme Theory 2 in section 6.5. This programme specifically details how helping individuals to understand how programmes can meet their needs may help with the earliest points along the engagement pathway: referral, and programme arrival.

CMO-C 1 Referral

During phase 1, practitioners reported that engagement with programmes could be improved if participants had a better understanding of the programmes and a consistent message from healthcare practitioners about their aims and benefits (M resource) prior to their attendance on the programmes. An increased understanding of programmes was perceived to help individuals identify how programme participation could meet their needs (M response) and alleviate concerns about attending (M response) resulting in improved initial engagement (O). Understanding how a programme could align with individuals' needs may be especially important for those who have felt passed around in the health system (C). The referring practitioner's understanding of the programme and the participant's needs (C) were considered necessary to mobilise the mechanism of aligning needs.

I think for the participants, they come in, they're intimidated, they're scared, they come to an environment like this, it takes a couple of weeks before they get that like "oh this is what this is". So, the priming does two things: one it shows that health professionals are all on a similar wavelength. It starts the patient activation earlier, that narrative around "you can actually do something about your pain". I'm conscious I'm talking about pain a lot, I don't know if cancer clinics and those things would be different. It shows the participant that the wider health professionals value self-management, which I don't think that comes across at all, ever. But also get them thinking "ok this is what's gonna be. I'm not going to be running on a treadmill, I'm not gonna be given some sort of prescription, this is about me trying to learn about myself and take control back and someone's going to guide me towards that". (Phase 1 Programme Practitioner)

During theory development, practitioners described different referral pathways to the H&W programmes (C), as is reflected in the engagement pathway framework (Nobles et al., 2018). For example, referral to the Leg Programme had originally been opt-in. Following poor uptake of the service, the programme became a part of the care package for lower limb care, and the referral process was changed from opt-in to opt-out. Although practitioners reported that initial attendance had improved, some participants did not appear to have a clear understanding of why they had been referred.

And partly it's because they are invited to us as part of a service that is opt in now [corrected to] opt out now so they, sometimes we get people who don't really know why they're coming to see us, and so we do try and emphasize, at least at the very start, but through all the sessions, you know, the benefit of and why we're doing what we're doing. You know, "we're asking you to do this, and this is what you'll get if you do it", so that seems to help with some people's engagement. You know, when you spell out to them like we can help you not have to rely on your stick quite so much we can help you get out of a chair more easily. We can help get you out of these compression bandages and into stockings that are easier to manage, if you're able to do some of these things that we talked about. (Phase 1 Programme Practitioner)

Practitioners highlighted that passive automatic referral alone was not sufficient to improve engagement with the programmes. Practitioners proposed that a discussion with a HCP could help participants understand how the programme could meet their needs (M resource) and enhance their intrinsic motivation to attend (M response) and improve engagement (O).

GP or practitioner will say “I’m gonna refer you to this thing” so they sell it because the person has to agree to it, not just in their conversation to get the referral but to actually turn up. They have to wanna do it, so they have to be sold it. (Phase 1 Programme Practitioner)

The alignment of programme offers to individuals’ needs was thought to be particularly important in avoiding “pseudo-engagement” where individuals may not feel they have a choice in attending, for example, because it is a requirement of receiving financial support (Bright et al., 2015). A lack of autonomy in this case may thwart the development of intrinsic motivation.

We’ve had people who just been told they’ve got to go or they think that they’ve got to go because of their job-seekers type thing, that they’ve got to show they’re in treatment and that allows them to still not work, we’ve had a few of those over the years and they sometimes stand out a little bit as unenthusiastic but they are just one example of one profile or multiple profiles of people that we get. But it’s not necessarily down to the referral, it’s just down to people. (Phase 1 Programme Practitioner)

It was theorised that a clearer understanding of how programmes may align with individuals’ needs beyond external motivations (M resource) may improve engagement (O) through enhanced autonomy and increase motivation (M response). Individuals may be motivated by a combination of external regulation and intrinsic motivation, but it is the overall level of relative autonomy which can support engagement outcomes, according to SDT (R. M. Ryan & Deci, 2020).

Phase 2 data supported this programme theory of aligning needs to improve engagement. The theory was further refined by identifying how participants engaged with programmes without the support of referring practitioners in the process of aligning needs. Participants with prior beliefs about the benefits of increased knowledge for successfully managing their conditions (C) were able to identify the alignment of the programme to their needs with little external input.

I've felt that since parts of the NHS are falling to bits and this part seems to be working quite well, it was right to give it a go at least. I think the other reason I was interested in, why I attended the course, was that I think it's something the NHS should do more of. Educating people in possible causes of their problem. How the problems manifest themselves. And why you're being advised to do what you're being advised to do. (Phase 2 Leg Programme Participant D1)

Many of the participants reported little information being provided about the programmes, particularly those attending the Leg Programmes, where referral was an opt-out process. Most participants agreed that an opportunity to discuss the programme prior to attending (M resource) would have been helpful for engagement (O). One participant in particular, who did not engage as well with the programme, reflected on this lack of opportunity.

Nope, all I got was a little sheet, a little leaflet. Basically, you gotta work out what it was all about, you know. I would have liked a bit more information...because then I could interact with that person who was telling me and we could have a nice little bit of convo and I could get to the bottom of it personally. But no, they just scrape the surface... I wanna know what

percific things about what I've got wrong with me. (Phase 2 Leg Programme Participant A1)

This participant highlighted the context of her advanced age and frequent use of health services and that it felt as though some healthcare practitioners assumed that she either already knew or could not comprehend what was happening (C).

And I thought "this is a bit different" [referring to doppler] but they didn't explain exactly what it was all about, I had to ask. I shouldn't have to ask. I need someone to say "right my dear, now this is what we're gonna do bla bla bla". And I know it's all day long they're doing it but I'm a new person and I don't know what they're gonna do...I mean, some people at my age, they're a bit dinny [slang for foolish] aren't they? You know what I mean?

Interviewer: So, do you think people then assume that you're a bit dinny?

Oh yeah definitely. (Phase 2 Leg Programme Participant A1)

When describing experiences of referral on to the programmes, some participants discussed the trust they had in the practitioner who encouraged them to attend. A particular, highly regarded, nurse was named on a few occasions who had conveyed their understanding of the programme to the participants, which included positive feedback from other participants. One participant explained that this helped them feel that they were not alone and encouraged them to attend.

The nurses did, certainly. The doctor didn't mention it so much. But that could be because they weren't aware of the system. ... it was put to me basically that this was part of my treatment rather than you can go if you want to sort of thing. Although it was voluntary, that they did say it was voluntary, they just

said “go along, we've had good feedback from people who have attended” so that’s why I went. (Phase 2 Leg Programme participant D3)

This corroborated the theory that the referring practitioner’s knowledge of the programme and how it might align with participants’ needs (C) is an important context to support these pre-attendance conversations. The regular contact that nurses working in the leg wound service have with participants attending the Leg Programmes (C) may help them gain not just an understanding of the programme activities and aims but relatable feedback (M resource) which they can relay to participants being referred to the programmes.

CMO-C 2 Early conversations

Practitioners described ways in which they sought to mitigate pseudo-engagement during the first session of the programmes, in instances where individuals had not received satisfactory information about the programmes. Individuals have varied experiences of their condition and the care pathway (C). Conversations with participants early in the programme to understand these experiences and their needs (M resource) were deemed to allow practitioners to manage participant expectations and align the programme’s offers with their needs (M response), enhancing engagement and avoiding pseudo-engagement (O).

Yes, so this was our first session, met them, found out a little about their pain.

What they wanted to get from it, kind of coproducing it I suppose, in terms of shaping it and then gave them an idea of how this differs. (Phase 1

Programme Practitioner)

Phase 2 data supported that early impressions about whether the programmes would meet individuals' needs were important for engagement. Practitioners on the programmes took time to listen to participants at the start of the programme and then framed activities and information in the context of how it would support each person with their individual goals and circumstances, taking individuals' frame of reference, which is key to autonomy-supportive practices in SDT (R. M. Ryan & Deci, 2020). When this was done more frequently and consistently, participants appeared more engaged during the sessions. Participants provided examples of this mechanism during interviews, highlighting that practitioner skill was necessary (C) to communicate how programme activities aligned to their needs.

He was so skilled at pinpointing different pieces of information and putting them together week on week so that he was building that individual programme for people. And everyone, went right this is particularly, from what you've told me. How he's memorised everyone's sort of backgrounds and things, hats off to him, I think an absolutely sterling job in doing that so he has made, by referring it to the individual, very personal to everyone I think. And that's quite a skill. (Phase 2 Back Programme Participant H1)

The refined CMO-Cs for the programme theory of alignments of needs are presented in Table 6.5.

Table 6.5

Refined programme theory 5: Alignment of needs

Context	Mechanism	Outcome
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CMO-C 1	Referring practitioner knowledge of programme and participants' experiences of programmes. Participant relationship with referring practitioner. Participant beliefs about personal responsibility for health.	Pre-enrolment alignment of programme and individuals' needs which includes feedback from other participants.	Engagement
CMO-C 2	Time to listen to participants and practitioner skill in linking programme content to participants' needs.	Early and continuous conversation in programmes about participant needs and how programmes may meet these needs.	Engagement

Programme theory 5 summary

Programme theory 5 explained how participants can be supported in developing greater internal motivation to engage with programmes by actively helping them identify how programmes meet their individual needs. The initial CMO-Cs explained this process at the referral and first attendance points of the engagement pathway. The role of the alignment of needs at these points were verified in Phase 2. The referring practitioner's use of relatable feedback from individuals who had previously attended programmes was added to the mechanism resource in the referral CMO-C, shaped by the additional context of the referring practitioners' therapeutic alliance with service users. The practitioner's skill in communicating this information was also added as a necessary context. Finally, the context of participants' beliefs about taking

responsibility for their health mitigating a lack of alignment of needs conversations was added to this programme theory.

6.9 Programme theory 6: Student Involvement

A unique aspect of the H&W self-management programmes is the active involvement of students in their delivery. Students contribute to the provision of some of the mechanism resources presented in the programme theories so far. For example, students contribute to feedback and differentiation (section 6.5) by increasing the capacity to provide one-to-one feedback and to gather information about participants' individual needs; and to the emotional environment (section 6.6) by contributing to a fun and relaxed atmosphere. In addition to these contributions, students were identified to play a specific role in supporting needs for relatedness through their established role as learners, as opposed to experienced practitioners, and a resulting reduction in power-differentials. Distinct mechanisms for reducing power-differentials in this programme theory were shared vulnerability, genuine learning, and reciprocity. Non-dominant, non-hierarchical relationships are key tenets of person-centre care (McCormack et al., 2021) and students were viewed as key in creating an authentic knowledge-sharing environment. The equitable and fair sharing of knowledge supports individuals' empowerment through a change in power-relations (Pulvirenti et al., 2014). Engagement can be seen as both a pre-cursor to and consequence of empowerment as participants need to engage to increase their power in relationships with HCPs and require sufficient power to engage with self-management (Fumagalli et al., 2015). The following CMO-Cs provide nuanced explanations for how students support the reduction of power-differentials in group-based self-management

programmes. Of the three CMO-Cs initially proposed, only two were verified. The CMO-C which was not verified has been labelled CMO-C 0 accordingly.

CMO-C 0 Shared vulnerability

During Phase 1, practitioners explained that students often began their placements with little confidence, in part due to the unfamiliar environment. Some practitioners described or alluded to an idea of shared vulnerability (M resource) between students and participants which also contributed to a reduction in power differentials (M response) and enhanced participant engagement (O). The fact that the programmes are still led and overseen by experts may allow students and participants to benefit from this shared vulnerability whilst maintaining trust in the programme (C). However, this was not verified in programme testing.

CMO-C 1 Genuine learning

Phase 1 interviews set the scene of the co-delivery of H&W programmes by practitioners and students (C). Students' involvement in the programmes has been shown to provide a real-world learning opportunity, with an essential source of learning being from the participants themselves (Cotton et al., 2024). The Student-Led Knowledge Exchange (SLKE) Project, described previously in Chapter 2, elucidated the value students placed on learning directly from participants (C). This genuine desire to learn from participants was theorised to be an important context to help students treat participants as experts to learn from (M resource), reducing the power differential in their relationship to enhance relatedness (M response) and enhancing engagement (O).

Since starting my time on placement in clinic, I have managed to accumulate 100 Hours of real-life experience across a wide range of patient types. I

particularly find it a lot better to work through experience practically opposed to just lecture driven. Being able to relate to a patient has provided value to my experiences so far. At a time where I have worked through a rehab technique or a particular pathology and have found it extremely valuable and it has helped to provide me with the necessary skills to execute whatever it is I am doing. I think having all the knowledge in the world is all well and good but not being to execute this, by having practical experience is really important. I think learning communication skills and building up a rapport with the patient has helped me to build confidence. It is difficult to replicate this kind of practice and skillset, outside of practical experience, and something I have noticed I have improved on in my short time within the clinic(s). (Phase 1 SKLE Student)

During Phase 2 observations, students appeared genuinely interested in learning from programme participants. Students and participants appeared engrossed in conversation and demonstrated active listening. One student verified their genuine interest during an interview, saying that, “some things that they told us we were like “oh that’s really helpful, I’ll go research into that a little bit more” or they’d explain to us their journey with it or how they got it and things like that”.

Some participants felt that students contributed to the relaxed environment just by joining in with chatting, sharing experiences and supporting activities, and that they were more like fellow participants on the programme.

... we had a discussion in every session about how our weeks have gone and then we’re sat there with the students, it was great, you know, like you’re coming in talking to a mate, type thing. And then they join but you don’t see

them as a student, you see them as like someone else who's going through what you're going through. So, you don't have to separate them, they're part of it. It's a comfort thing, it's a really quite comforting environment when everybody's joining in. (Phase 2 Back Programme Participant H6)

Participants' view of students as peers supported the proposition of a reduced power differential mechanism to help relatedness but also illuminated the students' role in the emotional environment, as discussed in Programme Theory 4. Students' contribution to enhanced relatedness was contingent on how they were involved in the programme (C). When practitioners encouraged students to introduce themselves and share what they hoped to gain from the programmes, participants seemed to easily connect with them by having conversations about the students' interests as well as their own experiences.

Even letting them talk, like obviously, like you'll be chatting and one of the students will join in with actually "in my life this is what's going on as well" and you think actually you're a human as well and it's good that you're interacting, you know because then you've come part of it, you become part of that little journey type thing, you're not sat back being a viewer, you're becoming part of this little journey that we've just had. (Phase 2 Back Programme Participant H1)

During the Leg Programmes, when there was less time for introductions, students had an observing rather than interactive role, which one participant explained could make them feel judged.

You don't want everybody sat behind you, listening to a conversation, you're thinking, what are they doing? Are they taking notes? Are they recording this?

Are they doing it for their own purpose? Are they listening or are they thinking that they're going to another meeting at some point? But then instead of that they're sat next to you and they're going, I understand where you're coming from there.... it doesn't make you feel that they're like almost judgemental or not joining in. They're there, it's complete. (Phase 2 Back Programme Participant H6)

CMO-C 2 Reciprocity

During Phase 1, practitioners explained that programme participants were generally aware that the additional practitioners on programmes were students and that the programmes were an important learning opportunity for them (C). Some participants enjoyed contributing to students' education and the students gained satisfaction from helping participants as part of their education, which created a mutual sense of reciprocity (M resource), which was thought to contribute to the reduction of power differentials in their relationship (M response). This reciprocity was thought to enhance both student and participant engagement (O) through enhances relatedness.

And, quite frankly, they can't they couldn't be run without the students. And I don't think it would be as successful without the students either, because normally, my experience kind of tells me that a lot of the people who come on to the clinics, buy into the fact that there are students there and feel as though they need to support the students. (Phase 1 Programme Architect – SKLE data)

During Phase 2, some participants confirmed that supporting students in their learning contributed to their engagement with the programmes.

Well, the thing is I'm interested anyway, 'cause don't forget, I've got a family and I've got grand-children...and I wanna know what this world is gonna be coming to, you know when I'm not here. I wanna know if they're gonna follow careers like some of these people are now. (Phase 2 Leg Programme Participant A1)

However, one participant considered contributing to students' education as a bonus rather than a key mechanism for engagement, saying that "It hadn't really crossed my mind in that way" (Phase 2 Back Programme Participant). A similar mechanism, termed continued social functioning, has been identified in realist enquiry into social outcomes for Lindsay Leg Clubs where volunteers found purpose and fulfilment in supporting others (Galazka et al., 2021).

The refined CMO-Cs for the programme theory of connecting with students are presented in Table 6.6.

Table 6.6

Refined programme theory 6: Student involvement

	Context	Mechanism	Outcome
CMO-C 1	Genuine desire to learn and feeling valued. Students being actively involved rather than simply present.	Reduced power-imbalance and enhanced relatedness.	Engagement
CMO-C 2	Participants with an interest in supporting	Reciprocity	Engagement

Programme theory 6 summary

The involvement of students in the H&W programmes was theorised to enhance engagement in programmes through a reduction in power-differentials and supporting feelings of relatedness. Student involvement operated contextually in programme theories 2 and 4 by increasing staff capacity and contributing to a positive atmosphere, but their mechanistic contribution has been defined in this programme theory along with the contexts shaping their impact. Student involvement was verified to support engagement through supporting relatedness due to their genuine desire to learn from participants, demonstrating the volition necessary for developing good quality relationships (R. M. Ryan & Deci, 2017). Student involvement also contributed to engagement for individuals who were keen to support their education. The positive impact of students in programmes specifically depended on their active involvement rather than their presence alone.

6.10 Programme theory 7 Co-constructed engagement

This final theory of co-constructed engagement builds upon the theories thus far, which explain how practitioners and students can work with participants to co-construct engagement. This theory provides an explanatory account of how engagement in one person can directly generate engagement in another, acting in a cyclical feedback fashion (Emmel et al., 2018). This central concept of co-constructed engagement can be supported through SDT's concept of relatedness and SDT's mini theory of relationship motivation theory.

Connecting with people is a key engagement process (Bright et al., 2015) and principle of how the programmes were conceptualised to bring about positive change (Downey et al., 2021). Many of the mechanisms central to the programme theories in this chapter explain how connections with participants, practitioners and students are generated, leading to engagement through relatedness. Relationship motivation theory asserts that high quality relationships require a mutual authentic willingness to participate in the relationship and that volitional giving is what shows that someone genuinely cares (R. M. Ryan & Deci, 2017).

The perception of another's genuine care is reflected in examples of patients' perception of clinician engagement being important in their own decision to engage (Bright et al., 2015) and was demonstrated empirically during theory testing in this research. The central position of this theory within the programme theories presented in this chapter is deliberate. All other generative mechanisms of engagement discussed in the programme theories have been shown to directly impact engagement, yet all mechanisms can influence engagement additively through the co-construction of engagement described in this section.

During Phase 1, practitioners discussed the impact that participants' engagement had on their own engagement, describing their work enthusiastically when they felt that participants were benefiting from the programmes.

You wanna know that people are getting benefit from it and you're not just doing it and then after the 4 weeks or 6 weeks they're just like back in. Because I think that adds a sense of accomplishment to practitioners and people involved with the logistics of the programme, you feel vindicated, I'm glad I'm doing this programmes because I know they're having a beneficial effect on people. (Phase 1 Programme Practitioner)

Student practitioners further supported the development of this theory by highlighting how participants shaped their engagement with delivery of the programmes and working with participants.

I really enjoyed working with such a range of ages and abilities in the clinics. Given we had such a small-time frame to work with our clients there were noticeable differences in their confidence and behaviours. This was so nice to see week to week and encouraged me to really engage with the clients. I really enjoyed listening to their stories as many would talk to you and again, this enhanced their time with us encouraged them to keep returning week after week. (Phase 1 SLKE student)

In these examples, students and practitioners appeared to engage due to a satisfaction of the psychological need for relatedness, as explained by SDT. This need for relatedness has been demonstrated in learning environments where for teachers to actively support the needs of learners, they must experience need supports themselves (R. M. Ryan & Deci, 2020).

Likewise, a lack of perceived engagement from participants seemed to negatively impact practitioner engagement. Practitioners explained that the efforts required to support participants could feel draining in instances where there is little reciprocation, leading to less enthusiasm on the practitioner's part to engage.

...and then they unload their whole life on to you. I struggle with them, not because, what it's like, they use you as a vessel to work through stuff as opposed to me trying to foster engagement, it's me trying to offer a humanising hand and someone to listen to and think that's hard to get engagement. But if you can work through that sometimes I have had engagement but a lot of the times I don't so it's quite taxing and draining.

(Phase 1 Programme Practitioner)

Similarly, the negative influence of perceived disengagement of others has been demonstrated through an SDT lens where issues of disengaged students have been shown to negatively impact teachers' autonomous motivation, engagement and teaching vitality, and subsequently their autonomy support for students (R. M. Ryan & Deci, 2020). Practitioners were therefore theorised to respond to perceived participant engagement, or lack thereof (M resource) by feeling valued, or not (M response), leading to enhancement or reduction of their own engagement respectively (O). The other, previously discussed programme architecture mechanisms were considered to act contextually in this programme theory by shaping participant engagement, which could then be perceived by practitioners (C).

Additional contexts for practitioner engagement appeared to be their working environment and their own values and beliefs. For example, one practitioner believed a level of caution toward engaging too much was necessary to prevent burn-out (C).

Yeah, I think it's, uh, anyone working in healthcare, I think you've got to, people told me early, "Watch out for burnout. Do not give too much". And you know, and I really believe that, you know, you can do a good job and you can be nice and friendly to people but at the same time, you know, keep things back a little bit and, yeah, it's better for everyone. (Phase 1 Programme Practitioner)

Work-overload and pressures to boost student performance have been shown to negatively impact teachers' engagement and autonomy support for students (R. M. Ryan & Deci, 2020), and staff burnout in healthcare has been linked to reduced quality of patient care and patient satisfaction (De Hert, 2020; Razai et al., 2023; Rollins et al., 2021).

The perceived engagement of participants generating engagement in practitioners was proposed to also act in reverse, acting in a similar way for participants, as identified by Bright et al. (2015, 2017), therefore potentially generating a reciprocal mechanism and perpetual cycle of engagement or indeed disengagement. There is recognition that there may be a maladaptive cycle of negative feelings from both healthcare practitioners and dissatisfied patients (Gascon et al., 2013). For example, if a practitioner becomes disengaged (O) because they have received little positive feedback from participants (M resource), they may feel their efforts are futile (M response) and become less engaged in their work (O). The lower engagement of the practitioner may be perceived by a participant (M resource), leading to the participant's further disengagement (O).

Phase 2 data verified the role of the bidirectionally acting mechanism (Emmel et al., 2018), of perceived engagement in others, on engagement as an outcome and

contributed to the refinement of this programme theory. Key contexts impacting practitioner engagement were identified during this phase, as well as a further theoretical explanation for the transference of engagement, contributing to the refinement of this theory.

Participants described the influence of practitioner engagement on their own engagement with the H&W programmes as well as other health services and provided additional explanation for how participants recognised and perceived practitioner engagement. Being genuinely listened to and having respectful conversations; practitioners presenting information in a variety of ways rather than from a script; and observing practitioner enthusiasm all helped programme participants to perceive practitioners as genuinely engaged.

I certainly got a feeling that James was fully engaged. And he wasn't just telling us stuff which someone had told him to tell us, that he was a believer in the process, in what he was saying. And that's good. In fact, again, I think it's essential if you can read body language to know that the person up there is telling you something they believe themselves rather than just reading off a script. (Phase 2 Leg Programme Participant D1)

Likewise, practitioners and students reported the impact of participants contributing to their own satisfaction of needs and subsequent engagement. A student explained that “you just need to feel like you are respected, and you’re wanted, and you’re needed”. A Leg Programme practitioner described the contribution of participants’ engagement to their satisfaction of needs as an energy cycle:

So, I find if someone is super enthusiastic, quite talkative, in a good balance and they’re asking questions to show that they’re interested, that can boost

your energy levels and that can reflect back and forth, so it's almost an energy cycle. If they're responding to you, your energy goes up and that applies to almost any scenario as well. And that's how you get the best out of it. If their energy's good, they're asking the right questions, or asking questions full stop, their conversation's interested, then you feed off that interest and that enables you to give the best to them. (Phase 2 Leg Programme Practitioner)

Another practitioner reported that their engagement was lower in instances where these needs were not met, for example, "...when you're there to help people and you're not even offered the courtesy of kind of like the time of day sometimes. Like how poorly sometimes patients can speak to you". (Phase 2 Leg Programme Practitioner)

For one practitioner a lack of engagement from a participant had a less direct impact via an increased connection with other, more engaged participants. In this example the outcome was a comparative lesser connection as opposed to reduced enthusiasm to work with that individual.

It's not that their low enthusiasm makes my enthusiasm drop. My enthusiasm's still high but as time progresses and connection is not established, but it is with others, that makes a difference to my maybe engagement with him. (Phase 2 Back Programme Practitioner)

Practitioners described additional contexts shaping their engagement with programmes, which contributed to theory refinement. Practitioner engagement with the programmes waned when there was little opportunity to take annual leave and recoup (M resource). Leave was, for some, difficult to book due to limited staff capacity and contractual obligations to deliver programmes throughout the year (C), leading to burn-out (M response) and reduced engagement (O).

The energy given is the energy you get back and I do agree that if your energy is poor then the energy they give you might be lower as well, especially if you show body language that you're in a certain type of mood, seem disinterested or just don't want to be there. A prime example of that, like, I went almost a year without taking a break from clinical environment... and it wasn't until I had that holiday that I realised how burned out I actually was because I was losing interest myself. I was just like getting to that point where like I can't be bothered, I don't wanna be at work. And then I had a week off, did absolutely nothing, didn't have any thought processes about work whatsoever and I actually feel more enthusiastic and more energised coming back and more willing and able. And it's not until I reached that point that I recognised that I need to actually think more about my own health and wellbeing sometimes, because I lose my energy and enthusiasm for the group sessions and that if I don't. It's difficult though, in my particular department there's only two main practitioners and we are very caught up on our time ... we don't get relief in order to take leave the way we would like to because there's only two of us and all the contracted clinics need to be run in some form or another. (Phase 2 Leg Programme Practitioner)

The additional time required and 'nuisance' of moving furniture around prior to programmes, described in section 6.6, contributed to reducing enthusiasm, particularly when practitioners were already under time pressure (C).

A more positive mechanism for practitioner engagement was the lack of pressure to get numbers of people through the door and meet key performance indicators. This lack of pressure and space to work in a way that aligned with the practitioner's focus

on providing genuine, person-centred care was made possible by the support from senior management and commissioners of the programme, presented in section 6.4.

I have freedom just to support things that I think are important, so give people genuine care, give them a range of options that tailor to them, give them the space to trial things out and in a safe manner. So I don't sit there and go "this is brilliant because I don't feel like I'm gonna fail" or funding's going to be cut, I see it more as "isn't that brilliant that's not being pushed on me, which is person-centred and now I can be person-centred with other people. (Phase 2 Back Programme Practitioner)

As previously described, a number of participants were sensitive to the feeling of health care professionals and services being under pressure to 'get numbers through the door', and that this impacted engagement, as highlighted by a participant on the Back Programme:

I think we all felt secure coming here and being able to talk about how we felt and what we felt because I think you all made us feel like we're able to do that. Because again it's not like going to your GP or somewhere else where you've only got 5 or 10 minutes and you know, you're feeling rushed out because they wanna get onto the next person. (Phase 2 Back Programme Participant H4)

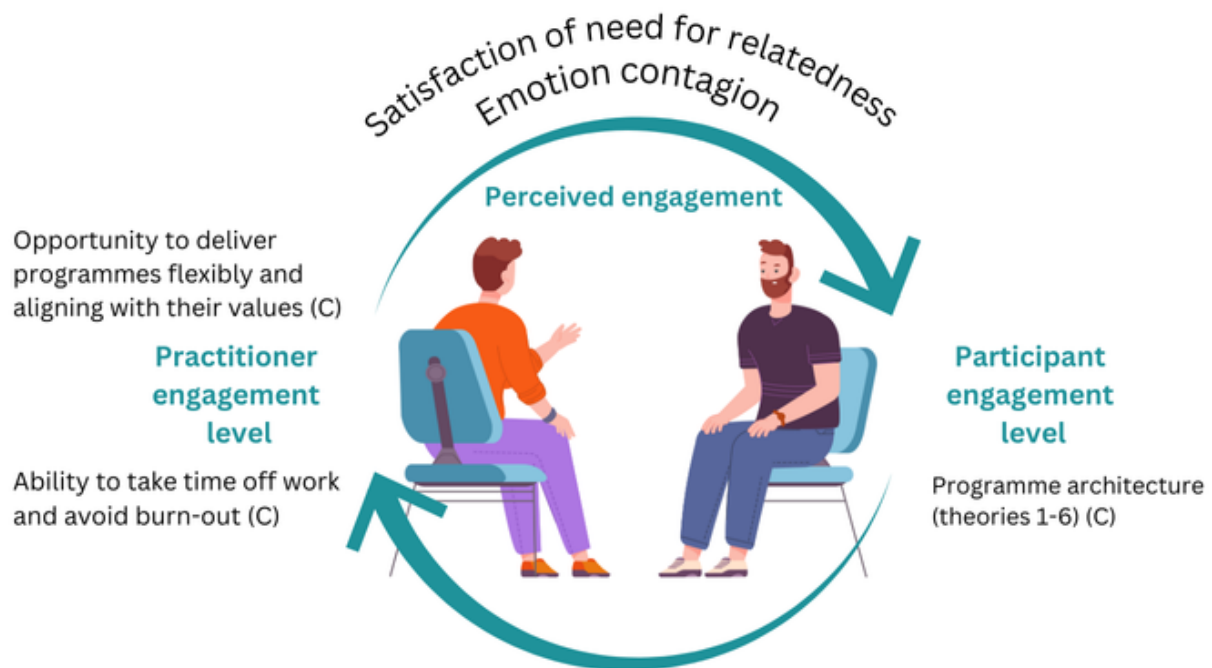
Participant awareness of and response to practitioner engagement in this way further supports the theory that practitioner engagement is an important causal mechanism for participant engagement.

Phase 2 observations and interviews also identified reciprocal engagement occurring via a potentially more subtle and less conscious mechanism of emotion contagion. Contagious engagement, or emotion, has been described in the positive psychology literature as crossover theory. Crossover theory was originally described by Westman (2001), positing the bi-directional inter-individual transference of both positive and negative emotions, moods and dispositions. The significance of mutual emotional and behavioural influence between teachers and students in the field of education has been well documented. Examples of the negative manifestations of crossover theory include students' perception of teacher boredom negatively impacted their learning through their own boredom, and teachers feeling depressed when their efforts are met with little positive return (Tam et al., 2020; van der Ross et al., 2023). More positively, contagious engagement has been identified in healthcare practitioners with engagement being passed between team members and enhancing vigour, dedication absorption in their work (Bakker, 2018).

The refined CMO-Cs for this programme theory of co-constructed engagement are depicted in Figure 6.7.

Figure 6.7

Refined programme theory 7: Co-constructed engagement



Programme theory 7 summary

Programme theory 7 explained how engagement is co-constructed between practitioners and participants through a satisfaction of the need for relatedness. Phase 2 verified this reciprocal mechanism between participants and practitioners and revealed a second, less conscious, mechanism of emotion contagion. This theory of co-constructed engagement showed that participants and practitioners could perceive engagement levels in one another, which impacted their own engagement. All other mechanisms of engagement in the programme architecture could therefore contribute to engagement additively by influencing engagement in a participant, subsequently impacting practitioners' engagement, and vice versa. This programme theory was situated centrally (see Figure 6.1) in relation to the other six programme theories to depict this additive process.

Co-constructed engagement was confirmed to operate both positively and negatively as both engagement and disengagement could be perceived by and impact engagement in others. Therefore, contexts impacting practitioner engagement were considered important in supporting participant engagement. An additional context for practitioner engagement was identified in Phase 2, highlighting that reduced staff capacity can lead to practitioner burn-out and lower practitioner engagement, which may negatively influence participants' engagement, according to this theory.

6.11 Chapter Summary

This chapter has presented seven programme theories of engagement with group-based self-management programmes, from their inception to their refined and verified form. Each programme theory has been discussed in relation to substantive theory, facilitating their abstraction to theory of the middle-range, increasing their portability and potential use for informing engagement with other programmes of a similar kind. The first six programme theories provide explanations for how specific aspects of programme architecture can support engagement with programmes and in which circumstances. The seventh programme theory of co-constructed engagement was presented as central to all engagement mechanisms due to its additive and reciprocal effect on engagement; all other mechanisms of engagement may additionally support or thwart engagement via this central mechanism. This central generative mechanism of engagement epitomises the synergistic aspects of engagement and provides an explanatory account of why engagement is not a sum of its constructs; engagement outcomes are more than the sum of their generative mechanisms. The programme theories of engagement in this chapter provide nuanced explanatory accounts relating to the relational construct of engagement and how the way in which programmes are

delivered can impact engagement, which have so far been underexplored in the literature.

The next and final chapter of this thesis will present the key findings of this research and discuss them in the context of wider literature. The novel knowledge contributions to the field of self-management interventions will be elicited as well as the methodological contributions of this work. The strengths and limitations of this research, and recommendations for future research and practice will be presented.

Chapter 7 Discussion

7.1 Chapter Overview

This chapter begins by summarising the work undertaken for this thesis in response to challenges identified in the literature and by stakeholders, regarding the delivery of group-based self-management support (SMS) for people living with long-term conditions (LTCs). The discussion will focus on placing the findings of this research within wider discourses around supporting people living with LTCs. Specifically, the contribution of the programme theories to the conceptualisation of engagement and SMS are discussed. The discussion continues with the contribution of this thesis to the current literature on the role of student involvement in engagement with group-based SMS programmes. The novel contributions of this thesis to realist methodology are then articulated, followed by a critical discussion and reflection of the research process undertaken for this thesis. Recommendations for future practice, policy and research are presented, followed by pathways to impact from this realist evaluation.

7.2 Chapter introduction

The broad aim of this realist evaluation was to develop an understanding of what works, for whom, why, and in which circumstances in group-based SMS programmes. A realist approach was adopted due to the complex and social nature of group-based SMS, and the need for more nuanced, causal explanations for how and why SMS programmes succeed or fail. Generating causal explanations for how group-based SMS programmes work aimed to provide insight to support the development, spread and scale-up of person-centred group-based SMS programmes. A single realist evaluation cannot answer all questions regarding how a programme works so refinement of the thesis aim was undertaken during a scoping phase. The scoping

phase was described in Chapter 2 and determined that a priority area for investigation was engagement with group-based SMS programmes.

Clear definitions of engagement are often elusive in healthcare literature, and engagement and its related terms are used interchangeably. The lack of clarity in the definition of engagement has led to a fragmented debate on the concept, potentially hindering opportunities for shared learning (Graffigna, 2017). A clearer understanding of the concept and its constructs are necessary to inform policy, practice and research and to allow the investigation of strategies to improve patient engagement (Higgins et al., 2017). The narrative review of the literature in Chapter 3 revealed that the way in which engagement had been conceptualised, and therefore investigated in the self-management literature, was often incongruent with existing engagement theory, rarely exploring its relational nature (Bright et al., 2017). Further, the engagement literature examined in Chapter 3 lacked theory-informed approaches to investigation.

Without explanatory theory for how engagement may be impacted, it is difficult to determine why the inconsistencies regarding the myriad factors associated with engagement in group-based SMS programmes, discussed in Chapter 3, manifest. Accordingly, as presented in Chapters 4 and 5, this realist evaluation sought to develop and test generative causal explanations of how engagement occurs in the H&W group-based SMS programmes.

The findings of this realist evaluation, presented in Chapter 6, demonstrate empirically that there are aspects of group-based SMS programmes that have a causative effect on engagement. Choice and variety, feedback and differentiation, the emotional and physical environment, time and space, the alignment of individuals' needs with what programmes can offer, and the involvement of students were all identified as important

mechanisms of engagement in the H&W programmes. Further, the inextricable link between practitioner and participant engagement was clearly evidenced, along with key examples of contexts affecting both. The programme theories bring to light pertinent contexts and mechanisms at varying levels of social systems, which have so far been elusive in the predominantly individualistic concept of engagement in healthcare literature. Ortiz Halabi et al. (2020) highlight that contexts affecting engagement in the wider system are particularly challenging because they are not modifiable by actors of the healthcare system. For example, individual complexity, social stigma and policy drivers cannot be easily or quickly changed. However, the findings of this realist evaluation have demonstrated that there are modifiable mechanisms and contexts which may be manipulated and implemented in SMS programmes to support engagement.

The previous Chapter 6 discussed the programme theories developed in this realist evaluation in relation to existing substantive theory. The following sections 7.3 and 7.4 discuss how the findings of this research contribute knowledge to the conceptualisation of engagement in SMS, and the conceptualisation of SMS for LTCs respectively. A distinctive feature of the H&W programmes was the role of students in their delivery and student involvement was shown to contribute to supporting engagement in the verified programme theories. Section 7.5 considers these research findings in relation to existing literature in the field of student involvement in healthcare delivery.

7.3 The conceptualisation of engagement in self-management support interventions

The following subsections discuss the findings of this thesis in relation to how engagement in SMS is currently conceptualised in the literature. How engagement is understood and therefore supported (or not), as elucidated in this research, will be discussed in relation to some of the known challenges of supporting individuals with LTCs engaging with group-based SMS programmes.

7.3.1 A realist understanding of engagement in self-management support

The aim of this thesis was to explore programme architecture and the role of wider contexts to unearth generative mechanisms for engagement beyond the level of individuals with LTCs. This aim was addressed by generating explanatory theory using a realist approach and contributes to the current conceptualisation of engagement in group-based SMS programmes. The generative, rather than successional understanding of engagement depicted in this research contributes to a shift away from the dominant individualistic view of engagement because generative causal explanation recognises that outcomes are generated by mechanisms located at a different layer of social reality (Pawson & Tilley, 1997). For example, mechanisms at programme level, shaped by contexts at institutional level, can impact engagement at an individual level. The literature reviewed in Chapter 3 was dominated by successional causal accounts which focus on identifying repeated observations rather than explaining how outcomes are generated (Pawson & Tilley, 1997). Viewing engagement through a realist lens therefore expands the focus beyond the individual to explaining how mechanisms and contexts at other layers of social systems influence engagement. For example, in Chapter 3, low socio-economic status (SES) was

identified as being associated with low engagement but explanations for why were absent from the literature. A lack of understanding of how low SES results in low engagement makes it challenging to effectively support engagement in individuals with low SES. However, through a realist lens, searching for causal explanations, it has been possible to elucidate how low SES as a context influences how individuals might respond to a given mechanism resource offered by a programme. For example, autonomy supportive approaches and a non-judgemental environment were identified as particularly important for fostering engagement in those with lower SES and will be discussed in more detail in section 7.3.3.

Understanding causal mechanisms of engagement may help counter the sometimes fatalistic view practitioners have regarding patient engagement (Robinson et al., 2014) because understanding causation can support a move from fate to human agency (Stone, 1989). For example, rather than accepting that individuals with low SES will be less likely to engage, the explanations generated in this research provide theory informed ideas about how to actively support engagement. There was a paucity of literature identified in Chapter 3 in relation to interventions or theories to improve engagement with group-based SMS programmes. By identifying mechanisms of engagement in the architecture of SMS programmes and the contexts which shape them, the programme theories developed in this research may be used to train practitioners in using autonomy-supportive approaches, manipulate programmes to create space for fostering an emotionally safe environment, and potentially influence wider system contexts, to actively support engagement.

Further to the development of a generative causal understanding of engagement, this realist evaluation has contributed to a deeper understanding of the relational and co-

constructed nature of engagement, by eliciting reciprocal mechanisms and their contextual influences. Authors in the field of engagement agree that there are relational and collaborative elements of engagement which support an individual to adopt self-management and health behaviours; however, these factors are often presented as unidirectional adjuncts to the central idea that engagement is an individual trait or behaviour (Hibbard & Mahoney, 2010; Kimerling et al., 2020; Mittler et al., 2013). The reciprocal mechanism of co-constructed engagement in this research was placed more centrally in the engagement programme theories because it could not be separated from other engagement mechanisms. Several contexts and mechanisms in the programme architecture shaped participant engagement. Practitioners' perception of participant engagement influenced their own engagement, meaning that all mechanisms of engagement in programme architecture could contribute to practitioner engagement via participants. Participant engagement was also influenced by practitioner engagement, inextricably linking all mechanisms of engagement via this reciprocal mechanism.

The central positioning of the relational nature of engagement in this research aligns more with Hickmann et al. (2022) who argue that the attribute of therapeutic alliance is what differentiates engagement from other related and overlapping concepts. The findings of this thesis augment the understanding of practitioner approaches to partnership-building by demonstrating how practitioner engagement is perceived by participants. The relational aspects of engagement between practitioner and patient have been demonstrated empirically in other research showing that patient engagement can be enhanced when a collaborative and partnership-building approach is used by practitioners (Alvarez et al., 2016). The mechanisms of engagement identified within the programme architecture of the H&W programmes,

and contexts for supporting co-produced engagement contribute tangible ideas of how to enhance these collaborative approaches in practice. For example, supporting the avoidance of burn-out and allowing practitioners the flexibility to deliver programmes in a person—centred way were important for practitioner engagement.

The inseparable and reciprocal nature of engagement mechanisms identified in this work contribute granular detail to Boivin et al.'s (2022) ecology of engagement model. Boivin et al. (2022) conceptualise engagement as the 'together piece of healthcare', stressing that it is relationship-focused and systemic. The authors highlight the qualitative difference between individuals' engagement and the emergent nature of engagement in groups. The realist approach used in this research seeks to map and explain the emergent effects of programmes (Pawson, 2013). The programme theories in this realist evaluation partly explain the emergent properties of engagement through the additive impact of programme architecture mechanisms on engagement, and engagement contagion between participants and practitioners. For example, individual participants, practitioners and stakeholder partners were found to contribute contextually and mechanistically to the emotional and physical environment of programmes but the emergent properties of the environment, such as the enjoyable atmosphere, are beyond those of any individual. The findings of this research explicate the interdependence and multidirectional influence of individual and collective factors outlined in Boivin et al.'s (2022) ecology of engagement model, in the setting of group-based SMS programmes.

This section has discussed how using a realist approach for this research provides new perspectives, which augment the current understanding of engagement in SMS programmes. Exploring engagement by examining interactions between context,

mechanisms and outcomes, which all operate at different levels of social systems, has demonstrated that engagement is not simply an individual trait. The explication of generative causal mechanisms and the reciprocal nature of engagement have also identified *how* interactions between contexts and mechanisms result in engagement outcomes, presenting novel possibilities for intervening to support engagement in group-based SMS programmes. The following sub-sections discuss how the nuanced theories developed through this realist approach support a shift toward a more holistic view of engagement and its measurement, and explain the complex relationship between engagement and health stigma in group-based SMS programmes.

7.3.2 The responsibility for engagement in self-management support

Much of the existing SMS literature has focused on identifying and removing barriers to engagement, which is arguably based on a view that people should want to engage with services, ultimately placing responsibility with individuals (Powell et al., 2017). This individualistic view of engagement is apparent in the paucity of literature on specific strategies used by providers to facilitate engagement (Austin et al., 2024). The current research sought to address this gap in the literature and identified several mechanisms beyond the individual level which influenced engagement in SMS programmes. The view that engagement is not an individuals' responsibility enabled the identification of engagement mechanisms beyond the individual. In turn, explicating programme and interpersonal mechanisms of engagement in this research further support a non-individualistic view of engagement.

Not only is there a lack of focus on actively supporting engagement with SMS programmes in the literature, there is also evidence that some programmes exclude individuals from services based on an individualistic view of engagement. Some SMS

programmes only enrol individuals demonstrating a willingness to engage to maximise the benefit of resources (Fleming et al., 2017). Providers in Fleming et al.'s study assessed people's willingness to attend programmes based on their verbal agreement to attend programmes, returning HCPs' calls and attending first appointments. However, the findings of this realist evaluation demonstrated that individuals required more information about programmes and how they might meet their needs to help them decide whether to attend. This need for informative discussions about programmes prior to enrolment clearly implicates HCPs in the engagement process. Determining eligibility for programme enrolment based on a view that engagement is a state of individual willingness can therefore unfairly exclude people from these services, which is a concern shared by others (Hardman et al., 2020). Offering care based on an individualised conceptualisation of engagement may inadvertently exacerbate health inequalities by disproportionately benefiting more affluent groups and individuals with greater economic, social and cultural resources to support self-management of LTCs (Franklin et al., 2021; Frohlich & Potvin, 2008; Hardman et al., 2020).

Some participants in the current study described strong beliefs about preventative healthcare and taking responsibility for one's own health and for attending the programmes on offer, a view which has been reported by programme participants in other work (Franklin et al., 2018). These collective findings are consistent with other literature reporting that people attending SMS programmes often have high levels of activation (Girard et al., 2021). There is evidence that individuals from minority groups, those with lower educational attainment and who are unemployed have lower activation (Golubinski & Wild, 2021; Hendriks & Rademakers, 2014; Naamneh-Abuelhija et al., 2024). Further, people from lower socioeconomic (SES) backgrounds

are often underrepresented in self-management programmes (Boakye et al., 2018). Assigning responsibility for engagement to individuals may therefore particularly disadvantage groups with low SES by further limiting their access to care, yet this group are in greatest need of support due to higher prevalence of LTCs and higher associated morbidity and mortality (Estechea Querol et al., 2020; Marmot, 2017). Hardman et al. (2020) advocate supporting more vulnerable groups to engage with SMS using theory-informed approaches to mitigate the potential contribution of SMS to health inequity. The findings of this research contribute theory-informed ideas about how to support engagement, including for those with low SES.

The unique contribution to existing engagement theory in this thesis provides an extended holistic proposition where responsibility for engagement is shared between the various actors in systems involved in SMS provision. A shift to a more holistic view of engagement may have implications for engagement with SMS programmes, as well as wider issues of health stigma and health inequity, and therefore the lives of those living with LTCs. If engagement with SMS programmes is deemed to be the responsibility of people with LTCs, a failure or decision not to engage with services may result in individuals being further blamed for their LTCs, contributing to the lifestyle drift discussed in Chapter 1. Further, blame-laden narratives associated with an individualised view of engagement may contribute to stigma, which was found to be inextricably linked with engagement in this research. The following section discusses how the programme theories of engagement are interrelated with stigma.

7.3.3 Engagement and stigma in self-management support

An important context identified in the programme theories in this evaluation was participants' experience of feeling judged in previous healthcare interactions and by

society in general, which is a consequence of the lifestyle drift in LTC narratives, discussed in Chapter 1. Participants who had experienced stigma had struggled to engage with other healthcare services due to their feelings of being judged, which is consistent with other research (Addison et al., 2023). Health-related social stigma is widely reported in the literature (Perugino et al., 2022) and specifically impacts individuals with LTCs, such as leg ulcers, chronic pain and cancer (Earnshaw & Quinn, 2012; Pagnamenta et al., 2023). The findings of this research contribute an explanation for how stigma impacts engagement within group-based SMS. Participants reported feeling blamed by HCPs and society for their inability to work. This blame was found to lead to feelings of needing to prove themselves rather than engaging autonomously with services. This extrinsic form of motivation may lead to attendance on programmes but does not necessarily result in the satisfaction of autonomy as proposed in Self-Determination Theory (R. M. Ryan & Deci, 2017) and identified to be important in engagement in this research.

The finding that stigma impacts engagement in this research contributes a nuanced explanation for why there is lower engagement with group-based SMS in those with low SES, as identified in Chapter 3. The relationship between health stigma and engagement identified in this research may be more pertinent in individuals with low SES because health stigma co-occurs with other, intersecting stigmas such as gender, race, sexual orientation and socioeconomic status (Stangl et al., 2019). These intersecting stigmas were corroborated by several programme participants in this research when they discussed their feelings and experiences regarding accessing healthcare. LTCs disproportionately affect people with lower SES (Estechea Querol et al., 2020) meaning they are particularly vulnerable to social stigma. Further, according

to the findings of this research, less likely therefore, to engage with programmes if stigma is compounded by stigmatising experiences in healthcare settings.

The stigmatising experiences in health settings reported by participants in this research are consistent with the wider literature (Cromptoets et al., 2024). Experiences and anticipation of stigma in healthcare settings have been widely reported in people with low SES (Davidson et al., 2006; Murray et al., 2009; Okoro et al., 2020; Simons et al., 2017) and anticipated stigma is a barrier to accessing healthcare (Earnshaw & Quinn, 2012; Westbury et al., 2023). Exploring engagement in this research has elucidated mechanisms to actively reduce stigma in group-based SMS programmes, which has been recommended due to the inverse relationship between stigma and self-management behaviours (Damla & Betül, 2023). These stigma-reducing mechanisms found to support engagement will now be discussed.

Choice, presented in Chapter 6, section 6.4, was identified as a key engagement mechanism in this research, which was particularly valued by participants who had experienced stigma. When participants are afforded genuine choice in the extent to which they participate in activities; provided with a variety of activities on programmes; and can work towards goals of their own choosing, then they may engage better with programmes, through the satisfaction of the need for autonomy (R. M. Ryan & Deci, 2017). Although choice is an essential tenet of person-centred care and shared-decision making (Grover et al., 2022), programme participants in this research asserted that choice it is not always afforded in group-based SMS interventions. Further, person-centred elements, including choice, are often not made explicit in research publications (Lafontaine et al., 2020).

The realist approach employed in this thesis allowed the clear articulation of the role of choice in group-based SMS, particularly for those who had experienced stigma. These research findings therefore demonstrate the impact of failing to incorporate the person-centred element of choice into group-based programmes, especially for groups more vulnerable to stigma. This research contributes possible solutions to support the implementation of choice by identifying its supporting contextual factors of practitioners' beliefs and values, programme flexibility, and an institutional culture of humanity, which were presented in Figure 6.4, Chapter 6. Other realist work has also identified informal design and flexibility to foster a sense of ownership for members in Lindsay Leg Clubs (LLCs) (Galazka et al., 2021), which may contribute further to engagement.

The emotional environment was another key mechanism for engagement important for those with previous experience of feeling judged. Psychological safety and a non-judgemental environment were achieved in the H&W programmes partly through practitioners taking the time to listen to participants' experiences and points of view. Similar strategies to reduce stigmatising practices in health care settings are proposed by L. Ryan et al. (2023) and include demonstrating empathy and adopting a non-judgemental approach to health concerns, active listening, building rapport, and working in collaboration with patients to address health concerns that are grounded in the individual needs of the patient (L. Ryan et al., 2023). However, stigmatising experiences in healthcare services persist (Cromptvoets et al., 2024). The current research identified the contexts of informal space and time to allow practitioners to foster a judgement-free environment. Space and time were afforded by the flexibility of the programmes, which was shaped at institutional and stakeholder partner level. Elucidating the interactions between these contexts and mechanisms of time and

space, and environment has contributed to existing knowledge by explaining how the implementation of recommendations for reducing stigma in group-based SMS may be supported.

The way that responsibility for engagement in SMS is framed, as discussed in section 7.3.2, may have implications for addressing stigmatising experiences in healthcare settings because attributing responsibility for health conditions is a driver and facilitator for stigma in LTCs (Stangl et al., 2019). Work has been done to explore the language used in conversations with patients in healthcare practice to reduce stigma, and recommendations include avoiding blame-insinuating language (NHS England, 2023; L. Ryan et al., 2023). Albury et al. (2020) recommend avoiding language which attributes responsibility with patients living with obesity and avoiding terms such as adherence and non-compliance, which have also been identified as counterproductive terms for engagement in this research. Yet, the focus of individual responsibility in SMS remains (Hughes et al., 2020; Morgan et al., 2017) and the term noncompliance continues to be used in the SMS literature (DiMatteo et al., 2000; Volpato et al., 2021). This research has revealed a complex relationship between the conceptualisation of engagement, how people engage with group-based SMS, and stigma in SMS interventions for people with LTCs. Therefore, to add new theoretical insight, a conceptualisation of successful engagement where responsibility is shared, rather than placed entirely on individuals, may potentially avoid perpetuation of stigmatising practices in healthcare and subsequent cyclical poor engagement.

7.3.4 Measuring engagement in self-management support

The findings of this study show that measuring attendance as a proxy for overall engagement is problematic because participants may attend but not completely

engage. In agreement with Bright et al. (2015), the presence of both observable behaviours and internal states were found to constitute engagement in this study. Engagement is multifaceted and nuanced, therefore difficult to capture (Fleming et al., 2017). Yet, engagement is an important factor in intervention effectiveness (Carroll et al., 2007; Nobles et al., 2018) making it an outcome of interest for interventions. Although attendance is one of the observable outcomes of engagement, without an internal state of engagement with a programme, a participant may not gain what they personally require to support their self-management from the intervention.

Engagement measures in self-management interventions are predominantly quantitative measures of engagement with digital content, uptake of interventions, and adherence and enactment of self-management behaviours (Rookes et al., 2022), yet compliance and adherence do not constitute patient engagement (Fleming et al., 2017). The current research demonstrates that not only is adherence an insufficient proxy measure of engagement, focusing on adherence and compliance may in fact compromise engagement through a reduction in autonomy. Failing to consider engagement beyond observable behaviours may have consequences beyond an intervention because effective self-management is not simply a behaviour to be achieved. Self-management includes the cognitive and emotional responses and ongoing self-regulatory processes necessary to lead a life of satisfactory quality (Grady & Gough, 2014).

For future research and evaluation of engagement in practice, it may be possible to use a combination of existing engagement measures which capture particular constructs of engagement but do not capture the concept in its entirety. Combining measures of observable behaviours from the perspective of practitioners (Mayhew et

al., 2019), with a participant self-reported measure which includes behavioural, cognitive and emotional aspects of engagement, such as with the Patient Health Engagement Scale (Graffigna et al., 2015), could offer a more comprehensive way to measure engagement. However, even combining existing measurement tools in health may not be sufficient to measure engagement in group-settings and with interventions that precede engagement with health behaviours. In this research, a survey was devised, aiming to test the process and outcome of engagement (described in section 5.6.3) and although it was not used in the way it was intended in this research, similar surveys could be developed for programmes to collect feedback regarding engagement. Further, as is recommended in relation to developing programme theory in realist research, engagement measures could be borrowed and developed from other disciplines and subsequently validated in group-based health intervention settings.

The current section has discussed the contribution of the programme theories in this research to the conceptualisation of engagement and how it is measured in group-based SMS programmes. The relationship between engagement and stigma in people living with LTCs has been explained and discussed in relation to the current challenges in reducing stigmatising practices in healthcare. Some of the stigma-reducing practices supporting engagement in this research were underpinned by how the H&W programmes were conceptualised by stakeholder partners, programme architects and practitioners. The following section discusses the findings of this research in relation to how group-based SMS is conceptualised and how this influences engagement in programmes.

7.4 Conceptualising self-management support

The nuanced understanding of engagement developed in this research has identified mechanisms for engagement which are shaped by the various aims of SMS programmes. The conceptualisation and intended role of SMS impacts the way in which it is commissioned and implemented (S. Fletcher et al., 2019; Reidy et al., 2016). Others agree it is important to question the motivation behind SMS and consider whether the aim is to genuinely empower people with chronic illness or achieve healthcare cost-saving (Harvey & Docherty, 2007). The original premise of SMS was that it should be underpinned by a humanistic and person-centred approach however, the promotion of SMS in health policy has arguably become an exercise in cost-saving and reduction of healthcare service utilisation (Kendall & Rogers, 2007). This research has identified how these drifts in conceptualisation from humanistic to cost-saving motives can influence engagement and will be discussed throughout this section.

Patient engagement with health services shape their development (Clavel et al., 2021), making engagement and SMS conceptualisation interrelated. Whether people engage with SMS programmes may impact outcomes for people with LTCs (Walton et al., 2020) and consequently how programmes are designed and commissioned in future. Failure to effectively support people living with LTCs, due to poor engagement may, for example, undermine attempts to reduce healthcare utilisation. Higher demand for services due to lack of support could increase waiting lists. Increased waiting lists may lead to changes in programme delivery, as seen with shortened programmes in this research, which reduces engagement, and so the cycle of disengagement continues.

This perpetual (dis)engagement cycle exemplifies the complexity theory argument that elements of systems restrain one another, and that causation operates both upwards and downwards (Westthorp, 2012), in this case via the way SMS is conceptualised. The problem of negatively impacting engagement in programmes as an unintended consequence of trying to reduce pressures on health systems provides an example of this upward and downward causation. Conceptualising SMS in a way which prioritises individuals' quality of life, that is meaningful for them may enhance engagement with SMS programmes, as found in this research. As improved engagement is likely to lead to more positive patient outcomes and satisfaction (Graffigna et al., 2015; Rookes et al., 2022), improved engagement may contribute to reduced demands on health services, or at least maintain services as the prevalence of multimorbidity rises.

Lawn et al. (2011) have argued that there is a danger of SMS becoming bound in 'healthism', where people's choices are judged as good or bad, subsequently assigning blame to those living with LTCs. The findings of this research augment existing knowledge by explaining how practitioner judgement of how patients should respond to SMS may impact engagement. When participants are expected to take responsibility and follow expert advice they can be subsequently classified as 'good' and 'bad' patients by practitioners (Franklin et al., 2021). When practitioners work with 'good patients' this can invoke positive feelings from practitioners, motivating them to invest more in those individuals (Franklin et al., 2021). The co-constructed nature of engagement developed in this research highlights that practitioners' positive feelings and greater investment may be perceived by participants, further enhancing their engagement. The positive cycle of compliant individual and more invested practitioner may therefore reinforce the problem of healthism, proposed by Lawn et al. (2011), in SMS.

The current research also offers explanation for a negative cycle of engagement that is shaped by how SMS is conceptualised. Practitioners can become frustrated when patients fail to meet their expectations, which will shape their interactions (Franklin et al., 2018). Consequently, if practitioners view individuals as 'bad' or less engaged due to an expectation that they comply with advice, practitioners may feel less engaged. Programme participants in this research reported being able to directly perceive low practitioner engagement and that this negatively impacted their own engagement. The current research findings therefore illuminate a link between the way SMS is conceptualised and how engagement is co-constructed in group-based SMS programmes.

The underpinning principles of the original H&W programmes are firmly rooted in the intended humanistic and person-centred care approaches of SMS (Downey et al., 2021), which have been shown to positively influence engagement in this research. The verified theories demonstrate the effects that conceptualisations of SMS across varying system levels can have on individuals' health and wellbeing. Adopting and enacting the belief that SMS should aim to support people to live well with their condition shaped service delivery, from commissioning to interactions between practitioner and participants during interventions, and therefore engagement. This work provides empirically tested theory which supports arguments to reconsider motivations behind SMS and align them with calls to shift the non-communicable disease discourse from an economic view toward health and human rights (Buse et al., 2017; Mialon, 2020). The following subsections seek to challenge some of the existing conceptualisations of SMS programmes and their delivery.

7.4.1 Self-management support as an intervention

Conceptualising SMS as an intervention at all may be problematic if SMS is delivered mechanistically with a focus on intervention fidelity. Intervention fidelity is often advocated to avoid type III errors, where programme outcomes are poor due to a failure in implementation, rather than genuine ineffectiveness (Mars et al., 2013; Schinckus et al., 2014). This research demonstrated that a focus on task adherence and achieving specific pre-determined programme outcomes were counterproductive for engagement, partly through thwarting basic needs for autonomy. Although task adherence is an important aspect of fidelity, participant responsiveness and differentiation are also key fidelity constructs (Carroll et al., 2007). The influences of higher levels of adherence on programme outcomes are conflicting with some studies reporting more positive outcomes and others finding that greater adherence reflects a lack of flexibility and compromises outcomes (Mars et al., 2013). The delivery of complex interventions requires a complexity-informed approach that focuses on effective adaptation of interventions over fidelity (Braithwaite et al., 2018), which is supported by this research. The findings of this thesis present an explanation for why adherence and a lack of flexibility can compromise engagement through reducing autonomy. If practitioners are focused on adhering to programme content and less so on its core theoretical elements, they may compromise participant engagement and subsequently undermine overall programme aims of supporting individuals to live well with their condition.

7.4.2 Self-management support as education

In the current research, practitioners held the common view that the H&W programmes sought to help people with LTCs become empowered to improve their quality of life through person-centred approaches. However, SMS interventions have been

conceptualised to equip people with self-management skills primarily through knowledge acquisition and support to manage medication, sign/symptom monitoring, problem-solving skills and improving health behaviours (Jonkman et al., 2016). The prioritisation of knowledge acquisition is reflected in work reporting that many SMS interventions are focused on education and instruction, leaving little time for the other aspects of SMS, such as social support (Hughes et al., 2020). Some practitioners also perceive patients' knowledge and understanding as more easily influenceable than other factors relating to self-managing their condition (Ogunbayo et al., 2017).

The autonomy-supportive approaches identified as an important mechanism of engagement in this research may be reduced in SMS programmes if they are offered with the primary goal of educating people with LTCs. SMS should be tailored to individuals' needs and preferences (Lorig & Holman, 2003; Taylor et al., 2014). Yet, in much of healthcare practice practitioners can assume that patients require education to comply with expert advice, creating tension when trying to offer them choice in their care (Carr et al., 2014). If, however, SMS is conceptualised more holistically, as elucidated in this research, with less focus on whether participants comply with advice, people with LTCs may better engage with group-based SMS programmes. Enhanced engagement with SMS may allow individuals to benefit from other aspects of what group-based programmes have to offer beyond education, for example social support.

Focusing on educating individuals in SMS may also result in the adoption of more paternalistic approaches and didactic delivery (Stenov et al., 2018). This research confirmed didactic approaches to be a negative influence on engagement by reducing optimal arousal and limiting opportunities for social connection. Less didactic approaches, especially when supported by one-to-one support from student practitioners, allowed practitioners to gain a greater understanding of participants'

individual lives, needs and circumstances. Individuals with LTCs, and practitioners alike, identify relationships with practitioners, where practitioners learn about individuals' life contexts and act on this knowledge, as necessary for holistic and effective self-management support (Ogunbayo et al., 2017; Sheridan et al., 2019). Epistemic reciprocity, involving exploration, reflexive listening and reciprocal enquiry between patients and practitioners has been identified as a necessary component of person-centred interactions (Dell'Olio et al., 2023). However, teacher-centred approaches are often used in group interventions and can undermine this person-centred approach (Stenov et al., 2018).

Non-didactic approaches to delivering group-based SMS have been demonstrated in research to improve programme outcomes and are valued by practitioners and participants in group-based SMS programmes (Odgers-Jewell et al., 2015; Skinner et al., 2008; Taylor et al., 2014). Despite support from practitioners for more discussion-based and interactive approaches to programme delivery, practitioners can find shifting away from a didactic mode challenging, leading to teacher-centric delivery (Stenov et al., 2018; Taylor et al., 2014). The findings of this research have demonstrated how the conceptualisation of group-based SMS by commissioners and stakeholder partners can further contribute to the difficulties in achieving non-didactic delivery.

This research identified contexts which facilitated and restrained opportunities for less didactic approaches and subsequent possibilities for relationship development and trying out different activities in group-based SMS. Time to explore movements, and gain feedback from practitioners has been identified as important for engagement with exercise in individuals participating in back rehabilitation programmes (Kühn et al.

2024). The longer Back Programme in this research afforded time to incorporate a greater range of non-didactic delivery, which included this time for exploring activities, whereas the Leg Programmes were shorter due to efforts to reduce waiting lists. Valuing and focusing on the educational content of the Leg Programmes contributed to the notion that content could be delivered in fewer sessions, providing part of the rationale to shorten the programmes. However, longer programmes are not always associated with better outcomes (Carnes et al., 2012). This research identified shorter programme duration as a context which constrained opportunities for non-didactic delivery and connection with participants but other contexts, not elucidated in this research may reduce non-didactic delivery even in longer programmes. Explaining the impact of programme duration on mechanisms of engagement in this research has provided a more nuanced explanation for why programme duration may not be consistently linked with improved outcomes.

Further, the current research findings offer new perspectives on how less didactic approaches can improve engagement in group-based SMS programmes through interpersonal connections. Participants on both back pain SMS programmes and leg programmes, similar to those evaluated in this research, highly value peer interaction (Galazka et al., 2021; Wilson et al., 2025). However, non-didactic approaches in group-based SMS may still focus on education, albeit through peer-discussion and varied activities (Odgers-Jewell et al., 2015). In this research, informal opportunities for social interaction and space to explore activities were important for engagement. The benefits of social interaction have also been reported in LLCs, which although are not specifically categorised as SMS interventions, have sociability at their core by creating a social space for members to interact whilst waiting for communal treatment for their legs (Galazka, 2023). The sociability of LLCs is emphasised across studies

and is cited as a key reason for continued engagement by participants, or ‘members’ (Ghazaleh et al., 2018).

The benefit of social interaction in group-based SMS, and specifically for individuals attending back and leg programmes is the opportunity for social comparison and peer-learning (Galazka et al., 2021; Wilson et al., 2025). However, space for informal chatter gave participants in this research respite from thinking and conversing about their condition(s), which enhanced engagement. The opportunity for informal connection in the Back and Cancer Programmes in this research may be subtly different from the peer-interaction opportunities afforded in organised peer-discussions, and in the communal treatment element of LLCs, where members are focusing on and can have open conversations about their legs (Galazka et al., 2021). The valuable space for informal conversations in the current research may be more similar to interactions that take place in the designated socialising areas in LLCs, which are separated from the treatment area (Galazka, 2023). Designated socialising opportunities which created space for individuals to divert their focus from their condition to an activity or general conversation created an enjoyable atmosphere in this research, which facilitated engagement.

Creating opportunities for these informal connections may be pertinent in supporting engagement in individuals who find social connection in group interventions to be a barrier, rather than facilitator of engagement. Sharing experiences has been cited as a mechanism for disengagement with programmes for those who do not want to identify with their condition (Ackerman et al., 2013; Harris et al., 2019). Some participants express concern about focusing on the negative aspects of their condition (Bossy et al., 2017; Harris et al., 2019), which was also highlighted in participant

feedback in the theory development phase for the programme theory: environment (Chapter 6, section 6.6). The findings of this realist evaluation offer insight into the mechanism of informal space for mitigating the focus on the negative experiences of living with LTCs. By creating opportunities for discussions unrelated to their condition and education, and therefore not strengthening disease-related identity, individuals found more enjoyment in participating in programmes and were therefore more engaged. An enjoyable atmosphere has been found to be necessary for forming connections in other SMS research (Vissenberg et al., 2016), further supporting the argument to incorporate informal opportunities for connection in group-based SMS.

Many SMS programmes seek to empower individuals to better manage their LTC, or live well with their condition (Cheng et al., 2021; Kuo et al., 2014; Yu et al., 2022). However, in some literature, empowerment is conceptualised as acquiring knowledge and promoting patient responsibility (Bogaert, 2021), which aligns with the conceptualisation of SMS as an educational intervention. The relationship between empowerment and engagement were demonstrated in this research as autonomy-supportive approaches and reduced power differentials were identified as mechanisms for engagement with programmes. Empowerment and engagement are distinct from one another but are intricately related concepts (Hickmann et al., 2022) as empowerment is necessary for engagement and vice versa (Fumagalli et al., 2015). The findings of this research add nuance to the relationship between empowerment and engagement by highlighting how the conceptualisation of empowerment influences engagement. Empowerment in the H&W programmes was considered as a process of collaborating with individuals to support them in taking control, rather than taking responsibility, and activities were designed to support transformative learning rather than as a drive to encourage compliance with expert advice (Downey et al.,

2021). However, the empowerment process in SMS is often seen as a way of making patients change and behave differently, rather than as a mutual process where there is a genuine transition of power (Halvorsen et al., 2020; Protheroe et al., 2008). The programme theories of engagement in this research demonstrated the need for reduced power differentials to support engagement, therefore supporting a need to view empowerment as a mutual process rather than as a transfer of knowledge.

The realist approach used in this research enabled the delineation of the complex influences of power at different levels of the system and how this impacted engagement. Power has been explored in SMS by S. Fletcher et al. (2019) who assert that different types of power can exist in parallel and at different levels of the system. Engagement in this research was enhanced through mutual power at the level of practitioner-participant through autonomy-supportive practices and a judgement-free environment. However, hierarchical power from healthcare organisations and commissioners influenced whether mutual power and engagement mechanisms were fully realised due to their influence on programme design. Engagement was most successful in programmes in this research when SMS was conceptualised by all stakeholders as humanistic support over an educational intervention. S. Fletcher et al. (2019) agree that power in SMS is complex, comprising a convergence of rhetorical, hierarchical, personal and mutual power, the balance of which is intricately related to how SMS is conceptualised. This research has produced tangible theories of engagement which explain how the convergence of powers, and conceptualisation of SMS and empowerment manifest.

This section has discussed how assuming people require education to live well with their condition may impact the delivery of, and therefore engagement with SMS programmes. Outcome measures of SMS programmes may also impact the way they

are delivered, which can shape engagement, as found in this research. The relationship between engagement and outcomes measured in group-based SMS programmes will now be discussed.

7.4.3 Self-management support to change biomedical outcomes

The importance of personalised SMS discussions incorporating individuals' goals and preferences for motivation was evident in this research and is supported in other SMS literature, including back pain interventions, and healthcare more widely (Drake af Hagelsrum et al., 2024; Gregersen et al., 2024; Lewinski et al., 2020; Makoul et al., 2024). Practitioners may wish to support individual choice but practitioners can override patient preferences because they are obligated to demonstrate changes in biomedical outcomes and health utilisation (Franklin et al., 2021). Prioritising biomedical outcomes as an outcome of SMS influences how practitioners provide self-management support, as practitioners can default to focusing on meeting external targets, for example NHS Quality Outcomes Framework targets, and providing 'over-medicalised' care (Ogunbayo et al., 2017). Practitioners in this research felt able to focus on providing tailored and person-centred support, which is an important outcome for patients from SMS interventions (Boger et al., 2015; Drake af Hagelsrum et al., 2024) and important in reinforcing humanistic practices in healthcare (Makoul et al., 2024). Practitioners in Ogunbayo et al.'s (2017) study recognised pressures to meet performance targets as a barrier to providing personalised support. In contrast, practitioners in the current research were able to focus on self-management constructs important to individuals because they were not under pressure to focus on the medical management more commonly supported in SMS interventions (Packer et al., 2018; Van De Velde et al., 2019).

Commissioners can have a tendency to prioritise measures and outcomes which are tangible, traditional and safe which are endorsed by top-down national agendas (Reidy et al., 2016) and commissioning arrangements can influence the delivery of SMS (Ogunbayo et al., 2017). A lack of these top-down pressures was identified as a pertinent context for providing individuals with choice in programmes, which enhanced engagement in this research. Verifying the impact of top-down influences on engagement mechanisms in this research offers support for calls to move away from a biomedical focus on SMS (Reidy et al., 2016; Stenov et al., 2018) and that this shift is necessary at multiple levels of the system.

A conflict between programme aims to change biomedical outcomes and what individuals wish to gain from SMS programmes may be detrimental to engagement, according to the findings of this research. Helping people with LTCs identify how programmes can support their needs and goals was identified as important for engagement in the H&W programmes. However, disconnect regarding self-management priorities between people with LTCs, practitioners, other stakeholders and SMS has been identified in numerous studies (Boger et al., 2015; Hessler et al., 2019). Conflicts can also arise when participants have a biomedical focus. Specifically, individuals living with chronic non-specific back pain commonly have a biomedical perspective on their condition and strong preferences for biomedical diagnostics, treatment and exercise approaches, which when not addressed in interventions can lead to reduced motivation to engage (Kühn et al., 2024). Understanding the needs and beliefs of individuals and aligning what programmes can offer to these needs is therefore necessary to support engagement.

This research demonstrated that better alignment of SMS priorities with what individuals want and need to live well with their condition can support engagement with SMS programmes, particularly in the early stages of the engagement pathway. People with complex health needs want to have conversations with HCPs about their personal values and needs; being understood by HCPs can motivate individuals to use the self-management strategies recommended to them (Tuzzio et al., 2021). Programme participants in this research corroborated the importance of conversations with HCPs to better align SMS with what is important to them and that it supported their engagement with programmes. An additional finding was that HCPs' knowledge of programmes and being able to illustrate how other individuals with LTCs had experienced the programme enhanced meaning in these conversations, and therefore engagement.

Measuring outcomes was confirmed as a mechanism resource in this research, influencing the experience and engagement of participants on programmes. The impact of measuring outcomes has been identified in other research, for example, being weighed can be emotive and deter individuals from seeking medical care (Ross et al., 2024). Programme architects and practitioners achieved a balance between measuring biomedical outcomes and a person-centred approach because they were able to offer individuals genuine autonomy when participating in measuring activities. The autonomy-supportive approaches helped to mitigate the negative emotional experience of being measured and allowed participants to approach these activities with curiosity, if they chose to participate. This research confirmed the necessary context of programme flexibility afforded by stakeholders for being able to offer such autonomy to participants. The reduced focus on biomedical outcomes from stakeholder partners prevented associated constraints reported in other work

(Ogunbayo et al., 2017) on the H&W programmes, allowing an emphasis on person-centred approaches and engagement with programmes.

Outcome measures had an important positive mechanistic role of providing feedback to both participants and practitioners in this research. As a mechanism, outcome measures supported engagement through providing task-inherent feedback to participants, and informative feedback to practitioners about participants' ability relating to programme activity. Practitioner and programme architects were able to choose outcome measures based on their value in providing information about individuals whilst in a group setting, rather than being required to measure biomedical changes. Physical measures of fitness, for example, were useful for practitioners in assessing participants' physical ability, allowing practitioners to differentiate activities within programmes accordingly.

Tailoring SMS to individuals' needs is an important component of SMS programmes (Taylor et al., 2014), however this can be difficult to achieve in group-settings (Horigan et al., 2017; Mensing & Norris, 2003; Stenov et al., 2018). The freedom to choose outcome measures based on their value in providing useful feedback to participants and practitioners, rather than on demonstrating changes in biomedical outcomes, shaped the mechanism of feedback and differentiation for supporting engagement in this research. This novel finding demonstrates that outcome measurement activities are an active component of programmes, which can positively and negatively shape participants' experience and engagement, and are not simply tools for evaluation.

Patient Reported Outcome Measures (PROMs) had the potential to negatively impact engagement if they inadequately captured what was meaningful and important to the individual or by emphasising negative feelings about their condition. The use of

PROMs was introduced to evaluate care (NHS England, 2018), however, other realist research has shown that PROM completion is not a neutral or inert activity simply for data collection (J. Greenhalgh et al., 2018). The use of PROMs may enhance communication between patients and HCPs (Govindaraj et al., 2023; Lapin et al., 2018). Feedback from PROMs was also associated with small improvement in disease control and patient quality of life in a Cochrane Systematic Review (Gibbons et al., 2021). The authors reported no adverse events associated with completing PROMs were identified in the reviewed literature, for example anxiety or depression. However, J. Greenhalgh et al. (2018) found that PROM completion can upset patients and/or trivialise their problems. The current research contributes to this more nuanced understanding of the negative impact of PROM completion in patient care. The programme theories in this thesis explain how negative experiences of PROM completion may be mitigated by practitioners prioritising personal narratives of their health and wellbeing, how this can be achieved in group settings, and why choosing PROMs must be person-focused.

7.4.4 Self-management support to deliver healthcare to large numbers at low cost

The theories verified in this research contribute to arguments against viewing SMS primarily as a cost-saving and value for money initiative in LTC care (Harvey & Docherty, 2007; Hughes et al., 2020) by demonstrating the negative impact that prioritising cost-efficiency goals can have on engagement. Aims to educate, as discussed in section 7.4.2, and cost-effectively reducing waiting lists contributed to the shortening of SMS programmes in this research, subsequently reducing the time and space identified as important for engagement. Participant engagement with interventions is likely to determine whether desired outcomes from interventions are

achieved (Rookes et al., 2022; Walton et al., 2020). Therefore, if engagement with SMS programmes is poor, reductions in healthcare utilisation may be limited.

Cost-saving and efficiency are welcome aspects of group SMS interventions, however prioritising what should be viewed as additional benefits over what is most important for people living with LTCs can undermine the specific benefits of delivering SMS in group settings. Social interaction in group-based SMS has been shown to result in improved self-management (Gucciardi et al., 2021; Vissenberg et al., 2016). Designing group-based interventions as a response to meeting demand for services, long waiting lists and limited resources undermines the ethos of group programmes, which includes social interaction (Hughes et al., 2020). The findings of this thesis contribute to this argument by explaining how primary goals of efficiency not only undermine the ethos of group programmes but can also negatively impact engagement.

The research presented in this thesis has contributed to the field of group-based SMS interventions by providing theories which can be used to inform practice. This realist evaluation has advanced knowledge in this field by explicating engagement mechanisms and the multi-level contexts which shape them in practice. This research has exemplified how individual and practitioner factors, formal and informal programme architecture, and the relationship between them all influence engagement with group-based SMS programmes. The conceptual model and programme theories resulting from this research provide tangible ideas about what programmes should include to enhance engagement and may therefore be used to examine proposed or existing programmes for opportunities to enhance engagement in their particular context. This research can be used to help facilitate discussions with commissioners and stakeholder partners about how programmes are conceptualised and therefore

implemented and measured. Informed choices can then be made about SMS provision for people with LTCs and how best to support their engagement.

7.5 Student-led self-management support

An important context of the H&W programmes examined in this thesis was the involvement of students in several programmes. Although student involvement in healthcare delivery is widespread across health disciplines (Scheffer et al., 2018; Sokkar et al., 2019; Vaughn et al., 2015) and their contribution to delivering SMS programmes is not unique (Nickelson et al., 2022; Wang et al., 2023), the examination of the role of students in engagement offers some novel insights into their contribution in group-based SMS programmes. Student involvement was found to enhance engagement through a reduction of power differentials, increased one-to-one support for programme participants, a positive emotional environment, and co-constructed engagement.

Student involvement in delivering healthcare has been frequently explored in General Practice (Scheffer et al., 2018; Vaughn et al., 2015) and there are more recent examples in the literature from a range of other settings, for example in speech and language pathology (Sokkar et al., 2019), manual therapy (Nim et al., 2024; Vaughan et al., 2019), and gynaecology (Ren et al., 2025). Wang et al. (2023) investigated the attitudes of students, patients and faculty members toward community-based student-led health education services for people with LTCs and found a generally positive attitude across all stakeholders. However, the study used quantitative methods only, meaning that explanations for attitudes towards student involvement were not explored. Similarly, Nickelson et al. (2022) focused on effectiveness of student-led DSME interventions in their systematic review rather than explaining the nature of their contribution. The findings of the current research provide explanatory theory for

student contribution to group-based SMS, which is currently lacking. Further, the realist approach in this research enabled the identification of contexts which shape how programme participants experience student involvement. This section will discuss student involvement in healthcare delivery and how the nuanced theories of engagement from this research contribute to existing knowledge in this field.

Student HCPs need training in person-centred approaches. Ensuring HCPs have the appropriate training and skills in delivering person-centred care has been identified as a key context for supporting self-management and improving patient outcomes in other realist work (Ahmed et al., 2022). Specifically, practice-based learning is essential in healthcare because it allows healthcare students to perform, think and interact in context-specific situations (Gudgeon et al., 2023; McConnell & Hale, 2024; Teunissen, 2015), and improve patient care (O’Leary et al., 2020). From a student perspective, there is a need to learn SMS skills through observing health care professionals and working with people with LTCs, both in placement environments (McConnell & Hale, 2024). However, training of HCPs for group-based SMS is commonly delivered through lectures, experiential learning with role play, discussions, educational tools and manuals, and very little through clinical placement (Kristjansdottir et al., 2021). Although this research did not specifically focus on the education of HCPs, exploring engagement in SMS programmes involving students in this thesis has provided detail about HCP training in group SMS interventions which is currently lacking in the literature (Kristjansdottir et al., 2021). The findings of this thesis therefore offer explanatory theory to support both HCP education and people with LTCs to engage with group-based SMS programmes, which will now be discussed.

Students actively contributed to participants' positive experience on the H&W programmes, which is consistent with other research. Patients receiving care from students in healthcare settings have reported that student-led care is more person-centred and agree that student involvement can have an immediate positive impact on patient care, as opposed to purely enhancing care of future individuals (McElhinney & Bartlett, 2021; Scheffer et al., 2018). Patients in Scheffer et al. (2018) study reported increased person-centredness to be a result of students being perceived as highly engaged, good collaborators, competent supporters and being better understood due to patient-oriented dialogue. These findings align with the theories of co-produced engagement and opportunities for dialogue during programmes in this research. Students' engagement during the H&W programmes was perceived and appreciated by programme participants. Students' enthusiasm demonstrated their authentic participation in the student-patient relationship, which was important for engagement. The theory of co-constructed engagement contributes additional knowledge by illustrating that opportunities for students to portray their engagement through active participation and interaction is necessary to enhance person-centredness and engagement in programmes.

The findings of this research contribute to the existing understanding of the benefits of practice-based learning by demonstrating how students can directly support engagement in self-management programmes. Student presence in medical settings is generally regarded positively by patients (Kolshus et al., 2022a; Mol et al., 2011; Vaughn et al., 2015) with patients valuing contributing to students' education, the opportunity for more time with practitioners and to learn more about their condition (Richards et al., 2022; Sayed-Hassan et al., 2012; Sokkar et al., 2019). These mechanisms are similar to those identified in this realist evaluation, however, the

empirical testing of programme theories revealed that the way students are involved in programmes is important to how participants experience their presence. Students are involved in patient care both actively and passively (Mol et al., 2011) and some learning experiences for student HCPs have been criticised for their passive nature (Scheffer et al., 2018). An important means for students to learn about person-centred care is through conversing with service users and building relationships (Currie et al., 2015), necessitating an active involvement in their care.

Students supporting the H&W programmes did so for the duration of the programmes, attending weekly and spending time getting to know participants and building relationships with them. Scheffer et al. (2018) and others (McElhinney & Bartlett, 2021; Nickelson et al., 2022) agree that contact time is necessary for developing trust, person-centredness and improved outcomes when working with students. The role of time and continuity has been illustrated in other SMS research where specialist practitioners who spend more time getting to know individuals are better able to offer a more holistic approach to care (Ogunbayo et al., 2017). This research elicited the necessary contexts for affording time for this connection in group-based SMS, for example through less didactic delivery and sufficient programme duration.

The consequences of passive student involvement may not be limited to diminishing the added benefit of student presence, according to this research. Student presence in health settings is not always perceived positively by patients and these instances are commonly related to sharing personal and intimate problems, and being examined (Kolshus et al., 2022b; Mol et al., 2011). Although it might be assumed that sharing intimate information or being examined may not be such an issue in group-based SMS programmes, the current research highlighted an example of the negative perception

of student presence in group settings. This research revealed that participants can feel judged if students are watching rather than being actively involved in the programme because the role of the student is unclear. The fear of judgement by students in the H&W programmes was ameliorated by the active involvement of students in supporting participants and conversing with them as equals. Many patients in one study (Kolshus et al., 2022) felt that more student interaction and 'proper' introduction would help them feel at ease, supporting the findings of this research. As discussed earlier in this chapter, perceptions of judgement are problematic for individuals with LTCs, particularly for those experiencing multiple types of stigma and/or poor mental health. Active involvement of students in group-based SMS should therefore be considered to reduce fear of judgement and support a positive and safe emotional environment.

The programme theory explaining student involvement in this work identified the additional role of students in creating a positive and enjoyable atmosphere. To the researcher's knowledge, students' contribution to creating an enjoyable environment as a mechanism of engagement is a novel finding in the student-led healthcare literature. The novelty of this finding may be due to the limited research undertaken in group-based interventions where a more relaxed and enjoyable atmosphere may be more beneficial and appropriate compared with some other healthcare settings.

The NHS Long Term Workforce Plan (2023) state the rise in healthcare need is outpacing workforce growth. The plan further argues that a shift towards preventative healthcare is necessary and that the growing workforce will require more flexibility, with skill sets that include generalist and core underpinnings. The work undertaken in this thesis demonstrates that involving healthcare students in SMS programme

delivery offers an opportunity to deliver the generalist and core skills training required whilst directly supporting participants on programmes. Apprehension exists amongst practitioners regarding offering clinical placements for healthcare students, citing lack of time and increased burden associated with providing student support (Richards et al., 2022; B. Smith et al., 2023). However, this research supports previous claims that active student involvement can enhance person-centred care (Scheffer et al., 2018).

In summary, with the rise of chronic health conditions and multimorbidity (Kingston et al., 2018), the healthcare workforce needs to be well equipped to support patients to self-manage their conditions. This research has demonstrated that actively involving students in the delivery of group-based SMS programmes can answer calls for more practice-based learning for HCP students to learn SMS and person-centred approaches, and directly benefit participants during their placements. Involving students can help to make group-based SMS not only more person-centred, but more enjoyable and engaging. Further, the programme theories explain the necessary contexts to realise the benefits of students' contribution, which has so far been under explored in the literature.

7.6 Novel contributions to realist methodology

The previous sections have discussed the contributions of this thesis to the field of engagement and SMS. Through the documenting of and reflecting on the methodology used in this research, a contribution has also been made to realist methodology. The philosophy rather than method driven approach in realist research, is undoubtedly a strength in developing understanding of how complex interventions work. However, unbound by set methods, the myriad ways in which realist research and analysis may be conducted can create challenges, especially for new researchers. Disseminating

learnings from undertaking realist evaluations is necessary to enhance quality and research capacity because at present most available guidance is ad hoc, and informal help and support is from more experienced realist researchers, for example via the realist research community mailing list (Wong et al., 2017).

The reality of conducting iterative analyses can be difficult when little practical guidance is available. Further, assessing the integrity of realist research is limited when there is a lack of information regarding the messy process of theory development and refinement. The development of programme theories, described in Chapter 5, contributes knowledge to the field of realist methodology by providing an example of a practical approach to analysing these challenging concepts, with a focus on reflexivity and transparency. Realist evaluation cannot be conducted by following set protocols, rather it requires the researcher to think, reflect and interpret data in a manner consistent with underlying realist philosophy and principles (T. Greenhalgh et al., 2015). Given the complexity of the realist understanding of causality, this presents an intellectual challenge when trying to analyse multiple causal explanations in complex interventions. By using the tools and methods described in Chapter 5, the cognitive load of juggling multiple theories and data was reduced to allow focused retroductive theorising and continuous, traceable reflexivity. Such detailed and transparent methods for theory development have not yet, to the researcher's knowledge, been described in the literature. The use of table sorting in Excel, wall-mapping of CMO-Cs, NVivo and linked memos made it possible to 'zoom' in and out of programme theories and consider connections between them as well as the nuances of each individually. The work undertaken in this thesis to develop theory, with specific regard to the practice of reflexivity, has contributed to a recent peer-

reviewed publication: “Reflecting on reflexivity in realist evaluation: A call to action” (Downey et al., 2024).

7.7 Critical reflections of the research undertaken

This chapter section presents a critical reflection of the research undertaken by discussing the strengths and limitations of the work.

7.7.1 Strengths

The programme theories presented in this thesis were developed and refined through the triangulation of a range of primary and secondary data from relevant stakeholders, which enhanced the quality of this realist evaluation (T. Greenhalgh et al., 2017a). The use of a substantial volume of historical participant feedback data, and data from stakeholders from a concurrent project allowed the development of rich and granular programme theory without over-burdening stakeholders. Using existing data afforded more time to focus on in-depth analysis and theorising, and subsequent data-collection. The multi-case study design and participant observation of programme delivery made it possible to take both physical and social aspects of systems into account in programme theory development.

Further notable strengths of this thesis included the transparent and methodical approach taken to develop programme theory, which is an important quality standard of realist evaluation (Wong et al., 2016). Developing realist programme theory is a notoriously challenging process. Despite the growing popularity of realist research and because of its freedom from specific methods, to date, little guidance exists on the practical steps researchers can take to developing programme theory. The use of explicit and clearly documented reflexivity, and tools for organising and visualising the

theory development process helped to clarify thinking and contributed to the transparency and integrity of this realist research. This methodological work was presented at the CARES Realist Training Conference in November 2023 and in the peer-reviewed journal article referred to in the previous section (Downey et al., 2024).

My immersion in the organisation where the H&W programmes were developed and delivered was an important strength of this work, and a particular achievement given that this PhD studentship began during the COVID-19 pandemic when social distancing and operational changes made socialising and working with others more challenging. I made a concerted effort to develop positive working relationships with all those involved in the development and delivery of the H&W programmes as well as other students and staff members across the institution. I immersed myself in the culture of the institution by being curious and involving myself in a range of activities at the university to understand how people went about their daily work, and their experiences, beliefs and aspirations. By contributing to teaching and learning during my PhD I adopted the relatively unusual position of staff member and student, which helped me to understand participating in the organisation from different social and working positions. This immersion helped me to achieve the necessary social competence to investigate the H&W programmes (Dumont, 2023) and develop the granular descriptions required for realist theorising (Westthorp, 2012).

A further strength of the current research is the use of patient and public involvement, which is not often documented in realist research, nor is the transparent reporting of contributions made by each stakeholder group (Abrams et al., 2021). Contributions were reported for people with LTCs, previous participants on H&W programmes, partners, programme architects and practitioners separately which was subsequently

triangulated to inform the direction of the realist evaluation and the choice of conceptual frameworks. The culture of the institution in which this PhD was undertaken also contributed to the focusing of the realist evaluation. An interest in what was important to patients, public, stakeholder partners and staff on the programmes was explicit from the outset. The positive and established relationships between programme staff, the PhD supervisory team and partner stakeholders, and the autonomy-supportive environment within which I was able to work made it possible to explore what mattered to stakeholders.

7.7.2 Limitations

Although programme participants, members of the public and stakeholder partners were consulted prior to commencing the realist evaluation and informed the focus of the research, there may have been value in involving them at additional points throughout the evaluation. Due to the involvement of stakeholders in a concurrent study of student-led knowledge exchange (Cotton et al., 2024), it was considered potentially too onerous to request additional input from stakeholders who had already contributed significant time to support research activities. Members of the public were consulted when designing the participant information sheets, which helped improve their readability. However, members of the public were not involved in developing a recruitment strategy and their insight may have improved recruitment from participants who did not attend or engage with programmes.

Engagement was not quantitatively analysed in this realist evaluation. As explained in Chapter 5, current engagement measures do not capture the conceptualisation adopted for this research. The social nature of engagement makes it a difficult phenomenon to capture because the key interactions between engagement

constructs are emergent and contingent upon one another (Cohn et al., 2013). Bright et al.'s (2015) engagement constructs guided the qualitative measurement of engagement in this work, however, part of this measurement will have undoubtedly been intuitive, which is often the case in clinical practice (Fleming et al., 2017). My identification of elements of engagement during participant observations in the theory testing phase were dependant on my own ability and experience of recognising signs of engagement, which may have been a source of bias. This was, in part, mitigated by discussing and checking these impressions of engagement with programme participants and checking interpretations of engagement with practitioners and students during realist interviews.

The findings of this realist evaluation predominantly focused on answers to the question “what works, in which circumstances and why” with relatively few examples of what does not. Although learning from instances of when engagement has been successful has value, it is necessary to further develop and test theory about non-attenders and non-completers. Theory was developed regarding the role of aligning individuals' needs with what programmes had to offer at the point of referral, yet this theory was only tested with individuals who ultimately attended. It was therefore not possible to verify mechanisms leading to decisions not to engage. Further, the participants who attended but did not complete the programme did not contribute to the refinement of theories about how programme architecture influenced their decision to leave the programme. It was not possible, within the approved ethical framework, to contact patients unless they agreed and provided contact details directly. Consequently, communication with patients was limited to the pre-programme participant information sheet sent to them when they were enrolled on to the programmes, unless they ultimately attended. No non-attenders or non-completers of

the programmes responded to an invitation for interview. However, reflecting on these limitations, and identifying some of the socioeconomic contexts impacting mechanisms of engagement has informed additional work to be undertaken for another PhD, which will be discussed in section 7.9.

This realist evaluation tested theory in a small selection of programmes delivered in the Southwest of England. Many of the contexts may be quite specific to the systems, programmes, and individuals in this region and could differ from the key aspects of programme architecture important for engagement elsewhere. However, the aim of realist inquiry is to build knowledge with a firm acceptance that knowledge is only ever partial (Jagosh, 2019). The goal of realist inquiry is to build knowledge, layer upon layer (Pawson, 2018).

The small number of programmes available during Phase 2, and therefore programme participants and practitioners from which to recruit for theory verification and refinement, may also be considered a limitation to the generalisability of findings from this realist evaluation when considering generalisability in statistical terms. The sample of programmes and their participants may not represent typical group-based SMS programmes elsewhere and therefore how engagement is shaped in other programmes. However, the aim of theory testing in realist evaluation is not to generate theoretical truths but to establish whether truth holds in particular cases (Pawson, 2013). Realist enquiry aims to contribute knowledge through more extensional generalisation where findings are not representative but offer transferrable explanations, supported by substantive middle-range theory (Pawson 2024). Therefore, it is not the number or representativeness of cases that matters but the explanatory work they are shown to do (Emmel, 2013).

Focusing on programme architecture in developing an understanding of engagement with group-based SMS programmes will have undoubtedly led to the omission of explanations for other mechanisms which can impact engagement. Mechanisms of engagement which are equally, if not more important for informing engagement support in other similar programmes may have been unearthed by expanding the enquiry to other points in the interventions, for example, at or prior to the referral stage, or further beyond programme completion. However, as previously argued, the aim of realist evaluation is to generate knowledge through the accumulation and constant adjudication of explanatory theories (Pawson, 2013). This research therefore contributes reusable theories in relation to how programmes are delivered so that they may serve as a framework for exploring engagement mechanisms within programme architecture, which has previously been under explored.

7.8 Recommendations for future practice

The outputs of realist evaluation provide nuanced yet portable explanations that can transfer learning to and from similar types of programmes (Punton et al., 2016). This section presents the novel contribution of explanatory theories of engagement from this work in the form of practice recommendations which may be used to inform the development and delivery of SMS programmes. SMS is essential to help improve the lives of people living with long-term health conditions, and group-based interventions offer an opportunity for people to gain this support with the additional benefit that comes from connecting with others. However, a lack of engagement with programmes poses a persistent challenge, meaning that many people who need support are not benefiting from these types of programmes. This realist evaluation has addressed the paucity of explanatory engagement theories in the literature and the resulting lack of useable theory to inform the enhancement of engagement in programmes. The

programme theories presented in this thesis can give practitioners direction when considering features of programmes which are important for engagement in certain circumstances and therefore what to consider when scaling up or rolling out programmes (Punton et al., 2016). The findings of this research are intended to provide a conceptual framework within which to consider engagement in group-based SMS and similar programmes. The following sections present key considerations for programme practitioners and architects, and organisations delivering, co-ordinating and commissioning SMS for people living with LTCs.

7.8.1 Recommendations for practitioners and programme architects

Based on the findings of the current research, programme practitioners and architects can look to enhance engagement in group-based programmes by identifying and maximising opportunities to incorporate mechanisms of engagement in programmes. These mechanisms and contexts are outlined in the recommendations below.

Central to the implementation of engagement mechanisms in programme architecture is the need to first consider the engagement of practitioners and how this may be perceived by participants.

- Enhance **co-constructed engagement** by
 - first reflecting on practitioner engagement and opportunities to enhance this prior to meeting with programme participants;
 - consider ways to show participants that practitioners enjoy being with them and are enthusiastic about working with them;
 - plan the support of practitioner engagement when designing and delivering programmes. For example, by pro-actively building in

sufficient annual leave, and identifying and addressing barriers to the smooth running of programmes.

Following the consideration of practitioner engagement and how this may be perceived by participants, the following aspects of programme delivery may be explored:

- Provide **choice and variety** by
 - giving participants genuine control over their level of participation during programmes whilst showing them positive regard;
 - offering a variety of activities for them to explore and take part in;
 - considering ways in which content can be delivered other than through direct instruction and information delivery from practitioners;
 - allowing participants to work towards goals that they have chosen and are meaningful to them.
- Deliver **differentiated sessions** that utilise **meaningful feedback** by
 - making time and considering ways to get to know individuals' needs in order to provide participants with an appropriate level of challenge;
 - considering how PROMs may be used to enhance feedback to participants and practitioners, rather than simply as measures for service evaluation;
 - providing individual feedback to participants during activities;
 - engaging in conversations with stakeholders about the role of PROMs in engagement with programmes so that mutually beneficial outcome measures can be used in programme evaluation.
- Foster an **environment conducive to engagement** by

- using the physical environment to encourage relaxed discussion between participants and practitioners, for example, by arranging chairs in a circle;
- providing a supportive, enjoyable and judgement-free environment through active listening and reducing power-differentials.
- Create **informal space** for participants to connect with others by
 - incorporating breaks and/or interactive activities within sessions;
 - providing a pleasant environment for participants to meet socially before and after programme sessions;
 - reducing the amount of didactic content delivery within programmes;
 - considering engagement and not simply programme content when deciding on programme length and session duration.
- Facilitate participants' understanding of how the programme **aligns to their needs** by
 - considering ways to gain information about participant needs prior to and during the first session of a programme;
 - provide clear explanations of programme content prior to attendance and during programmes so that participants may identify activities of interest early on;
 - help participants see where programme offers can meet their individual needs;
 - gain feedback from participants on programmes to share with prospective participants and share this feedback with participants and referring HCPs.

- Consider **involving student HCPs** in programmes, if possible, to enhance engagement by
 - directly involving them in activities with participants, rather than limiting their role to observing;
 - creating opportunities to learn from students' interactions with participants for a better shared understanding of participants' needs;
 - preparing and allowing students to provide participants with additional one-to-one feedback and support under the guidance of a qualified practitioner.

7.8.2 Recommendations for organisations and commissioners

Organisations responsible for the development of policy, commissioning and delivery of group-based SMS programmes can help to support engagement by doing the following:

- Deliver practitioner training which includes strategies for enhancing engagement and effective differentiation, with specific consideration for the increasing complexity of individuals' health and needs.
- Supporting practitioner engagement through supportive leadership and staff capacity building. Investment in additional staffing or reducing pressures on programme teams to deliver more for less, may ultimately improve engagement with programmes and their outcomes.
- Consider building partnerships with educational institutions to identify opportunities for mutually beneficial collaboration.
- Developing relationships with referring HCPs to help them understand how programmes may meet the individual needs of their patients. Establishing

participant feedback mechanisms to referring HCPs may provide HCPs with more meaningful information to give patients.

- Commissioners and healthcare organisations can work together to choose outcome measures which are useful for practitioners and meaningful to participants.
- Commissioners and healthcare organisations can work with people who have LTCs to determine outcome measures that are meaningful to them.

7.9 Recommendations for future research

This realist evaluation has illustrated the complexity of engagement in group-based SMS programmes and the need to avoid reducing engagement to its constituent parts. It is therefore recommended that further research should be undertaken to develop measures and frameworks for evaluating engagement in more consistent and replicable ways, which are congruent with the more comprehensive conceptualisations demonstrated by this realist evaluation and others in the literature. Without advancements in our assessment of engagement, there is a risk of perpetuating its perception as a ‘patient problem’.

The programme theories in this research were tested and refined using a small sample of programmes. However, realist enquiry is transparent in its acceptance that knowledge is never finite and that the overall aim is to build understanding through testing and refining programme theories in different settings (Pawson, 2018). The findings from this realist evaluation are portable and can be used to inform decisions and practice in other similar programmes (Punton et al., 2020) and can subsequently be refined in other settings to build this knowledge. The recommendation to further

examine and test programme theories is an essential part of the overall philosophy of scientific realism and process of realist enquiry.

Engagement was explored in this thesis within group-based SMS programmes. Although the boundaries created to focus the realist evaluation were permeable to allow the identification of contexts, there is still work to be carried out in understanding engagement prior to attending programmes, and longer-term engagement and self-management of LTCs.

To build upon and accumulate knowledge, effective labelling of engagement research is necessary. The social nature of engagement and its multiple constructs makes identifying relevant literature a challenge and potentially important lessons inaccessible. The challenge of identifying and assimilating relevant research on engagement in SMS programmes was identified and discussed in more detail in Chapter 3. Indexing research more consistently and appropriately may help researchers more readily identify useful research, particularly qualitative research whose titles tend to be more narrative than informative.

As previously discussed, this realist evaluation built and tested theories about engagement with participants who attended the H&W programmes, meaning that most of the theories focused on what works and less so on what does not work. The next essential step to better understanding engagement is to explore what does not work. Non-attenders to healthcare services, often referred to as “hard-to-reach”, are notoriously difficult to recruit for research participation, which was the case for this realist evaluation, making it difficult to improve services based on their needs (Bonevski et al., 2014). Recruitment strategies for hard-to-reach groups are sparsely described in research literature (Rockcliffe et al., 2018). Plans for patient and public

involvement in research is now required by the National Research Ethics Service in research applications and its use can improve the quality and relevance of research (National Instituted for Health and Care Research [NIHR], 2021).

The conceptualisation of engagement used and developed in this thesis may be a useful lens through which to consider engaging with people who do not attend programmes. As discussed earlier in this chapter, individuals who have experienced stigma are less likely to access healthcare, and may also avoid participating in research (NIHR, 2020). Reduced power-differentials and a non-judgemental environment were important for engagement in programmes in this research. It is feasible that these mechanisms may also be important for engagement with research. Peer researchers can bridge important gaps between researchers and research participants, for example through building trust and shared cultural understanding (Condon et al., 2022). Therefore, future research into engagement could consider the use of peer researchers to learn from non-attenders of group-based SMS programmes.

7.10 Pathways to impact from this research

This PhD was undertaken in a university that provides apprenticeship, undergraduate and post-graduate training for health and allied-health professionals. The delivery of group-based SMS interventions is within the scope of many of the professions receiving education at the institution. The theories produced by this research have already been disseminated through their incorporation in the training of new practitioners delivering the H&W programmes and will be formally included in taught modules in the various health degree and apprenticeship programmes delivered at the University. Part of the University's wider strategy is to offer training to external

stakeholders, for example through continuing professional development opportunities for healthcare and public health professionals. Preparation is underway for the offer of training in the delivery of group-based SMS programmes.

The need to explore engagement in group-based SMS programmes with under-represented groups and the so called 'hard-to-reach' is a key future research recommendation of this thesis. An outline proposal for a PhD has been prepared to encourage a potential PhD candidate to undertake this important work. This outline proposal will be advertised along with details of funding opportunities to facilitate the continuation of this engagement inquiry.

Since the start of this PhD, several opportunities have arisen to develop new health and wellbeing programmes and refine existing programmes for the local community. This work has informed the development of these programmes by supporting programme architects with theory- and evidence-informed guidance on programme design and delivery.

Finally, two manuscripts are being prepared to submit to peer-reviewed journals. The first is a paper presenting the theories developed and verified in this realist evaluation, with the aim that other researchers may use the findings to further verify and refine these theories in other areas of practice. A second publication is planned to detail the process of developing realist programme theory as there are calls for practical and worked examples of theory development within the realist research community. Additional ideas for papers are in their earliest stages of conception and aim to explore and disseminate some of the discussion points arising from this work more widely, for example, the value of student-led delivery of group-based SMS programmes.

7.11 Thesis conclusion

The research undertaken for this thesis has culminated in a set of verified explanatory theories of engagement with group-based self-management support interventions. The tentative yet tangible theories provide transferrable lessons on the mechanisms of engagement and the contexts which shape and influence them. The provision of choice and variety; feedback and differentiation; a psychologically safe and sociopetal environment; informal space and continuity for connection; and supporting participants in aligning offers of the programme to their individual needs have all been identified to support engagement with programmes. Investigating the role of students in the programmes of focus for this research demonstrated and explained the multi beneficial processes of their involvement in the delivery of group-based programmes. Finally, and most central to the process of engagement, this work explicates the reciprocal nature of co-constructed engagement, unequivocally demonstrating that engagement must be considered as a multi-actor process which considers the engagement of both practitioners and people living with LTCs.

References

- Abrams, R., Park, S., Wong, G., Rastogi, J., Boylan, A. M., Tierney, S., Petrova, M., Dawson, S., & Roberts, N. (2021). Lost in reviews: Looking for the involvement of stakeholders, patients, public and other non-researcher contributors in realist reviews. *Research Synthesis Methods*, (12) 239-247 <https://doi.org/10.1002/jrsm.1459>
- Ackerman, I. N., Buchbinder, R., & Osborne, R. H. (2013). Factors limiting participation in arthritis self-management programmes: An exploration of barriers and patient preferences within a randomized controlled trial. *Rheumatology (United Kingdom)*, 52(3), 472–479. <https://doi.org/10.1093/rheumatology/kes295>
- Addison, M., Lhussier, M., & Bambra, C. (2023). Relational stigma as a social determinant of health: “I’m not what you _____ see me as.” *SSM - Qualitative Research in Health*, 4(January), 100295. <https://doi.org/10.1016/j.ssmqr.2023.100295>
- Adjaye-Gbewonyo, K., & Vaughan, M. (2019). Reframing NCDs? An analysis of current debates. *Global Health Action*, 12(1). <https://doi.org/10.1080/16549716.2019.1641043>
- Ahmed, A., van den Muijsenbergh, M. E. T. C., & Vrijhoef, H. J. M. (2022). Person-centred care in primary care: What works for whom, how and in what circumstances? *Health and Social Care in the Community*, 30(6), e3328–e3341. <https://doi.org/10.1111/hsc.13913>
- Ahn, S. N., Smith, M. L., Cho, J., Jiang, L., Post, L., & Ory, M. G. (2015). Factors associated with successful completion of the Chronic Disease Self-Management Program among

middle-aged and older Asian-American participants: A national study. *Frontiers in Public Health*, 2, Article 257. <https://doi.org/10.3389/fpubh.2014.00257>

Albury, C., Strain, W. D., Le Brocq, S., Logue, J., Lloyd, C., & Tahrani, A. (2020). Engagement between healthcare professionals and with people living with obesity, the importance of language: A joint consensus statement. *Lancet Diabetes Endocrinol*, 8(5), 447–455.

Allen, C., Vassilev, I., Kennedy, A., & Rogers, A. (2016). Long-term condition self-management support in online communities: A meta-synthesis of qualitative papers. *Journal of Medical Internet Research*, 18(3), 1–17. <https://doi.org/10.2196/jmir.5260>

Allory, E., Lucas, H., Maury, A., Garlantezec, R., Kendir, C., Chapron, A., & Fiquet, L. (2020). Perspectives of deprived patients on diabetes self-management programmes delivered by the local primary care team: A qualitative study on facilitators and barriers for participation, in France. *BMC Health Services Research*, 20(1), 1–9. <https://doi.org/10.1186/s12913-020-05715-3>

Alsayed Hassan, D., Curtis, A., Kerver, J., & Vangsnes, E. (2020). Diabetes self-management education and support: Referral and attendance at a patient-centered medical home. *Journal of Primary Care and Community Health*, 11. <https://doi.org/10.1177/2150132720967232>

Alvarez, C., Greene, J., Hibbard, J., & Overton, V. (2016). The role of primary care providers in patient activation and engagement in self-management: A cross-sectional analysis. *BMC Health Services Research*, 16(1), 1–8. <https://doi.org/10.1186/s12913-016-1328-3>

Anderson, R. T., Eton, D. T., Camacho, F. T., Kennedy, E. M., Brenin, C. M., DeGuzman, P. B., Carter, K. F., Guterbock, T., Ruddy, K. J., & Cohn, W. F. (2021). Impact of

comorbidities and treatment burden on general well-being among women's cancer survivors. *Journal of Patient-Reported Outcomes*, 5(1).
<https://doi.org/10.1186/s41687-020-00264-z>

Ashtarian, H., Woolridge, M., Cheater, F., & Firth, J. (2012). Factors influencing attendance at structured self-management education programs for diabetes. *Iranian Journal of Nursing and Midwifery Research*, 17(7), 480–484.
<http://www.ncbi.nlm.nih.gov/pubmed/23922593%0A>

Astbury, B., & Leeuw, F. L. (2010). Unpacking black boxes: Mechanisms and theory building in evaluation. *American Journal of Evaluation*, 31(3), 363–381.
<https://doi.org/10.1177/1098214010371972>

Atkinson, P., & Hammersley, M. (1998). Ethnography and participant observation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of Qualitative Inquiry* (pp. 110–136). SAGE.

Atmann, O., Linde, K., Werner, C., Dorn, U., & Schneider, A. (2019). Participation factors for asthma education programs - A cross sectional survey. *BMC Pulmonary Medicine*, 19(1), 1–9. <https://doi.org/10.1186/s12890-019-0979-3>

Austin, E., O'Brien, Q., Ruiz, M., Ratzliff, A., Williams, E., & Koch, U. (2024). Patient and provider perspectives on processes of engagement in outpatient treatment for opioid use disorder: A scoping review. *Community Mental Health Journal*, 60(2), 330-339.
<https://doi.org/10.1007/s10597-023-01175-1>

Bakker, A. B. (2018). Job crafting among health care professionals: The role of work engagement. *Journal of Nursing Management*, 26(3), 321–331.
<https://doi.org/10.1111/jonm.12551>

- Bambra, C., Riordan, R., Ford, J., & Matthews, F. (2020). The COVID-19 pandemic and health inequalities. *Journal of Epidemiology and Community Health*, 74(11), 964–968. <https://doi.org/10.1136/jech-2020-214401>
- Barhorst, E. E., Boruch, A. E., Cook, D. B., & Lindheimer, J. B. (2022). Pain-related post-exertional malaise in Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and fibromyalgia: A systematic review and three-level meta-analysis. *Pain Medicine (United States)*, 23(6), 1144–1157. <https://doi.org/10.1093/pm/pnab308>
- 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. *The Lancet*, 380(9836), 37–43. [https://doi.org/10.1016/S0140-6736\(12\)60240-2](https://doi.org/10.1016/S0140-6736(12)60240-2)
- Barry, E., Greenhalgh, T., & Fahy, N. (2018). How are health-related behaviours influenced by a diagnosis of pre-diabetes? A meta-narrative review. *BMC Medicine*, 16(1). <https://doi.org/10.1186/s12916-018-1107-6>
- Bauman, A. E., Reis, R. S., Sallis, J. F., Wells, J. C., Loos, R. J. F., & Martin, B. W. (2012). Correlates of physical activity: Why are some people physically active and others not? *The Lancet*, 380(9838), 258–271. [https://doi.org/10.1016/S0140-6736\(12\)60735-1](https://doi.org/10.1016/S0140-6736(12)60735-1)
- Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, 117(3), 497–529. <https://doi.org/10.1037/0033-2909.117.3.497>
- Beaulac, J., Kristjansson, E., & Cummins, S. (2009). A systematic review of food deserts, 1966-2007. *Preventing Chronic Disease*, 6(3). <http://www.ncbi.nlm.nih.gov/pubmed/19527577>

- Benzian, H., Daar, A., & Naidoo, S. (2023). Redefining the non-communicable disease framework to a 6 × 6 approach: incorporating oral diseases and sugars. *The Lancet Public Health*, 8(11), e899–e904. [https://doi.org/10.1016/S2468-2667\(23\)00205-0](https://doi.org/10.1016/S2468-2667(23)00205-0)
- Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219–234. <https://doi.org/10.1177/1468794112468475>
- Bernell, S., & Howard, S. W. (2016). Use your words carefully: What is a chronic disease? *Frontiers in Public Health*, 4(August), 2–4. <https://doi.org/10.3389/fpubh.2016.00159>
- Bhaskar, R. (1978). *A realist theory of science*. Verso.
- 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(3), 363–386. <https://doi.org/10.1057/jphp.2014.19>
- Blawat, A., Green, E., Belloni, A., Jaccard, A., Adomako-Mensah, V., de Preux, L., Thiébaut, S., Sassi, F., Webber, L., & Retat, L. (2020). The health and social care costs of a selection of health conditions and multi-morbidities. https://assets.publishing.service.gov.uk/media/5f04447be90e075c4e144cfd/The_health_and_socialcare_costs_of_a_selection_of_health_conditions_and_multi-morbidities.pdf
- Bloxham, S., Barter, P., Scragg, S., Peers, C., Jane, B., & Layden, J. (2016). Person-centered, physical activity for patients with low back pain: Piloting service delivery. *Healthcare*, 4(2), 28. <https://doi.org/10.3390/healthcare4020028>

- Bloxham, S., Gibson, K., Layden, J., & Jane, B. (2021). Marjon Health & Wellbeing: A new approach to enable the self-management and prevention of long-term conditions in the community. In Research Excellence Framework 2021. <https://results2021.ref.ac.uk/impact/5f052fbf-f6e5-403b-a18f-ff3e579018d9?page=1>
- Bloxham, S. R., Layden, J., Jane, B., Peers, C., & Scragg, S. (2020). The longitudinal effects of a physical activity programme on the physical fitness and disability of back pain patients: Service evaluation. *Journal of Back and Musculoskeletal Rehabilitation*, 33(1), 7–13. <https://doi.org/10.3233/BMR-170856>
- Boakye, E. A., Varble, A., Rojek, R., Peavler, O., Trainer, A. K., Osazuwa-Peters, N., & Hinyard, L. (2018). Sociodemographic factors associated with engagement in diabetes self-management education among people with diabetes in the United States. *Public Health Reports*, 133(6), 685–691. <https://doi.org/10.1177/0033354918794935>
- Bobitt, J., Aguayo, L., Payne, L., Jansen, T., & Schwingel, A. (2019). Geographic and social factors associated with chronic disease Self-Management Program participation: Going the “extra-mile” for disease prevention. *Preventing Chronic Disease*, 16(3), 1–11. <https://doi.org/10.5888/pcd16.180385>
- Bogaert, B. (2021). Need for patient-developed concepts of empowerment to rectify epistemic injustice and advance person-centred care. *Journal of Medical Ethics*, 47(12), E15. <https://doi.org/10.1136/medethics-2020-106558>
- 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(7). <https://doi.org/10.1371/journal.pone.0130990>

- Boivin, A., Dumez, V., Castonguay, G., & Berkesse, A. (2022). The ecology of engagement: Fostering cooperative efforts in health with patients and communities. *Health Expectations*, November 2021. <https://doi.org/10.1111/hex.13571>
- Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J., Brozek, I., & Hughes, C. (2014). Reaching the hard-to-reach: A systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Medical Research Methodology*, 14(1). <https://doi.org/10.1186/1471-2288-14-42>
- Booth, A. (2016). Searching for qualitative research for inclusion in systematic reviews: A structured methodological review. *Systematic Reviews*, 5(1), 1–23. <https://doi.org/10.1186/s13643-016-0249-x>
- Booth, A., Briscoe, S., & Wright, J. (2019). The “Realist Search”: a systematic scoping review of current practice and reporting. *Research Synthesis Methods*. <https://ore.exeter.ac.uk/repository/handle/10871/39669>
- Booth, A., & Carroll, C. (2015). Systematic searching for theory to inform systematic reviews: Is it feasible? Is it desirable? *Health Information and Libraries Journal*, 32(3), 220–235. <https://doi.org/10.1111/hir.12108>
- Booth, A., Papaionnaou, D., & Sutton, A. (2016). *Systematic approaches to a successful literature review* (2nd Ed). SAGE.
- Booth, A., Sutton, A., Clowes, M., & Martyn-St James, M. (2022). *Systematic approaches to a successful literature review* (3rd ed). SAGE Publications Ltd.
- Borek, A. J., Abraham, C., Greaves, C. J., Gillison, F., Tarrant, M., Morgan-Trimmer, S., McCabe, R., & Smith, J. R. (2019). Identifying change processes in group-based health

behaviour-change interventions: development of the mechanisms of action in group-based interventions (MAGI) framework. *Health Psychology Review*, 13(3), 227–247. <https://doi.org/10.1080/17437199.2019.1625282>

Bossy, D., Knutsen, I. R., Rogers, A., & Foss, C. (2017). Group affiliation in self-management: support or threat to identity? *Health Expectations*, 20(1), 159–170. <https://doi.org/10.1111/hex.12448>

Bossy, D., Knutsen, I. R., Rogers, A., & Foss, C. (2019). Moving between ideologies in self-management support—A qualitative study. *Health Expectations*, 22(1), 83–92. <https://doi.org/10.1111/hex.12833>

Boudreaux, C., Noble, C., Coates, M. M., Kelley, J., Abanda, M., Kintu, A., McLaughlin, A., Marx, A., & Bukhman, G. (2020). Noncommunicable Disease (NCD) strategic plans in low- and lower-middle income Sub-Saharan Africa: framing and policy response. *Global Health Action*, 13(1). <https://doi.org/10.1080/16549716.2020.1805165>

Braithwaite, J., Churrua, K., Long, J. C., Ellis, L. A., & Herkes, J. (2018). When complexity science meets implementation science: A theoretical and empirical analysis of systems change. *BMC Medicine*, 16(1). <https://doi.org/10.1186/s12916-018-1057-z>

Brand, S., Bramley, L., Dring, E., & Musgrove, A. (2020). Using patient and public involvement to identify priorities for research in long-term conditions management. *British Journal of Nursing*, 29(11), 612–617. <https://doi.org/10.12968/bjon.2020.29.11.612>

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <http://www.ncbi.nlm.nih.gov/pubmed/11752478>

- Bright, F. A. S., Kayes, N. M., Cummins, C., Worrall, L. M., & McPherson, K. M. (2017). Co-constructing engagement in stroke rehabilitation: A qualitative study exploring how practitioner engagement can influence patient engagement. *Clinical Rehabilitation*, 31(10), 1396–1405. <https://doi.org/10.1177/0269215517694678>
- Bright, F. A. S., Kayes, N. M., Worrall, L., & McPherson, K. M. (2015). A conceptual review of engagement in healthcare and rehabilitation. *Disability and Rehabilitation*, 37(8), 643–654. <https://doi.org/10.3109/09638288.2014.933899>
- Britten, N., Moore, L., Lydahl, D., Naldemirci, O., Elam, M., & Wolf, A. (2017). Elaboration of the Gothenburg model of person-centred care. *Health Expectations*, 20(3), 407–418. <https://doi.org/10.1111/hex.12468>
- Brown-Podgorski, B. L., Shi, Y., & Vest, J. R. (2021). Patient need and provider referrals to diabetes self-management education. *The American Journal of Managed Care*, 27(6), e201–e207. <https://doi.org/10.37765/ajmc.2021.88669>
- Buffel du Vaure, C. B., 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(3). <https://doi.org/10.1136/bmjopen-2015-010119>
- Burton, C. D., Entwistle, V. A., Elliott, A. M., Krucien, N., Porteous, T., & Ryan, M. (2017). The value of different aspects of person-centred care: A series of discrete choice experiments in people with long-term conditions. *BMJ Open*, 7(4), 1–10. <https://doi.org/10.1136/bmjopen-2016-015689>
- Buse, K., Tanaka, S., & Hawkes, S. (2017). Healthy people and healthy profits? Elaborating a conceptual framework for governing the commercial determinants of non-

communicable diseases and identifying options for reducing risk exposure. In *Globalization and Health* (Vol. 13, Issue 1). BioMed Central Ltd. <https://doi.org/10.1186/s12992-017-0255-3>

Byng, R., Norman, I., & Redfern, S. (2005). Using realistic evaluation to evaluate a practice-level intervention to improve primary healthcare for patients with long-term mental illness. *Evaluation*, 11(1), 69–93. <https://doi.org/10.1177/1356389005053198>

Cane, J., O’connor, D., & Michie, S. (2012). Validation of the theoretical domains framework for use in behaviour change and implementation research. <http://www.implementationscience.com/content/7/1/37>

Carlin, A., Perchoux, C., Puggina, A., Aleksovska, K., Buck, C., Burns, C., Cardon, G., Chantal, S., Ciarapica, D., Condello, G., Coppinger, T., Cortis, C., D’Haese, S., De Craemer, M., Di Blasio, A., Hansen, S., Iacoviello, L., Issartel, J., Izzicupo, P., ... Boccia, S. (2017). A life course examination of the physical environmental determinants of physical activity behaviour: A “Determinants of Diet and Physical Activity” (DEDIPAC) umbrella systematic literature review. *PLoS ONE*, 12(8). <https://doi.org/10.1371/journal.pone.0182083>

Carnes, D., Homer, K. E., Miles, C. L., Pincus, T., Underwood, M., Rahman, A., & Taylor, S. J. C. (2012). Effective delivery styles and content for self-management interventions for chronic musculoskeletal pain. *The Clinical Journal of Pain*, 28(4), 344–354. <https://doi.org/10.1097/AJP.0b013e31822ed2f3>

Carr, S. M., Paliadelis, P., Lhussier, M., Forster, N., Eaton, S., Parmenter, G., & Death, C. (2014). Looking after yourself: Clinical understandings of chronic-care self-

management strategies in rural and urban contexts of the United Kingdom and Australia. *SAGE Open Medicine*, 2, 1–9. <https://doi.org/10.1177/2050312114532636>

Carroll, C., Patterson, M., Wood, S., Booth, A., Rick, J., & Balain, S. (2007). A conceptual framework for implementation fidelity. *Implementation Science*, 2(1), 1–9. <https://doi.org/10.1186/1748-5908-2-40>

Cassell, A., Edwards, D., Harshfield, A., Rhodes, K., Brimicombe, J., Payne, R., & Griffin, S. (2018). The epidemiology of multimorbidity in primary care. *British Journal of General Practice*, 68(669), 1–7.

Cauch-Dudek, K., Victore, J. C., Sigmond, M., & Shah, B. R. (2013). Disparities in attendance at diabetes self-management education programs after diagnosis in Ontario, Canada: a cohort study. *BMC Public Health*, 13(85), 1471–2458. <https://doi.org/10.1001/jama.1989.03430070055030>

Cavallo, M., Morgana, G., Dozzani, I., Gatti, A., Vandoni, M., Pippi, R., Pucci, G., Vaudo, G., & Fanelli, C. G. (2023). Unraveling barriers to a healthy lifestyle: Understanding barriers to diet and physical activity in patients with chronic non-communicable diseases. In *Nutrients* (Vol. 15, Issue 15). Multidisciplinary Digital Publishing Institute (MDPI). <https://doi.org/10.3390/nu15153473>

Cheng, L., Sit, J. W. H., Choi, K., Chair, S., Li, X., Wu, Y., Long, J., & Yang, H. (2021). The effects of an empowerment-based self-management intervention on empowerment level, psychological distress, and quality of life in patients with poorly controlled type 2 diabetes: A randomized controlled trial. *International Journal of Nursing Studies*, 116, 103407. <https://doi.org/10.1016/j.ijnurstu.2019.103407>

- Chiu, T. K. F. (2022). Applying the self-determination theory (SDT) to explain student engagement in online learning during the COVID-19 pandemic. *Journal of Research on Technology in Education*, 54(sup1), S14–S30. <https://doi.org/10.1080/15391523.2021.1891998>
- Clavel, N., Paquette, J., Dumez, V., Del Grande, C., Ghadiri, D. P., Pomey, M. P., & Normandin, L. (2021). Patient engagement in care: A scoping review of recently validated tools assessing patients' and healthcare professionals' preferences and experience. *Health Expectations*, 24(6), 1924–1935. <https://doi.org/10.1111/hex.13344>
- Cohn, S., Clinch, M., Bunn, C., & Stronge, P. (2013). Entangled complexity: Why complex interventions are just not complicated enough. *Journal of Health Services Research and Policy*, 18(1), 40–43. <https://doi.org/10.1258/jhsrp.2012.012036>
- Condello, G., Puggina, A., Aleksovska, K., Buck, C., Burns, C., Cardon, G., Carlin, A., Simon, C., Ciarapica, D., Coppinger, T., Cortis, C., D'Haese, S., De Craemer, M., Di Blasio, A., Hansen, S., Iacoviello, L., Issartel, J., Izzicupo, P., Jaeschke, L., ... Boccia, S. (2017). Behavioral determinants of physical activity across the life course: A “DEterminants of Diet and Physical ACTivity” (DEDIPAC) umbrella systematic literature review. *International Journal of Behavioral Nutrition and Physical Activity*, 14(1). <https://doi.org/10.1186/s12966-017-0510-2>
- Condon, L., Curejova, J., LEEANNE Morgan, D., Miles, G., Barry, D., & Fenlon, D. (2022). Public involvement in participatory research: the experiences of peer interviewers from Roma, Gypsy and Traveller communities. *Nurse Researcher*, 30(1), 17–23. <https://doi.org/10.7748/nr.2022.e1818>

- Connelly, J. (2001). Critical realism and health promotion: effective practice needs an effective theory. *Health Education Research*, 16(2), 115–120. <https://doi.org/10.1093/her/16.2.115>
- Conner, M., & Norman, P. (2017). Health behaviour: Current issues and challenges. *Psychology & Health*, 32(8), 895–906. <https://doi.org/10.1080/08870446.2017.1336240>
- Cookson, R., Proper, C., Asaria, M., & Raine, R. (2016). Socio-economic inequalities in health care in England. *Fiscal Studies*, 37(3–4), 371–403. <https://doi.org/10.1111/j.1475-5890.2016.12109>
- Cooper, S. (2017). *Participatory evaluation in youth and community work: Theory and practice*. Routledge.
- Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, 8(3), 224–247. <https://doi.org/10.1007/BF00989485>
- Corbin, J., & Strauss, A. (2015). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (4th ed). SAGE Publications Ltd.
- Coronini-Cronberg, S., John Maile, E., & Majeed, A. (2020). Health inequalities: the hidden cost of COVID-19 in NHS hospital trusts? *Journal of the Royal Society of Medicine*, 113(5), 179–184. <https://doi.org/10.1177/0141076820925230>
- Cortis, C., Puggina, A., Pesce, C., Aleksovska, K., Buck, C., Burns, C., Cardon, G., Carlin, A., Simon, C., Ciarapica, D., Condello, G., Coppinger, T., D’Haese, S., de Craemer, M., Di Blasio, A., Hansen, S., Iacoviello, L., Issartel, J., Izzicupo, P., ... Boccia, S. (2017). Psychological determinants of physical activity across the life course: A

“DEterminants of Diet and Physical ACTivity” (DEDIPAC) umbrella systematic literature review. PLoS ONE, 12(8). <https://doi.org/10.1371/journal.pone.0182709>

Cotton, D. R. E., Bloxham, S., Cooper, S., Downey, J., & Fornasiero, M. (2024). Breaking boundaries: a model of student-led knowledge exchange for higher education. *Journal of Further and Higher Education*, 48(2), 168–181. <https://doi.org/10.1080/0309877X.2023.2300384>

Coulter, A., Roberts, S., & Dixon, A. (2013). Delivering better services for people with long-term conditions. The King’s Fund, October, 1–28.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *The British Medical Journal*, 337. <https://doi.org/10.1136/bmj.a1655>

Crompvoets, P. I., Nieboer, A. P., van Rossum, E. F. C., & Cramm, J. M. (2024). Perceived weight stigma in healthcare settings among adults living with obesity: A cross-sectional investigation of the relationship with patient characteristics and person-centred care. *Health Expectations*, 27(1). <https://doi.org/10.1111/hex.13954>

Cronin, M. A., & George, E. (2023). The why and how of the integrative review. *Organizational Research Methods*, 26(1), 168–192. <https://doi.org/10.1177/1094428120935507>

Csikszentmihalyi, M. (2002). *Flow: The classic work on how to achieve happiness*. The Random House Group.

Currie, K., Bannerman, S., Howatson, V., MacLeod, F., Mayne, W., Organ, C., Renton, S., & Scott, J. (2015). ‘Stepping in’ or ‘stepping back’: How first year nursing students begin

to learn about person-centred care. *Nurse Education Today*, 35(1), 239–244.
<https://doi.org/10.1016/j.nedt.2014.06.008>

Cuthbert, C. A., Farragher, J. F., Hemmelgarn, B. R., Ding, Q., McKinnon, G. P., & Cheung, W. Y. (2019). Self-management interventions for cancer survivors: A systematic review and evaluation of intervention content and theories. *Psycho-Oncology*, 28(11), 2119–2140. <https://doi.org/10.1002/pon.5215>

Dahlgren, G., & Whitehead, M. (1991). Policies and strategies to promote social equity in health.

Dahlgren, G., & Whitehead, M. (2021). The Dahlgren-Whitehead model of health determinants: 30 years on and still chasing rainbows. *Public Health*, 199, 20–24.
<https://doi.org/10.1016/j.puhe.2021.08.009>

Dalkin, S., Forster, N., Hodgson, P., Lhussier, M., & Carr, S. M. (2016, October 3-5). Layering programme, pathway and substantive theories in realist evaluation. [Conference presentation]. Centre for the Advancement of Realist Evaluation and Synthesis (CARES), London, UK.
<https://researchportal.northumbria.ac.uk/en/publications/layering-programme-pathway-and-substantive-theories-in-realist-ev>

Dalkin, S., Forster, N., Hodgson, P., Lhussier, M., & Carr, S. M. (2021). Using computer assisted qualitative data analysis software (CAQDAS; NVivo) to assist in the complex process of realist theory generation, refinement and testing. *International Journal of Social Research Methodology*, 24(1), 123–134.
<https://doi.org/10.1080/13645579.2020.1803528>

- Dalkin, S., 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(1), 1–7. <https://doi.org/10.1186/s13012-015-0237-x>
- Damla, E., & Betül, A. (2023). An investigation of stigma and self-management in individuals diagnosed with epilepsy. *Epilepsy & Behavior*, 149, 109494. <https://doi.org/10.1016/j.yebeh.2023.109494>
- Davidoff, F., Dixon-Woods, M., Leviton, L., & Michie, S. (2015). Demystifying theory and its use in improvement. *BMJ Quality and Safety*, 24(3), 228–238. <https://doi.org/10.1136/bmjqs-2014-003627>
- Davidson, R., Kitzinger, J., & Hunt, K. (2006). The wealthy get healthy, the poor get poorly? Lay perceptions of health inequalities. *Social Science and Medicine*, 62(9), 2171–2182. <https://doi.org/10.1016/j.socscimed.2005.10.010>
- Davies, M. J., Kristunas, C. A., Alshreef, A., Dixon, S., Eborall, H., Glab, A., Huddleston, L., Hudson, N., Khunti, K., Martin, G., Northern, A., Patterson, M., Pritchard, R., Schreder, S., Stribling, B., Turner, J., & Gray, L. J. (2019). The impact of an intervention to increase uptake to structured self-management education for people with type 2 diabetes mellitus in primary care (the embedding package), compared to usual care, on glycaemic control: Study protocol for a mixed methods stu. *BMC Family Practice*, 20(1), 1–15. <https://doi.org/10.1186/s12875-019-1038-0>
- Davy, C., Bleasel, J., Liu, H., Tchan, M., Ponniah, S., & Brown, A. (2015). Effectiveness of chronic care models: Opportunities for improving healthcare practice and health outcomes: A systematic review. *BMC Health Services Research*, 15(1). <https://doi.org/10.1186/s12913-015-0854-8>

- De Hert, S. (2020). Burnout in healthcare workers: Prevalence, impact and preventative strategies. *Local and Regional Anesthesia*, 13, 171–183.
<https://doi.org/10.2147/LRA.S240564>
- de Silva, D. (2011). Helping people help themselves. In The Health Foundation.
<https://doi.org/10.1002/j.1551-8833.2000.tb08928.x>
- Dell'Olio, M., Whybrow, P., & Reeve, J. (2023). Examining the knowledge work of person-centred care: Towards epistemic reciprocity. *Patient Education and Counseling*, 107.
<https://doi.org/10.1016/j.pec.2022.107575>
- Dewing, J., & McCormack, B. (2015). Engagement: a critique of the concept and its application to person-centred care. *International Practice Development Journal*, 5(Suppl), 1–10. <https://doi.org/10.19043/ipdj.5sp.008>
- DiMatteo, M. R., Lepper, H. S., & Croghan, T. W. (2000). Depression is a risk factor for noncompliance with medical treatment meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine*, 160(14), 2101–2107.
<https://doi.org/10.1001/archinte.160.14.2101>
- DoH. (2012). Long Term Conditions Compendium of Information Third Edition.
- Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Dabrh, A. M. A., & Murad, M. H. (2014). Patient engagement in research: A systematic review. *BMC Health Services Research*, 14, 1–9.
<https://doi.org/10.1186/1472-6963-14-89>

- Downey, J., Bloxham, S., Jane, B., Layden, J. D., & Vaughan, S. (2021). Person-centered health promotion: Learning from 10 years of practice within long term conditions. *Healthcare (Switzerland)*, 9(4). <https://doi.org/10.3390/healthcare9040439>
- Downey, J., Harris, N., Rybczynska-Bunt, S., Golder, E., Shearn, K., & Bradley, N. (2024). Reflecting on reflexivity in realist evaluation: A call to action. *International Journal of Qualitative Methods*, 23. <https://doi.org/10.1177/16094069241284206>
- Downey, J., Shearn, K., Brown, N., Wadey, R., & Breckon, J. (2024). The implementation of behaviour change practices in Physical Activity Referral Schemes: a narrative review. *Health Psychology and Behavioral Medicine*, 12(1). <https://doi.org/10.1080/21642850.2023.2278293>
- Drake af Hagelsrum, K., Larsson, I., Bremander, A., Einarsson, J. T., Lindqvist, E., & Mogard, E. (2024). Lifestyle discussions facilitate self-management in RA: a qualitative study of patients' perceptions. *BMC Rheumatology*, 8(1). <https://doi.org/10.1186/s41927-024-00433-3>
- Duca, L. M., Helmick, C. G., Barbour, K. E., Guglielmo, D., Murphy, L. B., Boring, M. A., Theis, K. A., Odom, E. L., Liu, Y., & Croft, J. B. (2021). Self-management education class attendance and health care provider counseling for physical activity among adults with arthritis — United States, 2019. *MMWR. Morbidity and Mortality Weekly Report*, 70(42), 1466–1471. <https://doi.org/10.15585/mmwr.mm7042a2>
- Dumont, G. (2023). Immersion in organizational ethnography: four methodological requirements to immerse oneself in the field. *Organizational Research Methods*, 26(3), 441–458. <https://doi.org/10.1177/10944281221075365>

- Earnshaw, V. A., & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology*, 17(2), 157–168. <https://doi.org/10.1177/1359105311414952>
- Eassey, D., Reddel, H. K., Ryan, K., & Smith, L. (2020). 'It is like learning how to live all over again' A systematic review of people's experiences of living with a chronic illness from a self-determination theory perspective. *Health Psychology and Behavioral Medicine*, 8(1), 270–291. <https://doi.org/10.1080/21642850.2020.1794879>
- Easton, G. (2010). Critical realism in case study research. *Industrial Marketing Management*, 39(1), 118–128. <https://doi.org/10.1016/j.indmarman.2008.06.004>
- Eaton, S., Roberts, S., & Turner, B. (2015). Delivering person centred care in long term conditions. *BMJ (Online)*, 350(February), 1–4. <https://doi.org/10.1136/bmj.h181>
- Edmondson, A. C., & Lei, Z. (2014). Psychological safety: the history, renaissance, and future of an interpersonal construct. *Annual Review of Organizational Psychology and Organizational Behavior*, 1, 23–43. <https://doi.org/10.1146/annurev-orgpsych-031413-091305>
- Elster, J. (2007). *Explaining social behaviour*. Cambridge University Press.
- Emmel, N. (2013). *Sampling and choosing cases in qualitative research: a realist approach*. SAGE Publications Ltd.
- Emmel, N., Greenhalgh, J., Manzano, A., Monaghan, M., & Dalkin, S. (Eds.). (2018). *Doing realist research*. SAGE Publications Ltd.
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196(4286), 129–136. <https://doi.org/10.1126/science.847460>

- Enriquez, J. P., & Archila-Godinez, J. C. (2022). Social and cultural influences on food choices: A review. In *Critical Reviews in Food Science and Nutrition* (Vol. 62, Issue 13, pp. 3698–3704). Taylor and Francis Ltd. <https://doi.org/10.1080/10408398.2020.1870434>
- Erdem, E., & Korda, H. (2014). Self-management program participation by older adults with diabetes: Chronic disease self-management program and diabetes self-management program. *Family and Community Health*, 37(2), 134–146. <https://doi.org/10.1097/FCH.0000000000000025>
- Estecha Querol, S., Clarke, P., Sattler, E. L. P., Halford, J. C. G., & Gabbay, M. (2020). Non-visible disease, the hidden disruptive experiences of chronic illness in adversity. *International Journal of Qualitative Studies on Health and Well-Being*, 15(1). <https://doi.org/10.1080/17482631.2020.1857579>
- Eton, D., Elraiyah, T. A., Yost, K., Ridgeway, J., Johnson, A., Egginton, J., Mullan, R. J., Murad, M. H., Erwin, P., & Montori, V. (2013). A systematic review of patient-reported measures of burden of treatment in three chronic diseases. *Patient Related Outcome Measures*, 7. <https://doi.org/10.2147/prom.s44694>
- Evans, D. (2002). Database searches for qualitative research. *Journal of the Medical Library Association*, 90(3), 290–293.
- Evans, M., & Boucher, A. R. (2015). Optimizing the power of choice: Supporting student autonomy to foster motivation and engagement in learning. *Mind, Brain and Education*, 9(2), 87-91. <https://doi.org/10.1111/mbe.12073>

- Falasinnu, T., Bao, G., Brady, T. J., Lim, S. S., & Drenkard, C. (2021). Factors associated with the initiation and retention of patients with lupus in the chronic disease self-management program. *Arthritis Care & Research*. <https://doi.org/10.1002/acr.24811>
- Faro, J. M., Mattocks, K. M., Mourao, D., Nagawa, C. S., Lemon, S. C., Wang, B., Cutrona, S. L., & Sadasivam, R. S. (2021). Experiences and perceptions of referrals to a community-based physical activity program for cancer survivors: a qualitative exploration. *BMC Health Services Research*, 21(1), 1–10. <https://doi.org/10.1186/s12913-021-06365-9>
- Farre, A., & Rapley, T. (2017). The new old (and old new) medical model: four decades navigating the biomedical and psychosocial understandings of health and illness. *Healthcare*, 5(4), 88. <https://doi.org/10.3390/healthcare5040088>
- Ferguson, L., Taylor, J., Zhou, K., Shrubsole, C., Symonds, P., Davies, M., & Dimitroulopoulou, S. (2021). Systemic inequalities in indoor air pollution exposure in London, UK. *Buildings and Cities*, 2(1), 425–448. <https://doi.org/10.5334/bc.100>
- Ferrari, R. (2015). Writing narrative style literature reviews. *The European Medical Writers Association*, 24(4). <https://doi.org/10.1037/1089-2680.1.3.311>
- Fleming, M. D., Shim, J. K., Yen, I., Thompson-Lastad, A., Rubin, S., Van Natta, M., & Burke, N. J. (2017a). Patient engagement at the margins: Health care providers' assessments of engagement and the structural determinants of health in the safety-net. *Social Science and Medicine*, 183, 11–18. <https://doi.org/10.1016/j.socscimed.2017.04.028>
- Fleming, M. D., Shim, J. K., Yen, I., Thompson-Lastad, A., Rubin, S., Van Natta, M., & Burke, N. J. (2017b). Patient engagement at the margins: Health care providers' assessments

of engagement and the structural determinants of health in the safety-net. *Social Science and Medicine*, 183, 11–18. <https://doi.org/10.1016/j.socscimed.2017.04.028>

Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, 20(2), 181–194. <https://doi.org/10.1080/13645579.2016.1144401>

Fletcher, S., Kulnik, S. T., Demain, S., & Jones, F. (2019). The problem with self-management: Problematising self-management and power using a Foucauldian lens in the context of stroke care and rehabilitation. *PLoS ONE*, 14(6). <https://doi.org/10.1371/journal.pone.0218517>

Foster, G., Taylor, S. J., Eldridge, S., Ramsay, J., & Griffiths, C. J. (2007). Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD005108.pub2>

Franklin, M., Lewis, S., Willis, K., Bourke-Taylor, H., & Smith, L. (2018). Patients' and healthcare professionals' perceptions of self-management support interactions: Systematic review and qualitative synthesis. *Chronic Illness*, 14(2), 79–103. <https://doi.org/10.1177/1742395317710082>

Franklin, M., Willis, K., Lewis, S., Rogers, A., & Smith, L. (2021). Between knowing and doing person-centredness: A qualitative examination of health professionals' perceptions of roles in self-management support. *Health (United Kingdom)*, 25(3), 339–356. <https://doi.org/10.1177/1363459319889087>

Frohlich, K. L., & Potvin, L. (2008). Transcending the known in public health practice: The inequality paradox: The population approach and vulnerable populations. In *American*

Journal of Public Health (Vol. 98, Issue 2, pp. 216–221). American Public Health Association. <https://doi.org/10.2105/AJPH.2007.114777>

Fukami, T. (2023). Shared decision making with psychological safety. *The Lancet*, 401(10383), 1153–1154. [https://doi.org/10.1016/S0140-6736\(23\)00344-6](https://doi.org/10.1016/S0140-6736(23)00344-6)

Fuller, J. (2017). The new medical model: a renewed challenge for biomedicine. *Canadian Medical Association Journal*, 189(17), E640–E641. <https://doi.org/10.1503/cmaj.160627>

Fumagalli, L. P., Radaelli, G., Lettieri, E., Berteletti, P., & Masella, C. (2015). Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. *Health Policy*, 119(3), 384–394. <https://doi.org/10.1016/j.healthpol.2014.10.017>

Furley, P., & Goldschmied, N. (2021). Systematic vs. narrative reviews in sport and exercise psychology: Is either approach superior to the other? *Frontiers in Psychology*, 12. <https://doi.org/10.3389/fpsyg.2021.685082>

Galazka, A. M., Edwards, T., & Harding, K. (2021). Realist evaluation of social outcomes in community care: The application of affordance theory to the Lindsay Leg Clubs. *Journal of Critical Realism*, 20(3), 280-299.

Galazka, A. M. (2023). Field, place or space? A carnal ethnography of a therapeutic space-construct. *Journal of Organizational Ethnography*, 12(2), 209-222.

Gascon, S., Leiter, M. P., Andrés, E., Santed, M. A., Pereira, J. P., Cunha, M. J., Albesa, A., Montero-Marín, J., García-Campayo, J., & Martínez-Jarreta, B. (2013). The role of aggressions suffered by healthcare workers as predictors of burnout. *Journal of*

Clinical Nursing, 22(21–22), 3120–3129. <https://doi.org/10.1111/j.1365-2702.2012.04255.x>

Ghazaleh, H. A., Artom, M., & Sturt, J. (2019). A systematic review of community Leg Clubs for patients with chronic leg ulcers. *Primary Health Care Research & Development*, 20, e65.

Gibbons, C., Porter, I., Gonçalves-Bradley, D. C., Stoilov, S., Ricci-Cabello, I., Tsangaris, E., Gangannagaripalli, J., Davey, A., Gibbons, E. J., Kotzeva, A., Evans, J., van der Wees, P. J., Kontopantelis, E., Greenhalgh, J., Bower, P., Alonso, J., & Valderas, J. M. (2021). Routine provision of feedback from patient-reported outcome measurements to healthcare providers and patients in clinical practice. *Cochrane Database of Systematic Reviews*, 2021(10). <https://doi.org/10.1002/14651858.CD011589.pub2>

Gibson, K., & Malcolm, D. (2020). Theorizing physical activity health promotion: towards an Eliasian framework for the analysis of health and medicine. *Social Theory and Health*, 18(1), 66–85. <https://doi.org/10.1057/s41285-019-00098-w>

Gilfoyle, M., Melro, C., Koskinas, E., & Salsberg, J. (2023). Recruitment of patients, carers and members of the public to advisory boards, groups and panels in public and patient involved health research: a scoping review. *BMJ Open*, 13(10). <https://doi.org/10.1136/bmjopen-2023-072918>

Gilmore, B. (2019). Realist evaluations in low- and middle-income countries: reflections and recommendations from the experiences of a foreign researcher. *BMJ Global Health*, 4(5), 1–8. <https://doi.org/10.1136/bmjgh-2019-001638>

- Gilmore, B., McAuliffe, E., Power, J., & Vallières, F. (2019). Data analysis and synthesis within a realist evaluation: Toward more transparent methodological approaches. *International Journal of Qualitative Methods*, 18, 1–11. <https://doi.org/10.1177/1609406919859754>
- Girard, M., Kaczorowski, J., Lussier, M. T., & Martin, V. (2021). Attendance, activation and health profiles of participants, a prospective study on a regional cardiometabolic disease self-management program in Laval, Canada. *BMC Public Health*, 21(1), 1–8. <https://doi.org/10.1186/s12889-021-10558-6>
- Godziewski, C. (2021). Is 'Health in All Policies' everybody's responsibility? Discourses of multistakeholderism and the lifestyle drift phenomenon. *Critical Policy Studies*, 15(2), 229–246. <https://doi.org/10.1080/19460171.2020.1795699>
- Gold, R. L. (1958). Roles in sociological field observations. *Social Forces*, 36(3), 217–223.
- Golubinski, V., & Wild, E.-M. (2021). Factors associated with patient activation in a socially deprived population: Evidence from Germany. *Patient Education and Counseling*, 104(11), 2791–2802. <https://doi.org/10.1016/j.pec.2021.03.039>
- Gordon, R., & Bloxham, S. (2017). Influence of the Fitbit Charge HR on physical activity, aerobic fitness and disability in non-specific back pain participants. *Journal of Sports Medicine and Physical Fitness*, 57(12), 1669–1675. <https://doi.org/10.23736/S0022-4707.17.06665-8>
- Górna, K., Szpalik, R., Rybakowski, J. K., & Jaracz, K. (2023). Health behaviours of patients with affective disorders: a cross-sectional study. *BMC Psychiatry*, 23(1). <https://doi.org/10.1186/s12888-023-05056-5>

- Gough, D., Oliver, S., & Thomas, J. (2017). *An introduction to systematic reviews* (2nd ed). SAGE Publications Ltd.
- Govindaraj, R., Agar, M., Currow, D., & Lockett, T. (2023). Assessing patient-reported outcomes in routine cancer clinical care using electronic administration and telehealth technologies: realist synthesis of potential mechanisms for improving health outcomes. *Journal of Medical Internet Research*, 25(1), e48483. <https://doi.org/10.2196/48483>
- Grady, P. A., & Gough, L. L. (2014). Self-management: A comprehensive approach to management of chronic conditions. *American Journal of Public Health*, 108(8). <https://doi.org/10.2105/AJPH.2014.302041>
- Graffigna, G. (2017). Is a transdisciplinary theory of engagement in organized settings possible? A concept analysis of the literature on employee engagement, consumer engagement and patient engagement. *Frontiers in Psychology*, 8(JUL), 1–17. <https://doi.org/10.3389/fpsyg.2017.00872>
- Graffigna, G., & Barello, S. (2018). Spotlight on the patient health engagement model (PHE model): A psychosocial theory to understand people's meaningful engagement in their own health care. *Patient Preference and Adherence*, 12, 1261–1271. <https://doi.org/10.2147/PPA.S145646>
- Graffigna, G., Barello, S., Bonanomi, A., & Lozza, E. (2015). Measuring patient engagement: Development and psychometric properties of the patient health engagement (PHE) scale. *Frontiers in Psychology*, 6(MAR), 1–10. <https://doi.org/10.3389/fpsyg.2015.00274>

- Graffigna, G., Barello, S., Riva, G., Corbo, M., Damiani, G., Iannone, P., Bosio, A. C., & Ricciardi, W. (2020). Italian consensus statement on patient engagement in chronic care: Process and outcomes. *International Journal of Environmental Research and Public Health*, 17(11), 1–27. <https://doi.org/10.3390/ijerph17114167>
- Graffigna, G., Barello, S., & Triberti, S. (2016). Giving (back) a role to patients in the delivery of healthcare services: Theoretical roots of patient engagement. *Patient Engagement: A Consumer-Centered Model to Innovate Healthcare*, 13–26. <https://doi.org/10.1515/9783110452440-003>
- Green, J., & Lynch, R. (2022). Rethinking chronicity: public health and the problem of temporality. In *Critical Public Health* (Vol. 32, Issue 4, pp. 433–437). Routledge. <https://doi.org/10.1080/09581596.2022.2101432>
- Greenhalgh, J., & Emmel, N. (2018). ‘The harmony of social theory in evaluation’ – commentary on ‘The art and science of non-evaluation evaluation.’ *Journal of Health Services Research and Policy*, 23(4), 270–271. <https://doi.org/10.1177/1355819618790991>
- Greenhalgh, J., Gooding, K., Gibbons, E., Dalkin, S., Wright, J., Valderas, J., & Black, N. (2018). How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? a realist synthesis. *Journal of Patient-Reported Outcomes*, 2. <https://doi.org/10.1186/s41687-018-0061-6>
- Greenhalgh, J., & Manzano, A. (2021). Understanding ‘context’ in realist evaluation and synthesis. *International Journal of Social Research Methodology*, 00(00), 1–14. <https://doi.org/10.1080/13645579.2021.1918484>

- Greenhalgh, T., & Papoutsis, C. (2019). Spreading and scaling up innovation and improvement. *BMJ (Online)*, 365(May), 1–8. <https://doi.org/10.1136/bmj.l2068>
- Greenhalgh, T., Pawson, R., Wong, G., Westhorp, G., Greenhalgh, J., Manzano, A., & Jagosh, J. (2017a). Quality standards for realist evaluation: For evaluators and peer-reviewers.
http://ramesesproject.org/media/RE_Quality_Standards_for_evaluators_and_peer_reviewers.pdf
- Greenhalgh, T., Pawson, R., Wong, G., Westhorp, G., Greenhalgh, J., Manzano, M., & Jagosh, J. (2017b). Retrodution in realist evaluation: RAMESES II Project.
- Greenhalgh, T., Pawson, R., Wong, G., Westhorp, G., Greenhalgh, J., Manzano-Santaella, A., & Jagosh, J. (2017c). Realist evaluation and ethical considerations. 1–3.
<http://evaluation.ishtm.ac.uk/2017/03/27/realist-evaluation-mechanisms/>
- Greenhalgh, T., Robert, G., MacFarlane, F., Bate, P., Kyriakidou, O., & Peacock, R. (2005). Storylines of research in diffusion of innovation: A meta-narrative approach to systematic review. *Social Science and Medicine*, 61(2), 417–430.
<https://doi.org/10.1016/j.socscimed.2004.12.001>
- Greenhalgh, T., Thorne, S., & Malterud, K. (2018). Time to challenge the spurious hierarchy of systematic over narrative reviews? *European Journal of Clinical Investigation*, 48(6), 1–6. <https://doi.org/10.1111/eci.12931>
- Greenhalgh, T., Wong, G., Jagosh, J., Greenhalgh, J., Manzano, A., Westhorp, G., & Pawson, R. (2015). Protocol-the RAMESES II study: Developing guidance and reporting standards for realist evaluation. *BMJ Open*, 5(8).
<https://doi.org/10.1136/bmjopen-2015-008567>

- Gregersen, M. H., Nielsen, K. R., Lynge, N. H., Heiberg, B. D., Hartvigsen, J., Kawchuk, G., & Kongsted, A. (2024). Goal setting in people with low back pain attending an education and exercise program (GLA: D Back) and the impact of demographic factors. *BMC Musculoskeletal Disorders*, 25(1), 339.
- Grover, S., Fitzpatrick, A., Azim, F. T., Ariza-Vega, P., Bellwood, P., Burns, J., Burton, E., Fleig, L., Clemson, L., Hoppmann, C. A., Madden, K. M., Price, M., Langford, D., & Ashe, M. C. (2022). Defining and implementing patient-centered care: An umbrella review. In *Patient Education and Counseling* (Vol. 105, Issue 7, pp. 1679–1688). Elsevier Ireland Ltd. <https://doi.org/10.1016/j.pec.2021.11.004>
- Gucciardi, E., Reynolds, E., Karam, G., Beanlands, H., Sidani, S., & Espin, S. (2021). Group-based storytelling in disease self-management among people with diabetes. *Chronic Illness*, 17(3), 306–320. <https://doi.org/10.1177/1742395319859395>
- Gudgeon, M., Wilkinson, A., & Hale, L. (2023). Healthcare professional students' perceptions of supporting patient self-management: A mixed method study. *Chronic Illness*, 19(2), 395–408. <https://doi.org/doi:10.1177/17423953211073367>
- Haig, B. D., & Evers, C. W. (2016). *Realist inquiry in social science*. SAGE Publications Ltd.
- Hajdarevic, S., Norberg, A., Lundman, B., & Hörnsten, Å. (2024). Becoming whole again—Caring for the self in chronic illness—A narrative review of qualitative empirical studies. In *Journal of Clinical Nursing*. John Wiley and Sons Inc. <https://doi.org/10.1111/jocn.17332>
- Halvorsen, K., Dihle, A., Hansen, C., Nordhaug, M., Jerpseth, H., Tveiten, S., Joranger, P., & Ruud Knutsen, I. (2020). Empowerment in healthcare: A thematic synthesis and critical discussion of concept analyses of empowerment. In *Patient Education and*

Counseling (Vol. 103, Issue 7, pp. 1263–1271). Elsevier Ireland Ltd.
<https://doi.org/10.1016/j.pec.2020.02.017>

Handley, M., Bunn, F., Lynch, J., & Goodman, C. (2020). Using non-participant observation to uncover mechanisms: Insights from a realist evaluation. *Evaluation*, 26(3), 380–393. <https://doi.org/10.1177/1356389019869036>

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 Policy Partnership* 1–140.
<https://www.healthpolicypartnership.com/app/uploads/The-state-of-play-in-person-centred-care-summary.pdf>

Hardman, R., Begg, S., & Spelten, E. (2020). What impact do chronic disease self-management support interventions have on health inequity gaps related to socioeconomic status: A systematic review. *BMC Health Services Research*, 20(1).
<https://doi.org/10.1186/s12913-020-5010-4>

Harris, S., Joyce, H., Miller, A., Connor, C., Amiel, S. A., & Mulnier, H. (2018). The attitude of healthcare professionals plays an important role in the uptake of diabetes self-management education: analysis of the Barriers to Uptake of Type 1 Diabetes Education (BUD1E) study survey. *Diabetic Medicine*, 35(9), 1189–1196.
<https://doi.org/10.1111/dme.13704>

Harris, S., Miller, A., Amiel, S., & Mulnier, H. (2019). Characterization of adults with type 1 diabetes not attending self-management education courses: The Barriers to Uptake of Type 1 Diabetes Education (BUD1E) Study. *Qualitative Health Research*, 29(8), 1174–1185. <https://doi.org/10.1177/1049732318823718>

- Harris, S., Shah, P., Mulnier, H., Healey, A., Thomas, S. M., Amiel, S. A., & Hopkins, D. (2017). Factors influencing attendance at structured education for Type 1 diabetes in south London. *Diabetic Medicine*, 34(6), 828–833. <https://doi.org/10.1111/dme.13333>
- Harvey, P. W., & Docherty, B. M. (2007). Sisyphus and self-management: the chronic condition self-management paradox. *Australian Health Review : A Publication of the Australian Hospital Association*, 31(2), 184–192. <https://doi.org/10.1071/AH070184>
- Heath, A., Levay, P., & Tuvey, D. (2022). Literature searching methods or guidance and their application to public health topics: A narrative review. *Health Information and Libraries Journal*, 39(1), 6–21. <https://doi.org/10.1111/hir.12414>
- Heggdal, K., Mendelsohn, J. B., Stepanian, N., Oftedal, B. F., & Larsen, M. H. (2021). Health-care professionals' assessment of a person-centred intervention to empower self-management and health across chronic illness: Qualitative findings from a process evaluation study. *Health Expectations*, 24(4), 1367–1377. <https://doi.org/10.1111/hex.13271>
- Helduser, J. W., Bolin, J. N., Vuong, A. M., Moudouni, D. M., Begaye, D. S., Huber, J. C., Ory, M. G., & Forjuoh, S. N. (2013). Factors associated with successful completion of the chronic disease self-management program by adults with type 2 diabetes. *Family and Community Health*, 36(2), 147–157. <https://doi.org/10.1097/FCH.0b013e318282b3d1>
- Henderson, S., Horne, M., Hills, R., & Kendall, E. (2018). Cultural competence in healthcare in the community: A concept analysis. *Health & Social Care in the Community*, 26(4), 590–603. <https://doi.org/10.1111/hsc.12556>

- Hendriks, M., & Rademakers, J. (2014). Relationships between patient activation, disease-specific knowledge and health outcomes among people with diabetes; a survey study. *BMC Health Services Research*, 14(1), 393. <https://doi.org/10.1186/1472-6963-14-393>
- Herrick, C. (2022). Clean problems: Simplicity, complexity and the contemporary history of global noncommunicable disease prioritisation. *SSM - Qualitative Research in Health*, 2. <https://doi.org/10.1016/j.ssmqr.2022.100068>
- Hessler, D. M., Fisher, L., Bowyer, V., Dickinson, L. M., Jortberg, B. T., Kwan, B., Fernald, D. H., Simpson, M., & Dickinson, W. P. (2019). Self-management support for chronic disease in primary care: Frequency of patient self-management problems and patient reported priorities, and alignment with ultimate behavior goal selection. *BMC Family Practice*, 20(1). <https://doi.org/10.1186/s12875-019-1012-x>
- Hibbard, J. H., & Mahoney, E. (2010). Toward a theory of patient and consumer activation. *Patient Education and Counseling*, 78(3), 377–381. <https://doi.org/10.1016/j.pec.2009.12.015>
- Hickmann, E., Richter, P., & Schlieter, H. (2022). All together now – patient engagement, patient empowerment, and associated terms in personal healthcare. *BMC Health Services Research*, 22(1), 1–11. <https://doi.org/10.1186/s12913-022-08501-5>
- Higgins, T., Larson, E., & Schnall, R. (2017). Unraveling the meaning of patient engagement: A concept analysis. *Patient Education and Counseling*, 100(1), 30–36. <https://doi.org/10.1016/j.pec.2016.09.002>
- Hobbs, M., Milfont, T. L., Marek, L., Yogeeswaran, K., & Sibley, C. G. (2022). The environment an adult resides within is associated with their health behaviours, and

their mental and physical health outcomes: a nationwide geospatial study. *Social Science and Medicine*, 301. <https://doi.org/10.1016/j.socscimed.2022.114801>

Horigan, G., Davies, M., Findlay-White, F., Chaney, D., & Coates, V. (2017). Reasons why patients referred to diabetes education programmes choose not to attend: a systematic review. *Diabetic Medicine*, 34(1), 14–26. <https://doi.org/10.1111/dme.13120>

Horrell, L., Knafl, G. J., Brady, T., Lazard, A., Linnan, L., & Kneipp, S. (2020). Communication cues and engagement behavior: Identifying advertisement strategies to attract middle-aged adults to a study of the Chronic Disease Self-Management Program. *Preventing Chronic Disease*, 17, 1–9. <https://doi.org/10.5888/pcd17.190413>

Horrell, L., & Kneipp, S. (2017). Strategies for recruiting populations to participate in the Chronic Disease Self-Management Program (CDSMP): A Systematic Review. *Health Mark Q*, 34(4), 268–283. <https://doi.org/10.1080/07359683.2017.1375240>.Strategies

Howell, D., Mayer, D. K., Fielding, R., Eicher, M., Verdonck-de Leeuw, I. M., Johansen, C., Soto-Perez-de-Celis, E., Foster, C., Chan, R., Alfano, C. M., Hudson, S. V, Jefford, M., Lam, W. W. T., Loerzel, V., Pravettoni, G., Rammant, E., Schapira, L., Stein, K. D., & Koczwara, B. (2021). Management of cancer and health after the clinic visit: A call to action for self-management in cancer care. *JNCI: Journal of the National Cancer Institute*, 113(5), 523–531. <https://doi.org/10.1093/jnci/djaa083>

Hughes, S., Lewis, S., Willis, K., Rogers, A., Wyke, S., & Smith, L. (2017). The experience of facilitators and participants of long term condition self-management group programmes: A qualitative synthesis. *Patient Education and Counseling*, 100(12), 2244–2254. <https://doi.org/10.1016/j.pec.2017.06.035>

- Hughes, S., Lewis, S., Willis, K., Rogers, A., Wyke, S., & Smith, L. (2020). How do facilitators of group programmes for long-term conditions conceptualise self-management support? *Chronic Illness*, 16(2), 104–118. <https://doi.org/10.1177/1742395318792068>
- Institute for Health Metrics and Evaluation (IHME). (2024). Global Burden of Disease 2021: Findings from the GBD 2021 study. <https://www.healthdata.org/research-analysis/library/global-burden-disease-2021-findings-gbd-2021-study>
- Jackson, M., Jones, D., Dyson, J., & Macleod, U. (2019). Facilitated group work for people with long-term conditions: a systematic review of benefits from studies of group-work interventions. *British Journal of General Practice*, e363–e372.
- Jackson, S. F., & Kolla, G. (2012). A new realistic evaluation analysis method: Linked coding of context, mechanism, and outcome relationships. *American Journal of Evaluation*, 33(3), 339–349. <https://doi.org/10.1177/1098214012440030>
- Jagosh, J. (2019). Realist synthesis for public health: Building an ontologically deep understanding of how programs work, for whom, and in which contexts. *Annual Review of Public Health*, 40, 361–372. <https://doi.org/10.1146/annurev-publhealth-031816-044451>
- Jagosh, J. (2020). Retroductive theorizing in Pawson and Tilley's applied scientific realism. *Journal of Critical Realism*, 19(2), 121–130. <https://doi.org/10.1080/14767430.2020.1723301>
- Jagosh, J., Bush, P. L., Salsberg, J., Macaulay, A. C., Greenhalgh, T., Wong, G., Cargo, M., Green, L. W., Herbert, C. P., & Pluye, P. (2015). A realist evaluation of community-based participatory research: Partnership synergy, trust building and related ripple effects. *BMC Public Health*, 15(1), 1–11. <https://doi.org/10.1186/s12889-015-1949-1>

- 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(2), 131–141. <https://doi.org/10.1002/jrsm.1099>
- Jagosh, J., Stott, H., Halls, S., Thomas, R., Liddiard, C., Cupples, M., Cramp, F., Kersten, P., Foster, D., & Walsh, N. E. (2022). Benefits of realist evaluation for rapidly changing health service delivery. *BMJ Open*, 12(7), 1–5. <https://doi.org/10.1136/bmjopen-2021-060347>
- Jahandideh, S., Kendall, E., Low-Choy, S., Donald, K., & Jayasinghe, R. (2018). The process of patient engagement in cardiac rehabilitation: A model-centric systematic review. *Behaviour Change*, 35(4), 185–202. <https://doi.org/10.1017/bec.2018.20>
- James, T. L. (2021). Improving referrals to diabetes self-management education in medically underserved adults. *Diabetes Spectrum*, 34(1), 20–26. <https://doi.org/10.2337/ds20-0001>
- Jane, B., & Gibson, K. (2018). Corporate sponsorship of physical activity promotion programmes: Part of the solution or part of the problem? *Journal of Public Health (United Kingdom)*, 40(2), 279–288. <https://doi.org/10.1093/pubmed/fox065>
- Jiang, L., Smith, M. L., Chen, S., Ahn, S. N., Kulinski, K. P., Lorig, K., & Ory, M. G. (2015). The role of session zero in successful completion of Chronic Disease Self-Management Program workshops. *Frontiers in Public Health*, 2(APR), 1–6. <https://doi.org/10.3389/fpubh.2014.00205>

- Johnson, M. T. (2022). The knowledge exchange framework: understanding parameters and the capacity for transformative engagement. *Studies in Higher Education*, 47(1), 194–211. <https://doi.org/10.1080/03075079.2020.1735333>
- Jones, M. C., MacGillivray, S., Kroll, T., Zohoor, A. R., & Connaghan, J. (2011). A thematic analysis of the conceptualisation of self-care, self-management and self-management support in the long-term conditions management literature. *Journal of Nursing and Healthcare of Chronic Illness*, 3(3), 174–185. <https://doi.org/10.1111/j.1752-9824.2011.01096.x>
- Jonkman, N. H. (2016). Self-management interventions for patients with a chronic disease: what works and in whom? [Unpublished doctoral dissertation]. University Utrecht.
- Jonkman, N. H., Schuurmans, M. J., Jaarsma, T., Shortridge-Baggett, L. M., Hoes, A. W., & Trappenburg, J. C. A. (2016). Self-management interventions: Proposal and validation of a new operational definition. *Journal of Clinical Epidemiology*, 80, 34–42. <https://doi.org/10.1016/j.jclinepi.2016.08.001>
- Kane, P. M., Murtagh, F. E. M., Ryan, K., Mahon, N. G., McAdam, B., McQuillan, R., Ellis-Smith, C., Tracey, C., Howley, C., Raleigh, C., O’Gara, G., Higginson, I. J., & Daveson, B. A. (2015). The gap between policy and practice: a systematic review of patient-centred care interventions in chronic heart failure. *Heart Failure Reviews*, 20(6), 673–687. <https://doi.org/10.1007/s10741-015-9508-5>
- Katz, I., & Assor, A. (2007). When choice motivates and when it does not. *Educational Psychology Review*, 19(4), 429–442. <https://doi.org/10.1007/s10648-006-9027-y>
- Kendall, E., Ehrlich, C., Sunderland, N., Muenchberger, H., & Rushton, C. (2011). Self-managing versus self-management: Reinvigorating the socio-political dimensions of

self-management. Chronic Illness, 7(1), 87–98.
<https://doi.org/10.1177/1742395310380281>

Kendall, E., & Rogers, A. (2007). Extinguishing the social?: State sponsored self-care policy and the Chronic Disease Self-management Programme. In *Disability and Society* (Vol. 22, Issue 2, pp. 129–143). <https://doi.org/10.1080/09687590601141535>

Keogh, A., Tully, M. A., Matthews, J., & Hurley, D. A. (2015). A review of behaviour change theories and techniques used in group based self-management programmes for chronic low back pain and arthritis. *Manual Therapy*, 20(6), 727–735.
<https://doi.org/10.1016/j.math.2015.03.014>

Keyworth, C., Epton, T., Goldthorpe, J., Calam, R., & Armitage, C. J. (2018). Are healthcare professionals delivering opportunistic behaviour change interventions? A multi-professional survey of engagement with public health policy. *Implementation Science*, 13(1), 1–9. <https://doi.org/10.1186/s13012-018-0814-x>

Khan, M. M., Roberson, S., Reid, K., Jordan, M., & Odoi, A. (2021). Geographic disparities and temporal changes of diabetes prevalence and diabetes self-management education program participation in Florida. *PLoS ONE*, 16(7 July), 1–22.
<https://doi.org/10.1371/journal.pone.0254579>

Kickbusch, I., Allen, L., & Franz, C. (2016). The commercial determinants of health. *The Lancet Global Health*, 4(12), e895–e896. [https://doi.org/10.1016/S2214-109X\(16\)30217-0](https://doi.org/10.1016/S2214-109X(16)30217-0)

Kimerling, R., Lewis, E. T., Javier, S. J., & Zulman, D. M. (2020). Opportunity or burden? A behavioral framework for patient engagement. *Medical Care*, 58(2), 161–168.
<https://doi.org/10.1097/MLR.0000000000001240>

- Kingston, A., Robinson, L., Booth, H., Knapp, M., Jagger, C., Adelaja, B., Avendano, M., Bamford, S. M., Banerjee, S., Berwald, S., Bowling, A., Burgon, C., Bustard, E., Comas-Herrera, A., Dangoor, M., Dixon, J., Farina, N., Greengross, S., Grundy, E., Wittenberg, R. (2018). Projections of multi-morbidity in the older population in England to 2035: Estimates from the Population Ageing and Care Simulation (PACSim) model. *Age and Ageing*, 47(3), 374–380. <https://doi.org/10.1093/ageing/afx201>
- Kneipp, S. M., Horrell, L., Gonzales, C., Linnan, L., Lee Smith, M., Brady, T., & Trogon, J. G. (2019). Participation of lower-to-middle wage workers in a study of Chronic Disease Self-Management Program (CDSMP) effectiveness: Implications for reducing chronic disease burden among racial and ethnic minority populations. *Public Health Nursing*, 36(5), 591–602. <https://doi.org/10.1111/phn.12623>
- Kolshus, E. M., Akinmoluwa, S., Sloan, D., MacSuibhne, S., & Kolshus, E. H. (2022a). Patients' attitudes towards medical student presence in psychiatric consultations. *Irish Journal of Psychological Medicine*, 1–8. <https://doi.org/10.1017/ipm.2022.40>
- Kosmala-Anderson, J. P., Wallace, L. M., & Turner, A. (2010). Confidence matters: A Self-Determination Theory study of factors determining engagement in self-management support practices of UK clinicians. *Psychology, Health & Medicine*, 15(4), 478–491. <https://doi.org/10.1080/13548506.2010.487104>
- Kristjansdottir, O. B., Vågan, A., Svavarsdóttir, M. H., Børve, H. B., Hvinden, K., Duprez, V., Van Hecke, A., Heyn, L., Strømme, H., & Stenberg, U. (2021). Training interventions for healthcare providers offering group-based patient education. A scoping review. *Patient Education and Counseling*, 104(5), 1030-1048. <https://doi.org/10.1016/j.pec.2020.12.006>

- Kuo, C., Lin, C., & Tsai, F. (2014). Effectiveness of empowerment-based self-management interventions on patients with chronic metabolic diseases: A systematic review and meta-analysis. *Worldviews on Evidence-Based Nursing*, 11(5), 301–315. <https://doi.org/10.1111/wvn.12066>
- Lafontaine, S., Bourgault, P., Girard, A., & Ellefsen, E. (2020). Dimensions, application, and outcomes of person-centered self-management interventions for those living with type 2 diabetes: A scoping review. *Patient Education and Counseling*, 103(10), 1961–1982. <https://doi.org/10.1016/j.pec.2020.06.020>
- Lander, J., Langhof, H., & Dierks, M.-L. (2019). Involving patients and the public in medical and health care research studies: An exploratory survey on participant recruiting and representativeness from the perspective of study authors. *PLOS ONE*, 14(1), e0204187. <https://doi.org/10.1371/journal.pone.0204187>
- Lane, C., McCrabb, S., Nathan, N., Naylor, P. J., Bauman, A., Milat, A., Lum, M., Sutherland, R., Byaruhanga, J., & Wolfenden, L. (2021). How effective are physical activity interventions when they are scaled-up: a systematic review. *International Journal of Behavioral Nutrition and Physical Activity*, 18(1), 1–11. <https://doi.org/10.1186/s12966-021-01080-4>
- Lapin, B., Udeh, B., Bautista, J. F., & Katzan, I. L. (2018). Patient experience with patient-reported outcome measures in neurologic practice. *Neurology*, 91(12), e1135–e1151. <https://doi.org/10.1212/WNL.00000000000006198>
- Lawn, S., McMillan, J., & Pulvirenti, M. (2011). Chronic condition self-management: Expectations of responsibility. *Patient Education and Counseling*, 84(2), e5. <https://doi.org/10.1016/j.pec.2010.07.008>

Layder, D. (1998). *Sociological Practice. Linking theory and social research*. SAGE Publications Ltd.

Leung, T. Y. M., Chan, A. Y. L., Chan, E. W., Chan, V. K. Y., Chui, C. S. L., Cowling, B. J., Gao, L., Ge, M. Q., Hung, I. F. N., Ip, M. S. M., Ip, P., Lau, K. K., Lau, C. S., Lau, L. K. W., Leung, W. K., Li, X., Luo, H., Man, K. K. C., Ng, V. W. S., ... Wong, I. C. K. (2020). Short-and potential long-term adverse health outcomes of COVID-19: a rapid review. *Emerging Microbes and Infections*, 9. <https://doi.org/10.1080/22221751.2020.1825914>

Lewinski, A. A., Shapiro, A., Gierisch, J. M., Goldstein, K. M., Blalock, D. V., Luedke, M. W., Gordon, A. M., Bosworth, H. B., Drake, C., Lewis, J. D., Sinha, S. R., Husain, A. M., Tran, T. T., Van Noord, M. G., & Williams, J. W. (2020). Barriers and facilitators to implementation of epilepsy self-management programs: A systematic review using qualitative evidence synthesis methods. *Systematic Reviews*, 9(1), 1–17. <https://doi.org/10.1186/s13643-020-01322-9>

Lewis-Beck, M., Bryman, A., & Liao, T. (Eds.). (2004). *Encyclopedia of social science research methods*. SAGE.

Lin, A. M., Vickrey, B. G., Barry, F., Lee, M. L., Ayala-Rivera, M., Cheng, E., Montoya, A. V., Mojarro-Huang, E., Gomez, P., Castro, M., Corrales, M., Sivers-Teixeira, T., Tran, J. L., Johnson, R., Ediss, C., Shaby, B., Willis, P., Sanossian, N., Mehta, B., ... Towfighi, A. (2020). Factors associated with participation in the Chronic Disease Self-Management Program: Findings from the SUCCEED Trial. *Stroke*, October, 2910–2917. <https://doi.org/10.1161/STROKEAHA.119.028022>

- Lleal, M., Baré, M., Ortonobes, S., Sevilla-Sánchez, D., Jordana, R., Herranz, S., Gorgas, M. Q., Espauella-Ferrer, M., Arellano, M., de Antonio, M., Nazco, G. J., & Hernández-Luis, R. (2022). Comprehensive multimorbidity patterns in older patients are associated with quality indicators of medication—MoPIM Cohort Study. *International Journal of Environmental Research and Public Health*, 19(23), 15902. <https://doi.org/10.3390/ijerph192315902>
- Lorig, K. R., & Holman, H. R. (2003). Self-management education: History , definition , outcomes , and mechanisms. *Annals of Behavioral Medicine*, 26(1), 1–7.
- Luo, H., Basu, R., Bell, R. A., Rafferty, A. P., Zeng, X., Qu, H., & Dove, C. (2021). Rural-urban differences in uptake of diabetes self-management education among Medicare beneficiaries: Results from the 2016 to 2018 Medicare Current Beneficiary Survey. *Journal of Rural Health*, 1–8. <https://doi.org/10.1111/jrh.12588>
- Lyonnais, M. J., Bray, P., Rafferty, A. P., Winterbauer, N. L., & Bell, R. A. (2020). Potential effect of vouchers on the completion of self-management education among patients with diabetes. *Journal of Public Health Management and Practice*, 26(1), 67–70. <https://doi.org/10.1097/PHH.0000000000000985>
- Mackenbach, J. P. (2011). Can we reduce health inequalities? An analysis of the English strategy (1997-2010). *Journal of Epidemiology & Community Health*, 65(7), 568–575. <https://doi.org/10.1136/jech.2010.128280>
- Mackert, N., & Schorb, F. (2022). Introduction to the special issue: public health, healthism, and fatness. *Fat Studies*, 11(1), 1–7. <https://doi.org/10.1080/21604851.2021.1911486>
- Makoul, G., Noble, L., Gulbrandsen, P., & van Dulmen, S. (2024). Reinforcing the humanity in healthcare: The Glasgow Consensus Statement on effective communication in

clinical encounters. *Patient Education and Counseling*, 122.
<https://doi.org/10.1016/j.pec.2024.108158>

Manderson, L., & Jewett, S. (2023). Risk, lifestyle and non-communicable diseases of poverty. In *Globalization and Health* (Vol. 19, Issue 1). BioMed Central Ltd.
<https://doi.org/10.1186/s12992-023-00914-z>

Mannucci, E., Giaccari, A., Gallo, M., Bonifazi, A., Belén, Á. D. P., Masini, M. L., Trento, M., & Monami, M. (2022). Self-management in patients with type 2 diabetes: Group-based versus individual education. A systematic review with meta-analysis of randomized trails. *Nutrition, Metabolism and Cardiovascular Diseases*, 32(2), 330–336.
<https://doi.org/10.1016/j.numecd.2021.10.005>

Manzano, A. (2016). The craft of interviewing in realist evaluation. *Evaluation*, 22(3), 342–360. <https://doi.org/10.1177/1356389016638615>

Marchal, B., van Belle, S., van Olmen, J., Hoérée, 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(2), 192–212.
<https://doi.org/10.1177/1356389012442444>

Marmot, M. (2017). Social justice, epidemiology and health inequalities. *European Journal of Epidemiology*, 32(7), 537–546. <https://doi.org/10.1007/s10654-017-0286-3>

Marmot, M., Allen, J., Boyce, T., Goldblatt, P., & Morrison, J. (2020). Health equity in England: The Marmot review 10 years on.

Marmot, M., & Bell, R. (2019). Social determinants and non-communicable diseases: Time for integrated action. *BMJ (Online)*, 364, 10–12. <https://doi.org/10.1136/bmj.l251>

- Mars, T., Ellard, D., Carnes, D., Homer, K., Underwood, M., & Taylor, S. J. C. (2013). Fidelity in complex behaviour change interventions: A standardised approach to evaluate intervention integrity. *BMJ Open*, 3(11), 1–7. <https://doi.org/10.1136/bmjopen-2013-003555>
- Martin, A. J., Ginns, P., & Papworth, B. (2017). Motivation and engagement: Same or different? Does it matter? *Learning and Individual Differences*, 55, 150–162. <https://doi.org/10.1016/j.lindif.2017.03.013>
- Maxwell, J. A. (2012). *A realist approach for qualitative research*. SAGE Publications Ltd.
- Mayhew, E. T., Beresford, B. A., Laver-Fawcett, A., Aspinall, F., Mann, R. C., Bechtold, K., & Kanaan, M. (2019). The Hopkins Rehabilitation Engagement Rating Scale - Reablement Version (HRERS-RV): Development and Psychometric Properties. *Health and Social Care in the Community*, 27(3), 777–787. <https://doi.org/10.1111/hsc.12696>
- Mc Sharry, J., Dinneen, S. F., Humphreys, M., O'Donnell, M., O'Hara, M. C., Smith, S. M., Winkley, K., & Byrne, M. (2019). Barriers and facilitators to attendance at Type 2 diabetes structured education programmes: a qualitative study of educators and attendees. *Diabetic Medicine*, 36(1), 70–79. <https://doi.org/10.1111/dme.13805>
- McConnell, L., & Hale, L. (2024). Undergraduate physiotherapy students' perspectives on optimising the curriculum for supported self-management education. *New Zealand Journal of Physiotherapy*, 52(1), 17–25. <https://doi.org/10.15619/nzjp.v52i1.359>
- McCormack, B., & McCance, T. (2016). *Person-centred practice in nursing and health care theory and practice* (2nd ed.). John Wiley and Sons Inc.

- McCormack, B., McCance, T., Bulley, C., Brown, D., McMillan, A., & Martin, S. (Eds.). (2021). *Fundamentals of person-centred healthcare practice* (First edition). Willey-Blackwell.
- McCrabb, S., Lane, C., Hall, A., Milat, A., Bauman, A., Sutherland, R., Yoong, S., & Wolfenden, L. (2019). Scaling-up evidence-based obesity interventions: A systematic review assessing intervention adaptations and effectiveness and quantifying the scale-up penalty. *Obesity Reviews*, 0–2. <https://doi.org/10.1111/obr.12845>
- McElhinney, Z., & Bartlett, M. (2021). Disrupting the consultation: students empowering patients in a longitudinal clerkship. *Education for Primary Care*, 32(6), 344–350. <https://doi.org/10.1080/14739879.2021.1939169>
- Mckee, M., & Stuckler, D. (2018). Revisiting the corporate and commercial determinants of health. *Am J Public Health*, 108, 1167–1170. <https://doi.org/10.2105/AJPH>
- Mead, R., Thurston, M., & Bloyce, D. (2022). From public issues to personal troubles: individualising social inequalities in health within local public health partnerships. *Critical Public Health*, 32(2), 168–180. <https://doi.org/10.1080/09581596.2020.1763916>
- Mendez-Luck, C. A., Govier, D. J., Luck, J., Julyan, E. J., Mahakalanda, S., & Herrera-Venson, A. P. (2020a). Participation of Latinos in the Diabetes Self-Management Program and Programa de Manejo Personal de la Diabetes. *Innovation in Aging*, 4(1), 1–9. <https://doi.org/10.1093/geroni/igaa006>
- Mensing, C. R., & Norris, S. L. (2003). Group education in diabetes: Effectiveness and implementation. In *Diabetes Spectrum* (Vol. 16, Issue 2).
- Merton, R. K. (1968). *Social theory and social structure*. Free Press.

- Mezirow, J. (1997). Transformative learning. *New Directions for Adult and Continuing Education*, 74, 201–204.
- Mialon, M. (2020). An overview of the commercial determinants of health. *Globalization and Health*, 16(1), 74. <https://doi.org/10.1186/s12992-020-00607-x>
- Michie, S., Johnston, M., Abraham, C., Lawton, R., Parker, D., & Walker, A. (2005). Making psychological theory useful for implementing evidence based practice: A consensus approach. *Quality and Safety in Health Care*, 14(1), 26–33. <https://doi.org/10.1136/qshc.2004.011155>
- Miller, W. R., Lasiter, S., Bartlett Ellis, R., & Buelow, J. M. (2015). Chronic disease self-management: A hybrid concept analysis. *Nursing Outlook*, 63(2), 154–161. <https://doi.org/10.1016/j.outlook.2014.07.005>
- Minary, L., Trompette, J., Kivits, J., Cambon, L., Tarquinio, C., & Alla, F. (2019). Which design to evaluate complex interventions? Toward a methodological framework through a systematic review. *BMC Medical Research Methodology*, 19(1), 1–9. <https://doi.org/10.1186/s12874-019-0736-6>
- Mingo, C. A., Smith, M. L., Ahn, S. N., Jiang, L., Cho, J., Towne, S. D., & Ory, M. G. (2015). Chronic Disease Self-Management Education (CDSME) program delivery and attendance among urban-dwelling African Americans. *Frontiers in Public Health*, 2(APR), 1–9. <https://doi.org/10.3389/fpubh.2014.00174>
- Ministry of Housing, Communities & Local Government (2019). Accredited official statistics: English indices of deprivation 2019. <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019>

- Mirzoev, T., Etiaba, E., Ebenso, B., Uzochukwu, B., Ensor, T., Onwujekwe, O., Huss, R., Ezumah, N., & Manzano, A. (2020). Tracing theories in realist evaluations of large-scale health programmes in low- and middle-income countries: experience from Nigeria. *Health Policy and Planning*, 1–10. <https://doi.org/10.1093/heapol/czaa076>
- Mittler, J. N., Martsolf, G. R., Telenko, S. J., & Scanlon, D. P. (2013). Making sense of “consumer engagement” initiatives to improve health and health care: A conceptual framework to guide policy and practice. *Milbank Quarterly*, 91(1), 37–77. <https://doi.org/10.1111/milq.12002>
- Mol, S. S. L., Peelen, J. H., & Kuyvenhoven, M. M. (2011). Patients’ views on student participation in general practice consultations: A comprehensive review. *Medical Teacher*, 33(7), e397–e400. <https://doi.org/10.3109/0142159X.2011.581712>
- Morgan, H. M., Entwistle, V. A., Cribb, A., Christmas, S., Owens, J., Skea, Z. C., & Watt, I. S. (2017). We need to talk about purpose: a critical interpretive synthesis of health and social care professionals’ approaches to self-management support for people with long-term conditions. *Health Expectations*, 20(2), 243–259. <https://doi.org/10.1111/hex.12453>
- Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V., & Ustun, B. (2007). Depression, chronic diseases, and decrements in health: results from the World Health Surveys Saba. *Lancet*, 370, 851–858. <https://doi.org/10.3390/en10010025>
- Mukumbang, F. C., Kabongo, E. M., & Eastwood, J. G. (2021). Examining the application of retroductive theorizing in realist-informed studies. *International Journal of Qualitative Methods*, 20, 160940692110535. <https://doi.org/10.1177/16094069211053516>

- Mukumbang, F. C., Marchal, B., Van Belle, S., & van Wyk, B. (2020). Using the realist interview approach to maintain theoretical awareness in realist studies. *Qualitative Research*, 20(4), 485–515. <https://doi.org/10.1177/1468794119881985>
- Mulligan, H., Wilkinson, A., Chen, D., Nijhof, C., Kwan, N., Lindup, A., & Dalton, S. (2019). Components of community rehabilitation programme for adults with chronic conditions: A systematic review. *International Journal of Nursing Studies*, 97, 114–129. <https://doi.org/10.1016/j.ijnurstu.2019.05.013>
- Murphy, L. B., Brady, T. J., Boring, M. A., Theis, K. A., Barbour, K. E., Qin, J., & Helmick, C. G. (2017). Self-management education participation among US adults with arthritis: Who's attending? *Arthritis Care and Research*, 69(9), 1322–1330. <https://doi.org/10.1002/acr.23129>
- Murray, R. L., Bauld, L., Hackshaw, L. E., & McNeill, A. (2009). Improving access to smoking cessation services for disadvantaged groups: A systematic review. *Journal of Public Health*, 31(2), 258–277. <https://doi.org/10.1093/pubmed/fdp008>
- Naamneh-Abuelhija, B., Yogev-Seligmann, G., & Kafri, M. (2024). Does affiliation with a minority group affect patient activation? *Patient Education and Counseling*, 118, 108011. <https://doi.org/10.1016/j.pec.2023.108011>
- Naik, Y., Baker, P., Ismail, S. A., Tillmann, T., Bash, K., Quantz, D., Hillier-Brown, F., Jayatunga, W., Kelly, G., Black, M., Gopfert, A., Roderick, P., Barr, B., & Bamba, C. (2019). Going upstream - An umbrella review of the macroeconomic determinants of health and health inequalities. *BMC Public Health*, 19(1). <https://doi.org/10.1186/s12889-019-7895-6>

- Nguyen, H., Manolova, G., Daskalopoulou, C., Vitoratou, S., Prince, M., & Prina, A. M. (2019). Prevalence of multimorbidity in community settings: A systematic review and meta-analysis of observational studies. *Journal of Comorbidity*, 9, 2235042X1987093. <https://doi.org/10.1177/2235042x19870934>
- NHS (2019). The NHS Long Term Plan. <https://doi.org/10.12968/jprp.2019.1.3.114>
- NHS England. (2015). National action for local change: Our declaration - person centred care for long term conditions. <https://www.england.nhs.uk/wp-content/uploads/2015/09/nat-act-chang.pdf>
- NHS England. (2017). Involving people in their own health and care: Statutory guidance for clinical commissioning groups and NHS England. <https://www.england.nhs.uk/wp-content/uploads/2017/04/ppp-involving-people-health-care-guidance.pdf>
- NHS England. (2018). The national patient reported outcome measures (PROMS) programme. <https://www.england.nhs.uk/wp-content/uploads/2018/08/proms-guide-aug-18-v3.pdf>
- NHS England. (2023). Language Matters: Language and Diabetes. <https://www.england.nhs.uk/long-read/language-matters-language-and-diabetes/>
- National Institute for Health and Care Excellence (2015a). Type 1 diabetes in adults: diagnosis and management (NICE Guideline NG17). <https://www.nice.org.uk/guidance/ng17>
- National Institute for Health and Care Excellence (2015b). Type 2 diabetes in adults (NICE Guideline NG28). <https://www.nice.org.uk/guidance/ng28>

National Institute for Health and Care Excellence (2017). Asthma: diagnosis, monitoring and chronic asthma management (NICE Guidance NG245). <https://www.nice.org.uk/guidance/ng245>

National Institute for Health and Care Excellence (2021). Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain (NICE Guideline NG193). <https://www.nice.org.uk/guidance/ng193>

Nickelson, J., McFadden, N., Johnson, P., & Boucher, A. (2022). Effectiveness of student-led interventions on improving diabetes outcomes: A systematic review. *American Journal of Health Education*, 53(5), 325–341. <https://doi.org/10.1080/19325037.2022.2100020>

National Institute for Health and Care Research (2020). Improving inclusion of under-served groups in clinical research: Guidance from the NIHR-INCLUDE project. www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435

National Institute for Health and Care Research (2021). Briefing notes for researchers - public involvement in NHS, health and social care research. <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>

Nim, C., Ziegler, D. S., Hansen, A., & O'Neill, S. (2024). Patient satisfaction with clinical services provided by chiropractic students under supervision compared to licensed chiropractors: An observational study. *Journal of Chiropractic Education*, 38(2), 120–128. <https://doi.org/10.7899/JCE-23-6>

- Nkhoma, K., Norton, C., Sabin, C., Winston, A., Merlin, J., & Harding, R. (2018). Self-management interventions for pain and physical symptoms among people living with HIV: A systematic review of the evidence. *Journal of Acquired Immune Deficiency Syndromes*, 79(2), 206–225. <https://doi.org/10.1097/QAI.0000000000001785>
- Noble, H., & Smith, J. (2018). Reviewing the literature: Choosing a review design. *Evidence-Based Nursing*, 21(2), 39–41. <https://doi.org/10.1136/eb-2018-102895>
- Nobles, J. D., Perez, A., Skelton, J. A., Spence, N. D., & Ball, G. D. (2018). The engagement pathway: A conceptual framework of engagement-related terms in weight management. *Obesity Research and Clinical Practice*, 12(2), 133–138. <https://doi.org/10.1016/j.orcp.2017.12.005>
- Odgers-Jewell, K., Ball, L. E., Kelly, J. T., Isenring, E. A., Reidlinger, D. P., & Thomas, R. (2017). Effectiveness of group-based self-management education for individuals with Type 2 diabetes: A systematic review with meta-analyses and meta-regression. *Diabetic Medicine*, 34(8), 1027–1039. <https://doi.org/10.1111/dme.13340> Licence:
- Odgers-Jewell, K., Hughes, R., Isenring, E., Desbrow, B., & Leveritt, M. (2015). Group facilitators' perceptions of the attributes that contribute to the effectiveness of group-based chronic disease self-management education programs. *Nutrition and Dietetics*, 72(4), 347–355. <https://doi.org/10.1111/1747-0080.12190>
- Office for National Statistics (2023a). Rising ill-health and economic inactivity because of long-term sickness, UK: 2019 to 2023. <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/economicinactivity/articles/risingillhealthandeconomicinactivitybecauseoflongtermsicknessuk/2019to2023>

Office for National Statistics (2023b). Dataset: Population and migration statistics transformation, ethnicity, England and Wales. <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationandmigrationstatisticstransformationethnicityenglandandwales>

Office for National Statistics (ONS). (2022). Health state life expectancies by national deprivation deciles, England: 2018 to 2020. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbyindexofmultipledeprivationimd/2018to2020>

Ogunbayo, O. J., Russell, S., Newham, J. J., Heslop-Marshall, K., Netts, P., Hanratty, B., & Kaner, E. (2017). Understanding the factors affecting self-management of COPD from the perspectives of healthcare practitioners: a qualitative study. *Npj Primary Care Respiratory Medicine*, 27(1), 54. <https://doi.org/10.1038/s41533-017-0054-6>

Okoro, O. N., Hillman, L. A., & Cernasev, A. (2020). “We get double slammed!”: Healthcare experiences of perceived discrimination among low-income African-American women. *Women’s Health*, 16. <https://doi.org/10.1177/1745506520953348>

O’Leary, N., Salmon, N., & Clifford, A. M. (2020). ‘It benefits patient care’: the value of practice-based IPE in healthcare curriculums. *BMC Medical Education*, 20(1), 424. <https://doi.org/10.1186/s12909-020-02356-2>

Oni, T., & Unwin, N. (2015). Why the communicable/non-communicable disease dichotomy is problematic for public health control strategies: Implications of multimorbidity for

health systems in an era of health transition. *International Health*, 7(6), 390–399.
<https://doi.org/10.1093/inthealth/ihv040>

Ortiz Halabi, I., Scholtes, B., Voz, B., Gillain, N., Durieux, N., Odero, A., Baumann, M., Ziegler, O., Gagnayre, R., Guillaume, M., Bragard, I., & Pétré, B. (2020). “Patient participation” and related concepts: A scoping review on their dimensional composition. *Patient Education and Counseling*, 103(1), 5–14.
<https://doi.org/10.1016/j.pec.2019.08.001>

Osmond, H. (1957). Function as the basis of psychiatric ward design. *Psychiatric Services*, 8(4), 23–27. <https://doi.org/10.1176/ps.8.4.23>

Packer, T. L., Fracini, A., Audulv, Å., Alizadeh, N., van Gaal, B. G. I., Warner, G., & Kephart, G. (2018). What we know about the purpose, theoretical foundation, scope and dimensionality of existing self-management measurement tools: A scoping review. In *Patient Education and Counseling* (Vol. 101, Issue 4, pp. 579–595). Elsevier Ireland Ltd. <https://doi.org/10.1016/j.pec.2017.10.014>

Pagnamenta, F., Lhussier, M., & Rapley, T. (2023). A review of leg ulcerations coverage in the United Kingdom print media: A growing problem for the vulnerable adult. *Journal of Vascular Nursing*, 41(2), 47–55. <https://doi.org/10.1016/j.jvn.2023.02.002>

Palla, I., Turchetti, G., & Polvani, S. (2024). Narrative Medicine: theory, clinical practice and education - a scoping review. *BMC Health Services Research*, 24(1), 1116.
<https://doi.org/10.1186/s12913-024-11530-x>

Palmer, K., Monaco, A., Kivipelto, M., Onder, G., Maggi, S., Michel, J.-P., Prieto, R., Sykara, G., & Donde, S. (2020). The potential long-term impact of the COVID-19 outbreak on patients with non-communicable diseases in Europe: consequences for healthy

ageing. *Aging Clinical and Experimental Research*, 32(7), 1189–1194.
<https://doi.org/10.1007/s40520-020-01601-4>

Paparini, S., Green, J., Papoutsis, C., Murdoch, J., Petticrew, M., Greenhalgh, T., Hanckel, B., & Shaw, S. (2020). Case study research for better evaluations of complex interventions: rationale and challenges. *BioMed Central Medicine*, 18(301), 1–6.

Paparini, S., Papoutsis, C., Murdoch, J., Green, J., Petticrew, M., Greenhalgh, T., & Shaw, S. E. (2021). Evaluating complex interventions in context: systematic, meta-narrative review of case study approaches. *BMC Medical Research Methodology*, 21(1).
<https://doi.org/10.1186/s12874-021-01418-3>

Paré, G., Trudel, M.-C., Jaana, M., & Kitsiou, S. (2015). Synthesizing information systems knowledge: A typology of literature reviews. *Information & Management*, 52(2), 183–199. <https://doi.org/10.1016/j.im.2014.08.008>

Parmenter, J., Basit, T., Nelson, A., Crawford, E., & Kitter, B. (2020). Chronic disease self-management programs for Aboriginal and Torres Strait Islander people: Factors influencing participation in an urban setting. *Health Promotion Journal of Australia*, 31(1), 104–111. <https://doi.org/10.1002/hpja.256>

Parsons, S., Winterbottom, A., Cross, P., & Don Redding. (2010). The quality of patient engagement and involvement in primary care. *The King's Fund*, 1–100.

Patterson, T. G., & Joseph, S. (2007). Person-Centered Personality Theory: Support from Self-Determination Theory and positive psychology. *Journal of Humanistic Psychology*, 47(1), 117–139. <https://doi.org/10.1177/0022167806293008>

Pawson, R. (1996). Theorizing the Interview. *The British Journal of Sociology*, 47(2), 295–314. <https://doi.org/10.2307/591728>

Pawson, R. (2004). Evidence-based policy: A realist perspective. *Making Realism Work: Realist Social Theory and Empirical Research*, 26–49. <https://doi.org/10.4324/9780203624289>

Pawson, R. (2006). Evidence-based policy: A realist perspective. In *Making realism work: realist social theory and empirical research*. SAGE Publications . <https://doi.org/10.4324/9780203624289>

Pawson, R. (2013). *The science of evaluation: a realist manifesto*. SAGE Publications Ltd.

Pawson, R. (2016a). Realist evaluation caricatured: A reply to Porter. *Nursing Philosophy*, 17(2), 132–139. <https://doi.org/10.1111/nup.12118>

Pawson, R. (2016b). The ersatz realism of critical realism: A reply to Porter. *Evaluation*, 22(1), 49–57. <https://doi.org/10.1177/1356389015605206>

Pawson, R. (2018). The realist foundations of evidence-based medicine: A review essay. In *Evaluation* (Vol. 24, Issue 1, pp. 42–50). SAGE Publications Ltd. <https://doi.org/10.1177/1356389017746718>

Pawson, R. (2024). *How to think like a realist: A methodology for social science*. Edward Elgar Publishing.

Pawson, R., & Manzano-Santaella, A. (2012). A realist diagnostic workshop. *Evaluation*, 18(2), 176–191. <https://doi.org/10.1177/1356389012440912>

Pawson, R., & Tilley, N. (1997). *Realistic evaluation*. SAGE Publications Ltd.

- Pearce, N., Ebrahim, S., McKee, M., Lamptey, P., Barreto, M. L., Matheson, D., Walls, H., Foliaki, S., Miranda, J. J., Chimeddamba, O., Garcia-Marcos, L., Haines, A., & Vineis, P. (2015). Global prevention and control of NCDs: limitations of the standard approach. *Journal of Public Health Policy*, 36(4), 408–425. <https://doi.org/10.1057/jphp.2015.29>
- Pearson, M., Brand, S. L., Quinn, C., Shaw, J., Maguire, M., Michie, S., Briscoe, S., Lennox, C., Stirzaker, A., Kirkpatrick, T., & Byng, R. (2015). Using realist review to inform intervention development: Methodological illustration and conceptual platform for collaborative care in offender mental health. *Implementation Science*, 10(1), 1–12. <https://doi.org/10.1186/s13012-015-0321-2>
- Perugino, F., De Angelis, V., Pompili, M., & Martelletti, P. (2022). Stigma and chronic pain. *Pain and Therapy*, 11(4), 1085–1094. <https://doi.org/10.1007/s40122-022-00418-5>
- Phillippi, J., & Lauderdale, J. (2018). A guide to field notes for qualitative research: Context and conversation. *Qualitative Health Research*, 28(3), 381–388. <https://doi.org/10.1177/1049732317697102>
- Porter, S. (2015a). Realist evaluation: An immanent critique. *Nursing Philosophy*, 16(4), 239–251. <https://doi.org/10.1111/nup.12100>
- Porter, S. (2015b). The uncritical realism of realist evaluation. *Evaluation*, 21(1), 65–82. <https://doi.org/10.1177/1356389014566134>
- Powell, K., Thurston, M., & Bloyce, D. (2017). Theorising lifestyle drift in health promotion: explaining community and voluntary sector engagement practices in disadvantaged areas. *Critical Public Health*, 27(5), 554–565. <https://doi.org/10.1080/09581596.2017.1356909>

- Powers, M. A., Bardsley, J., Cypress, M., Duker, P., Funnell, M. M., Fischl, A. H., Maryniuk, M. D., Siminerio, L., & Vivian, E. (2016). Diabetes self-management education and support in type 2 diabetes: A joint position statement of the American Diabetes Association, the American Association of diabetes educators, and the Academy of Nutrition and Dietetics. *Clinical Diabetes*, 34(2), 70–80. <https://doi.org/10.2337/diaclin.34.2.70>
- Preston, J. L., Berryman, V. R., Hancock, A., Patrick, M., Worthington, A., Hitman, G. A., & Hood, G. A. (2019). Developing patient and public involvement and engagement (PPIE) in diabetes research: a local approach. *Practical Diabetes*, 36(3), 81–85. <https://doi.org/10.1002/pdi.2220>
- Protheroe, J., Rogers, A., Kennedy, A. P., Macdonald, W., & Lee, V. (2008). Promoting patient engagement with self-management support information: A qualitative meta-synthesis of processes influencing uptake. *Implementation Science*, 3(1), 1–12. <https://doi.org/10.1186/1748-5908-3-44>
- Pulvirenti, M., Mcmillan, J., & Lawn, S. (2014). Empowerment, patient centred care and self-management. *Health Expectations*, 17(3), 303–310. <https://doi.org/10.1111/j.1369-7625.2011.00757.x>
- Punch, K. F. (2014). *Introduction to social research* (3rd ed). SAGE Publications Ltd.
- Punna, M., Kettunen, T., Bagnall, A. M., & Kasila, K. (2019a). Implementation and outcomes of lay health worker-led self-management interventions for long-term conditions and prevention: A systematic review. *Health Education and Behavior*, 46(6), 1045–1072. <https://doi.org/10.1177/1090198119863842>

- Punton, M., Vogel, I., Leavy, J., Michaelis, C., & Boydell, E. (2020). Reality bites: Making realist evaluation useful in the real world. CDI Practice Paper 22, Brighton: IDS. <https://www.ids.ac.uk/publications/reality-bites-making-realist-evaluation-useful-in-the-real-world/>
- Punton, M., Vogel, I., & Lloyd, R. (2016). Reflections from a realist evaluation in progress: Scaling ladders and stitching theory. CDI Practice Paper 18, Brighton: IDS. <https://www.ids.ac.uk/publications/reflections-from-a-realist-evaluation-in-progress-scaling-ladders-and-stitching-theory/>
- Queen, M., Crone, D., Parker, A., & Bloxham, S. (2017). The impact of physical activity for recovering cancer patients. *European Journal for Person Centered Healthcare*, 5(2), 225–236. <https://doi.org/10.5750/ejpch.v5i1.1227>
- Razai, M. S., Kooner, P., & Majeed, A. (2023). Strategies and interventions to improve healthcare professionals' well-being and reduce burnout. *Journal of Primary Care and Community Health*, 14, 10–12. <https://doi.org/10.1177/21501319231178641>
- Reddy, S., Carey, T. A., & Wakerman, J. (2016). A realist case study of a regional hospital's response to improve emergency department access in the context of Australian health care reforms. *Health Services Research and Managerial Epidemiology*, 3. <https://doi.org/10.1177/2333392816631101>
- Rees, C. E., Davis, C., Nguyen, V. N. B., Proctor, D., & Mattick, K. L. (2024). A roadmap to realist interviews in health professions education research: Recommendations based on a critical analysis. *Medical Education*, 58(6), 697–712. <https://doi.org/10.1111/medu.15270>

- Reeve, J., Nix, G., & Hamm, D. (2003). Testing models of the experience of self-determination in intrinsic motivation and the conundrum of choice. *Journal of Educational Psychology*, 95(2), 375–392. <https://doi.org/10.1037/0022-0663.95.2.375>
- Reid, A. M., Brown, J. M., Smith, J. M., Cope, A. C., & Jamieson, S. (2018). Ethical dilemmas and reflexivity in qualitative research. *Perspectives on Medical Education*, 7(2), 69–75. <https://doi.org/10.1007/s40037-018-0412-2>
- Reidy, C., Kennedy, A., Pope, C., Ballinger, C., Vassilev, I., & Rogers, A. (2016). Commissioning of self-management support for people with long-term conditions: an exploration of commissioning aspirations and processes. *BMJ Open*, 6(7), e010853. <https://doi.org/10.1136/bmjopen-2015-010853>
- Ren, S., Zhan, H., Fernando, A., Xu, X., & Lu, W. (2025). From shadowing to active learning: exploring the impact of supervised teaching clinics on gynecology education. *Frontiers in Medicine*, 11. <https://doi.org/10.3389/fmed.2024.1498393>
- Renmans, D., & Castellano Pleguezuelo, V. (2023). Methods in realist evaluation: A mapping review. *Evaluation and Program Planning*, 97(July 2022), 102209. <https://doi.org/10.1016/j.evalprogplan.2022.102209>
- Reynolds, R., Dennis, S., Hasan, I., Slewa, J., Chen, W., Tian, D., Bobba, S., & Zwar, N. (2018). A systematic review of chronic disease management interventions in primary care. *BMC Family Practice*, 19(1), 1–13. <https://doi.org/10.1186/s12875-017-0692-3>
- Richards, E., Elliott, L., Jackson, B., & Panesar, A. (2022). Longitudinal integrated clerkship evaluations in UK medical schools: a narrative literature review. *Education for Primary Care*, 33(3), 148–155. <https://doi.org/10.1080/14739879.2021.2021809>

- Robinson, L., Newton, J. L., Jones, D., & Dawson, P. (2014). Self-management and adherence with exercise-based falls prevention programmes: A qualitative study to explore the views and experiences of older people and physiotherapists. *Disability and Rehabilitation*, 36(5), 379–386. <https://doi.org/10.3109/09638288.2013.797507>
- Rocca, E., & Anjum, R. L. (2020). Complexity, reductionism and the biomedical model. In *Rethinking causality, complexity and evidence for the unique patient: A cause health resource for healthcare professionals and the clinical encounter* (pp. 75–94). Springer International Publishing. https://doi.org/10.1007/978-3-030-41239-5_5
- Rockliffe, L., Chorley, A. J., Marlow, L. A. V., & Forster, A. S. (2018). It's hard to reach the "hard-to-reach": the challenges of recruiting people who do not access preventative healthcare services into interview studies. *International Journal of Qualitative Studies on Health and Well-Being*, 13(1). <https://doi.org/10.1080/17482631.2018.1479582>
- Rollins, A. L., Eliacin, J., Russ-Jara, A. L., Monroe-Devita, M., Wasmuth, S., Flanagan, M. E., Morse, G. A., Leiter, M., & Salyers, M. P. (2021). Organizational conditions that influence work engagement and burnout: A qualitative study of mental health workers. *Psychiatric Rehabilitation Journal*, 44(3), 229–237. <https://doi.org/10.1037/prj0000472>
- Ronkainen, N. J., & Wiltshire, G. (2021). Rethinking validity in qualitative sport and exercise psychology research: a realist perspective. *International Journal of Sport and Exercise Psychology*, 19(1), 13–28. <https://doi.org/10.1080/1612197X.2019.1637363>
- Rookes, T. A., Schrag, A., Walters, K., & Armstrong, M. (2022). Measures of fidelity of delivery and engagement in self-management interventions: A systematic review of measures. *Clinical Trials*, 19(6), 665–672. <https://doi.org/10.1177/17407745221118555>

- Ross, J., Poduval, S., Albury, C., Lau, A., Whitaker, N., & Stevenson, F. (2024). Achieving patient weighing in UK primary care. A conversation analytic study. *SSM - Qualitative Research in Health*, 5. <https://doi.org/10.1016/j.ssmqr.2023.100384>
- Ryan, L., Coyne, R., Heary, C., Birney, S., Crotty, M., Dunne, R., Conlan, O., & Walsh, J. C. (2023). Weight stigma experienced by patients with obesity in healthcare settings: A qualitative evidence synthesis. *Obesity Reviews*, 24(10), e13606. <https://doi.org/10.1111/obr.13606>
- Ryan, P., & Sawin, K. J. (2009). The Individual and Family Self-Management Theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook*, 57(4), 217-225.e6. <https://doi.org/10.1016/j.outlook.2008.10.004>
- Ryan, R. M., & Deci, E. L. (2017). *Self-determination theory: basic psychological needs in motivation, development, and wellness*. Guilford Press.
- Ryan, R. M., & Deci, E. L. (2020). Intrinsic and extrinsic motivation from a self-determination theory perspective: Definitions, theory, practices, and future directions. *Contemporary Educational Psychology*, 61, 101860. <https://doi.org/10.1016/j.cedpsych.2020.101860>
- Santorelli, M. L., Ekanayake, R. M., & Wilkerson-Leconte, L. (2017). Participation in a diabetes self-management class among adults with diabetes, New Jersey 2013-2015. *Preventing Chronic Disease*, 14. <https://doi.org/10.5888/pcd14.170023>
- Sav, A., King, M. A., Whitty, J. A., Kendall, E., Mcmillan, S. S., Kelly, F., Hunter, B., & Wheeler, A. J. (2015). Burden of treatment for chronic illness: A concept analysis and review of the literature. *Health Expectations*, 18(3), 312–324. <https://doi.org/10.1111/hex.12046>

- Sayed-Hassan, R. M., Bashour, H. N., & Koudsi, A. Y. (2012). Patient attitudes towards medical students at Damascus University teaching hospitals. *BMC Medical Education*, 12(1). <https://doi.org/10.1186/1472-6920-12-13>
- Sayer, A. (2010). *Method in social science: A realist approach* (2nd ed.). Routledge.
- Scharp, Y. S., Bakker, A. B., & Breevaart, K. (2022). Playful work design and employee work engagement: A self-determination perspective. *Journal of Vocational Behavior*, 134. <https://doi.org/10.1016/j.jvb.2022.103693>
- Scheffer, C., Valk-Draad, M. P., Tauschel, D., Büssing, A., Humbroich, K., Längler, A., Zuzak, T., Köster, W., Edelhäuser, F., & Lutz, G. (2018). Students with an autonomous role in hospital care – patients perceptions. *Medical Teacher*, 40(9), 944–952. <https://doi.org/10.1080/0142159X.2017.1418504>
- Schinckus, L., Van den Broucke, S., & Housiaux, M. (2014). Assessment of implementation fidelity in diabetes self-management education programs: A systematic review. *Patient Education and Counseling*, 96(1), 13–21. <https://doi.org/10.1016/j.pec.2014.04.002>
- Schwartz, L. N., Shaffer, J. D., & Bukhman, G. (2021). The origins of the 4 × 4 framework for noncommunicable disease at the World Health Organization. *SSM - Population Health*, 13. <https://doi.org/10.1016/j.ssmph.2021.100731>
- Schwennesen, N., Henriksen, J. E., & Willaing, I. (2016). Patient explanations for non-attendance at type 2 diabetes self-management education: A qualitative study. *Scandinavian Journal of Caring Sciences*, 30(1), 187–192. <https://doi.org/10.1111/scs.12245>

- Self-Management Resource Centre. (2022). Implementation and fidelity manual. https://selfmanagementresource.com/wp-content/uploads/SMRC_Implementation_and_Fidelity_Manual_2022.pdf
- Selzler, A. M., Moore, V., Habash, R., Ellerton, L., Lenton, E., Goldstein, R., & Brooks, D. (2020). The relationship between self-efficacy, functional exercise capacity and physical activity in people with COPD: a systematic review and meta-analyses. *COPD: Journal of Chronic Obstructive Pulmonary Disease*, 17(4), 452–461. <https://doi.org/10.1080/15412555.2020.1782866>
- Shearn, K., Allmark, P., Piercy, H., & Hirst, J. (2017). Building Realist Program Theory for Large Complex and Messy Interventions. *International Journal of Qualitative Methods*, 16(1), 1–11. <https://doi.org/10.1177/1609406917741796>
- Sheridan, N. F., Kenealy, T. W., Fitzgerald, A. C., Kuluski, K., Dunham, A., McKillop, A. M., Peckham, A., & Gill, A. (2019). How does it feel to be a problem? Patients' experiences of self-management support in New Zealand and Canada. *Health Expectations*, 22(1), 34–45. <https://doi.org/10.1111/hex.12823>
- Shi, J., Ferretti, L., & McCallion, P. (2021). Attending with family members, completion rate and benefits accrued from chronic disease self-management program. *Chronic Illness*, 18(4), 784–795. <https://doi.org/10.1177/17423953211032263>
- Shi, J., McCallion, P., & Ferretti, L. A. (2017). Understanding differences between caregivers and non-caregivers in completion rates of Chronic Disease Self-Management Program. *Public Health*, 147, 128–135. <https://doi.org/10.1016/j.puhe.2017.02.001>
- Silva, M. N., Sánchez-Oliva, D., Brunet, J., Williams, G. C., Teixeira, P. J., & Palmeira, A. L. (2017). “What goes around comes around”: Antecedents, mediators, and

consequences of controlling vs. need-supportive motivational strategies used by exercise professionals. *Annals of Behavioral Medicine*, 51(5), 707–717. <https://doi.org/10.1007/s12160-017-9894-0>

Simmons, L. A., Wolever, R. Q., Bechard, E. M., & Snyderman, R. (2014). Patient engagement as a risk factor in personalized health care: A systematic review of the literature on chronic disease. *Genome Medicine*, 6(2). <https://doi.org/10.1186/gm533>

Simons, A. M. W., Koster, A., Groffen, D. A. I., & Bosma, H. (2017). Perceived classism and its relation with socioeconomic status, health, health behaviours and perceived inferiority: the Dutch Longitudinal Internet Studies for the Social Sciences (LISS) panel. *International Journal of Public Health*, 62(4), 433–440. <https://doi.org/10.1007/s00038-016-0880-2>

Skinner, T. C., Carey, M. E., Craddock, S., Dallosso, H. M., Daly, H., Davies, M. J., Doherty, Y., Heller, S., Khunti, K., & Oliver, L. (2008). “Educator talk” and patient change: Some insights from the DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) randomized controlled trial. *Diabetic Medicine*, 25(9), 1117–1120. <https://doi.org/10.1111/j.1464-5491.2008.02492.x>

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. *The BMJ*, 374(2018), 1–11. <https://doi.org/10.1136/bmj.n2061>

- Smale-Jacobse, A. E., Meijer, A., Helms-Lorenz, M., & Maulana, R. (2019). Differentiated instruction in secondary education: A systematic review of research evidence. *Frontiers in Psychology*, 10(November). <https://doi.org/10.3389/fpsyg.2019.02366>
- Smith, B., Robson, K., Robinson, C., & Patton, & N. (2023). Factors influencing provision of clinical placements for health students: A scoping review. *Focus on Health Professional Education*, 24(2), 63–103. <https://doi.org/10.3316/informit.258483856511192>
- Smith, M. L., Ahn, S. N., Jiang, L., Kulinski, K. P., & Ory, M. G. (2015). Factors associated with Hispanic adults attending Spanish-language disease self-management program workshops and workshop completion. *Frontiers in Public Health*, 2, 1–7. <https://doi.org/10.3389/fpubh.2014.00155>
- Smith, M. L., Bergeron, C. D., Ahn, S. N., Towne, S. D., Mingo, C. A., Robinson, K. T., Mathis, J., Meng, L., & Ory, M. G. (2018). Engaging the underrepresented sex: male participation in Chronic Disease Self-Management Education (CDSME) programs. *American Journal of Men's Health*, 12(4), 935–943. <https://doi.org/10.1177/1557988317750943>
- Smith, M. L., Ory, M. G., Jiang, L., Lorig, K., Kulinski, K. P., & Ahn, S. N. (2015). Workshop characteristics related to Chronic Disease Self-Management Education program attendance. *Frontiers in Public Health*, 3, 1–7. <https://doi.org/10.3389/fpubh.2015.00019>
- Sokkar, C., Penman, M., Raymond, J., & McAllister, L. (2019). An evaluation of client satisfaction with student delivered speech-language pathology services in private

practice. *Journal of Clinical Practice in Speech-Language Pathology*, 21(2), 65–69.
<https://doi.org/10.1080/22087168.2019.12370252>

Stafford, M., Steventon, A., Thorlby, R., Fisher, R., Turton, C., & Deeny, S. (2018). Briefing: Understanding the health care needs of people with multiple health conditions.

Stagg, A. L., Hatch, S., Fear, N. T., Dorrington, S., Madan, I., & Stevelink, S. A. M. (2022). Long-term health conditions in UK working-age adults: a cross-sectional analysis of associations with demographic, socioeconomic, psychosocial and health-related factors in an inner-city population. *BMJ Open*, 12(11), 1–14.
<https://doi.org/10.1136/bmjopen-2022-062115>

Stangl, A. L., Earnshaw, V. A., Logie, C. H., Van Brakel, W., Simbayi, L. C., Barré, I., & Dovidio, J. F. (2019). The Health Stigma and Discrimination Framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, 17(1). <https://doi.org/10.1186/s12916-019-1271-3>

Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Suleman, R., Thomas, V., & Tysall, C. (2017). GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research. *BMJ*, 358:j3453.
<https://doi.org/10.1136/bmj.j3453>

Stenberg, U., Haaland-Øverby, M., Fredriksen, K., Westermann, K. F., & Kvisvik, T. (2016). A scoping review of the literature on benefits and challenges of participating in patient education programs aimed at promoting self-management for people living with

chronic illness. *Patient Education and Counseling*, 99(11), 1759–1771.
<https://doi.org/10.1016/j.pec.2016.07.027>

Stenov, V., Hempler, N. F., Reventlow, S., & Wind, G. (2018). An ethnographic investigation of healthcare providers' approaches to facilitating person-centredness in group-based diabetes education. *Scandinavian Journal of Caring Sciences*, 32(2), 783–792.
<https://doi.org/10.1111/scs.12509>

Stone, D. A. (1989). Causal stories and the formation of policy agendas. *Political Science Quarterly*, 104(2), 281–300. <https://doi.org/10.2307/2151585>

Sutton, A., Clowes, M., Preston, L., & Booth, A. (2019). Meeting the review family: exploring review types and associated information retrieval requirements. *Health Information and Libraries Journal*, 36(3), 202–222. <https://doi.org/10.1111/hir.12276>

Tam, K. Y. Y., Poon, C. Y. S., Hui, V. K. Y., Wong, C. Y. F., Kwong, V. W. Y., Yuen, G. W. C., & Chan, C. S. (2020). Boredom begets boredom: An experience sampling study on the impact of teacher boredom on student boredom and motivation. *British Journal of Educational Psychology*, 90(S1), 124–137. <https://doi.org/10.1111/bjep.12309>

Tam, K. Y. Y., van Tilburg, W. A. P., Chan, C. S., Igou, E. R., & Lau, H. (2021). Attention drifting in and out: The Boredom Feedback Model. *Personality and Social Psychology Review*, 25(3), 251–272. <https://doi.org/10.1177/10888683211010297>

Tan, M. M. J., Han, E., Shrestha, P., Wu, S., Shiraz, F., Koh, G. C. H., McKee, M., & Legido-Quigley, H. (2021). Framing global discourses on non-communicable diseases: a scoping review. *BMC Health Services Research*, 21(1).
<https://doi.org/10.1186/s12913-020-05958-0>

- Taylor, S. J., Pinnock, H., Epiphaniou, E., Pearce, G., Parke, H. L., Schwappach, A., Purushotham, N., Jacob, S., Griffiths, C. J., Greenhalgh, T., & Sheikh, A. (2014). A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical Systematic Review of Self-Management Support for long-term conditions. *Health Services and Delivery Research*, 2(53), 1–580. <https://doi.org/10.3310/hsdr02530>
- Testerman, J., & Chase, D. (2018). Influences on diabetes self-management education participation in a low-income, Spanish-speaking, Latino population. *Diabetes Spectrum*, 31(1), 47–57. <https://doi.org/10.2337/ds16-0046>
- Teunissen, P. W. (2015). Experience, trajectories, and reifications: an emerging framework of practice-based learning in healthcare workplaces. *Advances in Health Sciences Education*, 20(4), 843–856. <https://doi.org/10.1007/s10459-014-9556-y>
- The RAMESES II Project. (2017). “Theory” in realist evaluation. https://www.ramesesproject.org/media/RAMESES_II_Theory_in_realist_evaluation.pdf
- Thomas, T. W., & Cankurt, M. (2024). Influence of food environments on dietary habits: Insights from a quasi-experimental research. *Foods*, 13(13), 2013. <https://doi.org/10.3390/foods13132013>
- Timmermans, L., Golder, E., Decat, P., & Foulon, V. (2023). Characteristics of self-management support (SMS) interventions and their impact on quality of life (QoL) in adults with chronic diseases: an umbrella review of systematic reviews. *Health Policy*, 104880. <https://doi.org/10.1016/j.healthpol.2023.104880>

- Tomlinson, C. A., Brighton, C., Hertberg, H., Callahan, C. M., Moon, T. R., Brimijoin, K., Conover, L. A., & Reynolds, T. (2003). Differentiating instruction in response to student readiness, interest, and learning profile in academically diverse classrooms: A review of literature. *Journal for the Education of the Gifted*, 27(2–3), 119–145. <https://doi.org/10.1177/016235320302700203>
- Torralba, K. D., Jose, D., & Byrne, J. (2020). Psychological safety, the hidden curriculum, and ambiguity in medicine. *Clinical Rheumatology*, 39(3), 667–671. <https://doi.org/10.1007/s10067-019-04889-4>
- Towne, S. D., Smith, M. L., Ahn, S. N., & Ory, M. G. (2015). The reach of chronic-disease self-management education programs to rural populations. *Frontiers in Public Health*, 2(APR), 1–7. <https://doi.org/10.3389/fpubh.2014.00172>
- Trappenburg, J., Jonkman, N., Jaarsma, T., van Os-Medendorp, H., Kort, H., de Wit, N., Hoes, A., & Schuurmans, M. (2013). Self-management: One size does not fit all. *Patient Education and Counseling*, 92(1), 134–137. <https://doi.org/10.1016/j.pec.2013.02.009>
- Tuzzio, L., Berry, A. L., Gleason, K., Barrow, J., Bayliss, E. A., Gray, M. F., Delate, T., Bermet, Z., Uratsu, C. S., Grant, R. W., & Ralston, J. D. (2021). Aligning care with the personal values of patients with complex care needs. *Health Services Research*, 56(S1), 1037–1044. <https://doi.org/10.1111/1475-6773.13862>
- Unwin, N., Epping Jordan, J., & Bonita, R. (2004). Rethinking the terms non-communicable disease and chronic disease. *Journal of Epidemiology & Community Health*, 58(801).

- van de Bovenkamp, H. M., & Dwarswaard, J. (2017). The complexity of shaping self-management in daily practice. *Health Expectations*, 20(5), 952–960. <https://doi.org/10.1111/hex.12536>
- Van De Velde, D., De Zutter, F., Satink, T., Costa, U., Janquart, S., Senn, D., & De Vriendt, P. (2019). Delineating the concept of self-management in chronic conditions: A concept analysis. *BMJ Open*, 9(7). <https://doi.org/10.1136/bmjopen-2018-027775>
- van der Ross, M. R., Olckers, C., & Schaap, P. (2023). Crossover of engagement among academic staff and students during COVID-19. *Psychology Research and Behavior Management*, 16, 3121–3137. <https://doi.org/10.2147/PRBM.S416739>
- Vaughan, B., Burns, C., Burrige, L., Wigger, J., Blair, S., & Mulcahy, J. (2019). Patient satisfaction and perception of treatment in a student-led osteopathy teaching clinic: Evaluating questionnaire dimensionality and internal structure, and outcomes. *International Journal of Osteopathic Medicine*, 31, 21–27. <https://doi.org/10.1016/j.ijosm.2019.01.002>
- Vaughn, J. L., Rickborn, L. R., & Davis, J. A. (2015). Patients' attitudes toward medical student participation across specialties: A systematic review. *Teaching and Learning in Medicine*, 27(3), 245–253. <https://doi.org/10.1080/10401334.2015.1044750>
- Verevkina, N., Shi, Y., Fuentes-Caceres, V. A., & Scanlon, D. P. (2014). Attrition in Chronic Disease Self-Management Programs and self-efficacy at enrollment. *Health Education and Behavior*, 41(6), 590–598. <https://doi.org/10.1177/1090198114529590>
- Viderman, D., Tapinova, K., Aubakirova, M., & Abdildin, Y. G. (2023). The prevalence of pain in chronic diseases: an umbrella review of systematic reviews. *Journal of Clinical Medicine* 12(23), 7302. <https://doi.org/10.3390/jcm12237302>

- Viens, A. M. (2019). Neo-liberalism, austerity and the political determinants of health. *Health Care Analysis*, 27(3), 147–152. <https://doi.org/10.1007/s10728-019-00377-7>
- Vissenberg, C., Stronks, K., Nijpels, G., Uitewaal, P. J. M., Middelkoop, B. J. C., Kohinor, M. J. E., Hartman, M. A., & Nierkens, V. (2016). Impact of a social network-based intervention promoting diabetes self-management in socioeconomically deprived patients: A qualitative evaluation of the intervention strategies. *BMJ Open*, 6(4). <https://doi.org/10.1136/bmjopen-2015-010254>
- Volpato, E., Toniolo, S., Pagnini, F., & Banfi, P. (2021). The relationship between anxiety, depression and treatment adherence in chronic obstructive pulmonary disease: A systematic review. *International Journal of COPD*, 16, 2001–2021. <https://doi.org/10.2147/COPD.S313841>
- Vygotsky, L. S. (1978). *Mind in society: the development of higher psychological processes*. Harvard University Press.
- Wagner, E. H. (1998). Chronic disease management: what will it take to improve care for chronic illness? *Effective Clinical Practice: ECP*, 1(1), 2–4. <http://www.ncbi.nlm.nih.gov/pubmed/10345255>
- Walton, H., Spector, A., Roberts, A., Williamson, M., Bhatt, J., Tombor, I., & Michie, S. (2020). Developing strategies to improve fidelity of delivery of, and engagement with, a complex intervention to improve independence in dementia: A mixed methods study. *BMC Medical Research Methodology*, 20(1). <https://doi.org/10.1186/s12874-020-01006-x>
- Wang, S., Yan, D., Hu, X., Liu, J., Liu, D., & Wang, J. (2023). Comparison of attitudes toward the medical student-led community health education service to support chronic

disease self-management among students, faculty and patients. *BMC Medical Education*, 23(1). <https://doi.org/10.1186/s12909-023-04008-7>

Westbury, S., Oyeboode, O., van Rens, T., & Barber, T. M. (2023). Obesity stigma: Causes, consequences, and potential solutions. *Current Obesity Reports*, 12(1), 10-23. <https://doi.org/10.1007/s13679-023-00495-3>

Westthorp, G. (2012). Using complexity-consistent theory for evaluating complex systems. *Evaluation*, 18(4), 405–420. <https://doi.org/10.1177/1356389012460963>

Westthorp, G. (2014). Realist impact evaluation. *Methods Lab*. <https://media.odi.org/documents/9138.pdf>

Westthorp, G., & Feeny, S. (2024). Using surveys in realist evaluation. *Evaluation Journal of Australasia*, 25(1), 45-64. <https://doi.org/10.1177/1035719X241292083>

Westthorp, G., & Manzano, A. (2017). Realist evaluation interviewing – A ‘starter set’ of questions. The RAMESIS II Project. https://www.ramesesproject.org/media/RAMESES_II_Realist_interviewing_starter_questions.pdf

Westthorp, G., Prins, E., Kusters, C., Hultink, M., Guijt, I., & Brouwers, J. (2011). Realist evaluation: an overview report from an expert seminar with Dr. Gill Westthorp. Centre for Development Innovation. https://www.researchgate.net/publication/259999155_Realist_Evaluation_an_overview_Report_from_an_Expert_Seminar_with_Dr_Gill_Westthorp

Westman, M. (2001). Stress and strain crossover. *Human Relations*, 54(6), 717–751. <https://doi.org/10.1177/0018726701546002>

- White Perkins, D., Milan, P., Miazek, K., Havstad, S., & Wegienka, G. (2021). Identifying factors affecting diabetes education program participation within a metro Detroit integrated health system. *Preventive Medicine Reports*, 24, 101646. <https://doi.org/10.1016/j.pmedr.2021.101646>
- Whitehead, L. C., Unahi, K., Burrell, B., & Crowe, M. T. (2016). The experience of fatigue across long-term conditions: A qualitative meta-synthesis. *Journal of Pain and Symptom Management*, 52(1), 131-143.e1. <https://doi.org/10.1016/j.jpainsymman.2016.02.013>
- Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553. <https://doi.org/doi.org/10.1111/j.1365-264>
- Wilson, M. K., Wilson, D. J., Searle, A. K., & Mackintosh, S. F. (2025). Consumer perspectives of the group itself in group-delivered programs for people with chronic pain: a systematic review and meta-synthesis. *The Journal of Pain*, 104774.
- World Health Organization (2002). Innovative care for chronic conditions: Building blocks for action: Global report. <https://www.who.int/publications/i/item/innovative-care-for-chronic-conditions-building-blocks-for-actions>
- World Health Organization (2013). Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020. <https://doi.org/10.1590/0034-7167.2016690422i>
- World Health Organization (2018). Noncommunicable Diseases Country Profiles 2018. <https://doi.org/10.1002/9781119097136.part5>

- World Health Organization (2023, September 16). Noncommunicable diseases.
<https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases>
- Wilkins, P. (2000). Unconditional positive regard reconsidered. *British Journal of Guidance & Counselling*, 28(1), 23–36. <https://doi.org/10.1080/030698800109592>
- Williams, O., & Gibson, K. (2018). Exercise as a poisoned elixir: Inactivity, inequality and intervention. *Qualitative Research in Sport, Exercise and Health*, 10(4), 412–428.
<https://doi.org/10.1080/2159676X.2017.1346698>
- Wong, G. (2015). Special Invited Editorial. *International Journal of Qualitative Methods*, 14(5), 160940691562142. <https://doi.org/10.1177/1609406915621428>
- Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J., & Pawson, R. (2013a). RAMESES publication standards: Meta-narrative reviews. *BioMed Central Medicine*, 11(20).
<https://doi.org/10.1186/1741-7015-11-20>
- Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J., & Pawson, R. (2013b). RAMESES publication standards: realist syntheses. *BioMed Central Medicine*, 11(21).
<https://doi.org/doi:10.1186/1741-7015-11-21>
- Wong, G., Westhorp, G., Greenhalgh, J., Manzano, A., Jagosh, J., & Greenhalgh, T. (2017). Quality and reporting standards, resources, training materials and information for realist evaluation: the RAMESES II project. *Health Services and Delivery Research*, 5(28), 1–108. <https://doi.org/10.3310/hsdr05280>
- Wong, G., Westhorp, G., Manzano, A., Greenhalgh, J., Jagosh, J., & Greenhalgh, T. (2016). RAMESES II reporting standards for realist evaluations. *BMC Medicine*, 14(1), 1–18.
<https://doi.org/10.1186/s12916-016-0643-1>

- Wordell, D., Daratha, K., Mandal, B., Bindler, R., & Butkus, S. N. (2012). Changes in a middle school food environment affect food behavior and food choices. *Journal of the Academy of Nutrition and Dietetics*, 112(1), 137–141. <https://doi.org/10.1016/j.jada.2011.09.008>
- World Health Organization. (2017). Fact sheet on Sustainable Development Goals (SDGs): health targets. <https://iris.who.int/bitstream/handle/10665/340852/WHO-EURO-2017-2381-42136-58046-eng.pdf?sequence=1>
- Wurz, A., St-Aubin, A., & Brunet, J. (2015). Breast cancer survivors' barriers and motives for participating in a group-based physical activity program offered in the community. *Supportive Care in Cancer*, 23(8), 2407–2416. <https://doi.org/10.1007/s00520-014-2596-2>
- Yin, R. K. (2018). *Case Study Research and Applications: Design and Methods* (6th ed.). SAGE.
- Yu, D. S., Li, P. W., Li, S. X., Smith, R. D., Yue, S. C.-S., & Yan, B. P. Y. (2022). Effectiveness and cost-effectiveness of an empowerment-based self-care education program on health outcomes among patients with heart failure. *JAMA Network Open*, 5(4), e225982. <https://doi.org/10.1001/jamanetworkopen.2022.5982>
- Yufe, S. J., Fergus, K. D., & Male, D. A. (2021). Storying my lifestyle change: How breast cancer survivors experience and reflect on their participation in a pilot healthy lifestyle intervention. *International Journal of Qualitative Studies on Health and Well-Being*, 16(1). <https://doi.org/10.1080/17482631.2020.1864903>
- Zuccala, E., & Horton, R. (2020). Reframing the NCD agenda: a matter of justice and equity. *The Lancet*, 396(10256), 939–940. [https://doi.org/10.1016/S0140-6736\(20\)31910-3](https://doi.org/10.1016/S0140-6736(20)31910-3)

Appendix A Phase 1 Ethics



MEMORANDUM

Application Code: EP142

Date: 25 May 2021

To: Elena Golder

Cc: Prof Saul Bloxham, Prof Pam Dawson

From: Dr Kass Gibson, Chair of the Research Ethics Panel

Subject: Ethical Review Decision

Dear Elena

Thank you for submitting your amendment to your project: **Person-Centred Group-Based Self-Management in Long-Term Conditions: a realist evaluation**

After careful consideration of your amendment, as Chair I issue a favourable ethical opinion of the above research on the basis described in the application form, amendment document, and supporting documentation.

Please note, the University Research Ethics Panel will be undertaking an audit during academic year 2020-21, and your application may be selected for this process. Please ensure you keep a record of your Ethics documentation. You will be informed if your application is selected for audit.

If you have any queries do not hesitate to get in touch with me. We wish you the best with your research.

Yours sincerely,

Dr Kass Gibson
Chair, University Research Ethics Panel
Plymouth Marjon University
01752 636700 (ext: 8611)
Email kgibson@marjon.ac.uk

Appendix B Phase 2 Ethics



MEMORANDUM

Application Code: EP192

Date: 17 November 2022

To: Elena Golder

Cc: Prof Saul Bloxham, Prof Pam Dawson, John Downey

From: Dr Kass Gibson, Chair of the Research Ethics Panel

Subject: Research Ethics Review Opinion

Dear Elena

Thank you for your application for research ethics review of your project: **Engagement in Group-Based Self-Management in Long-Term Conditions: a realist evaluation**.

Your application has undergone review and I am pleased to inform you that your project received a favourable opinion.

The review process has four possible outcomes: favourable opinion, minor amendments, major amendments and unfavourable opinion. On the basis described in the application form and supporting documentation, the opinion of the Panel is favourable.

Please note, the University Research Ethics Panel will be undertaking an audit during academic year 2022-23, and your application may be selected for this process. Please ensure you keep a record of your Ethics documentation. You will be informed if your application is selected for audit.

If you have any queries do not hesitate to get in touch with me. We wish you the best with your research.

Yours sincerely,

Dr Kass Gibson,
Chair, University Research Ethics Panel
Plymouth Marjon University
01752 636700 (ext: 8611)
Email kgibson@marjon.ac.uk

Appendix C Phase 1 interview schedule

Can you tell me what your involvement in the programmes has been?

How do you conceptualise engagement in the programmes?

What do you think is important for engagement in the programmes?

Are the specific things about the programme, or the way you deliver it that influence engagement?

If so, how?

Can you give some examples?

Do different groups of people engage differently?

In what ways are they different?

Do you have any examples of when people don't engage?

Are there any specific things about the context of delivering these programmes that help engagement or make it more difficult?

Can you compare with experiences of delivering similar programmes in different contexts?

Is there anything else you think is important for us to understand about engagement with these programmes?

Appendix D Phase 2 indicative questions for participant interviews

Questions will be based on programme theories and tailored to those who don't attend, attend but don't continue and those that complete the programmes.

Interview introduction

The purpose of this interview is to try to understand what works and doesn't work in helping people engage with the MHW programmes and why. For example, what helps people want to come onto and continue on the programme and why people might not want to carry on with the programme. I have some ideas about what might be important about the programme itself based on previous work and I would like to know what you think about these ideas.

Examples for a person who attends

"I noticed that on the programme there were a few different activities that you could try and sometimes people didn't join in on a particular activity. One idea is that having a choice about what you take part in is important for people to want to stay on the programme. What do you think?"

Follow on question: *"We have some possible theories that it might be because it helps people feel more in control and more valued as a person, do you think this is the case or do you think there are other reasons?"*

"There were some students supporting this programme and we wonder if people find it easier to talk to them than the practitioners, what do you think?"

Follow on questions: *"Is this just because it's a chance to speak to somebody one-to-one, or perhaps they are more approachable because you know they are learning from you as well? Or is it something else?"*

Examples for a person who does not attend

Introduction with open questions about why they did not attend and then introduce the idea that we think there are things to do with the pre-enrolment process and the

programme that might influence whether people attend, independent of some of the physical barriers to attending.

“Did you have a discussion with anybody, like your GP for instance, about what to expect on the programme and how it might be relevant to you and your needs? One idea we have is that if your GP understood what you wanted and how the programme might help you with what you wanted to achieve then it might help you find a reason to attend. What do you think?”

“We think some people are happier to attend somewhere non-medical, like the university sports centre, because it makes them think less about their health condition and more about normal life but some people might be put off by that. What do you think?”

Examples for a person who only attends once

Start with open questions about why they stopped attending. Then depending on answers, introduce theories for testing.

“I noticed that in the first session that you attended, people had a range of fitness levels and one idea we have is that if people feel as though it is too easy or too difficult, that they might lose interest in the programme, what do you think?”

“We think that the environment and mood of the programme might make a difference in whether people continue to attend the programme. For example, some people really like to share their experiences with others in the group but other people find this quite off-putting, what do you think?”

Appendix E Phase 2 observation schedule

Notes can be made per session as well as for the programme overall

It is fully expected that programmes will not have all of the architecture relevant to all programme theories

Notes of anonymised examples can be made to add detail to the following questions.

Programme Theory 1 - Choice

Do participants have an opportunity to communicate in a variety of ways during the session. E.g in a group, one-to-one, informal discussions.

Do participants have a choice in how they participate in activities? E.g. can they opt out of activities or is there are prescribed set of activities?

Are there a variety of activities for participants to try throughout the programme?

Are there specific outcomes for the programmes and/or is there flexibility in goals and outcomes for participants?

Programme Theory 2 – Feedback

Do practitioners have access to any feedback from participants during the programme? This may be verbal, physical participation or written feedback, for example.

Do participants have access to regular feedback on the activities they are participating in?

Programme Theory 3 – Environment

Where is the programme set? Description of physical setting:

What is the atmosphere like and who (participants/practitioners) contributes to this atmosphere and how?

Programme Theory 4 – Space

Is there informal/less structured time and space in the programmes to allow participants to explore activities, connect with other participants and/or students and practitioners? If so, how is this space built in?

Programme Theory 5 – Alignment of needs

Are the perceived benefits of the programme outlined in the context of what matters to the participants during the programme?

How are participants' expectations discussed and/or managed during the programme?

Programme Theory 6 – Student practitioners

Are there student practitioners involved in the programme? If so, how are they involved?

Programme Theory 7 – Co-constructed engagement

Do participants', practitioners' and/or students' observable signs of engagement appear to change in relation to observable signs of engagement in others in the room?

Appendix F Phase 2 Surveys

Pre Back Programme Survey (engagement constructs highlighted in bold)

1. How long have you had back pain for?
2. Roughly how many times have you seen your doctor or sought treatment for your back pain?

3. My past experience of using health services has generally been positive

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly agree	Agree	Disagree	Strongly disagree

4. The person who referred me to the Back Wellbeing Programme was able to help me understand how it could meet my needs

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly agree	Agree	Disagree	Strongly disagree	N/A

5. I know what to expect from the Back Wellbeing Programme

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly agree	Agree	Disagree	Strongly disagree

6. I feel comfortable expressing myself in group settings

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly agree	Agree	Disagree	Strongly disagree

7. I feel comfortable expressing myself in one-to-one interactions

☐

☐

☐

☐

Strongly agree

Agree

Disagree

Strongly disagree

8. I feel enthusiastic about attending the Back Wellbeing Programme

☐

☐

☐

☐

Strongly agree

Agree

Disagree

Strongly disagree

9. I am willing to invest time and energy to attend the Back Wellbeing Programme

☐

☐

☐

☐

Strongly agree

Agree

Disagree

Strongly disagree

10. I feel committed to attending the Back Wellbeing Programme

☐

☐

☐

☐

Strongly agree

Agree

Disagree

Strongly disagree

Post Back Programme Survey

1. This programme has been relevant to my needs and what matters to me.

☐ ☐ ☐ ☐

Strongly agree Agree Disagree Strongly disagree

2. **I have connected with other participants on this programme.**

For example, shared experiences, connected socially, supported one another.

☐ ☐ ☐ ☐

Strongly agree Agree Disagree Strongly disagree

3. **I have connected with the practitioner(s) on this programme.**

For example, built trust, felt comfortable talking with them, felt listened to, felt valued.

☐ ☐ ☐ ☐

Strongly agree Agree Disagree Strongly disagree

4. **I have connected with student practitioners on this programme.**

For example, built trust, felt comfortable, felt listened to, felt valued.

☐ ☐ ☐ ☐

Strongly agree Agree Disagree Strongly disagree

5. **I have connected with activities** (e.g. exercises, nutrition information) on this programme. For example, enjoyed, found relevance, interest, or benefit.

☐ ☐ ☐ ☐

Strongly agree Agree Disagree Strongly disagree

6. I have been enthusiastic about attending this programme.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly agree	Agree	Disagree	Strongly disagree

7. I have invested time and energy to attend this programme.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly agree	Agree	Disagree	Strongly disagree

8. I have felt committed to attending this programme

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly agree	Agree	Disagree	Strongly disagree

Appendix G Audit trail of data sources for theory verification and refinement

Back Programme = B, Cancer Programme = C, Leg Programme = L

Programme Theory	Participant interview	Practitioner interview	Student practitioner interview	Observation
Programme Theory 1 Choice and Variety				
CMO-C 1	B, L	B, C, L		B, C, L
CMO-C 2	B, L	B, C, L		B, C, L
CMO-C 3	B	B, L		B, C, L
Programme Theory 2				
Feedback and Differentiation				
CMO-C 1	B	B, C, L		B, C, L
CMO-C 2	B, L	B, C, L		B, C, L
Programme Theory 3 Environment				
CMO-C 1a	B, L	B, C, L		B, C, L

CMO-C 1b	B, L	B, C, L		B, C, L
CMO-C 2a	B, L	B, C, L	B	B, C, L
CMO-C 2b	B, L	B, C, L	B	B, C, L
Programme Theory 4 Space and Time				
CMO-C 1	B, L	B, C, L	B	B, C, L
CMO-C 2	B, L	B, C, L	B	B, C, L
Programme Theory 5 Alignment of Needs				
CMO-C 1	B, L	B, L		B, L
CMO-C 2	B, L	B, L, C		B, L, C
Programme Theory 6 Student Involvement				
CMO-C 1	B, L	B, C, L	B, L	B, L, C
CMO-C 2	B, L	B, C, L	B	B, L, C
Programme Theory 7 Co-constructed Engagement	B, L	B, C, L	B	B, L, C
