Training health professionals to support people with progressive neurological conditions to self-manage:

A realist inquiry

PhD (Medicine)

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## Summary

#### Introduction

Supporting patients to effectively self-manage their own conditions is known to be challenging for health professionals. It requires specific skills and often challenges existing practice. Supporting self-management among people with progressive neurological conditions may represent additional challenges due to the multiple evolving symptoms people with these conditions may experience.

#### Methods

Realist methods were used to investigate how training interventions that target health professionals working with people with progressive neurological conditions and aim to improve self-management support provision work, for whom and in what circumstances. Phase One (used for theory development) included a survey of 186 health professionals and a realist literature synthesis including 44 papers (supplemented by stakeholder advisory groups and five key informant interviews). Phase Two (used for theory refinement) involved the evaluation of a two-day training course in "Health Coaching Skills" delivered to twenty health professionals. Data were collected in Phase Two through observations of the training days, individual telephone interviews with participants and trainers (total = 33 interviews) and pre-and post-training questionnaires. Relevant formal theories informed the analysis.

#### Results

Four initial rough theories were developed in Phase One and subsequently refined in Phase Two. Context-mechanism-outcome configurations were generated during each stage and used to develop an overall programme theory. Key training mechanisms identified included critical reflection on current practice and the development of knowledge, skills and confidence. Training participants need to become convinced of the relevance of the training to their setting, a process which is influenced by their experiences of implementing the training.

#### Conclusions

Implementation patterns following training vary widely. Training tends to be most successful when participants build self-belief in the new skills, while also becoming convinced that patients will be responsive, and that their working patterns can accommodate a change in approach. Experiencing significant role conflict can inhibit change.

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# Abbreviations used within the thesis

СМО	Context-Mechanism-Outcome	
CPD	Continuing Professional Development	
CS-PAM	Clinician Support for Patient Activation Measure	
GP	General Practitioner	
НСР	Health Care Professional	
MI	Motivational Interviewing	
MS	Multiple Sclerosis	
NHS	National Health Service	
NICE	National Institute for Health and Care Excellence	
NPT	Normalisation Process Theory	
ОТ	Occupational Therapist	
PAM	Patient Activation Measure	
PD	Parkinson's Disease	
PNC	Progressive neurological condition	
PPI	Public and Patient Involvement	
SMS	Self-management support	
TAM3	Technology Acceptance Model 3	
TGROW	Topic Goal Reality Options Will (stages of coaching process)	

## Contents

1 In	troduction	1
1.1	What is self-management?	1
1.2	The push for self-management	4
1.3	What is support for self-management?	6
1.4	Terminology used within the thesis	8
1.5	Key concepts in the study of self-management support	10
1.6	A focus on progressive neurological conditions	16
1.7	Selecting an area of focus	26
1.8	Chapter Summary	30
1.9	Aims and objectives of the PhD	31
1.10	) Thesis outline	32
2 R	ealist methodology	35
2.1	Common paradigms in research of health professional education	35
2.2	What is realism?	41
2.3	Research design: Using the realist approach	47
2.4	Chapter summary	68
	escribing current practices in supporting self-management and identifyin using a health professional survey	
3.1	Introduction	69
3.2	Background	69
3.3	Defining aims and selecting an instrument	70
3.4	Methods	73
3.5	Results	83
3.6	Discussion	101
3.7	Implications and next steps	113
4 R	ealist synthesis	115
4.1	Introduction	115
4.2	Methods	115
4.3	Key informant interviews	130
4.4	Included studies	134
4.5	The role of existing formal theory	146
4.6	Theories generated from the review	153
4.7	Strengths and Limitations of the Review	179
4.8	Chapter Summary	180
5 E\	valuation of a health coaching skills development programme	182

	5.1	Developing theories	182
	5.2	Selecting an intervention for theory testing	184
	5.3	Justifying a focus on health coaching	187
	5.4	The intervention	198
	5.5	Evaluation plan	207
	5.6	Chapter summary	226
6	Resu	ılts of training evaluation	227
	6.1	Contributory data sources	227
	6.2	Training participant characteristics	229
	6.3	Critical reflection	230
	6.4	Relevance to setting	247
	6.5	Knowledge, skills and confidence	264
	6.6	Experiences of Implementation	275
	6.7	Key findings	288
7	Resu	ılts 2: Further analysis and applying formal theory	289
	7.1	Introduction	289
	7.2	Overall response patterns	290
	7.3	Making sense of complexity – a realist perspective	294
	7.4	Applying formal theory	300
	7.5	Chapter Summary	323
3	Disc	ussion	324
		Core question 1: How, and in which circumstances, do SMS training intervention of the community of the commu	ons 327
	8.2	Core question 2: Does training clinicians in specific SMS skills help them to see	
		kills as applicable to a wider (including more challenging) population?	
	8.3	Core question 3: How does team support influence the implementation of SM 340	S?
	8.4 SMS?	Core question 4: How do organisational priorities influence how individuals va 344	lue
	8.5	A refined programme theory	347
	8.6	Strengths and Limitations	350
	8.7	Recommendations for organisations and providers	368
	8.8	Recommendations for future research	372
	8 9	Conclusions	374

# Appendices table

		Page
Appendix A	Publications and presentations produced during the thesis	417
Appendix B	Completed RAMESES Checklists for realist synthesis and evaluation	
Appendix C	Online survey discussed in Chapter 3	455
Appendix D	Stages in the review process	471
Appendix E	Search strategy	474
Appendix F	Abstract screening tool	481
Appendix G	Materials relating to key informant interviews	482
Appendix H	Evidence of data saturation for review	488
Appendix I	Ideas for interventions	490
Appendix J	Materials relating to focus groups	496
Appendix K	Completed TIDieR checklist for intervention reporting	505
Appendix L	Example pages from web resource	509
Appendix M	Evaluation stage questionnaires	511
Appendix N	Materials relating to evaluation stage	535
Appendix O	Coding framework used during analysis of evaluation data	545
Appendix P	Example of how multiple lower level If-Then statements were consolidated into a higher-level theory	548

## 1 Introduction

This thesis explores how the support for self-management provided by health professionals for people with progressive neurological conditions can be improved through staff training. The thesis is divided into eight chapters. This first chapter discusses how self-management has been conceptualised and how it relates to other important approaches to person-centred care. It explains the rationale for the research focus and presents the aims and objectives of the thesis. The structure of the rest of the thesis is presented at the end of this chapter.

# 1.1 What is self-management?

On a daily basis, people living with long-term conditions make decisions about how to manage their condition (Lorig and Holman 2003). Corbin and Strauss (1988) described the process of self-management as comprising medical management (such as using medications), emotional management (dealing with the psychological impact of living with a long term condition), and management of behaviours and life roles (working out how to make the required lifestyle adaptations). Recognising the lack of a consensus definition for self-management, Barlow et al. (2002, p.178) proposed the following, now commonly cited version:

"self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition."

Lorig and Holman (2003) expanded on earlier definitions, identifying five key self-management skills that people with long term conditions need to be supported to develop: taking decisions based on knowledge of their condition; identifying and using appropriate resources; problem solving; working in partnership with clinicians; and making plans for action and following these through.

While there are many similarities and overlaps between the different definitions of self-management support proposed, there is recognition that the concept is complex, evolving and often contested (Bishop et al. 2008; Morgan et al. 2017). More recently, researchers have begun to explore the underlying assumptions upon which ideas about self-management are based, particularly in relation to its aims. Two differing perspectives have been identified in the literature. The first tends to view self-management in relation to disease management, focussing on compliance with healthcare professionals' advice, and with a more limited view of patient empowerment (Bishop et al. 2008; Audulv et al. 2016; Morgan et al. 2017). This perspective therefore tends to assume that self-management behaviours would be specific to the diagnosis, focussed on meeting the biomedical goals related to the condition (Auduly et al. 2016; Morgan et al. 2017). Viewing people as being in need of instruction, rather than as individuals who manage their own lives has been criticised for failing to take into account the important influence of the wider social, political and economic context in enabling self-management (Kendall et al. 2011).

The second perspective identifies self-management more broadly, focussing primarily on supporting people to live well with their condition, and seeing disease control as one way to facilitate this (Auduly et al. 2016; Morgan et al. 2017). Using

this perspective, self-management may be associated with key skills such as problem solving and resource use, and so can be understood across different diagnoses (Audulv et al. 2016; Morgan et al. 2017). This view moves towards a more collaborative view of the practitioner-patient relationship, and away from the emphasis on the expertise and authority of health professionals which predominates in the first perspective (Morgan et al. 2017). This second perspective is more sensitive to the idea that individuals' responses to any efforts to promote self-management are shaped by their own context (Wilson 2001).

While these two perspectives describe understandings of self-management among health professionals, other research has focussed on how patients' and professionals' conceptualisations differ. Evidence clearly shows that lay people think differently about self-management when compared with clinicians. While some lay people have a compliance-based understanding of self-management similar to that of many health professionals (Sadler et al. 2014), many others have a broader focus, considering their lives as a whole, rather than specifically focussing on health-related behaviours (Kendall et al. 2011).

There is variability in the level of involvement people wish to have (with some preferring a more active role than others), but generally people emphasise the importance of being supported to self-manage in a way that is appropriately tailored to fit within the context of their lives (Sadler et al. 2014; Boger et al. 2015). People may feel a moral responsibility to self-manage, both to meet the expectations of society (taking responsibility for one's own health, using healthcare

services appropriately), and to ensure they are able to fulfil their social roles and avoid burdening their family (Kendall et al. 2011; Ellis et al. 2017). However, people with long term conditions see 'good' self-management as taking a selective approach which balances the need to follow medical advice with the need to maintain valued social roles and behaviours (Ellis et al. 2017).

People with long term conditions also emphasise self-management as being a social practice, enabled through interactions with others, but clinicians are often seen to give limited consideration to the role of social context (Franklin et al. 2018). Other areas of significant importance to lay people, which are less frequently discussed by clinicians include the role of the relationship between the clinician and patient, and the need for the psychosocial impact of the condition to be addressed (Sadler et al. 2014; Franklin et al. 2018).

This brief review of existing ideas about self-management has revealed that the concept is not as straightforward or easily understood as might first be expected.

While opinions on the purpose of supporting self-management remain varied, there has been a significant policy drive to encourage self-management among people with long-term conditions.

# 1.2 The push for self-management

At the policy level, self-management has been promoted as a potential panacea to address the strain currently facing under-resourced healthcare systems (Kendall et

al. 2011; Sadler et al. 2014). The World Health Organization has suggested that empowering people to manage their own conditions may be one way to improve the efficiency and quality of health services (Sixty-sixth World Health Assembly 2013). In the UK, key policy documents emphasise self-management as a priority. The NHS England Five Year Forward View published in 2014 makes a commitment that health services will actively support people to manage their own health, specifically mentioning investment in group-based education approaches and a wish to encourage peer-to-peer communities to emerge (NHS England 2014). The National Clinical Strategy for Scotland heavily emphasises the need to shift towards a self-management approach to build people's resilience rather than create dependency on the healthcare system (The Scottish Government 2016). The Welsh Government strategy document: A Healthier Wales: Our plan for Health and Social Care includes promoting independence through supporting self-management as one of ten design principles to guide service transformation (Welsh Government 2018). Influential third sector organisations including The King's Fund and The Health Foundation have called for a greater emphasis on self-management in healthcare (Naylor et al. 2013; de longh et al. 2015).

While service commissioners recognise self-management support as an important priority, in practice the way in which services are evaluated and funded still tends to drive the allocation of resources towards the achievement of biomedical outcomes (Reidy et al. 2016). Critics of the policy push for self-management have voiced concerns that this is motivated by a desire to reduce service usage and costs (Kendall et al. 2011). Services wishing to manage increasing demand have delegated tasks to do with managing illness and promoting health to the patient

(May et al. 2014). This delegated work may often represent a burden on patients and their wider support network, taking significant time, often requiring high levels of literacy, numeracy and technical skills (Mair and May 2014). This delegation may disadvantage people who lack adequate resources, whether due to cognitive impairment, social isolation, low health literacy or physical disabilities (Mair and May 2014). This leads to an important conclusion, that if self-management is to be promoted by policy, it is imperative that we understand how to effectively support people as they take on new responsibilities.

# 1.3 What is support for self-management?

If people are expected to take more responsibility for their own health they will require support to do so, especially when they have a significant disease burden (Imison et al. 2017). Individual health care professionals, and the wider healthcare system have important roles in supporting people to live well with their conditions (Long Term Conditions Alliance Scotland 2008). Bodenheimer et al. (2005) suggest that self-management support (SMS) can be viewed either as the application of specific tools and techniques to facilitate behaviour change, or as a more fundamental shift in the traditional patient-provider relationship towards a more collaborative interaction. Taylor et al. (2014) developed a taxonomy to classify the range of activities considered to facilitate self-management. These included support delivered directly to patients, and indirect components (related to changes at the level of the health professional or organisation). Fourteen direct components of SMS were described some of which may already be part of routine

care (such as provision of education and regular clinical review) and some which are more specific to supporting self-management (such as training in psychological strategies and communication with healthcare professionals). Indirect components of SMS interventions included professional training and feedback, financial incentives, prompts and equipment. While no single component was identified as being effective in isolation, and generally most interventions involved multiple components, those components considered to be core were: information provision, psychological strategies, practical condition-specific support, and social support (Taylor et al. 2014).

An earlier review conducted for The Health Foundation emphasised that although information provision is an important aspect of supporting self-management, increases in knowledge do not automatically change levels of confidence, or influence subsequent health behaviours (de Silva 2011). Many self-management support interventions focus specifically on self-efficacy. This concept originates from the work of psychologist Bandura (1977) and relates to an individual's belief that they can successfully accomplish a task. Tactics known to build self-efficacy are often incorporated into self-management interventions, including providing opportunities to experience success and learn from the successes of others, and verbal and social persuasion. Increasing self-efficacy is an important target for self-management interventions because self-efficacy has been shown to strongly correlate with self-management knowledge and behaviours (Wilski and Tasiemski 2015). More active approaches to supporting self-management which utilise techniques such as motivational interviewing, coaching and goal setting can help to

build self-efficacy and tend to result in more behaviour change (de Silva 2011).

Although the evidence about the impact on clinical outcomes is mixed,
improvements in self-reported health, measures of disease control (such as blood sugar levels), and unplanned admission rates have been observed (de Silva 2011;
Taylor et al. 2014). Due to the variety of ways in which self-management can be supported I present the definition adopted in this thesis below, along with definitions for two other important pieces of terminology.

# 1.4 Terminology used within the thesis

## 1.4.1 Self-management support

This thesis adopts a broad view of self-management support, defining it as any activity or approach which helps a person to live well with their condition. While it is recognised that self-management support may come from a variety of sources including family, friends and others with the same condition, for the purpose of this thesis the focus is on support provided by health professionals. As discussed above, health professionals may be involved in the delivery of structured courses which aim to empower people to self-manage. However, this thesis focusses on the provision of support as part of routine clinical encounters, rather than on specific courses. When self-management is discussed in the literature, other concepts related to patient-centred care are also frequently mentioned. Several of these concepts, and their relationship to SMS are briefly considered in Section 1.5.

#### 1.4.2 Patient

While the use of the word patient has been debated, with suggestions that it indicates passivity rather than active involvement (Neuberger and Tallis 1999), I have chosen to use the term within this thesis. This decision was made because the term is commonly used across healthcare, is easily understood, and tends to be the term preferred by the people themselves receiving healthcare (Deber et al. 2005). While I fully recognise that alternative terminology, such as service users or clients is preferred by some, for consistency a single term is used throughout. The use of the word patient is chosen for clarity. Although I am aware it may sometimes be perceived as disempowering, or as failing to recognise the many more important life roles that people take on, this is not intended.

## 1.4.3 Training

The term training is used frequently throughout the thesis. This is not meant to confine the scope of the inquiry to only the didactic delivery of a standardised way of working. Rather I use the term to discuss educational activities which contribute towards continuing professional development (CPD). I recognise that CPD may occur through a variety of activities (e.g. discussions with colleagues and reflective practice) (Health and Care Professions Council 2019) which also contribute to how 'training' may lead to outcomes.

## 1.5 Key concepts in the study of self-management support

Several other concepts, important to the provision of person-centred care are often discussed in relation to self-management support. The concepts of patient activation, health literacy, co-production, shared decision-making, and care and support planning are briefly described below and their relevance to SMS provision is discussed.

### 1.5.1 Patient Activation

Interest in measuring patients' knowledge, confidence and skills for self-management led to the development of the Patient Activation Measure (PAM), a 13-item questionnaire (Hibbard et al. 2005). Patients' responses are scored at one of four levels of activation and tailoring treatment to take this into account is recommended as outlined in Table 1.1 (Hibbard et al. 2009). PAM scores have been used both as an outcome measure to assess the benefits of self-management support interventions, and as a tool to inform the approach taken by health professionals within consultations. PAM can also be used to assess levels of activation across a patient population (Roberts et al. 2016).

Table 1.1 Levels of Patient Activation and suggested tailoring of support

All definitions taken directly from Hibbard et al. 2009

Activation Level	Typical Patient	Focus of support
1	Overwhelmed and unprepared	Build patient self-awareness and understanding of behaviour patterns
2	Lacks knowledge and confidence for self-management	Making small changes to existing behaviours
3	Beginning to take action	Adoption of new behaviours, problem solving skills
4	Adopted many behaviours but may not be able to maintain them in the face of challenges	Handling new situations or challenges as they arise

PAM scores have been correlated with important health outcomes. For example, patients who have lower activation levels have higher rates of hospitalisation and emergency department attendance, (Greene et al. 2015; Kinney et al. 2015) while more activated patients are more likely to take part in positive health behaviours (e.g. attending screening programmes), and are less likely to be smokers (Greene et al. 2015). The PAM has been more widely used outside the UK context (Roberts et al. 2016) and challenges with using the PAM (which was developed in the USA) within the NHS have already been identified. These include the fact that not all items are relevant to all patient groups (e.g. an item about knowing how to prevent health problems was seen as inappropriate by people with progressive conditions) (Armstrong et al. 2017). UK clinicians attempting to use the PAM to tailor the support they provided to stroke patients found that the measure did not facilitate tailoring and did not find it helpful (Roberts et al. 2016). Furthermore, concerns have been raised that the concept of patient activation assumes that people are able to make choices and act on them. It therefore does not recognise how social

context can constrain the choices available and inhibit change even among highly activated patients (Armstrong et al. 2017).

## 1.5.2 Health literacy

Health literacy relates to the knowledge and skills people require to effectively manage their health (Sørensen et al. 2012). While many definitions of health literacy have been proposed, no single definition has been accepted as effectively capturing this multi-dimensional and evolving concept (Poureslami et al. 2017). Sørensen et al (2012, p.3) used 17 definitions, to develop their own definition in which health literacy is described as relating to "people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions". These decisions can relate to maintenance or improvement of health, and are taken across the life course (Sørensen et al. 2012).

While some literature conceptualises health literacy as a risk factor to be managed, an alternative perspective views health literacy as an asset which can be built (Nutbeam 2008). Low health literacy makes it challenging for people to effectively self-manage (for example due to difficulties interpreting labels and health messages) (Berkman et al. 2011). It is associated with lower levels of positive self-management behaviours (appropriate medication use, attendance for screening and vaccinations), and with worse health outcomes, including increased mortality among older people (Berkman et al. 2011).

# 1.5.3 Co-production

Co-production has been defined as "an asset-based approach to public services that enables people providing and people receiving services to share power and responsibility, and to work together in equal, reciprocal and caring relationships" (Co-production Network for Wales 2019). The term may be used in relation to the co-production of healthcare services, when service users become involved in the process of service provision (Realpe and Wallace 2010; Bovaird and Loeffler 2013). Service users can be involved at various stages, including in co-commissioning, codesign, co-delivery or co-assessment of healthcare services (Bovaird and Loeffler 2013). Co-production of services may occur at the macro level (between policy makers and patient organisations), the meso-level (between a GP partnership and their patient advisory group) or the micro-level (during interactions between health professionals and patients) (Vennik et al. 2016). A co-productive approach recognises the assets that service users can bring to generate service improvements, while also having the ideological function of democratizing the process of making decisions in health service delivery (Bovaird and Loeffler 2013; Vennik et al. 2016). It has been suggested that we need to recognise that health services are always being co-produced by patients and professionals, but in systems that either support or constrain their efforts (Batalden et al. 2016). Co-production may also be used to refer to the active role that individuals take in co-producing their own health itself. Supporting patients to self-manage can be seen as one way to engage and enable people to effectively co-produce their health. However recognised barriers to co-production, including a resistant healthcare culture, and the fact that not all patients desire or have the capacity to take a more active role,

are important to consider in the context of efforts to improve self-management support provision (Batalden et al. 2016).

Two methods for actively engaging with individuals in the co-production of health and healthcare (shared decision-making and care and support planning) are briefly described below.

## 1.5.4 Shared decision-making

Shared decision-making has been defined as "an approach where clinicians and patients make decisions together using the best available evidence" (Elwyn et al. 2010). Shared decision-making consultations identify patients' preferences and use these to guide choices made, valuing the autonomy of the patient and encouraging them to be actively involved in their care (Elwyn et al. 2010). While self-management support is seen to overlap with the practice of shared decision making, how exactly they are related has been debated (Ahmad et al. 2014).

Shared decision-making has been variably conceptualised as a narrow concept which sits within the broader concept of SMS, as being a different concept to SMS but with the same underlying values, or as being another aspect of person-centred care alongside SMS (Ahmad et al. 2014).

### 1.5.5 Care and Support Planning

Care and support planning is promoted by NHS England as a mechanism through which person-centred care can be achieved (NHS England undated). It involves a

professional, which focusses on the things that matter to the individual. These collaborative conversations, which often occur annually, aim to identify goals, discuss options and support needs (including any support required to self-manage) and to formulate and document a plan (Eaton et al. 2015; Coalition for Collaborative Care 2016). Care and support planning uses a shared decision making process, in which the expertise of both the patient and the clinician are valued, and seen as necessary to facilitate effective condition management (Coulter et al. 2015). A Cochrane review of personalised care planning for adults with long-term conditions found that the interventions resulted in small improvements in some markers of physical health, together with a small increase in self-efficacy. However, all of the included studies featured elements intended to support behaviour change which is not always a component of care and support planning (Coulter et al. 2015). While policy documents clearly state that these conversations should not amount to a "tick-box exercise" (Coalition for Collaborative Care 2016, p.17), in practice concerns have been raised that the policy objective has had little impact on routine practice within the NHS (Mathers and Paynton 2016). This lack of reach is exemplified by the fact that 85% of people with neurological conditions report that they have not been offered a care plan (Neurological Alliance 2017).

conversation between an individual living with a long-term condition and a health

## 1.5.6 Relevance of these concepts to self-management support

The evidence relating to health literacy and patient activation highlights how individuals' skills and confidence to manage their own health impact on a wide

range of health behaviours and outcomes. For clinicians who wish to support patients to self-manage it serves as an important reminder that people are starting from different levels and are likely to need tailored support. A single approach is unlikely to be effective across a whole patient population. Both shared decision-making and co-production highlight the importance of empowering individuals to take an active role in their own health, while recognising that they may need to be supported to do so. Care and support planning offers one way to formalise and operationalise the process of SMS, although it has not yet become fully integrated into routine practice.

Having discussed self-management, self-management support and other overlapping concepts, the next section of this chapter sets out the specific patient group focussed upon in this PhD alongside the rationale for this focus.

# 1.6 A focus on progressive neurological conditions

The idea for this thesis was inspired by a research project I was involved in from 2013-2015. The study used qualitative methods to explore the experiences and support needs of people with secondary progressive multiple sclerosis, commissioned by The MS Trust (Davies et al. 2015). I led the data collection and analysis and found that the themes identified by clinicians about supporting self-management resonated with me both as a clinician (I am a general practitioner) and a researcher. Clinicians described a desire to support self-management but expressed frustration that they did not always feel successful and identified significant barriers (Davies et al. 2016). The project formed the basis of my Masters

in Medical Education dissertation, in which I explored how understanding how to provide effective SMS was currently an unmet learning need for professionals in this area. The motivations for this thesis were to confirm whether the findings from the small qualitative study had broader relevance, and to identify potential ways in which the learning need could be addressed.

Although it was originally the intention to target staff working with people with MS, as the first year of the PhD progressed I noted that the challenges that faced these professionals were likely to have commonalities with the issues faced by staff working with other progressive neurological conditions (PNCs). In some settings a single staff member (e.g. a neurology specialist nurse, physiotherapist or occupational therapist) might be working with patients with a range of PNCs, making a focus on a single condition somewhat artificial. The themes identified in my previous MS research and those planned for exploration within my thesis were discussed with local clinicians working with people with Parkinson's disease (PD). They found the findings highly relatable and were enthusiastic about the development of training and support in this area. During the first year of the PhD I therefore decided to broaden the focus to staff working with people with any progressive neurological condition. A short description of two of the commonest conditions is provided below.

Neurological conditions are often grouped into four main categories, being either sudden onset (e.g. stroke), intermittent (e.g. epilepsy), stable with changing needs (e.g. cerebral palsy) or progressive (e.g. multiple sclerosis) (Neurological Alliance

2014). Although dementia is within the progressive group, it is often considered separately (as is the case in this thesis) because it is managed primarily by mental health teams rather than medical teams (National Audit Office 2015).

Parkinson's disease is the second commonest progressive neurodegenerative disorder (Alzheimer's disease being the commonest) (Wirdefeldt et al. 2011). An estimated 145,519 people in the UK had Parkinson's disease in 2018 with the prevalence expected to rise by 18% to 168,000 by 2025 (Parkinson's UK 2018). Parkinson's disease is typically a disease of older adults, with very few cases occurring before age 40, and a steep increase in the incidence after age 60 (Wirdefeldt et al. 2011). Parkinson's disease is caused by dopamine deficiency which is the result of degeneration of the substantia nigra area of the brain (Chaudhuri et al. 2006; National Institute for Health and Care Excellence 2017). While Parkinson's disease was initially recognised as a movement disorder, causing the classic symptoms of bradykinesia (slowed movements), rigidity, tremor and postural instability, non-motor symptoms including sleep disturbance, autonomic dysfunction and neuropsychiatric symptoms are common and cause significant morbidity (Chaudhuri et al. 2006; National Institute for Health and Care Excellence 2017).

Multiple sclerosis (MS) is the commonest disabling neurological condition among young adults, with a mean age at diagnosis of 30 (O'Connor 2002; Murray 2006). The MS Society estimates that there are 110,000 people living with MS in the UK (Multiple Sclerosis Society 2018). Multiple sclerosis is caused by an inflammatory process which leads to demyelination and axonal injury in discrete areas of the

central nervous system (O'Connor 2002). Most patients are diagnosed with the relapsing-remitting form of multiple sclerosis, and experience episodic relapses followed by partial or complete recovery. Over time, many will transition to the secondary progressive phase of the disease, although a smaller proportion of patients are diagnosed with progressive disease from the outset (Murray 2006). Axon damage is thought to be responsible for the permanent disability that occurs at this stage (O'Connor 2002). Symptoms vary depending on the area of the central nervous system involved, but commonly include visual and sensory disturbance, cognitive problems, problems with balance and gait, weakness, spasticity, fatigue, and bladder dysfunction (Kesselring and Beer 2005; Murray 2006).

There is also a wide range of other less common progressive neurological conditions including Huntington's disease, motor neurone disease, Charcot-Marie-Tooth disease and muscular dystrophies (Neurological Alliance 2014).

# 1.6.1 Supporting self-management among people with progressive neurological conditions

The nature of PNCs may make self-management and supporting self-management particularly challenging for several reasons. Because of the complexity of their conditions, people with PNCs often require support from a wide range of different sources (including different professional groups and from within their social network). A coordinated approach is therefore crucial but challenging (Neurological Alliance 2018a). The symptoms of PNCs, such as fatigue and mobility impairments, may make engaging in positive heath behaviours problematic (Plow

and Golding 2016). Cognitive impairment, which can increase over time, can make it difficult for people to concentrate on information provided or to make decisions effectively (van der Eijk et al. 2011).

Communication problems may also occur, requiring consultations to be tailored to meet people's changing needs (National Institute for Health and Care Excellence 2017). Mental health problems commonly occur alongside neurological conditions, but providing an accurate diagnosis and appropriate treatment is challenging as it is not always clear which symptoms may be due to the underlying neurological condition and which may be due to a specific mental health problem (Neurological Alliance 2018b). Management of mental health problems, together with the wider emotional and cognitive needs of patients with neurological conditions are not always a priority for neurological services (Neurological Alliance 2018b). However, co-morbid mental health conditions can limit people's ability to self-manage their physical health problems and lead to missed appointments and less concordance with advised treatments (Neurological Alliance 2018a). Finally, it is important to note that the progressive nature of these conditions generates ever-changing demands, and effective self-management in this setting requires frequent adaptation (Auduly et al. 2016). Even highly motivated patients who self-manage effectively may see continued progression of their condition (Owens et al. 2017). The unpredictability of the disease course, together with limited modifiable elements mean that it is difficult for self-management (or effective selfmanagement support) to impact on clinical indicators (e.g. level of disability) (While et al. 2010). This may be demotivating for patients and clinicians, and also influence how organisations value the provision of SMS.

# 1.6.2 Current healthcare provision for people with progressive neurological conditions

Progressive neurological conditions differ from other long-term conditions such as diabetes and chronic obstructive pulmonary disease because primary care has little role in disease management (While et al. 2010). Most disease management is delivered through secondary care in a planned fashion, with more limited involvement with acute care services compared with conditions where frequent exacerbations are common (While et al. 2010).

Concerns have been voiced over the variability in service provision for people with neurological conditions. In England (where the evaluation described in Chapters 5-7 was based) clinical services provided by hospitals and in the community are commissioned by local clinical commissioning groups (CCGs) (National Audit Office 2015). However, there is also some centralised commissioning by NHS England of specialised services for certain neurological conditions (e.g. diagnosis of rare neuromuscular disorders) (National Audit Office 2015). This has led to a level of uncertainty around which organisations should commission which services (Neurological Alliance 2015). The 2015 Neurological Alliance report *The Invisible Patients* showed that less than a fifth of CCGs had assessed costs in relation to the provision of local neurology services. They concluded that services were often fragmented, commissioning responsibilities were not understood, and neurological patients appeared to be invisible to commissioners due to a lack of recognition and monitoring (Neurological Alliance 2015).

Guidelines for the management of Parkinson's and MS produced by the National Institute for Health and Care Excellence (NICE) recommend that all patients should have access to a single point of contact who can help with access to services and coordination of care, and that specialist nurses can fulfil this role (NICE 2014; NICE 2017). The guidelines also stress the value of a multidisciplinary approach, highlighting the important role that allied health professionals, including physiotherapists, occupational therapists and speech and language therapists, have in the management of PNCs (NICE 2014; NICE 2017).

Parkinson's UK advocate for the provision of care through specialist Parkinson's or movement disorder clinics provided by a multidisciplinary team. However, in reality they found that PD services may be situated within neurology or care of the elderly services, and a fully integrated multidisciplinary model was only available at 13.5% of clinics (UK Parkinson's Excellence Network 2017). Most occupational therapy and physiotherapy services provided were not integrated within the Parkinson's clinic but were based in community settings, such as rehabilitation or day hospital teams.

Service models for the provision of care for people with MS also vary significantly (Mynors et al. 2015). In some areas community-based neurology teams see people with progressive MS as part of their wider caseload. Some services have MS teams focussed only on patients on disease-modifying therapies, while in a third service model, there may be an MS team that sees everyone with MS in their area (Mynors et al. 2015). There is also variability in how care is provided across the disease

course, with people with progressive MS having less contact with specialist nurses and neurologists, but more contact with social workers, community nurses and therapists when compared to people with relapsing-remitting MS (Mynors et al. 2015).

The current neurology system has been described as overstretched, with demand that currently exceeds capacity (Neurological Alliance 2018a). There are low numbers of neurologists in the UK in comparison to other European countries (Neurological Alliance 2018a). Similarly there is a lack of specialist nurse posts, and this may result in high workloads and difficulties in meeting all patient needs for those nurses in posts with unsustainable caseloads (Axelrod et al. 2010; Mynors et al. 2015; Neurological Alliance 2018a). In this challenging setting it has been suggested that self-management approaches may both free up capacity within the healthcare system and also meet the needs of patients better than traditional approaches where follow-up consultations are sporadic (Neurological Alliance 2018a).

# 1.6.3 Current healthcare experiences of people with progressive neurological conditions

As outlined above, at a policy level there appears to be a push towards empowering people to self-manage, but in practice this does not yet seem to be impacting on the way in which people experience health services. In their 2016 survey of just over 7,000 people with neurological conditions, The Neurological Alliance (2017) found that only 63% of respondents felt involved in making choices about health

services. Significant proportions of respondents were dissatisfied with the information they had been provided on their condition (45%), care and treatment options (46%), and sources of emotional support (63%) (Neurological Alliance 2017).

These findings echo those of several systematic reviews of the relevant qualitative literature. For example, in their review of how people with long term neurological conditions experience community rehabilitation services, Jackson et al. (2018) identified that while people clearly valued active participation within consultations, some continued to experience didactic approaches, which left them in a passive role and failed to take into account their personal preferences. Communication skills of professionals were reported to be variable, and information provided was sometimes inadequate (Jackson et al. 2018).

A review of 37 qualitative studies focussed on the experiences of people with Parkinson's and noted that poor quality interactions with healthcare professionals could act to challenge wellbeing, while positive interactions in which patients felt valued could help to build confidence and enhance coping (Soundy et al. 2014). The authors emphasised the importance of clinicians understanding the valued social identities of their patients, suggesting that restoring previous identities, or creating new ones was an important therapeutic task (Soundy et al. 2014).

The literature specific to MS has also identified a predominance of paternalistic approaches, with authors of a review of 66 papers cautioning that when consultations remain task orientated, this is associated with dependency on clinicians as well as decreased emotional well-being (Soundy et al. 2016). They

concluded that clinicians may require more training to enable them to build better relationships and work in a more patient-centred fashion.

# 1.6.4 Supporting self-management as a research priority in the progressive neurological condition setting

In comparison with other long-term conditions such as diabetes, there has been much more limited research about supporting self-management specific to the PNC setting (Taylor et al. 2014). Gaps in the existing evidence base have been recognised, together with calls for research in this area to be prioritised. For example, in 2012 the MS society began a research priority setting process, conducted in collaboration with people with MS, their families and health professionals. They identified "How can people with MS be best supported to self-manage their condition?" as one of their top ten research priorities (MS Society Undated). A modified Delphi technique was used by the Chartered Society of Physiotherapy also to identify specific priorities for neurological physiotherapy, and identified addressing the question: "What is the role, content and effectiveness of self-management strategies in long term neurological conditions?" as one of their top three questions to be addressed (Rankin et al. 2012, p.265).

As well as addressing a gap in the evidence base that is important to both patients and providers, additional benefit from focussing on PNCs within the PhD was anticipated. The issues commonly faced by people with PNCs including managing multiple interacting symptoms, and dealing with depression and cognitive impairment, are also experienced by people with multi-morbidity (Bayliss et al.

2007). I therefore considered that an improved understanding of how to support people with PNCs to self-manage would have significant transferability to other settings. PNCs could therefore provide a helpful exemplar of complex long-term conditions.

# 1.7 Selecting an area of focus

As outlined above, efforts to improve self-management and self-management support can involve interventions which target patients, clinicians, organisations, or a combination of these groups. It was unlikely to be possible to study interventions acting at multiple levels to sufficient depth within the confines of a PhD. Most studied self-management support interventions are delivered directly to patients, often in community settings (Plow et al. 2011). Condition-specific programmes often cover topics such as physical activity, fatigue, medication, mood and cognition (Plow et al. 2011). A focus on specific symptoms might risk further perpetuating the biomedical model of self-management support which prioritises adherence to medical advice.

More generic self-management support training focusses on skills such as problem solving which might be applicable to a wide range of conditions. However people with MS who attended a lay-led generic expert patient programme demonstrated little benefit, with the authors of the evaluation concluding that the attendees had already developed a range of self-management skills, so had less to gain from the programme (Barlow et al. 2009a; Barlow et al. 2009b).

As well as difficulties in pitching SMS interventions correctly for people with PNCs, there are also more pragmatic reasons a focus on SMS courses for patients may not be as fruitful as expected. It is recognised that only a small number of people are reached by a course-based approach, resulting in significant unmet demand for SMS, in part because delivering these sessions may not be part of the core work of clinical staff (Mynors et al. 2015). Even if capacity to undertake these additional activities were created, evidence from clinical trials suggests that around half of eligible participants are expected to refuse to participate (Arafah et al. 2017). It has been suggested that ideally people would be exposed to the principles of self-management within the clinical setting and then further interventions could be provided as additional support (Plow et al. 2011). Targeting routine clinical consultations might enable the intervention to reach more people, while using less resources than dedicated stand-alone support provision.

My own research interest in targeting clinicians, generated by my earlier work and interest in health professional education, has also been recognised in the literature as an area requiring further exploration. Kayes et al. (2015) highlight the relative lack of evidence available examining the influence of health professional behaviour on the outcomes of rehabilitation interventions. They call for a greater focus on the influence of health professionals' attitudes, beliefs and approach to practice (Kayes et al. 2015). Similarly, following their review of the experiences of people with long term neurological conditions, Jackson et al. (2018) called for the links between healthcare interactions, engagement and subsequent self-management to be further explored.

A gap has been identified between what matters to individuals and what is actually discussed in consultations, suggesting that health professionals need further training to better support a more patient centred approach to consultations (Soundy et al. 2016; Sezier et al. 2018). Specific training needs identified include taking an asset-based approach to capitalise on people's existing strengths, behavioural change techniques (e.g. motivational interviewing), and the provision of psychological support (While et al. 2010; Soundy et al. 2016; Jackson et al. 2018; Sezier et al. 2018).

## 1.7.1 Interventions targeted at health professionals to improve selfmanagement support

One of the main motivations to conduct this PhD study related to the heterogeneity of SMS interventions targeting clinicians and the variability of the outcomes reported. In brief, it is accepted that providing high quality SMS requires specific skills, including general person-centred skills (such as communication skills), behaviour change skills (e.g. motivational interviewing) and organisation/system skills (e.g. use of electronic recall systems) (Battersby et al. 2008). However these skills are often not part of routine professional training. In addition, it is recognised that training in skills alone is likely to be insufficient, because working in a more person-centred way also requires a shift in attitudes and beliefs which have developed through the course of professional training and clinical experience (Eaton et al. 2015; Mathers and Paynton 2016). The policy push for self-management support has been accused of failing to take into account the

uncertainties and challenges to professional values that clinicians attempting to provide SMS experience (Entwistle et al. 2018). SMS interventions targeting clinicians should therefore also explore the underlying assumptions on which they base their current practice (Wilson 2001). Essentially SMS interventions aim to affect a behaviour change among both professionals and patients (Feys et al. 2016).

A large review of systematic reviews which related to SMS interventions delivered across a wide range of conditions concluded that training health professionals as a standalone intervention was ineffective (Taylor et al. 2014). However professional training was described as one facilitator to providing SMS, acting in synergy with facilitators such as including multidisciplinary team working, a supportive healthcare system and effective patient education programmes (Taylor et al. 2014). Researchers have cautioned that SMS interventions should not be considered as being a 'magic bullet', as they are unlikely to be accepted by all clinicians or appropriate for all patients (Newbronner et al. 2013).

A wide range of differing approaches has been recommended to accommodate differences in individual learning styles, and the time and resources available (Newbronner et al. 2013). There are however examples of training interventions that have generated changes in clinicians' behaviours. For example, the Bridges self-management programme delivered training to staff working in stroke rehabilitation showed that trained clinicians demonstrated the use of between five and seven of the seven SMS principles taught in the training, whereas untrained clinicians used two or fewer (Jones et al. 2016). The WISE (Whole Systems

Informing Self-Management Engagement) study provides an example of how even an apparently unsuccessful intervention, which did not change practice for the majority, can still be well received and practice changing among a small group of participants (Kennedy et al. 2014a). An earlier Cochrane review that focussed on making consultations patient-centred concluded that while interventions were successful in upskilling clinicians, the impact of training on patients' satisfaction, behaviours and health outcomes was more variable (Dwamena et al. 2012). This evidence raises important questions for the evaluation of SMS interventions. For example, what is it about successful interventions that makes them successful? What is different about the people who go on to successfully implement interventions in practice? Is it something to do with them as individuals or the settings in which they work? How these questions can be successfully addressed using a realist methodology is explored in the next chapter.

## 1.8 Chapter Summary

Supporting people to self-manage their long-term conditions is an important policy objective, and while the motivations behind the policy remain controversial, it is clear that many people do want to have more collaborative interactions with healthcare professionals. Supporting people with progressive neurological conditions to self-manage is relatively under-researched when compared with other long-term conditions. In this setting, self-management could help people to feel more empowered and also relieve some burden on services that are already stretched. However specific challenges to successful self-management exist, due in

part to the symptoms and co-morbidities often experienced by people with PNCs. The role of health professionals in engaging people to become more actively involved in their healthcare has not been fully explored although there is acknowledgement that it is likely to require a specific set of skills and attitudes. Existing training interventions have demonstrated variable results, leaving important questions about how the required ethos and competencies can be fostered, and how the successful transfer of training into practice can be ensured.

## 1.9 Aims and objectives of the PhD

**Aim:** To understand how training interventions focussed on improving support for self-management work for health professionals working with people with PNCs, in what circumstances, with which clinicians.

## **Objectives:**

- Explore current self-management support practices among UK health
  professionals working with people with PNCs to identify approaches used,
  perceived barriers and training needs
- To develop theories from current literature, with a focus on PNC settings, about how training to support self-management works, for whom and in what circumstances
- To identify or design an appropriate training intervention, which is likely to
  meet the needs and interests of participants and provides the opportunity to
  test the initial theories

- To ensure the training intervention delivered takes into account the potential challenges specific to the PNC context that have been identified and can be tailored accordingly
- 5. To evaluate the training intervention and use the findings to test, develop and refine a programme theory, describing how when and for whom the training intervention works.

## 1.10 Thesis outline

The realist approach to research, and why it was chosen for this thesis is discussed in Chapter 2, together with an outline of how this shaped the later stages of the research. The data presented in Chapters 3 – 7 are outlined below in Figure 1.1, which summarises the two phases of the PhD. Chapter 3 presents the results of a survey of health professionals who work with people with MS and Parkinson's disease, identifying their current approach to supporting self-management and their self-identified training needs. Chapter 4 describes a realist synthesis of the existing literature relevant to training health professionals to provide selfmanagement support. Chapter 5 discusses the decisions made in planning the evaluation stage of the research, and the processes undertaken to support these. Health coaching is identified as an intervention which could be valuable for staff working with people with PNCs. Chapter 6 presents the qualitative and quantitative results of the evaluation of a health coaching training course delivered to a group of staff working with people with PNCs. Chapter 7 discusses the overall outcome patterns observed in the data and examines the data using several existing formal

theories. Chapter 8 features a discussion of the results of the thesis as a whole, arriving at the development of a theory which describes how, when and for whom the training works. The strengths and limitations of the thesis are discussed, and a set of key recommendations for policy and practice is presented.

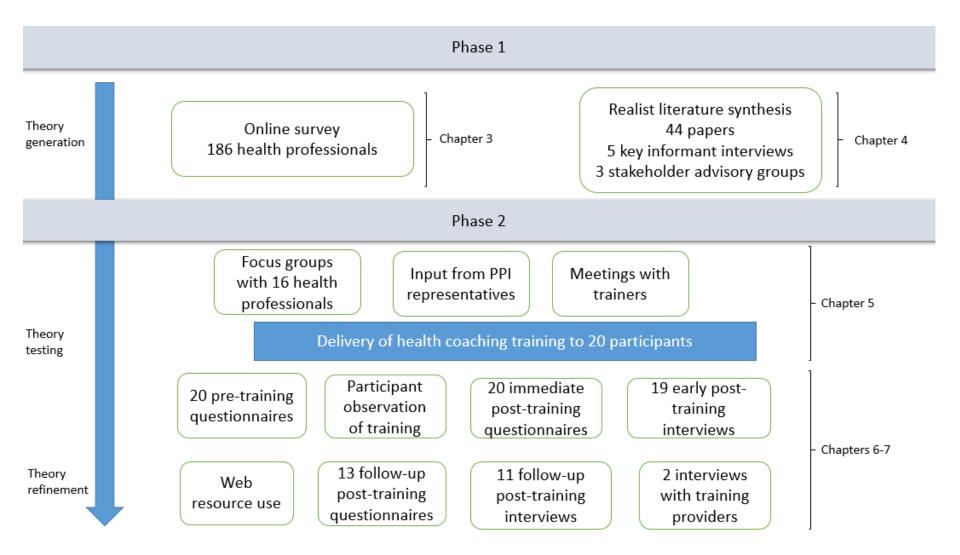


Figure 1.1 A summary of the data collected at each stage of the PhD and the chapter in which it is first discussed

## 2 Realist methodology

In Chapter 1, I explained why I am interested in trying to develop clinicians' skills in supporting self-management, and highlighted features of the setting of interest (supporting people with PNCs) which may make training and subsequent implementation particularly challenging.

In this chapter I present the decisions taken during the design of the PhD study, together with the rationale for my chosen approach. The first section focusses on the research methodology. I briefly outline two common paradigms in research into health professional education and identify possible weaknesses in the research associated with these traditions. I then introduce realist research methods as an alternative, outline the background of realist methodology, and explain the impact of adopting a realist approach on the overall study design. In the second section of this chapter, I discuss how realist researchers use a variety of methods to generate, test and refine theory. The adaptations required to several specific methods are briefly outlined in this chapter, with further more in-depth discussion of the methods I chose following in Chapter 5.

## 2.1 Common paradigms in research of health professional education

Paradigms are sets of philosophical beliefs that provide a particular lens through which the research process is viewed, impacting on the methods chosen and the way in which the results are interpreted (Weaver and Olson 2006). Research in health professional education has been described as "a careful or systematic study

designed to answer the fundamental questions raised by medical educators in order to make educational decisions that can be based on rigorous research-based findings" (Tavakol and Sandars 2014, p.747). Research into health professional education to date has most often been guided by one of two research paradigms, positivism or constructivism (Tavakol and Sandars 2014).

Positivists believe that a single objective world exists and can be measured. For positivists, knowledge exists objectively, to be discovered by the researcher. This requires researchers to set aside their own preconceptions and identify objective facts (McEvoy and Richards 2006; Weaver and Olson 2006). Therefore, positivist research methods focus on detached scientific observation, with strict control of contextual variables, in order to minimise subjectivity and maximise objectivity (McEvoy and Richards 2006; Weaver and Olson 2006). Typically this involves research which is quantitative in nature and focuses on outputs, using methods such as structured questionnaires and meta-analysis of trial data (McEvoy and Richards 2006; Tavakol and Sandars 2014). The randomised-controlled trial, generally defined as the gold-standard of evidence in medicine, sits firmly within this paradigm. Because of health professionals' familiarity with the positivist approach, it is often transferred to the study of health professional education (Bunniss and Kelly 2010). However, the dominance of the positivist paradigm has been questioned, with researchers recognising its incompatibility with a more holistic view of health and the practice of providing healthcare, due to its lack of recognition of the powerful influence of contextual factors such as personal relationships and political pressures (Weaver and Olson 2006; Bunniss and Kelly 2010).

In the social sciences, the paradigm of constructivism is often more accepted. Constructivist ontology holds that there is no single objective reality to be uncovered during the research process; instead constructivists assert that there are multiple realities constructed by those involved (Bunniss and Kelly 2010). The truth is viewed as a belief system which is held in a certain context (Healy and Perry 2000). Knowledge is also viewed as socially constructed, with both the researchers and the participants contributing to this construction process, which is recognised to be value-laden and subjective (Tavakol and Sandars 2014). Research within this paradigm typically employs qualitative methods which aim to explore participants' views and reasoning processes, with a focus on interpreting the meaning of experiences (McEvoy and Richards 2006; Bunniss and Kelly 2010; Tavakol and Sandars 2014). Critics of a constructivist approach note that it often involves the study of the perspectives of a particular group of participants for its own sake without considering how these perceptions may relate to any wider reality, or even actively avoiding considering other perspectives to minimise contamination of the data (Healy and Perry 2000). While some mixed methods researchers who combine both qualitative and quantitative approaches have suggested that mixed methods research could be considered as its own paradigm, others view combining methods from different paradigms as a method, which may be driven by particular research questions and the data required to address these (Creswell and Tashakkori 2007).

# 2.1.1 Criticisms of traditional approaches often used in researching health professional education

Traditional models for evaluating the success of CPD interventions tend to depict educational outcomes in a fairly simplistic linear fashion. For example, Kirkpatrick's (2006) well-known framework suggests evaluating intervention success on four levels (learner reaction, learning, behaviour change and results of attending training) while Moore et al. (2009) propose a model for evaluating CPD interventions which includes the outcomes of attendee satisfaction, learning, improved physician competence, improved physician performance, improved patient health and improved population health. Concerns have been raised that these models fail to take into account the many factors which may influence whether the intended outcomes of CPD interventions are achieved (Sargeant et al. 2011). The outcomes of CPD programmes will vary considerably depending on factors such as who delivers the training, who are the target recipients, what are the circumstances in which the training is provided in and which educational techniques are employed (Wong et al. 2012). In addition to the characteristics of the CPD intervention and attendees, other characteristics of the workplace will also influence CPD. A review of evaluations of interventions in neurological rehabilitation found that less than half of papers gave any description of context, and only 9% gave details of pre-existing service provision and how it had changed over time (Masterson-Algar et al. 2016). Davis et al. (2008) identify contextual influences as existing at the levels of the immediate healthcare environment (including team members, availability of resources and culture of ongoing education), the broader healthcare environment (such as regulations about CPD

requirements for professional revalidation), and the societal level (government mandates, shifting demographics of society). Regehr (2010) suggests that the dominance of the outcome-focussed positivist paradigm may result in little meaningful learning from evaluations because of a lack of attention to why programmes succeed or fail. There is agreement that while positivism-based primary quantitative research and secondary meta-analysis may be able to determine and compare outcomes, they fail to address important questions about why interventions work, or to sufficiently explore the important influence of context (Sargeant et al. 2011; Wong et al. 2012).

Although the issues of non-linearity and complexity resonate strongly with educators, they also provide significant challenges for education researchers (Wong et al. 2012). Rather than attempting to give simple explanations to complex problems, research methods that are able to represent this complexity are required (Regehr 2010). Although qualitative research methods grounded in the constructivist paradigm may go some way to answering questions about why and how interventions work, they are often significantly criticised for lacking generalisability to different settings (Wong et al. 2012). Complex social interventions (including educational interventions) may achieve their target objectives by multiple different means, although some of these means (such as incentives) may be seen as more socially acceptable than others (e.g. punishment) (Chen 1994). Therefore, it is of crucial importance to understand not just whether the intervention works or not, but also how the intervention generates the desired results (Chen 1994).

The requirements for research into health professional education have therefore been clearly outlined. Research projects must be designed in a way that can answer the questions that practitioners really need to know – what intervention should be delivered, how, where and to whom (Fletcher et al. 2016)? This will require approaches that account for complexity and take context into account (Davis et al. 2008; Olson 2012; Fletcher et al. 2016). We should recognise the differing and complementary strengths of both qualitative and quantitative methods and use these to improve our understanding of how interventions generate outcomes (Olson 2012; Wong et al. 2012). Additionally, we should also move away from simply proving our hypotheses towards providing a rich description of how we understand the problem, what has been learned during the research process and the resultant changes in our thinking (Regehr 2010).

Proponents for this style of research have identified realist methodology as a

promising way to address these requirements (Sargeant et al. 2011; Wong et al. 2012). Realist research is often described as the 'middle-ground' sitting between positivism and constructivism, and utilising approaches from both traditions. Realist research methods are increasingly being recognised within healthcare and education settings as a useful way in which to harness the strengths of both qualitative and quantitative approaches to produce results with greater explanatory power (Wong et al. 2012). For example, Sargeant et al. (2011) suggest that the method may be particularly helpful in the evaluation of CPD interventions to generate an increased understanding of how context influences the way in which knowledge is used and subsequently how clinical practice is changed. Similarly, Williams and colleagues (2017) suggest that in a healthcare setting, realist research

can move away from simplistic description of what an intervention involves and towards an understanding of what it is about the intervention that actually works.

The core principles of a realist approach to research are now explored in further detail below.

## 2.2 What is realism?

During this PhD I have adopted the approach of scientific realism, introduced by Pawson and Tilley in their work *Realistic Evaluation* (1997) which is now often referred to simply as "realist evaluation" for primary research and "realist synthesis" for secondary research (Pawson 2013). Realism as a philosophy has a long history and Pawson (2013) describes realist evaluation and synthesis as research strategies that aim to apply these philosophical principles to practical research problems. Unlike positivists (who aim to identify generalisable laws) or constructivists (who focus understanding the lived experience), realist researchers focus on developing explanatory theories (McEvoy and Richards 2006). Realist research is judged by the explanatory power of the theories produced, and these theories remain open to future refinements (McEvoy and Richards 2006).

## 2.2.1 Realist ontology

The realist ontology is that a real world exists, independent of our thoughts about it. Although the constructivist position that there are multiple independent realities is rejected, there is acceptance that there are different valid perspectives

on reality. What is considered to be real includes physical objects but also social structures that have causal powers (Sayer 2000). It is recognised that causal powers can exist (and therefore be real) even if they remain unexercised. This leads to an acceptance that something does not have to be observable for it to exist (although observability is likely to increase confidence that it does exist). Sayer (2000) summarises the way in which the realist philosopher Bhaskar describes the world as being made up of the real, the actual, and the empirical. This view of reality as being stratified into layers, not all of which can be experienced or observed is key to realist thinking. The 'real' refers to underlying structures and their causal powers, which may not be observable, or active at a particular time (Sayer 2000; McEvoy and Richards 2006). The actual refers to what happens when those powers are enacted and relates to phenomena that actually occur. The empirical relates to what is experienced, with a recognition that these experiences occur whether or not we have an understanding of what is happening in the domains of the actual and the real (Sayer 2000; McEvoy and Richards 2006). Social constructs are recognised to have an important influence on how things work (Westhorp 2014). For example, professional norms and standards will influence the attitudes of professionals and patients.

Equally, there is recognition that in complex social interventions, such as health professional training, there will be interactions between individuals and organisations and between micro and macro social processes (Pawson and Tilley 1997). Realist writers talk about the importance of the interactions between structure (the constraints on individual action put in place by society, and institutions) and agency (the ability of individuals to act independently) in

understanding how things work (Pawson 2011,2013; Williams et al. 2017). There is also recognition that social systems are not closed systems, there is a flow of people, knowledge, ideas and resources between different systems which may interact with each other (Westhorp 2014).

Pawson (2011) describes the important influence of the work of Margaret Archer (1995) in developing the idea of "morphogenesis"; that society is in a permanent state of self-transformation. The choices that individuals can make are both influenced and constrained by existing social structures, and the choices made by individuals can go on to influence the structure itself, which in turn influence the choices made by the next decision makers. This means that social interventions will evolve over time and to think of an intervention as reproducible is likely inaccurate. Because interventions change the setting into which they are introduced (and in turn the conditions which might have made them work in the first place) they are therefore unlikely to continue to work in the same way as time progresses (Pawson 2011,2013). The understanding that individuals' actions are embedded within a wider social structure significantly influences how realists think about causation, moving away from seeing causation as a simple linear relationship between cause and effect and towards attempts to understand individuals' actions in terms of their location within different layers of social reality (Pawson and Tilley 1997).

## 2.2.2 Realist understanding of causation

Positivist researchers adopt a 'successionist' view of causation. Their research attempts to identify causal agents (a treatment for example), to determine that an

association between a treatment and an effect is real (rather than spurious) and then estimate the magnitude and importance of the effect (Pawson 2008). Realist researchers do not ascribe to a successionist view, but to a *generative* model of causation, significantly influenced by the early works of philosopher Bhaskar (Pawson 2011,2013). In this model, outcomes are believed to be brought about through underlying generative mechanisms. These mechanisms involve the actions and decision-making processes of individuals so may not always be directly observable or measurable. Causal explanation requires researchers to theorise about the mechanisms at play which lead to (or inhibit) the outcomes of interest (Pawson 2008; Westhorp 2014).

Pawson and Tilley (1997) describe mechanisms as involving both intervention resources and individual reasoning. For example, a CPD intervention may provide a new consultation technique (a resource) and the participant then decides how and when they think it might be useful. This reasoning process may lead to an outcome of interest (e.g. increased patient satisfaction) or might prevent an outcome of interest from occurring (e.g. if the participant decides the new technique is too time consuming).

Crucially there is recognition that all interventions are introduced into a pre-existing social context and that this context (including social norms, relationships and values) may facilitate or constrain the operation of the mechanism (Pawson and Tilley 1997; Sayer 2000). Because interventions work via peoples' responses and the choices they make, intervention outcomes will always be context-dependent (Sayer 2000). Context will influence both whether mechanisms operate, and also

which mechanisms are at play in a given setting (Westhorp 2014). Realist researchers therefore focus on the identification of generative mechanisms, and on understanding the extent to which features of the context act to facilitate or inhibit the intended mechanism (Pawson and Tilley 1997). Generative mechanisms are not considered in isolation but explored in relation to the setting in which they occur or 'fire'. Interventions which aim to improve health often do so by altering the context in which health is produced, and this new context in turn influences the way in which future interventions operate and the outcomes they produce (Craig et al. 2018). Adequate exploration of context and how it relates to different mechanisms is required in order to make judgements on why interventions succeed or fail, how they work, together with whether they are likely to be sustainable or transferable (Craig et al. 2018).

In order to emphasise the importance of both context and mechanism in understanding causation, Pawson and Tilley (1997) developed the Context-Mechanism-Outcome (CMO) configuration as a heuristic to be used when presenting the results of realist research. This was expanded upon by Dalkin and colleagues (2015) to clarify that intervention mechanisms usually comprise both intervention resources and participant reasoning. The diagram below (Figure 2.1) outlines their depiction of a realist view of causation, in which intervention resources are introduced into a pre-existing context, triggering participant reasoning which in turn generates outcomes. Realist researchers use CMO configurations to present their theories about how interventions work, for whom, and in what circumstances.

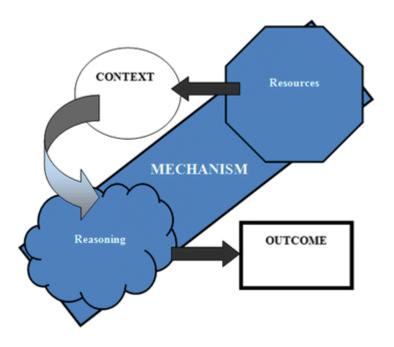


Figure 2.1 A diagrammatic representation of a realist view of causation (Dalkin et al. 2015)

## 2.2.3 Realist Epistemology

Maxwell (2012) suggests that realist researchers adopt a realist ontology but accept a constructivist epistemology, that is to say that our understanding of the world is constructed based on our own viewpoint. All forms of realism agree that we cannot have any truly objective knowledge about the world. All knowledge is seen to be partial and incomplete, as it is grounded in a particular perspective. There is acceptance that multiple valid accounts of any phenomenon may exist (Maxwell 2012). Realists remain sensitive to the influence of their own assumptions on data interpretation and recognise that they cannot reach certainty (Hammersley 2013; Westhorp 2014). While realists acknowledge that because research is shaped by human interpretations and it cannot represent a final 'truth', they believe it

remains possible to move towards a better understanding and representation of reality (Hammersley 2013; Westhorp 2014). Checking the compatibility of the findings with the other assumptions that we believe to be true, and critically reflecting on the chance of error given the way in which the knowledge was developed allow researchers to interpret how close the knowledge generated might be to reality (Hammersley 2013; Westhorp 2014).

## 2.3 Research design: Using the realist approach

During the early months of my PhD, while planning my literature review, I identified realist synthesis as a method of systematic review that was likely to provide more useful information than a traditional systematic review approach. Performing a realist synthesis would allow me to try to understand the reasons why SMS training interventions appear to work differently, rather than simply focussing on their average effectiveness (Pawson 2006). I made the decision to undertake a realist synthesis and undertook specific training in realist methods. As my understanding grew, I saw how a realist approach could be helpful across the entirety of my PhD study, and planned the second phase of the PhD as a realist evaluation, which would utilise and build on the findings of my literature review. The ways in which the realist approach to research have influenced the design of my PhD are outlined below. It is worth noting at this point that because my PhD was not planned from a realist perspective from the outset, the design of the first piece of early work I completed (a survey of health professionals) was not informed by realist thinking, although the results were used in to inform the selection of an appropriate

intervention for evaluation and also in the development of the refined programme theory presented in Chapter 8. The design of the survey is discussed in Chapter 3, along with suggestions about how I might have gone about this differently if I had planned to use a realist approach from the outset.

## 2.3.1 Using a theory driven approach

Realist research is one of several forms of theory driven evaluation (see Box 2.1 for definitions of the different types of theory referred to within this thesis). These types of evaluation focus on the settings in which interventions are implemented, and the mechanisms which generate outcomes in order to understand how and when interventions work (Weiss 1997). Pawson (2013) emphasises that realist research should be explanatory in nature and should focus on understanding causation rather than simply identifying correlations. Weiss (1997) suggests that theory driven evaluations may have both programme theory (which focusses on the participants' response to the intervention components) and implementation theory (which examines fidelity, intensity, and quality of delivery). Realist evaluators tend to describe their overall programme theory of how an intervention works using context-mechanism-outcome configurations. A realist programme theory therefore usually uses multiple context-mechanism-outcome configurations to explain how interventions operate and these include descriptions of context, generative mechanisms, implementation processes and outcomes.

Pawson and Tilley (1997, pp. 75-77) identified two important questions realist evaluators need to address:

- 1- "What are the mechanisms for change triggered by the programme and how do they counteract the existing social processes?"
- 2- "What are the social and cultural conditions necessary for change mechanisms to operate and how are they distributed within and between programme contexts?"

They propose the use of a cyclical process (the realist evaluation cycle) which involves generating an initial set of working theories and hypotheses (describing elements of context, mechanism and outcome) to explain how and when an intervention works, and then gathering data to test and subsequently refine these theories (Pawson and Tilley 1997). In a theory driven evaluation any data which help the research team to understand how an intervention works can be used (Chen 1994). The initial theories to guide evaluation planning can come either from existing formal theories or from working with stakeholders to develop programme theory (Chen 1994). These processes are further discussed below.

Box 2.1 Types of theory referred to within this thesis

Initial rough theory: early ideas about how, for whom, in what circumstances the intervention might work based on early literature scoping and stakeholder input

Developing theories/ theories generated: theories developed using data collected, formulated using context-mechanism-outcome configurations (see below)

Programme theory: An overall theory summarising at a high level how the intervention works, developed using the theories generated from the data

Formal theory: existing social theories used as a lens through which to examine the data

## 2.3.2 The role of formal theory

Pawson and Tilley (1997) were significantly influenced by Merton's (1967) concept of 'middle-range theory' in advocating for the integration of existing formal theory into realist evaluation. A theory that is middle-range in nature can be explanatory in a range of different settings, not just the setting in which it was developed, meaning that knowledge generated elsewhere can be useful in a new setting of interest. Formal theory (as it will be referred to in this thesis) is sometimes also described as substantive theory, or middle-range theory (Wong et al. 2013b; Greenhalgh et al. 2017). The formal theories of most value to realist evaluators tend to be those which were developed to explain a specific phenomenon (e.g. Bandura's Social Learning Theory) rather than higher level 'grand theories' such as Marxism (Greenhalgh et al. 2017). Formal theory may be utilised in a range of different ways during realist research. The aim of realist research is not to prove or disprove existing formal theories, but to provide a plausible explanation for the variety of different patterns seen in the data which are based on (and may help

elaborate) the current best available explanations (Wong et al. 2012). Existing formal theories may be used early in the research process, during the development of an initial programme theory for an intervention (Shearn et al. 2017), they may be applied as an analytical lens during the data analysis phase or used to explain emerging findings (Astbury 2018). A match between theorised relationships and the empirical data collected can strengthen the causal explanations generated by a primary research study (Yin 2014). Realist studies can involve the simultaneous processes of using a formal theory to interpret the empirical data while also using the empirical data to refine a programme theory (which may have been derived from a formal theory) (Ragin 1992; Astbury 2018).

#### 2.3.3 Methodological pluralism

Using a realist methodology does not mandate the use of specific methods and has been described as 'methods neutral' (Pawson and Tilley 1997). Methods themselves are not linked exclusively to specific philosophical standpoints and can be used by researchers who come from different ontological and epistemological starting points (McEvoy and Richards 2006). Realist researchers strongly advocate for pluralism of methods, an approach Pawson and Tilley describe as "the only methodological gold standard" (2001, p.323). The use of multiple methods fits well with the realist ontology and epistemology, that there is a single reality, which may be perceived differently by different individuals, and therefore necessitates triangulation of multiple data sources to develop a fuller understanding (Healy and Perry 2000). The use of different techniques and approaches is advocated, in order

to allow the researcher to explore different facets of the same phenomenon (Olsen 2004). Qualitative and quantitative data can act in a complementary fashion, providing more complete explanations than might be available using one method alone. Quantitative methods provide important data on outcomes (ideally measured before and after an intervention) (Pawson 2013). Accurate comparative data may also help to identify patterns or associations that were not immediately visible, pointing towards new mechanisms (McEvoy and Richards 2006). The openended nature of qualitative approaches helps facilitate the identification of important topics which may not have been anticipated in advance, as well as allowing complex concepts and reasoning processes to be explored in depth (Sayer 2000; McEvoy and Richards 2006). Both qualitative and quantitative approaches may generate ideas that require further testing or exploration using an alternative approach (Risjord et al. 2002). Pawson and Tilley (1997) emphasise that combination of both qualitative and quantitative data should accomplish more than just providing a large body of evidence, but that it should bring a sense of completeness to the explanations the researcher is able to make about the subject.

## 2.3.4 Theory building and testing

Realist researchers cannot follow a single standard research approach but instead require flexibility and creativity to design their research based on the requirements of individual studies (Astbury 2018). That said, all realist studies focus on an iterative process of theory building and testing. The way in which I built and then refined my theories during my PhD are summarised in Figure 2.2 below. My initial

theory building had a broad focus, exploring a range of different interventions as at this point I was undecided which intervention I might focus on in more depth. A realist synthesis of the literature (Chapter 4) was used to develop a set of theories.

A relevant intervention for evaluation was then selected (see Chapter 5) and used to develop and test my theories further. The final stage involved the synthesis of all the data collected to produce a refined programme theory.

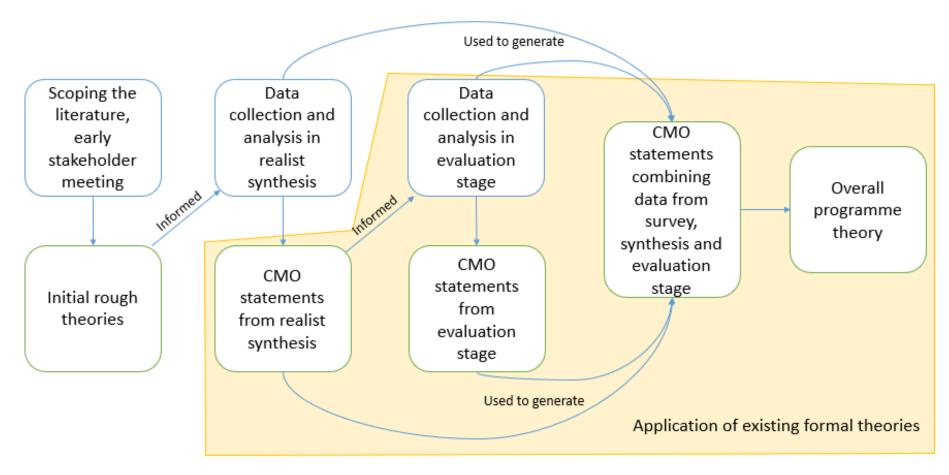


Figure 2.2 Process of building and refining my programme theory throughout the thesis

#### 2.3.5 Data collection methods

Having emphasised the need for a multi-method approach to data collection, it is important to consider how applying a realist lens influences the approach taken using each specific method. This is discussed in the sections below. The realist approach to literature reviewing is described in detail in Chapter 4. Specific details about the evaluation methods I chose and how they were used are provided in Chapter 5. This chapter concludes by outlining the influence of the realist methodology on the data analysis approach together with a discussion of how realists define and measure quality.

## 2.3.5.1 The role of stakeholders

Early and sustained engagement with stakeholders is actively encouraged in realist research approaches. Firstly, any evaluation needs to meet the needs of the stakeholders involved in the process. Early stakeholder engagement can ensure that the evaluation addresses the issues that really matter to stakeholders, which may promote buy-in to the evaluation process itself, as well as a sense of ownership of the outcomes, and an increased likelihood that any recommendations made might be accepted (Chen 1994). Secondly, for the researcher, stakeholders are a valuable source of knowledge about the content of interventions, how they are intended to work and when they appear to succeed or fail. These "folk conjectures" can be an excellent starting point for initial theory development and prioritisation of areas for investigation (Pawson and Manzano-Santaella 2012, p.181). The researcher needs to develop a clear understanding of the background

of both the intervention and the delivery setting early in the evaluation as analytical judgements will be required throughout the data collection stage (Yin 2014). Early stakeholder involvement can provide this valuable background data. In Chapters 4 and 5, I outline how various stakeholders were involved during the realist synthesis and evaluation stages.

#### 2.3.5.2 Observations

Participant observation as a research technique arose from traditional ethnographic research in anthropology, its objective being to help researchers to understand the perspectives of their study population (Mack et al. 2005). Observations provide the researcher the "nuanced understanding of context" essential for realist research which might only be possible to obtain through gaining personal experience (Mack et al. 2005, p.14). Importantly, observations provide data on both how people actually behave as well as on people's own accounts of their behaviours (Green and Thorogood 2014). Observations may be used to generate detailed descriptions, to identify patterns of thoughts and behaviours, to test hypotheses or to facilitate data interpretation (DeWalt and DeWalt 2011). Participant observation has therefore been described as both a data collection activity and an analytical tool because it helps to enhance the quality of the interpretations made from data (whether it be data collected by observation or other methods) (DeWalt and DeWalt 2011). Observations are commonly used by realist researchers, alongside a range of other data collection techniques (Williams et al. 2013; Manzano 2016). The triangulation of both observations and interviews provides a more complete

account than would be possible by using either method in isolation (Maxwell 2012). Observations can be a chance to illuminate routine thought patterns that people might not have thought were worth mentioning in an interview unless specifically asked (Green and Thorogood 2014). The effect of organisational culture (for example, how patient behaviours are viewed by staff) is often only visible to an outsider and would not necessarily be uncovered by interviews alone (because these are seen as 'normal' by the staff involved) (Pope and Mays 2006). In addition, there may be elements of participants' perspectives that they would be reluctant to describe directly within an interview setting, which observations will provide an opportunity to identify and understand (Maxwell 2012). As well as aiding the interpretation of data collected through other methods such as interviews, observations can also inform the design of a realist interview schedule, by surfacing important ideas about contexts, mechanisms and outcomes and enabling the researchers to ask the 'right' questions (Mack et al. 2005). Performing observations can also enhance the quality of any subsequent interviews, as the knowledge gained during observations can help interviewers better interpret subtleties within participant responses and so formulate more appropriate follow-up questions (Mack et al. 2005). Interviews can be used to check the accuracy of the observations and provide additional information which may have been missed (Maxwell 2012).

Participant observations may involve conversations or informal interviewing. In both techniques the researcher doesn't necessarily direct what will be discussed but follows up on points raised in the natural course of discussions (DeWalt and DeWalt 2011). Detailed field notes are the main source of data from observations.

## 2.3.5.3 Realist qualitative interviews

In order to explore context, mechanisms and outcomes within interviews, realist interviewers recognise that people in different roles bring differing levels of insight into each of these areas, necessitating a purposive sampling strategy (Pawson and Tilley 1997). For example, staff who have participated in SMS training are likely to be able to explain their own reasoning in response to the resources an intervention has provided but may be less sensitised to contextual constraints or general outcome patterns (Pawson and Tilley 1997). Trainers are likely to have some understanding of when and for whom the training seems to work well, as well as an understanding of what works, but are unlikely to have spent time considering this in a systematic fashion (to generate CMO configurations) (Pawson and Tilley 1997). Researchers have the advantage of knowledge of theories from other settings but do not necessarily understand important elements of local context (Pawson and Tilley 1997). During a realist evaluation, the same subject may be interviewed more than once. This would not necessarily be for the purpose of understanding how the interviewees experiences or opinions had altered, but rather to give the researcher the opportunity to discuss their theories again, once they have been further developed (Manzano 2016).

Data collection in realist interviews (as in other elements of realist evaluation) is theory driven. The researcher's theories are the subject of the interview and the role of the interviewee is to help refine the researcher's theories, by confirming, contradicting or elaborating upon them (Pawson and Tilley 1997). From the perspective of traditional case study research this puts the interviewees in the role of informants rather than simply participants (Yin 2014). Depending on the stage of

the study, interviews may have different roles in the theory development process, from theory gleaning, through to theory refining and theory consolidation (Manzano 2016).

Undertaking realist interviews requires the researcher to take a different role to that undertaken in other qualitative interviews. In a realist interview, the researcher does not need to behave in a neutral fashion, instead they actively engage with the interviewee, using what has been described as a teacher-learner approach (Pawson and Tilley 1997; Manzano 2016). The researcher and the interviewee both take on the roles of teacher and learner during the interview process. Initially, the researcher teaches the interviewee their theories about how and when the intervention works. This requires the researcher to go into the interview with a good understanding of what happens within the intervention (obtained for example via literature review, or observations) (Manzano 2016). The research questions are not hidden from the interviewee, but are made transparent, encouraging more equal and collaborative relationship between researcher and interviewee (Maxwell 2012). The researcher seeks to learn from the interviewee who can teach the researcher their own interpretations, insights and explanations relating to how the intervention operates, facilitating the conceptual refinement of the researcher's initial theories (Pawson and Tilley 1997; Yin 2014). The quality of the interview data generated is therefore not solely based on ensuring an accurate depiction of participants' worldview but relates to ensuring that descriptions generated capture participants experiences and understandings in relation to theory under investigation (Pawson and Tilley 1997). Realist interviewers need to remain aware of the influence which they may have over the interviewees and their own biases during the interpretation of interview data (Yin 2014; Manzano 2016). Focus group interviews have also been used by realist researchers, sometimes for pragmatic reasons, (to allow a large number of participants to be involved within the constrained resources of a study) (Caffrey et al. 2016), but also with the intention of facilitating reflection on interventions among participants (Dalkin et al. 2012) and providing additional data about group dynamics within teams (Goicolea et al. 2013).

#### 2.3.5.4 Quantitative data collection

Although there are good arguments for using qualitative data for exploring mechanisms, it should not be relied on as a method of outcomes assessment, as explaining outcome patterns cannot be done solely on the basis of anecdotal remarks (Pawson and Manzano-Santaella 2012). Realist researchers are interested in proving whether the intended outcomes of interventions occur or not, and in explaining outcome patterns to understand whether the proposed context-mechanism linkages are confirmed. For example, variation in responses to the intervention among different sub-groups might give important information about the influence of context on whether a certain mechanism 'fires' (Pawson and Tilley 1997). Without using quantitative data to test the proposed CMO configurations it is difficult to establish causal connections (Bonell et al. 2012). However realists criticise traditional randomised-controlled trials undertaken in the positivist paradigm for their focus on average or aggregate effects (Fletcher et al. 2016).

emergence and as such are unsuitable for the assessment of complex social interventions (Byrne 2013). A realist approach to the use of quantitative data is theory driven, requiring careful conceptualisation of the important outcomes, and possible indicators of these outcomes. In order to assess change in relation to the intervention baselines should be established, before and after measures taken, and complete cohorts followed-up (Pawson and Manzano-Santaella 2012). Importantly, outcome patterns are seen as the possible outward signals of the inner workings of the intervention. Realists recognise that variables themselves do not have causal powers, and so correlations must not be conflated with intervention mechanisms (Pawson and Manzano-Santaella 2012). It is possible to use quantitative analysis in a theory driven way to look for correlation between items of interest but an explanation building process will always be required to make sense of the results of quantitative data obtained (Pawson and Manzano-Santaella 2012).

## 2.3.6 Approach to analysis

Realist research is an iterative process. While there will always be a specific analysis stage in a realist research project, the work of analysis starts much earlier. Analytic choices are made by the researcher as they choose how to collect data to address their research questions (Thorne 2000). Data collection tends to occur in parallel with analysis, meaning that each stage can inform the other, as emerging findings influence what further data is sought out, and also how the existing data is interpreted (Thorne 2000). While realist researchers recognise complexity, they also need to work to contain the scope of their investigation within the constraints

of time and resources. This inevitably means that not all potentially fruitful lines of enquiry can be pursued, and some must be prioritised (Pawson 2013; Astbury 2018). Researchers may choose to focus on adjudicating between rival theories, seeing how the same theory applies across a variety of different settings or comparing the policy ambition of a programme to the real-life application (Pawson 2006).

Realist data analysis begins with searching for what are known as demi-regularities within the empirical data. These demi-regularities are identifiable trends or patterns of outcomes (Wong et al. 2013b; Fletcher 2017). While demi-regularities are not expected to occur universally, because interventions work differently in different circumstances, they provide a helpful starting point in understanding how, where and for whom interventions are more likely to succeed (Pawson 2006; Wong et al. 2013b; Fletcher 2017). Demi-regularities may be identified using an inductive reasoning process, which uses empirical data as a starting point for building theories (Hyde 2000). In addition, realist researchers also employ deductive reasoning, by identifying relevant theories for testing (either an initial rough theory or a formal theory) and using the empirical data collected to test or refine the theory (Hyde 2000). In addition to utilising both inductive and deductive reasoning processes, realist researchers also draw on a third reasoning process (retroduction) which specifically focusses on understanding causality.

Retroduction involves trying to establish what could have caused the patterns seen in the data (Olsen 2004). It is an interpretative process in which researchers explain events by suggesting or identifying the causal mechanisms which produced them

(Sayer 2000). Realists accept that important causal factors are often unobservable (e.g. power, status) but use the interpretative process of retroduction to try to make sense of empirical data recorded by working out what the world may be like in order to make sense of the observations made (Olsen 2004). The retroductive process also aims to identify the contextual conditions that are required for a particular mechanism to 'fire' to create the observed outcomes (Fletcher 2017). Utilising retroduction helps researchers to decide whether to accept, reject or refine existing theories about how an intervention works, to move closer towards a more accurate representation of reality (Fletcher 2017).

Realist data analysis may involve multiple different approaches, which can aid theory development and refinement. Pawson (2006) describes the use of the strategies of include juxtaposing, adjudicating, reconciling, consolidating and situating further evidence. Juxtaposition may involve comparing data from several different sources, which may increase explanatory power (e.g. qualitative data can be used to suggest which mechanisms lead to the outcomes observed in quantitative data) (Papoutsi et al. 2018). Processes of adjudication and reconciliation may be required to deal with conflicting findings from settings which appeared similar, and this can result in an improved understanding of which elements of context are most influential on which mechanisms (Papoutsi et al. 2018). The processes of consolidating and situating the evidence involves deciding whether the data can be brought together to generate theories while also attempting to highlight any important nuances (Papoutsi et al. 2018). As new data are incorporated into the analysis researchers continually question the novelty of

the data and how it can help to refine or challenge their developing understandings (Pearson et al. 2015).

As discussed above, a realist analysis aims to generate CMO configurations. These may be produced directly after examining the data, or researchers may use intermediate steps to move towards CMO building. If-then statements are sometimes chosen as a way to move between the data itself and higher level CMO configurations. They may be easier to work with initially as they offer the opportunity to partially describe certain aspects or links within the CMO, which can then be integrated into full CMO configurations later in the analysis (Pearson et al. 2015). The steps taken to develop CMO configurations in this thesis are described in detail in Chapters 4 and 5.

# 2.3.7 Quality considerations in realist research

There is recognition that despite increasing interest in realist research methods there remains some confusion over what represents a high-quality realist evaluation (Wong et al. 2016). Publication standards for realist synthesis and evaluation have been developed (Wong et al. 2013a; Wong et al. 2016), but their scope is limited to providing guidance on what should be reported on, to allow the readers to understand what was evaluated and judge the quality and rigour of the research process (Wong et al. 2016). These reporting checklists have been used to guide the content of this thesis and can be found completed in Appendix B. The publications do not aim to provide detailed guidance on exactly how high-quality research should be conducted (Wong et al. 2016). Realist methods themselves are

still in development, and it is expected that further adaptations of the guidelines may be required in future to accommodate the evolution of the approach (Flemming et al. 2018). Some of the key quality concerns for realist researchers are now outlined below.

# 2.3.7.1 *Validity*

Aspects of validity which may be considered include descriptive validity (the factual accuracy of the account), interpretative validity (accuracy of the meaning derived from the data) and theoretical validity (whether the data embodies some sort of theory, e.g. actors conforming to social norms) (Maxwell 2012). Because in realist research the aim is to develop programme theory, concerns about validity generally focus on whether the data collected provides helpful insights into the phenomenon of interest, rather than solely on the methods used for data collection (Maxwell 2017). The interpretative nature of realist research means that study design or procedures are not solely relied upon to ensure quality (as might be the case in a positivist approach). Instead, the methods are assessed in relation to the credibility of the results and conclusions produced (Maxwell 2012; Maxwell 2017). Considering how the results have been produced therefore allows potential threats to validity to be identified and addressed (Maxwell 2012). Depending on the stage of the study, even data which might be considered to be of low quality (such as anecdotes or personal opinions) may still prove extremely valuable to the inquiry, by providing new avenues to explore, and guiding the direction of the ongoing research (Wong 2018). Several tactics are used by realist researchers to increase confidence in the validity of their findings. Researchers should actively seek out

rival theories which could provide alternative plausible explanations to challenge their developing programme theories and design their data collection to ensure that their theory is sufficiently tested to increase confidence in the interpretations made (Hammersley 2013; Yin 2013). Triangulation of data sources and data collection methods can also act to increase confidence in the validity of the developing theory, when convergence of the results is identified (Maxwell 2017; Wong 2018).

### 2.3.7.2 Generalisability

Realist researchers are interested in attempting to produce findings from their research that have generalisability to other settings. While positivist researchers may focus on identifying universal laws and constructivist researchers may argue that generalisation is impossible, realists focus on the generalisability of causal explanation (Astbury 2018). Realists recognise causal mechanisms as 'real' and assume the same mechanisms may act to explain causation in a variety of different settings (Punton et al. 2016). Case study researchers refer to prioritizing analytical generalisation rather than statistical generalisation (Yin 2014; Maxwell 2017). An analytical generalisation is described as a "carefully posed theoretical statement, theory or theoretical proposition" (Yin 2014, p.68), in keeping with the product of realist studies (a programme theory described using CMO statements). Analytic generalisations are posed a higher conceptual level than the specific case studied allowing transferable lessons to be learned (Yin 2014). The generalisability of theories produced by realist studies is emphasised as one of the major advantages of adopting a realist approach. It allows small interventions to be used to test

higher level theories and promotes the accumulation of knowledge by building a theoretical base for related interventions (Pawson and Tilley 2001; Yin 2013; Astbury 2018). The realist focus on exploring contextual influences in detail can also assist other researchers who wish to attempt to generalise the findings to their own setting, provided that researchers provide sufficient information about the context of their study when reporting their findings (Hammersley 2013).

# 2.3.7.3 Plausibility

Wong (2018) suggests that for the findings of realist research to be seen as plausible, it requires the evidence used to make claims to be adequately trustworthy, and for the arguments built to appear coherent. The coherence of arguments or theories may be judged based on how closely they fit with the existing knowledge base and relevant formal theories, how well they explain the data and how clearly they do this without requiring special caveats or assumptions (Wong 2018). The amount of evidence required is also likely to depend on the initial plausibility of the claims being made and how closely they relate to what is already accepted (Hammersley 2013).

# 2.3.7.4 Researcher role

Realist researchers need to recognise that the knowledge and beliefs that they bring to the research process may be advantageous or disadvantageous (Maxwell 2012). My experiences as a General Practitioner influence how I think about the importance and practicality of trying to support self-management. My background

as a researcher with an interest in person-centred care and clinician training also has an impact. As well as impacting on the decisions and interpretations I made during the research process, my role is also likely to have influenced the way in which research participants engaged with me. A full discussion of the impact of my role is presented in Chapter 8.

# 2.4 Chapter summary

This chapter has shown that while a range of approaches to evaluating educational interventions for health professionals exist, many of these do not adequately address complexity and the influence of context. A realist approach to research has been highlighted as a method that can successfully account for these issues to generate more usable research findings. Realist researchers focus on understanding causation, which they understand to be a generated by mechanisms which are context sensitive. The way in which a realist philosophy influences the processes of data collection and analysis has been outlined. Chapter 3 which follows focusses on describing current practice in self-management support among staff who work with people with progressive neurological conditions. Chapters 4 and 5 then provide further details about how the realist approach was operationalised to conduct a realist literature synthesis and realist evaluation.

3 Describing current practices in supporting self-management and identifying training needs using a health professional survey

#### 3.1 Introduction

This chapter describes the design, delivery and analysis of an online survey completed by 186 health professionals who work with people with PNCs. The survey findings describe current practice in relation to self-management support and identify priority areas for future training. Key barriers to supporting self-management in routine practice are also identified.

# 3.2 Background

I started my PhD with an awareness of the complexity of providing self-management support (as described in Chapter 1). I had previously been involved in a qualitative research project, which involved interviewing health professionals working with people with multiple sclerosis (Davies et al. 2016). The study had indicated that SMS provision could be challenging for health professionals and had given me the initial idea for a PhD project exploring whether training health professionals could improve SMS provision. I was wary about basing my PhD around data from a very small number of participants, which might not have been transferable. I decided to undertake a survey to map patterns of current practice rather than relying solely on the anecdotal accounts from earlier qualitative interviews (McEvoy and Richards 2006). A survey could provide important early background orientation to the nature and scale of the challenges of providing SMS

in PNCs. The results would help to confirm that the planned PhD was investigating an important problem and provide information to help guide the direction of the later stages of work. Specialist nurses and therapists were chosen as the target respondents as my earlier qualitative study suggested self-management supporting activities fell largely within their remit. I planned the survey as the first research activity within my PhD, before I had decided to use a realist lens throughout the PhD. The survey distribution and analysis were undertaken over the same period as the realist synthesis of the literature. As a result, although the survey was not designed with the aim of generating and testing realist theories, it was possible for the emerging results to influence the later theory refinement process. As discussed earlier (Chapter 1), the initial focus of the PhD (limited to multiple sclerosis) was later broadened to include other PNCs. This meant that the survey was initially designed and distributed with a focus on MS and was then subsequently amended and distributed to Parkinson's disease specialist nurses.

# 3.3 Defining aims and selecting an instrument

Initially I considered using a pre-existing validated survey instrument. Several potential instruments were identified from a large literature review undertaken by The Health Foundation to identify ways of measuring various aspects of personcentred care (de Silva 2014). These instruments generally focussed on a single aspect of self-management support (e.g. Clinician Support for Patient Activation Measure assesses staff attitudes to SMS (Hibbard et al. 2010), Practices in Self-management Support describes current usage of SMS activities (Kosmala-Anderson

et al. 2011)). I was concerned that these focussed instruments would not provide the broad overview required for my PhD and therefore decided to design a bespoke survey. This would allow several of the important aspects highlighted by the other surveys to be covered. Firstly, the survey needed to describe current practice, to provide an indication of baseline levels of SMS provision. Questions about current practice could also act as a form of 'gap analysis', by asking respondents to selfassess their current level of practice against a set of intended competencies to identify potential learning needs (Grant 2002; Norman et al. 2004). Secondly, in line with the principles of adult learning theory, in order for adults to be motivated to learn, interventions need to address challenges in their own practice that they have identified (Knowles et al. 2005). I therefore felt it would be important to ask health professionals questions about which SMS techniques they thought would benefit their patients, and to gauge their level of interest in future training in SMS techniques. Finally, multiple barriers to implementing the learning from CPD activities have been identified, at the level of the individual practitioner, patient and wider organisation (Price et al. 2010). An understanding of possible barriers to implementation could help ensure these could be proactively addressed during the design and delivery of future training interventions.

The overall aim of the survey was therefore to describe health professionals' experiences and self-identified training needs in relation to SMS provision. The specific objectives were to describe:

 The characteristics of survey respondents (including level of experience and previous training in SMS)

- Health professionals' current levels of use of a set of self-management supporting techniques
- The proportion of patients that health professionals believe will benefit from the application of SMS techniques within routine appointments
- The self-management supporting techniques that health professionals see
   as areas of most interest for future training
- The **barriers staff experience** to providing SMS in routine practice

The findings of the survey were used to address Thesis Objective 1 (Explore current self-management support practices among UK health professionals working with people with PNCs to identify approaches used, perceived barriers and training needs). The findings also contributed to the selection of a training intervention which might meet the needs and interests of participants (Thesis Objective 3) and to the tailoring of the intervention to account for barriers identified (Thesis Objective 4). Although the survey was entitled "Supporting self-management in Multiple Sclerosis/Parkinson's Disease" I did not include in the introductory information any definitions of self-management and self-management support. This was a deliberate choice as I did not wish influence the responses received.

### 3.4 Methods

# 3.4.1 Survey design

The survey was divided into five sections, to address the objectives outlined above (See Appendix C for the full survey):

- Demographic characteristics of respondents (including previous SMS training)
- Current use of identified SMS techniques
- Proportion of patients the respondents believed would benefit from each
   SMS technique
- Level of interest in future training in each SMS technique
- Barriers to providing SMS

Initially, I undertook a brief scoping of the literature to identify the key health professional skills commonly associated with the provision of self-management support. Literature used included policy documents, reviews and original research related to both generic self-management supporting skills and more condition-specific examples. Fifteen key reference documents informed this stage and were used to identify important topic areas (Glasgow et al. 2003; Embrey 2004; Royal College of Nursing 2008; Lake and Staiger 2010; Jones et al. 2011; Knaster et al. 2011; Kawi 2012; NHS Education for Scotland 2012; Ploughman et al. 2012; Deibel et al. 2013; Fraser et al. 2013; UK Multiple Sclerosis Specialist Nurse Association 2013; Boger et al. 2015; Mudge et al. 2015; Rieckmann et al. 2015).

Twenty-four potential techniques were included in the long list generated from the data. In general, surveys that are shorter and easier to complete tend to have

higher completion rates (Boynton 2004). I therefore decided to prioritise a smaller number of techniques to focus on, given that I wanted to ask several questions in relation to each technique. Reasons for excluding identified techniques were: descriptions were too generic/lacked specificity (e.g. working to empower patients) or were likely to be seen as part of standard practice (multi-disciplinary working); techniques related to general communication skills not specifically SMS (e.g. working with interpreters); related only to information provision (e.g. signposting); related to organisational systems rather than personal practice (e.g. ability to change how your organisation works). I identified nine SMS techniques described within the literature, which I felt would be highly relevant to the design of future training for inclusion. I also attended a self-management support training course for staff during the survey design stage. The Bridges training (Jones et al. 2016) strongly emphasised helping patients to reflect as a core SMS skill so an additional item related to encouraging reflective skills was added to the questionnaire (see Box 3.1). Ten important barriers were identified from the scoping of the literature and the findings of my earlier study, (Davies et al. 2016) with one further barrier added after the pilot stage (not understanding what self-management support involves)(see Box 3.2).

Box 3.1 Self-management support techniques included in survey

Assessing a patient's capability to self-manage

Agenda setting

Involving people in shared decision-making

Goal setting

Action plans

Structured problem-solving approaches

Helping patients to reflect on their past experiences and successes to generate new ideas

Effective psychological support strategies

Motivational Interviewing techniques

Documenting self-management plans

Box 3.2 Barriers to supporting self-management included in the survey

Not entirely sure about what self-management support involves

Patients were not interested in self-management

Needed to prioritise other tasks to complete within the time with the patient Supervisors did not view supporting self-management as a core component of your role

Worried about patients bringing up difficult issues you wouldn't be able to deal with

Lacked training in specific self-management support strategies

Felt that the healthcare team had a responsibility to deal with patients' problems

Unsure how to troubleshoot when patients seemed unable to self-manage

Work pattern has made it difficult to follow people up

Felt that self-management is too difficult for some of your patients

Colleagues did not believe in supporting self-management

The demographics section used multiple choice items for ease of completion and analysis. The other four sections involved a single stem question, with multiple response items ranked on a Likert-like scale. Likert-like scales were chosen to make these sections as quick and easy to complete as possible. The number of response options on the scale was limited to the fewest possible to gain meaningful data (either three-point or five-point scales were used depending on the level of discrimination required). Each section also included a free-text response box for participants to include additional relevant information. The question about training

priorities also included an additional item asking participants to indicate up to three priority training needs from the list of techniques provided.

# 3.4.1.1 *Survey piloting*

I drafted a list of possible survey questions and response options and discussed these with my supervisory team. I revised the survey based on feedback from my supervisors and then undertook a pilot of a paper version of the questionnaire with three MS nurses, an MS occupational therapist and an MS physiotherapist. During this pilot stage the staff completed the survey and then we discussed their thoughts on the relevance of the included items, and points of clarification required. Several changes were made after this pilot stage including removing the term 'behaviour change' from the description of motivational interviewing as staff associated this with managing challenging behaviour, and adding an item relating to how well staff understood what self-management support was to the barriers section. The questions and response options were finalised and uploaded to the online platform. I then asked three colleagues to complete the survey online as a technical test of its functionality and no problems were identified.

Before circulating the survey to the Parkinson's disease staff group, references to MS in the original survey were replaced with references to PD. Job roles were amended to maintain relevance to the PD staff cohort. A Parkinson's specialist nurse reviewed the content of the survey to check that the questions remained clear and relevant to the PD staff group and confirmed that she felt the survey items were relevant and appropriate.

# 3.4.2 Ethical Approval

Ethical approval for the MS survey was obtained from Cardiff University School of Medicine Research Ethics Committee (SMREC Reference Number 16/22). An amendment to the original ethical approval was sought and granted to allow for redistribution of the amended Parkinson's survey. The first page of the online survey explained the purpose of the research project, and how the data collected would be stored and used, before asking participants to confirm their consent to participate.

### **3.4.3** Sample

For the MS staff survey, the Multiple Sclerosis Trust sent an email invitation to all nurses and therapists on their mailing lists. These lists are regularly maintained and have coverage across the UK. Staff are familiar with receiving similar requests about research through the Trust. By recruiting via the MS Trust I hoped to capitalise on the goodwill professionals feel towards the Trust (which provides training materials and bursaries) and to enhance the perceived legitimacy of the survey as professionals are aware of the Trust's involvement in health professional training.

For the PD survey a link was posted to the website of the Parkinson's Disease Nurse Specialist Association (PDNSA) and email notifications were sent to the regional PDNSA leads for local dissemination.

#### 3.4.4 Data collection

I chose to distribute the survey using an online platform because I planned to invite professionals via emailing lists and websites of professional organisations.

Collecting data using the Bristol Online Survey website (now Online Surveys run by Jisc) facilitated economical and timely data collection with no delays in response returns, compared to paper-based methods (Hewson 2003). The data were automatically collated through the online platform. Evidence from other questionnaire studies suggested that response rates could be boosted significantly by using reminders (McColl et al. 2001). Two reminders were sent out during the period the MS survey was open. Reminders were also sent to the coordinator of the PD survey distribution although it was not possible to be sure whether these were then sent on to the target recipients.

The MS survey data collection took place during April and May 2016 with the survey staying open for just over 4 weeks. Data collection from the Parkinson's Specialist Nurses took place in December 2016 with the survey staying open for the whole month (just over 4 weeks).

# 3.4.5 Data processing

The data were imported from Bristol Online Survey initially to a Microsoft Excel spreadsheet. IBM SPSS Statistics (Version 23, 2015) was then used to run the required statistical tests. Graphs were generated using Microsoft Excel.

# 3.4.6 Data analysis – quantitative – descriptive

Descriptive statistics (percentages) were used to describe the demographic characteristics of the respondents and the frequencies of responses to each question across each of the two surveys. To simplify the presentation of the results, where a five-point Likert-like scale had been used, the responses were combined into two categories. For the question about current technique use the response options not at all, occasionally or sometimes were categorised as "infrequent" and the responses often or very often were defined as "frequent". For the question relating to the number of patients that staff thought would benefit from the named SMS techniques the responses all and most were grouped together ("all or most") with the remaining response options (around half, a few, none) being defined as "half or fewer".

The remaining two questions used a three-point response scale. As most professionals expressed some interest in every technique listed, the results focus on the proportion of respondents who were very interested in each technique. This result was then compared to numbers of staff choosing each of the techniques as being one of their top three priority training needs.

The results for the question about barriers to SMS were explored in two ways.

Firstly, I focussed on reporting the percentage of respondents affected by each barrier to a significant extent. I then combined the responses for "to a significant extent" and "to some extent" to identify the percentage of respondents who had been affected by each barrier at least to some extent.

# 3.4.7 Data analysis – quantitative – inferential

At the time of the initial survey design, the analysis plan largely focussed on the use of descriptive statistics, although I was aware that the testing of associations between responses to different questions might provide valuable additional data. By the time the survey analysis took place, I had learned more about the realist ideas of theory building and testing, and so wished to test some early developing hypotheses. These hypotheses (developed from my growing understanding of the literature and discussion with supervisors) mostly describe how contextual influences (e.g. prior training, previous experience) may be linked with outcomes of interest (e.g. use of skills in practice). I also hoped to try to identify possible mechanisms for training effectiveness by examining patterns of perceived benefits and barriers reported (or not reported) by trained and untrained staff.

I chose to analyse the data from the MS and PD surveys as a single dataset during this stage as the results from the descriptive statistics phases showed very similar patterns of responses across the two surveys.

Rather than testing the hypotheses in relation to all ten of the SMS techniques covered in the survey, this stage focussed only on the four highest priority techniques identified in the descriptive analysis, as these were the techniques likely to be most relevant to future training.

# I hypothesised that:

- Previous training in SMS would be associated with:
  - o greater current usage of SMS techniques

- a perception that a greater proportion of patients would benefit from SMS
- o fewer reported barriers to SMS.
- More frequent use of SMS techniques would be associated with:
  - o greater clinical experience
  - believing a large proportion of patients could benefit from the particular SMS technique
- Greater interest in future training in SMS would be associated with:
  - o believing SMS would benefit a large proportion of their patients.
  - o current infrequent use of SMS techniques
- Inexperienced clinicians would be more affected by barriers to SMS.

For hypothesis testing the relevant results were cross-tabulated and the Chisquared test was used to assess for statistical significance. The *p* value reported for the Pearson Chi-Square test is the exact significance (2-sided) generated by SPSS, which is recommended for use when datasets are small, unbalanced or poorly distributed (Garth 2008). This significance level is based on the exact distribution of the test statistic and so enables an accurate *p*-value to be obtained without relying on assumptions that might not be met by the data (which was important in this analysis as often cells within the cross-tabulations had below expected cell counts) (Mehta and Patel 2011). Using the exact *p*-value in SPSS is recommended because it protects against incorrectly rejecting a null hypothesis which is actually true (type 1 error) (Mehta and Patel 2011). However, generating the exact *p*-value is not be possible when the dataset is larger (due to computational requirements) so the

Monte Carlo *p* value was used in these cases (North et al. 2002). When results were statistically significant, row and column percentages were calculated to look for patterns in the data and the results were critically reflected upon to assess whether the significant results appeared reasonable. Expected frequencies were also calculated to highlight important patterns in the data. Although further statistical testing was considered, (for example using regression analysis) due to the unvalidated nature of the questionnaire used this was not considered likely to be reliable or appropriate.

# 3.4.8 Data analysis – qualitative

The free text comments in each section were read and checked for relevance to the question (some respondents used boxes to make general comments). The basic principles of content analysis were followed, by grouping together responses featuring particular keywords or similar content and counting the number of comments within each group (Hsieh and Shannon 2005). A brief description of the content included in each group was tabulated alongside illustrative quotations and the total numbers of related responses. A more in-depth latent analysis of the data to explore the underlying meaning of the identified content was considered (Hsieh and Shannon 2005) but was not undertaken due to the brevity of most of the freetext comments.

### 3.5 Results

# 3.5.1 Response rate

Table 3.1 Response rate

	MS Survey	PD survey	
Potential recipients	643	320 (estimate)	
Total number invited	643	(unknown)	
Responses received	146	40	
Response rate	22.7%	(approximately 12.5% of	
		target)	

My contact at the Parkinson's Disease Nurse Specialist Association informed me that there are around 320 PD specialist nurses working in the UK. The distribution process required for the PD survey meant that we had no access to details about the number of people who may have seen the invitation to participate so it was not possible to calculate a response rate.

# 3.5.2 Responses to individual items

The response rate to individual core items (those applicable to all respondents) ranged from 88% to 100% in the MS survey (only 2 items had a completion rate <95%) and 97.5% to 100% in the PD survey. The percentages for responses presented below are based on the total number of participants who completed each item rather than the total number of survey participants (missing values have been excluded).

# 3.5.2.1 Characteristics of respondents – professional background

Table 3.2 Professional background of respondents

	MS survey	PD survey
Nursing	63.0%	92.5%
Physiotherapy	21.2%	2.5%
Occupational Therapy	15.1%	0
Speech and Language	0.7%	0
Therapy		
Background unclear from	n/a	5%
job title		

For the MS survey I had a better response rate from nurses (92/329 invited, response rate 28%) than from therapists (54/314 invited, response rate 17%). The PD survey particularly targeted PD specialist nurses as I did not identify a specific network of PD therapists to survey. For both surveys a wide spread of responses was obtained from professionals working across all regions of the UK.

# 3.5.2.2 *Previous experience*

As shown in Figure 3.1, an experienced group of staff completed the survey with more than half of respondents in each survey reporting more than 10 years of experience of working with the people with PNCs. Although they did not measure length of time working with people with MS, in their 2016 survey the MS Trust found that most MS nurses (between 64% and 82% across England, Scotland and Wales) are employed at Band 7 or above – which is in keeping with a more experienced group of staff (Mynors et al. 2016).

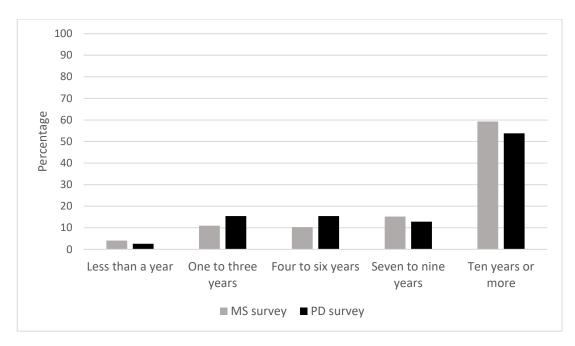


Figure 3.1 Length of time survey respondents have been working with people with MS or PD

Figures 3.2 and 3.3 show the proportion of respondents who had received any training in supporting self-management, and how long ago they attended training. Less than half of respondents in each survey had received previous training in SMS. The duration of training attended varied from less than one day (31.7% MS survey, 35.7% PD survey), one to two days (27% MS survey, 28.6% PD survey) and more than two days (41.3% MS survey, 35.7% PD survey). Most often participants had attended training five or more years ago.

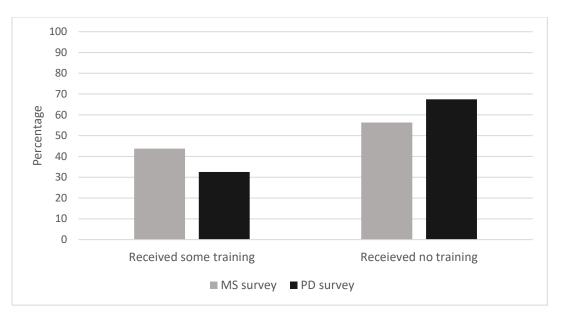


Figure 3.2 Previous training in self-management support reported by survey respondents

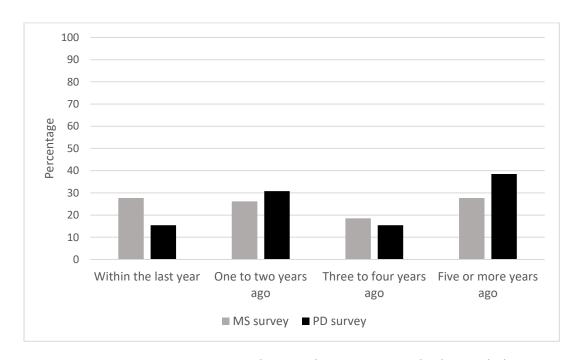


Figure 3.3 Time since survey respondents with some training had attended training

# 3.5.2.3 Work environment

In the MS survey 51.2% of respondents reported working within a specialist MS team while  $64.1\,\%$  of the PD survey respondents were based within specialist

teams. In the MS survey 36.1% of respondents reported being the only member of staff in their professional role where they work compared to 57.5% of PD survey respondents.

# 3.5.2.4 Current practice

There was a wide variation in reported current use of the different SMS techniques listed, from 46.2% reporting frequent use of the least frequently used technique (motivational interviewing in MS survey) compared to 97.5% of staff reporting frequently using shared decision making in the PD survey. The distribution of responses was similar across the two surveys, as shown in Figure 3.4.

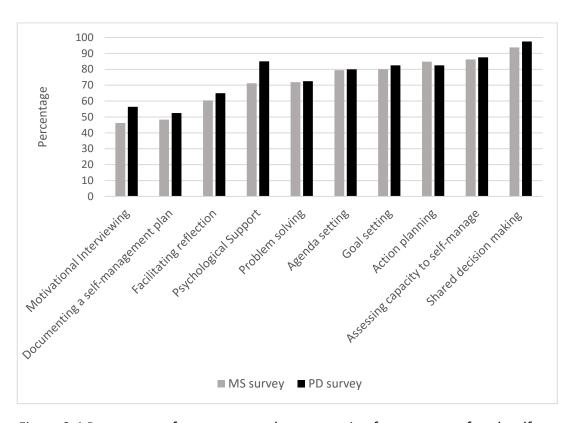


Figure 3.4 Percentage of survey respondents reporting frequent use of each self-management support technique

# 3.5.2.5 Proportion of patients health professionals believe would be likely to benefit from SMS techniques being used within the consultationAs Figure 3.5 demonstrates, most staff in both surveys reported that all or most of their patients would benefit from each of the listed SMS techniques.

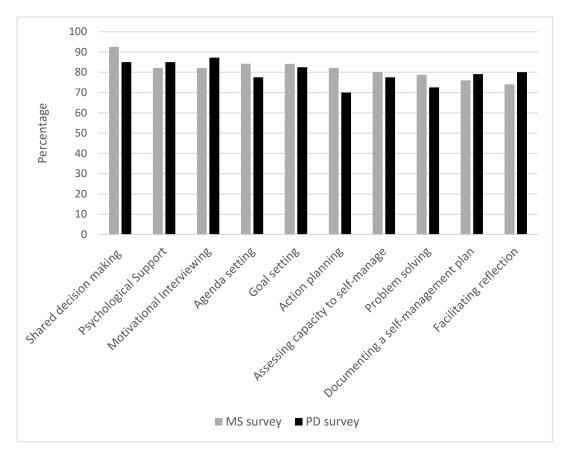


Figure 3.5 Percentage of respondents stating all or most of their patients would benefit from selected technique

# 3.5.2.6 Future training interests

There were similarities in the priority training areas across the two staff groups, with the same techniques appearing in the top four in both surveys across both of the questions about training interests (communication techniques such as motivational interviewing, psychological support, assessing capacity to self-manage and structured problem solving)(see Figures 3.6 and 3.7). The biggest differences in areas of training interest were in action planning (61.5% of PD staff very interested compared to 40.6% of MS staff) and goal setting (59% of PD staff very interested compared to 41% of MS staff).

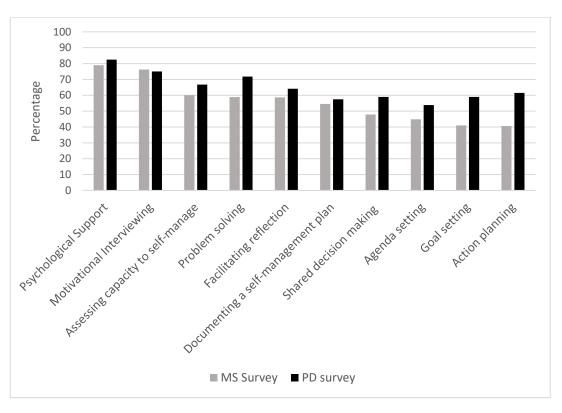


Figure 3.6 Percentage of respondents very interested in training in each selfmanagement support technique

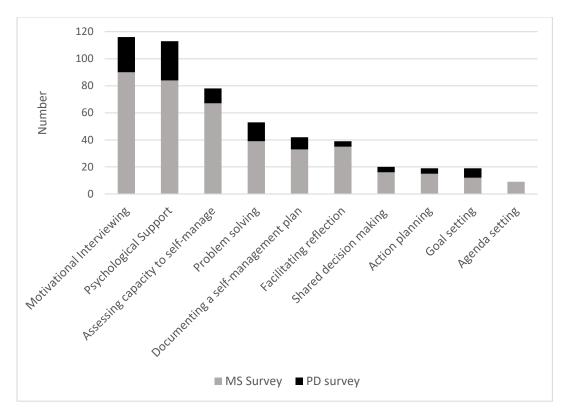


Figure 3.7 Total number of respondents selecting each technique as a priority training need

# 3.5.2.7 Barriers to self-managements support provision

Across both surveys the barriers most often cited as having a significant effect relate to the time available for professionals to provide SMS. 34.3% of MS survey respondents and 32.5% of PD survey respondents reported that the need to prioritise other tasks had impacted on them to a significant extent, with a further 50.9% (MS survey) and 57.5% (PD survey) reporting being affected to some extent (see Figure 3.8). Some of the barriers reported might indicate training needs. For example, a lack of training was recognised as a barrier for many respondents (72% MS survey, 72.5% PD survey). Although it was not a significant barrier for the majority, 46.8% in the MS survey and 50% in the PD survey stated that being unsure

of what exactly self-management support involved had affected them to some extent.

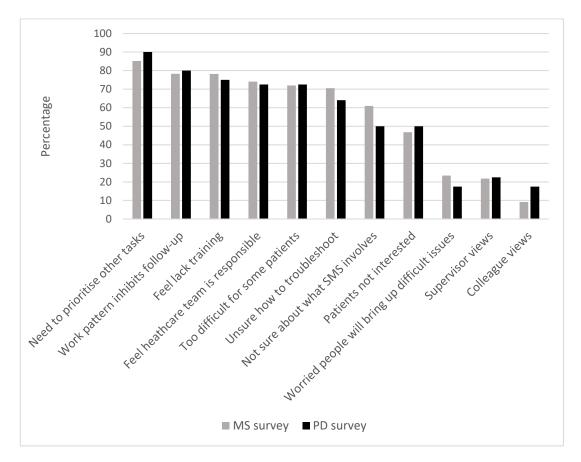


Figure 3.8 Percentage of respondents reporting being affected by selected barriers to self-management support at least to some extent

# 3.5.3 Hypothesis testing

As outlined above, hypotheses were developed to test early ideas about possible links between context and outcomes (e.g. previous experience and current SMS practices), and to try to identify some potential mechanisms (e.g. training might work by decreasing perceived barriers to SMS provision). Using the combined data from both surveys the selected hypotheses were tested against responses relating to the four SMS techniques already identified as being the highest priority for future training. The results are summarised in Table 3.3.

Table 3.3 Results of hypothesis testing

Hypothesis	Supporting evidence identified?	Comment
Clinicians who report attending previous training in SMS will report using SMS techniques more frequently	Supporting evidence in relation to the technique of motivational interviewing only.	Higher proportions of trained staff reported using motivational interviewing often (32.4%) or very often (27%), compared with untrained staff answering often (18.9%) or very often (21.7%) (Chi squared value 9.457, p= 0.050).
Clinicians who report attending previous training in SMS will report that a larger proportion of their patients could benefit from the use of SMS techniques	No supporting evidence	Most staff in both the trained and untrained groups reported that most of their patients would benefit from each of the four priority techniques being used within routine appointments
Clinicians who report attending previous training in SMS will report being less affected by barriers to the implementation of SMS in practice	Supporting evidence in relation to two barriers (lack of training, uncertainty about what SMS involves)  Opposite to expected direction seen for barrier of supervisor support (trained staff more affected).	9.3% of trained staff reported a lack of training as a significant barrier compared to 25.5% of staff who had not received training (Chi squared test value 14.289, p=0.001).  Untrained staff reported uncertainty about what SMS involved as a barrier more frequently than trained staff. (Chi squared value 9.333, p= 0.008)  More staff in the untrained
		group reported being affected "not at all" by the barrier of a supervisor who did not see selfmanagement as a core component of their role (89/105, 84.8%) compared to staff in the trained group (70.7%, 53/75 answering 'not at all') (Chi squared value 7.116, p= 0.025)

	I a	
Clinicians with less experience of working with people with PNCs will report being more affected by barriers to the implementation of SMS in practice	Supporting evidence in relation to two barriers only	The barriers about lack of training in SMS (Chi square value 20.325 p= 0.009) and worrying about patients bringing up difficult issues were reported less frequently as experience increased (Chi square value 22.736, p= 0.007), though caution is required as there were very small numbers in the least experienced staff group. Although analysis of the barrier "you felt that the healthcare team had a responsibility to deal with patients' problems" produced a statistically significant result, there was no obvious pattern of responses in the cross-tabulations.
Clinicians with more experience of working with people	No supporting evidence	Frequent usage of the techniques was reported across all groups with no pattern
with PNCs will report using SMS techniques more frequently		relating to experience identified.
Clinicians who currently use a technique infrequently will be more interested in receiving training in this technique	No supporting evidence	No consistent pattern in the relationship between current usage and interest in future training observed. Difficult to meaningfully interpret the results due to the high proportion of staff reporting frequent skill usage and high interest in training in these skills.
Clinicians who believe a large proportion of their patients could benefit from a technique will report using this technique more frequently	Supporting evidence for two techniques (problem solving, psychological support)	Pattern of increasing perceived benefit associated with increasing skill usage seen for responses about structured problem solving (Chi squared test value 89.935, $p$ = <0.001) and psychological support (Chi squared test 30.799 $p$ = 0.011)  Results for assessing capacity to
		self-manage and motivational

		interviewing showed no pattern or significant association.
Clinicians who believe that a large proportion of their patients could benefit from a technique will be more interested in receiving training in this technique	Supporting evidence for one technique (motivational interviewing)	Pattern of increasing perceived benefit associated with increasing training interest seen for responses about motivational interviewing (Chi squared value 16.126, p=0.019).  Statistically significant result also obtained for initial assessment of capacity to selfmanage (Chi square value 24.706, p=0.024) but analysis of the response pattern showed staff who thought most, or around half of their patients would benefit were more interested in training than staff who thought all of their patients would benefit.

# 3.5.4 Qualitative results

Staff reported receiving a wide variety of different types of training in their free text responses (60 responses in MS survey, 13 in PD survey). The most commonly reported types of specific training included fatigue management (in the MS survey only), motivational interviewing, cognitive behavioural therapy, health coaching, goal setting and Bridges self-management support training. There were also descriptions of less specific training broadly relating to self-management which had occurred via personal reading, conference workshops, study days or as part of obtaining post-graduate qualifications.

3.5.4.1 *Is there anything else you have done to support self-management among your patients?* 

Fifty-five free-text comments were provided in answer to this question in the MS survey (see Table 3.4). One comment contained only the answer "no". One comment related to use of medications, and one related to taking a holistic approach. Eighteen comments were provided in the PD survey. Some comments in both surveys included descriptions of multiple different strategies. These were thematically categorised into groups with an example comment provided for each activity.

Table 3.4 Responses to the question: "Is there anything else you have done to support self-management among your patients?"

Activity reported	n responses MS	n responses PD	Example quotation
Signposting to services or sources of information	13	5	"Helped signpost to local facilities and resources that will allow them to self-manage"
Information provision	11	6	"Give people information booklets giving advice on self-management i.e. with fatigue."
Running or referring patients to specific courses – fatigue management	10	3	"Facilitated a Mindfulness based cognitive therapy course for clients in conjunction with Clinical Psychologist"
Review/follow-up, being available	9	0	"Arrange follow up on an individual basis depending on need"
Diaries/tools for reflection and agenda setting	5	1	"keep a diary and ask patients what things from the list they would like to discuss"
Written plans – e.g. relapse management	4	2	"Care plans for particular aspects showing steps to follow to try to resolve issues - Red, Amber, Green steps."
Facilitated peer support from other patients	3	2	"Buddy system"
Making onward referrals to other services	2	2	"referred to neuropsychology colleagues for help with anxiety/depression"
Using sources of support within own friends and family	3	0	"Identified their network of supporters such as close family and friends"
Making patients aware of their responsibility to self-manage	2	0	"Make sure from diagnosis the patient aware of their responsibility re self-management with support from MS team."

# 3.5.4.2 Are there any other techniques that you think would support self-management?

Twenty-six free-text responses were provided in answer to this question in the MS survey (see Table 3.5). Eleven additional responses were received in the PD survey. Some responses provided more than one suggestion.

Table 3.5 Responses to the question: Are there any other techniques that you think would support self-management?

Techniques	n	n	Example quotation
suggested	responses	responses	
	MS	PD	
Involving	3	3	"self-management can still involve
carers/family/social			carers as some patients may need
services			assistance to implement strategies"
Information	3	2	"Provide written information about
provision/signposting			specific problems relating to MS to
			help them to understand more about
			the condition"
Make access to the	4	0	"more options for follow-up such as
service easier/pro-			telephone clinics to check on progress
active follow-up			and provide further advice"
Cognitive	3	0	"We use a CBT approach with
Behavioural Therapy			supervision from psychology"
Techniques			//
Facilitating peer	3	0	"There is a local coffee group who
support			meet and support each other"
Discuss patients' role	3	1	"Discussion re ownership of the
0.15			condition"
Self-management	2	1	"HOPE MS course supported by MS
support courses for			Society and Coventry University"
patients	2	0	((A 4):- alfl., a a a tura in in a "//
Mindfulness	2	0	"Mindfulness training"
Agenda setting	1	1	"we use the non-motor questionnaire
			prior to appointment to help set
Ballian I and allian	4	4	agenda"
Patient activation	1	1	"we are trialling the Patient Activation
			Measure (PAM) tool to assess patients
			who may benefit from self-
Hoalth coaching	1	0	management."  "We use health coaching"
Health coaching			
Motivational	1	0	"Motivational Interviewing"
interviewing Counselling	1	0	"counselling skills"
Exercise	0	1	"Facilitation to exercise in a self-
Exercise	U	1	managed way"
Treating mental	0	1	"help with apathy and depression for
health problems			those who struggle most with self-
			managed goals."

3.5.4.3 Do you have any suggestions for other training which might help you to support self-management?

Nine free-text responses were provided in response to this question (all from the MS survey). Two respondents suggested training within their own multi-disciplinary team, and one respondent suggested each of the following: opportunities for local networking, use of mobile technology, cognitive behavioural therapy, health coaching, neuro-linguistic programming, mindfulness, psychological support, strategies to deal with resistance and training to facilitate an MS specific patient self-management course.

3.5.4.4 Are there any other barriers you have encountered to supporting selfmanagement?

There were 29 responses from the MS survey describing barriers to the provision of SMS (see Table 3.6). Two respondents from the MS survey answered 'no' and one said that not all the listed barriers were applicable. Eight free-text responses were provided in the PD survey (two addressed more than one barrier).

Table 3.6 Responses to the question: Are there any other barriers you have encountered to supporting self-management?

	Barriers described	n responses MS	n responses PD	Example quotation
Patient level barriers (disease related)	Physical disability, cognitive impairment, depression, apathy	2	3	"depression and apathy make self-management obstacles seem larger to patients" "Cognitive function and mental capacity are what limits self-management"
Patient level barriers (not necessarily disease related)	Patient expectations, lack of understanding of the concept of SMS, patients do not follow through with goals	3	3	"Patients need time to get used to the concept and have successes for motivation."
Professional level	Confidence, skills, understanding the concept, concerns about over- burdening patients	3	2	"I worry about my patients' ability to self-manage, I would like to follow up or complete reviews, my confidence would grow with feedback from patients succeeding."
Organisation level	Time/workload, record-keeping practices, colleague perception of selfmanagement, ethos of the service	13	2	"Limited time and resources available. It is probably not seen as a 'priority' part of treatment and so the opportunity is missed."
Wider social factors	Influence of friends and family, resources available in the community, influence of external agencies (e.g. benefits assessments)	5	0	"Getting partners/spouses /carers to understand the importance of selfmanagement /empowerment"

#### 3.6 Discussion

### 3.6.1 Discussion of key results

The survey achieved the core aim of describing health professionals' experiences and self-identified training needs in relation to SMS provision. Importantly, there were very similar patterns in the responses from the MS and PD surveys, indicating that both the challenges and the solutions may be the same in both settings, and supporting the decision to study staff working across different PNCs as a group for the later stages of the PhD.

Objective 1: Describe the characteristics of survey respondents (including level of experience and previous training in SMS)

One hundred and eighty-six responses were received in total, mostly from staff with nursing backgrounds, but with good representation from therapists in the MS survey. Although an experienced cohort responded to the survey fewer than half had received previous SMS training. Those who had received training had been trained in a wide variety of different techniques, via methods including personal study, postgraduate qualifications, conferences and workshop attendance.

# Objective 2: Describe health professionals' current level of use of a set of selfmanagement supporting techniques

There was wide variation in the use of SMS techniques in routine practice (with motivational interviewing, documenting a self-management plan and facilitating reflection being the least frequently used, while shared decision making and assessing capacity for self-management were reported to be used most frequently). There were very similar patterns of technique use across both the MS and PD surveys. The free-text comments highlighted some additional techniques commonly being used to support self-management which were not included in my shortlist of techniques including providing information, building patients' skills (e.g. running fatigue management courses) and helping patients to access other services or sources of support. Specific SMS techniques that staff thought might also be useful in addition to those listed included cognitive behavioural therapy, mindfulness, using the patient activation measure, and health coaching. The qualitative data indicated the broad and holistic view staff took in relation to self-management and in particular the emphasis that they placed on support from outside the healthcare system (e.g. from family or peers). The statistical analysis found that increasing levels of experience were not associated with using SMS techniques more often, suggesting that it should not be assumed that staff will increase their support provision as time goes on. I also found that the relationship between previous training and technique usage was only statistically significant for motivational interviewing skills. This may be explained by the fact that motivational interviewing is a very specific approach that staff without training would be unlikely

to believe they undertook, whereas other techniques such as making an action plan may be used by staff without any formal training. Untrained staff may only have a limited understanding of some of the techniques which might have led them to overestimate their current performance (Howard 1980). It may also be that the survey was not specific enough to pick up an association between training and subsequent practice as it did not ask participants to specify details of the type of training undertaken, and the qualitative results have indicated a very wide variety of training opportunities in relation to different aspects of SMS exist.

Objective 3: Describe the proportion of patients that health professionals believe will benefit from the application of SMS techniques within routine appointments

The responses related to the proportion of patients thought likely to benefit from each SMS technique are less discriminatory than other elements of the survey as the majority of respondents felt that all or most of their patients would benefit from each technique (ranging from 74% to 92% in the MS survey and 70% to 87.2% in the PD survey). No association was demonstrated between previous training and perceptions about the number of patients likely to benefit, suggesting that training may not necessarily work by convincing participants of the benefit of using SMS techniques. However, perceived benefit may have an important influence on how often staff apply SMS techniques in practice as I found significant associations between these factors for two techniques (structured problem solving and psychological support). The results were also mixed regarding the relationship

only for the technique of motivational interviewing) but require cautious interpretation because very low numbers of respondents expressed no interest in training or expected only a small proportion of patients to benefit.

# Objective 4: Describe the self-management supporting techniques that health professionals see as areas of most interest for future training

The priority topics for training were the same across both surveys. These seem to fit with the concerns identified in earlier work that self-management could be seen as too difficult for some patients (especially those who were struggling psychologically), and that some patients were not ready or willing to take on a self-management role (Davies et al. 2016). The techniques of assessing capacity to self-manage, motivational interviewing and psychological support could all be seen as ways to address patients' readiness to self-manage. It appeared that effectively addressing patient-level factors that might influence how ready a patient was to take on a self-management role was a major concern for professionals working with people with PNCs. The training interests listed in the free-text responses also included topics relating to improving psychological wellbeing (e.g. mindfulness, cognitive behavioural therapy). I did not find any statistically significant relationship between how often a technique is currently used and whether staff see the technique as a priority area for further training.

# Objective 5: Describe the barriers staff experience to providing SMS in routine practice

Both the quantitative and qualitative results indicate that organisational constraints are reported to have the biggest impact on staff trying to provide SMS. It is therefore crucial that any interventions aiming to improve SMS provision are tailored to the challenging work environment the respondents describe. A perceived lack of training in specific SMS techniques was also reported as a barrier by many staff. Staff who had received training were less likely to report that they lacked training or that they were unsure about what SMS involved. Similarly, as staff gained experience, they were less likely to see a lack of training as a barrier and also reported that worrying about their patients bringing up difficult issues affected them less frequently. Neither training nor experience made any difference to how staff perceived organisational barriers to SMS provision. The qualitative data described some condition-specific patient level barriers (e.g. apathy in

#### 3.6.2 Strengths and Limitations

There were multiple sources of potential bias encountered at each stage of the development, distribution and analysis of the survey which are briefly described below.

#### 3.6.2.1 Survey design

No alternative single validated instrument was available for use to address all of my objectives. Using a combination of validated instruments might have been an option but this could have been more burdensome for participants and it would have been more challenging to analyse the relationship between responses to different surveys designed for different purposes.

I decided upon the content of the survey (particularly which techniques to include) following a scoping of the literature. This may have been subject to a degree of publication bias (only identifying skills commonly reported within the SMS literature). There is also a risk that my own personal views of which techniques were likely to be most relevant or successful influenced my choices of techniques included. Although I performed a check of face validity (Burns et al. 2008) with volunteers from the target staff groups during the pilot stage, more in depth testing of content validity was not undertaken due to the time constraints within this phase of the PhD. It is therefore expected that some important SMS techniques or barriers to SMS provision have not been fully described. The inclusion of qualitative responses did help to mitigate these issues by allowing for respondents to add their own suggestions, while ensuring that the survey remained of a reasonable length to facilitate completion.

To facilitate the online delivery of the survey, short descriptors of each technique which could be easily read were chosen. Although some techniques were self-explanatory (e.g. documenting a self-management plan), others, in particular motivational interviewing, were difficult to describe concisely and there is a risk

that respondents understood some of the techniques described differently to how I might have intended. The patterns of responses did seem to suggest that the survey had internal consistency (e.g. those who attended training were less likely to report lack of training as a barrier).

#### 3.6.2.2 *Sample*

The MS Trust keeps an up-to-date list of specialist nurses and therapists who work with people with MS in the UK which provided access to a large number of target participants. However, the list does rely on professionals having provided their details to the MS Trust (meaning the list is likely to be populated by staff with a special interest in MS). There is a range of other health professionals (including inpatient and community nurses, neurologists, rehabilitation physicians, geriatricians and general practitioners) also involved in the care of people with PNCs whose views I have not explored. I used a personal contact to facilitate distribution of the PD survey, who in turn used her own network to share details of the survey. My distance from the distribution process made it more difficult to understand who the survey might have reached and may partly explain the lower response rate. Nonetheless the inclusion of the relatively smaller number of PD responses has been very valuable because it allowed for comparison with the MS data. It may be that another method of distribution (such as launching the survey at a national conference or via alternative professional networks) could have generated further responses. No detailed data were available from the distributing organisations about the list membership which might have allowed the

characteristics of responders to be compared with those of the cohort as a whole to highlight any notable differences and under-represented groups.

#### 3.6.2.3 Responses

Surveys in general risk non-response bias (Sax et al. 2003) and I am aware that the results must be interpreted with caution as I have only captured the views of a small proportion of the total population. In their literature review, Gould et al. (2004) found that survey-based needs assessments varied very widely in their response rates — between 21% and 100%. It is possible that those professionals with most interest in supporting self-management completed the questionnaire and, in this case, I may have over-estimated the appetite for training among professionals. Alternatively, those who had difficulties or concerns with supporting self-management may have been more motivated to respond, resulting in the impression that self-management support is more troublesome than it actually is for many professionals

The responses provided may have been biased for several reasons. Other studies have shown that self-reported data on SMS provision may be unreliable and that clinicians tend to describe the levels of SMS provision they provide differently before and after training (with a tendency to over-estimate provision before training) (Yank et al. 2013; Mudge et al. 2015). Over-reporting amongst untrained professionals may have meant that my survey has underestimated the influence of training. Responses may have also been biased by social desirability (Calsyn and Winter 1999), with staff feeling that they should give responses that show their

attitudes and behaviours regarding SMS in a positive light. Although I intentionally did not provide definitions of SMS within the survey, respondents may have inferred that the list of techniques provided was seen as best practice or expected competencies. There is also a risk of bias due to acquiescence, when respondents tend to answer questions affirmatively, regardless of their content (Calsyn and Winter 1999).

#### 3.6.2.4 Data analysis

Decisions I made during the data analysis process may have also biased the results. For two of the survey questions, responses from the original five-point Likert-like scales were grouped into two categories. Although this facilitated the interpretation and presentation of the results, it is possible that if the results had been grouped and presented differently, the findings could have changed.

I chose to focus on the hypothesis testing on four techniques in which participants had expressed the greatest interest in receiving future training. It is possible that focussing on another set of techniques might have generated a different set of results so the statistical testing needs to be interpreted with caution as it may not be generalisable across all SMS techniques.

No power calculations were undertaken to check whether the sample size was adequate for hypothesis testing. This was because of the exploratory and untested nature of the questionnaire instrument, and because hypothesis testing was a secondary objective, with descriptive analysis being the main focus. The small

sample size may have increased the risk of type II error, and some of the null hypotheses may have been accepted incorrectly.

#### 3.6.2.5 Applying a realist lens

The survey was undertaken early in the PhD when I was in a theory generation stage. The survey provided useful contextual data about the participants including their level of experience, previous training specific to SMS and current ways of working. If the survey had been planned with a realist lens, more free text responses would have been included instead of the large number of fixed response items. This would have provided richer data with potentially greater explanatory power to identify descriptions of mechanisms at work, and to identify links between elements of context, mechanism and outcome. However, the potential to gain more explanatory data would have needed to be balanced against the greater time investment required to analyse such data.

To further my theorising of how, when and for whom training interventions work it would have been helpful to include more items directed at staff who had already attended training. This could have helped to develop theories around how training influences practice as well as helping to prioritise a specific intervention for further evaluation during the second phase of the PhD. Had the survey been undertaken later in the PhD, when I was more focussed on theory testing, questions could have presented theories in development for participants to rate how well these reflected their own experiences. A validated survey instrument could also have been used to test for either specific mechanisms (e.g. improved self-efficacy) or specific

outcomes (e.g. increased SMS provision) identified as parts of a theory in development.

#### 3.6.3 Findings in the context of the current literature

#### 3.6.3.1 *Use of self-management support techniques*

It is difficult to compare the findings from my bespoke survey with those carried out using other measures of SMS as each instrument includes different lists of SMS techniques. However, broadly there are similarities between my survey findings and existing work. For example, Kosmala-Anderson et al. (2010a) surveyed 213 UK clinicians from a range of clinical backgrounds and found, as in my survey, that there was no relationship between length of experience and reported use of SMS techniques. The rates of self-reported SMS provision I found also seem broadly in keeping with a large NHS England survey of 1759 clinicians where, for example, over 70% of staff reported using agenda setting skills frequently (compared to 80% of staff in my surveys) (NHS England 2015).

#### 3.6.3.2 Attitudes/perceived benefits

The Clinician Support for Patient Activation Measure (CS-PAM, a validated measure of clinicians' beliefs about how important it is for patients to demonstrate a set of self-management behaviours) (Hibbard et al. 2010) has been used by several studies. Clinicians have been shown to most highly value patient behaviours relating to following medical advice, while seeking information independently is

least valued (Hibbard et al. 2010). Interestingly the combination of demographic variables and clinician role was shown to account for only 4% of the variance in CS-PAM scores in a large UK study (NHS England 2015). Multiple studies have shown significant correlations between measures of clinicians' belief in SMS and self-reported SMS provision, showing that as belief in SMS increases, so does SMS provision (NHS England 2015; Alvarez et al. 2016; van Hooft et al. 2016). My survey only showed a relationship between current technique use and the proportion of patients expected to benefit for two of the four techniques examined during the hypothesis testing phase. This could represent a type 2 error. It is also possible that for some techniques use was low for other reasons not associated with a lack of belief in the potential benefit (e.g. a lack of previous training in motivational interviewing).

3.6.3.3 The impact of self-management support training and future training needs In keeping with my findings, staff in other surveys have also reported a need for further education in SMS provision (NHS England 2015; van Hooft et al. 2016). Priority training needs identified, in keeping with those raised by my respondents, included communication skills, motivational interviewing, health coaching and being able to assess and adapt to different patient activation levels. Two studies (Kosmala-Anderson et al. 2010a; Kosmala-Anderson et al. 2010b) by the same team found that staff performed more SMS practices following training, although one of these demonstrated a ceiling effect in relation to elements of SMS which focus on the provision of patient-centred care (Kosmala-Anderson et al. 2010a). Completing

training was also found to increase confidence in ability to provide SMS (Kosmala-Anderson et al. 2010b).

#### 3.6.3.4 Barriers

Seven hundred respondents to an NHS England survey (2015) described barriers to SMS provision in free text comments. Clinician level barriers were the least frequently reported while most common barriers were patients' abilities or willingness to take a more active role in their care, insufficient local support services and lack of time during consultations. Van Hooft et al. (2016) also found that a lack of time was the most frequently reported barrier to SMS provision, and that most of the barriers to SMS nurses described related to external factors (at either the patient or organisational levels).

#### 3.7 Implications and next steps

My survey achieved its main aim, providing useful information about the current level of SMS provision, and describing the self-identified training needs of staff working with people with PNCs. It has shown there is a clear appetite for training in a wide variety of SMS techniques among staff working with people with PNCs together with a belief that these techniques could help a large proportion of their patients. It therefore supports the calls made by other authors to provide clinicians with training in SMS techniques to increase their confidence in SMS provision (Kosmala-Anderson et al. 2010a; van Hooft et al. 2016).

It is also important that any future training takes into account the barriers to SMS that staff report at the levels of the individual patient and the wider organisation. The provision of SMS occurs in a context and these perceived contextual barriers may influence the effectiveness of future interventions. Van Hooft and colleagues (2016) suggest that learning from training may be inhibited when staff attribute negative results to external factors beyond their control. They emphasise the importance of including strategies for dealing with these external factors within any training intervention. The level of concern about patient-level barriers to SMS provision in particular is reflected in the priority training areas selected by staff in my survey, many of which relate to assessing and improving patients' readiness to self-manage.

The findings from this early stage were taken forward to influence the chapters that follow in several ways. Firstly, and perhaps most importantly, the survey provided reassurance that health professional training in SMS was an important topic, and that the ideas I developed during the work done prior to my PhD were worth continuing to follow-up. Secondly, the survey findings relating to priority training interests helped to inform the selection of a training intervention for evaluation in the later stages of the PhD, a process described fully in Chapter 5. Finally, the emerging survey findings aided the interpretation of the data generated by the realist synthesis in Chapter 4. In particular, the barriers reported by survey respondents helped me to remain aware of the significant influence of workplace context, and how contextual barriers could overwhelm the intended impact of any training interventions. The realist synthesis of the literature is now described in detail in Chapter 4.

## 4 Realist synthesis

#### 4.1 Introduction

Training health professionals in SMS is a complex intervention, consisting of multiple interacting components (Craig et al. 2008). Evidence related to training and its implementation needs to be synthesised using an approach that acknowledges this complexity. Chapter 1 briefly explored what is already known about training health professionals to support self-management, identifying heterogeneous outcomes from training interventions. A realist literature synthesis uses a theory driven approach, informed by an acknowledgement that interventions will operate differently when delivered into different contexts. I planned to use this approach to synthesise the evidence about interventions which aim to increase or improve the support for self-management provided by health professionals working with people with PNCs. The synthesis described below was used as the first step in starting to theorise these interventions. It addresses Thesis Objective 2 (develop theories from current literature, with a focus on PNC settings, about how training to support self-management works, for whom and in what circumstances).

### 4.2 Methods

The review process is described here according to the six stages of realist synthesis outlined by Pawson: identifying the review question, searching for primary studies,

quality appraisal, extracting the data, synthesising the data and disseminating the findings (Pawson 2006). Unlike a traditional systematic review, these stages frequently overlap and occur in parallel due to the iterative nature of the realist approach. Appendix D provides details of the review stages in detail and illustrates the movement back and forth between the different stages over the course of the review. The realist synthesis stage of the PhD was supported by a grant from the Royal College of General Practitioners Scientific Foundation Board (Grant number SFB 2015-18). This funding supported information specialist input into the search strategy and dissemination of the findings (see Appendix A). The review protocol was published (Davies et al. 2017) and extracts from the protocol are included in the description of methods below.

#### 4.2.1 Roles within the review process

I was responsible for each stage of the synthesis, supported with input from my PhD supervisors (regular discussion about emerging findings) and a stakeholder advisory group. Unlike a traditional systematic review, key stakeholders are consulted throughout the realist synthesis process from refining the focus of the review to challenging or validating emerging review findings (Rycroft-Malone et al. 2012). The stakeholder advisory group for this study included my PhD supervisory team who are academics from health, social sciences and education, with interests in self-management support and/or post-graduate health professional training. Other members of the group were clinicians working with people with a PNC (MS Specialist Nurse and Occupational Therapist), service users with PNCs, a researcher

working for a SMS training provider, and third sector representation (MS Trust) (Davies et al. 2017). Attendance at the advisory group meetings (three held over the course of the synthesis) varied, with between seven and nine people attending each meeting (with some additional input from members not able to attend on the day via phone, email and face-to-face meeting).

#### 4.2.2 Identifying the review question

An initial period of reading around the subject was undertaken which allowed key recurring themes from the wider literature about SMS to be identified (Davies et al. 2017). The aim was to gain a broad overview of what was already understood about the topic to take forward to the stakeholders to inform the development of the review questions. This scoping stage involved informal searches of the literature and identified papers from a range of clinical settings (including those discussed in Section 3.4.1). In the literature relating to training health professionals in SMS, specific SMS skills (and confidence in their use), perceptions of workplace fit and belief in the concept of SMS itself all appeared to be influential factors.

Research exploring the implementation of SMS in practice identified issues that included patient level barriers, the influence of health professional, local multidisciplinary team, and wider organisational characteristics (Wallace et al. 2012; Newbronner et al. 2013; Harvey et al. 2015; Mudge et al. 2015).

The range of issues identified was presented at the initial stakeholder advisory group in March 2016. Informed by the group's discussion on priority areas, two key review questions were formulated, with the <u>overarching aim</u> of improving

understanding of the circumstances in which health professionals could implement and sustain SMS. Therefore, the scope of the review was planned to include both professionals' experiences of receiving training in supporting self-management and their experiences of applying their learning in clinical practice (Davies et al. 2017). For each review question I developed one or more initial rough theories, based on the early literature scoping and stakeholder input, which were used as a starting point for further theory development. The role of these initial rough theories in the later stages of the PhD is discussed in section 5.5.

The initial review questions chosen (Davies et al. 2017) were:

1. What is the influence of a shared concept of SMS within healthcare teams caring for people with progressive neurological conditions and how can it be achieved?

Three initial rough theories relating to this review question were drafted, focussing on individual, team and organisational factors respectively.

- i.) Health professionals who believe they already support self-management effectively, or who feel uncomfortable with sharing responsibility are unlikely to engage with training or change their practice. When training interventions demonstrate how self-management support is different to current practice and emphasises its benefits, professionals are more likely to value training and try to integrate new skills into practice (Davies et al. 2018).
- ii.) Training in self-management support is most likely to be successful when whole teams develop a shared understanding and work collaboratively

to optimise support. This may be achieved via whole team training and providing regular space to discuss self-management within the team.

Conversely staff who attend SMS training but return to work in an area where there is little colleague support for the idea are unlikely to continue to use and develop their skills (Davies et al. 2018).

- iii.) If organisational priorities do not include self-management support, this will be viewed as a low-priority activity and other activities may be prioritised. Conversely if the organisation proactively supports SMS provision (for example through the structure of appointments, providing practitioners flexibility to adapt how they work, availability of clinical supervision/ongoing training, and through the collection of feedback about SMS), individual professionals will also value the activity more (Davies et al. 2018).
- 2. What is known about how SMS can be successfully tailored for people with progressive neurological conditions?

One further initial rough theory was developed in relation to this question. It was:

In the context of a complex caseload, when patients have multiple
interacting symptoms which make self-management a challenge,
professionals may feel that self-management is too burdensome. If
professionals are trained in specific skills that take into account these
complexities (e.g. how to tailor self-management support) they will be more

likely to attempt self-management support within complex situations (Davies et al. 2018).

As the synthesis progressed, in order to keep the review manageable, it became necessary to confine the scope to examining outcomes at the level of the health professional only (and not any resultant outcomes on the patient, carer, or the wider organisation). As the main aim of the synthesis was to understand how professionals could best be trained and supported to provide SMS, examining professional-level outcomes made sense as these are the most proximal outcomes following interventions (and required before more distal patient and organisational outcomes could be achieved). Patient and organisational factors were still considered if they formed part of the context or the mechanism which resulted in a clinician-level outcome.

#### 4.2.3 Searching for primary studies

The PRISMA diagram below (Figure 4.1) summarises the search process. The overlap in the searching, extraction and synthesis processes is illustrated in Appendix D. The database search strategy was designed with input from an information specialist. It used three search threads in combination: health professional terms, self-management terms, and progressive neurological condition terms (both relevant MESH headings and free text terms) (See Appendix E for details of searches run). Search terms relating to self-management were informed by terms used in previous systematic reviews (Taylor et al. 2014; Boger et al. 2015; Mudge et al. 2015) and by terms under which existing known papers were indexed

(for example (Yank et al. 2013)). At this stage the aim was to be as inclusive as possible. Therefore, goal setting and health coaching terms were included as these were seen to be important skills for facilitating self-management which might not be indexed under the term self-management (Davies et al. 2017). The use of a fourth thread including training and education terms was piloted, but relevant papers relating to implementation were not identified, so this thread was not used in the searches (Davies et al. 2017).

The initial search was developed for Medline via Ovid and then adapted for other databases (EMBASE, Cochrane Library, CINAHL, PEDro, ERIC and PsycInfo). The search was limited to English language papers (due to resource constraints) and to papers published in the last 20 years (as the concept of SMS is relatively recent) (Davies et al. 2017). Following a particularly high recall from a search engine previously found to have a low specificity in relation to this topic (EMBASE) (Taylor et al. 2014), additional limitations were placed on the search to ensure only the most relevant papers were retained (non-OECD countries, children, palliative care and diagnosis related studies were excluded) (Davies et al. 2017). Initial searches were performed in April - May 2016. A further search of the CINAHL database was performed in December 2016 when the original search terms were reviewed and noted to be missing some free-text terms which might help yield additional results.

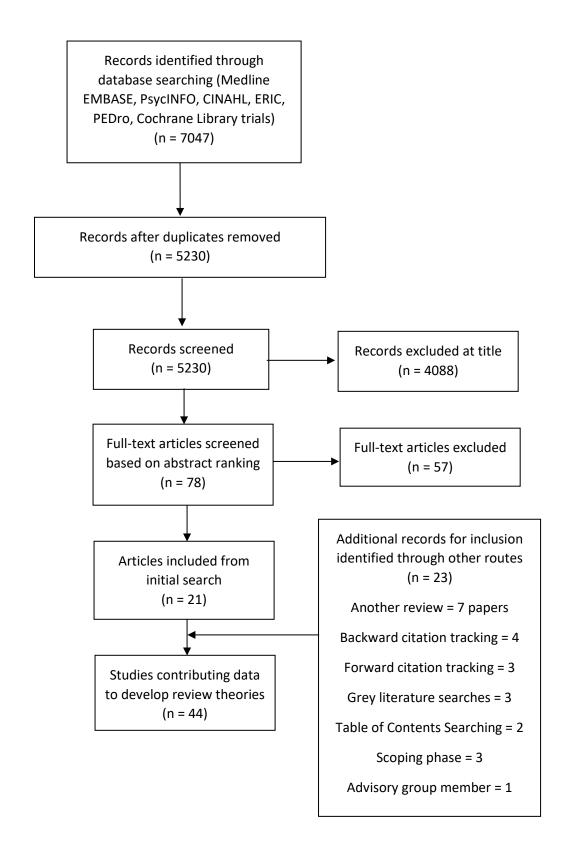


Figure 4.1 Sources of studies included in the review (Davies et al. 2018)

Reference lists of included papers were examined to identify additional relevant papers and Google Scholar was used to identify forward citations of the included papers. Table of Contents searching was also undertaken to supplement these searches. A review of the journals which had published papers in the synthesis (performed at the point when 39 papers had been included) showed that one journal (Disability and Rehabilitation) had published a significant proportion of the included papers (8 papers), compared to other journals. Therefore, all titles from this publication were screened going back three years, with an additional within journal search for key terms relating to the review going back a further five years. Papers were also sourced from those already identified in the scoping stage and advisory group member recommendation. A systematic review identified in the scoping stage (Mudge et al. 2015) provided additional papers for inclusion. The last searches were undertaken in January 2017 to identify any grey literature not already located using the database OpenGrey, Google Scholar and key websites (Health Foundation, King's Fund, PNC charities).

An abstract screening tool was developed and tested in collaboration with a supervisor (See Appendix F). The tool ranked papers on a four-point scale based on their likely relevance to either of the review questions. In brief, abstracts that both related to a PNC and to health professionals' experiences of training in or implementation of SMS were prioritised. Papers not specific to PNCs were ranked lower, and those where professional involvement in SMS was unclear were ranked as least likely to be relevant. Although the tool provided basic guidance on the likely relevance of papers for inclusion, I also used my judgement to ensure that potentially highly relevant papers were not deprioritised because they did not meet

pre-defined rigid criteria. This application of researcher judgement is a key element of the realist approach to literature review which differs significantly from traditional systematic review (Pawson 2006). The full text of all papers ranked of the highest relevance were sourced and assessed for potential inclusion. The most relevant of the papers ranked in category 2 (second most relevant) were also sourced, and those ranked lower were not taken forward for full-text screening.

A clear audit trail of the source of included papers was maintained. It is suggested that realist reviewers consider further searching in the later stages of the review informed by the improved understanding of the review topic (The RAMESES Project 2014). Further searches were not undertaken for this review. The comprehensive nature of the initial search strategy meant that it was likely that a large number of papers relevant to the context of interest should have already been located. The aim of this synthesis was to explore how the intervention (self-management support training) operated in practice in the setting of interest (Pawson 2006). There was the risk the review could have become unmanageable very quickly if further data had been sought from other settings. During the process of undertaking the review it became clear that context-specific data were fairly limited and that the review was likely to be very useful for theory generation but potentially less reliable for theory testing. The later stages of the PhD were planned to offer further opportunities to test and refine the theories derived from the synthesis.

#### 4.2.4 Appraisal of identified studies

Realist reviewers do not generally rely on traditional quality assessment tools, but instead make judgements on each piece of included evidence based on both relevance and rigour (Pawson 2006). All titles were initially screened for basic relevance. Titles that were obviously irrelevant were excluded as were those that focussed predominantly on: paediatric patients, carers or families, nursing homes/managed care settings, diagnostic or end-of-life periods, epidemiology, imaging or testing, measurement instruments, and specific treatments or devices. At the full text screening stage, prior to data extraction a judgement was made about whether the paper provided information relevant to the research questions. Reasons for exclusion on the basis of relevance were recorded (Davies et al. 2017). Judgements about relevance were influence by the stage of the synthesis at which the paper was reviewed as my ideas about relevance naturally developed over time as the theories became more refined, and gaps in the evidence base became more obvious. Some papers may only have been identified as relevant later in the review process because I had become sensitised to important new issues during the course of the review, informed by the application of formal theory. Similarly, some papers which were seen as highly relevant when located early in the review process might not have been taken forward if identified later because data saturation in an area had already been reached, so at the point of reading the study would not have offered new relevant information. The assessment of rigour was an ongoing process throughout the data extraction and synthesis phases (Davies et al. 2017). Critical reflection on all evidence contributing to the synthesis was used to try to

safeguard the inferences made on the basis of individual extracts by ensuring that they were used appropriately (Pawson 2006).

#### 4.2.5 Data extraction and data synthesis

A core set of descriptors for each study was collected including identifiers (author, title, year), type of data (primary research evidence, opinion piece) patient group details, staff group details, brief description of intervention, relationship with other studies included in the review, and setting (country and healthcare setting) (Davies et al. 2017). Initially, papers were read and explanatory accounts which provided information about context, mechanism or outcome patterns were formulated as "If-Then" statements. An example was: "If self-management is not valued by colleagues *Then* staff will feel discouraged from applying training in practice" (Davies et al. 2017). The source of each If-Then statement was recorded.

This approach was successfully used by another realist synthesis project which aimed to inform future training design (Pearson et al. 2015). Generating If-Then statements rather than Context-Mechanism-Outcome configurations had the advantages of being an accessible way of starting to extract data with a 'realist lens' and providing a practical way for partial knowledge to accrue through the review process (Pearson et al. 2015, Davies et al 2017). Although the "If-Then" statements did not always contain each element of context, mechanism, and outcome, the partial information provided was still informative for the synthesis. As the review progressed the data extraction process became more focussed on data which could

help to refine the key theories of interest, rather than continuing to extract data to develop new unrelated theories.

A similar approach to that described by Pearson et al. (2015) was used to consolidate multiple If-Then statements into CMO configurations. The overlapping extraction and synthesis processes are described in Appendix D. Initially, apparently linked statements were grouped together. The grouped statements were read and re-read and used to formulate a refined account in the format of a theory which comprised one or more CMO configurations. A worked example of this process is shown in Box 4.1.

A 'node' in the analysis software NVivo 11 (QSR International) was created for each proposed review theory and the original data that were used to derive the constituent If-Then statements were coded under this node. This allowed direct reference to the original data to help ensure that the developing theories continued to accurately reflect the source material. Later in the data extraction process, when the synthesis was already well progressed, it became unnecessary to use "If-then" configurations and instead data were extracted and coded directly under the theory nodes. To facilitate thinking about CMO configurations, data relating to each developing theory were then tabulated under the headings of Mechanism (resource), Enabling context, Inhibitory Context, Mechanism (reasoning) and Outcome.

Box 4.1 A worked example of how several explanatory accounts were consolidated into one (adapted from Davies et al. 2018)

**Original data extract:** "both physical therapists perceived the possibility of resistance by health services to incorporate the philosophy of the Blue Prescription approach because, in their opinion, current services tend to be aimed at remediation of an incident (e.g., provision of rehabilitation after a fall), with the intent being discharge of a patient once the incident has been resolved." (Mulligan et al. 2013, p.55)

#### If-Then statement generated:

"IF a service focusses its efforts on treating acute events and then discharging patients THEN a health promoting self-management approach is unlikely to be accepted"

#### Other overlapping If-Then statements generated:

"IF professionals work in a time pressured environment THEN institutional needs will tend to take priority and guide the therapeutic agenda over the needs/preferences of an individual"

"If professionals try to take time to implement SMS in a team where others are not doing so THEN they may feel that others do not value the time they spend on the activity and perceive them as 'not pulling their weight'"

#### **Contributing to final refined C-M-O:**

Organisational context (both at a high level and within local teams) (C) influences whether clinicians perceive SMS as something that they can and should integrate into their current role (Mreason) leading to variable application of SMS (O) among trained staff (Mresource).

Although I undertook the majority of the synthesis process myself, several techniques were used to add rigour to the process. This included a member of the supervisory team extracting data from four papers which allowed the working theories to be further developed and refined following discussion. This step was undertaken once I had developed most of my theories, to allow my developing assumptions to be challenged. The developing theories were also discussed at two stakeholder advisory group meetings (once early in the synthesis process and once towards the end to confirm the proposed CMO configurations).

The stakeholder group helped to prioritise which of the developing theories were likely to be critical to pursue and which were likely to be of less immediate relevance. The developing theories were also the main subject of discussion during the key informant interviews described below. The data extraction tables were annotated with any additional ideas generated by the key informant interviews or the advisory group meetings so that data from all sources could be considered when compiling the final summary of results. This triangulation of data sources helped to develop and corroborate the interpretation of the data (Mays and Pope 2000).

During the synthesis phase it was necessary to prioritise certain theories for continued exploration while others were not taken forward. Weiss (2000) suggests evaluators should prioritise the programme theories which are most central to the success of the intervention, appear plausible, fit with the ideas of the key stakeholders and test critical assumptions about the manner in which the intervention works. Ideas about the centrality of certain theories were informed by literature identified during the scoping stage (Lloyd et al. 2013; Kennedy et al. 2014b) together with the application of formal theory which highlighted important implementation chains. The stakeholder advisory group provided input on their ideas about the most important theories. Close attention was paid to the level of evidence contributing to each developing theory and a clear audit trail was maintained to ensure the plausibility of the theories developed. Significant attention was also paid to the context in which the contributing data were

gathered. Some theories were derived with only limited evidence direct from the PNC setting. Transparent reporting about the source data for each theory allows the reader to judge my assumptions about relevance to the PNC setting.

#### 4.2.6 Disseminating the findings

The protocol for the review was registered on PROSPERO (Registration Number CRD42016035596) and subsequently published (Davies et al. 2017) (see Appendix A). A paper based on the results was also accepted for publication (Davies et al. 2018) (see Appendix A).

# 4.3 Key informant interviews

#### 4.3.1 Rationale for using interviews

Three different groups have been recognised to bring differing and useful perspectives which can inform the development of realist programme theory.

Firstly, the subjects of an intervention (in this case trained health professionals) are likely to be able to be able to describe how the intervention worked for them (mechanisms), though they may be less aware of outcome patterns or contextual constraints (Pawson and Tilley 1997). In this synthesis, data about the experiences of intervention subjects came from the included papers. Secondly, programme evaluators are thought to bring awareness of how previous interventions have worked, and have knowledge of existing theories (Pawson and Tilley 1997).

Evaluator perspectives for the synthesis were gained from both the discussion

sections of the included papers and also from members of the advisory group who had been involved in health professional training in the past. Finally, staff involved in intervention delivery are recognised to have a unique position which allows them to have a good understanding of mechanisms, while also gaining insights into contextual influences and outcome patterns (Pawson and Tilley 1997). Only one member of the advisory group had experience of delivering training specifically on the subject of self-management support. As research literature tends to focus on reporting participants' experiences and researchers' interpretations of these, there was a risk that the trainer perspective would not be fully represented.

To address this gap, key informant interviews were planned. The aim was to gain input from individuals with experience of training health professionals using a variety of different approaches, all of which related to supporting self-management in some way. Unlike in other approaches which use interviews, in a realist approach the main subject matter of the interview is the researcher's theory, and the role of the interviewees is to confirm, falsify, expand upon and refine the theories discussed (Pawson and Tilley 1997). Realist interviews are recognised to have differing purposes, depending on the stage of the project at which they take place (Pawson and Tilley 1997; Manzano 2016). The interviews were performed between the second and third advisory group meetings while the process of data searching, extraction, and synthesis was still ongoing. This allowed the working theories to be tested, and for important gaps identified by the key informants to influence the direction of the ongoing review.

#### 4.3.2 Sampling

The aim was to interview individuals from a range of different backgrounds, with experience in delivering different types of training that promote self-management support. It was expected that a small number of interviews (estimated 4-6) would be sufficient as these interviews were expected to be information rich (Emmel 2013) and so have significant 'information power' (Malterud et al. 2016). When participants hold characteristics highly specific to the study aims and are interviewed by an interviewer with significant knowledge of the subject, the quality of the data gathered is likely to be higher, meaning a smaller sample is required (Malterud et al. 2016).

This number of interviews was practical to undertake alongside the synthesis, within the time available. In addition, there was no aim to reach theoretical saturation using the interview data alone, as the interview data would be integrated with the literature contributing to the synthesis. A convenience sampling approach was used initially. Seven participants were invited by email and the five participants who responded were interviewed. Two interviewees were contacts I made during the course of the project, one was recommended by a member of the stakeholder group, one via a direct approach to her employing training provider and one was recommended by another interviewee. Three interviewees were health professionals (specialist nurse, psychologist and occupational therapist) and two were lay trainers on SMS courses. The health professionals interviewed had varying levels of experience in training provision

#### 4.3.3 Preparation of the interview guide

A topic guide was prepared consisting of core questions about training provision, and supplementary prompts which focussed on the related theories in development. The interview guide is provided in Appendix G. The core questions focussed on training content, training process, implementation facilitators and barriers, and perceived training outcomes. Early developing theories informed the prompts. Theories were explored in differing levels of depth across the interviews depending on the level experience of the interviewees and my developing ideas at the time of the interview. Additional follow-up questions were used to gather further details if unanticipated relevant issues are brought up by the participant during the course of the conversation (Manzano 2016).

#### **4.3.4** Ethics

Ethical approval for the key informant interviews was obtained from Cardiff
University School of Medicine Research Ethics Committee (SMREC Ref 16/46) (see
Appendix G). All participants provided verbal consent using a recorded telephone
consent procedure before the interview.

#### 4.3.5 Results

The interviews lasted between 28 and 42 minutes. The interviews were audiorecorded and transcribed verbatim. The transcripts were imported into the qualitative analysis software NVivo 11 (QSR International) for analysis alongside the data extracted for the synthesis.

#### 4.3.6 Using the findings

The interview transcripts were analysed using both a deductive approach (by comparing the data with the theories generated during the literature review) and an inductive approach (searching for new theories arising from the data itself). Data that related to existing programme theories were coded in NVivo to the existing programme theory node. A 'memo' of important insights not relating to existing theories was created and referred back to during the synthesis process, informing the way in which the literature was viewed. The interview findings are presented below, alongside the literature review findings, reflecting the ways in which they were used.

#### 4.4 Included studies

Forty-four original research articles contributed data to the synthesis (Davies et al. 2018) (see Table 4.1). Towards the end of the review process it was recognised that although new papers were being identified, the data which they provided acted to support the theories already described rather than add further refinement. These papers were seen as providing evidence that theoretical saturation of some concepts was beginning to emerge (Pawson 2006). At this stage, supporting data that provided no additional insights were not extracted, but details of the papers

providing support were recorded (see Appendix H). Table 4.1 also shows which of the seven review theories each paper provided evidence for. The theories generated from the review which are described in Section 4.6 are shown in Box 4.2.

Table 4.1 Papers included in the synthesis (from Davies et al. 2018)

First author	Title	Country	Data collection approach	Context in relation to PNCs	Participants	Self-management support intervention (If any)	Contributed to theory number
Annesley (2015)	A qualitative study of policy and action: How the Scottish Government has implemented selfmanagement support for people with long-term conditions	UK	PhD thesis including policy document review, qualitative interviews and observations of meetings	Other LTC/LTCs in general	11 policymakers 20 policy implementers (both groups included managers and clinical staff)	Government-backed policy document on self-management support	1,5,6,7
Barnard (2010)	Strategies used in the pursuit of achievability during goal setting in rehabilitation	UK	Recordings of goal setting meetings for conversation analysis	Includes PNCs	6 patients and the team of HCPs involved in their treatment	Goal setting information pack for patients, keyworker meetings during inpatient stay	5,6
Boscart (2009)	A communication intervention for nursing staff in chronic care	Canada	Audio-recordings of consultations before and after a nurse training intervention	Other LTC/LTCs in general	27 patients and 24 nurses pre- intervention; 20 patients and 21 nurses post- intervention	3-hour nurse training based on solution focussed brief therapy.	3
Bright (2012)	Implementing a client- centred approach in rehabilitation: an autoethnography	New Zealand	Co-autoethnography	Other neurological condition	3 clinical researchers	Goal setting intervention as part of an RCT	5,6

Conneeley (2004)	Interdisciplinary collaborative goal planning in a post-acute neurological setting: A qualitative study	UK	Qualitative interviews	Includes PNCs	18 patients and their 18 'significant others'	Goal planning process co- ordinated by a keyworker	6,7
Connolly (2014)	The Impact of the SAGE & THYME Foundation Level Workshop on Factors Influencing Communication Skills in Health Care ProfessionalsSetting, Ask, Gather, Empathy Talk, Help, You, Me, End	UK	Pre- and post- training questionnaires, sub- groups had additional follow-up questionnaires or video recording o consultations	Not specified	173 HCPs attending training (not all participants completed all assessments)	3 hours communication skills training for HCPs in using a structured approach	2,6
Cope (2012)	Perceptions of Chronic Disease Self-Management in rural primary health care and implications for routine clinical practice: a mixed methods study	Australia	Online survey Qualitative interviews	Other LTC/LTCs in general	34 nurses, 30 other HCPs completed survey 7 nurses interviewed	n/a	2,3,6,7
Daley (2015)	Qualitative evaluation of adherence therapy in Parkinson's disease: A multidirectional model	UK	Qualitative interviews	PNC only	10 patients, 6 spouses or carers.	7-week programme of adherence therapy as part of a clinical trial	7
Deane (2003)	A Delphi survey of best practice occupational therapy for Parkinson's disease in the United Kingdom	UK	Delphi survey	PNC only	150 occupational therapists (completing both rounds)	n/a	2,6,7
Duggan (2005)	Reflection as a means to foster client-centred practice	Canada	Seven discussion meetings using an action research approach.	Not specified	4 Occupational therapists	n/a	3

Frich (2014)	Participants', caregivers', and professionals' experiences with a group- based rehabilitation program for Huntington's disease: a qualitative study	Norway	Qualitative interviews and focus groups	PNC Only	11 patients 9 carers 15 HCPs	Residential rehabilitation (3 stays over 1 year)	7
Gregory (2012)	Improving sleep management in people with Parkinson's	UK	Post training evaluation questionnaires and semi- structured interviews	PNC only	38 HCPs (patient questionnaires and interviews also undertaken – numbers not stated)	Three-day staff training course on sleep management	2
Holliday (2007)	Goal setting in neurological rehabilitation: Patients' perspectives	UK	Focus group study	Includes PNCs	28 patients	Two different approaches to goal setting (participants one of the two different approaches)	6
Holloway (2006)	Traversing the network: a user-led Care Pathway approach to the management of Parkinson's disease in the community	UK	Qualitative interviews	PNC only	22 patients 1 neurologist 1 specialist nurse	Resources for patients: Information pack, problems/needs forms, clinic summaries and service record sheets	1,6,7
Hunt (2015)	Elucidating a Goal-Setting Continuum in Brain Injury Rehabilitation	Canada	Qualitative interviews	Other neurological condition	13 Occupational therapists	Routine goal setting practices	5,6,7

Hutchings (1999)	Partnership in education: An example of a Client and Educator Collaboration	Canada	Description of educational intervention	PNC only	HCPs (numbers not specified)	'In-service' training session on implications of MS, co- delivered by a person with MS	4
Jones (2013a)	Getting the Balance between Encouragement and Taking Over' — Reflections on Using a New Stroke Self-Management Programme	UK	Analysis of HCP case reflections completed post-training	Other neurological condition	60 HCPs	Two-day staff training in 'Bridges' stroke self- management programme	2,6,7
Kennedy (2005)	Training professionals to engage with and promote self-management	UK	Post-training questionnaires  Qualitative interviews (as part of a larger RCT)	Other LTC/LTCs in general	24 staff trained and completed questionnaires Interviews: 11 consultants 28 patients	Part of an RCT. Two hours of training including demonstration video, role-play and feedback. Use of patient information guidebooks and written self-management plans.	3
Kersten (2015)	Bridging the goal intention- action gap in rehabilitation: a study of if-then implementation intentions in neurorehabilitation	New Zealand	Qualitative interviews and focus groups, questionnaires, functional performance measures.	Includes PNC	10 intervention and 10 control patients (not every patient completed every measure), 4 study physiotherapists.	Pilot study – goal setting only (control) compared to goal setting augmented with 'if-then' plans	2,4
Kopke (2012)	Implementation of a patient education program on multiple sclerosis relapse management	Germany	Questionnaires for trained HCPs and patients	PNC only	31 HCPs 261 patients	One day of training for health professionals who went on to provide a 4hr educational session to patients	1

Kulnik (2017)	Implementing an interprofessional model of self-management support across a community workforce: A mixedmethods evaluation study	UK	Training participant questionnaires, written case reflections and group discussions. Patient questionnaires and interviews.	Other LTC/LTCs in general	92 staff attended training (not all completed all measures) 10 patients	'Bridges' self-management training for staff – 3x 3- hour face to face sessions	3,5,6,7
Lake (2010)	Seeking the views of health professionals on translating chronic disease self-management models into practice	Australia	Qualitative interviews	Other LTC/LTCs in general	31 HCPs	n/a	7
McPherson (2009)	A pilot study of self- regulation informed goal setting in people with traumatic brain injury	New Zealand	Qualitative interviews, focus groups and observations. Questionnaires relating to goal attainment for patients.	Other neurological condition	22 intervention group patients and 12 usual care patients. 11 clinicians	Participating staff randomised to provide goal management training, identity orientated training or usual care. Staff received 3 training sessions about study and intervention provision.	1,3,6
Mikkonen (2012)	Health care professionals' views about supporting patients' self-management	Finland	Analysis of written assignments submitted as part of an online education course	Not stated	14 HCPs	One component of a larger online study module (400hrs) for HCPs related specifically to patient education and counselling	2,3
Mudge (2014)	Are physiotherapists comfortable with personcentred practice? An autoethnographic insight	New Zealand	Co-autoethnography	Other neurological condition	2 physiotherapists	2-day HCP training course in activity coaching	2,6

Mulligan (2013)	Combining self-help and professional help to minimize barriers to physical activity in persons with multiple sclerosis: a trial of the "Blue Prescription" approach in New Zealand	New Zealand	Qualitative interviews, clinical notes review, advisory group meeting notes	PNC only	27 patients 2 physiotherapists	Feasibility trial of collaborative approach to promote community physical activity based on motivational interviewing. Therapist training not described.	2,3,5,7
Newbronner (2013)	Sustaining and spreading self-management support Lessons from Co-creating Health phase 2	UK	Qualitative interviews, discussion groups, workshops, surveys, review of documents.	Other LTC/LTCs in general	7 NHS Trusts involved in earlier self-management support initiative. Evaluation at both trust and programme level.	Practitioner Development Programme for clinicians (varied from basic 2-hour training to 1 ½ days course) Self-management programme for patients (5-7 weeks) – both adapted to local requirements. Centrally led service improvement programme.	2,5,6
Norris (2014)	From dictatorship to a reluctant democracy: stroke therapists talking about selfmanagement	UK	Qualitative interviews	Other neurological condition	7 Physiotherapists 4 Occupational Therapists	Staff trained in professionally facilitated self-management approach specific for stroke patients	7
Peng (2014)	Self-management goal setting: Identifying the practice patterns of community based physical therapists	Canada	Retrospective medical records review	Includes PNCs	296 care home clients	Staff training in a structured goal setting approach with an emphasis on selfmanagement (no further details)	5,6,7

Pill (1999)	Can nurses learn to let go? Issues arising from an intervention designed to improve patients' involvement in their own care	UK	Qualitative interviews Observations	Other LTC/LTCs in general	18 practice nurses	Staff received at least 3 hours of training in use of illustrated agenda setting chart, Training included discussion, demonstration and role-play	2,6
Portillo (2009)	Evaluation of a nurse-led social rehabilitation programme for neurological patients and carers: an action research study	Spain	Qualitative interviews, observations, questionnaires. Action research approach.	Includes PNCs	27 nurses 18 patients and 19 relatives (plus 17 patients and 16 relatives in control group)	4 education sessions for nurses on social care and social rehabilitation. Computerised checklist for use in daily care. Patient education materials.	2,4
Robinson (2008)	Transforming clinical practice amongst community nurses: mentoring for COPD patient self-management	Australia	Recorded monthly group feedback meetings. Action research approach.	Other LTC/LTCs in general	21 community health nurses	Staff workshop including training on motivational interviewing, telephone coaching and teambuilding.	3,4
Roy (2011)	Partnering in primary care in New Zealand: clients' and nurses' experience of the Flinders Program™ in the management of long-term conditions	New Zealand	Qualitative interviews Focus groups Web-based survey	Other LTC/LTCs in general	Interviews = 11 patients, 4 nurses Focus groups= 13 nurses Web-survey= 355 trained staff	HCP training in Flinders Program™ of self- management support (including structured assessment, collaborative problem identification, goal setting and care plan development)	5
Satink (2015)	Self-management: challenges for allied healthcare professionals in stroke rehabilitation - a focus group study	Netherlands	Focus groups	Other neurological condition	20 occupational therapists 4 physiotherapists 3 speech therapists	n/a	2,3,6,7

Sixsmith	Implementing the National	UK	Qualitative interviews	Includes	50 patients	National Service	5
(2014)	Service Framework for long			PNCs	15 HCPs	Framework for long-term	
	term neurological				15 social care	neurological conditions	
	conditions: service user and				professionals		
	service provider experiences				15 3 <sup>rd</sup> sector		
					employees		
Smith (2013)	Healthcare provider beliefs	New	Qualitative interviews,	PNC only	6 physiotherapists	N/A	2,5,7
	about exercise and fatigue	Zealand	focus groups		3 Occupational		
	in people with multiple				therapists		
	sclerosis				3 neurologists		
6.1	D ( : 1 1 :		-	0.1	3 charity staff	21/2	467
Solvang	Professional roles in	Norway	Focus groups	Other	12 Physiotherapists	N/A	4,6,7
(2016)	physiotherapy practice:			LTC/LTCs in			
	Educating for self-			general			
	management, relational matching, and coaching for						
	everyday life						
Speelman	Evaluation of	Netherlands	Qualitative interviews,	PNC only	116	Part of an RCT. 3	2
(2014)	implementation of the	Netherlands	questionnaires	l ite omy	physiotherapists in	educational sessions for	_
()	ParkFit program: A multi-		4		trial, 113	study staff including	
	faceted intervention aimed				completed	behaviour change theory,	
	to promote physical activity				interviews. 108	coaching strategies, and	
	in patients with Parkinson's				completed	goal setting. Use of activity	
	Disease				questionnaire.	monitors, workbooks,	
					225 patients	logbooks and contracts.	
					completed	Refresher session at 1	
					questionnaire.	year.	

Stretton (2013)	Activity coaching to improve walking is liked by rehabilitation patients but physiotherapists have concerns: a qualitative study	New Zealand	Qualitative interviews	Other neurological condition	5 physiotherapists 5 patients	1 session of activity coaching with two telephone follow-ups. Coaching delivered by trained research physiotherapist and observed by usual treating physiotherapists who were interviewed.	3,4,7
Van De Weyer (2010)	Goal setting in neurological rehabilitation: staff perspectives	UK	Focus groups	Includes PNCs	4 Occupational therapists (+1 student) 4 physiotherapists 3 nurses 2 Speech Therapists 1 Doctor	Staff involved in clinical trial with 2 different goal setting approaches. Increased participation approach included use of keyworker meetings and use of a booklet.	2,3,6,7
Wallace (2012)	Co-creating health: Evaluation of the first phase	UK	Qualitative interviews Observations Surveys Health outcome data Document analysis	Other LTC/LTCs in general	Evaluation across 8 participating NHS sites. 465 clinicians completed training.	Advanced Development Programme for Clinicians (3x 4-hour group workshops in SMS techniques) 1-day service improvement workshop Alongside patient Self- management Programme (7x 3hour group sessions)	2,5,6
Wilson (2009)	Effectiveness of neurodisability simulation training for NHS staff working in brain injury rehabilitation	UK	Questionnaires	Other neurological condition	78 HCPs	3 hours neurodisability simulation training, made up of seven different 'stations' simulating different problems.	4

Wilson (2010)	Self-management and self- efficacy across the multiple sclerosis journey	UK	PhD thesis including focus groups and interviews with HCPS and a longitudinal study of patients and carers	PNC only	Focus group with 9 HCPs Supplementary HCP interviews (number unconfirmed) 6 patients 6 carers	n/a	3,5,6,7
Yank (2013)	Web-based self- management support training for health professionals: a pilot study	USA	Focus groups Questionnaires	Other LTC/LTCs in general	57 primary care HCPs received training. 37 completed survey 30 participated in focus groups.	4 one-hour webinars on the topic of self- management delivered weekly with homework exercises in between	2,4,6

Abbreviations: HCPs = healthcare professionals, LTCs= long-term conditions, PNCs= progressive neurological conditions, RCT= randomised controlled trial, SMS= self-management support

# Box 4.2 Seven theories generated from the review

Review Theory 1 – Evidence

Review Theory 2 – Knowledge, skills, confidence and self-efficacy

Review Theory 3 – Reflection

Review Theory 4 – Empathy

Review Theory 5 – Team and organisational support

Review Theory 6 – Redefining professional role

Review Theory 7 – Picking the right patient

# 4.5 The role of existing formal theory

# 4.5.1 Why apply formal theory?

The final step of the realist review process involves trying to make sense of the pattern of findings, most commonly by using existing formal theories (Wong et al. 2013b). Existing theories may be explanatory theories (explaining why behaviours occur) or change theories (emphasising how change happens), or may fulfil both purposes (Glanz and Bishop 2010). These theories are 'middle-range' in nature (Merton 1967) and so operate at a level of abstraction above the theories developed in the review.

#### 4.5.2 How formal theories were identified

A number of formal theories already known to myself and my supervisors were thought to be potentially relevant to the review (for example Diffusion of Innovations and Normalisation Process Theory) (Rogers 2003; May and Finch 2009). Concerns have been raised that drawing on the expertise of the review team may lead to a disproportionate reliance on theories already known to the team (Booth and Carroll 2015). Other relevant theories were identified through citations by the included studies. Using only the theories described in included studies relies on the authors having both identified and reported on potential connections between theory and practice (Booth and Carroll 2015). To address these concerns about methods of theory identification a further targeted search for theories was undertaken using Google Scholar (see Box 4.3). Google Scholar is particularly suited to searching for theory because it searches within full texts where available, rather

than being confined to keyword searching within titles and abstracts (Booth and Carroll 2015), thus increasing the likelihood of identifying theory which often may not be mentioned within titles and abstracts.

Box 4.3 Google Scholar Search run 16/8/16

("logic model" OR "theory of change" OR "theory of action" OR "outcomes chain" OR "program \* theory" OR "program \* logic" OR "logical framework") AND "self management support" AND ("nurses" OR "therapists" OR "physicians" OR "doctors" OR "clinicians")

The theories considered in detail as potentially relevant to the review are detailed in Table 4.2.

Table 4.2 Relevant formal theories considered (with sources)

Theory	Already	Cited by	Google	Reading
	known to	papers	Scholar	around
	supervisory	included	search for	the
	team		theory	subject
COM-B Model/ Behaviour change wheel (Michie et al. 2011)	Υ			
Self-efficacy (Bandura 1977)	Υ	Υ		
Social learning theory (Bandura and Walters 1977)		Υ		
Transtheoretical model of change (Prochaska and DiClemente 1983)	Υ	Υ		
Adult learning theory (Knowles et al. 2005)	Υ	Υ		
Normalisation Process Theory (May and Finch 2009)	Υ	Υ		
Diffusion of Innovations (Rogers 2003)	Υ		Υ	
Transformative learning theory (Mezirow 2000)	Υ		Υ	
PARiHS framework (Kitson et al. 2008)	Υ		Υ	Υ
Implementation of Innovations framework (Chaudoir et al. 2013)			Υ	
Technology Acceptance Model (Venkatesh and Bala 2008)				Υ

# 4.5.3 Formal theories applied

Three of the identified theories (Normalisation Process Theory, Transformative learning theory and Technology Acceptance Model 3) drawn from different domains (implementation science, adult education and information technology) were identified as being particularly relevant to the review, with each providing a unique contribution (Glanz and Bishop 2010). These formal theories were chosen on the basis of their close fit with my developing CMOs. The theories chosen all provided a level of detail about their constructs that helped to explain patterns and relationships within the developing CMOs. Although many of the other theories might have provided additional insights, limiting the analysis to considering three in detail allowed focus and clarity of thinking to be maintained.

#### 4.5.3.1 Normalisation Process Theory

Normalisation process theory (NPT) focusses on how work is socially organised, and how new practices become embedded and then sustained within a social context (May and Finch 2009). In keeping with realist thinking it recognises the context-dependent and emergent nature of the normalisation process, and describes normalisation as occurring via four generative mechanisms: coherence, cognitive participation, collective action and reflexive monitoring (May and Finch 2009). Within each of these mechanisms, four sub-components are described which relate to both the immediate work and the organising work involved in the process of normalisation (see Box 4.4). Flexible application of the theory is advocated, including utilising NPT in conjunction with other theories, and choosing either to

focus at the level of the four main generative mechanisms or on the individual subcomponents as required (May et al. 2018).

Box 4.4 – Constructs of Normalization Process Theory (adapted from May and Finch 2009; May et al. 2015)

**Coherence** relates to the process of making sense of the work involved in implementing a new intervention. It comprises the processes of differentiation, communal specification, individual specification and internalisation.

**Cognitive Participation** relates to the process of working out who will be involved in the new work required. It comprises the processes of initiation, enrolment, legitimation and activation.

**Collective Action** relates to understanding the process through which the new intervention is enacted, and the possible constraints on this process. It comprises the processes interactional workability, relational integration, skill set workability and contextual integration.

**Reflexive Monitoring** refers to how people make judgments about the new intervention. It comprises the processes of systematisation, communal appraisal, individual appraisal and reconfiguration.

This theory has been applied by researchers aiming to understand how health professionals implement new approaches following training (Lloyd et al. 2013), including in studies relating specifically to self-management support (Jones and Bailey 2013; Kennedy et al. 2014b). The implementation focus of NPT meant it was very useful in considering factors influencing the transfer of training into practice, but less helpful in exploring the process of training itself.

### 4.5.3.2 Transformative Learning Theory

Transformative learning theory is a theory of adult learning described by Mezirow (1997), which is centred on the idea that the goal of adult education is to assist the learner to become a more independent thinker through a process of critical reflection on their own values, meanings and purposes (Davies et al. 2018). This type of learning is noted to occur through a process of discussion with others, which facilitates improved understanding of the meaning of experiences (Mezirow 2000). Transformative learning theory focusses on how learning can challenge what it calls 'frames of reference'. These frames of reference are described as the sets of fixed expectations we all hold about how the world works (Mezirow 2003). These frames of reference act as largely unnoticed and taken-for granted triggers of habitual behaviour, covering areas such as moral and ethical norms, cultural biases, stereotyped attitudes and occupational habits of mind (Mezirow 2003). They are usually developed from the uncritical absorption of values and beliefs (Cranton and Carusetta 2004). Individuals' expectations about the world often mirror those held by the people around them, meaning their assumptions continue to be confirmed by events (Apte 2009). Transformative learning is said to occur through a process of deliberate, critical reflection on these frames of reference, through an exploration of the assumptions on which they are based (Mezirow 1997).

The transformative learning process is described in ten stages (see Box 4.5) moved through by a learner who initially faces a 'disorientating dilemma' which challenges the status quo. This theory fitted well with some of the higher-level ideas generated during the synthesis and provided a useful overview of the process of a shift in practitioners' perspectives about SMS.

### Box 4.5 Mezirow's (2000) stages of transformative learning

- 1- A disorientating dilemma
- 2- Self-examination triggers negative feelings (guilt, anger, fear)
- 3- A critical assessment of existing assumptions
- 4- Realising that others are also dissatisfied
- 5- Exploring options for new roles and actions
- 6- Planning the course of action
- 7- Acquiring the knowledge and skills required
- 8- Trying out a new role
- 9- Building confidence and competence in new role
- 10-Integration of the newly developed perspective

# 4.5.3.3 Technology Acceptance Model 3.

Technology Acceptance Model 3 (TAM3) was developed to describe the determinants of use of new technology (information technology specifically) (Venkatesh and Bala 2008). The TAM3 developed constructs from the Theory of Planned Behaviour, which suggests that people are more likely to carry out a certain behaviour if they believe that it will lead to a valued outcome, that others would think that they should do it, and that they have the required resources and opportunities for it to be within their control (Ajzen 1991). The TAM3 groups these beliefs under the headings of perceived usefulness and perceived ease of use which act to determine behavioural intention to use a new technology. TAM3 defines a range of determinants of perceived ease of use and perceived usefulness. Although the model was developed with a specific focus on the implementation of technological innovations, it has been recognised as making an important contribution to the evaluation of changes occurring at an individual level (May 2013). Some of the constructs are not transferrable to other settings (such as computer playfulness), however, instinctively this model appeared to fit well with many of the findings in the SMS literature as it provided a way to conceptualise the

interplay often described, between how useful staff felt SMS might be and how practical it was to provide SMS.

### 4.5.4 How the formal theories were applied

Both NPT and TAM3 are depicted in diagram form (Venkatesh and Bala 2008; May and Finch 2009). I used these diagrams to map the developing programme theories on to the formal theories. This provided a useful visual way to assess the 'fit' between the theories. In particular, mapping my own theories to the formal theories highlighted gaps in my review theories, where no CMO configuration related to an important construct within a theoretical model.

The constructs relating to perceived ease of use in the TAM3 highlighted the importance of self-efficacy around performing a new task. Early in the synthesis no theory around specific skills and self-efficacy had been developed, and applying this model prompted me to revisit the included papers to look specifically for data relating to this construct. The theory diagrams also provided a useful way to start thinking about how my programme theories might be linked together, and how several theories might need to be in operation simultaneously in order to produce the final desired outcomes. The mapping of the programme theories onto the theory diagrams also generated ideas about where 'ripple effects' might be in play (whereby the outcome of one CMO configuration becomes the context of the next CMO configuration) (Jagosh et al. 2015).

Transformative learning theory fitted well with the emerging idea that providing SMS challenged preconceptions about professional role and required a paradigm

shift. It provided a useful higher-level overview of the process of learning, which informed the interpretation of which CMOs were likely to be significant at which stage of the learning process.

# 4.6 Theories generated from the review

Seven theories were developed and refined during the synthesis and are described in turn below. Each section starts with a description of a theory generated during the review process, described using a context-mechanism outcome configuration. The evidence from the literature used to develop this theory is then summarised, supported by extracts from the papers to demonstrate the evidence on which inferences have been made (Pawson 2006). Important elements of context are labelled as (C), outcomes are labelled as (O), and mechanisms are broken down into two parts (Mresource): the resources provided by the intervention and (Mreason): the reasoning triggered by the resource (Dalkin et al. 2015). My interpretation of the evidence from the literature, and how this was shaped by the key informant interviews, advisory group meetings, and existing substantive theories is then discussed. These theories were first published in a paper outlining the results of the synthesis, extracts of which are included in the sections below (Davies et al. 2018).

### 4.6.1 Review Theory 1 - Evidence

# 4.6.1.1 *Overall theory*

Training provides evidence for the benefits of SMS provision (Mresource). Whether the evidence is deemed as sufficient to make SMS appear worthwhile (Mreason) depends on the type of evidence staff value most and their work context (C). If the evidence is judged as insufficient (Mreason) then SMS provision is not prioritised (O) (Davies et al. 2018).

#### 4.6.1.2 *Evidence from the literature*

Four articles provided evidence for this theory (see Table 4.1). A lack of convincing evidence for adopting the new approach was a recognised barrier to staff changing their practice. When evidence was judged as insufficient (Mreason), new practices were not seen as worthwhile adopting (O), especially if they ran counter to current established routines (Davies et al. 2018). Professional background (C) appeared to influence the type of evidence that was valued, with medical staff in particular emphasising the need for research evidence.

"I think we need to be very careful in that some of the clinical community historically looked at randomised controlled trials at that kind of evidence base. I think we're looking at much more action research and lived experience and sharing what works at a personal level. So while we're keen to help support and implement evidence based practice, it doesn't have to be based on randomised controlled trials." (Annesley 2015, p.240)

A lack of evidence could also become more important when staff tried to provide SMS in a setting where they had multiple other competing demands (C).

"Whilst they reported interest and remained involved, practically it was very difficult for staff to prioritise a focus on the intervention given competing

demands and current lack of evidence about its effectiveness" (McPherson et al. 2009, p.306)

In this setting the lack of evidence led staff to feel that providing SMS could not be justified (Mreason) and other tasks had to be prioritised (O) (Davies et al. 2018).

# 4.6.1.3 Interpreting the evidence

While some trainers had experienced training participants' emphasis on the evidence base, others felt that it was less a less significant influence.

"So it was always really quite difficult because that was always what they really wanted "Show us the evidence!" "Where is the evidence?" that was the scream that used to come." (Interviewee 1)

"I think they're interested when you bring it [evidence] to their attention but I don't, I think a lot of the time it's something that's not been considered." (Interviewee 2)

My stakeholder group suggested that the relative lack of data in the literature relating to the importance of evidence might be related to an assumption that the importance of evidence is accepted and does not need to be explained or emphasised in reporting. The importance placed on evidence appears to be context specific. It may be influenced by professional norms in relation to what is seen as gold standard evidence. Evidence may also be more heavily relied upon when there is a need to justify a change in the way limited resources are used. The importance of being convinced of the benefit of a new intervention is emphasised in normalisation process theory under the mechanism of coherence (sense making work about the value of a new intervention). Due to the limited data available in the literature exploring the role of evidence in training this theory requires further testing and refinement.

# 4.6.2 Review Theory 2 - Knowledge, skills, confidence and self-efficacy

### 4.6.2.1 *Overall Theory*

Providing specific tools and approaches to SMS (Mresource) to clinicians who previously lacked knowledge about how to provide SMS (C) improves understanding of how to operationalise SMS (Mreason) which leads to an increased confidence in ability to provide support (O). However, this confidence depends on the complexity of the support needs (C) and needs to be maintained through access to ongoing clinician support (C) as if this is not available, confidence is likely to decrease (Mreason) resulting in SMS not being provided (O) (Davies et al. 2018).

### 4.6.2.2 Evidence from the literature

Eighteen articles contributed data to this theory (see Table 4.1). Many of the included studies made passing mention of increases in knowledge, skills and confidence but this process often seemed to be assumed as an obvious routine consequence of training attendance and was often not explored in depth. The need for specialist knowledge about PNCs was emphasised as it could inform the appropriate tailoring of self-management support to address symptom-specific barriers (M) (Davies et al. 2018) (e.g. strategies to avoid over-heating while exercising for people with multiple sclerosis (Mulligan et al. 2013). However, professionals reported a lack of focus on certain symptoms (notably 'invisible' symptoms and psycho-social issues) in their initial training left them under-skilled to address the challenges experienced by their patients (C) (Deane et al. 2003; Gregory et al. 2012; Smith et al. 2013). Lack of practice guidelines and outcome

measures tailored specifically to PNCs (Deane et al. 2003; Smith et al. 2013) were also seen as barriers (Davies et al. 2018).

The provision of practical tools which could be used in the workplace (Mresource) was associated with an increased confidence (O), because it made it easier for staff to see how they could operationalise SMS (Mreason). The literature also suggested that the approaches advocated in training should be simple and relevant to the context in which they would be used (Portillo et al. 2009) (Mresource) as then staff appeared more likely to become confident in applying these skills in practice (O) (Davies et al. 2018).

"It's given me a lot more confidence in things that I have been thinking about but given me a lot more organized approach and tools" (Yank et al. 2013, p.33)

Increased knowledge was a particularly important outcome for those staff who prior to training had little understanding of how to support self-management in practice (C).

"What I have found really useful is that the (self-management) packages that are developed for the client population are probably just as helpful to the professional population because we assume a knowledge base around self-management that is not there." (Lake and Staiger 2010, p.64)

There was also evidence indicating that staff attending training who already felt both confident in SMS and engaged with the concept actually gained most from training (Wallace et al. 2012).

Patient contextual factors sometimes acted as barriers to applying new knowledge and skills in practice.

"Only 1% (1/113) of therapists believed that their knowledge of behavioral change was not sufficient.... Main reasons for not succeeding were: patients'

co-morbidity, cognitive disturbances, patients' lack of motivation, and increased disease severity" (Speelman et al. 2014, p.137)

In the context of a challenging caseload (C), being able to discuss difficulties with colleagues during mentoring clinical supervision or refresher training (Mresource)

colleagues during mentoring, clinical supervision or refresher training (Mresource) means that potential solutions can be generated and confidence maintained (Mreason), resulting in the ongoing provision of SMS (O) (Cope 2012; Newbronner et al. 2013).

# 4.6.2.3 *Interpreting the evidence*

While building knowledge, skills and confidence are accepted to be core training outcomes there was relatively limited exploration of how these were achieved. The stakeholder group felt this was more likely to relate to the way that studies are reported than any problem with the literature search strategy used. The evidence seems to indicate that while increasing knowledge and confidence in SMS is a necessary component of training, it is not alone sufficient to ensure ongoing SMS provision in practice. Confidence appeared to be fairly fragile, changeable over time, and influenced by work setting. It may be that while training helps staff to feel confident in dealing with straightforward situations, ongoing support is needed to build self-efficacy for dealing with more complex scenarios. The important role of self-efficacy for a new skill is highlighted in Technology Acceptance Model 3. The mechanisms by which training activities work to build this self-efficacy, and how it is influenced by context would benefit from further exploration.

# 4.6.3 Review Theory 3- Reflection

# 4.6.3.1 *Overall theory*

Training frequently provides opportunities for staff to reflect on their current practice in relation to SMS (Mresource). Influenced by pre-existing ideas about SMS (C) this reflective process may act to validate current practice (Mreason) or demonstrate a need for practice change (Mreason – leading to O). Characteristics of the training (Mresource) influence the likelihood of facilitating helpful reflection, and in some cases, training is insufficient to overcome pre-existing ideas about SMS (C) and meaningful reflection (Mreason) and practice change (O) does not occur (Davies et al. 2018).

# 4.6.3.2 Evidence from the literature

Thirteen articles contributed data to this theory (See Table 4.1). Facilitating reflection on current practice was frequently described as a key part of training in SMS (Mresource). Training frequently encouraged staff to reflect on their current practice, and to consider how this fitted with the way in which they saw their professional role. This ability to be reflective was seen an essential attribute for participants (C):

"Good, patient-centred education and counselling presumes reflection; the professional has to critically assess her own values, attitudes, and beliefs." (Mikkonen and Hynynen 2012, p.402)

Reflection in a group setting was facilitated when the group trusted each other, felt confident that confidentiality would be maintained and felt able to challenge each other (Duggan 2005). Training with staff from different professional backgrounds

(Mresource) could prompt critical reflection on personal perspectives (Kulnik et al. 2017). Sometimes the reflective process was described as highly structured but it could also be an 'invisible' reaction to the resources presented.

For staff who were already committed to the idea of SMS (C) then exploring the concept further in training could act as validation (Mreason) of their preferred approach and a sense of encouragement and motivation to continue their current practice (O) (Davies et al. 2018).

"Actually I use a client-centred, client-expert perspective in my work. I think the process has empowered me to use/recognise this approach" (Kulnik et al. 2017, p.79)

For some staff, the training led to a realisation that their current practice did not really fit with their values about a patient-centred approach (Mreason), and this acted as motivation to adopt a different approach(O) (Boscart 2009; McPherson et al. 2009). One study provided an example of how they facilitated this process:

"A critical part of the intervention consisted of confronting staff with their own transcripts of interacting with patients. Most expressed shock when shown parts of the transcribed interaction. They had not expected to see any negativity in their interactions, and became acutely conscious of the importance of positive communication." (Boscart 2009, p.1830)

In this situation training acted to highlight an unidentified learning need. In other settings, it was highlighted that voluntary attendance (which I interpreted as potentially being associated with a recognised learning need) (C), might be important to ensure that participants were willing to actively participate in critical reflection (Duggan 2005). Critical reflection (Mreason) was inhibited by the practitioner's view that they were already providing adequate SMS (C) (Davies et al. 2018), resulting in a belief that no change in practice was required (O) (Kennedy et

al. 2005). One study reported the unintended outcome of offending staff (O) who felt that they already practiced in a patient-centred manner and did not need to be reminded to do this (Kennedy et al. 2005).

Reflection was not a one-off event at the training stage. There was also a continuous ongoing process of reflection when staff attempted to apply SMS in the workplace and evaluated the results. During implementation, reflection provides evidence of success (Mresource) which can help staff become convinced of benefits (Mreason) and motivated to continue (O) (Mulligan et al. 2013). The contextual factors that enabled this process were the same as those explored in the theory about skills and confidence (Davies et al. 2018) including clinical supervision and the opportunity for discussion with peers (C) (Robinson et al. 2008; Van De Weyer et al. 2010).

#### 4.6.3.3 *Interpreting the evidence*

Trainers recognised the key role of reflection and could give examples of triggering new insights:

"we ask [the trainees] the question the second time again, 'actually maybe I wasn't doing as well, maybe I wasn't asking the right questions' so they're reflecting, and I think that's really good." (Interviewee 4)

They agreed that various factors that could create (or inhibit the creation of) the right environment for reflection with group size and trainer credibility seen as particularly important. Their experiences about mandated versus voluntary training also fitted with the literature findings.

"When they were made to come on it, 'you need to do this', that's when we got the resistance. So people who had chosen to do the training, were far more open." (Interviewee 1)

The stakeholder group agreed that there was likely to be an interaction between training quality and trainee characteristics, and that higher quality more structured training might be needed for less motivated trainees to trigger successful critical reflection. Critical reflection is a key process within transformative learning theory and is also an element of the coherence, collective action and reflexive monitoring stages of normalisation process theory. Although the literature highlighted important practitioner level contextual influences, more exploration of the wider contextual influences and measurable outcomes resulting from critical reflection would be useful to broaden my understanding of its role.

# 4.6.4 Review Theory 4 - Empathy

# 4.6.4.1 *Overall theory*

Both training activities and applying SMS principles in practice (Mresource) can generate new empathy for patients based on a different perspective on their lives (Mreason). This new perspective can alter professionals' expectations of their patients (O). The development of empathy relies on reflective skills which may be facilitated or inhibited by personal, organisational and training characteristics (C) (Davies et al. 2018).

# 4.6.4.2 Evidence from the literature

Eight articles provided evidence for this theory (see Table 4.1). The importance of the role of empathy was recognised both explicitly and implicitly in many of the papers reviewed. Some training interventions specifically focussed on developing empathy by giving staff the opportunity to experience similar challenges to those their patients face (Mresource). Tactics described included asking health professionals to apply self-management techniques to their own lives (Yank et al. 2013), using lay trainers to highlight the patient experience (Hutchings 1999) and running disability simulation activities (Wilson et al. 2009). These experiences helped staff to think about how they could adapt their clinical practice to take into account the challenges their patients were facing (Mreason) and they were able to apply what they had learned from their personal experiences, resulting in a changed approach to interactions and different expectations of their patients (O) (Davies et al. 2018).

There was some indication that this type of training might be most impactful if it provided a new experience staff had not previously encountered themselves (C) (Wilson et al. 2009; Yank et al. 2013). There was little clear evidence about contextual factors that inhibited the development of empathy, although, as this often required a reflective process, it may be that the barriers to critical reflection already identified are relevant here.

During implementation there were examples of the training continuing to increase empathy when staff went out and started applying the training in practice.

Adopting a self-management approach tended to encourage professionals to

dedicate more time and effort to understanding each patient's unique context (Mresource), leading to a better understanding of the complexity of people's lives (Davies et al. 2018). This often resulted in a shift in perspective (Mreason) which changed staff's expectations of their patients (O).

"The approach also facilitated them to think beyond adherence. 'It's not just about adherence and about motivation to be able to do exercise, it's about. It's about other things. It's life complexities.'" (Kersten et al. 2015, p.1077)

Team support could facilitate the reflective process which seemed to increase empathy during the implementation phase.

"Having the opportunity to meet together and consider their mentoring role facilitated the development of new insights into patients' perspectives and into changing their own positions of perceived relative futility associated with their interactions with these patients" (Robinson et al. 2008, p.374)

#### 4.6.4.3 *Interpreting the evidence*

The trainers interviewed agreed that it was important that training helped to encourage participants to think more about their patients' experiences of living with their condition. Some training specifically included lay trainers to provide this perspective.

"it's actually about bringing that reality piece in because, understanding what it is like for the individual because you know as I say compliance is great but you know there's different reasons why we don't comply as patients, it's not that we're actively naughty, (Laughs) it's just that, there's just so much else that goes on in our lives" (Interviewee 4)

The stakeholder group agreed with the findings about team support, emphasising that team meetings had an important role in developing and maintaining a shared value base around the concept and purpose of SMS. Developing empathy is likely

to be one way that participants start to understand the benefits of using an alternative approach (Normalisation process theory – coherence). Developing collective empathy through team meetings may then influence perceived usefulness via changes in subjective norms and image (Technology Acceptance Model 3). Evidence from the literature about contextual influences on empathy development was relatively limited, and this requires further exploration.

# 4.6.5 Review Theory 5 - Team and organisational support

# 4.6.5.1 *Overall theory*

Organisational context (both at a high level and within local teams) (C) influences whether clinicians perceive SMS as something that they can and should integrate into their current role (Mreason) leading to variable application of SMS (O) among trained staff (Mresource) (Davies et al. 2018).

# 4.6.5.2 *Evidence from the literature*

Thirteen articles contributed evidence to this theory (see Table 4.1). Following training in SMS (Mresource) some professionals still felt unable to integrate supporting self-management into their routine work (O). For some, this was due to concern that SMS was not an activity valued by colleagues or the wider organisation and an impression that other activities should be prioritised (Mreason). This impression could be created directly, from conversations with colleagues, or more indirectly, through the way in which the service was set up (Davies et al. 2018).

"the issue of health services providing long-term management versus shorter-term remediation for individuals with disability needs to be resolved before an innovative approach such as ours can become part of "usual" practice" (Mulligan et al. 2013, p.56)

Some staff felt pressure not to prioritise SMS because of worries about being seen to pull their weight and fulfil the role assigned to them within the organisation (Mreason) (Roy et al. 2011), while for others SMS was seen as impractical to integrate into their current role (Mreason) due to a lack of time, a lack of continuity of care, or fixed targets, all of which were caused by organisational design (C) (Hunt et al. 2015; Kulnik et al. 2017).

"A perceived lack of support by the organization for client-centered goal setting practices and lack of power to make changes led to procedures being abandoned over time.... Stress and frustration result as therapists perceive there is little freedom to pursue clients' goals that fall outside the range of expected goals for that care setting. Feelings of "demotivation" and "burn out" ensue..." (Hunt et al. 2015, p.1050)

As this quotation shows, the influence of an unsupportive organisational context was particularly strong when individual clinicians lacked any power to make meaningful changes (C). In this context, the gap between what the service wants the clinician to do for the patient, and the approach the clinician wishes to take, could be a source of stress and dissatisfaction amongst clinicians (Mreason) leading to demotivation (Outcome) (Davies et al. 2018).

In other settings, the working environment had a more positive effect. When the organisation was seen to value SMS (and this was made highly visible to staff through the way in which work was organised) (C), providing SMS became seen as an expected part of routine work (Mreason) and clinicians felt encouraged to integrate SMS activities into their work (O) (Davies et al. 2018). Factors described as

important in demonstrating that SMS was valued by the organisation included senior clinician support, political drive and the work of local champions (Annesley 2015; Kulnik et al. 2017). Training whole teams was suggested as a way to ensure that SMS was seen as a valued activity by all members (Mreason) (Davies et al. 2018), by creating a shared understanding about how and why to provide SMS (M-O) (Wallace et al. 2012; Kulnik et al. 2017). There was no indication that training only a few members of the team impacted on the work of colleagues who did not attend training (Wallace et al. 2012).

The literature also described how high-level executive support was not always enough to convince staff at ground level to implement the approach. There needed to be both organisational support and also available resources (C) in order for SMS to be seen as both valuable and practical (Mreason) (Davies et al. 2018).

"Working in an environment where client-centred practice and the therapeutic relationship were prioritized, significantly altered our practice... we felt freer to be with the person, not do to the person." (Bright et al. 2012, p.1000)

The use of tools, templates and IT systems could help SMS become integrated into routine work. It was also helpful if attention was paid to ensuring that the new approach could fit within existing organisational structures (Newbronner et al. 2013).

#### 4.6.5.3 Interpreting the evidence

Interviewees agreed that organisational goals were highly influential and also highlighted the value of training whole teams together. The stakeholder group also

discussed how organisational factors and individual factors interact, suggesting that in a supportive organisational context, a lack of personal belief in SMS provision might lead to half-hearted implementation at best. However, a lack of organisational support was seen as an even greater barrier as even a highly motivated individual is unlikely to be able to successfully provide SMS in this situation.

It is therefore important to consider the risk that training staff in a new approach without attending to organisational level barriers may increase staff dissatisfaction in their role. The Technology Acceptance Model highlighted the importance of participants' perceptions of external control (e.g. organisational factors) on perceived ease of use of a new approach. Normalisation process theory highlights the way in which teams interact together to normalise new approaches. It was challenging to identify when team support was an element of context (as seen for some of the other theories) and when it was the trigger of specific reasoning (when it was considered as the mechanism through which the intervention worked). The role and influence of team support on different individuals in different settings could be further explored. Some significant overlap has already been identified between this theory and the other review theories where team support is an important barrier or facilitator.

# 4.6.6 Review Theory 6 - Redefining professional role

# 4.6.6.1 *Overall theory*

Staff choose to work in a way that aligns (O) with their professional values or employers' expectations (C), which influences how they see their responsibility and remit (Mreason). When staff are able to critically examine their own role, and have the autonomy to make changes in the way they work (C), training in SMS can lead to a broadened view about professional role and new definitions of success (Mreason), leading to staff working differently and feeling more satisfied (O) (Davies et al. 2018).

# 4.6.6.2 Evidence from the literature

Twenty-three articles contributed data to this theory (See Table 4.1). Both reflection and empathy have key roles in the process of professionals challenging their current ideas and redefining their professional role. Most of the other review theories described are likely in some way to contribute to this change in perception.

The included papers indicated that staff started training with different understandings of the purpose of SMS (C). Some successful interventions helped practitioners to broaden their view about what their role should entail (Mreason) which encouraged them to undertake a wider range of activities, if these would result in improved SMS (O). This was not a straightforward process for staff, as it often challenged core beliefs around professional purpose and identity.

"she [the patient] felt listened to, valued and more empowered than she did with previous approaches. But we are compelled to ask, is it good enough that we empower her through physiotherapy and that is the sole outcome? Is it good enough that we don't get a functional outcome?" (Mudge et al. 2014, p.459)

Staff who were relatively junior and new to their posts were reported to find it more difficult to accept a broadened remit, and to work more flexibly (Van De Weyer et al. 2010). Other evidence suggested that more experienced staff might have a deeply entrenched view of their professional role (Annesley 2015).

Organisational context (C) often acted as an important barrier to the process of role redefinition which could be insurmountable. Staff were unable to change their own practice if they lacked sufficient autonomy or worked within a setting where their supervisors had a narrow definition of the purpose of their role (C).

"a community-based therapist explains that there is no room for client participation in the goal-setting procedures used in her workplace. She describes how she is obligated to follow her workplace practices for establishing goals; goals are predetermined by an intake worker and simply given to her. She reports little or no opportunity to explore or engage the client in any meaningful goal-setting process." (Hunt et al. 2015, p.1049)

Time pressures also acted as a significant barrier to integrating SMS within routine care. The quotation below shows how in practice, professional background, individuals' views, and organisational factors all act as potential barriers.

"Although the occupational therapists considered that addressing the social and psychological needs of people with Parkinson's disease was as important as addressing their physical needs, their current practice emphasises functional goals such as transfers, mobility and self-care.....

Several factors may contribute to it: a similar emphasis during the occupational therapists' postgraduate training and experience, a feeling that these goals may be of lesser practical importance and constraints on the occupational therapists' time." (Deane et al. 2003, p.252)

Staff are also influenced by how they feel their patients view their professional role.

This seemed particularly important for physiotherapists, who felt that patients associated their role with hands-on treatment (C), and so worried about not meeting their patients' expectations (Mreason) (Davies et al. 2018).

"It's a talking intervention – hard for physiotherapists – what do clients think about me talking when I should be doing physical goals?" (McPherson et al. 2009, p.307)

When training was able to help staff to re-evaluate their role and take on a different perspective, as more of an 'enabler' and less of a 'fixer', this could have a major impact on morale. When staff felt permitted to see their role differently (Mresource), they also started to define success differently, which meant if they followed the 'process' of providing SMS they could feel successful, even if the outcomes they would have previously valued were not always achieved (Mreason). This could lead to increased satisfaction and lessen feelings of frustration (O) (Davies et al. 2018).

"I think it's reminded me of something I might have forgotten. That is that I don't have to do all of the work. The power to heal lies within the patient, and it's my job to help them find that" (Yank et al. 2013, p.33)

Even if during training professionals started to see the value of adapting their traditional approach, when they started providing SMS in practice, further dilemmas were generated. The literature around goal setting demonstrated that frequently, when health professionals applied a more patient-centred approach this often led to the identification of goals that did not fit with those the professional would have usually prioritised on their patient's behalf (Mresource) (Hunt et al. 2015). Staff appeared to respond to this mismatch in two different ways, with

some prioritising their sense of professional responsibility while others prioritised a patient centred approach.

Some staff described discomfort (Mreason) when they felt that their patients made 'bad choices' and this often led them to take a more directive or paternalistic approach (O) in order to meet what they felt were their professional responsibilities (Pill et al. 1999). Organisational pressures also tended to encourage professionals to prioritise achievability over patient-centredness (Peng et al. 2014).

There were examples of situations where practitioners did start to prioritise patient-centredness over maintaining control and achievability of goals (Mreason) (Davies et al. 2018). This seemed to occur when training spent significant time on exploring the concept and purpose of SMS and when continued exploration of what this meant for professional role was facilitated by discussions with colleagues who had also received training (C) (Kulnik et al. 2017). This shift was described as requiring "emotional work" (Mreason) on the part of the professional to feel comfortable with the new approach (Mudge et al. 2014, p.5). However, even when professionals did act in a way which they felt was in line with supporting self-management they could sometimes become frustrated (O) because they felt that if patients were more compliant then the outcome would be improved (Mreason) (Wilson 2010).

Importantly, although adequate organisational support provided a context which enabled the process of redefining professional role, organisational expectation of SMS provision did not always produce the desired outcome. I found one example

of a team who worked to 'keep up the appearance' of supporting self-management, while actually practicing in a more directive manner.

"Most notably, the treating team never agreed to goals they did not consider achievable within the time frame of the admission. The treating team remained oriented to the participation agenda and used strategies to reframe goals in such a way that maintained the appearance of shared decision making" (Barnard et al. 2010, p.247)

## 4.6.6.3 *Interpreting the evidence*

One of the interviewees suggested that junior staff feel more comfortable with a structured approach that ensures they will be doing the right thing rather than a more flexible approach which introduces uncertainty. Interviewees also recognised that certain professions (e.g. occupational therapists) tended to be more accepting of a self-management approach because of the alignment with their undergraduate training. The stakeholder group agreed that staff held differing personal views about whether they feel they should act primarily as an employee required to fulfil the aims of the organisation, or more as a patient advocate. This theory operates at a higher level that the other theories described so far and redefining professional role could be seen as the outcome of several of the other theories (e.g. critical reflection, developing empathy and having adequate team/organisational support). The process of redefining of professional role appears to require a transformational learning process – including a critical examination of current beliefs and a period of trying out alternative new roles before the new approach becomes integrated into routine practice. Although the literature provided many examples of how context could prevent the process of redefining role, more exploration of enabling contexts would be useful.

## 4.6.7 Review Theory 7 - Picking the right patient

### 4.6.7.1 *Overall theory*

Clinicians make a judgement about supporting self-management and select who they believe is the right patient for support (O), based on their own view that the pros of supporting self-management outweigh the cons (Mreason). This judgement is influence by patient characteristics, professional characteristics and the organisational setting (C) (Davies et al. 2018).

## 4.6.7.2 *Evidence from the literature*

Twenty of the included articles provided data for this theory (See Table 4.1). In some situations, despite an awareness of self-management support approaches, and the opportunity to use these in practice, professionals chose not to provide self-management support (O). This outcome was visible across the literature review, interviews and advisory group discussions, and seemed to occur via several different mechanisms. Clinicians reasoned that some of their patients were not able to self-manage meaning that supporting self-management was not worthwhile (Mreason) (Davies et al. 2018).

"Some clinicians in the current study reported that, dependent upon their subjective assessment, various aspects of SM were not emphasised if the patient was considered unable to manage the requisite tasks." (Lake and Staiger 2010, p.66)

This was commonly associated with patient level contextual barriers which could relate to the patient's medical condition (cognitive impairment, complex condition)

(C) (Lake and Staiger 2010; Satink et al. 2015). Although cognitive impairment was

recognised as a potential barrier to identifying meaningful goals and planning or performing self-management activities (C), professionals sometimes adapted their approach (Mreason) by providing more time, involving family members, and delivering interventions in the home environment (O) (Frich et al. 2014; Daley et al. 2015).

Other patients were seen as unwilling to engage in self-management (Mreason), due to lack of motivation (which could be a symptom of their PNC) (Smith et al. 2013), personality type, cultural barriers or existing expectations of the service 'providing for them' (C) (Wilson 2010; Kulnik et al. 2017). When professionals had the impression that their patients were not interested in self-management (C), they used the notion of patient choice and autonomy as a way to ease the frustration that this could generate (Mreason) (Davies et al. 2018), and a justification for not continuing with efforts to provide SMS (O) (Cope 2012).

"there are some people who at the risk of reinterpretation, do want to be passive and they want the MS nurses and doctors to make decisions for them" (Wilson 2010, p.197)

As well as reasoning which related to the likelihood of success following self-management support, clinicians also based their reasoning on the perceived risks of promoting self-management such as triggering emotional distress (Stretton et al. 2013). When clinicians judged that their patients could be vulnerable and might feel under undue pressure or abandoned if self-management was promoted (Mreason), this led to clinician discomfort (O).

Clinicians also seemed to make an overall assessment of patients' readiness to selfmanage. "Practitioners described 'waiting for the right time', and this included an individual appraisal of 'readiness' of each individual, often conceptualised as when individuals had 'accepted' their stroke and were ready to take on some responsibility" (Jones et al. 2013a, p.94)

In situations where patients signalled that they had reached acceptance of their condition, had observable "lightbulb moments" about self-management, and actively engaged with the professionals (C), clinicians found their encounters more enjoyable and tended to be more active in the strategies they used to support self-management. In settings where there was continuity of care (C) it was easier for clinicians to identify the 'right time' for self-management support (Mreason) and so effective support could be provided when the patient needed it, increasing job satisfaction (O) (Davies et al. 2018).

"Participants who were able to monitor, review, observe, and interact with clients over long periods of time seemed to experience greater satisfaction in their role. This, in part, appeared related to optimal timing concerning client readiness to change coinciding with the HCP being ready and able to intervene." (Smith et al. 2013, p.738)

Optimal timing for SMS provision was seen as particularly important in the PNC setting (Davies et al. 2018), as professionals recognised that patients might require increasing support as their disease progressed as well as the option to defer to professionals during crisis periods (C) (Wilson 2010). However organisational set-up did not always facilitate regular re-assessment (C) (Deane et al. 2003).

While the literature used to generate this theory focussed heavily on contextual influences at the level of the patient, the authors of one study in the review noted that in some settings specific client characteristics seem to be less influential, due to other contextual factors – notably prior professional training, clinical experience and organisational support (Peng et al. 2014).

When providing SMS appeared to empower patients to take a more active role in managing their own condition (Mresource), and the benefit for the patient was visible, clinicians felt more satisfied (Mreason) and were motivated to continue this approach (O).

"I enjoyed the fact that they . . . I guess that they had the power to choose what they wanted to do long-term and they had the freedom to do that. I got quite a lot of good feedback from them about how helpful they found that, so it was really rewarding to feel like you were on the same team from the outset." (Mulligan et al. 2013, p.54)

This mechanism was more likely to occur among clinicians who already highly valued partnership working and active engagement of patients, and for whom SMS fitted with how they saw their professional role (C) (Mulligan et al. 2013; Hunt et al. 2015).

#### 4.6.7.3 Interpreting the evidence

The interviewees recognised that the level of demand on the service, and the wish to find ways to manage this demand could be key motivators in staff learning and applying SMS skills.

"What I'm finding now in the audiences is they want to know what they can do to empower their patients. Because they recognise that if they can empower their patient, actually it reduces their clinical load as well." (Interviewee 3)

They also raised some concerns about professionals using SMS selectively, recognising a risk that decisions may be based on incorrect assumptions.

"if I'd have guessed the people that would have taken on those skills and have got the best out of it I would have been completely wrong.... I would

have been completely wrong if I'd have made that presumption." (Interviewee 2)

The stakeholder group noted that in some situations it may be entirely appropriate for patients to be 'managed' by the service. However, in other cases they suggested that selectivity might represent a misunderstanding about SMS among professionals or an organisational setting that does not support self-management. In particular they suggested that judgements about which patients were and were not suitable for SMS may be more related to professional factors than patient factors, and that how selectively staff use the approach relates to how they understand the concept and purpose of self-management.

Stakeholders considered that if training facilitates adequate reflection then staff may be able to recognise that they might not be able to accurately 'pick the right patient' and sometimes may get it wrong. It was hoped that this might lead staff to think of self-management as suitable for all patients, provided they are given appropriate support. The group felt that ideally staff need to develop skills to adapt their practice to the needs of their patients, rather than limiting SMS provision.

It was more difficult to see how this theory fitted with the middle range theories, possibly because it describes a higher-level decision making that is influenced by multiple lower level CMOs. However, the concern about patient factors could be seen as the external control influence on perceived ease of use in the Technology Acceptance Model. It could also represent the behavioural intention stage of the TAM which demonstrates the 'mental calculations' done as professionals weigh up usefulness and ease of use.

## 4.7 Strengths and Limitations of the Review

The review questions were chosen in collaboration with a stakeholder advisory group to ensure the results of the review would be relevant. Bounding the scope of the review inevitably means that some outcomes have not been addressed but is essential to keep the review manageable (Pawson 2006).

A comprehensive search strategy was developed. The flexibility and inclusivity of the realist approach allowed the inclusion of studies from a range of clinical settings (Rycroft-Malone et al. 2012) which helped to provide more depth and nuance to the developing theories and mitigated the risk of utilising only the condition-specific literature which might have had inadequate explanatory power. The triangulation of data sources acted to increase the comprehensiveness of the data set (Mays and Pope 2000).

Relevance and rigor were continually considered while working with the data.

Throughout the synthesis I also considered how my own role as both health professional and researcher influenced my interpretation of the data (Davies et al. 2018). Transparency about the evidence sources used, including the provision of quotations within the results sections allows the reader to see how the theories have been generated and make their own judgements about their validity (Mays and Pope 2000; Pawson 2006).

I performed title and abstract screening, together with the majority of data extraction alone. Although Pawson (2006) does not suggest that double reviewing of papers for inclusion is required, other authors have used this step to make the realist synthesis process more robust (Rycroft-Malone et al. 2012). Discussions

were held with a supervisor and with the stakeholder group at key points. Although this may have increased the subjectivity of the process, it also meant I was fully immersed in the data which helped me to develop a clear overall understanding of how the developing theories were inter-related. As with any realist synthesis (Wong et al. 2010) the interpretive nature of the review process means that it is possible that another reviewer might have derived a different set of theories from reviewing the same papers (Davies et al. 2018).

The synthesis was significantly limited by the nature of the published literature available, which often lacked attention to how training was expected to work, and did not provide any description of the potential contextual influences at play. This is a recognised issue and has caused difficulties for other realist reviewers exploring health professional education (Wong et al. 2010). The quality of evaluations of training in health professional education and the reporting of research in this setting has been criticised by other authors (Cook et al. 2007; Nabulsi et al. 2007). It may be that the context-specific challenges relating to PNCs have not yet been fully identified. However, the level of abstraction at which the review operates has made it possible to generate potentially transferable theories.

# 4.8 Chapter Summary

This chapter presented the findings of a realist synthesis of evidence from 44 papers, five key informant interviews and three stakeholder advisory groups. Seven theories were proposed, each of which comprised one or more CMO configurations. Important contextual influences have been identified at the level of 180

the practitioner, patient and workplace. Key target mechanisms for any SMS intervention included creating meaningful reflection, providing a new perspective on patients' lives, broadening the view of professionals' own role in relation to SMS, changing how success is defined, providing new techniques and ways to maintain confidence in their use, creating a shared understanding of SMS within teams and convincing staff SMS is worthwhile. The outcomes observed in association with these mechanisms included: SMS being seen as a valuable priority activity, staff becoming aware that practice change is needed and becoming motivated to change, staff altering their expectations of their patients, staff feeling confident in SMS provision, and staff integrating SMS into their routine work. Gaps in the theories developed were also identified, which I planned to address through the collection of primary data in the evaluation phase of the PhD. Chapter 5 now describes the selection an existing training intervention, based on the findings of this synthesis, and outlines the decisions made in planning the evaluation.

# 5 Evaluation of a health coaching skills development programme

## 5.1 Developing theories

In this chapter I consider how the findings from my survey (Chapter 3) and the theories developed from the realist synthesis (Chapter 4) can inform the selection and evaluation of an appropriate intervention, to allow for the further testing and refinement of my theories.

My survey highlighted the priority training interests of staff working with people with PNCs, several of which centred around developing 'readiness to self-manage' (assessing capacity for self-management, psychological support, motivational interviewing); while staff also expressed an interest in developing more structured approaches to supporting problem solving. Organisational constraints around limited time and competing priorities were the most significant contextual barriers reported. Although the survey was not designed to explore possible intervention mechanisms, it is worth noting that most staff appeared to believe in the benefits of using SMS techniques, so my survey might indicate that training may need to focus more on the practicalities of SMS provision (including building skills and tackling organisational barriers) rather than focussing on belief in the concept of SMS. Interpretation of the survey responses suggests that a successful SMS training intervention could increase use of specific techniques that staff are currently interested in but unable to perform.

My literature review generated seven CMO statements describing training and subsequent implementation. Important contextual influences, key training

mechanisms, and both intended and unintended outcomes were described.

Although in some areas I had developed well-evidenced theories, some of the other theories developed were based on more limited evidence and remained largely speculative. I had gathered only limited data that explained what particular difficulties might be associated with SMS provision in the PNC context, over and above the difficulties of providing SMS to people with other long-term conditions.

Many of the studies I reviewed only provided very brief descriptions of any health professional training provided. The mechanisms identified from the literature review were often inferred from small extracts of primary data, or from the interpretations provided by the study authors. Using these limited descriptions meant it was likely that many other mechanisms also act during both the training and implementation phases of any intervention.

The first part of this chapter describes how I went about addressing Thesis

Objective 3 (identify or design an appropriate training intervention, which is likely
to meet the needs and interests of participants and provides the opportunity to test
the initial theories). I then discuss how the issues specific to the PNC context were
identified and explained to the training providers to allow for appropriate tailoring
of the intervention (Thesis Objective 4). The chapter concludes with a description
of the specific methods used to address Thesis Objective 5 (To evaluate the training
intervention and use the findings to test, develop and refine a programme theory,
describing how when and for whom the training intervention works).

## 5.2 Selecting an intervention for theory testing

### 5.2.1 Options considered with rationale for chosen approach

In their realist evaluation cycle, Pawson and Tilley (1997) suggest that once initial theories have been formulated, the next step is to collect empirical data to test and refine these theories. I therefore began looking at options to collect empirical data relating to elements of context, mechanisms and outcomes (and their interactions), to further develop my existing theories, while also remaining open to the emergence of new important CMO configurations not yet described. I also planned to use the data to further my understanding of the relatedness of the different CMO configurations and whether any of the theories were essential to allow others to operate. This relatedness had been difficult to establish using the data from the literature review.

Several practical issues required consideration. As a staff PhD candidate, I did not have any specific budget available to run a training intervention, so it was necessary to explore potential sources of funding, which might become available in a timescale that would fit within the PhD timeline. I also considered how timeconsuming the design and set-up of any new intervention would be.

I met with my supervisors and put together a tabulation of possible approaches to use in the evaluation phase (see Appendix I). This outlined the expected project timescale, the research questions it would be possible to address using each method, anticipated ease of set-up and recruitment, funding requirements, the work that would be required in the planning and intervention stages, and my assessment of the advantages and disadvantages of each approach.

The options considered were:

- 1. To design and deliver an intervention to my local clinical team
- To use a seminar at a national conference to deliver basic training which could be followed up with provision of an online resource
- To perform case study research using participants who had signed up to an existing training course
- 4. To seek grant funding for an intervention to be delivered to the target group of professionals by an experienced training provider, so that I could evaluate professional level outcomes (and patient level outcomes if possible)

Option 4 was selected as the preferred option because it would allow me to focus on theory development and refinement rather than on designing a new intervention. Commissioning training from an established training provider meant I could arrange for staff in my target group to attend and could focus my attention on the evaluation of the training. I considered several issues when deciding which pre-existing SMS intervention would be most helpful to evaluate to further my theory development. It was important that the training should meet at least some of the priority training needs that health professionals identified in my survey to stimulate interest in attending and fill an existing training gap. I was also keen to evaluate an intervention that had already been used within the NHS and which fitted with current policy aims and objectives. This would help to maximise the relevance of the findings and the chance of influencing future recommendations.

theorised but with which my developing theories seemed to align well with, to ensure that my findings would provide an important new contribution.

5.2.1.1 Specific training interventions considered as possible options for evaluation I used my literature review and survey findings to identify specific training interventions in current use. I focussed on identifying a named intervention that could be replicated to promote SMS in the UK. The majority of interventions described within my literature review and by survey respondents related to a single specific technique such as, motivational interviewing, solution focussed brief therapy, goal setting and cognitive behavioural therapy. Two approaches that look more broadly at working in a way that supports self-management, and focus on attitude shift in addition to specific techniques are the Bridges self-management programme (Jones et al. 2013a; Norris and Kilbride 2014; Kulnik et al. 2017) and health coaching (Robinson et al. 2008; Stretton et al. 2013; Mudge et al. 2014; Speelman et al. 2014). I decided to further explore health coaching as an intervention for improving self-management support because although it has a broad focus it also includes specific motivational interviewing type techniques which were of significant interest to my survey participants. The background of health coaching as an intervention, the level of current policy interest, and the identified gaps in the evidence base which informed this decision are outlined in section 5.3.

### 5.2.1.2 *Funding*

I identified a potential source of funding from Novartis, a major multi-national pharmaceutical company, active in research in MS and Parkinson's. Novartis offer educational event grants to reputable healthcare or healthcare-related organisations for events which provide considerable educational value. I believed that a training course in SMS would meet these criteria and started to look for training providers to deliver the intervention. I identified an organisation with extensive experience in developing and delivering health coaching training within the NHS and asked them to provide a quotation for a two-day training package. I compiled an application for funding and the strategic fit of the project was confirmed by the research management group within my department. Full costings were then obtained in liaison with the School of Medicine Research Office and a small grant application was made to Novartis. I was awarded the funding to arrange the training in September 2017. Novartis had no input into the content or delivery of the training.

## 5.3 Justifying a focus on health coaching

## 5.3.1 What is health coaching?

Health coaching has been described as an umbrella term for a range of different interventions which aim to support people to set their own goals and feel empowered to make changes to improve their health (The Evidence Centre for Health Education East of England 2014). This approach requires a shift in the traditional relationship between the healthcare provider and their patient from a

more dependent model, towards an approach that focuses on developing intrinsic motivation for behaviour change (Hayes and Kalmakis 2007; Caldwell et al. 2013; The Evidence Centre for Health Education East of England 2014). A concept analysis, informed by 215 articles, proposed to define health coaching as:

"a goal-orientated, client centred partnership that is health-focused and occurs through a process of client enlightenment and empowerment." (Olsen 2014, p.24)

Health coaching focusses on a person's values and vision for their life and views individuals as resourceful partners in their care (Wolever et al. 2011; The Evidence Centre for Health Education East of England 2014). Health coaches help people to explore their options, identify potential challenges, and make plans for future change, but do not take responsibility for the outcomes (The Evidence Centre for Health Education East of England 2014; Brook and McGraw 2018). The 'spirit' of health coaching emphasises the importance of holding an unconditional positive regard along with a belief that the coachee is an expert in their own life and has the capacity for change (Huffman 2016; International Consortium for Health and Wellness Coaching 2018). Health coaches are encouraged to develop their own self-awareness and foster a respectful and non-judgmental presence (Wolever et al. 2016; International Consortium for Health and Wellness Coaching 2018). Based on a systematic review of 284 studies, Wolever et al. defined a health coach as:

"a healthcare professional trained in behavior change theory, motivational strategies, and communication techniques, which are used to assist patients to develop intrinsic motivation and obtain skills to create sustainable change for improved health and well-being" (Wolever et al. 2013, p.52)

Health coaching is recognised to have similarities with motivational interviewing (MI), and MI is often described as a component of health coaching interventions

(Olsen and Nesbitt 2010; Caldwell et al. 2013). However it is worth noting that the aims of health coaching tend to be wider than those of MI (which mainly aims to overcome ambivalence), and that MI can be more directive than health coaching, often addressing a goal determined by the health professional (Caldwell et al. 2013). Health coaching may be offered in various settings, by various professionals (for example, dedicated health coaches may see patients in specific coaching appointments, while clinicians may integrate health coaching approaches into their routine consultations (The Evidence Centre for Health Education East of England 2014). Health coaching is therefore one approach health professionals can use to support self-management and as such fitted well with the aim of my thesis.

#### **5.3.2** Policy context

In recent years there has been an increased interest in attempting to spread health coaching within the UK (The Evidence Centre for Health Education East of England 2014). The health coaching approach is currently more widespread in North America, where for example coaching is a mandated educational competency for nurse practitioners (Hayes and Kalmakis 2007). In the UK, health coaching has been promoted as a way to decrease patients' dependency on NHS services, by empowering them to take more control over their own conditions to free up valuable NHS resources (Garland and Norton 2013).

As discussed in Chapter 1, the *NHS Five Year Forward View* includes a focus on supporting self-management (NHS England 2014). The *Realising the Value* project (Finnis et al. 2016) was commissioned by NHS England to gather evidence to

support the aims of the Five Year Forward view. The study included health coaching as one of the five important person-centred ways of working described in detail. Further support from NHS England has been provided by the NHS Innovator Accelerator Programme, which identified health coaching as an innovation worthy of investment to rapidly scale up (The Health Coaching Coalition 2016b). In 2015, Health Education England commissioned a strategic review, to develop a quality framework to support the commissioning of high-quality health coaching training interventions. They recognised that while health coaching was high on the policy agenda, the opportunities for training were described as "variable, limited and even lacking for many staff groups" (NHS Health Education England 2015, p.2). Professional organisations are also beginning to consider the role of health coaching skills in clinical practice (for example the Royal College of General Practitioners (2018) include information on health coaching in their person-centred care toolkit). Practitioners and organisations already involved in health coaching have also collaborated to promote the role of health coaching, forming the Health Coaching Coalition, and producing resources including a website, a PDF resource guide (The Health Coaching Coalition 2016b), Slack channel and Twitter account, with the aim of spreading the 'social movement' of health coaching (The Health Coaching Coalition 2016a). The health coaching approach appears to be gaining momentum in the UK, is well-aligned with NHS policies and is being actively promoted by policymakers. The identified policy drive together with the potential for the health coaching approach to support self-management informed my

decision to focus on health coaching in the evaluation stage.

## 5.3.3 Existing evidence

Previous research has generally tended to focus on the recipients of health coaching rather than the perspective of those trained to become health coaches (Ickes and McMullen 2016). However systematic reviewers of health coaching interventions have struggled to draw meaningful conclusions about the benefits for patients involved in previous studies. Reviews published between 2010 and 2017 (Olsen and Nesbitt 2010; Kivelä et al. 2014; Hill et al. 2015; Dejonghe et al. 2017) identified problems with the heterogeneity of the interventions described, including variations in the person delivering the coaching (peers, health professionals), training of the coach, underlying conceptual model of coaching used, the modality of coaching (face-to-face, telephone, online and mixed), the duration and intensity of the intervention, the health problems the coaching set out to address, and the outcome measures used. Olsen and Nesbitt (2010) raised particular concerns about the need to ensure that interventions do actually work by providing coaching, and not simply via information provision and support by a likeable coach. Although individual studies have shown positive results, the two most recent systematic reviews failed to reach conclusions about the effectiveness of health coaching interventions, calling for improved reporting of intervention details, measurement of process variables (e.g. goal attainment or self-efficacy) and more specific outcome measures that relate to important clinical questions (Hill et al. 2015; Dejonghe et al. 2017). Proponents of the health coaching approach have interpreted the positive findings on behaviour change from individual studies included in these reviews as a strong signal worthy of further research (Wolever et al. 2016).

There are also positive reports about the impact of health coaching available from qualitative evaluations of local projects. For example, the Institute for Employment Studies conducted interviews and focus groups with a total of 56 NHS staff from five different NHS organisations who had been trained in health coaching during 2013/14 (Carter et al. 2015). Reported benefits for patients (perceived by their clinicians) included improved motivation, increased confidence and greater satisfaction, while clinicians reported coaching offered a more sustainable way of working to manage growing their workload. Clinicians felt more confident and resilient, able to deal with more challenging patients, and believed that their increased productivity could impact on the wider system (Carter et al. 2015).

#### 5.3.4 Training in health coaching skills

While there is acceptance that some form of training is essential for health coaches (Wood et al. 2016), with most research studies stating that health coaches have received specialist training, this training is usually not described in detail. A rapid review of 275 studies undertaken by The Evidence Centre for Health Education East of England (2014) concluded that there was insufficient detail in the included studies to extract details about the suggested content of training interventions or the competencies suggested for coaches. And yet while there remains what has been called a "dearth of research exploring the training and development of efficacious health coaching skills" (Ickes and McMullen 2016, p.162), interest in health coaching has grown rapidly. Concerns have been raised that both individuals and organisations from different settings are now promoting their version of

training and certification programmes to meet demands from the marketplace, with over 50 organisations offering training programmes in North America (Huffman 2016; Wolever et al. 2016). There have been calls for future research to help understand which training methods are most impactful (Ickes and McMullen 2016). This provided a powerful rationale for exploring health coaching training in more detail within this PhD.

### 5.3.4.1 Content and competencies

Health coaching draws upon multiple different theories and approaches from psychology and behaviour change (e.g. motivational interviewing, social cognitive theory, positive psychology, social cognitive theory, mindfulness and stages of change) (Newman et al. 2013; Wolever et al. 2016). Newman et al. (2013) suggest that health coaching integrates skills and techniques from these fields together with the existing knowledge and skills of the health practitioner, and techniques used in performance coaching (including coaching models, focussing on potential, and using challenge). In the US, Jordan et al. (2015) reported the results of a job task analysis process informed by an expert panel and validated using a survey of 885 health and wellness coaches. This resulted in an agreed list including eleven knowledge areas (e.g. goal-setting techniques, models of motivation and behaviour change) and 38 skills required for effective health and wellness coaching (e.g. responding to client resistance, building positivity, structuring the coaching process). In the US these results have been used by the International Consortium for Health & Wellness Coaching to plan a comprehensive certification programme

which includes participating in a registered training programme which incorporates a practical skills evaluation, documenting at least 50 coaching sessions and completing a national certification exam (Jordan et al. 2015). In the UK, where the focus has often been on training health professionals to integrate coaching into their existing work, rather than on the provision of standalone interventions by dedicated health coaches, one leading training provider has produced a model that suggests a stepped-approach to the integration of health coaching (The Health Coaching Coalition 2016b). In this model, they suggest that a health coaching mindset can be used in all consultations, that knowledge of health coaching skills can be used in many appointments, and that specific coaching models may be helpful to inform conversations about behaviour change. (Ahluwalia et al. 2013; The Health Coaching Coalition 2016b).

## 5.3.4.2 *Process*

It is recognised that training should be tailored to the needs of the trainees, and relevant to how they intend to use health coaching in future (Wood et al. 2016). There is general agreement that two days of face-to-face training is seen as a minimum requirement (Ahluwalia et al. 2013; The Evidence Centre for Health Education East of England 2014; Wood et al. 2016). A 2015 project by NHS Health Education England produced a quality framework to assist commissioners and programme developers based on a synthesis of available research together with examples of best practice drawn from across the UK (NHS Health Education England 2015). Their focus was on training health professionals to use coaching skills within their routine consultations. In summary their recommendations include that

training should be evidence based (using both research, case studies and patient experience) and should align with the needs of the local care system. It should prioritise training staff who have time and continuity of working with people with long term conditions, those who are willing to get involved and who will subsequently have the time to practise and embed the skills. They recommend two days of immersive training away from day to day activities, with a gap between the sessions to allow for opportunities to practise. Opportunities to revisit the skills and participate in ongoing reflection should be promoted (e.g. via webinars, refresher courses and online support). Training should be practical, focussing on training small groups to provide adequate opportunities for meaningful discussions, experiences of coaching and of being coached. They recommend that trainers should be health professionals who have credibility with and are from the same discipline as trainees and seen as expert trainers. Training should create a safe space for trainees, using tactics such as establishing ground rules, making participation voluntary and not having colleagues present who might threaten the safety of opening up (NHS Health Education England 2015). Other suggestions from the literature include ensuring that plenty of time is left for role play to practise the techniques and build self-efficacy (Ickes and McMullen 2016). If these role play activities can be based on the personal experiences of the trainee this can further highlight the usefulness of the approach (The Health Coaching Coalition 2016b).

The literature clearly highlights the need to further understand the 'black box' of health coaching training interventions, while already providing some suggestions of important 'active ingredients' of training. It also hints at the important influences

of context, with evaluators recognising that trainees respond to the same training differently, exhibiting a spectrum of reactions from a complete and fundamental change in practice to a much more limited response (Carter et al. 2015). Coaching may be utilised in a more or less directive fashion (where health professionals may maintain or relinquish control over the goal setting and problem-solving stages) (Kessler and Graham 2015). There is recognition that a trainee's readiness to change is also likely to play a significant role in responsiveness to training (The Evidence Centre for Health Education East of England 2014), and that an individual's professional role and the needs of the organisation influence how they utilise health coaching (Liddy et al. 2014). My initial rough theories and those developed in the from the realist synthesis appeared to fit closely with what was already understood about how training and subsequent implementation of health coaching worked. It was anticipated that using a realist lens to examine the process would help to further illuminate how and why certain outcome patterns occur.

#### 5.3.5 Health coaching in the PNC setting

There remains a degree of uncertainty around how helpful a health coaching approach might be for health professionals working with people with progressive neurological conditions for several reasons. Firstly, because much of the evidence about health coaching comes from settings where health coaching is delivered as a standalone intervention by dedicated health coaches, it is unclear whether the delivery of coaching within an already established patient-clinician relationship might be more powerful (The Evidence Centre for Health Education East of England

2014). Caldwell et al. (2013) suggest that it may be more difficult for professionals who need to take on an expert role during part of the consultation (e.g. performing an evaluation or administering a treatment) to shift out of this stance towards a fully patient-centric interaction.

Secondly, staff have expressed discomfort about using a coaching approach with patients they perceive to be complex or vulnerable (Stretton et al. 2013). Being diagnosed with a PNC may act as a 'biographical disruption' and is associated with significant ongoing uncertainty about the possible disease course (Bury 1982). People with PNCs may be struggling with the threat to their identity posed by their condition, along with associated pressures from their family and financial worries, which may all increase their vulnerability (Wolever et al. 2016). Vulnerability may also relate to what resources the person has available to them to support change (Wolever et al. 2011). In order to make the best use of coaching, people need to be able to tolerate honest feedback and openly communicate about discrepancies between their stated goals and their current behaviour, and this may be challenging for more vulnerable people (Wolever et al. 2011).

Thirdly, the main focus of health coaching is typically on behaviour change and the attainment of specific goals (Hayes and Kalmakis 2007). This focus may be of less relevance to people with a progressive condition who may not be able to have any control over the course of their disease. People with PNCs may also have impaired self-awareness and it is not yet well understood how behaviour change strategies can be used in these settings (Stretton et al. 2013).

All these uncertainties provide a clear rationale for further exploring how health coaching training is received and subsequently implemented by staff working with people with PNCs. Recognising that generic training in health coaching may not meet the specific needs of this staff group I undertook further work to understand what modifications might be required, and shared these with the training provider in order to meet Thesis Objective 4 (To ensure the training intervention delivered takes into account the potential challenges specific to the PNC context that have been identified and can be tailored accordingly.)

## 5.4 The intervention

The following section describes how the intervention was organised and provided.

## 5.4.1 Tailoring activities undertaken

From September 2017 to January 2018 in between the confirmation of funding and the delivery of the first training day I discussed the need to tailor the training with the training providers and gathered views from a variety of stakeholders. I met with the local Parkinson's UK research interest group and held two teleconference meetings with the trainers (one of which involved public and patient involvement (PPI) contributions). I also held two focus groups at a national MS conference which were attended by nurses and therapists who would be the target audience for the training.

I decided to use focus groups to gather additional data before the training and evaluation because I recognised that my literature review had provided limited insights into the context-specific challenges of providing SMS in the PNC setting. I planned to use the further data to inform theory building and aid the interpretation of the earlier data from the survey and review. At this point I had already decided to evaluate training in health coaching, so the groups also provided the opportunity to explore the perceived relevance of a coaching approach to staff working in PNCs. The data gathered also helped to design the topic guides for the evaluation stage, by further sensitising me to issues of most importance to potential participants. The contextual information gathered was shared with the training provider so they were aware of the priorities of staff working in this setting and the barriers and facilitators they thought could affect the implementation of training. Ethical approval for the focus groups was provided by Cardiff University School of Medicine Ethics Committee (SMREC REF 17/57) (see Appendix J). A topic guide was developed which focussed on exploring the perceived relevance of health coaching, and ideas about how training could help to develop knowledge, skills and confidence (see Appendix J). Potential barriers at the levels of the clinician, the patient and the wider organisation were explored. Training that participants had already received was also discussed to try to identify what worked for whom. The focus groups were advertised during the conference using posters and an announcement following a workshop that I led on the subject of SMS. Formal analysis of the focus group transcripts was undertaken later alongside analysis of data collected in the evaluation phase (see Chapter 6). As a first step I made notes on the key themes arising in the transcripts. These themes were then discussed at

the teleconference with PPI representatives and the trainers. At this stage I was also able to provide the trainers with details about the background of the attendees who had signed up for the training. I hoped that sharing information about the trainees' context and the challenges described by staff working in the PNC setting would help the trainers to appropriately tailor the training package to meet the participants' needs. I did not have any role in tailoring the design or delivery of the training package itself. My role was limited to providing information and arranging for discussions to occur. The trainers chose how to use the information I had provided them. A brief description of the important topics discussed at each time point is outlined in table 5.1.

Table 5.1 Sources of stakeholder input which helped to inform the tailoring of the health coaching training

Time point	Activity undertaken	Participants (including me)	Important issues discussed
Sep-17	Meeting with local Parkinson's research interest group	4 people with PD, 6 carers, 2 representatives of Parkinson's UK, 2 researchers	The need for empathy from health professionals Their impression that the complexity of PD, interaction of symptoms and variability of experience was not fully appreciated The desire to have more personalised information, and for information provision to be more proactive than reactive The importance of the role of the carer in selfmanagement
Oct-17	Initial planning tele-conference with training provider	Lead trainer	<ul> <li>My research findings to date (including literature review, survey, stakeholder views)</li> <li>Their advice on recruitment – trying to train some peers together to increase the chance of training being embedded</li> <li>How coaching could relate to the PNC setting</li> <li>What they would like to know from staff and patient perspective to help with tailoring the training (what do their best conversations look like, what behaviour changes would professionals like to see)</li> </ul>
Nov-17	Two focus groups (facilitated by me) with staff attending a national MS conference	6 nurses, 5 physiotherapists 5 occupational therapists	<ul> <li>Acceptance (not accepting diagnosis or adaptations that need to be made can hinder self-management)</li> <li>Progression (how to work with people who are progressing in spite of 'doing everything right')</li> <li>Challenging scenarios (cognitive impairment, competing priorities, preference for a paternalistic style)</li> <li>Self-awareness and being proactive (staff would like to see people take ownership of their condition)</li> <li>Working with carers (helping them to be comfortable with risk, not overburdening them)</li> <li>Working in a team (busy teams might just keep doing the same thing, how to 'sell' a coaching approach)</li> <li>Organisational constraints (mandatory assessments, fixed length follow-up, infrequent contacts)</li> <li>What worked in previous training (role play and feedback, patient stories, understanding that you don't have to fix everything)</li> </ul>
Jan-18	Follow-up tele- conference with PPI representa- tives and trainers	3 PPI representatives attended the meeting 2 PPI representatives provided input by email before the meeting	- Issues raised at the staff focus groups were shared - PPI members expressed a desire for patients experiences to be valued and to move away from a 'clinician knows best' approach - Recognition that appointments can be challenging for people with PNCs (stress and discomfort can slow the thinking process, it may

Both trainers	take time to be able to listen and concentrate, carer support may be needed)  Recognition of the value of preparing for appointments before attending  Enthusiasm from PPI members that this type of training would be valuable  Suggestion that case studies and patient stories can be valuable within training
	can be valuable within training - Details about the background of participants
	recruited and planned evaluation approach

#### 5.4.2 Recruitment

I took responsibility for course advertising and recruitment as this allowed me to target health professionals working with people with PNCs. The course was advertised via several channels including emails to contacts, and posters, flyers and announcements at conferences for relevant professional groups (Parkinson's Disease Specialist Nurse Association and The Multiple Sclerosis Trust). Course advertising materials stated that the course was being organised as part of a PhD project so participants were aware that research activities would be running alongside the training. Interested training participants returned a refundable holding deposit for the course along with basic information about their job title, patient group and place of work. These data were gathered so that it would be possible to purposively sample should certain professional groups or conditions be significantly under-represented, although this did not prove necessary. Recruitment was fairly slow although there was a late flurry of interest in places following the circulation of the course flyer to members of the Parkinson's research interest group local to the training venue. One clinical team expressed interest in sending eight team members to the training. At the time, one of their team members had already been offered a place and a further four places were available

and offered to this team. Subsequent dropouts (people who were offered a place but did not return the holding deposit) meant that another member of the team was offered a place on the course. Of note, although this was a community rehabilitation team, two of the team members who attended work exclusively with people with neurological conditions that are not progressive. I felt that the data that could be gathered about training a large number of individuals from a single team would be directly relevant to my developing theory around team support so decided it would be beneficial to include these individuals in my study.

Twenty-one trainees accepted places on the course and attended the first training day (my target was for 20 participants, but I chose to offer one extra place in case of any last-minute withdrawals). One participant was unable to attend the second training day, so 20 trainees completed the training. Twenty-three further individuals expressed an interest in attending the training, of whom seventeen either declined a place on the training or did not book the place that they were offered. Six people were declined a place on the training due to lack of available spaces.

#### 5.4.3 Training intervention provided

The training intervention provided is described here, in line with the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al. 2014) (See Appendix K for completed checklist).

The health coaching skills development programme was designed and delivered by an external training provider. It involved a two-day face-to-face training course for 20 participants (plus myself as a participant observer). The training commenced at 9.30am and finished at 5pm with a 45-minute lunch break and two short (usually approx. ten minutes) coffee breaks. The training is usually delivered with a two to four-week gap between the two sessions. Due to heavy snow and associated Met Office severe weather warnings the second training day was postponed resulting in a gap of just over 11 weeks between the first and second training days. The first training day was held on January 30<sup>th</sup> and the second on April 20<sup>th</sup> 2018. Given the long interval between the two training days, the trainers arranged to host a onehour refresher webinar discussion ten days before the second training day which was attended by six participants. This provided an opportunity for attendees to reflect on their experiences with trying to implement the training and to revise content from the first training day. Other participants had the opportunity to watch a recording of the webinar online. This refresher webinar is not part of the standard training programme but has been used in the past when there has been a delay between the first and second training days.

The training was delivered in a meeting room of a hotel, using a horse-shoe shaped seating layout. Two highly experienced trainers (both with clinical backgrounds) facilitated the training, alternating between one trainer leading the discussion and the other providing support. All trainees were provided with a 123-page resource guide (which included space for notes). The booklet included all the slides presented by the trainers during the two workshops (and a small number of extra slides that were not discussed during the training days). The slides were also

projected on a screen and the facilitators also regularly annotated flip charts during the sessions.

The training involved a variety of different activities including: silent individual reflection exercises; discussions in pairs, small groups and as a whole group; group work activities using flip-charts; short presentations given by trainers referring to slides; live demonstrations of coaching provided by trainers; and working as a pair to practise coaching and being coached. Trainees were regularly required to get up and move around the room during the activities. The training actively encouraged participant interaction. Group discussion sessions were shaped by the issues raised by the participants and felt to be most relevant to them. The trainers modelled a coaching approach during the training by encouraging participants to identify their own challenges and generate their own solutions. Practice coaching sessions were not systematically observed and there was no structured feedback provided to trainees on their performance (though some ad hoc discussions occurred). Important topics discussed included: an introduction to the coaching mindset and approach; goal setting; directive and non-directive approaches; clinical applications of coaching; patient activation (Hibbard and Gilburt 2014); challenge and rapport; transactional analysis (Schlegel 1998); and stages of change (Prochaska and DiClemente 1983). Specific techniques demonstrated by the trainers and practised by the trainees included the TGROW model of coaching (topic, goal, reality, options, will/way forward)(Jones et al. 2013b); the Diamond model of coaching (McDowell 2018); the ABC model of coaching (antecedents, behaviour, consequences) (Jones et al. 2013b); managing interferences using coaching (McDowell 2018); solution

focussed coaching (Grant 2011); and brief motivational interviewing using decisional balance tools (Miller and Rollnick 2012). As the trainers were responsive to the topics raised by the group and tailored their delivery accordingly it was difficult to undertake any formal fidelity assessment (as the trainers would have planned to be flexible in their delivery).

#### 5.4.4 Web resource

The standard health coaching training package does not facilitate any interaction between training participants either between the two training days or after the training has ended. I was concerned that as I expected a large proportion of participants would attend the course alone, it might be difficult for them to embed the training into practice without some ongoing team support (which my developing theories had suggested was important). I hoped that it might be possible to create an online community of practice (Jiménez-Zarco et al. 2015) to support staff during and after the training. I therefore set up a basic secure website (accessible only by course attendees who were allocated usernames and passwords at the first training day) using the platform MoodleCloud. This platform was chosen because it was free to use, designed to be easy to programme for users with no experience of web design, and could fulfil the necessary security requirements (including having servers based within the EU). Screenshots of the website sections can be seen in Appendix L. The website aimed to provide a safe space for participants to discuss issues relating to their experiences of trying to implement the training. It also acted as a resource repository, providing links to some related

websites and journal articles and encouraging participants to share other resources with the group.

# 5.5 Evaluation plan

# 5.5.1 Designing a realist evaluation

The initial rough theories generated in Chapter 4 were used to generate four core research questions to focus the scope of the evaluation. The more detailed CMO configurations produced from the literature review in Chapter 4 also helped inform the direction of the investigations.

Table 5.2 Core research questions generated from initial rough theories

Initial Rough Theory	Core question to address
Health professionals who believe they already	How, and in which
support self-management effectively, or who feel	circumstances, do SMS training
uncomfortable with sharing responsibility are	interventions help participants
unlikely to engage with training or change their	to recognise the difference
practice. When training interventions demonstrate	between current practice and a
how self-management support is different to current	new approach and to value the
practice and emphasises its benefits, professionals	new approach over existing
are more likely to value training and try to integrate	ways of working?
new skills into practice.	
In the context of a complex caseload, when patients	Does training clinicians in
have multiple interacting symptoms which make	specific SMS skills help them to
self-management a challenge, professionals may feel	see these skills as applicable to a
that self-management is too burdensome. If	wider population?
professionals are trained in specific skills that take	
into account these complexities (e.g. how to tailor	
self-management support), they will be more likely	

to attempt self-management support in complex situations. Training in self-management support is most likely How does team support to be successful when whole teams develop a influence the implementation of shared understanding and work collaboratively to SMS? optimise support. This may be achieved via whole team training and providing regular space to discuss self-management within the team. Conversely staff who attend SMS training but return to work in an area where there is little colleague support for the idea are unlikely to continue to use and develop their skills. If organisational priorities do not include self-How do organisational priorities management support, this will be viewed as a lowinfluence how individuals value priority activity and other activities may be SMS? prioritised. Conversely if the organisation proactively supports SMS provision (for example through the structure of appointments, providing practitioner flexibility to adapt how they work, availability of clinical supervision/ongoing training, and through the collection of feedback about SMS) individual professionals will also value the activity more.

As described in chapter 2, realist evaluation necessitates a mixed methods approach in order to gather appropriate data to fully understand context, mechanisms and outcomes.

I planned to collect four different and complementary sources of data for the evaluation phase of the project, all of which were intended to help refine the theories developed in the first stage. The data collection methods used were:

- participant observation of the training,
- telephone interviews with the training participants and trainers
- pre- and post-training questionnaires
- analysis of web resource use

I decided to use predominantly qualitative methods (Schifferdecker and Reed 2009). Although quantitative data is typically used for outcome testing, I recognised that identifying some of the subtle and nuanced target outcomes around shifts in professional identity would be challenging using mainly quantitative instruments.

## 5.5.2 Observations

## 5.5.2.1 Rationale

I outlined the advantages of using observations in a realist evaluation in Chapter 2. Attending the training provided the most efficient way to gain a thorough understanding of what the training experience involved. The opportunity for me to attend was easily available (as I had organised the training and liaised with the training provider) and I anticipated being accepted fairly easily into the group due to my professional background. Making observation notes in a training setting was also less likely to be seen as intrusive as many participants were also taking notes during the sessions (Schensul et al. 1999).

### 5.5.2.2 Approach used

All training participants (together with the trainers) were provided written information about the study prior to the training. I also gave a brief verbal description of my role as a participant/observer at the beginning of the first session. All participants and trainers provided written informed consent for the observations to take place. They were also offered the opportunity to redact any comments they did not wish to be included in my notes. Initially I had intended to take on the role of non-participant observer. I had envisaged that it would be possible to observe the presentations given by the trainers alongside the trainees and then, when breakout activities occurred to act as an observer by walking around and 'listening in' on groups conversations, rather than becoming a group member myself. During the first training day it quickly became apparent that as many activities were done in pairs, observing a pair for a prolonged period (in order to get a good sense of what was happening) might feel very intrusive, could influence what was discussed and might impact on the trainees overall experience of the training. Furthermore, the trainers were very keen that I should take a more active role as a full participant observer. They felt that I needed to have the experience of coaching and being coached to fully understand how the training was working for attendees, and I could see the value of a fuller form of participation in allowing me to experience the training mechanisms for myself. I therefore joined in all the pair and small group work as an active participant. We rotated groups and partners for each activity, so this gave me the opportunity to work with multiple individuals. I did not get any sense that the participants were unwilling or uncomfortable in working with me as a fellow participant.

My role as an observer was more visible to the participants during the presentations, small group work and larger group discussions when I took notes describing the topics covered and participants' responses and reactions. I had originally intended to use a structured template to record my observation notes. In the event it proved easier to just document my thoughts in notes which I then wrote up shortly afterwards and augmented with further details and reflections. During note taking I was cautious to identify when a note related to my own feelings and interpretations (Schensul et al. 1999). This fitted with the approach advocated by Spradley (1979) (making brief notes at the time which are later expanded, while also keeping a separate record of ongoing analysis and interpretations made). I also tried to document when comments came from the trainers rather than participants. I was less successful in this approach during the group feedback sessions, when often a point would be raised by a trainee and then elaborated on by one of the trainers. My resultant notes did not always make clear what proportion of an idea belonged to a trainee and how much came from the trainer. I was more sensitised to the need to differentiate these in note taking on the second day of observations. An administrative colleague assisting with the organisation of the training also observed the session and took notes. I was able to refer to these notes alongside my own when writing up my more detailed observation notes to supplement and triangulate my own observations.

## 5.5.3 Telephone interviews

### 5.5.3.1 Rationale

Qualitative interviews with the participants in training were an important way to gather data, particularly around training mechanisms. The ways in which a realist qualitative interviews differ from other interviewing approaches (including having my theories as the main subject of the interview and using a teacher-learner approach) were outlined in Chapter 2.

## 5.5.3.2 Approach used

The interview topic guide was written around the theories developed during the first phase of the PhD. Multiple open questions were used to encourage trainees to reflect on their own experiences as well as more focussed questions specific to elements of context, mechanism or outcome that I believed were likely to be important. The topic guide was developed in advance of the first training day so that ethical approval could be sought for all elements of the intervention within one application. This meant participants could receive one combined information leaflet about the whole study rather than needing to read multiple similar leaflets for each individual component. The topic guide included questions about the training itself, the implementation process and relevant existing substantive theories, with a plan to focus on different topics at different time points. The submitted ethics application also highlighted that emerging findings from the ongoing analysis would be used to refine the questions relating to specific elements of context, mechanism and outcome.

All training participants were invited for a telephone interview following the training. A sign-up sheet for interview times and dates was circulated at the second training day. Participants who were unsure of their availability on the day were emailed with suggested days and times. The initial interviews were scheduled to start from two weeks after the completion of the second training day. Although I had some theories from my earlier work, the first set of interviews still focussed on theory generation and involved mostly open questions to encourage participants to describe their experiences (Manzano 2016).

Those training participants who participated in the first set of interviews were asked for permission to be re-contacted 3 months following the training for a second follow-up interview. These repeat interviews focussed much more on testing the theories that had been developed and refined during the ongoing analysis of all the data already collected. As a result, these interviews used the learner-teacher style more, sharing insights gained from the data and experiences of other participants and encouraging participants to dispute or elaborate on my findings (Manzano 2016).

All interviews were audio-recorded for transcribing. I transcribed eight interviews and the remainder were transcribed by professional transcribers. When I had not transcribed the interview myself I listened back to the interview while reading the transcript produced to make any necessary corrections. This also acted as a first step in the analysis process, by further familiarising myself with the data and allowing me to use the way in which the participants spoke (which is easier to

identify from the audio recording rather than the written transcripts) to better grasp the meaning of what the participant was trying to convey (Bailey 2008).

### 5.5.4 Questionnaires

### 5.5.4.1 Rationale

Using questionnaires provided the opportunity to gain some quantitative data to assess outcomes. A questionnaire could assess participants' self-reported levels of knowledge, confidence and coaching technique usage and before and after training to examine areas in which the training may have had an impact. I was aware that the sample would be too small to identify statistically significant correlations and relationships and I would be limited to performing a descriptive analysis. This would provide useful evidence for the basic underlying assumption of the training (that it would improve participants' knowledge and confidence in specific health coaching skills). It would also provide evidence about whether any changes reported immediately after training were subsequently maintained.

My initial preference was to use an existing validated questionnaire instrument in order to save time in producing an instrument, facilitate comparison between my findings with those from other settings and increase confidence in the validity of the findings (Boynton and Greenhalgh 2004). The criteria I applied when looking for an appropriate instrument were as follows:

1) The instrument had to be freely available for use

- 2) The instrument should be relatively short (this would allow for the questionnaire to be completed within the training sessions to maximise the response rate, and would avoid the risk of participants becoming fatigued and disengaging from providing meaningful responses (Galesic and Bosnjak 2009))
- 3) The instrument should be able to identify specific areas in which changes have been made rather than being a generic measure of general attitudes or confidence.
- 4) The outcomes of interest within the CMOs already developed during the review stage should all be covered (those outcomes are mapped to the CMOs below)

Table 5.3 Identifying measurable outcomes related to the review stage theories

Review Theory	Expected outcome	
1 - Evidence	Change in knowledge	
	Change in attitude	
2 - Knowledge, skills, confidence and self-efficacy	Change in knowledge	
	Change in confidence	
3 - Reflection	Change in attitude	
4 - Empathy	Change in attitude	
5 - Team and organisational support	Change in confidence	
	Change in attitude	
6 -Redefining professional role	Change in attitude	
7 - Picking the right patient	Change in intended/actual	
	use	

### 5.5.4.2 Existing measures

My starting point for identifying validated measures of self-management support was a large review of self-management measures undertaken by The Health Foundation (de Silva 2014). This review summarised themes from 23,000 studies relating to measuring elements of person-centred care, including specific examples from 921 studies. Of the 200 validated tools they reviewed across all aspects of patient centred care, they concluded that there was insufficient evidence to recommend one particular tool, both because comparative studies were lacking, and also because the relevance of a specific tool depends on the context in which it will be used. Similarly, no single tool was found to be most commonly used for assessing the level of SMS provision. The three measures cited in this review that were specific to measuring SMS from the perspective of health professionals were considered in further detail, together with two measures that I had identified during my wider reading.

Table 5.4 Instruments considered for gathering outcomes data during the evaluation

Instrument	Items	Coverage of outcomes of interest	Comments
Assessment of Chronic Illness Care (ACIC) (Bonomi et al. 2002)	28 (only 4 relate to SMS)	Knowledge - NO Confidence - NO Attitude - NO Usage – YES	SMS is one of 6 elements of chronic care assessed. Focus is on the team/organisation rather than the individual
Assessment of Primary Care Resources and Supports for Chronic Disease Self- Management (PCRS) (Brownson et al. 2007)	16 (8 relating to patient support, 8 to organisation al support)	Knowledge – NO Confidence - NO Attitude - NO Usage – YES	Used by whole teams who complete and discuss results as quality improvement exercise. Focus is team activities rather than individual activities.
Practices in Self- management Support (PSMS) (Kosmala- Anderson et al. 2011)	25	Knowledge - NO Confidence - NO Attitude - NO Usage – YES	Contains three sub-scales: clinical SMS, patient centredness and organisational SMS. Staff asked how often they apply strategies. Attitude is not directly measured but could possibly be inferred from some practices
Clinician Support for Patient Activation Measure (CS-PAM) (Hibbard et al. 2010)	14	Knowledge - NO Confidence - NO Attitude - YES Usage – NO	Attitudes relate the importance of patients: functioning as a member of care team; being an independent information seeker; following medical advice; and making independent judgements.
Self-efficacy and performance in self-management support instrument (SEPPS) (Duprez et al. 2016)	36 (each item ranked twice against two different statements)	Knowledge - NO Confidence - YES Attitude - NO Usage – YES	Asks respondents what activities they currently do and what they can do. Instrument intends to measure usage and confidence though knowledge and attitudes might be inferred from some items.

As shown in table 5.4, none of the measures identified covered all the outcomes of interest. Although it might have been possible to combine multiple measures, this is likely to have overburdened participants and decreased the quality of responses. There were also issues with the availability of these measures (for example, licences to use the CS-PAM are only provided to research projects with more than 75 participants) (Insignia Health 2018).

### 5.5.4.3 Designing a bespoke measure

In order to meet my criteria, it therefore became clear that the design of a bespoke questionnaire would allow me to focus on all of the outcomes of interest at the level of detail that was relevant to my study. To design an appropriate questionnaire, I first looked at what outcome measures had been used in the studies in my realist synthesis, together with those included in a 2017 systematic review of interventions to enhance self-management competencies among nurses (Duprez et al. 2017). I examined the bespoke measures used in eleven studies (Woodcock et al. 1999; Borrelli et al. 2008; Simm et al. 2011; van Eijk-Hustings et al. 2011; Cheffins et al. 2012; Gregory et al. 2012; Walters et al. 2012; Jones and Bailey 2013; Yank et al. 2013; Connolly et al. 2014; Juul et al. 2014) along with the questionnaires developed by the training provider for the routine evaluation of their programme. Reviewing these measures identified which constructs were prioritised for assessment by other authors and the styles of questionnaire items used.

### 5.5.4.4 *Format*

Rating scales were frequently used by other studies (with the scales varying from 3-point to 100-points). The advantages of Likert-like scales (as previously outlined in Chapter 3), include that they are easy to complete and subsequently analyse. The difficulties of using self-rating questionnaires specifically in relation to SMS training have been highlighted by other authors (Yank et al. 2013). The major concern relates to response shift bias (Howard 1980). Before training participants will often

over-rate themselves (based on only a partial understanding of the topics covered in the course). An improved understanding of SMS can lead trainees to rank their post training performance at the same or lower level (despite improvement), eliminating any possibility for the questionnaire to detect differences in practice. I decided to issue the questionnaire at three time points, immediately pre-training, immediately post-training and 3 months post-training. I chose a set of core questions which would be asked in each questionnaire (see Appendix M). For the final questionnaire I also asked participants to repeat a pre-training self-rating alongside a post-training score in order to try to identify response shift bias. I was however aware that this approach might be influenced significantly by social desirability bias (Nederhof, 1985) (as participants had been provided a place on a free training course they might have felt obliged to demonstrate within their answers that they had learned something from attending). The first questionnaire was limited to multiple choice and ranking scale items, and also collected basic demographic details from participants to identify potentially relevant context. The post-training questionnaires also included questions with free-text responses for staff to make additional comments. This provided an opportunity for staff to provide more detailed stories and could also allow for topics of unanticipated importance to be raised.

#### 5.5.4.5 *Content*

The first section of each questionnaire contained items relating to participants' attitudes towards supporting self-management (see Appendix M). Informed by the

topics covered in previous studies, questions were included with the aim of assessing:

- The perceived importance of providing SMS (Woodcock et al. 1999; van Hooft et al. 2016)
- The belief that patients would be able to self-manage effectively (Yank et al.
   2013)
- The perceived usefulness of health coaching approach (Gregory et al. 2012;
   Connolly et al. 2014)
- The perceived ease of using a health coaching approach (Woodcock et al. 1999; Borrelli et al. 2008; Simm et al. 2011; Yank et al. 2013; Connolly et al. 2014; Juul et al. 2014; Duprez et al. 2016)
- The level of motivation to use a health coaching approach (Connolly et al.
   2014)

In the second section of the questionnaire I aimed to address my other core outcome measures, (knowledge (Cheffins et al. 2012), confidence (Woodcock et al. 1999; Borrelli et al. 2008; Simm et al. 2011; Yank et al. 2013; Connolly et al. 2014; Juul et al. 2014; Duprez et al. 2016) and usage (Woodcock et al. 1999; Borrelli et al. 2008; Kosmala-Anderson et al. 2011; Duprez et al. 2016)), all of which had been assessed in some way in previous studies. To keep the questionnaire specific to the training intervention I used the competency descriptors developed by the training providers for their existing evaluation questionnaires. However, this questionnaire contained 15 descriptors (ranked only for usage). As I wanted to ask about each

items would make the questionnaire excessively long. I therefore selected seven competencies which were most specific to health coaching and did not include competencies which might be considered to be more generic patient-centred communication skills (e.g. building rapport, active listening, awareness of cues). I knew from my survey results that participants were likely to rate themselves highly in these types of skills, so these items were likely to be less discriminatory. The format and content of the questionnaires were reviewed for face validity by both my supervisory team and also the course trainers.

## 5.5.4.6 Distribution

All questionnaires were numbered with a participant identifier which allowed me to track changes in responses over time at an individual level as well as at a whole group level. Paper questionnaires (see Appendix M) were circulated to all training participants at the beginning of the first training day, and at the end second training day. An email containing a personalised link to a follow-up questionnaire on the Online Surveys platform was circulated three months after the second training day. A reminder was sent at two weeks to participants who had not completed the survey. Those participants who completed a follow-up telephone interview before completing the questionnaire were also verbally reminded after their interview.

### 5.5.5 Website usage

### 5.5.5.1 Rationale

Although it was designed primarily to facilitate contact between participants between and following the training days, analysis of web resource usage could also contribute important research data. Analysing how the web resource was used (e.g. number of visitors, number of posts created) could identify whether the provision of the resource itself was an important element of the training, triggering new mechanisms, or reinforcing those triggered on the face to face training days. Analysing what was discussed online could also provide indications of how the face-to-face training had worked for participants, from the way in which they discussed the content. Discussion board conversations might also highlight knowledge gaps, levels of confidence and contextual barriers to implementation.

### 5.5.5.2 Approach used

The MoodleCloud website provides detailed usage tracking for individual registered users (e.g. – number of logins, pages viewed, duration of viewing). This was important as it is accepted that a large proportion of participants in online communities of practice are observers who engage with the community by reading the comments of others rather than by actively posting themselves (Ikioda et al. 2013). It was therefore important to distinguish staff who engaged with the web resource through posting, those who engaged through observation, and those that did not engage at all. As well as producing a basic descriptive quantitative summary of website usage statistics, the discussion board posts themselves were used as an

additional source of qualitative data and comments made were imported directly into NVivo 11 (QSR International) for analysis alongside the observation and interview data.

## 5.5.6 Ethical Approval

Ethical approval for the activities within the realist evaluation stage was obtained from Cardiff University School of Medicine Research Ethics Committee (SMREC 17/66) (see Appendix N). Confirmation was provided by the Research Governance Officer at Cardiff University Research and Innovation Services that NHS Research and Development approvals were not required. Participants in all study activities received written study information before providing written informed consent. When there was a delay between consent provision and data collection (e.g. at the follow-up interviews), consent was re-confirmed prior to data collection. Copies of the participant information leaflet provided, and the consent forms used are included in Appendix N.

## 5.5.7 Data Analysis Plan

A triangulation approach to analysing the mixed methods data collected was adopted, with quantitative and qualitative data being collected and analysed concurrently (Schifferdecker and Reed 2009).

#### 5.5.7.1 Quantitative data

Descriptive statistics were generated to summarise the distributions of responses to the rating scale and multiple-choice sections of the questionnaires. The analysis focussed on the frequency of responses and on identifying the changes in individuals' responses over time. I chose to focus on describing how individual's responses had changed, rather than on average response changes across the whole group, as this is more in keeping with a realist analytical logic and could help different responses to training to be identified. No further statistical analysis was undertaken due to the small sample size and incomplete follow-up data available.

## 5.5.7.2 Qualitative data

NVivo 11 was used to manage the qualitative data (pre-training focus groups, free text questionnaire responses, interviews, observation notes and web resource entries). The analysis made use of both a deductive approach (by coding the data under the theories generated during the review stage of the PhD) and an inductive approach (searching for new theories arising from the data itself).

At the start of the coding process, a set of nodes was generated for each existing theory from the review (one high level node and several 'child nodes' which described different aspects of the theory). These were supplemented by a set of nodes developed based on the reflective notes I made during the interviewing stage, which identified issues not already explored in depth in my existing theories. This set of inductively developed nodes was added to during the coding of the initial questionnaire responses and the first five interviews, after which point no new

nodes were needed (see Appendix O for coding framework). Initial first pass coding of all the initial questionnaires and interviews was undertaken. At this point the data coded under all nodes was reviewed, and this process allowed some nodes to be merged. Decisions taken during this process were recorded in a linked 'memo' attached to each node.

The coded data were read and re-read and used to develop If-Then statements to begin the process of theorising. Related statements were group together and key areas of significance were identified with four overarching themes emerging which were developed into higher level theories. The content and organisation of these theories was informed by the quantitative findings, the theories developed in the review stage and my existing knowledge of the formal theories identified during the review stage. For example, understanding of the Technology Acceptance Model (Venkatesh and Bala 2008) was particularly helpful when exploring perceptions about the value of the training. I used the writing process as a further analytical tool. During this phase there was frequent movement between data already coded at relevant nodes and the transcripts as a whole. I also continually referred to the coded data while working to generate the higher-level theories which formed the basis of the reporting. This helped to ensure important findings from the original data were adequately represented. The quantitative data were also examined alongside the qualitative data at this stage, with an emphasis on triangulating the findings around reported outcomes.

Cartwright and Hardie (2012) discuss theorising as occurring in two different directions. The analysis required frequent horizontal theorising to identify how

context influenced the training outcomes. This was often an interpretative process as data about context was not always described by participants as directly linked to mechanisms or outcomes. Vertical theorising was also required, where the level of abstraction increases with a move from very context-specific towards more generalizable theories. This was one of the most difficult parts of the analysis, necessitating a balance of theorising at a level high enough to be useful, while also being specific enough to maintain relevance and applicability to the setting of interest (Cartwright and Hardie 2012).

## 5.6 Chapter summary

This chapter has described the rationale for choosing to evaluate an existing training programme in health coaching skills. I first outlined why evaluating an existing programme was favoured over designing a new intervention. I then explained how health coaching skills might meet the needs of the training participants. The background of health coaching as an intervention has been outlined and gaps in the existing evidence base identified. In the second part of the chapter I outlined the methods used to inform the tailoring of the training, and then described the data collection methods used during the evaluation.

The results of the evaluation stage are now presented in Chapter 6. The role of existing formal theory in the analysis of these results is explored in Chapter 7.

Discussion of the results in the context of the wider literature then follows in Chapter 8, together with reflections on the thesis as a whole and suggestions about the next steps.

## 6 Results of training evaluation

This chapter presents the data from the second phase of the PhD and shows how these data have been used to further develop theories specific to the health coaching intervention evaluated. The data are organised and presented in relation to the theory they helped to develop, rather than by data source, in order to make the contribution of the different data sources to each theory explicit. For each theory developed I first discuss the background and relationships with theories derived from the realist synthesis. I then present data which relates to outcomes, the reasoning element of mechanism, the resource element of mechanism and context. This is followed by a diagram which aims to summarise the important causal pathways identified. The section for each of the four theories then concludes with a theory statement derived from the evaluation results. These are presented at a higher level of abstraction than the original data. Each theory statement represents the consolidation of multiple lower level more granular theories which were developed during the analysis. An example of this consolidation process is provided in Appendix P. The new theories generated from this evaluation stage are integrated with those from the review (Chapter 4) in Chapter 7.

## **6.1** Contributory data sources

The data presented within this chapter were derived from the sources outlined in table 6.1.

Table 6.1 Evaluation data sources

Time point		Activity	Participants	Duration
Pre- training	November 2017 (before training day 1)	Two focus groups held at national conference	16 (6 nurses, 10 therapists)	Each group lasted 50 minutes
	January 2018 (immediately before training started)	Questionnaires	20 (100% response rate)	
During training	January 2018 and April 2018	Observations	20 course participants and 2 trainers	2 full days of training
Post- training	April 2018	Questionnaires	20 (100% response rate)	
	From 10 days to 7 weeks post training (17/19 within 4 weeks)	Initial participant interviews	19 (95% response rate)	11-33 minutes
Follow-up post training	12-24 weeks post training	Questionnaires	13 (65% response rate)	
	14-24 weeks post training	Follow-up participant interviews	11 (55% response rate)	29-41 minutes
	September- October 2018	Trainer interviews	2	49-60 minutes
	Website open for duration of evaluation	Website discussion board posts	3	

Data extracts below are labelled according to participant number P1 to P21 for training participants and T1 and T2 for trainers. The time point at which the interview took place is also highlighted for training participants whose data come either from initial or follow-up interviews. Focus group participants are labelled

according to which group they attended, (FG1 or FG2) followed by a participant number (e.g. FG1P1). Extracts from my own observation notes are also labelled.

# **6.2** Training participant characteristics

Twenty-one professionals attended the first training day but one professional was unable to complete the second day, resulting in twenty participants in total completing the training.

Background	Number of participants (% of total participants)
Nursing	5 (25%)
Physiotherapy	5 (25%)
Occupational Therapy (currently working in therapist role)	5 (25%)
Occupational Therapist (currently working as Clinical Specialist)	4 (20%)
Speech and Language Therapy	1 (5%)

Nineteen of the twenty participants were female. Over half had worked in the neurology setting for more than ten years (see Figure 6.1). Half of the participants (n=10) specialised in working with people with a single neurological condition while half worked with people with a range of different neurological conditions.

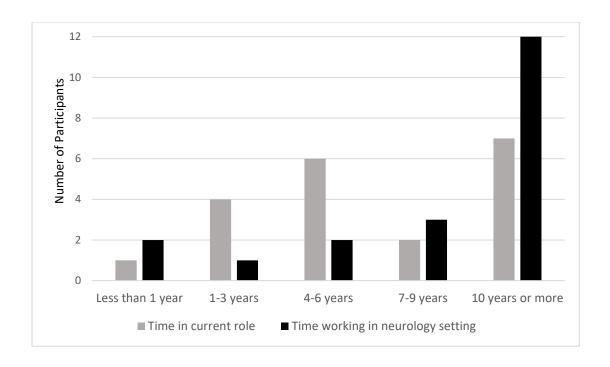


Figure 6.1 Length of time participants had worked in current role and in the neurology setting

After the initial round of post-training data collection, complete data (completed questionnaire and interview) were available for 19/20 participants, with partial data (questionnaire only) for one participant.

After the second round of follow-up data collection complete data (second interview and questionnaire) were available for eight participants, partial data were obtained for a further eight participants (questionnaire only = 5, interview only = 3), and no further data were obtained from four participants.

## 6.3 Critical reflection

## 6.3.1 Background

The theory described in this section focusses on the process of critical reflection that was triggered by the training, which caused participants to think differently

about their role within consultations. This process then went on to impact significantly on how participants perceived the value of the health coaching approach, which will be described in detail in section 6.4. This section provides evidence to support and refine two of the theories developed from the realist review, which were:

Review Theory 3: Training frequently provides opportunities for staff to reflect on their current practice in relation to SMS (Mresource). Influenced by pre-existing ideas about SMS (C) this reflective process may act to validate current practice (Mreason) or demonstrate a need for practice change (Mreason – leading to O). Characteristics of the training (Mresource) influence the likelihood of facilitating helpful reflection, and in some cases, training is insufficient to overcome pre-existing ideas about SMS (C) and meaningful reflection (Mreason) and practice change (O) does not occur.

Review Theory 4: Both training activities and applying SMS principles in practice (Mresource) can generate new empathy for patients based on a different perspective on their lives (Mreason). This new perspective can alter professionals' expectations of their patients (O). The development of empathy relies on reflective skills which may be facilitated or inhibited by personal, organisational and training characteristics (C).

#### 6.3.2 Outcomes data

The qualitative data clearly indicated that an important outcome for many participants was a change in the way in which they viewed their role within a consultation.

P13: It has made a very big difference in the way I view my interactions with patients (initial post training questionnaire)

In particular, participants emphasised how they started to shift towards thinking of their role as enabling patients to take a more active role in their health rather than simply providing solutions.

P2: I'm very eager to please and fix things, so that learning not to do that, I can't say I've stopped doing that, but realising there's more, there's more, there must be more to my interventions than doing that. (initial interview)

This key outcome had also been experienced by some of the focus group participants who had attended training courses on motivational interviewing.

FG1P1: I think in certain, like, years ago in training it was like you had to make everything right didn't you? You had to be that

FG1 (speaker unclear): Solve that problem?

FG1P1: Solve that problem, and sometimes you can't, and it's being, I felt it was just suddenly thinking, well actually sometimes we can't and we have to be, not feel bad about that.

Participants described no longer feeling that they needed to provide a solution for every problem presented or to impart as much knowledge as possible within a single appointment in order to feel that they had done a good job.

The questionnaire did not appear responsive enough to fully capture the subtlety of this outcome, but two items were relevant. When asked about the importance of supporting self-management most participants rated this as very important before

the training and the majority did not change the rating on the 1-5 Likert-like scale (not important to very important) they gave before and after training (see Figures 6.2 and 6.3).

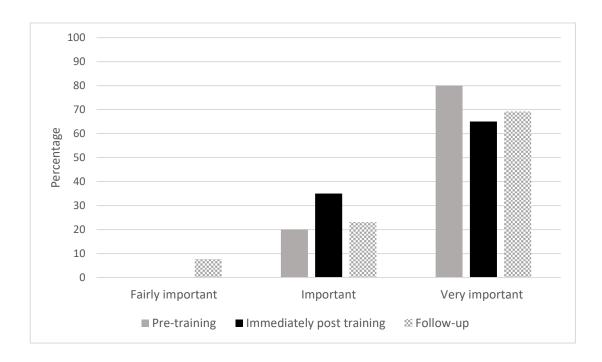


Figure 6.2 Importance of supporting self-management in relation to other tasks rated over time

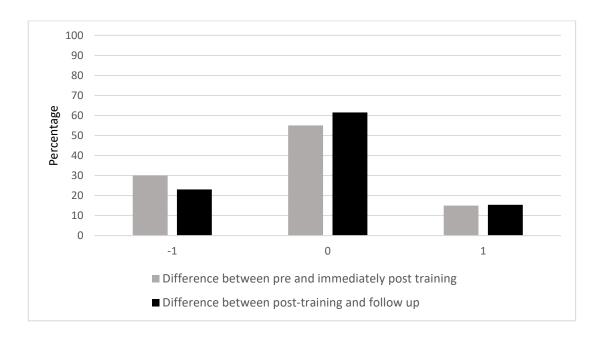


Figure 6.3 Percentage of respondents with each change in score of importance of self-management support at two time points

The spread of agreement with the statement "With support, my patients can self-manage their condition effectively" was similar before and after training, with a suggestion that with more experience of trying to apply the intervention in practice, participants might be less likely to agree. Most participants did not change their score when compared to the previous rating they provided at either time point (see Figures 6.4 and 6.5).

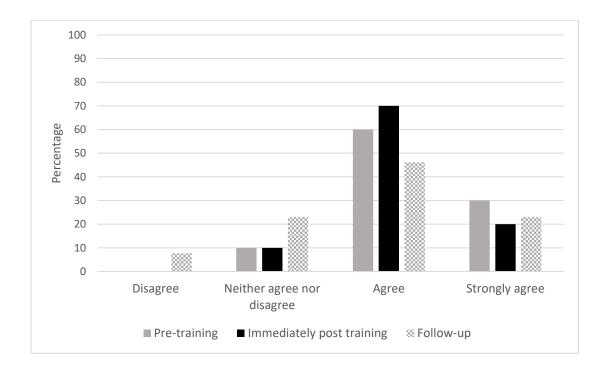


Figure 6.4 Agreement with the statement: With support my patients can self-manage their condition effectively

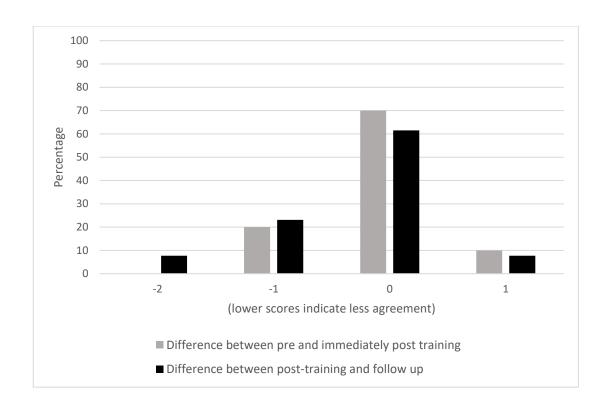


Figure 6.5 Change in agreement with the statement: With support my patients can self-manage their condition effectively

## 6.3.3 Mechanism reasoning data

During the training days participants fed back that increasing self-awareness about their current approach had been an important part of the learning experience, and this was echoed in the interview findings.

P21: It's definitely made me think more about how I, and have more of an awareness about how I am in sessions and how that determines the outcome really. (follow-up interview)

Participants became sensitised to the impact of their approach and recognised how their current style might not be entirely helpful and could even foster dependency.

P14: I thought that was really powerful actually because you think now I know how a patient feels when we're asking 21 questions (initial interview)

More often the empathy developed seemed to relate directly to how people experienced consultations. There were also examples of participants gaining

appreciation of why people struggle to make positive behaviour changes when participants reflected on their own difficulties in making behaviour changes successfully. Participants were also able to reflect on the advantages of using a coaching approach in comparison to their usual style. The benefits listed by participants during the training included that coaching helped them to gain clarity and perspective on a problem, understand why they had not already made a change, decide exactly what they wanted to do and identify ways to move forward.

#### 6.3.4 Mechanism resource data

The simplest way in which the training facilitated critical reflection was by the provision of dedicated time outside of the workplace.

P18: I always find you learn a lot at work, but then you can think about how you practise much better when you're not in that environment (follow-up interview)

As well as providing time to reflect, it was also important to participants that the training had provided what felt like a safe space to critically examine personal practice. The trainers emphasised the importance of a contracting process which they undertook early on the first training day when the group jointly agreed their rules for successfully learning together.

T2: It's not because they're all from the same profession that they were such a great group, they were a great group because of the environment that we created.

Interestingly, none of the participants referred to these rules when discussing the safety of the training, but instead referred to an atmosphere of mutual respect and feeling connected to the group which they often attributed to their similar

caseloads and understanding of each other's roles. One participant highlighted the value of the opening circle introductions in building a shared understanding among the group members.

P15: It was good that we shared a little bit about where we were coming from we did that to start with, I think that did give us a sort of bond that we were all fairly likeminded in wanting to do our job better (initial interview)

The trainers also emphasised how they ensured that the learning processes throughout the training mirrored a coaching type approach, providing triggers for reflection and encouraging participants to identify their own solutions.

T1: we want them to discover that themselves, rather than feel condemned for doing the things that actually most clinicians do and find tricky

Participants noticed that the trainers 'practised what they preached' when, for example, the trainers responded to questions by inviting the participants to come up with their own answer, and this modelling of the coaching approach prompted reflection on its benefits. Several participants also commended the trainers on their willingness to be vulnerable during the training by discussing 'real-life' issues adding to the authenticity of the experience. This modelling of vulnerability may have also encouraged the trainees to be more authentic in their own role-plays as I noted during the observations:

"This feels like witnessing a real demonstration as opposed to a 'performance piece'... the trainers are modelling how they want the trainees to perform in the next section — working with genuine issues and providing a degree of self-disclosure in a limited way." (Day One observation notes on first coaching demonstration)

As well as modelling a coaching approach during their interactions with the participants, the trainers also demonstrated critical reflection on their own clinical practice through the provision of frequent anecdotes. These anecdotes, which the

trainers used extensively during the training days provided prompts for reflection as participants could identify with the experiences described. Anecdotes also acted to remind participants that the trainers came from a healthcare background. This significantly enhanced the credibility of the trainers, which the participants rated highly, and helped participants to identify with the trainers and the relevance of the approach they were advocating.

P17: They were obviously clinicians as well so it felt like they understood the issues that we might come across. (initial interview)

However not all participants found the trainers use of the coaching approach helpful for their learning. My observation notes indicated my sense of frustration when specific queries about using the coaching in more challenging scenarios were not adequately addressed (with participants instead encouraged to generate their own solutions) and this might have explained why a few participants expressed uncertainties about how to handle more difficult situations.

P21: I think it's a useful tool, where I think the challenges are though, is that I work with quite a lot of cognitively impaired patients, and I'm not sure where that fits in (initial interview)

A wide range of activities were provided as triggers for critical reflection over the two training days. One of the triggers many participants described as helpful was an analogy about how a patient's problem was like a shiny box that they put down during a consultation and the clinician was desperate to pick up.

P8: the analogy of the shiny object really brought it back to me, kind of summarises it – just because you know a lot of the time as health professionals we focus on that shiny object and want to solve it for them – but actually we need to take that step back and focus on them solving the problem (initial interview)

This analogy helped clinicians to understand the difference between their usual approach and a coaching approach, and they identified strongly with the automatic tendency to focus on providing solutions.

Role play exercises offered another opportunity for participants to identify their typical consulting behaviours and highlight how these differed from a health coaching approach. They also offered an opportunity to reflect on the patient experience and to understand how it might be necessary for participants to change their approach to better accommodate their patients' needs.

P8: it really helped me understand why, how some of them are like what they are, and I think it's not that we should complain .... the onus is on us to try and understand them better to help them better (initial interview)

Finding the experience of being coached useful also helped to confirm for participants its potential role within consultations.

P12: it was interesting how easy it was to say 'oh yes I should be doing that shouldn't I' and actually, it's almost like giving yourself a good talking to isn't it? (initial interview)

Following demonstrations and role-play activities, the trainers often asked questions during group feedback discussions to ensure that trainees had noticed what was intended and to draw their attention to areas of importance that they might not have otherwise observed and reflected upon.

Despite the focus on learning a range of different coaching models within the training, from the trainers' perspectives developing competence in using specific techniques was not the main aim of practicing these different approaches. Instead,

demonstrations and role plays focussing on specific models were used as a way of triggering reflection on current practice.

T2: The rationale is that learning the technique and practicing the technique causes them to evaluate their skillset in a way which influences their mindset around what they're doing and why they're there, and how they have conversations

A more confronting exercise in which pairs were asked to stare at each other while thinking about their partner in a range of different ways (e.g. as a problem to be fixed) received mixed reviews, with some finding it too uncomfortable to be worthwhile, while others found it genuinely enlightening.

P17: when we're reflecting about how we see ourselves and how we see others going into the consultation, that was, that was quite, that was a bit of a light bulb moment in some ways (initial interview)

The trainers emphasised that providing exposure to the views and experiences of fellow trainees is another way in which the training prompts critical reflection.

There were frequent opportunities for discussion in pairs and amongst the wider group provided throughout both days, with participants often being set a topic to discuss with a partner before the same issue was discussed in the wider group.

Efforts were also made to encourage participants to continually change the people who they talked to, to facilitate exposure to a wide range of viewpoints and trigger personal reflection.

T1: they're hearing their colleagues, that's the issue, it's not the course or the content so much as what's normalised by their colleagues, I think

Participants did frequently describe the other group members as having significantly contributed to their own learning by providing a safe non-judgmental space in which they felt supported to reflect. Participants also recognised that the training provided an unusual and welcome networking opportunity to share experiences with staff who work with similar caseloads. This may be particularly influential in the PNC setting where staff in specialist roles may not frequently meet with colleagues who work with the same cohort of patients. Recognising shared challenges with routine practice could act as reassurance as well as providing ideas about how practice could be changed.

P10: It would've been less meaningful if we were in there with a group of district nurses, or musculoskeletal physios or whatever... no it was really good that the cohort all had similar roles, or you know worked within similar areas, definitely (initial interview)

Junior staff mentioned learning from the experiences of senior colleagues, while other participants found the training provided insights into how other members of the multi-disciplinary team worked. One whole group activity that participants frequently described as a trigger for critical reflection involved participants standing on a scale, positioning themselves to rate how directive their routine practice was.

P16: when we all had to stand in that line of directive to non-directive and I just had to stand right at the back because I thought 'Oh God I do talk far too much' and then that really made me think about the way I do things (initial interview)

While participants had to reflect on their own performance to decide how to rank themselves, they were simultaneously seeing how their colleagues described their practice and this comparison process may have acted to trigger further reflection.

A presentation given on the first training day about patient activation levels also strongly resonated with the challenges of participants' daily practice. Some were already aware of the concept of activation while for others it was new. Thinking about patient activation caused participants to critically reflect on their expectations of their patients and how they needed to tailor their consultation levels to provide appropriate support. Participants also recognised that in order to be activated to self-manage their own condition, patients first needed to reach a level of acceptance.

P14: it's not a failing on your behalf, they're just not ready, and I think that has been a massive shift in my mindset of just thinking just because they don't want to know it now doesn't mean that you've failed (follow-up interview)

Often participants expressed a sense of relief when they came to accept that patients were starting from different points, and that people with lower activation might need a different type of support, which focussed more on "a suggestion that things could be different" (Participant 17, initial interview).

While for most reflecting on activation levels appeared empowering, for a few it led to a further sense of a being under-skilled to address the needs of this group appropriately. A small number of participants also appeared to react with a sense of resignation that some people just were not ready to selfmanage.

## 6.3.5 Context data

The majority of participants requested training places in response to course advertising. However, six trainees from a single organisation were encouraged to

attend by their manager in response to the need to meet an incentivised target for staff training in this area. Perhaps because not all of these team members had made the choice to attend the course themselves, they were a little less engaged with the research project running alongside the training (all completed the immediate post-training interviews but only three of six provided any follow-up data, compared to 13/14 of the other participants providing at least some follow-up data).

Some members of this group may have started from a different point to participants who had made an active choice to attend following reflection on their practice. Several participants who appeared highly engaged in the training process talked about having already been on a journey which involved a reappraisal of their professional role, and saw the training as a useful continuation of an ongoing process.

P9: there are certain changes that have happened over the last few years that have really made me change the way I conceive my role and I think that the coaching really cemented that and probably took that a bit further (follow-up interview)

Other participants attended the training unsure of exactly what it might offer for their practice, but still holding a strongly positive attitude about its potential and a willingness to embrace new ideas.

P16: [the course] was totally, totally different and everybody [in team] was looking at me thinking 'why on earth are you doing it?' and I thought 'it's going to be good we're gonna go for it, we'll embrace this' (initial interview)

One participant highlighted the unusual opportunity to attend a course focussed on communication skills when most CPD opportunities generally covered specific clinical topics. More experienced participants also noted that

it was helpful to have advice on communication as once you are established in role no-one ever watches you consult or provides suggestions. These characteristics which seemed to make trainees more responsive to the training were defined by Trainer 2 as a "growth mindset".

T2: if people are coming with openness and are psychologically aware they are more likely to, to land, and they are keen to learn and embrace the experience, and it's also if they get some, if it aligns to what they already do and what they already know and they've chosen to come themselves

Many of the participants identified with this position, and this mindset may have been part of why they were motivated to attend and what helped them to successfully critically reflect during the training. The trainers recognised that true critical reflection is a challenging process and that not all training participants are comfortable with being challenged to an extent that could threaten their professional identity.

T2: it's very challenging thinking that actually we haven't been doing as well as we thought we could for many years

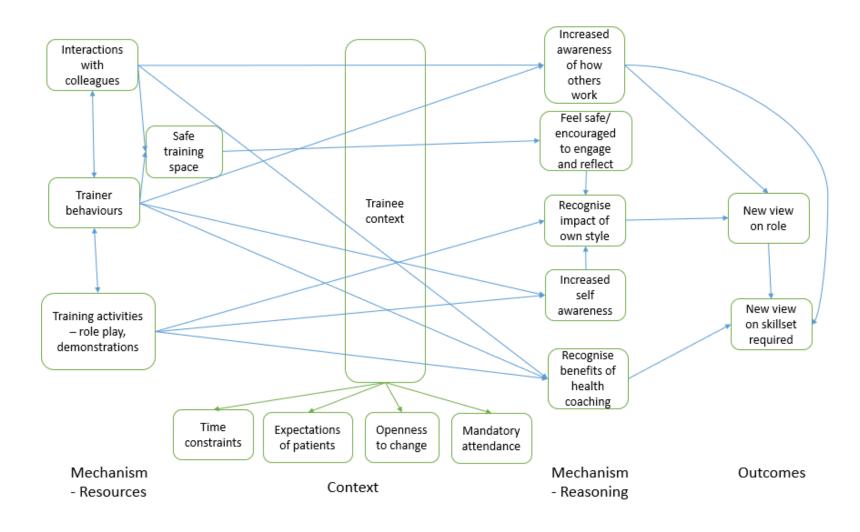
Critical reflection also seemed to be inhibited when participants became focussed on issues that were outside of their control, seeing these as the major barrier to practice change. Concerns about how the health coaching approach could realistically fit within existing routines were frequently voiced and a lack of compatibility with the other demands of the job could shift participants' focus away from reflecting on their own practice.

P1: Once it started to come to light, in the first day, you identified what your style was and how you could change it, I think the time constraint is probably the biggest challenge really. Because, at the end of it all you have a proforma that has to be ticked for auditing processes, a letter has got to be generated, and you've got people sitting outside. (initial interview)

Similarly, fixed views about how some patients might respond to a coaching style intervention caused participants to focus more on patient level issues than on adapting their own approach. The trainers recognised these barriers to participants critically reflecting on their own roles, describing the shift in thinking that was required.

T1: it comes down effectively to whether you believe in the resourcefulness of the other person being the trigger for you changing your approach, or irrespective of the resourcefulness of the other person, my ethical and value based role is to be person centred, which means changing my approach.

# 6.3.6 Theory summary diagram – Critical Reflection



In this diagram training resources are depicted as being introduced to the trainees' context. Although the influence of context was identified, it was not possible to clearly map how reasoning process were impacted upon by the different contextual factors described.

## 6.3.7 Theory derived from the results

Training activities, interactions with colleagues and trainer behaviours (Mresource) help participants to develop an increased self-awareness, an improved understanding of how others work, and of the impact of their own consulting style, and to recognise the benefits of a health coaching approach (Mreason). These training experiences lead participants to develop a new view on their own role, and the skillset they require (O). The creation of a safe training space facilitates this reflection (Mresource). Participants who attend training because it meets a pre-identified learning need are more receptive to the training (C). Those who attend because the training is mandated, or whose main focus is on issues outside their own control (patient and organisational factors) may be less critically reflective about their own performance (C).

## 6.4 Relevance to setting

## 6.4.1 Background

The theory described in this section shows how participants value the health coaching approach as being relevant to their work, and how this perceived value leads to motivation to apply the skills learned in training. Although this section focusses on how participants judged the potential value of the approach during the training course, these value judgements continued and were further informed by participants' experiences of implementing the training in practice. As this implementation started when the training was still ongoing (between the first and second training days) it has not always been possible to unpick the influence of

training from the influence of implementation. As such this theory overlaps with the theory presented in the section 6.6 which has a focus on implementation experiences.

This section develops two of the theories generated in the realist review which were:

Review Theory 1: Training provides evidence for the benefits of SMS provision (Mresource). Whether the evidence is deemed as sufficient to make SMS appear worthwhile (Mreason) depends on the type of evidence staff value most and their work context (C). If the evidence is judged as insufficient (Mreason) then SMS provision is not prioritised (O).

Review Theory 5: Organisational context (both at a high level and within local teams) (C) influences whether clinicians perceive SMS as something that they can and should integrate into their current role (Mreason) leading to variable application of SMS (O) among trained staff (Mresource).

Additionally, one further, broader theory from the review relates to the link between the process of critical reflection described in section 6.3 above, and the value judgments made by professionals about the approach.

Review Theory 6: Staff choose to work in a way that aligns (O) with their professional values or employers' expectations (C), which influences how they see their responsibility and remit (Mreason). When staff are able to critically examine their own role, and have the autonomy to make changes in the way they work, (C)

training in SMS can lead to a broadened view about professional role and new definitions of success (Mreason), leading to staff working differently and feeling more satisfied (O).

### 6.4.2 Outcomes data

Responses to the post-training questionnaires were extremely positive, with participants evaluating the training enthusiastically and reporting high levels of motivation. Prior to training most participants reported high levels of motivation, and immediately after training most maintained or improved their motivation levels (see Figures 6.6 and 6.7). Subsequent decreases in motivation after the training are explored further in Section 6.6 below.

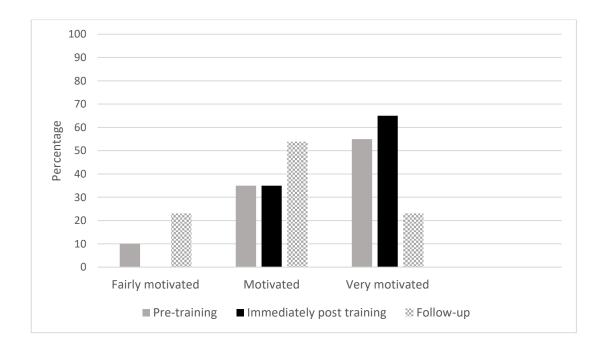


Figure 6.6 Level of motivation to use a health coaching approach in routine appointments

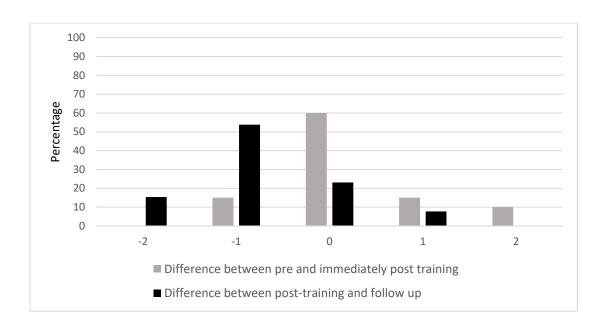


Figure 6.7 Percentage of respondents with each change in motivation score at two time points

## 6.4.3 Mechanism reasoning data

Participants reported that the health coaching approach offered a different way of working which they felt was closely aligned with their desire for patients to take a more active role in their own health.

P16: a lot of our patients want to be quite passive and just receive the therapy and I've been working for years now trying to actually move them on and get them to take a little bit more ownership. (initial interview)

During the training they reported reflecting on previous consultations that had not gone well and considering how using the coaching techniques might have made a more positive impact. Recognising the benefits of the new approach helped to convince participants of the relevance to their day to day work.

P13: I thought 'oh looking back could I have talked around the issue more, or been a bit more thorough and helped her come up with other ideas (initial interview)

Prior to training most participants already expected the health coaching approach to be very useful and most did not change their view immediately after training (see Figures 6.8 and 6.9). This could reflect a lack of responsiveness in the questionnaire (a ceiling effect) or may indicate that most of the group trained were already enthusiastic.

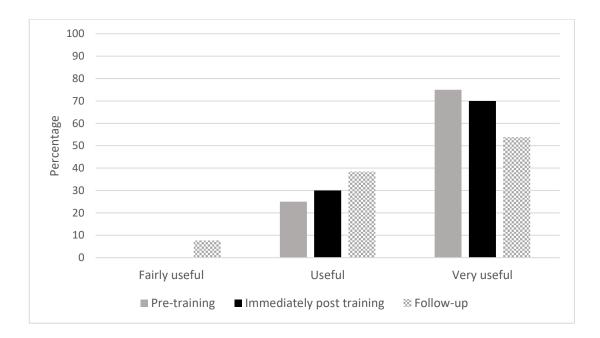


Figure 6.8 Usefulness of health coaching skills rated over time

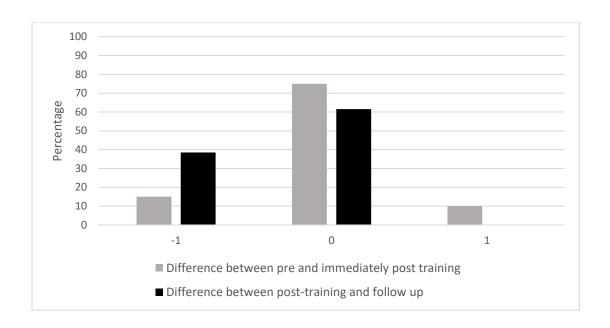


Figure 6.9 Percentage of respondents with each change in usefulness score at two time points

More changes were seen in the questionnaire item about how easy participants thought it would be to apply health coaching in practice (see Figures 6.10 and 6.11). A wider range of responses was seen in both the pre-training and post-training questionnaires. Immediately post training 37% of participants did not change their rating for how easy health coaching would be to apply from their pre-training rating, 21% of participants rated it easier after training and 42% rated it as more difficult. This might suggest that an improved understanding of what providing health coaching involved led participants to be more concerned about possible barriers to implementation.

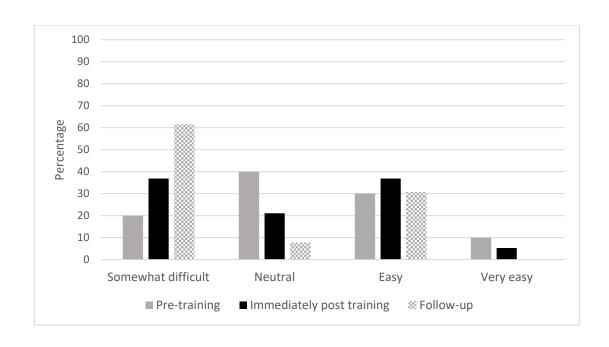


Figure 6.10 Ease of applying health coaching rated over time

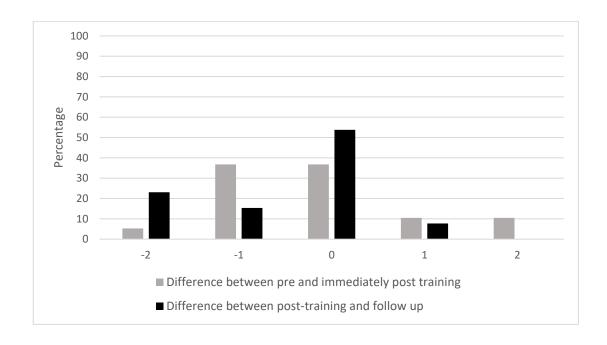


Figure 6.11 Percentage of respondents with each change in score for ease of use of health coaching

# 6.4.4 Mechanism resource data

As described in Section 6.3 on critical reflection, participants reported that training in a group was an important training resource in itself. Seeing others who were

open to changing their practice, and learning more about their experiences helped participants to think about how the health coaching approach could also be relevant to them. The practical activities which allowed participants to gain experience of the benefits of delivering and receiving coaching also acted to increase the perceived value of the approach. This element of the training is discussed in more detail in Section 6.5 about building knowledge, skills and confidence. The trainers emphasised how the experiential nature of the training was crucial in getting participants to recognise the need for practice change.

The realist synthesis highlighted the potential importance of evidence provision during training. When asked about the role of evidence participants were generally quick to agree that this was the basis for all clinical practice.

P7: we're all supposed to work to evidence-based practice so whatever we doing we're supposed to have that evidence to underpin it (follow-up interview)

Evidence had particular significance when participants felt the need to justify the reason for changes in practice, or when they worked in senior roles which might involve instigating changes in how their team worked.

P14: in our place you have to kind of prove why you're doing it, and show why you're doing it, so I think being able to quote something like 'evidence shows' or, I think that is quite powerful (follow-up interview)

Just being able to label their approach as health coaching also acted to legitimise a new way of working, and this was important for those who felt they needed to justify how they worked.

P9: there's always that slight aspect as well of having that permission to really, to give what you're doing a label (follow-up interview)

Although the materials provided during the training day included references, there was fairly limited emphasis on the underlying evidence base. Trainers felt that participants valued practical experiences more highly and while participants generally agreed, a few were more concerned about the lack of evidence provided. Most appeared to accept the knowledgeability of the trainers as an indication of the credibility of the approach they advocated. Many also recognised that when considering personal practice change it was personal experience that was more influential than research evidence.

P6: obviously it's a good thing if something is evidence based, if I find that I can actually apply it and get positive results with my patients then to me that is the most important thing (follow-up interview)

Although the evidence provided around patient activation resonated with participants, in general most 'lightbulb moments' were not triggered by evidence but came from anecdotes and personal experiences during and following the training.

Another important way in which participants became convinced (or remained unconvinced) of the relevance of the training to their setting related to how the trainers handled questions about challenging scenarios. Some participants highly valued that the trainers were open in acknowledging the genuine challenges they faced, rather than dismissing these. For this group the identification and acknowledgement of challenges was sufficient to maintain the perceived relevance of training. However, others were left with unanswered questions about how problems could be managed. My own observation notes highlighted my uncertainties.

Little attention is paid to the other staff level or patient level barriers in terms of offering any solutions— there is acceptance that they exist but these don't seem to be tackled/addressed (Observation notes from group feedback on perceived barriers, Day 1)

#### 6.4.5 Context data

Context, at the levels of the patient, the practitioner and the wider organisation all influenced the way in which participants perceived the relevance of health coaching for their work.

### 6.4.5.1 Patient level context

Participants commonly cited cognitive impairment and mental health problems as reasons that patients would not be able to benefit from a health coaching approach.

P2: I didn't feel that I could really use it with people with cognitive problems (follow-up interview)

P6: the psych issues need to be dealt with first before we can be more effective in our roles (follow-up interview)

Although some participants felt the approach was simply unsuitable for certain groups of patients, others felt that it could be suitable if they had the right skills to adapt the approach, which they felt that they currently lacked. Some of the most confident participants talked differently about seeing the value of the approach even with people with cognitive impairments, but this view was often generated as a result of their confidence to trial the approach and then witnessing positive results.

P9: using some of those really simple listening skills because they're in the moment they have an impact to the overall conversation (follow-up interview)

Wider barriers to patients engaging with an alternative approach to consultations were also identified. Participants described that existing cultural norms and social deprivation could both normalise negative health behaviours or could mean that people were generally less engaged in actively managing their own health.

Similarly, participants described patients often having high expectations of the service, and wishing to 'be done to' rather than to take an active role. Some were also able to recognise that this type of attitude may have been created by exposure to a healthcare system which typically places people in a more passive role. These participants could see the important influence of their own approach on patients' attitudes.

Other scenarios in which health coaching was seen to be challenging included where patients were still struggling to come to terms with their diagnosis, with participants feeling that a certain level of acceptance was a prerequisite for engagement

P11: some people don't want to have MS they don't like you for telling them they've got it and they want you to take it away and moving them forward from that is really tricky (initial interview)

For patients whose prognosis was short, participants noted that it was difficult to generate goals and they often felt it was more appropriate to focus on the provision of practical support. Finally, as health coaching requires the coach to believe in the resourcefulness of the person they are coaching, participants often found this challenging when their patients appeared to have limited resources to draw on.

P21: I tend to see mainly housebound patients that don't feel they have any control over their lives, they've got carers, their needs are anticipated for, they might have severe cognitive impairment, and that's really where it's difficult, because they need that support, they need sometimes they need

more of a directive approach because they don't know where to start (follow-up interview)

Interestingly, although patient level barriers were often cited as challenges to applying health coaching, when participants first started to try out health coaching, they often picked more challenging consultations. In particular, participants commonly reported that 'heart sink' patients, with whom they felt they were making no progress were often initially targeted. In these scenarios participants had already recognised that their current approach was not working, and they were keen to try a different tactic, especially as there was little to lose in these situations. The trainers also highlighted that it was helpful if participants attended training with a recognition of the limitations of their usual practice.

T2: if someone is very senior and they are, so comfortable with their skills as a clinician but they are a bit disillusioned because they are still not making a difference that they want to, then the skills they look at as a top up because they've got a reason to change because they see what they're doing isn't working

### 6.4.5.2 Clinician level context

Several other clinician level factors also influenced how the relevance of the training was perceived. How participants defined the boundaries of their own roles and what they considered to be an appropriate use of their time impacted on how they envisaged utilising the health coaching skills.

P2: I don't think that I would ever be getting to the point where I would be doing coaching as a whole session with somebody, and I don't see that as my role (follow-up interview)

Participants who worked in roles which had a strong focus on biomedical issues and required significant technical expertise generally found it harder to see the relevance of coaching. Coaching was often seen as relevant only in situations

where professional expertise alone was insufficient.

P10: if someone is presenting with pain or spasticity and swallowing issues that they don't know what needs to be done, or what medication needs to be prescribed ... but when it's more about talking to them about physiotherapy and exercise and lifestyle changes that I think is where the coaching will come in a little bit more (initial interview)

This emphasis on the value of professional expertise was recognised as a barrier to valuing a coaching approach by the trainers.

T1: if my identity is really tied up in expertise it's harder to shift that into thinking not of yourself but of the other person and what's going to help them

Some participants suggested that their prior professional training (including mental health and learning disabilities training) had already encouraged them to take a broader view on their own role in relation to empowering patients. There was also recognition among both the participants and the trainers that therapists often found the coaching fitted well with their professional identity. This seemed to relate to therapists often addressing behaviour change as a key component of their role, and discussions about lifestyle modifications being well suited to more active patient involvement. In addition, therapists were often already using strategies to try to empower patients, and were familiar with the processes of setting goals and challenging their patients to try to achieve these goals.

P5: a lot of our physical treatment challenges the patients anyway, so they're [therapists] I think maybe a bit more used to that from a therapeutic perspective ... you know we're always pushing our patients within treatment sessions (follow-up interview)

Several of the nurse participants reflected on how therapists had been trained to adopt a different attitude to nurses, whose professional identity was often closely tied to the provision of help and solutions.

P11: I think working with a lot of therapists you do realise as a nurse ((laughs)) you will want to solve things for people (initial interview)

Of note, some of the clinical specialists whose initial training was in a therapist role but who now worked in a role more traditionally adopted by nurses had also noticed a shift in the way they practiced, towards a more medical model, suggesting the influence of work context may be greater than that of prior professional training.

P2: I've perhaps I've overcompensated in my attempts to fulfil my new role and I'd become too directive (initial interview)

## 6.4.5.3 *Organisational context*

Wider organisational factors influenced the perceived relevance of the health coaching approach in several ways. A few of the more junior participants who tended to have shorter term relationships with patients and shorter clinical encounters were unsure of how well health coaching could fit into their roles. However, most participants worked in roles where longer appointments were the norm and which afforded them significant autonomy and flexibility in how they organised their time and they recognised that this made the approach more practical for them to attempt to integrate.

P4: in my role I tend to have more time than if you got people through in the clinic, I know that my home visits are going to take longer and I can fit in to my day (initial interview)

Despite long appointments, participants were often still somewhat constrained by mandatory assessments that needed to be completed and these were almost always prioritised. One participant in a senior position had the ability to change her team's assessment forms as a result of her learning from the health coaching

course and she cited this as they key factor in enabling the ongoing application of the coaching approach. Others, who were not in a position to make these changes in their teams also recognised the potential value.

P18: if we said right, we're gonna adopt this as a regular part of our

assessment, or as a particular piece of paperwork or something like that I think it would make more of a defined impact... (follow-up interview)

The content of these mandatory assessment forms and the auditing of their completion gave a clear message to staff about organisational priorities. Using a health coaching approach was often only considered once participants felt their core work of performing these assessments was completed. Recognising workplace constraints appeared to make participants less confident about the relevance of the

The attitudes of colleagues also had an important influence on how health coaching was perceived. It appeared helpful if participants could identify that the health coaching approach fit with the existing ethos of their team.

training to their day-to-day work.

P8: in our hospital we're a lot for explaining things so that health coach approach does fit in nicely with that... we always try and find ways to you know stop that frequent flyer cycle (initial interview)

Workload pressures were noted to act as motivators for both individuals and wider teams to work differently and try new approaches.

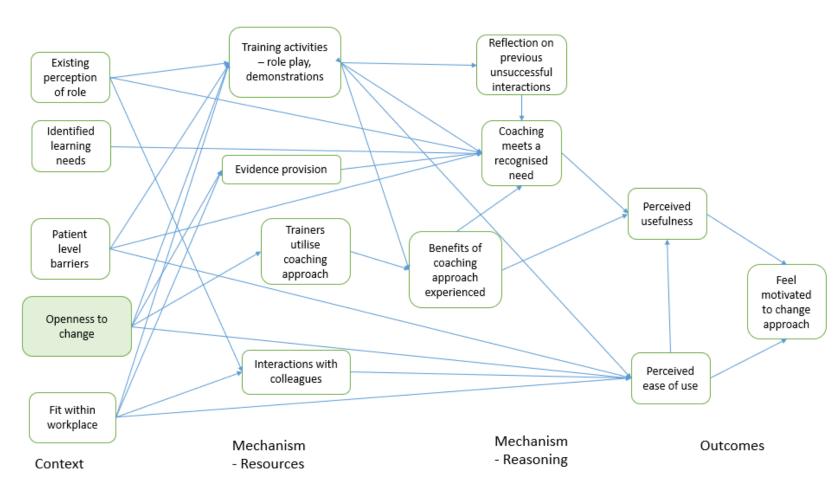
P16: the demand on our service is huge and we, as I say we are short staffed with maternity leave and some retirement... so therefore we're having to work out new ways of actually getting patients a bit more compliant and not relying on us for such a long, long term treatment sessions (initial interview)

Participants who collaborated with colleagues in the care of the same patients (e.g. running joint clinics) raised concerns about how they could use the health coaching approach when their colleagues had not received

training. Clinicians seemed concerned about patients receiving 'mixed messages' or conflicting advice as a result and emphasised the importance of a congruent approach across the team.

P18: it probably does require as a team for us to be understanding and using it together and I think it's probably something not to use on your own (follow-up interview)

# 6.4.6 Theory summary diagram - Relevance to setting



On this diagram, openness to change is shaded as its influence could not be directly determined by the data. While all participants stated they were open to change, in practice some appeared more open than others, but as this was not directly measured, the impact is uncertain.

## 6.4.7 Theory derived from the results

During training participants weigh up how useful they believe a health coaching approach is and how easy it would be to adopt, and this results in motivation (or lack of motivation) to apply the training in practice (O). Modelling of coaching by the trainers, provision of evidence for the approach and experiencing coaching (Mresource) can all highlight the usefulness of health coaching (Mreason). When the approach also fits with pre-existing ideas about professional role and meets a recognised learning need perceived usefulness is increased(C). Participants also evaluate how easy it will be to apply health coaching, influenced by interactions during training, (Mresource) and perceived fit with existing working practices and caseload demands (C).

# 6.5 Knowledge, skills and confidence

### 6.5.1 Background

This theory focusses on the relationship between increases in knowledge and skills, and feeling confident in the health coaching approach, as well as exploring the training resources and contextual factors that influence the confidence building process. It relates to the refinement of the first part of the theory about knowledge, skills and confidence generated from the review.

Review Theory 2: Providing specific tools and approaches to SMS (Mresource) to clinicians who previously lacked knowledge about how to provide SMS (C) improves

understanding of how to operationalise SMS (Mreason) which leads to an increased confidence in ability to provide support (O).

### 6.5.2 Outcomes data

At the pre-training focus group, participants identified increasing confidence as an important outcome as well as recognising a link between knowledge of specific techniques and feeling more confident to deal with challenging scenarios.

FG2P1: I think there's a confidence element, so confidence in terms of working with those clients that are struggling with approaching rehabilitation, and confidence in knowing what the tools are and using the tools, so both the knowledge and an application

The questionnaire data indicated that training did generally improve participants' confidence in health coaching techniques. Comparing the mean confidence scores (generated from confidence ratings relating to seven health coaching techniques) before and immediately after training showed that 19/20 participants had an increase in their mean score. Using a 5-point Likert-like scale (5 being highest confidence) pre-training mean scores ranged from 2 to 3.57, while immediately post training mean scores ranged from 3.14 to 4.43.

Figure 6.12 shows the change in scores for individuals comparing pre-training and immediately post-training mean confidence scores.

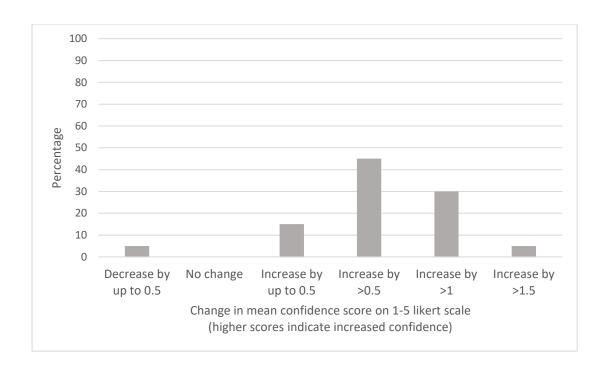


Figure 6.12 Change in mean confidence scores across seven health coaching techniques pre and immediately post-training

The questionnaire data were consistent with the trainee interview data, in which participants cited an increase in confidence as an important training outcome.

P10: yeah, I felt a lot more confident, as I say it's still kind of a work in progress but compared to how I was before it has definitely improved my confidence (initial interview)

It is worth noting that there was some variation in what it was that participants actually felt more confident about. While the questionnaire indicates increases in confidence in relation to the application of specific approaches, in the interviews participants often talked more about confidence in adopting the health coaching ethos (avoiding trying to fix people's problems for them and helping them to generate their own solutions).

P13: I'm definitely, yeah more confident because I wouldn't have even tried, tried that before whereas now I'd, I am more confident just to yeah to hand it back and try something different (initial interview)

### 6.5.3 Mechanism reasoning data

During the interviews participants emphasised that their increased confidence was linked to an improved understanding of what they could do and how they could work differently to support self-management.

P8: before I went on the course you want to help the patient, but you're not sure how and everything, just being on the course really broke that down taught us how we could do it and because I'd had that training behind me I felt that I had that confidence to go and be able to do it in practice (initial interview)

This increase in understanding was also evidenced in the questionnaire findings. Comparing the mean of scores for understanding of seven different health coaching techniques showed 18/20 participants improved their overall understanding (see Figure 6.13). Pre-training mean understanding ratings ranged from 2.14 to 4.14, while immediately post-training the means were between 3.29 and 5.

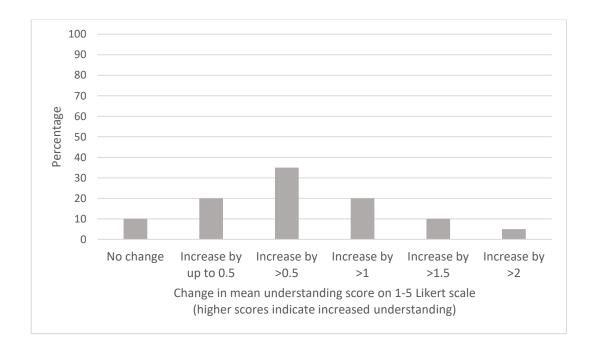


Figure 6.13 Change in mean understanding scores across seven health coaching techniques pre and immediately post training

Confidence in using the new techniques was generated not just through information provision but through practical experience of applying the techniques. Participants recognised that the role-play element of the training was critical to building confidence.

P15: Having the opportunity one to witness the trainers doing it, the role play and then to have a chance to practise it... rather than use it straight away on different clients, that gave me the confidence I think (initial interview)

As well as acting as a safe space to try out a new technique, the role play activities also acted to provide evidence of the benefits of coaching which when recognised by the participants boosted their confidence in what they could achieve even as 'novice' coaches.

P9: all of us said we were not experts, you know we consider ourselves skilled practitioners, but even so as a coachee I came away feeling like I had got something from being coached and so it was really heartening to feel that actually even if you don't have all the skills, or you don't feel totally that you are practised with them, just implementing the principles can lead to change (initial interview)

### 6.5.4 Mechanism resource data

Participants highly rated the practical nature of the skills taught on the course and felt like they had come away with some tangible new knowledge and techniques.

P6: I think the practicality of it, the fact that it's easy for us to utilise and pick, relatively easy to, to apply (initial interview)

The physical training handbook provided was also highly valued as an important reference resource. The immediate post-training questionnaire specifically asked participants what helped them to build confidence most, and of 20 free text responses 15 mentioned the opportunities for practising the skills within the

sessions. Interestingly most participants also expressed a general dislike for roleplay during training sessions but there was acceptance of its value on this course as
well as recognition that the role play activities did not feel like role play. In their
interviews the trainers described these activities as 'real-play' rather than role play,
because participants discuss topics from their own lives rather than pretending to
take on another role. Participants recognised how the authenticity of the activity is
what made it a valuable learning experience, while also recognising that a having a
'real' conversation can only happen when the participants feel safe enough within
the training environment to discuss genuine issues.

P10: although I hate that kind've role play thing, but it didn't feel like role play because you were actually doing it with a real issue for you and it felt very safe to do that (initial interview)

However, although the authenticity of the 'real-play' appeared crucial if it were to impact on confidence building, if the activity was too authentic it could have a negative effect. Although the trainers provided clear guidance on the first day about how to pick an appropriate topic to discuss several trainees reported finding this challenging. I also observed that such detailed guidance on topic selection was not revisited on the second training day. One trainee reported a dislike of the activity as during coaching she discussed an emotive personal issue which she was unable to resolve. Colleagues who came to the training together often avoided working together in pairs, and there was a suggestion that it would be more challenging to discuss genuine personal issues with colleagues you would see again outside of the training. Recognising the personal discomfort raised by the coaching process also triggered reflection on how patients might experience being coached.

she chose to avoid discussing anything too important or emotive, but as a result did not feel particularly engaged with the coaching she received. Some trainees also mentioned that that coaching in a setting where the coachee was already willing to be coached and understood the process was far removed from the realities of clinical practice, where they expected to encounter resistance and to need to justify their new approach.

P21: I think because we didn't really prepare a lot of challenges, you know getting stuck with patients, being challenged, then that for me is probably more of the reality, that's probably why I'm a little bit apprehensive about starting to embed it because I think well, what if it doesn't work (initial interview)

Although the aims of both the demonstrations and the role play were to increase understanding of how to use the techniques and so increase confidence in their application, this did not always happen. Some trainees found that the activities highlighted how far away their current approach was from that advocated during the training and that this could have a negative impact on confidence.

P2: well I think it was when you had those unpleasant little insights into how little you know (laughs) it was a bit like that..... I didn't come away thinking 'right I know what to do now I'm going to get started', it was much more 'oh heck' (follow-up interview)

#### 6.5.5 Context data

Individual, team level and wider institutional factors had an important influence in whether training participants felt adequately skilled in health coaching to be confident in adopting the approach.

At the individual level participants' existing level of confidence in their current job role impacted on their confidence in integrating a new skill. Staff who were new in post or frequently rotated through different specialities discussed how their focus was on the medical knowledge required to do the job. Their lack of confidence and security in their current role often related to feeling like they still had significant knowledge gaps. These participants described that going back to providing information was easier than using a coaching approach. More experienced participants sometimes appeared to find it easier to accept a different role which was not based solely on their medical expertise but recognised that not providing solutions took significant confidence.

P7: I think if you're not so confident, or you're, then you feel that you've got to solve it, or sort it and actually you haven't (follow-up interview)

A few participants also described how they became more confident in dealing with complexity as their experience grew, and in turn they seemed more confident to try and implement health coaching with a broader range of patients.

P16: [dealing with comorbidities] can be bread and butter, I don't think I've got one patient that's just a 'routine patient', there is no routine patient in my life, you know (follow-up interview)

In other cases, staff discussed concerns about the suitability of promoting selfmanagement among people with PNCs, revealing that they had limited confidence that there would be measurable change as a result.

P2: we're not entirely happy that our patients have been the ones who have been picked for this (local self-management support initiative) because we think that maybe people with long term chronic progressive neurological conditions, you know, it was probably meant to be more like a stop smoking kind of thing, or weight management or something a bit more measurable (follow-up interview)

Clinician's pre-formed views on the likelihood of a positive outcome particularly influenced their confidence in changing their approach when they had established relationships with patients. Multiple participants cited concerns about how they could change the dynamic within these established relationships and the training did not appear to provide them with adequate knowledge of how to broach this with patients, or any confidence that it was worthwhile trying.

P19: Because the other ones I've got a dialogue with them and have probably seen them for 13 years so you know you can't really just change everything, how you approach things with those people because they would think I'd lost the plot because I was acting differently so..(initial interview)

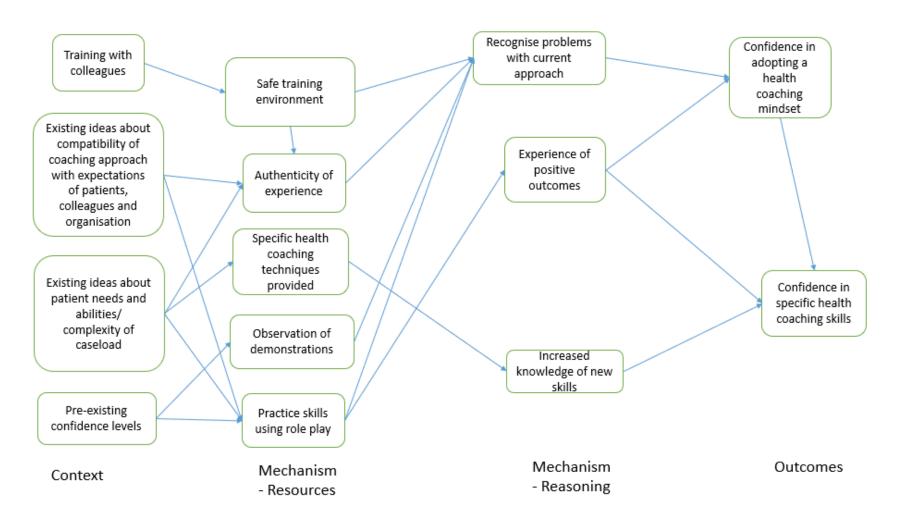
These views appeared to be built on participants' concerns about potential problems, rather than any negative experiences. This led many clinicians to reason that they were only confident to try applying health coaching techniques with new patients where there was no established dynamic between the clinician and patient to disrupt. These concerns were not reported as a problem for staff who had shorter term relationships with their patients, or who had very large caseloads or infrequent appointments which prevented forming a close relationship with individuals. If clinicians were unhappy with an established dynamic between them and their patients (particularly with frequent callers/attenders) then they seemed more confident to try the new skills as they felt they had more to gain and less to lose. Participants identified that as well as previous consultations with them, previous experiences of the wider healthcare system and societal attitudes had conditioned patients to expect a more directive approach within consultations. Clinicians who felt that health coaching was closely aligned with their existing approach were more confident in how to integrate these skills into their normal

practice. Those who seemed to have embraced the ethos of health coaching more fully also started to recognise that it might be their own confidence in handling a more challenging scenario that was a barrier.

P5: I think there would be some patients who it doesn't work so well for, who maybe just don't respond to that type of situation as well, but maybe that's partly the clinician as well, you know not being confident in, in sort've seeing that session through (initial interview)

At the team level, fixed working patterns which were outside of the control of the clinicians (e.g. mandatory initial assessment forms to complete) made them less confident about their ability to use health coaching as they struggled to adapt the skills they had learned to their routine work setting. This meant that clinicians were often only confident to use health coaching skills when they had sufficient free time and no competing priorities, and they described creating these opportunities during repeated follow-up appointments or by conducting home visits.

# 6.5.6 Theory summary diagram – Knowledge, skills and confidence



## 6.5.7 Theory derived from the results

If training provides a safe and authentic environment in which to learn and practise new practical skills (Mresource), and participants experience success (Mreason), then participants become more confident in their understanding of what doing health coaching would mean for them and in their own ability to implement the health coaching approach (O). If trainees experience the training negatively (Mreason), because it highlights their own skills deficit, fails to create a feeling of safety or appears impossible to integrate into routine care then professionals lack confidence in their own ability to implement the health coaching approach (O). Low pre-existing confidence levels, or existing views on patient, team and organisational expectations may make it more difficult to develop confidence in the new approach (C).

# 6.6 Experiences of Implementation

### 6.6.1 Background

This theory describes how participants' experiences of implementing the health coaching approach influenced their confidence in their skills and how valuable they believed the approach was. It can be seen as a continuation of the three theories already described above in sections 6.3 to 6.5 which focussed on the training stage. Critical reflection, changes in perceived relevance and value, and changes in confidence all continue to occur and evolve during the implementation stage.

Although implementation was not the main focus of any of the theories from the

realist synthesis, the influence of implementation on participant reasoning was recognised explicitly in some theories developed (e.g. empathy development).

Review Theory 7 (Picking the right patient) which describes the process of how staff decide when to implement coaching is also relevant here, but the main focus of this section lies on how experience of actually using the intervention influences subsequent behaviour. Data to support this theory were relatively weaker than those available for the training stage theories because follow-up data were incomplete and objective evidence about implementation patterns was not collected.

# 6.6.2 Outcomes data

There were mixed responses to the follow-up questionnaire relating to confidence in specific health coaching skills, with just over half of respondents rating their confidence higher at follow-up than it was immediately after training (see Figure 6.14).

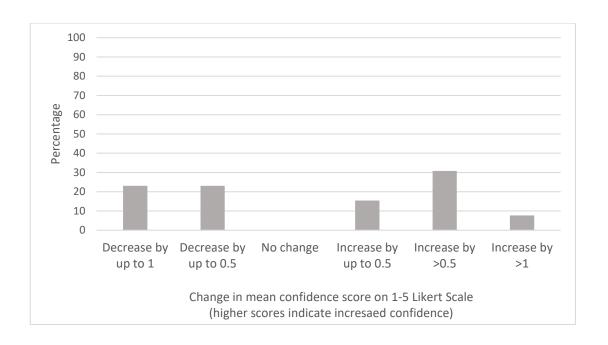


Figure 6.14 Change in mean confidence scores across seven health coaching techniques between post-training and follow-up

With increasing experience of implementation (or possibly increasing time after the training) motivation, perceived ease of application and perceived usefulness were not always maintained. Only 31% of respondents maintained or improved their post-training motivation level at follow-up compared to 69% of participants whose motivation showed a decrease at follow-up (see Figure 6.7). 54% of respondents to the follow-up questionnaire gave the same rating for ease of applying health coaching as immediately post training. 8% rated it as easier at follow-up, compared to 39% who rated it as more difficult (see Figure 6.11). 62% of participants did not change their usefulness rating at follow-up compared to immediately after training, while the remaining 39% rated coaching as less useful (see Figure 6.9). The qualitative data discussed below appear somewhat contradictory with these findings, though this may be explained in part by the fact only partial data (either questionnaire or interview) were available for some participants.

### 6.6.3 Mechanism reasoning data

Some participants were able to provide clear examples of where they felt that using a health coaching approach resulted in positive outcomes for their patients, and these visible successes appeared to be highly motivating.

P15: she felt so hopeless and helpless at the beginning of it and that kept coming through. I kept taking it back to what she had said she could do and she actually ended it saying I know what I'm going to do now... which was lovely (initial interview)

Recognising the benefits of the new approach also prompted participants to reflect on the deficiencies of their previous approach. They were able to identify that the successes they experienced could be directly attributed to the change in the way they consulted.

P5: seeing for some patients that actually that's what they needed all along and I've not been giving them that opportunity necessarily (follow-up interview)

These successes also prompted some participants to re-evaluate the previous assumptions that they made about their patients.

P21: before I probably would have said 'oh I don't know, I can't really help him, he doesn't want help, you know he's not in the right frame of mind to help himself' (follow-up interview)

While identifying benefits for their patients made health professionals value the health coaching approach, they also gave examples of personal benefits of using the new approach. Participants noted that if a coaching approach allowed them to identify what really mattered to a patient then this often made consultations more efficient.

P19: certainly from the use of it recently, I think the fact that you're not, you can get more done in a short amount of time with better outcome

and I think that you know I wouldn't have thought of it that way before but I think using these types of techniques everybody is a winner (initial interview)

One participant also noted that giving patients more responsibility within consultations resulted in interactions that were less emotionally draining, making clinics easier and less tiring. These examples highlight that when implementation resulted in positive experiences either for patients or for clinicians themselves then participants valued the new approach and felt motivated to continue. There were a few examples of where following attempts to use health coaching clinicians felt less certain about the value of the approach due to a lack of initial success.

P21: you try and start with open questions and it's closed down quite quickly and I don't really know how to open it up again... and I just go into directive mode because that's what they're expecting (follow-up interview)

One participant also reported feeling more distanced from her patients and less supportive as a result of adopting the health coaching techniques in her initial interview. However, in her follow-up interview when she had gained more experience she described that integrating coaching was no longer having a negative impact on her relationships.

Participants who were most enthusiastic about the coaching approach appeared to be able to see the value in 'unsuccessful' health coaching consultations in having an important role in introducing their patients to the possibility of a new way of interacting.

P5: even if it hasn't gone so well in terms of coaching, but it's maybe just planted that seed a little bit about how they have to take some responsibility (follow-up interview)

Many participants also described a pragmatic acceptance that even the most useful techniques would not be successful all of the time.

As well as impacting on how participants valued the health coaching approach, visible successes in the implementation phase also acted to build their confidence in their developing skills.

P8: I actually did ... just see those small changes in a very small period of time which was, it made it, it built up my confidence further which was great (initial interview)

As well as increased confidence that they could make a positive impact by using coaching techniques, participants also described becoming more confident to do less.

P16: I became... more confident to actually allow my patients to actually do everything for themselves and not needing me keeping an eye on everything that's going on for them, so I think it evolved slowly (follow-up interview)

This participant (P16) went on to explain that this confidence came from challenging her patients and seeing them experience success (which acted to develop their confidence, and also her belief that they could safely manage independently). When early attempts to use the new approach were perceived as unsuccessful participants sometimes struggled to maintain their confidence.

#### 6.6.4 Mechanism resource data

The web resource provided alongside the training is not part of the usual

training package but was offered to participants on this course as part of the PhD project. It served the dual purposes of providing a way for the widely geographically dispersed attendees to gain peer support from trained colleagues while also providing an opportunity to collect data around the feasibility of delivering post-course peer support online.

The engagement with the web resource was very limited. Fourteen of the participants (70%) never accessed the website. Three participants (15%) visited the website once, making a short visit (between 4 and 13 minutes) and not posting any content. Three participants (15%) engaged more with the website making two or three visits each (longest visits being between 33 minutes and 2 hours). Each of these participants posted once on a discussion group, with a single post which referred to an earlier entry being the only example of any interaction between participants.

Although during their interviews the training participants did identify the potential for a web resource to facilitate networking and troubleshooting, those who had trained together suggested colleagues might be able to fill this role. A lack of time during the working day and the relatively low priority of accessing the web resource in comparison to other tasks were cited as key barriers. Practical difficulties with computer access together with simply having forgotten about the existence of the resource were other reasons given for lack of engagement.

P13: I must say I didn't, I didn't get around to checking that. I mean, I think it was just because of what I had on, I think work generally just quite full on so (initial interview)

The low level of engagement from the group as a whole also had a demotivating effect on the few participants who did attempt to interact with their peers using the web resource.

P6: I did actually use it when after the first session and then, maybe I was just a bit impatient but nobody got back to me and there was no other reply and I thought oh and then I didn't go back on (initial interview)

In this theory, the second key intervention resource involves clinicians applying the health coaching approach in the workplace. There was a small group of participants who had little opportunity to experience either benefits or difficulties with the using health coaching due to their limited implementation of the training.

Participants recognised that most of their consulting behaviours were well-established routines and that it was not easy to break with their longstanding habits.

P12: I'm still doing the appointments how I did and then coming away and thinking 'oh but I could've done that' (initial interview)

Participants recognised that breaking these established routines would need an active effort and a commitment on their part. This lack of implementation experience could be in part due to participants waiting for 'the right patient' with whom to try the approach. Another group of participants clearly expressed it had been very important to them to implement the training quickly.

P7: in order to embed it into my memory I have to just start using it straight away otherwise I'd forget everything (follow-up interview)

Promptly integrating the approach into practice was easier when participants had adequate confidence to take the first step and could identify an opportunity to attempt the approach in what they perceived to be a 'low risk' setting.

P5: I certainly remember thinking I just need to try it, I'm just gonna give it a go I'm in the clinic on my own so nobody's gonna hear what I'm saying. If it goes wrong, it goes wrong (follow-up interview)

Getting going with the health coaching approach was more challenging when participants felt that it had limited applicability to their caseload, either because they felt it would not work for everyone or that it was not suitable for every type of issue.

P17: I find it's knowing the right patient, having the right patient or having the right patient issue that is something that they can kind've work on themselves, or self-determine (follow-up interview)

A few participants discussed how they would only use health coaching once they had established a relationship with their patient to allow them to make a clinical judgement on the merits of the approach.

As well as significant differences in whether health coaching techniques were used at all, and the frequency of use, there was also significant differentiation in how participants operationalised the approach. Of the eleven participants who completed a follow-up interview, seven said they were using some skills they learned on the course either most days or in most consultations, while the other four reported less frequent use (weekly (1) or every few weeks (3)). The qualitative data from those who said they frequently used learning from the training, indicated this generally related more to the health coaching ethos rather than specific skills and techniques.

P7: so I think maybe the full on using, using one of the methodologies like the Diamond model which I really like, or TGROW probably only 4 or 5 times actually, but the whole you know the lessons learned from that I think I'm bringing in to daily practice (follow-up interview)

In general participants seemed to welcome the flexibility to use the coaching approach as they saw fit, and for some even making minor tweaks in their language or approach felt like a major shift in their overall consulting style. Most participants liked the fact that they felt they had permission to adapt the approach to fit their own requirements.

P5: it's working for me having the concept there and being able to think about the questions, but not getting too hung up on following a particular model (follow-up interview)

A small number of participants remained more focussed on the application of specific health coaching tools and models and appeared to view health coaching more as a treatment to be delivered rather than a change in their own routine consulting style. The trainers recognised this as a possible outcome of training and felt this focus was driven partly by personality.

T1: they're a certain type of person as well, they have very structured, or are structurally orientated

Trainer 1 also suggested that the elongation of the training may have meant that these perceptions were not challenged as much as they usually would be when the training days are delivered closer together.

It is also notable that clinical encounters were not the only setting in which participants were able to gain experience of using a coaching approach. Six of the participants specifically mentioned applying their newly acquired coaching skills in other settings (including with friends, family, colleagues and to help to structure meetings). Being able to practise the skills in non-clinical settings provided an opportunity to build confidence and see the benefits of the approach in a low risk way.

#### 6.6.5 Context data

Individual participant level factors played a part in implementation experiences, and the likelihood of attempting to use the approach. Participants' usual attitudes to adoption of new ideas were discussed in eight of the follow-up interviews, and half of the participants described themselves as enthusiastic early adopters while only two identified themselves as being more sceptical. The attitudes of colleagues to the health coaching approach also had a significant impact on how participants experienced implementing health coaching.

When there was a good 'fit' between the health coaching approach and the way the team worked, and the team were open to embracing new approaches, participants found it easier to recognise the value of the approach. A few participants worked in teams where psychologist input was available and highlighted that the approach was well aligned with psychology practice, and that psychologists acted to provide expert peer support while their skills developed. One participant, who attended training alone had found her team so receptive to the possible benefits of health coaching that she started receiving referrals from colleagues.

P7: I've been asked to see people that I don't really know by other colleagues and they're the patients that they've got to ((laughs)) they've got to the end of their tether with saying 'well I've tried everything and they're just not moving on' (initial interview)

Just over half of the participants attended the training with at least one colleague.

The influence of training together appeared most significant when there were opportunities for joint working with the same patient. Working closely with colleagues not trained in a health coaching approach could be seen as a barrier to

effective implementation and could prompt participants to revert to the traditional way of working.

P14: what I found difficult was being in a clinic with a physio, because I do joint clinics with a physio and they didn't, others hadn't always been on the training so that was quite hard (follow-up interview)

Colleagues who trained together but who worked independently of each other (doing similar roles with different patient groups) had fewer opportunities for collaborative working, which resulted in fewer naturally occurring opportunities for informal peer support.

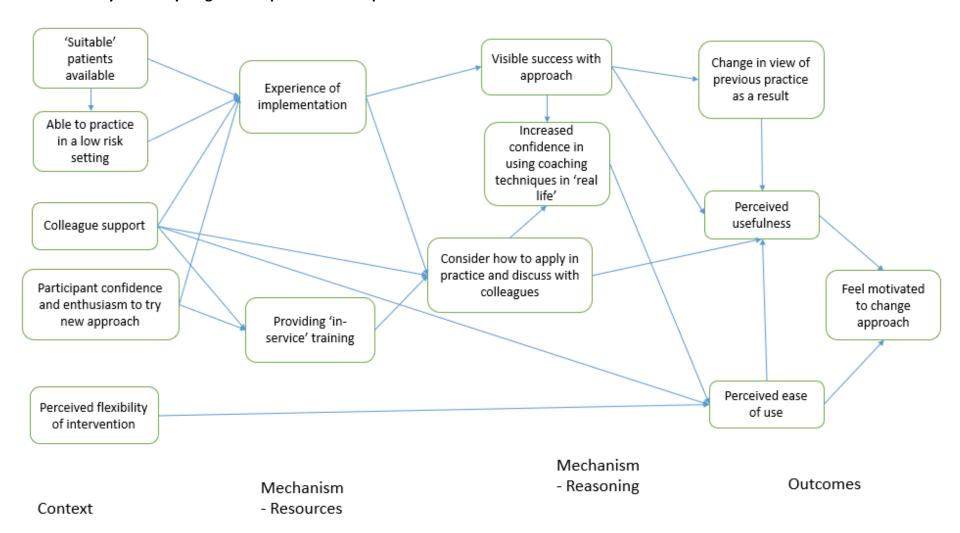
One important contextual facilitator was the requirement in many teams for staff who had attended external training to provide an 'in-service' training session for their colleagues following the course. This requirement ensured that staff spent time reviewing the training materials after the course, and critically reflecting on the most useful elements of the training for their own setting.

P16: it made me think more because I had to do a presentation and sell it to the team as it were, so I kind've went back through the workbooks and I picked out the bits that I knew were going to be relevant for our team (follow-up interview)

Even when these formal opportunities were not present, participants were frequently enthusiastic about sharing their new knowledge with their colleagues.

There were examples given of where joint working with an untrained colleague was used as an opportunity to demonstrate health coaching skills, and participants seemed encouraged when colleagues noticed that they were working differently.

# 6.6.6 Theory summary diagram – Experiences of implementation



#### 6.6.7 Refined theory

If participants experience success when they try out health coaching in practice, this leads them to re-evaluate their previous practice (Mreason) and increases how useful they believe the health coaching approach to be and their own confidence in their developing skills (O). In order to implement training, participants first have to be adequately motivated and confident, and identify appropriate low risk opportunities to practise (C). Participants also need to be convinced that health coaching can fit within their role (O), which may happen more in situations where they perceive coaching to be a flexible intervention (Mreason) and have adequate team support (C).

### 6.7 Key findings

This chapter has used the results from data gathered in the evaluation phase to test theories developed in the review stage and produced four more refined theories about how the training and implementation process works. Three of these theories focus on the training stage, exploring how training triggers critical reflection, builds knowledge, skills and confidence, and alters perceptions about how easy and how useful applying health coaching techniques could be. The fourth theory describes how experiences of implementing the training influence practice. In the next chapter, these results are further examined by exploring differing patterns of outcomes among different trainees and considering the results in relation to several existing formal theories. In Chapter 8, a refined programme theory based on the findings across the whole PhD is presented.

### 7 Results 2: Further analysis and applying formal theory

### 7.1 Introduction

In Chapter 6 I generated CMO configurations describing in detail, how, when and for whom the various elements of the training worked. I also showed how, despite being exposed to the same training intervention, participants responded differently, resulting in different implementation patterns. In this chapter I will further explore the different training responses with a focus on theorising at a higher level to describe the overall impact of training and how that related to the variable implementation of the health coaching approach in practice. Using a realist understanding of causation suggests that the variability is driven by different training mechanisms being triggered (or not triggered) for different individuals. However, identifying why this was the case was one of the most challenging aspects of the analysis because links between context and either mechanism or outcome were not always clearly apparent. The chapter begins by outlining four different implementation patterns identified and beginning to link these to context and mechanism. A discussion of the complexity encountered in the analysis then follows. Several formal theories are used to explore and explain the implementation patterns observed. In Chapter 8, the data from both results chapters (Chapters 6 and 7), and the data from the survey (Chapter 3) and realist synthesis (Chapter 4) will be integrated, and a refined programme theory proposed.

# 7.2 Overall response patterns

During the analysis it became clear that the overall learning from the training and how it was subsequently applied, differed significantly. A spectrum of responses was identified from those who fully embraced and implemented the training, to those for whom it made little impact on their routine practice. Four broad types of response emerged. These categories are not mutually exclusive but overlapped on a spectrum, with individual participants sometimes demonstrating responses that seemed consistent with adjacent categories. As a result, it was not always possible to provide a number of participants in each category, but a broad indication of the proportion of participants in each group is provided. Each of these response types is described below. To maintain a realist lens on this patterning, a CMO configuration has been generated to summarise the key features seen in each. These CMO configurations focus less on the specifics of the individual intervention components, prioritising a higher-level description of participants' reactions to the training as a whole.

#### 7.2.1 Enthusiasts

The enthusiasts' category was based particularly on the experiences of two participants who attended the training with very high levels of interest in supporting self-management. Their descriptions of their pre-training ways of working were very closely aligned with the health coaching approach and as a result the training worked largely to reinforce and expand on their existing ideas and to provide specific techniques that they could use to enact an attitude that they

already held. Both of these staff were experienced and worked in therapist roles. As Participant 9 explained during a follow-up interview "this aligned really closely with my approach which I think [is] why I liked it so much, so it definitely gave me the tools to enable me with that approach." Table 7.1 shows a proposed CMO configuration describing members of this group.

Table 7.1 CMO configuration: "Enthusiasts"

Context	Significant pre-existing expertise specific to supporting self-
	management together with a mindset that prioritises this, and
	working in an organisation where this is valued activity
Mechanism	Training provides additional practical skills that align with and
	augment preferred style of practice
Outcome	New techniques are highly valued as a way to embody existing
	goals and are easily integrated into existing ways of working

#### 7.2.2 Converts

Over a third of participants could be described as converts. For these participants the training appeared to work as intended. Training acted to help them identify a skills deficit and provided specific techniques to address this. This group developed enough confidence during the training that they felt able to implement the approach in practice, which in turn acted to bolster their confidence further. The participants in this group appeared open to the idea of changing their approach and recognised that there was a good fit with their role. The way in which health coaching was operationalised differed, but all felt that the coaching approach had

become an element of their routine practice. Participant 14 described this shift in thinking during the initial interview saying "we do get the same patients sometimes coming through and I think sometimes we think it's them and I do, that's my kind of shifting thought now is – is it because it's them? or are we actually giving them any responsibility over their health?" Table 7.2 shows a proposed CMO configuration describing members of this group.

Table 7.2 CMO configuration: "Converts"

Context	Open and interested in learning new techniques, highly valuing
	patient autonomy and working in a setting where changes can be
	made
Mechanism	Training illuminates problems with current style and provides
	specific techniques that can be used to facilitate an alternative
	approach and builds confidence in these techniques
Outcome	Participants start to see their role differently and have practical
	skills they can draw on to enact the new role

### 7.2.3 Interested but lacking confidence

Around a third of participants appeared to belong to this category. Participants in this group often appeared conflicted when discussing the training and disappointed that they had not been able to implement the approach as fully as they might have liked, exemplified by participant 21 during the follow-up interview "I'm a little bit kind of torn really because I initially found it quite helpful and then I just feel like I just don't have the skills to fully embrace the approach. And also I feel my client

group are so complex ... I just don't feel I have enough knowledge to draw on."

Members of this group perceived significant barriers to implementing the approach relating to their own lack of skills and confidence, the characteristics of their caseload and organisational constraints. Difficulty in breaking existing consulting routines was often cited. Table 7.3 shows a proposed CMO configuration describing members of this group.

Table 7.3 CMO configuration: "Interested but lacking confidence"

Context	A more fixed view of what activities currently lie within their remit,
	and with more concerns about their patients/ organisational
	barriers, or lack of belief in their own control/ability to influence
	outcomes
Mechanism	Training provides suggestions about alternative ways of working
	which are interesting and valuable, but training does not
	adequately overcome concerns about personal ability to trigger
	changes in the context of contextual resistance. Training is viewed
	as a bigger shift in usual practice/further removed from usual care
Outcome	Trainees use new skills selectively but lack confidence in their own
	ability to generate effective results

#### 7.2.4 Non-starters

Although all trainees described the training as interesting and offering new ideas and techniques, some of the interviews suggested that a few participants had made limited changes to their routine practice. As Participant 11 described "I think the

difficult thing is holding it there isn't it? It's really easy to get back into how you've always done it before". There were limited data to draw on for this category, partially because an assumption has been made that some of the participants who did not complete follow-up interviews may fall into this group, based on their responses during the initial interviews. It is therefore unclear to what extent this exists as a category in its own right, and how much it might just represent the far end of the 'interested but lacking confidence group'. Table 7.4 shows a proposed CMO configuration describing members of this group.

Table 7.4 CMO configuration: "Non-starters"

Context	A more fixed view of what activities currently lie within their remit,
	mandatory attendance to training rather than to address a pre-
	identified learning need and see other activities as the core work
	of the role
Mechanism	Training seen as incompatible with usual routines (which remain
	unchallenged) or as similar to other person-centred approaches
Outcome	Training does not trigger a significant change in routine practice

# 7.3 Making sense of complexity – a realist perspective

While I felt that the identification of these groups of outcome patterns provided a helpful overview of the differing responses to training I observed, I still felt unable to entirely explain why particular participants had responded in the way that they had. Superficially, levels of post-training enthusiasm about the course were similar among all participants, but subsequent implementation differed. During the

interviews it became obvious that participants had come away from the training with a variety of views on what health coaching actually was, and how suitable it was as an approach to use with people with PNCs. Applying realist thinking I knew that the same training had been offered to each participant, and that their differing responses to the resources presented were likely to be explained, at least in part by differences in their context (both the context which they 'brought' to the training and that in which they tried to implement the training). This presented challenges for the analysis, as participants may lack insight into the influence that a variety of complex and interacting contextual factors might have on their own motivation. I could only make inferences about possible contextual influences on participants' responses to the training which they had not directly identified.

Pawson's work on unpacking complexity in *The Science of Evaluation* (2013) provided a helpful lens to further my understanding of why identifying causality was proving extremely challenging. In this section I examine some of the drivers of complexity as classified by Pawson (2013) (volitions, implementation, context, time, rivalry and emergence) and how their impact was visible during my evaluation.

Pawson (2013) suggests that interventions should be considered as complex systems inserted into complex systems. This fits with the systems perspective advocated by others, which recognises the complexity which arises from the setting into which interventions are introduced, including the existing social relationships and structures, and the interactions of agents within the system (Hawe et al. 2009; Petticrew et al. 2019).

The first driver of complexity identified by Pawson (2013) relates to volitions of the individuals involved. Participants are not passive recipients of training but active agents who make choices about how to respond, based on both their pre-existing mindsets and also activities occurring during the training (Pawson 2013). Views on how well health coaching fitted with their understanding of their role, together with anticipated challenges influenced individual volitions. Further theories that explore the decision-making of individuals and how this is influenced by their understandings of social role, identity and causal attribution are discussed later in this chapter. The varying ways in which individuals chose to utilise the health coaching approach (minor tweaks to existing approach versus coaching consultations following a structured model) affected both how they experienced the implementation and also the subsequent impact. Individual agency may influence the potential outcomes of an intervention not just through how they choose to engage with and implement the approach, but also through other choices that they make that are not part of the intervention itself (Coldwell 2019).

One example of this included a participant who instigated a new opt-in approach to allocating appointments following attending the training. It is possible that the outcomes she described were at least in part due to changes triggered by this new system (e.g. only the most motivated patients attend clinic) rather than due to the health coaching approach that she used during consultations.

Another aspect of complexity linked to individual volitions relates to the variability with which **implementation** occurs. All complex interventions have long implementation chains, and often involve multiple actors, each with their own

agency. No interventions are ever likely to be implemented in exactly the same way twice (Pawson 2013). In an intervention like health coaching, when professionals are encouraged to use their judgement about how and when to integrate the techniques within their routine appointments this is even more relevant.

While individuals express their agency during implementation this expression may be constrained by the context in which they work (May 2013). The impact of context is well described throughout realist research and is included in Pawson's (2013) unpacking of complexity. Context, operating at the levels of individuals, interpersonal relations, institutional settings and wider infrastructure, potentially enables or constrains the ways in which participants respond to an intervention and no two interventions ever take place in exactly the same set of contextual conditions (Pawson 2013). Furthermore, context is recognised to be dynamic and ever-changing and so may exert different influences at different times as implementation and evaluation occurs (Coldwell 2019). Although some elements of context thought to be influential were explicitly considered (e.g. professional background, level of team support available) many others remained unexplored. Including participants who came from a range of professional backgrounds and who worked within a variety of different roles for multiple different organisations allowed for some comparing and contrasting of findings, but the small numbers of participants involved made identification of the most influential elements of context extremely challenging. While it was sometimes possible to identify important contextual facilitators, confirming the absence of such facilitators was more difficult. For example, a high level of alignment between the training and

existing organisational ethos was often mentioned by participants who were most positive about the training. However, those who were less confident, or implemented less of the training did not tend to mention a lack of alignment, and often highlighted the autonomy they were allowed within their role and that they were supported to manage their patients however they saw fit. It was difficult to know therefore whether these participants were simply unable to miss something they had not experienced, or whether for them organisational ethos was not the main driver of their practice. Hawe et al. (2009) have suggested a movement away from evaluating programmes and towards a focus on context evaluation, which might enable opportunities for change to be better identified and understood. Pawson also recognises how the **time** at which the intervention is delivered can influence how impactful it might be. The setting into which an intervention is introduced has its own history, changes may have already occurred, and may continue to occur that make the setting more or less favourable (Coldwell 2019). Social processes (such as power differentials across professions) are historical, and agents are constrained by this history (Chandler et al. 2016). Pawson (2013) suggests that the same intervention could be successful due to novelty value and enthusiasm at one time point, only to be met with cynicism and disinterest at another point if participants have experienced many earlier unsuccessful interventions. Exposure to previous similar training acted to prime some participants for embracing the health coaching approach, while there was at least one example of a participant struggling to identify what specifically the training added to what had already been learned elsewhere.

These issues are related to another element of complexity – the issue of **rivalry**. Complex systems such as healthcare settings are in a constant state of flux, with new policies and targets frequently being introduced (Chandler et al. 2016). In organisations where multiple schemes and initiatives co-exist, all of which seek to trigger similar improvements, it is very challenging to work out the impact of each rival intervention (Pawson 2013). Many of the participants had attended some kind of training relating to consultation skills or motivational interviewing in the past and it was not always clear how much attitude and practice shift could be attributed solely to the health coaching training, whether the training was supplementing what they had already learned, or whether it was acting synergistically to produce a greater impact than either intervention could have alone. As learning is often a slow and incremental process, this might not always be easy for participants to remember, or for researchers to capture (Billett 2016).

Finally, complexity is generated by **emergence**, one of the key tenets of realist philosophy, which recognises that the implementation of any intervention can lead to changes which in turn impact on how the intervention itself operates (Pawson 2013). The idea of emergence is important as it highlights that the outcomes of any training intervention are not entirely in control of the trainers, as the intervention will continue to evolve once participants start to use it (Pawson 2013). For example, one participant who was enthusiastic about health coaching asked her colleagues to refer her patients who were struggling to make progress. When colleagues made these referrals this validated her approach, consolidated her position within the team as someone with specialist expertise and gave her a reason to dedicate an appointment specifically to utilising a health coaching model.

However, it may have also inhibited the spread of the health coaching approach as it became seen as a technique requiring a dedicated appointment by a trained expert.

The risk, having identified so many causes of complexity, is that the evaluation may become confusing and impractical (Petticrew et al. 2019). Pawson (2013) is clear that no evaluation will ever be able to account for every element of complexity discussed above. Instead he advocates for focus to be maintained at the level of developing programme theory, which will allow an evaluation to provide useful and transferable insights. Developing these programme theories at a higher, more middle-range level may help to maintain the pragmatic balance advocated by Petticrew et al. (2019), between appropriately representing complexity and ensuring that the product of the evaluation remains useful. In the next section, existing formal theories are used to provide another lens through which to examine the data.

# 7.4 Applying formal theory

Three formal theories were first described in Chapter 4 as providing a useful lens to explore the findings of the realist synthesis. These theories (Transformative Learning Theory, Normalisation Process Theory and the Technology Acceptance Model 3) are used to explore the findings from the evaluation stage below.

Additional formal theories are also discussed in relation to these known theories, where they provide additional insights into the data emerging from the evaluation data inadequately covered by the theories utilised earlier.

### 7.4.1 Transformative learning theory

Triggering transformative learning, a process in which adult learners challenge and change their assumptions about the world, could be seen as the overarching aim of health coaching training. The transformative learning occurring following the training related to a change in how participants perceived their influence on the outcome of consultations.

As first outlined in Chapter 4, the key process required for transformative learning to occur is critical reflection. Mezirow's work on transformative learning is accepted to have made a major contribution to understanding reflective practice along with the work of several other key authors (Hickson 2011).

The role of reflection in improving practice was first raised in work by Dewey (1933 cited in Mamede and Schmidt 2004), who similar to Mezirow described how a difficulty in solving a problem generates a state of doubt or confusion, which leads individuals to work to define the problem and consider potential solutions. The work of Schon (1983) provides the helpful distinction between this type of reflection 'on action' which occurs deliberately after the event and reflection 'in action' which occurs in the moment. Reflection 'in action' may be a tacit process, especially among experienced health professionals who make spontaneous adjustments (e.g. thinking about how to phrase a question during a conversation)(Mann et al. 2009; Ghaye and Lillyman 2010). Trainers may therefore need to model reflection in order to clarify the role of reflection in learning (Mann et al. 2009). A further level of reflection, meta-reflection has been described which requires practitioners to step back and examine their own reflections, often

facilitated by support from supervisors or colleagues (Ghaye and Lillyman 2010). This may prompt what has been described as double loop learning (Argyris 2002). Whereas single loop learning is said to occur when errors in practice are corrected, double loop learning involves examining and altering the underlying values that triggered the initial error (Argyris 2002). One key role of reflection in clinical practice is to make clear for professionals the link between values and actions, as espoused values (what is said about practice) do not always match with what is actually done (Ghaye and Lillyman 2010).

Fully transformative learning does not occur when what is learned fits into existing frames of reference (Mezirow 1997). Learning, in general, has been described as occurring at one of three levels. It may be possible for new information to be easily integrated into our existing habitual expectations about what will happen in given situations (what Mezirow (1990b) terms as a 'meaning scheme'). This type of learning occurs when new information supplements or complements what is already known (Kitchenham 2008). Participants with two different response patterns appeared to exhibit this type of learning. Members of the 'non-starters' group sometimes described coaching as another form of person-centred working and believed that they already practised in a person-centred way. They saw the coaching techniques as possibly complementing their current approach. Similarly, the 'enthusiasts' group who were already completely aligned with the ethos of the coaching approach before attending could easily integrate what they learned, without any challenge to their existing frame of reference.

The second level of learning described by Mezirow involves learning new meaning schemes, which fit with those that the participant already holds, and are compatible with their existing frame of reference (Kitchenham 2008). This type of learning could be seen across most study participants. For example, participants talked about changing their habitual consulting behaviours by starting consultations differently, including additional questions, leaving more space for silence, and provide opportunities for patients to generate their own solutions. Practicing in this way was associated with altered expectations of how patients might respond but remained consistent with how they viewed their professional role.

The third level of learning, at which transformation is said to occur, happens when the problem presented cannot be resolved by learning at the other two levels, and instead requires the problem itself to be re-defined (Kitchenham 2008). This process requires critical reflection on the frame of reference which underpins the behaviour currently in use. This transformative experience was evident both among those who were 'interested but not confident' and 'converts'. Participants gave clear examples of starting to examine their previous assumptions, when they talked about how prior to the training they would have believed that some of their patients' behaviours indicated that they were not ready or willing to change. They described that when they applied a health coaching approach, and witnessed increased engagement they came to a realisation they their previous approach to providing support was not what the patient needed, and that the 'problem' was their own approach rather than entirely being due to patient characteristics.

This clearly visible transformative learning was never reported as occurring as a result of the training activities themselves, but as a consequence of reflecting on implementation experiences. It is also important to note that not all participants needed to have a transformative learning experience in order for the training to be successful in initiating practice change. For those in the 'enthusiasts' group, who attended training with a compatible 'frame of reference' (usually as a product of previous training or professional experience), transformation was not required.

The key transformation seen was a change in the way professionals attributed the success or failure of consultations which aimed to support or promote self-management. This is important because the nature of the 'disorientating dilemma' is different to how it might initially appear. The visible dilemma presented early in the training, as a potential motivator to consider practice change, is that existing paternalistic, expert-orientated approaches to consultations do not work to drive successful behaviour change. This in itself was not a new dilemma to any of the course participants, who appeared well aware of the limited impact they often had in such situations. However, I saw many examples of participants attributing their lack of success externally, either to patient level factors, such as activation levels, or organisational level factors, such as limited time and competing priorities. For these participants, the 'disorientating dilemma' actually needed to trigger critical reflection, was that their own current consulting behaviours were not adequately meeting the needs of their patients.

Two additional areas of formal theory were identified which could help to explain the influences on the transformative learning process in more detail. Firstly, as already discussed participants' existing frames of reference and ways of seeing their role as health professionals differed. Social identity and role theories can provide additional insights into how these frames of reference are formed and maintained, and the influence they exert on the training process. Secondly, attribution theory provides a useful lens to explore why people may make errors when they try to understand the causes of their own behaviour and that of others.

### 7.4.2 Social identity and role theories

The social identity approach originates from social psychology, and is based on two related theories, Social Identity Theory and Self-Categorisation Theory (Burford 2012; Haslam 2014). The approach describes how in most social settings, social identities act to structure how people think and behave, shaping their values and norms (Haslam 2014). Individuals may hold multiple social identities (e.g. parent, health professional), but the identity that determines social behaviour at any one time is the one that they perceive to be most relevant to the particular context, a concept described as salience (Burford 2012). Individuals tend to choose activities that are aligned with salient aspects of their social identity (Currie et al. 2010). Understanding and capitalising on social identities may impact on the success of training. Trainers should try to identify and explore the social identities that participants value, as it is suggested that when identities are recognised and respectfully treated this enhances legitimacy and trust (Haslam 2014). Training can

capitalise on the power of social influence, as participants are more likely to value messages derived from those with whom they share a social identity (Burford 2012; Haslam 2014). This was clearly visible in the accounts of the participants who believed the shared 'health professional identity' of the trainers enhanced their credibility. Participants also described feeling that the expertise that they brought to the training was validated by the trainers, and this also acted to increase engagement.

The literature suggests that training should try to tap in to and mobilise valued social identities to facilitate implementation of new interventions (Kreindler et al. 2012). However, there is recognition that this requires an active process in which participants work together to define the group identity (Kreindler et al. 2012) (similar to the process of critical discourse described by transformative learning theory). Maintaining the group identity developed during the health coaching training was challenging for participants who attended alone. Kriendler et al. (2012, p.365) also caution that to avoid the training being "just another staff development workshop" it is essential not to underestimate the power of context to either facilitate or inhibit change. Changes to working environments and practices may be needed to allow mobilised social identities to be enacted (Kreindler et al. 2012).

Related to social identity theory, role theory has been broadly defined as being concerned with patterned social behaviours, the parts that are assumed by different actors, and the scripts or behavioural expectations that are understood and adhered to by those involved (Biddle 1986). The idea of socially conditioned

scripted interactions, in which everyone understands their role appeared to strongly influence those participants with long-standing relationships with their patients, who believed that disrupting the usual pattern of a consultation would be met with surprise and resistance. In common with social identity approaches, role theory recognises that people usually occupy different roles within different groups. Role conflict is said to occur when differing behaviours associated with each role need to be performed at the same time (Pennington et al. 1999). For example, the expectation to complete required administrative documents for audit purposes might compete with the provision of clinical care (Brookes et al. 2007). Related to the concept of role conflict, role overload is said to occur when an individual lacks the capacity to take on the extra demands of a role due to limitations such as inadequate level of skill or lack of time (Brookes et al. 2007). In settings where clinicians experience role conflict and overload, feelings of stress, anxiety and frustration may be triggered (Brookes et al. 2007). People tend to resolve role conflict by performing the behaviours that fit with the role that is most important to them (Pennington et al. 1999).

In order to integrate health coaching into routine practice, participants in the training were asked to try to maintain two roles simultaneously (that of expert healthcare professional alongside that of coach). It is therefore unsurprising that many participants reported prioritising activities that aligned with their long-held and highly valued role of expert health professional. Some tried to deal with this role conflict by performing coaching only within a set time within the consultation (often after the 'medical work' had been done). However, the more enthusiastic participants who had been able to transform how they saw their role, appeared to

have been able to integrate coaching into their existing identity. Neale and Griffin (2006) recognise that roles may be perceived differently by different role holders, suggesting that individuals' expectations are influenced by system requirements (the expectations of their employers), role schema (what people understand the role of a nurse or therapist to entail) and self-concept (how people see themselves). People will feel least conflicted when all these three elements are aligned. Differences between how nurses and therapists conceptualised their roles were noted by both the trainers and the participants. Generally, a coaching approach was seen as a better fit with the existing role schema and self-concept of therapists who already used goal setting and elements of challenge within their routine practice. However, some therapists remained conflicted, as they did not see coaching as the most valued part of their role, and this impression was reinforced by organisational priorities. Those who worked in clinical specialist roles recognised that the expectations of their new role (which focussed on their medical expertise) meant that they had moved away from their therapist schema, while feeling that their background continued to inform their new role. Nurses identified that historically nurses were seen to take on a 'fixing' role (Tomm-Bonde 2012) and that this position conflicted with the health coaching approach. All professionals were required to reconsider how they could help their patients benefit from their professional expertise while also empowering people to generate their own solutions. Social identity and role theories offer some explanation as to why holding the role of expert and coach simultaneously was seen as challenging, especially when working with patients whose expectations have been encultured by previous interactions with the health service. The training appeared to be most

successful when participants were able to integrate health coaching into their view of their own identity and role (a transformative process for some).

#### 7.4.3 Attribution

The attribution approach in social psychology relates to how individuals attribute the causes of both their own and other peoples' behaviour (Pennington et al. 1999). Attribution theory focusses on how behaviours are perceived to be caused rather than how they are actually caused. In daily life, people try to make sense of the world by developing explanations, searching for information to help reduce their uncertainty (Pennington et al. 1999). Behaviours may be attributed to internal causes (e.g. personality, effort, ability) or external causes (e.g. social norms, environmental constraints). Clinical decision-making is likely to be influenced by attribution, with clinicians making attributions both about the ways their patients behave, and also about the reasons for the success or failure of their own chosen approach (Murray and Thomson 2009). Attributions are more likely to be made in certain circumstances, often when something unexpected happens, when people fail to reach their desired goal, or when they are in a negative emotional state (Pennington et al. 1999).

In their study of nurses, van Hooft et al. (2016) noted that most barriers to supporting self-management identified were externally attributed (including time pressures and patient factors). How clinicians perceive the causes of people's behaviour is likely to impact on the approaches they choose to take (Murray and Thomson 2009). External attribution could act as a barrier to clinician learning, and

it has been suggested that the influence of external factors should be acknowledged and addressed within training (van Hooft et al. 2016). It is also worth considering whether these external attributions (which were also commonly cited by the participants following the training in my study) are entirely accurate, or whether participants may have made some common attribution errors. The actorobserver difference describes a tendency to emphasise the cause of one's own behaviour as being situational (Pennington et al. 1999; Parkinson 2012). Therefore, if clinicians experience a lack of success in providing self-management support, they are more likely to attribute this to factors outside their control rather than to internal factors (such as their own consulting style). Fundamental attribution bias refers to the tendency to attribute the behaviour of others to internal rather than external factors (e.g. patient motivation inhibits engagement with self-management activities) (Pennington et al. 1999). These could also be considered to represent a self-serving attributional bias (used to maintain or enhance self-esteem) by attributing failures externally while successes are attributed internally (Pennington et al. 1999; Parkinson 2012).

As introduced above, attribution theory does not focus on working out the 'correct' attribution of causality, rather on what people think the causality was and how this influences their behaviour. Objectively, it may be that the reasons clinicians struggle to provide self-management support are largely external, and that patients who do not embrace the approach do so for internal reasons. Attribution theory is useful because it reminds us that clinicians are likely to prioritise certain causal explanations over others, and that this may make them see facilitating self-management effectively as less within their personal control. As noted above,

those trainees who experienced transformational learning seemed to demonstrate changes in attribution, towards a greater recognition of the influence of internal factors (their own behaviour) as influencing the outcome of self-management support consultations. When discussing the drivers of patients' self-management behaviours in situations where they felt coaching would not work, participants recognised both internal factors (e.g. people who had taken on 'the sick role') and situational factors (e.g. housebound) as influences on the patient, but less frequently included their own behaviour as a potential influence. This could represent a self-protecting bias (failure is externally attributed to characteristics of the setting and the patient) (Parkinson 2012). There were however several participants who clearly recognised their own lack of confidence and skills as key barriers.

### 7.4.4 How can training facilitate transformative learning?

The above sections explore the influences on how the 'disorientating dilemma' is perceived and reflected upon and covered the first three steps of the transformative learning process (see Box 4.5). Empirical studies have suggested that critical reflection is crucial for the transformative learning process, while also emphasising the role of two other important stages: engaging in critical discourse and trying out new roles. In this section, I explore how the training created a conducive environment for these stages of transformative learning to occur.

The emotionally challenging nature of transformative learning means participants must feel safe to learn if transformation is to occur. Although most participants

commended the training environment, there were also examples of those who found being coached too emotionally challenging, with some electing to discuss relatively superficial issues to avoid sensitive subjects. Those participants who avoided challenge learned the least from the experience of being coached.

The trainers recognised the crucial role of group membership, suggesting that learning from colleagues was often more influential than the course content. Group activities that exposed participants to the differing views, experiences and interpretations of other course participants provided accessible examples of alternative frames of reference, which could act as a transformative learning trigger (Apte 2009). Transformative learning is recognised to be a social process, facilitated by critical discourse (conversations which allow participants to assess competing interpretations of situations by critically examining their evidence base and alternative points of view) (Mezirow 1997). Role play, which featured heavily in the training, is also recognised to be an important transformative learning trigger, as it allows participants to actively engage with the course content in the context of their own lives, and to critically assess its value together (Mezirow 1997). While interactions with other group members can provide opportunities to recognise the shared experience of discontentment and engage in critical discourse, the trainers also have a key role in supporting transformative learning.

The trainers demonstrated many of the facilitation techniques known to support the process, including modelling critical reflection, demonstrating their own sincerity and vulnerability, and encouraging the participants to recognise contradictions between their beliefs and their current practice (Mezirow

1990a,1997; McEwen et al. 2011). Although the training may have been designed and delivered in a way that made transformative learning possible there is recognition that the dilemma that acts as a trigger for transformation may differ among individuals, who may also favour different learning styles and respond at different rates to their experiences (McEwen et al. 2011).

Learners at different points in the transformative learning process require different types of training activities (Mezirow 1990a). Some of the participants might have benefitted from more time to explore the disorientating dilemma and what was driving their current approach, while others were clearly ready to spend time trying out their new role and building confidence in the use of the health coaching techniques. When learning is 'troublesome' for learners because it involves leaving a previously comfortable position, transforming one's own understanding and shifting identity, it is recognised that people sometimes become stuck in what has been referred to as a liminal or in-between state, where they oscillate between their old and new identities (Land et al. 2005). This oscillation was visible in the participants' accounts as they sometimes seemed to hold contradictory views, both endorsing the coaching approach while also maintaining their previous ways of working. Loss of confidence and frustration can occur during this liminal phase as learners move back and forth in their thinking (Land et al. 2005). Not all of the participants successfully navigated the required process of letting go of their earlier positions (Land et al. 2010) to fully integrate the health coaching ethos (although for the 'enthusiasts' this process was not required).

In conclusion, although it appears that transformative learning is not always required if participants arrive at training with a compatible frame of reference, when transformative learning occurs it can instigate a change in how participants view the impact of their own behaviour within consultations. All those participants who gave examples of experiencing a transformation described it as being a result of experimenting with the health coaching approach in a clinical setting, rather than from the training activities. Health coaching training days alone seem unlikely to trigger transformative learning. The theories discussed above have focussed on the attitudes and beliefs of individuals as influences on reactions to training. To understand the implementation process fully, it is also useful to consider how people act when they start using a new intervention, and how these actions are shaped by social interactions (Johnson and May 2015). These processes are the focus of Normalisation Process Theory, which is now considered below.

### 7.4.5 Normalisation process theory

As introduced in Chapter 4, Normalisation Process Theory (NPT) is a middle-range theory focussed on how and why certain practices become fully embedded or integrated ('normalised') into daily work (May and Finch 2009).

### 7.4.5.1 Coherence

The first construct of NPT, coherence, involves participants building their understanding of what the work is that needs to be done (May and Finch 2009).

The components of developing coherence are recognising the difference between old and new approaches (differentiation), understanding your role in delivering the intervention (internal specification), building a shared understanding of the new practice with others (communal specification) and starting to value the new approach (internalisation) (May et al. 2015). The trainers emphasised developing coherence as a core aim of the training. Differentiation could also be described as the core process required for transformative learning. The trainers suggested that differentiation could only be fully achieved when participants experienced health coaching during the 'real-play' activities. Most participants seemed to achieve this differentiation, but challenges relating to the safety and authenticity of the 'real play' experience could mute the impact of the exercise. The trainers recognised that the process of encouraging differentiation could be confronting and upsetting for participants as it challenged their strongly held identity as caring professionals who do the best for their patients.

The process of internal specification differed across the participants. For most people, enacting the health coaching training mostly involved 'tweaks' to current practice which were informed by a better understanding and acceptance of the health coaching mindset. However at least one participant focussed much more on coaching as a specific 'treatment strategy' and saw doing health coaching as working through a specific model as it was demonstrated during the training.

Others talked about not doing 'true health coaching' when they had only tweaked their practice rather than using the formal approaches. The processes of differentiation and individual specification were closely linked. How different the coaching was perceived to be depended on an (accurate) appraisal of current

practice as well as how participants' understanding of the way in which health coaching was supposed to be enacted developed during the training. The impact of differences in how participants made sense of the required work of health coaching is further considered below when intervention plasticity is explored.

Sense making also has a communal element, the value of which has already been discussed in relation to social norms, perceived role and facilitating transformative learning. However, NPT focusses on how teams make sense of the new work they will be involved in and nearly half of participants attended the training alone. While the trainers felt that collective sense-making occurred during group interactions during the training days, during implementation participants generally focussed more on health coaching as an individual action rather than a shared change in practice. Participants did give clear descriptions of how they started to understand the value of adopting a health coaching approach (internalisation). This element of coherence developed most strongly when they had experiences of the benefits to draw upon (linking to the NPT construct of reflexive monitoring discussed below). The different components of coherence building appeared to act synergistically. The strongest impact appeared to occur when both differentiation and internalisation were demonstrated. If people accepted the value of health coaching but did this without really seeing it as particularly different from their current practice, they seemed more likely to implement it in a more limited way.

#### 7.4.5.2 *Cognitive participation*

The second NPT construct, cognitive participation, relates to developing an understanding of who should be involved in the work (May and Finch 2009).

Cognitive participation focusses on who is driving the change forward (initiation), how people are recruited to be involved (enrolment), whether their involvement is seen as appropriate (legitimation) and how the new work practices are sustained (activation) (May et al. 2015). This construct was less visible in the data perhaps because the main focus of the training was on promoting individual level changes in consultation style. Many participants worked largely independently and with a high degree of autonomy so this cognitive participation work did not appear to be a significant consideration.

The most enthusiastic participants did provide examples how they tried to use their experiences at the training to drive wider change within their service. For example, one participant, a team leader, used her experience of the health coaching training to re-design the way in which the service operated (new referral system, new documentation). In this way her team was able to start working differently even though they had much more limited learning. Similarly other participants had acted to try to raise interest among their team by providing in-service training.

The key barrier here was that most participants felt that the training they had received was of such high quality that it was essential for colleagues to attend the training themselves, and that they could only provide a flavour of the approach.

The larger team who attended trained together but worked only in parallel showed no evidence of any collective efforts to establish the new approach following the

training. A few participants also discussed how they negotiated the legitimacy of integrating health coaching into their routine consultations. Being able to cite the evidence base and being able to refer to health coaching as a named approach made some participants more confident in the justification of working in this way and in discussing the approach with others.

Even during the follow-up interviews there were limited examples of how participants were working to maintain the approach, although aspirations to embed the approach further and involve colleagues more were discussed (e.g. further work within team, working more with a psychologist). It is possible that this work may have continued to develop after the study period.

#### 7.4.5.3 Collective action

The third NPT construct, collective action, relates to how the required work gets done (May and Finch 2009). One particular component of collective action was particularly relevant. Interactional workability refers to the work done with others when implementing a new intervention (May et al. 2015). Participants were aware that delivering health coaching was a collaborative process, with coaching being done with, rather than to a patient, and would disrupt the traditional way of doing things, familiar to both them and their patients. The issues discussed above around social and role identity and attribution of causality all influenced decision-making about the interactional workability of the new health coaching approach.

## 7.4.5.4 *Reflexive monitoring*

The fourth NPT construct, reflexive monitoring, relates to how people appraise the impact of doing the work of the intervention (May and Finch 2009). The evaluation stage theory I developed describing experiences of implementation demonstrates this monitoring process. Individuals' positive experiences influenced their ongoing sense-making process and increased the perceived value of the approach. Fewer examples of communal appraisal of the impact of the approach were described. Although the second day of the training acted as a form of communal appraisal, at this stage participants generally saw themselves as only partly trained and were waiting for training to be completed before evaluating its utility. Some mentioned that they would have valued a later opportunity for communal appraisal following the training, but the web resource was unsuccessful in facilitating this.

7.4.5.5 Extensions of Normalisation Process Theory – Considering context
In developing NPT, and considering how implementation is impacted by context,
May et al. (2016) introduced the further concepts of plasticity and elasticity which
are useful for understanding the influence of context on implementation. Plasticity,
essentially how flexible an intervention is perceived to be, will influence how easily
it can be embedded. If interventions are highly plastic they put less strain on
existing practice norms and relationships. Elasticity of the setting describes the
"room for manoeuvre" (May et al. 2016, p.7) available within the setting for the
implementation of a new intervention. May et al. (2016) note how a study of a selfmanagement support intervention targeting the behaviours of clinicians in primary

care (Kennedy et al. 2014b) exemplified the influence of an inelastic context. In that study the plasticity of the intervention which allowed participants a high level of discretion about how it was delivered was insufficient to overcome the inelastic context (how the work was organised and funded), resulting in intervention failure.

The participants in my study of the health coaching training described varying degrees of elasticity in their work context, and while an inelastic context was a clear barrier, a highly elastic context was not sufficient to drive practice change.

Similarly, as discussed above, participants conceptualised the plasticity of the intervention itself differently. Most appeared to see health coaching as a highly plastic intervention that could be adapted as required. However, this plasticity may have also had a negative impact on normalisation. The more health coaching was viewed as a minor tweak to existing practice allowing significant agency to participants, the more difficult it became for participants to clearly identify what exactly should be done, and how it would add distinct value to usual care, threatening coherence.

#### 7.4.5.6 How does Normalisation Process Theory help?

While NPT focusses on what happens as groups collectively implement new interventions, it has also proven to be relevant to the training and implementation experiences of the individuals in my study. Effective interventions to change healthcare professionals' behaviour tend to act across more NPT areas and particularly on collective action and reflexive monitoring (Johnson and May 2015). These two areas, particularly collective action, were not well described in my data,

in part due to the individual focus of the training. This might also explain the difficulties noted by some participants in maintaining and building on the learning from the training in practice. There was a strong focus on the development of coherence within the training, in line with other similar interventions (May et al. 2018). Review evidence shows that interventions that focus mostly on persuasion tend to be less successful and that professionals do not always change their behaviours as a result of changes in their attitudes or intentions (Johnson and May 2015). Successful interventions tend to focus on specific actions, providing a clear set of rules on how to behave and ensuring that these become associated with group norms so that enacting them becomes part of routine work (Johnson and May 2015). Health coaching training does provide these specific techniques, but the delivery of the training to individual clinicians may have failed to tap in to the potential for the use of the approach to be seen as an organisational norm.

## 7.4.6 Technology Acceptance Model

The Technology Acceptance model (TAM3) (Venkatesh and Bala 2008) was first applied in Chapter 4 to help make sense of the results of the realist synthesis.

TAM3 indicates that determinants of perceived usefulness and perceived ease of use differ, but that perceived ease of use can directly influence perceptions about usefulness (Venkatesh and Bala 2008). The emphasis on how the perceived practicality of the intervention can influence how useful it is seen to be aligned well with my evaluation data which indicated participants frequently focussed on how easy or difficult they believed implementation would be. When participants

believed that health coaching could not be practically implemented in their setting, this strongly influenced how valuable they thought the approach was. Various determinants of perceived ease of use are identified in TAM3 including anxiety and enjoyment, but those that have the most enduring influence are self-efficacy for the task and perceptions of external control (i.e. organisational resources and support) (Venkatesh and Bala 2008). While the health coaching training did use strategies to build participant self-efficacy, some participants remained low in confidence after training, and lost more confidence over time. Participants were frequently encouraged to consider how to use health coaching in their own setting, but the training required them to generate their own ideas rather than providing suggestions, and some participants struggled to understand how organisational constraints could be overcome.

TAM3 suggests that the influence of perceived ease of use is likely to be strongest when people have less experience, and to then decrease over time. Perceived usefulness has been shown to be the strongest determinant of behaviour over time and is influenced by both social influence and individual cognitive processes (Venkatesh and Bala 2008). Determinants of perceived usefulness include relevance to role; demonstrability of results; subjective norms (expectations of others); how using the new approach might act to enhance personal image; and perceived ease of use. Those for whom the training had been more successful tended to focus more on describing the usefulness of the approach (including how well it fitted with their current role and the benefits they had achieved through its use). Applying the technology acceptance model to my data would suggest that in

order to maximise perceived usefulness, early in the training significant attention should be paid to determinants of ease of use. If these are not addressed they may represent an ongoing barrier to practice change.

## 7.5 Chapter Summary

This chapter has explored the varying ways in which participants responded to training and utilised a realist understanding of complexity, together with several existing formal theories, to explore the possible reasons for this variability. Chapter 8 will now integrate these analyses with those from the earlier chapters and present a refined programme theory.

## 8 Discussion

This chapter discusses the findings of the PhD study as a whole. I will review the data gathered to address four key research questions (based on the initial rough theories developed in Chapter 4). A refined programme theory, which forms the product of this research is then presented. Reflections on the strengths and limitations of the PhD study are discussed, alongside a consideration of how the findings sit within the wider literature. The chapter concludes with a set of practical recommendations for commissioners/policy makers and training providers, derived from the study.

The aim of the PhD study was to understand how training interventions for health professionals working with people with PNCs, which focus on improving support for self-management, work, for whom, and in which circumstances.

A realist evaluation approach was chosen. In the first phase of the PhD, a survey of health professionals (Chapter 3), and a literature review were undertaken, supplemented by stakeholder advisory groups and key informant interviews (Chapter 4). In the second phase of the study, primary data were gathered from a mixed-methods evaluation of a health coaching training intervention (Chapters 5-7). The processes used in the two phases are summarised in Figure 1.1 (Chapter 1). The data from these two phases are now summarised. To ensure that those areas identified as a priority for investigation at the outset of the study have been adequately explored, they are organised using the research questions developed from the initial rough theories first described in Chapter 4. Table 5.2 in Chapter 5 summarised the initial rough theories and presented a core research question

derived from each theory. During each stage of the research these theories were used to guide the direction of the study but were not specifically refined at each stage. Instead, in Chapters 4 and 6 the findings from the realist synthesis and the evaluation stage were explored inductively, to generate theory directly from the data. Chapter 7 explored the evaluation findings in the context of existing formal theories. The process of building and refining my programme theory throughout the thesis is summarised by Figure 2.2 in Chapter 2. The following section now uses the data collected throughout the PhD as a way of deductively testing the initial rough theories. For each core question, I present below a summary of the findings from the data gathered throughout the PhD, compare these to the existing literature, and produce a refined theory which addresses the question. The way in which the theories developed during the different stages of the PhD contributed to the development of each refined theory is demonstrated in Figure 8.1.

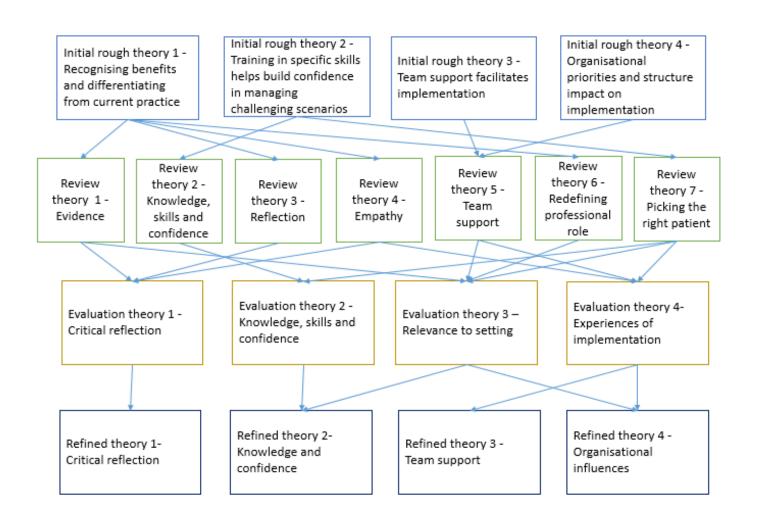


Figure 8.1 Contribution of earlier theories to the refined theories produced

8.1 Core question 1: How, and in which circumstances, do SMS training interventions help participants to recognise the difference between current practice and a new approach and to value the new approach over existing ways of working?

The survey findings suggested that staff already highly value SMS techniques, with the majority thinking that most of their patients would benefit from the approaches suggested. There was some variation in current practice identified, but core SMS skills including agenda setting, goal setting and action planning were reported as being used frequently by over three quarters of respondents. Respondents were most interested in developing new skills related to assessing or improving patients' readiness to self-manage.

The realist synthesis suggested that training in SMS could challenge perceptions about existing ways of working. Critical reflection was required during training and implementation, but this experience could be challenging for professionals.

Features of the training supporting critical reflection including voluntary attendance, inter-professional training and a perception of group safety were described. Exercises that developed participants' empathy or provided evidence for the new approach could be useful. Reflection was noted to occur during training and also to continue as staff started trying out the new approach.

The evaluation stage provided further evidence for the role of reflection and the circumstances in which it triggered shifts in attitudes and practice. Training provided an opportunity to develop self-awareness and learn about alternative

ways of working. The training encouraged participants to recognise the impact of their own style on the outcomes of consultations, with the trainers modelling reflection using examples from their own experience. However, reflection on personal performance occurred in parallel with reflecting on contextual barriers (at the level of the patient and the organisation). Participants who became focussed on issues outside their own control seemed to concentrate less on reflecting on their own behaviours.

The evaluation findings suggested that those participants who had already started to consider issues relevant to SMS or saw health coaching as well aligned with their existing approach were most open to the training messages. Staff whose role involved a lot of medical or technical tasks found it more difficult to see how coaching could be integrated. It was important for staff to experience the benefits of coaching to become convinced of its value. This could occur during the training but appeared most powerful when benefits were witnessed during implementation in clinical encounters.

## 8.1.1 Exploring the findings in relation to the wider literature

In this section, the characteristics of clinicians, and in particular their view on their professional role, is explored in relation to its influence on critical reflection. The training activities (particularly role play) that were most frequently associated with triggering reflection are further explored later in core question 2.

Highly developed reflective skills have been identified as a marker of expert practice. While all physiotherapists in a study by Resnik and Jensen (2003) were committed to CPD, expert therapists (whose patients had outcomes in the top 10%) exhibited greater levels of inquisitiveness, humility and reflection.

My study highlighted the role of critical reflection in helping people to understand how the new approach fits with their existing ideas, which health coaching frequently challenged. This aligns with the findings of other studies highlighting how the congruence of the new intervention with existing roles influences how professionals react to training. For example, staff with backgrounds in mental health, and those working in the third sector have reported that a coaching role fitted well with the biopsychosocial approach that they already used (Brook and McGraw 2018). Conversely pharmacists, general practitioners and practice nurses have all been reported to experience role conflict, observing that sometimes a coaching approach did not fit with their usual roles in which patients were seeking their professional opinion, and in which professionals wanted to do what they thought was best for the patient (Ahluwalia et al. 2013; Brook and McGraw 2018; Lenzen et al. 2018). In line with my findings, a study of asset-based approaches in healthcare, (which encourage a shift away from treating illness and towards actively promoting health) found that the staff who embraced the approach tended to be those who recognised a fit with their existing perspective, were already working in a similar way, and felt the intervention reinforced their existing practice (Rippon and Hopkins 2015). This may suggest that the less challenging critical reflection is, the easier it is for staff to embrace new ways of working.

The participants in my study, particularly those with a nursing background recognised their roles were traditionally associated with problem-solving (Tomm-Bonde 2012). In line with my findings, research indicates that staff seem to struggle most with using a coaching approach when they see their own role as that of expert (Newman and McDowell 2016). GP trainees felt it was important that patients understood whether they were adopting a coaching role or a traditional doctor role (Ahluwalia et al. 2013). Clinicians expect that technical expertise is what their patients most value (Bright et al. 2015), and if the provision of expertise is seen as core to their role, then this is likely to be an important source of professional fulfilment that the coaching approach may threaten (Lindgren et al. 2013). Furthermore, some of the participants in my study had moved into clinical specialist roles, which had encouraged them to develop skills outside of their initial clinical focus or expertise (Burton et al. 2009). For some these new skills were still under development, while for others they defined the core role they now took. Clinicians who feel confident in their own expertise appear to be more confident in encouraging patient participation without experiencing this as a threat to their own professional identity (Wilson et al. 2006), in line with my findings that unconfident or inexperienced participants found it easier to revert to 'telling people what to do'. Concerns about a lack of control, managing clinical risk and professional accountability are all further recognised barriers to promoting self-management (Wilson et al. 2006; Newman and McDowell 2016).

## 8.1.2 Refined theory

Training in self-management support requires practitioners to critically reflect on their current practice (Mreason). This critical reflection can be facilitated by exposure to the ideas of others in a safe training space (Mresource). Views on what current practice should entail are shaped by personal views, professional background and organisational expectations(C). Critical reflection on personal practice may be less impactful if SMS is seen as too difficult to integrate into routine care. Meaningful critical reflection can help participants to identify deficits in their current approach and become motivated to address these (O).

8.2 Core question 2: Does training clinicians in specific SMS skills help them to see these skills as applicable to a wider (including more challenging) population?

The initial survey showed that a lack of health professional training was seen as a barrier to SMS provision, and just under half of respondents recognised that they were not entirely sure what SMS provision involved. Respondents wanted extra training in specific skills, mostly around working out which patients were ready to self-manage, and how this readiness could be improved. Training did not seem to impact on how the survey respondents viewed patient level barriers such as concerns self-management would be too difficult for some patients or that patients were not interested in self-management.

The literature review identified that clinicians needed to learn about SMS and build new skills. Providing information about practical tools which could be easily integrated helped to build confidence. Professionals needed to use their PNC-specific expertise to anticipate potential difficulties with self-management and tailor their support accordingly. Echoing the survey findings, in the literature health professionals frequently cited patient level barriers as reasons that SMS provision was unsuccessful. These included concerns that patients were not willing to be involved or that they were not able or too vulnerable to participate. There was recognition that readiness to engage in self-management changed over time.

Clinical supervision and refresher training provided opportunities for professionals to work out how to best provide SMS in challenging clinical scenarios.

The participants in the evaluation also emphasised the importance of leaving training with tangible new techniques to enable more effective SMS provision.

Training provided a 'step-by-step' guide of how to support self-management and allowed participants to practise the new approach in a low risk setting, so helping to build confidence. However, confidence was not always maintained in the implementation period. Barriers including cognitive impairment and mental health problems made it difficult for participants to believe in the resourcefulness of their patients (a key element of the health coaching mindset). Participants also described lacking the skills to deliver health coaching to these groups. This may have been exacerbated by the training approach which relied on modelling coaching and encouraged participants to generate their own solutions, but inadvertently sometimes left them with unanswered questions. Challenging clinical

scenarios could be seen as an opportunity to try something different, especially when there was recognition that existing approaches had been ineffective.

## 8.2.1 Exploring the findings in relation to the wider literature

Two inter-linked issues which relate to the initial research question will now be discussed. Firstly, the way in which skills were learned is considered, and this is followed by discussion of the role of patient factors in the process.

Participants in my study highly valued the experiential nature of the training and in particular the opportunities to practise the health coaching approach. Recognised advantages of role play include the need to react spontaneously (as in real clinical scenarios), the opportunity to receive feedback and the ability to reflect on how others approach the same task (Pilnick et al. 2018). The trainers in my study were keen to stress the importance of using 'real play', a typical element of training in motivational interviewing where the pair discuss a real issue from the life of the coachee about which they feel ambivalent (Levounis et al. 2017). The importance of "making it real" (Williams et al. 2016, p.4) has been emphasised in other training settings, where successful interventions highlight the relevance of training to the daily work of participants through physical proximity (holding workplace training) or cognitive proximity (ensuring the content was highly relatable to the work context) (Williams et al. 2016). The training focussed on the coaching process, rather than specific clinical issues meaning participants were able to experience the real benefits of being coached. My participants and those in other studies also developed their coaching skills by using the techniques in a variety of settings

outside the training with colleagues, family and friends (Carter et al. 2015; Russell et al. 2017). While the trainers' modelling of a coaching approach allowed participants to experience the style, it also highlighted an important challenge that they faced. Coaches believe that it is important for coachees to develop their own solutions to problems, to ensure that they become empowered, and not dependent on the coach (Ladyshewsky 2006). However, it is also recognised that constraints must be adequately explored in order to avoid frustration and loss of trust on the part of the coachee (Ladyshewsky 2006). Some participants remained unsure about how the skills could be used in challenging clinical environments. Other evaluations of coaching training have also suggested that training should provide clearer guidance on exactly how coaching can be integrated into existing roles and routines (Carter et al. 2015; Lenzen et al. 2018).

The limited ability of short training courses to change ongoing clinical practice is recognised. In motivational interviewing, for example, a three-day training intervention was seen as enough to provide basic skill development, but insufficient to ensure participants reached the target level of proficiency (Fortune et al. 2019). While brief training can be effective in increasing understanding of the basic spirit and techniques of the approach, the emotional insight required to embed the approach may not be achieved (Moore et al. 2012; Fortune et al. 2019). Trainers and participants see training as a starting point but recognise that ongoing skill development happens during implementation (Moore et al. 2012). The challenge of supporting practitioners to continue to use their newly learned skills is recognised, and strategies including refresher training, mentoring, promoting ongoing reflection and ensuring that the new consulting approach can fit alongside

existing roles (such as performing structured assessments) have been recommended (Moore et al. 2012; Fortune et al. 2019).

A major contextual influence, health professionals' perceptions about their patients' receptivity to coaching, is now explored in more detail. Certain problems, particularly around making lifestyle changes, are seen as well suited to adopting a coaching approach (Ahluwalia et al. 2013). There is recognition that people need different types of SMS and that the support needed may change over time (Taylor et al. 2014). This is particularly relevant to people with PNCs whose conditions fluctuate and deteriorate over time. For example, at different points in the disease course a patient may require mostly psychological support (for example, to facilitate the acceptance of their diagnosis), or mostly practical support (for example to adapt to impairments impacting on activities of daily living) (Taylor et al. 2014). Being able to adapt to the needs of individuals to provide appropriate tailored support, which also takes into account patients' existing levels of engagement and self-efficacy, is therefore a core skill professionals need to develop (Taylor et al. 2014).

Some studies have used assessments which allow patients to be classified according to factors including their level of activation, acceptance of their diagnosis and perceived level of control (Kidd et al. 2015; Lenzen et al. 2018). While the aim of these assessments is to help professionals to provide the right support for the right patient, my study showed that they were at risk of being misinterpreted. While some participants felt people with low activation needed more support

which health coaching could provide, others believed that patients with low activation were more difficult to coach or would not benefit. Other clinicians trained in coaching have also reported that people who were already motivated to change are most likely to benefit from coaching (Ahluwalia et al. 2013).

Patient suitability for self-management is a significant consideration for practitioners. However, patient suitability is judged by clinicians and assessed in relation to a number of different factors. Some patients are identified as having major barriers to self-management as a product of their wider social setting (for example a lack of access to social or economic resources, concerns with other major life events) (Liddy et al. 2014; Owens et al. 2017; Brook and McGraw 2018). Health professionals appear to recognise that seeing self-management as an individual responsibility is often inappropriate given the impact of wider social context, and have concerns about health services promoting self-management as a way to delegate responsibility to patients and spread professional resources more thinly (Howard and Ceci 2013; Brook and McGraw 2018).

Concurrent health problems could also mean patients are seen as too unwell to benefit or as unable to focus on a single issue (Brook and McGraw 2018). Mental health problems in particular were highlighted by study participants as a barrier, in line with other research (Liddy et al. 2014). Coaching requires psychological effort on the part of the patient to make a realistic appraisal of their current situation (Newman and McDowell 2016). In progressive neurological conditions, where both mental health problems and cognitive impairment are common, this is particularly important. Cognitive factors such as insight, mental capacity and attentional skills

can also impact on motivation (Burton et al. 2015). Some patients are perceived by clinicians as having low motivation, taking on a passive role in their care in which they have an expectation of solutions being provided for them (Newman and McDowell 2016; Rose et al. 2017). These patients have been characterised as lacking an understanding of their role, being disinterested in setting their own goals and finding it difficult to problem solve (Rose et al. 2017).

Participants in my study reflected on how patients' expectations were shaped by previous interactions with the health service, based on a biomedical model which encourages the adoption of a passive role. The wider literature shows that patients are seen as "habituated" (Rippon and Hopkins 2015, p.34) into their role, and their expectations of consultations are shaped by previous experiences, down to factors such as what uniform the clinician wears (Wilson et al. 2012; Carter et al. 2015).

Patients' adoption of a passive role acts to establish and maintain the clinician's accepted role as the expert. Clinicians also have a role in creating this asymmetry within consultations, as they reinforce their own expertise (Parry 2004; Bright et al. 2012). It therefore follows that the disruption in this dynamic required to successfully use a coaching approach is not easily achieved (Parry 2004).

As a starting point it has been suggested that patients should be clearly introduced to a new approach, their preferred level of involvement should be sought, it should be made clear why patients' active involvement is helpful, and that seeking patients' opinions is not a sign of clinician incompetence (Elwyn et al. 2012; Joseph-Williams et al. 2014; Rose et al. 2017). Starting health coaching conversations with this type of introduction might have helped those participants who worried about

the confusion a coaching approach could cause if used unannounced within established patient relationships.

It is also likely to be crucial to highlight to clinicians their own role when patients fail to engage. For some of my participants this was the most transformative element of learning generated during implementation of the health coaching approach. While currently a lack of engagement is generally seen as attributable to the patient, calls have been made to view engagement as a co-constructed process, making explicit the important role of the clinician (Bright et al. 2015). Viewing engagement as a process instead of as a behaviour could help clinicians to think differently about how they work with patients who they consider to be disengaged (Bright et al. 2015).

Lent and Lopez's (2002) tripartite view of efficacy beliefs within therapeutic relationships provides a helpful lens through which to consider the roles of patient and clinician during health coaching and to summarise potential areas for intervention. The model suggests that in a therapeutic relationship, each member of the dyad makes three efficacy judgements about: their own self-efficacy, the efficacy of the other person and the way in which the other person perceives their efficacy (Lent and Lopez 2002). In an ideal health coaching relationship, patients would build their own self-efficacy, they would believe in the skilfulness of their coach and they would believe that their coach believed in them. Coaching processes are well suited to building self-efficacy and also demonstrating how the coach believes in the capability of the coachee, and this belief is likely to be particularly influential when the coach is seen as highly knowledgeable and credible

(Lent and Lopez 2002). However, as highlighted above it may be unclear to the patient how skilled the clinician is, if the approach is unintroduced and unexpected.

Ideally the clinician in the relationship would have high self-efficacy in relation to their coaching skills, they would believe in their patients' abilities to self-manage, and they would also believe that their patients saw them as highly competent. The data from my study suggested that none of these aspirations are currently consistently achieved, but emphasise the importance of both building clinicians' confidence in the approach, and also their confidence in applying the approach with their patient population. Positive implementation experiences appear to provide crucial feedback to improve confidence in all these areas.

## 8.2.2 Refined theory

Clinicians generally recognise the challenge of providing self-management support and are interested in learning new techniques to try to improve care (C). Learning about specific tools and practicing techniques in training helps to build knowledge (of how to operationalise SMS) and confidence (through opportunities to practise in a low risk setting and experience success) (M). For confidence to develop, the training needs to feel authentic (promoted by a safe training space), relevant to setting (which will depend on perceived organisational barriers/ patient barriers (C) and the extent to which they are addressed (M), and the perceived flexibility of the intervention itself (M)), and to fit with views about existing identity, role and

responsibilities (M). Successful training gives clinicians confidence to use the skills flexibly with a wider range of patients (O).

# 8.3 Core question 3: How does team support influence the implementation of SMS?

Colleagues' opinions were the least frequently reported barrier to providing SMS in the survey. However, the realist synthesis suggested that the level of team support available could explain variability of implementation. Team views were noted to be a reflection of organisational priorities, but even if these were broadly supportive, practical resources were required before trained staff could make changes to their practice.

The evaluation findings reflected the views expressed in the initial survey that in general other team members' views were not a barrier to implementation, and that team support was high. Colleagues appeared least influential when staff worked with a high level of autonomy. When staff worked highly collaboratively, colleagues' lack of knowledge of a health coaching approach could be a barrier to implementation, while working with those who understood the principles was seen as beneficial. Training provided a useful way to 'label' the work that professionals did, for those working in settings when they felt that they needed to justify their approach to others.

The evaluation also highlighted examples of how the training participants sought to influence their teams. There was general enthusiasm for sharing the learning from

the training and delivering 'in service training' acted to both enhance the wider team's understanding of the approach as well as providing a useful 'revision' opportunity for the trained staff. The online resource was ineffective in providing ongoing peer support due to lack of engagement from the majority of participants.

## 8.3.1 Exploring the findings in relation to the wider literature

When considering the influence of other team members, it became clear that an absence of team level barriers was alone insufficient to facilitate implementation. More active support from colleagues is likely to be required. NHS Health Education England (2015) recognises that while whole team training aspires to create a shared understanding and develop shared implementation plans, consideration needs to be given to the risk to perceived safety generated by training with colleagues. This negative impact was identified by some members from the team in my study who attended together. Programmes that encourage volunteers to attend from across organisations can allow for more objective reflection on current practice without concerns about colleagues being present (NHS Health Education England 2015). However, there was also real appetite from many participants in my study to spread the health coaching approach within their teams. Carter et al. (2015) also found that staff felt their colleagues should be trained, both because the training was viewed as beneficial, and also because they believed a consistent approach was important for patients. This poses a challenge for the planning future training, as the benefit of the freedom of expression possible while training with strangers may

be outweighed by the disadvantage of lacking support from trained peers during implementation (Carter et al. 2015).

It has been suggested that staff who have adequate time, space and continuity to utilise the skills should be targeted for training (NHS Health Education England 2015). Many of my study participants were highly autonomous practitioners, and although this meant they had opportunities to make changes to their practice, it also meant that many of them worked independently. Those who worked more collaboratively had more opportunities to experience 'naturally occurring' peer support for the new approach.

If autonomous practitioners are targeted for training, specific attention may need to be paid to providing more structured opportunities to encourage the embedding of the approach. Ladyshewsky (2006) suggests that asking a pair of clinicians to develop joint learning objectives and commit to peer coaching before attending training can act to increase the transfer of training into the workplace. Other studies have suggested workplace observations with feedback, buddying and mentoring as methods to support the embedding of the approach (Brook and McGraw 2018; Lenzen et al. 2018). Plans to support the sustainability of the health coaching approach include the development of resource banks to facilitate the sharing of good practice and ongoing personal study (NHS Health Education England 2015). The lack of engagement with the online resource provided during my study suggested that online communities of practice may not provide a viable source of peer support. Utilising a proactive group moderator to set discussion topics and tasks could have been trialled to improve engagement (Ikioda et al.

2013), but organisational constraints and lack of motivation appeared more influential.

If health coaching is perceived as a way to manage demand on an overloaded team, or to work more successfully with 'heart sink' patients then individual team members are likely to be more receptive to the approach (Carter et al. 2015). My study showed that health coaching could be 'sold' to teams in this way by trained individuals acting as champions. However, the spread through teams was limited by the perceived need to attend the specialist training, which is where train-the-trainer models, which build local capacity, could offer an opportunity to improve dissemination (NHS Health Education England 2015).

## 8.3.2 Refined theory

In the PNC setting (where there is a good fit between the ethos of the service and the health coaching approach) (C) the influence of team support on an individual's consulting behaviours is likely to be greatest when there is greater interaction among team members (shared caseloads, joint working), whereas collaborating with untrained colleagues might lead individuals to prioritise their previous approach (M-O). Trained staff can act as champions (M) for the health coaching approach and create interest and enthusiasm among their colleagues (O) especially when existing practices are identified to inadequately meet patients' needs (C).

# 8.4 Core question 4: How do organisational priorities influence how individuals value SMS?

The survey showed that organisational level constraints, including work patterns and competing workload priorities, were reported as the barriers with the biggest impact on respondents' ability to provide SMS. Although supervisor support only impacted on a small proportion of respondents, it was more commonly reported as a barrier by trained rather than untrained staff. This may indicate that training could change participants' ideas about SMS provision and how it should be supported.

In line with the survey findings, the realist synthesis described how the way in which work is organised provides messages about what needs to be prioritised and may make it difficult to integrate SMS. Organisational support needs to be backed up with resources if SMS is to be seen as practical. Adopting new practices such as templates for data collection can facilitate integration of the new approach.

Making changes in practice was easiest for staff with adequate autonomy. The risk of creating dissatisfaction among training participants if they were unable to use their new SMS skills because of organisational constraints was also identified.

The evaluation data appeared consistent with the findings of the survey and review.

Certain work settings (e.g. short appointments, lack of continuity) made it more

difficult for participants to be sure about how health coaching fitted with their

existing work. How flexible the health coaching intervention was perceived to be

influenced the level of organisational support required. All participants reported

broad organisational support for the high level aims of the health coaching approach, but not necessarily practical support for enacting it. When the organisational context was seen as very challenging, participants struggled to see how learning new skills could overcome the barriers they identified. Individual levels of interest and readiness to actively participate are likely to differ when training is mandated by the organisation, when trainees may attend with a degree of reluctance and scepticism.

#### 8.4.1 Exploring the findings in relation to the wider literature

As discussed in Chapter 1, supporting self-management is high on the national policy agenda. In resource constrained settings struggling to cope with demand, supporting self-management may be seen as particularly important (Sezier et al. 2018). Organisational support has been described as crucial in enabling health care professionals to integrate SMS into routine clinical care (Taylor et al. 2014). When person-centred approaches are identified as an organisational priority, there is evidence that this increases individual health care professionals' engagement and prioritisation of these activities (Bunn et al. 2018).

In my evaluation it was easier to recognise proactive organisational support than to detect its absence. While all participants reported support in principle from their organisation, many struggled with meeting competing organisational priorities.

Inadequate time is usually cited as the greatest barrier to integrating person centred approaches, such as shared decision-making, into routine care (Légaré et al. 2008).

Currently, person-centred care is not routinely measured by many organisations giving a clear message to staff about what is valued and driving clinicians to prioritise other tasks (Newman and McDowell 2016). The organisational cultural shift required for clinicians to move away from a biomedical focus and towards a more person-centred approach has not yet been achieved and is likely to require further service reorganisation (Taylor et al. 2014; Bunn et al. 2018). Silo-ed working, organised on the basis of diagnostic categories and to meet organisational needs, is the norm within the health service, and this also acts as a significant barrier to the provision of more personalised and integrated care (Procter et al. 2013; Newman and McDowell 2016). Dealing with increasing workloads may encourage short-term thinking and a focus on 'firefighting' and employers should identify and address organisational factors that influence their employees' behaviours (Wilson et al. 2006; Newman and McDowell 2016). This is likely to require strong leadership and high-level commitment to prioritising SMS (Taylor et al. 2014).

Organisational capacity to facilitate change, motivate staff, support teams and monitor impact will influence the successful implementation of any SMS intervention (Taylor et al. 2014). Organisations have a role in convincing staff that approaches like health coaching can become the way that routine work gets done, rather than extra work to do on top of other clinical tasks (Lloyd et al. 2013). Alignment between organisational and individual priorities can also help to minimise the level of role conflict that individuals experience, which as discussed above, has a major influence on the transfer of training into clinical practice.

## 8.4.2 Refined theory

Individuals need to become convinced that health coaching is an appropriate use of their time (M). The way in which work is organised and assessed sends a message to participants about what should be prioritised, and this may be more influential that the 'stated ethos' of the organisation. In a time and resource constrained setting (C), health coaching is more likely to be valued if it is seen as a practical way in which to meet organisational targets (e.g. reduce contact from 'heart-sink' patients) but less so if it is seen as an extra task to be done once higher priority activities have been completed (M). A lack of identified organisational barriers (C) does not guarantee implementation (O). Restructuring of existing work (M) may be required to embed health coaching (O).

## 8.5 A refined programme theory

The overall programme theory, fitting together the theories developed to address each core question, is represented in Figure 8.1. The diagram provides a high-level overview of the training and implementation process. The dashed arrow between the training outcomes towards the implementation context is intended to represent the fact that this area remains partially theorised. Unpicking the relative influence of the training stage outcomes and the implementation context remained challenging, with different factors appearing to be more influential on different participants.

The refined CMO configurations presented in sections 8.1 to 8.4 and summarised in figure 8.2 represent my refined programme theory, which identifies the thought processes training needs to trigger, and the characteristics of the training, the participants and their workplaces which make it more likely for the required reasoning processes to occur. Although I focussed the evaluation stage on a single type of training which aims to upskill clinicians in supporting self-management, the majority of the findings are not specific to health coaching, but are highly relevant to other SMS training interventions as evidenced by the fit with the findings from the wider literature. Similarly, while the focus of this thesis has been on staff who work with people with PNCs, many of the findings are were not unique to this setting and have been reported elsewhere. Commonalities have also been identified with the challenges faced by other interventions aiming to promote clinician behaviour change particularly around person-centred care. This provides the opportunities for trainers in health coaching and for those working in the PNC setting to learn from what is already known, as solutions generated in other settings may be transferable.

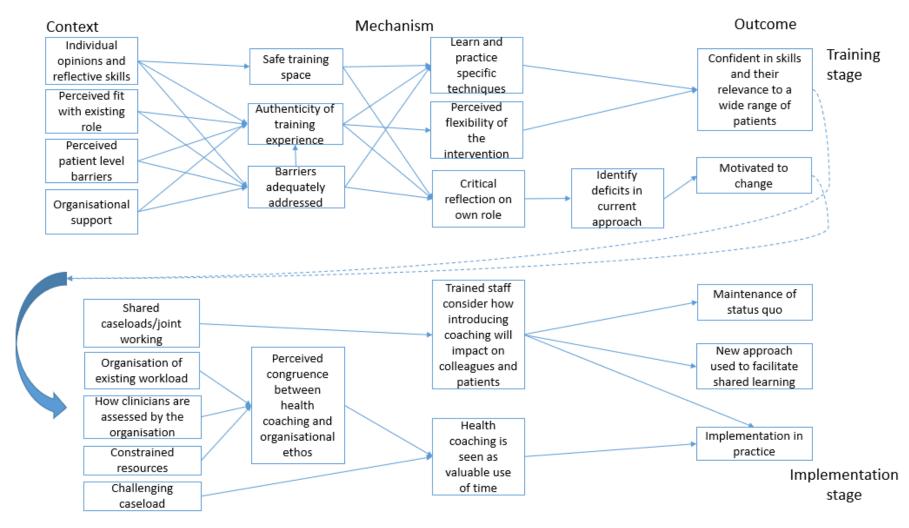


Figure 8.2 A refined programme theory for training and implementation of self-management support skills

Having presented a refined programme theory, the next section focusses on the strengths and limitations of the processes used throughout the thesis, considering the chosen methodology and methods in more detail.

## 8.6 Strengths and Limitations

#### 8.6.1 Realist methodology

A realist approach has been a helpful method to use to start to unpack the complexity of the provision and implementation of a training course for health professionals. The choice of realist methodology significantly influenced how the research questions developed and how data were collected and analysed. Overall, adopting a realist approach has allowed me to identify and explore the different ways in which training was experienced and implemented, among a group of participants working in similar roles with similar patient groups. Rather than focussing on describing average effects, I concentrated on developing a nuanced understanding of differential impact of training, with a focus on exploring generative causation. These methods could be incorporated more widely into the evaluation of CPD interventions. As with all realist studies, while identifying the complexity of the intervention, it has been important to limit the scope of the inquiry to keep the research manageable and achievable. At times this has been a source of frustration, and I recognise that there are many influences that have remained unexplored. Each phase of the research is now considered below.

### 8.6.2 Survey methods

The strengths and limitations of the initial survey were described in Chapter 3. The survey was developed after scoping the literature and underwent pilot testing before distribution. It was designed early in the PhD before the decision was taken to use a realist lens for the entire study. Had the survey been designed later in the process, I would have considered trying to explore the experiences of staff who had already attended training in more depth. This could have provided insights into additional training mechanisms. It would also have been useful to ask respondents to define the most important outcomes of SMS training, as this could have guided outcome measurement during the evaluation stage. Nevertheless, despite the recognised potential biases, the survey provided useful early data to inform the direction of the later stages. Notably, it identified how training interests appeared greatest around a set of skills relating to patients' readiness to self-manage.

Assessing and improving readiness continued to be a major theme in the later stages.

#### 8.6.3 Review methods

The strengths and limitations of the realist synthesis were discussed in Chapter 4.

The review developed seven CMO statements which identified important training mechanisms and contextual influences. The synthesis was conducted largely by myself alone, and this will have inevitably influenced which theories I prioritised for development. As with all reviews it was limited by the quality of included papers in particular, and a lack of detailed descriptions of training interventions and the

contexts in which they took place (Masterson-Algar et al. 2016). I recognised that the review was more helpful as a theory building exercise, and that theory refinement could be better achieved in the later evaluation stage. Data were also sought from a variety of other sources both during the review process (stakeholder group and key informant interviews) and following the review (staff focus groups and PPI involvement) which helped to address identified gaps in the literature.

### 8.6.4 Evaluation stage

The training intervention evaluated was specifically arranged as part of my PhD study meaning that it differed from the way in which training might routinely be delivered to NHS staff, which in turn may have impacted on the transferability of my findings. Lack of funding is recognised to be a major barrier to nurses and therapists continuing their professional development (Haywood et al. 2013).

Participants commented on how unusual it was to be offered an opportunity to attend such high-quality training for free. While removing the barrier of funding was possible in the context of a PhD study, it would not be possible in other settings. Providing the training for free may have increased the willingness of managers to support participants' attendance. However, it is also possible that only participants from the most supportive settings were given the opportunity to attend, given that two full days of study leave were required.

The way in which the training I studied was advertised and delivered meant that it was possible for enthusiastic individuals to attend, provided that they had some support from their organisation. Most participants requested to attend due to

personal interest, some as a result of colleagues' recommendations, and others to try to meet an organisational requirement for training completion.

The significant time I was able to dedicate to recruiting staff from my groups of interest is unlikely to be reflective of other settings. Participants whose organisations had commissioned and funded the training might have experienced the training differently, particularly as it is may not have met a pre-identified learning need or interest, which is an important element of adult learning (Knowles et al. 2005). Had the training been commissioned by an NHS Trust, it is unlikely that it would have been possible to bring together so many staff working in such similar roles.

Participants at the training I organised highlighted how much they valued networking with others who worked in similar roles to learn how things were done differently in other teams. It also allowed the training to focus more on the experience of working with people with PNCs. Training whole teams who engage in joint working may have better facilitated implementation. However, if staff who worked in very different settings trained together, the risk of participants leaving the training with unanswered questions about how it should be applied with their patient group might have increased.

At times it has been challenging to unpick the impact of the training intervention and the impact of the research. Some participants were less engaged in the research data collection. Those participants who were recruited early on and understood how the PhD study would run alongside the training intervention seemed more engaged than those who were recruited last minute to fill the final

available places, or via their manager. It has been difficult to know whether lack of completion of research processes reflects a lack of enthusiasm for the training itself, disinterest in the research, or limited time available to engage due to competing demands.

It was also clear from participants' accounts that being involved in the research influenced their experience of the intervention. Participants spoke about how knowing that they would be participating in a research interview acted as motivation to review the course content and to practise the skills within consultations before the scheduled interview. During the interviews themselves, participants had the opportunity to 'think aloud' about their experiences, and this often provided space for them to explore their own thoughts and reach conclusions (Darra 2008). In this way the process of being interviewed may have influenced future implementation.

It is also important to note that the trainers were concerned that participants did not experience the 'standard' training package, (in which the two sessions are delivered with a 2 to 4 week gap between) because severe adverse weather necessitated the postponement of the second training day. They voiced concerns that some momentum was lost and as a result the training may have appeared less impactful than is usually the case. This does however demonstrate that this was a 'real world' evaluation, likely to be reflective of routine delivery where similar obstacles could be encountered.

Identification of contextual influences in the evaluation stage relied largely on participants' self-reported data. When some participants identified contextual barriers and facilitators to implementation, it was difficult to assess what the absence of these data in the accounts of other participants might mean. It is recognised that what is not said within research interviews is as important as what is said; it is the interplay between the two that creates meaning (Cunliffe 2003). There is a risk that certain contextual factors were so taken for granted by participants that they were not identified during the interviews (Poland and Pederson 1998). Similarly, it may be that although I tried to raise questions about the impact of context, the factors I identified were not considered to be relevant by participants (Poland and Pederson 1998). Assessing the relative impact of different contextual factors on individual participants, given the variety of possible influences, range of different training responses, and the relatively small number of participants, remained difficult.

The influence of my status as an 'insider' researcher on the data collection and interpretation is discussed in the reflexivity section below. Observational work 'on site' at some participants' workplaces could have been helpful to generate a deeper understanding of organisational norms and their influence. As all participants described their organisations as broadly supportive in principle, examining how this appeared to differ in practice could have impacted on interpretation. A documentary analysis from different sites could have been incorporated to explore this influence further. There were some examples in the data of how the content included within audited assessment forms impacted on what participants perceived

to be their core role and encouraged them to focus on specific measured tasks (Jamtvedt et al. 2012). Individual cognitive factors, such as attribution and social identity which have been identified as significant could also be explored further in future investigations.

#### 8.6.4.2 *Mechanisms*

As a realist evaluation, my study attempted to focus on how and why the training actually worked to create changes, a focus which is often lacking from evaluations of educational interventions (Olson 2012). Mechanisms are considered to consist of both the resources which the intervention offers, and the participants' response to these resources, and both of these elements have been explored within the evaluation stage (Dalkin et al. 2015). While the complexity of the training itself meant that identifying whether all activities were required proved difficult, there were clear messages about those which most trainees highly valued (with a notable emphasis on the benefits of role play). Identifying the specific learning processes that were triggered was somewhat impeded by the incremental nature of how learning often occurs, with learning sometimes representing a gradual realisation rather than a sudden event, without participants being fully aware or able to recall the process (McEwen et al. 2011; Billett 2016). The longitudinal nature of the study did allow for changes to be described in the way participants thought after experience with implementing the intervention. The application of formal theory highlighted the transformative process of developing a new understanding of the impact of one's own behaviour on the consultation as a key training mechanism for

some of those who went on to implement training successfully. The theory building work conducted during the course of the PhD could help future studies to target the measurement of specific areas such as self-efficacy to assess whether and to what extent the identified mechanisms appear to operate.

#### 8.6.4.3 *Outcomes*

At the outset of the evaluation it was clear that any objective measurement of changes in participants' clinical practice would be beyond the scope of the PhD, despite this clearly being the end goal of the training. It was therefore necessary to rely on assessing intermediate outcomes of changes in knowledge and confidence, together with exploring self-reported change in practice using the interviews and questionnaires. The limitations of self-reported data have been well described. There tends to be only a modest correlation between self-reported skills and actual performance, with people tending to be overly optimistic about their skills and knowledge (Dunning et al. 2004). Complex forces influence all social interactions, and individuals often lack sufficient information to make accurate judgements about their own behaviour (Dunning et al. 2004). Two particular sources of bias in self-reported data are particularly relevant to this study.

## Response shift bias

Using pre-test and post-test questionnaires relies on the assumption that participants' understanding of the concept being measured will not change between the two rating points (Drennan and Hyde 2008). However, as a specific aim of the health coaching training is for participants to improve their

understanding of specific health coaching techniques, training <u>is</u> likely to influence how participants rate their own performance (Howard 1980). This effect has been referred to as a response shift bias, meaning that there is a risk that the impact of training is underestimated due to participants evaluating themselves differently once they have a better understanding of a concept (Howard 1980).

Utilising retrospective pre-tests was trialled. In this approach participants are asked to look back to rate their pre-training performance following the training, which allows them to make the judgement from the same perspective as that used to make the post-test rating (Howard 1980). I chose to use pre-training questionnaires, and also to add a retrospective pre-training rating to my threemonth follow-up questionnaire, similar to the approach chosen by Yank et al. (2013) in their study of clinician training in SMS. I hoped that this would allow me to assess for the presence of response shift bias, and without relying solely on collecting data after training when there was a risk of high rates of non-completion. In the event the retrospective pre-test data proved to be of limited value. Only 13 of the 20 participants completed the three-month questionnaires and the patterns of response shift varied significantly within this small group (with retrospective preratings being higher, the same or lower than pre-ratings for different individuals). For clarity these data were not included in the presentation of the results, but it remains important to acknowledge that response shift bias may well have influenced ratings of at least some participants, although I have not been able to determine to what extent, or why others appeared unaffected.

### Social desirability

The second important source of bias on the outcomes data is that of social desirability. People tend to claim traits or behaviours they see as socially desirable (such as being a reflective and person-centred clinician) and deny those which may paint them in a less favourable light (Nederhof 1985). This may have influenced participants' reporting of their pre-training and post-training behaviours.

Participants were grateful for the opportunity for free training, were aware of my role in organising this training, and may have wished to appear thankful for the opportunity, and committed to ongoing professional development by providing a positive review of the training itself. The training clearly positioned the performance of health coaching as a desirable behaviour for health professionals who wish to support patient-centred care. The interviews involved a process of social interaction with a fellow health professional, meaning social norms and the desire to give a good impression of their own practice may have influenced the responses given (Nederhof 1985; Darra 2008).

The nature of this PhD study meant that a small number of participants was studied, attending a single training course. Longitudinal data collection using mixed methods strengthened the theory refinement process during the evaluation stage. However, significant variability in the way in which the trainees responded, together with variability in the way in which participants defined 'doing health coaching' made linking the outcomes to their generative mechanisms and specific contexts more difficult.

While using validated questionnaire instruments was considered, as outlined in Chapter 5, no single suitable instrument was identified, and the risk of noncompletion of a battery of detailed measures was thought to be high. In future evaluations, development of more reliable outcome measures could be considered, but a mixed methods approach is likely to always be required to understand contextual complexity. Measuring the direct impact of clinician training would be extremely valuable, but is it recognised that direct observation of consultations is often impractical (Eccles et al. 2006). Intention to change practice is often measured due to the correlation between intention and behaviour (Eccles et al. 2006). However, an 'intention-behaviour gap' has been recognised, usually largely related to a group of people with positive intentions who fail to subsequently change their behaviour (Sheeran 2002). Sheeran (2002) reviewed the evidence relating to patients making health behaviour change and found that on average 47% of those with positive intentions did not enact these. The literature from interventions relating to clinician behaviour change shows similar patterns (Eccles et al. 2006). Awareness of a potential intention-behaviour gap and which group of participants drive this gap could help trainers to address implementation barriers more effectively. Interventions for the group of 'disinclined abstainers' could focus on motivation, whereas for 'inclined abstainers' it may be more effective to focus on the processes involved in translating their intention into performance (Orbell and Sheeran 1998). For example, making specific action plans, as well as coping plans around what to do if something goes wrong may be a helpful strategy (Reuter et al. 2010).

Participants could also be equipped with a set of outcome measures to facilitate both the monitoring of the effectiveness of training, and to provide personalised performance feedback. Any patient-level outcome measures used would need to take into account the fact that health coaching may encourage a move away from quantifiable medical outcomes (timed walks for example) and towards the functional outcomes that matter to patients. Measures such as goal attainment scaling (Turner-Stokes 2009) and Patient's Global Impression of Change (Hurst and Bolton 2004) may be better suited to assessment of patient-level outcomes.

#### 8.6.5 Researcher role

Reflexivity involves active consideration on how one's own role as the researcher impacts on the research process (Reeves et al. 2013). Researchers need to consider their own background and past experiences, how these influence what they may take for granted and how they interpret situations (Cunliffe 2003; Reeves et al. 2013; Tai and Ajjawi 2016). The aim of this section is to bring these factors from the unconscious into the conscious to allow the reader to judge the possible impact on the research and so demonstrate adequate rigour (Cunliffe 2003; Reeves et al. 2013; Tai and Ajjawi 2016). Realist research in particular is an inherently interpretive process, so transparency around decisions made and what may have influenced these is particularly important. My reflections on the possible impacts of my own role during the intervention, data collection and analysis stages are discussed below.

### 8.6.5.1 During the intervention

A spectrum of observer roles has been described from complete participant, to participant as observer, observer as participant and complete observer (Gold 1957). Anthropologists describe how researchers may have an 'emic' perspective (that of an insider or full participant) or an 'etic' perspective (that of the outsider or analyst) and may move between these roles. There is recognition that adopting either of these perspectives completely has its own advantages and disadvantages and that ideally an element of both perspectives is required to generate good quality data (Green and Thorogood 2014). The personal characteristics of the researcher influence the level of participation the researcher chooses or is forced to adopt (DeWalt and DeWalt 2011).

In my case, as a health professional it was impossible for me to take a complete outsider view. My own clinical experience meant I could easily identify with the issues and challenges raised by attendees. This insider perspective had the advantage of allowing me to develop an empathetic understanding of the participants' thought processes, motivations and priorities (Green and Thorogood 2014). As an active training participant I was able to provide better descriptions of what was actually involved in the training, and how it felt to be trained, by sharing the experience with the participants, and this in turn may have helped me to identify the important mechanisms at play by experiencing them first hand (Yin 2014). Disclosing my own views and experiences during the training may have also helped the group to accept my presence as a researcher and to develop trust, as through my participation I made it clear to participants that I understood the realities of clinical practice (Allen 2004).

On a practical level, it was important to ensure that the demands of the participant role did not make it impossible to fulfil the observer role (by leaving inadequate time to take sufficient notes for example) (Yin 2014). I noted that after the first day of training my observation notes did not always reflect whether a trainer or a participant first raised a particular issue, presumably because I was engaged in active participation. This was something I became mindful to specifically observe during the second day. I also used notes taken by an observing administrator to supplement and triangulate my own observations.

My overall impression was that my health professional status and active participation facilitated my acceptance in the group. Although it is possible that my presence could have influenced the way in which participants behaved while I was present, my active participant role appeared to help to move me away somewhat from being considered solely as a researcher evaluating their performance (Atkinson and Pugsley 2005). The presence of researchers alone does not trigger behaviour change in those observed; behaviour change is a product of what has been termed 'participant reactivity', referring to the cognitive work performed (Paradis and Sutkin 2017). I did not note any occasions when my presence appeared to influence participant behaviour, though I recognise that this impact might not be clearly visible to me.

#### 8.6.5.2 *Collecting data using interviews*

Having established some relationship with the interviewees by engaging with them during the training appeared to facilitate rapport building during the interview

stage (Hammersley and Atkinson 2007). All participants were made aware and appeared to remain aware of my clinical background, and the assumptions that they made about me based on this knowledge would have shaped how they responded in the interviews and tried to present themselves (Poland and Pederson 1998). It may have been helpful that although I was a health professional, my background as a general practitioner meant I did not have specific expertise in the same field as the participants. Coar and Sim (2006) noted in their study, when GP researchers interviewed physiotherapists, they appeared to appreciate the opportunity to have a conversation with a fellow professional but were less concerned about being judged on their physiotherapy expertise than they might have been if the interviewee shared the same clinical background.

There were examples in the interview data of when participants appeared to feel the need to justify their actions and how these aligned with their professional identity (often relating to the way in which they were permitted to exercise clinical judgement and how they conducted consultations) (Coar and Sim 2006). These may have indicated that participants felt under scrutiny or that there was a level of moral judgement occurring, which could have been exacerbated by my health professional status (Chew-Graham et al. 2002; Coar and Sim 2006).

As an interviewer there is also a risk that my own professional background meant I failed to explore areas of theory which I thought I already understood (Coghlan and Brannick 2014). However, I think this was partly mitigated by my lack of in-depth understanding of the work of the participants, meaning I remained curious to

understand more, and also by my interest in exploring differences among the different participants' experiences.

There were also examples of how my clinical role enhanced my role as an interviewer. My understanding of the way NHS services are organised, and of participants technical knowledge and jargon, helped the interviews to flow (Coar and Sim 2006; Coghlan and Brannick 2014). I was able to use my own experiences during the development of the interview topic guides and also during the interviews when generating follow-up questions (Coghlan and Brannick 2014).

Participants often referred specifically to my own clinical role, referring to the fact that I would understand what they meant. Other researchers have suggested that being interviewed by a colleague may mean the interviewee expresses a sense of camaraderie and is more willing to be vulnerable, facilitating access to privileged information and a greater insight into attitudes held (Chew-Graham et al. 2002; Coar and Sim 2006).

### 8.6.5.3 During analysis

While gaining acceptance from the participants was crucial, it was equally important to avoid becoming so immersed in the group culture that it would be challenging to stand back and analyse the data appropriately (Pope and Mays 2006; Green and Thorogood 2014). Being too close to the data can mean assumptions are made automatically rather than challenged, and having a similar background to participants can also lead to a shared conceptual blindness (Chew-Graham et al. 2002; Coghlan and Brannick 2014). Furthermore, I needed to be cautious that while

I might have assumed that as health professionals we shared the same tacit knowledge base around clinical practice, my professional socialisation during medical training and practice may not mirror that which occurs in other professions (Atkinson and Pugsley 2005). There was a risk that while I might have assumed I understood participants' perspectives, this was unlikely to be entirely true. While analysing the interview data, my own experiences of the training itself are likely to have influenced how I viewed the participants' responses — in particular I may have found it easier to describe theories that resonated with my own experience of the training, and more difficult to understand the perspectives of participants who seemed to have experienced the training differently. It was important to attempt to bracket my own views and preconceptions to ensure that the voice of the participants could be clearly heard (Chew-Graham et al. 2002).

Furthermore, my own role in the organisation of the training may have created a vested interest in the success of the training. However, I think overall the results presented demonstrate my recognition of the range of different training outcomes and some of the possible reasons for the variability in responses observed. Because I come from a different professional group to participants and attended with a different perspective (including a better understanding of the aims of the training), I felt that this helped me to maintain a certain level of distance. In addition, I met regularly to discuss my findings with my supervisory team, two of whom have non-clinical backgrounds. This helped facilitate critical reflection on my own interpretations of the data.

My prior experiences of research are also likely to have influenced how I approached the PhD as a whole as well as the analysis of the evaluation stage data. My familiarity with using thematic analysis in qualitative research (Braun and Clarke 2006) meant I felt most comfortable analysing the data generated from each stage inductively, before considering my findings in relation to existing formal theory. An alternative theory-driven approach, utilising a specific theoretical lens for data collection and analysis (for example the Normalisation Process Toolkit with the NoMAD instrument for data collection) (May et al. 2015), may have yielded very different results. My prior research training in medical education also influenced the way in which I thought about the data and the formal theories I recognised as being likely to be of particular relevance.

Having considered the strengths and limitations of the approaches used to develop and refine my programme theory, I believe I have demonstrated the trustworthiness of the explanation this provides. The programme theory has identified important mechanisms and described some of the facilitating or inhibitory contexts in which these may or may not lead to outcomes. The complexity of the variety of contextual influences has made it difficult to be confident that its influence has been entirely accounted for, though several key areas have been highlighted. I now present a number of key recommendations derived from the findings, before summarising my conclusions.

# 8.7 Recommendations for organisations and providers

A number of core recommendations can be derived from the results of the PhD.

 Staff working with people with PNCs value training in specific approaches to supporting self-management

For providers: Staff already recognise the challenge of providing effective support for self-management. They value the opportunity to train with others who work with a similar patient group.

For organisations: Do not assume that health care professionals automatically possess the skills to effectively support self-management. Training for staff working with people with PNCs can result in a major shift in routine practice.

Evidenced within: Chapter 3 (survey), Chapter 4 (literature), Chapter 6 (evaluation).

Recognise the significant role of professional identity

For providers: Tailor the training to take into account professional norms and values and how these may differ (especially when training multi-professional teams).

Different groups may have different core objectives, so showing how coaching can be used to achieve a range of aims may be important.

For healthcare organisations: Understand certain staff groups may find coaching easier to integrate than others. Additional organisational restructuring and proactive support may be needed to embed the coaching approach, and ensure it becomes seen as core to clinicians' roles.

Evidenced within: Chapter 4 (literature), Chapter 6 (evaluation), Chapter 7 (formal theory).

• Make the practical application of the approach clear

For providers: While 'real-play' allows clinicians to experience a coaching relationship, they may struggle to understand how training can be transferred to the clinical setting. Provision of concrete examples directly relevant to clinical practice can help this process. In the progressive neurological conditions setting, common barriers such as mental health problems and cognitive impairment should be proactively addressed, and relevant techniques specifically signposted within the training.

For healthcare organisations: Staff need to be able to see the training as relevant to their workplace. Staff who have the fewest competing priorities are likely to find it easiest to see the practical application of the approach, facilitating implementation. Evidenced within: Chapter 4 (literature), Chapter 6 (evaluation), Chapter 7 (formal theory).

• Consider the influence of voluntary versus mandatory attendance

For providers: Consider what extra support might be required to help staff who attend the training on a mandatory basis to become ready for learning. More intensive training interventions, which focus on exploring professional norms further may be required in this group.

For healthcare organisations: Allowing staff to self-select to attend may be a way to identify future champions for the approach. Subsequent spread may be slower and require more intensive efforts.

Evidenced within: Chapter 4 (literature), Chapter 6 (evaluation).

Deal proactively with competing priorities

For providers: Ask staff to bring along to the training routine assessment forms used in daily work. These could be used to trigger reflection on the alignment between health coaching and their current working practices. Attempting to complete existing assessment tools using a health coaching approach could be practised. Exemplar documents developed in other services which fit with the principles of coaching could be provided.

For healthcare organisations: The strong messages provided by the way in which work is organised and audited should be considered. Consider a review of institutional documentation and procedures alongside staff training to ensure a coherent approach.

Evidenced within: Chapter 4 (literature), Chapter 6 (evaluation), Chapter 7 (formal theory).

• Facilitate ongoing peer support and reflection

For providers: Consider how learning during the implementation phase can be optimised. For example, provide templates for reflective logs that could be shared

and discussed with colleagues. Help trainees to identify health coaching 'buddies' within the training and set specific expectations of providing ongoing mutual peer support. Provide examples of data collection instruments or completed audits for participants to understand how they might monitor the effectiveness of a change in practice.

For healthcare organisations: Training groups of staff who are involved in direct coworking allows for naturally occurring opportunities for peer support. While highly autonomous practitioners may have the fewest initial barriers to implementation, they are also most at risk of lacking ongoing peer support, which may need to be provided in a more structured way (e.g. through clinical supervision, refresher training, networking events for trained staff). Train-the-trainer models could be used to develop expertise and build local capacity. Gather data at an organisational level and provide feedback on this to clinicians so they can understand how changes in their approach influence patient-level outcomes.

Evidenced within: Chapter 4 (literature), Chapter 6 (evaluation), Chapter 7 (formal theory).

### Identify limited implementation early

For providers: Participants who manage to sustain the approach usually implement the training early. Consider whether those who have not made significant implementation efforts after initial training can be identified and offered additional support.

For healthcare organisations: Identify the level of implementation among trained staff. Use the information to consider whether there are significant organisational barriers hampering implementation in certain settings that can be addressed.

Evidenced within: Chapter 6 (evaluation).

These recommendations relate specifically to training interventions for health professionals. Taking a broader view, it is also worth considering whether introducing the principles of person-centred care and self-management support earlier into undergraduate health professional education might make it easier to integrate these approaches. However, as students and curricula focus heavily on the development of the necessary professional knowledge and expertise, it may be equally counter-cultural to attempt to integrate approaches which attempt to move the focus away from the role of clinician as expert.

#### 8.8 Recommendations for future research

Key questions have been raised during this thesis which would benefit from further exploration. Firstly, the perspective of people with PNCs should be further explored. Work with patients to explore ideas around readiness to self-manage, how this can be identified and how it can be supported would also help to inform the tailoring of future interventions. It would also be helpful to understand more about what people with PNCs would consider to be good outcomes from health

professional training and self-management support consultations so that appropriate outcome measures can be identified or designed.

Future research should attempt to focus on the measurement of patient-level outcomes attributable to clinician training, which was beyond the scope of this thesis. While assessing changes in knowledge, skills and attitudes remains important, these are intermediate steps in a pathway that aims to improve patient-level outcomes (Chen et al. 2004). Attributing outcomes to a specific intervention is undeniably challenging, due to the considerable complexity of the ever-changing context of the lives of individuals and the wider healthcare system (Chen et al. 2004). Realist approaches could offer a way forward to assessing this stage of the causal pathway.

There is already recognition that the culture of an organisation can act to enhance the effectiveness of interventions targeting patients or clinicians, enabling the integration of a self-management approach (Taylor et al. 2014). While whole systems approaches targeting patients, clinicians and organisations have been suggested as the optimal way in which to achieve successful support for self-management, further work is required to understand how the required organisational culture shift can be achieved (Taylor et al. 2014). The dispersed nature of the majority of participants in my intervention made an in-depth focus on organisational culture impossible. Further research, in settings where the desired culture shift has been achieved or is in progress would be informative for organisational leaders. Settings where practices to support person-centred care

such as shared decision-making have been effectively embedded could provide relevant information.

As with all realist studies, this PhD has involved theory development and refinement, using multiple data sources. As the realist evaluation process is cyclical, further data collection could help to further develop the theories presented here. Most notably, it would be helpful to share the findings with participants and providers to see how well they resonate with their own experiences, and to identify contextual influences and training mechanisms that may have remained unexplored. This process has already started with the production of a set of infographics which have been distributed to participants and stakeholders (see Appendix A). Sharing the findings with participants and trainers working outside the PNC setting might also help to further illuminate how this particular context presents different challenges, or whether the theories identified are readily transferable. Dissemination of the findings in papers and conference presentations is planned.

### 8.9 Conclusions

This realist inquiry has produced a refined programme theory describing the training of staff who work with people with progressive neurological conditions to support self-management. This theory may be more widely applicable, both to the training of professionals who work with different groups of patients, and also to other training interventions which challenge existing attitudes and ways of working.

This study has identified that participants respond to training in a highly varied fashion. Training tended to be most successful when participants built self-belief in the new skills, while also becoming convinced that their patients would be responsive, and that their working patterns could accommodate a change in approach. This helped participants to avoid experiencing significant role conflict which inhibited change.

Staff who went on to implement the training in practice experienced the most transformative learning, in which they began to more clearly understand the coconstructed nature of engagement and the impact of changes in their own behaviour. Experiencing success allowed momentum to build and maintained motivation.

The policy drive towards promoting self-management among people with long term conditions appears to be based on an assumption that clinicians already have the required attitudes and skills to provide support. However, in many curricula, specific techniques for self-management support are not taught, and what is learned, whether formally or within the workplace, often directly contradicts with a self-management support approach, privileging biomedical goals and clinician expertise. Ongoing professional development interventions, such as the training in health coaching evaluated in this thesis are presented as one way to address the deficit in knowledge and specific skills. Future self-management support training should ensure the practical application of any new approach is made clear. This may require an exploration of how the new approach fits with current views about professional identity and the requirements of the participants' current professional

role. Training should also consider how strategies such as ongoing reflection and peer support can be facilitated after a short course to maximise implementation success.

Training occurs in a specific context, unique to each individual participant attending. The findings of this thesis support wider calls for the context into which the training is provided to be taken into account during intervention planning. Interventions may need to target altering this context to facilitate practice change. Organisations for example, could work more proactively to support the implementation of the training, by ensuring that supporting self-management is adequately resourced and measured so it becomes seen as both valued and practical to implement.

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### Appendix A – Publications and presentations produced during the thesis

The following abstracts, posters and papers are attached:

**Poster presentation:** Improving the self-management support provided to people with progressive neurological conditions: Using a realist synthesis to inform intervention design. The state of the art of realist methodologies

conference (PhD Student and Early Career Researcher Day), Leeds, November 2015

**Poster Presentation:** Training health professionals to support self-management among people with multiple sclerosis. South West Society for Academic Primary Care, Cardiff, March 2016

**Protocol paper:** Davies, F. et al. 2017. Interventions to improve the self-management support health professionals provide for people with progressive neurological conditions: protocol for a realist synthesis. BMJ Open 7(3), p. e014575.

**Elevator pitch:** Designing training in self-management support: Lessons from using a realist synthesis (abstract)

**Poster presentation:** Helping health professionals to support self-management among people with progressive neurological conditions: A realist synthesis

South West Society for Academic Primary Care, Oxford, March 2017

**Oral presentation:** Using the findings of a realist synthesis to select and adapt a self-management support training intervention for health professionals. (abstract) International Conference for Realist Research, Evaluation and Synthesis, Brisbane, October 2017.

**Realist synthesis paper:** Davies, F. et al. 2018. Shifting mindsets: a realist synthesis of evidence from self-management support training. Medical Education 52(3), pp. 274-287.

**Poster express presentation:** Providing self-management support: A survey of UK health professionals who work with people with multiple sclerosis

**Poster express presentation:** Training staff who work with people with progressive neurological conditions in health coaching: A realist evaluation

Rehabilitation in Multiple Sclerosis (RIMS) Annual Conference. June 2018. Amsterdam.

Infographics: disseminated to participants and stakeholders, July 2019



# Improving the self-management support provided to people with progressive neurological conditions:



# Using a realist synthesis to inform intervention design.

Freya Davies<sup>1</sup>, Fiona Wood<sup>1</sup>, Alison Bullock<sup>2</sup>, Carolyn Wallace<sup>3</sup>, Adrian Edwards<sup>1</sup>.

- Both patients and professionals believe people should be supported to self-manage their own conditions(1) but at present people with progressive neurological conditions (PNCs) are often not as involved in their care as they would like to be. (2)
- Interventions have been designed to improve the self-management support that health professionals provide but these do not always impact positively on clinical practice.  $^{(3)}$
- We aim to synthesise the existing evidence from a variety of specialities. We will use the results to inform the design of a new intervention for professionals working with people with PNCs.

### Planned Approach Project stage A realist synthesis will be undertaken. Theory Is rapid realist review most The intervention targets (health generation Realist synthesis of professionals), the intended providers appropriate to inform intervention existing interventions (NHS and charities), and the intended beneficiaries (people with PNCs) all have important perspectives to inform Use CMO configurations the review. A group of these key stakeholders will be consulted generated to design new Has anyone else used a realist synthesis to design an intervention in intervention and plan the context of a PhD? throughout the review process to evaluation ensure that the direction of the review remains relevant to routine practice. Should we select participants from The review will aim to identify the key Pilot the new different contexts or observe the context-mechanism-outcome (CMO) contextual differences within preintervention configurations related to implementing existing teams? self-management support for people with PNCs. Focus will be placed upon How do we balance measuring identifying mechanisms that it might be Test if the CMO outcomes with identifying possible to target with a new configurations operate as mechanisms? intervention. An intervention will be expected designed based on the programme theories the synthesis generates. Pilot interventions will be undertaken and Theory intervention characteristics or how evaluated to assess whether the Refine the theory refinement the participants applied learning to identified mechanisms work as their routine practice? predicted Candidate theories of potential interest Adult learning Diffusion of How can these help us? theory Normalisation Communities of determination process theory practice theory Affiliations. 1. Institute of Primary Care and Public Health, Deibel F. et al. Patients', carers' and providers' experiences and requirements for support in self-man Cardiff University 2. Cardiff Unit for Research and Evaluation in Medical and Dental Education Cardiff

1. Delice F. et al. Patients', carers' and providers' experiences and requirements for support in self-management of Multiple Sciencis: a qualitative study. European Journal for Person Centred Healthcare. 2013;12):457-67.

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# Training health professionals to support self-management among people with multiple sclerosis



Freya Davies<sup>1</sup>, Fiona Wood<sup>1</sup>, Alison Bullock<sup>2</sup>, Carolyn Wallace<sup>3</sup>, Adrian Edwards<sup>1</sup>.

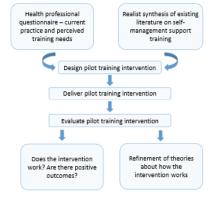
### Background

- Professionals recognise providing self-management support (SMS) requires specific skills, (1) and that, even after training, providing SMS in practice is not straightforward. (1.2)
- While SMS in some conditions has been extensively researched, progressive neurological conditions such as multiple sclerosis (MS), have been relatively neglected.
- The symptoms of MS, including low mood, cognitive impairment and fatigue may make supporting selfmanagement particularly challenging
- It is currently unclear how we can improve the SMS health professionals provide for people with MS within their routine consultations.

### The air

To design a training package to upskill health professionals in self-management support

### The approach



We are currently in the first phase of this project, designing a questionnaire and developing theories for our realist synthesis.

### **Developing realist review questions**

Realist reviews are guided by a group of key stakeholders (now recruited).



### **Emerging ideas**

Early immersion in the data suggests that self-management support training interventions have two main purposes (see blue boxes below) which are addressed through a variety of different activities.



### **Next Steps**

- First study advisory group in March 2016 to define the key review questions
- Develop a customised search strategy working with an information specialist.
- Produce refined theories about how and when self-management support interventions work.
- Use these theories to inform the intervention design stage of the project.

### Why realist synthesis?

- We need to know how transferable the findings from differing contexts might be to the challenges associated with supporting people with progressive neurological conditions.
- The aim of a realist synthesis is to generate theories about how interventions work, what outcomes they have, and how local context
  influences how the intervention functions. The synthesis can include information from any relevant field.<sup>(3)</sup>
- We aim to focus our theory development around the issues which are likely to be most important for professionals who support people with progressive neurological conditions like MS.

References: 1. Mudge et al. BMJ Open. 2015;5(5). 2. Kennedy et al. International Journal of Nursing Studies. 2014;51(8). 3. Pawson et al. Journal of Health Services Research & Policy. 2005;10(s1)

Affiliations: 1. Division of Population Medicine, Cardiff University. 2. Cardiff University and Education, University of South Wales. Funding: The realist synthesis phase of this research will be funded by the Scientific Foundation Board of the Royal College of General Practitioners (Grant No SFB 2015-18)

Open Access

# BMJ Open Interventions to improve the self-management support health professionals provide for people with progressive neurological conditions: protocol for a realist synthesis

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Introduction: Supporting self-management among people with long-term conditions is recognised as an important component of healthcare. Progressive neurological conditions (PNCs), for example, Parkinson's disease and multiple sclerosis are associated with problems such as fatigue and cognitive impairment which may make self-management more challenging. Health professionals may need to develop specific skills in order to provide effective selfmanagement support for these patients. The review aims to develop explanatory theories about how health professional-targeted interventions to improve selfmanagement support provision for people with PNCs operate in different circumstances.

Methods and analysis: A realist synthesis of the evidence is proposed. There are 2 priority questions for the review to address. These relate to the role of a shared concept of self-management support within the healthcare team, and the need to tailor the support provided to the requirements of people with PNCs. Key stakeholders will be involved throughout the process. The initial search strategy uses terms relating to (1) self-management, (2) health professionals and (3) PNCs. Searching, data extraction and synthesis will occur in parallel. Studies will be prioritised for inclusion based on anticipated contribution to generating explanatory theories. Key informant interviews are planned to direct supplementary searches and help further refine the theories developed. Results will be expressed in the form of context-mechanism-outcome configurations.

Ethics and dissemination: Publication guidelines on realist synthesis will be followed. The results will be published in a peer-reviewed journal and made available to organisations involved in the provision of health professional training.

### INTRODUCTION

People living with long-term conditions make decisions that relate to the management of

### Strengths and limitations of this study

 The application of a realist approach to evidence synthesis will lead to theory development about the contexts in which interventions are most

Protocol

- Describing the mechanisms by which existing interventions work will facilitate future theory-
- driven intervention design and evaluation.
  The breadth of interventions which might be considered to support self-management may make defining the scope of the review
- challenging.

  If evidence available relating to supporting people with progressive neurological conditions is limited the reviewers will need to consider the transferability of knowledge generated in other

their condition on a daily basis,1 from choosing how they use their medication to how they plan their activities. Corbin and Strauss suggest that self-managing a condition involves three tasks: medical management, role management and emotional management. Health professionals have tended to focus on optimising the medical management of conditions, but there is increasing understanding that the focus of efforts may need to shift towards an approach that encompasses all of these tasks to help people to live well with their condition. People often have different definitions of successful self-management compared with their clinicians, with patients emphasising the need for self-management support (SMS) that is relevant to the context of their lives.4 This may be particularly important in progressive neurological conditions (PNCs). PNCs are conditions in which patients experience a progressive deterioration in their functioning

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Davies F, et al. BMJ Open 2017;7:e014575. doi:10.1136/bmjopen-2016-014575

(eg. Parkinson's disease and multiple sclerosis). In these conditions successful self-management is not necessarily expected to modify the disease course itself, but may have a significant impact on how well people live with their symptoms.

### What is SMS?

SMS may be delivered directly to patients, for example, via attendance at SMS programmes. These programmes may include activities such as information provision, emotional and behavioural management skills, and tech-Ondition-specific selfnical skill development.6 management programmes for people with a PNC often cover issues such as physical activity, medication adherence, cognitive impairment, depression and fatigue. Limitations to these types of approaches have been recognised, including the fact that patients who volunteer to attend such programmes may already be moti-vated and skilled in self-management, while those who may benefit from support most may not access these types of courses. <sup>10</sup> If SMS becomes integrated into routine clinical care more patients will have access to support. To encourage this integration, interventions aiming to promote SMS may include indirect components delivered either to individual professionals (such as education and training) or at an organisational level (eg, financial incentives). <sup>11</sup> The variety of skills health professionals require to effectively support selfmanagement has been broadly divided into general person-centred skills (such as communication skills), behaviour change skills (eg, motivational interviewing) and organisation/system skills (eg, use of electronic recall systems). 12

### What is known about training health professionals to support self-management?

Supporting self-management is not a straightforward task for clinicians as it requires judgements to be made around patient readiness, professional role boundaries and service expectations. The evidence for training health professionals to support self-management is mixed. While there is some evidence that training health professionals can change clinicians' behaviours, others have shown that clinicians failed to apply training in SMS in their routine work.<sup>14</sup> Implementation of SMS in routine practice is recognised to be inherently complex, with multiple potential barriers at the levels of the patient, the professional and the wider organisa-tion. <sup>11</sup> The need for further research to understand how provider burden can be minimised and selfmanagement programmes can be made more widely acceptable has been recognised.<sup>15</sup>

Previous suggestions for optimising professionaltargeted interventions include involving staff members in the intervention design process; and ensuring that any intervention is seen as professionally desirable, and fits within existing clinical routines. 11 16 The context into which an intervention will be delivered should be

considered if the intervention design is to be successful. In particular, staff preconceptions about their role in supporting self-management, and its relative importance in relation to other tasks should be addressed.

### Supporting self-management in the context of PNCs

Although supporting self-management has been shown to be challenging across a range of settings, supporting people with a PNC may raise particular issues. Depression, cognitive impairment and fatigue are common comorbidities in PNCs and may all make it more challenging for patients to effectively self-manage, and for professionals to know how best to support self-management in these circumstances. <sup>17</sup> Professionals working in this area already have a wide remit including providing education and support, symptom manage ment, medication advice, care coordination, and ongoing care planning. High workloads and a lack of time to meet all patient needs have been reported. <sup>18</sup> time to meet all patient needs have been reported. Much of the available research evidence relating to selfmanagement comes from conditions, such as diabetes, where objective measures of disease control which may respond to successful self-management are available. In PNCs the expected outcomes of supporting selfmanagement are likely to be harder for professionals to define and measure. While this may mean that professionals are encouraged to take a more holistic view of supporting self-management than a narrow focus on the medical management of a condition, it may also lead to difficulties in recognising how interventions to support self-management add value to routine clinical care.

Professionals are required to make their own judgements about the level of self-management that they might expect their patients to engage in, and the level of support they provide to attempt to facilitate this process. Interventions aiming to improve SMS provision need to influence these decisions. For example, some professionals may worry that expecting people with a PNC to take an active role in self-managing their condition could be excessively burdensome. Training which encourages exploration of the purpose and goals of SMS may work well for this staff group. Others may feel that they lack the time required to provide SMS. In this case, training which provides ideas which can be easily integrated into their current practice may be seen as most valuable. A review approach designed to take into account this type of complexity is therefore required.

## METHODS AND ANALYSIS

### Chosen methodology

Research into continuing professional development activities has been criticised for focusing only on whether or not interventions work--without attention being paid to the mechanisms by which they have an or the relevant contextual influences that moderate their effectiveness. The realist synthesis approach has been proposed as an effective method for

synthesising evidence from complex interventions which addresses these concerns. A realist synthesis uses a theory-driven approach, informed by an acknowledgement that interventions will operate differently when delivered into different contexts. Realist synthesis seeks to unpick what type of intervention works, for which professionals, working in which settings, to what extent and why. This is done through the development of programme theories, developed and refined throughout the review process, which describe how the context into which the intervention is delivered influences how the intervention functions (its 'mechanism') in order to produce a range of differing intended and unintended outcomes.

We plan to use the realist synthesis approach to review the evidence about interventions which aim to increase or improve the support for self-management provided by health professionals working with people with PNCs. Training health professionals in SMS is by definition a complex intervention, consisting of multiple interacting components<sup>21</sup> and therefore well suited to a synthesis approach that acknowledges this complexity. During this review, we will focus specifically on understanding how training in SMS and delivery of support operates at the level of the health professional, rather than at the level of the patient.

The approach to searching for evidence in a realist review is more iterative than a traditional review procedure, and allows reviewers to purposively search for and select literature likely to be informative. This is likely to be particularly helpful in this review because self-management itself is a complex concept to define, and this also makes a conventional literature search challenging. The more inclusive nature of a realist review allows data which may not be indexed under the heading of SMS (but do relate to an important element of SMS) to be included, as researcher judgement on relevance is used in place of strict inclusion/exclusion criteria.

Realist reviews operate at the level of transferable programme theories (rather than at the level of a specific intervention). As a result, realist reviewers recognise the transferability of knowledge from other settings and may include evidence from areas that relate to the programme theory (but not necessarily the narrow topic area under review). Again this is likely to be relevant here, to ensure that this review identifies sufficient evidence to be useful and informative. A recent review of systematic reviews of self-management identified only limited evidence related to self-management in PNCs.<sup>11</sup> However, evidence on the implementation of SMS for many other patient populations was identified and may be able to provide useful insights where condition-specific literature is sparse. One challenge for the review team will be in trying to decide to what extent knowledge gained from other settings may be transferable to the context of supporting people with PNCs with the challenges discussed above. Significant stakeholder

involvement in the review process should help to ensure the relevance to the population of interest.

### Context of the review

The review is part of a larger planned project which forms the basis of a PhD for FD. The programme theories generated during the review process will be used to design a theory-based training intervention. Use of realist reviews for this purpose has been recommended<sup>23</sup> and applied in other settings.<sup>24</sup>

### Current stage of review work

The iterative nature of realist reviews means it is difficult to prespecify the direction of the review before significant work has already been undertaken to identify and prioritise areas of focus. The authors have attempted to strike a balance in producing this protocol at a point when the review has progressed sufficiently to be able to provide useful detail but not so far into the process to make this an entirely retrospective account. The accompanying online supplementary file indicates the steps in the review process completed at the time of writing and those still anticipated. Initial searching, data extraction and synthesis have all started, with further searching, extraction and synthesis planned. For ease of reading the initial search process is described retrospectively, and the subsequent searches, data extraction and synthesis are described prospectively. Our aim in publishing the protocol at this stage is to add transparency to the synthesis process, especially since the method is open to interpretation.

The synthesis is being undertaken in parallel with two other pieces of work. The iterative nature of the review will mean that learning collectively from these work streams can usefully inform the direction of further searches and the refinement of the programme theories. An online survey of health professionals working with people with an exemplar PNG mulitple sclerosis (MS) was distributed in April to May 2016 with the aim of getting a snapshot of current practice, future training interests and important barriers in relation to the provision of SMS. Although the primary purpose of the survey data was to help prioritise specific intervention content for the later phase of the work, the data relating to barriers may helpfully inform programme theory development in the synthesis. Interviews with a small group of key informants with experience of training health professionals in skills relating to SMS are planned for October 2016. We will use a convenience sample of contacts made by the stakeholder group from a range of different training backgrounds. These interviews will allow the early developing programme theories from the synthesis to be discussed with the participants and sub-sequently further refined.<sup>25</sup> A clear audit trail will be maintained so that the sources of programme theories remain transparent and these will be clearly reported on.

3

#### Planned review strategy

The planned review strategy was registered on the PROSPERO database (CRD42016035596). The review process will follow the five stages of realist review described by Pawson et ak<sup>26</sup> clarification of scope, searching for evidence, appraising evidence and extracting data, synthesis, and dissemination.

#### Clarification of scope

A period of reading around the subject was undertaken by the first author (FD) which allowed key recurring themes from the wider literature about SMS to be identified. In the literature relating to training health professionals in SMS, specific SMS skills (and confidence in their use), perceptions of workplace fit and belief in the concept of SMS itself all appeared to be influential factors. Research exploring the implementation of SMS in practice identified issues that included patient-level barriers, the influence of health professional, local multidisciplinary team and wider organisational characteristics. These issues were discussed at an initial stakeholder group meeting in March 2016. Our stakeholder group includes the study authors who are academics from health (two of whom also work clinically as general practitioners), social sciences and education, with interests in SMS and/or postgraduate health profes sional training. Other members of the group were clinicians working with people with a PNC (MS specialist nurse and occupational therapist), service users with PNCs, a researcher working for a SMS training provider and third sector representation (MS trust). Unlike a traditional systematic review, key stakeholders are consulted throughout the review process from refining the focus of the review to challenging or validating emerging review findings.<sup>27</sup> Informed by the group's discussion on priority areas, two key review questions were formulated, with the overarching aim of improving understanding of the circumstances in which health pro fessionals could implement and sustain SMS. Therefore, the scope of the review was planned to include both professionals' experiences of receiving training in supporting self-management and their experiences of applying this training in clinical practice.

The initial review questions chosen were:

 What is the influence of a shared concept of SMS within healthcare teams caring for people with PNCs and how can it be achieved?

The first question aimed to examine what professionals thought about SMS, and how this was influenced by training interventions and existing contextual factors (eg, professional role, previous experience and workplace factors).

What is known about how SMS can be successfully tailored for people with PNCs?

This question aimed to focus on how SMS might need to be provided differently for people with PNCs than for other conditions, and to examine whether training

health professionals to adopt a more flexible or tailored approach was important.

Although dementia could be classified as a PNC, people with dementia are usually managed by a different healthcare team (old age psychiatry) to people with other PNCs, so for the purpose of this review we have not included dementia within our definition of PNCs. 28

#### Search strategy

Iterative searches were planned in line with the realist methodology. The overlap in the searching, extraction and synthesis processes is illustrated by the flow chart in online supplementary file S1. Our initial search strategy, designed with input from an information specialist used three search threads in combination: health professional terms, self-management terms and PNC terms (both relevant MeSH headings and free-text terms; see online supplementary file S2). Search terms relating to selfmanagement were informed by terms used in previous systematic reviews <sup>4</sup> <sup>11</sup> <sup>29</sup> and by terms which existing known papers were indexed under.<sup>30</sup> At this stage the aim was to be as inclusive as possible. Therefore, terms relating to goal setting and health coaching were included as these were seen to be important skills related to supporting self-management but which might not be indexed under the term self-management. Although we initially planned to include a fourth search thread of terms relating to education or training, after piloting the searches we noted that relevant papers relating to implementation of SMS interventions were not identified, so we removed this thread from the search.

The initial search was developed for MEDLINE via Ovid and then adapted for other databases (EMBASE, Cochrane Library, CINAHL, PEDro, ERIC and PsycInfo). The search was limited to English language papers (due to resource constraints) and to papers published in the past 20 years (as the concept of SMS is relatively recent). Following a particularly high recall from a search engine previously found to have a low specificity in relation to this topic (EMBASE), 11 additional limitations were placed on the search to ensure only the most relevant papers were retained (non-Organisation for Economic Co-operation and Development (OECD) countries, children, palliative care and diagnosis-related studies were excluded). Details of the search dates and terms used are provided in online supplementary file S2. Initial searches were performed in April to May 2016.

Going forward, a grey literature search for relevant websites and policy documents is planned. In addition, forward and backward citation tracking of key papers will be used together with hand searching of relevant journals. Key papers already known to the authors, and identified through initial scoping exercises will also be eligible for inclusion, as will any recommended by members of the stakeholder group. A clear audit trail of the source of included papers will be maintained. The need for and direction of further iterative searching will be informed by the findings of the ongoing synthesis,

4

Davies F, et al. BMJ Open 2017;7:e014575. doi:10.1136/bmjopen-2016-014575

stakeholder advisory group and key informant interviews as described below.

#### Data extraction

Titles will initially be screened for basic relevance by FD. Any titles that are obviously irrelevant will be excluded at this stage. Studies will be excluded if they focus predominantly on: paediatric patients, carers or families, nursing homes/managed care settings, diagnostic or end-of-life period, epidemiology, imaging or testing, measurement instruments, and specific treatments or devices.

An abstract screening tool developed by FD and tested in collaboration with FW will then be used to screen the remaining abstracts (see online supplementary file \$3 for further detail). The tool will rank papers 1-4 based on their perceived likely relevance to either of the review questions. In brief, the highest ranked abstracts will be those that both related to a PNC and to health professionals' experiences of training in or implementation of SMS. Papers not specific to PNCs will be ranked lower, and those where professional involvement in SMS is unclear will be ranked as least likely to be relevant. Although the tool provides basic guidance on the likely relevance of papers for inclusion, author expertise and judgement will also be applied here to ensure that the tool is flexible enough to ensure potentially highly relevant papers are not deprioritised because they do not meet the predefined criteria. This application of researcher judgement is a key element of the realist approach to literature review which differs significantly from traditional systematic review.<sup>20</sup> The full text of all papers ranked of the highest relevance will be sourced and assessed for potential inclusion. Full-text screening of the lower ranked abstracts will be undertaken selectively once data extraction from the initial papers provides further direction. If data saturation for some areas of the review is achieved early in the review process then it is anticipated that including data from these studies is unlikely to provide additional new information. Decisions about saturation will be made collaboratively through discussion among the authors.

Realist reviewers do not generally rely on traditional quality assessment tools, but instead make judgements on each piece of included evidence based on relevance and rigour.<sup>20</sup> At the full-text screening stage, prior to data extraction, the researcher will decide whether the paper can provide information relevant to the research questions. Reasons for exclusion on the basis of relevance will be recorded. The assessment of rigour will be an ongoing process in the data extraction and synthesis phases. The researcher will critically reflect on all evidence during this phase with the aim of safeguarding the inferences made on the basis of individual extracts by ensuring that they are used appropriately.<sup>20</sup>

A core set of descriptors for each study will be collected including identifiers (author, title, year), type of data (primary evidence, review, opinion piece), patient

group details, staff group details, brief description of intervention, relationship with other studies included in the review and setting (country and healthcare setting). Data relevant to the research questions will be extracted in the form of explanatory accounts configured as 'If-Then' statements. For example: 'If self-management is not valued by colleagues Then staff will feel discouraged from applying training in practice'. This approach was successfully used by another realist synthesis project which aimed to inform future training design. Extracting data as If-Then configurations rather than as context-mechanism-outcome configurations (the standard expression of realist programme theories) has the advantages of being an accessible way of starting to extract data with a 'realist lens', and providing a practical way for partial knowledge to accrue through the review A single 'If-Then' configuration may not process. contain each element of context, mechanism and outcome but may still be informative for the synthesis. When explanatory accounts derived from one data source are recognised to recur in another, this will be noted. The principles of meta-ethnography<sup>31</sup> have been applied during realist synthesis in order to provide clear evidence of the type of data that is used to support the theories developed.<sup>32</sup> We will follow this model so that during the extraction process data will be labelled as first order (direct from participants), second order (from study authors' interpretation) or third order (from synthesisers' interpretation of participants and authors' statements).

#### Data synthesis

We will take a similar approach to that described by Pearson et ales to consolidating our initial explanatory accounts into more refined programme theories. The data synthesis process will begin while data extraction is still ongoing and be facilitated by regular discussion between the review team members. Initially the first author will group together apparently linked explanatory accounts. NVivo V.10 (OSR International) will then be used to facilitate movement between the explanatory accounts and original data. A 'node' will be created for each group of linked accounts and original data that was used to derive the constituent explanatory accounts will be coded under this node. This will allow the reviewers to look back at the original data when generating a consolidated account, to help ensure that the consolidated account continues to accurately reflect the source material. The consolidation process, which will result in refined explanatory accounts, will be carried out in conjunction with a second author (FW). In addition, throughout this process (once early in the consolidation process and once towards the end to confirm the refined context-mechanism-outcome configurations) two further stakeholder meetings will be held. The stakeholders will have an important role in ensuring that the researchers' interpretations of the literature are seen as both relevant and important by professionals. The

5

stakeholder group will also help to prioritise which of the explanatory accounts are seen as crucially important to continue to pursue and which may be of less immediate relevance. If 'priority' programme theories are felt to be described in insufficient detail by the literature identified in the initial searches, supplementary targeted searches of the academic and grey literature will be performed.

Key informant interviews are also planned. Individuals with experience of training health professionals using a variety of different approaches, all of which may relate to supporting self-management in some way, will be recruited (4-6 participants anticipated). These interviews will act as another check of the relevance of the theories developed. Trainers may also be able to help fill in the gaps not fully explored within the literature by reflecting on their own experiences, and to indicate whether any important areas have not yet been addressed.

During the later stages of the review, once the pro gramme theories are relatively refined, existing middle range theories<sup>33</sup> which could help to further our understanding of the programme theories will be sought. There are already a number of candidate middle-range theories known to the authors thought to be potentially relevant to the review (eg, diffusion of innovations and normalisation process theory). 34 35 These known theories will be considered along with any substantive theories used within the included papers to explain their findexplanatory fit, targeted searching for theory will be undertaken.  $^{36}$ 

#### ETHICS AND DISSEMINATION

Ethical approval is not required for the literature synthesis. However, ethical approval has been obtained for the online survey and supplementary interview data via Cardiff University School of Medicine Research Ethics Committee

The RAMESES publication standards for realist synthesis have been consulted during the planning of the review and will be followed for future publication.<sup>37</sup> We will publish the synthesis in a peer-reviewed journal and make the findings available to relevant interested bodies including third sector organisations. We also aim for the theories to be useful to those designing training in SMS for health professionals, to help to identify what may be likely to work and where.

Owing to the relatively limited data expected to be available that are specific to the clinical area (PNCs) and the intervention (improving SMS provision by health professionals), we recognise that some of the theories developed during the synthesis may be partially or weakly supported. We will be fully transparent about the level of evidence available to support each theory developed to allow readers to draw their own conclusions about the relevance of the developed theories to their own contexts of interest

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Contributors FD planned the synthesis approach with input from AB, AE, CW and FW. All authors participated in the initial stakeholder event to define the direction of the review. FD prepared the first draft of the protocol which was reviewed and critically revised by the other authors.

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8

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## Accepted abstract: South West Society for Academic Primary Care 2017- Elevator pitch Designing training in self-management support: Lessons from using a realist synthesis

**Objectives:** Continuing professional development (CPD) interventions which target self-management support are often complex, consisting of multiple interacting components. Participating professionals may react to CPD in many ways, producing a variety of intended and unintended outcomes. CPD providers do not always consider why the same intervention operates differently across different settings and how potential contextual barriers can be addressed. Recognised differences among professionals in the perceived purpose and desired outcomes of supporting self-management may influence training effectiveness. In order to plan an effective intervention for professionals working to support self-management among people with progressive neurological conditions (PNCs), we sought to synthesise the existing evidence using an approach which allows for complexity to be explored and understood.

**Method:** Realist synthesis (Pawson, 2006) was chosen as the method of literature review. The approach is theory-driven. It results in the formulation of explanatory programme theories, in the form of context-mechanism-outcome configurations which describe how and when interventions work. A worked example of how one programme theory was constructed from the review data will be presented to illustrate: how primary evidence was located using a variety of techniques, with consideration for both relevance and rigor; how the data was extracted to form 'explanatory accounts'; how these accounts were synthesised; and how key informant interviews, a stakeholder advisory group and existing theory informed the analysis.

**Results:** Thirteen programme theories were developed from the data, some reflected the training process, while others described implementation. Two substantive middle range theories were used to inform the synthesis (Normalisation Process Theory and Technology Acceptance Model). These theories helped to: highlight gaps in the primary data requiring further exploration, indicate how the different programme theories might be linked in chains, and illustrate how feedback loops may operate.

**Conclusion:** Study inclusion based on relevance rather than pre-set criteria meant that even though relatively limited data directly related to PNCs were available, valuable insights from other settings could form part of the review. However, as a consequence, keeping the scope of the review narrow enough to ensure it was deliverable within time and resource constraints became challenging. The theories generated can inform both intervention design (aiming to ensure key mechanisms operate) and selection of a favourable intervention context which will maximise the chance of success. However the focus on developing theory in this type of review means that detailed intervention content has not been defined and this will require further work.



#### Helping health professionals to support selfmanagement among people with progressive neurological conditions: A realist synthesis



Freya Davies<sup>1</sup>, Fiona Wood<sup>1</sup>, Alison Bullock<sup>2</sup>, Carolyn Wallace<sup>3</sup>, Adrian Edwards<sup>1</sup>.

#### Background

- More than 200,000 people in the UK have a progressive neurological condition (PNC) such as multiple sclerosis or Parkinson's disease.
- The evidence about how to support these people to self-manage their own condition is less well developed than for other conditions.<sup>1</sup>
- We wanted to understand how training health professionals to provide self-management support (SMS) works and whether there are any particular challenges associated with supporting people with PMCs

#### Aims

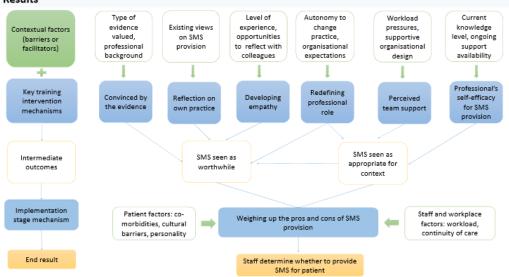
- To synthesise the existing evidence describing the impact of interventions which aim to encourage health professionals to provide SMS for people with PNCs.
- To develop realist programme theories using context-mechanismoutcome configurations (CMOs).<sup>2</sup>

#### Methods

- Structured database searching for primary evidence, key informant interviews (N=5) and stakeholder group meetings (N=3)
- Data used to generate and refine CMOs about SMS training and implementation.

#### Search strategy Initial database searches run April – May Identified via other sources 2016 (MEDLINE, EMBASE, Cochrane Library, CINAHL, PEDro, ERIC and PsycInfo) Another systematic review = 7 Backward citation tracking = 4 5230 records after de-duplication Forward citation tracking = 3 Grey literature searches = 3 Table of Contents Search = 2 1142 relevant titles for abstract screening Scoping phase = 3 Advisory group member = 1 78 full texts 44 original articles contributing data to the refined programme theories 21 papers provided data

#### Results



#### Conclusions

- Analysis of the data was informed by Normalisation Process Theory<sup>3</sup> and Technology Acceptance Model 3<sup>4</sup>
- Seven theories were developed around the key mechanisms described in the blue boxes above which describe how mechanisms 'fire' or 'fail
  to fire' in certain contexts to produce intended and unintended outcomes relating to SMS provision.
- o Staff need to be convinced of both the benefits of SMS and how it will fit within their routine work. Staff appear to weigh up the pros and cons of SMS provision on a case-by-case basis taking into account patient and organisational level factors.
- o Training should address the professional paradigm shift required to fully embrace SMS and facilitate the integration of SMS into routine care.

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Accepted abstract: International Conference for Realist Research, Evaluation and Synthesis 2017. Oral presentation.

Using the findings of a realist synthesis to select and adapt a self-management support training intervention for health professionals

#### Introduction

There is an increasing drive for health professionals to support their patients to manage their own long-term conditions. Providing self-management support (SMS) requires specific skills and can challenge traditional models of working. Previous professional training interventions which aimed to improve SMS provision have shown variable results. To develop effective training for professionals in our setting of interest (progressive neurological conditions (PNCs), we set out to explore the contexts in which, and mechanisms by which, SMS training operates, and the associated outcomes.

#### Methods

We performed a realist synthesis of the literature. Our two research questions, formulated in conjunction with key stakeholders examined 1) how health professionals, teams and organisations view and adopt self-management; 2) how SMS needs to be tailored for people with PNCs. Database searches were supplemented with citation tracking, grey literature searching and stakeholder recommendations. Key informant interviews (n=5), stakeholder advisory group meetings, and three existing middle range theories informed the synthesis process.

#### Results

Forty-four original articles were included, from which seven programme theories were developed. The theories identified several important training components (evidence provision, building skills and confidence, facilitating reflection and generating empathy) as well as notable contextual factors that facilitated or inhibited the acceptance and application of SMS techniques. These results were used to select an existing training approach which seemed most likely to trigger the key training mechanisms required for further evaluation. Our understanding of contextual barriers at the individual and organisational level will inform discussions with training providers to allow these to be proactively addressed in training.

#### Conclusions

The results of a realist synthesis can be used to select a training intervention, and to suggest adaptations to training content. Developing programme theories prior to training delivery can also inform theory-based training evaluation, which will form the next phase of our planned work.

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#### medical education in review

### Shifting mindsets: a realist synthesis of evidence from self-management support training

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CONTEXT Accompanying the growing expectation of patient self-management is the need to ensure health care professionals (HCPs) have the required attitudes and skills to provide effective self-management support (SMS). Results from existing training interventions for HCPs in SMS have been mixed and the evidence base is weaker for certain settings, including supporting people with progressive neurological conditions (PNCs). We set out to understand how training operates, and to identify barriers and facilitators to training designed to support shifts in attitudes amongst HCPs.

METHODS We undertook a realist literature synthesis focused on: (i) the influence of how HCPs, teams and organisations view and adopt self-management; and (ii) how SMS needs to be tailored for people with PNCs. A traditional database search strategy was used alongside citation tracking, grey literature searching and stakeholder recommendations. We supplemented PNC-specific literature with data from other long-term conditions. Key informant interviews and stakeholder advisory group meetings informed the synthesis process. Realist context-mechanism-outcome configurations were generated and mapped

onto the stages described in Mezirow's Transformative Learning Theory.

RESULTS Forty-four original articles were included (19 relating to PNCs), from which seven refined theories were developed. The theories identified important training elements (evidence provision, building skills and confidence, facilitating reflection and generating empathy). The significant influence of workplace factors as possible barriers or facilitators was highlighted. Embracing SMS often required challenging traditional professional role boundaries.

CONCLUSION The integration of SMS into routine care is not an automatic outcome from training. A transformative learning process is often required to trigger the necessary mindset shift. Training should focus on how individual HCPs define and value SMS and how their work context (patient group and organisational constraints) influences this process. Proactively addressing potential contextual barriers may facilitate implementation. These findings could be applied to other types of training designed to shift attitudes amongst HCPs.

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#### INTRODUCTION

Supporting patients to self-manage their long-term conditions is seen as an important part of the role of health care professionals (HCPs).<sup>1</sup> The World Health Organization suggests that empowering people to manage their own conditions may be one way to improve the efficiency and quality of health services.<sup>2</sup> Self-management support (SMS) has been described on two levels.<sup>3</sup> One relates to specific tools and techniques that HCPs use within the consultation (for example goal setting and action-planning) to try to empower patients to take a more active role in their health. At a higher level it can also be seen as a fundamental shift in how HCPs approach their relationships with patients, promoting collaboration over paternalism. However, there is recognition that without specific training, HCPs may not have the necessary skills or mindset to effectively provide SMS.4-7 Previous initiatives attempting to enhance HCPs' skills in SMS have shown variable results. 4.7-10 This may be partly because HCPs' attitudes to their role in relation to SMS vary, and SMS training often challenges a traditional biomedical approach with which HCPs may be familiar and comfortable. Evidence from the related area of shared decision making shows that training interventions alone do not foster adequate attitudinal shifts among teams to facilitate ongoing practice change. 11 Learning when and why HCP-targeted SMS interventions succeed or fail may provide transferable lessons to other settings in which a significant professional paradigm shift is a prerequisite for change in

There is a large volume of research relating to SMS in selected conditions, with type 2 diabetes frequently being a focus. <sup>12-14</sup> There are concerns though that this has tended to encourage an approach to SMS that focusses narrowly on disease control and defines success using biomedical measures such as blood glucose levels. <sup>13,14</sup> which may be less meaningful to the patient. <sup>12</sup> Although this approach may be understandable, both because of the significant implications blood glucose control can have on short and long-term health, and because of the use of blood glucose levels as a measurement of quality care, it may not be a suitable model for use in other settings. <sup>14</sup> We planned to focus our review on HCPs working with people with progressive neurological conditions (PNCs). This setting is relatively under-researched when compared with other conditions. <sup>1</sup> A broader and more holistic approach to SMS is likely to be

required by HCPs working with people with PNCs because there may be less that patients are able to do to control disease progression. <sup>14,15</sup> In addition, SMS for people with PNCs may be complicated by commonly occurring co-morbidities, including depression and cognitive impairment, which can also affect individuals with a wide range of other long-term conditions. How HCPs learn to conceptualise and enact SMS in this setting may therefore provide valuable lessons for those working elsewhere who wish to provide a broader form of SMS that employs diverse and flexible strategies and focuses on living well with a condition. <sup>14</sup>

We undertook a realist synthesis, a method of evidence synthesis designed for complex interventions, which aims to answer the questions: What works, for whom and in what circumstances?<sup>16</sup> We set out to understand how training operates, what facilitates training designed to support shifts in attitudes amongst HCPs, what barriers exist and how these can be addressed. Targeted research questions were developed as part of the review process outlined below. The product of a realist synthesis is a refined theory or set of theories that describe the mechanisms by which (in this case) training operates to produce intended and unintended outcomes. These mechanisms can consist of the resources that training provides to participants and the reactions of the participants. 17 Training mechanisms are contextually dependent (delivering the same training in different settings will not always result in the same outcomes). Realist theories are described as configurations of contexts and mechanisms that lead to certain outcome patterns. 16,17 The aim is to produce theories that are 'middle-range' in nature; that is, at an adequate level of abstraction to be transferable to other settings. <sup>18,19</sup>

#### METHODS

The review protocol was registered with PROSPERO (CRD42016035596). A more detailed description of the methods used, and how the review stages overlapped, is described in detail elsewhere. <sup>20</sup> In brief, initial scoping of the literature was undertaken by FD for key themes relating to training HCPs in SMS, using both known key papers and informal searches. The themes arising from the scoping phase were discussed at a meeting of stakeholders (research team, HCPs, service users and advocates), <sup>20</sup> priorities for the review were

agreed, and two detailed review questions with associated 'initial rough theories' were formulated.<sup>19</sup> (See Box S1 for further details.)

#### Review questions

The first question focused on the influence of how SMS is conceptualised at the levels of the individual, team and wider organisation on how SMS is enacted. The second aimed to examine how HCPs needed to tailor SMS for people with PNCs. Professional-level outcomes are the most immediate outcomes of training, and are essential if HCP training is to have any impact on patients or the wider organisation. To keep the review focused and manageable, as the review progressed, theories associated with outcomes at the level of the professional were prioritised for further exploration.

#### Identifying papers for inclusion

A database search strategy using free-text and MeSH headings relating to (i) HCP terms, (ii) selfmanagement terms and (iii) progressive neurological condition terms was piloted and refined with the support of an information specialist.  $^{20}$  (See Box S2 for further details of terms used.) A bespoke abstract screening tool was used to prioritise papers identified via database searching for review.<sup>20</sup> In brief, papers were identified as 'highly relevant' if they described HCPs providing SMS in the context of PNCs (including general views, receiving training or experience of implementation). Papers relating to the same issues but not within the PNC context were ranked as 'probably relevant'. Papers addressing other aspects of SMS (e.g. descriptions of patient needs) or when the role of SMS in an intervention or the identity of the SMS provider was unclear were ranked lower. All highly relevant papers underwent full-text review, and abstracts ranked probably relevant were selectively reviewed based on their content and the direction of the developing theories. Database searches were supplemented by forward and backward citation tracking of included articles and existing systematic reviews, grey literature and table of contents searches, and papers known to the stakeholder group (see Fig. 1). These supplementary approaches overlapped the data extraction and synthesis process, which allowed emerging ideas to inform decisions about the inclusion of identified articles.

Articles were included based on their relevance to the review questions, with no restrictions on the

type of evidence. Initially, the searching and extraction process focused on the PNC setting, but as the review progressed, articles from clinical settings not involving PNCs but which provided rich and relevant explanatory data were included with the aim of answering the review questions more comprehensively. This was an iterative process, and the decisions about relevance were influenced by the stage of the review and the level of theory development achieved at the time of assessment. Papers identified late in the review process from non-PNC settings that provided supportive data without generating new insights were seen as providing evidence of emerging theoretical saturation of some concepts.<sup>16</sup> The were recorded but not included in the review (see Table S1). Quality assessment was performed not at the level of whole articles, but at the level of individual data extracts, the credibility of which were considered when interpreting the results and how they should be used in the synthesis.<sup>16</sup> A core set of descriptors for each study was collected, including study identifiers, setting (patient group, staff group and country) and intervention described.

#### Synthesis process

Initially, explanatory data relating to either of the research questions were extracted in the form of 'If-Then' configurations, 21 which described links between elements of contexts, mechanisms and outcomes (see Box 1 in Results section). As the synthesis progressed, related If-Then configurations were grouped together and used to generate realist context-mechanism-outcome configurations. During the synthesis process we further divided contextual influences into enabling or inhibitory factors. We described mechanisms as being comprised of the resource provided by an SMS intervention and the associated reasoning generated by exposure to the resource in a given context.<sup>17</sup> The majority of the data extraction and synthesis was undertaken by FD, who was fully immersed in the data, with FW double-coding a sample of included articles (four). NVivo 10 (QSR International, Victoria, Australia) was used to manage the data and provided a way to organise the source data under developing theories. Groups of related context-mechanism-outcome configurations formed the basis of the set of seven refined theories that are the product of the review. The aim of a realist synthesis is to move from using the literature to generate theory, towards using the literature to test the theories

### F Davies et al

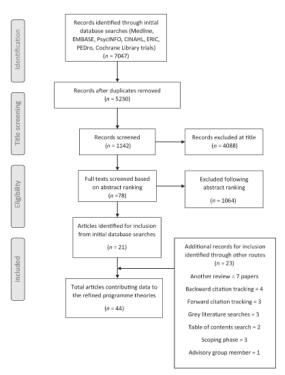


Figure 1 Sources of included articles

developed. <sup>16</sup> We recognised as the review progressed that the limited depth with which interventions were described was likely to limit the scope for theory testing. This problem has been encountered in previous realist reviews of the educational literature. <sup>22,23</sup> While the review was ongoing, we also conducted five telephone interviews with key informants (three HCPs and two lay trainers) involved in SMS training and held two further stakeholder meetings. Both of these steps allowed us to discuss the emerging review findings and informed our interpretation of the available literature. Realist reviewers also make use of existing formal theories (e.g. constructivist learning theory) to make sense of the evidence generated during their reviews. <sup>19</sup> During the

review process we identified existing formal theories referred to within included articles, and used these together with those already known to the authors to help us interpret the findings emerging from the data.

#### RESULTS

Forty-four original research articles contributed data to the synthesis. Eleven of the included papers were specific to a PNC, with a further eight including PNCs alongside other conditions. Of the remaining included papers, nine related to another neurological condition, 13 to other long-term conditions and three papers did not specify

Supporting self-management: a realist synthesis

the patient population. (See Fig. 1 'Included Studies Diagram' and Table S2 showing characteristics of included studies.) Where sufficient detail was available to make specific reference to how SMS had been adapted to the PNC setting this is reported on, but such descriptions were often fairly limited. Elements of context-mechanism-outcome configurations are labelled in brackets within the results as context (C), features of the intervention resource (I), mechanism (the reasoning that was triggered) (M) and outcome (O). A list of all papers contributing to each theory is presented together with examples of specific contributions. In the final phase of the synthesis we looked for existing formal theory that would help us to demonstrate how the refined theories generated from the literature synthesis might fit together under an overall explanatory framework. We found that several existing theories were informative, including normalisation process theory<sup>24</sup> and a technology acceptance model,<sup>25</sup> but in this paper we focus on how transformative learning theory<sup>26</sup> helped us to understand our emerging findings.

Transformative learning theory is a theory of adult learning centring on the idea that the goal of adult education is to assist the learner to become a more independent thinker through a process of critical

reflection on their own values, meanings and purposes, leading to restructuring of existing frames of reference. 26-28 The theory recognises the significant role of contextual influences and interpersonal interactions in the learning process, as well as highlighting the emotionally challenging nature of the process for learners.<sup>28</sup> Our refined theories are presented below, organised under the stages of transformative learning theory. Figure 2 summarises the overall findings of the synthesis. Although the stages of transformative learning are presented here in a linear fashion, in reality there will be pauses in the transformation process and the process may be cyclical. Within the refined theories developed from the synthesis, this cyclical nature is demonstrated, as each stage may occur during training and then be repeated during implementation.

The first stage of transformative learning involves participants being confronted with a 'disorientating dilemma'. We found that the presentation of evidence was sometimes used as a way to challenge HCPs' current practice, leading to the development of theory 1.

Theory 1: Training provides evidence for the benefits of SMS provision (I). Whether the evidence is deemed sufficient to make SMS appear worthwhile (M) depends on

Box 1 Process of moving from original data towards refined theories

#### Original data extract:

'both physical therapists perceived the possibility of resistance by health services to incorporate the philosophy of the Blue Prescription approach because, in their opinion, current services tend to be aimed at remediation of an incident (eg, provision of rehabilitation after a fall), with the intent being discharge of a patient once the incident has been resolved.'

#### 'If-then' statement generated:

"IF a service focusses its efforts on treating acute events and then discharging patients THEN a health promoting self-management approach is unlikely to be accepted."

#### Other overlapping 'if-then' statements generated from other articles:

"IF HCPs try to take time to implement SMS in a team where others are not doing so THEN they may feel that others do not value the time they spend on the activity and perceive them as "not pulling their weight"

"IF HCPs work in a time pressured environment THEN institutional needs will tend to take priority and guide the therapeutic agenda over the needs/preferences of an individual."

#### Consolidated into the more refined theory:

Organisational context (both at a high level and within local teams) (C) influences whether HCPs perceive SMS as something that they can and should integrate into their current role (M), leading to variable application of SMS (O) among trained HCPs (I).

#### F Davies et al

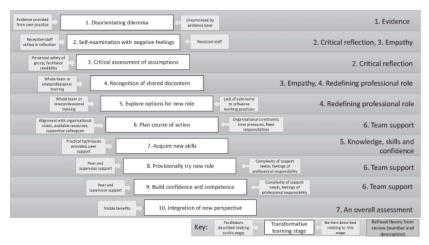


Figure 2 Summarising links between review findings and the stages of transformative learning.

the type of evidence HCPs value most (C). If the evidence is judged insufficient (M), then SMS provision is not prioritised (O).

Four articles<sup>29–32</sup> provided evidence for this theory. Professional background (C) appeared to influence the type of evidence that was valued. Medical staff were reported to prioritise evidence from research trials, and the lack of this type of evidence was a significant barrier to accepting an SMS approach. A policymaker from one study<sup>29</sup> noted:

... some of the clinical community historically looked at randomised controlled trials, at that kind of evidence base. I think we're looking at much more action research and lived experience and sharing what works at a personal level ... it doesn't have to be based on randomised controlled trials.

When evidence was judged as insufficient (M), new practices were not seen as worthwhile adopting (O), especially if they ran counter to current established routines.<sup>31</sup> In settings where HCPs were expected to provide SMS but had multiple other competing demands on their time, (C) a lack of evidence led HCPs to feel that providing SMS could not be justified (M) and other tasks had to be prioritised (O).<sup>32</sup>

The next phases of transformative learning involve a process of self-examination that generates negative feelings and a critical assessment of current assumptions. Two of our theories mapped under these stages.

Theory 2: Training provides opportunities for HCPs to reflect on their current practice in relation to SMS (I). Influenced by pre-existing ideas about SMS (C) this reflective process may act to validate current practice (M) or demonstrate a need for practice change (M - O). Characteristics of the training (I) influence the likelihood of facilitating helpful reflection.

Thirteen articles contributed data to this theory. <sup>32-44</sup> For HCPs who had already 'bought in' to the idea of SMS (C), exploring the concept further in training could act as validation (M) of their approach, leading to a sense of encouragement and motivation to continue their current practice (O). In a written case reflection, completed after training, a therapist from one study <sup>37</sup> described:

I use a client-centred, client-expert perspective in my work. I think the process has empowered me to use/recognise this approach.

Critical reflection (M) was sometimes inhibited by the HCPs' pre-existing views that they were already

Supporting self-management: a realist synthesis

providing adequate SMS (C), resulting in a belief that no change in practice was required (O). Training elements (I) influencing the likelihood of facilitating helpful reflection included interprofessional training, the perception of the group as a safe environment and providing direct evidence of current consulting behaviours (e.g. recordings). \$33,35,37

For some HCPs, the process of critical reflection facilitated by the training (I) led to a realisation (M) that their current practice did not fit with their values regarding a patient-centred approach (C), and this acted as motivation to start working differently (O).<sup>32,33</sup> During the implementation stage when HCPs started providing SMS and reflection provided evidence of success (I), HCPs became convinced of benefits (M) and motivated to continue (O).<sup>39</sup> This process was facilitated by clinical supervision and peer support (C).<sup>40,43</sup>

Theory 3: Both training activities and applying SMS principles in practice (I) can generate new empathy for patients based on a different perspective on their lives (M). This can alter HCPs' expectations of their patients and make their work more satisfying (O). The development of empathy relies on reflective skills that may be facilitated or inhibited by personal, organisational and training characteristics (C).

Eight articles provided evidence for this theory. 40.42.45-50 There was limited evidence relating to contextual barriers to fostering empathy. Some training interventions specifically focused on developing empathy (I), using simulations, 50 or using lay trainers to highlight the patient experience. These experiences helped HCPs to think about how they could adapt their clinical practice to take into account the challenges their patients were facing (M), and applying this learning resulted in a changed approach to interactions (O).

During implementation, adopting a selfmanagement approach tended to encourage HCPs to dedicate more time and effort to exploring each patient's unique context (I), leading to a better understanding of the complexity of people's lives, again triggering a shift in perspective (M) that changed HCPs' expectations (O). A therapist in one study<sup>46</sup> who had been trained to use a new approach to goal setting explained: It's not just about adherence and about motivation to be able to do exercise ... It's about other things. It's life complexities.

When HCPs started to see their patients as the experts in their own lives, then they valued their patients' experiences more highly (M) and started to learn from their patients (O). 45,47 Team support could facilitate the reflective process, which seemed to increase empathy during the implementation phase (C). 40

The process of transformation is then described as continuing with recognition that the identified discontent is shared by colleagues and the exploration of new options. This step is clearly described in theory four.

Theory 4: HCPs choose to work in a way that aligns (O) with their professional values or employers' expectations (C), which influences how they see their responsibility and remit (M). When HCPs have autonomy to make changes in the way they work (C) and are able to critically examine their own role, training in SMS can lead to a broadened view of professional roles and new definitions of success (M), leading to HCPs working differently and feeling more satisfied (O).

Twenty-three articles contributed data to this theory. <sup>7,8,29,30,32,24,37,41,43,44,48,50-61</sup> Redefining of professional role was often reported as a key way in which interventions functioned, and could be an outcome related to the mechanisms involved in some of the other theories described (e.g. critical reflection and empathy).

Health care professionals (HCPs) who were relatively junior and new to their posts were reported to find it more difficult to accept a broadened remit and to work more flexibly (C). <sup>43</sup> A lack of confidence in addressing issues that did not fall within their traditional professional remits could also act as a barrier to role expansion (C). Physiotherapists in particular felt that their patients expected hands-on treatment (C) and worried about not meeting patients' expectations (M). <sup>32,58,59</sup> We suggest that this could be a reason that HCPs might prioritise activities seen as more aligned with their 'traditional' role (O). When HCPs did feel permitted to see their role differently, they also started to define success differently. Thus, if they followed the 'process' of providing SMS, they could feel successful, even if the outcomes they would have previously valued were not always achieved

#### F Davies et al

(M). This could lead to increased satisfaction and lessen feelings of frustration (O). <sup>52,54</sup> During a focus group discussion about an online SMS training course, one doctor reflected <sup>30</sup>:

I think it's reminded me of something I might have forgotten. That is that I don't have to do all of the work. The power to heal lies within the patient, and it's my job to help them find that.

If when implementing training and using a more patient-centred approach (I) HCPs experienced discomfort (M) when they felt that their patients made negative choices, this could lead them to take an approach that prioritised what they saw as good medical care over patient autonomy (O),  $^{61}$  to ensure they met what they felt were their professional responsibilities. Although concerns about negative choices related significantly to how HCPs saw their own role, they were more likely to arise while working with certain patients, such as those felt to lack insight into their condition (C). There were examples of situations where HCPs did start to prioritise patient-centredness over maintaining control and goal achievability (M). This appeared to be facilitated when initial training spent significant time on exploring the concept and purpose of SMS (I) and when continued exploration of what this meant for the professional role was facilitated by discussions with colleagues who had also received training (C).37 This attitude shift was described as requiring 'emotional work' (M) on the part of the HCP to feel comfortable with the new approach.<sup>59</sup>

The next stages of transformative learning involve planning a course of action, acquiring new skills and provisionally trying out a new role. We developed one theory (theory five) specific to skill development, and another that described how the setting influenced the development of a new role (theory six).

Theory 5: Providing specific tools and approaches for SMS (1) to HCPs who previously lacked knowledge and skills in SMS (C) improves understanding of how to operationalise SMS (M), which leads to increased confidence in their ability to provide support (O). However, this confidence depends on the complexity of the support required (C) and needs to be sustained.

Eighteen articles 7,8,34,38,39,41,43,46,47,50,54,55,58,59,61-64 contributed data to this theory. Although knowledge, skills and confidence are important determinants of training success there was relatively little in-depth

exploration of these factors. Specialist knowledge about PNCs was crucial as it allowed HCPs to tailor advice appropriately and to generate solutions for symptom-specific barriers to self-management (M) (e.g. strategies to avoid over-heating while exercising for people with multiple sclerosis). <sup>39</sup> However, HCPs reported that a lack of focus on certain symptoms (notably 'invisible' symptoms and psychosocial issues) in their initial training left them under-skilled to address the difficulties experienced by their patients (C). <sup>55,62,64</sup> A lack of practice guidelines and outcome measures tailored specifically to PNCs were also seen as barriers. <sup>55,64</sup>

Often increases in knowledge, skills or confidence seemed to be assumed as an obvious routine consequence of attending SMS training. The literature suggested that the approaches advocated in training should be simple and relevant to the context in which they would be used (I). <sup>47</sup> as then HCPs appeared more likely to become confident in applying these skills in practice (O). Following SMS training, a participant in one study <sup>50</sup> described:

It's given me a lot more confidence in things that I have been thinking about but given me a lot more organized approach and tools.

In the context of a challenging caseload (C), being able to discuss difficulties with colleagues (C) (during team meetings or clinical supervision) means that potential solutions can be generated and confidence maintained (M), resulting in the ongoing provision of SMS (O). 8,34

Theory 6. Organisational context (both at a high level and within local teams) (C) influences whether HCPs perceive SMS as something that they can and should integrate into their current role (M), leading to variable application of SMS (O) following training (I).

Thirteen articles contributed evidence to this theory. <sup>7,8,29,57,39,44,51,52,57,60,64-66</sup> Some HCPs felt pressure not to prioritise SMS because of worries about being seen to 'pull their weight' and fulfil organisational expectations (M), <sup>85</sup> whereas for others it was felt impractical to integrate SMS into their role (M) because of a lack of time, a lack of continuity of care or fixed targets, all of which were caused by organisational structures (C). <sup>37,57</sup> HCPs working with PNCs perceived that providing funding for SMS was a low organisational priority because these conditions resulted in a relatively small proportion of acute hospital admissions compared with other conditions that were the focus

Supporting self-management: a realist synthesis

of SMS efforts. 44 In their interview study, Hunt et al. 57 described in their results section how:

A perceived lack of support by the organization for client-centred goal setting practices and lack of power to make changes led to procedures being abandoned over time.

When individual HCPs lacked adequate autonomy to make meaningful changes (C), their inability to provide SMS could be a source of stress and dissatisfaction (M), leading to demotivation (O).<sup>57</sup> When organisations were seen to value SMS (through the way in which work was organised, senior clinician buy-in, political drive and the work of local champions) (C), <sup>29,37</sup> providing SMS was more likely to be seen as an expected part of routine care (M) and HCPs felt encouraged to spend time on SMS activities (O). 52 Training whole teams was suggested as a way to ensure that SMS was seen as a valued activity by all members (I), by creating a shared understanding of how and why to provide SMS (M- O)<sup>37</sup> Organisations needed to support not just the principles, but also the practicalities of SMS provision, by providing adequate resources (C) 66 which we felt appeared to allow staff to see SMS as both valuable and practical (M). The use of tools, templates and IT systems, and ensuring the new approach could fit within existing organisational pathways (I), increased perceived usability (M) and so could help SMS become integrated into routine work (O)

The final stages of transformative learning describe the building of confidence and competence, and the integration of the new perspective. Our final theory demonstrates how HCPs sometimes struggle to see how SMS could fit within their setting.

Theory 7: HCPs select who they believe are the right patients for SMS (O) based on their own judgement that the pros of supporting self-management outweigh the cons (M). This judgement is influenced by patient characteristics, professional characteristics and the organisational setting (C).

Twenty of the included articles provided data for this theory. 29,39,34,37,39,41–44,48,55,55,57,58,60,64,67-70 This theory describes how HCPs attempt to integrate SMS into clinical practice, influenced by the reasoning processes described in the earlier theories. Health care professionals (HCPs) reasoned that some of their patients were not able to self-manage, meaning that supporting self-management was not worthwhile (M). This was commonly associated with barriers

relating to the patient's condition (cognitive impairment or a complex condition) (C). 41.69 These factors could also lead HCPs to judge that their patients could be vulnerable (M) 42 and at risk of feeling under pressure or abandoned if self-management was promoted. This led to HCP discomfort (O), and our impression was that this discomfort might be a reason why HCPs elect not to provide SMS (O). Other patients were seen as unwilling to engage in self-management (M), because of lack of motivation (which could be secondary to their PNC<sup>64</sup>), personality type, cultural barriers or existing expectations of the service 'providing for them' (C). 87.44 In this situation, HCPs sometimes used the notion of patient autonomy as a way to ease the frustration generated (M), and as a justification for not continuing with efforts to provide SMS (O). 34

The impact of PNCs on cognition could make it challenging for patients to identify meaningful goals and to plan or perform SM activities (C). HCPs responded to these challenges (M) by providing more time, involving family members and delivering interventions in the home environment where patients with cognitive impairment may be more at ease(O). <sup>67,68</sup>

In settings where there was continuity of care (C), it was easier for HCPs to identify when they felt was the 'right time' for SMS (M) and so effective support could be provided when the patient needed it, increasing job satisfaction (O). Smith et al. 64 describe in their paper how they found that:

Participants who were able to monitor, review, observe, and interact with clients over long periods of time seemed to experience greater satisfaction in their role. This, in part, appeared related to optimal timing concerning client readiness to change coinciding with the HCP being ready and able to intervene.

Optimal timing for SMS was seen as particularly important in the PNC setting, as patients might require increasing SMS as their disease progressed as well as the option to defer to HCPs during crisis periods (C). <sup>44</sup> However, the organisational set-up did not always facilitate regular reassessment. (C). <sup>55</sup>

#### DISCUSSION

We formulated seven refined theories about SMS training and implementation which suggested that

#### F Davies et al

this process can trigger a transformative learning experience for HCPs. <sup>26</sup> Although we focused our review on identifying particular theories relating to provision of SMS to patients with PNCs, the inclusion of data from other related settings has meant that the theories formulated are less context specific than we initially expected and more transferable to a range of different settings. Although some of the theories identify important training activities (e.g. evidence provision, skills building, facilitating reflection and generating empathy), others describe how the paradigm shift required to embrace an SMS approach can be initiated and maintained (critical reflection and redefining professional role). Our refined theories demonstrate how training interventions influence HCP reasoning directly, but also how reasoning is affected by existing context. Some of our theories highlight that contextual factors can be the main influence on HCP reasoning (e.g. level of organisational support and patient characteristics) and that in certain settings, with multiple contextual barriers, the impact of training may be limited. As expected, patient-level barriers to SM were described in the PNC literature, but were also described in the papers from other settings. Our review suggests that patient-level barriers appeared likely to be less influential when there was adequate organisational support and when the training intervention had successfully created a clear shared vision of how and why to provide SMS among the

Our use of the realist approach of configuring contexts and mechanisms together adds explanatory power to help us understand how these elements interact to produce outcomes of interest. Some of the important contextual influences we identified have been described by other reviewers. For example, in their review Morgan et al.<sup>14</sup> identified how working in an organisation with a highly medicalised culture, with colleagues who hold a narrow view of the purpose of SMS, or with patients who were seen as 'non-compliant' made it difficult for HCPs to expand their own view of the purpose of SMS and adopt a more holistic approach. Both Mudge et al.5 and Taylor et al.4 highlighted how HCPs need to be supported, and that change can be either inhibited by practical barriers such as lack of resources, or facilitated through meaningful organisational commitment. Our findings suggest that contextual influences should be described in detail in the reporting of future training interventions in order to understand why HCPs respond to training in the way that they do. The key

10

training mechanisms identified here could be targeted in future interventions, which can be more robustly evaluated if their intended mechanism of action and intended outcomes are better understood. Some of the mechanisms we identified have also been highlighted by reviewers in other settings. Duprez et al. <sup>10</sup> reviewed 25 studies focusing on training nurses in SMS and found evidence that training could influence knowledge, skills and confidence, but noted that the evidence for subsequent practice change was more mixed. In their 2014 review (which helped us identify seven papers for inclusion in this review) Mudge et al.5 described the shift towards integrating SMS provision into the routine care of patients with long-term conditions, including diabetes, chronic obstructive pulmonary disease and stroke, as being a transformative process. They recognised the key role of facilitating reflection in producing the necessary paradigm shift among HCPs. In addition, they emphasised that this process was challenging for HCPs and was likely to be a gradual ongoing process

#### Strengths and limitations

Using a realist approach allowed us to draw on learning from training delivered in different settings, to develop our understanding of how training might operate for HCPs working with people with PNCs. Although this maximised the chances of generating useful and meaningful refined theories, the inclusivity of the review approach represented a significant challenge 16,71 and a pragmatic approach to keep the review manageable was required. Addressing patient-level outcomes was beyond the scope of the review but is clearly of key importance and ideally should be explored in the future. Like other reviewers, <sup>22,23</sup> we were limited by the depth with which the literature describes training and the types of training evaluation undertaken. There was relatively little indepth description of the context-specific challenges related to PNCs and there may be particular issues we have failed to identify. We consider our review to have been more successful in theory generation than theory testing in relation to the PNC setting. The quality of evaluations of training in health care education has been criticised for a tendency to focus on short-term changes in knowledge or skills, rather than resultant change in practice and patient-level outcomes, <sup>72</sup> and the reporting of research into health care education has been described as poor. <sup>73</sup> There are now recommendations for all complex intervention

Supporting self-management: a realist synthesis

evaluations to provide enough details about the intervention to allow for replication, and the use of specific reporting guidelines may improve the quality of evidence available in the future.<sup>74</sup>

As with any realist synthesis, the interpretive nature of the review process means it is possible that another reviewer might derive a different set of theories from reviewing the same articles. <sup>22</sup> The first author, who led the data selection, extraction and synthesis, is a clinical (general practitioner) academic and may have been influenced by her own experiences and views about SMS. The key informant interviews and stakeholder advisory group meetings provided opportunities to assess the face validity of the developing theories. The inclusion of original data extracts within the results allows readers to see how the theories have been generated and make their own judgements about their validity. <sup>16,75</sup>

#### Future research

In future, longitudinal research that aims to explore how and when transformative learning occurs and can be maintained could help to identify further barriers and facilitators to SMS implementation. <sup>10</sup> Integration of SMS approaches into undergraduate and postgraduate professional training programmes may also be a promising way to facilitate the required paradigm shift to ensure that SMS is viewed as an integral part of care.

#### CONCLUSION

Training HCPs to integrate SMS into routine care is not straightforward as it represents a major challenge to traditional clinical practice. To successfully trigger the necessary paradigm shift, a process of transformative learning is often required. This may start with training interventions at the individual level but is an evolving process, shaped by interactions with patients and colleagues and bound by workplace constraints. Trainers should be aware of the contextual factors that influence HCPs' reasoning about SMS provision, which can act as barriers to both the process of transformative learning and the implementation of SMS in practice. We identified some examples of how perceived patient-level barriers to SMS among people with PNCs could be addressed by tailoring SMS provision appropriately, but often condition-related factors such as cognitive impairment were cited as

reasons HCPs elected not to prioritise SMS. The level of organisational support available also shapes professionals' views on both the perceived value and practicality of SMS provision. Training should focus on how individual HCPs define and value SMS and how their work context (patient group and organisational constraints) influences this process. Proactively addressing contextual barriers at the training stage may facilitate implementation. These findings could also be applied to other types of training designed to shift attitudes amongst clinicians.

Contributors: FD planned the review approach, performed the searches and led the data extraction and analysis process. She produced the first draft of the manuscript. FW assisted in the development of the abstract screening tool, double coded a sample of data extracts and discussed the emerging findings with FD. FW, AB, CW and AE advised on the planned review approach, attended regular meetings to discuss the emerging findings and contributed to the synthesis. FW, AB, CW and AE all helped revise the first draft of the manuscript and all authors approved the final version for submission.

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#### SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Box S1. Initial review questions with associated initial theories.

**Box S2.** Search strategy developed for Medline and adapted for EMBASE, PsycINFO, CINAHL, ERIC, PEDro, Cochrane Library (trials).

Table S1. Evidence of saturation

Table S2. Characteristics of Included Studies.

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# Providing self-management support: A survey of UK health professionals who work with people with multiple sclerosis



Freya Davies<sup>1</sup>, Fiona Wood<sup>1</sup>, Alison Bullock<sup>1</sup>, Carolyn Wallace<sup>2</sup>, Adrian Edwards<sup>1</sup>.

#### Background

- Self-management support (SMS) is increasingly seen as part of the role of health professionals.
- We surveyed UK nurses and therapists who work with people with MS to describe:
  - o Current usage of SMS techniques
  - Proportion of patients expected to benefit from these techniques
  - o Future training interests
  - o Barriers to providing SMS

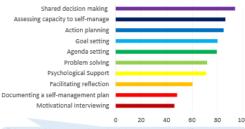
#### Methods

- Online survey distributed to 643 health professionals via a UK MS charity mailing list April-May 2016.
- Survey designed following scoping of the literature and piloted with a local MS team.
- o Used multiple choice items alongside free-text comments
- Responses to the multiple choice items are shown in the graphs below with details about the free text comments in speech bubbles.

#### Results

- o 146 responses received (22.7% response rate).
- 63% of respondents had a nursing background, 21.2% were physiotherapists, 15.1% were occupational therapists, and 0.7% were speech and language therapists.
- 59.3% of respondents had worked with people with MS for >10 years.
- 43.8% had received some previous training in relation to supporting self-management.

Percentage of survey respondents reporting frequent use of each self-management support technique



Other activities respondents had done to support self-management included information provision, signposting, running courses for patients, and providing written plans or tools.

Percentage of respondents stating all or most of their patients would benefit from the listed techniques



Additional techniques respondents thought might help included involving carers, family, peer supporters or social services; information provision/signposting, and proactive follow-up.

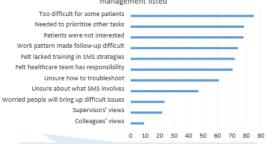
Affiliations: 1. Cardiff University, UK. 2. University of South Wales, UK

Percentage of respondents very interested in training in each self-management support technique



Further training interests included training within a multidisciplinary team, local networking, using mobile technology, health coaching, mindfulness, and cognitive behavioural therapy.

Percentage of respondents reporting being affected at least to some extent by the barriers to supporting selfmanagement listed



Additional barriers included: patients not taking on selfmanagement tasks, professionals lacking confidence and skills in supporting self-management, and organisational pressures.

#### Conclusions

- 100 O Staff working with people with MS can see the benefits of providing SMS but are inhibited by organisational constraints.
  - Staff also feel that they lack training in SMS skills and priority topics for future interventions have been identified.



# Training staff who work with people with progressive neurological conditions in health coaching: A realist evaluation



Freya Davies<sup>1</sup>, Fiona Wood<sup>1</sup>, Alison Bullock<sup>1</sup>, Carolyn Wallace<sup>2</sup>, Adrian Edwards<sup>1</sup>.

#### Background

- Supporting self-management can be challenging for health professionals who work with people with progressive neurological conditions (PNCs) such as multiple sclerosis.
- Health coaching is an approach which encourages health professionals to 'coach' patients to define their own goals and develop their own solutions.
- There is limited evidence about the 'active ingredients' of health coaching training, and whether it is a suitable approach for professionals working with people with PNCs.



#### Methods

- We planned to evaluate a two day face-to-face health coaching skills development training course delivered by two experienced facilitators
- 20 nurses and allied health professionals who work with people with a neurological condition attended both training days (Day 1 in January and Day 2 in April 2018).
- We used a mixed methods realist evaluation approach, which aims to answer the question: What works, for whom, in what circumstances and how?(1)
- We used theories developed from our earlier literature review as a starting point to focus our evaluation strategy.(2)
- These theories which describe how and when training succeeds or fails will be refined using the data sources described below.

#### Evaluation **Initial findings** Sample strategy Likert scale ratings (5 being highest) used to score understanding, confidence Bespoke questionnaires and current usage in relation to seven health coaching technique Mean understanding score increased from 3.2 to 4.1. Mean confidence score increased from 2.8 to 3.7. distributed pretraining, and after Day 2. Follow-up There was no change in the self-reported usage of health coaching techniques in between training days one and two. (Mean score 3.7 on both questionnaire planned at 3 months questionnaires) Role plays provided the opportunity for participants to experience providing coaching and being coached. Two days of participant Trainers modelled the coaching approach during their interactions with the observation of training undertaken during participants. Training staff who work with similar patient groups together provided a safe space for learning alongside like-minded colleagues. training intervention Trainees highlight the importance role play activities using health coaching 2 interviews. First Follow-up techniques to build confidence and allow them to experience the benefits of interview within 1 month of training completion, second at 3 months. the approach. Trainees value having practical 'tools' that they can take away and start using in their consultations straight after training. There has been limited uptake of web resource to date. Five participants accessed the website between the first and second training private website including links to resources and discussion boards dates (an 11 week period), with three posting on the discussion boards. IT firewalls may have prevented participants accessing the website from

#### Next steps

- o Follow-up questionnaires will explore whether changes in understanding and confidence have been maintained, and if usage has increased.
- o The course web page remains available for participants. Usage will be monitored up to three months post-training completion.
- Realist analysis of the findings will use each data source to formulate a set of explanatory statements known as "context-mechanismoutcome configurations" which will describe the overall "programme theory" of how the intervention works.
- o We expect to be able to make recommendations about the circumstances in which training in health coaching is likely to be most effective

References: 1. Pawson R, Tilley N. Realistic Evaluation. London: Sage Publications; 1997. 2. Davies F, Wood F, Bullock A, Wallace C, Edwards A. Shifting mindsets: a realist synthesis of evidence from self-management support training. Medical education. 2018; 52(3): 274-287. Affiliations: 1. Cardiff University, UK. 2. University of South Wales, UK.

Funding: The training course was funded by Novartis pharmaceuticals. Novartis had no involvement or influence on the training content, delivery or evaluation.

### TRAINING HEALTH PROFESSIONALS TO SUPPORT SELF-MANAGEMENT WHAT WORKS?

#### A SUMMARY OF A PHD STUDY

### 186

### SPECIALIST NURSES AND THERAPISTS



completed an online survey describing current practice, training interests and barriers to providing support

### REALIST LITERATURE SYNTHESIS



research papers were reviewed



3 stakeholder meetings held



### 2 DAYS

provided to 20 specialist nurses and therapists who work in neurology

### HEALTH COACHING TRAINING





# TRAINING EVALUATED USING



interviews with trainers and participants

- questionnaires
  - pre-training
  - post-training
  - follow-up
- days of participant observation

#### **DR FREYA DAVIES**

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# WHAT WORKED?



Here are some ideas from participants about how the health coaching approach can be used with people with progressive neurological conditions.

### CHANGE THE WAY PEOPLE ACCESS THE SERVICE

One service started an opt-in process to allocating appointments to get people engaged and thinking about what they wanted to achieve before attending



#### **2 USE YOUR PAPERWORK**

Routine assessment forms were redesigned by one service to remind clinicians to ask people what matters to them. This also helped to spread the idea throughout the team



### 3 START THE CONSULTATION DIFFERENTLY

Some participants say they have changed the opening questions they use. They also rely less on the information in referral letters and concentrate on exploring people's priorities early on.



### FIND OUT WHAT REALLY MOTIVATES PEOPLE

When people appeared not to be motivated, spending time talking about their lives often helped to identify something they would like to achieve and motivation increased.



### 5 EARLY INVESTMENT SAVES TIME LATER

Some participants found that using a coaching approach early on saved time later as people were able to solve their own problems requiring less clinical input



## REMEMBER YOUR ROLE IS ABOUT MORE THAN JUST FIXING

This was a key learning point for many participants. Focussing on enabling rather than providing solutions for every problem could make consultations less draining for staff.



### OACHING CAN HELP WHEN YOU FEEL STUCK

Many participants found that coaching offered them a different way to work with people who they felt they weren't making progress with



### 8 USE YOUR COLLEAGUES SKILLS

Sharing ideas with other members of the multi-disciplinary team who understood the coaching approach (e.g. psychologists) helped participants to continue to develop their skills



A summary of the findings of an evaluation of a 2-day training course in health coaching skills, undertaken by Dr Freya Davies as part of PhD study. For more information contact: DaviesF9@cardiff.ac.uk

# WHAT WERE THE CHALLENGES?



Some of the common probelms participants encountered



#### HABITS ARE HARD TO BREAK

Participants recognised their own established consulting routines could be difficult to disturb, and that people were also used to a certain style of appointment



#### **ASSESSMENT FORMS**

The ways in which teams already organised their work could make it difficult to integrate the coaching approach. Completing assessment forms which were used by all team members and audited by the organisation usually needed to take priority.





Participants who spent a lot of their time on technical tasks which required them to use their clinical expertise found it harder to see how coaching could fit in. Coaching seemed to be better suited to consultations when the expertise of the patient could be drawn upon more.



#### **TIME CONSTRAINTS**

Many participants described having multiple tasks to complete within the time they had available.





A common problem for people with progressive neurological conditions, some participants lacked confidence in adapting a coaching approach for this patient group. Others felt more confident that because coaching changes the interaction 'in the moment' it could still be helpful for people with cognitive impairment

#### **MENTAL HEALTH**



Problems including apathy, anxiety and depression were often noted to have an impact on how people engaged with coaching. While some participants felt that mental health problems need to be addressed first, others had found that coaching provided a useful way to work with people with mental health problems.

A summary of the findings of an evaluation of a 2 day training course in health coaching skills, undertaken by Dr Freya Davies as part of PhD study.

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# HOW DOES TRAINING WORK?

Three important mechanisms through which the training worked were identified

#### CRITICAL REFLECTION ON PRACTICE

How others work

The impact of current style of practice



The constraints on changing current practice

The benefits of an alternative approach

## BUILDING KNOWLEDGE, SKILLS AND CONFIDENCE

Understand why a directive approach doesn't always work

How to use formal coaching models when appropriate



How to make tweaks to language used

Thinking differently around the role of the clinician

## BECOMING CONVINCED THE APPROACH IS VALUABLE

The approach aligns with how I see my role



The approach will work with my patient group

The approach will work in my workplace

A summary of the findings of an evaluation of a 2 day training course in health coaching skills, undertaken by Dr Freya Davies as part of PhD study. For more information contact: DaviesF9@cardiff.ac.uk

# WHICH PARTICIPANTS

WORKING IN

HAVE THE MOST SUCCESS IN IMPLEMENTING THE TRAINING IN PRACTICE?



#### **Therapists**

More therapists than nurses participated in the study so we have more evidence about their experiences. Many felt that a coaching fitted

well with their usual style



#### Adequate autonomy

Participants needed to have enough autonomy to be able to make significant changes to the way that they worked. Existing organisational procedures (such as mandatory assessment forms) could make implementation more challenging

#### **Enthusiasts**

Those participants who attended training with high levels of motivation and enthusiasm for making changes found it easier to embrace the approach.

#### Colleagues understand the approach

Working with others who understood the principles of the approach even if they had not attended the training was valued by participants.

#### Those with previous training

Participants who had already attended training on a related subject such as motivational interviewing found that the crossover in the mindset required and the techniques used was helpful

#### Joint working

Working collaboratively provided opportunities to share the learning with others and learn through interactions with colleagues. Participants who usually worked independently did not benefit from these naturally occurring opportunities.

of an evaluation of a 2 day training course in health coa Dr Freya Davies as part of PhD study. For more information contact: DaviesF9@cardiff.ac.uk

### Appendix B – Completed RAMESES Checklists for realist synthesis and evaluation Realist synthesis checklist

Item	Explanation	Where this
	(taken direct from: Wong G, Greenhalgh T,	is
	Westhorp G, Buckingham J, Pawson R. RAMESES	addressed
	publication standards: realist syntheses. BMC	
	medicine. 2013;11(1):21.)	
1. Title	In the title, identify the document as a realist	4
	synthesis or review	
2. Abstract	While acknowledging publication requirements	Not
	and house style, abstracts should ideally contain	applicable
	brief details of: the study's background, review	to thesis
	question or objectives; search strategy; methods of	
	selection, appraisal, analysis and synthesis of	
	sources; main results; and implications for	
	practice.	
3. Rationale for	Explain why the review is needed and what it is	4.1
review	likely to contribute to existing understanding of	
	the topic area.	
4. Objectives and	State the objective(s) of the review and/or the	4.2.2
focus of review	review question(s). Define and provide a rationale	
	for the focus of the review.	
5. Changes in the	Any changes made to the review process that was	4.2.2
review process	initially planned should be briefly described and	
	justified.	
6. Rationale for	Explain why realist synthesis was considered the	4.1
using realist	most appropriate method to use.	
synthesis		
7. Scoping the	Describe and justify the initial process of	4.2.2
literature	exploratory scoping of the literature.	4.2.2
8. Searching	While considering specific requirements of the	4.2.3
processes	journal or other publication outlet, state and	Appendix E
	provide a rationale for how the iterative searching	
	was done. Provide details on all the sources	
	accessed for information in the review. Where	
	searching in electronic databases has taken place, the details should	
	include, for example, name of database, search terms, dates of coverage and date last searched. If	
	individuals familiar with the relevant literature	
	and/or topic area were contacted, indicate how	
	they were identified and selected.	
9. Selection and	Explain how judgements were made about	4.2.3, 4.2.4
appraisal of	including and excluding data from documents, and	1.2.3, 7.2.7
documents	justify these.	
10. Data	Describe and explain which data or information	4.2.5
extraction	were extracted from the included documents and	
	justify this selection.	
	jastily this selection.	

11. Analysis and synthesis	Describe the analysis and synthesis processes in detail. This section should include information on	4.2.5
•		
processes	the constructs analyzed and describe the analytic	
12. Document	Provide details on the number of documents	Figure 4.1
		Figure 4.1
flow diagram	assessed for eligibility and included in the review	
	with reasons for exclusion at each stage as well as	
	an indication of their source of origin (for example,	
	from searching databases, reference lists and so	
	on). You may consider using the example	
	templates (which are likely to need modification to	
42 Day and	suit the data) that are provided.	Table 4.4
13. Document	Provide information on the characteristics of the	Table 4.1
characteristics	documents included in the review.	4.6
14. Main findings	Present the key findings with a specific focus on	4.6
	theory building and testing.	
15. Summary of	Summarize the main findings, taking into account	4.8
findings	the review's objective(s), research question(s),	
_	focus and intended audience(s).	
16. Strengths,	Discuss both the strengths of the review and its	4.7
limitations and	limitations. These should include (but need not be	
future research	restricted to) (a) consideration of all the steps in	
directions	the review process and (b) comment on the overall	
	strength of evidence supporting the explanatory	
	insights which emerged. The limitations identified	
	may point to areas where further work is needed.	
17. Comparison	Where applicable, compare and contrast the	8.1-8.4
with existing	review's findings with the existing literature (for	
literature	example, other reviews) on the same topic.	
18. Conclusion	List the main implications of the findings and place	8.7
and	these in the context of other relevant literature. If	
recommendations	appropriate, offer recommendations for policy and	
	practice.	
19. Funding	Provide details of funding source (if any) for the	4.2
	review, the role played by the funder (if any) and	
	any conflicts of interests of the reviewers.	

#### Realist evaluation checklist

Item	Explanation taken direct from: Wong G, Westhorp	Where this
	G, Manzano A, Greenhalgh J, Jagosh J, Greenhalgh	is
	T. RAMESES II reporting standards for realist evaluations. BMC Medicine. 2016;14(1):96.	addressed
1. Title	In the title, identify the document as a realist evaluation	See thesis title
2. Abstract	The abstract or summary should include brief details on: the policy, programme or initiative under evaluation; programme setting; purpose of the evaluation; evaluation question(s) and/or objective(s); evaluation strategy; data collection,	Not applicable to thesis

Г		1
	documentation and analysis methods; key findings	
	and conclusions Sufficient detail should be	
	provided to identify that a realist approach was	
	used and that realist programme theory was	
	developed and/or refined	
3 Rationale for	Explain the purpose of the evaluation and the	5.1
evaluation	implications for its focus and design	
4 Programme	Describe the initial programme theory (or theories)	5.5.1
theory	that underpin the programme, policy or initiative	
5 Evaluation	State the evaluation question(s) and specify the	5.5.1
questions,	objectives for the evaluation. Describe whether	Table 5.2
objectives and	and how the programme theory was used to	
focus	define the scope and focus of the evaluation	
6 Ethical approval	State whether the realist evaluation required and	5.5.6
	has gained ethical approval from the relevant	
	authorities, providing details as appropriate.	
7 Rationale for	Explain why a realist evaluation approach was	2.3
using realist	chosen	
evaluation		
8 Environment	Describe the environment in which the evaluation	5.4.3
surrounding the	took place	
evaluation		
9 Describe the	Provide relevant details on the programme, policy	5.4.3
programme	or initiative evaluated	
policy, initiative		
or product		
evaluated		
10 Describe and	A description and justification of the evaluation	5.5
justify the	design (i.e. the account of what was planned, done	
evaluation design	and why) should be included, at least in summary	
	form or as an appendix, in the document which	
	presents the main findings.	
11 Data collection	Describe and justify the data collection methods –	5.5
methods	which ones were used, why and how they fed into	
	developing, supporting, refuting or refining	
	programme theory. Provide details of the steps	
	taken to enhance the trustworthiness of data	
	collection and documentation	
12 Recruitment	Describe how respondents to the evaluation were	5.4.2
process and	recruited or engaged and how the sample	- <del>-</del>
sampling strategy	contributed to the development, support,	
	refutation or refinement of programme theory	
13 Data analysis	Describe in detail how data were analysed. This	5.57
	section should include information on the	7.1
	constructs that were identified, the process of	8
	analysis, how the programme theory was further	_
	developed, supported, refuted and refined, and	
	(where relevant) how analysis changed as the	
	evaluation unfolded	
14 Details of	Report (if applicable) who took part in the	6
participants	evaluation, the details of the data they provided	Table 6.1
participarits	evaluation, the actails of the data they provided	I UDIC U.T

	and how the data was used to develop, support,	Section 6.2
	refute or refine programme theory	
15 Main findings	Present the key findings, linking them to contexts, mechanisms and outcome configurations. Show how they were used to further develop, test or refine the programme theory	6.3 – 6.6
16 Summary of findings	Summarise the main findings with attention to the evaluation questions, purpose of the evaluation, programme theory and intended audience	8.1-8.4
17 Strengths, limitations and future directions	Discuss both the strengths of the evaluation and its limitations. These should include (but need not be limited to): (1) consideration of all the steps in the evaluation processes; and (2) comment on the adequacy, trustworthiness and value of the explanatory insights which emerged In many evaluations, there will be an expectation to provide guidance on future directions for the programme, policy or initiative, its implementation and/or design. The particular implications arising from the realist nature of the findings should be reflected in these discussions	8.6
18 Comparison with existing literature	Where appropriate, compare and contrast the evaluation's findings with the existing literature on similar programmes, policies or initiatives	8.1-8.4
19 Conclusion and recommendations	List the main conclusions that are justified by the analyses of the data. If appropriate, offer recommendations consistent with a realist approach	8.7, 8.8, 8.8
20 Funding and conflict of interest	State the funding source (if any) for the evaluation, the role played by the funder (if any) and any conflicts of interests of the evaluators	5.2.1.2



## Supporting self-management in multiple sclerosis

#### Page 1

Thank you for your interest in this research.

We want to find out how MS professionals currently support self-management among their patients and how this support could be improved. We are particularly interested in the sort of support provided within routine appointments. We will use this information to design future training for MS professionals.

The research is being undertaken by Dr Freya Davies from Cardiff University as part of a PhD.

The survey will take you approximately ten minutes to complete. Your participation in this study is entirely voluntary and you can withdraw at any time.

Your answers will remain confidential. We will ask you to provide details about your work role but we will not ask for your name or workplace. Any data from the study that is published will not be identifiable as yours.

If you would like more information about the study or wish to ask any questions, please email <a href="mailto:DaviesF9@cardiff.ac.uk">DaviesF9@cardiff.ac.uk</a> or Professor Adrian Edwards (supervisor)

EdwardsAE@cardiff.ac.uk

1 / 16



#### Section One - Your Current Practice

During routine appointments over the last three months, how often have you done any of the activities described to help a patient with MS to self-manage their condition?

	Very Often	Often	Sometimes	Occasionally	Not at all
Assessed a patient's capability to self-manage	Γ	Г	Г	Г	Г
Set the agenda for the consultation jointly with a patient	Г	Г	Г	Г	Г
Shared the responsibility for decision making with a patient	Г	Г	Г	Г	Г
Helped a patient to set specific goals	Г	Г	Г	Г	Г
Made an action plan with a patient	Г	Г	Г	Г	Г
Discussed how to approach problem solving	Г	Г	Г	Г	Г
Encouraged a patient to reflect on their past experiences and successes	Г	Г	Г	Г	Г

3 / 16

Provided psychological support to help a patient cope and adjust	Г	Г	Г	Г	Г
Used specific communication skills (e.g. Motivational Interviewing) to help strengthen a patient's motivation to make changes in	Г	г	Г	г	г
their life					
their life  Documented a self-management plan for future follow-up	Г	Γ	Г	Γ	Г
Documented a self-management plan for future	else not listed				
Documented a self-management plan for future follow-up	else not listed				

# Section Two - Do you think your patients would benefit from support to self-manage?

Of the patients that you see, how many do you think could benefit from the following techniques being used during your appointments?

	All of my patients	Most of my patients	Around half of my patients	A few of my patients	None of my patients
An initial assessment of their capability to self- manage	Г	Г	Γ	Γ	Г
Being involved in setting the agenda for the appointment	Г	Г	Г	Г	Г
Being actively involved in decision making	Г	Г	Г	Г	Г
Being helped to set specific goals	Г	Г	Г	г	Г
Making an action plan	Г	Г	Г	Г	Г
Discussing how to approach problem solving	Г	Г	Г	Г	Г
Help to reflect on their past experiences and successes to generate new ideas	Г	Г	Г	Г	г
Psychological support to assist their coping and adjustment	Г	Г	Г	Г	Г

more motivated about making	г	г	Г	Г	Г
changes in their lives					
A documented self- management plan for future follow-up	Г	Г	Г	Г	Г
are there any other ted	chniques that	you think wou	ild support se	lf-manageme	nt?

# Section Three - Do you need further training?

How interested would you be in receiving targeted training to improve your skills in the areas listed below?

	Very interested	Somewhat interested	Not interested
Assessing a patient's capability to self- manage	Г	Г	Г
Agenda setting	Г	Г	Г
Involving people in shared decision making	Г	Г	Г
Goal setting	Г	Г	Г
Action plans	Г	Г	Г
Structured problem solving approaches	Г	Г	Г
Helping patients to reflect on their past experiences and successes to generate new ideas	Г	Г	Г
Effective psychological support strategies	Г	Г	Г
Motivational Interviewing techniques (a style of communication used to help patients feel more motivated and committed to making changes in their lives)	Г	Г	Г
Documenting self-management plans	Г	Г	Г

Which of these would be your priority areas for training? (Please tick up to three areas)

ГА	ssessing a	patient's	capacity for	self-management
----	------------	-----------	--------------	-----------------

☐ Agenda setting

☐ Involving people in shared decision making

☐ Goal setting

☐ Action plans

 $\ \ \Box$  Structured problem solving approaches

7 / 16

new ideas	flect on their past experiences and successes to generate	
☐ Effective psychologica	al support strategies ving techniques (a style of communication used to help	
	ated and committed to making changes in their lives)	
☐ Documenting self-mai	nagement plans	
Do you have any sugges self-management?	stions for other training which might help you to suppo	rt

# Section Four - Barriers to supporting self-management

Over the last 3 months, to what extent have these barriers to supporting self-management affected you?

	To a significant extent	To some extent	Not at all
You were not entirely sure about what self- management support involves	Г	Г	Г
Your patients were not interested in self- management	Г	Г	Г
You needed to prioritise other tasks to complete within the time you saw the patient	Г	Г	Г
Your supervisors did not view supporting self- management as a core component of your role	Г	Г	Г
You have worried about patients bringing up difficult issues you wouldn't be able to deal with	Г	Г	Г
You have felt you lacked training in specific self-management support strategies	Г	Г	Г
You felt that the healthcare team had a responsibility to deal with patients' problems	Г	Г	Г
You have been unsure how to troubleshoot when patients seemed unable to self-manage	Г	Г	Г
Your work pattern has made it difficult to follow people up	Г	Г	Г
You have felt that self-management is too difficult for some of your patients	Г	Г	Г
Your colleagues did not believe in supporting self-management	Г	Г	Г

Are there any other barriers you have encountered to supporting self-

9 / 16

management?		
	10 / 16	

Where do you work?		
C England – South East C England – North East C Scotland	<ul><li>England – South West</li><li>England – North West</li><li>Wales</li></ul>	
What is your job?		
MS Specialist Nurse     Neurology Nurse -     clinic / out-patient     based     Physiotherapist  If you selected Other, please	Neurology Specialist Nurse Continence Nurse Speech and Language Therapist specify:	<ul><li>Neurology Nurse - ward based</li><li>Occupational Therapist</li><li>Other</li></ul>
Are you based within a spec	cialist MS team?	
	staff in your professional role	where you work?

C Yes - I am the only person who does this role	<ul> <li>No - other people I work with have the same role as me</li> </ul>	
How long have you worked	in your current role?	
C Less than a year C Seven to nine years		○ Four to six years
How long have you been re	gularly working with people v	with MS?
C Less than a year C Seven to nine years		○ Four to six years
How often do you have cont	act with people with MS?	
C Daily	<ul> <li>Two or three times a week</li> </ul>	← Weekly
C Every few weeks C Less than every few months	C Monthly	© Every few months
Which of the following paties with:	nt groups do you work with?	(Tick all that apply) Patients
☐ Clinically Isolated Sync	drome	
	12 / 16	

	S – on disease modifying the S – not on disease modifying	
☐ Secondary progressive		
☐ If you are unsure abou	t these labels tick here	
Have you received any train qualified?	ning which related to support	ing self-management since you
c Yes	○ No	
What was the name/topic o	f the training you attended?	
How long ago did you atter	nd the training?	
<ul><li>Within the last year</li><li>Five or more years ago</li></ul>	○ One to two years ago	○ Three to four years ago
	e training?	
What was the duration of th	3	
What was the duration of th	C Between one and two days	

Feedback	
There are no more qu	uestions. Please press finish to submit your answers.
If you would like to re please provide your e	eceive a summary of the survey results when they become available, email address here:
	15 / 16
	13 / 10

Thank you	
Thank you for taking the t	time to complete the survey.
We hope the results will h	nelp to guide future training provision in this area.
If you have any further que please email: <u>DaviesF9@</u>	estions or comments now that you have completed the survey <u>@cardiff.ac.uk</u>
	16 / 16

# Appendix D – Stages in the review process

Time	Identifying data for inclusion	Data extraction	Data synthesis
	Initial searches run		
	Title screening for		
-	relevance		
-	Abstracts ranked for		
	relevance 1-4		
+	Televance 1-4		
	All relevance 1 papers		
	prioritised for full text		
	screening		
		Full text article read and	
		assessed for relevance	
		Basic study details recorded	
		Important vices of	
		Important pieces of explanatory data identified	
		and labelled	
		and labelled	
		Data used to formulate initial	
		explanatory accounts which	
		relate to the research	
		questions in an "If-Then"	
_		configuration	
_		, , , , , , , , , , , , , , , , , , ,	
		"If-Then" configurations	
		exported to Excel along with details of the source data	
		details of the source data	
	Abstracts of relevance 2		
	papers re-read and		
	researcher judgement used		
	to select those likely to be		
	useful based on		
	understanding gained from		
-	data extraction to date		
	Citation tracking from		
	included papers and		
	existing systematic		
	reviews.		
		Full text papers accessed and	
		relevant extracts used to	
		generate explanatory account	
		as above	
			Author begins to group
			together accounts that
			appear related
		1	

		Grouped accounts read and used to formulate a refined account in the format of CMO
	Original source data that contributed data to each new working CMO imported into NVivo	configuration
	Original data extracts that were used to formulate the explanatory accounts are coded in NVivo under working CMO headings	
		Data extracts read alongside working CMOs to check these are true to the original data and refined as needed.
		Working CMOs used to inform realist interviews with key informants
		Working CMOs presented to stakeholder group
Paper recommended by stakeholder group member included.		, , , , , , , , , , , , , , , , , , ,
		Priority areas for further exploration identified
Continue citation tracking. Grey literature search and table of contents search		
	New relevant data imported directly to NVivo and coded under related CMO.	
		CMOs further refined through discussion of the study authors
		CMOs considered alongside existing known formal theories
Priority areas for further searching identified - Searching for alternative formal theories - Searching for primary data to fill possible 'gaps' indicated by the formal		

		New relevant data imported directly to NVivo and coded under related CMO	
			CMOs further refined in discussion with supervisors
			Refined CMOs presented to stakeholder group for further discussion and confirmation

#### Appendix E – Search strategy

#### Medline via Ovid 1996-present.

Searched 27/4/16

- 1. exp Self Care/ or Patient Care Planning/ or Patient Education as Topic/ or Patient Participation/ or Adaptation, Psychological/ or Self Efficacy/ or Rehabilitation/
- 2. (self manag\* or Self-manag\* or Self-car\* or Self care).mp.
- 3. (Action plan\* or Care plan\* or Management plan\* or Health coach\* or Train\*).tw.
- 4. (Self-efficacy or Self efficacy or empower\* or rehab\* or coping).tw.
- 5. (goal\* adj5 (set\* or plan\*)).tw.
- 6. 1 or 2 or 3 or 4 or 5
- 7. exp Health Personnel/ or Physicians/ or Nurses/ or Psychology/ or Occupational Therapy/ or Physical Therapists/ or Professional-Patient Relations/ or Physician-Patient Relations/ or Nurse-Patient Relations/ or Attitude of Health Personnel/
- 8. (therapist\* or clinician\* or health professional\* or health personnel or practitioner\* or physiotherapist\* or psychologist\* or nurse\* or provider\* or doctor\* or physician\* or staff).tw.
- 9.7 or 8
- 10. Motor Neuron Disease/ or Multiple Sclerosis/ or Parkinson Disease/ or HuntingtonDisease/ or Supranuclear Palsy, Progressive/ or Amyotrophic Lateral Sclerosis/ or Nervous System Diseases/
- 11. (motor neuron\* or multiple sclerosis or demyelinating disease\* or parkinson\* or Huntington\* or progressive supranuclear palsy or amyotrophic lateral sclerosis or Progressive neurological or Degenerative neurological).mp.
- 12. 10 or 11
- 13. 6 and 9 and 12
- 14. limit 13 to (english language and yr="1996 -Current")

# **PsycINFO**

Searched 29/4/16.

- exp Self Management/
- 2. Adjustment/
- Self Efficacy/
- 4. Rehabilitation/ or exp Neuropsychological Rehabilitation/

- 5. Treatment Planning/
- 6. Client Education/
- 7. Client Participation/
- 8. Coping Behavior/
- 9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
- 10. (self manag\* or Self-manag\* or Self-car\* or Self care).mp.
- 11. (Action plan\* or Care plan\* or Management plan\* or Health coach\* or Train\*).tw.
- 12. (Self-efficacy or Self efficacy or empower\* or rehab\* or coping).tw.
- 13. (goal\* adj5 (set\* or plan\*)).tw.
- 14. 9 or 10 or 11 or 12 or 13
- 15. (therapist\* or clinician\* or health professional\* or health personnel or practitioner\* or physiotherapist\* or psychologist\* or nurse\* or provider\* or doctor\* or physician\* or staff).tw.
- 16. exp Health Personnel/
- 17. Physicians/
- 18. Nurses/
- 19. Clinical Psychologists/ or Psychologists/
- 20. Occupational Therapists/
- 21. Physical Therapists/
- 22. Health Personnel Attitudes/
- 23. Therapeutic Processes/
- 24. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
- 25. (motor neuron\* or multiple sclerosis or demyelinating disease\* or parkinson\* or Huntington\* or progressive supranuclear palsy or amyotrophic lateral sclerosis or Progressive neurological or Degenerative neurological).mp.
- 26. exp Multiple Sclerosis/
- 27. exp Parkinson's Disease/
- 28. exp Huntingtons Disease/
- 29. exp Progressive Supranuclear Palsy/
- 30. exp Amyotrophic Lateral Sclerosis/

- 31. Nervous System Disorders/ or exp Neurodegenerative Diseases/
- 32. 25 or 26 or 27 or 28 or 29 or 30 or 31
- 33. 14 and 24 and 32
- 34. limit 33 to (english language and yr="1996 2016")

#### **CINAHL**

Searched 29/4/16

(MH "Self Care+") OR (MH "Patient Care Plans") OR (MH "Patient Education") OR (MH "Consumer Participation") OR (MH "Adaptation, Psychological") OR (MH "Self-Efficacy") OR (MH "Rehabilitation")

(TX self-care) OR (TX self-manag\*)

(AB "action plan\*") OR (AB "care plan\*") OR (AB "management plan\*") OR (AB "health coach\*") OR (AB "train\*")

(AB self-efficacy) OR (AB empower\*) OR (AB rehab\*) OR (AB coping)

AB (goal\*) N5 (set\* OR plan\*)

1 or 2 or 3 or 4 or 5

(MH "Health Personnel") OR (MH "Attitude of Health Personnel") OR (MH "Physicians") OR (MH "Nurses") OR (MH "Psychologists") OR (MH "Occupational Therapists") OR (MH "Physical Therapists") OR (MH "Professional-Patient Relations") OR (MH "Physician-Patient Relations") OR (MH "Nurse-Patient Relations")

(MH "Motor Neuron Diseases") OR (MH "Multiple Sclerosis") OR (MH "Parkinson Disease") OR (MH "Huntington's Disease") OR (MH "Supranuclear Palsy, Progressive") OR (MH "Amyotrophic Lateral Sclerosis") OR (MH "Nervous System Diseases")

TX ("motor neuron\*" or "multiple sclerosis" or "demyelinating disease\*" or parkinson\* or Huntington\* or "progressive supranuclear palsy" or "amyotrophic lateral sclerosis" or "Progressive neurological" or "Degenerative neurological")

8 or 9

6 and 7 and 10

limit 13 to (english language and yr="1996 -Current")

#### **ERIC**

Searched 29/4/16

(TX self-care) OR (TX self-manag\*)

(AB "action plan\*") OR (AB "care plan\*") OR (AB "management plan\*") OR (AB "health coach\*") OR (AB "train\*")

(AB self-efficacy) OR (AB empower\*) OR (AB rehab\*) OR (AB coping)

AB (goal\*) N5 (set\* OR plan\*)

1 or 2 or 3 or 4

AB (therapist\* or clinician\* or "health professional\*" or "health personnel" or practitioner\* or physiotherapist\* or psychologist\* or nurse\* or provider\* or doctor\* or physician\* or staff)

TX ("motor neuron\*" or "multiple sclerosis" or "demyelinating disease\*" or parkinson\* or Huntington\* or "progressive supranuclear palsy" or "amyotrophic lateral sclerosis" or "Progressive neurological" or "Degenerative neurological")

5 and 6 and 7

#### **PEDro**

Searched 29/4/16

Self-management (in abstract and title) AND sub-discipline = neurology

#### **Cochrane Library - Trials**

Searched 3/5/16

- #1 self manag\* or Self-manag\* or Self-car\* or Self care:ti,ab,kw (Word variations have been searched)
- #2 Action plan\* or Care plan\* or Management plan\* or Health coach\* or Train\*
- #3 Self-efficacy or Self efficacy or empower\* or rehab\* or coping or goal
- #4 #1 or #2 or #3
- #5 therapist\* or clinician\* or health professional\* or health personnel or practitioner\* or physiotherapist\* or psychologist\* or nurse\* or provider\* or doctor\* or physician\* or staff
- #6 #4 and #5
- #7 "motor neuron\*" or "multiple sclerosis" or "demyelinating disease\*" or parkinson\* or Huntington\* or "progressive supranuclear palsy" or "amyotrophic lateral sclerosis" or "Progressive neurological" or "Degenerative neurological"
- #8 #6 and #7

#### **EMBASE**

#### Searched 3/5/16

- 1. patient care planning/
- 2. exp self care/
- 3. patient education/
- 4. patient participation/
- 5. adaptive behavior/
- 6. \*self concept/
- 7. rehabilitation/
- 8. (self manag\* or Self-manag\* or Self-car\* or Self care).mp.
- 9. (Action plan\* or Care plan\* or Management plan\* or Health coach\* or Train\*).tw.
- 10. (Self-efficacy or Self efficacy or empower\* or rehab\* or coping).tw.
- 11. (goal\* adj5 (set\* or plan\*)).tw.
- 12. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
- 13. exp health care personnel/
- 14. physician/
- 15. nurse/
- 16. psychologist/
- 17. physiotherapist/
- 18. occupational therapist/
- 19. \*human relation/
- 20. exp health personnel attitude/
- 21. (therapist\* or clinician\* or health professional\* or health personnel or practitioner\* or physiotherapist\* or psychologist\* or nurse\* or provider\* or doctor\* or physician\* or staff).tw.
- 22. 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
- 23. (motor neuron\* or multiple sclerosis or demyelinating disease\* or parkinson\* or Huntington\* or progressive supranuclear palsy or amyotrophic lateral sclerosis or Progressive neurological or Degenerative neurological).mp.
- 24. multiple sclerosis/
- 25. Parkinson disease/
- 26. Huntington chorea/

- 27. progressive supranuclear palsy/
- 28. amyotrophic lateral sclerosis/ or motor neuron disease/
- 29. \*neurologic disease/
- 30. 23 or 24 or 25 or 26 or 27 or 28 or 29
- 31. 12 and 22 and 30

31 not (Algeria\* or Egypt\* or Liby\* or Morocc\* or Tunisia\* or Western Sahara\* or Angola\* or Benin or Botswana\* or Burkina Faso or Burundi or Cameroon or Cape Verde or Central African Republic or Chad or Comoros or Congo or Djibouti or Eritrea or Ethiopia\* or Gabon or Gambia\* or Ghana or Guinea or Keny\* or Lesotho or Liberia or Madagasca\* or Malawi or Mali or Mauritania or Mauritius or Mayotte or Mozambig\* or Namibia\* or Niger or Nigeria\* or Reunion or Rwand\* or Saint Helena or Senegal or Seychelles or Sierra Leone or Somalia or South Africa\* or Sudan or Swaziland or Tanzania or Togo or Ugand\* or Zambia\* or Zimbabw\* or China or Chinese or Hong Kong or Macao or Mongolia\* or Taiwan\* or Belarus or Moldov\* or Russia\* or Ukraine or Afghanistan or Armenia\* or Azerbaijan or Bahrain or Cyprus or Cypriot or Georgia\* or Iran\* or Iraq\* or Jordan\* or Kazakhstan or Kuwait or Kyrgyzstan or Leban\* or Oman or Pakistan\* or Palestin\* or Qatar or Saudi Arabia or Syria\* or Tajikistan or Turkmenistan or United Arab Emirates or Uzbekistan or Yemen or Bangladesh\* or Bhutan or British Indian Ocean Territory or Brunei Darussalam or Cambodia\* or India\* or Indonesia\* or Lao or People's Democratic Republic or Malaysia\* or Maldives or Myanmar or Nepal or Philippin\* or Singapore or Sri Lanka or Thai\* or Timor Leste or Vietnam or Albania\* or Andorra or Bosnia\* or Herzegovina\* or Bulgaria\* or Croatia\* or Faroe Islands or Greenland or Liechtenstein or Lithuani\* or Macedonia or Malta or maltese or Romania or Serbia\* or Montenegro or Svalbard or Argentina\* or Belize or Bolivia\* or Brazil\* or Colombia\* or Costa Rica\* or Cuba or Ecuador or El Salvador or French Guiana or Guatemala\* or Guyana or Haiti or Honduras or Jamaica\* or Nicaragua\* or Panama or Paraguay or Peru or Puerto Rico or Suriname or Uruguay or Venezuela or developing countr\* or south America\*).ti,sh.

- 33. limit 32 to (human and english language and yr="1996 -Current")
- 34. 33 not (palliative or paediatric\* or child\* or diagnos\*).ti.

#### New CINAHL search run 21.12.16

- 1. (MH "Self Care+") OR (MH "Patient Care Plans") OR (MH "Patient Education") OR (MH "Consumer Participation") OR (MH "Adaptation, Psychological") OR (MH "Self-Efficacy") OR (MH "Rehabilitation")
- 2. (TX self-care) OR (TX self-manag\*)
- 3. (AB "action plan\*") OR (AB "care plan\*") OR (AB "management plan\*") OR (AB "health coach\*") OR (AB "train\*")
- 4. (AB self-efficacy) OR (AB empower\*) OR (AB rehab\*) OR (AB coping)
- 5. AB (goal\*) N5 (set\* OR plan\*)

- 6. 1 or 2 or 3 or 4 or 5
- 7. (MH "Health Personnel") OR (MH "Attitude of Health Personnel") OR (MH "Physicians") OR (MH "Nurses") OR (MH "Psychologists") OR (MH "Occupational Therapists") OR (MH "Physical Therapists") OR (MH "Professional-Patient Relations") OR (MH "Physician-Patient Relations") OR (MH "Nurse-P
- 8. AB (therapist\* or clinician\* or "health professional\*" or "health personnel" or practitioner\* or physiotherapist\* or psychologist\* or nurse\* or provider\* or doctor\* or physician\* or staff) atient Relations")
- 9.7 or 8
- 10. (MH "Motor Neuron Diseases") OR (MH "Multiple Sclerosis") OR (MH "Parkinson Disease") OR (MH "Huntington's Disease") OR (MH "Supranuclear Palsy, Progressive") OR (MH "Amyotrophic Lateral Sclerosis") OR (MH "Nervous System Diseases")
- 11. TX ("motor neuron\*" or "multiple sclerosis" or "demyelinating disease\*" or parkinson\* or Huntington\* or "progressive supranuclear palsy" or "amyotrophic lateral sclerosis" or "Progressive neurological" or "Degenerative neurological")
- 12. 10 or 11
- 13. 6 AND 9 AND 12
- 13. limit 13 to (english language and yr="1996 -Current")

Additional limits placed – Abstract available, country = Australia and NZ, USA, Canada, Europe, Continental Europe, UK and Ireland, All adult, middle aged, 19-44, 65+ and 80+

# Appendix F - Abstract screening tool

Ranking	Criteria for assessing likely relevance of sources
1 – Highly relevant	Relates to a PNC AND describes the implementation of a health professional initiated SMS activity OR Relates to a PNC and describes training health professionals in SMS OR
	Relates to a PNC AND Likely to include description of health professionals' views and experiences of SMS in general
2- Probably relevant	Describes the training of health professionals in a SMS approach OR Describes the implementation of a health professional initiated SMS activity OR
	Likely to include description of health professionals' views and experiences of SMS  OR  Describes experiences of people with PNCs who have been provided with SMS
3 –Possibly relevant	SMS described but involvement of health professionals is unclear (SMS only) OR Unclear whether intervention described involves self-management OR Quantitative data on a SMS intervention OR Describes the specific self-management support needs of people with PNCs
4 – Likely irrelevant	Does not meet above criteria

Definitions

PNCs= Progressive neurological conditions— Multiple Sclerosis, Motor Neuron Disease (includes ALS), Huntington's, Parkinson's, Progressive Supranuclear Palsy. (exclude dementia, exclude acute brain injury, exclude stroke)

SMS = Self-management support – Apply definition used by Mills et al. (2014). Must include at least one of the following life skills: problem solving, decision-making, resource utilisation, patient-provider relations, taking action, goal setting and/or confidence building mechanisms. Must involve a patient-centred or empowerment approach to learning (vs traditional education approach of one-way transmission of information)

Health professionals that work within the NHS – exclude complementary therapists and gym instructors.

Mills, S. L. et al. 2014. Understanding how self-management interventions work for disadvantaged populations living with chronic conditions: protocol for a realist synthesis. *BMJ Open* 4(7), p. e005822.

# Appendix G Materials relating to key informant interviews

This appendix includes materials relating to the key informant interviews undertaken as part of the realist synthesis

Confirmation of ethical approval

Participant information leaflet

Consent form

Topic guide

#### Freya Davies

From: Claire Batten

**Sent:** 09 September 2016 15:55

To: Freya Davies

Subject: RE: Letter from the School of Medicine Research Ethics Committee

Dear Freya,

Thanks for this additional information. This has been reviewed by the Chair and he is happy to now confirm ethical approval for your study, "Supporting Self-Management in Multiple Sclerosis – Trainer" (SMREC Ref 16/46). Please accept this email as confirmation of your ethical approval. A formal letter confirming approval will be sent to you when I return from leave during the week commencing 26<sup>th</sup> September.

Best wishes,

#### Claire

Miss Claire Batten
Research Manager,
Research Support

Miss Claire Batten
Rheolwr Ymchwil,
Cefnogi Ymchwil

Cardiff University School of Medicine
College of Biomedical and Life Sciences
Heath Park
Cardiff
Cardiff
CF14 4XN

Ysgol Meddygaeth Prifysgol Caerdydd
Coleg y Gwyddorau Biofeddygol a Bywyd
Parc y Mynydd Bychan
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The University welcomes correspondence in Welsh or English.
Mae'r Brifysgol yn croesawu gohebiaeth yn Gymraeg neu'n Saesneg.

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#### Supporting Self-management in Multiple Sclerosis

## **Participant Information Sheet**

We would like to invite you to take part in this study. We are interested in how to train health professionals to support self-management among people with multiple sclerosis (MS) and would like to hear you views. Thank you for taking the time to read this information.

# What is the purpose of the study?

This study is part of a PhD which aims to design a training intervention for health professionals who work with people with MS to improve the support for self-management they provide to their patients. In the first phase of the project we surveyed health professionals to find out about their training needs. We now plan to interview people who have already been involved in delivering training to this group to try to better understand how these types of training interventions work.

## Why have I been chosen?

We have asked you to participate because you have had experience of training health professionals (either in supporting self-management in general or in specific skills which might help them to support self-management). We hope to interview around six trainers during this phase of the project.

#### Do I have to take part?

Participation in the study is entirely voluntary. If you decide to take part you are still free to withdraw at any time and without giving a reason.

## What will happen to me if I take part?

A researcher will contact you arrange a telephone interview at a time convenient to you to discuss your experiences of training and to ask you your opinions of the study findings to date. The interview is expected to take around 45 minutes. It will be audio-recorded for analysis.

#### What about confidentiality?

All quotations used from the interviews in any future publications will be anonymised so there will be no way to link these back to you. The audio-recordings and interview transcripts will be stored securely on Cardiff University password-protected computers for five years after the study ends and then destroyed.

#### Are there any risks?

There are no expected risks associated with participating in the project. If you have any concerns about the way in which the study is conducted you can contact Professor Adrian Edwards, Cardiff University at <a href="mailto:EdwardsAG@cardiff.ac.uk">EdwardsAG@cardiff.ac.uk</a>. Explain what, if any mechanisms are in place to compensate the participant in the event of an adverse event

## What will happen to the results of the research study?

The study is part of a PhD being conducted by Dr Freya Davies, a Clinical Research Fellow employed by Cardiff University. The results of the study will form part of the PhD, and will be used to inform the direction of the next phase of the work. In addition the results may be used in academic presentations and publications.

#### **Contact for Further Information**

If you have any questions about the study please contact Dr Freya Davies on <a href="mailto:DaviesF9@cf.ac.uk">DaviesF9@cf.ac.uk</a> or telephone 02920 687226.

# CONSENT FORM FOR TELEPHONE INTERVIEW PROCEDURE

# Title of Project: Supporting Self-Management in Multiple Sclerosis

Name of Rese	earcher: Dr Freya Davies	
Participant Na	ame:	
Participant St	udy ID number:	
	Researcher to	initial
	box to co	onfirm
1. Participan	t confirms that they have read and understood the information sheet	
dated 24/ questions	7/16 (Version 1) for the above study and had the opportunity to ask .	
	t understands that participation is voluntary and that they are free to at any time, without giving any reason.	
3. Participan	t agrees for the interview to be audio-recorded.	
4. Participan	t agrees for anonymised quotations from the interview to be used in	
publicatio	ns related to the research.	
5. Participan	t agrees to take part in the above study.	
Researcher na	ame Date Sign	nature

Supporting Self-Management in MS Consent Form Version 1.0 25/7/16

#### **Supporting Self-Management in Multiple Sclerosis**

#### **Training Provider Interview Guide**

(The below questions provide a basic framework for the structure of the interview. Supplementary questions may be added to follow-up on ideas raised by participants or to help develop ideas emerging from the ongoing analysis)

#### Introduction

Can you tell me a bit about how you have been involved in health professional training?

# **Training content**

What are the specific skills the training involves? How do trainees react to the possibility of using these new skills?

What do you think it is about WHAT is taught that helps clinicians to promote self-management?

How much is tailoring self-management support for individual requirements addressed? How well does this work?

#### **Training process**

What is it about HOW the training is delivered that impacts on its outcome?

How does the training help clinicians to think differently about what self-management is and what supporting self-management means?

## Implementation in practice

Who does training seem to work well for? (Clinician group, workplace factors etc)

Who does training not work well for? Why?

#### **Outcomes**

What changes do you see in clinicians after attending training?

What do you think are the intended outcomes of training clinicians in self-management support?

What unintended outcomes have you witnessed?

How are the outcomes of training measured or how could they be measured?

# Appendix H - Evidence of data saturation for review

These papers were read in full and provided supporting evidence for the existing theories.

Data were not extracted but they do provide support for the idea that saturation had been reached.

At the stage at which these papers were read they did not contribute new data. I recognise that had the papers been read earlier in the synthesis process that they might have been included.

1	Roets-Merken LM, Vernooij-Dassen MJFJ, Zuidema SU, et al. Evaluation of nurses' changing
	perceptions when trained to implement a self- management programme for dual
	sensory impaired older adults in long-term care: a qualitative study. BMJ Open
	2016;6:e013122.
	doi:10.1136/bmjopen-2016-013122
2	Doyle D, Copeland HL, Bush D, Stein L, Thompson S. A course for nurses to handle
	difficult communication situations. A randomized controlled trial of impact on self-
	efficacy and performance. Patient Education and Counseling. 2011 Jan
	31;82(1):100-9.
3	MacGregor K, Handley M, Wong S, Sharifi C, Gjeltema K, Schillinger D,
	Bodenheimer T. Behavior-change action plans in primary care: a feasibility study of
	clinicians. The Journal of the American Board of Family Medicine. 2006 May
	1;19(3):215-23.
4	van Hooft SM, Dwarswaard J, Jedeloo S, Bal R, van Staa A. Four perspectives on
	self-management support by nurses for people with chronic conditions: a Q-
	methodological study. International journal of nursing studies. 2015 Jan
5	31;52(1):157-66.  Levack WM, Dean SG, Mcpherson KM, Siegert RJ. How clinicians talk about the
)	application of goal planning to rehabilitation for people with brain injury–variable
	interpretations of value and purpose. Brain injury. 2006 Jan 1;20(13-14):1439-49.
6	Caladine L. Physiotherapists construction of their role in patient education.
	International Journal of Practice-based Learning in Health and Social Care. 2016 Jan
	19;1(1):37-49.
7	Lévesque M, Hovey R, Bedos C. Advancing patient-centered care through
	transformative educational leadership: a critical review of health care professional
	preparation for patient-centered care. Journal of Healthcare Leadership.
	2013;5:35-46.
8	Jones F, Waters C, Benson L, Jones C, Hammond J, Bailey N. Evaluation of a shared
	approach to interprofessional learning about stroke self-management. Journal of
	interprofessional care. 2012 Nov 1;26(6):514-6.
9	Caeiro C, Cruz EB, Pereira CM. Arts, literature and reflective writing as educational
	strategies to promote narrative reasoning capabilities among physiotherapy
	students. Physiotherapy theory and practice. 2014 Nov 1;30(8):572-80.
10	Macdonald W, Rogers A, Blakeman T, Bower P. Practice nurses and the facilitation
	of self-management in primary care. Journal of advanced nursing. 2008 Apr
	1;62(2):191-9.
11.	Health Foundation. 2013. Case study: Cambridge University Hospitals NHS
	Foundation Trust

	Developing training for clinical staff in facilitating personal health planning and self-management Available at: http://personcentredcare.health.org.uk/sites/default/files/resources/sms_case_study_care_planning_training_cambridge.pdf
12	Fronek P, Kendall M, Ungerer G, Malt J, Eugarde E, Geraghty T. Towards healthy professional-client relationships: The value of an interprofessional training course. Journal of Interprofessional Care. 2009 Jan 1;23(1):16-29.
13	Kennedy A, Rogers A, Bowen R, Lee V, Blakeman T, Gardner C, Morris R, Protheroe J, Chew-Graham C. Implementing, embedding and integrating self-management support tools for people with long-term conditions in primary care nursing: a qualitative study. International journal of nursing studies. 2014 Aug 31;51(8):1103-13.
14	Kennedy A, Rogers A, Chew-Graham C, Blakeman T, Bowen R, Gardner C, Lee V, Morris R, Protheroe J. Implementation of a self-management support approach (WISE) across a health system: a process evaluation explaining what did and did not work for organisations, clinicians and patients. Implementation Science. 2014 Oct 21;9(1):129.
15	Jones F, Bailey N. How can we train stroke practitioners about patient self-management? Description and evaluation of a pathway wide training programme. European Journal for Person Centered Healthcare. 2013 Sep 29;1(1):246-54.

Appendix I

# **Ideas for interventions**

Intervention component	Locally delivered intervention to a small clinical team	2. Conference seminar plus follow up online	3. Case study approach examining existing SMS interventions	4. Grant funded intervention
Timescale	3-4/12 set-up+ ethics Intervention delivery ?one off ?seminar series/ breakfast club etc – could be 3-6 fortnightly meetings in total with another 3/12 follow up.	Use MS Trust Conference Nov 17 – seek approvals prior. Probably want 6/12 at least of f/u data	Could be at any stage post- intervention delivery but ideally close to delivery then 3- and 6- month f/u	Ethics 3/12 Recruitment 3/12 Whole day training Whole day follow up at 1-2 months (+/- ongoing consolidating activities – online or face to face) 6-month follow up
Research questions	Could this format help to 'fire' the key mechanisms already identified? Would it work in other ways? If not, why not?	Does the development of an online community of practice change attitudes and behaviours about SMS following a brief introductory talk?  Does the online forum fire the mechanisms already identified and why/why not?	How does existing training work, for whom, in what circumstances etc	Can we design (create) successful bespoke training for HPs working with people with PNCs to improve SMS? And how does it work?
Aim/Objectives	Use theories to inform design  Test whether intervention causes theories to operate as expected	Use theories to inform online content  Test whether intervention causes theories to operate as expected	Test theories generated from the literature against pre-existing training programmes in the PNC context – Implementation rather than design focus	Use theory to inform design  Test whether intervention causes theories to operate as expected

				Understand how consolidation activities influence ongoing implementation
Planning phase	I could draw together existing resources for discussion  Also aim for content to be participant driven	Requires set up of appropriate online resource/ linking in with existing discussion groups  And then drawing together existing resources ?any new resource creation  Might wish to consult with content experts about content development  Extra theory development phase might be needed in line with online delivery format	Interview trainers from the specific programmes  Examine training programme manuals etc  To generate any new theories and check for fit with those already developed	Base content on another pre-existing approach – e.g. health coaching – and identify an expert to deliver the training tailored to the audience (with an emphasis on covering the areas included in my theories – so developed in collaboration with me and possibly some stakeholders?)  Plus plan consolidation phase online/ face to face support
Intervention phase	? a format that could try to address 1 theory a week Aim would be to present the issue and for group to discuss and problem solve Also provide opportunity to reflect on success/challenges from previous week I could have more of a facilitator type role	Moderated sessions when ask everyone to join at same time  Set activities and provide resources periodically for when people are able to complete	Might not be involved – or could attend pre-arranged sessions	Pilot of training  Pilot of follow up activities

Expected	Provide specific evidence	Provide specific evidence	n/a	Designed by external provider but to
content	Reflective exercises	Reflective exercises		cover key theories
	Empathy generation	Empathy generation		
	Addressing team issues	Addressing team issues		
	Examining professional role	Examining professional role		
	Specific skills – agenda setting,	Specific skills – agenda setting,		
	comm skills	comm skills		
Recruitment	Would need to be a team local	?recruit after conference as a	Approach training providers for	?open invite
	enough that I could travel to	follow up – at a stand etc.	collaboration	?selected clinical teams
	regularly			?what approach might be acceptable
	And big enough to create good	Could aim to identify a whole	Find out via MS teams if they have	to a funder
	peer support (at least 4-5)	team who might be interested	attended recent training	
	Ideally multi-disciplinary but			
	?practicality	Might be able to recruit a 'control'		
		group who don't have the online		
		follow-up for comparison		
Evaluation	Recordings of group discussions	Qualitative analysis of online	? training observations if timing	Pre-and post-training ratings –
elements /		discussions	permitted	Knowledge, skills, attitudes,
level of	Pre- and post- questionnaires			behaviours,
evaluation	both for satisfaction with the	Quantitative analysis of how	? pre-post training questionnaires	Some immediate, some at 3-6
	process, change in attitudes/	frequently participants accessed		months
	measures of normalisation	resources etc	? interviews with participants 0,3,6	
			months	Training observations
	Interviews with participants	Pre and post questionnaires		
		completed online		Interviews: training mechanisms,
				barriers and facilitators, perceived
		Plus some qualitative telephone		usefulness.
		interviews (or even an online focus		
		group) about the feasibility and		

		acceptability and key learning		
		points, barriers and constraints		
Products	Refined programme theories	Refined programme theories	Refined programme theories	Refined programme theories
	Potential model for roll-out/ future evaluation	Potential model for roll-out/ future evaluation	Recommendations for existing programme providers	Training recommendations
				(Is there a problem that the product – i.e. the training approach might be 'owned' by the training provider?)
Funding requirements	Incentives for attendance (refreshments etc)	Possible web development costs	Travel to sites/ accommodation?	Payment of expert trainer/s Venue Hire
	Travel Transcription	Transcription	Transcription costs	Accommodation Transportation Transcribing
Pros	Cheap Expect to be deliverable Potential to start sooner if not awaiting funding	Relatively cheap  Capitalises on a planned activity to reach a receptive audience (and team members may well be in	Cheap Cuts down on time required for intervention design – means time freed up for potentially more participants or to attempt patient	Allows me to have a role as evaluator (and designer to some extent) but without having to facilitate the sessions themselves.
		attendance together)	level evaluation. Also gives option to compare and contrast different training approaches/ settings. Fit with NPT/TAM implementation focus	Funding would probably facilitate a larger number of people being involved – so potentially richer results (more varied contexts) and also guards against drop-out of participants to some extent. Might

				minimise individual participant
				burden.
				burden.
				Allows for a longer/more intensive
				intervention which is more likely to
				have a positive impact
Cons	May be hard to recruit and	Big risk of lack of uptake – and	Might be difficult to identify relevant	Nature of condition specific funding
	maintain momentum	would be difficult to create any	participants	might limit to a single condition
		momentum if people don't engage		audience
	Risk of bias due to existing	, , , , , , , , , , , , , , , , , , ,	Implementation rather than design	
	relationships	If doesn't work out it will have	focus might not sit as well with	Would need to identify an
	I may need to have dual role of	caused a major delay	stages of work done already	appropriate facilitator – might be
	both facilitator and evaluator	Caasea a major a cia,	stages or from come an easy	difficult.
		Might be quite labour intensive	Concern about how much would be	annoan.
	Evidence seems to suggest you	while running due to need to	enough for PhD	Significantly increased running costs
	need to do this PLUS two initial	provide moderation	chaghioring	Significantly increased ranning costs
	days of training – so how do I	provide moderation	Might need NHS ethics at multiple	If I use a training approach known to
	justify this approach	Might the theories around how an	sites.	be successful in a different setting
	justify this approach	online communities of practice	sites.	(or which might even have been
		work be very different for those		used in this setting already) novelty
		I've developed that largely come		for PhD needs to come more from
		from face to face training?		theory development
Other	? this would have an action	?would be worthwhile applying for		theory development
considerations	research flavour – researcher	CPD accreditation to increase		
Considerations	and participants collaborating?	motivation		
	and participants collaborating:			
	Might it he worth considering if	(costly)		
	Might it be worth considering if	Confidentiality and data		
	a similar format might work	Confidentiality and data		
	online?	protection might be a particular		
		issue?		

Content is mapping more to my		
theories than to the felt		
educational needs identified in		
the survey –is this a problem?		

#### Appendix J - Materials relating to focus groups

This appendix includes materials relating to the focus groups held in November 2018.

- Confirmation of ethical approval
- Advertisement for focus groups
- Focus group participant information leaflet
- Focus group consent forms
- Focus group topic guide



School of Medicine Ysgol Meddygaeth Cardiff University

Main Building Health Park Cardiff CF14 4XN Wales UK

Wednesday 8th November 2017

Dr Freya Davies Division of Population Medicine, 5th Floor, Neuadd Meirionnydd, School of Medicine, Heath Park.

Dear Freya,

Prifysgol Caerdydd

Prif Adeilad Parc y Mynydd Bychan Caerdydd CF14 4XN Cymru, Y Deyrnas Unedig

Re: Health coaching skills development for staff working with people with progressive neurological conditions

SMREC Reference Number: 17/57

This application was first reviewed by the Committee on October 2017, Additional revised documents were reviewed on Wednesday 8th November 2017.

Ethical Opinion

On review, I can confirm ethical approval for this study

#### Conditions of Approval

The Committee must be notified of any proposed amendments to the methodology and protocols outlined in your submission. Also, any serious or unexpected adverse reactions that may arise during the course of the study must be reported to the Committee. As a condition of this approval, the Committee retains the right to audit and review the study

#### **Documents Considered**

Document Type:	Version:	Date Considered	
Application	Signed 09/10/2017	October 2017	
Study Protocol	V1 11/10/2017		
Focus Group Topic Guide		October 2017	
Participant Information Sheet	V1 11/10/2017	October 2017	
Consent Form for Focus Group	V1 11/10/2017	October 2017	
Poster	V1 11/10/2017	October 2017	
	V1 11/10/2017	October 2017	
Email from MS Trust	19/09/2017	October 2017	
Email to Committee Secretary	04/11/2017	08/11/2017	
Participant Information Sheet	V2 04/11/2017	08/11/2017	
Consent Form	V2 04/11/2017	08/11/2017	

With best wishes for the success of your study.

Yours sincerely,

1 House

Dr Jonathan Hewitt

Chair, School of Medicine Research Ethics Committee











Registered Charity, no. 1136655 Elusen Gofrestredig, mil 1136655

## Health Coaching Skills Development Training

## **FOCUS GROUP PARTICIPANTS NEEDED DURING CONFERENCE**



Please come and share your views and experiences on Monday afternoon:

Group 1 - 4.15pm

Group 2 - 5.15pm

Venue: Room 12

#### We will be discussing:

- What is health coaching and how might it fit with your role?
- What are the challenges of supporting people with MS to selfmanage?
- What are the organisational barriers we need to address?

SHARE YOUR VIEWS AND HELP US IMPROVE THE TRAINING AVAILABLE

Please pick up an information sheet and add your name to the sign up sheet for the group you plan to attend





Canolfan PRIME Cymru
PRIME Centre Wales

Health coaching training is being customised and evaluated by
Cardiff University as part of a PhD project

# A focus group to identify what factors need to be considered for developing a training programme for health coaching skills

#### **Participant Information Sheet**

This research project is exploring how the approach called health coaching could help staff working with people with progressive neurological conditions to support self-management.

What is the purpose of the study?

This focus group is part of a PhD project exploring how we can deliver effective training for staff who work with people with MS and Parkinson's disease to improve the support for self-management they provide to their patients. We are working with a health coaching training provider to evaluate whether health coaching is helpful in this setting and how training might need to be adapted. After the focus group you will be able to register your interest in attending the future planned training course but attending the focus group does not guarantee that you will be offered a place on the training.

#### Why have I been chosen?

We want to hear the views of staff who would be part of the target audience for our planned training.

#### Do I have to take part?

Participation in the study is entirely voluntary. If you decide to take part you are still free to withdraw at any time and without giving a reason. You can withdraw from the focus group at any time by leaving the room. If you decide to participate in the focus group, your comments along with other participants will be recorded during the group discussions. Because of the way in which the focus group discussions are recorded, the research team will not be able to withdraw or destroy individual participant responses from the analysis.

#### What do I have to do?

Attend a group focus discussion and share your views on the proposed training. The focus group is expected to take around 45 minutes to one hour. It will be audio-recorded for analysis.

#### What about confidentiality?

All quotations used from the interviews in any future publications will be anonymised so there will be no way to link these back to you. The audio-recordings and focus group transcripts will be stored securely on Cardiff University password-protected computers for five years after the study ends and then destroyed.

#### Are there any risks?

There are no expected risks associated with participating in the project. If you have any concerns about the way in which the study is conducted you can contact Professor Adrian Edwards, Cardiff University at <a href="mailto:EdwardsAG@cardiff.ac.uk">EdwardsAG@cardiff.ac.uk</a>.

What will happen to the results of the research study?

The results of the study will help us to tailor the training and the planned methods of evaluating the training so that these are relevant to staff working with people with MS and PD. The results of the study will also form part of the PhD report and may be used in academic presentations and publications.

Who is organising and funding the research?

This focus group is part of a PhD study being undertaken by Dr Freya Davies, Clinical Research Fellow at Cardiff University and has received no specific funding. The planned Health Coaching Skills Development training will be funded by Novartis pharmaceuticals. Novartis will have no input into the content of the training. The evaluation of this training will be conducted independently by Dr Freya Davies, Cardiff University.

Contact for further information: If you have any questions about the study please contact Dr Freya Davies on <a href="mailto:DaviesF9@cardiff.ac.uk">DaviesF9@cardiff.ac.uk</a> or telephone 02920 687226.

#### **CONSENT FORM FOR FOCUS GROUP**

Title of Project: A focus group to identify what factors need to be considered for developing a training programme for health coaching skills

Name of Researcher: Dr Freya Davies	
Participant Name:	
If you would like to receive an email summary of the focus group provide your email address here	results please
	Please initial
	box to confirm
1. I have read and understood the information sheet dated 11/2	10/17
(Version 1) for the above study and had the opportunity to ask qu	uestions.
2. I understand that participation is voluntary and that I am free	to withdraw
at any time, without giving any reason.	
3. I agree for the focus group to be audio-recorded.	
4. I agree for anonymised quotations from the focus group to be	e used in 🗌
publications related to the research.	
<ol> <li>I understand that participation in the focus group does no</li> </ol>	ot 🗌
guarantee that I will be offered a place on the forthcoming train	ing course.
6. I agree to take part in the above study.	

Participant name	Date	Signature	
Researcher taking consent	———— Date	Signature	

# Health coaching skills development for staff working with people with progressive neurological conditions

#### **Focus Group Topic Guide**

#### 1. Introductions

Each group member to explain their role, level of experience and any previous related training they have received. Facilitator to set ground rules for group (one person talks at a time, respect the confidentiality of other group members)

#### 2. Opening questions to the group

What are the important behaviour changes that you would like to see in your patients? What would you like people to do differently?

What are some of the best/most productive conversations that you have had with your patients?

3. Facilitator briefly outlines proposed training programme. Explains purpose of health coaching, style of training and core skills to be developed Ask the group: How relevant would these skills be to your job?

4. Facilitator suggests that the training will involve staff developing knowledge, skills and confidence.

Ask the group: What about the training might help this process? What could help you grow in confidence after training? What trainee characteristics might influence this process?

5. Facilitator suggests that we understand that factors not always within the control of individual professionals might also influence how easy the approach is to implement. Facilitator suggests particular characteristics of patients with progressive neurological conditions might be a barrier.

Ask the group: What are your concerns? How could a training intervention particularly address these? What are the particular challenges of working with carers?

6. Facilitator suggests that factors in the workplace could also be significant barriers (e.g. resource allocation, policies and procedures, views of supervisors)
Ask the group: Which of these do you think have the biggest influence on your practice?

How do you think training could help to address these?

#### 7. Defining training success

Ask the group how they know that the training had 'worked' for them/things were going well in implementation? How would they know it was working for their patients? Ask about what kind of feedback on their performance staff would value?

After each topic area is discussed the facilitator will follow up with prompts where relevant asking participants to specify:

How does this relate to your experience?
 How do you think this would relate to your setting?

#### Appendix K – Completed TIDieR checklist for intervention reporting

#### **BRIEF NAME**

 Provide the name or a phrase that describes the intervention. Health coaching skills development programme

#### **WHY**

Describe any rationale, theory, or goal of the elements essential to the intervention. Trainers try to model a coaching approach during the training by encouraging participants to identify their own challenges and generate their own solutions

Development of a coaching mindset – exploring what coaching is, how it differs to other types of relationship

Opportunity to experience being coached and being a coach

Development of particular coaching skills and techniques

Opportunities to discuss how coaching skills could be used in

practice

#### **WHAT**

physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).

All trainees were provided with a 123page resource guide (which included space for notes)

The booklet included all of the slides presented by the trainers during the two workshops (and some extra slides that were not discussed during the training days)

Participants were encouraged to write in the resource guides.

4. Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities. Personal reflection exercises
Discussions in pairs, small groups
and as a whole
Group work with flip charts
Short presentations given by trainers
Live demonstrations provided by
trainers

Practise sessions with colleagues
Very limited individual feedback on
performance

Activities often physical – involving walking around the room as a group to discuss different flip charts pinned on the walls

#### **WHO PROVIDED**

5. For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.

The training was provided by two highly experienced facilitators (both with clinical backgrounds)

#### **HOW**

6. Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.

Face-to-face 2-day training course Supplemented by the availability of an online closed group forum which provided reference material and discussion boards.

#### WHERE

7. Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.

Delivered in a meeting room of a hotel, seating in a U-shaped layout. Slides displayed on a screen and flip chart used by facilitator.

#### WHEN and HOW MUCH

8. Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.

Delivered over 2 whole days just over 11 weeks apart (training commenced at 9.30 and, finished just after 5 day 1 – 50 min lunch, 2 short coffee breaks of 10-15 mins)- just over 6 hrs.

Day 2 had same start time, finished at 5, lunch break 40-45mins, tea breaks shorter – 10mins AM, 5 mins PM)

#### **TAILORING**

9. If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how. Intervention encouraged participant interaction. Group discussion sessions were shaped by the issues raised by the participants and felt to be most relevant to them

#### **MODIFICATIONS**

- **10.** If the intervention was modified
- during the course of the study, describe the changes (what, why, when, and how).

The training is usually delivered with a 4-week gap between the two sessions. Due to adverse weather the second training day was postponed resulting in a gap of just over 11 weeks between the first and second training days. Due to the long interval between the two training days the trainers arranged to host a one-hour refresher webinar ten days before the second training day which was attended by 6 participants. This provided an opportunity for attendees to reflect on their experiences with trying to implement the training and to revise content from the first training day. Other participants had the opportunity to watch the webinar recording online

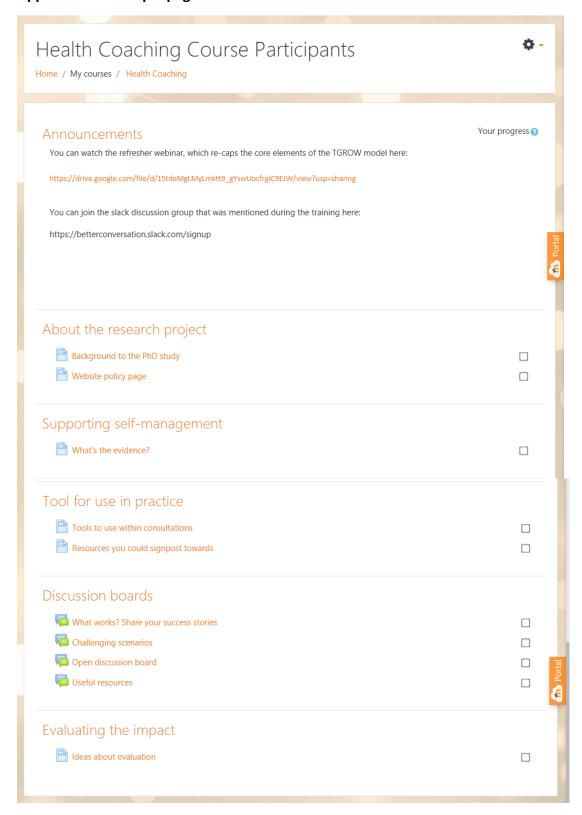
#### **HOW WELL**

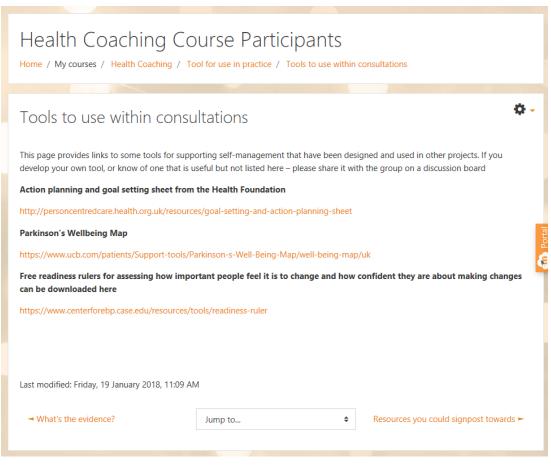
- 11. Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.
- No planned fidelity assessment

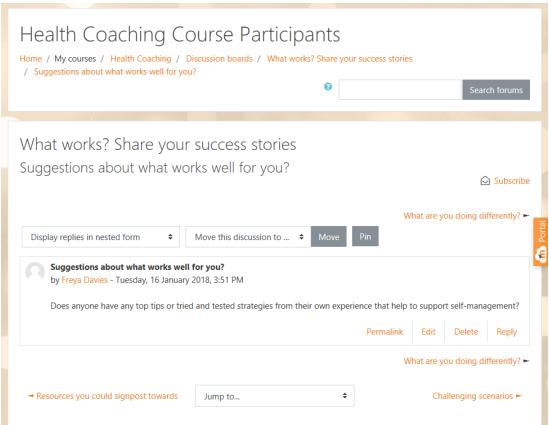
- **12.** Actual: If intervention
- \* adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.

Majority of slides were discussed in the training day. Not clear whether it was planned for those which were not discussed should have been, or if they were just provided for additional information.

#### Appendix L – Example pages from web resource







### Appendix M – Evaluation stage questionnaires

	Evaluation of health coaching training for staff working with people with progressive
	neurological conditions
	Pre-Training Questionnaire
	Participant number:
	Thank you for completing this research questionnaire before the health coaching training starts. The
r	esearch is being undertaken by Dr Freya Davies from Cardiff University as part of a PhD.
	The survey will take you approximately five minutes to complete. Your participation in this study is entirely voluntary and you can withdraw at any time.
	We want to find out your current ideas about supporting self-management and what you do at the
c	noment in your routine practice. We do not expect that you will already be using a lot of health coaching techniques without having any training. Please try to honestly answer the questions abou what you are doing now. We will ask you similar questions again after the training to get an idea of
ŀ	now the training might have worked for you.
	Your answers will remain confidential. Any data from the study that is published will not be dentifiable as yours. If you would like more information about the study or wish to ask any
c	questions, please email DaviesF9@cardiff.ac.uk or Professor Adrian Edwards (supervisor)  EdwardsAE@cardiff.ac.uk
	By completing this questionnaire, I am consenting to take part in this study. I understand my data
٧	will be held securely and I have a right to withdraw from this study at any time. I understand that when this information is no longer required for this purpose, official university procedure will be followed to dispose of my data.
	evaluation of health coaching training for staff working with people with progressive neurological conditions
P	Pre-training questionnaire Version 1.0 4.12.17

1.

	Not important	Slightly important	Fairly important	Important	Very important
In relation to the other tasks that					
you do, please rank the importance					
of supporting self-management					

2.

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
To what extent do you agree with the statement: With support, my patients can self-manage their condition					
effectively					

3.

	Not at all useful	Slightly useful	Moderately useful	Very useful	Extremely useful
How useful do you think the health					
coaching approach might be in helping					
you to work with your patients?					

4.

	Very difficult	Somewhat difficult	Unsure	Fairly easy	Very easy
How easy do you think it might be to apply a health coaching approach during your routine work?					

5.

	Not at all motivated	Slightly motivated	Moderately motivated	Very motivated	Extremely motivated
How motivated do you currently feel to try using a health coaching approach in your routine appointments?					

Evaluation of health coaching training for staff working with people with progressive neurological conditions  $Pre-training \ questionnaire \ Version \ 1.0 \ 4.12.17$ 

6. How much do you feel you currently understand about each of the following health coaching techniques and behaviours?

	Do not understand at all	Understand a little	Understand a fair amount	Understand a significant amount	Understand completely
Focusing on patient's goals				diriodire	
- understanding what the					
patient really wants to					
achieve and developing					
commitment to those goals					
more than the focus on					
your own clinical objectives					
Demonstrating empathy –					
aiming to understand the					
patient's context by					
putting yourself 'in their					
shoes'					
Raising awareness – asking					
questions that encourage					
your patients to develop					
new insights that support					
self-management					
<b>Encouraging responsibility</b>					
<ul> <li>supporting patients to</li> </ul>					
take responsibility for their					
own management rather					
than relying on your advice					
Supportive challenge –					
challenging the ideas and					
perspectives of your					
patients in a supportive					
manner					
Awareness of self-					
monitoring your own					
thoughts and feelings					
during consultations, being					
aware of judgements and					
habits					
Patient resourcefulness –					
communicating in a way					
that conveys confidence,					
respect for and belief in					
the patients' ability to be					
resourceful					

Evaluation of health coaching training for staff working with people with progressive neurological conditions  $Pre-training \ question naire \ Version \ 1.0 \ 4.12.17$ 

7. How confident do you feel at the moment about your ability to use each of the following health
coaching techniques and behaviours? (see page 3 for definitions):

	Not at all confident	Slightly confident	Moderately confident	Very confident	Extremely confident
Focusing on patient's goals					
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					
Patient resourcefulness					

8. How often do you think you currently use each of the following health coaching techniques and behaviours in your routine consultations? (see page 3 for definitions):

	Not at all	Occasionally	Sometimes	Often	Very often
Focusing on patient's goals					
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					
Patient resourcefulness					

#### 9.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How would you rate your current level of job satisfaction?					

Evaluation of health coaching training for staff working with people with progressive neurological conditions  $Pre-training \ question naire \ Version \ 1.0 \ 4.12.17$ 

## Evaluation of health coaching training for staff working with people with progressive neurological conditions

#### Follow-up Questionnaire

Participant	number	
rarticipant	number.	

Thank you for completing this research questionnaire following your two days of health coaching training. The research is being undertaken by Dr Freya Davies from Cardiff University as part of a PhD.

The survey will take you approximately ten minutes to complete. Your participation in this study is entirely voluntary and you can withdraw at any time.

This survey asks similar questions to those we asked you before, and shortly after the training. In this questionnaire we will also ask you to look back to before you had the training and think again about what you were doing then, compared to what you are doing now. We have also provided spaces for you to share any other feedback on how your practice might have changed since attending the course.

Your answers will remain confidential. Any data from the study that is published will not be identifiable as yours. If you would like more information about the study or wish to ask any questions, please email DaviesF9@cardiff.ac.uk or Professor Adrian Edwards (supervisor) <a href="mailto:EdwardsAE@cardiff.ac.uk">EdwardsAE@cardiff.ac.uk</a>

By completing this questionnaire, I am consenting to take part in this study. I understand my data will be held securely and I have a right to withdraw from this study at any time. I understand that when this information is no longer required for this purpose, official university procedure will be followed to dispose of my data.

Evaluation of health coaching training for staff working with people with progressive neurological conditions Follow-up questionnaire Version  $1.0\,4.12.17$ 

In relation to the other tasks that you do, please rank the importance of supporting self-management  2.  Strongly disagree  To what extent do you agree with the statement: With support, my patients can self-manage their condition effectively  3.  Not at all useful self-manage their condition effectively  4.  Very difficult difficult Easy easy  Very easy difficult Woderately Unsure easy  Not at all Slightly Moderately Unsure easy  Very easy  Somewhat Unsure easy Very easy easy  Very easy easy  Not at all Slightly Moderately Very Extrement  Somewhat Unsure easy easy  Very easy easy  Very easy easy  Somewhat difficult Woderately Very Extrement  Somewhat Unsure easy easy			ot	Slightly		Fairly	Important	
2.  Strongly disagree Undecided Agree Strongly agree  To what extent do you agree with the statement: With support, my patients can self-manage their condition effectively  3.  Not at all useful Unsure Fairly easy  4.  Very difficult difficult difficult of difficul	In relation to the other tasks that you do.	ım	iportant	Importa	ant	Important		importa
Strongly disagree   Disagree   Undecided   Agree   Strongly agree    To what extent do you agree with the statement: With support, my patients can self-manage their condition effectively  3.   Not at all coaching approach been in helping you to work with your patients?   Very difficult   Very difficult   Very easy difficult   Very easy difficult   Very easy difficult   Very easy easy   Very easy easy easy   Very easy easy   Very easy easy   Very easy easy   Very easy easy easy	please rank the importance of supporting							
To what extent do you agree with the statement: With support, my patients can selfmanage their condition effectively  3.  Not at all useful us	2.							
statement: With support, my patients can self- manage their condition effectively  3.  Not at all useful us				_	ee	Undecided	Agree	
Not at all useful usefu	statement: With support, my patients can	self-						
A	3.							
How useful has the health coaching approach been in helping you to work with your patients?  4.  Very Somewhat difficult difficult difficult difficult  How easy has it been to apply a health coaching approach during your routine work?  5.  Not at all motivated motiv			all			,		Extremely useful
Very difficult   Somewhat difficult   Unsure easy   Very easy	been in helping you to work with your	ach						
How easy has it been to apply a health coaching approach during your routine work?  5.  Not at all motivated Moderately	4.							
5.  Not at all Slightly Moderately Very Extremel motivated do you currently feel to use a health coaching approach in your						at Unsure		Very easy
Not at all slightly motivated with motivated motivated with motiva		rk?						
motivated motiva	5.							
use a health coaching approach in your				· .	- 1	, ,		Extremel motivate
	use a health coaching approach in your							

Evaluation of health coaching training for staff working with people with progressive neurological conditions Follow-up questionnaire Version  $1.0\,4.12.17$ 

7. **Looking back** – how much do you think you understood about each of the following health coaching techniques and behaviours BEFORE you attended training?

	Did not understand at all	Understood a little	Understood a fair amount	Understood a significant	Understood completely
				amount	
Focusing on patient's goals –					
understanding what the patient					
really wants to achieve and					
developing commitment to those					
goals more than the focus on your					
own clinical objectives					
Demonstrating empathy – aiming					
to understand the patient's					
context by putting yourself 'in					
their shoes'					
Raising awareness – asking					
questions that encourage your					
patients to develop new insights					
that support self-management					
Encouraging responsibility –					
supporting patients to take					
responsibility for their own					
management rather than relying					
on your advice					
Supportive challenge – challenging					
the ideas and perspectives of your					
patients in a supportive manner					
Awareness of self- monitoring					
your own thoughts and feelings					
during consultations, being aware					
of judgements and habits					
Patient resourcefulness –					
communicating in a way that					
conveys confidence, respect for					
and belief in the patients' ability to					
be resourceful					

Evaluation of health coaching training for staff working with people with progressive neurological conditions Follow-up questionnaire Version 1.0 4.12.17

coaching techniques and bel	haviours?				
	Do not understand at all	Understand a little	Understand a fair amount	Understand a significant amount	Understand completely
Focusing on patient's goals					
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					

8. Following the training, how much do feel you NOW understand about each of the following health

Awareness of self						
Patient resourcefulness						
9. What was the most useful thi	ing you learne	ed durin	g the traini	ng?		
10. Looking back – how confiden	t do you thinl	k you w	ere about u	ising each o	f the following	health
coaching techniques and beh	aviours BEFO	RE you a	attended tr	aining? (see	page 3 for de	finitions):
		at all fident	Slightly confident	Moderate	, , ,	Extremely
Focusing on patient's goals	Con	nuent	connuent	connident	connuent	connucin
Demonstrating empathy						
Raising awareness						
Encouraging recognibility						

Evaluation of health coaching training for staff working with people with progressive neurological conditions Follow-up questionnaire Version  $1.0\,4.12.17$ 

Supportive challenge
Awareness of self

Patient resourcefulness

11. Following the training,	how confident do you feel NOW	/ about using each of the foll	owing health
coaching techniques an	d behaviours?		

	Not at all confident	Slightly confident	Moderately confident	Very confident	Extremely confident
Focusing on patient's goals					
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					
Patient resourcefulness					

12. What has helped you the most to build confidence in using the health coaching skills?

13. Looking back – How often do you think you were using each of the following health coaching techniques and behaviours in your routine consultations BEFORE you attended training? (see page 3 for definitions):

	Not at all	Occasionally	Sometimes	Often	Very often
Focusing on patient's goals					
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					
Patient resourcefulness					

Evaluation of health coaching training for staff working with people with progressive neurological conditions Follow-up questionnaire Version  $1.0\,4.12.17$ 

	Not at	Occasiona	lly Sometime	s Often	. , ,
Focusing on patient's goals	all				often
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					
Patient resourcefulness					
15. Can you give an example of when	n you used hea	lth coaching in	an appointme	nt and wh	nat happened
	Very	Dissatisfied	Neither	nt and wh	Very
as a result?			Neither satisfied nor		
as a result?	Very		Neither satisfied		Very

# Health Coaching in Neurological Conditions - follow-up survey

#### Page 1

Thank you for completing this research questionnaire following your two days of health coaching training. The research is being undertaken by Dr Freya Davies from Cardiff University as part of a PhD.

The survey will take you approximately ten minutes to complete. Your participation in this study is entirely voluntary and you can withdraw at any time.

This survey asks similar questions to those we asked you before, and shortly after the training. In this questionnaire we will also ask you to look back to before you had the training and think again about what you were doing then, compared to what you are doing now. We have also provided spaces for you to share any other feedback on how your practice might have changed since attending the course.

Your answers will remain confidential. Any data from the study that is published will not be identifiable as yours. If you would like more information about the study or wish to ask any questions, please email DaviesF9@cardiff.ac.uk or Professor Adrian Edwards (supervisor) <a href="mailto:EdwardsAE@cardiff.ac.uk">EdwardsAE@cardiff.ac.uk</a>

By completing this questionnaire, I am consenting to take part in this study. I understand my data will be held securely and I have a right to withdraw from this study at any time. I understand that when this information is no longer required for this purpose, official university procedure will be followed to dispose of my data.

# Page 2: About supporting self-management 1. In relation to the other tasks that you do, please rank the importance of supporting self-management O Not important O Slightly important O Fairly important Important O Very important 2. To what extent do you agree with the statement: With support, my patients can self-manage their condition effectively O Strongly disagree O Disagree O Neither agree nor disagree O Agree O Strongly agree 3. How useful has the health coaching approach been in helping you to work with your patients? O Not at all useful O Slightly useful O Fairly useful O Useful O Very useful

4. How easy has it been to apply a health coaching approach during your routine work?
O Very difficult
O Somewhat difficult
O Neutral
○ Easy
O Very easy
5. How motivated do you currently feel to use a health coaching approach in your routine appointments?
O Not at all motivated
O Slightly motivated
O Fairly motivated
O Motivated
O Very motivated
6. Have there been any barriers to applying the training in your routine work?

7. **Looking back** – how much do you think you **understood** about each of the following health coaching techniques and behaviours **BEFORE** you attended training?

Please don't select more than 1 answer(s) per row.

	Did not understand at all	Understood a little	Understood a fair amount	Understood a significant amount	Understood completely
Focusing on patient's goals  understanding what the patient really wants to achieve and developing commitment to those goals more than the focus on your own clinical objectives					
Demonstrating empathy – aiming to understand the patient's context by putting yourself 'in their shoes'					
Raising awareness – asking questions that encourage your patients to develop new insights that support self- management					

Encouraging responsibility – supporting patients to take responsibility for their own management rather than relying on your advice			
Supportive challenge – challenging the ideas and perspectives of your patients in a supportive manner			
Awareness of self- monitoring your own thoughts and feelings during consultations, being aware of judgements and habits			
Patient resourcefulness  communicating in a way that conveys confidence, respect for and belief in the patients' ability to be resourceful			

8. Following the training, how much do feel you NOW understand about each of the following health coaching techniques and behaviours? Please don't select more than 1 answer(s) per row. Understand Understand Do not Understand Understand а understand a fair significant completely a little at all amount amount Focusing on patient's goals understanding what the patient really wants to achieve and developing commitment to those goals more than the focus on your own clinical objectives Demonstrating empathy aiming to understand the patient's context by putting yourself 'in their shoes' Raising awareness asking questions that encourage your patients to develop new insights that support selfmanagement Encouraging responsibility -

supporting patients to take responsibility for their own management rather than relying on your advice			
Supportive challenge – challenging the ideas and perspectives of your patients in a supportive manner			
Awareness of self- monitoring your own thoughts and feelings during consultations, being aware of judgements and habits			
Patient resourcefulness - communicating in a way that conveys confidence, respect for and belief in the patients' ability to be resourceful			

9.	. What was the most useful thing you learned during the training?
L	

## Page 5: Looking back at your confidence

10. **Looking back** – how **confident** do you think you were about using each of the following health coaching techniques and behaviours **BEFORE** you attended training?

Please don't select more than 1 answer(s) per row.

	Not at all confident	Slightly confident	Moderately confident	Very confident	Extremely confident
Focusing on patient's goals					
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					

## Page 6: Your confidence now

11. Following the training, how confident do you feel NOW about using each of the following health coaching techniques and behaviours?

Please don't select more than 1 answer(s) per row.

	Not at all confident	Slightly confident	Moderately confident	Very confident	Extremely confident
Focusing on patient's goals					
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					
Patient resourcefulness					

resourceiumess					
12. What has hel	ped you the	most to build	d confidence i	n using the l	nealth

# Page 7: Looking back at skill usage

13. **Looking back** – How often do you think you were **using** each of the following health coaching techniques and behaviours in your routine consultations **BEFORE** you attended training?

Please don't select more than 1 answer(s) per row.

	Not at all	Occasionally	Sometimes	Often	Very often
Focusing on patient's goals					
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					
Patient resourcefulness					

# Page 8: Your skill usage now

*14.* **Following the training,** how often do you **NOW use** each of the following health coaching techniques and behaviours?

Please don't select more than 1 answer(s) per row.

	Not at all	Occasionally	Sometimes	Often	Very often
Focusing on patient's goals					
Demonstrating empathy					
Raising awareness					
Encouraging responsibility					
Supportive challenge					
Awareness of self					
Patient resourcefulness					

- 1	<ol><li>Can you give</li></ol>	an exampı	ie of when you i	used nealth co	oacning in a	n
-	anaintment and w	what banna	and an a requit	)		
а	ppointment and v	vnat nappei	neu as a result			

16. How would you rate your current level of job satisfaction?					
lease don't select more than 1 answer(s) per row.  Neither					
	Very dissatisfied	Dissatisfied	satisfied nor dissatisfied	Satisfied	Very satisfied
Current satisfaction level					

# Page 10: End of questionnaire

Thank you for taking the time to complete the questionnaire.

If you would like to make any additional comments, you can email DaviesF9@cardiff.ac.uk.

A summary of the results of the training evaluation will be distributed as soon as the analysis is complete.

# Appendix N – Materials relating to evaluation stage

This appendix contains the following materials from the evaluation stage

- Ethical Approval
- Participant information
- Consent Forms
- Interview Topic Guide



School of Medicine Ysgol Meddygaeth **Cardiff University** 

Main Building Heath Park Cardiff CF14 4XN Wales UK

Monday 25th June 2018

Dr Freya Davies, Division of Population Medicine, 5th Floor, Neuadd Meirionnydd, Heath Park.

Dear Freya,

Prifysgol Caerdydd

Prif Adeilad Parc y Mynydd Bychan Caerdydd CF14 4XN Cymru, Y Deyrnas Unedig

Re: Evaluation of health coaching training for staff working with people with progressive neurological conditions

SMREC Reference Number: 17/66

This application was reviewed by the Committee on Thursday 14th December 2017. An amendment request was considered and approved on Monday 18<sup>th</sup> June 2018.

#### **Ethical Opinion**

On review, I can confirm ethical approval for this study, inclusive of the amendment request sent to the Committee Secretary on Monday 11th June 2018.

#### Conditions of Approval

The Committee must be notified of any proposed amendments to the methodology and protocols outlined in your submission. Also, any serious or unexpected adverse reactions that may arise during the course of the study must be reported to the Committee. As a condition of this approval, the Committee retains the right to audit and review the study for our own records.

#### **Documents Considered**

Document Type:	Version:	Date Considered
Application	Signed 01/12/2017	14/40/0047
Study Protocol	V1 04/12/2017	14/12/2017
Participant Information Sheet	V1 04/12/2017 V1 04/12/2017	14/12/2017
Pre-Training Questionnaire	V1 04/12/2017 V1 04/12/2017	14/12/2017
Post-Training Questionnaire	V1 04/12/2017 V1 04/12/2017	14/12/2017
Follow-Up Questionnaire		14/12/2017
Observation Template	V1 04/12/2017	14/12/2017
Consent Form for Training Observations	V1 04/12/2017 V1 04/12/2017	14/12/2017
Consent Form for Telephone Interview		14/12/2017
Follow-up Telephone Interview Topic Guide	V1 04/12/2017	14/12/2017
Email response to expressions of interests in the training	V1 04/12/2017	14/12/2017
Website Policy Page	No Date or Version	14/12/2017
Email to Committee Secretary	V1 04/12/2017	14/12/2017
Email to Committee Secretary (Response to Query)	11/06/2018	18/06/2018
(nesponse to Query)	18/06/2018	18/06/2018

With best wishes for the success of your study.

Yours sincerely,

Me HINDE

Dr Jonathan Hewitt

Chair, School of Medicine Research Ethics Committee



THE QUEEN'S ANNIVERSARY PRIZE 2015







Registered Charity, no. 1136855 Eluson Gofrestredig, rhif 1136855 Evaluation of health coaching training for staff working with people with progressive neurological conditions

Participant Information Sheet

This research project is exploring how the approach called 'health coaching' could help staff working with people with progressive neurological conditions to support self-management.

What is the purpose of the study?

The two-day training event has been organised as part of a PhD project exploring how we can deliver effective training for staff who work with people with progressive neurological conditions to improve the support for self-management they provide to their patients. We are working with a health coaching training provider to evaluate whether health coaching is helpful in this setting and how training might need to be adapted. The evaluation involves a number of different activities described below. The aim is not to rank or judge participants in any way.

Why have I been chosen?

We want to understand how the training works for all those taking part in the training course.

What do I have to do?

Questionnaires

We will ask you to fill in questionnaires before, immediately after and then again 3 months after training. These will ask questions about your current practice and training experience.

Training observations

You do not have to do anything different to be involved in this stage of the research. The researcher will make notes about what happens during the training. The researcher observing the session might also ask you some short informal questions during the training days about what happens, and your responses could be recorded.

Follow-up interviews

We will ask you to take part in a telephone interview with the researcher to discuss your experiences of the training. We will interview half of participants 1-2 weeks after the training and the other half will be interviewed after 3 months. The interview is expected to take around 45 minutes and can be arranged at a time that is convenient to you. It will be audio-recorded for analysis.

#### Website usage

You will be offered access to a website to discuss your experiences of training with the other course participants. Usage of the website will be monitored and any comments you post could be analysed as part of the research.

#### Do I have to take part?

Participation in the study is entirely voluntary. You can choose which parts of the research you wish to participate in. If you decide to take part you are still free to withdraw at any time and without giving a reason. You can choose not to fill in all or part of the questionnaires. During the observations, if you do not wish for any notes to be made specifically in relation to your participation in the course, let the researcher know at morning registration for the course. At the end of the day, if you are worried about specific activities or conversations that have been observed please discuss this with the researcher who can remove any extracts required from the final research report. You can choose not to be interviewed, or ask for the interview to stop at any time. If after the interview you wish to withdraw your consent please let the researcher know (DaviesF9@cf.ac.uk). You can also choose to access the website without making any comments.

#### What about confidentiality?

All quotations gathered during the research that are used in any future publications will be anonymised so there will be no way to link these back to you. The study data, including notes, audio-recordings and interview transcripts will be stored securely on Cardiff University password-protected computers for five years after the study ends and then destroyed.

## Are there any risks?

There are no expected risks associated with participating in the project. If you have any concerns about the way in which the study is conducted you can contact Professor Adrian Edwards, Cardiff University at <a href="mailto:EdwardsAG@cardiff.ac.uk">EdwardsAG@cardiff.ac.uk</a>.

#### What will happen to the results of the research study?

The results of the study will help us to better understand how health coaching training works for staff working with people with progressive neurological conditions. The results

of the study will also form part of the PhD report and may be used in academic presentations and publications.

Who is organising and funding the research?

The PhD research is being undertaken by Dr Freya Davies, Clinical Research Fellow at Cardiff University and has received no specific funding. The planned Health Coaching Skills Development training was funded by Novartis pharmaceuticals. Novartis had no input into the content of the training. The evaluation of the training is being conducted independently by Dr Freya Davies, Cardiff University.

Contact for further information: If you have any questions about the study please contact Dr Freya Davies on <a href="mailto:DaviesF9@cardiff.ac.uk">DaviesF9@cardiff.ac.uk</a> or telephone 02920 687226.

#### CONSENT FORM FOR TRAINING OBSERVATIONS

Title of Project: Evaluation of health coaching training for staff working with people with progressive neurological conditions

Name	of Researcher: Dr Freya Davies	;			
Particip	pant Name:				
	ave read and understood the i for the above study and had t	·		Please initial box to confirm	
	nderstand that participation is consent at any time, without	,	to withdraw		
thi	3. I consent to the processing of my personal information for the purposes of this study. I understand that such information will be treated as confidential and handled in accordance with the Data Protection Act 1998				
,	gree for the researcher undert rinvolvement in the training	aking observations to make	notes about		
<ol> <li>I agree for anonymised quotations from which might be recorded during the training to be used in publications related to the research.</li> </ol>					
6. la	gree to take part in the above	study			
	pant name	 Date		Signature	
Resear	cher taking consent	 Date		Signature	

Evaluation of health coaching training for staff working with people with progressive neurological conditions Observations Consent Form Version 1.0 4.12.17

### CONSENT FORM FOR TELEPHONE INTERVIEW

Title of Project: Evaluation of health coaching training for staff working with people with progressive neurological conditions

Naı	me of Researcher: Dr Freya Davies				
Par	ticipant Name:				
Bes	t Contact Telephone number:				
Any	/ dates you are unavailable in the ne	ext 3 months			
			Please initial box to confirm		
1.	I have read and understood the inf 1) for the above study and had the		· I I		
2.	I understand that participation is v my consent at any time, without gi	,	o withdraw		
3.	I consent to the processing of my personal information for the purposes of this study. I understand that such information will be treated as confidential and handled in accordance with the Data Protection Act 1998				
4.	4. I agree to be contacted for a telephone interview				
5.	I agree for the interview to be aud	io-recorded			
6.	I agree for anonymised quotations in publications related to the research	,	g to be used		
7.	I agree to take part in the above st	udy			
— Par	ticipant name		Signature		
Res	earcher taking consent	Date	Signature		

Evaluation of health coaching training for staff working with people with progressive neurological conditions Telephone Interview Consent Form Version 1.0 4.12.17

For researcher use:		
Telephone interview date:		
I have confirmed the above consen interview today.	t with the participant who wis	shes to proceed with the
Researcher taking consent	Date	Signature

Evaluation of health coaching training for staff working with people with progressive neurological conditions Telephone Interview Consent Form Version 1.0 4.12.17

# Evaluation of health coaching training for staff working with people with progressive neurological conditions

#### Follow-up telephone interview topic guide

#### **Opening questions**

Can you tell me about your current role? (experience, work setting, patient group)

Can you tell me a bit about what you thought about the health coaching training?

What was the most important/most practice changing element? Most significant change for you?

# Questions to explore specific mechanisms

We have some ideas about the common ways in which people say that training influences them. I'd like to find out which of these might apply to you and the way you learn.

Do you have any thoughts on what really worked for you?

Did the training it change what you knew about SMS/health coaching? Did it change how confident you were to adopt this approach in practice?

Did it change how much you believed in health coaching as an approach? How?

How much could you relate the training to your own practice? Did it make you reflect on your own practice? How? Or – What made you think about your own normal practice?

How did the training influence how you thought about your patients?

How did the training fit with how you see your own role as a health professional? In your current role? Within your team? Did it make you think differently?

Tell me about how you used the web resource? How did it help? Was anything about it less helpful?

#### Questions to explore specific contexts

We also have some ideas about some of the things that can influence people's experiences of training that I'd like to discuss

Training context – trainer characteristics, delivery methods, other people on the training – were these an influence?

Personal views/background – Did these influence how you experienced the training?

How did what you knew about how your team operated effect how you experienced training? And how you thought about how training would fit into your workplace?

Patient characteristics – Were you thinking about particular 'challenging' patients during the training? During the implementation? How did this influence you?

#### **Questions to explore outcomes**

Has the training changed the way you work so far? How?

Have you seen any changes in your patients?

Have there been any challenges with trying to apply the training?

### Other thoughts or comments

- Who training might work for?
- Where it might be effective?
- How it might make people think differently?

# Other possible areas to consider based on middle range theories (selected questions may be added in if time permits)

- Transformative learning theory— was there a disorientating dilemma, a period of critical reflection, did it prompt dissatisfaction with status quo, were there opportunities to discuss with others to make new meanings,
- Technology Acceptance Model 3 overall how easy do they think training would be to implement/how easy have they found it? (inc. self-efficacy and perceived external control) How useful do they think the new approach is? (inc. relevance to job, how they see their professional role and whether it is a valued activity by others)
- Normalisation Process Theory
  - Coherence (how did you/the other trainees/your colleagues see the value/benefits/importance of the new approach)
  - Cognitive participation (did you and others buy-in to new way of working?
     Did you make changes as a result)
  - Collective action (when you started using the new approach how did it impact on relationships with patients and colleagues, who was allocated to doing the work, who had the right skills, how did you maintain confidence in the new approach)
  - Reflexive monitoring (how did it work, how did you monitor its effects, did you discuss with others? Did you collect data? Did you make changes as a result?)

## Appendix O – Coding framework used during analysis of evaluation data

#### 1. Evidence

- 1.1 Importance of evidence
- 1.2 Lack of evidence as a barrier
- 1.3 Type of evidence valued

# 2. Knowledge, skills and confidence

- 2.1 Building and maintaining confidence
- 2.2 Existing knowledge gaps
- 2.3 How to handle challenging scenarios
- 2.4 Importance of specific tools

#### 3. Reflection

- 3.1 Continuing to reflect after training
- 3.2 Exercises that prompted reflection
- 3.3 How reflecting influenced reaction to training
- 3.4 Recognising problems with current approach
- 3.5 Transferability outside work setting

# 4. Empathy

- 4.1 Activities creating empathy
- 4.2 Changes in expectations

# 5. Team and organisational support

- 5.1 Enthusiasm for sharing the learning
- 5.2 Interactions with colleagues
- 5.3 Organisation level barriers and facilitators
- 5.4 Training together

## 6. Redefining professional role

- 6.1 Change in definition of success
- 6.2 Compliance
- 6.3 Core medical tasks take priority
- 6.4 Employers expectations
- 6.5 Fits with existing ethos
- 6.6 Patient expectations
- 6.7 Prior professional training
- 6.8 Professional responsibility
- 6.9 Shift in mindset already on journey

# 7. Picking the right patient

- 7.1 Accepting that people aren't ready
- 7.2 Making a decision
- 7.3 Patient level barriers
- 7.4 Situations where it will work
- 7.5 Situations where it won't work
- 7.6 Using with 'heartsink' patients
- 7.7 Willingness to give it a go

# 8. Experiences of implementation

- 8.1 Frequency of use
- 8.2 Is coaching minor tweak or full models
- 8.3 Redesigning services
- 8.4 Role of early successes

# 9. Trainee personal context

- 9.1 Confidence in working with caseload
- 9.2 Early adopter or late adopter
- 9.3 Keen to learn
- 9.4 Learning style
- 9.5 Long term relationships with patients
- 9.6 Reason for attending
- 9.7 Similarities to previous training

# 10. Training resources

- 10.1 Authenticity
- 10.10 Web page
- 10.2 Interactivity
- 10.3 Other trainees
- 10.4 Role play experiences
- 10.5 Too much material covered
- 10.6 Trainer characteristics
- 10.7 Training is enjoyable
- 10.8 Unanswered questions
- 10.9 Visual metaphors

# Appendix P – Example of how multiple lower level If-Then statements were consolidated into a higher-level theory

If-then statements related to the evaluation stage theory: Relevance to setting

When training works as planned	When training does not work as planned
IF the clinician works with patients they	IF the clinician works with patients they
perceive as challenging and they see health	perceive as challenging and the training
coaching as providing an alternative	does not address how the health coaching
approach to dealing with these challenging	approach can be adapted to these
scenarios, THEN this creates enthusiasm	situations THEN clinicians lack confidence
amongst clinicians who are looking for a	in using the approach and struggle to see
better way to manage these patients.	the relevance
IF participants think of coaching as a very	IF participants think of coaching as
rigid approach which requires a significant	involving only minor adaptions to their
practice shift and is separate to normal	existing routines (something that is easily
care THEN they are less likely to	integrated) THEN they are more likely to
incorporate the new skills.	incorporate the new skills.
IF staff see health coaching as a flexible	IF the intervention appears to be too
approach which they can adapt to the	flexible / poorly defined, THEN the
individual in front of them THEN they are	trainees will struggle to know how to use it
more likely to use it more widely.	and may lack confidence in the approach
IF trainers model the health coaching	IF trainers model the 'health coaching
approach during the training by	approach' during the training by
encouraging trainees to generate their own	encouraging trainees to generate their
answers to difficult questions THEN	own answers to difficult questions THEN
trainees become aware of the	trainees remain unsure about the answers
effectiveness of the strategy and buy in to	to their questions and uncertain about
the approach	how useful this style might be.
IF training participants feel that the	IF training participants have a negative
experience of being coached feels	experience of being coached (either due to
authentic, and they experience the	lack of authenticity or because the
benefits of the approach THEN they	experience is too challenging) THEN they
become convinced of the potential benefits	do not become convinced of the benefits
for their patients	to the same extent as those who have a
	positive experience
IF trainees attend training with a lot of	IF staff see a large part of their role as
experience in person-centred care	being information provision (or following a
approaches THEN they may strongly	medical model) THEN they may struggle to
identify with the training materials and be	understand the relevance of a coaching
keen to try to integrate the new skills into	approach and continue to use their usual
their existing skill set.	routines.
	IF coaching is seen to only be applicable to
	a small proportion of a practitioner's
	caseload or to a small element of the
	overall work done within an appointment
	THEN the chance of the approach being
	embraced is decreased.
IF staff have significant autonomy within	
their role to use their time as they choose	
within appointments THEN they are likely	

to find it easier to integrate the health	
coaching approach into their routine work	
IF staff highly value evidence that is	
derived from personal experiences (their	
own or that of others) and this is provided	
during the training THEN they will consider	
changing their own personal practice (C).	
IF staff need to influence others or require	
management buy-in (C) THEN they expect	
that research evidence will be required in	
order to convince others of the benefit of	
the new approach.	
IF trainees work within a team where there	
is already ongoing discussion about	
different models of consultations/ person-	
centred approaches THEN they can easily	
see the relevance/ fit of the training ethos	
with their existing workplace ethos and this	
increases their engagement with the	
training and subsequent enthusiasm about	
implementation. (O)	