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# **A QUALITATIVE EXPLORATION OF USER ENGAGEMENT AND HEALTH-RELATED BEHAVIOUR CHANGE IN THE NHS HEALTH TRAINERS INITIATIVE**

**SHELINA VISRAM**

A thesis submitted in partial fulfilment  
of the requirements of Northumbria  
University for the degree of Doctor of  
Philosophy

Research undertaken in the School of  
Health, Community and Education  
Studies

October 2011

# Abstract

Lay health workers have been widely used to deliver health improvement activities in developed and developing countries. Although there is some data to support their efficacy, reviews of the research literature have consistently found insufficient evidence to assess which intervention strategies are likely to be most effective. Furthermore, there is a dearth of research exploring service user views and experiences. This study contributes to evidence and theory in relation to lay-led models of promoting lifestyle change. By adopting a grounded theory methodology underpinned by a subtle realist perspective, the study aimed to understand better the experiences of users and the mechanisms underlying intervention outcomes.

The focus for this research was the NHS Health Trainers Initiative, which is part of an attempt to shift the emphasis in UK public health from 'advice on high to support from next door'. Participants were sampled from three heterogeneous health trainer services in northern England. Semi-structured interviews with service users (n=26) were conducted at 0, 3, 6 and 12 months, and with health trainers (n=13) and their managers (n=5) at 0 and 12 months. A longitudinal approach was chosen to allow for a more in-depth exploration of the processes involved in attempting to make and maintain health-related behaviour changes. Informal observations of selected health trainer activities were also undertaken in order to generate additional data for triangulation. All data were analysed using the constant comparative method.

Health trainers were found to employ a tailored, holistic approach that takes into account the context of a person's life and their access to resources for health. This builds upon the salutogenic theory of health, and is in direct contrast to the paternalistic, deficit model traditionally found in public health. It also draws on theories of 'person-in-situation' more commonly found in the social work literature, which present an alternative to the emphasis on person-centredness and psychological aspects of behaviour change. An integrated model is developed – called the theory of lay-led behaviour change in context – and contrasted with the logic models typically used to conceptualise similar interventions.

This research is one of few qualitative studies to investigate the role of lay health workers in the UK. Furthermore, the use of a longitudinal approach to explore behaviour change has produced results that are likely to have high policy relevance. The research represents an important application of a user-focused perspective affording new insights, which may also be applied to other complex interventions.

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## **Declaration**

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

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the School Ethics Committee (on 06/01/09), Newcastle and North Tyneside-1 NHS Local Research Ethics Committee (on 16/03/09), and the research and governance departments of the relevant NHS Trusts (on 21/05/09, 15/07/09 and 09/09/09).

Name:

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# Chapter 1: Introduction

This doctoral thesis presents a longitudinal grounded theory study conducted to explore staff and service user experiences of local health trainer services in England. The research provides the theoretical basis for an integrated model for understanding the processes involved in the delivery of contextualised lay-led behaviour change interventions. In this chapter, I provide a brief background to health trainers, before setting out the rationale for the study and introducing the research aims. The chapter ends with an overview of the structure of the thesis.

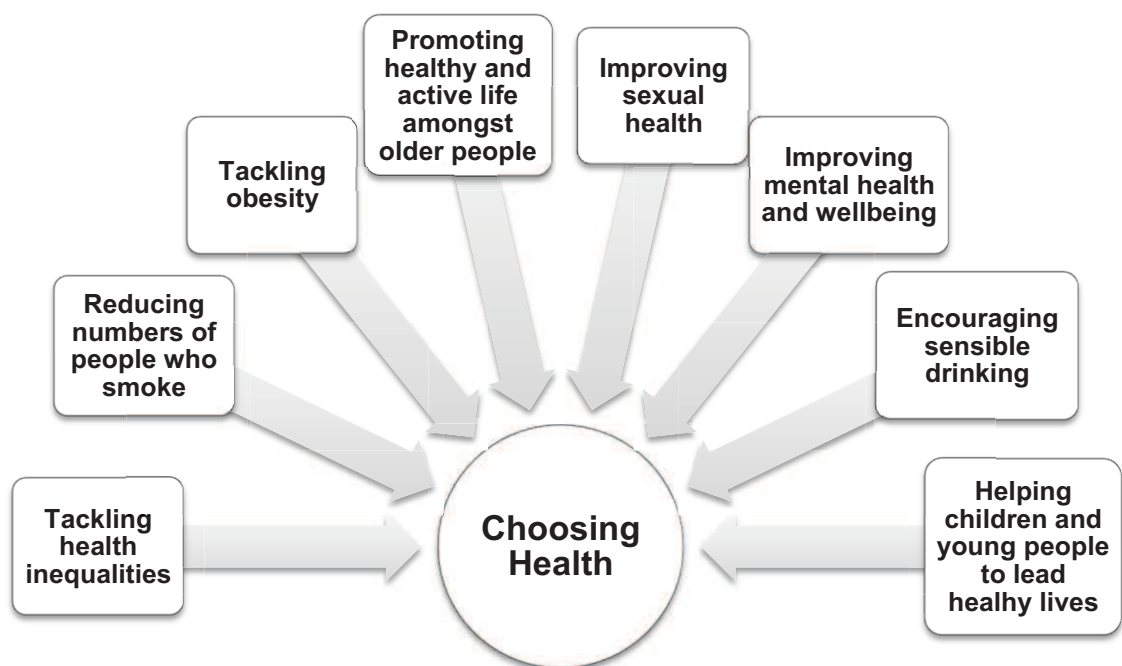
## Background to the NHS Health Trainers Initiative

There have been substantial improvements in the health of the UK population, with average life expectancy increasing from 45 years for males and 50 years for females born in 1900, to 78 years and 82 years respectively for those born in 2009 (Department of Health, 2004; National Audit Office, 2010). Life expectancy has also improved in the most socio-economically deprived areas but not as quickly as in the general population, contributing to growing health inequalities. So-called 'lifestyle diseases' such as type 2 diabetes, coronary heart disease and smoking-related illnesses are becoming increasingly prevalent and tend to be patterned by socioeconomic status (Department of Health, 2004; 2010a). Some progress has been made in tackling these issues; for example, the prevalence of smoking among adults in Britain fell from 45 per cent in 1974 to 21 per cent in 2009, and deaths from cancer and circulatory diseases are falling faster in England than the European average (Department of Health, 2010a; Robinson & Harris, 2011). However, lifestyle diseases continue to represent a key public health challenge and, due to their largely preventable nature, provide a compelling argument for investment in upstream interventions to improve health. At the same time, there is an increasing need to determine how to make these interventions accessible and acceptable to those who might benefit most in order to reduce social inequalities in health (Adshead & Thorpe, 2006; Marmot *et al.*, 2008).

Since the publication of the Black Report, successive UK governments have attempted to tackle the problem of health inequalities with variable degrees of success (Black, 1980; Hunter, 2007). For example, an economic analysis commissioned by the previous Labour government recommended a rebalancing of policy away from health care to health, and provided support for those advocating a

more assertive approach to public health intervention (Wanless, 2002; Adshead & Thorpe, 2006). This message was reinforced in a second report, which introduced the vision of a 'fully engaged scenario', while emphasising the role of lifestyle change and individual choice (Wanless, 2004). The government built on this vision in a white paper entitled *Choosing Health: making healthy choices easier* and subsequent delivery plan setting out eight priority areas (see figure 1) (Department of Health, 2004; 2005b). *Choosing Health* emphasised consumer choice and personal responsibility, whilst, paradoxically, acknowledging that socioeconomic disadvantage limits opportunity and restricts choice for many of those in the poorest health. In the first public health white paper published by the current coalition government, entitled *Healthy Lives, Healthy People*, the emphasis remains largely on the influence of individual lifestyle factors, as well as modifying the environment to enable people to make healthy choices (Department of Health, 2010b). Rather than aiming to improve their circumstances, the intention is to help people make informed lifestyle choices through a mix of education, advice and personal support.

**Figure 1: *Choosing Health* priority areas for action**



Health trainers represent the personalised strand of the *Choosing Health* white paper (Department of Health, 2004). See box 1 for an overview of the role. The NHS Health Trainers Initiative set out to empower people to change their health-related behaviours by widening access to appropriate health information and

services, and by offering practical support from someone who understands the pressures and problems they face (Department of Health, 2005a). The initiative also aims to combat social exclusion by providing opportunities for local people to obtain entry into the health and social care workforce. Health trainers were initially launched in the most health-deprived areas in England in 2006, before being rolled out across the country in 2007, in order to have the greatest impact on health inequalities. Critics have questioned whether there was sufficient demand to warrant an intervention of this scale and whether it would provide added value above expanding existing roles (Food Ethics Council, 2005; UKPHA, 2005). By 2009, over 90 per cent of primary care trusts (PCTs) had implemented a health trainer service and more than 3,100 individuals had commenced or completed the accredited training programme (Department of Health, 2009a). The largely grass-roots development of the role has been relatively *ad hoc*, resulting in a diversity of local service delivery models that tend not to be underpinned by theory or evidence.

**Box 1: Key features of the health trainer role** (Department of Health, 2004, p.103)

- In keeping with a shift in public health approaches from 'advice from on high to support from next door', health trainers will be drawn from local communities, understanding the day-to-day concerns and experiences of the people they are supporting on health.
- They will be accredited by the NHS to have skills appropriate for helping members of their community to achieve the changes they want to make.
- In touch with the realities of the lives of the people they work with and with a shared stake in improving the health of the communities that they live in, health trainers will be friendly, approachable, understanding and supportive.
- Offering practical advice and good connections into the services and support available locally, they will become an essential common-sense resource in the community to help out on health choices.
- A guide for those who want help, not an instructor for those who do not, they will provide valuable support for people to make informed lifestyle choices.
- Different neighbourhoods will need different types of health trainers and in developing good practice we will learn from seeing which models work best for different communities and individuals.
- By starting in the most deprived communities we will learn how best to ensure that health trainers reach the most deprived groups.



There is a lack of empirical evidence specifically on the subject of health trainers, which is unsurprising given the relatively recent inception of the role. Published papers generally report on process evaluations of local health trainer programmes or descriptive studies relating to the characteristics of their service users (South, Woodward & Lowcock, 2007; Dugdill *et al.*, 2009; Ball & Nasr, 2011; Wilkinson, Sniehotta & Michie, 2011). Only one economic evaluation has been published to date, concerning a health trainer-led intervention to promote cardiovascular health (Barton *et al.*, 2011). This suggested that the intervention represented value for money, but was based on a small sample and therefore may not be reliable. Much of the relevant literature comes from North America, where health improvement programmes that rely on lay<sup>1</sup> health workers (LHWs) have become increasingly common since the 1970s (Lowe, Barg & Stephens, 1998; Earp & Flax, 1999; Visram & Drinkwater, 2005). There is limited evidence to support the belief that LHW programmes can be more successful than professional-led interventions, particularly in increasing access to care amongst so-called 'hard-to-reach' populations (Swider, 2002; Andrews *et al.*, 2004). Recent systematic reviews have found promising benefits in the use of LHWs to improve outcomes for selected conditions (Lewin *et al.*, 2005; Viswanathan *et al.*, 2009; Carr *et al.*, 2011). However, insufficient evidence exists to assess which LHW strategies are likely to be most effective, largely due to varied and inadequate reporting on the intervention components. There is a growing body of literature focusing on the experiences of lay workers (Booker *et al.*, 1997; Dickson-Gomez, Knowlton & Latkin, 2003; Struthers *et al.*, 2003; Racz & Lacko, 2008). These studies tend to be based in specific cultural contexts and therefore may not be transferable to a UK context. There is a need for further research to explore in-depth the views and experiences of lay workers and service users, as well as examining the intervention components.

## **Rationale for the study**

In spite of the lack of evidence, lay-led interventions are becoming increasingly important in healthcare environments that are challenged by limited financial and human resources (Murphy, 2007). These interventions have the potential to address key issues such as the need to care cost-effectively for expanding populations with chronic illness, enhance the equity of service provision and ensure compliance with treatments (Lorig, 2002; Donaldson, 2003). However, there is a risk that introducing

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<sup>1</sup> For the purpose of this thesis, the term 'lay' is used to refer to any person recruited into a particular role without necessarily having a professional background or formal qualifications pertaining to that role.

roles such as health trainers could weaken the public health workforce by creating another professional grouping to be developed and managed in an already complex system (UKPHA, 2005). My previous experience in conducting evaluations of local health trainer services has demonstrated a high level of uncertainty amongst service providers and concern about the future direction of the initiative (Visram *et al.*, 2006; Visram & Geddes, 2007). However, it provides an opportunity to explore the complexity of introducing a new role in the NHS and to enhance our understanding of the needs of 'hard-to-reach' groups in order to inform the development of tailored health improvement interventions. Any evaluation of these interventions needs to be balanced between an outcomes-based approach that measures lifestyle changes and a qualitative approach that examines the processes of engagement, quality of the interactions, and user satisfaction (Nutbeam, 1998; MRC, 2008). The impact on health trainers, service users and local communities are all recognised as key outcomes of the overall initiative (Department of Health, 2007).

In conducting a review of the existing evidence to support the implementation of health trainers, I identified various lay-led intervention models (Visram & Drinkwater, 2005). These were classified in two ways, according to whether they: 1) addressed generic health issues in the local population or focused on a specific target group; and 2) offered the intervention at a one-to-one or community level. This resulted in four broad service delivery models, which were used to categorise local health trainer services in a national activity report commissioned by the Department of Health (Wilkinson *et al.*, 2007). The report found that almost half of respondents saw themselves as taking a predominantly 'targeted individual' approach, while 13 per cent chose 'generic individual' and the remaining 16 per cent were either 'targeted community' or 'generic community'. These data demonstrate the level of heterogeneity within the NHS Health Trainers Initiative. The components of the various delivery models need to be clearly described and there needs to be an understanding of the underlying mechanisms by which they influence outcomes, before a definitive outcome evaluation can be conducted. This process is consistent with the Medical Research Council (MRC) framework for the evaluation of complex interventions (Craig *et al.*, 2008; MRC, 2008). The study described here is one component of a wider research programme concerning health trainers and other lay public health roles in the UK<sup>2</sup>. Given the increasing interest in this area and the

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<sup>2</sup> This body of work includes: an evidence synthesis to explore different versions of the health-related lifestyle adviser format led by Professor Susan Carr at Northumbria University; a large-scale exploration of lay roles in public health led by Professor Jane South at Leeds Metropolitan University; a national evaluation of health trainers led by Professor

opportunity it offers to address health inequalities, it is timely to conduct an in-depth qualitative study to further define the intervention and develop a detailed understanding of its processes and mechanisms.

## **Research aims**

This research attempts to address some of the gaps in the existing literature by generating knowledge and understanding of a UK-based lay health worker role and its perceived impact on individuals and communities. The initial aim of the study was to enhance understanding of the issues of user engagement and health behaviour change in the NHS Health Trainers Initiative. Over time, this was clarified and developed into two separate but closely linked aims:

1. To explore the processes involved in attempting to make and maintain health-related behaviour changes from the perspectives of people living in socio-economically disadvantaged areas; and
2. To qualitatively evaluate the contribution of local variations on the NHS health trainer role to supporting people in these attempts

The study aims were met by conducting a longitudinal, qualitative comparison of individual- and community-level approaches to local health trainer service provision. The detailed study objectives are set out in Chapter 4.

## **Structure of the thesis**

The purpose of this chapter has been to introduce the concept of health trainers and provide background information on the role, as well as setting out the rationale and aims of the study. The main body of the thesis commences with Section A, which incorporates the background to the study (Chapter 2) and an extensive review of the existing research literature relating to lay-led health improvement interventions (Chapter 3). Chapter 2 (Historical and theoretical context) begins with a description of contemporary public health practice in the UK, informed by historical and policy perspectives. Each core element of the health trainer role is then considered in turn, before I provide an overview of lay health worker models, their epistemological basis and the likely contribution to a reduction in health inequalities.

Chapter 3 (Review of the research literature) draws on published and unpublished literature to examine the evidence base for health trainers and similar lay-led health improvement interventions. The chapter begins with an overview of the strategies used to locate papers for inclusion in the review, which are then critically discussed under the following headings: evidence of intervention effects; qualitative research findings; and evaluations of local health trainer programmes. This review identified a paucity of literature specifically on the components of interventions delivered by health trainers in the UK and, more generally, a gap in the evidence regarding the service user experience.

Section B sets out the main features of the underlying research paradigm for this study (Chapter 4) and the processes involved in data construction (Chapter 5). The research aims and objectives are set out in Chapter 4 (Philosophical and methodological approach), followed by a summary of the research methodology and my justification for selecting this approach. A grounded theory approach has been used, informed by subtle realist and symbolic interactionist perspectives. This enabled me to explore the experiences of people attempting to make health-related behaviour changes within the context of their everyday lives and social interactions. The use of a longitudinal qualitative approach allowed for fuller exploration of the dynamic behaviour change process.

Chapter 5 (Data construction) provides a detailed description of the way in which data were constructed using the qualitative, interpretivist approach. An account of the way in which the research sites were selected and then approached is provided here, including the barriers and enablers to this process. Issues such as ethics and governance, maintaining research relationships and researcher reflexivity are discussed. The implications of choosing to conduct one-to-one interviews and observations in naturalistic settings are highlighted. Techniques associated with grounded theory, including theoretical sampling and the constant comparative approach, were used to enhance the rigour and credibility of the study, in conjunction with NVivo 8 qualitative analysis software.

Section C begins with a summary of the data analyses, including diagrams produced during the processes of axial and selective coding. The study findings are then presented in Chapters 6 to 8, organised around the emergent theoretical framework derived from the data. Chapter 6 (Contextualising behaviour and behaviour change) involves exploring the way in which personal, biographical and

contextual factors contribute to the development of 'unhealthy' behaviours. Chapter 7 (Personalised intervention models) provides an overview of the health trainer delivery models and the components of their interventions. Chapter 8 (Outcomes and impact) considers the impact of these interventions in terms of knowledge gains, individual behaviour changes, health improvements, psychosocial outcomes, and organisational outcomes.

Chapter 9 (Discussion) provides a summary and interpretation of the study findings, before I go on to discuss the strengths and limitations of the research in order to provide justification for my claims of making a contribution to knowledge. I also present my reflections on the process of designing and conducting the research. A series of implications for theory, practice, commissioning and policy-making are then set out, as well as potential areas for future research. The integrated theory discussed in this final chapter (based on the categories of contextualising, personalising and reciprocating) adds to existing evidence and theory in relation to working with people from 'hard-to-reach' communities and motivating them to adopt healthier lifestyles using lay- or peer-based approaches. The chapter ends with concluding remarks which draw together the main argument of the thesis.

These nine chapters form the main body of the thesis, which is then followed by a series of appendices and a full bibliography.

## Section A: Background and literature review

This section begins with an exploration of key concepts underpinning the NHS Health Trainers Initiative, which constitute the conceptual framework used to support and inform the research process. Conceptual frameworks provide a structure for linking the theoretical elements – that is, the concepts, assumptions and expectations – that describe, explain or predict the phenomenon under study (Robson, 2002; Maxwell, 2005). Although the NHS Health Trainers Initiative is a largely atheoretical phenomenon, it comprises interventions that have some grounding in the theoretical and empirical literature. For example, the training for health trainers draws on the extensive literature from health psychology that provides models for understanding behaviour and behaviour change. It also makes reference to the literature on community capacity building, lay health worker models and reducing health inequalities. Core constructs underpinning the initiative are shown in figure 2, organised using the PICO (Population, Intervention, Comparison, Outcome) approach. This is a commonly used method for undertaking a systematic approach to literature searching (Sayers, 2008).

**Figure 2: PICO framework of concepts underpinning the study**

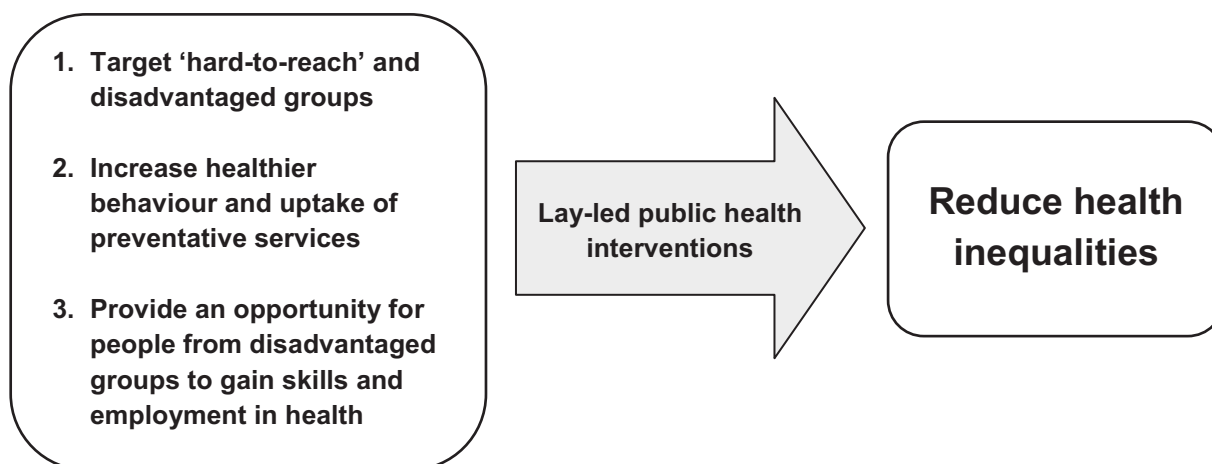
Population	Intervention	Comparator	Outcome
<ul style="list-style-type: none"><li>• Hard-to-reach' disadvantaged and excluded groups</li><li>• General population</li></ul>	<ul style="list-style-type: none"><li>• Health trainers and other lay workers</li><li>• Individual behaviour change strategies</li><li>• Community capacity building</li></ul>	<ul style="list-style-type: none"><li>• Interventions delivered by professionals</li><li>• Alternative health resources, e.g. written or web-based information</li></ul>	<ul style="list-style-type: none"><li>• Behaviour change</li><li>• Improvements in individual physical and mental health</li><li>• Reduction in health inequalities</li></ul>

Chapter 2 details existing knowledge regarding the populations targeted by health trainers and the interventions they deliver, as well as providing an overview of UK public health policy and practice. In Chapter 3, I go on to review the empirical literature regarding the outcomes of lay-led health improvement interventions and identify gaps in the evidence base. The purpose of this section is to establish the boundaries of the study and make explicit the concepts 'borrowed' from the research literature that have been used to inform the study aim and objectives (Charmaz, 2003).

## Chapter 2: Historical and theoretical context

The *Choosing Health* white paper and subsequent guidance relating to the implementation, delivery and monitoring of health trainers suggest that there are three core elements of the role (Department of Health, 2004; 2005a; 2007). Figure 3 illustrates the way in which the role encompasses more than the delivery of basic advice and support. The guidance states that, “In targeting those people who would like to change behaviours relevant to their health, and have previously been hard-to-reach via other services, the health trainer has the potential to reduce inequalities” (Michie *et al.*, 2008, p.4). This work is undertaken within the context of rapidly changing health and social environments, alongside other initiatives to reduce inequalities and improve population health. The chapter begins with an overview of contemporary public health practice in the UK, informed by historical and policy perspectives. Each element of the health trainer role is then considered in turn, before I introduce the epistemological basis of the role and the challenges and opportunities this creates within the context of professional-led health services. The chapter ends with a description of similar lay worker roles and an exploration of the likely contribution to a reduction in health inequalities.

**Figure 3: Key aims of the health trainer role** (Wilkinson *et al.*, 2007)



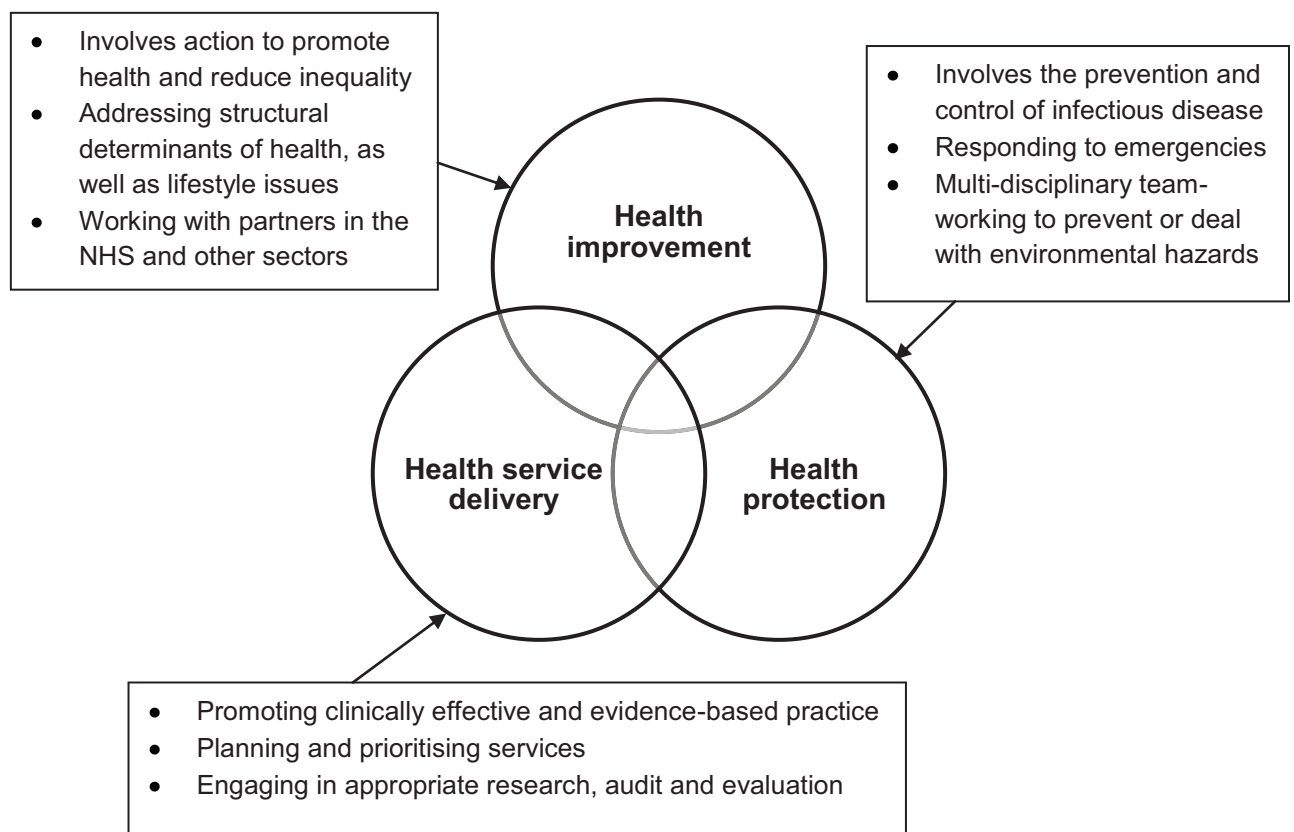
### Public health in the UK

Public health is a broad concept that can be defined in many different ways. Following the work of C-E. A. Winslow in 1920, it is frequently referred to as, “The science and art of preventing disease, prolonging life and promoting health by the organised efforts of society” (Acheson, 1998). This definition locates disease



prevention and health promotion under the umbrella of public health, with these three fields being closely linked but not synonymous with one another. Health promotion is defined more specifically as, “The process of enabling people to increase control over, and to improve, their health”, although this term has gradually been disappearing from the public health discourse in the UK (World Health Organisation, 1986; Tones, 1990; Scott-Samuel & Springett, 2007). ‘Health improvement’ now tends to be the preferred term, suggesting a shift away from individual-focused health education to more population-based approaches. Along with health protection and health service delivery, it constitutes the model of public health practice favoured by the UK Faculty of Public Health (2010). See figure 4 for an illustration of the model, which conceptualises the public health system as comprised of three separate but overlapping domains.

**Figure 4: Three domains of public health** (Griffiths, Jewell & Donnelly, 2005)



This model locates action to address the structural determinants of health and lifestyle issues within the health improvement domain. There has been growing

recognition of the importance of these issues in the fields of public health practice and theory, although they have a long history (Orme *et al.*, 2007). A focus on the contribution of socio-ecological factors to health and wellbeing began with the essays of Hippocrates on the influence of climate, water and situation on health and continued throughout the centuries. However, with the development of germ theory in the 1800s and subsequent emergence of bacteriology and epidemiology, Western civilisations have observed increasing medicalisation of health (Szreter, 1988; Kessel, 2006). Following its inception in 1948, the National Health Service (NHS) gradually developed a monopoly over public health and an increasing focus on technological and curative fixes for illness. The World Health Organisation (WHO) played an influential role in broadening the concept of health, but their holistic perspective was initially understood only in relation to societies without access to technologically advanced medical systems (Orme *et al.*, 2007). It was not until the end of the twentieth century, following the publication of the Black Report, that the UK saw a gradual acceptance that the weight of scientific evidence supports a socioeconomic explanation of health inequalities (Black, 1980). A broader ecological perspective emerged and was reinforced by the WHO's 'Health for All' strategy and the Ottawa Charter (World Health Organisation, 1985; 1986; Scott-Samuel & Springett, 2007). These global developments were accompanied by a range of health-promoting initiatives and policy drivers in the UK.

### ***Global and national policy developments***

Table 1 on the following page summarises relevant UK public health policies and strategies implemented over recent decades (Hunter, 2007, p.26-7). This begins with the Black Report, which suggested that economic inequality was the most likely explanation for the observed widening of health inequalities (Black, 1980). Although these analyses had a major impact on subsequent research, the direct policy impact at the time was non-existent as a result of the Conservative government's attempts to suppress dissemination of the findings (MacIntyre, 1997). It was not until the election of a Labour government in 1997 that public health experienced a renaissance, enacted in the appointment of the first ever Minister for Public Health (Hunter, 2007). The Minister began by initiating an independent inquiry into health inequalities, followed by a new white paper and several large-scale initiatives such as the New Deal for Communities, Neighbourhood Renewal and Sure Start programme (Acheson, 1998; Department of Health, 1999; Hunter, 2007). The first UK health inequalities targets were set in 2001, focusing on reducing the gap in infant mortality and life expectancy at birth by 2010. A health inequalities strategy

update, produced ten years after the publication of the Acheson Report, identified significant improvements in population health and a fall in infant mortality rates to historically low levels (Department of Health, 2009c). However, it also highlighted persistent inequalities and slower improvements in disadvantaged areas.

**Table 1: Key policies and strategies in UK public health**

1980	The Black Report demonstrates the continuing presence of health inequalities in the UK
1984	The <i>Health for All by the Year 2000</i> initiative is launched and serves as a focal point for health strategy for the WHO and its member states
1986	The Ottawa Charter for Health Promotion sets out a number of prerequisites for health, emphasising the importance of employing a holistic understanding
1987	The Whitehead Report sought to update the Black Report, reviewing progress towards achieving the recommendations and examining possibilities for the future
1988	Acheson's first report on public health in England employed a broader definition of the field, acknowledging its complex and contested nature
1992	<i>The Health of the Nation: A Strategy for England</i> white paper is published, setting out a national framework for achieving health gains in five priority areas
1998	Acheson's second report, <i>An Independent Inquiry into Inequalities in Health</i> , summarises the evidence on inequalities in health and life expectancy
1999	<i>Saving Lives: Our Healthier Nation</i> outlines the Government's action plan to improve the health of the population in general, and the worst off in particular
2000	The NHS Plan is published and attracts criticism for its lack of focus on public health
2002	Wanless publishes his first report on future health trends, supporting public health action to bring health and economic benefits <i>Tackling Health Inequalities</i> is published on the action needed
2004	The second Wanless Report is published on the state of public health and calls for greater investment in evidence-based interventions to demonstrate cost-effectiveness A new health strategy for England, <i>Choosing Health: making healthy choices easier</i> , is published and marks a shift in the role of government
2006	The <i>Our Health, Our Care, Our Say</i> white paper emphasises the need to shift the focus of care from acute to primary and community settings, placing more attention on long-term conditions and public health
2010	The Marmot strategic review of health inequalities in the UK, <i>Fair Society, Healthy Lives</i> , proposes the most effective evidence-based strategies for reducing health inequalities The coalition government publishes <i>Healthy Lives, Healthy People</i> , which sets out the long-term vision for public health in England

Public health moved further up the Labour government's agenda after an economic analysis forecasted the growing burden of ill-health on the Treasury and on the quality of life of the UK population by 2020 (Wanless, 2002; 2004). The government built on the Wanless Report's vision of a 'fully engaged scenario' in the publication of its second white paper, *Choosing Health: making healthy choices easier*, which introduced the health trainer role (Department of Health, 2004; 2005a). A third white paper, *Our Health, Our Care, Our Say*, briefly mentioned health trainers in the context of NHS 'Life Checks'<sup>3</sup> (Department of Health, 2006). However, they did not appear in *Healthy Lives, Healthy People*, the first white paper to be published by the coalition government (Department of Health, 2010b). This document sought to focus health efforts on the causes rather than treatment of ill-health, but the emphasis remained largely on the influence of individual lifestyle factors. These policy developments represent a fundamental shift from short-term reactive perspectives about illness to a long-term proactive policy about health, but fail to resolve philosophical tensions between individual freedom and state intervention (McKee & Raine, 2005). The individualistic lifestyle approach resonates with the ideology of neo-liberalism, which largely ignores the potential for choices to be manipulated, conditioned or determined by an individual's social location or by inequalities in social structure (Germov & Williams, 1996). There has subsequently been a call for a sense of proportion between a focus on individual behavioural factors and the societal, systemic and structural determinants of health and wellbeing (Popay *et al.*, 2007b; Chan, 2009). The concept of being able to 'nudge' people towards changing their behaviour by modifying the social or physical environment has also generated a great deal of interest (Thaler & Sunstein, 2009; Marteau *et al.*, 2011).

### Core elements of the health trainer role

With its dual aims of supporting individuals to adopt healthy lifestyles and tackling wider issues such as unemployment and social exclusion, the NHS Health Trainers Initiative is at the forefront of recent developments. In the remainder of this chapter, I set out the theory and evidence underpinning core elements of the health trainer role and similar peer- or lay-led intervention models. An ongoing debate in public

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<sup>3</sup> NHS 'Life Checks' are interactive questionnaires designed to help people to assess and manage their own health at major life stages, e.g. parents and carers of babies aged between five to eight months (Early Life Check), young people aged 12 to 15 years (Teen Life Check) and people aged between 45 and 60 years (Mid-Life Life Check). The 2006 white paper stated that health trainers would be available to discuss the outcomes of the Life Check, explore action to improve health, and signpost or refer into other services.

health centres on whether the focus of action should be the whole social gradient or specific marginalised groups and individuals within the population (Marmot *et al.*, 2008; Rose, Khaw & Marmot, 2008; Whitehead & Popay, 2010). The contribution of health trainers to this debate is discussed below.

### ***Targeting hard-to-reach groups***

It is implicit within *Choosing Health* – and made explicit in subsequent guidance – that health trainers will target so-called ‘hard-to-reach’ groups (Department of Health, 2004; Michie *et al.*, 2008). In a public health context, this label is used in relation to people who are difficult to contact, fail to access appropriate services or do not follow health recommendations (Brackertz, 2007). Other terms that are often used synonymously with ‘hard-to-reach’ include disadvantaged, excluded, marginalised and health illiterate. These labels have negative connotations and tend to define the problem as one within the group itself, rather than resulting from wider organisational, social and economic conditions. They also imply a homogeneity that may not exist in reality. Members of hard-to-reach populations are unlikely to identify themselves in this way, although they tend to share features such as poor health and educational outcomes (Freimuth & Mettger, 1990; Brackertz, 2007). Individuals from low socioeconomic status (SES) backgrounds and minority ethnic groups tend to be over-represented in these populations. Rather than making themselves hard-to-reach, they might be better described as underserved by services that are either inaccessible or inappropriate in terms of meeting their needs (Eng, Parker & Harlan, 1997; Brackertz, 2007). Disengagement often results either from ‘rational apathy’ or because individuals face a number of disadvantages and barriers to participation (Zwart, Brackertz & Meredyth, 2005). This sense of feeling disillusioned or disconnected from services provides the rationale for the attention devoted to these groups in recent health and social policy.

Inequities in access to, uptake of and outcomes from health interventions play an important role in the creation and maintenance of health inequalities, referred to as intervention-generated inequalities (IGIs) (White, Adams & Heywood, 2009). It has been suggested that there exists an ‘inverse prevention law’ due to preferential uptake of some interventions by more affluent groups, contributing to a widening of the inequalities gap (Acheson, 1998; White, Adams & Heywood, 2009). Examples include the promotion of immunisation, breastfeeding and smoking cessation programmes involving education. The concept of IGIs has been used to provide

impetus to the argument for targeting interventions in an attempt to mitigate against the increasing marginalisation of hard-to-reach groups (Eng, Parker & Harlan, 1997; Adshead & Thorpe, 2009). A focus on those identified as being 'at risk' from a particular health condition can help to ensure that patients are motivated to complete the intervention and have the support of their physician. However, it can be difficult and costly to identify high-risk individuals, and interventions based on this approach have limited utility at the population level (Doyle, Furey & Flowers, 2006). They also require that specific groups are identified as 'deviant', whereas most health risks are distributed across a continuum. Rose argued for a shift from an emphasis on sick individuals to 'sick populations', with the use of strategies to change social norms and address the root causes of ill-health (Rose, 2001; Rose, Khaw & Marmot, 2008). This radical approach has the potential to shift the whole distribution of exposure, resulting in large reductions in risk and adverse health outcomes. However, Rose's argument has attracted a number of criticisms (Charlton, 1995; Adams & White, 2005).

The 'sick populations' approach is not easy to enact due to threats to compliance resulting from the low benefit-to-risk ratio. Rose termed this the prevention paradox, in recognition that public health measures offering large benefits to populations will often have little or no benefit to individual population members (and may involve significant costs) (Hunt & Emslie, 2001; Rose, Khaw & Marmot, 2008). There is also a need to balance health improvement against principles such as justice, freedom and happiness, and avoid the 'medicalisation of human life' (Charlton, 1995). Charlton argued that Rose's hypothesis was based on bad science, as well as having the potential to increase inequalities for the reasons outlined above. However, it is possible for population-level interventions to favour deprived rather than affluent individuals and thereby reduce inequalities; for example, the effect of water fluoridation on child dental health and the impact of price increases on cigarette smoking (White, Adams & Heywood, 2009). Strategies that use regulation or incentives may be particularly successful but raise a series of ethical dilemmas relating to coercion, informed choice and stigmatisation, as well as lacking a robust evidence base. Reviews of the literature on the use of financial incentives have found that any positive effects tend to be small and dissipate over time (Paul-Ebhohimhen & Avenell, 2007; Cahill & Perera, 2008). These programmes are also administratively costly and difficult to target (Popay, 2008).



### ***Facilitating health behaviour change***

Public health policy in the UK continues to favour interventions that rely on voluntary behaviour change, such as those delivered by health trainers. The health trainer handbook<sup>4</sup> states that the role involves “training people in skills to... manage their own behaviour” using techniques based on evidence and theory from health psychology (Michie *et al.*, 2008, p.4). Effective behaviour change is known to be goal-driven and so health trainers receive training to support others to set achievable goals and make concrete plans to reduce the discrepancy between current and goal-related behaviours (Shilts, Horowitz & Townsend, 2004; Abraham & Michie, 2008). These ideas are underpinned by the theory of planned behaviour and implementation intentions theory (Ajzen, 1985; Gollwitzer, 1999). Setting and achieving ‘mini goals’, coupled with the use of self-monitoring techniques, also helps to improve confidence by providing markers of increasing mastery (Phillips & Gully, 1997; Michie *et al.*, 2009a; Michie *et al.*, 2009b). This may be particularly important in interventions targeting disadvantaged groups, who often experience a lack of control over their circumstances and have a lower confidence and skill base (Michie *et al.*, 2009b). The theoretical basis of these ideas comes from control theory and self-regulation theory, which involve comparing performance to a set standard and reinforcing positive behaviours (Skinner, 1969; Carver & Scheier, 1998).

Several authors have emphasised the importance of devising behaviour change interventions that are theory-driven, rather than based on ‘common sense’ or ideology (Tones, 1990; VanRyn & Heaney, 1992; Rutter & Quine, 2002; Craig *et al.*, 2008). For example, a systematic review of the literature on interventions to reduce HIV risk identified that all of the studies with good evidence of effectiveness were based on at least one behaviour change theory (Lyles *et al.*, 2007). The main theories and models used in health promotion are summarised in table 2 on the following page. Some – including control theory and cognitive dissonance theory – are based on abstract or psychological constructs that are difficult to measure and predict. Others – such as the health belief model and social comparison theory – are concerned primarily with the determinants of behaviour rather than behaviour change. The trans-theoretical model is used in the training for health trainers in terms of understanding concepts such as readiness to change, the importance of allowing for setbacks, and treating behaviour change as a process rather than a discrete event (Prochaska & DiClemente, 1986). However, there is limited evidence

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<sup>4</sup> This handbook was developed for the Department of Health by the British Psychological Society (BPS) Health Psychology Team and is used in the training for health trainers. It provides a number of evidence-based techniques and resources for behaviour change.



for its effectiveness as a model for behaviour change and, in particular, linear progress through the stages is not supported. Individual-focused theories tend to neglect factors such as the influence of the material and social world on behaviour. Social cognitive theory explains behaviour change as the continual interaction of personal cognitive factors, behaviour and environmental influences in a process of reciprocal determinism or causality (Bandura, 1998; 2004). This inter-personal approach introduced the concepts of modelled behaviour and vicarious reinforcement, which form the basis of the health trainer role.

**Table 2: Key theoretical approaches to understanding and changing health-related behaviour**

Level	Theory	Focus	Key Constructs
Individual	Operant control theory (Skinner, 1969)	Learning through rewards and punishments for behaviour	Antecedent behaviours Target behaviours Reinforcing behaviours Consequences
	Self-regulation theory (Carver & Scheier, 1998)	The negative feedback loop represents the fundamental unit of human action and motivation	Goal setting, prioritisation Self-regulation Barriers to action Relapse
	Cognitive dissonance theory (Festinger, 1957)	Focuses on the consonance between thought and action Disrupted equilibrium causes discomfort and anxiety	Cognition Conflict Consonance Dissonance
	Health belief model (Rosenstock, 1974)	Perception of threat of health problem Appraisal of recommended behaviour(s) for preventing or managing the problem	Perceived susceptibility Perceived severity Cues to action Perceived benefits Barriers to action
	Information-motivation-behavioural skills model (Fisher & Fisher, 2002)	Must have information that will translate easily into action, plus motivation and skills to act	Information Motivation Skills
	Locus of control (Wallston <i>et al.</i> , 1976)	Belief that events result primarily from behaviour or actions, as opposed to fate, chance or actions of others	Expectancy Health internals/externals Powerful others Reinforcement

*Chapter 2: Historical and theoretical context*

	Trans-theoretical model (Prochaska & DiClemente, 1986)	Individual's readiness to change or attempt to change toward healthy behaviours	Pre-contemplation Contemplation Decision and planning Action Maintenance or relapse
	Theory of planned behaviour (Ajzen, 2002)	Emphasises behavioural intentions as the outcome of a combination of beliefs (logic)	Intention Attitude towards behaviour Subjective norms Outcome expectancy Perceived control
	Implementation Intentions (Gollwitzer, 1999)	Forming intentions to respond to future cues can facilitate habit formation	Plans Cues to action Repetition of behaviour Habitual action
<b>Interpersonal</b>	Social comparison theory (Festinger, 1954)	Individuals evaluate their own attitudes and behaviours in comparison to others	Comparison Significant others Evaluation of attitudes and abilities
	Social cognitive theory (Bandura, 1998)	Interaction of personal factors, environmental influences and behaviour	Behavioural capability Reciprocal determinism Outcome expectations Self-efficacy Observational learning Reinforcement
	Social network and social support theories (Caplan, 1974)	Behaviour change depends on level of participation and sense of ownership	Social capital Types of support: emotional, informational, instrumental and appraisal
<b>Community</b>	Communication theory (Foulger, 2004)	The receipt of information is influenced by the quality and concentration of the message, as well as the relationship with the messenger	Quality of information Comprehension Interpretation Messenger role
	Community organisation theories (Rothman & Tropman, 1987)	Emphasise active participation and development of communities that can better evaluate and solve health and social problems	Empowerment Community competence Participation Relevance of issue Critical consciousness
	Diffusion of innovations theory (Rogers & Shoemaker, 1971)	How new ideas, products and practices spread within and between groups or societies	Relative advantage Compatibility Complexity Triability Observability
	Social marketing (Kotler, Roberto & Lee, 2002)	Behaviour changed with the use of strategies adopted from commercial marketing	(Social) goal setting Audience segmentation The four Ps: price, product, place, promotion

The limited success of many lifestyle interventions is often attributed, at least in part, to a failure to take into account the theories and principles underlying behaviour. However, where studies report a lack of effect, this may be due to implementation failure rather than genuine ineffectiveness, highlighting the need for process evaluation alongside formal outcome evaluation (Craig *et al.*, 2008). For example, a randomised trial of a theory-based intervention to increase physical activity amongst adults at risk of type 2 diabetes found that the intervention was no more effective than provision of an advice leaflet (Kinmouth *et al.*, 2008). However, the researchers were able to demonstrate the acceptability and feasibility of the intervention, and small-to-moderate positive effects across all groups suggest that study participation was the key factor. Reviews and analyses have demonstrated a high degree of heterogeneity in intervention content and design, with many studies failing to report the inclusion of theory-derived techniques (Sibley & Abraham, 2008; Michie *et al.*, 2009a; Michie *et al.*, 2009b; Gardner *et al.*, 2010).

In the interests of devising evidence-based strategies, the National Institute of Health and Clinical Excellence (NICE) advise that providers should be as specific as possible about the content of an intervention and the theories that will make explicit the causal links between actions and outcomes (NICE, 2007). This information is needed to provide a theoretical understanding of precisely how complex interventions cause change and which techniques or components are most effective (Craig *et al.*, 2008). The various theories are generally used in isolation and have not been tested against one another; therefore it is not known which has the greatest potential to maximise behaviour change (Aunger & Curtis, 2007). A potential solution involves theory consolidation, which Michie *et al.* (2005) achieved by working with health psychologists and practitioners to agree a set of key constructs for use in evidence-based practice. They reduced 20 types of behaviour change theory to 12 domains, which are shown in figure 5 on the following page.

**Figure 5: Theoretical domains for evidence-based practice in behaviour change** (Michie *et al.*, 2005)



There is a growing body of evidence to demonstrate that these techniques can be effective when delivered by appropriately skilled individuals. A meta-analysis comparing experts, lay community members and others as ‘agents of change’ confirmed the hypothesis that demographic and behavioural similarity between the intervention provider and recipient facilitated change (Durantini *et al.*, 2006). However, the effects were greatest in the case of interventions delivered by experts. This is supported by communication theory, which suggests that people are more likely to adopt innovations or practices if they are delivered by someone similar to the audience but with greater prestige, and reinforced by peer pressure and support (Foulger, 2004). Using the terminology of diffusion of innovations theory, the health trainers become ‘early adopters’ who are influential in encouraging others to adopt new practices. They also employ approaches based on social network and community organisation theories to engage and work with local people in defining the issues that they feel are important. Community-level interventions may be less intense than individual interventions but they have the potential to reach more people, making them potentially more sustainable and cost-effective in the long-

term (Ory, Jordan & Bazzarre, 2002). However, the tendency to evaluate health outcomes at a population level makes it difficult to assess the links between specific intervention components and individual behaviours (Aunger & Curtis, 2007). Furthermore, reliance on structural theories alone implies an overly passive view of people and assumes the individual has little power over their health (Popay *et al.*, 2007a). This supports the case for multi-level interventions that include an integration of individual, inter-personal, organisational and community systems in an attempt to avoid deterministic approaches (Kelly, Charlton & Hanlon, 1993).

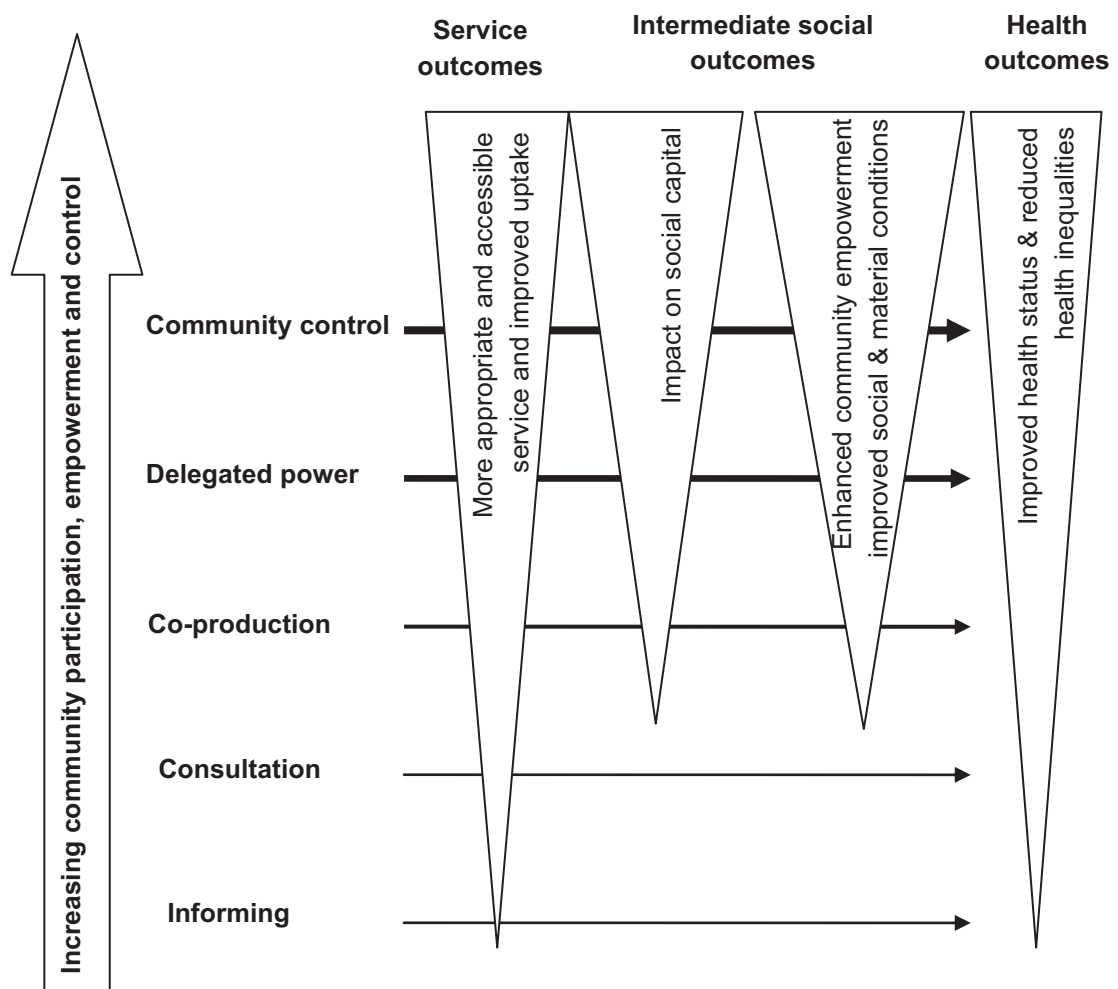
### **Community engagement and capacity building**

The final element of the health trainer role involves building capacity within local communities. Much like the 'hard-to-reach' label, 'community' is a broad and value-laden term that is given a variety of context-specific meanings (Hoggett, 1997; Parker *et al.*, 1999; Smith, 2001). It is rarely defined explicitly in the health literature but the implicit definition is of a "locality-bound aggregation of people who share economic, socio-cultural and political characteristics, as well as problems and needs" (Jewkes & Murcott, 1996, p.558). The symbolic aspect of community plays a crucial role in generating a sense of belonging and has a number of health and social implications (Smith, 2001). For example, one study recorded lower levels of smoking in men and women who were most actively engaged in community life, whilst another found that those with more than two close relatives or friends living nearby were less likely to suffer from stress and reported better physical and mental health (Cooper *et al.*, 1999; Hunter & Taylor, 2005). These benefits are often attributed to the concept of social capital, which is defined as the norms of reciprocity and trust arising from the networks or connections between individuals (Putnam, 2000). High levels of trust and density of group membership have been shown to be associated with reduced mortality, whereas low social support and high social dysfunction may contribute to increased morbidity (Morgan & Swann, 2004).

Measuring social capital is problematic and the evidence for the underlying mechanisms is ambiguous, with socioeconomic status a likely confounding factor (Adams & White, 2003; Doyle, Furey & Flowers, 2006). Furthermore, there has been little consideration of the variation in sense of attachment and experience of belonging between and within communities (Muntaner, Lynch & Smith, 2001; Smith, 2001). In spite of this, recent global and national policy initiatives have recognised the influence of social networks, community cohesion and internal resilience on

health, as well as encouraging community participation as an end in itself. In Britain, these efforts form part of the Big Society policy idea to encourage people living in local communities to take control over their own lives (Conservative Party, 2010). The underlying assumption is that bringing people together around a common cause will subsequently empower them and help to build social cohesion. However, some communities and community members will be better equipped to take advantage of these opportunities than others, particularly those in more affluent areas. Increasing community capacity to address the barriers to participation has been described as an objective that is as important as improving health status itself (Parker *et al.*, 1999). The NICE guidance on community engagement provides a theoretical framework to demonstrate the ways in which participation might directly or indirectly affect health in the short- and long-term (NICE, 2008). See figure 6 for an illustration. One of the recommendations from NICE is that community members should be recruited to assist in addressing the wider determinants of health, as well as gaining new skills and enhancing their employability.

**Figure 6: Pathways from participation to health improvement (Popay, 2010)**



There are clear policy imperatives for providing training and employment opportunities for people living in areas that tend to be characterised by high levels of unemployment and reliance on state benefits. This contributes to government strategy on social exclusion and worklessness by targeting those who tend to be left out of mainstream action on health or who have lost confidence in their ability to find employment (DWP, 2010; Parekh, McInnes & Kenway, 2010). Creating suitable jobs for the unemployed or under-employed can impact directly on their income, skills and personal satisfaction levels, as well as having an indirect impact on their health and that of their families (Doyle *et al.*, 2005; Dorling, 2009). Hence, one of the aims of the NHS Health Trainers Initiative is to provide opportunities for people from disadvantaged areas to obtain skills and employment in health (Department of Health, 2005a). Health trainers and other paraprofessionals are likely to play an increasingly important role in health services that are challenged by limited financial and human resources. However, concerns have been raised about the hidden costs associated with coordination, training and supervision for these new roles (Duckett, 2005). It has also been suggested that the substitution of health professionals with unregulated workers might lead to reductions in the quality of care, although this is likely to be influenced by fears about risks to the job security, income and status (Murphy, 2007). These tensions are discussed further in the section below.

### **Lay-led health interventions**

In recent decades, fundamental shifts in the organisation and delivery of health care have impacted on the relationships between practitioners and patients or service users. Contemporary western societies are characterised by populations with increased knowledge of medical terminology and easier access to information via the internet, coupled with a high chronic disease burden and a growing emphasis on the role of behavioural factors in health (Kangas, 2002; Department of Health, 2004). The current policy rhetoric suggests that this situation creates the ideal conditions for partnership-working between health services and the public (Department of Health, 2004; 2010b). However, there is concern that paternalism within the NHS remains a barrier to meaningful doctor-patient partnerships (Coulter, 1999; Fox, Ward & O'Rourke, 2005; Crinson, 2008). By virtue of their lay status, patients have traditionally been deemed unable to judge doctors' technical competence and are thus caught in an unusual circumstance of social exchange without the tools to judge the appropriateness or value of the other person's actions (Roter & Hall, 1991; Gabe, Kelleher & Williams, 1996). Role theory states that the



resolution of this situation involves suspension of the patient's judgement of value, which is seen as warranted because professional norms guiding doctors' behaviour oblige them to act in their patients' best interest (Parsons, 1951). However, there is sufficient scepticism amongst the general public to suggest that patients do not take on a wholly passive role. Tensions arise from the power imbalance created by the perceived competence gap and social distance between patients and health professionals (Stimson & Webb, 1975; Pappas, 1990).

There has been growing acknowledgement of patients as experts in their own lives, illnesses and preferences (Coulter, 1999; Fox, Ward & O'Rourke, 2005).

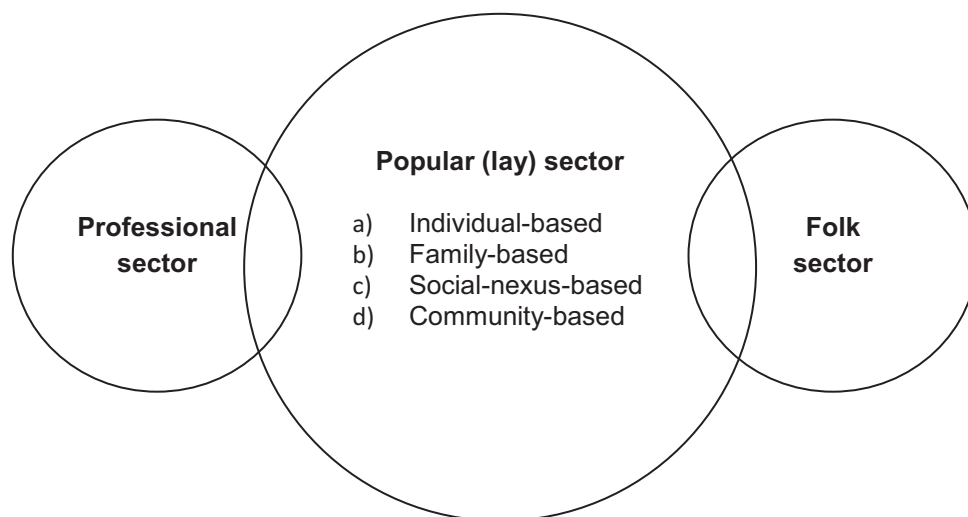
Recognition of lay knowledge as a 'privileged' form of expertise about health contributes to the transformation from paternalistic, professional-led interactions to partnership models of care. This was expressed in the *Choosing Health* white paper as a shift in public health approaches from "advice on high to support from next door" (Department of Health, 2004, p.106). At the same time it must be recognised that lay expertise poses an epistemological and political challenge to the institutional power of professional knowledge (Popay *et al.*, 1998; Bury, 2004; Popay, 2006). Hence, moves towards greater involvement and autonomy for patients and the general public have been met with scepticism, anxiety and resistance by some health professionals (Fox, Ward & O'Rourke, 2005). Other commentators have associated these developments with the increasing organisation of health care according to consumerist market principles (Douglas-Scott, Solomon & McGowan, 2001). In her book 'The Logic of Choice', Mol argues that consumerism leads to a sidelining of care as the market principles of freedom and choice are prioritised over values that are traditionally associated with health care, such as dignity and trust (Mol, 2008). Patients are consequently reconceptualised as consumers, clients or citizens, implying a set of relationships and obligations that extend beyond the sick role. The expectations of compliance and responsibility associated with the patient choice agenda are argued as reflecting an extension of the Foucauldian 'gaze' that makes visible all aspects of a patient's life (Wilson, 2001). The use of lay-led health interventions may be seen as either a reaction against or component of this extended gaze (Springett, Owens & Callaghan, 2007; Lhussier & Carr, 2008).

### ***The lay resource in health care***

In his seminal paper on medical systems as social systems, Kleinman proposed that almost every health care system is made up of three sectors: the professional

sector, folk sector and lay or popular sector (Kleinman, 1978). See figure 7 for an illustration. Folk medicine involves non-professional or complementary forms of healing, whilst the popular sector comprises self-care and lay referral networks. Evidence demonstrating the existence of an 'illness iceberg' suggests that the vast majority of episodes of ill-health are dealt with initially or solely by the popular and folk sectors (Levin, 1986; Scambler, 2002). Little is known about the popular sector as studies of caring have tended to focus on what Scambler (2002) refers to as 'special' cases (severe or disabling conditions) rather than 'mundane' caring. This sector draws on lay epistemologies that come from a very different paradigm of knowledge creation compared with the focus on evidence-based practice that pervades professional-led health services (Roter & Hall, 1991; Kangas, 2002). Whereas medical science is based on the concept of disease as something that can be 'treated' objectively, lay-led approaches are more likely to incorporate the individuals' experiences of their everyday lives (Popay & Williams, 1996; Springett, Owens & Callaghan, 2007). The resistance of disadvantaged groups to lifestyle advice often reflects a valid lay epidemiology whereby 'unhealthy' behaviours can be deemed a rational response to everyday life, as well as being health-promotion mechanisms in themselves (Davison, Davey-Smith & Frankel, 1991; Popay *et al.*, 1998; Lawlor *et al.*, 2003).

**Figure 7: Three sectors of the medical system (Kleinman, 1978)**



Harnessing lay expertise is important both for understanding the aetiology of ill-health and for informing health improvement and disease prevention practices. However, policy-makers and practitioners experience a number of challenges in

attempting to make use of lay knowledge, particularly in terms of working with disadvantaged or marginalised communities (Popay & Williams, 1996; Smith, 2010). Extended periods of engagement are often required to gain access to these communities and achieve a mutual understanding, which can be time- and resource-intensive. Instead, lay health workers can be recruited from the local population and trained to act as a bridge between community members and the formal health care system (Earp & Flax, 1999). The assumption is that these workers will be more in tune with the habitus in which people from disadvantaged areas operate, with habitus defined as the norms and practices of particular social groups (Bourdieu & Wacquant, 1992). As a result of their shared cultural norms and experiences, they may be better able to provide the support people require to help negotiate their notions of self, identity, health and wellbeing (Springett, Owens & Callaghan, 2007). In the case of health trainers this involves supporting people to access appropriate health services and adopt health-related behaviour changes. Philosophically, lay-led interventions are grounded in an egalitarian model of user-provider partnership which advocates rejection of expert-dominated relationships and encourages an active patient or client role (Roter & Hall, 1991). Health trainers are just one element of a wider cultural shift aiming to encourage greater pluralism and more openness to lay participation in health and social care in order to create fully engaged communities (Wanless, 2004; Cayton, 2006).

### ***Lay health worker models***

A variety of different, often confusing, terms has been used to describe lay or non-professional workforce roles in health (see box 2 for examples). Lay health worker (LHW) is used throughout this thesis for consistency and ease of understanding. The WHO defines LHWs as those who “live in the community they serve, are selected by that community, are accountable to the community they work within, receive a short defined training, and are not necessarily attached to any formal institution” (World Health Organisation, 1987). There are few data to indicate how closely existing roles conform to this definition; however, most published descriptions reference lay workers as being from or like the target population in relevant ways (Swider, 2002). Other common components include conducting outreach to underserved communities, providing culturally sensitive care, and delivering health education and counselling (Nemcek & Sabatier, 2003). LHWs are typically trained in some way but have no formal professional certification, and perform one or more functions associated with health care almost exclusively in community settings (Witmer *et al.*, 1995; Haines *et al.*, 2007). This distinguishes

them from auxiliary health workers, such as health care assistants and paramedical workers, who are trained for longer periods and are usually facility-based. However, precise classification can be difficult because of the wide range of backgrounds and roles of such workers. For example, health trainers in the UK receive extensive training and may be based in community or clinical settings.

**Box 2: Alternative terms for non-professional health workers<sup>5</sup>**

Breastfeeding supporter	Lay practitioner
Community champion	Natural healer / helper
Community health activist	Neighbourhood assistant
Community health representative	Neighbourhood wellness advocate
Community mother / parent	Outreach worker / specialist
Family health advisor	Paraprofessional
Health aide / advocate	Patient navigator
Health coach	Peer educator / mentor / supporter
Lay health advisor / supporter	Promotoras / promotores
Lay opinion leader	Village / indigenous health worker

The LHW concept was born out of the belief that every community has people to whom others turn naturally for advice, help and support (Eng, Parker & Harlan, 1997; Jackson & Parks, 1997). LHW programmes typically identify and train these ‘natural helpers’ to offer a community-based system of care and support that complements the formal health care system. Their core activities can be seen as residing along a continuum of informal to formal helping (Eng, Parker & Harlan, 1997; Moore & Earp, 2007). The concept of deploying community members to identify local health needs, develop innovative solutions and translate them into practice is not new (World Health Organisation, 1987; Cowbrough, 2008). The Chinese barefoot doctor programme, which became a nationwide programme in the mid-1960s, and the use of village health volunteers in Thailand both date back to the early 1950s (Lehmann & Sanders, 2007; Cowbrough, 2008). Historically these lay-led programmes have emerged in different political and social contexts, and lay workers have been given various labels and responsibilities. The most commonly used label in the 1950s was village health worker or volunteer. This term was used to describe local representatives involved in health care provision, health advocacy

<sup>5</sup> This list was largely derived from the overseas literature and therefore includes several role labels that are not found in a UK context. For example, promotoras(es) are Hispanic lay workers who work with their own communities in Latin American countries or the USA.

and acting as agents for social change. In the words of David Werner, they were 'liberators rather than lackeys' (Werner, 1981). Village health workers have been used extensively in developing countries, particularly in areas where professional health care providers are scarce (Earp & Flax, 1999; Lehmann & Sanders, 2007).

More recently, LHWs have been used in developed countries to disseminate health advice and deliver interventions to groups that have traditionally lacked access to adequate care (Earp & Flax, 1999; Viswanathan *et al.*, 2009). In the United States the use of LHWs developed in the 1960s under the Federal Migrant Health Act (1962) and the Economic Opportunity Act (1964) to provide mandated outreach services in poor neighbourhoods and migrant labour camps (Lowe, Barg & Stephens, 1998). African Americans and Native American Indians also became target populations following the civil rights movement and Indian Health Services Act (1969), and lay-led programmes proliferated from this point onwards (Nemcek & Sabatier, 2003). The Alma Ata Declaration described LHWs as one of the cornerstones of comprehensive primary care but, by the 1990s, enthusiasm had waned for reasons that included the challenges of scaling-up programmes and ensuring their sustainability (Kahssay, Taylor & Berman, 1998; Haines *et al.*, 2007). The recent renewed interest in lay-led models derives primarily from recognition that health needs are not being met by existing services, compounded by workforce shortages and new health problems such as HIV/AIDS. This is particularly the case in developing countries, where the high costs of professional training, health worker migration and fragmented health care systems pose additional challenges (Haines *et al.*, 2007).

In the UK, a number of nationwide, community-based programmes have been implemented in recent decades, including Sure Start Children's Centres, the Expert Patients Programme and the NHS Health Trainers Initiative. These programmes typically target disadvantaged groups and involve staff or volunteers who share the language, beliefs, social or cultural characteristics of the local community (Earp & Flax, 1999). LHWs continue to act as 'cultural brokers' between communities and formal health services, but there has been a shift away from their role as advocates for social change towards a predominantly technical and community management function (Lehmann & Sanders, 2007). This pragmatic approach has gained currency within the prevailing political and economic climate but there remains a fundamental tension between LHWs as community advocates and as an extension of formal health care provision (Kahssay, Taylor & Berman, 1998). In other words, they are at risk of becoming lackeys rather than liberators (Werner, 1977). LHWs are often

called upon to fulfil one or more roles and engage in a combination of natural helping and formal advising activities (Earp & Flax, 1999; Moore & Earp, 2007). Ideally, local needs and interests should determine the most suitable intervention – in light of the available evidence – but political imperative tends to exert a powerful influence (Sowden & Raine, 2008). The potential for LHW programmes to contribute to health improvement and community capacity building must be balanced against their costs and the risk of intervention-generated health inequalities.

### **Reducing health inequalities**

Many public health interventions aim to improve health across the population, whereas initiatives such as health trainers have as their goal reducing health inequalities within the population. This is for the aforementioned reason that members of hard-to-reach and disadvantaged groups tend to have worse health than those from more affluent groups. These inequalities apply to mental as well as physical health and operate at every stage of the life cycle; for example, the infant mortality rate is 19 per cent higher in the lowest social class than the average rate for England and Wales (Department of Health, 2009b). There has been a growing acceptance that the weight of scientific evidence supports a materialist explanation of health inequalities (Black, 1980; Davey-Smith, Blane & Bartey, 1994; Acheson, 1998). The UK exhibits less social mobility than many other countries and the gap between the highest and lowest socioeconomic groups is still greater than in three-quarters of countries in a study by the Organisation for Economic Co-operation and Development (OECD, 2008). The income gap narrowed steadily for much of the twentieth century and then began to widen in the late 1970s. During the New Labour years, the ratio between the earnings of the most and least affluent groups rose from 3.6 to 3.9, meaning that the poor became relatively less well-off (Dorling, 2010). At the same time, there has been an increase in the health inequalities gap. Between 1998 and 2007, the difference between the worst mortality rates and the English average increased from 16.1 per cent to 18.6 per cent for men and from 13.9 per cent to 15.2 per cent for women (Audit Commission, 2010).

The existence of socioeconomic differentials for almost every major cause of morbidity and mortality suggests the presence of a common pathway, with potential mechanisms including material, psychosocial and biological factors (Charlton & White, 1995; Adams & White, 2004; Wilkinson & Pickett, 2009). However, considerable attention has been paid in government policy to the role of individual



lifestyle factors. This emphasis has been criticised as a “politically safe interpretation that reinforces a status quo of significant and increasing social, economic and health injustice within and between nations” (Dunn, 2010, p.1199). Yet it is based on the indisputable association between health risk behaviours, such as being overweight or tobacco smoking, and socioeconomic indicators, such as income or level of education. There is a tacit assumption that inequalities might be reduced through promoting lifestyle change within less affluent groups, in spite of contradictory evidence. For example, the findings of large-scale longitudinal research conducted in the USA suggest that policies and interventions that focus exclusively on individual risk factors have limited potential for reducing inequalities (Lantz *et al.*, 1998). Limitations of this study include the reliance on self-reported, retrospective data, but this is more likely to produce an overestimation of the effects of lifestyle on health. Numerous other studies have shown that, after controlling for relevant behaviours, there is still a significant amount of socioeconomic variation in health outcomes (for examples, see Marmot *et al.*, 1978; Schrijvers *et al.*, 1999; Oort, Lenthe & Mackenbach, 2005).

The processes of determining risk exposure and disease incidence linked to socioeconomic status (SES) are poorly understood. Potential mechanisms include differences in exposure to occupational and environmental health hazards, lack of social support, lower self-esteem, or chronic and acute stress in life and at work (Davey-Smith, Blane & Bartey, 1994; Lantz *et al.*, 1998). There is a substantial body of evidence providing support for the hypothesis that stressors in the social and physical environments influence health outcomes, and that the likelihood of exposure is linked to SES (Adams & White, 2004; Marmot *et al.*, 2008; Wilkinson & Pickett, 2009). There also appears to be a negative association between the number of stressors and access to resources with which to respond to those stressors, meaning that individuals from lower SES groups are more adversely affected by the same experiences than those who are more economically or educationally advantaged (Charlton & White, 1995; Lantz *et al.*, 1998). At the same time, the costs of lifestyle change are likely to be greatest for these groups as health risk behaviours often bring social and psychological benefits; for example, the use of smoking as a coping mechanism for stress amongst single mothers living in disadvantaged areas (Graham, 1976; 1987). There is a growing literature to suggest that the experience of stress and unhealthy behaviours have common roots in early life, leading to calls for increased funding for programmes and policies to tackle the social determinants of health from childhood (Dunn, 2010; Marmot, 2010). However, the evidence to support the effectiveness of these programmes is patchy.



Individuals from low SES groups have proven notoriously difficult to reach with public health interventions and the social patterning of efficacy has already been discussed, in terms of the potential for intervention-generated inequalities (White, Adams & Heywood, 2009). Baird *et al.* (2009) collated evidence from existing reviews of interventions aimed at changing the dietary and other health-related behaviours of women from disadvantaged backgrounds. They were primarily interested in evidence relating specifically to women of child-bearing age, as infants born to lower SES mothers are less likely to have healthy diets. However, few papers met the inclusion criteria (n=14) and the final narrative synthesis included reviews focusing on the general population as well as disadvantaged groups. Four aspects of intervention design found to be effective were: use of an educational component; provision of continued support after the initial intervention; social support from peers or lay health workers; and family involvement with the intervention. These findings are supported by similar scoping reviews of the evidence, although few UK studies have been identified and caution must be exercised about the generalisability of the findings (Michie *et al.*, 2009b). A review of interventions to reduce social inequalities in health commissioned by the Netherlands Government found that successful strategies combined providing information with either structural measures or personal support (Gunning-Schepers & Gepekens, 1996). However, a more recent and comprehensive review conducted in the UK concluded that evidence for the effects of many interventions on health inequalities is unclear (Bambra *et al.*, 2010). Suggestive evidence was found for the impact of specific interventions in the fields of housing and the work environment, but the evidence base for public health interventions was sparse.

The Marmot Report identified a need to measure the scale of health inequalities and evaluate any action taken to reduce the gap, thereby expanding the existing knowledge base (Marmot *et al.*, 2008). It also called for increased public finance for policies and programmes to improve the social determinants of health, including education, child development, and improved working and living conditions. Critics have argued that the report was too cautious in terms of criticising the role of large corporations and existing power bases, as well as being vague at a national level (Nathanson & Hopper, 2009; Navarro, 2009). At the same time, it is acknowledged as going further than any WHO publication in highlighting the structural determinants of health inequalities and calling for 'closing the gap in a generation' as a matter of fairness and social justice. This requires action across the whole social gradient in recognition that, rather than a simple gap between the 'haves' and 'have-nots', there exists a continuum characterised by unequal and unjust

distributions of resources, capabilities and rights (Charlton & White, 1995; Popay *et al.*, 2008; Whitehead & Popay, 2010). Marmot (2010) used the term 'proportionate universalism' to describe the measures needed to reduce the steepness of the social gradient in health. However, the residual or gap approaches to health inequalities continue to dominate public health policy and practice in the UK. Furthermore, although it is widely recommended that concerted action is required across society, the history of the Black Report demonstrates that it can be more apt to offer 'quick-fix' recommendations in order to have a policy impact (Adshead & Thorpe, 2009). Health trainers fall into this category, as well as representing an example of the "street-level workers envisioned by the Marmot report as leading the health charge at the local level" (Nathanson & Hopper, 2009, p.1238).

### **Chapter summary**

This chapter has explored key concepts underpinning the NHS Health Trainers Initiative that contributed to the conceptual framework used in developing the study aims and objectives. Each of these concepts has been discussed in turn, using examples from the theoretical and empirical literature, to illustrate common understandings and debates surrounding core elements of the health trainer role. These elements combine to produce a lay-led, community-based behaviour change intervention that is attempting to reduce health inequalities by targeting groups that are currently underserved by health services. However, questions have been raised regarding the degree of homogeneity and cohesion within these groups, the tensions involved in attempting to combine lay and expert knowledges, the most appropriate levels for intervention, and the likely impact on health inequalities from utilising a largely individualistic lifestyle approach. These ideas are explored further in the next chapter, which involves a critical review of the empirical literature to support the implementation, delivery and evaluation of lay-led health interventions.

## Chapter 3: Review of the research literature

In this chapter I draw on published articles and grey literature to examine the empirical evidence base for health trainers and similar lay health workers. I begin with an overview of the strategies used to locate and select papers for inclusion in the review, with reference to a fundamental debate in grounded theory research. The remainder of the chapter is organised into three sections, each of which summarise and critique the available literature in the following areas: (1) quantitative evidence on the feasibility, effectiveness and cost-effectiveness of lay-led health improvement programmes; (2) qualitative research exploring the experiences and perceptions of key stakeholders, lay health workers and intervention recipients; and (3) research (both quantitative and qualitative) relating specifically to the NHS Health Trainers Initiative. The chapter summary highlights gaps in the evidence base and demonstrates the way in which the existing literature has been used to inform the study described in the remainder of the thesis.

### Review methods

The grounded theory approach employed in this study is detailed in Chapter 4. However, this methodology requires careful consideration of the role of the literature review in the research process. Literature reviews are generally undertaken to determine gaps in earlier research and also to identify key concepts for investigation, whereas the 'grounded' nature of grounded theory means that concepts should be generated from empirical data rather than the literature (McGee, Marland & Atkinson, 2007; Walls, Parahoo & Fleming, 2010). Efforts must be made to avoid entering the field with an *a priori* conceptual framework and, instead, remain open-minded to whatever emerges in the field (Hallberg, 2010). Employing a classical approach to grounded theory would involve ignoring the existing literature before entering the field, whereas more contemporary approaches advise conducting an initial review to stimulate questions and direct sampling (Glaser & Strauss, 1967; Corbin & Strauss, 2008). See table 3 for a summary of this argument. I made the decision to conduct an initial literature review so as to demonstrate that my findings will constitute a unique addition to knowledge and therefore meet the criteria for a doctoral thesis. This was essential in obtaining funding and ethical approval for the study. My aim in conducting an initial exploratory review was to identify possible directions for the research whilst not restricting the freedom to discover other patterns (Glaser, 1978). This was followed by a second, more focused review, undertaken to link existing research and theory

with the concepts, constructs and properties emerging from my data (described in the section on data analysis in Chapter 5).

**Table 3: The place of literature reviews in grounded theory research** (McGee, Marland & Atkinson, 2007)

<b>Arguments <u>for</u> a literature review before developing research categories</b>	<b>Arguments <u>against</u> a literature review before developing research categories</b>
To provide justification for the study	To be strictly in keeping with a post-positivist ontology
To meet the requirements of research ethics committees	To prevent the researcher being constrained, contaminated or inhibited
To avoid conceptual and methodological pitfalls	To prevent recognised or unrecognised assumptions
To discover the extent of previous knowledge and therefore assess whether grounded theory is an appropriate method	To avoid generating a focus from the literature rather than from the emerging data
To be 'open minded' but not 'empty headed'	To promote 'telling it as it is' rather than 'telling it as they see it'

My involvement in research on the subject of health trainers began with a narrative review of the evidence base (Visram & Drinkwater, 2005), and was followed by local evaluation studies that required further reading of the literature (Visram *et al.*, 2006; Visram & Geddes, 2007). More recently, I was part of a team commissioned to conduct an evidence synthesis of quantitative and qualitative research on different versions of the health-related lifestyle advisor role (including health trainers) (Carr *et al.*, 2011). This involved the use of systematic review methodology to locate, select and quality appraise the existing literature. See Appendix A for a summary. The searches generated a total of 22,898 results and 26 studies were assessed as meeting both the inclusion criteria and rigorous quality appraisal criteria. Limited evidence was found to suggest that lifestyle advisors are effective in producing positive changes in health knowledge, behaviours or outcomes, and even fewer studies demonstrated their cost-effectiveness. However, the study methods and findings are highly relevant to the research described in this thesis. Rather than attempting to put this knowledge aside, I have sought to incorporate it into this exploratory review and avoid any duplication of effort.

The first two sections of the chapter draw heavily on previous reviews, updated with studies located primarily following electronic searches using NORA<sup>6</sup>. My role in the systematic review by Carr *et al.* (2011) involved developing the search string; by using this as the basis for the present review, I was confident in its validity based on experience. The string incorporated terms used to describe variations on the health trainer role, in combination with public health topics and research terms (see box 3).

### Box 3: Search terms

#### List one: role labels

Health trainer OR expert patient OR natural helper OR paraprofessional OR promotora OR link worker OR breastfeeding supporter OR lactation consultant; plus various combinations of the following: (peer OR lay OR community OR lifestyle OR village OR indigenous OR neighbourhood OR family) WITH (health) AND/OR (worker OR advisor OR trainer OR coach OR supporter OR champion OR leader OR educator OR promoter OR practitioner OR mentor OR counsellor OR assistant OR activist OR aide OR advocate OR navigator OR networker OR representative OR midwife)

#### List two: topic areas

Public health OR health promotion OR health improvement OR health education OR behaviour change OR lifestyle change OR prevention

#### List three: methods and outcomes

Evaluation OR study OR trial OR RCT OR questionnaire OR survey OR interview OR focus group OR observation OR economic OR effectiveness OR cost-effectiveness OR equity OR acceptability

These terms were also used in conducting searches of the internet using the Google and Google Scholar search engines, manual searches of key journals, retrieval of references cited in reviews and primary research articles, and by scanning information received via relevant email discussion lists and table of contents alerts. In recognition of the unique features of the health trainer role, additional searches were conducted using lists two and three combined with 'health trainer' instead of list one. When few results were returned, searches were simplified to 'health trainer' used in combination with 'research' or 'evaluation' only, and the results are discussed in the third section of the chapter (evaluations of local health trainer programmes). All searches were conducted regularly over the

<sup>6</sup> NORA is an online tool that enables users to simultaneously search the Northumbria University library catalogue, databases of journal articles, news services and selected Internet resources. See: <http://nuweb.northumbria.ac.uk/library/norapowersearch/index.html>.

duration of the study to ensure the literature review remained up to date. As this was an exploratory rather than a systematic review, the aim was to locate papers that might help to inform the research question and study design, rather than provide an exhaustive summary of literature relevant to a predetermined question. My approach involved scanning the first 100 results returned by the searches, making an initial assessment based on the title and/or abstract, and retrieving papers that described an evaluation of a lay-led intervention aimed at enhancing knowledge and/or changing adult behaviour to improve health<sup>7</sup>. A broad and inclusive approach was adopted, with no exclusions made on the basis of study design, date or lack of peer review. However, the review focused on health improvement rather than the provision of treatment or care, and on evaluations of lay-led activities rather than descriptive accounts of programme implementation or delivery. The results are summarised below, beginning with an overview of the quantitative evidence base.

### **Evidence of intervention effects**

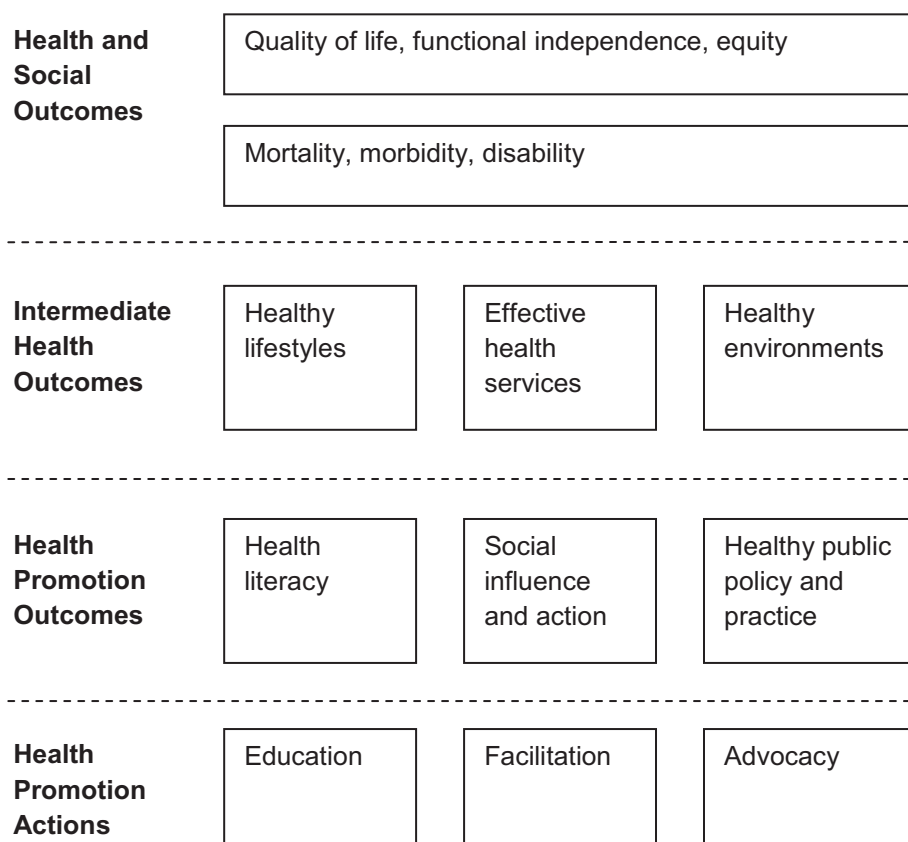
Before lay health worker (LHW) programmes can be advocated as potential solutions to public health problems, questions relating to their feasibility, effectiveness and safety need to be answered (Lewin *et al.*, 2005). There are frequent calls for better evidence about the effects of interventions, along with increasing recognition that positivistic methods such as randomised controlled trials (RCTs) might favour interventions most amenable to this type of study design (Rychetnik *et al.*, 2002; Ogilvie *et al.*, 2005a). Although RCTs have high internal validity, they use samples that often do not represent certain social groups and do not allow understanding of individual cases, thereby undermining the potential application to service development research (Watson, Procter & Cochrane, 2004). Preliminary searches of the literature revealed that the LHW interventions studied in RCTs represent only a subset of all those that could be or have been advocated. Furthermore, there is an abundance of unpublished material regarding LHW projects. Finding and appraising this 'low grade' evidence was deemed to be important in evaluating the effects of LHWs across the breadth of their activities and settings, as well as demonstrating how the evidence base might best be strengthened (Ory, Jordan & Bazzarre, 2002; Ogilvie *et al.*, 2005b).

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<sup>7</sup> Interventions delivered by or targeting children and young people, e.g. peer education in schools, were excluded as health trainers only work with people aged 16 and over (the junior health trainer is a separate role). Interventions delivered by and targeting adults but having an impact on infant and child health, e.g. breastfeeding peer support, were included to allow for an assessment of the full range of lay health worker activities and potential outcomes.

The diversity of studies located in this exploratory review, combined with time and resource limitations, meant that a statistical meta-analysis of the resulting data was not possible. Instead, I employed the principles of narrative synthesis to inform the development of my research aims and methodology. Guidance on this approach suggests that, following data extraction, the results should be organised in such a way as to describe patterns in the data and allow for exploration of relationships within and between studies (Popay *et al.*, 2006; Arai *et al.*, 2007). To expedite this process, I organised the literature using Nutbeam's (1998) outcome model for health promotion interventions. This model provides a theoretical framework for evaluating a range of strategies to promote sustainable health improvement and reductions in health inequalities (Watt *et al.*, 2006). It was felt to be appropriate for use in this review because of its ability to accommodate the diverse LHW interventions and their action on the social determinants of health. The remainder of this section combines unpublished and published literature, organised around the four categories of effect shown in figure 8 below.

**Figure 8: A summary outcome model for health promotion** (Nutbeam, 1998)





### **Health promotion actions**

The first category concerns the activities involved in delivering health promotion programmes, rather than the outcomes achieved. The implementation and delivery of LHW interventions represent indicators of success in terms of demonstrating the feasibility of lay-led approaches. Systematic reviews of the evidence have demonstrated the diversity of LHW programmes, not only in terms of the targeted health issue but also in the intervention aims, content and outcomes (Lewin *et al.*, 2005; Viswanathan *et al.*, 2009; Carr *et al.*, 2011). These reviews have consistently found that varied and inadequate reporting on the intervention components limits the ability to assess which types of lay-led strategy deliver positive outcomes. Studies generally describe the place and type of intervention but fail to include information on the intervention content (or its theoretical basis), techniques used, duration of interaction or length of follow-up. A systematic review of evidence on the characteristics of LHWs<sup>8</sup>, LHW interventions and training, in addition to their outcomes, costs and cost-effectiveness, was conducted by researchers in the USA (Viswanathan *et al.*, 2009). They included 53 studies on characteristics and outcomes of LHW interventions, nine on training, and six on cost-effectiveness, and found that intervention intensity varied with context, but there was no evidence of an association with outcomes. Where reviews and meta-analyses have identified positive effects of peer-based programmes, these have been most prominent in terms of increasing access to care for underserved populations (Swider, 2002; Andrews *et al.*, 2004). A Cochrane review of LHWs in primary and community care found that of the 35 studies undertaken in high income countries, 15 of these targeted low-income and minority populations (Lewin *et al.*, 2005). The use of local people to deliver community-based interventions provided greater access to rural and other hard-to-reach locations.

In addition to feasibility and acceptability, lay-led programmes must be judged on their value for money. However, there is a dearth of data relating to intervention component costs and few studies report a standard measure of costs per quality adjusted life-years (QALYs) saved. Previous reviews have therefore failed to reach a definitive conclusion as to which LHW strategies are most cost-effective (Lewin *et al.*, 2005; Viswanathan *et al.*, 2009; Carr *et al.*, 2011). Areas where the evidence is either inconclusive or suggests that lay-led interventions are not cost-effective include: breastfeeding support, mental health promotion, screening uptake, and

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<sup>8</sup> The authors of this review use the term community health worker, abbreviated to CHW, but lay health worker/LHW is used here and throughout the thesis for consistency.

interventions for diet and physical activity (Carr *et al.*, 2011). However, potential biases in measurement and methodological challenges tend to limit interpretation of study results. For example, a study was undertaken in three areas of England to investigate the effects of access to a 'befriender facilitator' for carers of relatives with progressive dementia (Charlesworth *et al.*, 2008). The mean incremental cost per incremental QALY gained was in excess of £100,000 but only 52 per cent of carers in the intervention group took up the offer of being matched with a lay befriender, and only 32 per cent of these were befriended for the recommended six months. Where care-recipient QALYs were included, the mean incremental cost per incremental QALY gained was £26,848. A study investigating the costs and impacts of family planning services in Tanzania concluded that any benefits arising from lay-led programmes needed to be balanced against the costs of training and supervision (Janowitz *et al.*, 2000). The programme that paid the highest annual compensation had the highest costs per LHW but also the highest number of visits per worker. Similar results were reported in a South African study, which found that the costs of LHW supervision and support were proportionately greater in small programmes than in larger programmes, suggesting that there may be economies of scale (Makan & Bachman, 1997). However, these findings are likely to have limited application in a UK context due to the considerable differences in health needs and health service provision between developed and developing countries.

Areas where the best available evidence suggests that LHW interventions are cost-effective include: smoking cessation, tuberculosis treatment, education to reduce neonatal and maternal mortality, management of chronic conditions, and HIV prevention (Islam *et al.*, 2002; Sinanovic *et al.*, 2003; Manandhar *et al.*, 2004; Borghi *et al.*, 2005; Carr *et al.*, 2011). The aforementioned study of primary care services in South Africa found that LHW unit costs were comparable to those of other care providers, although this analysis failed to account for differences in disease severity and professional training (Makan & Bachman, 1997). Also, there was no evaluation of cost-effectiveness. Pioneering research conducted in the early 1980s explored the effects of LHWs trained for 12 weeks and deployed in two locations in Kenya to provide basic health care and health promotion advice (Wang'ombe, 1984). A cost-benefit analysis (CBA) was performed using the willingness-to-pay approach and found a benefit:cost ratio of between 9.36 and 9.85 (depending on the choice of discount rate). Limitations of this study include the partial nature of CBA evaluations and the challenges of valuing community time. Many core elements of LHW programmes, such as volunteerism, building trust, social mobilisation and changing community norms, are not easily quantifiable and

therefore do not lend themselves to economic analyses, meaning that these analyses are often insensitive to the full range of social benefits (Walker & Jan, 2005; Lehmann & Sanders, 2007). The realist analysis by Carr *et al.* (2011) found that although LHWs were not proven to be cost-effective in promoting screening uptake and HIV prevention in a UK context, they were successful in building on social capital and demonstrating high degrees of acceptability. The additional costs incurred by service providers in implementing LHW programmes may be offset by a reduction in demand for professional-led health care and also result in significant cost savings for users in terms of travel costs, wasted time and lost economic opportunities while seeking clinic-based care (Reilly *et al.*, 2004; Lewin *et al.*, 2005).

### ***Health promotion outcomes***

According to Nutbeam's model, the immediate results of health promotion activities can be categorised under the headings of social influence, health literacy, or healthy public policy and practice (Nutbeam, 1998). No examples could be found in the quantitative evaluation literature relating to changes in social connectedness, community empowerment, social benefits or organisational practices as a result of participation in lay-led health improvement programmes. Instead, this sub-section focuses on the limited literature concerning changes in health knowledge, skills and attitudes. There is modest evidence from reviews of the existing literature to suggest that LHW interventions can be effective in improving knowledge on disease prevention, cancer screening and diabetes (Nemcek & Sabatier, 2003; Viswanathan *et al.*, 2009). However, the evidence comparing LHWs with a comprehensive range of alternative providers is lacking and so it is not possible to determine whether they are more effective in improving participant knowledge. The review by Viswanathan *et al.* (2009) identified a small subset of comparators suggesting that LHWs may be more effective than using mass media or usual care plus pamphlets.

Studies targeting women from marginalised communities have demonstrated that peer- or lay-led interventions can lead to increases in knowledge, but the evidence that this produces subsequent changes in behaviours or health outcomes is mixed (Watkins *et al.*, 1994; Bird *et al.*, 1998). Bird *et al.* (1998) conducted a community trial to demonstrate that LHWs could be successfully utilised to raise awareness of cancer screening tests amongst Vietnamese-American women. In the intervention community, significant increases were observed in the recognition, receipt and maintenance of clinical breast examination, mammography and Pap smears.

However, the analyses were based on self-reports of screening behaviour and the authors acknowledge that their results are not generalisable to other populations. A study by Watkins *et al.* (1994) used non-validated questionnaires developed for use with migrant (Latina) farmworker women to demonstrate significant improvements in knowledge of maternal and child health issues. These changes were measured on a population basis and correlated with a separate questionnaire on exposure to the LHW intervention, but insufficient detail is given regarding the content of the questionnaires to judge their validity. This is one of few studies to measure the impact of the programme on LHW knowledge and skills. Reviews have also found evidence of improvement in this area, coupled with changes in health-related behaviours exhibited by LHWs (Viswanathan *et al.*, 2009; Ayala *et al.*, 2010).

### ***Intermediate health outcomes***

Much of the literature focuses on the indirect or interim effects of LHW interventions, which Nutbeam (1998) defines as the determinants of health and social outcomes. These inter-linked outcomes include lifestyle behaviours, appropriate use of health services and the creation of health-promoting environments. Evidence relating to the intermediate effects of LHW interventions is mixed. The review by Viswanathan *et al.* (2009) identified 22 relevant studies, five of which demonstrated improvements in behaviours relating to workplace safety, diabetes and asthma in comparison with alternatives such as usual care combined with a pamphlet or a lower intensity LHW intervention. However, the overall strength of this evidence was graded as moderate to low and no significant differences were found for interventions aiming at health promotion amongst Latina groups, injury prevention at home and smoking cessation to reduce asthma. This is in direct contrast to a systematic review focusing exclusively on the use of LHWs with Latino communities, which found significant improvements in health behaviours in 12 of 13 studies identified as utilising randomised controlled or quasi-experimental designs (Ayala *et al.*, 2010). The authors employed a rigorous approach in identifying relevant literature to answer the review questions. However, it is not clear whether or how the quality of the included studies was assessed and therefore the conclusions drawn must be treated with some caution.

Four areas where LHWs have been used extensively to promote behaviour change are smoking cessation, sexual health, parenting (including breastfeeding) and general health promotion (mainly involving diet and physical activity). The evidence relating to interventions for smoking cessation is promising, with significantly higher

rates of abstinence maintained up to 12 months following participation in a lay-led intervention relative to a comparison group receiving usual care (Woodruff, Talavera & Elder, 2002; Emmons *et al.*, 2005). These studies rely on self-reported smoking status as the main outcome measure but expired carbon dioxide monitoring is often used to verify this data. The literature relating to adult sexual health primarily focuses on prevention of HIV infection, often amongst marginalised populations such as sex workers or illicit drug users. One US study found that outreach activity conducted by LHWs resulted in significant reductions in unsafe practices, such as injected drug use or needle sharing, and greatly increased the likelihood of cessation (44 per cent of intervention participants, in comparison with 22 per cent of controls) (Dickson-Gomez, Knowlton & Latkin, 2003). Although there were no changes observed in condom use with regular partners, significant reductions were reported in unprotected vaginal sex with casual partners and also in the number of casual partners. A second study by the same authors found similar outcomes, plus positive effects for many of the LHWs in terms of reduction or cessation of illicit drug use, increased usage of condoms and other risk reduction activities (Dickson-Gomez *et al.*, 2006). Both studies relied on self-report data.

There is a long history of using lay workers to provide parenting advice and support. A trial conducted in the 1980s examined the use of LHWs to deliver a child development programme to disadvantaged first-time mothers in Dublin (Johnson, Howell & Molloy, 1993). Compared to standard care, mothers who received monthly visits from a LHW were more likely to read to their children, played more cognitive games, and were less likely to introduce cows' milk before 26 weeks. They also had better diets than the controls, reported more positive feelings and were less likely to be tired. This study was based entirely on self-report data and the lack of blinding may have created some bias, although the data were cross-checked where possible. Various systematic reviews have identified promising benefits in the use of LHWs to promote breastfeeding and provide support during pregnancy (Fairbank *et al.*, 2000; Sikorski *et al.*, 2002; Lewin *et al.*, 2005; Britton *et al.*, 2007; Hodnett, Fredericks & Weston, 2010; Hodnett *et al.*, 2011). The review by Carr *et al.* (2011) identified two robust studies examining the effects of peer counselling on breastfeeding rates. Women in the intervention groups were significantly more likely to be breastfeeding up to three months post-partum (Morrow *et al.*, 1999; Dennis *et al.*, 2002). The effect was greatest amongst multiparous women and those with uncertainty about infant feeding plans. An additional study found that women who met their LHW face-to-face were significantly more likely to continue breastfeeding than those in contact by telephone (Graffy *et al.*, 2004). No overall effect was found

on the prevalence or duration of breastfeeding but only 62 per cent of women in the intervention group contacted their LHW postnatally.

Evidence to support the use of LHWs in general health promotion interventions is mixed. Carr *et al.* (2011) located five studies in this area, two of which focused on diet alone (Resnicow *et al.*, 2004; Elder *et al.*, 2006) and three focused on diet and physical activity (Keyserling *et al.*, 2002; Staten *et al.*, 2004; Anand *et al.*, 2007). All five studies identified dietary changes but these did not always reach significance and were not sustained at the follow-up periods. Physical activity levels were not found to differ significantly between the LHW and clinic-based interventions. Other studies have examined lifestyle changes resulting from participation in interventions to promote cardiovascular health. A before-and-after design was used to explore the impact of lifestyle education delivered to Latinas recruited through the LHWs' social networks (Kim *et al.*, 2004). Significant improvements were observed one month after completion of the intervention but these findings are suggestive rather than definitive due to the lack of randomisation or a comparison group. A RCT of the Braveheart Project – an intervention to educate and empower older people with heart disease in Scotland – found significant improvements in dietary intake and exercise levels (Coull *et al.*, 2004). Individuals who participated in the lay-led education group over a one-year period spent an average of one hour more per week walking, although there was no change in exercise tolerance. These data were gathered using self-completion food and activity diaries, and therefore may be subject to recall bias. Furthermore, the authors acknowledged that widespread community interest in the study and subsequent increased awareness of the risk factors for heart disease may have diluted the effect of the intervention.

An additional category of intermediate outcomes involves appropriate use of health care and preventative health services. Reviews of the literature have found that LHW interventions can impact positively on service utilisation, measured by outcomes including reduced emergency department visits, improved appointment keeping, perinatal appointments and primary care provider visits (Nemcek & Sabatier, 2003; Viswanathan *et al.*, 2009). Evidence of enhanced medication compliance has also been found, for example, in the aforementioned Braveheart Project (Coull *et al.*, 2004). Lay-led health advocacy interventions have the potential to increase demand for professional health care in the short-term but they can also successfully divert patients away from professional-led primary care services and reduce staff workloads (Reilly *et al.*, 2004). Reviews have found mixed evidence for the use of LHWs in the areas of disease prevention, breast self-examination and



childhood immunisations (Carr, 2005; Martin, 2005; Viswanathan *et al.*, 2009; Ayala *et al.*, 2010). Numerous studies have examined the impact of interventions to promote the uptake of cancer screening. This literature focuses exclusively on interventions delivered in the USA and targeting women from one or more minority ethnic groups. LHW programmes have been shown to be effective in promoting cervical cancer screening amongst Chinese-American (Taylor *et al.*, 2002) and Vietnamese-American women (Bird *et al.*, 1998; Lam *et al.*, 2003), and in promoting breast cancer screening amongst Latina (Navarro *et al.*, 1998), Vietnamese-American (Bird *et al.*, 1998) and African-American women (Earp *et al.*, 2002)

A separate but linked evidence base concerns the use of LHWs to support people to live with an illness or condition, rather than making lifestyle changes to prevent disease. There is good evidence to demonstrate positive outcomes from lay-led self-management programmes across a range of indicators, including self-efficacy, health care utilisation and health status. These programmes have been shown to be an effective and cost-effective compliment to existing health care provision (Lorig, Mazonson & Holman, 1993; Barlow, Turner & Wright, 1998; Kruger *et al.*, 1998; Lorig *et al.*, 1999). Systematic reviews demonstrate the potential of LHWs to improve outcomes for various conditions, such as arthritis, diabetes mellitus, hypertension, asthma, back pain, mental health and tuberculosis (Viswanathan *et al.*, 2009; Carr *et al.*, 2011). Two trials focusing on asthma care demonstrated that LHW interventions were more effective than alternatives in reducing unscheduled use of health care services, improving psychological outcomes and changing behaviour (Krieger *et al.*, 2005; Parker *et al.*, 2008). However, symptom measures improved equally in the intervention and control groups. Findings from an evaluation of the Expert Patients Programme (EPP) in England found that 45 per cent of those consulted felt more confident that they would not let common symptoms interfere with their lives and 38 per cent felt that their symptoms were less severe up to six months after the course (NHS Expert Patients Programme, 2005). This evaluation involved approximately 1,000 former EPP participants but it is not clear how they were sampled and whether a validated questionnaire was used.

### ***Health and social outcomes***

The final level of Nutbeam's model comprises health outcomes, such as improvements in morbidity, mortality and disability, and social outcomes, including enhanced quality of life, functional independence and equity (Nutbeam, 1998).



Although it can be difficult to evaluate the success of small-scale or community-level interventions according to these outcomes, a limited amount of evidence is available. In the developing world, studies have demonstrated reductions in child and infant morbidity and mortality resulting from the delivery of lay-led maternal education programmes and the provision of community- or home-based care (Haines *et al.*, 2007). An unpublished evaluation of the effect of LHWs in Pakistan showed good skills in diarrhoea management and vaccination counselling, but weaker performance in recognising and treating acute respiratory symptoms (Oxford Policy Management, 2009). Broadly similar programmes have been implemented in developed countries, generally with interventions targeting disadvantaged groups. A retrospective study of a programme aiming to improve obstetric outcomes amongst women from minority ethnic communities in Hackney found significant differences between those accompanied by a lay advocate and a reference group (Parsons & Day, 1992). The proportion of induced labours in non-English speaking women increased at the reference hospital but remained much the same at the intervention hospital. Changes in Caesarean section were statistically significant, rising from 11 to 17 per cent at the reference hospital, and falling from 10.8 to 8.5 per cent at the hospital using lay advocates.

Other areas where LHWs have been found to improve health outcomes include reducing back pain, managing hypertension and treatment for tuberculosis in certain patient groups, (Zwarenstein *et al.*, 2000; Levine *et al.*, 2003; Clarke *et al.*, 2005; Lewin *et al.*, 2005; Viswanathan *et al.*, 2009). Promising results were identified in a recent cluster randomised control trial conducted in 39 Canadian communities to evaluate a Cardiovascular Health Awareness Programme (CHAP) delivered by peer health educators (Kaczorowski *et al.*, 2011). Statistically significant reductions were found in hospital admissions for acute myocardial infarction and congestive heart failure in the intervention communities, equating to 3.02 fewer annual hospital admissions for cardiovascular disease per 1,000 people aged 65 and over. These effects may be over-estimated due to the author's original power calculations being based on higher hospital admission rates than actually occurred during the study period<sup>9</sup>. However, successful implementation of CHAP in all 20 intervention communities demonstrates the feasibility and acceptability of lifestyle advice delivered by peer health educators. Evidence for other outcomes, including child development and diabetes, is mixed, whilst no difference has been observed for a reduction in BMI or increase in mental health benefits in comparison with

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<sup>9</sup> This situation occurred due to a secular decline in hospital admissions for cardiovascular disease and the unavoidable use of rates based on less accurate data from 2001.

alternatives such as advice from a nurse or print materials (Gary *et al.*, 2003; Viswanathan *et al.*, 2009). In some cases the results are clinically important but do not reach statistical significance due to limitations in the study design. The aforementioned trial involving carers of relatives with progressive dementia found a reduction in Hospital Anxiety and Depression Scale (HADS) depression scores that approached statistical significance (95% CI -0.09 to 2.84) (Charlesworth *et al.*, 2008). However, uptake of the voluntary 'befriender facilitator' service was not high. In the review by Carr *et al.* (2011), a limited number of studies examining mental health or social outcomes were identified relative to those reporting physical health outcomes. Mixed evidence was found to support the use of LHWs in contributing to statistically significant decreases in fatigue, anxiety, depression and social role limitations, and increases in energy, self-rated health, positive mood and psychological wellbeing when compared with controls. These outcomes were more likely in interventions seeking to improve chronic disease management and therefore may be linked to the fact that the target groups were already engaged.

### ***Summary of the quantitative evidence***

The preceding sections demonstrate that the quantitative evidence base relating to lay-led health improvement interventions is limited in quality and quantity, yet suggestive of effectiveness in some settings and for certain health conditions. For example, there is good evidence to support the use of LHW programmes in promoting self-care, smoking cessation, uptake of cancer screening and reducing cardiovascular disease risk. These interventions often target 'hard-to-reach' or high risk groups, including black and minority ethnic communities. Studies suggest that support from a LHW brings potential benefits but that merely offering support has little effect. In order to fully evaluate the effectiveness of LHWs, it is necessary to conduct further research that addresses the methodological limitations of prior studies. Study recruitment and retention difficulties may make the potential benefits of an intervention less clear, along with the difficulty of blinding participants to the intervention and controlling for spillover to control groups. Much of the existing literature comes from developing countries and North America, where differences in the organisation and funding of health services, as well as racial factors, are likely to mean that the findings are poorly generalisable to a UK context. Additional research is needed to assess the effectiveness and cost-effectiveness of LHW interventions in different settings and for different user groups, including men. Furthermore, there is a need to identify the intervention components and processes, in order to explore which specific components are more or less effective and under which conditions.

## Qualitative research findings

The impact and sustainability of lay-led programmes is heavily influenced by a range of contextual factors operating at the international, national, socioeconomic, health system and community level (Haines *et al.*, 2007). These factors can only be captured through the generation and use of diverse data sources to provide more illuminating, relevant and sensitive evidence of effects than a single 'definitive' study. The importance of supplementing data from quantitative studies with results of qualitative research to provide depth and insight into people's experiences is of particular relevance to the successful replication and sustainability of interventions (Weightman *et al.*, 2005). Evidence relating to the experiences and perceptions of key stakeholders, LHWs and their clients is discussed in the sections below. Study quality has been assessed using the criteria for judging the validity of qualitative health services research set out by Popay *et al.* (1998). Papers were selected for inclusion if they met the primary criterion of privileging subjective meaning or lay knowledge. However, most failed to meet other important criteria such as evidence of reflexivity on the part of the researcher or potential for assessing transferability. Where possible, data extracts (i.e. participant quotes) have been used to illustrate key points, although these were not provided in several publications.

## Key stakeholder views

No studies were found focusing exclusively on the views of commissioners, service planners, coordinators or hosts of LHW programmes. The limited number of reports and articles incorporating feedback from small samples of these key stakeholders have, on the whole, found them to be highly positive about the LHW model. The reasons for this include a perception that local people are best placed to tackle local problems and to empower other community members to gain control over their health. Stakeholders report that the flexible approach employed by LHWs is a particular advantage in terms of being able to respond to the health needs of target communities (Beam & Tessaro, 1994; Britten, Hoddinott & McInnes, 2006; Reinschmidt *et al.*, 2006). They also valued their bridging role in delivering health advice to communities and feeding back knowledge of local concerns (May & Contreras, 2006). By virtue of their non-professional status, LHWs are perceived as being better able to translate technical information into simple, practical and culturally relevant messages. In an evaluation of lay food and health workers in England, one key stakeholder expressed this as "*thinking more in terms of food and meals, rather than in terms of nutrients and nutrition*" (Kennedy, Milton & Bundred,

2008). By translating information on local health needs into messages that have salience for health professionals, LHWs are also seen as being able to raise awareness of gaps in service provision and created additional demand for existing services by addressing access barriers (May & Contreras, 2006). This is supported by quantitative studies showing LHWs to be effective in engaging with 'hard-to-reach' groups and increasing their uptake of relevant health services.

As they do not share the same demands on their time as health professionals, LHWs may be viewed as an additional resource for use in meeting the aims of health, social care and other agencies (Kennedy, Milton & Bundred, 2008). They are reported by stakeholders to be successful in engaging with typically hard-to-reach groups, thereby increasing service coverage in a way that is felt to represent good value for money (Kennedy, 2010). As such, they are often seen as a cost-effective substitute for professional services by stakeholders who perceive community work as expensive and time-consuming. However, risks have been identified in viewing LHWs as a replacement for professionals, in terms of the potential for duplication of effort and both parties feeling undermined (Britten, Hoddinott & McInnes, 2006; Ward, Brough & Power, 2009). Some stakeholders felt that developing networks between LHWs and more formal agencies would help to reduce these risks and increase the likelihood of lay-led programmes being sustained as complimentary to professional services (Beam & Tessaro, 1994). There were reports that recruitment and training for LHWs can be time-consuming and that they often require more ongoing support than anticipated (Elford *et al.*, 2002; Kennedy, Milton & Bundred, 2008). Ensuring that host organisations have some ownership of LHW programmes and that these become an accepted part of the services they offer can potentially help to enhance their acceptability and reduce conflict (Ziersch, Gaffney & Tomlinson, 2000; Kennedy, Rogers & Gately, 2005; Ward, Brough & Power, 2009).

### ***Feedback from lay health workers***

A growing number of studies have sought to explore the experiences of LHWs by using open-ended interviews or focus groups, often supplemented with observations and/or written activity logs. These studies have demonstrated a high degree of motivation, enthusiasm and commitment to the LHW role, and also identified variation in the factors that initially motivate someone to accept a lay worker position (Miller, Klotz & Eckholdt, 1998; Whittemore *et al.*, 2000). These factors include wanting to contribute something to the community or set an example for their children, and hoping to secure paid employment after gaining experience in a

voluntary LHW role (Downing *et al.*, 1999; Dickson-Gomez, Knowlton & Latkin, 2003; Racz & Lacko, 2008). The primary motivation of these workers, coupled with the flexibility inherent to most LHW programmes, can help to shape the activities they undertake on a day-to-day basis. In the case of a work-based programme delivered in the USA, LHWs were categorised as primarily motivated by an interest in general health (prevention-oriented) or because of a specific health concern or event (health issue-oriented), with the majority falling into the second category (Tessaro *et al.*, 2000). Those identified as prevention-oriented were seen as more proactive in approaching co-workers to disseminate health information, whereas the health issue-oriented LHWs tended to respond to specific requests for advice. A qualitative study conducted in Hungary investigated workers matched with their clients by age (age-based peer helpers) or due to their shared status as ex-drug addicts (way-of-life peer helpers) (Racz & Lacko, 2008). The age-based helpers emphasised the importance of individual competence and limits of the LHW function as the defining elements of the role, whereas the way-of-life helpers placed greater emphasis on personal credibility and similarity in terms of life experiences. The latter group also demonstrated greater personal involvement with their clients.

The LHW role comprises multiple dimensions and domains of practice, including health advocacy, dissemination of health advice, increasing service utilisation, establishing social networks, building community capacity, and mobilising community resources (Whittemore *et al.*, 2000; McQuiston & Flaskerud, 2003; Struthers *et al.*, 2003; Daniels *et al.*, 2005; Teela *et al.*, 2009). In addition to providing emotional and social support, LHWs are often required to provide practical support to those living in marginalised communities. This might involve making appointments, providing transportation, distributing materials such as condoms, and providing an informal translation service (Beam & Tessaro, 1994; Baker *et al.*, 1997; McQuiston & Flaskerud, 2003; May & Contreras, 2006). Queries have been raised about the sustainability of this strategy. Instead of driving people to their appointments, LHWs may feel it is more appropriate to look into bus routes or lobby for better public transport services (Baker *et al.*, 1997; Kennedy, Milton & Bundred, 2008). Their role as a bridge into local communities offers a number of advantages but could also result in frustration when it leads to highlighting issues that remain unresolved (Racz & Lacko, 2008). Other reported sources of frustration include having to explain the service to each new client due to its low visibility, attempting to work with people who are not motivated and being measured against standardised measures that fail to account for unanticipated successes (Whittemore *et al.*, 2000; Elford *et al.*, 2002).

Specific features of lay-led interventions that were perceived to enhance their effectiveness included the core principles of mutuality, reciprocity and trust. Having shared illness experiences or shared socio-demographic characteristics facilitated empathy and mutual support, encouraging clients to take control of their own lifestyles (Whittemore *et al.*, 2000; Springett, Owens & Callaghan, 2007). This made it possible for LHWs to use themselves as reference points or role models, often sharing their own personal struggles in order to build confidence and enhance motivation amongst clients (Stevens, 1994). In one study, sharing their stories with other team members and recognising the similarities between their experiences also resulted in enhanced self-esteem for the LHWs (Downing *et al.*, 1999). Reciprocity is a key feature of lay-led interventions that leads to a number of mutual benefits for LHWs and clients. Various qualitative studies report increases in empowerment and knowledge, awareness of health messages, personal development, enhanced communication skills, positive behaviour changes and resolution of personal problems by the lay workers themselves (Booker *et al.*, 1997; Miller, Klotz & Eckholdt, 1998; Downing *et al.*, 1999; Whittemore *et al.*, 2000; Racz & Lacko, 2008; Karwalajtys *et al.*, 2009). A small study involving four Native American LHWs identified benefits including the experience of a self-growth process and a sense of pride (Struthers *et al.*, 2003). Other studies also reported positive feelings and intrinsic rewards arising from the delivery of interventions. This is illustrated by the following quote from a LHW involved in providing telephone-mediated social support to older heart patients: *"I've had people say that they enjoy the talks, and I say the same thing. I say they're beneficial to me. So I think that they get something out of it, and I get something out of it"* (Whittemore *et al.*, 2000).

LHWs report that it takes time to build and maintain the trust required to work effectively with people from marginalised communities. Working with people from their own social networks can represent something of a shortcut, although challenges remain in terms of addressing difficult or embarrassing issues (Downing *et al.*, 1999; McQuiston & Flaskerud, 2003). A gym-based intervention targeting gay men presented challenges for the LHWs in terms of approaching men to discuss safe sex practices (Elford *et al.*, 2002). The LHWs preferred to discuss the less taboo issue of steroid use and to approach people who were already known to them, although this created the potential for personal conflict. Lay-led approaches can also create concerns relating to confidentiality, leave LHWs feeling vulnerable and make it difficult for them to end relationships with their clients (Whittemore *et al.*, 2000). This is illustrated by the following quote from a LHW, talking about a



client who had lost her daughter: “It was very difficult... I felt emotionally tangled... It made me so sad, so I cannot imagine how she must have felt”. LHWs are identified in the research literature as being at particular risk of fatigue and burnout (Haour-Knipe, Fleury & Dubois-Arber, 1999). They also report concerns about marginalised communities becoming dependent on them to provide services that would typically be provided by health professionals (Daniels *et al.*, 2005). Other studies report feelings of mistrust, particularly where LHWs are required to perform basic medical services (Daniels *et al.*, 2005; Teela *et al.*, 2009). These findings highlight a perceived need for ongoing support and training, as well as sufficient recognition in terms of remuneration (Karwalajtys *et al.*, 2009).

Similar to the feedback from key stakeholders, studies involving LHWs highlight the importance of working closely with professional-led services to deliver effective health improvement interventions. A study conducted in Alaska set out to compare villages with high and low retention rates for LHWs involved in providing primary care services (Landon *et al.*, 2004). Interviews with 41 LHWs from 15 villages identified that those reported to be receiving professional support, in terms of their respect for and understanding of the role, had the highest retention rates. Support from the local community and their families, as well as adequate supervision, training and pay, were also reported to help to increase retention. Other studies report that professional support can enhance the experiences and effects of LHWs, but that it takes time to build these relationships (Booker *et al.*, 1997; Doherty & Coetzee, 2005). LHWs may initially be seen as a threat or burden, but cooperation can be achieved once others achieve an understanding of their role (Haour-Knipe, Fleury & Dubois-Arber, 1999). In situations where LHWs feel unsupported or actively discriminated against, this can undermine the work of the intervention (Ziersch, Gaffney & Tomlinson, 2000). Other potential threats to LHW programmes include: dealing with gatekeepers and illegal activities (Dickson-Gomez, Knowlton & Latkin, 2003); the challenges and risks involved in conducting outreach in public drug use sites (Dickson-Gomez *et al.*, 2006); and rapid changes in the target communities, particularly migrants (Haour-Knipe, Fleury & Dubois-Arber, 1999).

### ***Experiences of intervention recipients***

The few studies incorporating feedback from clients or users of lay-led health services largely reinforce the feedback from LHWs and key stakeholders. People seem to value the natural helper and bridging roles of LHWs, and appreciate their



flexible, user-centred approach (Springett, Owens & Callaghan, 2007). Matching LHWs and clients by socio-cultural and personal characteristics can increase the likelihood of them relating well to one another, enabling clients to gain confidence and feel secure during the intervention (Reinschmidt *et al.*, 2006). Semi-structured interviews with 29 older African-American women to elicit perceptions of the North Carolina Breast Cancer Screening Programme (NC-BCSP) found that the LHWs were seen as credible sources of information (Flax & Earp, 1999). Almost half of those interviewed were related to a LHW, whilst others described them as friends or people who had grown up in the same area. The authors of this study suggest that the willingness of the women to talk about a sensitive topic like breast cancer is indicative of the credibility of the information source. A similar issue was raised with negative implications in a study of a LHW intervention to deliver HIV prevention education to lesbian and bisexual women (Stevens, 1994). In this case, a small minority of women reported feeling resentful that the intervention had made HIV an issue within the lesbian community. LHWs are often seen as a valuable source of information that is either not available elsewhere or that they would have been too embarrassed to seek out (Ziersch, Gaffney & Tomlinson, 2000). They take information to the community in a way that is perceived as accessible and consistent, as illustrated by the following quote: *“Always seeing you around challenges me to keep looking at what I’m doing that could be risky”* (Stevens, 1994). However, some people feel that professionals are the most appropriate source of information on health matters and prefer to receive advice from someone who is not personally known to them (Ziersch, Gaffney & Tomlinson, 2000; Reinschmidt *et al.*, 2006).

Where users report negative perceptions of LHW programmes, this is largely due to concerns about confidentiality or feeling uncomfortable in talking about certain issues outside of the family setting (Flax & Earp, 1999). Most feedback is wholly positive and users report a range of perceived health and social outcomes as a result of receiving support from a LHW. In a six-year follow-up study of an asthma self-management programme, participants reported being better able to communicate with health services, being more involved in a range of social and recreational activities, and having strengthened links with other community members (Ratima *et al.*, 1999). They reported altering their smoking, exercise and dietary habits, as well as making changes that affected the whole family, such as having a smoke-free home. However, this research was conducted with a rural Maori community in New Zealand and therefore may not be applicable in other settings. A study conducted with Latino communities in the USA demonstrated the

importance of the bridging role for recent immigrants, who perceived the LHWs as both a friend and a valuable resource (May & Contreras, 2006). An outcome of this intervention was enhanced self-esteem, as illustrated by the following quote: *“Yes, my self-esteem was very low. I cried all of the time. Instead of saying no, I cried. I could not defend myself. Until the day I started to participate with [the LHW programme]. I noticed that step-by-step they were helping me. They made me feel I was worth something”*. Other LHW programmes result in raised awareness of health issues and local services, as well as increased access to health resources (Stevens, 1994; Baker *et al.*, 1997). Participants in an intervention targeting lesbian and bisexual women suggested it had had an important effect on attitudes towards HIV risk. This is illustrated by the following quote: *“I’ve seen your presentations several times and it has changed my whole outlook. Now I’m exploring sexuality through my commitment to practice only safe sex”* (Stevens, 1994).

### **Summary of the qualitative evidence**

The available qualitative research literature has demonstrated that LHW interventions are generally perceived in a positive light by key stakeholders, lay workers and service users. The basis of these interventions in local communities is felt to offer value in terms of the dissemination of health messages to community members and the communication of information on local health needs back into health services. Stakeholders also value the flexible, informal approach employed by the LHWs, who are highly motivated for personal and professional reasons. The lay workers themselves are often beneficiaries of lay-led interventions, in terms of the training received and changes made to their own lifestyles. However, there are a number of risks and challenges involved in working with local communities, including embarrassment about talking to people within their own social networks, concerns about confidentiality and the potential for issues to remain unresolved. Furthermore, some service users prefer to discuss health concerns with a professional. This qualitative data can be used to supplement quantitative studies, which tend to focus on gathering evidence of lifestyle change and physical health improvements at the expense of outcomes such as health literacy and social influence (the second level of Nutbeam’s model). Additional research is needed to explore in depth the user experience and determine the range of outcomes that can be expected from LHW interventions.

## **Evaluations of local health trainer programmes**

As with the existing quantitative research, much of the qualitative literature relating to lay-led interventions comes from an overseas context and particularly North America. The final section of this chapter concerns evidence relating specifically to the evaluation of health trainer programmes in the UK. This evidence was sought in recognition of the unique features of the health trainer role. A total of 13 service evaluations were identified for inclusion in the review; no exclusions were made on the basis of study design or quality in order to provide a comprehensive overview of the existing literature. A summary is given in table 4, with the evaluations presented in chronological order to demonstrate the accumulating evidence base. Key findings are discussed below, organised into sub-sections on recruitment and training, service delivery, outcomes and cost-effectiveness.

### ***Recruitment and training issues***

Evaluations of the implementation of health trainer programmes have shown that there tends to be an initial lack of clarity about the role, alongside enthusiasm regarding its potential benefits (Brooker & Sirdifield, 2007; Simpson, 2008; Ward & Banks, 2009; Ball & Nasr, 2011). Ambiguity arising from the combination of a lay or 'common sense' approach with a highly structured behaviour change model may mean that potential support needs are not anticipated. For example, an evaluation of health trainers in West Sussex identified a perceived need for more structured learning and opportunities for staff to improve their computer literacy (Ward & Banks, 2009). A similar evaluation conducted in Rotherham found that the skill requirements of the role were felt to be too high for some of those recruited, who reportedly found it difficult to communicate outside of their own communities (Simpson, 2008). Focus groups with health trainers in criminal justice settings have identified increased knowledge and confidence levels following participation in tailored training programmes (Brooker & Sirdifield, 2007; Ball & Nasr, 2011). They also identified a need to spend more time on each topic to increase the depth of their knowledge. Tension arises from the need for training to be more practical whilst recognising that the full skills base for health trainers can only be gained in 'live' settings (Ball & Nasr, 2011). A qualitative study by Jackson *et al.* (2008) found that, following completion of training, the health trainers' views of behaviour change shifted from an understanding of limiting factors to an appreciation of complexity. However, this study was described in a published conference abstract and was therefore lacking in detail on key issues such as sampling and data collection.

**Table 4: Overview of health trainer programme evaluations**

Reference	Focus	Publication type			Methods		
		Peer reviewed paper	Unpublished report / dissertation	Published abstract	Qualitative	Quantitative <sup>10</sup>	Economic evaluation
Sirdifield (2006)	Piloting prison-based health trainers to promote mental health	✓			✓		
South <i>et al.</i> (2006)	Recruitment, training and delivery of health trainers		✓		✓	✓	
Brooker & Sirdifield (2007)	Piloting the health trainer role in criminal justice settings		✓		✓	✓	
South <i>et al.</i> (2007)	Stakeholder perspectives on a pilot health trainer programme	✓			✓		
Jackson <i>et al.</i> (2008)	Evaluating the implementation and training of health trainers			✓	✓		
Simpson (2008)	Evaluating the implementation of a local health trainer programme		✓		✓		
Dugdill <i>et al.</i> (2009)	Reflective learning mechanisms employed by health trainers and community food workers	✓			✓		
Ward <i>et al.</i> (2009)	Evaluating the first year of provision of HIV health trainer services			✓		✓	
Ward & Banks (2009)	Recruitment, training and delivery of health trainers		✓		✓	✓	
Ball & Nasr (2011)	Evaluating health trainer programmes in two PCTs	✓			✓		
Barton <i>et al.</i> (2011)	Economic evaluation of health trainers to improve heart health	✓				✓	✓
Power <i>et al.</i> (2011)	Evaluating HIV health trainer services			✓	✓	✓	
Wilkinson <i>et al.</i> (2011)	Baseline data from a local health trainer service	✓				✓	

<sup>10</sup> In all but two evaluations, the term 'quantitative methods' refers to the use of monitoring data routinely collected by health trainer services; for example, client numbers, demographic characteristics and completion rates. The evaluations by Barton *et al.* (2011) and Power *et al.* (2011) involved the collection of outcome data, although the latter is a published conference abstract and therefore lacking in the detail required to assess the validity of the methods.

### **Service delivery**

The majority of published and unpublished works on the subject of health trainers are process evaluations, often involving the use of qualitative methods and small sample sizes. A recurring theme is the challenges involved in promoting the service, with these efforts reportedly being hampered by public perceptions of the health trainer label as well as misunderstandings amongst professional groups (South, Woodward & Lowcock, 2007; Ward & Banks, 2009). One evaluation reported that the role label was perceived as 'middle class' by communities (Simpson, 2008). The tensions between maintaining a local focus and a standardised national profile can result in feelings of frustration and isolation amongst staff (Ball & Nasr, 2011). Although key stakeholders tend to be less clear about the remit of the role, they generally perceive health trainers to be an acceptable way of giving people more responsibility in looking after their own health. Telephone interviews undertaken with 16 placement organisations in Bradford highlighted the value of providing employment opportunities for local people who could serve as role models for others (South, Woodward & Lowcock, 2007). However, these stakeholders had a track record of partnership working and the one-to-one health trainer model was particularly valued by organisations with an emphasis on group activities. Health trainers may be seen as either complementary to existing service developments or duplicative if the boundaries of the role are unclear (South *et al.*, 2006; Ward, Brough & Power, 2009). Efforts are required to connect both with professionals and community members to ensure that the services are accepted.

Studies documenting the characteristics of the client populations served by local health trainer services have shown that they often attract significant proportions of women and clients from black and minority ethnic (BME) communities. For example, in the aforementioned evaluation of health trainers in Bradford, complete monitoring data collected on 97 clients found that 83 per cent were female and 47 per cent were White British (South *et al.*, 2006). Reaching men through this service was reported to be particularly difficult. In contrast, a London-based service targeting people with HIV achieved an even sex ratio, whilst 61 per cent of clients were categorised as either Black Caribbean or Black Other (Ward, Brough & Power, 2009). However, the sample size for this evaluation is not given due to these findings being reported in a published abstract. Wilkinson *et al.* (2011) conducted a cross-sectional study examining baseline data obtained from questionnaires completed by 864 service users at their first meeting with a health trainer. This involved a mostly female client group, with 43 per cent from BME communities, 77

per cent living in rented accommodation and 40 per cent with no qualifications. The average BMI (where measured) was approximately 32kg/m<sup>2</sup> and 53 per cent of clients smoked. These data suggest that the health trainers had reached clients from low socio-economic groups who were engaging in unhealthy behaviours. However, these findings come from one London-based service and therefore cannot be generalised to other areas. Furthermore, the significant proportion of clients educated to degree level (22 per cent) highlights the potential to attract those who may be more able to seek help elsewhere. Data available for 406 clients demonstrated that the main referral route was via the client's GP (77 per cent). The authors of this study suggest that encouraging community- and self-referrals might help to ensure that health trainer services reach those least likely to seek help (Wilkinson, Sniehotta & Michie, 2011).

Another recurring theme in the literature involves the complex and challenging issues faced by health trainers, such as bereavement, alcoholism, abuse and debt (Dugdill *et al.*, 2009). Clients often present multiple physical, mental and social needs that may be revealed over time and only once a trusting relationship has been established (South, Woodward & Lowcock, 2007; Ball & Nasr, 2011). Less than one per cent of clients in the aforementioned cross-sectional study chose a mixed behaviour change goal (Wilkinson, Sniehotta & Michie, 2011). Smoking cessation and healthy eating were the most common priorities (41 per cent and 39 per cent respectively), although it is likely that these were influenced by the GP referral route and constrained by the goal-setting system. Qualitative research suggests that unhealthy behaviours tend to be symptomatic of underlying concerns, and linked to low confidence and self-esteem (South, Woodward & Lowcock, 2007; Dugdill *et al.*, 2009; Ball & Nasr, 2011). Holistic, flexible and tailored interventions are perceived as being most successful, particularly those that combine practical and emotional support (Dugdill *et al.*, 2009; Ward & Banks, 2009; Ward, Brough & Power, 2009). Clients highlight the appeal of the one-to-one approach and having sufficient time to discuss any issues with an impartial but approachable stranger (Ball & Nasr, 2011). The literature indicates a need to set clear boundaries so that clients, health trainers and stakeholders understand the limits of the role (Sirdifield, 2006; Ward & Banks, 2009). Although the emphasis is on listening rather than advice-giving, this can sometimes be a cause of tension where clients would prefer a more directive approach (South, Woodward & Lowcock, 2007; Simpson, 2008). A key issue is avoiding a 'one-size-fits-all' intervention. Health trainers generally find the role rewarding and feel that they are making a difference, whilst recognising that this may be difficult to quantify (Dugdill *et al.*, 2009; Ball & Nasr, 2011).



### **Outcomes and impact**

Fewer publications were available to assess the intended outcomes and impact of local health trainer services. A qualitative evaluation of the service in Rotherham identified perceived benefits to the health trainers, in terms of lifestyle changes, a willingness to undertake further training, increased confidence and a sense of pride in their work (Simpson, 2008). This unpublished evaluation did not seek to include the views of service users and is lacking in detail on recruitment to the sample. A published conference abstract by Power *et al.* (2011) reported on the evaluation of health trainers working with people who had HIV in five areas in England. This study involved the collection of quantitative outcome data from service users and demonstrated that, of those showing improved scores, 86 per cent increased their knowledge of HIV and 59 per cent adopted healthier living practices. However, information is not given on the overall sample size and so it is not possible to judge the scale of these improvements. In Bradford, interviews were conducted with 22 former clients and 18 were reported to have made lifestyle changes following completion of a health trainer-led intervention (South *et al.*, 2006). Ten clients also said it had benefitted their friends and family members, and 20 said they would recommend it to others. A similar 'ripple effect' was reported in West Sussex, along with weight loss, increased confidence levels and a sense of wellbeing (Ward & Banks, 2009). Some clients had not achieved changes to the extent they would have liked but were perceived to have made progress and were 'on the right track'.

Two publications relate specifically to outcomes for health trainers in criminal justice settings; one of these is a published paper concerning the pilot programme (Sirdifield, 2006) and the other is an unpublished report detailing a more comprehensive impact assessment (Brooker & Sirdifield, 2007). The pilot study identified a perception that offenders are more likely to take the advice from a health trainer on board than health professionals or prison staff (Sirdifield, 2006). There were also reports of health trainers making changes to their own behaviours, although this study was based on a focus group involving just two participants. The broader impact assessment found that key staff within the pilot sites were optimistic that the programme could contribute towards meeting prison work-skills targets and lead to a reduction in re-offending (Brooker & Sirdifield, 2007). They also reported increases in service use, particularly in areas such as smoking cessation and gym-based exercise, and increases in staff awareness of health issues. This evaluation was based on feedback from stakeholders in prison and probation settings.



### **Cost-effectiveness**

Only one publication detailing an economic evaluation of a local health trainer service was located. Barton *et al.* (2011) recruited patients with one or more cardiovascular disease risk factors from five GP practices serving deprived communities in Liverpool. The control group received health promotion literature only, while the intervention group also had access to a theory-based intervention (using social cognitive models) delivered by health trainers. The mean intervention cost was calculated at £151.01 per participant, although this ranged from £17.25 to £766.41. The impact of the intervention on health-related quality of life was estimated using the EQ-5D, a standardised instrument which participants completed at baseline and at the end of the six-month trial period. The mean baseline EQ-5D scores were 0.829 for controls and 0.833 for intervention recipients, increasing to 0.915 (mean gain= 0.086) and 0.946 (mean gain= 0.113) respectively after six months. This gave respective mean QALY gains of 0.022 and 0.028, resulting in an estimated QALY gain of 0.007 for the intervention. The mean NHS and social service costs fell in both groups but by slightly more in the intervention group, resulting in an incremental cost per quality adjusted life-year (QALY) of £14,480.34. This is more favourable than the threshold of £30,000 per QALY gained set by NICE, suggesting that the intervention represents value for money. Furthermore, this may have been a conservative estimate if the benefits of the intervention were sustained beyond the six-month trial period. Limitations of the study centre on the short follow-up period and small numbers involved. A total of 38 individuals were recruited to the control group and 72 to the intervention group, although letters were sent out by GPs to 2,275 patients. It is therefore likely that the sample included the most highly motivated patients. Furthermore, complete QALY data were available for only 41 intervention recipients, 25 of whom achieved a QALY gain. Many had no face-to-face contact with a health trainer but those who did had the highest mean QALY gains. The authors of this paper conclude by stating that, "Further (qualitative) research might therefore be undertaken to assess why some individuals seem to engage more with the intervention" (Barton *et al.*, 2011 , p.5).

### **Chapter summary**

There are a number of commonalities between the findings of evaluations of local health trainer services and research literature concerning similar lay workers. These services tend to attract higher numbers of women and individuals from BME groups, both as clients and volunteers or employees. The holistic, flexible nature of lay-led

interventions is seen as a potential advantage in attempting to tackle complex health and social issues. Qualitative studies demonstrate that LHWs are perceived as having the potential to increase the coverage and equity of service delivery at low cost, although few studies have sought to definitively evaluate LHWs in comparison with professional-led interventions. The specific strengths of the LHW role include high levels of accessibility, acceptability and cultural sensitivity, but there are also a number of limitations, including concerns regarding confidentiality and the potential for conflict when working in their own communities. Lay-led interventions can be used to improve selected outcomes for some health conditions but the evidence of their ability to yield significant health impacts that are sustained over time is mixed. Furthermore, much of the existing literature derives from poor quality studies conducted in developing countries or involving interventions targeted at specific BME communities. There is a need for additional research in a range of contexts and with different population groups to fully evaluate the effectiveness, cost-effectiveness and acceptability of LHW programmes.

The Medical Research Council (MRC) provide guidance on the development, evaluation and implementation of complex interventions (Craig *et al.*, 2008). This guidance sets out important questions to be asked that include: “Are you clear about what you are trying to do, what outcomes you are aiming for and how you will bring about change?... Can you describe the intervention fully, so that it can be implemented properly for the purposes of your evaluation and replicated by others?” (MRC, 2008, p.4). The exploratory literature review described in this chapter demonstrates that it is not possible to answer these questions using the existing evidence base to support the implementation of health trainers in the UK. Therefore, further development work is needed before a definitive outcome evaluation can be implemented. Robust qualitative studies can shed light on intervention components and unexpected outcomes, as well as furthering our understanding of why some individuals choose not to engage with lay-led interventions. This is consistent with the development stage of the MRC framework, and the problem definition and solution generation stages of Nutbeam’s model for the evaluation of health promotion (Nutbeam, 1998; MRC, 2008). Furthermore, the findings of longitudinal qualitative studies can help to inform policy and practice by suggesting which types of intervention might be most appropriate and effective in particular contexts over a period of time. This provides the rationale for the selection of a longitudinal qualitative research approach, which is described in detail in the next two chapters.

## Section B: Research strategy

The purpose of the following section is to describe in detail the study design and methodology employed in conducting the research. It incorporates an overview of the research paradigm used to inform the study. The basic beliefs that define a researcher's worldview or inquiry paradigm can be summarised by the responses given to the following questions, from Guba and Lincoln (1994):

1. What is the form and nature of reality and, therefore, what is there that can be known about it? (The ontological question)
2. What is the relationship between the knower and would-be knower, and what can be known? (The epistemological question)
3. How can the inquirer go about finding out whatever he or she believes can be known? (The methodological question)
4. What are the means by which knowledge can be collected or constructed? (The methods question)

These four components (shown in figure 9) constitute the research strategy, which represents the interface between methodic practice, substantive theory and the epistemological underpinnings of a study (Harvey, 1990). Each of the stages is discussed in the following two chapters. Chapter 4 outlines my philosophical and methodological approach to the study, whereas Chapter 5 describes the activities involved in constructing the data that are presented in the remainder of the thesis. The term 'data construction' has been deliberately chosen over alternatives such as 'gathering' or 'obtaining' data to reflect the way in which the participants are acknowledged as having contributed to the mutual construction of their accounts.

**Figure 9: Stages of a research strategy**



## **Chapter 4: Philosophical and methodological approaches**

At the outset of any research project it is important to make explicit the philosophical perspectives and presuppositions that will inform the knowledge generated by the process of enquiry (Guba & Lincoln, 1994). This chapter outlines my philosophical approach to the research, after the study aims and objectives have been introduced. I provide a rationale for the ontological, epistemological and methodological decisions made in devising the research strategy, in comparison with available alternatives. Grounded theory is presented as the chosen methodology and alignment with my research philosophy is demonstrated. The chapter concludes with a brief argument for pragmatic pluralistic approaches in studying complex public health issues and interventions.

### **Aims and objectives**

The initial aim of the research was to address the gaps in the existing evidence base by conducting a qualitative exploration of user engagement and health-related behaviour change in the NHS Health Trainers Initiative. Over the course of the study, it became apparent that accessing support from a health trainer was just one element of service users' efforts to adopt and maintain healthy lifestyles. In order to achieve a fuller understanding of the behaviour change process, my initial aim was refined into two separate but closely linked aims:

- i. To explore the processes involved in attempting to make and maintain health-related behaviour changes from the perspectives of people living in socio-economically disadvantaged areas; and
- ii. To qualitatively evaluate the contribution of the health trainer role to supporting people in these attempts

More specifically, the study objectives were as follows:

1. To explore the factors that motivate users to access lay-led health improvement interventions such as those delivered as part of the NHS Health Trainers Initiative
2. To identify perceived barriers and facilitators to the engagement of individual users and communities with lay-led interventions

3. To identify perceived barriers and facilitators to the adoption and maintenance of health-related behaviour changes by users of health trainer services
4. To compare and contrast the experiences and perceptions of users, managers and health trainers operating within different models of local service provision
5. To inform the future development and evaluation of the NHS Health Trainers Initiative and similar lay-led interventions

By conducting a qualitative comparison of one-to-one and community-level approaches to health trainers, I sought to highlight the underlying mechanisms by which different intervention models might influence outcomes. The following sub-sections describe the study design employed to address the aims and objectives.

### **Philosophical approach**

As shown in figure 9, the process of developing a research strategy begins with the inquirer's ontological position. Ontology is the philosophical study of the form and nature of reality, and addresses questions about the nature of being (Guba & Lincoln, 1994). The study described here is primarily concerned with participants' perceptions of the factors that help or hinder in attempting to lead a healthy lifestyle, their experiences of accessing or delivering a health trainer-led intervention, and the perceived impact of these interventions. Reality in this research is viewed from the perspective of the researched and gives primacy to their individual understandings of the NHS Health Trainers Initiative, which are influenced by their experiences of the world and the meanings they place on things. However, it was also recognised that participants would be likely to refer to shared experiences such as material disadvantage, ill-health and disability. The chosen research approach therefore had to acknowledge the existence and value of both the participant's interpretation and their lived reality. Critical realism has been advocated as both an explanatory and action theory in health promotion, due to its emphasis on the existence and influence of structures that lie beneath the surface of social reality (Archer *et al.*, 1998; Connelly, 2001). Unlike positivism, critical realism argues against the idea that human beings are reducible to passive subjects and, unlike interpretivism, opposes all forms of relativism as inadequate in leading to positive action. Whilst I am in favour of advocacy and activism in public health, a pragmatic approach had to be taken in recognition of the limits of the doctoral project to influence change.

***Subtle realism***

My ontological position in conducting this study can be described as a form of subtle realism, which assumes that a social world exists independently from individual subjective understanding but that this is only accessible from my interpretation of the accounts constructed by others (Hammersley, 1992; Hammersley & Atkinson, 1995). The advantage of subtle realism over other forms of realism is that it acknowledges the paradox of only being able to discuss the 'real world' in the relativist arena of discourse and representation (Cromby & Nightingale, 1999). As such, it involves attempts to explore and represent this underlying reality, rather than attain 'the truth'. There exist many truths and multiple realities, resulting from our individual interpretations that simultaneously enable us to understand and construct the social world around us (Grant & Giddings, 2002). In this research I set out to explore these many truths by exploring what meanings people attach to their health-related behaviours and the events of their lives. Hence, the study is informed by symbolic interactionism and, to a lesser extent, social constructionism. The former is concerned with the study of interactions and relationships between individuals and society, and the way in which social structures develop from these repeated interactions (Denzin, 1978). The use of a symbolic interactionist approach in this study was intended to highlight issues that arose from health promoting activities mediated through the symbolic significance of phenomena to individuals (for example, attitudes to food and physical activity) and through others (for example, the language used by health trainers versus professional advice-givers).

The social constructionist view also assumes an emergent reality fundamentally shaped by social interaction. It argues that the social reproduction and transformation of structures of meaning, conventions and discursive practices principally constitutes both our relationships and ourselves (Cromby & Nightingale, 1999; Edley, 2001). Language is therefore central as the dominant carrier of categories and meanings, although there is some disagreement amongst social constructionists as to whether a real world exists beyond the text. Within the subtle realist perspective it can be argued that phenomena such as poverty, inequality and disease are both socially constructed and real, emerging through social processes that are shaped by influences such as power relationships and material resources. As this approach offers an open-ended and flexible means of studying both fluid interactive processes and more stable social structures, it was deemed highly relevant to the aims of this research (Charmaz, 1990). Taking a subtle realist view also provided tools for linking subjective consciousness and personal choice to

macro social structures, and brought a critical posture to examining the data. This perspective fosters asking critical questions about how society impinges upon the individual and how individuals reproduce dominant ideas within society (Charmaz, 1990; Hammersley, 1995). These questions have inevitably been addressed in the present study due to its focus on marginalised groups, along with the factors that contribute to their disadvantaged social positions and poor health outcomes.

### ***Interpretivism***

A major focus of social constructionism is to uncover ways in which individuals and groups participate in the creation and consolidation of the perceived social reality (Bury, 1986). In the present study, this involved exploring the participants' stories for the creation of taken-for-granted definitions, ideas and knowledge about health and behaviour. It also involved paying attention to my own social constructions – influenced by my personal and professional background and experiences – and to the role of power in this process. This highlights the importance of considering the researcher's epistemological position at the outset of any study. Epistemology is the theory of knowledge and concerns the means of knowledge production (Benton & Craib, 2001). In considering the most appropriate approach to this study, I began by drawing upon my prior experience as a research assistant and my formal training via a recently completed Masters degree in public health. This allowed me to develop a broad understanding of the main research paradigms and their underlying theoretical assumptions, as well as a working knowledge of historical debates in health and social research. However, I was aware that I also needed to explore in depth the precise position of public health research in the context of rapidly changing health services. In order to appreciate the various perspectives, an exploration of the underlying epistemological and methodological assumptions was undertaken via extensive reading and formal training<sup>11</sup>.

Through this process I became aware that, although large randomised controlled trials (RCTs) have traditionally been seen as the 'gold standard' for investigating health problems, recent decades have seen an increasing recognition of the important role for social sciences and qualitative approaches in understanding complex health issues (Baum, 1995; Watson, Procter & Cochrane, 2004). For some

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<sup>11</sup> During the first year of the PhD, postgraduate modules were undertaken in research philosophies and issues (Northumbria University), public health intervention (Newcastle University), social divisions and inequalities (Newcastle University), and theories, methods and principles of medical anthropology (Durham University). These formed part of the tailored training programme associated with an NIHR doctoral training fellowship.



time it has been generally accepted that methodologies for public health research should be diverse and selected to suit the problem being investigated. Furthermore, there has been a growing acceptance of the need to take seriously people's own views about health (Popay & Williams, 1994). Ideological developments such as a move towards more upstream and collaborative approaches have created conditions for acknowledging the place for lay theories and understandings about health. The epistemological perspective taken in this research is interpretivism, which is founded on the study, expression and interpretation of human experience (May & Williams, 1998). In this approach, knowledge is created through the self-understandings of participants, rather than by the direct observations involved in positivistic methodologies. Furthermore, whilst positivists tend to distinguish between the objects of study and techniques used to research them, interpretivists emphasise the importance of the collaborative relationship between the researcher and subject in co-constructing the data (Guba & Lincoln, 1994; Grant & Giddings, 2002). Hence, the conventional distinction between ontology and epistemology becomes blurred, as that which can be known is inextricably intertwined with the way in which knowledge is created. The researcher's position must be made explicit to enable them to interpret a participant's story credibly (Grant & Giddings, 2002). This highlights the need for open-mindedness and reflexivity in order to move beyond a strict problem focus to a more general exploration of social phenomena.

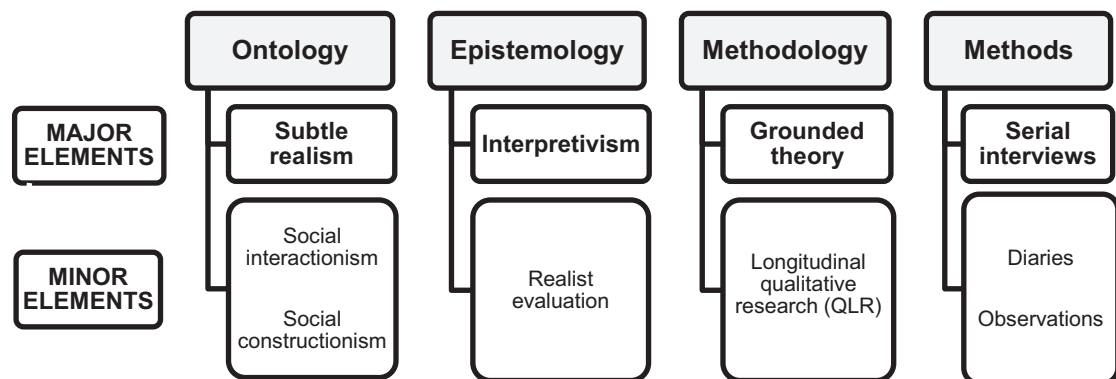
My epistemological stance is based on an understanding that the participants in this study are experts in their own lives and that my role was to investigate the socially constructed meanings and behaviours that constitute their realities. This follows from the literature on lay knowledge described in previous chapters, which recognises that people acquire an 'expert' body of knowledge through a combination of life experience, circumstances and personal history (Popay & Williams, 1996; Popay *et al.*, 2003). A qualitative approach was used to engage people in active, meaning-making dialogues and challenge their taken-for-granted beliefs and assumptions. Qualitative research involves the use of multiple methodologies to study real-world settings and generate rich narrative descriptions, in an attempt to make sense of phenomena in terms of the meanings people bring to them (Denzin, 1978; Fraser, 2004). This approach is most appropriate where quantitative methods would not be able to adequately describe or interpret a situation, or where one needs to identify the variables that might be tested quantitatively (Corbin & Strauss, 2008). In the present study, a qualitative interpretive strategy was employed in a manner consistent with the development phase of the Medical Research Council's (MRC) framework for the evaluation of

complex interventions (Craig *et al.*, 2008; MRC, 2008). It also shares the aims of realistic evaluation research, which involve understanding the causal mechanisms of an intervention and the conditions under which they operate to produce specific outcomes (Pawson & Tilley, 1997). Rather than asking “Does the intervention work?”, the question asked in undertaking a realistic evaluation is “What works for whom and under what circumstances?” This approach was deemed suitable for use in the present study as the emphasis is on understanding the mechanisms through which lay-led interventions produce behaviour change, identifying the contextual factors necessary to trigger these mechanisms and predicting the range of likely outcomes (Pommier, Guevel & Jourdan, 2010). Pawson and Tilley (1997) describe this as the context-mechanism-outcome (CMO) framework. The ability to evaluate the effects of health improvement interventions and how they might be replicated means that realistic evaluation is highly relevant to policy development.

## **Research methodologies**

Ontology and epistemology are key components of research paradigms, which provide frameworks of inquiry that define the nature of the world, the researcher's place within it and what falls within and outside the limits of legitimate inquiry (Guba & Lincoln, 1994). The following sections describe the final component of the chosen paradigm – the research methodology. In this study, the methodology involved the use of grounded theory, delivered through a longitudinal qualitative research approach (abbreviated to QLR in much of the existing literature). See figure 10 for an overview. Alternative options were explored in developing the study proposal; for example, a phenomenological approach could have been utilised to ask questions about the lived experiences of individuals seeking help from a health trainer (VanManen, 1990). However, the emphasis in phenomenology is on the common features of the lived experience, whereas this research was concerned with comparing and contrasting narratives to further understanding of different interventions. Employing a phenomenological approach would also have involved attempting to put aside or ‘bracket’ my presuppositions and understandings about health trainers in order to get back to the ‘real’ lived experience of the participants. Given my prior research in this area and existing links with the local health trainer teams, bracketing would have been very difficult to achieve. Grounded theory researchers, on the other hand, are recognised as social beings who create and recreate social processes (Charmaz, 1990; Baker, Wuest & Noerager-Stern, 1992). Ideas and assumptions about the situation are not put aside, but are instead used to understand better the processes being observed.

**Figure 10: Overview of the research design**



The possibility of using discourse analysis was also considered in order to investigate the way in which stakeholders use language and words to create meaning in relation to health, inequality and behaviour change. Discourse analysis involves examining how language both shapes and reflects cultural, social and political practices, through tracing the historical evolution of language practices (Gee, 2005). Grounded theory, on the other hand, involves inquiring about the ways in which social structures and processes influence the experience of individuals through their social interactions (Starks & Trinidad, 2007). This approach was felt to be most suitable in meeting the study aims and objectives due to the emphasis on identifying structural as well as contextual, symbolic and interactional influences, thereby highlighting the need to take account of both macro and micro influences on the phenomenon under investigation (Subgranon & Lund, 2000; Corbin & Strauss, 2008). Grounded theory has been described as “particularly useful in new, applied areas where there is a lack of existing theory and concepts to describe and explain what is going on” (Robson, 2002, p.90). This approach was considered appropriate for use in the present study as, although there exists a substantial body of literature on behaviour change theories and models, this relates primarily to professional-led interventions. The lack of theoretical and empirical research on the processes involved in lay-led behaviour change interventions was identified in Chapter 3, providing the rationale for the grounded theory methodology described here.

### ***Grounded theory***

Grounded theory was first developed in 1967 as a rigorous methodology for use in developing theory that is grounded in data systematically gathered and analysed (Glaser & Strauss, 1967). What differentiates grounded theory from other interpretive approaches is that it goes beyond induction to making conjectures and hypotheses and then checking them, so that the researcher engages in deductive reasoning as the inquiry proceeds. Concepts and theories are derived from the stories constructed by participants to explain and make sense of their lives (Corbin & Strauss, 2008). The 'groundedness' of this approach results from a commitment to analyse what has been observed in the field or in the data and remaining open to unanticipated directions, rather than being limited to preconceived hypotheses (Charmaz, 1990). This involves following interests, leads and hunches found in the data throughout the research and writing processes. There is also an ongoing search for evidence that disconfirms the emerging theory in an attempt to enhance its validity in accounting for the research phenomenon or situation. In the present study, it rapidly became clear that a narrow focus on behaviour change would not result in the development of a theory that accounted for the main concerns of the participants. This demonstrates one of the main features of grounded theory – resulting from its theoretical basis in social interactionism – which is that the researcher must remain open and sensitive to the main concern or problem for people in the study setting (Baker, Wuest & Noerager-Stern, 1992; Becker, 1993).

The original grounded theory methodology sought to combine the precision of statistical methods with the more fluid theory-generating style of the Chicago school of sociology (Baker, Wuest & Noerager-Stern, 1992). Positivism was the prevailing paradigm of that time and so the method had to be couched in language that could easily be understood and that was acceptable to quantitative methodologists (Coyne, 1997). However, this led to criticisms regarding the use of terminology that is often alien to other disciplines. Furthermore, Glaser and Strauss' earliest works have both phenomenological and positivistic emphases and therefore sometimes seem confusing and inconsistent. They lean towards assuming that the theoretical categories derive from the data and that the researcher remains passive, coming close to positing an external reality (Charmaz, 1990). Strauss' more recent explication of grounded theory reveals an actively involved researcher who constructs categories and concepts, and acknowledges the multiple standpoints and realities of both researchers and participants. This approach was considered suitable due to the relation with micro-sociological perspectives, which focus on the

interactions, exchanges and choices of people in the social context in which they occur. It also involves the provision of clear guidance on how to structure the data via a well-defined coding paradigm (Robson, 2002; Corbin & Strauss, 2008). Table 5 summarises key differences between Glaser's version of grounded theory and the Corbin and Strauss version employed in this study (Cooney, 2010).

**Table 5: A comparison of the main approaches to grounded theory**

<b>Key Features</b>	<b>Glaser</b>	<b>Strauss and Corbin</b>
<b>Ontology and epistemology</b>	Realist: assumes the existence of an objective and external reality Follows positivism	Relativist: multiple realities exist and are interpreted rather than fully known Post-positivist, then constructivist
<b>Researcher role</b>	Independent, neutral observer who discovers data	Researcher and participant co-construct the data and resulting theory
<b>Literature review</b>	Postponed until fieldwork is completed and used to support the emerging theory	Preliminary review enhances theoretical sensitivity Later reviews support emerging theory
<b>Research question</b>	Emerges over the course of the study	Derived from early literature searches, prior experience, etc, and modified during the study
<b>Data analysis</b>	Vague description of substantive and theoretical coding processes Largely inductive and unstructured	Clearly described process, with an emphasis on deduction and validation Criticised as being programmatic and over-formulaic
<b>Outcomes</b>	A grounded theory Failure to produce a theory is contrary to the goals of the methodology	A grounded theory Some studies will use the techniques associated with the methodology to produce thick descriptions

My rationale for the place of the literature review in this research was set out in Chapter 3. It would not have been appropriate to ignore the existing literature, nor would it have been appropriate for me to remain passive and independent, rather than being actively involved in constructing categories and concepts during the study. The social constructionist perspective put forward by Charmaz (1990; 2003) views the process of categorisation as dialectical and active; the interaction

between the researcher and participants, and subsequent interaction between researcher and data, results in 'discovering' the key concepts. Whereas objectivist grounded theory views the data as 'real' in and of themselves, constructivists view data analysis as a construction that locates the data in time, place, culture and context. This fits with the aim and theoretical basis of the present study, in terms of attempting to explore the experiences of people making health-related behaviour changes within the context of their everyday lives. It also builds upon a symbolic interactionist perspective in being based on the following assumptions: a) multiple realities exist; b) data reflect the researcher's and the participant's mutual constructions; and c) the researcher enters and is affected by participants' worlds (Charmaz, 2003). By selecting this approach, I set out to produce a theory that was relevant and able to guide action and practice.

### ***Longitudinal qualitative research***

Grounded theory researchers should return to the field continually in order to test the relevance of their ideas and achieve more nuanced understandings of the social processes in action (Glaser & Strauss, 1967; Charmaz, 2003). Sequential interviews were used in this study to explore the dynamic process of receiving support from a health trainer and attempting to make and maintain lifestyle changes. One of the specific strengths of repeated interviews is the accumulation of responses that can be read and compared against each other, so that a picture is built up of beliefs and orientations across different times, moods and situations. This approach, referred to as longitudinal qualitative research (QLR), involves recursive, comparative movement between past, present and future to give insight into the histories, orientations and aspirations of individuals (McLeod, 2003; Saldana, 2003). The distinguishing feature of QLR is the way in which temporality is designed into the research process, making change a central focus of analytic attention (Thomson, Plumridge & Holland, 2003). Longitudinal designs focus on the interaction of institutional and social contexts and the conditions these create, as well as personal biographies (McLeod, 2003). The use of QLR in this study – under the umbrella of grounded theory – has enabled prospective and retrospective understandings of health and lifestyle, as well as providing an opportunity to compare and move between the two. This approach is highly relevant in the current context in which individual behaviour change is seen as key to achieving policy goals (Thomson, Plumridge & Holland, 2003; Corden & Millar, 2007a). Following people over time provides an opportunity to explore how and why they make choices that add up to



trajectories of individual life histories and, more specifically, to understand the ways in which they respond to and use particular services (Corden & Millar, 2007b).

All QLR studies involve data collection at more than one point in time, although the overall duration of the research can differ widely. A long-term approach is often required to investigate life course transitions, whereas short-term studies might involve intensive tracking through an organisational process (Holland, Thomson & Henderson, 2006). Given the duration of the doctoral project, a pragmatic approach was taken in the selection of a 12-month follow-up period for this study. It is recognised that windows of observation are rarely sufficient to pick up all relevant change and that knowledge about prior history is generally needed to contextualise particular changes (Corden & Millar, 2007a). Asking prospective and retrospective questions over time means that a body of evidence from different perspectives is accumulated, and that responses can be read, checked and compared against each other (McLeod, 2003). The purpose is not to check for accuracy; instead, putting individual stories 'in conversation' with one another provides an opportunity to explore any gaps between the things people say and do. Asking participants to apply hindsight to their narratives is one of the tools of QLR and can produce important insights (Corden & Millar, 2007a). Returning to the field also contributes to the theoretical sampling process, which is a fundamental aspect of grounded theory research. This involves obtaining additional data to make the emerging theoretical categories more precise, explanatory and predictive (Charmaz, 2003). However, the possibility for changing interpretations over time can present a challenge to drawing clear conclusions from study findings. Other challenges associated with longitudinal approaches include sample attrition, maintaining informed consent and confidentiality, and the risk of conditioned responses or other effects associated with the extended research relationship. These are discussed in detail in Chapter 5.

### **An argument for pluralism**

Figure 10 demonstrates the hierarchical relationship between grounded theory and QLR in this study, as well as the various other elements of the research design. It is possible that adopting a pluralistic approach might render the study vulnerable to accusations of 'method slurring' (Baker, Wuest & Noerager-Stern, 1992). One of the strongest arguments for sticking to a particular methodology is to avoid the possibility of competing explanations for phenomena. However, this argument arises from the misconception that conformity with well-known analytic techniques and methods automatically guarantees rigour (Johnson, Long & White, 2001). By



ignoring their instincts and focusing too closely on published procedures, the researcher may find themselves in a situation with “the technical tail beginning to wag the theoretical dog” (Melia, 1996, p.376). Hammersley and Atkinson (1995, p.6) called for a more flexible and naturalistic approach, suggesting that “A first requirement of social research... is fidelity to the phenomena under study, not to any set of particular methodological principles”. This provides support for pragmatic pluralism, which is entirely consistent with my own view of research methodologies as complementary strategies to help the researcher come to grips with a complex social world and the data which might emerge from its study. An eclectic research design drawing on methods from a range of qualitative approaches could potentially have broader relevance to wider socio-political issues (Johnson, Long & White, 2001). It has also been suggested that more applied and pragmatic approaches might enhance both the theoretical and practical relevance of research findings, and thereby have greater potential to advance public health science. At the same time, the consistent use of grounded theory throughout the research process described in this thesis ensures that the study findings remain grounded in the data.

## **Chapter summary**

In this chapter, key philosophical debates around health and social research have been explored and conclusions drawn regarding the most appropriate approach for this study. There is considerable support for pragmatic and interpretive approaches to studying complex public health problems. The research aim of seeking an understanding of the processes involved in making health-related behaviour changes required an approach capable of capturing the meaning of these experiences for the participants. Hence, a qualitative interpretive approach was chosen. Corbin and Strauss’s (2008) take on grounded theory is presented as the over-arching methodology, with the use of a longitudinal study design. Grounded theory is particularly well suited to exploring basic social processes such as health service use and behaviour change, which constitute the focus of this research. The decision to use Corbin and Strauss’s version of the methodology is justified by its acknowledgement of the existence of multiple realities that can only be interpreted rather than fully known. This is supported by both the subtle realist and symbolic interactionist perspectives. The following chapter details the activities involved in constructing the study data through sample selection, fieldwork and analytical processes, as well as ethical considerations and efforts to enhance rigour.

## Chapter 5: Data construction

This chapter is organised into three sections. The first describes the activities undertaken before potential research participants could be contacted, including obtaining ethical approval and devising a sampling strategy. In this section I explain the rationale for selecting three local health trainer services as the focus of this research. Section two provides an overview of the fieldwork process, incorporating a description of the activities associated with recruitment and data collection. Section three sets out the practicalities of data analysis and measures taken to enhance the rigour of the study, including a description of the reflexive approach maintained throughout the research process. Although the various activities involved in sampling, data collection and analysis are described here as separate stages, in practice they occurred simultaneously in keeping with the iterative nature of both grounded theory and longitudinal qualitative research (QLR). This allowed each stage of fieldwork to inform the next, as part of the constant comparative approach. The chapter ends with a summary of the main components of the study design.

### **Stage one: preparing to enter the field**

#### ***Ethical considerations***

The first practical step towards fieldwork was to submit my research proposal and all supporting documentation for internal peer review at Northumbria University. This process was helpful for two reasons: firstly, the reviewers provided constructive feedback to strengthen the submission for NHS research ethics approval. For example, they advised that participants should be able to opt out of keeping a diary rather than using this as an excuse to withdraw from the study (discussed further in the sub-section on methods). Secondly, I was required to undertake a full risk assessment for insurance purposes and, after setting out the actions to minimise any risks, I felt more confident when entering the field. These actions included developing and adhering to a personal safety protocol at all times and reporting any untoward incidents to my supervisors. As the research involved human participants and the use of personal information, it raised a number of ethical issues which were amplified by prolonged contact with the study participants (Corden & Millar, 2007b). These included: ensuring informed consent, avoiding coercion and distress, maintaining confidentiality, and safekeeping of data.

Informed consent was achieved by providing potential participants with information about the research and encouraging them to consider this carefully before deciding whether or not to participate. It was made clear that there would be no penalty for those that decided not to take part or withdraw from the study at any time, and this was reiterated at each interview to reduce the likelihood of coercion. Contact details for a local Patient Advice and Liaison Service (PALS) were provided so that participants were able to seek independent advice about the research, if desired. The risks of incurring physical harm or psychological trauma through this study were assessed as being low, but there is always the potential for participants to become distressed or feel their privacy is being invaded (Robson, 2002). I informed the interviewees that they did not need to speak about anything they did not want to and could stop the interviews at any time, either for a short break or completely. All participants were asked for their written consent to take part in the study, have the discussions audio-recorded and for the (anonymised) information to be used in published material. Consent forms (Appendices B-D) were signed at the first interview in all but two cases, involving visually impaired participants. I read the form to these individuals and asked them to give verbal consent, which was audio-recorded. This technique has been described as “legally equivalent [to written methods] as a record for consent but practically superior as a method” for visually impaired people (Saleh, 2004, p.310). Due to the longitudinal study design, consent was seen as an ongoing process rather than a one-off event and all participants were asked to give verbal consent at each follow-up interview.

Materials relating to this study were treated as confidential and kept secure at all times in compliance with the Data Protection Act (1998), either in a locked cabinet at Northumbria University or in a database on a password-protected computer. Where direct quotations from study participants are used, these are identified either by a job title or pseudonym only to preserve the anonymity and privacy of the individuals and organisations involved. Having considered the above, I submitted an application to an NHS research ethics committee (REC) and attended the REC meeting with my principal supervisor to answer any queries. The study was granted a favourable ethical opinion, with no amendments required, and governance approval was obtained from the relevant NHS Trusts. This process took place more rapidly than anticipated but delays arose from staffing changes within the NHS Trust responsible for issuing the honorary contract. Data collection was subsequently delayed by three months, although this allowed additional time to build good working relationships with the research sites.

### **Approaching research sites**

To avoid misrepresenting the NHS Health Trainers Initiative by focusing on a specific delivery model, I set out to conduct the research in two contrasting local services. These were chosen from the north east of England for various reasons. First, I live and work in the region, so the travelling time to conduct fieldwork was minimised. Second, through my previous research, I had good links with the regional health trainer lead as well as several of the local teams. This helped in obtaining their input to the research proposal in order to ensure its relevance for developing policy and practice. Third, I was aware that conditions in the north east provide an ideal opportunity to conduct research on health inequalities. The health of people in the region is generally worse than for England as a whole, with the worst levels of deprivation and life expectancy, as well as the highest rates of binge drinking, adult smoking and early deaths from cancer (NEPHO, 2011). In 2005, nine of the region's 10 primary care organisations were allocated funding to implement health trainers before the initiative was rolled out nationally.

I had previously mapped the nine local health trainer services onto a framework that was developed during a review of the evidence base (Visram & Drinkwater, 2005; Visram *et al.*, 2006). The framework broadly classified the services in two ways, according to whether they: 1) addressed generic health issues or focused on a specific target population; and 2) primarily utilised one-to-one approaches or delivered activities at group or community level. This exercise allowed me to select two contrasting models for the purpose of the present study. Site A<sup>12</sup> was identified as adhering most closely to the targeted, one-to-one model described in the *Choosing Health* white paper, whereas Site B builds on a pre-existing community development-oriented model. These two sites provided an ideal opportunity for a type of 'natural experiment' to enhance understanding of the underlying processes by which contrasting health trainer models influence outcomes (Pawson & Tilley, 1997; MRC, 2011). However, due to limited capacity within the team at Site A, the decision was made to add a third research site. Following discussions with the regional health trainer lead, Site C was identified as offering potentially interesting insights that might contrast with Sites A and B. The health trainers in Site C deliver gym-based exercise interventions to people referred for existing health conditions. All three health trainer services are based in areas of multiple deprivation and provide an excellent basis for comparative analysis.

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<sup>12</sup> The names of the research sites have been omitted to preserve the anonymity of individual service users, staff members and organisations.

Following an introduction via email by the regional health trainer lead, I arranged meetings with the managers in Sites A and B to discuss and gain their support for the research. Both managers were enrolled on courses delivered by colleagues at Northumbria University and I feel that the good reputation of the University added credibility to the study. Furthermore, several team members in Site A knew me through the research conducted for my Masters degree, and I had previously worked with a key stakeholder well-known to the team at Site B. I believe these were enabling factors in establishing their trust in me as a researcher and gaining their support for the recruitment of service users to the study. I had not previously met any of the team members from Site C and it was challenging to gain the trust of the manager in particular. There seemed to be some confusion about the purpose of the research and how the findings would be disseminated, with concerns about their 'politically sensitive' nature that I had not encountered in the other two sites. At first I worried that I had not explained the study clearly but it became apparent through the research process that there were particular issues in this site. During each of our meetings, the manager emphasised the ways in which Site C was felt to be different from other health trainer services. These differences influenced the sampling and recruitment processes, which are discussed in the sections below.

### ***Sampling strategy***

I set out to devise a sampling strategy that would incorporate representation from the health trainer teams and client populations in each of the research sites. This would enable me to obtain an understanding of the various domains of change – individual, organisational, temporal and spatial – from both the service user and provider perspective (Thomson & Holland, 2003). Furthermore, the nature of the role meant that most health trainers were from socio-economically disadvantaged communities and could therefore offer additional insights into the needs of those communities. Inclusion criteria for the study were as follows:

- Over 18 years of age at the time of recruitment to the study<sup>13</sup>
- A user of the health trainer service in Site A, B or C at the time of recruitment to the study or in the preceding six months
- Employed as a health trainer in one of these sites at the time of the study
- Having any line management, supervision or co-ordination responsibility for these health trainers

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<sup>13</sup> Recruitment to the study took place between June 2009 and January 2011.

Exclusion criteria were: being under 18 years of age; inability to give informed consent for any reason; having had no contact with or knowledge of health trainers; and being recruited as a health trainer but not operational at the time of the study. Only two health trainers in Site A met the inclusion criteria; one team member was absent due to ill-health, while others had not completed their mandatory training and were therefore not operational during the study recruitment period.

Within a grounded theory methodology, the processes of sampling, data collection and analysis take place simultaneously and the evolving analysis drives the subsequent selection of units of data (Baker, Wuest & Noerager-Stern, 1992). However, sample sizes in any form of qualitative research tend to be chosen for reasons that are both theoretical and pragmatic (Coyne, 1997). All five managers consented to take part in the study, which constitutes a form of convenience sampling, whilst health trainers were initially selected using a purposive sampling strategy. By sampling data from contrasting sources, the aim was to develop variation and maximise the possibilities of obtaining leads for additional data (Lincoln & Guba, 1985). Seeking a diverse sample during the initial stages of a study can also help to foster depth and comprehensiveness, as well as enhancing the conceptual power of the findings (Charmaz, 1990). Analysis of initial staff interviews provided insight into specific issues within each of the research sites, which were used to guide subsequent study recruitment. This is known as theoretical sampling and is essential to the inductive-deductive process of grounded theory (Glaser & Strauss, 1967). For example, gender was identified as an important issue following interviews with two male health trainers in Site C and two female participants were subsequently recruited to the sample from a team of 15 staff. In Site B, initial staff interviews revealed length of time in post to be a key issue, and the final sample included a diverse mix of new and established health trainers from a team of 17 staff. An overview of the sample is given in table 6.

I initially proposed that 15 service users<sup>14</sup> would be recruited from each of the two original research sites during a six-month period (May to October 2009). A total sample size of 30 users was felt to be both achievable and sufficient to reach data saturation (i.e. the point where the initial 'working' theory stands up to all additional data) (Glaser & Strauss, 1967). This was based on the findings from a review of

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<sup>14</sup> For the purposes of this study, a 'service user' was considered anyone who receives support, advice or assistance from a health trainer on more than one occasion and undergoes some form of assessment that results in the initiation of a case record. This excludes anyone who has one-off contact with the service.

**Table 6: Features of the staff sample**

<b>Characteristics</b>	<b>Site A (n=4)</b>	<b>Site B (n=9)</b>	<b>Site C (n=5)</b>	<b>Totals (n=18)</b>
<b>Role:</b>				
Manager	2	2	1	<b>5</b>
Health trainer	2	7	4	<b>13</b>
<b>Sex:</b>				
Female	3	7	3	<b>13</b>
Male	1	2	2	<b>5</b>
<b>Time in post:</b>				
Less than 1 year	1	3	0	<b>4</b>
1-5 years	3	2	3	<b>8</b>
More than 5 years	0	4	2	<b>6</b>

published studies involving grounded theory approaches, which found that saturation generally occurs between 10 and 30 interviews (Thomson, 2006). By aiming to recruit a maximum of 30 users I hoped to counterbalance the effects of any loss-to-follow-up, which I predicted would be significant given the 'hard-to-reach' nature of the target populations. I also wanted to design an approach where my findings could not easily be seen as arbitrary or dismissed as the story of a few individuals (Yates, 2003). On adding the third research site, my strategy was modified to aiming to sample 10 users from each health trainer service. However, this proved difficult within Site A and only six users were sampled from this service. An overview of the user sample is shown in table 7 on the following page.

The uneven sex ratio of both the staff and user samples (a total of 28 women to 13 men) is common to most health trainer services. Otherwise, the sample is relatively diverse in terms of age and occupation, although more than half of the users are over the age of 60. The aim of grounded theory research is to gain an in-depth understanding of the realities and issues at hand, rather than selecting participants based on variables such as age and gender which may be irrelevant to the emerging theory (Coyne, 1997). A shortcoming of the sample is the lack of ethnic diversity and efforts were made to recruit individuals from black and minority ethnic (BME) communities as part of the theoretical sampling process discussed below.



**Table 7: Features of the service user sample**

<b>Characteristics</b>	<b>Site A (n=6)</b>	<b>Site B (n=10)</b>	<b>Site C (n=10)</b>	<b>Totals (n=26)</b>
<b>Age group:</b>				
Under 30	0	1	0	<b>1</b>
30-39	0	2	0	<b>2</b>
40-49	1	4	1	<b>6</b>
50-59	1	1	1	<b>3</b>
60-69	2	1	6	<b>9</b>
70-79	2	0	2	<b>4</b>
80+	0	1	0	<b>1</b>
<b>Sex:</b>				
Female	5	8	5	<b>18</b>
Male	1	2	5	<b>8</b>
<b>Ethnicity:</b>				
White European	6	9	9	<b>24</b>
British Asian	0	1	0	<b>1</b>
Mixed – White & Asian	0	0	1	<b>1</b>
<b>Occupation:</b>				
Employed	1	5	1	<b>7</b>
Retired	3	2	7	<b>12</b>
Incapacity benefit	2	2	2	<b>6</b>
Homemaker	0	1	0	<b>1</b>

## **Stage two: conducting fieldwork**

### ***Sample recruitment***

As a result of my prior research experience, I was aware that meeting potential study participants in person tends to be a more effective recruitment strategy than simply distributing written information. This is particularly the case with individuals from disadvantaged communities who are more likely to have low literacy levels and little knowledge of academic research (Sixsmith, Boneham & Goldring, 2003). Furthermore, they may exhibit a wariness and mistrust of 'officialdom'. Time and effort is required to build sufficient trust and legitimacy with these communities, as well as working with gatekeepers who are supportive of the research (Hemmerman, 2010). The service managers acted as gatekeepers in this study and, on the whole, were very helpful in recruiting staff and service users to the sample. Due to the lack of any local or national evaluation of health trainers, they were keen to obtain in-depth feedback on their services and were particularly interested in the longitudinal aspect. However, as stated previously, the manager at Site C expressed concerns

about the 'politically sensitive' nature of this feedback and was keen to exert a high degree of control over the research process. My intention was to attend a team meeting in each site in order to explain the purpose of the study and what would be expected from the health trainers if they decided to take part. I hoped to deal with any queries or concerns about the research, and also obtain their feedback on draft study information for users to ensure its readability. The managers at Sites A and B were wholly supportive of this suggestion and the team meetings were invaluable in gauging staff attitudes towards the research.

The manager at Site C expressed a preference for identifying team members based on a combination of the sampling criteria and their workloads, to avoid burdening particular individuals. It is not uncommon for gatekeepers to attempt to influence the research process by recommending only participants 'approved of' by themselves (Sixsmith, Boneham & Goldring, 2003). Although this does not follow the principles of purposive or theoretical sampling, I felt it was more important to follow the manager's advice and avoid creating barriers to accessing this site. Each health trainer received an information pack containing an invitation letter addressed from their manager (Appendix E) and an information leaflet explaining the purpose of the study (Appendices F). Managers received separate information (Appendix G and H). They were asked to contact me using the reply slip included in the pack if they were interested in taking part, and arrangements for an initial interview were then made by telephone or email. Due to the risk of coercion, I spent time at the start of each interview reiterating the requirements of the research, informing staff that only anonymised information would be fed back to managers, and asking for their informed consent. It became apparent that some staff had been asked to participate by their managers, rather than volunteering of their own accord, and I made every effort to reassure them that they were free to withdraw from the study at any time. None of the health trainers chose to withdraw at this stage.

In order to comply with the requirements of the Data Protection Act (1998), I was not permitted to access service user contact details and therefore recruitment of this sample took place via the health trainers. An advantage of this approach is the potential for the researcher to be perceived as a 'friend of a friend', which can help to even out inherent power relations (Sixsmith, Boneham & Goldring, 2003). My intention was that users would be recruited by their health trainers as soon as possible after accessing the service and selected for inclusion in the study using a theoretical sampling matrix. Health trainers were asked to approach service users at

their first or second session of the intervention and invite them to participate in the research. My rationale for recruiting users at this early stage was to avoid having to rely on retrospective accounts of their motivation for accessing the service and first impressions of the health trainer. However, it quickly became apparent through discussions with staff that they were not comfortable with raising the subject of the research so soon and preferred to use these initial sessions to establish a rapport with users. They felt it would be more appropriate to introduce the research towards the end of the intervention, which would reduce interference with their work and allow them to identify individuals who might be confident in talking about their experiences. Agreeing to this approach 'got the ball rolling' in terms of recruitment but also increased the risks of bias associated with allowing the health trainers to 'cherry pick' their users. These risks were felt to be counter-balanced by the need to access individuals who would be willing to participate in the study for up to 12 months in order to provide deeper insight into the intervention processes.

Recruitment was particularly challenging in Site A, where staff reported that the term 'research' had negative connotations for people within local communities. This site was characterised by a high number of incapacity benefit claimants and it was felt that the longitudinal study design created suspicion in terms of people assuming I wanted to 'check up' on their health and disability status. Furthermore, the health trainers themselves seemed wary of the study due to awareness that their area had previously been the subject of research and seen little improvement as a result. This illustrates the aforementioned mistrust of 'officialdom' and challenges of working with gatekeepers who do not share the researcher's social position or motivation (Hemmerman, 2010). These issues were raised when I attended a team meeting in an attempt to alleviate the health trainers' concerns and discuss potential solutions to the recruitment problems. We reached a consensus that describing the study as a piece of government-funded research was not helpful in this context and instead agreed that they should invite users to participate in a 'student project', emphasising that they would be reimbursed for their time<sup>15</sup>. I had some concerns about whether or not this amounted to misleading the participants but it is common practice to tailor research messages to suit the target audience. Whilst it was appropriate to highlight the funding source and academic rigour of the research in communicating with professional stakeholders, this language held less currency with the lay participants

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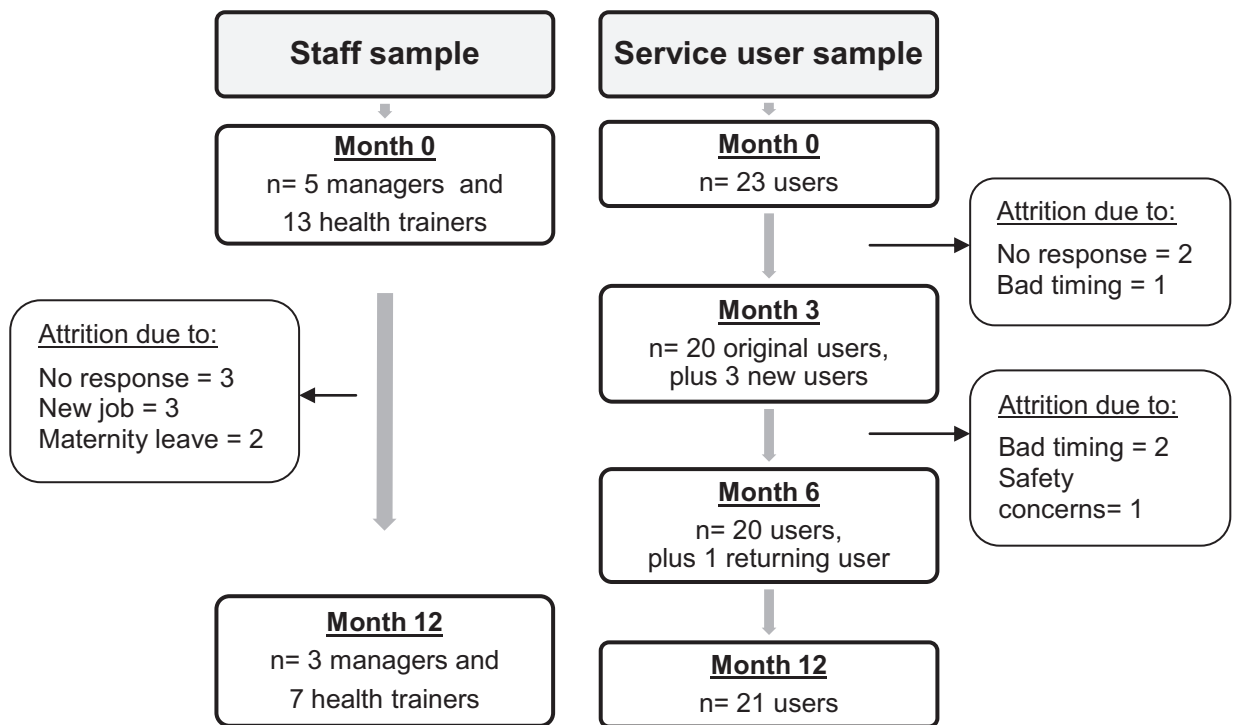
<sup>15</sup> Service users received a £5 voucher for participating in each interview, resulting in a maximum total payment of £20. The implications of this are discussed in Chapter 9.

and a different set of terms had to be used. Through these challenges, I was able to begin the process of theorising about working with ‘hard-to-reach’ communities and the differences between lay and professional health workers. This is congruent with the grounded theory approach of viewing method as inseparable from theory-building (Glaser & Strauss, 1967; Glaser, 2004).

Each health trainer was initially given 10 study information packs and asked to discuss these with service users, highlighting if information was required in other languages or formats. These packs contained an invitation letter addressed from the local health trainer service (Appendix I), reply slip, prepaid envelope and information leaflet (Appendix J). After a period of poor recruitment, the manager in Site B suggested sending information packs in the post to individuals randomly selected from their database, which generated a number of additional replies. It transpired that some users from Site C had been asked to take part without being given an information pack and a staff member had completed the reply slip on their behalf, more than likely because the health trainers were trying to help by speeding up the process. These participants were immediately given copies of the study information and asked to consider this carefully before consenting to take part. All users were contacted by telephone to arrange the first interview, where I made every effort to ensure that they understood the purpose of the study and did not feel pressured into participating. A total of 23 users were initially recruited, with a further three added following the first round of interviews (discussed below in the sub-section on data analysis). Figure 11 illustrates the service user and staff sample sizes at each wave of data collection, along with factors contributing to sample attrition.

‘No response’ meant that attempts were made to contact the participant on at least two occasions, at different times of the day, as well as leaving an answerphone message or email. ‘Bad timing’ refers to participants who asked if I could call back at a later date because a family member was ill or had recently given birth. ‘Safety concerns’ occurred when a male participant repeatedly asked me intrusive personal questions and was very persistent in offering to drive me to the train station. After discussion with my supervisors, it was decided that he should be removed from the study sample and no further contact was made.

**Figure 11: Study flowchart**



### **Data collection**

The primary mode of data collection in this study involved in-depth interviews with service users, health trainers and managers. Interviews are particularly useful in gaining insights into participants' experiences through the stories they tell and locating those stories within basic social processes (Kvale, 1996; Charmaz, 2003). I chose this approach above alternatives such as self-completion questionnaires or focus groups because I wanted the ability to gather and probe individual narratives about health, lifestyles and disadvantage. Furthermore, I was aware that the research topic held the potential to uncover sensitive issues and did not feel it would be appropriate to discuss these in a group setting. Sequential interviews were chosen to chart each service user's path through the process of making lifestyle changes, as well as exploring staff experiences of the changing organisational and broader context. My intention was that the interview data would be supplemented by diaries completed by the health trainers but these efforts were unsuccessful. The reasons for this are given below, following a description of the interview method.

*(i) Sequential interviews*

I began with a semi-structured interviewing approach to provide a framework that would enable comparisons to be made between interviews, as well as allowing participants the freedom to raise issues that were important to them (Britten, 2000). Interview topic guides (Appendices K-M) were developed based on findings from the empirical literature and psychological theories of behaviour change. In keeping with the flexible nature of grounded theory research, the guides were modified over time to focus attention on areas of particular importance, and exclude questions that were found to be unproductive (Charmaz, 2003). For example, after one participant made critical comments about her health trainer's body shape, a question on this issue was asked in subsequent interviews until saturated. This is a key element of the theoretical sampling process associated with grounded theory, which involves gathering specific data to support or disconfirm the emerging framework (Glaser, 1978). Over time I adopted more of an informal, conversational style as I developed a relationship with each participant and an understanding of their lives, whilst seeking to remain open to new information relevant to the research aims and objectives. The staff interviews lasted between approximately 20 and 75 minutes, and user interviews were between 15 and 150 minutes.

Researchers' questions and the way that they are framed, paced and managed inevitably shape possible responses. Charmaz (2003) suggests that the grounded theory interview should be a 'directed conversation', but states that being too directive poses hazards in terms of cutting off interesting leads or loading assumptions into the questions. This demonstrates the need to achieve a balance between asking general questions to elicit the participant's story and probing to explore specific experiences. It also highlights the importance of remaining reflexive throughout the research process. Efforts were made to avoid superimposing my own concerns and ideas during the interviews, and open-ended questions were used to give the interviewees sufficient opportunity to express their viewpoints extensively. The first question may suffice if stories 'tumble out', in which case the researcher need only use nods and prompts to keep the story coming (Charmaz, 2003). This happened on several occasions, as illustrated by the following example:

- Int:           So can I just start by asking you to tell me a little bit about yourself – about your family and if you've got a job or anything?
- Sian:          Well, technically I have got a job at the moment (laughs). I work part-time in a bank usually. But I've got two children and one of whom has

been diagnosed with ADHD [attention deficit hyperactivity disorder]. They've both got dyslexia and they have... [name of son] hasn't been fully diagnosed yet but I think he's got short-term memory loss, the same as [name of daughter]. So it's a bit challenging, you know, dealing with them on a day-to-day basis. And with working and being a full-time mum, it sort of got me down so I was a bit depressed and I've had to take some time off work. So I've been off work for about six months now, and when I met [name of health trainer] – well, I knew her before she started working with the [health trainer service] – but she said, "Well, why don't you try taking this up?" So I did the cookery part first and now I'm doing the keep-fit part. So it's just to try and help my, sort of, self-esteem and to help, you know, like if I go out and keep fit, I might feel better about, you know, about how I'm feeling, how I'm looking, and that type of thing.

A technical issue for consideration involved how to record the interview data. Some qualitative researchers (e.g. Lincoln & Guba, 1985) have argued against the use of electronic recording devices by citing their intrusiveness and the possibility of technical failure, whilst others (e.g. Charmaz, 2003) emphasise the advantages of capturing data more faithfully than written notes. Interviews undertaken during this study were audio-recorded with participants' consent to provide clear verbatim accounts for analysis and to maintain the conversational tone without distraction. Notes were also taken to highlight key issues for consideration during analysis or to remind me of points to return to later in the interview.

Interviews were conducted with health trainers at the beginning and end of the data collection period (12 months later), to explore their changing experiences of working with local communities. Managers were interviewed at the same time points to provide insight into the changing organisational context and the perceived contribution of health trainers to a reduction in inequalities over time. Service user interviews were conducted at the beginning of the study and roughly three, six and 12 months later. The initial rationale for these timings was to construct a qualitative 'baseline' for each individual at the point of accessing a health trainer service, explore their experiences of the interventions (which generally last for 12 weeks), and then conduct a short-term (at six months) and medium-term follow-up (at 12 months) to explore their attempts to make and maintain behaviour changes. However, the aforementioned recruitment difficulties and the fact that most users received support from their health trainer for significantly longer than 12 weeks meant that the interview timings did not map onto their entry into and exit from the interventions. Instead, the longitudinal approach enabled participants to disclose



information at their own pace and gave me the opportunity to follow up on earlier leads, thereby strengthening the emerging analysis.

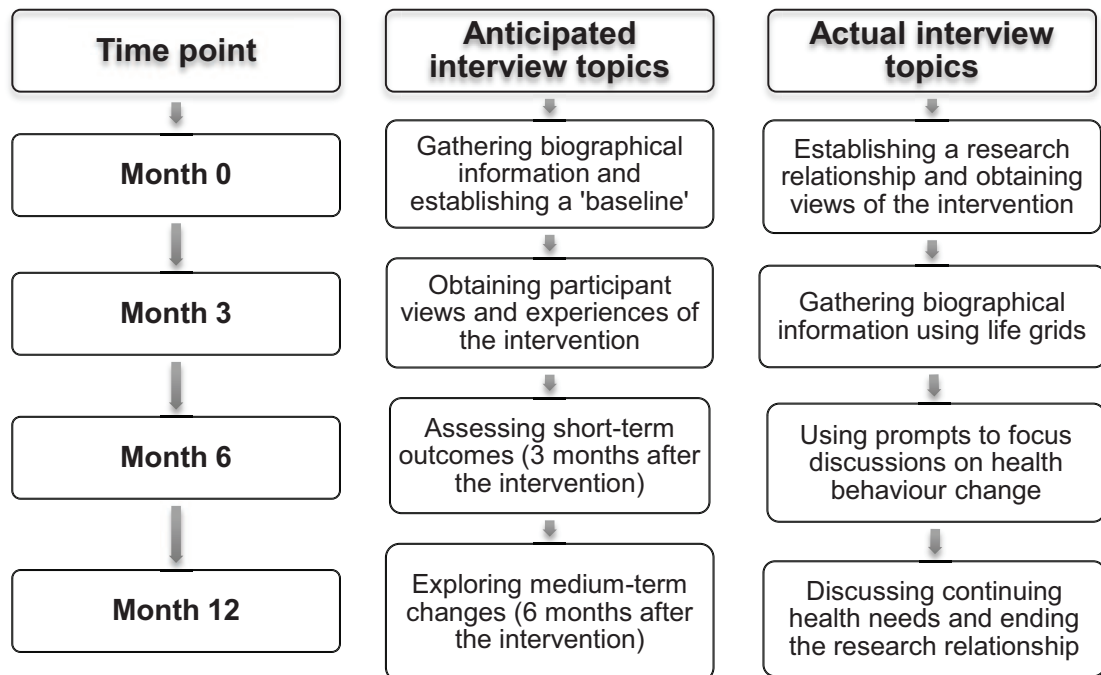
During the initial interviews it became clear that a narrow focus on behaviour change would not result in the development of a theory that accounted for the main concerns of the participants. Instead, I recognised the need to reach a holistic understanding of different aspects of lifestyle change, and to explore associations between life experiences and behaviours. A life grid approach was employed to collect detailed data on participants' lives. This method has been used in the literature on smoking behaviour and found to be particularly useful in research with older respondents (Parry, Thomson & Fowkes, 1999; Blane, 2005). The life grid (Appendix N) consisted of a number of columns designed to gather information on the participant's family and living situation, occupation, health status and lifestyle, and how these changed over time. By cross-referencing the dates of any changes in the areas of interest against the dates of personal and public events, the aim is to prompt recall of routine behaviours (Parry, Thomson & Fowkes, 1999). For example, it can help participants to describe years of smoking behaviour, rather than the critical events of starting or stopping. Completing the life grid was a joint endeavour and the resulting data provided a resource for discussion in subsequent interviews. At the same time, I was aware of the need to return to behaviour change in order to address the study aims and objectives. A series of prompts (Appendix O) was developed from the initial interviews and behaviour change literature, for use in the month 6 interviews. See figure 12 on the following page for an overview of the topics discussed at each of the service user interviews.

*(ii) Diaries and observations*

A second proposed method involved asking the health trainers to keep diaries that could provide a rich source of comparative data from which to draw insights about the processes of the intervention. The value of this method lies in the ability to record routine or everyday activities as they happen, thereby reducing the likelihood of recall bias, retrospective censorship or reframing (Corti, 1993; Elliott, 1997). A diary template (Appendix P) was produced in collaboration with the health trainer managers at Sites A and B at the beginning of the study, and shared with the health trainers during team meetings. Queries were raised as to why service user records could not be used instead but the managers were concerned that this would mean additional time spent on anonymising and copying the records, as well as requiring

further approval from each NHS Trust. Health trainers were supplied with copies of the diary and asked to record any contact with users in the study sample (anticipated to involve a weekly meeting or telephone call over a 12-week period), with the user's permission. The intention was that analysis of these written accounts would direct the focus of the 12-month interview, which would be used to check the internal consistency of participants' accounts, fill in omissions and move beyond recorded events into more general experiences and attitudes. However, none of the health trainers completed a diary, citing a variety of reasons such as problems with literacy and lack of time. This is in spite of my making every effort to accommodate their needs; for example, offering the option of recording the diary entries using a Dictaphone or providing updates over the telephone.

**Figure 12: Anticipated and actual topics of sequential user interviews**



My hope was that the diaries would form part of a research process in which the health trainers participated actively in both recording and reflecting upon their behaviour, becoming collaborators in the construction of the research account. Their reluctance to engage in this process was disappointing but I came to realise it was linked to their lack of confidence in undertaking activities associated with 'office work'. Part of my rationale for choosing this method was that the diaries would act as a substitute for observations, allowing me to access situations which might be altered by the presence of an observer (Elliott, 1997). During initial discussions with

the teams I was told that one-to-one meetings between a health trainer and service user would be negatively affected by my presence. However, as I spent more time with the staff and gained their trust, I found that they began to invite me to attend events and meetings to get a better understanding of their work. Without the necessary ethical approval, it was not possible to conduct formal observations of health trainer-user interactions in private settings. Instead, I chose to attend public events on invitation from the participants and shadow the health trainers in community settings. A summary is shown in table 8.<sup>16</sup>

**Table 8: Overview of shadowing activities**

Site	Activity	Duration	Description
B	Weight management group	1.5 hours (morning)	<ul style="list-style-type: none"> <li>• 1 health trainer and 1 nutrition assistant</li> <li>• 9 women (from approx. 20 to 80 years)</li> <li>• Individual weigh-ins followed by a group discussion on weight loss strategies</li> <li>• Planning future body image sessions</li> </ul>
	Women-only swimming session	1 hour (evening)	<ul style="list-style-type: none"> <li>• 4 health trainers (including 2 BME workers)</li> <li>• 103 women and children of all ages, mostly young Asian women with their families</li> <li>• Sent out 50 flyers via schools; others heard about the sessions through word of mouth</li> <li>• Lots of social interaction between families</li> </ul>
	Walking group for the over 50s	4 hours (mid-day)	<ul style="list-style-type: none"> <li>• 1 health trainer</li> <li>• 5 women and 1 man</li> <li>• Take the bus for a walk by the coast</li> <li>• Continuous interaction between service users and health trainer, demonstrating concern for one another's welfare</li> </ul>
C	Community gym, locality 1	2 hours (morning)	<ul style="list-style-type: none"> <li>• 4 health trainers and 1 manager</li> <li>• Varying numbers of users (4 to 6)</li> <li>• Observe 'banter' between staff and users</li> <li>• Users chat to and help one another</li> </ul>
	Community gym, locality 2	2 hours (afternoon)	<ul style="list-style-type: none"> <li>• 5 health trainers</li> <li>• 2 men and 1 woman, little interaction</li> <li>• Conversations between staff and users</li> <li>• Quiet time in the gym and also affected by a recent change in the bus timetables</li> </ul>
	Community gym, locality 3	2 hours (morning)	<ul style="list-style-type: none"> <li>• 4 health trainers</li> <li>• 3 men, with 1 woman undergoing an induction in the office</li> <li>• Loud music makes conversation difficult</li> </ul>

<sup>16</sup> No public events took place in Site A during the data collection period. The health trainers were solely involved in undertaking one-to-one sessions with users and so it was not possible to conduct any shadowing activity in this site.

These activities enabled me to observe first-hand the interactions between health trainers and users, and develop an understanding of the context in which the interventions occur. Furthermore, I was able to explore these observations during the follow-up interviews with staff and users. Detailed fieldnotes were written up after every shadowing activity and interview, incorporating observations on the environment, actions and interactions of the participants, their appearance, non-verbal cues, and any feelings or emotions expressed (Berg, 2001). This information was considered in generating concepts for the emerging theory as part of the fundamental grounded theory principle that ‘all is data’ (Glaser, 1978). A research diary was also kept to detail day-to-day activities and decision-making procedures, as well as recording my personal thoughts and feelings on the process.

### ***Research settings***

The health trainers and managers all chose to be interviewed at their workplaces, which included offices, meeting rooms or private consulting rooms within community centres, healthy living centres or GP surgeries. Two health trainers suggested that the interviews be conducted in the cafe within the healthy living centre. Although this created some distractions and background noise, I chose to give priority to ensuring that the health trainers felt comfortable and relaxed during the interview. Furthermore, it was not anticipated that staff interviews would raise any sensitive or distressing topics and so the public setting was seen as unproblematic. In contrast, interviews with service users tended to take place within the interviewee’s home. This was the preferred option for most participants (n=20) and the familiar, comfortable environment helped to increase openness. Two service users were also PCT employees and chose to be interviewed within their workplaces<sup>17</sup>, whilst others were interviewed at Northumbria University (n=1), in a public library (n=1) or at home in the first instance and then at various community venues (n=2). Interviews undertaken within participants’ homes or workplaces allowed me to observe them in their ‘natural environments’ (Lincoln & Guba, 1985). However, conducting fieldwork in private settings raises a series of ethical, emotional and methodological issues that cannot always be anticipated. As noted by Yee and Andrews (2006, p.401), “ethical choices are always ‘situated’ within every local encounter, every home”.

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<sup>17</sup> One service user was employed by the PCT at the outset of the study, whilst another gained employment as a health trainer during the data collection period. Our first two interviews (months 0 and 3) were conducted in her private home, while the final two (month 6 and 12) were conducted in her workplace. This change in setting afforded me additional insight into her change in role from stay-at-home mother to health trainer.

Yee and Andrews (2006) suggest that ethical dilemmas arising from research conducted in the home setting can be encapsulated as a struggle between the conflicting requirements of the professional researcher and the 'good guest'. They identify informed consent and protection of the research participants as key issues, although researcher safety is another important area for consideration. I implemented clear protocols for obtaining consent and assessing risk within the various research environments, but no amount of training or background reading could prepare me for every eventuality. For example, I used a digital voice recorder to assist in gathering clear information on the research topic, but often noise or disturbances from pets and family members would impact on the recordings. My training suggested that a professional researcher should ask participants to relocate to a quiet room or at least turn off the television. However, I was aware of being in their homes and wanting to observe the appropriate behaviour of a 'good guest', therefore I did not always feel able to control the interview conditions (Yee & Andrews, 2006). The presence of family members also posed a threat to my attempts to ensure confidentiality, although the risks associated with sensitive information being overheard were lower than those occurring when interviews took place in public settings. Efforts were taken to safeguard the participants' privacy but priority was given to respecting their autonomy and maximising their comfort in order to maintain productive research relationships.

### ***The research relationship***

This study was based on the premise that qualitative research is a social interaction in its own right and therefore reflects the social world in which it is situated (Parry, Thomson & Fowkes, 1999). As such, it is necessary to acknowledge my interactions with the participants as mutual, though unequal, social relationships. Researchers need to be conscious of how they present themselves to participants and the effects this might have on the developing relationship (Berg, 2001; Yee & Andrews, 2006). For example, I wore smart clothing when interviewing managers, casual clothing when interviewing users, and clothing appropriate to the setting when interviewing health trainers. This was part of my efforts to present an identity that would allow me to build trust and credibility with the participants. Researchers may also reveal facts about themselves in an attempt to develop and maintain relationships with participants, although some of these facts are self-evident (Yee & Andrews, 2006). My status as a woman from a minority ethnic background was enough to prompt confidences from some health trainers and users, although I initially worried that it

might impact negatively on interviews with those from predominantly White, working-class communities. Gender is often highlighted when women interview men because the researcher “is required to take on an acquiescent, attentive and assenting role very close to traditional notions of femininity” (Green *et al.*, 1993, p.630). However, age was a more important factor in this research<sup>18</sup>. Combined with my status as a student, this led to the participants taking particular interest in my welfare, for example, checking I had enough money for bus fares. Richards and Emslie (2000) suggest that seemingly contradictory signs of status – for example, being casually dressed and travelling by public transport, but producing ‘tools of the trade’ such as digital recorders and consent forms – can make researchers hard to place, particularly for older respondents. My age and student status, combined with the opportunity to build relationships with participants through the longitudinal research approach, contributed to the resolution of these tensions.

Various measures were employed to maintain my relationships with participants over time and reduce the risks of sample attrition. Hemmerman (2010) recommends that contact should be continuous and informal rather than involving scheduled appointments, as this is more likely to fit into the rhythm of people’s lives. However, I did not think it would be feasible or appropriate in this study to ‘pop round’ without due notice. Instead, I scheduled interviews that took place as soon as possible and made sure that participants had my contact details in case they needed to cancel or rearrange for any reason. Contact was maintained between interviews using letters, phone calls, ‘get well’ and Christmas cards, which many participants commented on and some reciprocated. The literature advises that researchers should avoid becoming too emotionally involved with participants or sharing their personal beliefs and values but, at times, it can be difficult to maintain the appropriate social distance (Yee & Andrews, 2006). This distance is minimised when we share the same characteristics or life experiences. For example, one interviewee was nervous about applying for a job as a health trainer and I briefly considered contacting the manager to ‘put in a good word’, in part because I identified with her experiences of being a single mother from a working class background<sup>19</sup>. Sustaining an impartial and detached approach is not always desirable, as being able to identify with participants’ stories can provide greater insight into social processes (Yee &

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<sup>18</sup> There was a 30-year gap between my age at the time of conducting the fieldwork (27-28 years) and the average age for service users in the study sample (58.1 years).

<sup>19</sup> This was my mother’s experience, rather than my own. Due to the age gap between myself and most participants, it was often more appropriate to draw on the experiences of older family members in demonstrating empathy. Names and other personal information were not shared to preserve the privacy of my family and maintain some level of impartiality.

Andrews, 2006). The quote below demonstrates the way in which I was able to draw on the experience of a family member to empathise with a participant:

- Pam: I still worry about my health. I'll wake up on a morning..... I'm going to get upset.
- Int: Oh sorry, I didn't mean to upset you.
- Pam: But I'll move my leg to see if it'll move. Because I'm frightened in case I have another stroke. So you do worry... [...]
- Int: Are you alright?
- Pam: [Crying]... Excuse me – I just have to get a tissue [Leaves the room]. You see, I don't like anybody to see me like this but my family. Nobody.
- Int: It's okay... My mam's the same because she was in intensive care a couple of years ago. She says every morning she thinks about what it was like and is still grateful that she's healthy.

Deploying empathy in this way creates a platform for the genuine exchange of sensitive and personal information, which can enrich the quality of the data (Sixsmith, Boneham & Goldring, 2003). However, it also creates emotional risk for both the researcher and participant. Parallels have been drawn between research interviews and therapeutic interactions, which often places researchers in roles for which they are untrained and unprepared (Richards & Emslie, 2000; Yee & Andrews, 2006). I was unprepared for one participant to share a personal story about sexual abuse but was able to deal with this appropriately with the support of my supervisors. This individual and others assumed I was training to be a nurse or doctor, highlighting the ambiguous nature of research and the need to be clear about the limits of my expertise and capacity to offer assistance. On several occasions I was asked for input that extended beyond my role as an impartial observer; for example, a number of participants asked for my thoughts on the future of their local health trainer service, with users reporting that they could not get a 'straight answer' from anyone else. Failure to answer direct questions could be seen as exploitative in the sense that the research relationship would be based on taking without giving anything meaningful in return (Yee & Andrews, 2006). There were times when I revealed more than I was comfortable with, in the interests of reciprocity and fulfilling the requirements of a 'good guest'. This highlights the risks of blurring the boundaries between being a professional researcher and friend, which are increased when employing a longitudinal qualitative approach. It is also inevitable that the presence of an observer will introduce a distortion of the 'natural scene', which the researcher must work to minimise (Berg, 2001).



## Stage three: working with the data

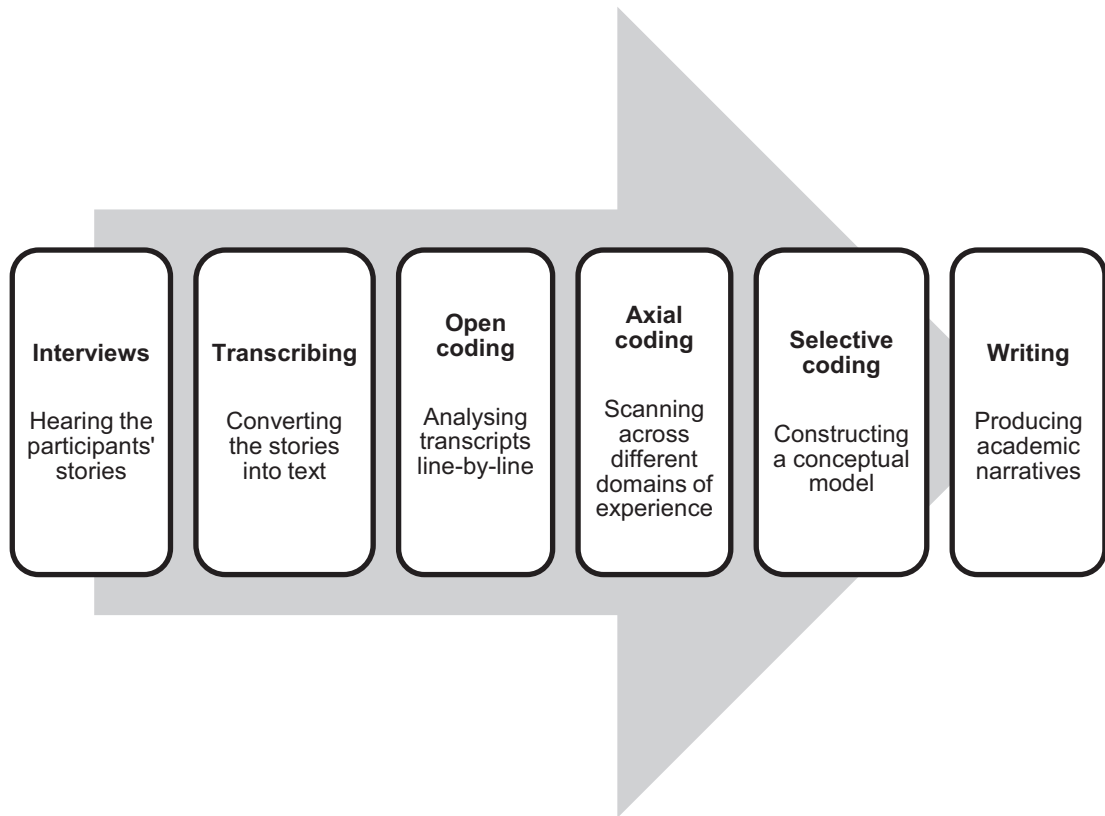
### ***Data analysis***

A key feature of grounded theory is the constant comparative method, which involves comparing data with data, category with category and concept with concept (Charmaz, 2003). Comparison is also the foundation of QLR approaches both in terms of the research design and as an analytic and interpretive strategy (Thomson, Plumridge & Holland, 2003). It is recommended that initial analysis should take place immediately, alongside data generation, and guide subsequent sampling and data collection (Fraser, 2004). In this study, feeding back preliminary findings to the health trainer teams revealed that participants in the initial service user sample were significantly older than expected by staff in Sites A and B. As a result, they were more likely to be retired and have multiple health problems, and the teams felt the sample did not reflect the full spectrum of their work. I also had concerns about the impact on my ability to explore the process of making and maintaining health-related behaviour changes, and the lack of ethnic diversity within the sample. Three additional users were recruited to the study sample at the first follow-up interview stage, including one participant from a BME background. This contributed to the theoretical sampling approach, which involves sampling to develop the emerging theory rather than to represent a population (Charmaz, 2003).

Analysis in this study took place in six phases, shown in figure 13 on the following page. These phases are described here in a linear fashion, whereas in reality they often took place concurrently and alongside theoretical sampling (see figure 14). The process began with hearing the participants' stories during the interviews and beginning to note down theoretical insights, followed by transcription of the interview recordings. I transcribed the initial service user interviews (n=23) myself, which was helpful in ensuring my immersion in the data but also extremely time-consuming. The remaining user and staff interviews were transcribed by a colleague who is highly skilled in this activity and appreciates the importance of maintaining confidentiality. Following the advice of Fraser (2004), I briefed the transcriber to highlight any particular issues of note within the interviews and requested a debriefing after each transcription to gather their feedback, either in person or via email. These activities were undertaken in recognition that transcripts are situated

rather than objective texts and that researchers may hold different views on what constitutes material to be transcribed<sup>20</sup> (Green, Franquiz & Dixon, 1997).

**Figure 13: Stages of the analytical process**



The next phase involved coding the transcripts, which is a pivotal step in the move from description towards conceptualisation (Charmaz, 2003). I followed the clear procedure set out by Corbin and Strauss (2008), whilst acknowledging my role in defining rather than discovering what was happening in the data. This involved looking for specific evidence of behaviour change, as well as seeking to remain open to new and disconfirming information. Line-by-line coding ensures that the researcher stays close to the collected data, rather than basing their codes on preconceived assumptions. I initially conducted this process manually to create a more sensitive and nuanced analysis, by using highlighter pens to colour-code important text, making theoretical notes in the margins and recording meaningful statements on a separate sheet of paper. NVivo 8 qualitative analysis software was

<sup>20</sup> Some researchers prefer to 'clean up the text' by choosing not to transcribe repetition, vocal ticks and unfinished sentences. In order to achieve an accurate record of each interview, I requested that they be transcribed verbatim, including all speech, sounds and silences, whilst recognising that different people will hear sounds differently (for example, crying may be confused with laughter). I listened to each of the interview recordings whilst initially analysing the transcripts by hand and added any missing information.

then used to store and refine these notes, which became conceptual categories that formed the preliminary framework for analysis. This corresponds with the open coding phase of grounded theory analysis, which involves breaking the text apart for scrutiny and attaching meaning labels to the resulting segments of data (Corbin & Strauss, 2008). The use of NVivo facilitates open coding because it allows for the creation of nodes that provide storage areas for references to coded text (Hutchinson, Johnston & Breckon, 2010).

In the creation of free nodes, I was able to move beyond thick description to the micro-analysis of the data. These nodes largely reflected the language used by the participants so that the product of analysis could remain close to the primary data (Chiovitti & Piran, 2003). For example, several participants used the term “*the powers that be*” in reference to decision-makers within the NHS, and this was assigned as a free node label. Other examples include “*hitting rock bottom*”, “*quick fixes*” and “*fitness as a way of life*”. I then went on to identify common properties and make early comparisons between the concepts, which involved linking the free nodes to a series of higher level tree nodes. This process, known as axial coding, begins the process of reassembling data that were fractured during open coding (Corbin & Strauss, 2008). The final stage is selective coding, which involves translating the emerging conceptual model into a tightly woven account that cuts across multiple interviews and represents recurrent themes in the data. In making explicit decisions about which selective codes to adopt, the researcher checks the fit between the emerging theoretical framework and the empirical reality that it seeks to represent (Corbin & Strauss, 2008). However, I acknowledge that my definitions of ‘reality’ have clearly shaped the categories that were constructed during this process. For example, I was specifically looking for evidence of health-related behaviour change in order to address the study objectives; a researcher with different objectives might have produced a very different set of findings.

A key element of grounded theory analysis is memo-writing, which involves breaking the categories into components and elaborating on the codes (Charmaz, 1990). See box 4 for an example. By committing ideas, hunches, questions and elaborated categories to organised memos, the researcher can spark fresh ideas, create new concepts and find novel relationships within the data. NVivo can be used to construct memos but I used it primarily to code, categorise and store the data, whilst using my (hard copy) research diary to detail the ongoing theoretical

development and model-building. Memo-writing is also a crucial intermediate step in terms of linking coding to writing the first draft of the analysis (Charmaz, 2003).

#### Box 4: Example of a memo

##### Extract from interview transcript (with codes)

*[The health trainer] was a... a big person (comments on HTs' body shape). And I know when I was going to the circuit training class there was people there who [the health trainer] was seeing as well (user community), and they weren't amused at her telling them how to eat healthily and have this healthy lifestyle when she wasn't herself (negative user experiences; making judgements). You know, she wasn't what you would expect to see (expectations)... I mean, somebody was telling me they'd got really stropky with her (negative user experiences). I mean, I never did. I mean, to me it was like we were both learning together, you know what I mean? (empathy; learning together)*

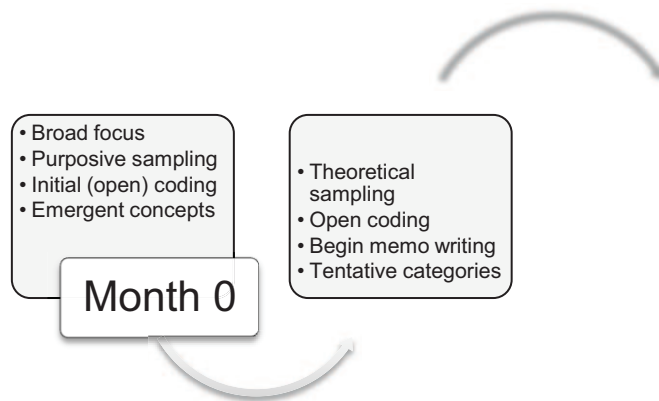
##### Research notes

It is interesting that this interviewee was the first to raise the issue of her health trainer's appearance (as a proxy for lifestyle) in a negative sense, yet she seems to have had a positive experience. The idea of learning together suggests a mutually beneficial relationship, as seen in the research literature. Reciprocity as a defining feature of the lay health worker concept? However, there is also the negative experience of others. Probe this idea with participants – do they have similar concerns about having an 'unhealthy' health trainer? Or do they set themselves apart from judgemental 'others'?

The discovery process extends into writing and rewriting, in terms of identifying arguments and problems, making assumptions explicit, and sharpening the concepts. It is at this stage that the study should be framed within the literature to show where and how it fits (Charmaz, 1990). As recommended by Glaser and Strauss (1967), I largely delayed reading and integrating the conceptual literature until later in the research process to decrease the likelihood that I would become locked into preconceived conceptual 'blindness'. This enabled me to foster analytic clarity and develop an initial set of categories before reading in relevant fields and then using this literature to gain greater theoretical comprehensiveness and precision (Charmaz, 1990). The iterative processes of sampling, coding, memo-making and literature searching are summarised in figure 14. These processes were complete once data saturation had been reached and the core category (contextualising) had been generated, along with two secondary categories (personalising and reciprocating). The categories are all gerunds (i.e. 'ing' words)

and therefore represent basic social processes, which are central to grounded theory (Glaser, 1978). In Section C of this thesis, each category is presented in turn and the substantive theory derived from this study – the theory of lay-led behaviour change in context – is discussed in detail. This chapter continues with a description of the strategies undertaken to enhance the rigour and credibility of the study.

**Figure 14: Developing a grounded theory**



### ***Enhancing rigour***

Qualitative methods are now widely used in health and social research, yet they remain at greater risk of being dismissed as anecdotal, overly subjective, lacking generalisability or “unscientific” in comparison with quantitative methods (Lincoln & Guba, 1985; Popay, Rogers & Williams, 1998). Furthermore, each qualitative approach has its own distinctive features and therefore its own specific risks. Table 9 outlines three areas where threats to the validity of this study were identified, alongside the strategies employed to reduce these threats. The decision to audio-record and transcribe the interviews, as well as the process of briefing and debriefing the person responsible for transcribing, was described earlier in the chapter. This helped to ensure that an accurate record of the interviews was produced, although it is acknowledged that there were limitations in terms of the ability to record inaudible or non-verbal data. The completeness of the transcripts enabled use of participants’ own language during the coding process, which can further grounded theory construction and add to the credibility of the findings (Chiovitti & Piran, 2003).

**Table 9: Potential threats to validity** (adapted from Robson, 2002)

Area	Threat to validity	Strategies to reduce threat
Description	Inaccurate or incomplete data	<ul style="list-style-type: none"> <li>• Audio-recording and note-taking</li> <li>• Interviews transcribed verbatim</li> <li>• Full analysis using NVivo software</li> <li>• Use of multiple data sources</li> </ul>
Interpretation	Imposing an inappropriate framework	<ul style="list-style-type: none"> <li>• Theoretical sensitivity</li> <li>• Let participants guide the inquiry process</li> <li>• Respondent validation</li> </ul>
Theory	Failing to consider alternative explanations	<ul style="list-style-type: none"> <li>• Sharing analyses with colleagues</li> <li>• Actively seeking non-consonant data</li> <li>• Maintaining a reflexive approach</li> </ul>

Analyses were shared with colleagues who had no connection to the study, in order to ensure neutrality and openness to unexpected information (Robson, 2002). This enabled me to determine whether the interpretive processes were clear and accurately described. Use of NVivo provided a transparent account of these processes, which should enhance the validity of the study (Hutchinson, Johnston & Breckon, 2010). There were potential drawbacks to using NVivo, which are discussed in Chapter 9. Trustworthiness of data interpretation was addressed by having the supervision team independently analyse a selection of transcripts (i.e. triangulation of analysis) (Denzin, 1978). This led to agreement and confirmation of the themes, and helped to reduce researcher bias and reactivity. The use of interviews and observations (i.e. methodological triangulation) also helped to provide a more substantive picture of the health trainer-led interventions and represented a means of verifying the emerging concepts (Berg, 2001).

Grounded theorists use the term 'theoretical sensitivity' to refer to the researcher's ability to use their personal and professional experiences to see the research situation in new ways and exploit the potential of the data for developing theory (Glaser & Strauss, 1967; Corbin & Strauss, 2008). My background in conducting research relating to health trainers helped in understanding the processes under investigation; for example, I was aware of the national data collection system for health trainers and was therefore able to understand comments on the burden of maintaining 'paperwork'. One way to enhance the quality of grounded theory research is to maintain theoretical sensitivity through constant comparisons and continuous memo-writing (Hallberg, 2010). Using diagrams and memos has

increased the trustworthiness of this study by maintaining a clear audit trail throughout the analytical process, as well as enabling me to simultaneously immerse myself in the data and gain some distance from it by encouraging a focus on the relationships between concepts. Furthermore, the longitudinal study design made it possible to re-visit and verify the emerging concepts, and fill any gaps in the participants' stories. The constant comparative approach meant that participants' stories largely guided the inquiry process, thereby enhancing the credibility of the study (Chiovitti & Piran, 2003). These issues are discussed further in Chapter 9.

### ***Maintaining reflexivity***

A final strategy for enhancing rigour involved employing a reflexive approach to reduce researcher bias and optimise objectivity. Reflexivity is defined as the process of critically examining the ways in which the researcher – as an individual with a particular social identity and background – has an impact on the research process (Hall & Callery, 2001; Robson, 2002). Reflexive analysis is commonly used in an attempt to “reveal forgotten choices, expose hidden alternatives, lay bare epistemological limits and empower voices which had been subjugated by objective discourse” (Lynch, 2000, p.36). However, this analysis must be carried out consciously and consistently if it is to be meaningful and avoid accusations of superficiality (Alvesson & Skoldberg, 2000; Lynch, 2000). Rather than being a one-off activity, I have attempted to reflect on the way the research has been shaped by my personal and professional biography throughout the process. This involved taking a step back to evaluate the influence of my experiences, values and behaviours on the research setting and the processes of sampling, data collection and analysis. For example, I was open with participants when asked about my knowledge of other health trainer services, whilst recognising that too much disclosure could lead to assumptions being made and block off areas of the interview. Furthermore, it is important to acknowledge that reflexivity rests on an awareness of self that can only ever be partial (McGee, Marland & Atkinson, 2007).

In grounded theory, developing self-awareness is supported through the process of memo-making, which is seen as integral in terms of enabling the researcher to locate and deal with data that oppose their own prejudices (McGee, Marland & Atkinson, 2007; Lambert, Jomeen & McSherry, 2010). By creating a series of memos whilst coding the data, I was able to reject or confirm ideas as part of the inductive approach associated with grounded theory. Nascent memos were created



during the fieldwork process in the research diary. Maintaining this diary helped in my efforts to develop self-awareness and ‘turn back’ on my initial reactions to the data, as well as contributing to a clear audit trail of decisions taken over the course of the study (McGee, Marland & Atkinson, 2007). NVivo was also used as part of the reflexive approach by coding all feedback on the research process and data collection tools, as well as any comments from participants on my age, body shape or any other personal attributes that might have influenced the interactions. It is important that reflexivity does not stifle creativity and result in failure to produce a theoretical account rather than a rich description, in what Glaser (2001) refers to as ‘reflexivity paralysis’. Overall, the processes of note- and memo-taking were found to be helpful in moving from empirical data to theorising in this study.

## **Chapter summary**

The purpose of this chapter has been to describe the activities involved in data construction and provide a context within which readers can more fully understand my interpretation of the data presented in the remainder of the thesis. I have provided a detailed description of the sampling and recruitment processes, and the challenges I encountered in attempting to work with various gatekeepers. The recruitment challenges gave me an early insight into the experiences of health trainers in attempting to engage with local people, which enabled me to begin to address my study aim and objectives. The use of a longitudinal qualitative approach has facilitated the processes of theorising through my methodology and developing meaningful, productive research relationships with the study participants. However, there are risks associated with this approach, which include the difficulty in maintaining an impartial stance. These have been described in terms of the tensions between the roles of ‘professional researcher’ and ‘good guest’ resulting from research conducted in private settings. Techniques associated with grounded theory have been used in an attempt to reduce bias and enhance the rigour of the study. For example, theoretical sampling, constant comparison and line-by-line analysis all help to ensure that emerging concepts are grounded in and supported by the data. Ethical and methodological issues have been considered throughout this chapter. The next section concerns the study findings and discussion of the implications of this research for advancing theory, policy and practice.

## Section C: Study findings and implications

In this section I begin by extending the description of the analytical process introduced in the previous chapter, providing examples of the diagrams used to identify and refine the emerging theoretical model. This centres on accommodating context in the behaviour change process through the delivery of personalised and reciprocal interventions. Chapters 6 to 8 consider in turn each of the three sections of the model shown in figure 16. These chapters broadly correspond to the three categories of Pawson and Tilley's (1997) realistic evaluation framework (i.e. context-mechanism-outcome). A key point of difference from this framework is that social and physical environments are considered key components of the health trainer-led interventions, as well as being modified as part of the process. In other words, contexts, mechanisms and outcomes are inextricable, rather than separate variables in this study. The contribution of the research to existing knowledge is discussed in Chapter 9. Implications for policy and practice are provided, along with key areas for future research.

### Summary of analyses

In Chapter 5 I detailed the way in which the raw data were coded using NVivo into free nodes (open coding), organised into tree nodes or themes (axial coding), and then analysed further to identify the key concepts (selective coding). The use of memos and diagrams helped in exploring the relationships between these concepts, as part of the analytical procedures described in Corbin and Strauss's (2008) version of grounded theory. The processes involved in the health trainer interventions are illustrated in figure 15, which provides an overview of the concepts identified from staff and service user interviews at the axial coding stage, and figure 16, which demonstrates the way these ideas evolved into a more complex integrative model. The core category for the study is 'contextualising', in recognition of the interacting effects of personal factors, the social environment and wider contextual factors on health and health-related behaviours. Personalised interventions that act on each of these three levels – by addressing individual barriers to change, promoting social interaction and creating safe, comfortable environments – appear to be the most acceptable and effective from the service user perspective. Health trainers draw on their own experiences and social networks in engaging with users and supporting them to make lifestyle changes, as well as experiencing personal benefits from the role. The impact on local organisations, which in turn shape and constrain the work of health trainers,

### Section C: Study findings and implications

represents an additional element of reciprocity. Variation by space/place and change over time add further dimensions of complexity to the model.

Ultimately the purpose of grounded theory is to generate a theory around a core emergent category that summarises what is happening and explains variation within the data (Corbin & Strauss, 2008). Figure 17 therefore presents the product of this study – the theory of lay-led behaviour change in context – in diagrammatic form. This model was developed at the selective coding stage and incorporates the three categories: contextualising, personalising and reciprocating. *Contextualising* is represented graphically by location of the service user within their social and biographical context, and location of the behaviour change intervention within a particular setting and organisational context. The health trainers' are placed at the centre of this diagram as their activities span these contexts, as well as being located within the wider spatial and temporal context. *Personalising* of the interventions is influenced by the networks and experiences shared between the health trainer and user, and also by the organisational culture. *Reciprocating* refers to outcomes reported both by staff and service users in this study, and the impact of these outcomes in terms of changes in the organisational context, indicated by the double arrows at the bottom of the diagram. The elements of the theory are discussed separately in the remaining chapters of this thesis, although it must be recognised that these elements are interdependent and overlapping.

Figure 15: Diagram showing the antecedents, processes and consequences of health trainer-led interventions

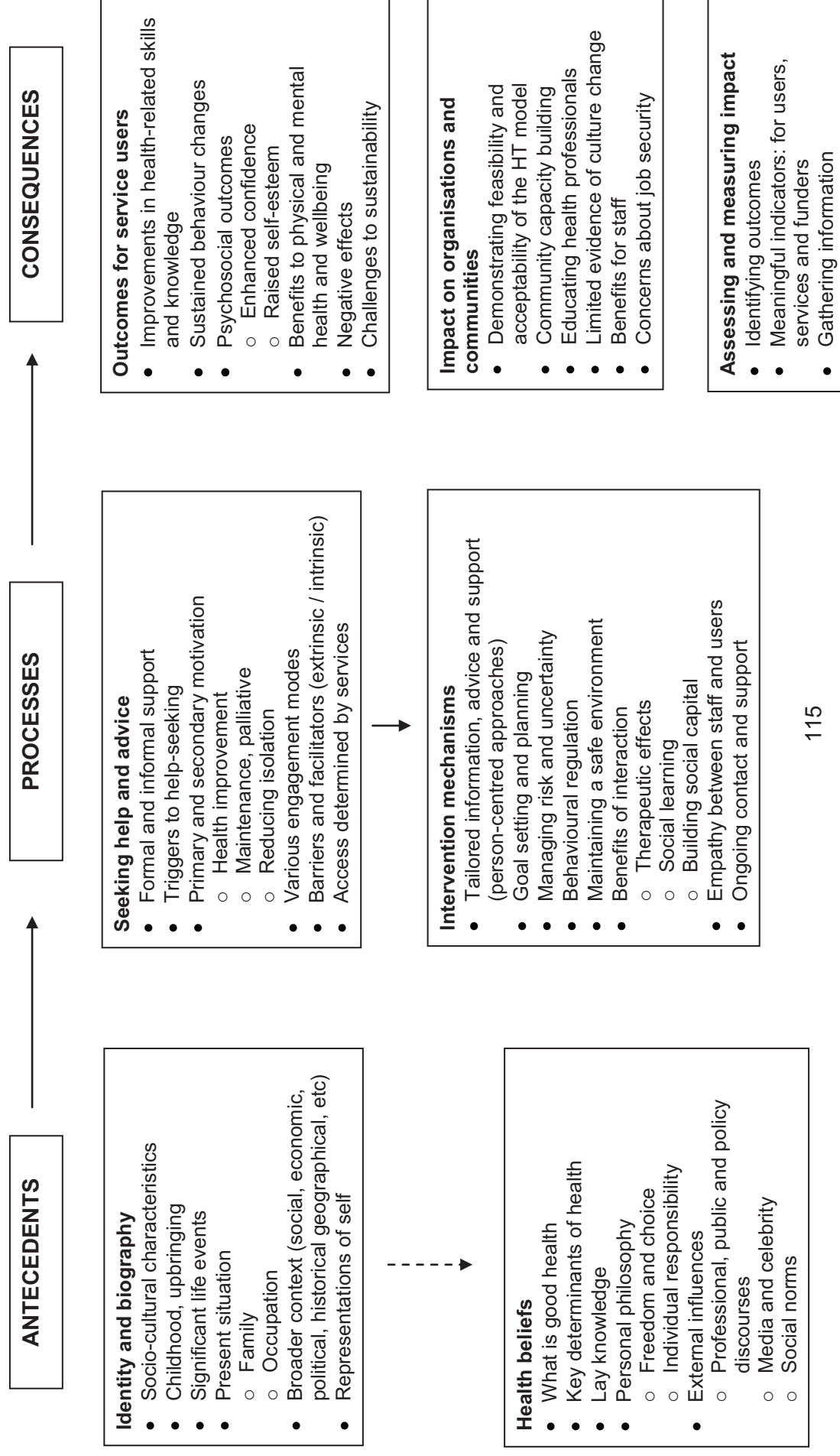


Figure 16: Integrative diagram showing change and complexity in the behaviour change process

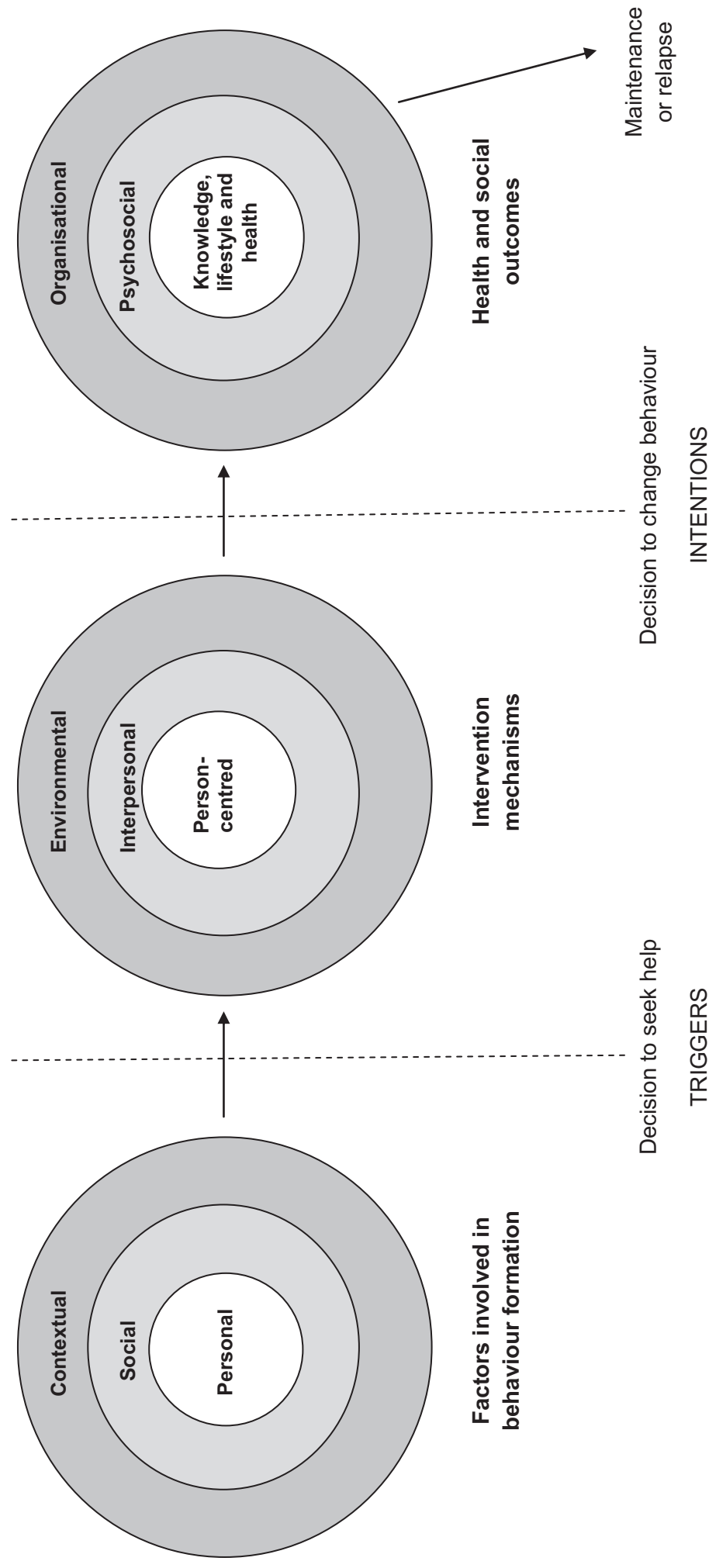
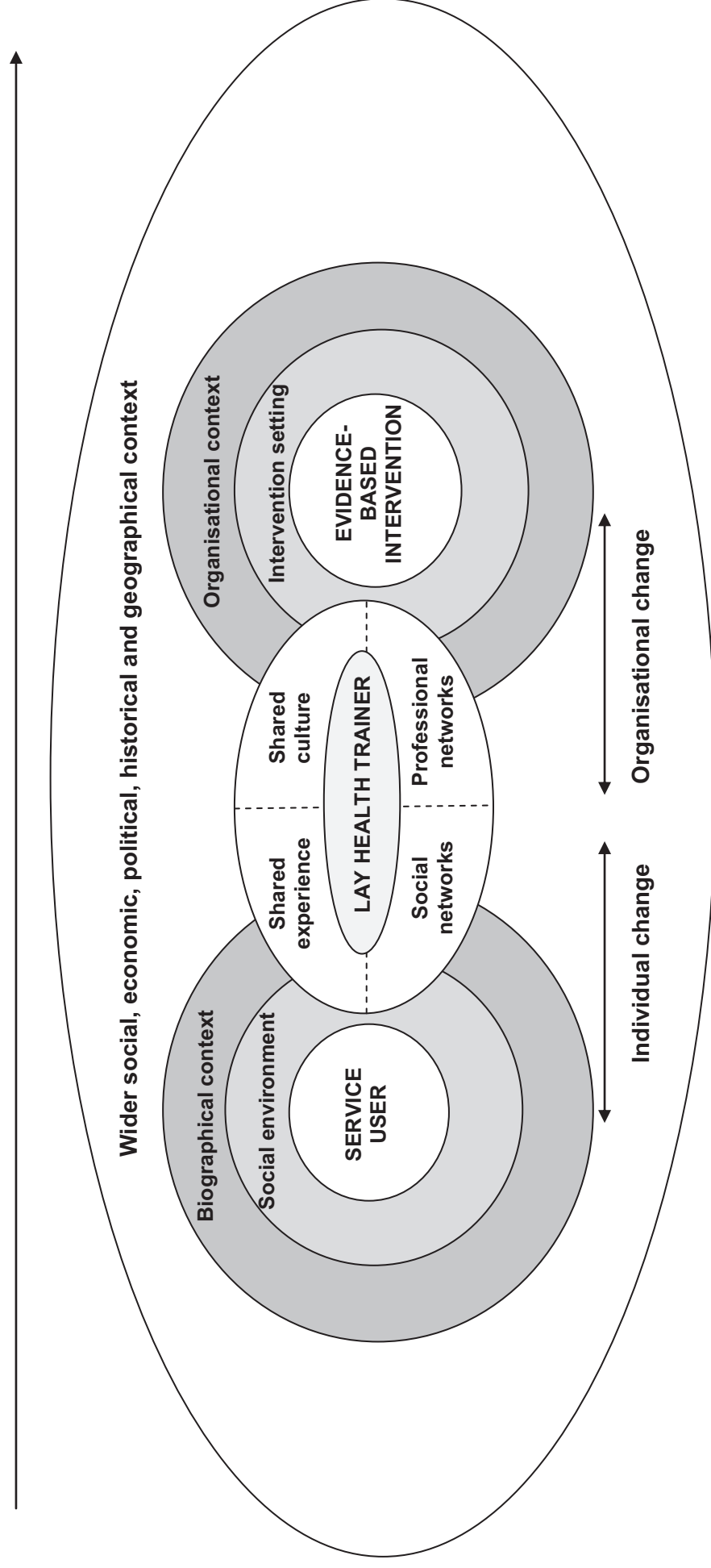


Figure 17: Diagram showing the theory of lay-led behaviour change in context

CHANGE OVER TIME AND SPACE



## Chapter 6: Contextualising behaviour and behaviour change

In this chapter I present the core category derived from the study data, which involves exploring the way in which various personal, biographical and contextual factors contribute to the development of ‘unhealthy’ behaviours. The many dimensions of context, including the biographical, social, economic, political, cultural, geographical and historical, are addressed primarily from the perspectives of service users. The influence of the organisational context is considered in the next chapter, which focuses more heavily on data from the health trainers and managers. Short vignettes and direct quotations from study participants are used to illustrate and support the analysis relating to the category ‘contextualising’ (see Appendix Q for a transcribing key). The chapter ends with a summary that draws together the main points to have emerged during the analysis.

### Personal characteristics

Service user participants were asked at each interview to describe their current health status and the factors they felt impacted on their ability to live the life that they would like to lead. These questions were worded carefully in an attempt to avoid imposing ideas about a ‘normal’ or ‘healthy’ lifestyle. Participants were encouraged to provide their own definitions of health and wellbeing, which ranged from the ability to take part in regular physical activity to being able to leave the house. Most described a state of compromise and willingness to accept a certain level of ill-health. This is illustrated by the following quote from Cathy, a woman in her nineties who was housebound and needed daily care for multiple conditions, yet still described her health as good:

Cathy: I’ve been registered blind for four years now. Luckily my vital parts, you know... I’ve had lots of operations – don’t ask me what (laughs). But I’ve, my general health is pretty good up to now, with my heart and up to now my general health... If it wasn’t I keep breaking my bones a lot, I’d be fine. [...] Thank God I’ve still got this [indicates towards head]. If you’ve got your brain, you can put up with a lot.

Participants in this study identified age, disability status and various other personal factors that influence an individual’s health experiences and health-related behaviours. These are considered in turn in the sub-sections below.



## Age

Age and the ageing process were identified as key contributors to the current health status of participants in this study, most of whom were over the age of 60 or had taken early retirement as a result of ill-health. Participants tended to report multiple physical conditions and expressed these as an inevitable aspect of the ageing process due to 'wear and tear' suffered over the years:

Kevin: It's just crumbling of the spine – hard life you've had and it's payback time now. This is the time it gets you. When you get over 50 it suddenly creeps up on you and it hits you, you know. But that's life, isn't it? It could be worse.

Losing a degree of mobility, slowing down and subsequently gaining weight were seen as accepted features of approaching old age. There was also felt to be a temptation to take the easy option and "*vegetate*", by sitting at home and watching television every day. However, the participants were keen to identify themselves as responsible individuals who were making efforts to maintain their health and halt the decline, as illustrated by the quotes below. This was partly for their own benefit and partly due to a desire to avoid becoming a burden on others, including the state.

Kaye: I think when you reach a certain age, there's a lot of people who I work with who are my age and they're reaching the same point as I am. And your hormones change and you start putting weight on and it's really hard to shift it, and all the things that you've tried in the past don't work. And you can either accept it and think, "Well I'm just getting old", or you can try to do something about it.

Int: I've kind of already asked about what you're hoping to achieve in the longer term. Is it mainly preventative?

Peter: To live longer (laughs). To have as good a quality of life as I can as I get older, you know. I know I can't run as fast as I was when I was a young man. I can't do things as quickly as I can and I'm not as agile as I can. But I am more agile and run faster and do things better than most people of my age. And I have less illness.

As well as separating themselves from their less health-conscious peers, older participants were keen to distinguish their generation from younger people who were seen as being primarily concerned with vanity and consumption. This difference was attributed to wisdom gained with age, as well as having fewer demands on their time. The staff interviews largely reinforced this perception, although there were some barriers reported to working with older age groups, such as physical limitations and an initial resistance to new information. It was recognised

that offering activities during normal working hours would be more likely to attract retired people who tend to be free during the day and are less likely to have childcare responsibilities. This links to the influence of occupation on health-related lifestyle behaviours, as described in the next sub-section.

### **Occupation**

A substantial body of literature documents the relationship between employment and health. On the whole, people who are in employment tend to have better physical and mental health than those who are out of work, partly due to increased status and economic independence. Participants in this study reported a decrease in access to financial resources following retirement due to reliance on state benefits, although most did not feel that money was a significant factor in their health. The primary concern was maintaining their pre-retirement lifestyle whilst on a fixed income, which involved making resource allocation decisions:

Terry: It [attending a private gym] boils down not to the convenience, it's the expense. You know, when you retire, you're counting your pennies and looking at things like that.

For many, paid work represented a form of structured activity, whilst retirement initially represented a life without structure or routine. Employment had been the main source of physical activity for those involved in manual or non-manual roles. It was also associated with social activity and access to resources such as sporting teams or exercise facilities linked to the workplace. In this sense employment was seen as having both health promoting and protective effects:

Int: And so before that [retirement], was your... you hadn't really had problems with your health or anything?

Sheila: No, nothing. No, I mean, I was on the go all the time. When you think, you had a routine. I mean, working full-time. [...] You used to sit at your desk maybe 10, 15 minutes, then you were up again and you never sat still. As soon as I retired, I sat down... I put the weight on and I'm convinced that's what got the diabetes – putting the weight on. You know, once you've packed in work and then you're just, you just slow down. You seem to just slow down to a nil and it just catches up on you.

In a minority of cases, employment was reported to have a negative impact on the ability to lead a healthy lifestyle, often due to the demands of a specific job. For example, Kevin described himself as a “*fry-up merchant*” whilst working as a long-distance lorry driver, whereas Brian “*lived off the fat of the land*” in hotels as a senior

manager in the banking sector. Full-time and shift work act as barriers to attending health care appointments and services that are primarily open during office hours. Active work also places a strain on the body and can exacerbate existing health conditions, whilst work-related stress impacts negatively on mental health.

Kevin: I've never been a heavy smoker. I mean I haven't got a smoker's cough or anything, you know. But it's just something I've done for 40-odd years. You know, I can't give it up. Being a truck driver, long distance, you always smoke when you're driving.

Participants generally reported mental health benefits as a result of being in paid employment, which was felt to give them a sense of purpose, identity and increased self-esteem. For some female participants, paid work outside of the home was seen as a form of release from the stress of their caring responsibilities within the family. Boredom was identified as a major factor in the development of unhealthy eating patterns which, in turn, was associated with an unstructured lifestyle resulting from being out of work. To counteract this, participants had sought to reintroduce structure into their lives by taking part in regular, often health-related, activities:

Pam: I mean, if the hotel had been still open I would have still been [working] there. I would have still... I think it gives you a bit of purpose in life. I think that's why I go to the gym and that. Rather than just, like, sit here.

Int: Work seems quite important to you.

Sian: Yeah. I think it's just for self-respect and, like, esteem inside. And I think that's part of the thing that keeps you ticking over, know what I mean? If you can go out and say, "I work", even if it's just part-time, you know. I work, I'm contributing. [...] For my own wellbeing, I think that's important, you know. So I give myself a pat on the back and say, "I'm doing this" rather than just sitting at home, having everything being given to me.

Participants who were unable to work for health-related reasons reported a decrease in self-esteem and loss of independence, leading to boredom and other negative effects. This is illustrated by the following quote and explored further in the section on disability below:

Kevin: I haven't worked since my brain haemorrhage in 2004. Basically, nobody would employ me as I am at the moment. Bit of a risk, you know. Bit of a liability. I miss work terribly, you know. [...] It does change your life. As well as losing that... your independence and losing your job. Thirty years behind the wheel of a big truck is a long time and I still want to do it but I can't. It's just not going to happen. So that's when depression kicks in as well. Your whole life has got to change.

## **Disability**

The sample included a diverse mix of individuals with limiting physical conditions, mental health problems and physical or sensory disabilities, as well as relatively healthy participants. None of those recruited to the study described themselves as having a developmental or learning disability, and some staff identified this as an area of unmet need within the local community. Two participants were mothers of children with learning difficulties and their experiences as carers are described in the section on family below. Participants affected by some form of disability encountered a number of challenges in attempting to lead a healthy, active lifestyle. These included a paucity of local services suited to their needs, practical access barriers and safety concerns. The following illustrative quote is from Frances, a woman in her early forties with progressive multiple sclerosis (MS):

Frances: [After writing to] the local MP, he got in touch with the PCT and he just said, "Oh well, the council gyms offer one-to-one support." But in theory they might, not in practice. They haven't got the staff to do it in practice. And I looked into a couple of private gyms but they're not insured. So I can't even join a private gym. And again they wouldn't offer the help that I need. So that's it, basically.

Int: And is it the one-to-one support you need, in terms of getting on and off machines and things like that?

Frances: That's exactly it. It's the getting on and off. And the weights I can't do without being physically tied on to the machine. So I can't go anywhere else. So it was a bit of kick in the teeth.

Frances spoke about an ongoing struggle to find ways to access services in order to meet her needs around engaging in activity and slowing the physical decline due to her condition. Over the course of our interviews, she spoke passionately about feeling shut off from an increasing number of avenues that would enable her to maintain a degree of dignity and independence. In part, this was due to her fear of exercising alongside able-bodied people and being subject to negative comments. Although Frances was speaking from her own personal experience, her comments are likely to be representative of many others with physical disabilities.

Frances: That's what it's like at a normal gym – you feel embarrassed and self-conscious because that's the way they make you feel. Like you've got be ashamed because you don't fit the stereotype, I suppose, of people that go to a gym. Fortunately they don't make Lycra big enough (laughs). But it's like the gym thinks, like, all you should see in the gym is fit, healthy people and it's a great advertisement for them. You see a disabled person or whatever and it doesn't fit [that image]

The staff also spoke of the difficulties experienced in attempting to support disabled people, mainly due to a shortage of appropriate follow-on services. There were particular challenges in working with wheelchair users, which can cause frustration for both the service user and health trainer. A situation where a wheelchair-bound user could not be given support to use her local library was described by one health trainer as “*heartbreaking*”. Deaf people were also felt to be particularly vulnerable to feelings of isolation and social exclusion. Staff reported challenges to working with these individuals that included the small size of the community, its diffuse nature, a lack of awareness amongst GPs, and language barriers:

HT: Within the Deaf community, information and access to information is way behind the access that hearing people have. They don't just pick things up via, you know, sound, via radios or people speaking or overhearing things. [...] Deaf people as well find it difficult, when they're on their own, to go into like a gym where it's full of hearing people where there's no communication. And so then, yes, I would go along to a gym and be there as a bit of company and support. It's a language barrier, you know, that they face.

### ***Ethnicity and religion***

Similar communication barriers are experienced when individuals from black and minority ethnic (BME) communities attempt to access health and social services. These are often compounded by high levels of illiteracy, as well as specific cultural, religious and gender issues that may make it difficult for them to follow healthy lifestyles. For example, one of the health trainer teams identified a local need for advice and support around supari<sup>21</sup> addiction that was not being met by existing smoking cessation services. Lack of awareness and understanding of health messages combined with low confidence levels were reported to be key issues in attempting to work with BME communities. However, the following quote from a Pakistani health trainer demonstrates that individuals from BME and White communities may experience similar challenges resulting from a lack of confidence:

HT: I would say the biggest barriers are the culture and the language, in terms of Asian communities. But in terms of White communities, I've seen some of them... I used to think when I first came [to live in England], because they are English, they speak English, they have no problems, they know their... They are confident. But they're not. I've seen so many White people with lower confidence and self-esteem than myself.

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<sup>21</sup> Supari is a mix of tobacco and betel nut that is chewed for its mild effect as a stimulant by members of some South Asian communities.

People from similar ethnic or cultural backgrounds do not constitute a homogenous group; for example, there were differences reported between the experiences of Muslim women of Asian and Middle Eastern origins. This highlights the importance of considering the role of individual attitudes and beliefs towards health in shaping health-related behaviours, as described below.

### ***Attitudes towards health***

A key factor reported to influence an individual's lifestyle was their attitude towards health and fitness. Maintaining a healthy, active lifestyle was often described as a "*way of life*", particularly for those who had been involved in sport from a young age. Participants described themselves as having the 'correct' attitude in terms of "*doing as they should*" and making health a priority; for example, allocating limited funds to fitness classes rather than alcohol or bingo. The emphasis was on individual choice and personal responsibility, as indicated by the following quote:

Maxine: It's up to the individual – if you want to do it, you do it. It's the same as when you stop smoking – it's got to be you and you alone. I mean, you do get help, but at the end of the day you don't have to put that patch on your arm, you don't have to chew that chewing gum.

These ideas were explored at the six-month follow-up interviews, when participants were asked to consider a series of prompts (see Appendix O) and discuss whether or not they felt these might act as barriers to leading a healthy lifestyle. The prompt that generated the strongest reaction was 'Life is too short to worry about health', as participants unanimously disagreed with this statement:

Sheila: 'Life's too short to worry about health'? That's a good one (laughs). No, that's stupid. You've got a sense of humour anyway. [...] 'Don't think I control my health'? Of course you do. You're the only one that can control it really.

Terry: 'Life is too short of worry about health'? I think life's too short because you don't worry about your health. I think people – young ones now, you know – all they think about is drink [alcohol] and I don't think they eat well and all that. And then it must have an effect as they get older but is it too late then? And I think you should look after your health from being taught at school.

People who do not worry about or prioritise their health were generally felt to be ignorant, lazy or lacking in self-control. One of the health trainers used the term "*tunnel vision*" to describe certain individuals who were unwilling to accept their



help. Participants emphasised the importance of people having the freedom to do “*what they want to do with their own body*” and that any efforts to control the behaviours of others would be futile:

Jim: I can't see where you could do any more. I mean, it's the same old saying – you can lead people to water but you can't make them drink. And I mean, if they're going to go for the easy [fast] food, you can't stop them. There's nowt you can do for them. You can try to talk to them but whether it goes in or not is a different matter.

Unlike those who choose to lead unhealthy lifestyles, participants perceived themselves to be ‘normal’ yet flawed individuals. Indulging over Christmas or whilst on holiday, craving certain foods or being a fussy eater were seen as acceptable behaviours, whereas binge eating or drinking to excess were unacceptable. This relates to Gina's view that “*You've got to have a little bit of what you fancy*” and that there are “*more important things in life than dieting*”. Alcohol was reported to have a role in pain relief, sweet treats were used in demonstrating affection, and smoking acted as an appetite suppressant as well as providing pleasure:

Gail: I can't say that I ever over-ate as such. I was a good eater, but not bingeing like you hear some stories of. And the patients that I used to have [whilst working as a nurse], like, that were bulimic or anorexic or that – the things that they used to do, I never, ever did that. I couldn't sit down and eat packets of biscuits or... There was a girl I used to work with, she once ate six packets of Mars bars. So that was like... what's six...? Twenty-four Mars bars. And I was like... you know? I really wanted to be sick and she was just... when she was under stress she went for chocolate. If I'm under stress, I tend to go for bread.

Int: And you've got no plans to quit [smoking]?

Kevin: No, not at all. I wouldn't give it up, no. I enjoy it too much. It's the only thing I do, you know. And fair enough, if I was in the pub every day – like some people are – you think, well, you know, you've got to draw the line somewhere. But a cigarette doesn't hurt me. I tend not to smoke in here if I can help it. I tend to go outside. Because my carer, she doesn't like cigarette smoke. So I won't smoke when anybody is in the house.

The second quote illustrates the way in which participants presented themselves as ‘responsible citizens’ who exercise their freedom and choice in ways that do not harm the health of others. They saw themselves as ‘decent’ people who were trying to make the most of their lives. Unlike others who were simply seen as making excuses, the participants felt they had valid explanations for their current unhealthy lifestyles or health states, including weight gain due to pregnancy, accidents or medication usage. Some highlighted specific health-damaging incidents, which are



outlined in the section below. Although a minority of participants seemed to be playing the role of victim, most were keen to present themselves as survivors:

Linda: I think the best thing could have happened for me was being put in care [as a child], you know. I'm not bitter about it. I'm not sad about it. I think it's made me, probably, the person I am today and I'm quite strong-willed.

### **Significant events**

Many participants recounted stories of life experiences which were offered as partial explanations for their current lifestyles and health experiences. Often these were traumatic events, such as suffering abuse as a child, domestic violence, accidents, bereavement and family breakdown, that had taken place some time in the past. The stories were generally told in ways that seemed to convey a sense that the story-teller had dealt with the experience and moved on. The following quote illustrates the impact that an acute health episode can have on a person:

Kevin: I had to change my lifestyle completely because you're restarting your life again. There's things I couldn't do anymore, you know. I had a serious memory loss, you know. I couldn't remember anything. I couldn't remember my door number, I couldn't remember my address – anything. So you had to change your whole lifestyle and find that you have to have people like Social Services and home helps coming in. And I'm not used to that. I couldn't get used to that, I really couldn't. I've always been independent and worked, you know. But you have got to change your lifestyle. Things that you took for granted that you did previously, you can't do them anymore. Even something silly like having a bath – oh no, you can't have a bath anymore. You've got to have a built-in shower put in. You know, a walk-in shower in case you blackout in the bath and go under the water, like, you know.

Kevin suffered a brain haemorrhage and stroke which led to him developing partial epilepsy, but the effects of his illness were compounded by the death of his mother, father, sister and brother within a three-month period. Although this is an extreme example, other participants spoke about periods during their lives when a number of traumatic events took place and had a cumulative negative effect on their health. Linda referred to “*messy times*” that left her feeling out of control and unable to look after her own health. The effects of these events on participants ranged from struggling to control their food intake during a busy time at work, to finding it difficult to cope with everyday activities during extremely stressful periods:

- Linda: I have been thinking about it [stopping smoking] for years but then the last two years have been horrendous. Absolutely horrendous. [...] I mean, if the last couple of months hadn't been the way they were I would probably be in quite a good place at the minute. I'm just not. Circumstances aren't letting me be. It's not that I don't want to [stop smoking], because I do.
- Gail: I was pregnant with [her son] when my dad had the stroke, but it was afterwards I went really anaemic and then all of the stress with my dad... My mam wasn't too well either. So it was all offloaded onto me and I ended up working full-time, going up to see and help my mam with my dad and what-have-you. So I think... I never really noticed it, but the weight just crept on.

The second quote illustrates the impact of disruptive life events but also demonstrates the role of significant others in the health of an individual, which is explored in detail in the next section.

## **Social environments**

A person's social environment includes their contemporary living and working conditions, social and educational background, and interactions with other people and institutions. Two aspects of this environment – interpersonal relationships and the wider context – are considered in the remainder of this chapter. The sub-sections below focus on conditions and events taking place in an individual's past and present that are impacted on by their relationship with some form of significant other, as well as the negative effects associated with the absence of social support.

### ***Childhood***

In some cases, elements of a participant's current health experience could be directly attributed to a condition or disability present since childhood. For others a more complex relationship existed between childhood illnesses and present-day health and lifestyle factors. Andrea described herself as "*captain of all the [sporting] teams*" until she missed a month of school due to pneumonia and "*I would say my fitness level never got back to where it was*". Several participants reported having a weight issue since childhood. This tended to be explained away as "*puppy fat*" or seen as the norm within the family, as illustrated by the quote below. Other conditions such as diabetes, anxiety, hyperactivity and a tendency towards alcoholism were also seen as part of their family history.

Pam: Well I've never been thin. Never. But I've never been the type that, like, weighed myself and went on diets. I mean, I was always... I suppose I took after my mam. I mean, my mam always... It was, "Well, you're big boned. You're like that." You know, I took after my mam and you just took for granted, well, that's the size you were going to be.

Aside from genetics, parents have a direct influence on a child's weight by preparing their meals, making food choices on their behalf and creating a 'food environment' within the home. Virtually all of the participants identified home-cooked meals and "*proper dinners*" comprised of fresh meat and vegetables as the norm during their childhoods. However, some traditional foods such as meat pies or suet puddings were recognised as having a high fat content. According to Sylvia, "*It was wholesome, healthy food – they thought – but really it was just making you fat, wasn't it?*" This influence can continue into adulthood for those who live and/or eat primarily within the parental home.

Parents also indirectly influence their child's health by shaping their attitudes towards lifestyle factors and enabling them to develop health-related skills. For example, many participants attributed their attitudes towards food and cooking abilities to the influence of their mothers. Most described their upbringing as strict and luxuries such as sweets, restaurant meals or fish and chips were a rarity. However, there was less concern with portion sizes or maintaining a balanced diet, particularly during the post-war 'boom' years. It was also recognised that food serves a function beyond sustenance, in terms of demonstrating love and affection:

Eileen: But, you see, when we were kids I suppose it was just after the war, wasn't it? And they had hard times, didn't they? You know, I suppose after the rationing stopped and everything it must have been a big thing for people to be able to eat proper food. And my mother loved nothing more than to feed you up. She thought, you know, that was her way of being good to you.

Andrea: You see, I think food is always an issue. The whole family is food obsessed. My mam grew up in Ireland, one of six kids, and food was scarce. Now, when we were kids I might have never had my own clothes – everything might have been a hand-me-down – but we ate like kings and queens.

Int: And do you think you've kind of continued those patterns of making food like your mam did?

Andrea: Absolutely. People laugh – they come here and they walk through the door and go, "I don't want anything to eat". [...] She [her mother] loved to feed people and I'm the same. I still do that. People will always say, "Oh, you're never short of a meal at Andrea's house." Because they know they'll come here and they'll get a good feed.

Smoking behaviour was influenced by parental attitudes towards smoking, as well as the attitudes of siblings and peers. Parents were not mentioned in terms of behaviours relating to sport and physical activity. Instead, the key factor seemed to be finding an enjoyable activity and developing a “*love of keep-fit*” at a young age. Those who had been active their whole lives were less likely to be afraid of trying new activities or using sport and fitness facilities in older age. This is illustrated by the following case study:

### Box 5: Terry’s story

Terry is 71 years old and lives alone. He left school at the age of 15 and went to work as an engineer in the local shipyards, continuing in this profession until he retired at the age of 68. He appeared to be extremely fit and healthy for his age and attributed this to his lifestyle, which was associated with playing semi-professional football from a young age. Throughout our interviews, Terry referred to sport and fitness as a “*way of life*”. He accessed the local health trainer-run gym as a way of maintaining his fitness levels after he retired from work. He found it difficult to identify any challenges to leading a healthy lifestyle, instead saying, “*Fitness doesn’t worry me because I’ve trained since I was 18, playing football. [...] So it’s always been part of my life so it’s not a, it’s not a barrier*”. However, he recognised that barriers exist for others. He has tried to encourage neighbours to join the gym but said “*you can see the look of fear in them*”.

### Family

The majority of participants in the study sample were parents and/or grandparents, which influenced their health-related behaviours in a number of ways. On a practical level, the needs and preferences of other family members can shape the actions of an individual. For example, mothers might be required to prepare foods that they recognise are unhealthy in order to please their partners and children. This involves expending additional time, effort and expense to prepare separate meals or prioritising the needs of others above their own, as illustrated by the quote below. In some circumstances, the effects can be positive; for example, when Jenny’s husband was diagnosed with type 2 diabetes she started to prepare healthy, balanced meals for the whole family.

Pam: I wouldn't put myself out to make anything for myself. I've always seen to my husband and I've always seen to my two sons. And I would just have whatever was... whatever I had the most of left over. And I make it into something, you know, into an omelette or whatever. But never to sort out a meal just for myself.

Looking after and caring for others places demands on a person's time, particularly for women who tend to be the primary carers. Young children require a high level of input from parents, and older participants highlighted both the demands and joys of caring for grandchildren. There were also examples of women giving up their jobs and social lives to care for a sick partner. One participant described the way in which caring priorities change over time, from looking after young children to elderly parents and then grandchildren. This can result in the carer feeling confined to the home setting and experiencing a loss of self-esteem and identity. The demands of caring can cause stress and lead to exhaustion, leaving little time for the carer to look after their own needs. Once the need to provide care is removed, the individual may find themselves without a role and look to paid or voluntary work to provide them with a new sense of purpose:

Sylvia:      Caring has been my life. Yeah. So I haven't had it easy, like. But... I would do it all again. Uh-huh, yeah. And that's why... It was when my husband died, and then this [local community centre] decided to open up, and I thought, "Right, I'm going to have to do something, you know, to... Because I haven't him to look after", you know. And that's when I went to be a volunteer.

Linda and Sian were both primary carers of children with profound learning difficulties and described this as an ongoing source of stress, contributing to their diagnoses with depression. These challenges were exacerbated by their status as single parents and a perceived lack of support from various agencies, leading to frustration and anxiety:

Linda:      After years of me asking for help from Social Services, I feel really let down by them and I think she [the social worker] has handled it really badly. [...] You're out on a limb and if you haven't got support – and even if you've got, kind of, inside knowledge of Social Services, they're not forthcoming. You know, you've got to fight to get help. You've got to fight for... to be taken seriously. You've got to fight to get people on your side.

Other participants reported the benefits of being in a long-term relationship with someone who supported them both in their role as parents and in their efforts to lead a healthy, active lifestyle. This support might be financial, emotional or instrumental, in terms of providing transport or accompanying them to activities. In some cases, this role was filled by other family members or friends, as illustrated by the following quote and explored further in the section below:

HT: My family, they are... Although I do tell them, you know, "There's this event. There's that event" – sometimes they will go, sometimes they won't. But if one of my sisters is going to go, then the other sister will go. If one of them is not going, then "I'm not going." So, you know, there's confidence, there isn't a confidence to go by themselves. So if somebody else is going, then they will go. And if they're not, then they won't.

### ***Informal support networks***

Participants identified social relationships beyond their families – including friends, work colleagues and neighbours – that influenced their health-related lifestyle behaviours. These relationships can have a positive effect, in the example of attending fitness classes with a friend, or a negative effect, in the case of peer pressure and smoking. They can also have a more subtle influence through a form of observational learning. Participants reported numerous examples of making decisions about their own lifestyles based, in part, on observing the behaviours of others within their social environments. In situations where health-related behaviours failed to produce the expected outcomes, this created some confusion and ambivalence towards lifestyle change:

Jim: Somebody else was telling me there was a lady, 103 [years old], she smoked and she had a glass of whisky every night. And she died with pneumonia. So, I mean... You can't tell. I've heard of people running on this [Great] North Run – three of them died of heart attack. Non-smokers, non-drinkers, and they died fit as freaks. So what's the difference? I can't understand it at all.

There were examples of positive effects as a result of learning from the experiences of others. Andrea mentioned observing unhealthy weight loss techniques used by her sisters and friends, and deciding that she wanted to find a more sustainable approach. Participants who lived alone tended to be lacking in opportunities for social learning and social interaction, which contributed to feelings of loneliness, isolation and boredom. This impacted on their mental health and wellbeing, as well as health-related behaviours such as smoking, cooking and snacking:

Jim: See, I brought four children up on my own so I got into cooking. I used to love cooking for the kids. I'd make my own bread and everything. But now, with being on my own, I'm not too bothered of doing too much [...] I find I get bored and I, that's why I go across there [to visit neighbours] because I chat to them people. But they're going soon so I'm going to have nobody.

### **Formal support systems**

The most isolated individuals were more reliant on the input provided by health and social care agencies as a source of social interaction. Kevin reported that being visited by a support worker three times a week often gave him a reason to get out of bed on a morning:

Kevin: I mean even the support worker – [name] – she’s a fully trained... She’s got all the NVQs now, in the caring profession, haven’t they? They’ve got to, you know. She’s a trained nurse and everything, you know. Used to work at [name of hospital] and that. So I rely on her quite a bit, you know, if I’ve got any problems and that. She says, “Just tell me if you’ve got any problems, you know.” So with having no family I’ve got nobody to tell things to you know. So I just burden her with my problems.

Other participants identified housing wardens, occupational therapists and primary health care professionals as sources of additional support. Those who spoke highly of their GP or nurse tended to explain this as being a result of their non-judgemental, “*no nonsense*” approach:

Eileen: I mean, my doctor, she’s... You know, she’s just wonderful. She really is good. You go... If you go with anything she’s... she would sort it out. You know, like when I was out of breath and after that chest infection, I mean there was no – “Oh well, we’ll try this or we’ll try that. Or we’ll try something else.” It was just, “chest X-ray, that’ll show us if there’s something else wrong”, you know. She’s very good like that.

Health and social care professionals were relied on to deal with complex care needs, rather than dealing with queries relating to lifestyle factors or emotional wellbeing. Those with mental health concerns felt that “*doctors these days are too quick to put you on antidepressants*”, with some participants using the term “*pill pushers*” to describe their GPs. The implication was that the medical profession is primarily concerned with treating problems, rather than identifying and dealing with any underlying factors. Other complaints about health services related to a lack of flexibility, poor communication, and approaches that were perceived as not being sufficiently patient-centred:

Int: Do you ever talk to your doctor or a nurse about healthy eating and things like that?

Pam: Oh, I don’t think our doctors would care. They’re hopeless. I mean, I need to go along and see my friend. She had to go to the doctors the other day. She had a, like a rash under her skin. And as far as I know – because I’ve got to know from somebody when I was coming back from [name of town] – they’ve taken a blood test from her and the doctor has



told her she's overweight. Now that's what our doctors do – they tell you you're overweight. They don't tell you how they can help you.

Participants reported examples of feeling let down by various agencies, which resulted in a sense of hopelessness and loss of faith in these services. In Sian's case, the stress of dealing with her children's behavioural problems and lack of professional input had resulted in her taking an extended period of absence from work. Other participants described feeling frustrated and exhausted by their attempts to navigate the formal health care system. The following quote and case study (box 6) concern two individuals who felt not only had their health needs been neglected by the system but that their wellbeing had been damaged as a result:

### Box 6: Gail's story

Gail is 49 years old and lives with her husband and daughter. She worked for 20 years as a psychiatric nurse but retired due to ill-health. She has been overweight since childhood and gained weight in recent years after a series of accidents. At our first interview, Gail had completed a six-week weight management programme run by the health trainers. She had begun to lose weight and was optimistic about the possibility of bariatric surgery. At each follow-up interview she became upset about her inability to maintain this weight loss, which she attributed to her limited mobility and medication usage. She was angry that these factors were not taken into account by the bariatric nurse, who said, *"Well, you'll just have to cut your portion sizes down and you'll have to exercise more". And I'm sitting there with my [walking] stick and I could hardly move because of the pains in my back*". She also referred to the consultant as being unsympathetic towards her disability and creating barriers to the surgery, which led to her thinking *"Right, I don't care anymore". I just went really, really down. Really depressed. And I piled it [the weight] all back on again*". By the time of our final interview she had given up on her weight loss goals.

Pam: When I left hospital [following a mini-stroke], I wasn't given a programme. They said a physiotherapist would get in touch with me – they didn't. I phoned. I phoned all over to try and find out where was this person supposed to be. I was sitting here, I couldn't walk. [...] I was told somebody would come out within seven weeks. You need... You need something before seven weeks because I was just sitting here. She told me over the phone to get a jigsaw or do some knitting. I mean, that's a great help for your mobility... And like I say, I got the support from my family. I didn't get it from the National Health.

As a result, many participants avoided using health services or medication unless they felt it was absolutely necessary, which supports the aforementioned idea of

people taking action to protect and improve their own health. It was also suggested that the necessity to look after themselves was likely to increase with time, as illustrated by the following exchange between Brendan and Sheila (a married couple who accessed their local health trainer service together):

Brendan: We're going to get some cutbacks.

Sheila: Well, we'll get a lot more now with the change of government.

Brendan: It'll still get worse before it gets better.

Sheila: I think so.

Brendan: Like the old saying – the Lord helps those that help themselves.

This exchange illustrates a general concern amongst the participants that public services were becoming less dependable due to changes in the broader economic and political environment. These changes are described in the section below.

### **The wider context**

The rapidly changing context of health and health care at local, national and global levels provides the backdrop to this study. Fieldwork took place between June 2009 and January 2011, which was a time of economic austerity, political upheaval and major NHS reform in the UK. These changes in the wider context coloured my conversations with the staff and service user participants. For example, some interviews were undertaken around the time of the general election in May 2010, prompting Frances to make the following comment:

Frances: It's only just been decided in the last 48 hours, really, who's Prime Minister. And it's a coalition government so I'm not even sure who is what now. Who's in charge of the NHS now? Or who is the health minister? I have no idea.

Although the election itself did not have a direct impact on the health of participants in this study, it added to a general atmosphere of uncertainty and confusion. This was compounded by the influence of the media, changes within local communities, and historical factors, which are described in turn in the remainder of this section.

### ***Economic and political factors***

The economic climate impacted on participants in this study in terms of placing constraints on health and social care services, as well as impacting on individual

lifestyles. One Health Trainer manager noted a paradox in terms of public health services being cut at a time when there is a greater need for them as people “*let their health slip as their economic circumstances take a downturn*”. Service user participants also recognised the economic climate and political situation as being inextricably linked, illustrated by the following quote:

- Int: And do you have any idea why they've brought in these changes [to local services]?
- Sheila: Well, the only thing I can think of is the change in government because it just seems to stem down to money for the situation, isn't it? I don't know. But I mean, that's the way I, we look, well a few of us [at the gym] look at it like that. It all seems to have come about since the Conservatives took over in [name of town] and that's where a lot of the changes are coming from

Many were angry at the cutbacks in the public sector; for example, Kevin felt the government were putting people with illnesses under pressure whilst “*fat cats are creaming off the profits*”. There was an awareness of the need for services to become more cost-effective and to make savings within the NHS. However, participants described the cuts to public health as ‘short-sighted’ in recognition of the fact that treatment and acute care tend to be more expensive than prevention:

- Brian: I think this is a short-sighted way of [saving money] because they'll end up with me back where I am. And it'll cost them more if I have a heart attack, won't it? Or if I get obese again and have all the complications. It's going to cost the National Health Service a lot more – you tell them that. [...] I mean, you get these leaflets – they bang away at us that it's in their interests to keep us healthy, because it costs them less to keep us healthy than it does to treat us if we've got problems. So what do they do? They make it difficult for me to stay healthy. It's crackers.

### ***Public health campaigns and media***

There was a perception that the general public have become more aware over recent years of issues such as the economic and societal costs of ill-health and the role of health promotion. One manager speculated that the high proportion of service users seeking help with food and nutrition had been motivated by there being “*lots of talk of obesity and health issues*” in the media. Another manager credited the influence of recent public health campaigns:

- Manager: At the moment we're kind of swimming with the tide – all the Change 4 Life stuff and so on does make it easier. People are aware of the issues. [...] I always think of the five-a-day being the best example of that in that it was a fantastic campaign in terms of making people very aware that

they needed to eat five-a-day. And I think it's raised people's awareness around the benefits – the health benefits – of fruit and vegetables.

Service users referenced health messages in magazines, newspapers and TV programmes. There were also examples of 'unhealthy' messages; for example, the liberal use of butter and cream in cookery programmes. Jenny referred to the celebrity Hannah Waterman – who had been featured in the press for her significant weight loss – as looking "*terrible*" and used this as evidence of the importance of making sustainable dietary changes and losing weight slowly. In this way, the media can reinforce healthy behaviours or act as a trigger for behaviour change:

Farzana: You know how there's always these [TV] programmes saying there's like big [obese] people so big and they've got all these problems and they can't walk, they can't do this? And there are programmes about people and they can't even leave their own bed, they're too big. And that kind of scared me and I thought, "I have to go and see the doctor". [...] You see more things – more signs, more leaflets, more stories. And, well, that's... Me being heavy as well, that kind of... I thought, "No".

There were a minority of examples where the media were felt to have a negative influence, particularly in terms of its portrayal of overweight and obesity. This is illustrated by the quote below from Gail, who felt that the media were partly responsible for victim-blaming and stigmatisation of obese people, whilst portraying issues such as alcohol or drug misuse in a more sympathetic light. Frances also believed that images of disabled people were absent from the media and therefore absent from the public consciousness, citing the 2012 Olympics as an example.

Gail: But medias have got a lot to blame, and I think that will have made a lot of kids who would probably have grown up reasonably normal – they piled weight on because they haven't been skinny. It's the opposite effect. They get depressed because they're not thin and I think that's how anorexia and obesity has reared its ugly head some more. So I might be wrong, I don't know, but there just seems to be that the more media input, the worse things become. And then you get all of the hate, the loathing, the self... The low self-worth. And it just makes it worse, so you're on a vicious circle.

### ***Geographical context***

The features of an area can have an impact on health, in terms of access to local facilities, green spaces and opportunities for social interaction, particularly for older people. The following quote from Peter illustrates the positive influence of living in a suburban area on his health-related behaviour:

Peter: I go cycling in the summertime, a lot. And I usually do about 20 miles, 25 miles every day on my bike. And my weight comes really down with that. And that's really good. But I'm in a good area for that. You know, I can go straight up the track or I can go down the beach and along the promenade. And I think where you live is definitely a significant influence to how you exercise. You know, if you live... I don't know, in the middle of a city, it's much more difficult to go cycling there than it is here.

Negative effects associated with living in a deprived or “*rough area*” include feeling isolated, lacking access to health-promoting resources, and having concerns about personal safety. The health trainers reported that there are particular areas where it can be extremely difficult to engage people and encourage them to take part in activities. A reputation for housing a sizeable population of drug addicts, alcoholics or “*problem families*” can result in an area becoming stigmatised and impact negatively on the wellbeing of residents:

Kevin: I thought, well, yeah, [name of area], they won't have the funding for these things [activities] or the resources. Nobody is interested. There's a lot of drinkers round here just not interested in health whatsoever. [...] Lads round here... You know, only my age – 55 and that – and every day you see them they're on the drink, you know. Bottles of cider and that. What a waste.

This quote presents a negative picture of Kevin's local area and the characteristics of the local population. However, the quote below taken from the same interview portrays the same area in a far more positive light. This demonstrates that the way in which questions are framed can influence the responses received and also that contexts can change over time:

Kevin: It [the area] has improved a lot. I mean I've lived round here 21 years and, I mean, they're doing all the flats up at the top there. You know, it's completely changed now. They're like the flats on the river side down at the quayside there now. And there's a bit more police presence in the area, which gives you that little bit more support and help and that, you know. And I think all the bad families that used to live across the way there have all gone now. The council have pulled their socks up and said, “Right, let's get them out”, you know. There's not the amount of trouble on the streets as there used to be and I think the whole area has improved 100%, you know. I can't fault it.

### ***Changing times***

Participants talked at length about their childhoods and the way that times had changed; for example, fewer women worked once they started a family and more men went straight from school into manual jobs that kept them active. As stated

earlier, home-cooked food was seen as the norm and treats were a rarity, whereas participants felt that children now perceive eating takeaways and unhealthy snacks as their “*staple diet*”. It was acknowledged that this was partly due to an increase in the availability of convenience foods but also influenced by a change in mindset:

Sian: Things have changed, you know, so it's not as much of a treat. It's more like a sort of staple diet. Kids think you get cake every day, whereas when I was a kid you used to get cake, say, once or twice a week if you'd been good. But it's the same with biscuits. I mean, if there's no biscuits in the biscuit jar they [her children] think it's strange. And you know, like, at one time the biscuit jar was put on the top shelf and you had to be good or company had to come round before you got a biscuit, you know. But I think it's just the sort of mindset and perception the way it is now. It's changed and it's moved on.

To an extent, participants' accounts were influenced by a sense of nostalgia and having a 'rose-tinted' view of the past. Those living in small villages reported a sense of community that they felt had been lost over time. Others described having fewer worries in spite of difficult circumstances:

Peter: The house was very Spartan. We didn't have any hot water, didn't have any electricity. We had an outside toilet. And it was very, very basic. So it was a... But the camaraderie of everybody was very much so – especially at the end of the war. Nobody had anything and the instances of burglary, etc, were non-existent. There was no... Very little crime. Everybody sort of mucked in.

The widespread availability of new technologies such as satellite television and computers was felt to make it easier for people to remain sedentary during their leisure time. However, participants also recognised that this technology can be used to promote health and enhance wellbeing. For example, several of the older participants were taking computer classes and reported using the Internet to locate information or communicate with family members. In the case of individuals who might be prone to falls inside or outside the home, technology was available to preserve their health. Safety devices and mobile phones were used to keep carers or family members informed and give them peace of mind.

In some ways, the present context was felt to offer more opportunities to follow a healthy lifestyle than the past. For example, there were reported to be more after-school activities for children and free access to public swimming pools for those

aged under 16 and over 60<sup>22</sup>. The availability of certain foods has also changed over time. Participants reported regularly eating processed meat, pastries and treats such as bread dipped in sugar during their childhoods, which are now widely recognised as unhealthy practices. There was a perception that people are generally more aware of the importance of health and that norms such as smoking or 'eating for two' during pregnancy are less common in contemporary society:

Brian: People smoked a lot more in those days. And it was more a social thing. And if you would go out for a drink or something like that, you know, it was a natural thing to light up a cigarette. And that's what I did.

## **Chapter summary**

This chapter illustrates one of the main advantages of the grounded theory methodology in terms of allowing the priorities and concerns of study participants to emerge from the data, rather than being shaped by a framework imposed by the researcher. The emphasis in this study is on the process of making and maintaining health-related behaviour changes but the service users were more interested in providing justification for their 'unhealthy' lifestyles and behaviours. This was done by making reference to individual factors such as age, employment, ethnicity and disability status, as well as personal attitudes towards health and the influence of others within their social environments. There was a moral element to the discussions, with participants keen to present themselves as 'responsible citizens' facing multiple constraints on their lifestyles and resources, whilst making efforts to maximise their health within these constraints. Reference to the economic and political climate, the role of the media, and characteristics of the local area – as well as the way in which these factors change over time – highlights the need to view service users as located in time, space and being. The importance of context is considered further in the next chapter, which describes the role of health trainers in supporting people to make lifestyle changes using personalised approaches.

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<sup>22</sup> The termination of this national scheme was announced before the end of the data collection period (January 2011), although the scheme continued to April 2011.



## Chapter 7: Personalised intervention models

The previous chapter has shown that participants' accounts highlighted the significance of personal biography, the social environment and wider context in the development and maintenance of health-related behaviours. In this chapter, the processes of deciding to change these behaviours, accessing appropriate support, and participating in health trainer-led interventions will be addressed from the perspectives of service users and staff. Verbatim quotes and case studies are used to illustrate participants' experiences of implementing, delivering or taking part in these interventions. I also examine the various health trainer delivery models and intervention settings in terms of the impact on staff and service user experiences, as well as the perceived benefits of providing opportunities for interaction between users. Towards the end of the chapter, I highlight key features of the health trainer role in terms of representing a strategy used to facilitate engagement with local people and support them to make and maintain behaviour changes. Finally, conclusions will be drawn about the main emergent issues from this chapter.

### Time for change

The initial decision to engage with a local health trainer service was based on a combination of the participants' prior experience of attempting to make lifestyle changes and various motivating factors. These two components of the decision-making process are described in the sub-sections below.

#### *Previous lifestyle change attempts*

In the majority of cases, participants had previously made at least one attempt to implement lifestyle changes, either on their own or with the support of a specific service or facility. These included the use of smoking cessation products, commercial weight loss programmes or privately-funded sport and exercise facilities. Participants deemed the products or services to be ineffective when they failed to produce the desired effects or when they did so in ways that were perceived to be unhealthy and therefore unsustainable:

Maxine: I'd just stopped smoking and I went to Slimming World and I lost three stone there, but it wasn't healthy eating. I wasn't eating. I just needed to get the weight off because of stopping smoking. Well, apart from trying to stop smoking, I thought I was going to put lots of weight on so I've got to try and get it off first. So I was only eating one meal a day. And it

wasn't because of their plan – it was because of me. You know, so it wasn't healthy.

Commercial facilities were felt by participants to be motivated primarily by profit-making, rather than by a desire to promote and protect health. This results in a perceived emphasis on efficiency (i.e. attracting the maximum number of paying customers to be served by the minimum number of paid staff), and consequently a lack of interest from staff following the induction at a private gym. There was a perception that these gyms are large, noisy and expensive, which can be off-putting for people with low confidence and limited resources. The group sessions favoured by commercial weight loss programmes can also create feelings of discomfort:

Jenny: I've tried the Weight Watchers and things like that but I don't feel comfortable with them because they do sort of – you've put [weight] on and they let everybody know, you know, you've put something on. And it's, it's different circumstances for different people. Sometimes there's some weeks you can go and sort of lose, and other weeks you can eat the same thing but put on. But they don't look at it that way [...] And you're coming to your food and you wean everything out and you've got to – "Oh, you can't have this and you can't have that." And you sort of can't have it so you crave it. So it is just a waste of time and a waste of money. Because that's all they're after.

Jenny went on to state that *"you're not looked at as a person, you're just a number"*, which was a common view not only of commercial facilities but also of those provided by local authorities. There was a generally low opinion of council-run gyms, which were reported to be overcrowded and overpriced. Similar to commercial facilities, participants felt that these gyms were set up to generate income so that tax-paying customers were effectively paying twice. There was also a general perception that private and council-run facilities were targeted towards relatively fit and healthy individuals, with numerous comments made about *"Lycra-clad women"* and *"body-builder men"*. Participants reported concerns about feeling out of place in these environments:

HT: A lot of people have said that – especially with the weight management clients, with them being a lot larger – they don't like the idea of going into a normal gym. They see it for people that play sports and are super-fit. Where, when they walk in [the health trainer-run gym] and see all different ages with all different problems, they tend to see it more accessible than just even a council facility or a private gym.

Linked to this was a perception that these gyms were not equipped to deal with the participants' specific health needs, due to limited capacity but also limitations in staff

training and expertise. One of the health trainers provided an example of a family member with serious health problems who was not properly assessed by council staff during their gym induction. However, contrasting examples were given of service users praising the wide range of facilities on offer within council-run and private gyms, including saunas and swimming pools. It was also reported that previous attendance on a weight management programme could benefit the health trainers in terms of creating informed service users:

HT: Most of the people are quite good because they've been to Weight Watchers and things like that however many times. And they know everything so they... They're quite good. Like, they come and tell us, like, "Oh well I've tried this. This is really good, this works."

As stated in the previous chapter, participants tended to be mindful of making unhealthy choices, as well as maintaining a philosophy of 'everything in moderation'. However, there was a gap between knowing what they should do and being able to implement this advice, suggesting a level of health knowledge but a deficiency in health literacy:

Eileen: You see, I don't know whether it's just me but I think I really don't need anybody telling me what I've got to do, because I know what I've got to do. I know what I should be eating and what I shouldn't be eating and I'm just not doing it at the moment. So I know, you know what I mean? You know – you know yourself, don't you? I mean I know I shouldn't be putting chips in my mouth all the time because they're fattening and... you know, but I do it.

The next sub-section considers factors that move people from this position to seeking help with their attempts to make lifestyle changes.

### ***Motivating factors***

Triggers to help-seeking included reaching a 'watershed' weight or being diagnosed with a new illness, particularly a lifestyle-related condition such as type 2 diabetes. These developments often resulted in feelings of shock and openness to lifestyle changes suggested by health professionals. In other cases, participants had gone through a more gradual process of gaining weight or experiencing a decline in their physical and/or mental health. The trigger to seeking help resulted from a feeling of "*hitting a brick wall*" and a willingness to try anything as a last resort:

Jim: It was more or less things got me down at one point and I just decided to get my health back in. I was getting too fat. I don't know why, like. It was wrong food I think, as much as anything, and not getting enough exercise. So I started to get more exercise.

Three main types of primary motivation were identified from the data:

*(i) Health improvement*

This category includes those seeking to lose weight for medical reasons, as well as those aiming to reach a higher level of health and fitness. Many participants hoped to improve existing health conditions through a combination of weight loss and increased physical activity levels:

Jenny: I was having a lot of trouble with my back and I wanted to lose weight and I wanted to try and get, see if any, I could do anything that would sort of put any strength into my back. Which, I mean, they say it's not going to do anything to sort of make a big, miraculous recovery or anything like that, but just something to strengthen up.

One health trainer stated that the majority of their service users are motivated by a desire to lose weight, often because they have pre-diabetes or conditions such as arthritis that may be alleviated by reducing pressure on the joints. The following quote illustrates the way in which Brendan, a man in his late sixties with arthritis, saw the health trainer service as part of his ongoing treatment regimen:

Brendan: I mean, it was the doctor who sent me for physiotherapy for my arthritis in this knee. And it was the physiotherapist I was talking to at [the hospital], and I was telling her about [the health trainer service]. She said, "No problem. I'll just refer you there", you know, when I was finished with her. [...] I mean, when you think about it, it's just another form of physiotherapy really. You're carrying on from the hospital – you're going to the gym for 12 weeks.

*(ii) Health maintenance and illness prevention*

For older participants with minor health concerns, the emphasis tended to be on maintenance of their current health status and prevention of decline. This included halting or reversing any decline in pre-retirement activity levels. When Terry was asked where he would like to be in a year's time, he responded with the following:

Terry: I'd be quite happy to be as I am today talking to you (laughs), because then I'll be 72 and I'll think, "Yeah, I can go to the gym and I can..." I'm

not bothered about keeping up with the best but I've got my level and if I can keep that level, I'll be quite happy.

Other motivating factors included a desire to maintain a healthy weight, as well as keeping their blood sugar, blood pressure and cholesterol at safe levels. These factors were believed to have longer-term benefits in terms of illness prevention:

Peter: I sort of look at it as like preventive medicine, you know. It makes you feel better, you've got more energy. You certainly are fitter because obviously fitness is the ability to recover. You sleep better and you, you just have a better wellbeing. [...] But even if you can keep on this road and just even get a little bit better, it's worth it because the converse of not, or consequence of not doing it is so drastic. You know, you become housebound and you can't move and you get overweight and that makes you even less active. And it becomes worse and worse.

Older participants seemed more aware of the consequences of unhealthy lifestyles as a result of observing negative outcomes amongst their peers. Terry spoke about not wanting to become a burden on the state and end his life in a care home, as happened to his mother. In Pam's case, she had personally experienced the effects of leading an unhealthy lifestyle and was motivated to change her behaviour in an attempt to avoid similar effects in the future:

Pam: I mean, that's when I stopped smoking, after I had the stroke. Not particularly because I wanted to – because it frightened the life out of me. [...] It definitely frightened the life out of me. So I just try and do everything I'm supposed to. I mean, like I say, my brother he has the attitude, "Oh well, if you're going to go, you're going to go" and all this. But when something like that happens to you, you don't get another chance at life. So you make the most of... You try and behave yourself. Well, I do anyway.

### *(iii) Psycho-social wellbeing*

Younger participants were more likely to describe primary motivating factors related to their mental, emotional and social health, as opposed to physical health. Mothers of dependent children in particular spoke about a desire to have dedicated "*me time*" and engage in activities that would enable them to build self-esteem:

Linda: I lost my identity. And I think part of this with [the health trainer] was kind of little bits to get it back. You know, doing stuff for me, not just mentally but physically. And a little sense of achievement at the end of it, you know. [...] It's kind of a bit of all kinds. It's not just about the healthy eating, it's about me being – making something of myself, doing something with myself. I need to do it.

In Linda's case, as well as Sian's, this was linked to finding activities that would help them to cope with the stress of caring for children with behavioural problems. Sian described attending a meditation class which *"involves giving yourself permission to be quiet and sit still and not worry, which can be one of the hardest things to do"*. Other participants reported wanting to gain confidence and become more independent. This was particularly the case for individuals with physical or sensory disabilities, as illustrated by the following quote from Frances:

Frances: It's not about... I would say, maybe, it's 50% health. The rest is all mental. That's the way I perceive it. Some people might be there purely just for health but I think a lot of the people in the [health trainer service] go there because they're accepted as well. For the camaraderie. Because they know they're not going to be judged, they're not going to be stared at. And that's what matters.

For those who are socially isolated, accessing the health trainer service can represent a rare opportunity to meet and interact with others. This can serve a practical function – for example, if a person needs someone to accompany them whilst taking part in physical activity – or it can help to reduce feelings of loneliness:

Int: What was it that made you decide to take part?

Kevin: Basically because I was pretty lonely, didn't have any friends. [...] [This service] is for people who've got health problems, depression, whatever, you know. Just people who want to meet other people and get out and socialise a little bit, you know. And when you go out, you're not rushing around, you're not tearing about to do things. You do it at your own pace and just enjoy it. Well, it's company really. I love it.

Kevin was one of a few participants who reported opportunities for social interaction as their primary motivation for accessing the health trainer service. Others described this as a secondary factor in their decision to continue with the intervention, as illustrated by the following quote:

Int: So you don't, you don't go to [the health trainer service] mainly for the socialising and to get support...?

Terry: No, the first reason I ever went was to keep a good posture and to keep fit. The social side – you meet people, you talk, you know – and all that becomes part of the, part of why you stay, not why you go. It's like a benefit of going there.

This quote demonstrates the way in which secondary motivating factors can emerge over time and influence the sustainability of an activity. The health trainers and

managers reported a number of additional examples involving the emergence of mental health issues as secondary to an initial physical health concern:

Manager: And there is an argument, you know, around mental health. You kind of say, well, people don't put their hands up and say "Please can I refer myself to you because of my mental health." Whereas they're very comfortable, people would be more comfortable – not very – but more comfortable around disclosing and sharing a desire to lose weight or be more physically active or whatever. But we do, you know... A lot of people that we work with – as a secondary issue that comes out – have mental health issues.

One health trainer described a situation whereby users present with a "*double agenda*"; for example, wanting to stop smoking and lose weight, or seeking physical activity to alleviate depression as well as needing help with an alcohol problem. In these cases, a decision needs to be made whether to address both agendas simultaneously or prioritise one over the other, according to the degree to which these issues are interconnected or manifestations of the same underlying problem. There may also be broader concerns such as low literacy levels, unemployment and debt, which can emerge as priorities over the course of the intervention. Participants identified variation in primary motivating factors by age; for example, older people were felt to be more interested in health maintenance, where younger people were perceived as needing support for weight loss and pre-diabetes. There was also an association between motivation and the main mode of engagement with the health trainer service – and between the local service delivery model and target user populations – which are explored further in the section below.

### **Accessing sources of support**

An individual's ability to access support is contingent upon the availability and accessibility of local services, in addition to any referral criteria these services might have in place. In this way, the health trainer services can be seen to shape as well as meet demand amongst their users, as reported in the following sub-sections.

### ***Local health trainer models***

The three study sites were selected due to their heterogeneity, to enable exploration of a wider spectrum of health trainer activities. Diversity between local service delivery models largely results from differences in the host sector, funding sources and intervention settings. The following quotes illustrate a divergence in views



between health trainer services delivered in NHS settings and those delivered by the community and voluntary sector:

Manager 1: Our service has always been different because we deliver rather than signpost. But I think that's the way to go. If you can make yourself fit for purpose and make yourself indispensable, then you're going to be quite a cheap service to commission. [...] I know you have to have a community development aspect – and we do, you know... But the community development side of just empowering and signposting, I think that's changing. You've got to hit targets and be more of a medical model, I think.

Manager 2: I think it's a very good model in terms of the community development approach that we take. I think it embeds the service in the community and voluntary sector, which is often where you've got projects and workers with experience in working closely with local communities at a grass roots level on, you know, using a community development model. I think it moves it away from being a medical model. [...] I wouldn't want to criticise another service that was part of a PCT. But I think this way it allows us to have some... greater credibility and greater trust from the local community, and to be embedded in partnership work with other local organisations.

Being at different points on the medical model / social model continuum leads to differences in the concept of service user need. Staff describing their service as “demand-led” reported that the majority of users had primarily sought help around food and nutrition for the reasons described in the previous chapter. These services tend to operate an ‘open door policy’, although efforts are made to target individuals from disadvantaged communities who may be less likely to use health services. The health trainer service corresponding most closely to the traditional medical model works solely with users who have existing health problems, regardless of socioeconomic status. These two contrasting policies in relation to targeting of the service are illustrated by the following quotes:

HT: They've got to go to their doctors and get a doctor's note to say that they can use [the service]. And they must have a [medical] complaint. Because there was one guy – he was referred and the doctor had written on “No medical problems.” So we got back on the phone to the doctor and said, “Well, what have you sent this person to a gym for if there's nothing wrong with them?”

Manager: It's very client-led. We wouldn't turn anybody away. What we might do is signpost them to other services, especially if there's some sort of health issue. We may say – “Oh, you know, I think you should go and see a dietician or you could go and see your GP” is usually our stock answer. “For your health”. But no, anyone. Anyone over the age of 16.

There was a general agreement that the purpose of health trainers is to provide short-term support rather than encourage long-term dependence. This is partly due to limited capacity and resources, which make setting parameters on service delivery essential. Each of the services employs a different approach to rationing; for example, maintaining a waiting list for new users, setting strict criteria relating to medical need, or targeting by geographical area. One manager explained that they “employ local people to work in local communities” as a matter of policy, which helps in targeting the most health-deprived areas. Referral criteria tend to be closely linked to funding requirements and are therefore subject to change over time:

HT: The Lottery said we could have five years worth of money. And I think that ran out last April or June – or it might be before – and the NHS took [the service] on full-time. They changed the criteria, saying you’ve got to have this, this, this wrong with you to be able to use the gym. And we’re just getting rid of people now... I shouldn’t say that (laughs)... But people who don’t need the service.

Other restrictions on service delivery include PCT out-of-hours or lone worker policies, which can make it difficult for health trainers to provide support to people who are housebound or in full-time employment. NHS-based health trainers also tend to be attached to a particular centre or facility, whereas those employed by the third sector are more likely to be detached workers and have a greater degree of flexibility in their working arrangements. However, all new staff are subject to the same lengthy training process, which extends the gap from recruitment to delivery:

Manager: It’s a long process to get them trained up, which – it kind of gets in the way. Whereas in another post – somebody might come in to a higher grade post, have a probation period and then get on with it. We are taking a lot of care to make sure that these people are trained and happy and confident in themselves and have those skills to deliver the messages.

Managers described the way in which recruitment, training and other processes had developed as the local services and national initiative evolved over time. It had taken time for the services to become established and integrated into local public health systems, to a greater or lesser extent according to the chosen model. Where health trainers are based in local communities, it was reported that good working relationships with other practitioners and agencies had developed, from a position of suspicion and apprehension to one of understanding and collaboration:

HT: We're getting a lot of good partnership work going on now. It took a little while to build up the knowledge, their knowledge of our services. Or our knowledges – or knowledge – of theirs. But we are getting a lot of referrals from the different teams [within public health]. We've been able to interact with their teams better as well. There's less preciousness. Everybody is kind of wary of the unknown at first but the more they've worked with us, the happier they are to refer. As I say, the dieticians have come on board really well. And the doctors have started to refer now they're all seeing the benefits of the service. Yeah. And other organisations are coming to us to ask us to work with them.

In other areas, a lack of communication between the health trainers and staff within primary care or public health resulted in misunderstandings about one another's roles. This created competitive rather than collaborative working relationships, particularly if staff were working towards the same targets. There were also examples of health and social care professionals acting as gatekeepers to the health trainer service. Two of the three teams sought to avoid this situation by pursuing various engagement modes, which are summarised in table 10 and explored further in the next sub-section. This table also highlights the ways in which the services changed over the duration of the 12-month data collection period.

### ***Primary modes of user engagement***

Initial contact is made with a health trainer service via three main routes: professional referral, self-referral and activities associated with community engagement and outreach. Each of these is considered in turn below:

#### ***(i) Professional referral***

All three health trainer services had a formal referral system for receiving new users from health professionals such as GPs, nurses, occupational therapists and counsellors. Initially, work was needed to promote and explain the health trainer role to avoid misunderstandings and concerns about competition. This process was sometimes facilitated by the professionals and health trainers being co-located in the same premises. There were clear examples of services complementing one another; for example, health trainers providing input around food and nutrition to complement the work of physical activity development workers. In other cases, referral to a health trainer was seen as a way to support users between appointments or following discharge from a professional service:

Table 10: Overview of local health trainer models

	Purpose of the service	User and community engagement	
		Month 0 (Jun – Nov 2009)	Month 12 (Sep – Dec 2010)
NHS funded	Based within NHS-owned premises	<ul style="list-style-type: none"> <li>• New system introduced in September 2009: GP / health professional referrals only</li> <li>• Existing users permitted to continue for a limited period</li> <li>• New users attend for 12-weeks of gym-based support</li> </ul>	<ul style="list-style-type: none"> <li>• GP / professional referrals only</li> <li>• Appointment system introduced: 3x one-hour sessions per week</li> <li>• All users signed off at 12 weeks</li> <li>• Closed group exercise sessions for COPD patients</li> </ul>
		<ul style="list-style-type: none"> <li>• HT coordinator works with key referral agents in the community</li> <li>• Some primary care referrals</li> <li>• GP pilot scheme, largely for smoking cessation users</li> <li>• Waiting list for new users</li> </ul>	<ul style="list-style-type: none"> <li>• Most users are referred by other teams within public health</li> <li>• GP pilot scheme ended</li> <li>• Move to the Foundation Trust due to NHS reorganisation</li> <li>• New staff, no waiting list</li> </ul>
Various funding sources	Detached workers	<ul style="list-style-type: none"> <li>• Emphasis on community engagement and outreach work</li> <li>• Opportunistic recruitment, in addition to encouraging self-referrals through use of HTs' own social networks</li> <li>• Few referrals from primary care</li> </ul>	<ul style="list-style-type: none"> <li>• Continue to use community engagement, outreach and opportunistic methods</li> <li>• New funding sources</li> <li>• Several HTs attached to GP surgeries to receive and generate referrals</li> </ul>



HT: The community dietician and the diabetic dietician have took us to heart, I suppose. They really see the value of the support – the one-to-one support – that we can give, in between them seeing them. And we're giving the same information. They've got, obviously, more in-depth knowledge as being trained dieticians, whereas we've got infor... We've got knowledge but we're obviously not as well trained – highly trained – as they are. But they see the value in the support that we can give, and we meet up with them and they make sure we're all singing from the same hymn sheet.

Staff reported examples of referrals perceived to be inappropriate, although these were felt to be decreasing over time as other professionals develop a greater understanding of the service. A lack of information on referral forms and uncertainty about the level of support needed were sources of frustration for the health trainers. A key aspect of the manager's role is to follow up on any queries regarding users with complex needs. However, one health trainer felt that it was not possible to query a professional referral and that this could impact negatively on users:

HT: Anyone that wants to come here, we get every single referral form and we don't... We can't send... We can't not accept them because they've been referred. Whereas some of them you think, well, they shouldn't really be getting referred for that, really. But you just have to accept it. [...] We get them to come here and then they might get all comfortable and happy here, and then we're just going to take them to a council gym where they might be, like, "Oh..." and all flustered and everything.

There were conflicting views regarding the impact of professional referral on user motivation. Some participants felt that recommendation from a GP or other health care practitioner would alert users to the seriousness of their situation and motivate them to make sustained lifestyle changes. Others reported that users who do as they are told rather than what they choose to do themselves "*don't put their whole heart into it*" and are therefore less likely to complete the intervention. Terry had particularly strong feelings about the move towards a professional referral system within his local health trainer service:

Terry: The doctors push them into that, whereas I thought, "Oh that would be interesting. I would like to go and have a general fitness." And I think there's two different types of people. And I think the people like myself are being penalised by this new system they've got now to take the people that are doctor's referrals that don't go back. I think you must cater for the two. Well, it would be nice if they catered for the two – I think it's beneficial. But that's my view.

*(ii) Self-referral*

A number of professional referrals were made following a query from a patient who had heard about the health trainer service from a friend, partner or relative. The decision to self-refer was often prompted by observing the 'success' of this significant other, in terms of weight loss, opportunities to be physically or socially active, and enjoyment of the programme. Access to the service was also facilitated by having someone to accompany them to activities:

Maxine: One of my colleagues from work – well, we go to the Post Office when we have to pay in and everything – and they had lost weight. Started to lose weight. And they were saying, "Oh, it's really fun and, you know, come along." And I said, "Oh right, I'll come along." So I went. That's how I started. And then when I was up and running, this other girl who works for our company was at the Post Office and she went, "Oh, I think I'll come along." And I said, "Yes, come along." And she's done really well too.

The above quote illustrates the way in which users can become advocates for the service and encourage others to self-refer via word of mouth recommendation. This cascade effect is enhanced by health trainers being known as friendly and approachable individuals:

Manager: [The health trainer] is working with clients around, sort of, quite a few of them around smoking and then they're talking to friends, family or whatever, who are then saying "Oh, well I'll go along and see [the health trainer]." "Go along and see [name]. He's a nice bloke, he'll look after you." And we tend to get quite a few referrals that way.

With the exception of the professional referral-only service, the Health Trainer teams make efforts to generate self-referrals by actively promoting their services. Advertising and making links with other community-based agencies were seen as ways to increase the likelihood of uptake amongst people who are less likely to use professional health services:

HT: So there's always some way of going out and advertising what we're doing. You know, doing our research around the area to put things out – it's really important. Because that's another way of getting people to where we are at. You know, instead of just through your GP or, "Oh, I want to go to the gym". It's like working with other projects that are going around and... simple things like the corner shop or the supermarket. You know, if they're willing to put out information then we'll advertise as much as we can.

Several users felt that the health trainer service was not advertised widely enough, although there were mixed views on the most suitable promotional strategies. Some felt that flyers and articles in the local newspaper would be successful, whilst others emphasised the importance of using trusted sources such as school nurses and GPs to 'spread the word'. Using Facebook, text messages and email reminders were also offered as ways to increase and sustain service user motivation.

### *(iii) Community engagement and outreach*

The services varied in terms of the extent to which they employed community outreach activities as a means of generating referrals. One health trainer team is primarily involved in building relationships with community referral agents – such as local voluntary and public sector staff – whilst another regularly conducts and contributes to events that involve direct contact with members of the public. Examples include food tasting sessions and taking blood pressures or carbon monoxide readings, according to the target audience:

Manager: We're kind of getting into newer areas, so more health trainers are trained to take blood pressures and do, like, carbon monoxide testing and things like that. Which I possibly I would have resisted at one time but... I think they're tools that really help them to work with people [...] "Would you like your blood pressure taken?" rather than "Would you like to make a lifestyle change?" is just a little bit more accessible, really. Because I think men... I'm told they like gadgets and things, so they're going to quite perk up at that, I think.

Another manager said, "*We go out to them and wherever people are within their own communities. And that varies from community to community*". Face-to-face meetings were the preferred mode of contact between health trainers and potential users as this enables staff to explain their role and alleviate any initial concerns or anxieties. This process is facilitated by employing health trainers to work in their own communities, where they may already be well-known and seen as having "*street credibility*". Health trainers described the importance of using their listening skills and ability to "*grasp any opportunity*" to promote the service:

HT: I can see somebody in the gym who'll maybe want, who maybe needs a little bit more support. And, I mean, I've got no fears of going up to people in a very lovely way and saying to them, "Do you know we also have this on offer? It is free". And talk about what I do as a health trainer, how people can have individually, one-to-one support to get whatever – you know, to get them there.



Two participants became aware of the service through a friend who gained employment as a health trainer. This person was known to them through their children's school and had used this network to generate a number of other referrals:

Sian: Obviously when somebody gets a new job they want to tell everybody, you know, what kind of thing they're doing. And [the health trainer] was saying she was finding out all about what courses were on and where was the best places to go and things like that. And so I says, "Oh well, I wouldn't mind a bit of that", you know, and stuff like that. And it's just her natural enthusiasm sort of picked up on quite a few of the people that were part of the parents' forum. I don't think she quite got everybody (laughs) but, you know. I know me [and two others] all signed up.

The health trainers gave examples of being stopped by people asking for advice in the street or supermarket, having neighbours knock on their doors to seek help, and setting up a healthy eating group following a discussion with other parents at a children's football match. Recruiting staff with the skills and existing networks to facilitate this outreach work was seen as an advantage of the service. Although this was felt to be an effective way of working with people who might not otherwise seek help, it was acknowledged that it might not always be effective in engaging with the hardest to reach and most vulnerable groups in society:

Manager: Because we are opportunistically doing work in communities, you do worry about those people who are perhaps completely isolated in their own homes. And again, it is about networks and you hope that through neighbours, etc, you would perhaps get to know those people. But I do worry about those people who are so isolated. I think this is the best approach we can take, but I do think there will inevitably be some people that we don't manage to reach. You know, so it's about continuing to look at that and think of different ways of doing it. And literally knocking on doors – which we do do some of – standing outside of the Post Office, wherever it is that somebody is very likely to go

Other challenges associated with using the health trainers' own social networks to engage with people include boundary issues and concerns regarding confidentiality. This was perceived to be a particular problem by a health trainer working primarily with the South Asian community, where language and cultural differences make it difficult for her to reassure users that their concerns will remain private. The health trainer felt that she was able to work most effectively with members of her community who knew her but with whom she was not on "*family terms*". Users experienced a number of additional barriers to seeking help with their attempts to adopt healthy lifestyles, which are outlined in the next sub-section.

## **Access barriers**

Various barriers to accessing support from a local health trainer service were described by the service user and staff participants in this study. These can be classified as either intrinsic barriers – primarily a feature of the potential user – or extrinsic barriers – a feature of the organisation or wider context:

### *(i) Intrinsic barriers*

Many of the challenges to adopting and maintaining a healthy lifestyle were detailed in the previous chapter, including communication barriers, caring responsibilities and poor health associated with age and disability. Service user participants overcame these barriers to access the health trainer service, but poor health was identified as an ongoing issue in terms of restricting their ability to engage in certain activities. For example, a number of participants reported that they were unable to access the gym or use particular items of equipment due to an illness or injury. Attending medical appointments and coping with an unstable condition such as MS or epilepsy were also identified as barriers to taking part in activities:

Gina: We've gone in all weather – when it's pouring with rain and everything. We've never stopped, really, have we? The only time we've stopped is if I've had to go to the eye hospital, which is early in the morning. Or a doctor's appointment for my diabetes or something like that. That's the only thing that's stopped us from going to the gym.

Int: Would you say for you it's mainly your condition or are there other barriers?

Frances: No, no other barriers at all – just that my body lets me down. I would go [to the gym] more than twice a week if I was physically able to do that, but I'm not.

The feeling of being restricted by one's own body was articulated by Pam, who said, "*The mind is willing but the body isn't*". In contrast, it was felt that many people who do not access a health trainer service are either unwilling to look after their own health or in denial about the help they need. There was also a perception that a lack of awareness and understanding of the health trainer role amongst professionals and the public continues to act as a barrier:

Kevin: People I think, you know, are very set in their ways and they don't want anybody interfering in their lives. They think they're going to walk into that reception area at [the health trainer service] and somebody is going

to take over their whole life. It's not like that. You know, you go in there and they give you advice and help. You can get fit at the gym or whatever you want to do, you know. And I just don't think people are quite aware of what [health trainers] do.

Health trainers acknowledged that there will inevitably be people who are not interested in accessing support or taking part in the activities that they offer. It was recognised that gym-based activities can be particularly off-putting for older, unfit and overweight individuals, as well as those lacking in confidence. Participants identified shyness, self-consciousness and a general fear of the unknown as potential barriers to engaging with services:

Jenny: You're thinking, well, you're going in there and, "Eee, I'm overweight. They'll be all skinny things" and this, that and the other. Which, a lot of people do think that way. And, you know, it's just making... It's just your confidence. Whether you're confident enough to push yourself forward straight away. And I... I don't think a lot of people are, really. Not for something like that.

*(ii) Extrinsic barriers*

Economic factors were identified as important as, although most health trainer-run activities are offered free or at low cost to participants, they rely on funding from external sources. This funding is often short-term and precarious, which impacts on the ability of the health trainers to make activities accessible to local communities in the longer term. Introducing a fee can be off-putting to participants who are on low incomes or who resent paying for activities that were previously free:

Farzana: They stopped the healthy cooking [class] and they still... Well, they didn't stop it, they stopped the funding. So then there'd be us – we'd all chip in. Say it was £12, then everyone would chip in £1, £1.50 and we'd still do the classes. But then when they started involving money, people stopped coming to these classes.

Additional costs associated with attending health trainer-led activities include childcare and transport costs. These can act as barriers to taking part in activities on a regular basis or to accessing services altogether. Concerns were also raised regarding the availability and quality of local public transport:

Manager: Transport is probably the biggest barrier. Either because there are limited transport networks – and so some communities will have fewer facilities on their doorstep – and, you know, transport is quite costly for some people. And it's not always as good as it should be. So transport

is a major issue for some geographical communities. It's also a particular issue for older people.

Willingness to travel to the health trainer services by public or private transport can be affected by the prevailing weather conditions. During particularly bad weather, participants may be less likely to drive, use public transport or walk outdoors for fear of falling. This is illustrated by the quote below, which also highlights the impact of seasonality on the uptake of services. Some participants reported that they were more active during the warmer weather, whilst others were more likely to take a break from their healthy living efforts during the summer months.

Ben: I think the weather has affected my mood as well – bit of a bad mood. I like it to be sunny and then I'll have the confidence to go to the gym. But with the weather being so bad at the minute, I just think it's too risky going out and slipping on the ice or snow.

The health trainer services tend to offer fewer activities during the summer months and over the festive period, which can act as a barrier to participants' attempts to stay active. Those seeking one-to-one support may experience challenges in attempting to schedule regular meetings with the health trainer, for reasons including staff holidays and sickness absence:

Jenny: When we came back [from a holiday] I wasn't well on the Monday, the following Monday. And then [the health trainer] cancelled – what was it? I wasn't well, and then [the health trainer] cancelled. Then it was cancelled last Monday, like a week on Monday, and I went over on Monday and she was on leave. So I'm going on Monday and hopefully she'll be there. But it's just the way the circumstances have gone, so it's probably about four weeks since I've seen her.

The above quote demonstrates the way in which the busy lives of users and staff create barriers in terms of delivering a standardised intervention. This is particularly the case for those in full-time employment and in areas where health trainers are restricted to delivering activities during office hours. Retired and unemployed participants also need to schedule activities around their other commitments, such as caring for children or grandchildren, attending computer classes, and spending time with friends:

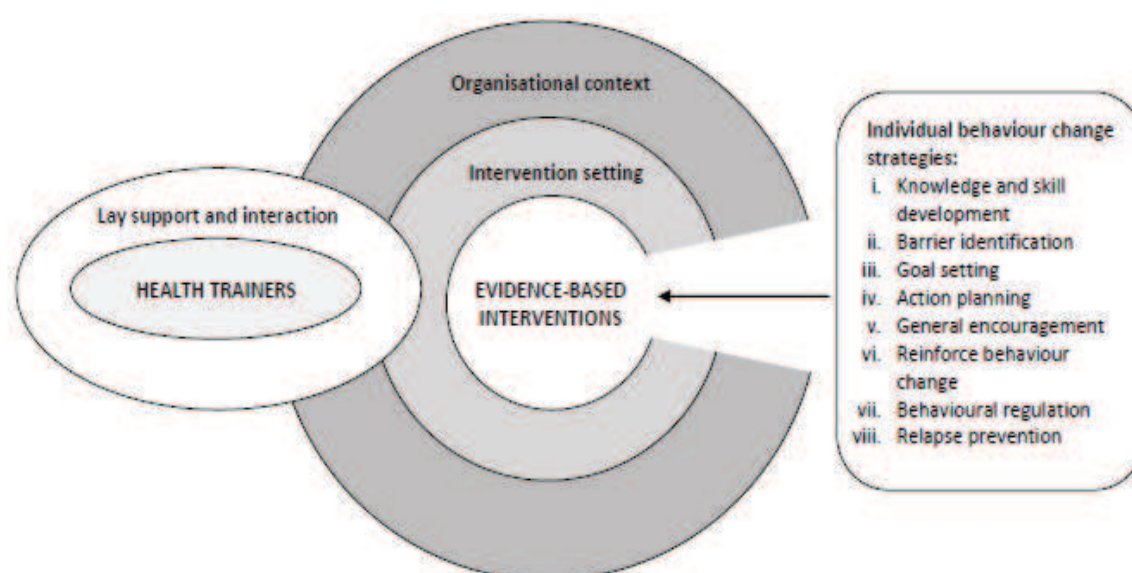
Sian: Sometimes it's the timetable of when the courses are on affecting your life – it won't fit into your schedule, you know. So a lot of things like that affect it, as well as where the course is and how much it's going to cost to get there.

A key issue for consideration by the health trainer services is convenience, in terms of the timing, affordability and location of the activities on offer. Participants were primarily interested in accessing services that met their needs with minimal disruption to their existing lifestyles. The specifics of the activities, processes and settings involved are described in detail below.

## Intervention components

Previous chapters have described policy and evidence relating to the use of lay-led intervention models and individual behaviour change approaches. Health trainers employ evidence-based techniques in their attempts to meet the needs of service users and the requirements of service commissioners. Interviews and observations conducted during this study suggest that health trainers are involved in delivering multiple interventions, often simultaneously, and that they target individual and group behaviours. The study participants also emphasised the importance of activities being delivered in environments that facilitate the adoption of lifestyle changes. These inter-related elements are shown in figure 18 and (with the exception of the organisational context, which is discussed above) are explored in turn in the sub-sections below.

**Figure 18: Components of health trainer-led interventions**



### **Individual behaviour change strategies**

A term used by the majority of staff to describe their health trainer service was ‘person-centred’, referring to the fact that interventions tend to be developed to suit the needs and circumstances of users. This involves taking time to assess those needs and recognising that some people present more complicated cases than others. Health trainers felt it was important to be mindful and sensitive towards a person’s situation, whilst trying to ensure that they are not made to feel stigmatised. For example, users with literacy problems may need help with reading information in a way that does not single them out in a group setting. A balance must be achieved between avoiding assumptions and making decisions about the most suitable intervention. The first meeting with a new service user is crucial in making an initial judgement about their motivation and the type of support they require:

HT:        You kind of get the feel of how long your person is going to want to talk after the first... first visit, really. Some people just want the information, they’re there, they’re gone. Other people, you can be there for an hour. One of my colleagues at [name of community venue] said “What are you doing with your clients – you’ve been in there for ages!” “I was talking, man” (laughs)... And again, it’s on an individual person’s aspect. With some people you end up talking about everything and anything. Other people it’s straight and to the point.

This meeting varies by user engagement mode; those who access the service through a formal referral route tend to be comfortable with completing a health behaviour check at the first session. Others who have accessed through outreach work or opportunistic methods may need time to develop rapport with their health trainer before completing any formal paperwork. In all cases, staff work with users to assess their priorities, which may or may not be health-related. Diet, physical activity and smoking are the three main issues presented by users, but a range of underlying issues often need to be dealt with first. One health trainer articulated this by saying, “*You’re not going to look at your nutrition if you’re living in a house that’s falling to bits*”. Lifestyle and social issues tend to be inter-related – for example, smoking and stress, or poor diet and debt – as illustrated by the following quote:

HT:        I can support them in the gym like, for instance, make them up a new programme, also monitor their weight loss, and if they’ve got other issues – like, I’m working with a young man at the moment who is struggling to find work, I can like... Like, part of my health trainer job is to get out there in the field of looking for employment for him. [...] So everything starts to fit in place – do you know what I’m saying? Like, he’s on his fitness programme, he’s losing his weight, his confidence is building up for him to go out and look for work. That’s how I’m trying to



work it – taking each individual, you know, and thinking, “What’s best for you? What’s the, like, underlying issues?” And for him it’s like low self-esteem because he has no work. You know, so we start with the gym, doing the weight loss, encouraging him to eat healthily and hopefully that will bring him in to some sort of employment.

Health trainers employ holistic approaches in supporting people to adopt healthier lifestyles whilst acknowledging these underlying factors. However, there is variation between the local services in the extent to which they deal with social or mental health issues in-house, as opposed to referring users to other relevant agencies. At the same time there has been some convergence between the services in terms of formal training for staff around individual behaviour change strategies. Each of the three health trainer services is now involved in delivering personalised interventions that employ the following evidence-based techniques:

*(i) Knowledge and skill development*

A key component of the health trainer interventions is the provision of information to enable people to understand and change their own behaviour. This involves educating them about the links between lifestyle and health; for example, many people were shocked at the number of calories in alcoholic and soft drinks. Health trainers use resources such as the Balance of Good Health<sup>23</sup> and the Eat Well Plate<sup>24</sup>, which ensures that all users receive accurate information. Participants also reported being given tools and materials to refer to outside of the intervention:

Int: And what sort of things were you talking about with [the health trainer]?

Jim: Food – what to eat and what not to eat, what was good for me and everything like that. And I found it very good. She gave me recipes to follow and that sort of thing. [...] I used to love going over to see [name] because she always had a lot of information. I’ve still got the folder that I used to use and I do look into it now and again to sort of jog my memory.

In addition to information provision, health trainers offer demonstrations in how to put the advice into practice. For example, they show people how to exercise safely or how to prepare healthy meals, as illustrated by the quote below. This also

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<sup>23</sup> The Balance of Good Health is a visual representation of the types and proportions of foods needed for a healthy diet, as defined by Government recommendations.

<sup>24</sup> The Eat Well Plate is another name for the Balance of Good Health and is used on the NHS Choices website. For information, go to:

<http://www.nhs.uk/Livewell/Goodfood/Pages/eatwell-plate.aspx>.



illustrates the importance of “*starting from the base*” in terms of building on the user’s preferences:

Sian: What they were saying to us was, “Well, what do you like to eat?” So we were saying like, “Oh, spaghetti Bolognese” and they were saying, “Right, this is the best way to do it because this is, like, leaner mince. This is, you know, less fatty kind of sauces” and things like that. So I think what – the course I went on wasn’t aimed at saying, “You mustn’t eat this.” It was a case of, “If you’re going to eat it anyway, why not try making it this way because it’s healthier.”

One of the advantages of receiving support from a health trainer as opposed to accessing a more formal intervention is the time taken to explain and explore the behaviour change messages. Users also felt able to ask basic questions, which they might not feel comfortable doing with a doctor or dietician. Although some participants described the information as “*common sense*”, most appreciated the use of plain language and found the interventions enlightening:

Manager: The information that we give could be the same information that everybody gives out, but if you can sit down with somebody in a nice, relaxed manner and they’ll take their time and talk to you about things and explain things to you... One of the things we had the other day – when I was out with one of the health trainers – was a lady who was middle-aged who’d never sliced a pepper before. And the health trainer sat there and explained how to do it and then what the person can do with it, you know – you can slice it this way or you can slice it that way, you can cook it like this or you can keep it whole and put rice and things in it and have it as a stuffed pepper. And it’s things like that that they bring to the table that possibly other people don’t have.

Another advantage is the ability to tailor the intervention to the user’s needs, rather than following a structured programme. This degree of flexibility helps to avoid wasting time for the user or the service, which was particularly important to individuals like Kaye who had a young child and was also in full-time employment:

Kaye: I think the fact that you get, you just get the information you need. You’re not bombarded with lots of other irrelevant information. I think to look through something and check out, you know, what a portion is and remind yourself with different things... I can flick through another piece of information and check food labelling and stuff. So I’m not, I’m not inundated with loads and loads of paperwork – I’ve just got the basic information I need. And that’s really all I want.

(ii) *Barrier identification*

Health trainers recognised that there exist a number of barriers to making behaviour changes, particularly for vulnerable or marginalised groups. Interventions involve building the users' confidence and self-efficacy to overcome these barriers:

HT: How do we help them to move from those barriers? Building their confidence in themselves... A lot of them... (sighs) Sometimes it's as if they want to ask questions, but they don't know who to ask. Or they think, "Are we allowed to ask questions?" you know. And they, you just... because they seem to come from a background where you don't question anything, you know. "The doctor has told me to lose weight, but he didn't tell me how to do it." So I said, "Well did you ask him for any help?" "Well, no... because you don't ask." Things like that. [...] Just by talking to them, you say "Well, there's some kind of help out there. Do you want to access it?"... Helping them access it, not accessing it for them. Encouraging them along the way.

Users living in socioeconomically disadvantaged communities often have concerns about the cost of healthy or 'diet' foods. Health trainers emphasise the importance of making small changes, rather than changing their whole diet; for example, switching from white to brown bread or from sugary to sugar-free drinks. They discuss health messages in a way that acknowledges the user's valid concerns and attempts to find affordable ways to address these barriers:

Manager: For many people, to go from eating almost no fruit and vegetables to eating five, it just feels like an enormous step to take and they don't know where to begin, really. And then there are all sorts of issues around feeling that fruit and vegetables are more expensive, and perhaps the children wouldn't eat it and that would be wasted food which, if you're on a small budget, is a major issue. Don't know how to cook it, don't know where to get it from. Sometimes it's hard for people to find good fruit and vegetables locally. And it's about breaking that down into a step-by-step approach with people and saying "Right, let's start first on how much it costs. And which fruit and vegetables are cheaper at different times of the year. And which can you get locally and then how can you cook those. And let's cook them in a way that the kids are going to eat them, you know (laughs)." [...] And give them the chance to do the cooking first and then take it home and try it with the kids so that they're not, from their point of view, wasting their week's budget on it.

Health trainers are up-front about the purpose of their service being to deliver short-term interventions rather than long-term support. Some users can be signposted to other agencies for additional support, whilst others are not confident to go anywhere on their own and feel intimidated in unfamiliar environments. Part of the health

trainer role involves recognising this as a potential barrier and accompanying people to other services or medical appointments:

Manager: And to some of the health trainers – I would say the majority – nothing is a bother. If it involves signposting to another service or possibly taking you to a first visit somewhere else because you're a bit nervous, say, going to the dentist or you want to get benefits advice – they would, within their remit, could, you know, escort somebody there and help them out for that first one. Or if they say they want to do line dancing – I'm not sure some of them could cope with line dancing themselves (laughs) – but they'll take them along to the first appointment and try and get them feeling comfortable with the group, until they're happy to do the exercise or take the service that's offered.

### *(iii) Goal setting*

Health trainers and users work together to set a specific behaviour change goal at an early stage in the intervention. Participants emphasised the importance of users identifying and having ownership over their own goals, with guidance to ensure that these are realistic and measurable:

HT: They set their own goals, we just help them, you know, guide them through it, and give them realistic ones. You know, like if somebody said to me "I've got to lose a stone in a fortnight. I'm going to a wedding." I'll go, "Well, you know, we'll start by breaking that down a bit", you know, getting realistic. Get in the real world (laughs).

Health trainers felt that setting small, measurable goals can help to enhance the user's motivation and resolve any ambivalence towards behaviour change.

However, there were mixed views from the user participants. Some felt that aiming for a specific target within a time limit would add unnecessary pressure. Others enjoyed being able to measure and assess their progress, particularly in the case of participants with a background in sport and fitness:

Frances: So normally for the challenges you try and beat what you've done but I can't do that [due to her condition]. I can't cycle more than two miles, I can't do more than 300 reps with the weights. So [the health trainer] is figuring out what I could do for a challenge to strive towards. He's figured out that my mentality needs a goal, a challenge to work towards. But that's the ex-athlete in me. I need something to work towards.

Terry: I'm a believer in, like, targets. I think there's always people have targets in life, you know. I go swimming and when I first went I couldn't do a length. Now yesterday I done 50 lengths so my target is, like, well, I done 48 yesterday but this week I'm going to go for 50. So I have little targets for my fitness, you know. I mean, at the gym there's, I think

there's a level you go, if I can say, "Right, I can, I can lift 15 times. I'm happy with that weight, I don't want to on and on and on lifting". I'm happy to find a level of fitness and keep that level.

In some cases the goal may not be strictly health-related; one health trainer gave an example of a man with severe mental health problems who set and achieved his goal to attend a group activity without his carer. Other users may have underlying issues that are dealt with before or during the intervention but are not necessarily part of the goal-setting process. Maintaining a flexible approach is important in order to accommodate any changes in the users' priorities over time:

- Int: Do you think that most people you work with make some sort of change and achieve their goal?
- HT: Oh definitely – they make a change and achieve their goal. But in my experience, it's not usually the goal that you initially went out to see them about. You've changed... The barriers have moved. It's changed – like you say, it could have been to do with healthy eating and before we can do this healthy eating, we say, "Well, shall we tackle the drink [alcohol] first?" Or they want to go out and exercise, but when they get there they can't do anything because they smoke that heavily. So it might change it to, "Shall we see about reducing the smoking first?" That's what I do.

#### *(iv) Action planning*

Once a goal has been set, users work with the health trainer to devise an individual action plan that will enable them to achieve their goal. This approach is based on behaviour change science which demonstrates the importance of intention formation and outcome expectancies in facilitating behaviour change. Health trainers encourage people to consider the impact of these changes:

- HT: There's no rocket science over it. It's just down-to-earth, simple action plans. Life action plans and, you know, how these changes can fit into their lifestyle. And yes, it's different for every individual, but there will be a way somehow. We do have challenges, you know, but it's like part of your job is, you kind of think "Right, well how can we get over this?"

The processes of goal setting and action planning were perceived to be facilitated by the one-to-one approach of most health trainer interventions. This enables health trainers to deliver personalised advice and support to individual users, as opposed to dealing with group issues. In group settings, health trainers generally have one-to-one contact with each user to assess progress towards meeting their goals.

*(v) General encouragement*

Users also spoke highly of the one-to-one approach in terms of facilitating the process of developing an open, trusting relationship with their health trainer. Providing information and general encouragement in this context was felt to enhance the users' motivation:

Jenny: I think really one-to-one is much better because you do – you connect and you can sort of get things, get your feelings out and sort of talking actually helps. It sounds a bit silly but it does help when it comes to sort of thinking about food. Because if you, you sort of know, “Oh well, I’m going to go and see [the health trainer]”, and “Oh well, I’ve got this, we’ll talk about that” and it, you sort of... It encourages you, you know. You want to do something to sort of see a difference when you go there

Some users described the health trainers as a ‘cheerleader’, in terms of building their confidence and reassuring them of their own capabilities. The emphasis is on helping people to help themselves by providing ideas and suggestions, rather than dictating what they can and cannot do. Staff were described as stern without being pushy, and giving people the kick-start they need to change their own lifestyles:

Linda: I want her on board for that [smoking cessation] because if there’s somebody else there it’s a push for me to do it. I mean, I want to do it and I have tried to before but not very successfully. And I don’t think she’ll be on my case or on my back but I think she’s honest and open enough to be upfront, you know. And she’ll kind of be telling you off in her own little way but not awful, not horrible.

*(vi) Reinforcing behaviour change*

The health trainer-user relationship can help to reinforce behaviour change as the users feel accountable to their health trainer and make efforts to avoid disappointing them. Staff also praise users for the healthy behaviours they exhibit and any positive changes made:

Brian: They don’t call you to account, but in some way you feel you’d be letting them down if you let it go. And not having them there, I suspect – I don’t know yet, it’s some way off – but I suspect it could be, “Well, we don’t worry about them anymore”. But it’s useful having them there because you feel you’ve got to account to them [...] And it’s nice to get a pat on the head. You know, “Ooh, you are doing well.”

Sanctions for those who do not follow the recommended advice or who cancel several appointments include being exited from the service. For example, users who

regularly fail to complete a food diary are told that the health trainers cannot fully support them and a discussion will take place to find out what else is going on in their lives at that time. Where users have completed a food diary, the health trainer can use this information to reiterate the implications of their behaviours:

HT: They just put on what they think you'll want to hear... And you say, "There's no way that it's got..." You know, they're just trying to please you really. [...] You've got to be honest with them. You do. And just get them to assess what goals they've set. Or say, like, if there's a weight loss they want to do, "By sticking to this food diary, you would have lost two pounds" or something. And they go, "Oh well, I might have had that that day. And I could have...I had that as well...Oh, I forgot about that."

*(vii) Behavioural regulation*

Food diaries are a key resource used to encourage monitoring and self-regulation of user behaviour. Within the service operating a waiting list, they were also used to maintain motivation in the time between referral and the first meeting with a health trainer. Participants reported using the food diaries to monitor progress towards their healthy eating goals, as well as any 'slip-ups':

Andrea: Oh, this food diary – when I first started going [to the health trainer service], as soon as I ate something...It ruled my life. And it was great, because when you saw it in black and white you would think, "Oh, hang on, I've only had three of my five-a-day. I need to have another two." And so you would squeeze that in. Or you would think, "Oh, well if I have a bit of chocolate cake, I've got to put it on my list, haven't I?" So you didn't have any chocolate cake. So I thought there was no point in doing it if you're not going to be honest. The only person you're kidding is yourself.

Health trainers reported examples of users who appear to have made significant changes to their eating habits and yet failed to lose weight. Their food diaries can be used to identify any areas for improvement, as well as reinforcing the positive changes made. They can also act as an aide-mémoire for those with memory problems, as illustrated by Pam's story (box 7).

Other users found the diaries less useful as they could not see the benefit of recording their food intake. Health trainers felt that some people would rather be given a prescriptive diet than take the initiative themselves. The emphasis is on empowering users to take responsibility for their own health, which requires effort and commitment. Many participants reported reaching a level where they know what they are doing and making their own behaviour changes; for example, trying different exercises within the gym or moving on to a higher impact exercise class. At



the same time, they appreciated having the support of a health trainer in monitoring their progress and identifying areas for improvement. Some were reluctant to self-regulate – for example, by buying scales and weighing themselves at home – due to concerns about becoming ‘obsessed’ with their weight. Regular checks undertaken by the health trainers also provided an incentive to maintain their progress.

### Box 7: Pam’s story

Pam is 63 years old and lives with her husband. She retired from her job as head housekeeper at a local hotel after having a mini-stroke and struggling to regain her coordination. She subsequently gained weight and accessed an ‘exercise on referral’ scheme after making enquiries at her local leisure centre. A physical activity development worker then referred her to a health trainer for one-to-one advice on food and nutrition. She found this advice helpful and lost over a stone in weight due to a combination of staying active and eating healthily. Maintaining a food diary was a key part of Pam’s meetings with the health trainer, which she described by saying *“it keeps me organised”*. She was still maintaining the food diary at our final interview (more than 12 months after completing the health trainer-led intervention) because, *“I think as you get older you forget. So if I’ve got it written down, then I know... Should I have a sandwich for my tea or...? No, I’ve had too many carbs – I’ll have a bowl of fruit instead”*.

#### (viii) Relapse prevention

Participants highlighted the time required to achieve sustained lifestyle changes, rather than expecting a ‘quick fix’. Long-term support is often needed to maintain the user’s focus and ensure they reach a point where they feel able to maintain the changes independently. This is particularly the case for people with mental health problems, low confidence and/or lacking support from family and friends. Health trainers act as a form of ‘safety net’ for users:

Andrea: I think you do need a good few months, I think, of somebody to fall back onto if you’re sort of waning. Even if it’s not a one-to-one, just somebody who’s just overseeing and seeing your weight each week and sort of going to you, “Right, come on, get that food diary done. What are you doing?” And stuff like that. Just to keep you on the track because I think it takes a long time. [...] I think you’ve got to give it at least six months – plus – before it becomes a lifestyle change.

Ongoing contact with users can take the form of an extended formal intervention or informal contact, either in person or over the telephone. For example, Jim called his



health trainer when he decided to stop smoking and asked her for advice on how to deal with food cravings. Staff may also maintain contact with users who exit the service prematurely, to remind them of the support that is available to them.

Sometimes “*life gets in the way*” and so users may either need to take a break from the intervention or receive additional support. The decision to exit people from the service relies on the judgement of individual health trainers. There is often an official cut-off after 12 sessions but staff can extend this period or gradually “*wean people off*” by switching from weekly to fortnightly or monthly support:

HT: I’ve got two clients that have been accessing the health trainer service for over a year now. But I only see them every month and it’s a quick cup of coffee downstairs in the canteen – [name of cafe] – where we chat to see what they’ve been up to for the month. I have a quick look at the food diaries because they like me looking at them to see make sure they’re still on track. Sometimes get weighed, sometimes don’t – it depends on what they’re feeling like. And I see them once a month. So although they’ve been on the client, like, on my list for over a year, it’s only 10 minutes once a month. And if that’s going to sustain their behaviour change, then I’m happy to do that.

Another method of relapse prevention used by the health trainers involves facilitating the formation of social networks between users so that they might support one another in their ongoing behaviour change attempts. This and other benefits of social interaction between users are explored in the next sub-section.

### **Group support and social interaction**

Whilst it was acknowledged that one-to-one support is a key element of the NHS Health Trainers Initiative, many participants felt that there were also advantages to group-based interventions. Groups can enable health trainers to work with larger numbers of users, help to tackle social isolation and contribute to the formation of social networks. There were mixed views on the importance of having shared characteristics with other group members. Some users valued opportunities to mix with different ages, whilst preferring to talk to people with similar illnesses or from similar backgrounds. Participants gained reassurance from interacting with people who they perceived to be “*in the same boat*”, as illustrated by the quote below:

Manager: With all of these [activities], people highlight the fact that it’s made them feel better because they’ve been in a session with other people who have similar issues and they’ve been able to talk about them. And they’ve been able to have some fun while they’re exercising or learning

about healthy eating. And I think that's... you know, that's been a success of a lot of them, of the programmes and a lot of the service.

There were examples of users meeting one another outside of the interventions and attending activities such as luncheon clubs together. However, most participants described the people they met through the health trainer service as associates rather than friends, separate from their existing social circles. They tended not to socialise but helped to make the activities more enjoyable through informal conversation and humour. They also showed concern for one another's welfare:

Frances: We all look out for each other. There's 10 of us on the same day and my mother goes as well. She started when I said it was really good. And there's other people that look out for you. If you're not there one day, they'll think, "Where's Frances? What's wrong?" (laughs). It's like a close-knit group and if somebody's struggling on a piece of equipment, somebody else will notice. If one of the staff is busy elsewhere, somebody else will notice and call [the health trainers] or whoever. So it's really good like that.

For some people, the interventions presented a rare opportunity to interact with others adults on a regular basis. As one health trainer said, "*They might have nobody at home to talk to, or nobody at home might listen to them*". The activities can help to reduce feelings of social isolation and loneliness, as illustrated by the following case study:

#### Box 8: Pauline's story

Pauline is 63 years old, retired and lives with her husband, who works full-time. Some years ago she broke her ankle badly, which contributed to her gaining weight, developing type 2 diabetes and becoming housebound. She was "*stuck in, which is bad for me, really bad, because I tend to curl in and I might not go out for weeks, months.*" A traumatic situation involving a family member then led to Pauline having a nervous breakdown. A counsellor suggested that she might benefit from getting out and making new friends, and gave her details of the local health trainer service. Around the same time, her husband was approached in the supermarket by two health trainers who were promoting a walking group for older people. They visited Pauline and she said, "*I thought, you know, I like these ladies. They seem to be on my wavelength*". At our first interview, she had been attending the walking group for several weeks and told me, "*Everything had seemed so complicated and so hard to do. But when I'm with these people, it's like we're all the same.*" By the time of our final interview she had been attending the group for over 12 months and made several new friends, even inviting them to a barbeque at her home.

Kevin attended the same walking group as Pauline and described mixing with other people as “*good because that’s bringing you out of yourself. Because if you sit at home moping over your problems you go down and down and it’s a job to get pulled back up again.*” These examples illustrate the impact of social isolation on mental health and wellbeing, and therefore highlight the potential for interventions that reduce isolation to improve mental and emotional health. Kevin, who suffered from depression and frequent blackouts due to partial epilepsy, had never experienced a blackout during the health trainer-led walks:

Kevin:      You don’t get bored, you know, because everybody is talking away to each other and it’s a good atmosphere and a good environment to be in. And if you’ve got something like depression – and talking from experience here – it does give you a boost. You know, it gives you a lift. Instead of sitting there feeling down, you think... You come home and you feel a lot better in yourself. [...] I just came off a course of antidepressants and they didn’t have any effect on me whatsoever, you know. It’s not... You don’t need drugs to get you right. You need outside activities and mixing with people. And, you know, just getting on with life as normal as you can. Being part of society, really.

Within a gym setting, interacting with other users helps to “*pass the time*” and make exercise more pleasurable. Health trainers encourage new users to attend with people they already know, for example, by arranging for members of a weight management group to have gym inductions at the same time. Participants reported that they “*egg each other on*” and frequently used the term ‘camaraderie’ to describe the way they support one another:

Peter:      I think that one of the main attributes which is overlooked is the internal motivation between the people who, who actually go there. It’s a bit like a football team. We all sort of muck in together and if anyone who is, you can obviously see are less fortunate because they’ve had a major illness and things like that, the actual camaraderie and the motivation from the people who are there does spur them on. And it, it becomes social as well as, as well as practical.

There was also a competitive element, which helped to enhance and sustain motivation. Participants observed others within the gym who were older or had more serious health conditions and felt inspired to be more active themselves. There were examples of upward and downward comparisons, with participants comparing themselves to those who lead less healthy lifestyles and feeling a sense of pride. Terry mentioned wanting to stay active into old age, as well as not wanting to be like his similar-aged neighbours who are sedentary and have “*beer bellies*”.

Terry: There was one woman at the time – at the [health trainer-run gym] – she was 82 and on the treadmill, and I thought, “I hope I’m coming to the gym when I’m 82.” And it just, it keeps you going, you know.

Andrea: I mean, there’s some really skinny, skinny Minnie, girls there [at the health trainer service] who were, like, very thin. But their food diary – they don’t know what a vegetable is, don’t know what a fruit is, do you know what I mean? [...] I mean, I could run circles around them. Just these young, thin little girls but they weren’t healthy.

The idea of competition did not appeal to everyone, particularly as some people were physically incapable of competing. One health trainer worked primarily with groups of men with a mix of abilities and fitness levels, and so he tried to discourage competition and emphasise the fun aspect of the activities instead. There was a suggestion that competition might be most successful in relation to weight loss rather than physical fitness because, as articulated by Brian, “*You can’t compare like with like, whereas – on the food side – you’re all on the same level*”:

Brian: One of the advantages of [groups] against doing it yourself is you’re sort of comparing yourself. Not necessarily in competition with other people but, you know, “Oh he’s or she’s losing it, you know. Where could I do better?” And you swap notes and, well, there’s a sort of a camaraderie about it all, which you don’t get obviously if you doing it by yourself.

The above quote also demonstrates the potential for learning from others within a group setting. Participants gave examples of “*comparing notes*”, sharing tips and swapping recipes. There were also more subtle references to vicarious learning, in terms of observing and learning from the experiences of others:

Maxine: A girl last week had been to the [local fair] and she’d eaten a coconut as she went round. And she went, “Well I was thinking it was fruit.” And [the health trainer] says, “Well it’s not... It’s not a bad fat.” She says, “It does contain – with the coconut oil and everything in it.” She says, “It’s not very good. But it’s better...” And I was like saying, “Well it’s better than a bar of chocolate.” (Laughs)

More experienced users spoke about passing on their knowledge to newer group members; for example, Terry attended the health trainer-run gym for almost three years and often demonstrated exercises to other users, whilst being careful not to contradict the advice from staff. Participants reported benefitting from opportunities to educate and assist other people, as illustrated by the following quote:

Sophie: There was a lady there [on a confidence-building course] who really needed help. Oh, I really did feel sorry for her but, you know, I sat with

her and I helped her through it. Yeah. And [the health trainer] gave me a big hug afterwards and said [whispers], “Thanks a lot Sophie”. And it makes you feel nice.

Health trainers generally encourage users to interact with and support one another, which can facilitate the formation of new social networks as well as social norming. Users share their experiences and offer themselves as role models; for example, spreading the word of any positive outcomes to generate new referrals to the service. The following quote demonstrates the way in which health trainers help to create an environment that facilitates social comparisons between users. This is explored in greater detail in the next sub-section.

- HT: You’ve just got to try and speak to people nicely to say you’ve got to be realistic and just look – you’ve got to give it six months or more.
- Int: And do you think people struggle with, sort of, thinking that far ahead?
- HT: Yes, they do struggle. The only thing we can do is if we’ve got anybody in the gym who’s doing really well is compare them. Not compare them... We just say, when they come over... Because, like I say, most people talk to each other and say, “How much weight have you lost?” “Six pounds” or whatever. “How long has it taken you?” You know, “It’s three months or something”. And just tell them that’s how long it takes.

### ***Intervention settings***

The most appropriate setting for a health trainer-led intervention is generally selected following a discussion between the service user and health trainer. Where staff are primarily based within purpose-built centres or community venues, the choice of setting for users is restricted. Health trainers employed within the third sector can be described as detached workers in terms of working in a range of different venues. These staff are able to meet users in familiar locations – including their own homes – which was felt to help in putting people at ease. Others avoided working in these settings due to concerns for the personal safety of staff and a policy of bringing users into the community with the aim of reducing social isolation.

- Manager: They tend to see the client wherever that client will feel comfortable meeting. So they, it’s entirely individual – based on that person that they’re meeting and where they want to meet. So sometimes it might be a local community café, it might be a local project... Some like, you know, it might be the local sports centre. Wherever that person feels comfortable meeting.

Participants described the health trainer services as being “*on their doorstep*” and therefore highly accessible, particularly in comparison with other health and fitness

facilities. Selecting venues within local communities reduced travel time and costs, and therefore caused minimal disruption to the user's existing routine:

Sheila: I mean we are benefitting from the fact that I'm only round the corner. That's why I'm lazy – I'll be honest. It's the fact that you can – you can just go round there and you're done and you're over... By 10 o'clock, you're finished, home and start your day.

For parents of young children and particularly those without access to private transport, it was important that activities did not require them to travel too far from their children in case of an emergency. Hence, some activities were delivered within or near local schools. This was a key factor for both users and staff, who are often unwilling to travel beyond their local communities for similar reasons:

HT: I think obviously everybody's selfish – so am I (laughs). Because it's [the service] on my doorstep, literally, so I, I don't need any travel money. I don't spend no travel money and plus my time doesn't get wasted. Plus the flexibility. And if my child is not well, if my husband or if my sisters look, they just call me and I'll be there in five minutes.

On the whole, users spoke highly of the venues and facilities used by the health trainers. One venue in particular received a number of compliments for its location at the centre of the community and the wide range of activities on offer. The health trainer based in this setting reported that users *"love this building in particular. It's so friendly and it's not just health – it's social wellbeing and mental wellbeing as well"*. Other centres were felt to be well-equipped, although there were some complaints about restricted access to equipment within the health trainer-run gyms. The aesthetics of the venues were also felt to be important:

Andrea: I mean, it's a nice, clean, modern environment. I think that does help if you're going somewhere like that. If you're going somewhere tatty and run down, I think you would be less likely to go. So I know there's some, like, older gyms, smaller gyms – people obviously still go, but from the outside they don't look that appealing.

The health trainer facilities were reported to be smaller but less crowded than commercial or council-run gyms. This makes them more accessible for people with physical and sensory disabilities, as well as those with mental health issues and others who might feel intimidated in large, noisy environments. Due to the size of the health trainer gyms and a policy of encouraging attendance at the same times each week, users are able to develop friendships with other gym users:



HT: It's small, it's snug and nobody seems to get a chance to not speak. As soon as you start... Plus, as well, like myself and the other gym instructors, one of the first things I do is if somebody goes on a bike and it's their first time, I'll say, "Oh, this is such-and-such on the next bike." So, immediately... I think they're quite sociable, the older people, so immediately they start talking and that's it. It's like they been there forever and they want to be there forever.

Participants described these venues as having a "*homely atmosphere*" and being like a small community, social club or family. Earlier in the chapter, I highlighted their concerns about feeling self-conscious in other health and fitness environments and the importance of being around others in similar situations. Health trainers were responsible for ensuring that the interventions were delivered in relaxed, informal settings and that new users were made to feel welcome. One member of staff expressed this by saying:

HT: These centres at the minute are working just because I think as soon as people walk in they feel like it's a friendly environment. There's nobody in any kind of Lycra gear or muscle men. Everybody is in the same boat, basically. So they feel the same as everybody else.

The intervention setting may be particularly important for someone with a physical disability or long-term condition. For example, Frances felt strongly about having opportunities to take part in health-promoting activities outside of the clinical environment. However, participants felt that activities targeting older people and other vulnerable groups should be delivered by the NHS rather than by organisations primarily concerned with profit-making and physical fitness:

Peter: I think a lot of people will find it difficult [to attend a private or council-run facility], basically because they're going somewhere where it isn't health-orientated. And also they don't have, maybe, the expertise that they have here. I'm not saying they [health trainers] are doctors or anything. But they...I think it's just the very nature of what it is. It's like a unique little thing that you feel very comfortable there. It's small enough to not be oppressive, but it's not large enough to be over-bearing.

Health and safety were key concerns for participants, many of whom had substantial experience of managing the risks associated with their disabilities or health conditions. The health trainer interventions were felt to be conducted in safe environments and this provided them with a sense of reassurance. Some examples were given of health and safety regulations acting as barriers to participation but, on the whole, users described the services as taking a relaxed approach and staff



spoke of not wanting to “*mollycoddle*” people. They try to be as unobtrusive as possible, whilst making themselves available to deal with any difficulties or queries:

Sheila: I mean, you would get the impression that they're not taking any notice, but they were watching what was going on. You could see certain... like, [the health trainers] looking at certain people or whatever, you know. And they would just go to them and have a quiet word and say, “Do it this way” or “Do it that way.”

This quote and the one above illustrate the users' perceptions of health trainers as having the appropriate skills, knowledge and expertise to support vulnerable people whilst, at the same time, empowering them to make their own lifestyle changes. Defining attributes of the role and the perceived impact on the service user experience are explored in the following sub-section.

### ***The health trainer role***

Service user feedback on the support received from the health trainers was almost universally positive, with high praise received for several members of staff. Negative comments related to a perception that some staff expend less effort than others and fail to employ user-centred approaches. On the whole, participants appreciated the relaxed and informal nature of the interventions, with many citing examples of humour and ‘banter’ between users and staff. Terry felt that the health trainer role was “*not like a paid job*” in terms of getting a “*personal touch*”, particularly in comparison with staff in commercial facilities. Most health trainers are based within local communities and this was believed to enhance their accessibility and approachability, with users being encouraged to call in if they needed to talk to someone. Kevin took advantage of this opportunity on a number of occasions:

Kevin: I think with [the health trainer], you see, she's very down-to-earth and she speaks her mind. She's well known and she's well liked and people have known her for a long time. And you get used to the same person. Nobody likes change. And nobody likes to be patronised or dictated to by somebody. So to have an outgoing person like [name] is very good. I mean, there's nothing you can't say to her, really. She just laughs at you. And that's the way I like people – down-to-earth, you know.

This quote illustrates the importance of interpersonal skills in being able to build a rapport with users and put them at ease. Another key factor is the ability to dedicate sufficient time to each user; as one manager said, “*They're not sat there, looking at their watch*”. Many participants felt these were more important factors than health

trainers being from the same geographical community as their target populations. However, the ability to capitalise on the shared backgrounds of health trainers and users was described as a key part of their 'toolkit'. This might involve living in the same area, having personal experience of similar health issues, or supporting the same football team, which provides the rationale for having diverse health trainer teams representing various 'communities of interest'. They draw on these shared cultural characteristics as a way of breaking down barriers and providing tailored health messages, as illustrated by the following quote:

Jenny: We were up at the caravan quite a bit and she [the health trainer] recognised, sort of, when you're at home you eat completely different to what you do when you're up the van. So trying to work food [into the healthy eating plan] for up the van, to what you sort of – really, what was best eaten but that was sort of viable to eat up there as well. So I found that quite good actually, because she said she finds the same problem because her dad's got a van.

Knowledge of the local area – in terms of health needs and available services – was seen as essential to the work of health trainers. This was facilitated by having experience of living in the area but staff also carry out 'research' on a regular basis to update their knowledge. Examples were given of providing information to health professionals, who were felt to be too busy to keep on top of developments within local communities. Health trainers were seen as a valuable resource for professionals and service users, in terms of their ability to disseminate health messages using technical or lay language. It was felt to be important to avoid the use of jargon and overly formal approaches when working with local people.

HT: That's one of the bonuses of living in the area, you know, and being brought up around here and having the job. Because I know, hands-on, what people would like to do. I mean, not 100 per cent but, you know, you have a really good idea and I know how to speak to people, you know, on their level. And that's not patronising or anything – it's dead straight, you know. If you tend to be that way – patronising or whatever or looking authoritative – they sort of go... They're a little bit unsure to relax around you, you know. To let you know what they're thinking or how we could help them, because there's that barrier there. It's, you know, it's difficult. But the way our approach is, it's completely relaxed and it's different and it's like, it's not something we've got in a textbook. It's something that comes from yourself, you know.

Another health trainer said living in the local area made it obvious that "*you're a normal person*", rather than "*posh*". These quotes encapsulate the ethos of 'support from next door rather than on high', which was universally seen as an asset to the

service. Managers reported that the health trainers were committed to their communities and enthusiastic about the role, and that they were recruited for those reasons. Although the teams were diverse in terms of their academic and personal backgrounds, participants generally felt that inter-personal skills were more important to this role than qualifications:

HT: I think you can have 1,000 qualifications but if you're no good at your job (laughs) or if you... You need to be able to speak to people and have time with people and listen to people. And if you can't and you've got all the instructions... all the qualifications in the world, you're still hopeless, really, for this job.

At the same time, health trainers were perceived to be highly trained and working in a professional manner. Several users were surprised to find out that they were not professionally qualified, although they did not regard them as 'experts'. Kevin reported that he would go to his GP or consultant for health advice but that his health trainer would be the first port of call for "*general advice about things in life*". Andrea said that she would be more likely to discuss lifestyle issues with her health trainer because she knew her on a "*personal level*", whereas she did not have the same sort of relationship with her GP. Participants valued the advice provided by the health trainers, which was felt to be relevant to their personal circumstances:

Int: Do you always feel comfortable that she [the health trainer] has got the right skills and knowledge to deal with all of the issues you come with?

Jenny: Yes, I do, because it's not a textbook thing is it? It's all sort of experience and what she's experienced with other people. [...] You know, when you're sitting talking about something that she spoke about with somebody else and they've come up with an idea, you're sort of helping each other because she'll say, "Oh well, so-and-so" – I mean, she won't say who it is – but, "Somebody was saying the other day", sort of thing. "Well, they've done this and that helps", so you're getting the experience of the community really as well... Knowledge she's getting in, she's handing out as well and it does seem to help. Where I think when it's all textbook – I mean, textbook just doesn't always work does it? It doesn't work for everybody. Everybody's not the same so you can't say, "Oh well, you've got to do this", because it doesn't work for everybody.

Health trainers tended to have personal reasons for taking up the role and were able to draw on or refer to their own experiences when working with users. This was particularly the case for staff members who had previously been users of the health trainer service, which was felt to help in building rapport and trusting relationships with users. They were able to reference themselves either as people who have

successfully made lifestyle changes or who are continuing to deal with similar issues to service users:

HT: You know, when they think “Oh, I’m struggling”, you think, I’ve been there and I’ve done it. I know what it’s like to be struggling. So you’re not dictating to them and saying “Well, you shouldn’t have had that cream cake”, you know – I’ve been there, I’ve done it and I’ve eaten the same cream cake. [...] I think that’s a big difference, because I’ve been through the system where I’ve been lectured by people that just sit on the other end of a table and lecture you, and it doesn’t work.

As health trainers tend to be selected for their shared characteristics with the target population they are often overweight or engage in health-damaging behaviours such as smoking. There were mixed views on this, with some users feeling that the ‘unhealthy’ lifestyle of their health trainer was either irrelevant or added credibility to the advice provided. There were examples given of staff and users learning together and sharing advice in the process of making lifestyle changes. Some also reported that a health trainer who appeared to be young, fit and healthy would make them feel uncomfortable and self-conscious about their own appearance:

Farzana: Well, her being a bit heavier herself does make a difference because, well, you think, oh, she’s normal like you as well. But then... Well I still, at the beginning, I did think, eh? She’s a health worker but she’s really big? But I have heard her stories about how she’s struggling with this [...] I think just because you’re a health worker it doesn’t mean you have to be really skinny. But I think her being overweight has, kind of, I think... That makes her more like us, sort of, if you can understand that.

On the other hand, a number of users felt that health trainers should ‘practice what they preach’ and follow a healthy lifestyle, with judgements primarily made based on their appearance. This was particularly the case with gym-based interventions, where users expected to see a certain physique amongst staff. It was expected that staff should be capable of participating in the interventions themselves. Those who were seen as unable to follow their own lifestyle advice were labelled as hypocrites, whilst those perceived to be fit and healthy were held up as role models:

Andrea: I think [the health trainer] is a good advert for her job. She lives her lifestyle as, you know... She does what she preaches, really. When [name] hasn’t been there on the odd occasion for some reason they’ve had stand-ins, which are just, like... They’re not trained. They get training when they get the job. I believe [name] is a trained fitness instructor and health trainer anyway. And, to be honest, some of the women that we’ve had – two in particular are very large women. While we were exercising one of them was behind us in the kitchen having a

cup of tea and eating biscuits. And I just thought, “You’re in the wrong job.” I wouldn’t have been motivated by her whatsoever.

Another potential drawback of the health trainer role is the risk of boundaries being over-stepped as service users begin to think of them as friends rather than professional advice-givers. Staff gave examples of users calling them on evenings and weekends or stopping them in the local supermarket to ask for help. Being approachable is a key element of the role but can create difficulties for health trainers in attempting to separate work from their personal life. This can be a particular issue for those working in black and minority ethnic (BME) communities; for example, a health trainer working with South Asian communities reported being pressured to invite users to her wedding or act as a reference on job applications. Staff must take steps to re-establish boundaries, which can feel uncomfortable and contradictory to the ethos of the health trainer role:

HT: They feel at ease with you over a coffee or whatever, and then they start telling you things that sometimes you can do without, like (laughs). Sometimes it gets a bit much. You know, it can do, because some people tell you some really serious problems. [...] I have people ringing on a Saturday and solving their problems... Now I do – I’ve just had to learn and think, “Uh-huh. I’m sorry”, unless it’s really, really urgent, you know, and desperate. That’s different. But now I’ll say, “Well give me a ring at work on Monday. I’ll be in on Monday” or whatever, you know. Or “I’ll ring you”, if I don’t think it’s serious.

Participants also reported having to manage the expectations of other health and social care teams, who often become attached to particular members of staff. The managers receive a growing number of requests for assistance with pieces of work which may not be within the remit of the health trainer role. This highlights the anticipated potential for health trainers to meet diverse health and social needs within local communities.

## **Chapter summary**

This chapter builds on the previous one in terms of recognising the influence of biography and context in health-related behaviours and behaviour change. Motivation for seeking help from a health trainer varied between the service user participants, although there appeared to be association with age. Participants in this study had overcome a range of intrinsic and extrinsic barriers in attending health trainer-led interventions, but recognised that some people would find it difficult to fit this into their existing lifestyles and schedules. The ability to access a local health

trainer service is also constrained by the aims and referral criteria of that particular service. This is one element of the complexity involved in the delivery of health trainer-led interventions. A second element arises from the personalised approach of the interventions, which results in a range of different activities and behaviour change strategies being employed to meet the needs of individual service users. Staff emphasised the importance of “*starting from the base*” in terms of recognising that users begin with a certain level of knowledge and skills in relation to health. Participants generally perceived the interventions as being holistic, flexible and offering opportunities for social interaction, which helped in making the activities more enjoyable as well as enabling users to learn from and support one another. Health trainers were part of this social environment, as well as offering interventions in safe, comfortable and well-equipped physical environments. Users were generally positive about the health trainers and their ability to draw on a wealth of local knowledge as well as their own personal experiences. However, there were mixed views on their status as ‘role models’ and whether or not they should be expected to ‘practice what they preach’ in terms of following a healthy lifestyle.

The variation in motivating factors and user engagement routes, in addition to the heterogeneity of health trainer models and interventions, hints that there may be similar heterogeneity in terms of the types of outcomes that can be expected from these interventions. These are described in the final findings chapter.

## Chapter 8: Outcomes and impact

The previous two chapters have explored factors involved in the development and maintenance of 'unhealthy' behaviours and the strategies for behaviour change employed by health trainers. This final findings chapter considers the impact of health trainer-led activities on service users, staff and local organisations. A range of self-reported behaviour changes, health improvements and psychosocial outcomes are presented. The impact on staff and local organisations is indicative of the reciprocal nature of lay-led health improvement interventions. By employing a longitudinal qualitative approach it has been possible to examine outcomes and impact in the short- and medium-term (i.e. over a 12-month period) and identify any challenges to sustainability. Furthermore, this approach has allowed for an exploration of the way in which the health trainer services evolved over time. The chapter begins with an exploration of the concept of impact in relation to the NHS Health Trainers Initiative, and how this might be measured. It ends with a summary that draws together key themes from all three findings chapters.

### Defining and measuring impact

The high degree of heterogeneity between the three research sites was reported in the previous findings chapter. In addition to differences in their aims, target populations and referral routes, the health trainer services also differ in the ways that they define, measure and evaluate their impact. This is in spite of the fact that, at the time of commencing the study, all services were required to provide regular updates to the national health trainer team within the Department of Health<sup>25</sup> using a standardised reporting template. Two of the three research sites had implemented the national data collection and reporting system (DCRS), which focuses on assessing progress towards the goals set by users on entry into an intervention. This enables the health trainer services to capture small- and large-scale changes made over the duration of the intervention:

Manager: It's not always about people wanting to lose four stone. Sometimes it's about people just wanting to be more active, and they're more active. It's about people who don't have breakfast and don't eat five-a-day, changing and having breakfast and five-a-day. And they might only lose one stone doing that but they're still healthier and they've made the changes they want to make. So it's not all about, you know, the big headline stories.

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<sup>25</sup> The national team ceased to exist in September 2010 and, instead, local health trainer services reported to regional project leads who continued to meet on a regular basis.



It was recognised that small changes can have a large impact in the life of an individual, but that these effects can be hard to capture. For example, many health trainers do not routinely weigh people in recognition of the fact that some would not be comfortable with being weighed. Staff may also neglect to record opportunistic contacts where they deliver brief advice or signpost people to other services, particularly if these are friends or family members. The DCRS was felt to be lacking in terms of the ability to capture psychosocial and other ‘soft’ outcomes. This was identified as a particular issue for the health trainer service employing a community development-oriented approach:

Manager: We’re using the national data collection system and it does very much focus on goal-setting. And it’s much harder to record those stories, if you like, about people and the kind of things that people will say about having increased their self-confidence and their self-esteem. It’s much more difficult to record than saying that somebody has lost half a stone, you know, which is much more tangible. So we try and get the health trainers to do case studies fairly regularly and in that way try and record that wider agenda.

The production of case studies enables health trainers to provide evidence of success in their own words. However, many struggled with maintaining these records and using the DCRS, particularly where staff have low levels of literacy and numeracy. The process of completing any form of ‘paperwork’ was often seen as stressful and requiring time that could be better spent on service delivery. At the same time, the health trainers understood the function of this paperwork in demonstrating the value of their role to the “*powers that be*”. Their work was often described as rewarding and resulting in observable benefits for service users:

HT: I’ve worked with [another health trainer] doing a weight management class down in the [area] where I live and it’s really, really been good. Really. I mean she’s got about 14, between 14 and 18 people come on a regular basis. It’s closed for the six-weeks holidays now, but you can actually see the people changing. Their fitness levels and....[...] You can actually see it for yourself that this person has lost... I mean, one of the girls was saying “Oh, I’ve only lost a stone” but she’s lost something like 10 inches off her hips and her waist and things like that. That’s amazing, you know what I mean? It’s really, really good. So you can actually see the results. Seeing the results is nice.

Staff provided numerous examples of users who reported that the interventions had helped to “*turn their lives around*”, often because they had lost significant amounts of weight. There were also reports of users making additional lifestyle changes after completion of the intervention. This information was not captured using formal

monitoring and evaluation techniques. Instead, health trainers were able to gather informal feedback as a result of being networked into their communities:

HT: We don't really do a feedback further down the line. It's something that we've talked about recently, actually. But I have had occasions where you bump into people in the street and you know whether or not they're doing really great. I've had... I've had a mother phone me to ask if the service was still going, could they refer somebody into it, because their daughter had done so fantastically well and they were so impressed with the service that they wanted to sing it from the rooftops, you know. I had sort of, "Thank you for giving me my daughter back". I was like "I didn't do it, she did it. It wasn't my effort." That was like... (laughs) amazing. You don't expect people to say that to you... So it's difficult to kind of gauge. But, on the whole, the people that I have seen are still maintaining doing what they were doing.

There was variation in terms of the credence given to this anecdotal evidence; case studies were viewed as a key source of evidence by the service located within the third sector, whilst others placed greater emphasis on quantitative monitoring data. One service had implemented a computer-based data collection system that pre-dated the DCRS and was felt to be equally comprehensive. Health trainers within this service seemed most comfortable with routinely assessing users and updating their records. However, their service users raised the most queries relating to the data collection process. They reported concerns regarding the inability to capture intangible effects such as interaction and rapport between people, and the perceived preventative effects of the intervention. There was felt to be an over-emphasis on cost savings:

Frances: Mentally and physically, it saved the council – the NHS – money because of the physical, mental aspects of it, if you see what I mean. Exercise helps depression. Obviously it helps your physical form. And a lot of people I've spoke to said they weren't going to the doctors as much because they knew that the gym was doing them some good and it was helping a lot of people. And that's been cut off. So I think it's going to show that they haven't even thought about it. They've just looked at the money side.

There was a general perception amongst users that routine assessments and paperwork were primarily for the benefit of the health trainer services and funders. Only one health trainer mentioned offering users a copy of their records, although they said that many declined this offer. There seemed to be a discrepancy between the measures that were meaningful for users and those that were most relevant for the services in terms of meeting their funding targets. For example, Frances

reported that her health trainer had become increasingly concerned with measuring her weight and discussing smoking cessation, whereas she had no interest in losing weight or stopping smoking. At each of our four interviews, Terry mentioned an unfulfilled desire to measure his fitness level:

Terry: I think I mentioned before – and I keep mentioning to the instructors – like, it would... I would like to know a percentage, fitness-wise, that I am. So that if I miss [the gym] for a couple of weeks, they could measure my fitness somehow and say, “Oh, you’ve dropped from 80% down to 50%.” Or if I said to you, “Haway, I’ll take you to the gym” – measure your fitness before you start and then after four weeks say, “Oh, you’ve improved by... whatever.” I can’t seem to get an answer to that.

### **Personal outcomes**

The following sections consider a range of personal health and social outcomes reported by users of health trainer services, as well as issues relating to the sustainability of these outcomes.

### ***Knowledge gains***

It was reported in the previous chapter that education sessions delivered during the health trainer interventions were often described as informative and enlightening. Users reported gaining knowledge around various lifestyle factors, particularly relating to food and nutrition. In the majority of cases, this knowledge appeared to have been retained at the 6- and 12-month follow-up interviews. Those with memory problems were more likely to make ongoing use of the resources obtained from their health trainers, whilst others described the information as being “*ingrained*”:

Jenny: Now and again I sort of look at it [the health trainer booklet] but you get to the stage where you sort of know what you can... what you can have and, like, how much of it. Sort of a portion and whatnot. And, like, how many you are allowed. [...] It’s just sort of ingrained in now. It’s there. You know what you’re doing so you’re not thinking, “Oh well, I can only have two carbohydrates here or two there.” It’s just automatic. You don’t even... Well I don’t think about it. I just go and do it.

In some cases, this resulted in users following the health trainer’s advice without question, suggesting that they were practising rote learning as opposed to critical thinking. For example, Jenny reported being given a “*dairy allowance*” of two portions per day and allocating this to having butter on her toast as opposed to milk

in her coffee. At each of my interviews with Pam, she described struggling to consume the recommended portions of food:

Pam: [Indicating towards her food diary] I've even put in when I first started what weight I was and I had to have seven carbs, seven fruit and veg, two protein and two dairy. But I can't always get seven. And she [the health trainer] said that's how I was putting weight on, because I wasn't eating enough. But I mean, sometimes it makes me feel sick to actually eat more and more. And to me it doesn't make any sense – to eat more to lose weight. But that's the way she explained it to me.

These users did not seem to be making particularly informed choices. There were other examples of users becoming more aware of health messages but continuing to choose less healthy options. This was particularly the case for those on a limited budget; for example, Jim reported eating less red meat on the advice of his health trainer but then filling his freezer with a 'job lot' of meat from the local market. One outcome was that users were more conscious of their unhealthy choices. Brian articulated this by saying, "*I make a conscious decision whether I'm going to transgress or not, but at least I've got a guilty conscience if I do*". Some continued to smoke or eat calorific foods because they found these behaviours mood-enhancing and used them as coping strategies in dealing with difficult situations:

Gail: I am more aware of portion size than what I was before. I do try to limit that, but it's... It's dependant on my mood, I must admit. When I'm... I call it my dark side comes out. Because it is really, really dark. I find that that's the worst time. And then I'm more easily triggered than normal people, for getting low, I must admit.

The above quote illustrates that users may gain knowledge from the intervention but that often "*life gets in the way*" when it comes to implementing this advice. Staff were optimistic that equipping people with relevant information would lead to some benefit in the longer term, with one health trainer describing this as "*planting the seed*". A time lag often exists between the dissemination of health information and associated behaviour changes, particularly in disadvantaged populations. However, this study identified numerous examples of behaviour changes made by participants and maintained at 12 months. These are reported in the section below.

### ***Behaviour change***

Staff reported that a key behavioural outcome for many users involved adopting and maintaining more structured lifestyles; for example, going from eating one to three

meals a day, or from being housebound to leaving the house on a regular basis. These changes were felt to be particularly important for users who were eventually hoping to find paid employment. The previous chapter highlighted weight gain and poor nutrition as a primary concern for the majority of service users. Therefore, much of the feedback from participants related to dietary changes. These ranged from relatively small changes such as not cooking with salt to larger changes such as growing their own fruits and vegetables. Many had modified their purchasing habits and reported making healthier choices, as illustrated by the following quote:

Kaye: I really now, really really try to eat breakfast every morning. And instead of eating muesli, I eat Shreddies and I don't eat so many as I used to. I don't eat as much. I have a small bowl, whereas before I would have muesli and I would always have loads. And then I'd put things in as well – I'd put loads more nuts in and, all the things I like – I don't do that now [...] I'm also more aware of, sort of, portion sizes. And I don't eat bread anymore and I haven't actually missed it, so... And if I, I don't eat sweets very often. But I've found I don't buy food – the wrong kind of food – I just don't buy it now.

Users were unwilling to make some changes; as Jenny put it, *"I mean, you can't have mince and no dumplings"*. Rather than asking people to give up their favourite foods, the health trainers suggested healthier ways to prepare these foods or substitute them for an alternative. Suggestions that were enacted included buying dark instead of milk chocolate, making oven chips and grilling meat instead of frying (as described in the quote below). These changes were often maintained but temporarily reversed during busy periods, on special occasions or whilst on holiday.

Jim: I do have chips but [the health trainer] has shown me a way of doing chips. You do them in the oven in foil and it's a better way of cooking plus you get the taste of the potatoes more than what you do from the fish shop. [...] And I was taking one sugar in my tea – I've now cut that out. I'm doing a lot more salads than I used to. If I have meat, it's got to be lean. And anything I have – meat – is grilled, instead of fried. There's been big changes in my diet.

A significant change involved preparing more home-cooked foods and planning meals ahead, particularly for those living alone. This involved using fresh, new ingredients, trying different food preparation techniques and considering portion sizes. Users initially found this element of planning and organisation a challenge but reported that it became easier over time:

Jenny: I'm having a more varied diet and the portion sizes are actually just cutting themselves down. I haven't actually said, "Right, oh well, I'm not having that, I'm..." It's just gradually as I've lost weight it's gradually just come down. Sort of, you're just ending up... You're putting less on your plate because you know, well, you know, I won't eat that so... And it's just come down that way. [...] Like, to me, I've just done it naturally. I know how much I can eat and don't bother putting more than what I can on my plate.

The health trainer-led interventions seemed to have changed participants' thinking about food and nutrition, and subsequently influenced their food choices. They had also become aware of the concept of energy balance, which some felt allowed them to consume more calorific foods if they maintained higher physical activity levels.

The quote below describes the converse situation. Brian attended a weight management programme and made a number of dietary changes, which had resulted in significant weight loss. At our 12-month follow-up interview, he said, "*I still want to lose about another stone so I've decided to put myself back on the [name of] programme*". He did this by asking for help in creating his own food diary at his computer class. Brian's story is just one example of the participants' ongoing use of self-regulation techniques.

Brian: Before [taking part in the intervention], I'd go to the supermarket for myself and think, "Oh, by God, that looks nice." And I'd take it home and cook it and eat it. I saw something just the other week at the supermarket – I forget what it was now, but it was something I thought "Oh yes, I really fancy that", you know. And then I did what I didn't used to do before, which is that I looked at the calories on the back. There was about 2,500 calories in it. Well, when I'm down at the gym and I work really hard and I really sweat, I am using between 400 and 500 calories. But when you put that in perspective, the work you have to do, and then you look at a packet with 2,500 calories – that's five visits to the gym, just to get rid of that. No.

Participants also described a cascade effect, whereby their personal dietary changes had prompted behaviour changes amongst friends and relatives. These unintended outcomes occurred either directly – through purchasing and preparing healthy foods for others – or indirectly – through disseminating health messages. Women were felt to be particularly responsible for this effect, as a result of primarily undertaking the food shopping and cooking for their families:

Sophie: For children a good idea is we grated the carrot as well and liquidised it with a hand blender just a tiny bit. And do you know I made it for [name] – my grandchild – and she loved it. And she used to hate it, you know. And it made her eat things what she wouldn't have eaten. [...] The people I've given the recipes to, because we came out with all the



recipes of everything and how to do it just like in layman's language. Yeah. It was brilliant.

There were also examples of users making and maintaining behaviour changes in relation to physical activity. The wider impact on families and communities is often underestimated, with one manager stating, "*It's almost about beginning to change a culture around understanding the benefits of exercise*". Many participants had become more physically and socially active following completion of the health trainer intervention, with some describing exercise as "*addictive*". A key factor was finding enjoyable activities that fit into their existing lifestyles:

Sian: I've been keeping up my salsacise. So Monday I'm back at work now, Tuesday I keep free for like doctor's appointments and things like that, Wednesday at work, Thursday's sewing and Friday's going to be salsacise in the morning, meditation in the afternoon and then if I keep it up there could be belly-dancing in the evening. But... So I'm keeping myself busy and keeping, trying to keep myself active. But I've tried to do things that I enjoy rather than, you know, like exercise classes and things like that. I still can't get away with them. [...] It's finding things that you know you'll keep up with if... It's all the good in the world trying something but if it's not going to keep, keep you interested...

Sian's salsacise class was subsidised for those in receipt of social benefits, which she said "*makes it easier for somebody like me*" by leaving her with money to pay public transport costs. Many participants reported that personal finances and perceived value for money were key factors in their ongoing attendance at a sport and leisure facility:

Terry: We joined there [a private gym] when we got evicted out of [the health trainer-run] gym. We went down there and they had a special offer on – a two-year deal – £175 for two years. So we joined for the two years and that works out at £1.60 a week. And there's a swimming pool, Jacuzzi's, steam room, gymnasium and all the classes. [...] So it's still good value, if you want to go. So I would continue after two years once I've got a taste for it. I think it's ideal.

Some users felt that they were unable to access a local authority or privately-owned gym for a variety of reasons, many of which have been described in previous chapters. Affordability was an issue and some participants chose to allocate their resources to purchasing home exercise equipment instead. For example, Brendan continued to use a cross-trainer and exercise bike at home, and the benefits of doing so are described in the quote below. Others favoured activities such as swimming, walking or cycling outdoors.



Brendan: I could see the muscle development, you know, using the machines at the [health trainer-run] gym. So the cross-trainer that I've got and the cycling, they are good, you know. I mean the rower and things for upper body strength, you just have to improvise. You know like on the benches on there? Press-ups keep your shoulders... [...] That'll do me – that gym, what we've got in the bedroom. I think those cross-trainers are brilliant. I mean because they do a multi... It's like a multi-purpose. You know, they do your calves, your thighs, your chest, your arms – all in the one... So that's good.

In cases where behaviour changes had been made but not maintained, the explanations given primarily involved cost, inconvenience and ill-health. Participants also described temporary setbacks and particular times when they found it more difficult to follow a healthy lifestyle. For example, Eileen gained weight over the festive period due to the combined effects of over-indulging and taking a break from her usual exercise regime. The quote below was taken from our six-month interview, when she seemed determined to return to the gym. By our final interview, Eileen was suffering pain in her hip that prevented her from being physically active:

Eileen: It was like a month or maybe five weeks or something of not doing anything. And I was sitting in bed, reading my book one morning and drinking my cup of tea and I thought, "Right – out of this bed and up to that gym because otherwise you're just not going to do it." Because you can soon get out of it, can't you?

In contrast, Andrea had taken a break from attending the health trainer intervention during a busy period at work and returned once things had become less hectic. She implied that the changes made during this intervention were likely to be more sustainable than previous weight loss attempts due to a change in her perspective:

Andrea: I will be going back [to the gym]. I just know this time of year is busy and so on. And I've done this before. When I first started out, if I missed the gym for a month that would have been it, I would have never gone back. But now I know I will so I don't worry over it now. I know, oh, that's alright – once I get my head sorted and back to normal and I'm not as busy, I'll get back into it.

At the time of our final interview, Andrea was exercising on a regular basis and had reintroduced the dietary changes recommended by her health trainer. It was not uncommon for participants to pause and then re-start their healthy living efforts, particularly if they had experienced some form of health improvement that they hoped to maintain.

### **Health improvement**

Due to the combined effects of increased physical activity levels and dietary changes, many participants reported significant weight loss following completion of the health trainer intervention. This was assessed either in terms of total weight lost or a replacement of body fat with muscle mass, measured in lost inches. Both of these measures are highlighted in the quote below. In some cases, participants had gained weight as a result of a new illness or medication, whilst others had managed to maintain a healthy weight in spite of these developments. For example, Pam was diagnosed with a thyroid problem but gained less weight than expected, which her GP attributed to her ongoing use of the food diary introduced by her health trainer. Others were surprised that they had continued to lose weight whilst on holiday or during special occasions, which was felt to indicate the effectiveness of the health trainer services over alternative lifestyle interventions.

Maxine: It was the 29<sup>th</sup> March last year when I first started with [the health trainer] and I was 13 stone 5. And now, last Wednesday I was 11 stone 13. But with doing the gym and that – I go to Body Blast and do four classes a week – it's, like, toned me up, you know. Like, the inches. Like, people say, "Eee, the weight you've lost." And it's not, it's not a lot of weight, but it must be because of the toning up. That's... And it does make you feel, like, better in yourself.

Maxine described feeling as if she had "*unzipped a fat suit*" after losing weight. There were also examples of family members having lost weight as a result of consuming healthier foods and taking part in activities associated with the health trainer interventions. Participants reported feeling better about themselves and noticing a change in their appearance, through being able to fit into smaller clothes or receiving compliments from others. Maintaining increased levels of physical activity was felt to bring benefits in terms of enhanced mood and energy:

Andrea: I think the exercise is the most natural anti-depressant you'll ever get. I think it just makes you feel so good. When you come out, the sweatier you are, and the more out of breath you are, and the more thirsty you are, you think, "Phew, that was good. I enjoyed that." You know, it does give you a good feeling.

There were also reported improvements in sleeping patterns, muscle tone, function and mobility. Participants felt their fitness levels had increased, assessed by a perceived change in their ability to comfortably undertake specific activities. Those

with musculoskeletal problems experienced marginal improvements, with some having reduced their medication usage:

Sophie: I'm fitter in myself, yeah. I can, I'll tell you what I'm finding – I'm bending down easier. That's, you know – I suddenly found I was in my cupboard for something and, eeh, I thought, I can get up here great, where before it was [makes groaning noise] (Laughs). [...] And I'm on no painkillers now. Just Paracetamol now, as needed, where I was on Diclofenac. So that's good, isn't it? Coming off that?

Improvements in existing physical health conditions were most frequently reported by users who regularly attended either a gym or an aerobic exercise class. For example, following attendance at the gym-based health trainer intervention, Brendan experienced fewer asthma attacks and was advised by his GP to reduce his angina medication. Other participants reported reduced blood pressure, fewer symptoms of irritable bowel syndrome, and improved blood sugar levels:

Denise: I'm a diabetic and it has actually, it brought my sugar levels down because I was getting exercise. [...] And then when I had my blood results, and even the dietician, she was so pleased. It had come from 9.1 or something to 8, you know. So she said, "Oh, keep it up", which as I say, I'm going to. Get down a bit further. Definitely, yeah.

There were a minority of cases where the intervention was felt to have exacerbated an individual's existing condition or contributed to a short-term decline in health. These negative consequences were often perceived to be age-related; for example, experiencing aches and pains after undertaking physical activity and requiring a longer recovery time. Although they felt that exercise helped to relieve conditions such as arthritis, some users reported that they would "*suffer for it the next day*". The general attitude was one of "*pushing through the pain*", resulting from a fear that the health improvements could be quickly reversed. This was borne out by the experience of those who had taken a break from their lifestyle changes and subsequently gained weight or experienced some form of decline. Participants expressed concern that they would not be able to sustain the improvements without support from the health trainer service. Gina's story (see box 9) illustrates this:

**Box 9: Gina's story**

Gina is 75 years old, retired and lives with her husband John, who is 65 years old and also retired. John is Gina's second husband. The domestic violence she suffered during her first marriage resulted in her sight loss and she also has type 2 diabetes. She attended a health trainer-run gym for over two years and told me repeatedly how much she loved it. John attended the same gym and Gina felt this had helped to bring them closer together, as well as saying he had *"lost a lot of weight and his blood pressure's down. Because he was a heavy drinker, you see. He doesn't drink as much either"*. She was very upset when the service moved to a system of limiting use of the gym to a 12-week programme. She felt that, *"People are going to say, 'Well what's the use of going for 12 weeks if we can't go any more?'"* and therefore, *"They just don't go. And you see, your body will go flabby and then go back to where it was before you started"*. At the time of our final interview, Gina had joined a local authority gym as well as continuing to attend her regular dance class, whereas John had stopped exercising and regained the weight he had lost by attending the gym.

In order to ensure that any health improvements are maintained, participants felt it was important to have ongoing access to services that were tailored to their needs. Many described the move to a 12-week intervention as *"short-sighted"* and *"a retrograde step"*. It resulted in an inability to accommodate the health needs and capabilities of users; as articulated by Peter, *"that's like saying that a man who needs six months to recover from something has only got 12 weeks to do it. And a man who would only want three or four weeks to recover from something, he's got 12 weeks"*. Health trainers also expressed reservations regarding the new system:

Int: Do you feel that [12 weeks] is the right time for you to be able to get people...?

HT: I don't. No, I don't to be honest. Maybe 24 weeks – you know, give somebody a whole, like, half of a year to really make a good effort of it and then you can go back to the doctors and say, "Well, we tried six months worth." Because it seems... You might just be getting into your stride on three months and then it's time to call it a day. But the bosses keep on saying it's everybody's own lifestyle – if they want to continue after three months, it's entirely up to them. It's their life.

The system had been in operation for approximately six months at the time of conducting the final follow-up interviews. In spite of their initial reservations, staff felt that there had been a shift towards *"quality not quantity"* in terms of providing personalised support to new users. However, there were concerns that former users

did not seem confident in sustaining their lifestyle changes in the community. The quote below highlights the potential impact of these service developments on physical, mental and social health, with the latter explored in the next section:

Frances: I feel more cut off now than I ever have done. Because the people I met at the gym are lovely, but they've got their own lives as well. And I don't see them anymore. I keep in contact with a couple of them, you know, on a phone call. But it's not the same as somebody next to you saying, "Come on, you can do it." And "How are you?" It's not the same. And I know a couple of people who are like me, on the one-to-one [intervention], they don't virtually... They're housebound now. They don't see anybody. Because they made the effort to go to the gym and... With them as well, I've no doubt, mentally, it was doing them some good, but when that door closes, it's like saying, "Oh, I can't be arsed with you anymore." And that's exactly what it feels like.

### **Psychosocial outcomes**

Health trainers became a key source of social and emotional support for users during the interventions. This was particularly the case for socially isolated individuals who felt they could not rely on anyone else for help. The following quote demonstrates the impact of this support at an early stage during the intervention:

Linda: I would say it's too soon because I've only had three sessions. But... subconsciously... is it subconscious? I know that there is somebody there. So yeah, I would actually say it has made a difference because now I wouldn't think twice, I could get her on the phone and say, "Oh, [name of health trainer], you know, I want to do something. How do you feel about...? Or could you...?", you know. I mean, we're already looking at things like the smoking [cessation] [...] And she does build your confidence up, you know. So yeah, I mean, for all it's been a short while, it probably has helped.

Some users required additional input and time with the health trainer to build their confidence. Examples were given of people who had virtually been housebound and who had begun to attend activities within the community; although their physical health may not have improved, these small changes were seen as major achievements. At our initial interview, Ben talked about accessing the health trainer service in attempt to relieve boredom and loneliness, which he felt had contributed to his mental health problems. Ben continued to receive support from the health trainer after 12 months but he had also joined the local Healthy Minds Forum and started to use public transport on his own to attend this and other activities:

HT: Working with Ben, it's been a slow process. Slow progress. And I have seen some changes. There's a lot more confidence and I'm really pleased. Encouraging him to go out and meet more Deaf people. On weekends he goes out with his friends – he might go to the pub or watch the football match. [...] So he seems like he's getting more involved with things, which is positive and that's really good. And I'm trying to encourage that.

Becoming more socially active was seen as a key outcome by many participants. Users reported developing the confidence to take part in activities such as walking groups, meditation courses and luncheon clubs, which they often became aware of through the health trainer service. These activities served multiple purposes; for example, attending a sewing class enabled Sian to save money by repairing her children's clothes, as well as relieving boredom and providing opportunities for social interaction. An art group also had 'spin off' effects for users:

HT: Well, since they started the pilot scheme for people who can't go far and to help with their mental health, we set up an art group. So, aye, it's lovely. And we've got a tutor and they've learnt how to do watercolours. It's mainly just for the socialising side and the isolation and stuff. But the art's a bonus because they were saying, "Well, we can't paint, pet", you know. But, "Come along and see", you know. And now it's unbelievable. We're talking about having a show with all their art because it's unbelievable, I've seen nothing like it. It's fantastic. It's brought things out in people that you wouldn't believe, even themselves.

Employment was reported to be an outcome for a small minority of users, resulting from their increased confidence and becoming more active within their communities. Health trainers would pass on relevant opportunities to enable their users to develop skills and enhance their employability. In Linda's case, this resulted in her gaining employment as a health trainer after being out of work for more than a decade. The impact of this lifestyle change is illustrated by the following quote, taken from an interview conducted when she had been in post for three months:

Linda: Just everything's different, you know. I've got much more confidence. I feel much better about myself than I have for a long time as well, you know. Hence, the haircut and (laughs), I just went for it, right. And it's noticeable. People are coming up and commenting, you know, "You look great. What've you done?" And, "I got myself a job", simple as. And it's a job I like doing so it makes a difference.

Many users and staff reported enhanced self-esteem as a result of participating in a health trainer-led intervention. The quote below illustrates the impact of this in terms of equipping users with the skills to cope with stressful situations:

Sian: I am coping. So it's sort of like a little reminder I can do stuff, you know. It's nice having family to fall back on but, you know... it's not the end of the world. So, it just feels better, you know, that I feel like I can manage it. [...] I mean, sometimes it's just taking 10 minutes to sit down and calm down, rather than losing my temper and thinking, "This is getting on top of me", which is what I used to let happen, you know. So now I'll say to myself, "Well, I'm calming down, I'm relaxing and I'm not letting this get on top of me." I mean, the situation's still the same, it's just my perception of it is trying to be different, you know.

Health trainers also benefitted from both their formal training and learning 'on the job', which are explored further in the next section. One manager gave the example of a member of staff who reported feeling better able to cope with her partner's alcohol problems as a result of the knowledge and contacts gained through delivering the interventions. By virtue of their lay status, health trainers tend to be key beneficiaries of the service and users were aware of this fact. They referred to helping their health trainer and supporting their local service as part of a reciprocal relationship. The previous chapter also highlighted the supportive relationships between users and the psychosocial benefits experienced in feeling that they were helping others. Staff and service users felt a sense of pride in witnessing someone else achieve their goals, as illustrated by the following quote which refers to a ten-pin bowling group for people with learning difficulties and mental health problems:

HT: There's this one man who goes and he's got no expression on his face at all. And he gets the ball and he throws the ball and then he turns around and sits down. And you've got to tell him to get back up and get his next ball and he throws it and he sits down. I saw him there a few weeks ago and he did it and he scored and he got a strike. And we were shouting and bawling and clapping our hands. Eee, and it was just like, he's just like, straight [serious], he's like that [demonstrates a straight face], and he turned around and he had the biggest smile on his face. And I think that just says it all. I just think, if we weren't there and he was just sitting in the house doing nothing, you know, and... Because he doesn't talk so he, nobody would approach him because he's really straight, you know. And his smile was the biggest... Oh, it was fantastic. Absolutely fantastic. And so I just think we do a fantastic – I think we make a big difference in people's lives.

Participants with a disability or limiting long-term condition experienced significant benefits from being given opportunities to interact with others and take part in



activities that fostered independence. During a visit to a health trainer-run gym, a member of staff introduced me to a young woman with a learning disability (not a study participant) who seemed very open and friendly. The health trainer informed me that the woman had initially accompanied her father to the gym and was too timid to speak, but that she became more confident in communicating after taking part in the activities. As someone with progressive MS, Frances also spoke passionately about the benefits she experienced from taking part in physical activity:

Frances: Well, physically, obviously I've gotten worse but my muscles are stronger. But however strong my muscle, it doesn't matter if it refuses to work. But mentally it has done me to the power of good. You don't feel so useless. You can go out and do something, and mentally that's brilliant. [...] The gym is the one place I don't have to take [her wheelchair]. And mentally that's such a high really – a victory, a one in the eye for the disease – if that makes any sense (laughs).

There is a danger that these mental health benefits are lost after users have completed the health trainer intervention. Frances was unable to access other sport and leisure facilities due to her condition, and was left feeling extremely angry and frustrated. In this case, the intervention appeared to have contributed to a decline in emotional health and wellbeing. A number of participants became upset during our interviews, suggesting that the withdrawal of support by a health trainer can create rather than alleviate stress and anxiety. Andrea described this by saying, *"It's like you've a carrot dangled and then it's taken away from you. I think it just seems a bit unfair"*. Some users also expressed concern for the future of their health trainer service, which created further anxiety. A minority reported feeling empowered through taking control of their own healthy living efforts, with the diminishing support of their health trainer. This is illustrated by Maxine's story (box 10 on the next page).

The weight management group described in this case study was formed through the local health trainer service and then taken over by its members, with the support of a health trainer. This input from a qualified or knowledgeable person was seen as essential in enabling users to reach a point where they would feel able to continue on their own. Users varied in the time taken to become independent; in Maxine's case, she attended the group for almost two years before feeling confident enough to continue without one-to-one support. Long-term interventions can become sustainable by employing a community development approach and encouraging users to organise and fund their own activities, allowing the health trainers to gradually reduce their input. There are a number of additional benefits offered by this approach, which are outlined below.

**Box 10: Maxine's story**

Maxine is 46 years old, works part-time and lives with her husband. She wanted to lose weight and accessed her local health trainer service after hearing about it from a colleague. They attend a weight management group where a health trainer provides one-to-one advice on food and nutrition, and an aerobics instructor delivers an exercise class. When she first joined the group, Maxine had *"a lot of one-to-ones with [the health trainer] for a good few months into it, where, you know, you start off and you're so determined"*. She felt the health trainer was very good at motivating and empowering people, and said, *"I think a lot of it is put back onto us – to do it for ourselves – which is a good thing"*. She had lost 1.5 stones but continued to attend the group on a weekly basis, saying *"I haven't had a lot of one-to-ones recently, but just knowing she [the health trainer] was there as a backup, I think, maybe, was a little security blanket"*.

**Organisational outcomes**

A core element of the health trainer model involves providing training and employment opportunities for local people in order to build community capacity. Managers felt that the recruitment of a diverse team of staff and high retention rates were key achievements of their service. Each service was reported to have a strong sense of team-working, although different health trainers may take on different roles within the team. Where staff have either felt the role was not suitable for them or *"moved on to better things"*, the managers still perceived this as a success in terms of community capacity building. This is achieved through formal staff training activities, which were often found to be challenging but highly rewarding:

HT: When I came into post I had... I didn't have all the knowledge but I had the enthusiasm to learn. I got lots of training. I've been provided with lots and lots of training. They've helped me get qualified, like, City and Guilds Level 3 as a health trainer. Nutrition – information and skills regarding nutrition. Smoking cessation. A whole range of courses I've been on which has really broadened my horizons and increased my awareness and my knowledge. So that's been really beneficial for me as well, as a person.

The above quote demonstrates the emphasis placed on recruiting people with the appropriate skills and qualities, rather than necessarily having formal qualifications or work experience. A number of participants were recruited as health trainers primarily based on their prior experience of voluntary and community work. Gaining qualifications was described as a *"bonus"* of being employed in the health trainer

role. This was particularly the case for those who previously had no qualifications and were encouraged to undertake additional training, as well as passing on their skills to new members of staff in a mentoring capacity:

HT: They even encouraged me – believe it or not – because I always liked English and I was always sad that I didn't go out of school with anything [qualifications]. And I actually sat and did my English Literature and passed that. That was in my own time. And I was really chuffed. I still am today. [...] I do feel proud of myself now because I never did, you know. I always thought I was thick or, like, I just didn't learn enough and not knowing where to go and what to do. And to think, what I've learnt, in the short years and especially at my... I keep saying my time of life, but you know what I mean.

One service placed particular emphasis on providing opportunities for users to gain employment as health trainers. As stated in the previous chapter, these individuals were felt to offer stories and experiences that would be inspiring to other people. Linda was described by her former health trainer as “*my biggest success story*” and an excellent advocate for the service. By recruiting from their target communities, the health trainers were seen as being inevitably committed to and passionate about those communities:

Manager: There's a strong ethos and everybody has kind of signed up to that – that ethos – and they see how it's kind of benefitted them and they want to share that as well. They want to be able to share that with other people, so that makes it a success. It means that the, you know, that the health messages are... it's not a theory, really, somehow. It's more than, it's kind of more than just the theory. And I know there are lots of health workers who are passionate and committed and it doesn't mean, you know, that there aren't lots of health workers who do have great relationships with the people that they work with and so on. But this is, you know, it's an integral part of it. And it's part of the design. And it means that it hopefully consistently works across the board, really.

Health trainers were perceived to have demonstrated the feasibility of this delivery model by being accepted by local people and organisations. For example, the service operating a waiting list for new referrals reported this as an indicator of their success as well as evidence of need within the local population. Other indicators included more than 40 men attending a weekly football session and over 100 women and children attending a women-only swimming session, largely from BME communities. Participants felt that the health trainer services continued to build a strong reputation, partly due to the role of staff in promoting their work and partly due to 'word of mouth' recommendations from users. It was also felt that health and

social care professionals had developed greater understanding and acceptance of the role, evidenced through increases in referrals, “*repeat custom*” and requests for their input at events:

HT: I just hope that it develops into a job that – that’s my idea – that everybody knows about. “A health trainer? Oh yeah, have you got one of them?” (Laughs) Instead of like “What...?” And that’s the stage that we’re just starting to, like, come out of at the minute, because locally there’s quite a few people know about us. People who are connected into the community environment, you know, who are involved.

In part, the role was considered to involve informing professionals about the needs of local communities and educating them about the potential benefits of a community development approach. This was seen as a particularly effective approach in attempting to work with ‘hard-to-reach’ communities. By the end of the study, changes in the political and economic climate meant that there was a greater emphasis on working closely with GP practices, who might be more concerned with addressing the needs of individual patients than taking a community-wide approach. However, the following quote demonstrates that some progress had been made towards addressing the wider inequalities agenda:

Manager: Some of the current PBC [practice-based commissioning] work that we have isn’t just linked to their patient lists. So they’re being quite... forward-looking and... What’s the word? Kind of open-minded. You know, it’s kind of blue-sky thinking, I suppose. I don’t even mean that, I think. Just... They’re just taking a broad approach to it and recognising that, you know, they’re in a community and that we can do work around health in that community, which is going to impact on services across the board, really, and on the health of the community. So part of what we’re doing with them is work specifically with their patient lists and particularly their diabetes – as I mentioned – their diabetes patient list. But also community engagement. And they are actually employing us to work on raising awareness around diabetes and the effects of diabetes and prevention work and so on, with communities, with BME [black and minority ethnic] communities in the area. So, you know, that’s really hopeful and that’s quite forward-looking

When asked about the future of the health trainer services, responses ranged from concerns regarding job security to optimism about their long-term impact on communities. The managers were confident that their services would be funded as long as there was a local need for the health trainer role. Staff were hopeful but uncertain about the future, largely due to the ongoing major NHS reforms and changing economic and political context (described in Chapter 6). This seemed to have filtered down to users, who were acutely aware of the potential for services to

be withdrawn if they were to lose their funding. Overall, participants felt that there was an ongoing need within communities for personalised services delivered in accessible environments to improve and maintain health and wellbeing. Health trainers were perceived to be an acceptable and effective way of meeting that need.

### **Chapter summary**

This final findings chapter further illustrates the degree of heterogeneity between the local health trainer services and the danger of employing a one-size-fits-all approach to monitoring and evaluation. Individual knowledge gains, behaviour changes and health outcomes, as well as various psychosocial outcomes, were reported by users of all three services. However, physical health impacts were more likely to be reported by those taking part in gym-based interventions, whilst wider impacts on communities and organisations were highlighted by those working in the community and voluntary sector. The use of a community development approach was felt to enhance the sustainability of the interventions and enable users to receive longer term support with their behaviour change efforts. The changes and outcomes reported by participants in this study were sustained at 12 months in the majority of cases. However, there were examples of users temporarily putting their lifestyle changes on hold for a variety of reasons. Factors that made it difficult for them to sustain healthy lifestyles included the costs of health-related activities and facilities, inconvenience in terms of the location or timing of these activities, and personal setbacks largely resulting from ill-health. Offering short-term interventions without follow-on support may result in a reversal of the health benefits and can cause users to feel disempowered or abandoned by the service. This has particular implications due to the reciprocal relationship and blurring of the boundaries between health trainers and service users. Health trainers are also key beneficiaries of the services due to the employment and training opportunities they offer, and the sense of achievement gained from observing success amongst users.

Overall, participants in this study perceived their local health trainer services to be effective in terms of facilitating knowledge gains and health-related behaviour changes amongst users, contributing to the formation of new social networks, and building community capacity. There was also evidence of a wider impact on local organisations through the use of a community development approach. The success of the services was felt to derive from the delivery of holistic, flexible and personalised interventions that employ asset-based approaches in terms of building

on users' existing knowledge and skill bases. Chapter 7 describes the way in which these interventions draw on evidence-based strategies for individual behaviour change but also provide opportunities for interaction and social support between users. This mirrors the influence of biographical factors and social environments in behaviour formation, as detailed in Chapter 6. Employing health trainers from the target communities was felt to add value in terms of having an innate understanding of the multiple disadvantages and complex situations faced by people living within those communities. Health trainers are able to draw on their extensive knowledge of the local context in supporting users to achieve their goals. Hence, the core category derived from the data in this study is 'contextualising behaviour change'. This is discussed in greater detail in the next chapter.

## Chapter 9: Discussion

The aims of this study have been addressed through developing the theory of lay-led behaviour change in context. These were: to explore the processes involved in attempting to make and maintain health-related behaviour changes from the perspectives of people living in socio-economically disadvantaged areas; and to qualitatively evaluate the contribution of the health trainer role to supporting people in these attempts. Literature to inform the study was drawn from health psychology – with regards to theories and models of individual and collective behaviour change – and also from the policy and evidence base for interventions to reduce social inequalities, which draws on a range of theoretical and disciplinary perspectives. The paucity of previous research on the subject of health trainers in the UK meant that much of the empirical evidence was found in the overseas literature and concerned various lay health worker roles operating in specific cultural contexts. This evidence, reviewed and synthesised in Section A of the thesis, demonstrated a need for robust qualitative studies to shed light on the components of lay-led interventions as well as investigating the views and experiences of people who choose to engage with these interventions. A description of the philosophical and methodological focus of the study was given in Section B, along with a detailed overview of the research design. The study findings were presented in Section C and divided into three chapters, corresponding broadly to Pawson and Tilley's (1997) realistic evaluation framework. In accordance with grounded theory, the findings have been derived from the study data rather than existing theoretical frameworks. However, linking them to the context-mechanism-outcome configuration contributed to meeting the study aims by illustrating the key role of social and contextual factors both in the formation of 'unhealthy' behaviours and in the perceived effectiveness and acceptability of health trainer-led interventions.

The purpose of this final chapter is to interpret the study findings in light of the strengths and limitations of the methods, and highlight the implications for theory, policy-making, practice and further research. The chapter begins with a summary of key issues that have been set out in previous chapters, supported by the existing empirical and theoretical literature on behaviour change and the use of lay health worker (LHW) approaches. In this section I have sought to demonstrate the extent to which the study objectives have been met. An appraisal of the research design and methods is then undertaken to demonstrate the validity of the findings and the extent to which they can be transferred to other contexts. This is followed by my reflections on the process of employing a longitudinal qualitative approach within a



grounded theory methodology. I then go on to highlight the contribution of this research to existing knowledge, in terms of the theoretical implications of the findings and development of the grounded theory. The theory of lay-led behaviour change in context, introduced at the outset of Section C, is discussed in greater detail here. The implications for service provision, practice and policy-making are also discussed, and an agenda for further research in this area is proposed. Finally, concluding remarks are made to draw together the main argument of the chapter.

### **Summary of key findings**

In order to draw conclusions from the study, a 'textual bridge' needs to be created to demonstrate the way in which meaning has been extracted from the study data (Trafford & Leshem, 2008). This section constitutes my attempt to create such a bridge by providing a summary of the key findings from this study and relating them to existing theoretical constructs. Drawing out connections between my data and relevant concepts in the literature has allowed me to raise the level of interpretation, as well as meeting the requirements of grounded theory in terms of extending the process of constant questioning that seeks categorisation, relationships and patterns within the data (Glaser & Strauss, 1967). I set out to demonstrate the way in which I have arranged my thinking into "ascending levels of abstraction between facts and conclusions" (Trafford & Leshem, 2008, p.128). The first level involves presenting 'facts' or ideas constructed during the fieldwork process that have enabled me to address the study objectives. The remainder of this section is organised into three categories that broadly encompass the objectives. These are: service user engagement and motivation (objectives 1 and 2); sustainable behaviour change (objective 3); and local health trainer models (objective 4). The final objective (5) – informing the future development and evaluation of the NHS Health Trainers Initiative – is addressed later in the chapter.

### ***Service user engagement and motivation***

The first study objective was to explore the factors that motivate people to seek support from a health trainer. Participants identified three broad categories of motivating factor, which were:

- i) Health improvement – often involving weight loss, as well as participants seeking to enhance their fitness levels and alleviate existing conditions

- ii) Health maintenance and illness prevention – more likely in older participants who were attempting to prevent further decline in their health
- iii) Psycho-social wellbeing – more common amongst younger participants and those seeking to reduce social isolation

This range of primary motivation is not unexpected, given that health is generally accepted as a relative state and one that is influenced heavily by the ageing process (Blaxter, 2004). The more interesting finding is that several participants in the service user sample could be described as socially isolated but most did not give this as their primary reason for seeking support. Instead, opportunities for social interaction were given as a key factor in their continued attendance at, and enjoyment of, the health trainer-led interventions. Theoretical literature from health psychology has shown that different explanations are needed to account for the actions of people who have not yet established an intention to change a particular behaviour (motivational theories), and those who are already motivated to change (action theories) (Michie *et al.*, 2005). Previous research suggests that the most frequent motivating factor for behaviour change is often a negative feeling, whereas changes such as weight loss are sustained largely by positive feelings about the self (Roberts & Ashley, 1999; Visram, Crosland & Cording, 2009). The initial impetus for change amongst participants in this study tended to come from a new diagnosis or reaching a specific 'milestone' weight. The majority of participants had previously attempted to make health-related behaviour changes and found these to be unsustainable for a variety of reasons. In this sense, seeking or accepting help from a health trainer was often described as a 'last resort'.

Access to the health trainer services was constrained, to varying degrees, by the implementation of different sets of referral and exclusion criteria (discussed further in the section on local health trainer models below). Users sampled from the service operating a professional-only referral system reported health improvement or maintenance as their primary motivation, as a result of having been referred for a specific physical health condition. Staff within services operating more of a demand-led system reported that the majority of users accessed their service for support relating to healthy eating and weight loss. However, these issues were often felt to mask underlying mental health, emotional and social needs, which had to be addressed before users could be expected to achieve their behaviour change goals. The limited literature on health trainers supports this finding in terms of the multiple issues presented by users and the challenges these create (South, Woodward & Lowcock, 2007; Dugdill *et al.*, 2009; Ball & Nasr, 2011). Excess weight is known to

be linked to mental health, with diagnoses of depression reported to be three to four times higher in morbidly obese individuals than those at a healthy weight (Greenberg *et al.*, 2005). Staff participants in this study felt that seeking help to lose weight may be seen as more 'acceptable' than admitting to issues such as depression, debt or poor literacy. This is in direct contrast to literature suggesting that overweight and obesity represent forms of discredited stigma – in terms of being immediately evident – whereas many social problems are concealable and therefore discreditable, using Goffman's definition (Goffman, 1990; Cossrow, Jeffery & McGuire, 2001; Rogge & Greenwald, 2004). Social problems conform more closely to Falk's definition of achieved stigma (i.e. stigma that is 'earned'), whilst weight gain was perceived more as a form of existential stigma (i.e. deriving from a condition over which a person has little or no control) (Falk, 2001). This was particularly the case when interviewees were asked to consider ways in which health trainers could engage with other people who might benefit from their help. When talking about the 'other', discussions tended to take on a judgemental tone as participants felt individuals were responsible for preserving their own health.

Users tended to externalise the reasons for their own 'unhealthy' behaviours by attributing them to factors that were felt to be out of their control; for example, weight gain due to illness, traumatic events or medication usage. This could suggest an external locus of control but, given that most users in the study sample were over 60 and had multiple health problems, it is arguably more suggestive of a realistic appraisal of their physical capabilities (Wallston *et al.*, 1976; Ajzen, 2002). Their definitions of health conveyed a sense of compromise and acceptance which was linked to age. In this sense, ill-health could be described as 'biographically anticipated', whereas events taking place earlier in life were more likely to represent 'biographical disruptions' (Bury, 1982; Williams, 2000). Most participants seemed to exhibit a high internal locus of control in that, after being made aware of the options available for adopting lifestyle changes, they were highly motivated to take action to improve their health. It is likely that there was a selection effect, in terms of highly motivated individuals choosing to access the interventions and also consenting to participate in this research. A commonly reported factor involved having free time as a result of being retired or out of work. Employment had previously represented a key source of physical and social activity for many participants, although it was occasionally associated with health-damaging effects such as stress and smoking. Work was also felt to contribute to a sense of self-esteem and identity or, in Pam's words, "*a bit of purpose in life*". This is reinforced by the research literature, which shows that employment generally promotes quality of life, wellbeing and social

inclusion, and that worklessness tends to be associated with poorer physical and mental health (Lewis & Sloggett, 1998; Waddell & Burton, 1998). For many users, accessing a health trainer-led intervention added structure to their lives and became part of a routine that contributed to building self-esteem.

The second study objective involved identifying barriers and facilitators to user engagement. Participants reported a number of personal, social and wider contextual barriers to accessing health promoting interventions or services. Illness and disability were key factors, with some users indicating that they felt let down or restricted by their bodies. There was a perception among these users that 'mainstream' health facilities were not able to accommodate their needs. The experiences noted in this study are similar to those of participants in 'exercise on referral' schemes, which tend to be perceived as better suited to relatively healthy and able-bodied individuals (Sowden *et al.*, 2008). Low confidence levels and feelings of isolation were felt to be key issues for people with disabilities and those from black and minority ethnic (BME) communities, who may experience additional barriers in terms of language, literacy and culture. Participants who lived alone tended to report feelings of loneliness and boredom, which were perceived as impacting negatively on their mental and physical health. However, living with and caring for others was also felt to be a cause of stress and anxiety. Mothers and wives often reported putting the needs of their families first and expressed a desire for "*me time*" outside of the domestic setting.

Childcare and transport costs were suggested as potential barriers to accessing health improvement interventions and facilities, along with the timing of activities. Participants also reported concerns about the cost of the activities themselves and a perceived lack of long-term funding for services. The wider economic and political context was felt to have an indirect impact on health and health-related behaviour in terms of placing constraints on public services and creating an atmosphere of uncertainty. Complexity and uncertainty are key features of contemporary, post-modern societies that need to be accounted for in interventions attempting to reduce health inequalities (Giddens, 1991; Popay *et al.*, 1998). Most services were perceived as being poorly equipped to meet participants' complex health and social needs, which were seen as distinct from their needs for health care and treatment. This has links with research on salutogenesis and a focus on health maintenance processes rather than disease processes (discussed further in the next sub-section) (Lindstrom & Eriksson, 2005; Harrop *et al.*, 2007). Many users felt they could not ask a health professional for lifestyle advice because their time is precious and

should not be 'wasted' on discussing non-clinical issues. This contradicts the assumption of role theory that patients do not make judgements regarding their clinicians' behaviour (Parsons, 1951; Roter & Hall, 1991). In a number of cases, participants reported negative experiences of health and social care agencies, which represented an ongoing source of stress and a barrier to accessing support. Participants also felt there was a lack of awareness of the health trainer role among local professionals and communities, which acted as a barrier to referral. Similar findings are observed in the existing literature on health trainers (South, Woodward & Lowcock, 2007; Simpson, 2008; Ward & Banks, 2009).

Participants identified several factors that facilitated engagement with the health trainer services. The first of these involved an individual's attitude towards maintaining their own health and wellbeing, which I have previously suggested was seen as a form of 'moral duty'. Personal choice and individual responsibility were emphasised, reflecting the individualistic ethos of the lifestyle approach advocated in recent UK public health policy (e.g. Department of Health, 2004; Department of Health, 2010b). The moral implications of this approach are that 'bad choices' are deemed to result from the self-determination of irresponsible individuals, rather than collective actions or structural factors (Clarke, 2005). In this study, participants tended to present themselves as 'good citizens' who made the 'right' choices most of the time, rather than making reference to the effects of poverty or low social status. The media and recent public health campaigns appeared to have had some influence, although users were more likely to attribute their current health beliefs to their upbringing. It was during childhood that they developed their food ideals and cooking skills, as well as their attitudes towards sport and fitness, which could act as facilitators or barriers to lifestyle change later in life. This was also true of the influence of significant others, who might provide support for the users' behaviour change attempts or inadvertently sabotage those attempts. The literature on weight management has shown that participants who receive support from a friend, partner or family member tend to have significantly better outcomes than those attempting to lose weight on their own (Wing & Jeffery, 1999; Burke *et al.*, 2002).

Social networks can act as facilitators of lifestyle change by acting as channels for the exchange of health-related resources and information. Word of mouth was seen as a key strategy for increasing referrals to the health trainer services, whether this resulted in an individual contacting the service themselves or requesting a referral. There were mixed views on whether encouraging professional referrals would enhance or reduce motivation amongst users, but it was generally felt that working

in collaboration rather than competition with other staff tends to produce beneficial effects. This finding is reinforced by the existing literature, with evaluations of local health trainer services highlighting the importance of partnership working to avoid conflict and duplication of effort (South *et al.*, 2006; South, Woodward & Lowcock, 2007; Ward, Brough & Power, 2009). The preferred engagement mode for users tended to be a personal recommendation from a trusted source, such as a friend or family member. It has previously been suggested that the majority of health-related activities, including diagnosis, discussing 'treatment' options and self-care, tend to take place within the lay sector (Kleinman, 1978; Levin, 1986; Scambler, 2002).

Characteristics of the health trainers themselves were felt to facilitate users' initial and ongoing engagement with the services, including interpersonal skills, the use of lay language and knowledge of the local area. Users particularly appreciated their informal, 'down to earth' approach and use of humour, although there were mixed views as to whether the health trainers should demonstrate evidence of following a healthy lifestyle themselves. Some felt that having someone to look up to enhanced their motivation, whereas others would be intimidated by a visibly fit or thin person. Previous research has shown that disadvantaged groups are more sensitive to the characteristics of intervention providers and that greater behavioural change is achieved when there is demographic and behavioural similarity between providers and recipients (Durantini *et al.*, 2006). This has links with communication and social learning theories (Bandura, 1998; Foulger, 2004). Participants in the present study felt it was important that health trainers had an understanding of what it was like to live in their communities and were able to offer tailored interventions that fit into their existing lifestyles. An additional factor in users' ongoing engagement with health improvement interventions involved the provision of free or low cost activities, which was particularly important for individuals on low incomes.

### ***Sustained behaviour change***

The third study objective was to identify perceived barriers and facilitators to the adoption and maintenance of health-related behaviour changes by users of health trainer services. It was also necessary to take into account other changes, such as debt management, enhancing employability or social network formation, which may be grouped under the banner of 'social capital' (Putnam, 2000). Health trainers relied on their expertise – drawn from a combination of their formal training and personal experience of living in the local area – to make judgements on the level



and type of support required by individual users. In some cases they would present with a “*double agenda*”, whilst in others new issues would emerge over the course of the intervention. Interventions were felt to be most effective and acceptable when they were able to accommodate these issues in a holistic fashion. This is in direct contrast to many professional-led interventions, which tend to decontextualise lifestyle factors by ignoring everyday reality and failing to address how these factors interrelate (Springett, Owens & Callaghan, 2007). The lay status of health trainers appeared to give them greater insight into the function of ‘unhealthy’ behaviours for their service users. These findings are reinforced by the literature suggesting that, similar to models of professional or expert knowledge, lay people assess their health risks by conducting routine observations and discussing cases with others in their social networks (Davison, Davey-Smith & Frankel, 1991; Popay *et al.*, 1998; Lawlor *et al.*, 2003).

Users entered the interventions with varying levels of knowledge, developed through their previous health experiences and behaviour change attempts, as well as having learned vicariously from the experiences of others. Those with a high level of baseline knowledge required practical support in its implementation, whereas those with low levels of knowledge initially required basic health education. Health trainers were generally felt to deliver personalised activities that build on this knowledge by “*starting from the base*”. This is congruent with current ideas about health literacy, defined as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health” (World Health Organisation, 2009). It also relates to asset-based approaches in public health that recognise and attempt to harness the existing resources within communities, rather than treating people simply as consumers of health care (Charlton & White, 1995; Nutbeam, 2000; 2008). Users particularly appreciated receiving personalised information that was delivered in an easy-to-understand but non-patronising way. The use of practical demonstrations and having time to ask questions were felt to be key factors. Participants reported gaining knowledge and skills that were sustained at 12 months, either with or without ongoing reference to the resources provided by the health trainers. Examples were given of users consciously choosing ‘unhealthy’ options but being aware of these choices and seeking to correct them.

Study participants identified a number of theory- and evidence-based behaviour change strategies employed by health trainers, including the use of goal-setting, action planning and self-regulation techniques, which derive primarily from the



theory of planned behaviour (Ajzen, 1985) and self-regulation theory (Carver & Scheier, 1998). The use of one-to-one approaches, even within group settings, was felt to facilitate the setting of personalised goals and give users ownership over their own behaviour change process. Food diaries were often used to encourage people to monitor their own lifestyles, with mixed success. Most preferred to rely on the health trainer to monitor and correct their behaviour, although some continued to maintain a food diary once the intervention had been completed. Health trainers also draw on social cognitive theory (Bandura, 1998; 2004), in terms of building self-efficacy (i.e. confidence that a person can change their behaviour) and outcome expectancy (i.e. expectations that changing their behaviour will lead to the desired outcome). Low confidence was an issue for many users and having someone acknowledge the validity of their concerns was an important first step in the behaviour change process. The findings of this study exhibit similarities with the literature on salutogenesis, which emphasises the importance of resilience and coping in adapting to difficult circumstances and experiences (Lindstrom & Eriksson, 2005; Harrop *et al.*, 2007). This approach represents an alternative to a pathogenic view of health and has gained currency in recent decades as a potential explanation for social inequalities in health (Charlton & White, 1995; Harrop *et al.*, 2007).

Service users and health trainers reported a range of positive outcomes, which map onto Nutbeam's (1998) model for the evaluation of health promotion interventions (discussed in Chapter 3). The status of LHWs as beneficiaries of lay-led interventions is recognised in the existing literature (for examples, see: Watkins *et al.*, 1994; Viswanathan *et al.*, 2009; Ayala *et al.*, 2010) but is rarely seen as a key outcome of these interventions. In the case of health trainers, measuring increases in the capacity and capability of the public health workforce is a core element of the national data collection and recording system (DCRS) (Department of Health, 2007). However, this is measured in terms of the numbers and demographics of people recruited from target populations, rather than capturing their knowledge gains and lifestyle changes. The DCRS focuses on health-related behaviour changes made by service users, which were identified in this study. A key change for many users involved adopting a more structured lifestyle; for example, regularly eating breakfast and planning meals in advance. Small changes were felt to have a big impact on the lives of individuals, in terms of enhancing confidence, resulting in further changes and a cascade effect within families and communities. Many participants reported setbacks and 'taking a break' from their efforts to follow a healthy lifestyle, often due to personal illness. This is unsurprising given the age and socioeconomic position of those within the user sample.

The cost of health and fitness activities was another key factor in the ability to sustain any lifestyles changes. Options that were perceived to be good value for money were sought out, and it was also important to find an activity that fitted with the user's existing lifestyle or habitus in order to enhance sustainability. Habitus is defined as the norms and practices of particular social groups; for example, Sian's insistence that she hates gyms and finds them boring is likely to be a commonly held view within her community (Bourdieu & Wacquant, 1992). The findings of this research support the assumption that health trainers are more in tune with the habitus of local people than health professionals and better able to negotiate their notions of self and identity as a result of their shared cultural norms and experiences (Springett, Owens & Callaghan, 2007). Participants reported building trusting relationships with their health trainers, who they perceived as "*one of us*" due to their lay status. These relationships gave users further motivation to sustain their behaviour change attempts, to avoid disappointing the health trainer. However, some challenges were identified as resulting from the blurring of the boundaries between staff and service users. Shared cultures and social networks are known to create the potential for conflict, concerns regarding confidentiality and feelings of vulnerability amongst lay workers and users (Whitemore *et al.*, 2000; Elford *et al.*, 2002; Daniels *et al.*, 2005). This study reveals an additional dimension of vulnerability not found elsewhere in the literature; that is, the appearance and lifestyles of the health trainers being more open to scrutiny than those of health professionals. A likely contributing factor is their liminal status (i.e. one that is socially and structurally ambiguous) resulting from occupying a position between stranger and friend, which is not uncommon amongst similar paraprofessionals and community-based workers (Zadoroznyj, 2009).

As part of strategies to prevent users from becoming dependent on their health trainer, efforts were made to foster interaction and networks between users. The provision of opportunities for social support and social comparison are recognised behaviour change strategies (Michie *et al.*, 2005; Abraham & Michie, 2008). Examples of upward and downward comparisons were found in this study, and participants also seemed to experience psychological benefits from supporting and observing success in others. Many users used the term '*camaraderie*' to describe the atmosphere created during the health trainer-led interventions. There were mixed views on the importance of being with people from a similar background and also on the potential benefits of encouraging competition between users. Instead, mental health benefits were reported from talking to and being listened to by other people, which represented a key outcome for socially isolated individuals in terms of

*“being part of society”*. At the 12 month interviews, some of these relationships and networks had been sustained over time. However, several participants reported finding it difficult to maintain relationships beyond the end of the health trainer-led interventions. In a minority of cases, this had resulted in participants feeling increasingly isolated, suggesting that the intervention might have a disempowering effect. It was recognised that these ‘softer’ outcomes tend to be valued less by health services, and also that any behaviour changes made during the intervention can be reversed without appropriate follow-on support. Previous studies have shown that regular meetings and ongoing contact with users can help in relapse prevention, and that face-to-face support from a lay worker is often more effective than advice delivered over the telephone (Graffy *et al.*, 2004; Barton *et al.*, 2011).

A key enabler of sustained behaviour change was users having access to facilities that were able to accommodate their specific needs. There was a reluctance to access commercial or local authority gyms, which were perceived as less welcoming and ‘cosy’ than the health trainer-run gyms. This was a particular issue for participants with physical or sensory disabilities, who had concerns about feeling unsafe or intimidated in ‘mainstream’ fitness facilities. Previous research suggests that older and medically vulnerable adults tend to be fearful of pain that may occur during exercise, whereas participants in this study were more fearful of the potential for stigmatisation and psychological discomfort (Seefeldt, Malina & Clark, 2002). Users highlighted specific characteristics of the intervention settings that were felt to enhance accessibility and inclusivity. These included the size of the gyms, their aesthetics, and the facilities on offer. Location was a key issue for users and staff, in terms of being in a familiar area that could be accessed by public transport. It was also important for disabled users to be able to take part in health promoting activities in non-clinical environments. The findings of this research demonstrate the perceived impact of place and space on behaviour, which is often missing from descriptions of health improvement interventions (Jones & Moon, 1993).

### ***Local health trainer models***

An additional study objective was to compare and contrast the experiences and perceptions of participants sampled from different models of local health trainer service provision. In order to preserve the anonymity of the participating individuals and organisations, it has not been possible to describe in detail the three services used as the focus of this research. However, it is clear that there are a number of

similarities and differences between the models. Each service has its foundations in the use of local knowledge and recruitment from marginalised communities to a greater or lesser extent. It was shown in Chapter 2 that LHWs tend to undertake a range of health promoting activities, but that the common factor is shared social or cultural characteristics with the local community (Earp & Flax, 1999; Moore & Earp, 2007). Managers in this study emphasised the importance of recruiting staff based on their interpersonal skills and experience within local communities, as opposed to formal qualifications and work experience. For example, staff in Site C had the highest level of qualification as gym instructors, yet they were clear that “*you can have 1,000 qualifications but... you need to be able to speak to people and have time with people and listen to people.*” Health trainers in all three sites received the same initial training on individual behaviour change techniques and community development approaches. However, there were major differences between the services in terms of the degree of emphasis on community development. LHW programmes have previously been described as residing on a continuum from informal natural helping to more formal, structured approaches that are more appropriately termed ‘paraprofessional’ rather than ‘lay’ (Eng, Parker & Harlan, 1997). This has implications for the primary modes of engaging and working with service users, as well as the way in which outcomes are defined and measured.

Sites A and B were described as offering a demand-led service, although they were able to target their services through the use of particular engagement strategies. Staff within both of these sites gave examples of referrals generated through opportunistic contacts, which was seen as an appropriate way of engaging with individuals who could be described as hard-to-reach using other approaches. Previous research has suggested that ‘snowball’ sampling and the use of existing social networks can prove advantageous in terms of accessing marginalised and disadvantaged groups (Atkinson & Flint, 2001; Hemmerman, 2010). In contrast, access to Site C could be gained only by professional referral, and a 12-week limit on the gym-based intervention was also introduced during the data collection period. There were mixed views on these changes, with staff feeling that there had been a shift from “*quantity to quality*”, while users described the changes as “*short sighted*” and resulting in a loss of flexibility to tailor interventions to individual needs. There are similarities between this model and exercise referral schemes, which show promising effects but lack a robust evidence base (Isaacs *et al.*, 2007; Sowden & Raine, 2008). Users sampled from Site C were more likely to be older and have multiple health problems, which could not be ‘fixed’ with a 12-week intervention. However, there was agreement amongst staff in all three sites that the

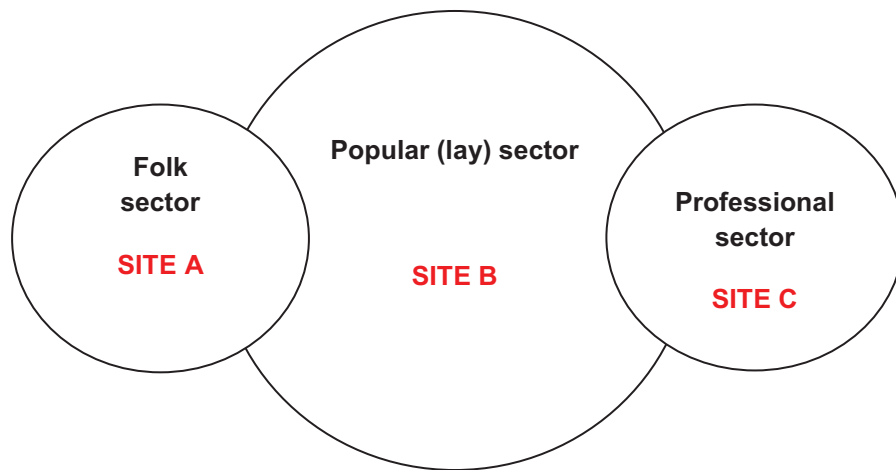
purpose of health trainers was to provide short-term support and empower people to take responsibility for their own health.

There were heterogeneous views on what constitutes success for each health trainer service. All three research sites used the DCRS to monitor progress in terms of goal-setting but Site B also placed importance on gathering case studies to provide evidence of progress in terms of the underlying determinants of health. Some important outcomes were felt to be difficult to measure, such as facilitating rapport and friendships between service users, fostering independence, and instilling a sense of pride or self-esteem. Gaps in the existing evidence base in terms of these 'soft' outcomes were also identified in Chapter 3 (Nutbeam, 1998). Users accessing a gym-based intervention were more likely to report weight loss and physical health outcomes, whereas activities such as walking groups and art classes were felt to enhance mental health and wellbeing. The feasibility of the delivery model and building community capacity through the employment of local people as health trainers were identified as key outcomes of the overall initiative. Examples of former service users gaining employment as health trainers were found only in Site B, yet this was perceived to be a key asset of the delivery model. Staff in this site credited the community development approach with delivering outcomes such as educating other professionals and organisations, and making a contribution to a reduction in health inequalities.

The three local health trainer models can be mapped loosely onto Kleinman's (1978) framework of health systems as social systems. An overview is given in Chapter 2. Kleinman developed this framework for use in cross-cultural studies but it can also be applied in the present study due to the differences between the research sites in terms of social and institutional cultures. Site A is located in the folk sector due to the model of recruiting health trainers from the local community and training them to deliver one-to-one interventions that mimic professional-led approaches, whilst drawing heavily on lay knowledge. Health trainers within Site B spend the bulk of their time in the community and utilise their own social networks to engage with users, therefore this site is located in the lay sector. Service C, which involves highly qualified health trainers and follows a medical referral-only model, is located in the professional sector. See figure 19 for an illustration. This framework helps in understanding the diversity in objectives between the health trainer models, their varying degrees of integration into local public health systems, and differences in staff and service user experiences. Kleinman stated that each sector has its own explanatory model and that conflicts are more likely when the differences between

these models are greater (Kleinman, 1978). However, the findings of my research suggest that conflict within local health systems was reduced when there was less similarity between health trainers and professionals. Health trainers in Sites A and B were seen as a complementary resource by other teams and agencies, whereas staff in Site C mentioned a lack of partnership working and were more likely to be competing with other services for the same targets. Use of this framework represents a new way of conceptualising health trainers and similar lay-led interventions, as well as having implications for practice and further research activities. These issues are discussed later in the chapter.

**Figure 19: Applying Kleinman's framework to health trainers**



### **Appraisal of the research design and methods**

The section above has provided a summary of the study findings and begun to make connections with the existing theoretical and empirical evidence base. This provides a foundation from which to draw conclusions about the meaning and implications of the data (Trafford & Leshem, 2008). In the following section, I critique my chosen methodology to demonstrate the rigour of the study and justify my claims about the relevance of the findings. There is considerable debate over the nature of the knowledge produced using qualitative methods and how the utility and quality of such research should be judged (Mays & Pope, 2000). I employ the criteria identified by Lincoln and Guba (1985), which are shown in table 11 and contrasted with those typically employed to appraise quantitative studies. Critics have argued that the two sets of criteria are indistinguishable in terms of assuming the existence of an independent reality (Hoepfl, 1997). The subtle realist stance employed in this study accepts that a social world exists independently of the human mind but that



this is only accessible via my interpretation of the participants' accounts. Therefore, it should be possible to select the most suitable interpretation of the external social world from those available (Hoepfl, 1997). It is hoped that making use of these criteria will help to reduce the likelihood of the research being dismissed as biased or lacking validity. The second half of this section represents an extension of the reflexive approach introduced in Chapter 5.

**Table 11: Criteria for judging quantitative vs. qualitative research**

<b>Conventional terms</b>	<b>Naturalistic terms</b>
Internal validity	Credibility
External validity	Transferability
Reliability	Dependability
Objectivity	Confirmability

### ***Strengths and limitations of the study***

This study had a number of limitations. Firstly, the findings relate to the views and experiences of participants drawn from three health trainer services within the same Strategic Health Authority (SHA), and it may not be possible to apply them to other services within the SHA or more generally across England. The use of a qualitative research approach also limits the ability to generalise the findings to other organisations or settings. However, a key strength of grounded theory is the emphasis on developing a substantive or formal theory, rather than stopping at the point of creating rich understandings of specific lived experiences (Glaser & Strauss, 1967; Glaser, 1978). The use of rigorous, systematic procedures (such as coding and memo-writing) has helped to ensure that the theory developed in this study remains close to the data generated within the specific research settings. At the same time, the outcome of these procedures is a theory from which hypotheses can be developed and tested in other contexts. Continuing the search for evidence to disconfirm the emerging theory until the point of data saturation was reached means that I can be reasonably sure that the theory 'works', in terms of fitting the situation and making sense of the participants' experiences (Dick, 2005).

Secondly, the relatively small sample sizes of 18 staff and 26 service users could render the study open to criticism in that the participants may not have been representative of all individuals involved in delivering or accessing health trainer



services. Within a naturalistic paradigm, selective sampling is more suitable than representative sampling because it increases the likelihood that the full array of multiple realities will be uncovered (Lincoln & Guba, 1985). Furthermore, credibility in qualitative research depends less on sample size than on the richness of the information gathered. The use of a longitudinal qualitative approach allowed for the collection of data of sufficient depth to address the study objectives, and the findings are supported by evidence from the existing empirical and theoretical literature. The sample sizes decreased over time (to 10 staff and 21 service users), although the level of attrition was not as great as anticipated given that participants were drawn from 'hard-to-reach' populations. The maintenance of a diverse user sample is a particular strength of the study, allowing for an in-depth exploration of the behaviour change process in different population groups. For some users, the offer of a £5 gift voucher at each interview may have been a factor in their ongoing engagement with the study. Debates in the literature on participant payments centre on freedom of choice and the potential for bias in study findings (Head, 2009). The maximum payment of £20 in this study was not believed to be large enough to represent a form of undue influence or coercive offer. Instead, it was recognised that payments can offer benefits in terms of increasing study recruitment and acknowledging the contribution of participants, particularly where the target population is characterised by low socioeconomic status (Russell, Moralejo & Burgess, 2000).

In positivist research, studies are judged primarily on the extent to which the findings accurately describe reality and therefore demonstrate internal validity. Furthermore, the ability to generalise these findings across different settings demonstrates external validity (Hoepfl, 1997). Although generalisability is not possible when using qualitative approaches, transferability need not be a problem if comparisons are made with similar people, settings and times (Johnson, 1997). It was therefore considered important in the written account of this study to provide detailed information regarding the participants, contexts, data collection and analysis, to enable readers to decide how far and to whom the findings may be transferred. However, some detail has been excluded in order to preserve the anonymity and privacy of the participants and organisations involved. When asked to suggest a pseudonym for themselves, several participants requested that their real name be used in materials produced from this research. Whilst I wanted to respect their preferences, I was concerned that identifying some individuals might compromise the anonymity of others and carefully explained that the use of pseudonyms is a research convention. The implications of this convention are discussed in the social science literature (Grinyer, 2002; Guenther, 2009). Grinyer

(2002) refers to a study of the effects on families when young adults are diagnosed with cancer, in which a mother described the reference to her dead son using a pseudonym as a feeling like a betrayal of his memory. Participants in the present study did not feel as strongly about this issue but it represents a challenge to the accepted norm that anonymisation is always in their best interests.

The credibility of a qualitative research report relies heavily on the confidence that readers have in the researcher's ability to be sensitive to the data and to make appropriate decisions in the field (Patton, 1990). Prolonged engagement with the participants, along with iteration between data collection and interpretation, allowed me to develop a deep and complex understanding of the phenomena under study. However, this approach also introduced bias in terms of people modifying their behaviour as a result of participation in the study. For example, a number of users admitted that my visits represented an excuse to "*keep behaving themselves*" and (jokingly) reported concerns that they would have no reason to maintain the lifestyle changes at the end of the study period. In experimental studies, this is referred to as the Hawthorne effect and represents a cause for concern in terms of influencing the measurement of behaviour change (McCarney *et al.*, 2007). In this study, it provided additional insight into the behaviour change process and the users' perceived need to be monitored in order to sustain motivation. Maintaining a robust audit trail and memo-making enabled me to separate my responses from those of the participants and 'locate myself in the data', thereby enhancing the credibility of the study. Using extracts from participants' verbatim accounts also increases dependability by grounding interpretations within the data (Johnson, 1997).

The final criterion in table 11 is confirmability, referring to the degree to which a researcher can demonstrate the neutrality of their interpretations (Hoepfl, 1997). Various strategies were used to enhance the trustworthiness of my interpretations, including micro-analysis using NVivo, respondent validation and analytical triangulation (described in Chapter 5). Techniques associated with grounded theory, such as theoretical sampling, line-by-line analysis and constant comparison, also helped to ensure that the emergent concepts were grounded in and supported by the data. These techniques were used in combination to check, refine and develop my ideas about the emergent findings as the data were being generated. For example, the idea that 'life is too short to worry about health' came from analysis of an initial user interview and was included as a prompt in the month 6 interviews with all users. This disconfirmed the assumption that people living in disadvantaged areas tend not to prioritise health. At the final interview, participants were asked to

review a summary of their narratives to verify the accuracy of the data and validate their experiences. In this sense, participants were treated as experts in matters of their own ontology and epistemology (Chiovitti & Piran, 2003). Feedback demonstrated that these narratives accurately represented what was said and were true to their lived experience of receiving support from a health trainer and making behaviour changes. It is not possible to say whether similar findings would arise from research involving other types of lay health worker. Furthermore, this study had a 12-month follow-up period and therefore it is not known what impact, if any, the lay-led interventions had beyond this period. Notwithstanding these limitations, this represents the first in-depth longitudinal qualitative study of health trainers and their service users, enabling them to articulate their constructions of context, personalisation and reciprocity in the behaviour change process.

### ***Reflections on the process***

In Chapter 5, I provided a transparent account of the processes involved in data generation by detailing methodological issues arising during the study and how these were dealt with. The following sub-sections extend this discussion to include my feelings and reflections on the whole research experience. This constitutes the reflexive approach commonly employed by qualitative researchers to validate their practices (Pillow, 2003; Lambert, Jomeen & McSherry, 2010).

### ***Reflections on the study sample***

Recruiting service users to the study and maintaining this sample was an aspect of the research that I anticipated would be difficult. It took some time to identify users who met the study inclusion criteria and were willing to take part in the research. However, once the initial interviews had been conducted, I was surprised that the majority of participants were more than willing to take part in subsequent interviews. This contradicts much of the existing literature, which suggests that sample attrition tends to be a major problem in longitudinal qualitative research and particularly with disadvantaged social groups (e.g. Blane, 2005; Murray *et al.*, 2009). The reasons for the high retention rate observed in this study might include participants tending to have chronic rather than acute health problems and having free time as a result of being retired. I would suggest that being introduced through their health trainer, and therefore being seen as a 'friend of a friend', was also a factor. In fact, there were several cases where an individual joined the study after it was mentioned to

them by a friend or family member who was also a participant. This prompted them to return their reply slips and also helped to relieve any concerns they might have about the research. I am confident that some participants actively enjoyed the process and were keen for others to have the same enjoyable experience. In some cases, users were looking for an outlet for their concerns about changes to the health trainer service; for example, the gym-based service moving to a 12-week intervention. Those who had used this service for a number of years often became upset during our interviews and, although I made it very clear that I did not work for the health trainer team, they seemed to feel that I might be privy to some 'inside information'. On one occasion a participant pleaded with me to put her case to the manager, which resulted in me contacting the manager and suggesting that she might want to speak to this woman herself. Although my intentions were good, in hindsight I recognise that this went beyond my remit as a researcher and I should have made more effort to distance myself from these situations.

In comparison with the service user sample, I found it more difficult to develop a rapport with some participants in the staff sample. There were particular challenges associated with Site C, some of which were highlighted in Chapter 5. I had not previously met the manager or health trainers in this site, whereas I was already known to most team members in Sites A and B. The challenge of 'starting from scratch' in terms of building relationships with staff in Site C were compounded by the aforementioned service developments and concerns about negative feedback from users. If I were to conduct this research again I would be more aware of the implications of these developments and ensure that all parties are clear that my role is to remain impartial in collecting feedback from users and reporting this (anonymised) information back to the team. It was difficult to convey this to the health trainers in Site C because the manager expressed a strong preference to act as the channel for any information about the study herself. I had the most contact with the health trainers within Site B, partly because they are the largest team and partly due to their location (i.e. being the shortest travelling time both from my home and the University). This made it relatively easy to 'pop in' to attend meetings and events or drop off information, which follows the approach recommended by Hemmerman (2010) of maintaining ongoing, informal contact with longitudinal study samples. My relationships with the staff in Site B seemed to be the most equitable; for example, they felt comfortable enough to ask me to locate and send them relevant research literature, which made me feel more comfortable about taking up their time to conduct my study. It was important that the participants did not see me as someone who would take from them without giving anything back. Overall, my

approach to sample recruitment and retention was successful in terms of developing mutually beneficial relationships with participants.

*Reflections on data collection*

Although I had prior experience of conducting one-to-one research interviews, my confidence grew over the course of this study and I was able to adopt an increasingly conversational style. I was aware of using colloquialisms and informal language, which caused some embarrassment when reading the interview transcripts! However, I feel this helped in encouraging the participants to see me primarily as an 'ordinary' person from the north east, rather than an academic researcher. Presenting a natural front is one of the '10 commandments of interview preparation' put forward by Berg (2001), along with being respectful, appreciative and practising active hearing. Furthermore, it is important to avoid using technical terms with lay participants. An unanticipated finding in this study was that most users were seemingly unaware of the 'health trainer' label and instead referred to the staff either by name or as instructors (if they delivered gym-based interventions). It is recommended that researchers use expressions from the lexicon of the participants' experience and reflect these back when asking for further detail, but using the health trainers' names sometimes made my questions feel overly personal (Kvale, 1996; Charmaz, 2003). I also avoided referring to older participants by their first names, unless they explicitly asked me to, as a sign of respect. These participants seemed to enjoy sharing their stories with someone from the 'younger generation' and I believe this helped in generating additional data, as they assumed that I would not be familiar with many of their reference points. There were also assumptions made about my health; for example, several individuals commented that I was too young and 'skinny' to know what it is like to have multiple health problems or to struggle with my weight. Regardless of whether or not these assumptions are true, they resulted in participants making an extra effort to help me to understand what it is like to be overweight or have particular health concerns.

I chose to use a longitudinal qualitative research (QLR) approach to explore the processes involved in making and maintaining behaviour changes over a 12-month period. However, the interview timings did not map onto the intervention entry and exit points, and so I was not able to explore short- (3 month) and medium-term (6 month) outcomes for all service user participants. Instead, the QLR approach enabled me to foster trust with users and led to more in-depth discussions about

their behaviours and biographies. Using the metaphor of peeling an onion, each interview was like removing another layer and moving closer to the core of their personal experience. I believe that a one-off interviewing approach would not have generated such rich data, in terms of being able to explore how behaviours are influenced by the wider social and economic context across the life course. The use of life grids and behaviour change prompts helped to generate additional data whilst keeping the discussions focused. However, I disagree with those who suggest that life grids allow interviews to remain flexible, whilst enabling interviewees to improve the accuracy with which dates are remembered (Parry, Thomson & Fowkes, 1999; Blane, 2005). In this study, participants often struggled to cross-reference the dates of any changes in their health or lifestyle against dates in their personal life and events in the external world, with one participant likening the grid to the UK citizenship test. Furthermore, I am not convinced that a technique developed for use in studying variations in physical health conditions is appropriate for exploring issues such as depression or obesity. I was uncomfortable in asking participants to be specific about dates of onset and the potential 'causes' of these problems.

On the whole, the use of grounded theory helped in giving participants the freedom to identify and discuss their own priorities. I tried to avoid asking questions that might upset them but there were times when they clearly wanted an opportunity to discuss difficult and upsetting issues. Although I sometimes felt out of my depth, it was good to know that participants trusted me enough to share their personal stories. For example, one user told me in detail about being sexually abused as a child, which left me feeling quite distressed. I called the next day to make sure she was okay and to ask if there was any way I could help (by providing information on relevant services), but she told me that talking to someone impartial had helped enough. At our next interview I was presented with flowers and chocolates to say 'thank you'. This helped to alleviate my concerns about exploiting vulnerable people for my own personal gain. It also provided me with an insight into the issues that health trainers deal with on a regular basis. There were times when I became concerned that participants were providing me with misleading information in order to avoid embarrassment and show themselves in the best possible light. One user told me repeatedly that he had stopped drinking some years previously, yet his health trainer confided that he had turned up to her group sessions whilst intoxicated and upset some of the other members. Participants (and researchers) inevitably manage their self-presentation during the research process, but I still found this experience confusing and upsetting. My way of dealing with this was to create a free node in NVivo called 'self-presentation' and code any data that I felt



obviously suggested participants were trying to manipulate the way they were seen by others. These data were then considered during the analytical process.

### *Reflections on data analysis and theory development*

A major challenge encountered during analysis was dealing with the sheer quantity of data generated in this study (a total of 116 interview transcripts plus fieldnotes). Despite having no prior experience of using NVivo qualitative analysis software, I decided early in the process that it would be the most effective way of managing the study data. I was aware that some authors have expressed concerns about the potential for this type of software to “turn qualitative research into a rigid, automated process that neglects the role of human interpretation and reflection” (Hutchinson, Johnston & Breckon, 2010, p.285). Becker (1993) suggests that the use of computer programmes to identify core categories is one of the ‘pitfalls’ of grounded theory studies. However, I disagree that using NVivo necessarily means that an analyst cannot remain sensitive to the data. Instead, I recognised its capacity for storing, sorting and retrieval, which I felt would enhance the efficiency and validity of the analytical process. I began by micro-analysing the data through line-by-line coding, but found this to be extremely time-consuming and it also led to confusion as meanings became lost in focusing on the minutiae of the data. I agree with Glaser’s view that this produced an ‘over-conceptualisation’ and reverted to his approach of identifying key constructs rather than individual words or sentences (Glaser, 2002). Yates (2003) has also expressed concerns that coding can result in fragmentation and de-contextualisation of qualitative data. The technical logic of this approach is that every case is considered in the same way and evidence can be provided that the data have been thoroughly searched. However, I found it challenging to code the data at this level, while trying to preserve the biographical meaning and social context of participant stories.

It was recognised that analysing all transcripts relating to each participant would only provide a sense of individual experience, whereas analysing across the participants at each time point would build cross-cutting themes at the expense of individual contexts (Murray *et al.*, 2009). I decided to focus initially on analysing across the study sample to generate emergent categories, and then piece together narratives for each participant towards the end of the process. This allowed me to fulfil the requirements of grounded theory, as well as being able to share preliminary findings with the health trainer teams after each round of service user interviews.



However, it was impossible to ensure that all user experiences were reflected in the cross-cutting themes and, although this was inevitable, it felt like a betrayal of the participants who expected their stories to be heard. I also experienced some difficulty in attempting to stay close to the data but going with my instincts, which is a common insecurity amongst novice grounded theorists (Charmaz, 2003). I was acutely aware of the need for creativity and intuition, in addition to intellectual rigour and continuous questioning during the theory-building process. There were times when I lacked confidence in my ability to meet these requirements but, through a continuous process of inductive and deductive reasoning, I feel I was able to develop a substantive theory that addressed the main concern of the study participants. The implications of this theory are discussed in the following sections.

### **Theoretical implications**

In this section, I extend the discussion of the study findings by highlighting the unique contribution to existing knowledge. I have sought to demonstrate the way in which this study addresses the gaps in the evidence base identified in Chapter 2. The theoretical implications of the research are described, with particular consideration given to the influence of existing theories of behaviour change, natural helping and professionalisation. A critical analysis of the theory of lay-led behaviour change in context is undertaken and the three emergent categories (contextualising, personalising and reciprocating) are highlighted throughout the discussion.

### ***Comparison with behaviour change theory***

A key issue addressed in this study which tends not to appear in the existing literature is fidelity (i.e. the extent to which an intervention is delivered as originally intended). Chapter 3 highlighted the fact that most studies fail to provide any description of the specific intervention components, whilst acknowledging that lay workers engage in a wide range of health-promoting activities. Evaluations of health trainer programmes have tended to reference the NHS health trainer handbook without providing evidence to demonstrate that these techniques and resources are used in practice. The findings presented here address this gap in the literature by providing a rich description of the health trainer interventions. Chapter 7 sets out the main intervention components, which are based on evidence and theory from the behaviour change literature (Michie *et al.*, 2005; Abraham & Michie, 2008). For example, participants emphasised the importance of goal-setting and making small

changes towards achieving those goals, which derive from control theory (Carver & Scheier, 1998) and social cognitive theory (Bandura, 1998). The latter states that achieving smaller goals can improve an individual's sense of self-efficacy, and that individuals with higher self-efficacy are able to recover more quickly after they experience setbacks in working towards longer-term goals. Study participants described this process without making reference to self-efficacy, indicating the existence of a valid lay theories of behaviour change in parallel to professional or 'expert' understandings (Davison, Davey-Smith & Frankel, 1991).

Social cognitive theory has links with social learning theory, i.e. learning based on observing and modelling the behaviour of others, which is then reinforced by elements of the social and physical environment (Bandura, 1998; 2004). Evidence of social learning was found throughout this study, both in terms of participants' experiences during the health trainer-led interventions and in other areas of their lives; for example, modelling the behaviours of parents and peers during childhood, or vicarious learning about health-related behaviours. Users gave examples of observing others who did not follow the lifestyle recommendations and yet apparently suffered few health problems, which supports the 'Uncle Norman' hypothesis<sup>26</sup> described in the literature on lay epidemiology (Davison, Davey-Smith & Frankel, 1991; Hunt & Emslie, 2001). Frances described a fear of bullying and stigmatisation within commercial gyms as a result of negative treatment reportedly experienced by friends and relatives. Communication theory reinforces the idea that people are more likely to pay attention to information delivered by someone they respect (Foulger, 2004). Users tended to access the health trainer-led interventions following a personal recommendation and then went on to recommend the health trainer service to others, providing an example of diffusion of innovations theory in action (Rogers, 1983).

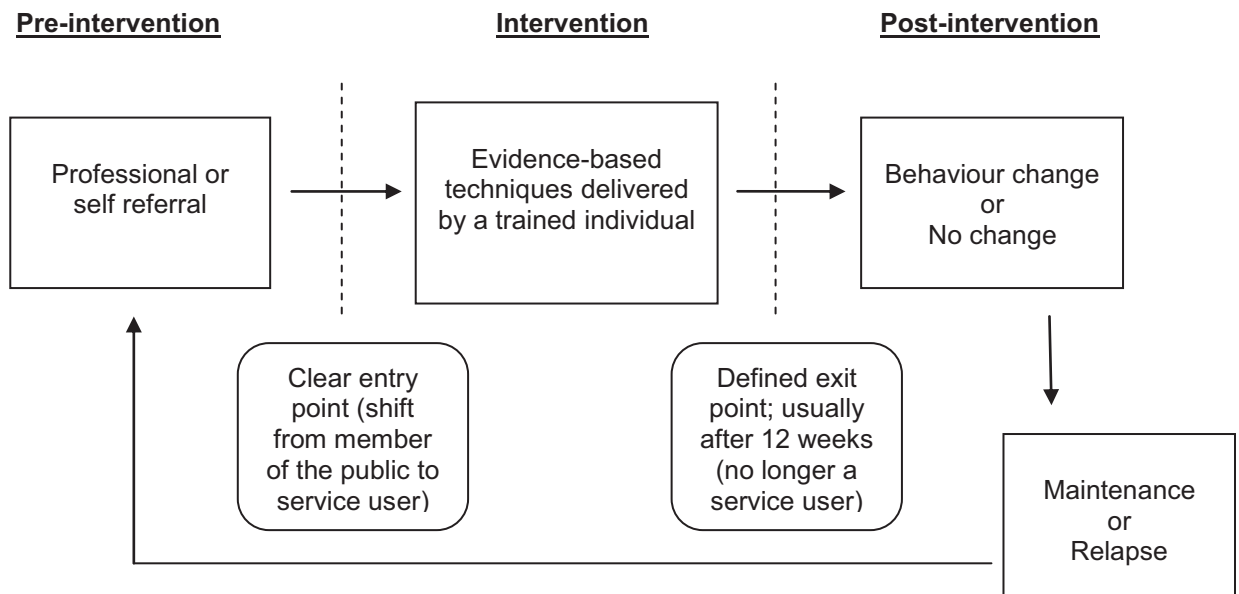
The findings of the present study add to existing behaviour change theory by emphasising the complex nature of lay-led behaviour change interventions. For example, social learning theory implies that individuals benefit from imitating or modelling positive behaviours exhibited by their peers. In other words, behaviour change can be achieved with the use of positive role models. This study suggests a more complex situation, whereby individuals benefit from making downward as well as upward comparisons. There is an element of competition, in terms of wanting to be 'better at health' than their peers, and also altruism, in terms of experiencing

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<sup>26</sup> This is the idea that everyone knows somebody who is physically inactive, overweight, drinks and/or smokes heavily, yet inexplicably survives to a ripe old age (i.e. Uncle Norman).

psychological benefits from assisting others. People may feel intimidated by someone who is perceived to be significantly fitter or healthier than them, although there were mixed views on whether or not the lifestyle and appearance of the health trainer was relevant. Users generally felt they were supporting the health trainer services as part of a mutually beneficial relationship. Although the characteristics of intervention providers are acknowledged as important in the behaviour change literature, little attention has been paid to changes in these individuals as a result of delivering the interventions (Durantini *et al.*, 2006). This study has identified outcomes for health trainers and local organisations as well as users, which add complexity to attempts to evaluate health trainers' activities. Logic models are increasingly being used to guide intervention development and evaluation, by linking inputs and activities to outcomes (Conrad *et al.*, 1999; Hardeman *et al.*, 2005). Figure 20 below shows a simplified logic model for a typified health trainer-led intervention based on traditional assumptions of behaviour change.

**Figure 20: Basic logic model of health-related behaviour change**



This diagram represents an archetypal behaviour change model that is unlikely to exist in reality, yet it forms the basis for much of the empirical and theoretical literature. For example, psychological theories of behaviour change tend to be based on the assumption of subjective universalism, i.e. people as self-interested individuals who proceed towards the goal of positive health by virtue of being free to make voluntary choices (Clarke, 2005). Deviations from this course are attributed to

health beliefs, which have tended to be evaluated for their proximity to empirically 'correct' biomedical knowledge (Good, 1994). Literature from medical anthropology and lay epidemiology suggests that these beliefs are grounded in culture and involve a system of beliefs and practices which, however variant from biomedicine, has its own logical structure (Davison, Davey-Smith & Frankel, 1991; Hunt & Emslie, 2001; Lawlor *et al.*, 2003). There remains a tendency within public health practice to focus on educating individuals to correct 'false' beliefs and modify 'irrational' behaviours, yet it has been recognised for some time that these behaviours may represent adaptive strategies involving a clear assessment of risk in relation to life chances (Graham, 1976; 1987; Springett, Owens & Callaghan, 2007). Emphasising professional expertise at the expense of the skills and experience of users also serves to decontextualise knowledge and results in a failure to deal with the issues that people face in their everyday lives. The inability to value different knowledge systems and situate lifestyle issues in a broader context is likely to have contributed to the differential impact of health interventions, resulting in increasing inequalities (Springett, Owens & Callaghan, 2007).

The complex diagram shown in figure 17 (page 117) attempts to address these issues in highlighting the role of context, personalisation and reciprocity in the behaviour change process. This diagram locates health trainer-led interventions in space and time, as well as highlighting the role of individual biography. In other words, users do not enter the intervention as 'blank slates' but instead draw on their life experiences in understanding and contributing to the delivery of interventions. For example, health trainers build on users' existing ideas and knowledge about food in the delivery of nutrition education sessions. This forms part of a holistic, asset-based approach that is supported by the salutogenic theory of health and is in direct contrast to the paternalistic, deficit model traditionally found in public health (Charlton & White, 1995; Lindstrom & Eriksson, 2005). It builds on the existing resources within local communities to support the creation of health, rather than the prevention of disease (Morgan & Ziglio, 2007). Health trainers represent a community resource or asset, as well as constituting part of the intervention mechanism and experiencing personal benefits as a result of delivering the interventions. This links to the point made earlier of context, mechanism and outcome being inextricable rather than separate variables, as in the realistic evaluation framework (Pawson & Tilley, 1997). The health trainer role is considered further in the following sub-section on lay health worker theory.

### **Lay health worker theory**

There is no formal lay health worker theory as such, but many lay-led interventions can be understood in light of relevant theories from health psychology and social science. The evidence synthesis by Carr *et al.* (2011) highlights a range of possible theoretical underpinnings, including social network theory, role theory and subcultures theory, whereas the literature from North America makes reference to 'natural helper' theory as a way of conceptualising lay-led health improvement programmes (Eng & Young, 1992; Moore & Earp, 2007). The model employed in Site B is closest to the natural helper concept, in terms of the emphasis on community development and outreach. However, all of the health trainers in this study were selected through formal recruitment mechanisms, rather than being nominated by their local communities, and are paid a salary for their work, rather than being volunteers or sessional workers. Furthermore, the role requires reaching out to people outside one's own social networks, and questions can therefore be raised as to whether this approach is consistent with the lay health worker tradition (Moore & Earp, 2007). Previous research conducted in the USA has suggested that the formal recruitment and training of lay workers may compromise their integrity in the community (Jackson & Parks, 1997). In the present study, health trainers were perceived as knowledgeable about lifestyle issues, yet distinct from 'experts' or health care professionals. Reference to their approach as "*down to earth*" suggests that the formal requirements of the role do not necessarily result in increased social distance between health trainers and users. However, the need to maintain 'professional' boundaries and avoid developing long-term relationships with users ensures that health trainers remain distinct from other community members.

It is also appropriate to examine the findings of this study in light of the sociology of professions. As one of the most high-status professions, medicine has drawn considerable attention in the sociological literature. Some authors have suggested that the medical profession evolved in order to uphold altruistic values and ethical standards (Parsons, 1951), whilst others have linked professionalisation to the pursuit of self-interest by elite groups seeking to create a monopoly for their services (Friedson, 1970; Johnson, 1972). More recent debates have begun to focus on the changing identities of professionals in light of globalisation, as well as the changing composition and status of the medical profession (Aldridge & Evetts, 2003; Evetts, 2003; Svensson, 2006). There have been dramatic changes in the context in which the health workforce operates, including changes in the incidence and treatment of diseases and the organisation of care (Duckett, 2005). Medical

interventions are often required to manage rather than cure chronic conditions, and patients tend to be better informed of the options available to them through prolonged contact with health services. The de-professionalisation thesis states that increasing rationalisation of medical knowledge and processes, combined with increasing lay knowledge of health, have undermined the cultural authority of doctors and weakened the monopoly of medicine (Gabe, Kelleher & Williams, 1996; Davey, Gray & Seale, 2001). The former chief medical officer, Sir Liam Donaldson, has said, "Health care in the 21<sup>st</sup> century will require a new kind of health professional: someone who is equipped to transcend the traditional doctor-patient relationships to reach a new level of partnership with clients" (Alexander, Ramsay & Thomson, 2004). The findings of this study demonstrate that health trainers fulfil these requirements in developing reciprocal relationships with users, yet this creates risk in terms of the disruption to current power and status hierarchies.

The study findings suggest that conflict may be less likely in settings where there is little overlap between the work of health trainers and other health professionals. For example, it was reported that the community-based health trainers in Sites A and B were seen as a complementary resource by other staff, whereas the more highly qualified health trainers in Site C were often seen as competitors. The existing literature suggests that the introduction of new lay or auxiliary health workers may be seen to disrupt current power and status hierarchies, and that professionals may have concerns about being replaced or having their skills undervalued (Murphy, 2007). The employment of lay workers can also bring hidden costs, in terms of higher absence and turnover rates, and concerns about possible harm to users if staff are required to work beyond their technical capacity (Buchan & DalPoz, 2002). These concerns were not borne out in the present study, where the majority of health trainers had been in post for several years and were clear about the limitations of the role. However, the heterogeneity in level of staff expertise, intervention objectives and outcomes highlights the need to take account of local variations in understanding and evaluating health trainer services. Studies of the sociology of professions, on the other hand, have tended to generalise features of particular professions (mainly law and medicine) in specific historical and geographical contexts (19<sup>th</sup> century Britain and America) as universal features of professionalism as a phenomenon (Evetts, 2003). The findings of the present study demonstrate temporal as well as geographical heterogeneity in the introduction of the health trainer role as a new occupational grouping in the NHS.

Diversity results from the flexibility inherent to the NHS Health Trainers Initiative in order to tailor local services to local needs. There has been growing recognition of the need to capitalise on sources of indigenous knowledge in the delivery of health and social care interventions (Ungar *et al.*, 2004). This requires an inversion of the privileged position of the professional as expert to give primacy to lay people's 'knowledgeable narratives' (Popay *et al.*, 2003). A challenge is posed by the traditional dominance within the NHS of what Finkelstein (1999) refers to as 'professions allied to medicine'. These professions constitute tools used to care for, cure and control 'defective' people, and individual 'deficiencies' are seen as the cause of social disadvantages requiring compensation by a 'caring' society. There are parallels between this view and feedback from participants in this study, who perceived that advice from health professionals should only be sought as a last resort for serious health concerns. Health trainers, on the other hand, were seen as being able address users' personal concerns and provide "*general advice about life*". This research also demonstrates the wider, organisational impacts of the health trainer role, which is the only NHS workforce role designed with the most disadvantaged individuals as its target population. As such, health trainers can be defined as a 'profession allied to the community' (Finkelstein, 1999). Whereas 'professions allied to medicine' work to defend their own philosophy and expertise, 'professions allied to the community' attempt to challenge the dominant values within society and improve conditions for disadvantaged groups. Health trainers carry out this work within the contexts and constraints of their host organisations, as illustrated in figure 17. This integrated model illustrates the way in which health trainers occupy a liminal space between the lay and formal health sectors, and are therefore both accountable to local communities and subject to organisational imperatives. These tensions are discussed in greater detail below.

### ***Integrated theory of lay-led behaviour change in context***

The product of this study – the theory of lay-led behaviour change in context – provides a hypothetical explanation for the role of health trainers in negotiating between two social worlds, by virtue of being a member of both. As lay workers, they have access to a local culture and tacit knowledge that is shared with other community members, some of whom will be potential or actual service users. Following recruitment into the health trainer role, they also receive formal and informal training that equips them with a degree of scientific knowledge and an understanding of a particular organisational culture. The findings of this study have shown that heterogeneity in health trainer models arises from a combination of



variation in the local context and differing organisational requirements. This highlights a need to acknowledge the role of contextual factors in both the development of health-related behaviours and in the delivery of interventions aimed at changing those behaviours. Participants in this study identified suitable intervention settings and opportunities for social interaction as key factors in the behaviour change process. Health trainers were seen to act as a bridge between social and organisational contexts, which has been highlighted as a core element of the lay health worker role in the existing literature (Earp & Flax, 1999; Ungar *et al.*, 2004; Racz & Lacko, 2008). This study adds evidence to support the idea that mutual benefits are experienced by service users, health trainers and their host organisations, but goes further in conceptualising these reciprocal relationships as making a potential contribution to a reduction in health inequalities.

Previous research has failed to account effectively for the ways in which individual, social and wider contextual factors interact to produce cumulative and unequal risks to health (Springett, Owens & Callaghan, 2007). Popay *et al.* (1998) provide an overview of conventional approaches to explaining social inequalities in health, before considering some of the main criticisms of these approaches. Three key issues to emerge from critiques of this work are:

- i. Existing theoretical frameworks fail to capture the likely complexity of explanations for health inequalities, particularly at the macro level
- ii. There is a need to re-conceptualise the notions of 'place' and time within explanatory models of health inequalities
- iii. A lack of attention has been paid to the role of individual agency (or behaviour) and how this links to structural factors

All three of these issues are addressed in the theory generated in the present study. The complexity inherent to the development of health behaviours and the delivery of lay-led behaviour change interventions has been emphasised throughout the research. Whereas positivistic epidemiological research tends to obscure complexity by ignoring the relational aspects of people's lives and decontextualising their health-related behaviours, the findings of this study have highlighted the importance of social networks in the maintenance of good health and identified context as a core category. This includes context in terms of time (i.e. historical and biographical) and space (intervention settings and the features and culture of local areas). Rather than being seen simply as "the canvas on which events happen", this research has considered the nature and role of particular places in shaping health-related behaviours (Jones & Moon, 1993, p.515). It has also moved beyond placing

structural and behavioural explanations for inequality in binary opposition, to fulfilling the requirements of a micro-level examination of the pathways by which social structures influence health and wellbeing (MacIntyre, 1997).

The third issue identified by Popay *et al.* (1998) can be addressed by reference to the literature on 'person-in-situation'<sup>27</sup>. This concept stems from the origins of social work in the USA and its dual focus on personal support and social reform, which mirrors the work of health trainers in facilitating individual behaviour change and addressing the wider determinants of health (Saari, 1992; Cornell, 2006). The historical development of the concept reflects wider debates within the social work profession that have a number of parallels in public health and health inequalities research. For example, social work theories have traditionally focused either on intra-psychic issues with minimal attention to the environment, or on structural and environmental issues with little emphasis on the individual (Kondrat, 2002; Cornell, 2006). These tensions are reconciled in Giddens' structuration theory, which states that the relationship between people, social structures and institutions is recursive (Giddens, 1987). In other words, there are certain processes through which social structures shape the behaviours of individuals, and those structures are in turn constituted by the behaviours and actions they condition. This can be contrasted with socio-ecological approaches, which view relationships between persons and environments as transactional rather than recursive (Kondrat, 2002). Similarities are observed with the work of Bourdieu, who integrated a respect for agency with an understanding of Marxist ideas about how culture and class shape society (Houston, 2002). Bourdieu noted that social inequality is reproduced by modern capitalist culture, while acknowledging that individuals can effect change in their own lives through choice and action.

The person-in-situation approach resolves tension between macro- and micro-level perspectives by acknowledging the structural determinants of health, while paying equal attention to the lived experience of inequalities. In doing so, it links to a subtle realist ontology in recognising the existence and influence of an objective external world (Cornell, 2006). This approach also helps to avoid victim-blaming or overly deterministic and dehumanising explanations for health inequalities (Popay *et al.*, 2007b). The theory of lay-led behaviour change in context draws on these ideas in explaining the way in which health trainers support individuals to deal with particular health-damaging situations, while taking action to change those situations.

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<sup>27</sup> This term is used interchangeably in the social work literature with 'person-in-context' and 'person-in-environment'.

Reciprocating was identified as a key category in this research to highlight the mutual benefits experienced by the various human actors involved in health trainer-led interventions. However, this category has also been used to refer to the way in which these actors shape and are shaped by the contexts in which they operate. As such, it is acknowledged that 'recursive' (as defined by Giddens) might be a more appropriate term than 'reciprocal' to denote the fact that health trainers and service users are co-constructors of their situations and settings, as opposed to persons and environments being separate but mutually influencing elements. The theory offered here has the potential for providing a foundation for understanding the role of lay workers in addressing both the material and behavioural causes of inequality.

### **Implications for policy and practice**

The final objective of this study was to inform the future development and evaluation of the NHS Health Trainers Initiative and similar lay-led interventions. It was my intention to generate knowledge and evidence that would assist lay practitioners, health professionals and others to overcome the barriers that currently prevent them from successfully addressing health inequalities. The rich descriptions and interpretations from the study participants may help others to recognise the importance of accommodating context in the design, implementation and delivery of interventions aimed at lifestyle change within disadvantaged communities. The implications of the study findings for practitioners, service providers, commissioners and policy-makers are considered in turn below.

A number of barriers to engaging with health improvement services were identified by users in this study, including location, cost and convenience. Practitioners should take action to reduce these barriers; for example, by delivering interventions at accessible venues within communities and discussing transport options with individuals who have limited mobility. The importance of creating safe, comfortable and supportive environments was emphasised, particularly by older participants and those with sensory or physical disabilities. Opportunities for one-to-one support and social interaction were also appreciated, and practitioners require the flexibility to tailor interventions to individual needs. A defining aspect of the health trainer role is being recruited from target communities and therefore having an understanding of those communities. Health trainers should therefore be recognised by other practitioners as a useful resource in terms of potentially being able to engage with 'hard-to-reach' groups using their social networks. Lay knowledge possessed by service users should also be seen as a resource or asset on which to build during

the delivery of interventions. The findings of this study confirm the view that there are limitations to being seen as a professional 'expert'; for example, users often preferred to discuss lifestyle issues with their health trainer rather than their GP. Health professionals should recognise the boundaries of their role and make use of lay health workers as a bridge into local communities.

Service providers can support health trainers and other lay practitioners by providing adequate training, supervision and leadership, as well as setting clear objectives that are made explicit from the outset. Training programmes should build on the lay workers' existing skills and knowledge, as well as equipping them with expertise in behaviour change and community development. Dealing with complex, emerging issues highlights a need for staff training and development opportunities to be provided on an ongoing basis. Service providers also have a role to play in setting clear boundaries for health trainers and facilitating their acceptance by other teams and agencies within public health. Professionals may be unwilling to offer support unless they can see clear benefits for their patients or clients, and so providers should collate and provide evidence on the prospective benefits of health trainers. There is a need for lay-led services to be promoted widely and using appropriate methods, such as advertising in local schools and GP surgeries, capitalising on opportunistic contacts and encouraging word of mouth recommendations. Reciprocity was a key finding of this study, as well as appearing as a recurring theme in the research literature. The status of lay workers as key beneficiaries of lay-led interventions should be recognised in any monitoring and evaluation activities. However, measures should also be put in place to reduce risks arising from the blurring of the boundaries between practitioner and service user. Lay workers may find it difficult to separate their work and home life, and users may expect to receive long-term support from someone they have come to see as a friend. Participants in this study felt that a gradual process of withdrawal was most acceptable; for example, moving from weekly to monthly meetings, and then to brief face-to-face meetings or providing support over the telephone.

Evidence of effectiveness and cost-effectiveness is needed to inform decisions about which lay-led interventions to fund, if any. Commissioning and evaluation of these interventions should be informed by a broad understanding of the full range of health and social outcomes identified in the present study. The research literature suggests that health trainers and other lay workers are not a cheap option or 'quick fix', but the findings of this study imply that they might have a role to play in reducing health inequalities. Longer-term objectives are more likely to be achieved by

adopting a strategic approach and investing in the wider infrastructure to support lay health workers, rather than commissioning short-term initiatives and interventions. Efforts should be taken to reduce bureaucracy, and sustain the flexibility and responsiveness of these services. The degree of complexity and heterogeneity within the NHS Health Trainers Initiative has been demonstrated; it is not a one-size-fits-all approach. Commissioners should therefore use the available evidence to select the intervention model that best meets the needs of the local population. Consideration should also be given to how this model or service integrates into the local public health system, as there is the potential for health trainers to be seen either as collaborators or competitors.

Policy-makers require evidence to enable them to advise commissioners and service providers; this issue is discussed further in the section below. Health trainer services have the potential to contribute to the government's Big Society policy idea, although there are broader policy implications in terms of worklessness, social inclusion and community capacity building. The labelling of lay health worker roles should be considered carefully in an attempt to increase the likelihood of acceptance by 'hard-to-reach' communities and health professionals. This study is supported by the research literature in suggesting that 'health trainer' is not seen as a suitable label for the work carried out by these individuals. There is a need for clear definition and regulation of health trainers and other lay health workers as new occupational groupings in public health. However, there has been a tendency in policy of seeing all health professions as health care professions, with perceived risks linked to clinical interventions and vulnerable patient groups. Future policy should devote sufficient attention to health as well as illness, and recognise the impact of the social and wider context on health rather than emphasising the role of individual lifestyle factors. It is also essential that appropriate monitoring and evaluation frameworks are put into place from the earliest stages of any lay-led health improvement programme in order to assess and measure the most appropriate outcomes, outputs and impacts for the interventions.

### **Areas for further research**

This study has highlighted the need for further research to explore the effectiveness, cost-effectiveness, acceptability and sustainability of lay-led health improvement interventions. A longer-term follow-up of the study sample would have allowed for further exploration of the perceived barriers and facilitators to sustained behavior

change. The study findings require corroboration with a larger sample of service users, health trainers and other key stakeholders, which could include GPs if health trainer services move to a practice-based commissioning model. It would also be worthwhile to consult other public health practitioners, such as health visitors and physical activity development workers, to explore their views on health trainers and their perceived impact. Future research could involve testing the product of this study (the theory of lay-led behaviour change in context) in other areas and with other types of lay health worker. It should also be tested with health trainers based in different settings, such as prisons or pharmacies. Repeating this research with particular user groups would produce findings of relevance for services that target those groups; for example, younger people or specific BME communities.

This study has demonstrated the utility of longitudinal qualitative research (QLR) in understanding behaviour and behaviour change within the context of the NHS Health Trainers Initiative. Future research should explore the use of QLR as a methodology to evaluate other complex health and social interventions. This approach has been used successfully in a number of recent studies to follow individuals through time and explore their health experiences, often in the context of a wider outcome evaluation (e.g. Platt *et al.*, 2009; Begh *et al.*, 2011; Noble, Moffatt & White, 2011). The effectiveness and cost-effectiveness of health trainers and similar lay worker roles can only be reliably determined with the use of randomised controlled trials, although previous attempts indicate that this would be far from straightforward. The findings of the present study also suggest that a variety of potential outcomes should be taken into account, as well as a range of potential beneficiaries. In this sense, the research findings might be used to inform a definitive outcome evaluation, in line with the MRC framework for the evaluation of complex interventions (Craig *et al.*, 2008).

Any trial conducted would need to capture the impact of health trainer-led interventions on providers and recipients, as well as their families, friends and local organisations, and not just in terms of individual behaviour change. It is unlikely that a definitive outcome evaluation would be sufficient to capture the full range of activities and outcomes arising from these interventions, which provides the rationale for conducting QLR alongside a trial as part of a process evaluation. A realistic evaluation approach would also be suitable, to explore what works for whom under what circumstances, and whether or not the various interventions represent value for money in comparison with professional services. Key issues for

future research and evaluation will involve assessing both the cost-effectiveness of lay-led approaches and the equity of outcomes arising from the interventions.

### **Concluding remarks**

In undertaking this research, my goal was to understand the work of health trainers from the service user perspective and thereby gain insight into the processes involved in making and maintaining health-related behaviour changes. I recognised that there was a lack of research specifically on the subject of health trainers and other lay roles in UK settings, and on the potential of these roles to contribute to a reduction in health inequalities. Furthermore, the voices of people from marginalised communities are seldom heard in the literature and I was motivated by a desire to shed light on their experiences of health, illness and disadvantage. Although their stories were sometimes difficult to hear, I feel that the study participants benefitted from being able to share them with me and I also benefitted from furthering my understanding of qualitative research methods. A pervasive finding of this study was that lay-led behaviour change is a fundamentally complex phenomenon, and one that it is influenced by three factors. First, behaviour and behaviour change must be viewed in social, economic, political, geographical and temporal context, while recognising the role of personal biography and individual agency. Second, interventions that are perceived as being tailored to individual needs (i.e. personalised) are seen as most effective, acceptable and sustainable. Third, reciprocity is a defining element of lay-led interventions in terms of service users, lay workers and local organisations experiencing benefits from the delivery of or participation in these interventions. The product of this study is the theory of lay-led behaviour change in context, which has value in understanding the work of health trainers and similar roles. Once the theory has been tested in the study context, it may be possible to apply and test it in other contexts and with different types of community-based worker. The study findings will be fed back to the health trainer teams and disseminated widely in order to have an impact on local, regional and national policy, practice and decision-making. They will also be shared across the academic community with the aim of informing future research. By adopting the situation-oriented, user-focused perspective advocated in this study, it is hoped that researchers, practitioners and policy-makers will be better able to meet the needs of disadvantaged communities and therefore address health inequalities.



## Appendices

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## **Appendix A: Summary of a key systematic review by Carr *et al.* (2011)**

### **Research aim**

This research aimed to identify, describe, classify and analyse the range of models developed to date for delivering health-related lifestyle advice or training for effectiveness, mechanism of effect, cost-effectiveness, equity and acceptability in improving the health and wellbeing of individuals and communities, with particular reference to the reduction of health inequalities in the UK.

### **Review questions**

1. What are the component intervention techniques of health-related lifestyle advisors (HRLAs) in the UK or similar contexts?
2. What are the outcomes of HRLA interventions?

These questions were answered by using a range of methods and search strategies that are described in detail in the full report.

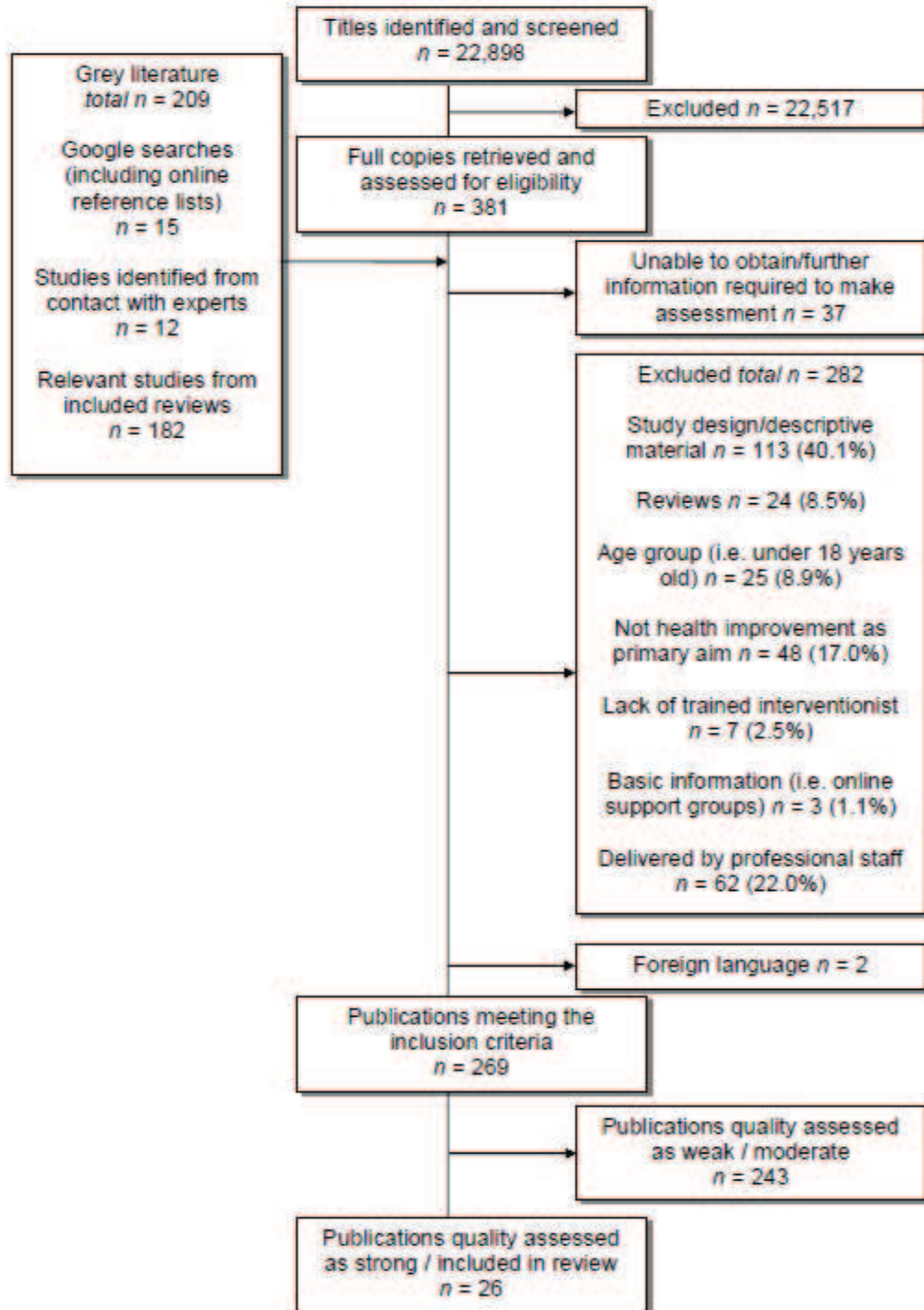
### **Exclusion criteria**

Studies that met the following criteria were included:

- Evaluations (quantitative, qualitative or economic) of HRLA interventions
- Research conducted in developed countries similar to the UK context, i.e. Western Europe, North America, Australia and New Zealand
- Interventions targeted at adult groups
- Interventions with the explicit aim of health improvement, including community-based secondary prevention for chronic disease
- Interventions that involved paid or voluntary work with an individual or group of peers acting in an advisory role
- Advice delivered by post, online or electronically, only if this involved an iterative process of interaction between the HRLA and service user
- Training, support or counselling delivered to patients, communities or members of the public.

## Study selection process

After quality assessment, conducted by two independent reviewers using standardised quality checklists, 26 studies were identified for inclusion in the review. A flowchart illustrating this process is shown below.



## Appendix B: Consent form (service users)

[Headed paper]

### Engagement and behaviour change in the NHS Health Trainers Initiative

Please initial  
each box

1. I confirm that I have read and understood the information leaflet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my taking part is voluntary and that I am free to withdraw at any time, without giving any reason and without my health care or legal rights being affected.

☐

3. I consent to the audio-recording of the interviews. I have been told that the recordings will be securely stored at Northumbria University for one year after the end of the study and will then be wiped.

☐

4. I give permission for the researcher to examine the diary my health trainer has agreed to keep to record our meetings. I have been told that the researcher will not disclose personal information from this diary to anyone (please choose one option).

NO

☐

YES

☐

5. I am aware that all recordings and documents will remain confidential and will be securely stored. I understand that any publications related to the study will not identify me or anyone else by name.

☐

6. I agree to take part in the above study.

☐

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix C: Consent form (health trainers)

[Headed paper]

### Engagement and behaviour change in the NHS Health Trainers Initiative

Please initial  
each box

1. I confirm that I have read and understood the information leaflet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my taking part is voluntary and that I am free to withdraw at any time, without giving any reason and without my employment or legal rights being affected.

☐

3. I consent to the audio-recording of the interviews. I have been told that the recordings will be securely stored at Northumbria University for one year after the end of the study and will then be wiped.

☐

4. I agree to keep a diary to record my meetings with service users in this study (with their consent). I have been told that the researcher will not disclose personal information from the diaries to anyone (*please choose one option*).

NO

☐

YES

☐

5. I am aware that all recordings and documents will remain confidential and will be securely stored. I understand that any publications related to the study will not identify me or anyone else by name.

☐

6. I agree to take part in the above study.

☐

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix D: Consent form (managers)

[Headed paper]

### Engagement and behaviour change in the NHS Health Trainers Initiative

Please initial  
each box

1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my taking part is voluntary and that I am free to withdraw at any time, without giving any reason and without my employment or legal rights being affected.

☐

3. I consent to the audio-recording of the interviews. I have been told that the recordings will be securely stored at Northumbria University for one year after the end of the study and will then be wiped.

☐

4. I am aware that all recordings and documents will remain confidential and will be securely stored. I understand that any publications related to the study will not identify me or anyone else by name.

☐

5. I agree to take part in the above study.

☐

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix E: Invitation letter (health trainers)

[Headed paper]

Dear health trainer,

### **Engagement and behaviour change in the NHS Health Trainers Initiative**

A PhD student at Northumbria University (Shelina Visram) is interested in speaking to people who have recently been to see a health trainer. She is hoping to find out what made them decide to see a health trainer, what changes they hope to make, and how easy or difficult they have found it to make those changes. Shelina would also like to speak to health trainers and their managers to get a better idea of their experiences of setting up and delivering the service and what difference they think it makes to local people.

We are contacting members of the local health trainer team and their managers to ask if they would be happy to take part in this research study. Shelina would like to interview you now and in 12 months time to gather your views of the health trainer service and find out how it changes over time. We will also be contacting people who start to see a health trainer between May and October 2009 and asking them if they would take part in interviews now, in 3 months, 6 months and 12 months time. This will help Shelina to keep in touch with people who leave the health trainers service at different times.

In this pack you will find an information leaflet that tells you a bit more about the study and gives you Shelina's contact details in case you would like to ask her any questions. You could also contact me on the details given above. If you think you might be interested in taking part then please complete and return the reply slip in the enclosed prepaid envelope. Shelina will then get in touch to have a chat with you about the research and arrange a time for your first interview.

Many thanks,

[Name]

Health trainer manager



## Appendix F: Information leaflet (health trainers)

Printed in colour and folded into a double-sided leaflet:

**Do I have to take part?**

It is completely up to you to decide whether or not to take part in this study. If you decide to take part you are still free to drop out at any time and without giving a reason.

A decision to stop or not take part will not affect you, your relationship with your manager, or your rights as an employee or volunteer in any way.



**What should I do next?**

If you don't want to take part then you don't need to do anything. But thanks anyway for reading this leaflet.

If you are interested in taking part, please complete and return the enclosed reply slip so that the researcher can get in touch to have a chat about the research.

**For information, please contact the researcher (Shelina Visram) at:**

H011, Coach Lane Campus East,  
Northumbria University,  
Newcastle-upon-Tyne, NE7 7XA.  
Phone: 0191 215 6682  
E-mail: shelina.visram@northumbria.ac.uk

**Or get in touch with her PhD supervisor (Charlotte Clarke) at:**

SMG, Coach Lane Campus West,  
Northumbria University,  
Newcastle-upon-Tyne, NE7 7XA.  
Phone: 0191 215 6075  
E-mail: charlotte.clarke@northumbria.ac.uk



**Please feel free to discuss this leaflet with your manager, colleagues or anyone else before making your decision.**

**Thank you for reading this.**

This study is being funded by a PhD Fellowship from the National Institute of Health Research (NIHR).



**Engagement and Behaviour Change in the NHS Health Trainers Initiative**

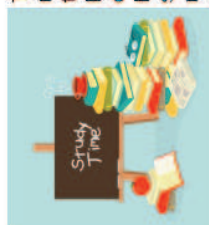
**Information for Health Trainers**



You are being invited to take part in a research study. Please read the following information carefully before you decide whether or not to take part.

### What is the purpose of the study?

Health trainers are a new workforce role in the NHS. At the moment, we don't know much about how health trainers are reaching people in local areas, and whether it's best for them to work with individuals or communities.



The aim of this research is to fill these gaps in knowledge by comparing different health trainer services in the north east. We want to speak to service users, health trainers and their managers to find out the best ways to help people lead healthy lifestyles.

### Why have I been chosen?

You and other people who are currently employed as a health trainer in [place name] are being asked if you would be willing to take part in this study.

### What does taking part involve?

You will be asked to take part in two interviews with the researcher. Each interview will last for about an hour, be audio-recorded (with your permission) and take place at a time and place where you and the researcher are both comfortable.



During the interviews you will be asked to talk about your views and experiences of working with people from local communities. The researcher would like to speak to you now and again in 12 months time to look at how your views and the service might have changed.

You will also be asked to keep a diary to record your meetings with users taking part in this study. This information will be kept confidential and will only be used (after being anonymised) with permission from you and the service user.

At the first interview you will be asked to read and sign two consent forms. One of these will be for the researcher and the other will be for you to keep.

### Will the things I say be treated as confidential?

A secretary will type up the interview recordings and information that could identify people will be removed. No-one other than the researcher, her supervisors and a secretary will be able to listen to the recordings or read the notes.

All notes will be stored securely in a locked cabinet at Northumbria University and destroyed six years after the end of the study. The recordings will be kept on a password protected computer and wiped after one year.

### What will happen to the results?

A full report will be produced and made publicly available, along with research papers and conference presentations. All participants will be sent a summary of the key findings.



The research is also being used as a PhD project and will be submitted to examiners at Northumbria University.

## Appendix G: Invitation letter (managers)

[Headed paper]

Dear [name],

### **Engagement and behaviour change in the NHS Health Trainers Initiative**

I am a PhD student at Northumbria University and I am interested in speaking to people who have recently been to see a health trainer. I am hoping to find out what made them decide to see a health trainer, what changes they hope to make and how easy or difficult they have found it to make those changes. I would also like to speak to the health trainers and their managers to get a better idea of their experiences of setting up and delivering the service and what difference they think it makes to local people.

I am contacting members of the local health trainer team and their managers to ask if they would be happy to take part in this research study. I would like to interview you now and in 12 months time to gather your views of the health trainer service and find out how it changes over time. I will also be contacting people who start to see a health trainer between May and October 2009 and asking them if they would take part in interviews now, in 3 months, 6 months and 12 months time. This will help me to keep in touch with people who leave the health trainers service at different points in time.

In this pack you will find an information sheet that tells you a bit more about the study. You can contact me on the details given above if you would like to ask any questions. If you think you might be interested in taking part then please complete and return the reply slip in the enclosed prepaid envelope. I will then get in touch to have a chat with you about the research and arrange a time for your first interview.

Many thanks,

Shelina Visram

PhD Student

## Appendix H: Information sheet (managers)

[Headed paper]

### Engagement and behaviour change in the NHS Health Trainers Initiative

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with other people if you wish. You can speak to the researcher (Shelina Visram) at Northumbria University if there is anything that is not clear or if you would like more information.

Thank you for reading this.

#### What is the purpose of the research?

NHS health trainers were first mentioned in the 2004 Department of Health publication '*Choosing Health*'. They are a new workforce role that offers advice, motivation and support to people who want help to choose healthier lifestyles. It is hoped that they will be known and trusted by people in their local community and have experience of what it means to live in, or be part of, that community. However, it is not known how they are reaching people in deprived areas, and whether it is best to focus on individuals or communities.

The aim of this research is to address these gaps in knowledge by comparing different health trainer services. By speaking to users, health trainers and their managers in [name of research site] about their views and experiences, it is hoped that the research will create new knowledge that can be used to help people lead healthy lifestyles.

#### Why have I been chosen?

You and other people who currently have responsibility for the management or supervision of health trainers in [name of site] are being asked if you would be willing to take part in this study to explore your views and perceptions of the service.

#### Do I have to take part?

It is completely up to you to decide whether or not to take part in this study. If you decide to take part you are still free to drop out at any time and without giving a reason. A decision to stop or not to take part will not affect you or your rights as an employee in any way.

#### What does taking part involve?

You will be asked to take part in two semi-structured interviews at a mutually convenient time and location. Each interview will last for about an hour and be audio-recorded (with your permission) to assist the researcher to recall information during analysis. During the first interview you will be asked to talk about your



experiences of managing or supervising the health trainers and your perceptions of the service they provide, in terms of engaging with people from local communities and encouraging them to make and maintain lifestyle changes. The researcher would like to speak to you again in 12 months time to explore if and how your views and the health trainer service have changed.

At the first interview you will be asked to sign two consent forms; one of these will be for the researcher and the other will be for you to keep.

**Will my taking part in this study be kept confidential?**

After the interviews have been conducted, a secretary will type up the recordings and any information that could identify people will be removed. No-one other than the researcher, her supervisors and the secretary will be able to listen to the recordings or read the interview transcripts. The transcripts and other documents containing your details will be stored securely in a locked cabinet at Northumbria University and then destroyed six years after the end of the study. The recordings will be stored on a password protected computer and wiped after one year.

**What will happen to the results of the research?**

The information will be looked at to identify the range of views and experiences of all those taking part. A report will be produced which presents these views to the Project Advisory Group and will then be made publicly available. This research will be used as a Doctoral Degree project (PhD) and will be submitted to examiners at Northumbria University. Research papers and conference presentations will also be produced. Participants will receive a summary of the findings after the final report has been disseminated.

**Who is organising and funding the research?**

The project is being carried out by a student (Shelina Visram) from Northumbria University and funded by the National Institute of Health Research (NIHR).

**What should I do next?**

If you do not want to take part in the study then you do not need to do anything.

If you are interested in taking part, please complete and return the enclosed reply slip so that the researcher can contact you to arrange a date, time and venue for the first interview.

**Contact for further information**

If you would like to speak to someone about the study or if you need any further information then please contact:

Shelina Visram (PhD Student)  
H011, Coach Lane Campus East,  
Northumbria University,  
Newcastle-upon-Tyne,  
NE7 7XA.  
Tel: 0191 215 6682  
Email: [shelina.visram@northumbria.ac.uk](mailto:shelina.visram@northumbria.ac.uk)

or Charlotte Clarke (Supervisor)  
SMG, Coach Lane Campus West,  
Northumbria University,  
Newcastle-upon-Tyne,  
NE7 7XA.  
0191 215 6075  
[charlotte.clarke@northumbria.ac.uk](mailto:charlotte.clarke@northumbria.ac.uk)

## Appendix I: Invitation letter (service users)

[Headed paper]

Dear service user,

### **Engagement and behaviour change in the NHS Health Trainers Initiative**

A student at Northumbria University (Shelina Visram) is interested in speaking to people who have recently been to see a health trainer. She is hoping to find out what made them decide to see a health trainer, what changes they hope to make and how easy or difficult they have found it to make those changes. Shelina would also like to speak to the health trainers and their managers to get a better idea of their experiences of setting up and delivering the service and what difference they think it makes to local people.

We are contacting people who have just started to see a health trainer between May and October 2009 and asking them if they would be happy to take part in this research study, which will involve a total of 4 interviews per service user. Shelina would like to speak to you as soon as possible and then again after 3 months, 6 months and 12 months, to talk about your experiences of speaking to a health trainer and the advice they have given you. For each interview you take part in, you will receive a £5 voucher to thank you for your time.

In this pack you will find an information leaflet that tells you a bit more about the study and gives you Shelina's contact details in case you would like to ask her any questions. You could also speak to me using the details above or get in touch with your local Patient Advice and Liaison Service (PALS) on [number]. If you think you might be interested in taking part then please complete and return the reply slip in the enclosed prepaid envelope. Shelina will then get in touch to have a chat with you about the research and arrange a time for your first interview.

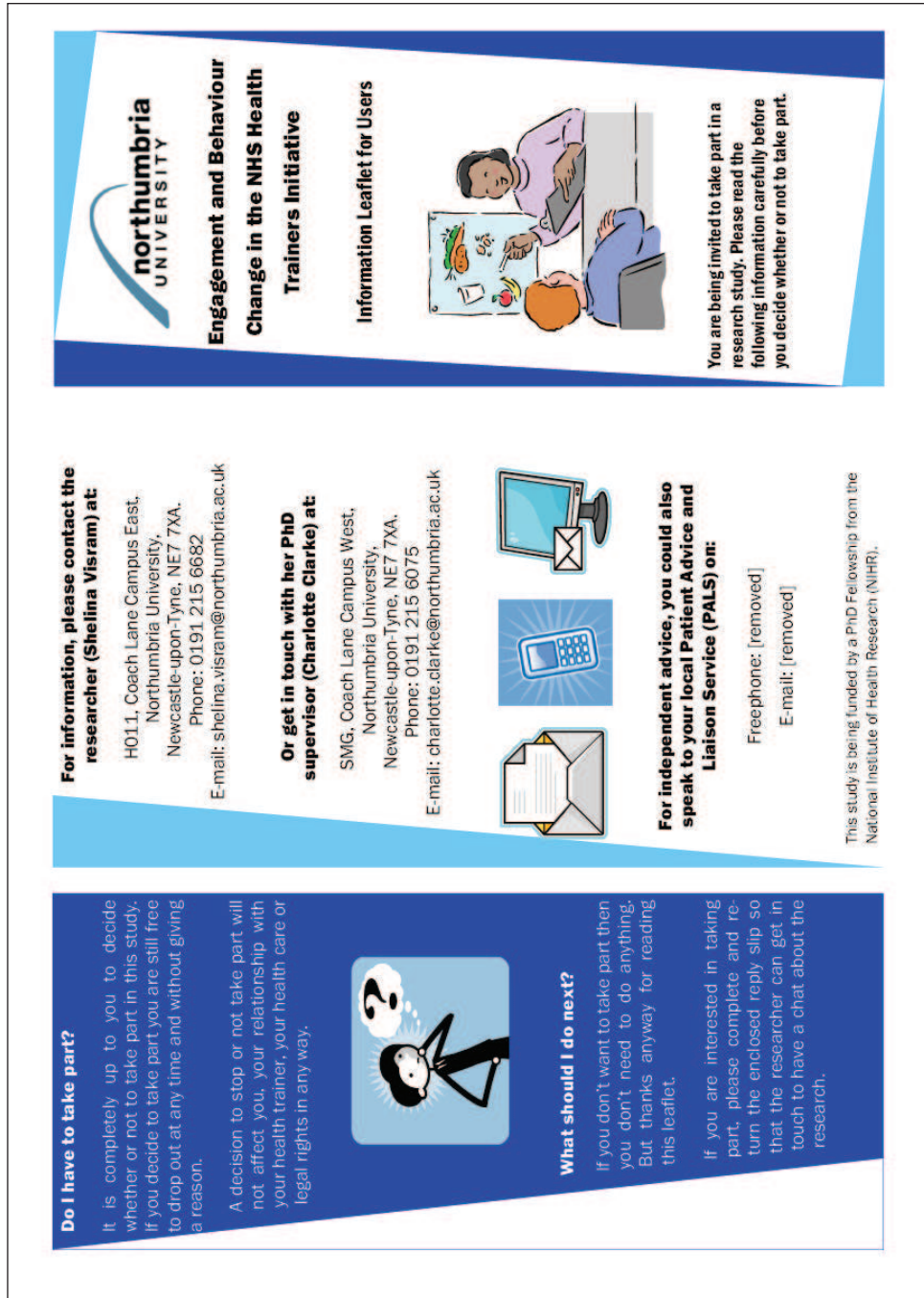
Many thanks,

[Name]

Health trainer manager

## Appendix J: Information leaflet (service users)

Printed in colour and folded into a double-sided leaflet:





### What is the purpose of the study?

Health trainers are a new workforce role in the NHS. At the moment, we don't know much about how health trainers are reaching people in local areas, and whether it's best for them to work with individuals or communities.



The aim of this research is to fill these gaps in knowledge by comparing different health trainer services in the north east.

We want to speak to users, the health trainers and their managers to find out the best ways to help people lead healthy lifestyles.

### Why have I been chosen?

You and other people who have recently started to see a health trainer in [place name] are being invited to take part in this study to explore your views and experiences.

### What does taking part involve?

You will be asked to take part in a series of one-to-one interviews with the researcher. She would like to speak to you as soon as possible, in 3 months, 6 months and 12 months time (a total of 4 interviews).

The interviews will last for about one hour, be audio-recorded (with your permission) and take place at a time and place where you are both comfortable. You will be asked to talk about why you decided to see a Health Trainer, what changes you are hoping to make, and what makes it easy or difficult to make these changes.



At the first interview you will be asked to sign a consent form. This also asks for your permission to let the researcher look at a diary kept by your Health Trainer to record the things you do together during your meetings.

For each interview you complete, you will be given a £5 voucher to thank you for your time. This means a possible total of £20.

### Will the things I say be treated as confidential?

A secretary will type up the interview recordings and information that could identify people will be removed. No-one other than the researcher, her supervisors and a secretary will be able to listen to the recordings or read the notes.

All notes will be stored securely in a locked cabinet at Northumbria University and destroyed six years after the end of the study. The recordings will be kept on a password protected computer and wiped after one year.

### What will happen to the results?

A full report will be produced and made publicly available, along with research papers and conference presentations. All participants will be sent a summary of the key findings.



The research is also being used as a PhD project and will be submitted to examiners at Northumbria University.

## Appendix K: Topic guide (service users)

### Initial interview (month 0)

#### **Purpose:**

- To establish a relationship between the researcher and participant
- To gather information regarding the service user's biography and their main health concerns / goals
- To explore their reasons for engaging with the local health trainer service

#### **Topics:**

- Current health state and significant health events in their past
- Understanding of the key determinants of health and wellbeing
- Previous experiences of attempting to make lifestyle changes or access sources of advice / support
- How they first heard about and came into contact with health trainers
- What motivated them to attend – particular health concerns or lifestyle issues
- Barriers or facilitators experienced in attempting to access the service
- What they hope to achieve – specific goals and expectations
- Perceived ability to make and maintain behaviour changes

### First follow-up interview (month 3)

#### **Purpose:**

- To extend the research relationship
- To explore their views and experiences of receiving support from a local health trainer, on completion of the formal intervention (~ 12 to 16 weeks)

#### **Topics:**

- Overview of topics covered and activities undertaken during the intervention
- Views on their relationship with the health trainer
- What motivated them to complete the intervention / caused them to disengage with the service
- Barriers or facilitators experienced in attending sessions with a health trainer
- Experiences of accessing other sources of advice and support
- Perceived progress towards initial goals and fulfilment of expectations
- Factors that influence their ability to make and maintain behaviour change
- Any change in their knowledge and perceptions of health and wellbeing
- Views on the health trainer service and suggested areas for improvement

**Second follow-up interview (month 6)**

**Purpose:**

- To extend the research relationship
- To explore their ongoing attempts to make and maintain lifestyle changes in the short term (3 months after completion of the health trainer intervention)

**Topics:**

- Current health state and significant health (or other) events that have occurred in the past 3 months
- Any ongoing contact with the health trainer service and reasons for this
- Experiences of accessing other sources of advice and support (particularly after being 'signposted' by their health trainer)
- Perceived progress towards initial goals, or new goals set since completion of the intervention
- Factors that influence their ability to make and maintain behaviour change
- If they have abandoned their attempts to change, what are the reasons
- Any change in their knowledge and perceptions of health and wellbeing
- Any changes to the local context and its impact on the health of local people

**Final follow-up interview (month 12)**

**Purpose:**

- To explore their longer-term attempts to make and maintain lifestyle changes, and any changes to their attitudes regarding health and wellbeing
- To identify their (health-related) hopes and expectations for the future
- To conclude the research relationship

**Topics:**

- Current health state and significant events occurring in the past 6 months
- Level of satisfaction with their current health state (particularly if they have abandoned all attempts to make or maintain behaviour change)
- Any ongoing contact with the health trainer service and reasons for this
- Experiences of accessing other sources of advice and support
- Perceived progress towards their health-related goals and factors that have influenced this
- Factors that are likely to influence their ability to maintain any changes in the longer-term
- Understanding of the key determinants of health and wellbeing
- Any changes to the local context and its impact on the health of local people
- Vision for the future – their own and that of their community

## Appendix L: Topic guide (health trainers)

### Initial interview (month 0)

#### **Purpose:**

- To establish a relationship between the researcher and participant
- To gather their views and experiences of being a health trainer
- To explore their role in attempting to engage with local people and supporting them to make and maintain lifestyle changes

#### **Topics:**

- Relevant personal, occupational or volunteering history
- Experiences of working as a health trainer
- Overview of service delivery to date – main activities, service user groups, referral sources, etc
- Barriers and facilitators in attempting to engage with service users and communities, or in working with other local agencies and staff groups
- Factors that influence user abilities to make and maintain behaviour change
- Perceived outcomes and impact of the initiative to date
- Anticipated changes or developments over the next 12 months

### Follow-up interview (month 12)

#### **Purpose:**

- To identify developments in the health trainers service and local context
- To explore future directions for the service and anticipated longer-term impact
- To conclude the research relationship

#### **Topics:**

- Any change in personal circumstances or occupational status
- Experiences of working health trainer over the past 12 months
- Update on service delivery – any change in main activities, service user groups, target areas, etc
- Any change in the barriers and facilitators to engaging with users, facilitating behaviour change or working with other agencies in the local area
- Anticipated future outcomes and impact of the initiative
- The future of the initiative as a whole and plans for their future

## Appendix M: Topic guide (managers)

### Initial interview (month 0)

#### **Purpose:**

- To establish a relationship between the researcher and participant
- To explore the role of health trainers in attempting to engage with local people and supporting them to make and maintain lifestyle changes
- To consider the positioning of the health trainers service within the local public health system

#### **Topics:**

- Description of their current role and relevant professional background
- Overview of implementation and service delivery to date – aims and objectives of the initiative, target groups, level of intervention (e.g. individual, family, community), main activities, etc
- Perceived barriers and facilitators to user engagement / behaviour change
- Links or boundaries with other local services, agencies and staff groups
- Perceived outcomes and impact of the local initiative to date
- Strategic direction for the initiative over the next 12 months

### Follow-up interview (month 12)

#### **Purpose:**

- To identify developments in the health trainers service and local public health context
- To explore future directions for the service and anticipated longer-term impact
- To conclude the research relationship

#### **Topics:**

- Any change in role or professional status, e.g. promotion or job change
- Update on service delivery – current objectives, activities, target groups, etc
- Any change in local public health context, including factors perceived to influence users' motivation to engage with a health trainer or their ability to make and maintain behaviour changes
- New and ongoing relationships with other services, agencies and staff
- Anticipated future outcomes and impact of the local initiative
- Views on the future of the local and national initiatives

## Appendix N: Life grid template

The life grid consisted of four sheets of A4 paper, each covering a 25-year period and beginning in 1901. As most participants were aged between 60 and 70 years, they were only given sheets two, three (see below) and four.

Year	External Events	Age	Family	Location	Occupation	Health	Lifestyle
1948 ↓ ↓	National Health Service launched						
1952 ↓	Death of George VI; accession of Elizabeth II						
1953 ↓	Coronation						
1955 ↓ ↓	European Union created						
↓ ↓ ↓							
1961 ↓ ↓ ↓	Berlin Wall erected						
↓ ↓ ↓							
1966 ↓ ↓ ↓ ↓ ↓	England win the World Cup						
↓ ↓ ↓							
1969 ↓ ↓ ↓	Apollo 11 lands on the moon UK troops in N. Ireland						
1972 ↓ ↓ ↓	Miners' strikes Bloody Friday in N. Ireland						
1974 ↓ ↓ ↓							
1979 ↓ ↓ ↓	Margaret Thatcher elected Prime Minister						

## Appendix O: Behaviour change prompts

The two sets of prompts shown below were printed on squares of colour card, which were shuffled and presented in a pile to each service user participant. They were asked to select any cards that they felt answered the following questions:

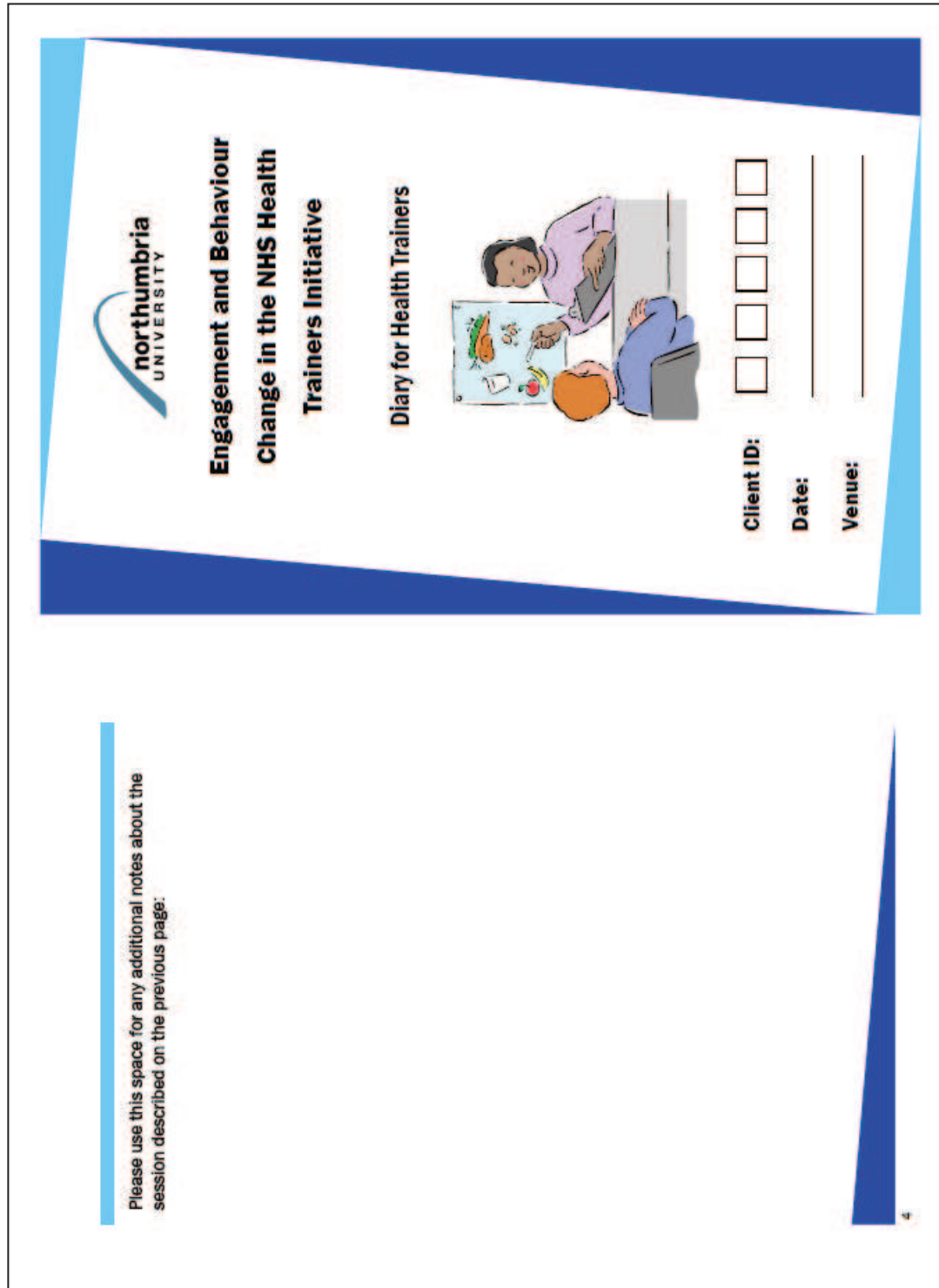
1. What makes it difficult for you to lead a healthy lifestyle (list one)?
2. What would make it easier for you to lead a healthy lifestyle (list two)?

List one: barriers	List two: facilitators
<ul style="list-style-type: none"> <li>• Caring for or worrying about other people</li> <li>• Lack of time</li> <li>• Stress and anxiety</li> <li>• Too embarrassed to ask for help</li> <li>• Concerns about not fitting in</li> <li>• Living alone</li> <li>• Don't like going out alone</li> <li>• Boredom</li> <li>• Lack of confidence</li> <li>• Lack of support</li> <li>• Don't think I need to be healthier</li> <li>• Don't know how to be healthier</li> <li>• Don't think I can control my health</li> <li>• Life is too short to worry about health</li> <li>• Poor health</li> <li>• Lack of activities or services in the local area</li> <li>• Mobility and transport issues</li> <li>• Money</li> </ul>	<ul style="list-style-type: none"> <li>• Services and activities tailored to my needs</li> <li>• Activities delivered at suitable times</li> <li>• Activities delivered in comfortable environments</li> <li>• Being with people who are a similar age to me</li> <li>• Being with people from a similar background to me</li> <li>• Opportunities to make new friends</li> <li>• Someone to talk to</li> <li>• One-to-one support</li> <li>• Support and advice from friendly workers</li> <li>• Support and advice from highly trained workers</li> <li>• Free or low cost activities</li> <li>• Use of tools and resources, e.g. food diaries</li> <li>• Setting and achieving measurable goals</li> <li>• Taking a relaxed approach</li> <li>• Better health care</li> <li>• Improvements to the local area</li> <li>• Services on my doorstep</li> <li>• Money</li> </ul>



## Appendix P: Health trainer diary template

Front and back cover (printed in colour as an A5 booklet):



Interior pages:

<div data-bbox="363 1637 485 1778" data-label="Image"> </div> <div data-bbox="454 1218 489 1603" data-label="Section-Header"> <h3>Instructions for completion:</h3> </div> <ul data-bbox="526 1162 1158 1718" style="list-style-type: none"> <li>• The purpose of this diary is to help us to understand the things that health trainers <u>say</u> and <u>do</u> to try to help people achieve their goals.</li> <li>• You should complete an entry <u>each time you speak</u> to your client, even if it's over the phone.</li> <li>• Please try to complete the diary <u>as soon as possible</u> after your session with the client ends.</li> <li>• We are <u>not</u> interested in personal information about your clients. If any sensitive issues are discussed, please make a note of this (e.g. by writing "sensitive issues were discussed") but you do not need to go into any detail.</li> <li>• Please try to avoid using <u>names</u> or any other information that could identify particular individuals when you are completing the diary.</li> <li>• You will be given a <u>unique client ID</u> that you should use instead of the client's name.</li> <li>• You can print out the diary and fill it in <u>by hand</u>, or complete it <u>electronically</u> if you prefer.</li> <li>• Once you have completed the diary, please get in touch with the researcher (Shelina Visram) on 0191 215 6682 or email <a href="mailto:shelina.visram@northumbria.ac.uk">shelina.visram@northumbria.ac.uk</a>.</li> <li>• She will either collect the diary from you or provide a pre-paid envelope so you can return it to her.</li> <li>• You can also contact Shelina if you have any questions or concerns about completing the diary.</li> </ul> <p data-bbox="1208 1169 1260 1718">Thank you for helping us with our study by agreeing to keep this diary.</p> <div data-bbox="1347 1713 1362 1727" data-label="Page-Footer"> <p>2</p> </div>	<div data-bbox="448 504 475 954" data-label="Text"> <p>What was the purpose of this particular session?</p> </div> <div data-bbox="601 609 628 954" data-label="Text"> <p>What did you discuss or do together?</p> </div> <div data-bbox="828 459 855 954" data-label="Text"> <p>How did you support the client to achieve their goals?</p> </div> <div data-bbox="1056 622 1083 954" data-label="Text"> <p>What was the result of the session?</p> </div> <div data-bbox="1347 952 1362 967" data-label="Page-Footer"> <p>3</p> </div>
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## Appendix Q: Transcribing key

Int:	Interviewer
Pseudonym:	Service user interviewee
Role (HT/Manager):	Staff interviewee
...	Short pause
... ..	Long pause
[...]	Break in transcription
_____	Gap in transcription (could not hear what was said)
[Text]	<ol style="list-style-type: none"> <li>1. Text removed to preserve anonymity, e.g. "I spoke to [name of health trainer] yesterday"</li> <li>2. Information added to provide clarification, e.g. "She is 46 [years old] today"</li> <li>3. Non-verbal gestures or actions, e.g. "Look at this [indicating towards leaflet]"</li> </ol>
(Text)	Sounds, e.g. laughter, crying, coughing, etc
<i>Italics</i>	Emphasis, e.g. "I <i>really</i> don't like that"

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