Utilising Normalisation Process Theory to understand the patient journey for high-risk individuals participating in the NHS Health Check programme

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List of figures and tables

List of Abbreviations

BME	Black and Minority Ethnic
BMI	Body Mass Index
COREQ	Consolidated Criteria for Reporting Qualitative Research
CVD	Cardiovascular Disease
CVR	Cardiovascular Risk
DH	Department of Health
GP	General Practitioner
HDL	High Density Lipoprotein
HHC	Healthy Heart Check
ICD	International Classification of Disease
IPA	Interpretative Phenomenological Analysis
LA	Local Authority
LDL	Low Density Lipoprotein
MOT	Ministry of Transport
NHS	National Health Service
NHSHC	National Health Service Health Check
NPT	Normalisation Process Theory
NRES	National Research Ethics Service
PCT	Primary Care Trust
PHE	Public Health England
UK	United Kingdom
UK NSC	United Kingdom National Screening Committee

Publications

Findings from the NHS Health Checks work have been published in academic journals and presented at academic and practice conferences. I was invited to present my findings at Public Health England's national NHS Health Check conference in 2014 and also Public Health England's regional NHS Health Check event. I was also invited, along with Professor Janet Shucksmith (Director of Studies at the time) to host a Fuse Quarterly Research Meeting on NHS Health Checks which was attended by national and local policy makers, practitioners, and academics. Below is a list of publications arising from the work. A copy of the publications is presented in Appendix 1.1.

Peer reviewed journal articles:

McNaughton, R. J., & Shucksmith, J. (2014). Reasons for (non)compliance with intervention following identification of 'high-risk' status in the NHS Health Check programme. *Journal of Public Health,* 37(2), 218-225. (http://jpubhealth.oxfordjournals.org/content/37/2/218.full.pdf+html)

McNaughton, R. J., Oswald, N. T., Shucksmith, J. S., Heywood, P. J., & Watson, P. S. (2011). Making a success of providing NHS Health Checks in community pharmacies across the Tees Valley: a qualitative study. *BMC Health Services Research, 11,* 222.

Conference presentations:

McNaughton, R. J., Gray, J., & Shucksmith, J. S. (2014). *Evaluation of the NHS Health Checks programme: cost effectiveness and patient compliance studies*. Paper presented at the Public Health England Regional Network Event, Durham.

McNaughton, R. J., Shucksmith, J. S., & Steven, A. (2014). *NHS Health Checks in Tees: acknowledging the patient journey*. Paper presented at the fuse Quarterly Research Meeting, Glass Centre, Sunderland.

McNaughton, R. J., Gray, J., & Shucksmith, J. S. (2014). *Evaluation of the NHS Health Checks programme: cost effectiveness and patient compliance studies.* Paper presented at the Public Health England: National NHS Health Checks Conference, London.

McNaughton, R. J., Gray, J., & Shucksmith, J. S. (2013). *Evaluation of the NHS Health Checks programme: cost effectiveness and patient compliance studies*. Paper presented at the Tees Valley Shared Service (Commissioners), Stockton-on-Tees.

McNaughton, R. J., Shucksmith, J. S., & Steven, A. (2013). *Diagnosing uncertainty: experiences of engaging with a CVD screening programme*. Paper presented at the BSA Medical Sociology Conference, York.

McNaughton, R. J., & Shucksmith, J. S. (2012). *Patient experiences of the Healthy Heart Check programme: eary findings*. Paper presented at the Tees-wide GP stakeholder event, Middlesbrough and Stockton-on-Tees.

McNaughton, R. J., Shucksmith, J. S., & Steven, A. (2012). *Patient experiences of cardiovascular disease screening and understanding of CVD risk*. Paper presented at the BSA Medical Sociology Conference, Leicester.

McNaughton, R. J., Shucksmith, J. S., & Steven, A. (2011). *Patient's reactions to the implementation of Health Heart Checks: an application for Normalisation Process Theory?* Paper presented at the fuse Knowledge Exchange Conference, Sunderland.

Invited encyclopaedia entry:

McNaughton, R. J., & Shucksmith, J. (2014). Utilization of Heart Disease Prevention Services. In W. C. Cockerham, R. Dingwall, & S. R. Quah (Eds.), *The Wiley Blackwell Encyclopedia of Health, Illness, Behavior, and Society*. London: John Wiley & Sons, Ltd.

Evaluation reports arising from NHS Health Checks:

McNaughton, R. J., Gray, J., & Shucksmith, J. (2013). Evaluation of the NHS Health Checks in Tees: a cost effectiveness and patient compliance study. Middlesbrough: Centre for Health and Social Evaluation.

Oswald, N. T., **McNaughton, R. J.,** Watson, P. S., & Shucksmith, J. S. (2010). Tees Vascular Assessment Programme: main evaluation report. Middlesbrough: Centre for Health and Social Evaluation.

Abstract

Background: In 2009 the Department of Health introduced a national cardiovascular risk assessment, management, and reduction programme – the NHS Health Check. The programme aimed to reduce premature morbidity and mortality for those aged 40-74. Individuals who are identified to be at high risk (>20%) of cardiovascular disease are offered lifestyle advice and/or prophylactic medication to reduce their risk. This study aimed to understand the factors that influence individuals' engagement with the programme. Normalisation Process Theory was used as a theoretical lens to underpin the study and make sense of the findings.

Methods: A secondary analysis of data collected through 26 semi-structured interviews was conducted. Purposive sampling was undertaken of patients who had previously been identified, through the NHS Health Check Programme, as being at increased cardiovascular risk. Participants had been identified as high-risk, been offered lifestyle advice, lipid lowering medications, and had attended at least one annual review. Data were initially analysed thematically. Themes were then compared to Normalisation Process Theory constructs to assess if they could provide insight into engagement with the programme.

Findings: Findings explore the work undertaken by participants to engage with (or not) each stage of the NHS Health Check journey. Focus is on four main areas, which relate to Normalisation Process Theory constructs; the *sense making* and *working out participation* work undertaken to decide to attend the check and understand what it means to be identified as at increased cardiovascular risk, and the *doing it* and *reflecting on it* work undertaken to implement lifestyle changes, adhere to medication regimens and engage in surveillance and monitoring activity.

Conclusions: Normalisation Process Theory helped to surface important aspects of the NHSHC programme that influence participants’ engagement with the NHSHC and their subsequent journey throughout the process from: attending the assessment, being identified as at-risk, making sense of this ‘diagnosis’, and engaging in lifestyle changes and/or a pharmaceutically aided journey. Evidence from this study suggests that the at-risk individual should be viewed as a participant in a social system, and that this wider social system is integral to engagement, both positively and negatively, with all aspects of the programme.

1 Introduction

This thesis presents work undertaken to explore the experiences of individuals who had been identified as at increased risk of suffering an adverse cardiovascular event through the National Health Service Health Check (NHSHC) programme in four localities in the North East of England. This work is nested within a collection of projects that were undertaken between 2008 and 2014 that initially explored the roll out of the NHSHC programme in general practices, community pharmacies, community settings, and workplaces (Oswald et al., 2010, McNaughton et al., 2011, McNaughton and Shucksmith, 2014). The initial phase of evaluation was commissioned by a collaborative of four Primary Care Trusts (PCTs) and focussed on the barriers and facilitators experienced by those organisations tasked with providing the NHSHC in the early stages of roll out, in order to inform the commissioning process and development of the programme locally.

The second commissioned phase of work consisted of two linked projects. Firstly, a cost effectiveness analysis of local uptake data and recommended treatment pathways was undertaken to build a case for the continuation of the local NHSHC programme (McNaughton et al., 2013). The second linked project was a qualitative study commissioned to provide insight into the experience of those people invited to attend the NHSHC. It was acknowledged locally that it was essential to explore how individuals felt about the NHSHC assessment and subsequent intervention pathways, in order to inform the NHSHC offer through local providers (McNaughton et al., 2013, McNaughton and Shucksmith, 2015).

The commissioning of the qualitative evaluation element presented an opportunity to undertake this PhD study. The evaluation required that the experiences of ‘at-risk’ individuals be explored and reported to inform the local programme. However, it also provided the opportunity to explore this in a much more theoretically driven way than required by the commissioning PCTs. It was agreed that the data should be analysed and presented initially for evaluation purposes of the commissioners (McNaughton et al., 2013) but that a theoretically driven secondary analysis was to be undertaken for the purposes of the PhD. This theoretically driven analysis was designed to focus on how NPT could illuminate the processes ‘at-risk’ individuals went through to make sense of being at increased CVR and also to analyse their engagement with aspects of the programme.

As this decision to pursue a PhD was agreed at the outset of the evaluation work it allowed the study to be designed to serve both purposes; that of the commissioned evaluation and the PhD study. The academic focus and identification and use of Normalisation Process Theory, the theoretical lens described in chapter 4, to inform the study design, analysis, and interpretation is what sets this PhD study apart from the evaluation work and is my original contribution.

1.1 Reflection on the [contemporary] context

The project was carried out against a backdrop of political change and both national and local reorganisation of the PCTs. The NHSHC programme was conceived under a Labour Government in 2008 and rolled out nationally in 2009. The programme was still in its infancy when, in 2010, the Conservative/ Liberal Democrat Coalition came into Government in England. There were many uncertainties about the future shape of the NHS generally and, specifically, the future of the national commissioning of the NHSHC assessment. As described in Chapter 2, responsibility for the commissioning of the NHSHC assessment stage was given to Local Authorities (LA) whilst the responsibility for commissioning the annual review became the responsibility of NHS England, meaning that the assessment, intervention, and follow-up became disjointed. Public Health England became concerned with conversion of invitation for a NHSHC into assessment, rather than being concerned with the longer-term outcomes of intervening. This meant that focus shifted away from the longer term outcomes of the programme and is reflected in the national evaluation work that was commissioned and undertaken (Chapter 2). Nationally funded evaluation work focussed on assessing population level effects and cost effectiveness of the programme as it was rolled out nationally. However less focus was put on the individuals who were part of the programme and the success (or not) with which they engaged with the programme, embraced (or not) the interventions, and managed to sustain (or not) their engagement over the longer term.

1.2 Research questions, aims, and objectives

The primary concern of this thesis is to explore the factors that influence the experience of those people identified as at increased risk of adverse cardiovascular events through the NHSHC programme. Therefore, I set out to explore the journey that individuals embark on from invitation to attend an NHSHC through their diagnosis of risk, adherence (or not) to lifestyle advice and lipid lowering medication, to their experience of annual review. Normalisation Process Theory (NPT) was used as a theoretical lens to view and illuminate the processes that people go through to implement, embed, and integrate the practices of the NHSHC programme and any recommended medication or lifestyle changes in the context of their lives. An explanation of this theoretical choice is provided in chapter 4. There were two primary research questions, which are outlined on the following pages.

Research question one

What factors influence high-risk individuals' engagement with the NHSHC programme?

Aim	To understand and explore at-risk individual's experience of engaging with the NHSHC programme in order to identify factors that promote or inhibit engagement with assessment, risk identification, intervention, and sustained engagement over the longer term (1year+).
Objectives	1. To examine how individuals make sense of the NHSHC programme 2. To understand how individuals interpret being at-risk of a cardiovascular event 3. To explore how individuals make sense of lifestyle advice and/or intervention 4. To catalogue how individuals make sense of the prescription of prophylactic medications 5. To discover how individuals integrate and sustain lifestyle changes and/or prophylactic medications 6. To determine how individuals engage with ongoing monitoring of risk

Research question two

Can NPT provide insight into engagement with the NHSHC programme?

Aim	To utilise the constructs of NPT to unpack and explore reported engagement with the NHSHC programme.
Objectives; to explore NPT's appropriateness to explain experience of:	To explore the appropriateness of NPT to explain people's understanding of and engagement with various stages of the patient journey towards living with a diagnosis of risk, i.e. 1. Invitation to attend assessment 2. Receiving a diagnosis of cardiovascular risk 3. Engagement with lifestyle advice and/or intervention 4. Engagement with prophylactic medication 5. Engagement with ongoing monitoring over the longer term

To answer these questions the thesis begins, in chapter 2, by providing contextual information about the introduction and implementation of the NHSHC. Chapter 3 then presents an overview of what is known about the experience of becoming and being a patient, before introducing, in chapter 4, the core theory – NPT – which has been used to structure the study design and to analyse the results. In chapter 5 I discuss the method employed to undertake this study. Study findings are presented in chapters 6 and 7, and these are followed by a discussion of findings (chapter 8) in relation to the theoretical framework provided by NPT. Finally, conclusions and implications for theory, policy and practice, training, support, and education, and research are presented in chapter 9. In the following pages, an overview of each chapter is presented to provide a roadmap of the thesis.

1.3 A roadmap of the thesis

Chapter 1 has situated the research in terms of how the project came about, has discussed the rationale for undertaking the study and presented the research questions, aims, and objectives.

In Chapter 2 I move on to explore cardiovascular disease and its impacts both globally and in the United Kingdom (UK) before turning attention to the development of a national cardiovascular risk assessment programme – the NHSHC. The structure of the national programme is described alongside how the programme is delivered in the local context. Evidence about uptake and engagement from the first few years of roll out is explored.

Chapter 3 turns to the sociological literature about what is known about 'being a patient'. Here the focus is on the concept and process of diagnosis, adopting a sick role, embodying illness and the work involved in being a patient.

In Chapter 4 Normalisation Process Theory is presented as the theoretical lens that underpins the study. The theory is described and explored, alongside literature about how it has been used in other studies. An interpretation of the core constructs of the theory is presented as well as a description of how those concepts have been interpreted and applied across the research process for this study.

Chapter 5 presents the methodology of the study, beginning with a discussion of the underpinning philosophical and theoretical foundations of the study before turning to the procedural methods employed to collect and analyse the data.

Chapters 6 and 7 present the findings from the study. Chapter 6 is concerned with participants' accounts of considering participation with the NHSHC and their experiences of being identified as at high risk of cardiovascular disease. Chapter 7 is concerned with levels of participation and adherence with lifestyle changes, prophylactic medications, and the annual review process.

Chapter 8 presents the synthesis of the findings chapters, using NPT as a framework to structure discussion.

Finally in Chapter 9, implications from the findings are presented. Implications for theory; policy and practice; training, support, and education; and research are discussed.

References and appendices complete the thesis. Peer reviewed journal articles that have been published by the PhD candidate arising from this study are presented as Appendix 11.1.

2 The NHS Health Check Programme

The primary concern of the thesis is not the NHS Health Check (NHSHC) programme itself, or its effectiveness (or otherwise), but rather the novel application of Normalisation Process Theory (Chapter 4), to explore the process of becoming a patient with a chronic condition. Chapter 2 provides background information. It is important to understand the wider context from which this data was collected – namely from patients participating in a novel but wide scale (and somewhat controversial) intervention who had undergone an NHSHC assessment and been identified as being at high risk of suffering a cardiovascular event in the next ten years.

To understand why and how the NHSHC programme came into being, this chapter starts by outlining the rates of cardiovascular diseases (CVD) both at a global level and at a national level in the United Kingdom (UK) and the global burden of the disease. This acts in part as a frame of reference which explains why CVD reduction and prevention in the population has become such a targeted priority. Following on from that, the development of a national systematic cardiovascular risk assessment, reduction and management programme is described, as well as the Tees Valley's specific response to this programme. Moving on from this rather descriptive background to the development of the CVD risk assessment programme, the more contentious aspects of the programme are explored alongside academic literature pertaining to the medicalisation of health and illness, the classification of illness, and the rise of the risk factor concept in surveillance medicine.

2.1 Cardiovascular diseases

2.1.1 The global burden of cardiovascular disease

Globally, the burden of non-communicable diseases such as diseases of the cardiovascular system, cancer, and chronic respiratory diseases is huge and they are a major cause of morbidity and mortality (World Health Organization, 2011c). These diseases collectively account for around 63% of deaths each year (World Health Organization, 2011c, World Health Organization, 2011b), which equated to approximately 57 million deaths in 2008 (World Health Organization, 2007, World Health Organization, 2011c).

In particular, CVDs and their consequences; heart attack, stroke, vascular complications of hypertension (high blood pressure), hyperlipidaemia (high cholesterol), and diabetes mellitus - cause around 17 million deaths each year, equating to 1/3 of all recorded deaths (World Health Organization, 2013). Hypertension alone accounts for 9.4 million deaths and approximately 40% of the world’s adult population has been clinically diagnosed (World Health Organization, 2013). The number of people with a clinical diagnosis of hypertension has risen sharply over the past few decades from 600 million in 1980 to 1 billion in 2008 and has been attributed to an aging population and lifestyle factors such as poor diet and decreased physical activity (World Health Organization, 2013).

2.1.2 Cardiovascular disease in the United Kingdom

In the UK, cardiovascular diseases were the leading cause of avoidable mortality between 2001 and 2006. However, over that time period the death rate fell by 29%, meaning that by 2007 neoplasms (cancerous and non-cancerous growths) had overtaken CVD as the leading cause of mortality (Office for National Statistics, 2013), potentially as a consequence of diagnostic and surgical improvements. In the latest data, to 2015, CVDs remained the second highest cause of mortality with Alzheimer's and dementia taking the first place (Office for National Statistics, 2016). In 2008 cardiovascular diseases accounted for 34% of deaths in the UK, despite downward trends for metabolic risk factors, systolic blood pressure and total cholesterol over the time period to 2008 (World Health Organization, 2011c). In 2009, 180,000 people died from CVD, again representing one third of all deaths that year (Townsend et al., 2012). Treatment of CVD in 2014 cost the National Health Service (NHS) around £15 billion, a figure that is projected to rise to £18 billion by 2020, and thus representing a huge financial burden on the UK health system (British Heart Foundation, 2014).

The prevalence of CVD has been attributed to worldwide population growth, aging, and behavioural risk factors such as unhealthy diets, physical inactivity, overweight and obesity, smoking, and harmful levels of alcohol use, as well as persistent exposure to stress (World Health Organization, 2013) and this is mirrored in the UK experience. Risk factors for CVD are, for the most part, modifiable, which has led to increased efforts to change the behavioural habits of the population. It has become widely accepted that around 80% of these premature deaths could be prevented through the modification of behavioural risk factors such as poor diet, low levels of physical activity, tobacco and alcohol use, and also through the identification of underlying physiological conditions such as increased cholesterol and high blood pressure (World Health Organization, 2011a, World Health Organization, 2007, World Health Organization, 2011b, Department of Health, 2008c, Department of Health, 2009). Alone, each individual risk factor may not be damaging, but the adverse effects are often compounded because individuals present with multiple risk factors (World Health Organization, 2011a, World Health Organization, 2007, World Health Organization, 2011c, World Health Organization, 2013). In order to tackle the growing problems related to the effects of behavioural risk factors on the individual and society, a mix of population-based approaches to risk reduction is recommended by WHO. For example:

- raising of taxes on tobacco and alcohol
- promotion of policies on smoke-free workplaces and public areas
- banning or restricting the advertising of products such as tobacco, alcohol, and high fat foods
- mass health promotion advertising about reducing the intake of salt, and
- awareness programmes about physical activity and diet (World Health Organization, 2013, Barton et al., 2011, Jørgensen et al., 2013)

In the UK, the burden of CVD is felt disproportionately in disadvantaged communities, not least because modifiable risk factors such as poor diet, smoking and low levels of physical activity contribute significantly to the prevalence of CVD (Capewell and Graham, 2010, Department of Health, 2008c, Department of Health, 2009, Bajekal et al., 2012, Stafford et al., 2012). Cardiovascular disease mortality rates within the population as a whole have been falling by around 6% per year. However, this reduction is experienced differently between socio-economic groups, meaning that, as overall mortality rates fall, health inequalities are increasing (Bajekal et al., 2012). Structural conditions of class and poverty play a role in the engagement with ‘risk behaviours’ and subsequent development of CVD (Raphael, 2003) meaning that people in low income groups might have worse diets, engage in less physical activity, consume more alcohol, and are more likely to smoke tobacco products. Traditionally, as a society, we have looked towards health services to attend to concerns about heath and illness. However, much of the burden of ill health and disease can be attributed to structural conditions around where people are born, grow up, live their lives, go to work, and grow old (Marmot et al., 2008). The effects of social policy and socioeconomic constraints on health and illness have been recognised for centuries (Marmot, 2001). However, the Black Report (Black, 1980) demonstrated the unequal distribution of morbidity and mortality in the British population and suggested that the gap in these health inequalities was widening, rather than shrinking (McIntosh-Gray, 1982). Despite efforts to recognise and tackle the structural and social impacts on the experience of health and illness within the population since the publication of the Black Report, similar findings were demonstrated in the Acheson Report of the 1990s (Acheson, 1998) and Marmot Review of 2010 (Marmot, 2010).

In spite of calls to tackle the incidence of CVD through population level intervention programmes such as the NHSHC – though national in scope - focus on finding individual (potential) cases for ill health and changing individual behaviour to reduce this risk, thus placing responsibility for CVR reduction at the door of the individual, rather than attending to the structural and social determinants of health and illness. Moreover, it could be argued that an integrated approach to prevent ill health that reduces or eliminates the impact of structural and social forces on health and addresses individual behaviours would likely be most beneficial.

2.2 The NHS Health Check Programme

In the following section the NHSHC programme is described. The Template for Intervention Description and Replication (TIDieR) framework is used to organise the description of the NHSHC intervention (Hoffmann et al., 2014). The TIDieR framework is made up of 12 items as presented in Table 1.

Table 1: TIDieR framework description

Item	**Description**
1. Brief name	National Health Service Health check (NHSHC) The NHSHC is a cardiovascular risk assessment, management and reduction programme. It offers systematic identification of individuals, aged 40-74 years old, within the English population who are at increased risk (>20%) of suffering an adverse cardiovascular event in the next ten years. For those identified as at increased risk of CVD, the intervention is offered through lifestyle modification advice and prophylactic lipid lowering medication
2. Why	In April 2008, under a Labour Government, the Department of Health (DH) announced plans to introduce a national vascular assessment programme. In light of the prevalence of CVD in the UK population (section 2.1.2), the number of deaths attributed to it per annum (section 2.1.2), and the associated costs of treatment (section 2.1.2), reducing cardiovascular disease risk (CVR) and burden of illnesses attributed to CVD became a priority for the UK government. The NHSHC programme was formally launched in April 2009 (Department of Health, 2008d, Department of Health, 2008c, Department of Health, 2009). The NHSHC was introduced to facilitate the identification of individuals who were displaying early warning signs of CVD and to provide intervention consisting of lifestyle advice and prophylactic medication in order to reduce CVR (Department of Health, 2008c, Department of Health, 2009). **Economic rationale for the programme:** Projections prior to implementation of the NHSHC programme indicated that, once fully implemented, the programme was estimated to cost £332m per annum – a significant sum – however, the annual benefits of the programme were projected to be £3.7bn (Department of Health, 2008a). Importantly, this model was built upon the assumption of a 75% uptake of invitation to attend assessment (Department of Health, 2008a).

	Health gain as rationale for the programme: The NHSHC programme aspired to make an impact on both morbidity and mortality occasioned by CVD. In initial guidance documents, it was claimed that huge savings could be made to the healthcare system and many lives could be saved, through the introduction of a CVR assessment and management programme. Programme aspirations included: 1. prevention of at least 9,500 heart attacks and strokes a year (2,000 of which would be fatal) 2. prevention of at least 4, 000 people a year developing diabetes 3. earlier detection of at least 25,000 people a year with diabetes or kidney disease (Department of Health, 2008c) (p9). This was to be achieved through the identification of those at increased risk and intervention through lifestyle modification. **Intervention provision:** Guidance produced by the Department of Health recommended that, for those identified as high risk of CVR, intervention should be offered in line with current National Institute for Health and Clinical Excellence (NICE) guidelines, as those interventions were evidence based and deemed cost effective. These interventions are presented in Table 2 and are reproduced from Department of Health (2008d).
3. What (materials)	**Providers:** Provider organisations were offered the opportunity to attend several training events and away days hosted by the PCT (as was) to offer opportunity to discuss the terms of the Local Enhanced Service agreement, aspects of programme delivery, and be updated about local programme progress. Specific training was offered to those delivering the checks in GP practices to develop skills in motivational interviewing to foster behaviour change in those identified as at high risk of CVD. Each GP practice delivering the NHSHC in Tees was provided with two separate lists of patients, generated by Primary Care Informatics (as was), on a quarterly basis. The first list identified all eligible patients that were registered with the GP practice (>40 years old not previously diagnosed with diabetes or hypertension). The second list was termed the ‘indicative list’ (Chamnan et al., 2010a, Marshall, 2008) and identified those

	patients registered with the GP practice who were predicted to be at the greatest risk for CVD based upon an assessment of routinely collected data (age, height, weight, blood pressure). **Participants:** Each patient who was invited by their GP practice, through a targeted approach (i.e. the eligible or indicative lists) was sent a formal invitation letter by their GP practice. The letters were devised by each individual GP practice making the provision of invitation content inconsistent. However, more recently work has been undertaken to develop a national NHSHC template letter (Public Health England et al., 2015) to standardise the invitation process using principles developed by the Behavioural Insights Team (Service et al., 2014). During the second CVR assessment appointment, when the individual's risk score has been calculated and delivered (figure 1, appendix 11.3) generic health promotional literature may have been offered to facilitate discussions about healthy diet, physical activity, smoking cessation and alcohol reduction. The materials provided were at the discretion of the individual health providers
4. What (procedures	Those eligible for an NHSHC are provided with a CVR risk assessment through the collection and synthesis of lifestyle information, anthropometric measurements, and family history. Using this information, a personal calculation of CVR is attained using an approved risk equation (discussed later in this chapter), and, for those who are identified as being at increased risk, there is an offer of intervention through lifestyle advice, provision of prophylactic medication (statins), and ongoing monitoring of CVR into the future (annual review). During the initial appointment, individuals were often asked to fast before they attend, so that they could have a blood test to assess their blood lipid levels – a cholesterol test. In fact, guidance changed over the course of this study and fasting lipid tests are now not required under best practice guidance. Details about age, sex, smoking status, physical activity, alcohol intake, family history, ethnicity, Body Mass Index, cholesterol test, blood pressure, blood glucose are collected for risk calculation. At the second appointment, the individual's risk is discussed, this provides an opportunity for brief motivational interviewing, discussion about lifestyle

	changes that could have a positive effect on projected risk of CVD and, if necessary, the prescription of prophylactic lipid lowering medications (Department of Health, 2009). Everyone who attends an NHSHC assessment, regardless of their risk score outcome, are entered into a recall system so they can have their risk reassessed as per best practice guidance. Individuals identified as low or medium risk (<10% and <19% respectively) are entered into a 5 year recall for reassessment. Individuals identified as at right CVR (>20%) are entered into an annual recall for monitoring (see figure 1 and appendix 11.3). **Risk management:** regardless of identified risk score, all individuals who have received an NHSHC should be offered information about smoking cessation, exercise on prescription/ physical activity intervention, weight management on referral, lifestyle management advice that is appropriate to their needs. In addition, those at high risk are offered lipid lowering medications regardless of their cholesterol levels, for the purposes of prevention and/ or antihypertensives as appropriate (figure 1 and appendix 11.3)
5. Who Provided	**Provider(s):** GP practices, Pharmacy, community venues (outreach/ workplaces) (see item 7) this section describes provision within GP practices. **Expertise:** The initial risk assessment is split into 2 appointments (item 8). Delivery model varies between GP practices (item 9). Initial clinical testing (appointment 1) may be carried out by a trained and competent member of GP staff i.e. a Healthcare Assistant, Practice Nurse, General Practitioner.

	Delivery of risk assessment (appointment 2) is normally carried out by an appropriately trained Practice Nurse or General Practitioner. **Specific training:** appropriate medical competencies to carry out clinical aspects of the assessment (i.e. anthropometric measurements, blood pressure etc…). Training on use of risk calculator (item 6) risk delivery and motivational interviewing was provided by the PCT.
6. How	The NHSHC is provided on a face to face basis with each patient seen individually. Intervention may be offered in a group setting (e.g. exercise on prescription)
7. Where	The NHSHC is offered in a variety of settings. Nationally, the NHSHC is offered primarily through General Practitioner (GP) practices, but best practice guidance from DH suggests that, in order to provide this equity of access and to reach those members of the public who are reluctant to access GP services, the NHSHC should also be delivered through a variety of other settings, for example community pharmacy and community venues (Department of Health, 2008c, Department of Health, 2009).
8. When and how much	The NHSHC is broken down into two main components. Firstly the CVR assessment and then the annual monitoring. **Cardiovascular risk assessment:** two separate appointments with the health professional each lasting around 10 minutes and spaced two weeks apart to allow for blood results to be processed in the laboratory. The first

	appointment is for collection of information about risk factors and clinical testing; the second appointment is for delivery of results and provision of intervention. **Annual monitoring:** one ten minute appointment annually.
9. Tailoring	The delivery of the NHSHC across the UK is varied. Primary Care Trusts were initially tasked with developing a programme that was relevant to their individual population, giving the local commissioning bodies' scope to design and deliver the NHSHC programme in whatever way they deemed best for their population, whilst adhering to national standards to provide quality assurance (Artac et al., 2013a, Graley et al., 2011). Primary Care Trusts also had to be mindful of providing equity of access to their local population to avoid inadvertently increasing health inequalities (Capewell and Graham, 2010, Department of Health, 2009). **Invitation:** Indicative list: GP practices used this list to identify and target those individuals who could gain most benefit from the NHSHC assessment and intervention. These individuals are invited to attend a NHSHC assessment, normally in 'waves', dependent on the GP practice's policy. However, GP practice engagement with the indicative list is variable across practices, with some practices engaging much more than others (Oswald et al., 2010). Alongside a targeted approach, calling individuals in from the indicative list, many GP practices have also adopted an opportunistic method of inviting people for a NHSHC assessment when they become eligible by age, or attend a new patient check. In some GP practices new patients that fall within the target age range are offered an assessment at their new patient check (Oswald et al., 2010). The invitation letter that was sent to patients of each practice was developed 'in house' by each GP practice. There was guidance offered from the PCT, however, this was not compulsory.

	Risk assessment: The advice, provision of medications, and subsequent recall for review of CVD risk is tailored to the individual, based on their CVR calculation (discussed later in this chapter) **Intervention:** Provision if intervention – lifestyle advice and/or prophylactic medication could be tailored to the individual’s needs, whist complying with programme pathway (figure 1 and appendix 11.3). Access to lifestyle management services is dependent on local service availability.
10. Modifications	Following the healthcare reforms in 2013 which abolished the Primary Care Trusts, the responsibility for the commissioning of NHSHCs was moved from the NHS to Local Authorities (LA), despite the fact that the majority of the checks are carried out in GP surgeries, which remain part of the National Health Service. The way in which the NHSHC is commissioned has changed dramatically since its inception and it is perhaps worthy of a brief note at this point. Initially, Primary Care Trusts (PCT) commissioned providers of the NHSHC to deliver both the initial assessment of risk and subsequent intervention and follow-up reviews for those at high risk on an annual basis. However, in February 2013 the NHSHC became a statutory programme, mandated in legislation (Secretary of State, 2013). In this legislation, the commissioning of the initial assessment became mandatory for LAs, and is commissioned by local public health teams as part of their population level prevention work. However, the provision of intervention for those discovered to be at high risk is not covered by the same legislation. NHS England is responsible for commissioning any intervention required and annual review of the NHSHC (NHS England, 2014). Since the fragmentation of the NHSHC assessment, intervention and follow up, attention from Public Health England (PHE) has shifted from monitoring outcomes of the NHSHC and focussed on monitoring the conversion of invitations to assessment. Since its inception, the NHSHC has also become a vehicle for delivering other health promotion information e.g. about dementia (NHS Health Check, 2014).

	Programme level aspirations (item 2) were substantially revised in 2013, 4 years after the introduction of the NHSHC programme to: 1. the NHSHC programme could save 650 lives per year by preventing 1,600 heart attacks 2. prevent development of diabetes in over 4,000 people per year 3. aid in the early detection of at least 20,000 cases of kidney disease and diabetes (Public Health England, 2013).
11. How well (planned)	Monitoring of uptake of the NHSHC is monitored locally through Local Enhanced Service Agreements and nationally through PHE.
12. How well (actual)	Early evidence from local evaluation work suggests that the actual uptake figure was between 29% to 45% (Artac et al., 2013b, Dalton et al., 2011, Cochrane et al., 2013, Richardson et al., 2008), well below initial estimates. Like Tees, some other areas in the UK have been offering NHSHC assessments both opportunistically and through a targeted approach, utilising previously held patient data to 'pre-assess' patients and offer screening appointments. Kumar et al. (2011) reported learning from the Stoke-on-Trent roll out of the NHSHC. They suggested that developing both a targeted and opportunistic strategy to offer the check coupled with the opportunity for patients to utilise a drop-in clinic for assessment was both an effective and cost effective way of delivering the check. Targeted approaches are, however, dependent on the quality of the existing patient data used, to pre-assess patients to indicate those at highest risk. National NHSHC programme figures, as of January 2016 show that 51.7% of the eligible population have been offered an NHSHC assessment since PHE took over responsibility for the programme in 2013. A total of 25% of the eligible population have received an assessment in that same time period (NHS Health Check, 2016). Table 3 shows national figures to January 2016. This demonstrates much lower than expected uptake of the NHSHC. Aspirational targets of covering 20% of the eligible population each year, until total coverage of the eligible population was achieved by 2013 were put forward by DH in 2008. It was then intended that, subsequently,

	the programme would focus on those people who became eligible by entering into the eligible age cohort each year (Department of Health, 2008b). Again, this was based on an assumed uptake of invitation of 75% (Department of Health, 2008a). Evidently, these targets have still to be met. Artac et al. (2013a) reported that national coverage of NHSHC was, on average 8.2% in 2012 with great variation between PCT areas, ranging from 0%-29.8%. Still in 2015 that figure stands at just 25% of the population receiving an assessment (NHS Health Check, 2016). Cochrane et al. (2013) suggest that such low uptake demonstrates a lack of interest for this assessment in the population. Early evidence does, however, suggest that the NHSHC has been effective in engaging Black and Minority Ethnic (BME) groups (Cochrane et al., 2013, Artac et al., 2013b, Lambert et al., 2012).

Table 2: Recommended Interventions

Intervention offered	**Existing guidance**
Brief exercise intervention	NICE guidance PHI002 Four commonly used methods to increase physical activity, March 2006
Multi-component weight loss programmes	NICE clinical guideline CG43 Obesity, December 2006
Impaired glucose regulation (IGR) intensive lifestyle management	NICE clinical guideline CG43 Obesity, December 2006
Stop smoking services	NICE guidance PHI001 Brief interventions and referral for smoking cessation in primary care and other settings, March 2006
Antihypertensives for those with hypertension	NICE clinical guideline 34 Management of hypertension in adults in primary care: partial update, June 2006
Statins for primary prevention	NICE technology appraisal 94 Statins for the prevention of cardiovascular events, January 2006
Renin angiotensin system blockers for those with proteinuria	NICE guidance on chronic kidney disease

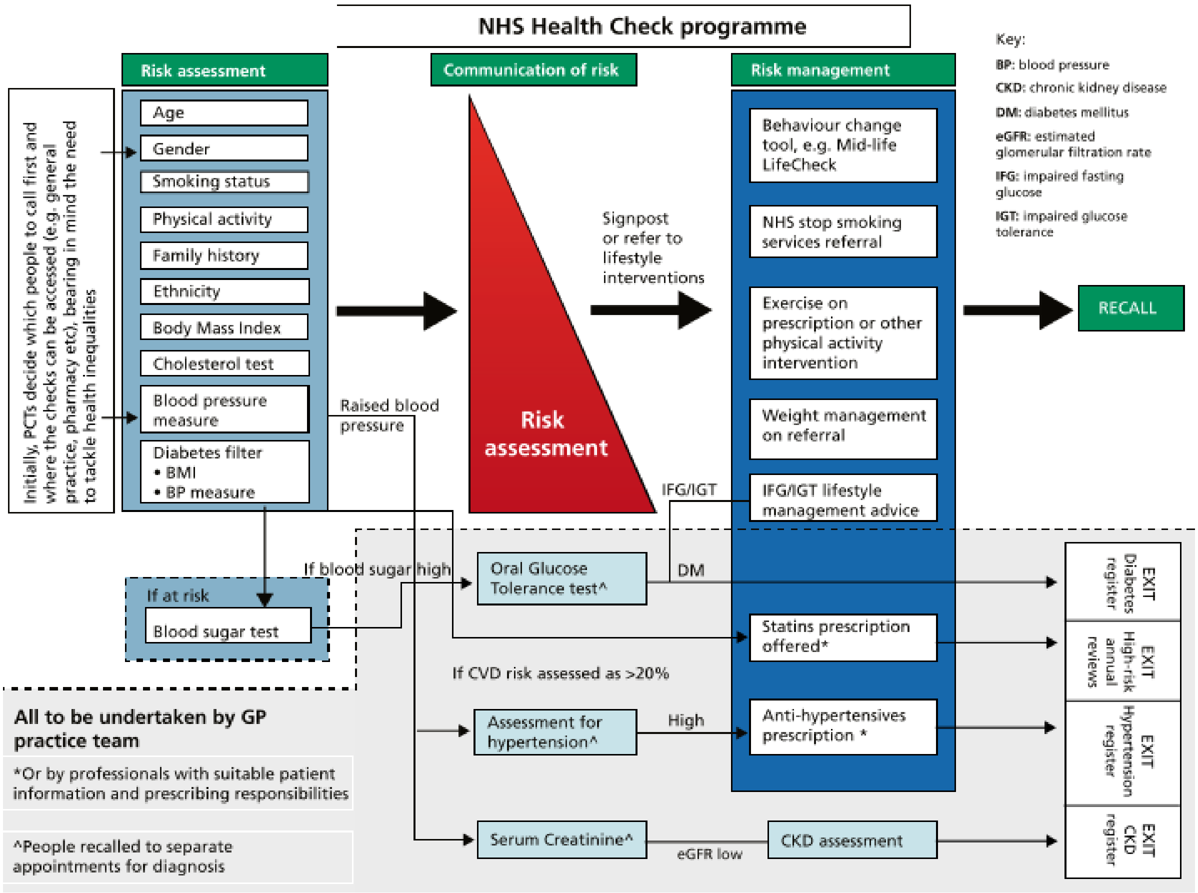

Figure 1: NHS Health Check pathway[1] [2]

Table 3: National NHS Health Check offers and assessments

	Number (%)
Eligible population	15579278
Number offered NHSHC	8053495 (51.7%)
Number accepted offer and received NHSHC	3887937 (25%)
% of those offered a check who accepted	48.3%
% uptake expected (2008 modelling)	75%

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[1] Source: Department of Health (2009), Best Practice Guidance, p4

[2] Figure 1 shows the pathway presented in the national guidance. Appendix 11.3 shows the local pathway that was developed for the Tees roll out of the programme, there is a slight variation to the Tees pathway as it includes assessment of alcohol intake. The decision to include assessment of alcohol within the local rollout of the NHSHC was taken by the PCT to tailor the check to their local population, discussion of this tailoring can be found in Item 9 of the TIDieR framework

Figured taken from NHS Health Check (2016)

2.3 Evidence from the first years of roll-out

The majority of published work, to date, from local and national evaluations of the NHSHC programme have focussed on coverage, uptake and conversion of invitations to appointments. Little has been published concerning patient reactions to their CVR assessment and their subsequent journey through making changes to lifestyle, adherence to medication, and engagement with annual review. The NHSHC has been suggested as a catalyst for change, especially in relation to making and sustaining dietary changes. These changes have been noted as being prioritised over engagement with physical activity as they are perceived to be easier to implement and sustain (Alford and Perry, 2010, Krska et al., 2014, Perry et al., 2014). Whilst in the Tees evaluation work with ‘at-risk’ individuals we found that dietary changes were the most common of the lifestyle changes to be adopted, many people were reluctant to make substantial changes in the belief that guidance about healthy eating was changeable. Instead patients opted to make small but sustainable changes such as reducing salt intake or limiting saturated fat consumption (McNaughton and Shucksmith, 2015). In this same sample, discussion about lifestyle changes were broached variably with participants with intervention via statins being the most common route of action to reduce CVR (McNaughton and Shucksmith, 2015).

It would seem evident that in order for people to instigate lifestyle changes or embark on medical regimens they must process the information about CVR and afford value to investing time, effort, and resources into change. The process of understanding CVR is not made in a rational way, as will be explored later in the findings section, Perry et al. (2014) suggest an interplay between emotional responses, cognitive responses and analytical understanding of risk. It has been proposed that the provision of clear and personalised information about CVR (Krska et al., 2014, McNaughton et al., 2013), and the utilisation of visual aids (Shaw et al., 2015, McNaughton et al., 2013) could positively influence cognitive understanding of CVR.

Findings from the early years of the NHSHC roll out indicate that provision of health checks through non-traditional providers, for example, community pharmacy and community outreach in places such as supermarkets, workplaces, and libraries are well received by those eligible for the checks (Perry et al., 2014). Outreach services based in the community have been observed as an effective mechanism to attract and recruit harder to reach populations such as younger (under 50 years old) men (Visram et al., 2014), the BME community (Hunt et al., 2013), and those living in areas of deprivation (Gidlow and Ellis, 2014) into the NHSHC (Dachsel and Lee, 2011). This community approach is perceived to be effective at allowing a spontaneous opportunity to engage with the NHSHC that would not have been prioritised had the individual needed to make a formal appointment to attend a GP practice (Perry et al., 2014). However, the main mode of NHSHC delivery is currently through GP practices and it is the experience of people accessing the NHSHC in this setting that is the focus of the thesis.

Graley et al. (2011) found that within one area (North West London) which was made up of eight PCTs, there was huge variation in the amount of budget allocated to implement and deliver the NHSHC programme. These findings suggest the likelihood of a ‘postcode lottery’ effect on the identification and therefore reduction of CVD. Whilst it is important to allow commissioners to have autonomy on service design and delivery, there are valid reasons for the setting of national minimum standards which emphasise equity of access.

2.4 The contentious nature of the NHS Health Check programme

It should be noted, at this point, that the NHSHC programme is not one of the UK National Screening Committee’s (UK NSC) approved screening programmes. In the UK, the UK NSC has the responsibility to advise the NHS and government about different aspects of screening such as; how a screening programme is defined, ethical implications and social impacts of screening as well as supporting the implementation of approved screening programmes in the UK (UK National Screening Committee, 2013). The UK NSC uses a standardised, 22 point, set of criteria to assess how viable, effective and appropriate a screening programme could be, set around four domains of assessment: the condition, the test, the treatment, and the screening programme (Appendix 2). In 2012, there were 12 approved screening programmes in the UK offered over the life course. Their availability varies between UK countries (UK National Screening Committee, 2012, UK National Screening Committee, 2013). In England, the screening programmes offered are shown below in Table 4.

Table 4: UK Approved screening programmes

	Life stage	
	Antenatal and newborn	**Young People and Adults**
Conditions	Downs syndrome Fetal Anomaly Ultrasound Scan Infectious Diseases in Pregnancy Antenatal Sickle Cell and Thalassaemia Newborn and Infant Physical Examination Newborn blood spot Newborn hearing screening	Abdominal Aortic Aneurysm Diabetic Retinopathy Breast Cancer Cervical Cancer Bowel Cancer

Alongside the approved set of screening programmes there are also three screening-related programmes of work that do not meet, for various reasons, the strict criteria to be adopted and approved by the UK NSC. These are; Prostate Cancer Screening, Chlamydia Screening and the NHS Health Check (UK National Screening Committee, 2013). The UK NSC did recommend the development of a vascular risk management programme in 2006 that would provide vascular risk assessment, risk reduction and risk management, but not a screening programme as it does not meet the UKNSC criteria (Davies et al., 2012). Capewell et al. (2015) argue that the NHSHC fails to meet several criterion in relation to the tests used to identify CVR and treatment offered (explored in more depth in section 2.10).

The NHSHC programme has raised a number of contentious issues that link into wider academic debates. For the purposes of the following section, the NHSHC programme and the issues that have been raised about it are explored under the UK

NSCs criteria for a screening programme; the condition, the test, the treatment, and the programme. Each section will explore the key issues raised by opponents and supporters of the programme and also the wider academic literature that links into the theme.

2.4.1 The condition

It is widely accepted that CVD is a clinical condition that is an important public health problem as it accounts for approximately 34% of UK deaths annually (Townsend et al., 2012). However, how a condition becomes classified and categorised as a condition is important to explore, especially as what the NHSHC programme actually identifies is not CVD but rather CVR. Cardiovascular risk is essentially a prediction of possible future illness based upon the synthesis of surrogate markers. The act of illness classification and categorisation requires a process of identifying or creating a problem that can be afforded a name and subsequently a treatment pathway. What constitutes a problem that is important enough to classify is culturally bounded and specific (Goldstein-Jutel, 2011). As Illich (1976) wrote:

> *Each civilisation defines its own diseases. What is sickness in one might be chromosomal abnormality, crime, holiness or sin in another* (p112).

The construction and management of health problems can be illustrated by the case of dyslexia, which in Western society is problematised and treated as a disorder. This disorder would, however, not be deemed as important in a society that did not place so much weight on the ability to understand the written word (Goldstein-Jutel, 2011).

It is only by developing a concept of what is normal, within a specific society or cultural group, that we can begin to classify and understand what is then deemed abnormal. Defining normality, through epidemiological inquiry, allows the imposition of thresholds and cut points, beyond which outliers and extreme cases can be described and explored and subsequently categories developed for these infrequent cases (Armstrong, 2011).

This is pertinent to the PhD study, especially in the context of the problematisation of one of CVRs surrogate markers – cholesterol. Cholesterol levels, ascertained from clinical testing of blood samples, are used to define an individual’s risk for cardiovascular disease and the associated complications that are attributed to elevated cholesterol levels. However, the cut off point for ‘normal’ cholesterol is contested between expert groups (Will, 2005). During the time of this study, the cut off point for the upper level of normal cholesterol has been lowered from a total cholesterol level of seven down to five. This demonstrates how the categorisation of a medical problem is subject to change and how such a small change in the categorisation of a problem can create huge numbers of ‘patients’ from a previously ‘healthy’ population (Smith, 2002a).

Therefore, how a society classifies and defines disease has a massive impact on how we view the population within it. Once a condition has been identified as problematic and adopted into a formal classification or categorisation system, the diagnostic label has the power to silence certain voices whilst giving credibility to others (Jutel and Nettleton, 2011). The classification of illness has the power to change the individual from a healthy member of society to one who is now a ‘patient’ with far reaching potential repercussions such as loss of insurance or employment, for example (Smith, 2002b). The power of the medical professions is kept through their elite medical knowledge, their power to diagnose, treat and provide access to services (Conrad, 1979).

To understand what constitutes a condition, illness, or disease it must first be acknowledged what it is to have health. Health is more than just the absence of illness. Illich (2003) writes that a healthy individual is one who shows the ability to cope with pain, sickness and death, all of which are an integral part of the ‘human condition’. Societally, we value health. As such we strive to make sense out of what it is to be healthy and more importantly we strive to understand what creates ill health and when it might strike (Rosenberg, 2002, Rosenberg, 2007, Conrad, 2011). Modern medicine has endeavoured to map and make sense of signs and symptoms of illness and their expected trajectories in order to treat them through medical intervention. Historically, through the practice of medicine, we have sought to find coherent, explanatory relationships between external threats to health or behaviours and their related consequences and outcomes (Rosenberg, 2007).

The process by which aspects of the human condition or symptoms of human existence become allocated to medicine so that they can be defined, categorised and ultimately managed by the medical profession has been termed ‘medicalisation’ (Goldstein-Jutel, 2011). The breadth of what is classified as a medical condition is constantly evolving (Armstrong, 2011, Eborall and Will, 2011). Medicine’s power to diagnose and claim conditions is a gradual process, encompassing and releasing conditions and syndromes within its elastic boundaries (Conrad, 1979, Smith, 2002b). The creeping boundaries of ‘medicalisation’ are constantly shifting, enveloping an expanding set of ‘conditions’ that have never previously been included within the medical domain. For example, ‘conditions’ such as; childbirth (Johanson et al., 2002), mental illness (Conrad, 2005), learning difficulties (Goldstein-Jutel, 2011), and even death (Clark, 2002) have become medicalised.

Whereas other conditions have become demedicalised by shifts in culture. Which conditions are deemed as lying within the purview of the medical professions is symptomatic of the views and priorities of each specific society and relative to points in history. However, whilst these boundaries have the capacity to grow and expand they simultaneously have the capacity to contract and withdraw through the process of demedicalisation (Conrad, 1992). One famously cited example is the removal of homosexuality as a disorder in the seventh printing of the Diagnostic and Statistical Manual II, in 1974 (American Psychiatric Association, 1968), which demonstrates how societal shifts in morals and ideals can shape the boundaries of what is defined, categorised, diagnosed and treated as a medical ‘problem’.

The expanding remit of medicalisation has arguably led to better care and outcomes for many (Ebrahim, 2002). The drive of the medical profession to develop tools to identify and treat illness has led to the eradication of many illnesses and the control of others, at least in the Western world (Rosenberg, 2007). However, the concept of medicalisation, has been associated with negative connotations through its link with overtreatment and making patients out of healthy populations (Conrad et al., 2010). There is thus a tension between the benefits to society and to patient outcomes that is experienced by ‘conditions’ being adopted and treated by medical professions and the overburden and treatment of conditions (Moynihan and Smith, 2002).

Medicalisation has been associated with the control of what society deems as deviant behaviours. Thus, behaviours which once may have been described as immoral, sinful and unacceptable have instead been branded with a medical meaning so that they can be controlled, monitored and treated (Gabe, 2013, Rosenberg, 2007). Some have argued that the expansion of medicine’s jurisdiction is primarily a consequence of the medical profession exercising its power to define and control what constitutes health and illness in order to extend its professional dominance (Turner, 1995). Others have considered medicalisation to be the result of broader social and pharmaceutical processes to which doctors are simply responding (Gabe, 2013). The ever growing remit of medicine has also been responsible for huge increase in health spending of governments and insurance companies (Conrad et al., 2010).

Inevitably, the rise of medical intervention has not reduced total mortality rates; we still experience a 100% death rate. What it has achieved is to shift the age at which we meet our end and the predominant causes of death. Arguably, it has also created social divisions and inequalities in how we die. Modern medicine has facilitated the decline of many illnesses and diseases and in some cases eradicated the threat of many infections which historically would have exterminated huge chunks of the population (Illich, 2003). This, alongside the technological advances in clinical procedures that allow the identification and diagnosis of a new breed of ‘illnesses’ – the risk factor.

Future risk of disease can be defined as a probability of a future event occurring, often expressed as a numerical value, or percentage chance of suffering an adverse event within a given time period (Spiegelhalter and Riesch, 2011). Recent decades have seen a sharp rise in interest in risks and risk factors, as demonstrated in a proliferation of academic literature, this obsession, it has been noted, itself reaching epidemic proportions (Skolbekken, 1995). Probabilities and percentages are helpful tools for policy makers when considering population level planning and allocation of resources (e.g. what proportion of a population might eventually require care for diabetes or cancer). However, these concepts may be less helpful in communicating possible health outcomes to individuals because population based probabilities are incapable of incorporating the specific circumstances of the individual (Heyman et al., 1998). Rather, we need to develop ways of looking beyond the expression of risk as a probability of a future event and acknowledge the effects of wider determinants of health on the individual (Aven, 2013).

It is clear that the process of medicalisation has the power to determine what is deemed to be a bona fide medical condition in need of intervention and treatment at any given time. This process of medicalisation leads to the categorisation of illnesses, giving them validity. In terms of CVR identification, which is the prediction of a possible future event rather than the identification of a physiological condition, it is clear that the medical profession has identified it as a ‘condition’ that is necessary to tackle. However, it is unclear if the general population accept this classification of CVR in the same way (explored in Chapter 3). The identification of *future risk* is pertinent to this thesis because it links to uncertainty rather than certainty of an event occurring or having already occurred which could influence the level of engagement with all aspects of the NHSHC programme. The following section focusses on the tests undertaken to identify CVR in the NHSHC programme.

2.4.2 The test

It has been argued that the testing offered as part of the NHSHC programme is not demonstrated to be either adequate or acceptable as the tools used to calculate CVR are imprecise at an individual level (Capewell et al., 2015) and low uptake of assessment suggests a lack of interest in the population (Cochrane et al., 2013). The NHSHC assessment involves a risk calculation based upon measurement of BMI, blood pressure, smoking status and lipid levels, alongside socio-demographic variables and anthropometric measurements (Department of Health, 2008c). These measurements are entered into a risk equation for calculation.

There are several available CVR calculators on the market that generate an individual’s ten year risk score, for example Framingham, JBS, QRISK2 (Davies et al., 2012). Each risk calculation is based upon a different equation, using varying surrogate risk factor markers within it. Initially it was recommended that the Framingham 1991 calculation be used in the NHSHCs. However, the Framingham equation has a tendency to overestimate risk in low risk populations and underestimate risk in high risk populations (Brindle et al., 2006). The underestimation of risk in high risk populations is especially pertinent when considering the reduction of health inequalities. For populations such as South Asians, other BME groups and all those living within deprived areas of the UK the underestimation of risk, when they could be at highest risk, is problematic (Davies et al., 2012). The QRISK2 calculation, which incorporates ethnicity, family history and deprivation into its calculation (Davies et al., 2012), is now recommended for use in the UK. The calculation is thought to be superior to the Framingham at *accurately* predicting ten year cardiovascular risk in a UK population (Collins and Altman, 2010, Collins and Altman, 2012, Scott, 2010, Jackson et al., 2009, Gholap et al., 2011, Wald et al., 2011). In March 2014 a new calculator, JBS3, was launched, which not only provides a ten year risk score but also provides a lifetime risk score alongside generating an individual's 'heart age' in years (Joint British Societies for the prevention of cardiovascular diseases, 2014).

The process of using surrogate markers to predict the risk of a future adverse event also locks into wider academic debates about the rise of surveillance medicine. Armstrong (1995) describes this rise of surveillance medicine, a medicine that is concerned with identification with precursory signs of illness – so called risk factors. Technological advancements have allowed this shift in focus from the outcomes of illness to a new space, as Armstrong describes it, a fourth dimension outside of the body – time. This is a space before any disease has taken form but where risk factors may point to the potential for disease. Technological advancement and the development of pharmaceutical intervention have been identified as facilitators of this increase in the jurisdiction of medicine and become drivers for medicalisation (Conrad, 2005), suggesting that technology and drugs were once responsive to need but that now they have been identified as drivers in the creation of conditions.

Moreover, in addition to these ‘supplier’ issues, there has been a rise in what is termed the ‘health consumer’ and there is more consumer demand for medical products and services than ever before (Conrad, 2005). Now, more than ever before, technology has the power to identify illness and precursors of disease. Skolbekken (1995) argues that technological developments have facilitated a shift in our beliefs about health and illness. The advancements in science and technology have shifted attention away from risks that are outside of our control that are situated outside of the body to factors that are inside of our bodies and within our control. By their nature, the use of surrogate markers is not fool proof, and identification of risk is not a guarantee that disease will develop. Rather, it shows evidence of a process that is assumed to be a predictor of disease (Temple, 1999). Indeed, risk of disease, as identified through surrogate markers, or genetic testing may be problematic. Traditionally, diagnostic boundaries, which trigger the validation of treatment through medical intervention, have expanded to include milder instances of disease or new categories have been defined to encompass pre or proto disease (Armstrong, 2011, Melzer and Zimmern, 2002, Rosenberg, 2007). Grimes and Schulz (2005) and Freemantle and Calvert (2007) both indicate that the use of surrogate markers is more useful to market interventions than it is in improving patient outcomes. This treatment of risk is explored in the following section.

The previous section highlighted how CVR has been identified as appropriate for medical intervention; however, the tools currently available to identify CVR in the population are imprecise and widely contested. Technological advancements have been shown to have the power to identify disease and illness before it physically manifests in the body. However, the CVR risk calculators used in the NHSHC programme rely on the computation of surrogate markers for CVD to offer a prediction of future risk expressed as a percentage which may or may not be reliable. This raises questions as to the appropriateness of rolling out a country-wide risk identification and management programme that relies on calculator tools that work better at a population level rather than at an individual level.

2.4.3 The treatment

The ‘risk factor’, essentially a surrogate marker, has been adopted within the medical sphere as synonymous with disease itself and managed and treated as such (Aronowitz, 2009). However, the treatment options offered within an NHSHC have been argued to be unacceptable. Studies have shown that behavioural interventions (diet and physical activity) often lead to short term behaviour changes; however, these changes are rarely sustained over the long term (Booth et al., 2014, Heath et al., 2012). Similarly, reduction of alcohol consumption through Brief Intervention has been shown to make only a small difference in the amount of alcohol consumed (Platt et al., 2016). Evidence also suggests that patients actively and successfully conceal their drinking behaviours from their healthcare providers (Haighton et al., 2016). There is evidence that smoking cessation offered within a healthcare setting that is mindful of people’s preferences and needs is effective in helping people to quit smoking for good (National Institute for Health and Care Excellence, 2018). Adherence to statins for primary prevention is also low (Benner et al., 2002). Added to this, general health checks as a mechanism to reduce morbidity and mortality in the population have been demonstrated to be ineffective (Krogsbøll et al., 2012). For a programme such as the NHSHC which relies on the impact of sustained behaviour change this means that the full intended positive outcomes of behaviour change on CVR may never be fully realised.

Oliver (2009) argues that annual health checks are contributing to the creation of patients out of an elderly population that is actually feeling fit and well. He states “they [patients] may feel reasonably well, but the NHS does not permit such euphoria” (p603). He argues that, once identified as an ‘at-risk’ person, individuals who entered the doctor’s office as happily aging people leave as a patient, with a treatment pathway which could, in turn, lead to feelings of being scared or uneasy, instead of comfortably aging. Individuals are, it is argued, being actively recruited into risk states (Aronowitz, 2009). This warning about turning healthy elderly people into patients and the dangers of over-prescription of medicines has also been echoed in the national press (Dawson, 2013, Smith, 2009).

Not all changes that occur to an aging body necessitate treatment, and certainly, some natural processes are actually beneficial. Oliver (2009) discusses how, as the body ages, the cardiovascular system becomes more rigid. If through medical intervention mild hypertension is reduced this could actually lead to vertigo in elderly people. Vertigo is dangerous in an aging population where falls can lead to disability.

As previously discussed, the main treatment offers through the NHSHC programme are behavioural advice and prescription of lipid lowering medications. Within the UK setting, the link between cholesterol and the effects of raised cholesterol on the body are familiar and well-rehearsed through health promotion campaigns and advertising through the media. Our supermarket shelves are crammed with products from bread and cereals to yoghurt and butter substitutes all claiming to reduce cholesterol, and improve heart health (Sainsbury's, 2017). For example, whilst cholesterol and the need for cholesterol reduction may sit firmly in the public consciousness, in recent times focus has shifted from reducing overall cholesterol levels to lowering low density lipoprotein cholesterol (LDL) (bad cholesterol) and increasing high density lipoprotein cholesterol (HDL) (good cholesterol) (Kritharides, 2014). It is also widely accepted that statins are both a safe and effective treatment for hyperlipidaemia (high cholesterol) and primary prevention of CVD (Taylor et al., 2011b).

As discussed, the links between saturated fat, cholesterol, and diseases of the cardiovascular system are well rehearsed in Western society. However, just because these ‘causal’ links have been drawn and accepted into the wider public and professional consciousness, it does not mean this ‘taken for granted’ knowledge is not contested. Health historian Greene (2007) maps a long and tempestuous history of cholesterol’s demonisation, from its identification as an marker that has been associated with CVD and the development of pharmaceutical interventions to ‘treat’ it. He writes;

> *The average consumer is not conversant with the chemical structure of this five ringed sterol [cholesterol] or its role in the biosynthesis of bile acids, sex hormones, and gallstones, chances are that he or she knows cholesterol to be an agent of progressive disease of the heart and blood vessels, to be avoided in one’s diet and minimised in ones bloodstream to prevent illness and promote longevity* (p151).

Cholesterol was first identified in the Framingham (1957) studies and identified as one of the top two “pre-pathological” categories, along with hypertension, that was predictive of CVD (Greene, 2007). Unlike other risk factors such as hypertension, diabetes, smoking, gout, and obesity which were branded as risk factors for CVD in the Framingham studies and had enjoyed a huge increase in promotion as preventable risk factors with prophylactic intervention available, cholesterol did not have an appropriate treatment available. Treatments that were available were intolerable, dangerous, or simply did not work. Cholesterol as a marker for CVD was subsequently shelved (Greene, 2007). Many treatments have been developed over the years and had limited success in managing cholesterol, and even those treatments that did show clinical effectiveness were often unpalatable:

> *The dose [of cholestyramine] is very large, and patient compliance is very low, because they don’t want to take all of this stuff. The side effects: it has an odor of rotten fish, which we had some trouble getting rid of it. It was a granular material, which sandpapered a part of your anatomy on the way out, it also caused fecal impaction in old people…but still, nevertheless, it’s still a drug that actually works. It’s safe, it’s not absorbed, it’s safe.* (Alfred Roberts, Merck, Sharpe, & Dohme Cholesterol Project Manager (1987) Cited in; Greene, 2007, p169).

It was not until 1987, when Merck launched lovastatin, that cholesterol had a more palatable treatment available. From that point, under heavy marketing and promotion, cholesterol enjoyed a process of categorisation and adoption into the medical domain as a modifiable risk factor for CVD.

The causal link between consumption of fat, the body's production of cholesterol, and subsequent development of CVD has not been proven. There are correlations between the three variables (Greene, 2007), and these associations are documented at a population level. However, they are not "sufficiently causal at the individual level" (Rockhill, 2001, p336). Historically, several trials were conducted to assess the impact of lifestyle intervention; diet, smoking, reduction of blood pressure but showed negligible results in reduction in morbidity and mortality (Greene, 2007). Nevertheless, diet, physical activity, and lipid lowering medications have become synonymous with CVR and CVR reduction and prevention.

Advice on the threshold for prophylactic statins treatment, within the NHSHC, has changed during the period of this PhD study from 20% to 10% (National Institute for Health and Care Excellence, 2016), now including those previously deemed at low CVR. This decision has been controversial, Abramson et al. (2013) suggest that the benefits derived from treating a low CVR risk population with statins are minimal, whereas the potential to cause harm is increased in this population, raising an ethical question about harm/benefit ratios. Their analysis shows that to prevent one serious cardiovascular event, 140 low CVR patients would need to be treated for five years with statins.

It seems logical that adherence to medication regimens is essential to the effectiveness of intervention. To reap the supposed benefits of prophylactic statin intervention, patients need to take their medication regularly and for sustained periods (Ho et al., 2009, Cramer et al., 2008). The monetary costs of non-adherence to medical intervention mean that this is not just an effectiveness issue but also represents a huge cost to the healthcare system that provides the medication. Hovstadius and Petersson (2011), in their Swedish population study, conclude that secondary non-adherence (where prescriptions are picked up by the patient but never taken) should be the focus of non-adherence cost reduction activity. They suggest that this specific and costly type of non-adherence is associated with free provision of medications, in that those prescribed free medications are less likely to adhere to the regimen.

Sustained adherence with statins treatment is generally low, with many patients discontinuing use within six months of initial prescription (Benner et al., 2002). In their study exploring adherence to simultaneous antihypertensive and lipid lowering medications, Chapman et al. (2005) found that patients with previous evidence of CVD were more likely to adhere consistently to their prescribed medication regimen than when statins were used for primary prevention. This finding has been replicated in other studies (Poluzzi et al., 2008), with one study reporting two year adherence rate for primary prevention at only 25.4% (Jackevicius et al., 2002).

Many reasons are proposed for discontinuation of statin treatment. In their cohort study of statin use and discontinuation analysing 107,835 real world patient records, Zhang et al. (2013) found that more than half of their sample had, at least temporarily, discontinued their statin. 17.4% of their study sample had a ‘statin-related event’ recorded within their record that may have contributed to the decision to discontinue statin therapy. Of those who discontinued, half reinstated a statin (reconfigured) and of those 90% of them continued with statin therapy at 12 months. Side effects such as gastric discomfort and muscular pain or heaviness of limbs have been attributed to statin use and cited as a reason for seeking reconfiguration or discontinuation of statin (McNaughton and Shucksmith, 2015, Mann et al., 2007).

Behaviour change interventions such as dietary advice, physical activity and brief intervention for alcohol consumption have been shown to instigate small but measurable changes in patients, however, these changes are often not sustained over the longer term. Conversely, the prescription of statins is thought to be both safe and effective for the primary prevention of CVD. However, studies have shown that adherence to statins is variable at best and low at worst. Many people who embark on a regimen of statin use experience side effects which are deemed to be intolerable and therefore discontinue their use. This raises questions for programmes such as the NHS Health Check that rely on such behaviour change interventions and medications to reduce individual CVR – if patients do not sustain the changes or take these medications over the longer term they are unlikely to reap the proposed benefits of CVR reduction.

2.4.4 The programme

Despite the aim of positively influencing the health of the population, the NHSHC has been met with voices of caution since its very inception. In 2012 the NHSHC programme came under very public criticism, when Krogsbøll et al. (2012) published the results of their systematic review which questioned the effectiveness of the programme and criticised the NHSHC programme for being rolled out based upon theoretical modelling, rather than evidence from randomised controlled trials.

Krogsbøll et al. (2012) highlighted evidence that suggested universal health checks were neither effective at reducing morbidity or mortality in the general population. This was further backed up by the findings of the inter99 trial that showed an intervention similar to the NHSHC programme had shown no benefit on morbidity or mortality (Jørgensen et al., 2014). Krogsbøll et al. (2013) went on to call for the abandonment of the NHSHC programme until such time as the evidence base for effectiveness of the programme is stronger. Rebuttals have been played out through the BMJ, with some defending the universality of the programme (Soljak et al., 2013) and suggesting that abandonment of the programme to wait for the evidence would be irresponsible (Waterall et al., 2015).

It has also been suggested that instead of delivering intervention to individuals, which relies on their sustained participation and engagement, population level intervention would be most appropriate (Barton et al., 2011, Capewell and Ford, 2011, Capewell and Graham, 2010, Jørgensen et al., 2013, O'Flaherty et al., 2013). In their view, changes to population-wide policies such as tobacco control and making healthy food choices affordable and accessible could promote cardiovascular health and would be more effective and cost effective than the NHSHC programme (Capewell et al., 2015). Tackling contributing factors to CVD and CVR in this way would, it is suggested, be effective in tackling health inequalities by acknowledging that environment and circumstance make many choices for us. Taking a true public health approach could positively influence the health of those most at need, who may not access the NHSHC (McCartney, 2014). Moreover, there has been a call from some quarters to develop a targeted approach, rather than a universal approach, to NHSHC delivery (Dalton, 2013). A targeted approach to inviting individuals for their check has been identified as more cost effective than offering the check universally, and has been demonstrated to effectively identify those at greatest risk by targeting invitations to deprived communities and family members of those with CVD (Chamnan et al., 2010b, Hingorani and Hemingway, 2011, Lawson et al., 2010)

To develop and implement a complex population-based intervention takes meticulous planning. Many warned that in order to be successful, the NHSHC programme needed to incorporate widespread advertising to raise awareness and normalise the new programme, an element of proactive case finding so as not to widen already disparate health inequalities, robust provision of appropriate lifestyle intervention and the development of robust IT systems (Patel et al., 2009, Khunti et al., 2011, Capewell, 2008). In our own evaluation of the NHSHCs in Tees, we identified the same factors as barriers to implementation in GP practices and community pharmacy (McNaughton and Shucksmith, 2014, McNaughton et al., 2011, Oswald et al., 2010).

Evidence has shown that intervention in the shape of universal health checks to identify CVR are relatively ineffective in reducing morbidity and mortality in the population. Rather, population level interventions that tackle the wider determinants of health (section 2.1.2) would likely lead to greater impact on the health of the population.

Chapter two has set the contextual scene about the NHSHC programme and how it came into being in the UK, how the programme is shaped and has evolved, and also highlighted some of the contentious issues around its development and implementation. It was noted earlier in this chapter that the majority of the evidence relating to the roll out of the NHSHC has focussed on the processes of implementation and neglected to focus on the experiences of those individuals who have accepted an NHSHC assessment and been identified as at increased risk. Any successes of the programme will essentially be brought to fruition only if those at-risk individuals implement and sustain changes to their lifestyles and engage with medications. This thesis is concerned with the patient journey from risk identification through making and sustaining (or not) changes post assessment. The following chapter introduces the idea of what it means to be a ‘patient’ and explores literature from the social sciences to provide further context to the thesis before moving on in chapter 4 to critique the theoretical lens used to underpin the analysis of data.

3 Being a patient

Chapter 3 explores some of the sociological literature that is pertinent to exploring what it means to be a ‘patient’ and some theoretical literature about how this is experienced. Modern western medicine is built around a biomedical model of health and illness (Portney and Watkins, 2009). This model assumes that there is specific and identifiable cause for illnesses that alter the anatomy and physiology of the body, in turn presenting symptoms which can be identified (Bury, 2013). Adoption of this conceptual framework of health and illness assumes a linear relationship between the cause of ill-health (pathology) and its resultant impairment (Portney and Watkins, 2009). ‘Health’ is often conceived as the absence of a biological abnormality, and it is assumed that illnesses have specific causes and subsequently end points. It is expected that through medical intervention illness can be treated, therefore stopping or reversing (curing) the biological process (Bury, 2013). In the UK, the medical profession has largely been built around the execution of this biomedical model. People expect and are expected to engage with a traditional pathway from identifying signs and symptoms of illness, undergoing medical testing, formal diagnosis, to treatment or intervention to halt or reverse illness.

This is, of course, a rather siloed way to conceive of health and illness and gives precedence to an objectivist epistemological explanation of health, illness, and treatment. The focus on a biomedical model neglects the contribution of social and environmental influences on health and illness. The following chapter is grounded in a socio-medical explanation of health and illness and what it means to become and ‘be’ a patient. Chapter 2 explored the medicalisation of conditions and briefly touched upon the process by which these become categorised, classified, and labelled. However further exploration of this is needed to unpack the effects of diagnosis and the patient journey.

For an illness to be recognised, diagnosed, and treated it must first be identified as problematic. Illness is socially defined and may range from physiological abnormalities, psychological disorders, to moral sickness. Each society deems what is and is not within the bounds of acceptability (Illich, 1976).

In modern western society, the classification and categorisation of health and illness is the privilege of the medical professions (Armstrong, 2011). Claiming power over people's bodies, medicine imposes labels on individuals or groups through the process of diagnosis, to identify physical or social conditions that are deemed to be in violation of what is acceptable for the time (Davis, 2011). A standard classification system for modern illnesses was first constructed in the 18th century. Over time this has been revised, updated and amended with the identification of new conditions. The International Classification of Disease (ICD) was developed as a standardised tool to catalogue these conditions (Armstrong, 2011). New disorders and illnesses are identified periodically. Thanks to technological advancement the scope of illness identification is ever expanding. Medical professionals now have access to a myriad of tools to facilitate their role i.e. blood tests and x-rays and routinely rely on technologies to accurately diagnose conditions (Goldstein-Jutel, 2011).

The pharmaceutical industry plays a major role in the creation, as well as treatment, of illness. Ebeling (2011) illustrates how pharmaceutical companies can create conditions, and thus demand for their product, by marketing signs and symptoms of ill health. If these symptoms are generic enough, a mass market can be created for their drug. Ebeling (2011) uses the recent case of the rebranding of the drug, Prozac, to fresh branding of Sarafem. The Prozac patent was coming to an end and so the manufacturer had to find novel ways to sell the drug, to avoid losses from Prozac generics being used. As such, Sarafem, a chemically identical drug to Prozac, had been approved, endorsed and marketed to treat a little known condition called premenstrual dysmorphic disorder (PMDD), illustrating how pharmaceutical companies promote disorders in order to create a market for their drug. Likewise, Greene (2007) recounts how statin was marketed for the control of cholesterol, a disorder that was not in the public consciousness until there was a drug that was available to treat it. In the UK, the role of cholesterol in the development of CVD has been heavily emphasised. Products to reduce cholesterol are marketed direct to consumers, e.g. Flora proactive, and lipid lowering medications are routinely offered to reduce cholesterol levels. Moynihan et al. (2002) warn of the dangers of ‘disease mongering’ alliances between pharmaceutical companies, doctors and consumer groups that take the newest ‘risk factor’ and market it as a disease in its own right. Goldstein-Jutel (2011) also highlights the effect of these alliances, below.

> *Helping people to consider themselves ill or at-risk of illness provides a platform for piggybacking commercial interests onto medical authority. And creating a disease category out of a self-identifiable statistical deviation such as weight enables the commercial exploitation of those afflicted* (p48-49).

Once a condition has been identified, categorised, and a suitable treatment developed, the first step to becoming an individual with a condition – or patient – is the act of diagnosis.

3.1 Diagnosis

The act of diagnosis, is central to modern medical practice, providing clarity, organisation, categorisation, and proposed course of action to an otherwise random set of signs and symptoms (Armstrong, 2011, Jutel and Nettleton, 2011, Rosenberg, 2007). Goldstein-Jutel (2011) describes this process as:

> *Like being handed a road map in the middle of the forest. It shows the way - but not necessarily the way out. It indicates what the path ahead is going to look like, where it will lead, the difficulty of the climb, and various potential turn offs along the way. Perhaps it identifies the destination, but not necessarily* (p1).

In this way, diagnosis can be understood to be an event that opens up doors of opportunity and access to treatments and services to manage the identified condition (Conrad, 2011, Rosenberg, 2007). Therefore, diagnosis not only provides a conceptual framework to organise symptoms into an illness or disorder, it also offers a proposed course of action – practical steps that can be taken to halt or navigate the illness trajectory. The 'space' created by the act of diagnosis is a place where differing knowledges, and practices converge with multiple vested interests, social values, and anxieties of different parties from which an ever expanding set of social consequences emerge (Jutel and Nettleton, 2011).

Diagnosis is thus a social act, constructed between a set of social actors i.e. government bodies, medical professionals, patients and wider social networks. Each has a role in deciding what deserves diagnosis, what can be diagnosed and subsequently what follows from diagnosis (Brown et al., 2011). Not only does medicine hold the power to legitimise illness through affording it a name and diagnosis, it also has the power to allocate resources, and treatment (Turner, 1995). This highlights how the process of diagnosis is an exercise that sets the professional apart from the layperson. Having the power to diagnose provides medical professionals authority in their superior medical knowledge and training, increasing the medical professional's status and introducing a power differential in the interaction with the layperson. However, whilst the act of diagnosis affords the medical professional power over illness and ultimately the individual’s body, it affords certain privileges to the patient too (Parsons, 1975). Diagnosis gives the individual access to resources, services and treatments permission to take sick leave from work, access to the sick role (described later in the chapter) and a label to identify with, or contest (Goldstein-Jutel, 2011).

Not all diagnoses are straightforward. Brown et al. (2011) describe how the act of diagnosis provides a place for contestation and compromise between actors (health professionals and laypersons). In cases where the opinion of the layperson and that of the medical professional are at odds, there is the opportunity to contest a diagnosis or treatment, especially when the individual receives a diagnosis that they were not expecting. This, however, is framed in the context of individuals that have sought a diagnosis of symptoms.

For the patient, the diagnostic event can be a powerful experience; an experience that can divide one’s life into ‘before’ and ‘after’ receiving the news.

> *"The verbal act of presenting a patient with a diagnosis is never a simple act of conveying value-neutral biomedical information. It is an act fraught with symbolism. If a person is told 'you have cancer' (or any life threatening disease) these words irrevocably alter that person's consciousness, view of the future, relationships with family and friends and so on. Moreover, the utterance marks a boundary. It serves to divide life into 'before ' and 'after', and this division is henceforth superimposed onto every rewrite of the individual's life story"* (Fleischmann cited in; Goldstein-Jutel, 2011; p10).

Diagnosis can mark a boundary and spur many chain-reactions in a person’s life. The effects of diagnosis reach far beyond the doctor’s surgery. As noted previously, diagnosis can provide access to resources, but also to the sick role and a host of other privileges but it can also have a huge effect on how the individual perceives themselves and their identity (biographical disruption is discussed later in this chapter).

The doctor-patient relationship is changing. Where once Parsons (1951) wrote that the patient was a helpless actor who was technically incompetent, with the rise of technology and the availability of information ever expanding laypeople can now be expert in their symptoms or condition well before approaching a medical expert for help and advice. Internet-based tools can be used to diagnose possible illness, research treatment options and have information to support or refute a clinician's opinion and course of action and ultimately question the doctor’s dominant status (May, 2007).

3.2 Sick role

Medical professionals, doctors and increasingly other professions allied to medicine, have the power to define a disease or condition, which ultimately gives them the power to treat it and provide access to resources and services (Smith, 2002b). These professionals are therefore gatekeepers to the ‘sick role’ and have the power to afford or remove exemptions from societal obligations, thus having a direct role in social control (Conrad, 1979). Beginning with the work of Talcott Parsons in the 1950s there has been a focus on the way in which individuals conceptualise illness, carry out the work of being a patient and conform to the expectations of what it means to be ‘ill’. Through the notion of the ‘sick role’, illness can be viewed, not just as a clinical condition with an expected trajectory, but also as a social role which brings along with it a set of expectations and obligations in return for certain rights and privileges for the duration of the illness (Parsons, 1951). The focus of this seminal work centred on the ‘labour’ that those who are ill are expected to undertake in order to become well again. For example, an individual is afforded the right to be relieved of their social obligations for the duration of a sickness ‘episode’, as long as they are seen to be doing the work of attempting to become well again by enlisting the expertise of health professionals and following their advice. Seeking out the sick role can be used as a tool to provide legitimation for signs and symptoms of illness and provide rational reasons for opting out of social responsibilities (Glenton, 2003). This release from social duty is afforded by peers (family, friends, work colleagues) in a reciprocal social agreement until such time as the sick person is able to resume their responsibilities (Miczo, 2004). However, for some conditions that are difficult to biologically determine, such as chronic back pain or Myalgic Encephalopathy (ME), individuals may strive to be accepted within the sick role. The lack of ‘clinical evidence’ that can be ‘objectively measured’ can leave these individuals lacking the professional endorsement of medical care and treatment and also provoking accusations of malingering or hypochondria (Glenton, 2003).

Given that healthcare professionals are the only group of people who can legitimately give access to the sick role and other benefits and treatments for the sick (Turner, 1995), the clinical encounter can be a fraught dynamic, with negotiations of power and dominance whereby the actors (professional and lay person) enact specific roles. These encounters may raise frustrations if the actors do not conform to their subject position (Fahy and Smith, 1999). However, in recent times – as a consequence of the change in the availability of medical information, but also because of the increasing number of long term or chronic conditions - there has been a shift in the dynamic of the medical encounter, away from the original Parsonian model of a patient seeking legitimation of illness and access to the sick role, to an encounter that also allows for co-construction of health, illness, and treatment pathways in a context where multiple complex agendas are at play (May, 2007, Parsons, 1975). This shift allows for a move towards a clinical encounter whereby the professional and patients come to a communal specification of an illness and its treatment pathway and make shared decisions about how the patient would like to proceed along their journey and especially when the patient is required to engage in self-management of their condition (Montori et al., 2006).

3.3 Illness careers

Building on Parsonian conceptions of the sick role, sociologists such as Bury (1984) turned to explore the experiences of those diagnosed with chronic conditions, a population unlikely to move back out of the sick role, to understand the meaning of illness and how it is experienced. Bury’s work surfaced the highly influential concept of biological disruption. He suggests that those identified with chronic illness journey through stages of biographical disruption from acknowledgement and identification of signs and symptoms of illness, leading to a decision to seek professional help, to constructing a narrative to explain why this has happened at the current time, to mobilising resources to deal with the disruption experienced. The process of internalising and identifying as a sick person has been highlighted as potentially producing feelings of engulfment with hopelessness and despair, and of having severe negative impacts on the lives of patients (Beanlands et al., 2003). Patients often develop narratives as a mechanism to explain their illness and contextualise it within their own lives (Bury, 2001). Prioritisation is often given to striving to continue to live a ‘normal life’ by continuing to engage in social roles such as being a parent or being in employment, so that ‘patienthood’ does not consume one’s entire identity (Townsend et al., 2006).

Other influential works have tried to unpack the processes of formation and management of patient identity. Karp (1994) likens the journey towards ‘patienthood’ to career progression – a process that moves through distinct stages to an ‘endpoint’. Like Bury, Karp identifies five stages of the process of becoming a patient and reshaping the concept of self and identity. Again, this is presented as a linear model moving through distinct stages, namely; noticing a symptom or set of symptoms, recognising the symptom as ‘wrong’, suffering a period of crisis (realising you are sick), restructuring narratives of the self to develop an illness identity, and arriving at a state of acceptance and ‘getting on with it’. It is acknowledged that the process of constructing illness narratives and new concepts of self are not achieved in a vacuum. Rather, these concepts are co-constructed in partnership with other people; spouses, family, friends, and health professionals to arrive at a narrative that not only explains the self of the past and present but also the self of the future (Radcliffe et al., 2013).

3.4 The work of being a patient

Sociologists of health and illness have characterised the effort required by individuals with health conditions to navigate the sick role and understand and manage their health as a form of ‘work’. These individuals are increasingly required to deal with and navigate highly complex healthcare systems, medication regimens, and carry out and sustain changes to their lifestyles and health related behaviours (May et al., 2009b). This often requires individuals to make substantial investments of time, effort and resources. In many respects, once an individual is identified as having a medical condition, they are required to behave differently in order to manage their condition.

One aspect of the work undertaken by patients is adhering to lifestyle advice and medications recommended as treatments by health providers. Within the literature there is a wealth of information on adherence to health interventions – a term often used, incorrectly, interchangeably with compliance. For the purposes of this study we use the following definitions as proposed by Horne et al. (2005):

Compliance: "the extent to which the patient's behaviour matches the prescriber's recommendations" (p12).

Adherence: "the extent to which the patient's behaviour matches agreed recommendations from the prescriber" (p12).

Concordance: "process in which doctor and patient agree therapeutic decisions that incorporate their respective views" (p12).

The nuanced differences between the terms demonstrates that in the case of *adherence* that the patient has an element of freedom to decide if they will adhere to the health professional's recommendations whereas *compliance* indicates a lack of involvement in decision making by the patient. A move towards *concordance* suggests a process of coproduction in the consultation processes to meet a mutually agreed treatment pathway (Horne et al., 2005).

Many factors have been identified as influencing patient's adherence to medications and lifestyle interventions in both positive and negative ways. Patient's knowledge about risk factors for CVD showed to have a positive impact on physical activity and diet interventions and increased adherence, however, knowledge had no impact on adherence to smoking cessation or statin use (Alm-Roijer et al., 2004). Higher education attainment and being in employment are associated with increased adherence, suggesting a social gradient (Mathes et al., 2014). Adherence is demonstrated to increase with age (Gadkari and McHorney, 2012, Walker et al., 2006) as well as increase in perceived necessity for medical intervention (Gadkari and McHorney, 2012, Horne et al., 2013). The value of support, trust, and effective communication in the relationship with healthcare providers is deemed to increase adherence (Martin et al., 2005). Moreover, increased social support through peer-led interventions have shown some capacity to increase adherence to medications (Enriquez and Conn, 2016). Many factors have also been demonstrated to have a negative impact on adherence. Patients from some ethnic minority groups have been shown to be less adherent with interventions (Mathes et al., 2014). Medication costs decrease people's adherence (Gadkari and McHorney, 2012, Mathes et al., 2014) as does having unresolved concerns about the medications themselves (Horne et al., 2013). It has also been demonstrated that the more complex treatment regimens are, increasing treatment burden, the less adherent people are to them (Benner et al., 2009, Mathes et al., 2014, May et al., 2009b, Gallacher et al., 2018).

Social networks are often relied upon in order to carry out the tasks of self-management and the work of being a patient (Vassilev et al., 2011). Health professionals are often acutely aware of the excessive burden of work passed on to the patient in order for them to conform to the monitoring and management of disease and as such can find discussions around self-management activity difficult to navigate (Blakeman et al., 2010). As an example, newly diagnosed diabetics may need to make changes to their diet in order to manage blood sugar levels, which may necessitate learning new skills around food. They may be required to lose weight and may choose to do this by increasing physical activity, meaning they now need to fit this into their daily lives and dedicate financial resources to new equipment. They may be required to inject insulin, requiring the acquisition of skills to do so safely and effectively. They will enter into a ‘contract of surveillance’ whereby they attend hospital appointments, undergo medical monitoring and have to dedicate resources to getting to the appointments. This new burden of work may have a huge impact on the individual’s life in both practical and emotional terms.

The acknowledgement and exploration of conceptualisations and understandings of health and health behaviours of the ‘lay populace’ is important, if our goal is to inform health promotion activity that is effective (Emslie and Hunt, 2008). Presenting ‘hard’, ‘rigorous’, ‘statistically sound’ evidence to the general population and expecting them to take this on board at face value is problematic and is probably ineffective. In their influential paper, Davison et al. (1991) propose a complex and highly evolved ‘lay epidemiology’ that exists within the collective consciousness to explain and predict ‘misfortune’.it is argued that lay epidemiology draws on many knowledges (professional, scientific, personal), explanations and direct observations of illness and disease. The results of this synthesis of information manifest in a complex conceptualisation and socially constructed explanation about an individual’s candidacy for disease.

3.5 Is there a difference between having a ‘condition’ and being ‘at-risk’?

Whilst these models of biographical disruption, illness careers, and identity have repeatedly been shown to have value when considering the journey to patienthood for those who are displaying signs and symptoms of ill health, it is unclear whether these same models would have the same utility for those newly adopting an ‘at-risk’ identity.

Since the rise of the identifiable risk factor there has been an assumption that knowledge is power for the individual patient and that this knowledge should equate automatically to uptake of preventative behaviours and interventions to reduce risk. Kenen (1996) coins this ‘the gift of knowing’ he suggests that once at-risk health statuses have been agreed, accepted and negotiated, at-risk status can be seen as "social positions accompanied by expected role performances and norms" (p1545).

This suggests that the process of screening and identification of risk factors has a similar power to transform an individual’s life as diagnosis of illness. Both types of diagnosis (of illness or risk) give reason to provide intervention, such as drug treatment or lifestyle advice, in people that consider themselves to be fit and well (Goldstein-Jutel, 2011). In his study of men identified as having elevated cholesterol or prostate specific antigen, Gillespie (2012) found that the identification of risk had the power to symbolically alter the concept of self and identity, as did Hindhede (2014) and Hindhede and Aagaard-Hansen (2014) in their study of patients with an increased risk of diabetes (prediabetes). The communication of a probability statistic that was intended to provide clarity in the face of uncertainty served to promote uncertainty and produce anxiety (Gillespie, 2012). In individuals who have sought out risk identification through, for example, genetic testing, the acceptance of an at-risk identity has been shown to act as a catalyst for change in behaviour and a sense of empowerment at being able to take control of one’s destiny (Harvey, 2010). However, it is unclear if this proposition would hold true for those individuals, like those in this study, who did not seek out a risk diagnosis, but who, rather, were invited for mass screening. There is limited evidence that identification of CVD risk leads to the enactment of healthier lifestyles. Farrimond et al. (2010) reported that at-risk individual’s *intention* to change was high at two weeks post intervention. However, intention to change is not the same as enacting change. Without longitudinal follow-up of individuals it is impossible to truly surface whether the gift of knowing their at-risk status did lead to any lasting engagement with preventative intervention.

In recent years there has been a focus on the concept and effects of what is termed ‘overdiagnosis’. There are several main drivers towards overdiagnosis: a culture that believes medical intervention is always the best avenue of action; healthcare systems incentivised to identify more disease and provide care; industrial and technological advancements that can identify ‘disease’; a fear of litigation should conditions not be identified in time; and public and patient expectations of the medical professions. All have been identified as contributing to the phenomenon (Pathirana et al., 2017). Linking to concepts of medicalisation (section 2.4.1), the awareness of a tendency in medicine to make patients out of healthy populations is widely explored in the literature (Smith, 2009, Smith, 2002b, Moynihan et al., 2002, Moynihan and Smith, 2002) and links directly to the concept of receiving a diagnosis of risk. The utilisation of risk factor identification in an otherwise asymptomatic population serves to increase the likelihood of unnecessary treatments that will benefit only a fraction of the individuals prescribed them (Brodersen et al., 2018). In many cases, where risk factor thresholds (or cut-off points) are commonly reduced (thereby increasing the potential population to treat), the prevalence of proto-diseases (pre-disease or risk states) increases to epidemic proportions, as is the case with prediabetes (Yudkin and Montori, 2014). Carter (2017), raises important questions about the ethical implications of such diagnoses and treatment in an age in which we have a rising trend for overdiagnosis of conditions and/or risk factors deemed to warrant medical intervention. Often, the decision to provide medical intervention for the reduction of risk leads to the prescription of treatments that can have unintended negative effects (side effects) without affording any direct benefit to the individual (Carter, 2017), as discussed in section 2.4.3. Overdiagnosis can have several effects, such as increasing unnecessary treatment in the patient, but increasing demand for (and cost to NHS of) pharmaceuticals (van Dijk et al., 2016).

Chapter 3 has outlined some of the pertinent literature about how illness is constructed and experienced in terms of beginning to identify as a patient and how this may relate to those individuals who are identified as at-risk of an illness or condition. The evidence reviewed indicates several issues that could impact on the proposed study and how I might approach it. As a society we are used to searching for disease and treating its causes or symptoms, we tend to classify conditions, thereby giving validity to their treatment with medical intervention. The very act of diagnosis has been demonstrated to act as a catalyst for taking action and engaging with the work of being a patient for those with physiologically diagnosable conditions. Much previous research has focussed on and unpacked the factors that may influence people's adherence with these medical interventions i.e. lifestyle intervention and pharmaceutical intervention but again this work is mainly conducted with groups of people who have received a clinical diagnosis. Moreover, research has identified discrete stages that people with chronic conditions move through to accept and internalise the news that they are no longer a healthy individual, rather they are coming to terms with becoming a ‘patient’. The work of being a ‘patient’ is far reaching and necessitates engagement in ‘work’ which brings its own burdens.

The population included in this study are qualitatively different from those whom the majority of this evidence is based upon. People who have been identified as at increased CVR through the NHSHC are asymptomatic; i.e. they did not seek a diagnosis because of feeling unwell. Nevertheless, upon attending their CVR assessment they were given a diagnosis, one based upon the probability of a future event. The diagnosis of risk transforms the individual from healthy to someone with illness potential and that potential is treated with medical intervention. It is unclear from the evidence if this transformation into an at-risk patient, one who must make changes to their lifestyle and take medications will be accepted readily or resisted because it is at odds with their own perception of their health and wellbeing. The overdiagnosis evidence encourages an analysis of the ethical implications of programmes such as the NHSHC and unintended negative consequences of being identified as at high risk of CVD. These issues will be discussed again later in the thesis. In chapter 4 the focus of the thesis turns to Normalisation Process Theory, why it was chosen, and how it was used to underpin this study.

4 The theoretical lens – Normalisation Process Theory

Chapters 2 and 3 have provided contextual information about the NHSHC programme and what is understood about how becoming a patient can affect people's interaction with their social world and take on (or not) the role and work of being a patient. In this chapter the theoretical lens that was used to develop the study and provide insight into analysis, Normalisation Process Theory (NPT), is mapped out and discussed. Firstly, a brief background about the theory and how it has been used, to date, in previous studies is provided. Thereafter the main components of the theory are mapped out and an interpretation of the theory in relation to this study is provided to illustrate how NPT was used as a practical tool at each stage of the research process.

4.1 Normalisation Process Theory

This PhD study seeks to understand the ways in which individuals who have been identified as at increased risk of cardiovascular disease (CVR) understand, engage and adhere with the NHS Health Check (NHSHC) assessment and intervention process. As identified in the previous chapter, accepting at-risk status may require the individual to adopt an illness identity (even though they are not ill), accept medication, referral to treatment, and deal with the consequent biographical disruption. For the participants in this study they must do this, even though they were not ill to begin with and they do not become ill as a consequence.

To provide a theoretical lens to the study, NPT was identified as an appropriate tool to engage with and sensitise the me to issues around *implementation* (the way in which practices are actioned through social organisation), *embedding* (the process of practices becoming routinised), and *integration* (the process of sustaining) of practices (May and Finch, 2009). This process of implementation, embedding and integration of practices, it is argued, results in what is described as *normalisation* of a practice (May, 2010). Normalisation Process Theory is termed a theory of action (May and Finch, 2009). It is primarily concerned with understanding the processes involved in what people 'do' and the way they construct what they 'do' both as individuals and collectively as part of a socially organised group (May and Finch, 2009, May et al., 2009a).

Developed between 2000 and 2009, by Carl May and colleagues, NPT has been defined as a 'middle range theory' (Boudon, 1991). Middle range theories are described by Davidoff et al. (2015) as frameworks for understanding problems and for guiding the development of interventions in a practical sense, and the authors highlight the fact that middle range theories can be restricted in their practical use to their specific area of application. It is an extension of previous work in which a Normalisation Process Model was developed (May et al., 2007). The Normalisation Process Model now forms the third construct of the wider NPT; collective action (discussed in section 4.5). Branded as a sociological tool, NPT can be used to understand the fluid, dynamic, and interactive processes that are at play between contexts, people, and objects (McEvoy et al., 2014). It offers a method to conceptualise and provide a rational, systematic description and explanation of the work of both individuals and groups. Rather than acting as a conceptual straight jacket, NPT can be utilised as a heuristic (problem solving) device (McEvoy et al., 2014).

Unlike other middle range theories that attempt to provide a theoretical understanding of how innovations spread through social networks and organisations, such as Diffusion of Innovation (Greenhalgh et al., 2004) or theories that are concerned with an individual's attitudes and intention to act in a specific way (Azjen, 1991), NPT focusses on the work that actors undertake to engage with social contexts and objects to implement, embed, integrate, and therefore normalise a new practice or way of working (May and Finch, 2009, May et al., 2009a, May et al., 2003).

As a relatively new theory, under development by a team of researchers since 2000, it is still being refined. Much work has been undertaken to develop an interactive 'toolkit' that is freely available online (May et al., 2015). The toolkit provides a resource for academics and practitioners to explore the utility of the theory to apply to their own contexts.

4.2 The core components of Normalisation Process Theory

Normalisation Process Theory seeks to surface factors that can promote, or inhibit, the normalisation of a set of practices and does so by identifying four core components (termed constructs) needed for normalisation; *coherence, cognitive participation, collective action, and reflexive monitoring* (May and Finch, 2009, May et al., 2015). A definition of each core construct can be found in Table 5. Each construct is explored individually in the following sections. In order to make NPT usable in this study, a great deal of interpretation work had to be undertaken to make the constructs relevant to the context of this study (May et al., 2015). In each of the following sections the constructs of NPT are explained as they appear in the academic literature initially. The interpretation of those terms and how each construct is conceptualised for this study is then laid out clearly in a section under the ‘interpretation’ heading. Subsequently the constructs and their underlying processes (mechanisms) were relabelled to provide clarity of meaning for the author and reader. Each table on the following pages presents the construct labels initially with the interpretations derived for this study in bold. Underneath these interpretations, in brackets, are the original labels for reference for the reader.

Table 5: Definition of Normalisation Process Theory constructs

Making sense of it **(Coherence - planning phase)**	**Working out participation** **(Cognitive Participation - planning phase)**
The process of sense making and understanding that individuals have to go through in order to promote or inhibit the routine embedding of a practice to its users. These processes are energised by investments of meaning made by participants (Finch et al., 2012).	*The process that individuals and organisations go through in order to enrol individuals to engage with a new practice. These processes are energised by investments of commitment made by participants* (Finch et al., 2012).
How people understand and make sense of a practice with an emphasis on understanding and conceptualisation of interventions and their work (McEvoy et al., 2014).	*How people engage and participate with a practice with an emphasis on notions of legitimation and buy in, both in terms of the individuals involved and involving others* (McEvoy et al., 2014).
Doing it **(Collective Action - doing phase)**	**Reflecting on it** **(Reflexive Monitoring - appraisal phase)**
The work that individuals and organisations have to do to enact the new practice. These processes are energised by investments of effort made by participants (Finch et al., 2012).	*The informal and informal appraisal of a new practice once it is in use, in order to assess its advantages or disadvantages and which develops user's comprehension of the effects of a practice. These processes are energised by investments in appraisal made by participants* (Finch et al., 2012).
The distribution of work required among stakeholders and the resources to support that with an emphasis on; organisational resources, training, divisions of labour, confidence and expertise as well as the workability of the intervention (McEvoy et al., 2014).	*How people reflect and appraise its (practice) effects. With an emphasis on appraising and monitoring implementation work* (McEvoy et al., 2014).

I have broadly divided the four constructs into two categories; the first category being a planning phase of work that individuals, working as actors within a socially organised group, undertake to make sense of and organise themselves around the ideas and requirements of a new practice. This involves processes of understanding, organising, and planning (coherence and cognitive participation). The second category is a doing phase, where individuals and collectives carry out the practices, then appraise and evaluate the appropriateness and effectiveness of what they are doing and take action to change practices once they have been appraised (collective action and reflexive monitoring).

For the purposes of interpretation of the theory, and so that it could be applied in a practical way, I relabelled each of the constructs for ease of understanding. I interpreted the construct coherence as "*making sense of it*", I interpreted cognitive participation as "working out participation", I interpreted collective action as "doing it", and finally I interpreted reflexive monitoring as "reflecting on it". From here on in, the four constructs will be labelled with their interpretations, for consistency.

Each of the four core constructs; *making sense of it* (coherence), *Working out participation* (cognitive participation), *doing it* (collective action), and *reflecting on it* (reflexive monitoring) are composites of four (each) underlying working mechanisms (or processes) (May et al., 2009a). Each core construct, its processes, and how I have interpreted it for the purpose of this study are described, in turn, over the following pages.

4.3 Making sense of it (coherence)

The *making sense of it* (coherence) construct is a planning phase of work that is concerned with identifying and unpacking what people actually do when trying to understand a new practice. Making sense of this new practice is achieved at both the individual level and in partnership with other people. This construct is made up of four discrete working processes; *differentiation, communal specification, individual specification, and internalisation* (May and Finch, 2009, May et al., 2009a). Each working mechanism is described, in turn, in Table 6.

Table 6: Making sense of it (Coherence) - working mechanisms

Understanding the uniqueness of it **(Differentiation)**	**Collectively interpreting it** **(Communal Specification)**
An important element of sense-making work is to understand how a set of practices and their objects are different from each other.	*Sense making relies on people working together to build a shared understanding of the aims, objectives and expected benefits of a set of practices.*
Individually interpreting it **(Individual Specification)**	**Coming to a conclusion** **(Internalisation)**
Sense making has an individual component too. Here participants in coherence work need to do things that will help them understand their specific tasks and responsibilities around a set of practices.	*Finally, sense-making involves people in work that is about understanding the value, benefits and importance of a set of practices.*

Definition of working mechanisms is taken from May et al. (2015).

My interpretation of the working mechanisms: Table 6 shows how each working process has been defined. Essentially, the process that people go through to make sense of a practice – or a thing – can be broken down into four interrelated processes. The first mechanism – differentiation – can be interpreted as how people understand the new practice to be unique or different from other ways of working (*understanding the uniqueness of it*). The second mechanism – communal specification – can be understood as the work people do, together, to interpret the new practice in order to come to a collective understanding of it (*collectively interpreting it*). The third mechanism – individual specification – can be understood as the work people do, individually, to interpret the new practice in order to come to an individual understanding of it (*individually interpreting it*). The fourth mechanism – internalisation – can be interpreted as the work people do to come to a conclusion about a practice and deciding to either engage with it, or not (*coming to a conclusion*).

The current study is interested in unpacking how individuals make sense of the NHSHC offer and how they begin to interpret its relevance in the context of their daily lives and what, if any, added value it offers. To do this the study explores the ways that individuals work individually and with others (health professionals, family, friends, and other social networks) to achieve an individual and shared understanding of the work involved to participate in the NHSHC process and in any recommended intervention. Table 7 shows the key questions raised by the construct of coherence, in relation to this study.

Table 7: Making sense of it (Coherence) - application

Making sense of it **(Coherence)**	
Mechanism	***Key areas to explore***
Understanding the uniqueness of it **(Differentiation)**	1. How does this differ from other routine checks I have been offered? 2. How does this differ from other interventions that have been aimed at me a. That I have sought out b. That have been offered to me c. General health promotion activity 3. Do I recognise the NHSHC brand? 4. What is unique about the invitation/ offer? 5. What were my expectations/ why did I attend?
Collectively interpreting it **(Communal Specification)**	1. Am I clear about everyone's role in the NHSHC process? 2. Am I able to work with others (health professionals/ family/ friends) to access information about the assessment and intervention? 3. How is risk communicated to me? 4. How is treatment/ intervention communicated to me? 5. Do my friends and family have an opinion about the assessment and subsequent intervention?
Individually interpreting it **(Individual Specification)**	1. Do I understand the purpose of having a CVD risk assessment? 2. What is my own role in the assessment and subsequent intervention?
Coming to a conclusion **(Internalisation)**	1. How do my previous experiences help me to make sense of a. The NHSHC b. CVD risk c. Intervention and treatment pathways 2. Do I think there is added value from the assessment/intervention? 3. What are the specific benefits to me from the assessment/ intervention?

4.4 Working out participation (cognitive participation)

The *working out participation* (cognitive participation) construct is a planning phase of work concerned with identifying and unpacking the work that people do when trying to think through and organise themselves and other people to undertake a new practice. It is about the relational work that is undertaken by people to build a group with shared agreement and engagement around the new practice. The four working mechanisms of cognitive participation are; initiation, enrolment, legitimation, and activation (May and Finch, 2009, May et al., 2009a). Each working mechanism is described, in turn, in Table 8.

Table 8: Working out participation (Cognitive Participation) - working mechanisms

Having the skills to engage **(Initiation)**	**Organising people** **(Enrolment)**
When a set of practices is new or modified, a core problem is whether or not key participants are working to drive them forward.	Participants may need to organise or reorganise themselves and others to collectively contribute to the work that may involve rethinking group relationships between people and things.
Believing practice is valid **(Legitimation)**	**Defining actions** **(Activation)**
An important component of relational work around participation is the work of ensuring that other participants believe it is right for them to be involved, and they can make a valid contribution to it.	Once it is underway, participants need to collectively define the actions and procedures needed to sustain a practice and stay involved.

Definition of working mechanisms is taken from May et al. (2015).

My interpretation of the working mechanisms: Table 8 shows how each working mechanism has been defined. Essentially, the process that people go through to think through and organise themselves and others around a practice – or a thing – can be broken down into four interrelated mechanisms. The first mechanism – initiation – can be interpreted as how people identify that they have the right skills set to drive forward the new practice (*having the skills to engage* (initiation)). The second mechanism – enrolment – can be understood as the work people do to organise themselves and other people so that they can carry out the new practice (*organising people* (enrolment)). This organisation work is the process of making sure that the right people, with the right skills are ready to carry out the work. The third mechanism – legitimation – can be understood as the work people do to come to an understanding that a new practice is a valid thing for them to do, a legitimate part of their role (*believing practice is valid* (legitimation)). The fourth mechanism – activation – can be interpreted as identifying what actions need to be undertaken to carry out the new practice (*defining actions* (activation)).

The current study is interested in exploring how high CVR risk individuals work to organise themselves and others to ‘buy into’ (or not) the NHSHC programme and define, explicitly, tasks need to be undertaken to engage with the NHSHC assessment and any recommended interventions. Table 9 shows the key questions raised by the core construct cognitive participation, in relation to this study.

Table 9: Working out participation (Cognitive Participation) - application

Working out participation **(Cognitive Participation)**	
Mechanism	***Key areas to explore***
Having the skills to engage **(Initiation)**	1. Do I have the right skills to a. Engage with the NHSHC b. Engage with the intervention(s) 2. Do I know *how* to a. Eat better b. Take more (appropriate) physical activity c. Take lipid lowering medications correctly
Organising people **(Enrolment)**	1. How do I engage with and organise other people in the NHSHC process? a. Health professionals b. Family c. Friends
Believing practice is valid **(Legitimation)**	1. Have I sought reassurance from others about a. Having the assessment? b. Treatment options? 2. Is risk reduction and prevention a legitimate part of my role?
Defining actions **(Activation)**	1. How can I arrange to carry out the requirements of the NHSHC a. Logistical issues (getting to appointments, shopping, physical activity) b. Administrative (ordering prescriptions etc…) c. Accessing services 2. Are ‘doors opened’ for me? (have I been given access to services?) 3. What are the actions I need to do to comply with the NHSHC? 4. What actions do I need to sustain to stay involved in the NHSHC?

4.5 Doing it (collective action)

The *doing it* (collective action) is a doing phase of work that is concerned with identifying and unpacking what people actually do when enacting a practice. This action work can, of course, relate to the work undertaken to comply, or resist and subvert the therapeutic intervention (in the case of this study, statin and lifestyle changes) and the self-monitoring work undertaken by the individuals (May and Finch, 2009). This construct is made up of four working mechanisms; interactional workability, relational integration, skill set workability, contextual integration (May and Finch, 2009, May et al., 2009a). Each working mechanism is described, in turn, in Table 10.

Table 10: Doing it (Collective Action) - working mechanisms

Performing the actions **(Interactional Workability)**	**Working with and trusting the work of others** **(Relational Integration)**
The interactional work that people do with each other, with artefacts, and with other elements of a set of practices, when they seek to operationalize them in everyday settings.	The knowledge work that people do to build accountability and maintain confidence in a set of practices and in each other as they use them.
Appropriate division of tasks **(Skill Set Workability)**	**Allocating resources** **(Contextual Integration)**
The allocation work that underpins the division of labour that is built up around a set of practices as they are operationalized in the real world.	The resource work - managing a set of practices through the allocation of different kinds of resources and the execution of protocols, policies and procedures.

Definition of working mechanisms is taken from May et al. (2015).

My interpretation of the working mechanisms: Table 10 shows how each working mechanism has been defined. The actions that people perform to carry out the work of a practice – or a thing – can be broken down into four interrelated mechanisms. The first mechanism – interactional workability – can be understood as the physical action taken to perform the task (*performing the actions* (interactional workability)). The second mechanism – relational integration – can be interpreted as the work that is done to work with others and trust their work (*working with and trusting the work of others* (relational integration)). The third mechanism – skill set workability - can be understood as the work that is undertaken to make sure that the tasks are divided appropriately according to people’s skill, knowledge and expertise (*appropriate division of tasks* (skill set workability)). The fourth mechanism – contextual integration – can be understood as the assigning of resources to undertake the task (*allocating resources* (contextual integration)).

The current study, is interested in how and if high-risk individuals enact the tasks that are required to comply (or not) with the NHSHC principles by accepting CVR, taking prescribed medications (or not) and making sustained changes to their lifestyle (or not). Table 11 shows the key questions raised by the construct of collective action, in relation to this study.

Table 11: Doing it (Collective Action) - application

Doing it **(Collective Action)**	
Mechanism	***Key areas to explore***
Performing the actions **(Interactional Workability)**	1. Do I perform the task of taking the tablets prescribed to me? a. Do I actively refuse to take tablets? b. How do I deal with side effects, practically? 2. Do I make changes to my lifestyle? a. If so, to what extent? 3. Do I attend appointments? 4. Do I actively refuse to ‘comply’ or resist an illness identity?
Working with others and trusting the work of others **(Relational Integration)**	1. Have I developed relationships with others involved in the NHSHC process? 2. Am I confident in the work that’s being carried out by the health professionals? 3. Do I have confidence in the actions of the people involved in the NHSHC? 4. Do I trust the actions of the people involved in the NHSHC?
Appropriate division of tasks **(Skill Set Workability)**	1. How are the tasks divided between actors? 2. Have I set up routines to carry out the tasks required? 3. Is the required ‘work’ appropriate for the skills that I have?
Allocating resources **(Contextual Integration)**	1. Do I integrate the notion of risk into my social life? 2. Do I integrate medications and lifestyle changes into my social life? 3. Do I have the financial resources to take medications and engage in lifestyle advice?

4.6 Reflecting on it (reflexive monitoring)

The *reflecting on it* (reflexive monitoring) construct is an appraisal phase of work concerned with the formal and informal processes that are involved in monitoring and evaluating the work that has been carried out during the collective action phase. This reflexive stage of the normalising process is carried out, again, both individually and with others involved in the process. Reflexive monitoring is made up of four working mechanisms; systematisation, communal appraisal, individual appraisal, reconfiguration (May and Finch, 2009, May et al., 2009a). Each working mechanism is described, in turn, in Table 12.

Table 12: Reflecting on it (Reflexive Monitoring) - working mechanisms

Collecting feedback information **(Systematisation)**	**Collectively evaluating it** **(Communal Appraisal)**
Participants in any set of practices may seek to determine how effective and useful it is for them and for others, and this involves the work of collecting information in a variety of ways.	Participants work together - sometimes in formal collaboratives, sometimes in informal groups to evaluate the worth of a set of practices. They may use many different means to do this drawing on a variety of experiential and systematized information.
Individually evaluating it **(Individual Appraisal)**	**Changing the way things are done** **(Reconfiguration)**
Participants in a new set of practices also work experientially as individuals to appraise its effects on them and the contexts in which they are set. From this work stem actions through which individuals express their personal relationships to new technologies or complex interventions.	Appraisal work by individuals or groups may lead to attempts to redefine procedures or modify practices - and even to change the shape of a new technology itself.

Definition of working mechanisms is taken from May et al. (2015).

My interpretation of the working mechanisms: Table 12 shows how each working mechanism has been defined. The process of gathering feedback on the actions performed in the *doing it* (collective action) phase of work and evaluating them can be broken down into four interrelated mechanisms. The first mechanism – systematisation – can be understood as collecting information and feedback about how performing the task worked, in practice (*collecting feedback information* (systematisation)). The second mechanism – communal appraisal – can be interpreted as the work that is done to with others to evaluate the practice (*collectively evaluating it* (communal appraisal)). The third mechanism – individual appraisal - can be understood as the work that is undertaken individually to evaluate the practice (*individually evaluating it* (individual appraisal)). The fourth mechanism – Reconfiguration – can be understood as the process that people go through to take the information and feedback gained through the other three working mechanisms, synthesise this information and make changes to the way they enact the practice in the future (*changing the way things are done* (reconfiguration)).

The current study is interested in how individuals appraise the NHSHC process, their engagement with the programme and how they evaluate the effectiveness and usefulness of the interventions both individually and in collaboration with others involved in the process (health professionals, family, and friends). It is also of interest how individuals may reconfigure their treatments again, individually or by engaging with others. Table 13 shows how the four working mechanisms of the reflexive monitoring construct have been interpreted in relation to the current study.

Table 13: Reflecting on it (Reflexive Monitoring) - application

Reflecting on it

(Reflexive monitoring)

Mechanism	*Key areas to explore*
Collecting feedback information **(Systemisation)**	1. How do I collect/ gather information about: a. Progress? b. Side effects? c. Usefulness of interventions? d. Effectiveness of interventions?
Collectively evaluating it **(Communal Appraisal)**	1. How do I work with other people (health professionals, family, and friends) to evaluate: a. If being involved in the programme is worthwhile? b. Medications are appropriate and effective? c. Lifestyle changes are appropriate and effective? d. Make a decision to continue or modify engagement?
Individually evaluating it **(Individual Appraisal)**	1. How do I use feedback from my experiences of the NHSHC process to: a. Evaluate appropriateness of interventions? b. Evaluate effectiveness of interventions? c. Make a decision to continue or modify engagement?
Changing the way things are done **(Reconfiguration)**	1. How do I use the information (from the first 3 mechanisms) to: a. Alter/ subvert/ modify my actions, moving forward

4.7 How has Normalisation Process Theory been applied, previously?

Normalisation Process Theory is said to have emerged, in a grounded way, from the work Carl May and colleagues were engaged with in trying to unpick the mechanisms that resulted in the normalising, or not, of new practices introduced as part of complex interventions (May, 2006, May, 2013b, May, 2013a, May et al., 2011a, May et al., 2011b). The theory has been refined over several iterations and continues to evolve as more practitioners and academics interact with it and utilise its concepts in their own work (May, 2013b, May and Finch, 2009, May et al., 2009a, May et al., 2015). Normalisation Process Theory was developed specifically to look at the processes at play within organisational settings, mainly the NHS. Since NPT's focus is to describe the processes at play when people work together to engage with and routinise practices, it has been described as having the potential to have an important role to successfully implement interventions that require interaction and engagement with improvement activities (Davidoff et al., 2015).

Normalisation Process Theory is promoted as a tool that can be utilised and helpful at any stage of a research project's lifecycle; from informing study design through to analysis and interpretation (May et al., 2015). McEvoy et al. (2014) found, in their systematic review, that researchers had used, and found useful, the constructs of NPT across the life course of the projects and that it had been used to inform study design, data analysis, and interpretation. The same systematic review concluded that NPT constructs had been operationalised and interpreted consistently across studies, with two notable exceptions (Gunn et al., 2010, Sanders et al., 2011). Regardless of these slight variations in interpretation, it was concluded that NPT constructs were helpful to researchers by providing a framework to highlight important issues relating to routinisation.

The majority of papers reviewed for this thesis and those included within McEvoy et al. (2014) systematic review of studies that have utilised NPT at various stages of the research process have identified NPT as a beneficial framework. NPT's utility seems to lie in its capacity to provide a systematic way of interrogating the processes of implementation, integrating and embedding (Macfarlane and O'Reilly-de Brun, 2012, McEvoy et al., 2014, Blakeman et al., 2012, Elwyn et al., 2008, Gunn et al., 2010).

There is little critique of NPT and any limitations encountered in its use in the literature. Finch et al. (2012) highlight that whilst NPT provides a framework to explore the processes of implementation, it cannot provide a definition of what ‘normalisation’ looks like in a given context. This is a judgement call to be made by those exploring any given intervention or practice. Other critiques relate to the interpretation of the constructs and mechanisms of NPT. Gunn et al. (2010), Atkins et al. (2011), Franx et al. (2012), and Macfarlane and O'Reilly-de Brun (2012) all describe difficulties in ensuring that interpretations of constructs are congruent with those in the original theory. Finch et al. (2012) also discusses the intensity of the translation work that has to be undertaken to ensure NPT constructs are interpreted in relation to the context in question.

I feel the core constructs of NPT could be seen to encapsulate the underpinning stages of biographical disruption (Bury, 1984) and developing an illness identity (Karp, 1994) (discussed in chapter 3). Table 14 shows the similarities between theories and how each stage could be mapped onto a core construct of NPT. This demonstrates one of the reasons I selected NPT as a tool for use in this study. It draws together concepts from divergent theoretical standpoints and processes into a single tool that can be applied across the research process.

Table 14: Biographical disruption, illness identities, and NPT

Bury's biographical disruption stages	**Normalisation Process Theory constructs**
Acknowledge signs and symptoms of illness	Coherence
Identification of illness	Coherence
Decision to seek help	Cognitive participation
Constructing a narrative	Collective action
Mobilising resources	Collective action
Karp's illness identities stages	
Noticing signs and symptoms	Coherence
Recognising the symptom is wrong	Coherence
Suffering period of crisis	Cognitive participation and collective action
Restructuring narrative to include illness identity	Coherence and reflexive monitoring
State of acceptance	Illness identity has been 'normalised'

The processes offered by the concept of biographical disruption and illness career progression mirror many of the stages of NPT and the normalising of behaviours or work by making sense of the issue, internalising and enrolling oneself and then practically dedicating resources to action.

Normalisation Process Theory has, in recent years grown in popularity – as seen by the increased number of publications that utilise it as their theoretical framework. It is widely used to illuminate issues around implementation of health interventions such as care for chronic conditions (Harris et al., 2017), digital health interventions

(Band et al., 2017). However, to my knowledge, only one previous body of work has used NPT to explore processes of routinising practices outside of a formal organisational setting. The work of Gallacher et al. (2011) explores the issue of treatment burden in a population that has chronic heart failure. This work and that around minimally disruptive medicine (May et al., 2009b, Montori et al., 2006) have resulted in the development of Burden of Treatment Theory (May et al., 2014a). However, this thesis focusses on how individuals, outside of a formal organisational structure, interact with a health intervention and work through the processes of understanding what the intervention is offering them, working out their participation, doing (or not) what is asked of them, and participating in ongoing monitoring and surveillance. To my knowledge, this is the first time that NPT has been utilised in this way.

Chapter 4 has introduced NPT as the theoretical lens used to underpin this study and discussed how it has been used previously in other research. I have unpacked the interpretation work I engaged with to make sense of the constructs and subordinate working mechanisms and then applied each one in practical terms to generate the questions used to build the interview questions for the semi-structured interview guide (discussed further in Chapter 5, section 5.2.3). The following chapter, chapter 5, moves on to discuss the methodology that was employed to collect and analyse the data.

5 Methodology and process

The following chapter is comprised of two parts. Part one (5.1) describes the methodological approach taken in the research and discusses the epistemological position, theoretical perspective, methodology, and methods used to collect data and analyse it. Part two (5.2) describes the procedural methods of the study, how the study was conducted, how data was analysed, and a description of the achieved sample.

As discussed in Chapter 1 this PhD project was developed alongside a collection of projects that were undertaken to explore the local roll out of the NHSHC programme. The PhD project was identified at the very beginning of the development phase of a commissioned piece of work that focused on patient adherence to the NHSHC. As such, the commissioned piece of work was constructed to serve both purposes – to meet the needs of the commissioning body (for which descriptive data, thematically analysed was required) but also to allow the collection and further theoretical analysis of data for the PhD study. The processes described over the following pages define the work undertaken by me to design and carry out the research. Essentially, because the analysis for the PhD study was carried out after the commissioned work was completed, what is described is a secondary analysis; however, this was planned from project initiation.

5.1 Methodology

This section (5.1) provides a rationale for the selection of a qualitative approach and a justification of its appropriateness for exploring how individuals experienced their involvement in the NHSHC programme and being identified as at increased risk of an adverse cardiovascular event. Drawing heavily on what Crotty (1998) describes as the ‘four pillars’ of research, the following section outlines the links between epistemological position that underpins this work, the theoretical perspective, the methodological design, and chosen methods of data generation and analysis. Below these ‘four pillars’ are displayed pictorially for the reader (Figure 2). These will be referred to throughout this chapter.

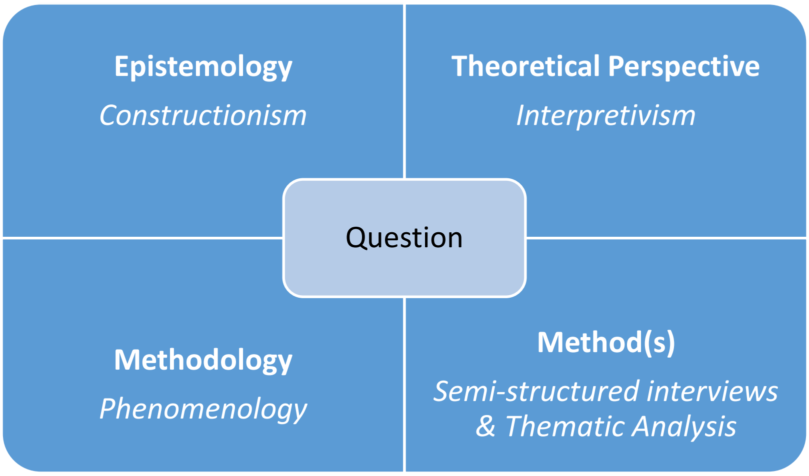

FIGURE 2: CROTTY’S FOUR PILLARS OF RESEARCH

The selection of method of data generation and analysis must be firmly rooted in its capacity to explore and illuminate the question(s) of interest. This forms the basis for study design, situating the question firmly within the centre of any decision making processes (Ritchie et al., 2014). Method selection and methodology are intrinsically linked to their parent theoretical perspective and overall epistemological position meaning that there must be congruence throughout the whole approach taken (Crotty, 1998). Each of the ‘four pillars’, in relation to this study, are discussed below.

5.1.1 Constructionism (Epistemology)

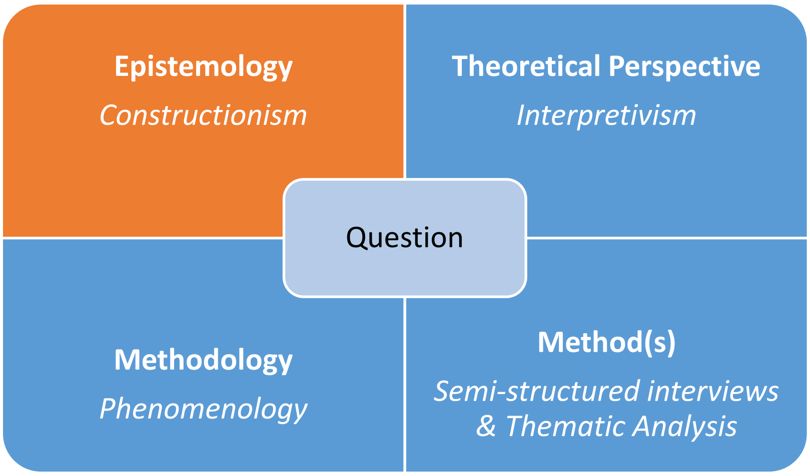

FIGURE 3: CROTTY'S FOUR PILLARS OF RESEARCH - EPISTEMOLOGY

> *What, then, is constructionism? It is the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context* (Crotty, 1998).

This study is borne from a constructionist (Silverman, 2005) standpoint; an epistemological position that at its core acknowledges that there is no singular objective truth about reality, experience, objects, or phenomena to be unearthed (Crotty, 1998). Rather, constructionism acknowledges that meaning is attributed to objects and experiences through a process of communal and individual interaction with the world (Silverman, 2005, Giacomini, 2010). Constructionism recognises the collective work of social groups, alongside the individual, to 'construct' understanding and generate meaning (Silverman, 2005, Crotty, 1998). A nuanced yet clear difference should be highlighted between constructionism and constructivism, the latter being concerned with generation of meaning by the individual (Crotty, 1998).

The theoretical lens (NPT) chosen to explore the data generated for this thesis is primarily concerned with the work that people do, interacting with each other, to make sense of processes in order to normalise actions and behaviours. Therefore, grounding the thesis in constructionism is congruent with both the methodology and data generation and analysis techniques (discussed below), but also the theoretical lens underpinning interpretation of the data.

A worked example from the thesis can be used to understand how this epistemological position is consistent with the topic under exploration. For example, how cardiovascular risk (CVR) is interpreted and internalised as meaningful (or not) will differ from individual to individual. No doubt there will be similarities in experience due to the shared social context from which the sample is drawn. This CVR meaning will be synthesised by the individual and will draw upon personal experiences of CVD and its component 'risk factors', knowledge passed on through interactions with other people, media coverage, health promotion activity, physiological symptoms, and so on. Each individual will take parts of these collective ideas to formulate their own understanding of CVR, and what it means within the context of their own lives. There will be similarities between individual interpretations of CVR but also nuanced differences. Evidence of similarities of interpretation of CVR experience will indicate a socially constructed reality present within this group of people (Ritchie et al) and help build an understanding of the ways in which this group of people engage, or not, in the work of being at increased CVR. Adopting a constructionist standpoint, epistemologically speaking, acknowledges and gives space for that voice and construction of reality to emerge (Quinn Patton, 2015).

5.1.2 Interpretivism (Theoretical Perspective)

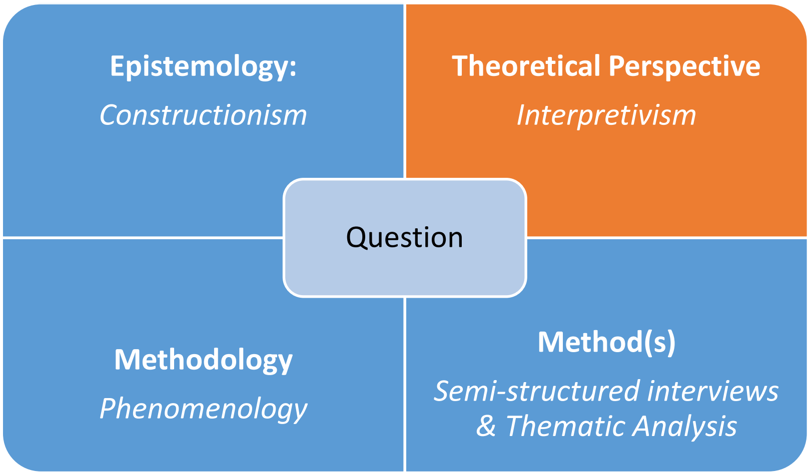

FIGURE 4: CROTTY’S FOUR PILLARS OF RESEARCH – INTERPRETIVISM

> *People are constantly involved in interpreting and reinterpreting their world – social situations, other people's actions, their own actions, and natural and humanly created objects. They develop meanings for their activities together, and they have ideas about what is relevant for making sense of these activities. In short, social worlds are already interpreted before social scientists arrive* (Blaikie, 2007).

If, through the adoption of a constructionist epistemological position, we believe that meaning is afforded to an object or phenomenon through a process of collective construction (Quinn Patton, 2015, Crotty, 1998, Silverman, 2005, Denzin and Lincoln, 2000, Giacomini, 2010), we must assume that those creating meaning are actively interpreting, integrating, and synthesising different forms of knowledge to make sense of the object or phenomenon (Smith et al., 2009, Weber cited in Blaikie, 2007). These perspectives and meanings are unique to the individuals involved in the process of interpretation and are directly related to their situation and their relationship to the world around them.

The process of interpretation is a common thread, weaving through the entire research process from initiation, through data collection, and analysis. Whist an aim is to capture and understand how individuals at-risk of CVD make sense of being an ‘at-risk individual’ and what that means for the integration, embedding and normalisation of associated practices, interpretation is happening at many other levels throughout the process. The researcher is bound within the research process (Creswell, 2013). She is an active participant in the process of data generation and interpretation process (Giacomini, 2010). Essentially, the participant and researcher are bound in what is termed the ‘double hermeneutic’ (Blaikie, 2007, Smith et al., 2009), whereby the participant constructs, explains, and makes sense of a phenomenon and the researcher, in turn engages in sense making of the participant’s interpretation (this is further discussed in section 5.2.4).

5.1.3 Phenomenology (Methodology)

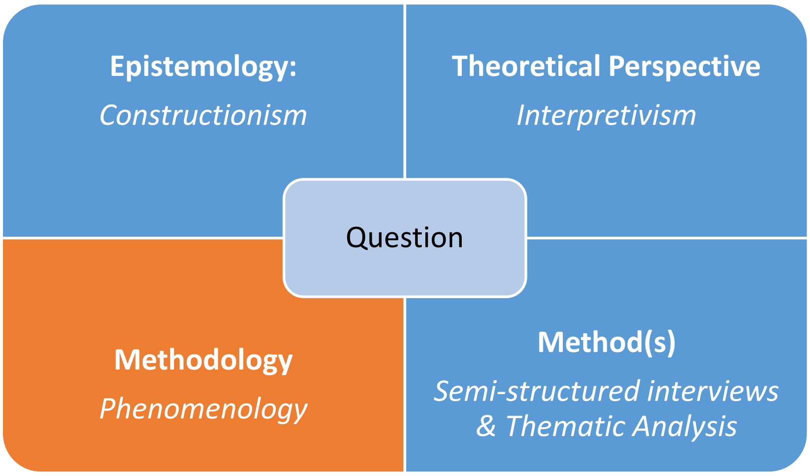

FIGURE 5: CROTTY'S FOUR PILLARS OF RESEARCH - PHENOMENOLOGY

> *[phenomenology calls us to] set aside all previous habits of thought, see through and break down the mental barriers which these habits have set along the horizons of our thinking…to learn to see what stands before our eyes* (Husserl, cited in; Crotty, 1996; p58).

Methodology refers to the research design selected to undertake the study; a phenomenological approach has been utilised for this study. Phenomenological approaches focus on and try to surface how individuals 'make sense' of their experiences of, for example, an organisation, a service or in the case of the current study a CVR reduction programme, as individuals and as members of a social group (Quinn Patton, 2015), making it congruent with both a constructionist epistemological perspective and an interpretivist theoretical perspective.

Developed by Husserl, phenomenology can be understood as both a philosophy and a methodology (Smith et al., 2009). A Husserlian phenomenological approach is concerned with understanding and surfacing how people come to know what they know and how they construct meaning of their experience of being participants in the world (Smith et al., 2009). However, Heidegger, originally a student of Husserl, expanded his own arm of phenomenological investigation to interpretative phenomenology (Crotty, 1996). For Heiddeger, a phenomenological approach not only describes the phenomenon, but is a process of interpretation, by participant and also researcher (van Manen, 1990, Creswell, 2013). This focus makes the selection of a phenomenological approach sit well within a constructionist epistemological standpoint and also an interpretative theoretical perspective. Moreover, it provides justification for the selection of NPT as a theoretical lens for the study, as NPT has, at its core, an interest in unpacking the individual and collective roles that people play in making sense of a practice when engaging in the process of 'normalising' and the interactions between 'actors' to that end (see chapter 2.1).

Taking a phenomenological approach is intrinsically linked to the selected methods to collect data (discussed in chapter 3.1.4). To elicit individuals' interpretation of an experience necessitates paying attention to how they perceive the experience, how they describe it and make sense of it (Quinn Patton, 2015), ideally lending itself to the selection of in-depth interviews as a data generation method (described in section 5.1.4).

5.1.4 Semi-structured interviews and Thematic Analysis (Methods)

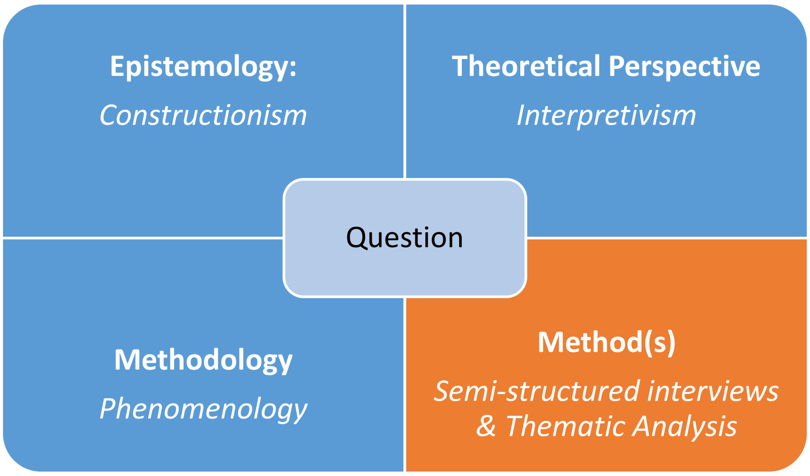

FIGURE 6: CROTTY'S FOUR PILLARS OF RESEARCH - SEMI-STRUCTURED INTERVIEWS & THEMATIC ANALYSIS

> *It takes no great self-awareness or self-confidence to report a statistically significant t test with confidence intervals based on a formula and calculations easily replicated and confirmed. It can take considerable self-awareness and confidence to report: I coded these 40 interviews, these are the themes I found, here is what I think they mean, and here is the process I undertook to arrive at those meanings. The latter statement calls for, even demands, a sense of voice and perspective* (Quinn Patton, 2002).

A semi-structured interview technique was utilised as the tool to generate data. Interviews, essentially a conversation with a purpose (Berg, 2007), are tools congruent with the methodological approach described on the previous pages. Semi-structured interviews allow the researcher to cover a standardised set of topics whilst giving the freedom to explore these topics in any order as the conversations flow and evolve, and also to explore new lines of enquiry as they arise, spontaneously (Quinn Patton, 2002, Berg, 2007, Rapley, 2007). The process of interview schedule generation and interviews is described in the following section (Chapter 5.2). Interviews were selected as a data generation technique because it is impossible to directly observe other people’s feelings and experiences of a phenomena – in this case engaging with the NHSHC programme.

The timing of the research is also crucial. Phenomenological studies require that the individual has had sufficient time to reflect upon the experience of interest. People are unable to reflect upon an experience whilst they are in the process of going through it, therefore, phenomenological studies are generally carried out ‘after the event’ (Van Maanen, 1979). In the current study, it was important to understand participant’s experience of not only the NHSHC assessment process, but also more longitudinally, their experience of living with a ‘risk diagnosis’ for a period of time, to understand their engagement with lifestyle advice and adherence to lipid lowering medication. Individuals were therefore approached who had undergone at least one annual review, so there had been ample opportunity to engage with the NHSHC programme and opportunity to reflect both individually (over the course of the year) and collectively (at the annual review appointment). The timing of interviews was also developed so all aspects of NPT, including reflexive monitoring, could be explored. Interview at an earlier time point would not have captured this important information. Of course, I should note that I am relying on rather historic accounts of their experience of the assessment, however, this trade off was deemed necessary to capture a more holistic interpretation of the NHSHC process.

In keeping with all other aspects of the methodology outlined, an inductive approach to data analysis was undertaken. This allowed analysis to be rooted in the descriptions of experience presented by the participants. A description of this process can be found in section 5.2.4.

Part of a phenomenological approach, as outlined by Husserl, is the process of *epoche* or bracketing. This process is achieved through the researcher attempting to set aside their own experiences of the phenomenon, in order to view it through a fresh lens (Creswell, 2013). One way in which bracketing is achieved is through the utilisation of a semi-structured interview approach, allowing the experiences and interpretations of the participant to be central. However, by acknowledging the constructionist, interpretative approach employed within this study we must also acknowledge the central role the researcher plays in eliciting the data and subsequently synthesising and interpreting it (Crotty, 1998). The data and the researcher, as an active participant in the research and ultimately the social context within which the research is situated, are inextricably bounded. The notion of objectivity is not in keeping with the epistemological and theoretical stance taken in this research. However, whilst not seeking objectivity I have tried to remain faithful to the interpretations provided by participants (Ahern, 1999) and provide an acknowledgement about my own position within the research in Chapter 1 and Chapter 3.4

5.1.5 Assessing methodological quality

Yardley (2000) offers a framework to explore and assess the characteristics of good quality qualitative research. Yardley describes four key areas of qualitative research where quality is demonstrated and can be assessed; sensitivity to context, commitment and rigour, transparency and coherence, and finally, impact and importance. Yardley's framework has been chosen to explore issues of methodological quality as the broad concepts are more applicable to assessing a study that is grounded in phenomenology rather than the more commonly cited concepts of trustworthiness (Lincoln and Guba, 1985).

Sensitivity to context

Demonstrating sensitivity to context includes awareness of, and engagement with previous theoretical and empirical work that has been undertaken in the same, or similar, area of study interest (Yardley, 2000). Chapters 2, 3, and 4 demonstrate how the policy and practice context, previous academic work, and underpinning theory have been acknowledged and explored. Furthermore, Yardley highlights the fact that the importance of sensitivity to participants' experiences and ethical issues is paramount. Participants' experiences are central to this study and care has been taken through data gathering stages, analysis, and reporting to ensure that findings and implications drawn from the study are rooted in participants' experiences.

Commitment and rigour

Yardley describes how commitment and rigour relate to depth of engagement with the topic and methodological competence demonstrated through data collection, analysis, and reporting. Methodological rigour was a concern over the lifespan of the study. Care was taken at the design stages by engaging with more experienced researchers (supervisory team) and utilising NPT to construct a study that was methodologically sound and robust. Supervisory meetings were held to discuss the unfolding project and issues that arose. Data analysis was guided by standardised processes and a proportion of transcripts were coded and agreed by both members of the supervisory team and myself. Care was taken in the reporting stages to ensure they were a true reflection of participants' experiences and NPT was used as a confirmatory tool to abstract the descriptive themes from the analysis to implications that were relevant and grounded in the findings.

Transparency and coherence

Yardley discusses the importance of clarity and power of description and argument, transparency of methods and how data are presented. In the study, this has been achieved through the presentation of verbatim quotations from the participants alongside a description of the theme to which they relate. Procedural methods are described later in chapter 5.2. The fit between method and theory is also imperative, states Yardley. Chapter 5.1 has described how Crotty's four pillars of social research were taken into account to ensure a congruent fit between epistemological position, theoretical perspective, methodology, and method. Section 5.1.6 demonstrates how NPT was utilised within the study also.

Impact and importance

Yardley's final measure of methodological quality relates to the impact and importance of the research and its ability to enrich understanding and its practical utility for those who may utilise the findings for example policy and practice. This study seeks to explicitly demonstrate the utility of the findings in Chapter 9. Implications derived from the findings are presented for future users of NPT (theory), for policy and practice, for training, for support and education and finally for future research.

5.1.6 Normalisation Process Theory's role within the methodology

Normalisation Process Theory was used as a tool across the lifecycle of the PhD project. In the initial planning stages, it provided a framework to sensitise me to issues around the implementation, embedding, and integration of knowledge and practices. At the planning stage, NPT helped to think through what, in a best-case scenario, would need to be in place within the NHSHC process to facilitate an individual's journey if adhering to the principles of the programme. With this in mind, the interview schedules were constructed in such a way that they would elicit information about the process of normalisation through '*making sense*' of the NHSHC and CVR (coherence), '*working out participation*' the NHSHC and suggested intervention (cognitive participation), '*doing the work*' of being at high CVR (collective action), and '*reflecting on it*' (reflexive monitoring).

At the analysis stage, NPT was utilised to make sense of the themes emerging through the inductive coding stage. Initially, the constructs and working mechanisms were used as the basis to undertake a Framework Analysis (Ritchie and Spencer, 1994). However, this process proved unhelpful and raised concerns about imposing a deductive approach to data analysis that did not sit within the ethos of the methodology previously outlined. Thus, Framework Analysis was abandoned in favour of an inductive analysis process, a blended approach taking principles from both Interpretative Phenomenological Analysis (Smith et al., 2009) and Braun and Clark's six-stage thematic analysis (Braun and Clarke, 2006, Braun and Clarke, 2013). Once the inductive coding was complete, the domains of NPT were considered in relation to the findings to see if the NPT domains could help to shed light on the issues that had arisen and help make sense of the findings. In essence, NPT was used as a theoretical lens with which to interrogate the findings. Three constructs; *making sense of it* (coherence), *doing it* (collective action), and *reflecting on it* (reflexive monitoring) were especially helpful when making sense of the data; the construct *working out participation* (cognitive participation) less so. However, this could be a reflection on how the constructs were interpreted initially and therefore the way in which the interview schedule was constructed, rather than the usefulness of the construct per se. The theory was helpful, however, in illuminating the strengths and weaknesses of the NHSHC programme, at the time of the study, and allowed the emergence of implications for policy, practice, and further research (discussed in Chapter 9).

5.2 Process and design

The following procedural methods section is described utilising the COREQ framework (Tong et al., 2007) for reporting qualitative studies.

5.2.1 Participant selection

A purposive sampling technique (Quinn Patton, 2015) was employed to include individuals who fitted the following inclusion criteria:

1. Had undergone a full NHSHC assessment at their GP practice
2. Had been identified as at high risk (>20%) of having a cardiovascular event in the next ten years
3. Had been given lifestyle advice and/or been prescribed prophylactic lipid lowering medication
4. Had attended at least one annual review

This approach was selected to fit the needs of the commissioned evaluation, to ensure that participants had experienced the entire NHSHC process from invitation through to annual review.

Participants were approached to take part through their GP practice. Four GP practices that had taken part in the first evaluation (Oswald et al., 2010) were approached to help with participant recruitment; one in each of the Hartlepool, Stockton on Tees, Middlesbrough and Redcar and Cleveland Primary Care Trust (PCT) localities. The practice manager or lead CVD nurse, who had overall responsibility for the delivery of the NHSHC programme, was contacted by email. The email explained the research project, and what would be involved in terms of fieldwork if their patients did decide to take part. Of the four practices that were initially contacted all agreed, in principle, to help recruit participants into the study.

Once a practice indicated they were happy to contact patients on behalf of the research team, each GP practice was visited to discuss what would be required of them and to answer any questions that they might have had. During this initial visit practices were provided with copies of key information for staff (Appendix 11.4), a participant information sheet (Appendix 11.6) and a patient contact details form (Appendix 11.7). Practices were asked to discuss the project with patients at the point of annual review using the key information sheet as a reminder. Patients who expressed an interest in taking part were then given a hard copy of the participant information sheet. Their contact details were recorded, using the contact details form, and kept in a safe place, according to each practice’s protocol for storing patient information, until they were ready to be collected.

The practices kept in contact through regular email and telephone contact. Once several patients had expressed an interest in taking part in the study, I visited each practice to collect the information. All this contact information was kept securely in a locked filing cabinet at Teesside University until the interview with that patient was complete. Once all data had been collected and all tapes transcribed. All of the participant contact details were shredded using Teesside University’s secure shredding system.

This method of patient recruitment posed a challenge, as the number of patients called into practices for their annual review was variable. Some practices had engaged with the programme much more than others (Oswald et al., 2010) and therefore had many more patients attending for the review. Some practices were experiencing difficulty getting patients to attend for their annual review appointments and speculated that this was because patients had not been taking their medications or keeping up with the lifestyle changes proposed at their assessment.

Recruitment of GP practices in the Middlesbrough locality was challenging and took some time. In Stockton one practice agreed to take part but, after recruiting two participants, withdrew from the study. Therefore, another practice was identified in that area in order to achieve the required number of participants. Table 15 shows the number of practices contacted in each area, how many agreed to take part and finally how many practices went on to identify and approach participants.

Table 15: GP practice recruitment

	Locality			
Number	Hartlepool	Middlesbrough	Stockton-on-Tees	Redcar
Contacted	1	14	2	1
Agreed	1	3	2	1
Took part	1	1	2	1

Each participant who expressed interest in the study was contacted, via telephone, to establish that they were happy to be interviewed. Participants were given the opportunity to ask any questions they had about the study and what would happen if they agreed to be interviewed. Each participant was asked if they had had the opportunity to read through the printed information sheet to ensure they had read and understood it. Once interest in the study was established an appointment was made for them to take part in an interview at a time and location that was convenient to them.

Thirty-one participants expressed an interest in the study and all went on to be interviewed. However, at the point of interview I had concerns about three of the patients' ability to give informed consent. Upon arriving at one interview the participant was found to be accompanied by a carer, who explained that the participant had suffered a hypoxic brain injury and might not be able to recollect the assessment. After a short conversation with the participant it became clear that they could not recollect their assessment or review, so the participant was thanked for their time and the interview was terminated. Another interview was terminated because it quickly became apparent that the participant was drunk. The final interview that was terminated was with a lady who was in a semi-secure forensic unit and who did not remember her NHSHC or review. In these three instances I made a decision to abandon the interview process. One other interview had to be removed from this analysis as the interview failed to record. One further interview was excluded from analysis as the interview was cut unexpectedly short when I left early because of safety concerns. Twenty-six interviews were therefore taken forward for analysis. No participants asked to be removed from the study once they had taken part in interview.

Participants were given the opportunity to choose the location where the interview would take place, for example, their home, at the university, a coffee shop or a local community centre. Many of the GP practices offered rooms in their buildings to host interviews. However it was felt preferable to conduct the interviews in a place that was neutral for the participant, to facilitate frank and open discussions about their experiences of being involved in the NHSHC programme. It was also important that participants did not assume that I was linked to their GP practice.

Interviews therefore took place either in participants’ homes or at Teesside University. As interviews took place at participants’ homes, the Teesside University lone worker policy was implemented. This necessitated the use of a ‘buddying’ system, whereby a colleague was aware of where interviews were to take place, to ensure my safety at all times.

For the majority of the interviews there was only the participant and I present. However, on five occasions the participant’s partner/ spouse was also present. This was because the interview was being conducted in their own home. Consent was also gathered from the spouses that were present so that their commentary could be included within the analysis, if it was relevant.

5.2.2 Ethics and ethical scrutiny

As discussed in the opening sections of chapter 5, this study is a secondary analysis of data that I collected as part of a commissioned piece of work. As such, approval to undertake the secondary analysis was sought from Teesside University’s School of Health and Social Care Research Ethics and Governance Committee. A copy of the approval letter is included in Appendix 11.5. The original commissioned study that this data was collected for received approval from the same committee in February 2011. Approval was sought from the National Research Ethics Service (NRES) (latterly replaced by the HRA) to undertake the study. However, it was classified, as per the guidance at that time, as a service evaluation. Therefore, full NHS ethics was not required for the original study. Local R&D permission was given by the relevant Trusts.

The acquisition of informed consent was an iterative process. Participants were given written and verbal information about the project and given the opportunity at several points, before the interviews took place, to ask questions. Immediately before the interview took place they were asked if they were happy to go ahead. Each participant was informed that they could stop the interview at any time to ask further questions or to stop participating. If they wanted to stop the interview and leave, they did not have to give a reason. No participants decided to stop the interview. However, on three occasions participants became distressed whilst recounting personal experiences. On these occasions the interviews were paused, the participants given time to collect themselves and I offered to terminate the interview. On each occasion the participant was happy to continue.

All participants were ensured that the information they gave would be kept confidential, in that only I and my supervisory team would read the transcripts in their entirety. However, each participant was made aware that direct quotations from what they said would be used when reporting the study. For this reason, they were assured that they, as participants, would be granted anonymity through the use of pseudonym. All transcripts were anonymised – all participants were given pseudonyms and I was selective about the demographic information that was attributed to direct quotations so as to maintain this.

5.2.3 Data collection

Data were collected through semi-structured interviews to (as much as possible) facilitate frank and open discussions and were guided by the interview schedule presented in Appendix 11.8. Chapter 4 described how I used NPT constructs to identify key areas to explore with participants to understand their engagement with elements of the NHSHC programme. I developed the interview schedule to cover the aims of the aforementioned evaluation but furthermore to probe into deeper questions which served to explore the aims of the PhD study.

To design the tool that would be used in each of the interviews (Appendix 11.8) I followed a six stage process as outlined by Braun and Clarke (2006): Brainstorming initial questions, considering the sequencing of questions, constructing and wording the questions, developing prompts and probes, piloting the interview guide, and finally refining the interview guide.

Brainstorming initial questions: I began by taking the four constructs of NPT and brainstorming how each construct and working mechanism might be helpful in understanding the journey that potential participants might travel through the NHSHC programme. Tables 7, 9, 11, and 13 demonstrate the types of questions that I generated through this process. Initial question generation was also informed by my previous work evaluating aspects of the NHSHC programme from an organisational perspective and the requirements of the commissioned piece of work already discussed. This was an important process to undertake as it identified a wide variety of issues and aspects of potential engagement with the NHSHC programme to explore (Quinn Patton, 2015).

Sequencing of questions: I then began a process of grouping questions by ‘topic’ or ‘theme’ in order to sequence the questions. I decided that the most logical way to sequence them was by stages of the NHSHC journey: receiving the invitation, attending the initial risk assessment, being informed of CVR status, making changes to lifestyle, attending annual review. This allowed the interview to progress logically and thereby shift from one topic to the next (Braun and Clarke, 2013).

Constructing and wording the questions: the next stage was to consider how the questions might be worded. In order to allow the interview to progress in a conversational manner, strict questions that had to be adhered to were not developed, rather example phrasings were developed whilst being mindful that the wording of the questions may change depending on participants' previous responses in the interview. I wanted to allow the interview conversations to emerge in a natural but purposeful way (Burgess, 2002), whilst being mindful of the specific topic areas I wanted to address.

Developing prompts and probes: the next stage of the process was to develop a set of prompts and probes for my questions. Prompts and probes can encourage participants to open up a little more and expand on their answers in more detail (Braun and Clarke, 2013). Prompts and probes were not developed for every question – only those where I felt it would be most helpful to delve a little deeper should the interview require it.

Piloting and refining the interview guide: the final stages in the development of the interview guide included the piloting of the tool and refining it prior to use. The tool was appraised and agreed with the supervisory team. Before I began piloting it members of the commissioning organisation also appraised the tool to ensure that it met their needs and to offer expert insight from those tasked with commissioning and implementing the NHSHC locally. I undertook a 'mock interview' with a colleague to ensure I was happy with the flow and wording of the questions prior to embarking on 'live' interviews.

Each participant was asked to sign a consent form (Appendix 11.9) prior to the commencement of the interview. Once interviews had been completed each participant was thanked for their time and given a £20 High Street voucher as a gesture of good will. Each participant was also sent a thank you card. Interviews lasted between 20 and 90 minutes. The interviews were, with the permission of the participants, digitally recorded and later fully transcribed ready for analysis. Field notes were made after each interview and were used to inform the analysis stage.

5.2.4 Analysis and findings

All interviews were conducted by RM and all transcripts were coded by her. JS and AS coded a subset of six transcripts. All coders met to discuss and agree the patterns and themes that were evident in the transcripts to ensure consistency of coding and to ensure that themes were not being overstated.

An inductive approach to data analysis was undertaken to ensure that all themes were derived from the data corpus. Data analysis drew on (Braun and Clarke (2006), Braun and Clarke (2013)) six stage thematic analysis framework and Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). Table 16 shows the stages of each type of analysis.

Table 16 Key stages of analysis

	Thematic Analysis (Braun and Clarke)	**Interpretative Phenomenological Analysis (Smith et al)**
Relevant stages of analysis	Stage 1: Familiarisation with the data	Stage 1: Initial familiarisation with the text
	Stage 2: Generating initial codes	Stage 2: Identification of initial, preliminary themes
	Stage 3: Searching for themes	Stage 3: Grouping of preliminary themes into clusters
	Stage 4: Reviewing themes	Stage 4: Tabulation of clusters and themes into a summary table (Smith et al., 2009, Biggerstaff and Thompson, 2008)
	Stage 5: Defining and naming themes	
	Stage 6: Producing the report	

Each participant's account was dealt with, initially, on an individual basis.

Each transcript was read whilst listening to the tape simultaneously. This allowed me to make notes on tone and language used by the participant and to immerse herself in the account that the participant was describing. During this process of familiarisation descriptive notes were made, about language used, repeated phrases, inconsistencies in the participant's account, questions about the data and my own emotions and preconceptions that may affect analysis. The latter notes were made in a separate research diary in an attempt to acknowledge, suspend and lay aside the my own opinions and judgements as a form of bracketing (Smith et al., 2009, Creswell, 2013).

Each transcript and the accompanying notes made in stage one were then re-read. NVIVO 10 was used to manage the large corpus of data and to facilitate the organisation of data into themes. At this second stage the descriptive ‘free notes’ were condensed and transformed into phrases which captured and summarised the meaning contained in the ‘free notes’. These phrases, or initial themes, became abstracted from the data and began to convey deeper meanings that had been derived from the text. This second stage of analysis saw me move away from working with the text of the transcript to working more analytically with the initial notes, but with regular cross checking back to the data to confirm interpretations. At this stage I was not only abstracting themes but looking for connections between the themes, in each transcript.

The third stage of analysis consisted of taking these newly derived initial themes and clustering them into a logical structure of concepts, clustering was tried in several ways, cross checking back to data. This stage of analysis aimed to arrange and group themes into super-ordinate categories and to identify relationships between the clusters (Biggerstaff and Thompson, 2008). During this phase of analysis I began to move into a stage of interpretation from the story the participant had told. Whilst the interpretation began to become more and more abstracted from the data it should be noted that the words and description from the participant were always the springboard for interpretation and all interpretation was rooted in the data from the participant, representing how the hermeneutic circle is manifest in the analysis (Smith et al., 2009).

Clusters and their related themes were then mapped to make sure they were distinct from one another and to show how the themes fit together. At this point in the analysis the constructs of NPT were cross referenced against the emergent themes to see if NPT could illuminate the themes derived from the data. This phase of deductive analysis was performed at this stage to ensure that any themes were directly derived from the data and data was not forced to fit the constructs of NPT. The themes were then named ready for reporting.

The themes reported in Chapters 6 and 7 are presented descriptively alongside direct quotations from the interview transcripts to show how the theme was derived from the data. The analytical interpretation is presented in the discussion chapter (Chapter 8) where it is linked back to relevant literature.

5.2.5 Research team and reflexivity

All interviews were conducted by me, a female full time Research Associate working in the School of Health and Social Care at Teesside University. I hold a BSc Psychology and MSc Social Research Methods and have a decade of practical qualitative research experience. I am not a medical practitioner. At the beginning of each interview this was stressed to participants so that they were aware she could not offer any medical advice or enter into conversations about the appropriateness of their treatment or care. On many occasions participants seemed conflicted by this information, as they did try to engage in these kinds of conversations. The participants were made aware that I was not affiliated with their GP practice and that anything they told me would not be passed back to their practice. This enabled participants to be frank and honest about their experiences of the NHSHC assessment, the staff delivering it, and their experience of the annual review process.

This process of identifying myself as separate to the intervention and the staff delivering it had both advantages and disadvantages. Participants could speak openly about the care and treatment they had received without fear of repercussions from practice staff. In many cases participants took the opportunity to tell me things they suggested they would not normally tell staff responsible for their care. This process of separating myself from the intervention also allowed me to ask naïve questions that perhaps a health professional would have taken for granted and to explore avenues that would otherwise have been left. However, this separation did have another side. I was not known to them and also not a ‘trusted professional’; I was not affiliated to any organisations that were responsible for care. On some occasions this caused participants to think I was an undergraduate student from the University carrying out a project for my course, very similar to the case outlined by Richards and Emslie (2000). In the case reported by Richards and Emslie, participants changed the way they interacted with the researchers based upon their perceptions of who the researchers were, professionally. One of the researchers was a trained medical doctor. When participants were aware of this information they tended to ask for reassurance about medical conditions and adopt a more subordinate role within the interview process. The other researcher was an academic. When participants were aware of this information they questioned if the researcher was a student, undertaking fieldwork for study. This study demonstrates that participants change how they interact with researchers based upon their perceptions of positions of power. This impacted on the project, as the reality that participants described me may well have been different to what had actually happened in the assessments or in the subsequent year leading to the annual review.

It must be acknowledged that I was integral to the analysis and that this analysis was formed and shaped by me. Phenomenology acknowledges the pivotal role of the researcher in generating the data and of course its subsequent analysis.

5.2.6 Limitations to study design

There are, of course, limitations to the chosen methods of data collection. Recruitment of patients was reliant on the cooperation of General Practice staff, mainly Practice Managers and Practice Nurses. Some practices that were approached to take part in the study agreed quite quickly. Others agreed but never actually produced any patient details or they refused completely. Recruitment of participants in one locality proved difficult, this was overcome by continual recruitment of practices until one finally agreed to help. However, this created a long delay in the project.

Once I had approached the relevant person within the GP practices, responsibility for recruitment was handed over. I had no way of knowing if the personnel were sticking to the protocol for giving out the appropriate information. Moreover, GP practice participation was subject to other professional priorities such as staff sickness and holidays which caused, in some cases, much delay in participant recruitment.

The sampling strategy was chosen to suit the priorities of the commissioner, the evaluation, and for pragmatic purposes. It must be noted that patients who agreed to take part were, to all intents and purposes, a self-selecting sample. To fully understand patient adherence with the NHSHC programme it would have been beneficial to include patients within the sample who had refused to have a NHSHC in the first place. Identifying and contacting that cohort of patients however, carries many practical and ethical implications. It should also be noted that participants were not recruited from all age groups eligible for the NHSHC. Through the sampling strategy employed, participants who agreed to be interviewed were from older age groups. No one between the ages of 40-56 years old is included within this sample. As stated earlier this could be a reflection on the approach taken by the Tees PCTs to target those who were most likely to be at increased risk of CVD in the early stages of roll out.

Chapter 5 has outlined the philosophical underpinnings of the research, the procedural methods employed in data generation, analysis and the limitations to this approach. The following chapters move on to discuss the findings of the study.

6 Findings – *making sense of it* and *working out participation*

The following chapters present the findings from the study and discussion about how findings can be understood through the theoretical lens adopted for this study. The two findings chapters (6 and 7) are presented descriptively. Each theme is presented alongside example verbatim quotations that demonstrate how the theme was derived from the data. Analytical interpretations of the data and how they relate to the NPT constructs are presented in chapter 8.

Chapter 6 presents findings that mainly relate to the patient 'work' involved in making a decision to attend assessment and understanding the initial diagnosis of increased cardiovascular risk. This can be illustrated through exploring the constructs of *making sense of it* (coherence) and, to some extent, *working out participation* (cognitive participation). Chapter 7 relates to phases of patient 'work' that relate mainly to the constructs *doing it* (collective action) and *reflecting on it* (reflexive monitoring). The themes presented in these two findings chapters thus follow the progression of the patient journey from invitation to attend assessment through to annual review. This was done purposively to allow the voice of the participant to shine through and to demonstrate how NPT constructs relate to each stage of the journey through the NHSHC. Deeper, conceptual discussion about the implications of the findings is presented in chapter 8.

This first findings chapter explores the phases of work that participants undertook to engage with the NHSHC programme, make sense of their diagnosis of risk, and engage with questions around preventative medicine. Therefore, the findings in this chapter relate primarily to the first two constructs of NPT; *making sense of it* (coherence) and *working out participation* (cognitive participation).

Section 6.1 presents demographic information about participants. Section 6.2 is concerned with the reasoning that took place to make a decision to attend and engage with the initial stages of the NHSHC assessment. 6.3 describes how people reacted to being told they were at increased CVR. 6.4 discusses the identity work undertaken after identification of increased CVR. Finally 6.4 assesses participant’s views on preventative action in terms of CVR.

6.1.1 Participant demographic information

Of the 26 participants, the majority (65.4%, n= 17) were male and nine were female (34.6%) (Table 17). Participants were aged between 57 years old and 76 years old at the time of interview. Whilst the NHSHC assessment is available to the entire English and Welsh population who are aged between 40 and 74 years old, no one from the younger age groups (40-56 years old) took part in the study. This could be a reflection on the way in which the Tees PCTs implemented the check by utilising a targeted approach alongside the recommended universal approach. It can be seen in Table 17 that the majority of participants in the sample (60%) were in the older age categories and aged between 65 and 74 years old. The majority, 84.6% (n=22), were currently married with 7.7% (n=2) divorced, 3.8% (n=1) widowed and a further 3.8% (n=2) being single.

Despite efforts to recruit evenly from each of the four PCT areas; Hartlepool, Middlesbrough, Redcar, and Stockton on Tees, the distribution of participants included within the sample was far from equal (Table 18). However, as participants were, essentially, a self-selecting sample, the distribution of participants across the localities was dictated by the responses to the study invitation.

The majority of participants included within the study were retired (78.6%, n=22), two were still in employment and two were unemployed due to disability (Table 18). All participants had attended at least one annual review. Twenty participants (76.9%) had attended just one annual review at the point of interview and six had attended two annual reviews (23.1%). It should be noted that the people included within this study are already compliant to some extent as they have received an assessment, been identified as at high risk and have attended at least one annual review. A majority of participants (69.2%, n=18) had a history of CVD in their family, eight (30.8%) stated that there was no history of CVD in their family but two (7.7%) of those eight did describe a history of cancer.

Table 17: Sex, age, and marital status of participants

	Sex		**Age group**					**Marital status**			
	Male	Female	55-59	60-64	65-69	70-74	75+	Married	Divorced	Widowed	Single
Number	17	9	3	5	3	7	2	22	2	1	1
(%)	(65%)	(34.6)	(11.5)	(19.2)	(4.6)	(26.9)	(7.7)	(84.6)	(7.7)	(3.8)	(3.8)

Table 18: Recruitment locality and employment status of participants

	Locality				**Employment status**			
	Hartlepool	Middlesbrough	Redcar	Stockton-on-Tees	Retired (semi-skilled)	Retired (professional)	Employed (professional)	Disabled
Number	2	9	6	9	13	9	2	2
(%)	(7.7)	(34.6)	(23.1)	(34.6)	(50)	(34.6)	(7.7)	(7.7)

Table 19: Statin status and dietary advice given to participants

	Statin status				Dietary advice		
	Taking	Discontinued	refused	Not prescribed	Made changes	Made no changes	No advice offered
Number	17	4	4	1	14	8	4
(%)	(65.4)	(15.4)	(15.4)	(3.8)	(53.8)	(30.8)	(15.4)

Table 20: Physical activity advice, alcohol consumption advice, and smoking status

	Physical activity			Alcohol consumption			Smoking status			
	Made changes	Made no changes	No advice offered	Made changes	Made no changes	No advice offered	Non smoker	Ex smoker	Made no changes	Quit
Number	2	7	17	1	3	22	10	13	1	1
(%)	(7.7)	(26.9)	(65.4)	(3.8)	(11.5)	(84.6)	(38.5)	(50)	(3.8)	(3.8)

Table 21: Participant Demographic information

✓=discussed and made changes
✗ =discussed and no changes made
- =no recollection of discussion

Name	**Sex**	**Age**	**Marital Status**	**Family history of CVD**	**Number of annual reviews**	**Statin status**	**Diet**	**Physical activity**	**Alcohol**	**Smoking**	**IMD quintile (LA) (1=least deprived)**
Alex	Male	67	Married	✓	2	Refused	✓	✓	-	Ex-smoker	3
Barbara	Female	66	Married	✓	2	Discontinued	✓	✓	-	Ex-smoker	3
Bernie	Female	61	Married	✓	1	Refused	✗	✗	-	Non-smoker	3
Brian	Male	66	Divorced	✓	1	Taking	✓	-	-	Non-smoker	3
Carol	Female	75	Divorced	✗	1	Taking	-	-	-	Ex-smoker	1
Colin	Male	57	Married	✓	1	Taking	✓	-	-	Ex-smoker	3
David	Male	62	Married	✓	1	Taking	-	-	-	Non-smoker	2
Dennis	Male	65	Married	✓	1	Taking	✗	-	-	Ex-smoker	4
Doug	Male	71	Married	✓	1	Not prescribed	✗	✗	-	Non-smoker	1
Fran	Female	70	Married	✓	1	Taking	✓	-	✗	Ex-smoker	3
Gary	Male	67	Married	✓	1	Taking	-	-	✓	✗	4
Harry	Male	75	Married	✗	1	Taking	✗	✗	-	Ex-smoker	1
Jeff	Male	71	Widow	✗	2	Discontinued	✗	-	-	Ex-smoker	1

Name	Sex	Age	Marital Status	Family history of CVD	Number of annual reviews	Statin status	Diet	Physical activity	Alcohol	Smoking	IMD quintile (LA) (1=least deprived)
Jim	Male	61	Married	✗	1	Taking	✓	-	-	Ex-smoker	1
John	Male	71	Married	✓	1	Taking	✓	-	-	Ex-smoker	3
Kate	Female	68	Married	✓	1	Refused	✓	-	-	Ex-smoker	4
Keith	Male	60	Married	✓	2	Taking	✓	✗	✗	Non-smoker	2
Ken	Male	74	Married	✗	1	Discontinued	✗	-	-	Ex-smoker	4
Linda	Female	66	Married	✓	1	Refused	-	-	✗	Ex-smoker	4
Maureen	Female	58	Married	✓	2	Taking	✓	✗	-	✓	3
Nigel	Male	72	Single	✓	1	Taking	✗	✗	-	Non-smoker	3
Paul	Male	63	Married	✗	1	Discontinued	✓	-	-	✗	1
Paula	Female	57	Married	✗	1	Taking	✓	✗	-	Non-smoker	2
Phillip	Male	65	Married	✗	1	Taking	✓	-	-	Non-smoker	1
Shirley	Female	72	Married	✓	2	Taking	✗	-	-	Ex-smoker	3
Tom	Male	66	Married	✓	1	Taking	✓	-	-	Non-smoker	3

✓=discussed and made changes
✗ =discussed and no changes made
- =no recollection of discussion

6.2 Making a decision to attend an NHS Health Check

The success of the NHSHC programme relies on several distinct processes taking place, these processes are congruent with the processes proposed by the constructs of NPT. Firstly, individuals must accept the invitation of assessment and attend their assessment appointment (*making sense of it* (coherence)). Individuals must then receive and accept their diagnosis of CVR (*making sense of it* (coherence) and *working out participation* (cognitive participation)) and go on to internalise the necessity to implement lifestyle changes and also accept, comply, and sustain engagement with prophylactic medications (*doing it* (collective action)). Individuals must also agree to long term monitoring of CVR through the annual review process (*reflecting on it* (reflexive monitoring)). Therefore, the way in which people are approached to undergo a CVD risk assessment may be pivotal to their initial 'buy in' to the NHSHC programme. In order to encourage people to attend assessment, the invitation needs to be presented in a way that makes sense and offers something that is attractive, coherent, and worthwhile for them to attend.

For the individuals in this study, the invitation offered to them to undergo risk assessment, was not initially interpreted as unique, or different from many other invitations to attend their GP practice (*understanding the uniqueness of it* (differentiation)). In fact, their invitation for assessment seemed to be part of a routine offering by their GP practice. As Jim summed up in his interview:

> *It was just a routine check* (Jim, 61).

General curiosity and interest in maintaining overall health led this group of patients to attend their NHSHC assessment. As Nigel described:

> *It was a letter from the surgery, and that was it, inviting me to take part. So I thought "I've got nothing to lose" so I went* (Nigel, 72).

The importance, or value of the health check was not particularly scrutinised at an individual level. It was suggested that if routine health checks are offered by health professionals, it must have some clinical importance, and therefore it is good practice to attend:

> *If they invite you to go and do these things then I think you should go and do them. They obviously regard it as something important, so why not? It doesn't cost you anything, just 20 minutes* (Kate, 68).

People often did not distinguish the NHSHC as different from their current ways of routinely engaging with their GPs (*understanding the uniqueness of it* (differentiation)). For example, Alex and Barbara described how Barbara had been having the NHSHCs for a number of years, even before the NHSHC programme was in existence. This lack of differentiation between the NHSHC and other checks that were routinely accessed led some participants to not even realise they were engaging with a 'new' programme:

> Alex: *Well, my wife has been going on a Healthy Heart Check (NHSHC) for what must be three or four years now, haven't you?*
>
> Barbara: *I think so, yeah?*
>
> Alex: *I don't know why the women got theirs, but the men's came after, if you like?* (Alex, 67. Barbara, 66).

In addition to the perceived routine nature of the offer of a health check, many participants interpreted the offer of assessment as a result of their advancing age (*individually interpreting it* (individual specification)). Again, reiterating the interpretation of risk assessment invitation as a routine offering from the health services:

> *I thought it was everybody of a certain age who got invited. I never actually wondered why I had been invited. I thought it was something people have to go through at a certain age, and that people at that age had all been invited* (Brian, 66).

People are used to being offered routine checks for many different possible health complaints right across the life course, and this was not distinguished as different from any of those other health screenings:

> *You get to a certain age and you need to come in and get a Healthy Heart Check-up for different things when you get to 60 you get that thing through the post for the check [of] your stools for the bowel cancer* (Paul, 63).

Another participant noted:

> *I was just called up. As far as I was aware, it was for an MOT*[3]*…I mean a lot of GPs do this thing now, every year or two, if you're over 60 you get invited for an MOT* (Gary, 67).

These findings highlighted how individuals were passively compliant in the initial stages of the NHSHC journey.

6.2.1 Feeling fit and well

Whilst the invitation to attend a health check did not, initially, seem out of the ordinary to participants, the need to have a health check to assess CVR was not something many of them had ever considered they needed, as, prior to the assessment, they all felt fit and well. All participants in the sample had been asymptomatic prior to invitation, and none of them had sought out or requested a CVD risk assessment. For example, as Brian describes:

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[3] MOT is an abbreviation of Ministry of Transport. MOT is a common name given to a vehicle safety test in the UK. https://www.gov.uk/getting-an-mot/when-to-get-an-mot

> *I mean I really wouldn't know? If you were having problems with your heart what it would be like? But I mean I have never felt as though I am having a problem with it…I mean, I walk miles!* (Brian, 66).

And Phillip describes:

> *I mean I only go to the doctors if I don't feel very well, but I felt healthy [prior to assessment]. So there were no signs of anything, I wasn't suffering with anything due to high cholesterol* (Phillip, 65).

The offer of CVR assessment did, for some, act as a catalyst to begin a process of analysis leading to the consideration that even though they felt fit and well now, the assessment could highlight underlying conditions or point to future ill health:

> *In one way you can think about it and think am I being healthy, am I doing the right things, is it worth it because I am feeling alright? I don't have any problems that I think would cause me any problems. So, do I really need to go? So, I suppose it can sow the seed of doubt* (Tom, 66).

It was clear from discussions about being invited for an NHSHC that whilst people feel fit and well, and in this respect may feel that attending the assessment may not make immediate sense, the routine nature of the request seemed to override this. For many, the offer of a CVD risk assessment is interpreted as something that is just par for the course – just one of those things you expect to do as you get older. People are used to being offered health checks for illness that may lie symptomless for many years, for example many forms of cancer, so in this respect the CVD assessment is not differentiated as unique in comparison to any other invitation that is accepted as 'normal' or 'routine'. Rather, the perceived routine nature of the assessment led many to attend the check. As people age, the number of routine health assessments they are invited to attend increases and the CVD risk assessment seems to fit neatly into just another one of those things that is offered.

6.2.2 Reasoning about the likelihood of being a candidate for cardiovascular disease

When making a decision about attending the NHSHC, and subsequently throughout the NHSHC journey, individuals considered their likelihood of being a candidate for CVD. Candidacy, as demonstrated in Davison et al. (1991), is a construction by individuals, drawing in many different types of knowledge about themselves, their lifestyles, experiences of CVD, understanding of clinical information, and the way in which numerical risk scores are calculated and presented. In one case, a participant described a very high level understanding of CVR and the way in which CVR scores were relevant to different sections of the population:

> *Well, that's another issue I have with numbers. It's calculated on a total population, which is nonsense, because I am not a total population. The white indigenous population is quite different to the Asian population; it's quite different to the black population…* (David, 62).

This high level analysis was not the norm; however, it demonstrates participants' methods of constructing a perceived likelihood of a cardiovascular event through processes of individual interpretation (individual specification) and *coming to a conclusion* (internalisation).

The impact of behavioural choices such as poor diet, carrying excess weight, physical inactivity, and smoking were highlighted as reasons that people would be expected to be at increased risk of cardiovascular disease. Participants often discussed who they felt *should* be at increased risk of CVD:

> *To me, I suppose, somebody who is overweight and has a bad lifestyle, you know [would be at high risk of CVD]. [Who has] bad eating habits and eats chocolate and stuff like that. Which I don't!* (Linda, 66).

Barbara:	*Alex's mother died of a heart attack. A massive heart attack, and that was at 80.*
Alex:	*But she had smoked, from when she was 12 year old, right through her life. So, she had created a problem for herself, I think!* (Alex, 67. Barbara, 66).

These interpretations at both the individual and collective (individual and collective interpretation) demonstrated a synthesis of myriad sources of information about candidacy gleaned from health promotion information and from interacting with friends, family and the social world to come to a conclusion (internalisation) about what factors affect CVR.

Interestingly, in the majority of interviews, when discussing what it was that would make an individual a candidate for a CVD related event, people were able to recall an instance of an exception to 'the rule'. People, who were physically fit, lived a virtuous lifestyle, yet in spite of this were still either disabled or killed by CVD. These stories seem to run counter to any coherent argument for risk reduction and management as they point to a more random and fatalistic understanding of CVD. Fran described:

> *I have a friend who's six years older than me. Five years ago we were all out [for a celebration]…and within two weeks of that she was paralysed with a stroke. She was about five foot, weighed about seven stone wringing wet, you know? Went swimming, I mean she'd been swimming that afternoon!* (Fran, 70).

Gary also noted:

> *I worked with a lad, and he was 38 [when he died of a heart attack]. He was built like a robber's dog; I mean he was fit and skinny…he rode his bicycle every day to work, and back… [He had] a heart attack at 38. Didn't drink, didn't smoke!* (Gary, 67).

These examples of exceptions to the rule were not limited only to cases of disability and death. Examples of the unfair nature of precursors to disease were also noted:

> *I don't eat butter; if I have anything it's margarine. I always have skimmed milk. So, yeah, that was a shock – because I have a friend; she has full cream, she has butter, and she hasn't got high cholesterol!* (Carol, 75).

6.2.3 Clinical testing for cardiovascular risk

In discussions, participants rarely focussed on the testing that they were offered as part of the NHSHC. When testing was discussed it was described as something that was routine. Again, this suggests that the NHSHC was not seen as offering anything particularly unique, by way of offer or testing:

> *[Testing was] the usual things; you know, blood pressure and all the rest of it. [The nurse] advised me to go on statins (laughs) and that sort of thing* (Jim, 61).

The lack of distinction of the NHSHC testing process from other routine tests that participants are offered locks in to the construct of *making sense of it* (coherence), particularly the working mechanism of *understanding the uniqueness of it* (differentiation). This could suggest that the type of tests offered to participants (height, weight, blood pressure, lipid testing) are already routinised, therefore leading participants to think there is no need to question or consider them in any great depth.

It has been previously noted (in chapters 2 and 3) that cholesterol and cholesterol testing are both very common notions in the UK population's collective consciousness. It is understandable, therefore, that this became the focus when recalling testing during the NHSHC process. There was an awareness, in general, about the thresholds of what is considered to be 'normal' cholesterol and what is considered to be 'high'. However, in some cases where an individual's total cholesterol lay within the recommended limits, the concepts of high density lipoprotein (HDL) – also termed 'good cholesterol' – and low density lipoprotein (LDL) – also termed 'bad cholesterol' – were introduced, by the nurses in the consultation, as a way of justifying the provision of statins. As Gary describes, below, how good and bad cholesterol were introduced as concepts during the assessment encounter as a way of encouraging him to take statins for the purposes of prevention, regardless of his seemingly low total cholesterol level:

> *She put me on statins. My cholesterol is 3.5, but I have got more bad statins than good statins. Err, more bad cholesterol than good cholesterol. So, she put me on these statins, which I don't like* (Gary, 67).

This demonstrates a tension between individual interpretation (individual specification) of what constitutes high cholesterol and therefore the need for medical intervention and collective interpretation with the health professional about the justification for pharmaceutical intervention and how the process of collective interpretation (communal specification) can be used as a tool to influence the outcome of the encounter.

6.3 Receiving and interpreting a diagnosis of cardiovascular risk

There were differing reactions displayed by participants regarding the news that they had been identified as at-risk of suffering a cardiovascular event in the next ten years. How people reacted to this news had the power to influence their subsequent journey and engagement with lifestyle advice and prophylactic medication. As mentioned previously, individuals who had been identified as at high risk, had, essentially been offered a ‘diagnosis of risk’. This diagnosis of risk was based on the assessment of surrogate markers (anthropometric measurements; family history; cholesterol screening; and lifestyle factors). These surrogate markers, when assessed singly do not constitute illness or disease but when assessed in conjunction with one another by means of an algorithm which calculates odds, it is posited that they indicate increased CVR. This lack of defined *clinical* diagnosis of a physiological condition meant that individuals did not always perceive that there was a problem that warranted attention through the implementation of behavioural changes or embarking on prophylactic medications.

Upon hearing the news that they were at increased risk of a cardiovascular event, individuals began to engage with another layer of sense making work in order to unpack this news and integrate (or not) the concept of risk into their identity and lives. The following pages will explore; the differential reactions to the ‘at-risk’ diagnosis, how individuals begin to interpret and understand CVR, the *working out participation* (cognitive participation) work that individuals do to resist or accept a risk identity and finally how individuals engaged with concepts of prevention and fatalism.

6.3.1 Reactions to being identified as at high risk of a cardiovascular event

Individuals reacted in three ways to the news that they were at CVR; some were shocked at the news; some felt they had had a diagnosis of ‘nothing’ and others felt that being identified as at-risk was actually reassuring. The following section will unpack these findings more fully.

For many, learning that they were now considered to be at increased CVR, came as quite a shock. Confirmation of CVR was something unexpected. For some, like Fran, the communication of CVR expressed as a percentage drove home the message of risk and allowed the recipients to begin to internalise risk as something real and tangible that could be changed. *Coming to a conclusion* (internalisation) that CVR was indeed a threat became a catalyst to engage with preventative behaviours and accept prophylactic medications:

> *But it was a bit of a shock because it was 25 point something chance of having a heart attack or stroke within ten years. I mean, I thought it would be high. I mean, I didn’t think it would be that high* (Fran, 70).

The emotion of shock allowed health professionals to work with individuals to co-construct the problem of CVR through the process of collective interpretation (communal specification) and provide reassurance to the individual about the extent of the risks posed to them. Brian demonstrates this co-construction of the problem and how the health professional provided legitimation of the problem by providing reassurance that he was ‘just’ over the limit, so there was preventative action that could be taken:

> *As I said it is something that came as a great shock, when they said that I had a problem, I've got to say. Because, I always felt I was pretty healthy, for a 66 year old. But it comes with a bit of shock. I couldn't quite believe it to be honest. The one consolation was she [the nurse] said "you are just over the limit"* (Brian, 66).

Again, Barbara describes how the health professional worked with her to co-construct the problem of CVR whilst allowing her as the individual to interpret, specify and internalise the news in relation to her current lifestyle practices and family history:

> *Yes, it came as a shock to me. And the cholesterol thing came as a shock as well because we do eat well…and it seemed the way the nurse put it over, it seemed to be the fact, that I was overweight, well, obese. That was the reason that I was at high risk of a heart attack. That was the only reason. Well, my cholesterol and my weight because everything else, we don't smoke, we don't drink, there's no family history of it. So it was only the fact that I was obese that was making me at-risk* (Barbara, 66).

As mentioned earlier, a diagnosis of CVR is based on mathematical calculations and projections of risk derived from surrogate markers. None of these markers constitute illness on their own – something that many individuals were well aware of. The lack of identification of a physiological condition that could be clinically diagnosed and treated led to many dismissing the concept of CVR. For these individuals, the NHSHC had failed to identify, classify or provide a name for a condition that warranted medical intervention:

> *If someone came along and said "I'm sorry to have to tell you this, but you have angina or your blood pressure is either too high or too low", then you could be like "oh right! What can you do for me?" and, they could give you something, whether that just be an aspirin or something to get your blood pressure up or down. You have got something then, where you can say that there is something wrong with me. They can put it right and I have to take whatever, and do whatever they tell me* (Alex, 67).

For those who recognised that the identification of CVR did not constitute a tangible illness to be treated with prophylactic medications and lifestyle intervention, attempts were made to open up a dialogue with the health professional who had undertaken the assessment to explore the reasons for the increased CVR and to acquire robust reasons for their at-risk status, providing an opportunity for collective interpretation (communal specification) about the reality of CVR. Health professionals often did not give a satisfactory explanation:

> *She didn't seem to know, really. You see, she went through did I smoke? Well, she knew I didn't smoke. Do I do this? Do I do that? She really didn't know what caused it to be honest with you…I mean if there was something that you could say "right that's what caused it" you could do something about it. If nobody can say that "that caused it" there is nothing, in my mind, there is absolutely nothing you can do about it. You just have to live with it, type of thing* (Brian, 66).

Brian had decided to accept his risk status (come to a conclusion/internalisation) and to take medication to reduce his risk, since there was nothing he could do to change it, demonstrating a perceived lack of control. However, this response was not the only way people reacted. Like Alex, Linda interpreted her risk as something that did not warrant medical intervention. Linda had also probed the nurse performing her assessment about what had caused her risk to be increased, and again, she did not get an answer that satisfied her. Linda resented being directed straight down the route of medication, a route that she felt very strongly was an unnecessary course of action:

> *But, if she'd [practice nurse] gone through and said "your cholesterol's high, we'll go through your diet and see what's what and see if we changed something in your diet and see if we can bring it down" but no. It was straight away, you know - take these [statin]. But there's nothing wrong with me, why do I want to? I believe people only take tablets if there's something wrong with them* (Linda, 66).

This demonstrates how the process of making sense of CVR through understanding CVR’s relevance, individual interpretation that CVR does not warrant intervention, and the process of communal specification between health professional and individual failing to convince that CVR is indeed a risk, leads to a breakdown in internalisation of risk.

In some cases, paradoxically, people found knowledge of their at-risk status comforting. Having a risk confirmed was preferable to having a physiological condition that could be life threatening. Risk in this case was something to aspire to, meaning that there was a lack of condition that needed treatment and could affect quality of life. Paula explained how she felt after her assessment:

> *I know I'm ok really. You know? It’s not… I've not got nothing life-threatening!* (Paula, 57).

People were sometimes concerned that visiting the doctors for a check-up inevitably meant that you went in feeling fit and well but came out 15 minutes later with a diagnosis of illness, and probably medications. However, the delivery of a risk diagnosis did not hold the same weight. It instead led to internalising a sense of relief, rather than fear of potential CVD:

> Y*ou go in thinking you are pretty fit and healthy, and you come out [after initial assessment, before calculation of risk score] thinking you might have something that is going to floor you. But, fortunately, they haven't come back with anything* (Tom, 66).

The NHSHC assessment provided the opportunity to assess current health status and led some people to leave feeling that they had excelled - it was almost like passing an exam. This was further reinforced by messages given by the health professionals conducting the assessment. In Harry's case the nurse had complimented him on his overall fitness, for his age. These positive messages left Harry feeling that he was doing well and that CVR was probably not all that bad, demonstrating that the process of collective interpretation during the assessment may lead to unintended (mis)understandings about health status:

> Harry: *[talking proudly] She [nurse] wishes she was as healthy as me!*
>
> Interviewer: *Did she?*
>
> Harry: *That was her words, not mine. Everything was above normal* (Harry, 75).

The number and frequency of tests relating to the NHSHC assessment also sent messages of comfort to individuals. The perceived concern of the health profession was related to the level of fear the individual experienced. Here, Colin describes how he relies on the health professions to alert him to health concerns and, if they are not overly concerned, neither is he:

> Colin: *Well, I mean, they aren't over concerned, otherwise they would have done more checks on my cholesterol levels, if they were worried about it*
>
> Interviewer: *So, if they are happy, are you happy?*
>
> Colin: *Yes. I put my faith in their hands* (Colin, 57).

The opinion of health professionals, who were perceived as being experts and of high standing, held weight for individuals. Positive messages seemed to reinforce the lack of an actual physical condition and provided a source of comfort for the individuals, and their families. As Ken’s wife explains:

> *Dr [name], who is the head of the doctors' association, he did say "you have got the body of a young man,* ***slim****"* (Ken’s wife).

Receiving a diagnosis of risk provided peace of mind by signalling that there was no biological disease present in the body at the current time. Doug, the only participant who had not been offered statins for the purposes of prevention, described how he had left his assessment with the sense that he did not need to worry, that the assessment had not identified elevated cholesterol that justified intervention and therefore he had been afforded peace of mind, regardless of being at increased CVR and therefore a candidate for intervention, according to NHSHC protocol and guidance:

> *They said my cholesterol was slightly up, but nothing to worry about at all. There was no need for any medication to bring the cholesterol down…it definitely is a good thing [the NHSHC], I think. It gives me peace of mind* (Doug, 71).

These positive messages, arrived at through the processes of collective interpretation (communal specification), were not limited to discussions about cholesterol and medication, Alex explained how, after refusing to initiate treatment with statins, he felt that the health professional who carried out his assessment must not have been overly concerned that anything was fundamentally wrong with him. Participants were relieved when a health professional confirmed that aspects of their health, such as weight or cholesterol, were within satisfactory limits. For example:

> *He said it was up to me but I said I don’t want to take them, full stop. I take enough tablets as it is! My weight was OK, so I wasn't really overweight...so as far as they were concerned I was OK* (Alex, 67).

These positive messages were reiterated, for some, at the annual review, giving people a clean bill of health, at least for the coming year. As Harry explained:

> *So when you go for these check-ups and they say you're fine, well you think to yourself "that's me for a year now, I'm good for a year"* (Harry, 75).

Doug also described how the annual review process reinforced positive messages about good health through the process of collective interpretation with the health professional:

> *But, going to the Healthy Heart Check once a year, I do find it reassuring - especially to come away with a fairly good, clean bill of health* (Doug, 71).

6.3.2 Understandings of CVD risk

Risk of future illness can be a difficult concept for health professionals to communicate clearly and accurately. In order for the recipient of this risk communication to make sense of what danger, if any, it poses, they must attribute meaning to risk to make sense of it in the context of their own life. Understanding of risk is not solely based on facts and figures and decisions that are based on risk perceptions are not always made in a clear cut rational manner. Rather, it is a synthesis through processes of individual interpretation of risk, where information gathered from interacting with friends, family, media is processed to conclusion.

Risk was often described by participants as a ticking time-bomb, over which the individual did not have ultimate control. The hereditary nature of certain illnesses and conditions were often acknowledged, as was the role of the genetic make-up of the individual, in relation to the likelihood of experiencing illness. In the extract below, Fran described how she had no control over the genetic nature of disease and subsequently cardiovascular risk. She acknowledged that measures could be put in place to reduce risk but ultimately felt that disease and illness progression is not controlled by the individual, but rather that fate played a role:

> Fran: *I think it is something in your genes, it's gonna be, I mean you can prevent it, I suppose you can? You know, help prevent it, but I think it's inevitable if it is in your genes that you're gonna, you know?*
>
> Interviewer: *So you've got a limited control?*
>
> Fran: *Yeah*
>
> Interviewer: *But you do have some control?*
>
> Fran: *You have some control over it but I think the older you get, the more (laughs) philosophical you get about it. I mean, when you're young you're invincible! (laughs)* (Fran, 70).

The influence of genetic and biological factors in the development of ill health was pertinent. These were factors that participants often felt were outside of their control. Whilst lifestyle choices and behaviours were within the remit of an individual's regulation, should they prioritise behaviour change, many changes within the body were hidden from sight and may present no symptoms.

In the extract below, Keith explains his realist view of illness and behaviour change. He describes how one must strike a balance between taking control of behaviours, acknowledging the limits of one's ability to control the biological nature of illness and live in a way that is sustainable, without going to extremes:

Keith:	*I will do what I have to do to get by, but you're not in control of the (clicking fingers)*
Interviewer:	*Outcome?*
Keith:	*You are not in control. I don't know what's inside of me, what's going on. I have no control of it really. In one sense, what goes in – lifestyle. I can control that. But you can't control, you know, whether you are going to get Alzheimer's or whatever. Who knows?*
Interviewer:	*So there are biological factors outwith your control?*
Keith:	*What was I reading the other day? Four out of five men over 50 catch some sort of cancer and you think "well what can I do about that?" You can't do anything, can you? I know that some are related to lifestyles but some are not, are they? Others are just part of life, if you abuse your body, you know. But you can't go the other way and be like a monk and eat porridge every morning!* (Keith, 60)

This 'realism' in attitude demonstrates how participants were aware that there is value in doing prevention work, but also acknowledge that preventative behaviour may not be enough to guarantee avoidance of an adverse event.

There was an acknowledgement that illnesses can be symptomless, for extended periods of time, and there was a feeling that family history, along with age, played a role in its development. Colin described:

> *You could have hardly any symptoms, you know. So, if it runs in your family, it will always be on your mind you know, and especially like when you come to a certain age* (Colin, 57).

Colin later went on to describe how his family history of asthma concerned him, rather than the possibility of cardiovascular disease:

> *It's always on my mind about certain things. Like I brought up with the doctor, the other week [when] I was there, one of my older brothers, 'cause I'm the youngest in our family, he died of emphysema and he was asthmatic, and with me being asthmatic it's a bit of a, I call it a bit of a phobia. It's in my head that one day I might get it. So, he died at 53 so, I'm past him now; I'm 57* (Colin, 57).

The onset of illness was described as unexpected in nature, something that could sneak up on you and expose itself, regardless of putting measures in place to lead a healthy lifestyle. Keith described this in the context of his own father who had been fit and healthy for the majority of his life, until he developed diabetes and suffered multiple heart attacks:

> *It could happen tomorrow, but you're not expecting it. Me dad cycled for 40 years. He didn't drink. He didn't smoke. He biked to work for 45 years. He had three heart attacks in one year and died at 68, and he was ten stone. But he caught diabetes. I looked at his death certificate and it said that one of the side effects was failure of the arteries, and that's what he died with* (Keith, 60).

The link between lifestyle factors and cardiovascular events was explored by participants and facilitated their interpretations, individual and collective, of CVR. Brian described how he was surprised that he had been told he was at-risk of such an event at this point in his life. For him, he had always made a connection between heart problems and being in a stressed state, something that he experienced more when he was employed and working in a stressful environment:

> *I was surprised, I'll be honest with you. I mean I always think of heart [problems] equals stress. I mean if I had got this problem when I was taxiing I would have said "well fair enough, it's all part of the job" but I really don't understand what caused it?* [The increased risk of CVD] (Brian, 66).

Often, ideas about likelihood of suffering an adverse event were linked to understandings of weight management and being physically fit. Tom and Maureen describe, below, how they had thought of themselves as reasonably fit and healthy for their age and had therefore not identified themselves as candidates for cardiovascular disease prior to their risk assessment:

> *I suppose it was [a surprise] in a way. I mean I don't think of myself as a fat person, and I'd have thought if I had been fat and that [I would have been at-risk]. But, because I wasn't so fat I would have thought I was reasonably healthy?* (Tom, 66).

> *I was surprised because I had always thought of myself as reasonably fit* (Maureen, 58).

David also described the link between physical fitness and the likelihood of suffering heart problems and suggested that this had not been taken into consideration within the NHSHC assessment and subsequent provision of advice about lifestyle and medication. He describes a tension between knowing his body's limits physically and being assessed as at high risk, based upon one consultation:

> *[I'd go to] the gym and I'd be on high impact aerobic type activity and I'd be going flat out. Now does that indicate a bad heart? That's what I would be doing… so that's what I mean, you've got to look at people [and] see what they are doing and [their] lifestyle…rather than [taking] a single reading. Even if you read medical books it says single readings have no meaning* (David, 62).

Whilst the hereditary nature of cardiovascular disease was widely acknowledged by participants it was noted that the NHSHC programme failed to acknowledge the very different lifestyles participants had from those experienced by their parents. Both Kate and Linda describe, below, how they acknowledge the role that family history may play in increasing their risk of cardiovascular disease but also noted that their lifestyles are very different to their parents. They were mindful to acknowledge not only the biological factors that contribute to CVD risk but also environmental and lifestyle factors too:

> *I don’t have the same lifestyle as my father and brother did. They were both manual workers. I mean, my father, it was hard work that killed him, purely hard work. I have never had that sort of lifestyle. Apart from that, my mother died of breast cancer and I have a very high risk of dying of breast cancer. One thing or the other is going to get me, so why worry?* (Kate, 68).

> *There’s nothing wrong with me – nothing at all! I said [to the nurse] I have a different lifestyle to my parents. They worked very hard, you know? My dad had a very manual job, in fact he had three jobs. My mum had six children, you know, it doesn’t help, does it? Especially during the war they were poor. I said I have a completely different lifestyle to my parents and I’m very healthy, I think, for my age of 66. I still go out on the motorbike, still go and do all of my exercise classes, still go line dancing. In fact I said to her [the nurse] “I think I have a healthier lifestyle than you” and she said “I think you have” (laughs)* (Linda, 66).

The role that family history of CVD plays in the development of disease risk provided participants with some understanding of why they had been identified as at high risk and that this genetic role increased the likelihood of experiencing a CVD related event:

> *My father and all his family have heart problems so it’s hereditary in that respect* (Dennis, 65).

Gary also described how illnesses such as heart disease and cancer have a tendency to ‘run in families’:

> *That sort of stuff, heart problems, I believe is family [related] and quite a lot of cancer is family [related]. Because, how often do you hear about someone say “she died of cancer. Oh yeah it was only two year since her sister died of cancer”. You know, and to me it all seems family related – in your genes – and I think [that] heart problems, [and] cancer, I’m not saying it’s all in your genes but I think a lot of it is in your genes* (Gary, 67).

Keith describes below how he felt his family were responsible for his increased risk of CVD, rather than acknowledging that multiple factors could have played a part:

Interviewer:	*When you were told that you were at high risk, how did that make you feel?*
Keith:	*Err, it's all their fault, not mine! (laughs)*
Interviewer:	*Who's fault?*
Keith:	*Well me mam and dad had the heart attack, and me brother's got diabetes, but I have always been pretty healthy.* (Keith, 60)

Although there was a link made between family history of disease and developing it oneself, there was an acknowledgement that other factors could also influence susceptibility to disease, such as lifestyle factors and, of course, chance or fate. Gary went on to describe how his mother had been a candidate, as he saw it, for a heart attack and that was indeed what had taken her life. However, his father who had also lived life in such a way as to make him a candidate for a heart attack had succumbed to pneumonia, highlighting how chance or fate plays a role making it difficult to predict what would finally end your life:

> *My mother did die of a heart attack when she was 72, but she had angina and she was really overweight. She loved dairy products and she loved fried food…. My father who lived to 87, I think he was, lived out of the frying pan all his life and he smoked all his life…and he died of pneumonia* (Gary, 67).

There was an air of mystery surrounding how CVD risk was actually calculated and an acknowledgement that family history obviously played a significant part in determining an increased risk and that lifestyle choices, family history, and propensity for disease were entwined. Linda uses the case of her husband to try and unpack why she had been offered intervention after her assessment and her husband had not. She concluded that even though her husband ate and drank the same as her (if not more) he was not at the same risk as her because cancer, rather than CVD, ran in his family:

> *My husband, she checked him [he received an NHSHC] and all she said to him was, I mean he drinks as much as I do, if not more because he has a pint. He's underweight, she said that, and then she didn't offer him any [statins] because his parents died of cancer. His aunties and uncles and cousins all died of cancer. Well you can't do anything about that. You can't stop getting that, well unless its lung cancer* (Linda, 66).

Diseases of the cardiovascular system, whilst they posed a threat to the individual, were not described as the only illness that was threatening. Alzheimer's disease was identified as much more of a risk. Barbara described taking measures to ward off Alzheimer's disease by keeping an active mind, not just an active body:

> *I do an awful lot of crosswords to keep the mind active – for Alzheimer's! You don't know what's going to happen* (Barbara, 66).

Alzheimer's was described, by Maureen, as being much more of a threat than CVD. Maureen, a full time carer for her husband with heart failure, was fearful of developing an illness that would cause her to be a burden on her family:

> *I think I'm more frightened of getting Alzheimer's or something like that. And then I think who is going to look after me? I've got both sons over here [in the UK], but they are absolutely useless...or like the unexpected happens and then you think "oh God! I'm a burden on somebody". I would hate to, I'm more scared of getting Alzheimer's or something like that* (Maureen, 58).

Much of the population of Teesside has, historically, worked in heavy industry and that comes with its own set of consequences. Gary describes, below, how fear of CVD was low on his list of priorities. Gary had worked with asbestos for many years, and had watched several of his colleagues die from complications attributed to asbestos:

> *I worked in the chemical industry, petrochemical industry all my life. The stuff you breathe on those plants, and you work with asbestos, you know the killer asbestos, I've been covered in it. I've eaten sandwiches amongst it. I've drank tea amongst it. So I've got asbestos in me without any doubt. So, I'm not going to worry about a heart attack!* (Gary, 67).

Risk is all around us, in everyday life, and many participants acknowledged it, whilst refusing to let it take over their lives or stop them from engaging in daily activities. Kate discussed how with each returning visit for her annual review her risk of CVD had increased, regardless of any changes she had made to her lifestyle in the previous year.

> *It has gone up again this year [risk score] of course, because I am a year older. Each year they add on a little bit more on. I say "yes but you are another year nearer the grim reaper anyway aren't you?" (Laughs) I don't take it terribly seriously as you can tell. You can't or else you would wrap yourself in cotton wool* (Kate, 68).

The acknowledgement that risk of future illness was something one has to live with, without it taking over your life, was reiterated by Keith:

> *Well without going over the top or morbid or stupid – you just have to live well, try to eat properly, exercise without it actually absorbing your life!* (Keith, 60).

Being conscious of one's health, keeping fit and active and being mindful of dietary habits were seen as a way of keeping risk of CVD 'in check':

> *I don't go mad. I do believe in healthy eating and looking after yourself. And as I say I don't smoke. I don't, I mean you couldn't call me a drinker…* (Carol, 75).

Linda described how she felt she already did enough to combat CVD risk through diet and exercise:

> *I've been aquafiting this morning and line dancing. I got a salad and salmon croutons for my lunch – what more could you want? (Laughs)* (Linda, 66).

Kate reiterates this vein of thought, stating that she felt a healthy lifestyle was sufficient to reduce any risk posed to her by CVD without the need for prophylactic intervention:

> *I think it is all just a bit of a lottery, but I think you can do as much you can by living a healthy lifestyle. I mean I have never been overweight and I am well within my band for my BMI. You now, I have always been pretty active and I eat as much fruit and veg as I can. I can't manage five [portions of fruit and vegetables] everyday but I eat healthily and I mean, what else can you do? You do everything you can apart from popping pills!* (Kate, 68).

However, there was sometimes surprise that looking after yourself in this way was not sufficient to eradicate risk, as Fran described:

> *I try and eat fairly healthy but you see, as I said to her [nurse], I do like my butter, I don't like the spreads and I would rather have the butter. But it was a bit of a shock because it was 25 point something chance of having a heart attack or a stroke within ten years. I thought it would be high but, I mean, I didn't think it would be that high!* (Fran, 70).

The mechanism used to deliver a person's CVD risk score had the potential to impact on an individual's embodiment, or internalisation, of the notion of 'risk' and subsequent action. Whilst Fran described, above, her horrified reaction to being told she was at 25% risk, this did not hold true for all individuals who recalled being told of their percentage chance of CVD. This interpretation of percentage risk had the potential to be reassuring. Jeff discusses how the interpreted his risk for CVD as low when her was told his risk score of 28%:

> *When they said that I was 28 out of 100, well I thought that was quite low. If I was 50%, 60%, 70% then I would be quite worried. At 28% I wasn't all that worried, if you know what I mean?* (Jeff, 71).

Paul also describes how the receipt of his risk score had not evoked a fear response that would be sufficient to instigate any significant changes to the way in which he lived his life:

> *If I was at a stage where I really, like I was told that you must change your lifestyle otherwise you are not going to last the next five years type of thing then, yeah, I would definitely change what I could* (Paul, 63).

Participants clearly drew on many sources of information about their current lifestyle and family history to formulate a conclusion (internalisation) about their candidacy for cardiovascular disease through processes of individual and collective interpretation of knowledge (individual and communal specification). They used this knowledge to either internalise, or not, CVR. This suggests that the internalisation mechanism of NPT is a product of the other three working mechanisms; differentiation, communal specification, and individual specification.

6.4 Identity and responsibility – am I really at-risk now?

Prior to the NHSHC assessment participants were asymptomatic and afterwards, despite their ‘diagnosis’, to all intents and purposes they still were, due to lack of physiological symptoms. Participants had not sought out assessment; rather they were invited to attend. Every participant described themselves as feeling fit and well (for their age) despite being classified as at an increased risk of CVD in the next ten years. The incongruence of feeling well within themselves and being told they were at increased future risk posed problems for many when trying to engage in sense making work about CVR and what could be done, if anything, to reduce risk through lifestyle changes and medications.

Shirley acknowledges, below, how experiencing symptoms is important to identifying as being ill. However, she was generally well within herself and felt there was no cause for concern:

Shirley:	*As long as I don't feel bad, I'm OK*
Interviewer:	*And do you feel healthy?*
Shirley:	*Oh yes; a few aches and pains, but that's old age!* (Shirley, 72).

Again, in the extract below, Paul describes feeling in good health. The absence of symptoms that could be explained by CVR led him to feel like nothing much has changed as a result of his check and subsequent diagnosis of risk, especially as he was not taking medication for the prevention and reduction of risk. Like Shirley, to Paul being an ill person was intrinsically linked to signs and symptoms of illness:

> *I am just doing what I am doing. I am quite happy with what I am doing. I don't feel unhealthy. I am not one of these people that is coughing and sneezing and dying all the time* (Paul, 63).

Tom expands on this below:

> *I suppose in one way it is a good service and I suppose in another it could make you think well "Am I healthy or not?" otherwise you could just plod on and carry on and not bother and not even think about these things. I suppose it's good and bad. In one way you can think about it and think "Am I being healthy?" "Am I doing the right things?" "Is it worth it?" Because I am feeling alright, I don't have any problems that I think would cause me any problems, so do I really need to go? [For annual review]* (Tom, 66).

Participants, especially those who had made a conscious decision not to embark on a pharmaceutically aided journey, tended to describe how they actively resisted the temptation to think of themselves as 'at-risk' or to begin to identify as an ill person when they had been given no clinical reason to do so. People were aware of their body's limitations and used this information to inform their understanding of potential candidacy for CVD, rather than accepting the clinical information that had been presented as their predicted ten year risk score. This suggests that without *coming to a conclusion* (internalisation), CVR participants were unlikely to undertake the 'work' of complying with the NHSHC by making and sustaining lifestyle changes or taking prophylactic treatments. Kate describes how she resisted the temptation to identify as being at-risk and changing her behaviours accordingly:

> *You could get yourself very depressed and think of nothing but that [being ill]. You can't! I mean if I thought like that then I wouldn't have gone out climbing in the hills in the Lake District because I would have been thinking I would have a heart attack. You can't live like that. I'm sure people do, but no way!* (Laughs) (Kate, 68).

Alongside the refusal to identify oneself as an ill or at-risk person, some participants described how they did not want the outside world to now perceive them as an ill person. Phillip describes, below, how he disliked taking medications whilst in public, for example with a meal, and would, in those circumstances, not take that particular dose of medication:

> *[If] I'm in a restaurant, you don't want to take a pill if you are in a restaurant (laughs), so you'll probably skip it once if you were eating out that day* (Phillip, 65).

Receipt of an NHSHC did act as a means to take stock of behaviours and lifestyle choices, sometimes regardless of any subsequent behaviour modifications. The process of spending time with a health professional, to engage in collective interpretation and collective evaluation, and having a sustained opportunity to discuss health, behaviours and the future was a valued opportunity for many:

> *I wouldn't say it was frightening in the very first meeting I had, but when they sort of lay it out, what's happening to your body, basically through taking all of these fats in, it does make you think that maybe I need to do something different that I haven't done in the last 30 or 40 years* (Phillip, 65).

6.5 The question of prevention

The majority of participants felt that taking preventative action to avoid future ill health was a good idea – it made sense. Phillip describes his reasoning about embarking on a preventative journey. He incorporates notions about candidacy for disease and the asymptomatic nature of 'risk' to make sense of and weigh the pros and cons of medicating for the purposes of prevention:

> *Otherwise I felt healthy. I mean I only go to the doctors if I don't feel very well, but I felt healthy. So, there were no signs of anything. I wasn't suffering with anything due to high cholesterol but then she did explain that it can lead to heart attacks and strokes, which I suppose can happen to the healthiest person, even if you are feeling healthy – it can happen to you anytime. So, I thought, well its good preventative medicine. I would rather go for preventative medicine than try and get somebody to sort me out after the event* (Phillip, 65).

Likewise, Fran justifies taking medications for the purposes of prevention by drawing in previous knowledge of visiting her husband after his heart attack and other benign preventative behaviours:

> *It's preventative. Well I mean a lot of people take aspirin – they think that that's going to be preventative and that. I don't mind taking it [statins] because I've been into heart wards and I have seen how some of them are. So I think if I can take this and it stops me being like that, along with other things, you know, I don't mind taking it, it doesn't bother me* (Fran, 70).

Taking preventative measures was seen as a way of planning for the future, in some respects. Keeping the body as fit and healthy as possible was a way of ensuring that participants got to enjoy the rest of their years, in relative good health, as Phillip describes:

> *I sometimes sit and think "do you realise you only live three score years and ten?"...if you look at all the programmes on the telly and that, that's what they are saying and anything over that is borrowed time. So I want a lot of borrowed time. There's a lot of places I want to go and see, a lot of things I want to do yet. So yeah, if I keep myself fit and healthy I'll be able to do it. That's the way I look at it* (Phillip, 65).

Dennis describes how engaging in preventative behaviours can act as an insurance policy for later life:

> *I think you can certainly put safeguards in place, well not safeguards, but you can sort of change your lifestyle. If you are having a [healthy] lifestyle then you would hope that that would pay off in future years* (Dennis, 65).

Whilst prevention may act as an insurance policy for the individual to allow them to enjoy a full and happy life, it may also mean that people can live independently for longer, as Maureen discusses:

> *The preventative things we are taking, I think that's better. I would rather know of something than the unexpected happens and then you think "oh God I'm a burden on somebody"* (Maureen, 58).

Wider society stands to benefit from preventing illness at an individual level. It was appreciated that "the powers that be" were being seen to be caring for the individual, even if the motive was to save money, in the long run, by reducing hospital admissions, morbidity and mortality. Phillip explains below:

> *So, as I say, I'm a big believer in preventative medicine and I think it's a good thing that they're going to see people and to help them. I suppose you're saving the medical system some money, aren't you, if you haven't got to be taken in with a heart attack* (Phillip, 65).

Whilst the majority of people felt that prevention of future ill-health was a good idea, there was feeling in some quarters that screening and intervention had gone a step too far. For these people, the ever growing remit of the medical gaze felt obtrusive:

> *Personally, I think we are going too far with a lot of these medical things. I think it's a load of bollocks, to be honest* (Gary, 67).

Whilst CVD was acknowledged as potentially life threatening, the necessity to reduce CVR through medical intervention was afforded meaning not only through interaction with health professionals during the assessment but also by taking into account one's own context or situation and future aspirations. Jeff described how he was reluctant to take prophylactic medications to reduce his risk when they had the potential to cause physical damage:

> *I am 72, right? What have I got to look forward to? Nothing. Old age, what's the point of going on a statin which probably destroys my kidneys or whatever it does?* (Jeff, 71).

Furthermore, Jeff acknowledged how he would prefer to suffer an acute event that caused his death, rather than lingering in a hospital bed. He felt that developing a fear of a CVD event may impinge on the small things he took pleasure in:

> *To be quite honest it didn't really bother me [being identified as at-risk of CVD]. Like I said, I don't want to end up in a hospital [or] in a care home or in a bed for two to three years. I don't care if I, I love walking, I go on the hills, I go by myself with the dog. I do a lot of walks – seven miles, ten miles. If I drop down dead there I'd be quite happy or if I dropped down dead here sitting down, I would be quite happy. I don't want to end up as a cabbage, you know what I mean?* (Jeff, 71).

The first two NPT constructs – *making sense of it* (coherence) and *working out participation* (cognitive participation) – help to illuminate the work patients undertake to make sense of their personal need for CVR assessment and taking part in the programme. These two constructs are helpful in unpacking people's journeys, regardless of whether or not they go on to engage with making changes to their lifestyles.

Understanding the uniqueness of it (differentiation) and *individually interpreting it* (individual specification) were the most useful constructs to understand the processes people underwent when considering their initial attendance to CVR assessment, this process was mostly undertaken at an individual level. However when participants began to describe their reasonings for being identified as at increased CVR individually and collectively, interpreting it (individual and communal specification) began to play bigger roles. Participants synthesised knowledge about their perceived current health status, their family history, knowledge about their wider social networks, media representations of CVR factors, and evidence gained from health professionals to construct their understanding of CVR and what its implications (or not) may be for them in real terms.

There was often a tension described between a participant's individual interpretation (individual specification) of their candidacy for CVD which was based upon the synthesis of many sources of evidence and the interpretation presented by the health professional which was based upon the aggregation of surrogate markers for CVD. The outcomes of the processes identified by the construct *making sense of it* (coherence) and its subordinate working mechanisms were good indicators to how engaged (or not) participants would become with aspects of the NHSHC programme that required them to make significant changes to their lifestyles (chapter 7).

Chapter 6 has explored participant's perceptions and experiences of their initial engagement with the NHSHC programme and their initial assessment for CVR. The following chapter will explore participants' experiences of trying to make changes to their lifestyle, being prescribed prophylactic medications, and engagement with the annual review process.

7 Findings – *doing it* and *reflecting on it*

Chapter 7 presents findings that relate to the patient 'work' involved in making changes to their lifestyle through implementing changes to their diet, physical activity levels, alcohol consumption, and smoking or through taking medications to reduce CVR. This is illustrated by exploring findings through the lens of NPT's construct *doing it* (collective action). Secondly, findings that relate to engagement in reflection and monitoring work through participation in the annual review can be explored through the lens of NPT's construct *reflecting on it* (reflexive monitoring). These themes represent the latter stages of the patient journey through the NHSHC programme.

Section 7.1 explores participants' reactions to making (or not) lifestyle changes based upon their CVR assessment. Section 7.2 unpacks participants' reactions to taking statins for the purposes of CVR prevention. Finally, section 7.3 explores participation in surveillance and monitoring activity.

7.1 Lifestyle advice and intervention

7.1.1 Patient adherence with advised lifestyle changes

Promotion of lifestyle changes e.g. making healthy dietary choices, reducing sedentary behaviour, reducing alcohol consumption, and smoking cessation, are all integral to the NHSHC. In order for it to be judged a success and if it is to reach the longer term targets set out in chapter 2, it is felt that those delivering the NHSHC assessment and intervention should engage with those identified as at high CVR, convince them that they should, and can, make positive changes to their lifestyle and facilitate long term and sustained engagement with the changes. In terms of NPT, professionals are required to facilitate the implementation, embedding, and integration of lifestyle changes. The activation of behaviour change cannot be the sole focus here, there also have to be appropriate and accessible services and intervention pathways available to individuals, if the NHSHC programme is to support behaviour change. In terms of NPT this is the stage where *making sense of it* (coherence) and *working out participation* (cognitive participation) come into fruition (or not) and the work of *doing it* (collective action) and *reflection on it* become activated.

During the interviews, all participants were asked to cast their mind back to the initial assessment that they had received, which for some participants had been as long as two years prior to interview. Participants were asked to recall if the health professional had discussed diet, physical activity, alcohol consumption, and smoking. Tables 19 and 20 show the distribution of participant's responses. Findings that relate to adherence with lifestyle and prophylactic medications are reported in (McNaughton and Shucksmith, 2015) (Appendix 11.1). It was clear that participants understood the link of 'unhealthy behaviours' to their current and future health, and valued the impact that adopting a healthier lifestyle could have on their CVR. Some even discussed how the NHSHC assessment and news that they were at increased risk had acted as a catalyst to begin considering the impact of lifestyle on CVR:

> *I wouldn't say it was frightening, the very first meeting I had, but when they sort of lay it out - what's happening to your body basically through taking all these fats in - it does sort of make you*

> *think ...maybe I need to do something different that I haven't done in the last 30 or 40 years* (Phillip, 65).

7.1.2 Discussions about diet

The majority of participants (n=22) did recall having a discussion about their diet with the health professional after they had been identified as high CVR (Table 19). Of these, 14 individuals felt they had taken on board the advice given to them as part of the assessment, and had made changes to the way they shopped for, prepared, and consumed food. Eight participants recalled being given dietary advice but had not made any changes to their diet as a result of the discussions, and four did not recall having a discussion about diet at all. None of the participants within this sample recalled being offered a referral to weight management services, either provided by the GP practice or in the community.

Discussions about diet and weight management can be difficult for those on the receiving end. The medical terminology used has the potential to offend individuals. Navigating the clinical encounter and receiving news that you are defined as clinically obese can be shocking. Barbara describes how she felt after her initial assessment, when she was told that she was obese:

> Barbara: *I must admit when she said to me that I was 'obese' I was devastated*
>
> Interviewer: *Were you?*
>
> Barbara: *Yes. It really shocked me, didn't it? [Husband nods] And I couldn't get over it. I was really like, "I can't believe I'm obese." But then we got a Wii and I got weighed on the Wii and according to that I am 'obese'!* (Barbara, 66)

Barbara describes the processes of collectively and individually interpreting her weight status (communal and individual specification) that she went through by being told by a health professional that she was obese and then double checking this for herself when she got home. Both sources of information that she sought out were congruent with each other, confirming she was in fact classified as clinically ‘obese’.

Discussions about diet within the clinical encounter had prompted many individuals to make changes to their diet. These changes were normally in line with heavily promoted guidelines such as reducing saturated fat and salt. For these participants the NHSHC assessment had provided a catalyst to engage in *making sense of it* (coherence) and *working out participation* (cognitive participation) work to subsequently spur *doing it* (collective action) work:

> *I don’t think I eat unhealthily, so I suppose it was a bit of a surprise. So, I just said ‘right, well that is fair enough then’ and the things I cut down on – cheese and milk and chips and stuff like that* (Tom, 66).

Participants who had made changes to their diet demonstrated how they were supported in their changes by family, normally spouses, supporting the notions of *working with and trusting the work of others* (relational integration) and *appropriate division of tasks* (skill set workability) by engaging those within the household who held responsibility for preparation of food:

> *I used to have a lot of salt at that stage but I've cut that down to zero, I don't have any salt now on my food and my wife doesn't cook with it. And I didn't eat a great lot of fatty food but I've reduced that as well, you know. I'm taking more exercise than what I did, I have lost weight* (Jim, 61).

The engagement of others in carrying out the behaviour changes was integral to the success of implementation and embedding of these new ways of working, which often led to increased work when shopping for and preparing food:

> *Like my wife says, the shopping takes about three hours longer because you now start to read the labels on food. Whereas you didn't bother looking for saturated fat before, we now look for very low fat, we eat low fat cheese most of the time, try to get foods that haven't got a high content of fat* (Phillip, 65).

For others, to engage in new behaviours that were sustainable and easily integrated into their daily lives, portion control, rather than making changes to the ingredients was the key to successful integration of dietary changes:

> Interviewer: *So, have you had to make any changes to the way that you eat?*
> Barbara: *Just to cut down on portions – that's all we have done really. We do eat a lot of...*
> Alex: *…good stuff really. We don't eat pies and things like that.*
> Barbara: *Or processed food* (Alex, 67. Barbara, 66).

This concept of 'balance' when making dietary choices, and any choices that were made needing to be achievable and sustainable, was a common thread through discussions of diet. This links to the notion of *allocating resources* (contextual integration); participants were in many cases reluctant to make huge changes to their diet and instead opted for consumption in moderation:

> *I eat everything. I don't have eggs every day. I maybe have them twice a week. I don't have bacon sandwiches every day; I maybe have it once a week. I eat veg, I eat fruit, I had a pear this morning for my breakfast – that kind of thing* (Jeff, 71).

The fact that any dietary changes had to work for all members of the household became an obstacle for some. The importance of eating a healthy balanced diet that included fresh fruits and vegetables could be a barrier, if all members of the household did not like the new menu. If everyone within a household was not on board (*believing the practice is valid/* legitimation) and engaged, it had practical implications for the dietary choices of individuals. Colin describes the difficulties of eating fresh fruits and vegetables in his household, because there is only him that enjoys them. He had to incorporate different techniques to satisfy both his agenda and his wife's palate whilst not being wasteful of resources of food and money, highlighting the importance of appropriate *allocation of resources* (contextual integration):

> *Because with the wife not eating all veg, we don't buy fresh veg because it goes off. I mean there's no point buying a pound of carrots because I don't eat that many, though I like them* (Colin, 57).

Those participants who had made a choice to not engage in dietary change activity cited dietary change as unnecessary. The internal processes of *making sense of it* (coherence) and *working out participation* (cognitive participation) had, in these cases, not acted as a catalyst for change. Rather, they had provided the individual with a reason not to engage in behaviour change:

> *You know, I'm 72 in this year and you think to yourself, 'Oh crumbs. I am done!' I am eating everything right. We both have a drink - we like a drink - but if my main doctor says, "Just go and live your life,", that's what I do* (Ken).

Despite the efforts of health professionals to come to a communal place where individuals understood the importance of making lifestyle changes, some participants had not internalised that there was anything to gain by making changes and instead carried on as before:

> Interviewer: *So, did she give you any advice about, sort of, losing weight or anything like that?*
>
> Harry: *Why, she gave me some paraphernalia, but it was a waste of money giving me that, because I didn't bother with it, because I'm quite happy* (Harry, 75).

The transient nature of health advice and current trends in health promotion activity were acknowledged by some, providing support for their non-engagement with lifestyle changes. Participants noted that there were often conflicting messages around foods and consumption, which made them reluctant to make significant changes to lifestyle and internalise the advice they were presented with:

> *I don't believe in all this stuff... when you read all this stuff about... don't do this. And years ago, potatoes, they were taboo. Don't eat them! Though, it is what you do with them that causes you problems* (Ken).

This distrust in the advice that is given, because within living memory advice has been subject to change, led some participants to be more cautious when being asked to change their diet:

> *They say eat margarine; then butter is better for you,* ***don't*** *eat margarine. That's what I am saying, I don't take any notice of all these "you must eat this" because two years later they are saying it is no good for you. You know ... at one time eggs was bad for you, do you remember? Then they decided no, eggs are good for you* (Jeff, 71).

7.1.3 Discussions about physical activity

Participants recalled discussions about physical activity much less frequently than discussions about diet and healthy eating. Nine participants recalled having a discussion about physical activity during the NHSHC assessment consultation, however, only two participants stated that they had made any changes to their physical activity levels on the basis of being identified as high CVR. The majority (n=17) did not recall being offered any advice about physical activity levels. One participant recalled being offered exercise on prescription (but had not attended). The rest of the participants did not recall being offered a referral to physical activity intervention at either the GP practice that they were registered at or in a community setting. As such, there was very limited discussion about the interaction between health professional and outcomes of the assessment on physical activity.

Regardless of CVR identification, some participants identified how they had begun to be more physically active as a result of having more free time after retirement:

> *Well when I retired - actually I worked part time for the last two years and I have been fully retired now for two years - I have just had much more free time. So I took up swimming. I go three mornings a week* (Keith, 60).

The population targeted in the NHSHC is aging (40-74 years old); the age range of participants interviewed in this study represented the older end of the spectrum. Participants acknowledged the aging process and the impact it had on them physically. Many participants were unable to engage in strenuous activity, as they once had:

> *I don't feel old, but then my body is telling me I am. I try running, because I used to do cross country at school, but now I couldn't run five yards and that's my body telling me I'm old. I only feel 19, but then when I try doing something, I know I'm not* (Colin, 57).

Often, engagement in physical activity was restricted by comorbidities, demonstrating the importance of being physically capable to undertake the recommended physical activity to reduce CVR (*having the skills to engage* (initiation)):

> *I can't do much. I can garden and that but I have got arthritis and so I battle a bit. I have got a thing that I kneel on to get up and down like that, but if I go on the floor and need to get up then I crawl to something to get hold of and things like that. And I need help with getting in the bath and things like that. But otherwise I am fine. So it would have to be gentle exercise* (Maureen, 58).

Physical activity was described by most as a form of leisure and of gaining pleasure, rather than something that was engaged with for the purposes of improving fitness levels or specifically losing weight:

> *She asked about what I do. Well I mean I don't do any. I mean I bowl twice a week, green bowling, lawn bowling, and in the wintertime it's once a week because we do carpet bowls. And I walk up and down the village every day and I go swimming about once a week and we go dancing once a week, so she said that was all....She said about housework and I said, "Well I do my own housework and my own gardening; nobody else will do it!" [Laughs]* (Fran, 70).

Few participants had taken up organised activities but, when they had, they were social activities undertaken in groups:

> *On average I walk four miles a day. I go on the hills, climb. I have the Ordnance Survey map with all these walks and so for the walks I go seven to ten [miles] up on the moors, everywhere. And then I joined a walking club for no reason, other than I walk on my own* (Jeff, 71).

7.1.4 Discussions about alcohol consumption

When asked to recall discussions about alcohol consumption and recommended limits, the vast majority of participants (n=22) could not recall any discussion. Four participants recalled having a discussion about alcohol consumption and of those, one had made a change to consumption of alcohol as a result.

For the most part, participants felt their alcohol consumption was within acceptable limits. Like discussions about dietary choices, participants discussed alcohol consumption in terms of moderation, rather than exclusion. When considering moderation, participants tended to take a holistic view of their behaviours and lifestyles and began trading between behaviours. Nigel describes his alcohol consumption:

> *I love wine, I drink wine, but I don't drink a bottle at a time. I'll have a glass or I'm more within limits, and I don't smoke - never smoked - and I exercise* (Nigel, 72).

Some participants, who had made a conscious decision not to change their alcohol consumption, described a process of negotiation (*collectively interpreting it/* communal specification and *believing the practice is valid/* legitimation) within the NHSHC consultation. Linda was clear about her drinking habits and how they were entwined with her social life. The pleasure derived from the social aspects of alcohol overrode the perceived gains from reducing her consumption:

> Linda: *Yeah, I have a drink every night, yeah.*
>
> Interviewer: *And did she advise you to stop doing that?*
>
> Linda: *Oh yes, [the nurse said], "I think you should have two nights off." Ohhh ! So I said, "Which nights would they be [nurse's name]?" [The nurse said] "Monday and Sunday?" [I said] "No, after line dancing it's my cricket club [night]. [The nurse said] "And Tuesday?" [I said] "Oh no, after I've been to my Aquafit I have my cider." She said, "you're not going to, are you?" I said, "No, I was young in the 60s, [nurse's name]. Nobody told you anything was bad for you in those days. Even when you were pregnant they didn't say stop drinking, like the silly things do in this day and age* (Linda, 66).

Some participants described discussions with health professionals that indicated their alcohol consumption was well within the recommended limits and therefore through the process of individual and communal specification process came to the conclusion that alcohol reduction was not needed to reduce CVR:

> *She said I was quite in the limit of what I drank, you know, because we have wine on the Sunday and a couple of brandies sometimes, not two on a night but one on a night a couple of times a week. But yeah, she said it was within the limit* (Fran, 70).

The limited discussions about alcohol consumption demonstrated how limits and thresholds for 'sensible drinking' limits were negotiated through interaction with health professionals but needed to be acknowledged within the wider social context of the individual's life. Lifestyle changes, whether dietary, physical activity, or alcohol consumption cannot be viewed in isolation.

7.1.5 Discussions about smoking

When asked about smoking habits, the majority of participants had either never smoked (n=10) or had stopped smoking many years before attending an NHSHC (n=13). Two participants were smokers at the time of assessment. Of those, one had decided to quit smoking after discussions within the NHSHC consultation and one was still smoking at the time of interview.

Gary was the only current smoker within the sample. He described the process of *individual interpretation* (individual specification) that he had gone through in making a decision to carry on smoking. For Gary, at this point in his life, he felt that it was a futile activity to engage with smoking cessation, as the effects would not be experienced for quite some time. This lack of perceived coherence around smoking cessation led him to make a mindful decision to carry on:

Interviewer: *So do you think that it's a pointless activity giving up smoking now then?*

Gary: *Well it is now for me …it's too late, yeah. It's far too late, I mean sixty seven… Say I live another twenty year, eighty seven, which would be brilliant, but it would take twenty year minimum for my lungs to get clear, minimum* (Gary, 67).

Evidence from discussion about lifestyle changes demonstrates a relationship between knowing and acknowledging being identified as at increased risk of cardiovascular disease and putting into action behaviours to tackle or reduce it. There seems to be a delicate interplay between and within the constructs of NPT in that equal weighting is not given to each working mechanism. The collective interpretation (communal specification), the negotiation work that takes place between health professional and individual is not afforded as much credibility or weight as the individual interpretation work (individual specification) work that people undertake, drawing in knowledges about their wider lives and social contexts. It would seem, again, that the first construct, *making sense of it* (coherence) is the most important initial step and that the *coming to a conclusion* (internalisation) process is crucial to instigating action(s).

7.2 Statins promotion and adherence

The majority of participants, in the sample, could recall being offered statins for the purposes of prevention. Twenty one participants had initially accepted the offer of statins as a direct result of their NHSHC CVR assessment. Of these, 17 were still continuing statin treatment at the time of interview, and four had decided to discontinue treatment due to unpleasant side effects that they found intolerable. There were four participants who had been offered statins but had refused outright to commence treatment at the time of assessment. Finally, one participant had not been offered statins, despite being identified as being at increased risk of CVR.

7.2.1 Prescription of medication

All participants were aware that they had been identified as at increased CVR and that as a result of this assessment, they were advised to take statins for the purposes of preventing a possible future event. Although participants recalled discussions about healthy lifestyles and the impact ‘being healthy’ could have on their CVR, cholesterol and cholesterol management became the focus for many when weighing up the concept of risk:

> *I was advised, last year, to go on statins, because when they did my cholesterol check and everything, it [cholesterol] was higher that what it should be at my age, and everything. I had a, I can’t remember, it was a 60% or a 40% chance of having a heart attack, or stroke, or whatever* (Jim, 61).

Individual and collective interpretations (individual and communal specification) about the need for intervention with statins were, in some cases, at odds with one another. Health professionals promoted the use of statins and their prophylactic capabilities in what is deemed a population with elevated CVR. However, it is not always as clear cut on the part of the individual patient, and this importance is not built in a shared understanding of CVR. There can be a lack of understanding of the purpose of engaging with medication, because the risk of CVR does not become internalised (*coming to a conclusion* (internalisation)) to an extent that becomes a catalyst for action:

> *She told me that my cholesterol was the main thing they were worried about. It was not really high, but it was high, and there was a higher risk of stroke or heart attack, or whatever, you know. She gave me some tablets and said "you need to start taking these tablets". I can't remember what they are. I don't bother taking them to be honest with you* (Paul, 63).

Many participants were aware that the thresholds and cut offs for what constitutes high cholesterol were subject to change, and had indeed changed during the time of assessment and annual review, for many. Whilst recommendations are to offer statins for the purposes of prevention, regardless of cholesterol levels, patients clung to the common concept of high and low cholesterol as a marker of CVR. These changing thresholds were rarely acknowledged by the health professional delivering the assessment, and only one participant discussed this in interview:

> *The results came through at something like 4.5 for my cholesterol so the doctor just said, "You don't really need statins." He did say though that the government keep changing the rules as to what the levels should be. He said it was up to me, but I said I don't want them …full stop! I take enough tablets as it is!* (Alex, 67).

These shifting thresholds and concepts of cholesterol within limits were further exacerbated by discussions of 'good' (HDL) and 'bad' (LDL) cholesterol. Whilst health professionals were seen to recommend statins for patients with increased LDL cholesterol, these conversations only served to muddy the waters and make participants question their own knowledge:

> *I was aware of my cholesterol, and have been for over fifteen years… [It's] about 3.5. That's about what my cholesterol is you know, always has been. She [the nurse] said, "Yeah but your bad cholesterol is higher than your good cholesterol." I thought, what's she on? Where's she coming from? Bad cholesterol, good cholesterol …never heard of it* (Gary, 67).

The concept of preventative medicine was familiar but not always valued by participants. In an ideal world, it would be unnecessary to embark on medical treatment. However, a few participants noted that, whilst they would prefer to be free of medication, they were unsure if they were able to put in the work to mean that it was unneeded:

> *All things being equal, and in a perfect world, you don't want to be taking tablets. So, it would be nice to think I wouldn't have to take them, and I wonder sometimes if I am doing enough to bring that to an end, but I don't know… perhaps it is something I will have to live with* (Tom, 66).

Six participants within the sample had, after discussions with the health professional conducting their assessment, decided that they would like to try and reduce their CVR by tackling lifestyle factors before embarking on a medication regimen:

> *At the beginning I said, "Look, rather than take tablets I will change my lifestyle". I am a social drinker. I don't drink a lot, never have. In fact, my grandson said to me (he's 14), "Grandad, I have never seen you drunk" and I said "No, and you never will see me drunk". I mean I like a glass of wine or a couple of pints of beer, but I'm not a heavy drinker. I said "I will cut back and I will eat better, rather than take tablets"* (Jeff, 71).

Again, this demonstrates the importance of *collectively interpreting it* (communal specification) within the NHSHC, to provide an opportunity to come to a shared understanding of the work that the patient is expected to undertake to reduce their CVR. The processes of *individually and collectively interpreting it* (individual and communal specification) led, in these cases to taking positive action to reduce CVR through lifestyle. However, when the individual returned to the GP practice to assess the effects of their lifestyle changes and have a repeat assessment, it was clear in their results that their efforts had not been sufficient to make a great impact on their CVR. This cycle of engaging in the work of *making sense of it* (coherence)*, working out participation* (cognitive participation)*, doing it* (collective action)*, and reflecting on it* (reflexive monitoring) encouraged these participants to embark on medical intervention to reduce risk:

> *I wouldn't take paracetamol unless I was nearly dying [laughs]. So I've an aversion, I've always had [it] to taking my tablets… I'd much sooner try and do it without them, you know. Because the first time that it was suggested that I went on the statins, I did decline it and I said I'll try and do it by myself, you know, by losing a bit of weight, getting rid of the salt and things like that, but then when I went for the review my cholesterol, my bad cholesterol, had gone up a bit, so I was advised to take them then, so I did* (Jim, 61).

There was acknowledgement that whilst making changes to their lifestyle was helpful and did make a difference to 'risk scores', these changes were not enough to make the same impact on cholesterol as medications:

Keith:	*Yeah. I tried without [statins] for three months.*
Interviewer:	*Oh, did you?*
Keith:	*…and it knocked it down a fraction, so on that level it would have taken me about 20 years to get it down to the level it needed to be [Laughs].* (Keith, 60)

However, for one participant, going through the process of trying to reduce CVR through lifestyle and seeing, at reassessment, that her cholesterol had reduced, albeit marginally, was enough validation to continue in the same vein, rather than commence medical intervention:

> *It was part of the check [reassessment of cholesterol], both in the first one and the second one I had about a month ago. We [participant and nurse] couldn't work it out [why CVR was 'high'] because I was eating no butter or margarine or cream <u>at all</u>. I had dry toast with a bit of marmalade on! I don't eat a lot of pastries, you know I eat everything in moderation. The only thing we could come to was that I eat too much cheese and chocolate. So now I eat very little cheese and my cholesterol has gone down from 5.3 to 5.0 in the year, so it has gone down!* (Kate, 68).

There was some discussion about the role of medications in the prevention and reduction of cardiovascular risk. In some cases, participants felt that, once on statins for prophylactic reasons, they could pass over responsibility for keeping risk 'in check' to medical science. Risk was therefore not something that had to be monitored by the individual, rather, it was monitored by the daily medication they were consuming. The relationship between statins use and cholesterol reduction is well known in the UK population. Its use is often covered in the UK press and media. It is therefore understandable that this became the focus for many people – the NHSHC assessment and programme was not focussed on as a risk reduction programme, rather as a means of keeping one's cholesterol levels under observation and surveillance. In the extract below, Phillip describes how he could easily be tempted to engage in what he deems unhealthy behaviours and allow the medication to take responsibility for his actions but he tries to keep himself under surveillance as well:

> *The one thing that you have to watch, I found out, when you take these tablets, it can sort of plant into your mind maybe I could have that big cream cake? I'm taking a tablet that will combat it. But, you can't do that because it might keep your cholesterol down but it knocks your weight back up and I think the two are linked. So yeah, you've got to sort of look the other way when you walk past the cream cakes* (Phillip, 65).

Similarly, Brian describes how he has not made significant changes to the way he lives his life, the only difference that he could define was that he was now on a daily medication, which was the sole step to reducing cardiovascular risk:

> *Really, I would say I am doing exactly what I was doing before, just that now I am taking the tablets* (Brian, 66).

Some people grappled with the idea that they were being asked to take medications for the prevention of an uncertain outcome. They had not been offered medication for the treatment of an existing condition, in which case medication could be lifesaving. This differentiation between physical illness and projections of uncertainty were pertinent to some people. As Linda explains:

Linda: *If I had high blood pressure and she offered tablets specifically for high blood pressure, I might take them, but the statin isn't for that, is it? It's not for high blood pressure.*

Interviewer: *No. It's marketed, as far as I know, for high cholesterol*

Linda: *So, if she thought my blood pressure was very high and say oooh, after monitoring it a few times, if she said "You'd better have some tablets" or the doctor did, I might take them to keep it low* (Linda, 66).

Likewise, Kate felt that life itself is uncertain, a lottery. She was unhappy taking medications based on risk:

Interviewer: *So, if you had some sort of event, like a heart attack or stroke, would you be happy to take them [medication]?*

Kate: *Yes. Because then it could be lifesaving! But I'm not so sure about just for prevention? I mean there is no way that I would go and have a double breast operation, removal, just because I am at high risk of breast cancer.* ***I just wouldn't do it!*** *Life is a lottery, it is. It's a lottery. And, nobody is going to live forever and would you want to?* (Kate, 68).

Linda highlighted, again, how she felt unnecessarily steered down the path of medications for preventing something that, in her mind did not exist:

> *So your blood sample comes back. Cholesterol is low. Your liver's good [nurse says] can't believe you drink that much and your liver's still good! And, they've tested for all these and your blood samples come back great, great, great and then she says family history and talks through it. "Oh well, I think you're high risk. I went "But you've just taken my blood pressure, and that was fine". "Yes, it's very good for your age". "Right, and you've done all that, why would I wanna take tablets?" "Well it might prevent…" I said, "There's nothing to say, in any of the results, that I'm in danger - is there? "Well, no…"* (Linda, 66).

Adverse side effects from taking statins were discussed by all participants, regardless of whether they were taking statins or not. Participants noted multiple sources of information about side effects, from personal experience, experience of family and friends, and stories in the British media. Whilst clinical trials of statins suggest that side effects are rare and tolerable, anecdotal evidence points to the contrary. The bombardment of evidence from multiple sources understandably creates doubt in the mind of those who are recommended to take them. The robustness of the evidence presented in the media was sometimes questioned:

> *The Saga magazine – they did a big article about people who are on the statins and the results, and there were a lot of people who had a lot of problems with them. I don't know if there had been some sort of official medical follow up with the side effects of statins* (Kate, 68).

However, information about side effects had a clear impact on participant's decision-making processes when considering whether to engage with medical intervention:

> *Well, you hear that many horror stories with Simvastatin, the side effects. I am not a tablet person. I would rather put up with pain than take tablets, I must admit that* (Jeff, 71).

Awareness of side effects did, in some cases, prompt a discussion between the patient and their GP. It allowed a dialogue to take place that enabled the GP to allay fears about serious side effects before the individual agreed to take medication:

> *I started taking the statins. Well, actually not straightaway, because I thought I've been reading about it in the papers. I was slightly concerned, because there's a report of all sorts of side effects. So, what happened? I made an appointment with one of the doctors and I went and quizzed him about it. He said, "Oh yes, well there are things could happen - like the main thing is kidney failure, right". Well he hasn't seen anybody like that, he said* (Nigel, 72).

All participants were asymptomatic at the point of assessment and CVR identification. Some participants, who had refused to take statins, felt adamant that there was no clinical need to take medication, especially medication that had the potential to cause unwanted side effects when they had felt fit and well prior to assessment:

> Linda: *It might reduce the risk of whatever, stroke or I don't know, but it has some terrible side effects 'cause I've heard about the side effects.*
>
> Interviewer: *Where have you heard that?*
>
> Linda: *I can't remember them all now. There's all different side effects to these tablets but I don't agree that they should offer you tablets when you're quite healthy, really and truthfully* (Linda, 66).

Many participants, who had embarked on a pharmaceutically aided journey reported side effects. These ranged from mild effects that were tolerable such as a little gastric discomfort to side effects that were intolerable:

> Interviewer: *How are you finding them?*
>
> Fran: *They're fine, I mean I take it before I go to bed at night but [laughs] it's when you get to bed ... it bubbles in here [pats tummy].*
>
> Interviewer: *Does it?*
>
> Fran: *I get wind, terrible wind, just bubbling away in here and seemingly that's a side effect of them* (Fran, 70).

Experience of side effects often led the individual to revisit their GP to discuss the treatment plan and allay any fears. In many cases, these discussions led to a reconfiguration of treatment (*changing the way things are done* (reconfiguration)), whereby the health professional would prescribe a different brand of statins which the patient found easier to tolerate. This was the case for Phillip, below:

> *Well they [legs] stiffened up. It felt as though you'd been stood in a bucket of concrete! And I got diarrhoea and I felt sick and had a fuzzy head with them and they said, "Well you usually get this over the first three months." Well I took them for three months and it didn't ease off and I thought, well I felt perfectly well before I went on these, I'd like to come off them, so I came off them* (Phillip, 65).

David described a similar journey of experiencing side effects which later resulted in the reconfiguration of his treatment:

> David: *The doctor then gave me statin which I couldn't take because it affected me very, very badly. I couldn't move my arms.*
>
> Interviewer: *Really?*
>
> David: *I was in that much pain, I couldn't move my arm…They took literally nine months to a year to get rid of it out of my system* (David, 62).

There were a small number of participants who had experienced side effects and come to the decision to discontinue treatment of their own accord. These participants had not sought the opinion of a health professional or sought reconfiguration of treatment. For these participants, the experience of side effects and knowledge of side effects from other sources led to the discontinuation of treatment:

> *I went in [to the GP surgery] and got them [statins] and she gave me a supply. I started taking them and all the muscles in my back started jumping about like that. 'I can't go on like this' and so rang up and said, "I am not taking them." But as you get older you are bumping into friends and they are all the same age as you, and everyone I have known, they have all got bad backs because of these cholesterol things. So I thought 'I am not taking them', and so I wouldn't take them* (Ken, 74).

The possibility of a 'prescription waterfall', whereby preventative treatment could lead to side effects that subsequently needed treating with other intervention was acknowledged by some as a valid reason not to engage with medical intervention, when they were asymptomatic in the first place:

> *It [statin] may protect you from one thing but you may end up getting something else, it could cause something else. You could get onto this sort of treadmill of taking one medication and having to take something else to counteract it and something else to counteract that!* (Kate, 68).

Refusers were resolute in their decision. They had synthesised knowledge of their family history, own personal health history, and current health status to arrive at a decision not to embark on a journey that included prophylactic medication. These participants showed sophisticated reasoning and articulated it well. This highlights how, if an individual is resolute in their own *individual interpretation of it* (individual specification), about the importance of CVR and their knowledge of treatment options, the process of *collective interpretation* (communal specification), whereby the health professional attempts to change their mind, is futile:

> Linda: *I mean my cholesterol's low, my weight's low, in fact she [the nurse] reckons I've lost weight since last year! I said, "No, your scales are wrong." She wanted to put me on those, is it stats?*
>
> Interviewer: *Statins?*
>
> Linda: *Yeah, I said "[nurse's name], I don't take tablets". I said, "If I have a headache I won't take painkillers. I don't believe in tablets"* (Linda, 66).

Refusers drew a distinct difference between medicating for secondary prevention and primary prevention. The lack of diagnosis of a clinical condition but rather a prediction of a possible future event was central to their decision to refuse medical intervention at this time point.

7.3 Surveillance and annual review

After an individual has been identified as at increased CVR and offered lifestyle advice and/ or treatment, they are entered into an annual recall system. Each year they are offered a review appointment which, in theory, provides a space for reflecting, monitoring and mapping progress in collaboration with a trained health professional. This annual review could provide an opportunity to renegotiate, collectively, treatment options and to discuss what is working and what is not (*reflecting on it* (reflexive monitoring)).

Generally, the annual review was seen as a positive part of the NHSHC programme, in that it was preferable to have health professionals monitoring progress alongside any self-surveillance (discussed later in this chapter) to give validity and legitimacy to changes that had been undertaken by the individual and their effects in reducing or managing overall CVR:

> *I also think it is good how I go back every year and someone is monitoring it and also them identifying it [CVR] because I would have lived oblivious to it!* (Keith, 60).

Another participant added:

> *Well it's no hardship is it? If it [review appointment] was every six months I'd do it, because, at the end of the day, who is it benefitting? It's for my benefit, so I have no problems that way* (Colin, 57).

It was, however, acknowledged that the annual review was not necessarily tailored to individual needs. Participants wanted an individualised service that was relevant to them and their lifestyles, instead of feeling like they were on a conveyer belt just being pushed along, through a generic pathway:

> *It's alright to say at a population level to be just going through the motions and making everyone do it [attend and NHSHC, make and sustain changes], but as an individual you want an individual service* (Dennis, 65).

Moreover, the time allocated to the annual review process was not deemed as particularly conducive to providing a shared space for reflection and often the health professional’s approach to the annual review was seen as being ‘soft touch’ rather than providing practical support and guidance to facilitate an individual’s adherence to the programme’s values:

> *It [review appointment] was only really a few minutes. They didn’t really ‘push it’, they said you should do this, you should do that, there was nothing really that you could disagree with – it is just in practice, doing it!* (Keith, 60).

Added to this, the experience and confidence of the health professional had the power to change the dynamic of the annual review consultation and ultimately the usefulness of the annual review appointment:

> *You don’t want to go in and see these nurses and them grill you like the Third Reich [such as] “you shouldn’t eat these”, ahhh pffft! You don’t need them to scold you, because you wouldn’t have people going back. But, on the other side [of it] I remember two [different health professionals who have carried out an annual review], the one I have just been to, she was a bit shy, I think? She did the basics and I was out. The one the year before was a bit of an older woman and there was a bit more interaction!* (Keith, 60).

Some participants used the opportunity to attend an annual review as an opportunity to set achievable goals for themselves:

> *I'm trying to lose a bit more weight. I'd like to go, it'll be in April I think [annual review], March or April. I'd like to go and sort of be able to get on the scales and see that I've lost a little bit more weight as well. I know my cholesterol will be down because I'm taking the medication, that's going to take care of that, I don't have any worry on that* (Phillip, 65).

The annual review was also used as an opportunity to seek reassurance, from a health professional, that CVR had not increased substantially over the past year:

> *[at the annual review] when they tell you things you know, you feel fifty times better – or more – when you come out of the doctors…But she [the nurse] said if there is 'owt wrong then they will phone me. There can't be 'owt wrong with me up until now since I went on Friday and I've heard nowt* (Jenny).

However, whilst the annual review was valued as a space to reflect on progress, by some, it could also be an opportunity to reflect on how CVR was a continual process that each year, by virtue of aging, increases regardless:

> *I think it is good that there's a follow-up. I can't see the point in them sending for you one year and never following up…[but] I mean, it's a bit shattering when you say you have done all these things [made changes], and she tells you that you at higher risk because you are another year older!* (Kate, 68).

The opportunity to engage in an annual review appointment was seen by some participants as an opportunity to impress the health professional with their progress over the last year and receive validation from the health professional that any efforts to make quantifiable differences to their physical selves had not been in vain:

> *I'd put half a stone on since the time before…so when I go back and see her next time, she will see a big difference, wont she!* (Paula, 57).

Another participant noted:

> *I was pleased because I had lost the weight and my blood pressure was down a little; it wasn't down a lot but it was down a little. It was nice to chat to her [the nurse]…it's nice to talk to someone who isn't telling you all doom and gloom* (Fran, 70).

The annual review, in some circumstances, provided a space to reflect on individual markers for CVR, such as cholesterol and how an individual lifestyle may impact on the numerical values afforded to such markers. This process of communal reflection was useful, to those who experienced it, in trying to unpick what changes they could make and what might be effective in reducing their individual CVR:

7.3.1 Self-surveillance and engaging the family

Alongside the annual review appointment, people noted how they had taken on the role of self-surveillance as a result of being identified as at increased CVR. The extent to which individuals took on this monitoring role varied from person to person, and what they monitored varied too. Depending on what measurement they felt was the causal factor for their increased risk, this became the fixation for the self-monitoring.

Technologies to facilitate monitoring of markers, such as cholesterol, can be obtained freely and carried out in the comfort of one's own home – for a price. The availability of such technologies can facilitate self-monitoring between annual review appointments and allow for individuals to map their own progress against the baseline provided at assessment. Having the opportunity to monitor cholesterol at home, in Phillip's case, facilitated the decision to take statins to manage cholesterol:

> *I used to buy the little Boots cholesterol checks. They're expensive though, they're about £11. You just prick the end of your finger and run it [the blood] onto a card and it gives you a basic reading. It's not a million miles out from what the hospital one is [results are comparable to those provided in a clinical setting]. So I monitored myself two or three times over the year, with that, but I couldn't get it down to below 5.6 or 5.7. So I said I would give the medical treatment a try* (Phillip, 65).

Self-surveillance of weight was common, with many participants commenting that they had begun to weigh themselves more regularly since their risk assessment:

> *I have put on half a stone since the last time I went in [for annual review]. Even with the exercise, which I was disappointed in. I knew it was creeping up because I weigh myself every Monday so I can keep a check on my weight* (Keith, 60).

In some cases, self-monitoring was facilitated by engaging with other members of the family, who had clinical expertise, to supplement the information captured within the consultations:

> *My blood pressure was on the high side [at the time of assessment]...so my daughter [who is a nurse] said "when I come I'll take it for you"...so over a period of two months she took my blood pressure and I wrote it all down and took it in for him [the GP]. Every reading was normal. It was all quite low* (Dennis, 65).

Partners also had a role to play in monitoring certain behaviours; they became enrolled in the task of surveillance:

> *We tell each other "look, we have been drinking three nights this week" then we have cocoa instead of drinking [alcohol] on a night time* (Ken).

7.3.2 How do I know if it is working?

The annual review appointment should provide an opportunity to map progress, year on year, against the baseline risk assessment in the first year. However, not all annual reviews were conducted to the same specification, across the sites from which the participants were sampled from. Cholesterol screening, as mentioned previously, was used as a marker by many participants as something that indicated CVR and was a common concept that had a numerical value that could be influenced through lifestyle changes and adherence with lipid lowering medications (statins). Cholesterol was, however, not reassessed in all annual review consultations (under national guidance), though this reassessment was an expectation as a way of monitoring their progress over the last year. This led to disappointment for some participants as it made them question the validity of the changes they had been trying to make:

> *She said "Oh no, we don't check that [cholesterol], we just check the liver function". So, I thought, "What's the point if I don't know whether it's working?"* (Nigel, 72).

Another participant added:

> *I said to her, you know, "Are you taking the cholesterol [again]"? She said, "There's no need to, with you taking them tablets [statins]". Them tablets obviously keep your cholesterol down, but I would have liked to know what it was; if it had come down, or if I'm wasting my time taking them?* (Carol, 75).

In other cases, however, the annual review served as a perfunctory occasion where there was little opportunity to engage in shared reflection:

> *[At the review] they give you the test and blood test and she said, "If we have a problem, we will get back to you". They have never got back to me so I just assume that everything is alright. They don't actually go through anything again…it's over a fortnight now, so I just assume everything is OK?* (Brian, 66).

Whilst the work undertaken to engage with the aspects of the NHSHC programme that require participants to make changes to their lifestyle, take medications, and reflect on the programme relate mainly to the NPT constructs *doing it* (collective action) and *reflecting on it* (reflexive monitoring) clearly, processes from each NPT construct are activated. Sense making work, thinking it through and organising work, actually actioning behaviours, and reflecting on results occur in parallel. The processes identified through the NPT constructs are not linear (though it is easier to describe them that way for clarity). Rather they interact with each other in a symbiotic relationship.

Chapters 6 and 7 have presented findings from the study that relate to stages of the patient journey through the NHSHC programme. Furthermore these chapters highlighted how NPT constructs can be used to explore and explain how people make sense of and engage with each stage of that journey. In the following chapter, chapter 8, a deeper conceptual discussion about how each of the NPT constructs and their subordinate working mechanisms can be used to explore the findings is presented.

8 Discussion

This thesis set out with the intention of exploring the factors that influence the experience of those people identified as at-risk of adverse cardiovascular events through the NHSHC programme. To achieve this, the journey that people embarked on from invitation to attend an NHSHC, through their diagnosis of risk, adherence (or not) to lifestyle advice and lipid lowering medication, to their experience of engaging with the annual review process was explored.

Two distinct research questions were posed and the following chapter intends to demonstrate how these questions were answered and how aims and objectives were met.

Research question one	
What factors influence high-risk individuals' engagement with the NHSHC programme?	
Aim	To understand and explore at-risk individual's experience of engaging with the NHSHC programme to identify factors that promote or inhibit engagement with assessment, risk identification, intervention, and sustained engagement over the longer term (1year+).
Objectives	1. To examine how individuals make sense of the NHSHC programme 2. To understand how individuals interpret being at-risk of a cardiovascular event 3. To explore how individuals make sense of lifestyle advice and/or intervention 4. To catalogue how individuals make sense of the prescription of prophylactic medications 5. To discover how individuals integrate and sustain lifestyle changes and/or prophylactic medications 6. To determine how individuals engage with ongoing monitoring of risk

Research question two

Can NPT provide insight into engagement with the NHSHC programme?

Aim	To utilise the constructs of NPT to unpack and explore reported engagement with the NHSHC programme.
Objectives; to explore NPT's appropriateness to explain experience of:	To explore the appropriateness of NPT to explain people's understanding of and engagement with various stages of the patient journey towards living with a diagnosis of risk, i.e. 6. Invitation to attend assessment 7. Receiving a diagnosis of cardiovascular risk (CVR) 8. Engagement with lifestyle advice and/or intervention 9. Engagement with prophylactic medication 10. Engagement with ongoing monitoring over the longer term

This chapter therefore synthesises the themes generated through data analysis and integrates them with the core concepts of NPT to show whether NPT was helpful, or not, in providing a lens to view the data. By interpreting and then extrapolating the data against the NPT constructs, implications for theory, policy and practice, training, support, and education, and research can be abstracted (chapter 9). Such an analysis can help to provide insight as to how programmes such as the NHSHC should be constructed and implemented, as well as providing insight into how this particular theory can be utilised in contexts for which it was not originally intended. Generally, the NHSHC assessment and subsequent journey can be divided into two fundamental categories, much like NPT itself. The first being the *making sense of it* (coherence) and *working out participation* (cognitive participation) work that patients must undertake to get on board with participating in the NHSHC. Secondly the work undertaken to implement the *practices* necessary to participate in the NHSHC and engage with making lifestyle changes and taking lipid lowering medications, and engage with surveillance and monitoring activity.

This discussion chapter is broken down into two main sections. Firstly, the findings are considered in relation to the constructs of NPT and secondly, the findings are compared to existing literature.

8.1 How Normalisation Process Theory provides insight into engagement

On the following pages, each construct of NPT is discussed in turn. Each section begins with a table that presents definitions for each core construct of NPT and its related four working mechanisms to refresh the reader’s memory before we turn to discuss each stage of engagement, or not, with the NHSHC programme and how NPT’s constructs were helpful, or not, in explaining the NHSHC journey for this group of individuals.

8.1.1 Making sense of it

<table>
<tr><th colspan="2">Making sense of it
(Coherence)</th></tr>
<tr><td colspan="2"><i>The process of sense making and understanding that individuals have to go through in order to promote or inhibit the routine embedding of a practice to its users. These processes are energised by investments of meaning made by participants</i> (Finch et al., 2012).</td></tr>
<tr><td colspan="2">Working mechanisms</td></tr>
<tr><td>Understanding the uniqueness of it
(Differentiation)</td><td>Collectively interpreting it
(Communal Specification)</td></tr>
<tr><td><i>An important element of sense-making work is to understand how a set of practices and their objects are different from each other.</i></td><td><i>Sense making relies on people working together to build a shared understanding of the aims, objectives and expected benefits of a set of practices.</i></td></tr>
<tr><td>Individually interpreting it
(Individual Specification)</td><td>Coming to a conclusion
(Internalisation)</td></tr>
<tr><td><i>Sense making has an individual component too. Here participants in coherence work need to do things that will help them understand their specific tasks and responsibilities around a set of practices.</i></td><td><i>Finally, sense-making involves people in work that is about understanding the value, benefits and importance of a set of practices.</i></td></tr>
</table>

The offer of an NHSHC assessment, at the programme level, was not interpreted by participants as anything out of the ordinary. Unlike the study conducted by Cheong et al. (2016) that concluded participants had attended NHSHCs based upon their readiness to face the outcome of the risk assessment. Rather, participants in this study discussed how they had attended because they thought it was a routine offering. What was being offered to them was not initially distinct, and therefore differentiation from other offers of general check-ups was not achieved. This lack of distinction, at least for this cohort of participants who were engaged in the programme, worked in its favour, as it had driven these participants to attend the initial assessment. Of course, the population from which this sample was drawn was quite specific. All participants within the sample had undergone a full NHSHC at their GP practice, been identified as at increased CVR, been given intervention, and attended at least one annual review. Therefore, this sample were already engaged and compliant to some extent. No comment can be made about why individuals do not engage with the NHSHC from the outset, or about those who attend assessment but do not return for intervention and/or annual review because they were not included within the sample for this study.

None of the participants in this sample had sought out the assessment because they were experiencing signs and symptoms of CVD, from seeing advertisements, or word of mouth. Rather, they had all been contacted by their GP practice and invited to attend assessment. Participants interpreted this offer as commonplace, normal, routine. It could be postulated that general check-ups and surveillance activity have already become normalised in a UK population. Many general health checks and screening opportunities exist and these offers have already become routinised behaviour for many. Of course, it should be highlighted that this group of participants were already engaged in the NHSHC programme for at least one year post assessment, so represent only a small cohort of those eligible for an NHSHC. That said, the NHSHC offer was understood to be just another one of those things offered to people, because of their age; an MOT check-up that aimed to assess their general health and wellbeing.

Many participants were confused about how long they had been engaged in the NHSHC programme, noting that they had been attending assessment and review for much longer than was possible – in many cases prior to the inception and roll out of the NHSHC. This may be explained by them misremembering how long had passed since assessment, or again could be a symptom of lack of *understanding the uniqueness* (differentiation) of the NHSHC from other routine check-ups they may have attended. It seemed that none of the participants had considered, prior to the assessment what the burden of being identified as at high risk of CVD would actually mean, and the changes that would be necessary to adhere to the suggested intervention that ensued ((May et al., 2014a, May et al., 2009b, Montori et al., 2006).

This lack of distinctness continued when they presented for assessment. The testing that was offered to them, the measurements that were taken, and the family history, were again routine. Again, this could be interpreted as a positive part of the NHSHC programme, as these types of testing are already routinised, for this population. However, the outcome of the tests, in particular the cholesterol screening, had been somewhat repurposed. Cholesterol screening is commonplace in the UK and the concept of total cholesterol, and its relevant thresholds, are firmly embedded in the public consciousness. Many products on the supermarket shelves, such as cereals, yoghurt drinks, dairy spreads and even breads are marketed as ‘heart healthy’ and as having the ability to help keep cholesterol levels within what is deemed as ‘normal’ levels (Sainsbury's, 2017). Products for home surveillance of cholesterol levels are also available for a price (Boots WebMD, 2017). Over the counter medications, such as statins, are familiar pharmaceutical products to reduce total cholesterol. However, as a result of cholesterol screening for the NHSHC, total cholesterol levels were, in many cases, disregarded and new concepts of LDL and HDL cholesterol were introduced as a way of promoting the initiation of statins therapy, for the purposes of prevention. This is distinctly different from usual ways of working and is something many participants struggled to make sense of, both individually and in conjunction with the health professional. Participants felt that they already had a good grasp on the concept of cholesterol and cholesterol management. In some cases the health professionals used this opportunity of *collective interpretation* through the co-construction of the ‘problem of CVR’ to use LDL and HDL cholesterol to their advantage. Essentially the health professionals took a familiar concept but turned the introduction of good and bad cholesterol concepts to their advantage as a tool to convince patients to engage in the repurposing, or prophylactic properties, of a drug that was understood to be used in cases of elevated total cholesterol. However, findings showed a tension between the two constructs – *individual interpretation* and *collective interpretation* in that participants used their own knowledge and understanding of cholesterol (as problematic or not) to build a picture of what level of cholesterol constituted a need for intervention. However, this was often different from the interpretation of the health professional. The process of collective interpretation could be used as a tool to change participant’s views about the need for intervention with medications; however, this did not always happen.

The use of data collected during the NHSHC assessment is used for a predictive purpose. It is utilised to feed a calculation that results in the percentage chance of the tested individual suffering an adverse CVD related event in the next ten years (Davies et al., 2012, Joint British Societies for the prevention of cardiovascular diseases, 2014). This concept of a *risk diagnosis* is distinctly different from other clinical *testing* that aims to identify signs and symptoms of a pre-existing condition – which could then be treated and managed by medical intervention. Instead it sets the NHSHC alongside other screening programmes and new forms of genetic testing, which focus on potential risk. As such, it has not been adopted by the UK Screening

Committee, as it does not meet the stringent criteria set out for a screening programme (UK National Screening Committee, 2013) (see Appendix 11.2). Nevertheless, the NHSHC programme, as a risk identification, management, and reduction tool, necessitates the communication of the potential risk of illness that has been projected many years into the future. The communication of a numerical risk score is intended, through a process of communal interpretation, to convince the individual that internalisation of risk is to be prioritised. However, findings demonstrate that participants do not always go on to internalise their CVR and adopt a patient identity (Karp, 1994).

Risk communication is fraught, and well documented as an area that health professionals struggle to articulate (Spiegelhalter and Riesch, 2011, Edwards and Elwyn, 2009, Edwards et al., 2002). Many participants were unaware of their actual risk ‘score’ and instead were just told that their risk was ‘high’, meaning they could not assess the likelihood or extent of the CVR. There was also a tension described between an individual being told that they were at high CVR, being asymptomatic, and being told by the health professional that they were currently in good health. This often resulted in participants feeling reassured about their current health status, rather than poised for action.

There was evidence that some participants had struggled to make sense and internalise the notion of risk and make sense of how their individual risk score had been constructed and arrived at. The assessment provided an opportunity for participants to engage in a process of both communal and individual interpretation. It was an opportunity, after risk identification, to co-construct a ‘problem’ of CVR, which could then be internalised as something that necessitated action and also could be treated, and therefore reduced. However, some participants (those who went on to refuse medical intervention) highlighted how the NHSHC had failed to identify, classify, or provide a name for any tangible condition or illness that should or could be treated through medical intervention (Armstrong, 2011, Armstrong and Eborall, 2012). This demonstrates how the working mechanisms of communal and individual interpretation can work together to produce a negative conclusion about engaging with the NHSHC.

Refusers displayed an active resistance to reconstructing their self-image and narrative of past, present and future selves in a way that positioned them as a patient or as someone in need of intervention (Bury, 1984, Bury, 2001). This apparent lack of coherence, for the group who refused medical intervention, had a detrimental impact on their engagement with the NHSHC programme overall. This process demonstrates the importance of engaging in *collective interpretation* to come to a shared understanding of the 'problem', and in some respects *working with and trusting the work of others* (relational integration) and how that can impact on *individual interpretation* (individual specification) and subsequently *coming to a conclusion* (internalisation) about the 'problem'. For this group of participants, the processes of *making sense of* CVR had failed to provide a catalyst to engage with the next construct or process of *working out participation* (cognitive participation), specifically the *believing the practice is valid* mechanism.

Participants actively sought out *collective interpretation*, in cases where risk and how the risk calculation had been arrived at was confusing and not immediately clear from the individual’s own construction (*individual interpretation)* of CVR, in relation to their lifestyle. Some participants recounted asking the health professionals to go through their ‘risk factors’ to try and pin point what it was *exactly* that had identified them as at increased CVR, seeking *collective interpretation* to justify and provide a causal link between a surrogate marker and CVR. This was demonstrated by those participants who went through their diet step-by-step with the health professional to identify what was responsible for their CVR. In many cases, participants were left unable to explain why they were at increased risk. Several participants were able to move past this apparent lack of coherence and go on to engage further with the programme. However, for those who refused to take statins, this lack of coherence was all the information that they needed to justify their disregard for engagement with the programme and subsequently non-acceptance of medications.

A small number of participants recalled the health professional who was delivering the assessment working hard to build a shared understanding (*collective interpretation*) with them about CVR and its potential physiological complications, in order to facilitate the internalisation (*coming to a conclusion*) of CVR being a problem that could be attended to and essentially the prevention of CVD. The use of demonstration aides (models of arteries clogged with cholesterol) were effective tools to help participants to visualise the processes that might be taking place within their bodies. In these cases, the work of collectively interpreting CVR led to the internalisation of risk and subsequently adherence with programme interventions. This demonstrates the importance of collective interpretation with sustained engagement with the NHSHC programme and its constituent parts.

The concept of candidacy for CVD (Davison et al., 1991) came out strongly, as participants explored how they had made sense of the NHSHC in relation to their specific personal circumstances, and as they made sense of the news that they were classified as at increased CVR. This concept of candidacy was strongly linked to the processes of *collective and individual interpretation* (communal and internal specification), and eventually *coming to a conclusion* (internalisation) about the concept of risk. Participants discussed drawing on multiple sources of knowledge to make sense of their candidacy for CVD, either knowledge that would explain their candidacy, such as family history, and lifestyle factors, or knowledge that highlighted exceptions to the rules and exploring the apparent random nature of CVD.

Much like the findings of Cheong et al. (2016), the use of genetic information, the hereditary nature of CVD, to make sense of CVR and its potential threat to future health was used by participants to make sense and internalise risk in two very distinct ways. The first way that this information was used was to provide justification for engaging with the NHSHC and preventative intervention. However, this information was also used, by those who actively refused to participate in the programme, to rationalise their non-engagement. This was done through a process of *individually interpreting it* (individual specification) and *understanding the uniqueness of it* (differentiation) *of* the NHSHC, in that it was acknowledged that current ways of living are very different from that of participants' parents and grandparents. These participants believed that they were not at-risk of CVD to the same extent as previous generations and therefore lacked motivation to engage.

The concept of candidacy for CVD was linked to the working mechanisms of *collectively interpreting it* (communal specification) and *coming to a conclusion* (internalisation), in that participants described individuals, other than themselves, that would benefit from the NHSHC intervention because of their apparent candidacy for CVD. Likewise, participants described exceptions to their perception of CVD candidates who were apparently able to flout the rules by being able to eat cake and butter but not be at increased risk of CVD, similar to the work of Davison et al. (1991). Whilst, it can be seen from previous discussion, that the information that individuals utilise to construct the problem of CVR and their perceived candidacy for CVD, it would seem that the role of the health professional is central to the co-construction of the problem. Those health professionals who can articulate risk and translate it as a relevant concept, regardless of the patient's asymptomatic presentation, facilitate the 'ignition' of internalisation of a problem.

The construct of *making sense of it* (coherence), in the context of understanding the processes participants engaged with and progressed through to form an opinion about the relevance of CVR in the context of their lives, was a helpful tool. It illuminated the sense-making work that individuals undertake at different stages of the NHSHC programme. The working mechanisms of *understanding the uniqueness of it* (differentiation), *collectively interpreting it, and individually interpreting it* (individual specification) can be identified as precursors to the *working out participation* (cognitive participation) work that followed. However, it would seem that those three working mechanisms can work independently and are essentially prerequisites for *coming to a conclusion* (internalisation). Those participants who displayed a lack of internalisation of a 'problem' that could and should be attended to by engagement with the NHSHC programme, went on to actively resist taking on an ‘at-risk identity’ and subsequently engaging with lifestyle and medication regimens. If the process of *coming to a conclusion* (internalisation) does not take place, it cannot act as a catalyst for change, or activation. The processes, or mechanisms, of *understanding the uniqueness of it* (differentiation), *collectively interpreting it* (communal specification), *and individually interpreting it* (individual specification) can be understood to provide the material that is needed to ignite the process of internalisation, recognising either that something needs action, or concluding that it does not, generating resistance. From the evidence explored in this chapter it could be argued that the *coming to a conclusion* (internalisation) construct is not an independent mechanism, as the theory suggests (May, 2013b), rather it is a *product* of the other three.

8.1.2 Working out participation

Working out participation

(Cognitive Participation)

The process that individuals and organisations go through in order to enrol individuals to engage with a new practice. These processes are energised by investments of commitment made by participants **(Finch et al., 2012)**.

Working mechanisms

Having the skills to engage **(Initiation)**	**Organising people** **(Enrolment)**
When a set of practices is new or modified, a core problem is whether or not key participants are working to drive them forward.	Participants may need to organise or reorganise themselves and others to collectively contribute to the work that may involve rethinking group relationships between people and things.
Believing practice is valid **(Legitimation)**	**Defining actions** **(Activation)**
An important component of relational work around participation is the work of ensuring that other participants believe it is right for them to be involved, and they can make a valid contribution to it.	Once it is underway, participants need to collectively define the actions and procedures needed to sustain a practice and stay involved.

The second phase of work that takes place, after making sense of the NHSHC offer and being at-risk, can be explored though the *working out participation* (cognitive participation) construct. This is the organisational work that people undertake to understand wat is required of them to participate, or not, in the programme. It can be understood to be the organisational work to be undertaken before taking physical action (*doing it* (collective action)).

In the thesis, this has been identified as appropriate to explain the work that participants undertook to organise themselves and others around any intervention offered, or participants' identification of lack of intervention offer. From the data derived from this study, the *working out participation* (cognitive participation) construct was helpful in highlighting gaps in the provision of services for participants. We have seen how this particular cohort of patients were routinely offered lipid lowering medications for the purposes of prevention, and, in some cases, struggled to understand the repurposing of this medication to reduce risk in a population that displays cholesterol levels which are within the thresholds for ‘normal’ total cholesterol levels. If participants *made sense* of this and internalised and valued the need for this preventative medication, *working out participation* (cognitive participation), with its focus on organisation, skills, and accessing medication was not very helpful in exploring the patient’s journey. What this construct did offer, however, was a framework to think through other intervention pathways around diet, physical activity, alcohol consumption and smoking cessation – all of which are at the NHSHC core.

When asked to recall what advice had been offered about healthy eating, physical activity, alcohol consumption, and smoking cessation, participants recalled these offers only sporadically (McNaughton and Shucksmith, 2015). Conversations about diet happened frequently but other modifiable risk factors that the NHSHC programme is concerned with were less frequently discussed. No participants recalled being offered access to services to facilitate change of these risk factors, either in house at the GP surgery or in a community based setting (McNaughton and Shucksmith, 2015). The task of tackling weight management and sedentary behaviour was placed firmly in the hands of the individual.

The concept of *having the skills to engage* (initiation) highlights the importance of having the right skills in place to engage with the NHSHC programme, such as knowing how to source, prepare and eat appropriate food, to locate and participate in appropriate physical activity. This could highlight another point at which the programme could increase inequalities through the differential ability to respond to the at-risk ‘diagnosis’. NHSHC guidance suggests that intervention should be offered to those classified as at increased CVR to facilitate change of the modifiable behavioural factors associated with increased CVR. Individuals were not offered this opportunity of intervention, rather they were offered brief advice within the assessment appointment and followed up at the annual review. This lack of an intervention offer highlights a huge missed opportunity to facilitate the journey of each individual towards healthier behaviours which could have had a positive impact on morbidity and early mortality.

Some participants showed their resourcefulness in making what they deemed positive changes to their food consumption. However, for physical activity, alcohol consumption and smoking cessation there as very little acknowledgement in the data of being offered intervention or seeking it out of their own accord. This suggests that participants did not engage in organising themselves or others in activities to instigate change for these modifiable risk factors.

The lack of intervention from an external source, the GP practice in this case, raises an ethical question around the identification of increased CVR with a lack of positive intervention to change it. As already discussed, participants had not sought an

NHSHC assessment, it had been offered. Yet participants were left in a state where they were navigating a potentially very worrying journey without professional guidance. In the case of many of the identified risk factors, they did not feel they *had the skills to engage* with or the capacity to *define the actions* needed to instigate change, and so they simply did not embark on changing these behaviours. This finding could indicate a role for health trainers who may be able to offer support outside of the assessment appointments as discussed as a success in (Visram et al., 2014).

There was evidence that participants enrolled the help of family members at many points in the process of engaging with the NHSHC programme, as did those in the study conducted by Cheong et al. (2016). One of the first instances of note was when they were considering whether or not to embark on a pharmaceutically aided journey or not. This reliance on family members to help make a decision links to the mechanism of *believing a practice is valid* and the earlier constructs of *collectively interpreting it* (communal specification), showing the influence of extended social networks in engagement with the NHSHC.

Families were also engaged in incorporating changes into daily lives, especially if it was deemed to be within the remit of that family member’s realm of labour within the family. For example, it was common for the men in the sample to identify their wives as having the prerequisite skills to shop for and prepare healthier food. Therefore, the men in the sample described their wives taking responsibility for organising, managing, and subsequently carrying out dietary changes (*appropriate division of tasks* (skill set workability)). The enrolment of others to perform the tasks of making lifestyle changes was integral to the success they felt they had achieved. This either worked positively, in cases where wives had incorporated dietary changes to support their husband's journey, or negatively, where one husband described not engaging fully with the programme because his wife would not eat or cook vegetables. Again, this demonstrates the importance of engaging wider social networks of the individual in engaging with the programme, as these 'relevant others' provide a system of support for those who are actively trying to make changes to their lifestyle.

The conceptualisation of engagement with the NHSHC as *practice that is valid* impacted on at-risk individuals' participation with the programme. This was demonstrated most strongly by those participants who had refused to take, or discontinued their lipid lowering medications. For these people, the assessing health professional had failed to build a shared understanding of CVR so that the participant had afforded meaning to it and therefore they did not cognitively enrol with the programme. This type of buy in to the programme's aims and objectives would be necessary to begin to identify as an at-risk individual and build an 'at-risk/ illness identity (Karp, 1994, Kenen, 1996, Goldstein-Jutel, 2011).

8.1.3 Doing it

Doing it **(Collective Action)**	
The work that individuals and organisations have to do to enact the new practice. These processes are energised by investments of effort made by participants **(Finch et al., 2012)**.	
Working mechanisms	
Performing the actions **(Interactional Workability)**	**Working with and trusting the work of others** **(Relational Integration)**
The interactional work that people do with each other, with artefacts, and with other elements of a set of practices, when they seek to operationalize them in everyday settings.	The knowledge work that people do to build accountability and maintain confidence in a set of practices and in each other as they use them.
Appropriate division of tasks **(Skill Set Workability)**	**Allocating resources** **(Contextual Integration)**
The allocation work that underpins the division of labour that is built up around a set of practices as they are operationalized in the real world.	The resource work - managing a set of practices through the allocation of different kinds of resources and the execution of protocols, policies and procedures.

When discussing the work of actually enacting changes to lifestyle and taking lipid lowering medications, NPT served to highlight the processes individuals undertook. The vast majority of participants had recalled conversations with the health professionals about making changes to their diet in order to reduce their CVR and many participants (n=14) discussed how they had gone on to make changes to what they ate. Changes to diet were most popular out of all potential changes that could be made, perhaps as it was the lowest threshold activity that they could control. However, again, the enrolment of family members in achieving this goal was pivotal to its success. The responsibility for preparing healthier alternatives was devolved to the person within the family with responsibility to prepare meals – normally the wife.

Moreover, family members had the potential to derail health focussed activity if they did not like the healthier options.

Whilst participants were, for the most part, willing to make dietary changes, there was acknowledgement that what is deemed as ‘healthy’ now is subject to change citing examples of how dietary advice has changed over the years resulting in conflicting messages, demonstrating a lack of trust in the system. Instead, participants discussed opting to make small but sustainable changes to their diet such as exercising portion control and eating in moderation.

A small number of participants did not make changes to their lifestyle as a consequence of the NHSHC assessment. These participants cited that making these changes was unnecessary for them as they were already doing all they could to stay fit and well. This highlights how the processes of *making sense of it* (coherence) and *working out participation* (cognitive participation) had not acted as a catalyst for change. A number of participants did not recall having discussions about diet representing a small cohort of participants who either did have a conversation about diet and had forgotten or a missed opportunity for health promotion.

Engaging with increased physical activity was cited as problematic for some participants. Comorbidities were often restrictive and they felt they could not engage in activity as they once had when they were younger. This demonstrates an opportunity for intervention by health professionals at the point of assessment to discuss options for physical activity that are appropriate to this population and signpost them to available services in their local area. Few participants stated that they did not need to increase their activity levels as they were already engaged in regular activities.

The vast majority did not recall discussions about either alcohol consumption or smoking cessation representing missed health promotion opportunities. However, the majority of participants had been offered a lipid lowering medication.

When it came to *working with and trusting the work of others* (relational integration) the way in which the assessment and monitoring components of the programme are constructed does not facilitate relationship building in that the individual is offered two ten minute appointments at assessment and another at annual review. This does not afford enough time to really do the work of building relationships where people can explore the options available to them and raise questions and concerns with the health professional. The use of props and visual aids, as highlighted earlier, did facilitate the work of building trust in the expertise of the health professional's knowledge and build confidence.

The NHSHC programme does, for the most part, divide tasks appropriately – in that the at-risk individual is expected to carry out tasks that should be within their skillset e.g. making changes to their particular lifestyle. However, this relies on the assumption that they have these skills to prepare and cook food, increase physical activity etc… At the time of undertaking this study there were very few (if any) lifestyle interventions that participants were signposted to in order to facilitate gaining skills to make changes. This was noted by many participants as an area that needed improvement as they had felt unsupported after assessment. The division of tasks to make lifestyle changes was often devolved to other members of the family. For example, in most cases for the male participants it was their spouse who was responsible for preparing meals. Therefore, this task was entrusted to them in order to make and sustain changes. This again. Highlights the importance of engaging the individuals’ wider networks of support to achieve the aims of the programme.

Participants were expected to *allocate resources* both financially and in giving time to reduce their CVR. Whilst no one discussed paying for medications, probably by virtue of all participants being older and eligible for free prescriptions, younger participants in the programme may well have to pay for medications which may impact on their adherence to them. Participants were, however, expected to invest financially in making dietary changes. Some people noted that they were not willing to start buying separate foods that were deemed to be healthy, such as fruits and vegetables, as they were not popular with other members of the family, representing an investment that might go to waste. Only two participants discussed that they had made changes to their physical activity levels as a result of the NHSHC. These participants (a married couple) had invested, financially, in a Nintendo Wii to exercise and monitor weight after being motivated to do so after being called obese. Regardless of the financial investment in making changes, these changes had to be appropriate to the individual and sustainable in the context of their everyday life.

8.1.4 Reflecting on it

Reflecting on it **(Reflexive Monitoring)**	
The informal and informal appraisal of a new practice once it is in use, in order to assess its advantages or disadvantages and which develops user's comprehension of the effects of a practice. These processes are energised by investments in appraisal made by participants **(Finch et al., 2012)**.	
Working mechanisms	
Collecting feedback information **(Systematisation)**	**Collectively evaluating it** **(Communal Appraisal)**
Participants in any set of practices may seek to determine how effective and useful it is for them and for others, and this involves the work of collecting information in a variety of ways.	Participants work together - sometimes in formal collaboratives, sometimes in informal groups to evaluate the worth of a set of practices. They may use many different means to do this drawing on a variety of experiential and systematized information.
Individually evaluating it **(Individual Appraisal)**	**Changing the way things are done** **(Reconfiguration)**
Participants in a new set of practices also work experientially as individuals to appraise its effects on them and the contexts in which they are set. From this work stem actions through which individuals express their personal relationships to new technologies or complex interventions.	Appraisal work by individuals or groups may lead to attempts to redefine procedures or modify practices - and even to change the shape of a new technology itself.

Evidence from the findings shows that participants engaged in reflexive work in many different respects. They reflected upon their progress, their medications, the annual review process, and their relationships with the health professionals.

Participants described processes by which they performed self-surveillance to assess their progress to reduce CVR whereby they *collected feedback information*. For those that were engaged with the programme, some did this by monitoring their weight at regular intervals, purchasing exercise equipment such as a Wii, or by purchasing equipment to monitor cholesterol levels at home as a way of *individually evaluating it* (individual appraisal) progress. These activities necessitated *allocation of resources* of time or money. This process of self-surveillance demonstrates how some participants were highly engaged with the work of ‘being at-risk’, had incorporated concepts of risk into their identity, and normalised/ embedded these practices into their everyday life (Jani et al., 2013, May et al., 2014b, Gallacher et al., 2011).

Experiences of the annual review process varied between participants. This review should act as a point in time where the individual can come together with the health professional and engage in a process of *collectively evaluating it* (communal appraisal) progress. In some instances, participants had a reassessment of cholesterol levels and for these people it served as an opportunity to monitor the effects of the work they had undertaken making lifestyle changes or taking lipid lowering medications. However, many participants noted that this was not the case for them and they noted that they would have appreciated the opportunity to monitor and track their progress, or not, in this way. This lack of opportunity to quantify progress led many to believe that any efforts they had made to reduce their CVR had been in vain. However, in reality, overall risk scores may have increased by virtue of being another year older but the introduction of chances to monitor changes in surrogate markers such as weight and cholesterol may encourage sustained engagement over the longer term.

Moreover, participants discussed how opportunities for *collective evaluation* were essentially missed within the construction and delivery of the NHSHC. Whilst discussing treatment options, many participants felt that they had been steered down a pathway that assumed that prophylactic lipid lowering medications were the first course of action. Some felt that they would have liked to reduce their CVR without the aid of prescribed medications by changing their lifestyle in the first instance. However, for many, there was no offer of community-based or in-house interventions that they could participate in to be supported in making lifestyle changes in the first instance, demonstrating the need for these types of services to be available. The advice that was offered to people was cited as being generic and CVR focussed, as discussed in previous sections.

Many opportunities for *changing the way things are done* (reconfiguration) presented. A cohort of participants had returned to the GP practice to discuss treatment options after experiencing side effects from medications. As discussed, all of the participants who had been offered alternative brands of medications had gone on to sustain their adherence over the longer term and reported no further side effects. However, for the small number of participants who had approached their healthcare providers about alternative treatment options and been refused them, all went on to discontinue treatment. Changing treatment options, without the say so of a health professional who is responsible for prescription, is not an option for the individual. Health professionals are the gatekeepers to medical intervention (Turner, 1995) and hold the power to impact on the success, or not, of each individual who seeks to change their regimen. The way in which these requests are handled could have implications for the success of the programme at the individual level. Without this engagement of health professionals there is limited scope for the individual to reconfigure treatment to fit into their lifestyle so that it is workable for them personally.

Individuals who seek this reconfiguration of treatment represent a cohort of patients who are willing to comply, have internalised the CVR and the importance of engaging with the programme and could be convinced to be compliant/ adherent over the longer term if they are given access to treatments that are tolerable. Those who discontinued with treatment also represent a cohort of individuals that were willing to engage with all aspects of the programme, if it fits into their lives and does not make them feel unwell. If they had not experienced side effects than they might have continued with lipid lowering medications.

As previously discussed, NPT was used across the life course of the study (section 5.1.6) and I found it more helpful in some stages than others. Below is a more general discussion about the usefulness of NPT at specific stages of the study.

Planning: in the planning stages of the study NPT acted as a tool that could sensitise me to issues that are important when thinking through people's engagement in the work required to implement, embed, and integrate knowledge and practices. As such, the constructs and their subordinate working mechanisms helped me to brainstorm possible questions for the development of the interview guide (section 5.2.3). However, initially I found the language that is used to describe the constructs and the subordinate working mechanisms a barrier to engaging with the constructs. To overcome this I undertook a significant amount of re-interpretation and re-labelling work to ensure that I could contextualise the constructs and working mechanisms to the specific setting I was interested in (chapter 4).

Analysis: NPT was used at the analysis stages of the project. Initially I had intended to use the constructs to undertake a Framework Analysis (section 5.1.6) but this proved unsuccessful as I was concerned about imposing a deductive framework on the data which was not congruent with the wider approach taken to the study. As such the Framework Analysis was abandoned in favour of an inductive approach. The NPT constructs were used post hoc in a confirmatory manner and as a theoretical lens by which to make sense of the data.

Interpretation: the constructs and subordinate working mechanisms of NPT were useful at the interpretation stages of the study. They helped to confirm the results of the inductive analysis and helped to think through, critically, the interplay of different processes that were taking palace between participants, health care professionals, friends and family, technologies, media, and health advice. Whilst all constructs were helpful in unpacking each stage of participants' journeys through the NHSHC programme, one construct *making sense of it* (coherence) was particularly helpful as it demonstrated the power to explain why people either engaged with the programme in a positive way or actively resisted aspects of it.

Originally, NPT was developed to explore the ways in which innovative practices were routinised in organisations. However, I have demonstrated in this study that NPT is a valuable tool for exploring engagement with practices outside of the context for which it was intended; in this instance, in relation to the engagement of people who were identified as at-risk of cardiovascular disease with the NHSHC programme.

8.2 How findings link to previous literature

The modelling exercise undertaken by the DH suggested that, if successfully implemented, the NHSHC programme could be cost effective (Department of Health, 2008a). The NHSHC programme is being delivered with the intention of meeting the following aims (which have been revised since its inception and implementation):

1. Saving 650 lives per year by preventing 1,600 heart attacks
2. Prevent development of diabetes in over 4,000 people per year
3. Aid the early detection of at least 20,000 cases of kidney disease and diabetes (Public Health England, 2013).

To achieve these aims it is imperative that the programme not only effectively identifies those people within the population who are at-risk of suffering an adverse cardiovascular event, but also encourages them to make (and sustain) positive lifestyle changes and adhere to prophylactic medications. Evidence suggests that the NHSHC is not achieving its targets, with only 25% of the eligible population having undergone an assessment (Cook et al., 2016). This is far below the DH's aspirational target of covering 20% of the target population each year until total coverage of the eligible population was achieved by 2013 (Department of Health, 2008a). This low coverage has been suggested (Cochrane et al, 2013) to indicate a lack of interest in the NHSHC programme in the population. However, evidence is emerging from national evaluation of uptake data that participation has increased year-on-year (Robson et al., 2016) it is unclear, however, if this means that the NHSHC is becoming normalised or if the programme is becoming more efficient at attracting people in.

The focus of the NHSHC programme on the so-called lifestyle factors tends to place responsibility for CVR at the door of the individual, taking attention away from the wider social determinants of health (Dahlgren and Whitehead, 2007). We know that in England, the burden of cardiovascular diseases is felt disproportionately in disadvantaged communities and therefore structural conditions of class and poverty play a role (Raphael, 2003). Cardiovascular disease mortality rates within the population as a whole have been falling by around 6% per year. However, this reduction is experienced differently between socio-economic groups, meaning that as overall mortality rates fall, health inequalities are increasing (Bajekal et al., 2012). One danger of universal programmes such as the NHSHC is that it may inadvertently increase health inequalities because of differential take up rates between demographic groups.

It is worth bearing in mind that members of the eligible population often believe that they are fit and well at the point of their initial invitation. They have been offered a CVR assessment to *predict* their future *chance* of suffering an adverse cardiovascular event. For those individuals who have attended a check and been advised that they are at high risk (>20% in the next ten years) they have been advised to make preventative changes to their lifestyle, and in most cases prescribed a lipid lowering medication for prophylactic purposes. Yet, to re-emphasise, this population is asymptomatic.

For those participants in the study, the NHSHC programme did not make clear predictive sense (Conrad, 2011, Rosenberg, 2007). Many noted the difference between being identified as having a 'condition' and being identified as at 'risk' of something happening in the future. Pre or proto diseases have been identified as an extension to diagnosis and treatment (Armstrong, 2011, Melzer and Zimmern, 2002, Rosenberg, 2002): however they are difficult concepts for people to understand and therefore take action to avoid.

The act of diagnosis has been noted to be an event that provides a catalyst to change (Goldstein-Jutel, 2011, Jutel and Nettleton, 2011), giving access to the sick role (Parsons, 1975, Parsons, 1951), and access to treatment and services (Smith, 2002b). Previous research into long term and chronic conditions suggests that patients move through stages to form an illness identity (Karp, 1994) or to build a new biographical narrative (Bury, 1984). However, there has been less discussion as to whether these concepts are relevant to those without a diagnosis of a physiological condition but only with a diagnosis of risk. (Gillespie, 2012) found that risk identification symbolically changed the concept of self and identity and (Hindhede (2014), Hindhede and Aagaard-Hansen (2014)) found that communication of risk served to incite anxiety and fear.

Evidence from early evaluation of engagement of at-risk individuals has found that the NHSHC programme has been effective in acting as a catalyst to make changes to dietary behaviour (Alford and Perry, 2010, Krska et al., 2014, Perry et al., 2014, McNaughton and Shucksmith, 2015). This is mirrored in findings from this thesis. Dietary changes were cited most often by participants as a method of reducing CVR to achieve weight-loss or to reduce cholesterol intake. Participants were happy to discuss diet within the context of the NHSHC assessment. However, the way in which the health professional broached the subject of weight and weight-loss had the potential to impact on participants' experience of the assessment. The use of terms such as 'obese' had the potential to negatively impact the individual.

Making small but sustainable changes to diet such as managing portion control or reducing fat and salt intake were preferable, as these were thought more achievable. Increased knowledge about risk factors for CVD has been shown to increase adherence to lifestyle interventions (Alm-Roijer et al., 2004). People in this study were reluctant to make radical changes to their diet and in many cases were cautious about cutting out certain food groups, citing how often official guidance on food consumption was subject to changes and even reverses. Many participants recounted how guidance about the consumption of eggs has changed over their life course from being a healthy food, to them being cited as a source of high cholesterol, then being declared a healthy option again.

The information provided to at-risk individuals about healthy lifestyles was deemed to be too generic and not focussed specifically on CVR reduction. This lack of specific CVR reduction advice left many feeling they were not being supported in reducing *risk*. Many conditions such as diabetes or irritable bowel syndrome have specific diets to which patients must adhere to reduce symptoms or disease progression. This was not the case for those with increased CVR. The development of branded materials with healthy lifestyle advice specifically for those involved in the NHSHC programme could provide much needed support and a point of reference for people once they have left the GP surgery and are expected to manage dietary changes (McNaughton et al., 2013, Krska et al., 2014)

The use of visual aids to explore and explain the physiological effects of high cholesterol on the body has been found to be effective (Shaw et al., 2015). Again, this was mirrored in findings from this study. Participants who recalled having these aids used in assessment consultations felt they understood the processes taking place within their body and felt motivated to reduce these effects by engaging in healthier lifestyles and taking lipid lowering medications.

The use of lipid lowering medications has been found to be effective in the primary prevention of CVD and associated complications (Taylor et al., 2011a). However, there is evidence that overall adherence to these medications has been found to be low, with only half of those prescribed medications taking them on a daily basis (Poluzzi et al., 2008). Patients who have received treatment with lipid lowering medications for the purposes of primary prevention, as opposed to secondary prevention, have been found to be more likely to discontinue treatment (Ellis et al., 2004, Jackevicius et al., 2002). The most often cited reason for discontinuation of medications is the development of side effects from taking the medications (Mann et al., 2007); this evidence is congruent with findings from this study.

The majority of participants were offered lipid lowering medications, for the purposes of prevention. Of those participants offered medications, four had refused outright to take them, as they did not believe they were suitable. Twenty-one participants had initially accepted the offer of medication and, of that number, 17 were still taking them at the point of interview, leaving four participants who had discontinued due to side effects. This is higher than the 50% expected adherence rate expressed by Poluzzi et al. (2008), however comment cannot be made about how regularly participants were taking their medications. Concerns about treatment options have been shown to negatively impact on medication adherence in previous studies with people who have long term conditions (Horne et al., 2013) Whilst the majority of participants who had started taking lipid lowering medications had continued to do so for at least one year post risk assessment, this sustained adherence could be attributed to a number of individuals being afforded the opportunity to change medications that were not suiting them. A number of participants had returned to their healthcare provider because they were experiencing side effects that they attributed to the commencement of treatment. Many people described a number of adverse effects of the treatment ranging in severity from mild and tolerable (such as gastric discomfort) to unbearable (such as severe muscular pains or heaviness of limbs). Side effects were cited as the reason for discontinuing with lipid lowering medications.

The way in which discussions about side effects were handled by the health professionals impacted greatly on people's decision to carry on with treatment or discontinue altogether. This finding is consistent with (Martin et al., 2005) who highlighted the importance of open communication to increase adherence with medications, Upon experiencing side effects that were attributed to the lipid lowering medication, a number contacted their GP practice to discuss the side effects. Many participants were offered the chance to swap from one brand of medication to another that might be easier for them to tolerate. In these cases, participants noted that they were able to tolerate a different brand better and that they were happy to continue taking them indefinitely. However, the opportunity to reconfigure medication regimens was not consistent across all GP practices. When some participants approached their GP practice to discuss the intolerable side effects that they were experiencing, they had been turned away and informed that the current medication was the only brand they could be offered. In each of these cases the individual had made the decision to discontinue treatment with lipid lowering medication. This inconsistency between practices in the way in which side effects were dealt with represents the impact that individual health practitioners can have on the outcomes of the programme. Had the individual had the opportunity to try another brand of medication, and tolerated it, they may have adhered to it over the longer term, therefore reducing their risk.

Testing for high cholesterol and trying to treat it through making dietary changes or by taking lipid lowering medications is a familiar concept in the UK, and it is regularly discussed in the media and national press. Cholesterol management was often discussed in interview and many participants emphasised that they had been advised to take a drug that they assumed was normally promoted for cholesterol reduction for a new purpose – prevention, rather than cure. Lipid lowering medications were, in the eyes of participants, now being offered regardless of cholesterol levels or whether an individual's cholesterol sat inside or outside of the current recommended thresholds. This apparent lack of regard for prescription according to measured cholesterol levels caused confusion and anxiety. New concepts such as high-density lipoprotein level (HDL/ 'good cholesterol') and low-density lipoprotein level (LDL/ 'bad cholesterol') were being introduced into discussion in consultations as a way of encouraging people to commence statins treatment. However, this only served to muddy people's understanding of concepts they had previously thought they had a grasp on.

9 Conclusions, implications, and limitations

The following chapter will draw together the salient points from the findings and discussion chapters to highlight the conclusions and then implications of the study for: theory; policy and practice; training, support, and education; and – finally – future research. Each will now be discussed in turn.

9.1 Conclusions of the study

Normalisation Process Theory has helped to surface important aspects of the NHSHC programme that influence participants’ engagement with the NHSHC and their subsequent journey throughout the process from: attending the assessment, being identified as at-risk, making sense of this ‘diagnosis’, and engaging in lifestyle changes and/or a pharmaceutically aided journey. Evidence from this study suggests that the at-risk individual should be viewed as a participant in a social system, and this wider social system is integral to engagement, both positively and negatively, with all aspects of the programme. The NHSHC programme places responsibility for CVR and lifestyle changes firmly at the door of the individual. Whilst it is the *individual* who is identified as at increased risk of CVR and it is the *individual* that ultimately makes changes to their lifestyle or adheres to prophylactic medications, their network of family, friends, and health professionals influence each stage of the journey. In this respect the individual is a single cog in a much wider system.

Findings have shown how the engagement of the health professional delivering the CVR assessment is pivotal to the individual and how they perceive their CVR and its potential impact on their life. The collective interpretation work that is undertaken between these parties has a huge influence on the individuals' subsequent journey through the NHSHC. Health professionals have the opportunity to positively or negatively influence the individuals' understanding of CVR. Those health professionals who are able to interpret and deliver CVR into something that is important to the individual have the capacity to help the individual to afford meaning and value to CVR and meaningfully engage in activities to reduce it. Those health professionals who are unable to meaningfully interpret CVR can likewise, negatively influence the individual's perception.

The role of family, friends, and anecdotal evidence about potential candidacy for CVD impacts individuals' engagement with the NHSHC programme, and this influence cannot be underestimated. Provision of 'scientific evidence' based upon the calculation of surrogate markers for CVR is not necessarily sufficient to convince many people that they should engage with lifestyle changes or take lipid lowering medications prophylactically. To be effective, messages about CVR must be contextualised into the individuals' specific circumstances. This may require involvement from at-risk individuals' families, friends, and may require sustained engagement from health professionals.

Social networks are called upon to make sense of, and engage with, the work of changing behaviours through modifying diet, increasing physical activity, monitoring alcohol consumption, and smoking cessation – all of which are social activities and have social determinants. Harnessing the influence of these social networks is essential if impacts on health are to be seen from the NHSHC programme.

Sustained interaction with health professionals was also shown to be important at stages of reconfiguration of treatment. For those individuals who had suffered adverse side effects from the prescribed medications, the relationship with the prescribing professional had the power to determine their continuation, or not, with medications. This demonstrates again the impacts of wider social networks on the individual's journey.

9.2 Implications arising from the study

The following section considers the implications that arise from the study. In particular it considers: implications for theory; implications for policy and practice; implications for training, support, and education; and implications for future research.

9.2.1 Implications for Theory

- Normalisation Process Theory proved useful at all stages of the research project. Other researchers or those interested in exploring people's engagement in health services and health intervention may also find NPT useful in guiding the construction and implementation of their project – especially relating to:
    a. In the planning phases NPT can act as a sensitisation tool to consider aspects of people's engagement with services/ interventions. i.e. the

   work undertaken to consider engaging with health interventions, organising resources, engaging with programme activities, and reflecting on the benefits or disadvantages of health services and interventions.

  b. When constructing interview schedules NPT provides a framework to inform the development of a comprehensive set of questions that consider aspects of engagement that may otherwise be overlooked.
  c. At the analysis stages of a project, NPT constructs can be used in a confirmatory manner. In this respect the constructs of NPT are helpful to abstract themes into higher order concepts.
  d. NPT is also helpful in providing a framework to discuss emergent themes and consider their implications.

- Normalisation Process Theory was developed to explore the ways in which innovative practices were routinised in *organisations*. However, this study shows that NPT is a useful tool to explore people's engagement with practices outside of an organisational setting. Normalisation Process Theory may be used to explore aspects of how individuals adopt (or reject) a diagnosis and subsequently engage with (or resist) lifestyle intervention and medication regimens.
- Normalisation Process Theory is presented as a universal tool that can be applied to any context. Whilst this is helpful to demonstrate its utility in a variety of contexts and settings, it means that the constructs and underlying working mechanisms need to be interpreted on a case-by-case basis to be relevant. The work required to contextualise the theory to a particular

problem or setting by interpreting what the constructs are asking of the ‘problem’ should not be underestimated, or avoided.

- In the context of this study, the construct of *making sense of it* (coherence) was the most useful construct to explore, as findings relating to this construct acted as an indicator as to whether participants would actively take part in the programme or actively resist aspects of it.
- A tension between the working mechanisms of *making sense of it* (coherence) – *individual interpretation (individual specification)* and *collective interpretation (collective specification)* was found, as the evidence underpinning each of these types of interpretation was often founded on contrary information. However, those delivering the programme may want to focus on the work of *collective interpretation* as it could influence engagement in programmes such as the NHSHC.
- Findings from the study suggest that the processes explored in the construct *making sense of it* (coherence) have the power to provide rationale for both engagement in programmes such as the NHSHC and also rationale for active resistance with it, or parts of it i.e. lifestyle changes or medication.
- Findings from this study suggest that the *coming to a conclusion* (internalisation) working mechanism is not a discrete process, like the other working mechanisms, rather it is a *product* of the other three working mechanisms of that construct. Therefore, those using NPT to explore how people make sense of a process or practice may want to focus on the processes involved in *understanding the uniqueness of it* (differentiation), *collectively interpreting it* (communal specification), and *individually interpreting it* (individual specification).

9.2.2 Implications for Policy and Practice

Findings from this study have implications for the structuring and delivery of the NHSHC.

- The way in which the NHSHC programme is expected to bring about change in a high-risk population could be developed and made explicit. Findings have highlighted that simply providing information about individual risk is not sufficient to spur adherence from individuals, over the longer term. Rather, there is significant work required to support patients to buy into the premise of the programme and the subsequent work they must engage in to reduce their CVR.
- The NHSHC offer was not viewed as distinct. The offer – in terms of what is provided in the assessment, treatment, and advice – was not considered novel. There is an opportunity for those tasked with programme delivery to promote the unique aspects and offerings of the NHSHC to those attending assessment.
- There is an opportunity to strengthen the relationship between healthcare provider and patient (*collectively interpreting it* (communal specification)) to encourage shared decision making and the implications of being identified as at high risk of CVR.
- When this research was conducted there were few defined referral pathways for those identified as at high risk, meaning that individuals were informed of their high-risk status but there was no defined intervention to support changes in lifestyle. Further programme development would benefit from having clear referral pathways to community and individual lifestyle interventions.

- The study highlighted a possible unintended outcome of the NHSHC programme – the perception, for some, that being identified as high risk of CVR was reassuring as no physiological *condition* had been identified. There is an opportunity for those delivering the programme to work with patients to build an understanding of the implications of being at-risk.
- The development of branded materials with healthy lifestyle advice specifically for those involved in the NHSHC programme could provide much needed support and a point of reference for people once they have left the GP surgery and are expected to manage dietary changes and increase physical activity levels.
- The annual review process demonstrates a missed opportunity to re-engage individuals with the NHSHC programme. Risk reassessment would offer an opportunity to monitor progress.
- Individuals who experienced debilitating side effects from the prophylactic medications they were prescribed often sought out opportunities to reconfigure their treatment options. However, in some cases alternative treatment was refused. In these cases, individuals discontinued their medications. Had the opportunity of treatment reconfiguration (to different types of statin that may cause less side effects) been offered – those patients may not have discontinued treatment altogether.

9.2.3 Implications for Training, Support, and Education

The delivery of the programme has been delegated in the GP setting to practice nurses and, in many cases, healthcare assistants, who do not have the depth of clinical knowledge to be able to sufficiently answer technical questions raised by individuals. Findings from this study highlight some areas for increased training, support, and education.

- Nurses are perceived as having difficulty explaining:
    a. complex concepts such as risk (absolute versus relative risk)
    b. how being at-risk of CVD interacts with pre-existing conditions

  Training specific to the communication of these complex concepts would be beneficial, perhaps accompanied by reference material that could be used in consultations.

- The use of demonstration aides worked well in cases where they were used. The extension of their use is recommended.
- Individuals do not make changes or decisions about their health in a vacuum. They include family and friends in their discussions, and utilise other forms of information to synthesise and come to a decision. Education of HPs should support this notion and facilitate the inclusion of the patient's wider social network in decisions and participation in all aspects of the NHSHC programme.
- Support and advice given to those identified as at high risk should be CVR specific. Dietary and physical activity advice was viewed as too generic.

9.2.4 Implications for Future research

The study has highlighted several areas for future research:

- Further research could explore the need to develop new theories about 'risk biographies' or 'risk narratives' to build upon and extend the work of Bury (1984) and Karp (1994).

- Further research with high risk individuals in other geographically locations to explore if these findings are consistent in other locales.
- Research with individuals who have not engaged with the programme to find out reasons why.
- Research with those identified as low and medium risk to explore their experiences of engagement with the NHSHC programme.
- Research with other, more diverse demographic groups to explore if these findings are consistent.

9.3 Strengths and limitations of the study

Findings from this thesis have been derived from a number of interviews with people who have been identified as at high risk of an adverse cardiovascular event in the next ten years. Much attention has been focussed on evaluating the impact of the NHSHC programme through monitoring the uptake of CVR assessment. However, a strength of this study is that it is one of a limited number that has explored the experiences of those people identified as at increased risk of CVD through the NHSHC programme. Studies such as this, which acknowledge the journey that those identified as at-risk undertake are essential to ensuring such offerings are appropriate and acceptable to the targeted population. Moreover, another strength of this study is that it is the first time (to my knowledge) that a theoretically driven approach (using NPT) to understanding the patient journey has been undertaken and the first time NPT has been used, prospectively, to understand the work patients do to interact with health provision.

Participants were sampled using a purposive approach – all needed to have undergone an NHSHC, been identified as at high risk of CVD, been given lifestyle advice and in most cases prescribed statins prophylactically, and attended at least one annual review. This sampling strategy enabled the inclusion of participants who shared common experiences to allow patterns and commonalities to be identified in the data (Gray, 2018). However, due to the sampling strategy and how it worked in practice (section 5.2.1) there were unintended limitations, (primarily homogeneity of the sample) which could impact on the transferability of these findings. This arose due to the type of people who agreed to be interviewed for the study. All participants in the study were White British – which reflects the particular catchment areas from which they were sampled. The majority of them were living in the least deprived quintiles of the Tees Valley (Table 21) and were over 55 years old, representing the older end of the possible spectrum of those offered an NHSHC (40-74 years old). Caution must therefore be taken when transferring these findings more widely to the population identified as at increased CVR through the NHSHC programme. Further research should aim to include additional investigation of patient adherence with the NHSHC programme by recruiting participants from more deprived communities, ethnically diverse participants, and younger participants.

Qualitative studies do not seek to achieve large representative samples from which results can be generalised to other populations. Rather, we seek insights developed through looking at issues in-depth (Kelly, 2010). The analysis presented in this thesis is based upon responses from 26 individuals. This represents a very small sample size in relation to the population from which it was drawn and again caution must be taken when transferring these findings to the wider population. Further research could explore, on a larger scale, the transferability of these findings to a wider population.

Individuals were asked to recall many aspects of the assessment they had received from invitation, delivery of risk score, what lifestyle advice, and medical intervention which had occurred some time prior to interview. The lapse of at least one year (patients were contacted after their first annual review) may have affected the accuracy of their recall around what was offered in terms of lifestyle advice/intervention. However, their current behaviour is obviously determined by their memory and understanding of that encounter.

Findings in this thesis were drawn from interviews with individuals who were already compliant, to some extent, with many aspects of the NHSHC programme. No data was collected from individuals who:

1. were invited for assessment but decided not to attend (refusers), or
2. attended assessment but did not attend an annual review (drop outs).

Further qualitative research is needed to understand the experiences and needs of these two groups and any new study along these lines should include representation from ethnically diverse populations.

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11 Appendices

11.1 Appendix 1: Publications

McNaughton, R. J., & Shucksmith, J. (2014). Reasons for (non)compliance with intervention following identification of ‘high-risk’ status in the NHS Health Check programme. *Journal of Public Health*, 37(2), 218-225. (http://jpubhealth.oxfordjournals.org/content/37/2/218.full.pdf+html)

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Reasons for (non)compliance with intervention following identification of ‘high-risk’ status in the NHS Health Check programme

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ABSTRACT

Background The Department of Health introduced a risk assessment, management and reduction programme, NHS Health Checks, which aimed to reduce premature morbidity and mortality from cardiovascular diseases for those aged 40–74. Those identified as at increased risk of CVD are offered prophylactic medication and lifestyle advice to reduce their risk. Health gains will only be achieved if patients are compliant with advice/intervention however. This study sought to understand factors that influenced adherence to medication and advice in ‘high-risk’ patients.

Methods Qualitative data were collected through 29 semi-structured interviews with a purposive sample of individuals who had been identified as at high-risk of CVD. Participants had been offered lifestyle advice, lipid lowering medications and attended at least one annual review.

Results Findings explore the challenges and experiences confronting ‘high-risk’ individuals when making decisions about engaging with intervention. Key findings explore: statin adherence, as well as adherence to advice about diet, physical activity, alcohol consumption and smoking cessation.

Conclusions Attention needs to be paid to the way prophylactic medications are prescribed and explained to high-risk patients. Consistent provision of tailored lifestyle advice and access to appropriate services could facilitate sustained changes to factors that increase CVD risk.

Keywords public health, screening, health services

Background

It is widely believed that the majority of deaths that are attributed to cardiovascular diseases (CVD) could be prevented through the early identification of risk factors (for example, underlying physiological conditions such as hypertension, dyslipidaemia, diabetes and chronic kidney disease) and through the facilitation of lifestyle changes.[1–3] It is said that identification of these risk factors and promotion of lifestyle changes to diet, physical activity, smoking and alcohol consumption could achieve a large reduction in mortality and morbidity associated with CVD[1,4] and reduce the economic burden experienced by the National Health Service (NHS).[5–7] However, the focus on so-called lifestyle factors tends to personalize the issues and frame them in terms solely of individual responsibility, deflecting attention from the social determinants of health. We know that in England, the burden of CVD is felt disproportionately in disadvantaged communities and therefore owes much to structural conditions of class and poverty.[8] Mortality attributed to CVD has been falling for the population as a whole by ~6% per year; however, this reduction has been experienced differently between socioeconomic groups, meaning that whilst overall rates fall, health inequalities are increasing.[9] A major challenge for NHS Health Check (NHSHC) is therefore to reduce death and illness from CVD overall without actually increasing inequalities.

In the UK, the Department of Health (DH) has responded to this situation by developing a national CVD risk

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assessment, management and reduction programme: the NHSHC[4,10] which was launched in 2009. The NHSHC aimed to offer CVD risk assessment to the entire population of 40–74 year olds in England and Wales within the first 5 years of the programme's implementation (by 2013).[4,10] However, this aspirational target has yet to be achieved. Individuals who do not have pre-existing CVD or diabetes are invited to attend an appointment with their primary care practitioner to undergo an assessment of their risk of suffering a cardiovascular event in the next 10 years. This assessment includes the collection of anthropometric measurements, noting of family medical history and cholesterol testing. A calculation is then performed to assess the individual's CVD risk, and the outcome expressed as a percentage chance of suffering an adverse event in the next 10 years. Those individuals identified as being at 20% risk or higher are classed as 'high risk' and are therefore eligible for lifestyle advice and intervention with prophylactic medication (commonly statins) to reduce and manage their CVD risk.[10]

Initially, the commissioning of the NHSHC at the local level was the responsibility of Primary Care Trusts (PCTs). However, with the 2013 restructuring of the NHS, this responsibility was passed to Local Government[11,12] with support from Public Health England.[13] PCTs were originally given scope to develop the NHSHC programme in a way that suited the needs of their local population, whilst being mindful of the need to provide equity of access and avoid increasing health inequalities.[10]

In the study area NHSHCs were offered primarily through general practitioner (GP) surgeries, but also through community pharmacies[14] (subsequently decommissioned) and in workplaces and other community settings, in an attempt to provide equity of access for the local population.

Under the current (national and local) guidance,[4] once an individual has received an NHSHC and has been identified as at high risk of CVD ($>20\%$) they are offered lifestyle advice, and in many cases will also be offered a lipid lowering medication (statin) for the purposes of prevention. In order to be successful the NHSHC must not only identify those at risk and offer intervention, it must also engage—and then sustain engagement—of the individual to comply with the intervention. Individuals must not only accept their invitation for assessment but also understand why they have been identified as at risk, understand advice given to them and adhere to any interventions offered over the long term. Without this adherence to the programme, the putative gains to the NHS from preventive[15] action are unlikely to be realized.

This study reports on findings from a qualitative study that sought to understand patients' experiences of, and compliance with, forms of intervention offered as part of the NHSHC.

Methods

Data described in this study were collected through 29 semi-structured interviews with patients who had received an NHSHC between 2009 and 2012. Participants were recruited through five GP practices located across four PCT areas in the North East of England, after they had attended an annual review. Those patients who agreed in principle to take part were provided with written information about the project to facilitate informed consent.

All participants had received an NHSHC, had been identified as at high risk ($>20\%$ of having an adverse cardiovascular event in the next 10 years), had received lifestyle advice and/or been prescribed a statin and had attended at least one annual review. These participants were chosen due to their experience of the NHSHC programme and because they had already had the opportunity to initiate and sustain lifestyle changes/medication regimens over a period of at least 1 year. Interviews were normally conducted in the participant's own home on a one-to-one basis, with the exception of three interviews where the participant's spouse was also present.

Interviews were conducted using a semi-structured interview schedule to facilitate frank and open discussions about the NHSHC and engagement with lifestyle advice and medical intervention. The interview schedule was developed using Normalisation Process Theory[16–19] as a framework to sensitize the researchers to the process of implementing, embedding and integrating new practices into everyday life.

Interviews were, with the permission of the participants, recorded and transcribed verbatim. Data were anonymized and subjected to a six-stage thematic analysis.[20] Initially, the researchers undertook a familiarization stage of analysis which led to the identification of initial codes. These codes were then applied to the whole dataset to enable the collation of codes into preliminary themes. These themes were reviewed by both researchers to produce a revised set of themes that were named and finalized. In the final stage quotations were selected which illustrated the thematic framework that had been generated. NVivo 9 was used to facilitate data management during the analysis stage.

The project proposal was scrutinized and approved by Teesside University School of Health and Social Care Research Ethics and Governance Committee.

Results

Responses presented in this study are from 19 males and 10 females who were aged between 53 and 76 years old at the time of interview (see Table 1). During interviews participants were asked to recall if they had been offered lifestyle advice

Table 1 Demographic characteristics of sample (sex, age, IMD quintile)

Sex	Male	Female				
No. participants	19	10				
Age in years	51–55	56–60	61–65	66–70	71–74	75+
No. participants	1	4	7	9	7	1
IMD (2010) quintile	Quintile 1 (least deprived)	Quintile 2	Quintile 3	Quintile 4	Quintile 5 (most deprived)	
No. participants	13	7	5	3	1	

Table 2 Breakdown of sample by medication status and adherence to lifestyle change

n = 29	*Not discussed at health check*	*Discussed: no changes made*	*Discontinued treatment*	*Successful change*
Statin medication	2	4 (statin refused at HC)	5	18
Dietary change	4	9	—	16
Increased physical activity	19	8	—	2
Reduced alcohol consumption	24	4	—	1
Smoking cessation	10 (non-smokers) 15 (ex-smokers)	3	—	1 (quit)

and access to services and if they had made changes to their lifestyle based on the advice received. Participants were also asked to recall if they had been offered a statin as a result of their risk assessment and, if they had, then initiated and continued treatment. An overview of the number of responses about each topic can be found in Table 2.

Statin adherence

All participants were asymptomatic before attending their Health Check; they had been invited for assessment, not sought it out. The majority ($n = 27$) were offered a statin for the purposes of prevention; only two participants had not been offered a statin as a result of their assessment.

Of the 27 participants who had been offered a statin, four had refused outright. However, 23 had initiated statin treatment. During the course of the first year, 5 of the 23 had discontinued taking the statin permanently.

Whilst 18 participants had continued to take a statin for at least 1 year, post-risk assessment, this sustained compliance was due, in part, to a number of individuals being afforded the opportunity to reconfigure their medications. Side effects that were attributed to statin treatment were the main reason for wanting to discontinue the initially prescribed treatment. Many participants recounted the side effects they had experienced, which ranged in severity from mild, tolerable side effects (e.g. gastric discomfort) to symptoms that were really quite debilitating in some cases (e.g. severe muscular pains and heaviness of limbs). Upon experiencing side effects which participants attributed to the commencement of statin treatment, a number of them approached their GP or practice nurse to discuss the side effects. The majority of these participants were offered the opportunity to swap from the brand of statin they were currently taking to a new brand, in the hope that they would tolerate the medication better. In all of these cases participants noted that the side effects had disappeared and that they were happy to continue taking the new brand of medication as long as they were able to tolerate it. The opportunity to reconfigure medications was not the same in all GP practices. When some participants had returned to their practice to discuss the side effects they were experiencing, they had been turned away and told that their current brand was the only one that could be offered—in these cases all of the participants discontinued using statin. It was also reported that participants had discontinued statin treatment without returning to their practice due to the side effects they had suffered.

Testing for high cholesterol and trying to treat it through making dietary changes or by taking statin medication is a familiar concept in the UK, and it is often discussed in the national press and media. The topic of cholesterol management was often discussed in interview and many participants highlighted that they had been advised to take a drug that they understood was being promoted for cholesterol reduction for a new purpose—prevention, rather than cure. Statins were, in the eyes of participants, now being offered regardless of cholesterol levels or whether an individual's cholesterol was inside or outside the current recommended thresholds. This apparent lack of regard for prescription according to measured cholesterol levels caused confusion and anxiety. New concepts such as high-density lipoprotein level (HDL/'good cholesterol') and low-density lipoprotein level (LDL/'bad cholesterol') were being introduced into discussion in consultations as a way of encouraging people to commence statin treatment. However, this only served to muddy people's understanding of concepts they had previously thought they had a grasp on (Box 1).

Box 1 Statin adherence

They're fine. I mean I take it before I go to bed at night but, [laughs] it's when you get to bed. . .it bubbles in here [pats tummy]. . . I get wind, terrible wind, just bubbling away in here. Seemingly that's a side effect of them (P11, Female, taking statin).

Well they [legs] stiffened up. It felt as though you'd been stood in a bucket of concrete! And, I got diarrhoea and felt sick and had a fuzzy head with them. They said [GP staff] 'well you usually get this over the first three months'. It didn't ease off and I thought [to myself] 'well, I felt perfectly well before I went on these; I'd like to come off them' (P13, Male, taking statin).

I went in [to the GP practice] and got them [statin] and she gave me a supply. I started taking them and all [of the] muscles in my back started jumping around like that [gestures with hands]. [I thought] 'I can't go on like this' and so I rang up [GP practice] and said 'I'm not taking them' (P19, Male, discontinued statin).

Interviewer: So if you had some sort of 'event' like a heart attack or a stroke, you would be happy to take them [statin]? Respondent: Yes, because then it could be lifesaving! But I'm not too sure about [taking them] just for prevention? I mean there's no way that I would go and have a double breast operation, removal, just because I am at high risk of breast cancer—I just wouldn't do it (P5, Female, refused statin).

I was aware of my cholesterol, and have been for over 15 years. . .[it is always] about 3.5. That's about what my cholesterol is, you know, always has been. She [the nurse] said 'yeah, but your bad cholesterol is higher than your good cholesterol'. I thought 'what's she on?' 'Where's she coming from?' 'Bad' cholesterol, 'good' cholesterol. . .never heard of it! (P15, Male, taking statin).

Advice about diet

Recollection of dietary advice in the NHSHC consultation was high. Twenty-five participants recalled being offered advice about their diet; 16 participants stated that they had made some changes to their eating habits based on that advice; 9 participants stated that they had made no changes to their eating habits; 4 participants could not recall being offered any advice.

Participants were happy to discuss diet as part of their NHSHC, but how these discussions were broached had an impact on the participant's experience, especially when these discussions were framed in the context of losing weight. Identification of individuals as obese had the potential to leave them with negative feelings about the whole assessment.

For many participants, making small and sustainable changes to their diet by consuming less salt and fat was achievable, as long as it did not cause too much disruption to their daily routines. A number of older participants felt that making changes to their lifestyle was unnecessary at their age, and the provision of healthy eating information was not always accepted and was branded too generic. There was a call for dietary advice that was CVD risk reduction focussed, as opposed to the normal information that could be picked up from any doctor's waiting room.

Like the discussions about thresholds for cholesterol and how they seemed to alter frequently, people showed reluctance to make changes to their lifestyle, noting that any guidance they were given was likely to be subject to change. Many cited the consumption of eggs as an example, stating that previous guidance about healthy eating suggested that the consumption of eggs should be restricted; then the reverse was promoted—eggs were recommended as part of a healthy balanced diet (Box 2).

Box 2 Advice about diet

I must admit, when she [the nurse] said to me that I was 'obese' I was devastated. . .it really shocked me, didn't it? [husband nods]. I couldn't get over it. I was really like 'I can't believe I'm obese' (P3, Female, discontinued statin).

You know, I'm 72 this year and you think to yourself 'oh crumbs, I'm done!' I am eating everything right. We both [he and his wife] have a drink, we like a drink, but if my main doctor says 'just go and live your life, that's what I do (P19, Male, discontinued statin).

She [the nurse] gave me some paraphernalia [about healthy eating] but it was a waste of money giving me that, because I just didn't bother with it. . .I'm quite happy [the way I am] (P17, Male, taking statin).

They say eat margarine, then butter is better for you, [then] don't eat margarine. That's what I'm saying, I don't take any notice of all of these 'you must eat this' because two years later they are saying they are good for you. . .at one time eggs was bad for you, do you remember? Then they decided, no, eggs are good for you (P27, Male, discontinued statin).

Advice about physical activity

When asked to recall advice that had been offered with regard to physical activity levels, 10 participants recalled receiving advice and 2 went on to take action and increase their personal physical activity levels. Eight participants did not make any changes to physical activity levels based on the advice they were given; 19 participants could not recall being offered any advice about physical activity levels. No one recalled being offered a referral to physical activity programmes either 'in house' at the GP practice or in a community setting.

Many interviewees were already fairly active before they attended their NHSHC. Many enjoyed swimming, walking and group activities such as bowls on a regular basis. However, many found that due to their advancing age, they were restricted in what activities they could now undertake. These people preferred to incorporate physical activity into their daily lives, through activities such as gardening, which in itself was often challenging, especially when they had co-morbidities such as arthritis, and they were of the view that any physical activity intervention suggested to them would have to take these impairments into account if it were to be acceptable (Box 3).

Box 3 Advice about physical activity

On average, I walk four miles a day. I go on the hills [and] climb (P27, Male, discontinued statin).

I mean I bowl twice a week; green bowling, lawn bowling, and in the wintertime it's once a week because we do carpet bowls and I walk up and down the village every day (P11, Female, taking statin).

I don't feel old, but then my body is telling me that I am. I tried running, because I used to be cross country at school. But now I can't run 5 yards, and it's my body telling me that I'm old. I only feel 19 but then when I try to do something, I know I'm not (P8, Male, taking statin).

I can garden and that, but I have got arthritis and so I battle a bit. I have got a thing that I kneel on to get up and down (P28, Female, taking statin).

Advice about alcohol consumption

Discussions about alcohol consumption were recalled less frequently. When asked to recall if they had been offered advice about alcohol consumption, five participants could recall being offered advice. One participant made changes to his/her alcohol consumption based on that advice, whilst 24 participants could not recall being offered any advice about alcohol consumption.

For the majority of participants, alcohol consumption was not discussed but they felt that their alcohol consumption was within guideline amounts, and for those who had discussed their consumption with the nurse at the HHC, this had been reiterated during discussions. There was only a small minority who had decided to reject advice from the nurse (Box 4).

Box 4 Advice about alcohol consumption

She said I was quite in the limit of what I drank. You know, because we have wine on a Sunday and a couple of brandies sometimes. Not two on a night, but one on a night, a couple of times a week (P11, Female, taking statin).

[the nurse said] 'I think you should have two nights off. 'Oooooh' I said 'which nights would they be [nurse's name]? [The nurse said] 'Monday and Sunday?' [I said] 'No, after line dancing it's my cricket club night!' (P9, Female, refused statin).

Advice about smoking cessation

The majority of participants were either non-smokers ($n = 10$) or ex-smokers ($n = 15$) so had not been offered smoking cessation advice. Four participants were smokers at the time of their risk assessment and were offered smoking cessation. One of these smokers went on to quit smoking as a result of the smoking cessation offered during the risk assessment. Amongst those who had discussed smoking cessation and declined the invitation, there was a feeling that it was being offered to them too late in their lives to make any difference to their health (Box 5).

Box 5 Advice about smoking cessation

. . .it's too late, yeah? It's far too late. I mean 67, say I live another 20 year, [that would make me] 87, which would be brilliant but it would take 20 year minimum for my lungs to clear, minimum (P15, Male, taking statin).

Discussion

Main findings of this study

All participants had engaged with the NHSHC programme insofar as they had attended their assessment, been offered advice and gone on to attend at least one annual review—making them already somewhat compliant with the programme. Nevertheless, the advice they were offered at the time of assessment and subsequent initiation and adherence to lifestyle changes and lipid lowering medications was highly variable within the sample.

Discussions about lifestyle changes were broached variably, with discussion about diet happening most frequently. Discussion about physical activity and alcohol consumption happened much less frequently and indicates an area for improvement within the programme. People were more receptive to making small but manageable changes to their lifestyle and they were open to the provision of information about how to reduce CVD risk through dietary changes. However, they were confused (and somewhat undermined) by the fact that guidance could be subject to change. When it came to the promotion of increased physical activity, people highlighted that there would need to be consideration of those who experienced co-morbidities often associated with ageing.

Side effects from statin were the main reason for discontinuation of drug treatment. How discussions about side effects were handled by health professionals had a great bearing on a participant's decision to try a different brand or to discontinue treatment on a permanent basis. Participants did not distinguish between the effect of statin to lower cholesterol or its promoted overall preventative effects.

The promised benefits from this universal intervention are theoretical rather than proven at this stage in the production of empirical evidence. Predicted gains from modelling assume high levels of compliance after testing and identification of 'high-risk' patients. This qualitative study indicates first a level of variability amongst health-care professionals in raising for discussion, post-test, different aspects of the available drug and lifestyle treatments. Secondly, it indicates that patients experiencing side effects from statins are more likely to remain adherent if GPs are willing to listen to their concerns and review medication. Thirdly, the study emphasizes that for patients deemed to be at high risk the Health Check is not so much an event as the start of a process of adaptation to a new lifestyle which requires far more personalized and tailored advice on diet and activity suitable for people in later age and possibly with existing co-morbidities.

What is already known on this topic?

The DH's modelling exercise estimated that, if successfully implemented, the NHSHC could be cost-effective.[15] However, early real-world findings suggest that uptake is lower than expected[21,22] and that national coverage stands at 8%, well below the DH's expected coverage of 18% by 2012.[23] In 2012 NHSHCs came under criticism as the intervention had been rolled out based upon theoretical modelling and not on evidence from randomized controlled trials,[24] leading to calls for the abandonment of the NHSHC programme until the evidence base for effectiveness is stronger.[25] Rebuttals have been played out in the *BMJ*, defending the universal programme,[26] but with some authors advocating the development of a targeted programme,[27,28] rather than the current universal approach.

Socioeconomic status, ethnicity and gender have all been positively associated with increased risk of CVD and it is known that many interventions can actually increase health inequalities.[9,29] It has been suggested that, rather than taking a universal approach to identifying and treating risk factors (which may increase inequalities even more as a consequence of differential uptake), a population approach (focusing on deprivation and population wide policies, e.g. tobacco control or making healthy food choices affordable) to promote cardiovascular health would be both more effective and more cost-effective.[30–34]

Although statins have been found to be effective in the primary prevention of CVD,[35] previous studies have found that overall adherence to treatment is low, with only half of those prescribed statin taking them on a daily basis.[36] Patients receiving treatment with statin for primary prevention, as opposed to secondary prevention, are more likely to discontinue treatment.[37,38] Side effects are often cited as the reason for discontinuation of statin treatment,[39] as was found in our study.

What this study adds

Much of the published work on NHSHCs so far has focussed on implementation, uptake and coverage of the UK programme. The focus in these studies has been on initial assessments and conversion of invitations into assessments for example. Less attention has been paid to the longer term adherence amongst those individuals who have been identified as at high risk of CVD. It is important, especially in a time of depleted budgets, to ensure that any intervention is offered to the right people, at the right time and most importantly that those people are accepting of and compliant with the intervention. If this does not happen, the NHSHC programme cannot realize its full potential.

This study suggests that attention needs to be paid to a more sophisticated prescription of prophylactic medications to reduce CVD risk and also to better explanation of their virtues and value to patients. The study also suggests the need for provision of more tailored lifestyle advice and access to appropriate services to facilitate sustained changes to factors that could increase CVD risk.

Limitations of this study

Findings in this study are derived from a relatively small number of interviews with individuals identified as at high risk. All were White British (reflecting the demographic balance in the catchment studied however) and the majority were residents in the least deprived quintiles of Tees (Table 2). With qualitative studies generalizability achieved through having a large, representative sample, is not the aim. Rather, we seek insights developed through looking at issues in great depth, but further studies of compliance in patients from more deprived quintiles or from populations with different ethnicity are clearly called for.

Participants were asked to recall what lifestyle advice and medical intervention had been offered to them some time ago. The lapse of at least 1 year (patients were contacted after their first annual review) may have affected the accuracy of their recall around what was offered in terms of lifestyle advice/intervention, but their current behaviour is clearly determined by their memory and understanding of that encounter.

Findings were drawn from interviews with people who were already compliant with some aspects of the NHSHC programme. We have no data from people who:

(1) failed to attend their risk assessment (refusers) or
(2) attended their risk assessment but did not attend an annual review (dropouts).

Further qualitative research is needed to understand the needs and experiences of these two groups and should include representation from ethnically diverse populations.

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Authors' contributions

R.M. contributed to developing the bid for funding, the design of the study, recruited participants, carried out fieldwork, analysed the data and wrote the article. J.S. secured funding for the project, designed the study, analysed data, and commented on and revised drafts of the article.

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RESEARCH ARTICLE **Open Access**

Making a success of providing NHS Health Checks in community pharmacies across the Tees Valley: a qualitative study

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Abstract

Background: In England and Wales, the Department of Health introduced a primary prevention programme, NHS Health Checks, to provide screening for cardiovascular risk amongst people aged 40-74. The aim of this programme is to offer treatment and advice to those identified with an increased risk of cardiovascular diseases (CVD).
The North East of England has some of the highest rates of CVD in the UK and prevention is therefore a priority. NHS Tees funded this programme of work under the local branding of Healthy Heart Checks (HHC). These were initially implemented principally through GP practices from October 2008 but, in order to mitigate the possibility that some hard to reach communities would be reluctant to engage with some primary care settings, plans were also developed to deliver the programme through workplace settings and through community pharmacies. This paper reports specifically on the findings from the evaluation in respect of the setting up of HHCs in community pharmacies and aims to offer some lessons for other service settings where this option is seen as a way of providing low threshold services which will minimise inequalities in intervention uptake.

Methods: In assessing the community pharmacy component of HHCs, a selection of staff having direct involvement in the process was invited to take part in the evaluation. Interviews were carried out with representatives from community pharmacy, staff members from the commissioning Primary Care Trusts and with Local Pharmaceutical Committee members.

Results: Evaluation and analysis identified challenges which should be anticipated and addressed in initiating HHC in community pharmacies. These have been categorised into four main themes for discussion in this paper: (1) establishing and maintaining pharmacy Healthy Heart Checks, (2) overcoming IT barriers, (3) developing confident, competent staff and (4) ensuring volume and through flow in pharmacy.

Conclusions: Delivering NHS health checks through community pharmacies can be a complex process, requiring meticulous planning, and may incur higher than expected costs. Findings from our evaluation provide insight into possible barriers to setting up services in pharmacies which may help other commissioning bodies when considering community pharmacy as a location for primary prevention interventions in future.

Background

The most common cause of death and premature disability worldwide is cardiovascular disease (CVD) [1,2], and in the UK diseases of this type cause high level of chronic illness which affect the quality of life of many and result in costly demands in terms of providing health services at every level. The impact of the disease is disproportionately felt amongst more disadvantaged populations, not least because modifiable risk factors such as diet, smoking and physical activity significantly contribute to the prevalence of CVD [3].

Reducing this illness burden has therefore become a major goal of the UK government, and in England and Wales, the Department of Health has introduced a national programme to screen individuals aged 40-74 for early warning signs of cardiovascular risk. This programme was branded as NHS Health Checks (NHS HC).

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The aim of the programme is to reduce premature morbidity and mortality associated with CVD [3]. In the Tees Valley Healthy Heart Checks (HHC) were established ahead of the national guidance, in response to recommendations made locally by the Health Inequalities National Support Team.

There is ample evidence, however, that such well meant, population-level interventions may actually contribute to widening health inequalities [4]. This intervention, for instance, is primarily offered through GP practices, but studies have shown that some groups of the public rarely visit their GP [5] and it was therefore a prime aim of the HHC programme to avoid making the inequalities worse by excluding groups which may be more vulnerable and at risk anyway. From the start of planning the programme in Tees (April 2008), easy access to checks in workplaces and community pharmacy settings was seen as a valuable addition to assessments offered in general practitioner surgeries.

This paper reports on the phase of initiation of the programme through community pharmacies as part of the strategic approach to deliver HHCs in a variety of community settings.

Delivery of vascular risk assessments in community pharmacy has been widely encouraged as a means of reaching out to people who may be more reluctant to access screening services at other venues [6,7]. In recent years the face of community pharmacy has shifted from one characterised predominantly by small single-handed pharmacies that dealt mainly with issuing prescribed medications, to one which has seen the rise of the multiple chain pharmacy which can offer many additional services [8,9]. It has therefore been argued that pharmacy is now ideally placed to offer public health interventions, screening services and to deliver basic lifestyle advice in the hope of widening access to health services [8,10-12]. In a large scale survey of the general public, Krska and Morecroft [13] report that the general public tend to access pharmacy for specific reasons, primarily to have prescriptions dispensed and to purchase medicines and non medical items. They use the service less frequently to seek out health advice A market research survey carried out by Readers Digest [14] indicate that people in relatively more deprived social classes, however, use community pharmacies more frequently than their affluent counterparts for health information and advice. In part this may be attributed to longer opening hours and access without appointment, but possibly also because pharmacies are regarded as less dauntingly professional in their response to clients [6].

Despite the government's endorsement for this approach, a recent review of the changing role of community pharmacy in the NHS noted the limited evidence for effectiveness and value for money of services such as screening in pharmacies [9]. Patel [15] also cautioned about the use of non NHS providers to deliver CVD assessments, and called for the development of robust data systems that could handle the transfer of data between the non NHS provider and primary care providers without duplicating results.

In a small scale, real world trial delivering targeted vascular assessments through community pharmacies in Birmingham, Horgan et al showed that they had achieved particular success in engaging individuals from minority ethnic groups, [10] suggesting that pharmacy may indeed be useful in reducing some health inequalities. Horgan et al went on to report that men - a segment of the population renowned for not attending services in GP practices [16] - had engaged with the programme delivered through community pharmacy [6]. This suggests that in the real world pharmacy may offer a better chance of engaging certain segments of the population. However, there is conflicting evidence which suggests that the general public do not always view pharmacy as a place to receive lifestyle advice or screening, owing to concerns about lack of capacity amongst pharmacy staff and confidentiality [13]. It is thus far from clear whether community pharmacy offers the panacea 'low threshold' service that commissioners had hoped for, in the sense of providing easy access services at times to suit the patient, without an appointment and provided by staff who are intrinsically more accessible and approachable.

The evaluation of the initiation of community pharmacy based screening in the Tees Valley allows us to share insights which may help other commissioning bodies both to assess realistically what is involved in setting up such assessments, and to model appropriately the likely cost per assessment. The complexity of population primary prevention and the emphasis on this as a future means of achieving health gain without increasing inequality suggests that our findings may provide lessons beyond the system we studied.

Methods

The study described in this paper was part of an overall evaluation which used a Theory of Change [17] framework, entailing a process of continual feedback between the researchers and the organisations being evaluated to provide a clear model of the logic of the programme, to shape the direction of programme change and provide evidence for suggested modifications. In this respect the commissioning organisation was provided with constant updates about findings from the evaluation. Staff in the delivery and implementation arms of the intervention kept the research team abreast of all changes made to the initial programme protocol.

Participants

Ten Primary Care Trust (PCT) members of staff who had direct professional involvement in setting up HHCs in community pharmacy were invited to take part in interviews. Staff included the Director of Public Health, project manager, clinical lead, public health nurses, pharmacy advisor (medicines management), community services manager, a professional executive committee member and the IT database developer.

All nine pharmacies that were hoping to take part in the pilot phase of the HHC programme were contacted and invited to take part in the evaluation. Eight pharmacists agreed to be interviewed. Pharmacy customers were not included within this evaluation.

Two representatives from the Local Pharmaceutical Committee (LPC) also took part in the evaluation.

Data collection

Each participant was contacted by letter and provided with written information about the aims of the project and what would be required of them should they agree to participate.

One-to-one interviews were undertaken with each participant. These interviews followed a semi structured format and centred around the setting up of the HHC programme within pharmacies. PCT members of staff and pharmacists were interviewed about the selection and recruitment of pharmacies into the HHC programme; clinical governance and health and safety issues; development of the Service Level Agreement (SLA); pharmacy accommodation; training provision and IT development, data collection and transfer. LPC members were asked about the role of the LPC in developing the SLA. Anonymity and confidentiality were assured and each participant was encouraged to be frank and open about their experiences of setting up the HHCs in community pharmacy. Each interview lasted between 20 and 60 minutes and was, with the consent of the participant, digitally recorded. Interviews were subsequently transcribed verbatim. All names, places of work and other identifying features were removed from the text of the transcriptions to avoid participants being identified. Pharmacists were interviewed at two time points, once before and once after they went live delivering the HHC assessments.

Data analysis

Transcriptions of each interview were read and independently scrutinised by two members of the research team. Data were then analysed and coded using a thematic content analysis [18] framework. Each analyst read all transcripts several times to familiarise him/herself with the issues raised and developed a coding framework to establish themes. Initial codes were identified independently and all data supporting the codes were highlighted in the transcripts. These initial codes were then grouped together to form themes which were then corroborated between analysts. Once agreement had been achieved between analysts, these themes were written into a narrative form to provide an accurate illustration of the theme using quotations taken directly from the transcripts.

The School of Health and Social Care Ethics Committee at Teesside University scrutinised and approved this study protocol.

Results

Eight pharmacies signed up to the Service Level Agreement and took part in the pilot phase of HHC delivery across the Tees Valley. Of these eight pharmacies six were small pharmacist led businesses that were located out in community settings and two were large multiples one of which was situated in a supermarket chain the other in a purpose built 'health village'. Pharmacies were required to provide CVD risk assessment to individuals, calculate possible CVD risk over the next ten years and signpost to medical intervention or offer lifestyle advice as appropriate. In this section we provide an overview of findings from the evaluation, grouped together under the main emergent themes; establishing and managing pharmacy Healthy Heart Checks, overcoming IT barriers, developing confident, competent staff, ensuring volume and through flow in pharmacy.

Establishing and managing pharmacy Healthy Heart Checks

It was decided in the Tees Valley that HHCs would be delivered through a selection of community pharmacies as a method to engage hard to reach populations that would not necessarily access this type of service through a GP practice. Guidance from the Department of Health suggested that PCTs look outside of GP practices as sites to deliver the NHS HC programme and that they should consider community based venues. PCT staff felt, at the time, there was sufficient evidence from around the UK to support the inclusion of community pharmacy as a place to offer the HHC programme.

The Department of Health had said they wanted us to look at other providers [other than GP practices], and community pharmacies, they thought, would be a good venue. There had been projects around the country like the big one in Birmingham that was very successful, fantastic results, doing CVD assessments. (PCT staff member)

It was assumed that pharmacies had become trusted sources of information within the community, through delivering services such as smoking cessation. Pharmacies also have a wide customer group which tends to access their services on a regular basis, again making them potentially ideal locations to situate a service like the HHC programme and providing a low threshold, non threatening service that might be less likely to increase health inequalities:

From my experience of working in a deprived area, as a health visitor, people do access pharmacies like they *would access their GPs at times. They trust their pharmacy, and from being in [names pharmacy] that is very evident. It's 'Hi Tom. I need this, I need that. What can I do about this? Can I try that?' They [the pharmacists] know their population very well.* (PCT staff member)

Accordingly, a plan was made to involve community pharmacies as a major partner in cardiovascular risk assessment, and initial preparations were made for marketing to the public the availability of checks in pharmacies. It was largely taken for granted that the initiation of checks in willing pharmacies would be straightforward and quick. In the event, however, implementation proved to be very complex, and the initiation of assessments (even in a small pilot group of pharmacies) was delayed by over a year.

Pharmacists were eager at first to be involved in delivering extra services, as the HHCs were potentially both a method of generating extra revenue and bringing more people into their stores:

We do focus on the services, we do a lot of morning after pills. We have started doing the flu and cervical cancer vaccinations. So in this store we like doing the services, because it brings people into the store (Pharmacy 1 representative)

As the Tees service began to roll forward, information began to be fed back, through the national NHS HC network, from other areas in the country that had been delivering checks through pharmacies. Some commissioners had begun to withdraw services from pharmacies because low levels of uptake had made them non viable.

[In other PCT areas] it has not worked for them. For instance in [names area], they had 30 pharmacies set up and they have taken the equipment off half of them because there was no activity. (PCT staff member)

During the initial set up for delivering HHCs through the Tees pharmacies many changes took place within the PCT. Swine flu hit the UK and required rapid and immediate response. Staff who had been involved with the early stages of managing the HHC programme were not able to see it through to completion, which also impacted on the HHC programme.

The PCT aimed to recruit pharmacies against set inclusion criteria that related to making sure pharmacies played a major part in addressing issues of disadvantage. However, after recruitment of pharmacies began, it soon became apparent that not all pharmacy accommodation was of a sufficient standard to deliver the HHCs. Each pharmacy was required to have in place a private consultation room with secure access to the Internet and hand washing facilities, but there was huge variability between pharmacies in the appropriateness of the accommodation:

Some [spaces offered for checks], are brilliant, whereas some were like an old broom cupboard. I would have liked to have visited them myself beforehand (PCT staff member)

Much work went into developing a Service Level Agreement for the HHC, this took over a year to develop. Many obstacles became apparent during this time, which had not been anticipated. It became clear that payments needed to be handled differently to those for GP practices, as pharmacies pay VAT on all services they deliver. This took time to resolve and required much input from organisations outside of the PCT:

We had to go away and create prices that would actually work; a set up fee, an annual fee and then a small fee for actually doing the service (LPC member)

Additional resources had to be assigned to the pharmacy roll out of the programme when it became apparent that, unlike staff working in other settings such as GP practices, pharmacy staff did not have the relevant vaccinations to enable them to deal with blood and bodily fluids. To this end all staff delivering the HHCs had to receive Hepatitis B vaccinations, which had an additional impact on the budget as clarified by a PCT staff member:

We have actually paid a lot of the pharmacies to have Hepatitis B vaccinations which is a requirement for nurses and GPs who deal with bodily fluids. We have actually paid for that out of our CVD budget (PCT staff member)

Overcoming IT barriers

It became clear very quickly that pharmacies did not have a sufficiently secure Internet connection to allow them to transfer patient identifiable data to the NHS server which held the HHC database. To overcome this problem pharmacies were required to upgrade their Internet connection and were issued with a special 'RAS' token for extra security. This RAS token generated random number combinations which increased security when accessing the NHS server, it worked in a similar way to a card reader for Internet banking. The requirement for increased Internet security and the use of such tokens posed much more of a problem for some of the larger chain pharmacies than the smaller independent ones. Larger chains found that their company policies dictated that they could not have open access to the Internet, which was one of the requirements to enable connection to the PCT server. For this reason some of the larger chain pharmacies were unable to take part in this roll out of HHCs in pharmacy. For those pharmacies that were able to connect freely to the Internet and met all of the security requirements, they were able to trial the database they would be using, and felt that it was user friendly:

It is nice that the computer system leads you through step-by-step (Pharmacy 7 representative)

Once the system went live however, it was evident that there were some technical errors which affected the calculation of patients' risk scores. This was attended to promptly by the PCT: however it did affect pharmacists' confidence in the system.

Developing confident, competent staff

From the PCT's point of view the training needs of pharmacy staff were much greater than initially envisaged. It had originally been expected that pharmacists would deliver the service to customers themselves, but it soon became clear that this was impractical due to the fact that many pharmacists are sole traders and have a variety of other daily commitments. It was then agreed that pharmacy assistants could carry out the initial assessment which involved; taking anthropometric measurements from the patients, medical history, blood pressure and blood samples. This meant that the pharmacist would only be involved at the end of the consultation, delivering the final risk score and giving lifestyle advice to the patient. This increased the training load significantly in order to make sure that pharmacy assistants were competent to carry out the assessment:

The pharmacists are highly skilled and highly trained. The people they have working for them, who are normally dispensing assistants, haven't got the background in care knowledge or expertise. It wasn't like a GP surgery where you have Healthcare Assistants and Practice Nurses who on a day to day basis take blood pressures, take pulses, take blood and give advice on health (PCT staff member)

To address this issue a training package was developed and delivered by the PCTs and it was well received by pharmacy staff. Due to the nature of pharmacy businesses it soon became apparent that training would need to take place out of office hours. The PCT took a flexible approach to this, which was appreciated by pharmacy staff as their needs had been taken into consideration. There was however quite a time lag between pharmacy staff being trained and then beginning to deliver the service to members of the public, and this then necessitated further refresher training from the PCT. Once trained, pharmacy assistants felt that delivering the HHC service was a good opportunity for staff development and were pleased with the increased responsibility that went with it:

One of our counter staff...said 'I never thought I would be doing this!' She's quite excited and it's a huge jump from their present role (PCT staff member).

In pharmacies, the HHC programme 'went live' in January 2010. As part of the agreement between PCT and pharmacy, all pharmacy staff were required to be trained and signed off, by the PCT, as competent to deliver the assessments. At the end of the service evaluation (August 2010), not all staff had achieved this. This was due to two main reasons. Uptake of the screening opportunity by the public had been very low, meaning the pharmacy staff had not had the opportunity to deliver many assessments. Pharmacy staff had also required a lot more training than initially anticipated and, even after being given this support, lacked confidence in delivering the new service:

One girl has already been signed off. The other lady is just waiting to be signed off. She is still a bit nervous about getting bloods from people (Pharmacy 6 representative)

Ensuring volume and through flow in pharmacy

Across the seven pharmacies that began to deliver the HHC programme, uptake has been low. Between January and September 2010, 204 assessments had taken place in pharmacies across the Tees Valley. During the same period, 2082 assessments had been completed in workplaces and 16,050 in GP practices across Tees. The number of completed assessments varied greatly from pharmacy to pharmacy, ranging from 9 assessments in one pharmacy to 49 in another. All pharmacies felt disappointed with this level of uptake, despite the PCT advertising the service within each pharmacy and through adverts in the local press. Pharmacy staff also advertised the service to patients entering their stores to try and raise awareness and increase uptake of the service themselves but with very little effect. Pharmacists tried to give reasons why uptake had been low despite efforts to raise awareness of the service they were offering. Some felt that it may have been due to their geographic locations and low foot-fall in store:

I don't know if it's our location, that there isn't enough people coming through (Pharmacy 4 representative)

This view was also held by some PCT staff, who added that some of the pharmacists delivering HHCs were very close to GP practices that were also delivering the HHC, introducing competition between providers:

Some [pharmacies] are really struggling because they are out of town and in locations close to GP practices - which is where the pharmacies get a lot of their business from (PCT staff member)

This view was held by pharmacists too. They felt pharmacies and GP practices were in direct competition, trying to entice a finite number of patients into what was, essentially, the same service:

Actually there's another problem, capturing the people. Everyone is out to capture them...it's very hard if you see someone coming in and say, 'Oh! You could be a candidate', and they say, 'The surgery has approached me and I'm going there' (Pharmacy 5 representative)

Discussion

This study gave us important insights into initiating primary prevention services in community pharmacy and some of the obstacles which, in future, might be avoided. To aid rollout of similar interventions in community pharmacy we would recommend that commissioning bodies critically consider the experience in the Tees Valley. Unforeseen problems resulted in a much delayed service in community pharmacies. The optimistic assumption that it would be simple to carry out HHCs in pharmacies was soon proved wrong. Critical phases in development were too dependent on individuals and contingency plans were not made in the event of sickness or other absence. The priority applied to NHS Health Checks, and the additional work entailed, needed to be made explicit to all of those responsible for operationalising the policy across the PCT directorates.

Because of the complexities involved in setting up this service the true cost per assessment was not anticipated. In advance of implementation the uptake of HHCs in pharmacy could only be estimated, as no intervention of this kind had been delivered through this setting before. Whether the price for the contract should include indirect as well as direct costs and VAT needed to be resolved at an early stage. Ancillary costs, most importantly those for pharmacy staff training, consumables, nursing support and IT support, are an essential part of the calculation and in the case of the Tees PCTs were much higher than originally expected. Moreover, the low throughput of patients could make the set up costs of this type of service uneconomical in the long term.

Commissioners will rightly expect pharmacies delivering HHCs to meet NHS standards for criteria such as privacy of consulting space, availability of hand washing facilities, secure Internet connections for patient data transfer and appropriate application of health and safety procedures, e.g. for disposal of sharps and handling of blood. These criteria are not always met in pharmacies. To establish equity of access for assessments substantial additional investment may be required in pharmacies with poorer facilities to bring them up to expected standards. PCTs need to balance cost, coverage and equity in rolling out pharmacy based health checks.

The SLA that is negotiated with pharmacies must recognise the important differences between general practice and pharmacy provision. In particular, general practice teams, which rely routinely on health care assistants and practice nurses to carry out such procedures, have clinical experience which is not generally mirrored in pharmacies. In a pharmacy team the pharmacist is likely to be the only person with the skills to undertake clinical assessment and communicate the level of risk assessed from the HHC. It is unrealistic to expect the pharmacist him/herself personally to deliver the 30-40 minute health check, especially if an open access policy (i.e. no appointment needed) is being followed. Therefore extra training costs should be considered when considering pharmacy as a venue to deliver this kind of service.

Commissioners need to consider carefully issues such as the VAT payable by pharmacies (but not general practices), and whether costs for the full service (including equipment, disposables, waste disposal and staff immunisation) is included in the detailed service specification.

The question of whether targets for activity should be set is contentious: a minimum level of activity seems necessary to maintain competence and efficient use of disposables, but may be incompatible with the aspiration to make checks available in all pharmacies. The calculation of cost per case, and decisions about value for money, are strongly influenced by both the service specification and HHC activity in individual pharmacies

Many pharmacies do not have the full access to the NHS network which is required for the efficient and secure transfer of information between pharmacy, PCT and general practice, even if a common database and a system of common codes has been agreed. Confidentiality standards and the degree of access permitted to staff within a pharmacy team are important issues.

In establishing HHCs in Tees pharmacies achieving connectivity with the NHS, staff IT training and continuing support proved time consuming and costly. In some cases, the data security practised by national pharmacy chains impeded the loading of software onto pharmacy systems. Once the system was live there were some issues with calculations of risk score which impacted on pharmacists' trust in the system. Thorough piloting of IT systems is essential in these situations.

The extent of training required to bring members of pharmacy teams to the level where they could competently and confidently carry out the HHC process was greatly underestimated. This was made worse by the length of time between initial selection and the activation of the service. Time is required not only for initial training, which is itself a problem given the constraints on releasing both pharmacists and team members during a six-day working week, but there is a need for continuing support to assure clinical governance and quality. The training received by pharmacy teams evaluated very positively, and there was clear evidence that staff felt empowered by the opportunity to add to their role by delivering a clinical service.

Conclusions

It may be said that all the issues that were identified could have been anticipated. However, being an early adopter of change in a complex intervention entails risks which can be avoided by others as experience accumulates, and our purpose in providing this paper is to indicate areas which deserve early consideration by commissioning bodies. We are aware, from anecdotal evidence, that PCTs in other regions have had similar experiences. We believe that considering the lessons learned in this report will improve the efficiency, increase the timeliness and may well benefit patients if it enhances the effectiveness of the national rollout of NHS Health Checks.

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Authors' contributions
RM contributed to the design of the project, carried out the fieldwork, analysed the data and was main author of this paper. NO contributed to the design of the project, analysis of data, day to day project management and made significant contributions to the writing of this paper. JS had overall managerial responsibility for the evaluation project, and contributed to the design of the project and the writing of this paper PH and PW contributed to the design of the project and the writing of this paper. PH was responsible for the commissioning of the original intervention and the local evaluation of the scheme. All authors read and approved the final manuscript.

Competing interests
The authors declare that they have no competing interests. All authors declare that they had (1) no financial support for the submitted work from anyone other than their employer; (2) no financial relationships with commercial entities that might have an interest in the submitted work; (3) no spouses, partners, or children with relationships with commercial entities that might have an interest in the submitted work; (4) no non-financial interests that may be relevant to the submitted work; (5) no personal competing interests.

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11.2 Appendix 2: UK National Screening Committee criteria

Below are the UK National Screening Committee's standardised criteria to assess the viability, effectiveness, and appropriateness of screening programmes. They are organised into four domains; the condition, the test, the treatment, and the screening programme (reference).

The condition

1. The condition should be an important health problem

2. The epidemiology and natural history of the condition, including development from latent to declared disease, should be adequately understood and there should be a detectable risk factor, disease marker, latent period or early symptomatic stage.

3. All the cost-effective primary prevention interventions should have been implemented as far as practicable.

4. If the carriers of a mutation are identified as a result of screening the natural history of people with this status should be understood, including the psychological implications.

The Test

5. There should be a simple, safe, precise and validated screening test.

6. The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed.

7. The test should be acceptable to the population.

8. There should be an agreed policy on the further diagnostic investigation of individuals with a positive test result and on the choices available to those individuals.

9. If the test is for mutations the criteria used to select the subset of mutations to be covered by screening, if all possible mutations are not being tested, should be clearly set out.

The Treatment

10. There should be an effective treatment or intervention for patients identified through early detection, with evidence of early treatment leading to better outcomes than late treatment.

11. There should be agreed evidence based policies covering which individuals should be offered treatment and the appropriate treatment to be offered.

12. Clinical management of the condition and patient outcomes should be optimised in all health care providers prior to participation in a screening programme.

The Screening Programme

13. There should be evidence from high quality Randomised Controlled Trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an “informed choice” (e.g. Down’s syndrome, cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened.

14. There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/ intervention) is clinically, socially and ethically acceptable to health professionals and the public.

15. The benefit from the screening programme should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment).

16. The opportunity cost of the screening programme (including testing, diagnosis and treatment, administration, training and quality assurance) should be economically balanced in relation to expenditure on medical care as a whole (i.e. value for money). Assessment against this criteria should

have regard to evidence from cost benefit and/or cost effectiveness analyses and have regard to the effective use of available resource.

17. All other options for managing the condition should have been considered (e.g. improving treatment, providing other services), to ensure that no more cost effective intervention could be introduced or current interventions increased within the resources available.

18. There should be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards.

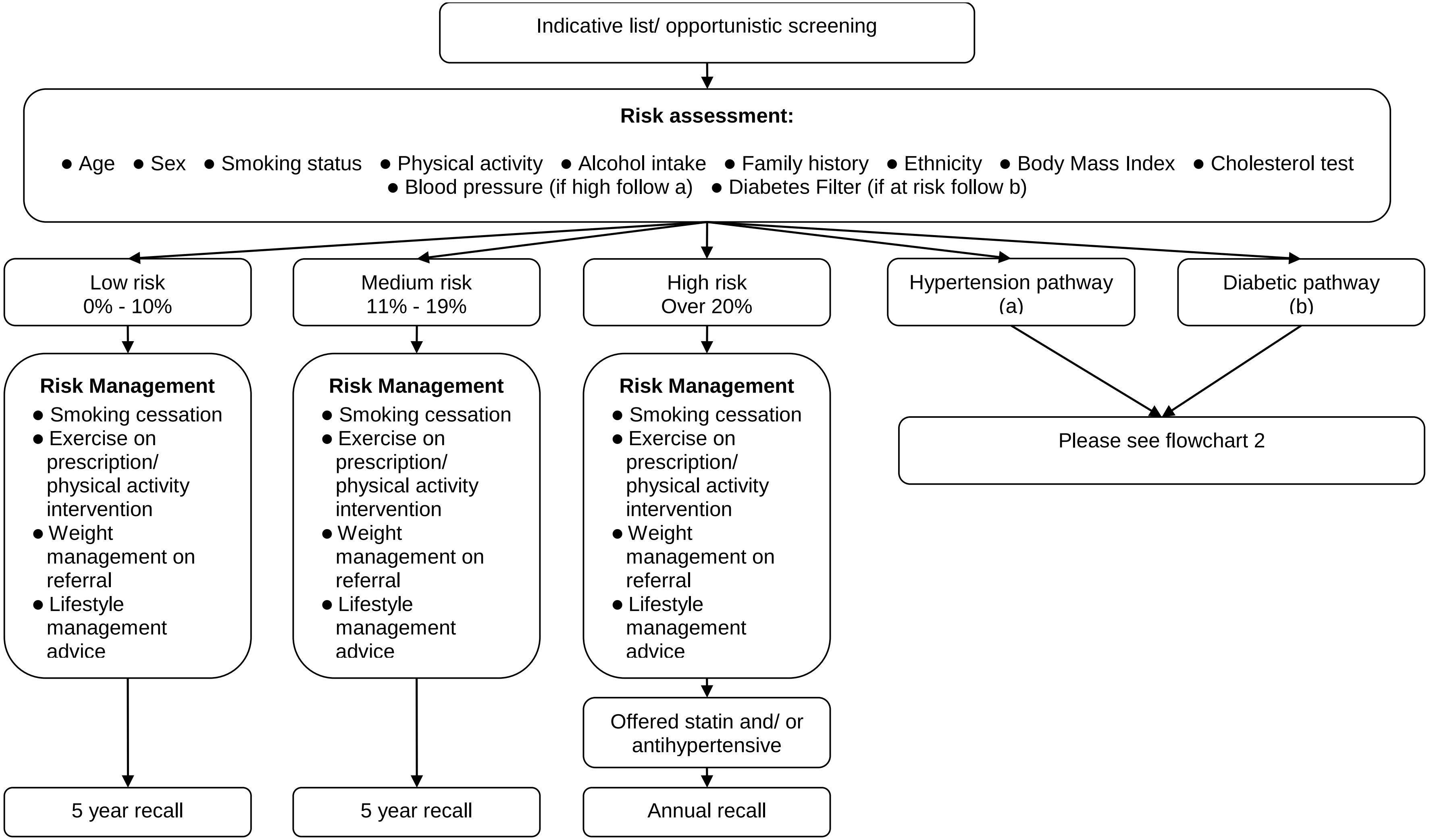
19. Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be available prior to the commencement of the screening programme.

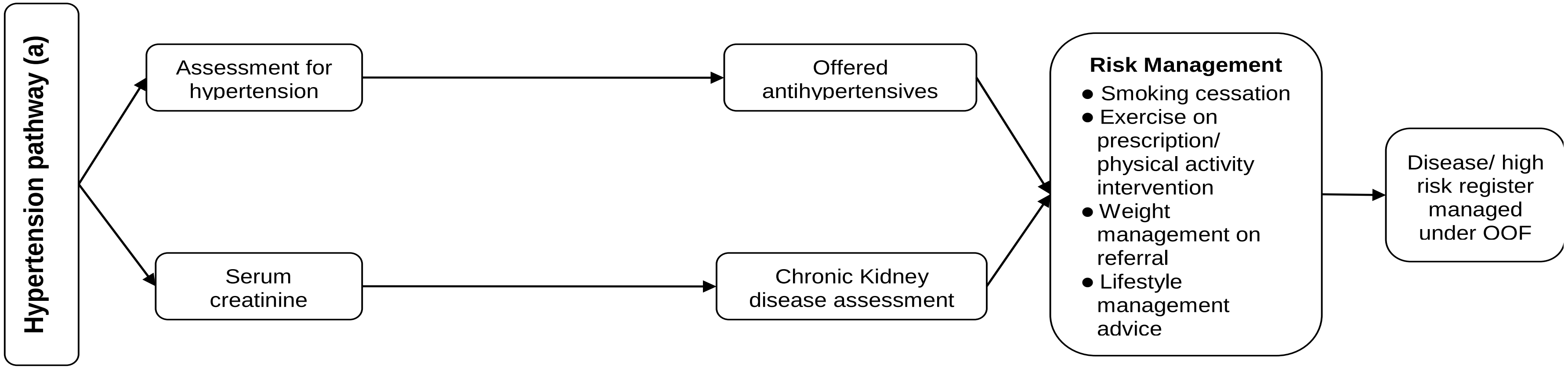
20. Evidence-based information, explaining the consequences of testing, investigation and treatment, should be made available to potential participants to assist them in making an informed choice.

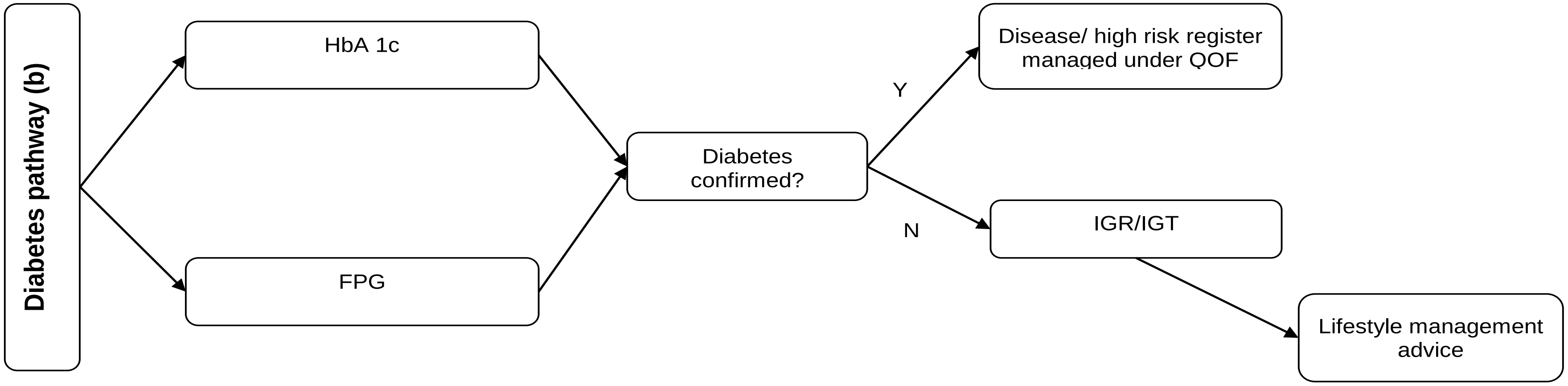
21. Public pressure for widening the eligibility criteria for reducing the screening interval, and for increasing the sensitivity of the testing process, should be anticipated. Decisions about these parameters should be scientifically justifiable to the public.

22. If screening is for a mutation the programme should be acceptable to people identified as carriers and to other family members.

11.3 Appendix 3: Local clinical pathways (low, medium, and high risk)




Hypertension pathway (a)
Assessment for hypertension
Serum creatinine
Offered antihypertensives
Chronic Kidney disease assessment
Risk Management
● Smoking cessation
● Exercise on prescription/ physical activity intervention
● Weight management on referral
● Lifestyle management advice
Disease/ high risk register managed under OOF


Diabetes pathway (b)
HbA 1c
FPG
Diabetes confirmed?
Y
N
Disease/ high risk register managed under QOF
IGR/IGT
Lifestyle management advice

11.4 Appendix 4: Key information for staff

Overview of evaluation project:

1. We would like to speak with patients who have just had their first annual review

2. We would like to hear how patients have felt over the last year about
    a. Making lifestyle changes
    b. Taking medications

3. We would like to have an informal chat for about an hour at a place to suit them.

4. Any travel costs will be reimbursed and a £20 high street voucher given at the end of the interview as a gesture of good will.

11.5 Appendix 5: Ethics approval letter

Teesside University
Middlesbrough Tees Valley
TS1 3BA UK
www.tees.ac.uk

PRIVATE AND CONFIDENTIAL

Direct Line: 01642 384124

15th February 2013

Janet Shucksmith
School of Health & Social Care
Teesside University

Dear Janet

Study No R019/13 - Understanding patient compliance to a cardiovascular screening programme. Researcher: Rebekah McNaughton. Supervisor: Janet Shucksmith.

Thank you for submitting an application for Ethical Clearance via a Research Ethics Release Form.

I have reviewed and approved your application on 12th February 2013 and your study may proceed as it was described in your application pack.

Please note:

Where applicable, your study may only proceed when you have also received written approval from any other ethical committee (e.g. NRES) and operational / management structures relevant (e.g. Local NHS R&D). If applicable please forward to me a copy of the approval letter from NRES before proceeding with the study.

In all cases, should you wish to make any substantial amendment to the protocol detailed, or supporting documentation included, in your approved application pack (other than those required as urgent safety measures) you must obtain written approval for those, from myself and all other relevant bodies, prior to implementing any amendment. Details of any changes made as urgent safety measures must be provided in writing to myself and all other relevant bodies as soon as possible after the relevant event; the study should not continue until written approval for those changes has been obtained from myself and all other relevant bodies.

On behalf of the School of Health & Social Care Research Governance and Ethics Committee please accept my best wishes for success in completing your study.

Yours sincerely

Dr. Alasdair MacSween
Chair
Research Governance and Ethics Committee
School of Health & Social Care

VAT REG NO. GB 686 4809 81

POSITIVE ABOUT DISABLED PEOPLE

INVESTOR IN PEOPLE

11.6 Appendix 6: Participant information sheet

Understanding patient experiences of the Healthy Heart Check Programme: First annual review

Study information for patients

You have been given this information sheet today because you have had an appointment for your first annual review since having a Healthy Heart Check assessment. We would like to invite you to take the time to give us your views about how you have felt since being told you are at high risk of cardiovascular disease.

Why have I been chosen?

You have been chosen because you have had a Healthy Heart Check and have been given either lifestyle advice to follow, medications to take or a combination of both.

Why do you want to speak to me?

The Healthy Heart Check programme is here to help people to know if they are at-risk of heart problems and provide advice and in some cases medication to reduce that risk. We would like to hear about your journey over the last year, since being told you were at-risk, so that we can understand if the Healthy Heart Check programme is working as well as it could. If you decide to take part, as a gesture of good will, you will receive a £20 high street voucher that can be used in many stores nationwide.

What will I have to do if I take part?

We would like to contact you and arrange a time to speak to you to ask you some questions about the Healthy Heart Check programme and the annual review you have just had. We would like to arrange this interview at a time and place that suits you – if you need to travel to a location to meet with us then your travel costs will be reimbursed.

This interview should last around one hour and will, with your permission, be recorded. Only members of the research team will listen to these recordings. You can change your mind about answering any of the questions and can stop the interview at any time and ask the researcher not to use your information.

What happens to the information that is collected?

The recording of your conversation (interview) with the researcher will be written up and used, along with other interviews to form the basis of a report. No personal details (name, address etc.) will be disclosed in the reports, so you can be assured that you will remain anonymous. The recordings of interviews and all paper documents relating to them will be held securely at Teesside University in accord with the data Protection Act (1998). Only staff directly involved in this evaluation will hear and see these. All data will be anonymised and held for a minimum of 20 years and may be used for future study but only in research projects that have received ethical approval from an appropriate committee.

What happens next?

You need not do anything. If you filled in your contact details to be passed to the research team, they will contact you soon to set up a time and place to hold the interview. If you would like to speak with the research team before then please contact Rebekah McNaughton on 01642 342755 or email her at R.McNaughton@tees.ac.uk

11.7 Appendix 7: Participant details form

Teesside University

Understanding patient experiences of the Healthy Heart Check Programme: First annual review

If you are happy to take part in the evaluation of the Healthy Heart Check programme please let us know the best way to get in contact with you by filling your details in below. Once it is completed, please hand it back to the nurse and she will make sure you have a printed information sheet to take away with you.

Name ....

Address ....
....
....
....

Telephone number ....

Email address ....

11.8 Appendix 8: Interview guide

Interview schedule (Patients)

Being invited for the HHC & results of assessment

What happened when you were invited for a HHC?

- Had you seen advertising/ read about the programme?
- Did you think attendance was compulsory/ voluntary?
- Were you told why you were invited for a HHC?
    - How did you feel about being identified for a HHC? (resentful/grateful/relieved/curious)
- Do you know anyone else that had been invited/ attended?
- Did you discuss the invitation with family/ friends?
- Were you pleased/ anxious to be invited?
- What made you decide to go for the check?
- Did you already have concerns about your health?
- Do you have a history of vascular disease in the family?

Interpretation of risk

- How did you feel when you were told you were high risk?
- What does being ‘at-risk’ mean to you?
    - Does it feel ‘real’?
    - Does it feel ‘likely’ to happen?

Making Changes

- What advice were you given once you were told you were high risk?
- Were you advised to make changes to the way you live your life?
- What were these changes?
    a. smoking, drinking, eating, exercise, medication

At this point note down what changes they were asked to make for use later in interview

- How did it feel to be asked to make changes to the way you live your life based on a ‘risk’ of being ill in the future?
- Was making these changes important to you?
    - Did you start to feel ‘sick’ or ‘at-risk’?
    - Did you feel in control?
    - Did you get others on board with the changes?

- Did making these changes seem achievable?
    - Family supportive, anxious, dismissive?
    - Other mentoring or support?

- Were you given professional help and advice to achieve this?
    - Did you understand why you were making the changes? (understand the ‘science’ behind the programme?)
    - Did you rely on the expertise of the HPs to implement the changes?
- If there are things you are uncertain about (aspects of health/conditions/changes), how do you manage this?
    - Where would you turn? (peers, family, professionals, internet...)

- How does it make you feel to be asked to take medications/make changes for life?
    - How do you fit it into your life? (extra job)
    - Remembering/coping strategies for taking medications?
    - Are the changes achievable in the long term?
    - Do you sometimes have to make compromises/ trade-offs to fit the changes into your lifestyle?

- How did friends and family react to your new lifestyle (smoking, drinking, exercise, and meds)?
    - Were they supportive?
    - Did they try to derail your efforts?

Making it happen

- Been making these changes for a year now, which ones have managed to ‘stick’?
- How have you achieved this?
    - Set reminders
    - Developed new habits
    - Aversion techniques?
- Have there been moments of doubt about why you are doing this?
    - What triggered these?
    - How have you managed these?
- Given help from the nurse/ GP that did the assessment?
- Anything outside general practice that helps you manage the changes?
    - Support groups
    - Internet
    - Other HPs
    - Friends
    - Family
    - Colleagues

probe about access to these, how they get there, are they enjoyable

Reflecting on the past year

- Have any noticeable changes happened to your health/ the way you feel mentally of physically since making all these changes?
- What would you attribute them to?
- How does that make you feel?

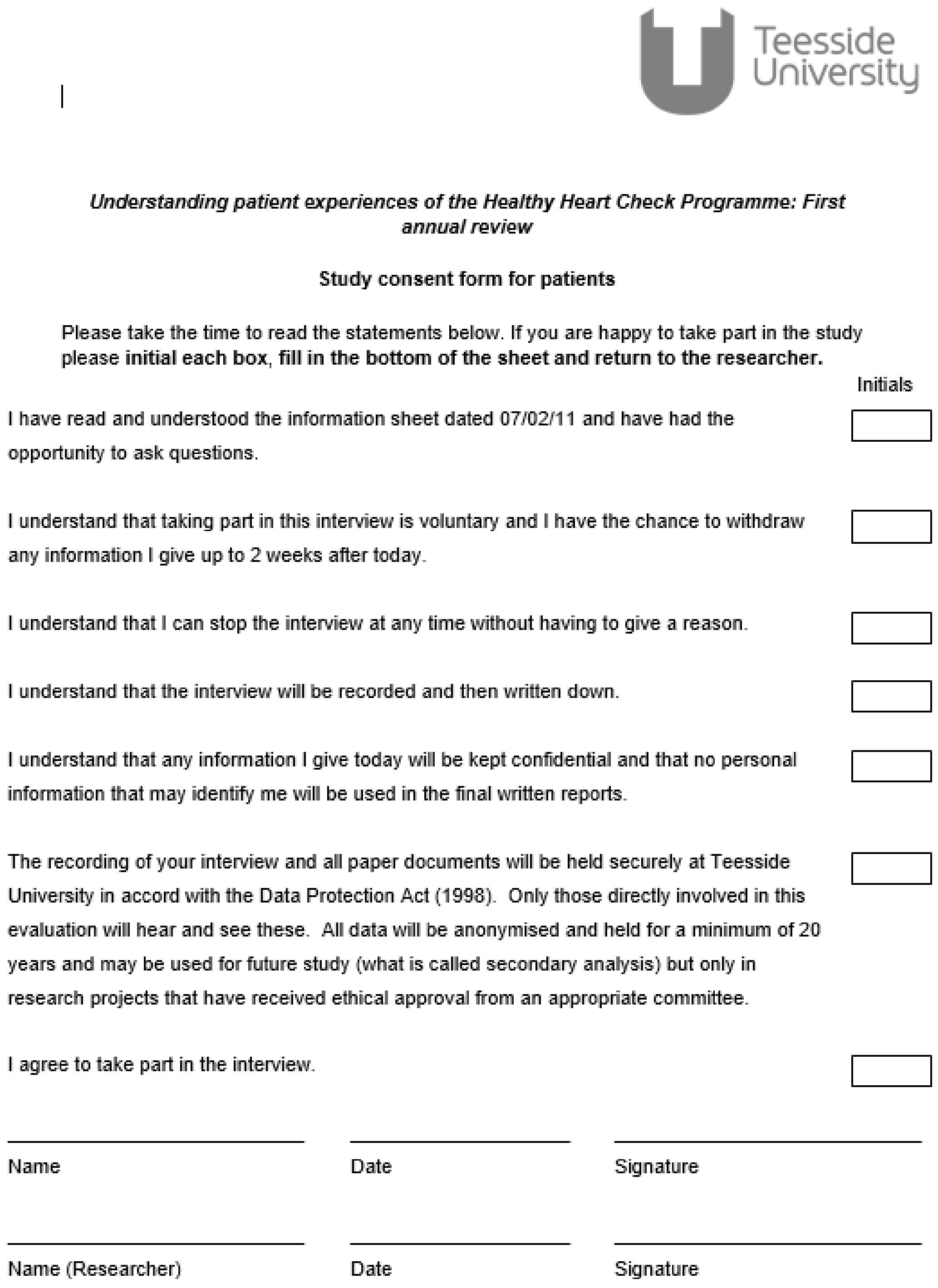
(generally feeling healthier, weight loss, feedback from family and friends?)

- Were there changes to be noted at the annual review?
- What feedback did you receive from the nurse?

(happy with it? Sad? Frustrated?)

- Do you feel that making the changes was worthwhile?
- Do you feel you will be able to continue with the changes in the long term?
- How do you feel about having review appointments annually?

11.9 Appendix 9: Consent form



Teesside University

Understanding patient experiences of the Healthy Heart Check Programme: First annual review

Study consent form for patients

Please take the time to read the statements below. If you are happy to take part in the study please **initial each box**, **fill in the bottom of the sheet and return to the researcher.**

	Initials
I have read and understood the information sheet dated 07/02/11 and have had the opportunity to ask questions.	☐
I understand that taking part in this interview is voluntary and I have the chance to withdraw any information I give up to 2 weeks after today.	☐
I understand that I can stop the interview at any time without having to give a reason.	☐
I understand that the interview will be recorded and then written down.	☐
I understand that any information I give today will be kept confidential and that no personal information that may identify me will be used in the final written reports.	☐
The recording of your interview and all paper documents will be held securely at Teesside University in accord with the Data Protection Act (1998). Only those directly involved in this evaluation will hear and see these. All data will be anonymised and held for a minimum of 20 years and may be used for future study (what is called secondary analysis) but only in research projects that have received ethical approval from an appropriate committee.	☐
I agree to take part in the interview.	☐

Name	Date	Signature
Name (Researcher)	Date	Signature